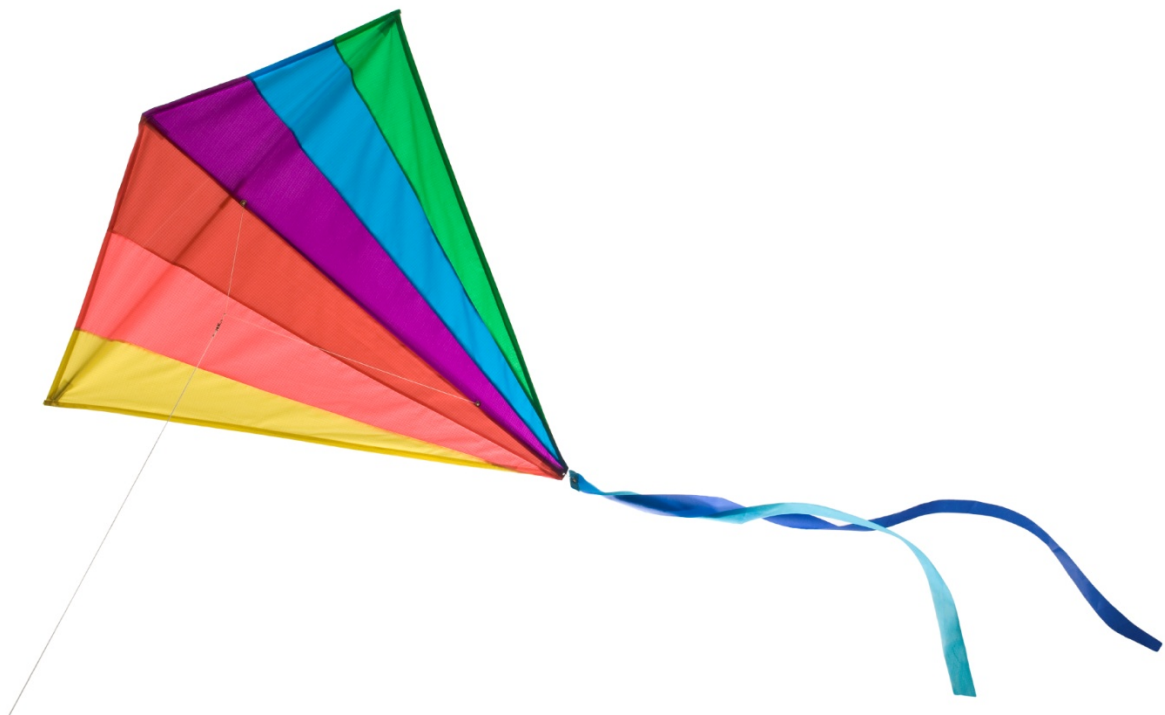


THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE



Public Health  
England

 hospice<sup>UK</sup>



**National Survey of Patient Activity Data  
for Specialist Palliative Care Services  
MDS Hospital Support 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](http://www.ncpc.org.uk)

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## About The National End of Life Care Intelligence Network

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

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



Public Health  
England

The NEoLCIN website is [www.endoflifecare-intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk)  
Public Health England's website is [www.gov.uk/phe](http://www.gov.uk/phe)

## About Hospice UK

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

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

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



## Hospital Support MDS report 2013/14

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### 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.*

