



National Audit Office

End of Life Care

The National Audit Office scrutinises public spending on behalf of Parliament. The Comptroller and Auditor General, Tim Burr, is an Officer of the House of Commons. He is the head of the National Audit Office which employs some 850 staff. He and the National Audit Office are totally independent of Government. He certifies the accounts of all Government departments and a wide range of other public sector bodies; and he has statutory authority to report to Parliament on the economy, efficiency and effectiveness with which departments and other bodies have used their resources. Our work saves the taxpayer millions of pounds every year: at least £9 for every £1 spent running the Office.

Design and Production by
NAO Marketing & Communications Team
DP Ref: 008725

This report has been printed on Consort Royal Silk and is produced from a combination of ECF (Elemental Chlorine Free) and TCF (Totally Chlorine Free) wood pulp that is fully recyclable and sourced from carefully managed and renewed commercial forests. The range is manufactured within a mill which is registered under the BS EN ISO 9001 accreditation, which provides the highest standard of quality assurance.



Published by TSO (The Stationery Office) and available from:

Online

www.tso.co.uk/bookshop

Mail, Telephone, Fax & E-mail

TSO

PO Box 29, Norwich, NR3 1GN

Telephone orders/General enquiries: 0870 600 5522

Order through the Parliamentary Hotline

Lo-call 0845 7 023474

Fax orders: 0870 600 5533

E-mail: customer.services@tso.co.uk

Textphone 0870 240 3701

TSO Shops

16 Arthur Street, Belfast BT1 4GD

028 9023 8451 Fax 028 9023 5401

71 Lothian Road, Edinburgh EH3 9AZ

0870 606 5566 Fax 0870 606 5588

The Parliamentary Bookshop

12 Bridge Street, Parliament Square,
London SW1A 2JX

Telephone orders/General enquiries 020 7219 3890

Fax Orders 020 7219 3866

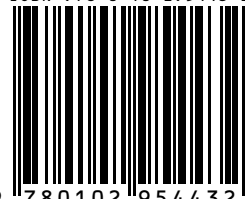
Email bookshop@Parliament.uk

Internet bookshop.Parliament.uk

TSO@Blackwell and other Accredited Agents

£14.35

ISBN 978-0-10-295443-2





National Audit Office

End of Life Care

LONDON: The Stationery Office
£14.35

Ordered by the
House of Commons
to be printed on 24 November 2008

This report has been prepared under Section 6 of the National Audit Act 1983 for presentation to the House of Commons in accordance with Section 9 of the Act.

Tim Burr
Comptroller and Auditor General
National Audit Office

18 November 2008

The National Audit Office
study team consisted of:

Karen Jackson, Tom McBride, Shamil Ahmad,
Rosie Buckley, Andy Nichols, Hannah Payne,
Kirsten Payne, Duncan Richmond, Colin Ross
and Steph Woodrow under the
direction of Karen Taylor.

This report can be found on the National Audit
Office web site at www.nao.org.uk

**For further information about the
National Audit Office please contact:**

National Audit Office
Press Office
157-197 Buckingham Palace Road
Victoria
London
SW1W 9SP

Tel: 020 7798 7400

Email: enquiries@nao.gsi.gov.uk

© National Audit Office 2008



CONTENTS

SUMMARY	4
PART ONE	
The role of end of life care services	10
PART TWO	
The extent and quality of end of life care services in England	14
PART THREE	
Providing more effective end of life care	25
APPENDICES	
1 Methodology	32
2 Detailed examination of patient records in Sheffield to identify alternatives to hospital	36
3 Economic modelling	39
4 Detailed PCT reviews	46
5 International comparisons	48
6 Case examples	52
GLOSSARY	56



SUMMARY

1 People are generally living longer and, of the half a million people who die each year in England, two-thirds are over 75 years old. The majority of deaths occur in an acute hospital (hospital) and do so following a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most people wish to be cared for and die in their home but the number of people who are able to do so varies with age, geographical area and, most significantly, by condition.

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 such as doctors, nurses, allied health professionals and social workers, although the exact number of people

involved in delivering this care is not known. 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.

3 The provision of end of life care services has become increasingly complex: people are living longer and the incidence of frailty and multiple conditions in older people is increasing. As a result, people approaching the end of their life require a combination of health and social care services provided in the community, hospitals, care homes, or hospices. Care is also provided by informal carers such as family members, close friends or volunteers.

4 Primary care trusts (PCTs) spent an estimated £245 million on specialist palliative care services in 2006-07. The Department of Health (the Department) estimates that the overall annual cost of end of life care to NHS and social care services is measured in billions of pounds. We estimate that the annual cost to NHS and social care services of providing care to cancer patients in the 12 months prior to death (27 per cent of deaths) is £1.8 billion.

5 The Department has acknowledged that the priority given to end of life care within NHS and social care services has been relatively low, and has worked to raise its profile in recent years. In July 2008, following consultation over two years, the Department published its *End of Life Care Strategy* (the Strategy) which aims to improve the provision of care for all adults approaching the end of their life, including support for their families and carers. The Strategy centres on:

- improving the provision of community services by, for example, making rapid response community nursing services available in all areas 24 hours a day seven days a week, and improving coordination of care between local authorities and PCTs;
- equipping health and social care staff at all levels with the necessary skills to communicate with, and deliver care to people approaching the end of life, and their carers; and
- developing specialist palliative care outreach services by encouraging PCTs and hospices to work together to provide appropriate support to all adults in the community, regardless of their condition.

6 The Department considers that the implementation of its Strategy should reduce inappropriate admissions to hospital and enable more people approaching the end of their life to live and die in the place of their choice. To this end the Department has committed additional funding of £286 million over 2009-10 and 2010-11. Against this background, this report considers the scope for improving the pattern of care in light of the available evidence on the impact and appropriateness of existing provision.

7 In preparing this report, we drew on the knowledge and experiences of a wide range of health and social care staff involved in the delivery of end of life care and, most importantly, people approaching the end of their life and those caring for them. In addition to our censuses of PCTs and independent and NHS hospices and our survey of care homes, three unique features of our methodology (Appendix 1) include a detailed examination of the

patient records of 348 people who died in Sheffield in October 2007 to identify the potential for people to die in their preferred place of care (Appendix 2); modelling of the provision of end of life care services to identify whether the quality of such services can be improved within existing resources (Appendix 3); and detailed reviews of end of life care services provided by three PCTs (Appendix 4).

Findings

Place of care

8 **Research suggests that the majority of people (between 56 and 74 per cent) express a preference to die at home, although this proportion may decline as death becomes more imminent and people want access to more extensive support, such as from a hospice. Mortality statistics for 2006 show, however, that 35 per cent of people die at home or in a care home.**

Fifty eight per cent of all deaths occur in a hospital, although this figure varies from 46 per cent to 77 per cent between PCTs. Place of death also varies by condition, and cancer patients are more likely than others to die at home or in a hospice; the majority of deaths from dementia occur in care homes; and the vast majority of deaths from heart disease and pulmonary disease occur in hospital. For some people approaching the end of their life, however, there will be clinical reasons for admission to hospital, and for some it is their preferred place of care.

9 **A lack of prompt access to services in the community leads to people approaching the end of their life being unnecessarily admitted to hospital.** The absence of 24 hour response services and timely access to advice and medication leads to unplanned admissions. In addition, information on patients is not always captured or shared effectively between the different agencies involved in delivering care. This can lead to Do Not Attempt Resuscitation orders not being known or recognised to providers such as out of hours GPs and the ambulance service, resulting in inappropriate admissions to hospitals.

10 **The proportion of care home residents who die in hospital could be reduced.** Our survey found that a quarter of care home resident deaths occur in a hospital. There were also wide variations between care homes in the number of residents who die in hospital, ranging from none to all residents. In one PCT, the proportion of residents dying in care homes could have been increased from 61 per cent to 80 per cent, if greater support and advice had been provided to those care homes.

11 Independent hospices have an important role in the delivery of end of life care services, both in inpatient care and increasingly in day care and in services in care homes and peoples' homes. Independent hospices currently provide around 2,150 inpatient beds, compared to 450 provided by NHS hospices. Although traditionally focused on cancer, hospices are also increasingly offering services to people with other conditions. Whilst the proportion of non-cancer patients receiving hospice services is low, it is growing.

Meeting the needs of patients and carers

12 NHS and social care services are not meeting the basic needs of many people approaching the end of their life. The findings of published research and work carried out by the Healthcare Commission were that people approaching the end of their life are not always afforded the dignity and respect they deserve. Our focus groups identified a similar picture, where the standard of hospital care and social service provision was below what had been expected and care plans for patients had not been drawn up and agreed. These issues had unnecessarily caused stress for people approaching the end of their life and those caring for them.

13 Despite all carers being entitled to an assessment of their health and social care needs, our census of PCTs found that only 29 per cent provided such assessments as standard. PCTs also do not routinely record whether carers have received an assessment. Caring for a person approaching the end of their life can place a heavy burden on the physical, emotional and mental wellbeing of carers but only 24 per cent of PCTs stated that they offer respite care to all who need it.

The skills and training of health and social care staff

14 Many healthcare professionals will come into contact with people approaching the end of their life, but our surveys found that only 29 per cent of doctors and 18 per cent of nurses had received any pre-registration training in end of life care. In addition, only 39 per cent of doctors and 15 per cent of nurses had received pre-registration training in communicating with patients approaching the end of their life.

15 Ninety care homes responding to our survey (74 per cent) stated that they provide specific training on end of life care, but in less than half of cases was this training compulsory. Data collected by Skills for Care in 2007 show that as few as seven per cent of care home workers and five per cent of nursing care home workers have an NVQ level 3 qualification which includes

optional training in supporting people at the end of life. Staff turnover rates also suggest that care homes are training fewer staff than they lose on an annual basis.

Approaches to improving the delivery of end of life care

16 Fifty four per cent of general nurses and a third of doctors reported being trained in the use of at least one of the three National Institute for Health and Clinical Excellence (NICE) recommended approaches to end of life care (Gold Standards Framework, Liverpool Care Pathway or Preferred Priorities for Care). For those specialising in palliative care, the figures were 91 per cent of nurses and 95 per cent of doctors. These approaches, rolled out as part of the End of Life Care Programme between 2003 and 2007, are well regarded by a range of users and both doctors and nurses reported that their use had improved their confidence in delivering end of life care. There has, however, been little measurement of the benefits for patients of using these approaches and the direct benefit to patient care associated with their use has yet to be fully demonstrated. What research has been done has shown that their use can decrease unnecessary hospital utilisation and increase the likelihood of people dying in their preferred place of care.

Commissioning services

17 PCTs' expenditure on specialist palliative care services does not reflect the pattern of need. Although there is likely to be some variation in expenditure depending on need and the delivery models used, our census of PCTs and data collected by the Department found large variations in the average amount spent on specialist palliative care services for individuals approaching the end of their life (£154 to £1,684 per death). There is also variation in the availability of palliative care beds, and in the number of staff within hospital and community specialist palliative care teams. The provision of care home places and hospice services is also in many cases not proportional to need.

18 Coordination between health and social care services in relation to the planning, delivery and monitoring of end of life care is generally poor and is hampered by different funding streams. It can be difficult to determine what proportion of patients' needs are medical and fall under the NHS budget, or non-medical (social care) and are funded, in part, by local authorities and by the patient based on a needs assessment. A lack of integrated services and an absence of a single point of contact to coordinate care can lead to particular frustration.

19 In 2006-07, hospices provided inpatient services to over 38,000 people and supported over 112,000 people in the community, yet current contractual arrangements with PCTs limit their ability to plan and develop services.

Seventy per cent of hospices have only one year contracts with PCTs. On average, independent hospices received funding of some 31 per cent of their net expenditure (approximately £130 million) from PCTs in 2006-07, though some received as much as 62 per cent.

20 The Department has not yet implemented a national tariff to underpin commissioning of palliative care for NHS and voluntary sector providers.

In its response to the House of Commons Health Committee's 2004 report on palliative care, the Department stated that it was on course to implement a national tariff which would allow full cost recovery by all palliative care providers by 2008-09. A number of factors (for example, the lack of robust costing data) mean that it has not been possible for the Department to deliver a national tariff to this timescale. Whilst the Department continues to work towards delivery of a national tariff for specialist palliative care, there is no specific timetable.

The potential for improving end of life care services within existing resources

21 Our detailed examination of patient records in one PCT found that 40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month.

Alternative places of care for these patients identified by our work were equally split between home based alternatives (in a patient's own home or a care home) and bed based care in a hospice. Local data suggest there was sufficient inpatient palliative care capacity to take many of the patients who died in hospital.

22 Reducing the amount of time people approaching the end of their life spend in hospital could make resources available which could be used to better support people in their preferred place of care.

We estimate that caring for cancer patients in the last year of their life costs some £1.8 billion, and that £104 million could be redistributed to meet people's preferences for place of care by reducing emergency hospital admissions by ten per cent and the average length of stay following admission by three days (a reduction of around 25 per cent in the current average length of stay). The lack of robust data on the cost of delivering end of life care to people with conditions other than cancer limits our

ability to extend this analysis to other conditions. People with other chronic conditions typically spend a greater proportion of their last year of life in hospital following emergency admissions, so there is likely to be scope for further redistribution of resources.

Overall conclusion

23 The majority of people would prefer not to die in hospital, but a lack of NHS and social care support services mean that many people do so when there is no clinical reason for them to be there. There is scope for more people to die in their home, care home, or a hospice by improving training of all NHS and social care staff in understanding and awareness of end of life care needs, and extending specialist palliative care services for those that need them, regardless of their condition. Improved delivery of these services will require more effective commissioning and partnership working between the NHS, social services and the voluntary sector. The skills in end of life care which have been developed in the hospice movement, primarily in working with cancer patients, could be extended to patients with other terminal conditions, and to the care home sector through outreach services and training.

24 Given the potential to redistribute resources identified in our work, there is scope for PCTs to improve services in all settings by deploying existing and future resources more efficiently and effectively in supporting people in their preferred place of care. To achieve this improvement, there will be a continuing need for the Department to support PCTs as they reconfigure services and redeploy resources to better meet the needs of their local population. The following recommendations set out the actions required to address the problems we have identified and are in line with the aims and recommendations of the Department's Strategy.

Recommendations

For the Department of Health aimed at supporting implementation of its Strategy

- a **The wishes of people approaching the end of their life are not always conveyed to those who need to know.** Such data should ideally be captured in the Summary Care Record; but until it is fully operational, the Department through the national End of Life Care Programme should support PCTs and strategic health authorities to develop protocols to help capture, document, and share accurate patient information on preferences. This information should be regularly updated and shared with all providers across the health, social care, independent and voluntary sectors who influence decisions concerning where and how patients receive care.
- b **There are significant gaps in the education and training curricula for health and social care professionals.** The Department should work with the relevant professional bodies to ensure that all trainee doctors, nurses, allied health professionals, and registered social care staff receive an appropriate level of training in the delivery of end of life care.
- c **Few care home staff have sufficient training in providing end of life care.** The Department should strengthen the existing standards against which care homes are assessed to include a requirement to demonstrate that staff have received such training, including: communication skills; how to avoid unplanned emergency admissions; the provision of adequate pain management; and treating all residents with dignity and respect.

Further recommendations for the Department of Health

- d **The Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care provide a framework for improving the delivery of end of life care, including identifying the point at which it should begin. Little is known, however, about the direct patient benefits associated with their use.** The Department should commission clinical evaluations to determine whether their use results directly in better quality care for patients. For example, the planned survey of bereaved carers may be appropriate in the evaluation of the Liverpool Care Pathway and aspects of the Gold Standards Framework and Preferred Priorities for Care.

- e **Commissioning end of life care services is complex and there is a limited understanding of the national picture of demand and supply of end of life care services.** The Department should provide more information and, as appropriate, guidance to assist PCTs to meet end of life care needs and allocate resources more efficiently and effectively by building on the evidence from our work. The guidance should apply the World Class Commissioning Framework which was launched in December 2007 and aims to improve the way health and social care services are commissioned.

For PCTs as commissioners of end of life care services in implementing the Strategy

- f **Advance care plans seek to make clear a person's wishes in anticipation of a gradual deterioration in their condition, which may result in a loss of capacity to make decisions or to communicate their wishes to others.** PCTs should encourage providers to develop care plans, including advance care plans, for those who wish to have one, and review and update them as necessary.
- g **A lack of coordination between services or a single point of contact can lead to frustration for patients and carers.** PCTs should commission effective coordination of end of life care services through a single point of contact for patients and carers, including access to advice and Carers' Assessments.
- h **PCTs generally contract with independent hospices on an annual basis leading to uncertainty in planning and sometimes financial pressures.** PCTs should work with independent hospices to develop three year contracts, based on commissioned services and levels of activity, to enable hospices to better plan the use of resources. These contracts should be in accordance with the existing guidance on how the Government and the voluntary sector should work together.
- i **Hospitals will continue to have an important role to play in end of life care but these services do not always meet the needs of patients and carers.** PCTs should use the World Class Commissioning Framework to commission end of life care services from hospitals to meet the needs of patients and carers. They should obtain assurance from hospitals on whether staff have received sufficient training; there is suitable inpatient accommodation including private, dedicated space for consultations for patients, their relatives and carers; and there are timely and effective discharge planning arrangements.

Further recommendations for PCTs

- j** **There is considerable variation between PCTs in how specialist palliative care services are commissioned and in the availability of such services to the local population.** When working with local authorities in carrying out Joint Strategic Needs Assessments and developing priorities for Local Area Agreements, directors of public health should monitor whether the current provision of end of life care services and the needs of the local population are fully assessed and gaps addressed. PCTs should use our feedback reports on the results of our PCT census to compare and contrast the extent of their services.
- k** **People's preferences for place of care are generally not being met and access to hospice services is primarily for people with cancer.** PCTs should explore the possibility of commissioning more services from hospices to support patients with conditions other than cancer. Such services could include the coordination of care in the locality, providing training to generalist staff working in other settings, and working in partnership with care homes to enhance the care that they provide.

For the General Medical Council and the Nursing and Midwifery Council

- l** **The current reviews of medical and nursing education present an opportunity to improve the level of basic training which doctors and nurses receive in end of life care.** The General Medical Council's Education Committee in its review of Tomorrow's Doctors should address how to improve skills in identification, delivery, and awareness of end of life care. The review by the Nursing and Midwifery Council of pre-registration nursing education should address similar issues.



The role of end of life care services

1.1 End of life care services aim to support those with advanced, progressive, incurable illness to live as well as possible until they die. In England, approximately 470,000 people die each year, almost two-thirds of whom are aged over 75 years. Around three quarters of deaths are 'predictable',¹ and follow a period of chronic illness where people may need access to end of life care. Over the last 20 years, the population of England has grown but the total number of deaths per annum has declined. Current projections predict that the number of deaths will continue to fall until 2012 and thereafter there is likely to be a steady increase in the number of deaths. By 2030, it is predicted that the number of deaths in the over 85s will have increased from around a third to 44 per cent.²

1.2 Faced with a terminal illness such as cancer, pulmonary disease, heart failure or dementia, most people would prefer to die at home and avoid dying in hospital.^{3,4,5,6} This proportion may decline as death becomes more imminent and people want access to more extensive support, such as from a hospice. Place of death is, however, influenced by condition and the majority of deaths occur in hospital. As well as not being supported to die where they wish, the findings of published research and work carried out by the Healthcare Commission were that people approaching the end of their life are not always afforded the dignity and respect they deserve.⁷

1.3 End of life care is a complex subject and there is no precise point at which it should begin. This lack of certainty leads to difficulties in identifying when it is best to discuss with a person how they would like to be cared for as they approach the end of their life. People often require a complex mix of health and social care services supplied by a range of providers such as the NHS, social services, the voluntary sector and family and friends in a number of settings, including care homes, hospices and the patient's home. In many cases patients will move between settings during the last year of their life.

1.4 The Department has recognised that much can be learned from the holistic approach to care which has been pioneered by hospices and specialist palliative care services in England over the past 40 years. The 2006 Mortality Statistics show that only four per cent of people die in a hospice, the majority of whom have cancer. Many more people receive other forms of hospice support through day care units or in their own home. In 2007, there were 174 hospice inpatient units⁸ in England offering 2,600 beds.⁹ Three quarters of units and beds are provided by the voluntary sector, with the remainder provided by the NHS.

1.5 We estimate that the full cost of independent hospice services was some £500 million in 2006-07, of which PCTs funded around £130 million (26 per cent). PCTs report spending a further £112 million on specialist palliative care in NHS run services, meaning the total spend on specialist palliative care in 2006-07 was just over £600 million.

1 Based on the calculation by Higginson (2001) that the number of people requiring palliative care is all cancer deaths and two thirds of all deaths, 76 per cent (358,000) of deaths in England in 2006 would have required some form of palliative care. Higginson I (2001) *The Palliative care for Londoners: Needs, Experience and, Outcomes and Future Strategy*. NHS Executive London Region cited on page 32 of Marie Curie's Phase 1 Report on Barnet.

2 Gomes B and Higginson I (2008) *Where people die [1974 2030]: past trends, future projections and implications for care*. *Palliative Medicine* 22: 33-41.

3 *See Views About Dying at Home*, 2004, survey commissioned by Marie Curie, carried out by You Gov.

4 *Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences*, Higginson I., Sen-Gupta G. 2000, *Journal of Palliative Medicine*, vol.3, no.3.

5 Higginson, I (2003) *Priorities and preferences for end of life care*.

6 Norfolk Health Overview and Scrutiny Committee (2005) *How We Manage Death and Dying in Norfolk County and Waveney*.

7 Higginson, I J and Hall, S (2007). *Rediscovering Dignity at the Bedside*. *British Medical Journal*, vol. 335, no. 7612, pp. 167-168.

8 Although there are 195 hospices in England, not all hospices offer inpatient care.

9 *Hospice and Palliative Care Directory: United Kingdom and Ireland 2007*.

Policies for end of life care

1.6 In 2000, the NHS Cancer Plan identified a need to provide more support for specialist palliative care services, including hospices. Subsequently, a central fund of £50 million per annum was made available from 2003-04. From 2006-07 this additional resource became available to PCTs as part of their baseline funding.

