THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

National Survey of Patient Activity Data for Specialist Palliative Care Services

MDS Full Report for the year 2009-2010

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 involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

For further information or to subscribe to NCPC to receive publications free of charge and reduced rates at conferences visit www.ncpc.org.uk.

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About the National End of Life Care Intelligence Network

The 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. It is managed and overseen by the National End of Life Care Programme to help 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.

For more information visit

www.endoflifecare-intelligence.org.uk

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INTELLIGENCE NETWORK

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Introduction

The 2009/10 Minimum Data Set for Specialist Palliative Care Services (MDS) report is the 15th since the original collection in 1995/6 and it is the first 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.

It is clearly too early to draw any links between emerging changes within specialist palliative care activity and the broader End of Life Care Strategy or equivalent policy developments in Wales and Northern Ireland. It will be useful, however, to monitor trends in activities over the coming years to see if and how they might be informed by the implementation of the relevant national approaches. We have highlighted below some of the changes in results from the 2008/9 collection.

The MDS is an evolving collection; as discussed below, NCPC is currently exploring opportunities to continue to develop it further to ensure the MDS is as useful and accessible a resource as possible in the changing health and social care environment.

Headline findings for 2009/10

There are signs of possible work pattern changes in some settings which it will be useful to monitor over the next few years. The nature of contacts (face to face or telephone) particularly seemed to have shifted in some areas, although this is only the second year of collection, so these are early results.

- In day care, the number of consultations with Clinical Nurse Specialists (CNSs) more than doubled, with increases in both face to face and telephone consultations.
- In home care, there was a marked rise in the total number of telephone contacts compared with those made face to face, while the reverse was true for hospice@home contacts. (Hospice@home services are defined as those without CNS input, while the majority of home care contacts were made by a CNS.)
- Hospital support reported an increase of 32% in medical consultants' face to face contacts but a drop in their telephone contacts by 94.3%. CNSs accounted for the majority of contacts (face to face and telephone) but their number of telephone contacts increased by roughly the same level as the medical consultants' decreased.
- Outpatients have the widest spread of contacts between the different professional groups. Physiotherapists recorded more than double last year's number of face to face contacts with fewer than half of their previous number of telephone contacts.

Efficient bed usage will be a continuing priority for inpatient services and commissioners as financial pressures increase. Over recent years, the average available number of beds has grown closer to the average total beds per unit (available beds excludes those kept empty because of staff shortages or ward closures).

The average availability rate increased from 96% to 98% while the average occupancy rate remained the same at 74%, which is a positive indication of more efficient use of beds.

This is the second year for the MDS collection since revisions to the reports were introduced. These revisions have enabled NCPC to perform new analysis that had not previously been possible. For example, we have been able to analyse the degree of access to specialist services for people with Motor Neurone Disease. These findings are set out in Chapter 8, and raise interesting questions for services to consider.

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. This year's dataset has also informed the work of the Pallative Care Funding Review, due to report in the summer of 2011.

Looking to the future, a significant priority is to develop the MDS so that data can be collected 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. NCPC is working with the NEoLCIN and other partners to identify the practicalities and challenges and will be contacting services about this in due course.

April 2011

About the Minimum Data Set for specialist palliative care services

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 will also be 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, as mentioned in the introduction, the dataset is being used to inform the work of the Palliative Care Funding Review, due to report in the summer of 2011.

The survey for 2009/10

The survey is of all hospice and specialist palliative care services located in England, Northern Ireland and Wales that are listed in the 2010 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 fall within the remit of the Scottish Partnership for Palliative Care rather than that of NCPC.

Over the last two years we have attempted to report more accurately the level of activity in the different countries; this process will continue as the response rate from Wales and Northern Ireland improves. Country analysis will therefore be an important part of this and future reports.

All services were contacted by email and asked to download the appropriate forms from the website. Some services had indicated that they would provide a joint response and these joint responses were considered as one service for the purpose of analysis. Data were returned during the summer of 2010.

Responders could submit electronically by email attachment; only 5% of forms were received on paper. The majority of forms (78%) 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. 17% of forms 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.

Individual reports

In November 2010 individual reports were sent to all services providing a response to the questionnaire. This was to enable services to compare their data with that of similar-sized services throughout the country. As with the 2008/9 individual reports, comparisons were also included with data from the service's local SHA, or, in the case of Wales and Northern Ireland, for the whole country. SHAs were used in preference to cancer networks as they cover a larger area and provided more robust data comparisons.

1. National overview

Response rate

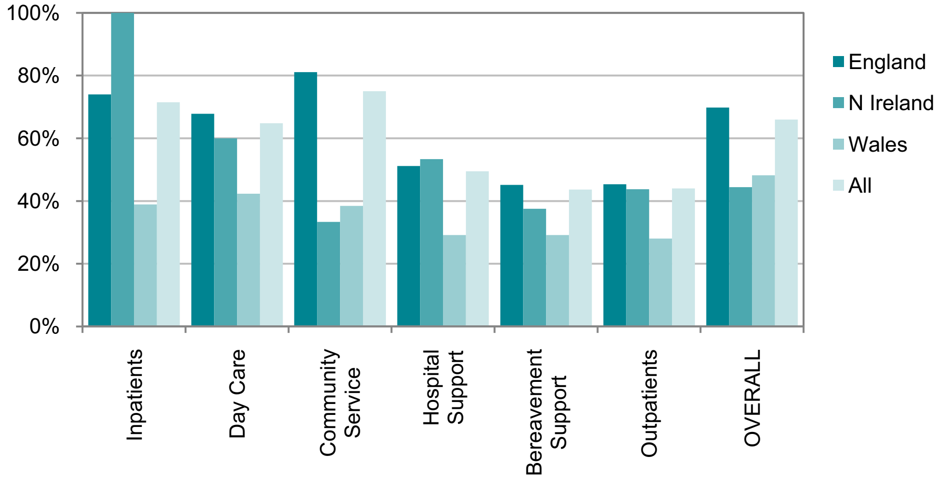
An overall response rate of 62% (328 services) was achieved this year. A number of services reported that their patient records systems had problems reporting data for the revised MDS, which meant that responses were slightly down from last year's 66%. We hope that the response rate will return to the levels seen before the review, as responders become more used to the new questionnaires.

Table 1 shows the overall response rate for the different parts of the questionnaire and it is seen that the response rates varied from 47% to 79%. Chart 1 compares the response rates from England, Northern Ireland and Wales with the overall response rate.

Table 1: Response rate

	Number of services				Overall Response
Service	England	N Ireland	Wales	Total	
Inpatient	131	5	7	143	72%
Day Care	135	3	11	149	65%
Home Care	176	3	10	189	75%
Hospital Support	129	8	7	145	49%
Bereavement Support	121	3	7	131	44%
Outpatients	141	7	7	155	44%
OVERALL RESPONSE	–	–	–	328	62%

Chart 1: Response rate for country and setting



Management

Services were asked to indicate whether they were managed by the NHS or independently.

Table 2 show the breakdown of units for each setting.

Table 2: Service management by units responding

Management	Independent	NHS	Not Recorded	Responses
Inpatients	76%	24%	0%	143
Day Care	82%	18%	0%	149
Home Care	44%	56%	0%	104
Hospice @ Home	83%	17%	0%	48
Combined	54%	46%	0%	37
Hospital Support	11%	88%	1%	145
Bereavement Support	69%	19%	12%	131
Outpatients	54%	37%	9%	155

Chart 2: Service management

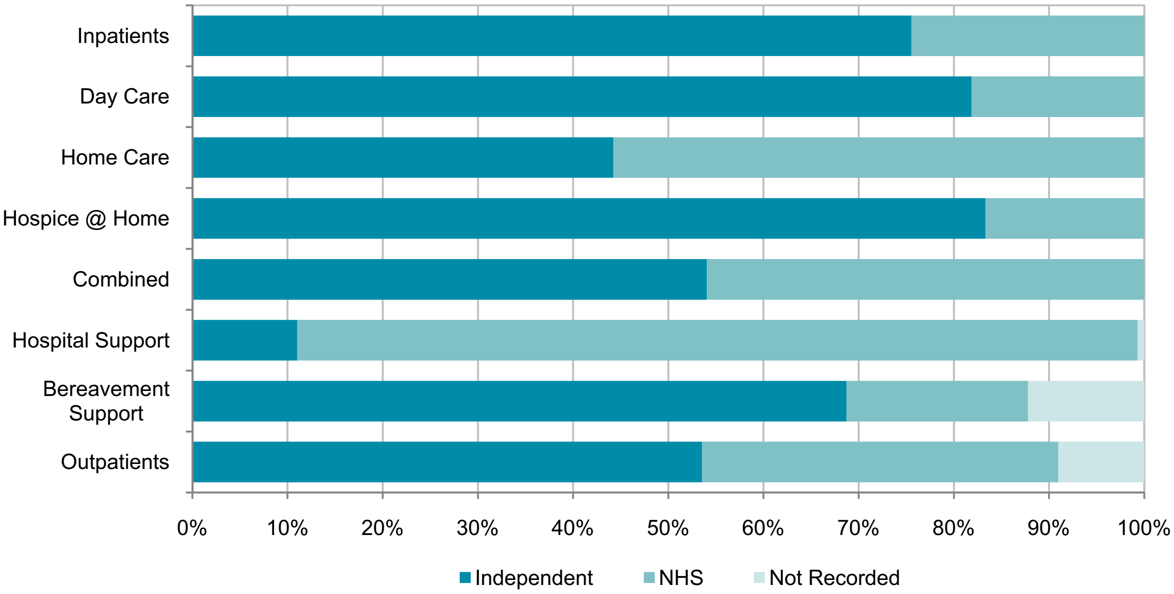


Table 3 breaks down the proportion of new patients attending independent and NHS services for each setting. Although the figures are largely similar to the breakdown by number of units, it should be noted that independent Bereavement and Outpatient units are seeing a higher proportion of patients than the number of units might suggest.

Table 3: Service management by new patient numbers

Management	Independent	NHS	Not Recorded	Response
Inpatients	75%	25%	0%	143
Day Care	86%	14%	0%	149
Home Care	51%	49%	0%	104
Hospice @ Home	79%	21%	0%	48
Combined	64%	36%	0%	37
Hospital Support	10%	90%	0%	145
Bereavement Support	63%	11%	26%	131
Outpatients	62%	27%	11%	155

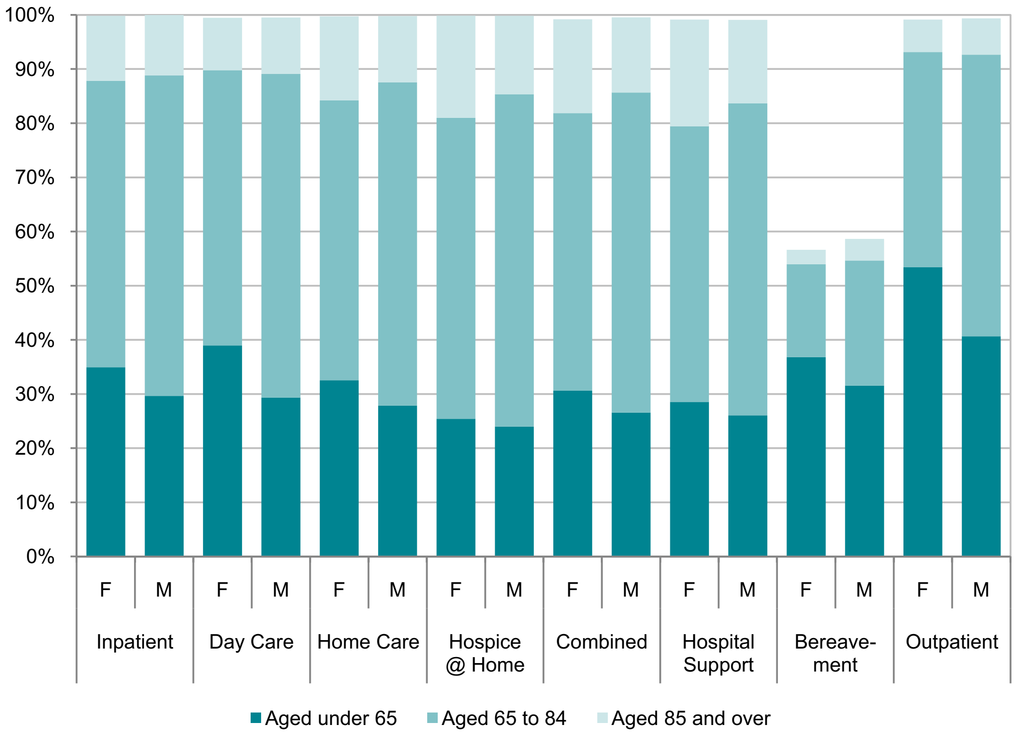
Age and gender

Chart 3 compares the different services with regard to age and gender of patients cared for.

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. Whilst there has been a slight increase in the number of clients whose details have been recorded for Bereavement Support, this is still significantly lower than other services, as can be seen in Charts 3 and 4.

We would encourage services to review how they might ensure more detailed data collection.

Chart 3: Breakdown of age by setting and sex

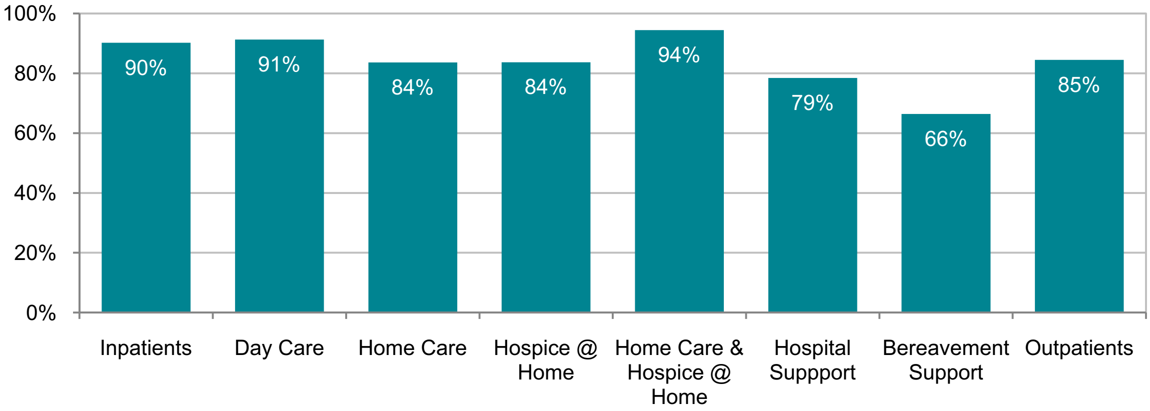


Ethnicity

Palliative care services are expected to categorise their patients according to the 17 ethnic groupings used by the Department of Health and, on average, 88% of respondents were able to do this. The proportion varied, however, from 66% for Bereavement Support to 94% for Combined Home Care & Hospice @ Home services.

The proportion of services returning ethnicity data improved for most settings, the exception being Hospital Support, which remained at 79%.

Chart 4: Percentage of units returning ethnicity data for new patients



It was found that, on average, 5% of patients described themselves as non-white, comprising 2% black (African, Caribbean or other), 1% Indian, Pakistani or Bangladeshi, 0% as mixed race, with 2% of other ethnicity including Chinese. In order not to discard too much data, the data were accepted even if up to half the ethnicity was 'not known' or 'not stated'.

The percentages given have been calculated using only those patients for whom an ethnicity is recorded.

There continues to be an improved response rate to this question, as shown in Table 4. It 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)

Although the response rate to the ethnicity questions had 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 12% in Bereavement Support up to half of non-white patients in Day Care.

Table 4: Response rate to ethnicity question

	2004/5	2005/6	2006/7	2007/8	2008/9	2009/10
Response rate	27%	36%	44%	44%	53%	83%
% non-white	3%	5%	5%	6%	6%	5%

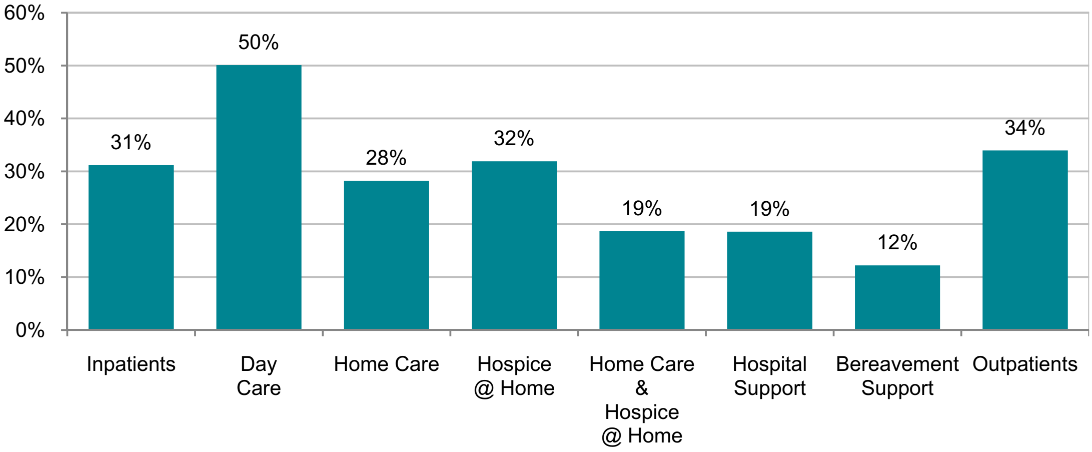


Chart 4: Percentage of units returning ethnicity data for new patients

Collecting data about ethnicity is important in order to be able to measure equity of access to specialist palliative care services. It is recommended that all services review their reporting systems and identify opportunities to improve their ethnicity data.

We recognise that people can find this a difficult piece of information to ask for, but it is a vital component to developing an accurate picture of the people you reach. Being able to demonstrate that services are responding to the needs of their local community is crucial.

Diagnosis

Chart 6 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 25%.

This is still a low figure, as cancer only accounts for about 27% of all deaths. (Cancer Research UK; Cancer in the UK July 2010)

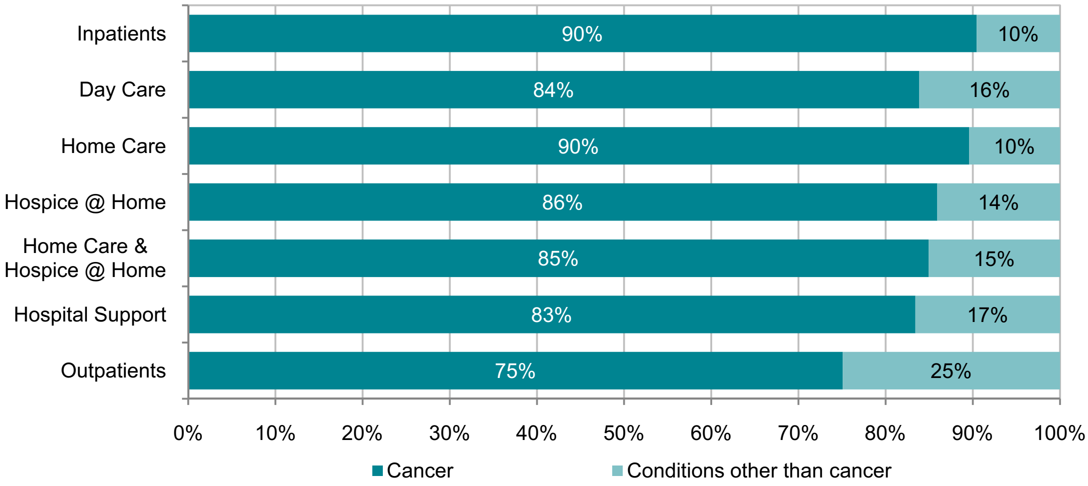


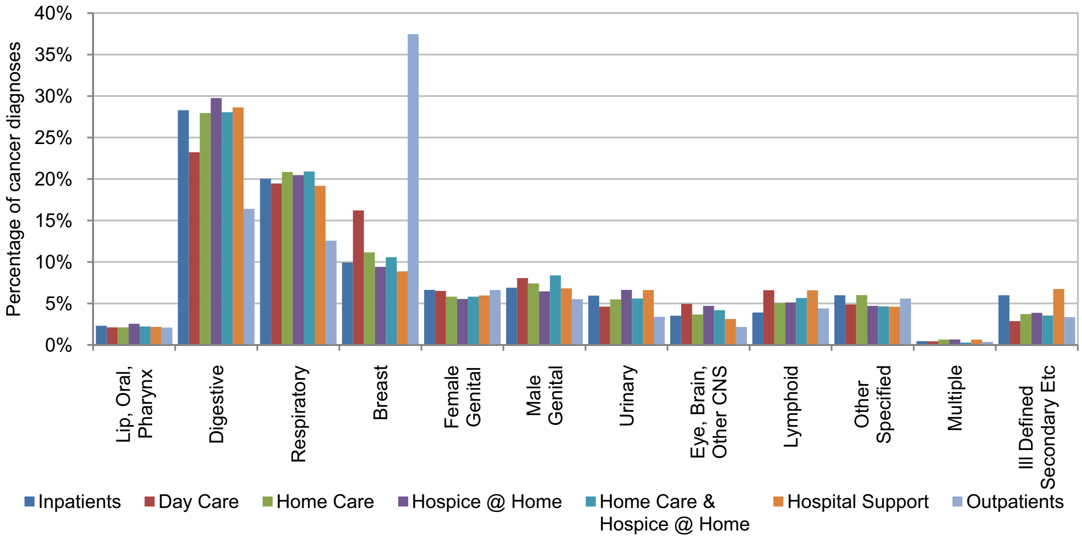
Chart 6: Proportions of cancer and conditions other than cancer, by setting

The proportion of patients diagnosed with conditions other than cancer increased in all settings, apart from Inpatients which remained the same at 10% and Hospital Support, which fell slightly from 18% to 17%.

