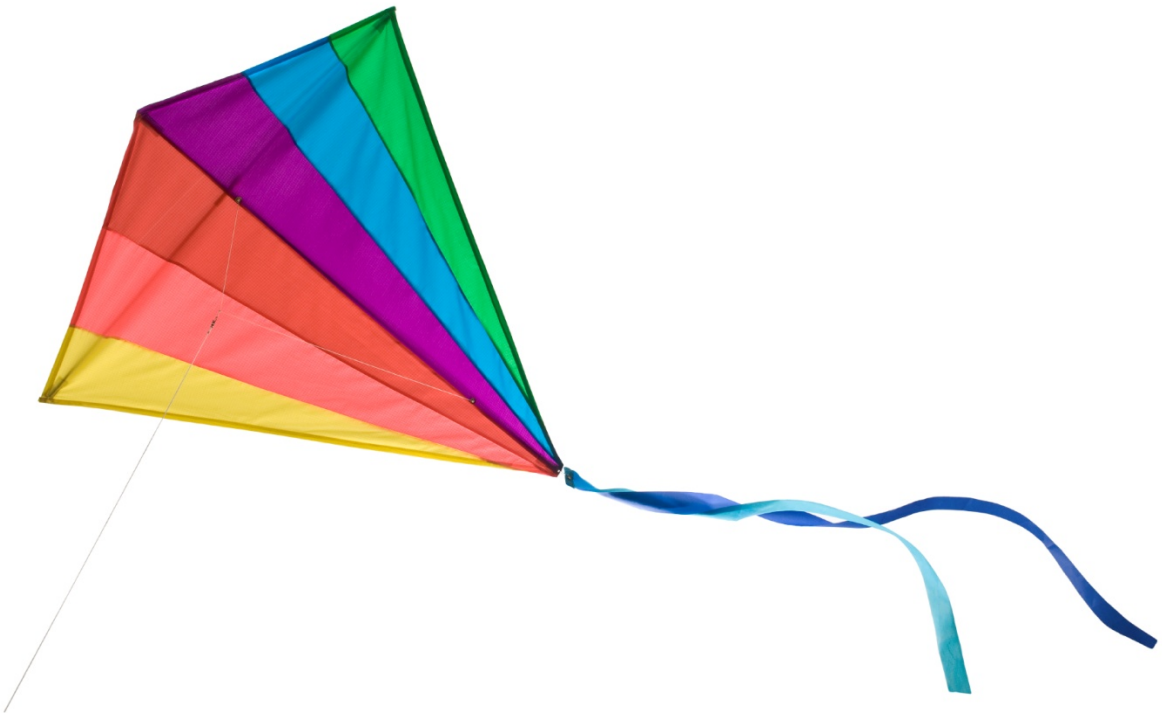
THE NATIONAL COUNCIL FOR PALLIATIVE CARE

Public Health England

hospice UK



National Survey of Patient Activity Data for Specialist Palliative Care Services

MDS Inpatients Report for the year 2013-2014

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.

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**

Inpatients MDS report 2013/14

Contents

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.

All tables referenced are available in the accompanying annex document.

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.

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

	Hospice		Hospitals*		
Year	**Managed by NHS**	**Managed by Independent**	**Managed by NHS**	**Managed by Independent**	**Total services responding**
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.

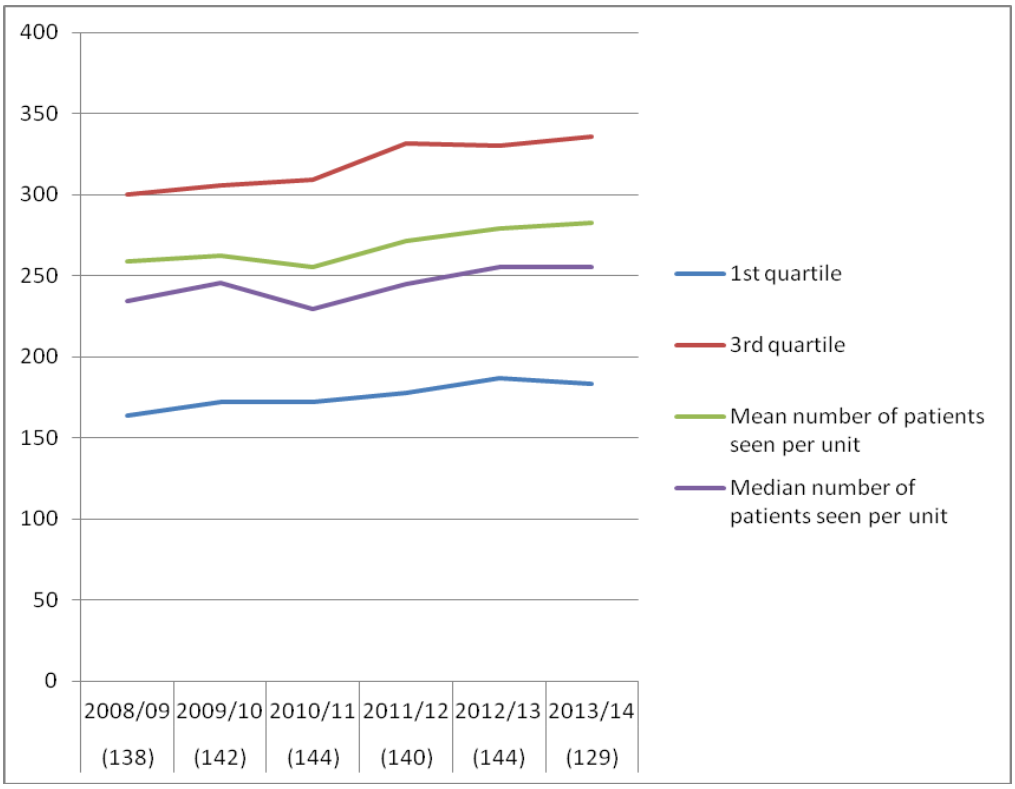
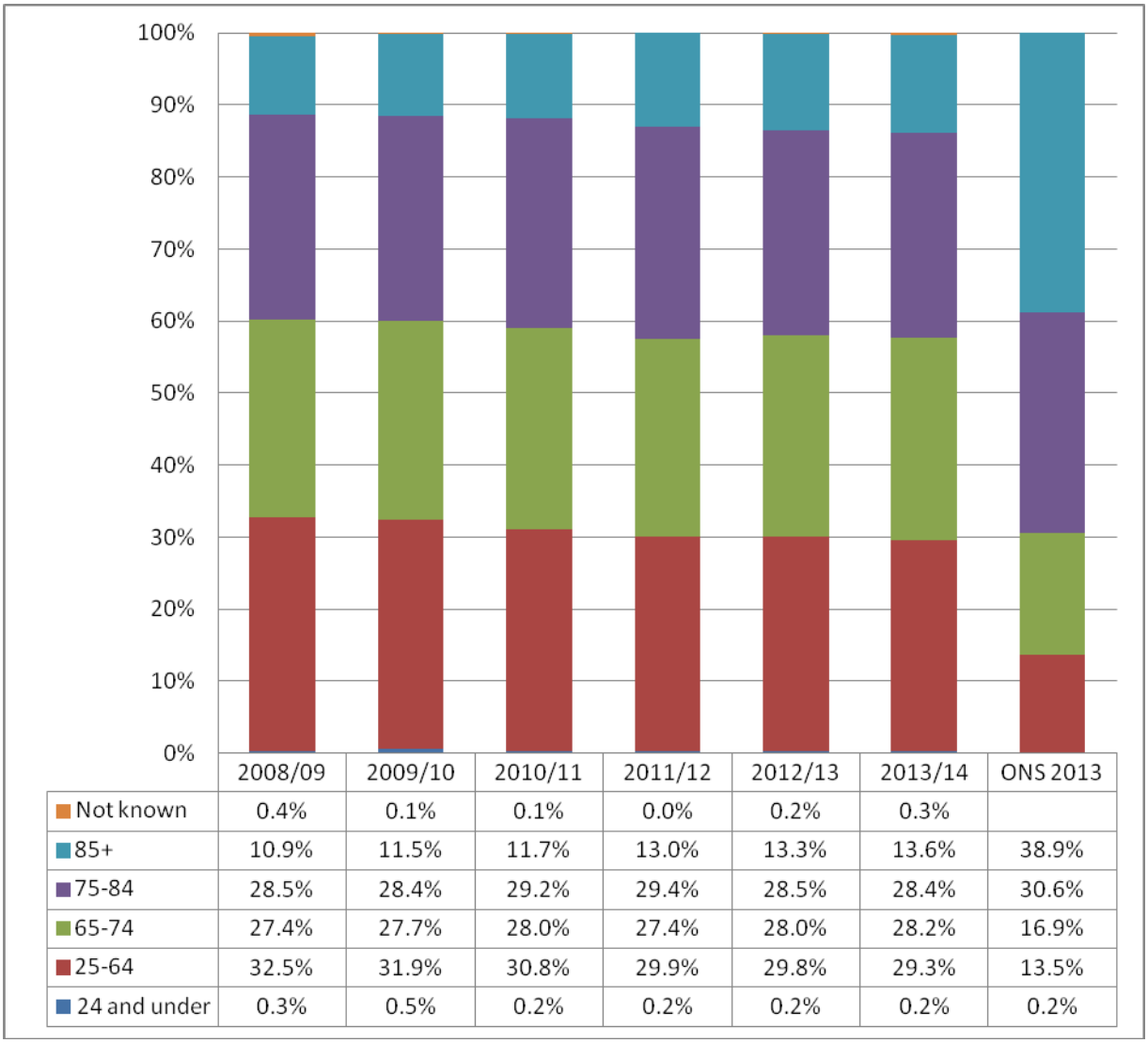


