THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

National Survey of Patient Activity Data for Specialist Palliative Care Services

MDS Full Report for the year 2011-2012

Public Health
England

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promotes palliative care in health and social care settings across all sectors to government, national and local policy makers.

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

About Dying Matters

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

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

About The National End of Life Care Intelligence Network

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

This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy.

On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.

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

Public Health England's website is **www.gov.uk/phe**

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1.1 General

- There are 466 organisations providing specialist palliative care in around 1,500 services across a range of different settings in England, Wales and Northern Ireland
- Data from survey respondents on the number of people using specialist palliative care services show the provision of palliative care through different settings differs markedly across regions. (page 18.)

1.2 Inpatients

- There have been increases in activity, available beds and occupancy in inpatient services (page 21)
- On average, there are 5.5 inpatient beds per 1,000 deaths. However, there is a large variation across regions from 3.2 inpatient beds per 1,000 deaths in East Midlands to 8.4 inpatient beds per 1,000 deaths in London – a 2.6 fold difference
- Almost half (45%) of people staying in inpatient units were discharged, dispelling the myth that hospices are only places where people go to die (page 22)

1.3 Day Care

- The majority (56%) of people accessing Day Care services attended for 90 days or fewer (page 23)
- The mean day care caseload has increased from 45.4 patients in 2009/10 to 55.6 patients in 2011/12.
- Non-specialist nurses provide most (41.4%) of the contacts in Day Care (page 56)

1.4 Community

- Clinical Nurse Specialists provide the vast majority (79.5%) of contacts in Home Care (page 62)
- Non-specialist nurses provide most of the contacts (60.1%) in Hospice @ Home (page 63)
- The majority (60.7%) of people experience community services for fewer than 61 days (page 27)
- Nearly half the people receiving care in the community who died (49.8%) died in their home. Less than a quarter (23.9%) died in hospital. This can be compared with ONS data for all deaths which shows that 21.8% of people died at home and 51.5% in hospital
- There are large regional differences in place of death; 65% of deaths recorded, who received specialist palliative care via community services, died at home in the North East compared to 41% in London (page 28)

1.5 Hospital Support

- Clinical Nurse Specialists provide the vast majority (78.7%) of contacts in Hospital Support (page 68)
- There is a far higher proportion of people using Hospital Support services in London (41%) than in the rest of the country (page 18)
- 63% of people received care via Hospital Support for a week or less (page 31)

1.6 Bereavement Support

- There was a wide variation in the types of face to face contacts across regions
- Over half of East Midlands' reported face to face contacts were in groups
- No other region had more than a quarter of face to face contacts in groups

1.7 Outpatients

- Average attendance per clinic is much lower than in Day Care sessions
- There is a much more even distribution of clinics amongst different heath care professionals than in other settings

1.8 Staffing

- The majority of people were seen by Home Care services, rather than Hospice @ Home or Combined services, and a marked increase in the number of contacts made by Clinical Nurse Specialists was recorded this year. This should be considered along with the findings in NCPC's Specialist Palliative Care Workforce Survey from 2010 which showed a decline in CNS staffing levels, combined with an increase in vacancies and the proportion of staff members aged over 50

1.9 Diagnoses

- The growth trends in the proportion of conditions other than cancer are continuing. Although the Outpatients growth is more erratic, there are very clear increases in other settings (page 44). It is recommended that responders review their systems to record diagnosis and consider what scope there is for improvement as data about primary diagnosis is important to enable measurement of equity of access to specialist palliative care.

1.10 Young people

- Reported numbers of young adults accessing adult specialist palliative care services are low. For example Table 41 to Table 43 (pages 59-60) report that 147 16-24 year olds accessed Home Care, 21 accessed Hospice@Home, and 46 accessed combined services. Adult providers are strongly encouraged to consider how they can ensure their services are available and appropriate for young adults and how they might be able to work in partnership with local children's services and other agencies to achieve that. Details about NCPC's Transitions partnership with Together 4 Short Lives and Help the Hospices, including research findings from the STEPP research project by the University of York, can be accessed at **http://www.ncpc.org.uk/transitions**

2 Introduction

2.1 About the Minimum Data Set

2.1.1 Background

The Minimum Data Set (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 to support service development, for example its dementia work, workforce survey of specialist palliative care, population based needs assessment, and funding surveys. The MDS is of great help in supporting the implementation of national initiatives to develop palliative and end of life care in England, Wales and Northern Ireland. For example, the dataset was used to inform the work of the Palliative Care Funding Review, which reported in the summer of 2011.

2.1.2 Individual reports

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

The government's reforms of the NHS in England led to the creation of 4 new SHA cluster boards. For this year's report we have analysed by cluster as well as by the old SHAs.

2.2 Developing the Minimum Data Set

Since the MDS was first launched, the commissioning, provision and delivery of specialist palliative care services have changed greatly. It is important that the MDS reflects these changes so as to continue to meet the original aims of the collection. To this end, in 2005/6 NCPC worked in partnership with Marie Curie Palliative Care Institute Liverpool (MCPCIL) to review the Minimum Data Set questionnaires with a new version being launched for first use in 2008/09. A series of guides has been produced which detail question-by-question exactly what data are to be collected. These guides are intended to be 'user-friendly' and will continue to be updated where necessary if difficulties of interpretation arise.

NCPC, working with NEoLCIN, recently completed a pilot project to investigate the feasibility of collecting MDS data at the level of individual people and episodes of care. We are now considering the findings from that project with our partners and stakeholders, and will continue this work in 2013/14. We will also be considering the further development of the MDS and its relationship with the data collection that will be needed to support a palliative care funding mechanism. We are working closely with the team responsible for the palliative care funding pilots. Looking to the future, robust data and evidence will be essential to the development of specialist palliative care services, and the MDS will remain an important source of intelligence.

2.3 The Minimum Data Set & 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. On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.

NEoLCIN's website can be found at: **www.endoflifecare-intelligence.org.uk**

Public Health England's website can be found at: **www.gov.uk/phe**

3 Method

3.1 Data Collection

The 2011/12 MDS survey covers 466 hospice and specialist palliative care provider organisations located in England, Northern Ireland and Wales. As far as we are aware, this is the best available list of service providers but we acknowledge that there may be gaps in our directory. A provider organisation may supply a range of palliative care services in different settings. In 2011/12, the 466 provider organisations supplied around 1,500 services across inpatient, day care and outpatient settings and through hospital support and bereavement support services.

Not included in the survey are providers of children's and specialist services, such as those for HIV/ AIDs or those provided by 'site specific' cancer specialist nurses such as breast care or chemotherapy nurses. Providers in Scotland are not included in the annual surveys because they fall within the remit of the Scottish Partnership for Palliative Care rather than that of NCPC.

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

3.2 Response rates

Responses were mostly submitted electronically by email attachment; of the 886 forms sent in, only eleven were received on paper. The majority of forms (81%) were submitted on NCPC's Word or Excel 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. 18% of forms (156) 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.

Of the 466 provider organisations surveyed, 303 responded - an overall response rate of 65%, down from 70% last year. (See Table 1.)

Table 1: Responses by provider and country

	Number of providers responding			
	England	**N Ireland**	**Wales**	**Total**
Providers Responding	**271**	**10**	**22**	**303**
Total Providers	**417**	**19**	**30**	**466**
Provider Response rate (%)	**65%**	**53%**	**73%**	**65%**

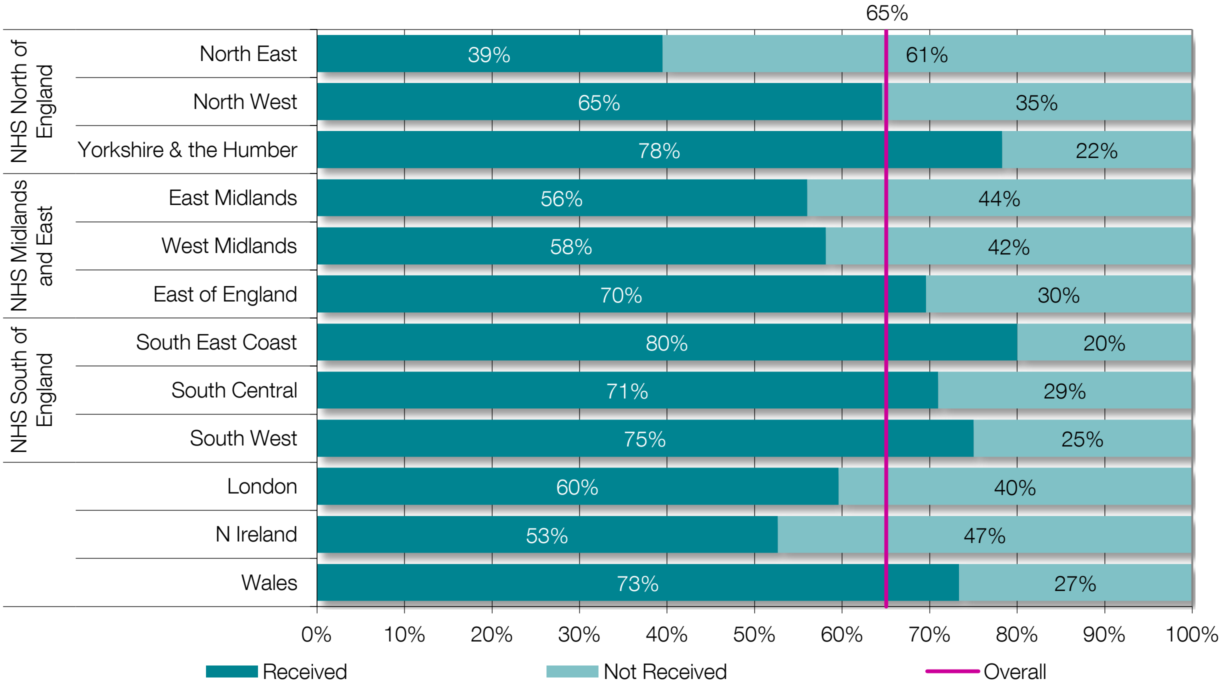
Table 2 shows the overall response rate for services provided in different settings and it is seen that the response rates varied across services from 49% to 75%.

Table 2: Response rate for services by setting and country

	Number of services responding					
Service setting	**England**	**N Ireland**	**Wales**	**Total**	**All services**	**Response rate**
Inpatient	126	5	10	141	190	74%
Day Care	129	4	9	142	204	70%
Community Care	167	3	9	179	288	62%
Hospital Support	125	6	10	141	256	55%
Bereavement Support	122	2	7	131	265	49%
Outpatients	136	7	9	152	308	49%
Services Responding	**805**	**27**	**54**	**886**	**1,511**	**59%**
All Services	**1,353**	**59**	**99**	**1511**		
Service Response rate (%)	**59%**	**46%**	**55%**	**59%**		

Chart 1 compares the response rates from each former Strategic Health Authority (SHA) area to provide a regional breakdown of overall response rates.

Chart 1: Response rate for regions



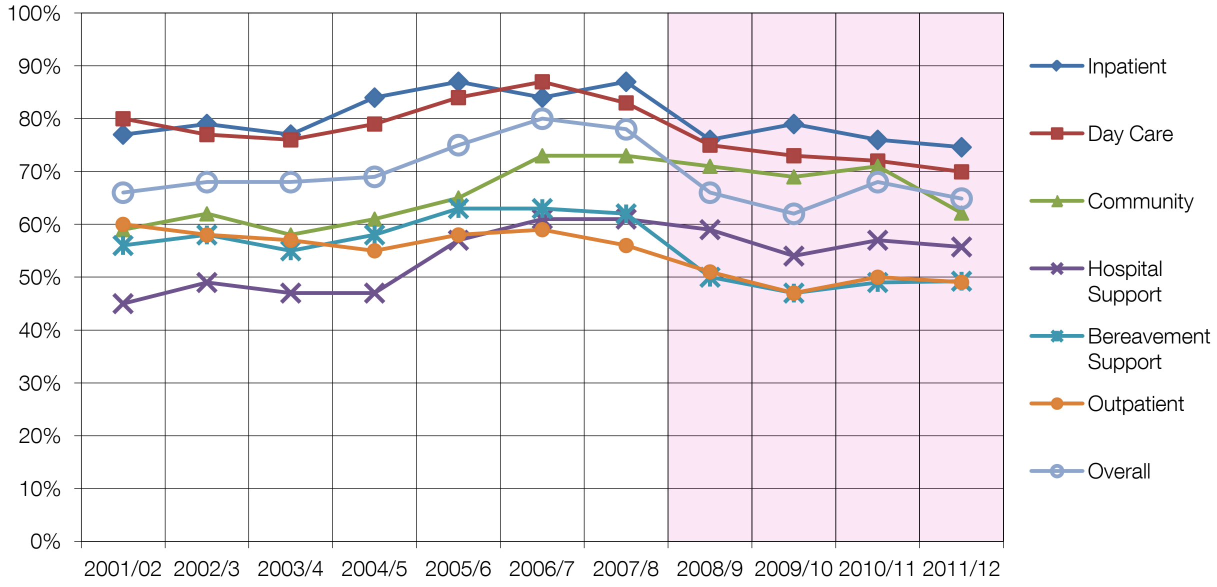
Data from Table 6 on Page 47

It can be seen that there are considerable variations in response rates, both between settings and regionally. The reasons for this are not clear. However all services are strongly encouraged to make MDS returns to help strengthen the evidence base for specialist palliative care.

3.3 Trend in response rates

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

Chart 2: Response rates trend



The shaded area indicates the period in which the revised MDS has been collected. Data from Table 8 on page 48

With the introduction of the revised MDS in 2008/09 there was a sharp drop off in responses. This was understandable as the new collection required a significant amount of work by services to set up their information systems to report the additional data.

The overall response rate, however, had remained around the 65% level, with Inpatient, Day Care continuing to fall. Community responses, having remained high, dropped significantly this year.

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3.4 Data quality and collection issues

3.4.1 Response rate

It was expected that the response rate would temporarily drop with the introduction of the revised MDS for 2008/09, but it was anticipated that it would pick up in later years. However, the overall response rate trend has remained around 65% since 2008/09, whilst responses by Inpatient, Day Care and Community services have continued to fall.

3.4.2 Ethnicity

As with previous survey years, the reporting of ethnicity was erratic. Although the percentage of services returning ethnicity data is increasing, the numbers of “Not Recorded” and “Other non-white” are also increasing.

3.4.3 Interpreting trends

The number of contacts, visits and consultations recorded has increased since the introduction of the revised MDS. However, as data quality is likely to have varied from year to year, interpreting trends in activity over time is problematic as any changes may partly reflect differences in data completeness between years..

3.4.4 Outpatient clinics

Survey responses suggest there are differences in the way services define outpatient clinics. Some services reported one single clinic, with hundreds of attendees, while others reported more clinics than the number of patients. In a few cases, a separate clinic was recorded for each person’s attendance.

To date, what constitutes a clinic has been quite loosely defined:

- The MDS guidance describes a clinic as “a regular event where patients attend at appointed times” and asks services to “Count the number of clinics according to the main staff member.”
- The data manual states: “A clinic usually lasts for one morning or afternoon.”

We would expect a clinic to be recorded as a day or half day session, run by a health care professional, seeing several people. Where a clinic is being run by more than one health care professional in the same role, (e.g. clinical nurse specialists) we would count that as a single clinic.

Where a clinic is being run by more than one health care professional in different roles, (e.g. a clinical nurse specialist and a physiotherapist) we would count that as a separate clinic for each type of health care professional.

More research needs to be done to identify how services are recording clinics and to create a definition which will allow data to be collected consistently.

3.4.5 Diagnosis

The proportion of diagnoses other than cancer are increasing, but the number of “Other” diagnoses are still very high and more remains to be done to ensure that people with diagnoses other than cancer have access to specialist services when needed.

4 Analysis

This section makes use of this year's survey results to provide a picture of the overall provision of specialist palliative care services across England, Wales and Northern Ireland and to gain an insight into the characteristics of people accessing palliative care services and the types of care those people receive.

To get a view of the totality of service provision some analysis is based on estimated figures which combine data from services responding to the 2011/12 survey with information we have on services that did not respond. Whilst this type of analysis cannot provide the same level of detail as analysis based on survey results, it does provide an overall picture of service provision and highlights differences in the way specialist palliative care services are provided across the country.

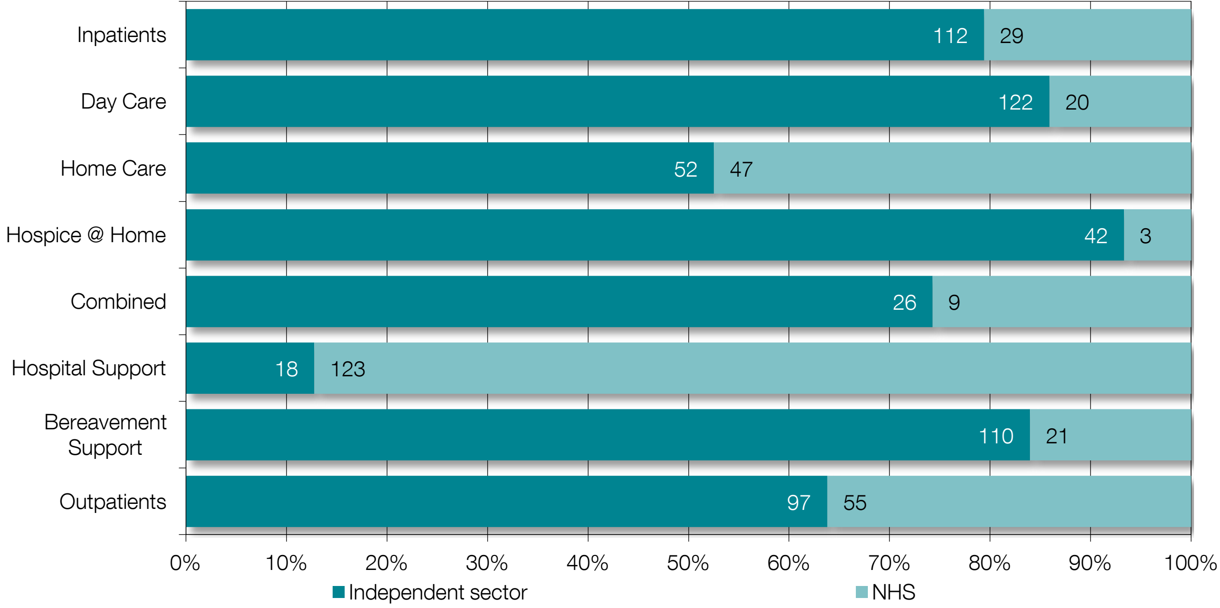
4.1 Service Provision

In 2011/12 there were, in total, around 466 organisations providing specialist palliative care in around 1,500 services across a range of different settings in England, Wales and Northern Ireland. However, the number of services, and the use of different settings in which care is provided, varies markedly between regions.

4.1.1 Split of management of services between NHS and independent sectors

Services were asked to indicate whether they were managed by the NHS or independently. Chart 3 shows the breakdown of service management by setting for survey respondents.

Chart 3: Provision of care – the split between NHS and independent sectors



Data from Table 9 on page 48

- The large majority of specialist palliative care services responding are provided by the independent sector, with the exception of hospital support services, 87% of which are provided by the NHS
- Just over half (51%) of Home Care services and 63% of Outpatients services are independently managed. Across all other service settings, over 74% are non-NHS managed

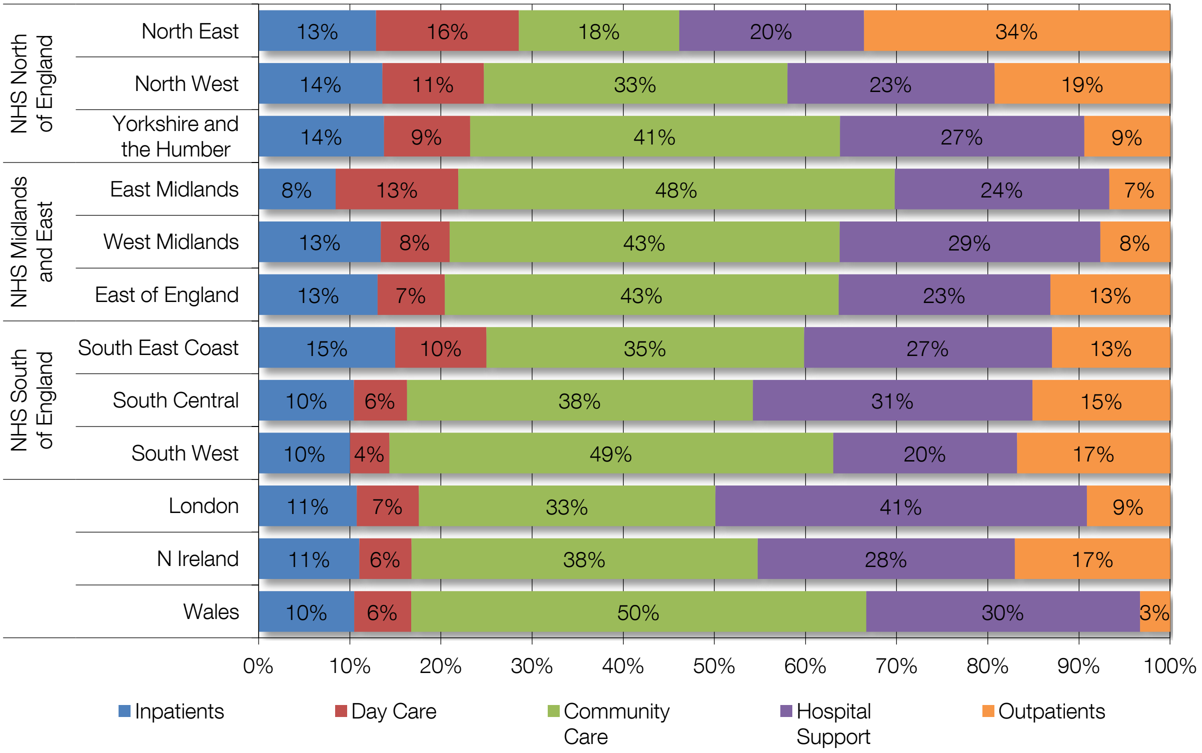
4.1.2 Service provision by region and setting

The number of specialist palliative care services (including non-responders to the 2011/12 survey) varies from 79 organisations providing 225 services in the North West to 19 organisations providing 55 services in Northern Ireland. Using the number of deaths in 2011 as a proxy measure of palliative care need (and acknowledging that this only provides a very broad estimate of need), the variation in the number of services per 1,000 deaths in each region suggest differing patterns of service provision across the country (see Table 12 on page 49).

- In the North East, for every 1,000 deaths in the region, there are on average 1.5 organisations providing 4.2 specialist palliative care services
- In the East Midlands, for every 1,000 deaths in the region, there are on average 0.6 organisations providing 1.7 specialist palliative care services
- On average across England, Wales and Northern Ireland, there are 0.9 organisations providing 2.8 specialist palliative care services for every 1,000 deaths

Data from survey respondents on the number of people using specialist palliative care services show the provision of palliative care through different settings differs markedly across regions.

