Improving choice at end of life

A DESCRIPTIVE ANALYSIS OF THE IMPACT AND COSTS OF THE MARIE CURIE DELIVERING CHOICE PROGRAMME IN LINCOLNSHIRE

Rachael Addicott and Steve Dewar

King's Fund

Delivery of care for patients at the end of their lives is increasingly a concern for policy. Although most people report that they would choose to die at home, only a minority of patients do so. In 2004 Marie Curie Cancer Care launched the Delivering Choice Programme, which aims to develop services that enable patients to be cared for and to die in the place of their choice. This paper provides a descriptive analysis of the impact and costs of new services as part of this programme, specifically in Lincolnshire.

Published by
King's Fund
11–13 Cavendish Square
London W1G 0AN
Tel: 020 7307 2591
Fax: 020 7307 2801
www.kingsfund.org.uk

First published 2008 by the King's Fund

Charity registration number: 207401

ISBN 978 1 85717 566 0

A catalogue record for this publication is available from the British Library

Available from:
King's Fund
11–13 Cavendish Square
London W1G 0AN
Tel: 020 7307 2591
Fax: 020 7307 2801

Email: publications@kingsfund.org.uk
www.kingsfund.org.uk/publications

Edited by Kathryn O'Neill
Typeset by Peter Powell Origination & Print Ltd
Printed in the UK by the King's Fund

Contents

List of figures and tables

About the authors

Rachael Addicott is a Senior Researcher in the Development Directorate at the King's Fund. Rachael is currently undertaking an evaluation of the Marie Curie Delivering Choice Programme – an initiative to give greater choice to patients in the place of their treatment and death. Rachael is working with service providers to streamline care processes in palliative care, as well as considering the Delivering Choice Programme as a model of service redesign. Rachael was previously a lecturer in health service management at Royal Holloway University of London and has a PhD in health service research from Imperial College London. Her current research interests include delivery of end-of-life care services, service redesign in health care and modes of governance in the public sector.

Steve Dewar is Director of Development at the King's Fund. He specialises in ideas for health care improvement, professionalism and the nature of personal and organisational learning. As a non-medic with a background in operational research, he had nine years' experience in the NHS as a researcher and public health specialist, and as change manager in a district general hospital. He has written extensively on a range of health care issues.

Acknowledgements

We would first like to acknowledge the assistance of Louise Price, from the Lincolnshire Marie Curie Delivering Choice Programme team, who generously undertook the onerous task of collecting data from local community service providers. We also extend thanks to the entire programme team and staff of Marie Curie Cancer Care, who provided valuable insights into the operation of the services and interpretation of the findings – particularly Nicky Agelopoulos, National Programme Director and Research and Development Advisor at Marie Curie Cancer Care.

We are especially grateful to Rod Jones (Statistical Advisor, Healthcare Analysis and Forecasting) and Rachael Williams (Research Statistician, Marie Curie Palliative Care Research Unit and Department of Mental Health Sciences, University College London), who provided expert advice and analysis of the data presented in this report.

We also wish to thank colleagues at the King's Fund for their invaluable support in refining the ideas presented in this paper – particularly Anna Dixon, John Appleby, Howard Glennerster and Theo Georghiou.

Summary

This report is a descriptive analysis of the impact and costs of new services implemented as part of a Marie Curie Cancer Care programme called Delivering Choice. The programme seeks to increase choice at the end of life, and this report looks at a project in Lincolnshire.

Marie Curie Cancer Care is a UK charity that provides nurses to give people with terminal cancer and other illnesses the choice of dying at home, supported by their families. It launched the Marie Curie Delivering Choice Programme in 2004. The programme aims to develop services that enable people to be cared for and die in the place of their choice. In 2007 Marie Curie Cancer Care commissioned the King's Fund to undertake this independent descriptive analysis of the impact and costs of the programme in Lincolnshire.

The analysis focuses on patients who accessed two new services – the rapid response team (RRT) and the discharge community link nurses (DCLNs). These services were specifically designed to improve choice for people who wish to die at home. The RRT is a community-based team that makes emergency and planned visits to patients in their homes during twilight (3.00pm–10.30pm) and out-of-hours periods (10.00pm–7.00am). The team also provides psychological support and guidance to patients and their carers over the telephone.

The programme has appointed two dedicated discharge nurses (based in the acute sector) whose role is to facilitate speedy discharge of patients with complex needs who are receiving palliative care to their preferred place of care. The DCLNs facilitate discharge by co-ordinating packages of home care, providing support and advice to patients and their carers, communicating patient needs to community health care teams and, if necessary, accompanying patients home to help them get settled. Part of their role is to provide information and support to patients, carers and their families, as well as to relevant primary care professionals.

The aim of this analysis was:
- to determine whether there are more people dying at home since the introduction of the programme
- to determine if there is a difference in the utilisation of acute and community care services (health and social care) before and after the programme was implemented
- to identify any changes in the pattern and scale of estimated costs as a result of changes in the use of acute and community services.

Given the retrospective nature of the analysis and the generic source of the data, it was not possible to define variables of specific interest regarding complexity of need in advance of the programme's implementation. Nor was it possible to establish a control group of patients to match those who accessed the programme services. However, within these limitations, we present a description of the changing patterns of activity over the period of the programme, using data from previous years for comparison.

Given the important and experimental nature of the Delivering Choice Programme, we believe this robust descriptive analysis to be a valid approach to gaining some insight into the impact of the programme. It will be useful in taking forward our understanding of how to improve services in an area that has for far too long remained under-researched.

Findings

HOME DEATHS

Overall, the Marie Curie Delivering Choice Programme is associated with an increase in the percentage of deaths at home and a corresponding decrease in the percentage of deaths in hospital when compared with previous years. The headline figure for home deaths rose from 19 per cent in 2005–6 to 23 per cent during the implementation of the programme (2006–7). This trend is statistically significant for all causes of death and for deaths from causes other than cancer (excluding accidental deaths), although not statistically significant for patients with cancer.

When the group of patients who accessed the programme services are considered in isolation, this percentage increase is even more pronounced. For those who accessed the programme services, the proportion of home deaths rose from 19 per cent in 2005–6 to 42 per cent in 2006–7, while remaining at 19 per cent for those who did not.

When we considered the type of service that patients accessed, we found that patients with cancer who accessed the DCLNs, and were then supported by the RRT to remain in the community, achieved an even higher rate of home deaths (54 per cent).

However, without a control group against which to undertake a more meaningful comparison, we have to leave open the possibility that the marked increases may demonstrate that the programme services are selecting and/or being accessed by patients who are able to and who wish to die at home.

ACUTE ADMISSIONS AND LENGTH OF STAY

In order to identify distinctive outcomes during the programme we focused our analysis on the main group of patients accessing its services – patients with cancer (who represent 77 per cent of the programme users for the locality and time frame chosen for the analysis). We focused on the last eight weeks of life, where we expected to see the programme having the greatest impact. We looked at descriptive data on length of stay, the number of admissions, the pattern of admission episodes and the costs associated with each event.

During implementation of the programme there was no statistical difference in the average bed days per admission used by all patients with cancer in the last eight weeks of life when compared to previous years. There was a fall in the average number of admissions per patient during this time, but this difference was not statistically significant. Among patients who accessed the programme services, we found that this fall in average number of admissions was more pronounced, although it was accompanied by an increase in the average length of stay per admission over the last eight weeks of life. It should be noted, however, that these results were also not statistically significant.

A more detailed look at the pattern of admissions and average length of stay per admission for those who accessed different services within the programme revealed some highly distinctive outcomes for the different services on offer.

- The average total length of stay and the number of admissions for those using the RRT were lower than the comparator provided by patients in previous years.
- Those who accessed only the DCLN service had a higher cumulative length of stay than an average patient with cancer in previous years.
- Those using the DCLNs and the RRT achieved a cumulative length of stay that was no different to the general population of comparable patients in the years preceding the programme.

It is difficult to accurately interpret these findings, given the lack of a control group and without being able to adjust the samples for complexity of need. Indeed, we might expect the group accessing the DCLNs to have increased length of stay given that the service was established with the intention of serving patients already in hospital with complex physical, emotional and/or social needs. In this case, the comparatively shorter average cumulative length of stay for the sub-group of patients using the DCLNs and the RRT might represent a positive outcome for a set of patients with potentially complex needs.

THE COSTS OF ACUTE CARE

The average cost of inpatient hospital care for patients with cancer in the last eight weeks of life in the year before the programme (2005–6) was £3,066. Following the introduction of the programme, the costs remained stable at £3,019. For patients specifically identified as being served by the programme, the costs of acute care were also similar, at £3,067.

However, there are differences in the costs of acute care across the different programme services.

- The group of patients who accessed the RRT have significantly lower average per person acute care costs than the corresponding average costs for all end-of-life patients over the previous two years.
- The group of patients with complex needs who accessed only the DCLN service have a significantly higher average per person cost than all the corresponding average costs for all end-of-life patients over the previous two years.
- For those patients who were served by the RRT and the DCLNs, there was no significant difference between their average costs and the corresponding average costs for all end-of-life patients over the previous two years.

Again, it is difficult to accurately interpret these findings given the lack of a control group, but the interpretation given to the pattern of length of stay and admissions is relevant here. Indeed, we might expect the group accessing the DCLNs to have increased costs in line with their increased likelihood of complex physical, emotional and/or social needs. The comparatively lower costs for those using the DCLNs and the RRT might represent a positive outcome for a group that is likely to have similarly complex needs.

THE COSTS OF COMMUNITY SERVICES

Providing a descriptive analysis of the costs of community services has proved difficult. In the absence of systematic, routine and electronic data on all the relevant aspects of the community care provided, we chose to collect data on a sample of 40 patients with cancer receiving palliative care before the programme was introduced and 40 patients with cancer receiving palliative care who accessed programme services.

The more detailed descriptive analysis of the services used by these patients reveals a mixed picture. While extra community support was being provided by programme services and community nurses, there was also a reduction in the number of GP contacts, 999 ambulance journeys and out-of-hours visits. Overall, there was no statistically significant change in the cost profile for community services.

OVERALL COSTS

Using these two sample groups, we also compared the average overall costs across acute and community services for each group. For the comparator group the average cost was £5,324; for those who had used programme services the average cost was £5,401. This combined acute and community average cost profile demonstrates no significant difference between the two samples.

We have set out to describe the distinctive outcomes that are identifiable from a retrospective analysis of generic data from before and after the Marie Curie Delivering Choice Programme was implemented. The rich picture of outcomes during the programme will take us forward in our desire to understand how to improve the complex system of end-of-life care, particularly to increase patient choice over the type of care they receive and where they receive it.

From our analysis, we can conclude that the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients with cancer receiving palliative care in the last eight weeks of life.

However, we should reiterate that there are some significant limitations to our analysis and consequent caveats to the conclusions. The distinctive outcomes achieved by different elements of the programme may indicate that individual services are reaching specific groups of patients, so it would be important to seek to define suitable control or comparator groups when taking this analysis forward. Only then will it be possible to reach more definite conclusions regarding the impact of the programme and its constituent parts.

Introduction

This is a retrospective descriptive analysis of the impact and costs of new services introduced to increase choice at the end of life for patients in Lincolnshire. The services at the heart of this descriptive analysis were established as part of a Marie Curie Cancer Care initiative called Delivering Choice.

Marie Curie Cancer Care is a UK charity that specialises in providing: high-quality palliative care to patients in their home; hospice care; training and education for health care professionals; research to improve quality of palliative care; and molecular research investigating the causes and treatments of cancer.

Marie Curie Cancer Care launched the Delivering Choice Programme in 2004. The programme aims to develop the best possible service for patients receiving palliative care, allowing them to be cared for and die in the place of their choice.

In 2007 Marie Curie Cancer Care commissioned the King's Fund to undertake this independent descriptive analysis of the impact and costs of the project in Lincolnshire. This report presents the results of that analysis and describes how the programme has changed the delivery of local health and social care services in the region.

The Delivering Choice Programme

Many more people, when well, express a preference to die at home than the actual numbers who go on to die at home (Higginson 2003; YouGov Survey 2008). Since people's preferences for their place of care are not systematically captured during the final months of their life, nor 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 in a different place than their actual place of death. It is, however, the contention of the Delivering Choice programme that many end-of-life patients are unable to achieve their preference because of a lack of choice.

Marie Curie 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 Marie Curie Delivering Choice Programme is that, through working in partnership with the NHS, the voluntary sector, social services and other health care providers, it is possible to develop patient-focused 24-hour service models that serve local needs and ensure that choice of place of care and death is available to all. The programme therefore set out to increase the proportion of home deaths across the Lincolnshire county.

The Delivering Choice Programme also aimed to ensure:

- the best possible care for patients receiving palliative care
- improvements in equity of access to services

- appropriate support services for patients receiving palliative care and their carers
- provision of information on choice to all patients receiving palliative care
- improvements in co-ordination of care among stakeholders.

All those involved in the programme, including the service providers and the commissioners of the newly designed services, wished to understand its impact on patient care. But they also wanted to know whether the new services may have led to shifts in the delivery of care from acute to community providers and the subsequent costs to the different providers and commissioners.

Palliative care is provided by a variety of organisations and professional groups that form a very complex system. The service redesign undertaken as part of the Marie Curie Delivering Choice Programme focused on co-ordinating the provision of palliative 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 palliative care, as well as opportunities to make improvements. The Marie Curie Delivering Choice Programme is currently active in five parts of the United Kingdom: Lincolnshire, Tayside (Scotland), Leeds, Barnet (London) and south-east London.

Each project is divided into three phases.

- **Phase I** This is the investigatory phase of the programme. It aims to understand the current state of services by gathering evidence and information on barriers to provision of care and choice for patients receiving palliative care. This evidence is then used to identify areas for improvement.
- **Phase II** Working closely with local stakeholders (such as the NHS, the voluntary sector and social service providers and commissioners), the project team redesigns services based on the areas for improvement identified during Phase I.
- **Phase III** This phase involves implementing the redesigned service models, performance monitoring and evaluation of outcomes.

Projects usually last for three years, with Phases I and II being completed in the first year and Phase III taking place over two years. This report analyses the impact and costs of service redesign during Phase III of the Lincolnshire project under the Marie Curie Delivering Choice Programme (September 2006 to March 2007).