1.7 In December 2003, following the publication of *Building on the Best: Choice, Responsiveness and Equity in the NHS*, the Department announced that it would allocate £12 million over three years to an NHS End of Life Care Programme. The Programme aimed to improve the quality of care at the end of life for all people and enable them to be cared for and die in the place of their choice. It sought to do so by spreading the best practice seen in the palliative care administered to cancer patients to those with other conditions through increasing the number of staff trained in the principles of palliative care.

1.8 The Programme worked with strategic health authorities (SHAs) to encourage the uptake in all healthcare settings of the Gold Standards Framework, the Liverpool Care Pathway and Preferred Priorities for Care, which were recommended by the National Institute for Health and Clinical Excellence.¹⁰ The Programme ended in March 2007 and was subsequently evaluated by the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham.¹¹ This work found a number of positive consequences were perceived by participants in the review although it was too early to assess the impact on patient outcomes.

1.9 Lord Darzi's *High Quality Care for All – NHS Next Stage Review Final Report*, published in June 2008, provides a policy framework for the NHS in making high quality care a consistent part of everyone's experience of community care. This review recognises the need for greater dignity and respect at the end of life. As part of the review, all SHAs have produced a vision document on eight clinical pathways, one of which was end of life care.

1.10 The Department's Strategy (**Figure 1 overleaf**), published in July 2008, attaches importance to end of life care services, both for the people approaching the end of their life and also for their families and friends. The Department has made clear that a step change is needed to provide high quality care in all settings to all patients approaching the end of their life. To this end, the Strategy recommends a care pathway approach to commissioning and delivering an integrated service (**Figure 2 on page 13**). The Strategy committed to provide an extra £286 million over two years to PCTs to improve end of life care services.

The scope of the study

1.11 Our work identifies the current picture of end of life care services in England and what improvements need to be made to better meet the needs of patients and carers. We evaluated whether:

- the services provided to people approaching the end of their life and their carers are fit for purpose;
- people are cared for in the place of their choice;
- health and social care staff have sufficient skills and training to deliver end of life care;
- the commissioning of end of life care services meets the needs of local populations;
- the use of recommended approaches to end of life care (Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care) is improving the delivery of end of life care; and
- end of life care services could be improved within existing and planned resources.

1.12 We focused on end of life care for adults in their last year of life. Children were excluded from the scope of our study because a report on children's palliative care services was published in May 2007.¹² We drew on a range of methodologies set out in Appendix 1. We also examined the situation in the USA, Canada, Scotland, Wales and Northern Ireland (Appendix 5).

¹⁰ National Institute for Health and Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*.

¹¹ *The NHS End of Life Care Programme: An Evaluation of Processes, Outcomes and Impact – Executive Summary*.

¹² *Palliative Care Services for Children and Young People in England*, Prof A Craft and Sue Kiele (May 2007).

1 A summary of the Department's End of Life Care Strategy

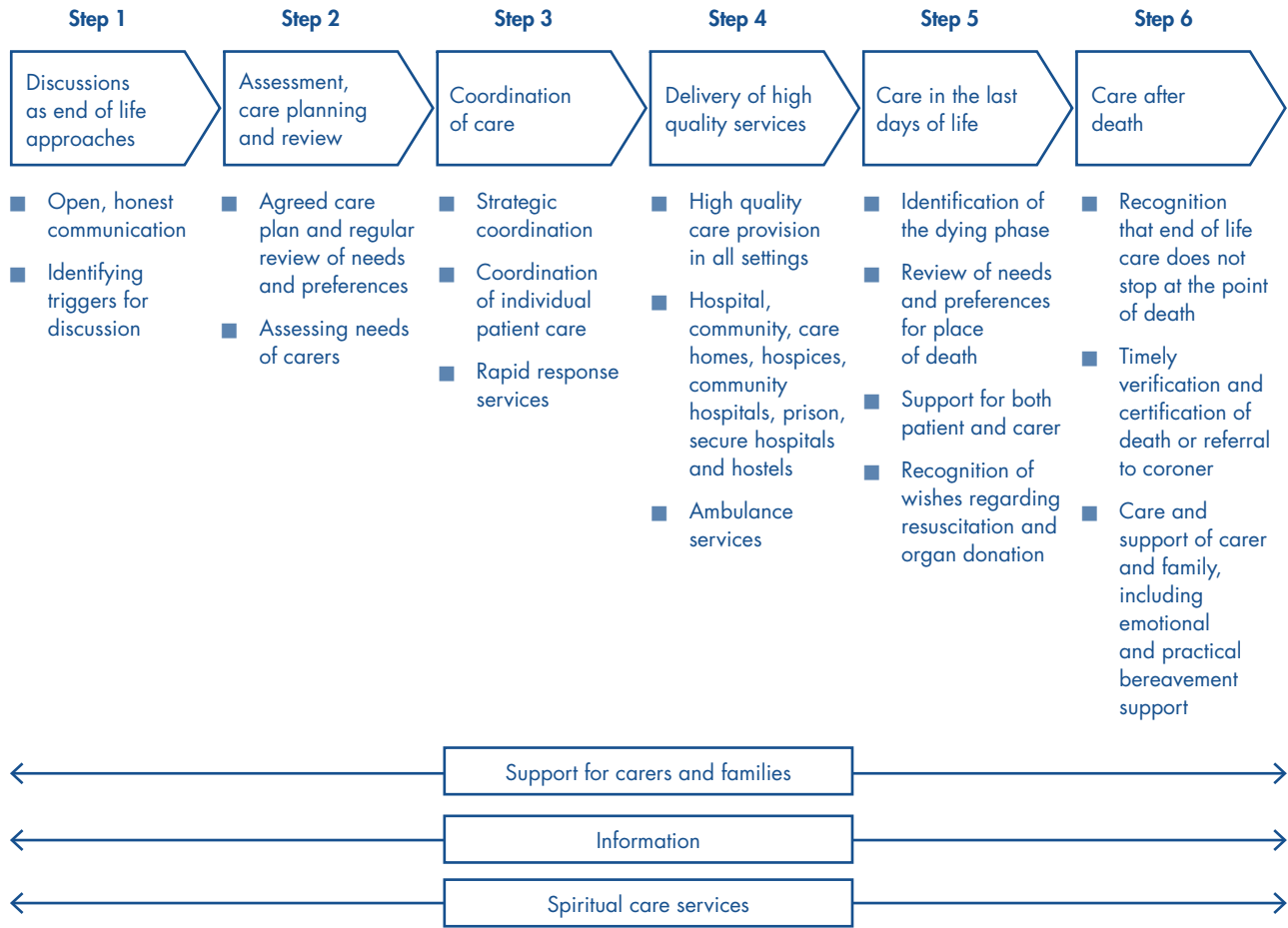
In July 2008, the Department published its End of Life Care Strategy, the aim of which is to improve access to high quality care for all adults approaching the end of life, irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socio-economic deprivation. This care should be available wherever the person may be: at home; in a care home; in hospital; in a hospice; or elsewhere. The Strategy was developed by an advisory board and six working groups consulting over 300 stakeholders and using existing research. It builds on the modern hospice movement; the NHS End of Life Care Programme; and the Marie Curie Delivering Choice Programme. Key areas to be addressed include:

- **Raising the profile** of end of life care and changing attitudes to death and dying in society.
- **Strategic commissioning** to provide an integrated approach to the planning and delivery of end of life care services across health and social care, led by PCTs and local authorities.
- **Identifying people approaching the end of life** to allow a discussion about the person's preferences for the place and type of care needed.
- **Care planning** to assess the needs and wishes of the person and to agree the subsequent care plan with the person and their carer. The care plan should be available to all who have a legitimate reason to see it (for example, out of hours and emergency services).
- **Coordination of care** to ensure that each person approaching the end of life receives coordinated care, perhaps with a central coordinating facility providing a single point of access for people.
- **Rapid access to care** with medical and personal care and support for people 24 hours a day, seven days a week. The provision of these services should prevent emergency admissions to hospitals and enable more people approaching the end of their life to live and die in the place of their choice.
- **Delivery of high quality services in all locations** in the community, care homes, hospices, hospitals and ambulance services.
- **Last days of life and care after death.** The Liverpool Care Pathway or equivalent approach will be used to empower generalist clinicians to care for the dying and manage pain and other symptoms in the last days and hours of life, and to coordinate care after death.
- **Involving and supporting carers** in the provision of care. Carers may need practical and emotional support both during the person's life and in bereavement. Carers have the right to have their own needs assessed and reviewed.
- **Education and training and continuing professional development** to embed end of life care in training curricula, induction and continuing professional development for all registered and unregistered health and social care staff whether working full time on such care or not.
- **Measurement and research** of structure, process and outcomes of care to monitor care given and to develop further end of life care services. The Department also wishes to enhance research into end of life care especially for those with conditions other than cancer.
- **Funding.** It is difficult to calculate the cost of end of life care across health and social care because of difficulties in defining the boundaries of such care and of identifying the cost to carers. The Department has provided extra funding of £286 million for 2009-10 and 2010-11 but believes that many improvements can be made by better use of existing resources, for example by reductions in hospital admissions and length of stay.

The Department also set out for patients and carers what the Strategy should mean for them.

Source: Department of Health: End of Life Care Strategy

2 The end of life care pathway



Source: Department of Health: End of Life Care Strategy



The extent and quality of end of life care services in England

2.1 This part of the Report evaluates the quality of end of life care and whether resources are used in the best way to benefit patients. It draws on the findings from a census of PCTs; a survey of care homes; censuses of NHS and independent hospices; surveys of doctors and nurses; focus groups of patients and carers; and existing research and data.

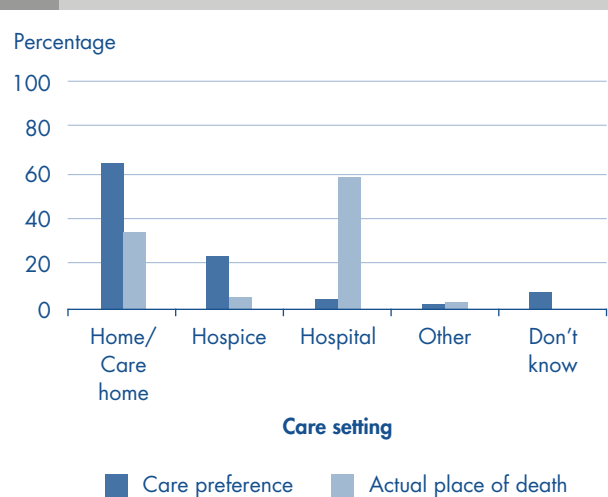
Place of care

Place of death varies by age and condition

2.2 There are significant differences in the place of death between age groups. Hospice death rates are highest for people aged 45 to 64 and care home death rates highest for those over 85. There are also important differences in place of death according to cause of death. For example, cancer patients are more likely to die in hospices, whilst patients dying from respiratory disease are more likely than average to die in hospital.

2.3 Most people express a preference to die at home (56 per cent to 74 per cent)^{13,14} or in a hospice and to avoid dying in hospital (**Figure 3**). The proportion of patients with cancer expressing a preference for home care has been shown to decrease as death approaches (90 per cent to 50 per cent) and be replaced by a preference for hospice care (10 per cent to 40 per cent).¹⁵ This may be because people do not want to die alone or be a burden to their family, or because they want access to more extensive support as death becomes more imminent.

3 A comparison between people's preferences and actual place of death



Source: "Views About Dying at Home", survey commissioned by Marie Curie in 2004 of 2,453 people in Great Britain, carried about by You Gov and 2006 Office for National Statistics Mortality Statistics for England

NOTE

As 'care home' was not an option in the 2004 You Gov survey, but is recorded as a place of death in the 2006 Mortality Statistics, these categories have been merged for the purposes of this comparison.

¹³ Higginson, I (2003) *Priorities and preferences for end of life care*.

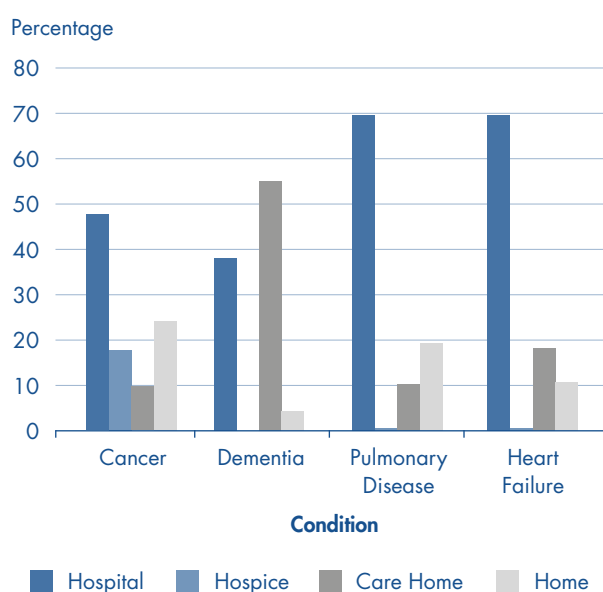
¹⁴ Norfolk Health Overview and Scrutiny Committee (2005) *How We Manage Death and Dying in Norfolk County and Waveney*.

¹⁵ Hinton J: *Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives?* *Palliative Medicine* 1994;8:183-196.

2.4 In 2006, 58 per cent of all deaths in England occurred in a hospital, ranging from 46 per cent to 77 per cent across PCTs. Many people are admitted to hospital for emergency treatment or symptom management and, for some people, hospitals remain their preferred place of care. Our analysis of mortality statistics in PCTs shows that the incidence of home deaths is not strongly related to the level of deprivation, a factor which is commonly thought to inhibit choosing to die at home. Type of illness does, however, influence the setting where people are likely to die. For example, 94 per cent of all hospice deaths are patients with cancer and over half of deaths from dementia occur in care homes (**Figure 4**).

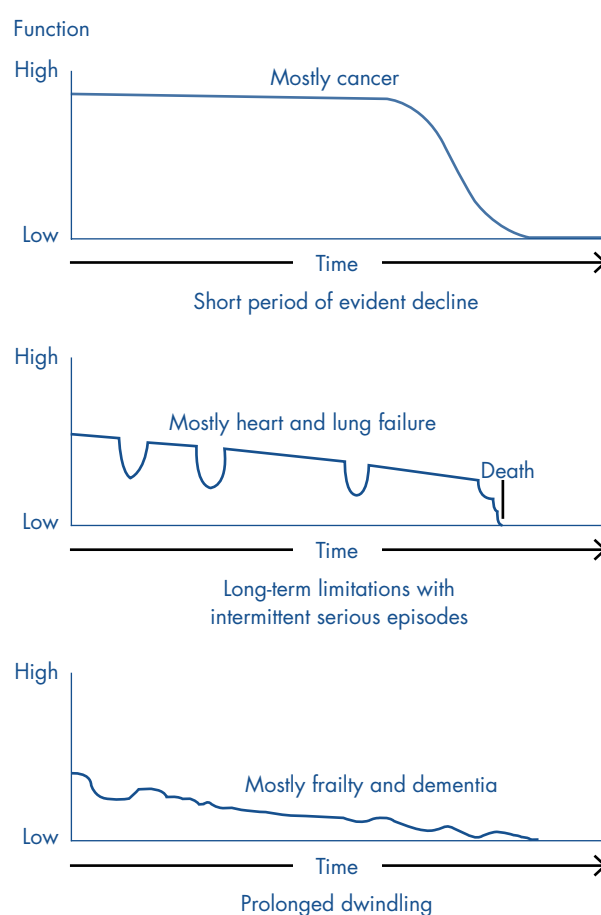
2.5 Variation in place of death can partly be explained by the way different diseases progress (**Figure 5**). For cancer, the disease trajectory is relatively predictable, with patients tending to experience a period of relatively rapid decline at the end of life, whilst dementia has a more gradual deterioration. For other conditions, the trajectory is less predictable. For example, people with chronic obstructive pulmonary disease experience sudden dips in their health leading to emergency admissions, followed by a period of relative stability, whilst motor neurone disease (MND) can progress rapidly from diagnosis to death (Appendix 6, Example 1). In the less predictable cases it is more difficult to identify when death is likely to occur and when end of life care should begin, leading to an increased incidence of deaths in hospital.

4 Place of death varies by condition



Source: National Audit Office analysis of 2006 Mortality Statistics for England

5 Chronic, progressive, and eventually fatal illnesses typically follow three trajectories



Source: Lynn and Adamson (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*

Meeting the needs of patients and carers

2.6 Whilst there is no single definition of good end of life care, the Department has identified that it should include treating people as individuals, with dignity and respect; ensuring that their pain and other symptoms are well controlled; in familiar surroundings; and in the company of close family and friends. In addition to meeting the needs of the patient, good quality end of life care should also take into account the needs of carers.¹⁶

2.7 A failure to treat patients as individuals was a consistent concern of the patients and carers we consulted. Common themes for improvement are highlighted in **Figure 6**. Positive experiences were often linked to being treated by specific individuals who understood, appreciated and empathised with the end of life process, with GPs and voluntary staff receiving particular praise.

2.8 In its second Spotlight on Complaints report, published in April 2008, the Healthcare Commission¹⁷ looked in detail at 50 complaints specifically related to end of life care. Common issues included poor support for basic comfort, family and patient privacy, and spiritual, cultural and psychological needs. In many cases, poor communication limited a patient's sense of empowerment and their ability to make an informed decision about their care. Often the decision to move from 'curing' to 'caring' was not clearly communicated, leading to needless and painful interventions that diminished the patient's quality of life, and referrals to specialist palliative care teams were sometimes made too late, or not at all.

2.9 From April 2009, the newly established Care Quality Commission (the Commission) will have responsibility for regulating services across health and social care including many of the key providers of end of life care such as hospitals, hospices, care homes and community-based services. In March 2008, the Department launched a public consultation on the framework for the registration of health and adult social care providers with the Commission. This consultation recognises the need for all care to be tailored to individual needs, to offer appropriate levels of dignity and respect and to ensure all care staff are properly trained.

6 Suggestions for improvements to end of life care services made by patients and carers

Improvements in equity and consistency of access to services across all disease groups.

Access to high quality respite care should be available to all individuals receiving end of life care services.

More information should be made available regarding accessing direct payments.

Training, particularly around dignity and respect at end of life, should be made compulsory for all health and social care staff, including GP receptionists.

The removal of all mixed sex wards to improve dignity of and respect for patients.

Easy access to counselling for both patients and carers.

There should be one key contact for patients and carers to access information and support regarding their specific needs.

Improved information provision, including information packs containing health and social care information, and a mentoring service for patients and carers.

There should be adequate permanent nursing staff on hospital wards in order to improve continuity of care.

Improvements in the availability of electric wheelchair provision.

Improved access to carer's assessments.

Improvements in PCT procedures regarding reviewing access to life-prolonging drug therapies.

Source: Focus groups carried out by Arup on behalf of the National Audit Office

¹⁶ Department of Health. *End of Life Care Strategy*. July 2008.

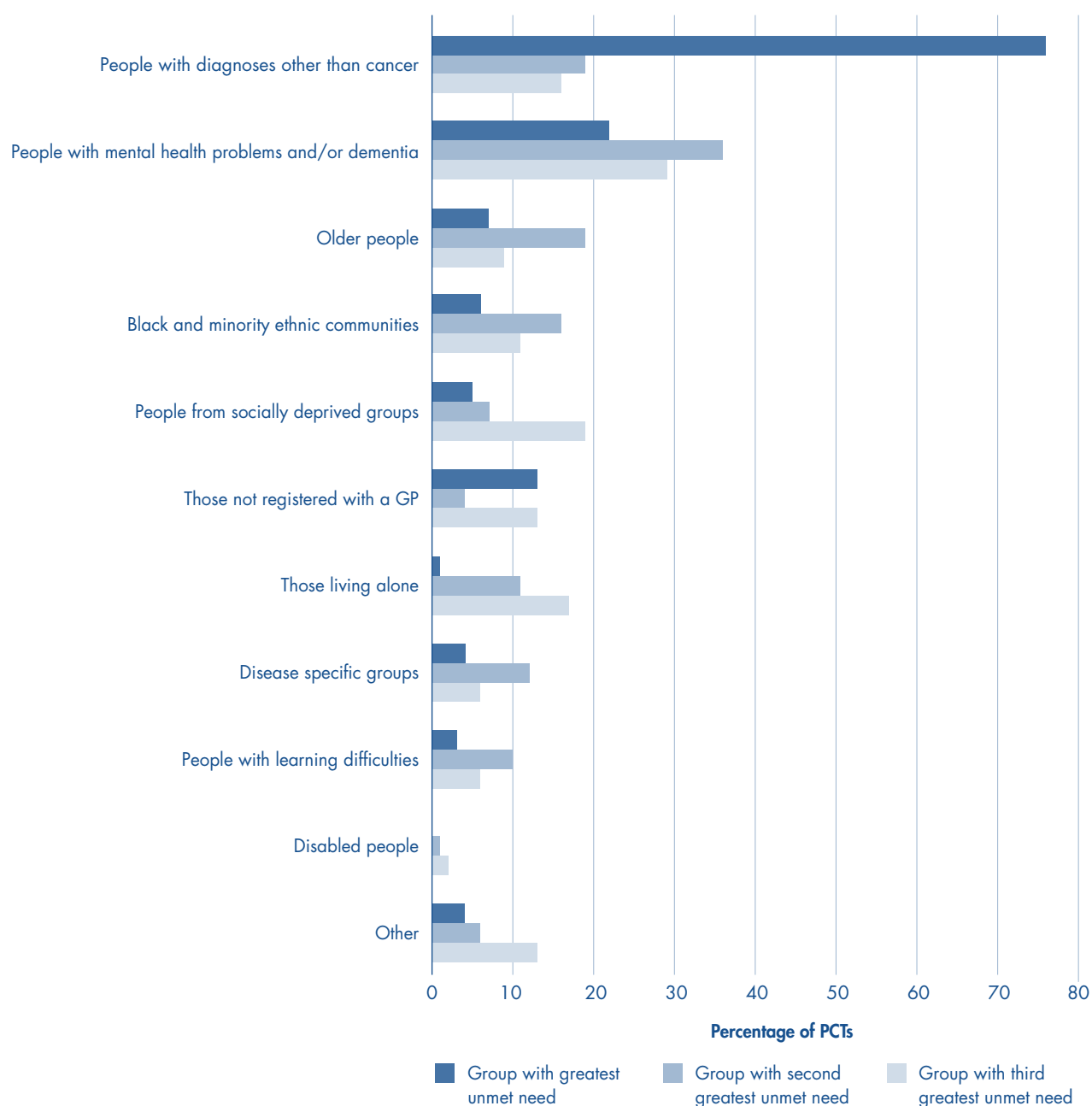
¹⁷ Healthcare Commission (April 2008) *Spotlight on complaints – A report on second-stage complaints about the NHS in England*.

