THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

National Survey of Patient Activity Data for Specialist Palliative Care Services

MDS Full Report for the year 2010-2011

National end of life care
INTELLIGENCE NETWORK

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 Dying Matters

Dying Matters is a broad-based and inclusive national coalition set up by the National Council for Palliative Care and is supported by the Department of Health. It aims to engage thousands of organisations across a range of sectors, generating, leading and supporting collective action to promote public awareness and debate on issues of death, dying and bereavement in England.

The Dying Matters website is **www.dyingmatters.org**

About The National End of Life Care Intelligence Network

The Department of Health's National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN).

The network is tasked with collating existing data and information on 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 will play a vital role in supporting the comprehensive implementation of the Government's End of Life Care Strategy.

The NEoLCIN website is **www.endoflifecare-intelligence.org.uk**

Contents

List of Tables

List of Charts

1. National Overview

The 2010/11 Minimum Data Set for Specialist Palliative Care Services (MDS) report is the 16th since the original collection in 1995/6 and it is the second to report on activities since the rollout of additional investment associated with the End of Life Care Strategy in England. Launched in 2008, the Strategy announced additional investment into end of life care of £88m in 2009/10 and a further £198m in 2010/11.

Key findings

More people with conditions other than cancer are accessing specialist palliative care, but more progress is needed:

- Across all settings, nearly a fifth (17%) of people using services now have a primary diagnosis other than cancer. This is compared to 5% in 2000 and 12% in 2008. Opening up services to people with a range of conditions was a key aim of the national End of Life Care Strategy, and continues to be a key goal of NCPC. This trend is therefore very encouraging, but more needs to be done to ensure that more people with conditions other than cancer can benefit from specialist palliative care services.
- The numbers are highest for Outpatients where nearly one in four (24%) people have a condition other than cancer. Lowest is Home Care, where this number is only one in ten (10%).
- Highest level of access is for chronic respiratory conditions, which account for around 15% of those accessing specialist palliative care with a condition other than cancer. Access is also improving for motor neurone disease, other neurological conditions and heart failure, although this varies hugely across localities. Chronic renal conditions remain low at around 5%.
- The MDS currently only collects primary diagnosis, so in the case of conditions like dementia, which often co-exist alongside other conditions, people could be accessing specialist palliative care but not being recorded. It is disappointing, however, that services like day care, which could have a lot to offer people with dementia, saw only 9 people with a primary diagnosis of dementia in 2010/11. We **strongly recommend** that services review their own admission policies, internal monitoring and staff education programmes to ensure that people with dementia have full access.
- Despite these improvements, too many conditions are appearing in the 'Non-cancer other' category. For example, 67% of the non-cancer contacts in Outpatients were categorised in this way, and around 30% of hospital support, home care and inpatient contacts. This is not a person-centred way of recording people using services. We **urge** services to feedback to us on whether the MDS forms need additional categories, or whether this data is simply not being collected locally.

See page 18 for further discussion of this.

The 'oldest old' are slowly having more contact with specialist palliative care:

- Around 14% of people accessing specialist palliative care services are 85 and over (hereafter referred to as 'the oldest old'). This has increased from around 11% in 2000.
- The most notable increase is amongst hospital support and community teams, a welcome development as these teams have a crucial role in preventing unnecessary hospital admissions and facilitating early discharge from hospital to the community.
- From a whole population view this still represents a small proportion of people 85 and over accessing specialist palliative care. There are currently 1.4m people in this age group in the UK and just over 30,000 contacts were made with specialist palliative care services in this group (the MDS is currently unable to say how many of these contacts represent the same person using multiple services, so there will be significant double-counting).
- We strongly recommend that services reflect on the proportion of the 'oldest old' they are reaching in their communities. This will be of increasing importance as the population continues to age. Consider that the number of people aged 90 and over in the UK is projected to more than triple by 2035, the number of people aged 95 and over to more than quadruple, and the number of centenarians to increase eightfold.[1] Meanwhile research shows that a large proportion of the oldest old would prefer to die in a hospice given the choice - 41% of people aged 75 and over prefer to

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[1] **National Population Projections 2010-based Statistical Bulletin**; ONS 2011.

die here, compared to 45% in their own home.[2] Currently only 12% of those accessing in-patient units (which includes both those who die there and those later discharged) are 85 and over.

See page 13 for further discussion.

Specialist palliative care community services help more people to die at home

- The MDS shows that of those receiving community specialist palliative care who died in 2010-11, a third died at home. This compares to 20.8% nationally[3] (a figure which slowly increasing each year). It is a powerful message that where specialist palliative care is involved, the likelihood of people dying at home increases.

See page 56 for further discussion.

More services are recording people's ethnicity

- Almost 9 out of 10 services (87%) are recording people's ethnicity according to the 17 ethnic groups used by the Department of Health. This has vastly improved since 2004 when just 49% recorded this information.
- However, we **strongly recommend** that services continue to improve their recording so that fewer people are categorised as 'non-white other', in order to achieve a person-centred service.

See page 15 for further discussion.

In-patient admissions

- That nearly half (45%) of the people referred to an inpatient service are discharged (42% to their home) helps dispel the myth that people only go into a hospice to die. See page 26 for further discussion.
- An interesting finding is that larger inpatient units admit people for longer. In 2010/11 units with more than 15 beds kept patients for an average of one day longer than in 2009/10. Bed occupancy (the number of beds occupied as a percentage of those available) has stayed broadly the same at 75%, as has mean length of stay, at 13.5 days now compared to 13.3 in 2009/10.
- We will monitor this change to see if the trend continues into future years. In the meantime we would encourage services to reflect upon *Are you there? Reviewing specialist palliative care inpatient admissions criteria* (NCPC, 2011) which highlights some of the ways productivity and quality of care can be improved by reviewing use of beds and admissions processes within inpatient services.

See page 25 onwards for further discussion.

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[2] **Local Preferences and Place of Death in Regions within England 2010**; Barbara Gomes, Natalia Calanzani, Irene J Higginson.

[3] **Mortality Statistics: Deaths registered in England and Wales (Series DR), 2010**; ONS 2010.

Response rate

Responders could submit electronically by email attachment; only 2% of forms were received on paper. The majority of forms (79%) were submitted on NCPC's Word documents which could be imported directly into the database. This cuts down considerably on data input time, reduces input errors and leaves more time for checking and querying. 19% of forms (172) were submitted electronically in formats which could not be imported automatically, necessitating manual entry of the data.

Only about half the expected number of replies had been received by the deadline (this is in line with previous years) and reminders were sent. This resulted in further submissions.

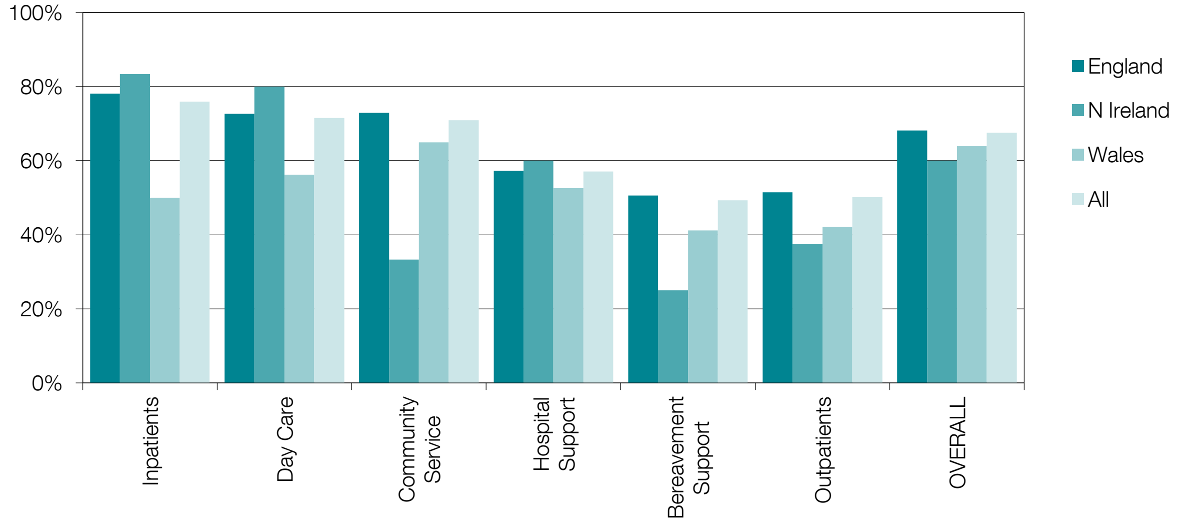
An overall response rate of 70% (318 services) was achieved this year, an increase from 62% last year. Table 1 shows the overall response rate for the different parts of the questionnaire and it is seen that the response rates varied from 49% to 76%.

Table 1: Response rate

	Number of Services Responding				
Service	**England**	**N Ireland**	**Wales**	**Total**	**Overall Response**
Inpatient	133	5	8	146	76%
Day Care	133	4	9	146	72%
Home Care	167	3	13	183	71%
Hospital Support	125	9	11	145	57%
Bereavement Support	125	2	7	134	49%
Outpatients	144	6	8	158	50%
Overall response				318	68%

Chart 1 compares the response rates from England, Northern Ireland and Wales with the overall response rate.

Chart 1: Response rate for country and setting



Trend in response rates

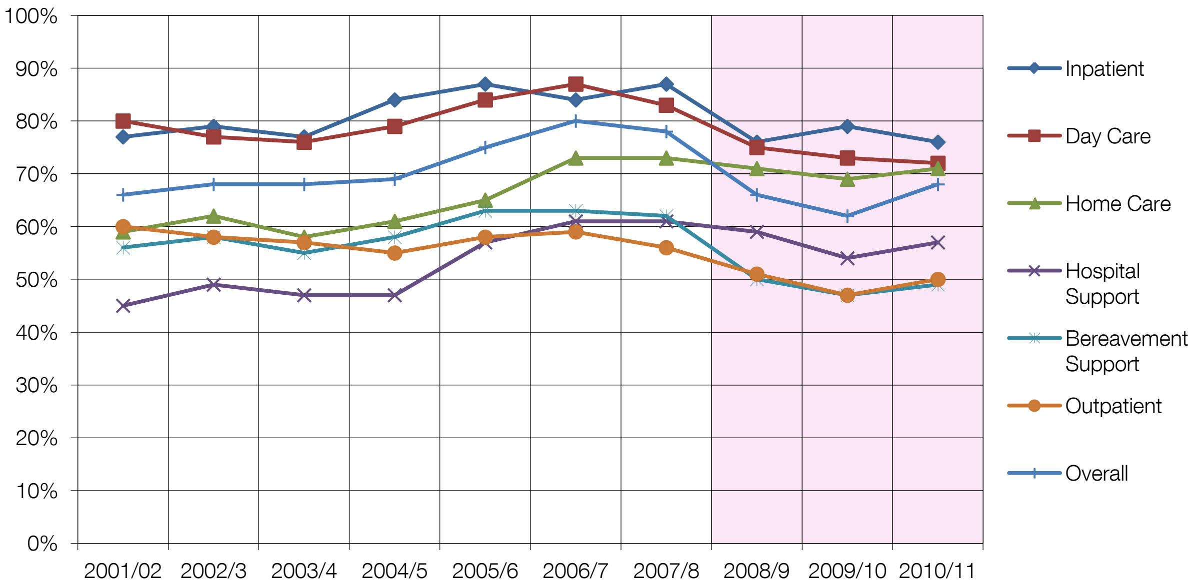
There is a noticeable variation in response rates across the different settings (see Table 2), as has historically been the case. We would like to understand more why some settings have a much lower response rate than others. Some of the reasons may be variations in administrative capacity and understanding of the role of MDS collection. However, within Bereavement Support, which has one of the lowest response rates, we are aware that the current data collection may not reflect the full range of bereavement care services. We are keen to work with services to identify if and how the questions might be revised so that the data is as useful as possible.

Table 2: Response rates trend

	Percentage responses									
	01/02	02/03	03/04	04/05	05/06	06/07	07/08	08/09	09/10	10/11
In-patient	77%	79%	77%	84%	87%	84%	87%	76%	79%	76%
Day Care	80%	77%	76%	79%	84%	87%	83%	75%	73%	72%
Home Care	59%	62%	58%	61%	65%	73%	73%	71%	69%	71%
Hospital Supp	45%	49%	47%	47%	57%	61%	61%	59%	54%	57%
Bereavement	56%	58%	55%	58%	63%	63%	62%	50%	47%	49%
Out-patient	60%	58%	57%	55%	58%	59%	56%	51%	47%	50%
Overall	66%	68%	68%	69%	75%	80%	78%	66%	62%	68%

The shaded area indicates the period in which the revised MDS has been collected.

Chart 2: Response rates trend



The shaded area indicates the period in which the revised MDS has been collected.

Summary of data by country

Table 3 shows some selected data by country. It should be recognised that the data from Wales and Northern Ireland have been obtained from a very small number of services and may well not be representative of the country as a whole.

Table 3: Data for the different countries 2010/11

	Country	Inpatient care	Day care	Community service	Hospital support
Number of services responding	**England**	133	133	167	125
	N Ireland	5	4	3	9
	Wales	8	9	13	11
Response rate	**England**	79%	73%	73%	57%
	N Ireland	83%	80%	33%	60%
	Wales	50%	56%	65%	58%
Diagnosis other than cancer	**England**	9%	14%	10%	16%
	N Ireland	7%	10%	12%	11%
	Wales	6%	9%	12%	17%
Mean length of care in days	**England**	13.3	181.9	51.4	21.0
	N Ireland	16.5	132.1	94.4	17.1
	Wales	17.4	132.6	111.9	61.0

Management

Services were asked to indicate whether they were managed by the NHS or independently. Table 4 shows the breakdown of units for each setting

Table 4: Service management by units responding

	Management			Units Response
	Independent	NHS	Not Recorded	
Inpatients	77%	23%	0%	146
Day Care	87%	13%	0%	146
Home Care	50%	50%	0%	102
Hospice @ Home	86%	14%	0%	42
Combined	64%	36%	0%	39
Hospital Support	10%	88%	1%	145
Bereavement Support	69%	19%	12%	134
Outpatients	57%	32%	11%	158

Chart 3: Service management by services responding

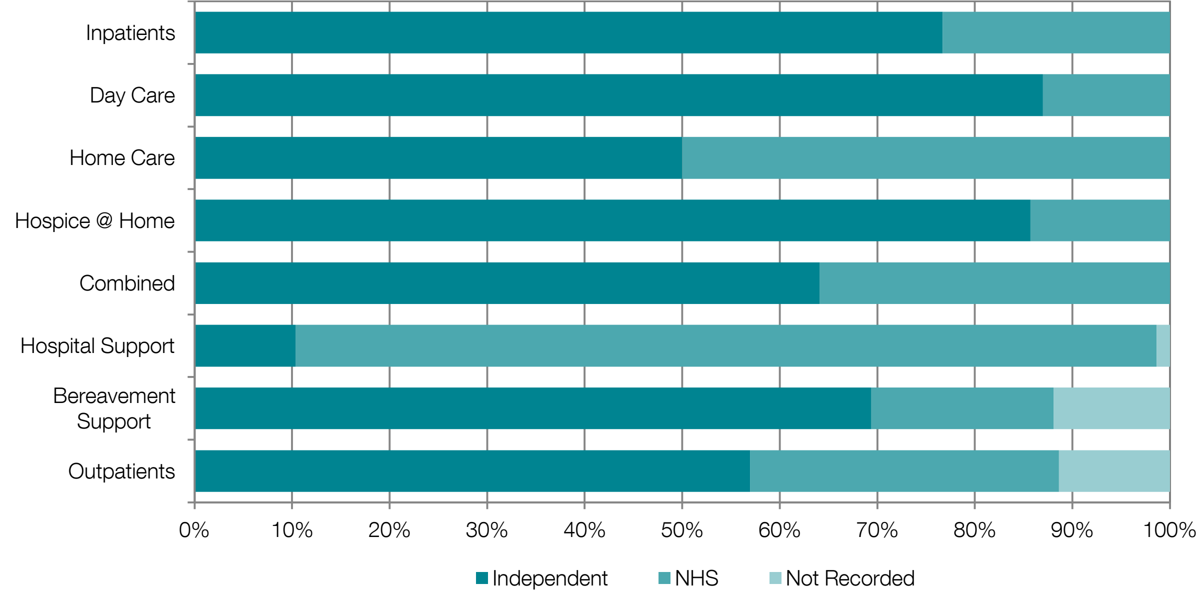


Table 5 breaks down the proportion of new patients attending independent and NHS services for each setting. Although the figures are largely similar to those in Table 2, which demonstrates the break down by number of units, it should be noted that overall independent units are seeing a higher proportion of new patients than they have units. This is most evident with Outpatients (57% of overall units seeing 70% of new patients) and Home Care (50% of overall units seeing 57% of new patients) units.

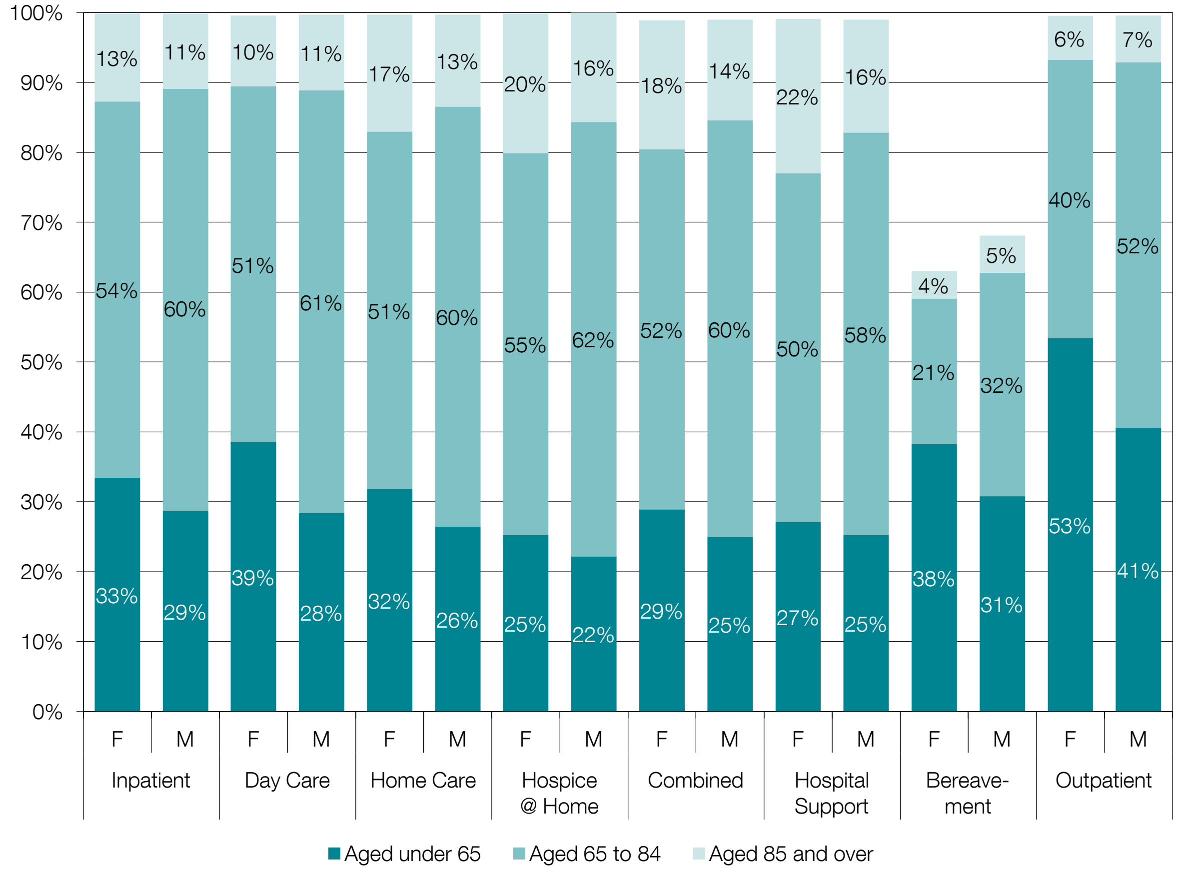
Table 5: Service management by new patient numbers

Management	Independent	NHS	Not Recorded	Response
Inpatients	81%	19%	0.0%	146
Day Care	88%	12%	0.0%	146
Home Care	57%	43%	0.0%	102
Hospice @ Home	89%	11%	0.0%	42
Combined	71%	29%	0.0%	39
Hospital Support	11%	89%	0.0%	145
Bereavement Support	74%	9%	16.7%	134
Outpatients	70%	19%	11.2%	158

Age and gender

Data from the returns of the individual services was used in Chart 4 to compare the different services with regard to age and gender of patients cared for.

Chart 4: Breakdown of age by setting and sex



There were 493,242 deaths registered in England and Wales in 2010, comprising 237,916 men and 255,326 women.[4]

The age, sex and ethnicity of people referred to under Bereavement Support are of the bereaved clients, rather than the deceased. Many bereavement services reported difficulties in asking clients for their date of birth and ethnicity. There has again been a slight increase in the number of clients whose details have been recorded for Bereavement Support (86% for age and 81% for ethnicity this year compared to 85% and 78% last year); this is still significantly lower than other services, as can be seen in Chart 4. We would encourage services to review how they might ensure more detailed data collection.

The proportion of people aged between 65-84 who access bereavement support is higher for men than for women (32% compared to 21%) and similar to the proportion of men aged under 65 years (31%). A much higher proportion of women aged under 65 accessed bereavement support (38%).

As with previous years, over half of the women using Outpatient services were under 65. This is almost certainly a reflection of the higher number of breast cancer patients seen by Outpatients.

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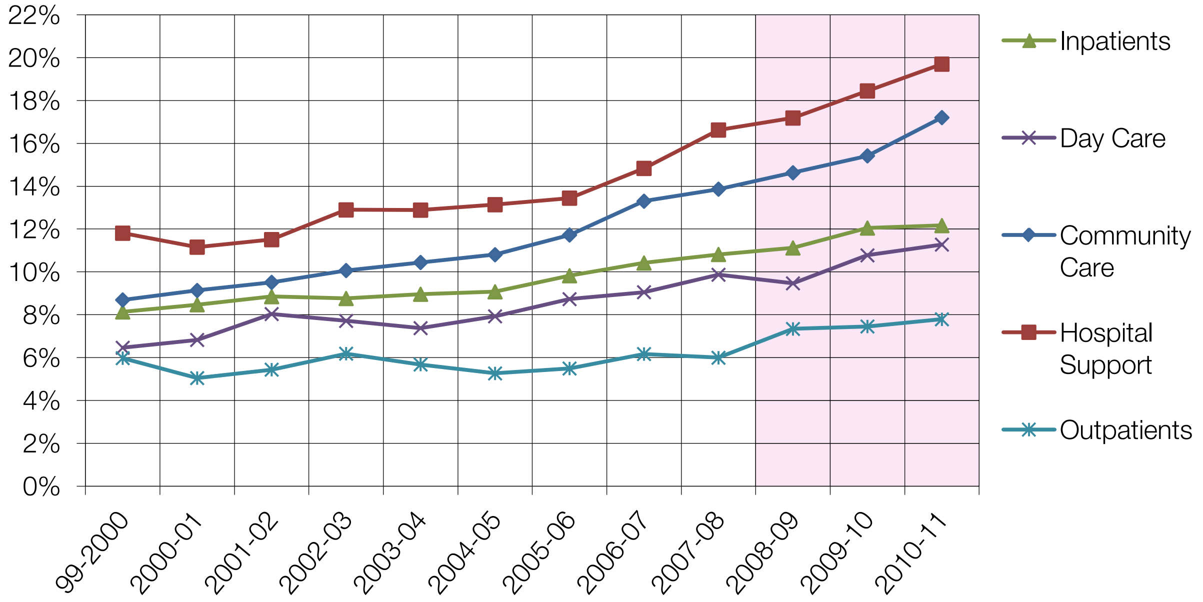
[4] **Deaths registered in England and Wales in 2010, by cause**, ONS Statistical Bulletin Oct 2011.

Patients aged 85 and over – trend data

Chart 5 shows the percentage of people accessing specialist palliative care services since 1999-2000, who are the oldest old. Across all services, 13.8% of people accessing specialist palliative care are the oldest old, compared to 8.8% in 2000.

Chart 5: Percentage of patients aged 85 and over



The shaded area indicates the period in which the revised MDS has been collected.

There was a particular spur from 2006, with the steepest increase amongst hospital support and community teams. Hospital support rose from 13.4% in 2005-06 to 19.7% in 2010-11. Community services rose from 11.7% in 2005-06 to 17.2% in 2010-11.

This is very encouraging, given that we know that the oldest old are most likely to experience frailty, cognitive impairment and multiple conditions, leading to more falls and complications and resulting in increased hospital admissions. The oldest old are nearly 10 times more likely to have an emergency admission than people aged 20-40.[5]

High-quality services in the community are absolutely essential in ensuring people can be helped to stay in the community into old age. Social care is also key, access to which NCPC continues to campaign for.

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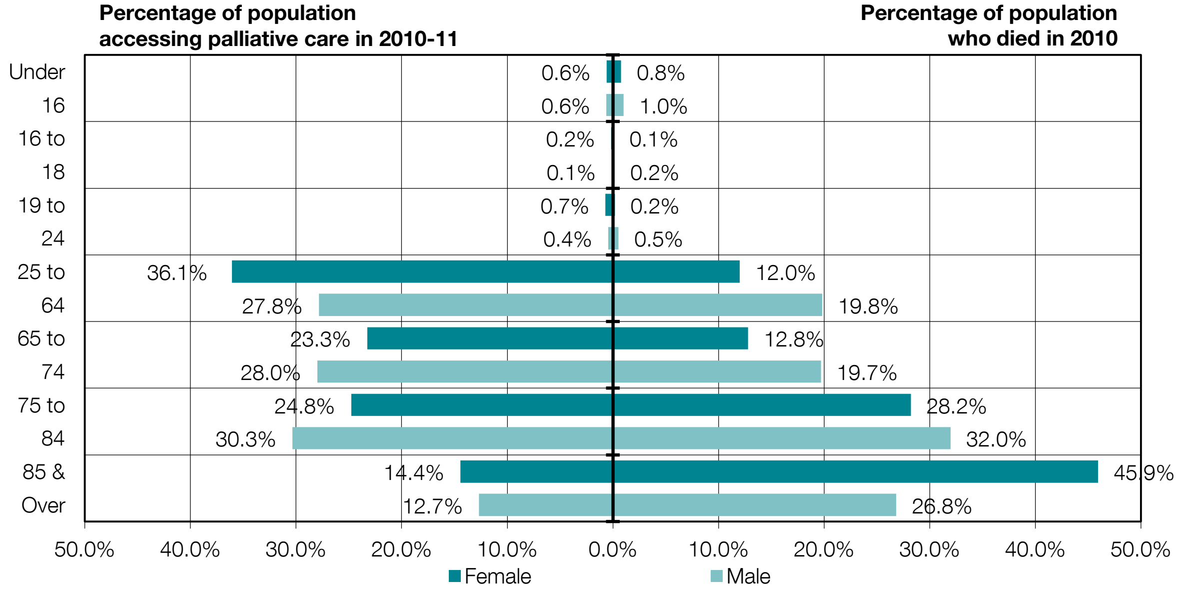
[5] **Trends in emergency admissions in England 2004–2009: is greater efficiency breeding inefficiency?** Nuffield Trust, July 2010.

Age of people accessing palliative care

Comparing data on the breakdown of age and sex in the Minimum Data Set with data on deaths for the United Kingdom in 2010,[6] Chart 6 shows that younger people (aged 25 to 74) have a disproportionately higher access to palliative care for the number dying than the oldest old.

Chart 6: Comparison of age of people accessing palliative care with recorded deaths



This raises important issues about people's needs and access to services. People aged under 75, particularly those aged 25 to 64, are more likely to receive access to specialist services than people aged 85 and over. This should be read in the context of Deaths in Older Adults in England[7] which showed that proportions of deaths from cancer decreased with increasing age (85 and over), in contrast to deaths from cardiovascular disease, 'other' causes and respiratory disease which increased with age. The reasons for this inequity by age may therefore be as much to do with access to services by people with conditions other than cancer, as to whether "older frailer" people need access to specialist services. However it is recommended that commissioners and providers check the age profiles of the local population against those accessing services and consider the reasons for any inequities.

