



The Nuffield Trust
FOR RESEARCH AND POLICY
STUDIES IN HEALTH SERVICES

Social care and hospital use at the end of life

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Summary

Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people. Of particular concern is the coordination of care between health and social services which is crucial for the wellbeing of many patients at this highly vulnerable stage of their lives. Yet this is also a time when efficient use of resources is important not least because the costs of care are often at their highest for individuals in the year before death. There may be scope for better use of resources that could enhance quality, in particular, by avoiding duplication of care and unnecessary high-cost hospital care, and by offering better quality care for people at home or in the community. The national End of Life Care Strategy emphasised the importance of recognising that many people who die in hospital would prefer to die at home. Part of the reason may be that adequate support for patients and their families and carers may not be available outside hospital.

At present there are gaps in the available information on the quality, volume or cost of health care provided outside hospitals for people in the last year of life. This includes care provided by NHS primary care or community services, the voluntary sector, or social services. Such information is important when considering where care in these settings might effectively substitute, or prevent, costly hospital care. But recent advances in information and data linkage now allow some progress to be made. This report analyses for large populations, for the first time as far as we are aware, the use of NHS care and local authority-funded social care of individuals who were in the last year of their lives. Through the use of pseudonymous record linkage, information on the use of health care and social care by people in the last months of life has been linked. The analysis is of a cohort of 16,479 people who died across three primary care trust (PCT)/local authority areas in England in 2007. The main objective of the work was to describe patterns in use of health and social care by individuals, and to identify areas for further analysis as to the quality of care that may increase the potential for appropriate substitution and greater efficiency in the use of resources.

The main findings were:

Level of uptake of social care

- On average, 30 per cent of the people in the study group had some form of local authority-funded social care service in the 12 months prior to death. For older people this proportion exceeded 40 per cent.
- There were marked differences in the use of local authority-funded social care between the three study PCT/local authority areas with one area showing much lower overall use.
- The numbers of people accessing local authority-funded social care in any one month gradually increases over the last 18 months of life. The proportion of the group accessing any social care in any one given month increases from 15 to 30 per cent during this period.
- A large proportion of the increase in social services used in the last twelve months can be attributed to increases in the use of care homes and medium-intensity home care services.

Interactions between hospital and social care

- For the cohort of 16,479 people – in the last year of life 7.2 per cent of the group accessed only social care, 49 per cent accessed hospital inpatient care and 23 per cent used both types of services.
- Use of local authority-funded social care increased gradually in the last 12 months of life, whereas use of NHS funded inpatient hospital care sharply increased, particularly in the final two months.
- The balance of hospital inpatient and social care costs shifted dramatically with increasing age. Above age 60, hospital costs at the end of life declined with increasing age, while social care costs increased. A crossover occurs in people aged 90 and above when estimated social care costs in the last year of life exceed the hospital inpatient costs.
- There is some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs.
- There were marked differences between the three sites in terms of the balance of hospital and social care costs. The area with the highest social care costs had much lower hospital inpatient costs which may reflect substitution of services.

Differences in social care use with long-term conditions

- The use of social care differs according to the presence of certain long-term conditions; people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more. People with cancer appeared to use local authority-funded social care the least – an effect not simply due to the younger age profile of these cases.
- Though the number of long-term conditions a person has is related to higher hospital costs, it appears to be unrelated to social care costs.

Policy implications

Social care is an important support for people in the last year of their lives, especially for older people. Though the data studied in this analysis had limitations, we were able to estimate that in the three study areas total expenditure on social care for the 16,479 individuals who died in 2007 was estimated at just under £50m, and inpatient hospital care £102m. Projections of future population changes suggest both an increase in the numbers dying in any one year – and a larger proportion of older people that could mean even greater demands for social care. Any increase in the number of people dying in a year (as is being predicted) could mean significant cost pressures for both health and social care services.

Social care and hospital use at the end of life

This analysis shows that it is possible to link social care records to identify the use and costs of NHS and social care by individuals in the last months of their lives. The techniques used in analysis could fill important gaps in both national and local understanding of the range and quality of services delivered and should be an essential part of local planning and commissioning of services for patients.

The balance of hospital inpatient and social care costs shifted dramatically with increasing age. After age 60, hospital costs at the end of life declined, while social care costs increased. A crossover occurs in people aged 90 and above when estimated social care costs in the last year of life exceed the hospital inpatient costs. In this age group, social care appears to be substituting for inpatient care.

The 'right' mix of health and social care use is not possible to define in the absence of information on: the quality of care; what may be appropriate given the circumstances of the patient or the type of illness experienced; or on the availability of other sources of care not analysed here (for example, charitable domiciliary or hospice care, privately funded social care). But the analysis presented here prompts further questions about whether social care options are being used enough (or available enough) by younger people to help support them at home where appropriate at the very end of life. Alternatively, it may be that inpatient care is inappropriately underused by those over 90 years of age.

This study looked at an opportunistic sample of three local authority/PCT areas, yet marked differences in use of social care were found between them. More work is needed to understand better the nature of these variations for patients, users and commissioners of care services. This work would also be usefully augmented through the additional analysis of other services used for care at the end of life as well as linking the findings with more detailed studies of the quality of care delivered.

The national End of Life Care Strategy and the recent White Paper advocates greater joint commissioning of health and social care by the NHS (soon to be GP Commissioning Consortia) and local authorities to help achieve more integrated and efficient care. It will be critical to develop analysis of the type presented in this paper for this aim to be realised.

Introduction

Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people.¹ About half a million people die each year, and the care of this group also affects a much larger number of relatives, carers and friends.² It has been estimated that the number of people who die in any one year is set to rise by 17 per cent from 2012 to 2030.³ Despite the fact that surveys strongly suggest the majority of people would prefer to die at home, many end up in hospital without a medical need to do so.⁴ An essential element of good commissioning for end-of-life care is to ensure that there are appropriate alternatives to hospital care that can align a person's wishes and be less costly to the system.

It is clear that supporting people at the end of their lives is a complex task – the individuals concerned may be highly vulnerable, require much support from varying services for a range of illnesses or conditions, and families and carers also need support. Services may also have to encompass a patchwork of services, providing organisations and commissioners.

Care at the end of life has been recognised as making up a significant proportion of all health care expenditure in the NHS. Though the National Council for Palliative Care has a long-established common dataset,⁵ there are still significant gaps in information on the use of care and expenditure for patients across services. This severely limits our understanding of the breadth and quality of services available, and the possibilities to improve quality and efficiency.⁶ The specific services directly involved in the care of the dying encompass hospital inpatient and outpatient care, hospice and specialist palliative care, community nursing services and care services at home or in residential settings. The Department of Health has concluded that it is 'difficult, if not impossible, to calculate the cost of end of life care. Across health and social care, the overall cost of end of life care is large (measured in billions of pounds) and there is widespread agreement that these resources are not all being used as well as they might be'.¹

Local authority-funded social care is an important support for many people at the end of their lives.⁷ Given the need to increase the quality and efficiency of care as demand rises, there are renewed searches for areas of avoidable expenditure and potentially wasteful duplication of care.⁸ For complex care, such as that at the end of life, this means even greater efforts to coordinate planning and commissioning across care sectors. Yet this requires much better information than is routinely held. The Wanless review into funding for long-term care pointed to the vacuum in information about the overlaps between health and social care.⁹ One of the key gaps is the availability of information on local authority-funded social care.

The Nuffield Trust has recently undertaken work for the Department of Health to develop see if it was possible to develop a model that predicts the use of social care.^{10,11} As part of this work it was necessary to accumulate person-level social care and health care datasets from a number of localities in England. With appropriate protection of an individual's identity it was possible to link data to identify whether a person had died, and the health care services and social care services used by that individual over a period of time.

Social care and hospital use at the end of life

This report uses these linked datasets at person-level to examine some basic questions over patterns of social care and health care use of each individual in the last months of life:

- What proportion of patients used social care services in the months/year before death?
- How did use of social care vary in the months before death and relative to use of health care?
- What is the cost of the use of social care relative to the cost of health care?
- Which patients were most likely to use social care?

Methods

Selection of sites

The selection of three primary care trust (PCT)/local authority areas for this analysis was opportunistic in that the areas had already contributed data for an earlier study funded by the Department of Health. The three areas included one suburban area, one large county and one unitary authority with a mixed population, including a significant population of retired people. The sites cannot be considered representative of England as a whole, but they had been selected in the earlier study based on the following pragmatic criteria:

- they were able to supply at least three years of data
- they were able to supply person-level data
- the person-level NHS and social care records contained a unique NHS number, or the sites were willing to complete this data field (for example using the National Strategic Tracing Service 'batch tracing' facility)
- they were able to use a data encryption key to encrypt the NHS number on health and social care records to protect patient confidentiality
- NHS and social care data were available for the same population.

Accessing core datasets

The core datasets for these analyses comprised electronic data routinely collected on operational administrative systems used in the NHS or by local authority social services departments. The basic datasets were drawn from the PCT/local authority areas and included:

- NHS Secondary Users Service (SUS) data (information on inpatient admissions)
- GP register information (information on the people registered with a general practice at any given time)
- information about the use of social care.

Before the datasets were transferred to the research team, all sensitive personal information was removed and key linkage fields were encrypted by analysts in the health/local authorities using dedicated software tools. This approach is in line with guidance from the Ethics and Confidentiality Committee of the National Information Governance Board (see Box 1) and means that the datasets transferred to the research team did not identify the individuals concerned.

