



National Audit Office

## Results of censuses of Independent Hospices & NHS Palliative Care Providers



National Audit Office

2008

# END OF LIFE CARE

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## Results of censuses of Independent Hospices & NHS Palliative Care Providers

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## Context for the censuses

1. During the course of 2008 we conducted two censuses of independent hospices and NHS inpatient palliative care providers covering a wide variety of issues. This work formed one strand of the methodologies for our Report *End of life care*<sup>1</sup> which was published in November 2008.
2. End of life care services aim to support people approaching the end of their life to live as well as possible until they die. End of life care is often delivered by a large number and wide variety of generalist staff although the exact number of people involved in delivering this care is not known.
3. Specialist palliative care is an aspect of end of life care delivered by health and social care staff with specific training in the management of pain and other symptoms and the provision of psychological, social and spiritual support. Around 5,500 staff work in specialist palliative care with a significant proportion doing so in either a hospice or palliative care unit.
4. Hospices provide care and support to people at the end of their life and their carers, through a range of services such as inpatient care, day care, community services, out patient appointments, sitting services, respite care and bereavement counselling. The first modern hospice was opened in south London in 1967 and, since then, hospice care has developed into a movement to change the way in which end of life care is delivered.
5. Most hospices in England are independent local charities which are part funded by the NHS, although some hospices operate nationally. A number of hospices and inpatient palliative care units are also provided by the NHS.
6. This document presents a summary of the quantitative results from the censuses. Unless specifically stated otherwise, all percentages and averages stated are the “valid” values i.e. they exclude blank and not applicable responses. It should be noted that our findings are based on self reported data, and whilst every effort has been made to verify answers and remove any outliers, the accuracy of all figures can not be guaranteed.
7. Where appropriate we have also included Minimum Dataset (MDS) values for 2006-07 for reference<sup>2</sup>. The MDS is collected by the National Council for Palliative Care through an annual survey of all specialist palliative care providers in England, Wales and Northern Ireland. The data includes information such as level of activity and demographics of patients receiving services.
8. We present our findings by first analysing results from the Independent and NHS hospices separately, and finish with a direct comparison of some of the more interesting features of the two.

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<sup>1</sup> End of Life Care Report by the Comptroller and Auditor General HC 1043 Session 2007-08

<sup>2</sup> All references to the MDS in the report below refer to 2006-07 figures unless stated otherwise.

## Part 1: Census of Independent Hospices

### Background

- 1.1. There are 155 adult independent hospices in England including 7 operated by Marie Curie Cancer Care and 6 by Sue Ryder Care.
- 1.2. We piloted the census with five hospices, and received final responses from 104 out of 155 (a response rate of 67 per cent) between March and May 2008.
- 1.3. In addition to using the results of the census to inform our report *End of life care* we also prepared feedback reports for each respondent to enable them to benchmark their responses against other hospices nationally.

### Activity

- 1.4. Respondents were asked to provide a range of data on the volume of key services they provided in 2006-07. The responses in respect of the number of inpatient beds, day care attendances, outpatient attendances, respite care and community services are analysed below along with the number of patients reported as receiving each service.

#### Inpatients

- 1.5. The range of available inpatient days provided by hospices in 2006-07 was 865 to 15,207 with a mean of 4,554 (n=94<sup>3</sup>). The mean length of stay<sup>4</sup> by patients ranged from 6.7 to 21.8 days with a mean stay of 13.2 days (n=94). This compares to an average of 12.9 days as per the MDS.
- 1.6. The average proportion of hospice beds that were occupied over the course of 2006-07<sup>5</sup> ranged from 57 to 98 per cent with a mean of 76 per cent (n=92). In total respondents to our census provided 428,049 days (n=94) of inpatient care in 2006-07. The corresponding total figure from the MDS was 448,996 days

#### Day Care

- 1.7. Respondents reported providing between 7 and 6,141 attendances in 2006-07 with a mean of 2,024 (n=99). The corresponding mean value from the 2006-07 MDS was 1,995. The average number of patients receiving day care support from each hospice was 186 with responses ranging from 25 to 2580 (n=99). The corresponding mean value from the MDS was 154 patients.
- 1.8. In total respondents reported that they provided 201,783 day care attendances to 18,433 patients. This implies that on average a patient attended 11 day care sessions at a hospice over the period of the

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<sup>3</sup> In this report the 'n' value represents the number of respondents who provided an answer to the question. For example 94 of the 104 respondents stated how many bed days they provided.

<sup>4</sup> which can be calculated by dividing the number of admissions by the number of inpatient days provided

<sup>5</sup> which can be calculated by dividing inpatient bed days by available bed days

census (n=99). The corresponding figure from the MDS was 273,354 attendances to 21,429 patients indicating 13 day care sessions were attended on average per patient.

### **Out Patients**

1.9. Respondents provided 14 to 4,864 attendances in 2006-07 with a mean of 869 (n=66). The corresponding mean from the MDS was 768 attendances per hospice. The mean number of patients receiving out patient support from a hospice was 305 ranging from 25 to 1,254 (n=63). The corresponding mean from the MDS was 257.

1.10. In total respondents to our census provided 57,356 day care attendances to 19,244 patients. This implies that on average a patient attended 3 out patient sessions at a hospice over the period of the census (n=63). The corresponding figure from the MDS was 60,147 attendances to 20,308 patients.

### **Respite Care**

1.11. Our census defined respite care as any service with the purpose of providing a break and positive experience for the person with care needs and the carer where there is one. Respondents provided 11,843 days of inpatient care (n=30) and 2,380 sitting service attendances (staying with patients who are severely ill in order to let the carer rest or out other tasks such as shopping) (n=4)

1.12. Those patients who received an inpatient service received an average of 9.2 days of inpatient respite care and those patients who received a sitting service received an average of 5.7 contacts of this form of respite care.

### **Bereavement Care**

1.13. Respondents provided 94,588 face-to-face bereavement support contacts in 2006-07 (n=94). This corresponded to a MDS figure of 94,737 contacts (n=93). In total, respondents reported supporting a total of 26,635 family members. The mean number of family members supported per hospice was 310 (n=86). This gives an approximate mean of 3.6 contacts per family member supported.

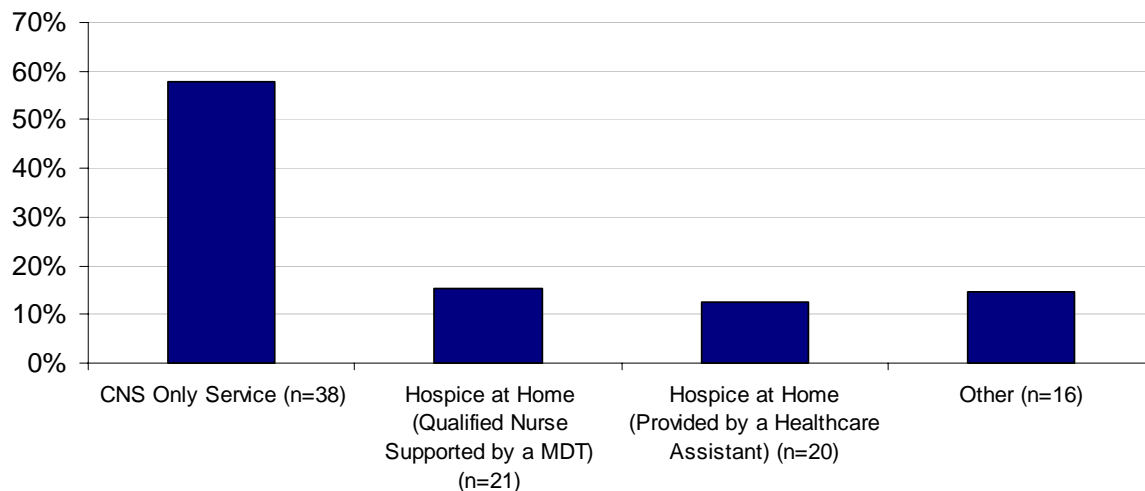
1.14. The corresponding figures from the MDS was a total of 94,737 contacts (n=93) with 25,056 family members supported which equates to a mean of 275 member per hospice (n=91).

1.15. Although a crude measure of the wider activity of hospices this shows that hospices which offer bereavement services provide support to 2.4 family members per death (n=83).

### **Community Services**

1.16. Figure 1 shows the number of hours of each community service provided as a proportion of the total amount of community care which respondents provided. The total number of community care hours provided was 870,175.

**Figure 1: Number of hours of each service provided by independent hospices as a proportion of the total number of community care hours**



NAO census of independent hospices in England

1.17. Only a small number of hospices were able to provide data on the place of residence for patients receiving community care. However, those who were able to reported that the majority, 13,206, were living in their own home (n=22), whilst 524 were resident in a care home (n=13) and 2,607 in another type of residence (n=10).

## Patients

1.18. Respondents were asked to provide a range of data on the number and demographics of patients who died in 2006-07 having received at least one service from their hospice.

1.19. Respondents reported that 45,051 patients who were receiving one or more service from them died in 2006-07. This ranged from 5 to 1,935 with a mean of 446 per hospice (n=101).

1.20. The proportion of patients who died with a primary diagnosis of cancer ranged from 56 per cent to 100 per cent with a mean of 88 per cent (n=65) (CI<sup>6</sup> 95% [82,94]). This proportion is smaller than the 92.7 per cent of inpatients in England who had a primary diagnosis of cancer as reported by the MDS 2006-07.

1.21. Breakdowns of the age, gender and ethnicity of those who died having received at least one service from a hospice in 2006-07 are displayed in Table 1 and Table 2 below.

<sup>6</sup> The respondents to this survey are only a sample of the total ‘population’ of hospices. This means that we cannot be certain that the figures obtained are exactly those we would have if every hospice had responded (i.e. the ‘true’ values). We can, however, predict the expected variation between the sample results and the ‘true’ values from knowledge of the size of the sample on which the results are based and the number of times that a particular answer is given. The confidence with which we have chosen to make this prediction is 95% (i.e. the chances are 95 in 100 that the ‘true’ value will fall within the specified range). So in this example we are 95 per cent confident that the ‘true’ mean proportion of patients who died with a primary diagnosis of cancer lies between 82 per cent and 94 per cent

Age	Male	Female	Total	% Total	% Excluding not known
16-24	27	27	54	0.1%	0.15%
25-64	5026	5489	10,515	27.6%	28.32%
65-74	5199	4697	9,896	25.9%	26.65%
75-84	6062	5592	11,654	30.6%	31.38%
85 and over	2427	2588	5,015	13.1%	13.51%
Not Known	501	511	1012	2.7%	
Total	19,242	18,904	38,146		

NAO census of independent hospices

	Proportion	Proportion excluding not known/ stated
White	70.6%	96.2%
Asian	0.9%	1.2%
Black	1.2%	1.7%
Chinese	0.1%	0.1%
Other Ethnic Group	0.4%	0.5%
Mixed	0.2%	0.3%
Not Stated/ Not Known	26.5%	

NAO census of independent hospices

- 1.22. The results in Table 2 would seem to add weight to the widely held belief that British Minority Ethnic (BME) groups and older people access less hospice services than the rest of the population. The 2006-07 MDS showed that for hospices who could provide the data 4.7 per cent of new patients were non-white, the largest proportion of which were black (African, Caribbean or other). Our census showed that 3.7 per cent of hospice patients who died in 2006-07 were from BME communities.
- 1.23. ONS Mortality Statistics show that in 2006 18 per cent of deaths from cancer in adults occurred in groups over 85 years of age. Our census data indicates however that only 14 per cent of patients with all conditions who died in 2006-07 having accessed at least one service from a hospice were in this age range. This shows there is a small but statistically significant difference ( $p < 0.05$ )<sup>7</sup> between the number of people over 85 who die of cancer and the number of people in this age group who access hospice services. The difference may be smaller than expected however and the under representation of elderly people in hospice services (the over 85s account for a third of all deaths) might be explained by the prevalence of cancer deaths in this group.

<sup>7</sup> A t-test performed on the data utilised indicates that there is less than a 5% chance of this result occurring simply by coincidence.

- 1.24. Research indicates that this lower proportion of ethnic minorities accessing specialist palliative care may be due to the lower prevalence of cancer among ethnic minorities, which is the primary diagnosis of the majority of hospice patients, and cultural differences such as attitudes towards death and the responsibility of family members<sup>8</sup>.
- 1.25. The vast majority of hospices (94 per cent n=87) reported surveying, interviewing or carrying out focus groups of patients and carers in order to improve services.

## Finances

- 1.26. Respondents were asked to provide data covering various aspects of their finances including the level and sources of their income and the level and proportion of their expenditure across a range of services and commodities.

### Expenditure

- 1.27. The revenue expenditure reported by respondents for hospices in 2006-07 ranged between £101k and £12 million with a mean of £3.7 million and a median of £3.0 million (n=99). The total revenue expenditure in 2006-07 by the respondents was £343 million (n=94).
- 1.28. It should be noted that hospices run by Sue Ryder Care and Marie Curie Cancer Care are part of national charities, and as such their fundraising costs and central overheads do not appear in individual hospice's accounts. The mean value for total expenditure increases to £3.8 million if these hospices are excluded from the results.
- 1.29. Data from Help the Hospices, based on a review of hospice accounts, indicates that non respondents to our census had on average 50 per cent less expenditure than those who responded. It is therefore not possible to perform a simple extrapolation of our respondents' total figure to get a total expenditure for all hospices. If the data from our census is combined with an assumption based on this indication that non respondents had 50 per cent less expenditure than those who responded, a figure of £494 million is arrived at. This compares to a total expenditure for 2006-07 of £499 million derived in the work by Help the Hospices. We thus estimate that in 2006-07 adult independent hospices spent between £494 million and £499 million.
- 1.30. The proportion of expenditure spent on a range of services and commodities is displayed in Table 3. It should be noted that care must be taken in interpreting this analysis as due to an error in the question structure all of the below were presented in one table, rather than splitting firstly by type of service (inpatient, community and day care) and then by components of services (staff costs drugs etc). Obviously the cost of providing a service such as inpatient care will be made up of staff costs, medicine costs etc. Because of this error and the way respondents will have interpreted the question we would not expect the totals provided to sum to the figure given for total revenue expenditure. However, the answers should provide a high level guide to what the major costs for hospices are.

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<sup>8</sup> Smaje and Field. *Absent minorities? Ethnicity and the use of palliative care services*. 1997.



