

# Exploring the cost of care at the end of life

*Research report*

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The quality of care received by people at the end of their lives has become a major policy concern in many countries. However, there is limited information available about care activity and costs at the end of life. In this analysis we have sought to use anonymised person-level datasets to estimate the hospital and non-hospital costs for people in the last 90 days of life relating to GP contacts, community nursing, local authority-funded social care, institutional hospice care and hospitals. We have also used these estimates to assess the hypothetical impact on the different care sectors of the Marie Curie nursing service – a previous evaluation of the service found that this service enabled individuals to remain out of hospital in their last days of life.

The approach we took often relied on a set of pragmatic assumptions, due to limitations in the data available. Our work demonstrates how crucial it is that we develop better ways to understand resource use in everyday care.

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## Key Points

- Approximately two thirds of patients saw their GP at least once during the last three months of life, and there were an average of four to five GP visits per person in this time – though rates of GP contact were much higher for cancer patients. GP contacts appeared to remain relatively stable over the last 90 days of life, with an average of 5% of people estimated to have had some GP contact on any one day.
- The study was able to look at community nurse contacts from one area. Only about a third of patients had a contact with a district nurse recorded in their last 90 days, so the average costs per person were not very high (average £278). However, for some patients using district nurses there was a clear increase in activity in the final days of life. The most intensive 10% of users averaged 40-50 minutes of district nurse time per day in their last few days of life.
- Although just over a quarter of people used local authority-funded social care in the final year of life, the high costs of nursing and residential care meant that this element of care was significant, at an average cost over the last three months of just over £1,000 per person who died. However, higher costs were more evident in the older age groups.
- Assessing the costs associated with institutional hospice care was difficult. However, our best estimates were that costs were of the order of £400 per day, so that an average 14-day stay amounted to £5,600. Averaged over all people who died we estimated a total inpatient hospice cost of approximately £550 per person.

- Hospital costs were by far the largest cost elements of end-of-life care – care in the final three months of life averaged over £4,500 per person who died. The bulk of this cost was due to emergency hospital admissions. Hospital costs increased rapidly in the last few weeks of life.
- Using the Marie Curie nursing service as an example, we attempted to estimate whether reduced hospital activity and costs at the end of life were likely to be offset by increased care costs in other health and social care sectors. Our findings suggested that the scale of likely changes in non-hospital costs was relatively small. We concluded that care costs were very likely to be lower (on the order of £500 per person, for the care types considered), even allowing for the commissioning costs of home-based nursing support at the end of life.

## Acknowledgements

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## Introduction

Good quality end-of-life care is recognised as an essential component of modern health care services (Department of Health, 2008; National Audit Office, 2008). In recent years a number of initiatives have been put in place to look at how we might improve the care provided at the end of life, and national indicators have been developed with the aim of helping us understand current care and supporting people's choices about where to die (Public Health England, 2014; Department of Health, 2012a; Royal College of Physicians, 2014). A major point of interest has been in helping to develop services that support people's preference to be cared for and die at home rather than in hospital (Cicely Saunders Institute, 2011; Department of Health, 2009).

Given the finite resources available for health care, it is important that there is some understanding of the costs of end-of-life care as one component of the wider picture of good-quality end-of-life services. Yet, as was noted by Hughes-Hallet and colleagues in a 2011 review of palliative care funding for the Department of Health: "there is a stunning lack of good data surrounding costs for palliative care in England" (Hughes-Hallet and others, 2011). Acquiring information on the costs of end-of-life care poses significant challenges, especially given that care services for those at the end of life are fragmented across many different providers of care (National End of Life Care Programme, 2012). This subject is being explored in NHS England's palliative care funding pilots (Sheers, 2013).

The Nuffield Trust has carried out several studies examining the care received at the end of life from a number of perspectives. These have included a study of local authority-funded social care use in a population of over 70,000 adults who died (Georghiou and others, 2012), and a large analysis of hospital use for almost all those who died in England in three recent years (Nuffield trust, forthcoming). In addition, we have also carried out a matched cohort study which found that Marie Curie's nursing service appeared to have significant impacts on hospital utilisation in the days and weeks just prior to death (Chitnis and others, 2012).

In this report, we further explore the costs of end-of-life care across different care sectors, drawing on information obtained from a range of available sources, including prior analyses undertaken at the Nuffield Trust, published literature and Marie Curie Cancer Care data. The first part of this report highlights the set of care sectors we examined, and the estimated costs of these services when provided at the end of life.

The second part applies these estimates to assess the hypothetical impact on the different care sectors of a successful intervention that enabled individuals to remain out of hospital in their last days of life. We used the specific example of the Marie Curie nursing service, a service which provides home-based end-of-life nursing care to around 28,000 people in the UK every year. In a previous evaluation of this service that we carried out (Chitnis and others, 2012), we found that individuals who had received palliative nursing care from Marie Curie died at home more than twice as frequently as a very closely matched control group. On average, the Marie Curie-nursed individuals spent two and a half fewer days of their final 90 days in hospital than the control group did (1.6 days versus 4.1 days for the control group during the nursing service period; a difference that was statistically significant). End-of-life hospital costs were correspondingly lower for the individuals with Marie Curie nursing care – by £1,140 per person.

In considering these results we discussed the possibility that an intervention which had been successful at reducing hospital admissions and stays might in part merely displace care activity (and costs) to other care sectors. Even where more intensive community-based care services were not being put in place, at the very least existing services would presumably need to continue for the additional time spent at home. To investigate this effect, we have tried to estimate the scale of increases in activity – in terms of costs per person – that we might see for each care sector. We reflect on the magnitude of these cost increases alongside the costs of provision of the Marie Curie nursing service. One of our aims was to test whether these sets of costs were still outweighed by the apparent savings identified in end-of-life hospital costs.

## 1. Estimating care costs at the end of life

In the analyses that follow we examined costs of services in a number of different care settings, and in particular looked for information about the care services people had used in the final 90 days of life. We considered the following health and social care services types:

- Primary care (limited to GP consultations)
- Community care (limited to district nursing care)
- Local authority-funded social care
- Inpatient hospice care
- Secondary (acute hospital) care.

This is not an exhaustive list of the services which are important at the end of life. There are some areas where costs are particularly difficult to unravel, and these are not reflected in this study, for example in areas such as self-funded social care or drug costs in primary care. In addition, while we have estimated costs of inpatient hospice stays, we have not included estimates of outpatient, day therapy or community hospice care. We also miss out costs of mental health care in the community or in institutions where this is not recorded in hospital or social care data. Our emphasis has been on the costs to the commissioner of these services and it is important to recognise that these may not be the same as the real costs. They also mean that reduction in activity may be a saving for the commissioners – but these may not be realisable by the provider of care.

Our approach was to, as far as possible, exploit information about individual patients, rather than aggregated costs. We concentrated primarily on previous analyses undertaken at the Nuffield Trust. This includes work we have done using pseudonymised person-level care data linked across different care sectors to answer specific questions about how particular groups use care services or to evaluate specific interventions. A number of our studies have focused on the care received by individuals at the end of life, and have exploited data from national sources or supplied by local care organisations.

We were able to make use of Nuffield analyses in this way to determine end-of-life care use and associated costs for all of the listed services except for hospice care. Specific sources of data used are outlined in each of the individual sections that follow.

We present the final 90-day costs as averages for all people who died, and not as those of a typical person in receipt of the relevant service. This is intended to make whole population estimates of end-of-life costs easier to calculate.

We also calculated average costs for people with cancer and for those who died of other causes separately where possible. In terms of broad disease grouping, cancer is the largest cause of death in England and Wales, with 29% of those who died in 2012 having had a cause of death due to cancer (Office for National Statistics, 2013a). Prior work by the Nuffield Trust has shown that individuals with a history of cancer tended to die at younger age groups than those who died from other causes of death, and they also had different patterns of social care service use in their last year of life compared with those who died of other causes (Georghiou and others, 2012). We identified individuals with a diagnosis of cancer in an opportunistic way, relying on any readily linked general practice or inpatient

data – both of which can be used to derive diagnostic markers. How this was done for each of the service types is outlined in the individual care sections which follow.

In the following pages, for each care service type in turn, we present estimates of average costs of care received in the final 90 days of life. We outline the sources of data or information used to determine our estimates, and briefly discuss the assumptions made in our calculations. Where possible, we also present figures showing how service use varied over the final three months of life.

