Understanding patterns of health and social care at the end of life

Research report

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In partnership with



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Care at the end of life is an important national priority in England. The national strategy (Department of Health, 2008) aims to help people have the care support they need beyond the gates of the acute hospital setting. Survey results show that many people with terminal illness would prefer to die with appropriate support at home rather than in hospital. This means developing a range of support services at the end of life, spanning both health and social care. Despite the importance of social care in supporting individuals at the end of their lives, there are remarkably few studies that look at how often these people receive social care services. This study, commissioned by the National End of Life Care Intelligence Network, builds on an earlier piece of work (Bardsley and others, 2010) to create and analyse the largest linked health and social care dataset in England. Using this data we were able to describe the uptake of key health and social care services for people in the last 12 months of life.

Key Points

- In England social care is a significant part of care for people in the last 12 months of their life, with some form of local authority-funded social care being given to around 27.8% of people who died. On average, 14.9% of all people who died had some residential or nursing care service in the last year of life.
- There was considerable variation in the use of social care between local authorities. For example, there were twofold differences in the proportion of social care users in any given month prior to death even when rates were standardised for age and sex differences between areas.
- Many more people used hospital care than social care in the last year of life (89.6% versus 27.8%), and total hospital costs in this period were approximately double those of social care services. However, for those people who did use a service, the average local authority social care costs exceeded hospital costs (£12,559 per social care user versus £7,415 per hospital user).
- Individuals in the last 12 months of their lives were significantly more likely to use a social care service than similar individuals in the general population (matched by age and sex).
- Social care needs were apparent well before the end of life. While hospital costs showed a sharp increase in the final few months, social care costs rose gradually up until death. The greatest increases in social care use were observed in care home use.
- Individuals with the highest social care costs had relatively low average hospital costs this was broadly the case irrespective of age, and suggests that use of social care may prevent the need for hospital care. This is linked with a phenomenon observed elsewhere concerning people in residential care settings (Bardsley and others, 2012): that they tend to use less hospital care than people in intensive home care settings.
- There were significant differences in the use of social care between groups of individuals with certain long-term conditions: of the more commonly occurring conditions, usage levels were highest in people with dementia, falls and cerebrovascular disease, and were lower for people with cancer (even when adjusted for age and sex).
- The least socioeconomically deprived groups within the population tended to use less local authority-funded social care which would be expected, given the role of means-testing for care. However, the relationship was not linear, and there was no discernible trend within the most deprived half of users. This suggests that means-testing only affected the provision of local authority-funded social care at the more affluent end of the spectrum, assuming that needs are constant.

1. Introduction

Although it has been recognised as making up a significant proportion of all health care expenditure it is still difficult to understand the scale of resources needed to support care at the end of life. The Department of Health has estimated that the overall annual cost of end of life care to NHS and social care services is measured in billions of pounds. The National Audit Office, meanwhile, has estimated that the annual cost to NHS and social care services for just cancer patients in the 12 months prior to death was \pounds 1.8 billion (National Audit Office, 2008). Moreover we know that about half a million people die in England each year, and that the care of this group also affects a much larger number of relatives, carers and friends. 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 (Gomes and Higginson, 2008). 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 (Abel and others, 2009).

Though the National Council for Palliative Care has a long-established common dataset (National Council for Palliative Care, 2010) there are still significant gaps in information on the use of care and expenditure for patients across different services at the end of life. This severely limits our understanding of the range and quality of services available, and the possibilities to improve quality and efficiency (Department of Health, 2008). The specific services directly involved in the care of the dying encompass hospital inpatient, outpatient care and emergency care; GP and out of hours primary care services; hospice and specialist palliative care; community nursing services; and care services at home or in residential settings. Local authority-funded social care is an important support for many people at the end of their lives (Social Care Advisory Group, 2010).

The recent financial constraints on care services demand a renewed focus on ways to improve efficiency of care without affecting quality; often this means seeking out areas of avoidable expenditure and potentially wasteful duplication of care (Dixon, 2010). For complex care, such as that at the end of life, this might mean even greater attention on ways 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 (Wanless, 2006). One of the key gaps is the availability of information on local authority funded social care.

Improving care at the end of life is an agreed national priority for health and social care services in England. However, evaluations and comparisons of the services provided are hampered by a lack of information about the patterns and quality of care delivered. The recent review of palliative care funding (Hughes-Hallet and others, 2011) noted *"There is a stunning lack of good data surrounding costs for palliative care in England" (p9).* Work undertaken as part of the national End of Life Strategy is beginning to address the problems of poor information (National End of Life Care Intelligence network website, 2012). This report is aimed at addressing one of the key gaps in our understanding of provision at the end of life, namely the use of local authority funded social care.

The Nuffield Trust has undertaken work linking health and social services data from the operational systems in a number of different localities in England (Bardsley and others, 2010). Using pseudonymisation to protect the confidentiality of individuals, and a range of data linkage techniques, the team has constructed a comprehensive person level

dataset spanning a wide range of health and social care services. These datasets allow for direct measurement of which social and health care services are used by each individual in the population. Such data are able to provide new insights into patterns of service use at the end of life, including any overlaps, gaps and trade-offs. As such they represent a unique resource for examining care across the whole statutory sector.

In December 2010 we published a report looking at social care in the last 12 months of life for a cohort of 16,000 people who died in three English local authority areas. Information from hospital and social care records were linked pseudonymously to reveal the profile of care use over the 12 months before death. This was the first time that operational social care data sets had been used to describe patterns of service use at the end of life for relatively large numbers of people.

That first report made significant progress but difficulties were encountered when trying to interpret the findings:

- Between the three local areas studied there were marked differences in social care provision it was a difficult to know with only three cases whether one or more of these were outliers nationally.
- The studied areas left many areas of the country unrepresented for example none were from the north of England.
- In order to look more closely at the relationship between patient variables and social care use, relatively large sample sizes are needed to standardise for the wide range of variables that might be important.

These issues were the reasons that this second study was undertaken to repeat the analysis using a wider set of local authority areas. We have also improved the range of analyses, included more detailed data and newer comparative methods. Our aim is that this work will contribute to our understanding of decisions made at the end of life, and has potential applications including:

- Guidance for commissioners on expected levels of health and social care need at end of life.
- Overall costs of health and social care together.
- Guidance on how best to compare health and social care costs for defined patient groups.

Structure of this report

This report is the first analysis we have undertaken on the extended data set. It is structured as follows:

Chapter 2 of this report presents details of the **methods** we used and the data sets that formed the basis for the analysis. The main analyses are organised into a series of questions within chapters 3 to 5.

Chapter 3: Level of social care use

- Description of the study cohort.
- How many people received any social care in the last months of life?
- Which types of care services did people receive in the last months of life?
- How did the use of social care change in the months leading up to death?
- Changes in use by care type.
- How did care use in the group that died differ from the wider population?
- How many people were new social care users in the last year of life?

Chapter 4: Overlap of hospital and social care - activity and cost

- How many people accessed hospital care?
- What were the costs of care in the last 12 months of life?
- How did costs change in the last 12 months of life?

Chapter 5: Social and demographic factors

- How do costs vary by age and sex?
- How does social care use influence hospital cost and activity?
- What's the link between deprivation and social care use?
- Are there differences by diagnostic group?

Chapter 6 of this report presents a general discussion of the findings.

2. Methods

2.1 Selection of sites

In an earlier study of end of life care we focussed on three local authority areas in the south of England which had provided us with health and social care data (Bardsley and others, 2010). For this study we purposely sought to extend the range of areas to include greater representations of urban areas and parts of the north of England. Whilst these were our priorities, it was necessary for us to be opportunistic in working with areas that were able to access the data and who could obtain the necessary permissions from both PCT and local authorities.

Our aim was to identify sites where:

- at least three years of service data could be supplied
- person and 'event' level data could be supplied
- either NHS and social care records contained NHS number, or the sites were willing to create an alternative linkage field
- a shared data encryption key could be arranged between all local parties to pseudonymise the NHS number (or alternative linkage field) on health and social care records so as to protect patient confidentiality
- NHS and social care data were available for the same population.

In total we started negotiations with over 10 sites that had been suggested by colleagues. Of these we were able to move forward with four areas. Table 2.1 summarises the seven sites whose data we were able to study (A to C are the original study sites).

Tab	Table 2.1 Summary information on seven sites												
Site	Population 2008 (nearest 100,000)	% population over 65	% population over 85	Crude deaths per 100,000 population	PCT rural/urban classification	Other PCT description	IMD 2007 decile (1= most deprived)						
А	300,000	10 - 15%	1.5 – 2.0%	700	Urban	London borough	6						
В	700,000	20 - 25%	3.0 - 3.5%	1,100	Mostly rural, some urban	Southern county	7						
С	100,000	20 - 25%	3.5 - 4.0%	1,300	Urban	Southern borough	4						
D	400,000	10 - 15%	1.5 - 2.0%	1,000	Urban	Northern city	1						
Е	800,000	10 - 15%	2.0 - 2.5%	800	Urban	Northern city	5						
F	300,000	20 - 25%	3.0 - 3.5%	1,000	Mostly urban, much rural	Part of Eastern county	7						
G	500,000	15 - 20%	2.0 - 2.5%	900	Urban	Northern city	4						

2.2 Accessing core datasets

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

- NHS Secondary Users Services (SUS) data (information on inpatient admissions, outpatient attendances and accident and emergency (AE) visits)
- GP register information (information on all people registered with a general practice at any given time) including information on deaths
- Information about local authority funded social care services received.

Before the datasets were transferred to the research team, all sensitive personal information was removed and key linkage fields (NHS numbers or other) were pseudonymised 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 2.1) and means that the datasets transferred to the research team did not identify the individuals concerned.