Box 1: Protecting confidential information:

This project required the analysis of health and social care data linked at a person-level using information derived from operational information systems. The size of the datasets involved meant it would not be feasible to seek individual consent from people to use their data for the project. Though informed consent is the fundamental principle governing the use of person-identifiable information by any part of the NHS or the research community.¹² The only exception to this rule is for essential NHS activities that are in the interests of patients or the wider public, where anonymous information will not suffice, and where obtaining consent is not a practicable alternative. Applications to use data in this way must be submitted to the National Information Governance Board and are typically dealt with by its Ethics and Confidentiality Committee. In this study we excluded sensitive information and used a process to anonymised key identifiers at source, i.e. before transfer to the research team. The predecessor group (the Patient Information Advisory Group (PIAG)) had previously issued a ruling stating that the requirements of the above principles may be met by encrypting data in such a way that they are effectively pseudonymous, i.e. they cannot be identified without a password.¹³ We obtained written confirmation from PIAG that the pseudonymisation process and use of encrypted media that we planned to use in this project would meet its requirements and that therefore no application was necessary under Section 60 of the Health and Social Care Act 2001.

Social care datasets

Basic information on the provision of social care funded by the local authority is typically recorded on a local client management system. The data systems used in social care have primarily been developed to fulfil local operational needs in managing care services commissioned by the local authority. Though these datasets may be used to generate some national aggregated information returns, they are not used directly for comparative analyses. Furthermore, there is currently no equivalent national dataset to Hospital Episode Statistics for social care. Consequently, different approaches to data collection were required for each local authority involved in this project. For example, we found that some areas have complex systems where a high proportion of the data fields are defined locally. These fields often incorporate free text, which is difficult to analyse or incorporate in predictive models. This posed a particular challenge for developing pooled models for this project, where we required a set of common definitions variables that could be applied across the three sites. In order to maximise the number of person-years' worth of data available for analysis, we prioritised compatibility between the datasets of the different sites at the expense of a reduced number of variables. This meant that our modelling was restricted to a relatively small number of resource-intensive aspects of social care.

Though local authorities offered similar types of services to people, they coded these services in slightly different ways. So, for example, while one site used a total of 400 distinct codes to specify services and client groups, another captured similar information in a much simpler set of 39 descriptors.

Therefore the care services recorded were themselves classified into a common typology, effectively grouping together local descriptions under the following headings:

- residential care
- nursing home
- home care
- residential respite care
- other accommodation
- equipment and adaptations
- direct payments made to users who can they 'buy' their own service
- day care meals
- other.

Grouping services in this way allowed more consistency between the sites, made the dataset used in the model simpler, and allowed us to apply national unit costs published by the Personal Social Services Research Unit (PSSRU)¹⁴ as shown in Table 1. Costs were estimated separately for each month. This approach provided a way to weight different activities and sum them over time. It assumes that the unit costs were applicable to all the sites and over time – so it makes comparisons easier. However, the estimated costs are purely indicative and do not relate to the accounts of the organisation concerned. They are not true costs.

Table 1: Unit costs used to weight social care activity

Service group	Unit cost	Source
Nursing care	£568 a week	National average across all councils and other provision for older people (from national returns PSSEX1 2007/08), plus an allowance for the NHS contribution to nursing care in nursing homes
Residential care	£465 a week	National average across all councils and other provision for older people from national returns PSSEX1 2007/08
Home care: high-intensity medium-intensity low-intensity	£244 a week £71 a week £16 a week	Based on average hours received per group and an assumed cost of £15.20 an hour (national average across all CSSR and other provision for adults and older people: PSSEX1 2007/08)
Respite	£465 a week	Assumed same as residential care
Other accommodation	£465 a week	Assumed same as residential care
Equipment and adaptations	£176 per installation	Calculation based on PSSEX1 and referrals and appraisals data
Direct payments	£124 a week	National average for older people from PSSEX1 2007/08
Day care	£80 a week	National average for older people from PSSEX1 2007/08
Meals	£22 a week	National average for older people from PSSEX1 2007/08
Other	Not costed	

Source: PSSRU¹⁴*Health datasets*

This analysis focused on the highest cost element of health care, namely inpatient admissions and used information extracted from local SUS datasets obtained from the local PCT. Data for individuals over three to five years were obtained, and any information that might help to identify individual patients was removed except a single identifying key field which was encrypted at the PCT before transfer to the research team.

Data on NHS-funded inpatient care of individuals contain diagnostic information recorded as a series of ICD-10 codes. These were used to group patients into broad categories indicating the presence of long-term conditions. A flag was attached to a person based on the presence of specific diagnostic codes in any admission in the previous two years. Details of the codes used are in Appendix 1. A single patient may have a number of different condition flags.

Health care costs were estimated for inpatient admissions using Healthcare Resource Groups (HRG)-based national average unit costs.¹⁵ An HRG was assigned to every admission based on the mix of diagnoses and procedures undertaken and the admission type ('ordinary' elective, day case, emergency). Where the number of days in the admission exceeded a specified HRG 'trim point', HRG specific excess day costs were used to calculate 'excess costs'. For admissions for which no HRG cost could be assigned, the average cost for that admission type was used (only three per cent of episodes needed to be treated in this way). The costs for outpatient, A&E or critical care were not added. Note that, as with the social care data, these 'costs' do not equate to local accounts and finances, but are a way of weighting different activities.

Linking health and social care records

In order to link the data files there needs to be some unique person-level identifier that is common to the different datasets. When encrypted in a consistent way – and made effectively anonymous to the research team – this field shows where two or more records belong to the same person. The preferred linkage field was the unique NHS number recorded on NHS data, such as on inpatient admissions. However, in England it is relatively rare for social care records to contain the NHS number, though there have been calls for this to be done more widely.¹⁶ The NHS number was routinely recorded in social care records in two of the three areas. Where the NHS number was not available (site A), an alternative identifier was constructed by the local staff using information on gender, date of birth and initials. The constructed key was encrypted before transfer and the individual data elements removed. In the older age groups, where use of social care was more likely, the matching rates ranged from 78 to 98 per cent (Table 3). As expected, the matching rate was higher where the NHS number was routinely recorded on social care records (sites B and C) and for users of more intensive social care.

Table 2: Summary statistics on the degree of matching between one year’s social care records and GP registration data in people aged over 75

Site	Any local authority-funded service received 2007	% linked to GP registration data
A	9750	78.0%
B	13205	94.9%
C	3823	94.2%

The data from hospital activity and social care were linked to a ‘member file’ based on people registered with a GP in the area and this file was used to identify the subset of the population that died and formed the cohort for analysis.

Key limitations of derived datasets

Though this work has been able to create new and innovative datasets it is important remember some of the limitations underlying this information. These include

- The sites used in this analysis were selected based on their ability and willingness to share information with the research team – these sites cannot be considered representative of England as a whole.
- The health care datasets used focused on the most costly elements of care – namely hospital inpatient activity. A complete analysis should also look to services delivered in other setting including primary- and community-based services and care from independent and voluntary sectors providers.
- The social care data in each site needed to be mapped into broad service categories meaning that some of the local detail was lost in the process. Inevitably, this meant that the data used tended to be the simpler coded descriptors rather than text-based information.

- The information on social care was based on what the local authority funded and recorded and not care funded by other means, including users themselves, voluntary sector or informal care.
- These data only reflect social care funding that can be attributed at the person-level, so for example, if the local authority is funding say independent sector services in block grant – these would not be identified.

Results

Table 3 shows some summary statistics on the cohort of people who died and were included in the analysis. In total 16,479 people died across the three sites, and their average age at death was just over 73 years and none of the areas were extreme in terms of the national distribution of deprivation.

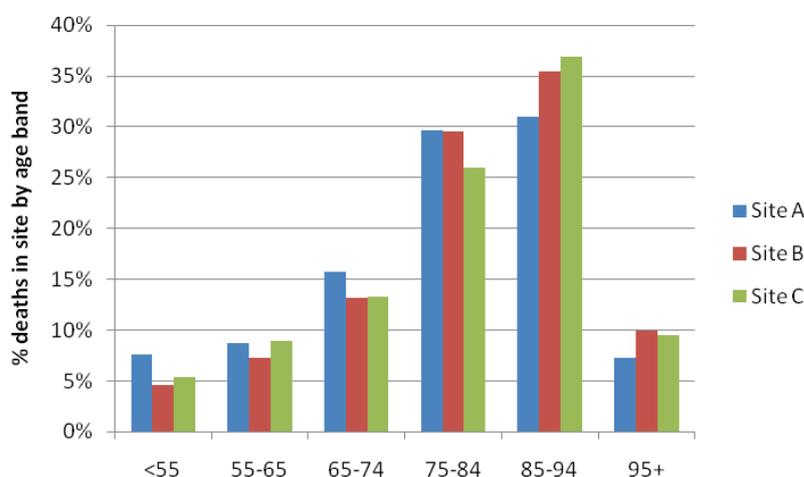
The sites did not produce data covering exactly the same time period, as is shown in the table. The study was restricted to a cohort of people who died and where we had sufficient information about prior services in the 18 months before death. This limited the time period during which we could select individuals who died, which was between 2007 and 2008 across all sites as shown in the table. For each site, all people recorded as having died during this time period were selected. The numbers selected in each site within these time periods is also shown.

Table 3: Summary statistics on the sites

	Site A	Site B	Site C	Total
Proportion of population aged 75+	7.1%	11.1%	12.6%	10.2%
IMD Decile. (1=least deprived, 10 most deprived PCT in England)	4	5	7	-
Time periods for cohort selection, i.e. all deaths between:	April 2007 – August 2008	January 2007 – March 2008	August 2007 – September 2008	-
No. cases who died	3,824	10,608	2,047	16,479
Average age at death	68.8	74.2	77.6	73.4
No. inpatients users	2,790	7,667	1,414	11,871
No. social care users	738	3,485	751	4,974

The age profile of the individuals in the study group is shown in Figure 1. A slightly higher proportion in Site A were in the younger age bands than for the other two sites (32 per cent of those who died were under 75, compared to 25 per cent and 28 per cent in sites B and C, respectively). This might be expected due to differences in the relative age structures of the populations of the sites.

Figure 1: Age profiles of the cohort of people who died



How many people received any social care in the last months of life?

For the 16,479 who died, we began by identifying how many had any record of local authority social care services in the last months of life. In the first instance, this was for any social care service we were able to cost (Table 1) so could include anything from meal services to nursing care.

