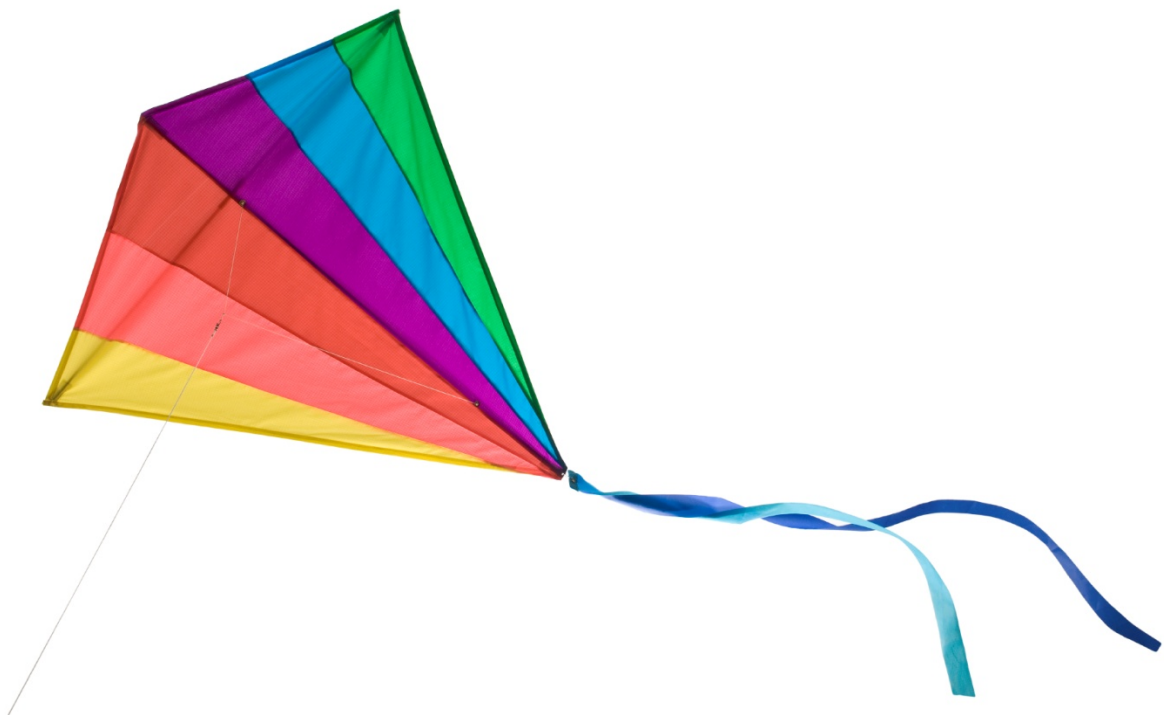


THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Public Health
England

 hospice^{UK}



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



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

Community Care MDS report 2013/14

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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.

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

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.