Box 2.1: 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. In order to process personal data lawfully for these purposes the national governing body for information governance (NIGB)advices that the first stage of gathering, linking and analysing data should only occur either (1) with the explicit consent of all the individuals whose personal data are to be processed; or (2) by using pseudonymised data (National Information Governance Board, 2012).

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. The NIGB guidance goes on to note that in developing linked data sets -(in this care for assessing risk), pseudonymisation by a third party is appropriate – "where a third party (such as the Nuffield Trust) was receiving and linking pseudonymised health and social care data together to generate a 'risk score'. In this situation, the third party would not have access to the identifiable data and could only disclose the derived risk score to the relevant health and social care organisations provided care was taken to ensure that additional information could not be inferred from the score."

Pseudonymisation is the technical process of replacing person identifiers within a dataset with other values (pseudonyms) available to the data user, from which the identities of individuals cannot be intrinsically inferred, for example, replacing a NHS number with another random number, replacing a name with a code or replacing an address with a location code. Pseudonyms themselves should not contain any information that could identify the individual to which they relate (e.g. should not be made up of characters from the date of birth etc.) From

http://www.connectingforhealth.nhs.uk/systemsandservices/pseudo

2.3 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 nationally mandated dataset (eg equivalent 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.

However, all sites could offer at a very minimum a basic set of key fields supplying information about services received by clients: service type, service start dates, and service end dates. Most sites were also able to give some further detailed information about the provision of the service, for example the numbers of hours per week of home care that was received.

Our main focus was on the more costly elements of social care. Home (domiciliary) care - provided in somebody's own home - would ideally be analysed according to the numbers of hours per week of carer time, although not all local authorities were able to supply this detailed information. Residential and nursing home stays were based on the number of nights spent in the home.

2.4 Self funders and NHS funded continuing healthcare

We recognise that in using only local authority datasets this analysis does not report on all social care. The first major area of omission is for those people who pay for all their own social care. These *self funders* are known to be a significant population, though the exact numbers receiving care are not clear. The Institute of Public Care has estimated that of the 378,000 registered care home places in England, around 170,000 (44.9%) were self-funded (Institute of Public Care, 2011). Forder has estimated the numbers of people who paid privately for social care to be around 25% of care users aged over 65 (Forder, 2007) (this is likely to have increased since the estimate was published in 2007). (A separate issue arises with self funded care where individuals themselves contribute to the cost of care provided by the local authority. We receive no information about who these individuals might be and so in such cases we risk overestimating costs.)

The second area of possible omission is in cases funded by NHS continuing healthcare (CHC) where nursing care costs (and potentially other social care services) might be met from NHS budgets. The criteria for CHC care include people with complex medical conditions and people near to the end of their lives. Where a local authority funded social care client becomes eligible for NHS continuing healthcare, it may be the case that a nursing care service (for example) continues, but the client's package is closed on the local authority's data systems. In this case we would underestimate use of care. Three sites in this study have stated that we would not have received any information of people transferred to CHC care. However, two other sites have suggested that their systems will in some cases have continued to record such social care services, despite responsibility (and funding) for care having been transferred to the NHS.

The Department of Health publishes statistics on the numbers of people in receipt of CHC funding by quarter from by PCT (Department of Health, 2012a) (the first figures available are from April 2009). The number of CHC funded clients in four sites D to G

(the sites for which we have 2009 deaths data) was around 2,200 people in the just the first quarter of 2009/10. It is difficult to know how many of these were represented in the 4,330 people in these four sites who died in that same quarter.

Site D social services provided no person level information on CHC funded social care packages, nevertheless they were able to identify the number of people transferred to CHC funded care in the year 2009/10. This was 225 people. In the same time period, the site reported that 2,859 people over 65 had some residential or nursing care (841 people had nursing care) – so CHC users represented a number equivalent to 8% of those care home users (or 27% of nursing home users). It should be noted that the 225 people identified by the local authority *for that year* is less than half of site D's documented number of CHC users *people/10*.

2.5 Standardisation of social care datasets

Even where local authorities offer similar types of services to people, another problem faced – arising again from the lack of nationally defined systems – is that these services tend to be coded in a variety of ways. So, for example, while one site was found to use a total of 400 distinct codes to specify services and client groups, another captured similar information with a much simpler set of 39 descriptors.

Therefore we reclassified all recorded care services in each site into a common typology, effectively grouping together local descriptions under the following headings:

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

Grouping services in this way allowed for more consistency between the sites and enabled us to apply national unit costs published by the Personal Social Services Research Unit (PSSRU) (Curtis, 2009) as shown in Table 2.2.

	Unit	0		, i	
Service group	cost £	Unit	Group	Scope	Source
Home care	17	Per hour	Adults and older people	National average across all LA & other provision	PSSEX1 2010/11
Residential care	529	Per week	Older people	National average across all LA & other provision	PSSEX1 2010/11
Nursing care	646	Per week	Older people	National average across all LA & other provision	PSSEX1 2010/11 & NHS nursing contribution cost. NHS contribution (standard rate) taken from the 2010/11 PSSRU unit costs for nursing care.
Meals	30	Per week	Older people	National average	PSSEX1 2010/11
Day care	106	Per week	Older people	National average	PSSEX1 2010/11
Direct payments	111	Per week	Older people	National average	PSSEX1 2010/11
Equipment and adaptations	199	Per installation	Older people	National average	Based on PSSEX1 and RAP
Respite	529	Per week			Assumed same as residential care
Other accommodation	529	Per week			Assumed same as residential care
Assessments	Not o	costed			

Table 2.2: Unit costs used to weight social care activity

In carrying out this grouping, we assume that the unit costs are applicable to all the sites and over all time periods. As such, the estimated costs are purely indicative and do not relate to the accounts of the organisation concerned. While they are not true costs, for reasons of brevity they will nevertheless be referred to in this report as costs.

To further aid consistency between sites we decided to exclude some of these service groups from the majority of our analyses. This was done where some sites had no (or very little) activity in one or other groups (see table 2.3). For example, meals services and the provision of equipment/adaptations played a large role in services recorded by sites A to E, while sites F and G did not record any such services. Due to this inconsistency and to the fairly low-cost nature of these services we exclude both services from the bulk of our analyses.

Table 2	.3 Summary	i headin	igs for so	cial care	e use, ma	apped fi	rom site:	s' data		
Service type code	Service type description	A	Count of p	oackages C	mapped by site D	l to servio E	ce types, F	G	Summary Groups	Included in comparable [′] SC
									٨	
ASS	Assessments	36,422	75,332			907			Assessm ents	No
НС	Home Care	6,544			9,018			26,864		Yes
НС-Н	Home Care (High Intensity)		5,820	2,793		7,619	16,632			Yes
НС-М	Home Care (Medium Intensity)		14,517	3,111		13,366	21,100		Home Care	Yes
HC-L	Home Care (Low Intensity)		3,304	357		4,911	2,506			Yes
NHC	Nursing Care	1,077	4,202	1,483	1,553	6,209	3,198	6,159	Care	Yes
RHC	Residential Care	3,692	10,439	3,685	3,708	11,019	16,013	27,493	Homes	Yes
0	Other	2,116	1,246	1,823	10,087	3,961	2	3,636		No
DC	Day Care	1,181	7,038	1,635	1,348	6,500	1,375	4,003		Yes
DP	Direct Payments	105	2,205	495	1,030	1,725	4,636	2,150		Yes
EQ	Equipment/ adaptations	6,938	19,243	4,953	14,050	31,464			Othor	No
OA	Other Accommoda tion	688				211	48	244	Other	No
PB	Personal Budgets					38	468			No
RES	Respite care	266	4,322	6			4,346			Yes
М	Meals	2,356	5,834	1,454	499	4,405				No
Grand To	tal	61,385	153,502	21,795	41,732	92,335	70,324	70,549		
Total in 'c SC group	comparable'	12,865	51,847	13,565	16,657	51,349	69,806	66,669		

2.6 Costing methods

We calculated an indicative cost of social care services by applying unit costs given in table 2.2 to each particular social care service received. For home care services some sites had supplied detailed information about the number of hours of care an individual had received, others supplied no such information. As a result, to standardise our analysis, all individuals receiving home care in any of the sites were assigned a home care duration of 1.12 hours per day. This was the average number of home care hours per day (for those receiving home care) in those sites where detailed information was given.

We recognise that this approach is an approximation which is likely to underestimate home care costs for sites where intensive provision is more common, and overestimate costs for low intensity users. However we believe that the resulting estimates provide a valid order of magnitude estimate of home care costs - costs which are relatively modest compared to some other aspects of end of life care.

All hospital activity was costed using the 2010/11 Payment by Results (PbR) national tariff (Department of Health, 2010a) In cases where the secondary care activity did not have a tariff, we estimated costs from the 2007/08 national reference costs (Department of Health, 2009a), taking account of inflation to make them comparable with the 2010/11 tariff. In this way, we calculated costs as the cost to the commissioner of care, rather than the actual costs of providing care. These methods had previously been used in creation of a national resource allocation formula for the Department of Health (Dixon and others, 2011).

We established the costs of inpatient admissions by calculating the Healthcare Resource Group (HRG) for each patient's whole stay in hospital. We derived the full cost using the PbR rules (Department of Health, 2010b) to combine the HRG, admission method and other details of the hospital stay. This included the unit cost of the HRG and any payments due because of an unexpectedly long stay in hospital, or for any specialist care or additional treatments and tests (so-called unbundled payments). We also calculated outpatient and A&E costs as recommended by the PbR rules.

For both social care and hospital care, where periods of care extended to more than a single day, we converted any 'per spell' cost to an appropriate per day cost. This was applied to each day of the spell. Thus, when summing costs over a specific period (the whole final year, or any constituent month) we only allowed days within that period of interest to contribute to costs. Note that this may be different to standard accounting methods where, for example, all inpatient costs are assigned to the period in which a spell ends.