Chart 4: The proportion of palliatve patients by setting



Data from Table 15 on Page 50

- The largest proportion of activity is within a community setting, although this does vary across regions with only 18% of activity in the North East seen in the community (see Chart 4). The North East is also characterised with a larger proportion of activity in an Outpatient or Day Care setting
- Between 20% - 31% of activity is through Hospital Support in all regions except for London, where the largest proportion of activity (41%) is provided through Hospital Support

4.1.3 Total inpatient beds by region

Looking at the provision of Inpatient services alone, and including data on the number of Inpatient beds in services not responding to this year's survey, there are on average 5.5 Inpatient beds per 1,000 deaths across England, Wales and Northern Ireland as a whole. However, there is a large variation across regions as shown in Chart 5.

Chart 5: Total inpatient beds per 1,000 deaths by region

Data from Table 14 on page 50

Sources: Responding and non-responding Inpatient units to the 2010/11 survey, ONS 2011 mortality data

- Chart 5 shows that the number of inpatient beds per 1,000 deaths across each region varies from 3.2 per 1,000 deaths in East Midlands to 8.4 per 1,000 in London – a 2.6 fold difference
- Note that this only applies to services in the Inpatient setting

4.2 Inpatients

An inpatient is a patient who is admitted and occupies a bed in the unit, not necessarily overnight. There are several types of inpatient admission:

- An *ordinary* inpatient is admitted with the intention of staying one or more nights in the unit
- A *day case* inpatient is admitted with a view to discharge the same day, that is, not staying overnight in the unit
- A *regular* inpatient is admitted as part of a planned series of short stays, usually of one day or one night each, for example for pain control adjustment or respite care. A series of day admissions differs from day care in that the patient occupies a bed while in the unit

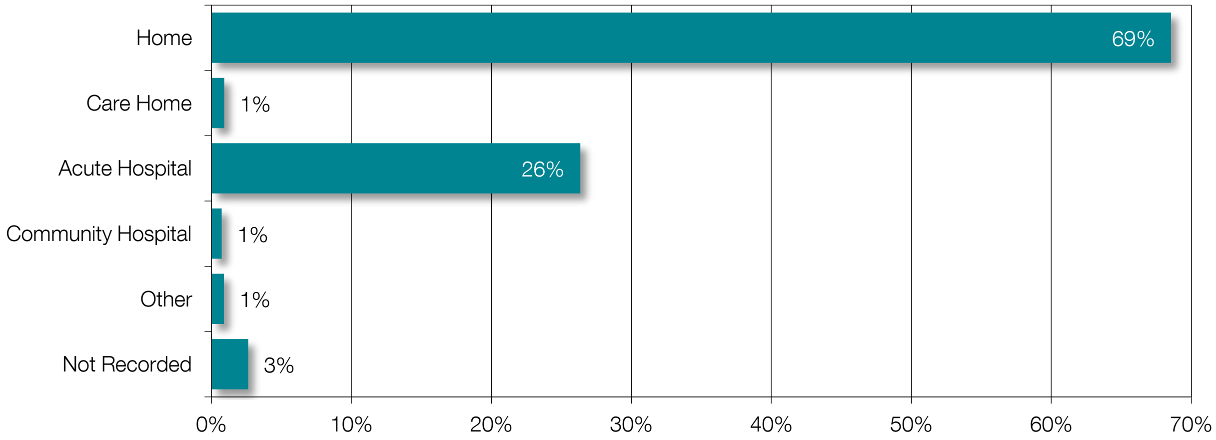
An ordinary inpatient who does not actually occupy a bed for one night, for example an urgent admission who dies the same day, is still counted as an ordinary inpatient.

A day case patient who for any reason does stay overnight in the unit becomes an ordinary inpatient, as does a regular patient who overstays the planned period of admission.

4.2.1 Admissions

Data from Inpatient services responding to the 2011/12 survey show around 27% of Inpatient admissions were a first admission for a patient. Of these of new Inpatient admissions, the great majority (69%) were referred from the patient's own home, and a further 26% from an acute hospital.

Chart 6: Location of inpatients before admission



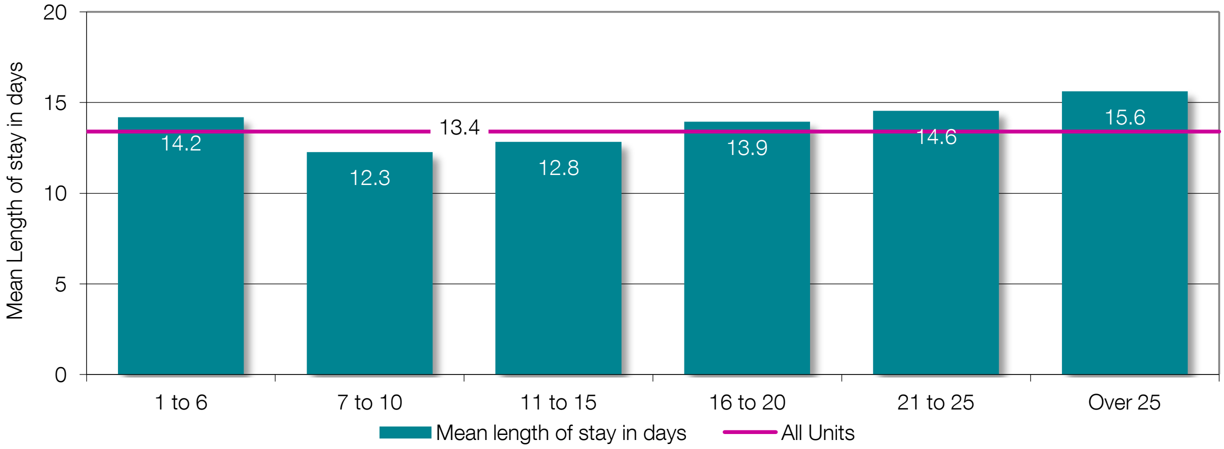
Data from Table 21 on page 52.

4.2.2 Inpatients beds analysis

A total of 75% of Inpatient services responded to the 2011/12 survey, covering 73% of the estimated number of beds in Inpatient units. The response rate varied widely by region. Services covering 96% of Inpatients beds in Northern Ireland responded, but services covering just over half the beds in Wales and the East Midlands returned data. (See Table 7 on page 47).

Overall, the mean length of stay for people in an Inpatient unit was 13.4 days among all Inpatient units responding. However, this average varies by the size of inpatient unit with 7-10 bed units having an average length of stay of 12.3 days and units with over 35 beds the longest average stay at 15.6 days.

Chart 7: Length of inpatient stay by size of unit



Data from Table 22 on page 52.

Compared with 2010/11, survey results for 2011/12 show an overall increase in Inpatient provision and activity.

- In 2011/12, there was on average 15.6 beds per unit, compared with 14.7 beds per unit in 2010/11 and reversing an overall downward trend over the previous 12 years
- The number of available beds per unit is up from 14.2 to 14.9 in 2011/12
- The number of occupied beds per unit is also up, from 10.7 to 11.1 in 2011/12
- In 2011/12 the average number of patients per unit has increased from 258.1 to 271.8

Table 3: Length of inpatient stay by region

	Region	Mean length of stay (days)
NHS North of England	**North East**	14.7
	North West	13.7
	Yorkshire & the Humber	14.0
NHS Midlands and East	**East Midlands**	12.6
	West Midlands	13.3
	East of England	13.4
NHS South of England	**South East Coast**	12.6
	South Central	13.7
	South West	12.5
	London	12.4
	N Ireland	15.9
	Wales	13.5

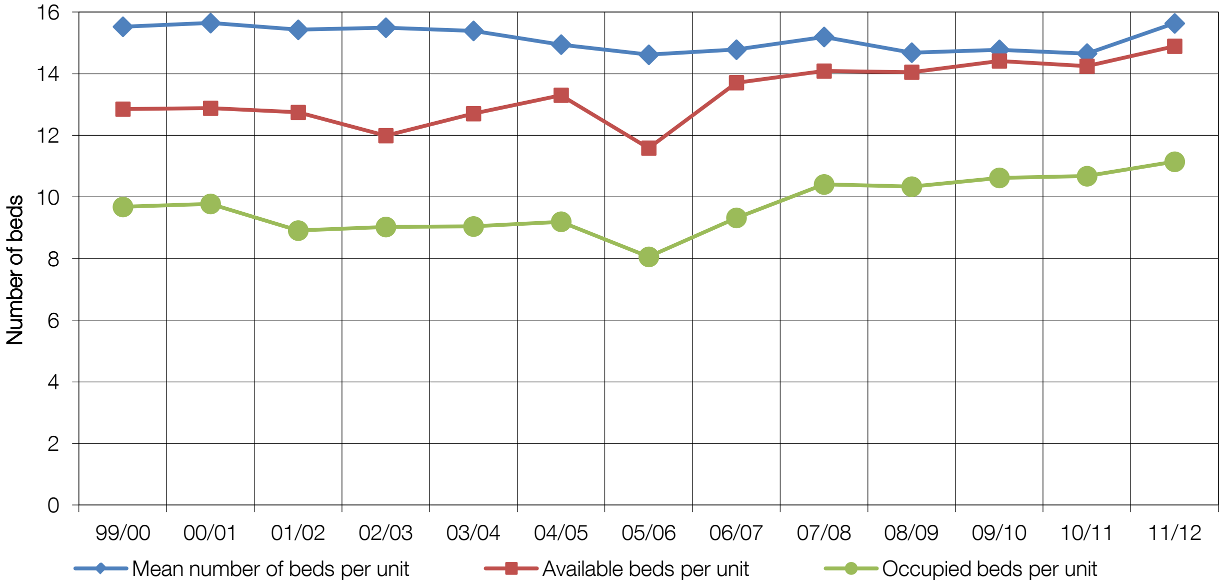
The longest average length of inpatient stay was in Northern Ireland units with 15.9 days, followed by the three former SHA areas in the North of England where length of stay averaged 13.7 – 14.7 days.

4.2.3 Bed usage

Services were asked to calculate the bed occupancy rate from a midnight count of the number of beds actually occupied (or reserved for a patient temporarily away), as a percentage of available beds. Available beds are all those which are occupied, reserved, or available for use the following day. Beds kept empty because of staff shortages, or ward closures, are considered unavailable. Beds kept empty for other reasons, such as a recent death, are considered available.

The mean bed occupancy overall was 75%. The variations in occupancy were between 41% and 100%. The numbers of reserved beds varied considerably, suggesting different ways of counting. There was a mean of 2% reserved beds, as a percentage of beds in use (occupied or reserved) but 38% of units (55) recorded no reserved beds (down from 43% last year) while others recorded up to 12%. 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.

Chart 8: Inpatient bed usage analysis

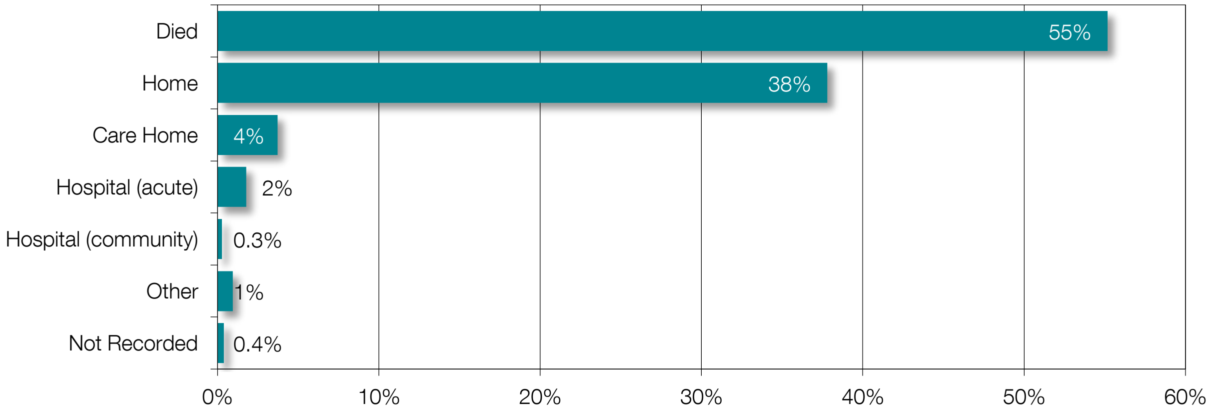


Data from Table 26 on page 53.

4.2.4 Discharge Location

The breakdown of location after end of a stay in inpatients for 2011/12 is virtually identical to that of 2010/11. Just over half (55%) of those people no longer being cared for by the Inpatients service (including day cases) had died. The remainder had been discharged; the majority of which (83%) were discharged to home. The fact that 45% of admissions ended in discharge should go some way to dispelling the myth that hospices are just somewhere where people go to die.

Chart 9: Location after end of inpatients stay



Note: These figures include day case patients.

Data from Table 24 on page 53

4.3 Day Care

A day care service is an arrangement whereby patients attend for all or part of a day for purposes such as:

- Social interaction, mutual support and friendship
- Creative and therapeutic activities
- Clinical surveillance and routine medical treatment
- Physical care (such as bathing)
- Respite to home carers

Practice varies widely and units put differing emphasis on the social and medical aspects of Day Care.

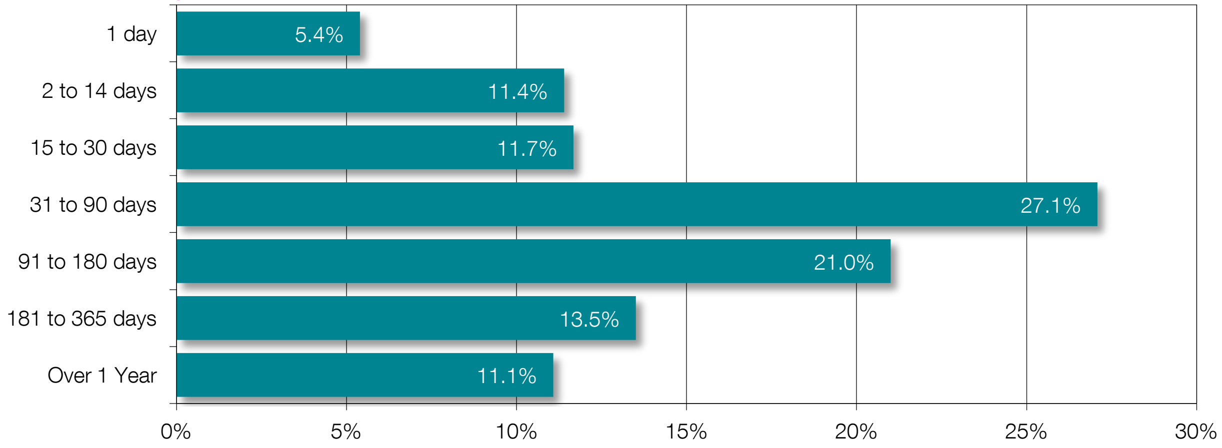
Many different activities may take place within a day care session, and there may be contact between patients and many different health care staff or volunteers.

Patients normally attend for the whole session, which may last a full day or a shorter period, rather than having individual appointments. A service where patients attend for nursing care or therapy by appointment would be recorded as Outpatient activity. However, an appointment *within* the day care session - for example, if the patient attends for a whole day during which he or she has an appointment with a hairdresser - should not be counted separately. Activities provided for inpatients *only* should not be counted as day care.

4.3.1 Length of care for Day Care

The length of time patients were under the care of the day centre prior to discharge was given by 132 services (90% of total number). Of 16,240 patients, over half (56%) attended for 90 days or fewer, a further 21% attended for between 91 and 180 days and 25% attended for more than 180 days. The average length of care recorded was about 6 months, ranging from less than a week to 22 months.

Chart 10: Length of care for Day Care services



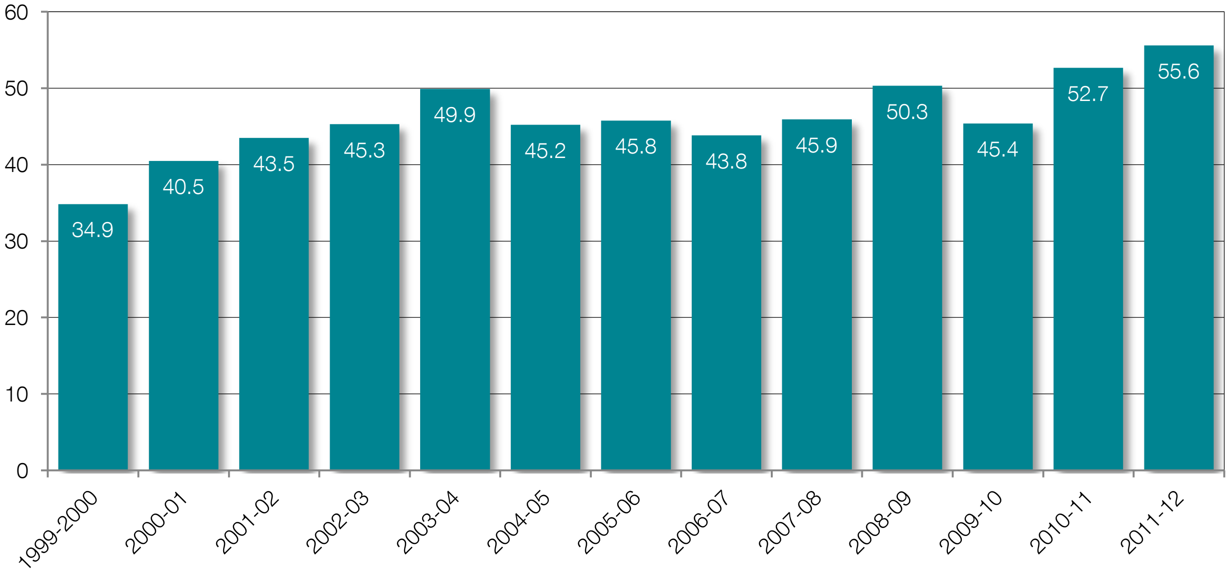
Data from Table 35 on page 57

4.3.2 Caseload for Day Care

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.

Over the last three years, the mean Day Care caseload has increased from 45.4 patients in 2009/10 to 55.6 patients in 2011/12 (derived from data in Table 38 on page 58, where the median length of care was 167 days). The median caseload in 2011/12 was 42 patients – compared with 45 last year.

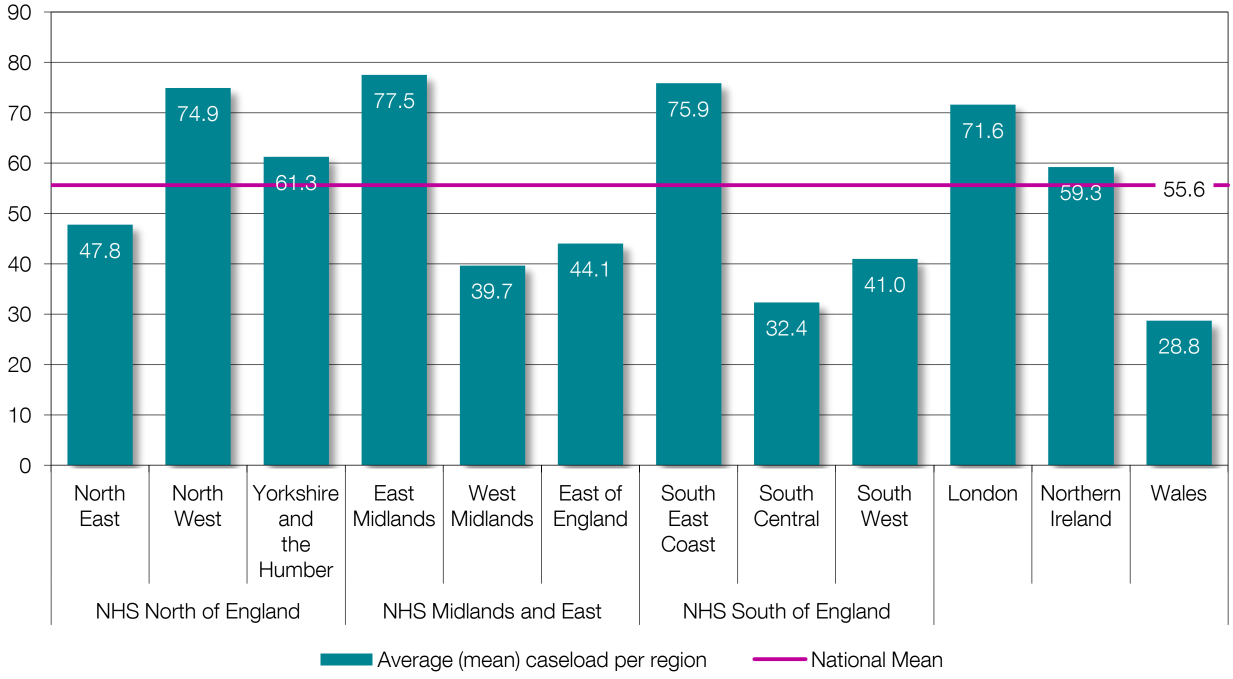
Chart 11: Average (mean) Day Care caseload trend



Data from Table 36 on page 57

The average caseload varied by region, from 28.8 patients in Wales to 77.5 patients in East Midlands.

Chart 12: Average (mean) Day Care caseload by region



Data from Table 37 on page 58

4.4 Community Services

A home care service is provided by means of visits to patients in their home or other place of residence. Home Care is mostly, but not exclusively, provided by specialist nursing staff such as Macmillan Nurses. Other staff such as doctors and social workers may also make home visits. These staff may carry out a wide range of services including:

- Clinical surveillance
- Physical and nursing care
- Counselling, advice and education for patients and families
- Consultancy and education for other health professionals

There are many different organisational and funding arrangements for staff providing Home Care. Specialist palliative care staff may be based in hospices, hospitals or NHS community units, and work closely with general practitioners and primary health care teams.

A series of home care visits involves one or more individual visits to a patient by home care staff. The visits making up a series may be by members of staff of different professional groups, for example nurses and social workers.

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

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

Hospice @ Home (H@H): A community service which self-identifies as providing 'Hospice @ Home', a mainly hands on nursing service, based in the patient's home without CNS input

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

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

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

4.4.1 Visits & contacts

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 1.1 to 41 visits, with a mean of 5.8 visits
- For the four years that we have collected data on consultations, the figures have varied quite widely
- As with Day Care the response rate to this section also varied quite widely

Home Care

A total of 86 organisations providing Home Care supplied data on the number of consultations made by a health care professional.