### **Primary care – GP consultations**

Primary care performs an important role for many people at the end of life. A key marker of the intensity of use of primary care is the frequency with which a person will see a GP. By looking at computerised, pseudonymised records from GP practices, we estimated how frequently a person saw their GP in the weeks before they died. For this analysis we used data from three London primary care trusts (PCTs). The data consisted of GP consultations (so called ‘Read code’) records, in addition to information on the date a person died. We were able to identify a total of 21,522 people who died in these areas between April 2006 and September 2011.

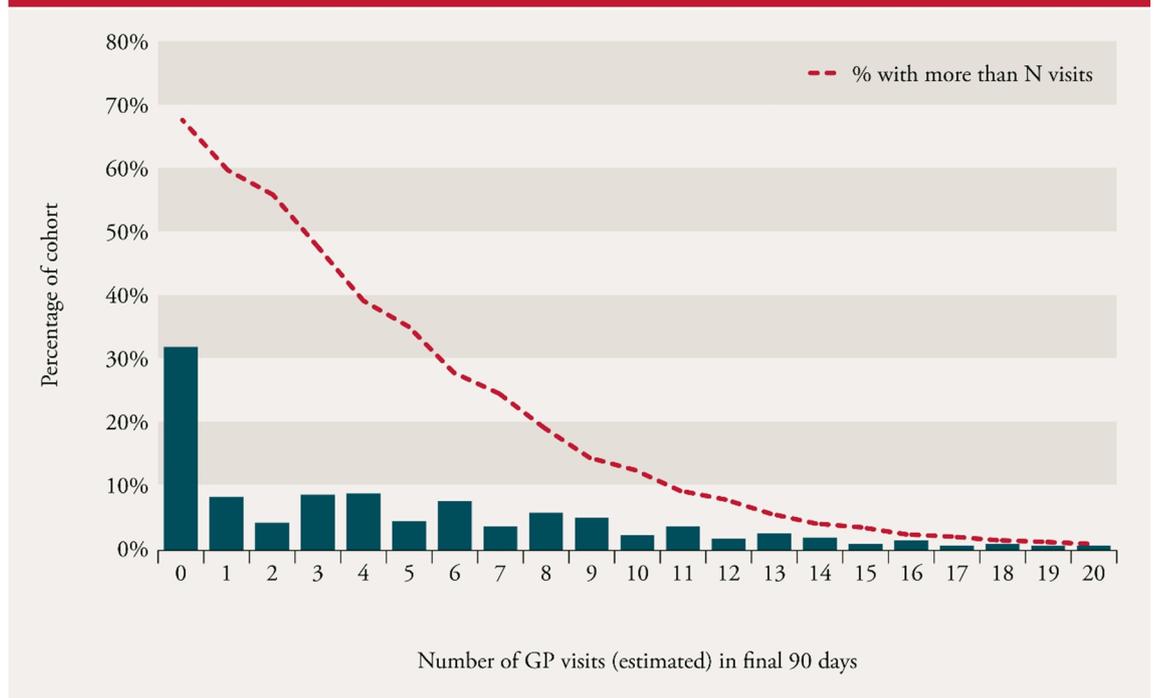
GP consultation data is a very rich source of information. Much of the information it contains directly links to individuals’ actual visits to GP surgeries, but it also includes information recorded where a person is not present (for example records of phone calls having been made or test results having been received). It is not, in general, easy to distinguish the former situation from the latter, and to therefore count precisely the number of consultations a person had in a given period. We relied instead on constructing estimates of the number of consultations in the last 90 days of life.<sup>1</sup>

Figure 1 shows the resulting distribution of total estimated GP contacts per person, showing the proportions of people who saw their GP at least once or several times during this period. Around a third of individuals who died didn’t see their GP at all in the final three months of life (remember that many would have been in hospital), whilst approximately half of the cohort had three or more contacts recorded in this time.

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<sup>1</sup> To estimate the number of consultations we first calculated the number of days on which there was at least one record for the person in the GP data in the final 90 days of life. We then multiplied this number by an adjustment factor which represented the approximate fraction of such dates on which there had probably been an actual GP consultation. This factor was 0.79 for individuals with a cancer diagnosis, and 0.59 for all other patients, as calculated using information derived from one PCT’s data in which GP consultations had been directly labelled. The remaining non-consultation dates would include activity recorded on the system without the person present, for example: test results received, repeat prescriptions filled, phone consultations.

Figure 1: Estimated number of GP consultations in the 90 days prior to death (N=21,522)



On average we found that individuals had 7.3 days in the final 90 days of life in which their GP data recorded some information about the patient. Using the adjustment factor (calculated to be 0.79 for those with cancer and 0.59 for those without), this translated to an overall figure of 4.6 estimated consultations per person (see Table 1). With a cost of a GP consultation of £32 (based on unit cost estimates from the Personal Social Services Research Unit; Curtis, 2010), this gave an average cost per person of £147.

Patients with cancer were identified where at least one 'Read code' recorded in their final year's GP data mapped to a Quality and Outcomes Framework (QOF) cancer code (Primary Care Commissioning, 2013). The number of people estimated to have had a history of cancer via this method was 1,836. This is only 8.5% of those who died and, as such, represents a lower prevalence of cancer than we expected for the cohort.<sup>2</sup> Estimated GP consultation costs for the cancer diagnosis group were higher than for the wider cohort, at £365 per person.

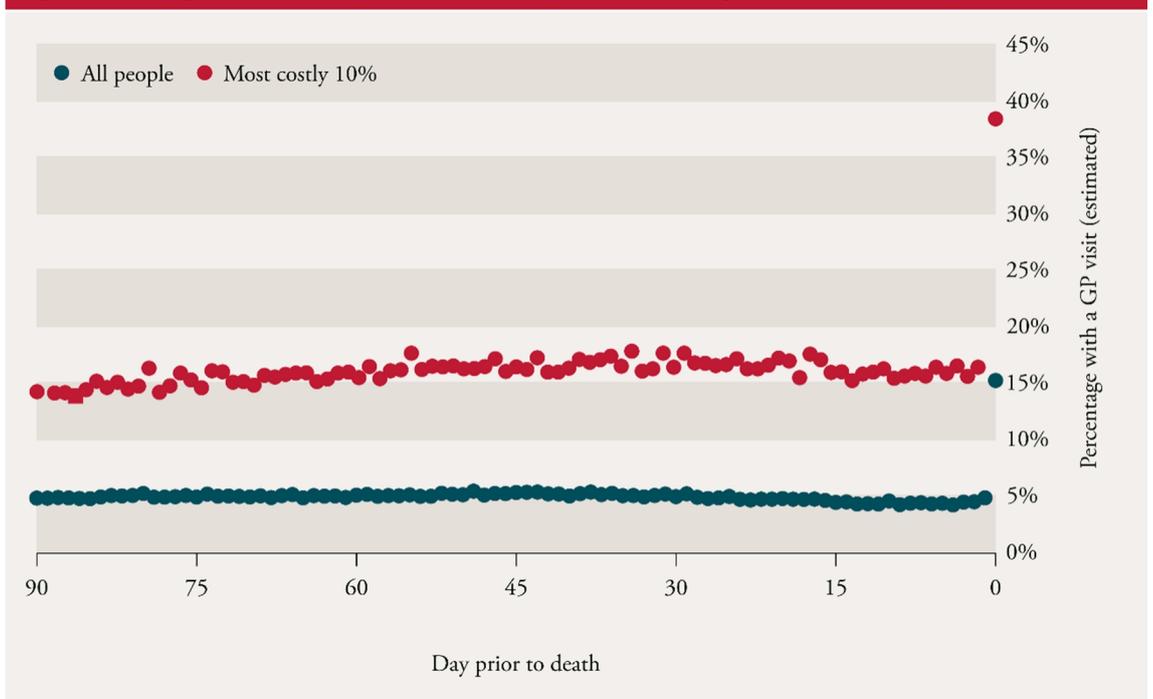
<sup>2</sup> With limited data, we only used information recorded in the last year of life, and so may have missed individuals with an earlier record of cancer. Note that the QOF cancer registers are populated using all data from 2003, although more recent prevalence indicators will look at just the most recent 15 months.

**Table 1: Summary costs associated with GP consultation**

Group	No. deaths	Unique GP record dates, final 90 days	Unique GP dates, final 90 days, per person (standard deviation)	No. estimated GP visits, final 90 days, per person (standard deviation)	Cost of GP visits, final 90 days, per person (standard deviation)
All people	21,552	157,249	7.3 (7.6)	4.6 (4.9)	£147 (£158)
Cancer diagnosis in final year	1,836	26,632	14.5 (7.9)	11.4 (6.2)	£365 (£199)
No cancer diagnosis	19,716	130,617	6.6 (7.3)	3.9 (4.3)	£125 (£137)

We also documented the pattern of GP consultations over time prior to death. Figure 2 shows the estimated proportion of people who had a GP consultation on each of the final 90 days. The number of consultations per day was relatively flat across this period, although on the final day of life there was a large peak in estimated consultations. This may reflect retrospective recording of the date of death in patients’ notes, in addition to direct GP activity on the date of death. The figure also shows the pattern for the 10% of patients with the highest number of estimated contacts with their GP. Although the baseline rate of estimated GP consultations was higher (approximately 15% had a GP contact on any one day), the profile remains fairly flat.