2.7 Assigning deprivation measures

For each individual who died, we received information on area of residence from the GP registration data. Unfortunately, this information was coded in different formats in different areas (the formats being postcode sectors, ward codes and lower super output areas). It was not possible to assign deprivation indicators to all these different residence codes, and so we therefore chose to use a measure that was consistent across all sites – a deprivation measure for person's registered GP practice as a whole. Practice level deprivation scores were calculated using Index of Multiple Deprivation 2007 scores (The English Indices of Deprivation, 2008) published at lower super output area, weighted for GP lists at April 2008.

2.8 Linkage between social care and health care

In order to link the information on social care to that on health care, there needs to be some unique person level identifier which is common to the different data sets. 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 (Department of Health, 2009b). Where the NHS number was not available an alternative identifier was constructed by the local staff using information on gender, date of birth and initials. The constructed key (or NHS number) was encrypted before transfer and the individual sensitive data elements removed before transfer to us. Each site created their own encryption key, and at no time did the Nuffield trust receive any information as to the key used. As the same key was used by each data provider within each site, the resulting pseudonymised person identifier would show where any data observations belonged to a single individual. In creating the linkage keys it is possible that some errors occur and that the linkage was not perfect. So for example an inconsistency in the first initial of a recorded name (Tony vs Anthony, say) would generate a completely different key that would not link correctly.

Normally (in studies of the general population) we would consider the GP register to be our full census population and social care users would be considered to be a subset of this group. Therefore we would report our linkage rates as (in crude terms) the proportion of all social care users we were able to successfully find in the GP register dataset. However in this study, the social care users come from a much bigger population than our cohort of individuals who have died. If a member of our cohort does not have any social care record, we have no way of identifying whether this is because of poor linkage, or whether they just didn't receive any social care service.

However in one site (site E) we linked social care and health care activity for the entire adult population, whether they had died or not (see section 3.6). The site has a large population (over 700,000) and made up a large proportion of all deaths in this study (28%). It thus offered a good case study to assess linkage rates. In site E there were 29,549 individuals who were recorded as receiving a social care package of care during a three year period (April 2007 to March 2010). We were able to link 87.5% of these to the health data (the GP register). The linkage success rate differed by age: being highest for 65–74 year olds (89.9%) and lowest for those aged 95 and over (78.3%). The linkage rates also differed by type of service received: we successfully linked 81.1% of those receiving residential/nursing home care and 92.8% of those receiving home care services.

On the surface, this seems slightly unfortunate for our purposes: in studying deaths we are disproportionately interested in older age groups and in those receiving costly residential/nursing care home services. If linkage is worst for these groups, we risk underestimating numbers of people receiving social care and the costs of these social care services.

However, there were indications that the social care data in site E might occasionally not record the close a package (perhaps where someone had died or had moved out of the area). If we focussed only on individuals where a service *started* during the three year period (N=21,840), we found 92.5% of individuals in the GP register, and the oldest age groups had the best linkage (93.5% for those 95+). Where a residential/nursing care home service started in the three year period we successfully found 92.8% of individuals; where a home care service started *or changed in intensity* (in terms of number of hours per week) we found 93.8% of individuals. In both these cases, we were more successful at identifying older age groups (up to 95% of those 95+).

3. Social care use

3.1 Study Cohort

We compiled records for 73,243 people who died across seven sites. Table 3.1 summarises the characteristics of the cohorts derived from individual sites in terms of age and sex. Figure 3.1 shows more detail on the numbers in age bands used throughout this report, whilst figure 3.2 shows the age at death for males and females separately.

Table 3.1 Characteristics of cohort by site												
				Si	te							
	А	В	С	D	Е	F	G	ALL				
Time periods for cohort selection i.e. all deaths between dates (number of months)	April 2007 - August 2008 (17)	January 2007 - March 2008 (15)	August 2007 - Sept 2008 (14)	April 2007 – March 2010 (36)	January 2007 – March 2010 (39)	April 2007 – March 2010 (36)	June 2007 – March 2010 (34)	January 2007 – March 2010 (39)				
Total deaths (proportion of all)	3,377 (4.6%)	9,769 (13.3%)	1,984 (2.7%)	13,588 (18.6%)	20,734 (28.3%)	10,117 (13.8%)	13,674 (18.7%)	73 , 243 (100%)				
Age at death mean (min, max)	77.5 (16,105)	80.0 (17,106)	79.6 (17,105)	74.9 (16,107)	76.7 (16,107)	78.9 (16,107)	77.8 (16,108)	77.4 (16,108)				
Age at death mean for females	80.6	82.5	82.7	77.9	79.6	81.3	80.5	80.2				
Age at death mean for males	74.1	77.1	75.9	71.8	73.5	76.1	75.0	74.4				
% 85 years and over	36.3%	43.2%	44.6%	27.2%	33.4%	39.9%	36.9%	35.5%				
% Male	47.4%	46.4%	45.7%	48.8%	48.3%	47.2%	46.7%	47.6%				

The mean age at death of the cohort was 77.4 years, with 35.5% aged 85 or over. There were marked differences between sites in the distribution of ages, with site D being the youngest (average 74.9 years; 27.2% aged 85+) and sites B and C the oldest (average 80.0 and 79.6 years respectively; 43.2% and 44.6% aged 85+). Overall, a majority of those who died were female (52.4%). Women died at older ages than men (average age 80.2, compared to 74.2 for men).





Deprivation

For each individual who died, we linked IMD 2007 scores mapped to each person's last registered GP practice. Figure 3.3 summarises the observed deprivation scores across the sites, indicating considerable variation. Several sites particularly stand out. For example:

- Site D appeared to be extremely deprived, with over 60% of people who died registered with a practice amongst the tenth most deprived in the country.
- Site C was notable for not having any extremes of deprivation either high or low.
- Site B was skewed to the more affluent side of the scale.

All remaining sites appeared to have a fairly broad, if not even, mix of deprivation. These differences may be important, as the means testing for funding social care will mean that the level of self paying care will vary by region. Also, deprivation will be associated with the age that people die, the prevalence of long term conditions and the causes of death.



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

We began by identifying those individuals who had any record of local authority funded social care services in the last 12 months of life. In the first instance this was for *any* social care service recorded by the local authority, so could include anything from meal services to nursing care. However as outlined previously, not all sites recorded entirely comparable types of social care services, and so a subset of services was defined such that equivalent comparisons could be made between all sites (see table 2.3).

In summary we found that whilst 31.9% of all people used any type of social care in the last 12 months of life (with a range between sites of 24.5% to 44.1%), 27.8% received one of the 'comparable' social care services (ranging from 18.6% to 35.9%), see figure 3.3.

Note that except where stated otherwise, all future references to 'any social care service' in this report refer those with the *comparable subset* of social care services (table 2.3). We believe this focuses on the major costs items of local authority funded social care and enables a more reliable comparison to be made.

Sites D and F had fewest users of social care services, averaging around 20%. In the case of site D the proportion of cases that were not in the 'comparable' set was relatively large and this may have contributed to its lower overall value. Sites B, C and G had proportionally the most users of social care with values between 30% and 35%.



Figure 3.4a shows the difference in use of social care at different age bands, revealing the strong relationship with age. 51.9% of those aged 95 and over had some social care service (ranging between 35.4% and 60.7%), compared to only 6.0% of those under 55 (ranging between 2.9% and 13.6%).

Site D had consistently fewer people receiving a social care service than any other site, at all age groups. Site C had the highest prevalence of social care use for age groups under 85, whilst for older age groups sites B, E and G had comparable and higher levels of social care use.



Figure 3.4a Use of social care services (comparable) in final year by age band, by site.

Figure 3.4b displays the use of social care in the final year as a standardised ratio by site (indirectly standardised by age and sex). Site E has a ratio very close to 1. This means that, given the age and sex structure of the site, it had almost exactly the 'expected' use of social care in the final year of life compared to all sites as a whole. Note that this was not entirely unexpected given that site E was our largest site (making up 28% of the cohort). Sites B, C and G have at least 15% more users of social care than we would expect given their age and sex structure; site D has over 20% fewer users of social care than we would expect.



3.3 Which types of care services did people receive in the last months of life?

Table 3.2 summarises the use of specific types of social care services in the final year of life. Overall 15.0% of people who died had some form of home care (ranging between 11.0% and 20.4%) in the last 12 months of life. The numbers of people who used home care made up around half of all social care users. The average (mean) number of home care days per person in the last year of life was 28.2 (ranging between 18.9 to 38.3 days) for all those who died. For those actually receiving home care, the average number of days was 188.4 (ranging between 124.6 to 218.9 days).

A similar proportion of people used residential and nursing care homes (14.9%) although there was a slightly larger range between sites (8.7% to 21.1%), presumably reflecting differences in the local care economies (e.g. accessibility of care) or polices of social services departments. The average (mean) number of days in a care home was 34.1 (ranging between 16.0 to 48.0 days) for the group as a whole, and 229.0 days (range 183.1 to 268.7) for those with any period in a care home.