Figure 2 shows how the proportion of the group accessing social care within any month gradually increased in the last months of life – a pattern seen in all three sites. In sites B and C the levels of social care use are almost identical, with a rise from 20 to 30 per cent of people accessing social care in the 18 months prior to death. Note that these figures relate to the number of people in each month. As some people will have stopped using care services during this time period, the monthly values will always tend to be lower than the cumulative figures for people who used the service at any time during the 12 months. The data from the final months has been excluded because we could not identify the exact date of death within the month. So it may be that if a person dies earlier in the month then their average monthly service use would appear artificially low.

The pattern in Site A is quite distinct. Here, the use of social care also increased for individuals nearer to death, but the proportion of people using social care is very much lower than the other two areas with a rise from just five per cent to 15 per cent. Note that these are crude rates – adjustments have not been made for age or other factors that could explain all or part of the difference between areas.

Figure 2: Percentage of people receiving local authority-funded social care in the months before death by site

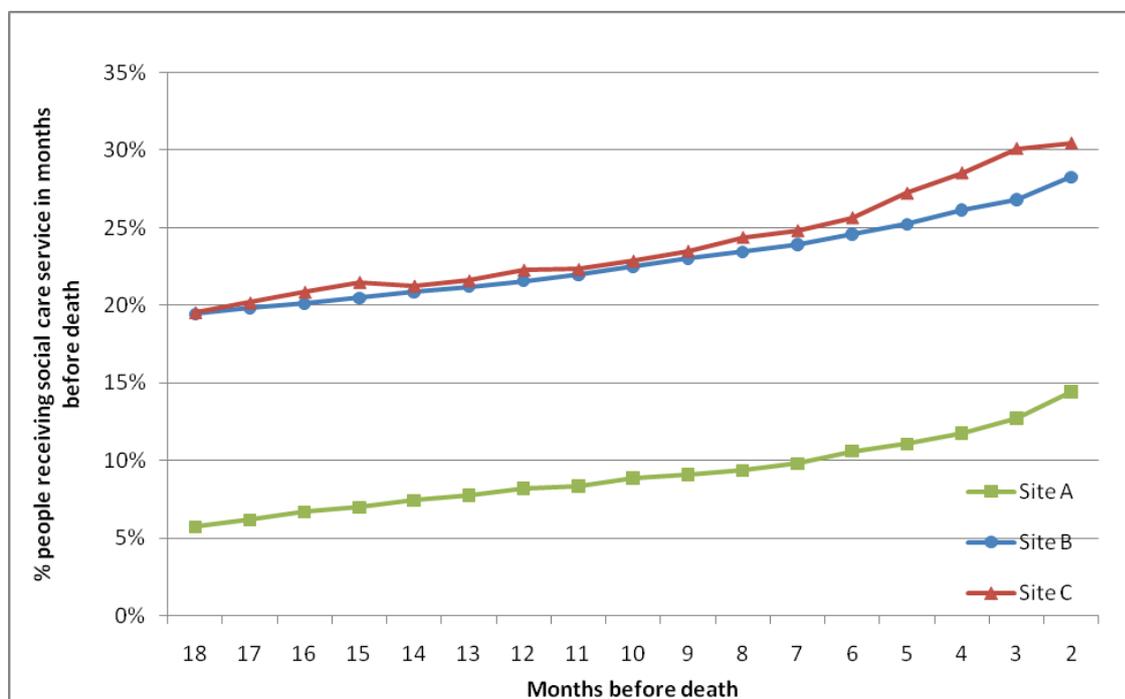


Figure 3 shows the proportion of people receiving any local authority-funded social care service in the last twelve months of life by age band and site. The average proportion of people using local authority-funded social care was 30 per cent across all sites – 19 per cent in Site A, 33 per cent in Site B and 37 per cent in Site C. In all sites older people were much more likely to receive social care services in their last year. So, for example, of those people who died aged over 95, 45 per cent accessed social care compared to 13 per cent of those under 75 years old. There was one exception to this general rule in that in Site A, people who died aged 85 to 94 were more likely than those aged over 95 to receive a social care service.

Figure 3: Proportion of people with any local authority-funded social care service in 12 months before death, by age band and site

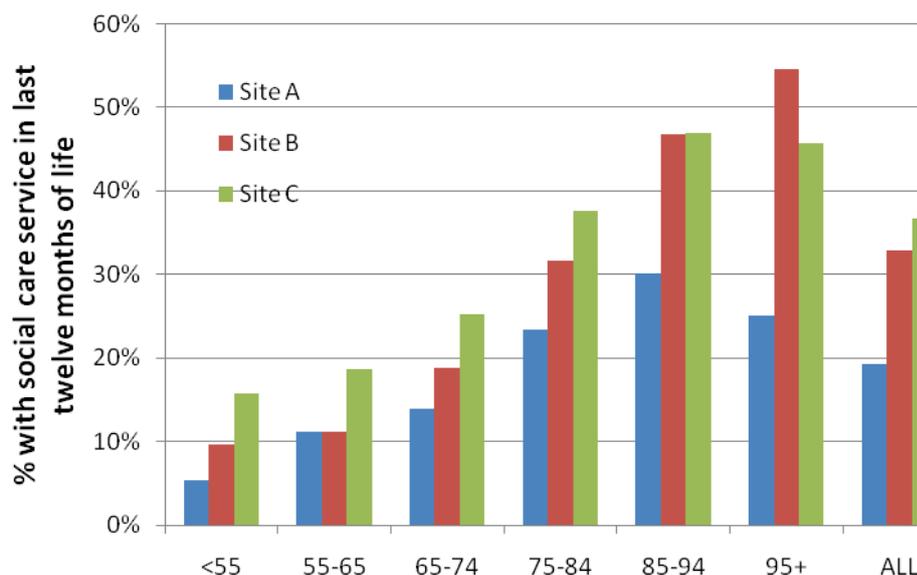


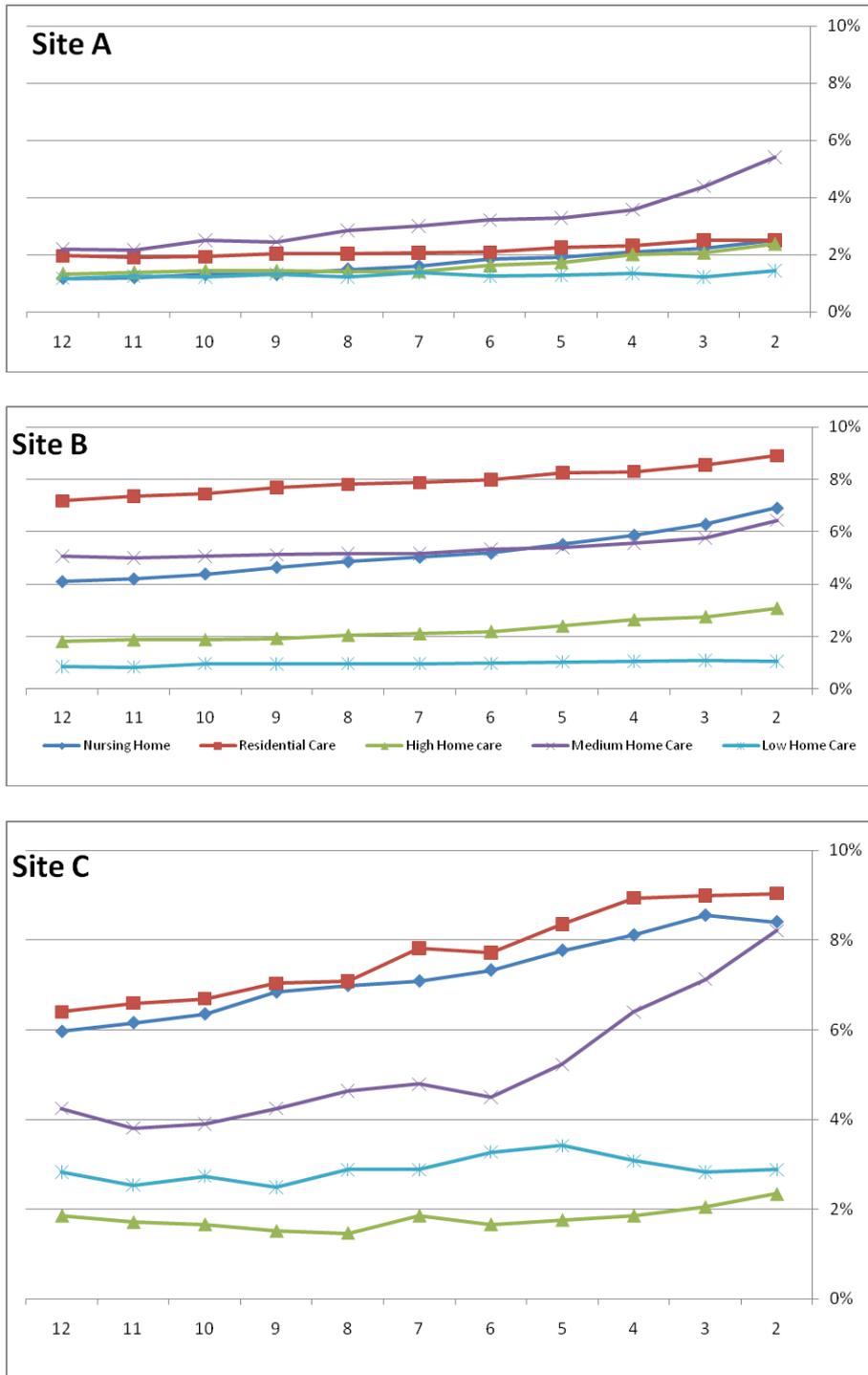
Figure 4 shows the month-by-month profile of the numbers of people accessing different types of services (care homes and home care) in the last year of life. The patterns of care services changed over time and varied across the three areas.