The Lincolnshire project

Lincolnshire was the first project site to be launched in September 2004, covering the whole county. This analysis focuses on findings across the first seven months of the full implementation period – from September 2006 to March 2007.

When the project began, the partner organisations were:

- West Lincolnshire Primary Care Trust (PCT)
- East Lincolnshire PCT
- Lincolnshire South West PCT
- United Lincolnshire Hospitals NHS Trust

- Lincolnshire Social Services
- Lincolnshire Ambulance and Health Transport Service NHS Trust
- St Barnabas Hospice, Lincoln
- GIFTS Hospice
- Marie Curie Nursing Service
- Mid Trent Cancer Network
- British Heart Foundation

In 2006 the three PCTs merged to become the Lincolnshire Primary Care Trust. Otherwise, the partner organisations have remained the same. All have supported the programme team from the beginning of the project.

The investigation carried out in Phase I identified a variety of barriers and made numerous recommendations to improve provision of palliative care in Lincolnshire. Not all of these recommendations could be taken forward in Phase II of the project. Therefore, the project team focused on those changes that had the greatest potential to improve choice for patients who wanted to die at home. Accordingly, the Lincolnshire programme implemented a range of services.

- **Palliative Care Coordination Centre (PCCC)** The PCCC is an administrative centre that books packages of care for patients in the community. The majority of referrals to the service are made by district nurses who assess patient needs and decide on the home care support required, as well as the type of professional required to deliver the care. The PCCC receives the assessments from district nurses and books the care provision requested – thus attempting to ease the burden of administrative work, particularly for district nurses.
- **Educational activities and videoconferencing** This workstream has involved the establishment of videoconferencing facilities in different areas to provide access to education and training opportunities for those involved in palliative care provision across the county. An education and training co-ordinator has been appointed to assess staff training needs and co-ordinate and provide training. A rolling programme of lectures on different aspects of palliative care has also been established.
- **Wider support for patients and carers** The project team has worked closely with St Barnabas Hospice in Lincoln to establish carers' support groups through a monthly luncheon club meeting, facilitated by nursing staff. Information and emotional support is offered at these sessions. Volunteers provide transport for carers, Hospice at Home sitters and care for the patient while the carer attends the meeting.

However, the analysis presented here focuses specifically on patients who accessed two further new services – the rapid response team (RRT) and the discharge community link nurses (DCLNs). These two services were designed to have the greatest direct impact on improving choice for people who wish to die at home.

- **Rapid response team (RRT)** This is a community-based team that provides nursing services to patients requiring palliative care and professionals during twilight (3.00pm–10.30pm) and out-of-hours periods (10.00pm–7.00am). The RRT covers Boston, South Holland and surrounding areas, and makes emergency and planned visits to patients in their homes during the late afternoon, evening and overnight.

The team's nurses and health care assistants also provide psychological support and guidance to patients and their carers over the telephone.

- **Discharge community link nurses (DCLNs)** The programme has appointed two dedicated discharge nurses in Lincoln County Hospital and Boston Pilgrim Hospital to facilitate speedy discharge of patients receiving palliative care to their preferred place of care. The DCLNs facilitate discharge by co-ordinating packages of home care, providing support and advice to patients and their carers, communicating patient needs to community health care teams and, if necessary, accompanying patients home and help get them settled. Part of their role is to provide the necessary information and support to patients, carers and their families, as well as to relevant primary care professionals.

The rationale behind these models is that quick and timely services are crucial in end-of-life care. Patients and carers should have direct access to health care professionals who can respond to needs as they arise, taking into account that some needs concern psychological and social support rather than physical or medical help.

Aim of this study

The aim of this study is to analyse shifts in the delivery of palliative care from hospital to home, and the financial consequences of more patients receiving care at home, as compared to hospital. The objectives of this analysis are:

- to determine whether there are more people dying at home since the introduction of the programme
- to determine if there is a difference in the utilisation of acute and community care services (health and social care) before and after the programme was implemented
- to calculate the costs arising as a result of any changes in the utilisation of these acute and community care services.

Our analysis focuses on the RRT and the DCLNs. The following section describes the methodology used to analyse the impact of these services.

Methodology

Overview

This section describes the methodology used to analyse changes since the introduction of the programme in:

- the place of death for patients receiving palliative care
- the use of palliative care services
- the costs of care.

This is a retrospective and descriptive analysis of patterns of activity using generic data sources. It was not possible to define variables of specific interest regarding complexity of need in advance of the programme's implementation, nor was it possible to establish a control group to match those patients who accessed the programme services. The analysis does not therefore match the highest standards of research rigour or offer a clear-cut acceptance or refutation of a hypothesis.

However, bearing in mind these limitations, it does present a description of the changing patterns of activity over the period of the programme. Given the important and experimental nature of the Marie Curie Delivering Choice Programme, this robust descriptive analysis is a valid approach to generating early insights into the impact of the programme. It is therefore a useful contribution in an area that has for too long remained under-researched.

We have structured our analysis of the data in a number of ways. First, we focused on a particular locality and period of time in which services were fully implemented and active, so that we could identify any changes in activity that could reasonably be considered to relate to the new programme services.

Second, we looked at how the pattern of activity compared to patterns of activity in previous years (for the same locality and time period) so that we might generate some tentative hypotheses about the impact of the programme to inform future work in this area.

Third, we considered how these patterns of activity have taken a different shape for patients with different diagnoses. We were aware that patients with cancer were most likely to use the new services and wanted to focus on any apparent differences in outcome that could be related to the impact of the new services for this key group.

Finally, we looked within the group of patients using the new Delivering Choice services to inform our emerging understanding of how the rapid response team (RRT) and the discharge community link nurses (DCLNs) might, independently and together, lead to a distinctive set of outcomes and patterns of service utilisation.

The data

The use of Hospital Episode Statistics (HES) and primary care trust (PCT) Informatics data were approved by the Lincolnshire PCT research and development (R&D) group and the Caldicott guardian (reference code: 05/Q0104/74).

The research team requested and received an extract of inpatient services data from Lincolnshire PCT Informatics. Data were requested on all patients who died in Lincolnshire from 2004 to 2007, up until the date of the request (March 2007). We received a combined file with internal data from PCT Informatics (detailing place and cause of death) and data from the HES database (detailing characteristics of acute admissions). The PCT Informatics service used NHS numbers to match patients across the two datasets.

There was the potential for some records not to be matched in instances where, for any number of reasons, the NHS number was not collected by the admitting trust. However, Information Services at Lincolnshire PCT are confident that there were no systematic problems regarding matching or data quality.

From this complete dataset, we restricted the analysis to all patient deaths in Boston (Appendix 3 lists the postcode areas used to define the Boston locality) over a seven-month period in each of the two years preceding the programme – from September 2004 to March 2005 and from September 2005 to March 2006. During the programme's implementation, data were analysed for the seven-month period from September 2006 to March 2007.

We focused our analysis on the Boston area of Lincolnshire because this is where the two programme services – the RRT and one of the DCLNs – were based. By focusing on this locality, it was expected that any impact could be more easily identified.

This seven-month period was chosen to represent the phase when the programme was fully implemented and considered to have made an impact on service provision and patient care. To account for seasonal variation, it is compared to the same seven-month time period in the two years preceding the programme. There have been a number of additional exclusions and adjustments made to this dataset. These are detailed in Appendix 1 (*see* page 35).

The population was then separated into:

- deceased patients who received or accessed programme services (RRT and/or DCLN)
- deceased patients who did not receive or access programme services.

The Lincolnshire project team used the NHS numbers supplied in the dataset to distinguish whether or not the patient had accessed programme services. Those patients who had accessed programme services were then categorised into which service they accessed: (a) RRT, (b) DCLN, or (c) RRT and DCLN.

Data on patients who accessed the programme services were compared to data from the two preceding years (from September 2004 to March 2006). We also compared data on patients who accessed the programme services to the group of patients who died during the same period but did not access programme services.

The group of patients receiving palliative care who did not access programme services during this time may not have done so for a variety of largely unexplored reasons. Utilisation of (or access to) programme services may depend on: patient need; appropriate referral from an acute or community health care professional; recognition that the patient's condition is palliative in nature; availability of funding for community care for the patient; or the patient's or carer's desire to remain in the community, rather than in the acute sector. Any or all of these reasons may impact on patients' utilisation of the programme services. As such, there is no clearly defined control group against which to compare the patients who did access programme services. It is therefore unclear whether the patients who did and did not access the programme services represent two groups of patients with significantly different characteristics either in terms of their illness, social demographics or social support, or their personal preferences for care.

Demographics

Given the lack of any clear distinction between the populations that did and did not access the Marie Curie Delivering Choice Programme, it was important to consider the demographics for each group and identify any differences. The group of patients who accessed the programme services exhibit a similar age and gender profile to the general population of patients with cancer who died in Boston in the same year, and to the group of patients who did not access the programme services. Approximately 55 per cent of patients with cancer who accessed the programme services were female and 45 per cent were male. This compares to 52 per cent (females) and 48 per cent (males) in the group of patients who did not access the programme services.

A similar gender demographic profile is also shown for patients who accessed the programme services depending on which service they accessed – the RRT, the DCLNs or both. Again, it is evident that there are no clear gender differences between these groups.

The patients who did and did not access the programme services had a similar age profile – with the majority being more than 75 years of age. However, patients who accessed the DCLNs tended to be older (28 per cent were 85 or older) when compared to the group of patients who accessed the RRT alone (13 per cent were 85 or older). More detail regarding the demographic profile is provided in Appendix 2 (*see* page 39).

Determining the impact of the programme on place of death

We have considered the impact of the programme on place of death by analysing patient deaths in Boston. The dataset included a coded field describing the location of death. Categories recorded were: hospital, home, care home or hospice.[1]

Place of death was compared over time and between the groups of patients who did and did not access the programme services. By considering patterns in the place of death over time, we wanted to assess any change in the place of death prior to the introduction of the programme.

---

[1] 151 patients in the dataset were recorded as having died in an 'other' location. 'Other' typically referred to a death that occurred in a public place, such as a shopping centre or golf course, or a relative's house. For the purposes of this analysis, the location of these patient deaths was recorded as 'home', as these patients were based in the community receiving their care and can best be described as a patient living at home at the time of their death.

We have examined data for the two years prior to the introduction of the programme (September 2004 to March 2005 and September 2005 to March 2006), therefore we do not have sufficient longitudinal data to suggest a statistical trend. However, we can consider whether or not there is the suggestion of a pattern of change in the place of death in Boston over time.

Data are reported on the place of death for all non-accidental death patients in Boston. The data are then divided into an analysis of place of death for patients with cancer and patients who died of causes other than cancer.

Determining changes in the use of palliative care services

In order to compare the utilisation of health and social care services by end-of-life patients in Boston before and after the introduction of the programme, we first analysed the HES inpatient data to consider inpatient admissions, followed by a more detailed consideration of community service utilisation for a sample of patients.

Using these data, we considered hospital and community service utilisation for the last eight weeks of life. This time period was chosen to represent the period during which Marie Curie Cancer Care considers the programme to be most active in serving patients receiving palliative care.

The majority of patients who accessed the programme services died with a cause of death listed as cancer. In order to ensure that the analysis compared groups of patients with similar disease trajectories, the analysis of inpatient services has focused only on patients with a cause of death listed as cancer. In the seven-month period under analysis (September 2006 to March 2007), 46 per cent of patients who died of cancer had accessed the programme services.

In order to understand changes in the use of hospital and community services, we used a two-staged approach. First, we analysed hospital admissions and inpatient stays from the HES dataset. Second, we took a randomly selected small sample of cancer patients from Boston and looked in detail at their use of both hospital and community services. This approach allowed for a broad understanding of shifts in acute service utilisation, as well as a more in-depth consideration of consequential use of community services for a subset of patients.

ANALYSING THE IMPACT OF THE PROGRAMME ON INPATIENT ADMISSIONS AND LENGTH OF STAY

For hospital inpatient services, we examined the number of hospital admissions and the length of inpatient stay. Data were collected retrospectively on the number of admissions and length of inpatient stay for all patients with cancer who died in the Boston locality.

From the data, we were able to calculate hospital utilisation for the last eight weeks of life. As explained previously, this time period represents the period in which Marie Curie Cancer Care considers the Delivering Choice Programme to be most active in serving patients receiving palliative care. Data were examined to determine any shift in patterns of inpatient care over this time period for the group of patients with cancer specifically in the Boston area.

ANALYSING THE IMPACT OF THE PROGRAMME ON COMMUNITY SERVICES

A detailed piece of work was undertaken to provide more comprehensive and in-depth information on the community services utilised by a random subset of 40 patients with a cancer diagnosis receiving palliative care in Boston, both before and after the programme (total = 80 patients). This analysis assessed the utilisation of community services for health (including NHS, voluntary sector and agency services) and social care services in order to ascertain the impact of the programme on use of services from a wide range of service providers.

We conducted this analysis using a sample of 40 patients who died between January and May 2005 (before the programme was in place) and a sample of 40 patients who had accessed the programme services and died between January and March 2007.

The samples were randomly[2] selected from patients in the large dataset of all deaths in Lincolnshire, where the primary diagnosis was cancer and the place of residence was Boston. We then examined the use of community services in the last eight weeks of life. Data were collected directly from community service providers by a clinical member of the Lincolnshire project team.

The sample was necessarily small due to the time-consuming task of collecting this more detailed data from community providers. A variety of organisations and professional groups provide services in the community, and records of their provision are maintained by individual teams and organisations. Some of these records are electronic but others are paper records, which required substantial time to examine and extract the necessary data.

Data collected on community service utilisation

Data on the number of contacts the sample of patients had with service providers were collected from the following health and social care services (*see* Table 1 below). The project team member contacted each service provider in Boston, and used NHS numbers to track the utilisation of these services in the eight weeks preceding death.

