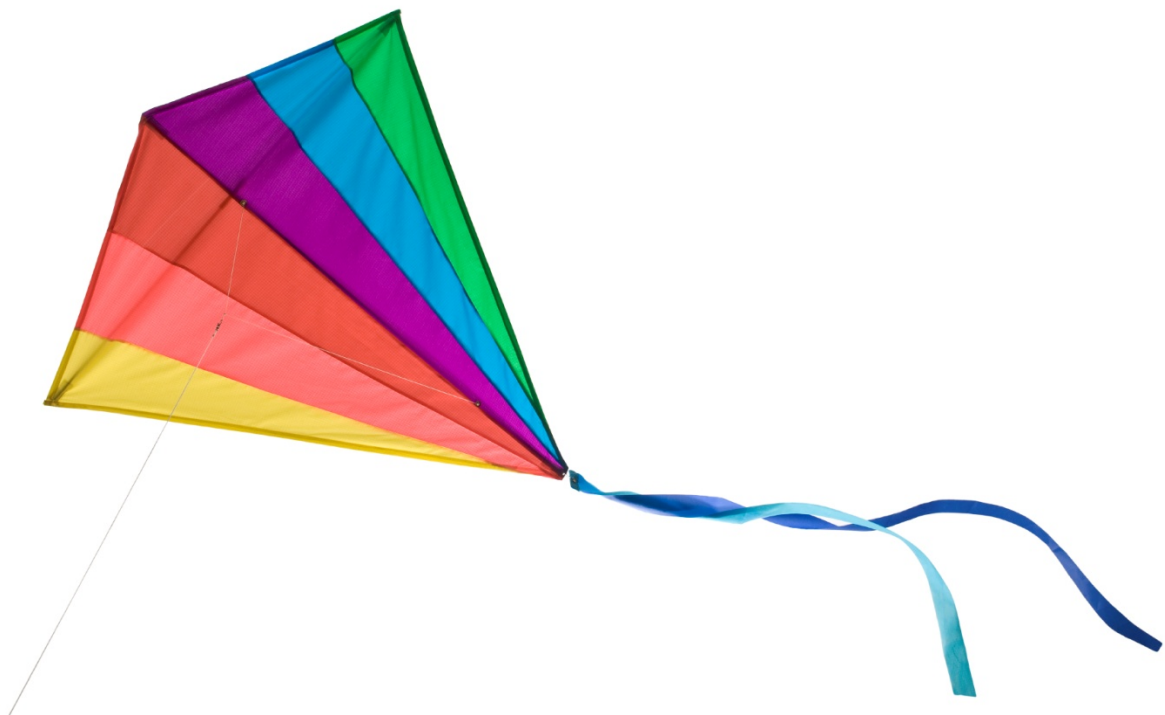


THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Public Health
England

 hospice^{UK}



**National Survey of Patient Activity Data
for Specialist Palliative Care Services
MDS Day Care 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

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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 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



Day Care MDS report 2013/14

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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.

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

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.