- The total number of visits recorded increased (from 331,425 to 379,896; (15%), as did the number of services responding (from 83 to 86)
- The number of telephone contacts recorded increased (from 631,788 to 699,390; 11%) while the number of services responding remained the same (78)
- Clinical nurse specialists made up the majority of both types of contacts

Hospice @ Home

A total of 33 organisations providing Hospice @ Home services supplied data on the number of consultations made by a health care professional. As would be expected by the nature of the service, consultations by clinical nurse specialists were much lower than for Home Care and accounted for 13% of face to face and 26% of telephone contacts.

- The total number of visits recorded increased (from 61,101 to 88,440; 45%), as did the number of services responding (from 24 to 33)
- The number of services recording telephone contacts increased (from 18 to 22) as did the number of contacts (from 73,939 to 94,831; 28%)
- The majority of both types of contacts were made by nurses other than clinical nurse specialists
- For the third year in a row, no telephone contacts were recorded by psychologists / psychotherapists and, this year, just one face to face contact

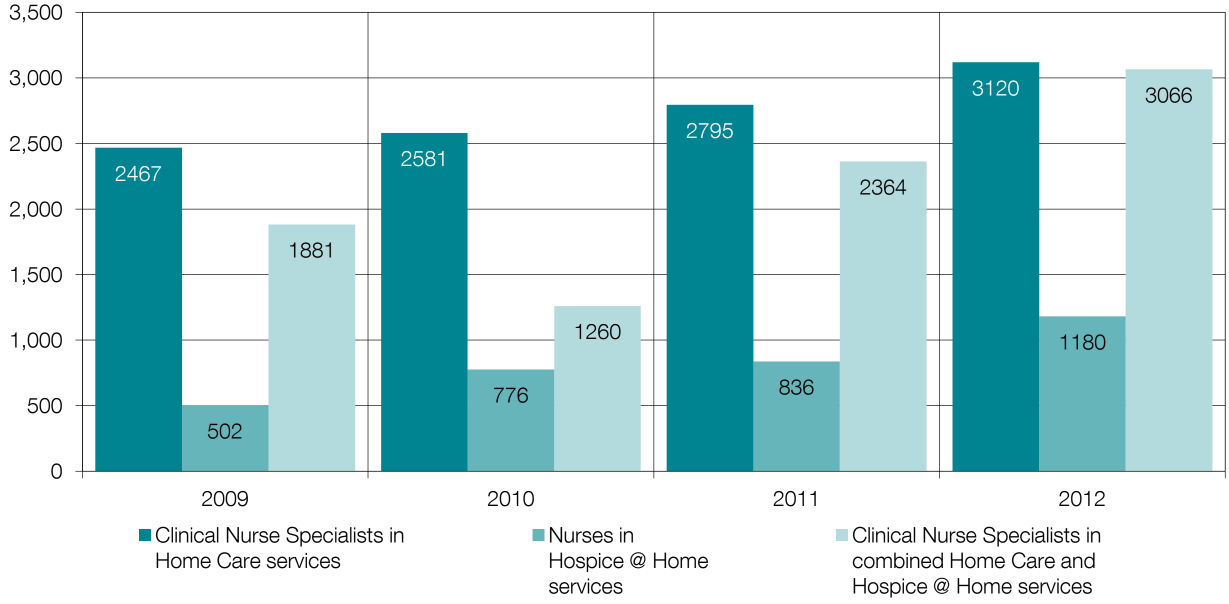
Combined Home Care & Hospice @ Home

A total of 28 organisations providing combined Home Care and Hospice @ Home services supplied data on the number of consultations made by a health care professional. Both visits and telephone consultations were recorded.

- The total number of visits recorded increased (from 135,645 to 170,088; 25%), although the number of services responding decreased (from 31 to 28)
- The number of services recording telephone contacts also decreased (from 27 to 26) while the number of contacts increased (from 191,992 to 242,286; 26%)
- The combined services' contacts are dominated by clinical nurse specialists, although the number of contacts by non-specialist nurses is increasing for both face to face and telephone

The majority of people were seen by Home Care services, rather than Hospice @ Home or Combined service, and a marked increase in the number of contacts by clinical nurse specialists was recorded this year. This should be considered along with the findings in NCPC's Specialist Palliative Care Workforce Survey from 2010 which showed a decline in CNS staffing levels, combined with an increase in vacancies and the proportion of staff members aged over 50.

Chart 13: Trends in visits by Clinical Nurse Specialists and Nurses



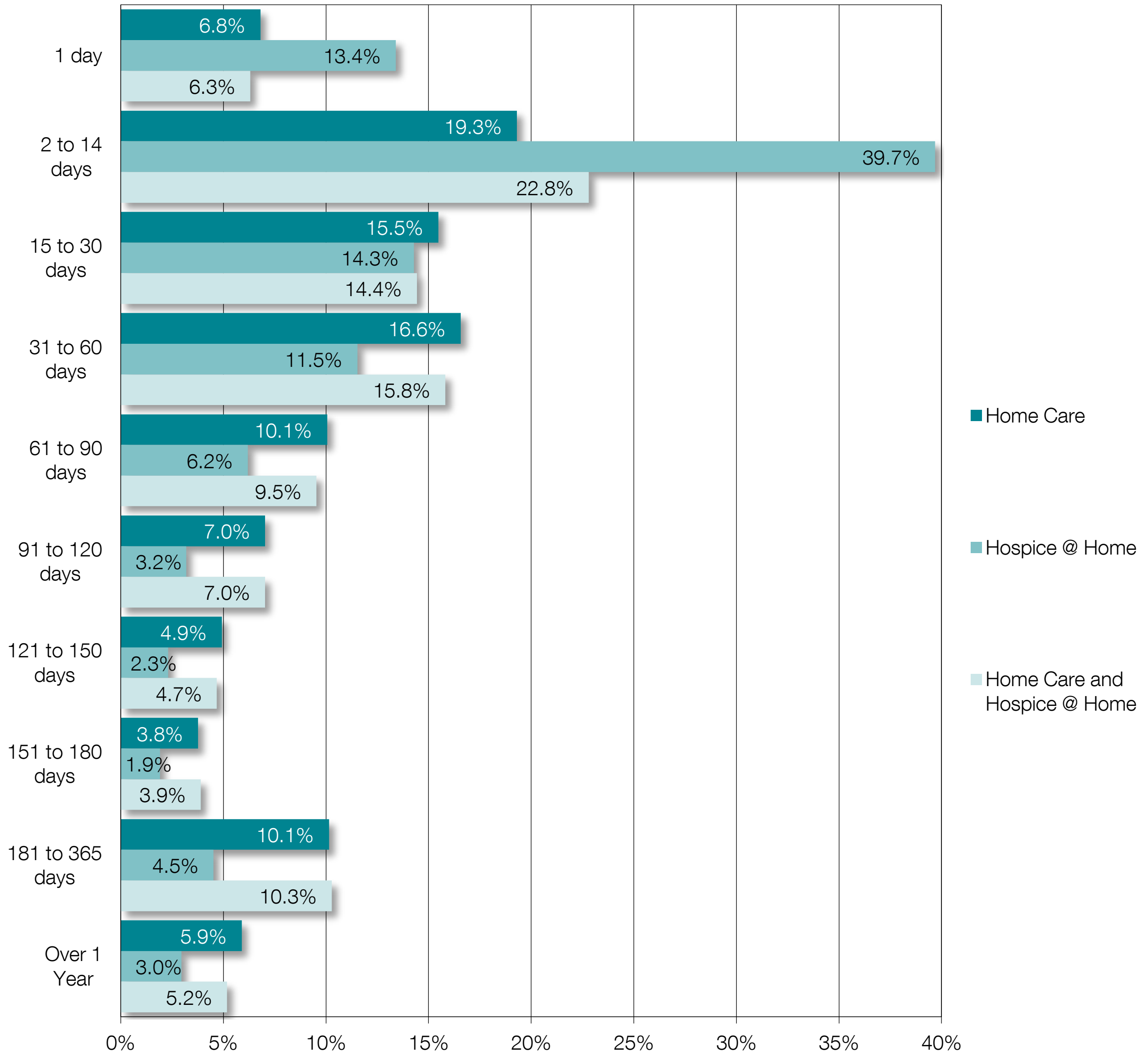
Data from Table 55 on page 64

4.4.2 Length of care in Community Services

The length of time people were under the care of the services was given by 80 Home Care teams, 35 Hospice @ Home teams and 30 combined teams. Chart 14 shows the breakdown of length of care for all three types of service.

- The majority had a length of care of fewer than 60 days
- More than two thirds of people in Home Care (68%), more than three quarters of people for Hospice @ Home (85%) and more than two thirds of Combined (69%) had a length of care of fewer than 90 days
- The average length of care for the 80 Home Care services that responded ranged from 14 days to 405 days with a mean of 114.8 days and a median of 96.2 days. 68% of patients were looked after for fewer than 3 months and 16% for more than 6 months
- For the 35 Hospice @ Home services that responded, the average length of care ranged from 3.6 days to 519 days with a mean of 51 days and a median of 32 days. 85% of patients were looked after for fewer than 3 months and 8% for more than 6 months
- The 36 combined services that responded had an average length of care of 108 days; this ranged from 10.8 days to 460 days with a mean of 113 days and a median of 110 days. 69% of patients were looked after for fewer than 3 months and 16% for more than 6 months

Chart 14: Community Services – length of care



Data from Table 58 on page 65

4.4.3 Deaths and discharges

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

Deaths accounted for 63% of the patients no longer receiving care from the Home Care teams, 73% of those cared for by H@H teams and 71% for combined teams.

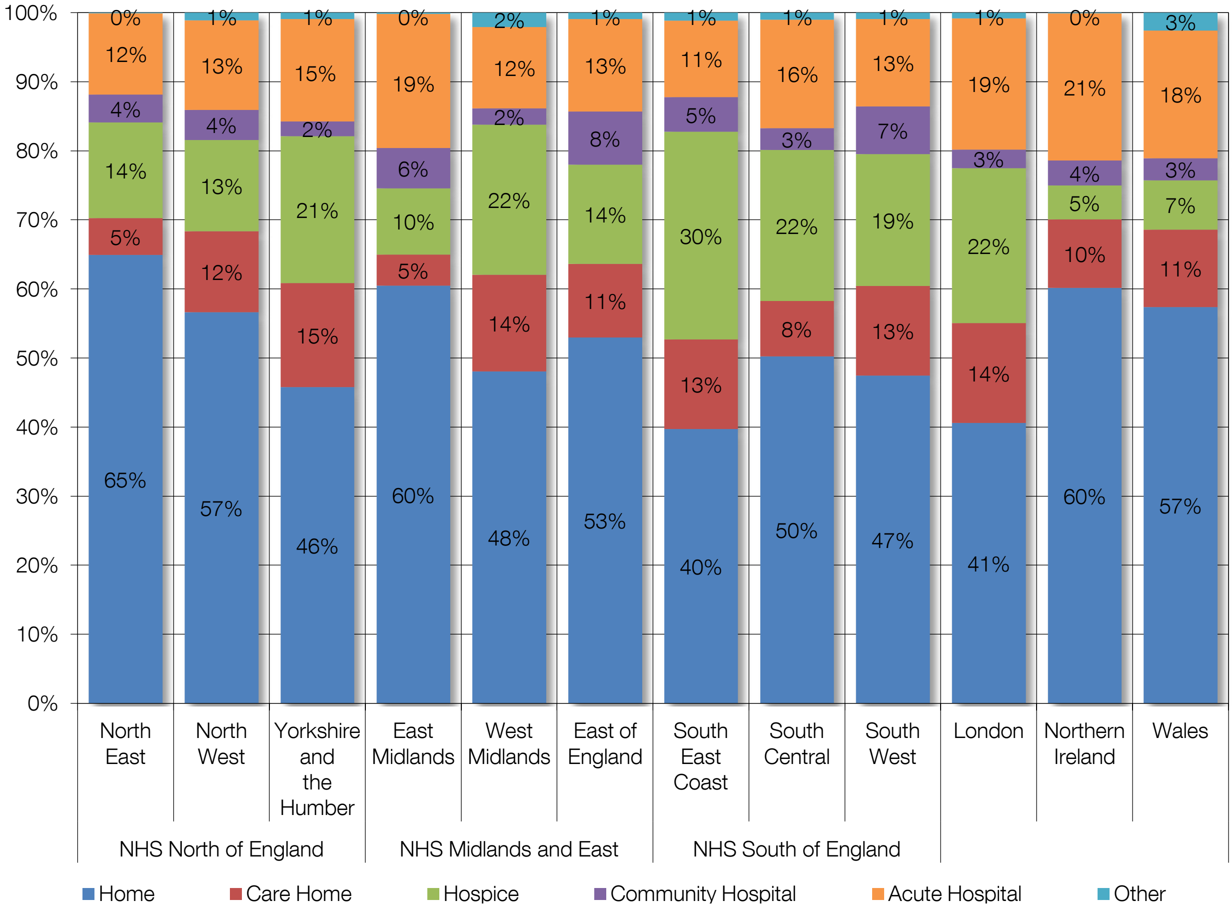
For the Home Care teams, home deaths accounted for 30% of new patients, ranging from 8% to 50%. For H@H teams there was a higher percentage of home deaths (57%), ranging from 29% to 84%. For Combined teams there were 38% home deaths, ranging from 9% to 86%.

As in the case of Day Care services, it might be expected that in the majority of cases the number of deaths and discharges would be approximately the same as the number of new patients. This assumes that there are only a small number of re-referrals of patients who had previously been discharged within the same or the previous year, and that the staffing provision does not alter. However, for the Home Care teams the number of deaths and discharges varied from 29% to nearly two and a half times the number of new patients (247%). For the H@H teams the range was from 31% to 199%, while for the combined teams the range was 67% to 150%. Overall, for the Home Care teams there were 17% more deaths and discharges than new patients. For the H@H team the figure was 6% and for the combined teams the figure was 11%.

4.4.4 Place of death for people receiving care in Community based services

Services were asked to report on the place in which people receiving care died. The response rate varied from 77% to 100%, with a mean of 94%.

Chart 15: Reported place of death for people receiving care in Community based services



Data from Table 60 on page 66

Nearly half the people receiving care in the community (49.8%) died in their home. Less than a quarter (23.9%) died in hospital. This compares with ONS data for all deaths which shows that 21.8% of people died at home and 51.5% in hospital.

4.5 Hospital Support

Hospital support teams work with other healthcare staff to provide specialist palliative care to patients in hospital. In a few services this role may extend into the community. The range of services varies and may include:

- Specialist patient care requiring particular expertise, such as symptom control
- Advice, support and education for patients and carers
- Consultancy and education for other health professionals
- Liaison with palliative care services outside the hospital

Hospital Support 'teams' vary in composition from a single specialist nurse to a consultant-led multidisciplinary group and go under a variety of titles. The team may be based in the hospital but managed by an independent hospice or other specialist unit; there are many different organisational arrangements.

A Hospital Support service involves one or more face-to-face contacts with a patient by hospital support team members, normally taking place during one Inpatient stay. Contact with a patient may or may not follow formal referral. Hospital support staff may also have a substantial workload not directly related to any individual patient.

4.5.1 Referrals and contacts

Each patient received an average of 6.8 contacts during the year, with a range from 1.1 to 37.3 contacts per patient. Of these contacts, 16% were by a doctor (medical consultant or other doctor) and 79% by a clinical nurse specialist.

4.5.2 Face to face contacts

The number of services responding to the face to face contacts this year increased to 111 from 97 in 2010/11. The number of contacts recorded also increased by nearly a fifth, from 360,994 to 424,963 contacts per service in 2011/12 – an average of 3,829 contacts per service. The majority of face to face contacts (79%) were with clinical nurse specialists. See Table 67 on page 68.

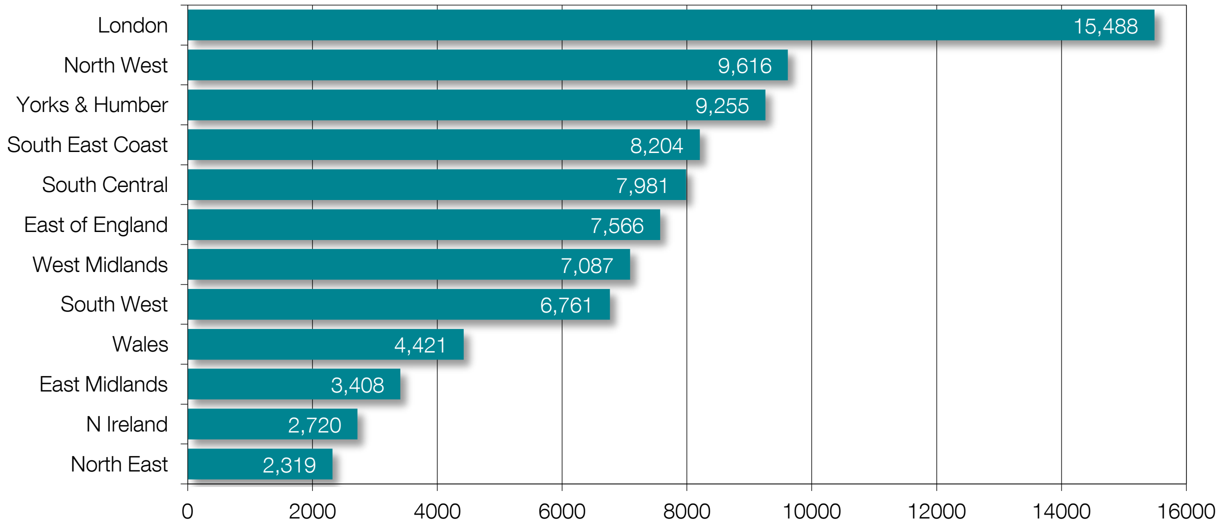
4.5.3 Telephone contacts

A total of 82 services reported the number of telephone contacts, with an average of 1051 telephone contacts per service. Again the vast majority of contacts (89%) were by clinical nurse specialists. See Table 68 on page 69.

4.5.4 Regional variations

As seen in Chart 4 on page 18, London had the highest proportion of its activity (41%) in Hospital Support. Over 15,000 people were reported as being seen in Hospitals in London during 2011/12, 61% more than in the North West – the next highest region.

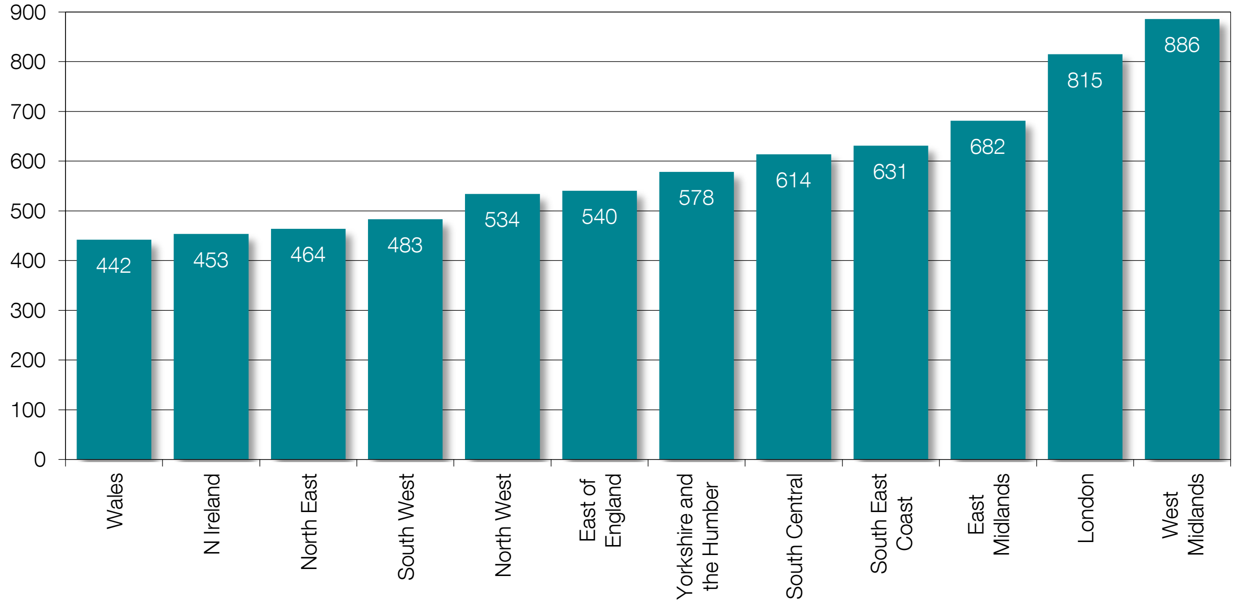
Chart 16: Number of patients receiving Hospital support, by region



Data from Table 69 on page 69

An average of 594 people were seen by each Hospital Support service, ranging from 442 in Wales to 886 in West Midlands. Although London services saw many more people than any other region, the higher number of services in London meant that it ranked second behind West Midlands.

Chart 17: Number of patients seen per organisation, by region



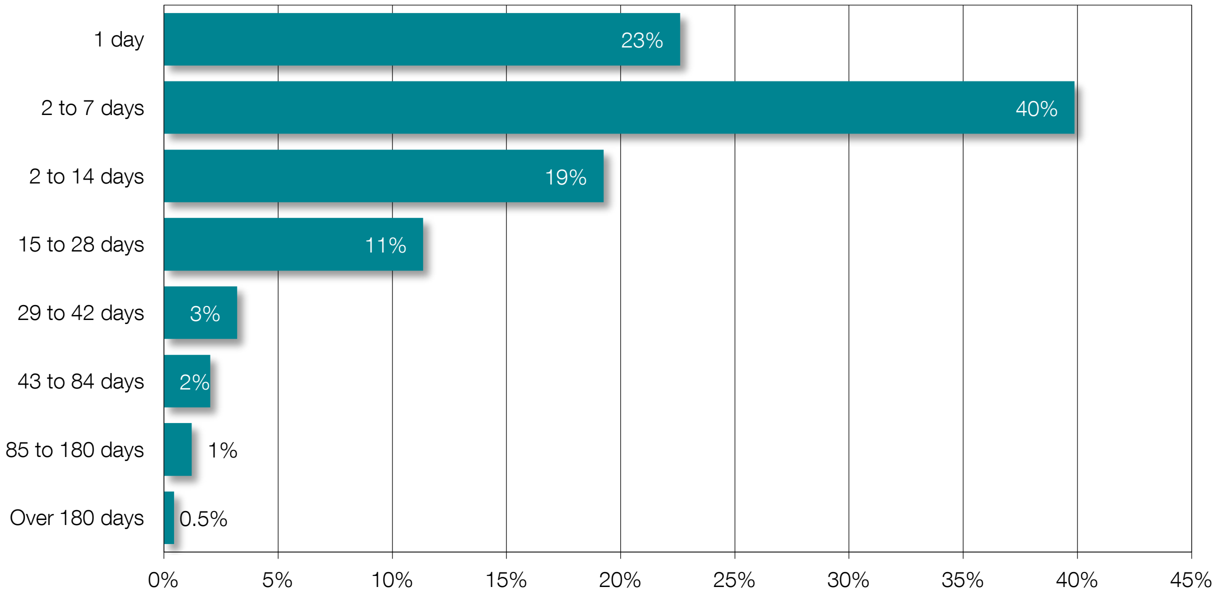
Data from Table 70 on page 69

4.5.5 Length of care

Data on the length of time patients were under the care of the support service show nearly a quarter of patients (23%) were seen only once and over 90% had died or were discharged within four weeks. Just 0.5% remained under care for over six months. The data does not give information as to whether these patients were actively receiving care or whether they simply remained registered with the service until they died.

