

# Use of health and social care by people with cancer

*Research report*

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# Executive summary

## Background

There are estimated to be around two million people living with cancer in the United Kingdom (UK). Improved survival rates, earlier detection and an ageing population have led to cancer incidence increasing by around three per cent annually (Maddams and others, 2009). Given the growing number of people who are living with cancer, there has been a shift from seeing it as a fatal illness to a chronic one, where people may be in one of a number of possible stages, ranging from diagnosis, active treatment, remission and relapse to end of life. This shift has led to a growing focus on survivorship, and on the long-term needs of those living with and after cancer.

There has been a significant amount of research into the use and costs of health care by people with specific cancers, as well as into the wider economic and social costs arising from loss of earnings and premature mortality (Bending and others, 2010; Bosanquet and Sikora, 2004; Broekx and others, 2011; Morris and others, 2009). However, as well as health care needs, people diagnosed with cancer may also have emotional and practical needs associated with the illness or treatment, which require the involvement of social care services. These services might range from home care or equipment/adaptations to assist with activities of daily living, emotional support services, through to short- or long-term residential or nursing home care. However, compared to health care, remarkably little is known about the use of social care by people with cancer.

A recent report argued that ‘cancer should be as much a social care concern as it is a health priority’ (Macmillan Cancer Support, 2010, p. 5). It found that social services in the UK are not meeting the needs of people with cancer. Often people were not referred for assessment by social services and did not know the sorts of services that might have been available to them. The report also found that organisations that commissioned social care services had limited understanding of the specific needs of cancer survivors. In a previous survey, Macmillan Cancer Support (2006) found that 35 per cent of those with cancer did not know how to access social care and support.

This report builds on work previously reported by the Nuffield Trust of health and social care use by people at the end of life (Bardsley and others, 2010). It focuses on the two periods when people with cancer make greatest use of hospital care – in the period around and following diagnosis, and at the end of life. It describes a set of analyses that sought to explore the use of health and local authority social care during both periods by people with cancer. Some of the key questions we set out to address are as follows:

### *For people living with cancer*

- What was the pre- and post-diagnosis use of health care and local authority funded social care in people with cancer? How does this vary by type of cancer?
- How did the use of health and social care by people with cancer, following diagnosis, compare with those without cancer? How did this vary by type of cancer?
- What were the predictors of the use of social care by people following a cancer diagnosis?

*For people with cancer at the end of life*

- What was the use of health and social care by people with cancer in the final year of life and what were the costs involved? How did these vary by type of cancer?
- How did the use of health and social care by people with cancer in the final year of life compare with other people at the end of life?

## Results

### Living with cancer

We studied the primary and secondary health care and social care use of 8,072 people with a first diagnosis of cancer from two areas of England, for a year before diagnosis and up to 18 months after, excluding activity that occurred around the time of death.

The results showed clear evidence of a social services response to a person being diagnosed with cancer. Ten per cent of people received a local authority social care assessment within three months of being diagnosed with cancer. This varied from three per cent of those with skin or breast cancer to 20 per cent of those with brain/central nervous system (CNS) tumours. The likelihood of being assessed varied between the two sites and also between the hospitals where people were treated. Those who were diagnosed while in hospital were more likely to be assessed, as were those who received non-surgical treatment.

Ten per cent of people received some form of local authority funded social care service in the year after diagnosis. Most cancers led to an increase in social care use after diagnosis, although there was less evidence of this among those with lung, breast or skin cancer. The rise in the number of people receiving social care was mainly due to higher use of home care and equipment/adaptations.

Those diagnosed with cancer were less likely to receive social care in the year before diagnosis than the age- and sex-standardised rate within each site. Conversely, more people with cancer than expected were receiving social care 18 months after diagnosis. This seemed to be due particularly to people receiving home care. Consistent with previous work by the Nuffield Trust (Bardsley and others, 2010), people with other chronic conditions were much more likely to use social care than those with cancer. Among people with cancer, those who had one or more chronic condition were more likely to use social care than those without.