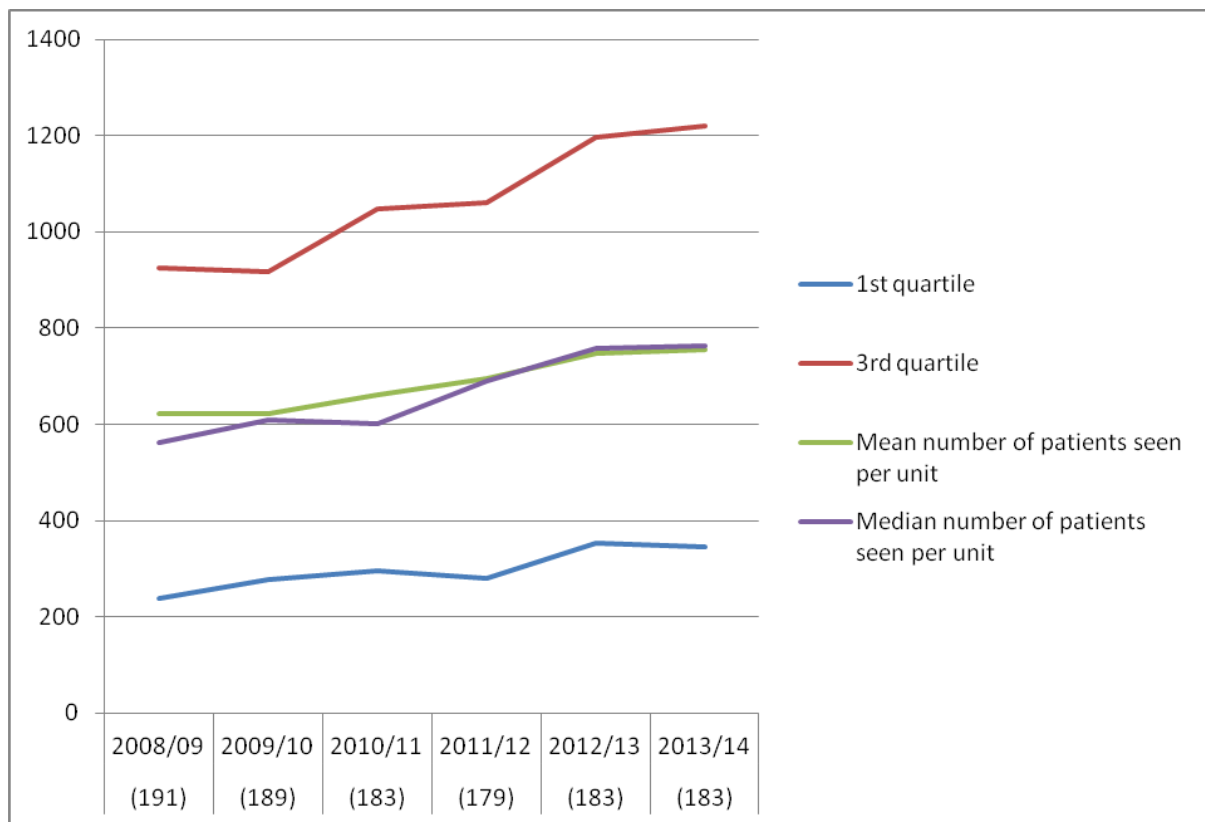
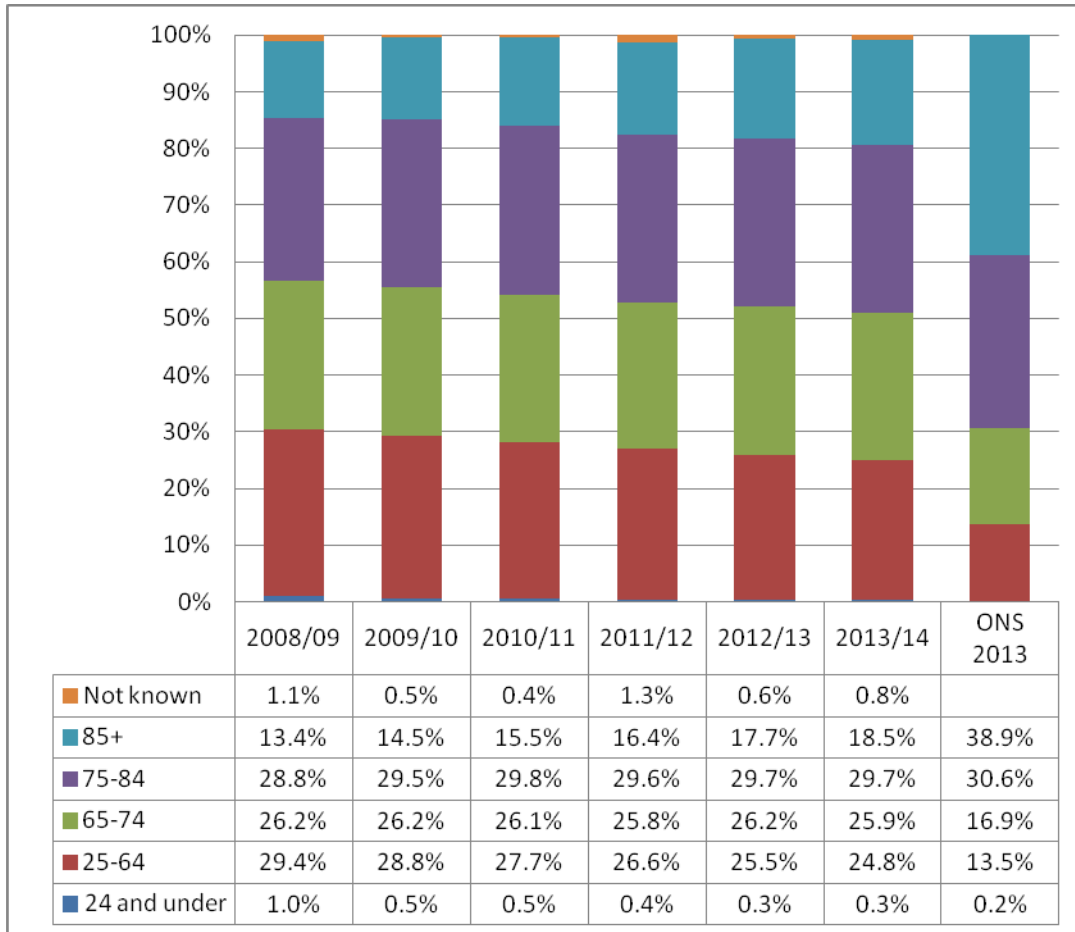


Figure 4.1: changes in the range of size of Community Care units over time (Table 1)

Age of patients



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

Figure 4.2: proportion of different age groups accessing Community Care, 2008-2014 (Table 2)

