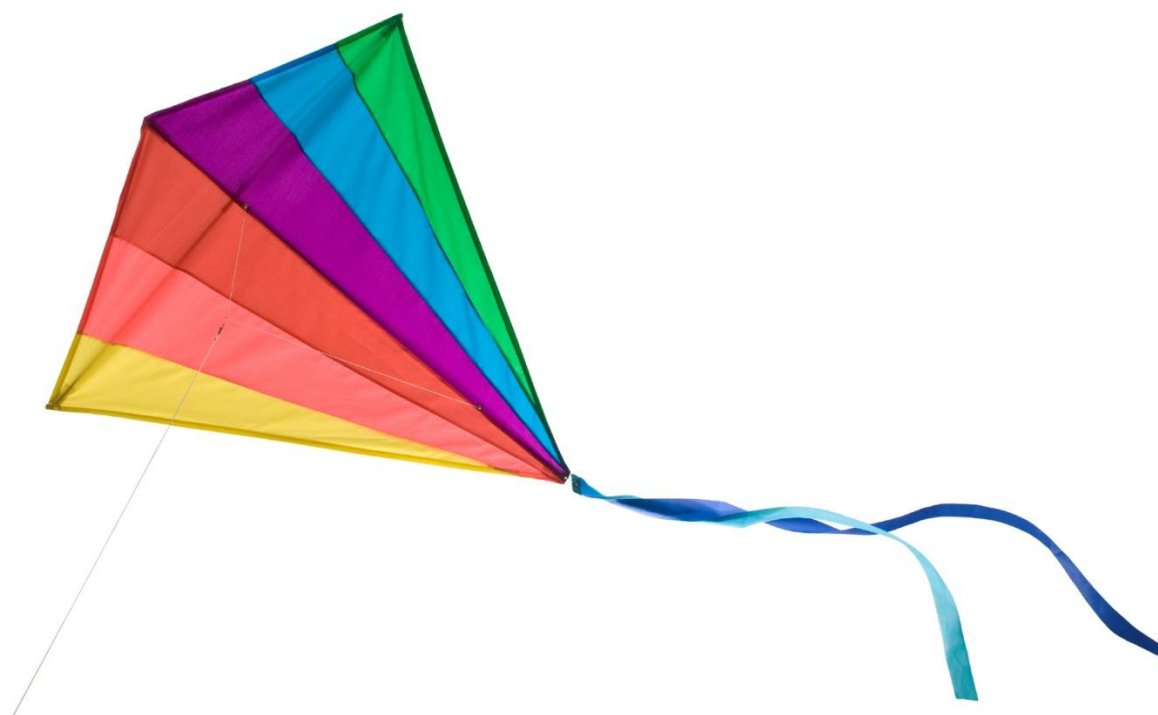


THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Public Health
England

 hospice^{UK}



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

The MDS: 2008-2014

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



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 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.



Public Health
England

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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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.

To help interpret graphs that show quartiles, it may be useful to think of it as: 25% of services are below the blue line, 25% of services are above the red line, and 50% of services sit between the blue and red lines.

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:

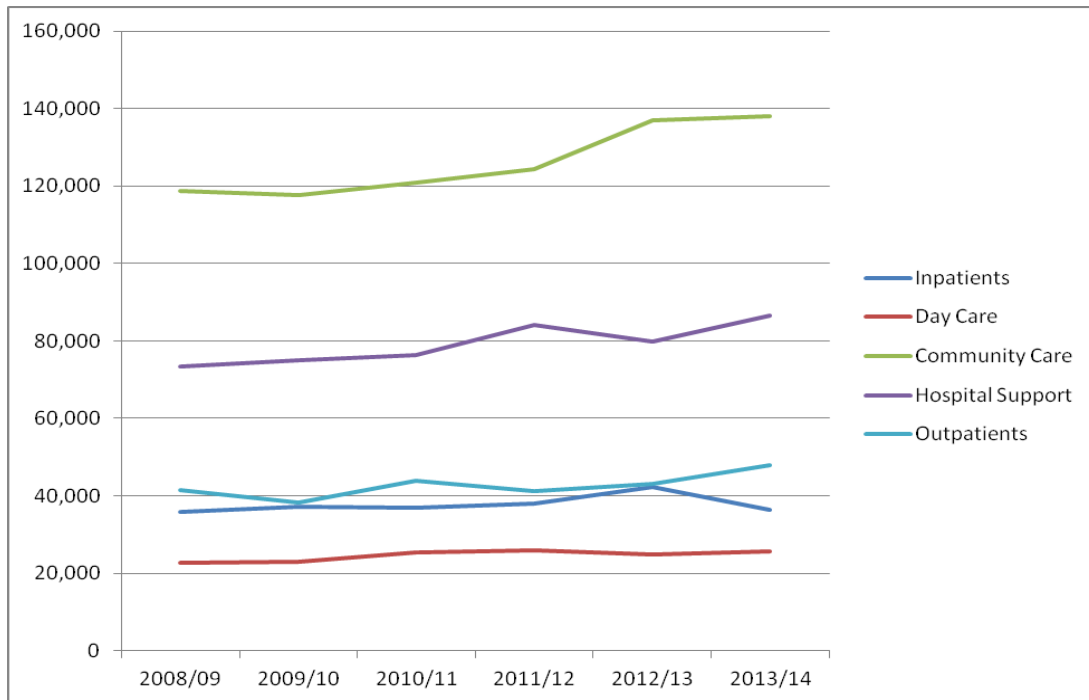


Figure 1.1: total number of patients in each setting, 2008-2014 (Table 2)

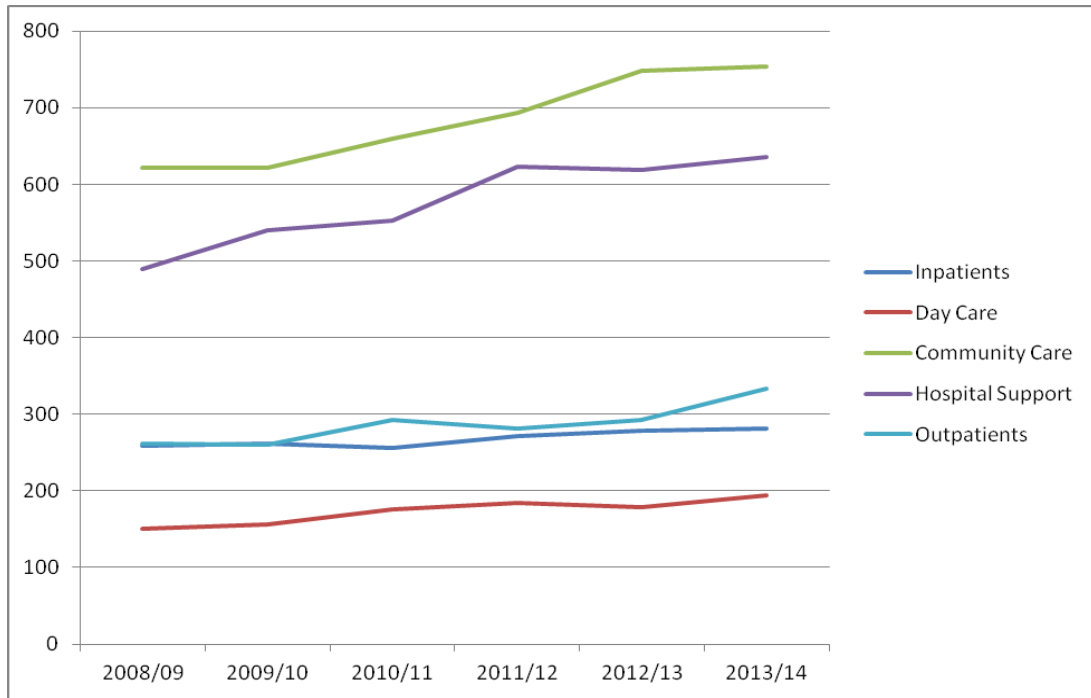
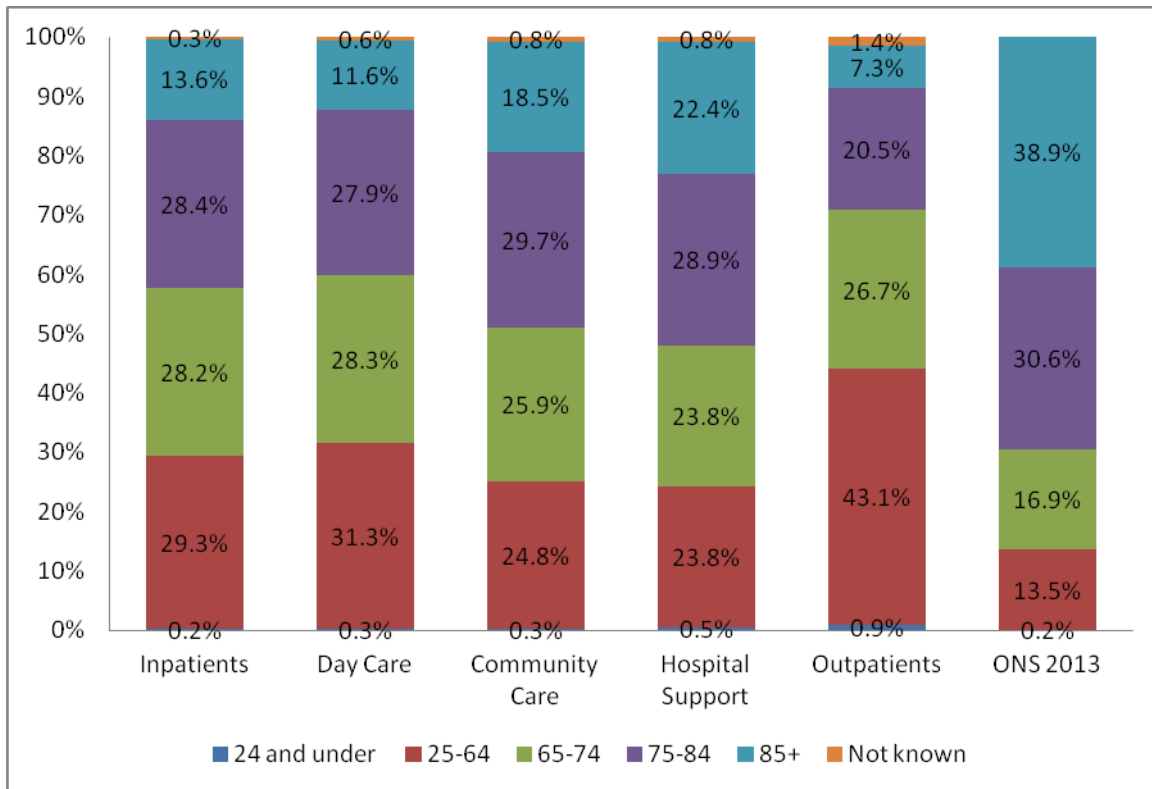


Figure 1.2: mean number of patients seen per service across all settings, 2008-2014 (Table 3)

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

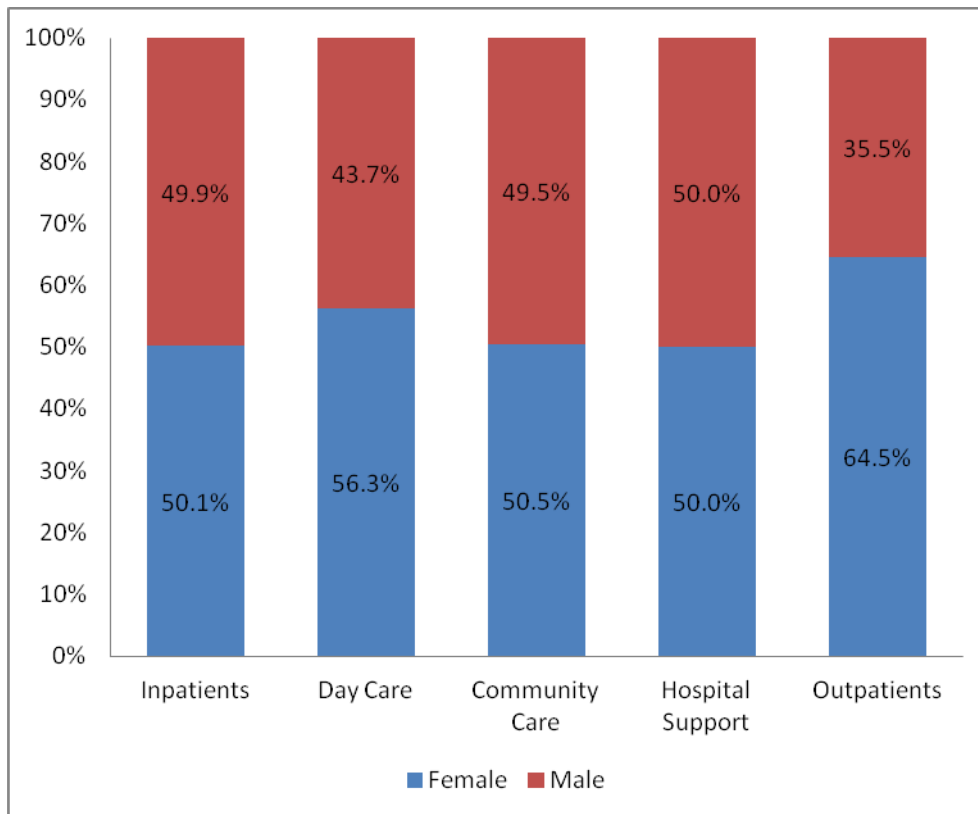


Figure 1.4: sex of people seen in each setting, 2013/14 (Table 5)

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

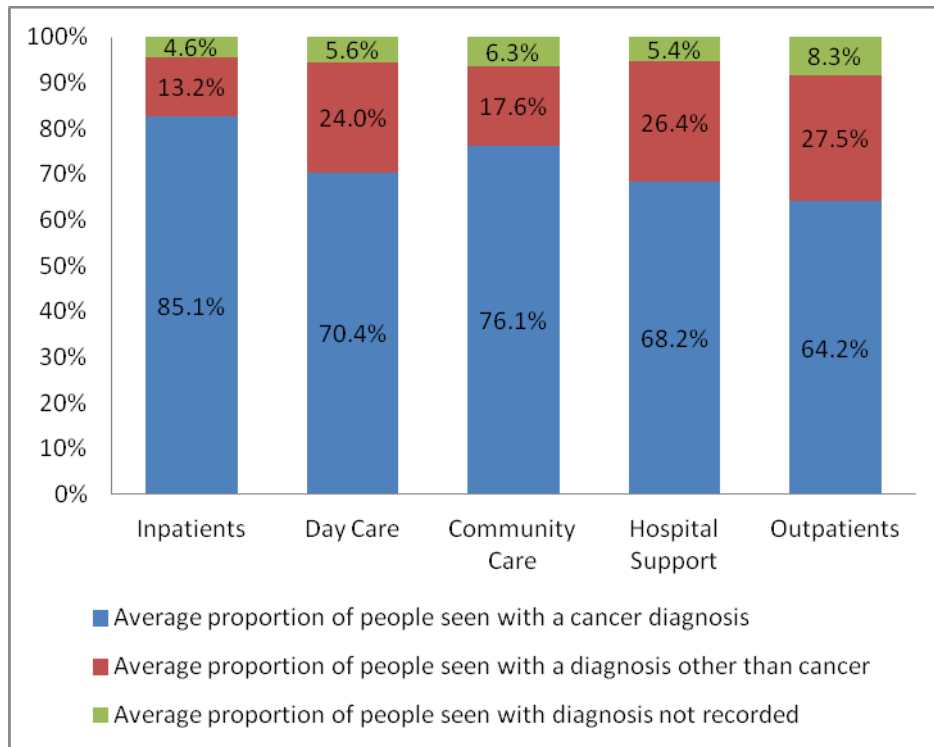


Figure 1.5: proportions of people with different diagnoses seen in specialist palliative care settings, 2013/14 (Table 6)

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

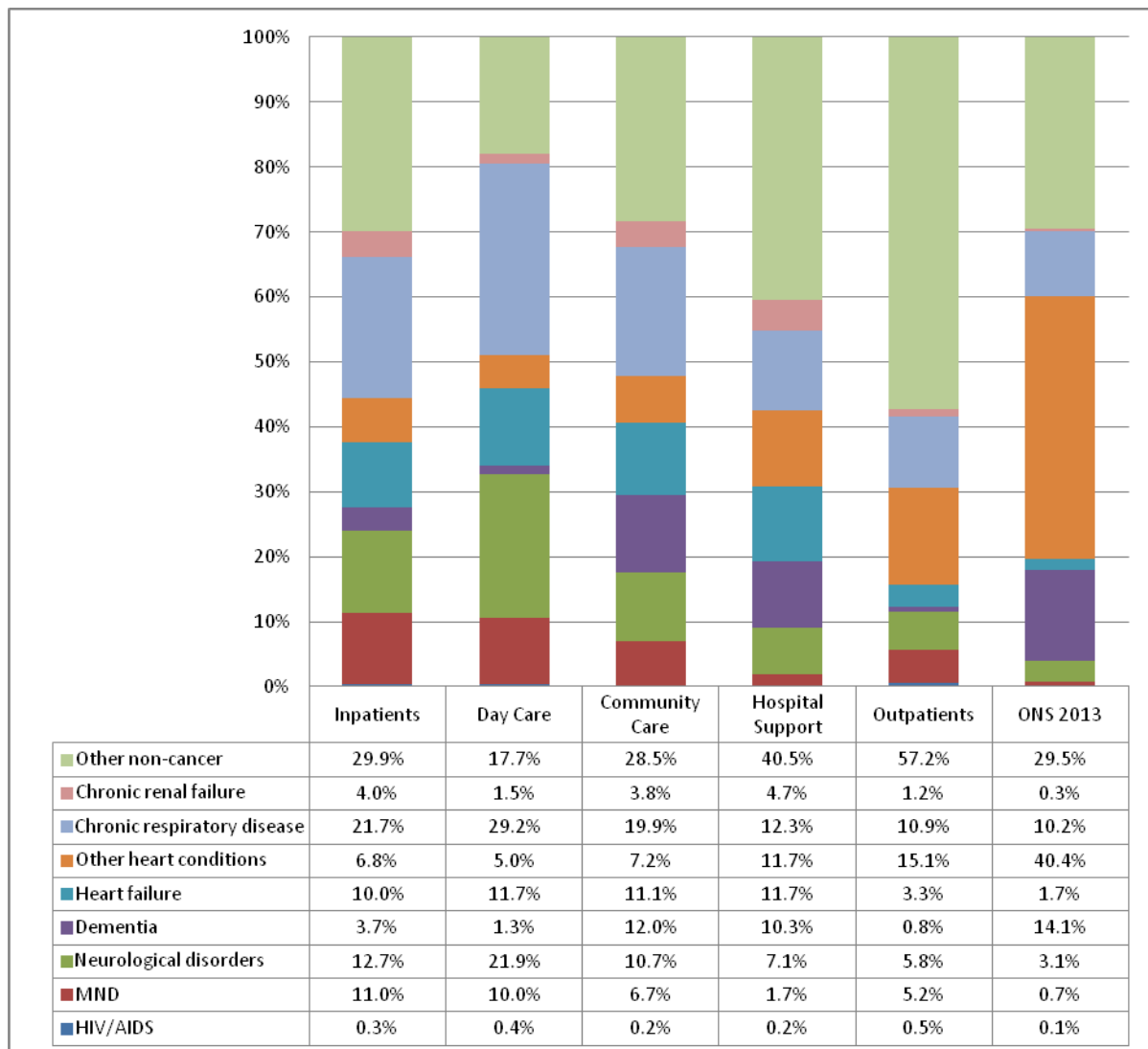


ONS data covers all deaths registered in 2013 under the ICD-10 codes for malignant neoplasms (ICD-10 codes C00-C99).

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 homes¹; this would appear to be reflected in the MDS data with the greatest

¹ 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

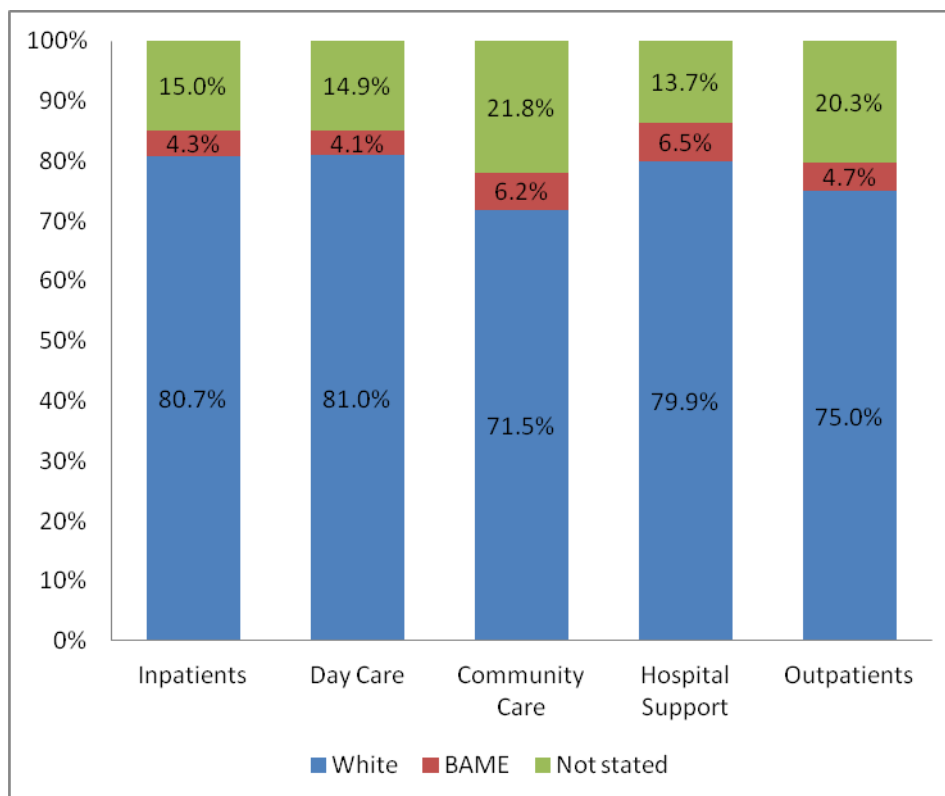


Figure 1.8: proportion of people from different ethnic backgrounds seen in each setting, 2013/14 (Table 10)

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 years².

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.

² 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*.

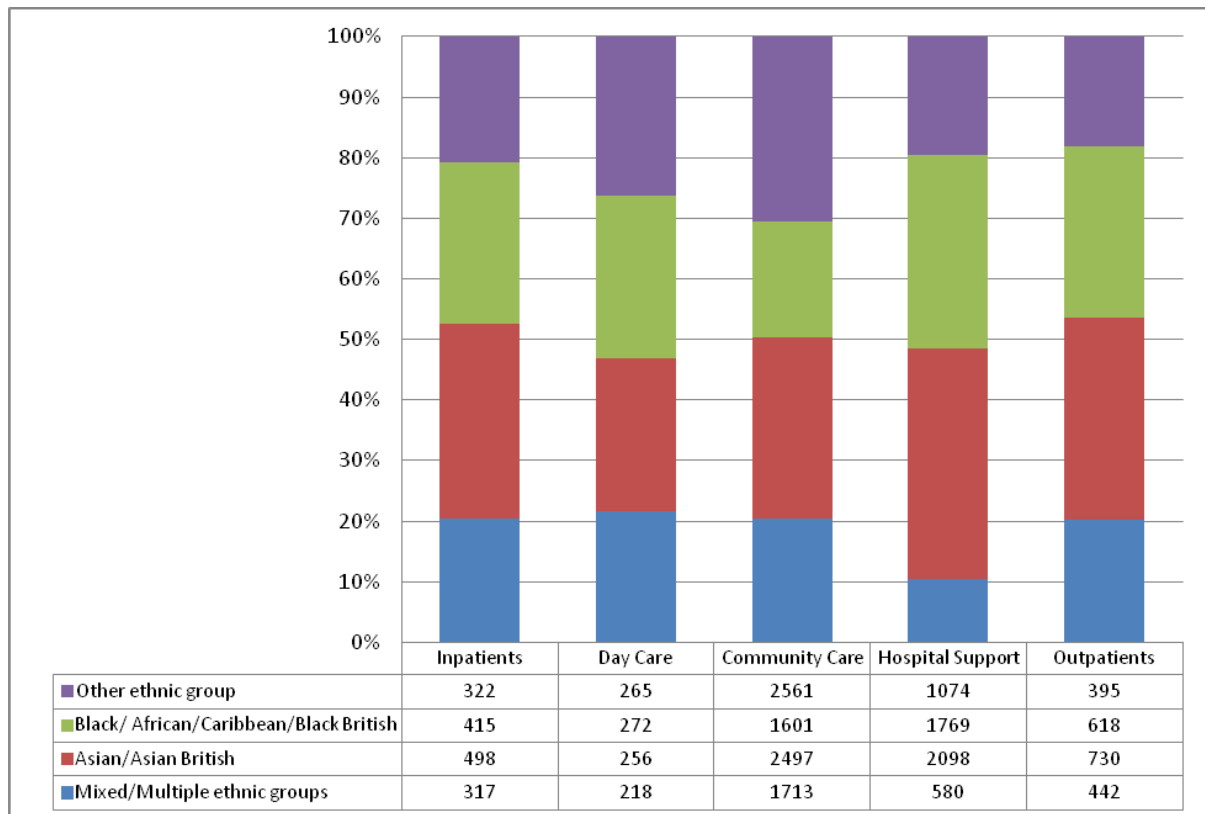


Figure 1.9: BAME groups accessing specialist palliative care settings, 2013/14 (Table 11)

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 ethnicity³ but this is acknowledged as a potentially flawed approach.

³ 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 SystemOne as their primary database. A large number of services also continued to use paper records alongside any electronic system.

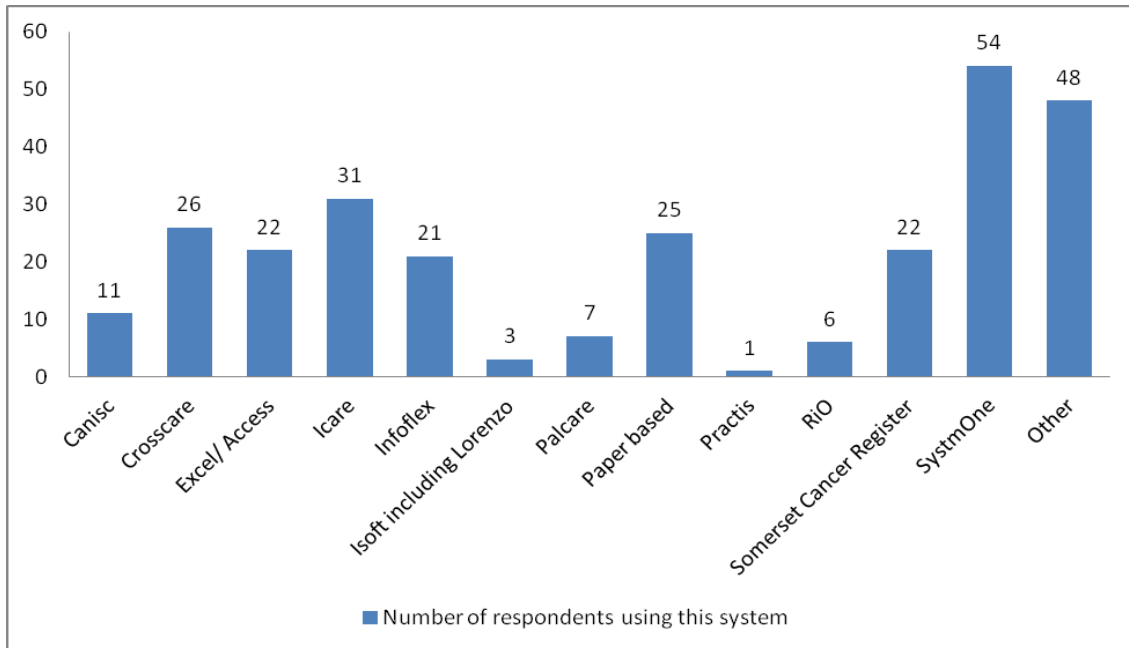


Figure 1.10: responses to NCPC IT survey question: Do you have a clinical information system for storing patient records? Which system do you use? (If you use more than one system, please select all that you use.)

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.

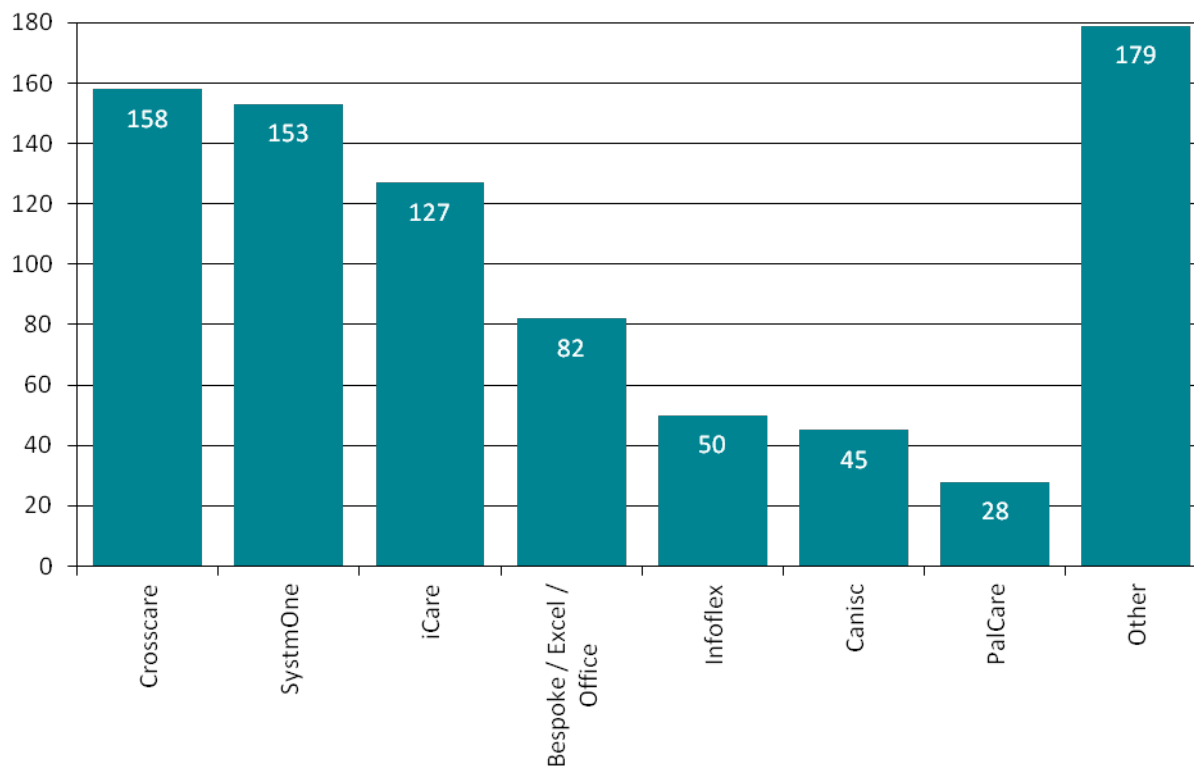


Figure 1.11: IT systems used by services in organisations responding to the MDS, 2013/14

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

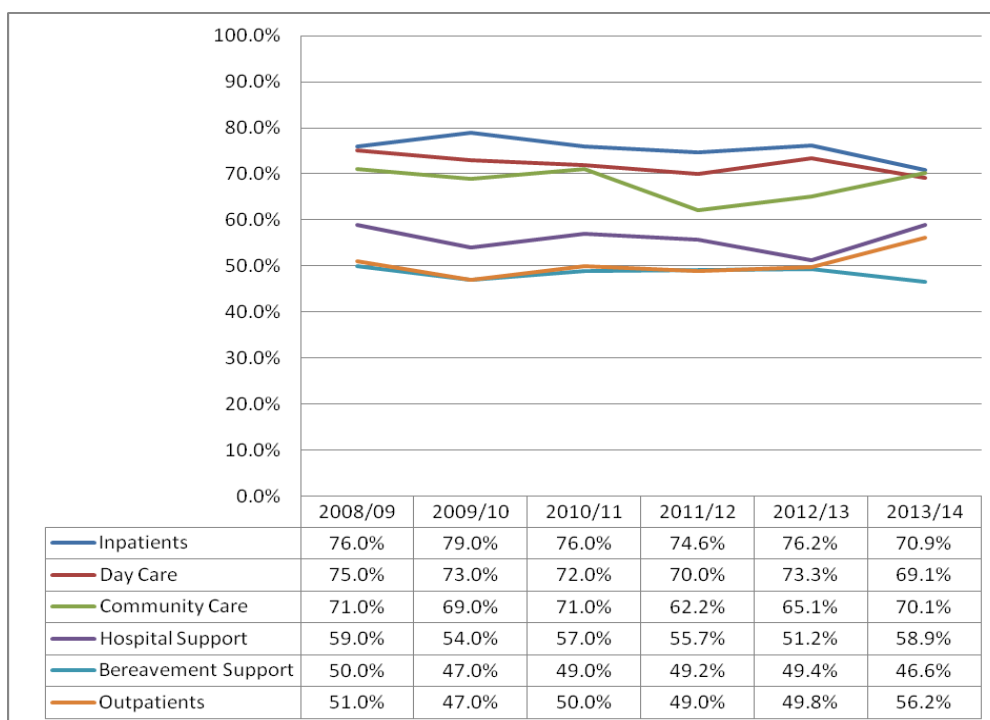


Figure 1.12: trend in response rates since the MDS revision in 2008/09

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.

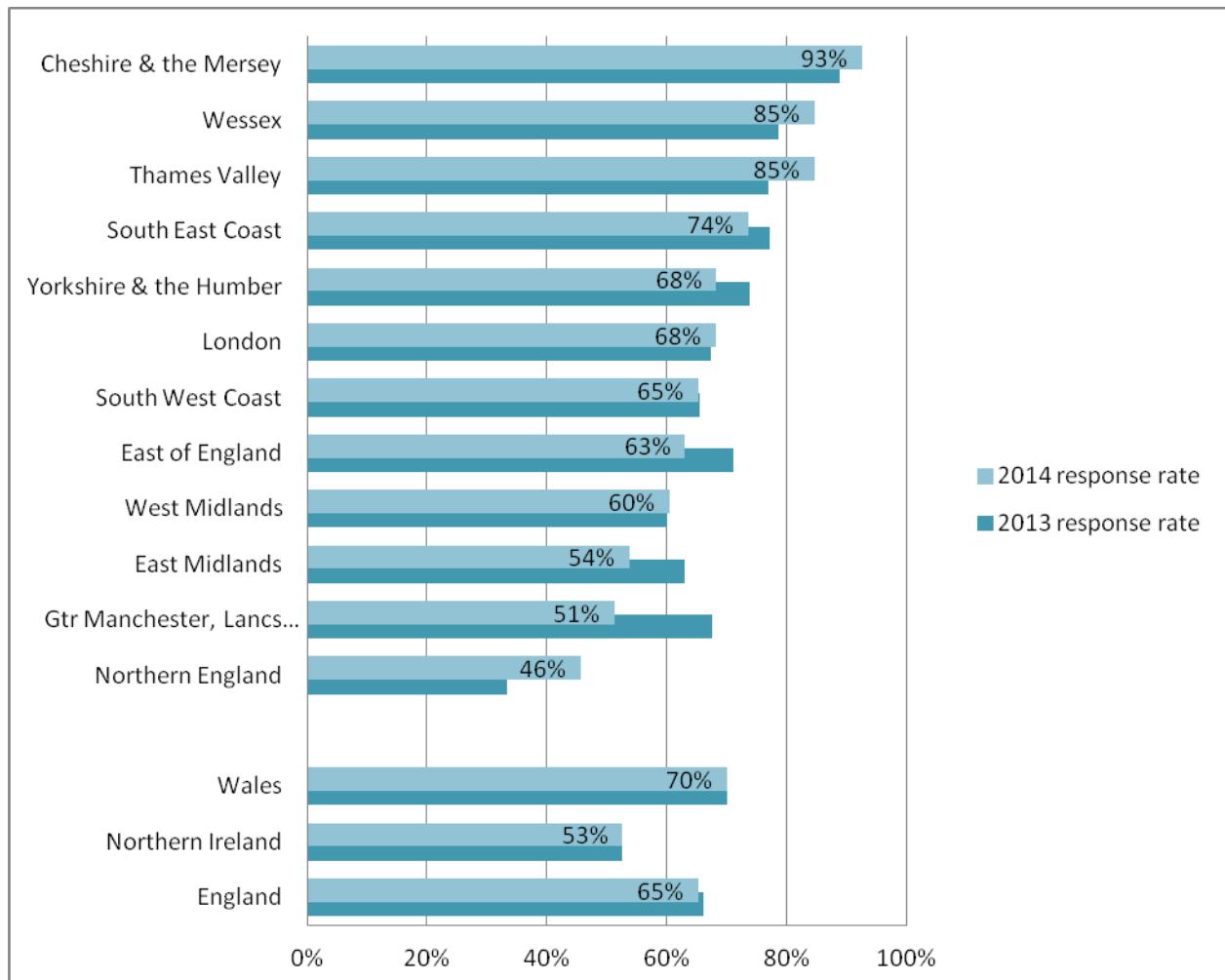
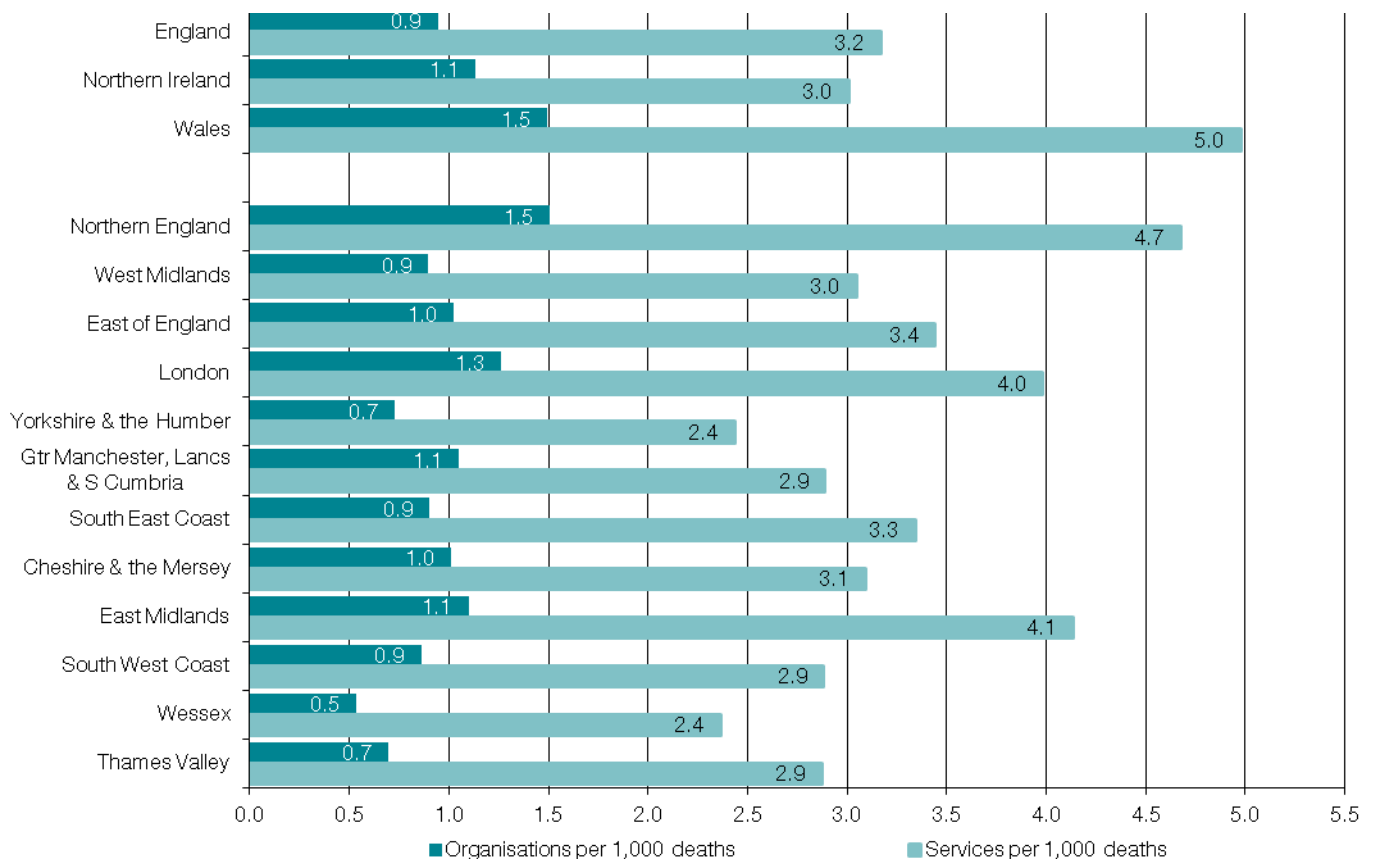


Figure 1.13: regional variation in response rates to the MDS in 2012/13 and 2013/14

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.

Issue	Proposed solution from last year's MDS report	Action taken in 2014/15
<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>

Issue	Proposed solution from last year's MDS report	Action taken in 2014/15
<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>

Issue	Proposed solution from last year's MDS report	Action taken in 2014/15
<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>

Issue	Proposed solution from last year's MDS report	Action taken in 2014/15
<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>

Issue	Proposed solution from last year's MDS report	Action taken in 2014/15
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.

Inpatients MDS report 2013/14

Key findings

- The number of people accessing Inpatient services is increasing over time, even given variation in the number of services returning data to the MDS
- The proportion of people accessing Inpatient services who have a diagnosis other than cancer is also increasing but people with cancer still account for a disproportionately high amount of Inpatient care
- A higher proportion of Inpatient stays ended in death in 2013/14 than in 2008/09

Definition

An inpatient is a person who is admitted and occupies a bed in the unit, not necessarily overnight. There are several types of inpatient admission:

- An ordinary inpatient is admitted with the intention of staying one or more nights in the unit
- A day case inpatient is admitted with a view to discharge the same day i.e. they do not stay overnight in the unit
- A regular inpatient is admitted as part of a planned series of short stays, usually of one day or one night each e.g. for pain control adjustment or respite care. A series of day admissions differs from Day Care in that a person occupies a bed while in the unit
- An ordinary inpatient who does not actually occupy a bed for one night is still counted as an ordinary inpatient e.g. an urgent admission who dies the same day
- Someone admitted as a day case who for any reason stays overnight becomes an ordinary inpatient, as does any regular inpatient who overstays the planned period of admission

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

129 of 181 Inpatient services returned MDS data in 2013/14 representing a 71.3% response rate, down from 76% in the previous MDS reporting year. The majority of responding services were independently managed hospices.

Table 2a: Inpatients response rates by type of organisation and type of management, 2008-2014

Year	Hospice		Hospitals*		Total services responding
	Managed by NHS	Managed by Independent	Managed by NHS	Managed by Independent	
2008/09	20	99	17	2	138
2009/10	17	106	17	2	142
2010/11	17	111	14	2	144
2011/12	16	110	13	1	140
2012/13	12	117	14	1	144
2013/14	12	104	13		129

*It should be noted that even where responses appear to be from hospitals, it may be that the data return is carried out by a hospital on behalf of a hospice Inpatient unit.

Number of people seen

The mean number of people per unit accessing each Inpatient service is increasing over time, although the total reported number of patients varies from year to year due to varying response rates. In total, 36,420 people were seen by responding Inpatient services in 2013/14.