It should also be noted that we do not currently break down data on access to specialist palliative care within the 25 to 64 age group, but anecdotal evidence strongly suggests that access amongst younger adults (25-40 years) is much lower than middle aged people. Again this probably relates to the conditions younger adults have, which adult specialist palliative care traditionally is not geared up for. NCPC continues to work with *Together for Short Lives* and *Help the Hospices*, and more recently *Marie Curie Cancer Care*, on the issue of transition from children's to adults' palliative care services (**www.ncpc.org.uk/transitions**)

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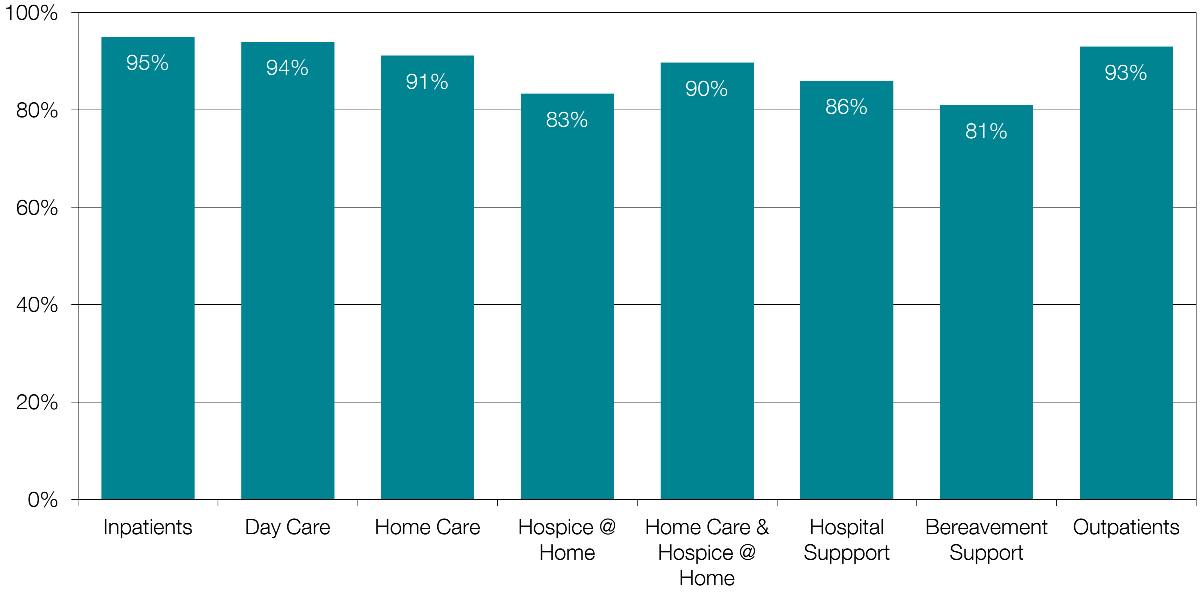
[6] **Death registrations by single year of age, United Kingdom 2010**; ONS December 2011.

[7] **Deaths in Older Adults in England**; National End of Life Care Intelligence Network, 2010.

Ethnicity

Palliative care services are asked to categorise their patients according to the 17 ethnic groupings used by the Department of Health. On average, 87% of respondents did this. The proportion varied however, from 81% for Bereavement Support to 95% for Inpatients services.

Chart 7: Percentage of units returning ethnicity data for new patients



It was found that, on average, 5% of patients were described as non-white, comprising 1% black (African, Caribbean or other), 1% Indian, Pakistani or Bangladeshi, 1% as mixed race, with 1% of other ethnicity including Chinese.

The exceptions to this are Hospice @ Home, which dropped from 84% to 83%, and combined services, which dropped from 94% to 90%.

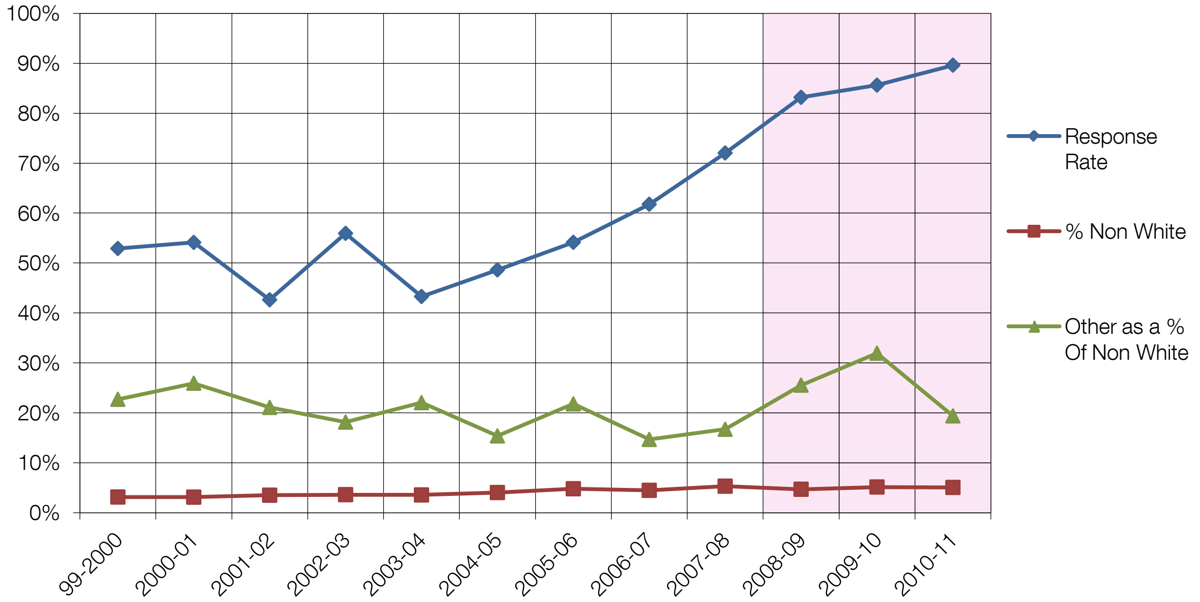
Table 6 also shows that the number of ethnic minority patients is increasing. A total of 8% of the population are reported as being of a non-white ethnicity. (ONS, 2001 Census)

Prior to the 2008-9 collection, ethnicity was collected for the “All patients” form. With the revised MDS, the All Patients form was no longer used and ethnicity was collected across all settings. The overall response rate has continued to rise, as shown in Table 6 and Chart 8, although the rate of increase has slowed slightly.

Table 6: Ethnicity trend data

	2004/5	2005/6	2006/7	2007/8	2008/9	2009/10	2010/11
Response Rate	49%	54%	62%	72%	83%	86%	90%
% Non White	4%	5%	4%	5%	5%	5%	5%
“Other” as a % Of Non White	15%	22%	15%	17%	26%	32%	19%
% Not Known	4%	8%	8%	11%	23%	26%	23%

Chart 8: Ethnicity trends



The shaded area indicates the period in which the revised MDS has been collected.

Although the response rate to the ethnicity questions has improved, and the percentage of non-white patients is increasing, a large proportion of non-white patients had been recorded as ‘Other’. This ranged from 13% in Hospital Support, up to nearly a third (33%) of non-white patients in Outpatients. In the wider population, of those who identify themselves as non-white, 4.9% are in the category “non-white other”[8] but Table 6 shows that an average of 16% are being recorded as such by specialist palliative care services.

As can be seen in Chart 8, there was a gradual downward trend in the percentage of people described as “Other non-white” until the revised MDS was introduced, when numbers increased to 32% for 2009-10. These have now dropped to 19%, but too many patients are still being classified as ‘non-white other’, possibly because staff members are noting that the person is physically not white, but not recording the person’s actual ethnicity.

We **strongly recommend** that services urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health’s 17 ethnic groupings. Only by doing so can specialist palliative care providers be confident that ethnic minority groups have equal access to their services. Previous studies have suggested that this is currently not the case.[9] Resources exist, for example posters from the Dying Matters coalition (**www.dyingmatters.org**), which services can use to try to open up access to all sections of their local communities.

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[8] **2001 Census**; ONS.

[9] **Improving the quality of palliative care**; Race Equality Foundation; 2007.

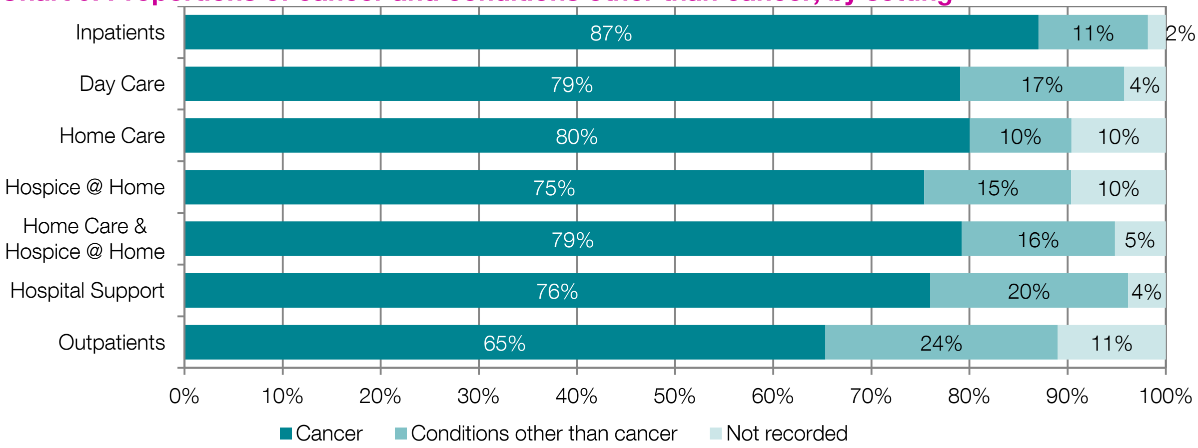
Diagnosis

Conditions other than cancer

Chart 9 shows the proportions of people with conditions other than cancer seen by the different services. It is seen that Outpatient services have the highest percentage at 24%.

This is still a low figure, as cancer accounts for about 28% of all deaths.[10]

Chart 9: Proportions of cancer and conditions other than cancer, by setting



The last 12 years have seen an overall increase in both the percentage and the number of people with diagnoses other than cancer who have been cared for.

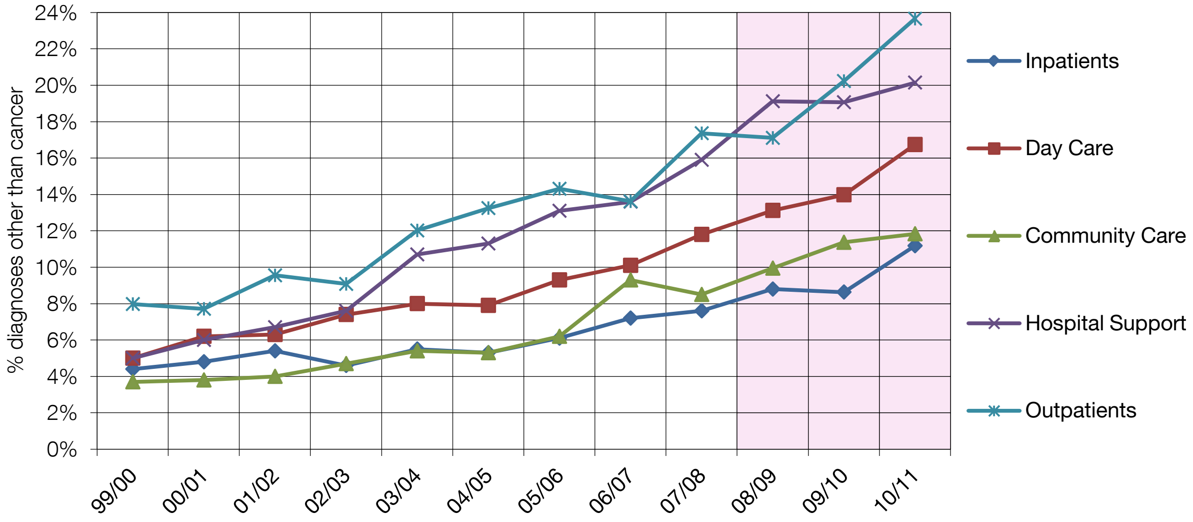
NCPC's Policy Unit (now the Policy and Parliamentary Affairs team) was set up in 2004 to 'produce practical policy solutions for the development of existing palliative care services and the expansion of palliative care services into new disease areas.' As Chart 10 illustrates, the biggest changes have occurred in the last 5 or 6 years.

The most striking increases are in Outpatients (8% to 24%) and Hospital Support (6% to 20%). Day Care is also showing steady increases (5% to 17%). For specialist palliative care inpatient units the proportion of patients with a diagnosis other than cancer has increased from 3% to 11%.

The trend is encouraging, but more remains to be done to ensure that people with diagnoses other than cancer have access to specialist services when needed.

It would be useful to explore to what degree the higher proportion of people with diagnoses other than cancer found in Day Care than in Inpatient setting is appropriate and how much is an indication of further work needed in Community Care and Inpatient settings.

Chart 10: Growth in non-cancer diagnosis



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[10] **Cancer in the UK**; Cancer Research UK; December 2011.

A breakdown of diagnoses other than cancer can be seen in Chart 11.

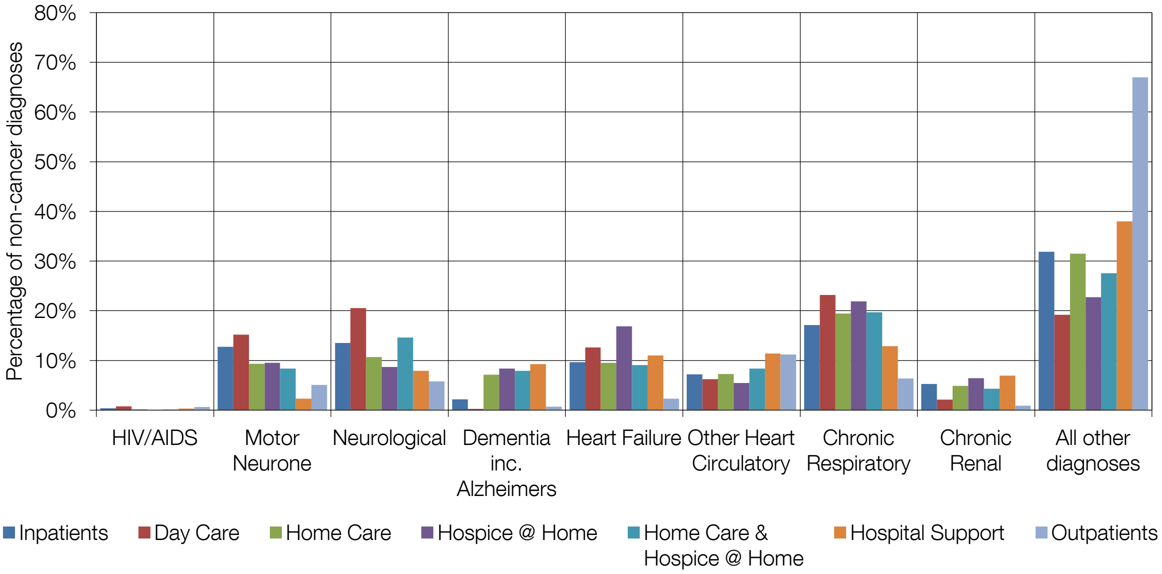
The proportion of "Other" diagnoses other than cancer has increased slightly to 39%, with a range from 19% for Day Care to 67% for Outpatients. We **strongly recommend** that conditions are accurately coded to reflect the conditions being referred and to demonstrate the importance of commissioning services that meet local population needs.

There is debate over the accuracy of the coding of MND diagnoses with regard to the recording of mortality figures by the Office of National Statistics (ONS). Deaths of people with progressive supranuclear palsy (PSP) may have been incorrectly coded as Motor Neurone Disease (MND).[11]

Dementia patients accounted for between 0.2% and 9.3% of diagnoses other than cancer, 0.04% to 1.90% of all patients with a diagnosis. Although a slight increase on last year, national figures show 15% of all deaths are directly attributable to dementia.[12] The number of people who die with dementia, however, is much higher at 1 in 3 people over 65.[13] The MDS is not set up to collect secondary diagnosis at present, so services are **strongly recommended** to track this locally.

It is recommended that responders review their systems to record diagnosis and consider what scope there is for improvement. As with ethnicity, data about primary diagnosis is important to enable measurement of equity of access to specialist palliative care and to enable services to demonstrate what reach they have into the community they exist to serve.

Chart 11: Breakdown of diagnoses other than cancer, by setting



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[11] **NEoLCIN Bulletin No. 1**; June 2010.

[12] **Deaths from Alzheimer's disease, dementia and senility**; NEoLCIN November 2010.

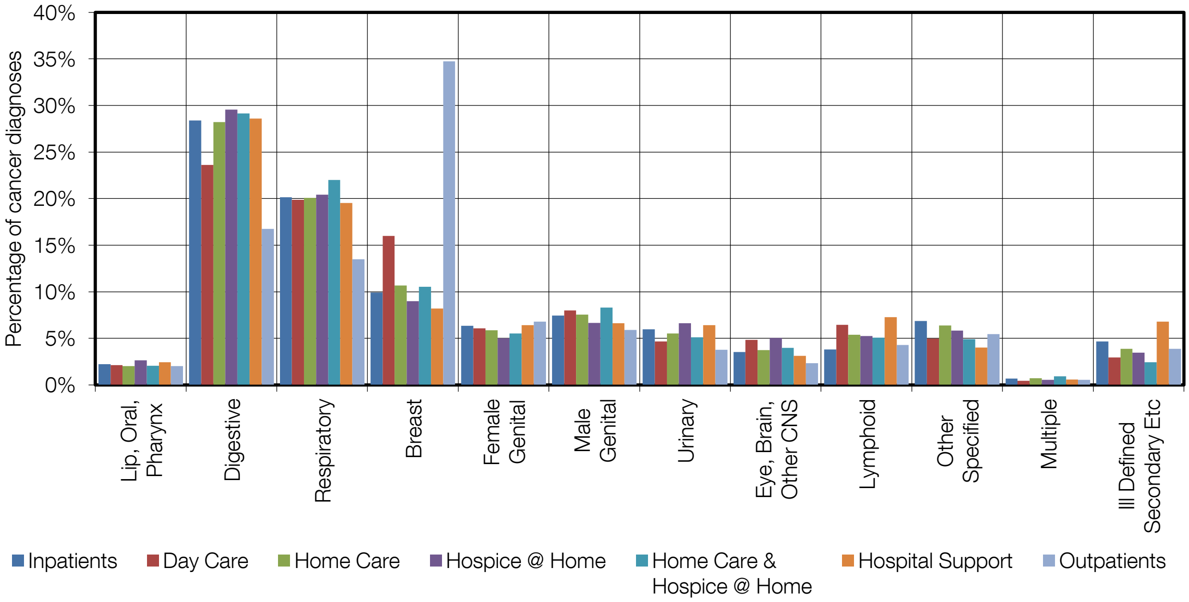
[13] **Dementia before death in ageing societies – the promise of prevention and the reality**; Brayne C et al, PLoS Med 2006; 3; 10.

Cancer diagnoses

The different types of cancer diagnoses can be seen in Chart 12. The highest rates were for cancers of the respiratory and digestive systems.

Breast cancer was diagnosed for the most patients in Outpatient services. This may reflect recent changes in services and the growing specialisation in community services.

Chart 12: Breakdown of cancer diagnoses by setting



Interventions

Inpatient, Day Care and Outpatient services are asked to report on the number of clinical interventions in the year. However this year the number of services responding was again too low to allow any meaningful analysis.

Responses were received from 39 Inpatient (27%), 46 Day Care (32%) and 28 Outpatient units (18%). Table 7 shows the breakdown of interventions for Day Care services.

Table 7: Interventions in Day Care

Intervention	Count	Min	Max	Mean
Blood Transfusion	32	1	66	16
Infusional Therapy	41	1	183	22
Neural Blockade	3	1	18	8
Paracentesis	6	2	20	8

We have not included further tables due to the low response rate for these data. However we can provide further analysis upon request.

As we continue in our vision of helping more people to be able to die in their preferred place of care, community teams will increasingly need to monitor what interventions are being delivered, and in particular, which interventions help to avoid unnecessary admissions to hospital. The Midhurst Macmillan Specialist Palliative Care Service, for example, have used such data to evidence a reduction in hospital admissions by 79% in 2010/11.[14]

This will be an important piece of data in the piloting and introduction of the Palliative Care Funding Review's proposed new funding mechanism. We therefore continue to recommend that services update their systems to record clinical interventions and return this data in the MDS annual collection.

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[14] **National End of Life Care Programme newsletter issue 41**; January 2012.

2. Inpatients

Key findings

- Nearly a third of all diagnoses other than cancer were under “all other conditions”
- Over two thirds of referrals were from the patient’s home
- A quarter of referrals were from an acute hospital
- Average length of stay was 13.5 days for services under independent management, 14.2 days for NHS managed services
- Nearly half of the people referred to an inpatient service (45%) were discharged, which dispels the myth that hospices are a place where people go to die
- 83% of discharges were to home

Responses

Data were collected from those services which provided a specialist palliative care inpatient service during 2010 to 2011, primarily to adults in a dedicated palliative care unit in England, Wales or Northern Ireland. Designated palliative care wards within general hospitals were included, but beds within the general wards of hospitals were excluded.

Data were received from 146 services, a 76% response rate, covering 79% of independent units and 63% of NHS units.

Out of the 146 units who responded, 142 services reported a total of 2,080 beds. The units varied in size from 1 to 51 beds, with a mean of 14.75, the most common size being 10 beds (25 units).

The response rate to individual questions varied between 27% (Interventions) and 99% (Location after Stay) with a mean of 83% and a median of 96%.

Age and sex

Almost a third (30%) of new patients were aged under 65 (33% of new female patients, 28% of new male patients), with fewer than 1% under 25 and 12% over 84 (13% female, 11% male).

Figures for all patients were similar; 32% under 65 (34% female, 29% male), 0.2% under 25, 12% over 84 (13% female, 11% male).

It should be remembered that the MDS collection relates to adult specialist palliative care services. We would therefore not expect any significant level of reporting of activity for people aged below 18, and nor does this data reflect the complete numbers of young people (of at least up to 25 years) accessing specialist palliative care through children’s services. Different services will apply different age criteria on their services and transition from children’s palliative and end of life care services to adults’ is a complex and often underdeveloped area. NCPC is working with Together for Short Lives and Help the Hospices as part of a Transitions Partnership to improve quality of and access to care for young people in transition.

Chart 13: Age and sex of new inpatients

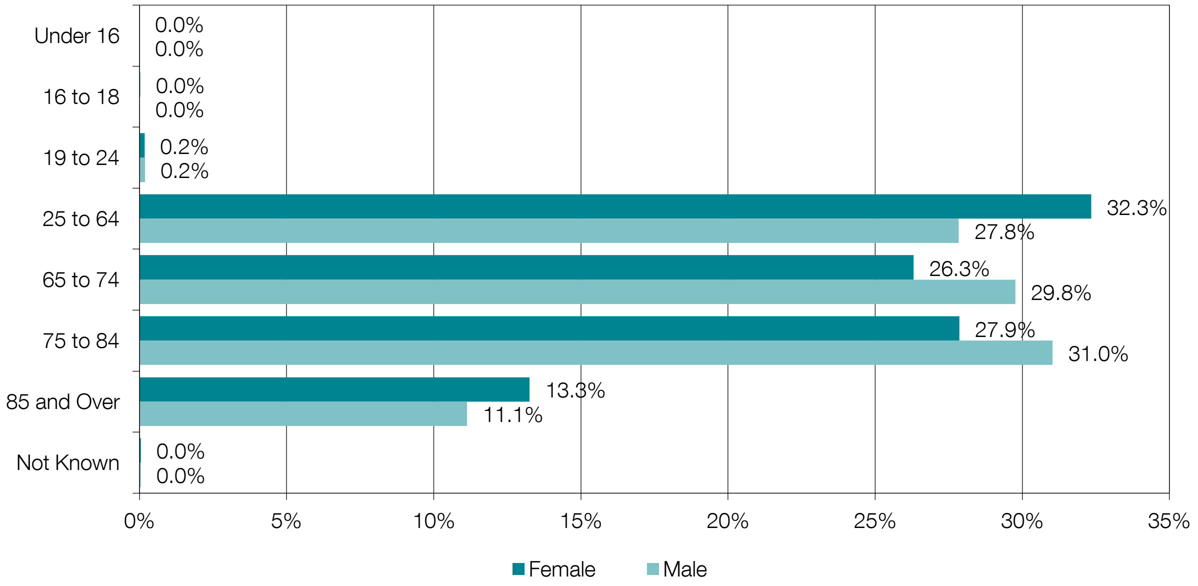


Table 8: Age and sex of inpatients

	New			All		
	Female	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	0	0	**0**	0	1	**1**
16 to 18	4	2	**6**	5	2	**7**
19 to 24	27	30	**57**	31	33	**64**
25 to 64	5,099	4,549	**9,650**	6,114	5,342	**11,487**
65 to 74	4,147	4,864	**9,015**	4,794	5,575	**10,410**
75 to 84	4,393	5,070	**9,465**	5,111	5,773	**10,888**
85 and Over	2,089	1,818	**3,907**	2,337	2,030	**4,367**
Not Known	7	7	**18**	17	17	**38**
Total	**15,766**	**16,340**	**32,118**	**18,409**	**18,773**	**37,262**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Ethnicity

Ethnicity data were collected by 94.5% of Inpatient services. More than three quarters (77%) of new patients were described as White British. A total of 4,822 new patients (15.5%) were 'not recorded'.

The numbers of 'non-white' patients have been grouped together in Chart 14, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 15.

Chart 14: Ethnicity – new inpatients

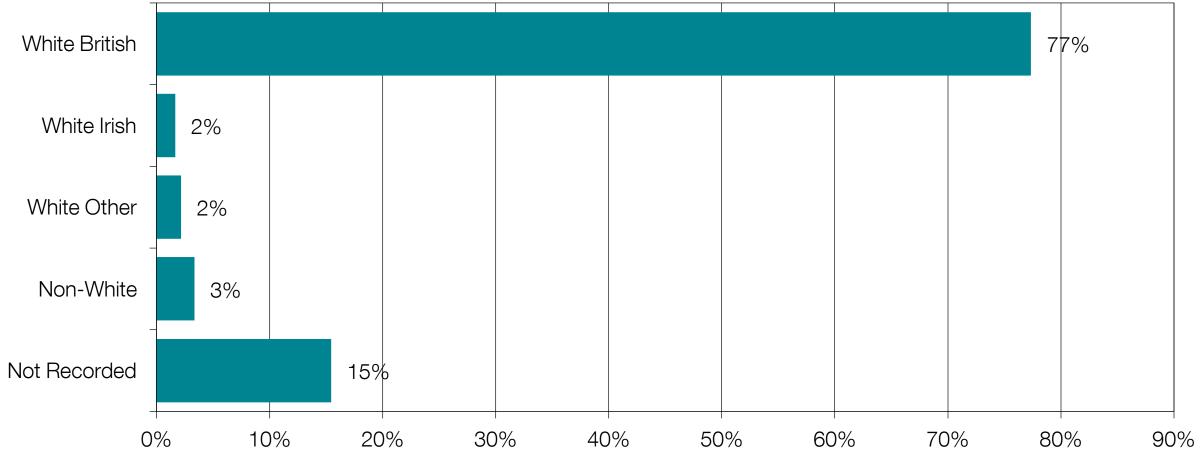
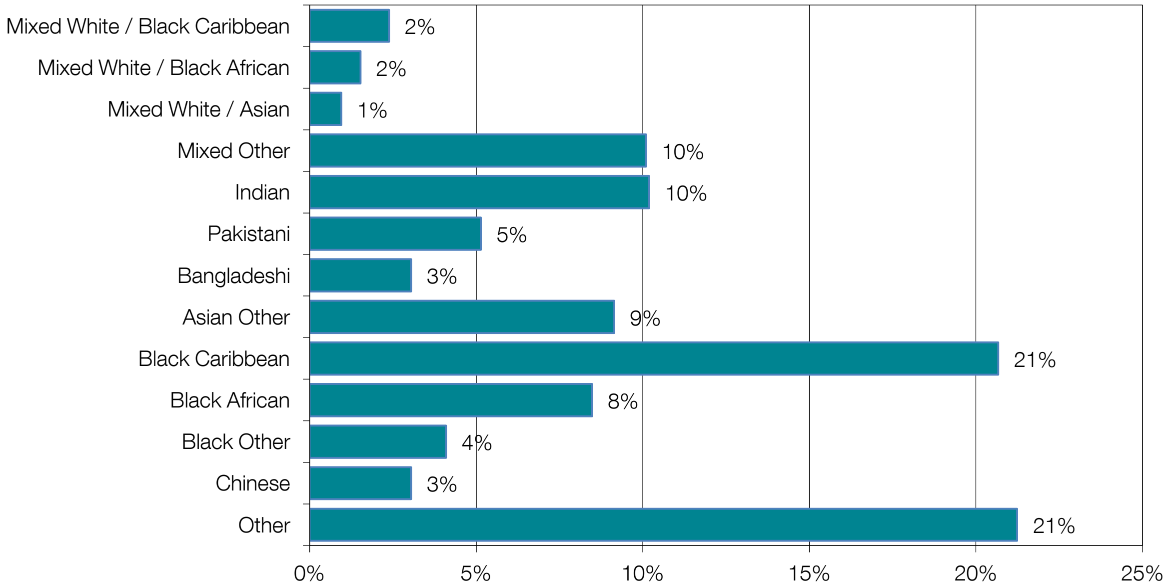


Chart 15: Distribution of "non-white" categories

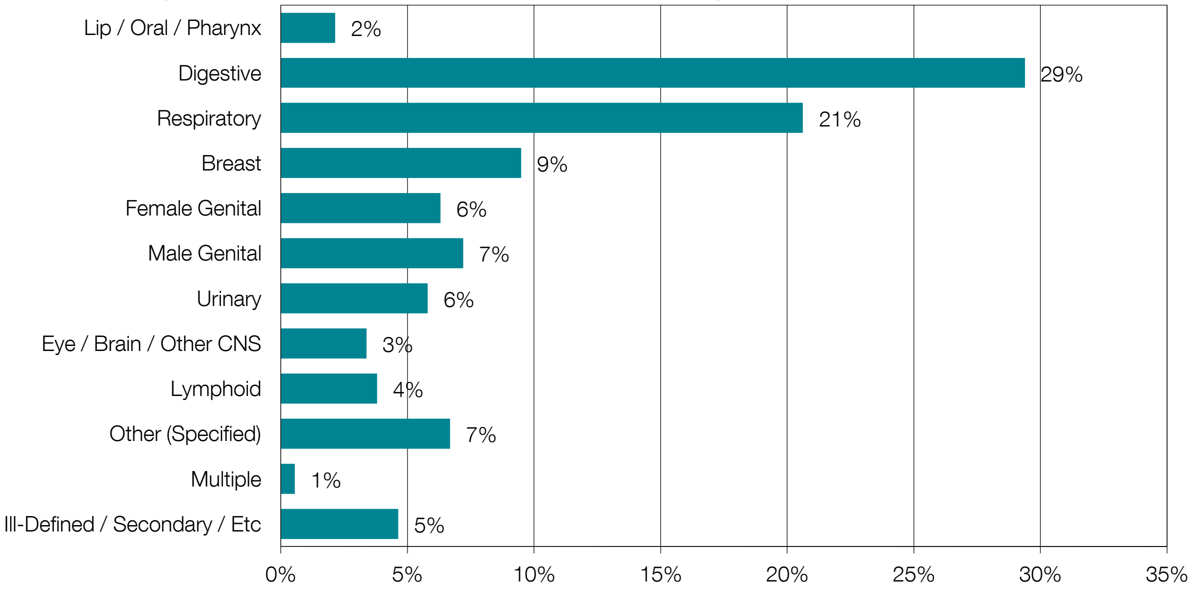


Over a fifth of those recorded as being non-white (21.2%) were under the category 'other'. As we recommend on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 31,325 new referrals to Inpatient units (87%). Cancer figures were divided into 12 diagnoses. Digestive and respiratory cancers accounted for half the diagnoses (50%).