Table 3: Proportion of expenditure spent by independent hospices on a range of services and commodities				
	n	Min %	Max %	Mean %
Inpatient	63	1	83.6	34.4
Nursing Staff	49	8.4	54.4	28.4
Other Staff	51	0.9	33.7	15.4
Other	51	0.62	55.4	14.2
Day Care	66	0.1	88.7	10.2
Other Clinical Staff	38	0.3	38.4	9.0
Medical Staff	51	0.8	18.6	7.4
Fundraising Staff	55	1.3	24.1	7.4
Fundraising non Staff	54	0.3	19.3	6.4
Respite	8	0.1	17.9	5.7
Maintenance	55	0.03	16.4	2.9
Drugs	30	0.03	8.3	2.7
Medical Equipment	51	0.1	7.1	1.5
Transport	46	0.04	5.2	0.9
Media	36	0.04	1.5	0.5

NAO survey of independent hospices

1.31. Our analysis indicates that, for those hospices which offer an inpatient service, then this represents largest proportion of their expenditure and that the major component within this is staff costs (specifically nursing costs) rather than medical equipment or drugs.

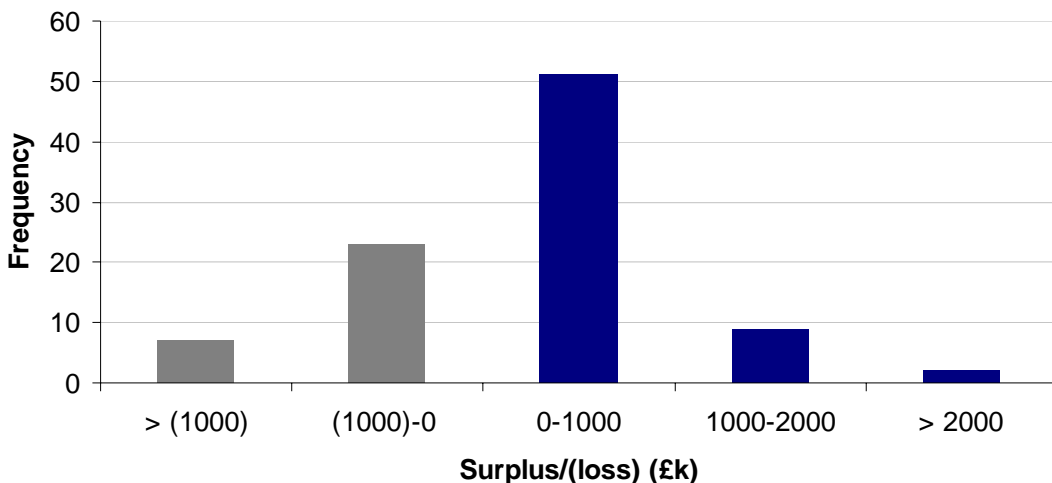
### Income

1.32. Respondents reported that their total income for 2006-07 (excluding money given specifically for capital projects) ranged between £2k and £13.6 million with a mean of £3.9 million and a median of £3.3 million (n=95).

1.33. The total revenue income in 2006-07 received by our respondents was £367 million (n=95). Data from Help the Hospices, based on a review of hospice accounts, indicates that non respondents to our census had on average 50 per cent less income than those who responded. It is therefore not possible to perform a simple extrapolation of our respondents' total figure to get a total income for all hospices. If the data from our census is combined with an assumption based on this indication that non respondents had 50 per cent less expenditure than those who responded, a figure of £487 million is arrived at. This compares to a total expenditure for 2006-07 of £552 million derived in the work by Help the Hospices. We thus estimate that in 2006-07, adult independent hospices spent between £487 million and £552 million.

1.34. Our data shows that for 36 hospices (33 per cent) expenditure exceeded income in 2006-07, whilst 62 (66 per cent) were left with a surplus. The range of surpluses/losses generated by hospices in 2006-07 is summarised in Figure 2.

**Figure 2: Net surplus/loss generated by responding independent hospices in 2006-07**



NAO census of independent hospices

**Source of Income**

1.35. Our census showed that on average hospices derived 30 per cent of their income from the state (principally via Primary Care Trusts who commission their services, with small amounts of additional funding from Strategic Health Authorities and Central Government), 41 per cent from charity donations (principally donations and legacies) and the remainder from other sources such as income from shops and investment income. The minimum, maximum and mean proportion of funding received by respondents from various sources is set out in Table 4

	n	Min %	Max %	Mean %
Proportion State Funding	93	1.2	100.0	31.6
Proportion Charity Donations	86	5.2	77.4	40.7
Proportion Net Trading Profit	73	(11.0)	54.6	11.5
Proportion Investment Income	84	0.1	62.6	4.6
Sundry Income	65	.02	39.5	6.9

NAO census of independent hospices

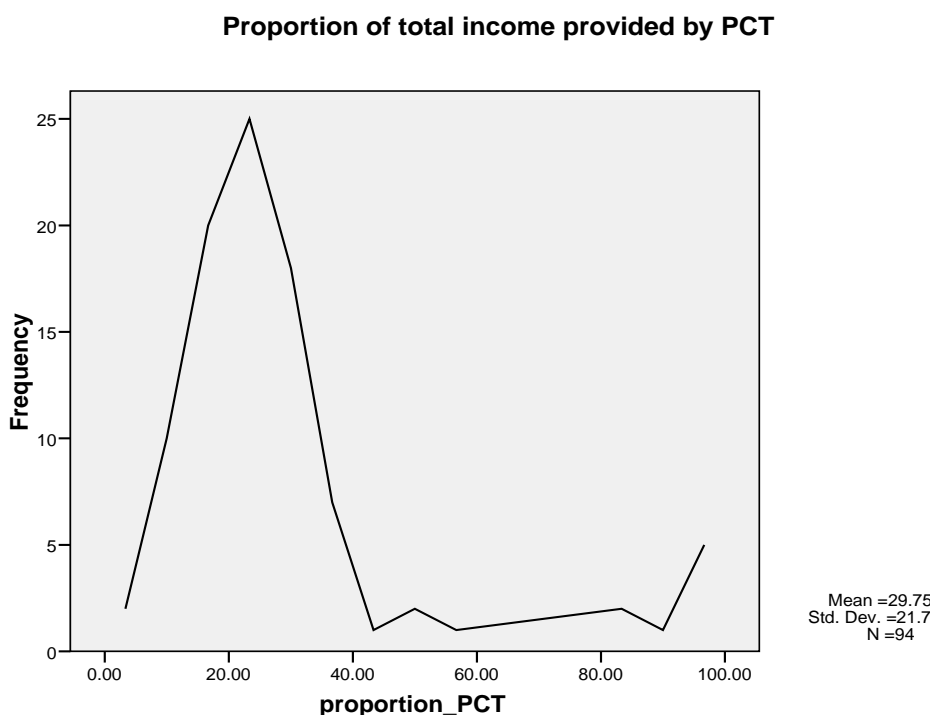
1.36. Work by Help the Hospices examining Hospice accounts shows that in 2006-07 the mean proportion of their total income provided by PCTs to adult independent hospices was 23 per cent with a median of 31 per cent however this figure ranged from less than 5 per cent to 62 per cent.

1.37. Our census also shows considerable variation in the proportion of funding which PCTs provide to hospices, with one respondent reporting that they received just 0.99 per cent of funding from the PCT and six stating that over 90 per cent of their income came from PCTs. It should be noted however, that all bar one of the hospices which stated they receive more than 62 per cent of their income from the PCT were Marie Curie or Sue Ryder run hospices.

1.38. As noted in paragraph 1.28, hospices run by Sue Ryder Care and Marie Curie Cancer Care are part of national charities, and as such their fundraising costs and central overheads do not appear in individual hospice’s accounts. This has the effect of making it appear that a higher proportion of their income is provided by PCTs than is actually the case.

1.39. Thus whilst our analysis also shows that on average hospices received 30 per cent of their income from PCTs as illustrated in Figure 3, this decreases to 26 per cent if Marie Curie and Sue Ryder centres are removed from the analysis.

**Figure 3: Funding provided by PCT(s) as a proportion of total independent hospice income**



NAO census of independent hospices

1.40. Our respondents received £159 million from charity in 2006-07 (n=93) equating to £1.7 million per hospice. If we assume that non respondents are not atypical then we can estimate that hospices in England received £264 million in charitable donations in 2006-07 from donations, legacies and community and opportunity funds<sup>9</sup>.

1.41. As is the case with the estimates of income and expenditure, however, this is likely to be an overestimate since there is evidence that hospices which did not respond to our census were smaller than those that did. However, the mean proportion of funding derived from charitable donations by respondents to our census was 41 per cent. If this is assumed to be consistent across all hospices regardless of size then we can use the estimate of income (£422 million to £556 million) to estimate that hospices in England received between £173 million and £230 million from charitable donations.

<sup>9</sup> This figure is derived by multiplying the mean by the total number of hospices (155)

1.42. In order to generate the level of charitable income required many hospices employ professional fundraisers. 82 of our respondents (79 per cent) reported employing fundraisers, with the number of Whole Time Equivalents (WTE) employed ranging from 1 to 33 with a mean of 7.6.

## Commissioning

1.43. Hospices were asked to provide information on the process by which PCTs commission their services by PCTs. Respondents were also asked to rate their satisfaction with the resulting contracts with PCTs.

1.44. Just 3 hospices (3.1 per cent) (CI 95% [82,94]) stated that they felt PCT funding sufficiently reimbursed them for the NHS services they provide (n=97). The deficit between income from PCTs and hospices' estimate of the amount they needed to be paid to cover NHS services as defined in NICE guidance<sup>10</sup> ranged from £40k to £9.4 million with a mean deficit of £4.3 million (n=42)<sup>11</sup>.

1.45. Hospices were asked to estimate the time spent negotiating contracts with PCTs in 2006-07. The mean answer was 30 hours (n=88). The majority of respondents (52 per cent) stated that more time should be spent negotiating contracts with PCTs (n=97).

1.46. Whilst some hospices provide services exclusively to one PCT, others provide services to multiple PCTs. As the Table 5 illustrates, the majority of hospices provide services to one or two PCTs.

Number of commissioning PCTs	Frequency	Percentage
1	46	45.1
2	34	33.3
3	9	8.8
4	4	3.9
5	4	3.9
7	2	2.0
8	2	2.0
9	1	1.0
Total	102	

NAO census of independent hospices

1.47. Respondents reported that 50 per cent of contracts between PCTs and hospices are Service Level Agreements (SLAs), the majority of which are in place for 1 year only, as shown in Table 6.

<sup>10</sup> Improving Supportive and Palliative Care Services for Adults with Cancer (2004)

<sup>11</sup> Note respondents who stated they required less than they were being provided with have been excluded

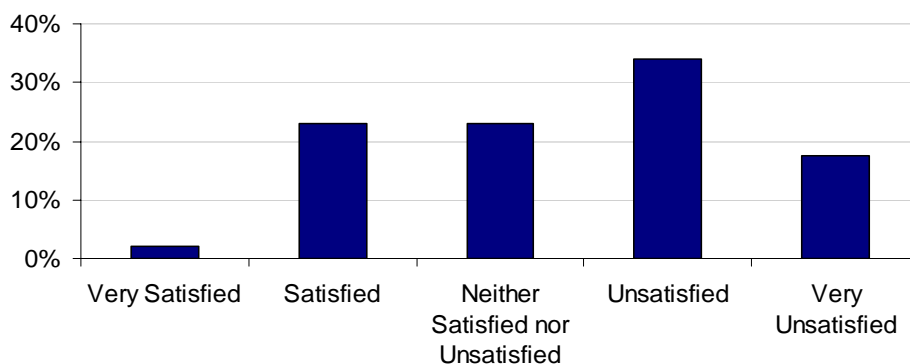
**Table 6: Lengths of contracts with independent hospices for services to PCTs**

Length of contract	Frequency	Percentage
1 year	115	70.6%
2 year	8	4.9%
3 year	36	22.1%
4 year	0	0.0%
5 year	3	1.8%
More than 5 years	1	0.6%

NAO census of independent hospices

1.48. Figure 4 shows the response to the question “to what extent are you satisfied or dissatisfied with the type of contract you have with the PCT?” Fifty two per cent reported being unsatisfied or very unsatisfied.

**Figure 4: Independent hospices’ satisfaction with contracts with PCT(s)**



NAO census of independent hospices

1.49. At the point of response (March-May 2008) 56 per cent of respondents reported having agreed funding for 2008-09, 8 per cent for 2009-10 and 4 per cent for 2010-11.

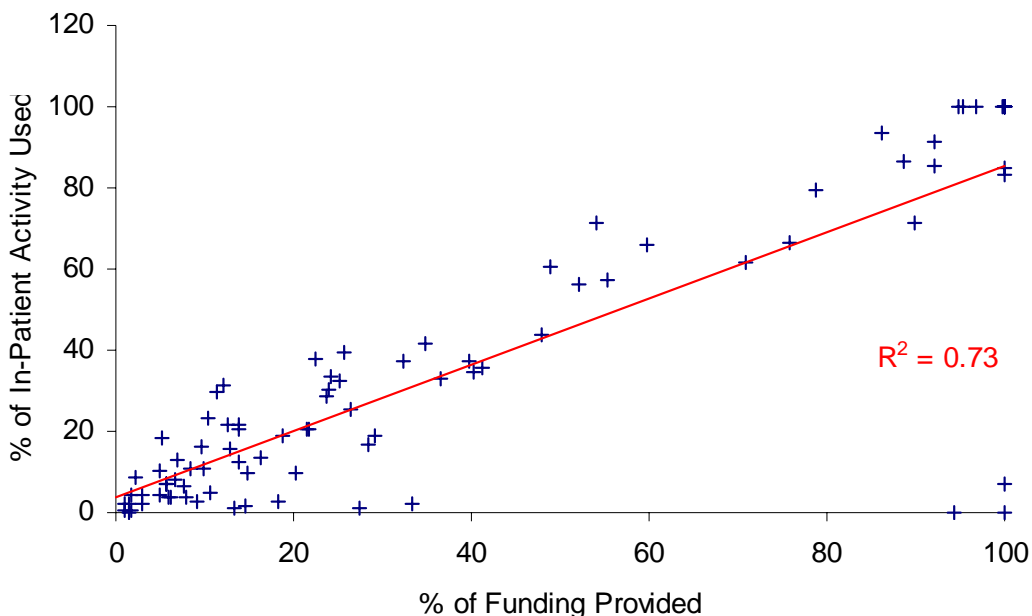
1.50. Established in 1998 the Compact is the agreement between government and the voluntary and community sector to improve their relationship for mutual advantage and community gains. The Commission for the Compact has issued guidance on funding and procurement the principles of which might be best captured as ensuring contracts are transparent, stable, formalised and representative of service. Hospices were asked to rate each contract they hold with a PCT out of 10 (where 1 is very poor and 10 is excellent) for each of these attributes. The results, as set out in Table 7, suggest that PCTs are far from putting the principals of the compact into place.