We note that these figures for care home use (14.9%, with a range 8.7% to 21.1%) are relatively low when compared to the ONS estimated proportion of people who die in a care home of around 20%. This difference (which is even greater considering that social care users who die in a care home are only a subset of users of social care during the final year of life) we presume is caused by people who pay for their own care in the last few months of life, in addition to smaller numbers receiving NHS funded continuing care.

year of file, by site (it	73,21		l .	(i .	i .	i .
				S	ite			
	А	В	С	D	Е	F	G	ALL
N (total deaths)	3,377	9,769	1,984	13,588	20,734	10,117	13,674	73,243
Any Social care								
Proportion receiving SC – any (comparable)	25.8%	34.0%	35.8%	18.6%	27.7%	24.4%	34.2%	27.8%
Proportion receiving SC – any (all, for reference)	33.7%	38.5%	44.1%	25.9%	33.3%	24.5%	34.4%	31.9%
Home care								
Proportion receiving care	17.5%	16.3%	18.4%	11.2%	14.5%	11.0%	20.4%	15.0%
No days per user	152.9	168.6	124.6	168.4	213.0	218.9	188.1	188.4
No days per decedent	26.8	27.5	22.9	18.9	30.8	24.0	38.3	28.2
Care home: nursing or residential home								
Proportion receiving care	9.7%	18.9%	21.1%	8.7%	15.1%	14.3%	18.6%	14.9%
No days per user	217.5	249.0	227.7	183.1	228.6	268.7	215.7	229.0
No days per decedent	21.1	47.0	48.0	16.0	34.6	38.4	40.0	34.1
Care home: residential home								
Proportion receiving care	4.9%	11.9%	12.8%	5.3%	8.5%	12.3%	11.8%	9.5%
No days per user	189.0	236.7	190.1	188.8	225.3	269.5	186.3	220.1
No days per decedent	9.3	28.1	24.2	10.0	19.2	33.1	22.0	20.8
Care home: nursing home								
Proportion receiving care	5.3%	8.2%	10.1%	3.9%	7.8%	2.1%	8.1%	6.4%
No days per user	221.1	230.5	235.5	151.1	196.8	250.0	222.2	208.5
No days per decedent	11.7	18.9	23.7	5.9	15.4	5.3	18.0	13.3

Table 3.2 Proportion of cohort using local authority funded social care services in final year of life, by site (N = 73.243)

3.4 How did the use of social care change in the months leading up to death?

We have already seen that in the final year of life 27.8% of decedents received some kind of social care service. But how did this service use vary during the final year itself?

Figure 3.5 shows the proportion of people who died (for each site and for all sites) who received any social care service on a month by month basis. In the twelfth month before death 18.0% of the cohort received a service. This rose fairly steadily, such that in the final month before death 24.4% were in receipt of a social care service, which is a rise of over a third after eleven months.

Looking at the patterns across sites it is clear that the changes over the final year were broadly consistent between sites. However, once again we observed large variation in levels of social care use by site: site D had low use (increasing from 8.7% to 15.9%) whilst site B had high use (increasing from 22.3% to 32.3%). The other sites tended to lie somewhere within this range.

Site C showed behaviour not observed in any other site: in the final month social care use apparently dropped by over a third from the month before. This has raised questions about the accuracy of the final date of death received from this site and we suspect there may be a data lag of a month or two. However, as the site made up less than 3% of the entire cohort we continued to include this site in the study.

Note that for reported levels of service use in the final month of life, adjustments were made throughout this report to remove artificially low activity. See box 3.1 for details.

Box 3.1 – Imputation of final month values

When sites provided data to the Nuffield Trust we typically received dates of death given to the nearest month and year, with no information about the actual date of death. For most purpose this did not create a problem. However when summing costs prior to death we used the last day of that month as the effective date of death, to ensure that all activity would be captured. As a result of this, counts of the number of people using social care in their final month were undercounted – some people who died very early in the month would have had very little time in which they could have received social care services. We therefore applied an adjustment factor to the final month's data. This factor was derived from analysis of one of the larger sites where we had received full dates of death. For example, we estimated that our measures of 'any social care use' were undercounted by 15% during this final month. Multiplying all final month results by a factor of 1.17 removed this artefact.

Appendix A gives details of all such imputed factors used throughout this report.





Table 3.1 notified us that the ages of people who died in site D were the lowest amongst all sites whilst site B's individuals were the oldest (alongside site C). Given the strong relationship between receipt of social care and age at death (figure 3.4) it was likely that some of the differences between sites would be attributable to the age (and sex) make up of the cohort in each site. In order to adjust for this possible effect we calculated age/sex standardised social care usage rates (see box 3.2). Figure 3.6 displays the same data as in figure 3.5, but here each site has been standardised for its own particular age and sex structure.



The lines in figure 3.6 appear to be closer together, as though all have been pulled towards the 'all site' line. This would indicate that some of the variance (but clearly not all of it) was indeed caused by differences in age and sex. This was certainly true for the two sites D and B, which rose and lowered respectively by up to a couple of percentage points. But two sites E and F became slightly more extreme (although both remained close to the all site average). Table 3.3 gives appropriate figures for each site.

Table 3.3 Users of any SC service 12 months and 1 month prior to death, standardised for age and sex (N = 73,243)

		Site							
		А	В	С	D	Е	F	G	ALL
Ν		3,377	9,769	1,984	13,588	20,734	10,117	13,674	73,243
% receiving any social care in	M = 12	14.5%	20.4%	19.7%	9.7%	19.7%	16.6%	23.1%	18.0%
month M prior to death (standardised)	M = 1	20.2%	29.9%	17.0%	17.7%	24.7%	23.6%	29.1%	24.4%
% increase fr M=12 to M	:om =1	38.9%	46.9%	-13.7%	82.4%	25.0%	42.7%	26.1%	35.4%

Box 3.2 – Standardisation of monthly social care use

We used indirect standardisation whereby observed counts of events for any given age and sex band for any site were compared to an expected value calculated from the full cohort overall age and sex specific averages. Indirect standardisation was used instead of direct standardisation as it is less sensitive to small numbers of cases in some of the age and sex bands. Rates were standardised for each month separately, resulting in outputs given as ratios of observed to expected use of social care for each site, for each month.

These ratios were then applied to the average 'all site' crude results to indicate the scale of the standardised value in our displayed charts.

Change over the final two years of life

To broaden the analysis on trends before death we extended the period of time prior to death by an additional year, in order to test whether overall patterns of social care use in this last year were continuations of patterns seen in the year before or a distinct change in use just prior to death. Figure 3.7 shows the (un-standardised) month by month proportion of people in each site who used any social care in the 24 months before death. Note that we required two full years of social care data prior to death and so various individuals were excluded (remaining N = 62,372). The data are summarised in table 3.4.

For sites B, D, E, F and G we observed that the patterns seen in months 12 to 1 prior to death are broadly matched by patterns from months 24 to 13, although there were some small differences across the areas.



Site C results did not appear to be as smooth as for the other sites. This might be caused by low numbers – having limited the cohort to those with two years' worth of data, site C contained only 815 people. Site A appeared to match other sites closely in the period two years before death. However, the behaviour displayed after this point was not observed in any other site; social care use peaked around 14 months prior to death, before falling away and remaining constant for a number of months. It then rose rapidly from around 5 months before death.

Although there are some changes in gradient the overall picture is that the last year of life is not radically different from the previous year in terms of social care uptake. This contrasts with the pattern for use of hospital care discussed later.

Table 3.4 Users of any SC service (comparable services) 24, 12, and 1 month prior to death, crude results (N = 62,372)

		Site							
		А	В	С	D	Е	F	G	ALL
Ν		2,386	7,640	815	8,876	18,864	10,117	13,674	62,372
% receiving	M = 24	13.2%	18.2%	12.6%	5.7%	16.6%	13.8%	19.6%	15.3%
any social care in Month M	M = 12	15.1%	22.0%	20.0%	10.4%	19.2%	17.3%	23.5%	18.8%
prior to death	M = 1	20.8%	31.5%	15.8%	16.8%	23.9%	24.7%	29.5%	25.0%
% increase	from M=24 to M=12	14.4%	20.9%	58.7%	82.5%	15.7%	25.4%	19.9%	22.9%
	from M=12 to M=1	37.7%	43.2%	-21.0%	61.5%	24.5%	42.8%	25.5%	33.0%

3.5 Changes in use by care type

We considered social care services in three main groups:

- Residential or nursing care home use
- Home care services
- Other services: day care, direct payments and respite care only.

Figure 3.8 shows how the use of each of these three groups changed from month to month in the final year. The results are shown by site, having been standardised for age and sex. Table 3.5 gives summary figures of the standardised rates.

It's clear that a great deal of change occurred in residential and nursing care homes over the final year. There were almost 50% more individuals using care homes in the final month before death than there were 11 months previously (a change from 8.9% to 13.1%). Site A appeared to have had a much smaller increase than any other site, having increased by only a quarter in 11 months. Site D showed the greatest relative increase in care home use – by 136% in 11 months - although this is from the lowest initial rate of any site.

Use of home care services increased more modestly overall with a 27.7% increase in the month before death compared to 11 months previously (from 8.1% to 10.3%). Sites A and D increased at the fastest rates (increasing by over 50%), whilst sites F and G showed the smallest growth (we have disregarded site C here). It should be noted that growth in site A increased at a similar rate to other sites until approximately 4 months prior to death, after which point it accelerated, giving it the highest relative growth in home care of all sites.

For other social care services we observed a small overall decline in use over time. There was wide variation by site in the proportion of people using services over the year and in the change over the year, however, three sites (A, D and F) seemed to show fairly similar patterns of (low) use.





