IMPLEMENTING THE END OF LIFE CARE STRATEGY

Lessons for good practice

Rachael Addicott
Shilpa Ross

The King's Fund

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About the authors

Rachael Addicott is a Senior Research Fellow in The King's Fund's policy directorate. Rachael has an interest in organisational change and models of governance and accountability in the health sector, and works on a number of projects in these areas, including work on foundation trusts, employee ownership and networks. She also leads on end-of-life care research for The King's Fund.

Rachael was previously a lecturer in health service management at Royal Holloway University of London. Rachael has a PhD in health service research from Imperial College London, focused on modes of accountability in networked organisations.
Rachael is originally from Australia, where she worked in various research positions for the Department of Health and in the acute sector.

Shilpa Ross (nee Patel) joined The King's Fund in 2009 as a Researcher in policy. She is currently working on the inquiry into the quality of general practice in the management of long-term conditions, as well as projects focused on the delivery of end-of-life care.

Shilpa previously worked as a qualitative social researcher at various universities and charities. Her research focused on substance misuse; substance misuse treatment; offender rehabilitation and service development.

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Summary

The publication in 2008 of the (then) government's *End of Life Care Strategy* (Department of Health 2008a) radically raised the profile of end-of-life care in England and signalled the need for development of its planning and delivery so as to ensure that individuals would have a genuine choice about where they were cared for and died.

The ageing population and what we know about patient preferences together suggest a need for considerable investment in the way that end-of-life care is organised and delivered at a local level. The current financial pressures and reform of the health service should not be allowed to distract from the innovation and improvement in the quality of end-of-life care that is needed. Indeed, such changes could promote efficiency savings.

This paper uses evidence from The King's Fund evaluation of the Marie Curie Delivering Choice Programme to highlight examples of good practice and learning for the organisation and delivery of end-of-life care across England.

The Marie Curie Delivering Choice Programme aims to improve the quality of end-of-life care and to work with other service providers to ensure the establishment of a comprehensive approach that is better able to fulfil individual patients' preferences for care as they near the end of their lives.

The King's Fund has been working closely with three programme projects in different areas of England to understand aspects of current practice that facilitate or prevent the effective provision of end-of-life care.

This paper, which is aimed at those responsible for commissioning and organising end-of-life care services at a local level, draws on this knowledge to provide some guidance about the delivery options and ongoing challenges in the organisation of end-of-life care. Many of the lessons that are presented in this paper will be of direct practical relevance to service providers and commissioners, as well as providing a valuable resource for those involved in the quality, innovation, productivity and prevention (QIPP) agenda.

The End of Life Care Strategy (Department of Health 2008a) outlined a six-step end-of-life care pathway and identified the services and support that patients should be able to access during the course of their illness, from the identification of their palliative and supportive care needs through to care after their death:

- discussions as the end of life approaches
- assessment, care planning and review
- co-ordination of individual patient care
- delivery of high-quality services in different settings
- care in the last days of life
- care after death.

These steps are underpinned by information and support for carers and relatives, and this paper also consider considers lessons for good practice in this area.

We have used the end-of-life care pathway to organise the findings presented in this paper, focusing on the following broad themes.

Identification of end-of-life care needs

Inadequate identification of patients' needs can prevent open communication with them and their carers when planning end-of-life care. In addition, some health care professionals appear to be reluctant to discuss end-of-life care issues with patients or their carers. These issues are a particular barrier for patients with non-malignant disease (for reasons that are explained below), and can affect access to end-of-life care services. It is important that service providers consider the timing of discussions about prognosis and end-of-life care preferences.

The research highlighted a number of points at which professionals were able to broach the subject of end-of-life care. All health and social care staff should learn these opportunities for dialogue as part of their training in end-of-life care. Examples include:

- a significant change in the patient's life, such as moving into a care home or sheltered accommodation
- a significant decline in the patient's health, even if he or she subsequently stabilises, which can be the case for patients with non-malignant disease in particular
- once trust has been established in a new therapeutic relationship, such as with a district nurse or social worker.

Training, multidisciplinary co-ordination of care, and interprofessional access to palliative care records could help to overcome some of these issues.

Encouraging greater communication about prognosis and care planning

The shift to providing more end-of-life care in the community setting requires health and social care professionals to work in a different way. Ward staff, in particular, require support to ensure that patients are appropriately discharged to their preferred place of care. This may require professionals to develop their skills in and knowledge of discharge processes, particularly in relation to funding criteria and processes. There is also a need for ward and community staff to understand the pressures and priorities that are faced by their colleagues in different health care settings, to develop a whole-systems view of service provision.

Specialist palliative care staff can work with general health care personnel to alleviate anxieties about initiating conversations about prognosis and care planning and to increase the confidence and competence of all providers.

Discharge arrangements designed specifically for patients who are nearing the end of their lives can be an effective mechanism for supporting ward staff in assessing the more complex cases and planning the delivery of end-of-life care in patients' preferred location.

Co-ordination of care

Advance care planning with patients and carers (and communication of those plans with all the different providers involved) is an essential aspect of the end-of-life care process, as well as being an effective mechanism for ensuring patients' care preferences are achieved.

The success of advance care planning depends on how well it is communicated, both between patients and carers and with health and social care professionals across organisations. An integrated approach to co-ordination of care requires a clear and transparent communications strategy (and ideally an information system) so that all the relevant providers are able to access the information about patients' preferences. Staff must be trained to oversee advance care planning as a continuous process and not as a one-off event.

Whole-systems approach

End-of-life care is provided in a variety of organisational settings by a range of health and social care professionals. Service improvement must therefore be addressed by a whole-systems approach, in which attention is given to the entire pathway of care to ensure that high-quality care is achieved irrespective of the location.

This research highlights many examples of the effective management of patients with end-of-life care needs that cross organisational settings. A whole-systems approach to end-of-life care benefits from the availability of a range of services across the care pathway, such as facilitation of discharge from the acute setting, rapid response services during periods out of hospital, and centralised co-ordination of care provision in the community.

The models considered in this research take a whole-systems approach to service redesign, combining expedition of discharge from the acute setting with increased and/or reconfigured provision of community services. The combined impact of a range of services on the organisation and delivery of end-of-life care is greater than that of any single service.

Finally, training, information and communication – not only for health and social care professionals but also for patients and their carers – are fundamental to the effective implementation of care. It is important for patients and their carers to have information about the options available for end-of-life care, as well as an awareness of the processes and outcomes.

In the current financial climate, there is a risk that providers and commissioners will cease to focus on redesigning services, but the two should not be seen as mutually exclusive: with an ageing population, the need to reform current patterns of care, such as unnecessary hospital admissions at the end of life, is even greater, both improving the quality of the end-of-life care offered and ensuring the best use of financial resources.

Below, we summarise examples of, and our recommendations for, ways in which commissioners and providers of end-of-life care can together address these challenges effectively within the framework of the end-of-life care pathway.

Summary of key lessons for practice

Discussions as the end of life approaches

- There is the potential for inequality in access to end-of-life care, depending on both the patient's diagnosis and the process of identifying needs used.
- These issues could be overcome by a combination of:
  - training and improvement in the definition of prognoses
  - multidisciplinary co-ordination of care
  - interprofessional access to palliative care records.

- However, this potential is exacerbated by an apparent reluctance among some health care professionals to discuss issues relating to death and dying.
- Specialist and general health care providers should work together to ensure that responsibility for alleviating some of the anxieties about initiating these conversations is shared, and to ensure that all providers are confident and competent in responding to questions from patients and carers.

Assessment, care planning and review

- Discharge arrangements designed specifically for patients who are nearing the end of their lives can be an effective mechanism for supporting ward staff in assessing the more complex cases and planning the delivery of end-of-life care in patients' preferred location.
- The development of models of discharge facilitation should take account of, and adapt to, factors within the local health economy to ensure that they work with rather than against existing processes and pressures on other end-of-life care providers. There is no one-size-fits-all approach to design and implementation.
- Advance care planning (and communication of plans between and among health and social care teams) can help to ensure patients' wishes are respected and accommodated. As an individual's wishes about end-of-life care may change as the disease process progresses, it is important to update the advance care plan regularly on the basis of ongoing discussions.

Co-ordination of individual patient care

- Dedicated models of co-ordination can be effective in freeing up district nurses and other community-based health providers, as well as allowing greater oversight with regard to the prioritisation of resources.
- Such co-ordination models could consider widening their remit to include other functions, such as the booking of equipment and the co-ordination of, or advice on, care home placement.

Delivery of high-quality services in different settings

- End-of-life care tools such as the Gold Standards Framework and the Liverpool Care Pathway are important mechanisms for ensuring high-quality, transparent provision of care that is more effectively able to accommodate patient preferences.
- A whole-systems approach to service improvement is necessary, combining expedition of discharge from the acute setting with increased and/or reconfigured provision of community services to cover patients 24 hours a day seven days a week.
- Training and education are necessary to ensure the provision of high-quality end-of-life care in different settings. Areas specifically identified by our research include:
  - identification of patients' needs
  - communication skills
  - the physical management of patients nearing the end of their lives.

Care in the last days of life

- Once a patient has been identified as nearing the end of his or her life, advance care plans should be reviewed continually to confirm that all of the resources are in place to provide the preferred end-of-life care services in the preferred location.
- Particular consideration should also be given to the needs of carers for information and support, to be included in major decisions, and to participate in the physical care and emotional support of the person who is dying.
- In the last days of life it is considered important for patients to be:
  - treated as individuals, with dignity and respect
  - without pain and other symptoms
  - in familiar surroundings
  - in the company of close family and/or friends.

Care after death

- Health and social care professionals should be aware of the procedures to follow after the death of a patient to show respect to the deceased and his or her carers.
- Bereaved carers should have access to good-quality information about the practical steps they need to consider and how to access emotional support if they need it.

Information for carers and relatives

- Carers should be seen as key stakeholders involved in the decision-making and planning around end-of-life care needs.
- Advance care planning and inclusive communication is a valuable process to make care preferences transparent and to ascertain gaps in carers' ability to deliver care themselves, including their own health care needs (and issues of bereavement).
- Health care professionals should be honest and transparent with patients and carers about the services and support that are available in the community to ensure that they have a realistic understanding and expectations.

1 Introduction and policy background

The number of deaths each year in the United Kingdom is expected to rise by 17 per cent between 2012 and 2030. In addition, the average age at death is predicted to increase, and those dying are likely to have increasingly complex co-morbidities (Gomes and Higginson 2008). These projections indicate that the commissioning and delivery of high-quality, equitable end-of-life care is likely to pose a considerable challenge in the future.

The organisation and delivery of end-of-life care has historically suffered from underinvestment. Furthermore, death and dying are seen as 'the last taboos', and the reluctance to talk about these issues increases the likelihood of patient preferences not being discussed or met.

The issue of preferences has been the main driver for the development of an end-of-life care policy, both locally and nationally. Research suggests that two-thirds of people would prefer to die at home, while in reality only about one-third of individuals actually do (Higginson 2003).

As a result of this gap, policy directives and research have sought to ensure that palliative and end-of-life care services are appropriately configured and delivered to allow a greater number of people to be cared for in the place of their choice. To this end, there have been many attempts to identify gaps in existing service provision and to make recommendations on how services should be developed so as to meet people's preferences more successfully.

The publication of the *End of Life Care Strategy* (Department of Health 2008a) radically raised the profile of end-of-life care in England, signalling the need for development of its planning and delivery to ensure that individuals would have a genuine choice about where they were cared for and died. The strategy is built on a range of existing evidence in the field, including prior policy documents and national standards.

In 2003, the Labour government published the strategy paper *Building on the Best: Choice, responsiveness and equity in the NHS* (Department of Health 2003). Setting out the government's ambition to increase patient choice, the paper established the objectives of:

- developing more responsive services
- offering patients real choices
- ensuring optimum use of provider services, which the government felt would flow naturally from patients having real choices.

The paper outlined six priority areas for increased patient choice, one of which was end-of-life care.

The White Paper *Our Health, Our Care, Our Say* (Department of Health 2006) furthered the commitment to choice in end-of-life care, including a pledge to double funding, establish networks to improve service co-ordination, and implement national roll-out of end-of-life care tools such as the Gold Standards Framework and the Liverpool Care Pathway (*see* box overleaf). More broadly, *Our Health, Our Care, Our Say* was significant in signalling a government commitment to moving from an acute to a community model of health care, with delivery of services closer to people's homes.

Developments in end-of-life care policy such as establishing community services that enable people to exercise genuine choice in end-of-life care and ensuring that people who want to be cared for at home can access suitable support for this, are in line with this agenda.

The Gold Standards Framework

The Gold Standards Framework is a systematic, evidence-based approach to optimising the care of patients nearing the end of their lives that is delivered by generalist providers. It is concerned with helping people to live well until the end of their lives, and includes care in the final year of life for people with any end-stage illness.

The framework is intended to help clinicians to:

- identify patients in the final years of life
- assess the needs, symptoms and preferences of those patients
- plan care on that basis, enabling patients to live and die where they choose.

The Gold Standards Framework embodies an approach that centres on the needs of patients and their families, and that encourages interprofessional teams to work together.

www.goldstandardsframework.nhs.uk

Liverpool Care Pathway

The Liverpool Care Pathway is an integrated pathway of the care that a patient can expect in the final days and hours of life, guiding health care professionals in continuing medical treatment, discontinuing treatment, and initiating comfort measures during that period.