The different types of cancer diagnoses can be seen in Chart 7. 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 7: Breakdown of cancer diagnoses, by setting

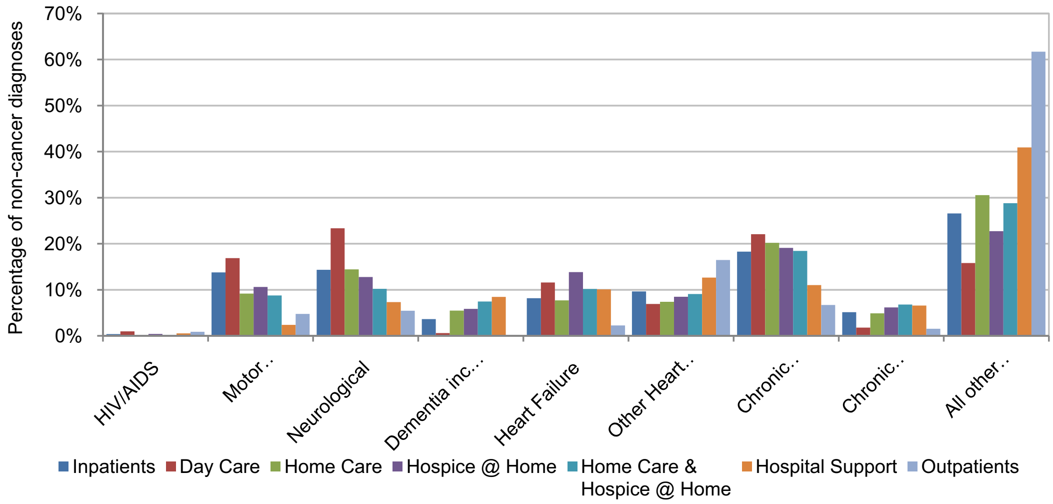


The proportion of "Other" diagnoses has been reduced from over half, to just over a third. There is a need for accurate coding to reflect the conditions being referred and to demonstrate the importance of commissioning services that meet local population needs.

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). (NEoLCIN Bulletin No. 1; June 2010)

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 8: Breakdown of diagnoses other than cancer, by setting



Dementia patients accounted for between 0% and 9% of diagnoses other than cancer, 0.06% to 1.40% of all patients. Although a slight increase on last year, national figures show 15% of all deaths are directly attributable to dementia. (National End of Life Care Intelligence Network; Deaths from Alzheimer's disease, dementia and senility; November 2010)

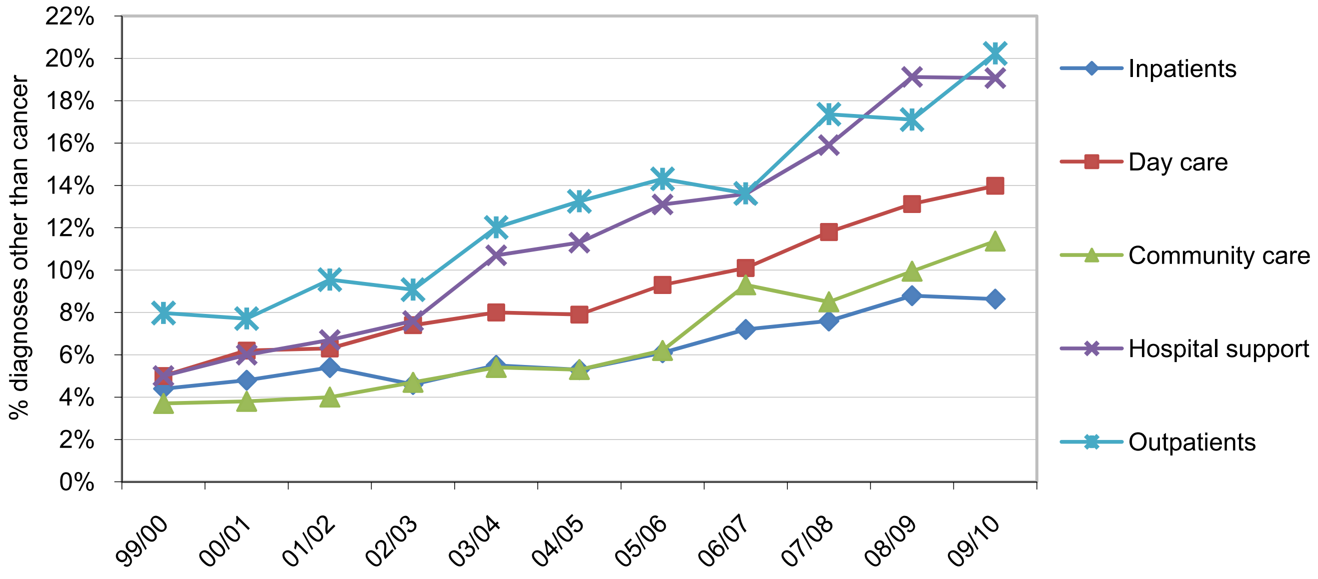
The last 12 years have seen an overall increase in both the percentage and the number of people with diagnoses other than cancer who have been cared for.

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 9 illustrates, the biggest changes have occurred in the last 4 or 5 years.

The most striking increases are in Outpatients (8% to 20%) and Hospital Support (6% to 16%), although diagnoses in Hospital Support dropped a little this year. Day Care is also showing steady increases (5% to 15%). For specialist palliative care inpatient units the percentage of diagnoses other than cancer has increased from 3% to 9%.

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.

Chart 9: Growth in diagnoses other than cancer



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 and Inpatient setting is appropriate and how much this is an indication of further work needed in Community Care and Inpatient settings.

Interventions

Last year, Inpatient, Day Care and Outpatient services were asked, for the first time, to report the number of clinical interventions in the year. There was a slight improvement in the response rate this year, but it was still too low to allow any meaningful analysis.

Responses were received from 32 Inpatient (22%), 47 Day Care (32%) and 31 Outpatient units (20%). Table 5 shows the breakdown of interventions for Day Care services.

Table 5: Interventions in Day Care

Intervention	Services	Min	Max	Mean
Blood Transfusion	32	1	66	16.4
Infusional Therapy	41	1	183	21.5
Neural Blockade	3	1	18	8.3
Paracentesis	6	2	20	7.5

We have not included further tables due to the low response rate for these data. However we can provide further analysis upon request. It is hoped that responses will improve over time as more services update their systems to record clinical interventions.

Trends

Response rates

There is a noticeable variation in response rates across the different settings (see Table 6), as has historically been the case. We would like to better understand 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 services provided. 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 6: Response rates

	Percentage responses									
Services	2000/1	01/02	02/03	03/04	04/05	05/06	06/07	07/08	08/09	09/10
Inpatient	77%	77%	79%	77%	84%	87%	84%	87%	76%	79%
Day Care	78%	80%	77%	76%	79%	84%	87%	83%	75%	73%
Home Care	55%	59%	62%	58%	61%	65%	73%	73%	71%	69%
Hospital Support	47%	45%	49%	47%	47%	57%	61%	61%	59%	54%
Bereavement Support	52%	56%	58%	55%	58%	63%	63%	62%	50%	47%
Outpatient	58%	60%	58%	57%	55%	58%	59%	56%	51%	47%
OVERALL RESPONSE	63%	66%	68%	68%	69%	75%	80%	78%	66%	62%

Summary of data by country

Table 7 shows some selected data by country. It should be recognised that the data from Wales has been obtained from a very small number of services and may well not be representative of the country as a whole.

Table 7: Data for the different countries 2009/10

	Country	Inpatient care	Day care	Community service	Hospital support
Number of services responding	England	131	135	176	129
	N Ireland	5	3	3	8
	Wales	7	11	10	7
Response Rate	England	74%	68%	81%	51%
	N Ireland	100%	60%	33%	53%
	Wales	39%	42%	39%	29%
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	13.1	172.4	101.0	12.3
	N Ireland	16.0	127.8	59.5	17.4
	Wales	13.7	155.9	77.4	7.0

2. Inpatients

Data were collected from those services which provided a specialist palliative care inpatient service during 2009-10, 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 143 services, a 78% response rate, covering 79% of independent units and 63% of NHS units.

Out of the 143 units who responded, 131 services reported a total of 1,888 beds. The units varied in size from 1 to 48 beds, with a mean of 14, the most common size being 9 beds (14 units).

The response rate to individual questions varied between 22% (Interventions) and 98% (Age & Sex and Location before Admission) with a mean of 83% and a median of 96%.

Age and sex

Almost a third (31%) of new patients were aged under 65 (34% of new female patients, 29% of new male patients), with fewer than 1% under 25 and 12% over 84 (13% female, 12% male).

Figures for all patients were similar; 32% under 65 (35% female, 30% male), 0.5% under 25, 11% over 84 (12% 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 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 ACT, Children's Hospices UK and Help the Hospices as part of a Transitions Partnership to improve quality of and access to care for young people in transition.

Chart 10: Age and sex of new inpatients

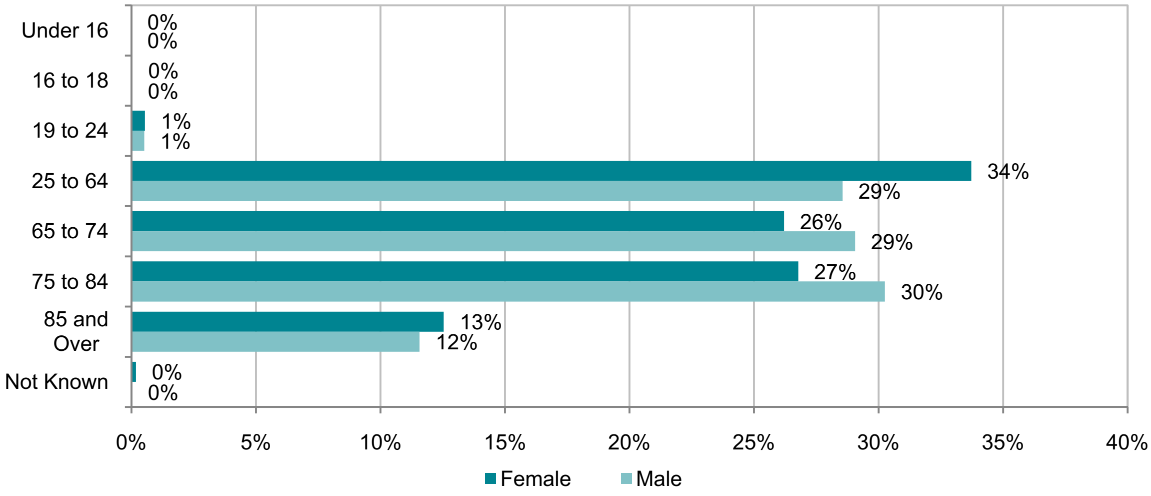


Table 8: Age and sex of inpatients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	0	0	**0**	0	0	**0**
16 to 18	5	3	**8**	5	6	**11**
19 to 24	85	83	**168**	90	90	**180**
25 to 64	5,291	4,571	**9,916**	6,243	5,320	**11,635**
65 to 74	4,112	4,652	**8,829**	4,804	5,277	**10,163**
75 to 84	4,201	4,843	**9,119**	4,801	5,527	**10,422**
85 and Over	1,967	1,852	**3,847**	2,179	2,037	**4,253**
Not Known	29	4	**36**	30	4	**37**
Total	15,690	16,008	31,923	18,152	18,261	36,701

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 90% of Inpatient services. More than three quarters (80%) of new patients were described as white British. A total of 3711 new patients (12%) were 'not recorded'.

The numbers of non-white patients have been grouped together in Chart 11, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 12.

Chart 11: Ethnicity – new inpatients

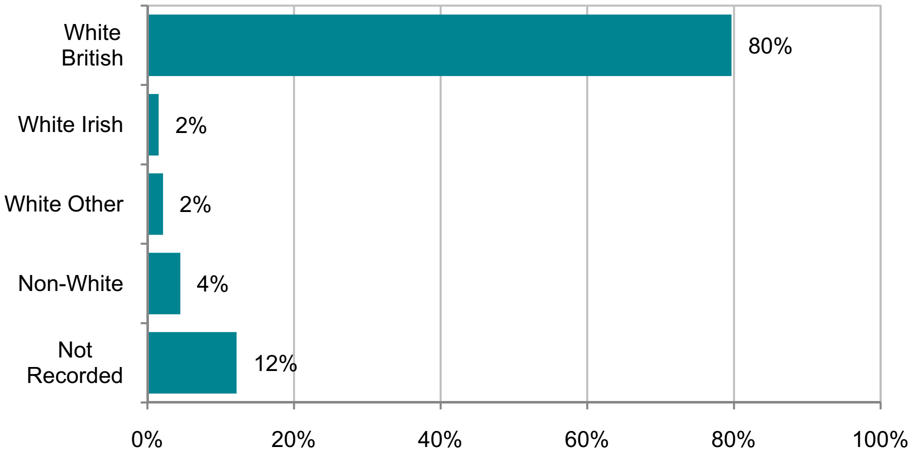
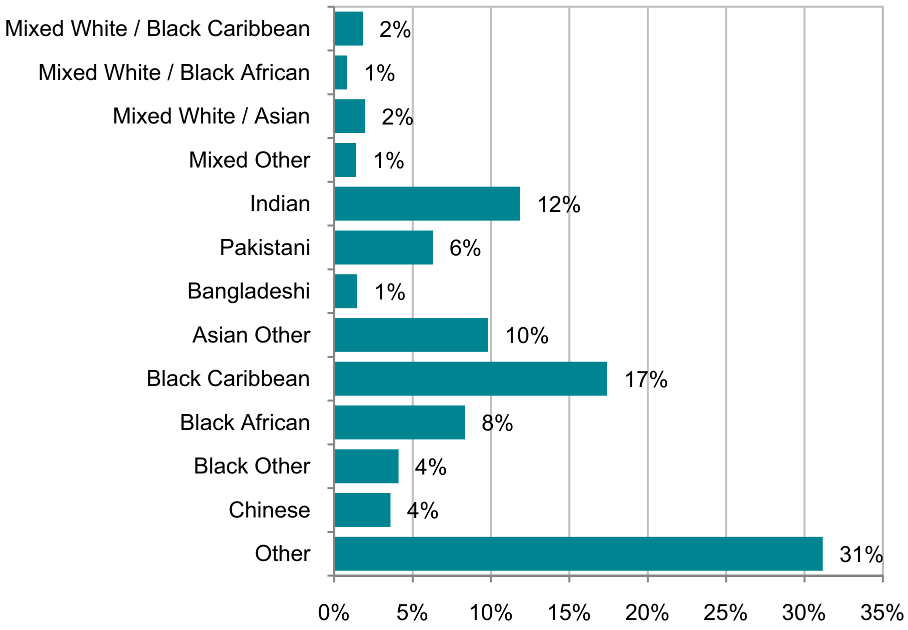


Chart 12: Distribution of non-white categories



Nearly a third of those recorded as being non-white (31%) were under the category 'other'.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 28,244 new referrals to Inpatient units (90%). Cancer figures were divided up into 12 diagnoses. Digestive and respiratory cancers accounted for half the diagnoses (50%).

Chart 13: Diagnoses of new inpatients with a primary diagnosis of cancer

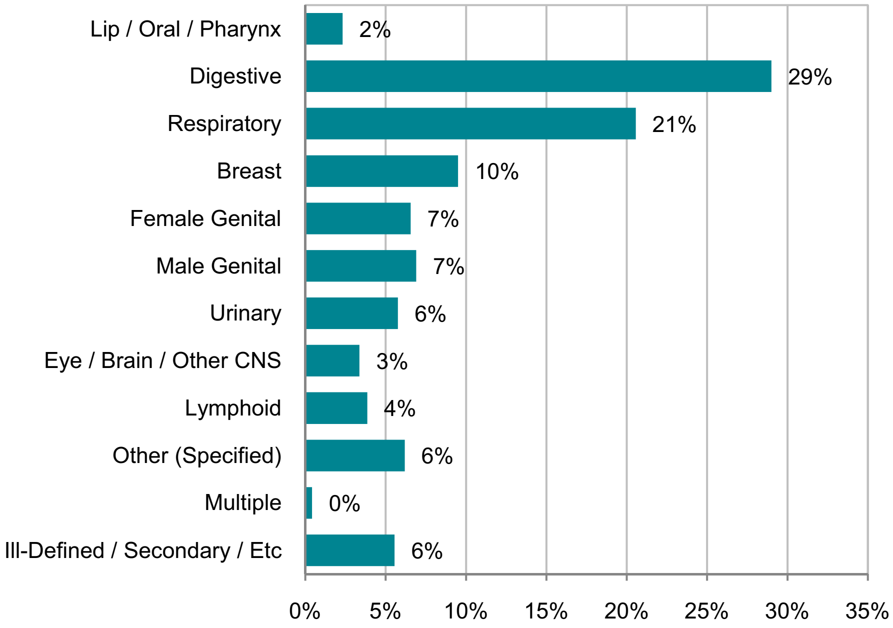


Table 9: Diagnoses of inpatients with a primary diagnosis of cancer

	2009-10		Percentage change from 2008-09	
	New	All	New	All
Lip / Oral / Pharynx	632	738	4%	2%
Digestive	7,905	9,049	8%	9%
Respiratory	5,604	6,403	9%	10%
Breast	2,591	3,179	8%	10%
Female Genital	1,787	2,124	8%	9%
Male Genital	1,882	2,204	9%	6%
Urinary	1,570	1,903	-7%	-7%
Eye / Brain / Other CNS	919	1,127	7%	7%
Lymphoid	1,052	1,251	-2%	-3%
Other (Specified)	1,686	1,917	7%	6%
Multiple	115	147	-9%	-6%
Ill-Defined / Secondary / Etc	1,514	1,918	13%	24%
Total	**27,257**	**31,960**	**7%**	**8%**

Primary diagnosis – conditions other than cancer

Excluding the patients with a ‘not known’ diagnosis, 2,669 new patients (9%) had a diagnosis other than cancer. The proportion of these new patients in the different units ranged from 0% to 32%. Over a third (36%) of responding units had more than 10% of new patients with a condition other than cancer while 3 units had cancer patients only.

The number of dementia patients recorded was low at just 4%. However, dementia is often under-diagnosed and we would also expect it to be an underlying condition in a significant number of cases.

Over a quarter (28%) 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 questions used to collect these data.

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

Chart 14: Diagnose of new inpatients with a primary diagnosis other tha cancer

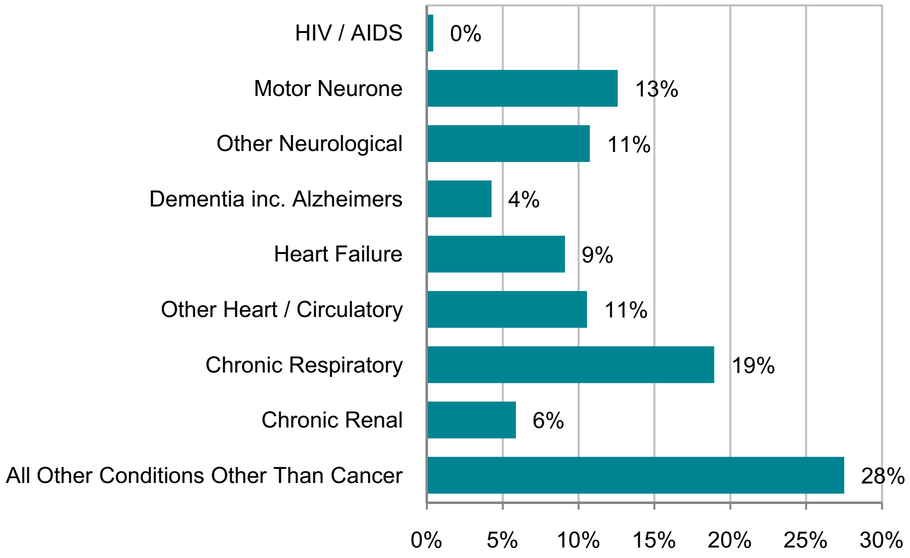


Table 10: Diagnoses of inpatients with a primary diagnosis other than cancer

	2009-10		Change from 2008-09	
	New	All	New	All
HIV / AIDS	11	13	120%	117%
Motor Neurone	330	465	6%	9%
Other Neurological	282	484	2%	3%
Dementia inc. Alzheimer’s	112	123	90%	71%
Heart Failure	239	276	-4%	-7%
Other Heart Circulatory	277	325	28%	30%
Chronic Respiratory	497	617	22%	30%
Chronic Renal	154	173	26%	24%
All Other Conditions	722	897	-9%	-4%
Total	2,624	3,373	8%	10%

The number of new patients with a diagnosis of HIV / AIDS more than doubled, but the numbers are so low that this may not be significant. The number of new patients with a diagnosis of dementia increased by nearly 90%, and “Other” diagnoses decreased by nearly 9%.

Analysis of Inpatient stays

Location before admission

The vast majority of new admissions (70%) were from the patient's own home, with 24% from an acute hospital.