Site A was again the most distinct of the three sites. In this area most of the rise in social care use over this period was associated with more people receiving medium-intensity home care (equivalent to between two and ten hours a week). The proportion of people in residential and nursing homes was consistently low in this site (maximum of three per cent of people in any month, compared with up to nine per cent in sites B and C), and any increase observed towards the month of death was small. The fact that Site A had lower use of residential and nursing home care than national averages is consistent with published aggregate statistics for this area.¹⁷

In contrast, Site B had a much higher baseline level of both residential and nursing home care. In this site the use of these services increased during the year: the proportion of people in residential care homes rose from around six per cent to nine per cent while use of nursing homes increased from six to eight per cent. There also appeared to be quite a sharp increase in the uptake of medium-intensity home care services (almost a doubling from four per cent to eight per cent) in the last six months of life.

Site C also had a relatively high baseline level of people using residential care and this showed a steady increase during the year from seven to nine per cent in any one month. The proportion of people using nursing home care in any month is smaller than that in Site B (four per cent rather than six per cent), but it rises to seven per cent just prior to death. The proportion of people receiving medium-intensity home care also rises steadily towards death.

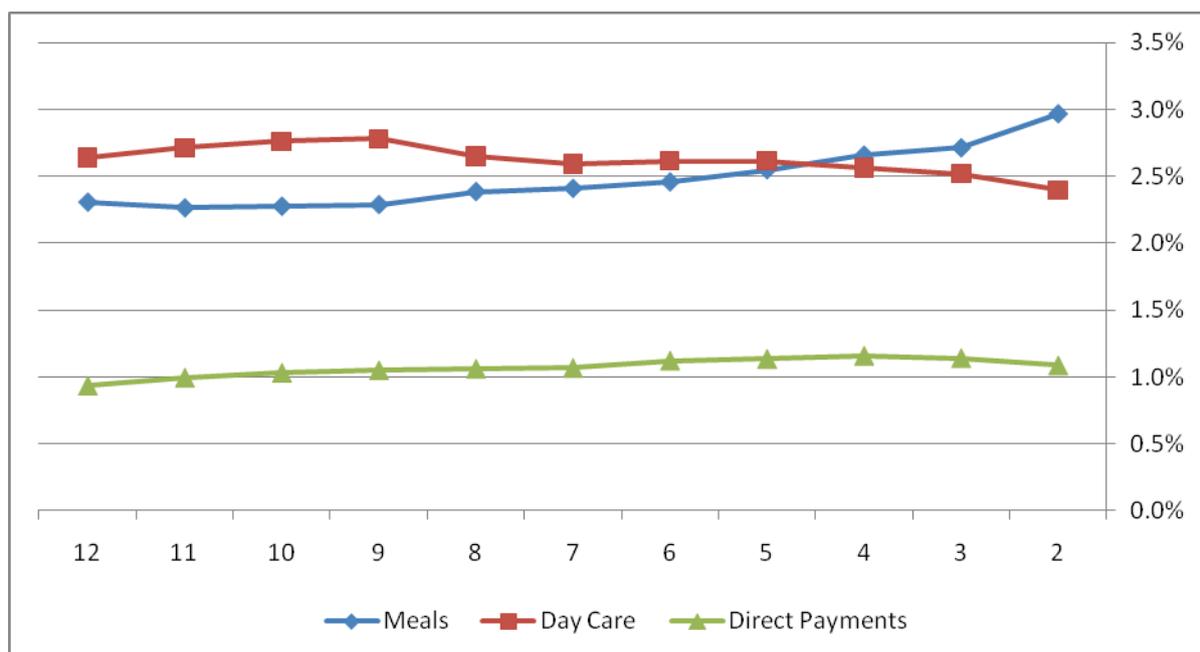
Figure 4a to c: Proportion of group accessing local authority-funded social care services in month before death



Social care and hospital use at the end of life

Figure 5 shows, for all sites grouped, how the use of the less costly services vary prior to death. Day care and direct payments are more or less stable, though the use of meals on wheels does increase during the year. The direct payments were associated with only a small number of cases (about one per cent) in the group.

Figure 5: Proportion of people using low-cost social care services (meals, direct payments and day care) funded by local authorities in last 12 months of life (all three sites)



Overlap of hospital inpatient care and social care in the last year of life

The previous analyses focused on the use of local authority-funded social care by individuals in the final months of life; this section includes information on their use of hospital inpatient care (admissions to hospital are the major element of health care expenditure). Table 4 shows, for each site, the numbers of individuals using social care and inpatient hospital care in their last 12 months of life.

Across all sites just under half of the total cohort of 16,479 people used some inpatient care but no social care in the last 12 months of life, while 7.2 per cent accessed only social care. A further 23 per cent accessed both social and inpatient care and 21 per cent accessed neither of these services. Within this latter group there are presumably people using non-inpatient health care services and some people paying for their own social care. Site A which has, as observed previously, noticeably lower social care use has a slightly higher proportion of people receiving inpatient care only. In all three sites almost three quarters of people who had social care also had an inpatient episode in their last 12 months.

Table 4: Use of inpatient social care services in final year of life, all sites

	Site A	Site B	Site C	Total
	n=3,824	n=10,608	n=2,047	n=16,479
Inpatient care only	55.9%	47.8%	42.6%	49.1%
Social care only	2.2%	8.4%	10.2%	7.2%
Inpatient and social care	17.1%	24.4%	26.5%	23.0%
Neither	24.8%	19.3%	20.7%	20.8%

For the whole group of 16,479 people, the total estimated costs in the last 12 months of life were £49.6m for social care and £102.6m for inpatient care (see Table 5a). It is important to remember that these figures are indicative and do not equate to the accounted spend in the local areas. Nevertheless, they are a useful guide as to where resources are being used. The relatively small group of individuals using both inpatient and social care (7.2 per cent of all people) accounted for a proportionately large share of overall costs (44 per cent). The average cost per person in the last 12 months of life for social care was £3,010 and £6,427 for hospital inpatient care. These average values include the people who did not access either service.

Table 5a: Estimated total costs of care services £m pooled across all sites

	Number of people	Social care £m	Inpatient care £m	Sum £m	% total
Inpatient care only	8,085	–	64.8	64.8	43%
Social care only	1,188	20.1	–	20.1	13%
Both inpatient and social care	3,786	29.5	37.9	67.4	44%
Neither	3,420	–	–	–	0%
All cases	16,479	49.6	102.6	152.3	–
Average cost per person		£3,010	£6,231	£9,241	–

Table 5b: Average costs per user (standard deviation) in the last 12 months of life

	Number of people	Social care spend per user £	Inpatient spend per user £	Social care plus inpatient cost per user
Inpatient care only	8,085	–	£8,017 (8,064)	£8,017 (8,064)
Social care only	1,188	£16,921 (9,597)	–	£16,921 (9,597)
Both inpatient and social care	3,786	£7,791 (8,410)	£9,998 (9,218)	£17,790 (11,576)

Table 5c: Hospital inpatient and social care costs per user and cost per death by site

	Site A	Site B	Site C	Total
Inpatient costs per user	£8,526	£9,395	£4,848	£8,649
Social care costs per user	£5,895	£10,818	£10,055	£9,972
Inpatient costs per death	£6,220	£6,790	£3,349	£6,231
Social care costs per death	£1,138	£3,554	£3,689	£3,010

Social care and hospital use at the end of life

The distribution of social care costs per individual in the last 12 months of life varied from zero to over £30,000. Table 5b summarises the average costs for those people that actually used a service. Individuals using only social care services had costs that averaged £16,921 which is higher than the average of £8,017 for those using only inpatient care. This is consistent with a general pattern that although fewer people use social care, the cost per user is generally higher than that for hospital care – a sustained period in residential care adds up to much more than a short hospital admission. The group of people accessing both types of service in the last 12 months incurred the highest costs overall, although the social care element was lower than for those people who used only social care (£7,791 per person versus £16,921).

As Table 5c shows each site had a different balance of health versus social care costs. In Site C, which had markedly higher social care costs per user, the hospital inpatients costs were much lower than in the other sites. Any increase in total expenditure will be a product of either change in the numbers of people using services, and/or the relative costs of those people that do use a service. Figures 6a to c summarise for social and inpatient care the proportion of individuals using a service in their final 12 months of life (Figure 6a), the average costs per user for the subset of people accessing the service (Figure 6b), and the overall expenditure (Figure 6c).

Figure 6a shows a gradual rise in the proportion of people using a social care service from 18 to 25 per cent per month. In contrast, the change in hospital inpatient care in this time period was much more marked. The numbers of people being admitted to hospital was generally lower than the number accessing social care, but rose continually and there was a large increase in the final two months – over 45 per cent of the group being admitted in the last month. These values underestimate total activity in the last month (as we did not have the precise day of death) and are shown as a dotted line. So it appears that though 87 per cent of the cohort accessed inpatient care in the last year of life, the vast bulk of this was in the last two months.