The pathway is organised into sections that allow for continuous and consistent evaluation and care. It is used in hospitals, hospices, care homes, and patients' own homes as well as in other community settings.

www.liv.ac.uk/mcpcil/liverpool-care-pathway

Marie Curie Cancer Care has been instrumental in raising the profile of patient choice in end-of-life care with its Delivering Choice Programme. Launched in 2004, the programme aims to improve service planning and co-ordination and ensure that comprehensive services are in place so that more patients are able to choose how and where they are cared for at the end of their lives. The programme has, in turn, influenced and shaped the wider development of end-of-life care policy and strategy.

Because people's preferences for where they are cared for and die are not systematically captured or routinely reviewed as their illness progresses and their needs change, it is not possible to get a clear picture of how many people would prefer to die somewhere other than their actual place of death. Marie Curie Cancer Care believes, however, that many patients are not able to die where and how they wish, because of either a lack of choice, or an inability to exercise that choice.

Marie Curie Cancer Care suggests that this lack of choice is frequently due to inadequate service design, poor co-ordination of care at a local level, lack of communication between health care professionals, and inadequate support for carers. The fundamental premise of the Delivering Choice Programme is that via a partnership between the National Health Service (NHS), the voluntary sector, social services and other health care providers, it would be possible to develop patient-focused 24-hour service models that cater for local needs and ensure that all patients are able to choose where they are cared for and die.

The programme aims to ensure:

- the best possible care for patients at the end of their lives
- improvements in equity of access to services
- appropriate support services for patients receiving end-of-life care and their carers
- provision of information on choice to all patients receiving end-of-life care
- improvements in co-ordination of care among stakeholders.

The aim of the End of Life Care Strategy (Department of Health 2008a) was to provide a step-change in access to high-quality care for all people approaching the end of life, irrespective of age, gender, ethnicity, religious belief, sexual orientation, diagnosis or socio-economic deprivation. The strategy calls for the provision of high-quality care in all care settings, to ensure that patients can exercise a meaningful choice about where they are cared for and where they die. Building on existing research and evidence of good practice in end-of-life care (including Marie Curie Cancer Care's programme), the strategy adopts a whole-systems approach by outlining an end-of-life care pathway, which is intended to guide both the commissioning and delivery of end-of-life care.

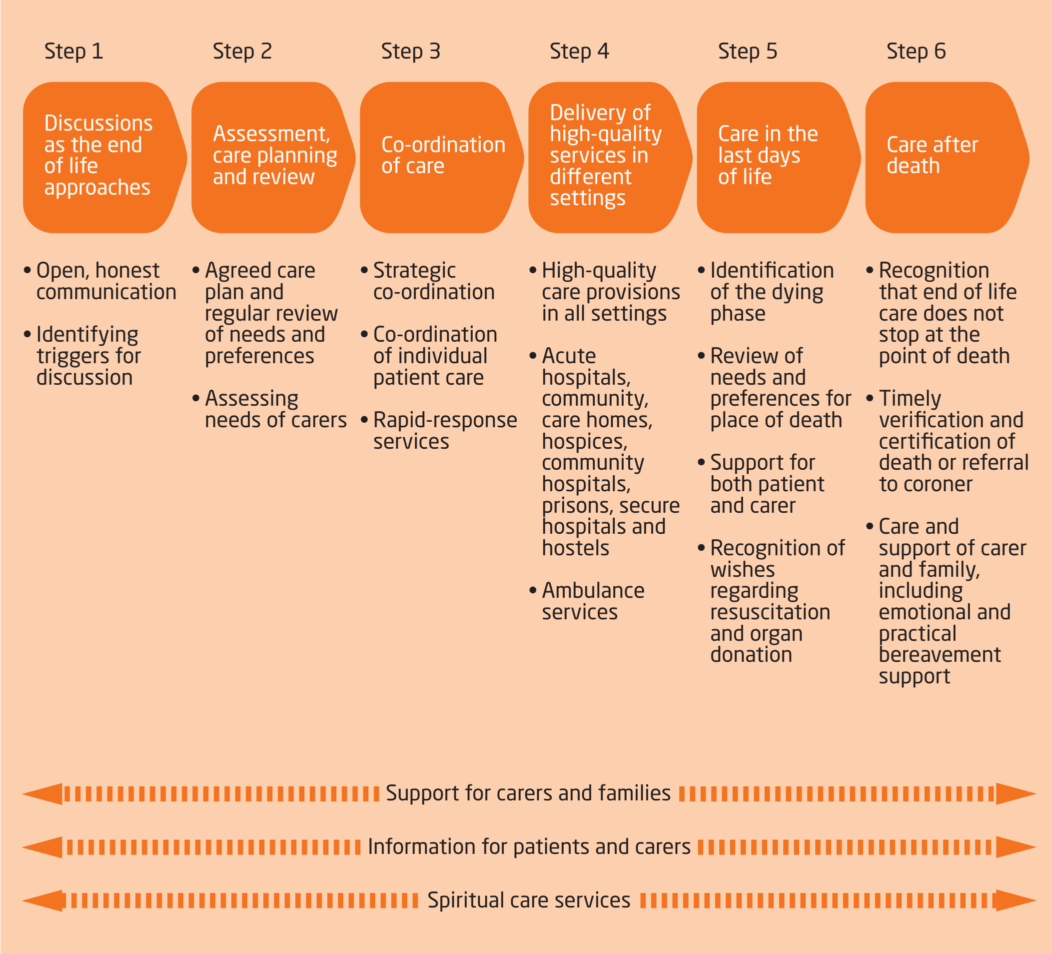
The pathway outlines six steps, identifying the services and support that patients should be able to access during the course of their illness, from the identification of their palliative and supportive care needs through to care after their death. These steps are underpinned by support for carers both during the illness and after death, information for patients and carers, and access to spiritual care (*see* Figure 1 overleaf).

The impact of cultural barriers in end-of-life care is acknowledged in the Department of Health's strategy. Death and dying tend not to be discussed openly in the United Kingdom, and this can make it difficult for health and social care professionals to initiate discussions with patients about end-of-life care. Furthermore, in some instances death may be perceived as a failure. The strategy notes that this cultural barrier prohibits effective care planning and, as a consequence, the potential for people to exercise choice as they approach the end of their lives.

The strategy is reasonably specific about the services and mechanisms that need to be in place to support people at each stage of the pathway. These include, for example, development of an agreed care plan subject to regular review, availability of rapid-response services, and use of the Liverpool Care Pathway (or equivalent) to guide the provision of care in the last days of life.

In addition, the strategy recommends significant workforce developments to enable and support professionals in delivering the improvements necessary, particularly in identifying and discussing end-of-life care needs and preferences with patients. Emphasis is given to generalist staff, for whom end-of-life care is only a small aspect of their work. Co-ordination is also a key theme of the strategy, both at a service level and also in ensuring strategic co-ordination across organisational boundaries.

Figure 1 The end-of-life care pathway



Step 1

Discussions as the end of life approaches

- Open, honest communication
- Identifying triggers for discussion

Step 2

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3

Co-ordination of care

- Strategic co-ordination
- Co-ordination of individual patient care
- Rapid-response services

Step 4

Delivery of high-quality services in different settings

- High-quality care provisions in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5

Care in the last days of life

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6

Care after death

- Recognition that end of life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services

Source: Department of Health (2008a)

The strategy recognises the inequalities that exist in access to end-of-life care, notably for patients with a non-malignant diagnosis, but does not make explicit reference to how the specific needs of these patient groups might be better met.

A series of quality markers has been produced to support implementation of the strategy (Department of Health 2008b). Consistent with the strategy's pathway approach, the markers set out what is necessary for the delivery of high-quality end-of-life care by outlining the structures and processes that are most likely to yield good outcomes for people approaching the end of their lives, as well as for their families and carers. They are designed to guide commissioners, providers and managers in developing end-of-life care services in their locality.

As a result of the recent political and policy changes – the formation of the coalition government, the recently published White Paper *Equity and Excellence: Liberating the NHS* (Department of Health 2010a), the proposed development of GP consortia, and the NHS Outcomes Framework (Department of Health 2010b) – the form and function of end-of-life care delivery and commissioning may look different in the future. However, it is intended that the quality markers (and proposed outcomes framework) will enable commissioners to align the priorities of the strategy with the world class commissioning vision (Department of Health 2007), and should inform both the commissioning decisions made and the means by which service delivery might best be monitored and evaluated.

Quality markers are included for each step of the care pathway and the full spectrum of providers involved in delivering end-of-life care, indicating what commissioners need to ensure is available locally for patients and carers, and suggesting the processes and mechanisms they should have in place in order to deliver improvements in this care (Department of Health 2008b). These include:

- mechanisms for identifying patients approaching the end of their lives
- systems for recording individuals' needs and preferences
- training for staff who are involved in discussing end-of-life issues.

Measures are assigned to the majority of quality markers. The measures included are focused predominantly on output rather than outcome, and are essentially quantitative in nature.

This paper draws on evidence from The King's Fund work with the Marie Curie Delivering Choice Programme between 2007 and 2010, and highlights examples of good practice and learning for the wider organisation and delivery of end-of-life care across England.

The King's Fund has been working closely with three programme projects in different areas of England (Lincolnshire, Leeds and Somerset) to understand aspects of current practice that facilitate or prevent the effective provision of end-of-life care. This paper, which is aimed at those responsible for commissioning and organising end-of-life care services at a local level, draws on this knowledge to provide some guidance about the delivery options and ongoing challenges in the organisation of end-of-life care.

Delivering Choice Programme

The operation of each of the three programme projects that participated in this research was divided into three phases over a three-year period.

- **Phase one** During the investigatory phase, the project team sought to understand the extant state of services by gathering evidence and information on barriers to provision of care and choice for patients receiving end-of-life care. This evidence was then used to identify areas for improvement.
- **Phase two** Working closely with local stakeholders (such as the NHS, voluntary sector and social service providers and commissioners), the project team redesigned services based on the areas for improvement identified during phase one.
- **Phase three** This phase involved implementing the redesigned service models, performance-monitoring and evaluation of outcomes.

Initial projects usually operated for three years, with phases one and two being completed in the first year, and phase three taking place over two years. (Marie Curie Cancer Care is now developing new methodologies for the programme, including an electronic toolkit, and new approaches to engaging commissioners in the planning of the projects.)

In each project area, end-of-life care was provided by a variety of organisations and professional groups that formed a very complex system. The service redesign undertaken as part of the programme focused on co-ordinating the provision of end-of-life care across an entire region and developing a range of interrelated services to tackle identified gaps in service delivery. By following patient journeys through the provider organisations, the service redesign team identified barriers to providing choice and high-quality end-of-life care, as well as opportunities to make improvements.

Research objectives

The King's Fund has been working with the project sites on a formative evaluation, to identify examples of good practice and to disseminate them across programme project areas. This paper is more of a summative analysis, considering the overall findings and focusing on distributing to a wider audience the examples of good practice identified, linking them to the steps of the end-of-life care pathway outlined in the End of Life Care Strategy (Department of Health 2008a).

This research sought to identify aspects of end-of-life care in the three programme project areas that were not performing effectively or were failing to reach their expected potential, as well as areas where examples of good practice or successful service development or delivery were evident. This paper draws particularly on the examples of good practice.

The research utilised a number of methodological approaches, including:

- analysis of existing research findings
- consultation with staff from Marie Curie Cancer Care
- documentary analysis
- observation of key meetings and intervention areas
- interviews with programme staff and with NHS and other service providers.

Data from all of these sources were analysed and triangulated to provide an overview of the project context, key challenges and examples of good practice. (*See* Appendix for a detailed overview of the methodology used.)

Section 2 gives an overview of the context of each of the three project sites involved in the research, and Section 3 discusses the research findings.

2 Overview of the Delivering Choice Programme projects

Lincolnshire Delivering Choice Programme

The programme in Lincolnshire was launched in October 2004 and had five work streams operational between June 2006 and March 2008. The Lincolnshire region has one acute trust, the United Lincolnshire Hospital Trust, which was formed in 2000 from a merger of three acute hospitals – Boston Pilgrim Hospital, Grantham and District Hospital, and Lincoln County Hospital. The trust continues to provide services from these three sites, as well as from community hospitals based in Louth, Spalding and Skegness. At the time of data collection, there was no palliative care consultant in Lincolnshire. The majority of end-of-life care in the area was provided by specialist nurses together with generalist health and social care professionals.

Before the Delivering Choice Programme began, some progress had already been made in improving end-of-life care in Lincolnshire's hospitals with the establishment of several local initiatives. For example:

- some areas of Lincolnshire had introduced a 'Green Card' system, which identified patients at the end of their lives and prioritised them in the out-of-hours system
- a multidisciplinary team was set up in Lincoln County Hospital to co-ordinate the discharge of patients at the end of their lives
- the Liverpool Care Pathway was introduced on several wards in the United Lincolnshire Hospital Trust as a tool for managing patients nearing the end of their lives in the acute setting.

The Delivering Choice Programme introduced a number of schemes to build on this progress (*see* box below).

Lincolnshire Delivering Choice Programme initiatives

Palliative care rapid-response team
The community-based rapid-response team covered Boston, South Holland and surrounding areas and made emergency and planned visits to patients in their homes during twilight and out-of-hours periods. The team's nurses and health care assistants also provided psychological support and guidance to patients and their carers over the telephone.