Figure 2.1: changes in the range of size of Inpatient units over time (Table 13)

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.



	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	ONS 2013
Not known	0.4%	0.1%	0.1%	0.0%	0.2%	0.3%	
85+	10.9%	11.5%	11.7%	13.0%	13.3%	13.6%	38.9%
75-84	28.5%	28.4%	29.2%	29.4%	28.5%	28.4%	30.6%
65-74	27.4%	27.7%	28.0%	27.4%	28.0%	28.2%	16.9%
25-64	32.5%	31.9%	30.8%	29.9%	29.8%	29.3%	13.5%
24 and under	0.3%	0.5%	0.2%	0.2%	0.2%	0.2%	0.2%

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

Figure 2.2: 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.

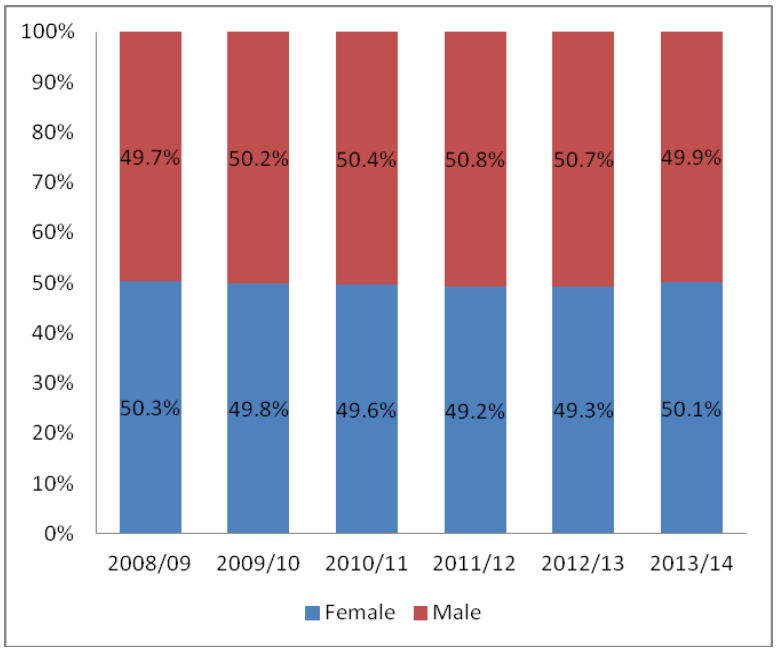


Figure 2.3: proportion of men and women accessing Inpatient care, 2008-2014 (Table 15)

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%.

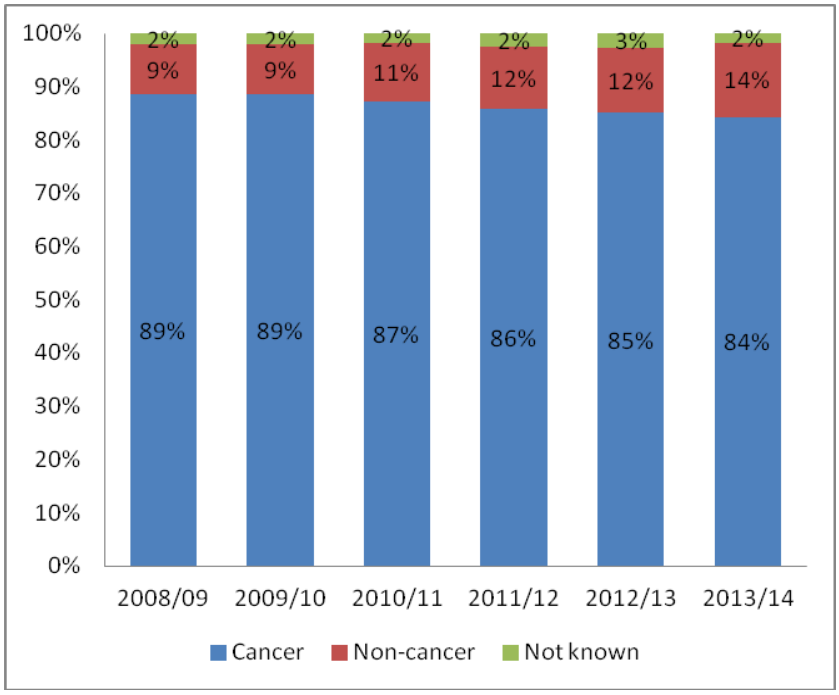


Figure 2.4: proportion of people with different categories of primary diagnosis accessing Inpatient care, 2008-2014 (Table 16)