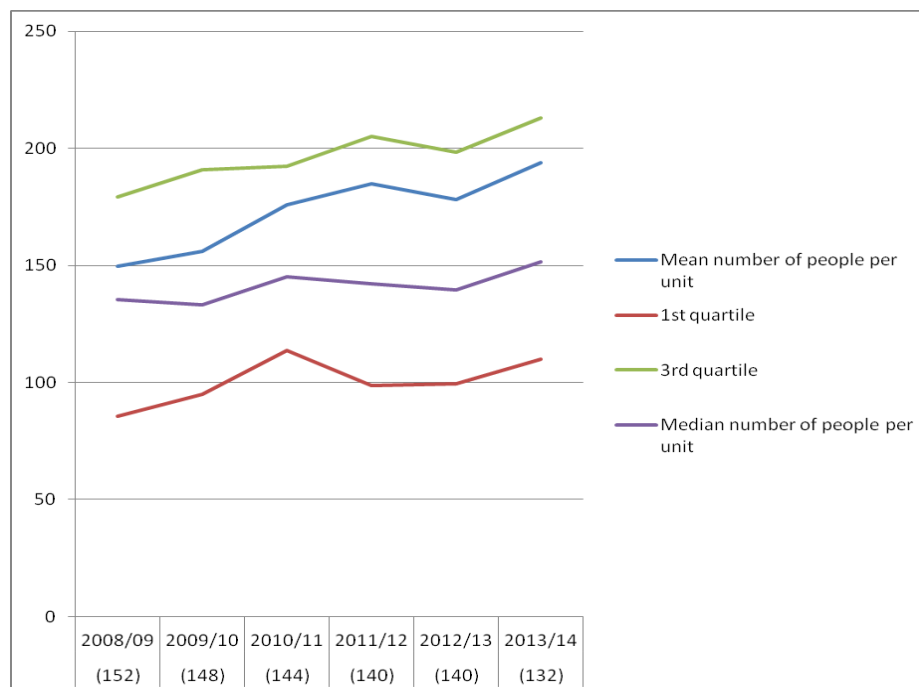
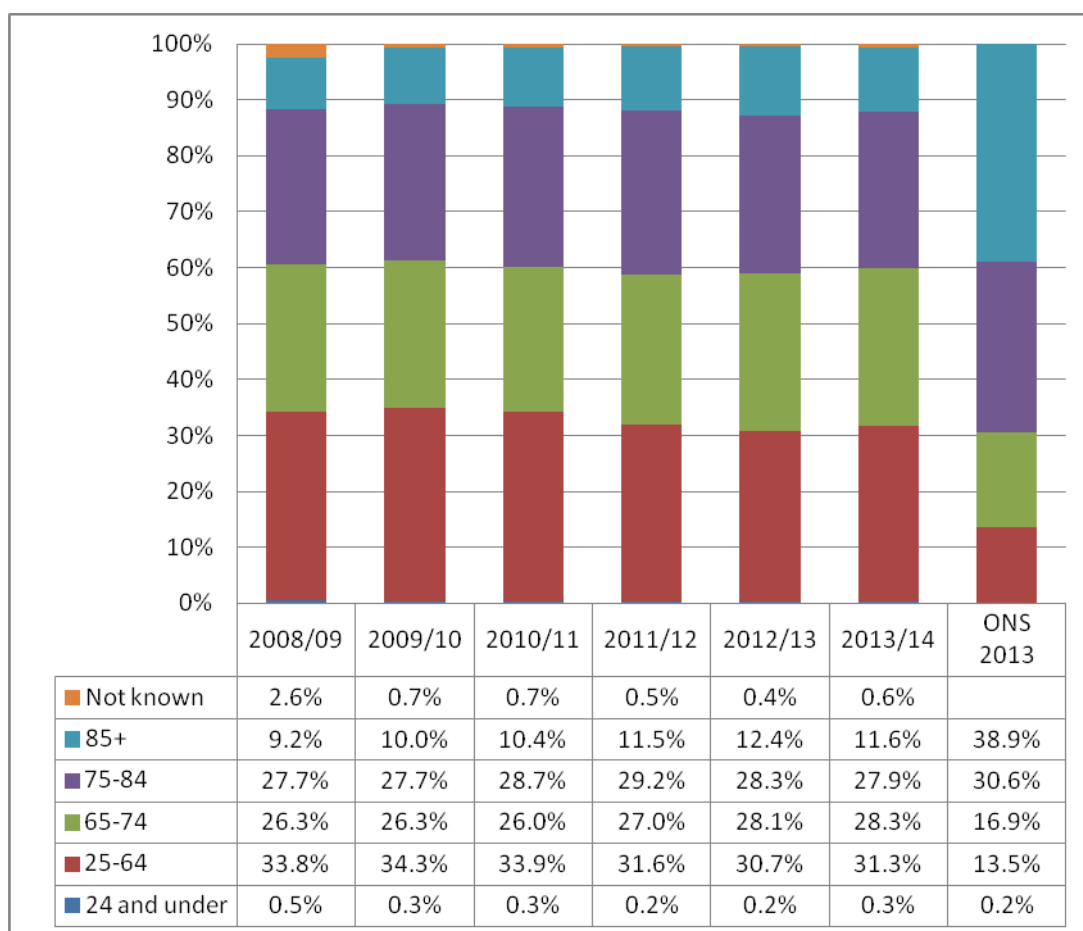


Figure 3.1: changes in the range of size of Day Care units over time (Table 36)

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 3.2: 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.