Palliative care co-ordination centre
This administrative centre was established to co-ordinate the booking of health and social home care for patients with palliative care needs.

Discharge community link nurse initiative
The discharge community liaison nurses provided a communication link between the hospital and the providers of care in the community in order to accelerate the discharge of patients at the end of their lives.

They co-ordinated packages of home care, provided support and advice to patients and their carers, communicated patient needs to community health care teams and, if necessary, accompanied patients home and helped them to get settled.

There were initially two discharge community liaison nurses in operation, one based at Lincoln County Hospital and one at Boston Pilgrim Hospital.

Education and training
This initiative aimed to ensure that people working in end-of-life care were able to access the education and training that they needed to be able to deliver appropriate, high-quality care.

A skills and training co-ordinator was appointed to develop and deliver a training plan together with the Lincolnshire Education and Training Forum. A new programme of training and education was implemented to combine existing courses with new initiatives, and involved the use of community-based video conferencing facilities to allow easier access to training and education in end-of-life care, by reducing travel time and improving frequency of delivery.

Support for patients and carers
The Lincolnshire project's 'support for carers' work stream was designed to provide practical and emotional support for carers, who play a vital role in a patient's choice to die at home. The primary aim of this work stream was to increase carers' confidence and help to decrease their feelings of fear and isolation.

The work stream also aimed to empower carers to deal with the different situations that can arise when caring for someone with a terminal illness, and to prevent instances where the patient might be inappropriately admitted to hospital.

The programme in Lincolnshire was built on a history of service developments and partnership working between the various organisations involved in the planning and provision of end-of-life care. Although partner agencies were already discussing how to improve services, Marie Curie Cancer Care's presence provided a focus for those discussions, facilitating and co-ordinating them. For this reason, there was reasonable confidence about the potential sustainability of the services.

The Lincolnshire programme formally came to an end in March 2008, although the cost of providing several of the work streams was subsequently taken up by Lincolnshire Primary Care Trust (PCT).

Leeds Delivering Choice Programme

The programme in Leeds started in May 2006. As a result of recruiting difficulties, the work streams were established at different points throughout 2007 and 2008. Some work streams were completed in March 2009 and others in September 2009.

The introduction of the programme in Leeds was built on a solid base of local partnership working and enthusiasm in the delivery of end-of-life care. Pre-existing developments (particularly the use of the Liverpool Care Pathway in the acute setting and the Gold Standards Framework in the community) ensured that local stakeholders had a reasonable awareness of patients' needs in relation to end-of-life care across the region, and of their roles and responsibilities in identifying and meeting those needs.

There were existing links between the specialist palliative care team based at Leeds Teaching Hospitals Trust and hospital wards and also with specialist teams based in the community. Similarly, there had been close working relationships between local hospices and other community providers. The programme built on these developments (*see* box below).

Leeds Delivering Choice Programme initiatives

Palliative care discharge facilitator
The palliative care discharge facilitator worked across acute trusts and the community to support the discharge from hospital to their preferred place of care of patients who were approaching the end of their lives.

Palliative care ambulance
Operated by the Yorkshire Ambulance Service, the dedicated palliative care ambulance provided a responsive service to transport patients approaching the end of life to their preferred place of care. The ambulance also transported patients to urgent admissions and appointments.

'Meet and greet' scheme
Patients and carers who needed support during the first 24 hours after discharge from hospital were referred to the 'meet and greet' scheme, which provided a Marie Curie Cancer Care nurse or health care assistant to meet the patient on discharge and provide up to 24 hours of care in order to ease the transition from hospital to home.

Complex and palliative continuing care service
This team consisted of health and personal care assistants, whose purpose was to support district nursing teams with their patient caseload. They were trained to provide patients with health care as well as to help with personal and social care, such as cleaning, cooking and other household tasks. The service provided an integrated health and social care response, thus aiming to minimise the problems that can arise when seeking to offer integrated and co-ordinated care.

Care homes end-of-life supportive services
Facilitators were established to support care home staff in providing palliative care to their residents through training workshops and better links to local community services.

South Leeds specialist day care
This facility was provided in Middleton, south Leeds, as a joint partnership initiative between the Sue Ryder Care – Wheatfields Hospice and St Gemma's Hospice. The centre aimed to provide a range of hospice services – including health care, physiotherapy and complementary therapies – closer to the homes of people living in the south Leeds area.

Black and minority ethnic palliative care link worker
A black and minority ethnic palliative care link worker was established to improve access to palliative care for communities from various ethnic and religious backgrounds in Leeds.

Palliative care co-ordinator for patients and carers
A co-ordinator was appointed to map out the support services available in Leeds and to work with patients, families and carers to identify what support services they would like to see available.

Education and training programme
An education co-ordinator was appointed, along with dedicated administrative support. This work stream had several functions and aims, including:

- supporting existing training programmes for health care and social care professionals
- developing tools that could be used to measure the impact of training
- developing new ways of delivering training
- developing a new website about palliative care in Leeds.

Leeds had recently undergone substantial strategic and operational development in end-of-life care services, and, alongside the developments made through the programme, the area experienced considerable further transformation during the period of data collection because of a number of factors:

- development of a local district nursing framework, giving guidance on the amount and nature of care that district nurses should be providing to patients with palliative care needs in Leeds
- publication of *High Quality Care for All: NHS next stage review final report* (Darzi 2008)
- as part of the above, the development of an end-of-life care pathway for Yorkshire and Humberside, as outlined in the strategy document *Healthy Ambitions* (NHS Yorkshire and the Humber 2008)
- publication of the national *End of Life Care Strategy* (Department of Health 2008a).

This shift in strategic emphasis was not so evident during the period of data collection in Lincolnshire, and might motivate improvements in strategic level involvement in the organisation and delivery of end-of-life care, encouraging executive-level stakeholders to take a greater role in the operation of care.

These developments in national policy and strategic-level involvement are likely to affect the long-term sustainability of the programme's initiatives.

Somerset Delivering Choice Programme

The Somerset project began in July 2008, and, at the time of writing, is in its third phase of implementation and evaluation. It is due for completion in March 2011.

This project covers both Somerset and North Somerset local authority areas, which have different histories of end-of-life care provision. It also currently covers two PCT regions, encompassing three acute trusts – Taunton and Somerset, Yeovil District Hospital and Weston Area Health. Each acute trust has a palliative care team, including palliative care consultant sessions.

The Lincolnshire and Leeds projects were part of the first wave of programme initiatives, and received significant investment to deliver new services and appoint new posts to fill gaps in current provision. The Somerset project, however, represented a different approach to service redesign, in which innovation was attempted within the restrictions of the extant budget and resources, rather than by investing in new services or posts.

This approach was intended not only to be more cost-effective and efficient but also to represent a potentially more sustainable approach to service redesign, limiting the risks to continuity at the end of the formal project period, when additional funding from the PCTs would typically have been sought.

The PCTs have been fully engaged in decision-making about the redesign of services during the project period, and fully responsible for the funding of local end-of-life care services. The work streams are therefore focused on service improvement, and not new stand-alone initiatives (*see* box below).

Somerset Delivering Choice Programme initiatives

Excellent patient and carer support
This work stream established a working group to consider how to provide:

- the right information available at the right time
- access to advice and support at all times
- respite care for carers
- education and skills for carers.

The right information, whenever and wherever it is needed
The timely sharing of adequate information about patients at the end of their lives, their social circumstances and care plans is vital to ensure co-ordinated care and reduce duplication in roles and processes.

Delivering seamless, co-ordinated care
Linked closely with information sharing, this work stream is focusing on the provision of seamless patient care at the point of delivery and a reduction in unnecessary duplication of roles and processes for health and social care professionals.

24-hour care, whenever and wherever it is needed
This work stream is building on existing good practice and looking at new service models that will provide high-quality, responsive and multidisciplinary community services to patients and carers at any time of the day.

Excellent palliative care delivered in care homes
This work stream is building on existing work around the implementation of end-of-life tools and supporting care homes to deliver outstanding care to patients and carers.

Appropriate places for care outside of the home
Many patients receive palliative care in other settings outside their homes throughout the course of their disease. To ensure that care in other settings is appropriate, high quality and not unnecessarily prolonged, this work stream is intended to minimise the need for care in alternative settings by supporting patient choice and enhancing experiences.

Excellent and innovative training and continuous professional development for all professionals delivering palliative care
The delivery of evidence-based, high-quality care to patients at the end of their lives is dependent on the skills and knowledge of all the professionals involved. This work stream aims to develop a confident and competent workforce in the delivery of palliative care across health and social care communities in Somerset and North Somerset.

More recently, the care pathway developed through the Somerset project has been approved by the project's local stakeholders. The pathway entails proposals for new services to support patients at the end of life, through:

- a register to identify patients with palliative and end-of-life care needs
- a dedicated centre to co-ordinate end-of-life care services, accessible by patients and professionals
- an advice and support helpline for patients and carers during out-of-hours periods
- improved provision of information on local services and support for patients, their families and carers.

The King's Fund research in Somerset focused specifically on organisation and delivery of end-of-life care within care homes and how care homes relate to other providers within the local health economy. The research particularly sought to focus on care homes that were identified as representing examples of good practice, from which positive lessons could be drawn and disseminated.

In the next section, we consider how the research findings from these three sites can provide some examples of good practice for each step in the end-of-life care pathway (Department of Health 2008a). We also draw attention to some ongoing challenges and considerations, as commissioners and providers work to implement the End of Life Care Strategy. The discussion about each step of the pathway is accompanied by a summary of the key lessons for practice.

3 Discussion: lessons for good practice on the end-of-life care pathway

Discussions as the end of life approaches

The End of Life Care Strategy (Department of Health 2008a) highlighted the importance of communication and open discussion between health and social care staff on the one hand, and people approaching the end of their lives and their carers on the other to ensure that those providing care are aware of the needs and preferences of each individual.

It stressed that constraint or limitation in such discussions presents a major barrier to the delivery of high-quality end-of-life care and that staff should be confident and capable of having such discussions with patients and their carers. It recommended further work to identify triggers that could initiate discussions around end-of-life care with all those involved in its planning and provision.

The strategy found that key issues around the identification of end-of-life care needs and the holding of timely discussions with patients and their carers were:

- the potential for inequality in the identification of need and eligibility
- provision of end-of-life care for patients with non-malignant disease or multiple conditions
- the difficulty that some professionals have in initiating conversations with patients and their families about their end-of-life care preferences and care planning
- the anxieties that some professionals have about the estimated prognosis and the affect that these have on discussions about end-of-life care.

Having open discussions with patients at the end of their lives requires knowledge, skill and confidence, and our research has indicated a number of opportunities to ensure professionals receive the appropriate training for this (*see* below).

Identifying the end-of-life stage

The available literature on disease progression suggests that identifying the point when a patient is nearing the end of his or her life tends to be relatively more straightforward in those with a diagnosis of cancer. Patients with cancer tend to experience a more clearly identifiable gradual decline in their condition, while, conversely, patients with non-malignant diseases predominantly follow a less predictable disease course, characterised by a series of ‘peaks and troughs’ (Murray and Sheikh 2008).

This was a view echoed by a significant proportion of the interviewees in our research, who frequently reported that it is difficult for clinicians to identify the stage at which patients with non-malignant disease – such as organ failure, dementia or the frail elderly – enter the palliative or end-of-life phase. Furthermore, many interviewees said that they felt that the more limited number of referrals to programme services for patients with non-malignant disease was predominantly due to the unpredictable nature of the course of such illness, which can render it difficult for clinicians to form an accurate prognosis of when an individual is approaching the end of his or her life.

If professionals feel unable to make (and therefore communicate) a confident prognosis about when patients are nearing the end of their lives, they may refrain from making onward referrals to appropriate services, particularly when there are also concerns about the resource and cost implications to be considered.

The combination of these two barriers – prognosis and referral – can have serious knock-on effects for care planning and care co-ordination (steps two and three on the pathway). Without identification of the end-of-life phase, there can be no discussion with patients about their care preferences. More research is evidently needed so that the risk of death for particular population groups and particular time periods (for example, within the next year) can be better predicted.

Nonetheless, some interviewees commented that they do feel it is possible to determine, with some certainty, the point at which a patient with a non-malignant illness is approaching the end of his or her life. Using the example of heart failure, a clinical nurse specialist commented that health care professionals can look for evidence of specific clinical symptoms and triggers that can help to recognise that patients are nearing the end of their lives. However, it was acknowledged that these triggers would not necessarily be so easily identifiable to a generalist health professional, who may have had less of a history of interaction with a particular patient. Generalist health professionals would include clinicians for whom end-of-life care is not a dedicated (or even common) part of their role – for instance, district nurses, ward nurses or general practitioners (GPs).

In terms of good practice, the research identified three strategies that can be adopted across organisational settings to address the difficulties in identifying the end-of-life stage:

- training in the clinical indicators of deterioration
- multidisciplinary meetings
- analysis of patients' health service use.

Training in the clinical indicators of deterioration

Training general nursing and general and junior medical staff in the clinical indicators of deterioration in non-malignant conditions would make a significant contribution to ensuring a widespread and comprehensive understanding of the end-of-life care needs of these patients. Development of such training should consider the availability of existing tools to support end-of-life care providers in this area and identify gaps in the availability of existing knowledge.