Access to specialist palliative care services

2.10 In the Strategy, the Department states that all people approaching the end of their life should be able to access high quality end of life care irrespective of diagnosis. Some patients, however, face barriers to accessing end of

life care services. When asked in our survey, 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 7**).

7 Groups with the most unmet needs in terms of end of life care



Source: National Audit Office census of primary care trusts

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.

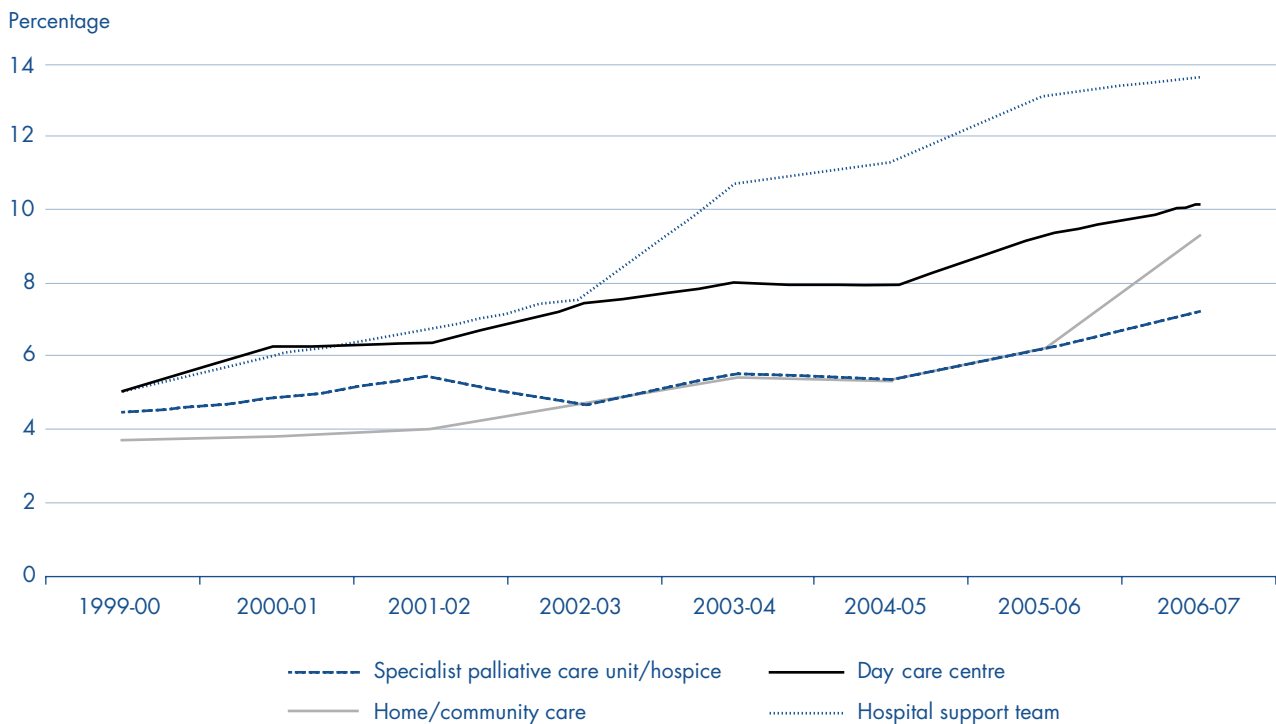
2.11 Cancer patients account for 27 per cent of deaths, yet make up the majority of patients receiving specialist palliative care services. Our survey of PCTs found that active case management occurs more frequently in all settings for cancer patients. Our work also found that many services were aimed solely at patients with cancer and that the level of information provided to these patients is not replicated for other conditions. Of those patients accessing specialist palliative care services, the proportion who have conditions other than cancer is increasing but remains low (**Figure 8**).

2.12 Although patients we consulted were positive about their experiences of using hospice services, some cited their own perceptions of what hospices offer and whom they serve as a reason for not initially taking up these services. Some were reluctant to use hospice services because they considered hospices to be institutions predominantly focused on providing inpatient care to those very close to death. In other cases, a common theme was the issue of pride and the belief that others were more deserving of services.

2.13 In our survey of independent hospices, four per cent of patients who died in 2006-07 were from ethnic minority communities, suggesting that these communities may be underrepresented as a proportion of those accessing hospice services. Research indicates that this lower proportion may be because of 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.¹⁸ A range of community outreach activities are adopted by some hospices to learn more about the needs of their local populations and to raise awareness of their services.

2.14 Whilst a third of all deaths were people aged over 85, only 14 per cent of this group had accessed a hospice service in 2006-07. This situation may be explained by the lower prevalence of cancer in this age group, with cancer recorded as the primary cause of death in only 18 per cent of cases.¹⁹

8 The percentage of patients accessing specialist palliative care services who have conditions other than cancer has risen, but remains low



Source: National Council for Palliative Care

18 Smaje and Field. *Absent minorities? Ethnicity and the use of palliative care services*. 1997.
 19 Office for National Statistics *2006 Mortality Statistics*.

2.15 In our July 2007 report, *Improving Services and Support for People with Dementia*, we found that over 60 per cent of all care home residents are estimated to have dementia²⁰ and that people with dementia often face difficulties accessing end of life care services. The steady decline in mental and physical function which is a symptom of dementia (Figure 5) means that patient wishes for end of life care need to be sought early enough to enable the person to participate fully, which in turn requires the diagnosis to be made early enough in the disease progression. Such wishes can be set out in advance through the Mental Capacity Act, which came into force in October 2007. The Act enables people to plan what they would like to happen should they be unable to make decisions about their care in the future, but in many cases of dementia diagnosis is not made early enough.

2.16 Fifty five per cent of people with dementia die in their care home, five per cent in their own home, and the rest die in hospital. Our July 2007 report found that although care for people with end stage dementia is beginning to be better understood, there is a lack of skill and understanding on the part of care home and community staff. Challenges in the delivery of end of life care to people with dementia include deteriorating mobility, forgetfulness and inability to communicate about pain. Whilst the end stage can be difficult to define, National Institute for Health and Clinical Excellence and Social Care Institute for Excellence²¹ guidelines state that dementia care should incorporate a palliative care approach from time of diagnosis to death. An account of how specialist palliative care can play a role in caring for people with advanced dementia in care homes can be found in Appendix 6, Example 2.

End of life care provided by informal carers

2.17 The 2001 census found that 5.2 million people in England and Wales provide some form of unpaid care to a family member or friend, including end of life care. Of these, over a million provide more than 50 hours of care per week. In 2007, Carers UK estimated that to replace all the care provided informally by carers in England with a professional service would cost £71 billion per year,

although this amount would cover all aspects of care not just end of life care. Research by the Motor Neurone Disease Society estimates that in the last year of life each patient with motor neurone disease receives informal care which would cost £101,000 to provide professionally.²²

2.18 Carers are often overwhelmed by the number of services they need to contact to get support. A lack of integrated services or a single point of contact to coordinate care can lead to frustration, and there was consensus among those we consulted that continuity of care was a key factor in positive experiences. An example of a PCT which provides a single point of contact for carers is given in Appendix 6, Example 3.

2.19 Providing informal care can have an adverse impact on carers' mental and physical health.²³ With the correct support, however, a carer's role can be a rewarding experience, knowing that they have played a vital role in enabling the person to be cared for in a place of their choice amongst family and friends. Not seeing themselves as carers but as fulfilling family duties, can, however, be a barrier to carers accessing available services.

2.20 All carers are entitled to an assessment by a social worker, to discuss the help they need to care, to maintain their own health, and to balance caring with other commitments. Social services may set eligibility thresholds on the services they provide according to the availability of resources. Amongst PCTs responding to our census, 19 per cent stated that carer's assessments were not provided, 29 per cent stated that they were provided as standard, and 52 per cent stated that assessments were provided for some carers but not all. The average proportion of carers receiving an assessment across all PCTs was 16 per cent, but 104 PCTs could not provide this information. Twenty four per cent of PCTs provide respite care to all those approaching the end of their life who need it, whilst 69 per cent provide it subject to eligibility criteria. The remaining seven per cent do not provide any respite care.

20 *Improving services and support for people with dementia: Report by the Comptroller and Auditor General HC 604 Session 2006-07/ 4 July 2007.*

21 National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006). *Dementia: Supporting people with dementia and their carers.*

22 Carers UK and University of Leeds (2007) *Valuing Carers – calculating the value of unpaid care.*

23 Barrows and Harrison, RA (2005) *Unsung heroes who put their lives at risk? Informal caring, health and neighbourhood attachment.* Journal of Public Health, 27(3): 292–207.

Integration of end of life care services

2.21 Given the number of agencies involved and that a patient's condition can deteriorate rapidly, good quality end of life care relies on providing an integrated and timely service. Integration between health and social services was rated poorly by respondents to our survey of care homes and independent hospices. Participants in our PCT reviews and focus groups raised concerns that the lack of integration had an adverse impact on patient care packages, often adding unnecessary delays in providing equipment and care when the patient only had a few days or hours to live. Integration between primary and secondary care (Appendix 6, Example 4) and between both statutory and voluntary providers of health and social care is essential as patients reaching the end of their life often move between care settings and require services from a number of providers, making continuity of care more difficult to achieve.

2.22 Timely access to equipment is an essential component of end of life care. For example, people approaching the end of their life may need a hospital bed and commode to be installed in their home to enable them to die there. This equipment must be readily available as often patients have a very short time in which they can be transferred from a hospital or hospice to home. Only 54 per cent of PCTs stated that they had timely access to equipment out of hours. Difficulties identified by PCTs included equipment being held by a separate organisation, equipment not being in stock, and a long waiting list for assessment.

2.23 Our PCT reviews identified concerns about out of hours services, especially GPs, where a lack of patient knowledge and available patient information led to inappropriate admissions. Our work has identified examples of services aimed at providing out of hours cover which prevent emergency admissions. These include a Rapid Response Team to visit patients and provide advice by telephone introduced in Lincolnshire as part of the Marie Curie Delivering Choice Programme (see paragraphs 3.21 to 3.22), and an Intensive Home Nursing Team which can provide 24 hour nursing services in a patient's home in Sheffield. Many hospices also offer an out of hours helpline for patients, carers and clinicians, although these often only cover patients who are receiving services from the hospice.

The skills and training of health and social care staff

2.24 Given the range of staff a patient with end of life care needs will come into contact with in the last year of their life, nearly all staff need to be able to deliver basic end of life care, and many will need to be able to discuss death and dying. Care is often delivered by generalist staff for whom end of life care represents a varying proportion of their role. As a result, they may not be trained in the delivery and discussion of end of life care. The Strategy recognises the diversity of staff involved in end of life care and identifies four core common requirements for workforce development across both registered and non-registered staff. These are training in:

- Communication skills
- Assessment of peoples' needs and preferences
- Advance care planning
- Symptom control

2.25 Our surveys of nurses and doctors highlighted a lack of training in end of life care. Only 18 per cent of nurses and 29 per cent of doctors stated that their pre-registration training covered end of life care, and 15 per cent and 39 per cent respectively stated that their training covered communicating with patients approaching the end of their life. Doctors and nurses were nevertheless fairly confident in their abilities when asked to rate their confidence in identifying, delivering and communicating about end of life care.

2.26 Doctors and nurses specialising in palliative care unsurprisingly rated their confidence higher than that of generalist doctors and nurses (**Figure 9**). Amongst generalist doctors, GPs ranked their confidence lowest in identifying the point when end of life care should begin; cardiologists were least confident in the delivery of end of life care; and emergency/intensive care specialists were least confident in discussing end of life care. In a 2008 survey of neurology nurses, who treat patients with conditions such as MND and Parkinson's disease, 68 per cent stated that they had palliative care training needs.²⁴

24 National Council for Palliative Care/Royal College of Nursing. *Exploring the Interface*. June 2008.

2.27 There are 18,500 care homes in England with around 400,000 beds. Based on responses to our survey of care homes and ONS mortality data for England, we estimate that between 92,000 and 119,000 residents of care homes will die each year, representing between 19 and 25 per cent of all deaths in England. Of these, approximately 70 per cent will die in the home, with the majority of the remainder dying in hospital. We found a significantly higher proportion of people were able to die in care homes where the care home had access to nursing staff (**Figure 10**).

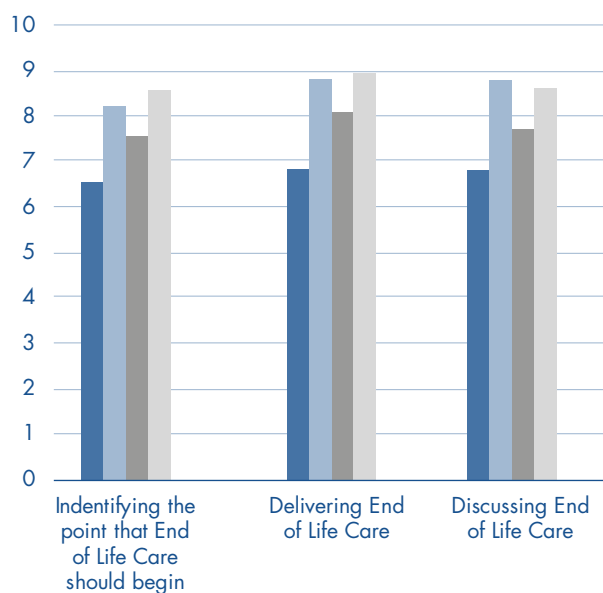
2.28 Work undertaken on our behalf by the Balance of Care Group (Appendix 2) in Sheffield found that care home residents who died in hospital were more likely to have had an admission which might have been avoided than people living in their own home. The proportion of residents dying in care homes could have been increased from 61 per cent to 80 per cent had these unplanned admissions been avoided and care delivered in a more appropriate setting.

2.29 In our survey 90 of 122 care homes (74 per cent) stated that they provide specific training on end of life care. In 49 per cent of cases this training is compulsory and in 44 per cent part of a formal qualification. There is no information on the proportion of care home workers who have a qualification relevant to care of the dying. For those care home workers who have undertaken an NVQ Level 3 qualification, a module titled 'Support for individuals through the process of dying' would have been available to them, but completion of this module is not mandatory. Data collected by Skills for Care in May 2007 suggest that seven per cent of care home workers and five per cent of nursing home care workers have an NVQ Level 3 qualification.²⁵

9 Clinicians are generally confident about their role in various aspects of end of life care

Rating of confidence out of 10

Average

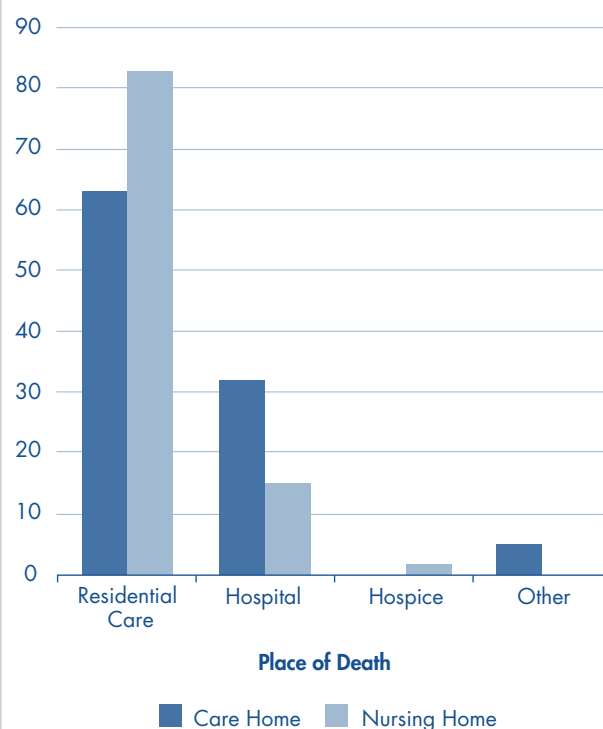


■ Doctors (Overall) number = 861
 ■ Doctors (Palliative) 40
 ■ Nurses (Overall) 102
 ■ Nurses (Palliative) 79

Source: National Audit Office surveys of doctors and nurses

10 Of those that live in residential care, nursing home residents are less likely to die in hospital than care home residents

Percentage of residents' deaths



Source: National Audit Office survey of care homes

NOTE

We surveyed over 1,400 care homes, of which 10 per cent replied. Results should, therefore, be treated with caution as these respondents were likely to be those most committed to end of life care. In our survey, 62 care homes and 36 care homes with nursing were able to provide data on residents' place of death.

2.30 When asked to rate the biggest challenge to delivering good quality end of life care, PCTs cited education and training in care homes. Whilst care homes themselves rated their skills highly, this opinion was not well supported by other service providers. In response to our survey, 48 per cent of independent hospices and 35 per cent of NHS run hospices rated skills of staff working in nursing or personal care homes as poor or very poor. Participants in our detailed PCT reviews also raised concerns about the standard of training in care homes and difficulties in recruiting and retaining staff.

2.31 Our work identified examples of specialist palliative care providers working with generalist staff who care for patients approaching the end of their life to increase their skills and confidence. Our hospice survey found that a third of independent hospices alone provided training to 18,000 external staff in 2006-07, including some from care homes. In addition, our detailed PCT reviews identified examples of hospices providing outreach training in care homes, doctor's surgeries, community hospitals and other care settings.

Commissioning of services

Variation in services to support people at the end of life

2.32 There are currently no estimates as to the full financial cost of end of life care to the NHS and social services, nor of the costs met by the voluntary sector and families. Difficulties in identifying the point at which end of life care begins meant that most PCTs responding to our census were unable to provide complete expenditure figures as they could not estimate with any certainty the proportion of time generalist staff, such as GPs and district nurses, spend with end of life care patients and their families. Although NHS continuing healthcare (services arranged and funded by the NHS for people outside hospital with ongoing health needs) is only provided following an assessment of need, 72 of the 142 PCTs responding to our census said they did not know how much of their continuing care expenditure related to end of life care.

2.33 A survey by the Department found that many PCTs also find it difficult to provide complete data on expenditure on specialist palliative care services.²⁶ The 151 PCTs responding to this survey estimated that they spent a total of £245 million on specialist palliative

care services in 2006-07, 54 per cent of which was for voluntary services with the remainder for NHS services. Our survey of PCTs found wide variation in the commissioning of services for people approaching the end of their life, including the availability of Marie Curie nursing and those services detailed in **Figure 11**.

2.34 Research carried out by the National Council for Palliative Care has also shown that the number of places in care homes with nursing varies from 16 to 762 per 100,000 of the population at local authority level.²⁷ Our census of PCTs also found that there is geographic variation across the country in the provision of adult palliative care services.

2.35 There is considerable variation in the comprehensiveness of PCT baseline reviews carried out in preparation for the publication of the Department's Strategy, and in how much information they could provide on expenditure and staffing levels for our survey. The PCTs visited for our detailed reviews also did not look at demand for services, cost of services, or examine how investment in community services might improve patient care and produce financial savings by reducing unplanned use of hospital services. Both care homes and independent hospices rated PCT commissioning of end of life care poorly. On a scale of one to ten, where one is 'well below resident and carer requirements' and ten is 'well exceeds requirements', care homes gave PCT commissioning an average score of 5.3 out of 10, whilst hospices gave an average score of 4.2.

End of life care commissioned from hospices

2.36 The need for specialist palliative care, and the service delivery models used, varies in different parts of England, so some variation in the level of expenditure on specialist palliative care services is to be expected. Expenditure on such services, however, varies more widely than expected. PCTs estimate that they spend £154 to £1,684 per death and, in the absence of any analysis of need at the local level, this variation cannot be explained. On average, independent hospices received 26 per cent of their funding from PCTs in 2006-07, and this proportion varied up to 62 per cent. The proportion of expenditure on direct patient care which, for example, excludes fundraising costs is, however, 31 per cent.

²⁶ Department of Health survey of expenditure on specialist palliative care.

²⁷ Peter Tebbit for the National Council for Palliative Care.

2.37 In 2004,²⁸ the Department stated that it was on course to introduce a national tariff for palliative care in both the NHS and the voluntary sector by 2008-09 as part of the Payment by Results programme. A number of factors (for example, the lack of robust costing data) mean that it has not been possible for the Department to deliver a national tariff to the original timescale. Whilst the Department continues to work towards delivery of a national tariff for specialist palliative care, there is no specific timetable.

2.38 In the absence of a national tariff, it is important that the prices decided and agreed locally are appropriate. The intention was that the tariff would allow 'full cost recovery' (payment of relevant overhead costs to voluntary sector providers) as recommended by the Treasury's *Cross Cutting Review on the Role of the Voluntary and Community Sector in Service Delivery*. The recommendations from the Treasury, the *Commissioning Framework for Health and Well-being, World Class Commissioning* and the 2008-09 NHS Operating Framework stress that funders should recognise that it is legitimate for voluntary sector providers to include overheads in their cost estimates for providing a given service under a contract or service agreement.

2.39 The hospice movement has traditionally raised considerable funds each year to provide services to people approaching the end of their life. Using data from our survey and analysis of accounts carried out by Help the Hospices we estimate that, in 2006-07, expenditure by independent hospices in England was £500 million. PCTs provided on average 26 per cent of independent hospices' total expenditure, implying PCT spending on hospice services of some £130 million. Ninety seven per cent of independent hospices responding to our survey stated that the funding they received from PCTs did not fully cover the costs of the NHS services they provided. The hospice movement relies on donated time from volunteers, with independent hospices reporting having received an average of 51,500 hours of donated time in 2006-07, whilst NHS hospices reported receiving an average of 9,600 hours. The largest proportion of time donated to independent units was for fundraising, whilst for NHS units it was volunteer carers.