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

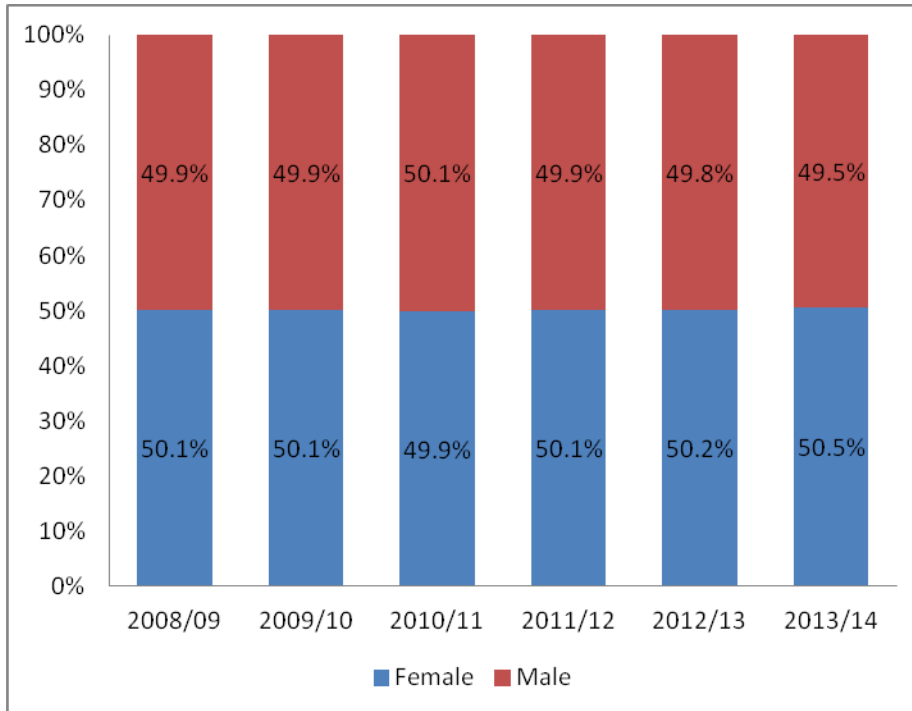


Figure 4.3: proportion of men and women accessing Community Care, 2008-2014 (Table 3)

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

Diagnoses

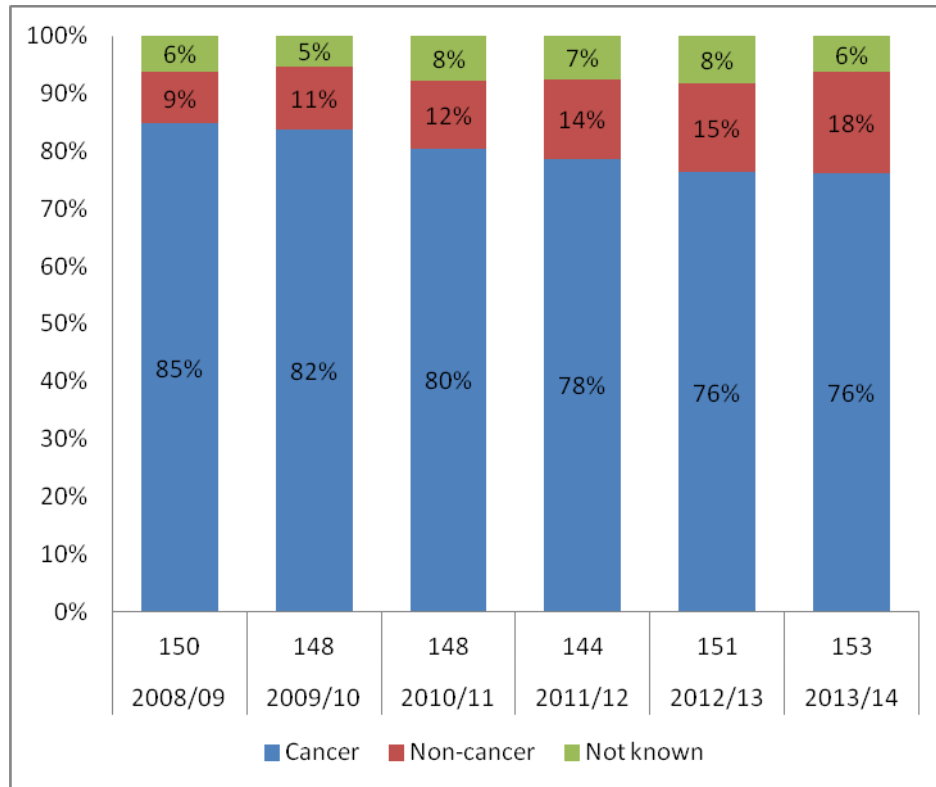


Figure 4.4: proportion of people with different categories of primary diagnosis accessing Community Care, 2008-2014 (Table 4)

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.

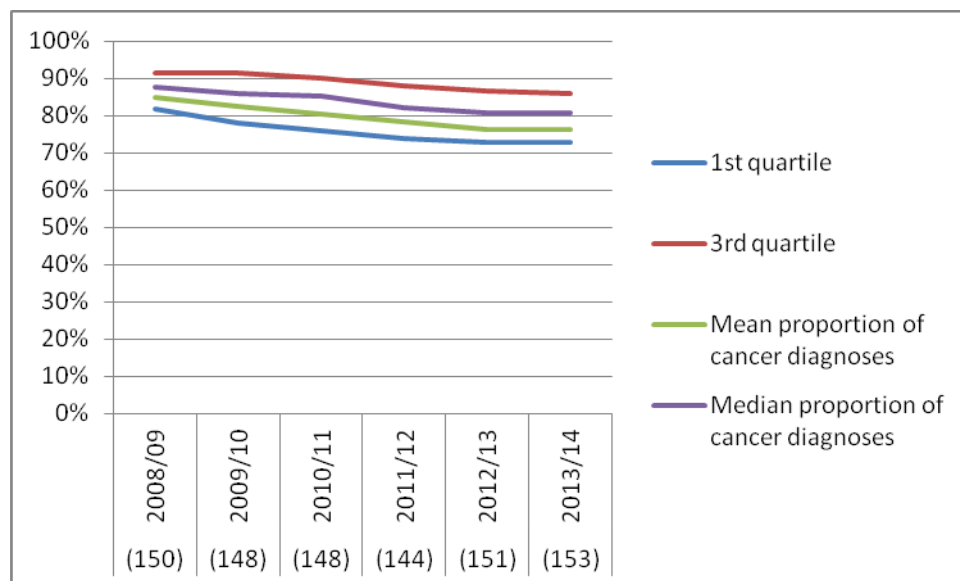


Figure 4.5: range in proportion of people with cancer diagnoses accessing Community Care, 2008-2014 (Table 5)