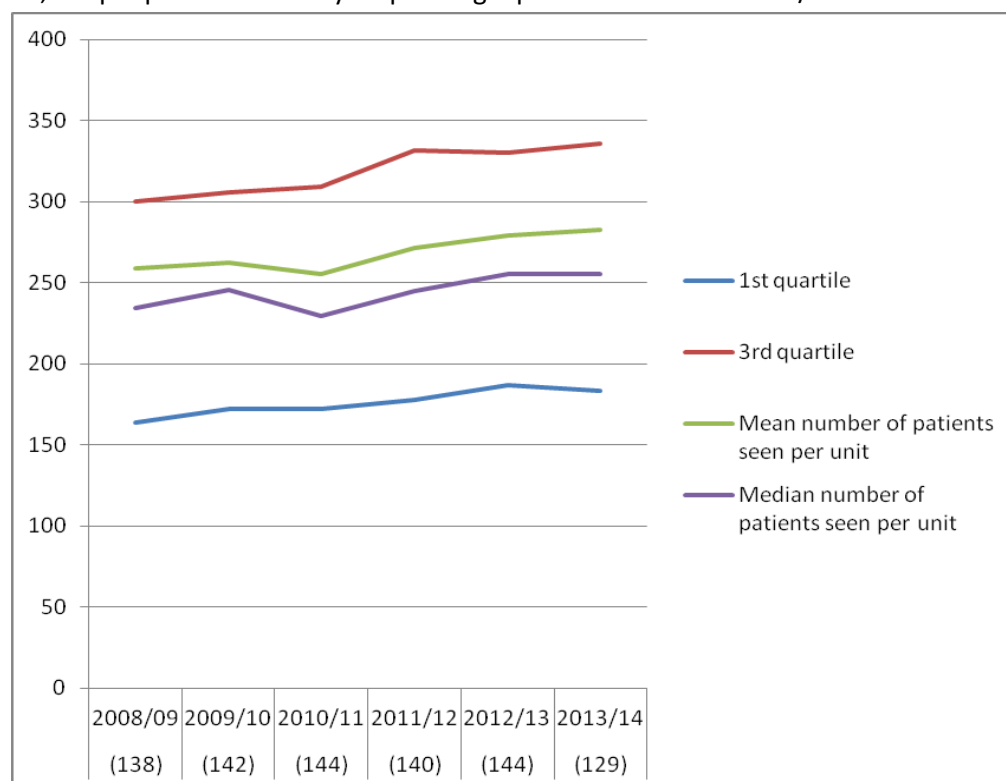
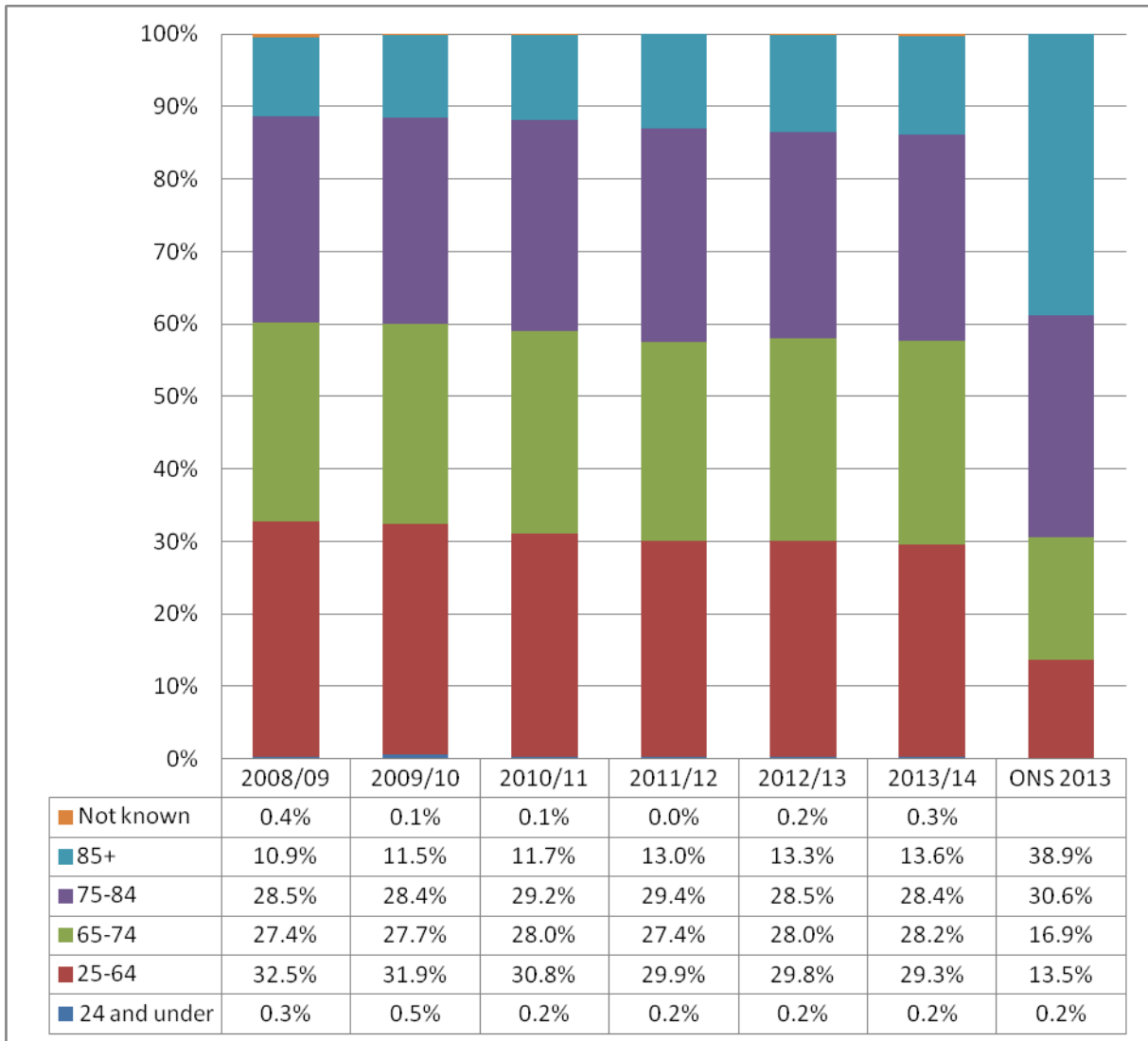


Figure 2.15: changes in the range of size of Inpatient units over time (Table 13)

Age of patients

The proportion of people aged over 85 who access Inpatient services has gradually increased over time, while the proportion of those aged 25-64 has slightly decreased. However, as compared with the ages of those who died in 2013, older people are still accessing Inpatient care less than might be expected while younger people have disproportionately high access.



*ONS data includes all deaths registered in 2013, excluding those from accidental causes.

Figure 2.16: proportion of different age groups accessing Inpatient care, 2008-2014 (Table 14)

Sex

The split in the sex of people accessing Inpatient services remains stable in each year, and is roughly equally split between men and women.

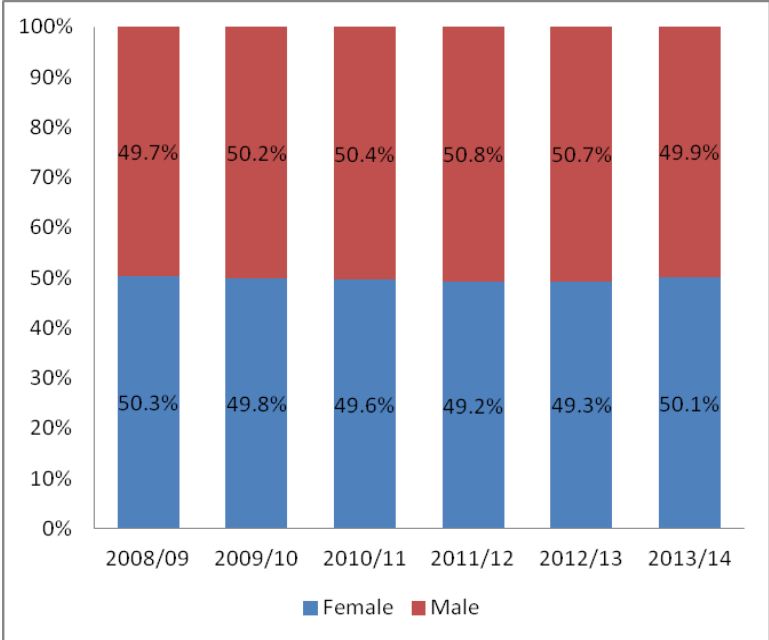


Figure 2.17: proportion of men and women accessing Inpatient care, 2008-2014 (Table 15)

Diagnoses

The mean proportion of people accessing Inpatient services who have a cancer diagnosis has fallen over time, from 89% in 2008/09 to 84% in 2013/14. 2012/13 was the first year of the revised MDS where no service reported 100% of people accessing their Inpatient service as having had a cancer diagnosis, with the maximum being reported as 99%. In 2013/14 this maximum has fallen further to 97%.

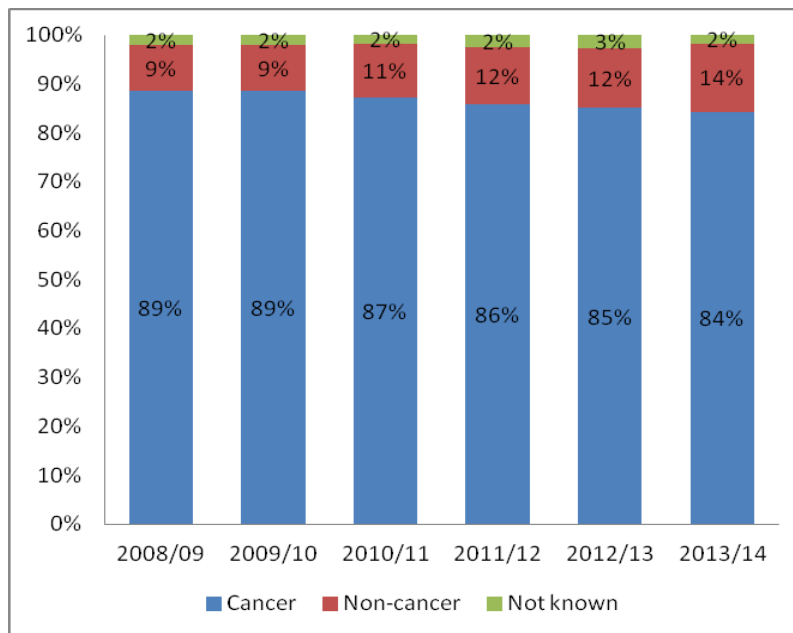


Figure 2.18: proportion of people with different categories of primary diagnosis accessing Inpatient care, 2008-2014 (Table 16)

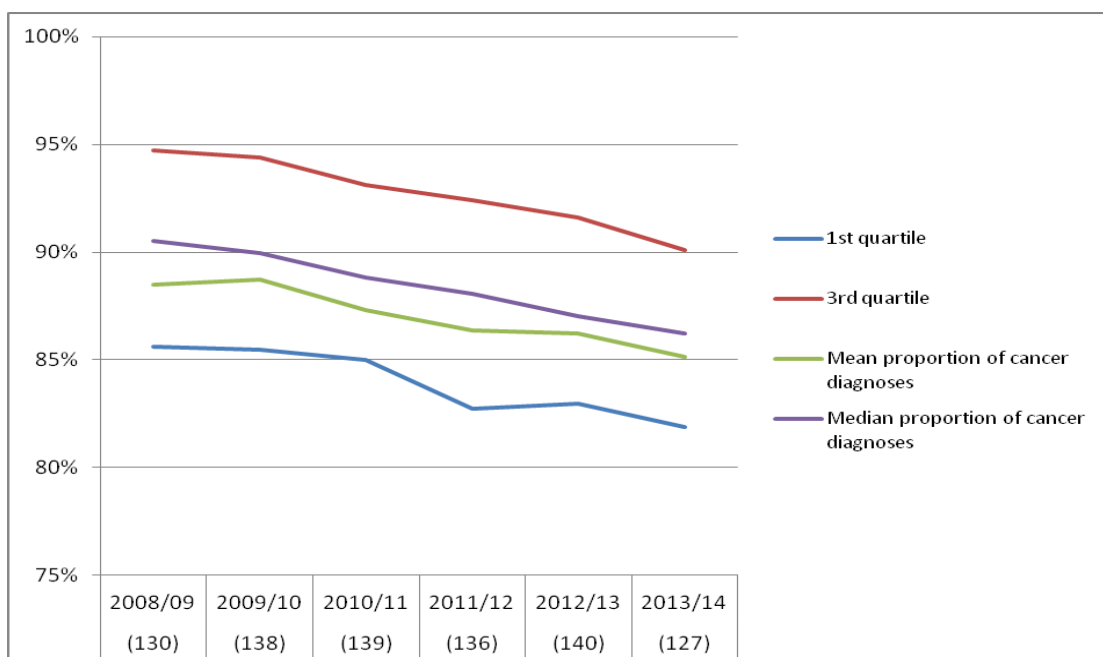


Figure 2.19: range in proportion of people with cancer diagnoses accessing Inpatient care, 2008-2014 (Table 17)

Correspondingly, the mean proportion of people with non-cancer diagnoses has increased over the period, from 9% in 2008/09 to 13% in 2013/14. No service has reported seeing more than 40% of people with a diagnosis other than cancer.

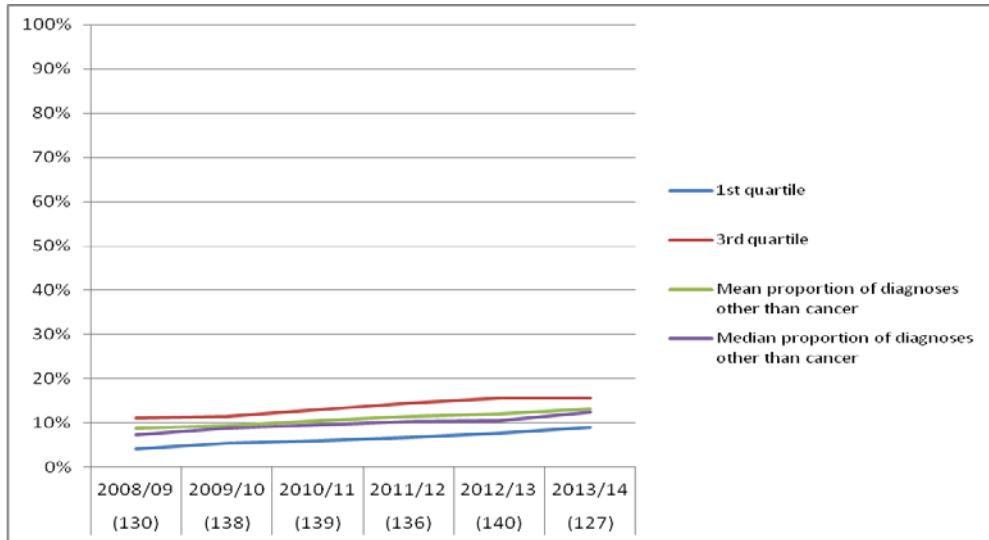


Figure 2.20: range in proportion of people with diagnoses other than cancer accessing Inpatient care, 2008-2014 (Table 18)

There are some services who do not know or do not record the diagnosis of all those accessing Inpatient care. The mean proportion of unknown diagnoses has dropped slightly over time from 2.1% in 2008/09 to 1.7% in 2013/14. Data quality continues to be an issue; in 2013/14 one service reported not having recorded the diagnosis of 50% of their patients. However, the number of services populating the 'Diagnosis not known' field has been dropping over time, suggesting an improvement in data quality overall.

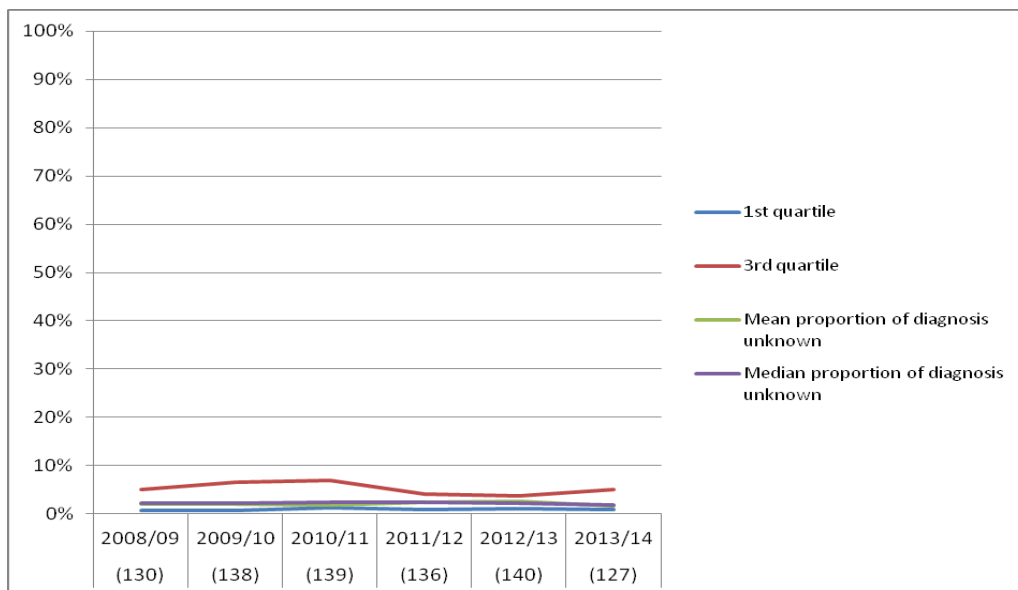


Figure 2.21: range in proportion of people with diagnoses unknown accessing Inpatient care, 2008-2014 (Table 19)

Case study: Increasing Inpatient access for people with diagnoses other than cancer

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Margaret Centre, Whipps Cross University Hospital

We are an NHS specialist palliative care unit on the site of a district general hospital which is part of Barts Health, the largest NHS Trust in the UK. Our activity is affected by the demands of the Trust to some extent but we have worked to develop good links with other services both within the Trust and in the community and this is where much of our non-malignant work comes from. For example, we accept many patients from ITU for end of life care and many of them will have non-malignant illness. This has proved a very successful collaboration and the supportive environment that we are able to offer particularly to relatives who have to move from a hopeful high tech place like ITU to facing the death of their loved one is valued.

More community focused work has resulted in the establishment of two MDTs.

Palliative MDT for COPD and Heart Failure Patients

The COPD/Heart failure Palliative Care MDT meets once a month with good representation from all invited teams. The community matrons are now regular members of this MDT. Members of the MDT are welcome to discuss any patient with palliative care needs with a diagnosis of COPD or heart failure. This may or may not be their primary diagnosis. The establishment of a more formal process for discussion and note keeping has allowed us to share the outcomes of our discussions with GPs. This directly influences patient management and empowers individual members of the MDT to act on the recommendations of the MDT.

We have noted a significant up-skilling and confidence in MDT members. Palliative care nurses have a greater understanding of COPD and heart failure. Community nurses are able to recommend simple symptom control measures and initiate discussions around advance care planning and end of life care. We have changed our model of working together and perform many joint visits. It continues to be considered a valuable educational and supportive resource which had a positive impact on the care of individual patients. One particular outcome of this meeting has been the use of inpatient respite for this group of patients.

MND MDT

This more recently established MDT has brought together clinicians from both primary and secondary care as well as our local MND co-ordinator and enabled better communication and team working. Patients have been referred to our service for everything from OT assessment to advance care planning discussions and we are now working to expand the group to include other neurological conditions.

Diagnosis breakdown: cancer

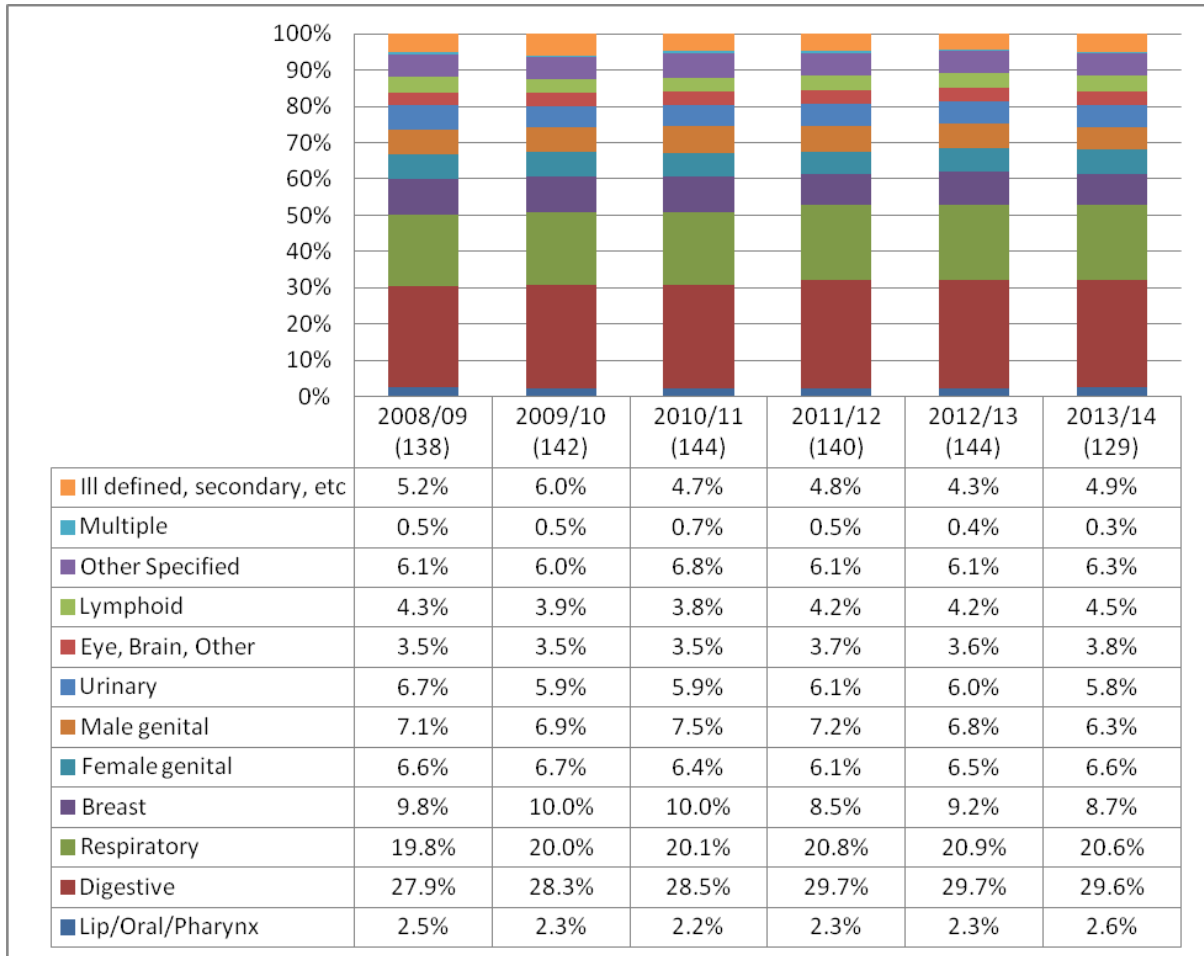


Figure 2.22: proportion of people with different cancer diagnoses accessing inpatient care, 2008-2014 (Table 20)

There has been very little change in the proportions of people diagnosed with different cancers recorded by Inpatient services over the past 6 years.

Diagnosis breakdown: diagnoses other than cancer

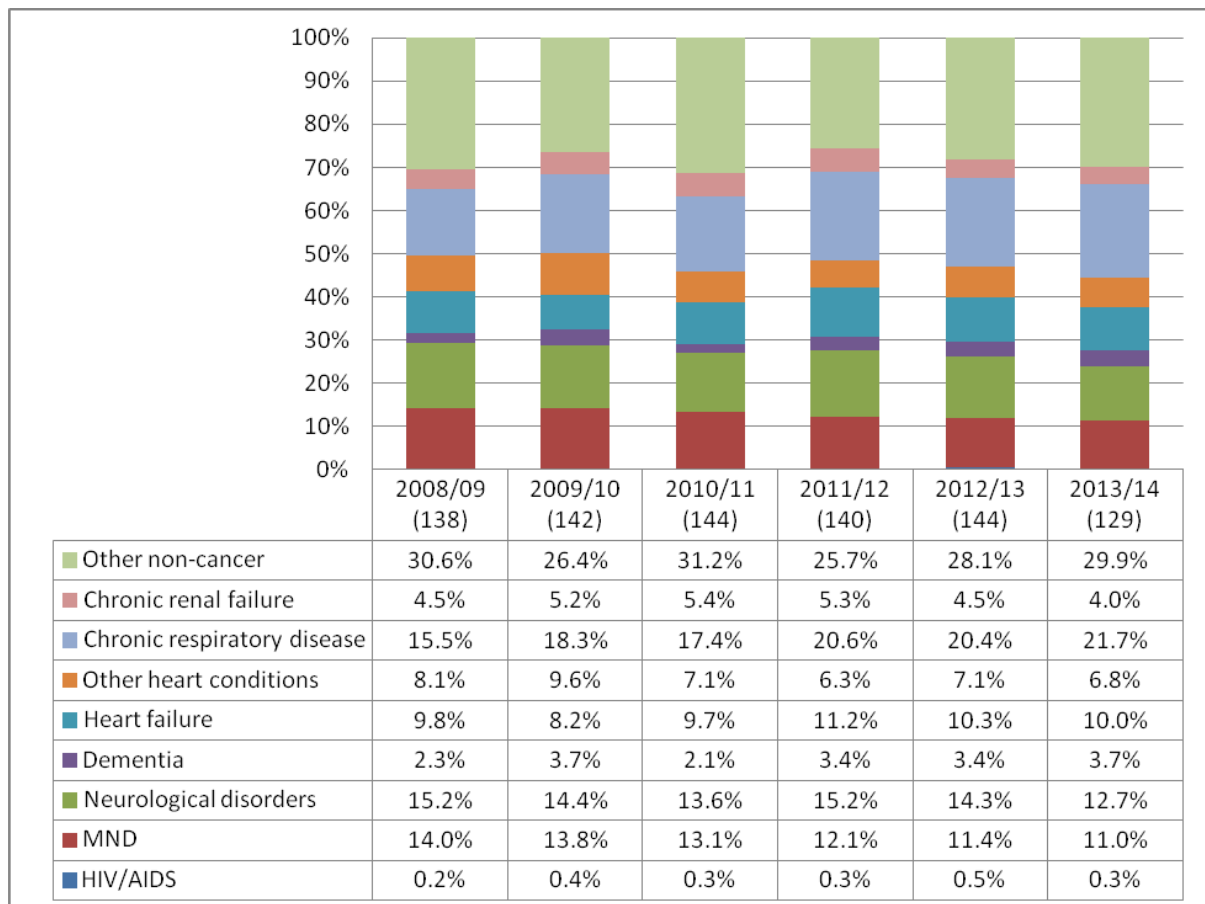


Figure 2.23: proportion of people with diagnoses other than cancer accessing Inpatient care, 2008-2014 (Table 21)

Proportions of reported people with non-cancer conditions accessing Inpatient services have also stayed largely stable over time, although the proportion of people with chronic respiratory disease has increased while MND and neurological disorders have fallen slightly as a proportion. As the total number of people with diagnoses other than cancer continues to increase, these proportionate shifts do not reflect a decrease in patient numbers (see Table 17).

Ethnicity

Since 2008/09, there has been very little change in the recorded proportion of BAME people who access Inpatient palliative care services. There has also been very little improvement in the recording of ethnicity by services with a steady percentage of 'Not stated' being returned.

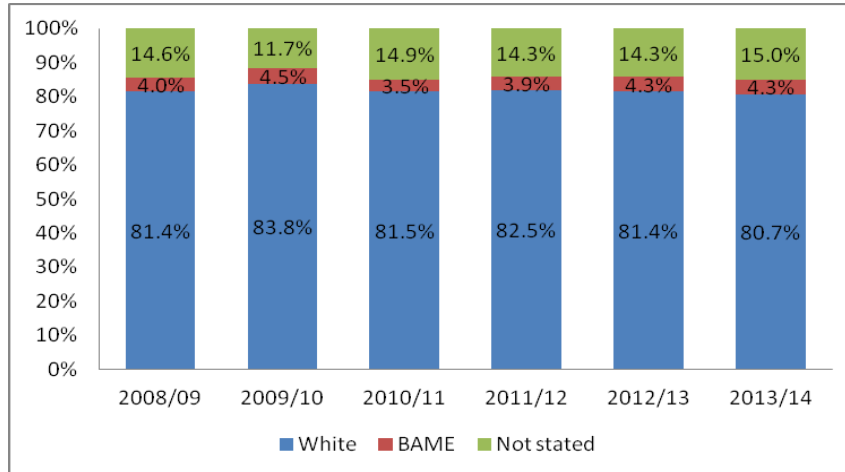


Figure 2.24: proportions of people accessing Inpatient care reported as white, BAME and not recorded, 2008-2014 (Table 23)

Breaking the BAME data down further, it can be seen that a large proportion of people are being recorded as 'Other'. Without consistently recorded ethnicity data, lack of access based on ethnicity will continue to be a difficult issue to address. 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.

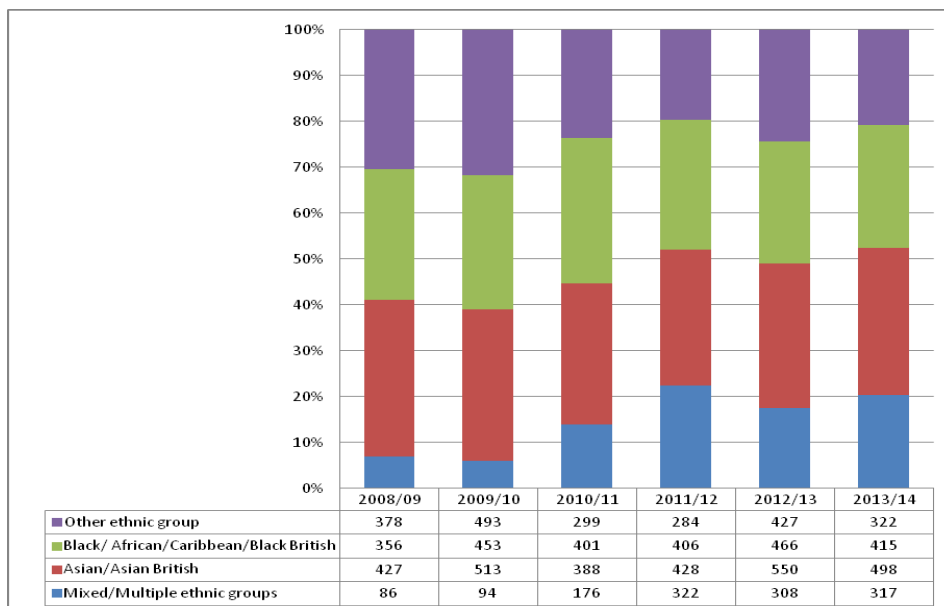


Figure 2.25: people accessing Inpatient care from grouped BAME categories, 2008-2014 (Table 24)

Location at end of stay

The proportion of Inpatient stays that end with death has risen by 6.7% from 2008/09 to 2013/14.

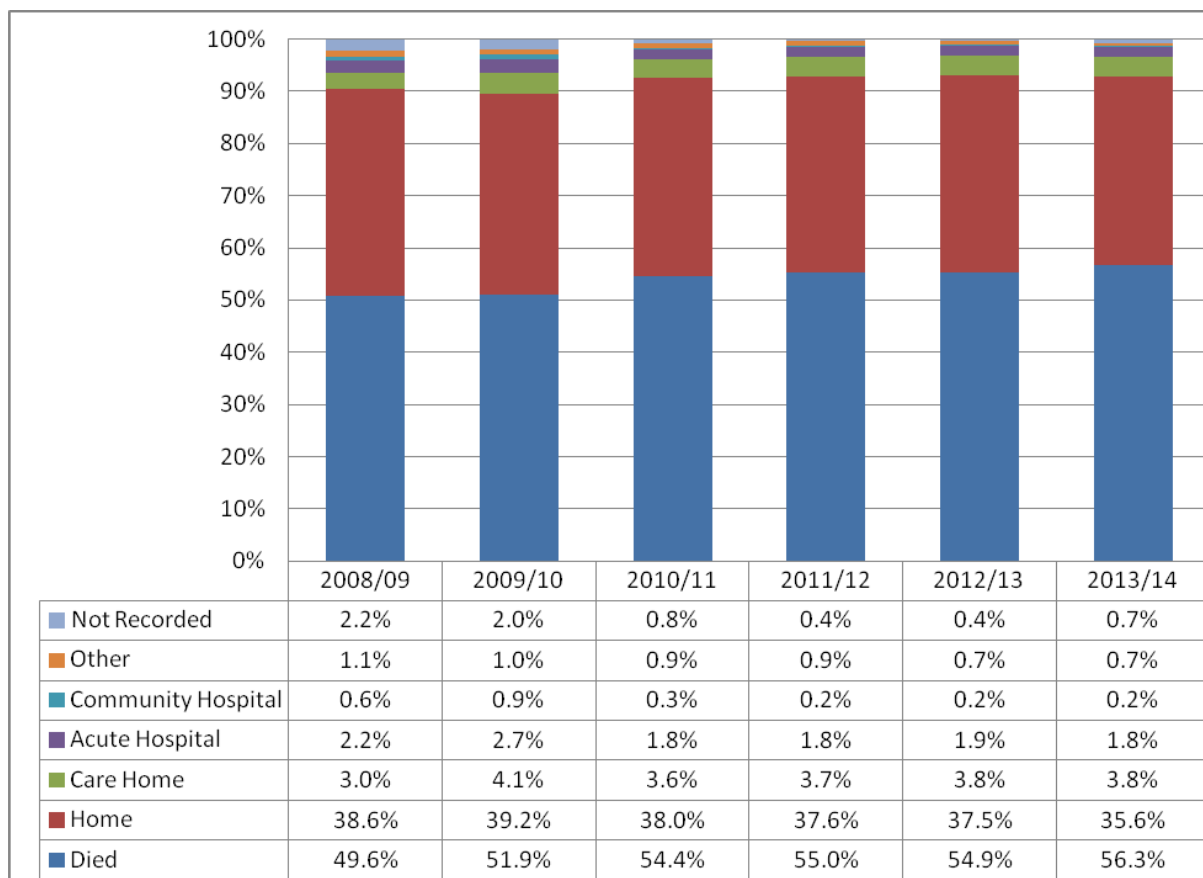


Figure 2.26: proportions of location of people at the end of completed Inpatient stays, 2008-2014 (Table 25)

No one service is responsible for the trend in increasing numbers of Inpatient stays ending in death, therefore it is likely to reflect a change across the sector. However, it is unclear from the data available what the change might be. For example, it may be due to a change in how severe someone's condition is by the time they are referred to an Inpatient unit with more people being able to have their symptoms managed at home and so being able to avoid an Inpatient referral altogether, or it may reflect difficulties in discharging before someone's condition deteriorates too far to discharge. Further investigation is needed to understand what is driving this trend.

Length of stay

Length of stay data varies very little from year to year; the majority of people stay on an Inpatient unit for under two weeks, with almost a quarter of people staying between 1 to 4 days.

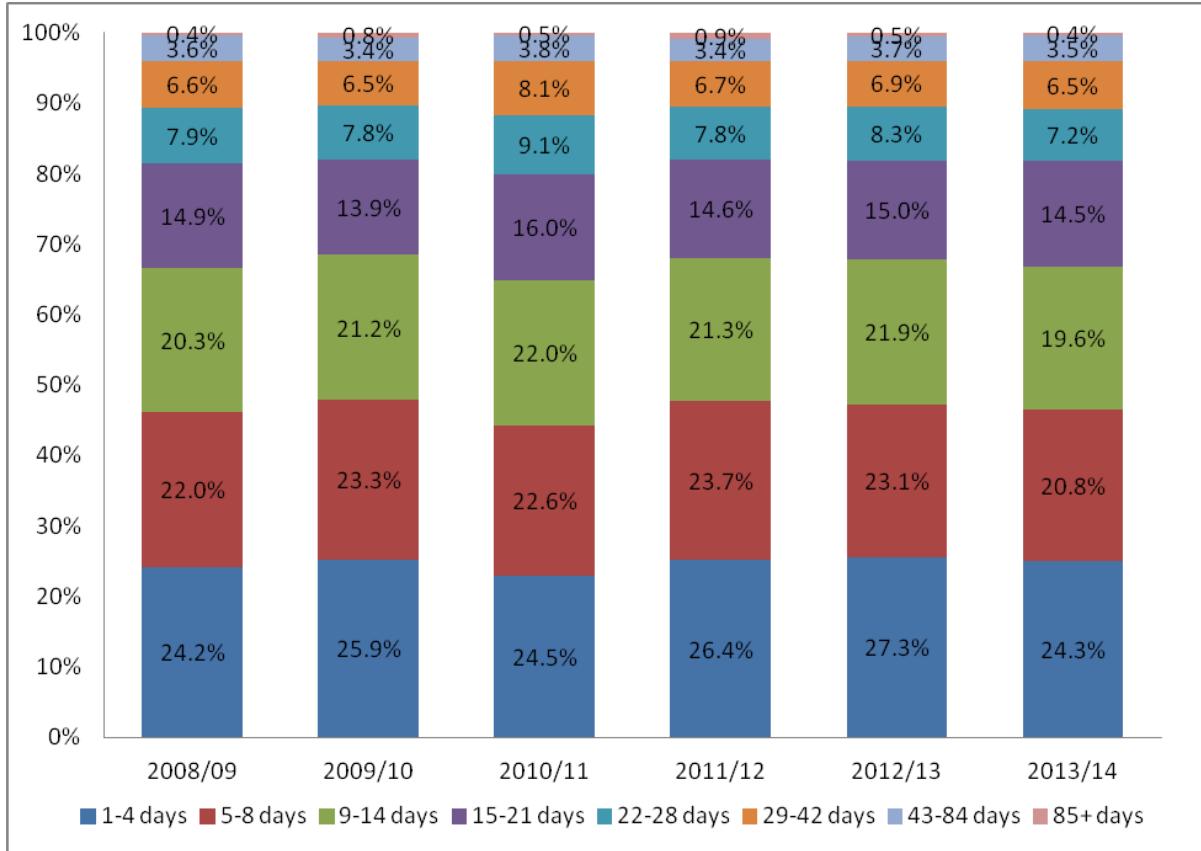


Figure 2.27: length of completed Inpatient stays, 2008-2014 (Table 26)

Mean length of stay across all units remains steady at around 13.7 days.

Long stay patients

A long stay patient is a patient who remains resident in the Inpatient unit throughout the MDS reporting year. The majority of services do not report any long stay patients and never have. No more than 6 long stay patients have ever been reported across all services in any given year; the highest number of long stay patients any service has reported in any one year is 3. In 2013/14, 6 long term-stay patients were reported, located in five different services.

Location prior to admission

A lower proportion of people are admitted to Inpatient units from their homes now than in 2008/09 although this is still by far the largest category. The proportion of people admitted from Acute Hospitals has increased which may reflect a change in service patterns that requires further investigation.

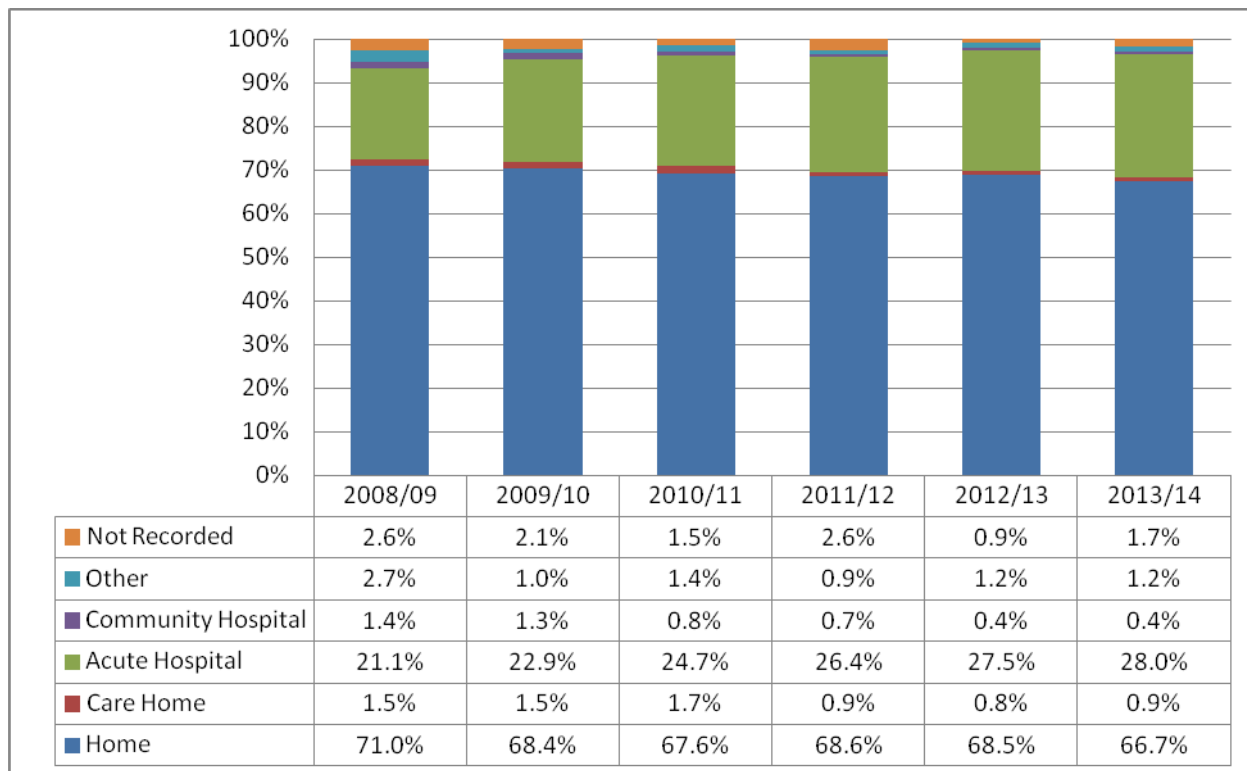


Figure 2.28: location of person prior to admission to Inpatient unit, 2008-2014 (Table 27)

Bed availability

Available beds are all beds which are occupied, reserved, or available for use the following day. Beds kept empty because of staff shortages or ward closures are considered unavailable. Beds kept empty for other reasons, such as a recent death, are considered available.

Bed availability has increased over time, although there was a slight decrease between 2012/13 and 2013/14, mirrored in the unavailability data. This suggests that overall Inpatient provision is increasing, allowing more people access to this service. The mean available number of beds per unit was 15.4 in 2013/14 (Table 24), but this masks a large range in the size of units. The smallest Inpatient unit reporting in 2013/14 has 3 beds, while the largest has 48 beds.

Unavailability has also increased this year and is currently the highest it has been since the start of the revised MDS in 2008/09. We believe this is largely driven by the temporary closure of one of the largest Inpatient units within this reporting year.

Bed occupancy

Bed occupancy is calculated from a midnight count of the number of beds actually occupied (or reserved for someone temporarily away) as a percentage of available beds.

- An occupied bed has someone in it, alive or dead.
- A reserved bed is being kept for a patient temporarily away. This category should not be used for a bed which is being kept empty because of a planned admission or because someone has recently died.
- An unoccupied bed is a bed which is empty whatever the reason, except for those few (if any) beds being kept because a patient has temporarily gone home.

The national occupancy rate (occupied bed days plus reserved bed days, divided by available bed days) for Inpatient units has stayed largely stable over the period, ranging between 74% and 78%, although the range in occupancy extends from 5% to 100%.

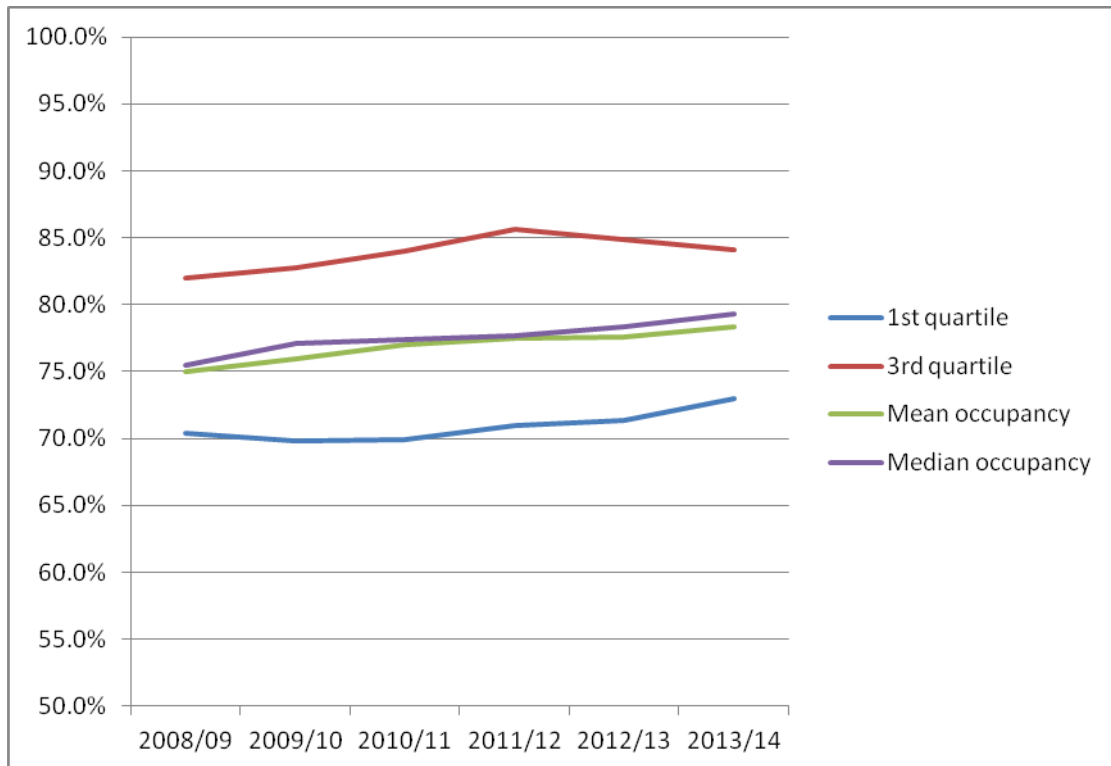


Figure 2.29: Inpatient occupancy levels, 2008-2014 (Table 33)

Looking at the historical occupancy rate, most services cluster around the mean with one service consistently reporting very low occupancy rates each year, accounting for the minimum occupancy rate for each year except 2010/11 and 2013/14. The majority of services report occupancy rates of between 71-90%.