Chart 16: Diagnoses of new inpatients with a primary diagnosis of cancer



Primary diagnosis – conditions other than cancer

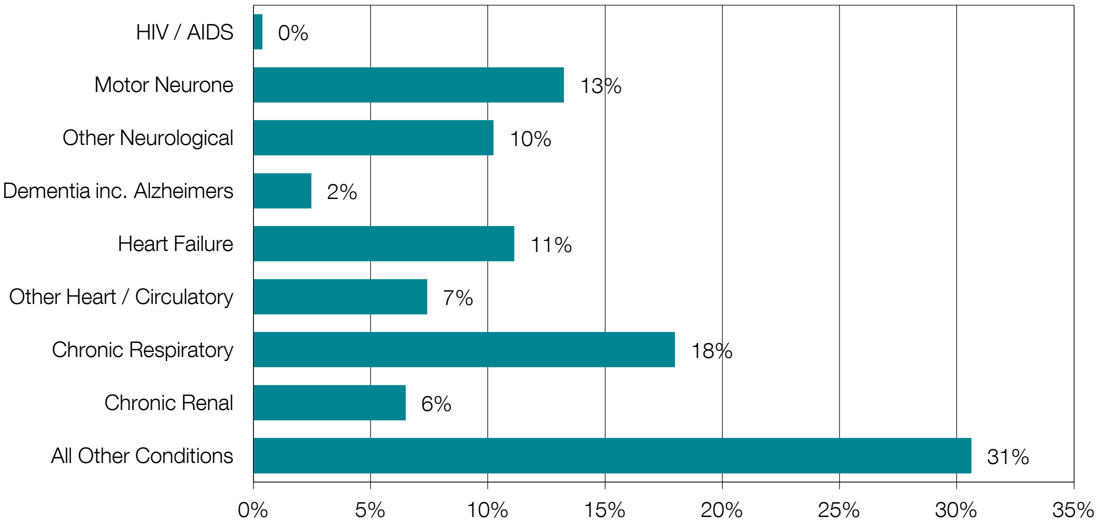
Excluding the patients with a 'not known' diagnosis, 4,024 new patients (11%) had a diagnosis other than cancer. The proportion of new patients in the different units ranged from 1% to 38%. Over a third (36%) of responding units had more than 10% of new patients with a condition other than cancer while 2 units had cancer patients only.

The number of dementia patients recorded was low at just 2%. It should be noted that dementia is often under-diagnosed and we would also expect it to be a secondary condition in a significant number of cases (See further discussion in 'National Overview').

Nearly a third (31%) of diagnoses other than cancer were recorded under 'Other'. It is not possible to say whether these are as a result of un-coded diagnoses, or other unspecified conditions. In the case of the latter, we may need to revise the questionnaire used to collect these data. We would very much welcome services' input on this issue, as it is unacceptable that 1 in 3 people with non-cancer conditions are being admitted to inpatient services but their condition not recorded.

There is a need for accurate coding to reflect the conditions being referred and to demonstrate the need for commissioning services.

Chart 17: Diagnoses of new inpatients with a primary diagnosis other than cancer



Analysis of inpatient stays

Location before admission

The great majority of new admissions (69%) were from the patient's own home, with 25% from an acute hospital.

Chart 18: Location of inpatients before admission

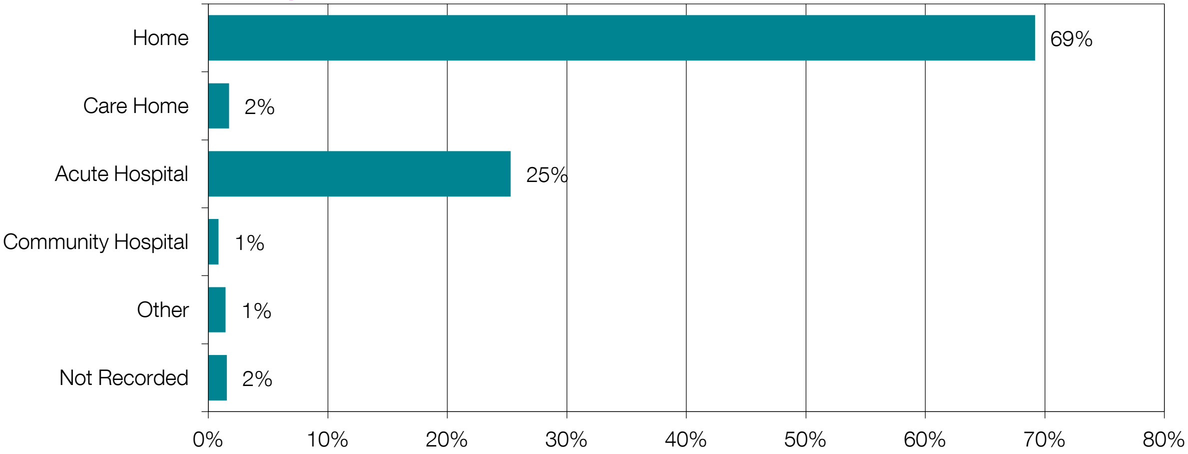


Table 9: Location of inpatients before admission

Location	Count
Home	28,145
Care Home	703
Acute Hospital	10,289
Community Hospital	348
Other	587
Not Recorded	624

Length of stay

The mean length of stay was much the same as for the 2009-10 survey and is shown in Table 10.

The mean length of stay in an NHS-managed inpatient unit was 13.5 days, compared with 14.2 days in an independently-managed unit, see Table 11.

Table 10: Length of stay by size of unit

Number of Beds	3 - 6	7 - 10	11 - 15	16 - 20	21 - 25	Over 25	All Units
Number of responding units	10	39	24	39	3	13	128
Mean length of stay in days	12.4	12.3	12.9	14.2	16.7	15.6	13.7

Chart 19: Length of stay by size of unit

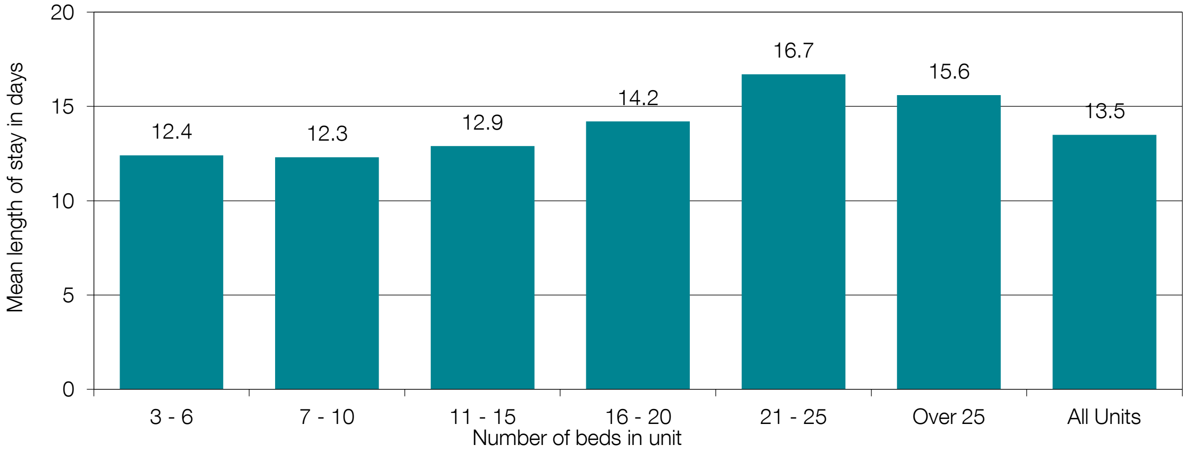


Table 11: Comparison of average length of stay between NHS and independent units

Management	Average Length of Stay
Independent	13.5
NHS	14.2

Location after end of stay

Just over half of those no longer being cared for by the service (55%) had died. The remainder had been discharged; of these, the majority (83%) were discharged to home. The fact that 45% of admissions ended in discharge should go some way to dispelling the myth that hospices are just somewhere where people go to die.

Chart 20: Location after end of stay

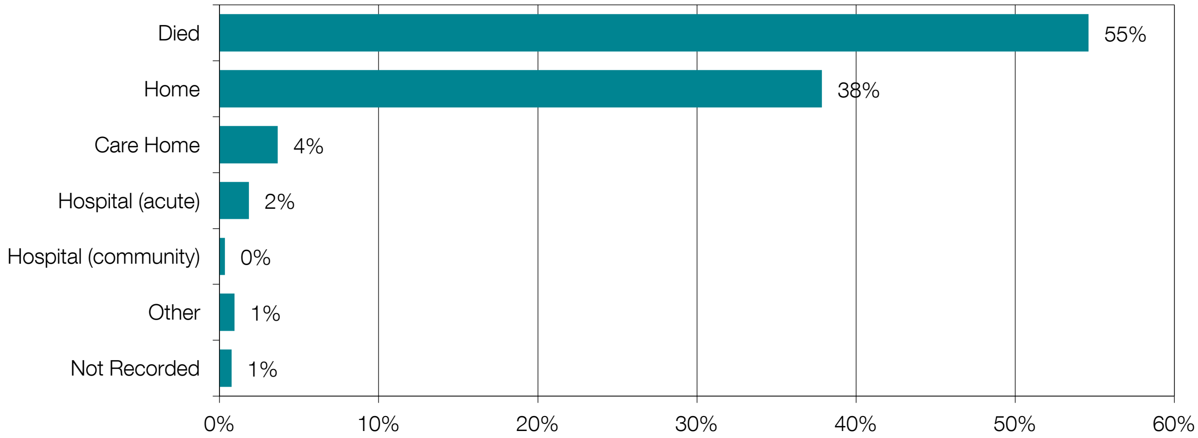


Table 12: Location after end of stay

Location	Died / Discharged	Discharged
Died	54.6%	-
Home	37.8%	83.4%
Care Home	3.7%	8.1%
Hospital (acute)	1.8%	4.1%
Hospital (community)	0.3%	0.7%
Other	0.9%	2.1%
Not Recorded	0.8%	1.7%

Bed usage

Services were asked to calculate the bed occupancy rate from a midnight count of the number of beds actually occupied (or reserved for a patient temporarily away), as a percentage of available beds. Available beds are all those 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.

The mean bed occupancy overall was 75%. The variations in occupancy were between 41% and 100%. The numbers of reserved beds varied considerably, suggesting different ways of counting. There was a mean of 1% reserved beds, as a percentage of beds in use (occupied or reserved) but 43% of units (56) recorded no reserved beds (down from 52% last year) while others recorded up to 12% (down from 14%). Reserved status should only be used where a patient is temporarily away, and not where a new patient is to be admitted the following day. It was impractical to check the validity of this in all cases, but it is known that there has been misinterpretation of this in the past.

The mean value of throughput (admissions per bed per year, including any beds designated for day patients) was 21.8 admissions per available bed, ranging from 9.2 to 53.4 excluding outliers.

The mean turnover interval when a bed is empty between admissions is defined as the number of unoccupied bed days divided by the number of completed stays (including day case admissions). This was found to be 4.2 days, varying between 0.9 days and 9.9 days.

Table 13: Inpatients – Bed usage

Data Item	Minimum	Mean	Maximum	Number Responding	Number of Admissions
% Bed Occupancy	41.3%	73.3%	100.0%	139	40,410
Throughput (Admissions per bed per year)	9.2	21.8	53.4	138	
Turnover (Interval between admissions)	0.9	4.2	9.9	130	

Beds analysis

Over 12 years, an analysis of services reporting on their total number of beds showed:

- The average number of beds per unit has fallen from 15.5 to 14.7
- The average number of patients per unit has increased from 237.2 to 258.1

More patients, with fewer beds would imply that the average length of stay would decrease, whereas it has actually increased from 12.4 to 12.6 days

This has been achieved through an increase in the average number of:

- Available beds per unit, up from 12.9 to 14.2
- Occupied beds per unit, up from 9.7 to 10.7

The average number of available beds per unit has almost reached the average number of total beds per unit.

Chart 21: Bed usage analysis

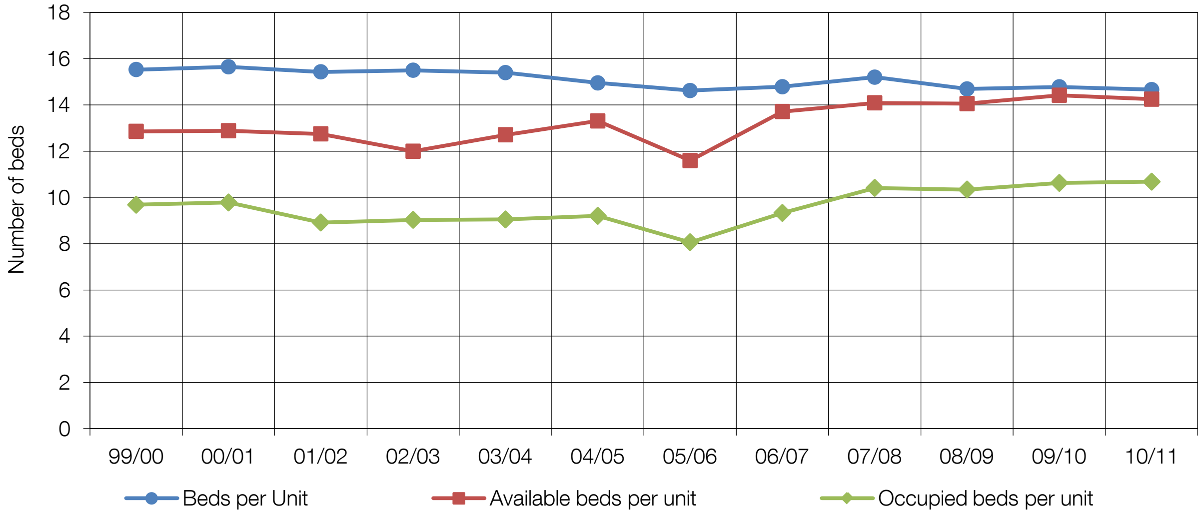


Table 14: Bed usage analysis

MDS year	Total beds per unit	Patients per unit	Mean of length of stay	Available beds per unit	Available beds as percentage of total	Occupied beds per unit	Occupied beds as percentage of available
99/00	15.5	237.2	13.1	12.9	83%	9.7	75%
00/01	15.6	257.3	13.4	12.9	82%	9.8	76%
01/02	15.4	242.9	13.1	12.7	83%	8.9	70%
02/03	15.5	247.6	12.8	12.0	77%	9.0	75%
03/04	15.4	241.4	12.7	12.7	83%	9.0	71%
04/05	14.9	240.3	13.3	13.3	89%	9.2	69%
05/06	14.6	235.6	12.7	11.6	79%	8.1	70%
06/07	14.8	257.0	13.2	13.7	93%	9.3	68%
07/08	15.2	261.6	12.9	14.1	93%	10.4	74%
08/09	14.7	254.3	13.9	14.1	96%	10.3	74%
09/10	14.8	260.1	13.3	14.4	98%	10.6	74%
10/11	14.7	258.1	13.7	14.2	97%	10.7	75%

National estimates

From the data supplied it is possible to make estimates of palliative care activity nationally in terms of admission, deaths and discharges. This makes the assumption that units which did not respond have similar patterns of activity to those which did respond. As there is such a high response rate, it seems likely that estimates based on the data collected will be reasonably accurate. In previous years data has been weighted to allow for varying response rates from the differently sized units, but it has been noticeable that with the improved response rates, there has been little difference between the aggregate data and the weighted data.

The ratio of deaths to discharges has increased from last year's figure of 1.03 to 1.22. In other words, 55% of all admissions (including re-admissions) result in death. The ratio of deaths to new patient admissions is 0.74. This means over a quarter of patients (29%) did not die in a palliative care inpatient unit on the first or any subsequent admission during the year.

Table 15 gives details of admissions, deaths and discharges from those units which responded to all the relevant parts of the survey.

Table 15: National estimates – Inpatient units

	Responding units	National totals and estimates
No of units	142	193
Total beds	2,037	2,769
Response rate for units	74.3%	-
Response rate for beds	97.2%	-
New patient admissions	32,283	43,878
Total patients	36,671	49,842
Deaths	22,828	31,027
Discharges	18,738	25,468
Deaths to discharges	1.22	
Ratio of new patient admissions to deaths & discharges	0.78	
Ratio of deaths to deaths & discharges	0.55	
Ratio of deaths to new patient admissions	0.71	

3. Day Care

Key findings

- The proportion of non-white patients recorded as "Other" has halved, but is still nearly a quarter of total non-white patients
- The mean length of care was six months
- The mean caseload was 53 patients and the median caseload was 45 patients
- Over a quarter of patients with a primary diagnosis other than cancer were diagnosed with chronic respiratory disease
- Nearly a third of new patients with a diagnosis other than cancer had a neurological condition.

Responses

Data were received from 146 services, a 72% response rate, covering 63% of independent units and 27% of NHS units. Some respondents did not answer all the questions, so the response rate for individual questions does vary. The response rate varied between 32% (Interventions) and 98% (Age & Sex and Location before Admission) with a mean of 82% and a median of 91%.

Age and sex

The mean number of new patients per service was 105 with a range from 1 to 696. New patients comprised 67% of the total number attending Day Care. This total included patients already receiving day care at the start of the period, together with any re-referrals of patients discharged in the previous year.

Most services were able to provide details of age and diagnosis for new patients. Nearly a third of new patients were under 65 and of 15,084 new patients there were 37 who were under 25 (0.2%). More females than males attended Day Care (57% female).

Chart 22: Day Care new patients – age and sex

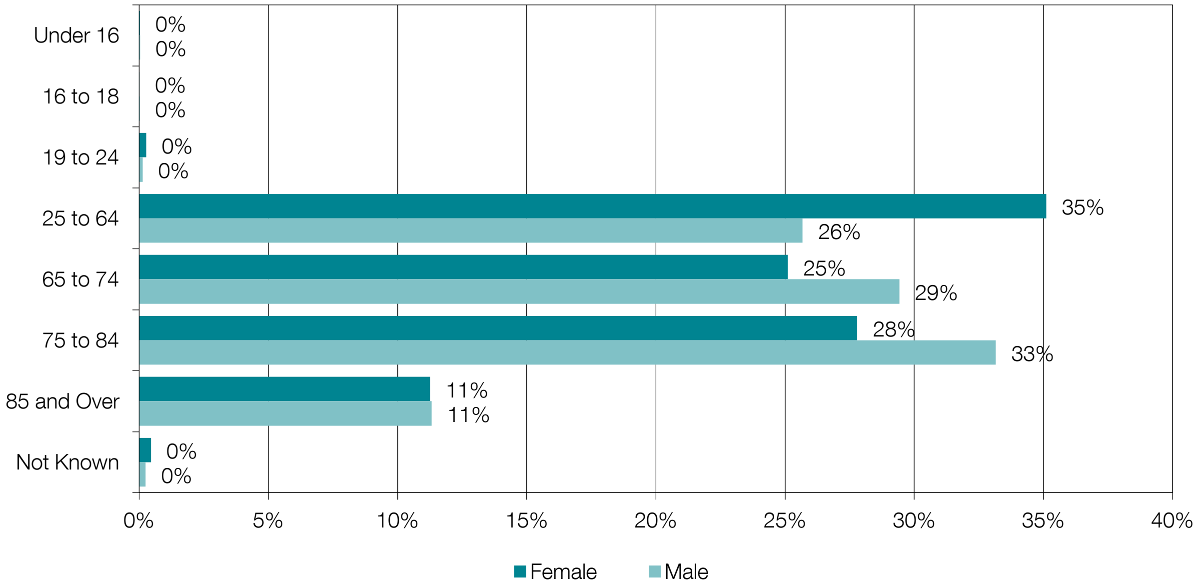


Table 16: Day Care patients – age and sex

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	2	2	**4**	11	7	**18**
16 to 18	1	1	**2**	3	4	**7**
19 to 24	22	9	**31**	37	10	**47**
25 to 64	2,880	1,765	**4,645**	5,350	2,984	**8,334**
65 to 74	2,059	2,023	**4,082**	3,404	3,027	**6,432**
75 to 84	2,280	2,279	**4,560**	3,718	3,390	**7,111**
85 and Over	923	778	**1,701**	1,416	1,149	**2,567**
Not Known	37	17	**59**	62	32	**177**
Total	**8,204**	**6,874**	**15,084**	**14,001**	**10,603**	**24,693**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Ethnicity

Ethnicity data were collected by 94% of Day Care services. More than three quarters (76%) were described as white British. A total of 2,490 new patients (17%) were 'not recorded'.

The numbers of 'non-white' patients have been grouped together in Chart 23, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 24.

Chart 23: Day Care new patients – ethnicity

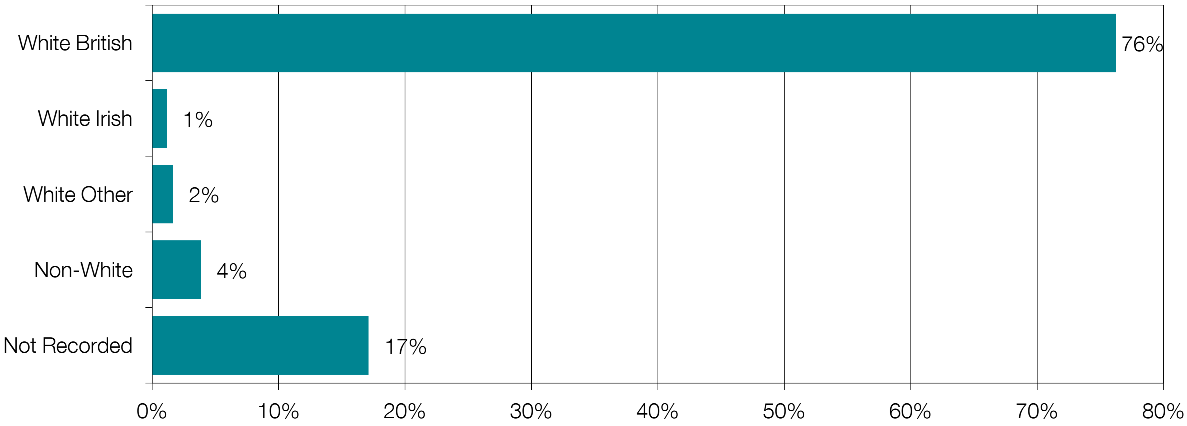
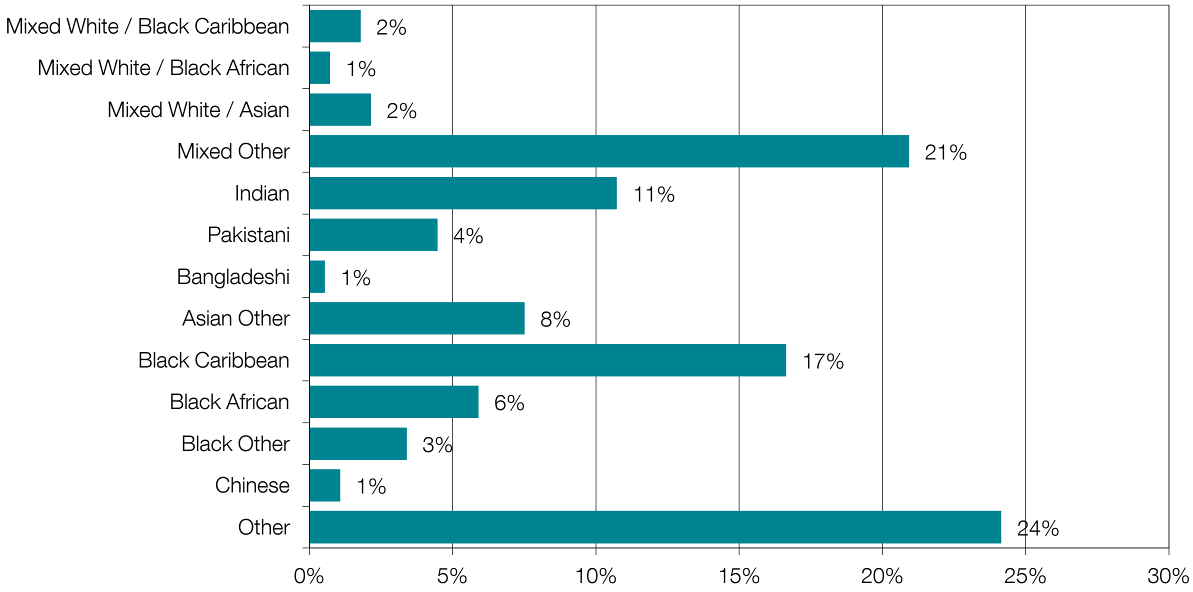


Chart 24: Day Care new patients – non white



Although the number of those under the category 'other' has more than halved from the 50% recorded last year, there are still nearly a quarter (24%) recorded under this category. As we recommended on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 11,609 new referrals to Day Care units (85%). Again, the largest numbers were diagnosed with digestive or respiratory cancers.

There was a higher proportion of patients diagnosed with breast cancer than in Inpatients (14% compared with 9%).