Figure 6a: Monthly values of the percentage of people using social care and inpatient care in the last months of life

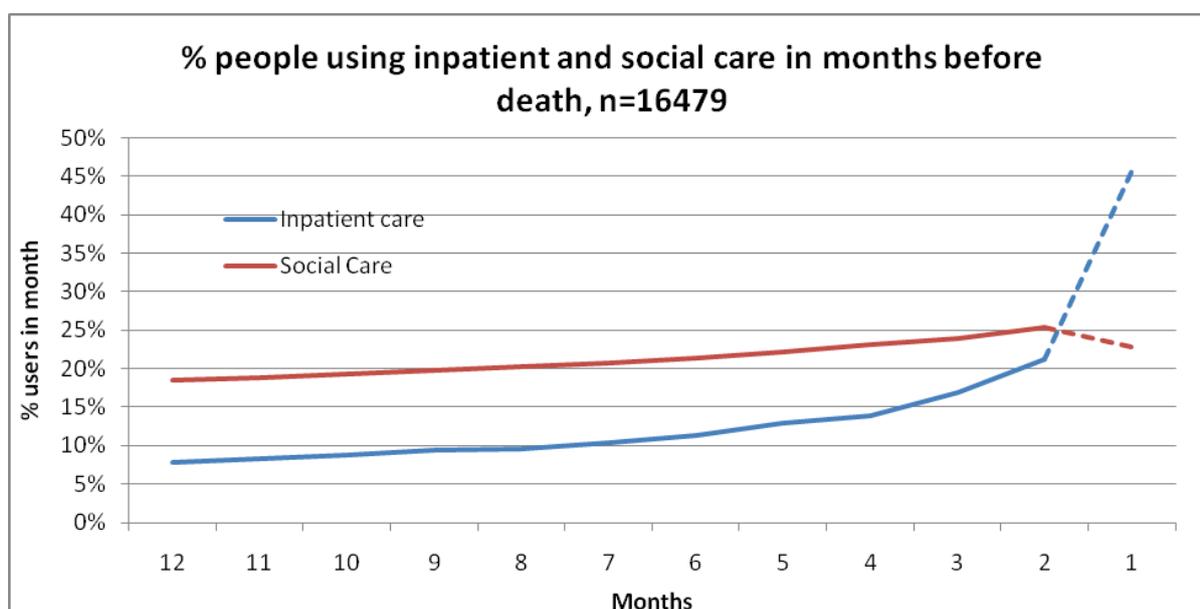


Figure 6b shows the cost per person per month for users of social care and inpatient care, respectively. The cost per person for social care stayed fairly constant at around £1,200 a month. The cost per person for those admitted to hospital rises in the last few months but not dramatically.

Figure 6b: Monthly costs per services user in last 12 months of life

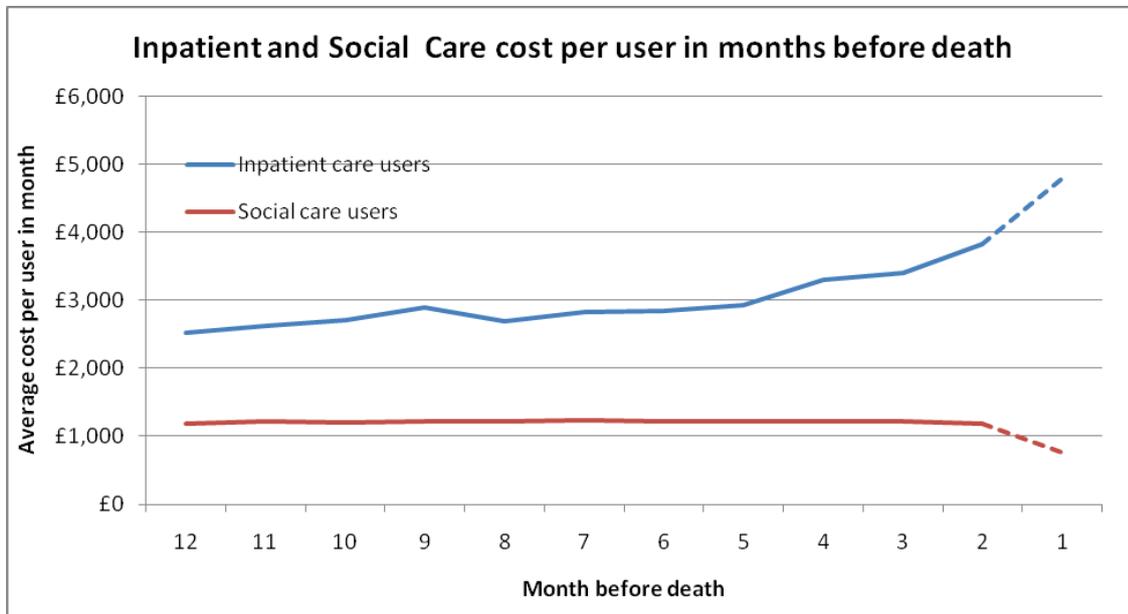
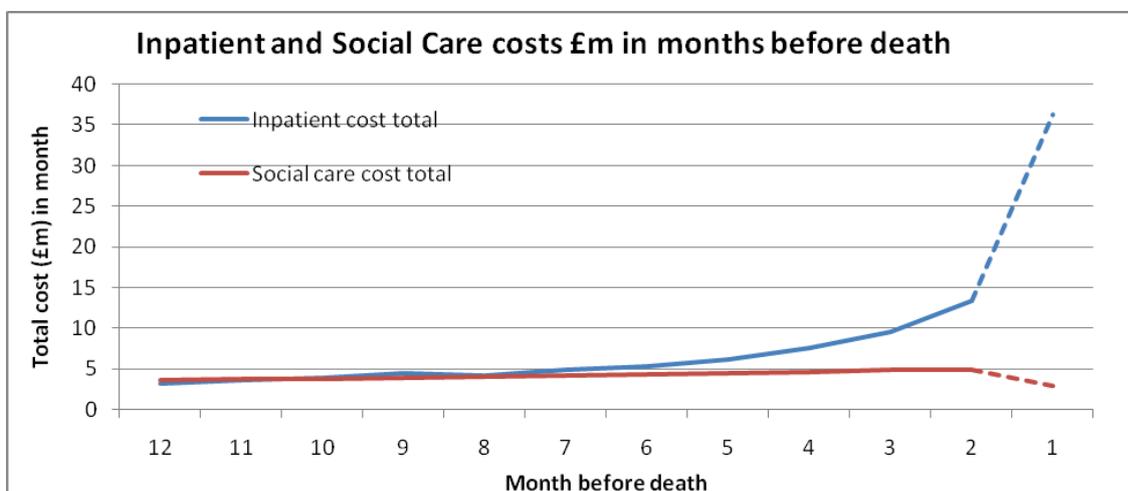


Figure 6c shows the average cost a month of inpatient and social care costs, respectively, for the whole cohort of 16,479 people who died. The figure shows a small but steady growth in costs for health and social care, with little difference between them. But at about six months before death, the costs of inpatient care for the group began to rise more steeply (before rising very steeply in the final two months). Inpatient costs in the last month of life made up of 35 per cent of total inpatient costs for the individual in their last year. The social care costs continue on the same steady slight growth until death.

Figure 6c: Total costs in the final 12 months for pooled cohort of 16,479 people who died



Differences in costs by age

Both social care costs and hospital costs varied dramatically with age. Figure 7 shows the share of total costs by age group and across social care and inpatient care. The graph neatly illustrates the concentration of expenditure in certain age groups so that over 20 per cent of total costs are associated with people aged 85 to 90 years old. It also shows a dramatic shift in the relative balance of hospital and social care costs in the older age groups. Social care expenditure becomes increasingly large and exceeds hospital costs in the last year of life for people aged 90 and over.

Figure 7: Share of total costs (social plus inpatient care) in the last year of life according to age group

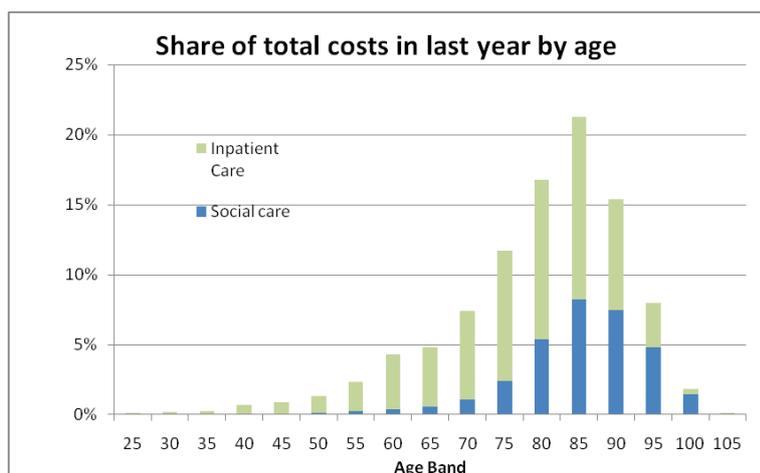


Figure 8: Average cost per person by age group

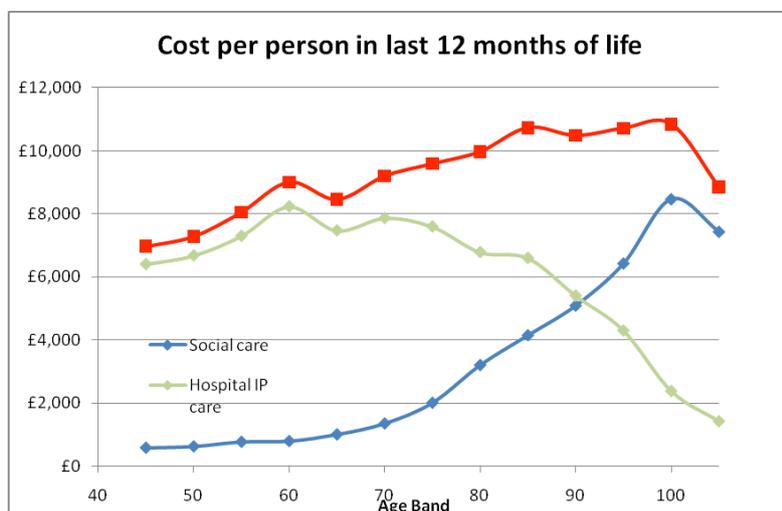
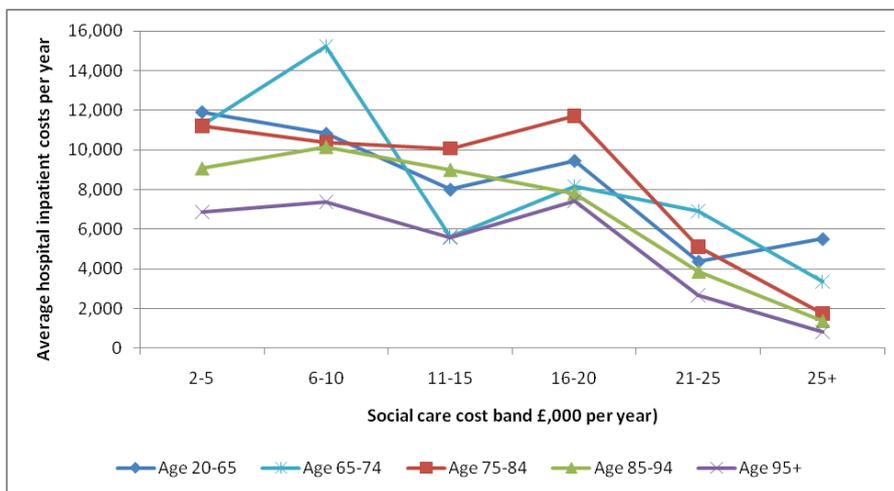


Figure 8 shows these same figures as average costs per person within age bands. The average social care costs increased from below £500 for those less than 50 years old up to nearly £8,000 per person for those in the oldest age bands. This a reflection of the increase in intensity of care services observed with an increased age shown earlier. Note that as the average social costs per person increase with age, so the average hospital inpatient costs actually decline. The fall in average inpatient costs is very dramatic and matches in scale the increase in social care costs. A crossover occurs, according to our estimations at around the age of 90. This picture is consistent with that that observed in some other studies.¹⁸

Looking at the dramatic changes in Figure 8 prompts questions about whether inpatient care is required to the same extent if a person is receiving high-intensity social care services compared to those who receive no, or low-intensity social care services. One problem is that this pattern may simply be a consequence of age itself – the oldest people are more likely to be in care homes and are less likely to receive aggressive hospital care.