**Figure 2: Change over final 90 days; estimated GP consultations per day**



We recognise that GP consultation costs make up only a proportion of all GP-related costs. However, they are potentially the best indicator available of the intensity of GP activity. GP services in England cost a total of £7.7 billion in 2010/11 (Department of Health, 2012b), which is an average of £147 per head of population using a population of England in 2010/11 of 52.6 million (Office for National Statistics, 2013a). This is very similar to our estimate of end-of-life care GP costs during just the last three months of life.

One of the areas we weren't able to document in this study was primary care prescribing costs for patients nearing the end of their lives. However, it is worth noting that total primary care prescribing costs in England are similar in scale to total GP service costs (£8.3 billion in 2010/11 against £7.7 billion). If prescribing costs were apportioned relative to the level of GP activity, it would therefore effectively double our cost estimates.

### Community care – district nursing

Information about the care delivered in community settings is extremely difficult to access on a consistent basis across the country. In order to study person-level activity you have to work with information recorded on local systems. For this analysis we drew on local data recording contacts with district nurses in a single London borough with a total population of approximately 360,000. In total there was available information on 10,779 patients who died between April 2006 and September 2011.

The community nursing dataset in this area was limited in scope but it did include the number of minutes of direct care delivered by a district nurse per visit. We summed all minutes of care received by each individual over the last 90 days of life to estimate the average number of minutes of care over the population as a whole.

Figure 3 shows the average number of minutes of direct district nursing care per person in the final 90 days of life. Nearly two thirds of those who died had received no district nursing care. This is a higher figure than that reported by the National Bereavement (VOICES) survey which found that 52% of those who died had not received a district nursing or community nursing service in the final three months of life (Office for National Statistics, 2013b). However, given the variation in community nursing provision that exists in England (Drennan and Davis, 2008), the data from our single area do not indicate a dramatically different picture of community nursing care.

Averaged over all those who died (not just those who received care), we calculated a per-person amount of 214 minutes of district nursing care during the final 90 days of life. Assuming district nursing costs of £78 per hour (Curtis, 2010), this translates to average district nursing costs in this period of £278 per person (see Table 2).

People with a history of cancer were identified using linked GP consultations data, as in the previous section. The number of people observed to have had a diagnosis of cancer was 1,034 (8.8% of those who died). Average district nursing costs for this group were higher than for the cohort as a whole, at £588 per person.

Figure 3: Total hours of district nursing care in final 90 days of life (N=10,779)

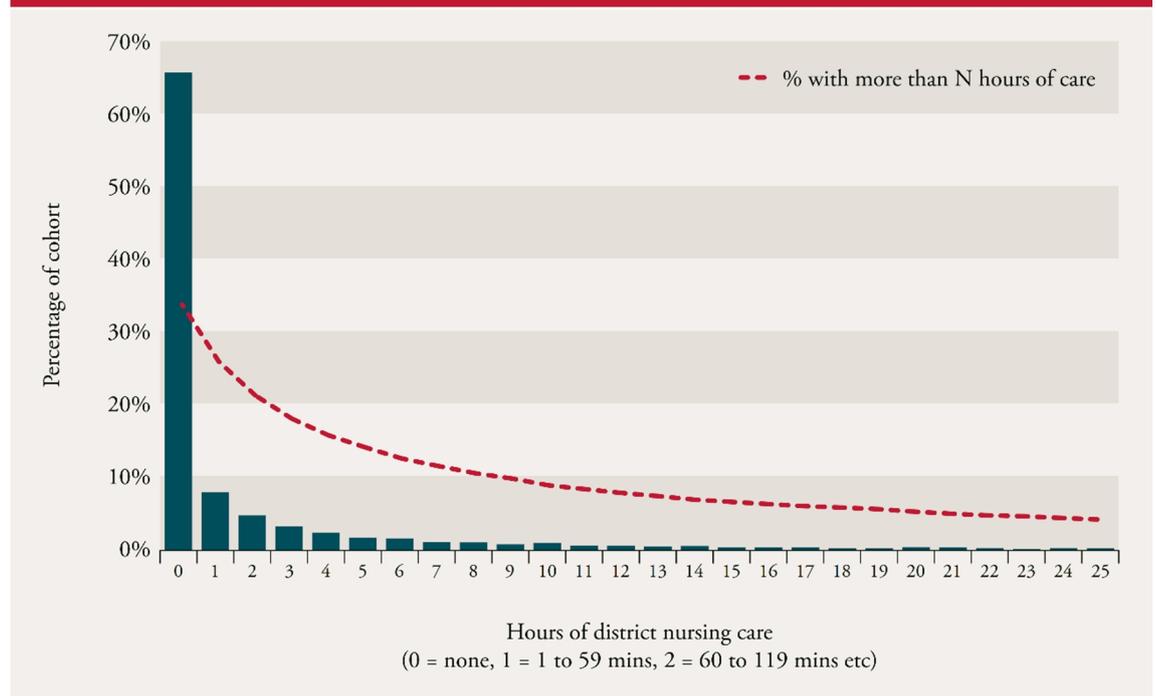


Table 2: Summary costs associated with district nursing care

Group	No. deaths	Total number minutes contact, final 90 days	Number minutes contact, final 90 days, per person (standard deviation)	Cost of district nursing care, final 90 days, per person (standard deviation)
All people	10,779	2,303,796	214 (806)	£278 (£1,048)
Cancer diagnosis in final year	929	420,363	452 (1,174)	£588 (£1,527)
No cancer diagnosis	9,850	1,883,419	191 (758)	£249 (£986)

Figure 4 shows the average number of minutes of care received per person per day during the final 90 days. This pattern was generally low and stable during most of the earlier part of the period, but showed a slight increase during the last few days of life. The average number of minutes of care of the 10% of the most costly patients is also shown for comparison.

Estimates of community nurse inputs to care are rarely studied for large populations as information systems in this area of care, if present at all, are often only kept as aggregate returns or are inconsistently available from one area to the next. There are therefore few figures that we can use to corroborate these estimates. Although we must caution against the generalizability of these findings, as they are from a single London borough, the data do suggest an interesting pattern of rising need for district nursing care in the last month of life and suggest that further studies would be of interest.

Figure 4: Average contact time with district nursing per person per day over final 90 days of life



### Local authority-funded social care

We have rather more information on local authority-funded social care use as a result of an earlier Nuffield Trust study, *Understanding patterns of social care at the end of life* (Georghiou and others, 2012). This study made use of linked hospital (inpatient, outpatient and accident & emergency (A&E)), social care and mortality data from seven PCTs and corresponding local authorities in England. These were a mix of areas, mostly urban but with some rural regions (three northern cities, a London borough, a south coast borough, a southern county and part of an eastern county). Deaths of PCT-registered adults (N=73,243) occurred between January 2007 and March 2010.

Figure 5 compares the findings across the seven areas and shows the proportion of people who died who had some form of local authority social care contact in the last 12 (not three) months of life. Although there were some differences between the areas, most of them indicated that between a quarter to a third of people who died (average 27.8%) used some form of local authority-funded social care in their final year. There was a clear pattern of social care service use by age – one in every two people who died aged 95 or over had received a social care service in their final year, compared with fewer than one in ten of those who died aged under 65.

Costs were used as calculated in the original study. Per-day national unit costs for different types of social care services were derived from those published by the Personal Social Services Research Unit (Curtis, 2009) and these were applied to all instances of recorded care activity. For consistency across the different areas we only included a subset of care types in our analysis: home care, nursing care, residential care, day care, direct payments, and respite care. Care types not captured in the costs included: equipment and adaptations, meals, personal budgets and any 'other' groups.