*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

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

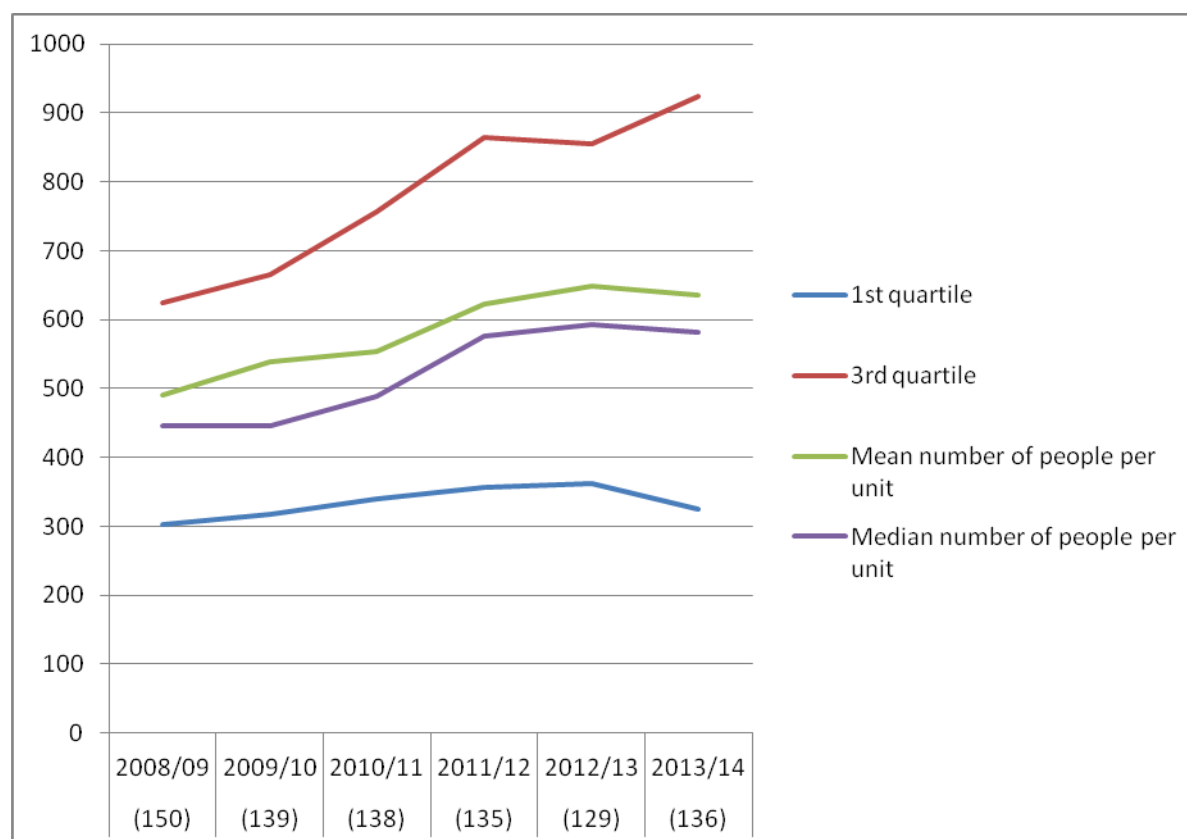
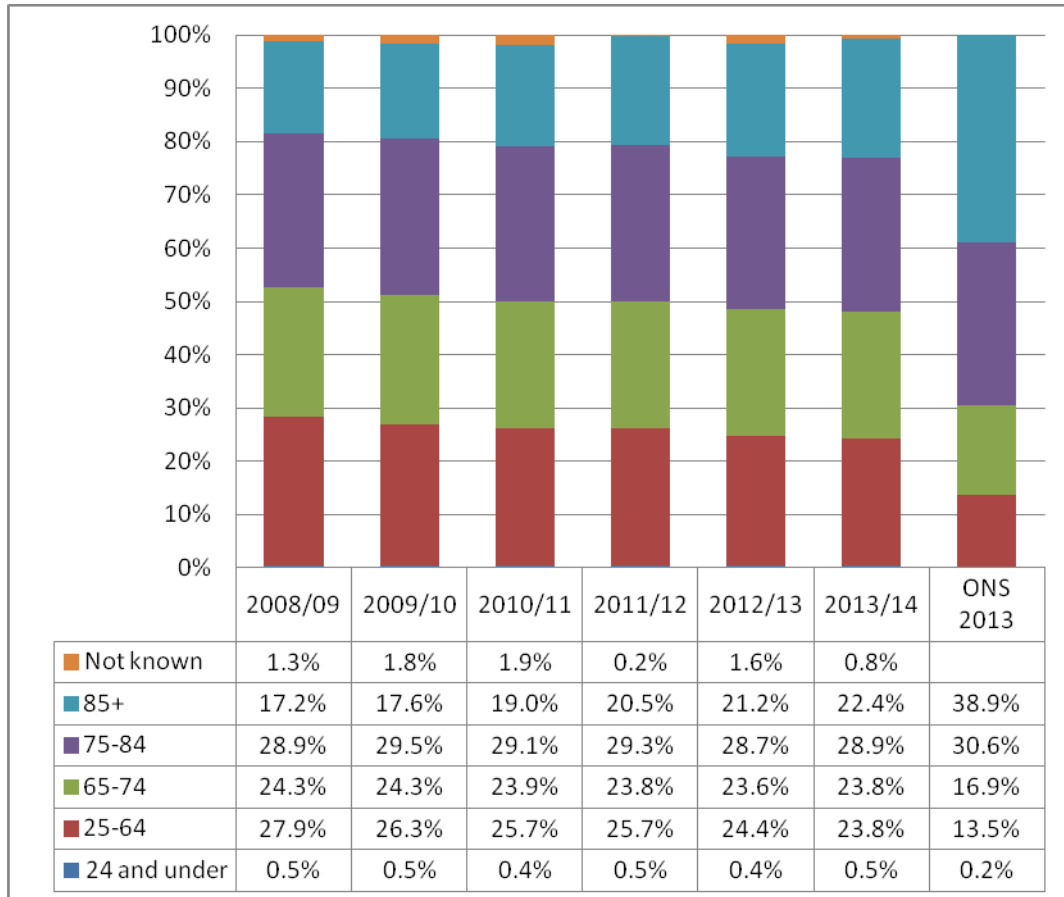


Figure 5.1: changes in the range of size of Hospital Support services over time (Table 67)

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 5.2: 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**

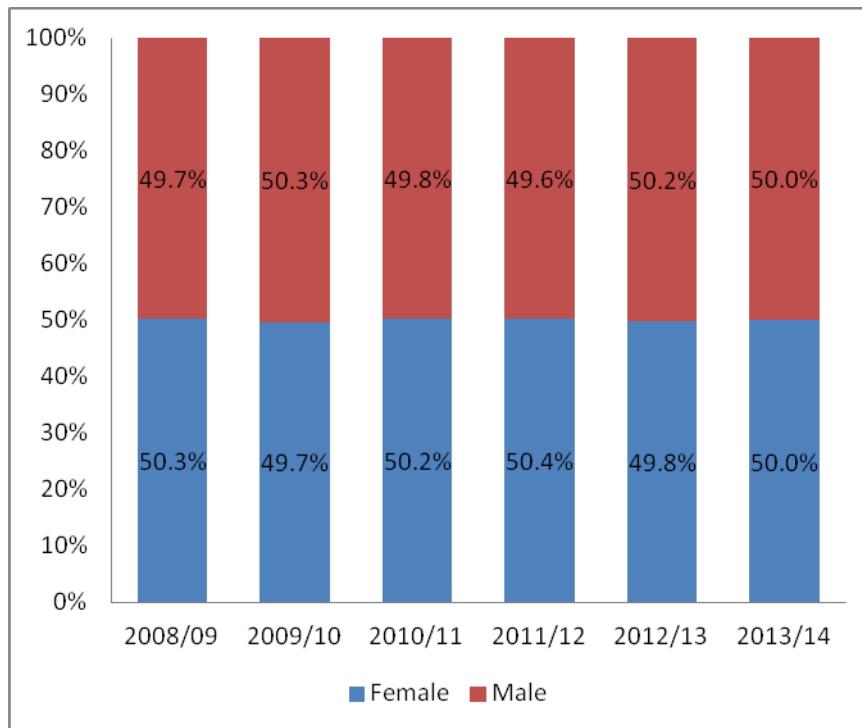


Figure 5.3: proportion of men and women accessing Hospital Support, 2008-2014 (Table 69)