Chart 25: Diagnoses of new Day Care patients with a primary diagnosis of cancer

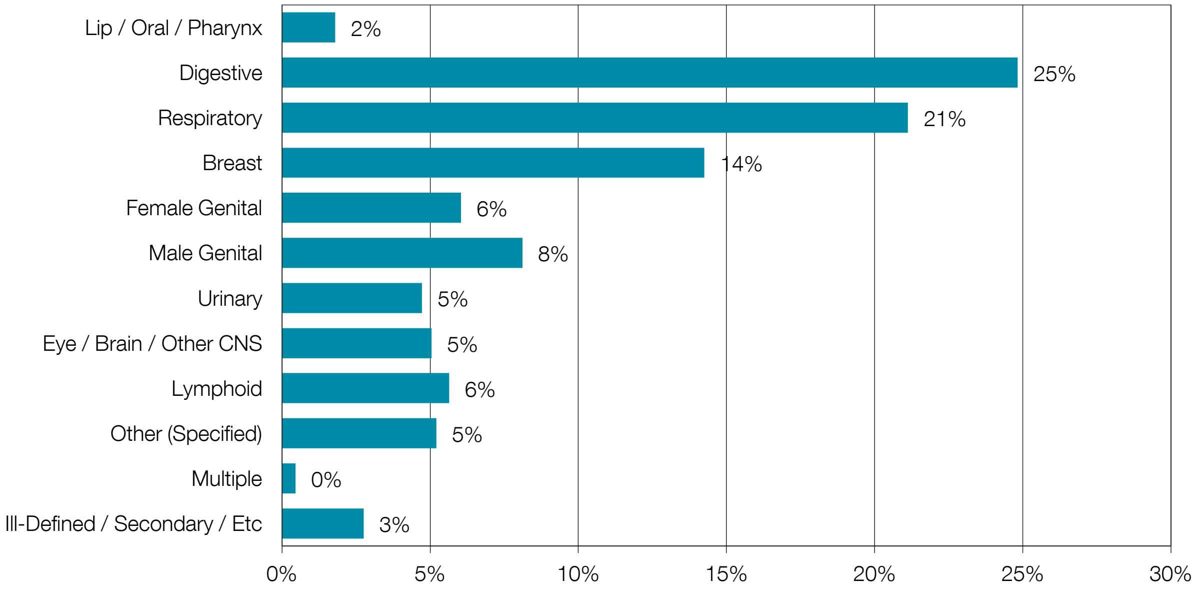


Table 17: Diagnoses of Day Care patients with a diagnosis of cancer

Cancer site	New	All
Lip / Oral / Pharynx	235	398
Digestive	2,965	4,396
Respiratory	2,503	3,700
Breast	1,604	2,976
Female Genital	648	1,131
Male Genital	930	1,488
Urinary	582	869
Eye / Brain / Other CNS	526	899
Lymphoid	638	1,198
Other (Specified)	610	929
Multiple	55	80
Ill-Defined / Secondary / Etc	313	551
Total	**11,609**	**18,615**

Primary diagnosis – conditions other than cancer

Excluding the patients with a 'not known' diagnosis, 2,115 new patients (15%) had a diagnosis other than cancer. Of the 132 services responding, over a quarter (27%) had more than 20% patients, reaching up to over 50% in the case of two services. There were 3 services which recorded no patients with a condition other than cancer.

The proportion of diagnoses other than cancer recorded under "Other" increased slightly from 17% last year to 18% this year.

Chart 26: Diagnoses of new Day Care patients with a primary diagnosis other than cancer

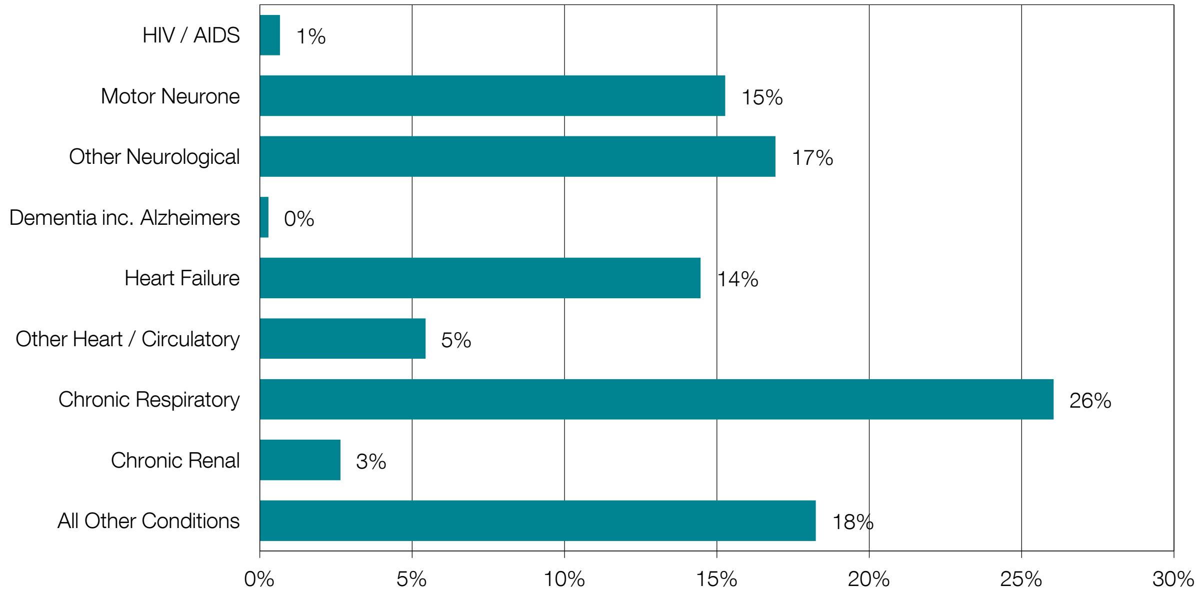


Table 18: Diagnoses of Day Care patients with a primary diagnosis other than cancer

Diagnosis	New	All
HIV / AIDS	14	29
Motor Neurone	323	599
Other Neurological	358	809
Dementia inc. Alzheimer's	6	9
Heart Failure	306	497
Other Heart Circulatory	115	245
Chronic Respiratory	551	915
Chronic Renal	56	84
All Other Non-Cancer	386	756
Total	**2,115**	**3,943**

Access to specialist palliative care in the day care setting for people with dementia is extremely low. As discussed in the National Overview, many people with dementia will have another condition resulting in their dementia being a secondary condition, and as such not captured by the MDS. Nevertheless that only 9 patients with a primary diagnosis of dementia accessed day care in 2010-11 is concerning.

We would **strongly recommend** day care services review their admission policies in relation to diagnosis to ensure that as many people as possible are able to access the benefits of specialist palliative care. Several resources have been developed by NCPC to help services to address this issue.[15]

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[15] **www.ncpc.org.uk/conditions**

Consultations

For the three years that we have collected data on consultations, the figures have varied quite widely. Although 74% of services responded in part to this question, the responses for each health care professional varied from 20% to 62%. It is difficult to know how much this variation is due to services being unable to record the contacts or not having those health care professionals providing consultations.

With the implementation of the Palliative Care Funding Review recommendations, this is a significant area in which services would need to record data.

Face to face consultations

A total of 108 organisations supplied data on the number of face to face consultations made by health care professionals, an increase of 7 on last year. Over a quarter of a million (254,517) consultations were recorded, an increase of 16%.

Table 19: Consultations – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	1,532	0.6%	18.9%	18.0	12.0	49
Other Doctor	11,306	4.4%	56.3%	127.0	84.0	67
Clinical Nurse Specialist	17,108	6.7%	74.9%	180.1	70.5	62
Other Nurse	101,094	39.7%	100.0%	981.5	879.0	91
Physiotherapist	24,200	9.5%	87.8%	249.5	178.0	71
Occupational Therapist	14,221	5.6%	39.5%	161.6	100.5	52
Social Worker	7,172	2.8%	72.5%	84.4	78.5	50
Pastoral / Spiritual Carer	12,654	5.0%	97.4%	147.1	129.0	50
Psychologist / Psychotherapist	3,061	1.2%	21.4%	38.3	22.0	29
Complementary Therapist	37,478	14.7%	99.5%	398.7	417.0	75
Other health care professional	24,335	9.6%	87.7%	286.3	233.0	58
Total	**254,517**			**2,356.6**	**2,111.0**	**108**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding increased from 101 to 108 (+7%)
- Consultations recorded increased from 220,244 to 254,517 (+16%)
- The number of consultations by social workers and complementary therapists dropped. (-12%, -3% and -9% respectively)
- The number of consultations by clinical nurse specialists dropped by 2,242 but one service reported that they had closed their Day Care service and opened a new service without CNS support, reducing their number of consultations by 4,107
- The average increase in contacts was 28%, ranging from +3% for Other Doctors to +54% for medical consultants
- The number of services reporting contacts increased for each type of health care professional, with the exception of social workers with one fewer service reporting and other health care professionals which remained the same
- The average increase in services reporting was 13%, ranging from +4% for occupational therapists to +29% for medical consultants

Comparing the 79 organisations who submitted consultation data for both 2009-10 and 2010-11, the number of first consultations was down overall for most professionals except medical consultants, social workers, chaplains, psychologists and other health care professionals which were slightly up.

Of these 79 organisations, follow up consultations were considerably lower for complementary therapists and clinical nurse specialists, although nearly three quarters of the drop in CNS consultations was down to one service changing the Day Care service they provide. Social Workers and Pastoral / Spiritual Carers showed smaller falls in the number of consultations.

Telephone consultations

A total of 91 organisations recorded telephone consultations, up nearly 10% on last year. However 88,240 consultations were recorded, a decrease of 6% on last year. This was due to a 73% drop in telephone contacts with Clinical Nurse Specialists.

Table 20: Consultations – telephone

Health Care Professional	Telephone contacts		Max	Mean	Median	Services
Medical Consultant	845	1.0%	14.5%	12.2	3.0	24
Other Doctor	2,025	2.3%	100.0%	27.0	18.5	38
Clinical Nurse Specialist	9,338	10.6%	100.0%	118.2	32.0	41
Other Nurse	55,534	62.9%	100.0%	638.3	299.0	81
Physiotherapist	1,244	1.4%	41.9%	16.8	12.5	38
Occupational Therapist	3,327	3.8%	71.7%	46.2	26.0	33
Social Worker	7,499	8.5%	96.0%	107.1	87.0	33
Pastoral / Spiritual Carer	657	0.7%	17.2%	10.1	5.0	17
Psychologist / Psychotherapist	285	0.3%	7.5%	4.3	9.5	16
Complementary Therapist	1,482	1.7%	100.0%	20.3	9.0	31
Other health care professional	3,620	4.1%	99.7%	53.2	22.5	40
Total	**88,240**	**–**	**–**	**969.7**	**591.0**	**91**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding increased from 83 to 91 (10%)
- Telephone consultations recorded by clinical nurse specialists dropped from 34,849 to 9,338 (-73%)
- Other Nurses showed the largest increase in consultations, over 10,000 (+24%)
- Psychologist / psychotherapist and complementary therapist telephone contacts more than doubled (+101% and +141%) and pastoral / spiritual care telephone contacts nearly trebled (+189%)

Comparing the 125 organisations who have submitted telephone contact data for at least one of the last three years, the mean number of contacts has risen from 556 to 970. The median has risen from 410 to 591.

Comparing the 42 organisations who have submitted telephone contact data for all of the last three years, the mean number of contacts has risen from 630 to 1003. The median has risen from 468 to 830.

Deaths and discharges

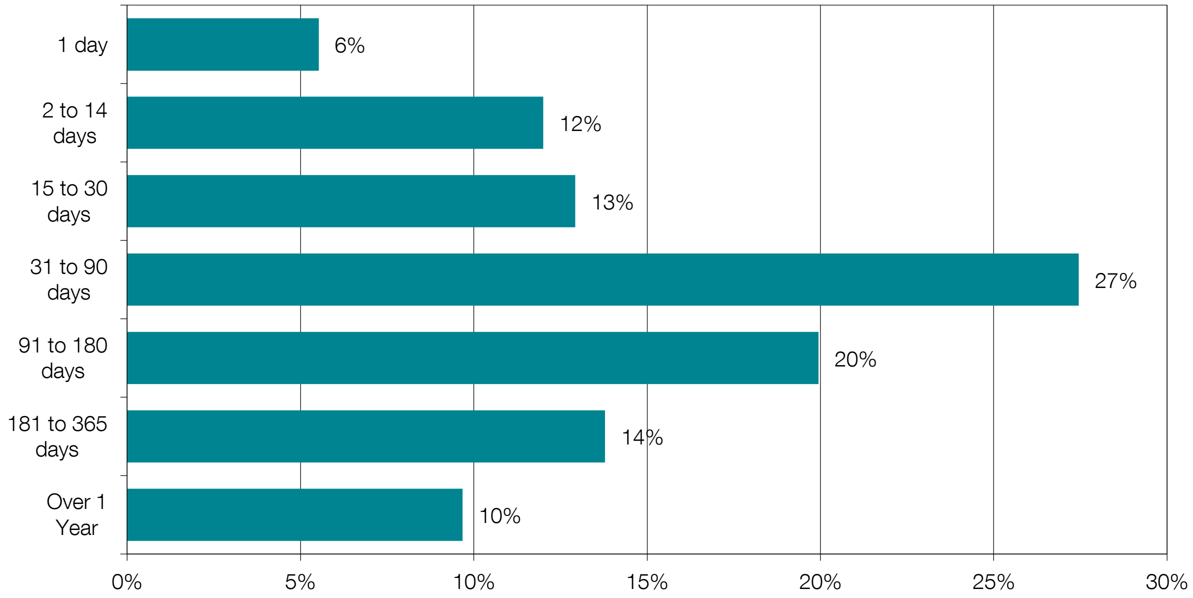
The number of patients who died or were discharged during the year was calculated from the total number of deaths and discharges, minus the number of re-referrals, since each re-referral should account for one discharge.

Overall, 17,291 patients either died or were discharged during the year (68% of all patients).

Length of care and caseload

The length of time patients were under the care of the day centre prior to discharge was given by 133 services (89% of total number). Of 13,889 patients, over half (58%) attended for 90 days or fewer while 24% attended Day Care for more than 180 days. The average length of care recorded was about 6 months, ranging from less than a week to 18 months.

Chart 27: Length of care for Day Care services



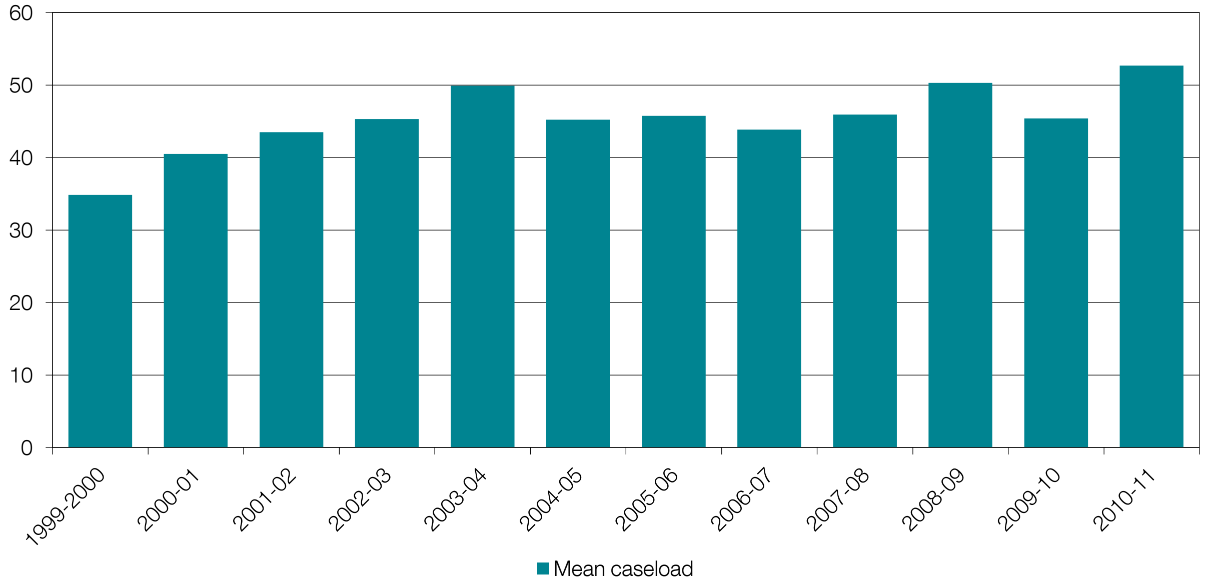
The caseload is the average daily number of patients registered as Day Care patients. It is calculated from the number of deaths and discharges in the year multiplied by the fraction of the year for which they received care.

Using the data shown in Table 21, where the median length of care was found to be 167 days, the mean caseload was 53 patients (up from 45 last year), although the median was lower at 45 patients (36 last year).

Table 21: Patient care

Data Item	Analysis	Results	Services Responding	Number of patients
Average length of care	Mean of service averages	180 days	127 (87.0%)	–
	Median of averages	167 days		
	Range	0.0 to 795.0 days		
Long term patients (registered for more than a year)	% of total number of patients	6.0%	128 (87.7%)	1,519 long term patients
	Range	0.3% to 32.0%		
Caseload	Mean for these services, based on mean length of care	53	127 (88.2%)	17,291 deaths and discharges
	Median based on length of care	45		

Chart 28: Average (mean) caseload trend



Day Care use

A Day Care session is defined as the time that one centre is open on one day. Reports from 89% of the total number of units showed that the average number of sessions per unit per year was 211.8, about 4 per week. This ranged from 52 (one per week) to 418 (about eight per week) with outliers of 623 and 703. (Some services provide day care on more than one site.) There is an average of 14.9 places per session, ranging from 7 to 54. The mean attendance rate is 74% ranging from 46% to 100%.

Table 22: Day Care places

	Results	Number of services responding	Numbers in responding services
Mean no of sessions per year per unit	211.8	130 (89%)	27,531 sessions 402,792 places 230,193 attendances
Range of number of sessions	52 to 418		
Mean number of places per session	14.9		
Range of number of places	7 to 54		
% use of available places	74%		
Range of % use of available places	46% to 100%		

4. Community Services

Key findings

- Mean length of care for Home Care was about 123 days.
- Mean length of care for Hospice @ Home was about 35 days.
- Mean length of care for combined services was about 108 days.
- Proportion of non-white patients recorded as "Other" was lower than in other settings, but the number of "Mixed Other" was much higher for Home Care and Hospice @ Home services (43% and 41% respectively).
- A third of Home Care patients with a diagnosis other than cancer were recorded under "all other conditions".
- A fifth of Hospice @ Home patients with a diagnosis other than cancer were recorded under "all other conditions".
- A quarter of combined services' patients with a diagnosis other than cancer were recorded under "all other conditions".

Defining Home Care, Hospice @ Home and combined services

For the purpose of our analysis we used the following three definitions:

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

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

Responders were asked to indicate if they considered themselves to be providing Home Care, Hospice @ Home or a combined service. The aim is to try to distinguish between primarily advisory services delivered by hospice or NHS based community specialist palliative care teams and other more sustained care provided in the patient's home, commonly referred to as Hospice @ Home.

However, there is currently no agreed definition of Hospice @ Home or Home Care, as services differ widely in purpose, staffing and mode of delivery.

It was decided that any service which did not self identify as Home Care or Hospice @ Home would be grouped according to Clinical Nurse Specialist (CNS) input. Those services stating that they included CNS input were added to the Home Care category while those with no CNS input were added to the H@H category. Those who self-identified as either, or as a combined service, were left in their chosen category, regardless of whether they specified CNS input.

Clearly this is not an ideal long term solution. It would be helpful if definitions could be agreed for different types of community services.

Response

Data was sought from all the palliative care services known to be providing care in the community, primarily to adults, in England, Wales and Northern Ireland during 2010-11.

- 183 units responded, sixteen of which sent two returns and one sent three returns
- 258 units were expected, giving a 71% response rate. NHS-managed services accounted for 39% of returns, whilst 61% were independently-managed
- There were 102 units who identified themselves as Home Care services
- A total of 42 services identified themselves as H@H
- Combined Home Care and H@H services accounted for 39 returns

Table 23: Community Services – responses

Service type	Services responding	Independent management	NHS management
Home Care	102	50%	50%
Hospice @ Home	42	86%	14%
Home Care and Hospice @ Home	39	64%	36%

For Home Care, the response rate for each question varied between 77% (Telephone Details) and 98% (Outcome) with a mean of 86% and a median of 86%.

For Hospice @ Home, the response rate for each question varied between 46% (Telephone Details) and 100% (Age & Sex) with a mean of 80% and a median of 85%.

For combined services, the response rate for each question varied between 69% (Telephone Details) and 97% (Age & Sex, Face to Face and Outcome) with a mean of 86% and a median of 90%.

Age and sex

Home Care

Chart 29 shows patient demographics for Home Care services. On average, each service cared for over 550 new patients, varying between 6 and 1,842 patients. These new patients comprised over two thirds of the total number cared for (68%). This total includes those already receiving care at the start of the year, any re-referrals of those who had received care in a previous year and been discharged, as well as new patients. Over a quarter of these new patients were under 65 (30%) with 17% aged 85 or over.

The breakdown of age and sex was similar for each type of community care service.

Chart 29: Home Care new patients - age and sex

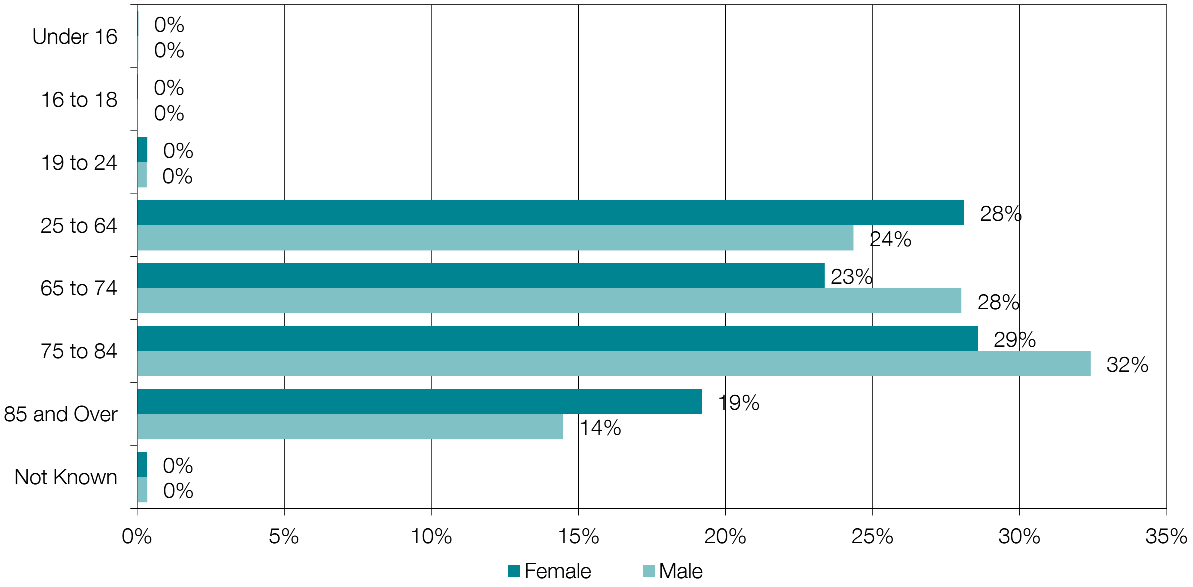


Table 24: Age and sex for Home Care patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	10	11	**21**	19	19	**38**
16 to 18	8	9	**17**	12	18	**30**
19 to 24	90	87	**177**	172	148	**320**
25 to 64	7,309	6,646	**13,956**	12,263	10,099	**22,363**
65 to 74	6,078	7,648	**13,734**	9,379	11,018	**20,426**
75 to 84	7,432	8,846	**16,283**	10,662	12,340	**23,009**
85 and Over	4,989	3,952	**8,932**	6,542	5,117	**11,663**
Not Known	87	95	**194**	116	120	**252**
Total	**26,003**	**27,294**	**53,314**	**39,165**	**38,879**	**78,101**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Hospice @ Home

Chart 30 shows patient demographics for Hospice @ Home services. On average, each service cared for nearly 250 new patients, varying between 15 and 765 patients. These new patients comprised over three quarters of the total number cared for (87%).

This total includes those already receiving care at the start of the year, any re-referrals of those who had received care in a previous year and been discharged, as well as new patients. Nearly a quarter of these new patients were under 65 (24%), with 19% aged 85 or over.

Chart 30: Hospice @ Home new patients - age and sex

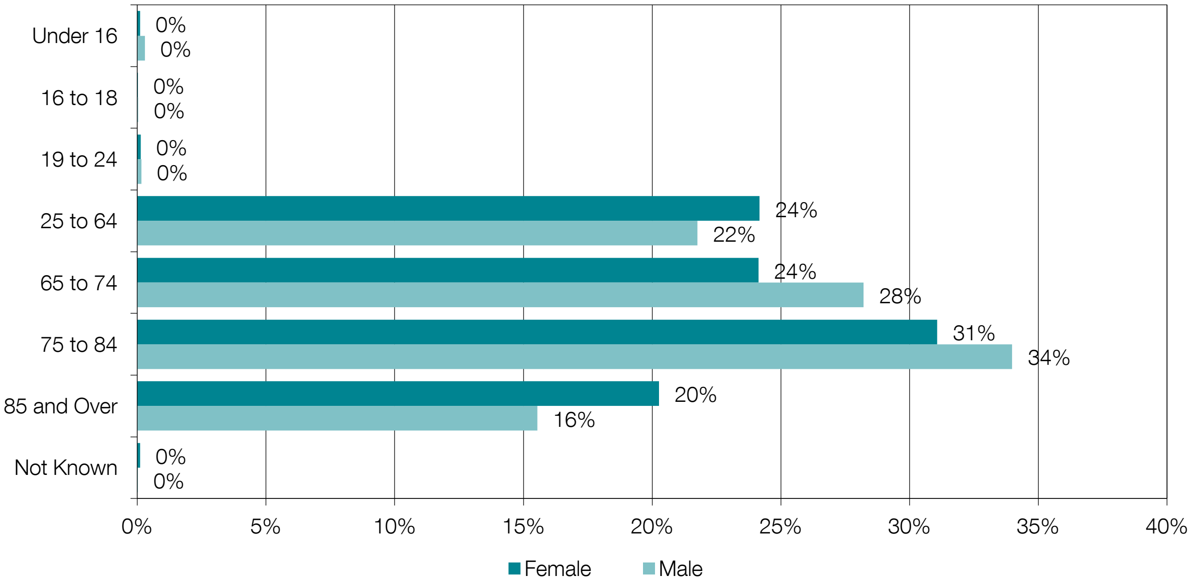


Table 25: Age and sex for Hospice @ Home patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	5	15	**20**	15	32	**47**
16 to 18	1	2	**4**	6	4	**11**
19 to 24	6	8	**15**	25	16	**42**
25 to 64	1,131	1,112	**2,360**	1,267	1,223	**2,607**
65 to 74	1,129	1,442	**2,730**	1,265	1,608	**3,019**
75 to 84	1,454	1,737	**3,425**	1,600	1,921	**3,755**
85 and Over	948	794	**1,846**	1,046	876	**2,019**
Not Known	5	1	**8**	5	1	**8**
Total	**4,679**	**5,111**	**10,408**	**5,229**	**5,681**	**11,508**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Combined Home Care & Hospice @ Home

Chart 31 shows patient demographics for combined Home Care and Hospice @ Home services. On average, each service cared for over 500 new patients, varying between 2 and 2,069 patients. These new patients comprised nearly three quarters of the total number cared for (72%).

This total includes those already receiving care at the start of the year, any re-referrals of those who had received care in a previous year and been discharged, as well as new patients. Over a quarter of these new patients were under 65 (27%), with 19% aged 85 or over.

Chart 31: Combined Service new patients - age and sex

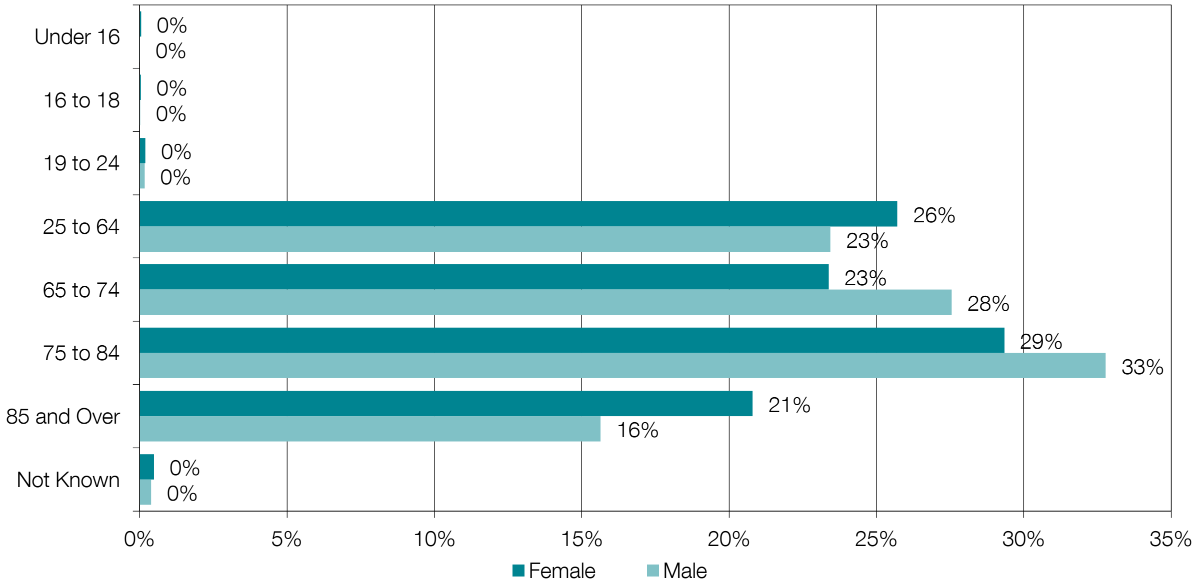


Table 26: Age and sex for combined Home Care & Hospice @ Home patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	5	1	**6**	8	2	**10**
16 to 18	4	2	**6**	5	4	**9**
19 to 24	19	17	**36**	27	28	**55**
25 to 64	2,491	2,375	**4,871**	3,884	3,387	**7,278**
65 to 74	2,265	2,792	**5,060**	3,183	3,846	**7,033**
75 to 84	2,843	3,322	**6,167**	3,809	4,314	**8,125**
85 and Over	2,015	1,585	**3,602**	2,498	1,973	**4,473**
Not Known	47	40	**108**	154	143	**341**
Total	**9,689**	**10,134**	**19,856**	**13,568**	**13,697**	**27,324**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Ethnicity

Ethnicity data were collected from 92% of community services. Nearly three quarters (74%) were described as White British. A total of 11,048 new patients (22%) were 'not recorded'.