Table 3.5 Users of any SC service 12 months and 1 month prior to death, standardised for age and sex (N = 73.243)

		Site								
		А	В	С	D	Е	F	G	ALL	
Ν		3,377	9,769	1,984	13,588	20,734	10,117	13,674	73,243	
	M = 12	6.2%	10.8%	11.5%	3.9%	9.2%	9.3%	11.3%	8.9%	
Any	M = 1	7.7%	16.6%	9.9%	9.1%	13.1%	14.5%	14.9%	13.1%	
Nursing or Residential care	% increase M=12 to M=1	24.3%	53.6%	-13.3%	134.6%	41.5%	56.2%	32.4%	47.8%	
	M = 12	7.8%	7.1%	6.4%	5.4%	9.1%	6.5%	11.2%	8.1%	
	M = 1	12.1%	10.9%	6.3%	8.2%	10.4%	8.0%	13.9%	10.3%	
Any Home care	% increase M=12 to M=1	55.4%	53.8%	-2.0%	50.4%	13.4%	24.4%	23.9%	27.7%	
	M = 12	1.4%	4.4%	4.1%	1.1%	3.6%	1.4%	3.2%	2.8%	
Any other	M = 1	1.3%	4.3%	2.4%	1.4%	3.6%	1.7%	2.7%	2.7%	
Any other social care service	% increase M=12 to M=1	-7.8%	-2.6%	-40.8%	36.1%	1.3%	22.8%	-15.4%	-1.5%	

3.6 Differences in care use from the wider population

Having outlined in prior sections the nature of the use of social care services towards the end of life, we've yet to describe the ways in which the patterns we've observed are different to those in the general population as a whole. When looking at those who do not die we have over 3 million people to choose from in the 7 sites. To make the task more manageable, we looked solely at one site: site E. This is one of the largest sites (approximately 24% of the total population, 28% of the cohort), and in terms of those who die, is fairly average on a range of demographic factors and in its social care and hospital use. We therefore suggest that it makes a good case study for comparing people who die with those who don't die within the period of the study.

In site E for those who died, we scanned back in time from the date of death. For those who didn't die, we did not have a date of death, so instead we assigned index dates randomly, but with the same profile as the dates of death in the site as a whole. All 'survivors' were required to have at least a year's worth of hospital or social care activity prior to this date, and to be registered with a GP in the site throughout the whole period. There were 521,762 such people (compared to 20,734 decedents). Table 3.6 outlines the numbers of people in each age and sex group.

Table 3.6. Site E, nu	Table 3.6. Site E, numbers of survivors and decedents in each sex and age group											
			Age g	group								
	<55	<55 55-64 65-74 75-84 85-94										
Male												
Survivors	191,311	32,873	21,180	11,510	2,463	119						
Decedents	1,102	1,153	2,001	3,385	2,151	223						
Decedents as proportion of all	0.6%	3.4%	8.6%	22.7%	46.6%	65.2%						
Female												
Survivors	183,901	32,397	23,718	16,415	5,485	390						
Decedents	626	732	1,445	3,362	3,688	866						
Decedents as proportion of all	0.3%	2.2%	5.7%	17.0%	40.2%	68.9%						

Firstly, we looked at the use of any social care service in the final year, by age and sex. Figure 3.9 shows that for all age and sex groups, people who died were many times more likely to use social care than those who didn't die. The greatest differences were for the youngest age groups in women: under 55s who died were 28 times more likely and 55-64s who die were 17 times more likely to have some social care in the year of interest. The smallest differences were for older women and the oldest men (2.6 times for men 95+ and women 85-94, and 1.6 times for women 95+).



Figure 3.10 shows an equivalent picture for the two significant social care services: residential and nursing home care, and home care. For all ages below 75, people who died were over ten times more likely to have received some residential or nursing care than those who didn't die.

For home care the case was similar but the differences were far more marked for the younger age groups. For example, women under 55 who died were 70 times more likely to use home care than similar women who didn't die. Older age groups showed less variation between those who died and those who didn't die. Indeed, for women who died age 95 or over, levels of home care use were comparable to those seen in the group who didn't die.



3.7 New social care users

We have documented the numbers of people in receipt of social care services in the final year of life and have shown how this increases during the year. However, we've not shown whether people just prior to death tend to have social care services started for the first time, or whether people who have already received recent services just tend to receive these more frequently. To investigate this matter, we moved back to looking at the two year view of change in social care use by month.

In figure 3.11 the overall lengths of the bars show the number of people who received a social care service in any month (this is equivalent to the 'all site' line in figure 3.6). Different groups of people in the cohort are shown in different colours. Those in light grey (labelled 'prior year') are all individuals who had received a social care service at some point in the *penultimate year* before death (N = 12,987). At month 13 just under 90% of this group received a service, whilst a year later (just before death) over 80% were still receiving a service. This suggests that once a person who is within two years of death has received a service, they are likely to continue to receive a service up until the point of death.

All other colours denote people who received a service *for the first time* (in at least a year) during their final year. Each colour here follows a group of the cohort who received a *first service* in each constituent month of the year. The numbers given above the bars show the number of people in that month who received a service for the first time. Twelve months from death, around 300 people (0.5% of the cohort) received a service for the first time. As the time of death approaches, this number rises so that by the fourth month prior to death over 600 people (1%) received a service for the first time. In the penultimate month of life almost 900 people (1.4%) received a social care service for the first time.

So the rate at which people received social care services for the first time accelerated during this last year. Each month approaching death added a growing group of individuals to the numbers receiving social care. Yet two thirds of social care users in the final year were not new and this group accounts for over 90% of care days used in the final year of life.



Figure 3.11 Users of any SC service by month, grouped by people who had received a service in year 2 before death, and - for those who hadn't - by month X prior to death when a service was first received (N = 62.372)

4. Overlap of hospital and social care – activity and cost

4.1 Hospital use

We have so far detailed the use of social care services for those have died, but it is known (Bardsley and others, 2011) that a large majority of all social care users are also users of hospital services. In this chapter we look at the use of hospital care and social care amongst those who died.

Within our group of 73,243 people we found that 89.6% (ranging by site from 85.7% to 93.4%) had some kind of hospital care in the final year: 79.4% as inpatients, 68.5% as outpatients, and 65.5% through visiting A&E. See table 4.1, which also gives further information for each of the types of care services, the number of inpatient admissions and A&E visits.

Three sites with high use of hospital services (both in terms of the proportion using services in the final year and in terms of counts of activity) were sites A, D and G (although site G has average A&E use).

Table 4.1. Summary of hospital use in final year before death (N = $73,243$)									
					Si	te			
		А	В	С	D	Е	F	G	ALL
N (total deaths	3)	3,377	9,769	1,984	13,588	20,734	10,117	13,674	73,243
Proportions,	Hospital - any	90.6%	85.7%	84.9%	93.4%	88.0%	89.5%	91.4%	89.6%
any use or	Inpatient	80.6%	75.0%	69.8%	83.5%	79.2%	77.0%	81.7%	79.4%
	Outpatient	68.8%	65.7%	61.8%	80.7%	59.8%	68.6%	72.3%	68.5%
	A&E	76.1%	54.2%	71.4%	75.4%	63.8%	65.6%	63.0%	65.5%
	No hospital	9.4%	14.3%	15.1%	6.6%	12.0%	10.5%	8.6%	10.4%
Counts per	IP admissions	2.8	3.0	2.3	2.7	2.4	2.1	3.1	2.6
ueceueni	IP days	28.9	25.1	9.9	30.5	25.8	20.1	30.6	26.4
	Emergency IP adms	1.5	1.2	1.2	1.7	1.5	1.3	1.6	1.5
	Emergency IP days	24.6	15.5	5.2	25.8	22.6	16.8	26.5	21.8
	OP attendances	6.8	4.7	4.1	9.1	3.3	6.1	5.3	5.3
	A&E visits	1.8	1.0	1.5	1.7	1.3	1.2	1.2	1.3

Having social care and health care data linked at the individual level we were able to find out just how many people received both hospital and social care services in the last year of life. We have already shown that 27.8% of people received a social care service and we know also that 89.6% received some hospital care in the final year of life.

But we can now go further and state that 24.9% of people in all sites received both social and hospital care, 64.7% received only hospital care, 2.9% received only social care and 7.5% received neither social care nor hospital care services (table 4.2).

Of all people who received some hospital care in their final year, 27.7% received some social care service. Of all who received some social care, 89.6% received some hospital service.

Table 4.2 Overlap of Social care use and Hospital care, last year of life, by site (N = 73.243)

	Site								
	А	В	С	D	Е	F	G	ALL	
Neither hospital nor SC	7.3%	8.6%	9.1%	6.0%	9.0%	7.6%	5.7%	7.5%	
SC only	2.1%	5.6%	5.9%	0.5%	3.0%	2.9%	2.9%	2.9%	
Hospital and SC	23.7%	28.4%	29.8%	18.1%	24.7%	21.5%	31.4%	24.9%	
Hospital only	66.9%	57.4%	55.1%	75.4%	63.3%	68.0%	60.1%	64.7%	

4.2 Estimated costs of care in last 12 months of life

Summing all services' costs in the final year of life (see table 4.3) we found that total hospital care costs across all 73,243 people were \pounds 486.6m – this equated to an average of \pounds 6,644 per person who died.

Total social care costs accounted for slightly more than half the total hospital costs at $\pounds 255.3m$. This was only $\pounds 3,486$ per person who died, but $\pounds 12,559$ per social care user.

In total, the social care and hospital care costs combined were \pounds 741.9m for the entire cohort. This was \pounds 10,130 per person in the final year of life. If we took this as an appropriate crude average cost nationally, with over 465,000 deaths in England in calendar year 2008 this would represent a total of \pounds 4.7bn final year hospital and social care costs.

The services which made up the greatest share of the costs were emergency inpatient admissions (£6,336 per user; 46.6% of all costs) and residential and nursing care (£18,788 per user; 27.6% of all costs). It is clear that emergency admissions and residential and nursing care made up the bulk of costs accumulated in hospitals and in social care (71.1% and 80.2% respectively).

Though some other social care services are fairly costly per person for those receiving those services (eg long term residential care), the number of users were fairly small and so made up only a small proportion of total costs in the last year of life.

