



National Audit Office

## Results of census of primary care trusts



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## Results of census of primary care trusts

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## Context for the census

1. As part of the development of its End of Life Care Strategy, the Department of Health instructed primary care trusts (PCTs) to review the services they provided. Information generated by these reviews was not, however, collected centrally. We therefore requested a range of information from PCTs on the services provided to adults in the 2006-07 financial year to enable us to create a national picture of end of life care services. This included information on:
  - expenditure;
  - services commissioned;
  - use of end of life care tools; and
  - areas of patient need.
2. The census was carried out in March 2008 and we received and processed final responses from 141 out of 152 PCTs (a response rate of 93 per cent). The census forms one strand of our work on end of life care which resulted in a full value for money report to Parliament in November 2008 (**End of Life Care**, HC 1043, 2007-2008), where the overall findings from the census are presented.
3. A summary of the quantitative results from the census is presented here. All percentages shown are the “valid percentages” i.e. they exclude blank and not applicable responses.<sup>1</sup>

## Expenditure on specialist palliative care

4. Total expenditure on specialist palliative care amongst PCTs in 2006-07 was £245 million. The average level of expenditure by PCTs was £1.6 million, ranging from £382,000 to £7.4 million. Based on Office for National Statistics mortality data for 2006, expenditure per death ranged from £154 to £1,684 between PCTs.<sup>2</sup>

## Inpatient beds commissioned from NHS hospices and voluntary hospices

5. Twenty six per cent of PCTs commissioned inpatient palliative care beds from NHS hospices. The number of beds commissioned by PCTs ranged from 0 to 52 with a mean of 4.2 beds. These beds provided, on average, 883 inpatient bed days or 210 days per commissioned bed (883/4.2). However, many PCTs responded that they did not commission specific beds and had alternative arrangements with hospices.
6. Sixty seven per cent of PCTs commissioned inpatient beds from voluntary hospices. The number of beds commissioned by PCTs ranged from 0 to 67 with a mean of 11.4 beds. These beds provided, on average,

<sup>1</sup> The data from the census have not been subject to audit, and therefore some of the variations in the information provided by PCTs may be due to different interpretation by individual organisations.

<sup>2</sup> These costings, which were obtained from the Department of Health Survey of expenditure on specialist palliative care, have not been subject to audit, and therefore some of the variations in both the unit and total costs of specialist palliative care may be due to different interpretation by individual organisations.

3,407 inpatient bed days or 299 days per commissioned bed (3407/11.4). As with NHS hospices, many PCTs responded that they did not commission specific beds and had alternative arrangements with voluntary hospices. PCTs most commonly commissioned hospice services through block contracts (Table 1).

Commissioning method	n=135	Percentage of PCTs using commissioning method
Block contract	109	80.7
Spot purchase	26	19.3
Other	27	20.0

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## Home care services

7. PCTs were asked to state which of four home care services they commissioned for patients approaching the end of their life, and whether they were provided subject to eligibility criteria. The service most commonly available to all was specialist palliative care advice/support, whilst the service most frequently subject to eligibility criteria was Marie Curie nursing. The services most frequently unavailable were rapid response and hospice at home services (Table 2).

Service	Yes, service provided to all	No, service not included	Yes, subject to eligibility criteria	n=
Hospice at home	33 (23.9 %)	51 (37.0 %)	54 (39.1%)	138
Rapid response service	33 (23.9 %)	66 (47.8 %)	39 (28.3%)	138
Marie curie nursing	59 (42.8 %)	9 (6.5 %)	70 (50.7 %)	138
Specialist palliative care advisory/support service	80 (58.0 %)	0 (0 %)	58 (42 %)	138

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## Care home beds providing personal or nursing care

8. PCTs most commonly commissioned care home beds through spot purchase arrangements, with 53 per cent utilising this method. Block contracts were used by just under a third of PCTs (31 per cent), and over a third stated that they commissioned care home beds using a combination of the two (37 per cent). Nine per cent of PCTs stated that they utilised other methods of commissioning. The majority (79 per cent) of PCTs could not state how many of the care home beds they commissioned were used by people approaching the end of their life.