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

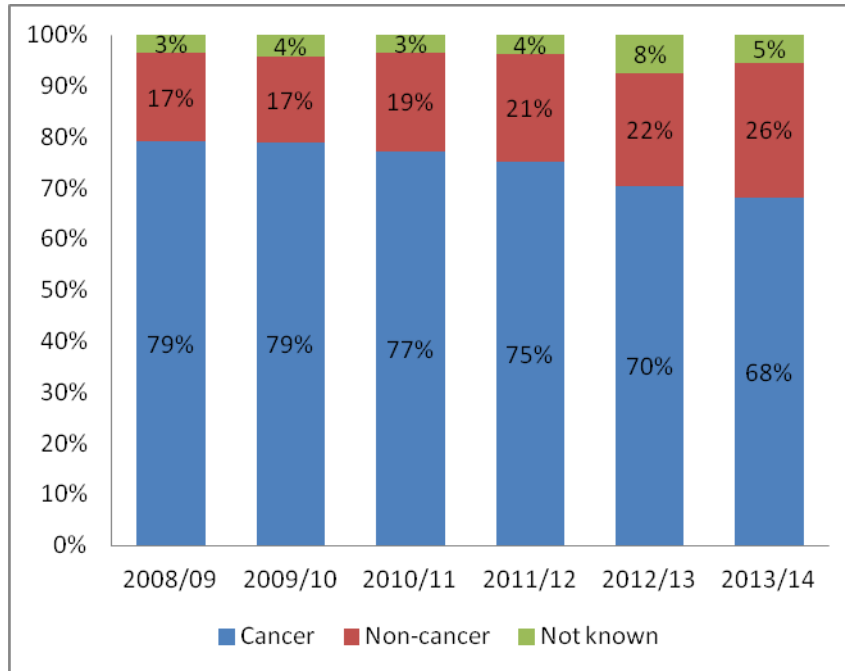


Figure 5.4: proportion of people with different categories of primary diagnosis accessing Hospital Support, 2008-2014 (Table 70)

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.

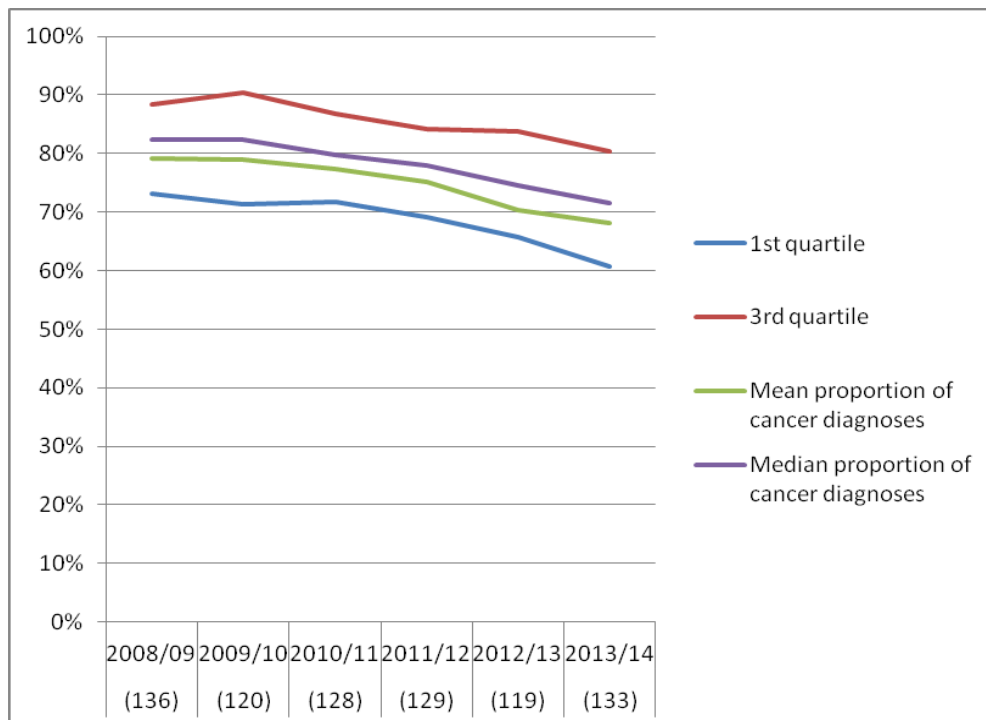


Figure 5.5: range in proportion of people with cancer diagnoses accessing Hospital Support, 2008-2014 (Table 71)