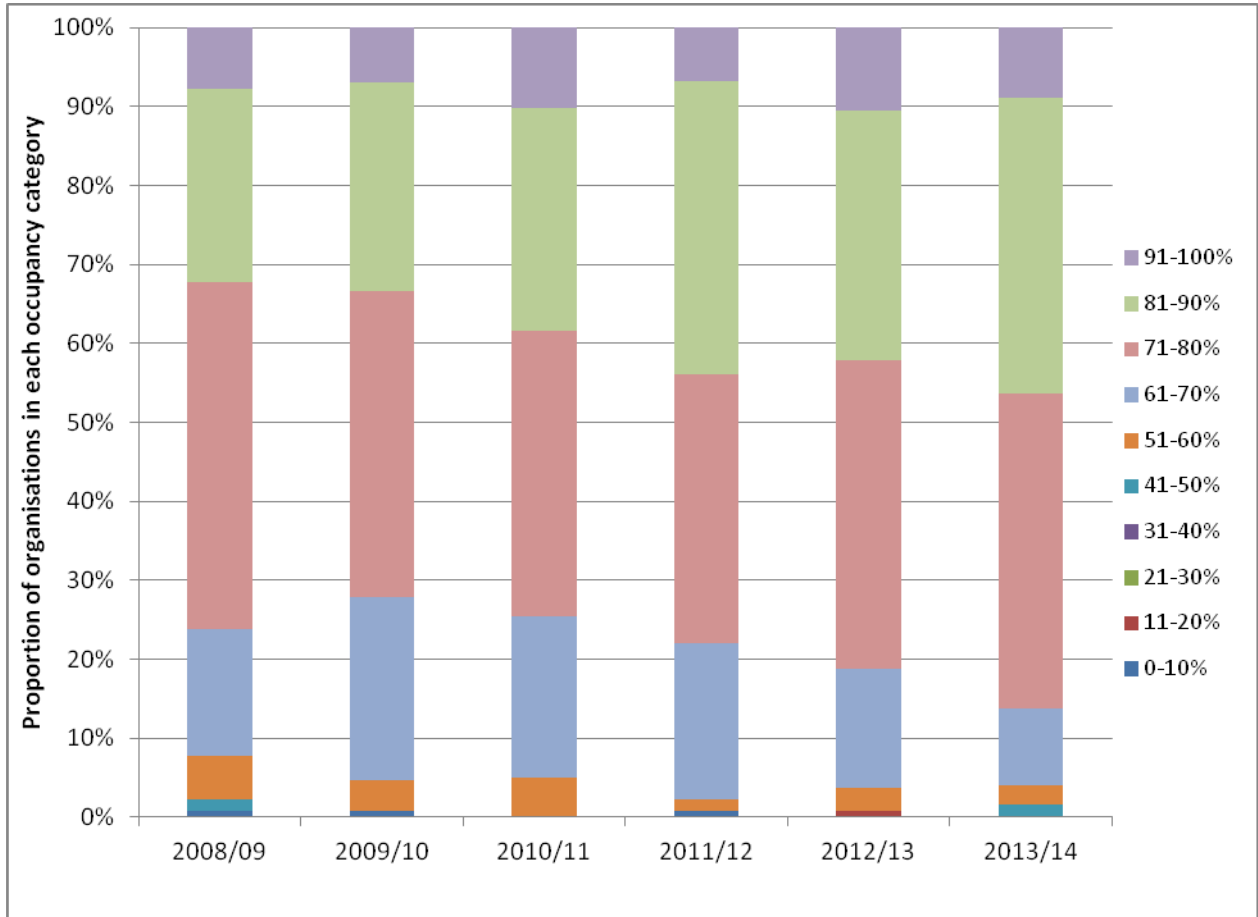


Figure 2.30: range in occupancy rate across all Inpatient units, 2008-2014 (Table 34)

Day Care MDS report 2013/14

Key findings

- The mean number of people accessing Day Care per organisation has increased by 29% over the past six years
- More women than men access Day Care services, differing from other specialist palliative care settings where the split between the sexes is typically balanced
- Day Care units are seeing an increasing proportion of people with diagnoses other than cancer, up from 14% in 2008/09 to 24% in 2013/14

Definition

A Day Care service is an arrangement whereby people attend for all or part of a day for purposes such as:

- Social interaction, mutual support and friendship
- Creative and therapeutic activities
- Clinical surveillance and routine medical treatment
- Physical care (such as bathing)
- Respite to home carers

Practice varies widely and units put differing emphasis on the social and medical aspects of Day Care. Many different activities may take place within a Day Care session, and there may be contact with many different health care staff or volunteers.

People normally attend for the whole session rather than having individual appointments. A session may last for a full day or a shorter period. Activities provided solely for Inpatients would not count as Day Care activity. A service where people attend for nursing care or therapy by appointment would fall under Outpatients activity. However, an appointment within the Day Care session – e.g. someone attending for a full session within which they have an appointment with a hairdresser - should not be counted separately.

Some specialist palliative care services may struggle to differentiate between their Outpatient care and their Day Care; consequently it is possible that two different services which are similar in structure may be reported under different MDS categories.

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

134 of 193 Day Care services returned MDS data in 2013/14 representing a 69.4% response rate, down from 73% in the previous MDS reporting year.

Table 3a: Day Care response rates by type of organisation and type of management, 2008-2014

Year	Hospice		Hospital		Clinic	Total services responding
	Managed by NHS	Managed by Independent	Managed by NHS	Managed by Independent	Managed by Independent	
2008/09	22	117	12	1		152
2009/10	17	121	10	1		149
2010/11	14	126	5	1		146
2011/12	14	119	6	1	1	141
2012/13	11	117	10	2	1	141
2013/14	13	110	9	2		134

Number of patients

The mean number of people per unit accessing each Day Care service has increased over time, although the total reported number of patients varies from year to year due to varying response rates.

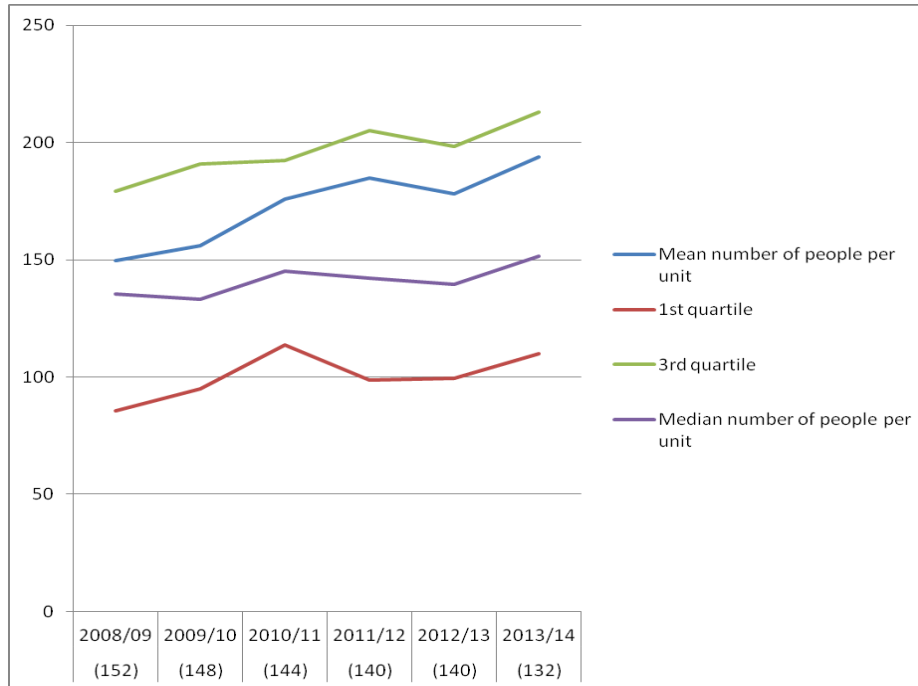
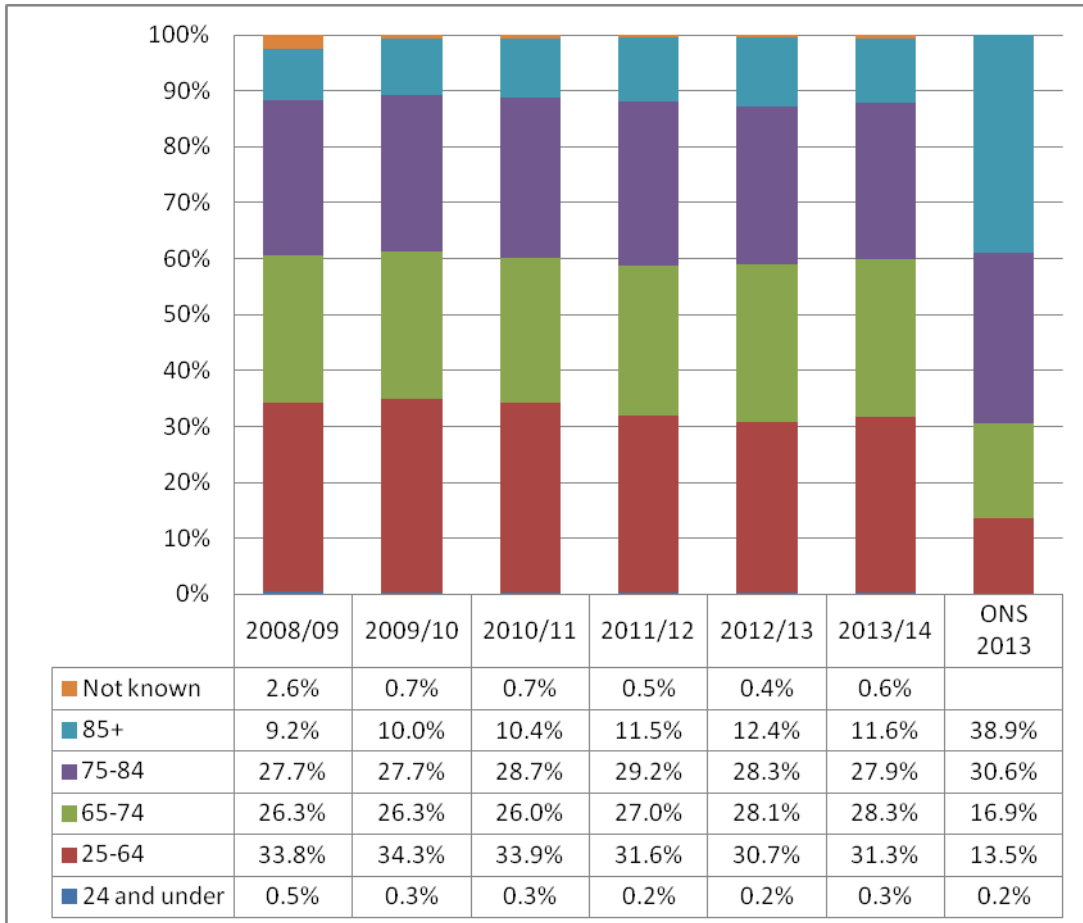


Figure 3.31: changes in the range of size of Day Care units over time (Table 36)

However, this average masks a huge variation in the size of services. The current largest service saw over 1700 people in 2013/14; the smallest service saw 12. Consequently, it can be assumed that provision and access to Day Care varies quite significantly between areas.

Age of patients

The proportions of people accessing Day Care from different age groups has changed very slightly over the past six years, with a very slight decline in the proportion of 25-64 year olds, and a very slight increase in the proportion of 85+ year olds.



*ONS 2013 data includes all deaths registered in 2013, excluding those from accidental causes.

Figure 3.32: proportion of different age groups accessing Day Care, 2008-2014 (Table 37)

Sex

Unlike other services which are accessed almost exactly 50-50 by men and women, Day Care services tend to be accessed by more women than men.

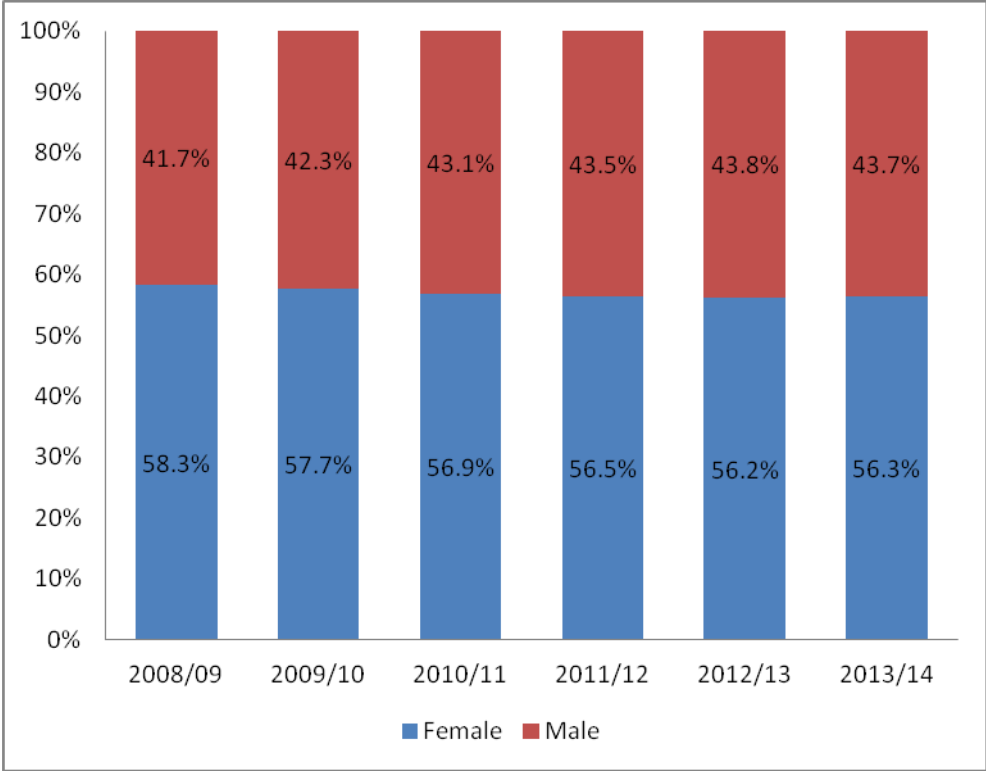


Figure 3.33: proportion of men and women accessing Day Care, 2008-2014 (Table 38)

Diagnoses

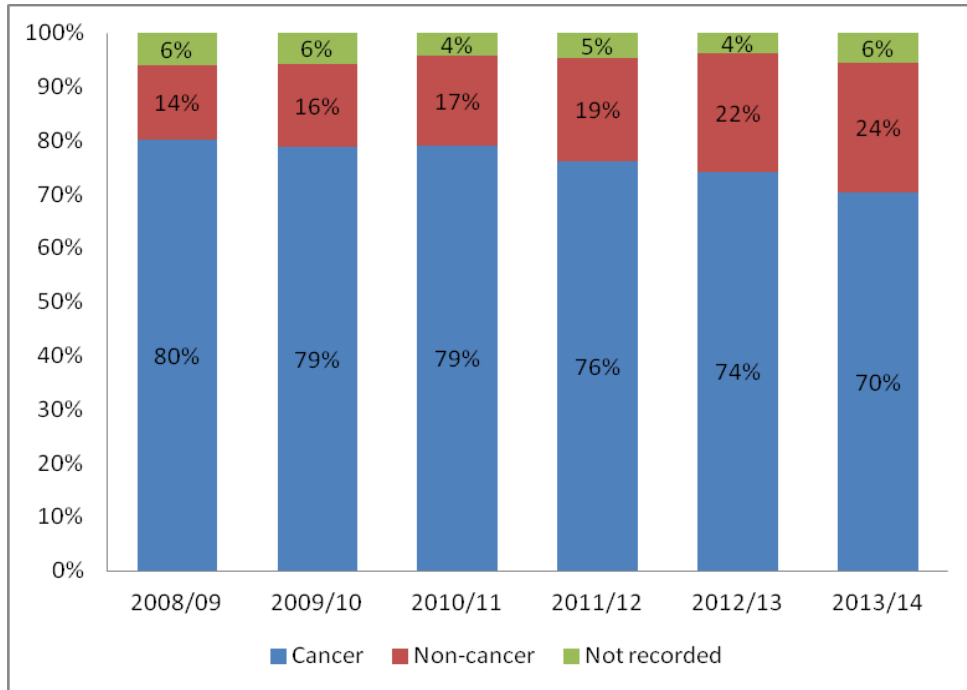


Figure 3.34: proportion of people with different categories of primary diagnosis accessing Day Care, 2008-2014 (Table 39)

The mean proportion of people accessing Day Care services who have a cancer diagnosis has fallen over time, from 80% in 2008/09 to 70% in 2013/14. In 2010/11, the highest percentage of people with cancer accessing any one service was 96%; in 2013/14 it was 99%. In all other years there have been Day Care services reporting that 100% of the people accessing their service have cancer. However, there are also services that see very low proportions of people with cancer, the lowest being 9% from one service in 2009/10.

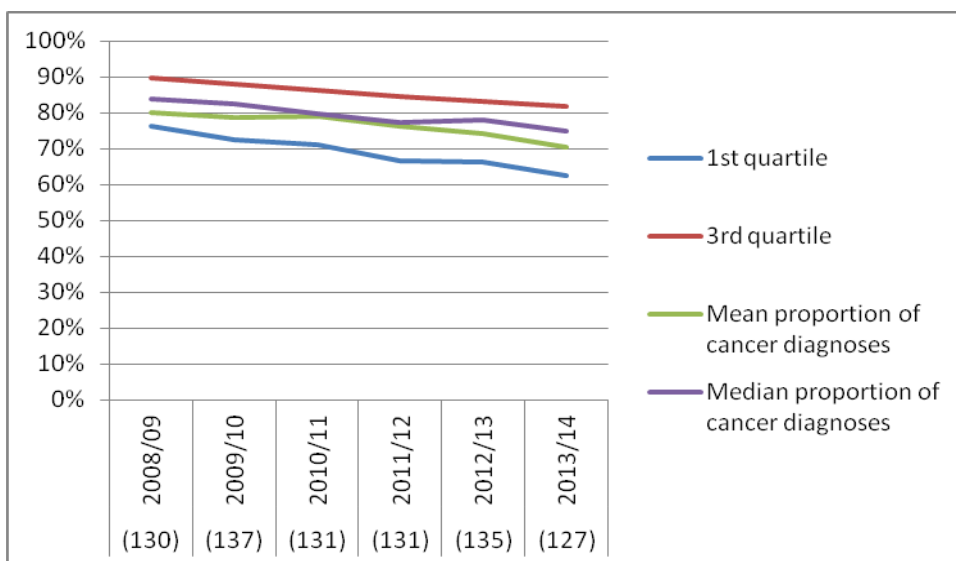


Figure 3.35: range in proportion of people with cancer diagnoses accessing Day Care, 2008-2014 (Table 1)

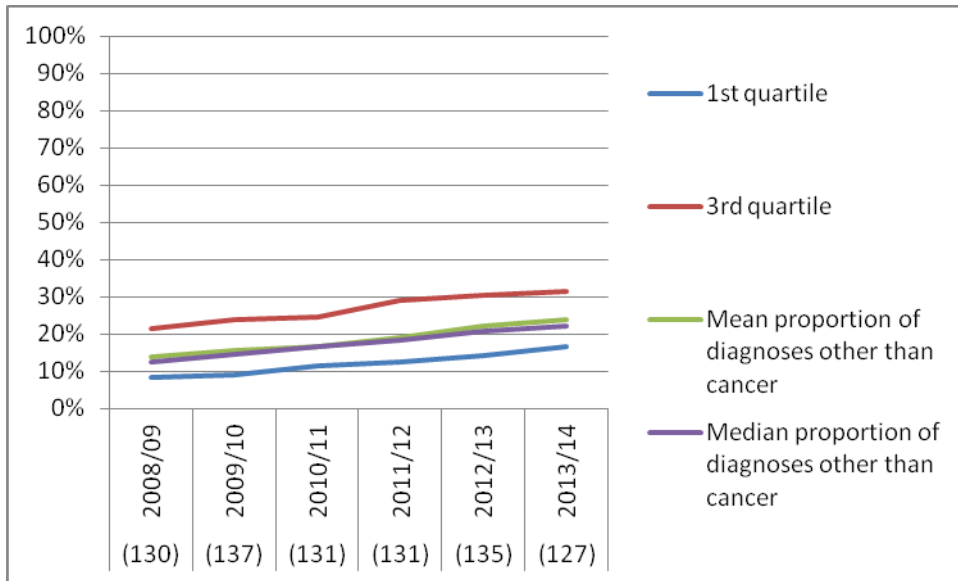


Figure 3.36: range in proportion of people with diagnoses other than cancer accessing Day Care, 2008-2014 (Table 2)

Some services have no unrecorded diagnoses, whereas in the majority of years there are Day Care services who do not record any diagnoses.

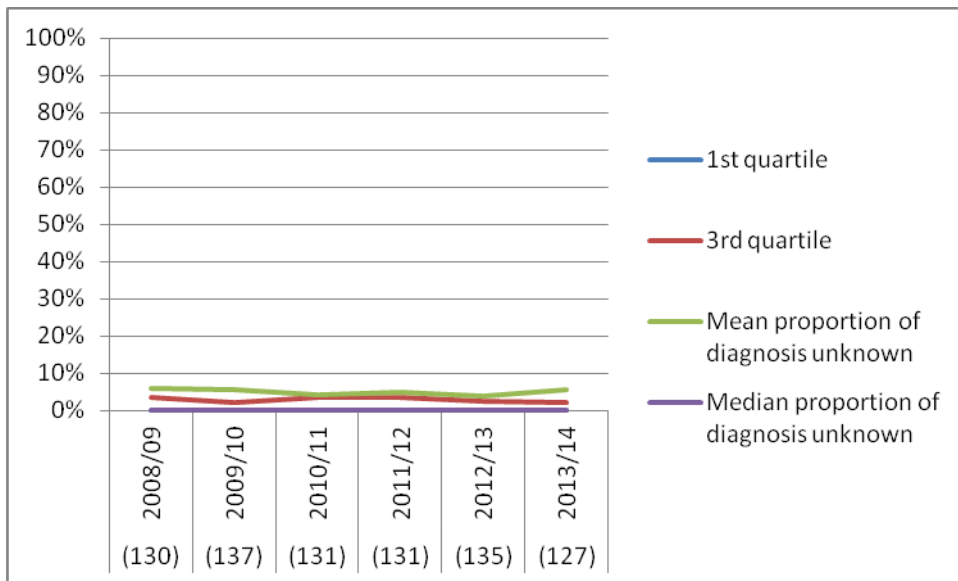


Figure 3.37: range in proportion of people with diagnoses unknown accessing Day Care, 2008-2014 (Table 3)

Diagnosis breakdown: cancer

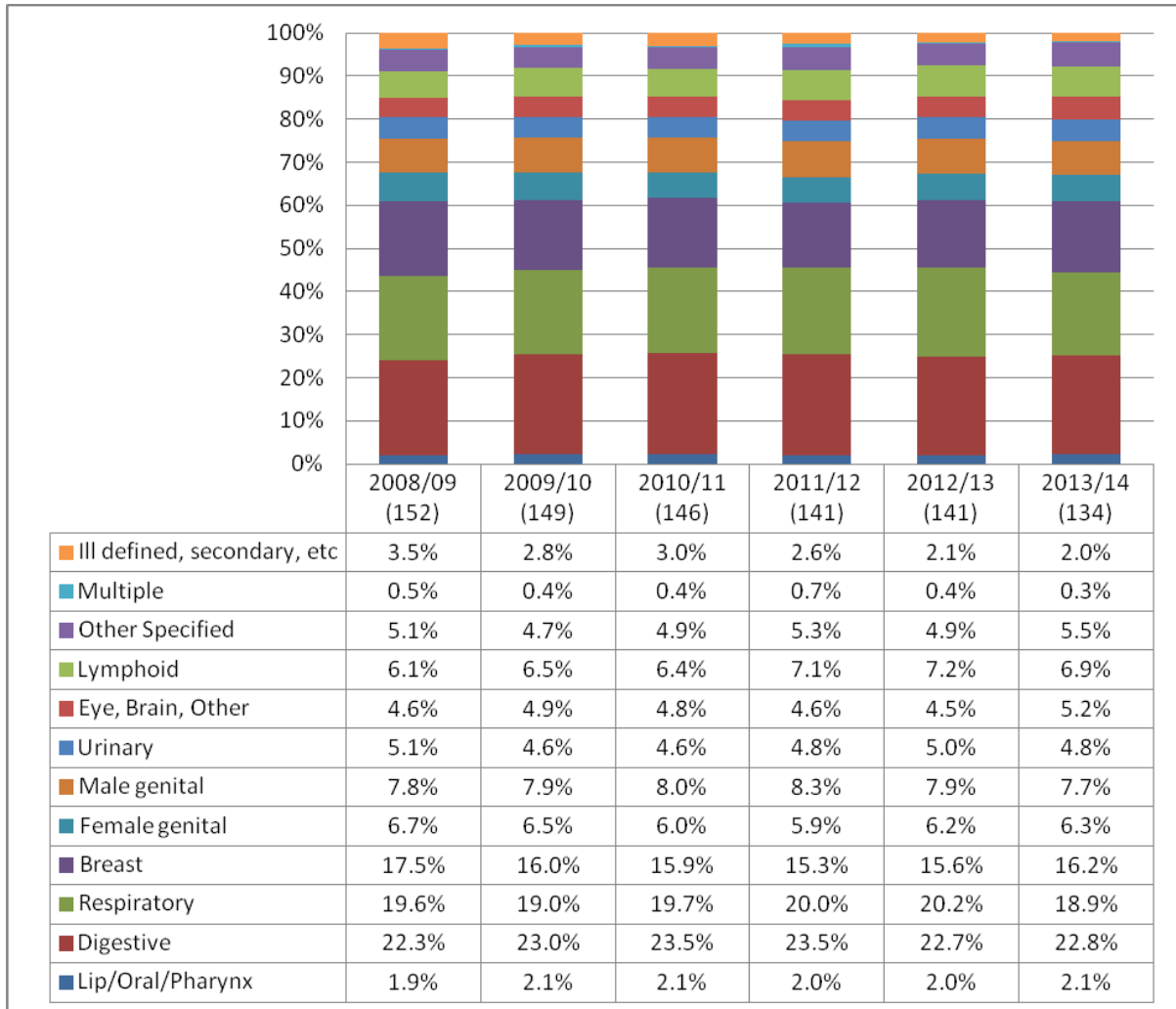


Figure 3.38: proportion of people with different cancer diagnoses accessing Day Care, 2008-2014 (Table 4)

There has been very little change in the proportions of people with each type of cancer recorded by Day Care services over time.

Diagnosis breakdown: diagnoses other than cancer

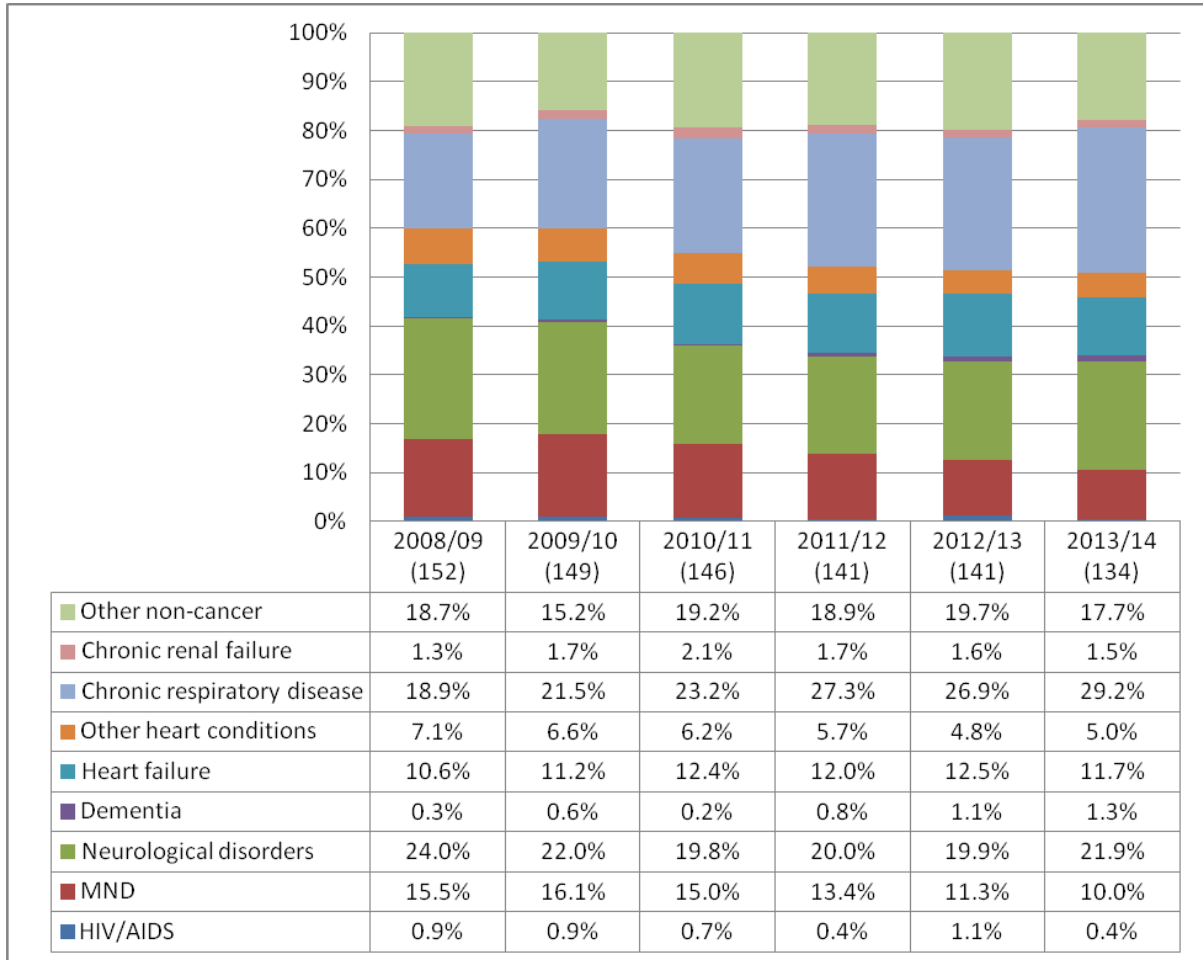


Figure 3.39: proportion of people with diagnoses other than cancer accessing Day Care, 2008-2014 (Table 5)

Although the proportions of people with diseases other than cancer have shifted over time between different diagnoses, the total number of people in with diagnoses other than cancer has increased (Table 44).

Case study: Increasing access to Day Care for people with MND

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

St Michael's Hospice (Hampshire)

The hospice has always offered care to people with life-limiting conditions regardless of diagnosis, which included people with Motor Neurone Disease (MND). Until 2011 care for people with MND was delivered in an unstructured way. Closer working between the Palliative Medicine and Neurology Consultants led to recognition that both early and advanced care could be improved, if services were to work in a more integrated way.

In 2011 a monthly multi-disciplinary clinic was set up for people with MND and their carers. The clinic allowed the patient and their carer access to all members of the multi-disciplinary team (Neurologist, Consultant in Palliative Medicine, Regional care centre Co-ordinator, Hospice at @Home Team, Social Worker, Physiotherapist, Occupational Therapist, Speech and Language Therapist and the MND Association Visitors). The MND Association facilitates improved access to their services and provides support in clinic for people with MND from their Association Visitors.

To date, the clinic has supported 32 people with MND over this 3 year period. Time from diagnosis to first attendance ranged from 1 month to 3.5 years. 50% of patients were seen within 4 months of diagnosis. 35% of patients have died in that period with 57% achieving preferred place of death. 43% had input from Hospice at Home Service. Patients reported that their anxiety was reduced through clinic attendance and understanding of illness and how to manage it increased. Patients' satisfaction scores for the clinic were 88%.

The frequency patients attend the clinic is primarily driven by the person with Motor Neurone Disease. Attending also enables them to access other professionals as required such as Specialist Palliative Care Social Worker, Speech and Language Therapist as well as other services such as the day services and at end of life, Hospice at Home services if required.

CARER EXPERIENCE: *'I was amazed and relieved; the staff go to great lengths to make patients feel less frightened which is very important. The atmosphere was very friendly. Any questions I had were always answered.'*

Ethnicity

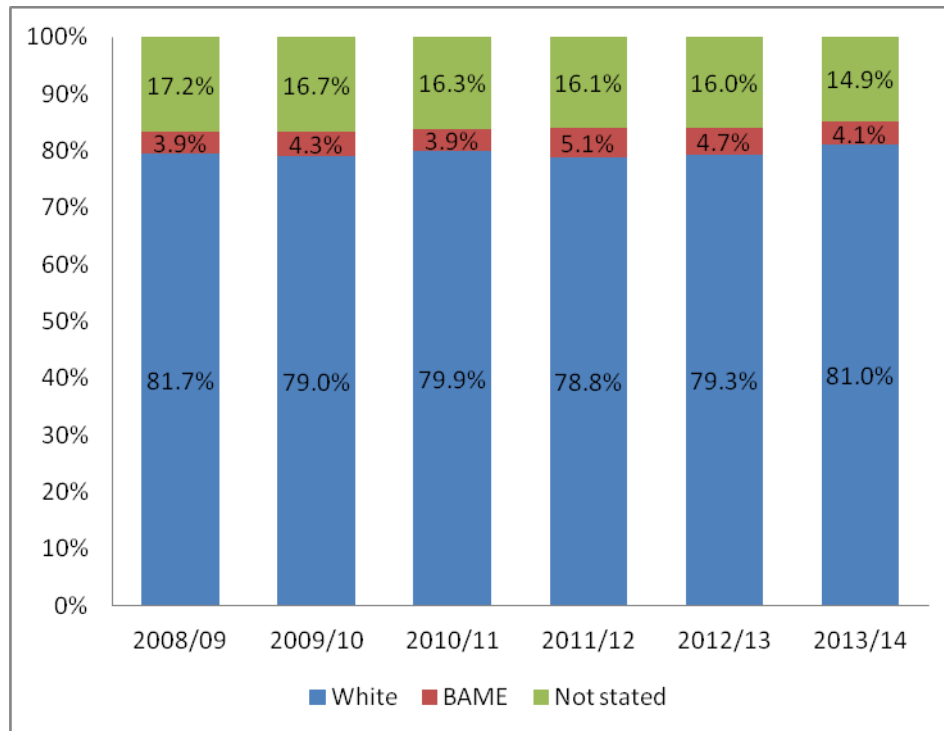


Figure 3.40: proportions of people accessing Day Care reported as white, BAME and not recorded, 2008-2014 (Table 6)

Since 2008/09, there has been very little change in the proportion of Black, Asian and Minority Ethnic (BAME) people who access Day Care palliative care services. There has also been very little improvement in the recording of ethnicity by services, meaning there may be many people accessing Day Care services who are in fact from a BAME background, but this is not recorded. 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.

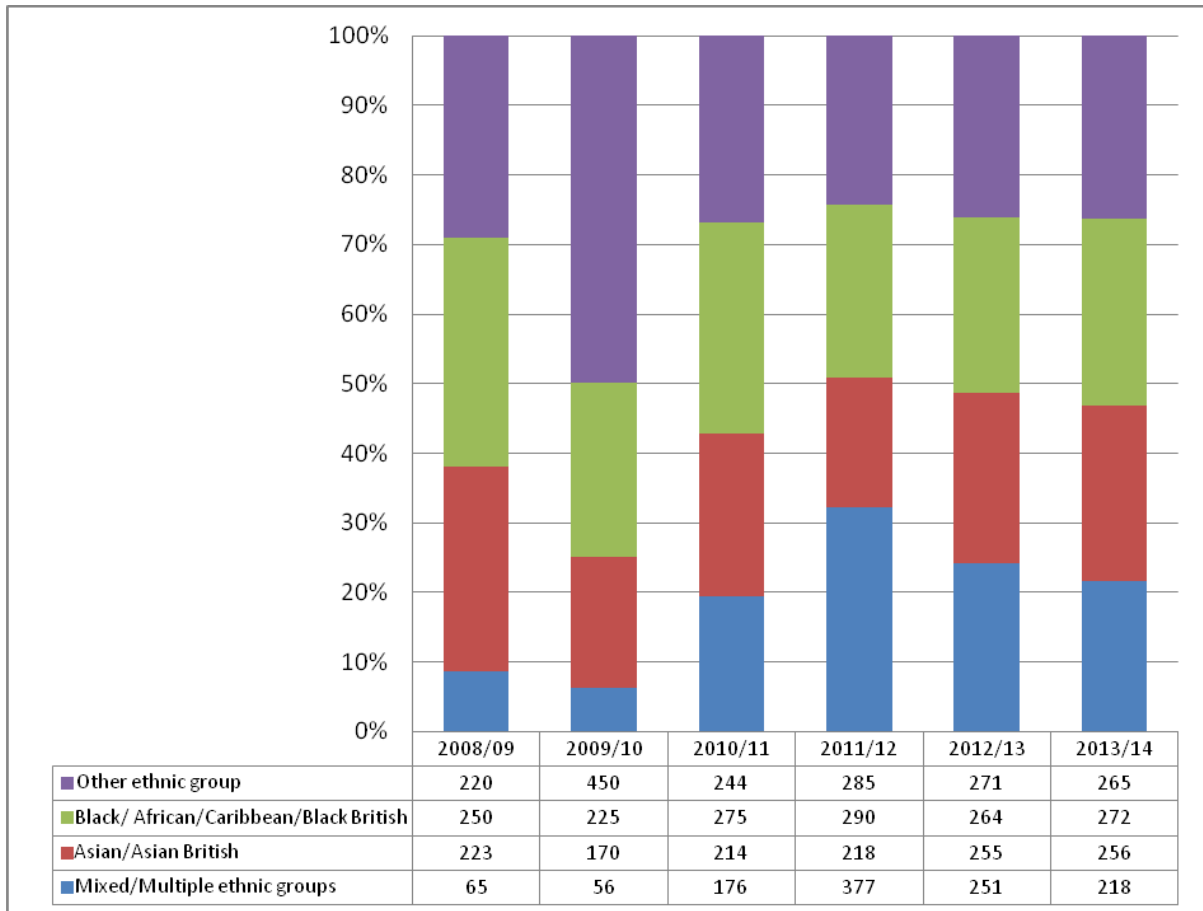


Figure 3.41: people accessing Day Care from grouped BAME categories, 2008-2014 (Table 7)

The proportion of people from BAME backgrounds varies considerably between geographic regions, and further work is underway to assess the variation in access to specialist palliative care on a regional basis. However, without consistently recorded ethnicity data, it will continue to be a difficult issue to address.

Day Care sessions, places, attendances and non-attendances

A Day Care session is usually equivalent to a day's worth of provision but no strict guidance is given to services about this and so some report more than 365 sessions in a given MDS reporting period. Services may be defining a session as a morning or afternoon, or may be counting sessions running on different sites but reported in one return. Consequently, there is no way to compare provision between services, as two services might report 365 sessions but one might be indicating that their service was open every day, and the other might be indicating that they are open every morning.

The guidance for Day Care places is given as 'the number of places available at each session multiplied by the number of sessions'. Excluding data from services that provided us with only session information and not places, the mean places per session across the sector is steady at around 14, with some services offering only 1 place per session, and some offering over 50. This suggests that Day Care is provided in very different ways in different services, further complicating the issue of comparison. Currently, there is no way to know whether an organisation offering 10 places per session is providing this with one member of staff i.e. running a music therapy group, or with ten members of staff each providing different aspects of care.

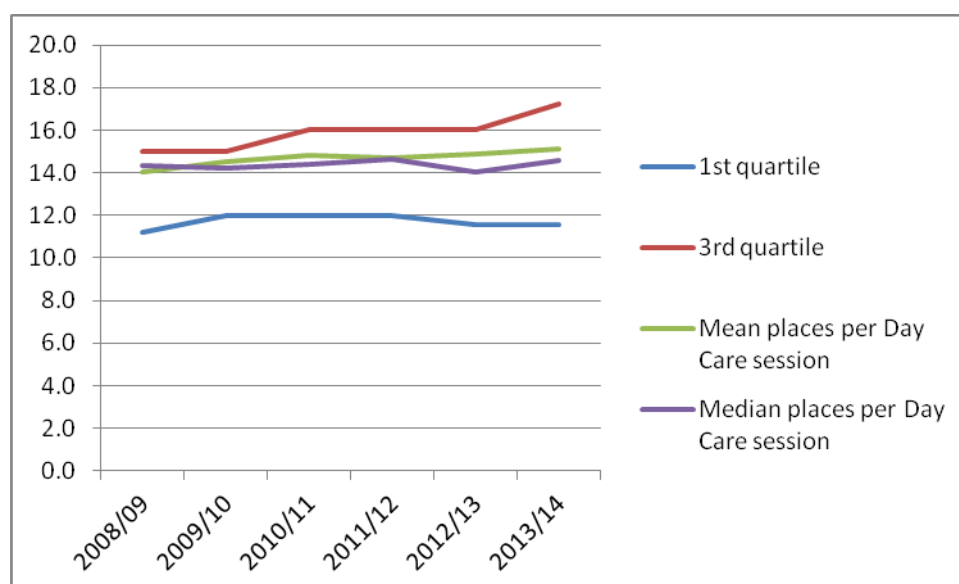


Figure 3.42: range in mean places per session offered by Day Care services, 2008-2014 (Table 8)

A substantial number of exclusions for poor quality data in this section is likely to reflect the vagueness of the MDS guidance. In order to more fully understand provision of Day Care and differing models of care, we will evaluate what information might be useful to capture instead.

Attendance and non-attendance data is similarly varied in quality. Unless services are consistently overbooking their Day Care places, it might be expected that the sum of attendances and non-attendances would not be greater than the places available and in fact would be likely to be lower, given that services might operate on a drop-in basis. However, consistently a substantial number of returns show more attendances and non-attendances than places available.

Length of care

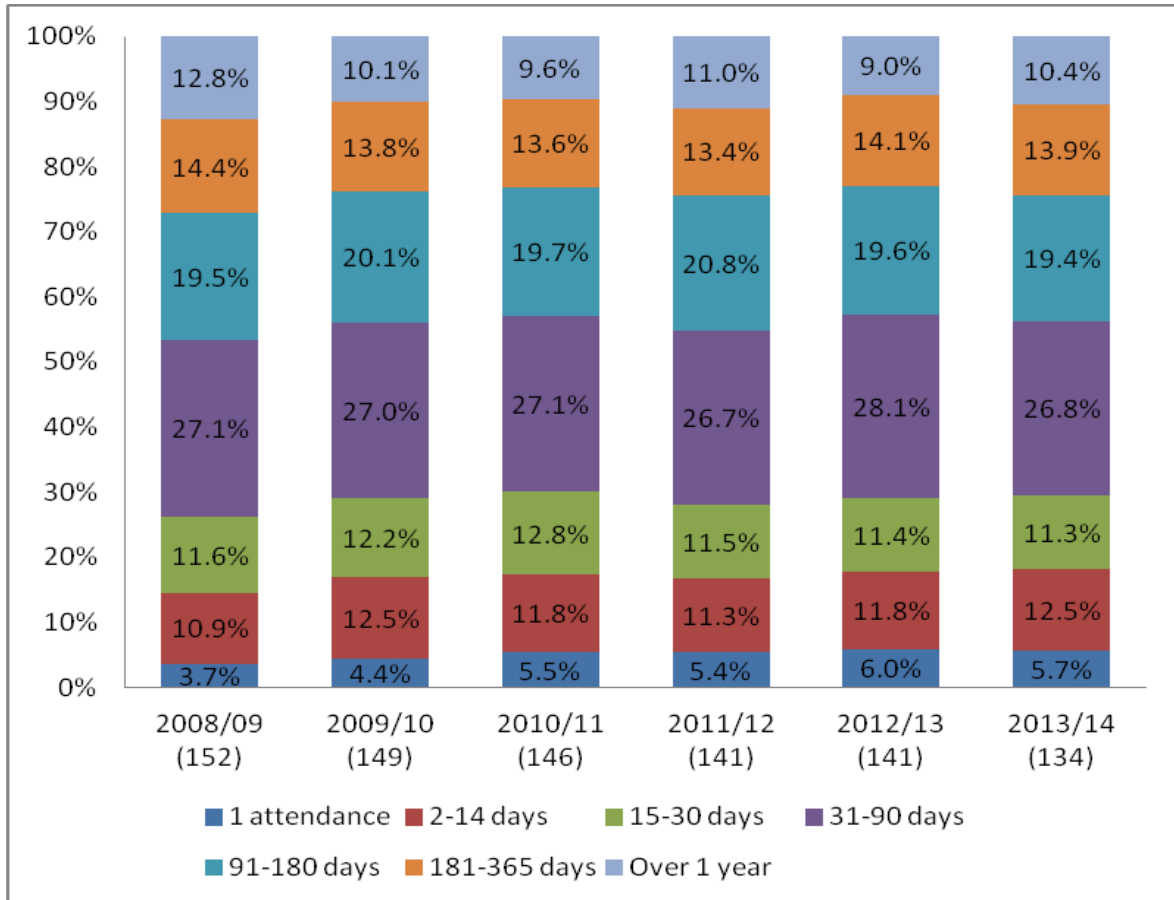


Figure 3.43: length of care for Day Care, 2008-2014 (Table 9)

There has been very little variation in length of care over time. The average length of care for Day Care has remained at around 6 months in each MDS reporting year.

Community Care MDS report 2013/14

Key findings

- Community Care services are seeing more people, in line with the sector's ambition to enable more people to be cared for at home
- Of those with conditions other than cancer, a larger proportion of people with dementia are reported by Community Care teams than in other settings.