11 There is wide variation in the level of palliative care services commissioned by PCTs

Service	Minimum	Maximum	Average (mean)	Number of PCTs responding
Palliative care beds commissioned in independent hospices	0	67	11.4	127
Carers provided with bereavement services	0%	100%	9.5%	42
Number of staff – hospital palliative care teams (Whole Time Equivalent) ¹	1	100	11.5	140
Number of staff – community palliative care teams (Whole Time Equivalent) ²	1	135	15.6	142
Spending on specialist palliative care per death ³	£154	£1,684	£504	151

Source: National Audit Office census of primary care trusts and Department of Health survey of expenditure on specialist palliative care

NOTES

- Five PCTs stated they had no staff working in hospital palliative care teams and it is clear that some PCTs have counted staff working for hospices within their figures.
- Six PCTs stated that they had no staff working in community palliative care teams and it is clear that some PCTs have counted staff working for hospices within their figures.
- The 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 the different interpretation by individual organisations.

2.40 Half of independent hospices responding to our survey were dissatisfied with their contractual arrangements with PCTs, and 70 per cent of contracts between independent hospices and PCTs are for one year only. By May 2008, only 56 per cent had agreed funding with the PCT for 2008-09, and respondents rated contracts lowly for transparency; stability; formality; and how representative they are of level of service. A reliance on charitable donations for core activities and uncertainty about future funding arrangements with PCTs makes the planning and development of services challenging. *The Compact on Relations between Government and the Voluntary and Community Sector in England (Compact)*, which establishes a framework agreement for how the Government and the voluntary sector should work together, recommends longer term financial arrangements of three years.

2.41 In October 2008, the Commission for the Compact and Help the Hospices published a joint report examining the implementation of the Compact. This report found that current contractual arrangements between PCTs and independent hospices would benefit from clearer output targets and establishment of agreed outcomes. In some cases hospices were not content with the balance of risk in their relationship with the PCT, often because of late notification of PCT funding levels. It was acknowledged, however, that recent PCT reconfiguration had contributed to delays in this process.²⁹

2.42 The majority of NHS hospices stated that they were satisfied or very satisfied with their contracts, although they are a much smaller group than the independent hospices. Independent hospices currently provide around 2,150 inpatient beds, compared to 450 provided by NHS hospices. Respondents to our survey of NHS hospices³⁰ derived an average of 85 per cent of their income from PCTs, although the proportion varied from 58 to 100 per cent with the majority of the remaining funds coming from charitable donations. Like independent hospices, the majority of NHS hospices had short term funding arrangements in place with one year contracts, and funding agreed for 2008-09 only.

29 *Help the Hospices and Commission for the Compact, Positive Engagement, Future Practice: Learning for End of Life Care – A study into the funding of palliative care* (October 2008).

30 *Hospice and Palliative Care Directory: United Kingdom and Ireland 2007*.



Providing more effective end of life care

3.1 This part of the report examines whether the use of recommended approaches to end of life care (Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care) has improved the delivery of end of life care, and whether services could be improved within existing resources by reducing inappropriate hospital admissions and length of stay following admission. It draws on the findings of our examination of patients' records in Sheffield; our modelling work; our surveys of doctors and nurses; and existing research and data.

3.2 Although various locally designed care plans have been implemented across England, the three main approaches designed to improve the standard of end of life care in various settings are shown below. All of these approaches require well trained and confident staff to implement them effectively.

- The 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.
- 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).

- Preferred Priorities for Care – A patient-held record documenting care on an ongoing basis which helps staff follow a 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.

The effectiveness of the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care

3.3 Whilst the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care are well regarded by clinicians, service providers and commissioners there is, as yet, little evidence that they benefit patients by improving care. A 2007 report³¹ examined levels of compliance with the principles of the Liverpool Care Pathway in hospitals and showed it was high in the 'physical comfort of the patient' domain and lower in the domains of 'psychosocial and spiritual aspects of care' and 'communication with patient, carer and healthcare professional'. The report did not, however, consider whether compliance with the Liverpool Care Pathway improved patient care. Our work has not identified any attempts to quantify the benefits to patients associated with use of the Liverpool Care Pathway, in part reflecting the difficulty in assessing the quality of care for dying patients. However, both published research³² and the Department's Strategy have suggested that modification of VOICES, a postal questionnaire of bereaved relatives, might be appropriate to evaluate the Liverpool Care Pathway.

31 Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians (2007) *National Care of the Dying Audit – Hospitals* (2007).

32 Maryland, C, R, Williams, E,M,I and Ellershaw, J,E (2008) *How well do current instruments using bereaved relatives views evaluate care for dying patients.* *Palliative Medicine* 22: 133-144.

3.4 Research into patient benefit arising from use of the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care is limited to local audits and small-scale projects, although the International Observatory on End of Life Care at Lancaster University currently has three studies underway which will report on the benefits to patients and staff of using Preferred Priorities for Care between 2008 and 2010. Current evidence indicates that use of these approaches can bring about decreased utilisation of hospital services by patients approaching the end of their life and increased numbers of home deaths which may be good proxy indicators for better patient care. For example, work in Surrey showed that increased use of the Gold Standards Framework by GPs was associated with a 12 per cent reduction in hospital deaths for cancer patients. It is estimated that if this level of reduction could be achieved across the entire PCT, £268,000 of resources could be redistributed from hospital to community services annually.³³

3.5 An audit by West Essex PCT of 100 patients who died with a Preferred Priorities for Care plan in place, of whom the majority had cancer, showed that 76 per cent of patients stated they wanted to be cared for at home, 23 per cent in a hospice and one per cent in hospital. Eighty eight per cent of the group died in their preferred

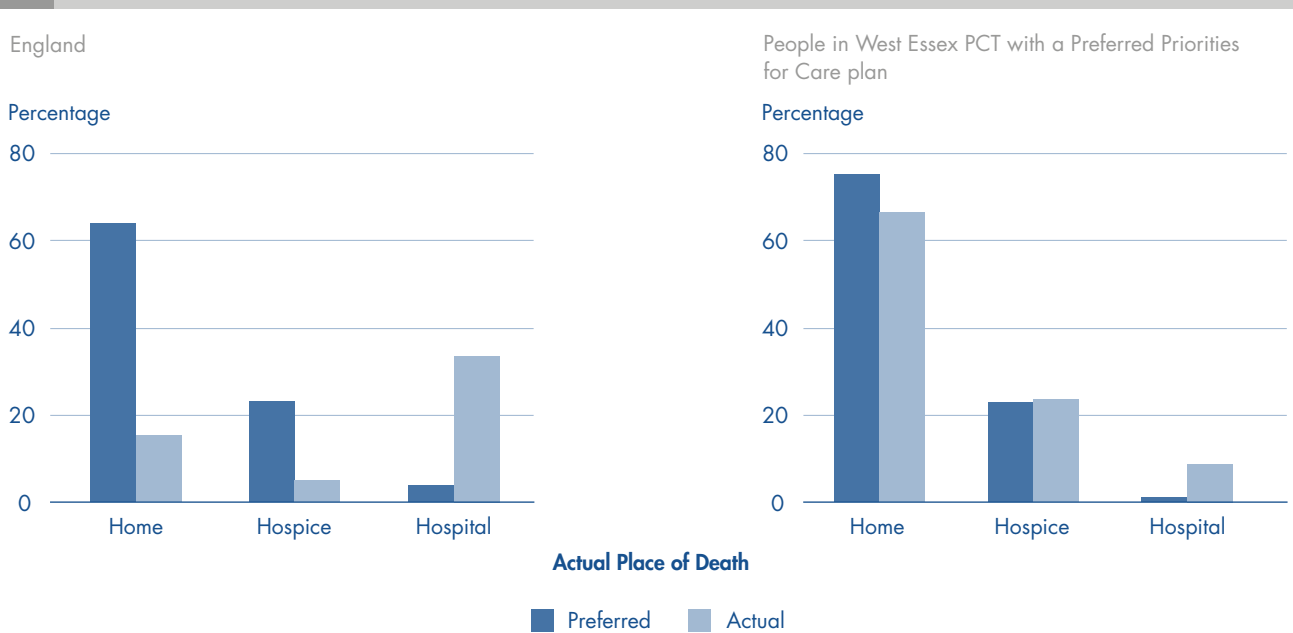
place of care. The proportion of deaths at home (including care homes) was 67 per cent, hospice 24 per cent and hospital nine per cent. The majority of those who died in a setting other than their stated preference suffered a sudden exacerbation which had led to an emergency admission to hospital. Regardless of condition, those patients who died with a Preferred Priorities for Care plan in place were more likely to die in their chosen place of care (**Figure 12**).

3.6 Similarly, work in Manchester PCT and Christie Hospital Foundation Trust indicates that for the 152 patients who had Preferred Priorities for Care discussions between October 2007 and June 2008, 65 per cent died in their preferred place of care. Additionally, it is claimed that having the plans in place saved 689 days of hospital care and prevented 39 emergency admissions.

Use of the recommended approaches to improve the delivery of end of life care

3.7 Whilst our survey of clinicians found a lack of pre-registration training in end of life care, it did reveal a significant amount of training amongst both doctors

12 Far more people died in their preferred place of care in the West Essex study than did so nationally



Source: "Analysis of Views About Dying at Home", 2004, survey commissioned by Marie Curie. ONS mortality statistics 2006 and data from West Essex PCT.

NOTE
 Figures for actual place of death do not include care homes or other settings and, as such, do not sum to 100 per cent.

33 Data Supplied by Amanda Free, a GP in Surrey.

and nurses in use of the Gold Standards Framework, Liverpool Care Pathway, and Preferred Priorities for Care post-registration. Fifty four per cent of general nurses and a third of doctors reported being trained in the use of at least one of these approaches. This compares to 91 per cent of nurses and 95 per cent of doctors specialising in palliative care. Three per cent of all doctors responding to our survey and 36 per cent of all nurses reported being trained in all three. Care should be taken in interpreting these results since whilst only four per cent of respondents to our survey of doctors were palliative care specialists, 44 per cent of nurses who responded work in palliative care. We cannot ascertain the degree of training which respondents have received, and experts agree that this proportion is likely to vary significantly both within and between the professions, and that the ability to use these approaches effectively will rely on good basic training in end of life care.

3.8 Figure 13 shows how clinicians rated the improvement that the recommended approaches had made to their ability to communicate with people at the end of life. The ratings given to the difference each approach had made to clinicians' confidence in delivering end of life care were almost identical. Nurses in our sample rated the improvements made more highly than doctors and in all but one case (the difference that Preferred Priorities for Care had made to delivering end of life care), this difference was found to be statistically significant.

3.9 Our survey found that uptake of these approaches varies between GP practices. PCTs report an average uptake by practices of 48 per cent for the Liverpool Care Pathway and 60 per cent for the Gold Standards Framework. Higher uptake of the Gold Standards Framework amongst GPs is likely to be driven in part by the fact that Quality and Outcomes Framework points are available for certain palliative care activities. In 2006-07, 99 per cent of practices met palliative care indicator one – maintaining a palliative care register, whilst 81 per cent achieved indicator two – discussing the register regularly with the multi-disciplinary team. Practices meeting both of these indicators are regarded as being at the minimum level of the Gold Standards Framework.

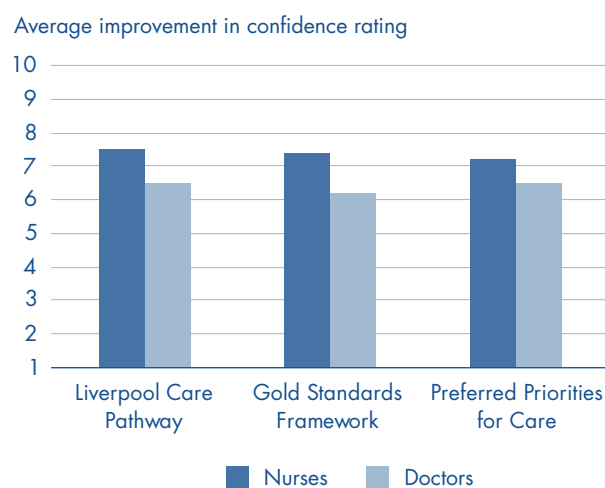
The scope for improving end of life care within existing resources

3.10 We commissioned the Balance of Care Group to work with local clinicians to carry out a retrospective review of the patient records of all people who died in

Sheffield PCT in October 2007 to identify alternatives to hospital for people approaching the end of their life. Fifty two per cent of deaths occurred in hospital; 19 per cent in care homes; 18 per cent at home; five per cent in hospices; five per cent in an ambulance or in accident and emergency. Place of death was not known in one per cent of cases. Cancer was found to be the condition with the highest proportion of deaths outside acute hospital care. Unexpected deaths, which made up only eight per cent of the deaths, followed by chronic disease had the highest proportion of deaths in hospital. Over three-quarters of the survey population were over 65 years old and 42 per cent were categorised as frail. As many as a quarter of the survey population were suffering from dementia when they died. Increasingly, end of life care services are likely to be needed by older frail people, many of whom may also have dementia.

3.11 These figures are broadly in line with national statistics, although the findings cannot simply be extrapolated to give a national picture. Sheffield is not atypical in terms of the number of deaths, place of death, and level of deprivation, all of which are key determinants of end of life care needs. The following findings can, therefore, be expected to be representative of issues faced in other PCTs across England.³⁴

13 Nurses rated the impact of the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care on their confidence when communicating with people at the end of life more highly than doctors



Source: National Audit Office surveys of doctors and nurses

NOTE

1 is no improvement and 10 is a significant improvement.

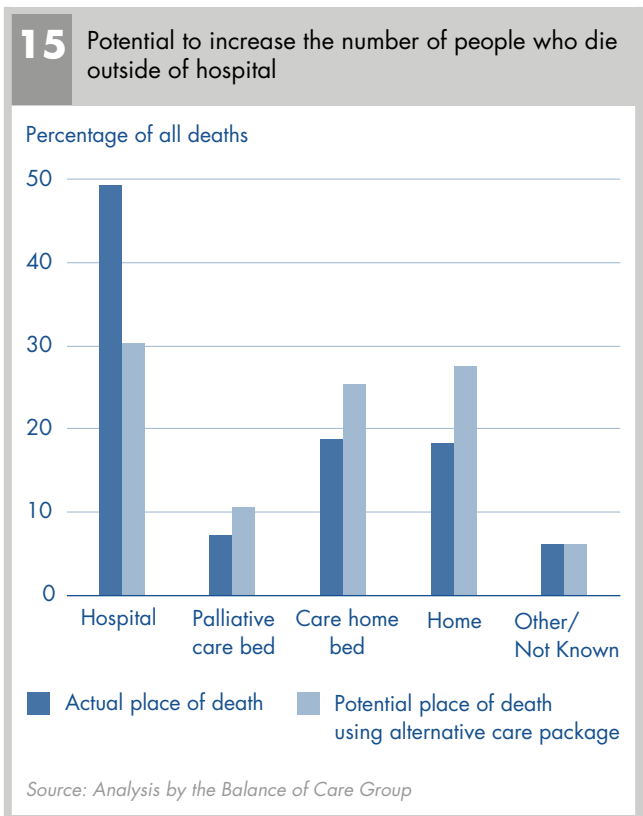
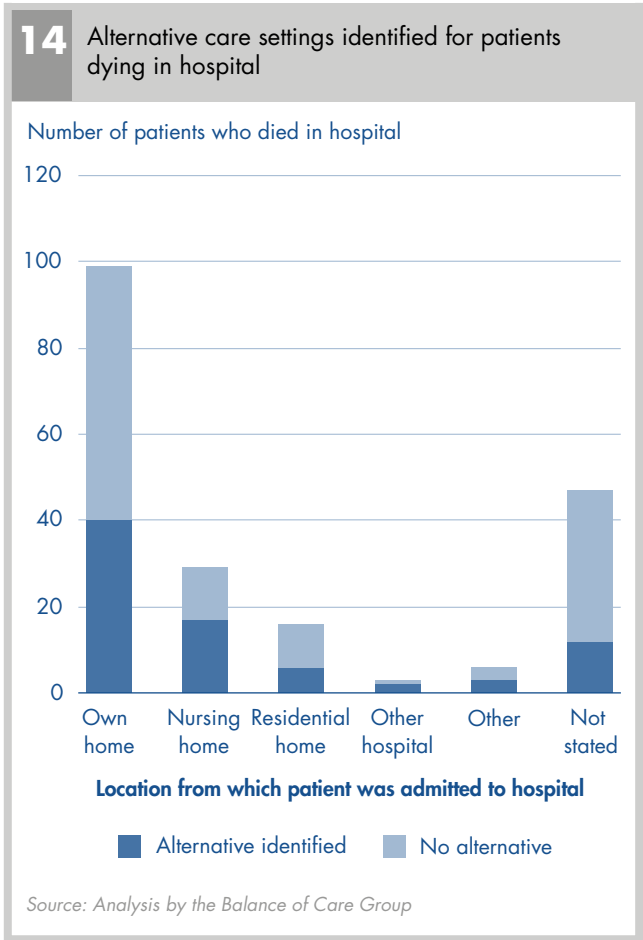
Potential for patients to die in settings other than hospital through avoiding inappropriate admissions

3.12 As **Figure 14** shows, patients who died in hospital for whom an alternative care setting was identified were mainly admitted from home and care homes. More support will need to be given in both settings if patient care is to be improved by reducing inappropriate admissions. In particular, care homes will need support from external services such as training by specialist palliative care experts and services from GPs.

3.13 In the 134 care homes responding to our survey, 70 per cent of care home resident deaths occurred within the home. In Sheffield, 61 per cent of care home residents who died during October 2007 did so in a care home. Our examination of patient records found, however, that the proportion of residents dying in care homes could have been increased from 61 per cent to 80 per cent if alternative care pathways had been followed, thereby avoiding inappropriate hospital admissions. Our analysis also showed that had these alternatives been utilised then the proportion of deaths in hospital could have been reduced from 50 per cent to 31 per cent with a corresponding increase in deaths in other settings (**Figure 15**).

Potential for patients to die in settings other than hospital through discharge to a more appropriate place of care

3.14 Forty per cent of the 200 patients who died in hospital were found not to have had medical needs which required them to be in hospital at the point of admission, and could have been cared for elsewhere. These patients used 1,500 bed days in acute hospitals. Assuming the cost of an inpatient day in an acute hospital to be £250,³⁵ the cost for all those who died in hospital unnecessarily in October 2007 in Sheffield would be £375,000. Since October is a relatively typical month in terms of the number of deaths, this suggests that over the course of a year up to £4.5 million could be made available for end of life care in the community in Sheffield through more appropriate use of hospital care for people approaching the end of their life.



35 Analysis by the Balance of Care Group.

3.15 When looking at place of care, a range of home based and bed based alternatives were considered to be more appropriate care settings, but the most appropriate location varied by condition (**Figure 16**). Home based care was the most frequently chosen option and included a range of care packages, such as GP support, care from a palliative care nurse, or a specialist condition nurse.

3.16 When looking at alternative care packages, cancer patients mainly needed hospice care. Although the majority of people accessing hospice services have cancer, our work found that there is still scope to decrease the number of cancer patients who die in hospital when they could have been cared for in a hospice.

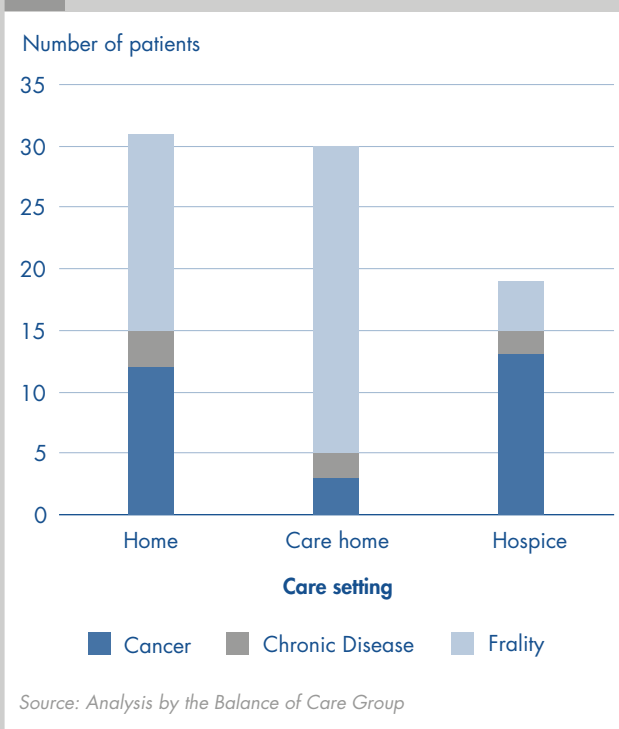
3.17 In Sheffield, hospice care is supplied by St Luke's Hospice (30 inpatient beds) or the Macmillan Palliative Care Unit (18 inpatient beds). In 2006-07, St Luke's operated at 73 per cent capacity whilst the Macmillan Unit operated at 79 per cent capacity, although occupancy at St Luke's has steadily increased since the period of our survey and over the first half of 2008-09 the average occupancy was 81 per cent. Whilst units cannot run at 100 per cent capacity because they need to respond quickly to sudden demands, these figures suggest it is not inpatient capacity constraints which are leading to cancer patients dying in hospital rather than another setting.

3.18 Some patients with frailty or chronic conditions were judged to have died in hospital when they could have been cared for in a hospice. However, the majority of these patients needed services involving general or specialist nursing which could be delivered in their own home or a care home.

Making decisions about the likelihood of death

3.19 Patients who died in hospital for whom an alternative was identified spent different lengths of time there prior to death. In total, 81 of the 200 patients who died in hospital were admitted less than one week before death occurred. Of these 32 (40 per cent) were identified as having had an alternative to hospital care, which raises questions about whether patients who are close to the point of death are being identified and their care managed appropriately. Forty two patients, however, were in hospital 28 days or over prior to death, 19 of whom (45 per cent) were identified as having an alternative to hospital care. Since their length of stay would not have precluded the consideration of alternative care packages there may not have been adequate systems to identify and discharge patients who no longer needed to be in hospital to a more appropriate place of care (**Figure 17 overleaf**).