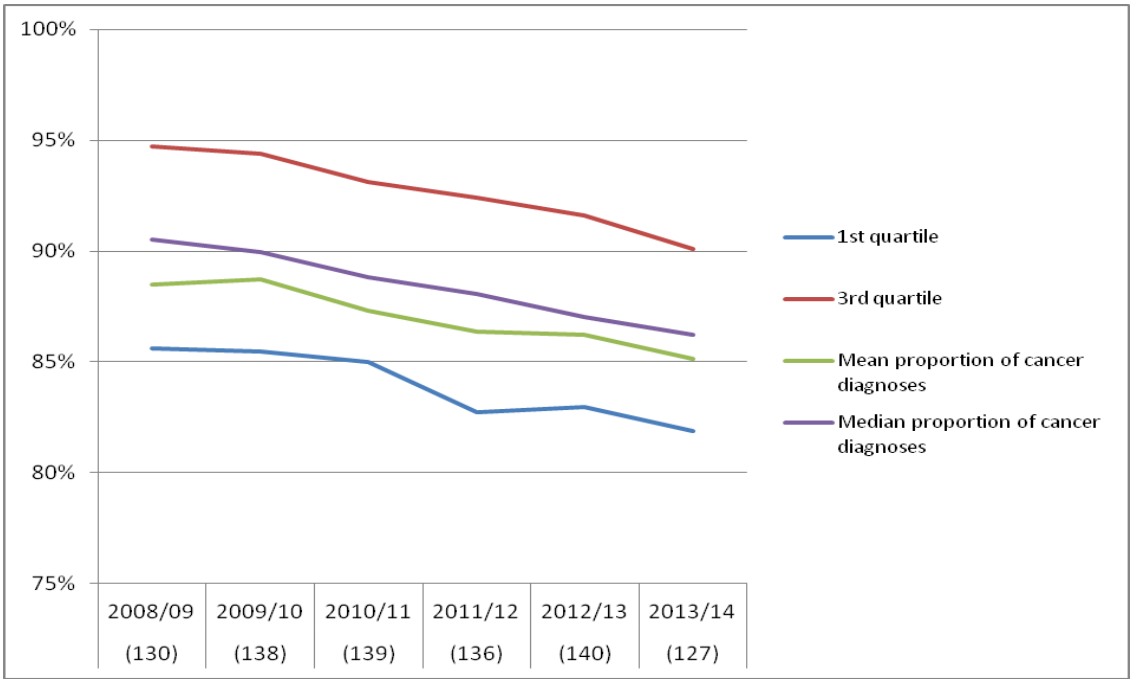


Figure 2.5: range in proportion of people with cancer diagnoses accessing Inpatient care, 2008-2014 (Table 17)

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.

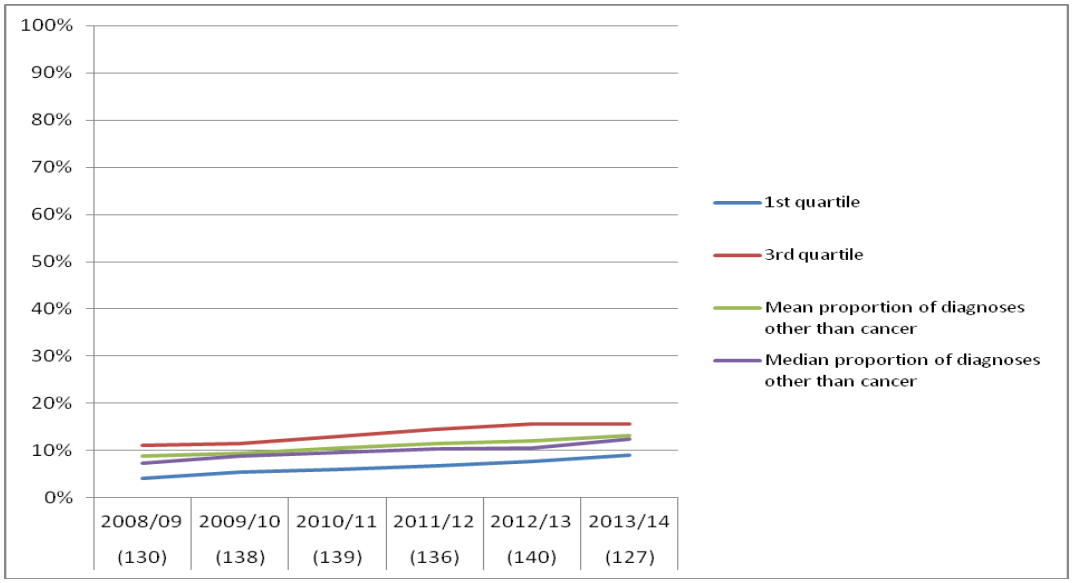


Figure 2.6: range in proportion of people with diagnoses other than cancer accessing Inpatient care, 2008-2014 (Table 18)

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.