Definition

A community care service is provided by means of visits to people in their home or other place of residence. Community care is mostly, but not exclusively, provided by specialist nursing staff such as Macmillan Nurses. Other staff such as doctors and social workers may also make home visits. These staff may carry out a wide range of services including:

- Clinical surveillance
- Physical and nursing care
- Counselling, advice and education for patients and families
- Consultancy and education for other health professionals.

There are many different organisational and funding arrangements for staff providing community care. Specialist palliative care staff may be based in hospices, hospitals or NHS community units, and work closely with general practitioners and primary health care teams. A series of community care visits involves one or more individual visits by community care staff. The visits making up a series may be made by members of staff of different professional groups, for example nurses and social workers.

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

183 of 261 Community Care services returned MDS data in 2013/14 representing a 70.1% response rate, up from 65% in the previous MDS reporting year. This increase is largely due to an audit of the service directory resulting in the removal of some defunct services.

Table 4a: response rates by type of organisation and type of management, 2008-2014

Year	Hospice		Hospital		Clinic	Community		Unknown	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	Managed by Independent	
2008/09	39	95	30	1	5	12	1	3	4	1	191
2009/10	36	103	25	1	4	9	2	4	5		189
2010/11	32	110	21	1	4	8	1	3	3		183
2011/12	28	115	18	4	3	8	1		2		179
2012/13	23	121	20	4	4	6	1		4		183
2013/14	23	116	24	3	4	8	1		4		183

Types of service

Since the 2008 review of the MDS, community-based services have been asked to assign themselves a service type. These have previously been defined as follows:

Home Care: A community service which self-identifies as providing home care, a mainly advisory service, based in the patient's home with Clinical Nurse Specialist input

Hospice @ Home (H@H): A community service which self-identifies as providing 'Hospice @ Home', a mainly hands on nursing service, based in the patient's home without Clinical Nurse Specialist input

Combined service: A single community service which self-identifies as providing both 'Hospice @Home' and Home Care

Examination of the data returned in each year suggests that some services do not consistently assign themselves the same type of community service each year and some services report as Hospice @ Home services but also report a significant proportion of contacts from Clinical Nurse Specialists. Consequently, although the aim of splitting out service types is to try and compare services with similar care models, it is unlikely that we are succeeding in that aim due to the quality of the data. The 2013/14 Community Care data has therefore been analysed without reference to service type.

Integrated teams

Services are also asked whether they run as an integrated team, where the same staff work in the community and in a hospital setting. This field is inconsistently completed, and there are instances where a community team indicates that they do operate as an integrated team, but no hospital data is received. We will consider the usefulness in the continued inclusion of this field.

Number of patients

Although response rates vary each year, the overall number of people reported as having been under the care of community teams has risen every year since 2008/09. There is a large variation in sizes of services, with one seeing only 1 person in 2013/14, while the largest service sees almost 4000 people.

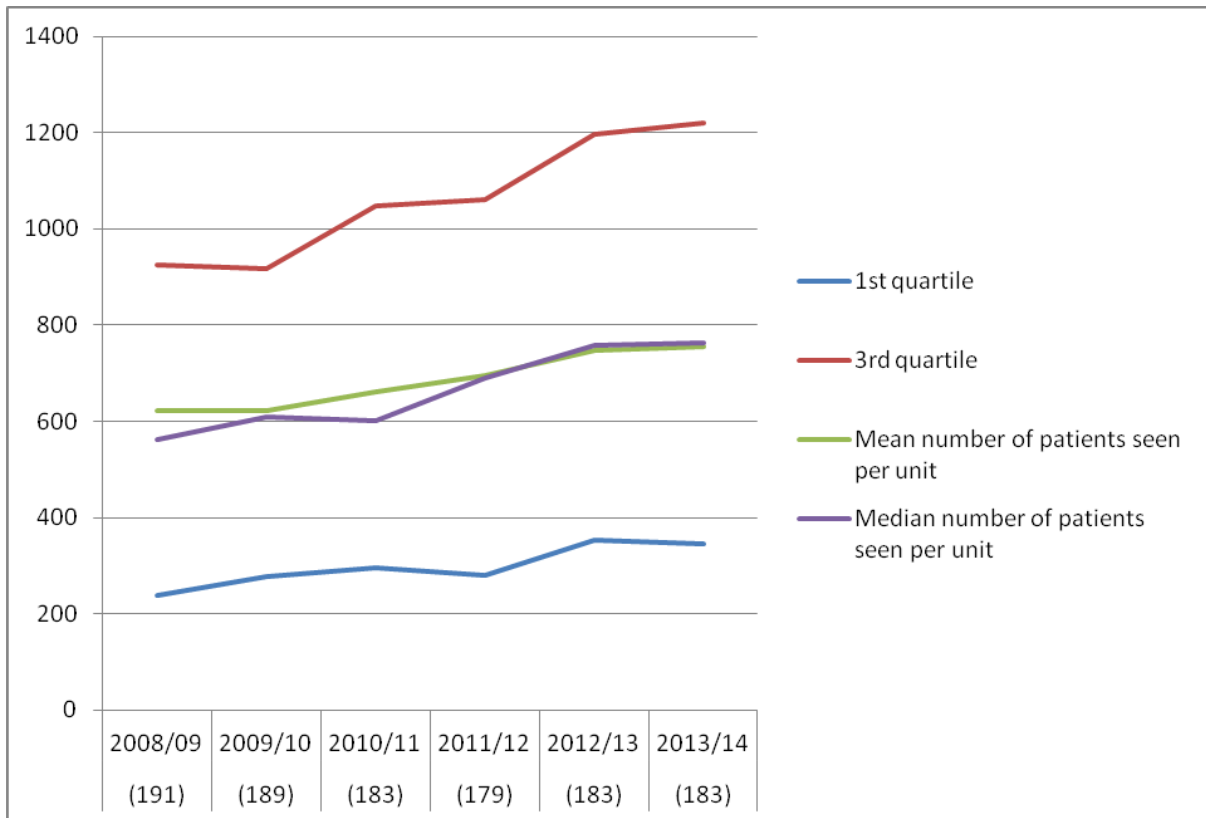
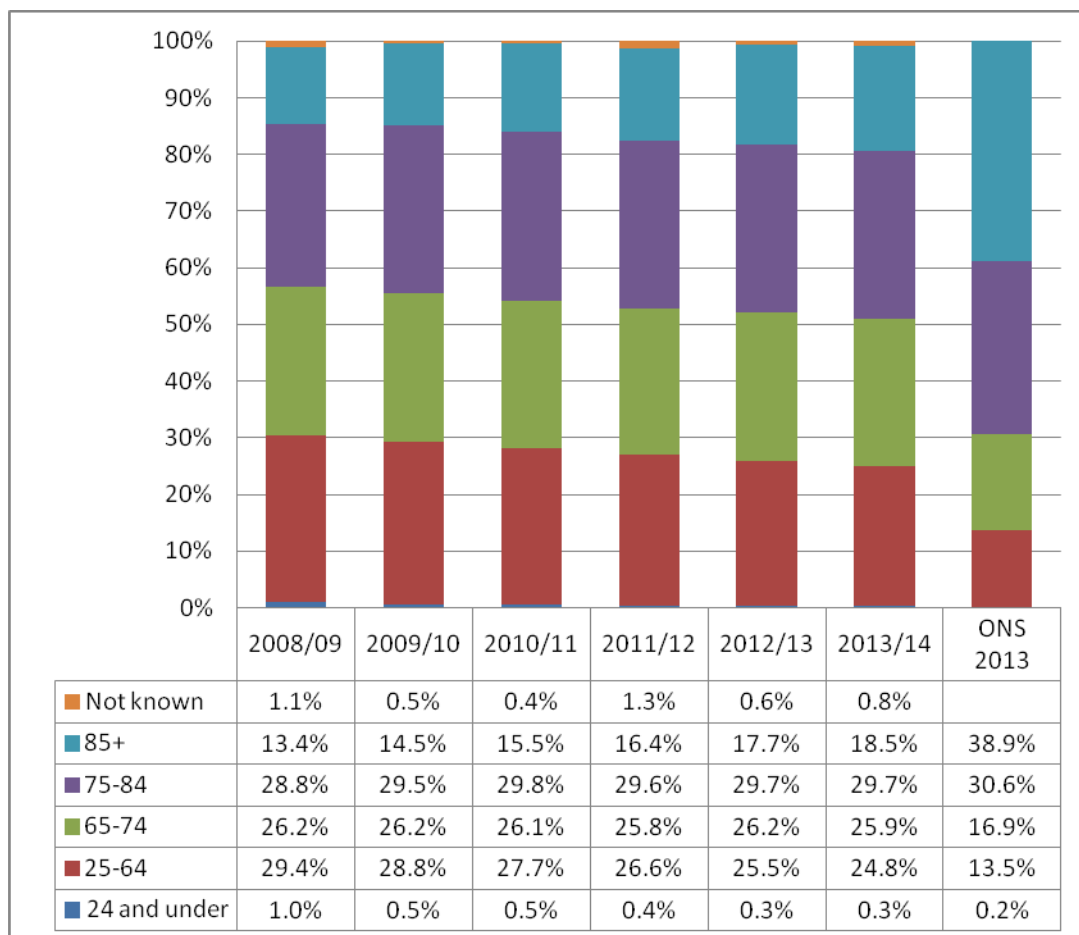


Figure 4.44: changes in the range of size of Community Care units over time (Table 10)

Age of patients



*ONS 2013 data includes all deaths registered in 2013, excluding those from accidental causes.

Figure 4.45: proportion of different age groups accessing Community Care, 2008-2014 (Table 11)

The proportion of older people seen by community teams is increasing each year, while the proportion of younger people seen is commensurately decreasing. Compared with ONS data on deaths registered in 2013, young people still appear to have disproportionate access to community-based specialist palliative care services, as is true across all other settings.

Case study: Community Care service with a higher than average proportion of patients aged over 84

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Rowcroft Hospice @ Home service

The service criteria are such that any adult in the last two weeks of life whose preference is to die at home can be referred to the service by their GP, district nurse, community matron, hospital health professional or the local GP out-of-hours service. Referrals can be acted on any time of night or day with an average response time from referral to contact of 2 ½ hrs. Whether a patient lives in their own private dwelling, or a residential or nursing home, they can access the service if this is their usual place of residence.

Public Health England (2014) reported that the proportion of deaths in people aged 85 and over and in care homes, is highest in the South of England (41% and 21% respectively). These factors may partly explain the high numbers of over 84's in South Devon accessing this service and the higher than average number of people dying in a care home. In this data set 50% (n = 57) of patients aged over 84 were supported to die in their own private dwelling, and the others were supported in their residential or nursing home.

The service accepts referrals from any health care professional for any patient dying from a life-limiting disease, regardless of complexity. The service has received referrals from all 36 GP practices in the locality, the GP out of hours' service, the ambulance service and the acute hospital. Hospice at Home works in collaboration with the other statutory and volunteer services in the locality to provide care in the last weeks of life. A high percentage of people accessing the service die in their preferred place of care because the service operates 24 hours a day, seven days a week supporting patients who wish to die in their home. A Hospice at Home sister/charge nurse is on duty 24/7 to take new referrals, to visit and plan care for all patients and answer calls from families at any time of day or night. Hospice senior health care assistants are available to provide direct nursing care for set periods of time day or night.

Sex

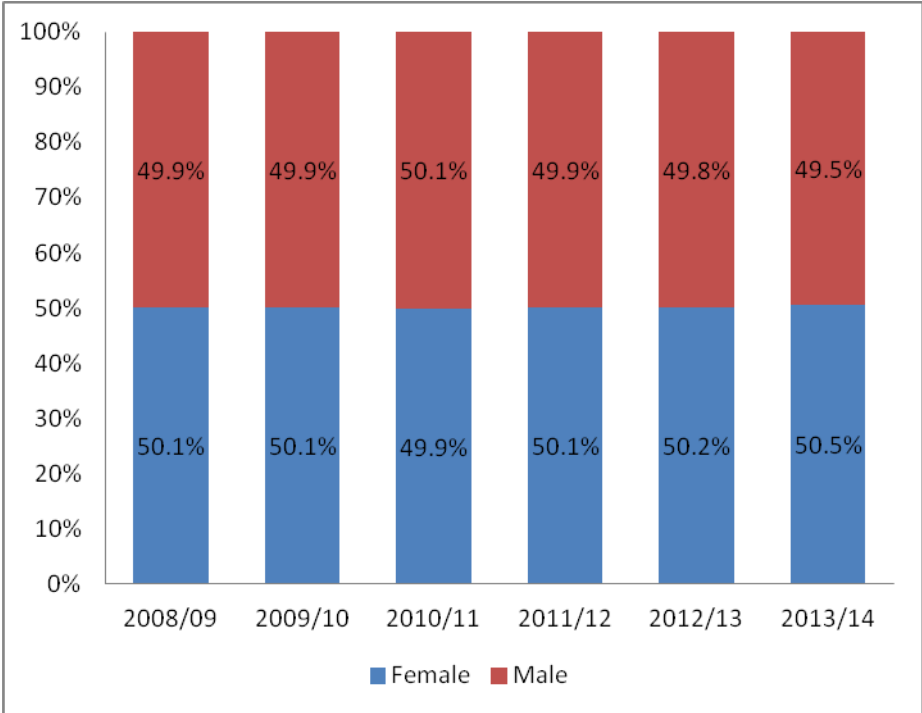


Figure 4.46: proportion of men and women accessing Community Care, 2008-2014 (Table 12)

The split in people accessing community-based services stays steady each year at almost exactly 50-50 between males and females.

Diagnoses

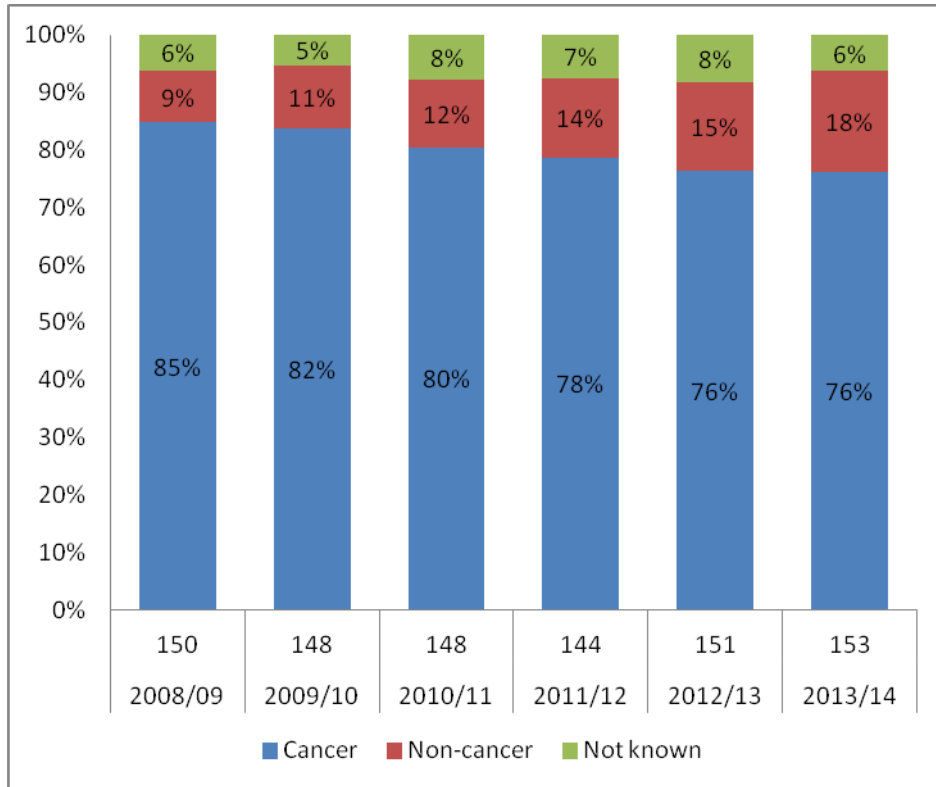


Figure 4.47: proportion of people with different categories of primary diagnosis accessing Community Care, 2008-2014 (Table 13)

The proportion of people seen by Community Care services who have a diagnosis of cancer has decreased over time, although people with cancer still represent the majority of those accessing community-based specialist palliative care services.

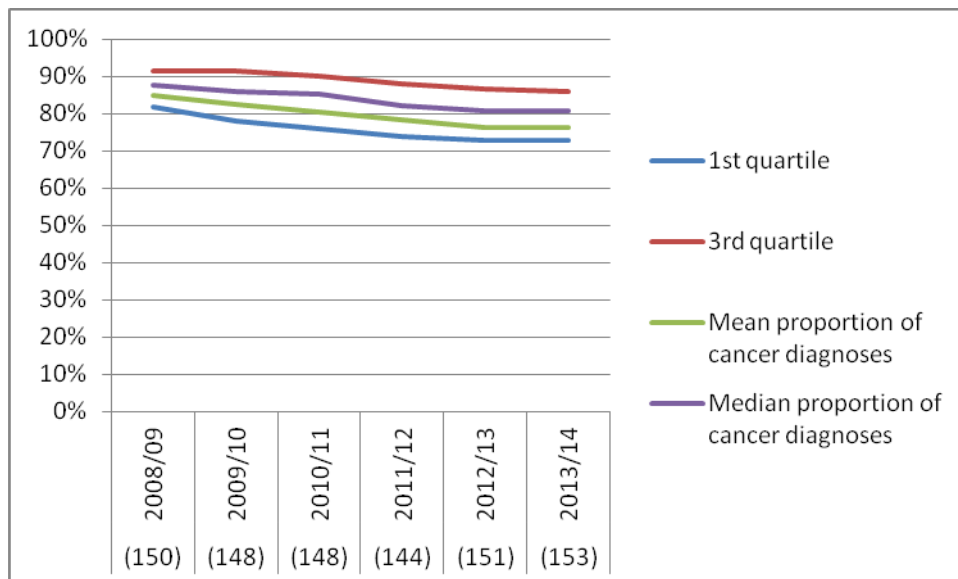


Figure 4.48: range in proportion of people with cancer diagnoses accessing Community Care, 2008-2014 (Table 14)

The proportion of people with diagnoses other than cancer accessing Community Care services has increased over time.

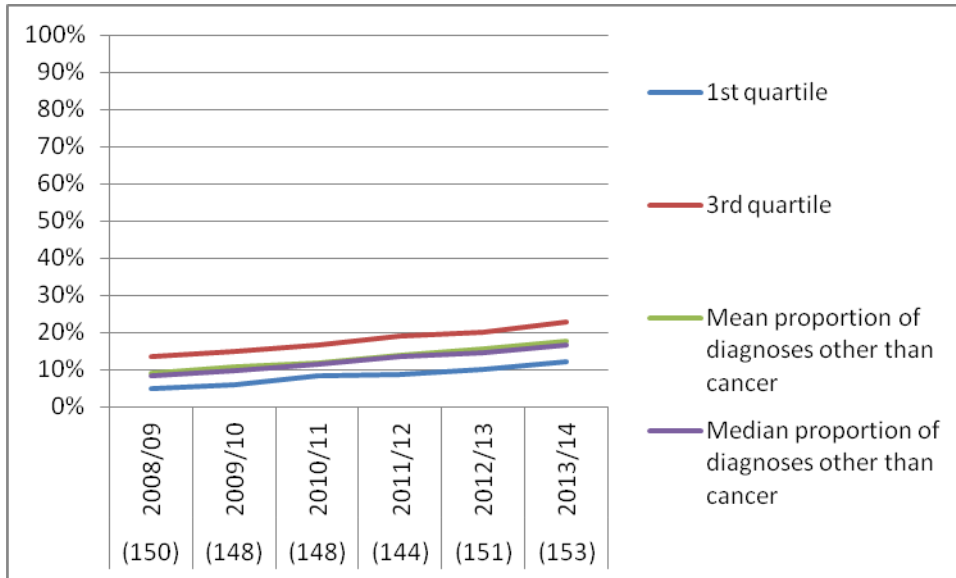


Figure 4.49: range in proportion of people with diagnoses other than cancer accessing Community Care, 2008-2014 (Table 15)

A small number of services (2 in 2013/14) are consistently unable to return any data on the diagnoses of the people their service supports and report 100% as unknown.

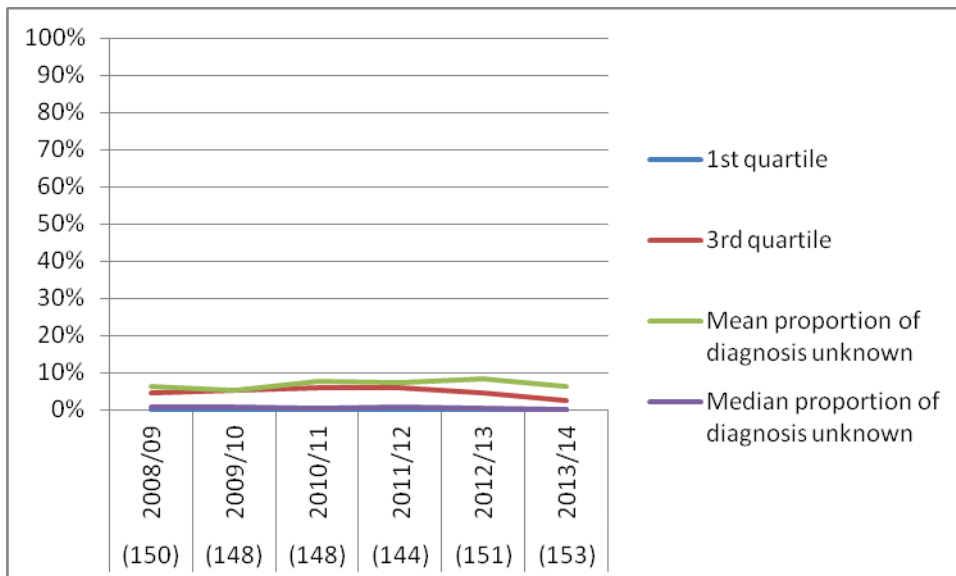


Figure 4.50: range in proportion of people with diagnoses unknown accessing Community Care, 2008-2014 (Table 16)

This may be due to reporting constraints rather than diagnosis not being recorded anywhere by these services, but this is impossible to tell from the MDS and will require further investigation.

Diagnosis breakdown: cancer

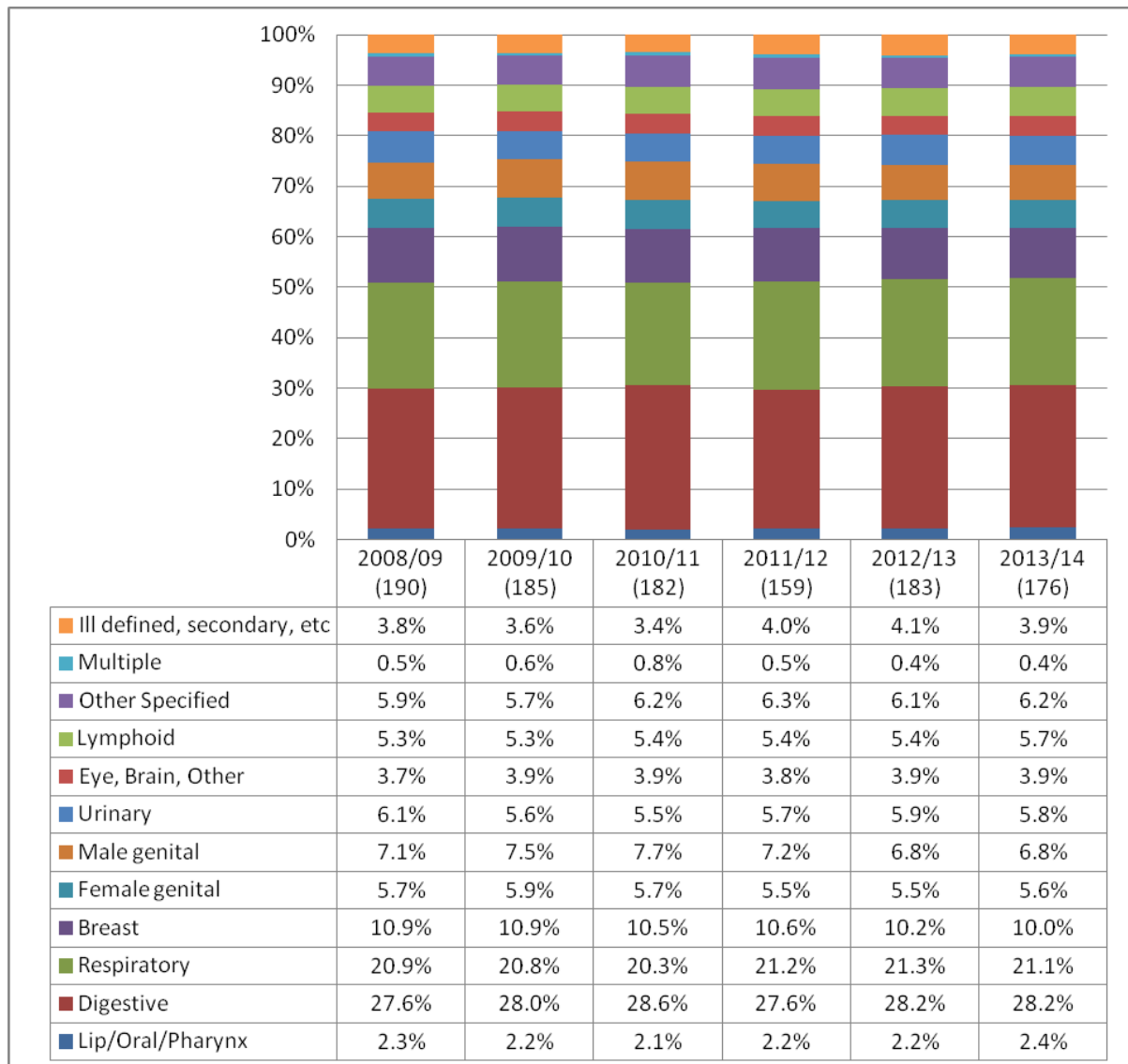


Figure 4.51: proportion of people with different cancer diagnoses accessing Community Care, 2008-2014 (Table 17)

Proportions of people with each type of cancer have remained stable over time in Community Care settings.

Diagnosis breakdown: diagnoses other than cancer

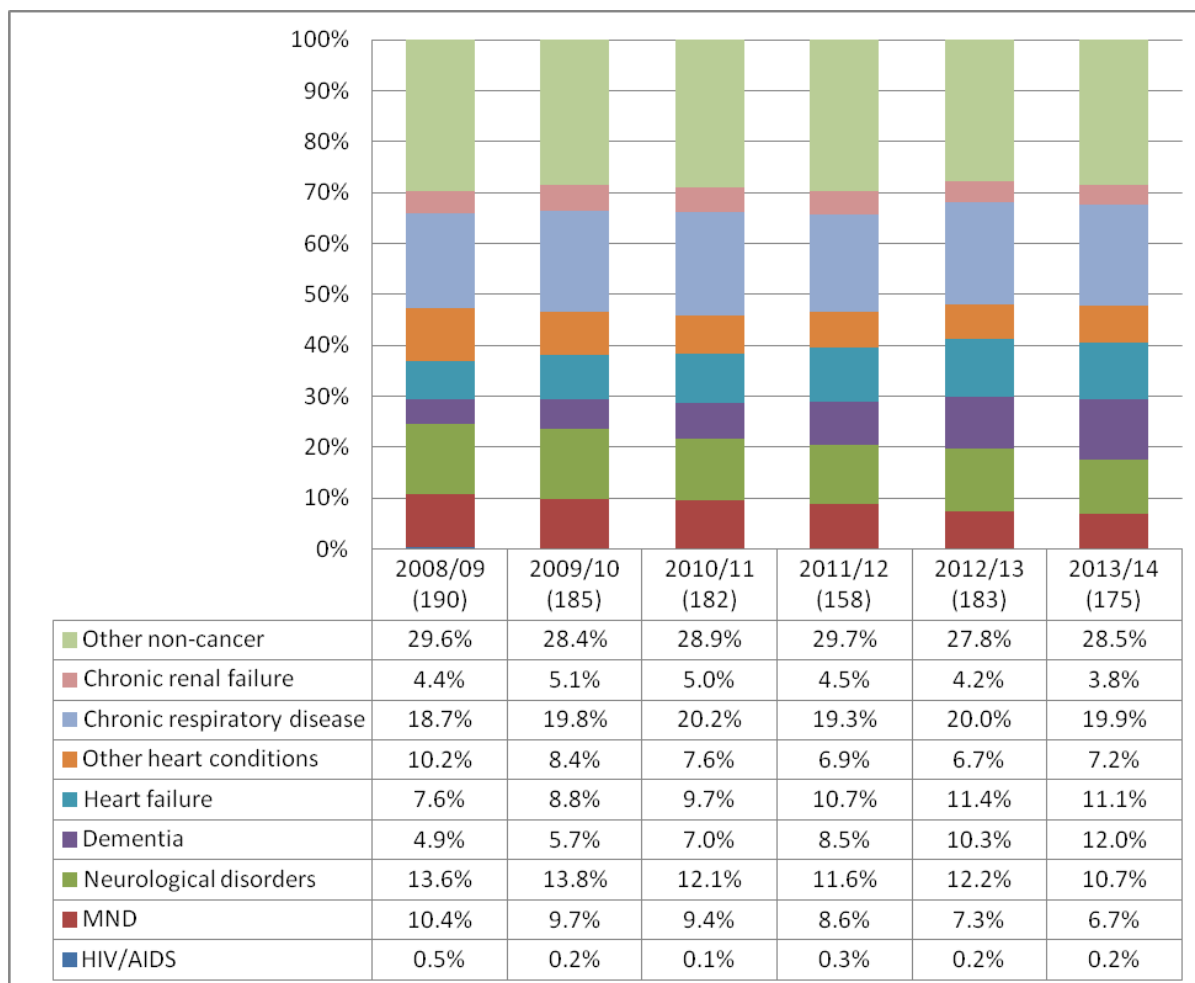


Figure 4.52: proportion of people with diagnoses other than cancer accessing Community Care, 2008-2014 (Table 18)

Community Care specialist palliative care services see a far higher proportion of people with dementia than other MDS settings, and this proportion has grown quickly over time, representing an increase from 414 people in 2008/09 to 2,676 in 2013/14, over 5 times the number of people (Table 55).

Ethnicity

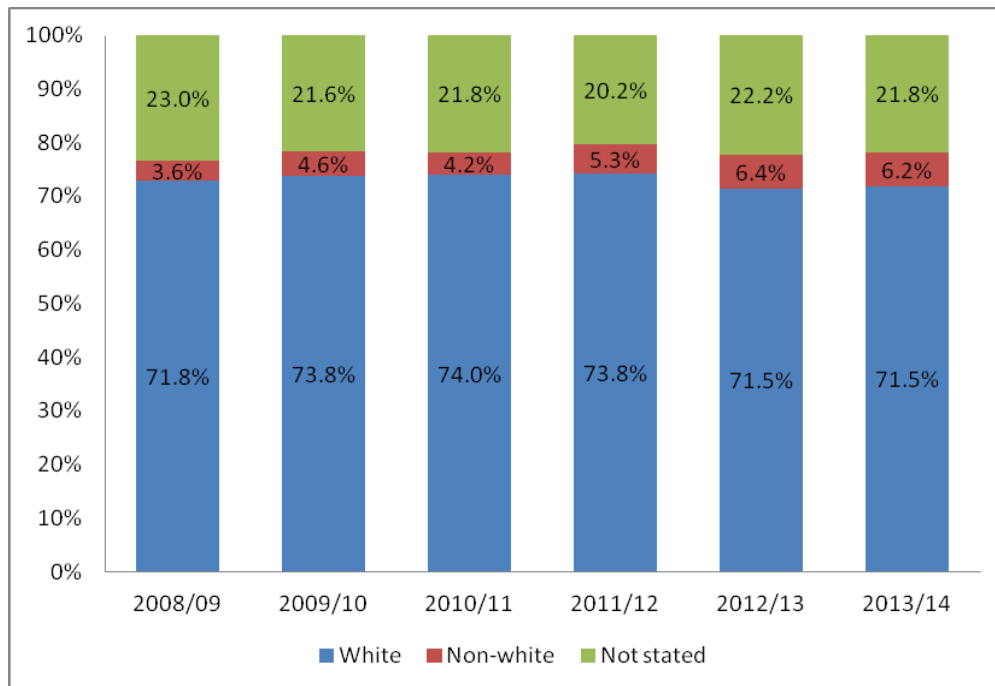


Figure 4.53: proportions of people accessing Community Care reported as white, BAME and not recorded, 2008-2014 (Table 19)

The percentage of people of non-white ethnicity accessing Community Care has increased over time although some people who do not have their ethnicity recorded by services may also be of non-white origin. 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.

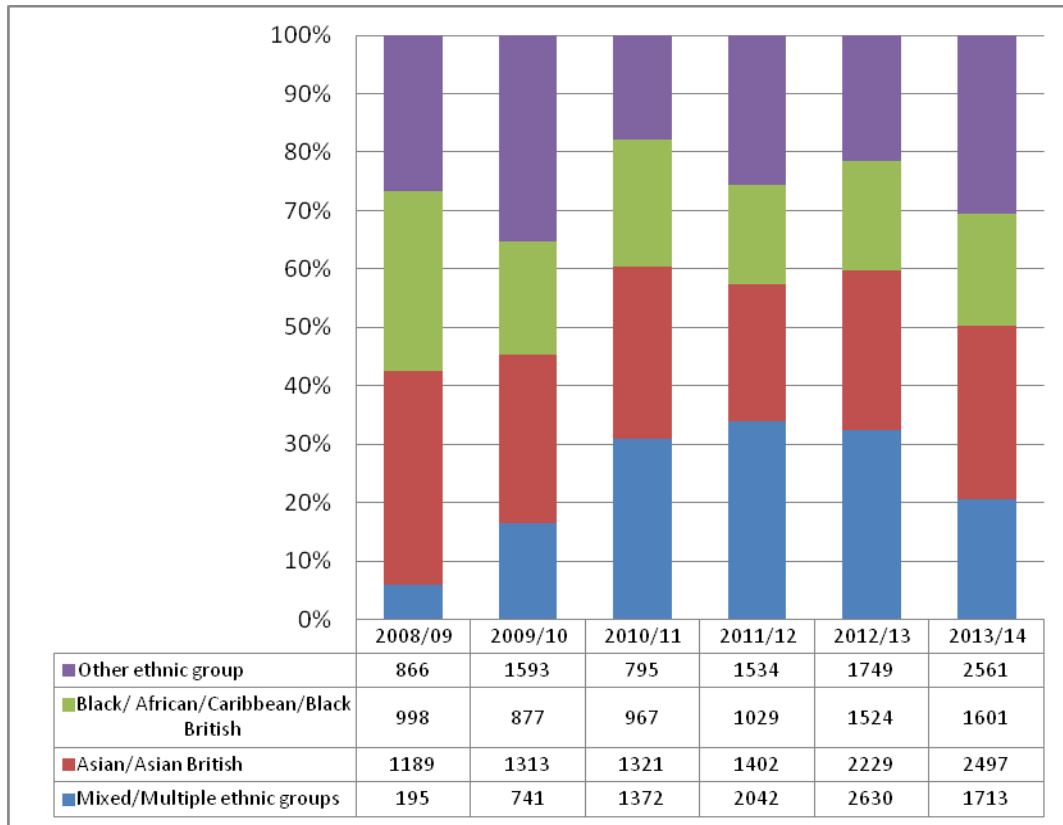


Figure 4.54: people accessing Community Care from grouped BAME categories, 2008-2014 (Table 20)

Detailed data on people of BAME origin accessing specialist palliative care shows that large numbers are recorded under ‘Mixed’ or ‘Other, making it difficult to ascertain which groups are accessing care. Improvement in the capture of ethnicity data is imperative in order to assess access to specialist palliative care services.

Outcome

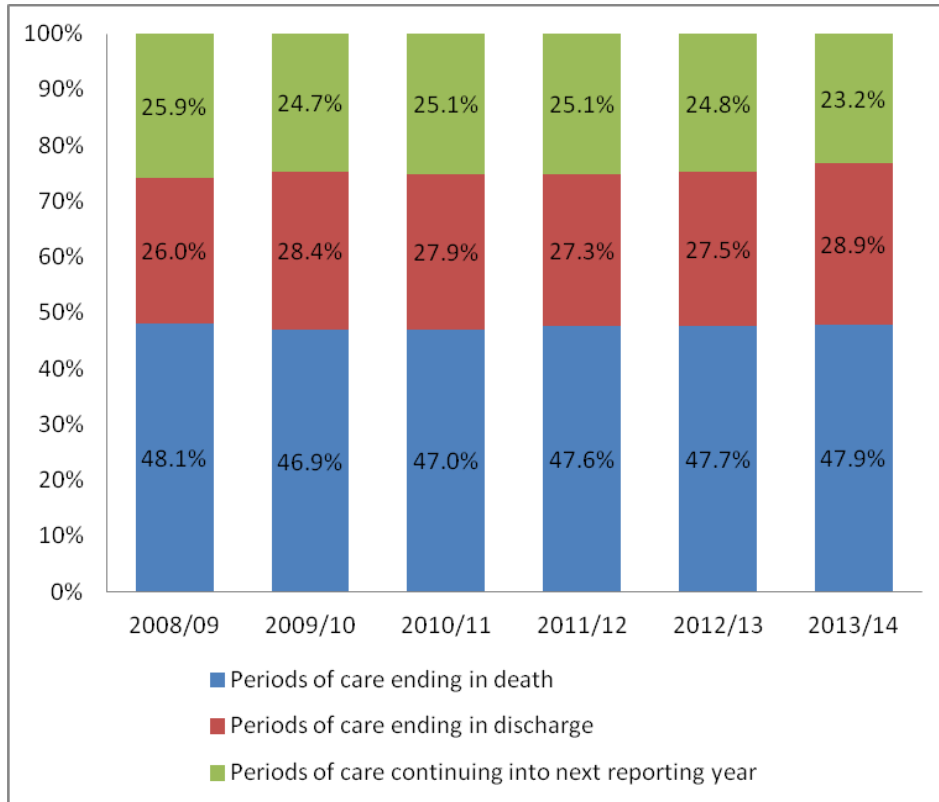
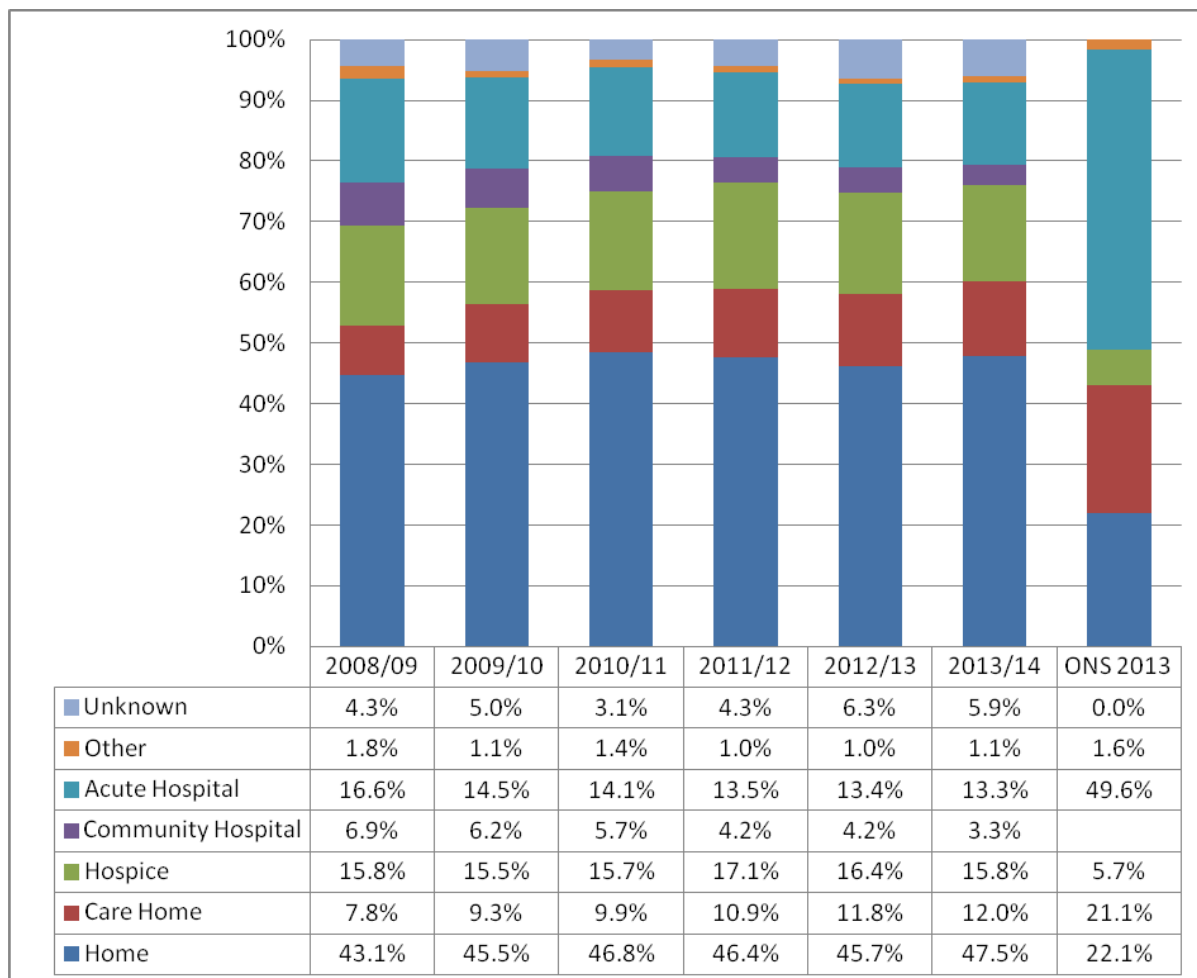


Figure 4.55: outcomes for people referred to Community Care, 2008-2014 (Table 21)

Just under half of any people seen in any given year by a community team die within that reporting year, with the remainder split evenly between discharge from the service and continuing under the care of the service.



*ONS 2013 data includes all deaths registered in 2013, excluding those from accidental causes or those under 15. ONS data does not split Hospital deaths into Community/Acute; consequently all Hospital deaths have been grouped under Acute.

Figure 4.56: location of death for people being seen by Community Care teams, 2008-2014 (Table 22)

For those patients who die under the care of a Community Care team, location of death is recorded where possible. Just under half died at home in 2013/14, up slightly from 2008/09 and an increasing proportion die in care homes. A decreasing proportion of people under the care of Community Care teams die in hospitals, although the absolute number of deaths in hospital remains relatively static. Compared with deaths in the whole population of England and Wales, people under the care of Community Care teams are much more likely to die at home or in a hospice.

Length of care

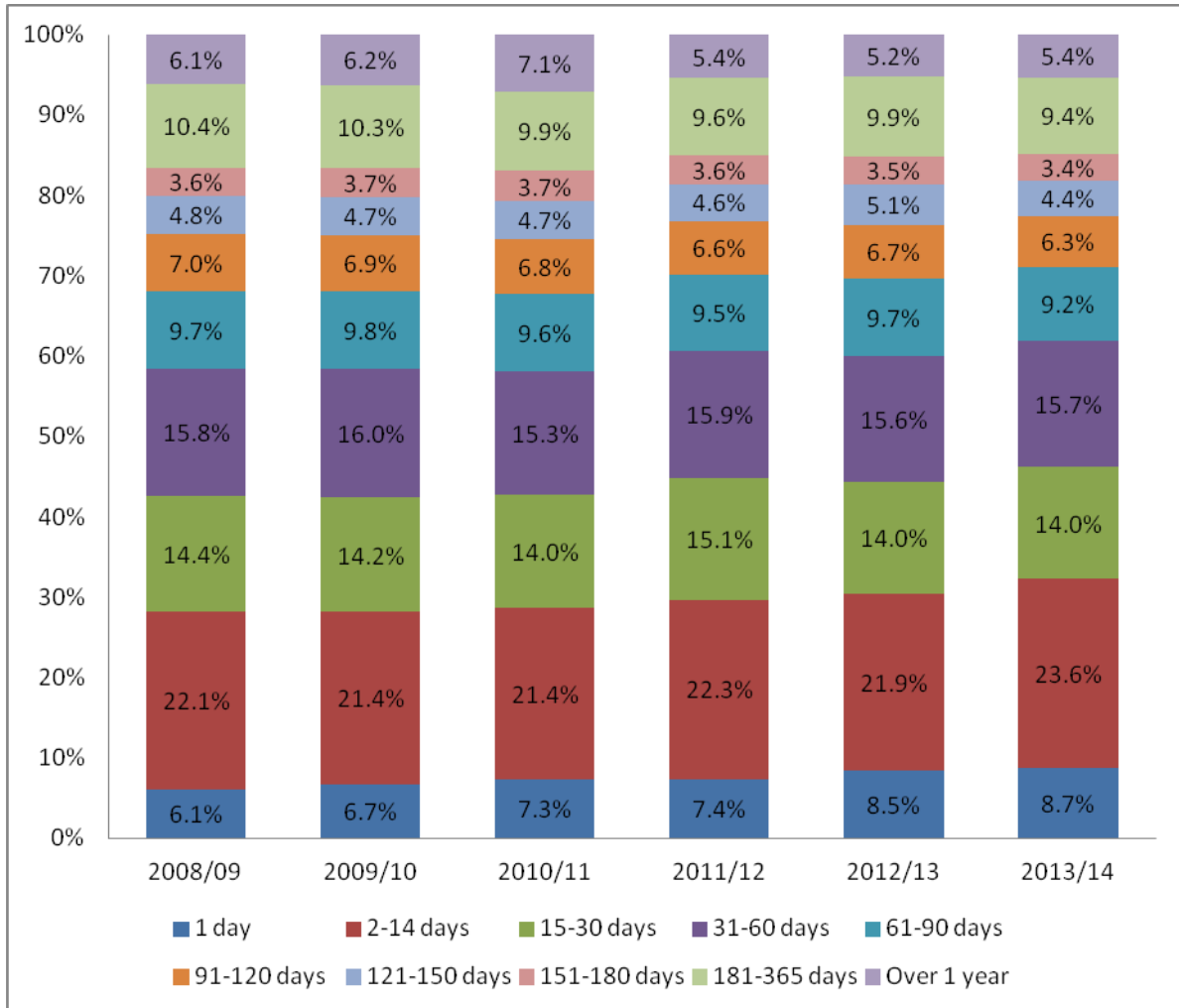


Figure 4.57: length of care for Community Care, 2008-2014 (Table 23)

There has been a gradual increase in the proportion of people remaining under the care of community-based services for only one day. The overall average length of care remains steady each year at around 100 days, or approximately three and a half months.