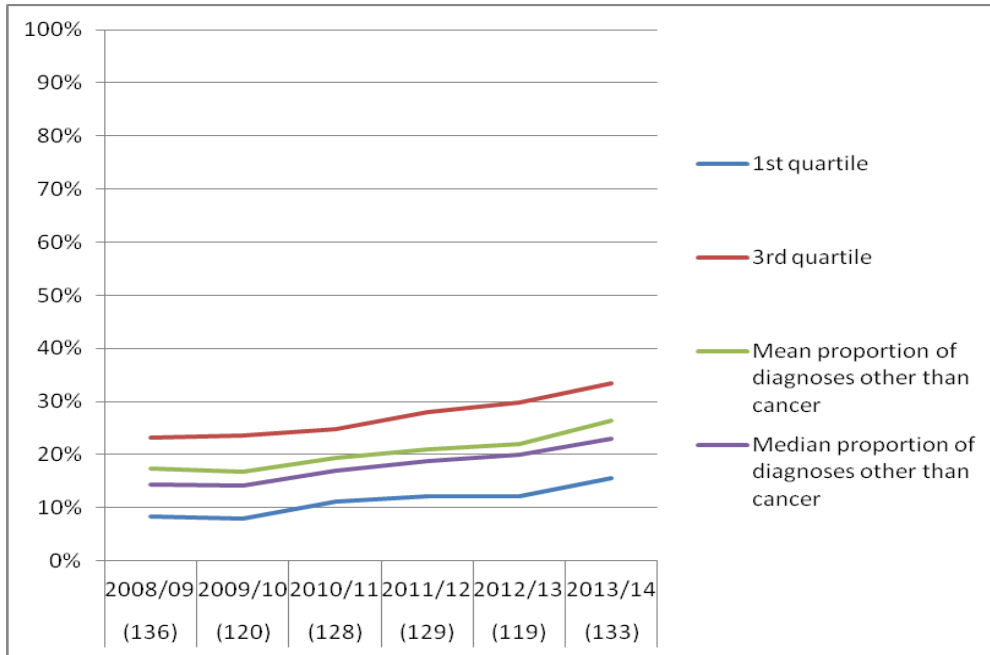


Figure 5.6: range in proportion of people with diagnoses other than cancer accessing Hospital Support, 2008-2014 (Table 72)

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

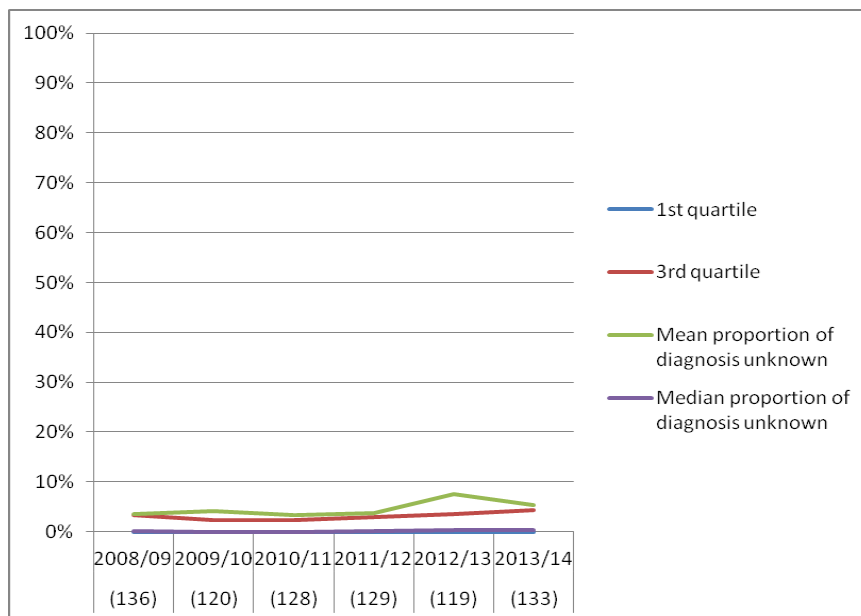


Figure 5.7: range in proportion of people with diagnosis unknown treated in Hospital Support settings, 2008-2014 (Table 73)