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

Chart 18: Length of care for Hospital Support



Data from Table 71 on page 70

4.6 Bereavement Support

A Bereavement Support service is provided to relatives, partners or carers of a deceased patient and may include individual counselling, home visits, and group activities. Although similar emotional and psychosocial support is often provided to carers of patients who are close to death, this data set records contacts *after* the death of the deceased patient.

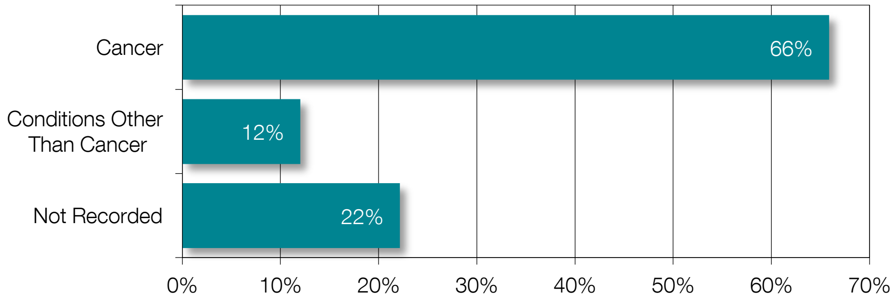
Bereavement Support services are organised with varying degrees of formality. Some are provided quite informally or integrated into the general pattern of services, while others have routine referral, assessment and discharge procedures. Services are encouraged to develop procedures to ensure that this important aspect of their workload is properly recorded.

4.6.1 Primary diagnosis of deceased relative or friend

A total of 110 Bereavement Support services reported the primary diagnosis of the deceased for new clients.

Excluding the not-recorded figures, 85% had cancer and 15% a diagnosis other than cancer. The number of "not-recorded" rose slightly from just under a fifth of new clients (19.7%) to just over (22.1%).

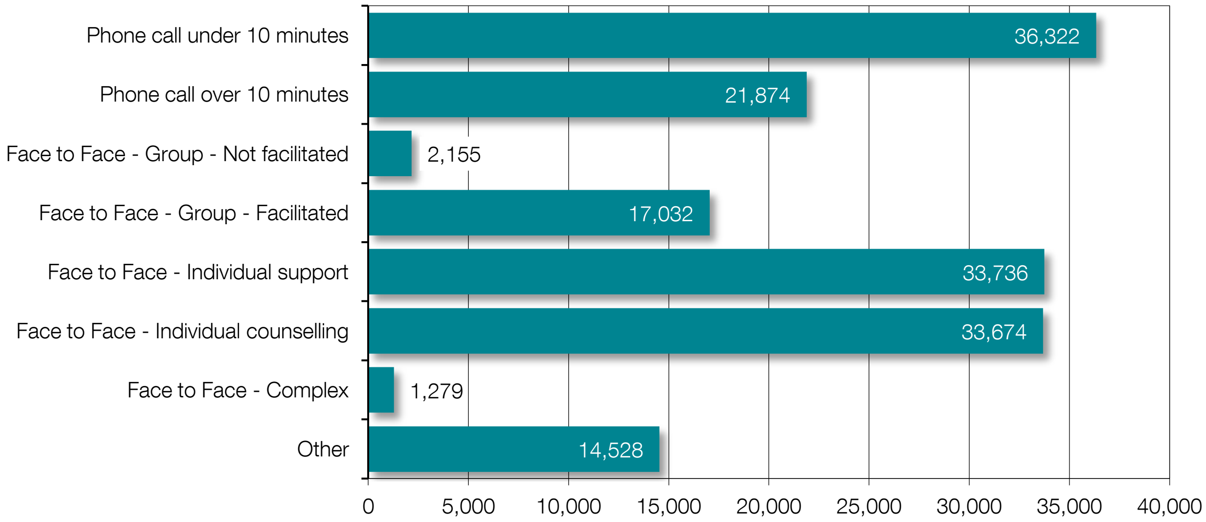
Chart 19: New Bereavement Support clients – primary diagnosis of deceased



Data from Table 74 on page 71

4.6.2 Contacts with bereaved

Chart 20: Number of contacts with bereavement clients

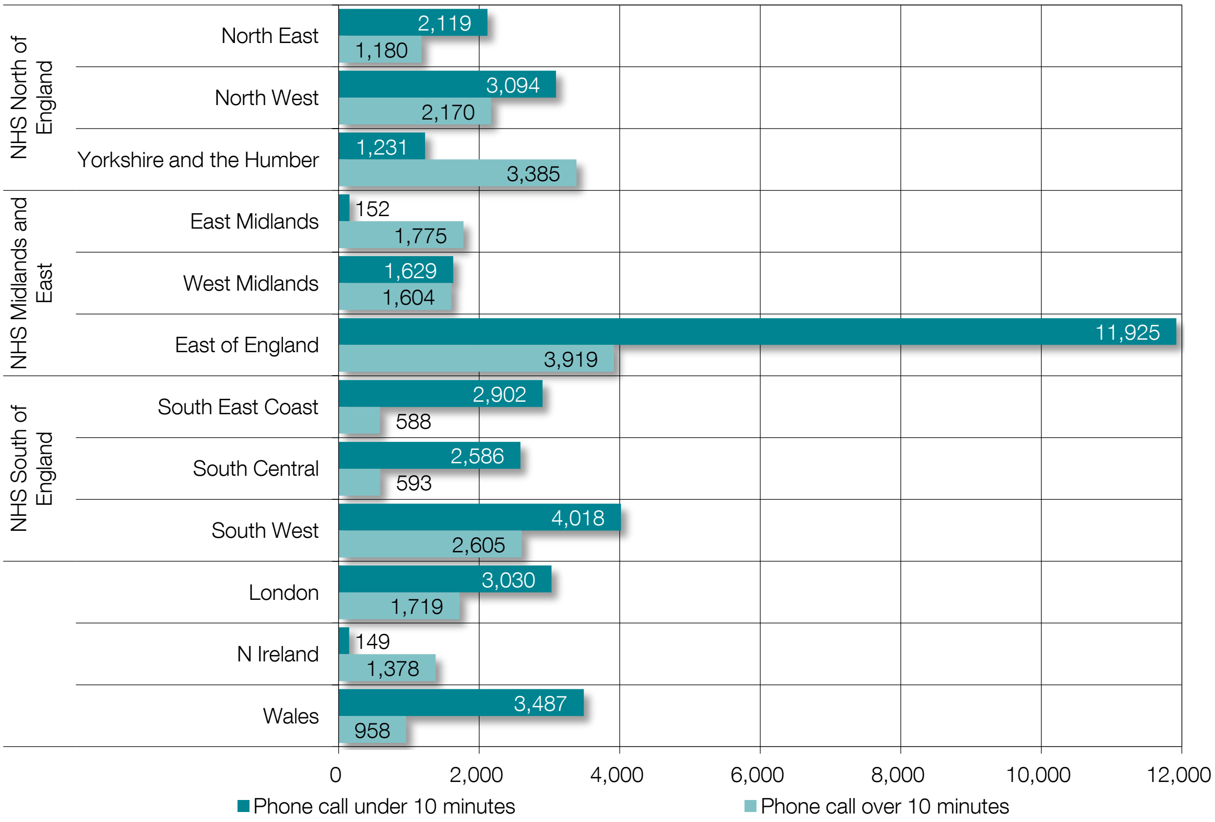


Data from Table 77 on page 72

4.6.2.1 Telephone contacts

The number of calls under 10 minutes varied widely, from 149 calls in Northern Ireland to nearly 12,000 in East of England.

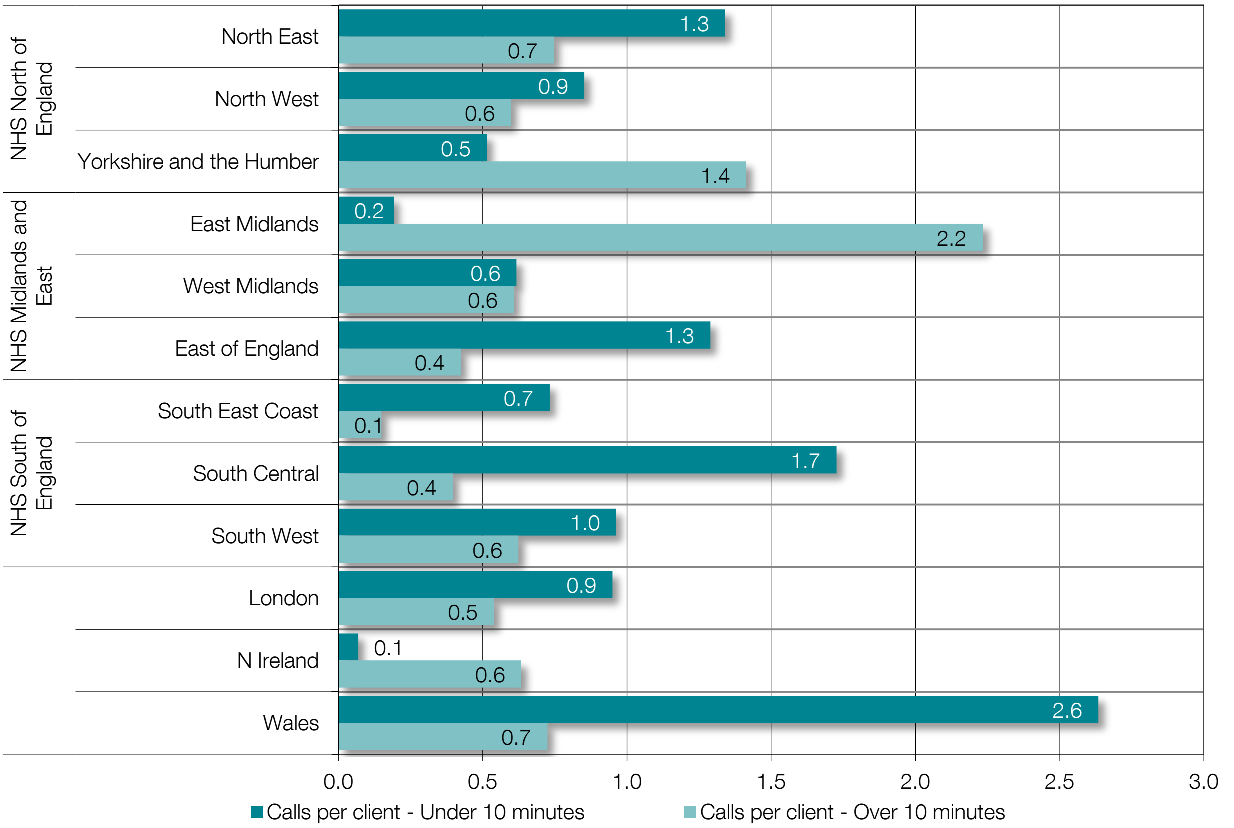
Chart 21: Number of telephone contacts by region



Data from Table 78 on page 72

Of the fifteen services who returned data from East of England, twelve reported on telephone contacts under 10 minutes. Of these, the lowest figure reported was 25 calls, while the highest was 2,687. (Mean 994, median 775.) The service making the most number of calls under 10 minutes was in Wales, with over 3,000 calls.

Chart 22: Calls per client by region



Data from Table 78 on page 72

Although East of England had the highest total number of calls under 10 minutes, it had the joint third highest calls per client.

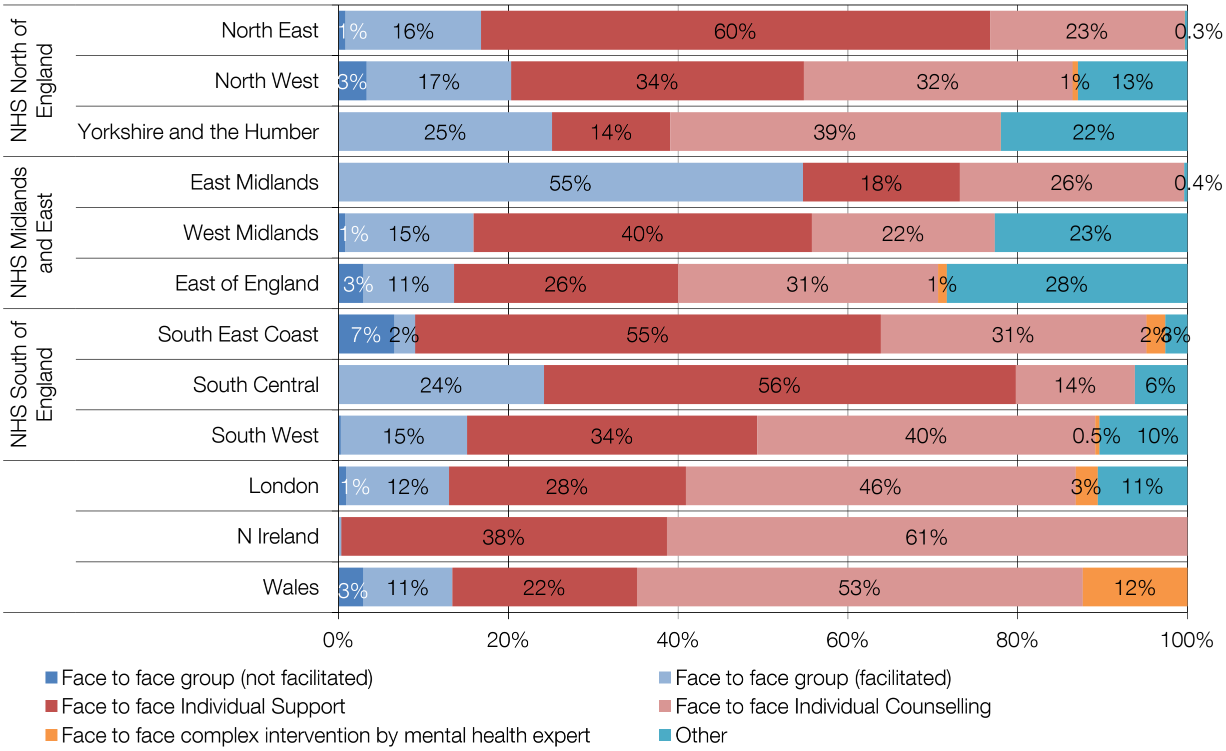
4.6.2.2 Face to face contacts

Data is collected on six different types of contacts, plus an "other" category.

Table 4: Bereavement support face to face contact types

Contact type	Description
Face to face - group - not facilitated	Mutual support group without a facilitator
Face to face - group - facilitated	Mutual support group with a facilitator
Face to face - individual support	One to one support with a trained and supervised person
Face to face - individual counselling	One to one support with a trained and professionally accredited person
Face to face - complex	A complex intervention by a mental health specialist
Other	Any other kind of contact, such as email

Chart 23: Face to face and "other" contacts by region



Data from Table 79 on page 73

- Over half of East Midlands' reported contacts were in groups
- No other region had more than a quarter of contacts in groups
- Northern Ireland had responses from just 2 services, with only 3 people attending a group
- The majority of services provided face to face services mostly with individuals

4.7 Outpatient services

An Outpatient clinic is an administrative arrangement which allows patients to see a doctor or other health care professional for consultation, investigation and minor treatment. Clinics do not necessarily have to be held at regular intervals or in the same location. A clinic usually lasts for one morning or afternoon.

Attendance at an Outpatient clinic is usually by appointment, but patients may sometimes arrive and be seen without prior notice. Some clinics, such as 'walk-in' clinics, are designated wholly or partly for patients without prior appointments. It is good practice for a patient arriving without an appointment to be allocated a time by the receptionist.

4.7.1 Clinics and attendances

Specialist palliative care clinic data were reported by 103 services (68%), although joint clinics were only reported on by 24 services (16%)

(A joint clinic is one held with non-palliative care specialists, rather than a clinic where a number of palliative care specialists are seeing a patient at the same time.)

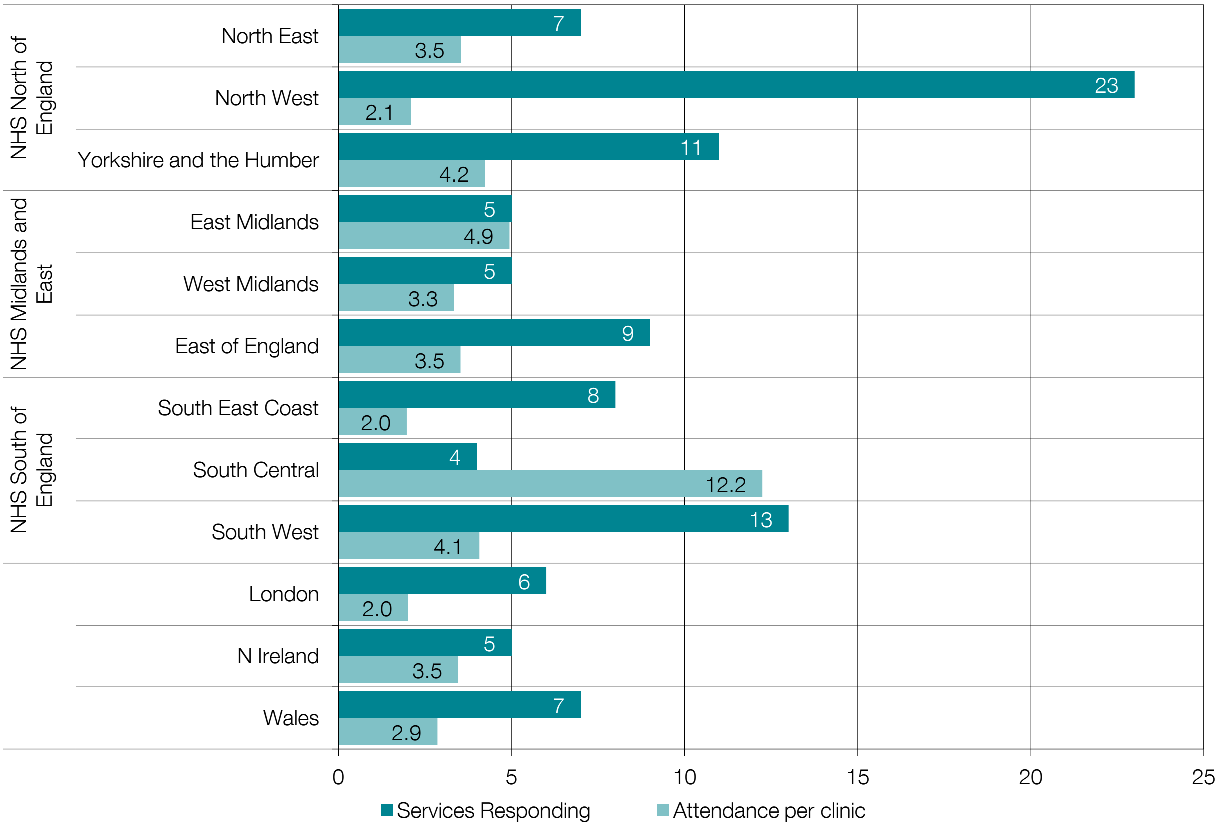
A fifth of specialist palliative care clinics (20%) were led by a clinical nurse specialist, 19% were led by a palliative care medical consultant, 16% by a complementary therapist and 16% by a nurse other than a clinical nurse specialist.

- The number of clinics recorded increased slightly (30,942 up to 31,187)
- The number of joint clinics recorded dropped by over two thirds (4,325 down to 1,294)
- First and follow-up attendances recorded dropped slightly (by 18% and 8%, respectively)

The number of services reporting clinic data varied by region, from 4 in South Central to 23 in the North West.

The average number of people attending clinic also varied, from 2.0 in South East Coast and London to 12.2 in South Central.

Chart 24: Outpatient services responding and average attendance per clinic



Data from Table 87 on page 76

4.7.2 Non-clinic contacts

The number of services reporting on face to face contacts increased from 81 to 86, and the number of face to face contacts increased from 43,426 to 52,553 (21%). Telephone contacts increased by 4,337 (19%)

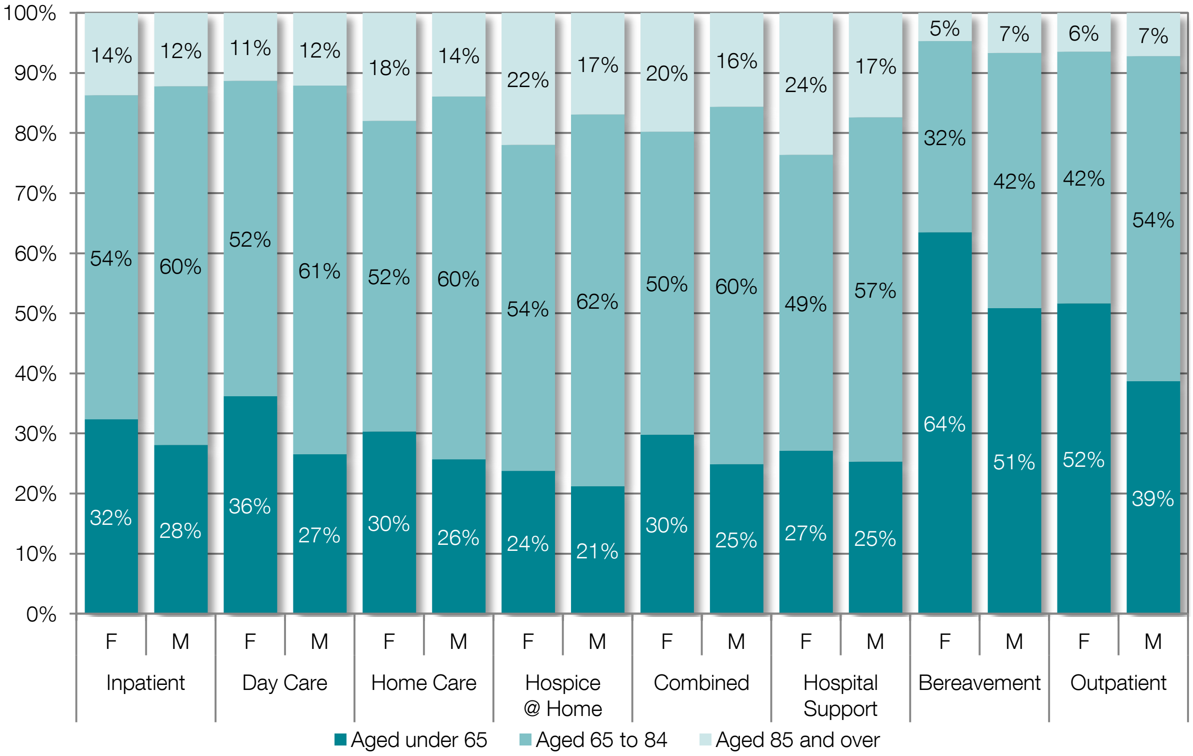
- The breakdown of health professionals seen by patients changed considerably this year. This could be down to improved recording of contacts or changes in working practices. With only three years of data, it is too early to infer any trends
- Contacts are much more widely spread amongst the different health care professionals in Outpatients, which perhaps reflects the nature of the setting
- There has been a considerable increase in the number of clinical nurse specialist face to face contacts this year, from 3,194 to 12,785 (up 300%), while telephone contacts increased by 31% (1,038)
- Clinical nurse specialists now account for nearly a quarter of contacts (24%), although other nurses still account for 25% of telephone contacts (16% for CNS)
- Physiotherapists’ face to face contacts continued to increase, by 2,284 this year (44%). Their telephone contacts also increased, by 363 (23%)

4.8 Characteristics of people accessing specialist palliative care services

4.8.1 Age and sex by setting

Data from the returns of the individual services was used in Chart 25 to compare the different services with regard to age and sex of patients cared for.