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

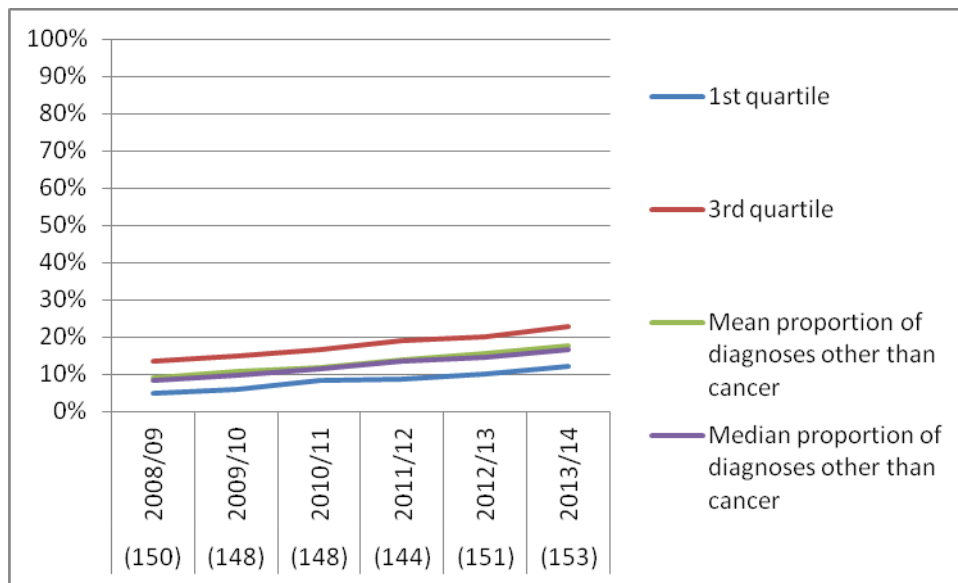


Figure 4.6: range in proportion of people with diagnoses other than cancer accessing Community Care, 2008-2014 (Table 6)

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.

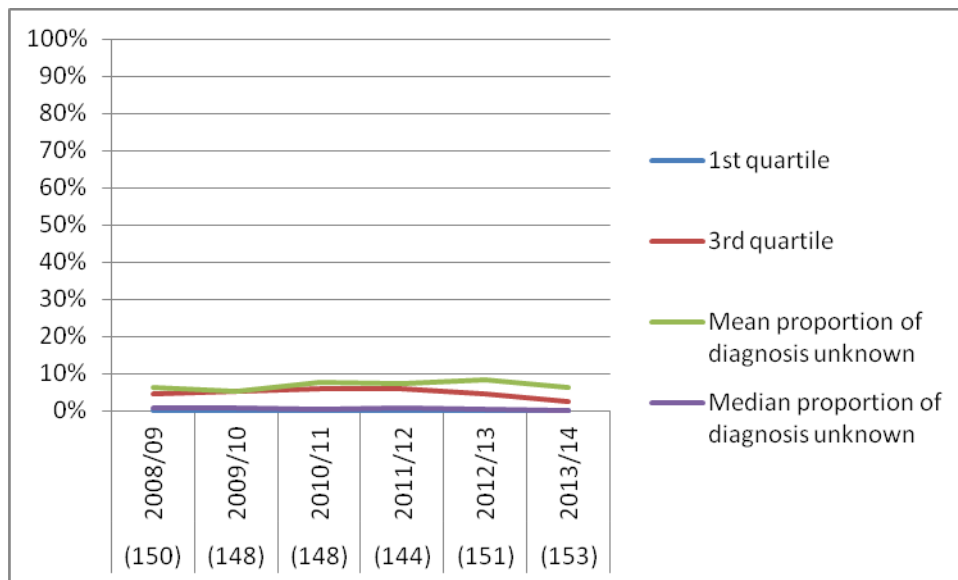


Figure 4.7: range in proportion of people with diagnoses unknown accessing Community Care, 2008-2014 (Table 7)