TABLE 1: DATA ON COMMUNITY SERVICES CONTACTS COLLECTED FOR THE RANDOM SAMPLE GROUPS OF PATIENTS

General practitioner
District nurse (daytime)
Marie Curie nurse
Marie Curie health care assistant (HCA)
Agency nurse
Social service assessment
Hospice at home nurse
Hospice at home HCA
Out-of-hours service (after-hours paramedic)
Community Macmillan nurse
Planned discharge from hospital (Patient Transport Service & 999)
Ambulance 999 admissions from the community
Hospice (inpatient stay)
Social service home care
Equipment – mattress
Equipment – hoist

---

[1] The sample was randomised by using an online random number generator (www.random.org/integers/). NHS numbers in the large datasets were ordered in two files for the time periods considered (January to May 2005 and January to March 2007) and linked to a chronological number sequence. The random number generator then identified 40 random numbers for each of the two files. These random numbers were then linked with the chronological number sequence, and the associated NHS numbers were chosen as the two samples.

In addition, for the sample of patients taken after the programme's implementation, the number of contacts with the programme services was also collected (RRT, DCLN and the Palliative Care Coordination Centre). Data on inpatient admissions and length of stay was also collected for these patients from the HES dataset.

Calculating the costs of any change in the use of services

In order to estimate the cost implications of changes in the use of services across the acute and community sectors, we used several different sources for reliable unit costs. The majority of community service unit costs are taken from Curtis and Netten (2005, 2007), while programme costs have been supplied by Marie Curie. The cost of pharmaceuticals was not included in this analysis, as the use of drugs was assumed to be cost-neutral between the acute and community sectors. The cost of using each of the community services (listed above in Table 1) was calculated according to national unit costs where available. We have compared constant 2007 prices, and have adjusted previously supplied unit costs for inflation to 2007 prices where appropriate. The full list of unit cost calculations, sources and assumptions is detailed in Appendix 4 (*see* page 42).

The average utilisation and costs of acute care for each patient in the samples before and after the programme were also calculated over the last eight weeks of life. These data were then combined with the total average cost of community service utilisation. The total average cost of acute and community care was then compared between the two sample groups to identify any overall cost shifts or savings associated with the introduction of the programme (*see* Table 2 opposite).

There are some limitations to this analysis, as we have explained previously. Particularly, there is some addition of costs incurred by the PCT, and costs incurred to the service provider. However, wherever possible we have considered the costs incurred by the PCT.

It should be noted that this report has not considered the direct costs to patients and carers in the community through lost earnings, or the costs to the welfare budget of individuals receiving Attendance Allowance or Carer's Allowance. Rather, we have focused on the costs incurred by the PCT.

This section has detailed the methodology used to analyse changes in service utilisation during the period under analysis and to understand corresponding costs. The following two sections present the results of the analysis, and describe the impact of the programme on the place of death for patients receiving palliative care in the Boston area of Lincolnshire.

TABLE 2: CALCULATION AND SOURCE OF OVERALL AVERAGE COST SHIFTS BETWEEN ACUTE AND COMMUNITY CARE IN THE LAST EIGHT WEEKS OF LIFE

	Acute care costs	Community care costs	Total
Before Delivering Choice Programme was implemented	Average costs were calculated from the total number of bed days in the last eight weeks of life for a sample of 40 patients with cancer who died between January and May 2005. The cost of the bed days was sourced from the national Health Resource Group (HRG) cost, related to the diagnostic code supplied.	Costs were calculated on the average total cost of community services accessed in the last eight weeks of life for a sample of 40 patients with cancer who died between January and May 2005. Data were collected by a member of the programme team directly from service providers.	Average acute care cost + average community care cost January to May 2005 (from a sample of 40 patients) = overall average total cost per patient.
After Delivering Choice Programme was implemented	Average costs were calculated from the total number of bed days in the last eight weeks of life for a sample of 40 patients with cancer who died between January and March 2007. The cost of the bed days was sourced from the national HRG cost, related to the diagnostic code supplied.	Costs were calculated on the average total cost of community services accessed in the last eight weeks of life for a sample of 40 patients who accessed the programme and who died between January and March 2007. Data were collected by a member of the programme team directly from service providers.	Average acute care cost + average community care cost January to March 2007 (from a sample of 40 patients) = overall average total cost per patient.

Impact on place of death

The aim of the Marie Curie Delivering Choice Programme in Lincolnshire was to help patients to be cared for and die in the familiar surroundings of their home, if that was their wish. Previous research has indicated that most patients would prefer to die in their own home if the appropriate support were available (Higginson 2003; YouGov Survey 2008). Therefore, the expected outcome of the programme was an increase in the proportion of deaths at home for patients who accessed the programme services. The analysis presented here will largely focus on any shifts in the percentage of deaths at home.

Tables 3–5 (below, opposite, p 14) illustrate the place of death from all causes, from cancer and from causes other than cancer respectively (the latter excludes accidental deaths). We can see the overall movement in place of death over a three-year period, as well as the difference between those who did and did not access the programme services.

Comparing place of death – regardless of cause

TABLE 3: PLACE OF DEATH FROM ALL CAUSES IN BOSTON (TOTAL NUMBER) AND PERCENTAGE OF TOTAL FOR YEAR

Year		Hospital	Home	Care home	Hospice	Total
2004–5[1]		(684) 63.5%	(186) 17.3%	(195) 18.1%	(13) 1.2%	1,078
2005–6[1]		(672) 62.6%	(205) 19.1%	(188) 17.5%	(9) 0.8%	1,074
2006–7[1]		(614) 58.0%	(246) 23.2%	(187) 17.7%	(12) 1.1%	1,059
	non-DCP[2]	(529) 60.8%	(166) 19.1%	(166) 19.1%	(9) 1.0%	870
	DCP[2]	(85) 45.0%	(80) 42.3%	(21) 11.1%	(3) 1.6%	189

[1] September to March

[2] non-DCP = patients who did not access Delivering Choice Programme services; DCP = patients who accessed Delivering Choice Programme services

During the implementation phase of the programme (September 2006 to March 2007), the proportion of home deaths in Boston increased significantly, from 19 per cent in 2005–6 to 23 per cent in 2006–7 (p=0.003).

However, care needs to be taken in ascribing this positive shift exclusively to the impact of the programme. The data also show that there was a general increase in the percentage of home deaths in the two years prior to the programme's implementation, although this is not statistically significant.

Looking at the proportions of home deaths for those who accessed the programme services and those who did not may help our understanding. There was a significantly greater proportion of home deaths for patients who accessed the programme services (42 per cent) compared to those who did not (19 per cent). This represents a significant increase in the proportion of home deaths for this group when compared to the previous year ($p<0.001$). Indeed, the odds of dying at home are 3.1 times higher for those patients who accessed the programme services than for those in the preceding years.

The proportion of patients who did not access the programme services but who died at home (19 per cent) was the same as the proportion who had died at home in the previous year. These data demonstrate a distinctively different and positive outcome for patients who accessed the programme services.

However, the limitations of the data make it difficult to draw any definitive conclusions about the overall impact of the programme based on this positive descriptive finding. There are two relevant caveats. First, we need to leave open the possibility that an existing trend towards a greater proportion of home deaths may partly explain this pattern. Second, we are not able to determine whether there was any systematic bias in the group of patients accessing the programme – that is, whether these patients were already more likely to die at home. Indeed, both alternative explanations could be relevant.

Comparing place of death – those who died of cancer

Among the group of patients who died of cancer (*see* Table 4 below), there was no statistically significant difference in the total percentage who died at home ($p=0.601$) compared to previous years.

However, of the patients with cancer who died during 2006–7 and had accessed the programme services, a much higher proportion – 45 per cent – died at home. This represents a significant increase in the proportion of home deaths for that group when compared to previous years ($p<0.001$). Indeed, the odds of dying at home are 3.7 times

TABLE 4: PLACE OF DEATH FOR PATIENTS WITH CANCER IN BOSTON (TOTAL NUMBER) AND PERCENTAGE OF TOTAL FOR YEAR

Year		Hospital	Home	Care home	Hospice	Total
2004–5[1]		(171) 59.0%	(72) 24.8%	(35) 12.1%	(12) 4.1%	290
2005–6[1]		(169) 57.1%	(82) 27.7%	(37) 12.5%	(8) 2.7%	296
2006–7[1]		(172) 54.8%	(95) 30.3%	(35) 11.1%	(12) 3.8%	314
	non-DCP[2]	(108) 64.3%	(30) 17.9%	(21) 12.5%	(9) 5.4%	168
	DCP[2]	(64) 43.8%	(65) 44.5%	(14) 9.6%	(3) 2.1%	146

[1] September to March

[2] non-DCP = patients who did not access Delivering Choice Programme services; DCP = patients who accessed Delivering Choice Programme services

higher for the group of patients who accessed the programme services than for those in the preceding years. This demonstrates that the group of patients with a diagnosis of cancer who were supported by the programme were much more likely to die at home than the general population of patients with cancer.

A closer look at the proportions of home deaths for patients with cancer – depending on whether they did or did not access the programme services – gives good reason to interpret these descriptive data with care. It is noticeable that of the patients who did not access the programme services, fewer die at home (18 per cent) when compared to the proportion who died at home before the programme (28 per cent), although these differences are not statistically significant (p=0.114).

This suggests that we may be witnessing some bias selection within the programme towards those patients who have a greater wish to die at home. We are unable to determine the degree to which the programme is enabling home deaths for patients with cancer who would otherwise have died in hospital, and the degree to which it is facilitating a home death for those patients who were already likely to die at home.

Comparing place of death – causes other than cancer

Among patients who died of causes other than cancer, over the two years prior to the programme, 65 per cent died in hospital and 15–16 per cent died at home (*see* Table 5 below). In the period September 2006 to March 2007, the proportion of all patients who died from causes other than cancer and who died at home increased significantly to 20 per cent (p=0.010).

This is a good outcome but, as in the other comparative groups, the descriptive data give us some reason to consider alternative explanations other than a direct or isolated programme impact.

Among patients who accessed the programme services the proportion of home deaths was 35 per cent. This represents a significant increase when compared to previous years (p=0.006). Indeed, the odds of dying at home are 2.2 times higher for the group of

TABLE 5: PLACE OF DEATH FOR PATIENTS WHO DIED OF CAUSES OTHER THAN CANCER IN BOSTON (TOTAL NUMBER) AND PERCENTAGE OF TOTAL FOR YEAR

Year		Hospital	Home	Care home	Hospice	Total
2004–5[1]		(513) 65.1%	(114) 14.5%	(160) 20.3%	(1) 0.1%	788
2005–6[1]		(503) 64.7%	(123) 15.8%	(151) 19.4%	(1) 0.1%	778
2006–7[1]		(442) 59.3%	(151) 20.3%	(152) 20.4%	(0) 0.0%	745
	non-DCP[2]	(421) 60.0%	(136) 19.4%	(145) 20.7%	(0) 0.0%	702
	DCP[2]	(21) 48.8%	(15) 34.9%	(7) 16.3%	(0) 0.0%	43

[1] September to March

[2] non-DCP = patients who did not access Delivering Choice Programme services; DCP = patients who accessed Delivering Choice Programme services

patients who accessed the programme services than for those in the preceding years. However, among patients who did not access the programme services there was also a significantly higher percentage of home deaths compared to previous years ($p=0.042$).

This leaves open the possibility that there are significant factors in the wider environment (which may or may not be related to the programme) that are having a powerful influence on home death rates for patients dying from causes other than cancer over and above any specific programme impact.

Comparing place of death – patients with cancer accessing different programme services

When we looked at patients with cancer in the round, we could not draw a definitive conclusion as to whether the more positive outcomes for the group who had accessed programme services were as a direct result of the programme or a bias in the group selection. The following descriptive analysis at a finer degree of resolution does not change this finding. However, it does demonstrate that, within the programme, each service achieves a distinctive and significant outcome.

Table 6 below describes the place of death for patients with cancer depending on the specific programme service they accessed – the rapid response team (RRT), the discharge community link nurse (DCLN) or both. As mentioned previously, the DCLNs are tasked with serving patients with complex needs in the acute sector to aid discharge to the community, while the RRT responds to patient and carer crises in the community, regardless of complexity of need.

Table 6 shows the place of death for patients during the two years before the programme (combined). The 2006–7 figures are split into those patients who did access the programme services and those who did not. This replicates the figures in Table 4 (*see* page 13). Then the data are further split according to which service the patient accessed.

TABLE 6: PLACE OF DEATH AND TYPE OF SERVICE ACCESSED FOR PATIENTS WITH CANCER IN BOSTON (TOTAL NUMBER) AND PERCENTAGE OF TOTAL

Intervention			Hospital	Home	Care home	Hospice
Pre-DCP (2004–5 and 2005–6)[1]			(340) 58.0%	(154) 26.3%	(72) 12.3%	(20) 3.4%
2006–7[2]			(172) 54.8%	(95) 30.3%	(35) 11.1%	(12) 3.8%
	non-DCP		(108) 64.3%	(30) 17.9%	(21) 12.5%	(9) 5.4%
	DCP		(64) 43.8%	(65) 44.5%	(14) 9.6%	(3) 2.1%
		DCLN	(30) 83.3%	(0) 0.0%	(5) 13.9%	(1) 2.8%
		RRT	(18) 25.4%	(44) 62.0%	(7) 9.9%	(2) 2.8%
		DCLN + RRT	(16) 41.0%	(21) 53.8%	(2) 5.1%	(0) 0.0%

[1] Pre-DCP is the average of the two years preceding the programme

[2] September to March

The group accessing the RRT has a significantly higher percentage of home deaths at 62 per cent ($p<0.001$) when compared to the previous years, while the group served by both the DCLN and the RRT had an increased percentage of home deaths at 54 per cent ($p=0.002$) when compared to the previous years.

An interesting and important point to note is that of the patients who accessed the DCLN only, almost all died in hospital. Part of the referral criteria for accessing the DCLN is that patients must have complex needs (through physical, emotional and/or social factors). Nevertheless, 54 per cent of the patients with complex needs who accessed the DCLN and then went on to access support in the community by the RRT died at home (significantly more than the proportion of home deaths for those patients who did not access the programme).

These data may suggest that it is the combined impact of the DCLN and RRT that is best able to support patients with complex needs to remain in the community. Nevertheless, we also need to leave open the possibility that the categorisations represent groups of patients with distinctive characteristics and degrees of complexity, some of whom (in the DCLN-only group, for example) could not be safely or effectively supported in the community but required the support of an acute hospital setting.