Chart 15: Location of inpatients before admission

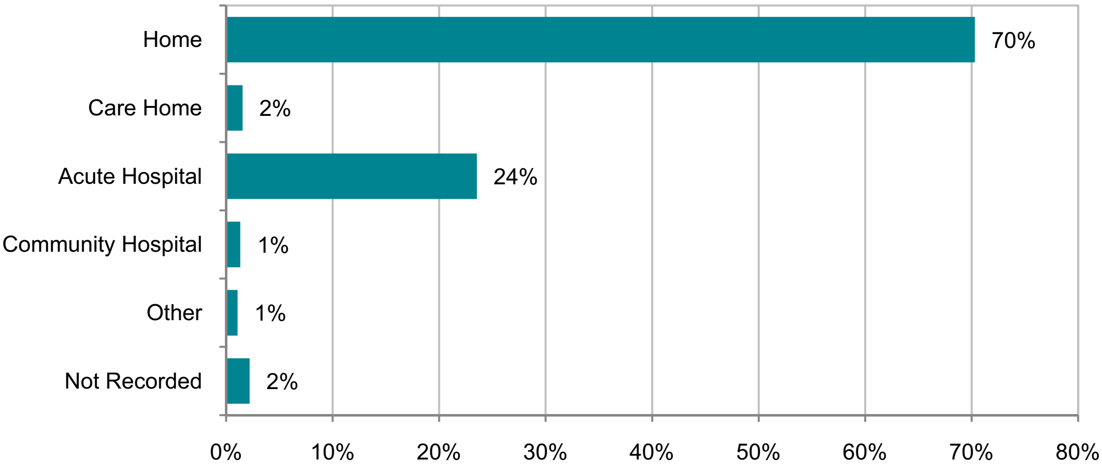


Table 11: Location of inpatients before admission

Location	Count
Home	28,808
Care Home	632
Acute Hospital	9,648
Community Hospital	547
Other	442
Not Recorded	906

Length of stay

The mean length of stay was much the same as for the 2008-09 survey, with the exception of units with 16-20 beds. After a peak of 17.1 days last year it returned to 13.3, closer to the mean of 13.8 in 2007/08, suggesting that last year's figure may have been anomalous. (Table 12)

The mean length of stay in an NHS-managed inpatient unit was 12.5 days, compared with 13.5 days in an independently-managed unit. (Table 13)

Table 12: Length of stay by size of unit

Size of unit (number of beds)	3 - 6	7 - 10	11 - 15	16 - 20	21 - 25	Over 25	All Units
Number of responding units	11	30	28	32	4	13	121
Mean length of stay in days	12.2	12.2	13.7	13.3	15.1	14.4	13.3

Chart 16: Length of stay by size of unit

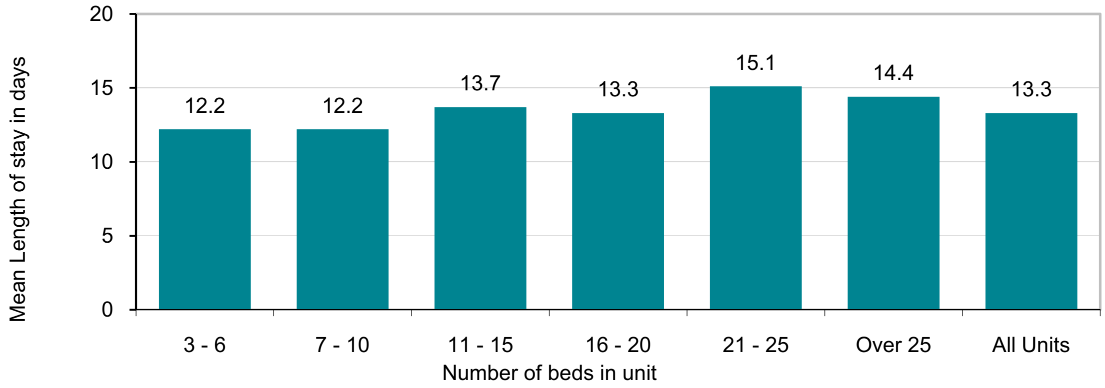


Table 13: Comparison of average length of stay between NHS and independent units

Management	Average Length of Stay
Independent	13.5
NHS	12.5

Location after end of stay

Just over half of those no longer being cared for by the service (51%) had died. The remainder had been discharged; of these, the majority (78%) were discharged to home.

The fact that 49% of admissions ended in discharge should go some way to dispelling the myth that hospices are just somewhere where people go to die.

Chart 17: Location after end of stay

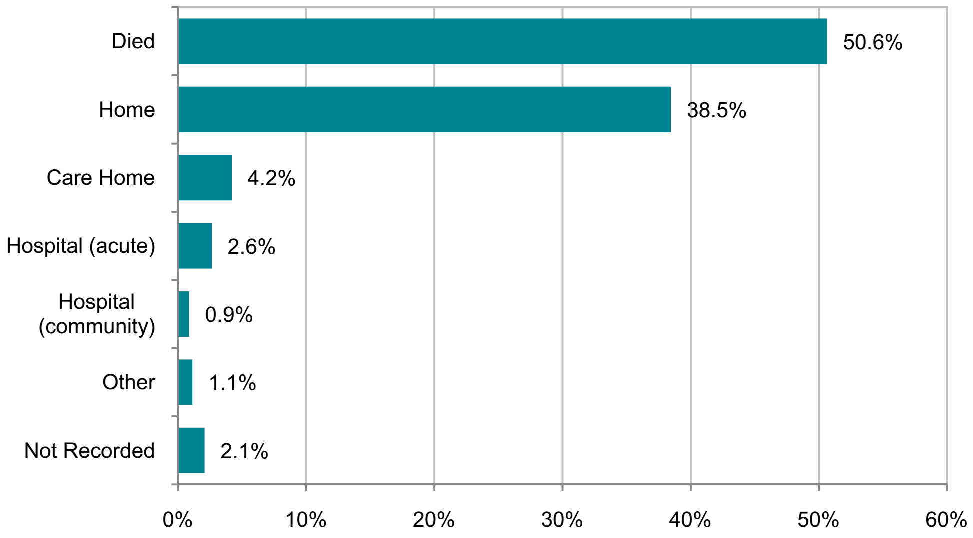


Table 14: Location after end of stay

Location	Died / Discharged	Discharged
Died	51%	-
Home	39%	78%
Care Home	4%	9%
Hospital (acute)	3%	5%
Hospital (community)	1%	2%
Other	1%	2%
Not Recorded	2%	4%

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 73%. The variations in occupancy were between 50% and 99%, the minimum increasing from 36% for 2009-10. 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 52% of units (75) recorded no reserved beds (up from 41% last year) while others recorded up to 14% (down from 17%). 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 23.3 admissions per available bed, ranging from 10.8 to 58.9 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 4.1 days, varying between 1.0 days and 15.0 days.

Table 15: Inpatients – Bed usage

Data Item	Minimum	Mean	Maximum	Number responding	Number of admissions
% Bed Occupancy	50%	73%	99%	128	41,756
Throughput (Admissions per bed per year)	10.8	23.3	58.9	131	
Turnover (Interval between admissions)	1.0	4.1	15.0	129	

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.

Table 16 gives details of admissions, deaths and discharges from those units which responded to all the relevant parts of the survey.

Table 16: National estimates – Inpatient units

	Responding Units	National totals and Estimates
No of units	142	193
Total beds	1949	2,649
Response rate for units	74%	-
Response rate for beds	93%	-
New patient admissions	32,703	45,300
Total patients	37,381	51,900
Deaths	21,710	30,000
Discharges	21,156	29,500
Ratio of deaths to discharges	1.03	
Ratio of new patient admissions to deaths & discharges	0.76	
Ratio of deaths to deaths & discharges	0.51	
Ratio of deaths to new patient admissions	0.66	

The ratio of deaths to discharges has decreased from last year's figure of 1.38 to 1.03. In other words, 51% of all admissions (including re-admissions) result in death. The ratio of deaths to new patient admissions is 0.66. This means a third of patients (33%) did not die in a palliative care inpatient unit on the first or any subsequent admission during the year.

Beds analysis

Over 11 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 14.8
- The average number of patients per unit has increased from 237.2 to 260.1

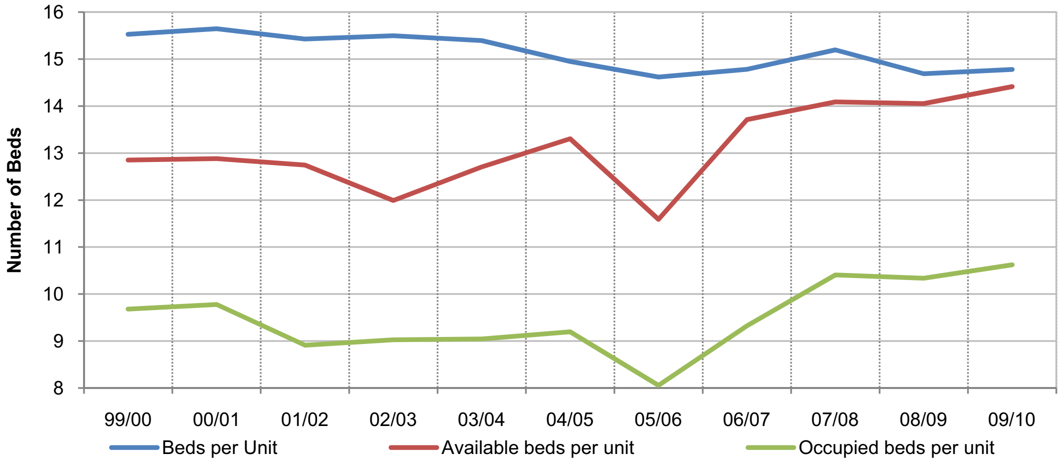
More patients, with fewer beds would imply that the average length of stay would decrease, whereas it has actually increased from 12.4 to 12.9 days.

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

- Available beds per unit, up from 12.9 to 14.4
- Occupied beds per unit, up from 9.7 to 10.6

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

Chart 18: Bed usage analysis



Please note: the graph's y-axis does not start at zero

Table 17: Bed usage analysis

MDS Year	Total beds per Unit	Patients per unit	Length of Stay	Available beds per unit	Available beds as % of Total	Occupied beds per unit	Occupied beds as % of available
99/00	15.5	237.2	12.4	12.9	83%	9.7	75%
00/01	15.6	257.3	12.8	12.9	82%	9.8	76%
01/02	15.4	242.9	12.4	12.7	83%	8.9	70%
02/03	15.5	247.6	12.7	12.0	77%	9.0	75%
03/04	15.4	241.4	12.3	12.7	83%	9.0	71%
04/05	14.9	240.3	13.1	13.3	89%	9.2	69%
05/06	14.6	235.6	12.1	11.6	79%	8.1	70%
06/07	14.8	257.0	12.1	13.7	93%	9.3	68%
07/08	15.2	261.6	12.5	14.1	93%	10.4	74%
08/09	14.7	254.3	12.8	14.1	96%	10.3	74%
09/10	14.8	260.1	12.9	14.4	98%	10.6	74%

3. Day Care

Data were received from 149 services, a 73% response rate, covering 75% of independent units and 54% 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 80% and a median of 89%.

Age and sex

The mean number of new patients per service was 97 with a range from 5 to 311. New patients comprised 63% 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. A third of new patients were under 65 and of 14,061 patients there were 65 who were under 25 (0.5%). More females than males attended Day Care (58% female).

Chart 19: Day Care new patients – age and sex

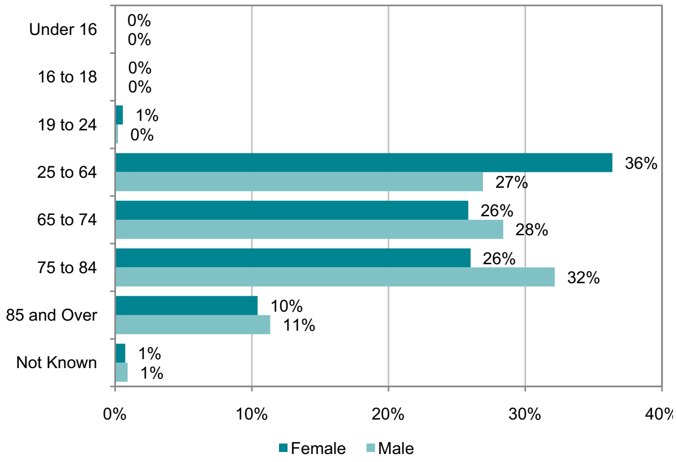


Table 18: Day care patients – age and sex

	New			All		
	Female	Male	All	Female	Male	All
Under 16	0	1	**1**	7	5	**12**
16 to 18	4	3	**7**	6	6	**12**
19 to 24	44	13	**57**	38	13	**51**
25 to 64	2,843	1,677	**4,520**	4,855	2,689	**7,577**
65 to 74	2,019	1,769	**3,794**	3,186	2,617	**5,838**
75 to 84	2,032	2,004	**4,042**	3,214	2,909	**6,166**
85 and Over	815	707	**1,524**	1,219	964	**2,200**
Not Known	58	57	**116**	67	45	**156**
Total	**7,815**	**6,231**	**14,061**	**12,592**	**9,248**	**22,012**

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 91% of Day Care services. More than three quarters (77%) were described as white British. A total of 2,284 new patients (17%) were 'not recorded'.

The numbers of non-white patients have been grouped together in Chart 20, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 21.

Chart 20: Day Care new patients – ethnicity

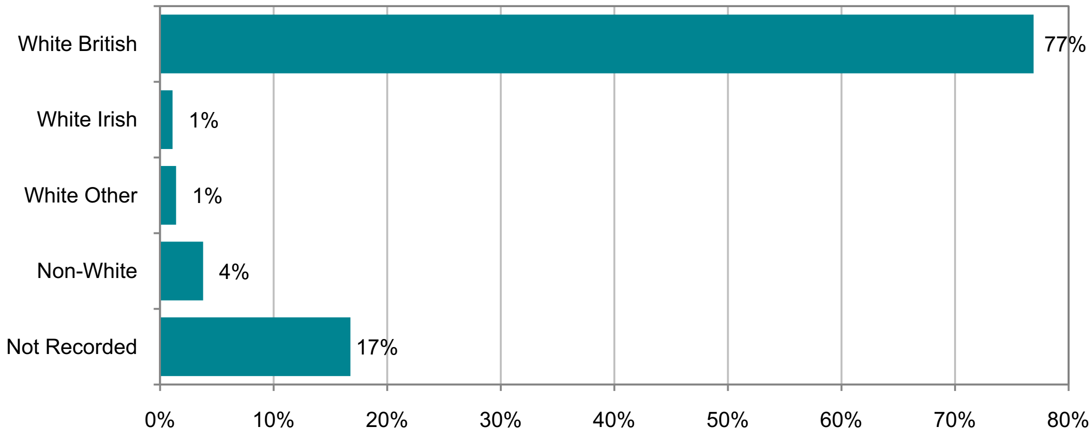
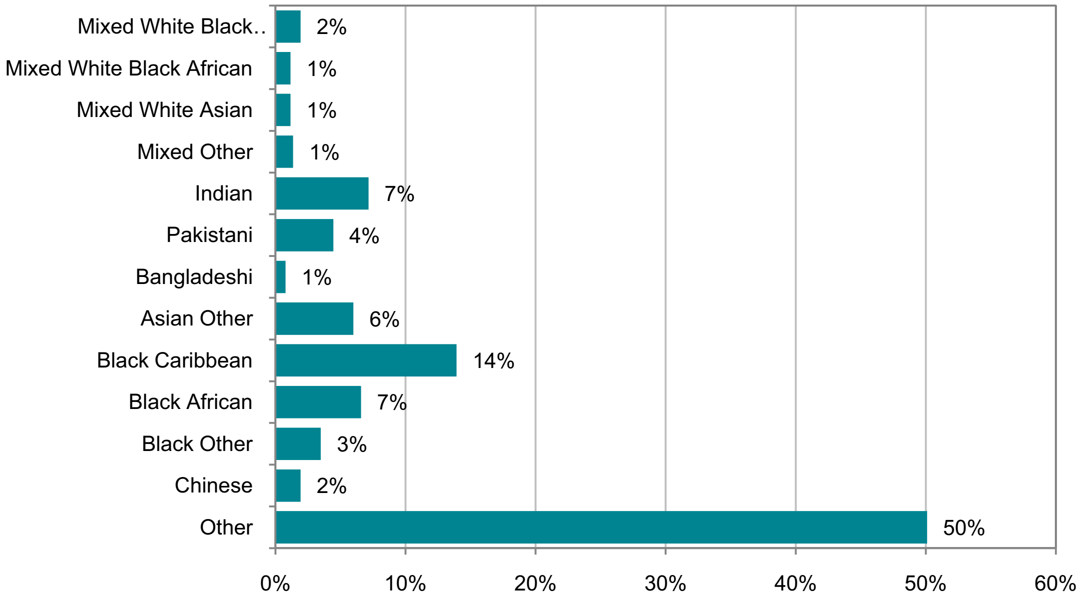


Chart 21: Day Care new patients – non white



Although the proportion of non-white patients has remained the same at 4%, half of those recorded as being non-white (50%) were under the category 'other', an increase from 35% last year.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 10,958 new referrals to Day Care units (86%). 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 10%).

Chart 22: Diagnoses of new Day Care patients with a primary diagnosis of cancer

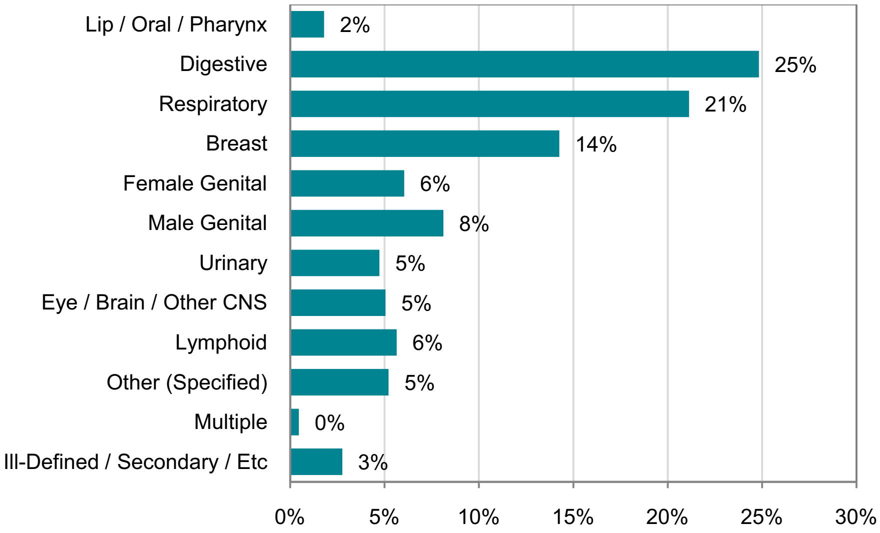


Table 19: Diagnoses of Day Care patients with a primary diagnosis of cancer

Cancer site	New	All
Lip / Oral / Pharynx	197	359
Digestive	2,721	3,931
Respiratory	2,315	3,293
Breast	1,562	2,744
Female Genital	662	1,102
Male Genital	889	1,364
Urinary	518	784
Eye / Brain / Other CNS	553	837
Lymphoid	618	1,116
Other (Specified)	571	826
Multiple	50	74
Ill-Defined / Secondary / Etc	302	487
Total	**10,958**	**16,917**

Primary diagnosis – conditions other than cancer

Excluding the patients with a 'not known' diagnosis, 1,799 patients (14%) had a diagnosis other than cancer. Of the 149 services responding over a quarter (26%) had more than 20% patients with a diagnosis other than cancer, reaching up to over 50% in the case of two services. There were three services which recorded no patients with a condition other than cancer.

The proportion of diagnoses other than cancer recorded under "Other" decreased slightly from a fifth last year (20%) to 17% this year.

Chart 23: Diagnoses of new Day Care patients with a primary diagnosis other than cancer

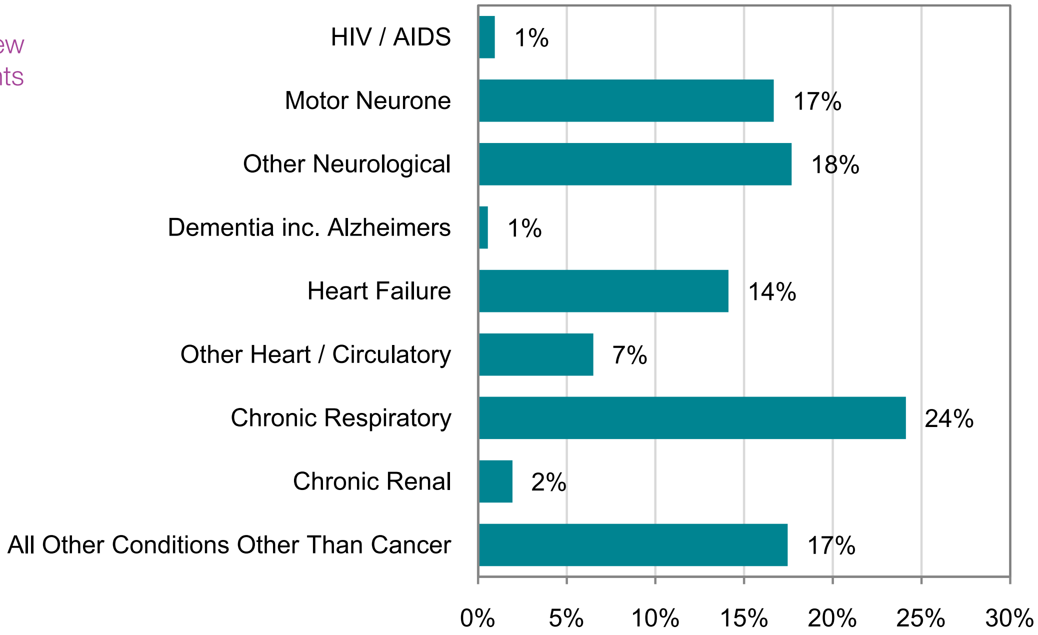


Table 20: Diagnoses of Day Care patients with a primary diagnosis other than cancer

Diagnosis	New	All
HIV / AIDS	17	32
Motor Neurone	300	549
Other Neurological	318	760
Dementia inc. Alzheimer's	10	20
Heart Failure	254	377
Other Heart Circulatory	117	225
Chronic Respiratory	434	719
Chronic Renal	35	58
All Other Conditions	314	515
Total	1,799	3,255

Consultations

Face to face consultations

A total of 101 organisations supplied data on the number of face to face consultations made by health care professionals, an increase of 28% on last year. A total of 220,244 consultations were recorded, an increase of 26%.