Chart 25: Breakdown of age by setting and sex



Data from Table 88 on page 77

For most settings, the majority of people attending are in the 65 to 84 year age band, the exceptions being Bereavement Support and women in Outpatients, where over half those attending were aged under 65. For all settings the proportion of women aged under 65 was higher than the proportion of men, while this was reversed for the 65 to 84 year age band.

The age, sex and ethnicity of people referred to under Bereavement Support are of the bereaved clients, rather than the deceased. Many bereavement services report difficulties in asking clients for their date of birth and ethnicity. There has again been a further increase in the number of clients whose details have been recorded for Bereavement Support (89% for age and 87% for ethnicity this year compared to 86% and 81% last year); this is still significantly lower than other services. We would encourage services to review how they might ensure more detailed data collection.

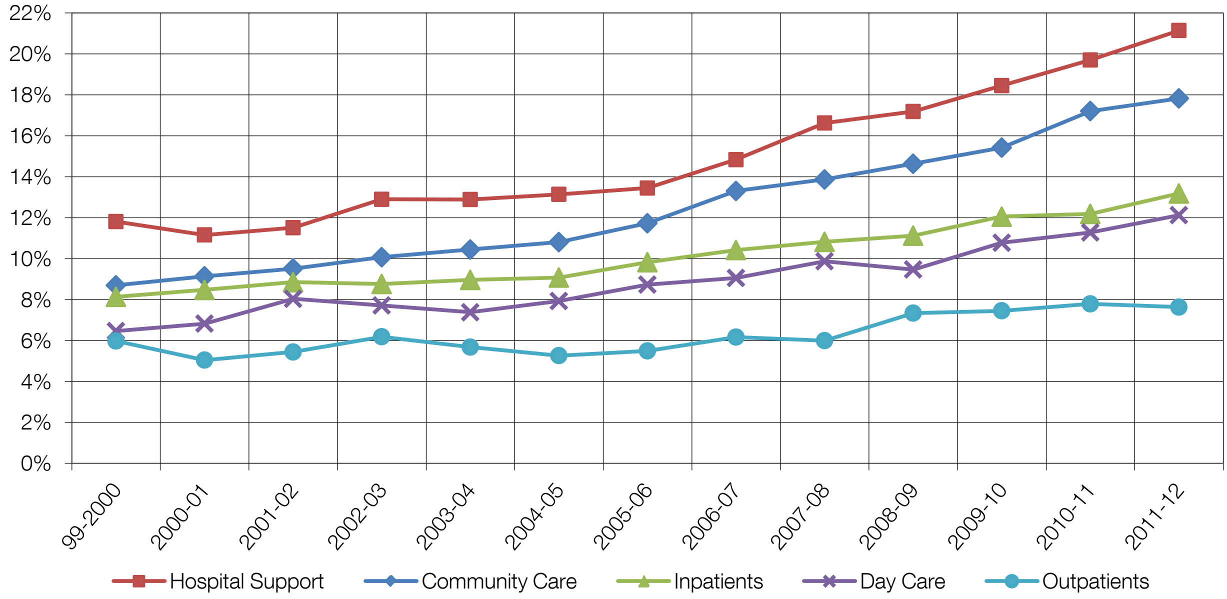
The proportion of people aged between 65-84 who access Bereavement Support is higher for men than for women (49% compared to 37%) and similar to the proportion of men aged under 65 years (51%). A much higher proportion of women aged under 65 accessed Bereavement Support (64%).

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

4.8.2 People aged 85 and over – trend data

Chart 26 shows the percentage of people accessing specialist palliative care services since 1999-2000, who are sometimes called the “oldest old”. Across all services, 14.8% of people accessing specialist palliative care are the oldest old, compared to 8.8% in 2000.

Chart 26: Percentage of people in each setting who were aged 85 and over



Data from Table 89 on page 77

There was a particular spur from 2005/06, with the steepest increase amongst Hospital Support and Community teams. Hospital Support rose from 13.4% in 2005/06 to 21.1% in 2011/12. Community services rose from 11.7% in 2005/06 to 17.8% in 2011/12.

This is encouraging given that we know that the oldest old are most likely to experience frailty, cognitive impairment and multiple conditions, leading to more falls and complications and resulting in increased hospital admissions. The oldest old are nearly 10 times more likely to have an emergency admission than people aged 20-40.[1]

High-quality services in the community are absolutely essential in ensuring people can be cared for in the place that they want to be, until the end of their lives. Access to social care and support, as well as nursing, is an important part of the picture for community services. NCPC, together with Help the Hospices, Macmillan Cancer Support, Marie Curie Cancer Care, the MND Association, and Sue Ryder, is campaigning for free social care for people approaching the end of life.

The PRISMA Survey of Preferences in 2010[2] showed that 45% of people aged over 75 years would prefer to die at home, and 41% in a hospice. Just 6% expressed their preference to die in hospital.

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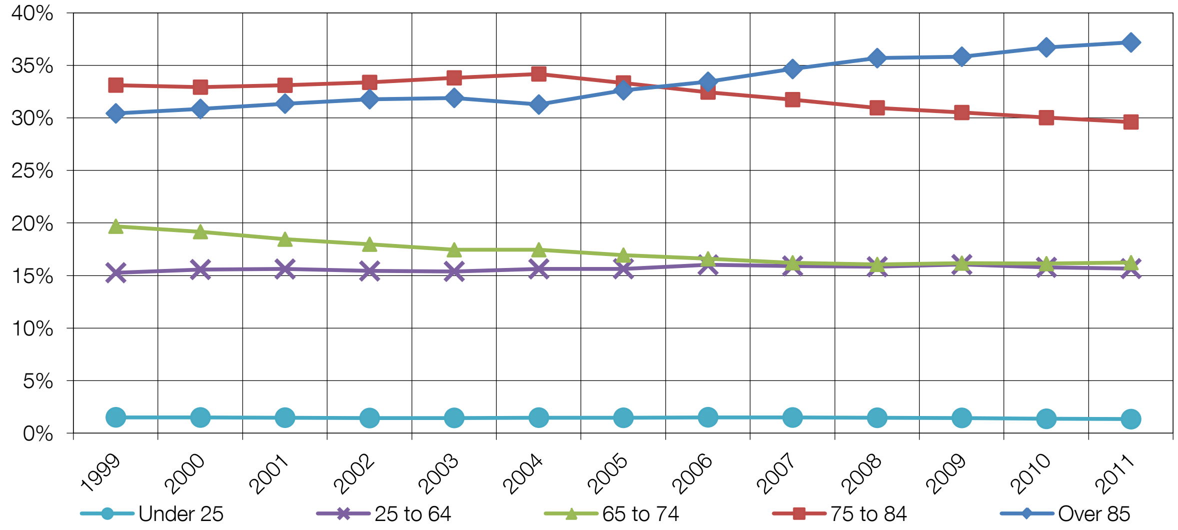
[1] **Trends in emergency admissions in England 2004–2009: is greater efficiency breeding inefficiency? Nuffield Trust, July 2010.**

[2] **Local preferences and place of death in regions within England 2010 Gomes et al, August 201**1

Over the same period, the proportion of oldest old dying increased from 30.4% to 37.2% while the proportion of deaths between 65 and 84 years old fell. The proportion of under 65s dying remained relatively constant.

Chart 27: Breakdown of deaths by age band

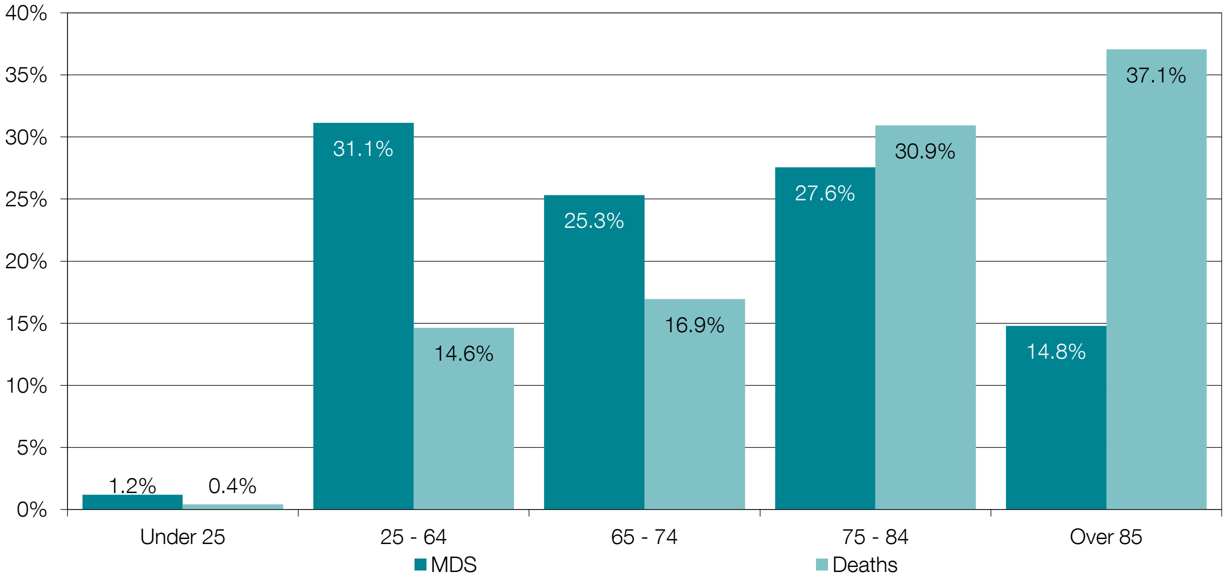


Data from Table 90 on page 78

4.8.3 Age of people accessing palliative care

Comparing data on the breakdown of age and sex in the Minimum Data Set with data on deaths for the United Kingdom in 2011,[3] Chart 28 shows that younger people (aged under 75) have a disproportionately higher access to palliative care for the number dying than the oldest old.

Chart 28: Comparison of age of people accessing palliative care with recorded deaths*



*Note: Mortality data excludes deaths from external causes

Data from Table 91 on page 78

This raises important issues about people's needs and access to services. People aged under 75, particularly those aged 25 to 64, are more likely to receive access to specialist services than people aged 85 and over. This should be read in the context of Deaths in Older Adults in England[4] which showed that proportions of deaths from cancer decreased with increasing age (85 and over), in contrast to deaths from cardiovascular disease, 'other' causes and respiratory disease which increased with age. The reasons for this inequity by age may therefore be as much to do with access to services by people with conditions other than cancer, as to whether "older frailer" people need access to specialist services. However it is

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[3] ONS – VS3 Mortality by cause – 2011 registrations to 2011 boundaries (excluding external causes)

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

recommended that commissioners and providers check the age profiles of the local population against those accessing services and consider the reasons for any inequities.

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

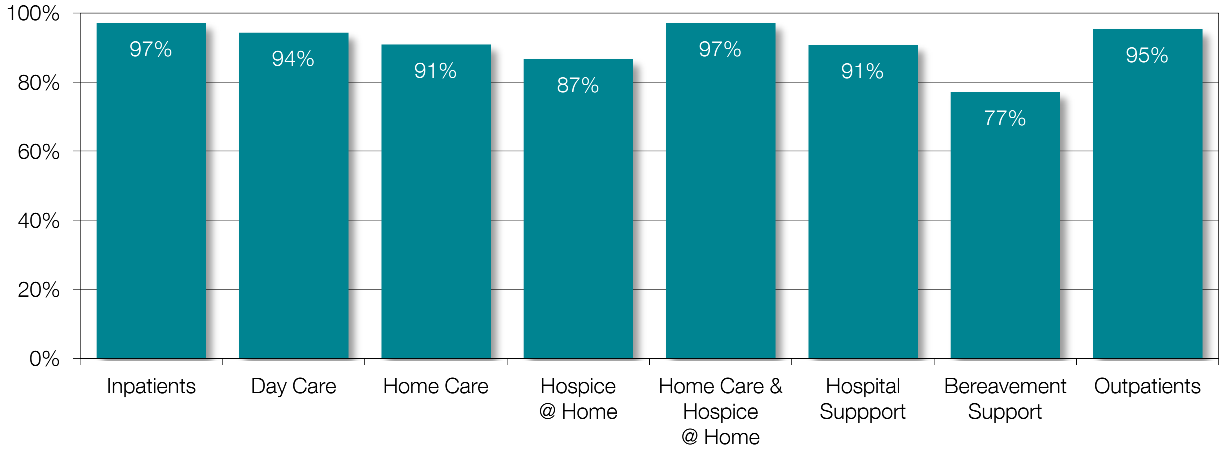
4.8.4 Young adults in transition

Reported numbers of young adults accessing adult specialist palliative care services are low. For examples Table 41 to Table 43 (pages 59-60) report that 147 16-24 year olds accessed Home Care, 21 accessed Hospice@Home, and 46 accessed Combined services. Adult providers are strongly encouraged to consider how they can ensure their services are available and appropriate for young adults and how they might be able to work in partnership with local children's services and other agencies to achieve that. Details about NCPC's Transitions partnership with Together 4 Short Lives and Help the Hospices, including research findings from the STEPP research project by the University of York, can be accessed at **http://www.ncpc.org.uk/transitions**

4.8.5 Ethnicity

Palliative care services are asked to categorise their patients according to the 17 ethnic groupings used by the Department of Health. On average, 91% of respondents did this. The proportion varied however, from 77% for Bereavement Support to 97% for Inpatients and Combined services.

Chart 29: Percentage of units returning ethnicity data for new patients



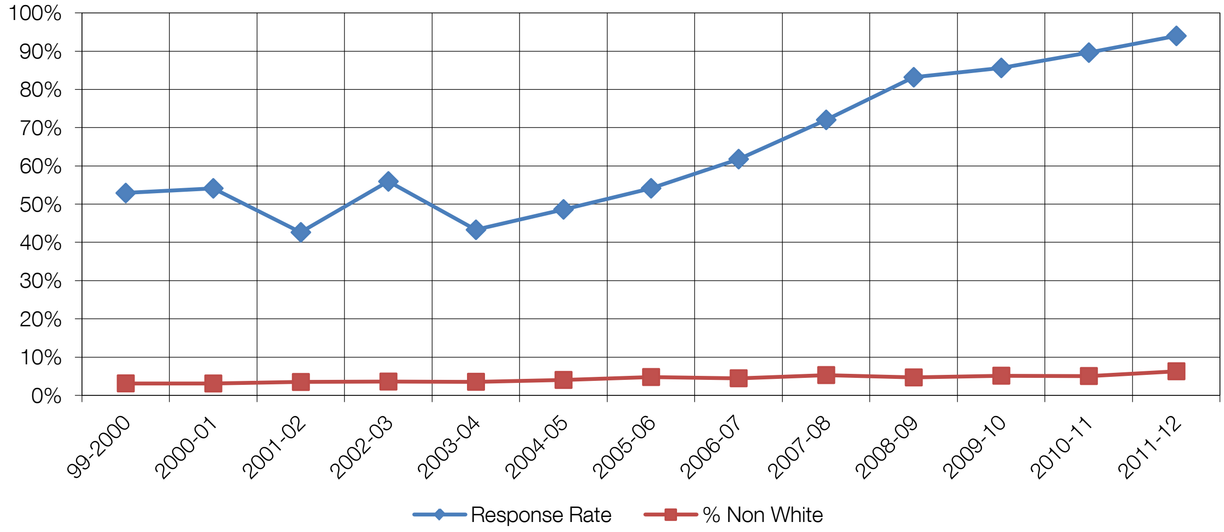
Data from Table 92 on page 78

It was found that, on average, 6.2% of patients were described as non-white, comprising 1.5% black (African, Caribbean or other), 1.1% Indian, Pakistani or Bangladeshi, 1.5% as mixed race, with 1.4% of other ethnicity including Chinese.

Table 16 (Page 50) also shows that the number of ethnic minority patients is increasing. A total of 14% of the population are reported as being of a non-white ethnicity[5].

Prior to the 2008/09 collection, ethnicity was collected for the “All patients” form. With the revised MDS, the “All Patients” form was no longer used and ethnicity was collected across all settings. The overall response rate has continued to rise, as shown in Chart 30, although the rate of increase has slowed slightly.

Chart 30: Ethnicity trends



Data from Table 93 on page 79

Although the response rate to the ethnicity questions has improved, and the percentage of non-white patients is increasing, a large proportion of non-white patients had been recorded as ‘Other’. This ranged from 15.2% in Bereavement Support, up to nearly half (49.0%) of non-white patients in Combined Home Care & Hospice @ Home services. In the wider population, of those who identify themselves as non-white,

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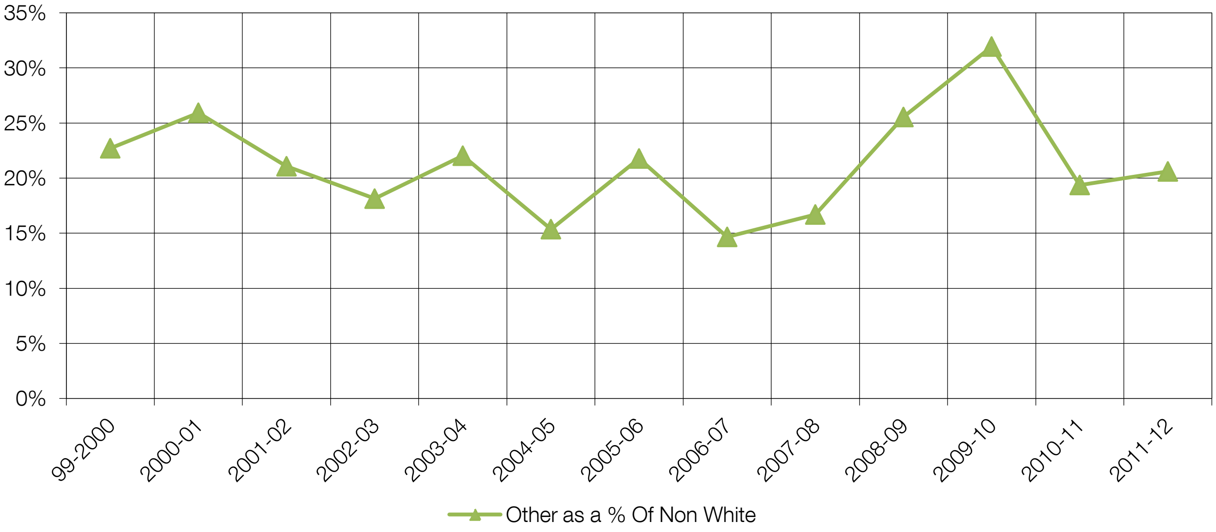
[5] **Ethnicity and National Identity in England; ONS December 2012.**

7.2% are in the category "non-white other"[6] but an average of 21% are being recorded as such by specialist palliative care services.

Chart 31: Other as a percentage of "non-white" ethnicity – trend



Data from Table 93 on page 79

As can be seen in Chart 31, there was a gradual downward trend in the percentage of people described as "Other non-white" until the revised MDS was introduced, when numbers increased to 32% for 2009/10. These have now dropped to 21%, but the trend appears to be upwards. Too many patients are still being classified as 'non-white other', possibly because staff members are noting that the person is physically not white, but not recording the person's actual ethnicity.

We **strongly recommend** that services urgently review their procedures for recording ethnicity and take steps to more accurately classify according to the Department of Health's 17 ethnic groupings. Only by doing so can specialist palliative care providers be confident that ethnic minority groups have equal access to their services. Previous studies have suggested that this is currently not the case.[7] Resources exist, for example posters from the Dying Matters coalition (**www.dyingmatters.org**), which services can use to try to open up access to all sections of their local communities.

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[6] **2011 Census**; ONS

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

4.9 Diagnosis

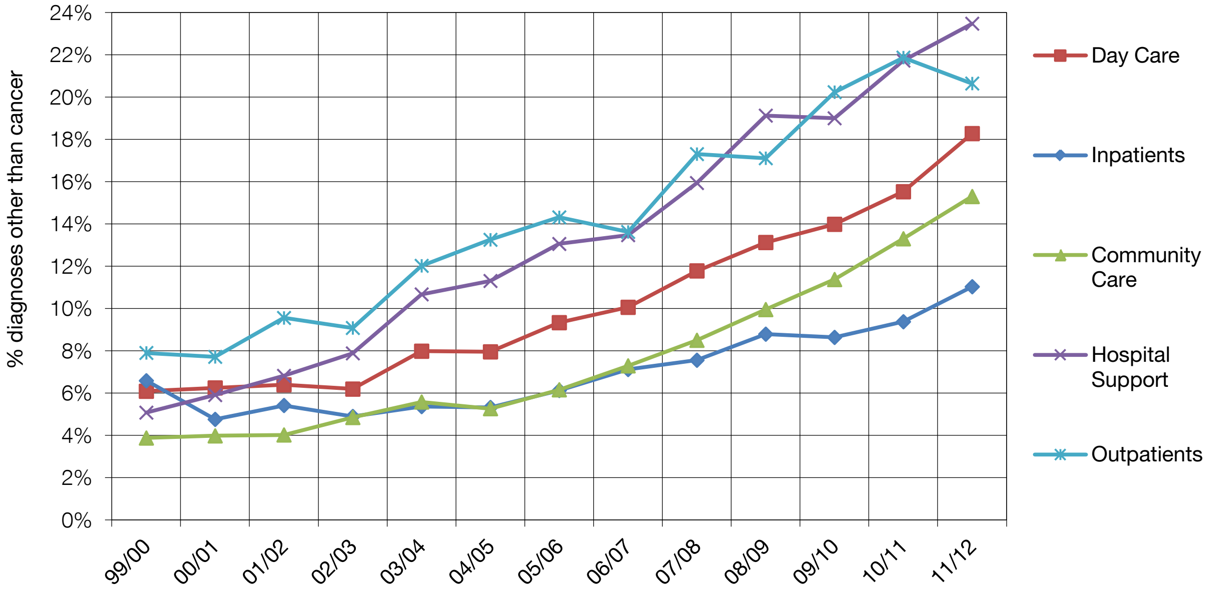
The MDS collects information on the primary diagnosis of people receiving specialist palliative care. The majority of patients receiving palliative care have a cancer diagnosis, although over the last 12 years there has been an overall increase in both the percentage and the number of people receiving palliative care with diagnoses other than cancer.