Conclusion

The proportion of patients dying at home was relatively stable in the two years prior to the intervention. Those who received the intervention were more likely to die at home than those in previous years, and this was over and above any changes seen among those who did not receive the intervention. Patients in different groups within a single year may have different characteristics, but even overall (for those who did and did not receive the intervention) the probability of dying at home increased.

This percentage increases significantly (particularly for the group of patients who died from causes other than cancer) during 2006–7. Although this is not conclusive, it constitutes strong descriptive support for a programme-specific impact.

When the group of patients who accessed the programme services is isolated, this percentage increase is even more pronounced, and is also reflected in the group of patients with cancer. This marked increase may demonstrate that the programme services are self-selecting by targeting patients who have a greater wish to die at home (demonstrated by the significant decrease in home deaths and increase in hospital deaths in the group of patients with cancer who did not access the programme services). As there are no rigid inclusion or exclusion criteria for accessing the programme, and no systematic or randomised referral requirement, it is difficult to ascertain whether the group of patients who accessed the services demonstrates comparable social or physical characteristics to the group of patients who did not.

However, these findings do show that patients who utilise the programme services are more likely to die at home and less likely to die in hospital when compared to the two years preceding the programme and to a group of patients from the same period of time who did not access the programme services. We can suggest that, when given the option of accessing services designed to support patients receiving palliative care in the community, the result is a distinctive and more positive outcome for these patients. Perhaps the most important finding described above is shown in Table 6, which breaks these results down further depending on which programme service patients accessed. Marie Curie Cancer Care and the Lincolnshire project team have consistently argued that the programme is comprised of an interrelated package of services that work together to help patients receiving palliative care who choose to die at home. While the RRT service appears to have been successful in supporting all patients (regardless of complexity of need) in the community, the DCLNs in isolation have not achieved the same degree of success. None of the patients who accessed the DCLN service alone died at home, and 82 per cent died in hospital. By referral definition, this group represents patients with more complex needs (through physical, emotional and/or social factors) who require greater support in their care. The group of patients with complex needs who accessed the DCLN but were not supported in the community by the RRT were more likely to die in hospital than anywhere else.

However, patients with complex needs who accessed the DCLN and were then supported by the RRT to remain in the community were more likely to die at home rather than in hospital. Because of the limitations of the retrospective data, we have not been able to make adjustments for social or physical complexity of need, and as such these groups of patients may have different characteristics. However, these findings may suggest that the DCLN service is effective in increasing the percentage of home deaths for patients with complex needs, if that service is accompanied by appropriate community support. Further work to control for case-mix or severity of need would be the logical next step in pushing forward our understanding of the impact of this element of the programme.

This section has described the impact of the programme on place of death. The following section considers the impact of the programme on inpatient admissions and length of stay in acute hospitals.

Changes in service use and the costs of care

Acute hospital utilisation and costs[3]

One of the aims of the Delivering Choice Programme is to expedite discharge from hospital and to prevent unnecessary admissions into the acute sector. The role of the discharge community link nurses (DCLNs) is to arrange packages of care for patients with complex needs currently receiving palliative care in the acute setting in order to aid their return to the community. The role of the rapid response team (RRT) is to support patients receiving palliative care and their carers in the community, thus attempting to avoid unnecessary 999 calls and hospital admissions. On this basis, the expected outcome of the programme was a decrease in the average number of admissions (particularly for patients accessing the RRT) and reduced length of stay in the acute setting (particularly for patients accessing the DCLNs).

The degree to which the descriptive data available allows us to test such outcomes is limited by the lack of a control group for RRT or DCLN users. Nevertheless, comparing admissions and length of stay during the programme with previous years will give us a valuable starting point in understanding any distinctive changes in behaviour during the programme's implementation. An analysis of different groups of users within the programme will reveal some of the distinctive outcomes for each service.

HOSPITAL ADMISSIONS AND LENGTH OF STAY IN THE LAST EIGHT WEEKS OF LIFE

Table 7 (opposite) summarises the average number of admissions and length of stay for patients with cancer in Boston, across all comparator groups.

There was no significant difference in the average number of bed days per patient admission during the last eight weeks of life between the years preceding the programme and the introduction of the programme services ($p=0.219$).

The table shows that the group of patients with cancer who accessed the programme services:

- experienced a similar average length of stay per admission for the same period compared to previous years ($p=0.219$) and compared to the group of patients who did not access the programme services

---

[3] The analysis considers all acute hospital utilisation in the last eight weeks of life. Analysis of the data shows that there is considerable substitution between elective and emergency care, especially for patients with a diagnosis of cancer. In addition, the DCLN service is targeted at any patient with complex needs (that might prevent a speedy discharge) and so will affect the cost of both elective and emergency admissions. The analysis therefore includes both admission types in the number of admissions and the length of stay.

- experienced a lower average number of admissions in the last eight weeks of life when compared to previous years ($p<0.01$) and to the group of patients who did not access the programme services ($p<0.01$)
- overall spent fewer days in hospital during the last eight weeks of life (although not statistically significant).

TABLE 7: AVERAGE ACUTE SERVICE UTILISATION FOR PATIENTS WITH CANCER IN BOSTON IN THE LAST EIGHT WEEKS OF LIFE

Description	2004–5 pre-DCP	2005–6 pre-DCP	2006–7	non-DCP	DCP			
						DCLN	DCLN + RRT	RRT
Admissions per patient	1.5	1.5	1.3	1.5	1.0	1.4	1.3	0.7
Bed days per patient admission	14.9	13.2	12.8	11.0	14.7	28.9	18.2	5.7
Total number of bed days	22.4	19.8	16.6	16.5	14.7	40.5	23.7	4.0

Pre-DCP = before the Delivering Choice Programme was implemented; non-DCP = patients who did not access Delivering Choice Programme services; DCP = patients who accessed Delivering Choice Programme services.

This table shows that the group of patients who accessed the programme services had fewer admissions than previous years, a longer average length of stay per admission and in total a slightly reduced average number of days in hospital during the last eight weeks of life.

Comparing the figures according to which service patients accessed illustrates the highly distinctive outcomes achieved by each service.

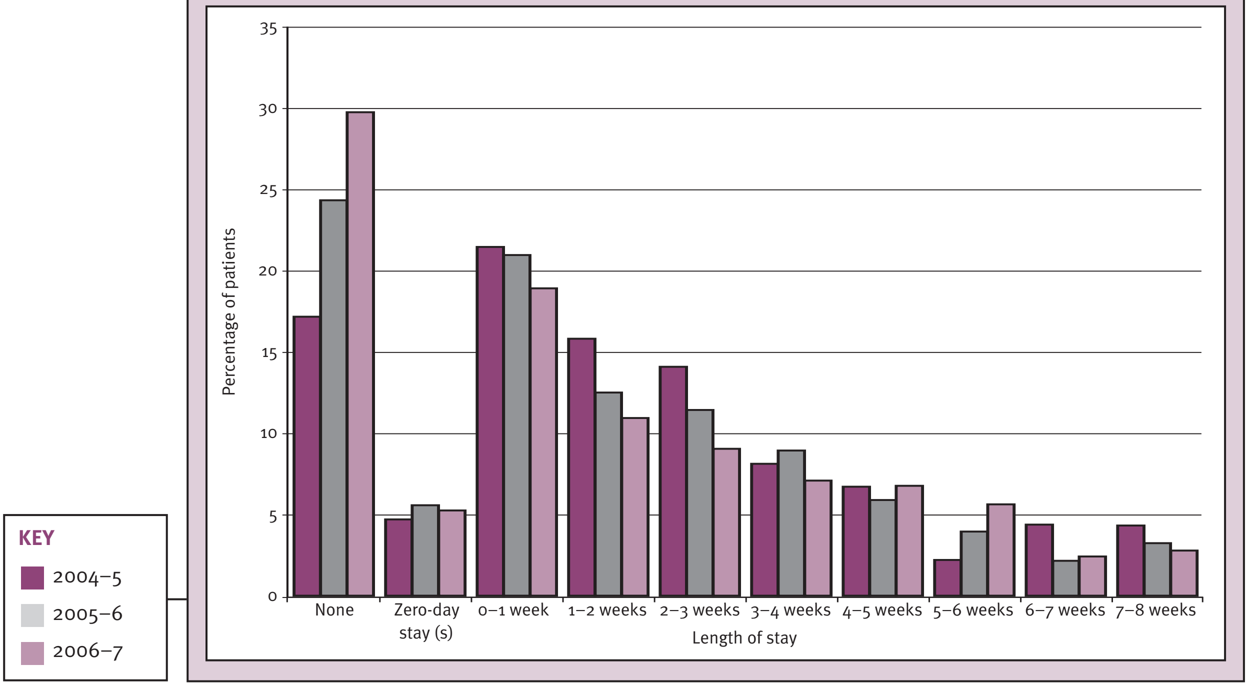
- The average length of stay per admission for patients accessing the RRT service was significantly lower than for patients in the years preceding the programme ($p<0.001$).
- Those patients who accessed the DCLN service had a significantly longer stay per admission than patients in the years preceding the programme ($p<0.001$).
- There was no significant difference in length of stay per admission between patients admitted in the years preceding the programme and the group of patients who accessed a combined RRT and DCLNs service ($p=0.103$).
- Those patients who did not access the programme services had a significantly lower number of bed days per admission than patients admitted in the years preceding the programme ($p=0.017$).

As the group of patients who did not access the programme also had a significantly shorter average per admission stay than patients admitted in the years preceding the programme, it might suggest that there is movement towards a reduction in the length of stay per admission for patients with cancer in Boston in general, regardless of the implementation of the Marie Curie Delivering Choice Programme. Or it could be that this descriptive analysis is consistent with highly distinctive groups of patients accessing the different services on offer, and differences we are seeing are because the services are attracting distinctive groups of patients with different complexity of need.

NUMBER AND LENGTH OF ADMISSIONS IN THE LAST EIGHT WEEKS OF LIFE

Figure 1 below shows the distribution of length of stay in hospital during the last eight weeks of life for patients with cancer in Boston in 2004–5, 2005–6 and 2006–7. This depiction is based on all patients with cancer in Boston who died during our selected seven-month time periods over the last three years. By examining overall yearly trends, we can assess the impact of the programme on the pattern of admissions for patients with cancer in the Boston area during the last eight weeks of their life.

1 LENGTH OF HOSPITAL STAY PER ADMISSION FOR PATIENTS WITH CANCER IN BOSTON DURING THE LAST EIGHT WEEKS OF LIFE[4,5]



The first set of three columns on the left-hand side of Figure 1 shows the percentage of patients with cancer in Boston who died outside of hospital with no admissions during the last eight weeks of life. It should be noted that this is only a subset of all those patients who die outside of hospital, as some patients may have had a hospital admission within the last eight weeks of their life but still died outside of hospital (these patients are represented in the other length of stay categories).

The other columns show the percentage of patients who experienced different lengths of stay per admission during their last eight weeks of life. It is important to note that a patient may have had a number of admissions during this period – for example: a zero-day stay admission, a two-day admission and a two-week admission. Each admission episode would be separately represented in this analysis.

---

[4] Some admissions crossed the eight weeks (or 56 days) before death boundary (ie, a patient may have been admitted to hospital 57 days before their death and remained in hospital for 5 days, thereby crossing the boundary into the last eight weeks before their death). For these admissions, only the length of stay within the last eight weeks of life was included in the analysis. This is to ensure that the analysis accurately and exclusively captures activity during the last eight weeks of life.

[5] A zero-day stay is defined as an admission and discharge on the same day.

Our aim in this analysis is to seek to understand what has happened to the pattern of admissions of different lengths of stay during the implementation of the Marie Curie Delivering Choice Programme. By using the percentage of patients with episodes of different lengths of stay we are controlling for the natural variation in the overall numbers of people dying. By looking at data for the last two years, we are seeking to put any changes in context, so that we can determine whether the change occurs only during the programme's implementation or may be part of a longer-term trend not related to the programme.

There are three relevant and useful findings illustrated by this descriptive data.

- First, during the period of the programme's implementation, an increasing percentage of patients with cancer in Boston died outside of hospital with no admissions during the last eight weeks of life. However, it is noticeable that this appears to be a growing trend even before the introduction of the programme.
- Second, there is an overall movement towards a reduction in the percentage of patients requiring admission for relatively short stays (zero-day stays, up to one week, between one and two weeks, between two and three weeks, and between three and four weeks) in the last eight weeks of life. In many cases this reduction was also evident before the introduction of the programme, although the movement has continued during the programme's implementation. However, the difference in length of stay across these time periods is not statistically significant ($p=0.219$).
- Third, there is an increase in the percentage of relatively longer stays (between four and five weeks, five and six weeks, and six and seven weeks) in the years preceding the programme.

Although none of these patterns reach statistical significance, they do provide a reasonable explanation for the overall increase in the cumulative stay per admission in hospital during the last eight weeks of life alongside a reduction in the average number of admissions per person.

What might these new patterns mean in cost terms for those commissioning services? It would be reasonable to expect costs to increase as a result of the longer length of stay per admission during the last eight weeks of life. However, we might expect this to be compensated for by the reduction in the percentage of shorter admissions, particularly zero-day stays and stays of less than a week, which attract a proportionally higher per diem cost.

COST OF HOSPITAL ADMISSIONS IN THE LAST EIGHT WEEKS OF LIFE

The corresponding costs of inpatient activity in the last eight weeks of life are shown in Table 8 overleaf. These inpatient costs were calculated using the Healthcare Resource Group's (HRG) admission code provided with admissions files in the Hospital Episode Statistics (HES) dataset.

When considering the average costs over time and the headline average costs for those who accessed the programme, the table illustrates the following key points.

- The average cost of inpatient hospital care per patient with cancer in the last eight weeks of life for the two years preceding the programme was £3,267 and £3,066 respectively.