Table 7: Independent hospice ratings of PCT contracts in respect of Compact principles				
	Min	Max	Mean	Mode
Transparent	1	10	4.4	2
Stable	1	10	4.4	5
Formal	1	10	4.3	5
Representative of level of service	1	10	3.3	1

NAO census of independent hospices

1.51. Although not a perfect measure, it is possible to look at how representative funding is of level of service by measuring the correlation between the proportion of PCT income an individual PCT provides and the proportion of each service (inpatient, community care, day care, outpatients, respite and bereavement counselling) it uses.

Figure 5: PCT Inpatient Activity Against Funding



NAO census of independent hospices

1.52. An example of this is shown in Figure 5 where the proportion of inpatient bed days used is plotted against proportion of PCT income provided.

1.53. The R<sup>2</sup> value is a measure of the degree of correlation between 2 variables where R<sup>2</sup>=1 represents perfect positive correlation and R<sup>2</sup>=0 represents a complete lack of correlation. The R<sup>2</sup>=0.73 result shown in Figure 5 indicates there is good correlation between the amount of funding a PCT provides and the amount of inpatient activity it uses. The corresponding measure for other types of care are displayed in Table 8 below.

Type of Care	R <sup>2</sup>
Inpatient	0.73
Community	0.21
Day Care	0.68
Out Patient	0.75
Bereavement	0.91

NAO census of independent hospices

1.54. Care must be taken in interpreting these results due to the fact that costs for types of care will vary significantly and PCTs might be purchasing a different range of care services for their patients. As a result the level of correlation between utilisation of any one type of care and the proportion of funding provided is unlikely to be perfect. However, since inpatient care forms the majority of service costs for hospices which provide it (see paragraph 1.31) then it is reasonable to expect that the level of correlation between the amount of this form of care provided to any PCT and the proportion of income provided by the same PCT to be amongst the highest if funding is representative of level of service. Our results confirm that this is the case, however whilst correlation is good it is clear there remains a number of examples of PCTs whose utilisation of inpatient activity is not well matched to the proportion of funding they provide.

## Staff

1.55. Our census asked hospices to provide details of the number of whole time equivalent (WTE) staff in post involved in the delivery of end of life care.

1.56. The range and mean of the WTE staff in post and the WTE vacancies as at 31 March 2007 are shown below in Table 9 and Table 10:

	n	Min	Max	Mean
Doctors	90	0.1	14.0	4.5
Nurses	97	1.0	123.0	41.9
Others	97	2.0	148.0	27.2

NAO census of independent hospices

	n	Min	Max	Mean
Doctors	20	1.0	5.0	1.7
Nurses	45	1.0	46.0	5.3
Others	45	1.0	25.0	3.6

NAO census of independent hospices

1.57. The results indicate that whilst the majority of respondents had no vacancies, those that did had a significant number of unfilled posts. The ratio of doctors to nurses backs up findings in the Income Expenditure section that the majority of hospice staff costs are for nurses.

## End of Life Care Tools

1.58. We asked hospices to provide data on their usage of the three main end of life care tools, the Liverpool Care Pathway, the Gold Standards Framework and Preferred Priorities for Care (formerly Preferred Place of Care) along with details of any other tools or modified versions of the above. We also asked hospices to rate the improvement in end of life care services as a result of using these tools.

1.59. Table 11, Table 12 and Table 13 below show the number of hospices using the three main end of life care tools. By far the most frequently used is the Liverpool Care Pathway. Twenty respondents reported using other tools, the majority of which, based on the descriptions given, seem to be local pathways or adaptations to the national tools.

Table 11: Usage of the Liverpool Care Pathway (LCP)					
		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percentage
Valid Responses	Yes	89	85.6	89.0	89.0
	No	11	10.6	11.0	100.0
	<b>Total</b>	<b>100</b>	<b>96.2</b>	<b>100.0</b>	
Missing Responses		4	3.8		
<b>Total</b>		<b>104</b>	<b>100.0</b>		

Table 12: Usage of the Gold Standards Framework (GSF)					
		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percentage
Valid Responses	Yes	58	55.8	65.9	65.9
	No	30	28.8	34.1	100.0
	<b>Total</b>	<b>88</b>	<b>84.6</b>	<b>100.0</b>	
Missing Responses		16	15.4		
<b>Total</b>		<b>104</b>	<b>100.0</b>		

NAO census of independent hospices



		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percentage
Valid Responses	Yes	53	51.0	61.6	61.6
	No	33	31.7	38.4	100.0
	<b>Total</b>	<b>86</b>	<b>82.7</b>	<b>100.0</b>	
Missing Responses	System	18	17.3		
<b>Total</b>		<b>104</b>	<b>100.0</b>		

NAO census of independent hospices

1.60. Respondents were asked to rate each tool out of 10 for the difference engaging with it had made to the standard of end of life care offered, where 1 is no improvement and 10 is a significant improvement. The ratings given are summarised in Table 14.

	Min	Max	Mean	Median
LCP	1	10	6.7	7
GSF	2	10	6.9	7
PPC	1	10	5.6	5
Other	1	10	7.3	8

NAO census of independent hospices

1.61. Although it is used less frequently than the Liverpool Care Pathway, the Gold Standards Framework was seen by those that use it to make the biggest difference to patient care (89 per cent of respondents used Liverpool Care Pathway whilst 66 per cent use Gold Standards Framework but the mean ratings are 67 and 6.9 respectively)<sup>12</sup>. Although mainly considered a tool for primary care these results suggest that this tool may have a wider application and that it may be worth considering its application in specialist palliative care settings.

## External Services

1.62. Respondents were asked to rate a series of external services out of 10 (where 1 is well below requirements and 10 is well above requirements) on how well they met patients' and carers' needs at the end of life. The results are displayed in Table 15.

<sup>12</sup> Note the difference in mean ratings is not statistically different

**Table 15: Rating of external services by independent hospices**

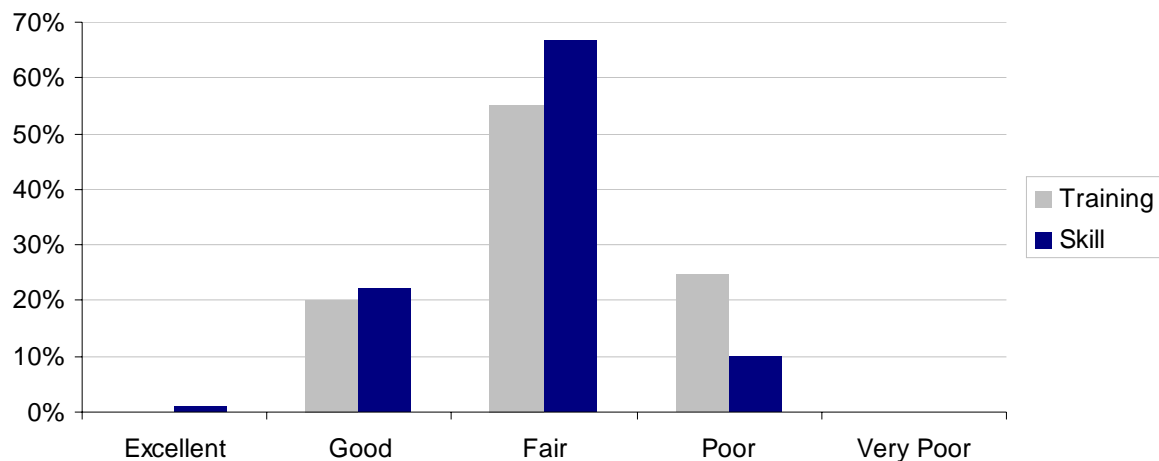
	Min	Max	Mean	Median
Out of hours services including access to palliative care medication	1	10	4.7	5
Out of hours services including access to palliative care equipment	1	10	4.0	4
Integration with residents' GPs surgeries	1	10	5.2	5
Integration with other primary care services	1	10	5.4	5
Integration with secondary care e.g. for blood results	1	10	5.5	6
Integration with social services	1	9	4.1	4
Commissioning of end-of-life care by PCTs	1	10	4.2	4

NAO census of independent hospices

1.63. Clearly hospices feel they are not as well supported by external services as they could be and there is considerable room for improvement to better meet the needs of patients and carers.

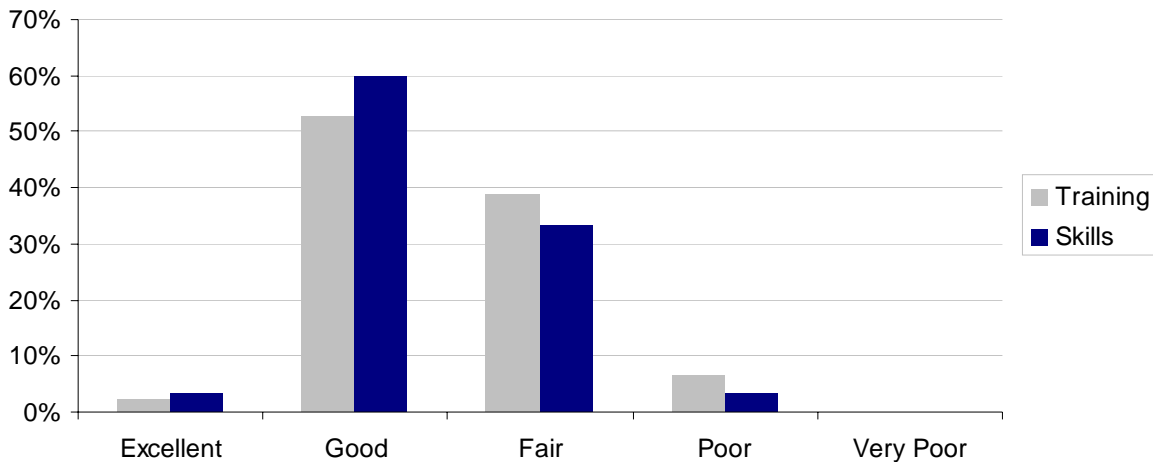
1.64. Respondents were also asked to rate the skills and training of staff working outside specialist palliative care who are likely to be involved in the care of patients approaching the end of their lives. The results are displayed for each profession in Figure 6 through Figure 12.

**Figure 6: Independent hospices' ratings of the skills and level of training of Primary Care Staff e.g. GPs and Practice Nurses**



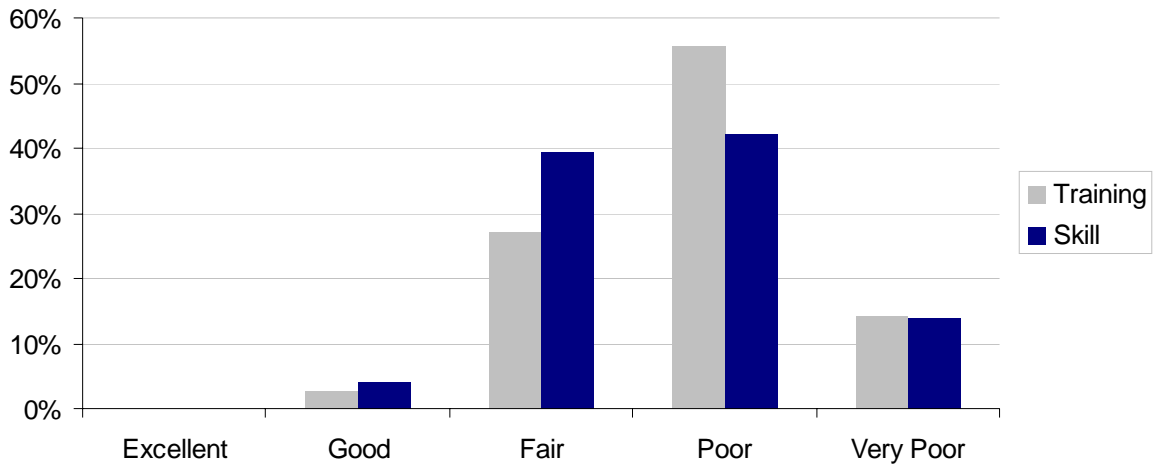
NAO census of independent hospices

**Figure 7: Independent hospices' ratings of the skills and level of training of Community Based Nursing Staff e.g. Community Nurses**



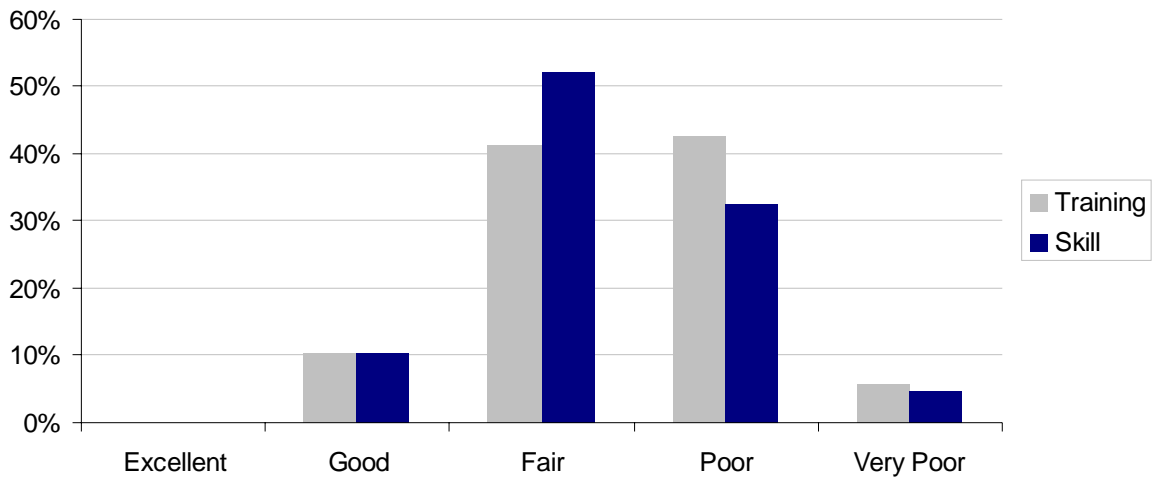
NAO census of independent hospices

**Figure 8: Independent hospices' ratings of the skills and level of training of Community Based Nursing Staff e.g. Community Psychiatric/Mental Health Nurses**