Figure 5: Use of social care services in final year by age band, in seven study areas. 95% confidence intervals (N=73,243)

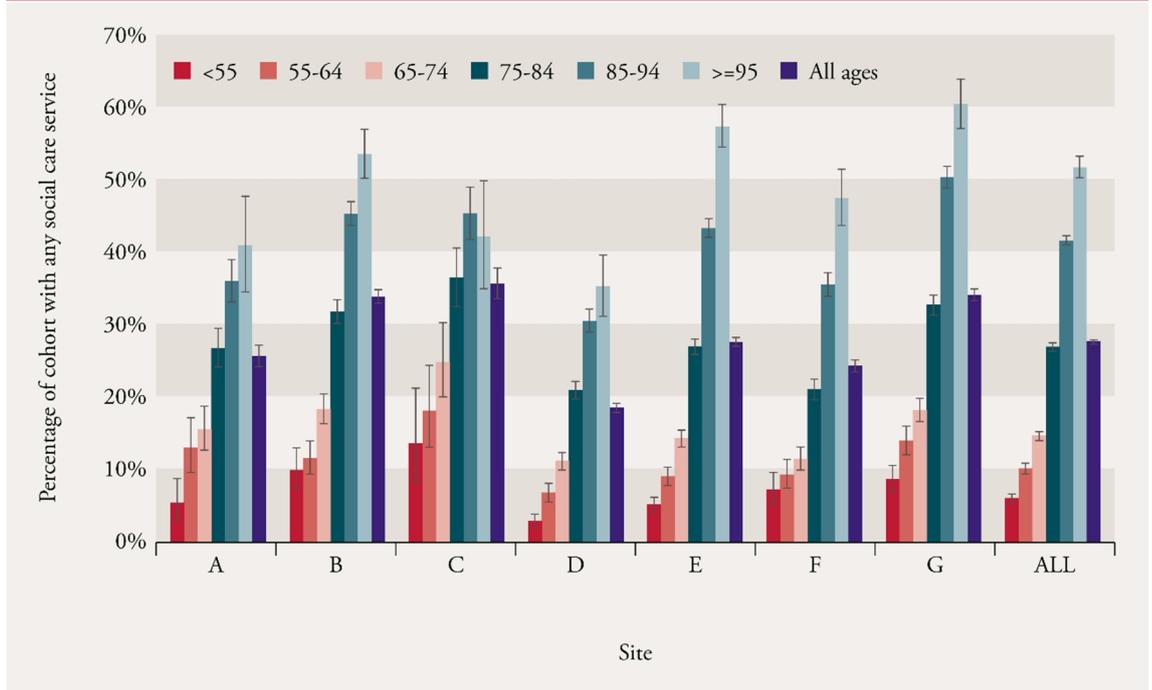


Figure 6 shows the estimated costs by month during the final year; the final three months are highlighted. The largest cost elements (residential and nursing care home services, and home care services) are shown separately from the remaining service costs. The progressive increases in costs per month were associated primarily with greater use of care homes over the last year of life. During the last three months, the average cost per person who died was calculated to be £1,010 (Table 3).

We identified individuals with a history of cancer where their linked inpatient data recorded at least one cancer diagnosis in the two years before death. Using this method, the number of people estimated to have had a history of cancer was 19,934 (27.2% of those who died). As has been observed in other analyses (Chitnis and others, 2014), social care use of patients with cancer was lower than for those without cancer – we found the cancer diagnosis group to have costs over the last three months of £444 (compared with £1,222 for the group without a cancer diagnosis, see Table 3). Some of this difference was related to the age of people with cancer – they tended to die at younger ages and so were less likely to use social care. Yet even when we standardised for age, social care use was observed to be lower for cancer patients – an effect that may have been partly due to greater access to hospice care.

Figure 6: Average cost per month over final year of life

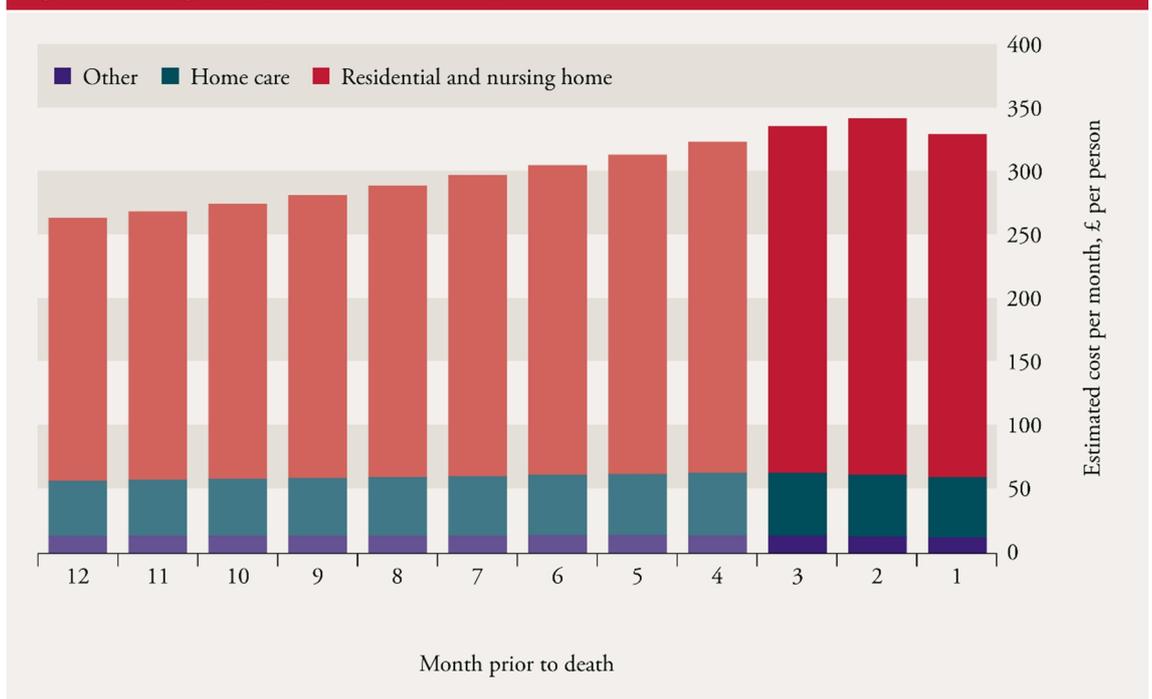


Table 3: Summary costs associated with local authority-funded social care

Group	No. deaths	Cost of local authority-funded social care in final 90 days, per person (standard deviation)
All people	73,243	£1,010 (£2,319)
Cancer diagnosis, final two years	19,934	£444 (£1,484)
No cancer diagnosis	53,309	£1,222 (£2,530)

### Inpatient hospice care

Institutional hospice care is a critical element of end-of-life care for many people. In the UK there are estimated to be over 220 adult hospice and palliative care inpatient units, with a total 3,200 beds. There are also 43 inpatient hospice units for children, with 338 beds (Help the Hospices, 2014). Data from the Office for National Statistics suggest that in 2012 approximately 5.5% of people died in a hospice (Office for National Statistics, 2013a).

Information about the costs of inpatient hospice care is not easy to determine, with NHS and voluntary sector providers funded in a variety of different ways. Person-level costs will be dependent on the time a person stays in the hospice and this period of care may be split over more than one visit. Although there have been recent experiments in developing person-level records of hospice use (Public Health England, 2013), these are by no means well established.

Some information about hospice use is collated at aggregated level by various national organisations. Across the UK it has been estimated by Help the Hospices that in 2012,

£1.8 million was spent on independent voluntary hospice care every day (Help the Hospices, 2013). In England, just over a third of this expenditure was reported to have been funded by the government. If this were spent solely on inpatient services (3,200 adult beds and 338 child beds), this would indicate a figure of around £450 per hospice and palliative care bed per day. However, this is an upper bound estimate, given that other hospice services will take some share of the total funding.

Information provided to us by Marie Curie Cancer Care suggested that while most hospice care is commissioned using block contracts, it is occasionally purchased at a bed-day rate. In five Marie Curie hospices the commissioner charge per bed day was reported to be around £350. In addition, Marie Curie were able to estimate the average length of stay for stays that ended in death as 14.6 days (14.8 for people with cancer and 13.3 for those without cancer) using information from a single hospice. A National Council for Palliative Care analysis of hospice and specialist palliative care providers reported a similar average length of stay of 13.4 days, although this was for all inpatient hospice stays, including those which did not end in death (these made up 45% of stays) (National Council for Palliative Care, 2013).

These sources broadly indicate costs of the order of £400 per day during a hospice stay. This is noted to be broadly in line with an estimate of average costs of an NHS bed day of inpatient specialist palliative care of £425 (Curtis, 2010). An average 14-day stay therefore equates to around £5,600. If we assume that the 45% of stays that do not end in death do also occur within 90 days of death, this would indicate an additional £4,500 of inpatient hospice costs to take account of each hospice stay that does end in death. This suggests costs of the order of £10,000 per death in a hospice. With 5.5% of deaths occurring in a hospice, the average hospice cost over all people who died we can estimate to be very broadly in the region of £550.