TABLE 8: ACUTE SERVICE UTILISATION COST TRENDS FOR PATIENTS WITH CANCER IN BOSTON IN THE LAST EIGHT WEEKS OF LIFE

Description	2004–5 pre-DCP	2005–6 pre-DCP	2006–7	2006–7 non-DCP	2006–7 DCP	2006–7 DCLN	2006–7 DCLN+ RRT	2006–7 RRT
Mean cost per patient (standard deviation)	£3,267 (£2,646)	£3,066 (£2,816)	£3,019 (£3,112)	£2,977 (£3,002)	£3,067 (£3,243)	£5,065 (3,778)	£3,909 (£3,074)	£1,611 (£2,228)

- Following the introduction of the programme, the average cost of acute hospital care per patient (regardless of whether they accessed programme services or not) has remained relatively stable at £3,019.
- For patients who accessed the programme services the average cost of acute care per death is also similar, at £3,067.
- The difference between these average costs is not significantly different statistically over time ($p=0.464$) or between the year the programme was implemented and the preceding year ($p=0.706$).

However, the analysis provides more distinctive patterns of cost when we consider the different groups of patients accessing different programme services.

- The group of patients who accessed the RRT have a significantly lower average inpatient cost than patients admitted in previous years ($p<0.001$).
- For those patients who accessed either the RRT or DCLNs, there was no significant difference between the average cost per patient in the years preceding the programme and the group of patients using the combined DCLN/RRT service ($p=0.103$).
- The group of patients with complex needs who accessed only the DCLN service has a significantly higher average cost than in previous years ($p<0.001$).

CUMULATIVE LENGTH OF STAY FOR PATIENTS WITH CANCER IN THE LAST EIGHT WEEKS OF LIFE

This further piece of descriptive analysis seeks to illustrate the pattern of fewer shorter stays and the increasing number of longer stays seen in the admission episodes. In this case we are looking to see if the pattern continues for cumulative length of stay for individual patients during the last eight weeks of life. Figure 2 opposite demonstrates the length of stay in hospital in the last eight weeks of life, and the cumulative proportion of people with a length of stay up to eight weeks.

Figure 2 demonstrates a shift in the median length of stay in hospital for patients with cancer in Boston in the last eight weeks of life (represented at the 50 per cent mark). However, the overall movement towards a reduction in the median length of stay over time is also noticeable, both before and since the introduction of the programme. As such, the reduction in the median length of stay, while evident during the implementation of the programme, cannot be directly attributed to it.

2 OVERALL LENGTH OF STAY IN THE LAST EIGHT WEEKS OF LIFE FOR PATIENTS DYING OF CANCER IN BOSTON[6]

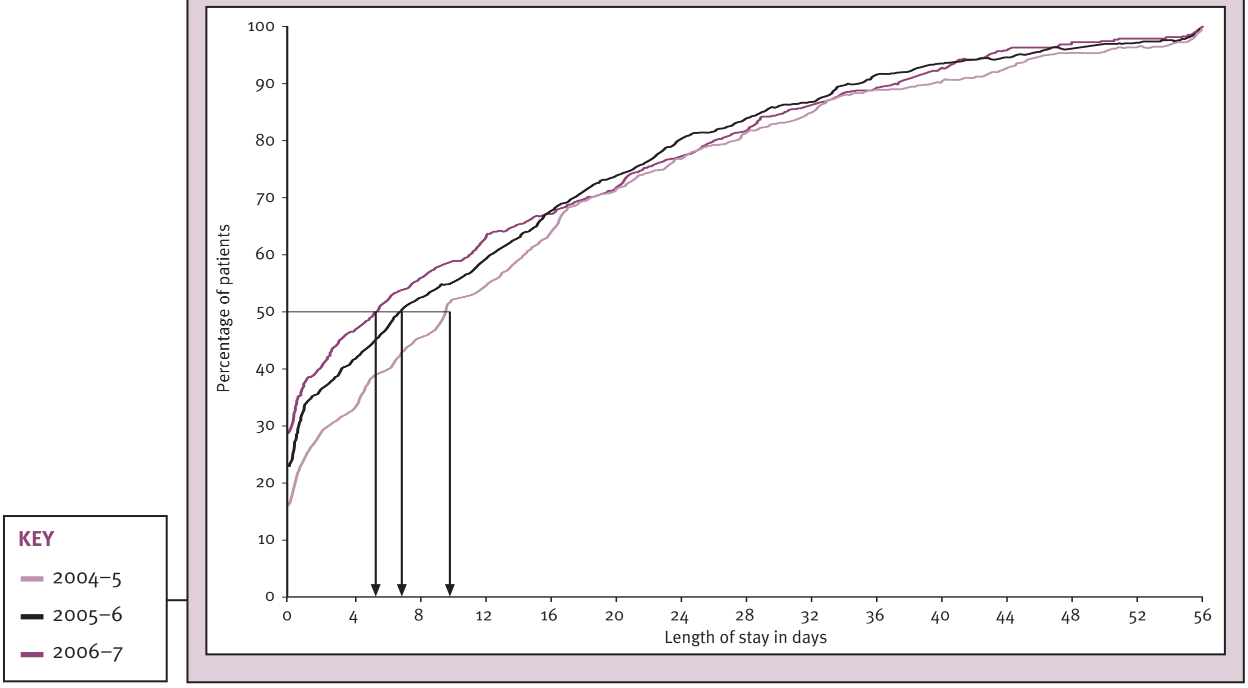


Figure 3 overleaf then divides the 2006–7 group into patients who did and did not access the programme services. The group of patients that did access the programme services is then further split into which service they accessed (RRT, DCLN or both). Figure 3 also includes data on the group of patients that did not access the programme services.

This graph demonstrates the following key points:

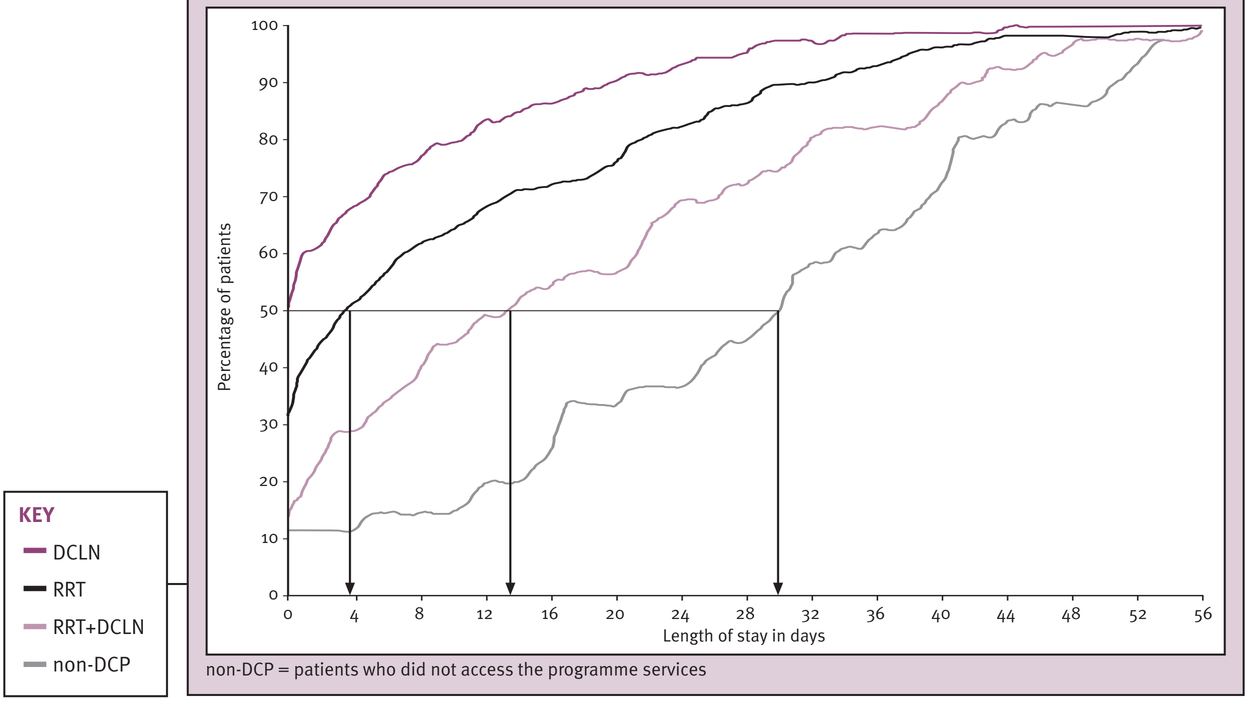
- The median length of stay in the last eight weeks of life (represented at the 50 per cent mark) is shorter for patients that accessed the RRT when compared to the group of patients that did not access the programme services.
- However, the group of patients that accessed the DCLN service alone had a considerably greater median length of stay when compared to patients who did not access the programme services.
- Those patients accessing both the RRT and the DCLNs also had longer median lengths of stay than the group of patients that did not access the programme services.

This analysis reinforces the earlier descriptive finding that within the Marie Curie Delivering Choice Programme we appear to have distinctive patterns of effect depending on which service or combination of services patients accessed. There are distinctive positive outcomes for those accessing the RRT service. Although the outcomes in terms of length of stay appear less positive for those accessing other services when compared to the overall comparative data, there are reasonable hypotheses that should be considered as to why the groups of patients accessing these services represent patients with more complex needs.

---

[6] On this graph, ‘0’ represents patients with no admissions, while a value of 0.5 has been ascribed to zero-day lengths of stay (ie, a patient who was admitted and discharged from hospital on the same day).

3 ADMISSION CHARACTERISTICS FOR PATIENTS DYING OF CANCER IN BOSTON[7]



non-DCP = patients who did not access the programme services

However, without robust and valid data for case-mix and the analysis of a control group, it is not possible to fully evaluate the impact of the programme on length of stay and acute care costs. Instead, we are able to present a picture of these distinctive patterns and plan future work to ensure that the issue of case-mix is factored into a more prospective and tailored exercise in data collection and analysis.

Community costs: analysis of a sample of patients

Community costs for patients receiving palliative care in Boston have been calculated using a sample of 40 patients before the introduction of the programme (January to May 2005) and 40 patients who accessed either the RRT, the DCLNs or both (January to March 2007). These are patients who died from cancer, and resided in the Boston locality of Lincolnshire.

Table 9 opposite details the average utilisation and associated cost for the specified community services for both samples in the last eight weeks of life. The table also details the average inpatient length of stay and associated costs for both groups. For reference, the median utilisation and cost for this sample is provided in Appendix 5 (*see* page 44).

---

[7] On this graph, ‘0’ represents patients with no admissions, while a value of 0.5 has been ascribed to zero-day lengths of stay (ie, a patient who was admitted and discharged from hospital on the same day).

TABLE 9: AVERAGE COSTS FOR COMMUNITY SERVICE UTILISATION[1]

	Sample of patients before introduction of the programme		Sample of patients who accessed the programme services		Mean difference (95% CI)		Summary of difference[2]
	Utilisation (SD)	Cost (£) (SD)	Utilisation (SD)	Cost (£) (SD)	Utilisation	Cost (£)	
GP contacts	4.2 (3.9)	730 (691)	2.2 (3.0)	378 (533)	-2.0 (-3.4, -0.4)	-352 (-597, -68)	Positive resource implications
Programme services Planned RRT visit (min)	0	0	9 (20)	13 (28)	9 (4, 16)	13 (5, 22)	Negative resource implications
Urgent RRT visit (min)	0	0	39 (68)	55 (96)	39 (20, 60)	55 (29, 85)	Negative resource implications
DCLN care (min)	0	0	82 (143)	192 (337)	82 (42, 128)	192 (100, 301)	Negative resource implications
PCCC[3] events	0	0	0.5 (0.5)	7 (7)	0.5 (0.3, 0.7)	7 (5, 9)	Negative resource implications
Agency HCA[4] day care (hrs)	2.6 (0.0)	49 (0)	7.8 (28.3)	149 (537)	5.2 (-1.8, 14.8)	99 (-35, 282)	Neutral
Agency HCA night care (hrs)	4.1 (0.0)	90 (0)	12.4 (38.7)	273 (851)	8.3 (-1.3, 22.3)	182 (-27, 471)	Neutral
Planned ambulance discharge	0.6 (1.0)	34 (54)	0.5 (1.3)	26 (68)	-0.2 (-0.6, 0.4)	-8 (-33, 21)	Neutral
Unplanned ambulance discharge	0.6 (1.0)	188 (307)	0.1 (0.3)	23 (110)	-0.5 (-0.8, -0.2)	-164 (-259, -69)	Positive resource implications
District nurse contacts (per visit)	9.7 (10.4)	679 (727)	8.1 (13.4)	565 (936)	-1.6 (-6.4, 3.7)	-114 (-451, 257)	Neutral
Out-of-hours care – after-hours paramedic	2.2 (3.3)	100 (147)	0.5 (0.8)	21 (37)	-1.8 (-2.8, -0.7)	-79 (-125, -33)	Positive resource implications
Hospice care (bed days)	0.1 (0.3)	16 (104)	0	0	-0.1 (-0.2, 0.0)	-16 (-55, 0)	Neutral resource implications
RN[5] day support (hrs)	1.6 (6.0)	44 (161)	3.4 (9.4)	91 (255)	1.7 (-1.3, 5.2)	46 (-35, 142)	Neutral
HCA day support (hrs)	0.6 (2.9)	8 (38)	4.5 (12.9)	59 (168)	3.9 (0.3, 8.6)	51 (4, 112)	Negative resource implications

[1] With mean difference and 95 per cent percentile confidence interval, based on 1,000 bootstrapped samples.

[2] Positive and negative resource implications are indicated only where the difference between the samples is statistically significant.

[3] PCCC: Palliative Care Coordination Centre.

[4] HCA: health care assistant.

[5] RN: registered nurse.