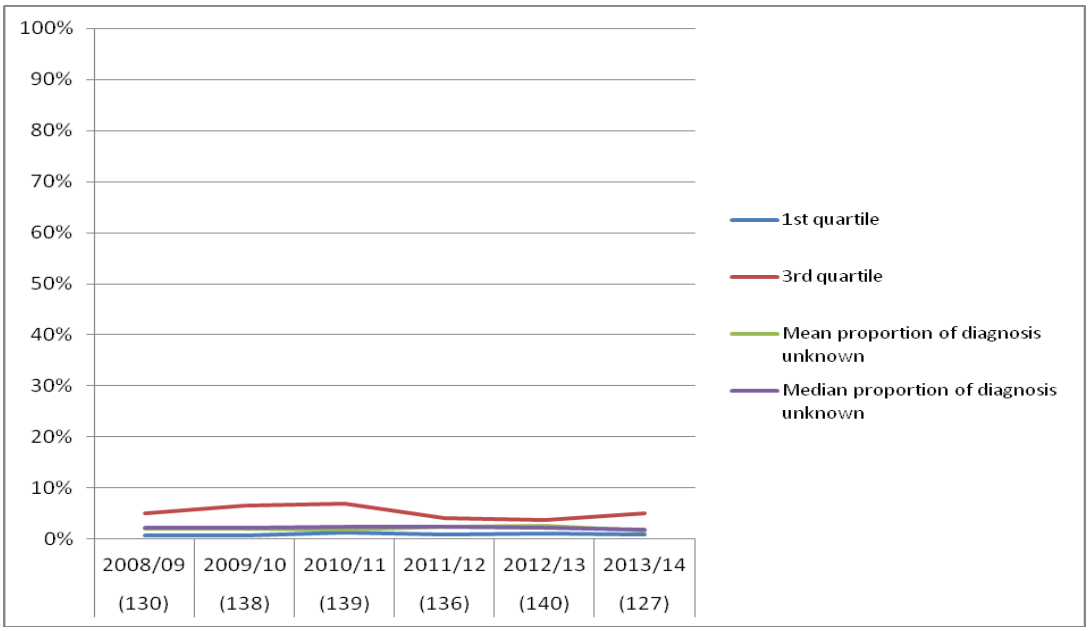


Figure 2.7: range in proportion of people with diagnoses unknown accessing Inpatient care, 2008-2014 (Table 19)

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.

<u>Palliative MDT for COPD and Heart Failure Patients</u>

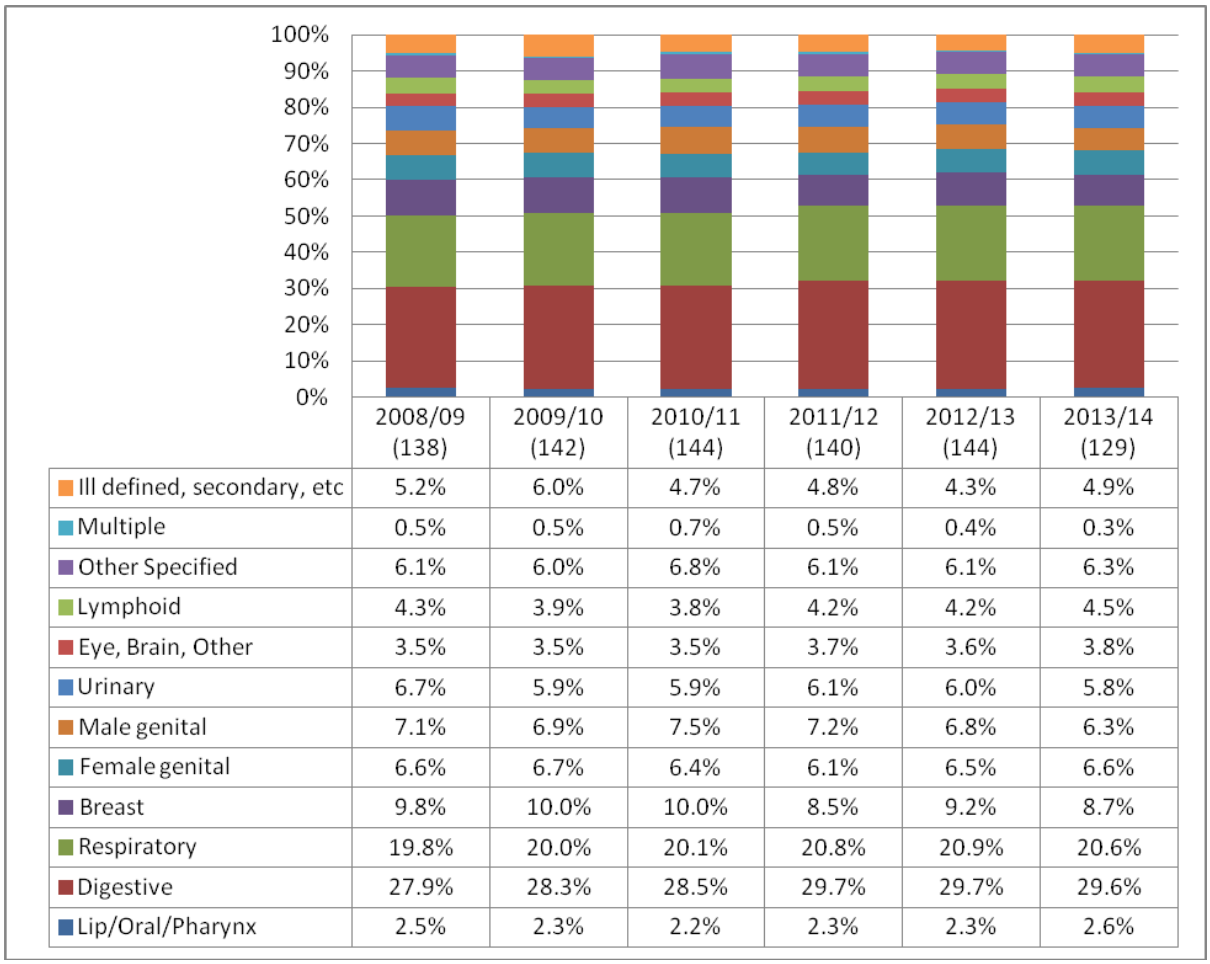
The COPD/Heart failure Palliative Care MDT meets once a month with good representation from all invited teams. The community matrons are now regular members of this MDT. Members of the MDT are welcome to discuss any patient with palliative care needs with a diagnosis of COPD or heart failure. This may 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.