Table 4.3 Estimated total costs of care services in last year of life, by type of service (N = 73,243)

	Total cost, £m	Total cost per decedent, £	% total cost	No. users	Total cost per user, £
Hospital Care	487	6,644	65.6%	65,624	7,415
Inpatient emergency	346	4,721	46.6%	54,577	6,336
Inpatient non emergency	92	1,259	12.4%	58,165	1,585
Outpatient	40	542	5.3%	50,155	791
A&E	9	122	1.2%	48,000	185
Social care	255	3,486	34.4%	20,330	12,559
Residential and nursing care	205	2,795	27.6%	10,896	18,788
Home Care	40	540	5.3%	10,970	3,608
Other	11	150	1.5%	4,084	2,698
All care services	742	10,130	100.0%	73,243	N/A

Whilst table 4.3 shows costs by the type of hospital or social care service, table 4.4 displays the costs by the combinations of hospital and social care users (those groups outlined in table 4.2). The 64.7% of people who had only hospital care in their final year accounted for 45.4% of total costs (\pounds 7,109 on average). The 24.9% who used social care services in addition to hospital services use almost half (48.1%) of the total costs (\pounds 19,609 per person on average). The small group of only social care users (2.9%) were the most expensive group on average, using 6.4% of total costs (\pounds 22,505 per person).

Table 4.4. Estimated total costs of care services in last year of life by combinations of hospital/social care users (N = 73,243)

	No	Proportion	Hospital Social cost care cost		Hospital and Social care cost			
	people	of cohort	Sum, £m	Sum, £m	Sum, £m	% total cost	Average per user, £	
Hospital care only	47,418	64.7%	337.1	-	337.1	45.4%	7,109	
Social care only	2,124	2.9%	-	47.8	47.8	6.4%	22,505	
Both hospital and social care	18,206	24.9%	149.4	207.6	357.0	48.1%	19,609	
Neither	5,495	7.5%	-	-	-	0.0%	-	
All cases	73,243	100%	486.6	255.3	741.9			

We've noted that the average cost of care is £12,559 per social care user, but the distribution of costs amongst these 20,330 users goes up to £39,500 and has multiple peaks (see figure 4.1). The main peaks correspond to a year's worth of home care (~£7,000), residential care (~£27,500) and nursing care (~£33,500). The median cost is approximately £6,500.

Contrast this with hospital costs, where the average cost of care is \pounds 7,415 per user (figure 4.2). Here, we find a single peak corresponding to a costly emergency admission (or a couple of emergency admissions), but otherwise the distribution is fairly smooth, with the highest cost individual being over \pounds 90,000. The median cost is approximately \pounds 5,500.



Figure 4.2. Final year hospital cost distribution for users of hospital services, divisions of $f_{2,500}$ (N = 65,624)



4.3 Changes in hospital and social care costs in last 12 months

For our group of 73,243 people who died, total hospital costs in the final year were twice as large as social care costs over the same period. But how do these costs mount up over the year? Figure 4.3 shows month by month costs per decedent for hospital and social care services over the final year.

Twelve months before death the average hospital costs were the same as social care costs (£264 per decedent). Social care costs then rose modestly in each following month, such that by the final month an additional 25% has been added to the monthly cost (£330 per decedent). Hospital costs on the other hand, showed a slightly steeper rise for the first half of the year, but this then rise accelerated such that by the fourth month prior to death costs had doubled (£522). They more than tripled by the

penultimate month (\pounds 922) and were over eight times higher (\pounds 2,242) in the final month than they were in the twelfth month before death.

With this very large rise in activity toward the very end of life, over half of all hospital costs were due to activity in the last 3 months of life and over 30% due to activity in the last month itself.



Figure 4.4 shows further detail on the costs of hospital and social care services in each of the twelve months before death.

Emergency admissions were responsible for 71% of all hospital costs in the final year. In the twelfth month prior to death, emergency admissions accounted for 55% of hospital costs (£147 per decedent). By the final month before death they accounted for 85% of hospital costs (an almost 13-fold rise to £1,898 per decedent). Elective inpatient costs more than tripled (from £73 per decedent to £249 per decedent), but reduced in relative terms (from 28% of all hospital costs to 11%). Outpatient costs rose only very modestly (£40 to £54), whilst A&E costs showed an 8-fold rise (£5 to £42).

Residential and nursing care accounted for 80% of social care costs in the final year. This was the only social care service to show a large change over the year (a 30% rise from £208 per decedent in the twelfth month before death to £271 in the month before death). Home care services rose by a modest 13% up to months 3 and 4 before death (£44 to £49 per decedent) and other services stayed largely constant over the final year (£13 per decedent per month).

It should be noted that the largest costs for residential and nursing care (and therefore, for social care as a whole) were observed to occur in the penultimate month before death - there is a slight drop (of 4%) in the final month. We suspect this is caused by people being admitted to hospital in this final month social care costs might result from

services shifting to hospital. We are aware of other work underway to look specifically at the frequency of people dying in hospital shortly after admission from a care home.



5. Social and demographic factors

5.1 Relationship between costs and age and sex

In prior sections we've summarised services and resulting costs over the last year of life by site, and by groups defined by the types of service people had used. Except for an earlier display of social care use by age, we have yet to show variations by social and demographic factors.

Figure 5.1 displays the average cost of hospital care and of social care (and of both together) per decedent of each age group. Peak average hospital costs in the final year of life occurred for 55 to 74 year olds, with costs around £8,000 per decedent. Average hospital costs then fell away progressively for the older age groups to under £4,000 for those who died aged 95 or older. As these hospital costs declined with increasing age, social care costs rose – from under £1,400 per person for those aged under 75 to just over £9,000 for those aged 95 or over. Total costs climbed from under £8,000 per person for people under 55 to almost £,13,000 for the oldest aged decedents.



Figure 5.2 reveals that there were marked differences not only by age, but also by sex. In terms of hospital care, women cost on average more than men below the age of 75. Above this age, men were more costly. In terms of social care costs, men and women had equivalent average costs up to the age of 74. After this, women were on average costlier. Women who died aged 95 or older were almost two thirds as costly as men (\pounds 9,810 vs \pounds 5,960). In terms of total costs, women were more costly at every age group, but especially so at the very oldest and very youngest groups.



At this point, it might be instructive to look not at average costs (after all, over 95s and under 55s make up only 13% of the cohort), but at total costs (figure 5.3). Total hospital costs were practically the same for men and for women at £243.3m each. Meanwhile it is clear that far more was spent on social care services for women than for men; over twice as much was spent on providing social services to women (£176.0m vs $\pounds79.4$ m).

In terms of all costs, slightly more was spent on men aged 55 to 74, but far more was spent on women at ages 85+, so that overall there was a 30% additional spend on women with respect to men (£419.3 vs £322.7). We suspect this will be linked to the longer life expectancy of women.



5.2 The relationship between social care costs and hospital costs

Looking at the use of social care and hospital care by age there appears to be a broadly inverse relationship between the costs of hospital care and those of social care: older people have the highest social care costs in their final year of life but the lowest hospital costs. In fact, this inverse relationship between social care costs and hospital costs appears to exist to an extent at all ages.

Figure 5.4 shows average final year hospital costs for six different groups of social care users. All people included in this analysis received social care services costing £1,000 or more over the whole year (N=17,992). This group was split into six roughly equal groups based on social care costs – from lowest cost (£1,000 to £3,999) to highest cost (£27,000 and above). The final year average hospital costs are plotted for each of these social care groups, for each age band separately.

For every age group there was observed to be a generally inverse relationship between hospital costs and social care costs.



Table 5.1 summarises a number of measures of hospital activity according to the level of social care input. The results are similar across the various indicators with higher levels of social care costs being associated with lower levels of inpatient admissions, inpatient bed-days, outpatient attendances and A&E visits. These effects are statically significant.

Table 5.1 Summary measures of hospital activity according to the level of social care use in the final year of life. Proportions and means (95% confidence intervals)

	Social care use group								
	<£1,000, including none	SC 1 – lowest use	SC - 2	SC - 3	SC -4	SC -5	SC - 6 – highest use		
Number of people	55,251	3,207	2,155	3,554	2,763	3,343	2,970		
Any hospital use	90.0% (89.7%, 90.2%)	96.9% (96.2%, 97.4%)	95.1% (94.1%, 96.0%)	94.0% (93.2%, 94.8%)	94.8% (93.9%, 95.5%)	81.9% (80.6%, 83.2%)	69.7% (68.0%, 71.3%)		
Number IP admissions	2.78 (2.76, 2.79)	3.18 (3.12, 3.24)	2.93 (2.86, 3.00)	2.35 (2.3, 2.4)	2.52 (2.46, 2.58)	1.42 (1.38, 1.46)	1.15 (1.11, 1.19)		
Number IP days	23.73 (23.69, 23.77)	50.4 (50.15, 50.64)	47.55 (47.26, 47.84)	34.87 (34.67, 35.06)	46.43 (46.18, 46.69)	20.33 (20.17, 20.48)	13.08 (12.95, 13.21)		
Number OP attendances	6.23 (6.21, 6.26)	5.73 (5.65, 5.81)	4.36 (4.27, 4.45)	3.58 (3.51, 3.64)	3.06 (3.00, 3.13)	1.70 (1.66, 1.75)	1.35 (1.31, 1.39)		
Number A&E visits	1.25 (1.24, 1.25)	1.84 (1.79, 1.89)	1.82 (1.76, 1.87)	1.59 (1.55, 1.63)	1.84 (1.79, 1.89)	1.27 (1.23, 1.31)	0.92 (0.89, 0.96)		

5.3 Deprivation of local area

Figure 5.5 shows standardised ratios for social care use and hospital use for ten groupings of the 73,423 people, with groupings defined by deciles of deprivation. As

sites had very different patterns of deprivation, for each decile of deprivation we have standardised by site in addition to age and sex.

We found that there was very little observed variation in hospital use with level of deprivation. Social care use did show some variation: the most deprived decile had slightly higher use than would be expected and, perhaps more convincingly, the three most affluent deciles showed lower than expected use of social care services. This study looked only at local authority funded social care, so this finding seems plausible, as we might expect people living in more affluent areas to be more likely to fund their own social care services.