Hospital Support MDS report 2013/14

Key findings

- Hospital Support teams are seeing an increasing proportion of people aged 85 and older.
- The mean proportion of people seen by Hospital Support teams who have a diagnosis other than cancer has increased over time from 17% in 2008/09 to 26% in 2013/14.

Definition

Hospital Support teams work with other healthcare staff to provide specialist palliative care to people who have been admitted to hospital. In a few services this role may extend into the community. The range of services varies and may include:

Specialist patient care requiring particular expertise, such as symptom control

Advice, support and education for patients and carers

Consultancy and education for other health professionals

Liaison with specialist palliative care services outside the hospital

Hospital Support teams vary in composition from a single specialist nurse to a consultant-led multidisciplinary group and go under a variety of titles. The team may be based in the hospital but managed by an independent/voluntary hospice or other specialist unit; there are many different organisational arrangements.

A Hospital Support service involves one or more face-to-face contacts with a patient by hospital support team members, normally taking place during one Inpatient stay. Contact with a patient may or may not follow formal referral. Hospital Support staff may also have a substantial workload not directly related to any individual patient.

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

136 of 231 Hospital Support services returned MDS data in 2013/14 representing a 58.9% response rate, up from 51% in the previous MDS reporting year. The increase in response rate is largely due to auditing of the service directory to remove services no longer in operation, although there was also an increase in the number of organisations sending in data.

Table 5a: response rates by type of organisation and type of management, 2008-2014

Year	Hospice		Hospital		Community	Clinic	Unknown	Total services responding
	Managed by NHS	Managed by Independent	Managed by NHS	Managed by Independent	Managed by NHS	Managed by NHS Management not recorded	Managed by NHS	
2008/09	15	17	113	6			3	154
2009/10	15	14	113	2			1	145
2010/11	15	14	114	1		1		145
2011/12	14	15	105	3		2	1	140
2012/13	8	17	96	3		2	1	127
2013/14	11	24	96	2	1	1	1	136

Number of patients

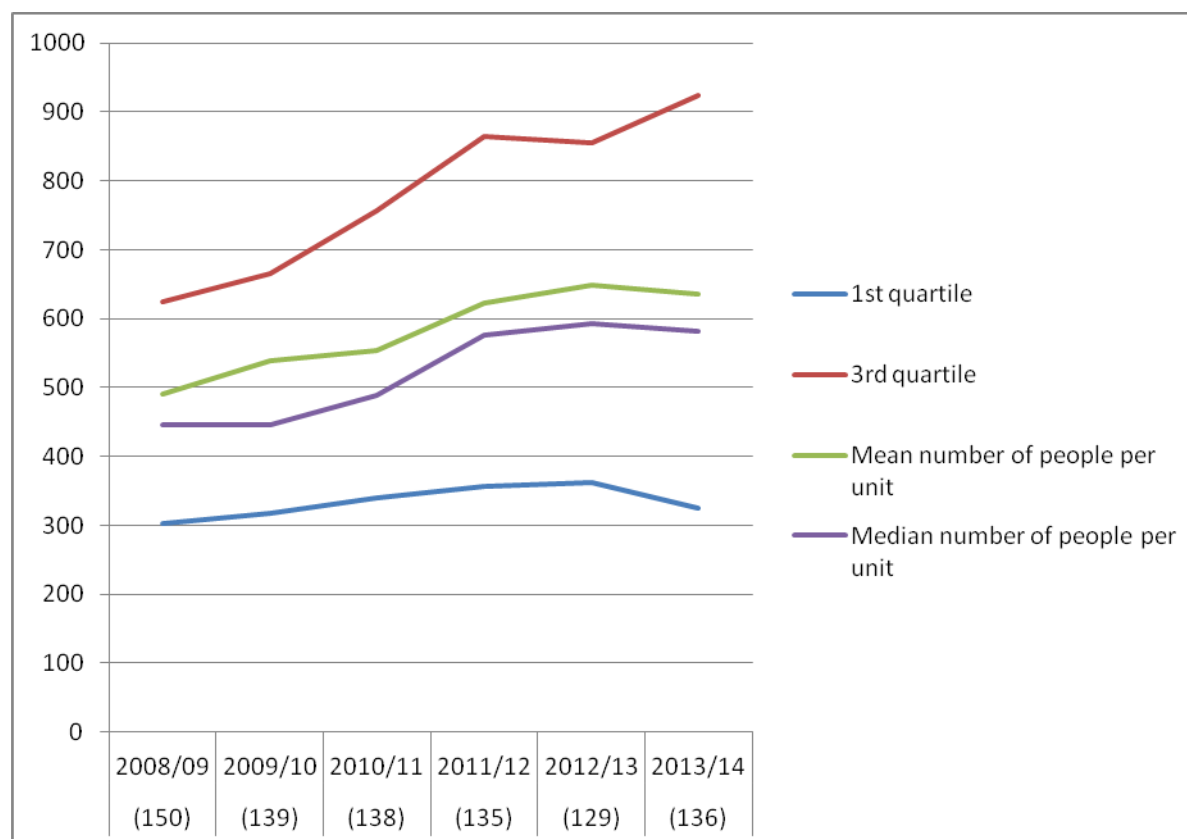
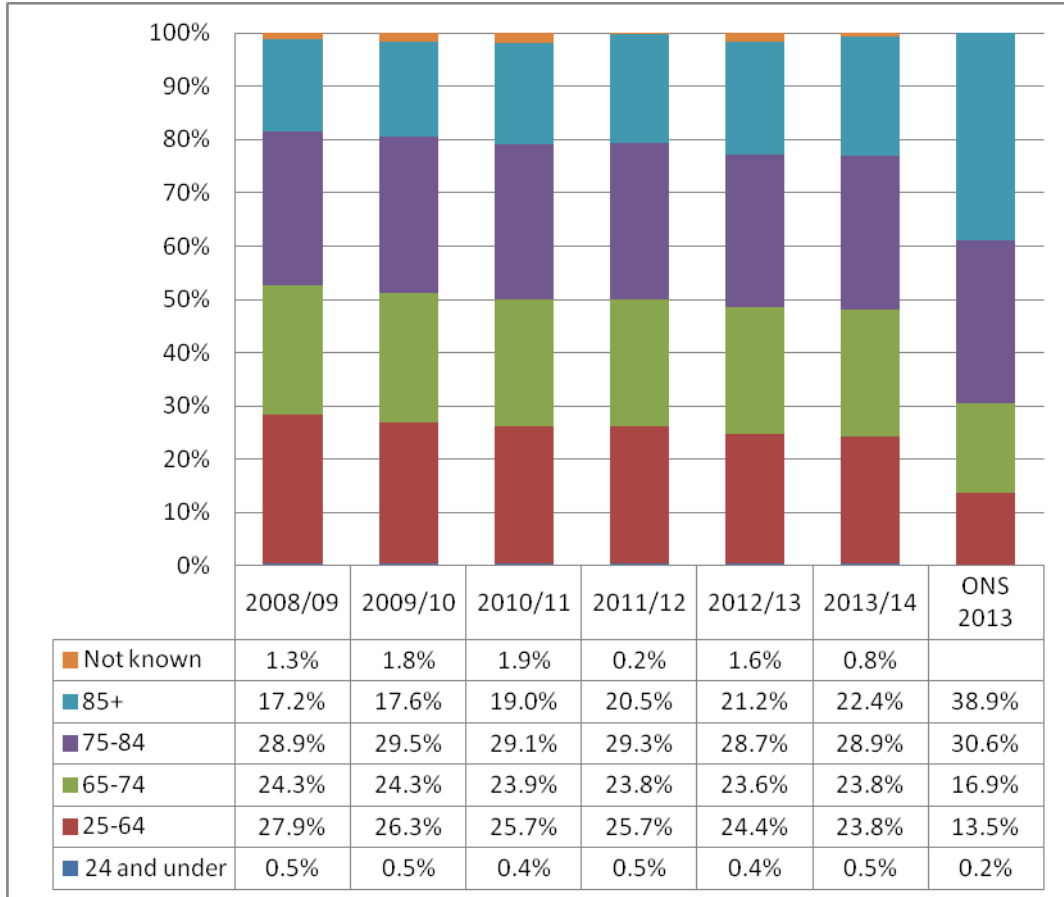


Figure 5.58: changes in the range of size of Hospital Support services over time (Table 67)

Hospital Support services have been seeing more patients each year, even given the fact that fewer organisations have responded to the MDS in recent years. In 2013/14, responding Hospital Support services reported seeing 86,443 people.

Age of patients



*ONS data includes all deaths registered in 2013, excluding those from accidental causes.

Figure 5.59: proportion of different age groups accessing Hospital Support, 2008-2014 (Table 68)

The decrease in unrecorded ages in 2011/12 appears to have been driven by two services improving data quality in that year; the subsequent increase is due to new services reporting with less well recorded age data. Hospital Support is the setting that sees the highest proportion of people aged 85 or older, and this proportion is increasing every year. The proportion of people aged 25-64 accessing Hospital Support has decreased over time.

Sex

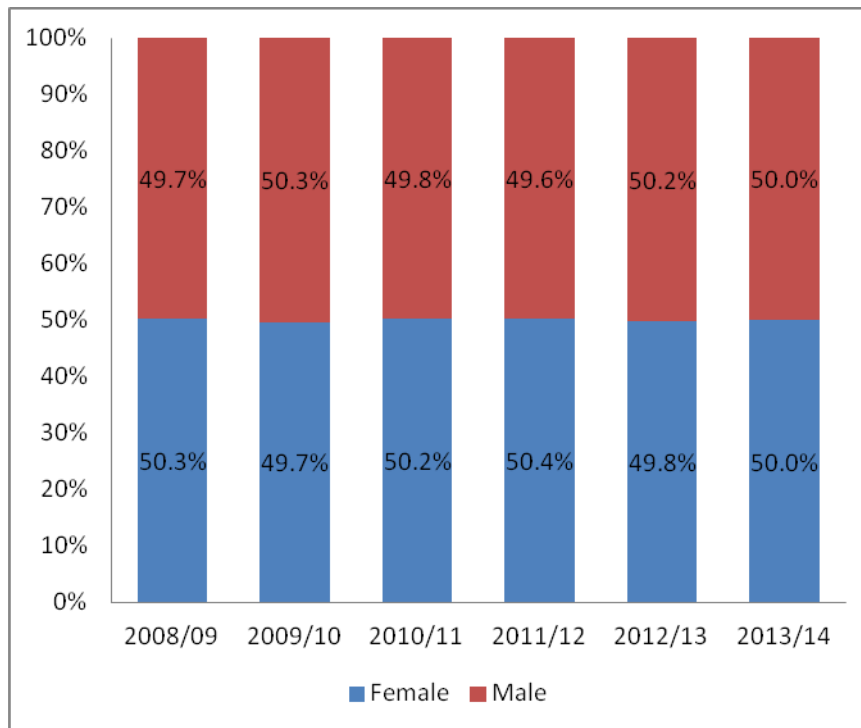


Figure 5.60: proportion of men and women accessing Hospital Support, 2008-2014 (Table 69)

In general, the sex balance of those seen by Hospital Support services is reasonably equally split between men and women, perhaps surprising given that Hospital Support services tend to see more older patients, who are more likely to be female.

Diagnoses

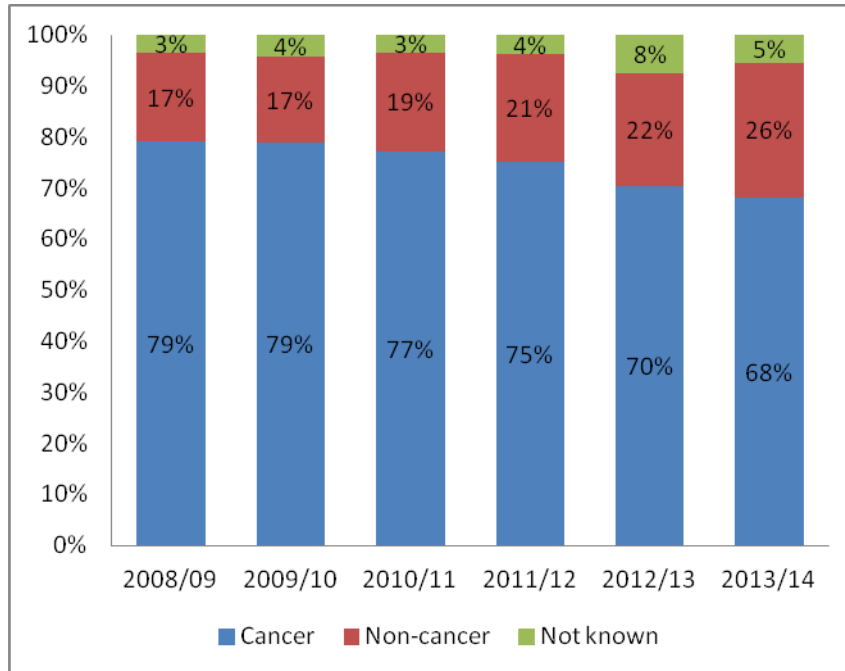


Figure 5.61: proportion of people with different categories of primary diagnosis accessing Hospital Support, 2008-2014 (Table 70)

Hospital Support services see a relatively high proportion of people with diagnoses other than cancer and have seen this proportion steadily increase over the past six years, although the majority of people seen do still have cancer as their primary diagnosis.

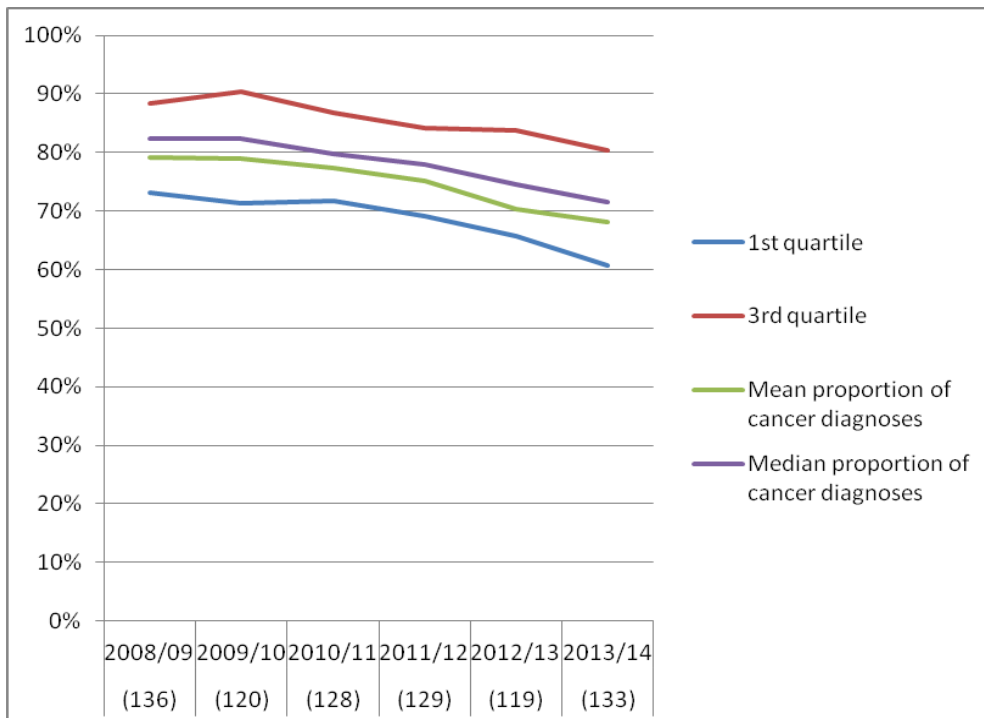


Figure 5.62: range in proportion of people with cancer diagnoses accessing Hospital Support, 2008-2014 (Table 71)

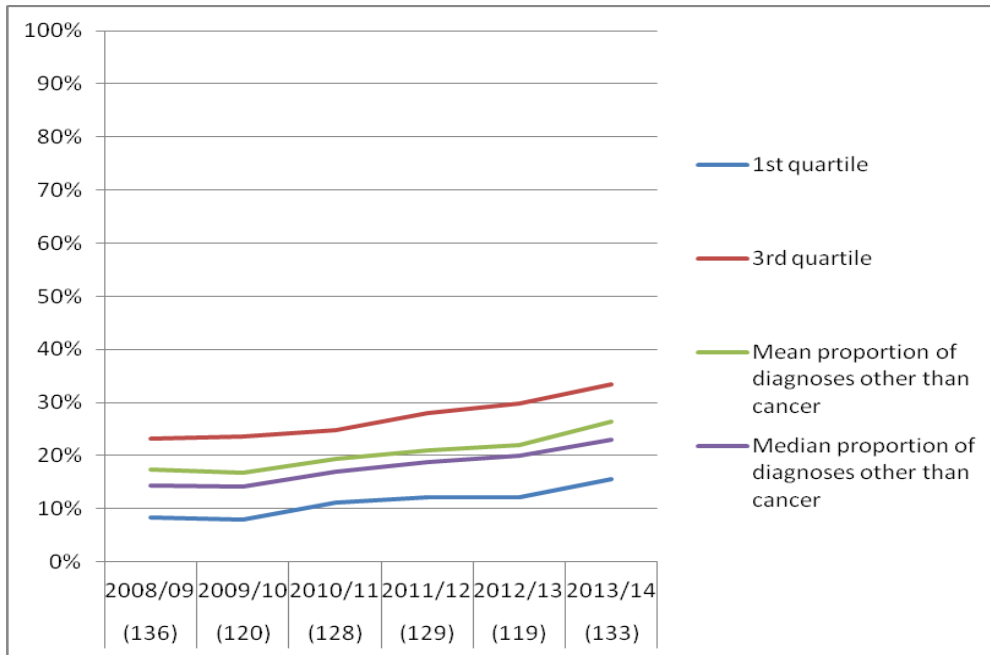


Figure 5.63: range in proportion of people with diagnoses other than cancer accessing Hospital Support, 2008-2014 (Table 72)

There has been a steady increase in the proportion of people with diagnoses other than cancer accessing Hospital Support.

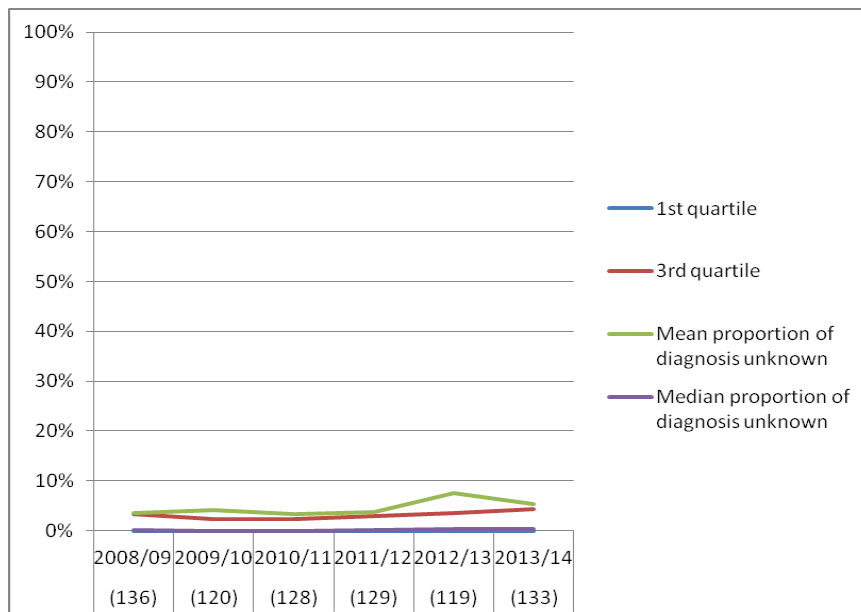


Figure 5.64: range in proportion of people with diagnosis unknown treated in Hospital Support settings, 2008-2014 (Table 73)

The majority of services do capture diagnosis information, but there are still some services who report up to 10% of patients having an unrecorded diagnosis, and one service reports 100% of patients having diagnosis not recorded, bringing up the mean for all services. It is unknown whether this is due to reporting constraints or whether this information is in fact not recorded.

Diagnosis breakdown: cancer

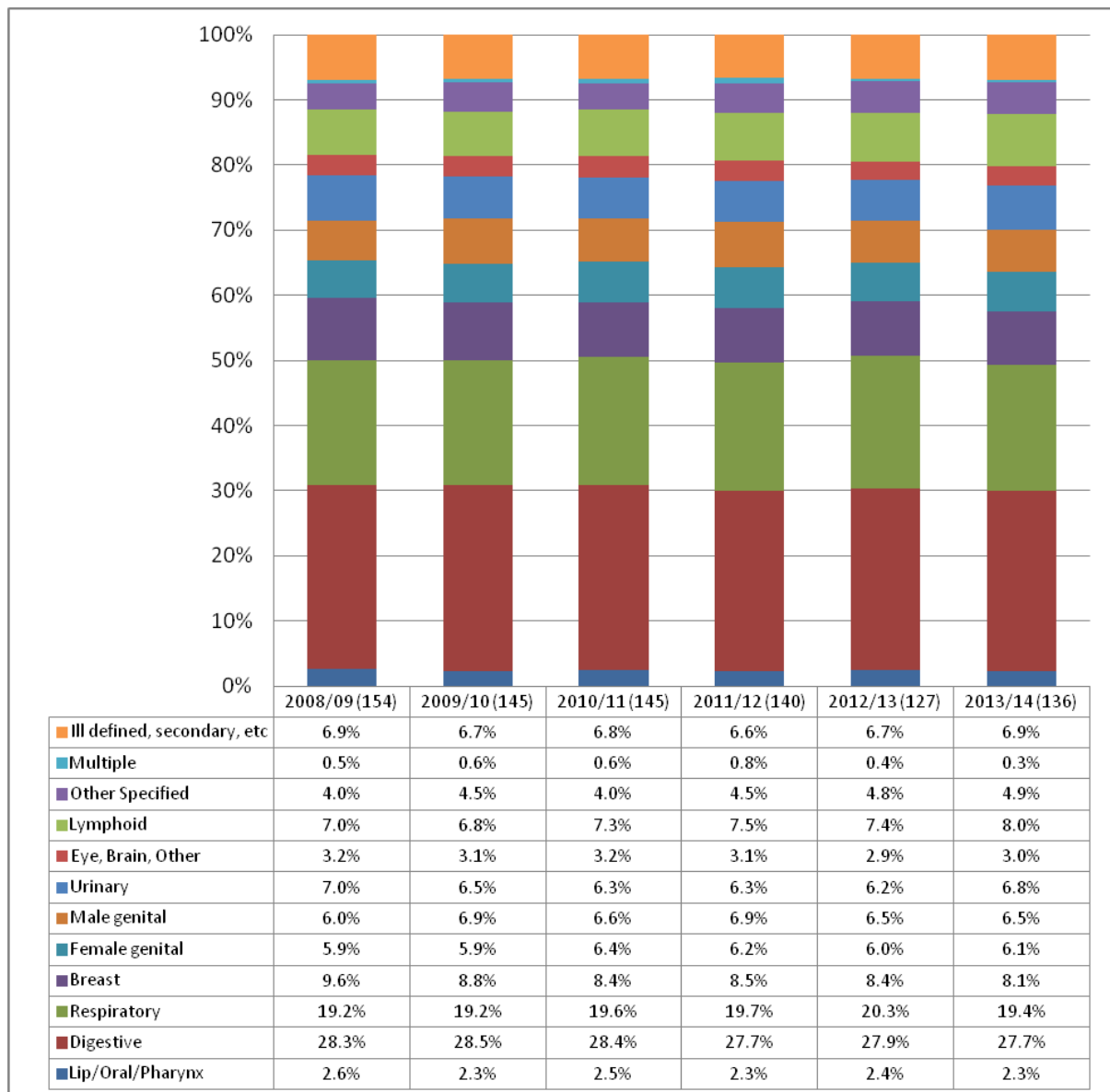


Figure 5.65: proportion of people with different cancer diagnoses accessing Hospital Support, 2008-2014 (Table74)

Of those patients accessing Hospital Support who have cancer, proportions of different types of cancer have remained relatively static over time.

Diagnosis breakdown: diagnoses other than cancer

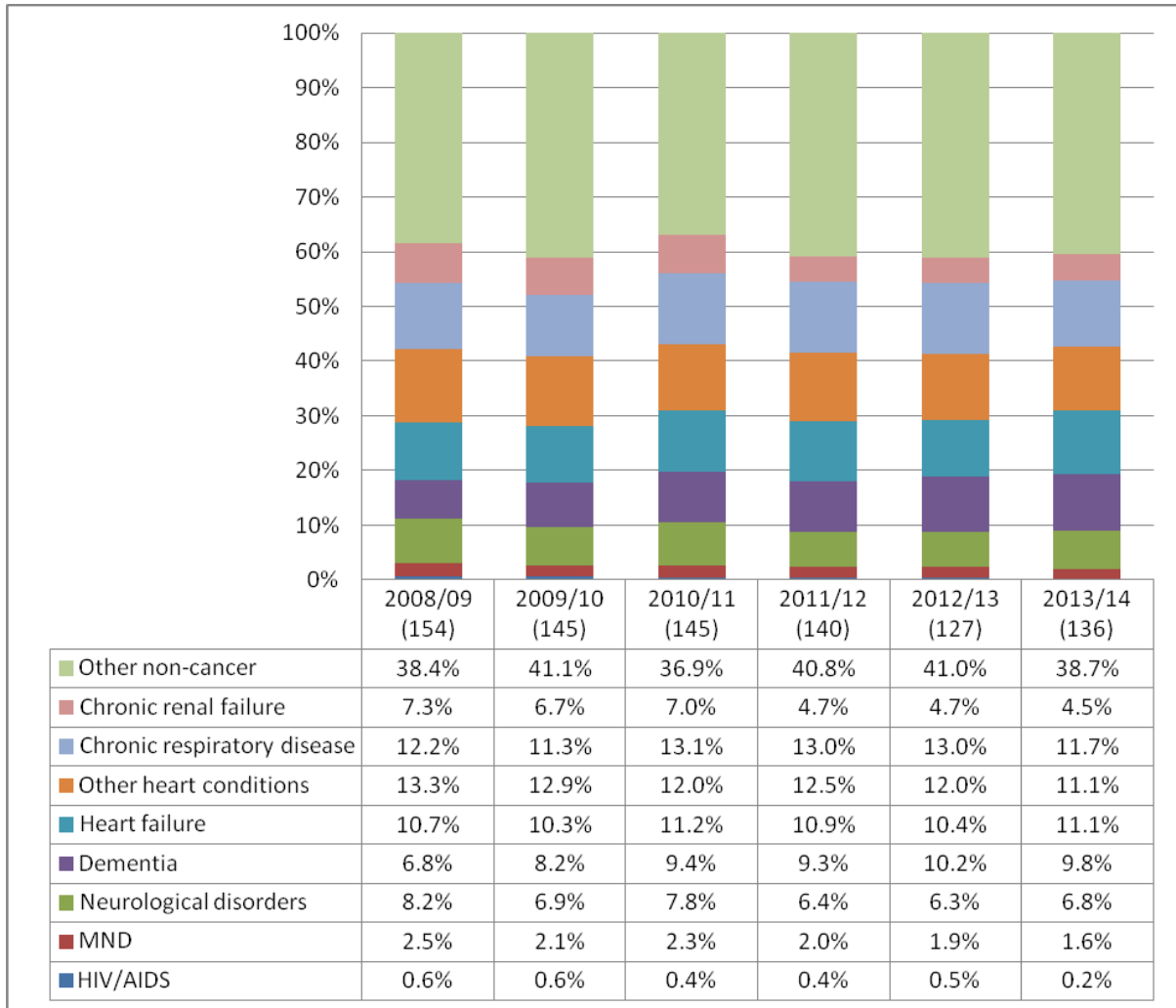


Figure 5.66: proportion of people with diagnoses other than cancer accessing Hospital Support, 2008-2014 (Table 75)

For people with a diagnosis other than cancer, a substantial proportion fall under ‘Other’. Hospital Support sees a higher proportion of people with dementia than any other MDS patient-facing setting except Community Care.

Case study: increasing access for people with dementia

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Downe Hospital, Downpatrick

The Inpatient service in the Downe Hospital consists of forty-six medical beds, a 20 bedded Dementia Ward and a 25 bedded Acute Psychiatry Unit.

The Downe Hospital medical wards would have adult patients of all ages who are diagnosed with cancer; some of these patients are palliative at diagnosis. Many of the patients in the medical wards are frail elderly with multiple co-morbidities. Referrals to the specialist palliative care team are for complex symptom management and referrals come from hospital consultants. The palliative care team consists of a Macmillan palliative care nurse specialist who works two days per week, and a palliative medicine consultant who is present in the hospital one session weekly.

Approximately 8 years ago, the Macmillan clinical nurse specialist and consultant began to promote the specialist palliative care service to the dementia team. This began with education sessions around palliative and end of life care and symptom management. The staff of the dementia ward expressed their frustration around their patients being transferred in their terminal phase to die in medical wards. So with syringe driver training and intensive support from the palliative care team, dying patients were enabled to end their lives in familiar surroundings cared for by the specialist dementia nurses, who knew them and their families well.

As the service has developed over the years, patients with dementia are now assessed earlier in their condition, for signs of pain and other symptoms and this on many occasions has led to a reduction in their challenging behaviour.

An unexpected consequence of this service has been that the nursing staff of the dementia ward saw the need to upgrade their skills to deliver intravenous and subcutaneous fluids and administer intravenous antibiotics, all in an effort to ensure that their patient does not have to leave their ward in their dying phase.

The service provided by the palliative care team in the dementia ward is viewed as an essential component of the holistic care they provide to their patients.

Ethnicity

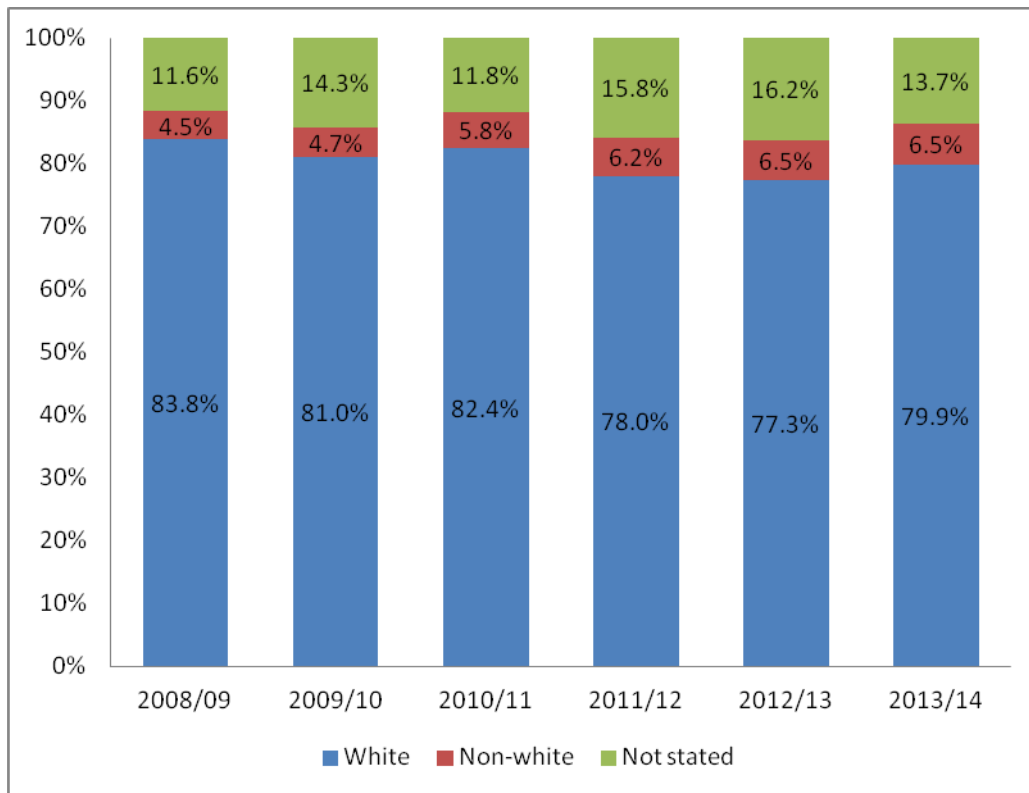


Figure 5.67: proportions of people accessing Hospital Support reported as white, BAME and not recorded, 2008-2014 (Table 77)

While the proportion of BAME people accessing Hospital Support has increased, so too has the proportion of people recorded as Not Stated, suggesting there is still work to be done on capturing ethnicity data in this setting. 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.

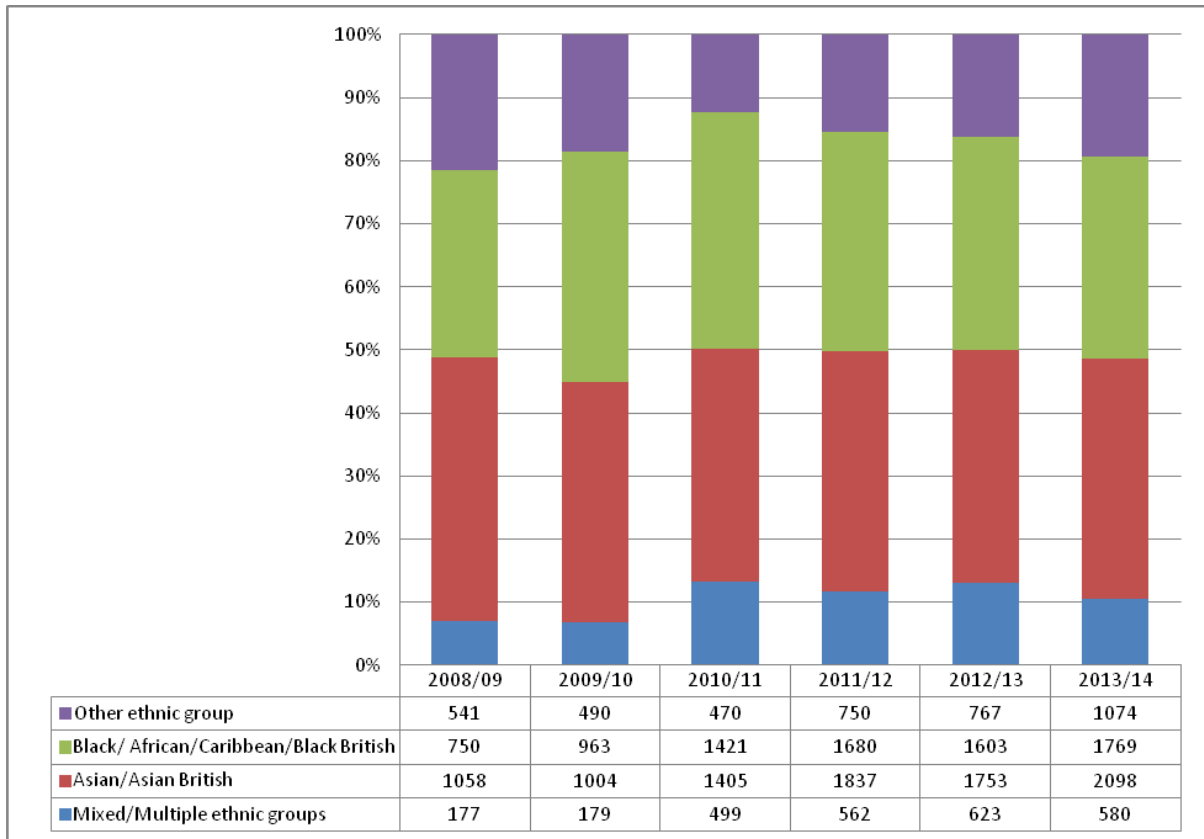


Figure 5.68: people accessing Hospital Support from grouped BAME categories, 2008-2014 (Table78)

Outcome of period of care

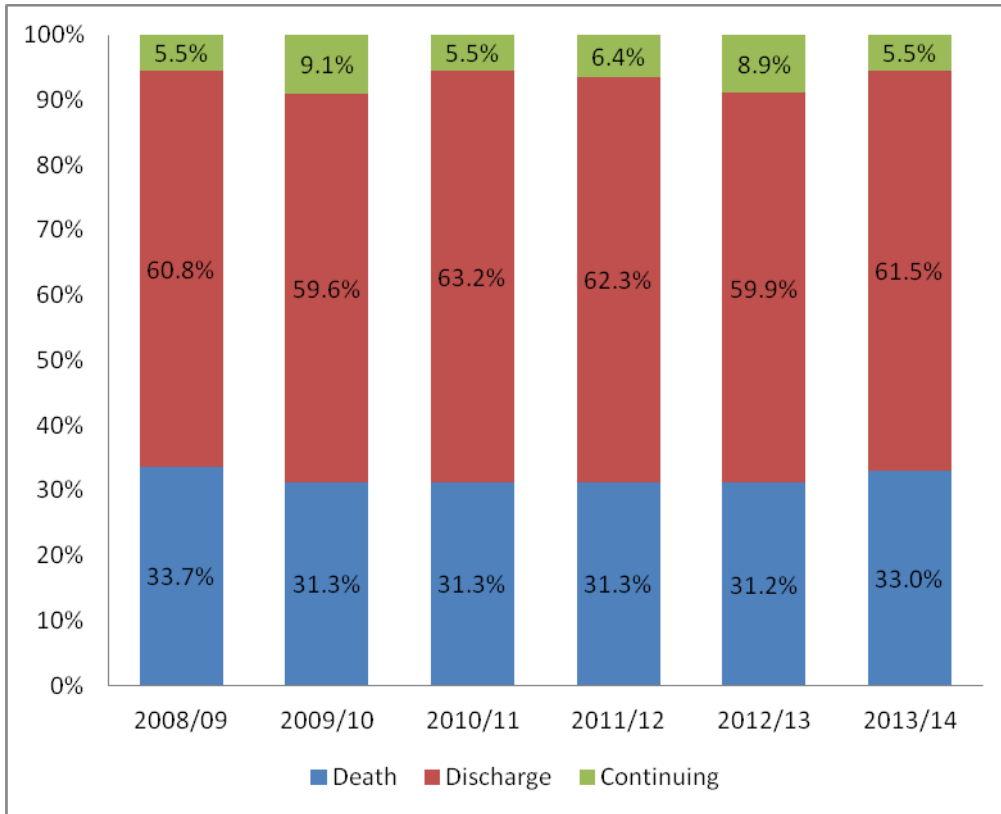


Figure 5.69: proportion of Hospital Support stays ending in death, discharge, or continuing across reporting years, 2008-2014 (Table79)

The majority of Hospital Support stays in each reporting year end in discharge, with around a third of patients recorded dying in hospital (accounting for 30,569 deaths in 2013/14). This pattern has remained stable over time.

Place of care after discharge

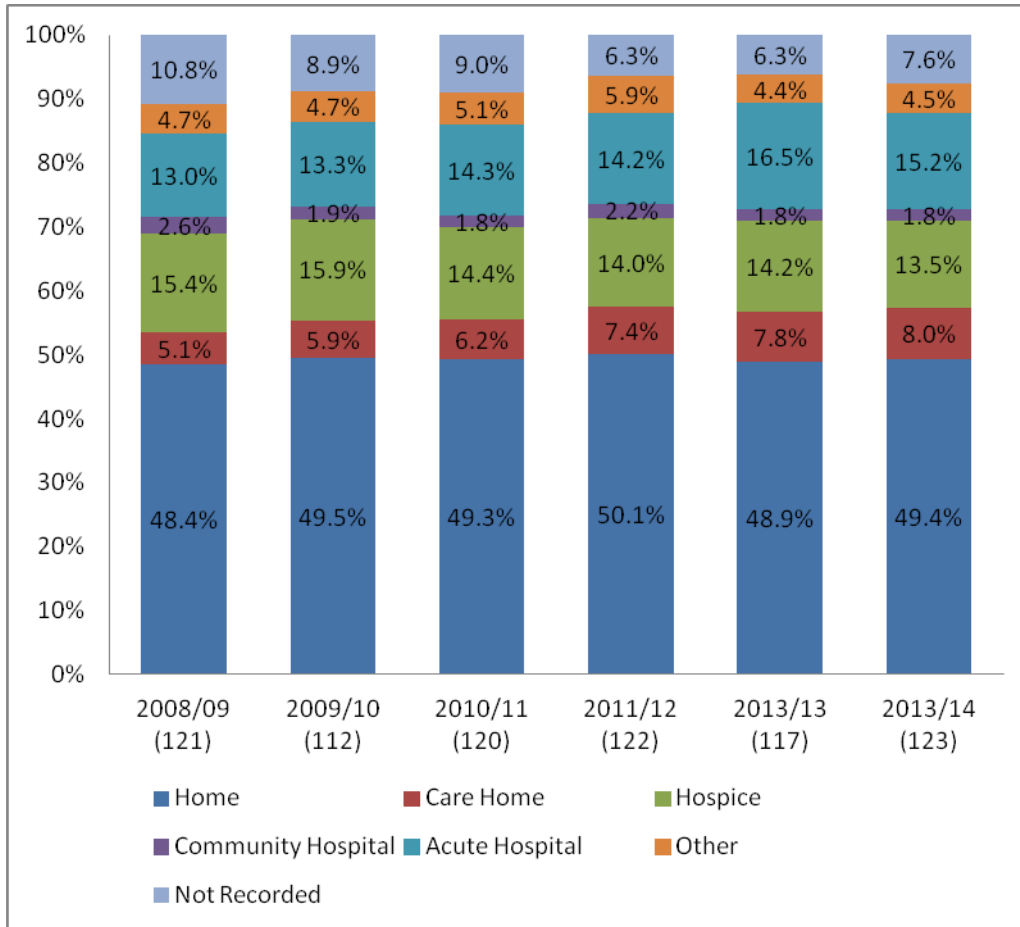


Figure 5.70: place of care after discharge for people leaving Hospital Support care, 2008-2014 (Table 8024)

Of those who are discharged from Hospital Support care, the majority return home or to a care home. A reasonably consistent proportion of patients are transferred to a hospice while a slightly higher proportion move to another hospital.

Length of care

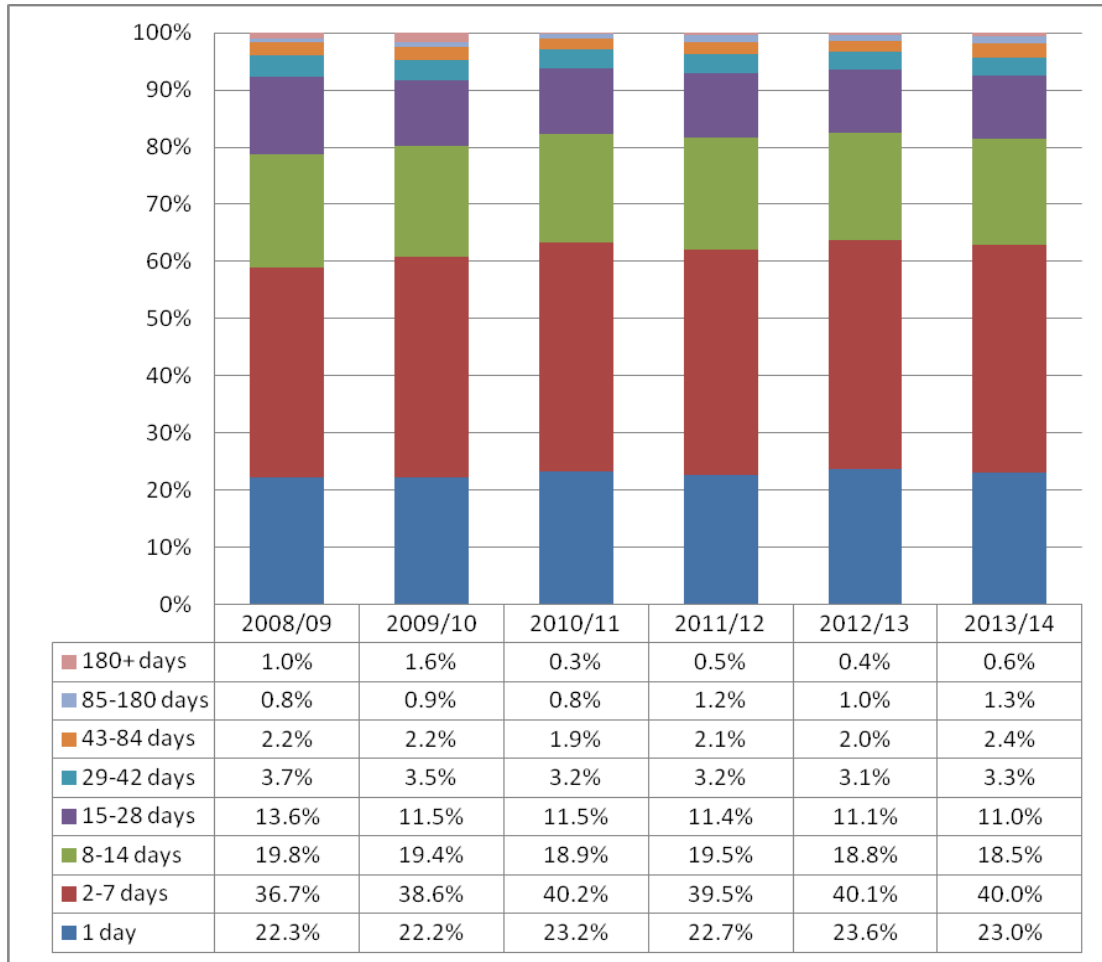


Figure 5.71: length of completed Hospital Support stays, 2008-2014 (Table 81)

On average, people are under the care of Hospital Support teams for around two weeks, although almost a quarter of those seen are seen for only one day. This pattern has remained stable over time.