<u>MND MDT</u>

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

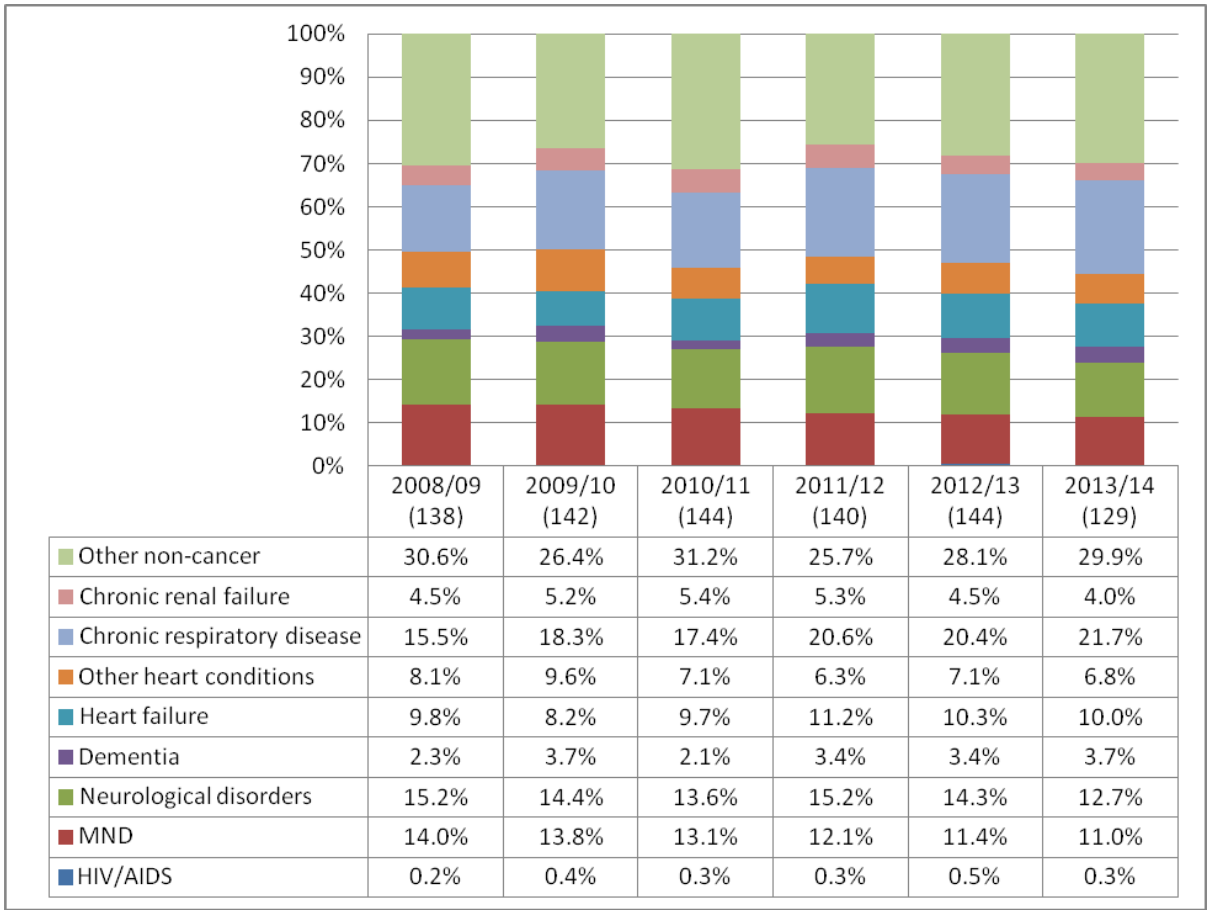


	2008/09 (138)	2009/10 (142)	2010/11 (144)	2011/12 (140)	2012/13 (144)	2013/14 (129)
Ill defined, secondary, etc	5.2%	6.0%	4.7%	4.8%	4.3%	4.9%
Multiple	0.5%	0.5%	0.7%	0.5%	0.4%	0.3%
Other Specified	6.1%	6.0%	6.8%	6.1%	6.1%	6.3%
Lymphoid	4.3%	3.9%	3.8%	4.2%	4.2%	4.5%
Eye, Brain, Other	3.5%	3.5%	3.5%	3.7%	3.6%	3.8%
Urinary	6.7%	5.9%	5.9%	6.1%	6.0%	5.8%
Male genital	7.1%	6.9%	7.5%	7.2%	6.8%	6.3%
Female genital	6.6%	6.7%	6.4%	6.1%	6.5%	6.6%
Breast	9.8%	10.0%	10.0%	8.5%	9.2%	8.7%
Respiratory	19.8%	20.0%	20.1%	20.8%	20.9%	20.6%
Digestive	27.9%	28.3%	28.5%	29.7%	29.7%	29.6%
Lip/Oral/Pharynx	2.5%	2.3%	2.2%	2.3%	2.3%	2.6%

Figure 2.8: 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



	2008/09 (138)	2009/10 (142)	2010/11 (144)	2011/12 (140)	2012/13 (144)	2013/14 (129)
Other non-cancer	30.6%	26.4%	31.2%	25.7%	28.1%	29.9%
Chronic renal failure	4.5%	5.2%	5.4%	5.3%	4.5%	4.0%
Chronic respiratory disease	15.5%	18.3%	17.4%	20.6%	20.4%	21.7%
Other heart conditions	8.1%	9.6%	7.1%	6.3%	7.1%	6.8%
Heart failure	9.8%	8.2%	9.7%	11.2%	10.3%	10.0%
Dementia	2.3%	3.7%	2.1%	3.4%	3.4%	3.7%
Neurological disorders	15.2%	14.4%	13.6%	15.2%	14.3%	12.7%
MND	14.0%	13.8%	13.1%	12.1%	11.4%	11.0%
HIV/AIDS	0.2%	0.4%	0.3%	0.3%	0.5%	0.3%

Figure 2.9: 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.

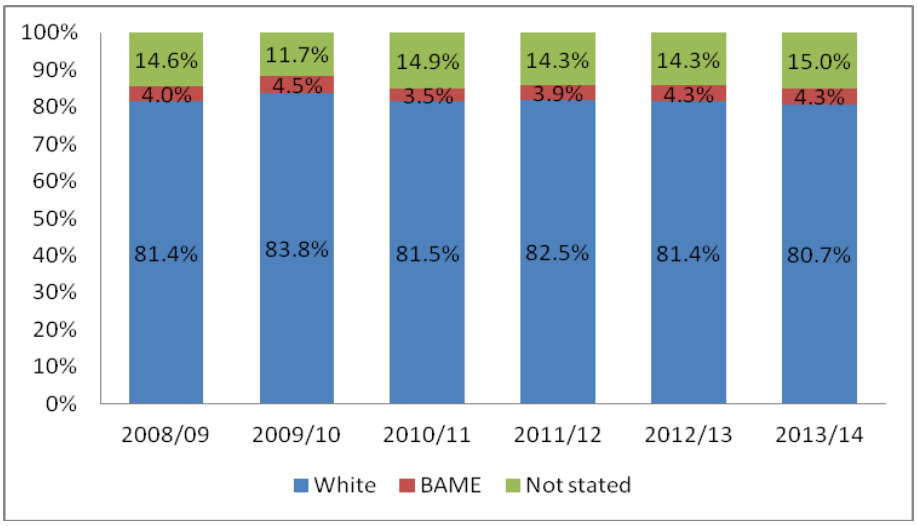
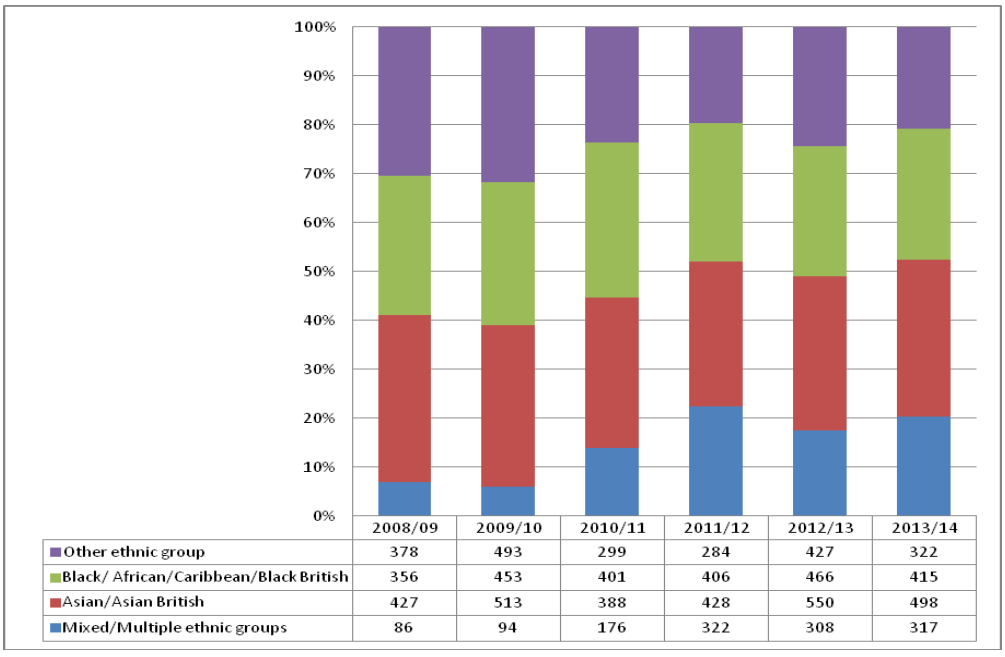