## Support for carers

9. A fifth of PCTs (19 per cent) stated that Carers Assessments were not provided to carers, 29 per cent said assessments were carried out for all carers as standard, and 52 per cent stated that assessments were provided to some carers but not all. The mean percentage of carers receiving a Carers Assessment across all PCTs was 16 per cent, although 104 PCTs could not provide this information.
10. A quarter (24 per cent) of PCTs stated that respite care was provided to all who needed it, whilst 69 per cent said it was available but was provided subject to eligibility criteria. The remaining seven per cent said it was not provided at all. Respite care was most frequently provided by the local hospice or the charity, Crossroads. Details of the types of respite care commissioned by PCTs can be found in Table 3.

Type of respite care	n=129;	Percentage of PCTs
In patient	113	87.6
Day care	116	89.9
Volunteer sitter	84	65.1
Night sitter	107	82.9
Other	27	20.9

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## Choice for patients

11. The majority of PCTs answered that choice was provided to 'some' patients rather than to all. Choice was most likely to be provided to all on wishes for more or less intensive treatment (Table 4).

	Yes, for all patients	Yes, for some patients	No	n=
Service provider	22 (15.6 %)	96 (68.1 %)	23 (16.3 %)	141
Location of end of life care	26 (18.4 %)	115 (81.6 %)	0	141
Patient wishes regarding more or less intensive treatment respected	48 (34.0 %)	92 (65.2 %)	1 (0.7 %)	141
Patient choices recorded	26 (18.4 %)	113 (80.1 %)	2 (1.4 %)	141

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12. Around three quarters of PCTs (77 per cent) stated that choices made by patients were reviewed with them at regular intervals, but 88 per cent of PCTs were not able to say what proportion of patients died in their preferred place of care. Amongst PCTs who knew the proportion of patients who were able to die in their preferred place of care, the mean percentage was 72 per cent. However, only 17 PCTs (12 per cent) were able to provide this data.

## Access to services

13. Around 53 per cent of PCTs stated that all patients could access district nursing in their home 24 hours a day seven days a week. Access to such services was available to some patients in around 18 per cent of PCTs and not available in 29 per cent of PCTs. Twenty four hour access to district nursing was less frequently provided to all patients in care homes, and hostels or other institutions (Table 5).

	At home	In a care home	In a hostel or other institution
Yes, for all patients	53.2	40.4	41.8
Yes, for some patients	17.7	28.4	21.3
No	29.1	31.2	36.9

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14. Fewer PCTs provided access to specialist end of life care services twenty four hours a day seven days a week, with around 36 per cent of PCTs providing this service to all patients in their home. Such services were not provided to patients in their home by around 32 per cent of PCTs. Access to such services was marginally lower in care homes, and hostels or other institutions (Table 6).

	At home %	In a care home %	In a hostel or other institution %
Yes, for all patients	36.2	34.8	30.5
Yes, for some patients	31.9	31.9	31.2
No	31.9	33.3	38.3

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## Roll out of end of life care tools across PCTs

15. As at 31 March 2007, 85 per cent of PCTs stated that the Gold Standards Framework had been rolled out in care settings across the PCT. Roll out of the Liverpool care Pathway was also high at 77 per cent, but lower for Preferred Priorities for Care (25 per cent). In some cases, PCTs indicated that they had rolled out equivalent tools instead (Table 7).

End of life care tool	Yes it has been rolled out	No	Yes a close equivalent has been rolled out	n=
Liverpool Care Pathway	108 (77.1 %)	19 (13.6 %)	13 (9.3 %)	140
Gold Standards Framework	119 (85.0 %)	15 (10.7 %)	6 (4.3 %)	140
Preferred Priorities for Care	35 (25.0 %)	91 (65.0 %)	14 (10.0 %)	140

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16. When examining roll out by care setting as at 31 March 2007, the Liverpool Care Pathway and Preferred Priorities for Care had most commonly been rolled out in hospices, whilst the Gold Standards Framework had most often been rolled out in GP practices (Table 8).