Outpatients MDS report 2013/14

Key findings

- On average, each reporting service is seeing an increasing number of patients, up to 322 people seen per service in 2013/14 from 250 in 2008/09
- Outpatient settings consistently see a higher proportion of younger women with breast cancer than other MDS settings, making their patient profile quite different

Definition

An Outpatient clinic is an administrative arrangement which allows people to see a doctor or other health care professional for consultation, investigation and minor treatment. Clinics do not necessarily have to be held at regular intervals or in the same location. A clinic usually lasts for one morning or afternoon.

Attendance at an Outpatient clinic is usually by appointment, but people may sometimes arrive and be seen without prior notice. Some clinics, such as 'walk-in' clinics, are designated wholly or partly for people without prior appointments. It is good practice for a patient arriving without an appointment to be allocated a time by the receptionist.

Some specialist palliative care services may struggle to differentiate between their Outpatient care and their Day Care; consequently it is possible that two different services which are similar in structure may be reported under different MDS categories.

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

149 of 264 Outpatient services returned MDS data in 2013/14 representing a 56.4% response rate, up from 50% in the previous MDS reporting year. The increase in response rate is largely due to auditing of the service directory, rather than an increase in organisations sending in data.

Table 6a: response rates by type of organisation and type of management, 2008-2014

	Hospice			Hospital			Community	NHS Trust	Total services responding
	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by NHS	
2008/09	12	77	23	50	2		2		166
2009/10	14	83	14	43			1		155
2010/11	15	88	13	35		5			156
2011/12	16	93		36	3		1	2	151
2012/13	12	96		40	2			1	151
2013/14	13	91		43	1			1	149

Number of patients

Although this year saw the lowest number of Outpatient returns since 2008/09, the total number of people seen by Outpatient services increased by almost 5,000 from the previous year, up to 47,984. The size of services ranges from those who see between 1 and 10 patients in a year, and those who see over 1,700 people.

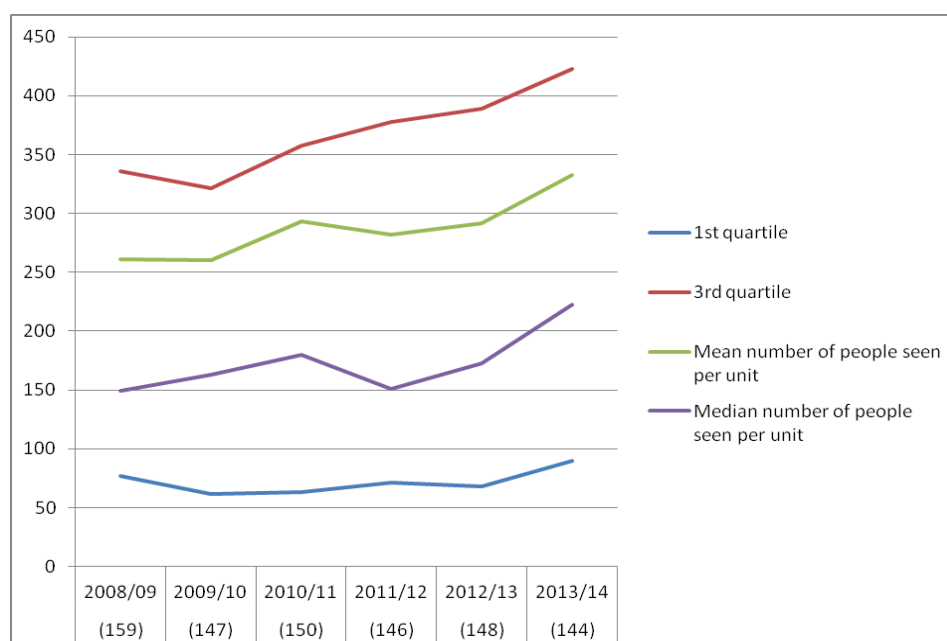


Figure 6.72: changes in the range of size of Outpatient clinics over time (Table 83)

Age of patients

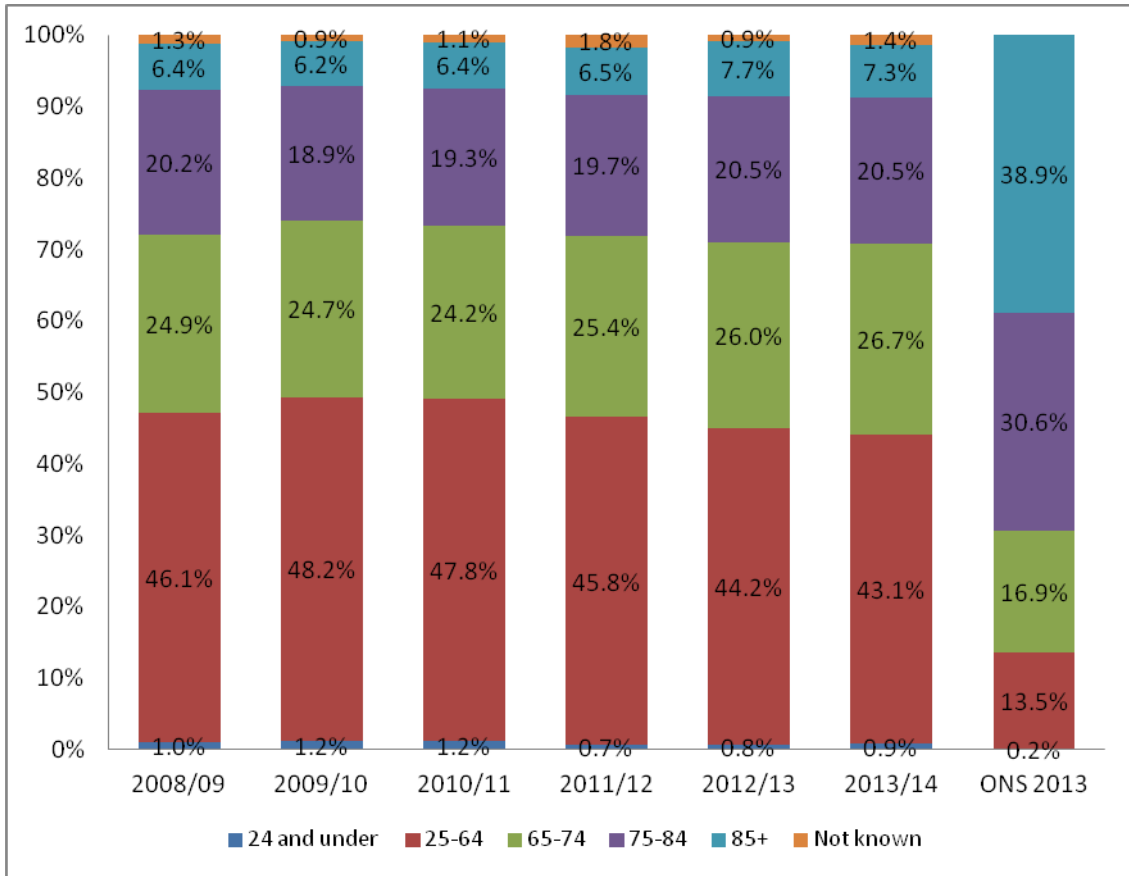


Figure 6.73: proportion of different age groups accessing Outpatient clinics, 2008-2014 (Table 84)

Outpatient attendees skew younger than other specialist palliative care settings. This is likely to be aligned with the high proportion of women accessing Outpatient care, and the high proportion of people diagnosed with breast cancer recorded in the diagnosis data.

Sex

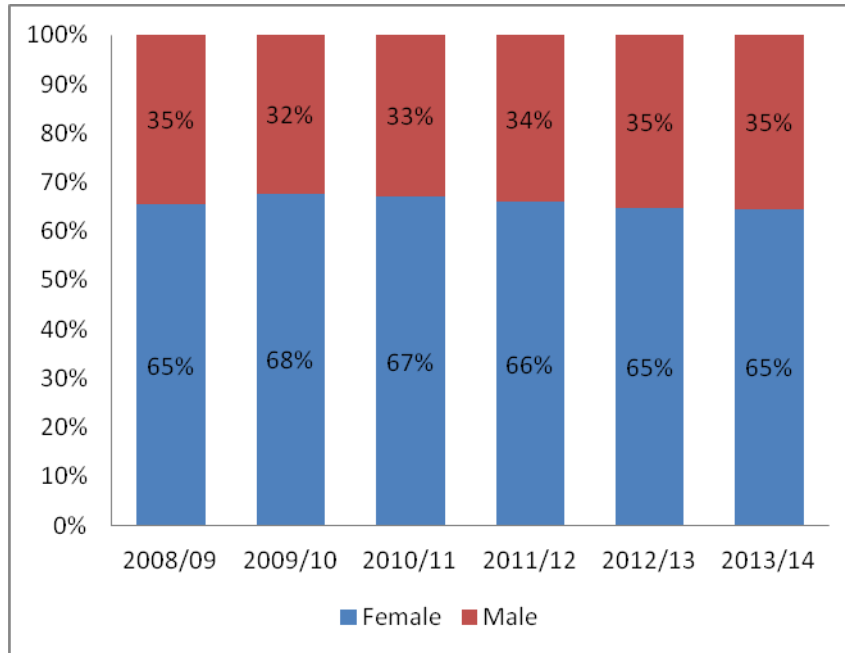


Figure 6.74: proportion of men and women accessing Outpatient clinics, 2008-2014 (Table 85)

Typically, more women than men access Outpatient services. This is again likely to be due to the increased number of younger women accessing breast cancer clinics.

Diagnoses

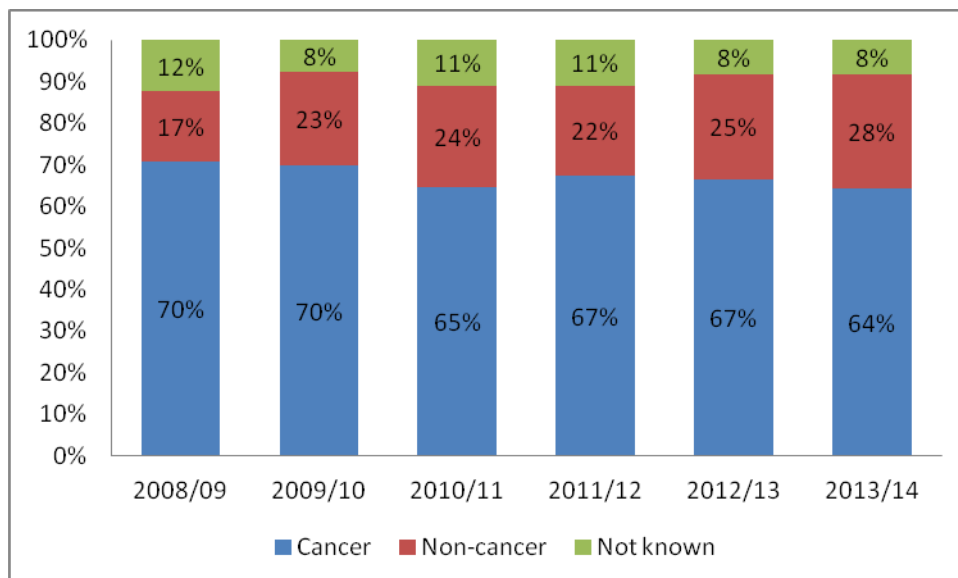


Figure 6.75: proportion of people with different categories of primary diagnosis accessing Outpatient clinics, 2008-2014 (Table 86)

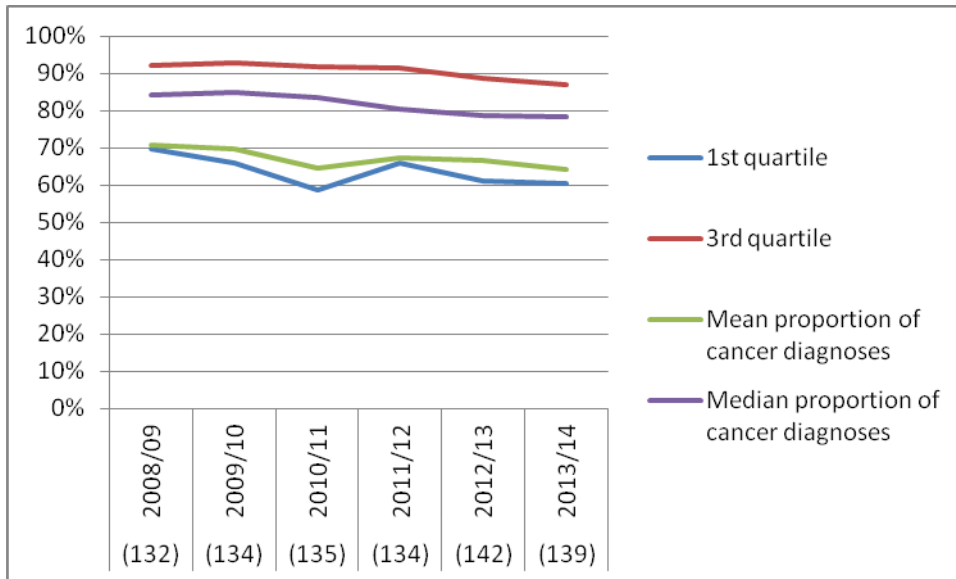


Figure 6.76: range in proportion of people with cancer diagnoses accessing Outpatient clinics, 2008-2014 (Table 87)

The average proportion of patients with a cancer diagnosis has dropped over time, from 71% in 2008/09 to 64% in 2013/14.

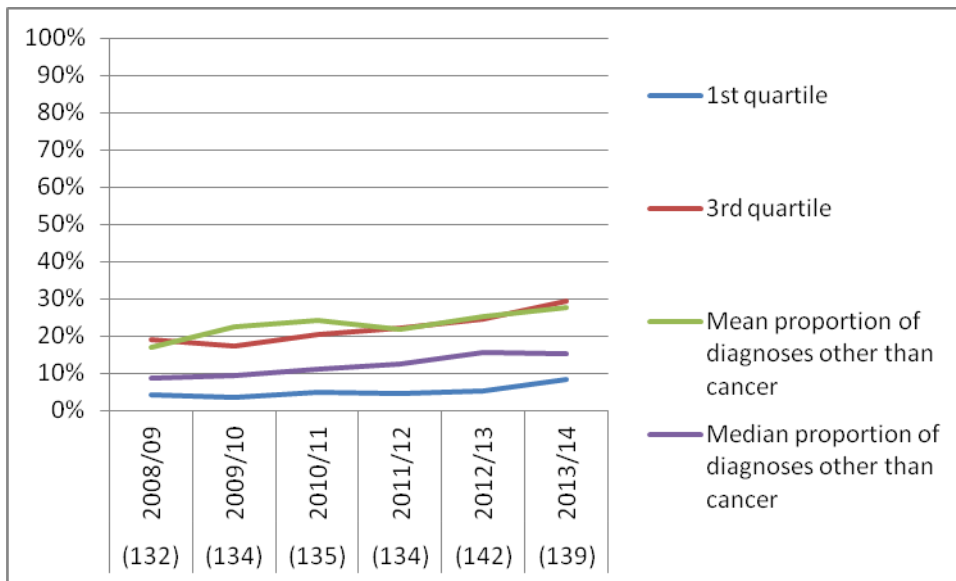


Figure 6.77: range in proportion of people with diagnoses other than cancer accessing Outpatient clinics, 2008-2014 (Table 88)

The proportion of patients with a diagnosis other than cancer has increased over this time period, although the average is being driven up by a few services who record a large proportion of people with diagnoses other than cancer; these may however be lymphoedema clinics recording that as a diagnosis rather the underlying terminal condition, which could be masking a higher proportion of people with cancer diagnoses.

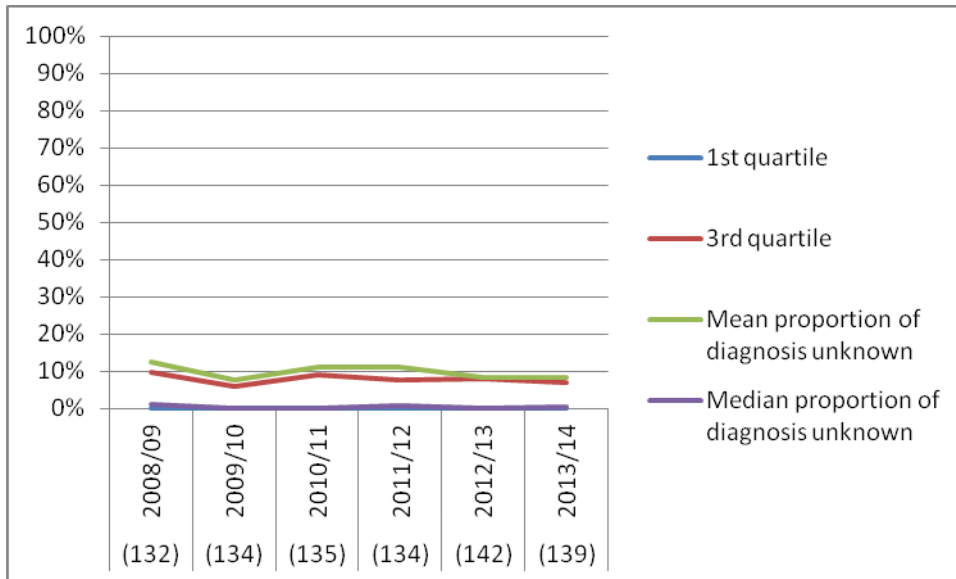


Figure 6.78: range in proportion of people with diagnoses unknown accessing Outpatient clinics, 2008-2014 (Table 89)

The given averages mask a wide range amongst services in the proportion of patients they see which each category of diagnosis. Each year, at least 6 services report that 100% of patients have cancer, while similarly each year at least 5 services report that 100% of patients have a diagnosis other than cancer. In each year there have also been at least 9 services reporting that the diagnosis of 100% of their patients was not known or not recorded.

Diagnosis breakdown: cancer

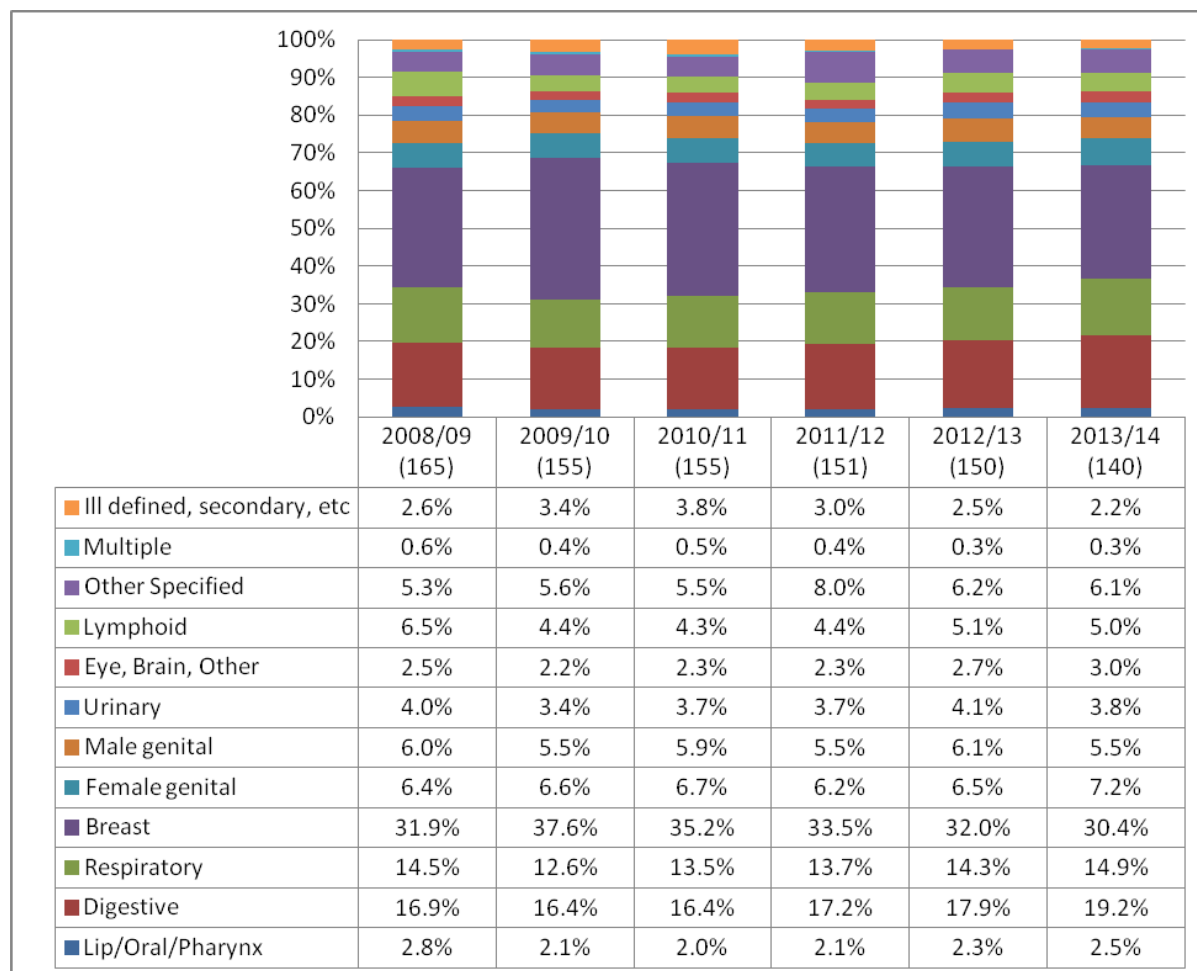


Figure 6.79: proportion of people with different cancer diagnoses accessing Outpatient clinics, 2008-2014 (Table 90)

Outpatients sees a higher proportion of people diagnosed with breast cancer than any other MDS setting. Otherwise, the proportions of each type of cancer treated in this setting remain relatively stable from year to year.

Diagnosis breakdown: diagnoses other than cancer

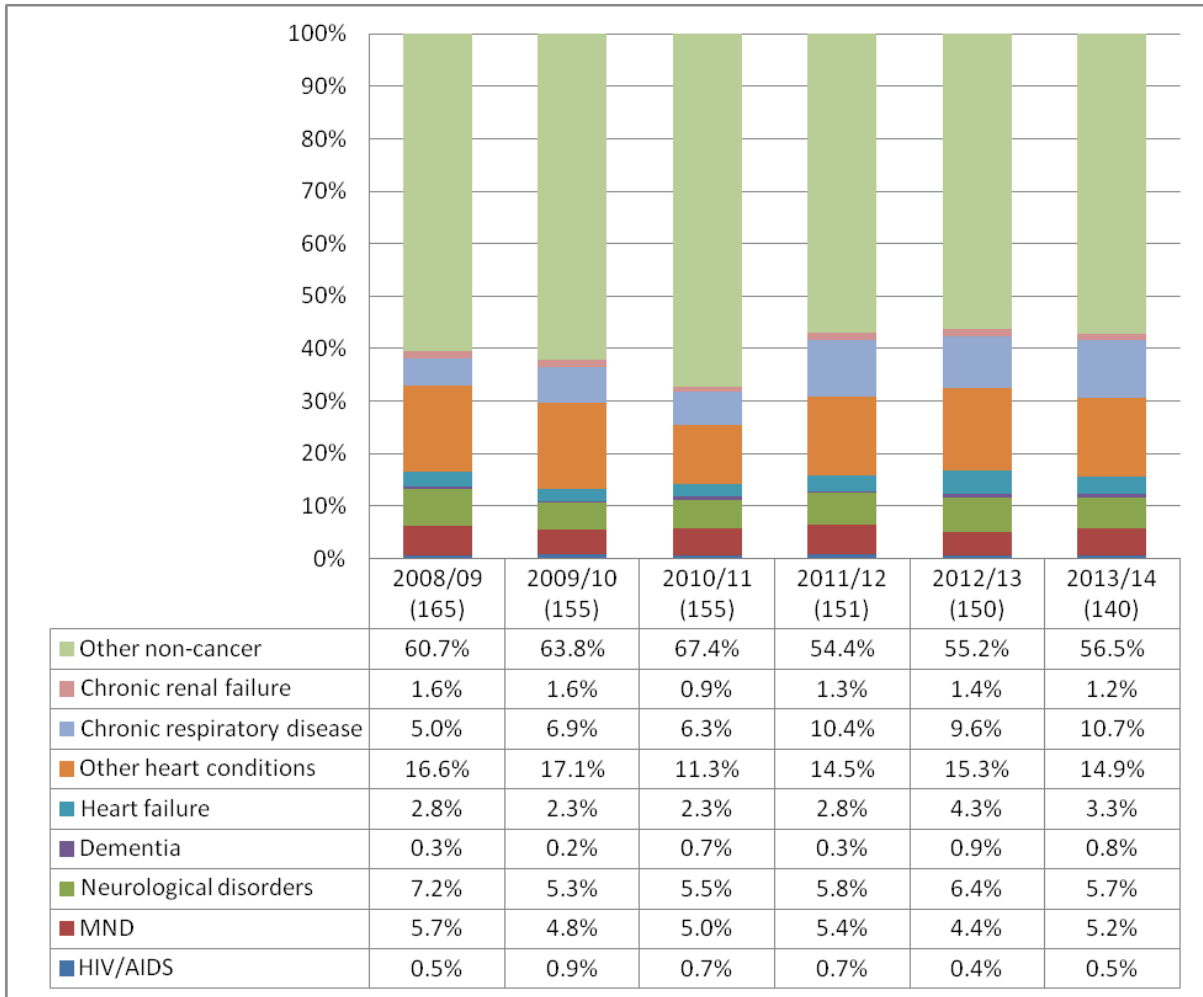


Figure 6.80: proportion of people with diagnoses other than cancer accessing Outpatient clinics, 2008-2014 (Table 91)

Outpatients has the highest proportion of ‘Other non-cancer’ of all MDS settings, which is likely to be due to the fact that many Outpatient returns come from lymphoedema clinics, and so lymphoedema is being recorded as the diagnosis. Further investigation is required to ascertain whether this is the case. As in other settings, there has been an increase in access for all conditions other than cancer recorded in the MDS.

Case study: Supporting Outpatients with chronic lung disease

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Lewis Manning Hospice

Since 2000 Lewis-Manning Hospice has run a breathlessness clinic, using non-pharmacological interventions (NPI) to help patients better manage their breathing. Initially the clinic saw patients with primary lung cancer, but over time has developed to support patients with cancer and chronic lung disease (CLD). Patients are seen on a one-to-one basis, rather than in a group setting. The CLDs affecting patients attending the clinic are mostly chronic obstructive pulmonary disease (COPD) at severe and very severe stages, pulmonary fibrosis and other interstitial lung diseases.

There is a strong body of evidence that supports the value of pulmonary rehabilitation for people with CLD. However, there is less evidence regarding individual NPI for patients with chronic lung disease. Patients referred to us are often unable to cope with pulmonary rehabilitation, due to physical and/or emotional frailty.

People with COPD have higher than average rates of anxiety, which can make pulmonary rehabilitation difficult for them. We work with these patients to help them explore the causes of their anxiety and then help them break the vicious circle. When this is successful, some patients are discharged from our clinic with a goal of going on to participate in pulmonary rehabilitation.

People with pulmonary fibrosis are often too physically frail to cope with pulmonary rehabilitation but can manage the “slower” pace of NPI. People with CLD frequently experience breathlessness, fatigue, anxiety and depression, these symptoms are often criteria for palliative care support.

NICE guidance for both COPD and pulmonary fibrosis recommend that palliative and best supportive care should be offered. However, attending our clinic is often the only link with palliative care for some patients with CLD. Whilst attending our clinic, patients can explore with us preferences for their future care. These can include preferred place of final care, decisions on resuscitation, intravenous antibiotics and invasive or non-invasive mechanical ventilation.

Pulmonary fibrosis has a prognosis of 2-5 years, which is similar to many cancers. In our clinic we consider the level of support a patient requires, rather than their diagnosis. An interesting observation is that some patients with CLD have been referred because their symptoms have deteriorated. Subsequent clinical investigations have revealed that they have developed a cancer in addition to their existing disease.

Ethnicity

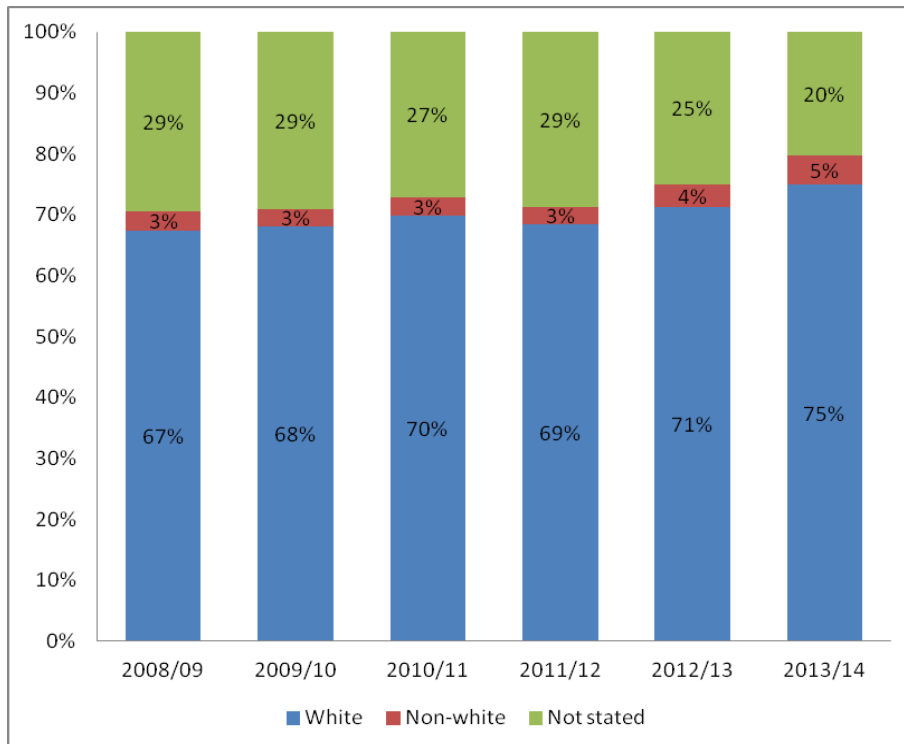


Figure 6.81: proportions of people accessing Outpatient clinics reported as white, BAME and not recorded, 2008-2014 (Table 93)

There has been a slight increase in the recording of ethnicity data, reducing the percentage of people where this information is unrecorded while the number of BAME people recorded as accessing Outpatient specialist palliative care has almost doubled over the past six years. 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.

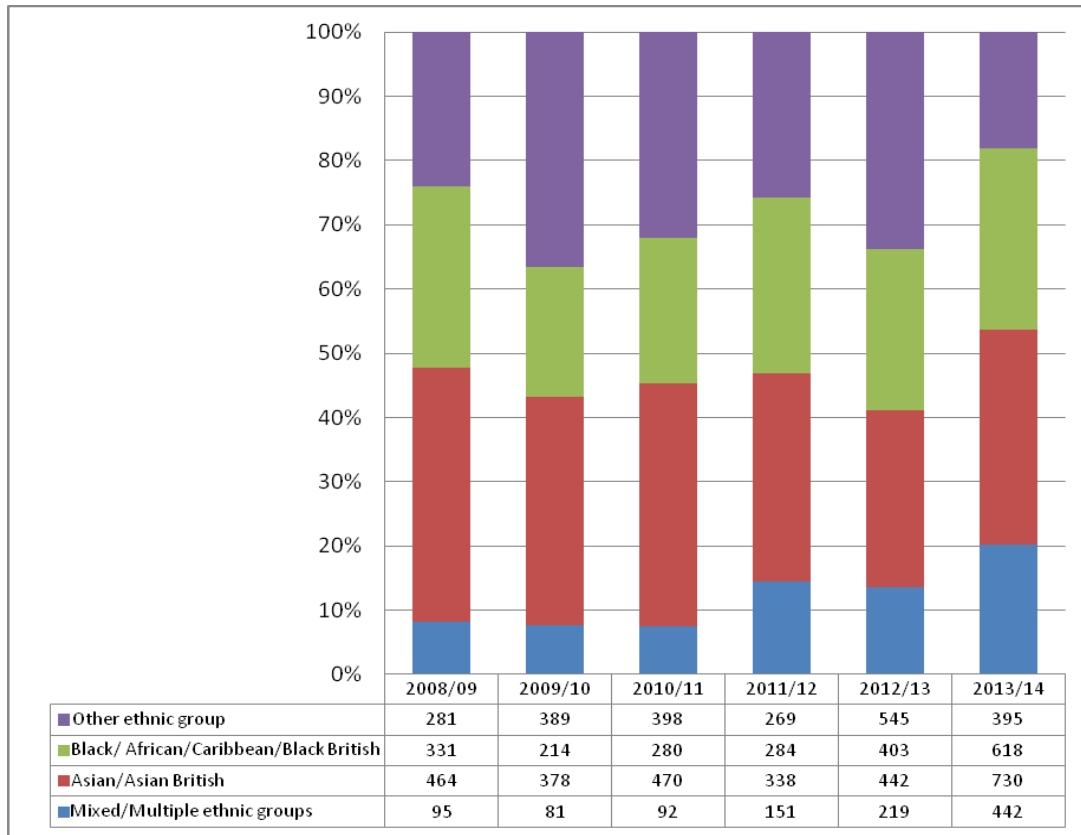


Figure 6.82: people accessing Outpatient clinics from grouped BAME categories, 2008-2014 (Table 94)

Bereavement Support MDS report 2013/14

Key findings

- Women are more likely to access Bereavement Support than men, and the proportion of women accessing Bereavement Support has increased over time
- Incomplete data capture on age and ethnicity makes it difficult to assess any other characteristics of people who access Bereavement Support
- There are no clear trends in the length of support or the type of contact offered by Bereavement Support services

Definition

A Bereavement Support service is provided to relatives, partners and carers of a deceased person and may include individual counselling, home visits, and group activities. Although similar emotional and psychosocial support is often provided to carers of people who are close to death, this dataset records after the death.

Bereavement Support services are organised with varying degrees of formality. Some are provided quite informally or integrated into the general pattern of services, while others have routine referral, assessment and discharge procedures. Services are encouraged to develop procedures to ensure that this important aspect of their workload is recorded.

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

Response rate

115 of 246 Bereavement Support services returned MDS data in 2013/14 representing a 47% response rate, down from 49% in the previous MDS reporting year.

This is consistently the section of the MDS with the poorest response rate, due to a number of possible factors:

- we believe the data is often held separately to patient data and so the form may not reach the person who should complete the return when it is often sent to a contact who is better able to complete the forms for other settings;
- the data asked for is not useful data for the sector so services see limited value in returning it;
- bereavement services in hospitals are held on our database but may not provide the kind of support we ask about here. If they provide logistical support around funeral arrangements and signpost on to counselling services not specifically associated with specialist palliative care then the majority of their work is not captured by the MDS form and so they may not return it.

Discussions are underway with Public Health England, Cruse Bereavement Care, the Childhood Bereavement Network, and the Association of Bereavement Coordinators as to how bereavement data could be captured more accurately and on a larger scale. In the meantime, NCPC would welcome feedback on how to improve response rates and capture a more complete picture of the work being done to support bereaved people.

Table 7a: response rates by type of organisation and type of management, 2008-2014

Year	Hospice			Hospital			Clinic			Community	Total services responding
	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	Managed by Independent	Management not recorded	Managed by NHS	
2008/09	18	83	21	11	1				1	2	137
2009/10	16	90	15	8		1				1	131
2010/11	16	93	16	8						1	134
2011/12	13	109		7						1	130
2012/13	9	106		10	1		1	1			128
2013/14	9	93		11	1		1				115

Number of service users

There has been a slight decrease over time in the mean number of people seen per service, which is likely to be due to the decrease in response rates from larger services (as shown by the variation in the 3rd quartile of the data).

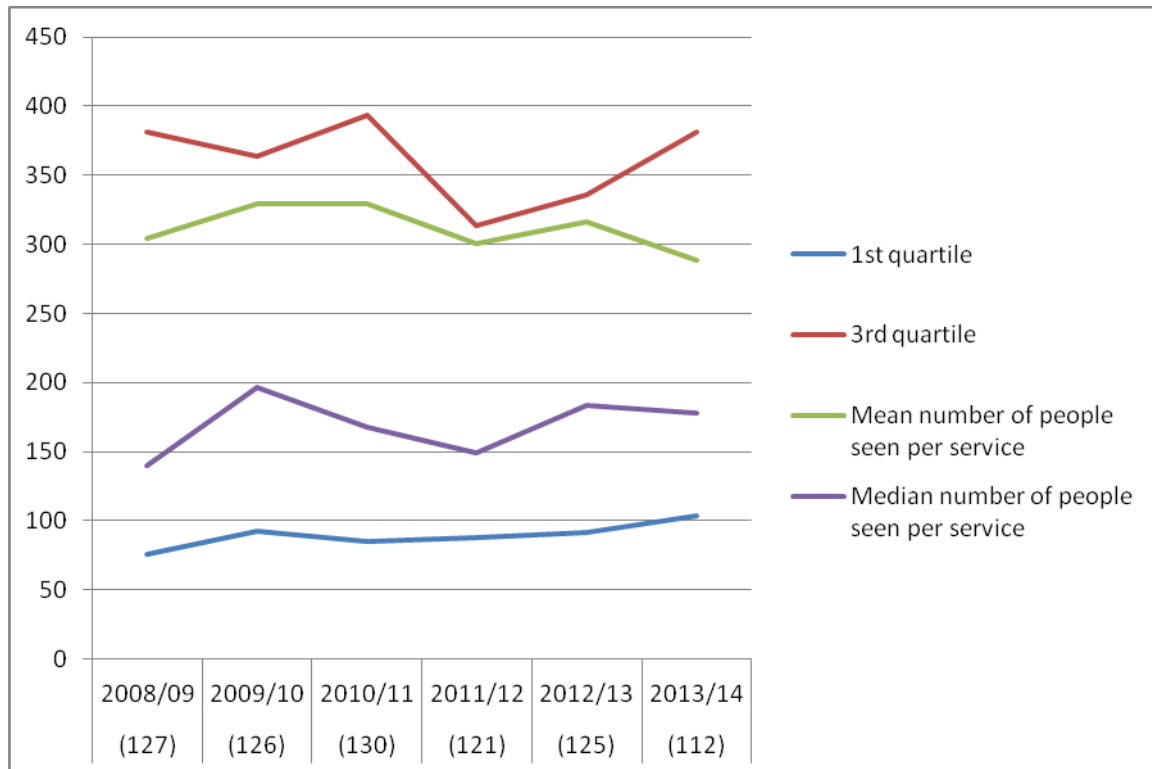


Figure 7.83: changes in the range of size of Bereavement Support services over time (Table 96)

Age of service users

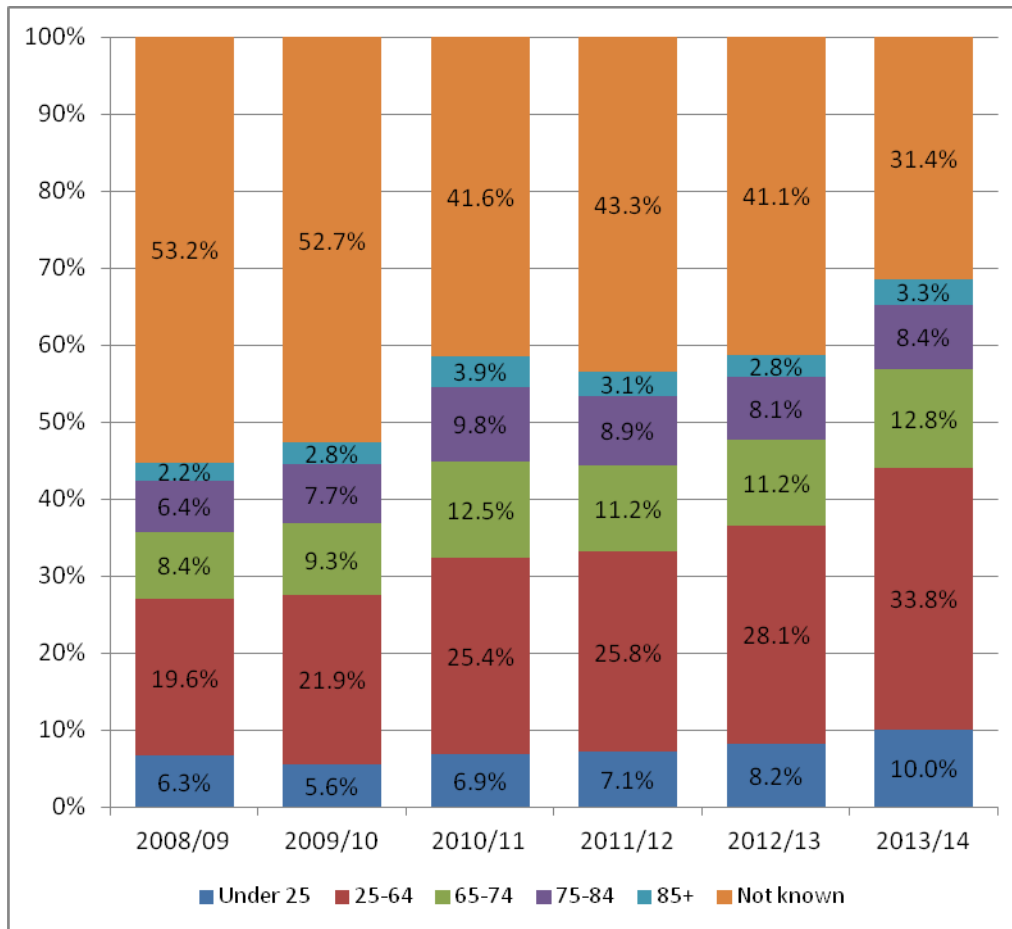


Figure 7.84: proportion of different age groups accessing Bereavement Support services, 2008-2014 (Table 97)

The apparent improvement in data quality is in fact due to services who historically record very little demographic data not submitting returns in 2013/14, rather than a general improvement in data quality across the sector. Consequently it is hard to make a judgement on whether the demographics of those accessing Bereavement Support are shifting or not; however, it does seem as though there is a proportionate increase in younger people making use of these services.

Sex

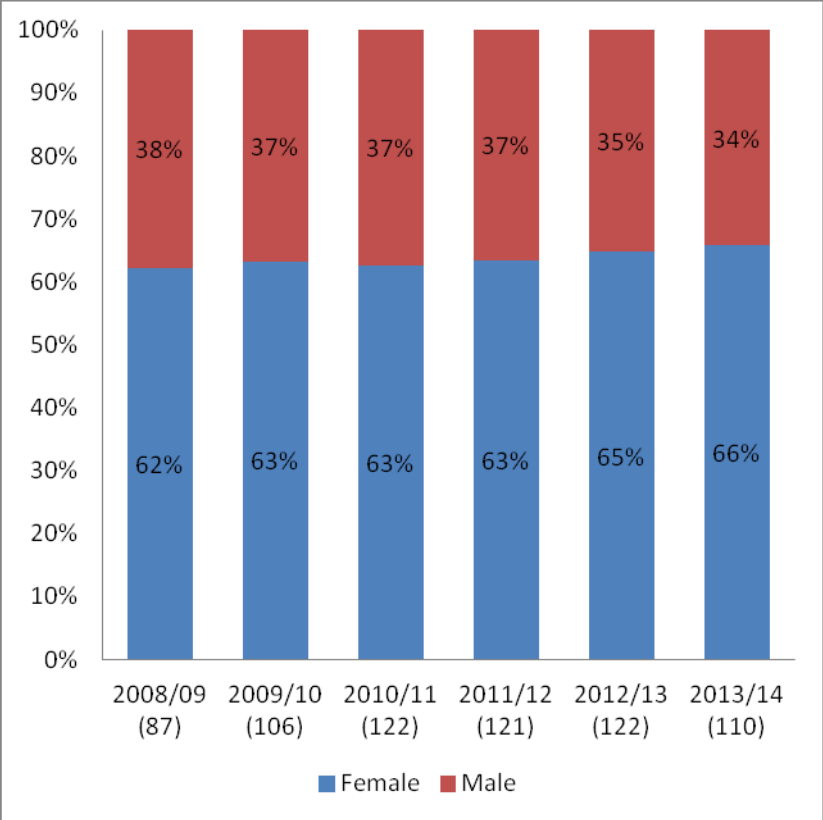


Figure 7.85: proportion of men and women accessing Bereavement Support services, 2008-2014 (Table 98)

A clear majority of Bereavement Support clients are female, with the proportion of men accessing this service decreasing slightly over time.