Table 21: Consultations – face to face

Health Care Professional	Face to face contacts		Max in unit	Average (mean)	Average (median)	Count of Services
Medical Consultant	995	1%	22%	26	15	38
Other Doctor	10,930	5%	64%	182	79.5	60
CNS	19,350	9%	96%	372	80	52
Other Nurse	79,241	36%	100%	978.3	718	81
Physiotherapist	18,834	9%	93%	281	147	67
Occupational Therapist	11,986	5%	43%	239	60	50
Social Worker	7,423	3%	43%	145	60	51
Pastoral / Spiritual Carer	11,414	5%	56%	243	117	47
Psychologist / Psychotherapist	2,246	1%	24%	98	15	23
Complementary Therapist	41,062	19%	100%	587	515.5	70
Other Health Care Professional	17,213	8%	90%	297	91	58
Total	**220,244**	–	–	**2,181**	**1869**	**101**

- The number of services responding increased from 79 to 101 (28%)
- Consultations recorded increased from 174,564 to 220,244 (26%)
- Clinical Nurse Specialists, Social Workers and Other Doctors showed the largest increase in numbers of consultations
- Clinical Nurse Specialists' consultations more than doubled from 9,386 to 19,350,
- The number of services reporting Pastoral / Spiritual Care and Psychologist / Psychotherapist consultations more than doubled
- But the number of Pastoral / Spiritual Care consultations dropped by 8%, and those with a Medical Consultant dropped by 30%

Comparing the 70 organisations who submitted consultation data for both 2008-09 and 2009-10, the number of first consultations was down overall for all professionals except Complementary Therapists and Other Health Care Professionals which were slightly up.

Follow up consultations were considerably higher for Clinical Nurse Specialists and Other Nurses, with smaller increases for Other Doctors, Social Workers and Complementary Therapists. The other professions saw a fall in numbers seen, with Other Health Care Professionals seeing the largest fall, perhaps because of better record keeping.

Telephone consultations

A total of 83 organisations recorded telephone consultations, up just 5% on last year. However 94,192 consultations were recorded, an increase of 116% on last year. This would imply that services are improving their systems for recording consultations.

Table 22: Consultations – telephone

Health Care Professional	Telephone contacts		Max in unit	Average (mean)	Average (median)	Count of Services
Medical Consultant	620	0.7%	21%	44.3	2.5	14
Other Doctor	1,075	1.1%	100%	43.0	22	25
Clinical Nurse Specialist	34,849	37.0%	100%	941.9	21	37
Other Nurse	45,251	48.0%	100%	718.3	350	63
Physiotherapist	759	0.8%	100%	25.3	15	30
Occupational Therapist	2,900	3.1%	100%	90.6	19.5	32
Social Worker	4,590	4.9%	99%	153.0	33.5	30
Pastoral / Spiritual Carer	227	0.2%	1%	17.5	2	13
Psychologist / Psychotherapist	142	0.2%	20%	17.8	14	8
Complementary Therapist	616	0.7%	65%	29.3	11	21
Other Health Care Professional	3,163	3.4%	100%	85.5	18	37
Total	**94,192**	–	–	**1,135**	**526**	**83**

- The number of services responding increased from 79 to 83 (5%)
- Consultations recorded more than doubled from 43,591 to 94,192 (116%)
- Clinical Nurse Specialists and Other Nurses showed the largest increase in consultations
- Nearly nine times the number of Clinical Nurse Specialist consultations were recorded compared to last year, with an increase in the number of services responding of 28%
- Other Nurse consultations increased by 50%, though the number of services responding dropped slightly
- Medical Consultants and Pastoral / Spiritual Carers' consultations also showed large percentage increases, but still had very few consultations recorded each year

Comparing the 53 organisations who submitted telephone contact data for both 2008-09 and 2009-10, Clinical Nurse Specialists and Other Nurses had the largest increase in telephone consultations this year (nearly 10,000 more), while Other Health Care Professionals and Social Workers were slightly down on last year.

Deaths and discharges

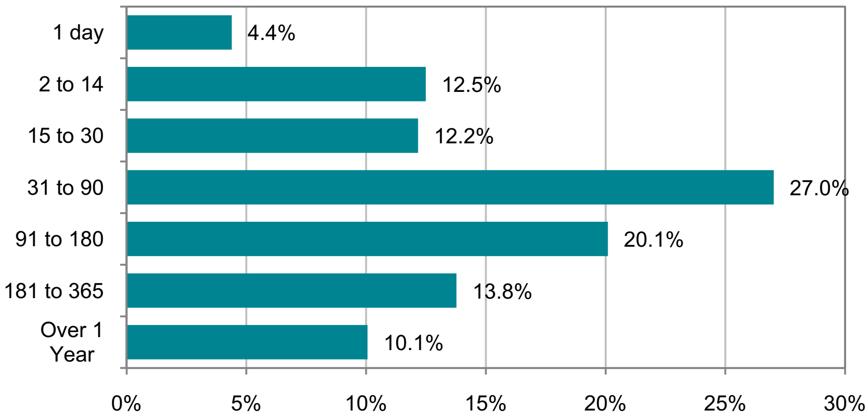
The number of patients who died or were discharged during the year was calculated from the total number of deaths and discharges, minus the number of re-referrals, since each re-referral should account for one discharge.

Overall, 15,153 (66%) of all patients either died or were discharged during the year.

Length of care and caseload

The length of time patients were under the care of the day centre prior to discharge was given by 130 services (87% of total number responding). Of 13,889 patients over half (56%) 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 half a week to 18 months.

Chart 24: 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 23, where the median length of care was found to be 154 days, the mean caseload was 44 patients, although the median was lower at 36 patients.

Table 23: Patient care

Data Item	Analysis	Results	Number of Services Responding	Numbers in responding services
Average length of care	Mean of service averages	172 days	126 (85%)	-
	Median of averages	154 days		
	Range	2.3 to 570 days		
Long term patients (registered for more than a year)	% of total number of patients	6%	123 (83%)	1,397 long term patients
	Range	0% to 32%		
Caseload	Mean for these services, based on mean length of care	44	127 (85%)	15,153 deaths and discharges
	Median based on length of care	36		

Day Care use

A Day Care session is defined as the time that one centre is open on one day. Reports from 91% of the total number of units showed that the average number of sessions per unit per year was 198.6, about 4 per week. This ranged from 31 (less than one per week) to 390 (about 7 per week) with outliers of 659 and 1,872. (Some services provide day care on more than one site.) There is an average of 14.5 places per session, ranging from 6 to 45. The mean attendance rate is 74% ranging from 48% to 100%.

Table 24: Day care places

	Results	Number of services responding	Numbers in responding services
Mean no of sessions per year per unit	199.1	136 (91%)	27,007 sessions 393,717 places 228,822 attendances
Range of number of sessions	31 to 390		
Mean number of places per session	14.5		
Range of number of places	6 to 45		
% use of available places	74%		
Range of % use of available places	48% to 100%		

4. Community Services

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 2009-10.

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 or a service based in the patient's home with CNS input.

Hospice @ Home (H@H): A community service which self-identifies as providing Hospice @ Home or a 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.

Respondants 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

- 169 units responded, eighteen of which sent two returns and one sent three returns
- 270 units were expected, giving a 63% response rate. NHS-managed services accounted for 44% of returns, 56% were independently-managed
- There were 104 units who identified themselves as Home Care services
- A total of 48 services identified themselves as H@H
- Combined Home Care and H@H services accounted for 37 returns

Table 25: Community Services – responses

Service type	Services responding	Independent management	NHS management
Home Care	104	44%	56%
Hospice @ Home	48	83%	17%
Home Care and Hospice @ Home	37	54%	46%

For Home Care, the response rate for each question varied between 65% (Telephone Details) and 98% (Outcome) with a mean of 82% and a median of 82%.

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 83%.

For Combined services, the response rate for each question varied between 60% (Face to Face (Follow up) Details) and 97% (Age & Sex, Ethnicity and Outcome) with a mean of 82% and a median of 85%.

Age and sex

Chart 25 shows patient demographics for Home Care services. On average, each service cared for over 520 new patients, varying between 11 and 1924 patients. These new patients comprised two thirds of the total number cared for (67%). 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 (28%) with 15% aged 85 or over.

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

Chart 25: Home Care new patients - age and sex

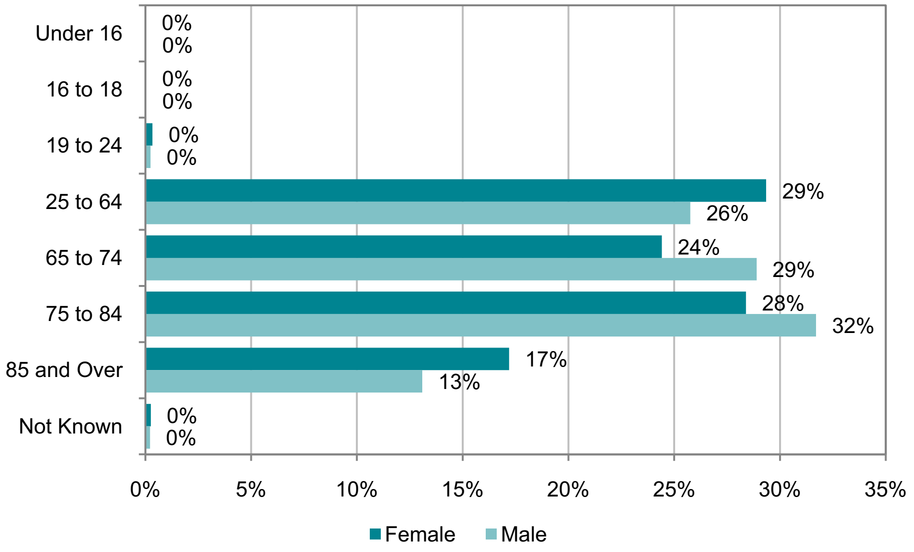


Table 26: Age and sex for Home Care patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	1	5	**6**	14	9	**23**
16 to 18	8	9	**17**	12	16	**58**
19 to 24	78	63	**147**	119	104	**232**
25 to 64	7,107	6,544	**14,152**	11,568	9,832	**22,154**
65 to 74	5,938	7,302	**13,668**	8,898	10,339	**19,892**
75 to 84	6,950	7,986	**15,427**	9,695	11,021	**21,482**
85 and Over	4,154	3,310	**7,636**	5,561	4,354	**10,220**
Not Known	158	168	**691**	195	194	**826**
Total	24,394	25,387	51,744	36,062	35,869	74,887

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

Chart 26 shows patient demographics for Hospice @ Home services. On average, each service cared for over 230 new patients, varying between 1 and 713 patients. These new patients comprised over three quarters of the total number cared for (88%).

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 17% aged 85 or over.

Chart 26: Hospice @ Home new patients - age and sex

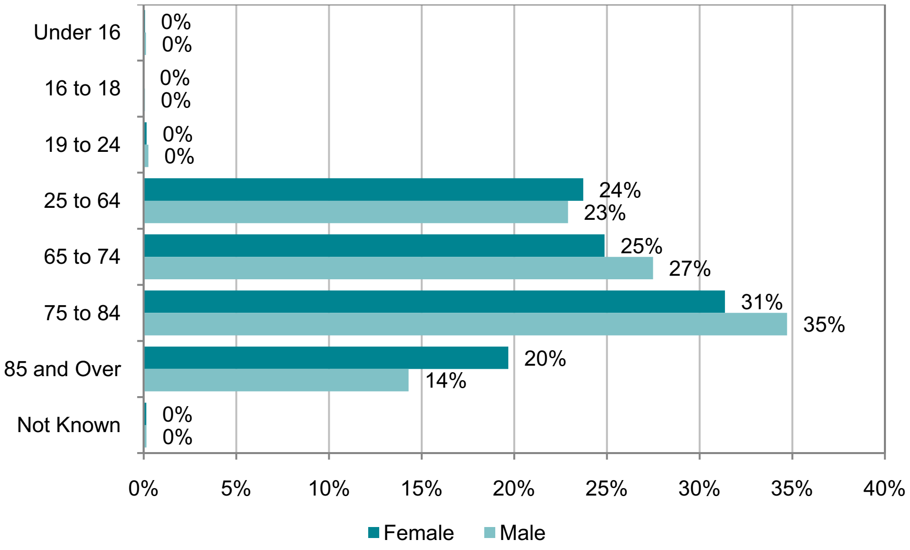


Table 27: Age and sex for Hospice @ Home patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	7	12	**19**	25	31	**56**
16 to 18	2	5	**11**	5	6	**15**
19 to 24	14	12	**33**	16	18	**41**
25 to 64	1,206	1,232	**2,654**	1,509	1,457	**3,183**
65 to 74	1,231	1,453	**2,935**	1,455	1,685	**3,398**
75 to 84	1,520	1,862	**3,749**	1,810	2,120	**4,301**
85 and Over	971	770	**1,919**	1,108	909	**2,204**
Not Known	10	8	**27**	13	12	**58**
Total	4,961	5,354	11,347	5,941	6,238	13,256

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

Chart 27 shows patient demographics for Combined Home Care and Hospice @ Home services. On average, each service cared for over 526 new patients, varying between 74 and 1799 patients. These new patients comprised just over three quarters of the total number cared for (76%).

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 17% aged 85 or over.

Chart 27: Combined Service new patients - age and sex

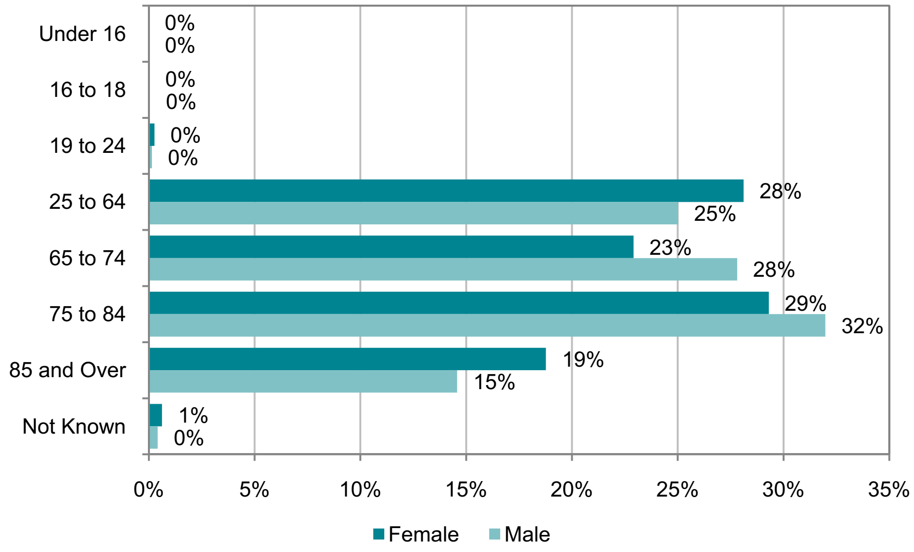


Table 28: Age and sex for combined Home Care & Hospice @ Home patients

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	0	1	**1**	1	2	**3**
16 to 18	2	5	**7**	4	6	**10**
19 to 24	25	14	**39**	35	28	**63**
25 to 64	2,654	2,376	**5,030**	3,759	3,201	**6,960**
65 to 74	2,163	2,641	**4,805**	2,868	3,392	**6,261**
75 to 84	2,767	3,037	**5,805**	3,499	3,808	**7,308**
85 and Over	1,772	1,384	**3,156**	2,150	1,692	**3,842**
Not Known	59	40	**99**	101	56	**159**
Total	9,442	9,498	18,942	12,417	12,185	24,606

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 77% of Community Services. Over three quarters (76%) were described as white British. The ethnicity of a total of 9,225 new patients (19%) was 'not recorded'.

The numbers of non-white patients have been grouped together in Chart 28, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 29.

Chart 28: Community Service new patients – ethnicity

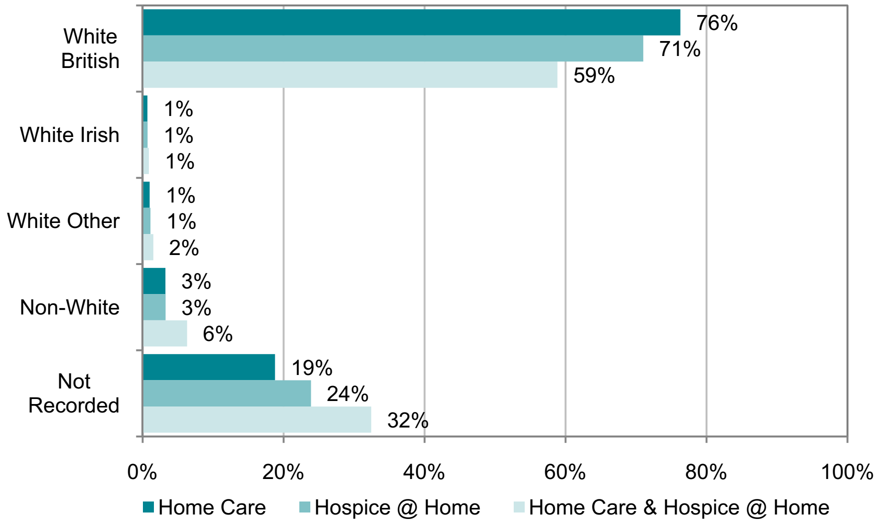
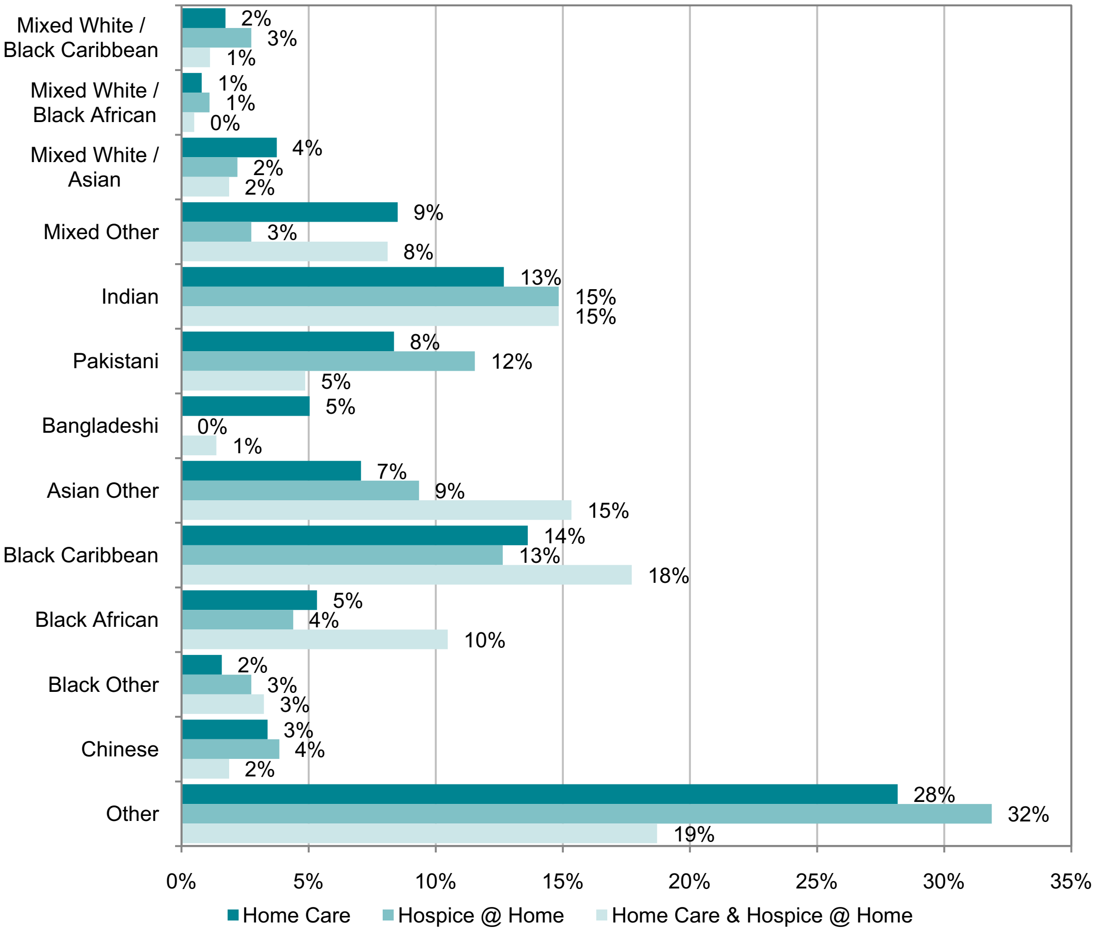


Chart 29: Community Service new patients – non white



Primary diagnosis – cancer

Excluding patients with a 'not known' diagnosis:

- 89% of patients using a Home Care service had a diagnosis of cancer
- 87% of patients using a Hospice @ Home service had a diagnosis of cancer
- 84% of patients using a combined service had a diagnosis of cancer

Although the three service types had 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 30: Community Services diagnosis – cancer