### Secondary (acute hospital) care

For hospital costs at the end of life, we report here on some results of a large-scale forthcoming analysis of hospital data covering the majority of individuals who died in England in the three years from April 2009 to March 2012 (N=1.22 million people). These analyses made use of Hospital Episodes Statistic data (inpatient, outpatient and A&E), linked to Office for National Statistics mortality data.

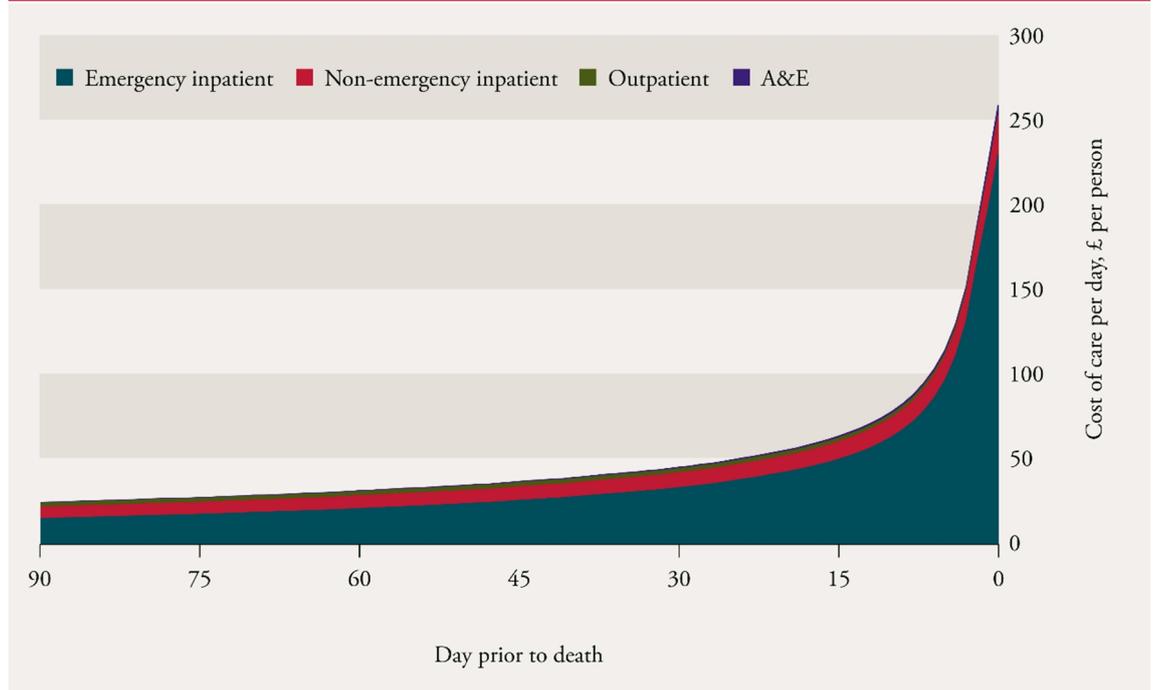
Costs were taken from the Payment by Results national tariff or Reference Costs<sup>3</sup>, and so do not directly reflect the costs paid by commissioners. Appendix A provides some details of the costing methods used.

Figure 7 shows the average cost of hospital care over the final 90 days, split by the type of hospital care. Daily costs were observed to rise very rapidly in the final week of life, with the increase primarily driven by a rise in unplanned (emergency) inpatient activity. The total average cost in the final 90 days was £4,580 (see Table 4).

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<sup>3</sup> Reference Costs are the unit costs to the NHS of providing specified types of care. They are submitted by NHS providers and form the basis of the Payment by Results national tariff.

Figure 7: Average hospital costs per day over final 90 days of life (N=1.22 million)



We identified individuals with a history of cancer where their linked inpatient data recorded at least one cancer diagnosis in the two years before death. The number of people estimated to have had a history of cancer via this method was 485,847 (37.8% of those who died), and these individuals had higher average costs than the cohort as a whole (£5,890 total hospital costs; Table 4).

Table 4: Summary costs of hospital care

Group	No. deaths	Cost of care in final 90 days, per person (standard deviation)				
		Emergency inpatient admissions	Non-emergency inpatient admissions	Outpatient attendances	A&E visits	Total
All people	1,286,005	£3,465 (£3,912)	£822 (£2,730)	£211 (£511)	£82 (£94)	<b>£4,580</b> (£4,915)
Cancer diagnosis final two years	485,847	£4,071 (£4,077)	£1,360 (£3,289)	£378 (£714)	£80 (£95)	<b>£5,890</b> (£5,264)
No cancer diagnosis	800,158	£3,096 (£3,760)	£496 (£2,264)	£110 (£288)	£83 (£94)	<b>£3,785</b> (£4,509)

As can be seen from these figures, the cost of hospital care at the end of life is substantial. To our knowledge our study of hospital costs at the end of life is the largest to have taken place in England to date. Forthcoming Nuffield Trust studies will report in more detail on costs of care at the end of life, and on variations in activity across England.

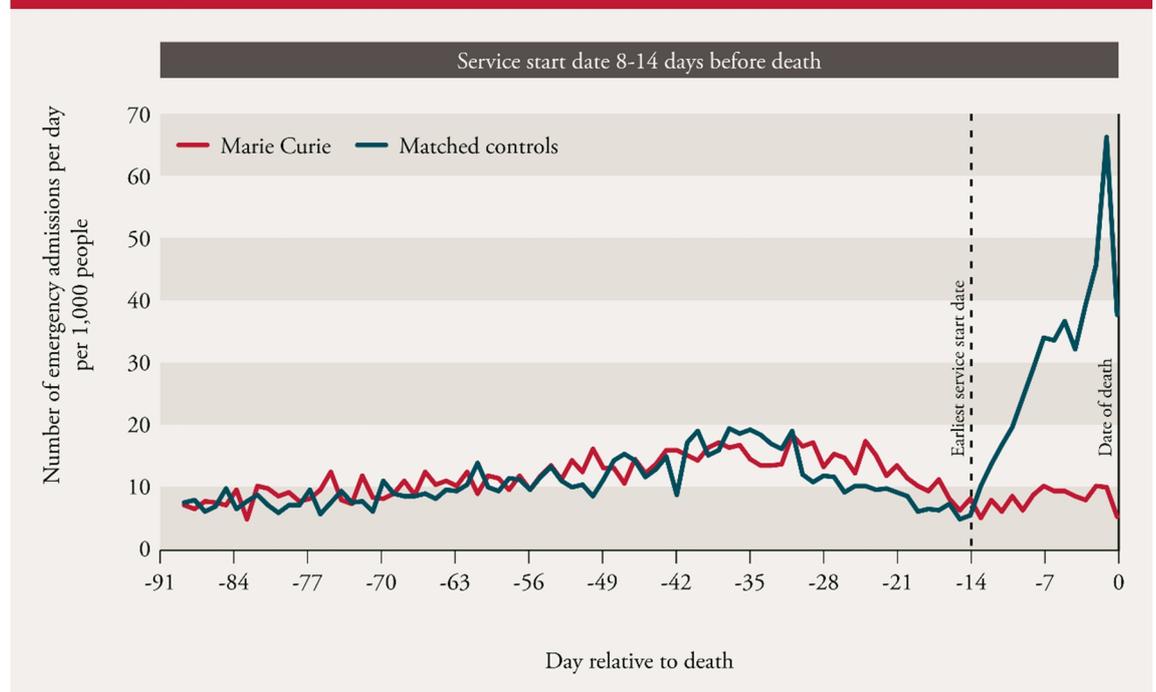
## 2. Modelling the wider impact of an end-of-life nursing service

In 2012, we published an evaluation of Marie Curie’s nursing service (Chitnis and others, 2012). The study documented the use of hospital services for a group of 29,538 people who had received a Marie Curie nursing service shortly before they died. For each of these individuals, we used advanced computational methods to select a very similar individual from a dataset of over a million other people who had also died. We were able to match people on a range of different factors: demographic, diagnostic histories (derived from inpatient hospital admissions data) and general patterns of hospital activity in the year before death.

This process resulted in a matched cohort group of 29,538 individuals who had – as far as we were aware – *not* received a nursing service from Marie Curie, but who otherwise looked strikingly similar on a very wide range of characteristics to those who had. The study drew its conclusions by comparing the use of hospital services in the final days of life for these individually matched groups.

Figure 8 shows an example of the typical difference observed between these two groups in terms of their emergency admissions before and after the nursing service had begun for the Marie Curie nursing cohort.