The numbers of 'non-white' patients have been grouped together in Chart 32, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 33.

Chart 32: Community Service new patients – ethnicity

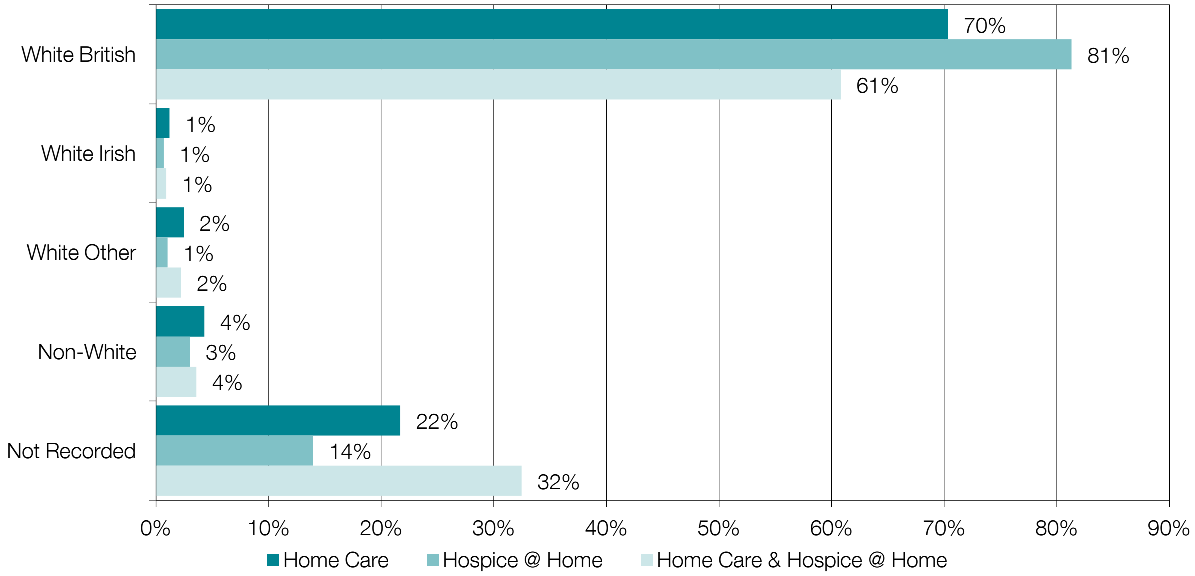
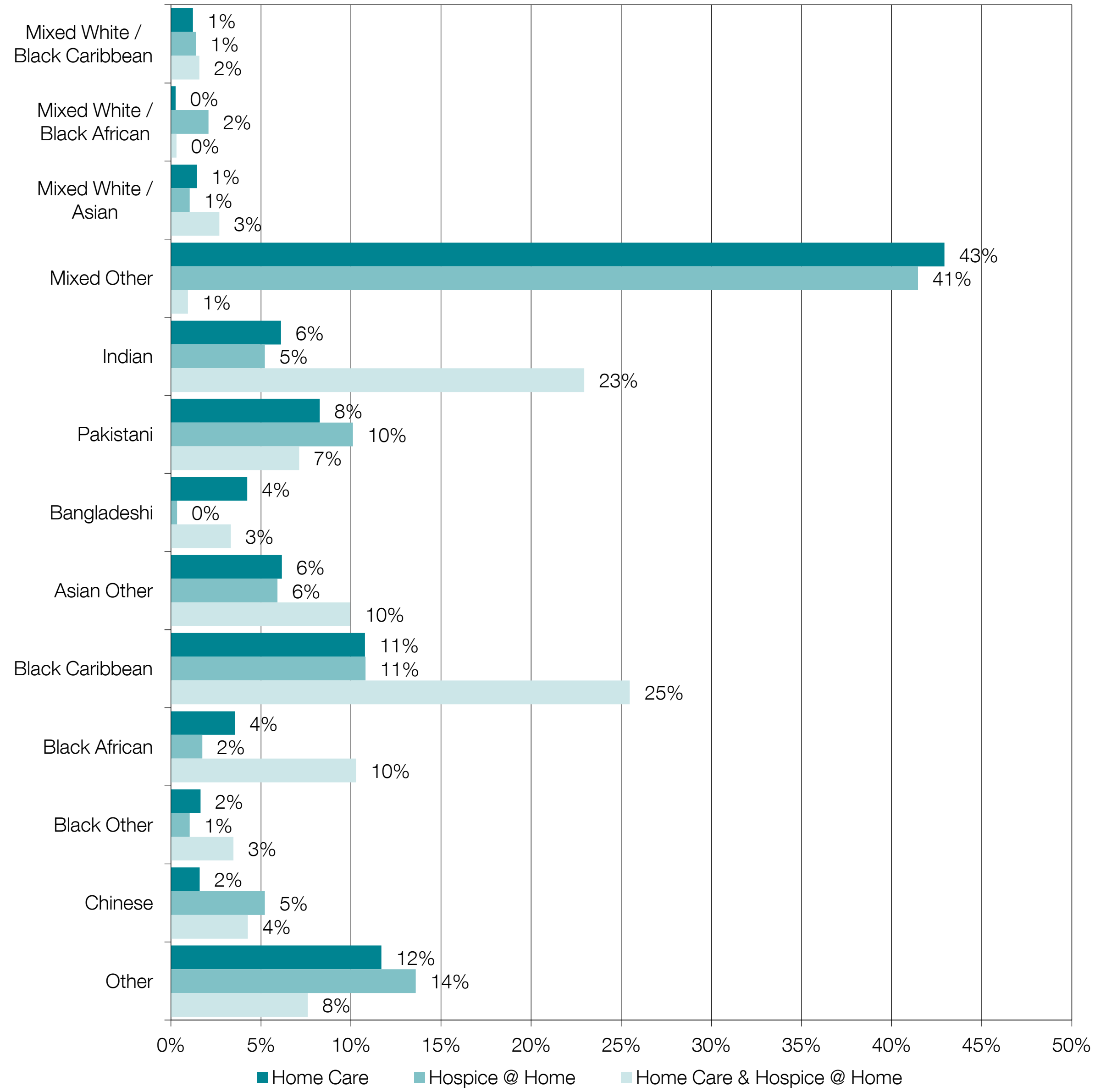


Chart 33: Community Service new patients – non white



The percentage of patients whose ethnicity was recorded as "other" in community care was considerably smaller than in other settings, ranging from 8% to 14%. However both Home Care and Hospice @ Home services recorded over 40% of patients under Mixed Other. No other setting recorded more than 21% of patients under this category.

As we recommend on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings.

Primary diagnosis – cancer

Excluding patients with a 'not known' diagnosis:

- 89% of patients using a Home Care service had a diagnosis of cancer
- 83% of patients using a Hospice @ Home service had a diagnosis of cancer
- 83% of patients using a combined service had a diagnosis of cancer

Although the three service types had a wide variation in the numbers of units responding and a different split between independent and NHS management, the breakdown of diagnosis is very similar for each type of service.

Chart 34: Community Service diagnosis – cancer

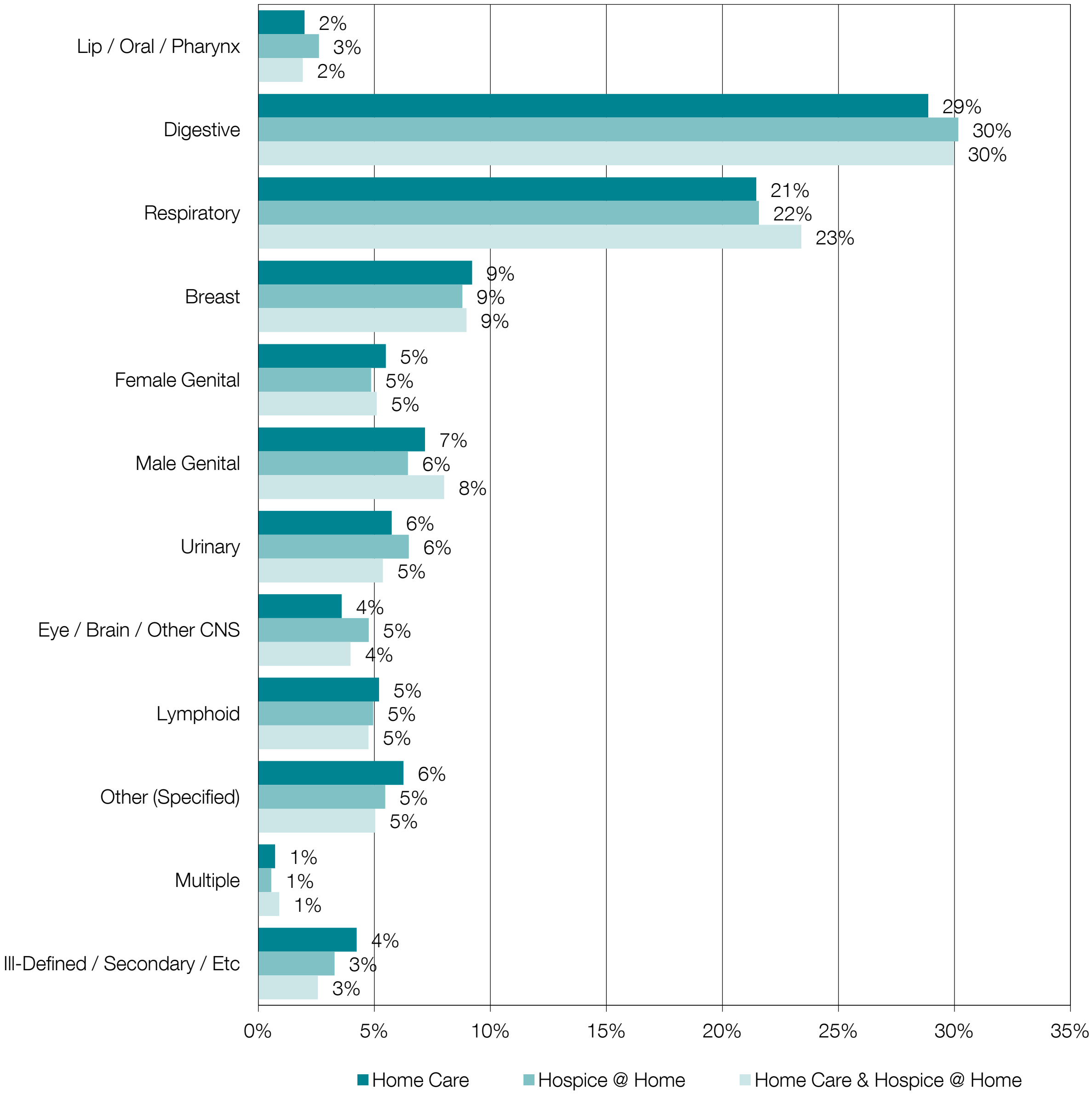


Table 27: Community Care diagnosis – cancer

	Home Care		Hospice @ Home		Combined	
	New	All	New	All	New	All
Lip / Oral / Pharynx	845	**1,265**	173	**187**	241	**365**
Digestive	12,252	**17,629**	1,998	**2,093**	3,769	**5,199**
Respiratory	9,109	**12,546**	1,429	**1,447**	2,943	**3,927**
Breast	3,912	**6,666**	583	**637**	1,129	**1,883**
Female Genital	2,331	**3,663**	322	**354**	642	**986**
Male Genital	3,049	**4,715**	427	**471**	1,008	**1,484**
Urinary	2,441	**3,463**	430	**469**	676	**914**
Eye / Brain / Other CNS	1,524	**2,346**	315	**357**	500	**713**
Lymphoid	2,211	**3,371**	328	**373**	597	**906**
Other (Specified)	2,656	**3,987**	362	**412**	634	**874**
Multiple	307	**442**	37	**38**	113	**165**
Ill-Defined / Secondary / Etc	1,801	**2,421**	218	**246**	323	**435**
Total	**42,438**	**62,514**	**6,622**	**7,084**	**12,575**	**17,851**

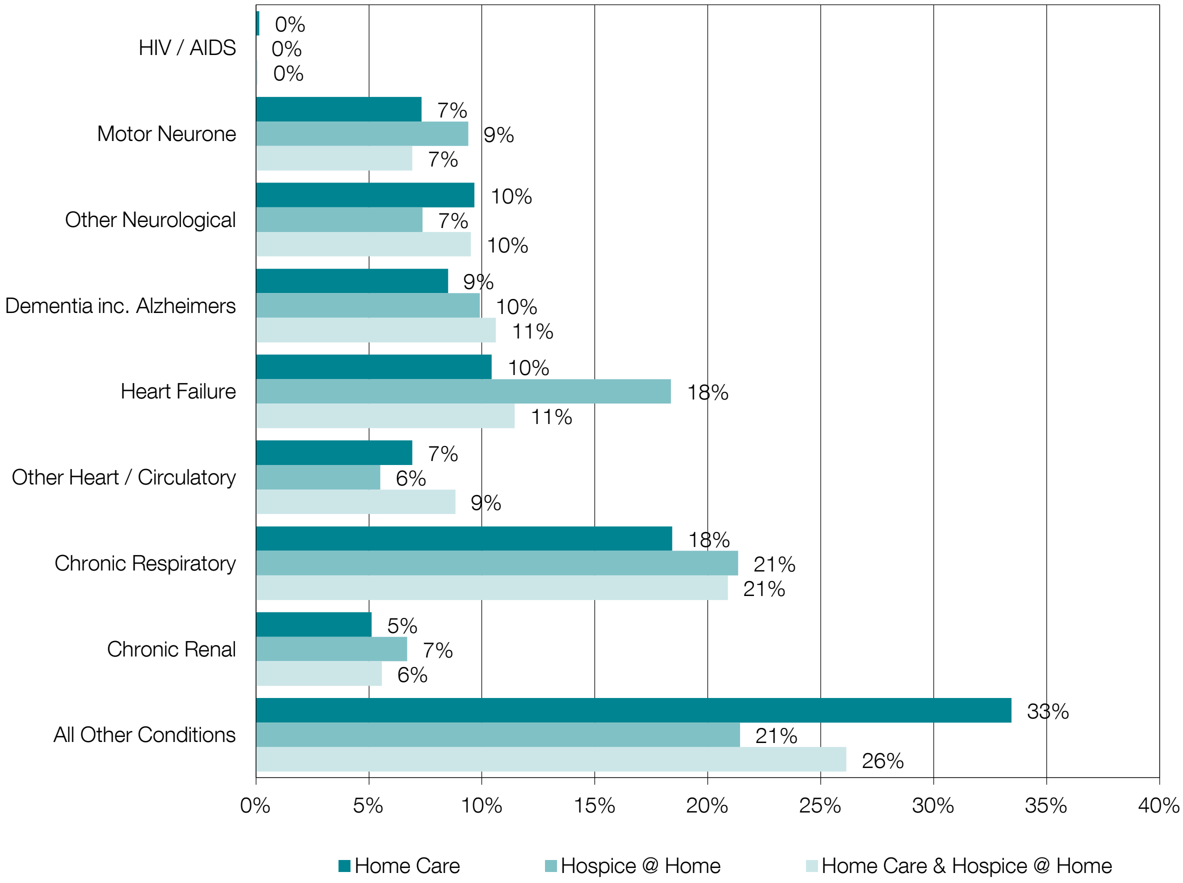
Primary diagnosis – conditions other than cancer

Excluding patients with a 'not known' or 'not recorded' diagnosis, for Home Care services there were 5,659 new referrals (12%) with a primary diagnosis other than cancer. For Hospice @ Home services there were 1,198 new referrals (15%). For combined services there were 2,776 new referrals (15%).

Table 28: Patients with a diagnosis other than cancer in community services

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
New Referrals	5,659 (12%)	1,198 (15%)	2,776 (15%)
Number of Units	88	35	33
Number seeing cancer patients only	1	0	0
Units seeing fewer than 10% of patients with a diagnosis other than cancer patients	40 (46%)	6 (17%)	8 (24%)
Units seeing between 10% and 20% of patients with a diagnosis other than cancer patients	42 (48%)	18 (51%)	20 (61%)
Units seeing more than 20% of patients with a diagnosis other than cancer patients	6 (7%)	11 (31%)	5 (15%)

Chart 35: Community services – patients with a diagnosis other than cancer



The proportions were similar in most categories, with a few exceptions. Combined services saw a higher proportion of dementia patients, and the hospice@home service saw more patients with motor neurone disease, chronic respiratory disease or heart failure.

Once again, the number of 'All Other Conditions' was higher than might have been expected, with over 30% of Home Care new patients in this category. Hospice@Home services recorded far fewer patients under 'Other' than last year.

Table 29: Community Services diagnosis – conditions other than cancer

	Home Care		Hospice @ Home		Combined	
	New	All	New	All	New	All
HIV / AIDS	9	**13**	0	**0**	2	**3**
Motor Neurone	431	**744**	111	**134**	174	**304**
Other Neurological	569	**861**	87	**122**	239	**536**
Dementia inc. Alzheimer's	500	**565**	117	**118**	267	**292**
Heart Failure	614	**753**	217	**237**	288	**339**
Other Heart Circulatory	407	**583**	65	**77**	222	**304**
Chronic Respiratory	1,084	**1,558**	252	**308**	525	**712**
Chronic Renal	301	**382**	79	**91**	140	**165**
All Other Non-Cancer	1,967	**2,642**	253	**320**	657	**862**
Total	**5,882**	**8,101**	**1,181**	**1,407**	**2,514**	**3,517**

Visits

The average number of visits received by each patient during the year was calculated using the total number of visits made by the service divided by the total number of patients seen in the year.

Overall this ranged from 0.4 to 13.7 visits, with a mean of 4.2 visits.

Table 30: Community Services visits

Average number of visits per patient	Range of visits per patient per service	Number of services responding	Numbers in responding services
4.2	0.4 to 13.7	95	76,356 total patients 328,216 visits

Contacts

For the three years that we have collected data on consultations, the figures have varied quite widely.

As with Day Care the response rate to this section also varied quite widely.

Table 31: Response rates to contacts

	Face to Face			Telephone		
Service	Response	Minimum	Maximum	Response	Minimum	Maximum
Home Care	81%	16%	75%	76%	13%	72%
Hospice @ Home	57%	0%	43%	43%	0%	31%
Combined	79%	8%	54%	69%	10%	49%

With the implementation of the Palliative Care Funding Review recommendations, this is a significant area in which services would need to record data.

Home Care

A total of 83 organisations providing home care supplied data on the number of consultations made by a health care professional. Both face to face (first and follow-up) and telephone consultations were recorded.

- The total number of face to face contacts increased, as did the number of services responding
- Both the number of services reporting telephone contacts and the number of contacts recorded increased
- Clinical nurse specialists made up the majority of both types of contacts

Table 32: Home Care contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	4,122	1.2%	100.0%	49.7	51.0	49
Other Doctor	4,015	1.2%	37.6%	48.4	36.0	42
Clinical Nurse Specialist	271,678	82.0%	100.9%	3,273.2	2,622.0	77
Other Nurse	19,445	5.9%	73.9%	234.3	60.0	33
Physiotherapist	6,098	1.8%	37.4%	73.5	127.0	35
Occupational Therapist	6,884	2.1%	42.7%	82.9	123.0	31
Social Worker	5,583	1.7%	83.7%	67.3	86.0	37
Pastoral / Spiritual Carer	1,528	0.5%	16.0%	18.4	14.5	24
Psychologist / Psychotherapist	1,442	0.4%	9.3%	17.4	65.5	16
Complementary Therapist	2,733	0.8%	11.3%	32.9	51.5	22
Other health care professional	7,894	2.4%	48.6%	95.1	40.0	32
Total Face to Face	**331,425**	–	–	**3,993.1**	**3,082.0**	**83**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- The number of services responding overall increased from 80 to 83 (+4%)
- Contacts recorded increased from 301,653 to 331,425 (+10%)
- Clinical nurse specialists showed the largest increase in recorded contacts, nearly 22,000
- Pastoral / spiritual carers had the largest proportional increase; nearly four and a half times the previous year's number of contacts were recorded
- Other nurses' contacts also increased by nearly 3,000
- Having almost halved last year, contacts by other health care professionals increased by over 2,000 this year
- Contacts reported by other doctors dropped by almost a quarter (-24%, 1,267 fewer contacts)

Table 33: Home Care contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	4,983	0.8%	34.8%	63.9	55.0	35
Other Doctor	5,181	0.8%	25.1%	66.4	33.0	35
Clinical Nurse Specialist	542,530	85.9%	100.0%	6,955.5	5,478.0	73
Other Nurse	19,912	3.2%	67.1%	255.3	182.5	34
Physiotherapist	3,818	0.6%	23.1%	48.9	106.0	27
Occupational Therapist	6,995	1.1%	64.3%	89.7	320.0	22
Social Worker	15,755	2.5%	95.2%	202.0	199.5	32
Pastoral / Spiritual Carer	1,117	0.2%	5.3%	14.3	20.0	17
Psychologist / Psychotherapist	1,217	0.2%	3.4%	15.6	53.0	13
Complementary Therapist	959	0.2%	6.5%	12.3	41.5	16
Other health care professional	16,885	2.7%	100.0%	216.5	22.5	30
Total Telephone	**631,788**	**–**	**–**	**8,099.8**	**5,656.0**	**78**

“Services” shows the number of organisations which reported at least one contact with each health care professional.

- Services responding increased from 68 to 78 (+15%)
- Contacts recorded increased from 596,708 to 631,788 (+6%)
- Telephone contacts by social Workers was the only category which recorded a drop in contacts, from 15,987 to 15,755 (-1.5%)

Hospice @ Home

A total of just 24 organisations providing Hospice @ Home services supplied data on the number of consultations made by a health care professional. Both face to face (first and follow-up) and telephone consultations were recorded. As would be expected by the nature of the service, consultations by clinical nurse specialists were much lower than for Home Care and accounted for 14% of face to face and 32% of telephone contacts.

Table 34: Hospice @ Home contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	8	0.0%	3.2%	0.3	4.0	2
Other Doctor	6	0.0%	2.6%	0.3	3.0	2
Clinical Nurse Specialist	8,346	14%	100.0%	347.8	1,066.5	6
Other Nurse	35,129	58%	100.0%	1,463.7	1,166.5	18
Physiotherapist	162	0.3%	3.9%	6.8	162.0	1
Occupational Therapist	19	0.0%	100.0%	0.8	2.5	4
Social Worker	0	0.0%	0.0%	0.0	0.0	0
Pastoral / Spiritual Carer	2	0.0%	0.5%	0.1	1.0	2
Psychologist / Psychotherapist	2	0.0%	0.3%	0.1	1.0	2
Complementary Therapist	958	2%	14.3%	39.9	112.5	8
Other health care professional	16,421	27%	100.0%	684.2	1,219.0	11
Total Face to Face	**61,101**	**–**	**–**	**2,545.9**	**1,925.5**	**24**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding decreased from 34 to 24 (-29%)
- Contacts recorded increased from 58,855 to 61,101 (+4%)
- Clinical nurse specialists and other health professionals were the only professionals to show significant increases. (Psychologist / psychotherapists also reported one extra contact from one extra service, double last year's figures)
- Other nurse contacts dropped by nearly 1,435 (-4%) while the number of services reporting contacts decreased by 8 (-31%)
- No contacts were reported by social workers

Table 35: Hospice @ Home contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	0	0.0%	0.0%	0.0	0.0	0
Other Doctor	4	0.0%	0.1%	0.2	4.0	1
Clinical Nurse Specialist	23,643	32.0%	100.0%	1,313.5	692.5	6
Other Nurse	46,176	62.5%	100.0%	2,565.3	2,254.0	13
Physiotherapist	113	0.2%	1.4%	6.3	113.0	1
Occupational Therapist	9	0.0%	0.1%	0.5	4.5	2
Social Worker	23	0.0%	100.0%	1.3	23.0	1
Pastoral / Spiritual Carer	0	0.0%	0.0%	0.0	0.0	0
Psychologist / Psychotherapist	0	0.0%	0.0%	0.0	0.0	0
Complementary Therapist	95	0.1%	0.8%	5.3	14.5	4
Other health care professional	9,596	13.0%	100.0%	533.1	623.0	7
Total Face to Face	**73,939**	**–**	**–**	**4,107.7**	**2,094.0**	**18**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding decreased from 22 to 18 (-18%)
- Contacts recorded increased from 45,486 to 73,939 (+63%)
- No contacts were recorded by psychologists / psychotherapists for the second year in a row.
- Medical consultants and pastoral / spiritual carers also recorded no telephone contacts this year.

Home Care and Hospice @ Home

A total of 31 organisations providing combined Home Care and Hospice @ Home services supplied data on the number of consultations made by a health care professional. Both face to face (first and follow-up) and telephone consultations were recorded.

- The combined services' contacts are dominated by Clinical Nurse Specialists, although the number of contacts by Other Nurses is increasing for both face to face and telephone

Table 36: Combined Home Care and Hospice @ Home service contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	869	0.6%	100.0%	28.0	37.0	11
Other Doctor	1,626	1.2%	5.1%	52.5	51.0	14
Clinical Nurse Specialist	89,026	65.6%	100.0%	2,871.8	3,120.0	19
Other Nurse	27,683	20.4%	100.0%	893.0	619.0	21
Physiotherapist	1,536	1.1%	100.0%	49.5	60.0	14
Occupational Therapist	2,065	1.5%	26.1%	66.6	32.5	12
Social Worker	3,385	2.5%	14.8%	109.2	220.5	10
Pastoral / Spiritual Carer	262	0.2%	1.6%	8.5	22.0	5
Psychologist / Psychotherapist	261	0.2%	11.8%	8.4	78.0	3
Complementary Therapist	3,400	2.5%	88.2%	109.7	111.5	10
Other health care professional	3,044	2.2%	33.3%	98.2	191.0	8
Total Face to Face	135,645	–	–	4,375.6	2,389.0	**31**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding increased from 23 to 31 (+35%)
- Contacts recorded increased from 76,247 to 135,645 (+78%)
- Clinical nurse specialist contacts more than doubled, while other nurses' contacts increased by 26%. There are now more than three times as many contacts by clinical nurse specialists as other nurses
- Contacts by Medical Consultants dropped by nearly a half (-44%)

Table 37: Combined Home Care and Hospice @ Home service contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	852	0.3%	100.0%	31.6	19.0	10
Other Doctor	1,494	0.5%	5.6%	55.3	11.5	12
Clinical Nurse Specialist	186,044	61.0%	100.0%	6,890.5	6,958.0	18
Other Nurse	89,052	29.2%	100.0%	3,298.2	1,189.0	19
Physiotherapist	961	0.3%	100.0%	35.6	16.0	11
Occupational Therapist	2,503	0.8%	4.7%	92.7	40.0	9
Social Worker	6,261	2.1%	72.7%	231.9	473.0	10
Pastoral / Spiritual Carer	2,057	0.7%	3.1%	76.2	23.0	7
Psychologist / Psychotherapist	225	0.1%	0.8%	8.3	50.0	4
Complementary Therapist	3,547	1.2%	16.9%	131.4	160.0	6
Other health care professional	3,933	1.3%	40.8%	145.7	190.0	8
Total Face to Face	**305,230**	**–**	**–**	**11,304.8**	**4,022.0**	**27**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding increased from 23 to 27 (+17%)
- Contacts recorded increased, from 191,992 to 305,230 (+59%)
- Telephone contacts by complementary therapists decreased 8%, but all other professionals reported an increase in contacts
- The number of Clinical Nurse Specialist telephone contacts increased by 21,879 (12%)

Deaths and discharges

There is some variation in the way services record the numbers of people who are discharged from a service and those who die while they are receiving care from the service. Some services automatically discharge any patient who is admitted to an Inpatient unit, but the patient may return home and be re-referred, whereas other services will not discharge the patient at every admission to another setting.

Deaths accounted for 59% of the patients no longer receiving care from the Home Care teams, 70% of those cared for by H@H teams and 67% for combined teams. For the Home Care teams, home deaths accounted for 29% of new patients, ranging from 6% to 48% with an outlier of 0.3%. For H@H teams there was a higher percentage of home deaths (53%), ranging from 22% to 88% with an outlier of 102%. For combined teams there were 38% home deaths, ranging from 14% to 97%.

As in the case of Day Care services, it might be expected that in the majority of cases the number of deaths and discharges would be approximately the same as the number of new patients. This assumes that there are only a small number of re-referrals of patients who had previously been discharged within the same or the previous year, and that the staffing provision does not alter. However, for the Home Care teams the number of deaths and discharges varied from 40% to nearly two and a half times the number of new patients (247%). For the H@H teams the range was from 78% to 180% while for the combined teams the range was 50% to 211%. Overall, for the Home Care teams there were 16% more deaths and discharges than new patients. For the H@H team the figure was 3% and for the combined teams the figure was 14%.