TABLE 9 (contd)

	Sample of patients before introduction of the programme		Sample of patients who accessed the programme services		Mean difference (95% CI)		Summary of difference[9]
	Utilisation	Cost (£)	Utilisation	Cost (£)	Utilisation	Cost (£)	
HCA night support (hrs)	0.6 (3.8)	8 (49)	5.8 (19.6)	75 (255)	5.2 (-0.2, 11.7)	68 (-2, 153)	Neutral
Marie Curie RN (hrs)	0	0	5.1 (11.6)	235 (534)	5.1 (1.9, 8.7)	235 (88, 402)	Negative resource implications
Marie Curie HCA (hrs)	0	0	9.9 (29.2)	208 (614)	9.9 (2.5, 19.9)	208 (52, 417)	Negative resource implications
Macmillan nurse (contacts)	3.0 (3.9)	235 (308)	2.4 (4.1)	190 (323)	-0.6 (-2.4, 1.3)	-45 (-186, 101)	Neutral
Social services assessment	0.4 (0.5)	31 (37)	0.2 (0.4)	13 (28)	-0.3 (-0.4, -0.1)	-19 (-32, -4)	Positive resource implications
Social services home care	1.9 (5.4)	26 (75)	0.1 (0.4)	1 (6)	-1.8 (-3.6, -0.3)	-25 (-51, -4)	Positive resource implications
Equipment – mattresses (days)	24.5 (25.1)	343 (352)	20.8 (24.8)	291 (345)	-3.8 (-15.0, 7.0)	-53 (-209, 97)	Neutral
Equipment – hoists (days)	21.0 (24.8)	105 (124)	5.6 (17.0)	28 (85)	-15.4 (-24.4, -6.0)	-77 (-122, -30)	Positive resource implications
TOTAL		2,689 (1,911)		2,892 (3,706)		204 (-909, 1,538)	Neutral
Acute service utilisation – mean (standard deviation) and median community service utilisation and cost							
	Sample of patients before introduction of the programme		Sample of patients who accessed the programme services		Mean difference (95% CI)		Summary of difference
	Utilisation	Cost (£)	Utilisation	Cost (£)	Utilisation	Cost (£)	
Acute service bed days	15.2 (17.0)	2,636 (2,495)	13.1 (15.2)	2,509 (3,405)	-2.1 (-9, 5)	-126 (-1,357, 1,305)	Neutral

It is worth explaining some of the complex detail in Table 9. One of the most notable features is that the sample of patients who accessed the programme services had a lower usage of GP services. Patients in the sample before the programme was introduced had an average of 4.2 GP contacts in the last eight weeks of their life (standard deviation = 3.9). This compares to an average of 2.2 GP contacts for patients who accessed the programme services (standard deviation = 3.0). The mean difference between the two groups is thus 2.0, with a confidence interval of this difference ranging from 0.4 to 3.4.

By taking the unit cost of a GP contact (as detailed in Appendix 4, *see* page 42), the associated mean costs are £730 per patient for the sample of patients before the programme was introduced, and £378 for the sample that accessed the programme services. This presents an average cost difference for GP contacts of £352 – with a confidence interval of this difference ranging from £68 to £597. As the confidence interval does not cross zero, we can conclude that the difference is statistically significant.

There were also significant reductions in 999 ambulance journeys, out-of-hours visits, hoists, social services assessments and home care for the sample of patients who accessed programme services. These reductions and cost savings are, however, offset by a higher level of programme and community nursing costs. All programme contacts and costs provided through the RRT, DCLN and PCCC are additional costs when compared to the sample of patients before the programme was introduced. We can also see a significant increase in the level of support provided to patients accessing programme services by HCAs (either agency staff or Marie Curie nurses and HCAs).

This may indicate that much of the reactive and emergency care that has been traditionally provided in the community is now being delivered in a more co-ordinated manner – specifically the increases in planned programme and other nursing contacts and a reduction in 999 ambulance journeys. These findings may have implications for service providers, with a reduction in the utilisation of GP services and an increase in the utilisation of planned nursing care.

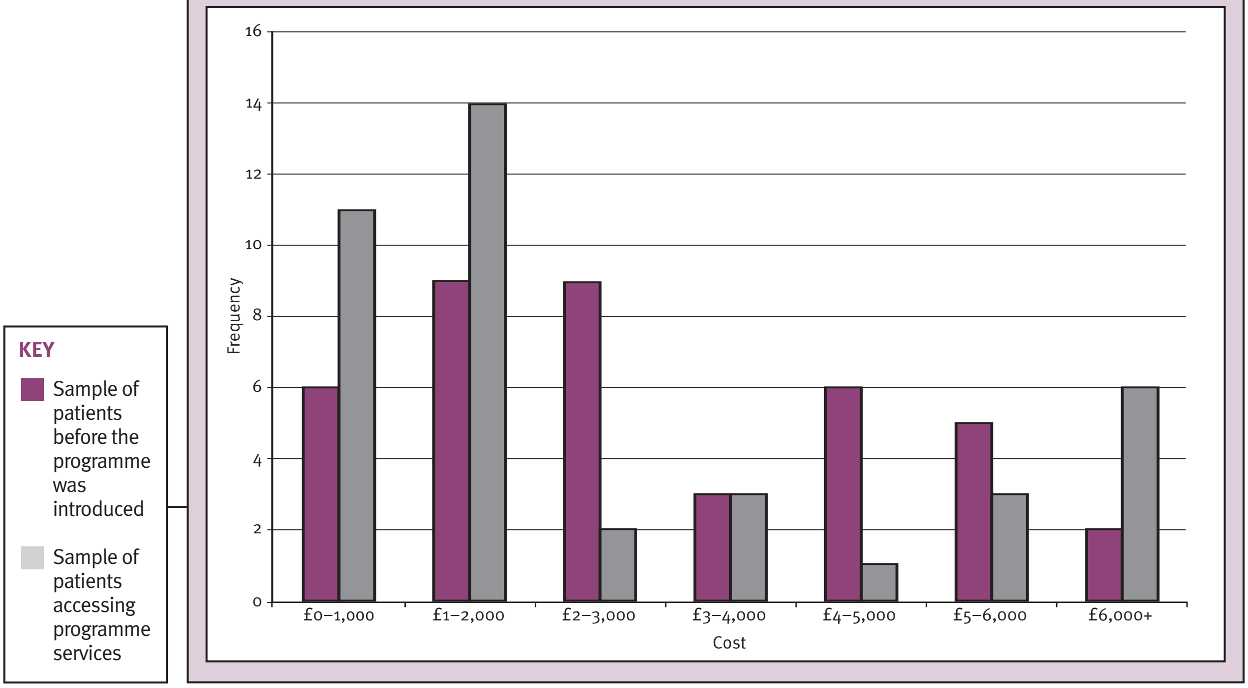
Table 9 describes the average number of contacts and costs across the sample groups. Figure 4 overleaf depicts the distribution of these community costs per patient in each group. The distribution of costs for the first group (before the programme) is much less variable, with the highest cost being £6,784 compared to £35,363 in the second group (patients who accessed the programme services). Indeed, the presence of some expensive outliers in the sample (patients who are costing a considerable amount of money to support in the community) highlights the potential for intensive care at home to reach very high costs in a small minority of patients.

Given this variability in costs, it is interesting to note that the median cost per patient is £2,697 for the first group and £1,632 for the second group. By examining the median instead of the mean, the difference between the two groups is more pronounced. It should be noted, however, that these findings are not statistically significant.

CASE STUDY COST PROFILES

The section below provides a more detailed description of the acute and community services utilised by the highest and lowest cost patients described above, comparing the highest cost patient from the first sample (before the programme was implemented) with the highest cost patient from the second sample (during the programme's implementation), and the lowest cost patient from the first sample with the lowest cost patient from the second. It should be noted that the high and low costs in Figure 4 and in the box overleaf are calculated on community service utilisation and do not take into consideration utilisation of acute services.

4 DISTRIBUTION OF COMMUNITY COSTS FOR SAMPLE OF 80 PATIENTS WITH CANCER IN BOSTON IN THE LAST EIGHT WEEKS OF LIFE



HIGHEST COST PATIENTS

Sample of patients before introduction of the programme

65-year-old female

Died at home, pancreatic cancer

Cost of £6,784.41 in the community

14 bed days (over 2 admissions)

Greatest expense accounted for through:

- 14 GP contacts (£2,257)
- 24 district nurse contacts (£1,361)
- hoist and mattress for the full eight weeks (£1,062)

This patient also received agency nursing, planned ambulance discharges, 999 calls from the community, out-of-hours calls, hospice at home RN support, and a social service assessment and home care.

Sample of patients who accessed programme services (outlier)

78-year-old male

Died at home, lung cancer

Programme service: 65 minutes of urgent RRT visits; 1 PCCC care package arranged

Cost of £35,362.83 in the community

No admissions

Greatest expense accounted for through:

- 353 hours of agency nurses and HCAs (£5,535)
- Marie Curie RN and HCA contacts (£4,949)
- Hospice at home support RN and HCA (£2,500)
- 13 GP contacts (£2,096)
- 30 district nurse contacts (£1,701)

Patient also received out-of-hours calls, Macmillan nurse contacts and a hoist and mattress for the full eight weeks.

LOWEST COST PATIENTS	
Sample of patients before introduction of the programme	**Sample of patients who accessed programme services**
60-year-old male	82-year-old male
Died in hospital, bladder cancer	Died in hospital (A&E), liver cancer
Cost of £414.16 in the community	Cost of £123.58 in the community
39 bed days (1 admission)	No admissions
Received minimal agency nursing in the community.	DCP service: 35 minutes of urgent RRT visits
	Received a social service assessment. No other community support.

Total health and social care costs

The combined community and acute costs are summarised in Table 10.

TABLE 10: SUMMARY OF AVERAGE ACUTE AND COMMUNITY COSTS PER PATIENT WITH CANCER IN THE LAST EIGHT WEEKS OF LIFE IN BOSTON

	Average cost per person in acute sector (standard deviation)	Average cost per person in community sector (standard deviation)	Total average cost per person (standard deviation)
Sample of 40 patients before introduction of the programme	£2,636 (£2,495)	£2,689 (£1,911)	£5,324 (£2,910)
Sample of 40 patients who accessed programme services	£2,509 (£3,405)	£2,892 (£3,706)	£5,401 (£4,409)

This combined acute and community average cost profile demonstrates no significant difference in costs between the two samples. The small rise in total average costs for those accessing the programme services should not attract attention given the large confidence interval and the large distribution of costs per patient in this sample. Indeed, removing one high-cost patient would have reduced average costs for this sample to below the average costs for the other sample (cost per patient before introduction of the programme). Similarly, an analysis of median costs would also have produced a substantial (if not significant) decrease in average costs for the group of patients who accessed programme services. It is important to emphasise that this analysis demonstrates no meaningful difference in the average overall cost of care per patient between the two samples.

Conclusions

This report provides an independent retrospective and descriptive analysis of outcomes associated with the Marie Curie Delivering Choice Programme. We have identified distinctive patterns of outcome for patients accessing different services within the programme. We have also compared these outcomes with comparative data from before the programme was implemented, and data on those patients who did not access the programme services. We have focused on describing changes in outcome in three key areas: place of death; inpatient admissions and length of stay; and community service utilisation and costs.

Impact on place of death

Overall, the Delivering Choice Programme is associated with an increase in the percentage of deaths at home and a corresponding decrease in the percentage of deaths in hospital for patients in Boston when compared with previous years. The trend is statistically significant for all causes of death and for deaths from other causes. The difference in the percentage of deaths at home for patients with cancer was not statistically significant when compared to the proportion of home deaths in the previous year.

When the group of patients that accessed the programme services is considered in isolation, this percentage increase is even more pronounced, and is also reflected in the group of patients with cancer. However, this marked increase may demonstrate that the programme services are selecting and/or being accessed by patients with a greater desire to die at home (evidenced by the significant decrease in home deaths and increase in hospital deaths among the group of patients with cancer that did not access the programme services). It is difficult to determine whether the patients who accessed the programme services demonstrate social or physical characteristics comparable to the group of patients who did not. However, they did appear to be of a similar age and gender profile.

When we considered the type of service that patients accessed, we found that patients with complex needs who accessed the discharge community link nurses (DCLNs) and were then supported by the rapid response team (RRT) to remain in the community were more likely to die at home than in hospital. These findings may suggest that the DCLN service is effective in increasing the percentage of home deaths for a group of patients with complex needs, but only if it is accompanied by appropriate community support. Further work to control for case-mix or severity of need would be the logical next step in pushing forward our understanding of the impact of this element of the programme.

Impact on acute length of stay and costs

In order to describe any distinctive outcomes during the programme we focused our analysis on the main group of patients accessing its services – patients with cancer (who represent 77 per cent of the programme service users for the locality and time frame chosen for our analysis). We also focused on the pattern of admissions, length of stay and costs associated with the last eight weeks of life where we expected to see the programme having the greatest impact.

During implementation of the programme there were no statistical differences in the average number of admissions per patient or the average bed days per admission used by patients with cancer in the last eight weeks of life when compared to previous years. When we looked at the patients who accessed the programme services we found a statistically significant fall in average number of admissions, although it was accompanied by an increase in the average cumulative length of stay per admission over the period.

To summarise, the group of patients that accessed the Delivering Choice Programme services had slightly fewer admissions than the comparator groups for previous years or those in the same year that did not access the programme services, although these admissions averaged a greater number of days.

A more detailed look at this pattern of admissions and average cumulative length of stay for those who accessed different services illustrated highly distinctive outcomes for each of the services.

- The average total length of stay as well as the number of admissions for those using the RRT was significantly lower than the comparator provided by patients in previous years.
- However, those who received the DCLN service alone had a greater total length of stay than a patient with cancer in previous years.
- Patients who accessed both the DCLN and the RRT averaged a cumulative length of stay that was no different to the general population of comparable patients in the years preceding the programme.

It is difficult to interpret these findings accurately given the lack of a control group or the inability to adjust the group of patients who accessed services and comparator groups for case-mix or severity of need. Indeed, we might expect the group accessing the DCLN service alone to have increased lengths of stay in line with its greater likelihood of complex physical, emotional and/or social needs. In this case, the comparatively shorter lengths of stay for those using both the DCLNs and the RRT might represent a positive outcome for a group of patients with similarly complex needs.

Looking at the pattern of admission episodes during implementation of the programme also helped us to provide a richer description of how the programme appears to have changed the pattern of services. When we considered how the pattern of admission episodes had changed, we found that during the programme's implementation there were fewer short-stay admissions and a slight increase in longer-stay admissions. This would be consistent with a more planned approach to care for patients with cancer over the last eight weeks of life.

We also looked at the implications of these changing patterns of care on the costs of acute care for this group, both before and after the implementation of the programme. The results, unsurprisingly, follow a similar pattern to the findings on length of stay and admissions, in that there is no significant change for the group of patients that accessed programme services as a whole compared to previous years. But there are some very distinctive findings for patients who accessed specific programme services.