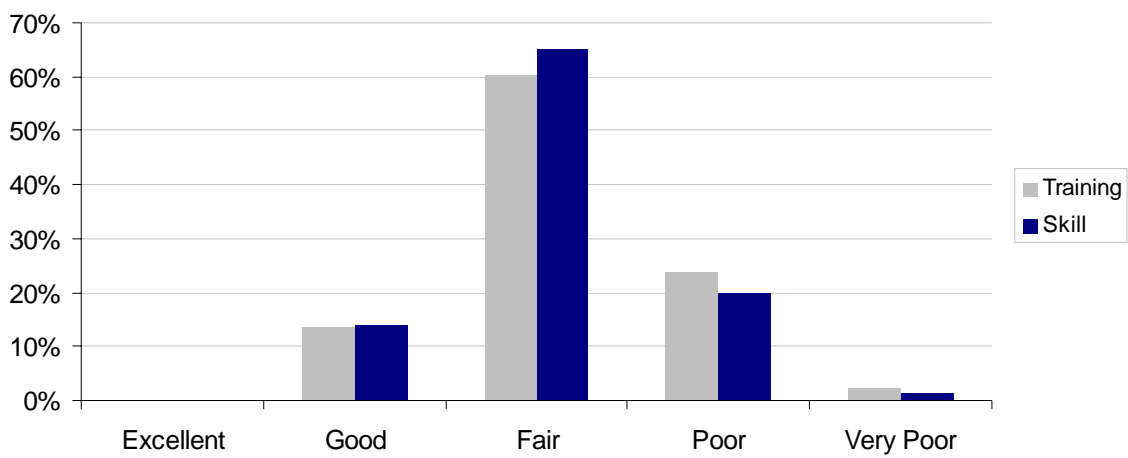
NAO survey of independent hospices

**Figure 9: Independent hospices' ratings of the skills and level of training of Medical Staff in Acute Secondary Care**



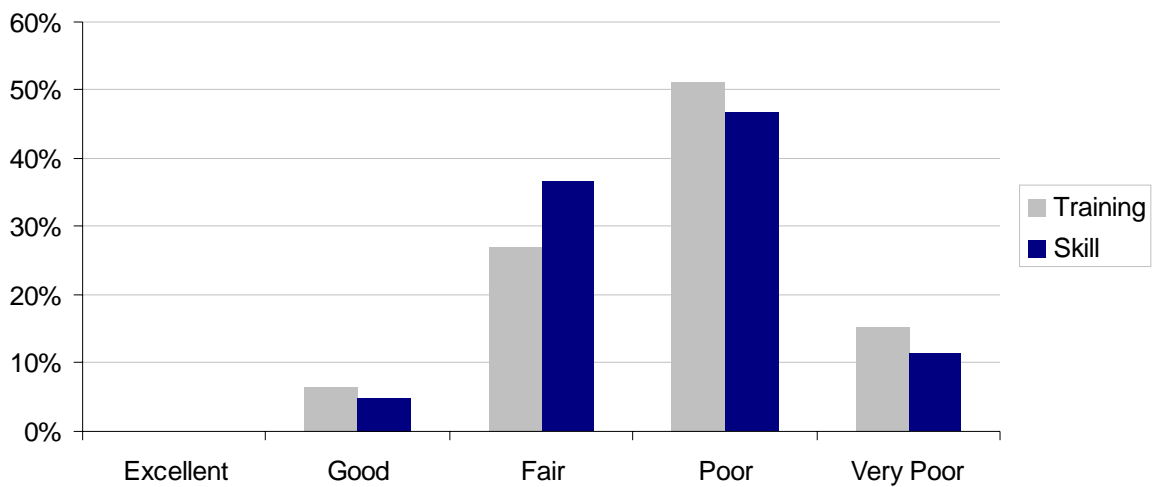
NAO census of independent hospices

**Figure 10: Independent hospices' ratings of the skills and level of training of Nursing Staff in Acute Secondary Care**



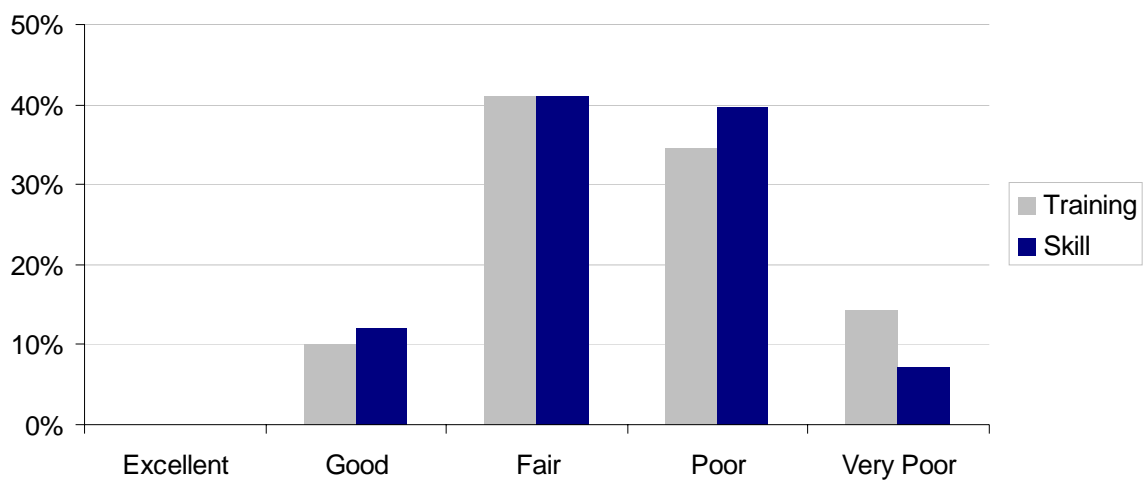
NAO census of independent hospices

**Figure 11: Independent hospices' ratings of the skills and level of training of Home Care Social Service Staff**



NAO census of independent hospices

**Figure 12: Independent hospices' ratings of the skills and level of training of Staff in Nursing/Personal Care Homes**



NAO census of independent hospices

1.65. The proportion of hospices awarding 'good' or 'excellent' ratings for training or skills for staff working outside specialist palliative care are summarised in Table 16 and Table 17. In terms of skill Community Nurses were rated the highest with 63 per cent of respondents rating their skills as good or excellent.

**Table 16: Summary of independent hospices' ratings of level of training of staff working outside specialist palliative care**

Staff type	% Good or Excellent
Community Based Nursing Staff: District Nurse	55%
Primary Care staff e.g. GPs and Practice Nurses	20%
Nursing Staff in Acute Secondary Care	14%
Medical Staff in Acute Secondary Care	10%
Staff in nursing/personal care homes	10%
Home Care Social Services	6%
Community Based Nursing Staff: Community psychiatric /mental health nurses	3%

NAO census of independent hospices

**Table 17: Summary of independent hospices' ratings of level of skill of staff working outside specialist palliative care**

Level of Skill	% Good or Excellent
Community Based Nursing Staff: District Nurse	63%
Primary Care staff e.g. GPs and Practice Nurses	23%
Nursing Staff in Acute Secondary Care	14%
Staff in nursing/personal care homes	12%
Medical Staff in Acute Secondary Care	11%
Home Care Social Services	5%
Community Based Nursing Staff: Community psychiatric /mental health nurses	4%

NAO census of independent hospices

- 1.66. Hospices were also asked to provide information on the volume of training they offer to external staff. Fifty six respondents reported providing training to a total of 17,734 external staff; whilst 53 respondents reported that they provided a total of 70,786 hours of training to external staff.

## Volunteers

- 1.67. Our census asked hospices to detail the level of services that they receive free of charge from volunteers. The results indicate that volunteers provide a significant proportion of hospice activity with respondents reporting receiving over 4.4 million hours of donated time in 2006-07 (n=85). This equates to a mean of 51,983 hours per hospice.
- 1.68. The biggest proportion of donated time was for fundraising (40 per cent of all donated time). This was followed by other (35 per cent) which respondents stated includes tasks such as shop staff, receptionists, gardeners and drivers. Next were care volunteers (20 per cent), trustees (3 per cent) and complementary therapists (2 per cent).
- 1.69. In 2006, Help the Hospices estimated the value of volunteer time by surveying hospices on the number of volunteer hours they were provided with, and what it would have cost per hour (excluding overheads) had they had to employ someone to perform the tasks which volunteers undertook. Their analysis was that the volunteer value (vv) of time given to all adult and children's Independent hospices in England was £112 million
- 1.70. Our census asked hospices to estimate what they would have had to pay per hour (excluding overheads) to employ someone to provide the fundraising, carer, complementary therapist and other roles which

volunteers carry out. This was then multiplied by the number of donated hours in each category to estimate the value of volunteer time which is donated. This gave a value from those who responded of £28 million or £446k per hospice (n=62). If we assume no significant differences between respondents and non respondents then we estimate that voluntary hospices in England received time donated by volunteers which would have cost £69 million<sup>13</sup>. However, it should be noted that analysis of hospice accounts by Help the Hospices indicates that non respondents to our census were significantly smaller in terms of income and expenditure than those hospices which did respond and so may have received less donated time.

- 1.71. If a 30 per cent overhead cost is applied to this to cover pensions, National Insurance contributions and sick pay then the extrapolated vv for all adult hospices in England in 2006-07 was £89 million. This would represent about 18 per cent of total revenue expenditure in 2006-07 (See paragraph 1.29). However, a major caveat to this finding is that estimates of what it would have cost to employ someone to carry out the tasks performed by the volunteers were extremely variable. For example, the estimate of the cost per hour for a Complementary Therapist ranged from £5 to £30, and the estimated cost for a trustee ranged from £5.50 to £99.
- 1.72. To address this, the total number of volunteer hours was multiplied by the current minimum wage in England (£5.52) in order to obtain a value for volunteers' time. Whilst we realise that the true value of money saved through the use of volunteers is significantly greater than this, and this value does not take account of the wider value that community volunteers provide, it enables us to estimate a minimum value for the volunteer time contributed.
- 1.73. This gave a value of £24 million in total or £287k per hospice (n=85). Once again assuming that non respondents are not atypical in terms of the number of donated hours they receive then the minimum extrapolated vv in England in 2006-07 was at least £44 million. Again if a 30 per cent overhead cost is applied to this the minimum vv increases to £57 million. This would represent about 11 per cent of total revenue expenditure for 2006-07 (See Income and Expenditure Section). However, this does not take account of the fact that non respondents were significantly smaller than respondents as highlighted in paragraph 1.70.

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<sup>13</sup> Derived by multiplying the mean by 154

## Part 2: Census of NHS Inpatient Palliative Care Providers

### Background

- 2.1. There are 40 adult NHS palliative care units/hospices in England (hereafter referred to as NHS hospices)
- 2.2. We surveyed all 40 NHS hospices to gain the same data as requested from independent hospices. Responses were received from 24 NHS hospices (a response rate of 60 per cent).
- 2.3. As for the independent hospices, in addition to using the results of the census to inform our report **End of life care** we also prepared feedback reports for each respondent to enable them to benchmark their responses against other hospices nationally.

### Activity

- 2.4. Respondents were asked to provide a range of data on the volume of key services they provided in 2006-07. The responses in respect of the number of inpatient beds, day care attendances, outpatient attendances, respite care and community services are analysed below along with the number of patients reported as receiving each service.

#### Inpatients

- 2.5. The range of available inpatient days provided by NHS hospices in 2006-07 was 730 to 8,395 with a mean of 4548 (n=24). The mean length of stay<sup>14</sup> by patients ranged from 6.7 to 18.5 days with a mean stay of 12.1 days (n=24). This compares to an average of 12.0 days as per the MDS.
- 2.6. The average proportion of hospice beds that were occupied over the course of 2006-07<sup>15</sup> ranged from 52 to 94 per cent with a mean of 76.0 per cent (n=24). In total respondents to our census provided 84,415 days of inpatient care in 2006-07. The corresponding total figure from the MDS was 448,996 days

#### Day Care

- 2.7. Respondents reported providing between 0 and 3,210 attendances in 2006-07 (n=21). Excluding zero responses, i.e. NHS hospices which report they do not provide this service, gives a mean figure of 1,744 attendances (n=18) provided per NHS hospice. The corresponding mean value from the 2006-07 MDS was 1,995. The average number of patients receiving day care support from each hospice, again excluding zero responses, was 125 with responses ranging from 32 to 400 (n=17). The corresponding mean value from the MDS was 154 patients.

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<sup>14</sup> which can be calculated by dividing the number of admissions by the number of inpatient days provided

<sup>15</sup> which can be calculated by dividing inpatient bed days by available bed days



2.8. In total respondents to our census provided 31,394 day care attendances to 2,132 patients. On average<sup>16</sup> a patient attended 18.1 day care sessions at a hospice over the period of the census (n=17). The corresponding figure from the MDS was 273,354 attendances to 21,429 patients indicating 13 day care sessions were attended on average per patient.

### **Out Patients**

2.9. Respondents provided 0 to 3,844 outpatient attendances in 2006-07 (n=23) with a mean value, excluding zero responses of 714 attendances per NHS hospice (n=19). The corresponding mean from the MDS was 768 attendances per hospice. The mean number of patients receiving out patient support from an NHS hospice, again excluding zero responses, was 406 ranging from 3 to 2,622 (n=19). The corresponding mean from the MDS was 257.

2.10. In total respondents to our census provided 13,557 day care attendances to 6,496 patients (n=16). This implies that on average a patient attended 3 out patient sessions at a hospice over the period of the census (n=). The corresponding figure from the MDS was 60,147 attendances to 20,308 patients.

### **Respite Care**

2.11. Our census defined respite care as any service with the purpose of providing a break and positive experience for the person with care needs and the care where there is one. One respondent provided 5 inpatient respite visits for 5 inpatients whilst overall, respondents just indicated that some form of respite care had been received by 17 inpatients (n=5).

2.12. One other NHS hospice reported provided 2,346 sitting service attendances (staying with patients who are severely ill in order to let the carer rest or out other tasks such as shopping). Those patients who received a sitting service from this respondent received an average of 10.7 contacts of this form of respite care.