16 Alternative places of care for patients who were cared for and died in hospital in Sheffield in October 2007

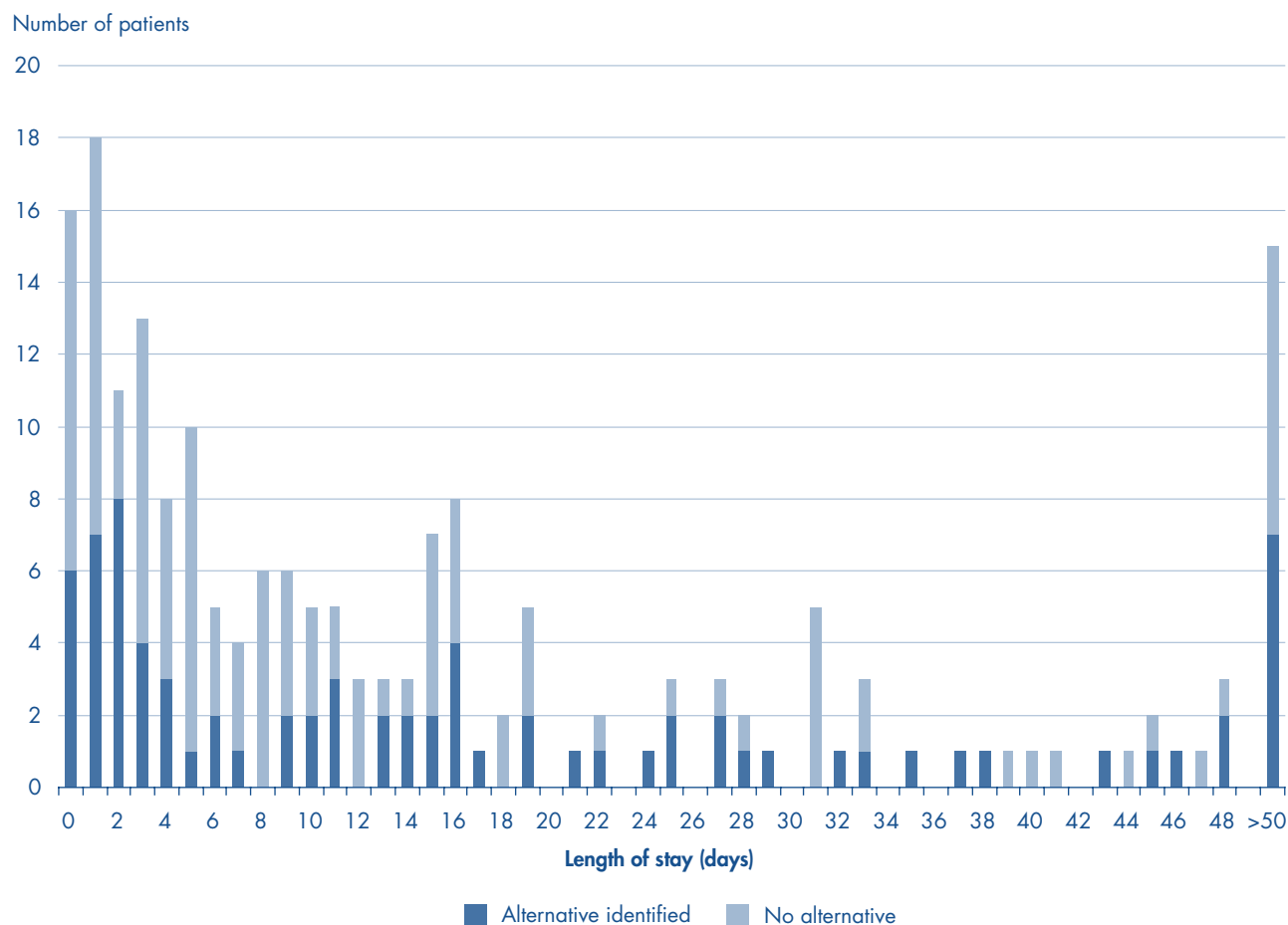


3.20 Sixty three per cent of patients who died in hospital had the fact that death was expected recorded in their notes. In most of these cases, however, this assessment was made less than one week before death. The timing of this assessment may have left insufficient time for an appropriate care package to be arranged.

Development and evaluation of new service models for end of life care

3.21 As well as providing direct patient care, organisations such as Macmillan Cancer Support, Sue Ryder Care, and Marie Curie Cancer Care carry out much of the development and evaluation of new service models for end of life care. For example, Marie Curie is currently running the Delivering Choice Programme in the UK. This programme aims to put in place needs-based interventions which allow more people to be cared for in a place of their choice by removing blockages in the system.

17 Length of stay for patients who died in hospital in Sheffield in October 2007



Source: Analysis by the Balance of Care Group

3.22 In Lincolnshire PCT, the Delivering Choice Programme ran over 3½ years and consisted of a comprehensive assessment of the barriers which prevent patients being cared for in a setting of their choice, followed by design and implementation of services to overcome these barriers in collaboration with local stakeholders. The Lincolnshire pilot was completed in 2008 and evaluated by the King's Fund³⁶ and Lancaster University.³⁷ A summary of the findings of these evaluations and an overview of the services put in place in Lincolnshire can be found in Appendix 6, Example 5.

The redistribution of resources through reduced hospital utilisation

3.23 Most people wish to avoid being cared for in a hospital when approaching the end of their life.^{38, 39, 40, 41} We developed a model which uses expenditure and utilisation data for end of life care to estimate the cost of delivering services to patients with cancer over the course of the last year of life, and to quantify the potential resources which could be redistributed by reducing their utilisation of hospital care. The model focused on cancer because of the lack of reliable data on the cost of delivering end of life care for other conditions. Patients with conditions such as heart failure and pulmonary

³⁶ Improving choice at the end of life. A descriptive analysis of the Marie Curie Delivering Choice Programme in Lincolnshire.

³⁷ Lancaster University (2008) Independent Evaluation of the Marie Curie Cancer Care 'Delivering Choice Programme' – Structured End Evaluation Report for Lincolnshire.

³⁸ *Views About Dying at Home*, 2004, survey commissioned by Marie Curie, carried out by You Gov.

³⁹ *Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences*, Higginson I., Sen-Gupta G. 2000, *Journal of Palliative Medicine*, Vol.3, No.3.

⁴⁰ Higginson, I (2003) *Priorities and preferences for end of life care*.

⁴¹ Norfolk Health Overview and Scrutiny Committee (2005). *How We Manage Death and Dying in Norfolk County and Waveney*.

disease spend a greater proportion of their last year of life in hospital than cancer patients. It is therefore likely that similar reductions in unplanned admissions for these conditions could lead to the redistribution of a similar magnitude of resources. This issue is explored in Appendix 3, where a fuller description of the methodology can also be found.

3.24 On average, cancer patients who died in 2005-06 spent 345 days at home, 17 days in hospital and two days in a hospice in the year prior to death. The average masks the fact that relatively few patients account for the majority of days spent in hospices.⁴² We estimate that the cost of providing care for the 12 months prior to death, for cancer patients who die over the course of the year is £1.8 billion. This figure is based on the accumulated cost of care being provided in hospital, home and hospice for the 126,000 people who die from cancer annually.

3.25 Reducing hospital utilisation by people at the end of life has the potential to improve patient care by transferring patients to their preferred care setting whilst releasing resources to be used to deliver care outside of hospital. Assuming that the level of hospice provision remains constant, reducing the amount of time a patient spends in hospital will mean that they spend more time in the community, either in their own home, or receiving some form of residential care for example in a nursing home.

3.26 The time patients spend in hospital could be decreased by reducing the number of:

- inappropriate admissions; and
- days spent in hospital following an admission.

Reducing the number of inappropriate admissions and ensuring timely discharge together will cause a larger reduction in time spent in hospital and hence make available the greatest amount of resources for redistribution.

3.27 We examined a range of scenarios and measured the impact they would have on hospital utilisation. If reductions of 10 per cent in the number of emergency admissions and a reduction of three days in the length of stay per admission could be achieved, £104 million would be made available nationally for redistribution, and four days in acute care avoided per patient (**Figure 18**). Our expert panel believed that such reductions were feasible in the medium term.

Achieving reductions in hospital utilisation

3.28 Reducing admissions will require services to respond quickly to patients' needs 24 hours a day in order to prevent inappropriate admissions when symptoms suddenly deteriorate. Many different service delivery models aim to address this issue. For example, many hospices provide a 24 hour helpline which patients and clinicians can phone for advice. Our PCT review of Sheffield found that the PCT offers an evening and night nursing service and an Intensive Home Nursing Service which can support patients at the end of life with a range of medical needs to remain in the community. Emergency admissions can also be reduced by having systems which prevent sudden deteriorations or exacerbations. One method is for GPs pre-emptively to prescribe drugs such as those for pain control for use in an emergency.

3.29 To reduce the average length of stay for patients following an emergency admission and when there is no longer a medical reason to be in hospital, arrangements need to be in place to ensure that patients can be discharged to the most appropriate place of care in a timely fashion. Facilitating timely discharge for many such patients involves multiple agencies and requires that the package of care needed to support them in the community is put in place quickly and efficiently. To achieve this within existing resources, hospitals would need to be able to reconfigure services in response to reduced demand, and the resources made available would need to be redeployed into the additional services required.

18 Potential resources made available for redistribution through decreased use of hospital care by cancer patients £ million

Reduction in emergency admissions	Reduction in mean length of stay per admission			
	0	1 day	3 days	5 days
0	0	26	78	132
5 per cent	16	42	91	141
10 per cent	33	56	104	151
15 per cent	49	71	117	161
20 per cent	66	87	129	171

Source: National Audit Office/RAND analysis

42 Only around 19 per cent of cancer patients have a hospice inpatient admission.

APPENDIX ONE

Methodology

1 Outlined below are the main elements of the methodology used to produce this report.

Economic modelling

2 The NAO worked with RAND to develop a model based on the prognoses of different conditions, to assess the potential savings and the utility of a more integrated approach to palliative care.

3 The work drew on a range of data sources, including national Hospital Episode Statistics, the National Council for Palliative Care's Minimum Dataset and academic literature. In our model, hypothetical reductions in the number of emergency admissions experienced by patients, and the average length of stay following an emergency admission, were made to monitor the impact this had on both the cost of delivering end of life care and the number of days in hospital an average patient experiences. Appendix 3 summarises the key findings from the model. The full report produced by RAND is available on our website at www.nao.org.uk.

Detailed examination of patient records in Sheffield

4 We commissioned the Balance of Care Group to carry out a retrospective survey based on the hospital records of all adults in Sheffield Primary Care Trust who died in October 2007, and were known to Sheffield Teaching Hospitals NHS Trust. Of the 420 adults that died, hospital records were available for 348 of them. The work established what percentage of deaths occurred in hospital, what proportion of patients who died in hospital could have been cared for elsewhere, and what alternatives existed for patients who died in hospital when another place of care would have been more appropriate.

The work also established the length of time patients were in hospital prior to death, and examined the level of contact patients at the end of life had with social services, specialist palliative care providers and specialist nurses. Appendix 2 summarises the key findings from this work. The full report produced by the Balance of Care Group is available on our website.

Detailed PCT reviews

5 In designing the study we sought to examine the drivers and barriers faced by commissioners and providers of services at a local level in responding as a whole health and social care system to the needs of people requiring end of life care. We carried out whole system reviews at Herefordshire, Sheffield, and City and Hackney Primary Care Trusts to identify the strengths and challenges in each system and met with representatives from PCTs; hospices; hospitals; care homes; GPs; and local authorities. Appendix 4 provides an overview of our findings and full reports on each PCT can be found on our website.

Focus groups with patients and carers

6 We commissioned Arup to hold two focus groups and six one-to-one interviews with terminally ill patients to identify individuals' experiences of different models of care; how well current services are meeting patients' needs; and barriers which exist to accessing end-of-life care. Participants were selected with assistance from the National Council for Palliative Care, Sue Ryder, and Trinity Hospice, Clapham and included a total of 12 patients from both rural and urban areas across England, suffering from a range of conditions including cancer, chronic obstructive pulmonary disease, heart failure, motor neurone disease and multiple sclerosis.

7 We also commissioned Arup to hold two focus groups and seven one-to-one interviews with current and former carers to understand how the standard of care provided and the availability of different services affects the experience of caring for a friend or family member and the quality of death. We also explored the barriers to accessing end of life care and what practical challenges carers face. Participants were selected with assistance from the Princess Royal Trust for Carers, Help the Hospices and clinicians working in the field and included a total of four current carers and 12 bereaved carers. These carers were responsible for caring for friends or relatives suffering from a range of conditions including cancer, kidney failure, dementia, chronic obstructive pulmonary disease, heart failure, motor neurone disease and Parkinson's disease. The findings from our focus groups are used to illustrate and triangulate with other evidence. The full report by Arup is available on our website.

Census of Primary Care Trusts

8 To prepare PCTs for the publication of the end of life care strategy, the Department instructed PCTs to review what services they have currently available. The results of this exercise were not collected centrally so we requested the data on the funding and provision of end of life care in order to create a national picture of services and to benchmark PCTs. We also used the survey to assess:

- Whether PCTs have the skills and knowledge to commission end-of-life care services effectively.
- How well integrated the PCT is with other stakeholders such as social services and the voluntary sector.
- Whether best practice is shared.

9 We piloted the survey with 12 PCTs, and received and processed final responses from 141 out of 152 (a response rate of 93 per cent). One further PCT responded after we had carried out our analysis of the census returns. The data from the census have not been subject to audit and therefore some of the variations in both the unit and total costs, and other information, may be due to the different interpretation by individual organisations.

10 In developing the survey we worked with relevant members of the Healthcare Inspection Concordat to minimise duplication of data collection. Feedback reports were prepared for each PCT to enable them to benchmark their responses and an overview report is available on our website.

Census of independent hospices in England

11 Through the contacts we established with Help the Hospices, we surveyed all independent adult hospices to generate data on capacity; funding; activity; and the level and range of services they offer.

12 We also used the census to gather the opinions of palliative care specialists on:

- The level of training and experience of NHS staff.
- How well services are integrated.
- What barriers exist to delivering good end-of-life care services to all.

13 We piloted the survey with five hospices, and received final responses from 104 out of 155 (a response rate of 67 per cent). Feedback reports were prepared for each hospice to enable them to benchmark their responses and an overview report is on our website.

Census of NHS hospices

14 All 40 adult NHS hospices in England were surveyed to gain the same data as requested from independent hospices. Responses were received from 24 (a response rate of 60 per cent). Feedback reports were prepared for each hospice to enable them to benchmark their responses and an overview report is available on our website.

Postal survey of care homes in England

15 With assistance from the English Community Care Association and the Commission for Social Care Inspection, we surveyed a sample of the 18,500 residential and nursing care homes in England with more than 10 beds, to find out about levels of training; numbers of deaths; access to medical assistance in and out-of-hours; and policies and procedures for when people are at the final end of life stage.

16 We piloted the postal survey with 10 care homes, and received final responses from 134 out of 1410 sampled – a response rate of 9.5 per cent. An overview report is available on our website.

Survey of doctors

17 We commissioned Doctors.net (who provide internet services to some 142,400 doctors across the UK) to administer an online survey of 1,140 doctors involved with the provision of palliative care. The survey contained 20 questions covering their attitudes, awareness and practice regarding palliative care. We received 901 responses (79 per cent) from doctors with the following specialisms:

- 40 palliative care specialists
- 204 emergency or intensive care specialists
- 98 cardiologists
- 98 respiratory specialists
- 111 oncologists
- 143 geriatricians
- 207 GPs

18 A summary report by Doctors.net is available on our website.

Survey of nurses

19 The Royal College of Nursing (RCN), on behalf of the NAO, hosted an online survey on their website, which invited all RCN members involved in the delivery of NHS end of life care to share their views on the provision of end of life care services, training and challenges. The survey was advertised in an article in the RCN newsletter and emails were also sent to all independent hospices and all palliative care nurses registered with the RCN. We received 181 responses over the course of April and May 2008, of which 44 per cent were from palliative care nurses. A summary report is available on our website.

Use of existing data

20 We drew on extensive academic and voluntary sector research on issues in end of life care including:

- Research in the UK and overseas on people's preferred place of death.
- ONS mortality data giving the age, cause and place of death at the PCT level for all deaths in England on a yearly basis.
- Hospital Episode Statistics for England.
- Research into the impact that caring for someone can have on an individual's physical and mental health.

- Evaluations of the cost of supporting people to remain at home versus the cost of delivering such services in hospital, including work by Marie Curie Cancer Care on the Delivering Choice Programme which aims to measure the quantitative and qualitative impacts of a series of interventions aimed at supporting terminally ill people to remain in the home.
- Research into the barriers that certain groups face in accessing end of life care services, including non cancer patients, older people, and ethnic minorities.
- Information on the provision of voluntary sector services and the benefit these services have for the NHS.
- Research on how to deliver good quality end of life care to people with conditions other than cancer, such as dementia and motor neurone disease.

Interviews with key stakeholders

21 We conducted interviews with Department of Health policy personnel to establish the position on policy and strategy for end of life care. We met with numerous stakeholders in the field of end of life care, including voluntary sector providers, private care home sector, patient and unpaid carer groups and national charities such as Help the Hospices and the National Council for Palliative Care.

International comparisons

22 We compared England's service provision against the context of other countries, including the USA, Canada, Scotland, Wales and Ireland, highlighting differences and examples of good practice. The data includes information on where people die; level and quality of services and funding; level of involvement of the voluntary sector; support to carers; and barriers to accessing services.

Expert panel

23 We assembled a panel of experts and stakeholders from a range of organisations with an interest in the subject of end of life care, to help guide our study. This panel included:

- Philip Hurst, Policy Manager – Health & Social Care, Age Concern England
- Professor Mike Richards, National Director for Cancer and End of Life Care, Department of Health
- Martin Green, Chief Executive, English Community Care Association
- Dr Amanda Free, GP
- Mary Casey, Joint Professional Adviser (Palliative Care, Healthcare Commission and Commission for Social Care Inspection)
- Paul Cann, Director of Policy, Help the Aged
- Jonathan Ellis, Director of Public Policy & Parliamentary Affairs, Help the Hospices
- Richard Croydon, Commissioning Manager Physical Disabilities, Palliative Care and Continuing Care, Lambeth Primary Care Trust
- Jeff Jerome, Director of Adult and Community Services, London Borough of Richmond upon Thames
- Peter Crutchfield, Director of Development and Care Research, Marie Curie Cancer Care
- Dr Teresa Tate, Consultant in Palliative Medicine and Medical Adviser to Marie Curie, Barts and the London NHS Trust and Marie Curie Cancer Care
- Lucy Sutton, Director of Policy Development, National Council for Palliative Care
- Claire Henry, Programme Director – National End of Life Care Programme, National Health Service
- Dr Adrian Treloar, Consultant Old Age Psychiatrist, Oxleas Trust
- Jane Burt, Assistant Director and Sheila Dent, former UK Director of Policy and Operations, Princess Royal Trust for Carers
- Anne Hooper, Chief Executive, Trinity Hospice
- Professor Mari Lloyd Williams, University of Liverpool
- Pam McClinton, Head of Palliative Care and Clinical Quality, Sue Ryder Care

APPENDIX TWO

Detailed examination of patient records in Sheffield to identify alternatives to hospital

1 The aim of the project, led by consultants the Balance of Care Group, was to explore the potential for change in care pathways for people at the end of life, and in particular to consider alternatives to patients dying in hospital. The full report on our work in Sheffield can be found on our website. We are grateful to the four participating organisations (Sheffield Primary Care Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield City Council, and St Luke’s Hospice) for volunteering to provide the setting for the case study, which was intended to be illustrative of the issues faced across England.

2 The central focus of the project was a retrospective survey based on hospital records of 348 out of 420 adults in Sheffield Primary Care Trust who died in October 2007, and were known to Sheffield Teaching Hospitals NHS Trust. The surveyors used a recognised clinical benchmark tool, the Appropriateness Evaluation Tool (AEP), to identify patients whose care needs might not have required an acute hospital setting at the point of admission. However, as acuity is not the only factor when alternatives to hospital are being considered for people approaching the end of their life, the surveyors also considered the options available against the criteria set out in the Gold Standards Framework and the Liverpool Care Pathway.

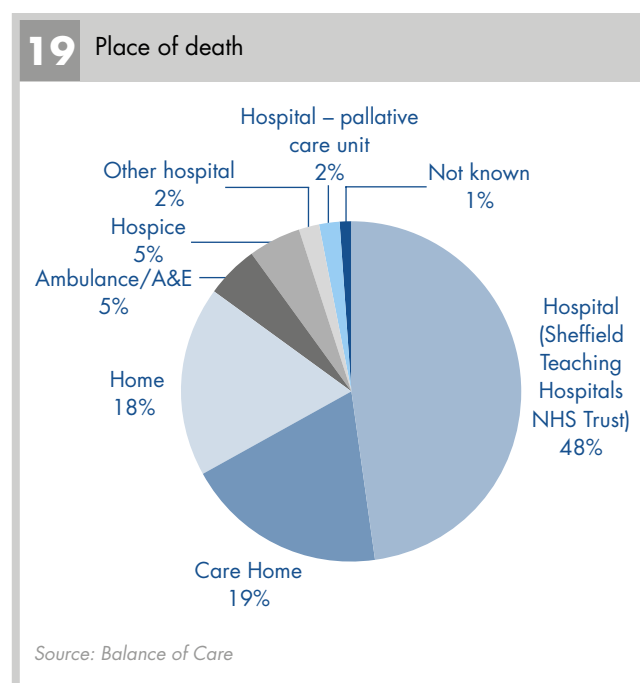
Key overall findings were:

Characteristics of people who died

3 Using the Gold Standards Framework patient groupings, the causes of death were frailty (42 per cent); cancer (30 per cent); chronic disease (20 per cent); and unexpected (eight per cent). The distribution of age at death was in line with most population death statistics with median ages at death for those who had cancer and chronic disease of 75 and 73 respectively, compared to an overall median value of 82. Most people who were frail at death were over the age of 75 and dementia was present in up to a quarter of patients.

Where people died

4 Half of people died in hospital, with a further 19 per cent dying in a care home and 18 per cent dying at home (**Figure 19**). Place of death did, however, vary with fewer cancer patients dying on acute hospital wards than any other patient group (38 per cent), and more dying at home (24 per cent) or in a hospice or palliative care unit (27 per cent). This compared to frailty where 59 per cent died on an acute hospital ward; 29 per cent died in a care home; eight per cent died in their own home; and one per cent died in a hospice; and none died in a palliative care unit. Only two of the 65 people with dementia diagnosed died in their own homes.