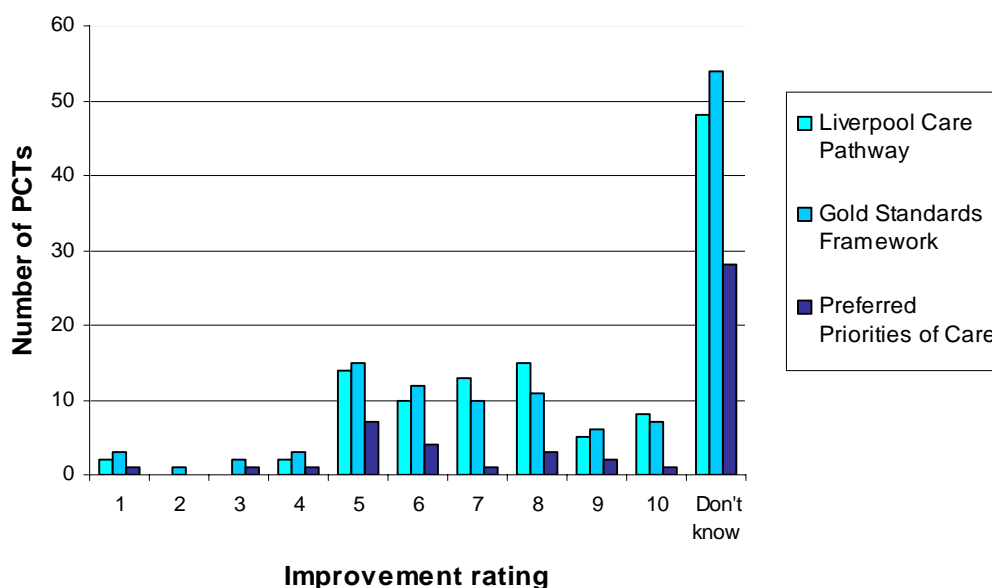
	Liverpool Care Pathway (mean %)	Gold Standards Framework (mean %)	Preferred Priorities for Care (mean %)	Other end of life care tools (mean %)	n=
Acute hospitals	74.5	26.8	49.7	44.4	140
Community hospitals	39.9	19.1	24.4	32.2	140
GP practices	47.7	60.0	49.4	53.3	140
Care homes	18.7	12.6	14.8	13.1	140
Hospices	90.4	45.9	66.9	77.3	140
Other	10.0	2.0	14.7	27.9	140

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## Improvements associated with use of end of life care tools

17. PCTs were asked to rate the improvement to end of life care which use of the tools had made. Ratings were requested on a scale of 1 to 10 where 1 is 'no improvement' and 10 is 'a significant improvement'. Mean improvement scores were 6.9 for the Liverpool Care Pathway, 6.5 for the Gold Standards Framework, and 6.0 for Preferred Priorities for Care. However, a large number of PCTs responded that they did not know (Figure 1).

**Figure 1: PCTs' rating of improvement to care as a result of using end of life care tools**



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Note: 1 is 'no improvement' and 10 is 'a significant improvement'.

### Training in end of life care tools

- 18. PCTs stated that in the majority of cases, training in the use of all end of life care tools was not compulsory. When such training was compulsory, this was most frequently the case for hospice staff and district nurses. (Table 9, Table 10, and Table 11).

Was training compulsory?	Yes (n=139)	Percentage of PCTs
Primary care staff, such as GPs and practice nurses	10	7.2
Community based nursing staff: district nurses	32	23.0
Community based nursing staff: community psychiatric/mental health nurses	5	3.6
Medical staff in acute secondary care	18	12.9
Nursing staff in acute secondary care	24	17.3
Home care social services workers	5	3.6
Staff in nursing/personal care homes	9	6.5
Hospice staff	49	35.3

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Table 10: Level of compulsory training in the use of the Gold Standards Framework tool		
Was training compulsory?	Yes (n=140)	Percentage of PCTs
Primary Care staff, such as GPs and practice nurses	16	11.4
Community based nursing staff: District Nurses	29	20.9
Community based nursing staff: Community psychiatric/mental health nurses	6	4.3
Medical staff in acute secondary care	6	4.3
Nursing staff in acute secondary care	6	4.3
Home Care social services workers	3	2.2
Staff in nursing/personal care homes	15	10.7
Hospice staff	21	15.0