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

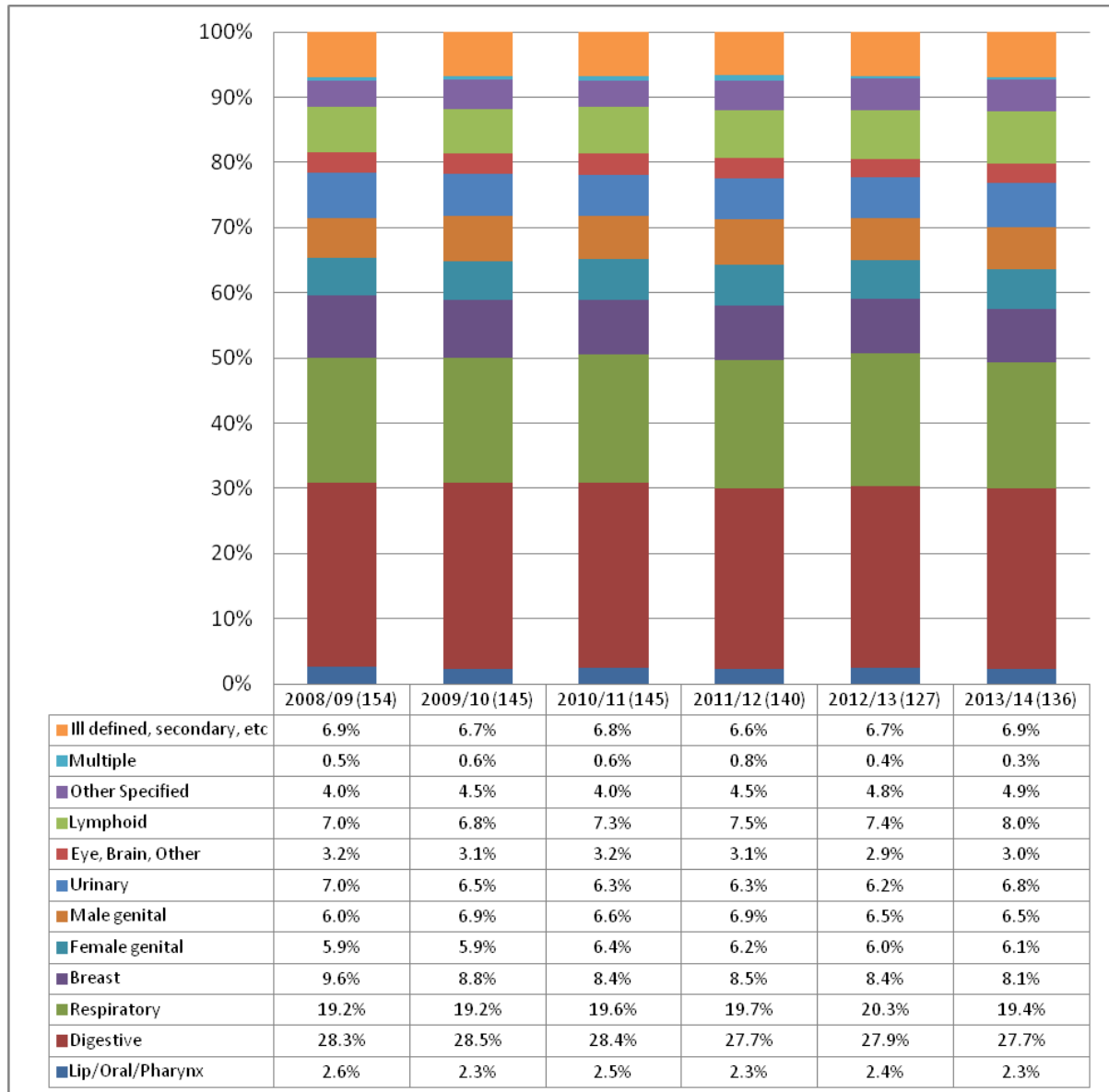


Figure 5.8: proportion of people with different cancer diagnoses accessing Hospital Support, 2008-2014 (Table74)

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

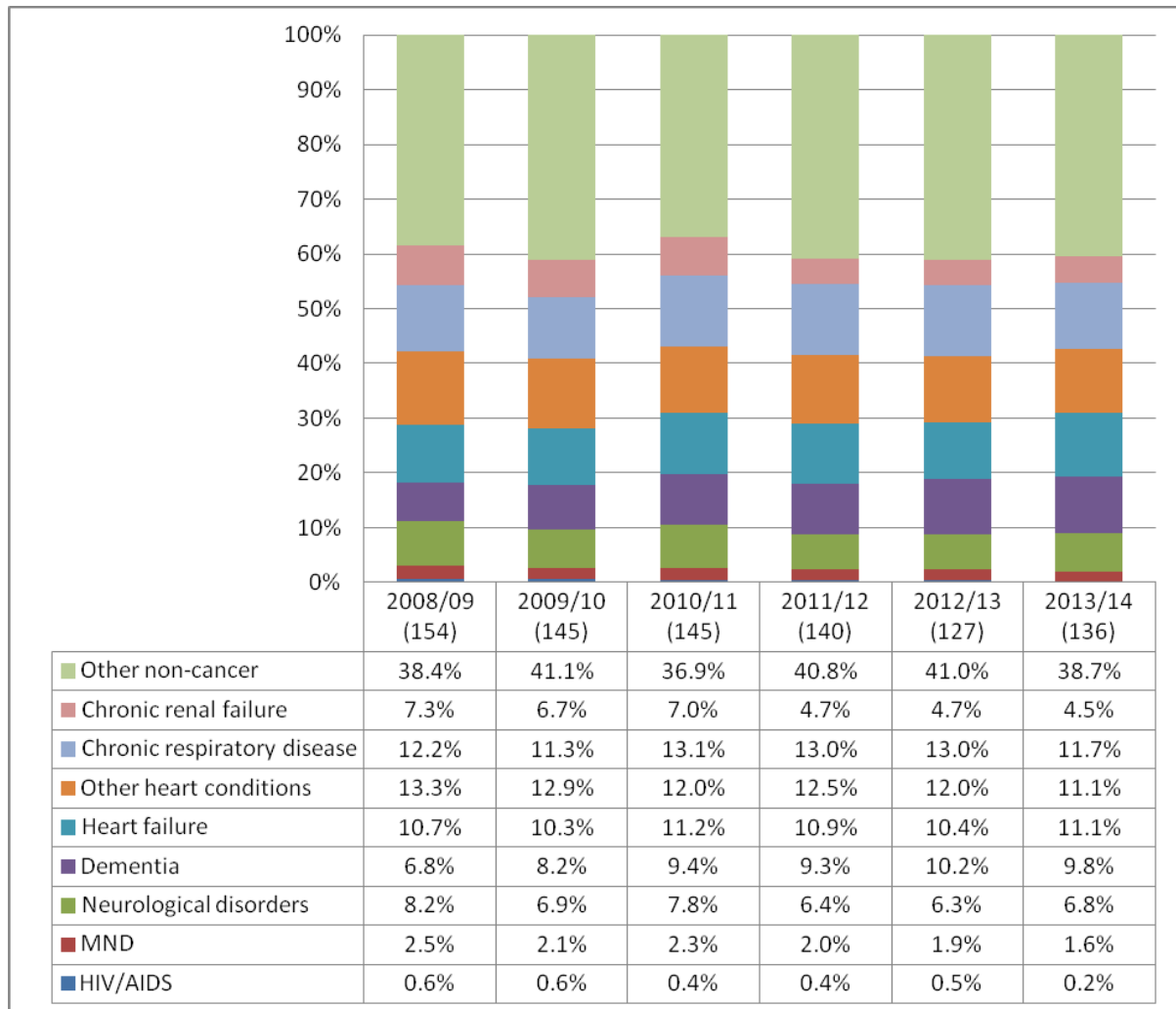


Figure 5.9: proportion of people with diagnoses other than cancer accessing Hospital Support, 2008-2014 (Table 75)