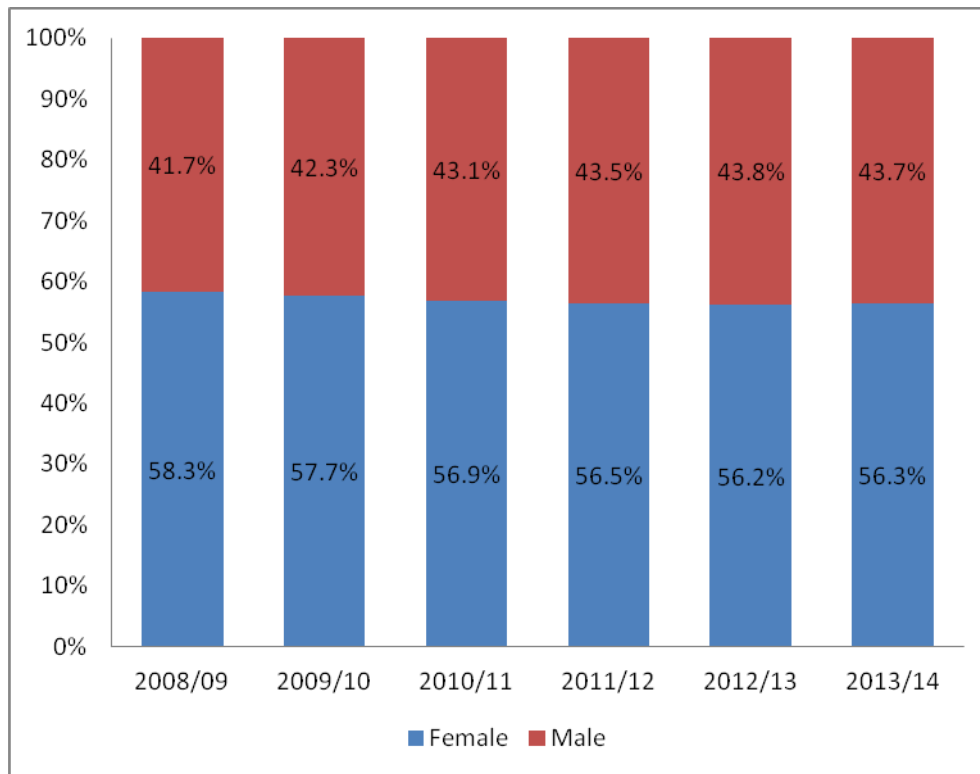


Figure 3.3: proportion of men and women accessing Day Care, 2008-2014 (Table 38)

Diagnoses

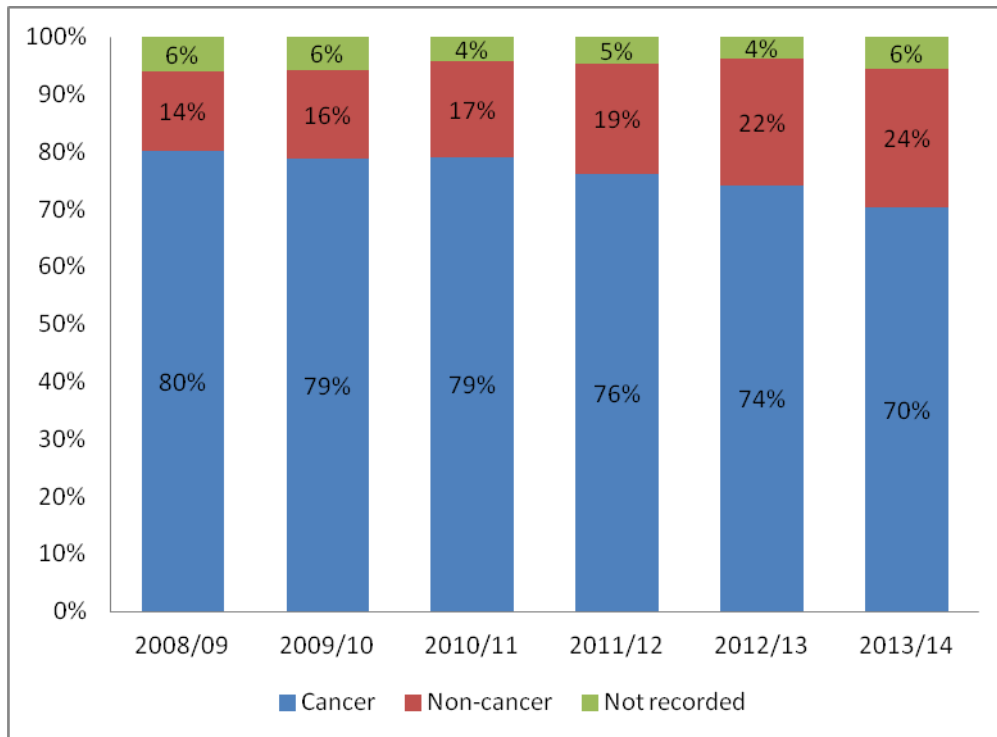


Figure 3.4: proportion of people with different categories of primary diagnosis accessing Day Care, 2008-2014 (Table 39)

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.