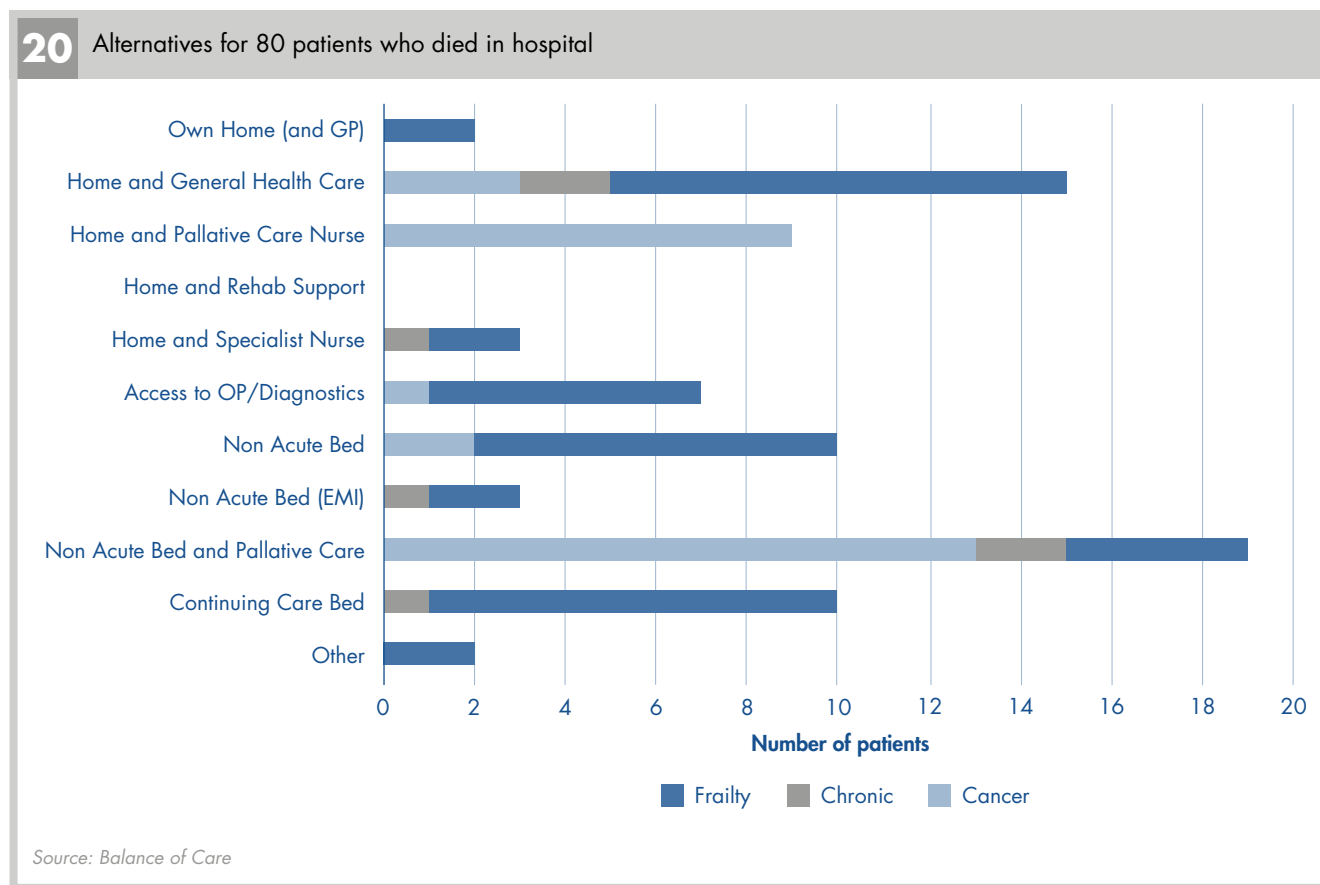
5 Nearly three quarters of those people who died in hospital were admitted from their own home. Just under a quarter were admitted from a care home, the majority of whom were already receiving nursing care. Source of referral was not stated in 26 per cent of cases, but most admissions involved self referral in some form or another (for example, a 999 call was the source of referral in 36 per cent of cases). GP involvement in the admission of patients who subsequently died in hospital was limited (19 per cent of cases) but did not appear to be affected to any significant degree by the use of out of hours services.

Potential alternatives to dying in hospital

6 Given that the case study was seeking to examine whether patient needs were being met rather than availability of resources, alternatives to acute hospital care were identified on the assumption that patient needs could always be met. The judgements made were, however, deliberately conservative to ensure that the alternative approaches identified were based on clinically robust judgements.

7 Of the 200 patients that died in hospital, alternatives at the point of admission were identified for 80 (40 per cent). Where alternative care packages were thought possible, the surveyors selected from an agreed list of care packages. The alternatives identified were equally split between home based alternatives (for example, in a patient’s own home or a care home) and bed based care in a hospice or palliative care ward. Palliative care services were most frequently identified for cancer patients, whilst the alternatives for chronic and frail patients most commonly involved more general and specialist nursing support (Figure 20).

8 When considering where patients had been admitted from, only nursing home residents showed an above average proportion who might have avoided admission: 17 out of 29 admissions (59 per cent). In most cases the surveyors considered that the patient could have remained in the care home or returned there after a suitable assessment, in some cases with additional specialist or palliative nursing input. Combined figures for residential care homes and nursing homes suggest that the proportion of care home residents able to die in their care home could be increased from 61 per cent to 80 per cent if alternative care pathways were followed.



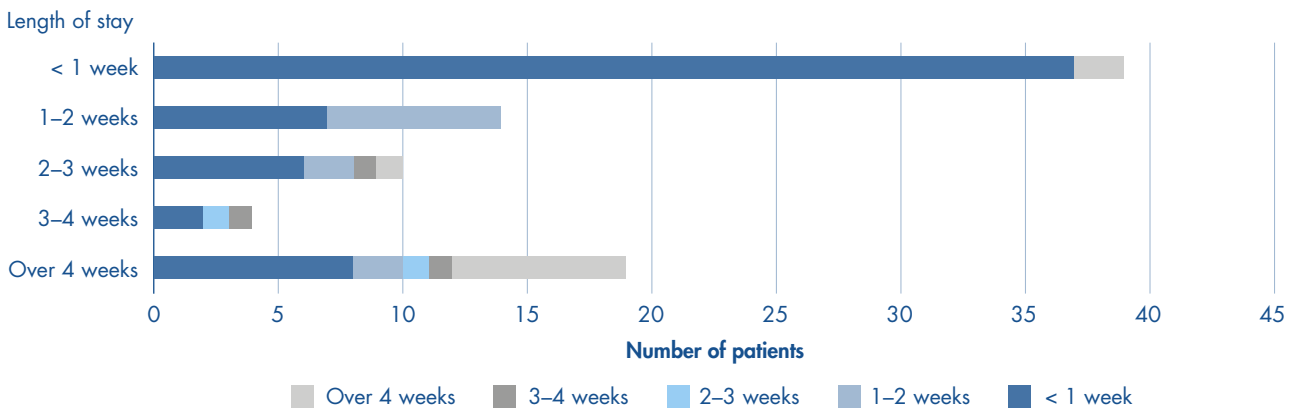
9 The peak number of patients with alternatives corresponded to a length of stay of two days. Although the numbers are small, this would be consistent with some of these patients being near death and this not being recognised upon admission. As a result, the consideration of alternative places of care would have been precluded. Some patients, however, also had a significantly longer length of stay prior to death with nearly a quarter of those for whom alternative care packages were identified having been in hospital for over 28 days.

10 The 80 patients for whom alternatives were identified used 1,501 bed days, which is equivalent to 48 beds being occupied for an entire month. Assuming a cost per inpatient day of £250, in a year £4.5 million could be made available for investment in end of life care services in the community.

Was death expected?

11 The ability to respond flexibly to patient needs towards the end of life may be affected by the degree to which clinical staff recognise the stage which the patient has reached. The surveyors therefore examined the patient records to identify whether recognition of dying had been recorded. They identified that recognition of dying had been recorded in the notes of 125 of the 200 patients that died in hospital. In the majority of cases, however, recognition of dying was recorded less than a week before death, which may have left insufficient time for an appropriate care package to be arranged. This was the case even for patients who had stayed in hospital substantially longer (**Figure 21**).

21 Length of stay in hospital, showing how long before death recognition of dying was recorded



Source: Balance of Care

NOTE
 Dates were identified for 86 of the 125 patients where recognition of dying had been recorded.

APPENDIX THREE

Economic modelling

1 The NAO and Rand Europe worked together to produce a model which simulates a patient's journey around a simplified health system over the course of the last year of life. The full report of this project can be found on our website but the following is a summary of how the model was developed, the findings produced and the assumptions made in the construction of the model.

The model

2 In the model at any point a patient can be in one of three states, hospital, hospice or community. For the purpose of the model community includes a patient's own home or some form of residential care such as a nursing home.

3 The model captures how patients flow through the system assuming a patient can be in only one state on each day and on each subsequent day they can either remain in that state or move to one of the alternative states, with some specified 'transition probabilities'.

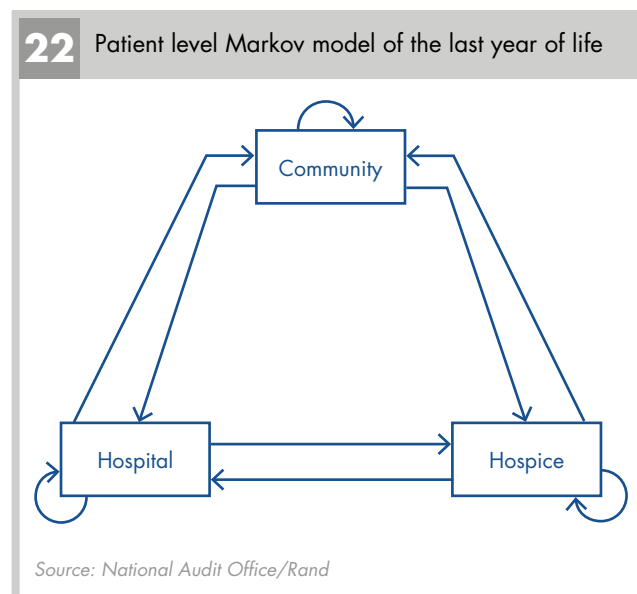
4 The model we constructed is a "Markov" model. This means that the transition probabilities which a patient experiences on some given day are determined by the state which the patient is in on that day; they do not depend on the states which they have experienced previously. We acknowledge that this is a simplification of the real situation – for example, the longer patients have stayed in hospital, the less likely they are to be discharged on any given day. However, this modelling framework is simple to understand and implement, and is likely to be relatively robust in the light of our present purposes which focus on population average costs.

5 To reconstruct the last year of life a patient in the model is 'alive' for 365 days with a probability of one of dying on day 366. The model structure is shown in **Figure 22**.

6 Given this model structure, a combination of Hospital Episode Statistics (HES) and Minimum Dataset (MDS) data can be used to calculate the probability that a patient with a certain condition, for example cancer, has of making any of the nine possible transitions (represented by the nine arrows in Figure 22), on each cycle.

7 All patients start at home and using these probabilities the average amount of time a patient spends in each state over the course of the 365 days which represent the last year of life can be calculated using modelling software.

8 Data on the cost of a day of care in hospital, hospice and the community and can be combined with data on the amount of time spent in each state, and the number of patients who die of the condition being modelled, to derive a cost of care for the last year of life.



Costs

9 Data are available on the cost of delivering care to patients with an active progressive disease for whom the intention of treatment was not curative in each care setting, although some of this dates back to 1999.⁴³ This can be combined with data on cost of residential care⁴⁴ and adjusted by use of health specific indices⁴⁵ to reflect inflation since the research was carried out. The model generates estimates of current costs and the potential for resources to be redistributed from hospital care to the community. Since the entire cost of hospital inpatient care is met by the NHS then the entire cost of day of hospital care is factored into the model at £222 per diem. The costs of a day of inpatient hospice care allows for the fact that the NHS funds only a proportion of both NHS and independent hospice costs, and the per diem cost reflects the proportion of these costs funded by the NHS. The per diem cost of hospice inpatient care in the model is therefore £132 which represents about 44 per cent of the actual cost of hospice care (the difference being funded by non-NHS funding streams).

10 The model uses inflation adjusted cost data from published research on the average per diem cost of providing end of life medical care in an individual's own home.⁴⁶ For the purpose of this model this cost is assumed to be the same for patients receiving end of life care in some form of residential care. The community care cost takes account of the number of cancer patients who die in residential care (which is relatively low) and the proportion of these costs which are met by NHS and social care funding. The model assumes all end of life care patients with cancer in nursing homes are receiving the NHS contribution to nursing care. The per diem cost of community care in the model is £28.

11 The cost of an emergency admission to hospital in an ambulance is included in the model.

12 The model focuses on cancer because there is little available data on the cost of delivering end of life care to patients with other conditions. We also considered chronic obstructive pulmonary disease and heart failure, but the limited availability of data on the cost of delivering care to people with these conditions (for example, the treatment they receive in hospital and the equipment they need to support them in the community) means that the findings are more theoretical than those for cancer, which are based on more robust evidence.

Current costs of caring for cancer patients in their last year of life

13 Using specific values for the costs of care (for example, the cost of an ambulance journey to hospital or a day spent in hospital) our model showed the current cost of caring for all those who die of cancer over the course of a year, for the last year of life is £1.81 billion. Sensitivity analysis (described below) allowing for 10 per cent variation in the cost of each type of care showed that the cost of delivering this care in the last year of life is between £1.64 billion and £1.98 billion.

Sensitivity analysis

14 The inputs to the model which are subject to some degree of uncertainty such as the cost of care in each state described above and the number of patients who have a hospice inpatient admission can be varied systematically to take account of any uncertainty. Given the level of uncertainty about how costs have increased since they were measured in 1999, and the applicability of these costs to a cohort of cancer patients, it was decided that varying all costs by 10 per cent should more than account for any uncertainty. For example the cost of care in each setting can be varied by plus or minus 10 per cent to account for any uncertainty in the calculations of the original figures, and the fact that they may not have increased exactly inline with the inflation indices used. This produces a range of possible costs rather than an exact figure.

15 Allowing for a 10 per cent variation, our model estimates the cost of delivering cancer care to end of life care patient in the last year of life to be between £1.64 and 1.98 billion. **Figure 23** shows the effect of varying the cost of each place of care by plus or minus 10 per cent. Varying the cost of community care has the biggest effect on the overall cost of delivering care in the last year of life as, despite being the cheapest form of care, this is where patients spend the majority of their time. A 10 per cent variation in the average cost of delivering community care would produce a £122 million variation in the overall cost of care over the last year of life, whereas varying the cost of hospital and hospice care by the same amount would produce cost variations of £49 million and £6 million respectively. This means that cumulatively varying the cost in each care setting would increase or decrease the total cost by £177 million, and hence we estimate the total cost

43 D. Coyle, N. Small, A. Ashworth, S. Hennessy, S. Jenkins-Clarke, R. Mannion, N. Rice and S. Ahmedzai (1999). *Costs of palliative care in the community, in hospitals and in hospices in the UK*. Critical Reviews in Oncology/Haematology 32(2): 71–85.

44 Lesley Curtis (2007), *Unit Costs of Health and Social Care 2007*, University of Kent, Tables on pages 38-42.

45 Consumer Price Index – Health available at www.statistics.gov.uk.

46 D. Coyle, N. Small, A. Ashworth, S. Hennessy, S. Jenkins-Clarke, R. Mannion, N. Rice and S. Ahmedzai (1999). *Costs of palliative care in the community, in hospitals and in hospices in the UK*, Critical Reviews in Oncology/Haematology 32(2): 71–85.

to be £1.64–£1.98 billion. In contrast, varying the inputs used to calculate the probability of moving between care settings on any given day by plus or minus 10 per cent has a limited effect on the overall cost of care.

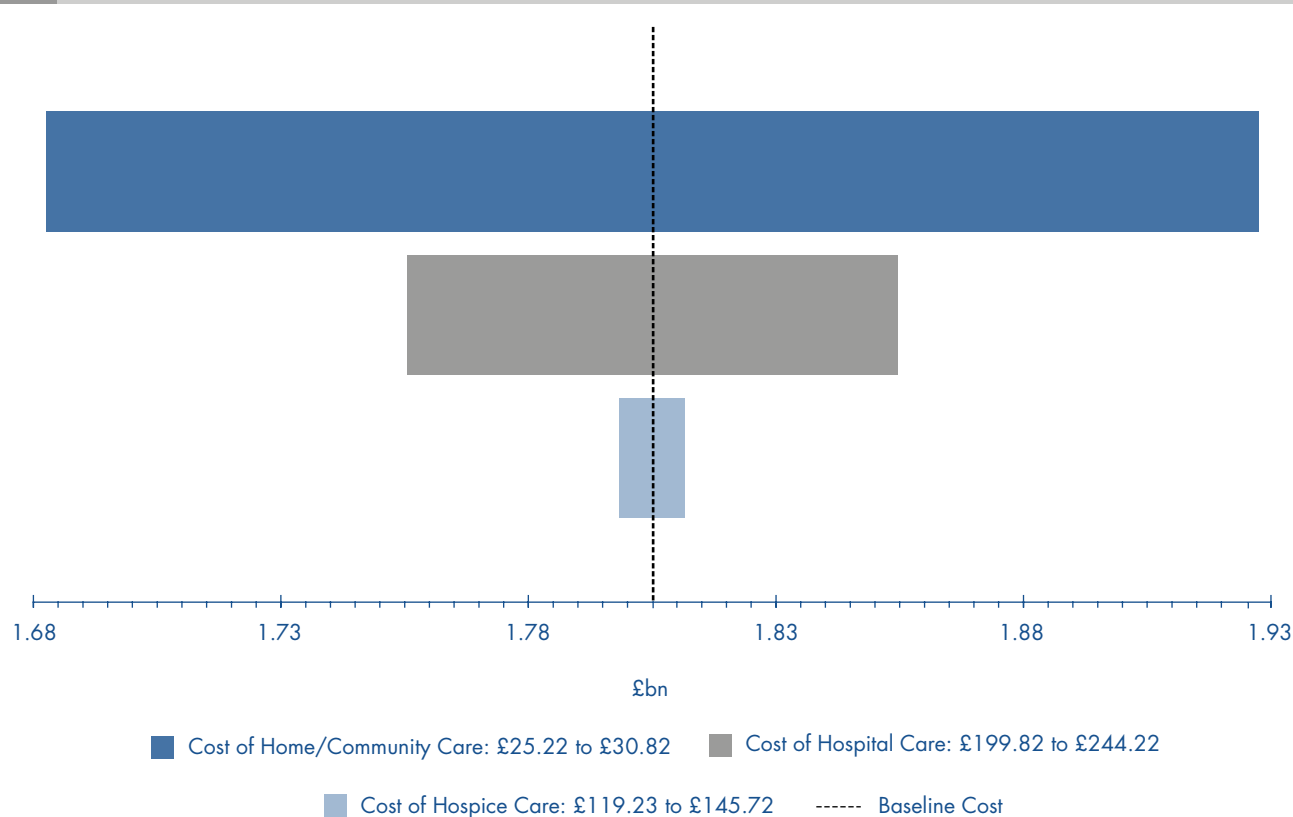
Scenario analysis

16 Once a baseline has been established which estimates the current cost of delivering care in the last year of life, hypothetical reductions to the model's inputs can

be made in order to examine what effect these reductions have on the total cost of care and number of days an average patient spends in hospital care.

17 In our scenario analysis of cancer, the effects of expanding hospice capacity was not explored. The total volume of emergency admissions to hospital was systematically reduced in steps of five per cent to a maximum reduction of 20 per cent. The average length of stay in hospital following an emergency admission was also systematically decreased by one, three and five days.

23 Variation in total cost of delivering end of life care to cancer patients in the last year of life caused by varying the per diem cost of care in each setting by plus or minus 10 per cent



Source: National Audit Office/Rand Analysis

NOTE

The above diagram shows the effect of varying the cost of each type of care by +/-10 per cent to account for any uncertainty in cost estimates. Each bar represents the total cost of delivering care for cancer patients in the last year of life if the cost of one care setting only is varied. Cumulatively, these variations have an effect on the baseline estimate (£1.81 billion) of +/-£177 million meaning we estimate the total cost of caring for cancer patients in the last year of life to be £1.64–£1.98 billion.

Results from modelling – cancer

18 Figure 24 shows the amount of money which our model indicates could be redistributed nationally if the specified reductions in the number of emergency admissions and length of stay following an emergency admission were achieved. Figure 25 details the days of acute care per patient which would be avoided through the same reductions.

24 Potential resources made available for redistribution through decreased use of hospital care by cancer patients £ million

Reduction in emergency admissions	Reduction in mean length of stay per admission			
	0	1 day	3 days	5 days
0	0	26	78	132
5 per cent	16	42	91	141
10 per cent	33	56	104	151
15 per cent	49	71	117	161
20 per cent	66	87	129	171

Source: National Audit Office/RAND analysis

25 Potential days of hospital care avoided for cancer patients in the last year of life

Reduction in emergency admissions	Reduction in mean length of stay per admission			
	0	1 day	3 days	5 days
0	0	1.1	1.6	2.1
5 per cent	0.6	2.7	3.3	3.2
10 per cent	1.2	3.6	4.1	4.5
15 per cent	1.8	5	5.4	5.7
20 per cent	2.4	6	6.4	6.7

Source: National Audit Office/Rand Analysis

19 This analysis shows that for cancer patients, a reduction of ten per cent in the number of emergency admissions and one day in the average length of stay following an emergency admission would release £56 million in resources which could be reinvested in delivering end of life care in the community, and on average avoid 3.6 days in acute care per patient. Similarly a reduction of 20 per cent in the number of emergency admissions and a decrease of five days in the average length of stay following an emergency admission would release £171 million and avoid 6.7 days in hospital.

20 Data on the practicability of achieving such reductions is limited. Members of our expert panel have stated their belief that reductions of 10 cent in the number of emergency admissions and a reduction of three days in the length of stay per admission would be achievable in the medium term. This reduction would make £104 million available to be redistributed in community services and achieve a reduction of around 4.1 days in hospital care per patient in the last year of life might be achievable for cancer patients.