Figure 5.5. Standardised ratio: use of service in final year of life by deprivation decile (standardised by age, sex and site); 95% confidence intervals shown (N = 73,243)



5.4 Differences by diagnostic group

Each individual's inpatient history was scanned for two years prior to death to identify all the diagnoses in their records. These diagnoses were used to map the individual into one or more of 25 disease groupings (cancer, COPD, etc). Each of these disease groupings was analysed for associated levels of social care use.

We standardised by age and sex to produce a standardised ratio for each disease group. This ratio reflected the observed number of people using any social care service divided by to the number expected based on age and sex alone. See figure 5.6.

Some of the groups with the highest levels of social care use in the final year of life were developmental disorders, congenital malformations and dementia. All three groups were over 50% more likely to receive social care services than we might have expected. In contrast people with cancer were the least likely to use any social care services in their final year, being almost 25% less likely to use social care than people of the same age and sex.

Table 5.2 gives further details for each of these groups, including prevalence rates and costs. The individual longterm conditions are sorted according to the estimated social care costs associated with people who had that conditions. Note a person may have more than conditon so the the groups are not mutually exclusive and the summ of individual rows exceed the total. Together with the estimates of prevlance these relative values indicate the importance of certain conditions for social care users at the end of life.

		Obser	ved /	Expect	ted use	of SC ir	n final ye	ar
	0	.0 0.	.5	1.0	1.5	2.0	2.5	3.0
	Developmental disorders			1	1			-
	Congenital malformations				 	—		
	Dementia			-	H			
	Mental disorders excl dem			1	H			
	Falls			F	4			
	Cerebrovascular Disease			iн				
	Injuries and external causes			н				
	Alcoholism			i 🛏	I			
Connective ti	issue disease, rheumatoid arthritis			<u> </u> ⊢⊣				
	Diabetes			iμ				
	Renal failure			H				
8 E	Iatrogenic			ÌН				
idn	Peripheral vascular disease			H				
gr0	COPD			iΗ				
tic	Anemia			н				
sou	Asthma			<u>IH</u>				
lagi	Congestive heart failure			н				
Õ	Drug use			1				
	Angina			H				
	Atrial fibrillation			Н				
	Any diagnosis			H				
	Ischaemic heart disease			H				
	All People			H				
	Hypertension			H				
	Respiratory infection			H				
	No diagnosis			H				
	Mild liver disease							
	Non rheumatic valve disorder			-1				
	Cancer		Н					

Figure 5.6. Standardised ratio: use of any social care service in final year of life by diagnostic group (95% confidence intervals shown) (N = 73,243)

Though conditions such as developmental disorders and congenital malformatiosn showed the highest relative use of social care these are relatively uncommon health problems. When the number of cases within each group are considered as well then some conditions are especially prominent including demantia, injuries and falls, hypertension and stroke and heart problems (ischemic heart disease and atrial fibrillation). In all these cases the health conditions themselves are relatively common and the use of social care in the last 12 months of life is higher than average.

Table 5.2 Use of social care services in final year of life by diagnostic group, with social care and hospital costs per decedent (N = 73,243)

e			Receive any social care service				Average	Approx		
Diagnostic group	Ν	Prevale	Percentage	SR	SR, lower 95%	SR, upper 95%	Hospital care, £	Social care, £	Hospital and social care, £	SC costs, £m
All People	73,243	100.0%	27.8%	1.00	0.99	1.01	6,644	3,486	10,130	255.3
Any diagnosis	51,125	69.8%	27.9%	1.01	0.99	1.03	8,102	3,141	11,244	160.6
No diagnosis	22,118	30.2%	27.4%	0.98	0.95	1.00	3,271	4,284	7,556	94.8
Injuries and external causes	17,540	23.9%	36.8%	1.22	1.19	1.25	9,785	4,187	13,972	73.4
Dementia	6,735	9.2%	56.9%	1.57	1.52	1.62	7,657	9,239	16,896	62.2
Hypertension	21,241	29.0%	28.8%	0.99	0.96	1.01	9,067	2,882	11,950	61.2
Falls	10,560	14.4%	44.4%	1.30	1.26	1.34	8,990	5,300	14,290	56.0
Atrial fibrillation	13,567	18.5%	32.6%	1.03	1.00	1.06	9,161	3,413	12,574	46.3
Ischaemic heart disease	13,213	18.0%	29.4%	1.01	0.98	1.04	9,293	2,908	12,201	38.4
Cerebrovascula r Disease	8,290	11.3%	37.3%	1.23	1.18	1.27	9,180	4,313	13,494	35.8
Congestive heart failure	10,474	14.3%	33.9%	1.09	1.05	1.12	9,337	3,303	12,640	34.6
Anaemia	9,210	12.6%	31.0%	1.09	1.05	1.14	10,711	3,138	13,849	28.9
Diabetes	8,697	11.9%	30.4%	1.16	1.12	1.21	9,323	3,241	12,564	28.2
Cancer	19,934	27.2%	17.9%	0.77	0.74	0.79	9,498	1,346	10,844	26.8
Respiratory infection	11,136	15.2%	25.5%	0.99	0.95	1.02	10,169	2,315	12,484	25.8
COPD	9,392	12.8%	28.7%	1.10	1.06	1.14	9,122	2,602	11,725	24.4
Renal failure	6,570	9.0%	33.1%	1.16	1.11	1.21	10,675	3,317	13,993	21.8
Peripheral vascular disease	6,780	9.3%	30.4%	1.12	1.08	1.17	10,577	2,875	13,452	19.5
Angina	6,549	8.9%	30.1%	1.03	0.99	1.08	9,982	2,940	12,923	19.3
Mental disorders, excluding dementia	4,814	6.6%	34.7%	1.38	1.31	1.44	10,012	3,734	13,746	18.0
Iatrogenic	4,190	5.7%	26.2%	1.14	1.07	1.21	14,429	2,619	17,048	11.0
Asthma	3,480	4.8%	28.1%	1.09	1.03	1.16	9,691	2,567	12,258	8.9
Connective tissue disease	1,574	2.1%	33.9%	1.17	1.07	1.27	9,985	3,101	13,086	4.9
Non rheumatic valve disorder	2,059	2.8%	27.2%	0.90	0.83	0.98	10,880	2,263	13,144	4.7
Developmental disorders	483	0.7%	40.8%	2.42	2.10	2.79	9,038	6,284	15,322	3.0
Alcoholism	2,437	3.3%	14.5%	1.17	1.05	1.30	8,837	1,199	10,037	2.9
Congenital malformations	602	0.8%	32.2%	1.64	1.42	1.89	11,259	4,019	15,278	2.4
Mild liver disease	1,093	1.5%	14.4%	0.93	0.79	1.09	11,189	1,040	12,230	1.1
Drug use	281	0.4%	9.3%	1.04	0.68	1.53	9,971	869	10,840	0.2

In addition, we used 11 of these diagnostic groups to define a set of long term (chronic) conditions. Figure 5.7 shows how social care and hospital costs in the final year varied with the *number of different* long term conditions an individual had. Hospital costs were higher for those with many long terms conditions (as might be expected). Social care costs decreased with increasing number of long term conditions – this was especially marked when looking at the average social care cost per user.



6. Discussion

Despite the importance of social care at the end of life there are remarkably few studies that look at how often people receive social care services, what types of care and when. A recent review of palliative care funding (Hughes-Hallet and others, 2011) estimated that 92,000 people were not being reached. Our earlier study showed that it was possible to develop linked data sets that reveal the uptake of key health and social care services in the last year of life. Building our understanding of this critical phase of care is vital if we are to develop better ways of planning, resourcing and managing high quality care services.

This study has extended our earlier work and has provided greater confidence in the estimates that we achieved. In total we have been able to plot service use in hospital and local authority funded social care for over 73,000 people. In doing so, across seven different areas of the country we have gained a better view of the extent of variability between areas.

Scale of social care use

The importance of social care can be reflected in the observation that over a quarter of people (27.8%) access some form of local authority funded social care at the end of life. In addition to this there are a proportion of people, unknown in scale, who fund their own social care and a further number who receive NHS continuing care who may not be reflected in our findings.

We note that the observed proportion of people in care homes in the last month of their lives was slightly lower than that reported by ONS estimated number who die in care homes (End of Life Care Network, 2010), however this was as we might expect given that our analyses only looked at local authority funded users.

The use of social care was strongly related to a person's age. People who died were many times more likely to use social care than those who didn't die. The greatest differences were understandably for the youngest age groups. For example women aged under 55 who died were 28 times more likely to use social care than other women of the same age. But even amongst older age groups the differences persisted (2.6 times more for men 95+ and women 85–94, and 1.6 times more for women 95+). People who died were over ten times more likely to use residential and nursing care than those who didn't die, for all ages under 75.

These patterns are indicative of higher care needs at the end of life, irrespective of age. It also seems that these care needs do not show any sudden changes in the last few months of life. When care use is tracked over the 24 months before death, there is a gradual incline – in marked contrast to the very sharp increases in hospital care just before death. The data support a picture of a group of people with care needs over long time periods.

There are some important limitations of the analyses presented here:

- The analysis is based on an opportunistic sample of areas.
- The study was limited to examining the social care funded by local authorities.

- The analysis was limited by the quality and completeness of local data.
- In addition to social care, this study only looked at 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. However, the techniques of data linkage used in this study can be extended to such services something we are undertaking in a wider evaluation of telehealth.

Type of social care use

Our analyses focussed on the most common and costly elements of social care across sites. Around half of social care users (15.0% of all those who died) had a home care service during their final year. In some sites this was as low as 11% and in another was just above 20%. The average (mean) number of days of home care was 28.2 for all those who died. This average was 188.4 days for the group who actually received home care. Similarly, 14.9% of the whole group had some residential or nursing care service. There was greater variation between sites in the proportion of people using a care home with values ranging from 8.7% to 21.1%. The average number of days in a care home was 34.1 for all those who died. This average was 229.0 days for the group who received any care home service.