Multidisciplinary meetings

In our research, multidisciplinary meetings occurred in both community and secondary care settings, bringing primary and secondary care professionals together with specialist palliative care and social care providers, and enabling the sharing of information that could identify when the end of life was approaching. These meetings focused on discussing the clinical indicators of a deterioration in a patient's health, the consequent likely prognosis, and the end-of-life care options.

Such multidisciplinary team meetings are a key element of the Gold Standards Framework used in community settings, which suggests focusing on three areas to identify patients (including those with non-malignant disease) in need of support or end-of-life care.

- General and specific clinical indicators of advanced disease for patients in the three main groups (cancer, organ failure, frail elderly/dementia).
- Whether the patient has expressed a preference for comfort care instead of curative treatment and/or is in need of supportive or palliative care (for example, has refused a renal transplant).
- Asking the intuitive ‘surprise question’: ‘Taking into consideration co-morbidity, social and other factors, would you be surprised if the patient were to die in the next 6–12 months?’ If the answer to the question is ‘no’, this should be seen as a trigger to begin the identification of and discussion about end-of-life care needs. The surprise question has been found to be effective in identifying patients with renal failure with a high risk of mortality and who were therefore in need of end-of-life care (Moss *et al* 2008), although the approach has been criticised in its application with older people (Gott *et al* 2009).

Analysis of patients’ health service use

Analysing patients’ use of the health service could help to identify significant deterioration in health. Providers of end-of-life care should have access to palliative care records (such as the Gold Standards Framework and other registries) to further this.

Efforts should be focused on creating a framework that allows data and information from different systems to be shared, rather than held separately for different purposes. It is recommended that such an interface be shared with other records and registries, rather than initiating an alternative or stand-alone patient database that could create further barriers to access for some professionals.

Such a framework is particularly pertinent for patients with non-malignant disease, who might have stable periods during which they need less intensive care, and might therefore currently be required to alert health professionals themselves of any change in their health and social care needs.

It would be useful to design this sort of information system with an algorithm to remind key community workers to contact patients who have not received recent health care interventions in order to track their status and ongoing care needs.

Confident discussions about the end of life and end-of-life care

It is worth noting that although several interviewees said that they felt clinicians (particularly disease specialists) are able to identify the point at which patients with non-malignant conditions are nearing the end of their lives, they also said that clinicians then fail subsequently to discuss that prognosis with the patient. Clearly, such tendencies will have an impact on the number of referrals made to the programme and other end-of-life care services, particularly those that are reliant on hospital ward staff initiating conversations with patients about their prognosis and preferences and planning care accordingly.

Some interviewees suggested reasons why clinicians might refrain from initiating these sorts of conversations with their patients. One medical professional commented that clinicians may simply ‘shy away from those sorts of conversations because they’re difficult conversations to have’. Several interviewees referred to the fact that many patients with non-malignant conditions could be in an ‘end-of-life-care phase’ for a prolonged period of time, which can consequently make it difficult to judge the appropriate point to initiate a conversation about prognosis and care planning.

It is clear that responsibility for broaching the subject with a patient is a shared one and should not necessarily be left specifically to specialist palliative care staff, and nor should it be shied away from altogether. A number of district nurses, in particular, mentioned that they discussed their patients' end-of-life care preferences some time before the end of life was approaching in order to co-ordinate the care packages required.

End-of-life care service providers should be encouraged to have clear and honest discussions with patients and their carers about the availability of community support, so that patients' needs can be met and to ensure that patients do not have unrealistic expectations about the care they are likely to receive. Similarly, such activity should consider the availability of existing tools to support end-of-life care providers in this area and identify gaps in the availability of existing knowledge.

Training and education should be provided to support generalist providers, such as acute ward staff and district nurses, to initiate timely and realistic discussions with all patients receiving end-of-life care about their care preferences. In the light of the discussions about whose role it is to initiate such conversations with patients and their carers, it is suggested that any education in this area is co-ordinated on a multidisciplinary basis in order to clarify such roles and responsibilities at a local level.

Our research highlighted the fact that not all professionals were comfortable with initiating the discussion about end-of-life care with patients. There did not appear to be any specific 'formula' for those who were more at ease doing it, but those who handled it particularly well were described as being confident, sensitive, and good listeners.

Skills in having difficult discussions develop over time and with experience – professionals learn how and when it is appropriate to discuss end-of-life care on an individual basis, managing neither to 'force' the issue nor hide from it. Professionals may be able to look for cues from patients to ascertain how ready and comfortable they are in listening and talking about the end of life. Professionals who feel less confident could benefit from shadowing those with greater competence and confidence in discussing end-of-life care.

Our research showed that positive outcomes to discussions about end-of-life care were also dependent on professionals offering realistic choices to patients and their carers. In acute settings across the research sites, it was observed that ward staff might not have sufficient, accurate information about the options for discharging the patient into the community. Examples given included patients being told they would get a place in a hospice when they did not actually meet the criteria or when there was no capacity for them locally. In other cases, there was concern that community services were not available locally to offer choice.

These mixed messages resulted in patients and carers being given unrealistic expectations and subsequently being disappointed, or ward staff not initiating a conversation about care preferences at all in order to avoid confusion or disappointment. There is also an important ethical issue to be considered if offering choice raises patients' expectations beyond what is, in fact, realisable.

Although professionals such as specialist palliative care providers had more experience at breaking bad news and discussing difficult issues with patients, it was acknowledged that some generalist staff, in particular, could benefit from training to build their confidence in this type of communication so that they do not avoid it until it is too late to co-ordinate the preferred type of care. Interviewees suggested that this training should be mandatory for everyone instead of being an 'opt-in' module, to maximise the number of trained and confident staff members in an organisation, and to increase the potential for a whole-systems approach to end-of-life care.

The comprehensive and collaborative method was key within the different approaches to initiating discussions about end-of-life options and care in the different organisations, because having the discussion with a patient was not dependent on a single catalyst or event.

The research highlighted a number of points at which professionals were able to broach the subject of end-of-life care, and these should be shared with all health and social care staff as part of their training in end-of-life care. The most common times for initiating end-of-life care discussions were:

- a significant change in the person's life, such as moving into a care home or sheltered accommodation
- a significant decline in the person's health, even if he or she subsequently stabilised, which is often the case for patients with non-malignant disease, in particular
- once trust has been established in a new therapeutic relationship, for example, with a district nurse or social worker.

The learning points from the programme highlighted how important it was to consider the timing of discussions about prognosis and end-of-life care preferences. The discussion must be handled with due attention and sensitivity, and not be treated as a mere 'box-ticking' exercise. Such discussions need to be undertaken on an individual basis and timed around patients' willingness and readiness to engage in such conversations, typically after a relationship has been established.

Interviewees in all the different organisational settings considered it important to include patients' families in discussions about prognosis and end-of-life care planning, whenever appropriate and practical. Patients and their carers should be equipped to understand fully what the prognosis means and what the coming months, weeks or days are likely to entail. This information helps patients and their carers to decide how they would like end-of-life care planning to proceed and assists health and social care staff with planning for equipment and care provision in the community.

Furthermore, the End of Life Care Strategy (Department of Health 2008a) stated that carers are entitled to their own needs assessment and care plan, particularly to provide support during bereavement (discussed further in step six). Thus, positive outcomes to discussions about end-of-life care also depend on inclusion of the family and carers.

The lessons for good practice arising from this research show that discussions about the end of life clearly cannot take place without more effective methods to identify the end-of-life phase and to provide support to staff undertaking this process with patients and their carers. This can be achieved by analysing existing patient data and seeking input from various health and social care colleagues. It is important to ensure professionals at all levels and across all disciplines (across the whole system) are trained and prepared to undertake confident discussions about end-of-life prognoses and care planning. This training should enable professionals to initiate and carry out well-timed and sensitive discussions with patients and their carers.

Key lessons on discussions as the end of life approaches

- There is potential for inequality in access to end-of-life care on the basis of diagnosis and identification of need.
- A combination of training and improvement in prognosis, multidisciplinary co-ordination of care, and interprofessional access to palliative care records could help to overcome some of these issues.

- However, this potential is exacerbated by an apparent reluctance among some health care professionals to approach discussions about death and dying.
- Specialist and generalist health care providers should work together to ensure that responsibility for alleviating some of the anxieties about initiating these conversations is shared, and that all providers are confident and competent in responding to patients' and carers' questions.

Assessment, care planning and review

The End of Life Care Strategy (Department of Health 2008a) proposed that people who are nearing the end of their lives should have their needs assessed by an appropriate professional. These care needs should then be recorded in the form of a care plan, and reviewed as their condition changes. Patients and their carers should be involved in this process as well as in all decisions involving planning and provision of care.

The content of these care plans – including preferences about care delivery and the place of death – should be available to all health and social care providers who would have reason to access them (including out-of-hours providers and emergency care services).

There are many different mechanisms and opportunities for the assessment, planning and review of care. The research presented here highlights particular examples from the programme, focusing on planning for discharge and advance care. One lesson particularly brought out in the research is how a comprehensive assessment of needs while a patient is in the acute setting can be supported by a specialist discharge facilitator resource. Furthermore, examples from the research in care homes demonstrated that the assessment of care needs can lead to the formulation of advance care plans, in which individuals expressed their preferences for end-of-life care, including whether or not they wished to be resuscitated in instances where their health deteriorated rapidly.

The research also demonstrated that the communication of advance care plans between and within health and social care teams helped to ensure that individuals' wishes were respected and accommodated. It was recognised that individual wishes about end-of-life care might change, and it is important to update advance care plans continually, based on ongoing discussions.

Discharge planning

Arranging the discharge from the acute setting of seriously ill patients who wish to die at home can pose a number of logistical problems. It is time and labour intensive for ward staff to make arrangements with various health and social care professionals and to complete funding application forms in order to arrange a package of care.

Our research examined two models of discharge facilitation that had been developed by the programme sites in Lincolnshire and Leeds and considered the appropriateness of elements of each model within their given context.

Both models involved the employment of dedicated end-of-life care discharge facilitators to support ward staff in conducting assessments in more complex cases, and planning for end-of-life care to be delivered in the individual's preferred location. However, there were clear differences in the context of the two health economies in which the two discharge models were operating, and these must be taken into consideration before planning discharge models.

Lincolnshire is a large, rural county with relatively small district general hospitals, whereas Leeds is a much more densely populated urban region, with services provided predominantly by two large teaching hospitals. Community care provision also differed across the two local health systems with regard to the level of engagement of district nursing with end-of-life care, the composition of specialist palliative care provision, and the degree of reliance on agency care.

Interviewees in Lincolnshire reported that out-of-hours care provision continued to be a key service gap, but this was not identified as a significant problem in Leeds. In addition, the introduction of a new framework for delivering district nursing services in Leeds provided a clear structure for specifying the roles and responsibilities of district nurses in providing end-of-life care in the community.

There were also significant differences between Leeds and Lincolnshire in the organisation and delivery of end-of-life care. In the absence of a palliative care consultant in Lincolnshire, most care was provided by generalist staff supported by specialist nurses. Conversely, the acute trust in Leeds had a well-established end-of-life care team, and a clear consultant presence, which helped to strengthen the profile of end-of-life care in the area.

In combination, these contextual factors influenced and affected the way in which the two discharge models developed. In Lincolnshire, there were two discharge facilitators, each operating from a district general hospital. However, this type of approach would have been unsustainable and ineffective in Leeds because of the size and scale of the acute trust there: one role could not have taken responsibility for co-ordinating the discharge of all patients approaching the end of their lives in Leeds.

If the Leeds model had operated in a similar fashion to that in Lincolnshire, it would have been necessary to have more than one role, which local stakeholders did not consider to be cost-effective. As a result, the Leeds model was deliberately designed to be much less operational in nature and instead had a clearer emphasis on facilitating and empowering ward staff to co-ordinate discharges, rather than taking responsibility for co-ordinating those discharges directly. Alongside the practical contextual issues, the different way in which the Leeds model developed was also the result of a conscious decision by local stakeholders, who were keen to ensure that the discharge skills of ward staff were not weakened by the introduction of a new post.

A small number of research participants were concerned that a potential disadvantage of the Lincolnshire model was that ward staff could become overly dependent on the discharge facilitator rather than taking any personal responsibility for arranging discharge from hospital. It was felt that this could lead ward staff to feel that end-of-life care was not really part of their role, which would be contrary to the whole-systems (or collaborative) ethos of the programme. Alternatively, others considered the discharge facilitators to be a resource to call on, particularly for advice or assistance with complex cases. This discrepancy in understanding the discharge facilitation role suggests that greater effort must be made to ensure that the remit of the role is clear to all staff from the outset.

In the Lincolnshire model, whenever possible, the discharge facilitators endeavoured to provide patients with a sense of continuity by meeting them at home after their discharge, taking the time to make them comfortable and to explain to them and their carers about their medication and the care they would receive. This personal relationship was a further advantage when patients were hospitalised and discharged again. However, such an approach was not considered to be necessarily sustainable, because as demand for the facilitation service increased, the discharge facilitators had less time to spend on home visits.

In the Leeds example, the discharge facilitation model was developed in conjunction with a ‘meet and greet’ service, under which a nurse or health care assistant met the patient in his or her home after discharge and gave up to 24 hours of care. This service was reviewed as part of a separate evaluation report by Lancaster University (*see* Payne *et al* 2009).