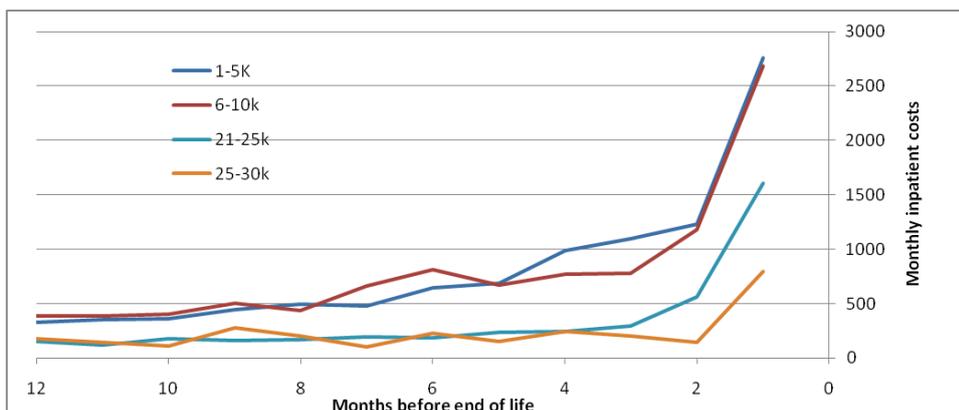
Another way to consider this is to look at the relationship between social care and hospital costs for different ages. Figure 9 plots the relationship between average hospital inpatient costs against average social care costs in the last 12 months of life. Separate lines are shown for different age bands and social care costs (grouped into broad cost categories). The graph clearly shows an inverse relationship: higher social care costs (mainly care home residents) are associated with lower hospital costs. This is a common pattern across all ages.

Figure 9: Average hospital inpatient cost per person according to level of social care costs for individuals in the last year of life



Finally, it is worth noting that the interaction between social care costs is seen throughout the last year – but these differences were widest in the last one to two months of life when hospital inpatient costs were highest, as shown in Figure 10. This graph shows that consistently lower level of hospital inpatient costs for those group with higher social care costs.

Figure 10: Monthly inpatient costs for the last 12 months according to the level of social care costs overall



Differences in social care use by long-term conditions

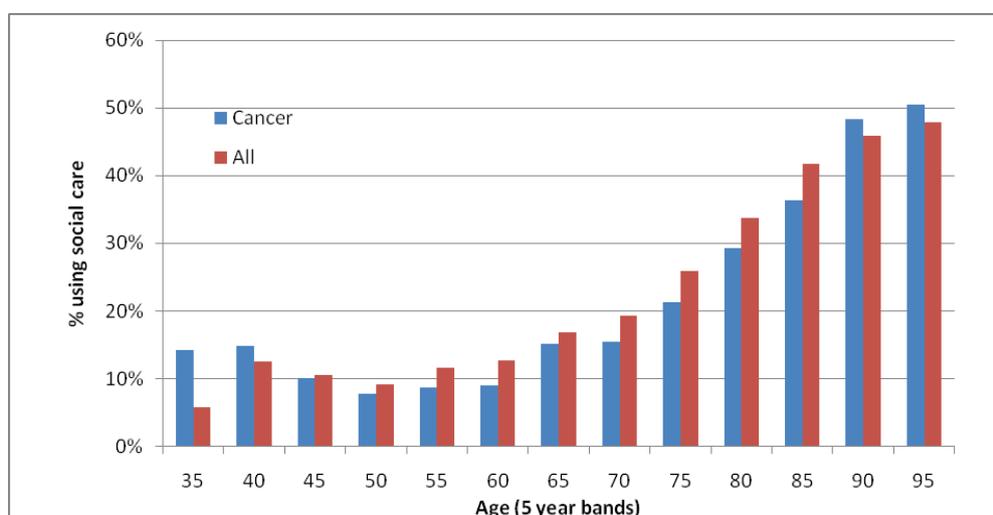
We examined the relative use of social care and hospital care for people in the last months of life according to the presence of selected clinical conditions. A Canadian study of care at the end of life used four relatively broad groupings to classify people as either: sudden death, organ failure, terminal illness and frailty.¹⁹ However, for this analysis we opted for a more detailed approach, choosing to look at differences according to a set of markers of clinical conditions recorded in the two years before death. The majority of people in the cohort had at least one of these markers and only 4,527 people (27 per cent of the group) had none of these condition flags – of these the vast majority (3,844) had no inpatient activity at all in the last year of life. It is important to remember that these underlying conditions do not necessarily represent the actual cause of death.

Of all people in the study cohort, 28 per cent had some record of cancer in the last two years of life. Twenty-four per cent of this group received a social care service in the 12 months prior to death, less than the value in the wider group where 30 per cent received any social service. However, the age profile of the group with cancer was lower than the overall group and, as found earlier, social care use increased with age, so it is important to look at age-specific differences.

Figure 11 shows by age band the proportion of social care users in the last 12 months of life – comparing the subset of people with a cancer diagnosis to the wider group. In the youngest and oldest age groups (where the numbers of people are relatively small) the proportion of those who used social care is slightly higher in the cancer group than for all people. However, at ages 50 to 85 the proportion using any social care was lower.

The proportion of people with a cancer diagnosis falls in the older age groups. So, for example, cancer was present in just under half of those who died aged 55 to 64 but in only one fifth of those who died aged 85 to 94. When these differences are summed across age groups the overall use of social care by the group with the cancer diagnoses was lower than the overall average. It is important to note that people with cancer are more likely to be accessing other services (for example, hospices and community-based support) outside of hospital and direct social care provision.

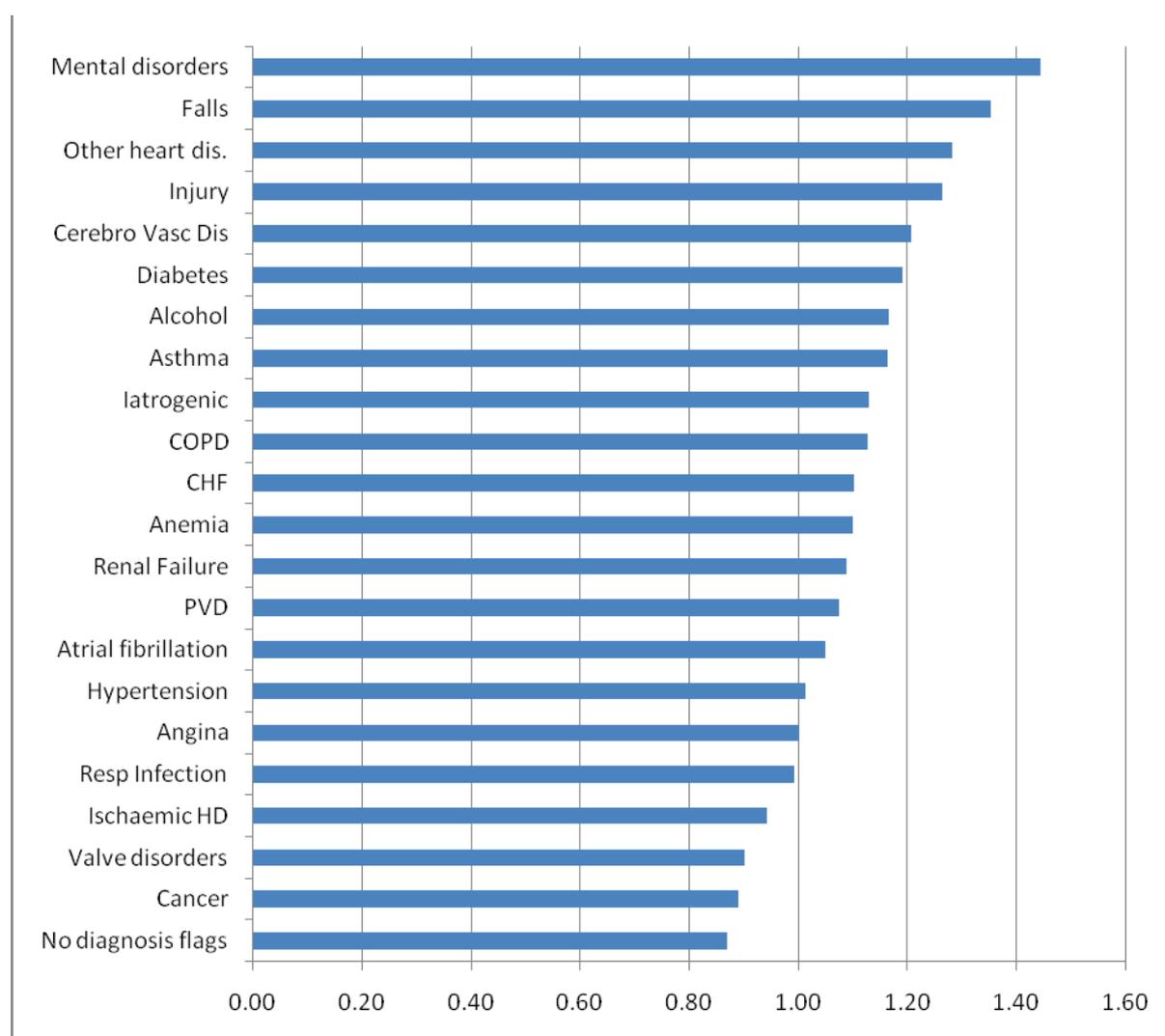
Figure 11: Percentage of people with a cancer diagnosis receiving social care in the last 12 months of life – compared to all people who died



The same type of analysis was undertaken for a range of other long-term conditions and the relative use of social care was compared in terms of the ratio of observed cases using social care divided by the expected cases (derived from overall age-specific rates). While this is a fairly crude measure, it nevertheless provides a useful indication of the differences in relative social care use associated with different health problems. Figure 12 summarises the results: values greater than one indicate a higher relative use of social care for people with that diagnosis.