The use of residential and nursing home care increased during the final year, from 8.9% of those who died in the month at the start of the year to 13.1% by the final month. The use of home care also increased during the year, but to a lesser extent: from 8.1% to 10.3% from the first to the final month. The other care services remained fairly low in terms of proportions of cohort (around 3%), and varied little during the final year. It seems therefore that additional demand for care services at the end of life is manifested primarily in the need for care homes. Yet this sector has been sensitive to the impacts of local authority budgetary constraints and the decline in the numbers of care home places - the boom in care home provision peaked (at around 575,500 places) in 1996 but has been declining ever since (Lievesley and others, 2011).

Our analyses showed that there were a group of people who appeared as new social care users in the last year of life – but these were still only a small proportion of the total number of people who died.

Variation in care use

We examined a number of factors associated with variation in social care:

Age: The differences in uptake varied strongly by age in the final year of life: 51.9% of over 95s use social care, compared to only 6.0% of those who die aged under 55.

Area: Use of local authority funded social care in final year of life varies from 18.6% to 35.9% in the lowest to highest use areas respectively. These differences could not be fully explained by differences in the age profile of different areas. Use of social care may vary between areas for a number of reasons including: different choices about services delivery, the availability of services, differences in eligibility. In addition to differences between areas in baseline uptake, there were also differences in the way uptake changed over time to death. There was large variation in the percentage of

people accessing care over the two year period we looked at: one site, for example, rose from 8.7% monthly users to 15.9% during this period, another from 22.3% to 32.3%. Some of these differences may be linked to the accessibility of alternative care provision in NHS or independent sector palliative nursing services or hospices.

Deprivation: Social care use did show some variation with deprivation: the most deprived decile had slightly higher use than would be expected and the three most affluent deciles showed lower than expected use of social care services. This is not surprising given the effects of means testing and the likely effects of self funded services which were not included in our analysis. It is perhaps surprising, however, given the means testing of social care, that differential uptake in the most affluent areas was at most only 20% below the average. Moreover the gradient with regard to deprivation was not linear across the whole cohort. For the most deprived half of our population there was no discernible trend in social care use, which suggest that the effects of the means test, plus an ability to pay directly, only impacts on the more affluent groups.

Long term conditions: There were clear and significant differences in social care use linked with certain long term conditions. This analysis did not look at cause of death itself but rather at chronic health problems that individuals may have had. People with developmental disorders, congenital disorders and dementia were over 50% more likely to receive social care services than we might have expected based on age and sex alone. People with cancer were the least likely to use any social care services in their final year, being almost 25% less likely to use social care than people of the same age and sex. One possible explanation for this may be linked with the fact that many people who die with cancers have support at home or in a hospice from voluntary sector providers, or it may be that other services either in the community or hospital are used more by this group.

Costs of care

Our analyses did not provide complete cost of care services, but the relative values give an indication of areas of greatest resource use. Total costs in the final year of life were \pounds 741.9m, or \pounds 10,130 per person who died. This latter figure will exclude some important costs elements, yet it is lower than might be expected given some reports of costs at the end of life.

Just under two thirds of these costs (65.6%) were due to hospital activity, the remaining third (34.4%) were due to social care services. However, as hospital use is much more common in the last year of life, when looked at by the number of users of each service, social care services come out as being more costly per user. The average hospital user's hospital costs were £7,415 in their final year but the average social care user's social care cost were £12,559 in their final year. The group of people with hospital *and* social care activity cost on average £19,609, however the most costly group were the small proportion (2.9%) who used only social care service in their final year. This group had average total costs of £22,505.

Average hospital costs in the final year of life were highest for 55-74 year olds, with costs around $\pounds 8,000$ per decedent. The average costs decreased progressively for the older age groups - to under $\pounds 4,000$ for those who died aged 95 or older. Other studies have observed relatively lower hospital costs of care at the end of life in older age groups (Payne and others, 2007).

In contrast social care costs rose with age – from under $\pounds 1,400$ per person for those aged under 75 to just over $\pounds 9,000$ for those aged 95 or over. The interaction between hospital and social care costs at the end of life prompts questions about the optimal mix of care services, especially given evidence of people's preferences for where they would like to die (Gomes and others, 2011). This type of crossover has been observed in other studies (Roos and others, 1987), and it has been suggested that costs across sectors even out so that increasing average age at death does not reduce the overall societal economic costs (Payne and others, 2007).

Interaction with hospital care

Only 7.5% of people who died had no hospital or social care records. The majority of people who died (89.6%) had some form of hospital care in their final year: 79.4% as inpatients, 68.5% as outpatients and 65.5% through visiting A&E. In the final year of life the average person who died had: 2.6 admissions (including 1.5 emergency admissions), 26.4 inpatient days (21.8 due to emergency spells), 5.3 outpatient attendances and 1.3 A&E visits. These significant health inputs were strongly focussed on the final few months of life. We estimated that half of all hospital costs occurred due to activity in the last three months of life and over 30% of hospital costs occurred in the final month itself.

Overall 24.9% of the cohort received both social care and hospital care in their final year of life, 2.9% received only social care and 7.5% received neither social care nor hospital care services. The analyses prompt a whole series of questions over whether it would be cost saving to encourage more social care use, and social care provision as an alternative to hospital care at the end of life. It also raises question of whether communication between health services and social care providers works as well as it should.

As in earlier studies we did observe a broadly inverse relationship between hospital costs and social care costs that existed at all age groups. This meant that the people incurring higher social care costs (which in most cases means those in a care home) tended to use less hospital care. This observation has also been made other studies (Hollander, 2009) and in analyses of older people in England (Bardsley and others 2011) The underlying reasons are not clear but include:

- A hospital admission can sometimes be avoided by support provided in a residential care 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.

These observations reinforce the important principle that when assessing and planning care needs for a community the impacts across both social care and health care are considered. We have seen recent cuts in social care services reported at the equivalent to a 6.8 per cent in 2012 on top of 7.7 per cent cut made the previous year (Smulian, 2012). As there are increasingly tight financial constraints on the health sector (Dixon, 2010), this becomes ever more pressing.

The overlap of health and social care demonstrates the importance of looking at care planning and delivery across sectors. There is currently a renewed interest in how health and care services can be better coordinated or integrated in some way, for example through joint budgets or integrated provision (Lewis and others, 2010). 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 (e.g. Torbay), or more commonly joint appointments and improved coordination of services (Primary Care Trust Network NHS Confederation, 2010). More recently the ideas of *Total Place* and *Community Budgets* have emerged as a way of unifying a range of public sector services linked to a common neighbourhood (HM Treasury, 2010; Department of Communities and Local Government, 2012). All these initiatives point to the need to improve the ways we use information and link together different events that relate to a single individual.

In this context the linkage of data undertaken here could be used as the basis for estimating expected commissioning budgets across sectors. This could incentivise the funding of approaches that offered better quality but lower cost services. In addition an understanding of the relative balance of health and social care provision in the local area could help determine local performance and the opportunities to achieve change (see for example the tool for commissioners to estimate potential savings developed by NICE) (National Institute of Health and Clinical Excellence, 2012). For example areas with very restricted access to care homes may find it harder to reduce hospital use at the end of life and achieve aspirations to increase the proportion of people dying in the place of their choice.

Our analyses go some way to crossing sector boundaries, but there are two important areas we have not explored in this study.

- Community and primary care based services. 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).
- Voluntary sector provision of palliative care in community setting or hospices. The Nuffield Trust is currently working with Marie Curie Cancer Care to explore analyses of hospital care for people receiving Marie Curie services.

These approaches to understanding patient pathways across care services will be important for future funding options. For example the recent palliative care funding review (Hughes-Hallet and others, 2011) which has proposed a new approach to funding care based on set tariffs linked to a patient level classification, is currently being piloted in seven areas (Department of Health, 2012b). One recommendation of the review was that social care costs are included within the tariff and the review advocated removal of means testing for social care at the end of life. Our analyses indicate that the level of costs for social care at the end of the life is broadly predictable based on earlier care patterns. The absence of a sharp increase in social care costs perhaps indicates that the economic risk to the exchequer of funding social care at the end of life are not great if the practice we observed is replicated elsewhere. The type of analysis described in this report can inform a number of key policy areas. This includes ways to improve the methods used to evaluate the impacts of new services, especially community based care strategies designed to improve quality and satisfaction for patients, and also avoid expensive hospital or institutional care. Given the short to medium term financial climate, now more than ever this type of analysis is critical if more value is to be extracted from public funds.

Appendix A. Imputation of monthly proportions and costs

Where a value for a month is given in the following table, we multiplied the crude result for that month (either a proportion or cost) by the given factor. Where months are not given in the table, we take the crude month value itself (ie the multiplication factor is 1).

	Multiplication factor
Type of month by month analysis	- month prior to
	death
Proportions: social care all/all types of social	Month 1 = 1.17
care	
Costs: Social care all	Month 1 = 1.80
Costs: Social care nursing/residential care	Month 1 = 1.79
Costs: Social care home care	Month 1 = 1.83
Costs: Social care other	Month 1 = 1.73
Costs: Emergency admissions	Month 1 = 1.66
	Month $2 = 0.69$
	Month $3 = 0.82$
	Month $4 = 0.87$
	Month $5 = 0.91$
Costs: Non-emergency admissions	Month $1 = 1.87$
	Month $2 = 0.89$
Costs: Outpatient attendances	Month 1 = 2.39
Costs: A&E visits	Month 1 = 1.70
	Month $2 = 0.72$
	Month $3 = 0.85$
	Month $4 = 0.87$

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