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

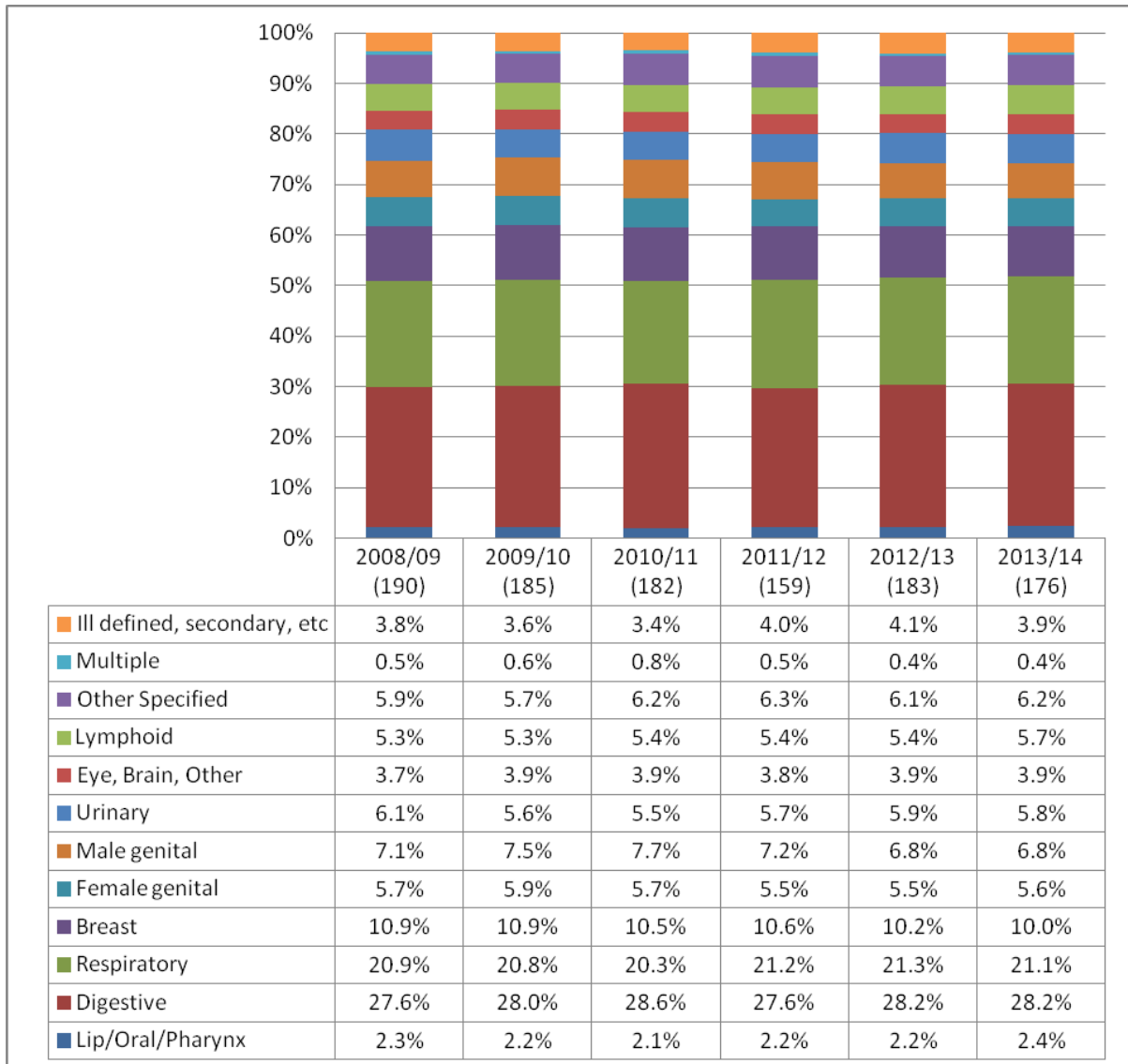


Figure 4.8: proportion of people with different cancer diagnoses accessing Community Care, 2008-2014 (Table 8)