### **Bereavement Care**

2.13. Respondents provided 6,378 face-to-face bereavement support contacts in 2006-07 (n=18). This corresponded to a MDS figure of 94,737 contacts (n=93). In total, respondents reported supporting a total of 3,969 family members with a mean of 248 family members supported per NHS hospice (n=16). Each family member supported received on average 3.0 contacts.

2.14. The corresponding figures from the MDS was a total of 94,737 contacts (n=93) with 25,056 family members supported which equates to a mean of 275 member per hospice (n=91).

2.15. Although a crude measure of the wider activity of NHS hospices, our census data indicates that those NHS hospice which offer bereavement services provide support to 9 family members per death (n=15).

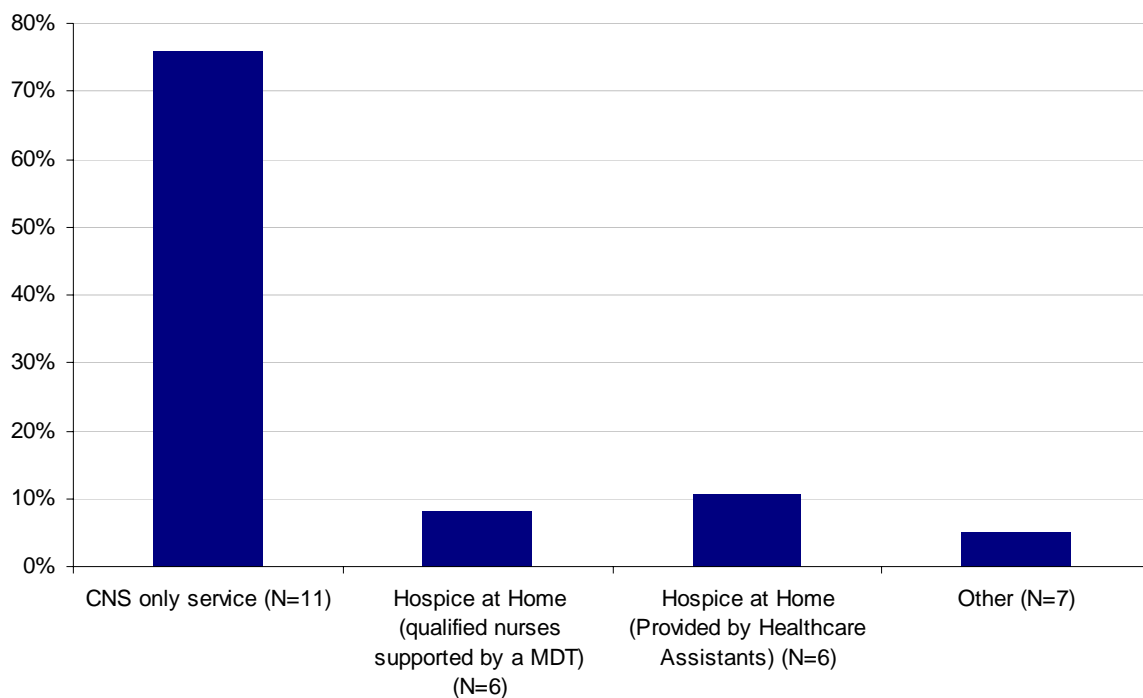
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<sup>16</sup> Average figure quoted is the mean average number of day care attendances provided by NHS hospice based on the data provided by each hospice. A simple average of the total attendances provided and total patients supported figures by all respondents indicates 15 attendances per patient.

### Community Services

2.16. Figure 13 shows the number of hours of each community service provided as a proportion of the total amount of community care which respondents provided. The total number of community care hours provided was 137,273.

**Figure 13: Number of hours of each service provided by NHS hospices as a proportion of the total number of community care hours**



NAO census of NHS inpatient palliative care providers

2.17. Only a small number of NHS hospices could provide data on the place of residence for patients receiving community care. However, those who were able to, reported that the vast majority (2,723) were living in their own home (n=3), whilst 208 were in a care home (n=3) and 141 in another type of residence (n=2). Those which provided data on what other places of residence they supported stated they do not record this data, or that the service was provided in an acute hospital.

### Patients

2.18. Respondents were asked to provide a range of data on the number and demographics of patients who died in 2006-07 having received at least one service from their hospice

2.19. Respondents reported that 10,009 patients who were receiving 1 or more service from them died in 2006-07. This ranged from 34 to 1,193 with a mean of 500 per hospice (n=20). The proportion of patients who died with a primary diagnosis of cancer ranged from 47 per cent to 100 per cent with a mean of 86 per cent, this is a significantly smaller than the 92.7 per cent of inpatients in England who

had a primary diagnosis of cancer as reported by the MDS 2006-07. This indicates that patients with non malignancies who receive hospice care are less likely than cancer patients to receive an inpatient admission. This is backed up by MDS figures which show a higher proportion of non-cancer patients receiving non inpatient services for example 87.2 per cent of patients who accessed day care from a voluntary hospice had cancer according the MDS (n=128)

2.20. A break down of the age and ethnicity of those who died having received at least one service from a hospice in 2006-07 is displayed in the tables below.

Age	Total	Per cent	% Excluding Unknowns
16-24	41	0.4%	0.6%
25-64	2260	24.8%	32.0%
65-74	1762	19.3%	25.0%
75-84	2002	22.0%	28.4%
85 and over	989	10.9%	14.0%
Not Known	2062	22.6%	
<b>Total</b>	<b>9116</b>	<b>100.0%</b>	<b>100.0%</b>

NAO census of NHS inpatient palliative care providers

Ethnicity	Proportion	Proportion excluding not known/ stated
White	84.6%	92.3%
Asian	1.9%	2.1%
Black	2.7%	3.0%
Chinese	0.2%	0.2%
Other Ethnic Group	1.8%	2.0%
Mixed	0.4%	0.4%
Not Stated/ Not Known	8.4%	

NAO census of NHS inpatient palliative care providers

2.21. This would seem to add weight to the widely held belief that British Minority Ethnic (BME) groups and older people access less hospice services than the rest of the population. The 2006-07 MDS showed that for hospices who could provide the data 4.7% of new patients were non white, the largest proportion of which were black (African, Caribbean or other). Our census showed that 7.7% of NHS hospice patients who died in 2006-07 were non white.

2.22. ONS Mortality Statistics show that in 2006 18 per cent of deaths from cancer in occurred in groups over 85 of age, but our census data shows that only 14 per cent of patients who died in 2006-07 having

accessed at least one service from a hospice were in this age range which is a statistically significant difference

- 2.23. Research indicates that this lower proportion of ethnic minorities accessing specialist palliative care may be due to the lower prevalence of cancer among ethnic minorities, which is the primary diagnosis of the majority of hospice patients, and cultural differences such as attitudes towards death and the responsibility of family members<sup>17</sup>.
- 2.24. The majority of hospices (79 per cent n=19) reported surveying, interviewing or carrying out focus groups of patients and carers in order to improve services.

## Finances

- 2.25. Respondents were asked to provide data covering various aspects of their finances including the level and sources of their income and the level and proportion of their expenditure across a range of services and commodities.

### Expenditure

- 2.26. The revenue expenditure reported by respondents for NHS hospices in 2006-07 ranged between £375k and £2.5 million with a mean of £1.7 million (n=13). The total revenue expenditure in 2006-07 by our respondents was £21.8 million (n=13). If we assume that non respondents are not atypical this would imply that total revenue expenditure for all voluntary adult hospices in England for 2006-07 was £68 million<sup>18</sup>.
- 2.27. The proportion of expenditure spent on a range of services and commodities is displayed in Table 20. It should be noted that care must be taken in interpreting this as due to an error in the question structure all of the below were presented in one table, rather than splitting firstly by type of service (inpatient, community and day care) and then by components of services (staff costs drugs etc). Obviously the cost of providing a service such as inpatient care will be made up of staff costs, medicine costs etc. Because of this error and the way respondents will have interpreted the question we would not expect the totals provided to sum to the figure given for total revenue expenditure. However, the answers should provide a good high level guide to what the major costs for hospices are:

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<sup>17</sup> Smaje and Field. Absent minorities? Ethnicity and the use of palliative care services. 1997.

<sup>18</sup> Total number of NHS hospices of 40 multiplied by reported average of £1.7m per NHS hospice

Service/Commodity	Number of hospices	Percentage of hospices	Percentage of expenditure	Percentage of total expenditure
Nursing Staff	11	4.79	263.03	66.34
Inpatient	8	32.68	95.23	64.38
Medical Equipment	11	0.45	398.75	37.62
Medical Staff	12	8.07	38.92	19.4
Transport	6	0.53	82.05	14.51
Maintenance	5	0.18	48	11.09
Other Clinical Staff	10	1.21	17.06	8.97
Other Staff	11	0.53	18.97	8.74
Day care	7	4.77	14.88	8.29
Fundraising non Staff	2	0.7	8.56	4.63
Fundraising Staff	3	1.6	4.43	2.72
Drugs	12	0.94	4.02	2.7
Other	6	0.53	8.34	2.66
Media	3	0.04	0.39	0.19
Respite	0	-	-	-

NAO survey of NHS Inpatient Palliative Care Providers

2.28. Our analysis indicates that, for those NHS hospices which offer it, the largest proportion of expenditure is on inpatient services, and that the major component of this is staff costs (specifically nursing costs) rather than medical equipment or drugs.

### Income

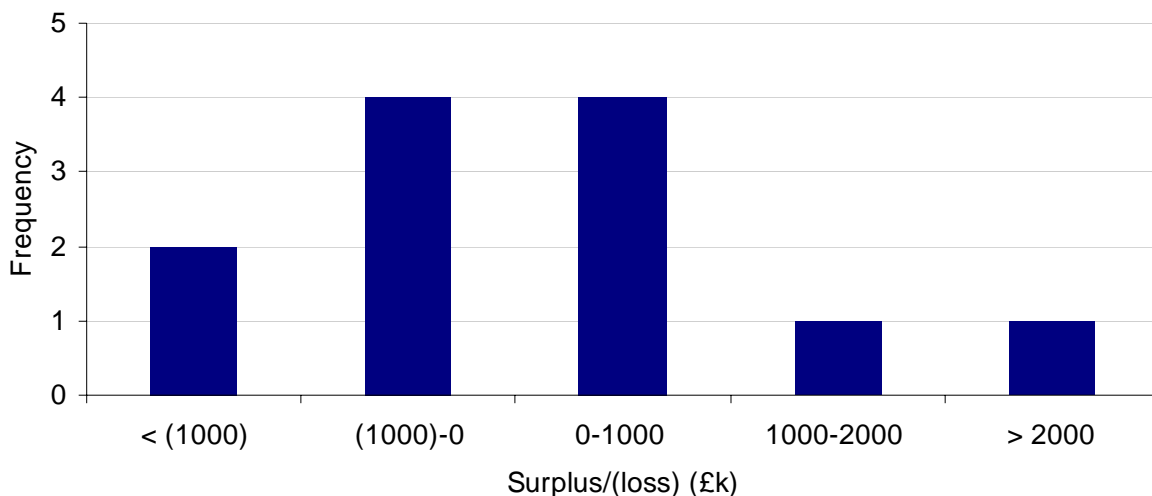
2.29. Respondents reported that their total income for 2006-07 (excluding money given specifically for capital projects) ranged between £0k and £3.9 million with a mean of £1.7 million (n=13).

2.30. The total revenue income in 2006-07 received by our respondents was £21.8 million (n=13). If we assume that non respondents are not atypical this would imply that total revenue income for all voluntary adult hospices in England for 2006-07 was £67 million<sup>19</sup>

2.31. Data provided showed that for 6 hospices (50 per cent of respondents) expenditure exceeded income in 2006-07, whilst the remaining 6 were left with a surplus for the period. The range of surpluses/losses generated by NHS hospices in 2006-07 summarised in Figure 14.

<sup>19</sup> Total number of NHS hospices of 40 multiplied by reported average of £1.7m per NHS hospice

**Figure 14: Net surplus/loss generated by responding NHS hospices in 2006-07**



NAO census of NHS inpatient palliative care providers

**Source of Income**

2.32. Our census showed that on average hospices derived 88 per cent of their income from the state (principally via Primary Care Trusts who commission their services, with small amounts of additional funding from Strategic Health Authorities and Central Government), 24 per cent from charity donations (principally donations and legacies) and the remainder from other sources such as income from shops and investment income. The minimum, maximum and mean proportion of funding received by respondents from various sources is set out in Table 21.

	n	Min %	Max %	Mean %
Proportion State Funding	9	58.2	100.0	87.6
Proportion Charity Donations	6	7.8	41.8	23.9
Proportion Net Trading Profit	3	2.9	20.5	12.4
Proportion Investment Income	2	0.9	4.0	2.5
Sundry Income	0			

NAO census of NHS inpatient palliative care providers

2.33. There is considerable variation in the proportion of funding which Primary Care Trusts (PCTs) provide to hospices, with responses ranging from 58.2 per cent to 100 per cent. The mean proportion of income provided to hospices by PCTs was 85.1 per cent.

2.34. Our respondents received £1.7 million from charity in 2006-07 or £286k per hospice (n=6). The mean proportion of funding derived from charitable donations by respondents to our census was 24 per cent. If we assume that non respondents are not atypical then we can estimate that hospices in England

received £11.4 million in charitable donations in 2006-07 from donations legacies and community and opportunity funds<sup>20</sup>.

2.35. In order to generate the charitable income required to supplement other forms of income some hospices employ professional fundraisers. 5 of our respondents (21 per cent) reported employing a fundraiser with one reporting that they employed four.

## Commissioning

2.36. Hospices were asked to provide information on the process by which PCTs commission their services by PCTs. Respondents were also asked to rate their satisfaction with the resulting contracts with PCTs. Five hospices (36 per cent) stated that they felt PCT funding sufficiently reimbursed then for the NHS services they provide (n=13).

2.37. Hospices were asked to estimate the time spent negotiating contracts with PCTs in 2006-07. The mean answer was 23 hours (n=5). Only two respondents (33 per cent) stated that more time should be spent negotiating contracts with PCTs (n=6).

2.38. Whilst some NHS hospices provide services exclusively to one PCT, others have provide services to multiple PCTs. As Table 22 illustrates, the majority of hospices provide services to one or two PCTs.

Number of commissioning PCTs	Frequency	Valid per cent
1	10	55.6
2	3	16.7
3	2	11.1
4	2	11.1
5	1	5.6
Total	18	

NAO census of NHS inpatient palliative care providers

2.39. Respondents reported that 44 per cent of contracts between PCTs and hospices are Service Level Agreements (SLAs) with another 44% being block contracts. The majority of contracts are in place for 1 year only as illustrated by Table 23.