Table 38: Deaths and discharges for Community Services

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
Deaths as % of deaths & discharges	59%	70%	69%
Range	1.6% to 100.0%	9.2% to 100.0%	23.1% to 100.0%
Home deaths as % of all patients	20%	48%	29%

Chart 36: Community Services – place of death

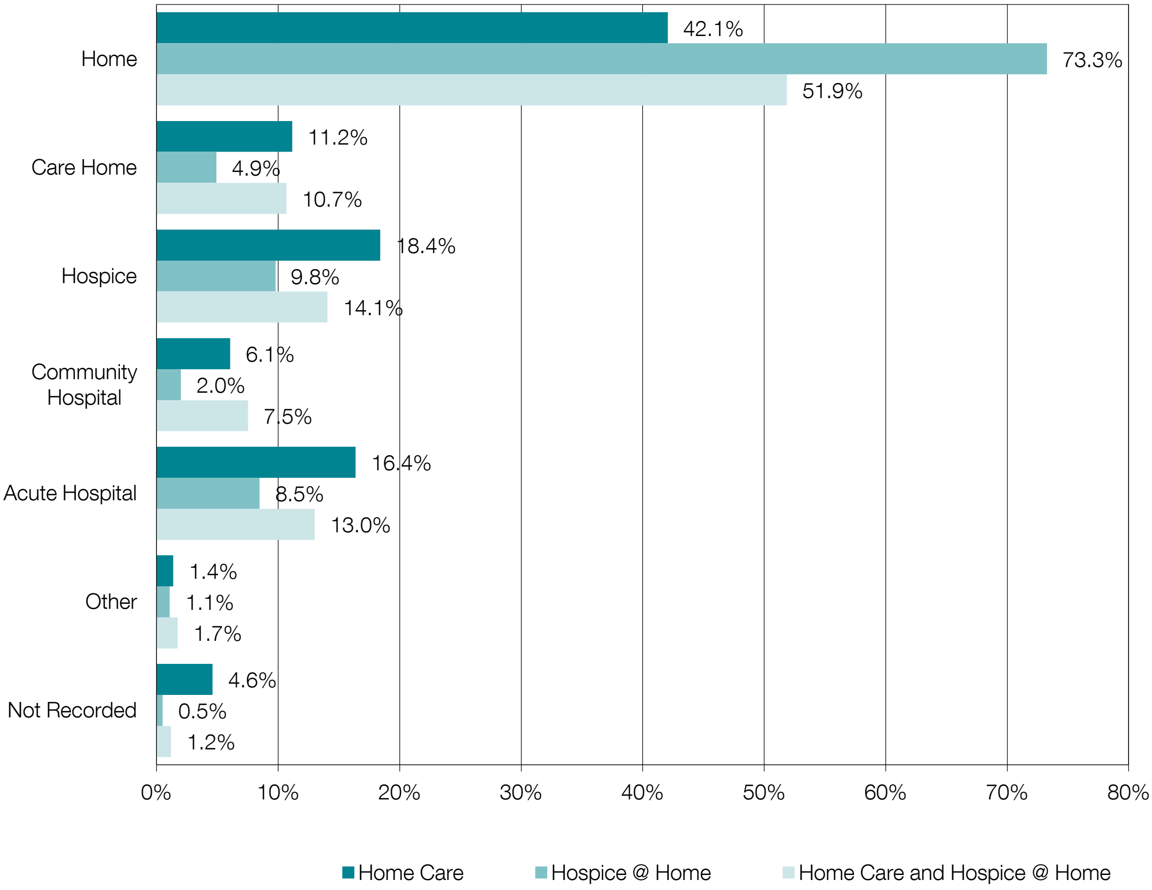


Table 39: Community Services – place of death

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
Home	13,335	5,523	7,090
Care Home	3,529	371	1,449
Hospice	6,127	737	1,997
Community Hospital	1,518	150	884
Acute Hospital	5,532	639	1,875
Other	375	80	245
Not Recorded	1,520	37	107
Total	31,936	7,537	13,647

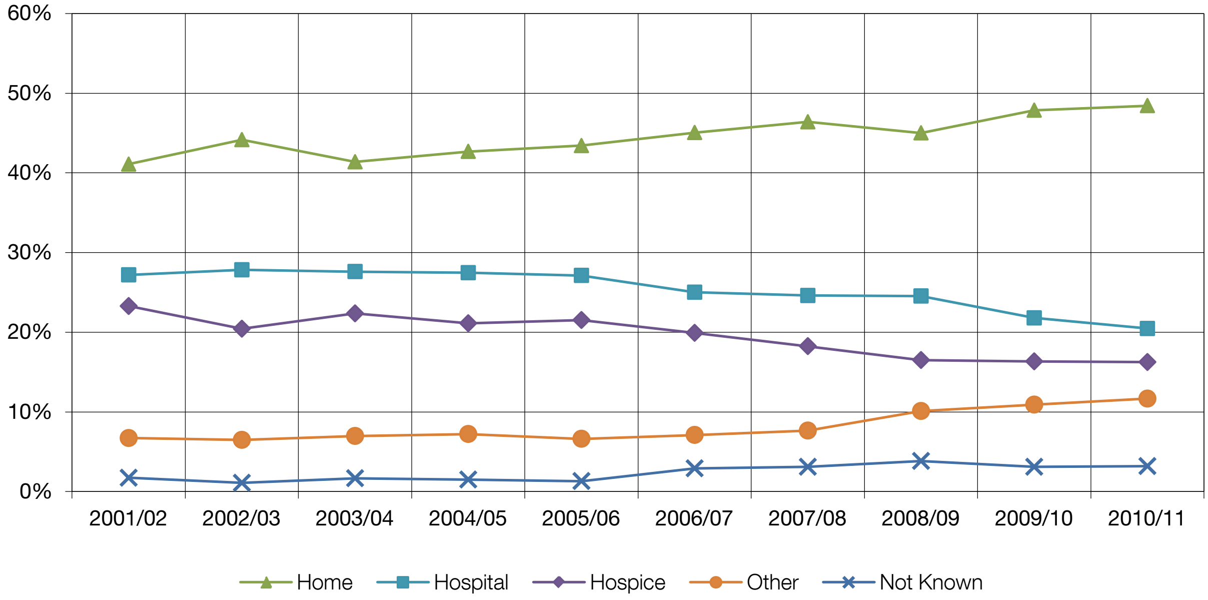
The proportion of people dying at home increased slightly overall for Community Services, while the proportion dying in hospital decreased.

Place of death – trends

Data on the place of death for people using Community Services has been recorded since 2001/02. When the MDS was revised, the number of categories was increased, adding Care Home and splitting Hospital into Community and Acute Hospital.

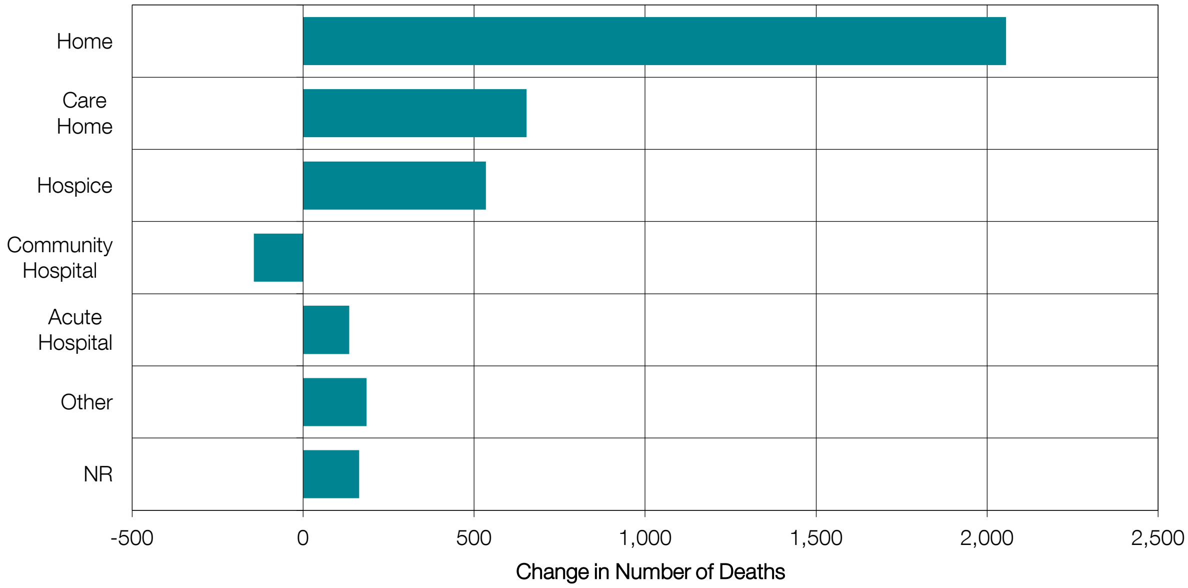
In Chart 37, to compare the revised MDS with the preceding years the hospital data has been combined and care homes have been included in Other.

Chart 37: Place of death – 2001 to 2011



For the third year of the revised MDS we have seen an increase in the number of people using Community Services who died at home or in care homes. The number of deaths in hospices also increased by more than 500 (5%). Community hospital deaths decreased slightly while deaths in all other settings increased slightly.

Chart 38: Change in number of deaths from 2008/09 to 2009/10



Length of care

The length of time patients were under the care of the services was given by 83 Home care teams, 37 Hospice @ Home teams and 36 combined teams. Table 40 and Chart 39 show the breakdown of length of care for all three types of service. Nearly two thirds of patients in Home Care (63%), more than three quarters of patients for Hospice @ Home (88%) and more than two thirds of combined (69%) had a length of care of less than 90 days.

The average length of care for the 79 Home Care services that responded ranged from 1 day to 257 days with a mean of 114.6 days and a median of 109.3 days. 63% of patients were looked after for fewer than 3 months and 21% for more than 6 months.

For the 37 Hospice @ Home services that responded, the average length of care ranged from 5 days to 141 days with a mean of 35 days and a median of 25 days. 88% of patients were looked after for fewer than 3 months and 5% for more than 6 months.

The 36 combined services that responded had an average length of care of 108 days; this ranged from 1 day to 311 days and had a median of 96 days. 69% of patients were looked after for fewer than 3 months and 17% for more than 6 months.

Table 40: Community Services – average length of care

	Average length of care (days)	Range	Units responding
Home Care	123	1 to 841	79
Hospice @ Home	35	5 to 141	35
Home Care and Hospice @ Home	108	1 to 414	35

The average length of care for people in Home Care was three and a half times the length of that for those receiving Hospice @ Home care. The majority of Hospice @ Home care (72%) was for a month or less. The majority of Home Care (63%) was for more than one month.

Chart 39: Community Services – length of care

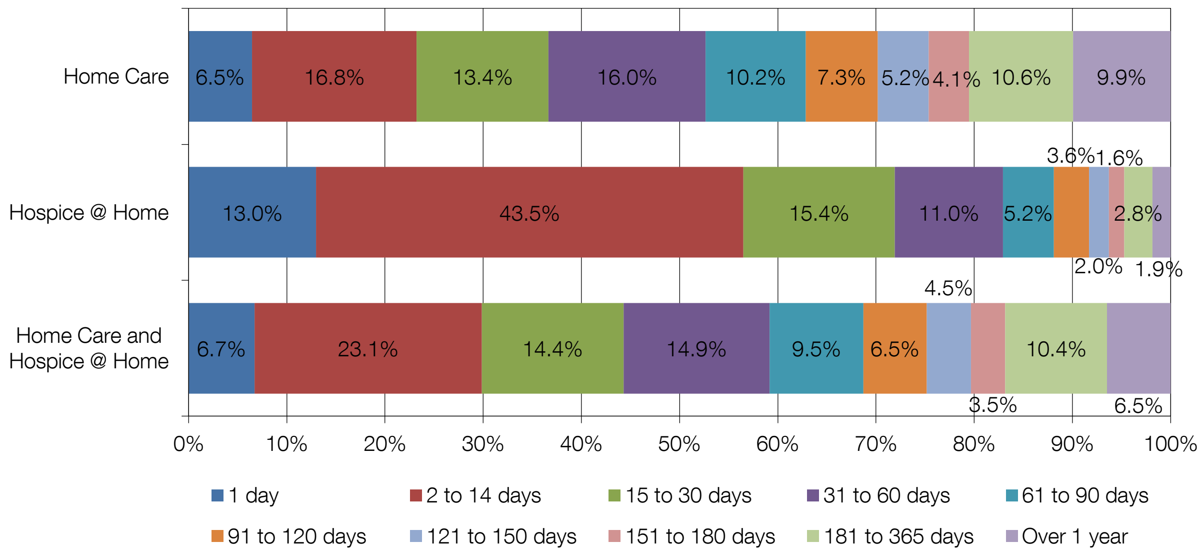


Table 41: Community Services – length of care

Length of care	Number of patients		
	Home Care	Hospice @ Home	Combined Services
1 day	3,645	1,175	1,468
2 to 14 days	9,457	3,943	5,049
15 to 30 days	7,581	1,395	3,152
31 to 60 days	9,018	997	3,249
61 to 90 days	5,768	471	2,081
91 to 120 days	4,132	324	1,411
121 to 150 days	2,927	184	980
151 to 180 days	2,320	142	764
181 to 365 days	5,971	258	2,264
Over 1 year	5,606	168	1,413
Total	56,425	9,057	21,831

Caseload

The caseload for each team is considered to be the number of patients they care for at any one time. This can be calculated from the number of deaths and discharges multiplied by the fraction of the year they are under the care of the team.

The mean length of care for Home Care was 123 days; the average caseload was 226 patients per team, median 177.

The mean length of care for Hospice @ Home was 35 days; the average caseload was 27 patients per team, median 17.

The mean length of care for combined teams was 108 days; the average caseload was 196 patients per team, median 115.

Table 42: Caseloads for Community Services

Service Type	Mean number of patients per team	Median number of patients per team	Services responding	Deaths and discharges in responding services
Home Care	226	177	79	53,592
Hospice @ Home	27	17	35	8,708
Home Care & Hospice @ Home	196	115	35	22,114

5. Hospital Support

Key findings

- The proportion of patients with a primary diagnosis other than cancer who were recorded under “all other conditions” was 39%
- Number of contacts recorded increased by 12% for face to face and 34% for telephone, despite a drop in the number of services responding to these questions
- Average number of contacts per patient was 4.2
- Nearly a quarter of a million face to face contacts were recorded
- The majority of contacts with patients were by Clinical Nurse Specialists (78% of face to face contacts and 92% of telephone contacts)

Responses

All services known to provide specialist palliative care to adults during the year April 2010 – March 2011 were asked to provide data on services provided within a hospital. This did not include palliative care services provided by specialists such as chemotherapy nurses, or site specific cancer services such as breast care nurses. There were 145 replies providing at least some information. This is a 57% response rate using a baseline of 254. Independently-managed services made up 11% of units responding.

The response rate to individual questions varied between 57% (Telephone Contact) and 94% (Age & Sex) with a mean of 78% and a median of 82%.

Age and sex

The total number of patients seen included new patients and those registered at the start of the year, as well as re-referrals of those who were first registered in a previous year, or re-referred after discharge in the present year.

New patients comprised 94% of the total. A quarter of the new patients were aged under 65 (24% male, 26% female), fewer than 0.5% were aged under 25 and 20% were aged 85 years and over.

Chart 40: Hospital Support – age and sex of new patients

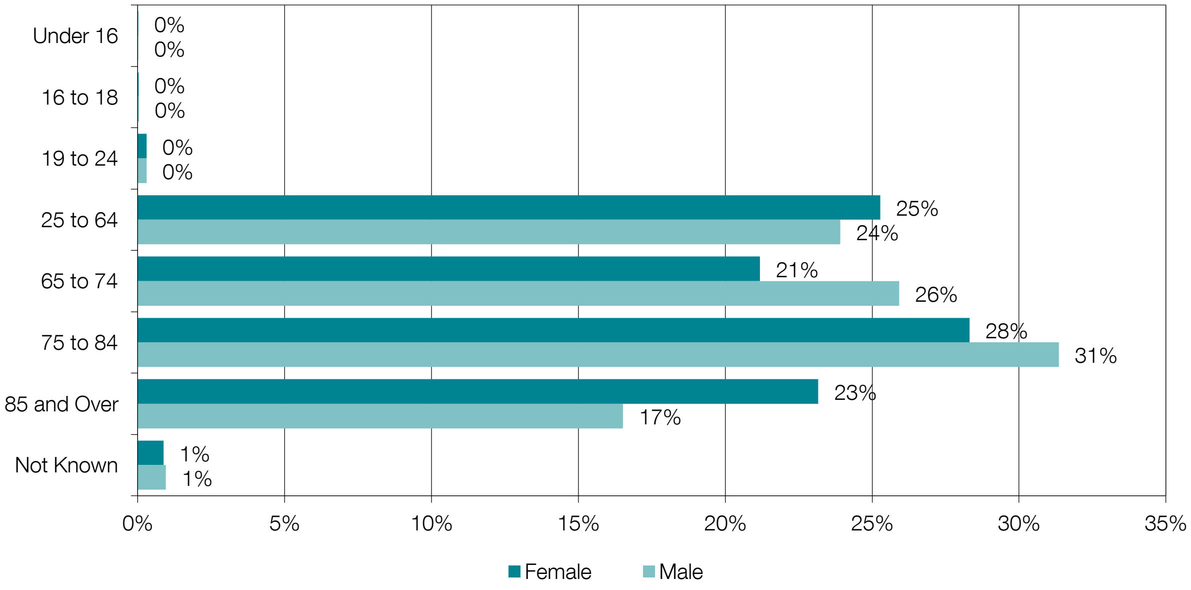


Table 43: Age and sex of patients receiving Hospital Support

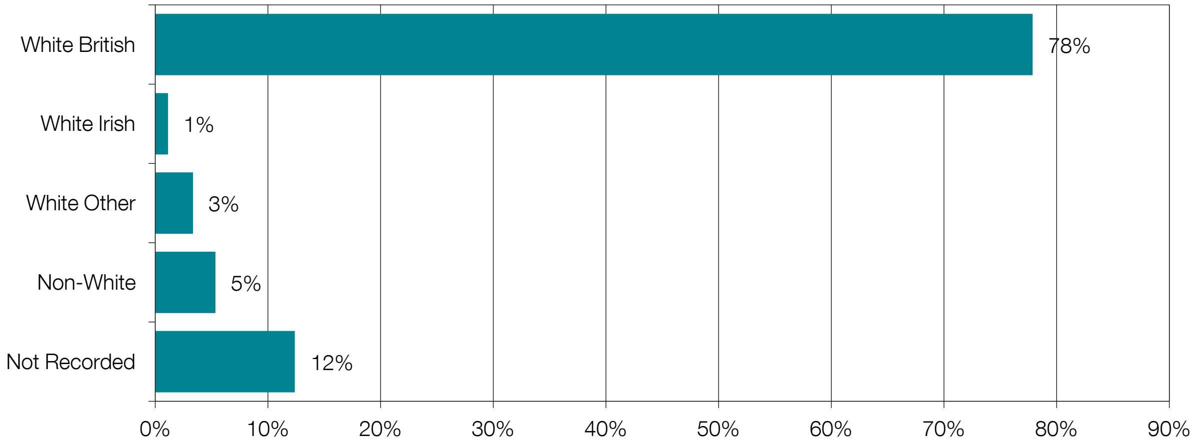
	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	7	7	**24**	7	8	**27**
16 to 18	9	13	**23**	9	15	**25**
19 to 24	98	96	**203**	128	138	**278**
25 to 64	8,202	7,772	**16,259**	9,848	9,078	**19,475**
65 to 74	6,873	8,423	**15,475**	8,124	9,698	**18,201**
75 to 84	9,191	10,197	**19,637**	10,396	11,458	**22,383**
85 and Over	7,509	5,360	**13,065**	8,188	5,929	**14,540**
Not Known	283	310	**1,039**	340	368	**1,727**
Total	**32,172**	**32,178**	**65,725**	**37,040**	**36,692**	**76,656**

Male and female figures may not add up to the total figures, due to some units not reporting on their patients' sex.

Ethnicity data

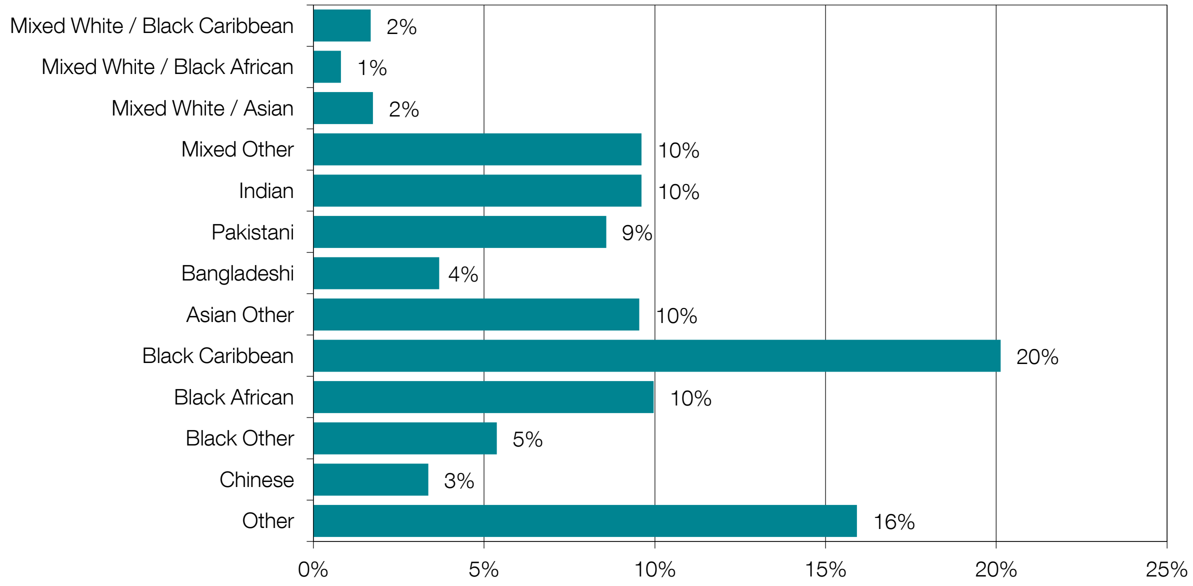
Ethnicity data were recorded by 86% of Hospital Support services. More than three quarters of new patients (78%) were described as White British. The ethnicity for a total of 7,201 new patients (12%) was not recorded.

Chart 41: Hospital Support – ethnicity



The numbers of non-white patients have been grouped together in Chart 41, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 42.

Chart 42: Hospital Support – non-white



The number of non-white patients recorded under the category ‘other’ dropped from 19% last year to 16% this year. As we recommended on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health’s 17 ethnic groupings.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 45,355 new referrals to Hospital Support units (78%). Cancer figures for Hospital Support were divided up into 12 diagnoses. Digestive and Respiratory cancers accounted for almost half the diagnoses (49%) as per last year.

Chart 43: New patients with cancer diagnosis in Hospital Support

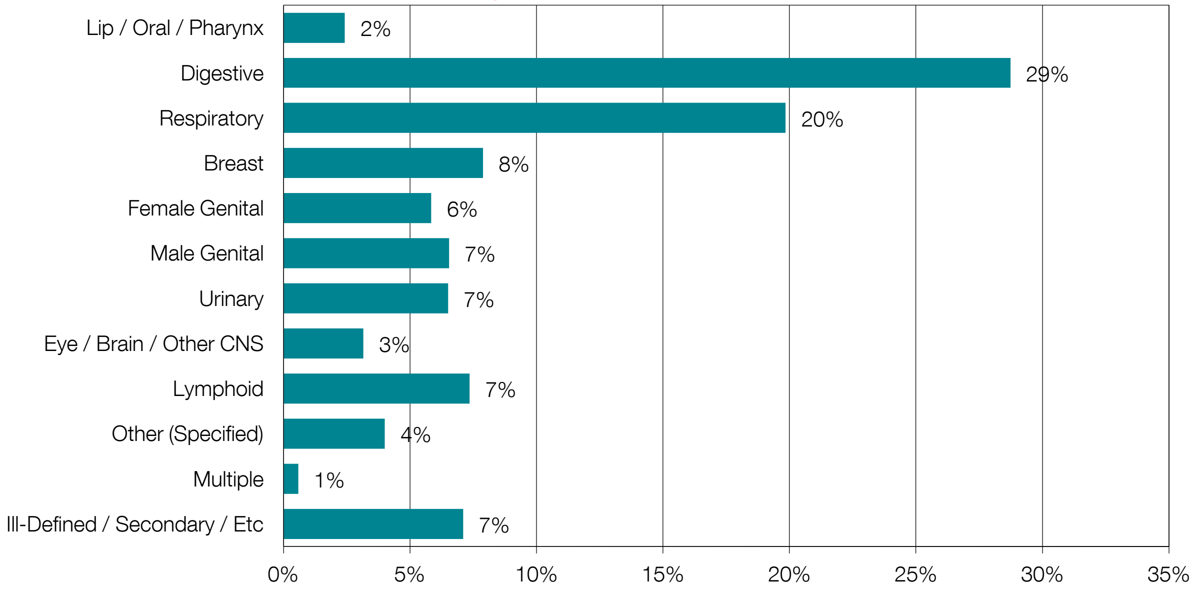


Table 44: Patients with cancer diagnosis in Hospital Support

Diagnosis	New	All
Lip / Oral / Pharynx	1,100	1,350
Digestive	13,034	15,791
Respiratory	9,001	10,787
Breast	3,577	4,537
Female Genital	2,650	3,539
Male Genital	2,968	3,660
Urinary	2,950	3,534
Eye / Brain / Other CNS	1,434	1,724
Lymphoid	3,339	4,023
Other (Specified)	1,817	2,210
Multiple	264	311
Ill-Defined / Secondary / Etc	3,221	3,757
Total	**45,355**	**55,223**

Primary diagnosis – conditions other than cancer

Excluding the patients with a 'not known' diagnosis, 12,895 new patients (22%) had a diagnosis other than cancer. The proportion of these patients in the different units ranged from 0% to 49%, up from 44% last year. Most responding units (80%) had more than 10% of patients with a diagnosis other than cancer, up from 56% last year. Five units had cancer patients only.

Although last year saw a slight drop in the proportion of patients with a condition other than cancer last year, (from 19% to 18%), it has increased again this year.

The number of dementia patients recorded by Hospital Support services was the highest of any setting at 9%. Dementia is under-diagnosed and we would also expect it to be an underlying condition in many cases.

Over a third (39%) of diagnoses other than cancer were recorded under All Other Non-Cancer, a slight decrease on 41% recorded last year. At present it is not possible to say whether these are as a result of un-coded diagnoses, or other unspecified conditions. In the case of the latter, we may need to revise the questionnaire used to collect these data. There is a need for accurate coding to reflect the conditions being referred and to demonstrate need to commission services accordingly.

Chart 44: New patients with a diagnosis other than cancer in Hospital Support

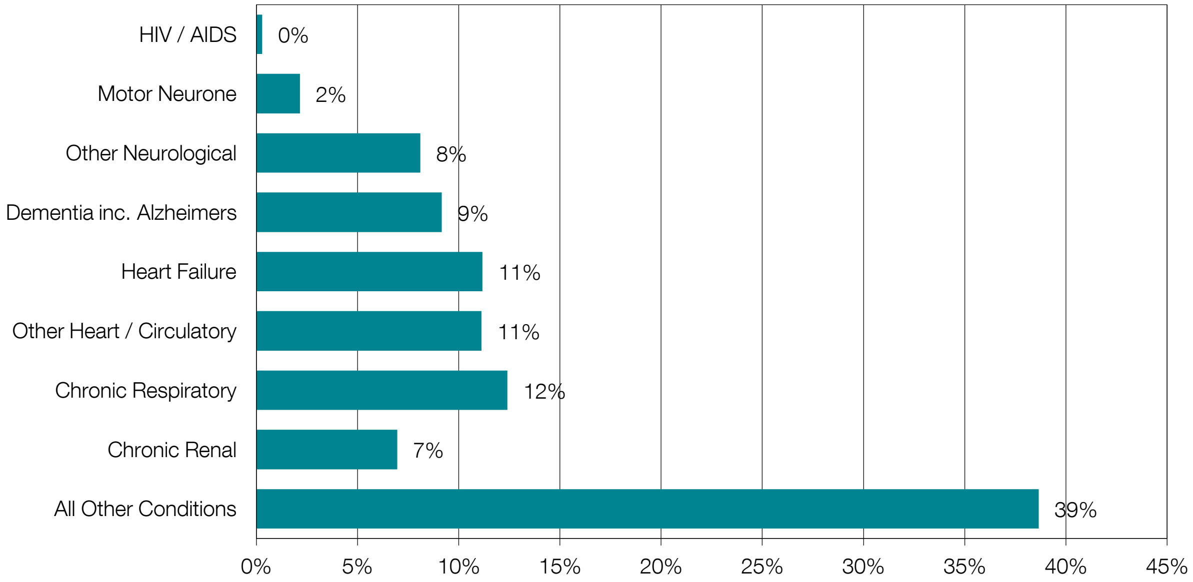


Table 45: Patients with a diagnosis other than cancer in Hospital Support

Diagnosis	New	All
HIV / AIDS	38	47
Motor Neurone	279	334
Other Neurological	1,052	1,156
Dementia inc. Alzheimer's	1,189	1,357
Heart Failure	1,450	1,608
Other Heart Circulatory	1,444	1,667
Chronic Respiratory	1,610	1,886
Chronic Renal	903	1,018
Other	5,020	5,563
Total	**12,985**	**14,636**

Referrals and contacts

Each patient received an average of 4.2 contacts during the year, with a range from 1.1 to 12.3 contacts per patient. Of these contacts, 17% were by a doctor (medical consultant or other doctor) and 78% by a clinical nurse specialist.