Figure 2.10: proportions of people accessing Inpatient care reported as white, BAME and not recorded, 2008-2014 (Table 23)

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.

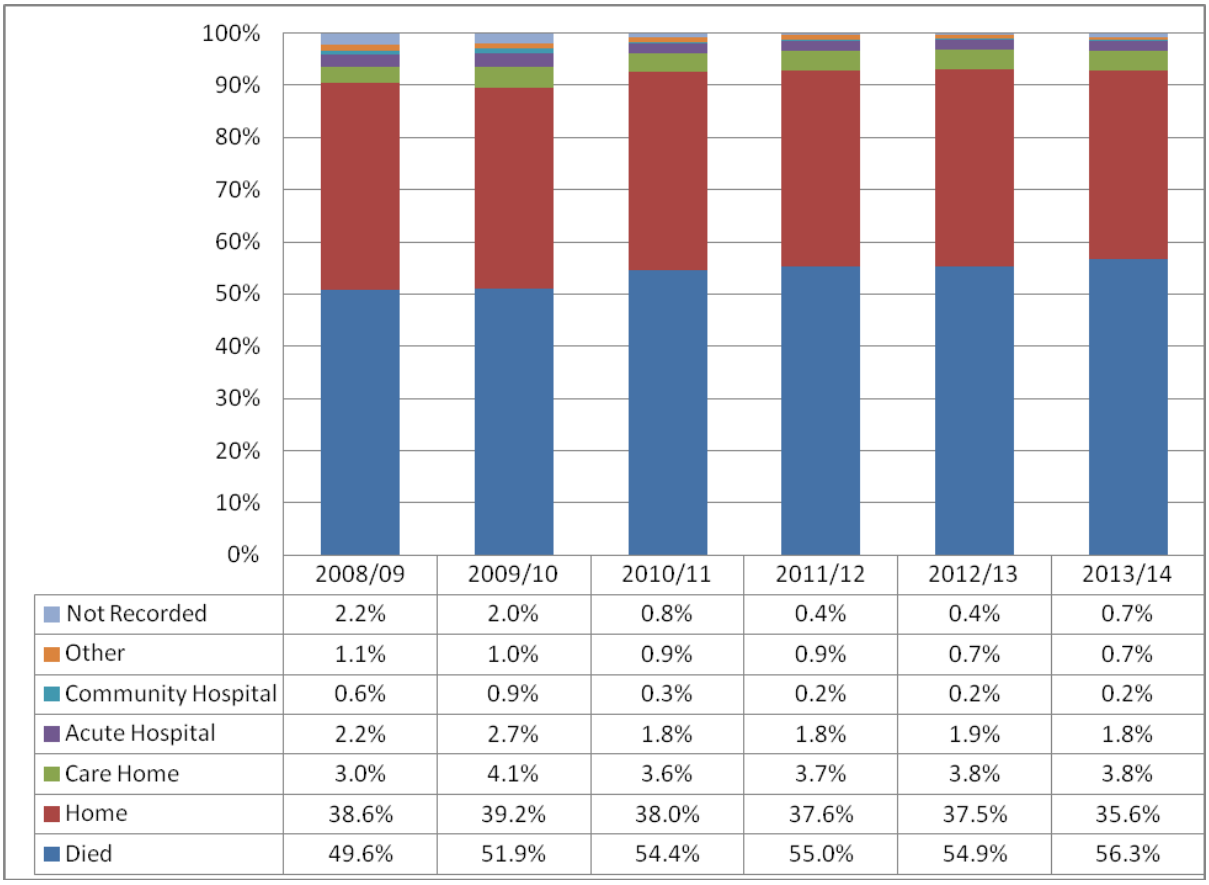


	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Other ethnic group	378	493	299	284	427	322
Black/ African/Caribbean/Black British	356	453	401	406	466	415
Asian/Asian British	427	513	388	428	550	498
Mixed/Multiple ethnic groups	86	94	176	322	308	317

Figure 2.11: 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.



	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Not Recorded	2.2%	2.0%	0.8%	0.4%	0.4%	0.7%
Other	1.1%	1.0%	0.9%	0.9%	0.7%	0.7%
Community Hospital	0.6%	0.9%	0.3%	0.2%	0.2%	0.2%
Acute Hospital	2.2%	2.7%	1.8%	1.8%	1.9%	1.8%
Care Home	3.0%	4.1%	3.6%	3.7%	3.8%	3.8%
Home	38.6%	39.2%	38.0%	37.6%	37.5%	35.6%
Died	49.6%	51.9%	54.4%	55.0%	54.9%	56.3%

Figure 2.12: 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.