The results suggest that people with prior diagnoses relating to mental health problems were more likely to access social care – their average value was 45 per cent higher than that of the total group. Similarly, higher rates of social care use were also seen in the groups recording diagnoses related to falls, injury, heart disease and cerebrovascular disease. The groups with a lower than average use of social care in the last 12 months of life were people with cancer and people with none of the specific diagnoses in the list (i.e. people without evidence of a long-term condition listed).

Figure 12: Proportion of people in each diagnostic group with use of social care in the year prior to death (expressed relative to age-standardised expected values)

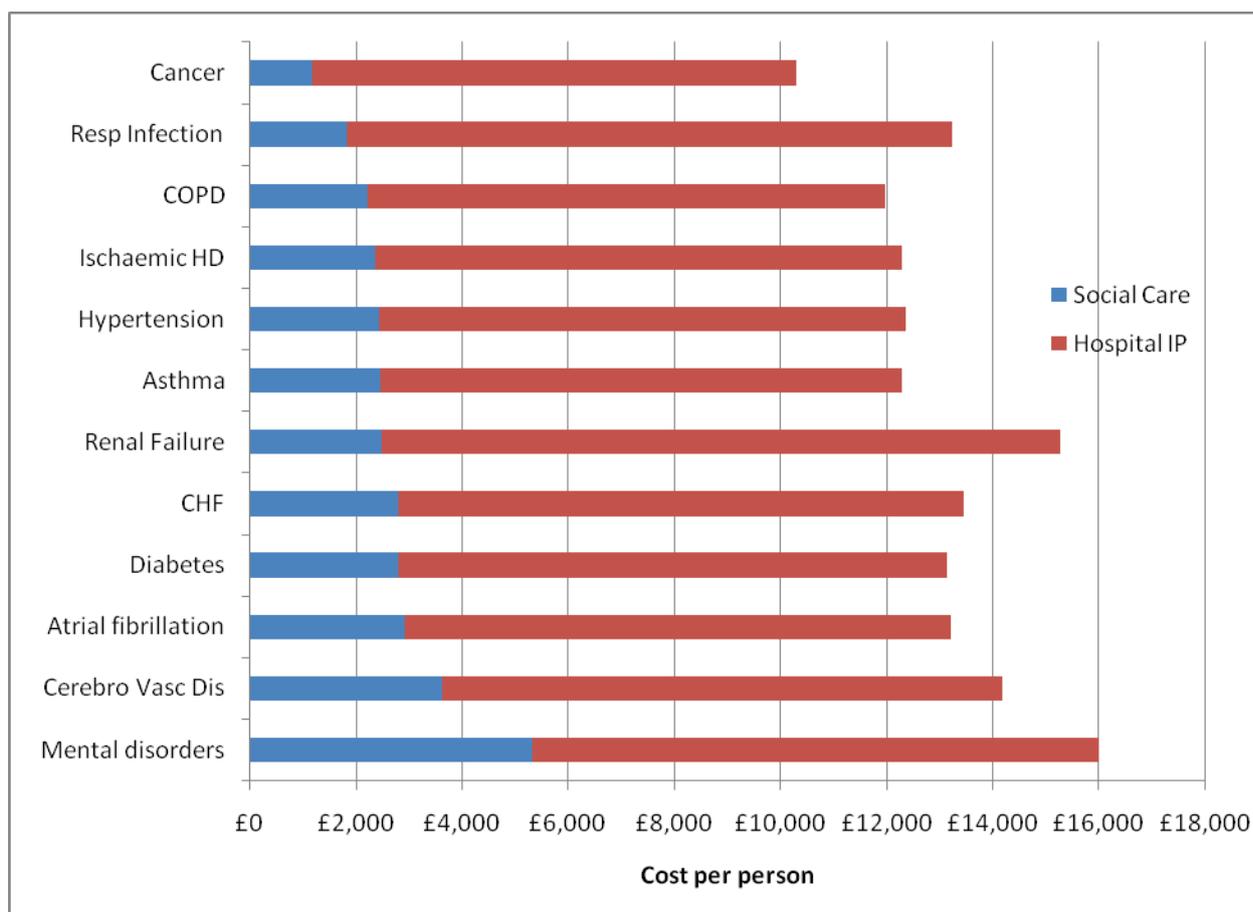


Ratio observed/expected social care

Social care and hospital use at the end of life

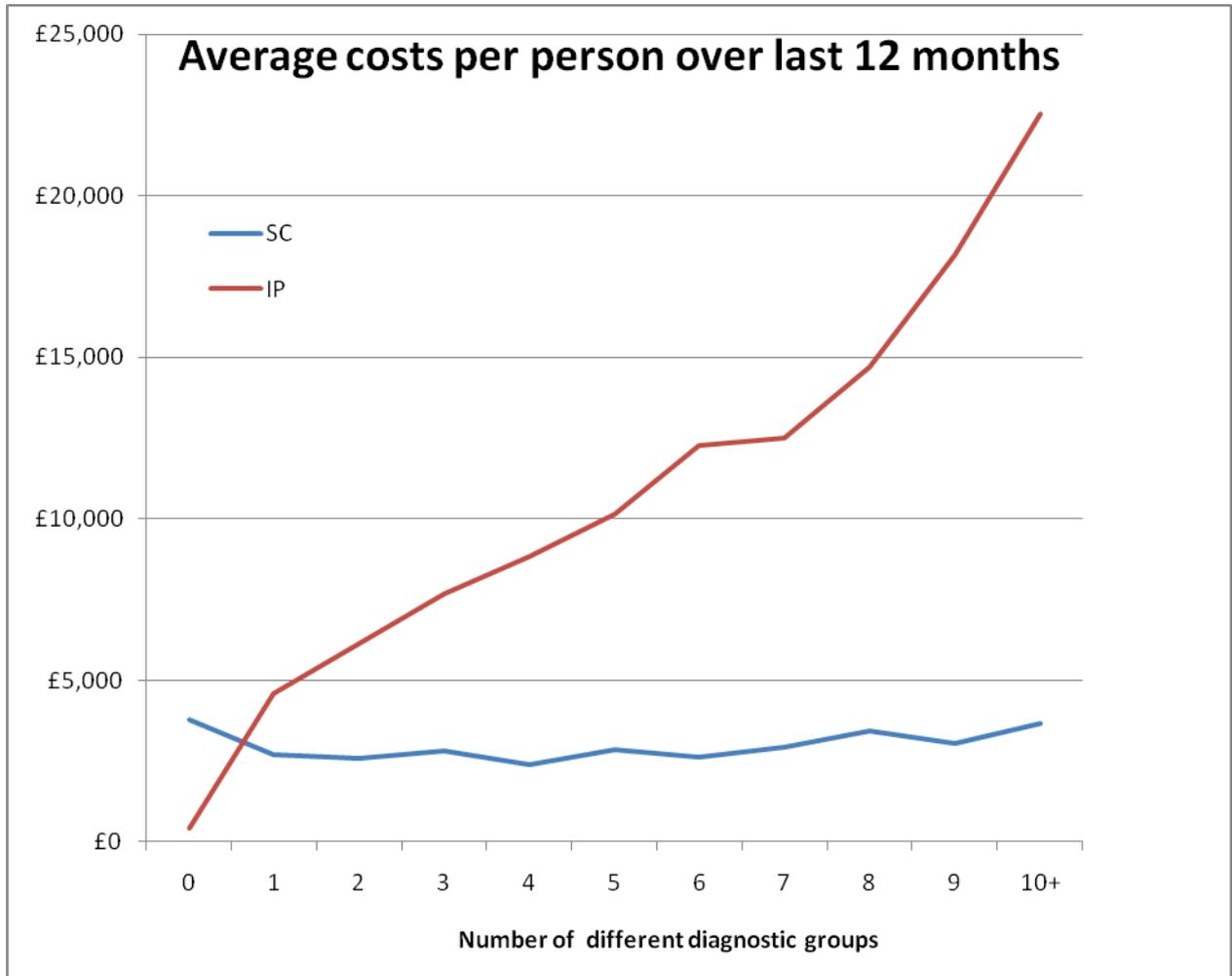
Figure 13 plots the average costs per case on social and inpatient care for individuals classified by diagnostic group. In each group, average inpatient costs are higher than average social care costs. The gradation between groups in terms of their social care costs, however, is quite marked – individuals with cancer had the lowest costs and those with mental health (including dementia) the highest. Much of this difference is likely to be due to the different ages of individuals with these conditions.