Figure 8: Emergency admissions in last 90 days of life; group whose Marie Curie service started in the penultimate week before death



The figure displays the patterns of emergency admissions in the last 90 days of life for a subset of the study cohort. Up until the last two weeks, the two groups had very similar patterns of emergency admissions. During the period in which the nursing service was being delivered (the final 14 days), the patterns of emergency admissions diverged markedly – members of the control group had many more emergency admissions than those in the Marie Curie group.

Across the whole of the study cohort we found that the Marie Curie nursing service group spent 2.5 fewer days in hospital than the matched control group did (an average of 1.6 days per person compared with 4.1 days for the control group, during the period in which the nursing service was being delivered). The difference across all types of acute hospital care was found to be equivalent to costs of around £1,140 per person (£610 per person versus £1,750 per person in the control group).

There were important caveats to be considered when interpreting these results. It was possible, for example, that there existed systematic differences between the Marie Curie and control groups that we were not able to correct for with the available data (for example the levels of carer or family support). Also, our analysis relied on the assumption that the receipt of Marie Curie nursing care did not affect the subsequent length of time people lived.

In addition, the findings prompted a question about the possible implications of an otherwise effective intervention at the end of life on the wider care system<sup>4</sup>. If a particular intervention was indeed to have a direct impact on reducing the need for hospital care – then what might the implications be on other out-of-hospital care services?

This is a question that we test in the remainder of this report, using the original Marie Curie nursing service evaluation results as a focus for our deliberations.

### **Applying the non-hospital cost estimates**

Our aim was to determine the scale of additional costs that might be accrued in non-hospital care services if 2.5 extra days were spent at home at the end of life, rather than in hospital. In an ideal analysis, we would directly compare the measured costs of the actual Marie Curie cohort that we studied in 2012, as well as those of the selected control group, using linked datasets that covered primary, community and social care services. As the Marie Curie study group came from across the whole of England, that was well beyond the scope of this study, and so we have relied on modelling the costs of these two groups using information presented in the first part of this report.

One of the assumptions made was that during the final months of life, all days not spent in hospital were available for care to be delivered by all other non-hospital services. We also assumed that every person received only the average intensity of care, as estimated in the first part of this report, from each of the non-hospital services, and that the only difference between the two groups was in the number of days at home – 2.5 extra days in the final 90 for the Marie Curie group. Where possible we weighted the costs used to those of a population where cancer had been diagnosed in 77% of individuals. This was the prevalence of cancer in the Marie Curie study cohort and in the control group.

The resulting differences in the estimates of the costs for the two groups were then considered alongside the large apparent reduction in estimated hospital costs found in the

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<sup>4</sup> We limit the sense of ‘effective’ here to mean an intervention which helps people to remain out of hospital during their final days, but acknowledge that this is not always desired or appropriate.

previous Nuffield Trust evaluation, in addition to the costs of Marie Curie nursing service provision itself. This allowed us to determine whether the potential scale of an increase in demand for care outside of hospital could outweigh the potential scale of reduction in hospital costs, at least given our somewhat rudimentary assumptions.

### Estimating the relevant timescales for each cost element

The average matched control individual spent 13.6 of their final 90 days in hospital, with the other 76.4 days spent in their usual place of residence. These individuals were considered to be those who were not in receipt of Marie Curie's nursing care, but rather those who were receiving 'normal care' (of whatever form) at the end of life. The similar individuals who did receive a Marie Curie care nursing service, meanwhile, were observed to have spent only 11.1 days in hospital.<sup>5</sup> The 2.5 extra days that this second group did not spend in hospital represented 3.3% more days in the person's usual place of residence ( $2.5/76.4 = 3.3\%$ ).

In determining the implications of this difference for GP consultations and for local authority-funded social care estimates, our calculations were relatively simple. In both cases, average costs per day were known to be more or less uniform over the final 90 days of life (see Figure 2 and Figure 6). As such, our estimate of additional costs due to these extra days at home was simply calculated to be 3.3% of the total 90-day average costs.

For community district nursing care – whose costs were not uniform across the final 90 days (Figure 4) – we used a more complex approach. With inpatient stays far more likely to have occurred in the very final days of life than in the immediately preceding weeks and months (as seen indirectly in Figure 7), any hospital bed days potentially prevented by a palliative care nursing service were correspondingly more likely to have occurred in these very final days. From the original Marie Curie evaluation data we were able to derive a distribution function to describe exactly how the 2.5 days difference in hospital stays were spread over the final 90 days of life (see Appendix B). Given that the average daily cost of district nursing care was found to vary over the final 90 days of life, we applied each day's average district nursing cost to the appropriate number of potential additional days at home using this adjustment factor.

For all three service types, in order to create estimates more relevant to the Marie Curie nursing service cohort studied, we used the average costs for individuals with cancer and for those without cancer separately where possible. We weighted all estimated total costs to the ratio of cancer and non-cancer patients, as in the Marie Curie and control cohorts (this ratio was 77% and 23%, respectively).

## Results

Table 5 displays the resulting estimated costs in the final 90 days for a Marie Curie cohort-like population across the different care sectors. The estimated differences in costs for primary, community and social care are modest – the additional 2.5 days equates to 3.3% of additional costs, or 8% in the case of community nursing care. These sum to just over £70 extra per person – a very modest increase when considered against the scale of total costs at the end of life.

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<sup>5</sup> The Marie Curie control group spent on average 13.6 days of the final 90 days in a hospital bed. Of these days, 4.1 (the figure quoted earlier) lay during the period during which the nursing service was being delivered.

**Table 5: Estimated costs for nursing service patients: GP visits, district nursing care and social care**

Care service type	Calculation method	Final 90-day costs estimated, per person		Difference, per person *
		Normal care	Nursing service modelled	
Primary care – GP visits	2.5 extra days home	£309	£320	+£10
Community care – district nursing	2.5 extra days home	£510	£550	+£41
Social care	2.5 extra days home	£624	£645	+£21

\* Apparent discrepancies in the difference figures are caused by rounding.

For hospice care estimates we used a different approach. Our original evaluation found a large difference in the number of people who died in a hospice between the Marie Curie nursing service cohort and the matched control group. Of the nursing service cohort 13.0% died in a hospice, compared with 21.5% of the matched control group. The estimates presented in Table 6 rely only on this difference, and assume that all individuals who died in a hospice (whether in the nursing service group, or in the control group) had the same costs in the final hospice stay (of roughly £5,600). We only accounted for stays in hospice units which ended in death, and did not assume any difference between the groups in activity that did not end in death.

Constructed in this way, our estimates of hospice care costs do show a large difference between the two groups – the nursing service group’s estimated costs are only three fifths the size of the normal care group.

**Table 6: Estimated costs for nursing service patients: hospice inpatient care**

Care service type	Calculation method	Final 90-day costs estimated, per person		Difference, per person
		Normal care	Nursing service modelled	
Hospice inpatient care	Death in hospice rates	£1,204	£728	-£476

Differences in hospital costs were taken directly from results of the Nuffield Trust’s original evaluation, and so these were the directly measured – and not modelled – differences between the Marie Curie group and the matched control group (see Table 7). The final 90-day costs shown do not represent all costs in the final 90 days – but only those as a result of care after the nursing service had begun (compare, for example, to Table 4 estimates). The difference, however, we have already noted as being a significant amount – the nursing service group had less hospital activity than the normal care group, and the costs of care were lower by £1,140.

**Table 7: Costs for nursing service patients: hospital care**

Care service type	Final 90-day costs estimated, per person, during receipt of nursing service		Difference, per person
	Normal care study cohort	Nursing service study cohort	
Secondary care	£1,750	£610	-£1,140

Source: Chitnis and others, 2012

The cost to the NHS of the Marie Curie nursing service itself was derived from the service's own administration system using data from late 2010 and 2011. The average cost of the service for each person with a cancer diagnosis was determined to be £542, while the average cost for those without a cancer diagnosis was £719. The average cost to the NHS over the whole Marie Curie study cohort was calculated to be £581. The 'normal care' group by definition had no Marie Curie nursing service costs – see Table 8.

**Table 8: Estimated costs for nursing service patients: Marie Curie nursing service cost to NHS**

Care service type	Final 90-day costs estimated, per person		Difference, per person
	Normal care	Nursing service	
Marie Curie Nursing Service	£0	£581	+£581

Source: Marie Curie

Discounting our estimates of inpatient hospice care, the total *additional* costs for the modelled Marie Curie group we calculated to be £653 per person – £72 in total for extra community, primary and social care services during the additional days at home, and £581 for the palliative care nursing service itself. This modelled increase in non-hospital care costs is clearly much smaller than the £1,140 per person reductions in hospital costs found in our original study. We concluded that it was likely that a person receiving a palliative care nursing service would have lower total care costs than a similar individual in receipt of normal end-of-life care. We calculated this reduction in costs to be somewhere in the region of £487 per person (£1,140-£653), although we emphasise that this figure is subject to large uncertainties, which are discussed below.