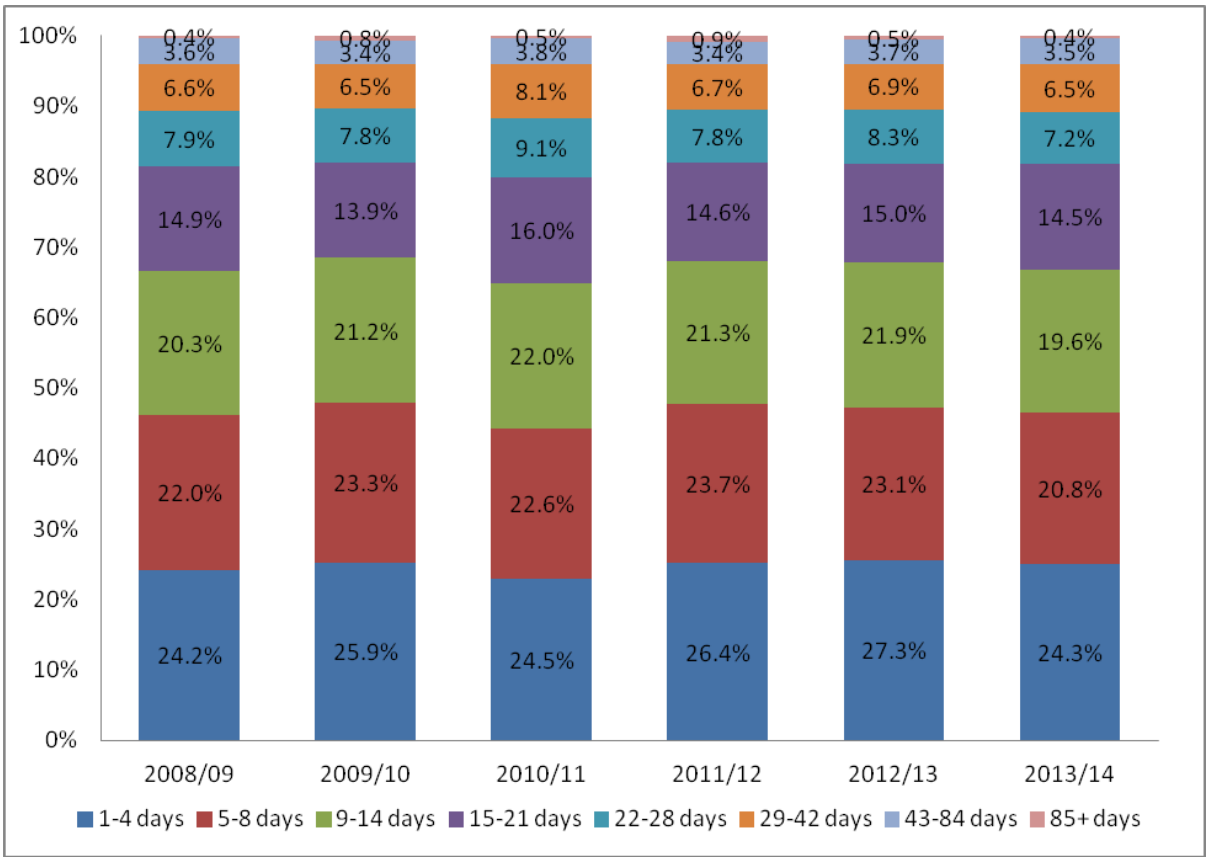


Figure 2.13: length of completed Inpatient stays, 2008-2014 (Table 26)

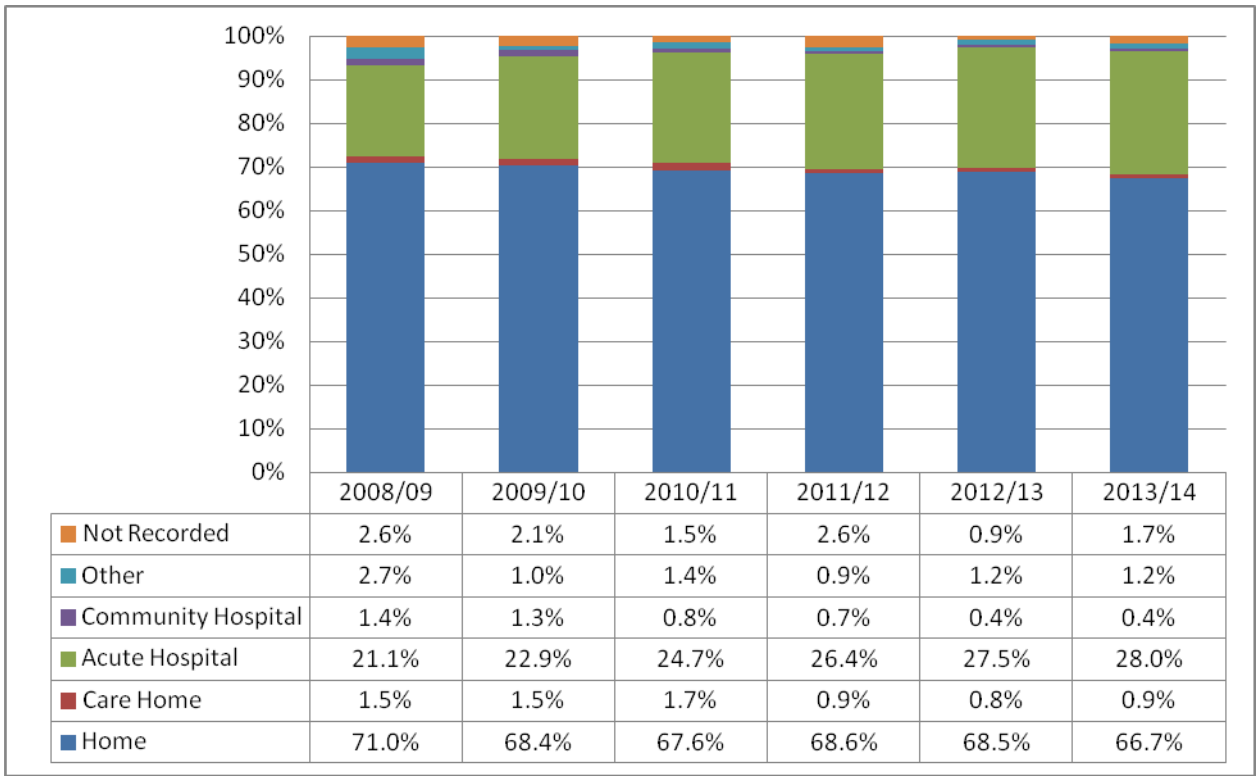
Mean length of stay across all units remains steady at around 13.7 days.

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.



	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Not Recorded	2.6%	2.1%	1.5%	2.6%	0.9%	1.7%
Other	2.7%	1.0%	1.4%	0.9%	1.2%	1.2%
Community Hospital	1.4%	1.3%	0.8%	0.7%	0.4%	0.4%
Acute Hospital	21.1%	22.9%	24.7%	26.4%	27.5%	28.0%
Care Home	1.5%	1.5%	1.7%	0.9%	0.8%	0.9%
Home	71.0%	68.4%	67.6%	68.6%	68.5%	66.7%

Figure 2.14: 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%.