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Table 11: Level of compulsory training in the use of the Preferred Priorities for Care tool		
Was training compulsory?	Yes (N=139)	Percentage of PCTs
Primary Care staff, such as GPs and practice nurses	6	4.3
Community based nursing staff: District Nurses	10	7.2
Community based nursing staff: Community psychiatric/mental health nurses	3	2.2
Medical staff in acute secondary care	6	4.3
Nursing staff in acute secondary care	6	4.3
Home Care social services workers	2	1.4
Staff in nursing/personal care homes	9	6.5
Hospice staff	20	14.4

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## Quality of care

19. Eighty one per cent of PCTs collect information on the quality of care given to patients approaching the end of their life and their family and carers. This is most commonly done through audits, or by monitoring complaints/contacts with Patient Advice and Liaison Services (PALS) (Table 12).
20. Less than a third of PCTs (30.5 per cent) stated that they record the level of psychological distress experienced by patients at the end of life. When asked to rate their compliance with the provision of psychological support laid down in the NICE Guidance for Supportive Palliative Care on a scale of 1 (not at all compliant) to 10 (completely compliant), PCTs rated themselves with a mean value of only 4.8.

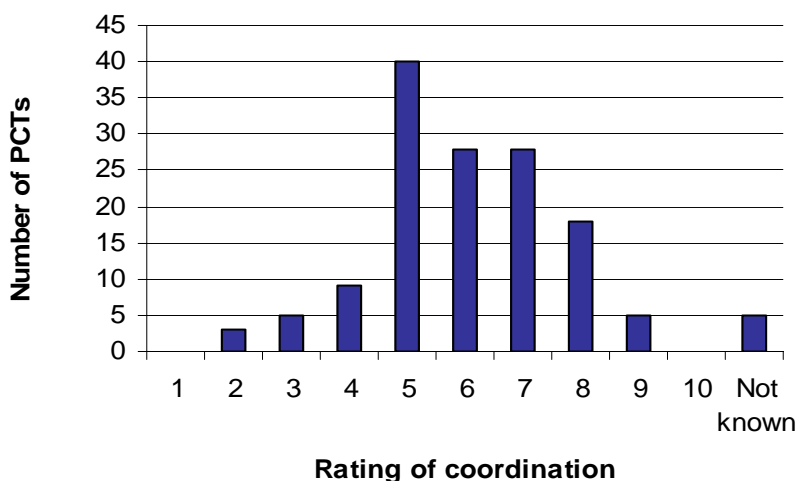
Table 12: Methods used to monitor the quality of end of life care		
	n=136	Percentage
Audits e.g. LCP audit	110	80.9
Monitoring complaints/ PALS contacts	109	80.1
Patient surveys	89	65.4
Correspondence e.g. thank you letters	85	62.5
Performance management of contracts	70	51.5
Carer surveys	68	50.0
Patient/ public involvement events	58	42.6
Percentage of patients achieving their preferred place of care and death	36	26.5
Monitoring bereavement services	29	21.3
Palliative care outcome score	19	14.0
Other	13	9.6

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## Coordination of services

21. PCTs were asked to rate coordination between health and social care services (Figure 2), and between hospital, community and out of hours services (Figure 3). Ratings were requested on a scale of 1 to 10 where 1 is 'not at all coordinated' and 10 is 'extremely well coordinated'. The mean rating for coordination between health and social care services was 6.0, whilst for hospital, community and out of hours services, the mean rating was 6.2.

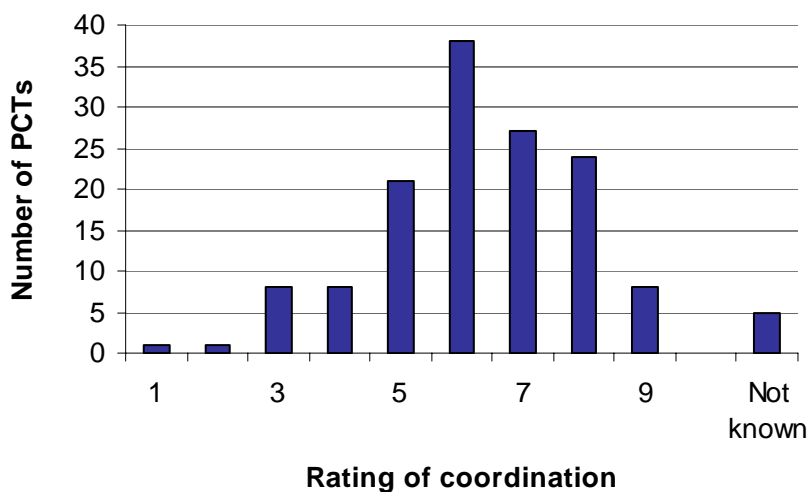
**Figure 2: PCTs' rating of coordination between health and social care services**