First, we considered the analysis of overall costs for acute care. The average cost of inpatient hospital care for patients with cancer in the last eight weeks of life in Boston for the two years preceding the programme was £3,267 and £3,066 respectively. Following the introduction of the programme, the average cost of acute hospital care per patient (regardless of whether they accessed programme services or not) has remained relatively stable at £3,019. For patients who accessed the programme services, the average cost of acute care per death is also similar at £3,067. The difference between these average costs and those of the pre-intervention period is not statistically significant.

Second, we looked at costs of acute care across the different programme services. Here, the analysis provides more distinctive patterns of cost.

- The group of patients that accessed the RRT had a significantly lower average inpatient cost than in previous years.
- The group of patients with complex needs that accessed the DCLN service alone had a significantly higher cost than previous years.
- For those patients who accessed the RRT and DCLN, there was no significant difference between the average cost per patient in the years preceding the programme and the group of patients using the combined DCLN/RRT service.

Again, it is difficult to interpret these findings accurately. But the interpretation given to the pattern of length of stay and admissions is relevant here. Indeed, we might expect the group accessing the DCLNs to have increased costs in line with its greater likelihood of complex physical, emotional and/or social needs, while the comparatively lower costs for that accessing both the DCLNs and the RRT might represent a positive outcome for a group with similarly complex needs.

Impact on the costs of community services

Providing a descriptive analysis of the costs of care in terms of community services has proved more difficult. In the absence of systematic routine and electronic data on all the relevant aspects of the community care provided, we chose to collect data on a sample of 40 patients from before the programme and 40 patients from during the programme's implementation.

Examining the data from this sub-set of cancer patients in Boston, there has been an increase in the utilisation and subsequent costs of community care for those patients in the programme group. This finding was expected, as palliative care patients need to be supported in the community in order to prevent admissions into the acute sector. However, this increase in community support provided by programme initiatives and community nurses is cancelled out by a reduction in the number of GP contacts, 999 ambulance journeys and out-of-hours visits. In addition, the sample demonstrates large variability across the 40 individual patient costs, including one highly expensive patient where the costs of community care were more than five times that of the most expensive pre-intervention patient.

Overall costs of care

On the basis of a detailed analysis of the costs for two random samples of 40 patients, one chosen from patients before the programme was implemented and one from those who accessed programme services, there appears to be no difference in the overall costs of care as a result of the new services.

Key findings

There are many limitations to such a retrospective and descriptive analysis of data without any control groups against which we might measure impact for patients accessing the Marie Curie Delivering Choice Programme services, with adjustments for case-mix or severity of need. However, the rich picture of distinctive outcomes for the programme includes a number of important findings that should not be lost amid the appropriate caveats about the limitations of this kind of study.

To summarise, the project in Lincolnshire has significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients receiving palliative care in the last eight weeks of life.

It is important to remember that the objective of the Marie Curie Delivering Choice Programme is to provide patients with greater choice over their care and place of death, rather than to specifically reduce the costs of palliative care.

As such, we can conclude that the findings presented here demonstrate that the programme has successfully achieved its objective while not incurring any additional costs on the health care system or indeed incurring any significant overall shifts in costs between the acute and community sectors.

However, we should reiterate that there are some limitations to this analysis – particularly regarding comparisons between the different groups of patients. All patients could have accessed the programme services and there is very limited information on the characteristics of the patients who did and did not access the services. We cannot therefore offer any more definite conclusions regarding the impact of the programme.

Data limitations and further research

We were unable to determine whether the two groups of patients (those who accessed the programme services and those who did not) have similar profiles, in either physical or social circumstance. It is possible that there is some self-selection bias, with patients (and their carers) who have a greater desire to remain in the community being more likely to be referred to, or access, the programme services. Therefore, the group of patients that did not access programme services may likewise be disproportionately comprised of patients who wished to remain in the acute setting, or who experienced more complex symptoms that required inpatient care.

Further research is necessary to identify a control group and attempt to match patients in this group with those who access programme services on factors of physical and social complexity, to ensure that a reliable comparison can be made. Similarly, the data presented on community service utilisation and costs have been based on a small sample size due to the burden on the resources required for data collection. As such, it is more difficult for results to reach statistical significance and they should be interpreted with caution. The sample includes some high-cost outliers, which also skew the data.

Finally, it should also be reiterated that this analysis focuses on the costs of palliative care incurred by service commissioners. We have not examined the costs incurred by patients and carers through lost earnings, or the costs to the welfare budget of individuals accessing Attendance Allowance or Carer's Allowance. There is a need for further research on the costs of the informal care that is necessary if patients receiving palliative care are to be increasingly cared for in the community.

Appendix 1: Assumptions and adjustments made to the large dataset

Cause of death

The analysis was focused on patients dying from a disease or old age rather than from all causes of death. Hence patients dying from all forms of self-harm, homicide and traumatic accident were excluded (ICD chapters S and T). Deaths associated with pregnancy and childbirth were also excluded. Elderly patients suffering falls and fractured neck of femur and resulting complications have been excluded. Patients whose underlying cause of death had been assigned to ICD chapters R, Y and X were individually assigned to more precise diagnostic groups by looking at all available codes. These ICD chapters represent ambiguous coding since chapter R is for signs and symptoms; the other chapters are more to do with reasons for contact with health services.

The underlying cause of death was used to locate patients falling into various diagnostic groups. Two other fields were available, namely the primary cause and the secondary cause of death. However, we used underlying cause of death as the most appropriate for this type of analysis since a patient with cancer (underlying cause) may die from a chest infection (primary cause). Use of the underlying cause of death includes slightly more patients in the 'cancer' category than use of the primary death field, but was considered to be more indicative of patterns of service utilisation.

Children are usually covered by specialist paediatric care and excluded from the Marie Curie Delivering Choice Programme services, and so persons up to age 19 were not included in the study.

Missing postcodes

Several patients had a missing postcode. The relevant postcode was identified using the address field for the place of death. A small number of those patients dying in a hospital with a missing postcode field were assumed to be non-residents (*see* exclusion of non-residents below).

Exclusion of non-residents

A review of the data showed that there were deaths and hospital admissions (mainly emergency) associated with visitors to Lincolnshire. These cases were identified by postcode and flagged as non-residents.

A further group of patients was identified that appeared to have moved into the area during the study period. They were identified by searching for all NHS numbers with one postcode outside of the area during the period of the study. These patients were also flagged as non-residents.

Non-residents have been removed from the analysis, as they would not have been expected to have utilised programme or other local community services.

HRG tariff

All hospital admissions were priced using the 2007/8 NHS Healthcare Resource Group (HRG) tariff (England) for admitted patient care. The 2007/8 indicative tariff was used for a range of HRGs specifically applicable to cancer and other specialist conditions. For all emergency admissions with a length of stay of less than two days, the relevant short-stay emergency tariff was applied. Patients who died in A&E were given a default assumed cost of £100 for a standard high-cost A&E attendance.

Excess bed days were calculated using the HRG length of stay upper trim point and these excess bed days were priced using the specific excess bed day tariff for each HRG. The tables below list the top 10 elective and emergency admissions for patients with cancer in the sample dataset. The top 10 HRGs account for 59 per cent and 28 per cent of elective and emergency admissions respectively. Emergency admissions account for 34 per cent of all admissions for patients with cancer.

To calculate the costs of an admission, we first established the length of stay. If the length of stay was longer than what is called the 'trim point', we added the per-day cost to the base price. For emergency admissions, we applied the short stay tariff only if the length of stay was 0 or 1 day. Some HRGs (usually having a low trim point) do not have a short stay emergency tariff.

TABLE 11: HIGHEST VOLUME ELECTIVE ADMISSIONS FOR PATIENTS WITH CANCER

HRG	Description	Tariff	Trim (days)	Price per day over trim point[13]
F98	Chemotherapy digestive system diagnosis	£367	1	£165
D98	Chemotherapy respiratory system diagnosis	£399	1	£165
S27	Malignant disorder lymphatic, etc with LOS <2 days	£398	1	£133
G98	Chemotherapy hepato-biliary or pancreatic	£347	1	£165
H98	Chemotherapy musculoskeletal system diagnosis	£671	1	£165
J98	Chemotherapy skin, breast or burn diagnosis	£304	1	£165
S98	Chemotherapy haematology, or non-specific	£678	1	£165
S05	Red blood cell disorders >69 or w cc	£496	1	£155
M98	Chemotherapy female reproductive system	£342	1	£165
F06	Diagnostic procedures, oesophagus and stomach	£407	1	£164

---

[13] A value of £165 has been inserted for the price per day over the trim point for all HRG covered by the 2007/8 indicative tariff. An indicative tariff is usually an area where prices were previously agreed locally but is now moving within the scope of the national tariff. In the first year of its introduction, trusts and PCTs are free to use whichever price they choose. This freedom is removed thereafter.

TABLE 12: HIGHEST VOLUME EMERGENCY ADMISSIONS FOR PATIENTS WITH CANCER

HRG	Description	Tariff	Trim (days)	Price per day over trim point	Short stay tariff
D25	Respiratory neoplasms	£3,003	33	£181	£601
F46	General abdominal disorders >69 or w cc	£1,745	13	£185	£349
F36	Large intestinal disorders >69 or w cc	£2,499	24	£185	£500
F07	Disorders of the oesophagus >69 or w cc	£2,296	24	£176	No
S05	Red blood cell disorders >69 or w cc	£2,350	22	£155	£470
S28	Malignant disorder lymphatic, etc with LOS >1 day	£3,223	29	£227	£645
F17	Stomach or duodenum disorders >69 or w cc	£1,876	19	£171	No
S29	Other admissions related to neoplasms	£3,029	33	£178	£606
D41	Unspecified acute lower respiratory infection	£2,059	21	£156	£412
L31	Malignant prostate disorders	£2,988	32	£177	£598

The dataset contained a number of missing HRG codes. The nearest match to an HRG code was assigned to these patients using the primary and secondary diagnosis fields. The analysis of costs would be unduly skewed if these admissions were not assigned to a relevant HRG group.

There was a very limited number of hospital admissions where the primary diagnosis field was missing. In these instances the code for the underlying cause of death was used to assign a nearest match HRG code.

Several patients who died in hospital appeared to have an incorrect discharge date, given as after the date of decease (usually the next day). The date of death was assumed to be the correct date of discharge and the values were adjusted accordingly.

On a very small number of occasions, an acute hospital admission will group to an HRG in chapter T, which covers mental health conditions. Chapter T HRGs do not have a national tariff and so these admissions have been priced using a conservative estimate of £440 per day for the first 10 days, assumed to reflect higher medical costs associated with initial diagnosis and intensive psychological treatment. Beyond 10 days a hotel cost of £200 per day was assumed. This figure is the average cost of a one-day stay beyond the upper trim point. The combination of the above costs gives an average cost (across all chapter T admissions in the database) of £251 per day, compared to £523 per day across all other admissions. Chapter T admissions tend to be longer stay, hence the average close to the £200 per day hotel costs. The constructed tariff for chapter T HRGs is therefore felt to be conservative and will not skew any calculations by introducing excessively high cost figures.

Unit costs for community care

Unit costs for various activities were taken from a number of sources, including Curtis and Netten (2006), which describes national average costs for the financial year 2005/6. These costs apply broad assumptions and hence unit costs were used to the nearest pound per hour of the activity.

Costs of agency nurses came from a local audit of agency costs conducted as part of the project in 2006/7. More detailed information regarding the calculation of costs is provided in Appendix 4 (*see* page 42).

Inflation

Inflation has been incorporated into the inpatient costs by using 2007/8 prices retrospectively for all admissions. Unit costs for staff derived from Curtis and Netten for 2005/6 have been increased by NHS pay and Agenda for Change inflation, equalling a total 7.5 per cent increase.

Appendix 2: Demographic profile of dataset

TABLE 13: NUMBER (AND PERCENTAGE) OF MALES AND FEMALES WHO DIED OF CANCER IN BOSTON

	Male		Female		Total	
Pre-DCP 2004–5	160	(55)	130	(45)	290	(100)
Pre-DCP 2005–6	168	(57)	128	(43)	296	(100)
2006–7	167	(53)	147	(47)	314	(100)
2006–7 non-DCP	87	(52)	81	(48)	168	(100)
2006–7 DCP	80	(55)	66	(45)	146	(100)
DCLN	19	(53)	17	(47)	36	(100)
RRT	39	(55)	32	(45)	71	(100)
DCLN+RRT	22	(56)	17	(44)	39	(100)

TABLE 14: NUMBER (AND PERCENTAGE) OF DIFFERENT AGE RANGES WHO DIED OF CANCER IN BOSTON

Age group	2004–5	2005–6	2006–7	non-DCP	DCP	DCLN	RRT	DCLN+RRT
20–24	0 (0)	1 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
25–29	0 (0)	0 (0)	1 (0)	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)
30–34	1 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
35–39	1 (0)	1 (0)	3 (1)	1 (1)	2 (1)	0 (0)	2 (3)	0 (0)
40–44	5 (2)	7 (2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
45–49	4 (1)	8 (3)	3 (1)	1 (1)	2 (1)	1 (3)	1 (1)	0 (0)
50–54	10 (3)	5 (2)	12 (4)	6 (4)	6 (4)	1 (3)	5 (7)	0 (0)
55–59	12 (4)	12 (4)	14 (4)	4 (2)	10 (7)	2 (6)	3 (4)	5 (13)
60–64	19 (7)	22 (7)	30 (10)	16 (10)	14 (10)	3 (8)	8 (11)	3 (8)
65–69	31 (11)	31 (10)	35 (11)	21 (13)	14 (10)	1 (3)	7 (10)	6 (15)
70–74	50 (17)	54 (18)	43 (14)	22 (13)	21 (14)	3 (8)	10 (14)	8 (21)
75–79	55 (19)	57 (19)	57 (18)	33 (20)	24 (16)	7 (19)	12 (17)	5 (13)
80–84	56 (19)	49 (17)	54 (17)	24 (14)	30 (21)	8 (22)	14 (20)	8 (21)
85+	46 (16)	49 (17)	62 (20)	39 (23)	23 (16)	10 (28)	9 (13)	4 (10)
Total	290 (100)	296 (100)	314 (100)	168 (100)	146 (100)	36 (100)	71 (100)	39 (100)