<sup>20</sup> <sup>20</sup> Total number of NHS hospices of 40 multiplied by reported average of £286k per NHS hospice

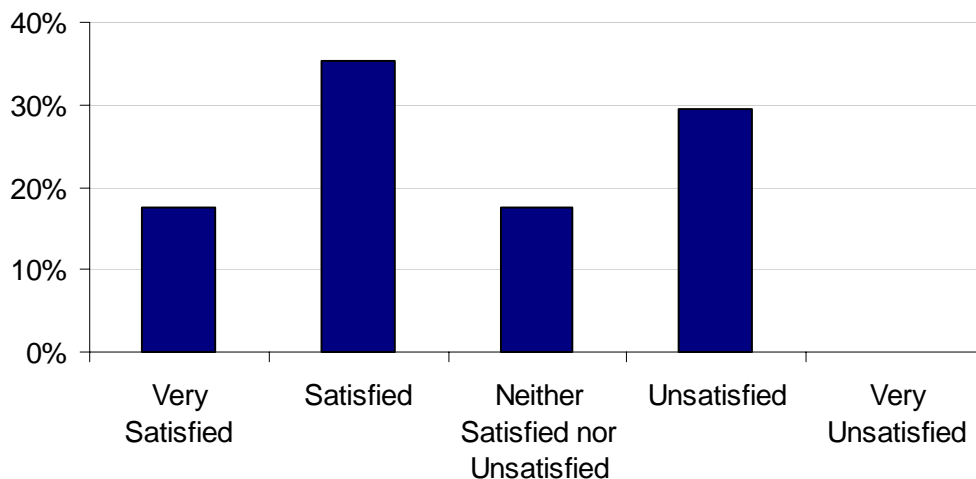
**Table 23: Lengths of contracts with NHS hospices for services to PCTs**

Length of contract	Frequency (n=7)	Per cent
1 year	10	76.90%
2 year	1	7.70%
3 year	1	7.70%
4 year	0	0.00%
5 year	0	0.00%
More than 5 years	1	7.70%

NAO census of NHS inpatient palliative care providers

2.40. Figure 15 shows the response to the question “to what extent are you satisfied or dissatisfied with the type of contract you have with the PCT?” 53 per cent reported being satisfied or very satisfied.

**Figure 15: NHS hospices’ satisfaction with contracts with PCT(s)**



NAO census of NHS inpatient palliative care providers

2.41. At the point of response, (March-May 2008) 89 per cent of respondents reported having agreed funding for 2008-09, 6 per cent for 2009-10 and 6 per cent for 2010-11.

2.42. Hospices were asked to rate each contract they hold with a PCT out of 10 (where 1 is very poor and 10 is excellent) in terms of how transparent, stable formal and representative of level of service they are:



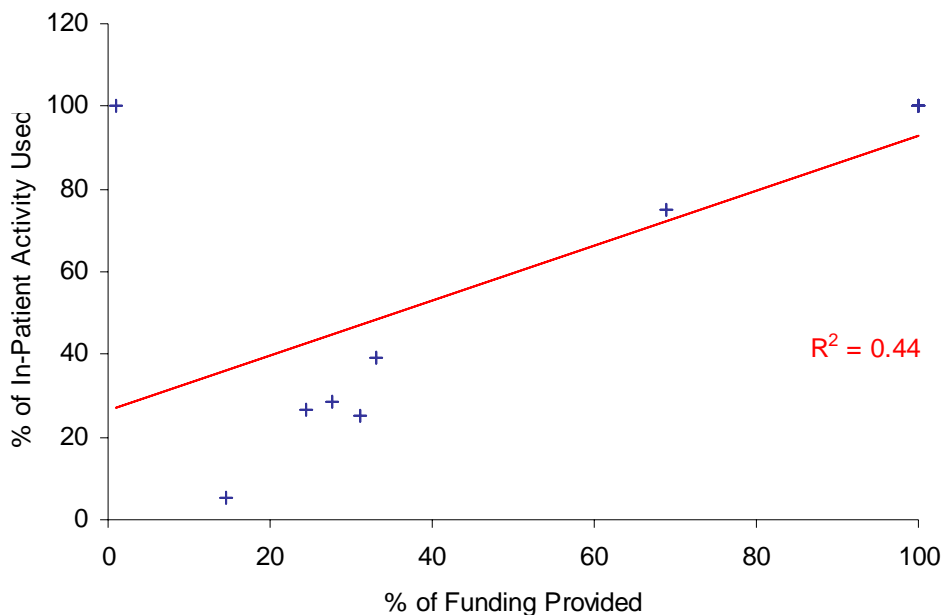
	Min	Max	Mean	Mode
Transparent	2	10	4.9	2
Stable	1	9	4.7	1
Formal	1	10	7.3	9
Representative of level of service	2	10	6.0	7

NAO census of NHS inpatient palliative care providers

2.43. Although far from a perfect measure it is possible to look at how representative funding is of level of service by measuring the correlation between the proportion of PCT income an individual PCT provides and the proportion each service (inpatient, community care, day care, outpatients, respite and bereavement counselling) it uses.

2.44. An example of this is shown in Figure 16 where the proportion of inpatient bed days used is plotted against proportion of PCT income provided.

Figure 16: PCT Inpatient Activity Against Funding



NAO census of NHS inpatient palliative care providers

2.45. The  $R^2$  value is a measure of the degree of correlation between 2 variables where  $R^2=1$  represents perfect positive correlation and  $R^2=0$  represents a complete lack of correlation. The  $R^2=0.44$  result shown in Figure 16 indicates there is some correlation between the amount of funding a PCT provides and the amount of inpatient activity it uses. The corresponding measure for other types of care are displayed in Table 25.

Type of Care	R <sup>2</sup>
Inpatient	0.44
Community	0.33
Day Care	0.96
Out Patient	0.92
Bereavement	0.99

NAO census of NHS inpatient palliative care providers

2.46. Care must be taken in interpreting these results as the fact that costs for types of care will vary significantly and PCTs might be purchasing different 'bundles' of care for their patients may mean that the level of correlation between utilisation of any one type of care and the proportion of funding provided is unlikely to be very high. However, since inpatient care forms the majority of service costs for hospices which provide it (see Income and Expenditure section above) then the correlation between this service and the proportion of the PCT funding provided should be the highest if funding is representative of level of service.

2.47. This is the case and whilst there is some correlation it is clear there remains a number of examples of PCTs whose utilisation of inpatient activity is not well matched to the proportion of funding they provide

## Staff

2.48. Our census asked NHS hospices to provide details of the number of whole time equivalent (WTE) staff in post involved in the delivery of end of life care or other services to NHS trusts.

2.49. The range and mean of the WTE staff in post on 31st March 2007 and the WTE vacancies as at 31 March 2007 are shown below:

	n	Min	Max	Mean
Doctors	24	0.0	12.0	4.7
Nurses	24	0.0	102.0	32.0
Others	24	0.0	59.0	8.3

NAO census of NHS inpatient palliative care providers

	n	Min	Max	Mean
Doctors	6	1.0	1.0	1.0
Nurses	11	1.0	26.0	4.9
Others	3	1.0	1.0	1.0

NAO census of NHS inpatient palliative care providers

2.50. Whilst the majority of respondents had either one or no vacancies those that did had a significant number of unfilled posts. The ratio of doctors to nurses (~1:9) backs up findings in the Income Expenditure section that the majority of hospice staff costs are for nurses.

## End of Life Tools

2.51. We asked NHS hospices to provide data on their usage of the three main end of life care tools, the Liverpool Care Pathway, the Gold Standards Framework and Preferred Priorities for Care (formerly Preferred Place of Care) along with details of any other tools or modified versions of the above. We also asked hospices to rate the improvement in end of life care services as a result of using these tools.

2.52. Table 28, Table 29 and Table 30 show the number of NHS hospices using the three main end of life care tools. By far the most frequently used is the Liverpool Care Pathway. Twenty respondents reported using other tools, the majority of which, based on the descriptions given, seem to be local pathways or adaptations to the national tools.

Table 28: Usage of the Liverpool Care Pathway (LCP)					
		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percentage
Valid Responses	Yes	19	79.2	79.2	79.2
	No	5	20.8	20.8	100.0
<b>Total</b>		<b>24</b>	<b>100.0</b>	<b>100.0</b>	

NAO census of NHS inpatient palliative care providers

Table 29: Usage of the Gold Standards Framework (GSF)					
		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percent
Valid Responses	Yes	9	37.5	52.9	52.9
	No	8	33.3	47.1	100.0
<b>Total</b>		<b>17</b>	<b>70.8</b>	<b>100.0</b>	
Missing	System	7	29.2		
<b>Total</b>		<b>24</b>	<b>100.0</b>		

NAO census of NHS inpatient palliative care providers

		Frequency	Percentage of all responses	Percentage of valid responses	Cumulative Percent
Valid Responses	Yes	12	50.0	63.2	63.2
	No	7	29.2	36.8	100.0
	<b>Total</b>	<b>19</b>	<b>79.2</b>	<b>100.0</b>	
Missing	System	5	20.8		
<b>Total</b>		<b>24</b>	<b>100.0</b>		

NAO census of NHS inpatient palliative care providers

2.53. Respondents were asked to rate each tool out of 10 for the difference engaging with it had made to the standard of end of life care offered, where 1 is no improvement and 10 is a significant improvement. The ratings are summarised in Table 31.

	Min	Max	Mean
LCP	1	10	7.4
GSF	6	9	7.5
PPC	2	10	6.3
Other	7	9	8.0

NAO census of NHS inpatient palliative care providers

2.54. Although it is used less frequently than the LCP, GSF was seen by those that use it to make the same contribution to patient care (79.2 per cent of respondents used LCP whilst 52.9 per cent use GSF but the mean ratings are 7.4 and 7.5 respectively). Although it is mainly considered a tool for primary care, these results suggest it may have a wider application and that it may be worth considering its application in specialist palliative care settings.

## External Services

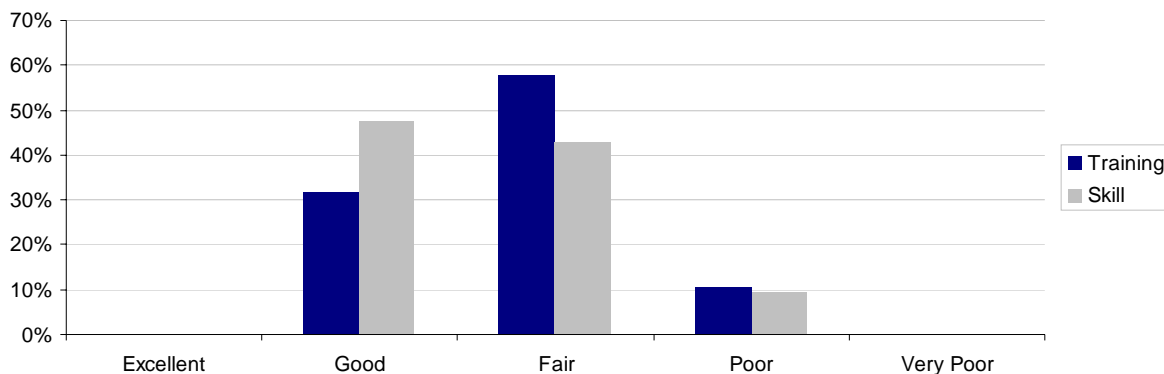
2.55. Respondents were asked to rate a series of external services out of 10 (where 1 is well below requirements and 10 is well above requirements) on how well they met patients and carers' needs at the end of life. The results are displayed below:

	Min	Max	Mean	Median
Out of hours services including access to palliative care medication (n=23)	2	8	5.1	5
Out of hours services including access to palliative care equipment (n=23)	1	8	4.7	5
Integration with residents' GP surgeries (n=23)	5	8	6.2	6
Integration with other primary care services (n=23)	3	8	6.4	7
Integration with secondary care e.g. for blood results (n=22)	3	9	7.1	7
Integration with social services (n=22)	2	8	5.4	6
Commissioning of end-of-life care by PCTs (n=21)	1	9	4.9	5

NAO census of NHS Inpatient Palliative Care Providers

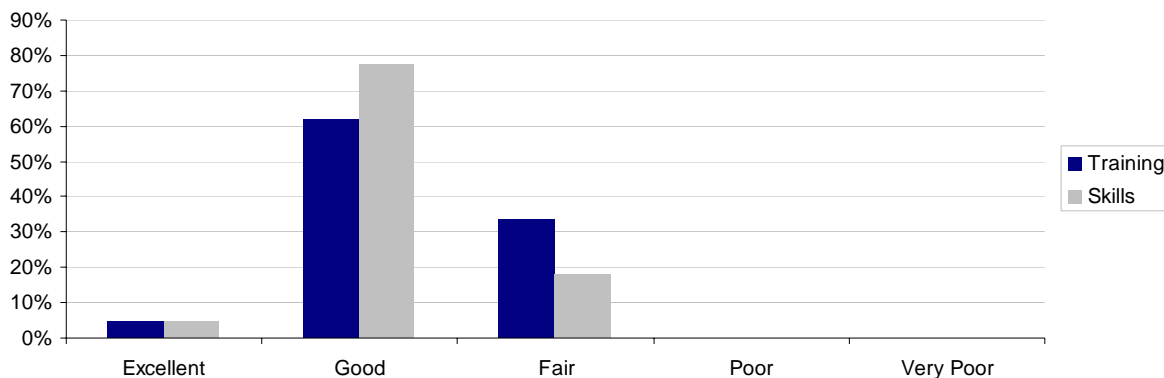
- 2.56. Clearly NHS hospices feel they are reasonably well supported by external services but there is room for improvement to better meet the needs of patients and carers.
- 2.57. Respondents were also asked to rate the skills and training of staff working outside specialist palliative care who are likely to be involved in the care of patients approaching the end of their lives. The results are displayed for each profession in Figure 17 through Figure 23.