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

Diagnosis breakdown: diagnoses other than cancer

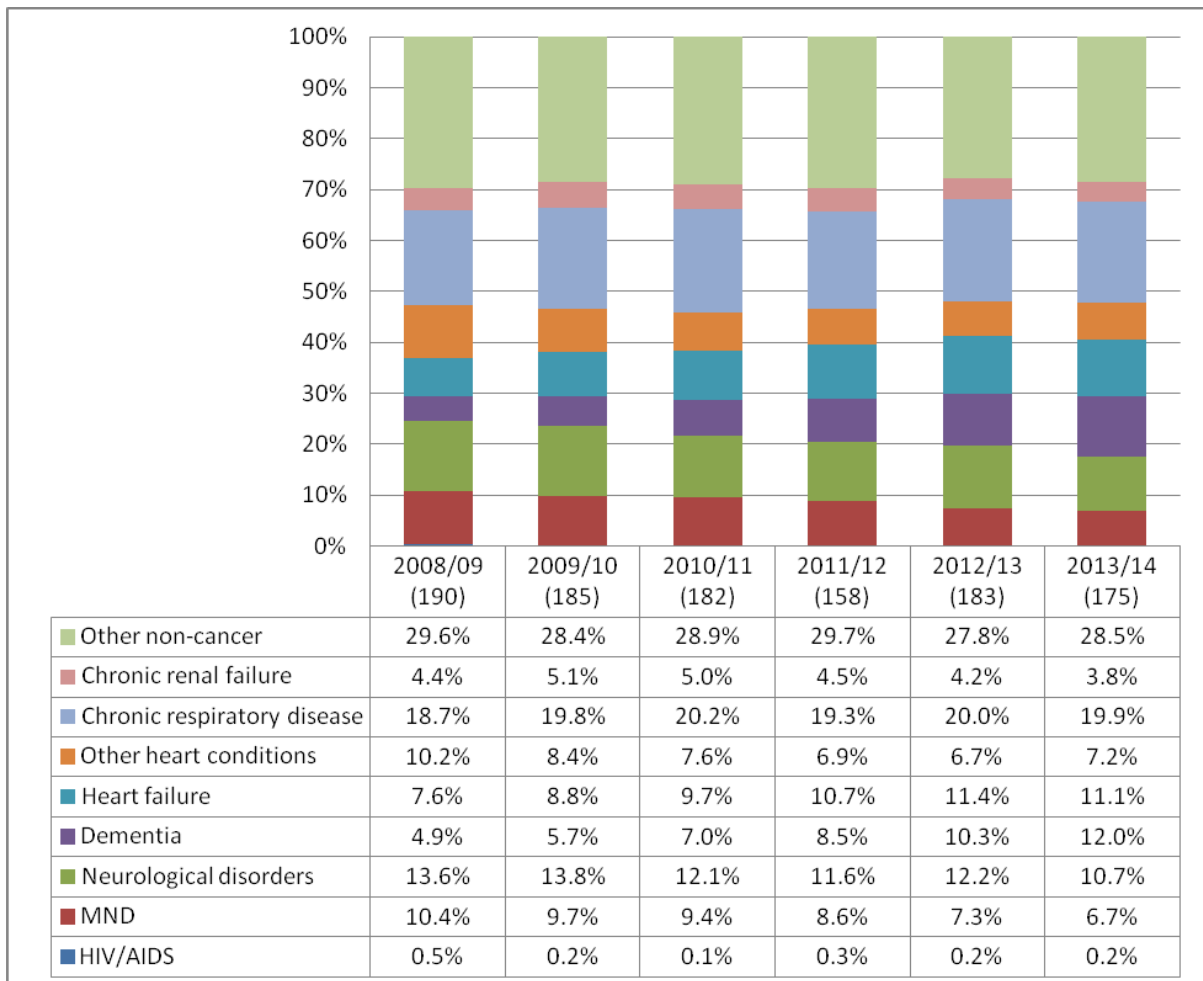


Figure 4.9: proportion of people with diagnoses other than cancer accessing Community Care, 2008-2014 (Table 9)

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

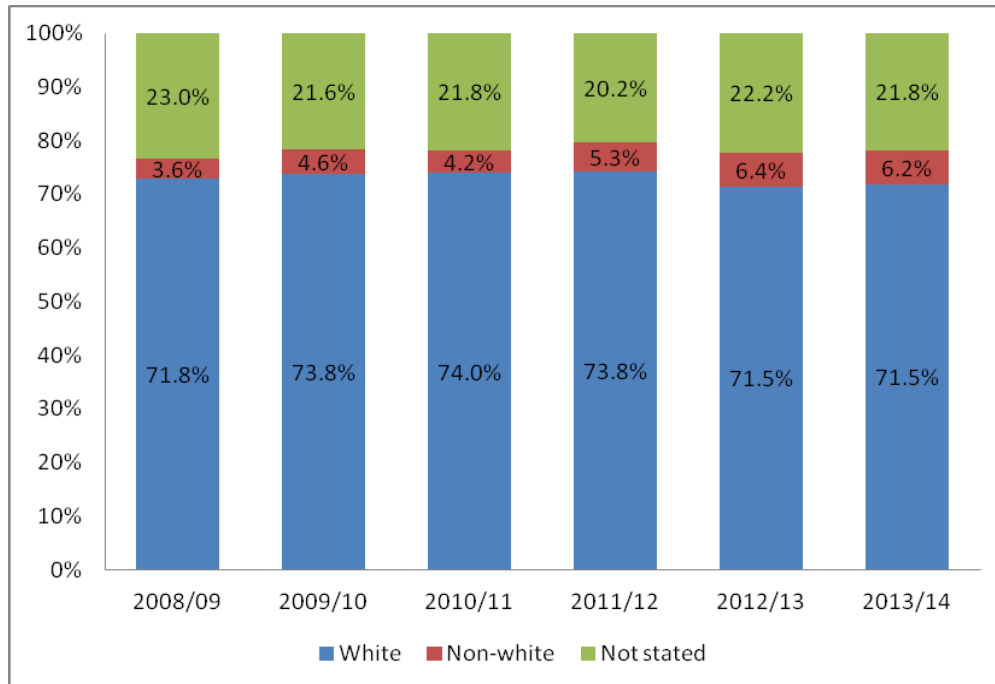


Figure 4.10: proportions of people accessing Community Care reported as white, BAME and not recorded, 2008-2014 (Table 10)

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.

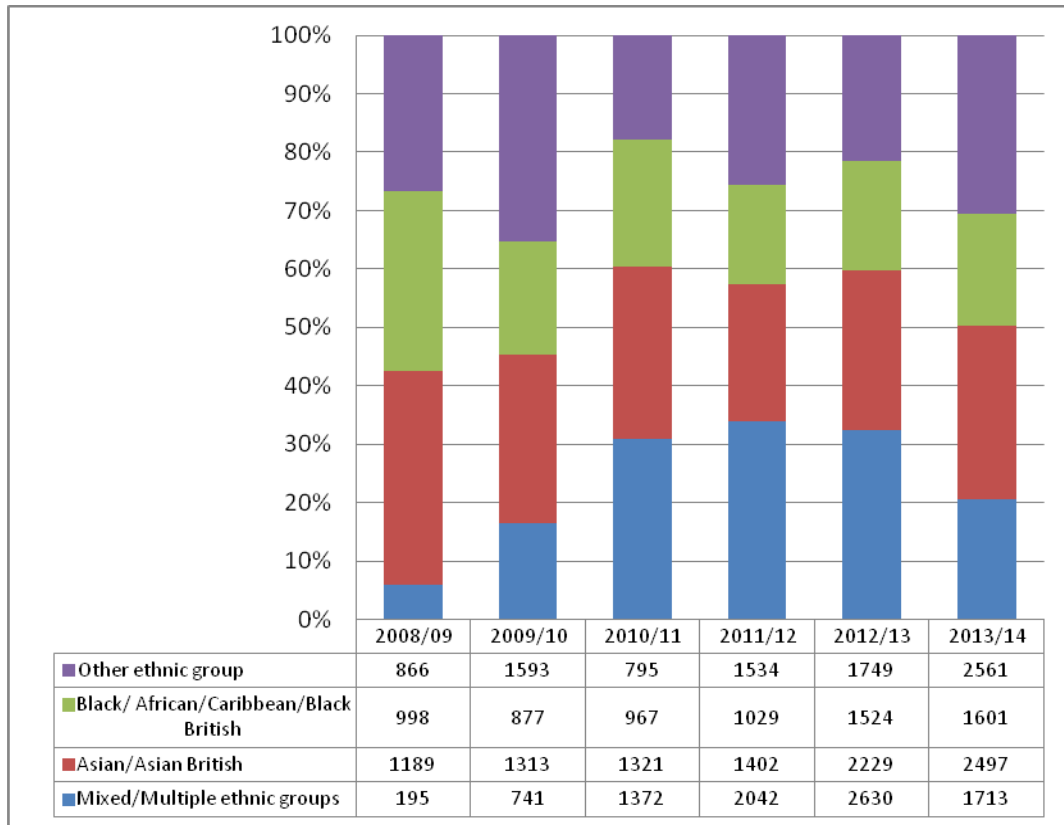


Figure 4.11: people accessing Community Care from grouped BAME categories, 2008-2014 (Table 11)