## Discussion

In the context of a general absence of person-level data documenting the full range of health and social care services, we have had to work within significant constraints in trying to assess overall costs of care for individuals at the end of life.

We have drawn together data from various different sources – in some cases extensive, in others necessarily modest – to try to build a picture of the costs of care during the final 90 days of life. As growing efforts are made to help people to die in the place of their choosing, it is crucial that we try to anticipate the impacts on wider service use in all relevant care sectors. The ultimate aim is to help care services to be responsive to the needs of those near to death, so that they can provide support and high-quality care in the most appropriate setting for the individual.

The analyses presented in the first part of this report go some of the way towards filling in existing uncertainties in what we know about use of different care services during the final months of life.

**Table 9: Summary of per-patient estimated costs/activity in the last three months of life**

		Cancer diagnosis	No cancer diagnosis	All people
<b>Secondary (acute) hospital care (n=1,286,005) (Table 4)</b>	Cost of all hospital contacts	£5,890	£3,785	£4,580
	Cost of emergency inpatient admissions	£4,071	£3,096	£3,465
	Cost of non-emergency inpatient admissions	£1,360	£496	£822
	Cost of outpatient attendances	£378	£110	£211
	Cost of A&E visits	£80	£83	£82
<b>Local authority-funded social care (n=73,243) (Table 3)</b>	Cost of local authority-funded social care	£444	£1,222	£1,010
<b>District nursing (n=10,779) (Table 2)</b>	Number of minutes contact	453	191	214
	Cost of district nursing care	£588	£249	£278
<b>GP contacts (n=21,552) (Table 1)</b>	Number of estimated GP visits	11.4	3.9	4.6
	Cost of GP visits	£365	£125	£147

Our estimates of care service costs (summarised in Table 9) were made using any sources of data that were available to us. As a result, the analysis cohorts for different care sectors may not have been comparable in terms of age, gender and disease burden. However, all patients studied shared the common factor that they were in the last few months of life. While direct comparisons between sectors are imperfect, it is clear that acute hospital care made up the largest source of costs at the end of life, with average costs of approximately £4,600 per person over the final 90 days. We found local authority social care costs to be

the next most costly area of care services in the same period, with average costs of just over £1,000 per individual who died. GP consultations and district nursing care were calculated to cost approximately £150 and £280 per death, respectively, although our confidence in these figures was somewhat more limited on account of the relatively small samples of data used. Finally, in the absence of any person-level hospice data, we estimated that hospice inpatient care costs might be somewhere in the region of £550 per death, but better estimates will have to wait for developments in palliative care datasets.

We have made some other interesting observations about the patterns of care in the final months, notably that GP activity remained rather flat during the last months of life, whereas district nursing care (based on data from a single borough) showed a modest increase in the final few days of life. Only one third of those who died received any district nursing care in the final 90 days of life, whilst twice as many had at least one GP consultation in the same time. We note that the National Bereavement (VOICES) survey found that 48% of individuals who died had received care from a district or community nurse and 79% from a GP in the last three months of life (Office for National Statistics, 2013b). Our figures are lower than these survey results suggest. These differences might be caused by possible gaps in the data we used, as well as by particular characteristics resulting from the limited number of areas used for our analysis.

One of our original intentions was to test whether the scale of any increase in non-hospital service costs would be likely to offset any savings in terms of reduced hospital activity which might be the result of a palliative care nursing service. We have done so in the second part of this paper using fairly conservative methods. But our overall finding is that any increase in activity that might occur in primary care, community care and in social care as a result of reduced hospital bed days is likely to be very modest when considered against the totality of care activity during the last months of life. Discounting our estimates of inpatient hospice care, the modelled Marie Curie nursing group had total additional costs of £653 per person (£72 for extra days of community, primary and social care services, and £581 nursing service commissioning costs). Set against our finding of £1,140 lower secondary care costs, this suggests almost £500 per person lower costs overall (£1,140-£653=£487).

In addition, with fewer deaths occurring in hospices for those individuals who had a Marie Curie nursing service in the last days of life, there are likely to be lower inpatient hospice costs compared with a similar cohort receiving normal care. We have proposed a difference as large as £476, although we would stress here our large uncertainty in the picture we have of utilisation of hospice care at the end of life.

Some of the difference we found in hospital costs (and, by extension, in hospice place of death) in our original study might have been due to methodological limitations of our original matched control evaluation. With this piece of work we have tried to address one of the possible implications around the impact on other care services. Some of the data we used and the assumptions we made are not as strong as we would have liked, and so caution is recommended in interpreting our findings. A summary of this study's weaknesses is given in Appendix C.

It is also important to stress that the figures presented in this study are only notional cost estimates which would not, even were they perfectly accurate, automatically translate into costs savings for the health system. Where a hospital bed is not filled by somebody at the end of life, another patient may simply take their place. Cashable savings to the hospital

would only be achieved if they were able to release staff or capital costs in some form (National End of Life Care Programme, 2012).

A key message of this work is that it is essential that we develop better ways to understand resource use in everyday care. NHS England's palliative care funding pilots are an important manifestation of this aim with respect to end-of-life care. It is worth emphasising that a better understanding of individuals' patterns of care use can be achieved most powerfully through a safe and secure approach of linking information for individual patients over time and across sectors. Though recent debates about care.data have raised some public concerns over data being brought together in this way, there is a widely recognised view that such linkage is invaluable for research that should ultimately lead to improvements in the ways individuals are cared for, not just at the end of life, but throughout their lives.

## Appendix A: Calculation of hospital costs

Hospital costs were taken from the Payment by Results (PbR) national tariff or Reference Costs, and so do not directly reflect the costs paid by commissioners.

### a) Inpatient spells

Admitted patient care spells were primarily costed on a Healthcare Resource Group (HRG) basis using the 2010/11 mandatory and non-mandatory national tariffs. Where national tariff prices were not available, 2007/08 national Reference Costs (adjusted for inflation) were used, as they formed the basis of the 2010/11 national tariff. If neither of these sources provided costs for a HRG, average specialty costs were applied. The spell cost was then converted to a daily figure, and summed over the number of days within the month or quarter covered by the spell.

Critical care costs were included and were modelled rather than applied directly due to concerns about the completeness of the critical care minimum data set (CCMDS). The rate of critical care utilisation by HRG was derived from HES records for 2005/06, prior to the introduction of CCMDS. This rate of critical care days per ordinary care days was then applied to activity in the HES inpatient datasets. Critical care costs were estimated using national Reference Costs as outlined above.

### b) Outpatient attendances

We only included outpatient appointments that were attended by the patient. As with inpatient costs, prices were either taken from the 2010/11 national tariff where there was a mandatory HRG or treatment specialty price, or otherwise derived from the 2007/08 Reference Costs. Costs of unbundled activity were included where applicable.

Radiotherapy, chemotherapy and some high-cost drugs generate an unbundled HRG but are excluded from the national tariff and in 2010/11 did not have a non-mandatory tariff. These elements (particularly the former two) are likely to represent a significant proportion of the costs of care for people with cancer. In order to capture these costs, we applied the 2007/08 Reference Costs (adjusted for inflation) for all unbundled HRGs whose costs were not included in the spell or attendance core HRG price as set out in PbR guidance (Department of Health, 2010).