**Figure 17: NHS hospices' ratings of the skills and level of training of Primary Care Staff e.g. GPs and Practice Nurses**



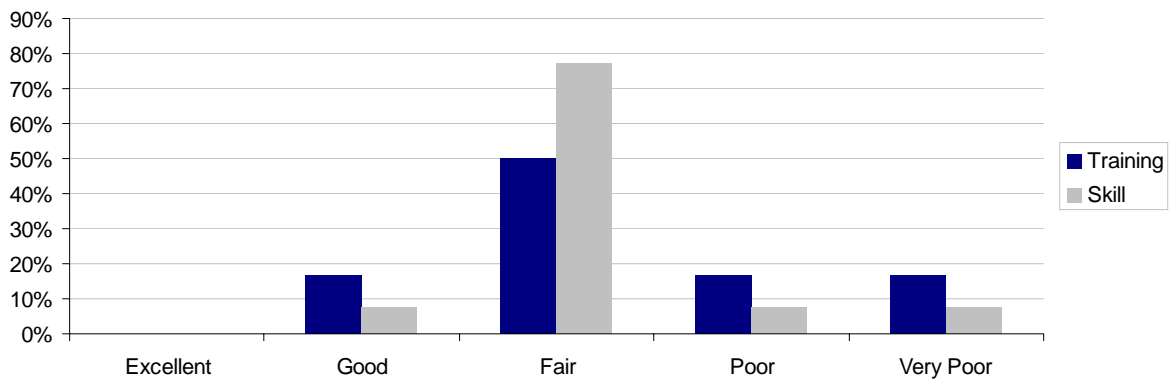
NAO census of NHS inpatient palliative care providers

**Figure 18: NHS hospices' ratings of the skills and level of training of Community Based Nursing Staff e.g. Community Nurses**



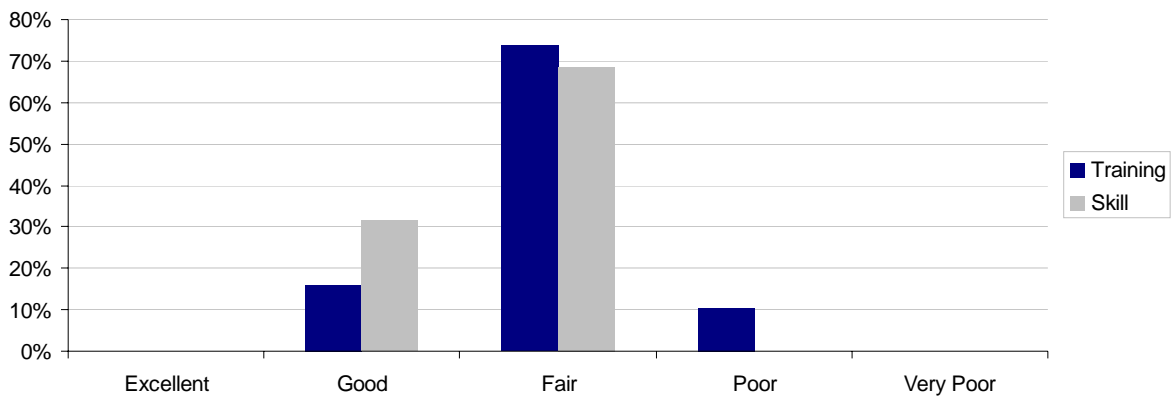
NAO census of NHS inpatient palliative care providers

**Figure 19: NHS hospices' ratings of the skills and level of training of Community Based Nursing Staff e.g. Community Psychiatric/Mental Health Nurses**



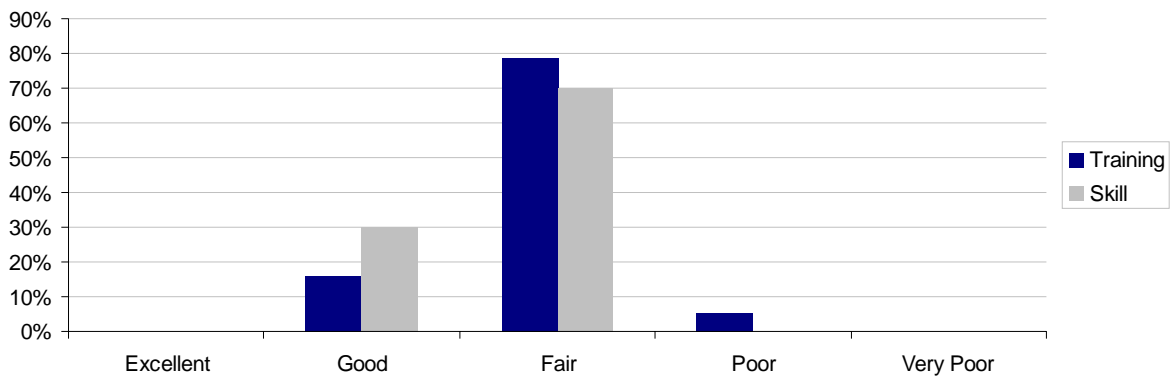
NAO census of NHS inpatient palliative care providers

**Figure 20: NHS hospices' ratings of the skills and level of training of Medical Staff in Acute Secondary Care**



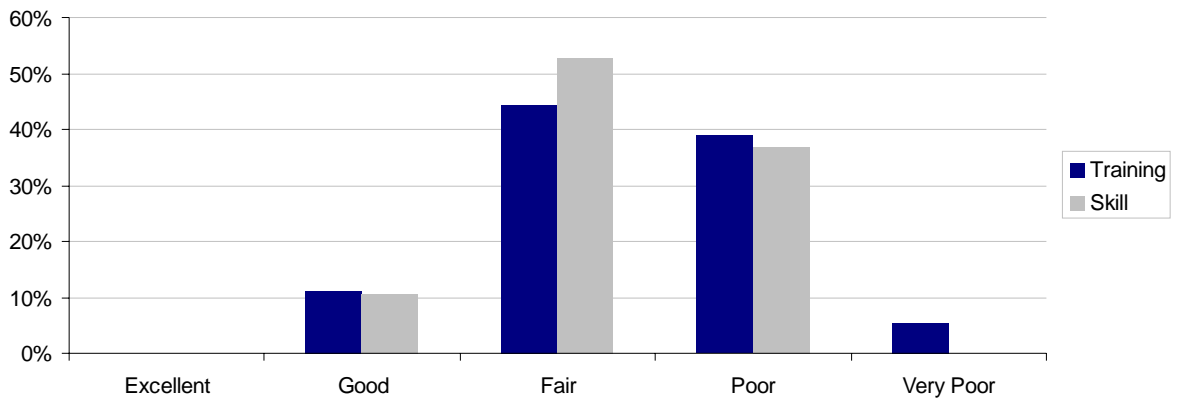
NAO census of NHS inpatient palliative care providers

**Figure 21: NHS hospices' ratings of the skills and level of training of Nursing Staff in Acute Secondary Care**



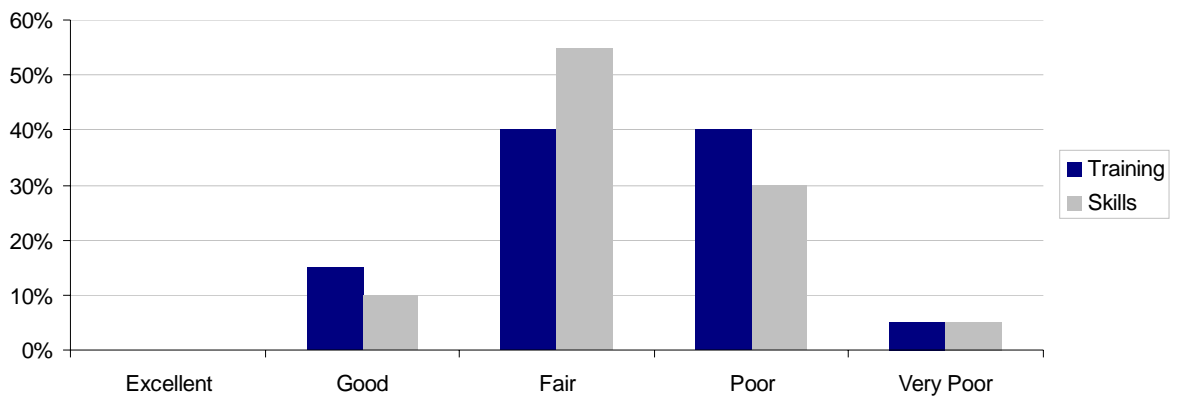
NAO census of NHS inpatient palliative care providers

**Figure 22: NHS hospices' ratings of the skills and level of training of Home Care Social Service Staff**



NAO census of NHS inpatient palliative care providers

**Figure 23: NHS hospices' ratings of the skills and level of training of Staff in Nursing/Personal Care Homes**



NAO census of NHS inpatient palliative care providers

2.58. In terms of skill Community Nurses were rated the highest with 83 per cent of respondents rating their skill as good or excellent. Ratings for all staff are displayed below.

Level of Training	% Good or Excellent
Community Based Nursing Staff: District Nurse	66.7%
Primary Care staff e.g. GPs and Practice Nurses	31.6%
Nursing Staff in Acute Secondary Care	15.8%
Medical Staff in Acute Secondary Care	15.8%
Staff in nursing/personal care homes	15.0%
Home Care Social Services	11.1%
Community Based Nursing Staff: Community psychiatric /mental health nurses	16.7%

NAO census of NHS inpatient palliative care providers

Level of Skill	% Good or Excellent
Community Based Nursing Staff: District Nurse	81.8%
Primary Care staff e.g. GPs and Practice Nurses	47.6%
Medical Staff in Acute Secondary Care	31.6%
Nursing Staff in Acute Secondary Care	30.0%
Staff in nursing/personal care homes	28.6%
Home Care Social Services	10.5%
Community Based Nursing Staff: Community psychiatric /mental health nurses	7.7%

NAO census of NHS inpatient palliative care providers

2.59. Hospices provide a significant volume of training to external staff. Respondents reported providing 2,184 external staff with 2,303 hours of training. Excluding respondents who stated that they provided zero hours of such training, this equates to each hospice providing on average 384 hours of training to 364 external members of staff (n=6).

## Volunteers

2.60. There is a significant amount of activity within NHS hospices which is provided free of charge by volunteers. Respondents reported receiving 116,674 hours of donated time during 2006-07 (n=13). This equates to a mean of 8,975 hours per hospice.

2.61. The biggest proportion of donated time was from volunteer carers (63.1 per cent of all donated time, an average of 60.6 per cent per hospice). This was followed by other (21.4 per cent of all donated time, average of 12.7 per cent per hospice) which respondents stated includes tasks such as driving and providing bereavement support. Next were fundraising volunteers (12.6 per cent, average of 8.0 per cent per hospice), complementary therapists (2.1 per cent, average of 10.3 per cent per hospice) and trustees (0.8 per cent, average of 8.3 per cent per hospice)

2.62. In 2006 Help the Hospices estimated the value of volunteer time by surveying hospices on the number of volunteer hours they were provided with, and what it would have cost per hour (excluding overheads) had they had to employ someone to perform the tasks which volunteers undertook. Their analysis that the volunteer value (vv) of time given to all adult and children's Independent hospices in England was £112 million



- 2.63. Our census asked hospices to estimate what they would have had to pay per hour (excluding overheads) for someone in each of the four categories listed above. Our intention was then to multiply these values by the number of donated hours in each category in order to estimate the value of volunteer time which is donated. Only eight NHS hospices responded to this question with the majority providing incomplete answers. As a result we were unable to draw any meaningful conclusions from the cost data provided via the intended calculation.
- 2.64. To address this, the total number of volunteer hours was multiplied by the current minimum wage in England (£5.52) in order to obtain a value for volunteers' time. Whilst we realise that the true value of money saved through the use of volunteers is significantly greater than this, and this value does not take account of the wider value that community volunteers provide, it enables us to estimate a minimum value the volunteer time contributed.
- 2.65. This gave a value of £644k in total or £49,542 per NHS hospice (n=13). Assuming that non respondents are not atypical in terms of the number of donated hours they receive then the minimum extrapolated value in England in 2006-07 was at least £2 million. If a 30 per cent overhead cost to account for pension, national insurance and sick pay costs is applied to this, the minimum value increases to £2.6 million. This would represent about 12 per cent of total revenue expenditure for 2006-07 (See Income and Expenditure Section).
- 2.66. If this minimum volunteer value is added to our estimate of the revenue income which NHS hospices derived from charity (£1.7 million) we can estimate that the end of life care services which hospices provide, relied on charitable donations of money and time amounting to around £4.3 million in 2006-07, in order to operate.

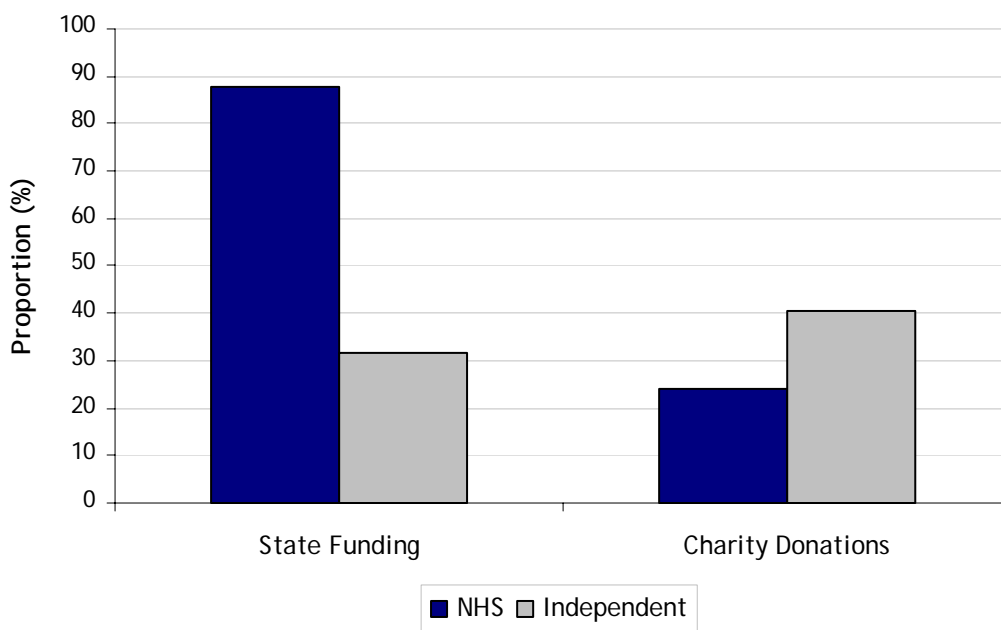
## Part 3: Comparison of key results from the two censuses

3.1. In this section we compare some of the key results of our two censuses to highlight differences in the responses from each type of hospice.