Case study: encouraging men to access bereavement support

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Macmillan Specialist Palliative Care Team North East Lincolnshire

As a team we work with patients and families to provide holistic care pre- and post-bereavement. Men who access bereavement counselling are generally familiar with the team prior to bereavement.

The team routinely makes contact following bereavement to pass on condolences and offer assistance with immediate difficulties, at which point formal bereavement support is offered.

Referrals to the Macmillan Specialist Palliative Care Social Worker follow in cases where there are complex bereavement needs and the man indicates a willingness to access formal bereavement counselling.

Counselling takes a person centred approach with sessions agreed with the bereaved enabling individuals to progress at a comfortable pace. One man stated 'bereavement sessions helped me to cope again.' As counselling progresses the frequency of sessions is reviewed and sessions cease when they are no longer needed.

The Macmillan social worker also facilitates a Social Bereavement Group for men and women finding it difficult coming to terms with the death of their life partner. Members state 'meetings are natural, we feel normal. When we were part of a couple we supported each other, as individuals in a group we support each other. We share our feelings, experiences and lots of laughter.'

Case study: encouraging men to access bereavement support

Services submitting MDS data that suggested the profile of their patients differed from the average were asked to submit case studies, to give some idea of what actions they take to make sure their services are accessible to as many people as possible.

Bolton Hospice

Our service offers support not counselling. We have a Bereavement Support Co-ordinator (who happens also be the Chaplain) and currently ten volunteer supporters. Within a month of the death of someone within our service, next of kin and other family or friends who are known to the hospice receive a card from the Hospice to offer condolence and to give contact details along with a slip about the service and upcoming dates for the two groups we run.

About three months after the death the bereaved are invited to a Time of Remembrance 'Service' (for want of a better word) and they are offered the facilities of the service again in the invitation letter, and then at the back of the 'Service' booklet. The two groups meet monthly: one session is held in the afternoon for those over 60 years old, the other in the evening for anyone. We also offer one to one sessions and sessions for families, whoever the bereaved see as their family.

We make no special provision for men but have men in both groups and men attend one to one, although more women actually contact the service and take up provision. As with all Bereavement Services we offer a service for all and will see anyone with a connection to a patient in our system. I, The Bereavement Support Co-ordinator, am a man and that may assure other men. Men tend to come to sessions for a shorter time, find emotions difficult but all those who have attended have left feeling stronger, although this is a generalisation. Our mission statement:

"We allow the bereaved the space, time and opportunity to tell their story as many times as they need, without judgement and without pre-conceptions. We give the bereaved the opportunity to be heard and to give a voice to their grief."

Ethnicity

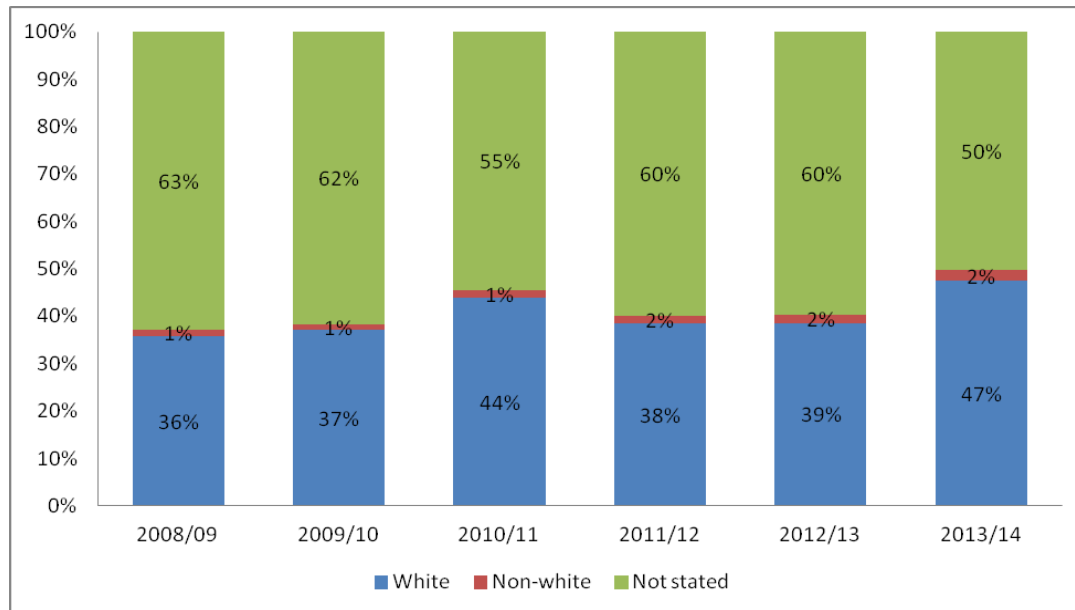


Figure 7.86: proportions of people accessing Bereavement Support services reported as white, BAME and not recorded, 2008-2014 (Table 99)

As Bereavement Support is the setting with by far the highest proportion of unrecorded ethnicity, it has commensurately low levels of recorded access for people of BAME origin. 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.

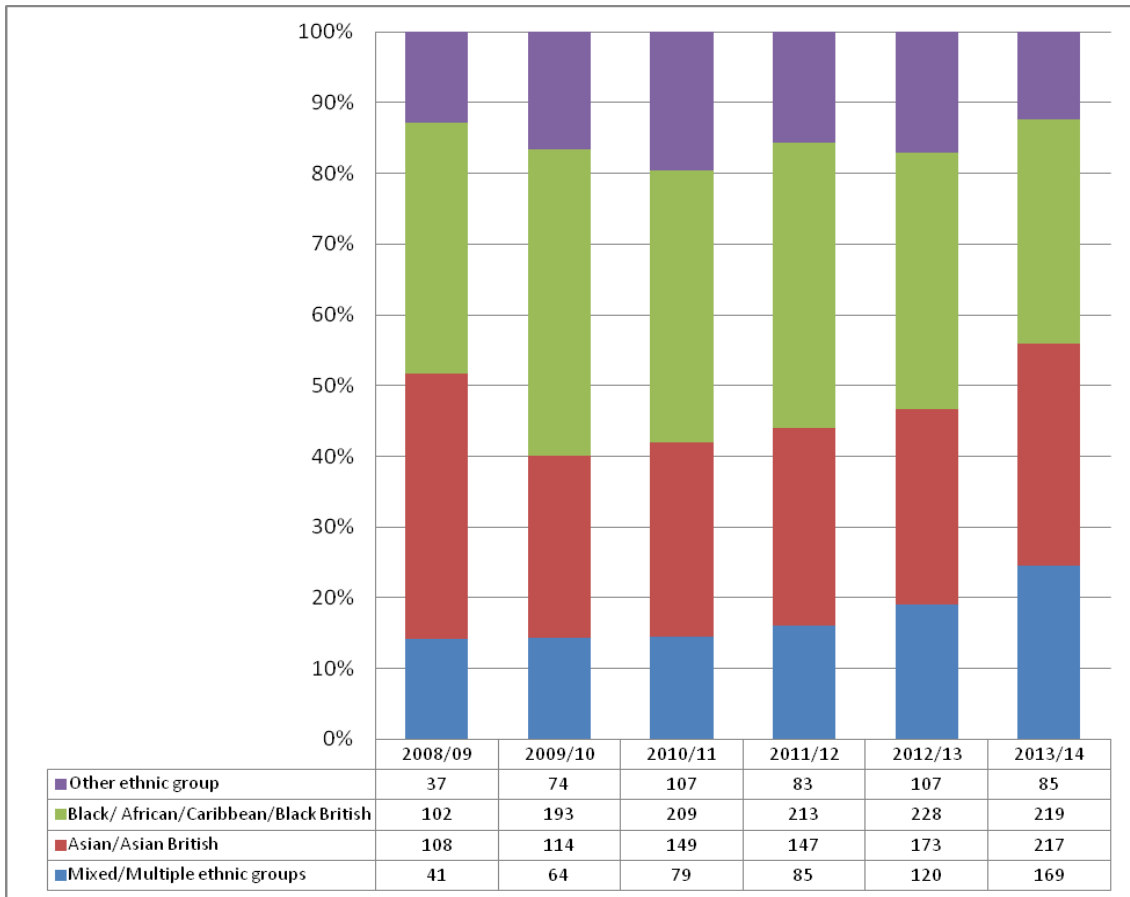


Figure 7.87: people accessing Bereavement Support services from grouped BAME categories, 2008-2014 (Table 100)

Contacts

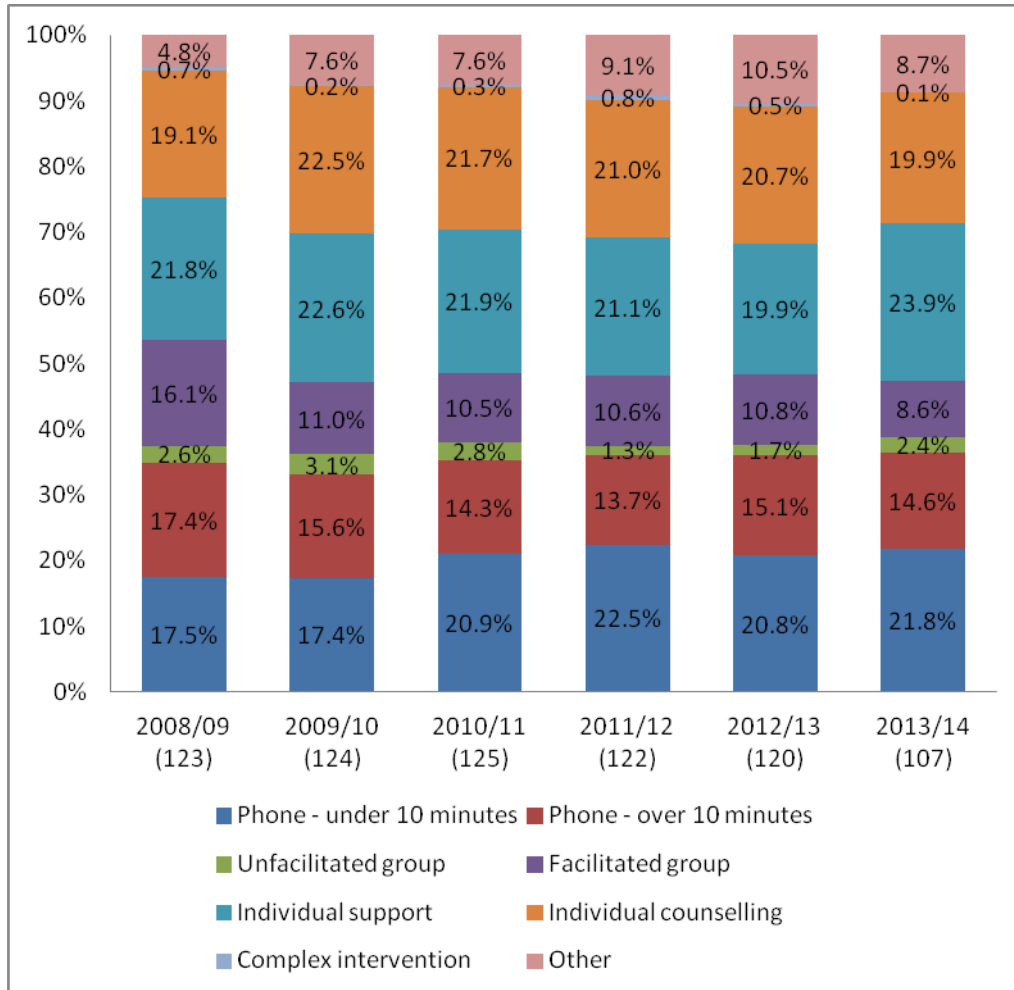


Figure 7.88: types of contacts recorded by Bereavement Support services, 2008-2014 (Table 101)

Overall, shorter phone calls and individual support (provided by a volunteer or other person, not necessarily a trained counsellor) are increasing, while facilitated groups are decreasing. Complex interventions have dropped significantly in 2013/14.

Length of support

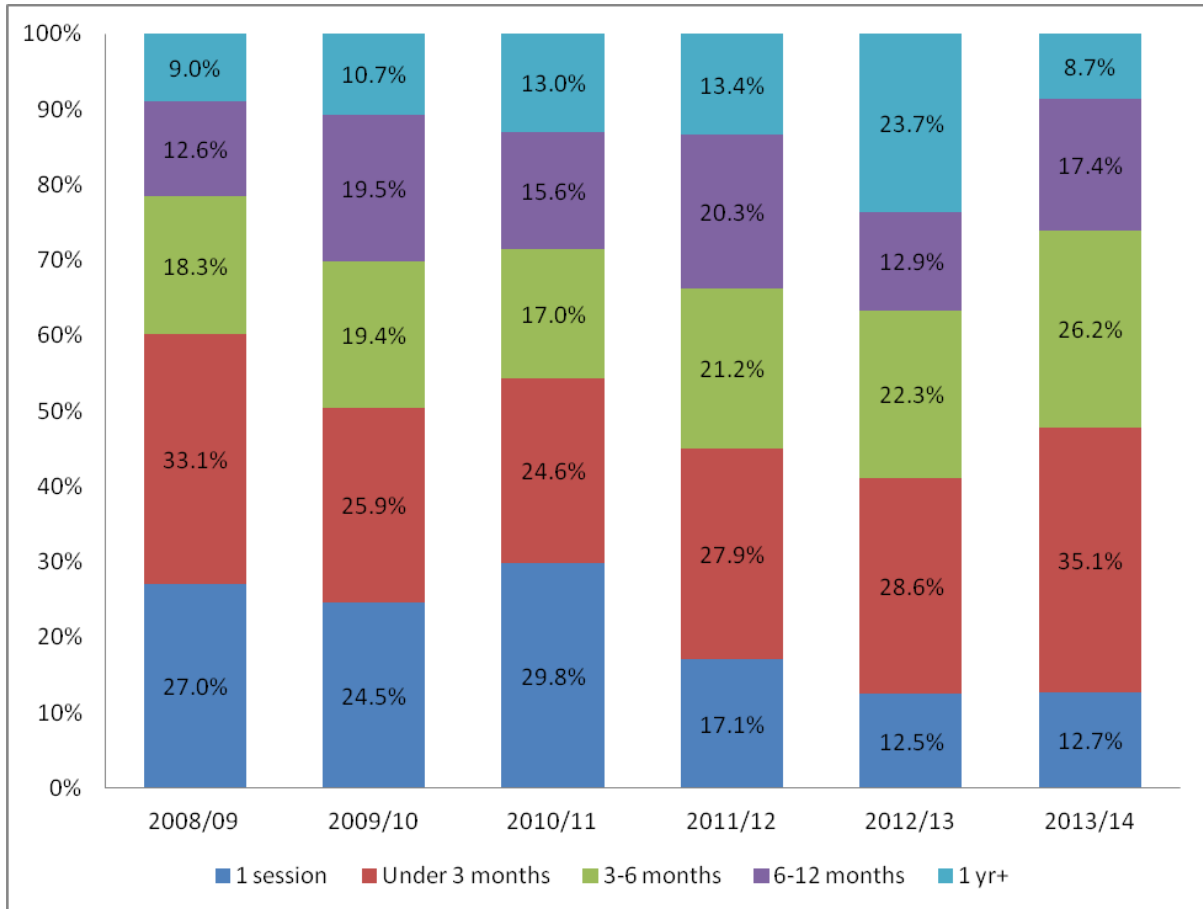


Figure 7.89: length of support recorded by Bereavement Support services, 2008-2014 (Table 102)

There is a large amount of variation in the recorded length of support data, reflecting both the data quality of submissions received and the changes in services responding from year to year. Consequently, it is difficult to make any judgements about trends in this area.

Diagnosis of deceased

Data is collected on the diagnosis of the deceased relative or friend whose loss has catalysed the service user to seek bereavement support. The data collected in the MDS on diagnosis of deceased shows the majority of people who access bereavement support that is allied with specialist palliative care have lost someone to cancer, as might be expected given the prevalence of people with cancer seen across all other MDS settings. We will cease to collect this data in the future, as there is no evidence that the diagnosis of the deceased has any impact on the length of support required, the type of support required, or the likelihood that someone will seek bereavement support.

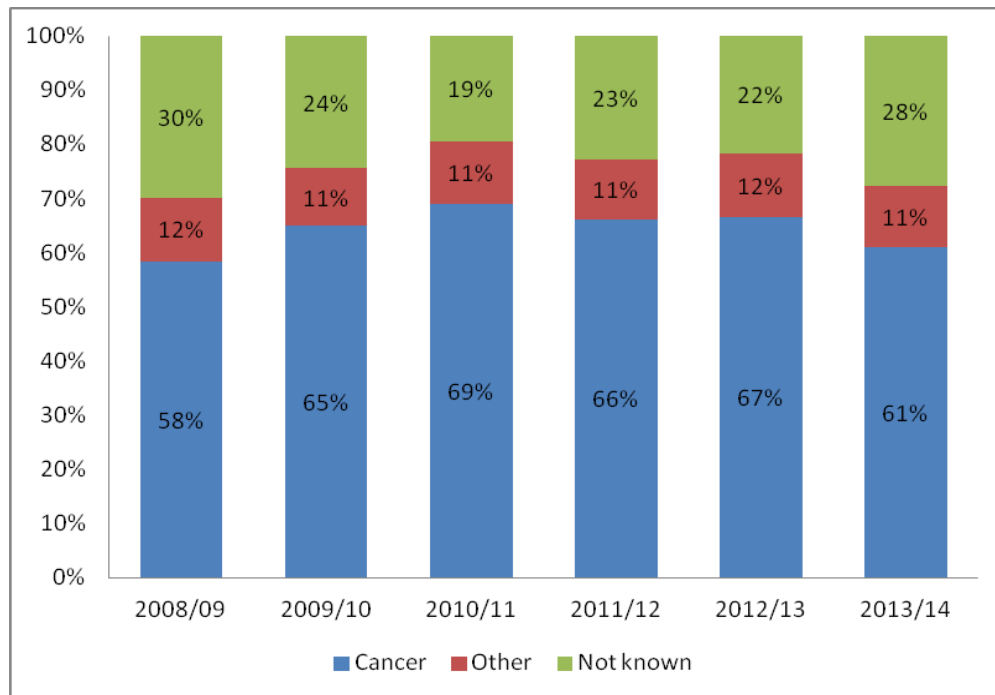


Figure 7.90: diagnosis of deceased relative or friend reported by Bereavement Support clients, 2008-2014 (Table 103)

Data from VOICES⁴ suggests that in fact, the likelihood someone will access bereavement support may be partially dependent on place of death, or rather that bereavement support is more likely to be offered in some settings than others. For example, looking at overall statistics from VOICES for the past three years, around two thirds of people say they did not access bereavement support and would not have wanted to, while 18% of people say they would have liked to access bereavement support but did not. Around 14% of people both wanted to and were able to access some form of bereavement support.

⁴ National survey of the bereaved (VOICES), ONS 2013.

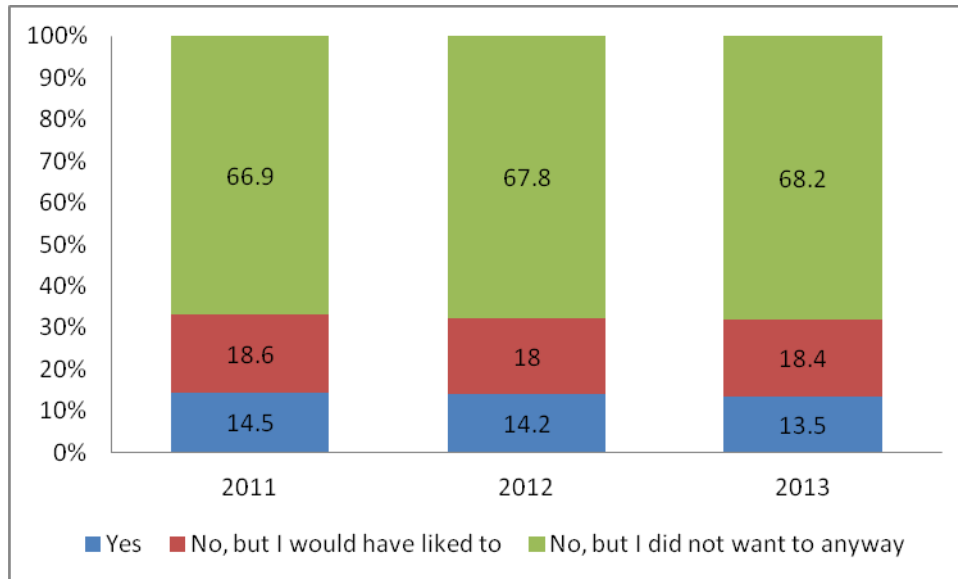


Figure 7.91: VOICES data across all settings: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For example, looking at overall statistics from VOICES for the past three years, around two thirds of bereaved people say they did not access bereavement support and would not have wanted to, while 18% of people say they would have liked to access bereavement support but did not. Around 14% of people both wanted to and were able to access some form of bereavement support. Yet breaking this down to setting level, these percentages vary significantly.

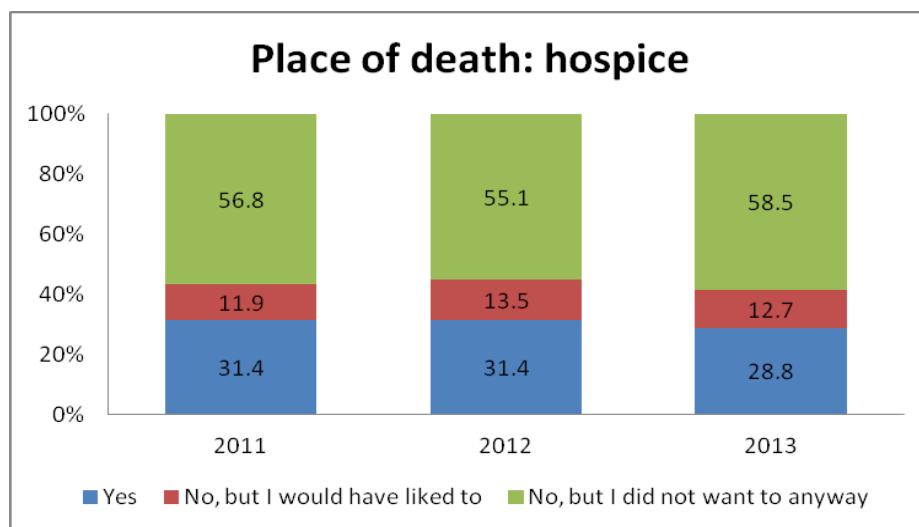


Figure 7.92: VOICES Q52 for hospice settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For people responding to VOICES who had had someone die in a hospice setting, 13% of people would have liked to access bereavement support but did not, compared with 18% of all bereaved people. For

those who had had someone die in a hospice setting, almost 30% of respondents access bereavement support, compared with around 14% of all bereaved people. Does this mean that people who experience the death of someone close to them in a hospice situation are more likely to require bereavement support? Or does this mean that hospices are more proactive in offering bereavement support and so meet an unspoken need for more support?

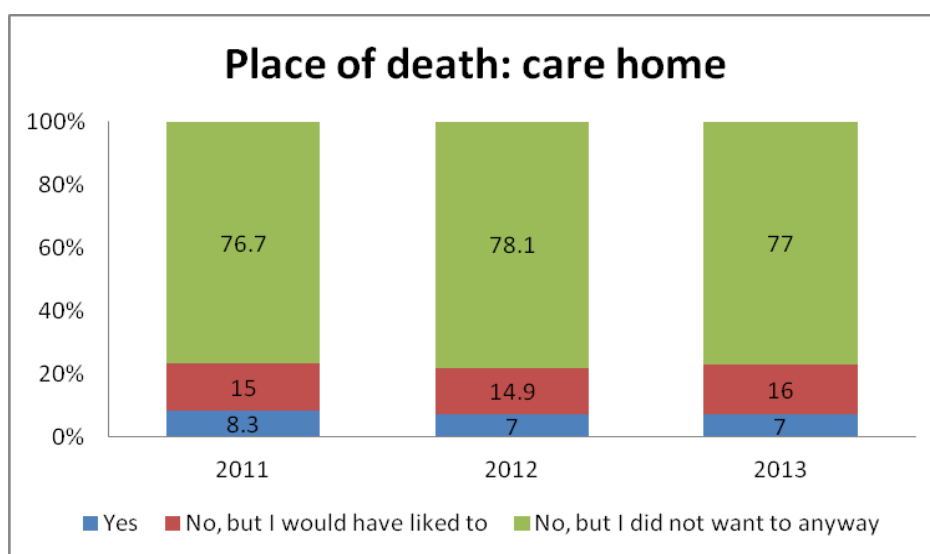


Figure 7.93: VOICES Q52 for care home settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

Conversely, where the place of death was a care home, people are more likely to say they did not want to access bereavement support. Does this reflect the fact that those who die in care homes are likely to be older⁵ and their deaths more expected, or does it reflect a lack of support available in this setting? It should be noted that the percentage of people wanting to access bereavement support but not doing so for deaths in care homes is not higher than the average across all respondents of 18%.

⁵ 67% of deaths in care homes in 2013 were people aged 85 or older. ONS Mortality Statistics, England and Wales, 2013.

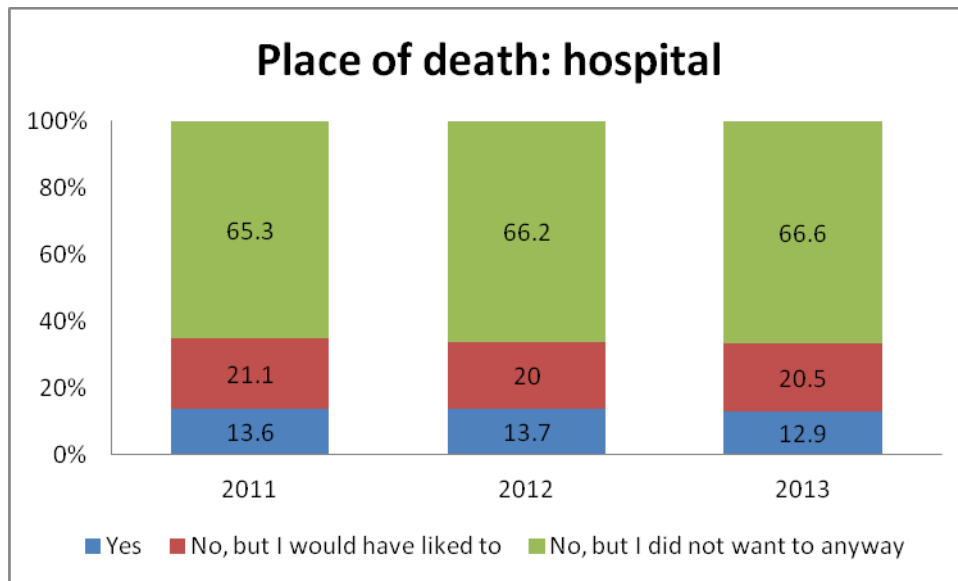


Figure 7.94: VOICES Q52 for hospital settings only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

For deaths in hospital or at home, desire to access Bereavement Support was close to the average across all settings, with a higher proportion accessing Bereavement Support after a death at home and a higher proportion unable to access support they would have wanted after a death in hospital. The vast majority of Bereavement Support MDS returns come from hospices; the sample from hospitals is too small to make any valid comparisons between settings even with weighting.

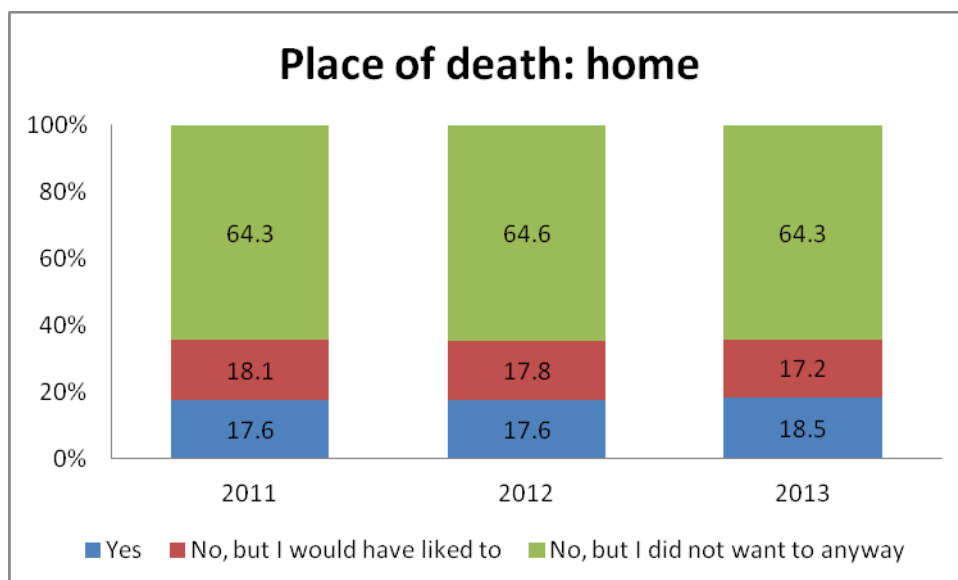


Figure 7.95: VOICES Q52 for home setting only: Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death? (Tick one only)

MDS annex: data tables

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.

Not all services report on all items of data; consequently the total number of people accessing a service varies from section to section of the report. Throughout the report, where services have provided clearly anomalous data, they have been excluded from the analysis.

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MDS overall

Table 25: response rates by setting and country for 2013/14

Service setting	Number of services responding				All services	Response rate
	England	N Ireland	Wales	Total		
Inpatient	115	5	9	129	181	71%
Day Care	120	3	11	134	192	70%
Community Care	166	2	15	183	261	70%
Hospital Support	118	6	12	136	230	59%
Bereavement Support	108	2	5	115	245	47%
Outpatients	135	6	8	149	263	57%
Services Responding	762	24	60	846	1,372	62%
All Services	1,232	43	97	1372		
Service Response rate (%)	62%	56%	62%	62%		

Table 26: total number of people accessing each MDS setting, 2008-2014

	Inpatients	Day Care	Community Care	Hospital Support	Outpatients
2008/09	35,741	22,740	118,861	73,483	41,475
2009/10	37,246	23,105	117,581	74,994	38,155
2010/11	36,802	25,326	120,777	76,343	44,001
2011/12	37,977	25,904	124,277	84,077	41,243
2012/13	42,240	24,921	136,843	79,871	43,204
2013/14	36,420	25,592	138,026	86,443	47,984

Table 27: mean number of people per organisation accessing each MDS setting, 2008-2014

	Inpatients	Day Care	Community Care	Hospital Support	Outpatients
2008/09	259	150	622	490	261
2009/10	262	156	622	540	260
2010/11	256	176	660	553	293
2011/12	271	185	694	623	282
2012/13	279	178	748	619	292
2013/14	282	194	754	636	333
% increase from 2008/09 to 2013/14	8.9%	29.3%	21.2%	29.7%	27.6%

Table 28: reported patient numbers by age and setting in 2013/14 compared with ONS death data from 2013.

2013/14	24 and under	25-64	65-74	75-84	85+	Not known	Total
Inpatients	87	10,661	10,256	10,351	4,964	110	36,429
Day Care	86	7,772	7,032	6,940	2,878	155	24,863
Community Care	378	32,909	34,449	39,434	24,581	1,065	132,816
Hospital Support	393	20,308	20,309	24,722	19,126	642	85,500
Outpatients	428	20,336	12,603	9,655	3,429	679	47,130
ONS 2013*	780	63,860	79,838	144,421	183,722	-	472,621

*This 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.

Table 29: reported patient numbers by sex and setting in 2013/14

2013/14	Female	Male	Total
Inpatients	18,227	18,131	36,358
Day Care	13,995	10,846	24,841
Community Care	66,588	65,236	131,824
Hospital Support	42,709	42,728	85,437
Outpatients	30,401	16,722	47,123

Table 30: number of types of primary diagnosis treated in all settings, 2013/14

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	138	31,181	3,310	726	35,217
2009/10	142	31,572	3,321	763	35,656
2010/11	144	30,980	3,916	649	35,545
2011/12	137	31,952	4,385	898	37,235
2012/13	144	35,536	5,146	1,101	41,783
2013/14	127	30,310	5,021	618	35,949

Table 31: reported patient numbers by type of cancer diagnosis and setting in 2013/14, compared with ONS cancer death data for 2013

2013/14	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Multiple, secondary, etc	Total
Inpatients	773	8,958	6,245	2,649	1,991	1,919	1,769	1,138	1,352	1,911	105	1,495	30,305
Day Care	369	3,918	3,245	2,777	1,078	1,324	819	898	1,182	943	50	346	16,949
Community Care	2,310	26,825	20,072	9,509	5,278	6,487	5,525	3,723	5,392	5,887	367	3,664	95,039
Hospital Support	1,288	15,243	10,696	4,505	3,414	3,648	3,785	1,689	4,451	2,722	189	4,234	55,864
Outpatients	716	5,605	4,341	8,865	2,092	1,620	1,122	879	1,448	1,795	89	637	29,209
ONS 2013*	2,232	40,629	31,382	10,230	6,721	9,901	8,185	3,694	11,259	6,794	1,043	9,839	141,909

*This covers all deaths registered in 2013 as being caused by malignant neoplasms (ICD-10 codes C00-C99).

Table 32: reported patient numbers by type of diagnosis other than cancer and setting in 2013/14, compared with ONS death data for diagnoses other than cancer for 2013

	HIV/AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non-cancer	Total
Inpatients	15	553	636	184	503	340	1,092	199	1,499	5,021
Day Care	22	585	1,278	73	686	292	1,706	86	1,036	5,840
Community Care	38	1,504	2,383	2,676	2,477	1,620	4,444	853	6,362	22,357
Hospital Support	46	368	1,545	2,244	2,545	2,546	2,679	1,031	8,840	22,871
Outpatients	61	659	725	103	416	1,893	1,367	156	7,198	12,733
ONS 2013*	208	2,214	10,503	47,112	5,525	134,776	33,869	1,072	98,323	333,602

*Deaths registered in 2013, minus any deaths due to external causes or neoplasms.

Table 33: proportions of each reported diagnosis for all patients by setting 2013/14, compared with proportions of all diagnoses across ONS death data for 2013

2013/14	Inpatients	Day Care	Community Care	Hospital Support	Outpatients	ONS 2013
Cancer						
Lip/Oral/Pharynx	2.2%	1.5%	1.8%	1.6%	1.6%	0.5%
Digestive	24.9%	16.3%	21.4%	19.3%	12.8%	8.5%
Respiratory	17.4%	13.5%	16.0%	13.6%	9.9%	6.6%
Breast	7.4%	11.5%	7.6%	5.6%	20.2%	2.2%
Female genital	5.5%	4.5%	4.2%	4.3%	4.8%	1.4%
Male genital	5.3%	5.5%	5.2%	4.6%	3.7%	2.1%
Urinary	4.9%	3.4%	4.4%	4.7%	2.6%	1.7%
Eye, Brain, Other	3.2%	3.7%	3.0%	2.1%	2.0%	0.8%
Lymphoid	3.8%	4.9%	4.3%	5.6%	3.3%	2.4%
Other Specified	5.3%	3.9%	4.7%	3.4%	4.1%	1.4%
Multiple	0.3%	0.2%	0.3%	0.2%	0.2%	0.2%
Ill defined, secondary, etc	4.2%	1.4%	2.9%	4.8%	1.5%	2.1%
Non-cancer						
HIV/AIDS	0.0%	0.1%	0.0%	0.1%	0.1%	0.0%
MND	1.5%	2.4%	1.2%	0.5%	1.5%	0.5%
Neurological disorders	1.8%	5.3%	1.9%	1.9%	1.7%	2.2%
Dementia	0.5%	0.3%	2.1%	2.8%	0.2%	9.9%
Heart failure	1.4%	2.8%	2.0%	3.2%	0.9%	1.2%
Other heart conditions	0.9%	1.2%	1.3%	3.2%	4.3%	28.3%
Chronic respiratory disease	3.0%	7.1%	3.5%	3.4%	3.1%	7.1%
Chronic renal failure	0.6%	0.4%	0.7%	1.3%	0.4%	0.2%
Other non-cancer	4.2%	4.3%	5.1%	11.1%	12.3%	20.7%
Not known	1.7%	5.7%	6.4%	2.8%	8.8%	-

Table 34: reported patient numbers by ethnicity and setting in 2013/14

2013/14	White	BAME	Not stated	Total
Inpatients	29,268	1,552	5,428	36,249
Day Care	19,879	1,011	3,658	24,548
Community Care	96,703	8,372	29,469	135,196
Hospital Support	68,167	5,521	11,652	85,340
Outpatients	34,870	2,185	9,438	46,493

Table 35: breakdown of people of BAME origin accessing each MDS setting in 2013/14

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group	Total
Inpatients	317	498	415	322	1,552
Day Care	218	256	272	265	1,011
Community Care	1,713	2,497	1,601	2,561	8,372
Hospital Support	580	2,098	1,769	1,074	5,521
Outpatients	442	730	618	395	2,185

Inpatients

Table 36: total people seen in Inpatient settings, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	138	35,741
2009/10	142	37,246
2010/11	144	36,802
2011/12	140	37,977
2012/13	144	42,240
2013/14	129	36,420

Table 37: range in the size of Inpatient services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per unit	Median number of people seen per unit
2008/09	138	164	300	259	234.5
2009/10	142	172	305.5	262	245.5
2010/11	144	172	309	256	229.5
2011/12	140	178	331.5	271	245
2012/13	144	187	330	279	255
2013/14	129	183	336	282	255

Table 38: ages of people accessing Inpatient care, 2008-2014

	Number of services responding	24 and under	25-64	65-74	75-84	85+	Not known	Total
2008/09	130	84	10,557	8,908	9,264	3,543	139	32,495
2009/10	136	188	11,277	9,796	10,039	4,053	37	35,390
2010/11	142	68	11,164	10,130	10,584	4,255	36	36,237
2011/12	138	92	11,131	10,232	10,964	4,852	12	37,283
2012/13	143	94	12,532	11,773	12,006	5,621	91	42,117
2013/14	129	87	10,661	10,256	10,351	4,964	110	36,429

Table 39: sex of people accessing Inpatient care, 2008-2014

Year	Number of services responding	Female	Male	Total
2008/09	130	16,181	15,966	32,147
2009/10	136	17,493	17,609	35,102
2010/11	142	17,927	18,231	36,158
2011/12	138	18,361	18,925	37,286
2012/13	143	20,714	21,304	42,018
2013/14	129	18,227	18,131	36,358

Table 40: number of types of primary diagnosis treated in Inpatient settings, 2008-2014

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	138	31,181	3,310	726	35,217
2009/10	142	31,572	3,321	763	35,656
2010/11	144	30,980	3,916	649	35,545
2011/12	137	31,952	4,385	898	37,235
2012/13	144	35,536	5,146	1,101	41,783
2013/14	127	30,310	5,021	618	35,949

Table 41: range in proportion of people with cancer treated in Inpatient settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of cancer diagnoses	Median proportion of cancer diagnoses
2008/09	130	85.6%	94.7%	88.5%	90.5%
2009/10	138	85.5%	94.4%	88.7%	90.0%
2010/11	139	85.0%	93.1%	87.3%	88.8%
2011/12	136	82.7%	92.4%	86.4%	88.0%
2012/13	140	83.0%	91.6%	86.2%	87.0%
2013/14	127	81.9%	90.1%	85.1%	86.2%

Table 42: range in proportion of people with diagnoses other than cancer treated in Inpatient settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnoses other than cancer	Median proportion of diagnoses other than cancer
2008/09	130	4.2%	11.1%	8.9%	7.3%
2009/10	138	5.4%	11.6%	9.4%	8.9%
2010/11	139	6.0%	13.1%	10.6%	9.6%
2011/12	136	6.8%	14.5%	11.5%	10.4%
2012/13	140	7.8%	15.7%	12.1%	10.5%
2013/14	127	9.0%	15.7%	13.2%	12.5%

Table 43: range in proportion of people with diagnosis unknown treated in Inpatient settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnosis unknown	Median proportion of diagnosis unknown
2008/09	130	0.8%	5.1%	2.1%	2.2%
2009/10	138	0.7%	6.6%	2.1%	2.3%
2010/11	139	1.4%	7.0%	1.8%	2.5%
2011/12	136	0.9%	4.2%	2.4%	2.5%
2012/13	140	1.2%	3.7%	2.6%	2.3%
2013/14	127	0.9%	5.1%	1.7%	1.9%

Table 44: breakdown of number of people with different cancer diagnoses seen in Inpatient settings, 2008-2014

	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Ill defined, secondary, etc	Total
2008/09	720	8,096	5,749	2,843	1,915	2,046	1,939	1,020	1,257	1,779	149	1,502	29,015
2009/10	737	8,975	6,349	3,156	2,119	2,195	1,871	1,112	1,246	1,899	145	1,904	31,708
2010/11	683	8,833	6,227	3,086	1,974	2,318	1,823	1,095	1,182	2,122	215	1,453	31,011
2011/12	745	9,490	6,659	2,715	1,960	2,290	1,955	1,172	1,345	1,942	168	1,544	31,985
2012/13	805	10,474	7,371	3,227	2,298	2,394	2,126	1,278	1,491	2,133	134	1,502	35,233
2013/14	773	8,958	6,245	2,649	1,991	1,919	1,769	1,138	1,352	1,911	105	1,495	30,305

Table 45: breakdown of number of people with different diagnoses other than cancer seen in Inpatient settings, 2008-2014

	HIV/ AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non- cancer	Total
2008/09	5	419	455	68	295	244	464	134	918	3,002
2009/10	13	464	484	123	276	322	612	173	884	3,351
2010/11	13	512	534	83	382	278	682	211	1,224	3,919
2011/12	11	526	663	146	490	274	897	232	1,119	4,358
2012/13	26	580	723	173	524	360	1,033	226	1,425	5,070
2013/14	15	553	636	184	503	340	1,092	199	1,499	5,021

Table 46: breakdown of all diagnosis types as a proportion of all people seen in an Inpatient setting, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Cancer						
Lip/Oral/Pharynx	2.2%	2.1%	1.9%	2.0%	1.9%	2.2%
Digestive	24.7%	25.1%	24.8%	25.5%	25.3%	24.9%
Respiratory	17.6%	17.7%	17.5%	17.9%	17.8%	17.4%
Breast	8.7%	8.8%	8.7%	7.3%	7.8%	7.4%
Female genital	5.8%	5.9%	5.5%	5.3%	5.6%	5.5%
Male genital	6.2%	6.1%	6.5%	6.1%	5.8%	5.3%
Urinary	5.9%	5.2%	5.1%	5.2%	5.1%	4.9%
Eye, Brain, Other	3.1%	3.1%	3.1%	3.1%	3.1%	3.2%
Lymphoid	3.8%	3.5%	3.3%	3.6%	3.6%	3.8%
Other Specified	5.4%	5.3%	6.0%	5.2%	5.2%	5.3%
Multiple	0.5%	0.4%	0.6%	0.5%	0.3%	0.3%
Ill defined, secondary, etc	4.6%	5.3%	4.1%	4.1%	3.6%	4.2%
Non-cancer						
HIV/AIDS	0.0%	0.0%	0.0%	0.0%	0.1%	0.0%
MND	1.3%	1.3%	1.4%	1.4%	1.4%	1.5%
Neurological disorders	1.4%	1.4%	1.5%	1.8%	1.7%	1.8%
Dementia	0.2%	0.3%	0.2%	0.4%	0.4%	0.5%
Heart failure	0.9%	0.8%	1.1%	1.3%	1.3%	1.4%
Other heart conditions	0.7%	0.9%	0.8%	0.7%	0.9%	0.9%
Chronic respiratory disease	1.4%	1.7%	1.9%	2.4%	2.5%	3.0%
Chronic renal failure	0.4%	0.5%	0.6%	0.6%	0.5%	0.6%
Other non-cancer	2.8%	2.5%	3.4%	3.0%	3.4%	4.2%
Not known	2.2%	2.1%	1.8%	2.4%	2.7%	1.7%

Table 47: ethnicity of people accessing Inpatient care, 2008-2014

	White	BAME	Not stated	Total
2008/09	25,653	1,247	4,592	31,517
2009/10	29,220	1,553	4,084	34,857
2010/11	29,190	1,264	5,342	35,794
2011/12	30,339	1,440	5,279	36,792
2012/13	33,194	1,751	5,814	40,759
2013/14	29,268	1,552	5,428	36,249

Table 48: breakdown of people of BAME origin accessing Inpatient care, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group
2008/09	86	427	356	378
2009/10	94	513	453	493
2010/11	176	388	401	299
2011/12	322	428	406	284
2012/13	308	550	466	427
2013/14	317	498	415	322

Table 49: location at end of stay for completed Inpatient stays, 2008-2014

	Died	Home	Care Home	Acute Hospital	Community Hospital	Other	Not Recorded
2008/09	20,304	15,823	1,243	911	259	458	919
2009/10	21,780	16,464	1,720	1,116	370	417	828
2010/11	22,733	15,874	1,523	760	143	385	322
2011/12	23,619	16,158	1,596	755	107	408	161
2012/13	24,339	16,625	1,704	825	81	294	156
2013/14	22,479	14,229	1,510	719	90	270	270