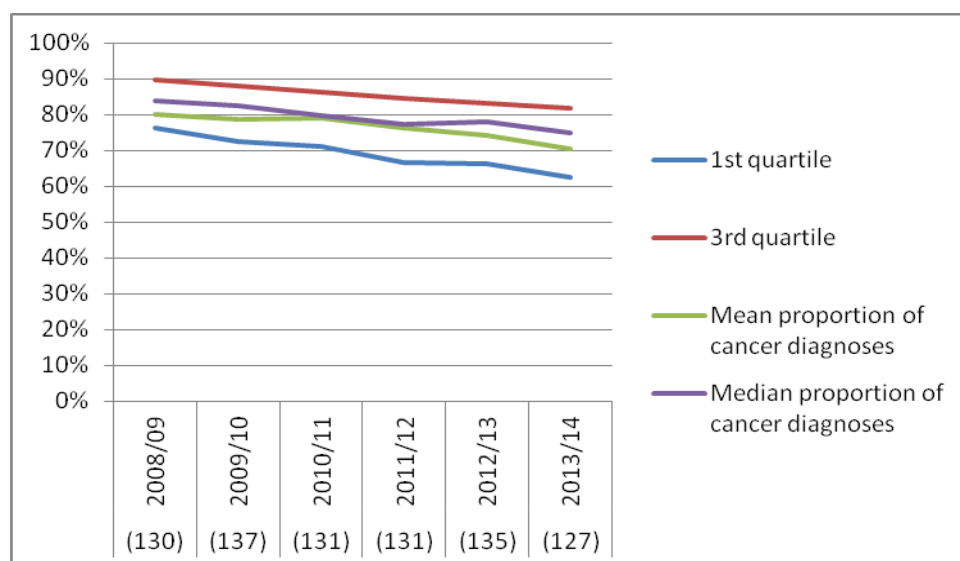


Figure 3.5: range in proportion of people with cancer diagnoses accessing Day Care, 2008-2014 (Table 1)

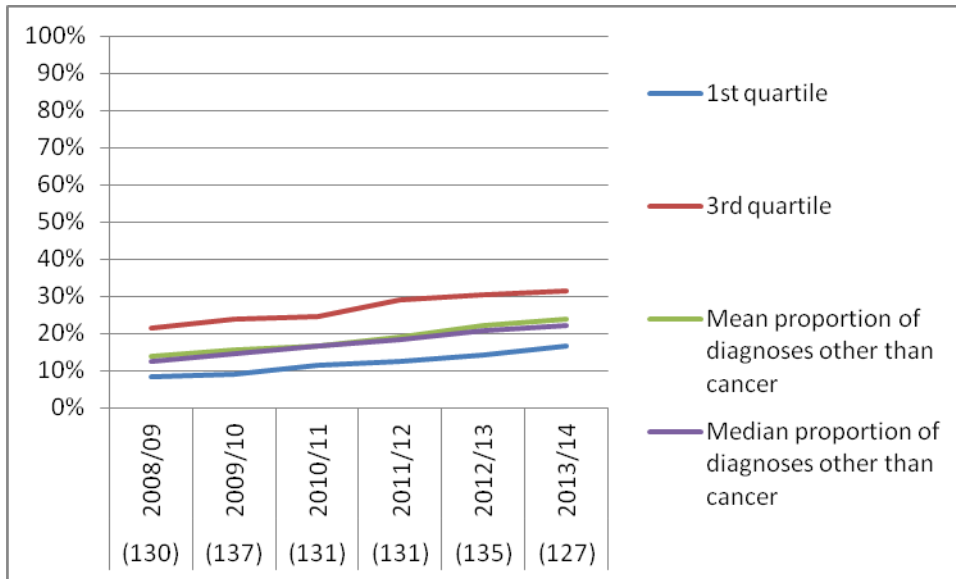


Figure 3.6: range in proportion of people with diagnoses other than cancer accessing Day Care, 2008-2014 (Table 2)

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

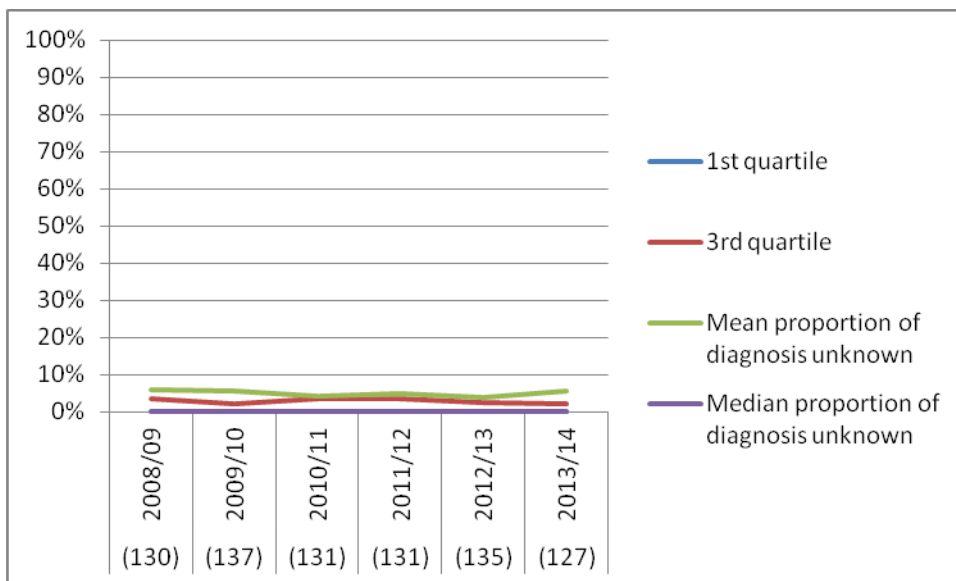


Figure 3.7: range in proportion of people with diagnoses unknown accessing Day Care, 2008-2014 (Table 3)