4.9.1 Diagnoses other than cancer

NCPC's Policy Unit (now the Public & Parliamentary Engagement 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 32 illustrates, the biggest changes have occurred in the last 5 or 6 years.

The most striking increases are in Hospital Support and Outpatients where non-cancer diagnoses now account for over one fifth of all diagnoses. Day Care and Community care also show a steady increase in the proportion of non-cancer diagnoses with 18% and 15% respectively. For specialist palliative care Inpatient units the proportion of patients with a diagnosis other than cancer has increased from 3% (in 1997-98) to 11%.

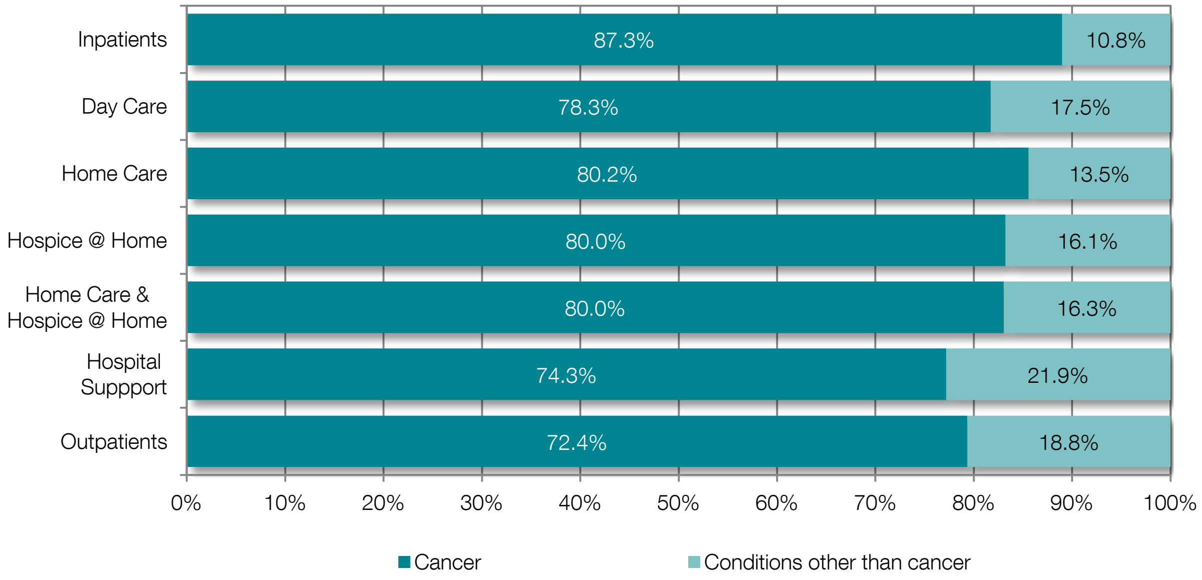
Chart 32: Growth in diagnoses other than cancer



Data from Table 96 on page 80

Chart 33 shows the proportions of people with conditions other than cancer seen by the different services. It is seen that Hospital Support services have the highest percentage at 22%. This is still a low figure, as cancer accounts for about 28% of all deaths.[8]

Chart 33: Proportions of people with cancer and conditions other than cancer, by setting



Note: Excludes people with no recorded diagnosis

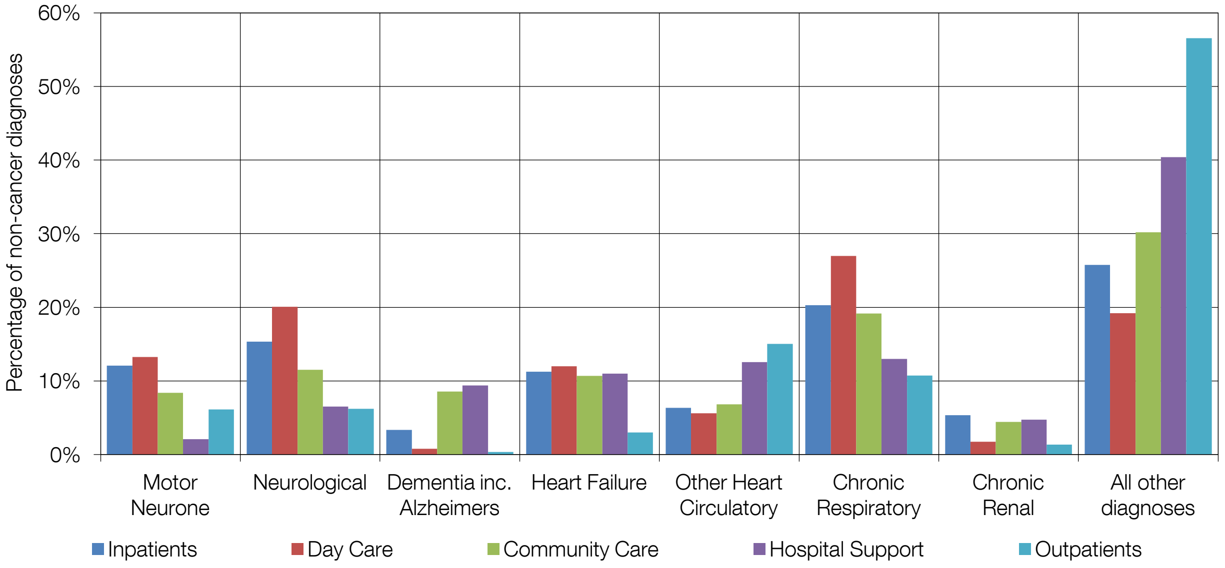
Data from Table 95 on page 79

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

It would be useful to explore whether it is appropriate that a higher proportion of people with diagnoses other than cancer is found in Day Care than in Inpatient settings, or whether it is an indication of further work needed in Community Care and Inpatient settings.

A breakdown of diagnoses other than cancer can be seen in Chart 34.

Chart 34: Breakdown of diagnoses other than cancer, by setting



Data from Table 97 on page 80

Among diagnoses other than cancer, the proportion recorded as “other” has decreased slightly from 39% to 37%, with a range from 19% for Day Care to 45% for Outpatients. Anecdotal evidence suggests that many of the outpatient figures may be lymphoedema patients. We still **strongly recommend** that conditions

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[8] **Cancer in the UK;** Cancer Research UK; May 2012.

are accurately coded to reflect the conditions being referred and to demonstrate the importance of commissioning services that meet local population needs.

There is debate over the accuracy of the coding of MND diagnoses with regard to the recording of mortality figures by the Office of National Statistics (ONS). Deaths of people with progressive supranuclear palsy (PSP) may have been incorrectly coded as Motor Neurone Disease (MND).[9]

Dementia patients accounted for between 0.4% and 10.4% of primary diagnoses other than cancer, 0.09% to 2.02% of all patients with a diagnosis. Although a slight increase on last year, national figures show dementia is mentioned on death certificates for 15% of all deaths.[10] The number of people who die with dementia, however, is much higher at 1 in 3 people over 65.[11] The MDS is not set up to collect secondary diagnosis at present, so services are **strongly recommended** to track this locally.

Despite the low figures, dementia patients appear to be mainly cared for in the most appropriate settings; Inpatients, Community or Hospital Support.

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.

Table 5: Data for the different countries 2011/12

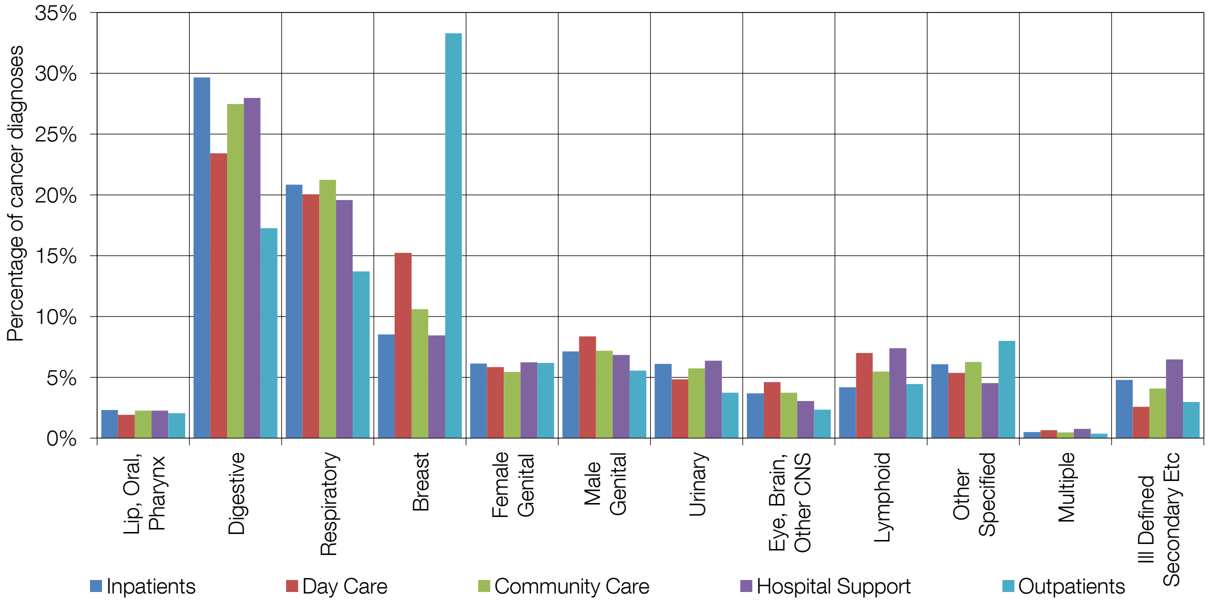
	Country	Inpatients	Day Care	Community Care	Hospital Support
Diagnosis other than cancer	**England**	11%	18%	14%	22%
	N Ireland	6%	14%	21%	16%
	Wales	7%	12%	18%	16%

4.9.2 Cancer Diagnosis

The different types of cancer diagnoses can be seen in Chart 35. 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 35: Breakdown of cancer diagnoses by setting



Data from Table 94 on page 79

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

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

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

5 Appendix

Providing detailed results for each service type based on the latest MDS data

5.1 Response Rates

Table 6: Responses by region

		Returns	Total
NHS North of England	**North East**	15	38
	North West	51	79
	Yorkshire & the Humber	36	46
NHS Midlands and East	**East Midlands**	14	25
	West Midlands	25	43
	East of England	32	46
NHS South of England	**South East Coast**	24	30
	South Central	22	31
	South West	24	32
	London	28	47
	N Ireland	10	19
	Wales	22	30
	Overall	303	466

Table 7: Inpatient response rate – number of beds

		Total Beds	Reported Beds
NHS North of England	**North East**	123	81
	North West	416	356
	Yorkshire & the Humber	339	257
NHS Midlands and East	**East Midlands**	128	67
	West Midlands	239	173
	East of England	297	207
NHS South of England	**South East Coast**	249	218
	South Central	235	163
	South West	252	182
	London	350	230
	Northern Ireland	69	66
	Wales	151	80

Table 8: Response rate trend

	01/02	02/03	03/04	04/05	05/06	06/07	07/08	08/09	09/10	10/11	11/12
Inpatient	77%	79%	77%	84%	87%	84%	87%	76%	79%	76%	75%
Day Care	80%	77%	76%	79%	84%	87%	83%	75%	73%	72%	70%
Community	59%	62%	58%	61%	65%	73%	73%	71%	69%	71%	62%
Hospital Support	45%	49%	47%	47%	57%	61%	61%	59%	54%	57%	56%
Bereavement	56%	58%	55%	58%	63%	63%	62%	50%	47%	49%	49%
Outpatient	60%	58%	57%	55%	58%	59%	56%	51%	47%	50%	49%
Overall	66%	68%	68%	69%	75%	80%	78%	66%	62%	68%	65%

Table 9: Service management by units responding

Management	Independent	NHS	Total
Inpatients	112	29	141
Day Care	122	20	142
Home Care	52	47	99
Hospice @ Home	42	3	45
Combined	26	9	35
Hospital Support	18	123	141
Bereavement Support	110	21	131
Outpatients	97	55	152

Table 10: Service management by new patient numbers

Management	Independent	NHS	Response
Inpatients	83%	17%	141
Day Care	89%	11%	142
Home Care	58%	42%	99
Hospice @ Home	98%	2%	45
Combined	74%	26%	35
Hospital Support	8%	92%	141
Bereavement Support	92%	8%	131
Outpatients	73%	27%	152

Table 11: Response by setting and service management

	Independent		NHS	
Management	**Returns**	**Total**	**Returns**	**Total**
Inpatients	112	140	29	53
Day Care	122	134	20	30
Home Care	52	126	47	151
Hospice @ Home	42	91	3	29
Combined	26	44	9	22
Hospital Support	18	44	123	225
Bereavement Support	110	164	21	98
Outpatients	97	137	55	118

Table 12: Number of specialist palliative care orgaisations, services, deaths and population

		Organisations	Total Services	Deaths[12]	Population (1,000s)[13]
NHS North of England	**North East**	38	108	23,968	2,596
	North West	79	225	61,613	7,056
	Yorkshire & the Humber	46	141	45,465	5,288
NHS Midlands and East	**East Midlands**	25	67	37,634	4,537
	West Midlands	43	112	45,683	5,609
	East of England	46	148	47,184	5,862
NHS South of England	**South East Coast**	30	95	38,857	4,476
	South Central	31	113	30,452	4,177
	South West	32	110	48,054	5,301
	London	47	134	43,108	8,204
	N Ireland	19	55	9,933	1,811
	Wales	30	91	28,286	3,064

Death figures exclude deaths caused by external causes

Table 13: Number of people seen in a specialist palliative care service per 1,000 deaths

		Total Patients	Deaths	Patients per 1,000 deaths
NHS North of England	**North East**	11,439	23,968	477
	North West	42,277	61,613	686
	Yorkshire & the Humber	34,519	45,465	759
NHS Midlands and East	**East Midlands**	14,478	37,634	385
	West Midlands	24,788	45,683	543
	East of England	32,559	47,184	690
NHS South of England	**South East Coast**	30,174	38,857	777
	South Central	26,034	30,452	855
	South West	33,545	48,054	698
	London	38,027	43,108	882
	N Ireland	9,648	9,933	971
	Wales	14,712	28,286	520

Death figures exclude deaths caused by external causes

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[12] ONS – VS3 MORTALITY BY CAUSE – 2011 REGISTRATIONS TO 2011 BOUNDARIES

[13] ONS – Mid-2011 Population Estimates: Quinary age groups for health areas in England and Wales; estimated resident population; Table 12

Table 14: Inpatient beds per region

		Inpatient Units	Beds per unit	Beds per million population
NHS North of England	**North East**	12	10	46
	North West	26	15	57
	Yorkshire & the Humber	23	14	64
NHS Midlands and East	**East Midlands**	7	14	28
	West Midlands	13	16	43
	East of England	23	12	51
NHS South of England	**South East Coast**	15	17	57
	South Central	16	15	57
	South West	16	14	48
	London	18	19	42
	Northern Ireland	6	12	40
	Wales	14	9	50

Table 15: Settings where people were seen in each region

	Region	Inpatients	Day Care	Community Care	Hospital Support	Outpatients
NHS North of England	**North East**	1,472	1,792	2,011	2,319	3,845
	North West	5,730	4,706	14,081	9,616	8,144
	Yorkshire & the Humber	4,740	3,259	14,009	9,255	3,256
NHS Midlands and East	**East Midlands**	1,221	1,950	6,930	3,408	969
	West Midlands	3,314	1,876	10,606	7,087	1,905
	East of England	4,247	2,399	14,067	7,566	4,280
NHS South of England	**South East Coast**	4,514	3,026	10,513	8,204	3,917
	South Central	2,718	1,514	9,885	7,981	3,936
	South West	3,356	1,457	16,329	6,761	5,642
	London	4,082	2,605	12,368	15,488	3,484
	Northern Ireland	1,066	550	3,666	2,720	1,646
	Wales	1,541	920	7,343	4,421	487

Table 16: Ethnicity trend data

	2004/5	2005/6	2006/7	2007/8	2008/9	2009/10	2010/11	2011/12
Response rate	27%	36%	44%	44%	53%	83%	87%	94%
% non-white	3%	5%	5%	6%	6%	5%	5%	6%
“other” as a % of non-white	15%	22%	15%	17%	26%	32%	19%	21%
% not known	4%	8%	8%	11%	23%	26%	23%	24%

5.2 Inpatients

Table 17: Age and sex of inpatients

	New			All		
Age band	**Female**	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	1	1	**2**	2	1	**3**
16 to 18	3	6	**9**	3	9	**12**
19 to 24	28	35	**63**	38	40	**78**
25 to 64	5,030	4,639	**9,672**	6,052	5,414	**11,474**
65 to 74	4,329	4,852	**9,180**	4,989	5,530	**10,515**
75 to 84	4,483	5,331	**9,814**	5,154	6,062	**11,214**
85 and Over	2,270	2,093	**4,365**	2,580	2,374	**4,954**
Not Known	8	5	**13**	8	6	**14**
Total	**16,152**	**16,962**	**33,118**	**18,826**	**19,436**	**38,264**

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

Table 18: Inpatients with a diagnosis of cancer

Diagnosis	New	All
Lip / Oral / Pharynx	664	753
Digestive	8,494	9,642
Respiratory	5,991	6,780
Breast	2,354	2,775
Female Genital	1,719	1,999
Male Genital	1,962	2,319
Urinary	1,760	1,987
Eye / Brain / Other CNS	1,036	1,198
Lymphoid	1,199	1,366
Other (Specified)	1,707	1,974
Multiple	136	168
Ill-Defined / Secondary / Etc	1,371	1,555
Total	**28,393**	**32,516**

Table 19: Inpatients with a diagnosis other than cancer

Diagnosis	New	All
HIV / AIDS	11	11
Motor Neurone	401	535
Other Neurological	429	678
Dementia inc. Alzheimer's	118	148
Heart Failure	410	498
Other Heart Circulatory	226	280
Chronic respiratory	737	898
Chronic Renal	196	237
All Other Non-Cancer	979	1,140
Total	**3,507**	**4,425**

Table 20: Ethnicity of inpatients

Ethnicity	New	All
White British	25,151	29,130
White Irish	545	619
White Other	738	804
Mixed White / Black Caribbean	27	27
Mixed White / Black African	15	20
Mixed White / Asian	14	16
Mixed Other	234	260
Indian	131	145
Pakistani	78	87
Bangladeshi	36	37
Asian Other	82	100
Black Caribbean	235	266
Black African	87	94
Black Other	38	47
Chinese	57	61
Other	237	285
Not Stated	4,865	5,388
Total	**32,323**	**37,120**

Table 21: Location of inpatients before admission

Location	Count
Home	29,538
Care Home	385
Acute Hospital	11,353
Community Hospital	312
Other	374
Not Recorded	1,125

Table 22: Length of stay by size of unit

Size of Unit by Number of Beds	3 - 6	7 - 10	11 - 15	16 - 20	21 - 25	Over 25	All Units
Number of Responding Units	6	32	28	38	4	13	123
Mean length of stay in days	13.2	12.3	12.9	22.8	14.6	15.6	16.2

Table 23: Comparison of average length of stay between NHS and independent units

Management	Average Length of Stay
Independent	13.5
NHS	16.5

Table 24: Location after end of stay

Location	Died or Discharged	Discharged
Died	55.2%	–
Home	37.8%	84.3%
Care Home	3.7%	8.3%
Hospital (acute)	1.8%	4.0%
Hospital (community)	0.3%	0.6%
Other	0.9%	2.1%
Not Recorded	0.3%	0.8%

Table 25: Inpatients – Bed usage

Data Item	Minimum	Mean	Maximum	Number Responding	Admissions
% Bed Occupancy	51.1%	74.9%	98.9%	132	37,437
Throughput (Admissions per bed per year)	1.1	26.0	451.0	134	
Turnover (Interval between admissions)	0.9	3.9	8.7	128	

Table 26: Bed usage analysis

MDS year	Mean beds per unit	Mean patients per unit	Mean of length of stay	Mean available beds per unit	Available beds as percentage of total	Mean occupied beds per unit	Occupied beds as percentage of available
99/00	15.5	237.2	13.1	12.9	82.8%	9.7	75.3%
00/01	15.6	257.3	13.4	12.9	82.3%	9.8	75.9%
01/02	15.4	242.9	13.1	12.7	82.6%	8.9	69.9%
02/03	15.5	247.6	12.9	12.0	77.4%	9.0	75.3%
03/04	15.4	241.4	12.7	12.7	82.5%	9.0	71.2%
04/05	14.9	240.3	13.4	13.3	89.0%	9.2	69.1%
05/06	14.6	235.6	12.7	11.6	79.3%	8.1	69.5%
06/07	14.8	257.0	13.3	13.7	92.7%	9.3	68.0%
07/08	15.2	261.6	13.0	14.1	92.7%	10.4	73.9%
08/09	14.7	254.3	14.0	14.1	95.7%	10.3	73.6%
09/10	14.8	260.1	13.4	14.4	97.5%	10.6	73.7%
10/11	14.7	258.1	13.7	14.2	97.2%	10.7	74.9%
11/12	15.2	271.4	15.8	14.9	98.0%	11.1	74.8%

Table 27: National estimates – Inpatient units

	Responding Units	National totals and Estimates
No of units	139	193
Total beds	2,072	2,881
Response rate for units	73.2%	–
Response rate for beds	96.4%	–
New patient admissions	33,583	46,630
Total patients	37,777	52,453
Deaths	23,712	32,924
Discharges	19,257	26,738
Ratio of Deaths to discharges	1.23	1.23
Ratio of new patient admissions to deaths & discharges	0.78	0.78
Ratio of deaths to deaths & discharges	0.55	0.55
Ratio of Deaths to new patient admissions	0.71	0.71

Table 28: Inpatient interventions trend

Year	2009	2010	2011	2012
Blood Transfusion	310	659	932	964
Blockade	39	111	117	101
Paracentesis	106	39	120	56
Infusional Therapy	301	412	588	595
Total Interventions	756	1,221	1,757	1,716

5.3 Day Care

Table 29: Day Care patients – age and sex

	New			All		
	Female	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	0	0	**0**	10	5	**15**
16 to 18	3	0	**3**	4	3	**7**
19 to 24	20	4	**24**	31	7	**38**
25 to 64	2,864	1,837	**4,705**	5,027	2,869	**7,904**
65 to 74	2,290	2,026	**4,320**	3,671	3,082	**6,754**
75 to 84	2,328	2,442	**4,774**	3,679	3,590	**7,272**
85 and Over	1,026	890	**1,917**	1,579	1,312	**2,878**
Not Known	48	19	**71**	70	35	**113**
Total	**8,579**	**7,218**	**15,814**	**14,071**	**10,903**	**24,981**