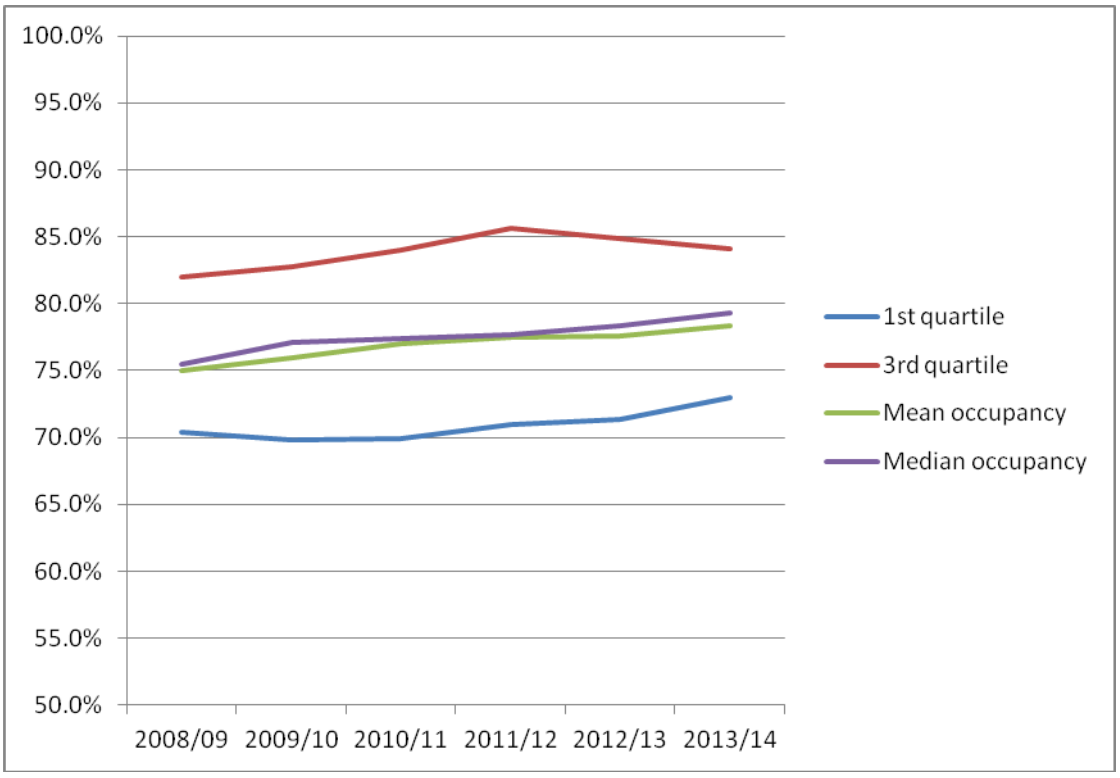


Figure 2.15: Inpatient occupancy levels, 2008-2014 (Table 33)

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%.

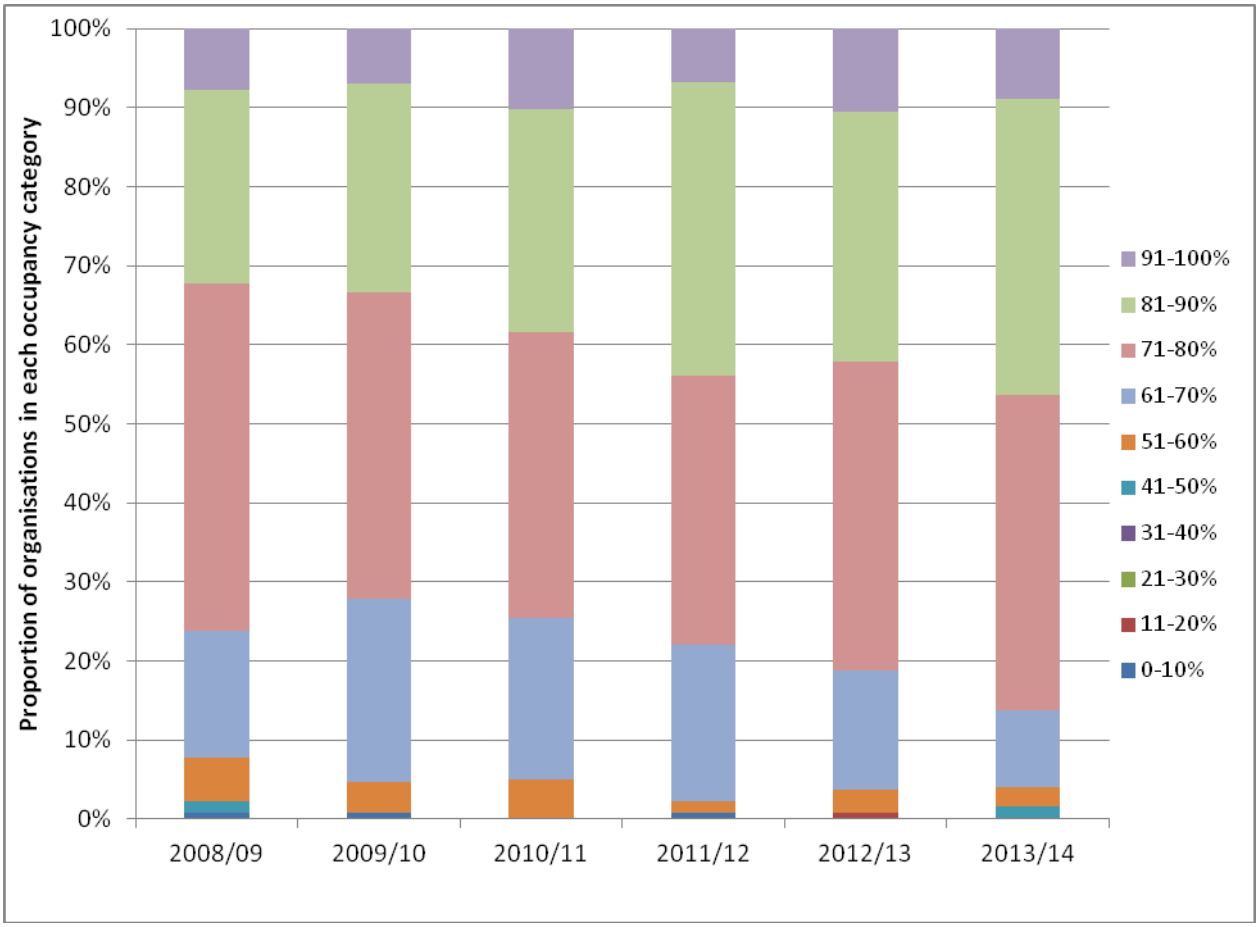


Figure 2.16: range in occupancy rate across all Inpatient units, 2008-2014 (Table 34)