Table 46: Contacts per patient in Hospital Support

Average number of contacts per patient	Range of contacts per patient per service	Number of services responding	Total patients	Total contacts
8.2	1.1 to 41.2	100	56,584	441,467

Face to face contacts

Although the number of services responding to the face to face contacts this year fell again, the number of contacts recorded increased, from 322,858 to 360,994. (Not all services reported a breakdown of all contacts, so this is lower than the figure above.) The breakdown of contacts across professions showed a number of changes, but with just three years of data it is still not possible to identify whether these are the result of better recording of contacts or changes in services' operations.

Most face to face contacts (78%) were with Clinical Nurse Specialists.

Table 47: Face to face contacts with patients in Hospital Support

	Face to Face		Max	Mean	Median	Services
Medical Consultant	38,732	11%	100%	399.3	51.0	82
Other Doctor	23,263	6%	100%	239.8	36.0	47
Clinical Nurse Specialist	283,629	78%	100%	2,924.0	2,622.0	91
Other Nurse	2,976	2%	30%	30.7	60.0	24
Physiotherapist	388	0.1%	17%	4.0	127.0	5
Occupational Therapist	2,189	1%	40%	22.6	123.0	14
Social Worker	5,526	1%	11%	57.0	86.0	16
Pastoral / Spiritual Carer	246	0.2%	4%	2.5	14.5	9
Psychologist / Psychotherapist	220	0.1%	3%	2.3	65.5	10
Complementary Therapist	644	0.2%	5%	6.6	51.5	7
Other health care professional	4,372	1%	19%	45.1	40.0	20
Total Face to Face	**360,994**	**–**	**–**	**3,721.6**	**3,082.0**	**97**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding decreased from 100 to 97 (-3%)
- Contacts recorded increased by 38,146, from 322,858 to 360,994 (+12%)
- Clinical nurse specialists accounted for most of the increase in contacts (36,502)
- Other nurses continued to drop, the largest drop, 63% of the previous year's contacts
- Medical consultants' contacts increased by more than 1,500
- Occupational therapists' contacts more than halved this year, after a six-fold increase last year

Table 48: Telephone contacts with patients in Hospital Support

	Telephone		Max	Mean	Median	Services
Medical Consultant	3,535	3.4%	68.4%	51.1	25.0	56
Other Doctor	2,749	2.6%	100.0%	49.6	28.0	44
Clinical Nurse Specialist	95,291	91.5%	100.0%	1159.0	598.0	79
Other Nurse	215	0.2%	40.0%	5.1	3.0	18
Physiotherapist	0	0.0%	0.0%	0.0	0.0	0
Occupational Therapist	243	0.2%	48.6%	6.6	25.0	8
Social Worker	1,556	1.5%	33.6%	38.9	27.0	14
Pastoral / Spiritual Carer	0	0.0%	0.0%	0.0	0.0	0
Psychologist / Psychotherapist	41	0.0%	5.3%	1.2	2.0	5
Complementary Therapist	9	0.0%	3.2%	0.3	4.5	2
Other health care professional	111	0.1%	4.0%	2.9	4.5	12
Total Face to Face	**104,160**	**–**	**–**	**1073.8**	**681.5**	**82**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- One fewer service responded this year
- No physiotherapists or pastoral / spiritual carers reported any telephone contacts this year
- Overall contacts recorded picked up again from 77,781 to 104,160 (+34%)
- Medical consultants' contacts increased by 24% after last year's drop of 94%
- Clinical nurse specialists' contacts increased again, by 40%, far less than the trebling see last year

Length of care

The length of time patients were under the care of the support service was one of the items of data collected. Nearly a quarter of patients (23%) were seen only once and over 90% had died or were discharged within four weeks. Just 0.3% remained under care for over six months. The data does not give information as to whether these patients were actively receiving care or whether they simply remained registered with the service until they died.

Services were asked to give the mean length of care. A total of 104 responded and the median was found to be 9 days although they were wide variations from less than one day to over four months.

Table 49: Length of care for Hospital Support

Length of care	Count
1 day	15,741
2 to 7 days	27,155
2 to 14 days	12,816
15 to 28 days	7,796
29 to 42 days	2,192
43 to 84 days	1,285
85 to 180 days	555
Over 180 days	192
Total	67,732

6. Bereavement Support

Key findings

- The ethnicity of more than half the new clients receiving bereavement support (55%) was not recorded
- The age of a third of new clients was not recorded

Responses

Data were received from 131 services, a 49% response rate from known services. Independently-managed services accounted for 69% of returns.

The response rate to individual questions varied between 78% (Ethnicity) and 93% (Contacts) with a mean of 86% and a median of 85%.

There were 118 services who submitted data for both clients and total face-to-face contacts. The mean for contacts per client was found to be 5.8 ranging from 1 to 44.

Support was split between telephone (35%), face to face (58%) and other (7%).

23% of face to face contacts were in group support, 38% were individual support and 38% individual counselling.

Just over a half of one percent of clients received complex counselling from mental health professionals.

Table 50: Face to face contacts in Bereavement Support

Group		Individual		
Not Facilitated	**Facilitated**	**Support**	**Counselling**	**Complex**
4,931	18,288	38,078	37,737	532
5%	18%	38%	38%	0.5%

Table 51: Telephone contacts in Bereavement Support

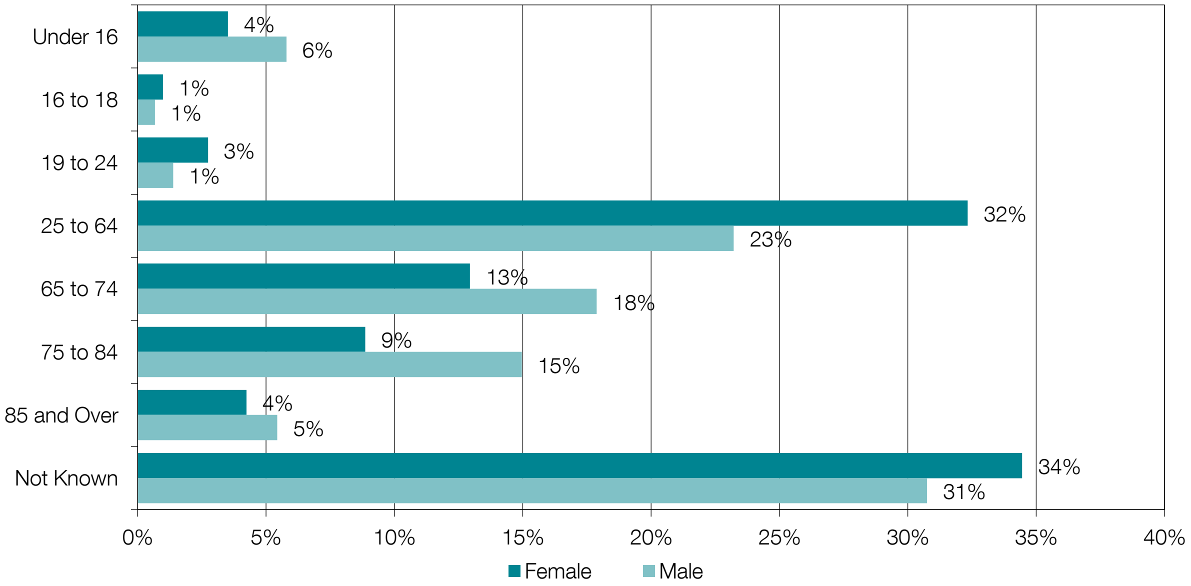
Phone calls under 10 minutes	Phone calls over 10 minutes
36,460	24,833
59.5%	40.5%

Complex counselling numbers were up slightly on last year and the number of face to face contacts dropped (Individual more than Group), while the number of telephone contacts has increased.

Table 52: Contacts in Bereavement Support

				Difference	
	2009	**2010**	**2011**	**2009-10**	**2010-11**
Phone under 10 minutes	25,802	30,216	36,460	4,414	+6,244
Phone over 10 minutes	25,590	27,119	24,833	1,529	-2,286
Face to face - group - not facilitated	3,769	5,439	4,931	1,670	-508
Face to face - group - facilitated	23,643	19,039	18,288	-4,604	-751
Face to face - individual support	32,096	39,235	38,078	7,139	-1,157
Face to face - individual counselling	28,176	39,116	37,737	10,940	-1,379
Face to face - complex	988	313	532	-675	+219
Other	7,119	13,115	13,177	5,996	+62

Chart 45: Age and sex for new clients in Bereavement Support



The proportion of clients whose age was recorded as “Not Known” has reduced again from 42% to 34% for female clients and from 42% to 31% for male clients, which is encouraging.

Patient profile

Table 53: Age and sex for clients in Bereavement Support

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	481	462	**977**	811	752	**1,623**
16 to 18	134	53	**200**	202	82	**308**
19 to 24	374	110	**508**	497	164	**707**
25 to 64	4,423	1,853	**6,489**	6,491	2,841	**9,709**
65 to 74	1,770	1,427	**3,226**	2,541	2,138	**4,758**
75 to 84	1,213	1,194	**2,418**	1,819	1,847	**3,719**
85 and Over	579	434	**1,015**	825	659	**1,485**
Not Known	4,713	2,454	**10,329**	7,754	4,008	**15,737**
Total	**13,687**	**7,987**	**25,162**	**20,940**	**12,491**	**38,046**

The number of ‘Not Known’ for Bereavement Support was considerably higher than for other services. Several units reported that they felt uncomfortable asking bereaved clients for their age. Bereavement Support also reported the highest percentage of female clients; a mean of 63%, with 94% of services reporting more than half their clients were women.

The National Institute for Clinical Excellence (NICE) published its Quality Standard for end of life care in November 2011. The Standard includes sixteen statements outlining what good care looks like, with the fourteenth being “People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences”. NCPC endorsed the Standard and will continue to work with NICE to ensure it is delivered at a local level. Sources of data on the availability of bereavement support such as the MDS provides will be essential in demonstrating the need for bereavement services to meet demand to local Clinical Commissioning Groups and Health & Wellbeing Boards.

Ethnicity

Ethnicity data were collected from 81% of Bereavement Support services, up from 66% last year. Over a third (43%) were described as White British. A total of 13,322 new patients were 'not recorded' (55%). This represents an increase in numbers from last year (13,182) but a slightly smaller proportion (60%).

The numbers of 'non-white' patients have been grouped together in Chart 46, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 47.

Chart 46: Bereavement Support new patients – ethnicity

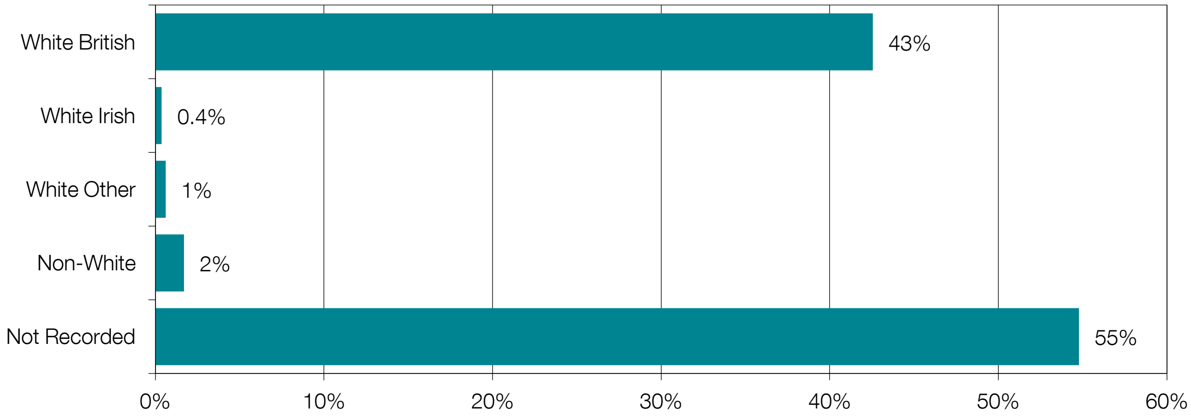
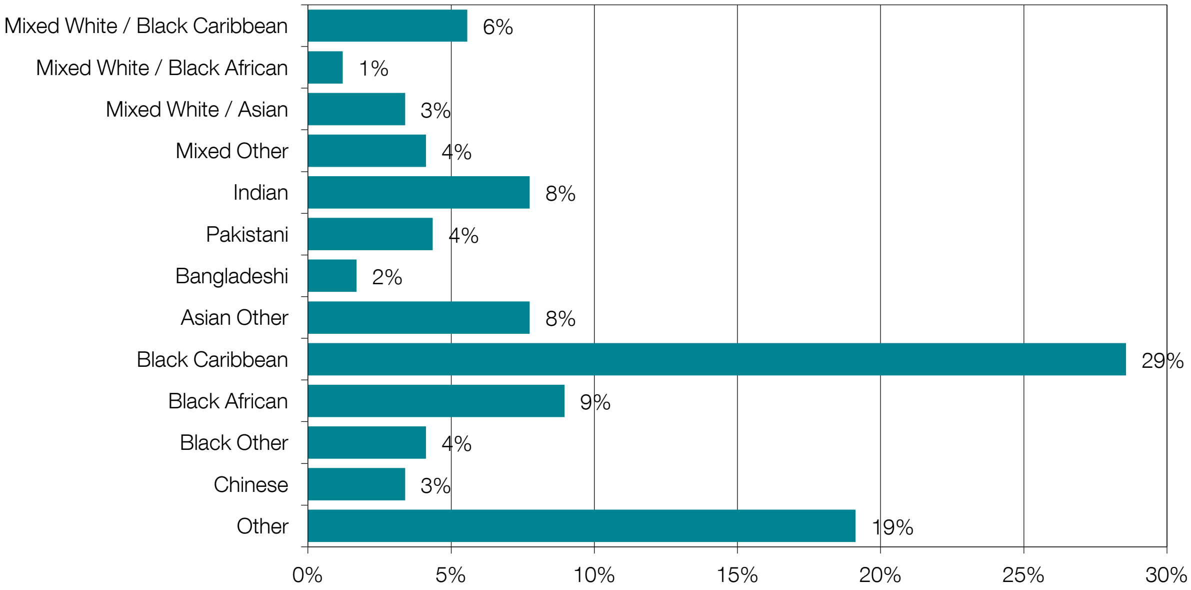


Chart 47: Bereavement Support new patients – non-white



Although there was a slight improvement this year, the ethnicity of over half the patients seen (55%) was still not recorded. In addition, nearly a fifth (19%) of non-white patients were recorded under "other". As we recommend on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings.

Primary diagnosis of deceased

A total of 105 services reported the primary diagnosis of the deceased for new clients.

Excluding the not-recorded figures, 86% had cancer and 14% a diagnosis other than cancer. The number of not-recorded fell slightly from just over a fifth of new clients (21%) to just under (19.7%).

Chart 48: Bereavement Support new clients – primary diagnosis of deceased

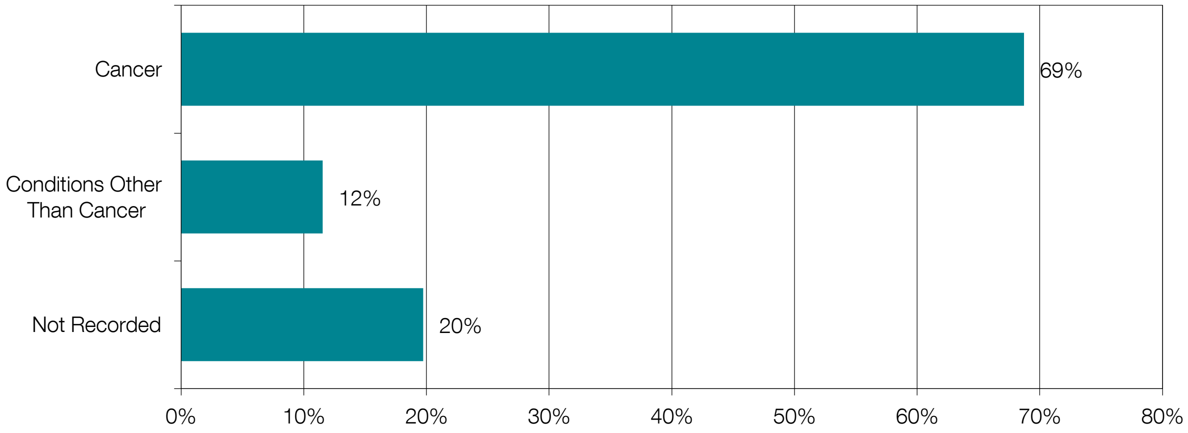


Table 54: Bereavement Support – primary diagnosis of deceased

	New	All
Cancer	15,618	24,050
Non-Cancer	2,623	3,976
Not Recorded	4,486	6,785
Total	**22,727**	**34,811**

7. Outpatients

Key findings

- Nearly 100,000 attendances at over 35,000 outpatient clinics were recorded
- Over a fifth of outpatients had a primary diagnosis of breast cancer, considerably higher than any other setting
- Two thirds of outpatients were female
- The ethnicity of nearly a third of outpatients was not recorded
- Nearly a third of outpatients recorded as non-white were under the category "Other"
- Two thirds of outpatients with a diagnosis other than cancer were recorded under "Other"

Responses

All palliative care services were given the opportunity to provide information on their Outpatient activity. An Outpatient clinic may be held regularly or occasionally and be attended by one or more patients (usually by appointment). It may be held in a hospital or a palliative care unit or other setting.

The response rate to individual questions varied between 17% (Joint Clinics and Interventions) and 96% (Age & Sex) with a mean of 61% and a median of 70%.

The total number of specialist palliative care services providing an Outpatient service is not accurately known but from previous surveys it is thought to be about 315. This has been taken as the baseline. 158 forms were returned (50%), of which 57% were from independently-managed services, 32% from NHS-managed services, and 11% did not record their management.

Age and sex

Chart 49: Age and sex of new outpatients

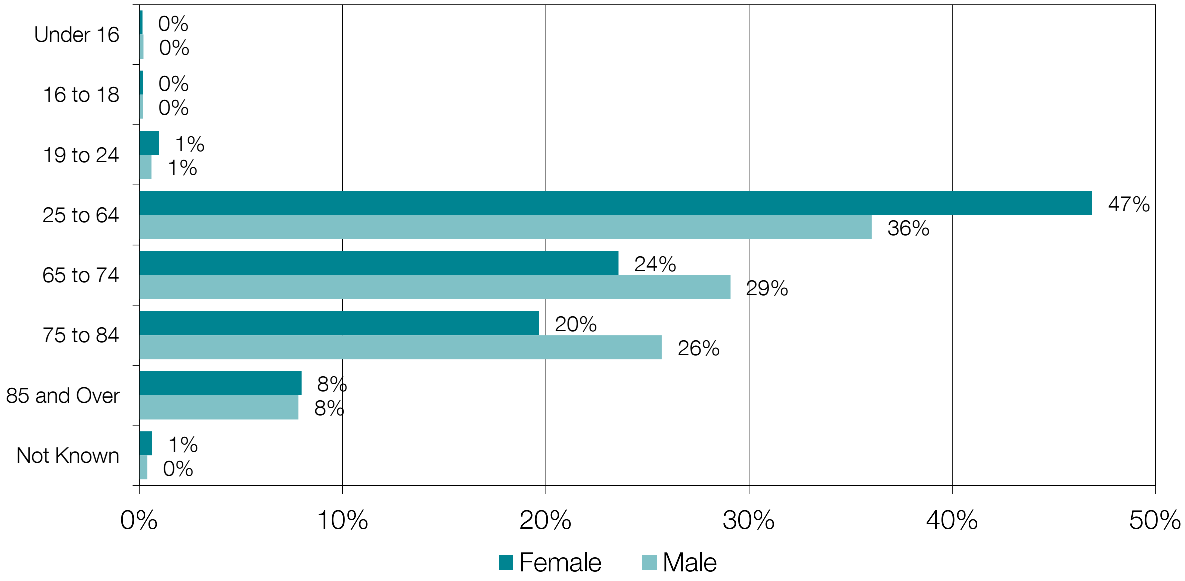


Table 55: Age and sex of Outpatients

	New			All		
	Female	**Male**	**All**	**Female**	**Male**	**All**
Under 16	19	18	**38**	63	38	**101**
16 to 18	21	15	**36**	38	25	**63**
19 to 24	116	51	**172**	235	100	**340**
25 to 64	5,720	3,130	**9,008**	14,463	5,376	**19,993**
65 to 74	2,876	2,526	**5,483**	6,261	3,864	**10,205**
75 to 84	2,399	2,233	**4,670**	4,776	3,268	**8,085**
85 and Over	973	680	**1,660**	1,760	916	**2,686**
Not Known	76	34	**241**	128	57	**433**
Total	**12,200**	**8,687**	**21,308**	**27,724**	**13,644**	**41,906**

Just over half the patients seen at Outpatient clinics were seen for the first time during the year (51%). Nearly half of new patients were aged under 65 (43%) and 8% were aged 85 or over.

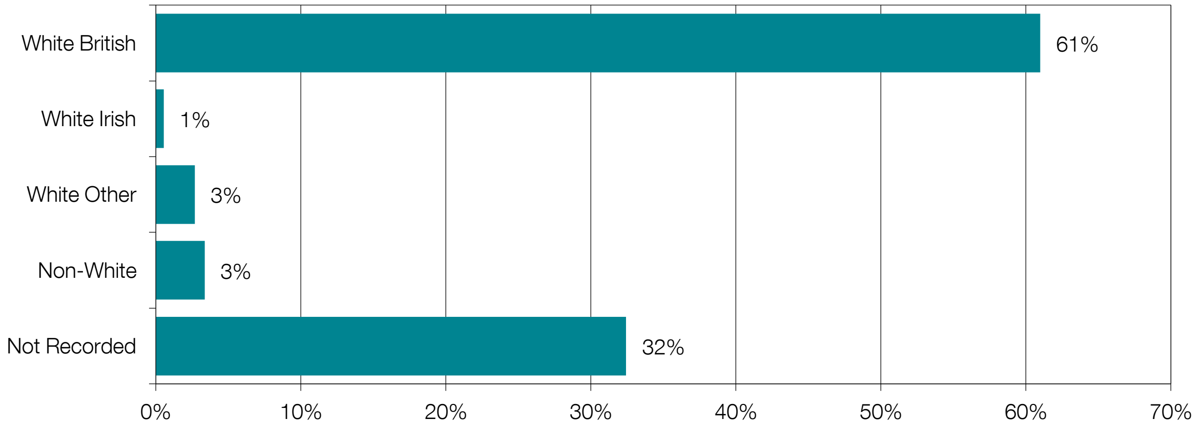
There was a big discrepancy between the sexes; overall 66% were female and in the age range 25 to 64 there were 72% females.

Ethnicity

Ethnicity data were collected from 93% of Outpatient services. Over three fifths (61%) were described as White British. A total of 5,503 new patients (32%) were 'not recorded'. This figure is too high and raises questions about why ethnicity data is not being accurately collected

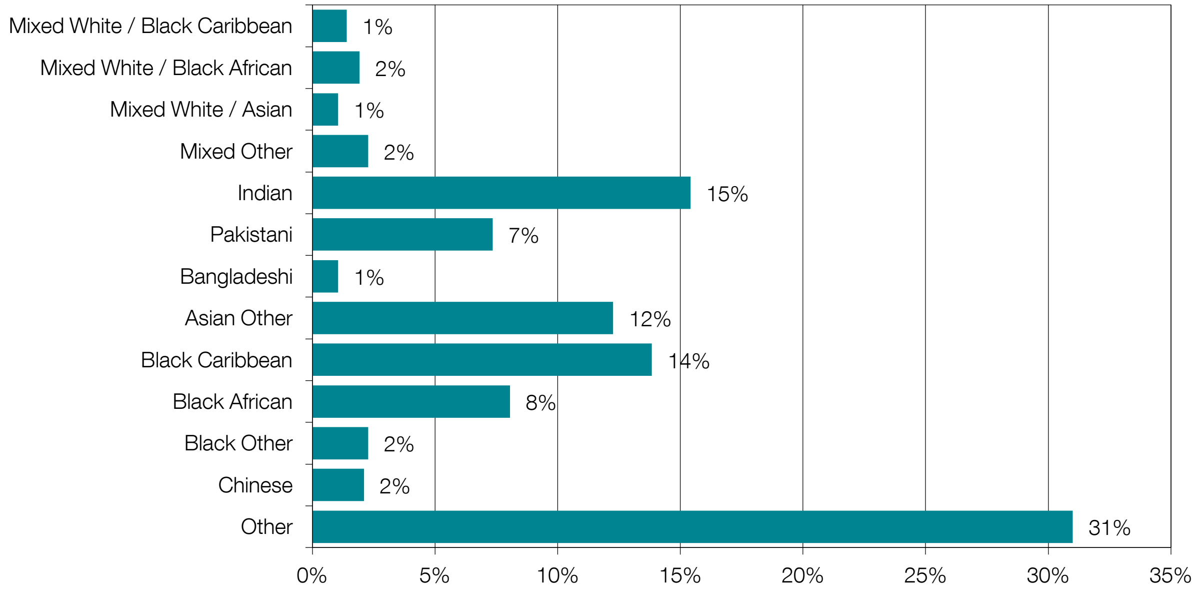
The numbers of 'non-white' patients have been grouped together in Chart 50, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 51.

Chart 50: Ethnicity of new outpatients



The proportion of outpatients classified as 'Other' in Chart 51 is 31%. This figure is again extremely disappointing. Questions need to be asked around why this figure is so high and why more attention is not currently being paid to establishing the ethnicity of outpatients. We would strongly urge all units to make a much greater effort to obtain data on the ethnicity of their patients and therefore collect more accurate data.

Chart 51: Distribution of "non-white" categories in outpatients



Nearly a third of those recorded as being non-white (31%) were under the category 'other'. As we recommend on page 17, services should urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 14,449 new referrals to Outpatient units (79%). In the revised dataset, outpatient cancer figures are divided into 12 diagnoses. Outpatient clinics showed the highest proportion of patients diagnosed with breast cancer; just over a fifth of new patients and over a third (35%) of all patients. Digestive and respiratory cancers accounted for a further 41% of diagnoses for new patients.

Chart 52: Cancer diagnoses in new outpatients

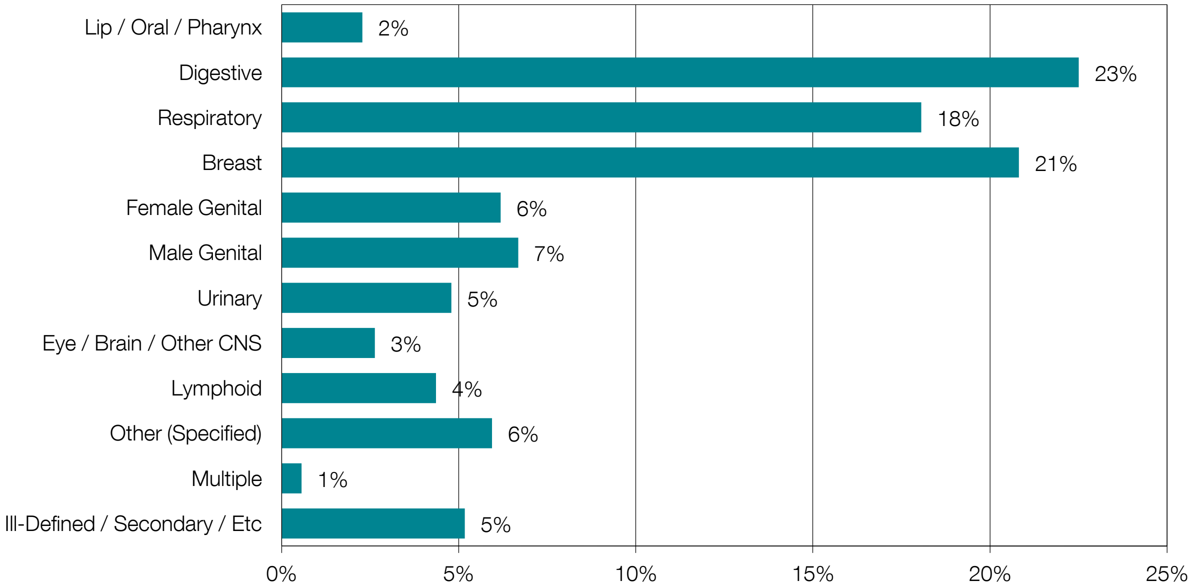


Table 56: Cancer diagnoses in outpatients

Diagnosis	New	All
Lip / Oral / Pharynx	330	550
Digestive	3,252	4,541
Respiratory	2,609	3,658
Breast	3,008	9,414
Female Genital	894	1,838
Male Genital	965	1,596
Urinary	693	1,018
Eye / Brain / Other CNS	381	630
Lymphoid	630	1,162
Other (Specified)	859	1,480
Multiple	81	148
Ill-Defined / Secondary / Etc	747	1,054
Total	**14,449**	**27,089**

Primary diagnosis – conditions other than cancer

Excluding patients with a ‘not known’ diagnosis, 3,920 new patients (21%) had a diagnosis other than cancer, although 9% of services had no such patients. The range of these patients varied up to one service that had 100% (5 patients). It may be noted that of all the different types of palliative care surveyed, Inpatient, Home Care, Day Care and Hospital Support, the Outpatient service had the highest percentage of patients with a diagnosis other than cancer. It also had the highest proportion of ‘Other Non-Cancer’ diagnoses at 59%.