Table 30: Diagnoses of Day Care patients with a diagnosis of cancer

Cancer site	New	All
Lip / Oral / Pharynx	220	363
Digestive	2,982	4,397
Respiratory	2,686	3,764
Breast	1,607	2,862
Female Genital	684	1,098
Male Genital	1,007	1,573
Urinary	628	910
Eye / Brain / Other CNS	580	866
Lymphoid	754	1,317
Other (Specified)	674	1,008
Multiple	85	127
Ill-Defined / Secondary / Etc	307	486
Total	**12,214**	**18,771**

Table 31: Diagnoses of Day Care patients with a primary diagnosis other than cancer

Diagnosis	New	All
HIV / AIDS	1	17
Motor Neurone	368	619
Other Neurological	450	939
Dementia inc. Alzheimer's	21	36
Heart Failure	346	560
Other Heart Circulatory	158	263
Chronic Respiratory	816	1,262
Chronic Renal	62	82
All Other Non-Cancer	525	899
Total	**2,747**	**4,677**

Table 32: Ethnicity of day care patients

Ethnicity	New	All
White British	11,632	18,125
White Irish	175	327
White Other	267	446
Mixed White Black Caribbean	16	28
Mixed White Black African	18	23
Mixed White Asian	7	17
Mixed Other	340	505
Indian	44	93
Pakistani	24	38
Bangladeshi	10	13
Asian Other	37	65
Black Caribbean	94	184
Black African	35	70
Black Other	19	37
Chinese	10	15
Other	187	285
Not Stated	2,554	3,808
Total	**15,469**	**24,072**

Table 33: Consultations – face to face

Health Care Professional	Face to face	%	Max	Mean	Median	Count
Medical Consultant	1,530	0.5%	14.5%	17.2	12.5	52
Other Doctor	11,293	4.0%	81.4%	125.5	77	69
Clinical Nurse Specialist	21,535	7.5%	94.1%	229.1	84	65
Other Nurse	118,027	41.4%	100.0%	1145.9	1007	96
Physiotherapist	21,612	7.6%	52.6%	218.3	159.5	80
Occupational Therapist	14,530	5.1%	47.4%	159.7	87	63
Social Worker	8,253	2.9%	29.9%	96.0	46	59
Pastoral / Spiritual Carer	13,957	4.9%	33.0%	162.3	71	61
Psychologist / Psychotherapist	2,772	1.0%	23.3%	40.2	20	22
Complementary Therapist	46,647	16.3%	100.0%	485.9	535	75
Other health care professional	25,087	8.8%	69.0%	288.4	101	65
Total	**285,342**	**–**	**–**	**2481.2**	**2195**	**115**

Table 34: Consultations – telephone

Health Care Professional	Telephone	%	Max	Mean	Median	Count
Medical Consultant	845	1.0%	8.4%	11.1	3.5	24
Other Doctor	2,025	2.3%	100.0%	21.3	8	35
Clinical Nurse Specialist	9,338	10.6%	100.0%	487.7	56	44
Other Nurse	55,534	62.9%	100.0%	623.2	293	79
Physiotherapist	1,244	1.4%	100.0%	13.1	10.5	44
Occupational Therapist	3,327	3.8%	79.1%	46.0	21	37
Social Worker	7,499	8.5%	100.0%	96.9	49	41
Pastoral / Spiritual Carer	657	0.7%	39.6%	12.4	15	15
Psychologist / Psychotherapist	285	0.3%	4.7%	6.7	12.5	16
Complementary Therapist	1,482	1.7%	100.0%	6.7	4	25
Other health care professional	3,620	4.1%	100.0%	68.1	18	41
Total	**88,240**	**–**	**–**	**1140.5**	**450.5**	**96**

Table 35: Length of care for Day Care services

1 day	2 to 14 days	15 to 30 days	31 to 90 days	91 to 180 days	181 to 365 days	Over 1 Year
5.4%	11.4%	11.7%	27.1%	21.0%	13.5%	11.1%

Table 36: Average (mean) Day Care caseload

Year	Mean caseload
1999-2000	34.86
2000-01	40.50
2001-02	43.52
2002-03	45.31
2003-04	49.91
2004-05	45.22
2005-06	45.77
2006-07	43.85
2007-08	45.92
2008-09	50.32
2009-10	45.39
2010-11	52.67
2011-12	55.60

Table 37: Day Care caseload by region

	Region	Minimum caseload per region	Average (mean) caseload per region	Maximum caseload per region
NHS North of England	**North East**	9.95	47.82	71.02
	North West	16.28	74.92	161.03
	Yorkshire & the Humber	33.02	61.31	125.30
NHS Midlands and East	**East Midlands**	14.47	77.52	386.29
	West Midlands	11.31	39.70	98.61
	East of England	0.45	44.09	101.77
NHS South of England	**South East Coast**	14.47	75.88	338.79
	South Central	6.78	32.36	70.11
	South West	14.02	41.00	116.25
	London	16.74	71.62	166.91
	Northern Ireland	13.57	59.26	112.63
	Wales	8.14	28.78	66.94

Table 38: Patient care

Data Item	Analysis	Results	Number of Services Responding	Numbers in responding services
Deaths and Discharges	Deaths & Discharges as % of new patients	107.5%	137 (96.5%)	16,841 deaths and discharges 15,975 new patients
	Range of above	34.8% to 325.8%		
Length of care	Less than 3 months	55.3%	134 (94.4%)	16,240 patients
	More than 6 months	24.8%		
Average length of care	Mean of service averages	188.0738	128 (90.1%)	–
	Median of averages	166.7		
	Range	4.6 to 681.0 days		
Long term patients (registered for more than a year)	% of total number of patients	7.1%	125 (88.0%)	1,799 long term patients
	Range	0.7% to 92.6%		

Table 39: Day Care places

	Results	Number of services responding	Numbers in responding services
Mean for these services, based on mean length of care	55.6	127 (92.7%)	16,841 deaths and discharges
Median based on length of care	42.1		

5.4 Community Care

Table 40: Community Care - responses

Service type	Services responding	Independent management	NHS management
Home Care	99	53%	47%
Hospice @ Home	45	93%	7%
Home Care and Hospice @ Home	35	74%	26%

Table 41: Age and sex for Home Care patients

	New			All		
	Female	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	7	10	**17**	24	19	**43**
16 to 18	13	12	**25**	16	18	**34**
19 to 24	65	57	**122**	131	103	**234**
25 to 64	7,645	7,125	**14,777**	12,020	10,232	**22,261**
65 to 74	6,752	8,224	**14,978**	9,780	11,460	**21,258**
75 to 84	7,849	9,414	**17,270**	10,964	12,862	**23,825**
85 and Over	5,528	4,234	**9,765**	7,209	5,616	**12,826**
Not Known	392	412	**808**	486	482	**973**
Total	**28,251**	**29,488**	**57,762**	**40,630**	**40,792**	**81,454**

Table 42: Age and sex for Hospice @ Home patients

	New			All		
	Female	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	6	8	**14**	16	26	**42**
16 to 18	0	2	**2**	2	3	**5**
19 to 24	10	7	**19**	12	10	**24**
25 to 64	1,109	1,018	**2,225**	1,293	1,179	**2,619**
65 to 74	1,163	1,359	**2,680**	1,351	1,536	**3,119**
75 to 84	1,443	1,760	**3,420**	1,667	2,014	**3,981**
85 and Over	1,096	861	**2,070**	1,221	969	**2,365**
Not Known	118	71	**189**	135	80	**258**
Total	**4,945**	**5,086**	**10,619**	**5,697**	**5,817**	**12,413**

Table 43: Age and sex for combined Home Care & Hospice @ Home patients

	New			All		
	Female	**Male**	**Total**	**Female**	**Male**	**Total**
Under 16	1	0	**1**	5	1	**6**
16 to 18	7	5	**12**	7	6	**13**
19 to 24	17	17	**34**	31	26	**61**
25 to 64	2,541	2,216	**4,760**	4,030	3,220	**7,381**
65 to 74	2,281	2,666	**4,947**	3,232	3,575	**6,920**
75 to 84	2,714	3,194	**5,909**	3,650	4,200	**7,964**
85 and Over	2,125	1,636	**3,761**	2,698	2,039	**4,777**
Not Known	18	13	**38**	196	167	**341**
Total	**9,704**	**9,747**	**19,462**	**13,849**	**13,234**	**27,463**

Table 44: Community Care diagnosis – cancer

	Home Care		Hospice @ Home		Combined	
	New	**All**	**New**	**All**	**New**	**All**
Lip / Oral / Pharynx	1,024	1,481	113	135	305	462
Digestive	11,811	16,764	2,231	2,513	4,230	5,748
Respiratory	9,619	13,130	1,509	1,702	3,304	4,510
Breast	3,910	6,605	607	747	1,364	2,312
Female Genital	2,151	3,402	346	407	768	1,157
Male Genital	2,865	4,516	490	581	940	1,458
Urinary	2,401	3,417	433	503	973	1,306
Eye / Brain / Other CNS	1,461	2,195	318	407	554	812
Lymphoid	2,283	3,400	320	399	806	1,184
Other (Specified)	2,755	3,993	424	503	773	1,216
Multiple	142	215	27	39	130	192
Ill-Defined / Secondary / Etc	1,639	2,245	250	280	909	1,201
Total	**42,061**	**61,363**	**7,068**	**8,216**	**15,056**	**21,558**

Table 45: Patients with a diagnosis other than cancer in community services

	Home Care		Hospice @ Home		Combined	
	New	**All**	**New**	**All**	**New**	**All**
HIV / AIDS	24	29	3	3	5	8
Motor Neurone	479	815	109	163	194	336
Other Neurological	551	1,169	127	179	289	462
Dementia inc. Alzheimer's	599	740	156	176	370	426
Heart Failure	745	1,004	207	262	324	411
Other Heart Circulatory	397	527	120	139	284	408
Chronic Respiratory	1,313	1,858	267	331	604	820
Chronic Renal	314	410	96	108	150	175
All Other Non-Cancer	2,322	3,135	445	537	813	1,067
Total	**6,744**	**9,687**	**1,530**	**1,898**	**3,033**	**4,113**

Table 46: Patients with a diagnosis other than cancer in community services

	Home Care	Hospice @ Home	Home Care & Hospice @ Home
New Referrals	6,739 (13.6%)	1,530 (16.9%)	3,034 (16.0%)
Number of Units	82	38	33
Number seeing cancer patients only	1	0	0
Units seeing less than 10% of patients with a diagnosis other than cancer patients	29 (35.4%)	7 (18.4%)	6 (18.2%)
Units seeing between 10% and 20% of patients with a diagnosis other than cancer patients	41 (50.0%)	21 (55.3%)	19 (57.6%)
Units seeing more than 20% of patients with a diagnosis other than cancer patients	12 (14.6%)	10 (26.3%)	8 (24.2%)

Table 47: Community Services Ethnicity

	Home Care		Hospice @ Home		Combined	
	New	**All**	**New**	**All**	**New**	**All**
White British	35,726	52,483	7,859	7,882	12,680	16,988
White Irish	627	869	87	102	161	241
White Other	2,359	2,578	114	138	299	443
Mixed White / Black Caribbean	55	63	9	7	9	12
Mixed White / Black African	24	20	6	7	21	23
Mixed White / Asian	33	50	6	6	6	9
Mixed Other	1,134	1,727	49	93	12	21
Indian	199	319	25	30	73	109
Pakistani	209	204	31	38	21	39
Bangladeshi	90	129	3	3	13	17
Asian Other	173	285	17	23	59	94
Black Caribbean	265	380	23	26	152	233
Black African	122	176	22	23	57	85
Black Other	36	57	8	9	31	40
Chinese	44	61	12	10	24	35
Other	761	859	98	100	459	575
Not Stated	11,436	14,649	1,523	1,896	4,132	6,154
Total	**53,293**	**74,910**	**9,892**	**11,071**	**18,209**	**25,118**

Table 48: Community Services visits

Setting	Average number of visits	Range	Number of services responding	Numbers in responding services
Home Care	4.5	1.1 to 22.5	86	75,480 total patients 324,793 visits
Hospice @ Home	8.4	2.4 to 21.2	37	11,143 total patients 97,749 visits
Home Care and Hospice @ Home	6.3	1.2 to 41.3	32	26,715 total patients 175,849 visits
All	5.8	1.1 to 41.3	155	113,338 total patients 598,391 visits

Table 49: Home Care contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	11,022	2.9%	100.0%	128.2	48.0	50
Other Doctor	5,152	1.4%	100.0%	59.9	31.0	44
Clinical Nurse Specialist	301,977	79.5%	100.0%	3,511.4	3,049.0	73
Other Nurse	24,407	6.4%	100.0%	283.8	128.0	40
Physiotherapist	5,788	1.5%	31.3%	67.3	71.5	38
Occupational Therapist	9,258	2.4%	34.6%	107.7	115.0	35
Social Worker	5,294	1.4%	81.9%	61.6	68.5	38
Pastoral / Spiritual Carer	902	0.2%	9.2%	10.5	17.0	19
Psychologist / Psychotherapist	2,131	0.6%	14.3%	24.8	23.5	18
Complementary Therapist	4,102	1.1%	71.4%	47.7	35.5	24
Other health care professional	8,366	2.2%	42.1%	97.3	74.5	34
Total Face to Face	**379,896**	**–**	**–**	**4,417.4**	**3,331.0**	**86**

Table 50: Home Care contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	10,993	1.6%	100.0%	140.9	36.0	45
Other Doctor	5,106	0.7%	42.3%	65.5	44.0	39
Clinical Nurse Specialist	604,361	86.4%	100.0%	7,748.2	5,404.0	69
Other Nurse	31,672	4.5%	100.0%	406.1	195.5	38
Physiotherapist	3,425	0.5%	15.7%	43.9	63.5	28
Occupational Therapist	10,578	1.5%	51.0%	135.6	127.0	27
Social Worker	14,385	2.1%	91.9%	184.4	164.5	30
Pastoral / Spiritual Carer	726	0.1%	1.7%	9.3	10.0	13
Psychologist / Psychotherapist	2,440	0.3%	20.6%	31.3	79.0	12
Complementary Therapist	874	0.1%	59.2%	11.2	21.0	17
Other health care professional	14,830	2.1%	49.0%	190.1	54.0	30
Total Face to Face	**699,390**	**–**	**–**	**8,966.5**	**5,351.5**	**78**

Table 51: Hospice @ Home contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	14	0.0%	0.4%	0.4	1.0	3
Other Doctor	29	0.0%	0.5%	0.9	4.0	5
Clinical Nurse Specialist	11,253	12.7%	100.0%	341.0	232.0	7
Other Nurse	53,120	60.1%	100.0%	1,609.7	1,152.0	28
Physiotherapist	202	0.2%	4.3%	6.1	101.0	2
Occupational Therapist	75	0.1%	100.0%	2.3	12.0	5
Social Worker	1	0.0%	0.0%	0.0	1.0	1
Pastoral / Spiritual Carer	19	0.0%	0.3%	0.6	2.0	3
Psychologist / Psychotherapist	1	0.0%	0.8%	0.0	1.0	1
Complementary Therapist	1,153	1.3%	8.1%	34.9	70.0	9
Other health care professional	22,573	25.5%	100.0%	684.0	977.0	18
Total Face to Face	**88,440**	**–**	**–**	**2,680.0**	**2,016.0**	**33**

Table 52: Hospice @ Home contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	14	0.0%	0.3%	0.5	14.0	1
Other Doctor	74	0.1%	18.2%	2.8	25.0	3
Clinical Nurse Specialist	24,437	25.8%	100.0%	939.9	4,143.0	4
Other Nurse	64,330	67.8%	100.0%	2,474.2	2,227.0	21
Physiotherapist	297	0.3%	3.6%	11.4	1.0	3
Occupational Therapist	31	0.0%	3.5%	1.2	11.0	3
Social Worker	100	0.1%	100.0%	3.8	50.0	2
Pastoral / Spiritual Carer	5	0.0%	2.9%	0.2	2.5	2
Psychologist / Psychotherapist	0	0.0%	0.0%	0.0	0.0	0
Complementary Therapist	288	0.3%	1.4%	11.1	65.5	4
Other health care professional	5,255	5.5%	100.0%	202.1	138.0	11
Total Face to Face	**94,831**	**–**	**–**	**3,647.3**	**1,938.5**	**26**

Table 53: Combined Home Care and Hospice @ Home service contacts – face to face

Health care professional	Face to face contacts		Max in unit	Mean	Median	Services
Medical Consultant	773	0.5%	3.0%	27.6	22.0	15
Other Doctor	1,202	0.7%	5.5%	42.9	83.0	13
Clinical Nurse Specialist	107,307	63.1%	100.0%	3,832.4	2,158.0	23
Other Nurse	38,175	22.4%	100.0%	1,363.4	969.0	17
Physiotherapist	4,689	2.8%	40.4%	167.5	166.0	18
Occupational Therapist	2,896	1.7%	59.6%	103.4	180.0	14
Social Worker	4,378	2.6%	15.1%	156.4	260.0	13
Pastoral / Spiritual Carer	138	0.1%	1.8%	4.9	10.0	7
Psychologist / Psychotherapist	404	0.2%	7.4%	14.4	20.0	7
Complementary Therapist	2,424	1.4%	52.3%	86.6	175.0	9
Other health care professional	7,702	4.5%	48.2%	275.1	62.5	12
Total Face to Face	**170,088**	**–**	**–**	**6,074.6**	**3,491.0**	**28**

Table 54: Combined Home Care and Hospice @ Home service contacts – telephone

Health care professional	Telephone contacts		Max in unit	Mean	Median	Services
Medical Consultant	477	0.2%	1.0%	18.3	30.5	10
Other Doctor	1,373	0.6%	4.4%	52.8	115.5	10
Clinical Nurse Specialist	197,713	81.6%	100.0%	7,604.3	6,828.5	22
Other Nurse	24,341	10.0%	100.0%	936.2	865.0	16
Physiotherapist	2,528	1.0%	100.0%	97.2	130.0	14
Occupational Therapist	3,165	1.3%	47.7%	121.7	327.0	9
Social Worker	8,635	3.6%	18.9%	332.1	643.0	13
Pastoral / Spiritual Carer	105	0.0%	1.8%	4.0	26.0	5
Psychologist / Psychotherapist	349	0.1%	2.1%	13.4	54.0	4
Complementary Therapist	526	0.2%	9.5%	20.2	82.5	6
Other health care professional	3,074	1.3%	20.3%	118.2	56.5	12
Total Face to Face	**242,286**	**–**	**–**	**9,318.7**	**6,192.0**	**26**

Table 55: Trends in visits by Clinical Nurse Specialists and Nurses

	2009	2010	2011	2012
Clinical Nurse Specialists in Home Care services	2,467	2,581	2,795	3,120
Nurses in Hospice @ Home services	502	776	836	1,180
Clinical Nurse Specialists in combined Home Care & Hospice @ Home services	1,881	1,260	2,364	3,066

Table 56: Deaths and discharges for Community Services

	Home Care	Hospice @ Home	Home Care and Hospice @ Home
Deaths as % of deaths & discharges	60.0%	72.0%	70.4%
Range	10.8% to 100.0%	42.1% to 100.0%	15.7% to 100.0%
Deaths & Discharges as % of new patients	116.5%	106.2%	111.4%
Home deaths as % of new patients	29.5%	56.0%	34.5%

Table 57: Community Services – average length of care

	Average length of care (days)	Range	Units responding
Home Care	127.7	14.0 to 1,158.0	81
Hospice @ Home	67.9	3.6 to 658.0	36
Home Care and Hospice @ Home	112.9	10.8 to 459.5	30

Table 58: Community Services – length of care

Length of care	Number of patients		
	Home Care	Hospice @ Home	Combined
1 day	4,030	1,288	1,344
2 to 14 days	11,429	3,811	4,858
15 to 30 days	9,166	1,372	3,075
31 to 60 days	9,813	1,108	3,370
61 to 90 days	5,956	595	2,031
91 to 120 days	4,167	306	1,497
121 to 150 days	2,917	222	998
151 to 180 days	2,229	184	831
181 to 365 days	6,008	434	2,191
Over 1 Year	3,492	284	1,104
Total	**59,207**	**9,604**	**21,299**

Table 59: 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	224.7	152.8	81	57,564
Hospice @ Home	70.2	20.6	36	9,646
Home Care and Hospice @ Home	184.1	140.8	30	19,131

Table 60: Community Services – place of death

					Hospital		
		Home	Care Home	Hospice	Community	Acute	Other
NHS North of England	**North East**	912	75	195	56	166	1
	North West	3,795	784	886	292	867	76
	Yorks & Humber	2,225	730	1,033	105	720	45
NHS Midlands and East	**East Midlands**	2,086	156	331	201	670	6
	West Midlands	2,948	860	1,332	145	723	128
	East of England	3,282	659	890	478	828	58
NHS South of England	**South East Coast**	2,522	824	1,910	318	705	73
	South Central	2,686	428	1,170	169	840	54
	South West	4,193	1,148	1,686	612	1,116	83
	London	2,403	854	1,329	159	1,124	49
	Northern Ireland	1,101	181	90	66	390	2
	Wales	1,900	372	236	106	612	86

Table 61: Place of Death 2011[14]

		Home	Care Home	Hospice	Hospital	Other
NHS North of England	**North East**	5,753	4,519	971	13,872	596
	North West	14,141	11,916	3,806	35,118	1,391
	Yorkshire & the Humber	10,331	9,727	2,820	24,630	1,019
NHS Midlands and East	**East Midlands**	9,111	7,983	1,567	20,799	919
	West Midlands	10,705	8,442	2,647	26,382	934
	East of England	11,720	10,496	2,445	24,836	1,064
NHS South of England	**South East Coast**	8,263	9,526	3,534	19,183	968
	South Central	7,221	6,856	2,037	15,806	741
	South West	11,577	12,361	2,644	23,710	1,090
	London	9,823	6,256	3,019	26,514	1,073
	Northern Ireland	3,693	2,557	–	6,980	974
	Wales	6,708	4,247	830	17,799	842

Available Northern Ireland data combines Hospice deaths with data on “Other” places of death. Figures were calculated from the percentage breakdown from NISRA.