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

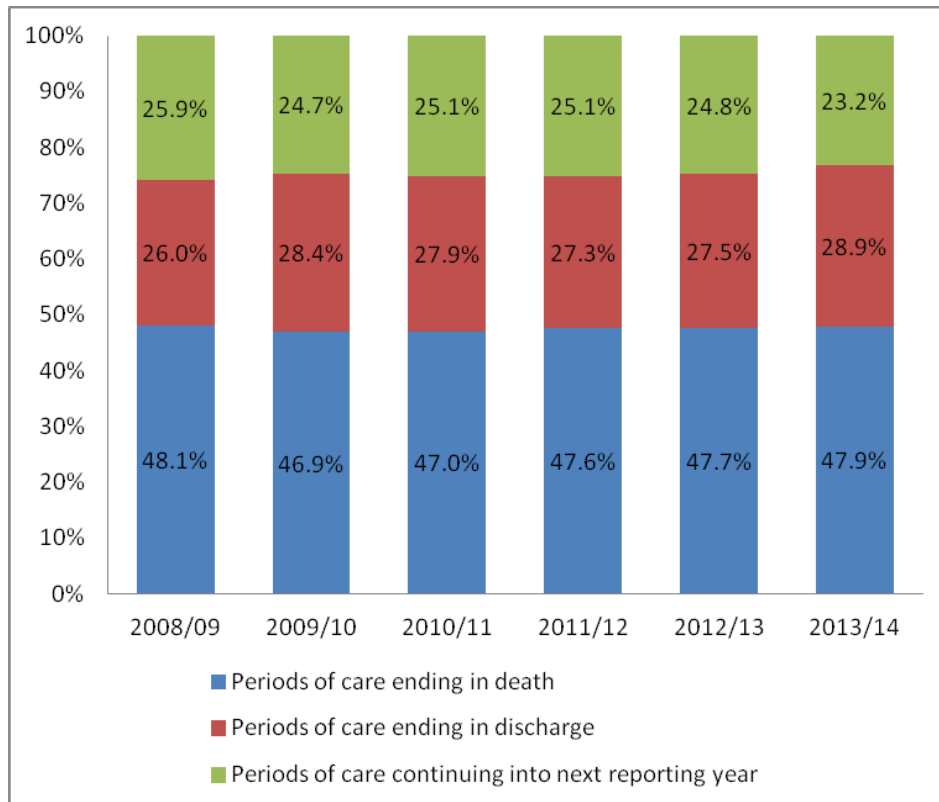
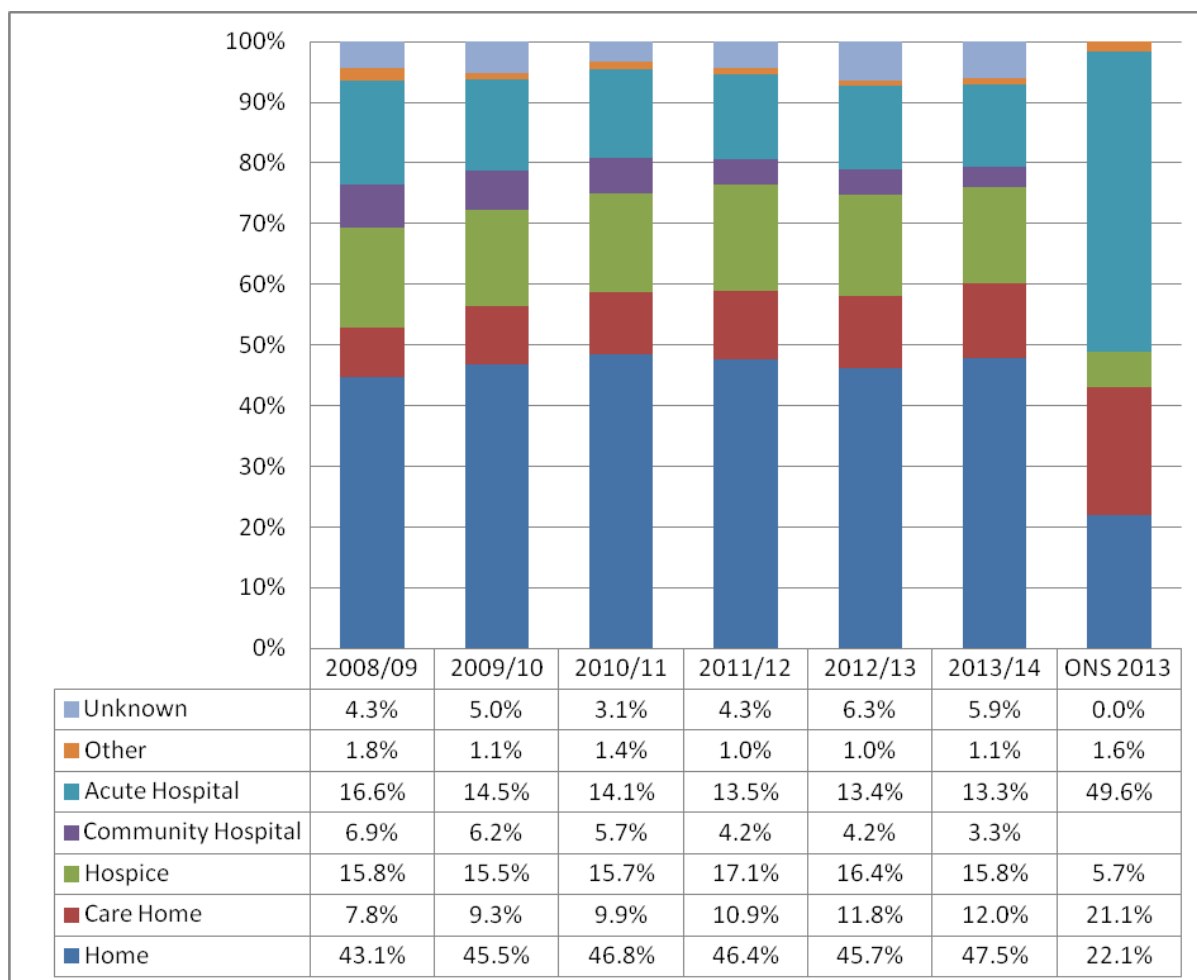