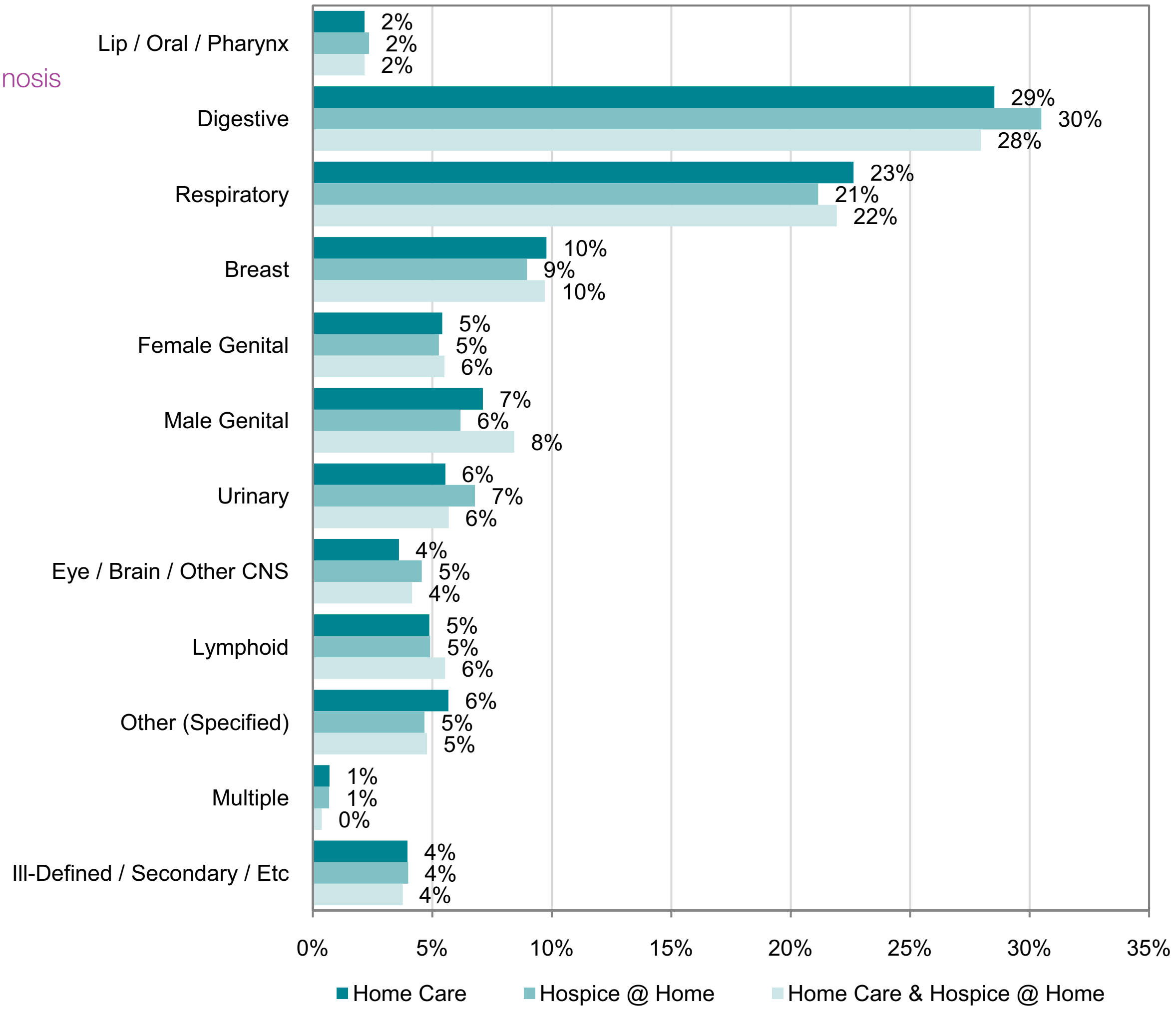


Table 29: Community Services diagnosis – cancer

Location	Home Care		Hospice @ Home		Combined	
	New	All	New	All	New	All
Lip / Oral / Pharynx	875	1,253	148	190	310	424
Digestive	11,532	16,488	1,919	2,208	4,005	5,319
Respiratory	9,151	12,300	1,331	1,519	3,141	3,965
Breast	3,953	6,586	564	698	1,392	2,005
Female Genital	2,190	3,430	332	411	789	1,105
Male Genital	2,878	4,380	389	479	1,208	1,591
Urinary	2,243	3,238	427	493	815	1,062
Eye / Brain / Other CNS	1,458	2,169	287	350	595	796
Lymphoid	1,972	2,996	309	381	793	1,076
Other (Specified)	2,296	3,552	294	350	684	881
Multiple	283	387	43	49	54	59
Ill-Defined / Secondary / Etc	1,602	2,196	251	288	539	672
Total	9,442	9,498	18,942	10,714	10,476	21,194

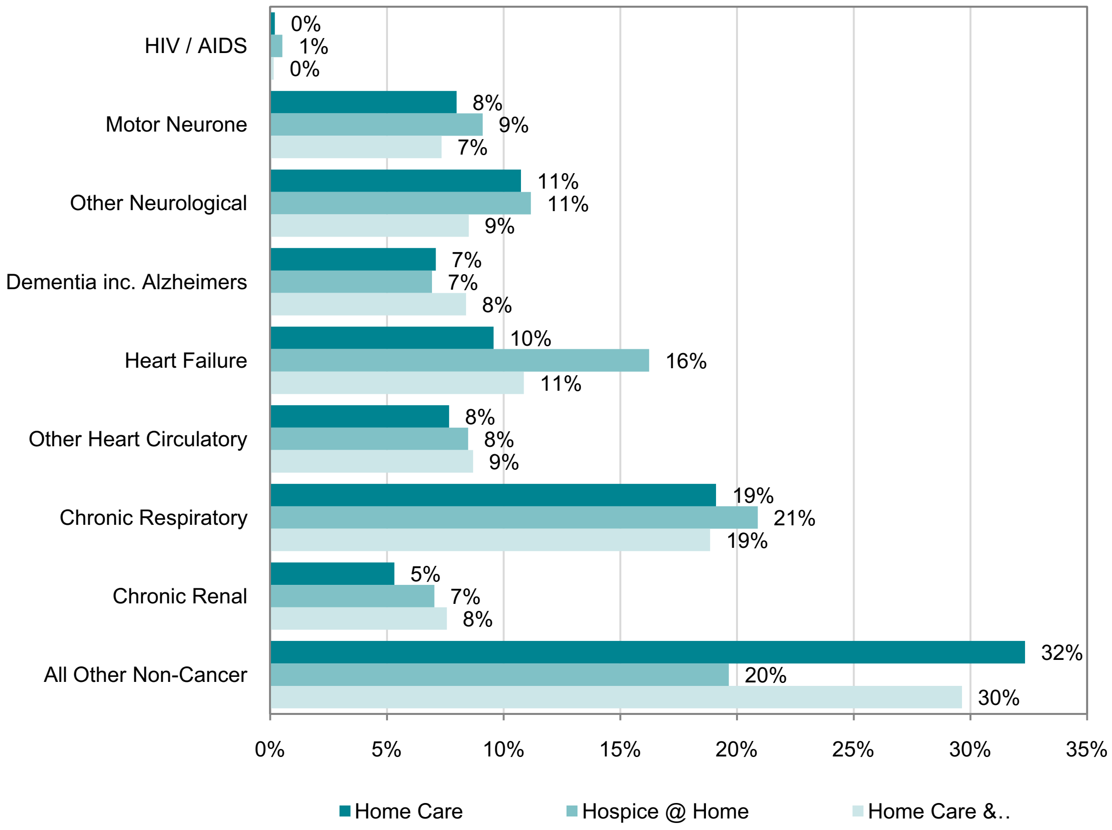
Primary diagnosis – conditions other than cancer

Excluding patients with a 'not known' or 'not recorded' diagnosis, for Home Care services there were 4,477 new referrals (10%) with a primary diagnosis other than cancer. For Hospice @ Home services there were 1,160 new referrals (13%). For combined services there were 2,364 new referrals (14%).

Table 30: Patients with a diagnosis other than cancer in Community Services

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
New referrals	4,477 (10%)	1,160 (13%)	2,364 (14%)
Number of units	84	40	29
Number seeing cancer patients only	2	0	0
Units seeing fewer than 10% of patients with a diagnosis other than cancer patients	47 (56%)	10 (25%)	11 (38%)
Units seeing between 10% and 20% of patients with a diagnosis other than cancer patients	30 (36%)	21 (53%)	14 (48%)
Units seeing more than 20% of patients with a diagnosis other than cancer patients	7 (8%)	9 (23%)	4 (14%)

Chart 31: 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 Non Cancer' was higher than might have been expected, with over 30% of new Home Care patients in this category. Hospice@Home services recorded far fewer patients under 'Other' than last year.

Table 31: Community Services diagnosis – conditions other than cancer

Diagnosis	Home Care		Hospice @ Home		Combined	
	New	All	New	All	New	All
HIV / AIDS	9	11	5	5	4	8
Motor Neurone	368	630	88	129	196	295
Other Neurological	495	991	108	155	227	343
Dementia inc. Alzheimer's	327	376	67	71	224	250
Heart Failure	441	528	157	168	290	342
Other Heart Circulatory	353	508	82	103	232	305
Chronic Respiratory	880	1,385	202	232	503	620
Chronic Renal	245	336	68	75	202	228
All Other Conditions	1,490	2,097	190	276	791	968
Total	**4,608**	**6,862**	**967**	**1,214**	**2,669**	**3,359**

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 0.5 to 10.2 visits, with a mean of 4.1 visits.

Table 32: 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	0.5 to 10.2	90	80,500 total patients 289,416 visits

Contacts

Home Care

A total of 80 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 dropped, but as the number of services responding also dropped, on average there was a slight increase overall.
- More telephone contacts were recorded, despite the number of services decreasing.
- Clinical Nurse Specialists made up the majority of both types of contacts.

Table 33: Home Care contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	3,803	1.3%	100%	52.8	42.0	43
Other Doctor	5,282	1.8%	22%	73.4	37.5	34
Clinical Nurse Specialist	249,933	82.9%	100%	3,471.3	2,852.5	75
Other Nurse	16,671	5.5%	63%	231.5	185.5	24
Physiotherapist	4,750	1.6%	15%	66.0	86.5	24
Occupational Therapist	6,947	2.3%	19%	96.5	234.0	24
Social Worker	5,388	1.8%	14%	74.8	116.0	30
Pastoral / Spiritual Carer	340	0.1%	12%	4.7	15.0	15
Psychologist / Psychotherapist	1,255	0.4%	10%	17.4	66.0	14
Complementary Therapist	1,507	0.5%	98%	20.9	40.5	18
Other Health Care Professional	5,778	1.9%	75%	80.3	44.0	27
Total Face to Face	**301,654**	**–**	**–**	**4,189.6**	**3,280.5**	**80**

- The number of services responding decreased from 88 to 80 (-9%)
- Contacts recorded decreased from 319,075 to 301,653 (-6%)
- Physiotherapists showed the largest increase in recorded contacts, nearly one thousand (26%)
- Other Nurses' and Occupational Therapists' contacts also increased by over four hundred each, despite a drop in the number of services responding (-25% and -20% respectively)
- Other Health Care Professionals' face to face contacts dropped significantly, which may be due to better recording of contacts

Table 34: Home Care contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	3,298	0.6%	100%	48.5	44.5	28
Other Doctor	2,834	0.5%	7%	41.7	25.0	26
Clinical Nurse Specialist	537,055	90.0%	100%	7,897.9	6,179.0	65
Other Nurse	13,685	2.3%	31%	201.3	281.5	24
Physiotherapist	3,058	0.5%	7%	45.0	46.0	19
Occupational Therapist	6,839	1.1%	35%	100.6	376.0	15
Social Worker	15,987	2.7%	100%	235.1	254.5	24
Pastoral / Spiritual Carer	317	0.1%	1%	4.7	12.0	9
Psychologist / Psychotherapist	587	0.1%	2%	8.6	42.0	10
Complementary Therapist	832	0.1%	7%	12.2	5.5	10
Other Health Care Professional	7,016	1.2%	33%	103.2	41.0	20
Total Telephone	**596,708**	**–**	**–**	**8,775.1**	**6,469.0**	**68**

- The number of services responding decreased from 71 to 68 (-4%)
- Contacts recorded increased from 517,127 to 596,708 (15%)
- Other Doctors and Other Nurses' contacts showed the largest drops, even after the drop in their responses was taken into account
- The number of services reporting Complementary Therapists' contacts dropped slightly, but the number of contacts doubled

Hospice @ Home

A total of just 34 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 from the nature of the service, consultations by clinical nurse specialists were much lower than for Home Care and accounted for just 12% of face to face and 22% of telephone contacts.

- The number of services reporting Clinical Nurse Specialist contacts increased by nearly 50%, but the number of Clinical Nurse Specialist contacts dropped by a fifth. This may be due to correcting errors in recording as Hospice @ Home services are defined as those without Clinical Nurse Specialists
- Complementary Therapist numbers are up slightly for both face to face and telephone contacts
- Other Health Care Professional numbers are down slightly

Table 35: Hospice @ Home contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	24	0.0%	4%	0.8	6.0	4
Other Doctor	236	0.4%	100%	7.4	4.5	4
Clinical Nurse Specialist	7,077	12.0%	100%	221.2	19.0	13
Other Nurse	36,564	62.1%	100%	1,142.6	1,057.0	26
Physiotherapist	392	0.7%	8%	12.3	76.0	5
Occupational Therapist	235	0.4%	11%	7.3	7.0	5
Social Worker	459	0.8%	93%	14.3	10.5	4
Pastoral / Spiritual Carer	87	0.1%	4%	2.7	6.0	3
Psychologist / Psychotherapist	1	0.0%	0%	0.0	1.0	1
Complementary Therapist	1,260	2.1%	100%	39.4	97.5	10
Other Health Care Professional	12,648	21.5%	100%	395.3	844.0	13
Total Face to Face	**58,855**	–	–	**1,839.2**	**1,309.5**	**34**

- The number of services responding increased from 33 to 34 (3%)
- Contacts recorded increased from 52,110 to 58,855 (13%)
- Other Nurse contacts increased by nearly ten thousand (36%) while the number of services reporting contacts increased by 18%.
- Medical Consultant contacts were reported by just four services, compared to eight last year a drop of 94%.

Table 36: Hospice @ Home contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	33	0.1%	4%	1.5	5.5	4
Other Doctor	3	0.0%	0%	0.1	3.0	1
Clinical Nurse Specialist	10,167	22.4%	100%	462.1	81.0	11
Other Nurse	29,163	64.1%	100%	1,325.6	661.5	16
Physiotherapist	244	0.5%	18%	11.1	87.0	3
Occupational Therapist	405	0.9%	26%	18.4	14.0	5
Social Worker	1,018	2.2%	98%	46.3	5.5	4
Pastoral / Spiritual Carer	85	0.2%	6%	3.9	10.0	3
Psychologist / Psychotherapist	0	0.0%	0%	0.0	0.0	0
Complementary Therapist	212	0.5%	6%	9.6	74.0	3
Other Health Care Professional	4,156	9.1%	95%	188.9	271.0	9
Total Telephone	**45,486**	**–**	**–**	**2,067.5**	**1,317.5**	**22**

- The number of services responding decreased from 27 to 22 (-19%)
- Contacts recorded decreased from 58,805 to 45,486 (-23%)
- The drop in Clinical Nurse Specialist contacts made up most of the difference. One more service reported on Clinical Nurse Specialist contacts.
- Other Nurses' contacts increased by nearly 10%, while the services reporting on them increased by 20%.

Home Care and Hospice @ Home

A total of 23 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 37: Combined Service contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	1,537	2.0%	11%	76.9	97.0	10
Other Doctor	899	1.2%	5%	45.0	97.5	8
Clinical Nurse Specialist	41,619	54.6%	100%	2,081.0	1,658.0	17
Other Nurse	22,034	28.9%	95%	1,101.7	993.5	13
Physiotherapist	1,481	1.9%	28%	74.1	77.0	9
Occupational Therapist	1,349	1.8%	18%	67.5	130.0	8
Social Worker	1,839	2.4%	10%	92.0	96.0	9
Pastoral / Spiritual Carer	213	0.3%	2%	10.7	37.0	5
Psychologist / Psychotherapist	288	0.4%	5%	14.4	15.5	8
Complementary Therapist	2,354	3.1%	54%	117.7	63.0	11
Other Health Care Professional	2,634	3.5%	63%	131.7	164.0	10
Total Face to Face	**76,247**	–	–	**3,812.4**	**2,628.0**	**23**

- The number of services responding increased from 20 to 23 (15%)
- Contacts recorded increased from 75,581 to 76,247 (1%)
- Clinical Nurse Specialist contacts are down in number, while Other Nurses' contacts are up by a similar amount, suggesting that, overall, services may be moving more towards Hospice @ Home from Home Care. However, there are still twice as many contacts by Clinical Nurse Specialists as Other Nurses

Table 38: Combined Service contacts – telephone

Health care professional	Telephone contacts	Max in unit	Mean	Median	Services	
Medical Consultant	713	0.4%	3%	31.0	63.5	8
Other Doctor	1,340	0.7%	5%	58.3	67.5	8
Clinical Nurse Specialist	164,165	85.5%	100%	7,137.6	5,565.0	19
Other Nurse	12,133	6.3%	100%	527.5	466.5	12
Physiotherapist	393	0.2%	12%	17.1	39.0	7
Occupational Therapist	2,057	1.1%	49%	89.4	261.0	7
Social Worker	4,593	2.4%	64%	199.7	483.0	8
Pastoral / Spiritual Carer	291	0.2%	1%	12.7	57.0	4
Psychologist / Psychotherapist	216	0.1%	1%	9.4	28.0	5
Complementary Therapist	3,839	2.0%	16%	166.9	91.5	6
Other Health Care Professional	2,252	1.2%	27%	97.9	131.0	10
Total Telephone	**191,992**	–	–	**8,347.5**	**4,509.0**	**23**

- The number of services responding decreased from 26 to 23 (44%)
- Contacts recorded increased from 94,332 to 191,992 (104%)
- Unlike face to face contacts, the number of Clinical Nurse Specialist telephone contacts nearly doubled.
- Other Nurse contacts increased by 8,616 (245%), although there are still thirteen times as many telephone contacts by Clinical Nurse Specialists as Other Nurses.

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 home care 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 9% to 80%. For H@H teams there was a higher percentage of home deaths (44%), ranging from 14% to 77% with an outlier of 3%. For combined teams the figure was 32%, ranging from 0.5% to 99%.

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 previous year, and that the staffing provision does not alter. However, for the Home Care teams the number of deaths and discharges varied from a third to over twice the number of new patients (206%). For the H@H teams the range was from 46% to 163% while for the Combined teams the range was 63% to 150%. Overall, for the Home Care teams there were 15% more deaths and discharges than new patients. For the H@H team the figure was 1% and for the Combined teams the figure was 9%.

Table 39: Deaths and discharges for Community Services

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
Deaths as % of deaths & discharges	59%	70%	67%
Range	13% to 100%	18% to 100%	1% to 100%
Home deaths as % of all deaths	43%	67%	46%

Chart 32: Community Services – place of death

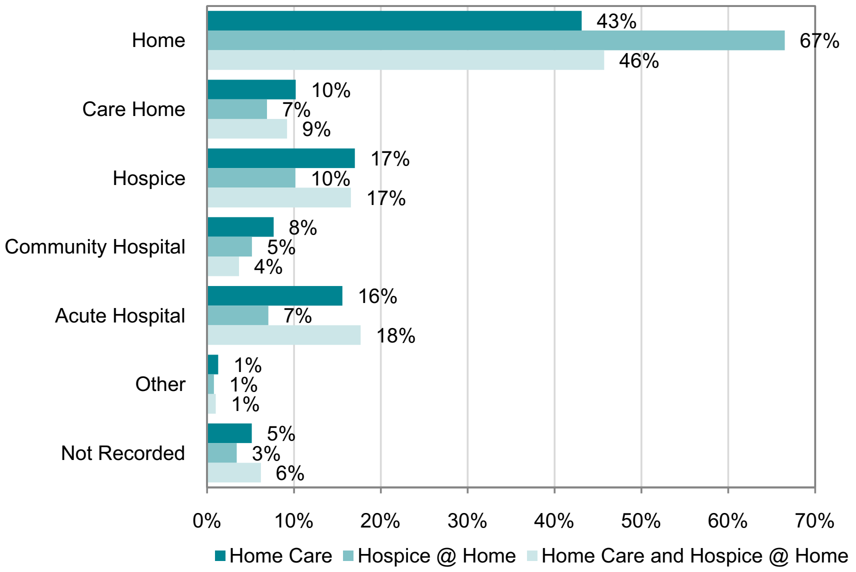


Table 40: Community Services – place of death

Type	Home Care	Hospice @ Home	Home Care and Hospice @ Home
Home	15,547	5,041	6,074
Care Home	3,679	523	1,223
Hospice	6,131	771	2,199
Community Hospital	2,760	391	489
Acute Hospital	5,617	535	2,347
Other	461	60	132
Not Recorded	1,857	259	822
Total	**36,052**	**7,580**	**13,286**

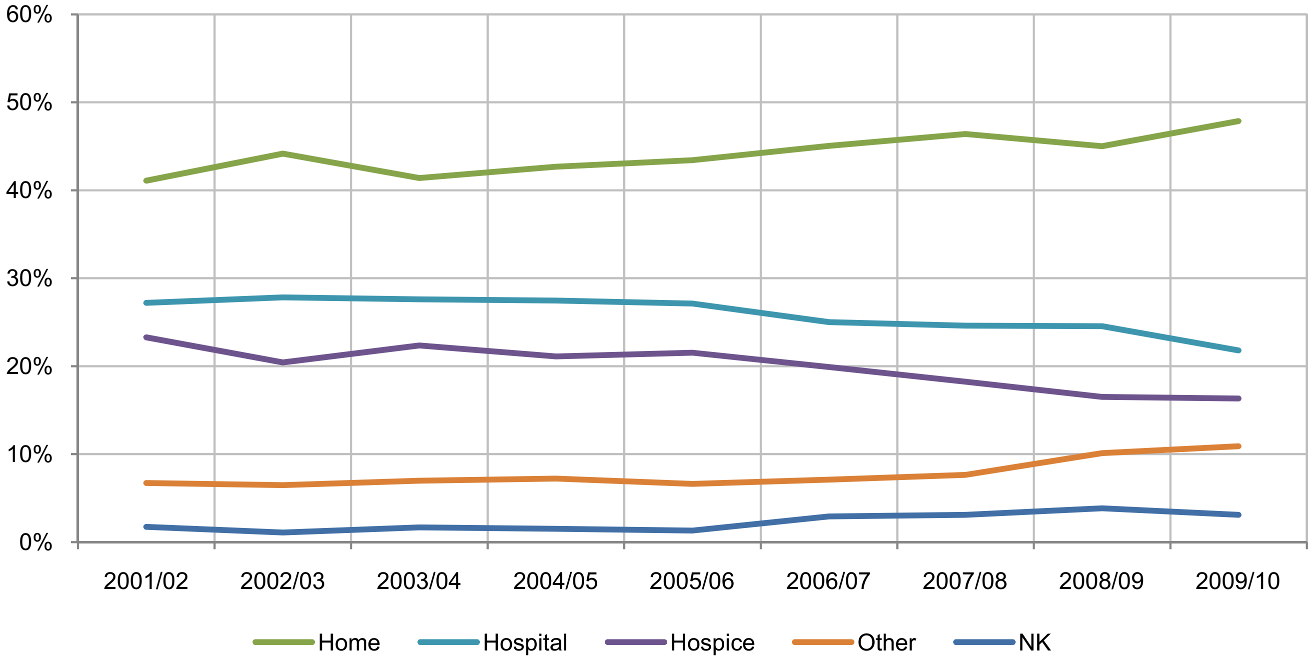
The proportion of people dying at home increased for all three types of community care, while the proportion dying in hospital decreased.