21 Bringing about reductions in hospital utilisation through reducing inappropriate admissions, and ensuring prompt discharge following treatment will require investment and cultural change. Data on the investment required to bring about such reductions is limited and so no attempt has been made to cost a national programme which might realistically produce the reductions detailed above. The level of resources made available will need to be offset against expenditure on additional services required to deliver good end of life care in the community. However, if the 126,000 people who die of cancer annually were to spend the average of 4.1 extra days in the community by making the reductions in emergency admission and length of stay discussed above, and this could be delivered at the current per diem cost of £28, this would cost £14.5 million. This is significantly less than the £104 million made available through the above reductions in hospital utilisation. Although reducing emergency admissions may well require more than just the expansion of current community support services, this does indicate it may be possible to deliver the proposed reductions for people with cancer without increasing end of life care expenditure.

Results from modelling – pulmonary disease and heart failure

22 The vast majority of published data on the costs of delivering end of life care focuses on cancer patients and because of this it is difficult to extend our analysis to other conditions. HES and MDS data can be used, however, to provide data on the amount of time patients who suffer from conditions such as heart failure and pulmonary disease spend in the three main care settings. Based on the assumption that the per diem cost of care in each care setting is the same for all conditions, and that these costs can be applied to the entire last year of life, we have estimated a baseline of current costs and modelled the potential to redistribute resources by reducing utilisation of hospital care.

23 We examined pulmonary disease – which includes conditions such as chronic obstructive pulmonary disease and emphysema – and heart failure. We estimate the total cost in the last year of life to be £1.76 billion. **Figures 26 and 27** show the potential resources which could be redistributed and days of hospital care per patient avoided by making the same hypothetical reductions in emergency admissions and length of stay, following an emergency admission, as we made for cancer.

24 Only 29,000 people die each year in England of heart failure and pulmonary disease, compared with around 127,000 deaths from cancer. However, because people with heart failure and pulmonary disease have higher numbers of emergency admissions and longer lengths of stay, the overall cost of care in the last year of life is similar to that for cancer, but the potential to redistribute resources is greater. Currently, the proportion of these patients who utilise hospice care is low so we have not attempted to model the impact of increasing access to hospices for such patients. Our analysis could be extended to other end of life care conditions such as renal failure or dementia, but for a more accurate picture of the baseline and potential to redistribute resources to be constructed we would need better data on the costs of care for these conditions.

Assumptions and caveats

25 In any project such as this it is necessary to make some assumptions to fill in gaps in data. In this model we make the following assumptions which we believe are justified and reasonable given the data constraints, and which are likely to understate the potential to redistribute resources.

26 Potential resources made available for redistribution through decreased use of hospital care by patients with heart failure and pulmonary disease £ million

Reduction in emergency admissions	Reduction in mean length of stay per admission			
	0	1 day	3 days	5 days
0	0	16	48	80
5 per cent	13	28	57	88
10 per cent	25	39	67	96
15 per cent	37	50	77	104
20 per cent	49	61	87	112

Source: National Audit Office/Rand Analysis

27 Potential days of hospital care avoided for patients with heart failure and pulmonary disease in the last year of life

Reduction in emergency admissions	Reduction in average (mean) length of stay per admission			
	0	1 day	3 days	5 days
0	0	2.7	8.3	13.9
5 per cent	1.9	4.5	9.8	15.1
10 per cent	3.8	6.3	11.3	16.3
15 per cent	5.8	8.1	12.8	17.6
20 per cent	7.7	9.9	14.3	18.8

Source: National Audit Office/Rand Analysis

Assumptions

Assumption	Justification	Likely effect on model
Being cared for in a hospice or the community is the preferred option for patients and reducing time in hospital improves the patient experience.	Surveys consistently suggest that the majority of people would prefer to be cared for outside of hospital.	No effect on the calculations of the potential resources which could be redistributed.
Interventions can be put in place to reduce emergency admissions or facilitate more timely discharge from hospital care without reducing the standard of patient care.	Work by Marie Curie Cancer Care and others highlighted in this report shows this to be the case	No effect on the calculations of the potential resources which could be redistributed.
The amount of time spent, or the treatment given, in any state will not effect patients' life expectancy.	We are not aware of data on how the care received in the various settings effects end of life care patients' life expectancy.	If care given in alternative settings does extend life this could affect the level of resources which could be made available for redistribution.
Hospice inpatient capacity is fixed.	In reality this may not be the case and given appropriate referrals hospices may be able to take more patients approaching the end of their life. However, given the small proportion of patients admitted to hospice as an inpatient, then there would need to be a substantial increase in referrals to have a significant effect on the cost estimates.	If referrals from hospital to hospice (rather than the patient remaining in hospital) and/or referrals from home to hospice (rather than a patient being admitted to hospital) were increased then the amount of time in hospital care would be reduced and the amount of resource available for redistribution increased in the various scenarios we examined.
The cost of care in a hospice is the same in NHS run and voluntary sector units.	We have not identified any research into the difference in cost of providing care in the two settings. The fact that a far greater proportion of NHS hospice funding is provided by the state is explicitly acknowledged in the method for deriving the cost of a day in hospice care.	If providing a day of care in an NHS hospice were cheaper than a voluntary hospice this would slightly decrease the baseline costs but not the potential resources available for redistribution in each scenario.
All costs for services received in a patient's own home are met by the tax payer.	In reality some of these will be subsidised as they will be supplied by a hospice or other charitable service but a proportion cannot be attributed to this.	Given that savings are essentially attributed to the difference in cost between community and hospital care this assumption, if anything, will lead to an underestimate of the potential level of resources available for redistribution in the various scenarios we examined.
The cost of delivering end of life care in the community is the same in someone's home and in residential care.	Since Care Homes and Nursing Homes have staff who could perform some of the roles performed by carers and District Nurses for patients in their own homes this might lead to a slight overestimate of the cost of community care.	If anything this will lead to an underestimation in the potential resources available for redistribution.
	But since only a small proportion of cancer, heart failure and COPD patients die in residential care this is unlikely to have a significant effect. More consideration would need to be given to this if a condition such as dementia was modelled.	

Assumption	Justification	Likely effect on model
The cost of delivering end of life care in all settings is the same for heart failure and pulmonary disease patients as it is for cancer patients.	This is unlikely to be the case as in all settings these patients will receive very different interventions. However, whilst good quality data on the cost of cancer care exists there is very little on other conditions.	In the absence of more accurate cost data it is not possible to state the likely effect this will have on the model. A first attempt at estimating current costs and the magnitude of potential savings has been made using costs for cancer care.

Caveats

Caveats	Caveat Justification	Likely effect on model
Informal carers' costs are not considered in this model.	The impacts on carers are considered elsewhere in our work. This model calculates costs from the perspective of the taxpayer.	May overestimate potential resources available for redistribution if patients become more reliant on friends and family to deliver care in the community.
The volume of patients who will be admitted to hospital from their own home but need to be discharged to some form of residential care and how this might be effected if average length of stay is decreased is not considered in this model.	In reality some patients who remain in hospital for a long period of time are likely to do so because they can no longer support themselves in their own home and they are reluctant to enter a Care Home, or a place cannot be found for them. We do not have up to date data on what proportion of patients this would represent.	If this is the case then the potential resources available for redistribution may be an over estimate. Although it should be noted that since most forms of residential care are cheaper than the cost of receiving end of life care in a hospital this will not alter the fact that reduced utilisation of hospital care will make available resources for redistribution.
The model assumes that the amount of time spent in a hospice by patients is not affected by varying number of the emergency admissions or the average length of stay.	The method for deriving the transition probabilities is based on the assumption that all hospital time avoided will be spent in the community.	If producing the reductions in hospital care utilisation specified require an expansion of hospice inpatient activity then the amount of resources available for redistribution would be less.
Patients in the model have no specific case history so it will be accurate for a cohort but not for an individual patient.	Since the model is from the perspective of the taxpayer at a national level this is justified.	No effect on potential resources available for redistribution.
The model is designed to examine resource used throughout the last year of life, it does not account for the fact that periods of hospital and hospice admission are often clustered towards the end of that year and does not predict place of death.	The model calculates the amount of time in hospital care which could be avoided and not how decreasing admissions and length of stay would affect place of death.	The savings calculated and time in hospital care avoided are still valid.
Some of the data on the cost of delivering care dates back to 1999.	This has been adjusted using the CPI Health Index to take account of inflation.	Given sensitivity analysis of ten per cent, variation was carried out. Any effect should be minimal.

APPENDIX FOUR

1 In order to gain an understanding of the delivery of end of life care at a local level we carried out detailed case study reviews at Sheffield PCT, Hereford PCT, and City and Hackney PCT. We spent two days at each location interviewing a range of people involved in commissioning and delivering end of life care services. This appendix provides examples of some of the challenges and strengths identified during our visits and the report on each health economy can be found on our website.

Challenges

Diversity and deprivation (City and Hackney)

2 City and Hackney PCT serves an extremely diverse urban population which means that services need to meet a wide range of needs and traditions around death and dying. It is also the sixth most deprived PCT area in England and local living conditions can be unsuitable for providing end of life care in the home (e.g. properties with small rooms, or high rise flats). The population is, however, relatively young with fewer people over the age of 75 than the national average and the PCT has a comparatively low number of deaths per 100,000 (ranked 148th of 152 PCTs).

Ageing rural population (Hereford)

3 In direct contrast to City and Hackney, Herefordshire is just outside the 25 per cent least deprived PCT areas in England and has a predominantly white British population. This population does, however, consist of an increasing number of people of retirement age and Herefordshire has a comparatively high number of deaths per 100,000 (ranked 36th of 152 PCTs). A further significant factor affecting the provision of end of life care services is the largely rural nature of the county which can mean that patients and staff delivering end of life care have to travel long distances, which is both costly and time consuming.

Detailed PCT reviews

Out of hours GP services (City and Hackney, Hereford, Sheffield)

4 Out of hours providers do not always have a detailed knowledge of the patients they are being called to treat and have to rely on patient records being up to date. At each of the sites visited interviewees raised concerns that this lack of patient knowledge and suitable notes may result in unplanned admissions out of hours. In Sheffield, we were made aware of one GP practice tackling this issue through its doctors providing a direct contact number on a rotational basis to patients expected to die in the near future.

24 hour access to equipment (Hereford, Sheffield)

5 In both Sheffield and Hereford the services which provide specialist equipment to enable patients to be treated at home is only available during office hours Monday to Friday. This restriction can cause difficulties for patients discharged from hospital out of hours who have a very short window in which they can be transferred from hospital to enable them to die at home.

Information and advice for patients and carers (City and Hackney, Hereford, Sheffield)

6 In both Hereford and City and Hackney, the need to provide more information to patients and carers regarding what end of life care services are available to them, and what benefits they are entitled to receive was highlighted. In Sheffield, an information centre has been established but it is only available to cancer patients and their carers.

24 hour access to palliative care drugs (City and Hackney, Sheffield)

7 Sheffield does not currently provide a 24 hour pharmacy service and controlled pain relief drugs are not carried by GPs. An on-call pharmacist is available out of hours but this service is rarely used and patients often have to wait until the next day for medication. There is also no 24 hour pharmacy service in City and Hackney. There are plans to develop a 24 pharmacy service but some staff have concerns about carrying injectable opioids in the community, particularly late at night.

Access to bereavement services (City and Hackney, Hereford)

8 Bereavement services provided by the local hospices are highly regarded but are only available to the families of hospice patients. The need for increased access to and coordination of bereavement services for families of patients in hospital and within the community was identified in City and Hackney and Hereford. For example it was acknowledged in Hereford that services were offered to all via a charity which was part funded by the PCT, although this service was not well advertised.

Strengths

Dedication and commitment of staff (City and Hackney, Hereford, Sheffield)

9 At each of the three locations we visited staff providing end of life care were highly committed to the work they do. This commitment should be acknowledged as crucial to championing end of life care and driving future change.

Locally Enhanced GP services (City and Hackney)

10 Thirty three of the 45 GP practices in City and Hackney provide locally enhanced services for palliative care. The practices involved meet internally on a monthly basis to review palliative care cases and as a wider group once a year to consider training needs. Since the introduction of the enhanced service, the number of local practices utilising the Gold Standards Framework has increased from three to 33.

Community hospitals (Hereford)

11 Five Community hospitals within Herefordshire act as a bridge between acute and primary care. Their presence enables end of life patients in rural areas to receive palliative care in a community hospital closer to their home and loved ones, rather than being admitted to the general hospital in Hereford.

Intensive Home Nursing Service (Sheffield)

12 The Intensive Home Nursing Service provides care and support to patients and carers in their own homes. Originally the service provided care seven nights a week to those thought to be in the last month of life, and 24 hour care to those thought to be in the last week of life. The service has since been extended to offer more flexible, variable intensity care to those with longer term palliative care needs.

Multi-disciplinary palliative care team (City and Hackney)

13 Homerton University Hospital has a dedicated multi-disciplinary palliative care team consisting of a consultant doctor; three clinical nurse specialists; a clinical psychologist; a social worker; chaplain; and team secretary. The team carries out a range of activities including providing support with pain and symptom control, coordinating community care on discharge from hospital, and bereavement support.

24 hour access to nursing (Hereford, Sheffield)

14 In Hereford a 24 hour district nursing service is available and has been highlighted as an example of good practice by the Department of Health. Introduced in December 2006, the service involves shift working between 8am and 10pm, with district nursing sisters providing an overnight on-call service. In Sheffield an evening and night nursing service operates from 5pm to 8am and builds on the daytime district nursing service to provide a 24 hour service. Sheffield's district nurses are also attached to local GP surgeries to provide patients with greater continuity of care.

Hospice care (City and Hackney, Hereford, Sheffield)

15 Common to all three locations we visited was the high regard for the care provided by the local independent hospice. Examples of the services offered by the hospices included inpatient care, outpatient care, bereavement support, day care and telephone advice lines. The hospice we visited in Hereford also undertakes training in nursing homes, doctor's surgeries, community hospitals and other care settings. A common concern at all three locations was the source of future funding.

APPENDIX FIVE

International comparisons

1 The World Health Organisation (WHO) found in its 2004 report *Better Palliative Care for Older People*⁴⁷ that England and Wales collectively had the lowest proportion of home deaths and the highest proportion of hospital deaths amongst all the international countries it examined (Figure 28). The England and Wales figure used does, however, include deaths that occurred in residential care homes.

2 Furthermore, the WHO noted that data from different countries are collected in different ways, and sometimes not at all, limiting the comparison that can be drawn and highlighting the need for different health care systems to begin collecting this data routinely, using comparable definitions. The comparisons that follow are therefore not quantitative, but provide a qualitative account of the different systems and arrangements that exist for end of life care in Scotland, Wales, the United States and Canada.

Scotland

3 There are over 55,000 deaths in Scotland each year and in 2006-07 the total expenditure on specialist palliative care was £59 million.⁴⁸ The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland.

4 Whilst palliative care is mentioned in a number of health strategies, there is no national strategy on palliative or end of life care. The Scottish Government Health Directorates (SGHD) is working with NHS Boards and the voluntary sector to produce a coordinated palliative care action plan by October 2008.⁴⁸

5 Audit Scotland reported in 2008⁴⁸ that most palliative care is provided by non-specialist staff in hospitals, care homes or in patients' own homes. However, not all generalist staff have the skills, confidence and support to care for palliative care patients. Nearly all GP practices working to the new General Medical Services contract keep palliative care registers. However, it can be difficult to assess when it is appropriate to introduce palliative care. Patients are entitled to a Community Care Assessment to assess whether they need services and support. Audit Scotland reported that a fifth of patients cared for at home were not offered this assessment.

6 Changes to the General Medical Services (GMS) contract saw the responsibility for out of hours service provision shift from GP practices to NHS Boards. Out of hours arrangements vary amongst NHS boards and may include a normal out of hours telephone number such as NHS 24 (rolled out in 2004), or a special phone number for palliative care patients and carers out of hours, or a special number for professionals.

7 The Scottish Partnership for Palliative Care in 2007 reported that there is inequity in services accessed by the dying, with cancer patients far more likely to receive specialist palliative care than patients with non-malignant conditions. Audit Scotland in 2008 also reported that specialist palliative care remains primarily cancer-focused.⁴⁸

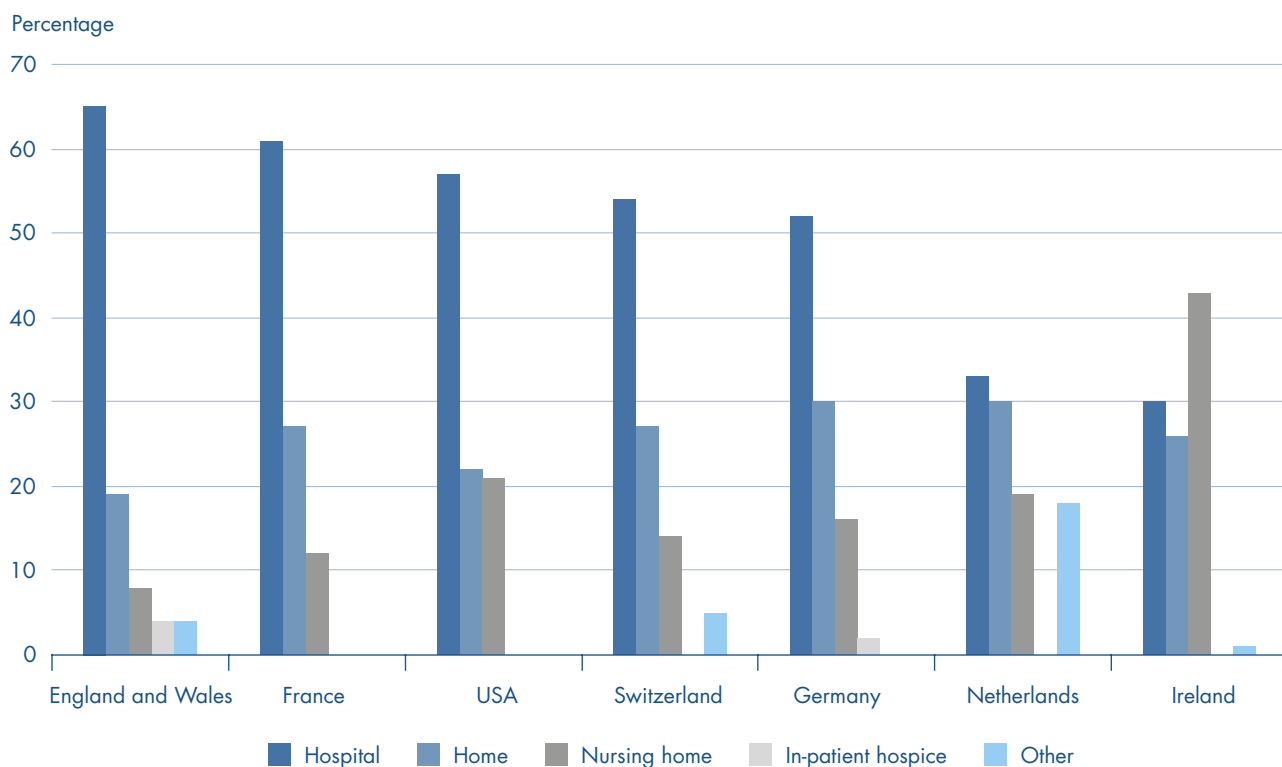
8 Implementation of the Liverpool Care Pathway across NHS Boards has not taken place in all care settings across all boards. However, 75 per cent of GP practices have signed up to the Gold Standards Framework Scotland (GSFS).⁴⁹

47 World Health Organisation Europe, *Better Palliative Care for Older People*, 2004.

48 Audit Scotland, *Review of Palliative Care Services in Scotland*, 2008.

49 Scottish Partnership for Palliative Care, *Palliative and end of life care in Scotland: the case for a cohesive approach – report and recommendations to the Scottish Executive*, 2007.

28 International comparison of place of death



Source: WHO Europe, *Better Palliative Care for Older People* (2004)

NOTES

- 1 For the purpose of this analysis for England and Wales deaths in residential care homes were grouped with hospitals.
- 2 Some 15 per cent of deaths in the Netherlands occur in residential homes. These are included in the 'other' category.

9 In 2007, the Scottish Partnership for Palliative Care⁵⁰ issued palliative care practice statements. Endorsed by the regulator, the Care Commission, they set out what people can expect from their current or future care home in order to meet their palliative care needs. Equally they aim to provide a resource for care home owners and managers to help them deliver palliative care to both an acceptable and achievable level.

10 Audit Scotland recently completed a study into palliative care in Scotland. Its report: *A review of palliative care services in Scotland* (August 2008), can be found on its website at www.audit-scotland.gov.uk.

11 The Scottish Government Health Department published *Living and Dying Well*, a national action plan for palliative and end of life care in Scotland, in October 2008. This action plan is supported by additional resource for primary care and for education and training. The action plan can be found on the Scottish Government website at www.scotland.gov.uk.

Wales

12 Local Health Boards are responsible for commissioning and funding palliative care and are expected to assess the need for palliative care services of their local populations and, to plan, organise and deliver services to meet that need. Provision of palliative care is similar to that in England. GPs and district nurses provide services in primary care. The NHS provides hospital inpatient and outpatient care whilst hospice and hospice at home services are provided by a mix of NHS and voluntary services.

13 In October 2007, the Minister for Health and Social Services established the All Wales Palliative Care Planning Group, which was chaired and supported by Viv Sugar, Chair of the Welsh Consumer Council. The Group's terms of reference included the preparation of a report which specified the elements of a core palliative care service (including end of life care for adults) which would form the basis of a commissioning specification to underpin funding considerations by the Welsh Assembly

50 Scottish Partnership for Palliative Care, *Making good care better: national practice statements for palliative care in adult care homes in Scotland*, 2006.

Government and Local Health Boards. The Group was also asked to develop a means of formally measuring the quality of core palliative care services which the Welsh Assembly Government and Local Health Boards could use to inform funding considerations for individual providers.

14 Following a short but extensive review, the Group published a report in June 2008 identifying where there were gaps in service provision, and barriers to accessing services. The review found that although there are many examples of good services across Wales, not all patients are able to access them due to geography and understaffing in services. A lack of consistency in the commissioning of services was also identified and the review recommended a move to regional commissioning.

15 The elements of a core palliative care service specified by the review included the provision of a 24 hour service to all patients across Wales; comprehensive needs assessments to all patients; and services which endeavour to enable patients to die in the place of their choice and offer support to families and carers through the illness and into bereavement. The review found that in order to achieve the service level specified, substantial investment would be required.