Table 50: number of stays falling into each length of stay category for Inpatient care, 2008-2014

	1-4 days	5-8 days	9-14 days	15-21 days	22-28 days	29-42 days	43-84 days	85+ days
2008/09	9,685	8,801	8,098	5,968	3,162	2,621	1,450	173
2009/10	10,363	9,293	8,477	5,570	3,130	2,584	1,348	315
2010/11	9,791	9,042	8,780	6,379	3,620	3,244	1,534	185
2011/12	10,539	9,475	8,529	5,845	3,133	2,680	1,363	361
2012/13	10,920	9,238	8,742	6,003	3,309	2,752	1,491	199
2013/14	9,703	8,323	7,816	5,799	2,882	2,588	1,412	173

Table 51: location prior to admission for people accessing Inpatient care, 2008-2014

	Home	Care Home	Acute Hospital	Community Hospital	Other	Not Recorded	Total
2008/09	28,396	598	8,418	540	1,097	1,048	40,097
2009/10	28,847	632	9,651	547	441	906	41,024
2010/11	27,913	702	10,198	348	584	624	40,369
2011/12	29,277	385	11,250	279	374	1,125	42,690
2012/13	30,115	368	12,084	189	527	397	43,680
2013/14	26,407	347	11,105	154	489	674	39,176

Table 52: available Inpatient bed days, 2008-2014

	Reported available bed days	Units returning availability data	Mean available bed days per unit	Mean available beds per unit
2008/09	677,397	133	5093	14.0
2009/10	689,257	133	5182	14.2
2010/11	722,495	140	5161	14.1
2011/12	723,565	134	5400	14.8
2012/13	759,285	134	5666	15.5
2013/14	696,979	124	5621	15.4

Table 53: unavailable Inpatient bed days, 2008-2014

	Reported unavailable bed days	Units returning availability data	Mean unavailable bed days per unit	Mean unavailable beds per unit
2008/09	35,686	127	281.0	0.8
2009/10	23,186	121	191.6	0.5
2010/11	31,255	129	242.3	0.7
2011/12	21,257	123	172.8	0.5
2012/13	21,985	125	175.9	0.5
2013/14	42,834	117	366.1	1.0

Table 54: occupied Inpatient bed days, 2008-2014

	Occupied bed days	Units returning occupancy data	Mean occupied bed days per unit	Mean occupied beds per unit
2008/09	494,564	130	3,804.3	10.4
2009/10	519,333	134	3,875.6	10.6
2010/11	541,816	140	3,870.1	10.6
2011/12	552,343	135	4,091.4	11.2
2012/13	590,742	136	4,343.7	11.9
2013/14	526,262	124	4,244.0	11.6

Table 55: unoccupied Inpatient bed days, 2008-2014

	Unoccupied bed days	Units returning unoccupied occupancy data	Mean unoccupied bed days per unit	Mean unoccupied beds per unit
2008/09	149,567	124	1,206.2	3.3
2009/10	167,528	130	1,288.7	3.5
2010/11	163,846	138	1,187.3	3.3
2011/12	161,174	132	1,221.0	3.3
2012/13	166,743	132	1,263.2	3.5
2013/14	136,733	121	1,130.0	3.1

Table 56: reserved Inpatient bed days, 2008-2014

	Reserved bed days	Units returning reserved occupancy data	Mean reserved bed days per unit	Mean reserved beds per unit
2008/09	5,948	113	52.6	0.1
2009/10	4,997	117	42.7	0.1
2010/11	5,717	129	44.3	0.1
2011/12	5,583	123	45.4	0.1
2012/13	4,611	119	38.7	0.1
2013/14	4,448	109	40.8	0.1

Table 57: range in Inpatient occupancy across all units (calculated as occupied+reserved/available), 2008-2014

Year	1st quartile	3rd quartile	Mean occupancy	Median occupancy
2008/09	70.4%	82.0%	75.0%	75.5%
2009/10	69.8%	82.8%	76.0%	77.1%
2010/11	69.9%	84.0%	77.0%	77.3%
2011/12	70.9%	85.6%	77.5%	77.7%
2012/13	71.4%	84.9%	77.5%	78.4%
2013/14	73.0%	84.1%	78.4%	79.3%

Table 58: number of Inpatient services reporting each level of occupancy, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
0-10%	1	1	0	1	0	0
11-20%	0	0	0	0	1	0
21-30%	0	0	0	0	0	0
31-40%	0	0	0	0	0	0
41-50%	2	0	0	0	0	2
51-60%	7	5	7	2	4	3
61-70%	21	30	28	26	20	12
71-80%	57	50	50	45	52	49
81-90%	32	34	39	49	42	46
91-100%	10	9	14	9	14	11

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Table 59: total people seen in Day Care settings, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	152	22,740
2009/10	148	23,105
2010/11	144	25,326
2011/12	140	25,904
2012/13	140	24,921
2013/14	132	25,592

Table 60: range in the size of Day Care services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per unit	Median number of people seen per unit
2008/09	152	86	179	150	135.5
2009/10	148	95	191	156	133
2010/11	144	114	192	176	145
2011/12	140	99	205	185	142
2012/13	140	99.5	198	178	139.5
2013/14	132	110	213	194	151.5

Table 61: ages of people accessing Day Care, 2008-2014

	Number of services responding	24 and under	25-64	65-74	75-84	85+	Not known	Total
2008/09	138	102	6,867	5,342	5,636	1,866	530	20,343
2009/10	138	74	7,381	5,668	5,978	2,155	156	21,412
2010/11	138	62	8,195	6,279	6,934	2,522	177	24,169
2011/12	135	58	7,728	6,602	7,128	2,819	113	24,448
2012/13	137	45	7,456	6,828	6,871	3,011	109	24,320
2013/14	132	86	7,772	7,032	6,940	2,878	155	24,863

Table 62: sex of people accessing Day Care, 2008-2014

Year	Number of services responding	Female	Male	Total
2008/09	138	11,619	8,303	19,922
2009/10	138	12,225	8,952	21,177
2010/11	138	13,690	10,390	24,080
2011/12	135	13,795	10,642	24,437
2012/13	137	13,667	10,645	24,312
2013/14	132	13,995	10,846	24,841

Table 63: number of types of primary diagnosis treated in Day Care settings, 2008-2014

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	130	15,645	2,734	1,156	19,535
2009/10	137	16,930	3,342	1,228	21,500
2010/11	131	18,543	3,934	988	23,465
2011/12	131	18,325	4,567	1,142	24,034
2012/13	135	17,816	5,277	910	24,003
2013/14	127	17,168	5,840	1,366	24,374

Table 64: range in proportion of people with cancer treated in Day Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of cancer diagnoses	Median proportion of cancer diagnoses
2008/09	130	76%	90%	80%	84%
2009/10	138	73%	88%	79%	82%
2010/11	139	71%	86%	79%	80%
2011/12	136	67%	85%	76%	77%
2012/13	140	66%	83%	74%	78%
2013/14	127	62%	82%	70%	75%

Table 65: range in proportion of people with diagnoses other than cancer treated in Day Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnoses other than cancer	Median proportion of diagnoses other than cancer
2008/09	130	8%	21%	14%	13%
2009/10	138	9%	24%	16%	15%
2010/11	139	11%	25%	17%	17%
2011/12	136	12%	29%	19%	18%
2012/13	140	14%	30%	22%	21%
2013/14	127	17%	32%	24%	22%

Table 66: range in proportion of people with diagnosis unknown treated in Day Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnosis unknown	Median proportion of diagnosis unknown
2008/09	130	0%	3%	6%	0%
2009/10	138	0%	2%	6%	0%
2010/11	139	0%	4%	4%	0%
2011/12	136	0%	3%	5%	0%
2012/13	140	0%	2%	4%	0%
2013/14	127	0%	2%	6%	0%

Table 67: breakdown of number of people with different cancer diagnoses seen in Day Care settings, 2008-2014

	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Ill defined, secondary, etc	Total
2008/09	300	3,499	3,076	2,747	1,049	1,229	794	720	953	801	75	552	15,795
2009/10	354	3,899	3,223	2,706	1,092	1,343	776	822	1,104	793	71	481	16,664
2010/11	395	4,360	3,656	2,954	1,119	1,481	861	889	1,192	906	79	548	18,440
2011/12	358	4,313	3,658	2,796	1,073	1,520	887	847	1,302	966	121	478	18,319
2012/13	357	4,049	3,598	2,786	1,099	1,411	890	810	1,285	878	76	380	17,619
2013/14	369	3,918	3,245	2,777	1,078	1,324	819	898	1,182	943	50	346	16,949

Table 68: breakdown of number of people with different diagnoses other than cancer seen in Day Care settings, 2008-2014

Year	HIV/ AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non- cancer	Total
2008/09	26	429	664	7	294	196	522	37	517	2,764
2009/10	31	539	736	20	374	222	718	56	508	3,342
2010/11	29	589	779	9	487	245	913	84	754	3,934
2011/12	17	613	912	35	547	262	1,246	78	861	4,567
2012/13	57	595	1,052	60	659	252	1,419	83	1,037	5,277
2013/14	22	585	1,278	73	686	292	1,706	86	1,036	5,840

Table 69: breakdown of all diagnosis types as a proportion of all people seen in a Day Care setting, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Cancer						
Lip/Oral/Pharynx	1.5%	1.7%	1.7%	1.5%	1.5%	1.5%
Digestive	17.8%	18.5%	18.7%	18.0%	17.1%	16.3%
Respiratory	15.7%	15.3%	15.7%	15.2%	15.2%	13.5%
Breast	14.0%	12.8%	12.7%	11.6%	11.7%	11.5%
Female genital	5.3%	5.2%	4.8%	4.5%	4.6%	4.5%
Male genital	6.3%	6.4%	6.4%	6.3%	5.9%	5.5%
Urinary	4.0%	3.7%	3.7%	3.7%	3.7%	3.4%
Eye, Brain, Other	3.7%	3.9%	3.8%	3.5%	3.4%	3.7%
Lymphoid	4.9%	5.2%	5.1%	5.4%	5.4%	4.9%
Other Specified	4.1%	3.8%	3.9%	4.0%	3.7%	3.9%
Multiple	0.4%	0.3%	0.3%	0.5%	0.3%	0.2%
Ill defined, secondary, etc	2.8%	2.3%	2.4%	2.0%	1.6%	1.4%
Non-cancer						
HIV/AIDS	0.1%	0.1%	0.1%	0.1%	0.2%	0.1%
MND	2.2%	2.6%	2.5%	2.6%	2.5%	2.4%
Neurological disorders	3.4%	3.5%	3.3%	3.8%	4.4%	5.3%
Dementia	0.0%	0.1%	0.0%	0.1%	0.3%	0.3%
Heart failure	1.5%	1.8%	2.1%	2.3%	2.8%	2.8%
Other heart conditions	1.0%	1.1%	1.1%	1.1%	1.1%	1.2%
Chronic respiratory disease	2.7%	3.4%	3.9%	5.2%	6.0%	7.1%
Chronic renal failure	0.2%	0.3%	0.4%	0.3%	0.3%	0.4%
Other non-cancer	2.6%	2.4%	3.2%	3.6%	4.4%	4.3%
Not known	5.9%	5.8%	4.2%	4.7%	3.8%	5.7%

Table 70: ethnicity of people accessing Day Care, 2008-2014

	Number of services responding	White	BAME	Not stated	Total
2008/09	132	15,736	758	3,316	19,267
2009/10	137	16,562	901	3,510	20,973
2010/11	136	18,847	909	3,837	23,593
2011/12	132	18,057	1,170	3,679	22,910
2012/13	132	17,738	1,041	3,588	22,363
2013/14	129	19,879	1,011	3,658	24,548

Table 71: breakdown of people of BAME origin accessing Day Care, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group
2008/09	65	223	250	220
2009/10	56	170	225	450
2010/11	176	214	275	244
2011/12	377	218	290	285
2012/13	251	255	264	271
2013/14	218	256	272	265

Table 72: range in places per session offered by Day Care services, 2008-2014

	1st quartile	3rd quartile	Mean places per Day Care session	Median places per Day Care session
2008/09	11.2	15.0	14.0	14.3
2009/10	12.0	15.0	14.5	14.2
2010/11	12.0	16.0	14.8	14.4
2011/12	12.0	16.0	14.7	14.6
2012/13	11.6	16.0	14.9	14.0
2013/14	11.5	17.3	15.1	14.6

Table 73: number of attendances falling into each length of support category for Day Care, 2008-2014

	Number of services responding	1 session	2-14 days	15-30 days	31-90 days	91-180 days	181-365 days	Over 1 year	Average length of care (days)
2008/09	152	495	1,455	1,555	3,618	2,606	1,928	1,707	183
2009/10	149	610	1,735	1,690	3,753	2,791	1,913	1,397	172
2010/11	146	868	1,884	2,029	4,309	3,130	2,164	1,519	180
2011/12	141	876	1,838	1,864	4,337	3,388	2,182	1,786	186
2012/13	141	993	1,971	1,890	4,685	3,270	2,341	1,496	178
2013/14	134	949	2,075	1,882	4,450	3,228	2,311	1,738	197

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Table 74: total people seen in Community Care settings, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	191	118,861
2009/10	189	117,581
2010/11	183	120,777
2011/12	179	124,277
2012/13	183	136,843
2013/14	183	138,026

Table 75: range in the size of Community Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per unit	Median number of people seen per unit
2008/09	191	239	924.5	622	562
2009/10	189	277	916	622	608
2010/11	183	295	1,048	660	601.5
2011/12	179	280	1,061	694	690.5
2012/13	183	353	1197	748	758
2013/14	183	346	1219	754	763

Table 76: ages of people accessing Community Care, 2008-2014

	Number of services responding	24 and under	25-64	65-74	75-84	85+	Not known	Total
2008/09	153	966	29,560	26,262	28,951	13,501	1,145	100,385
2009/10	151	443	28,310	25,716	28,988	14,286	443	98,186
2010/11	152	522	29,297	27,646	31,599	16,407	467	105,938
2011/12	149	451	29,669	28,722	32,937	18,272	1,399	111,450
2012/13	157	392	32,781	33,586	38,090	22,753	762	128,364
2013/14	156	378	32,909	34,449	39,434	24,581	1,065	132,816

Table 77: sex of people accessing Community Care, 2008-2014

Year	Number of services responding	Female	Male	Total
2008/09	153	49,018	48,735	97,753
2009/10	151	48,678	48,390	97,068
2010/11	152	52,794	53,041	105,835
2011/12	149	55,727	55,395	111,122
2012/13	157	64,189	63,742	127,931
2013/14	156	66,588	65,236	131,824

Table 78: number of types of primary diagnosis treated in Community Care settings, 2008-2014

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	150	83,371	8,814	6,145	98,327
2009/10	148	81,347	10,612	5,223	98,611
2010/11	148	84,573	12,378	8,203	105,072
2011/12	144	87,446	15,416	8,276	111,814
2012/13	151	95,657	19,367	10,349	125,389
2013/14	153	97,626	22,521	8,088	128,235

Table 79: range in proportion of people with cancer treated by Community Care services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of cancer diagnoses	Median proportion of cancer diagnoses
2008/09	150	81.8%	91.5%	84.8%	87.7%
2009/10	148	77.9%	91.3%	82.5%	86.0%
2010/11	148	75.8%	90.0%	80.5%	85.2%
2011/12	144	73.9%	88.1%	78.2%	82.1%
2012/13	151	72.9%	86.5%	76.3%	80.6%
2013/14	153	72.7%	86.0%	76.1%	80.6%

Table 80: range in proportion of people with diagnoses other than cancer treated in Community Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnoses other than cancer	Median proportion of diagnoses other than cancer
2008/09	150	4.7%	13.4%	9.0%	8.2%
2009/10	148	5.8%	14.8%	10.8%	9.7%
2010/11	148	8.3%	16.5%	11.8%	11.5%
2011/12	144	8.7%	19.2%	13.8%	13.3%
2012/13	151	10.0%	20.0%	15.4%	14.5%
2013/14	153	12.1%	23.0%	17.6%	16.5%

Table 81: range in proportion of people with diagnosis unknown treated in Community Care settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnosis unknown	Median proportion of diagnosis unknown
2008/09	150	0.0%	4.7%	6.2%	0.8%
2009/10	148	0.0%	5.3%	5.3%	0.6%
2010/11	148	0.0%	5.9%	7.8%	0.3%
2011/12	144	0.0%	5.8%	7.4%	0.6%
2012/13	151	0.0%	4.4%	8.3%	0.5%
2013/14	153	0.0%	2.5%	6.3%	0.1%

Table 82: breakdown of number of people with different cancer diagnoses seen in Community Care settings, 2008-2014

	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Ill defined, secondary, etc	Total
2008/09	1,881	22,197	16,823	8,760	4,619	5,722	4,941	2,963	4,252	4,761	422	3,032	80,373
2009/10	1,685	21,959	16,318	8,538	4,601	5,897	4,362	3,027	4,146	4,498	464	2,835	78,330
2010/11	1,718	23,599	16,802	8,709	4,715	6,342	4,543	3,231	4,427	5,082	631	2,823	82,622
2011/12	1,877	23,862	18,356	9,149	4,746	6,249	4,930	3,261	4,694	5,402	439	3,428	86,393
2012/13	2,014	26,373	19,917	9,571	5,193	6,373	5,525	3,618	5,078	5,757	391	3,804	93,614
2013/14	2,310	26,825	20,072	9,509	5,278	6,487	5,525	3,723	5,392	5,887	367	3,664	95,039

Table 83: breakdown of number of people with different diagnoses other than cancer seen in Community Care settings, 2008-2014

	HIV/AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non-cancer	Total
2008/09	38	873	1,146	414	639	860	1,571	367	2,490	8,398
2009/10	24	1,000	1,420	589	903	869	2,042	525	2,929	10,301
2010/11	15	1,146	1,468	851	1,175	920	2,445	602	3,506	12,128
2011/12	39	1,280	1,723	1,273	1,588	1,023	2,882	664	4,432	14,904
2012/13	34	1,387	2,306	1,951	2,166	1,280	3,785	792	5,266	18,967
2013/14	38	1,504	2,383	2,676	2,477	1,620	4,444	853	6,362	22,357

Table 84: breakdown of all diagnosis types as a proportion of all people seen in a Community Care setting, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Cancer						
Lip/Oral/Pharynx	2.0%	1.8%	1.7%	1.7%	1.6%	1.8%
Digestive	23.4%	23.4%	22.9%	21.8%	21.5%	21.4%
Respiratory	17.7%	17.4%	16.3%	16.8%	16.2%	16.0%
Breast	9.2%	9.1%	8.5%	8.3%	7.8%	7.6%
Female genital	4.9%	4.9%	4.6%	4.3%	4.2%	4.2%
Male genital	6.0%	6.3%	6.2%	5.7%	5.2%	5.2%

Urinary	5.2%	4.6%	4.4%	4.5%	4.5%	4.4%
Eye, Brain, Other	3.1%	3.2%	3.1%	3.0%	2.9%	3.0%
Lymphoid	4.5%	4.4%	4.3%	4.3%	4.1%	4.3%
Other Specified	5.0%	4.8%	4.9%	4.9%	4.7%	4.7%
Multiple	0.4%	0.5%	0.6%	0.4%	0.3%	0.3%
Ill defined, secondary, etc	3.2%	3.0%	2.7%	3.1%	3.1%	2.9%
Non-cancer						
HIV/AIDS	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
MND	0.9%	1.1%	1.1%	1.2%	1.1%	1.2%
Neurological disorders	1.2%	1.5%	1.4%	1.6%	1.9%	1.9%
Dementia	0.4%	0.6%	0.8%	1.2%	1.6%	2.1%
Heart failure	0.7%	1.0%	1.1%	1.4%	1.8%	2.0%
Other heart conditions	0.9%	0.9%	0.9%	0.9%	1.0%	1.3%
Chronic respiratory disease	1.7%	2.2%	2.4%	2.6%	3.1%	3.5%
Chronic renal failure	0.4%	0.6%	0.6%	0.6%	0.6%	0.7%
Other non-cancer	2.6%	3.1%	3.4%	4.0%	4.3%	5.1%
Not known	6.5%	5.6%	8.0%	7.6%	8.4%	6.4%

Table 85: ethnicity of people accessing Community Care, 2008-2014

	White	BAME	Not stated	Total
2008/09	63,959	3,248	20,460	89,030
2009/10	72,892	4,524	21,372	98,735
2010/11	78,370	4,455	23,092	105,917
2011/12	83,164	6,007	22,795	112,645
2012/13	90,696	8,132	28,218	126,841
2013/14	96,703	8,372	29,469	135,196

Table 86: breakdown of people of BAME origin accessing Community Care, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group
2008/09	195	1,189	998	866
2009/10	741	1,313	877	1,593
2010/11	1,372	1,321	967	795
2011/12	2,042	1,402	1,029	1,534
2012/13	2,630	2,229	1,524	1,749
2013/14	1,713	2,497	1,601	2,561

Table 87: outcomes for people referred to Community Care, 2008-2014

	Periods of care ending in death	Periods of care ending in discharge	Periods of care continuing into next reporting year	Total periods of care
2008/09	57,880	31,331	31,185	120,396
2009/10	58,591	35,463	30,829	124,883
2010/11	61,354	36,418	32,812	130,584
2011/12	64,721	37,070	34,064	135,855
2012/13	71,000	41,003	36,958	148,961
2013/14	72,523	43,756	35,138	151,417

Table 88: location of death for people being seen by Community Care teams, 2008-2014

	Home	Care Home	Hospice	Community Hospital	Acute Hospital	Other	Unknown	Total
2008/09	24,943	4,539	9,144	3,973	9,625	1,063	2,474	55,761
2009/10	26,638	5,421	9,101	3,636	8,496	649	2,938	56,879
2010/11	28,717	6,078	9,635	3,496	8,634	838	1,921	59,319
2011/12	30,053	7,071	11,088	2,707	8,761	661	2,780	63,121
2012/13	32,435	8,364	11,667	2,998	9,531	704	4,471	70,170
2013/14	34,413	8,696	11,485	2,384	9,676	828	4,293	71,775

Table 89: number of completed episodes falling into each length of care category for Community Care, 2008-2014

	1 day	2-14 days	15-30 days	31-60 days	61-90 days	91-120 days	121-150 days	151-180 days	181-365 days	Over 1 year	Mean length of care (days)
2008/09	4,020	14,567	9,507	10,409	6,415	4,625	3,132	2,349	6,841	4,052	103
2009/10	5,168	16,396	10,912	12,265	7,493	5,261	3,635	2,826	7,920	4,787	101
2010/11	6,211	18,181	11,927	13,036	8,185	5,796	4,034	3,184	8,403	6,018	96
2011/12	6,662	20,098	13,613	14,291	8,582	5,970	4,137	3,244	8,633	4,880	101
2012/13	8,726	22,533	14,377	16,035	9,927	6,842	5,211	3,595	10,187	5,357	102
2013/14	9,297	25,251	14,974	16,857	9,842	6,736	4,696	3,643	10,107	5,737	95

Hospital Support

Table 90: total people seen in Hospital Support settings, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	150	73,483
2009/10	139	74,994
2010/11	138	76,343
2011/12	135	84,077
2012/13	129	79,871
2013/14	136	86,443

Table 91: range in the size of Hospital Support services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per unit	Median number of people seen per unit
2008/09	150	303	625	490	445
2009/10	139	318	665	540	446
2010/11	138	340	756	553	489.5
2011/12	135	356.5	864	623	576
2012/13	129	363	855	649	593
2013/14	136	326	925	636	582.5

Table 92: ages of people accessing Hospital Support, 2008-2014

	Number of services responding	24 and under	25-64	65-74	75-84	85+	Not known	Total
2008/09	135	311	16,952	14,763	17,551	10,473	761	60,811
2009/10	120	345	16,680	15,403	18,706	11,162	1,124	63,420
2010/11	131	297	17,745	16,470	20,069	13,076	1,281	68,938
2011/12	128	378	20,378	18,907	23,286	16,280	131	79,360
2012/13	121	333	19,268	18,616	22,639	16,733	1,254	78,843
2013/14	135	393	20,308	20,309	24,722	19,126	642	85,500

Table 93: sex of people accessing Hospital Support, 2008-2014

Year	Number of services responding	Female	Male	Total
2008/09	135	30,703	30,283	60,986
2009/10	120	30,758	31,172	61,930
2010/11	131	34,286	34,043	68,329
2011/12	128	39,133	38,545	77,678
2012/13	121	39,238	39,503	78,741
2013/14	135	42,709	42,728	85,437

Table 94: number of types of primary diagnosis treated in Hospital Support, 2008-2014

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	136	51,360	11,204	2,251	64,815
2009/10	120	49,980	10,612	2,662	63,254
2010/11	128	55,554	13,910	2,415	71,879
2011/12	129	61,616	17,248	3,091	81,955
2012/13	119	56,742	17,805	6,063	80,610
2013/14	133	58,803	22,742	4,636	86,181

Table 95: range in proportion of people with cancer treated by Hospital Support services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of cancer diagnoses	Median proportion of cancer diagnoses
2008/09	136	73%	88%	79%	82%
2009/10	120	71%	90%	79%	82%
2010/11	128	72%	87%	77%	80%
2011/12	129	69%	84%	75%	78%
2012/13	119	66%	84%	70%	75%
2013/14	133	61%	80%	68%	71%

Table 96: range in proportion of people with diagnoses other than cancer treated in Hospital Support settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnoses other than cancer	Median proportion of diagnoses other than cancer
2008/09	136	8%	23%	17%	14%
2009/10	120	8%	24%	17%	14%
2010/11	128	11%	25%	19%	17%
2011/12	129	12%	28%	21%	19%
2012/13	119	12%	30%	22%	20%
2013/14	133	15%	33%	26%	23%

Table 97: range in proportion of people with diagnosis unknown treated in Hospital Support settings, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnosis unknown	Median proportion of diagnosis unknown
2008/09	136	0%	3%	3%	0%
2009/10	120	0%	2%	4%	0%
2010/11	128	0%	2%	3%	0%
2011/12	129	0%	3%	4%	0%
2012/13	119	0%	4%	8%	0%
2013/14	133	0%	4%	5%	0%

Table 98: breakdown of number of people with different cancer diagnoses seen in Hospital Support settings, 2008-2014

	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Ill defined, secondary, etc	Total
2008/ 09	1,225	13,563	9,191	4,585	2,816	2,873	3,364	1,526	3,353	1,904	240	3,334	47,974
2009/ 10	1,089	13,420	9,036	4,163	2,799	3,243	3,077	1,456	3,191	2,137	291	3,147	47,049
2010 /11	1,293	14,894	10,312	4,409	3,346	3,474	3,286	1,670	3,807	2,105	307	3,582	52,485
2011/ 12	1,383	16,805	11,923	5,137	3,780	4,169	3,807	1,885	4,530	2,740	472	4,017	60,648
2012/ 13	1,330	15,205	11,091	4,567	3,246	3,556	3,368	1,591	4,052	2,634	239	3,660	54,539
2013/ 14	1,288	15,243	10,696	4,505	3,414	3,648	3,785	1,689	4,451	2,722	189	4,234	55,864

Table 99: breakdown of number of people with different diagnoses other than cancer seen in Hospital Support settings, 2008-2014

	HIV/ AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non- cancer	Total
2008/09	59	239	797	665	1,040	1,290	1,181	709	3,732	9,712
2009/10	56	198	647	774	967	1,214	1,061	634	3,875	9,426
2010/11	48	310	1,058	1,268	1,518	1,617	1,772	947	4,986	13,524
2011/12	62	339	1,072	1,570	1,837	2,107	2,195	791	6,870	16,843
2012/13	80	338	1,118	1,796	1,845	2,121	2,296	828	7,246	17,668
2013/14	46	368	1,545	2,244	2,545	2,546	2,679	1,031	8,840	22,871

Table 100: breakdown of all diagnosis types as a proportion of all people seen in a Hospital Support setting, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Cancer						
Lip/Oral/Pharynx	2.0%	1.9%	1.9%	1.7%	1.8%	1.6%
Digestive	22.6%	22.9%	21.8%	21.1%	20.4%	19.3%
Respiratory	15.3%	15.4%	15.1%	15.0%	14.9%	13.6%
Breast	7.6%	7.1%	6.5%	6.4%	6.1%	5.6%
Female genital	4.7%	4.8%	4.9%	4.7%	4.4%	4.3%
Male genital	4.8%	5.5%	5.1%	5.2%	4.8%	4.6%
Urinary	5.6%	5.2%	4.8%	4.8%	4.5%	4.7%
Eye, Brain, Other	2.5%	2.5%	2.4%	2.4%	2.1%	2.1%
Lymphoid	5.6%	5.4%	5.6%	5.7%	5.4%	5.6%
Other Specified	3.2%	3.6%	3.1%	3.4%	3.5%	3.4%
Multiple	0.4%	0.5%	0.4%	0.6%	0.3%	0.2%
Ill defined, secondary, etc	5.6%	5.4%	5.2%	5.0%	4.9%	4.8%
Non-cancer						
HIV/AIDS	0.1%	0.1%	0.1%	0.1%	0.1%	0.1%
MND	0.4%	0.3%	0.5%	0.4%	0.5%	0.5%
Neurological disorders	1.3%	1.1%	1.5%	1.3%	1.5%	1.9%
Dementia	1.1%	1.3%	1.9%	2.0%	2.4%	2.8%
Heart failure	1.7%	1.6%	2.2%	2.3%	2.5%	3.2%
Other heart conditions	2.2%	2.1%	2.4%	2.6%	2.8%	3.2%
Chronic respiratory disease	2.0%	1.8%	2.6%	2.8%	3.1%	3.4%
Chronic renal failure	1.2%	1.1%	1.4%	1.0%	1.1%	1.3%
Other non-cancer	6.2%	6.6%	7.3%	8.6%	9.7%	11.1%
Not known	3.8%	3.8%	3.3%	2.8%	3.0%	2.8%

Table 101: ethnicity of people accessing Hospital Support, 2008-2014

	Number of services responding	White	BAME	Not stated	Total
2008/09	120	46,943	2,526	6,518	55,987
2009/10	113	44,980	2,636	7,915	55,531
2010/11	124	53,877	3,795	7,699	65,371
2011/12	128	60,658	4,829	12,297	77,784
2012/13	119	56,751	4,746	11,884	73,381
2013/14	135	68,167	5,521	11,652	85,340

Table 102: breakdown of people of BAME origin accessing Hospital Support, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group
2008/09	177	1058	750	541
2009/10	179	1004	963	490
2010/11	499	1405	1421	470
2011/12	562	1837	1680	750
2012/13	623	1753	1603	767
2013/14	580	2098	1769	1074

Table 103: number of Hospital Support stays ending in death, discharge, or continuing across reporting years, 2008-2014

	Death	Discharge	Continuing	Total stays
2008/09	24,392	44,004	4,003	72,399
2009/10	23,633	44,982	6,842	75,457
2010/11	25,939	52,362	4,591	82,892
2011/12	28,158	56,155	5,781	90,094
2012/13	28,462	54,693	8,166	91,321
2013/14	30,569	56,969	5,058	92,596

Table 104: place of care after discharge for people accessing Hospital Support, 2008-2014

	Home	Care Home	Hospice	Community Hospital	Acute Hospital	Other	Not Recorded
2008/09	19,497	2,055	6,190	1,037	5,253	1,907	4,330
2009/10	21,714	2,567	6,981	826	5,831	2,070	3,886
2010/11	25,943	3,234	7,579	937	7,497	2,661	4,732
2011/12	27,361	4,030	7,636	1,198	7,762	3,216	3,443
2013/13	26,437	4,218	7,679	996	8,927	2,379	3,392
2013/14	27,420	4,469	7,486	1,000	8,433	2,504	4,237

Table 105: number of completed episodes falling into each length of care category for Hospital Support, 2008-2014

	1 day	2-7 days	8-14 days	15-28 days	29-42 days	43-84 days	85-180 days	180+ days	Average length of care (days)
2008/09	13,978	23,016	12,425	8,527	2,343	1,357	480	606	13.9
2009/10	13,681	23,748	11,924	7,085	2,149	1,355	569	1,008	12.8
2010/11	15,741	27,275	12,838	7,814	2,193	1,285	555	192	14.0
2011/12	16,309	28,403	14,007	8,205	2,326	1,477	887	328	14.7
2012/13	16,984	28,813	13,519	7,953	2,227	1,468	713	265	11.4
2013/14	18,642	32,443	14,968	8,940	2,647	1,918	1,086	481	14.4

Outpatients

Table 106: total people seen in Outpatient clinics, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	166	41,475
2009/10	155	38,155
2010/11	156	44,001
2011/12	151	41,243
2012/13	151	43,204
2013/14	149	47,984

Table 107: range in the size of Outpatient clinics, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per unit	Median number of people seen per unit
2008/09	166	77	336	261	149
2009/10	155	61.5	321.5	260	163
2010/11	156	63.25	357.75	293	180
2011/12	151	71.25	378	282	150.5
2012/13	151	67.75	389.25	292	172.5
2013/14	149	89.75	423	333	222.5

Table 108: ages of people accessing Outpatient clinics, 2008-2014

	Number of services responding	24 and under	25-64	65-74	75-84	85+	Not known	Total
2008/09	135	377	16,808	9,090	7,383	2,348	472	36,478
2009/10	138	431	17,644	9,036	6,933	2,270	320	36,634
2010/11	143	501	19,526	9,898	7,872	2,607	429	40,833
2011/12	143	267	18,076	10,017	7,784	2,575	712	39,431
2012/13	148	331	18,853	11,096	8,743	3,276	394	42,693
2013/14	144	428	20,336	12,603	9,655	3,429	679	47,130

Table 109: sex of people accessing Outpatient clinics, 2008-2014

Year	Number of services responding	Female	Male	Total
2008/09	129	23,554	12,444	35,998
2009/10	138	24,750	11,842	36,592
2010/11	143	27,144	13,330	40,474
2011/12	143	25,391	13,111	38,502
2012/13	148	27,508	14,952	42,460
2013/14	144	30,401	16,722	47,123

Table 110: number of types of primary diagnosis treated in Outpatient clinics, 2008-2014

	Number of services responding	Cancer	Non-cancer	Not known	Total
2008/09	132	26,446	6,344	4,658	37,448
2009/10	134	25,101	8,097	2,801	35,999
2010/11	135	25,743	9,664	4,398	39,805
2011/12	136	25,468	8,181	4,198	37,847
2012/13	145	27,996	10,629	3,446	42,071
2013/14	143	29,670	12,730	3,843	46,243

Table 111: range in proportion of people with cancer treated by Outpatient clinics, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of cancer diagnoses	Median proportion of cancer diagnoses
2008/09	132	69.7%	92.2%	70.6%	84.3%
2009/10	134	65.9%	92.9%	69.7%	85.0%
2010/11	135	58.8%	91.8%	64.7%	83.3%
2011/12	134	65.9%	91.3%	67.3%	80.3%
2012/13	142	61.0%	88.8%	66.5%	78.5%
2013/14	139	60.4%	87.0%	64.2%	78.4%

Table 112: range in proportion of people with diagnoses other than cancer treated by Outpatient clinics, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnoses other than cancer	Median proportion of diagnoses other than cancer
2008/09	132	4.1%	18.9%	16.9%	8.8%
2009/10	134	3.4%	17.3%	22.5%	9.5%
2010/11	135	4.9%	20.5%	24.3%	11.2%
2011/12	134	4.5%	22.1%	21.6%	12.5%
2012/13	142	5.3%	24.6%	25.3%	15.4%
2013/14	139	8.3%	29.4%	27.5%	15.4%

Table 113: range in proportion of people with diagnosis unknown treated by Outpatient clinics, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean proportion of diagnosis unknown	Median proportion of diagnosis unknown
2008/09	132	0.0%	9.6%	12.4%	1.2%
2009/10	134	0.0%	6.1%	7.8%	0.0%
2010/11	135	0.0%	8.9%	11.0%	0.0%
2011/12	134	0.0%	7.8%	11.1%	0.6%
2012/13	142	0.0%	8.0%	8.2%	0.0%
2013/14	139	0.0%	6.8%	8.3%	0.3%

Table 114: breakdown of number of people with different cancer diagnoses seen in Outpatient clinics, 2008-2014

	Lip/Oral/Pharynx	Digestive	Respiratory	Breast	Female genital	Male genital	Urinary	Eye, Brain, Other	Lymphoid	Other Specified	Multiple	Ill defined, secondary, etc	Total
2008/09	712	4,367	3,741	8,226	1,648	1,550	1,021	639	1,669	1,360	164	681	25,778
2009/10	490	3,909	2,997	8,973	1,582	1,324	809	519	1,048	1,325	89	801	23,866
2010/11	536	4,332	3,568	9,272	1,777	1,551	976	610	1,132	1,441	144	1,010	26,349
2011/12	522	4,390	3,478	8,522	1,570	1,412	948	595	1,127	2,049	96	753	25,462
2012/13	631	4,960	3,969	8,881	1,810	1,694	1,148	754	1,403	1,711	71	681	27,713
2013/14	716	5,605	4,341	8,865	2,092	1,620	1,122	879	1,448	1,795	89	637	29,209

Table 115: breakdown of number of people with different diagnoses other than cancer seen by Outpatient clinic, 2008-2014

	HIV/ AIDS	MND	Neurological disorders	Dementia	Heart failure	Other heart conditions	Chronic respiratory disease	Chronic renal failure	Other non- cancer	Total
2008/09	29	340	425	19	166	987	297	93	3,600	5,933
2009/10	70	368	411	18	180	1,321	535	121	4,941	7,746
2010/11	65	487	533	71	222	1,095	610	83	6,547	9,719
2011/12	56	462	500	29	240	1,238	886	110	4,660	8,560
2012/13	48	480	688	96	463	1,657	1,040	147	5,959	10,796
2013/14	61	659	725	103	416	1,893	1,367	156	7,198	12,733

Table 116: breakdown of all diagnosis types as a proportion of all people seen by Outpatient clinics, 2008-2014

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Cancer						
Lip/Oral/Pharynx	2.0%	1.5%	1.4%	1.4%	1.6%	1.6%
Digestive	12.4%	11.9%	11.7%	12.0%	12.3%	12.8%
Respiratory	10.6%	9.2%	9.6%	9.5%	9.8%	9.9%
Breast	23.4%	27.4%	25.0%	23.2%	22.0%	20.2%
Female genital	4.7%	4.8%	4.8%	4.3%	4.5%	4.8%
Male genital	4.4%	4.0%	4.2%	3.8%	4.2%	3.7%
Urinary	2.9%	2.5%	2.6%	2.6%	2.8%	2.6%
Eye, Brain, Other	1.8%	1.6%	1.6%	1.6%	1.9%	2.0%
Lymphoid	4.7%	3.2%	3.1%	3.1%	3.5%	3.3%
Other Specified	3.9%	4.1%	3.9%	5.6%	4.2%	4.1%
Multiple	0.5%	0.3%	0.4%	0.3%	0.2%	0.2%
Ill defined, secondary, etc	1.9%	2.4%	2.7%	2.1%	1.7%	1.5%
Non-cancer						
HIV/AIDS	0.1%	0.2%	0.2%	0.2%	0.1%	0.1%
MND	1.0%	1.1%	1.3%	1.3%	1.2%	1.5%
Neurological disorders	1.2%	1.3%	1.4%	1.4%	1.7%	1.7%
Dementia	0.1%	0.1%	0.2%	0.1%	0.2%	0.2%
Heart failure	0.5%	0.6%	0.6%	0.7%	1.1%	0.9%
Other heart conditions	2.8%	4.0%	3.0%	3.4%	4.1%	4.3%
Chronic respiratory disease	0.8%	1.6%	1.6%	2.4%	2.6%	3.1%
Chronic renal failure	0.3%	0.4%	0.2%	0.3%	0.4%	0.4%
Other non-cancer	6.7%	9.2%	8.5%	9.6%	11.4%	12.3%
Not known	13.3%	8.6%	11.9%	11.4%	8.5%	8.8%

Table 117: ethnicity of people accessing Outpatient clinics, 2008-2014

	Number of services responding	White	BAME	Not stated	Total
2008/09	129	24,651	1,171	10,732	36,554
2009/10	134	24,405	1,062	10,420	35,887
2010/11	145	28,779	1,240	11,204	41,223
2011/12	147	25,758	1,042	10,795	37,595
2012/13	149	29,842	1,609	10,469	41,920
2013/14	149	34,870	2,185	9,438	46,493

Table 118: breakdown of people of BAME origin accessing Outpatient clinics, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black/African/Caribbean/Black British	Other ethnic group
2008/09	95	464	331	281
2009/10	81	378	214	389
2010/11	92	470	280	398
2011/12	151	338	284	269
2012/13	219	442	403	545
2013/14	442	730	618	395

Bereavement Support

Table 119: total people seen by Bereavement Support services, 2008-2014

	Number of organisations returning data	Total people seen
2008/09	127	38,698
2009/10	123	41,510
2010/11	130	42,798
2011/12	121	36,366
2012/13	125	39,574
2013/14	112	32,279

Table 120: range in the size of Bereavement Support services, 2008-2014

Year	Number of organisations responding	1st quartile	3rd quartile	Mean number of people seen per service	Median number of people seen per service
2008/09	127	75.5	381.5	305	140
2009/10	123	92.25	363.5	329	196.5
2010/11	130	85.25	393	329	168
2011/12	121	88	314	301	149
2012/13	125	92	336	317	184
2013/14	112	103.75	381	288	178

Table 121: ages of people accessing Bereavement Support services, 2008-2014

Year	Number of services responding	Under 16	16-18	19-24	25-64	65-74	75-84	85+	Not known	Total
2008/09	94	1,066	134	346	4,785	2,035	1,561	543	12,961	24,371
2009/10	111	1,421	268	484	8,495	3,627	2,971	1,097	20,473	38,834
2010/11	124	1,612	303	697	9,564	4,703	3,697	1,477	15,632	37,608
2011/12	122	1,724	355	390	8,984	3,885	3,100	1,070	15,047	34,790
2012/13	123	1,982	402	535	10,019	4,000	2,893	1,003	14,670	35,704
2013/14	112	2,048	394	702	10,631	4,022	2,646	1,030	9,864	31,416

Table 122: sex of people accessing Bereavement Support, 2008-2014

	Number of services responding	Female	Male	Total
2008/09	87	11,723	7130	18,853
2009/10	106	18,873	10,956	29,829
2010/11	122	20,718	12,362	33,080
2011/12	121	19,485	11,211	30,696
2012/13	122	22,032	11,999	34,031
2013/14	110	20,046	10,443	30,489

Table 123: ethnicity of people accessing Bereavement Support, 2008-2014

	Number of services responding	White	BAME	Not stated	Total
2008/09	88	7,912	288	13,908	22,109
2009/10	103	13,241	445	22,058	35,744
2010/11	108	15,977	544	19,827	36,348
2011/12	114	13,253	528	20,624	34,527
2012/13	119	13,684	628	21,148	35,502
2013/14	107	14,965	690	15,857	31,513

Table 124: breakdown of people of BAME origin accessing Bereavement Support, 2008-2014

	Mixed/Multiple ethnic groups	Asian/Asian British	Black African/ Caribbean/ Black British	Other ethnic group
2008/09	41	108	102	37
2009/10	64	114	193	74
2010/11	79	149	209	107
2011/12	85	147	213	83
2012/13	120	173	228	107
2013/14	169	217	219	85

Table 125: types of contacts recorded by Bereavement Support services, 2008-2014

	Number of services responding	Phone - under 10 minutes	Phone - over 10 minutes	Unfacilitated group	Facilitated group	Individual support	Individual counselling	Complex intervention	Other	Total
2008/ 09	123	25,802	25,590	3,769	23,643	32,096	28,176	988	7,119	147,183
2009/ 10	124	30,216	27,119	5,439	19,039	39,235	39,116	313	13,115	173,592
2010/ 11	125	36,460	24,833	4,931	18,288	38,078	37,737	532	13,177	174,036
2011/ 12	122	35,897	21,851	2,126	16,935	33,706	33,570	1,279	14,528	159,892
2012/ 13	120	37,579	27,344	2,994	19,453	35,966	37,423	874	18,951	180,584
2013/14	107	36,800	24,694	4,049	14,477	40,335	33,695	172	14,682	168,904

Table 126: length of support recorded by Bereavement Support services, 2008-2014

	1 session	Under 3 months	3-6 months	6-12 months	1 yr+	Total
2008/09	3,212	3,938	2,174	1,501	1,069	11,894
2009/10	4,496	4,750	3,554	3,576	1,964	18,340
2010/11	6,521	5,387	3,733	3,423	2,839	21,903
2011/12	3,497	5,714	4,348	4,158	2,750	20,467
2012/13	2,570	5,858	4,568	2,655	4,865	20,516
2013/14	2,314	6,404	4,789	3,170	1,590	18,267

Table 127: diagnosis of deceased relative or friend reported by Bereavement Support clients, 2008-2014

	Cancer	Other	Not known	Total
2008/09	13,488	2,716	6,878	23,082
2009/10	24,451	4,006	9,211	37,668
2010/11	24,050	3,976	6,785	34,811
2011/12	21,753	3,655	7,484	32,892
2012/13	22,427	3,970	7,300	33,697
2013/14	17,661	3,258	7,997	28,916