These findings indicate that in planning the development of similar discharge models, it is necessary to examine closely and take account of the local context in which the model operates. There is no one-size-fits-all approach to design and implementation: discharge models should be clearly aligned and suited to the features and needs of the local health economy and the availability of other resources. Considerations would include the size of the population and demographic features, as well as the nature of the services in place to support people at the end of their lives.

Furthermore, when designing a discharge model, there must be clarity and transparency about the purpose of the role. This is pivotal in ensuring that ward staff and community professionals understand the function of the model, how they will interact with it, and in which circumstances it is appropriate to do so. There should be a clear understanding of all roles and responsibilities in the discharge process, including the support that a dedicated discharge resource can provide. Where possible, it is important to preserve the boundaries of a discharge model consistent with these role objectives. This should prevent dependency on one person, and enable the transfer of learning and knowledge.

The shift to providing more end-of-life care in the community requires health and social care professionals to work in a different way. Ward staff, in particular, require support to ensure that patients are appropriately discharged to their preferred place of care. This may involve professionals developing their skills and knowledge in discharge processes, particularly funding criteria and processes. Ward and community staff must also have an understanding of the pressures and priorities that face their colleagues in different health care settings as a means of developing a whole-systems view of service provision.

Discharge models in both sites experienced similar barriers to effective service delivery:

- the appropriateness of referrals
- timely identification of patients' palliative and supportive care needs
- reluctance of ward staff to discuss prognosis and preferences with patients
- funding applications and continuing care funding
- the flexibility and responsiveness of community staff.

It was evident across both project sites that a facilitative model of discharge is required to empower existing ward staff to perform this function and thus alleviate some of the potential dependency on one person of a more operational approach.

Advance care planning

Advance care planning is undertaken in case patients lose their physical and/or cognitive capacity to make decisions and/or the ability to communicate their wishes about end-of-life care to others. It is a vital element of end-of-life care and in ensuring that individuals' wishes are respected. Advance care planning is defined as the *ongoing* discussions between individuals and their care providers, in the context of a possible future deterioration in health (Henry and Seymour 2007). The process should capture:

- patients' concerns about their future care
- their values or personal goals for care
- their understanding of their illness and prognosis
- their preferences for the type of care that may be beneficial to them in the future.

Advance care planning incorporates a 'statement of wishes and preferences', which refers to the individual's written or verbal expressions about their preferences for care and treatment. These preferences can be about both medical and non-medical aspects of their future care. A statement of wishes and preferences is not legally binding, but it can be used to make decisions about the best interests of patients who have lost the ability to do so themselves (Henry and Seymour 2007).

Lessons on advance care planning were predominantly gathered from the research on the provision of end-of-life care in care homes across Somerset and North Somerset local authorities. In this context, the level of detail from the advance care plan was captured across organisational settings by the various health and social care professionals and enabled them to co-ordinate the input required from services for all aspects of end-of-life care – physical, social and emotional. This was essential for ensuring that people had choices about their care at the end of their lives. In the main, these choices related to ensuring that the various health care teams were informed about whether or not an individual wished to be resuscitated in a crisis situation near the end of life.

This care planning also focused on contacting religious or spiritual advisors, solicitors and funeral directors if individuals wanted to discuss arrangements for the very end of their lives and what they and their families would wish to happen after their deaths.

In the care home settings considered in this research, advance care planning was a holistic process and provided residents with choices about the way in which they were looked after and what should happen when they had died. This involved asking people about diet and nutrition, activities they would like to participate in (or not) and when they would like to spend time alone or in the company of other residents. It involved discussing the type of medical care they might or might not wish to continue receiving, through to exploring whether they wished to make a will and state what type of funeral service they would prefer. These preferences were noted in individual care plans, which could then be used by all the staff in the care home – as well as any relevant external service providers – to ensure that residents' wishes were carried out.

Offering choice went hand in hand with the provision of accurate information about the resources available to allow individuals to receive end-of-life care in a place of their choosing. When that place was their own home, health and social care staff needed to be honest and clear with patients and their carers about the level of support they would receive from various services. For example, there were reports that some staff might give patients and their carers the impression that a night-sitting service would be available in all cases, throughout the night, seven nights per week. In fact, the night-sitting service was a finite, needs-based resource, the availability of which was dependent on the local contract between the night-sitting provider and the primary care trust (PCT).

This is particularly relevant to the point about carrying out a thorough assessment to ensure that care can be planned accordingly. Across the organisational settings, health and social care staff can help this process by including in the care plan detailed information about how much care is needed at different times in any 24-hour period.

The end-of-life care preferences discussed must be documented to enable care to be co-ordinated. Our research showed a variation in the method of documenting care preferences, both within and between the three programme sites, with some organisations utilising established tools such as the Gold Standards Framework, and others using locally developed documentation.

The Gold Standards Framework is intended to provide a systematic and consistent approach to the delivery and organisation of high-quality end-of-life care in general practice and care homes, and its implementation is highly reliant on strong communication between general practices and patients. It comprises three key processes:

- identifying patients in need of end-of-life care
- assessing their needs
- planning and co-ordinating the delivery of this care.

Regardless of the tool used, it is essential that information about the care plan and advance care decision is shared across the relevant health and social care providers, including general practitioners (GPs), district nurses, community palliative care teams, out-of-hours services, ambulance services and hospital wards. Problems arise when such plans and preferences are not communicated across providers, and choices about the nature and place of care are therefore not known or followed, particularly in circumstances where the patient is no longer able to make these preferences explicitly known. Transparency in advance care plans ensures all health and social care teams know about patients' preferred nature and place of care and, if applicable, hospital discharges can then be prioritised and expedited.

Many of the participants in our research explained that early or pre-emptive communication across health and social care teams meant that, in a crisis situation when a patient's health deteriorated, GPs, out-of-hours services, ambulance crews and hospitals were aware of the patient's choices about care and the place of death.

As well as strong communication with external teams, the research highlighted the value of ensuring that this also exists *within* an organisation. The content of advance care plans was made available and accessible to all staff involved in the care of a person nearing the end of his or her life in order to reduce the likelihood of inappropriate hospital admissions or physical interventions if the key worker or professional in charge of care was unavailable, particularly during out-of-hours periods. Furthermore, staff must be competent and confident about care planning and see it as a continual process rather than a one-off event. Care plans must be reviewed regularly, with any changes being communicated to all colleagues accordingly.

In summary, the lessons from this section of the research show a facilitative model of discharge can be effective in empowering ward staff to arrange for end-of-life care to be provided in the community. However, the commissioning and development of discharge-planning models must be based on a shared understanding of the purpose of the service, and take account of local factors, such as the level of need and existing service provision.

In addition, advance care planning is an essential aspect of planning and delivering end-of-life care that meets the physical, social and emotional needs of the individual. The success of advance care planning depends very much on how well it has been communicated to everyone in an organisation and to the other health and social care professionals involved.

Such an approach requires a clear and transparent communications strategy (and potentially an information system), in which all the relevant providers are able to access the information about patients' preferences that is necessary to meet their choices effectively. The competence of staff in overseeing advance care planning as a continuous process and not as a one-off event is also significant in this regard.

Key lessons on assessment, care planning and review

- Dedicated discharge facilitation for patients who are nearing the end of their lives can be an effective mechanism for supporting ward staff to conduct assessments in more complex cases and for the planning of end-of-life care to be delivered in the patients' preferred location.

- The development of such models of discharge facilitation should take account of and adapt to factors within the local health economy to ensure that they work with (rather than against) existing processes and pressures on other end-of-life care providers. There is no one-size-fits-all approach to design and implementation.
- Advance care planning (and communication of plans between and within health and social care teams) can help to ensure patients' wishes are respected and accommodated. As individuals' wishes about end-of-life care can change, it is important for advance care plans to be continually updated on the basis of ongoing discussions.

Co-ordination of individual patient care

The End of Life Care Strategy (Department of Health 2008a) stated that once a care plan had been developed and communicated, it was important that the provision of this care was co-ordinated across the range of local providers. Co-ordination was highlighted as a significant activity in itself and a major obstacle to patients not being able to achieve their care preferences.

The strategy suggests that this care co-ordination is required at various levels – within an individual provider team, between teams within a single institution, across organisational boundaries, and across providers from both health and social care. The strategy recommends various mechanisms for achieving this co-ordination, such as locality-wide registers, a dedicated helpline for people nearing the end of their lives (to avoid emergency calls to ambulance services), and a single point of access through which services are co-ordinated. The strategy also highlighted the importance of the use of effective information technology in achieving these aspirations.

It was clear from our research that effective co-ordination of care is underpinned by clear communication between the various health and social care teams, along with the building of productive relationships. The positive examples of co-ordination of care when discharging patients from hospital to their preferred place of care revealed by our research were described above. Below, we now describe the benefits and limitations of the various approaches taken by our programme sites to the co-ordination of end-of-life care in the community and during out-of-hours periods.

Co-ordination of care in the community

Research with the programme in Lincolnshire highlighted the value of a centralised model of end-of-life care co-ordination across a county or other defined geographical region. The Lincolnshire project team revealed that the time spent by district nurses (and other referring community nurses) arranging care packages constituted a significant barrier to providing responsive care and enabling a patient's preferred place of care to be achieved. In response, the Palliative Care Co-ordination Centre (PCCC) was established as a centralised administrative centre for co-ordinating the booking of community care for patients nearing the end of their lives. The PCCC responded to requests from community or ward nurses to arrange packages of care (provided by the voluntary sector, private nursing agencies and social services) based on the needs assessment of patients and the availability of funding support.

The PCCC was reported to have freed up some of the time of the community nurses by reducing the burden of more administrative aspects of their workload. Prior to the establishment of the PCCC, district nurses were themselves required to co-ordinate and organise care packages for each patient. This involved telephoning multiple care providers to assess availability, ensuring that the necessary components of a care package could be put in place, and liaising with patients and carers to inform them of what care packages would be delivered and when. The community nurses interviewed described this as a time-consuming process, involving many telephone calls, paperwork, and periods of time spent waiting for care providers to return calls. This, in turn, restricted the amount of time that community nurses were able to spend with all of their patients (not only those nearing the end of their lives). Many interviewees described the positive role that the PCCC had played in streamlining the process of co-ordinating care packages for them, namely that now they had to make only one telephone call, to the PCCC, rather than multiple telephone calls to various care providers. The PCCC typically provided one named contact person with whom community nurses could liaise for a geographical sub-region of Lincolnshire. Such continuity of care was important for professionals and patients alike.

A small number of participants, however, indicated some potential challenges to consider when developing a co-ordination centre of this type. In particular, they felt that the establishment of the PCCC had indirectly affected communication among existing community professionals, with some interviewees being especially concerned that since its inception there had been less communication between district nurses and the care agencies to which they had previously referred patients directly. This could affect the provision and co-ordination of services locally.

In addition, some interviewees were concerned that some referrers were tending to over-order care now that the burden of actually arranging the care packages themselves had been lifted. Several interviewees compared the PCCC with a ‘sweetie shop’, from which referring providers could build care packages, with limited discrimination about the wider allocation of resources. This, in turn, prompted the worry that such over-ordering of care packages through the PCCC could result in an inequitable allocation of resources across end-of-life care, especially when such resources were finite. In instances where a particular patient’s need was likely to go unmet, it was the co-ordinator’s role to liaise with the community nurses (most likely the district nurse) to establish which patient’s need was the greatest to ensure that decisions about prioritisation were made before the care was booked.

A principal concern that interviewees raised with regard to the process of co-ordinating care was whether the co-ordinators, as non-clinicians, were truly capable of prioritising the needs of patients within finite resources and of allocating care packages accordingly.

One benefit of the PCCC was that the co-ordinators had an overview of services and their availability across the region; they were able to see where services had been put in place for one patient, and where there might be unmet need elsewhere. However, as the co-ordinators did not have a clinical background, they were unable to prioritise allocation of the finite resources on a clinical basis. Several interviewees expressed concern that this situation could lead to the inequitable allocation of resources. As the co-ordinators were unable to prioritise need between different patients, a situation could arise in which care was booked for one patient that consequently limited the care available for the next patient to be referred, irrespective of whether that second patient’s need was actually greater.

It is worth noting that ongoing communication was essential to the effective operation of the PCCC and would provide the ideal opportunity for referrers, service providers and members of the PCCC to discuss operational and communication issues of this kind.

It is clear that the co-ordinators in the PCCC need to work closely with clinical staff in any prioritisation decisions.

There is the potential for considering extending the remit of such a model of co-ordination to the provision of additional services. For instance, it was suggested by some research participants that the PCCC could be used to monitor the availability and booking of care home places. In Lincolnshire, clinicians were referring patients to care homes directly, which could be a time-consuming process involving liaising with various institutions to ascertain availability and discussing suitable options with individual patients and their families and carers.

Another suggestion that arose from the interviews was that the PCCC could organise the ordering of home care equipment, such as specialist mattresses and hoists. Again, this could free up the time of health and social care professionals. To extend this potential still further, such co-ordination centres could also expand their role and remit to create a platform for education and the exchange of ideas across professional and organisational groups.

Co-ordination of care during out-of-hours periods

The co-ordination of care was considered to be particularly vital during out-of-hours periods so as to avoid unnecessary hospitalisation at the end of life. Rapid-response services played a critical role in managing the care of patients in the community during these periods. For example, the Rapid Response Team (RRT) in the Boston area of Lincolnshire provided emergency and planned visits to patients' homes, as well as emotional support and guidance to patients and carers over the telephone, during out-of-hours periods. The team also relayed information between patients, GPs, district nurses, discharge facilitators, hospice nurses and care home staff, enabling a whole-systems approach.