Diagnosis breakdown: cancer

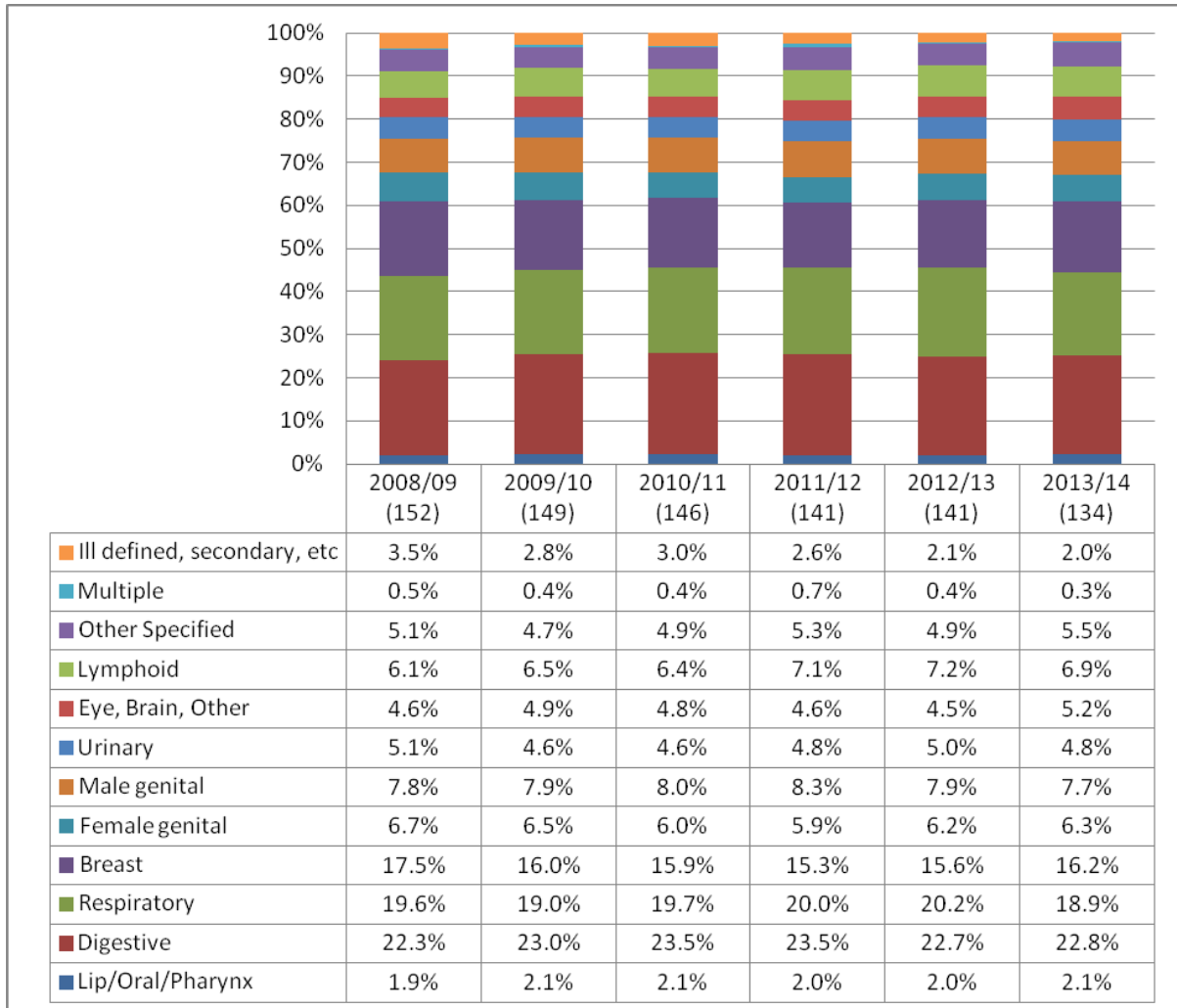


Figure 3.8: proportion of people with different cancer diagnoses accessing Day Care, 2008-2014 (Table 4)