Figure 13: Average costs per person in the last 12 months by diagnostic group



A further complication in the above analysis is that, in general, individuals in the cohort were in more than one of these diagnostic groups – on average each individual had 2.5 of the conditions listed, but 135 people had more than five. This means that the assessing the impact for each condition in isolation is difficult. The number of different conditions a person had appears to be strongly related to average hospital costs (Figure 14). This could be an indication of the care of more complex patients costing more but also the fact that more hospital activity may have led to more codes being recorded.²⁰ People with ten different conditions averaged over £18,000 while those with only two were around £4,000. There appears to be no such relationship with regard to the level of social care costs which appear to be broadly similar across the range – indicating that though the medical complexity of a person’s condition may have been greater this does not appear to influence the use of social care.

Figure 14: Summary of the relationships between average costs per person and the number of different diagnostic groups recorded



Discussion

Despite the fact that the state pays for the bulk of health and social care in England, analyses of how these services overlap for individual patients are rare because the information streams are usually distinct. The approach which underlies this study – that of extracting and linking health and social care data – seems to offer great scope for a range of new analyses. The use of existing operational data offers significant advantages in that costly new data collection is not required, and it is possible to study the full range of service users, not just a pre-specified subset or client group.²¹ The need for better information on the quality and cost of services to people at the end of their lives has been recognised as a key issue in national policy.

Health and social care costs at the end of life can form a substantial share of overall care budgets. The care needs of individuals in the last year of their lives are often complex and the demand for care is likely to increase as the prevalence of long-term conditions in older people rises. Moreover, it has been suggested that the number of people dying in any one year will rise by 17 per cent between 2012 and 2030.²² Such a change is likely to have a significant impact on expenditure in both health and social care services.

The main contribution of this study is that it is the first to examine social care use at the end of life of a large population group (16,479 people). Of this group, 30 per cent accessed local authority-funded social care in the last 12 months of life, costing an estimated £49.6m. There were surprisingly large differences between the three study sites in reported use of local authority-funded social care. The numbers of people using social care, and the associated costs, increased gradually during the last 12 months of life, in particular for the use of care homes (residential and nursing) or medium-intensity home care services. In contrast, the rise in hospital inpatient costs in the last two to three months is steep.

There are no routinely published data to validate our observations on social care use. However, the National Audit Office (NAO) reported that estimates of the proportion of people who die in care homes are of the order of ten to 20 per cent but with large variations by area.²³ More recently, a report by the End of Life Intelligence Network reported that in 2007, nine per cent of people died while in a nursing home and seven per cent while in an old people's home.²⁴ These figures broadly align with our observations for two of our areas but the combined numbers dying in residential and nursing care are slightly lower. We do note that our figures only related to local authority-funded services and is therefore an underestimate of the total numbers who die in care homes. It was not possible to identify those people who paid privately for social care, which has been estimated to be around 25 per cent of care users aged over 65.²⁵ While bringing these data together makes a significant step forward in terms of a better understanding of the picture of care for people at the end of life – it is still partial. This analysis was not able to identify important services in the community, in outpatients and A&E and in dedicated palliative care settings.

In terms of the basic level of social care use by individuals in the last months of life, it is difficult to find other analyses that can corroborate our findings. Across the whole study cohort the estimated costs of hospital inpatient and local authority-funded social care averaged approximately £9,200 per person in the last year of life – which is undoubtedly an underestimate as our analyses do not include all users and costs – for example, in community-based care and self-funding social care. The NAO estimated, for example, that specialist palliative care costs varied from £145 to £1,684 per

individual who dies and work by RAND has estimated that a patient who dies from cancer costs approximately £14,000 in terms of hospital, community and hospice care.²⁶ Our closest estimate for just hospital inpatient and social care costs of people with a diagnostic code for cancer – was in the area of £10,000 to £11,000 per person. Note that our data was limited to a subset of spending identifiable at the person-level.

There are clear differences in the use of social care linked with different chronic health problems within the group of individuals examined in this study. Note this analysis did not look at cause of death itself but rather at chronic health problems that individuals may have had yet some clear differences emerged. Patients with cancer were less likely to use social care, and their costs were subsequently lower. People with mental health problems, or who had an injury or fall, were conversely more likely to use social care. While it is true that the age profile of the people who died from cancer was lower than the group as whole, even when this was taken into account, use of social care was lower. One possible explanation for this may be linked with the fact that many people who die with cancers are more likely to have support at home or in a hospice from charitable groups such as Marie Curie or Macmillan. In contrast this has implications for future funding.

There are some important limitations of the analyses presented here:

- Though the numbers of cases are large in comparison with other studies, the analysis is based on an opportunistic sample of three areas which we cannot claim to be representative of the country as a whole. Clearly this work would benefit from considering much larger groups of local authorities.
- The study was necessarily limited to examining the social care funded by local authorities. There are possible ways that data linkage could include self-funded care but that would require a different study with more challenges pertaining to obtaining the necessary information in a way that protects patient confidentiality.
- The analysis was limited by the quality and completeness of local data. It is at present more straightforward to check the quality of NHS data but more difficult with datasets from social care.
- This study only looked at inpatient hospital care – the highest cost-aspect of NHS-funded care. Other services, such as community-based services, hospices or other specialist care for the dying were not included for pragmatic reasons. As a result, changes or differences in the observed use of inpatient or social care may be due to the use of services that we were not able to examine. The techniques of data linkage pioneered in this study can be extended – something we are undertaking in a wider evaluation of telehealth.²⁷

With those caveats in mind, there are still some interesting relationships in the balance of hospital and social care use for people at the end of their lives. In particular:

- There is a subset of people accessing both social and hospital care who are associated with proportionately higher costs.
- Social care costs in the last 12 months of life are most significant for older people. Increasing age is associated with higher social care costs and a broadly equivalent reduction in hospital inpatient costs.
- The level of hospital inpatient costs is lower for people with high social care costs (equivalent to people in care homes). This inverse relationship is observed at different age bands and is not solely linked with activity in the few final weeks of life.

The observation that those people with the highest social care costs (i.e. those in care homes) has been noted in a recent Canadian study.²⁸ There are a number of possible explanations. For example:

- Some people have health problems that are not amenable to hospital-based treatment and the concentration of these may be greatest in the population in care homes.
- Sometimes a hospital admission can be avoided by care in a residential setting – a substitution effect.
- There may be some discrimination about offering hospital-based treatment because the recipient is old and in a care home.
- People within care homes may feel better able, or better supported, to cope outside of the hospital.

The observation of an association between high social care use and lower hospital use does not imply causality and this empirical analysis does not tell us what might constitute the ‘right’ profile for service use at the end of life. Further work is needed to examine the quality of social care services that underlie some of these patterns. Nevertheless, when there is concern that too many people die inappropriately in hospital settings, it is important to identify the scale and nature of alternative services that could or should be used. These relationships also suggest that any reductions in the availability of local authority-funded social care might increase demands on hospital services.

The high degree of overlap for some users identified the groups where it is especially important to look at care planning across sectors. Where services overlap there is inevitably some consideration of how services can be better coordinated or integrated in some way, for example through joint budgets or integrated provision.²⁹ Integration of provision offers the promise of reducing duplication, minimising hand-offs between sectors and maximising the delivery of care in the most appropriate settings. Integration of provision can take many forms – a major structural integration (Torbay, for example), or more commonly joint appointments, and improved coordination of services.³⁰ More recently the idea of Total Place has emerged as a way of unifying a range of public sector services linked to a common neighbourhood.³¹ All these initiatives point to the need to improve the ways we use information and link together different events that relate to a single person.

It is therefore important that the analyses in this report be extended. We suggest that the two most important ways to achieve this are as follows:

- Repeat these studies with a wider range of local authorities and ones that represent a broader spectrum of the UK population.
- Extend the range of datasets that are used to construct person-level care histories. Many of the people receiving care at the end of their lives (particularly those not in institutional care and specifically those with cancer) will be accessing much of their care from NHS generalists (district nursing and GPs). Though linking more datasets presents a challenge, we believe it is an important direction for future research.

Finally, the type of analysis described in this report can inform a number of key policy areas. This includes ways to evaluate better the impacts of new services – especially community-based care strategies designed to improve quality and satisfaction for patients, and to avoid expensive hospital or institutional care. Given the financial climate, now more than ever this type of analysis is critical if more value is to be extracted from public funds.

Appendix 1: Diagnostic codes used for mapping long-term conditions

Flag label	ICD10 diagnostic codes (primary or secondary diagnoses recorded)
HIV	B200-B209
Cancer	C000-C97,D000-D489
Sickle	D570-D578
Diabetes	E100-E149, O240-O249, G632, H360, H280
Alcohol	F100-F109, K700-K709
Drug	F110-F169, F180-F199, K710-K719
Develop	F700-F89
Hyperten	I10-I159
CHF	I500-I509, I110, I130
COPD	J430-J447
Congen	Q000-Q999
Injury	T000-T799, S000-S999, U000-Y98
Iatrogenic	T800-T983
Fall	W00-W19
NRValve	I340-I379
Mental	F000-F09
IschamicHD	I210-I259
Asthma	J450-J46
Angina	I200-I209
Anemia	D500-D509, D640-D649, D539, D639
AtrIFib	I471, I48
CVD	I690-I698, G450-G459, H340, R298, R470, I600-I679
CTDRHART	M320-M368, M050-M069, M080-M089, I390-I398, I528, I418, I328, J990, G737
MildLiver	K743-K746, K703, K760, K769
PVD	I700-I702, I710-I729, I731-I739, I709, I792, I771, R200-R298
RenalFail	N180-N209, Z940
RespInf	J020-J029, J930-J939, J850-J853, J81, J320-J3290, J90, J860-9, J960-J969, J393, R091, R098, J869, J998, J840, J841, J040-J069, J200-J219, J384-J387

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- Commissioning
- The future organisation and delivery of care
- Competition in health care
- UK and international comparisons.

Social care and hospital use at the end of life

The Nuffield Trust gratefully acknowledges the support of the National End of Life Care Intelligence Network with this project.

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Nuffield Trust
59 New Cavendish Street
London W1G 7LP
Email: info@nuffieldtrust.org.uk
www.nuffieldtrust.org.uk