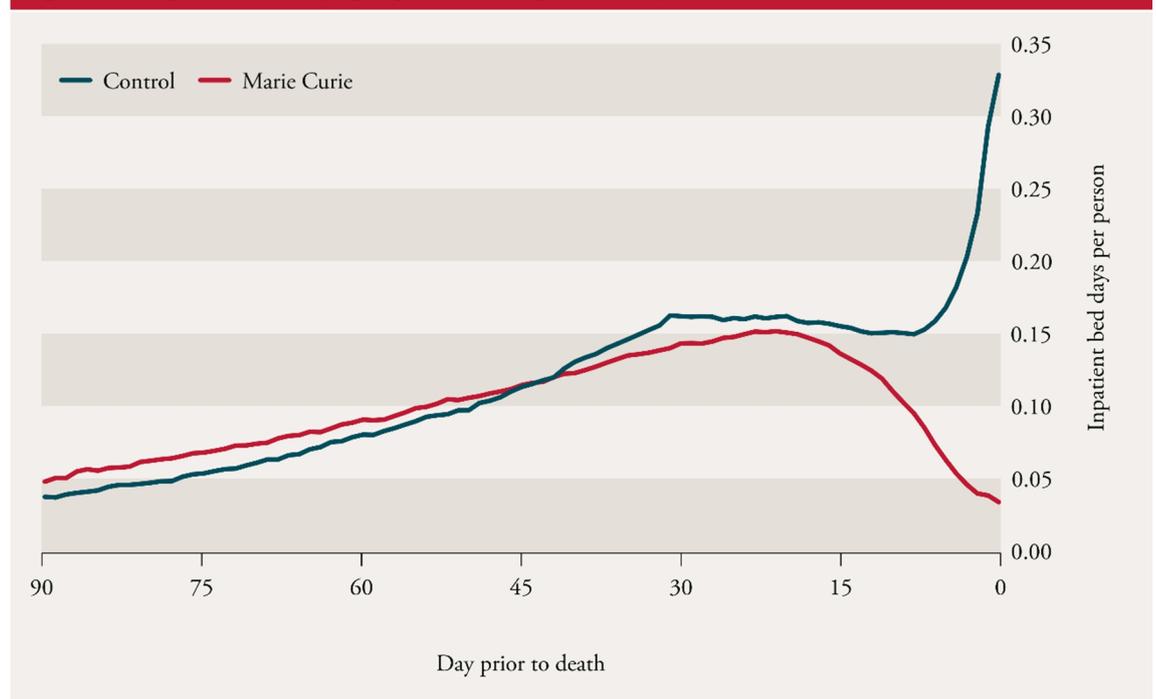
### c) Accident & emergency attendances

A&E visits were all costed using the 2010/11 national mandatory tariff. This provides a limited set of costs, based on the version 3.2 HRG code of the visit.

## Appendix B: Daily adjustment factor for non-uniform care activity at the end of life

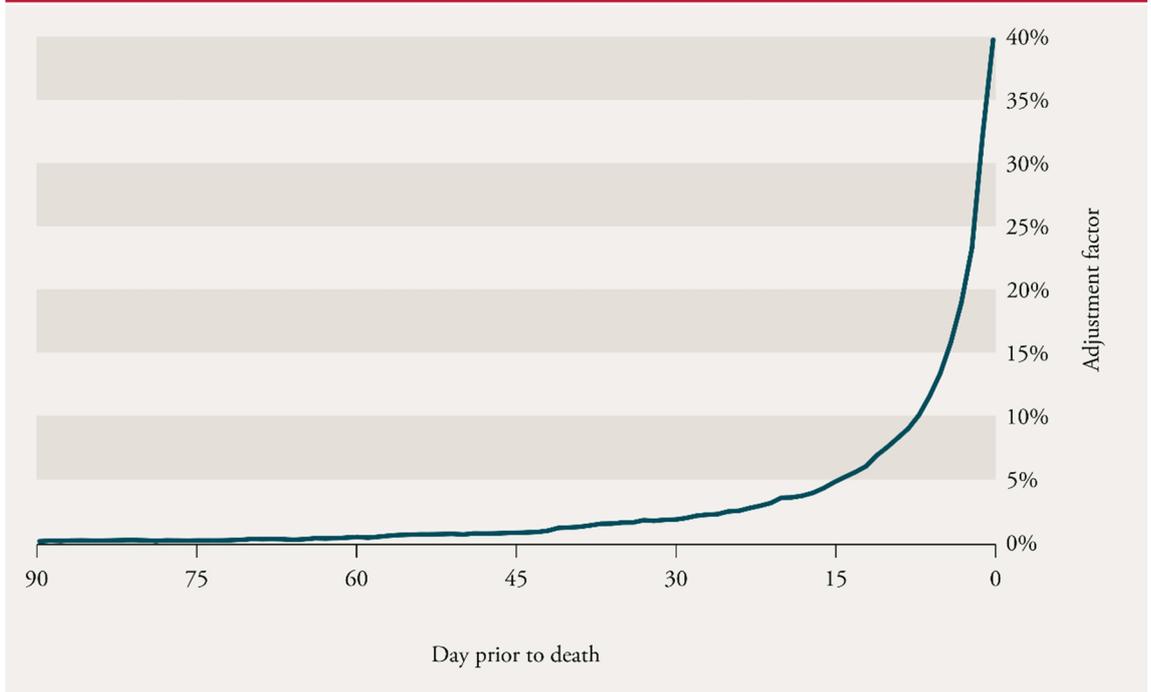
Figure A1 shows the average daily inpatient bed-day use for the Marie Curie care study group evaluated by Chitnis and others (2012), alongside that of the matched control group. The bed days per person measure can be interpreted as the proportion of each group who are in hospital as inpatients on any given day (in measuring bed days, we count any part of a day in hospital as a full day in hospital). The area between the two lines broadly sums to the total number of bed days difference between the two groups over the final 90 days of life (that is, 2.5 days per person).

Figure A1: Inpatient bed days per person during last 90 days of life



For any given day, the difference between the two lines can be expressed as a percentage value that describes the extra time that the Marie Curie nursing group were not in hospital as a percentage of the average time at home in the control group. For example, on the day prior to death, 30% of the control group were in hospital and 70% were at home – equating to an average 0.7 days per person at home. On the same day, only 8% of the Marie Curie nursing group were in hospital and 92% were at home – equating to an average extra 0.22 days per person at home. This equates to 31% more time at home ( $= 22/70$ ) for the Marie Curie group compared with the control group. If we know the size of out-of-hospital care activity that is delivered to the control group cohort on that day, our model proposes that the Marie Curie nursing group will effectively receive 31% more on that day, as 31% more of the cohort are at home and eligible for non-hospital care. This percentage value is used as the specific day's adjustment factor. Figure A2 describes how the factor changes by day during the 90 days.

Figure A2: Additional home days per person in the Marie Curie cohort, compared with the control group



## Appendix C: Methodological issues

**A number of weaknesses and gaps exist in this study's methodology. These are summarised below.**

We have made no estimates of the costs of the following types of care:

- self-funded social care
- primary care costs beyond GP consultations
- outpatient, day therapy or community hospice care
- institutional or community mental health care
- other costs borne by individual patients or carers.

GP consultations could not be directly identified, but were instead estimated from complex electronic GP care records.

GP and district nursing costs were based on small samples of data from areas in London. They relied on computerised activity recording of unknown quality and completeness.

Hospital activity was costed using national tariffs. This may have under estimated additional costs incurred by people at the end of life, for example, potentially expensive medications.

Our estimate of the costs of hospice care at the end of life was based on crude aggregated measures of national hospice care use alongside some detailed information from five Marie Curie hospices. In considering the final three months' cost of inpatient hospice care we also assumed that the (almost) half of all hospice stays that didn't end in death also occurred in the final 90 days of life, although it is not clear that this is the case. When modelling the differences between the Marie Curie nursing cohort and the control individuals, however, we only took account of the stays that ended in death and assumed that both groups had the same final length of stay and amount of prior inpatient hospice activity.

We have not assumed any special interactions between the patterns of care use in different care sectors, though these may be important. Nor have we allowed for any changes in the intensity of care received out of hospital – it may be that with the support of a nursing service the requirement for care in other services may be reduced or increased, depending on the way the services react to additional care out of hospital during a person's final days of life.

We assumed that each death in a hospice was preceded by 14 days spent in the hospice. In our original study (Chitnis and others, 2012), we found that two thirds more of the matched control group died in a hospice than the Marie Curie group did. Calculated as an average over all people who died in these two groups, our modelled 'normal care' group had 3.0 days of hospice care per person (ending in death), whilst the Marie Curie group had only 1.8 days. This is a possible *additional* 1.2 days (on top of the 2.5 hospital bed days) that the Marie Curie group would spend at home, compared with the control group. This represents nearly 5% more days at home for the Marie Curie group compared with the normal care group, rather than the 3.3% more days assumed using the methods above (that is, our estimates of the additional cost of Marie Curie nursing care patients would be an under-estimate). This emphasises the point above about interactions between all forms of care being an important consideration for a more complete economic evaluation of the effects of a palliative nursing service.

We used a variety of methods, and data, to identify individuals with a diagnosis of cancer. This resulted in mixed measures of the prevalence of cancer – from fewer than 10% of individuals, to almost 40%. The lower estimates were attained where we used general practice recorded 'Read codes' to determine a history of cancer. We used only data recorded in the final year of life, and so any earlier records of history of cancer would have been missed. In addition, primary care recording of symptoms and diseases can be extremely variable in practice. The implications are that we have an incomplete picture of the cohort in primary care and community care who have cancer.

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