Place of death – trends

Data on the place of death for people receiving community care 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.

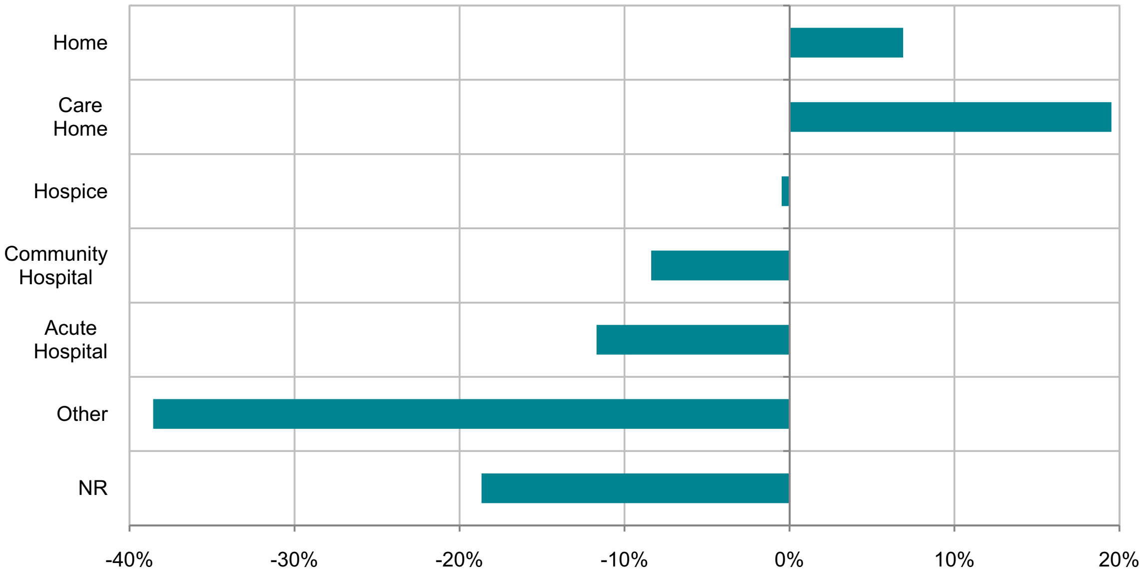
In Chart 33, to compare the revised MDS with the preceding years the hospital data has been combined and care homes have been included in Other.

Chart 33: Place of death – 2001 to 2010



In the second year of the revised MDS we have seen an increase in the number of people receiving community care who died at home or in care homes, while numbers of deaths in all other settings decreased.

Chart 34: 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 72 Home Care teams, 36 Hospice @ Home teams and 28 combined teams. Table 41 and Chart 35 show the breakdown of length of care for all three types of service. Nearly two thirds of patients in Home Care had a length of care of less than 90 days (65%), along with more than two thirds of patients for Hospice @ Home (82%) and Combined (70%).

The average length of care for the 72 Home Care services that responded ranged from 1 day to 259 days with a mean of 119 days and a median of 120 days. 65% of patients were looked after for less than three months and 19% for more than 6 months.

For the 36 Hospice @ Home services that responded, the average length of care ranged from 9 days to 246 days with a mean of 61 days and a median of 35 days. 82% of patients were looked after for less than three months and 8% for more than 6 months.

The 28 Combined services that responded had an average length of care of 102 days; this ranged from 4 days to 311 days and had a median of 88 days. 70% of patients were looked after for less than three months and 15% for more than 6 months.

Table 41: Community Services – average length of care

	Average length of care (days)	Range	Units responding
Home Care	119	1 to 259	72
Hospice @ Home	61	9 to 246	36
Home Care and Hospice @ Home	102	4 to 311	28

The average length of care for people in Home Care was almost twice the length of that for those receiving Hospice @ Home care. The majority of Hospice @ Home care (64%) was for a month or less. The majority of Home Care (61%) was for more than a month.

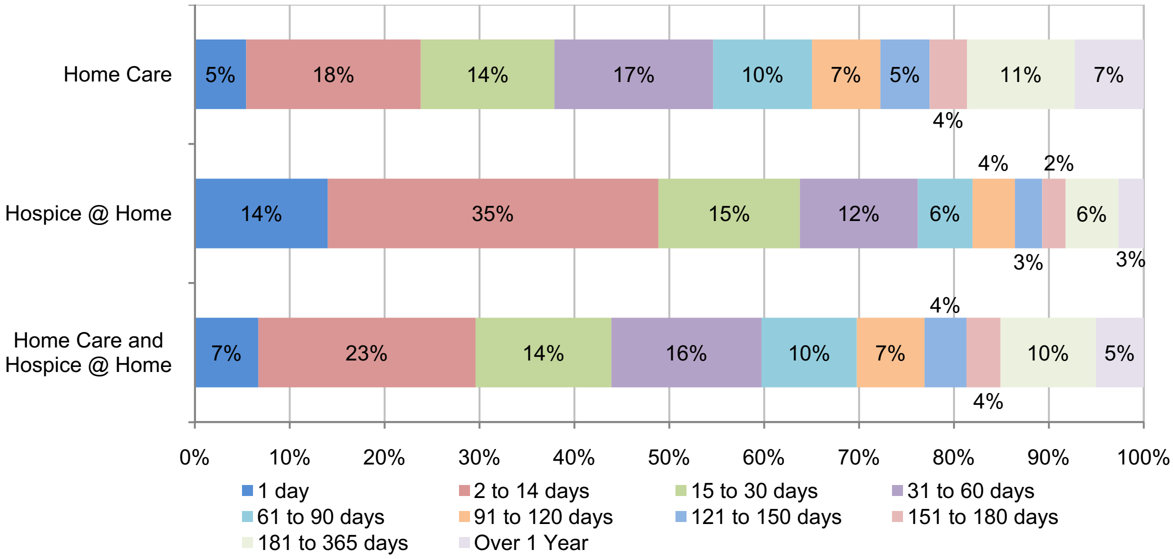


Chart 35: Community Service – length of care

Table 42: Community Services – length of care

Length of care	Number of patients		
	Home Care	Hospice @ Home	Combined Services
1 day	2,737	1,310	1,121
2 to 14 days	9,303	3,257	3,836
15 to 30 days	7,117	1,394	2,401
31 to 60 days	8,453	1,161	2,651
61 to 90 days	5,270	540	1,683
91 to 120 days	3,647	418	1,196
121 to 150 days	2,625	268	742
151 to 180 days	1,997	230	599
181 to 365 days	5,713	521	1,686
Over 1 Year	3,693	249	845
Total	**50,555**	**9,348**	**16,760**

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 for which they are under the care of the team.

The mean length of care for Home Care was 119 days; the average caseload was 213 patients per team, median 177.

The mean length of care for Hospice @ Home was 61 days; the average caseload was 43 patients per team, median 17.

The mean length of care for combined teams was 102 days; the average caseload was 178 patients per team, median 115.

Table 43: 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	213	177	72	48,123
Hospice @ Home	43	17	36	8,790
Combined	178	115	28	15,206

5. Hospital Support

All services known to provide specialist palliative care services to adults during the year April 2009 – March 2010 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 144 replies providing at least some information; a response rate of 55%. Independently-managed services made up 11% of units responding.

The response rate to individual questions varied between 58% (Telephone Contact) and 94% (Age & Sex) with a mean of 77% and a median of 81%.

Age and sex

The total number of patients seen included new patients and those already 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 86% of the total. Over a quarter of the new patients were aged under 65 (26%: 25% male, 27% female), less than 1% were aged 16 - 24 and 18% aged 85 years and over.

Chart 36: Hospital Support – age and sex of new patients

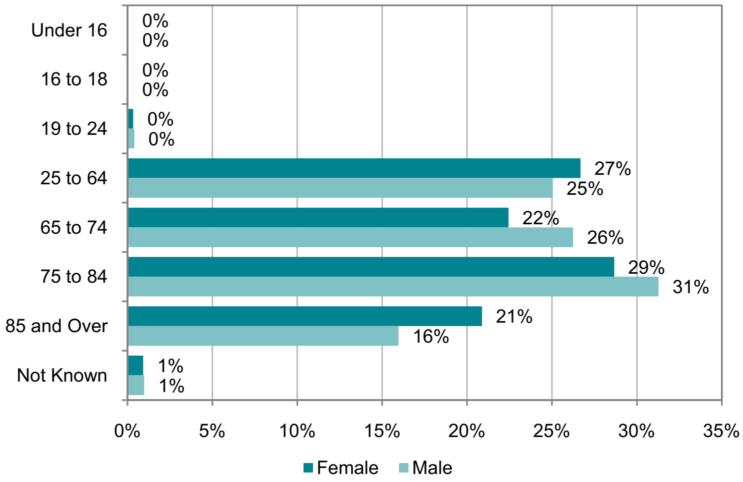


Table 44: Age and sex of patients receiving Hospital Support

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	11	15	**26**	17	23	**55**
16 to 18	10	12	**24**	13	16	**30**
19 to 24	98	117	**216**	126	148	**294**
25 to 64	7,701	7,264	**15,287**	9,276	8,494	**18,961**
65 to 74	6,473	7,615	**14,461**	7,533	8,881	**17,381**
75 to 84	8,267	9,099	**17,862**	9,279	10,349	**20,932**
85 and Over	6,032	4,633	**11,042**	6,512	5,141	**12,425**
Not Known	282	290	**1,060**	303	312	**1,537**
Total	**28,874**	**29,045**	**59,978**	**33,059**	**33,364**	**71,615**

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 79% of Hospital Support services. More than four fifths of new patients (82%) were described as white British. The ethnicity for a total of 5,526 new patients (11%) was not recorded.

The numbers of non-white patients have been grouped together in Chart 37, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 38.

Chart 37: Hospital Support – ethnicity

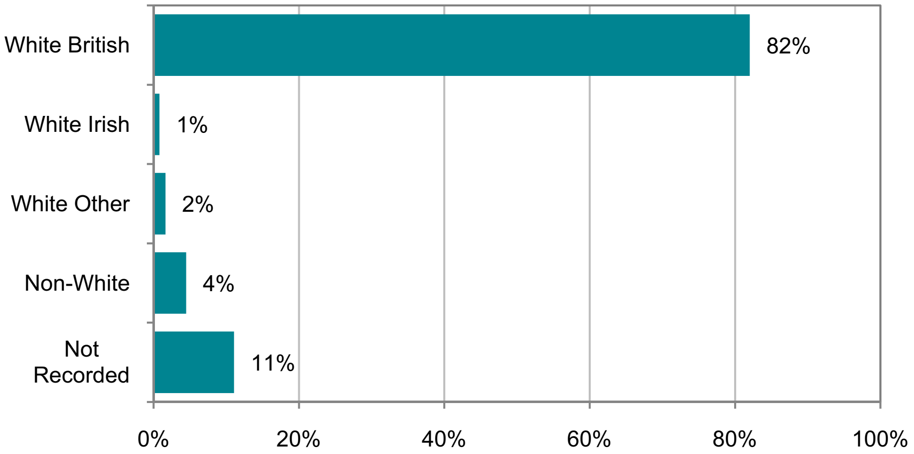
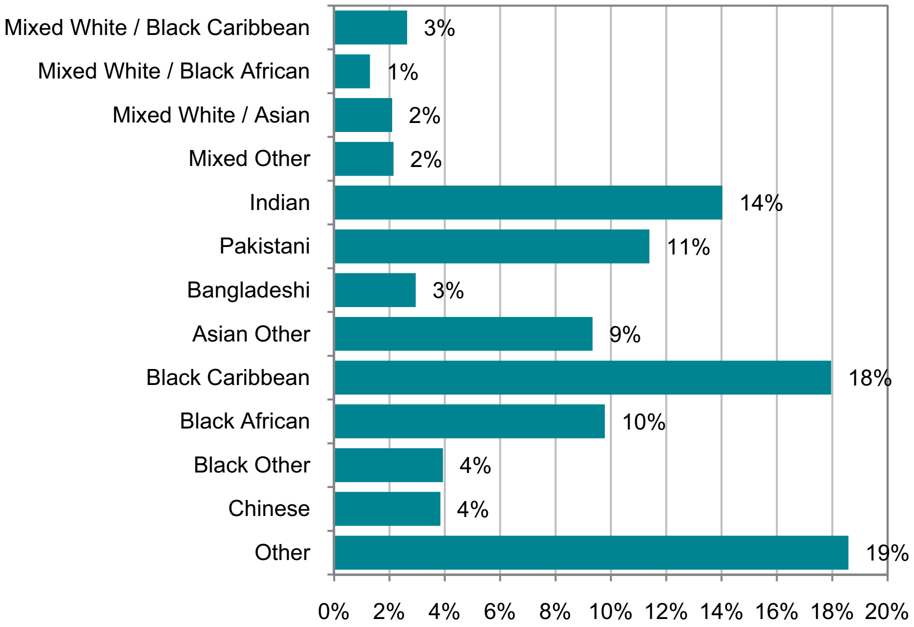


Chart 38: Hospital Support – non-white



Nearly a fifth of those recorded as being non-white (19%) was under the category 'other'.

Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 41,807 new referrals to Hospital Support units (82%). Cancer figures for Hospital Support were divided up into 12 diagnoses.

Digestive and respiratory cancers accounted for almost half the diagnoses (49%), as was also the case last year.

Chart 39: New patients with cancer diagnosis in Hospital Support

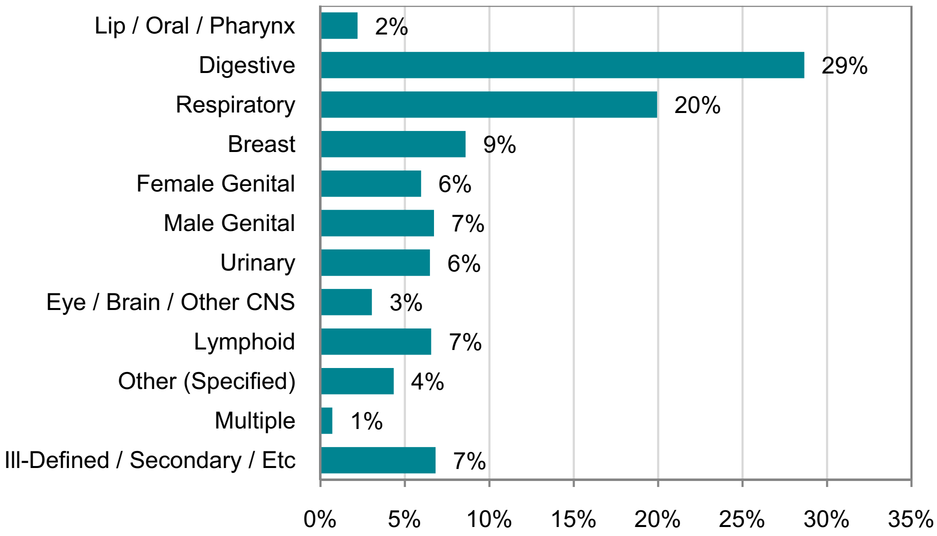


Table 45: Patients with cancer diagnosis in Hospital Support

Diagnosis	New	All
Lip / Oral / Pharynx	919	1,126
Digestive	11,979	14,786
Respiratory	8,333	9,911
Breast	3,594	4,585
Female Genital	2,490	3,076
Male Genital	2,810	3,524
Urinary	2,711	3,421
Eye / Brain / Other CNS	1,274	1,615
Lymphoid	2,741	3,400
Other (Specified)	1,814	2,381
Multiple	293	334
Ill-Defined / Secondary / Etc	2,849	3,485
Total	**41,807**	**51,644**

Primary diagnosis – conditions other than cancer

Excluding the patients with a 'not known' diagnosis, 9,008 new patients (18%) had a diagnosis other than cancer. The proportion of these patients in the different units ranged from 0% to 44. Over half (56%) of responding units had more than 10% of patients with a diagnosis other than cancer, down from 73% last year. Five units had cancer patients only.

Although the general trend for conditions other than cancer is increasing, there has been a drop in the proportion being seen this year, as well as in the number of returns received. We will need to look at next year's data to understand whether the upward trend continues and if this year's figures were affected by the drop in returns.

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 other cases.

Over a third (41%) of diagnoses other than cancer were recorded under All Other Conditions, a slight increase on 37% 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 questions 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 40: New patients with a diagnosis other than cancer in Hospital Support

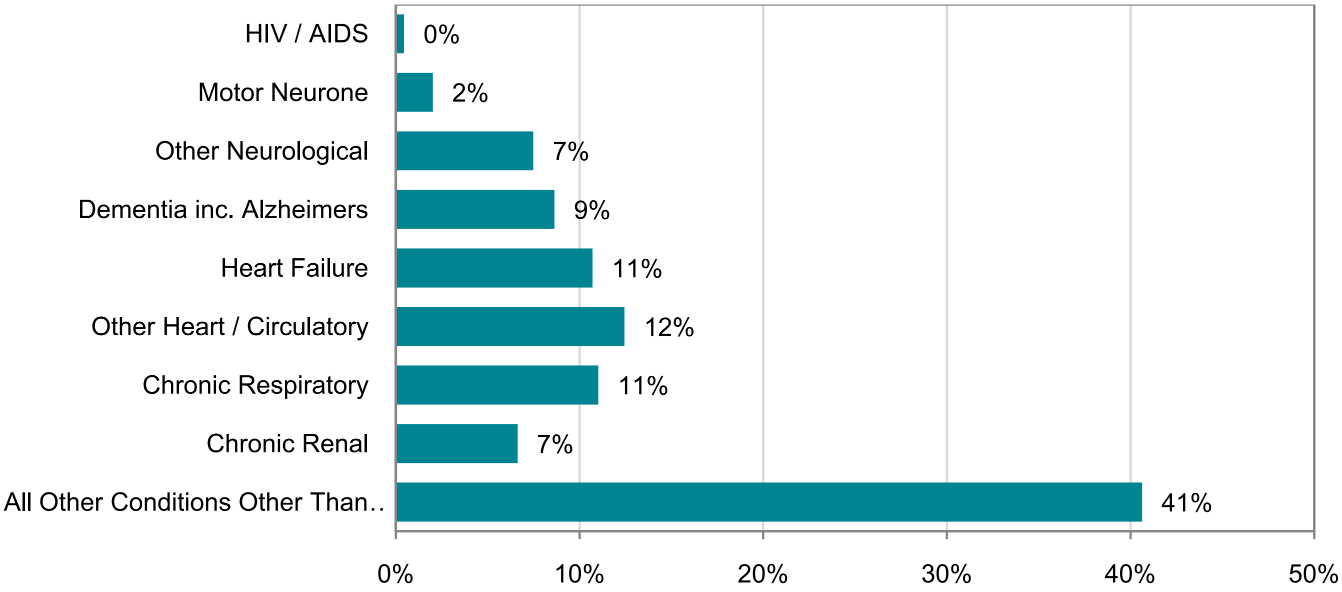


Table 46: Patients with a diagnosis other than cancer in Hospital Support

Diagnosis	New	All
HIV / AIDS	40	56
Motor Neurone	181	245
Other Neurological	674	753
Dementia inc. Alzheimer's	778	867
Heart Failure	964	1,036
Other Heart Circulatory	1,121	1,298
Chronic Respiratory	993	1,132
Chronic Renal	597	677
All Other Conditions	3,660	4,201
Total	**9,008**	**10,265**

Referrals and contacts

Each patient received an average of 3.7 contacts during the year, with a range from 0.2 to 7.1 contacts per patient. Of these contacts, 17% were by a doctor (medical consultant or other doctor) and 77% by a clinical nurse specialist.

Table 47: Contacts per patient in Hospital Support

Average number of contacts per patient	Range of visits per patient per service	Number of services responding	Total patients	Total visits
3.7	0.2 to 7.1	106	57,431	210,849

Face to face contacts

Although one fewer service responded to the face to face contacts question this year, the number of contacts recorded increased significantly, from 279,410 to 322,858. The breakdown of contacts across professions showed a number of changes, but with just two years of data it is not possible to identify whether these are the result of better recording of contacts or changes in services' operations.

Most face to face contacts (76.5%) were with Clinical Nurse Specialists. Contacts with Occupational Therapists increased from 0% to 0.9% and contacts with a Medical Consultant from 10% to 11.5%.