The RRT was staffed by a registered nurse and a health care assistant, and operated during twilight and overnight periods. Typically, patients and their carers were made aware of the RRT service by ward staff on discharge from hospital, or in the community by their district nurse or other community health provider. RRT staff liaised with ward and district nurses during handover periods through written logbooks or telephone updates.

Research participants interviewed in Boston were predominantly positive about the role of the RRT, feeling that it was a valuable addition to the delivery of palliative care in the community during out-of-hours periods, and contributed to the avoidance of unnecessary hospital admissions.

Key lessons on the co-ordination of individual patient care

- Dedicated models of co-ordination can be effective in freeing up the time of district nurses and other community health providers and allowing for greater oversight regarding the prioritisation of resources.
- Such co-ordination models could widen their remit to include other functions, such as the booking of equipment or co-ordination of or advice on care home placement.

Delivery of high-quality care in different settings

The End of Life Care Strategy (Department of Health 2008a) noted that people who are nearing the end of their lives might need to access a complex combination of different services from a range of different providers. These end-of-life care services need to be provided across a range of different care settings, not just the typical care environments such as hospitals, the community, care homes, sheltered/extra-care housing or hospices, but also locations such as prisons, hostels for the homeless, and independent living homes for people with learning disabilities.

Our research looked at how the projects involved in this study endeavoured to provide high-quality care. Our findings are explored below in relation to different organisational settings, in which partnership working was essential. Particularly in community settings, a wide range of services was involved in the delivery of end-of-life care, across both health and social care providers. We also consider here the support, training and educational needs of various staff involved in delivering high-quality care in different settings and the configuration of community health care services.

Hospitals

Although it is acknowledged that, given the choice, most people would prefer to be cared for and die in their own homes, it is appropriate for many patients at the end of their lives to be treated and die in acute settings. It is therefore imperative that attention is paid to ensuring that care in this setting is delivered in a patient-centred and compassionate manner.

As previously mentioned, various end-of-life care tools have been rolled out nationally to assist in identifying patients nearing the end of their lives, capturing their care preferences, and providing a systematic plan for the delivery of care in their last days. In the acute settings studied in this research, there was an increasing use of the Liverpool Care Pathway as a mechanism for managing the care of patients nearing the end of their lives. The research found that a number of participants thought the Liverpool Care Pathway to be particularly helpful in acute settings and nursing homes as it gave a structure to the delivery of end-of-life care, specifically by ensuring basic nursing practice was followed, and drew attention to the information and support needs of carers and family members.

Our research demonstrated that communication with family members was strengthened by discussing the Liverpool Care Pathway before initiating a patient on it. This meant that families were well informed, and confusion was avoided once the Liverpool Care Pathway had been instigated.

Community

Our research highlighted many examples of the effective management of patients with end-of-life care needs in the community. A comprehensive model for end-of-life care in this setting benefits from a range of services being in place, for example, discharge facilitation from the acute setting, rapid-response services during out-of-hours periods, and centralised co-ordination of care provision in the community (as discussed previously).

The models that were considered in this research represent a whole-systems approach to service redesign, in which expediting discharge from the acute setting is combined with increased and/or reconfigured community service provision. As well as the initiatives that were studied as part of the research presented here, other pilot services were established in the community as part of this whole-systems approach, namely dedicated patient transport, a 'meet and greet' programme, and a combined health and social care workforce. It was the combination of this range of services that was considered to represent the greatest impact on the organisation and delivery of end-of-life care (*see* Payne *et al* 2009).

As mentioned previously, a comprehensive model for end-of-life care in the community must include services that are responsive during out-of-hours periods, and that meet the ethos of the comprehensive and collaborative approach. Many respondents felt that it would be beneficial to develop standard, area-wide handover communication for patients known to be nearing the end of their lives as a means of ensuring enhanced co-ordination of care.

This communication would outline the information necessary for a professional responding during out-of-hours periods who did not necessarily know the patient. The information would include the patient's diagnosis, what anticipatory medication was kept at home, the patient's end-of-life care preferences, and whether he or she wished to be resuscitated. The provision and sharing of this information would aim for all health and social care professionals to be aware of patients' care plans and preferences and would work to ensure that these plans and preferences were complied with, regardless of the time of day or week.

Care homes

Our research showed many care homes to be committed to enabling their residents to remain in that setting as they neared the end of their lives, if that was their expressed preference. This could mean obtaining additional specialist equipment, liaising with a range of health and social care professionals, and ensuring that there was sufficient staff capacity in the care home to enable care assistants to provide particular attention to residents who were very close to death.

Our research encountered several examples of proactive care homes, where staff worked to ensure residents could receive high-quality end-of-life care in the home, which, in many instances, was the resident's long-term home. Particularly in the case of residential care homes, this involved close working with district nurses for advice on diet, specialist equipment, and physical care, such as the avoidance of pressure sores. These processes worked to ensure residents could remain in a familiar (and preferred) environment as they neared the end of their lives, rather than being transferred elsewhere, with all the potential emotional and physical distress.

Independent care agencies

Independent care agencies were frequently contracted to deliver care to patients nearing the end of their lives, particularly those with complex needs who required a greater degree of care than could be met through standing contracts between PCTs and voluntary or statutory service providers. Many interviewees expressed concern about the use of these care agencies, particularly around three interrelated issues:

- the high cost associated with using agency care workers
- the quality of care delivered by private agencies
- the knowledge, skills and experience of agency care workers.

Concerns such as these can also affect relationships between other end-of-life care providers and independent care agencies. Some respondents from independent care agencies commented that, as private providers, they often felt excluded from discussions about the planning of end-of-life care services, and could consequently feel undervalued. There is thus scope to improve communication, information-sharing and collaborative working across all providers of end-of-life care. There is evidently a need to consider how PCTs can involve independent care agencies in existing training activities, or the development of educational opportunities, on the practical and conceptual issues in the delivery of end-of-life care.

It is important to note that the success of all the services described above was likely to have been further supported by local changes happening alongside the programme. For instance, in Leeds, in addition to the project, a reconfiguration of the district nurse service was undertaken, changing the way in which teams responded to requests to discharge patients into the community and providing a greater focus on patients nearing the end of their lives, offering more intensive and frequent community support.

In each of the organisational settings studied in this research, the enthusiasm and co-ordination of providers across the region was key in delivering end-of-life care to meet patient preferences and provide high-quality support.

The lessons for good practice from this research show that there are advantages to using existing end-of-life care tools and services dedicated to end-of-life care patients to deliver high-quality care to this population.

The delivery of high-quality care in different settings is dependent on health and social care professionals sharing their knowledge and expertise across organisational boundaries. The positive examples of partnership working that were witnessed in this research should be adopted by commissioners and providers as they undertake further implementation of the End of Life Care Strategy (Department of Health 2008a).

Key lessons on delivery of high-quality care in different settings

- End-of-life care tools – such as the Gold Standards Framework and the Liverpool Care Pathway – are important mechanisms for ensuring high-quality and transparent provision of care that is more effectively able to meet patient preferences.
- A whole-systems approach to service improvement is necessary, in which expediting discharge from the acute setting is combined with increased and/or reconfigured community service provision that is available 24 hours a day, seven days a week.
- Training and education are necessary to ensure the provision of high-quality care in different settings. Such education is reportedly needed in a range of aspects of end-of-life care, including the identification of patients' needs, communication skills, and the physical management of patients nearing the end of their lives.

Care in the last days of life

The End of Life Care Strategy (Department of Health 2008a) gave particular attention to the identification and management of care needs in the last days of an individual's life. The strategy noted that this phase can be identified by various signs, which it is vital for the professionals involved with the patient to recognise and to communicate to the person's family/carers. It went on to state that it is equally important that this recognition is then followed by the making of any changes necessary in how care is provided. 'Do Not Attempt Resuscitation' decisions are an important element of such care and can be highlighted by advance care planning and discussions with patients and carers regarding their care preferences. Furthermore, the strategy noted that the Liverpool Care Pathway had been identified as one mechanism for ensuring that all patients and their carers receive high-quality care in the last days and hours of life.

Our research showed clearly that the care given to patients during their very last days of life was very much dependent on health and social care professionals having previously taken steps to identify, discuss and assess end-of-life care needs and also planning and reviewing care. The research demonstrated the importance of early preparation in order to meet the support and care needs of patients nearing the end of their lives and their carers. In addition, it highlighted the value of communication between stakeholders across different professional and organisational settings (especially across health and social care teams) and the provision of compassionate and person-centred care.

Preparation for the dying phase

Care professionals who had built up a relationship with a patient over time, and were therefore reasonably familiar with their characteristics and behaviour, were able to observe signs of deterioration or other changes in physical and cognitive capacity. The difficulties of making end-of-life prognoses, as well as the importance of having strategies to address these, were discussed above (*see* p 13). In addition to the strategies of training, multidisciplinary meetings and analysis of patients' use of the health service, the research demonstrated that continuity of care provided a considerable advantage in recognising the signs that an individual is nearing the very end of his or her life.

District nurses and care home staff who knew patients or residents well from spending time with them during the supportive and palliative care stages were alerted to the approach of the end of life by signals such as significant changes in strength, appetite or cognitive function. This prompted them to take the actions necessary to prepare for end-of-life care to be delivered in the preferred location, and with the appropriate support in place. For example, care home staff would inform the GP and out-of-hours services of developments and arrange anticipatory medication to avoid inappropriate admissions to hospital at the end of life.

When care professionals were less familiar with an individual's particular circumstances or preferences (for example, if the patient had only recently been transferred from one setting to another), it was vital to share information about care preferences and the current state of illness with different care teams, to ensure that any signs of deterioration were noticed. In practice, many patients (particularly those with co-morbidities and long-term conditions) experience acute exacerbations of their illness, followed by periods of stability or improvement. It is therefore important that continuity of care and communication between clinical teams is maintained.

As discussed previously, advance care planning is an essential process in ensuring that end-of-life care services are delivered according to patients' wishes. Once a patient has been identified as nearing the end of his or her life, it is necessary to review the advance care plan continually in order to check that all of the resources are in place to provide the preferred end-of-life care services in the preferred location. The sharing of information continues to be critical at this stage to ensure that health care professionals and carers are aware of the individual's care preferences and, if appropriate, wishes regarding resuscitation.

Our research demonstrated that communication with GPs, district nurses, their out-of-hours counterparts, rapid-response teams (if applicable) and local ambulance crews was especially important if a patient had expressed a preference to be cared for and die at home. Many of those involved in this research felt strongly that inter-organisational communication could benefit from the development of electronic information-sharing between professionals or a standardised paper form that could be disseminated across provider teams as soon as a patient was identified as nearing the end of life, if not earlier in the process.

The electronic sharing of information for end-of-life care does not necessarily require the creation of a new system, as there is the potential to use the GP-held Summary Care

Record (or similar) to make information such as resuscitation preferences available to authorised clinicians (Tait *et al* 2009). The Department of Health expected that the Summary Care Record would be available in the majority of care settings in England by 2010 (Department of Health 2008a). It should be noted that this implies that it is not currently operational in all settings, and the existing extent of coverage across the country is unclear. Furthermore, patients are being given the choice of opting out of having an accessible Summary Care Record (*see* NHS Connecting for Health 2010 for more information). It is therefore possible that information on care preferences will not be available for all patients via this mechanism, and so their end-of-life care plans must be communicated across organisations in other ways.

The inclusion of carers in discussions about end-of-life care needs and preferences and advance care planning (steps one and two) was considered to be good practice. During the last days of a patient's life, due attention should also be given to the need for information and support of his or her family and carers (discussed further on p 35) and their inclusion in major decisions as well as the physical care and emotional support of the individual who is dying. For example, in the care homes that participated in this research, managers would communicate regularly with carers about individuals nearing the end of their lives, to notify them of any changes and discuss changing care needs. In many instances, carers were also invited to stay on-site at the care home so they could be by the bedside of their loved one at the time of death.

As mentioned earlier, our research showed that, across different locations of care, health care professionals found the Liverpool Care Pathway particularly helpful for planning and communicating the various aspects of care in the last days of life. It helped staff to focus on individual needs, and to ensure that pain and agitation were controlled. In addition, the Liverpool Care Pathway requires staff to note whether physical and emotional comfort care measures have been carried out at regular intervals. In this way, the Liverpool Care Pathway was found to improve communication about end-of-life care between providers. It also provided a checklist to prompt health care staff to engage carers and pass information on to them.

For instance, a nurse working at a care home commented on her positive experiences of using the Liverpool Care Pathway with residents in the last days of their lives. She described how it kept staff focused on specific aspects of end-of-life care by noting how the individual was feeling on an hourly basis. These hourly assessments of patients' condition encouraged staff to seek a solution when problems arose, rather than allowing more time to pass in the hope that the situation would improve.

The Liverpool Care Pathway is being increasingly used across the health service, although there have been some anxieties voiced about its use in practice (Devlin 2009).

PCTs should ensure accurate information and training is provided to all staff delivering care at the end of life. Training on the Liverpool Care Pathway should also be available to non-NHS staff, such as care home managers, nurses, care assistants and nursing agency staff. Part of this training should be to ensure that staff are competent to explain the purpose of the Liverpool Care Pathway and the likely progression in the final days and hours of life to the family and carers of a patient to whom it has been decided to apply the pathway. This training and communication with carers could help to alleviate some of the anxieties about its use.