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

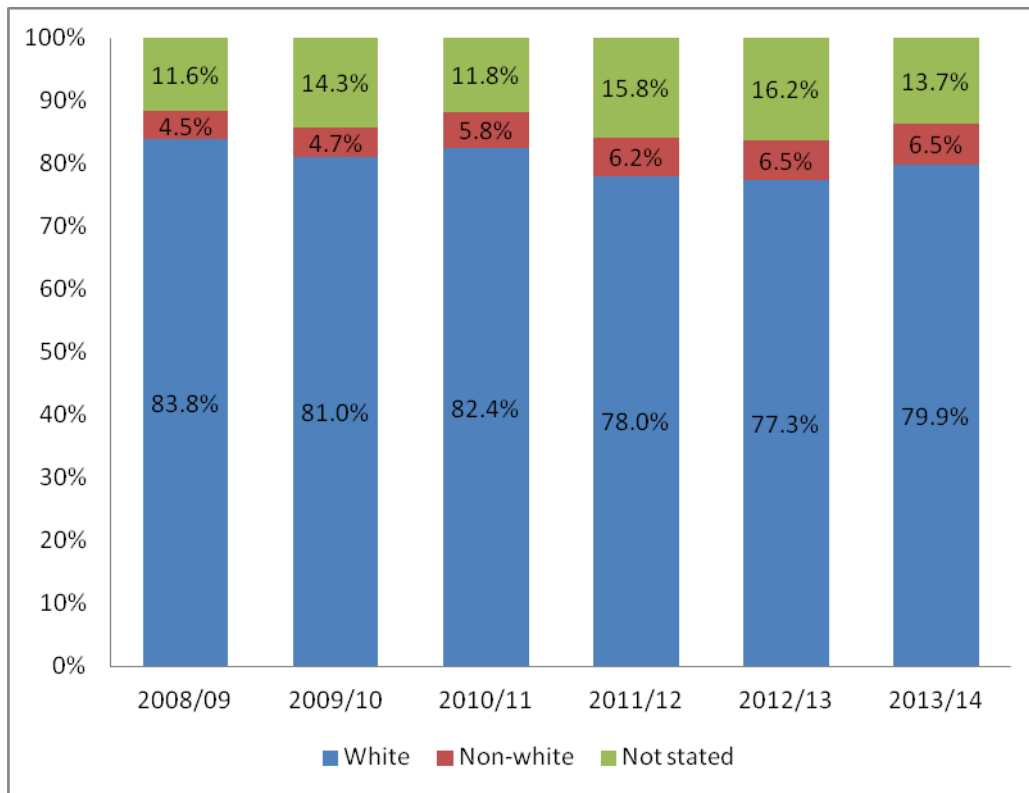


Figure 5.10: proportions of people accessing Hospital Support reported as white, BAME and not recorded, 2008-2014 (Table 77)

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.