Chart 53: Diagnoses other than cancer in outpatients

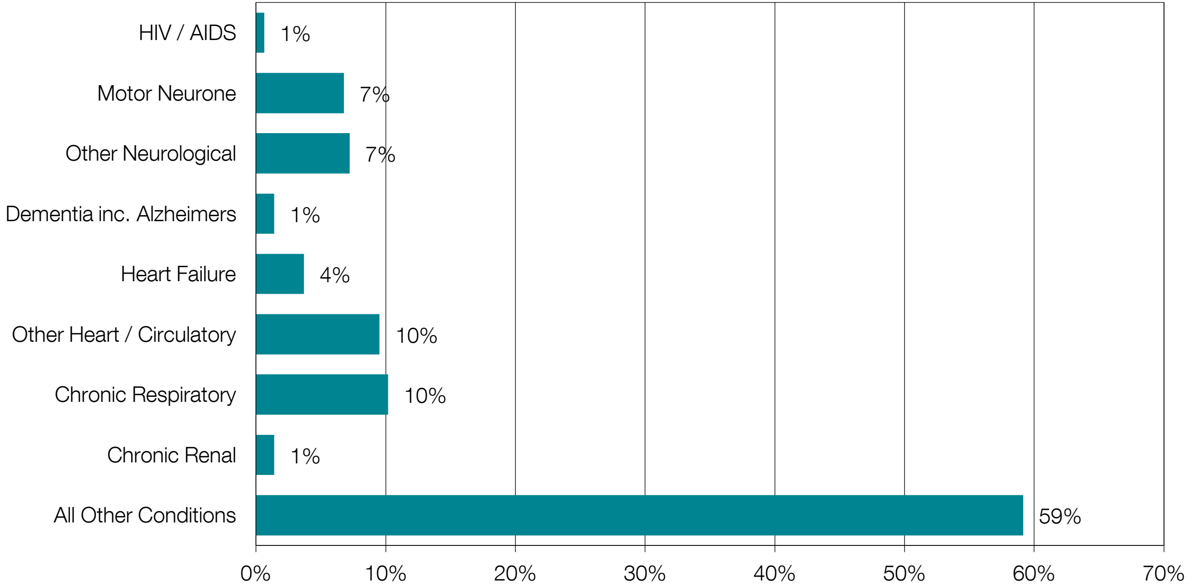


Table 57: Diagnoses other than cancer in outpatients

Diagnosis	New	All
HIV / AIDS	25	65
Motor Neurone	266	498
Other Neurological	283	565
Dementia inc. Alzheimer's	55	71
Heart Failure	145	229
Other Heart Circulatory	373	1,098
Chronic Respiratory	399	625
Chronic Renal	55	87
All Other Non-Cancer	2,319	6,571
Total	**3,920**	**9,809**

Clinics and attendances

Over a fifth of palliative care clinics (23%) were led by a clinical nurse specialist, 22% were led by a palliative care medical consultant, 15% by a complementary therapist and 14% by a nurse other than a clinical nurse specialist.

Table 58: Outpatient clinics

Lead health care professional	Palliative care clinics	Joint clinics	First attendances	Follow-up attendances
Palliative care medical consultant	6,783	683	6401	15,386
Palliative care - other doctor	1,798	86	1355	2,978
Clinical nurse specialist	6,965	60	3257	12,669
Other nurse	4,464	1,804	2395	16,985
Physiotherapist	1,797	267	1468	6,995
Occupational therapist	375	142	242	415
Social worker	617	58	541	1,167
Pastoral / spiritual carer	82	111	23	24
Psychologist / psychotherapist	762	2	319	2,647
Complementary therapist	4,591	12	2,094	13,075
Other health care professional	2,614	1,100	1,577	7,058
Total	**30,942**	**4,325**	**19,617**	**79,196**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Palliative care clinics recorded increased overall by 4%
- Joint clinics recorded increased overall by 242%
- First attendances recorded increased overall by 23%
- Follow-up attendances recorded increased overall by 20%

Non-clinic contacts

The number of services reporting on face to face contacts decreased from 95 to 81 (lower too than 2008-9's 87), although the number of contacts increased from 28,224 to 43,426 (higher than 2008-9's 40,404). This would imply that services are improving their recording and/or reporting of contacts.

- The breakdown of health professionals seen by patients changed considerably this year. This could be down to improved recording of contacts or changes in working practices. With only three years of data, it is too early to infer any trends
- Contacts are much more widely spread amongst the different health care professionals in Outpatients, which perhaps reflects the nature of the setting
- Physiotherapists' face to face contacts continued to increase, by 1,534 this year. Their telephone contacts remained about the same, decreasing by 78 (5%)
- The number of services reporting physiotherapist contacts, however, dropped by 39% for face to face, and by 68% for telephone contacts

Table 59: Face to face contacts with outpatients

Health care professional	Face to Face	%	Max	Mean	Median	Count
Palliative care medical consultant	2,533	6%	303	55	33.5	46
Palliative care – other doctor	1,006	2%	96	26	16	38
Clinical nurse specialist	3,194	7%	1111	94	17.5	34
Other nurse	10,312	24%	3225	264	55	39
Physiotherapist	5,158	12%	1535	112	52.5	46
Occupational therapist	1,606	4%	712	62	18.5	26
Social worker	3,666	8%	1092	147	15	25
Pastoral / spiritual carer	781	2%	343	46	5	17
Psychologist / psychotherapist	2,190	5%	796	122	27.5	18
Complementary therapist	8,532	20%	1750	237	168.5	36
Other health care professional	4,412	10%	839	130	21.5	34
Total	**43,426**	**–**	**–**	**554**	**378.5**	**81**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding decreased from 95 to 81 (-15%)
- Contacts recorded increased from 28,224 to 43,426 (+54%)
- Other nurses' contacts more than doubled (+217%), though the number of services responding fell from 70 to 39 (-44%)
- Medical consultants and clinical nurse specialists also showed an increase in contacts, while the number of services reporting dropped

The number of telephone contacts reported was also up this year, although the number of services responding decreased. Physiotherapists accounted for 7% of calls this year, down from last year's 11%. Complementary therapists, medical consultants and other health care professionals all increased their share of the calls.

Table 60: Telephone contacts with outpatients

Health Care Professional	Telephone	%	Max	Mean	Median	Count
Palliative care medical consultant	1,033	5%	211	38	9	27
Palliative care – other doctor	261	1%	34	10	5	25
Clinical nurse specialist	3,370	15%	984	135	26	25
Other nurse	5,220	23%	926	163	39.5	32
Physiotherapist	1,584	7%	384	72	20.5	22
Occupational therapist	1,587	7%	1338	99	12.5	16
Social worker	3,505	16%	1155	175	33	20
Pastoral / spiritual carer	99	0%	40	11	3	9
Psychologist / psychotherapist	691	3%	363	69	25	10
Complementary therapist	1,628	7%	393	74	31	22
Other health care professional	3,653	16%	2208	152	7	24
Total	**22,495**	**–**	**–**	**152**	**7**	**62**

"Services" shows the number of organisations which reported at least one contact with each health care professional.

- Services responding decreased from 82 to 62 (-24%)
- Contacts recorded increased from 14,659 to 22,495 (+53%)
- The number of services reporting on medical consultants more than halved but the total contacts almost quadrupled (374%)
- Clinical nurse specialist contacts increased by about 1,000 (41%), while the number of services responding dropped by 60%
- Medical consultants, other nurses and other health care professionals showed the largest increase in contacts

8. Motor Neurone Disease

The information collected with the revised MDS has enabled NCPC to perform some additional analyses which were not possible with the previous survey.

An example of this was a breakdown of the number of people with a primary diagnosis of motor neurone disease seen by services, for our Neurological Conditions Group.

Performing a frequency analysis on the number of people being seen by a service revealed that the majority of units in each setting were seeing a small number of patients. There were also a few services which were seeing a large number of patients.

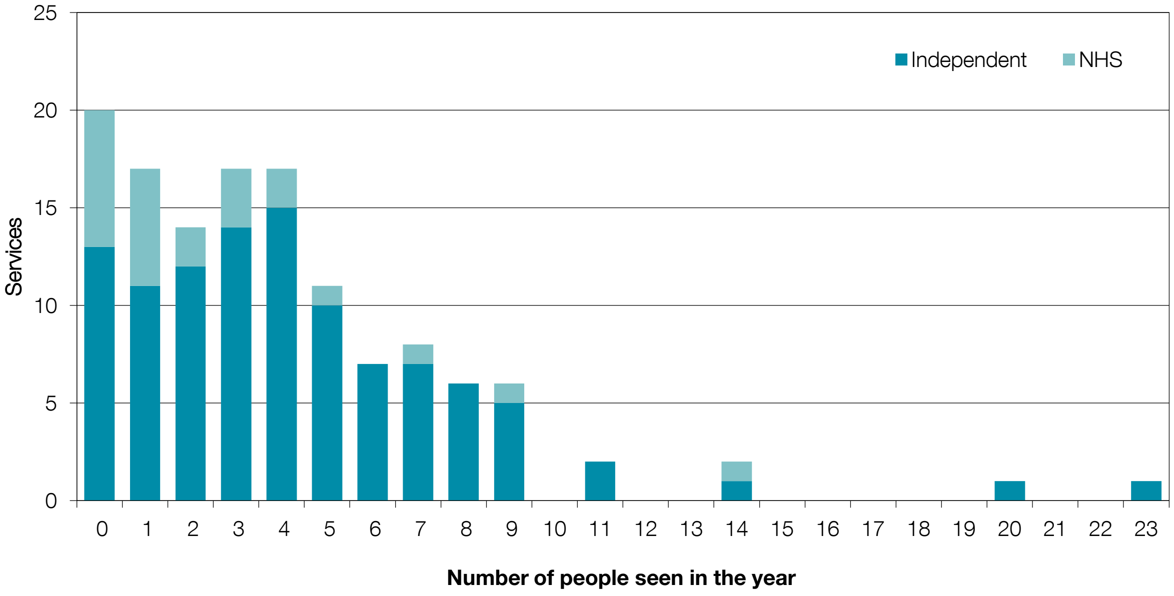
This analysis raises a number of different questions. For example, services that see no people with MND might wish to ask themselves why that is the case. Services that are seeing only one or a very few people with MND each year might be advised to consider whether their staff have sufficient understanding and experience of caring for people with MND and what levels of support from MND specialists, or from other specialist palliative care services with greater experience, might be required. People with MND who wish to access specialist palliative care services at an early stage after diagnosis, to establish a relationship, may wish to ask what experience their local services have of caring for people with that condition.

These figures should be seen in the context of the National End of Life Care Intelligence Network's findings that MND was mentioned on death certificates for about 1500 people each year in England during the period 2006- 8.

Inpatients

Of the 109 services seeing people with a primary diagnosis of MND, 105 (96%) saw 10 patients or fewer. Five independent and one NHS unit saw more than 10 patients.

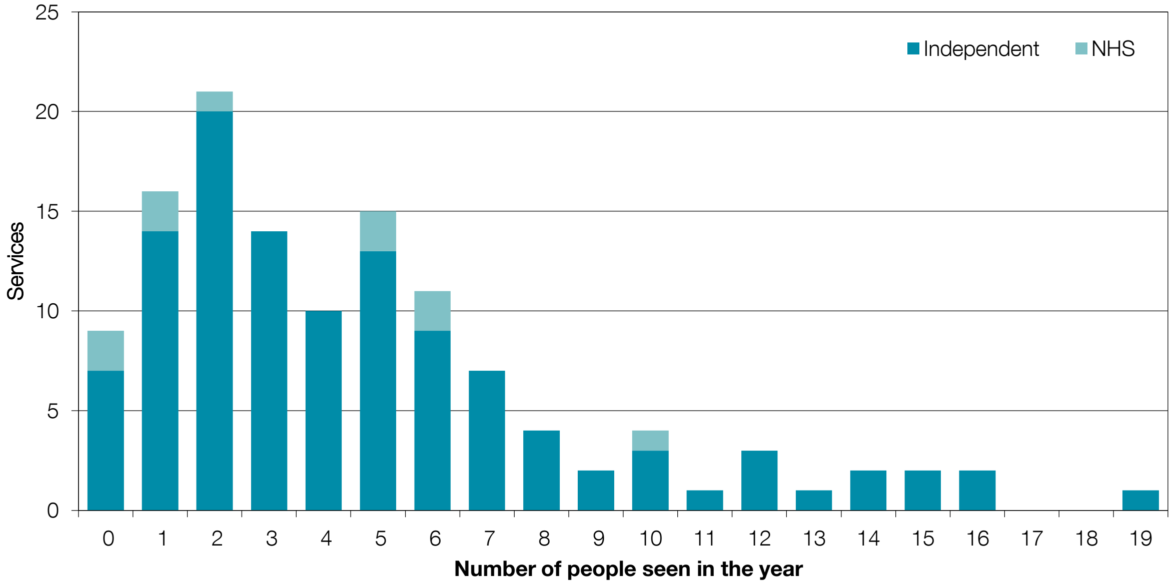
Chart 54: Motor neurone disease in inpatients



Day Care

Of the 116 services who reported seeing people with a primary diagnosis of MND, 104 (90%) saw 10 patients or fewer. No NHS services and 12 independent services saw more than 10 patients.

Chart 55: Motor neurone disease in Day Care

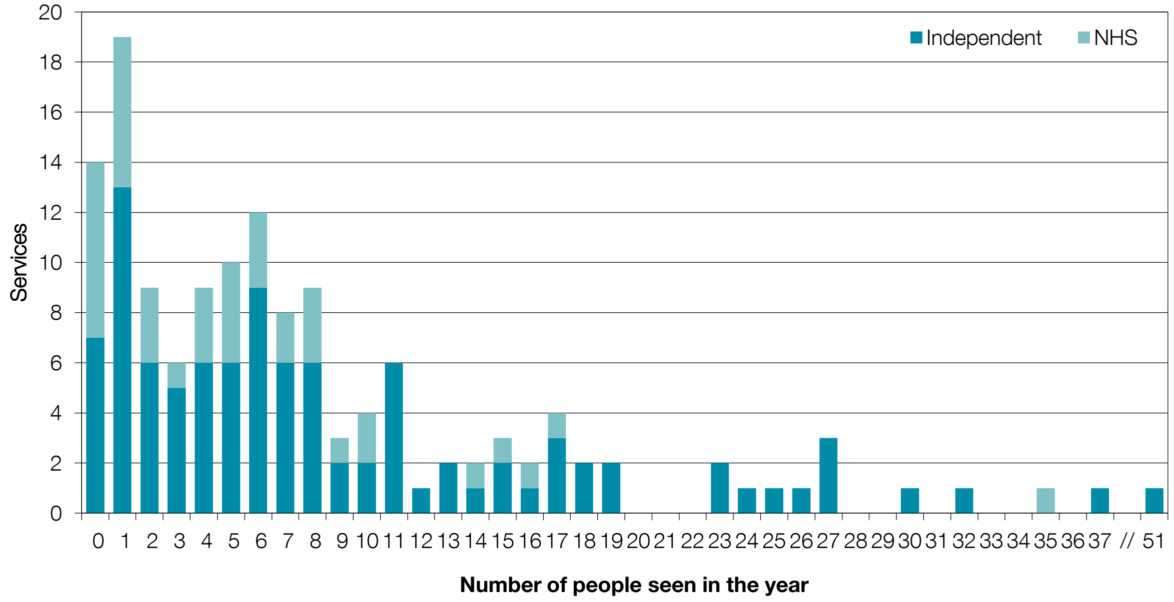


Community Care

Community Care services had a higher proportion of services seeing more than 10 people. Of the 126 services who reported seeing people with a primary diagnosis of MND, 86 (71%) saw ten or fewer, whilst 13 units (10%) saw more than 20 people.

One NHS service saw 35 people (3%) while one independently managed service saw 51 people, or 5% of the total.

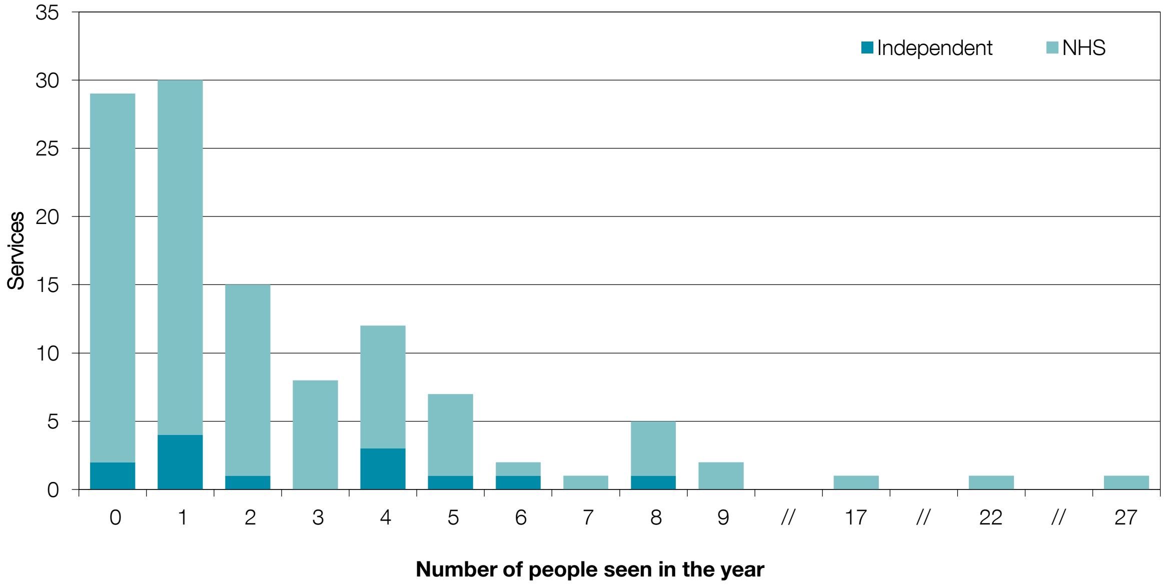
Chart 56: Motor neurone disease in community care



Hospital Support

Of the 85 Hospital Support services which saw people with a primary diagnosis of MND, 82 (97%) saw ten or fewer patients. The remaining three units saw a total of 66 people, 21% of the total.

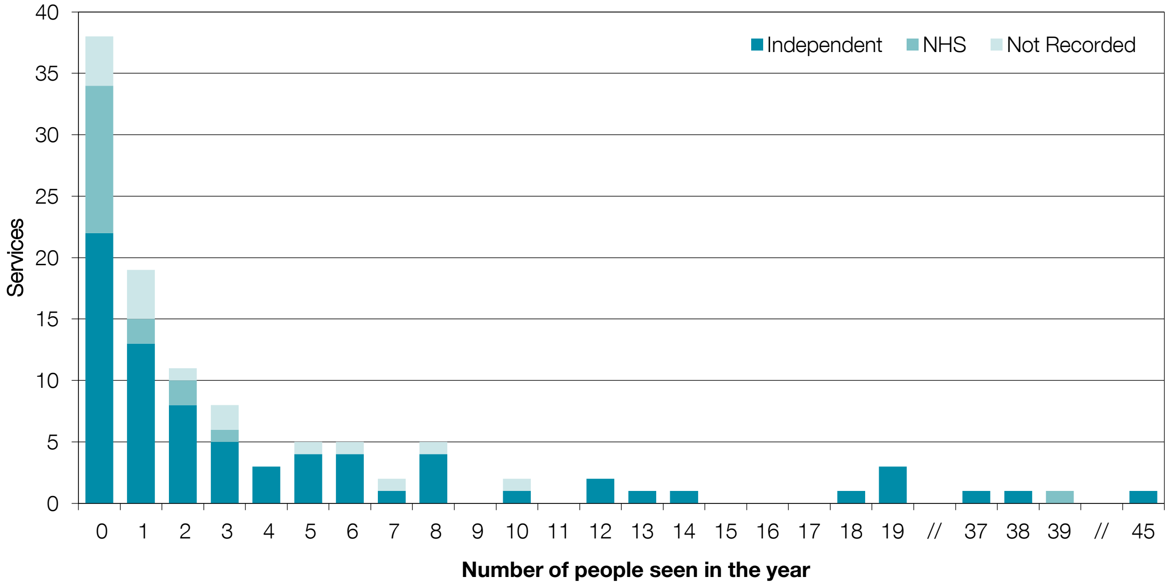
Chart 57: Motor neurone disease in Hospital Support



Outpatients

A total of 110 services completed data on primary diagnoses. Of these 38 (35%) did not see anyone with MND as a primary diagnosis. Of the 72 services who did, 60 (83%) saw ten or fewer people (55% of patients) and 12 saw more than ten. One unit alone saw 45 people with MND, 9% of the total number of people with MND.

Chart 58: Motor neurone disease in outpatients



9. Glossary

Referrals

New patient	A patient who was referred to the service for the first time during the financial year 2010-11.
Continuing patient	A patient who was referred in a previous year and was still being seen by the service on 1st April 2010.
Re-referred patient	A patient who was referred and discharged in a previous year, and then referred to the service again during the financial year 2010-11.
Total patients	The sum of new, continuing and re-referred patients.
Discharged	A patient who is no longer being seen by the service, but did not die whilst under their care.

Services

Inpatient Unit	A designated specialist palliative care unit.
Day care	A service attended at regular intervals.
Community care	A service provided by professional members of a specialist palliative care service to patients in their place of residence.
Home care	A community care team who provide mainly an advisory service.
Hospice @ Home	A community care team who provide mainly hands on nursing.
Hospice @ Home & Home care	A community care team who provide both Home Care and Hospice @ Home.
Hospital support	A specialist palliative care team, working in a hospital setting.
Bereavement Support	Contacts with the bereaved who are relatives or carers of a deceased patient and who need extra support.
Outpatient	A patient having an individual appointment to see a specific member of a multi-professional palliative care team.

Other

Bed occupancy	The number of days each bed is actually occupied by a patient.
Length of stay / length of care	The time that each patient spent with a service before death or discharge.
Caseload	The mean number of patients being cared for at any one time.
Palliative care clinic	A clinic held by a member of the specialist palliative care team.
Joint clinic	A clinic held jointly with non-palliative care specialists.
Clinical nurse specialist (CNS)	A registered nurse who has acquired additional knowledge, skills and experience, together with an accredited post-registration qualification (if available) in a clinical specialty. The four key elements of the Clinical Nurse Specialist role have been defined as: clinical practice, education, management/consultation and research.

10. Acknowledgements

With thanks to all the services who submitted data for this year’s Minimum Data Set collection.

Collated and written by Adrian Jones, Information Analyst, NCPC with support from the rest of NCPC’s Policy and Parliamentary Affairs Team:

- Simon Chapman, Director of Policy and Parliamentary Affairs
- Alice Fuller, Policy and Parliamentary Affairs Lead
- Alice Rigby, Policy and Events Officer

Appendix A – About the Minimum Data Set

Background

The MDS was developed in 1995 by the National Council for Hospice and Specialist Palliative Care Services (now the National Council for Palliative Care) in association with the Hospice Information Service at St. Christopher's Hospice, London. In 1996 its use was commended to the NHS by the Department of Health in Executive Letter 96(85).

This year's report has been funded through the National End of Life Care Intelligence Network.

The aim of the MDS is to provide good quality, comprehensive data about hospice and specialist palliative care services on a continuing basis. These data are useful on a variety of levels to inform:

- service management
- service monitoring and audit
- development of local palliative and end of life care strategy and service planning
- commissioning of services
- development of national policy

NCPC also provides other forms of information and data for this process, for example through its dementia work, workforce survey of specialist palliative care, population based needs assessment, and funding surveys. The MDS is also of great help in supporting the implementation of national initiatives to develop palliative and end of life care in England, Wales and Northern Ireland. For example, the dataset was used to inform the work of the Palliative Care Funding Review, which reported in the summer of 2011.

The survey for 2010/11

The survey is of all hospice and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the current Directory of Hospice and Palliative Care Services published by Hospice Information. Not included in the survey are services for children, and specialist services such as those for HIV/ AIDs or those provided by 'site specific' cancer specialist nurses such as breast care nurses, or chemotherapy nurses. Services in Scotland are not included in the annual surveys because they fall within the remit of the Scottish Partnership for Palliative Care rather than that of NCPC.

All services are contacted by email and asked to download the appropriate forms from the website. Some services provide a joint response and these joint responses are considered as one service for the purpose of analysis. Data are returned during the summer each year.

Individual reports

In autumn, individual reports are sent to all services providing a response to the questionnaire. This is to enable services to compare their data with that of similar sized services throughout the country. Comparisons are also included with data from each service's local region. In England this is for their SHA, in Wales and Northern Ireland, for the whole country. SHAs are used in preference to cancer networks as they cover a larger area and provid more robust data comparisons.

Developing the Minimum Data Set

Since the MDS was first launched, the commissioning, provision and delivery of specialist palliative care services have changed greatly. It is important that the MDS reflects these changes so as to continue to meet the original aims of the collection. To this end in 2005/6 NCPC worked in partnership with Marie Curie Palliative Care Institute Liverpool (MCPCIL) to review the Minimum Data Set questionnaires through a series of workshops and pilot projects. This review gave us the opportunity to examine whether data items were still appropriate and to add in new sections so that the MDS better reflected current specialist palliative care activities.

The new questionnaires were piloted at various sites around the country for a three month period. Adjustments were then made to the questionnaires and the final version was launched in June 2007 for first use in 2008/9. A series of guides has been produced which detail question-by-question exactly what data are to be collected. These guides are intended to be 'user-friendly' and will continue to be updated where necessary if difficulties of interpretation arise.

Developing the MDS has enabled us to collect additional data in relation to a range of different conditions. Once again this year, we have included information on access to specialist palliative care for people with MND.

The Minimum Data Set and the National End of Life Care Intelligence Network

In May 2010 the Department of Health commissioned the National End of Life Care Intelligence Network (NEoLCIN) to collate existing data and information on 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 is supported by the National End of Life Care Programme (NEoLCP).

NEoLCIN's website can be found at:

www.endoflifecare-intelligence.org.uk

NEoLCIN's main objectives include:

- Co-ordinating a national repository of diverse sources of data relating to end of life care which will enable people to create intelligence from the data and thereby improve quality and productivity
- Utilising and disseminating existing data sources more effectively for local service planning and driving improvement in standards of end of life care
- Exploring better use of data for commissioning, service delivery, research and audit

NCPC works closely with NEoLCIN, and is a member of its steering group. We believe it has a very significant role in improving end of life care. Improved data and intelligence is vital to drive forward quality and productivity of services and in helping to illustrate the ongoing need for palliative and end of life care. The MDS has been identified as a vital resource for the Network's stakeholders, to this end.

One of the priorities for future developments to the MDS is collecting the data at the level of individual patients and episodes of care, rather than aggregated for services. This would allow a greater breadth of analysis to be made of the dataset, significantly increasingly its applicability for individual services and for commissioners and thereby its potential to improve quality and efficiency of care. It is anticipated that the changes should make it easier to link MDS data within the national repository to that collected for other aspects of end of life care. Episode level data, therefore, would provide a richer understanding of specialist palliative care services' vital contribution to end of life care.

During the course of 2011-12 NCPC and NEoLCIN worked together with other partners to identify the practicalities and challenges in collecting individual level data, and piloted individual collections. We are now finalising a report to NEoLCIN with recommendations about how this should be taken forward.

In 2012-13 the Department of Health will also be piloting individual level data collection as part of its palliative care funding pilots, following the report of the Palliative Care Funding Review in 2011. NCPC and NEoLCIN will be working closely with the DH to ensure that individual level data collection is developed in a streamlined way that avoids duplication and keeps the burden on data providers to the lowest levels possible.

THE
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COUNCIL FOR
PALLIATIVE
CARE

NHS
National End of Life
Care Programme
Improving end of life care

National end of life care
INTELLIGENCE NETWORK

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