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

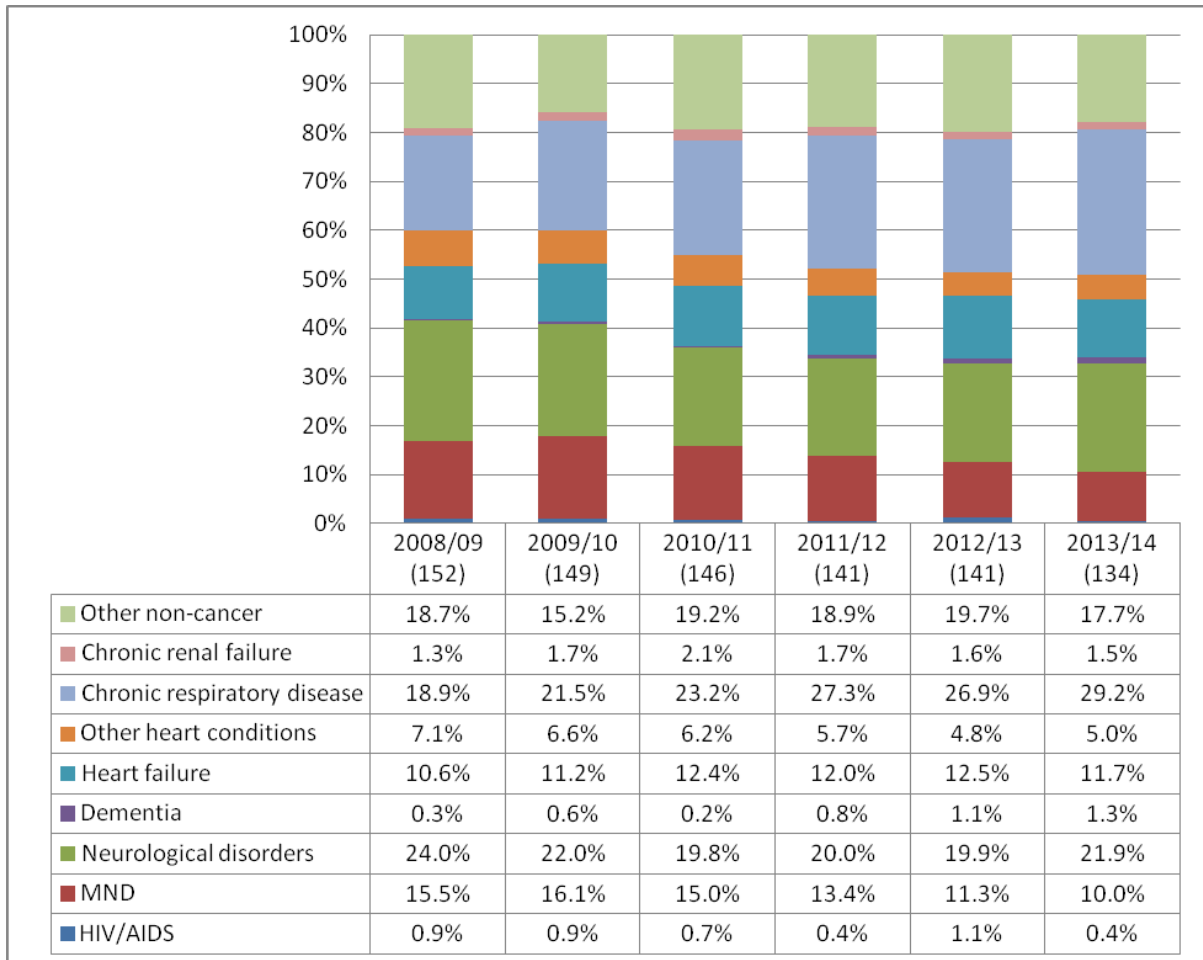


Figure 3.9: proportion of people with diagnoses other than cancer accessing Day Care, 2008-2014 (Table 5)

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 MNDA 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

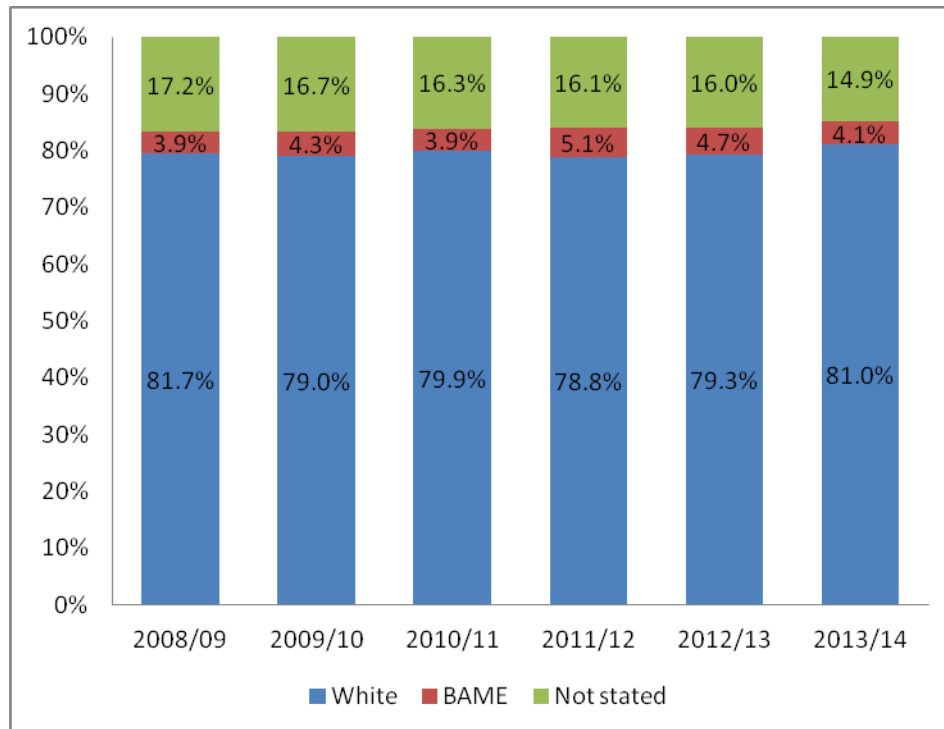


Figure 3.10: proportions of people accessing Day Care reported as white, BAME and not recorded, 2008-2014 (Table 6)

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.