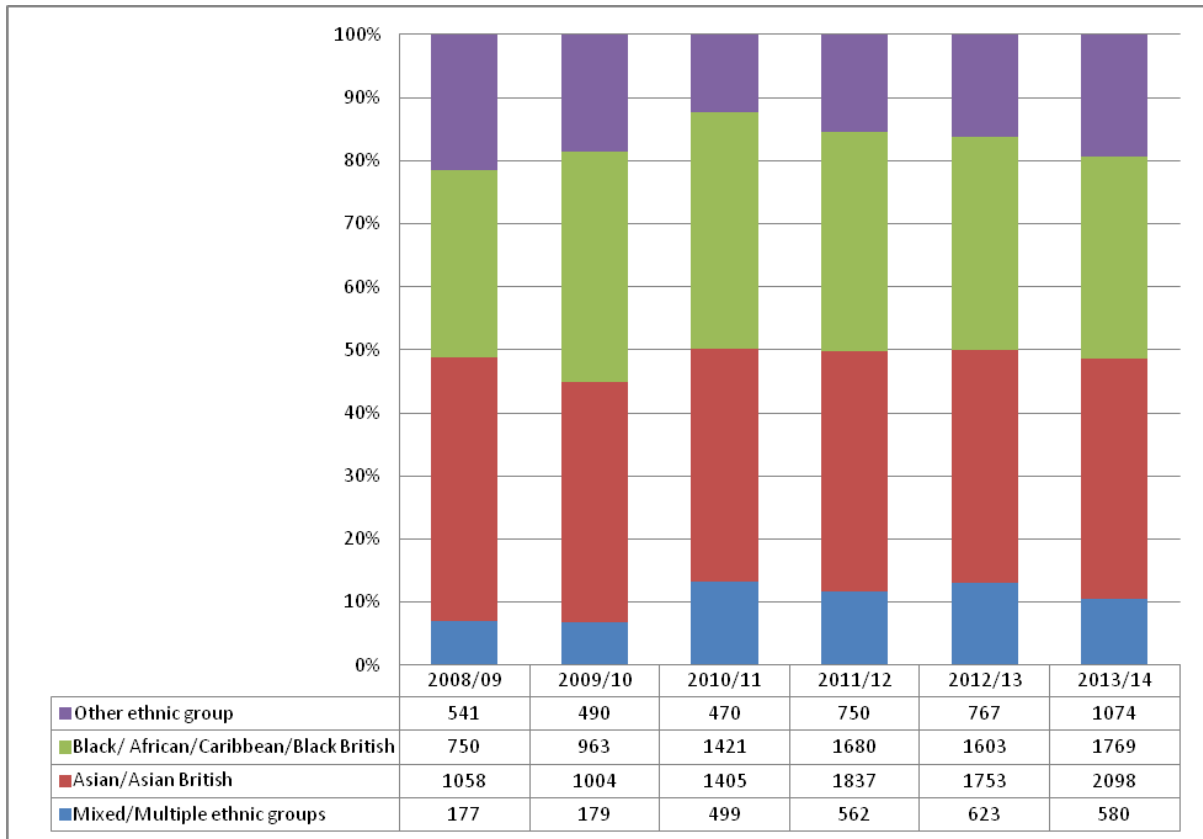


Figure 5.11: people accessing Hospital Support from grouped BAME categories, 2008-2014 (Table78)

### Outcome of period of care

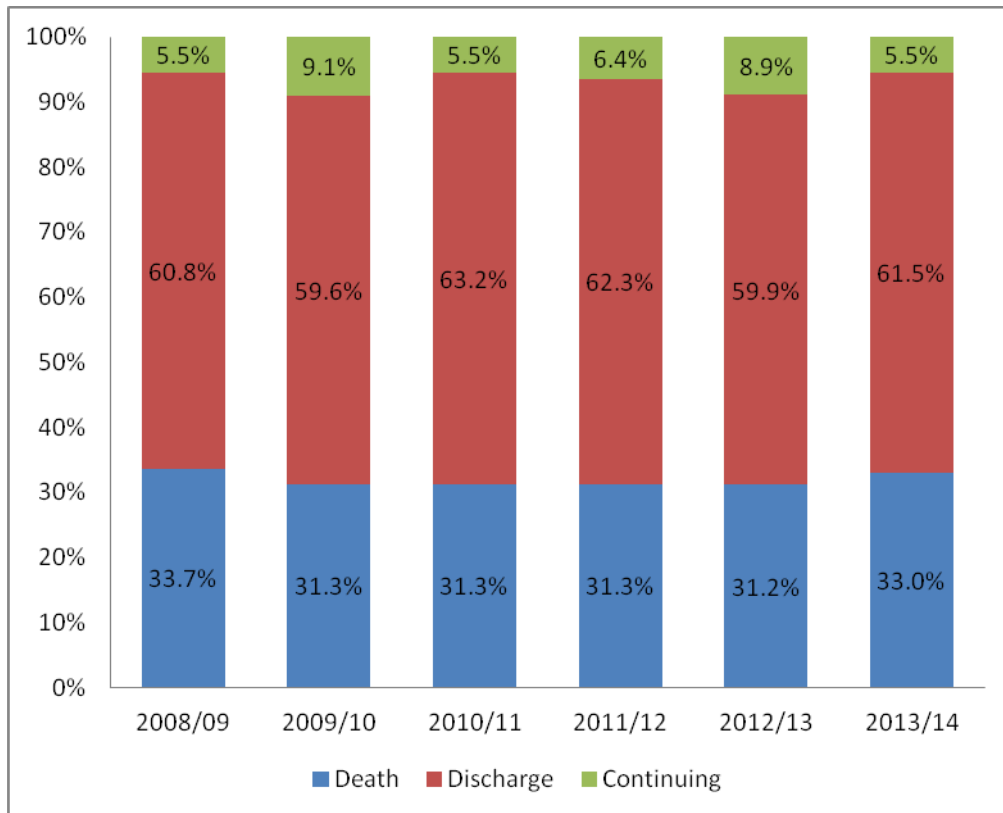


Figure 5.12: proportion of Hospital Support stays ending in death, discharge, or continuing across reporting years, 2008-2014 (Table79)