Table 48: Face to face contacts with patients in Hospital Support

	Number of Contacts	%	Max	Mean	Median	Services
Medical Consultant	37,143	11.5%	99%	371.4	47.0	82
Other Doctor	19,210	5.9%	97%	192.1	34.0	46
Clinical Nurse Specialist	247,127	76.5%	100%	2,471.3	2,730.5	95
Other Nurse	4,696	1.5%	41%	47.0	181.0	20
Physiotherapist	157	0.0%	10%	1.6	76.0	3
Occupational Therapist	4,780	1.5%	56%	47.8	238.0	15
Social Worker	4,785	1.5%	12%	47.9	109.0	17
Pastoral / Spiritual Carer	215	0.1%	4%	2.2	15.0	4
Psychologist / Psychotherapist	367	0.1%	6%	3.7	66.0	7
Complementary Therapist	717	0.2%	6%	7.2	40.5	7
Other Health Care Professional	2,858	0.9%	13%	28.6	44.0	18
Total Face to Face	**322,858**	–	–	**3,228.6**	**3,208.0**	**100**

- The number of services responding decreased from 101 to 100 (-1%)
- Contacts recorded increased from 279,410 to 322,858 (116%)
- Clinical Nurse Specialists accounted for most of the increase in contacts (31,131)
- Other Nurses showed the largest drop with less than half the previous year's contacts
- Medical Consultants' contacts increased by nearly nine thousand (32%)
- Occupational Therapists' contacts increased by over four thousand, nearly six times the previous year's contacts

Table 49: Telephone contacts with patients in Hospital Support

	Number of contacts	%	Max	Mean	Median	Services
Medical Consultant	2,852	3.7%	38%	34.4	20.0	57
Other Doctor	1,722	2.2%	71%	20.7	19.5	40
Clinical Nurse Specialist	68,193	87.7%	105%	821.6	371.0	78
Other Nurse	643	0.8%	100%	7.7	3.5	16
Physiotherapist	5	0.0%	2%	0.1	2.5	2
Occupational Therapist	1,272	1.6%	100%	15.3	14.5	12
Social Worker	1,386	1.8%	31%	16.7	11.0	9
Pastoral / Spiritual Carer	1	0.0%	0%	0.0	1.0	1
Psychologist / Psychotherapist	26	0.0%	1%	0.3	3.5	4
Complementary Therapist	61	0.1%	2%	0.7	61.0	1
Other Health Care Professional	150	0.2%	33%	1.8	7.0	11
Total Telephone	**77,781**	–	–	**937.1**	**460.0**	**83**

- The number of services responding increased from 76 to 83 (9%)

- Contacts recorded more than halved from 160,007 to 77,781 (-51%)

- Medical Consultants' contacts dropped by 94%. Either this is a radical shift in their work patterns or they are just not recording their contacts

- Clinical Nurse Specialists' contacts trebled, an increase of about the same amount as the Medical Consultants' contacts decrease. This may mean that the Medical Consultants are passing the telephone work onto the CNSs

- The majority of the decrease in contacts was attributable to Other Health Care Professionals, whose contacts but disappeared, dropping by 99.8% to just 150

Length of care

The length of time patients were under the care of the support service was one of the items of data collected. Over a fifth of patients (22%) were seen only once and over 90% had died or were discharged within four weeks. 2% remained under care for over six months, with one service reporting having 50% of their patients in this category. 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, the median of which was found to be 8.7 days although they were wide variations from less than one day to over three months. If the seven services with a stated mean length of care of one month or more are ignored, then the mean drops from 12.5 to 9.3 days and the median from 8.7 to 8.3 days. More than 80% of teams were able to give information on length of care.

Table 50: Length of care for Hospital Support

Length of care	Patients	
1 day	13,542	22.2%
2 to 7 days	23,748	39.0%
2 to 14 days	11,573	19.0%
15 to 28 days	7,003	11.5%
29 to 42 days	2,115	3.5%
43 to 84 days	1,350	2.2%
85 to 180 days	569	0.9%
Over 180 days	1,008	1.7%
Total	**60,908**	

Assuming that the data collected were typical of all services in the country then, using median values, it can be estimated that about 114,000 patients may have contact with Hospital Support services in the course of a year, with 104,000 patients being seen for the first time during that year.

The numbers of services in the three countries surveyed are: England 254, Northern Ireland 15 and Wales 24. Estimates of new patients for each country, calculated on a pro rata basis and not on the returns from each country, give England 93,000, Northern Ireland 5,800 and Wales 5,100 new patients.

6. Bereavement Support

Data were received from 131 services, a 47% response rate from known services. Independently-managed services accounted for 69% of returns.

The response rate to individual questions varied between 78% (Ethnicity) and 95% (Contacts) with a mean of 85% and a median of 82%.

There were 113 services who gave full details of both clients and total face-to-face contacts. (Six others reported fewer contacts than patients.) The mean for contacts per client was found to be 6.2 ranging from 1.0 to 44.4. Just one service recorded a mean of one contact per client.

Support was split between telephone (42%) and face to face (58%).

24% of face to face contacts were in group support, 38% were individual support and 38% individual counselling.

Less than a third of one percent of clients received complex counselling from mental health professionals.

Table 51: Face to face contacts in Bereavement Support

Group		Individual		Complex
Not Facilitated	Facilitated	Support	Counselling	
5,439	19,039	39,235	39,116	313
5%	19%	38%	38%	0.3%

Table 52: Telephone contacts in Bereavement Support

Phone calls under 10 minutes	Phone calls over 10 minutes
30,216	27,119
53%	47%

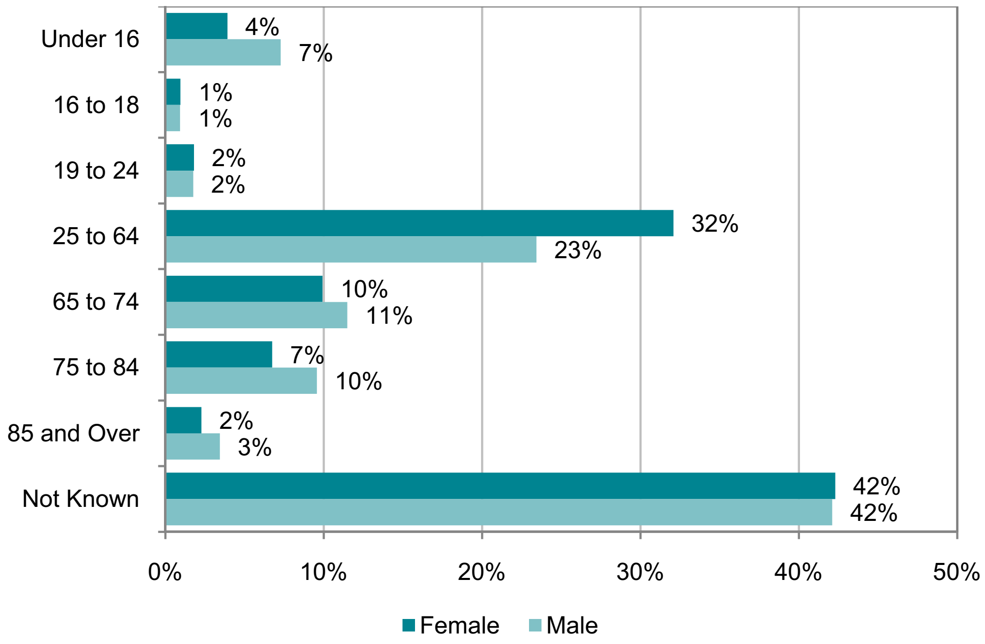
Complex counselling numbers were down on last year and there has also been a shift from group to individual support and counselling, while the number of telephone contacts has increased.

Table 53: Contacts in Bereavement Support

	2009	2010	Change	
Phone calls under 10 minutes	25,802	30,216	4,414	17%
Phone calls over 10 minutes	25,590	27,119	1,529	6%
Face to Face - Group - Not Facilitated	3,769	5,439	1,670	44%
Face to Face - Group - Facilitated	23,643	19,039	-4,604	-19%
Face to Face - Individual Support	32,096	39,235	7,139	22%
Face to Face - Individual Counselling	28,176	39,116	10,940	39%
Face to Face - Complex	988	313	-675	-68%
Other	7,119	13,115	5,996	84%

The Department of Health is to publish Quality Markers on Bereavement Support during 2011.

Chart 41: Age and sex for new clients in Bereavement Support



The proportion of Not Known for ages has reduced from 48% and 45% to 42% and 42% for female and male clients, which is encouraging.

Patient profile

Table 54: Age and sex for clients in Bereavement Support

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	474	477	**1,084**	707	706	**1,567**
16 to 18	115	61	**182**	177	94	**278**
19 to 24	218	115	**341**	307	173	**489**
25 to 64	3,879	1,534	**5,742**	5,827	2,511	**8,689**
65 to 74	1,200	752	**2,333**	1,882	1,353	**3,661**
75 to 84	816	626	**1,824**	1,391	1,197	**2,990**
85 and Over	275	225	**646**	514	441	**1,101**
Not Known	5,115	2,757	**12,225**	8,272	4,567	**20,473**
Total	12,092	6,547	24,377	19,077	11,042	39,248

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 64%, with 91% of services reporting more than half their clients were women.

Ethnicity

Ethnicity data were collected from 66% of Bereavement Support services, up from 52% last year. Over a third (38%) were described as white British. The ethnicity of total of 13,182 new patients (60%) was 'not recorded'. This is an increase in numbers from last year (9,132) but a slightly smaller proportion (60% vs 62%).

The numbers of non-white patients have been grouped together in Chart 42, as they constitute such a small proportion of the figures. A breakdown of these figures is shown in Chart 43.

Chart 42: Bereavement Support new patients – ethnicity

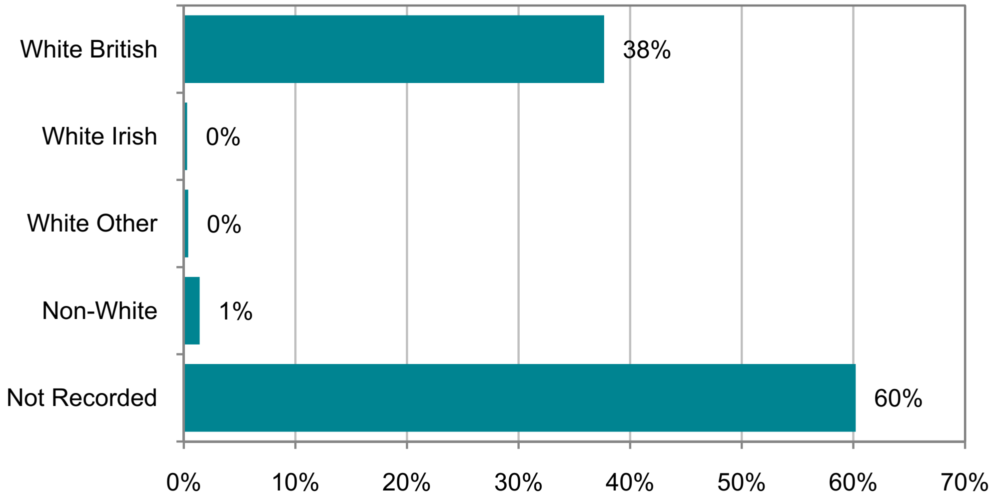
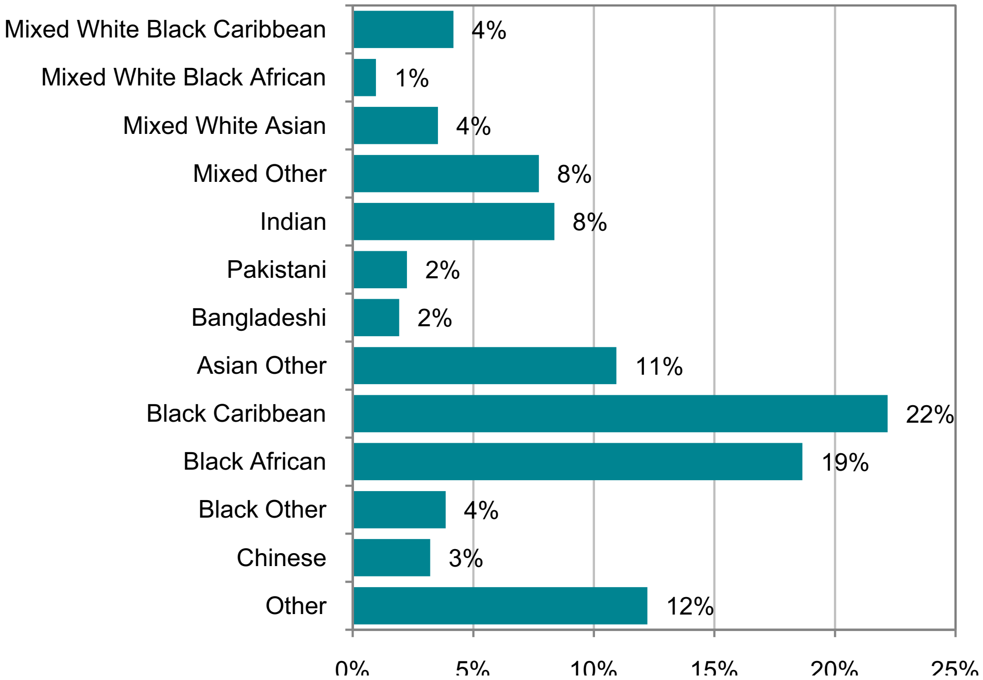


Chart 43: Bereavement Support new patients – non-white



Although the number of 'other' was lower than the other settings, the number of Not Recorded in ethnicity was considerably higher for Bereavement Support. Again feedback received indicated that services had difficulty asking for the ethnicity of their clients.

Primary diagnosis of deceased

A total of 93 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 from over a quarter (28%) to a little over a fifth of new clients (21%).

Performing the same analysis on the medians of the other services' diagnoses of cancer and 'other' gives figures of 83% and 17%.

Chart 44: Bereavement Support new clients – primary diagnosis of deceased

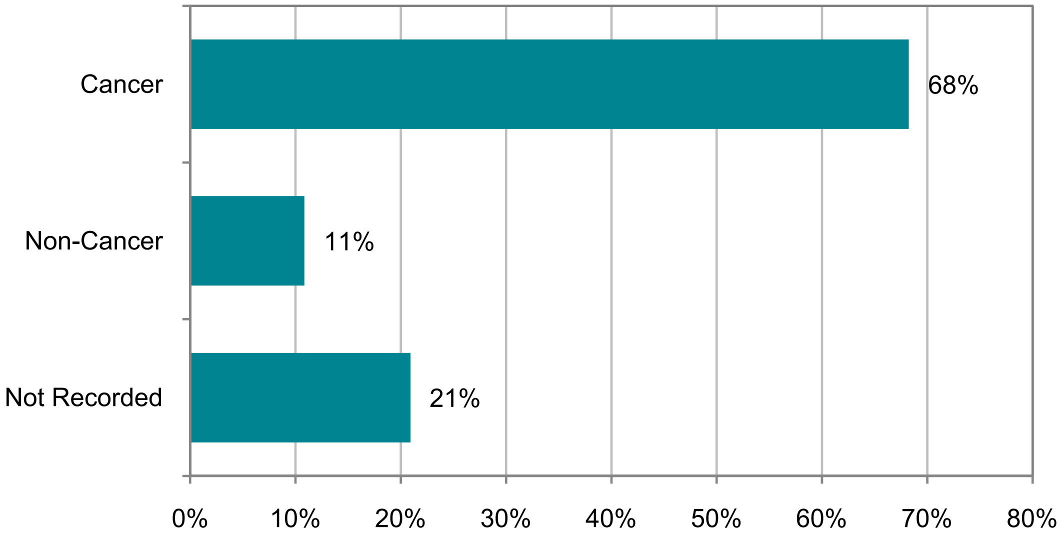


Table 55: Bereavement Support – primary diagnosis of deceased

	New	All
Cancer	15,610	24,451
Other	2,480	4,006
Not Recorded	4,783	9,211
Total	**22,873**	**37,668**

7. Outpatients

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 20% (Joint Clinics and Interventions) and 97% (Age & Sex) with a mean of 59% and a median of 67%.

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 300. This has been taken as the baseline. 155 forms were returned (52%), 54% from independently-managed services, 37% from NHS-managed services, and 9% did not record their management.

Age and sex

Chart 45: Age and sex of new outpatients

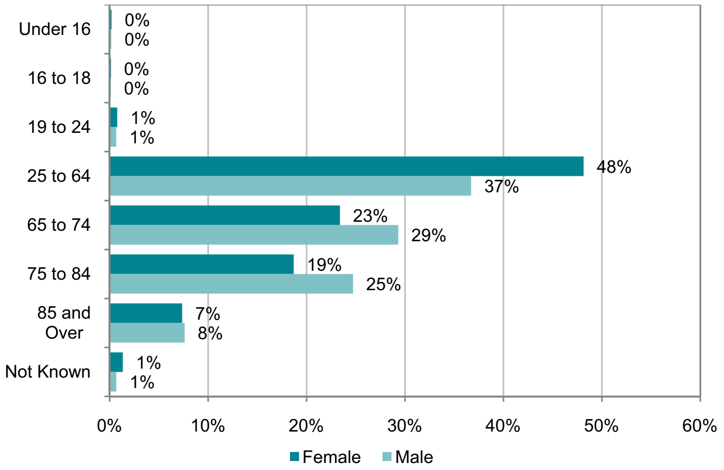


Table 56: Age and sex of outpatients

		New			All	
	Female	Male	All	Female	Male	All
Under 16	22	13	**35**	56	34	**90**
16 to 18	15	10	**25**	46	15	**61**
19 to 24	89	52	**141**	193	91	**284**
25 to 64	5,593	2,894	**8,488**	13,173	4,820	**17,996**
65 to 74	2,717	2,311	**5,030**	5,772	3,478	**9,253**
75 to 84	2,172	1,949	**4,122**	4,250	2,871	**7,122**
85 and Over	855	600	**1,455**	1,508	818	**2,327**
Not Known	155	53	**220**	221	78	**320**
Total	**11,618**	**7,882**	**19,516**	**25,219**	**12,205**	**37,453**

Just over half the patients seen at Outpatient clinics were seen for the first time during the year (53%). Nearly half of new patients were aged under 65 (45%) and 8% were 85 or over.

There was a big discrepancy between the sexes; overall 60% were female, and in the age range 25 to 64 there were 66% females.

Ethnicity

Ethnicity data were collected from 89% of Outpatient services. Nearly two thirds (63%) were described as white British. A total of 3,960 new patients (30%) were 'not recorded'.

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: Ethnicity of new Outpatients

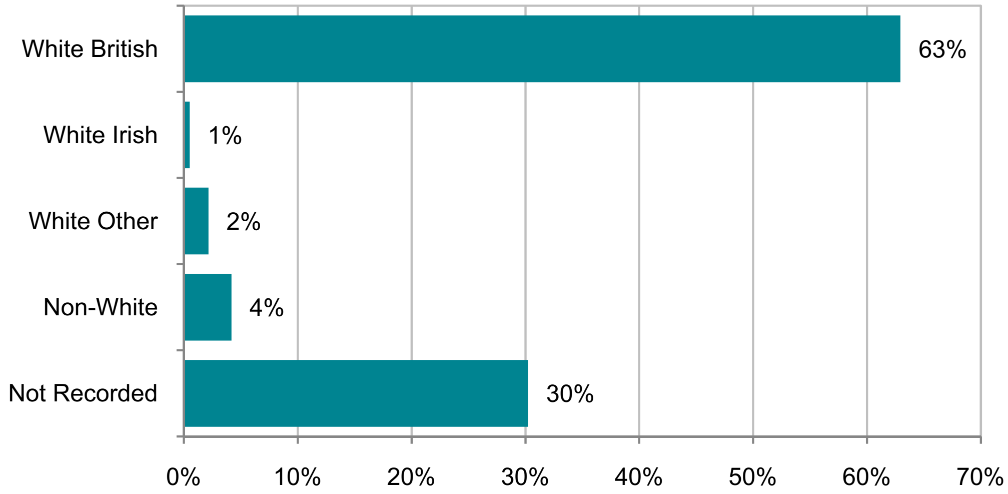
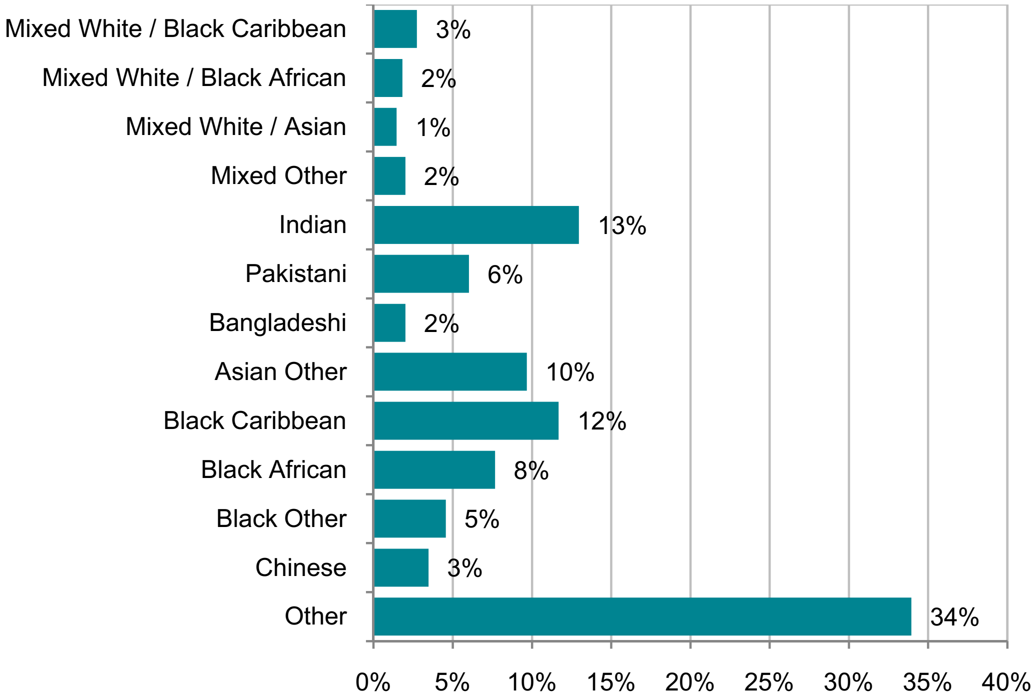


Chart 47: Distribution of non-white categories in Outpatients



Primary diagnosis – cancer

A primary diagnosis of cancer was recorded for 13,067 new referrals to Outpatient units (80%). In the revised dataset, outpatient cancer figures are divided into 12 diagnoses. Outpatient clinics showed the highest proportion of patients diagnosed with breast cancer; a quarter of new patients and over a third (38%) of all patients. Digestive and Respiratory cancers accounted for a further 39% of diagnoses for new patients.