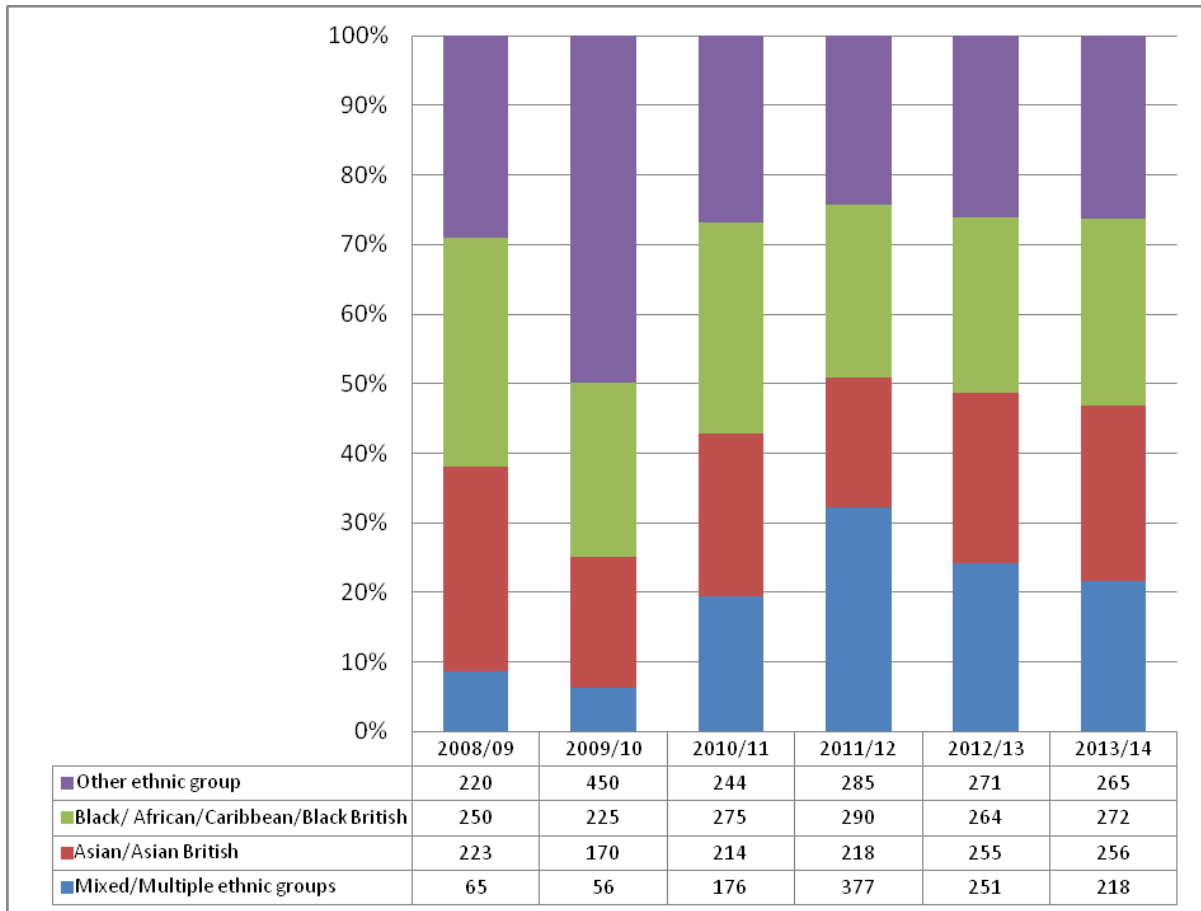


Figure 3.11: people accessing Day Care from grouped BAME categories, 2008-2014 (Table 7)

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.