Compassionate and person-centred care

A core aim of the End of Life Care Strategy (Department of Health 2008a) is that patients experience a 'good death'. For this to be achieved, it is considered important that, in the last days of life, patients are:

- treated as individuals, with dignity and respect
- without pain and other symptoms
- in familiar surroundings
- in the company of close family and/or friends.

Ensuring physical comfort at the end of life involves a range of very practical care processes, including regular turning of the patient to avoid pressure sores, mouth care, and close observation for signs of pain and agitation. At the very end of their lives, some patients may find it reassuring and comforting to have a 'friendly face' constantly present at the bedside. This stage of the end-of-life care process can be very labour intensive, but our research found that service managers in some of the organisations we studied understood the importance of making sure there were enough staff members available to carry out regular physical care and to sit with patients nearing the end of their lives. For example, some care home managers rearranged rosters to ensure that a care assistant could be with a resident at this stage at all times if necessary.

The provision of dignified and compassionate care during the last days of life was evident across the research sites. Chochinov (2007, p 186) offers a definition of compassion in the context of health care that 'refers to a deep awareness of the suffering of another coupled with the wish to relieve it'. Many of the staff who participated in this research considered such compassion or dignified care to be the most important part of their role as providers of high-quality end-of-life care to patients. They also believed themselves to be 'privileged' in helping to make the end of patients' lives as comfortable and peaceful as possible.

However, there was some contention about whether such traits could be taught, or whether they came from much more internal motivations. For some, compassion is a natural trait and for others it is developed over time through life experience, clinical experience, empathy and the realisation that everyone is vulnerable to ageing. Although it may take time to 'learn' compassion, it is easy to show it through understanding and communication, and acknowledging *who* a person is beyond his or her illness.

Recent research by The King's Fund through The Point of Care Programme draws on Chochinov's (2007) theory and other literature and develops a broader description of compassion that is applicable to health care in the acute sector. Compassion entails *real* dialogue between the care worker and patient, and acknowledges the patient as a person with an individual history, personality and differences. Compassion may also require the care worker to have courage and be honest at times. Research by Firth-Cozens and Cornwell (2009) demonstrated that compassion can be enabled through learning from role models who are compassionate towards patients and colleagues alike as well as through regular and positive interaction with team members.

Compassion has also been described as the 'little things' that are much appreciated by patients, but often overlooked or under-reported (Smith 2008). These little things are often very personal acts of care that are also perceived as respectful and comforting. Examples include cleaning a person's glasses or ensuring that a hearing aid is working. This type of care is particularly necessary in distressing situations, such as when someone is nearing the end of life (Hunter and Smith 2007).

In our research in care homes, these little acts of kindness were very much apparent in care assistants' descriptions of how they delivered end-of-life care. They wanted to ensure residents knew that they were cared for, or 'loved', and they showed this through physical gestures or simply by being present at the bedside to offer company and reassurance. One care assistant described herself and colleagues as being willing to go 'that extra mile' during the last days of a resident's life. This involved additional cover being arranged for the rest of the care home to enable a member of staff to sit at the resident's bedside and ensure he or she was comfortable.

It should also be recognised that sitting with someone nearing death (and all other aspects of end-of-life care) is emotionally demanding, and service managers must motivate and support care staff through these activities. This can be done by acknowledging the demanding nature of care providers' work and providing feedback and praise for their contribution. Care providers must be supported in this sensitive and demanding role, and their own concerns and anxieties addressed.

What takes place in the last days of life determines whether a 'good death' can be achieved and remembered by the family and carers. One lesson from our research is the importance of being well prepared for providing care in the last days of life. This can be achieved by taking steps to identify the end-of-life stage and referring back to individuals' advance care plans to ensure that all the necessary resources are in place and the relevant health care professionals and teams are aware of patients' wishes about end-of-life care. Preparation is underpinned by communication between various care providers, those nearing the end of their lives, and their families and carers.

Our research demonstrated that health and social care staff can ensure that people near the end of their lives receive high-quality, compassionate care during their final days. Service managers should ensure that there are sufficient resources in place to enable clinicians to provide continuous and personalised care to these patients.

Key lessons on care in the last days of life

- Once a patient has been identified as nearing the end of his or her life, advance care plans should be reviewed continually to confirm that all of the resources are in place to provide the preferred end-of-life care services, in the preferred location.
- Particular consideration should also be given to the information and supportive needs of carers, their inclusion in major decisions, and inclusion in physical care and emotional support of the individual who is dying.
- In the last days of life, it is considered important for patients to be:
  - treated as individuals, with dignity and respect
  - without pain and other symptoms
  - in familiar surroundings
  - in the company of close family and/or friends.

Care after death

The End of Life Care Strategy (Department of Health 2008a) was clear that when a person dies, all the staff involved should be familiar with good practice for the care and viewing of the body and be sensitive to carers' wishes and cultural, spiritual or religious needs. Furthermore, staff should communicate the death within their institution and across provider teams and update their records accordingly. The end-of-life care pathway highlighted a number of issues about care after death and the barriers involved in achieving high-quality care.

The strategy highlighted the timely verification and certification of death as a key element of good practice. Problems with processes, communication and timeliness have been known to arise, particularly in out-of-hours periods. Such problems and delays in this process can be particularly distressing for carers. Following verification of death, it is vital that the body is handled and laid out in a culturally sensitive manner and in keeping with any religious beliefs held by the deceased and his or her carers.

It was clear from our research that high-quality end-of-life care also means providing due care and attention to the patient and carers after death. In order to do this, it is important to refer to the care plan of the deceased (and to the wishes of his or her carers if applicable) to ensure that preferences are respected. The staff who were interviewed described how they ensured that the body of the deceased was treated with dignity and how they worked to be sensitive to the needs of the bereaved family.

Care and viewing of the body

As discussed above with regard to care planning, health and social care professionals should be aware of processes they can undertake after the death of a patient in order to show respect to that person and his or her carers. This is relevant across all types of care settings.

The King's Fund's Enhancing the Healing Environment programme encourages and enables teams to work in partnership with patients to improve the environment in which they deliver care. Fifteen acute trusts, two mental health trusts, two primary care trusts and one prison have undertaken projects to improve the environment of care at the end of life. Projects range from palliative care rooms with dedicated accommodation for relatives, to the creation of bereavement centres and the redesign of mortuary viewing areas (Waller *et al* 2008).

One area for professionals to focus attention on is the environment in which the body is available for viewing. Care home staff described how they ensured that the bodies of deceased residents were handled with sensitivity and dignity for presentation to carers. In the majority of positive instances of good practice encountered in our research, the service manager took the lead on the handling of the body and set a strong example of leadership at a difficult time for everyone involved.

Where care planning had been carried out effectively and good relationships had been built up with the deceased patient or resident, care staff had generally already determined how the deceased wished to be dressed and presented after death and whether there were any specific religious or spiritual processes to follow.

It was considered to be an emotionally challenging experience to 'lay out' the body, although a small number of care staff reported that carrying out this last act of personal care gave them a sense of pride and completion. Managers and senior staff should be aware of the emotional impact on less experienced staff of caring for the deceased and should provide guidance, supervision and support accordingly. Although these research findings relate specifically to the context of care homes, clearly these recommendations would be equally relevant to other care settings, such as hospital wards or hospices.

Care staff interviewed for this research stressed the importance of clearing reminders of the deceased person's illness – such as syringe driver equipment or a mouth care tray – from the immediate surroundings or room. It was felt that these items were potentially upsetting to the family and carers and that by their removal, care staff could emphasise that the resident was now at peace. Bereaved carers were allowed to take the time they needed with the deceased before arrangements were made for the transportation of the body to the funeral home. This enabled carers to undertake any cultural or spiritual rites or simply to have privacy for their grief.

Dignified and respectful farewells

A further aspect of care after death that was highlighted in the research was being able to wish the deceased person a respectful farewell. This was demonstrated in different ways in different settings, but the common principle was showing respect to the individual who had died. In the good practice examples we studied, staff were committed to the belief that residents should enter and leave the home through the front door. Therefore, when an individual died at the home, the staff did not attempt to hide the situation from other residents, arranging for the body to be carried out through the front door. Other residents and staff were given the opportunity to wish the resident farewell, when the body of the deceased was taken away from the care home, at the funeral, or at memorial service at the care home.

Information for family and carers

Information for the family and carers is discussed in more detail below, but it is important to note its relevance to this step of the pathway as well. Following the death of an individual, there is a range of information that family and carers may need. Practical issues such as obtaining a death certificate and registering the death are covered in the 'care after death' checklist included in the Liverpool Care Pathway. The checklist also covers signposting family and carers to bereavement services.

Bereavement support

In the care homes and hospices we studied, bereavement support for carers was often provided through formal or informal one-to-one sessions, as well as group sessions. Service managers encouraged carers to remain in contact with care homes and hospices in various ways, so that they could offer emotional support during the bereavement process. In some cases, the care home manager would contact the carers a short time after the death to check how they were coping and whether they wanted to talk to someone who was familiar with them and the deceased. In other cases, carers were invited to 'drop in' to the care home informally, or to attend open days.

The period after a person has died is obviously a sensitive time for the family and for carers of the deceased and the staff who were involved in providing end-of-life care. Care staff found it an advantage to have discussed and planned in advance what to do regarding any cultural or religious procedures that must be carried out immediately after death.

In summary, if a death occurs outside an individual's own home – for example, in a care home or hospital – staff must take responsibility for ensuring that the body is handled with due respect and dignity. The research demonstrated that staff felt positive about being able to give the deceased person a dignified 'goodbye'. Standard practice should incorporate the requirement to provide bereaved carers with good-quality information about the practical steps they need to consider, and where to access emotional support if they want it. Where possible, it should also be standard practice for service managers (or other senior members of staff) to make time to contact carers shortly after the death to find out how they are coping and to offer emotional support or signpost them to appropriate bereavement services.

Key lessons on care after death

- Health and social care professionals should be aware of the processes they can undertake after the death of a patient to show respect to the deceased person and their carers.
- Bereaved carers should have access to good-quality information about the practical steps they need to consider and where to access emotional support if required.

Information for patients and carers

An overarching principle of the End of Life Care Strategy (Department of Health 2008a) was that, for all the steps of the end-of-life care pathway, patients and carers must be able to access reliable, comprehensible and appropriate information as quickly as possible. The ready availability of this information could reduce some of the feelings of powerlessness and vulnerability that some patients and carers commonly feel near the end of life.

As outlined in the strategy, the carers of patients who are nearing the end of their lives play a significant role in enabling them to die in their place of choice, and carers should therefore be treated as co-workers, along with the wider health and social care team. One way to empower carers to participate in end-of-life care-planning, decision-making and support is to provide appropriate and timely information. Our research highlighted some examples of the importance of information in how professionals helped patients and carers. These included assessing the needs of carers, explaining the various aspects of end-of-life care, and signposting them to alternative or additional services if necessary and appropriate.

It was clear that the exchange of information between professionals, patients and carers was required and should therefore be available continually during the end-of-life care process (and after the process for carers).

Assessment and care planning

The research demonstrated how assessment and care planning were necessary for carers in order to determine at an early stage their own health care needs (such as their physical and emotional capacity to provide care) and the level of support they would need during the process of caring for a person nearing the end of his or her life and throughout the bereavement phase. In the community, these assessments and care plans also informed the health and social care professionals about the resources required by the carer to provide end-of-life care at home, such as specialist equipment or night-sitter assistance.

Carrying out an assessment also meant that professionals were prepared for issues that might arise for carers during the bereavement phase, for example, if the carer had previous experience of significant bereavement and/or had a limited social support network. Carers' needs can change over time and health care professionals should therefore treat assessment as a continuous process.

Hospices were particularly adept at routinely undertaking assessments and planning with carers, whereas care homes tended to do this in a more informal and ad hoc way. Sharing the expertise of hospices and care homes (as well as that of other health and social care providers) provides an opportunity for the consolidation of knowledge, culminating in the production of a standardised package consisting of guidance for professionals, care plan documentation and information leaflets about support services.

Information needed during the end-of-life care process

Information for patients and carers was shown by our research to be particularly essential when a patient wanted to die at home. Health care professionals we interviewed said that they would encourage patients and their carers to exercise the choice of being cared for at home by providing information about the types of support available, also explaining that it was necessary for such messages to be clear and realistic. Patients and their carers therefore required details about the resources that could be co-ordinated to help deliver end-of-life care at home.

Health care professionals should also ensure that carers have received clear directions about and understood when and how to administer medication, when and how to carry out care of pressure areas, and whom to contact if they are struggling to cope. At the same time, carers should be clear that support at home is dependent on demand and cannot always be available throughout a 24-hour period. Health care professionals should be clear about what carers can do during out-of-hours periods when service coverage may be reduced, for example, by explaining which hours GPs and district nursing teams work and by providing a direct telephone number for the out-of-hours GP service as an emergency contact.

In one care home we studied, care home managers described keeping an increased and regular level of contact with a resident's family/carers when it was clear that he or she was imminently approaching the end of life. This contact reassured the family and provided up-to-date information about the resident's condition, allowing the carers to prepare themselves and to make decisions about being present at the bedside when the resident died.