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Note: 1 is 'not at all coordinated' and 10 is 'extremely well coordinated'

**Figure 3: PCTs' rating of coordination between hospital, community and out of hours services**



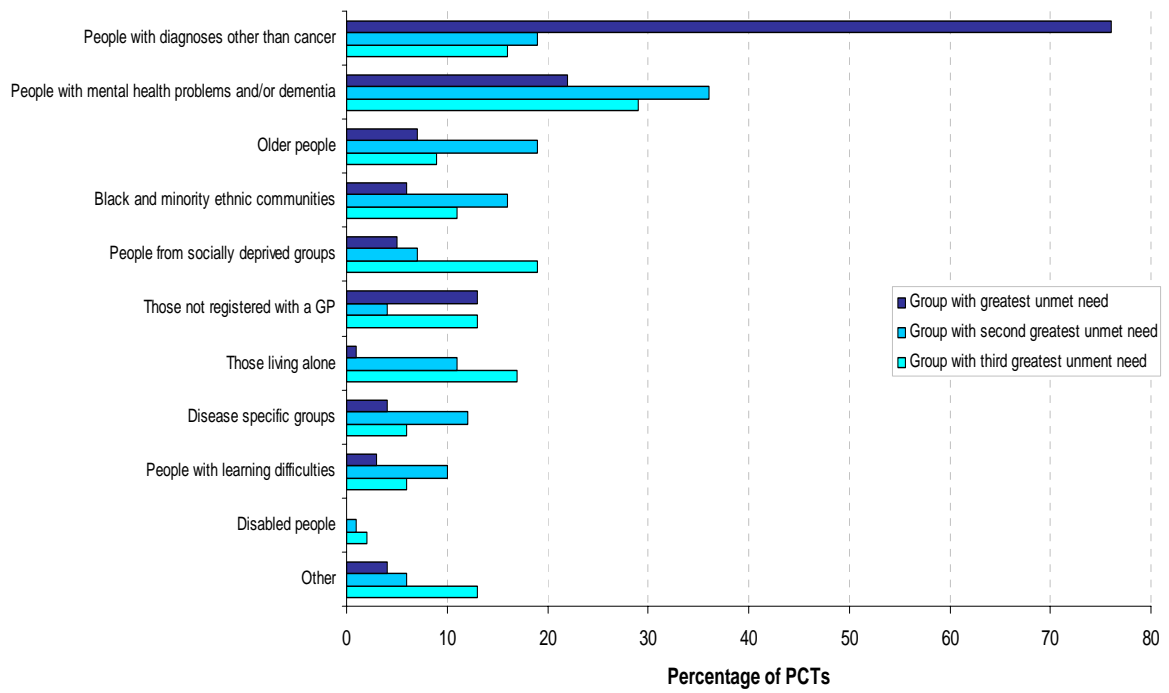
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Note: 1 is 'not at all coordinated' and 10 is 'extremely well coordinated'

### Areas of need

22. PCTs were asked to rate a number of areas of need in terms of the challenge presented to the PCT. The three biggest challenges were rated as education and training in care homes; number of patients achieving preferred place of care and death; and development of services for patients with conditions other than cancer. PCTs were also asked to rank their three biggest achievements. These were rated as timely access to medication; timely access to equipment; and implementation of end of life care tools.
  
23. PCTs were asked to rank in order of priority three local population groups which they thought had the most unmet needs in terms of end of life care. PCTs rated the groups with the most unmet need as patients with conditions other than cancer, people with mental health problems or dementia, and older people (Figure 4).

Figure 4: Groups with the most unmet needs in terms of end of life care



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Note: PCTs were asked to rank three local population groups which they thought had the most unmet needs in terms of end of life care. Some of these categories may overlap, for example, people with dementia and older people.

## 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.

### 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

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 in patient 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.

### 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).

**Nursing home**

See care home. In the report we use the term 'care home with nursing'.

**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 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.

**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.