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

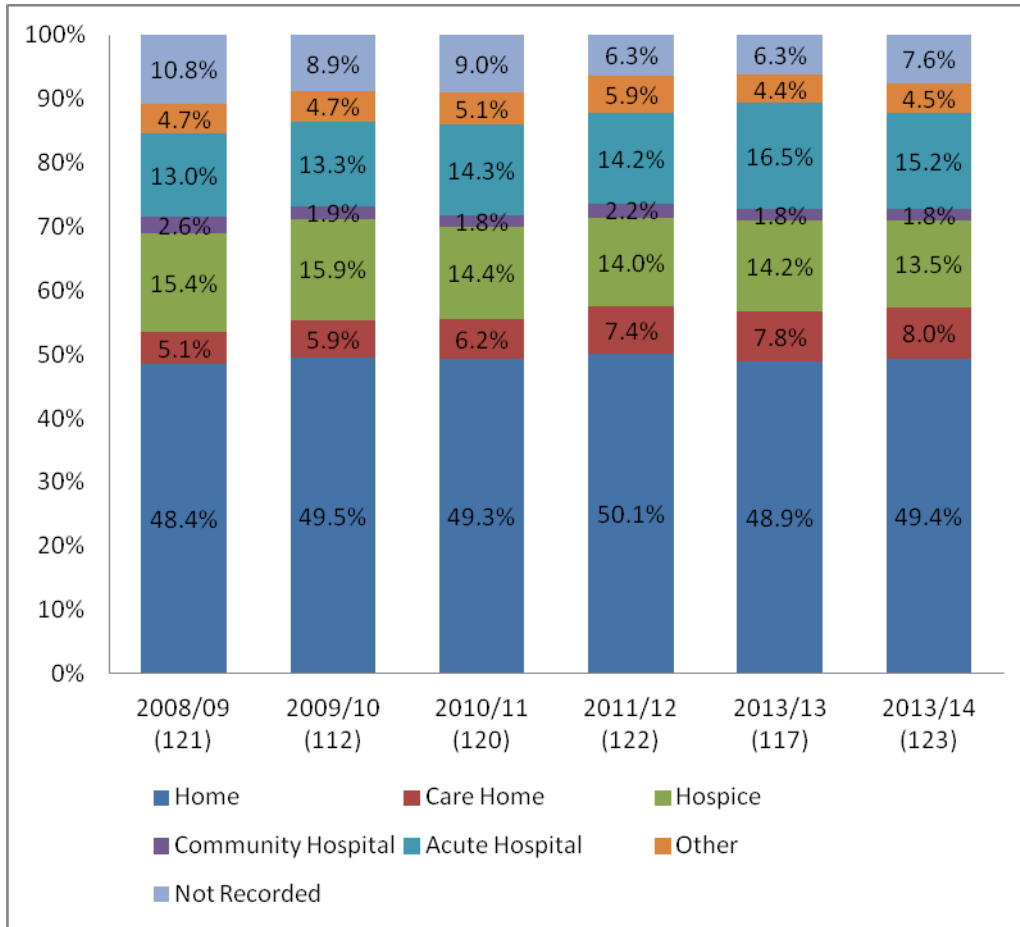


Figure 5.13: place of care after discharge for people leaving Hospital Support care, 2008-2014 (Table 801)

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

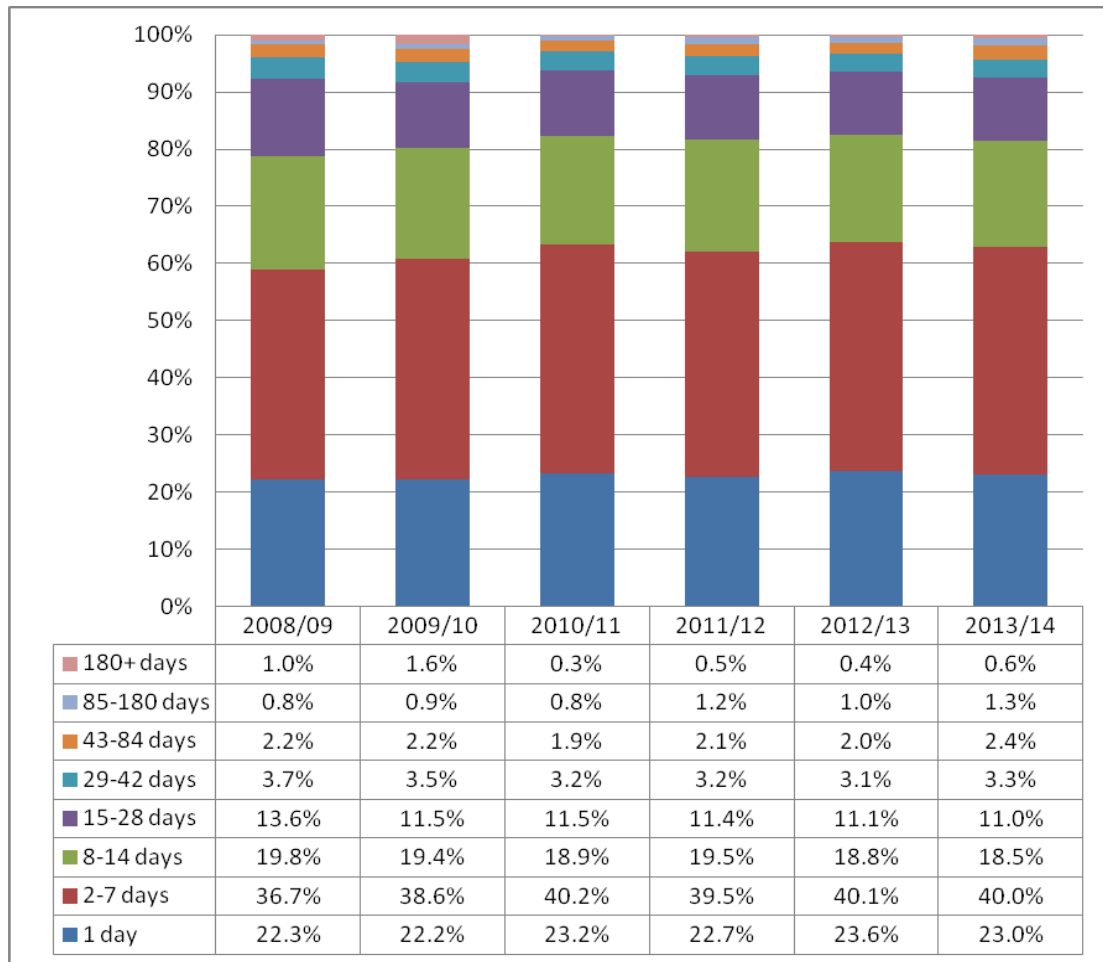


Figure 5.14: length of completed Hospital Support stays, 2008-2014 (Table 81)

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.