16 The review found that the current means of measuring the quality of core palliative care services was of a high standard, but was not applicable to all care providers. It therefore recommended that a single regulatory body be responsible for inspections covering clinical governance systems, facilities that provide inpatient and day care, and nursing homes. Training and education were also highlighted as drivers for quality improvement and the review recommended the development of standards and coordination of training and education for all specialist and generalist providers across Wales.

17 Following the publication of the review, the Minister for Health and Social Services asked Baroness Finlay to be the lead on the implementation of the review's recommendations. An Implementation Board has been established and an early priority for the Board was to provide advice on the allocation of central funding for palliative care.

18 The Board provided its advice in October 2008, which the Health Minister has accepted. The Board's Report sets the direction of travel required to improve palliative care services in line with the recommendations of the Sugar Report, for consultant led services. This Board will continue to take forward and monitor implementation of the recommendations in the Sugar Report and provide advice to the Minister on progress and future funding allocations.

⁵¹ Report by the Advisory Board for the National Audit Office, 2007.

United States of America

19 As is the case in England, the majority of Americans express a preference to die out of hospital. Statistics show that in the United States around 50 per cent of deaths occur in hospital and around 25 per cent at home. The National Hospice and Palliative Care Organization (NHPCO) is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States.

20 The USA operates a federal programme of hospital insurance, Medicare, for citizens unable to work due to disability and for all citizens over 65. The Medicare Hospice Benefit was implemented in 1983 and was designed to provide patients who have a terminal illness with comfort and pain relief, as well as emotional and spiritual support, generally in a home setting. By law, Medicare hospice services include nursing care, counselling, and home health aide services, as well as drugs and medical supplies. Hospice services are delivered by providers that operate as freestanding entities or are based in hospitals, home health agencies, or skilled nursing facilities. Medicare pays hospices a daily rate that covers all services provided to the patient, except for physician services.

21 To be eligible for hospice services, the patient must have Medicare cover, have a life expectancy of six months or less and must submit a written agreement not to pursue curative treatments. The Medicare Hospice Benefit covers 82.4 per cent of hospice patients, with most others covered by a private payer. As a result, annual expenditure by Medicare on hospice care totals \$8.2 billion per year, a figure which is expected to increase by nine per cent per year by 2015.⁵¹

22 Palliative care (or hospice care as it is termed in America) is provided in the place the patient calls "home" where possible. It can also be administered however, in hospice facilities, designated hospitals and nursing homes. Like England, the majority of patients accessing hospice care have cancer.

23 In 2007⁵² the United States Government Accountability Office identified six key components in the delivery of end of life care and examined programmes in four states which incorporated these components. The programmes identified were the Program for All-Inclusive Care for the Elderly (PACE), the Wisconsin Partnership Program (WPP), the Medicaid Arizona Long Term Care System (ALTCS) and palliative care programs. These programmes use care management, either through a case manager or an interdisciplinary care team of providers, to provide the following key components of care: care management to coordinate and facilitate service delivery; supportive services to assist individuals residing in non-institutional settings; pain and symptom management; family and caregiver support; communication among the individuals, families, and programme staff; and assistance with advance care planning to aid individuals with making decisions about their future care.

24 The report also identified challenges programme providers face in delivering these key components which included difficulties providing supportive services and family and caregiver support to rural residents because of travel distances, fewer community-based service options, and an inability to hire adequate numbers of staff in rural areas. Physician training and practices were also inhibiting the provision of pain and symptom management and advance care planning to individuals nearing the end of life.

25 A 2006 report⁵³ on hospice care in America found that the number of patients receiving hospice care is rising, although the length of stay has remained steady and most hospice care patients are dying in the place they call home. In terms of equity, the report found that there is increased racial diversity amongst patients being served, and an increasing number of over 65s are receiving care.

Canada

26 Most Canadians with life-threatening illnesses would prefer to die at home but 75 per cent die in hospital beds or long term care facilities.⁵⁴

27 There were some 259,000 deaths in Canada in 2007, of which 28 per cent were due to cancer. Canada has a national health insurance programme, Medicare, and approximately 25 per cent of Canadians have access

to hospice palliative care services, with those living in rural areas and those living with disabilities having severely limited access. Hospice palliative care services in Canada are offered in a variety of settings, including hospital care, long term care facility/complex continuing care, residential hospice or the home.^{55, 56, 57}

28 The Canadian Hospice Palliative Care Association (CHPCA) is the national charitable association which provides leadership in hospice palliative care in Canada. The CHPCA is the Secretariat of the Quality End of Life Care Coalition of Canada (QELCCC), a coalition of 30 national organisations concerned about quality end-of-life care for all Canadians.

29 A 2000⁵⁴ report highlighted the need for a national strategy and in March 2001 the Government of Canada appointed a Minister with Special Responsibility for Palliative Care. In June 2001 the Government established the Secretariat on Palliative and End of Life Care at Health Canada and the Canadian Strategy on Palliative and End of Life Care was launched in 2002.

30 In January 2004, the Canadian Government created new family Compassionate Care Leave benefits under the Employment Insurance program allowing six weeks of compassionate care benefits to employees absent from work providing care or support to a gravely ill family member.

31 In 2004, the Government recognised the need for good quality hospice palliative care services in the home and committed to funding the following home care services: case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life.⁵⁸

32 To support this commitment, the Canadian Hospice Palliative Care Association in partnership with the Canadian Home Care Association has defined the “gold standard” for each of the four home care services. These are designed to encourage and support a consistent approach across the country to these services.⁵⁹

33 A model to guide hospice palliative care is available for Canada⁶⁰ and accreditation exists in most settings, including the development of national indicators.

52 United States Government Accountability Office, *End of Life Care: Key Components Provided by Programs in Four States*, 2007.

53 National Hospice and Palliative Care Organisation, *2006 National Summary of Hospice Care*, 2007.

54 Carstairs, *Quality End-Of-Life Care: The Right of Every Canadian*. Final Report to the Senate, 2000.

55 Presentation at the Gold Standards Framework Annual Conference (June 2007) by Sharon Baxter, CHPCA, Experience and Lessons Learnt on End of Life Care in Canada.

56 Canadian Hospice Palliative Care Association Fact Sheet *Hospice Palliative Care in Canada*.

57 Canadian Institute for Health Information (2007) *Health Care Use at the End of Life in Western Canada*.

58 Government of Canada, *10-Year Plan to Strengthen Health Care*, 2004.

59 Canadian Hospice Palliative Care Association and the Canadian Home Care Association, *The Pan-Canadian Gold Standard for Palliative Home Care*, 2006.

60 Canadian Hospice Palliative Care (2002) *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*.

APPENDIX SIX

Case examples

1 The following case examples provide information on a range of initiatives which have been developed with the aim of improving care for people approaching the end of their life. Case examples 1 to 3 describe the development of services to improve care for people with specific

conditions (motor neurone disease, dementia, and heart failure). Case examples 4 and 5 describe the development of services aimed at improving services for all people at the end of their life by improving integration between care providers.

Condition specific initiatives to improve end of life care

EXAMPLE 1

The development of the Year of Care pathway for people with Motor Neurone Disease (MND) (paragraph 2.4)

Diagnosing the Disease

MND is a relatively uncommon neurodegenerative disease (around 5,000 people are currently living with MND in England). Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. Most cases of MND progress quite quickly, with noticeable decline occurring over the course of months. On average 50 per cent of people die within 14 months of diagnosis and 90 per cent within five years. There is no test to diagnose MND; instead a diagnostic process is used to eliminate other potential conditions. On average GPs may only see one or two cases in their career and the early symptoms can often be attributed to other reasons. Diagnosis can therefore often be delayed with significant repercussions and distress caused to people with the disease, and their family.

Providing the necessary support and equipment needs: The Year of Care Pathway

Effective care for people with MND depends on a coordinated, multi-disciplinary approach to care management. Because of the progressive nature of the disease, delays in diagnosis, lack of coordination and difficulties identifying a single point of contact

mean the equipment and support needed to help MND patients and their carers live independent lives as long as possible can be delivered too late and be of limited use, if not redundant, when they arrive. In July 2008, the MND Association launched the Year of Care Pathway, an innovative new guide to commissioning aimed at helping the NHS and Social Services improve the commissioning and provision of services and equipment for people with MND.

For the first time ever, the Year of Care pathway lists all the possible services and equipment needs that a person with MND may have over a 12 month period. By attaching a cost to each element, commissioners should be able to plan and deliver services more effectively and ensure that people with MND receive what they need, when they need it. The Pathway was developed with input from commissioners, healthcare professionals and patients. The total cost of services and equipment in the last year of a MND patient's life is estimated at around £200,000, including £83,000 for equipment and adaptations. This figure does not include the cost of high dependency care homes, estimated to cost £65,000, and the cost of informal care, estimated at £36,000. The Year of Care Pathway can be accessed on the MND Association website at www.mndassociation.org.

Source: National Audit Office

EXAMPLE 2

St Christopher's Hospice Palliative Care in Dementia Project (paragraph 2.15)

The aims of the St Christopher's Hospice Palliative Care in Dementia Project (Dementia Project), funded for three years in Croydon by the King's Fund, are:

- to investigate the palliative care needs of patients with advanced dementia and their families;
- to clarify the role of specialist palliative care for this patient group; and
- to examine the usefulness of one model of working.

Around a hundred referrals were made to the project in its first two years from a range of residential and domiciliary settings. The referrals were initiated by a wide range of professionals, but most commonly from care home managers or nurses (25 per cent) and GPs (25 per cent).

The project used two types of referral criteria: a combination of general and dementia specific criteria set out for the Gold Standards Framework, and an adapted surprise question ("Would you be surprised if this patient died within the next 6–12 months?"). An interim report on a review of the first 50 patients referred for care found that only five did not meet the referral criteria and did not require basic palliative care, suggesting that the GSF criteria are useful markers to help referrers to identify which patients need palliative care. A further four patients died before being seen. The remaining 82 per cent of patients, and their carers, were taken on and followed up by the project palliative care Clinical Nurse Specialist, with consultant backup.

Only two patients were seen as in need of the full hospice Home Care service at the end of life; the rest were managed within an advisory framework by the project palliative care specialist nurse. Four patients were admitted, and died in hospital; one of these admissions was considered inappropriate. Only a small number of patients had been referred for terminal care even though 40 per cent died within six months of their referral. The project team felt that this was possibly due to an inability amongst professionals or care home staff to recognise the dying phase in patients with advanced dementia.

Source: National Audit Office

The most prevalent symptoms (cough, constipation and sleep problems together with weight loss, fatigue, weakness, anorexia and drowsiness) were seen as symptoms that could be addressed by good basic nursing care. Symptoms that might need specialist intervention were rarer, for example few patients had major or difficult psycho-behavioural problems and pain problems were not as common as first expected and rarely required highly complex management.

The project team feel they have demonstrated that the Clinical Nurse Specialist played a crucial role by:

- helping staff and carers recognise and manage the dying phase;
- enabling staff to recognise and manage symptoms in patients unable to express themselves verbally;
- communicating with carers about management choices and prognosis;
- referring appropriate individuals to a broad selection of external services which nursing homes and carers were not familiar with;
- planning for crises in advance (thus, for example, reducing the pressure for inappropriate hospital admissions); and
- providing bereavement support.

As a next step, the hospice wants to establish whether the skills of the project Clinical Nurse Specialist are transferable to others taking up a similar role. It is therefore planning to set up a training programme for Clinical Nurse Specialists from a palliative care or mental health background from various boroughs in London, and running and evaluating the same model of care on a larger scale. It is also planning to use shared data collection instruments to pool information about patients and their carers, thus establishing one of the largest cohorts of people with advanced dementia being followed up internationally. This would provide an opportunity to collect invaluable information about symptoms and psychosocial issues, as well as to validate referral criteria, guidelines and pathways, analyse costings of end of life care more closely, and to set up an infrastructure for further research about care in this patient group.

EXAMPLE 3

Supporting people with end stage heart failure: Care Plus Project – Princess Royal Carers Centre – Tower Hamlets (paragraph 2.17)

Tower Hamlets Carers' Centre runs the Care-Plus project, which aims to support carers of people who have been diagnosed with end stage heart failure. Data collected by Tower Hamlets PCT show that circulatory diseases, including heart failure, have accounted for around a third of deaths in Tower Hamlets for the last three years. Fifty per cent of the population in Tower Hamlets are Bengalis, who are particularly susceptible to heart disease.

Percentage of deaths by condition in Tower Hamlets for the three years 2005-2007

	2005 %	2006 %	2007 %
Cancer	26	27	30
Circulatory	34	32	31
Respiratory	16	14	12
Other	24	26	26

Carers of heart disease sufferers are often overwhelmed by the number of services they need to contact to access the support they need for the person they are caring for. The project employs a full time dedicated project coordinator whose role is to provide

enhanced carer support services tailored to individual needs, a primary link into the services the carers may need and provide fast track access to health and social services across the borough. This help takes place through the Carers' Centre and home visits when necessary. Examples include:

- Advice on welfare benefits – many carers are not aware of the benefits that are available and under-claim.
- Helping carers to understand what a diagnosis really means through liaison with the carer's GP or consultant.
- Training for carers by local heart failure nurses on progression of the condition, what to expect, practical issues such as healthy eating, where to go for help and knowing when not to panic.
- A heart failure DVD giving information on the coordination of care, medications used, the typical patient and carer journey through end of life care services and the professionals and agencies they will meet and what each does.

Referrals to the service come from a range of sources, including GP practices, heart failure nurses and acute care. The project demonstrates the importance of improving the responsiveness and coherence of services for patients and carers and of having a person to support improvements in communication between the different organisations involved in delivering care.

Source: National Audit Office

Initiatives to improve the integration of end of life care services

EXAMPLE 4

An integrated service by the Royal Free Hospital (paragraph 2.21)

The Palliative Care Team at the Royal Free Hospital provides services both in the hospital and in the community. It is a nurse-led team offering specialist palliative care concentrating on quality of life issues for patients with advanced, progressive illness.

The Team has specialist skills in pain and symptom management and provides supportive care on social, emotional and spiritual matters. The Team consists of:

- four nurse specialists based in the hospital;
- four nurse specialists working out in the community; and
- doctors who act as a specialist medical resource brought in to assist where highly complex needs occur.

The lead palliative care consultants are joint posts working in the hospital and the local hospice. This facilitates referrals to hospice services and helps to ensure a smooth transition between home, hospice and hospital care. The Team provide a 9am to 5pm

service, seven days a week. Out of hours calls from the hospital are directed to an on-call medical consultant for the Team. Out of hours calls from patients in the community are directed to primary care providers and a specialist advice service is in development.

Recent projects and initiatives include:

- Introduction of handover forms so that out of hours doctors do not make inappropriate decisions and admit patients to hospital unnecessarily.
- A Service Level Agreement with a local pharmacy to provide palliative care patients with fast track access to drugs out of hours.
- The Macmillan nurse consultant is also the senior manager of Bereavement Services in the Trust. This combined role adds to the integrated way of working, helping to provide a joined up service to carers and family after death.

Source: National Audit Office

EXAMPLE 5

The Marie Curie Delivering Choice Programme in Lincolnshire (paragraph 3.22)

Services put in place

Rapid Response Team – A community based nursing team providing services to palliative care patients and professionals during the twilight (3.00pm to 10.30pm) and out of hours (10.00pm to 7.00am) periods.

Discharge Community Link Nurses – Two nurses whose dedicated role is to facilitate hospital discharge; provide advice and support to patients; provide a communication link between primary and secondary care providers; and, when necessary, accompany and settle patients at home.

Palliative Care Coordination Centre – An administrative centre that coordinates the booking of health and social home care for palliative patients. It is also envisaged that the centre will provide information to patients and carers and act as a central point of communication for education services.

Education – An education and training workstream has been developed to increase awareness and access to recommended palliative and end of life care education.

Support for patients and carers – Emotional support and respite is provided for carers away from the patient's home through monthly luncheon club meetings. The meetings are facilitated by nursing staff, and volunteers provide transport for carers and care for the patient while they attend the meeting. Training is also provided to carers in their home environment.

Findings of the King's Fund and University of Lancaster evaluations:

The Programme was associated with an increase in the proportion of deaths at home and a corresponding decrease in deaths in hospital. The home death rate in Lincolnshire increased from 19 per cent to 23 per cent. Forty two per cent of patients who accessed the services as part of the Programme died at home, whilst for patients not accessing the services, home deaths remained at 19 per cent. Patients and clinicians perceived the Programme to have made a difference in the availability of 24 hour care in the community and improved services for people approaching the end of their life.

The Kings Fund evaluation shows that there was a statistically significant reduction in the average number of admissions to hospital per patient in the last eight weeks of life for cancer patients using the Programme in comparison to patients who did not access the Programme, or patients who died prior to the start of the Programme. This decrease in number of admissions is accompanied, however, by a slight increase in the average length of stay per admission for patients who accessed the Programme. This decrease in admissions and increase in length of stay means that the overall number of days spent in hospital and, therefore, the cost of delivering care, are not significantly different between patients who accessed the Programme's services and those who did not.

It should be noted, however, that the results are more complex when the impact of individual services are examined. For cancer patients who only accessed the Rapid Response Team there was a significantly greater reduction in admissions and length of stay than for the Programme overall, whilst those with complex needs who used only the Discharge Community Link Nurse service had a significantly greater total length of stay.

All conclusions about the Programme are, however, limited by the absence of a control group to allow comparisons adjusted for case-mix and severity of need.

Source: Marie Curie Cancer Care and reviews by Lancaster University and the King's Fund

GLOSSARY

Advance care plan	Advance care planning (ACP) is a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.
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.
Carer's Assessment	An assessment, carried out by a social worker or a member of social services, which enables an unpaid carer to discuss with social services the help they need to care, to maintain their own health and to balance caring with their life, work and family commitments. Social services use the assessment to decide what help to provide and cannot refuse to meet an identified need solely on the basis of funding. They may, however, set eligibility thresholds according to the availability of resources.
Care plan	An agreed set of actions reflecting the choices made by a person about their care following an assessment of their needs. In the case of people approaching the end of their life, this may set out how they wish to be cared for and where they would wish to die.
Chronic Obstructive Pulmonary Disease (COPD)	A collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease, all of which can occur together. COPD is one of the most common respiratory diseases in the UK, and most commonly affects people over the age of 40.
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.

Dementia	A range of progressive, terminal organic brain diseases. Symptoms include decline in memory, reasoning and communication skills, and ability to carry out daily activities, and loss of control of basic bodily functions caused by structural and chemical changes in the brain. Late stage symptoms include increasing frailty, with people confined to bed or a wheelchair; inability to recognise familiar objects, surroundings or people; difficulty eating and swallowing; weight loss; incontinence; and loss of speech.
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.
Do Not Attempt Resuscitation (DNAR)	A written order from a doctor that resuscitation should not be attempted in the event of a person suffering cardiac or respiratory arrest. Such an order may be considered appropriate in cases where successful restoration of the circulation is likely to be followed by a quality of life that would be unacceptable to the patient, or when cardiac or respiratory arrest is the end result of a disease process in which appropriate treatment options have been exhausted.
Emergency admission	When a patient goes into hospital at short notice, also known as urgent admission and unplanned care.
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.
Full cost recovery	In the context of HM Treasury's Cross Cutting Review on <i>the Role of the Voluntary and Community Sector in Service Delivery (2002)</i> , 'full cost recovery' refers to relevant overhead costs. The Review recommended that funders should recognise that it is legitimate for voluntary sector providers to include overheads in their cost estimates for providing a given service under a contract or service agreement. In the context of hospice care, this does not mean the full costs of the hospice, but rather those services provided by the hospice that are commissioned by the PCT.

Heart failure	Heart failure is a complex condition that can result from any structural or functional cardiac disorder that impairs the ability of the heart to pump blood around the body.
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 unless specifically stated otherwise.
Local authority	National policy is set by central government, but local councils are responsible for day-to-day services and local matters. This includes the provision of social support and long term nursing and care for individuals who can no longer live unsupported in their own homes. Local authorities are funded by government grants, Council Tax and business rates.
Macmillan nurse	Macmillan nurses provide information, advice and support to people with cancer, and their families, friends, and carers. There are currently around 3,000 Macmillan nurses, most of whom work within the NHS. People may be referred to a Macmillan nurse by their GP, district nurse, or consultant.
Marie Curie nurse	There are currently more than 2,000 Marie Curie nurses providing nursing care to cancer patients and those with other terminal illnesses in their own homes. People may be referred to a Marie Curie nurse by their GP or district nurse.
Motor Neurone Disease (MND)	A neurodegenerative disease which leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. On average, 50 per cent of people die within 14 months of diagnosis and 90 per cent within five years.
National Institute for Health and Clinical Excellence (NICE)	An independent organisation covering England and Wales, responsible for providing guidance on the promotion of good health. NICE provides objective guidance on the clinical and cost effectiveness of drugs and treatments.
Needs assessment	Needs assessments are carried out by local authorities to establish the needs of an individual who requires help from local social care services and to arrange services to meet their needs. Local authorities may set eligibility thresholds on the services they provide according to the availability of resources.

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.
Payment by Results (PbR)	The aim of Payment by Results (PbR) is to link income to work actually performed and, by so doing, reward efficiency and encourage innovation. It is based on a prospective payment system where the price for a given unit of activity is set in advance, and income is based on multiplying the relevant price by the amount of activity actually delivered. The key components of PbR are the Healthcare Resource Group (HRG) and the tariff or price. The HRG is based on an 'episode' of care which is a defined package of treatments, alongside a typical hospital stay, for a particular condition.
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.
Quality and Outcomes Framework (QOF)	A component of GPs' contracts, the QOF sets targets for GPs against evidence-based criteria covering a range of general and condition-specific indicators. Payments to practices are calculated on the basis of the extent to which these targets are met.
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.
Skills for Care	The strategic body for workforce development for adult social care workforces in England, led by care employer networks and other sector interests. It is the adult social care for England part of the UK-wide Sector Skills Council, Skills for Care and Development.

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).
Social Care Institute for Excellence	An organisation that aims to improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector.
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.
Strategic Health Authorities	The body responsible for the supervision of the NHS Trusts within its boundaries to ensure that local services are commissioned and run effectively and efficiently.