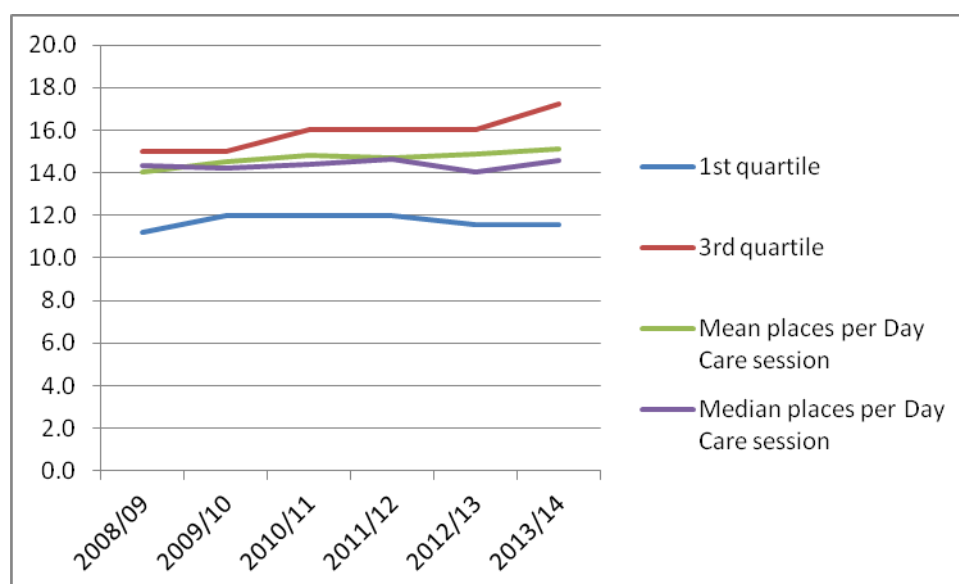


Figure 3.12: range in mean places per session offered by Day Care services, 2008-2014 (Table 8)

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

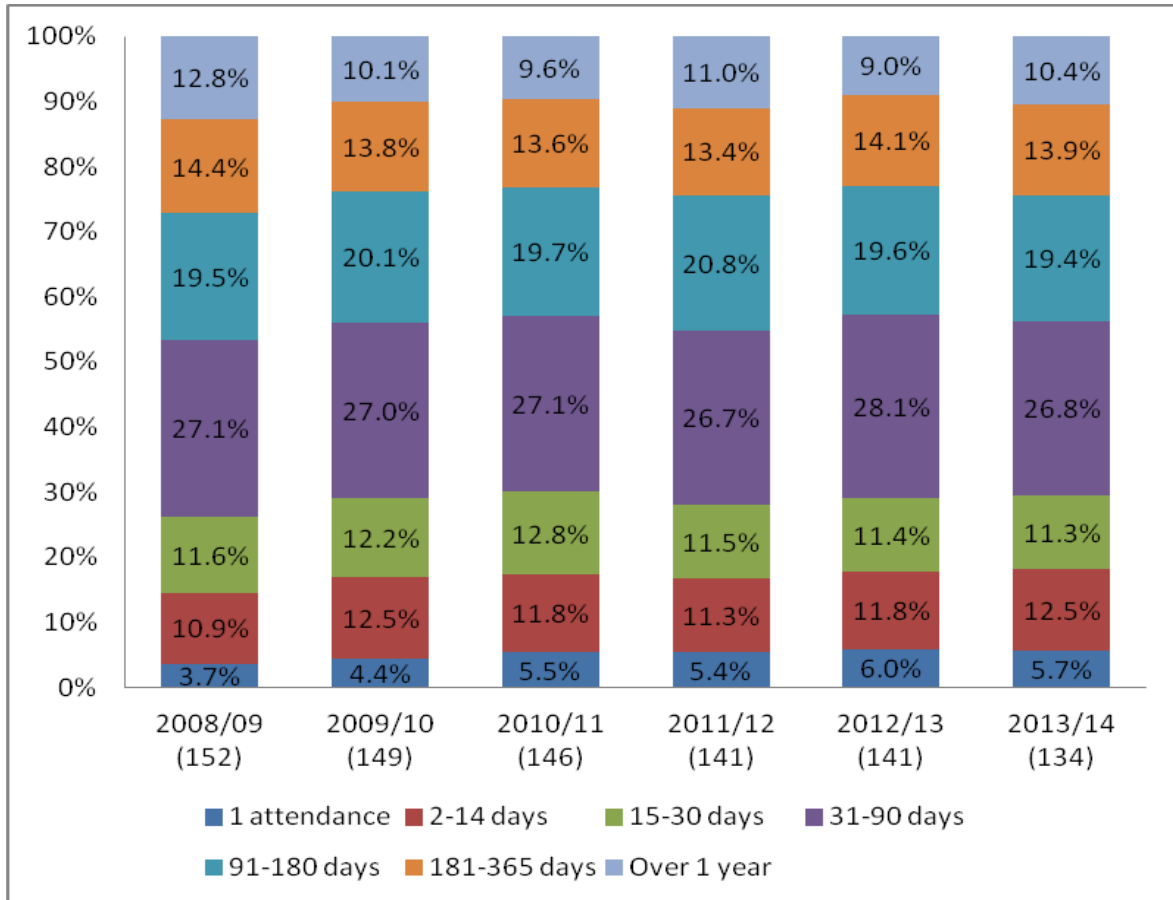


Figure 3.13: length of care for Day Care, 2008-2014 (Table 9)

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.