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[14] **ONS Deaths Registered in England and Wales (Series DR), 2011** – Table 13

NISRA Statistical Bulletin – Deaths in Northern Ireland 2011

5.5 Hospital Support

Table 62: Age and sex of patients receiving Hospital Support

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	4	18	**22**	8	22	**30**
16 to 18	15	19	**34**	16	22	**38**
19 to 24	171	129	**302**	216	175	**394**
25 to 64	9,211	8,749	**18,155**	10,999	10,111	**21,844**
65 to 74	7,975	9,235	**17,480**	9,095	10,576	**20,365**
75 to 84	10,164	11,544	**21,976**	11,286	12,792	**24,899**
85 and Over	8,995	6,551	**15,682**	9,764	7,081	**17,217**
Not Known	323	335	**664**	336	345	**704**
Total	**36,858**	**36,580**	**74,315**	**41,720**	**41,124**	**85,491**

Table 63: Patients with cancer diagnosis in Hospital Support

Diagnosis	New	All
Lip / Oral / Pharynx	1,148	1,436
Digestive	14,862	17,672
Respiratory	10,289	12,368
Breast	4,348	5,348
Female Genital	3,095	3,952
Male Genital	3,634	4,325
Urinary	3,438	4,028
Eye / Brain / Other CNS	1,654	1,937
Lymphoid	3,891	4,683
Other (Specified)	2,417	2,869
Multiple	422	482
Ill-Defined / Secondary / Etc	3,660	4,101
Total	**52,858**	**63,201**

Table 64: Patients with a diagnosis other than cancer in Hospital Support

Diagnosis	New	All
HIV / AIDS	43	63
Motor Neurone	313	361
Other Neurological	1,034	1,130
Dementia inc. Alzheimer's	1,494	1,626
Heart Failure	1,741	1,905
Other Heart Circulatory	2,041	2,181
Chronic Respiratory	1,913	2,256
Chronic Renal	709	824
All Other Non-Cancer	6,417	7,018
Total	**15,705**	**17,364**

Table 65: Ethnicity of patients receiving Hospital Support

Ethnicity	New	All
White British	53,215	58,220
White Irish	793	959
White Other	1,887	2,123
Mixed White Black Caribbean	91	110
Mixed White Black African	25	35
Mixed White Asian	38	41
Mixed Other	330	376
Indian	501	558
Pakistani	320	397
Bangladeshi	129	157
Asian Other	475	582
Black Caribbean	771	918
Black African	402	522
Black Other	189	241
Chinese	131	143
Other	637	751
Not Stated	11,326	12,317
Total	**71,260**	**78,443**

Table 66: Contacts per patient in Hospital Support

Average number of contacts per patient	Range of visits per patient per service	Number of services responding	Number in responding services
6.8	1.1 to 37.3	108	69,332 total patients 463,951 visits

Table 67: Face to face contacts with patients in Hospital Support

	Face to Face		Max	Mean	Median	Services
Medical Consultant	39,691	10.4%	100.0%	357.6	48.0	91
Other Doctor	22,820	5.9%	42.8%	205.6	31.0	56
Clinical Nurse Specialist	345,836	78.7%	100.0%	3,115.6	3,049.0	106
Other Nurse	4,357	1.6%	100.0%	39.3	128.0	30
Physiotherapist	284	0.1%	2.2%	2.6	71.5	3
Occupational Therapist	4,062	0.8%	34.6%	36.6	115.0	12
Social Worker	2,573	1.1%	8.2%	23.2	68.5	15
Pastoral / Spiritual Carer	81	0.1%	1.5%	0.7	17.0	5
Psychologist / Psychotherapist	1,202	0.1%	7.5%	10.8	23.5	7
Complementary Therapist	468	0.2%	3.8%	4.2	35.5	4
Other health care professional	2,103	0.8%	29.8%	18.9	74.5	18
Total Face to Face	**424,963**	**–**	**–**	**3,828.5**	**3,331.0**	**111**

Table 68: Telephone contacts with patients in Hospital Support

	Telephone contacts		Max	Mean	Median	Services
Medical Consultant	3,809	3.2%	94.9%	46.0	19.5	56
Other Doctor	2,722	2.3%	51.5%	46.2	28.5	44
Clinical Nurse Specialist	105,828	89.1%	100.0%	1,145.8	538.0	79
Other Nurse	1,772	1.5%	100.0%	33.5	3.5	18
Physiotherapist	38	0.0%	1.1%	0.8	1.0	0
Occupational Therapist	1,427	1.2%	68.9%	29.1	9.0	8
Social Worker	2,336	2.0%	37.3%	46.7	35.0	14
Pastoral / Spiritual Carer	2	0.0%	1.0%	0.0	2.0	0
Psychologist / Psychotherapist	86	0.1%	3.1%	1.9	17.0	5
Complementary Therapist	6	0.0%	0.3%	0.1	1.0	2
Other health care professional	319	0.3%	10.9%	6.3	10.0	12
Total Face to Face	**118,813**	**–**	**–**	**1,051.4**	**607.0**	**82**

Table 69: Number of outpatients seen by region

Region	All patients
North East	2,319
N Ireland	2,720
East Midlands	3,408
Wales	4,421
South West	6,761
West Midlands	7,087
East of England	7,566
South Central	7,981
South East Coast	8,204
Yorkshire & the Humber	9,255
North West	9,616
London	15,488

Table 70: Number of outpatients per service by region

Region	Patients per service
Wales	442
N Ireland	453
North East	464
South West	483
North West	534
East of England	540
Yorkshire & the Humber	578
South Central	614
South East Coast	631
East Midlands	682
London	815
West Midlands	886

Table 71: Length of care for Hospital Support

Length of care	Count
1 day	16,446
2 to 7 days	29,008
2 to 14 days	14,007
15 to 28 days	8,261
29 to 42 days	2,337
43 to 84 days	1,477
85 to 180 days	887
Over 180 days	328
Total	**72,751**

5.6 Bereavement Support

Table 72: Age and sex for clients in Bereavement Support

	New			All		
	Female	Male	Total	Female	Male	Total
Under 16	562	517	**1,085**	901	808	**1,727**
16 to 18	156	70	**229**	244	108	**356**
19 to 24	185	73	**258**	292	104	**396**
25 to 64	4,183	1,772	**5,983**	6,300	2,751	**9,086**
65 to 74	1,533	1,002	**2,539**	2,289	1,620	**3,914**
75 to 84	1,009	951	**1,961**	1,582	1,529	**3,113**
85 and Over	378	317	**696**	573	494	**1,070**
Not Known	5,109	2,659	**9,991**	7,477	3,921	**15,301**
Total	**13,115**	**7,361**	**22,742**	**19,658**	**11,335**	**34,963**

Table 73: Ethnicity of patients receiving Bereavement Support

Ethnicity	New	All
White British	8,164	13,018
White Irish	75	96
White Other	113	153
Mixed White Black Caribbean	20	24
Mixed White Black African	7	9
Mixed White Asian	14	21
Mixed Other	15	31
Indian	31	38
Pakistani	15	24
Bangladeshi	7	10
Asian Other	34	49
Black Caribbean	102	135
Black African	38	47
Black Other	20	31
Chinese	21	26
Other	58	83
Not Stated	13,710	20,796
Total	**22,444**	**34,713**

Table 74: Bereavement Support – primary diagnosis of deceased

	New	All
Cancer	13,732	22,002
Non-Cancer	2,505	3,675
Not Recorded	4,616	7,484
Total	**20,853**	**33,161**

Table 75: Face to face contacts in Bereavement Support

Not Facilitated	Facilitated	Support	Counselling	Complex
2,155	17,032	33,736	33,674	1,279
2.5%	19.4%	38.4%	38.3%	1.5%

Table 76: Telephone contacts in Bereavement Support

Phone calls under 10 minutes	Phone calls over 10 minutes
36,322	21,874
62.4%	37.6%

Table 77: Contact trends in Bereavement Support

	2009	2010	2011	2012
Phone Under 10 minutes	25,802	30,216	36,460	36,322
Phone Over 10 minutes	25,590	27,119	24,833	21,874
Face to Face - Group - Not Facilitated	3,769	5,439	4,931	2,155
Face to Face - Group - Facilitated	23,643	19,039	18,288	17,032
Face to Face - Individual Support	32,096	39,235	38,078	33,736
Face to Face - Individual Counselling	28,176	39,116	37,737	33,674
Face to Face - Complex	988	313	532	1,279
Other	7,119	13,115	13,177	11,793

Table 78: Contacts with bereaved clients – phone calls

				Phone call	
	Region	Services	Clients	Under 10 mins	Over 10 mins
NHS North of England	**North East**	8	1581	2,119	1,180
	North West	25	3633	3,094	2,170
	Yorkshire & the Humber	14	2395	1,231	3,385
NHS Midlands and East	**East Midlands**	6	795	152	1,775
	West Midlands	11	2641	1,629	1,604
	East of England	15	9255	11,925	3,919
NHS South of England	**South East Coast**	10	3967	2,902	588
	South Central	8	1498	2,586	593
	South West	15	4178	4,018	2605
	London	10	3191	3,030	1,719
	N Ireland	2	2177	149	1,378
	Wales	7	1324	3,487	958

Table 79: Contacts with bereaved clients – face to face and other

		Group		Individual			
	Region	Not facilitated	Facilitated	Support	Counselling	Complex Intervention	Other
NHS North of England	**North East**	29	569	2,139	816	2	10
	North West	510	2,619	5,298	4,868	97	1,981
	Yorkshire & the Humber	0	1,841	1,016	2,846	2	1,607
NHS Midlands and East	**East Midlands**	0	4361	1,474	2,105	0	30
	West Midlands	64	1,290	3,392	1,836	0	1,931
	East of England	666	2,465	6,077	7,058	231	6,530
NHS South of England	**South East Coast**	681	258	5,707	3,256	233	270
	South Central	2	773	1,783	450	0	198
	South West	21	1,230	2,830	3,291	40	858
	London	88	1,281	2,940	4,840	274	1,113
	N Ireland	0	3	374	598	0	0
	Wales	94	342	706	1,710	400	0

5.7 Outpatients

Table 80: Age and sex of Outpatients

	New			All		
	Female	Male	All	Female	Male	All
Under 16	6	7	**13**	34	16	**50**
16 to 18	14	9	**23**	28	19	**47**
19 to 24	49	26	**85**	113	51	**175**
25 to 64	5,381	2,963	**8,588**	13,085	5,067	**18,393**
65 to 74	2,913	2,631	**5,644**	6,179	3,900	**10,178**
75 to 84	2,255	2,301	**4,608**	4,559	3,297	**7,918**
85 and Over	927	688	**1,618**	1,659	958	**2,618**
Not Known	83	28	**620**	146	55	**713**
Total	**11,628**	**8,653**	**21,199**	**25,803**	**13,363**	**40,092**

Table 81: Cancer diagnoses in Outpatients

Diagnosis	New	All
Lip / Oral / Pharynx	323	533
Digestive	3,148	4,457
Respiratory	2,607	3,541
Breast	2,915	8,592
Female Genital	779	1,596
Male Genital	892	1,434
Urinary	627	968
Eye / Brain / Other CNS	426	609
Lymphoid	677	1,149
Other (Specified)	1,474	2,065
Multiple	59	98
Ill-Defined / Secondary / Etc	509	769
Total	**14,436**	**25,811**

Table 82: Diagnoses other than cancer in Outpatients

Diagnosis	New	All
HIV / AIDS	14	56
Motor Neurone	282	506
Other Neurological	263	513
Dementia inc. Alzheimer's	21	30
Heart Failure	191	248
Other Heart Circulatory	500	1,242
Chronic Respiratory	703	886
Chronic Renal	70	110
All Other Non-Cancer	1,685	4,674
Total	**3,729**	**8,265**

Table 83: Ethnicity of outpatients

Ethnicity	New	All
White British	13,911	25,027
White Irish	221	399
White Other	385	894
Mixed White Black Caribbean	28	40
Mixed White Black African	16	27
Mixed White Asian	10	17
Mixed Other	214	424
Indian	61	118
Pakistani	39	82
Bangladeshi	5	11
Asian Other	45	84
Black Caribbean	83	147
Black African	43	86
Black Other	31	51
Chinese	29	48
Other	126	272
Not Stated	5,825	11,607
Total	**21,072**	**39,334**

Table 84: Outpatient clinics

Lead Health Care Professional	Palliative care clinics	Joint clinics	First attendances	Follow-up attendances
Palliative care medical consultant	5,830	263	4937	12,732
Palliative care - Other Doctor	2,355	140	1597	3,454
Palliative care clinical nurse specialist	6,330	70	2483	10,420
Other Nurse	4,884	124	1971	17,912
Physiotherapist	3,582	54	1627	7,930
Occupational therapist	777	302	361	1,471
Social Worker	884	40	385	1,300
Pastoral / spiritual carer	43	0	26	109
Psychologist / Psychotherapist	790	0	288	1,469
Complementary Therapist	4,901	6	1507	10,806
Other health care professional	2,717	295	1579	7,783
Total	**31,187**	**1,294**	**16168**	**73,028**

Table 85: Face to face contacts with Outpatients

Health Care Professional	Face to Face	%	Max	Mean	Median	Count
Medical Consultant	4,351	8%	1675	91	22.5	48
Other Doctor	850	2%	108	22	13.5	38
Clinical Nurse Specialist	12,785	24%	8259	346	24	37
Other Nurse	7,593	14%	1382	195	52	39
Physiotherapist	7,442	14%	1464	173	80	43
Occupational Therapist	2,486	5%	651	86	27	29
Social Worker	2,678	5%	864	122	27	22
Pastoral / Spiritual Carer	460	1%	259	26	4.5	18
Psychologist / Psychotherapist	1,416	3%	455	83	14	17
Complementary Therapist	9,367	18%	1642	234	152.5	40
Other health care professional	5,651	11%	1459	202	53.5	28
Total	**52,553**	**–**	**–**	**636**	**462**	**86**

Table 86: Telephone contacts with Outpatients

Health Care Professional	Telephone	%	Max	Mean	Median	Count
Medical Consultant	2,859	11%	1697	89	11	32
Other Doctor	1,304	5%	339	43	11.5	30
Clinical Nurse Specialist	4,408	16%	1437	142	28	31
Other Nurse	6,621	25%	775	184	79.5	36
Physiotherapist	1,947	7%	524	78	30	25
Occupational Therapist	1,461	5%	1102	70	8	21
Social Worker	3,503	13%	1479	146	25	24
Pastoral / Spiritual Carer	114	0%	79	13	2	9
Psychologist / Psychotherapist	529	2%	167	35	18	15
Complementary Therapist	1,268	5%	280	58	24.5	22
Other health care professional	4,060	15%	2055	203	24.5	20
Total	**26,832**	**–**	**–**	**203**	**24.5**	**66**

Table 87: Outpatient services reponding, clinic numbers and attendances

	Region	Services Responding	Clinics	Attendances
NHS North of England	**North East**	7	4,723	16,667
	North West	23	7,450	15,630
	Yorkshire & the Humber	11	1,759	7,449
NHS Midlands and East	**East Midlands**	5	486	2,398
	West Midlands	5	1,380	4,604
	East of England	9	2,369	8,354
NHS South of England	**South East Coast**	8	2,113	4,159
	South Central	4	305	3,735
	South West	13	1,940	7,898
	London	6	7,940	15,954
	N Ireland	5	476	1646
	Wales	7	246	702

5.8 Patient Characteristics

5.8.1 Age and sex

Table 88: Breakdown of age by setting and sex

Setting	Sex	Aged under 65	Aged 65 to 84	Aged 85 and over
Inpatient	**Female**	6,095	10,143	2,580
	Male	5,464	11,592	2,374
Day Care	**Female**	5,072	7,350	1,579
	Male	2,884	6,672	1,312
Home Care	**Female**	12,191	20,744	7,209
	Male	10,372	24,322	5,616
Hospice @ Home	**Female**	1,323	3,018	1,221
	Male	1,219	3,550	969
Combined	**Female**	4,073	6,882	2,698
	Male	3,253	7,775	2,039
Hospital Support	**Female**	11,239	20,381	9,764
	Male	10,330	23,368	7,081
Bereavement	**Female**	7,737	3,871	573
	Male	3,771	3,149	494
Outpatient	**Female**	13,260	10,738	1,659
	Male	5,153	7,197	958

Table 89: Percentage of patients aged 85 and over

	Inpatients	Day Care	Community Care	Hospital Support	Outpatients
1999-2000	8.1%	6.5%	8.7%	11.8%	6.0%
2000-2001	8.5%	6.8%	9.1%	11.2%	5.0%
2001-2002	8.8%	8.0%	9.5%	11.5%	5.4%
2002-2003	8.8%	7.7%	10.1%	12.9%	6.2%
2003-2004	9.0%	7.4%	10.4%	12.9%	5.7%
2004-2005	9.1%	7.9%	10.8%	13.1%	5.3%
2005-2006	9.8%	8.7%	11.7%	13.4%	5.5%
2006-2007	10.4%	9.1%	13.3%	14.8%	6.2%
2007-2008	10.8%	9.9%	13.9%	16.6%	6.0%
2008-2009	11.1%	9.5%	14.6%	17.2%	7.3%
2009-2010	12.1%	10.8%	15.4%	18.4%	7.5%
2010-2011	12.2%	11.3%	17.2%	19.7%	7.8%
2011-2012	13.2%	12.1%	17.8%	21.1%	7.6%

Table 90: Deaths by age band

Mortality Year	Under 25	25 to 64	65 to 74	75 to 84	Over 85
1999	8,301	84,489	108,975	183,323	168,444
2000	7,975	83,727	103,119	177,100	165,956
2001	7,810	83,152	98,277	176,274	166,985
2002	7,665	82,598	96,229	178,706	170,158
2003	7,783	82,981	94,065	182,290	172,032
2004	7,558	80,354	89,750	175,771	160,817
2005	7,458	80,216	86,932	170,970	167,417
2006	7,559	80,485	83,383	163,122	168,050
2007	7,465	80,188	81,733	159,984	174,682
2008	7,413	80,603	81,745	157,626	181,703
2009	7,092	78,818	79,491	149,924	176,023
2010	6,698	77,809	79,559	148,084	181,092
2011	6,415	75,836	78,591	143,422	180,103

Table 91: Comparison of age of people accessing palliative care with recorded deaths

	MDS	Deaths[15]
Under 25	3,698	1,902
25 - 64	97,037	66,331
65 - 74	78,968	76,782
75 - 84	85,897	140,113
Over 85	46,121	167,912
Total	311,721	453,040

Table 92: Units returning ethnicity data for new patients

Service	Services reporting ethnicity	Total services
Inpatients	137	141
Day Care	134	142
Home Care	90	99
Hospice @ Home	39	45
Home Care & Hospice @ Home	34	35
Hospital Suppport	128	141
Bereavement Support	101	131
Outpatients	145	152

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[15] ONS – VS3 Mortality by cause – 2011 registrations to 2011 boundaries (excluding external causes)

Table 93:Ethnicity trends

	1999 - 2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012
Response Rate	53%	54%	43%	56%	43%	49%	54%	62%	72%	83%	86%	90%	94%
% Non White	3%	3%	3%	4%	4%	4%	5%	4%	5%	5%	5%	5%	6%
Other as % Of Non White	23%	26%	21%	18%	22%	15%	22%	15%	17%	26%	32%	19%	21%

Table 94: Breakdown of cancer diagnosis by setting

	Inpatients	Day Care	Home Care	Hospice @ Home	Home Care & Hospice @ Home	Hospital Support	Outpatients
Lip, Oral, Pharynx	664	220	1024	113	305	1148	323
Digestive	8494	2982	11811	2231	4230	14862	3148
Respiratory	5991	2686	9619	1509	3304	10289	2607
Breast	2354	1607	3910	607	1364	4348	2915
Female Genital	1719	684	2151	346	768	3095	779
Male Genital	1962	1007	2865	490	940	3634	892
Urinary	1760	628	2401	433	973	3438	627
Eye, Brain, Other CNS	1036	580	1461	318	554	1654	426
Lymphoid	1199	754	2283	320	806	3891	677
Other Specified	1707	674	2755	424	773	2417	1474
Multiple Sites	136	85	142	27	130	422	59
Ill Defined, Secondary, Etc	1371	307	1639	250	909	3660	509

Table 95: Diagnoses by setting

Service	Cancer	Conditions other than cancer	Not recorded
Inpatients	28,514	3,534	603
Day Care	12,337	2,757	662
Home Care	43,844	7,404	3,442
Hospice @ Home	7,906	1,595	383
Home Care & Hospice @ Home	15,450	3,154	720
Hospital Support	55,395	16,346	2,802
Outpatients	14,776	3,843	1,789

Table 96: Growth in diagnoses other than cancer

	Inpatients	Day Care	Community Care	Hospital Support	Outpatients
99/00	4.4%	5.0%	3.7%	5.0%	8.0%
00/01	4.8%	6.2%	3.8%	6.0%	7.7%
01/02	5.4%	6.3%	4.0%	6.7%	9.6%
02/03	4.6%	7.4%	4.7%	7.6%	9.1%
03/04	5.5%	8.0%	5.4%	10.7%	12.0%
04/05	5.3%	7.9%	5.3%	11.3%	13.2%
05/06	6.1%	9.3%	6.2%	13.1%	14.3%
06/07	7.2%	10.1%	9.3%	13.6%	13.6%
07/08	7.6%	11.8%	8.5%	15.9%	17.4%
08/09	8.8%	13.1%	9.9%	19.1%	17.1%
09/10	8.6%	14.0%	11.4%	19.1%	20.2%
10/11	11.2%	16.7%	11.8%	20.1%	23.7%
11/12	11.0%	18.3%	15.3%	23.5%	20.6%

Table 97: Breakdown of diagnoses other than cancer, by setting

	Inpatients	Day Care	Home Care	Hospice @ Home	Home Care & Hospice @ Home	Hospital Support	Outpatients
HIV / AIDS	11	1	24	3	5	43	14
Motor Neurone	401	368	479	109	194	313	282
Neurological	429	450	551	127	289	1034	263
Dementia including Alzheimers	118	21	599	156	370	1494	21
Heart Failure	410	346	745	207	324	1741	191
Other Heart / Circulatory	226	158	397	120	284	2041	500
Chronic Respiratory	737	816	1313	267	604	1913	703
Chronic Renal	196	62	314	96	150	709	70
All Other Non Cancer	979	525	2322	445	813	6417	1685
Total Non Cancer	3507	2747	6744	1530	3033	15705	3729

6 Glossary

6.1 Palliative Care Defined

Palliative care is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as follows:

> Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

6.1.1 Specialist Palliative Care Services

These services are provided by specialist multidisciplinary palliative care teams and include:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes
- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home
- This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home.
    - Many teams also now provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'
    - Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies
- Advice and support to all the people involved in a patient's care
- Bereavement support services which provide support for the people involved in a patient's care following the patient's death
- Education and training in palliative care

The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

6.2 Referrals

New patient	A patient who was referred to the service for the first time during the financial year 2011/12.
Continuing patient	A patient who was referred in a previous year and was still being seen by the service on 1st April 2011.
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 2011/12.
Total patients	The sum of new, continuing and re-referred patients.
Discharged	A patient who is no longer being seen by the service, but did not die whilst under their care.

6.3 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.

6.3.1 Other

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

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