Signposting carers to support services

Health and social care professionals must recognise the emotional impact that providing end-of-life care has on carers. It is important that all staff members involved in a patient's care are sufficiently trained in communication skills and can signpost carers to a source of support, such as a carers' group or a member of staff who can provide support. For example, in Lincolnshire, one hospice ran support sessions specifically for carers. These provided important information or training about aspects of end-of-life care, as well as advice from other carers and a health care professional.

The emotional impact of providing end-of-life care can also be felt by professional care staff working closely with someone who is dying, such as care assistants and nurses in care homes. Recognising the emotions of care workers is important to ensure that their motivation levels are sustained and that they have the emotional and physical capacity to continue to look after other patients.

Health and social care staff who reported that they were confident in providing good end-of-life care also described being well supported by their colleagues and managers up to and following the death of a patient. There were varying methods for this type of support, such as managers having an 'open-door policy' for staff to approach them to discuss how they were feeling, managers providing positive and transparent feedback about the end-of-life care given, or the staff member being referred for more formal or professional support if necessary. There was agreement among all the staff interviewed that they were given time and space to express their grief and they were supportive of each other. This relates to other themes that have emerged from the study, namely the importance of communication and team work in end-of-life care.

In summary, the assessment of the information and support needs of patients and carers should be embedded in the advance care planning process. Discussing and including these details in the care plan should alert health and social care professionals to the current and potential future needs of patients and carers. A common concern for carers is physical and emotional fatigue, and health and social care professionals must maintain an awareness of how family and professional carers are managing their own supportive care needs. There should be adequate respite facilities built into end-of-life care services both for carers and those nearing the end of their lives.

Key lessons on information for patients and carers

- Carers should be considered to be key stakeholders and involved in decision-making and planning around end-of-life care needs.
- Advance care planning and inclusive communication is a valuable process for making care preferences transparent and ascertaining gaps in carers' capabilities to deliver care themselves, including their own health care needs (and issues about bereavement).
- Health care professionals should be honest and transparent with patients and carers with regard to the provision of support that exists in the community, to ensure that they have a realistic understanding of the services available.

4 Conclusions

The Marie Curie Delivering Choice Programme has provided a novel approach to improvements in the provision of end-of-life care, focusing service redesign on both need and gaps in provision in a local context, while also using evidence of good practice from other regions and areas of care.

This paper has drawn on research findings from The King's Fund's work with the programme to highlight examples of good practice that commissioners and service providers could consider adopting in their local execution of the End of Life Care Strategy (Department of Health 2008a).

In order to support primary care trusts (PCTs) with this implementation, we have examined how these examples of good practice fit into the pathway described in the strategy. In addition, a series of key lessons has been provided in relation to each of the stages of the end-of-life care pathway (*see* pp viii–x for an overview).

While considerable progress has been made on effecting the End of Life Care Strategy (Department of Health 2008a) in England, there is considerable room for improvement in ensuring the equitable provision of care that can meet patients' care preferences and deliver high-quality support to patients and carers across organisational settings.

In all the sites involved in this project, good communication and functional relationships with external stakeholders were clearly essential for ensuring that individuals' end-of-life care preferences were effectively shared across providers – and that these care preferences were ultimately met. The research highlighted the need for providers to operate collaboratively and draw on the various sources of assistance available in order to be able to manage the end-of-life care needs of patients within all settings more effectively.

Participants in this research were adamant that advance care plans should be used as a specific mechanism for supporting this communication and should be shared across other health and social care providers. Communicating patients' advance care plans across providers was essential to ensuring that their end-of-life care wishes were met.

It was evident in the research that the co-ordination of care was underpinned by various professionals helping each other by passing on skills and knowledge. Examples of this included:

- palliative care specialists advising GPs and district nurses on symptom control
- Marie Curie, Macmillan or British Heart Foundation nurses passing on advice to care homes about anticipatory prescribing, notifying out-of-hours services and having confidence in advocating for the residents
- district nurses helping care homes with the delivery of end-of-life care for residents by setting up syringe drivers or arranging for 'just-in-case' boxes of medication.

A significant obstacle to individuals being able to die at home was the availability and responsiveness of good-quality services during out-of-hours periods when crises and breakdowns in communication are more likely to occur. Good communication between GPs and their out-of-hours counterparts and/or rapid-response services (as well as with other health and social care providers) is essential to prevent this type of situation. Such communication is also pivotal in ensuring that patients' preferences are shared across all those involved in care, with patients subsequently being more likely to achieve their preferred place of care and death. This process can be supported formally via the use and communication of advance care plans.

Delivering high-quality care in the locations described is underpinned by training and education in the various aspects and processes of co-ordinating and delivering end-of-life care. This point applies not only to those working in different locations of care, but also to those responsible for co-ordinating care at the boundaries – through a discharge liaison role or central co-ordinating function. Areas that potentially required further training and support were highlighted across all of these care settings, and included:

- identifying the dying phase
- communication skills to handle breaking bad news to patients
- advance care planning
- increasing awareness of end-of-life care tools such as the Gold Standards Framework and the Liverpool Care Pathway
- increasing awareness of the resources available locally to deliver end-of-life care in the patient's preferred location, and how to access them
- how to communicate confidently with external service providers
- physical aspects of end-of-life care, such as symptom control, syringe-driver management, pressure area care and nutrition.

It is essential that training is available regularly to ensure that staff (particularly those offering more general care and in organisations that have a higher staff turnover) can refresh their knowledge and skills. Whereas local PCTs can commission training for NHS staff, there can be barriers to accessing training in the private and independent sectors, in which many care homes and independent care agencies delivering end-of-life care at home operate.

Our research found that some care homes had the capacity to train their staff on end-of-life care annually, using training materials they had developed internally. Education and training can be standardised and shared across providers to avoid unnecessary replication of materials and assist smaller agencies that may not have the infrastructure or staff support to manage educational activities themselves. Such sharing and joint production and delivery of training materials could be initiated across organisations within geographical regions. Future education and training policy must address these unmet training needs.

Service commissioners and providers must work together to establish a model of local end-of-life care provision that is able to meet care needs and fill current gaps effectively. This paper has highlighted a number of examples of good practice, as well as challenges, centring on the following broad themes.

- **Identification of end-of-life care needs** Inadequate identification of end-of-life care needs can prevent open communication with patients and carers with regard to care planning. Training, multidisciplinary co-ordination of care, and interprofessional access to palliative care records may act to overcome some of these issues.

- **Encouraging greater communication about prognosis and care planning** Specialist palliative care providers have a role in working with generalist health care providers to alleviate anxieties about initiating conversations about prognosis and care planning and increasing the confidence and competence of all providers.
- **Co-ordination of care** Advance care planning (and communication of plans within and across providers) can be an effective mechanism for ensuring patients' care preferences are achieved. Such a whole-systems approach to co-ordination of care should also include patients and their carers.
- **Whole-systems approach** End-of-life care is provided in a variety of organisational settings by a range of health and social care professionals. Service improvement must therefore be addressed by a whole-systems approach, in which attention is given to the entire pathway of care in order to ensure that high-quality care is achieved irrespective of the location, and patient preferences are better able to be met.

It is evident that the need for training, information and communication – both for health and social care professionals and patients and their carers – is vital if these recommendations and lessons for practice are to be achieved. Our research highlighted various examples of how important the timely provision of information is in helping patients and their carers to identify their end-of-life care options and raise their awareness of processes and outcomes. These included:

- assessing the needs of carers
- explaining the various aspects of end-of-life care
- signposting them to alternative or additional services if necessary and appropriate.

The ageing population, current financial crisis and what we know about patient preferences all point towards the need for considerable investment in the way that end-of-life care is organised and delivered at a local level. As patients near the end of their lives, they frequently need to interact with a range of different health and social care providers, which has historically been confused and fragmented. The Department of Health's End of Life Care Strategy (2008a) provided a considerable impetus for commissioners and service providers to look at the local provision of care and to work towards a more seamless service that is able to meet patients' preferences with regard to their care and the place of their death.

The strategy set out a clear pathway to guide commissioners towards service improvement, suggesting areas on which to focus their efforts. However, many commissioners and service providers are still struggling to implement the strategy and deliver innovative models of care within the current financial constraints. Although recent political and policy reform mean that provision and commissioning could look different in the future, the need for quality improvement in end-of-life care remains and should continue to be a significant focus.

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Appendix

Methodology

This action research study was based on the principles of realistic evaluation (Pawson and Tilley 1997), which suggest that when conducting an evaluation of a particular intervention, it is necessary to consider the wider context in which it is placed: the interaction between the intervention and the context will have an effect on the outcome or success of the initiative. This study therefore examined the context in which each programme site (the intervention) was situated – geographic, demographic and political – and then identified and tried to enact realistic recommendations for improving outcomes.

As this was an action research study, it had a strong interactive aspect and two main aims:

- to work closely with the stakeholders to identify barriers to effective service delivery and implement strategies to overcome them
- to identify examples of good practice and service development and delivery so as to gain a better understanding of the factors that were pivotal in this success and disseminate these lessons, which are presented in this paper.

The data collection stage of this research sought to identify aspects of the programme projects that were not performing effectively or were failing to reach their expected potential, as well as areas where examples of good practice or successful service development or delivery were evident.

This process of identifying challenges and examples of good practice was conducted through a case study approach, a method that is particularly suitable for the complex nature of health care systems, which are characterised by continual and rapid change (Yin 1994). The use of comparative case studies by Pettigrew and colleagues (1992) to analyse organisational change in the National Health Service (NHS), allowed for the analysis of retrospective change, real-time analysis and prospective or anticipated change. We can learn from singular cases by comparing them with other cases (Stake 2000).

Qualitative research and case studies are often criticised for being ungeneralisable, unscientific, subjective, biased and unreplicable. Mays and Pope (2000) propose that there is no simple way of ensuring the quality of qualitative research, although they do suggest a number of mechanisms for improving validity, including triangulation. Case studies do not typically strive to generate findings to be generalised to other populations, concentrating instead on in-depth understanding of typically complex situational contexts (such as health care). However, qualitative research can increase external validity through the selection of multiple cases for comparative analysis (Eisenhardt 1989). Internal validity is typically achieved through multiple data collection methods.

The use of multiple data sources, or 'triangulation', is an important method within case study research for strengthening the empirical grounding. Stake (2000) proposes that the multiple perceptions gained through consideration of various data sources acts to clarify meaning and verify repeatability of an observation or interpretation.

Several methods were used in this study to gather the data necessary for the analysis. These multiple data sources addressed a wide range of issues and provided a more convincing and accurate contextual account.

- **Analysis of existing research findings** The evaluation considered findings from independent outcome analyses of the programmes, such as that already conducted by Lancaster University and internal progress reports.
- **Consultation with staff from Marie Curie Cancer Care** The research team asked staff at both the national office and the project sites about examples of good practice and areas of concern that needed attention or intervention.
- **Documentary analysis** Documentation from the project sites (including planning reports, strategy documents, organisational structures, minutes of meetings and so on) was collated and analysed in order to determine the programme structure, current processes, areas of planning, and key stakeholders.
- **Observation of key meetings** Each programme site has an executive committee and stakeholder group, comprising Marie Curie staff plus health and social care managers, clinicians and commissioners from the project region. The research team observed these meetings in each of the three project sites for two reasons: so as to consider their discussions about aspects of current practice that facilitated or prevented effective service delivery; and in order to assist in building relationships with key local stakeholders.
- **Observation of intervention areas** The research team observed the work streams of the project sites in action so as to gain a better understanding of operational processes in practice. This observation focused mainly on the provision of Marie Curie services, rather than on those offered by the NHS.
- **Interviews with programme stakeholders** Interviews were conducted with members of the executive committees and stakeholder groups in each project site to ascertain their perspectives on aspects of current practice that facilitated or prevented effective service development and delivery (*see* Table 1 below).
- **Interviews with NHS and other service providers** The programme project sites interact with NHS and other service providers (such as social care and voluntary sector organisations), and as such this research also sought to ascertain the perspectives of these stakeholders on the operation of the project sites (*see* Table 1).

Table 1 Interviewees by role

Role	Number of interviews
District nurse	10
Health care assistant	2
Hospice nurse	5
General practitioner	3
Palliative care consultant	4
Hospital specialist	4
Practice nurse	6
Delivering Choice Programme team member	11
Service manager	39
Specialist nurse	20
Ward nurse	11
Adult social care	7
Care home staff	19
TOTAL	141

We analysed these various data sources in order to identify areas and examples of good practice for each of the programme sites. The analysis ascertained the factors associated with effective practice and service delivery, and sought to discover any impediments.

Data analysis

The analysis of the data was an iterative process and occurred in stages. The data was analysed following the model developed by Miles and Huberman (1994), which involves three stages:

- data reduction
- data display
- drawing of conclusions/verification.

Before qualitative data analysis began, a thematic coding framework was established based on the research questions and objectives, and this was used by the research team to code all transcripts (reduction). The coded data was then sorted deductively (display), which provided the basis for generating key findings and learning with regard to the organisation and delivery of services at the project sites. Verification was achieved by different members of the team carrying out the analysis and feeding back to the research steering group and local executive and stakeholder groups.

Additional codes and themes also emerged during the process of analysis, and have been incorporated into the results presented in this report. Each researcher's coding was cross-referenced and discussed within the team to ensure reliability and validity of analysis.

The data have been organised into general themes, and links and contradictions between the themes were examined. The data were then scanned for specific cases to illustrate and provide evidence for these themes. These findings and key lessons are supported by relevant literature where appropriate.