Chart 48: Cancer diagnoses in new Outpatients

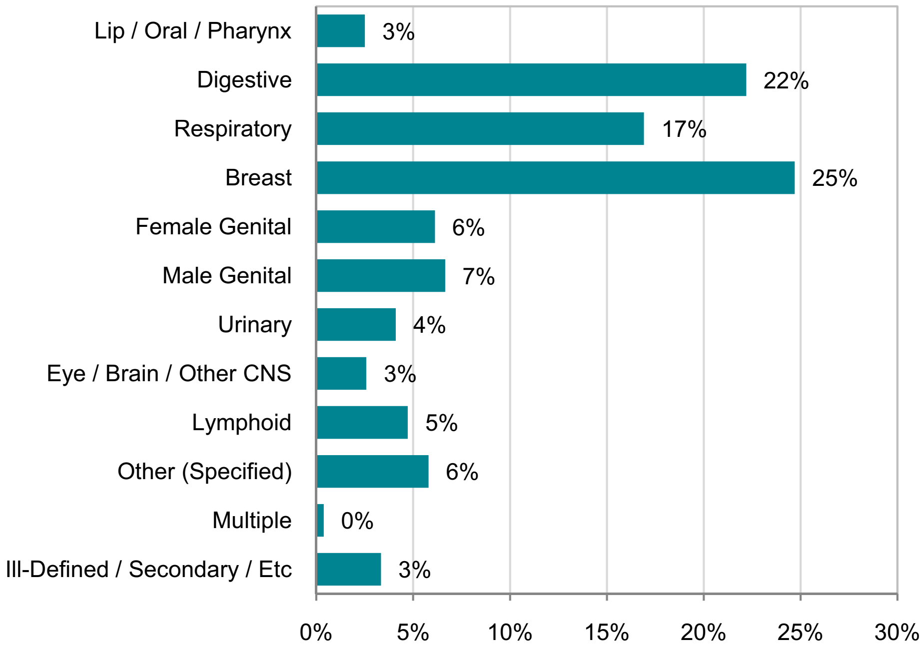


Table 57: Cancer diagnoses in Outpatients

Diagnosis	New	All
Lip / Oral / Pharynx	328	506
Digestive	2,900	3,961
Respiratory	2,210	3,034
Breast	3,227	9,046
Female Genital	800	1,598
Male Genital	869	1,336
Urinary	536	818
Eye / Brain / Other CNS	337	524
Lymphoid	617	1,065
Other (Specified)	757	1,351
Multiple	50	89
Ill-Defined / Secondary / Etc	436	810
Total	13,067	24,138

Primary diagnosis – conditions other than cancer

Excluding patients with a 'not known' diagnosis, 3,339 new patients (20%) had a diagnosis other than cancer, although 10% of the services had no such patients. The range of these patients varied up to 83%. It may be noted that of all the different types of service surveyed, the Outpatient service had the highest percentage of patients with a diagnosis other than cancer. It also had the highest proportion of 'All Other Conditions' diagnoses at 55%.

Chart 49: Diagnoses other than cancer in Outpatients

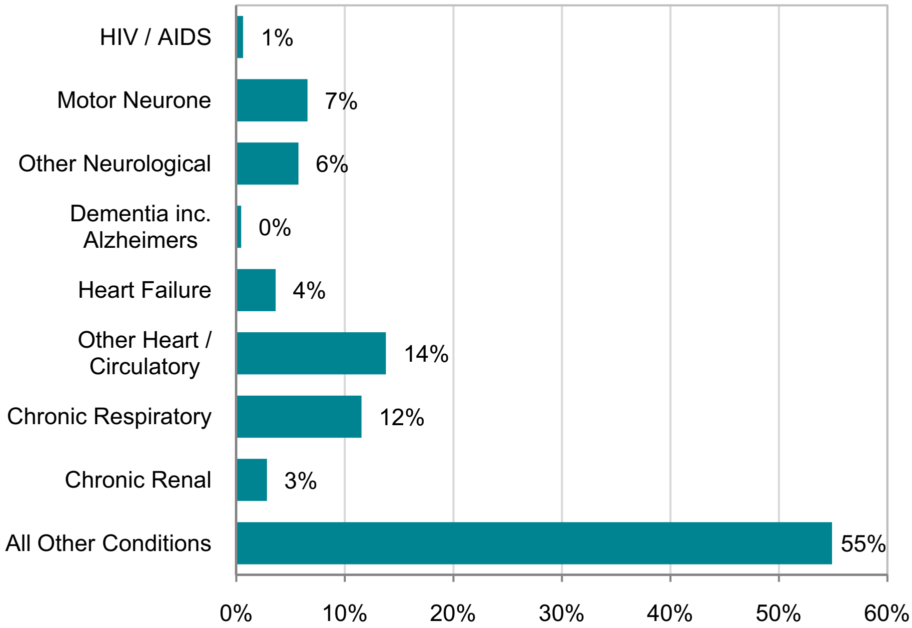


Table 58: Diagnoses other than cancer in Outpatients

Diagnosis	New	All
HIV / AIDS	21	71
Motor Neurone	219	381
Other Neurological	191	436
Dementia inc. Alzheimer's	15	18
Heart Failure	121	181
Other Heart / Circulatory	460	1,321
Chronic Respiratory	385	537
Chronic Renal	94	124
All Other Conditions	1,833	4,948
Total	3,339	8,017

Clinics and attendances

Over a fifth of palliative care clinics (21%) were led by a palliative care Medical Consultant, 17% by a Complementary Therapist and 15% by a nurse other than a Clinical Nurse Specialist.

This year comparatively fewer joint clinics were run by Complementary Therapists (2% compared to 17%) and more by physiotherapists (22% compared to 12%) and Other Doctors (15% compared to 6%).

Table 59: Outpatient clinics

Lead Health Care Professio`nal	Palliative care clinics	Joint clinics	First attendances	Follow-up attendances
Medical Consultant	6,163	233	5,201	14,455
Other Doctor	1,853	190	1,383	3,258
Clinical Nurse Specialist	4,004	188	1,667	7,377
Other Nurse	4,516	294	2,391	12,117
Physiotherapist	3,624	273	1,632	9,443
Occupational therapist	183	7	158	168
Social Worker	366	31	209	467
Pastoral / Spiritual Carer	18	0	8	57
Psychologist / Psychotherapist	1,287	0	601	2,754
Complementary Therapist	4,938	24	1,668	10,563
Other Health Care Professional	2,583	24	1,098	5,585
TOTAL	**29,534**	**1,261**	**15,937**	**66,048**

Non-clinic contacts

The number of services reporting on face to face contacts increased from 87 to 95, although the number of contacts was lower (28,224 down from 40,404)

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 two 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 more than doubled (by 2,466) their face to face contacts, but more than halved (by 2,196) their telephone contacts. The number of services reporting Physiotherapist contacts increased by a fifth for face to face, and by one for telephone contacts.

Table 60: Face to face contacts with Outpatients

Health Care Professional	Face to Face	%	Max	Mean	Median	Count
Medical consultant	1,042	3.7%	131	34	17	77
Other Doctor	823	2.9%	126	27	13	68
Clinical Nurse Specialist	2,337	8.3%	821	93	29	69
Other Nurse	4,746	16.8%	738	158	79	70
Physiotherapist	4,720	16.7%	1,674	118	55	75
Occupational therapist	2,004	7.1%	954	72	26	73
Social Worker	4,104	14.5%	1,346	132	35	70
Pastoral / Spiritual Carer	289	1.0%	150	26	4	63
Psychologist / Psychotherapist	300	1.1%	77	23	16	63
Complementary Therapist	5,363	19.0%	987	158	95	73
Other Health Care Professional	2,897	10.3%	456	97	22	71
Total	**28,224**	**–**	**–**	**467**	**207**	**95**

- The number of services responding increased from 87 to 95 (9%)
- Contacts recorded decreased from 40,404 to 28,224 (-30%)
- Other Nurses accounted for most of the drop in contacts
- Medical Consultants and Clinical Nurse Specialists also dropped by over two thousand contacts each

The number of telephone contacts reported was also down this year, although the number of services responding increased. Physiotherapists accounted for 11% of calls this year, half of last year's 23%. Complementary Therapists, Social Workers and Occupational therapists all increased their share of the calls.

Table 61: Telephone contacts with Outpatients

Health Care Professional	Face to Face	%	Max	Mean	Median	Count
Medical consultant	276	1.9%	71	4	9	71
Other Doctor	239	1.6%	87	4	3	65
Clinical Nurse Specialist	2,392	16.3%	1,027	38	21	63
Other Nurse	3,550	24.2%	1,179	55	41	65
Physiotherapist	1,662	11.3%	426	24	35	68
Occupational therapist	1,847	12.6%	1,129	28	19	67
Social Worker	3,027	20.6%	839	48	70	63
Pastoral / Spiritual Carer	34	0.2%	23	1	2	60
Psychologist / Psychotherapist	154	1.1%	82	3	6	61
Complementary Therapist	1,086	7.4%	244	16	29	66
Other Health Care Professional	575	3.9%	291	9	6	65
Total	**14,659**	–	–	**179**	**6**	**82**

- The number of services responding increased from 57 to 82 (44%)
- Contacts recorded decreased from 17,079 to 14,659 (-14%)
- The number of services reporting on Medical Consultants dropped by 29% (6 units) and the total contacts almost halved
- Physiotherapist contacts dropped by over two thousand despite one more service responding.
- Clinical Nurse Specialist contacts dropped by about a thousand (31%), while the number of services responding dropped by 11%
- Complimentary Therapists, Occupational Therapists and Social Workers 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 (MND) seen by services, carried out 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.

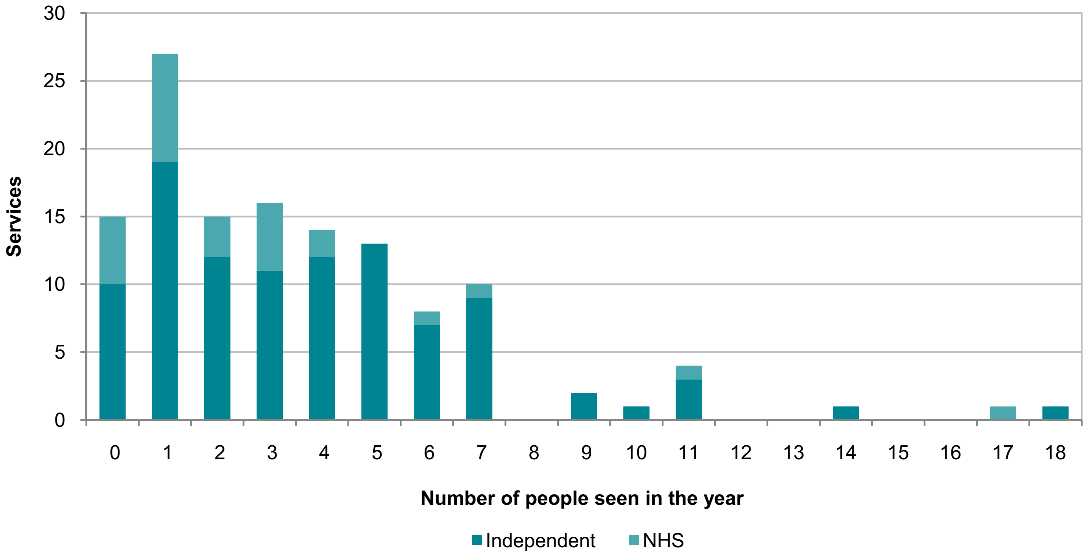
This analysis raises a number of different questions. For example, services that see no people with MND might wish to ask themselves why that is the case. Services that are seeing only one or a very few people with MND each year might be advised to consider whether their staff have sufficient understanding 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 113 services seeing people with a primary diagnosis of MND, 106 (94%) saw 10 patients or fewer. Five independent and two NHS units saw more than 10 patients.

Chart 50: Motor Neurone Disease in Inpatients

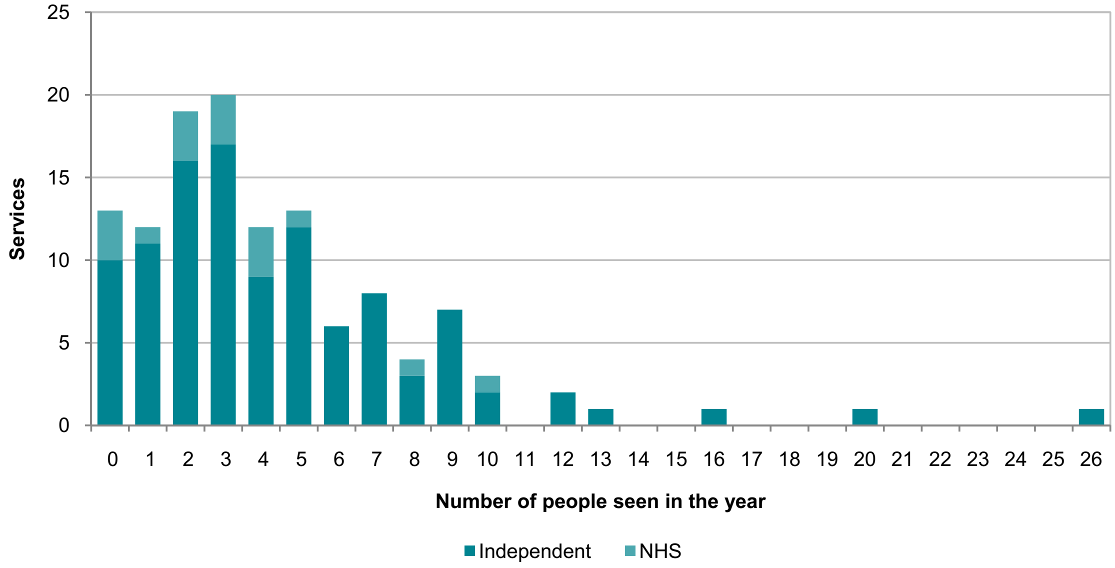


Day Care

Of the 110 services who reported seeing people with a primary diagnosis of MND, 106 (95%) saw 10 patients or fewer. No NHS services saw more than 10 patients.

One service alone saw 26 patients, which accounted for 5% of people seen.

Chart 51: Motor Neurone Disease in Day Care

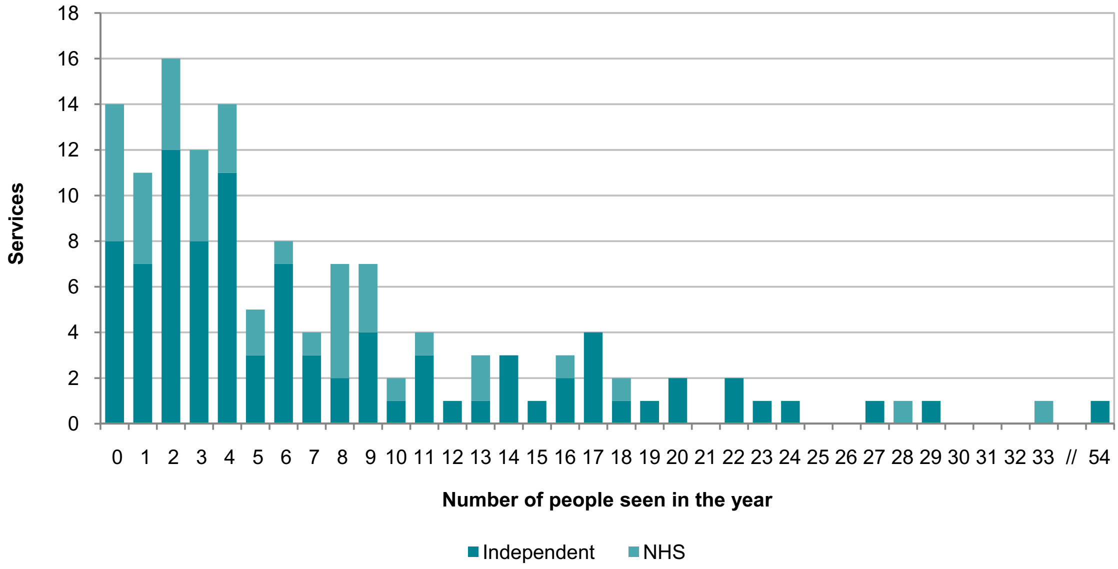


Community Care

Community care services were the only setting where the majority of services saw more than 10 people. Of the 119 services who reported seeing people with a primary diagnosis of MND, 86 (72%) saw ten or fewer and nine units (7%) saw more than 20 people.

One NHS service saw 33 people (3%) while one independently managed service saw 54 people, or 5% of the total.

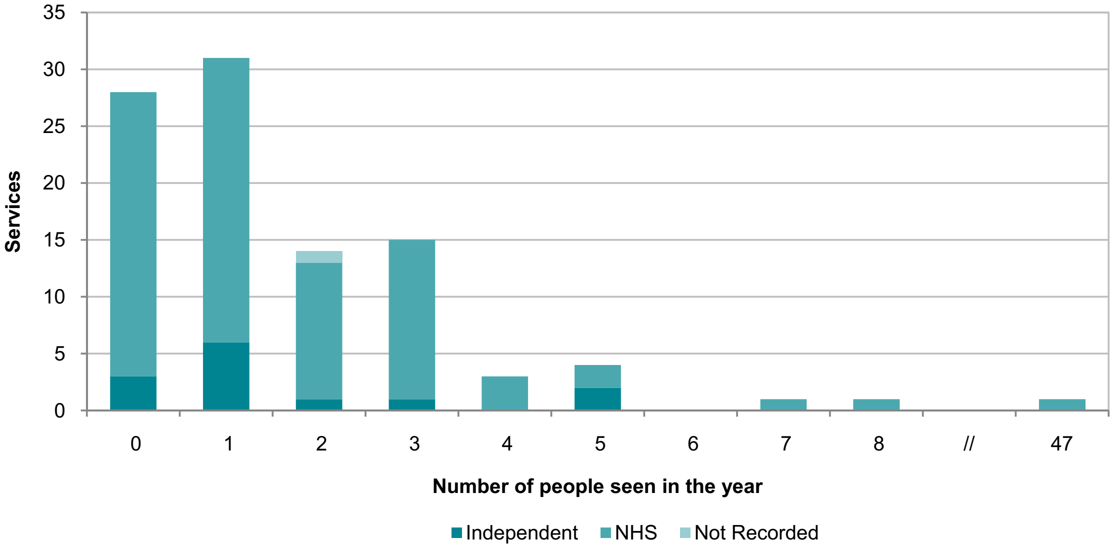
Chart 52: Motor Neurone Disease in community care



Hospital Support

Of the 69 Hospital Support services which saw people with a primary diagnosis of MND, 68 saw ten or fewer patients. The remaining unit saw 47 people, 24% of the total.

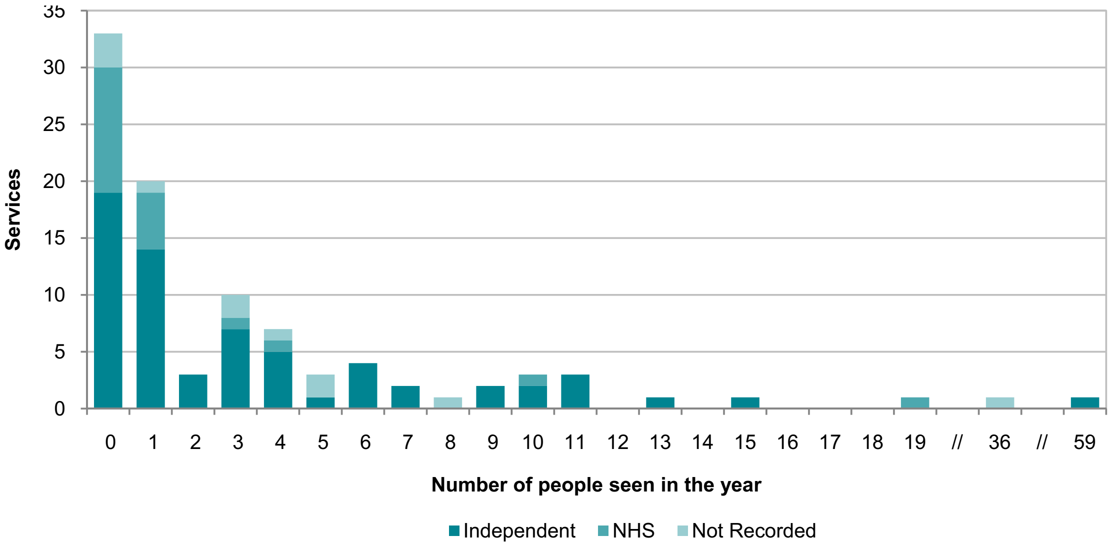
Chart 53:
Motor Neurone Disease in Hospital Support



Outpatients

A total of 96 services completed data on primary diagnoses. Of these 33 (34%) did not see anyone with MND as a primary diagnosis. Of the 63 services which did, 55 (87%) saw ten or fewer people (52% of patients) and 8 saw more than ten. One unit alone saw 59 people with MND, 16% of the total number of people.

Chart 54:
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 2009-10.
Continuing patient	A patient who was referred in a previous year and was still being seen by the service on 1st April 2009.
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 2009-10.
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 while 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 bed days 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 palliative care clinic is held by a member of the specialist palliative care team.
Joint clinic	A joint clinic is one 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

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