Appendix 3: Boston area defined by the following postcodes, as served by the RRT

Postcode district	Postcode sector
LN10	6 Woodhall Spa, Lincolnshire
LN4	4 Billinghay, Lincolnshire
	4 Coningsby, Lincolnshire
	4 North Kyme, Lincolnshire
	4 South Kyme, Lincolnshire
	4 Tattershall, Lincolnshire
	4 Tattershall Bridge, Lincolnshire
	4 Tattershall Thorpe, Lincolnshire
PE11	3 Church End, Lincolnshire
	3 Crossgate, Lincolnshire
	3 Deeping St Nicholas, Lincolnshire
	4 Donington, Lincolnshire
	4 Gosberton, Lincolnshire
	3 Little London, Lincolnshire
	4 Northorpe, Lincolnshire
	3 Pinchbeck, Lincolnshire
	3 Pinchbeck Bars, Lincolnshire
	3 Pinchbeck West, Lincolnshire
	3 Pode Hole, Lincolnshire
	4 Quadring, Lincolnshire
	4 Quadring Eaudike, Lincolnshire
	4 Risegate, Lincolnshire
	1/2 Spalding, Lincolnshire
	4 Surfleet, Lincolnshire
	4 Surfleet Seas End, Lincolnshire
	4 Westhorpe, Lincolnshire
PE12	0 Chapelgate, Lincolnshire
	6 Cowbit, Lincolnshire
	9 Dawsmere, Lincolnshire
	8 Fleet, Lincolnshire
	8 Fleet Hargate, Lincolnshire
	0 Gedney, Lincolnshire
	0 Gedney Broadgate, Lincolnshire
	9 Gedney Drove End, Lincolnshire
	0 Gedney Dyke, Lincolnshire
	0 Gedney Hill, Lincolnshire
	9 Guy's Head, Lincolnshire
	7 Holbeach, Lincolnshire
	8 Holbeach Bank, Lincolnshire
	8 Holbeach Clough, Lincolnshire
	0 Holbeach Drove, Lincolnshire
	8 Holbeach Hurn, Lincolnshire
	8 Holbeach St Johns, Lincolnshire
	8 Holbeach St Marks, Lincolnshire

Postcode district	Postcode sector
PE20	2 Algarkirk, Lincolnshire
	3 Amber Hill, Lincolnshire
	3 Bicker, Lincolnshire
	3 Brothertoft, Lincolnshire
	3 Drayton, Lincolnshire
	3 East Heckington, Lincolnshire
	3 Fenhouses, Lincolnshire
	2 Fosdyke, Lincolnshire
	1 Frampton, Lincolnshire
	1 Frampton West End, Lincolnshire
	3 Hoffleet Stow, Lincolnshire
	3 Hubbert's Bridge, Lincolnshire
	1 Kirton, Lincolnshire
	1 Kirton End, Lincolnshire
	1 Kirton Holme, Lincolnshire
	1 Sandholme, Lincolnshire
	1 Skeldyke, Lincolnshire
	2 Sutterton, Lincolnshire
	3 Swineshead, Lincolnshire
	3 Swineshead Bridge, Lincolnshire
	2 Wigtoft, Lincolnshire
PE21	9 Boston, Lincolnshire
	0 Fishtoft, Lincolnshire
	0 Skirbeck, Lincolnshire
	7 Wyberton, Lincolnshire
PE22	7 Anton's Gowt, Lincolnshire
	0 Benington, Lincolnshire
	0 Benington Sea End, Lincolnshire
	0 Butterwick, Lincolnshire
	7 Carrington, Lincolnshire
	8 Eastville, Lincolnshire
	7 Fishtoft Drove, Lincolnshire
	0 Freiston, Lincolnshire
	0 Freiston Shore, Lincolnshire
	8 Friskney, Lincolnshire
	8 Friskney Eaudike, Lincolnshire
	7 Frith Bank, Lincolnshire
	7 Frithville, Lincolnshire
	7 Gipsey Bridge, Lincolnshire
	0 Halltoft End, Lincolnshire
	0 Hill Dyke, Lincolnshire
	9 Lade Bank, Lincolnshire
	7 Langrick, Lincolnshire
	9 Leake Common Side, Lincolnshire

	8	Holbeach St Matthew, Lincolnshire
	9	Little London, Lincolnshire
	9	Long Sutton, Lincolnshire
	6	Loosegate, Lincolnshire
	9	Lutton, Lincolnshire
	6	Moulton, Lincolnshire
	0	Moulton Chapel, Lincolnshire
	6	Moulton Seas End, Lincolnshire
	8	Saracen's Head, Lincolnshire
	0	Shepeau Stow, Lincolnshire
	9	Sutton Bridge, Lincolnshire
	9	Sutton Crosses, Lincolnshire
	0	Sutton St Edmund, Lincolnshire
	0	Sutton St James, Lincolnshire
	6	Weston, Lincolnshire
	6	Weston Hills, Lincolnshire
	6	Whaplode, Lincolnshire
	0	Whaplode Drove, Lincolnshire
	6	Whaplode St Catherine, Lincolnshire
	0	Leake Hurn's End, Lincolnshire
	0	Leverton, Lincolnshire
	0	Leverton Outgate, Lincolnshire
	7	Mareham le Fen, Lincolnshire
	8	Midville, Lincolnshire
	7	Moor Side, Lincolnshire
	7	Moorby, Lincolnshire
	7	New Bolingbroke, Lincolnshire
	8	New Leake, Lincolnshire
	0	Northlands, Lincolnshire
	9	Old Leake, Lincolnshire
	7	Revesby, Lincolnshire
	0	Scrane End, Lincolnshire
	0	Sibsey, Lincolnshire
	8	Stickford, Lincolnshire
	8	Stickney, Lincolnshire
	7	Tumby, Lincolnshire
	7	Tumby Woodside, Lincolnshire
	7	Wood Enderby, Lincolnshire
	9	Wrangle, Lincolnshire
	9	Wrangle Lowgate, Lincolnshire
PE23	5	Ashby by Partney, Lincolnshire
	5	Candlesby, Lincolnshire
	4	East Keal, Lincolnshire
	4	East Kirkby, Lincolnshire
	5	Firsby, Lincolnshire
	5	Great Steeping, Lincolnshire
	4	Hagnaby, Lincolnshire
	5	Halton Holegate, Lincolnshire
	4	Hareby, Lincolnshire
	5	Hundleby, Lincolnshire
	4	Keal Cotes, Lincolnshire
	5	Little Steeping, Lincolnshire
	4	Mavis Enderby, Lincolnshire
	4	Old Bolingbroke, Lincolnshire
	4	Partney, Lincolnshire
	4	Raithby, Lincolnshire
	5	Spilsby, Lincolnshire
	5	Toynton All Saints, Lincolnshire
	5	Toynton Fen Side, Lincolnshire
	5	Toynton St Peter, Lincolnshire
	4	West Keal, Lincolnshire
PE6	0	Crowland, Lincolnshire

Appendix 4: Community service unit cost calculations and assumptions

Unit	Unit of measure	Cost applied	Comments	Source
GP contact	Per hour	£176	Adjusted for inflation from initial source Full cost including overheads per contact/hour	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Planned RRT visit	Per hour	£85		Marie Curie Cancer Care
Urgent RRT visit	Per hour	£85		Marie Curie Cancer Care
Discharge community link nurse	Per patient	£141		Marie Curie Cancer Care
PCCC involvement	Per hour	£14		Marie Curie Cancer Care
Agency RN days	Per hour	£70	2007–8 costs via Marie Curie local audit	
Agency HCA days	Per hour	£19		Curtis and Netten 2007, *Unit Costs of Health & Social Care*
Agency RN nights	Per hour	£90	2007–8 costs via Marie Curie local audit	
Agency HCA nights	Per hour	£22	Full cost including overheads	Curtis and Netten 2007, *Unit Costs of Health & Social Care*
Ambulance discharge	Per journey or visit	£54	Adjusted for inflation from initial source	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Unplanned transfer using 999	Per contact or journey	£313	Adjusted for inflation from initial source	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
District nurse activity	Per contact	£70	Adjusted for inflation from initial source Full cost including overheads	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
After-hours paramedic (out-of-hours)	Per visit	£45	Adjusted for inflation from initial source Full cost including overheads	Curtis and Netten 2005, *Unit Costs of Health & Social Care*

Unit	Unit of measure	Cost applied	Comments	Source
Hospice bed days	Per bed day	£328	Adjusted for inflation from initial source Full cost including overheads	NICE Guidance on Cancer Services (2004), *Improving Supportive and Palliative Care for Adults with Cancer*
Hospice day support – RN	Per hour	£27	Adjusted for inflation from initial source	Marie Curie Cancer Care estimate
Hospice home day support – HCA	Per hour	£13	Adjusted for inflation from initial source Full cost including overheads	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Hospice night support – RN	Per hour	£27	Adjusted for inflation from initial source	
Hospice home night support – HCA	Per hour	£13	Adjusted for inflation from initial source Full cost including overheads	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Marie Curie RN night	Per hour	£46	Adjusted for inflation from initial source	
Marie Curie HCA night	Per hour	£21	Adjusted for inflation from initial source	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Macmillan nurse	Per hour	£79	Adjusted for inflation from initial source Full cost including overheads	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Social services assessments	Per hour	£74	Adjusted for inflation from initial source Based on the cost of a social worker for adults: 'Direct outputs'	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Social services – home care	Per hour	£14	Adjusted for inflation from initial source	Curtis and Netten 2005, *Unit Costs of Health & Social Care*
Equipment – mattresses and bed	Per day	£14		www.talleygroup.com
Equipment – hoists	Per day	£5	Adjusted for inflation from initial source	NHS Equipment Hire and Loan Services for 2006

Appendix 5: Median costs for community service utilisation

	Sample of patients before the programme was introduced		Sample of patients who accessed programme services	
	Utilisation (reference interval)	Cost (£) (reference interval)	Utilisation (reference interval)	Cost (£) (reference interval)
GP contacts	3.0 (0.0, 14.0)	528 (0, 2,460)	0.5 (0.0, 12.9)	88 (0, 2,266)
Programme services				
Planned RRT visit (min)	0	0	0 (0, 85)	0 (0, 120)
Urgent RRT visit (min)	0	0	13 (0, 313)	18 (0, 444)
DCLN care (min)	0	0	0 (0, 597)	0 (0, 1,403)
PCCC events	0	0	0.5 (0.0, 1.0)	7 (0, 14)
Agency HCA day care (hrs)	2.6 (2.6, 2.6)	49 (49, 49)	0.0 (0.0, 135.5)	0 (0, 2,575)
Agency HCA night care (hrs)	4.1 (4.1, 4.1)	(90, 90)	0.0 (0.0, 214.1)	0 (0, 4,709)
Planned ambulance discharge	0.0 (0.0, 3.0)	0 (0, 162)	0.0 (0.0, 6.0)	0 (0, 323)
Unplanned ambulance discharge	0.0 (0.0, 3.0)	0 (0, 939)	0.0 (0.0, 2.0)	0 (0, 618)
District nurse contacts (per visit)	3.0 (0.0, 24.0)	210 (0, 1,680)	2.0 (0.0, 55.7)	140 (0, 3,896)
Out-of-hours care – after-hours paramedic	0.0 (0.0, 11.0)	0 (0, 494)	0.0 (0.0, 3.0)	0 (0, 135)
Hospice care (bed days)	0.0 (0.0, 2.0)	0 (0, 640)	0	0
RN day support (hrs)	0.0 (0.0, 36.1)	0 (0, 974)	0.0 (0.0, 53.3)	0 (0, 1,438)
HCA day support (hrs)	0.0 (0.0, 17.7)	0 (0, 229)	0.0 (0.0, 49.7)	0 (0, 646)
HCA night support (hrs)	0.0 (0.0, 23.4)	0 (0, 304)	0.0 (0.0, 87.6)	0 (0, 1,139)
Marie Curie RN (hrs)	0	0	0.0 (0.0, 44.9)	0 (0, 2,067)
Marie Curie HCA (hrs)	0	0	0.0 (0.0, 151.4)	0 (0, 3,180)
Macmillan nurse (contacts)	2.0 (0.0, 19.8)	158 (0, 1,560)	0.5 (0.0, 17.9)	40 (0, 1,412)
Social services assessment	0.0 (0.0, 1.0)	0 (0, 74)	0.0 (0.0, 1.0)	0 (0, 74)
Social services home care	0.0 (0.0, 24.9)	0 (0, 349)	0.0 (0.0, 2.0)	0 (0, 28)
Equipment – mattresses (days)	17.5 (0.0, 56.0)	245 (0, 784)	0.0 (0.0, 56.0)	0 (0, 784)
Equipment – hoists (days)	2.0 (0.0, 56.0)	10 (0, 280)	0.0 (0.0, 56.0)	0 (0, 280)
TOTAL		2,423 (140, 6,505)		1,632 (129, 20,625)
Acute service bed days	11.5 (0.0, 56)	2466 (0, 8,396)	5.5 (0.0, 46)	1,835 (0, 15,997)

References

Curtis L, Netten A (2007). *Unit Costs of Health & Social Care 2007*. Canterbury: Personal Social Services Research Unit, University of Kent.

Curtis L, Netten A (2006). *Unit Costs of Health & Social Care 2006*. Canterbury: Personal Social Services Research Unit, University of Kent.

Curtis L, Netten A (2005). *Unit Costs of Health & Social Care 2005*. Canterbury: Personal Social Services Research Unit, University of Kent.

Higginson, I (2003). *Priorities for End of Life Care in England, Wales and Scotland*. London: The National Council for Palliative Care.

National Institute for Health and Clinical Excellence (NICE) Guidance on Cancer Services (2004). *Improving Supportive and Palliative Care for Adults with Cancer*. Available at: www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10893 (accessed on 31 March 2008).

YouGov Survey (2008). *Patients Wanting Home Death Fear They Won't Get Care They Need*. Available at: www.campaign.mariecurie.org.uk/Scotland/press_centre/yougov_survey.htm (accessed on 20 March 2008).