Figure 4.12: outcomes for people referred to Community Care, 2008-2014 (Table 12)

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 4.13: location of death for people being seen by Community Care teams, 2008-2014 (Table 13)

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

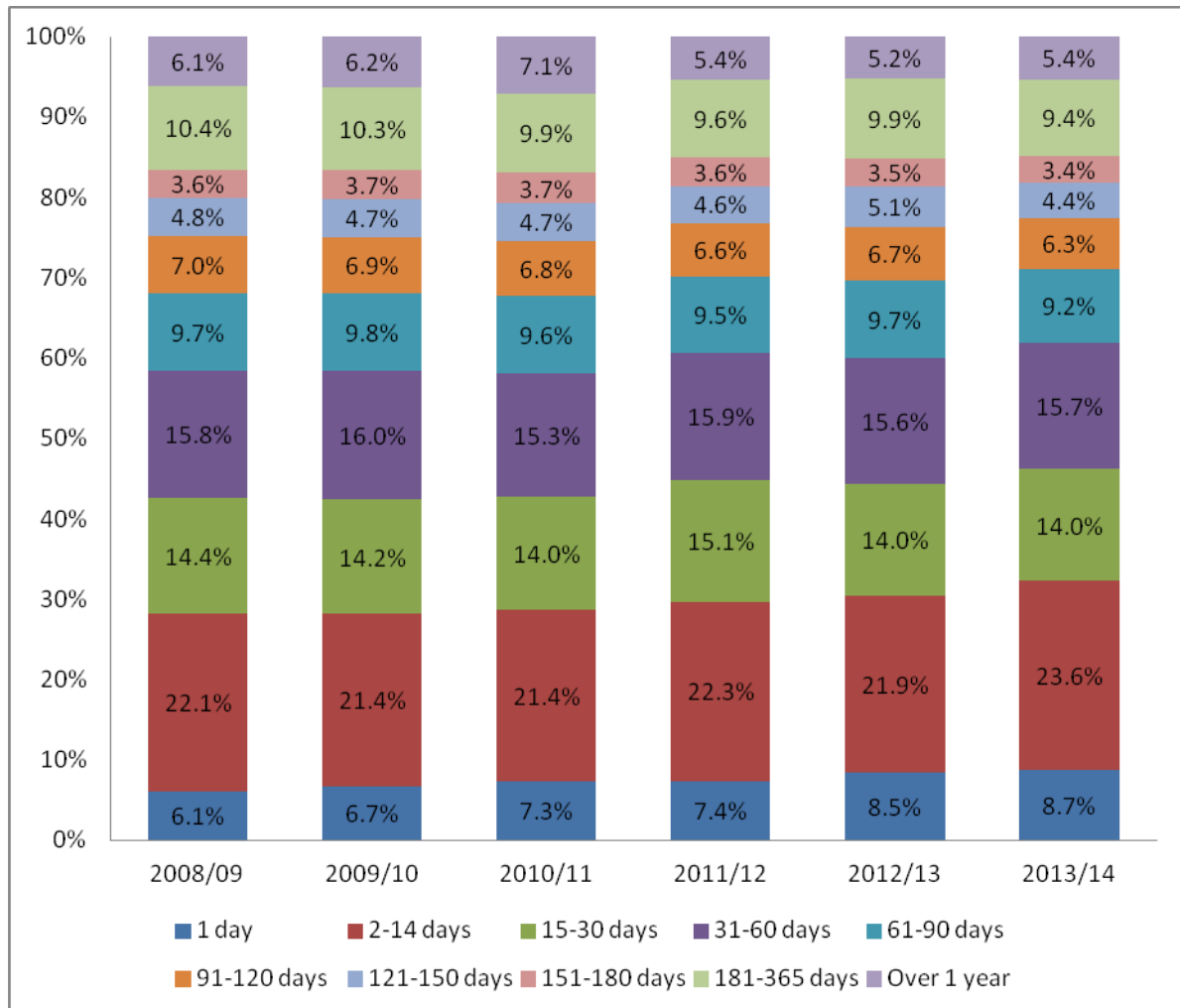


Figure 4.14: length of care for Community Care, 2008-2014 (Table 14)

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.