### Funding

3.2. Figure 24 illustrates the average proportion of income that independent and NHS hospices draw from both the state (largely through Primary Care Trusts) and other charity donations. The remaining income comes primarily from other sources such as income from shops and investment income.

**Figure 24: Comparison of the proportion of funding provided to independent hospices and NHS Inpatient Palliative Care Providers from the state and voluntary sector.**



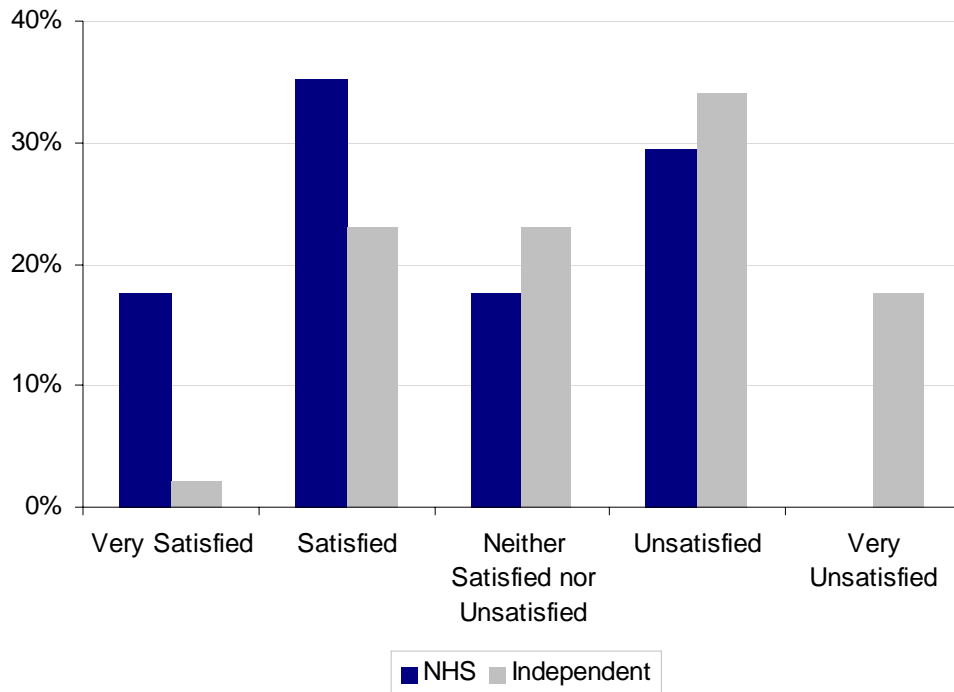
NAO censuses of independent hospices & NHS inpatient palliative care providers

3.3. The data we obtained shows that in 2006-07, 33 per cent of respondents from independent hospices (n=92) and 50 per cent of respondents from NHS hospices (n=12) stated that expenditure exceeded income. Just 3.1% of independent hospices compared to 39% of NHS hospices stated that they felt PCT funding sufficiently reimbursed them for the NHS services they provided (n=96 and n=13 respectively).

## Length and Hospice Satisfaction of Contract with PCT

3.4. Independent and NHS hospices were asked to estimate the time spent negotiating contracts with PCTs in 2006-07. The mean answer was 30 hours (n= 96) and 23 hours (n=5) respectively. The hospices were also asked the extent to which they were satisfied or dissatisfied with the type of contract they held with a PCT. Figure 25 illustrates the results.

**Figure 25: Independent and NHS hospices' satisfaction with contracts with PCT(s)**



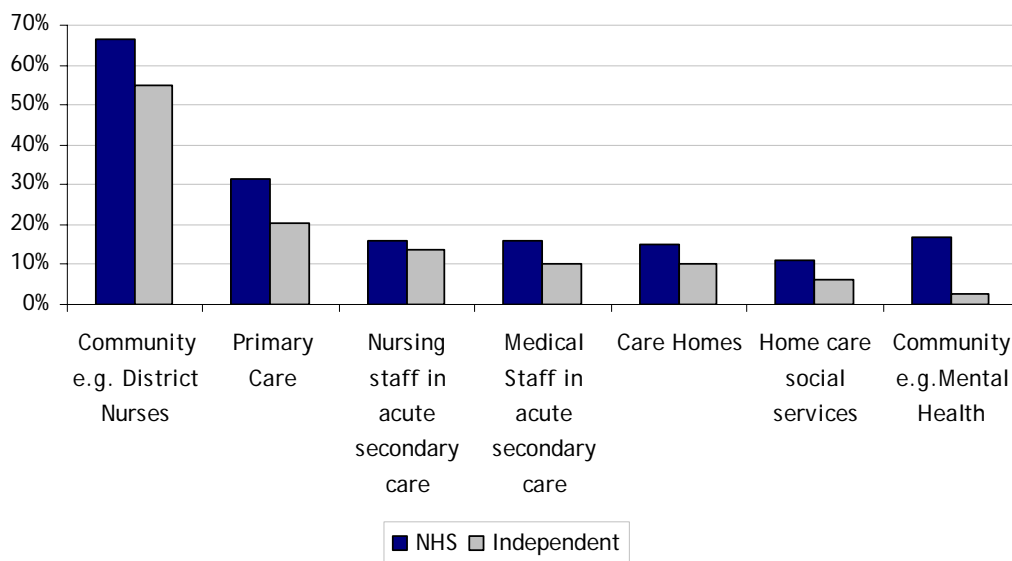
NAO censuses of independent hospices & NHS inpatient palliative care providers

3.5. The findings plainly highlight a lower contract satisfaction amongst independent hospices.

## Staff Level of Training and Skill

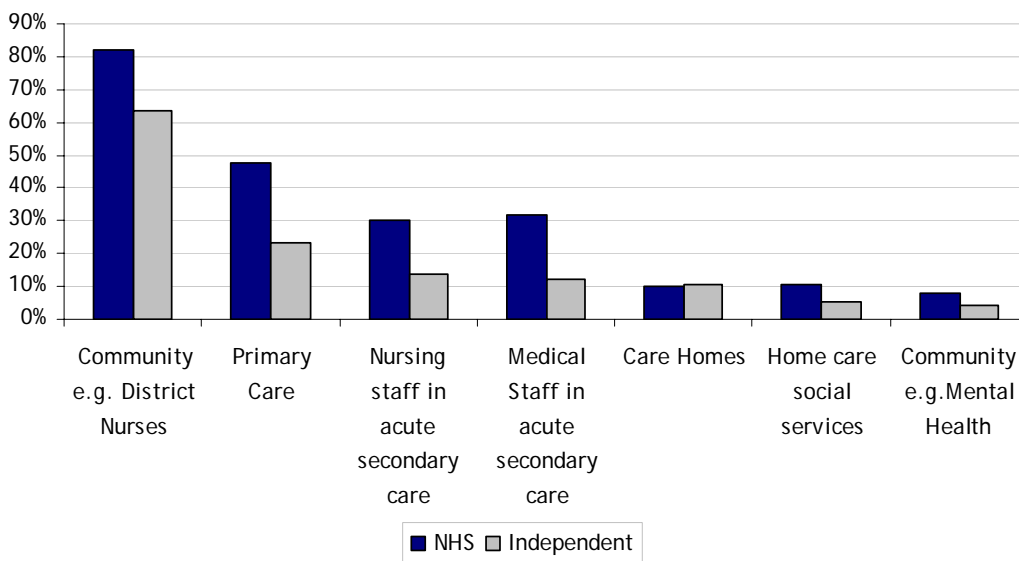
3.6. The two sets of respondents were asked to rate the skill and training of staff working outside specialist palliative care who are likely to be involved in the care of patients approaching the end of their lives. Staff were rated on a five point scale from very poor to excellent. The proportion of respondents who rated staff training and skill as excellent or Good (the upper two points on the scale) have been displayed for each profession in Figure 26 and Figure 27.

**Figure 26: Comparison of the proportion of staff working outside specialist palliative care whose level of training was rated as good or excellent by independent and NHS hospices**



NAO censuses of independent hospices & NHS inpatient palliative care providers

**Figure 27: Comparison of the proportion of staff working outside specialist palliative care whose level of skill was rated as good or excellent by independent and NHS hospices**

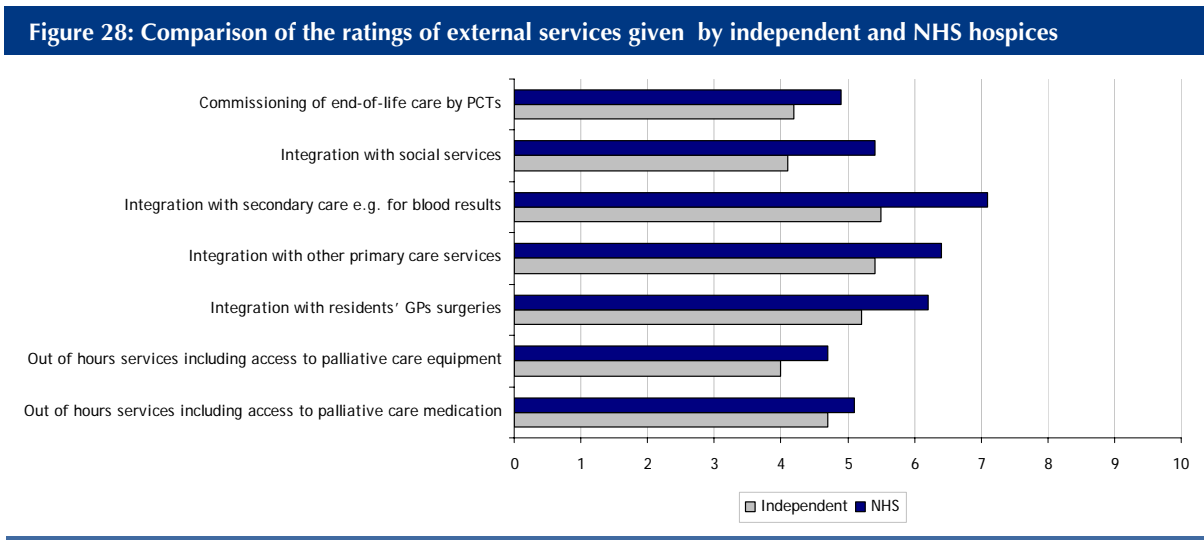


NAO censuses of independent hospices & NHS inpatient palliative care providers

3.7. Figure 26 and Figure 27 clearly show that the levels of skill and training working of staff working outside specialist palliative care who are likely to be involved in the care of patients approaching the end of their lives are perceived to be of a much higher standard by NHS rather than independent hospices.

### External Services

3.8. The two sets of respondents were asked to rate a series of external services out of 10 (where 1 is well below requirements and 10 is well above requirements) on how well they met patients and carers' needs at the end of life. The comparative results are shown in Figure 28.



NAO censuses of independent hospices & NHS inpatient palliative care providers

3.9. This clearly shows that independent hospices rate the support they receive from external services significantly lower than NHS hospices.

## Glossary

### Care home

A residential home which provides either short or long term accommodation with meals and personal care (e.g. help with washing and eating). Some care homes, known as nursing homes, also have registered nurses who provide nursing care for more complex health needs.

### Carer

Anyone who spends a significant proportion of their life providing unpaid support to family, friend or partner. This can include caring for an individual who is approaching the end of their life.

### Commissioning

The processes local authorities and PCTs undertake to make sure that services funded by them meet the needs of the patient and improve quality of life and health outcomes.

### District nurse

District nurses visit people in their own homes or in residential care homes, providing care for patients and supporting family members. As well as providing direct patient care, district nurses also have a teaching role, working with patients to enable them to care for themselves or with family members teaching them how to give care to their relatives.

### End of life care

Services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This support is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

### Gold Standards Framework (GSF)

A primary care based approach for identifying end of life care patients, assessing their needs, and coordinating their care. It provides prompts to a healthcare professional that discussions about the end of life should be initiated, if they have not already taken place, and enables GPs to identify patients for inclusion on a palliative care register.

### Hospice

Hospices provide care and support to people at the end of their life and their carers, through a range of services such as inpatient care, day care, community services, out patient appointments, sitting services, respite care and bereavement counselling. The first modern hospice was opened in south London in 1967 and, since then, hospice care has developed into a movement to change the way in which end of life care is delivered. Most hospices in England are independent local charities which are part funded by the NHS,

although some hospices operate nationally and a small number are provided by the NHS. For the purposes of this report, the term 'hospice' covers both independent and NHS run facilities unless specifically stated otherwise.

### **The Liverpool Care Pathway**

Developed for use in hospitals, but can be used in primary care, care homes, or hospices. It empowers generalist clinicians to care for the dying and manage pain and other symptoms in the last days and hours of life by providing guidance on comfort measures; anticipatory prescribing of medicines; discontinuation of inappropriate interventions; psychological and spiritual care; and care of the family (both before and after death).

### **Minimum Dataset (MDS)**

The data collected by the National Council for Palliative Care in their annual survey of all specialist palliative care providers in England, Wales and Northern Ireland. The data includes information such as level of activity and demographics of patients receiving services.

### **Nursing home**

See care home.

### **Out of Hours**

GPs can choose not to provide 24-hour care for their patients. The Out of Hours period is 6.30pm to 8am on weekdays and all weekends and bank holidays. During this time, PCTs are responsible for providing GP services for local people.

### **Palliative care**

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. Most palliative care is provided non-specialist staff such as GPs, hospital doctors, ward nurses, and staff in care homes.

### **Preferred Priorities for Care**

A patient held record documenting care on an ongoing basis which helps staff follow patient's expressed wishes. This record enables patients and carers to express preferences over the care they wish to receive, including where they wish to be cared for as they approach the end of life.

### **Primary care**

The collective term for all services which are people's first point of contact with the NHS (e.g. GPs, dentists).

### **Primary care trust (PCT)**

A statutory body and part of the NHS responsible for delivering healthcare and health improvements to local residents, for example by commissioning care from providers such as hospitals.

**Secondary care/acute care**

Care often provided in a hospital or particular specialised centre, which may be accessed directly or following a referral from primary care.

**Social care**

Services which support people in their day to day lives to help them play a full part in society. Services provided range from home care and nursing homes to the provision of a personal assistant for a disabled person, or support for an individual in emotional distress. Each of the 150 local authorities in England has a statutory duty to assess the social care needs of individuals and to arrange for the provision of appropriate services to address the needs of those who are considered eligible for support following an assessment of need (see needs assessment).

**Specialist palliative care**

See palliative care. Specialist palliative is provided by multi-disciplinary teams that might include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to advise on symptom control and pain relief.