Unplanned hospital activity peaked for most cancers in the period leading up to diagnosis, while elective admissions and outpatient attendances generally were at their highest in the three months after diagnosis. Use of hospital care varied by the type of treatment: those who only had surgery having many fewer admissions and attendances than those who had non-surgical treatment. Hospital use remained high for some time after diagnosis. Fifteen months after diagnosis, people with cancer had 60 per cent more accident and emergency (A&E) attendances, 97 per cent more emergency admissions, four times as many outpatient attendances and nearly six times more elective admissions than expected. A similar pattern was seen for GP visits, with cancer survivors having 50 per cent more contact with their GPs than expected 15 months after diagnosis.

The total cost of social care in the period after diagnosis for those living with cancer was around £5.8 million. The corresponding figure for hospital care was over £48 million. The average cost

of social care per person was relatively stable over time at around £140 to £180 a quarter. There was some variation between cancer types: people with skin or breast cancer tended to be more expensive compared with those with prostate cancer. The average cost of hospital care was similar to the cost of social care before diagnosis at around £170 a quarter, but then rose sharply after diagnosis, peaking at over £3,300. There was significant variation between cancer types in the relative spend on planned and emergency care.

## End of life

We had access to information on health and social care usage for 7,936 people where cancer was mentioned on the death certificate.

Forty-two per cent of those with cancer were assessed by social services in the final year of life, with an increasing number being assessed month-on-month. Twenty-seven per cent of patients received some form of local authority funded social care in the final year of life. This ranged from ten per cent of those with acute leukaemia, to over 30 per cent of those with breast or prostate cancer. The number of people who received social care nearly doubled over the last year of life, from nine to 17 per cent. This rise was primarily due to an increase in the use of home care, but was also seen for other service types.

Compared with other people who died, 20 per cent fewer people with cancer received social care in the last three full months of life than would have been expected. This was true of almost all cancer types, except brain/CNS tumours and prostate cancer. Overall, uptake of services such as home care and equipment/adaptations was as much or more than expected. However, there were very low levels of use of nursing (40 per cent of the expected level) and residential home care (50 per cent of the expected number of people).

We found that people with cancer had significantly greater use of hospital care than others at the end of life. In the last three full months of life, those with cancer had 20 per cent more emergency admissions, and more than 60 per cent had more elective admissions and outpatient attendances. Thirty per cent of people with cancer had an emergency admission in the last full month of life. There was some variation between cancer types in hospital use, with, for example, people with blood cancers having a very high rate of elective admissions towards the end of life.

Place of death varied significantly by cancer type, with people with brain/CNS tumours being the most likely to die at home, while those with blood cancers had the highest chance of dying in hospital. Place of death was also a significant differentiator of the use of health and social care towards the end of life. Those who died in a care home were, unsurprisingly, much more likely to be in receipt of local authority funded social care than those who died elsewhere. Interestingly, fewer of those who died at home or in a hospice used social care than expected. Consistent with other previous work (Bardsley and others, 2012), those who died in a care home used much less of all forms of hospital care than those who died in other settings. Of note, those who died in a hospice had significantly less hospital activity near the end of life than those who died in hospital.

The total cost of social care for those with cancer in the final year of life was £12.9 million, while the hospital cost was over £67 million. The average cost per person of social care for the final 12 months of life was £1,600, and rose only slowly over the last year. For hospital care, the average

cost was around £8,500 per person, and the gradient rose much more sharply, particularly in the final two or three months of life.

## Conclusions

With an increasing number of people surviving after a cancer diagnosis, there is a growing focus on the needs of cancer survivors. However, this is in the context that the next three to five years will see the National Health Service (NHS) facing the major challenges of implementing new organisational structures arising from the Health and Social Care Bill 2011 and, perhaps more importantly, addressing the need to stay within increasingly constrained financial budgets (Smith and Charlesworth, 2011). In social care, council spending on adult social services is falling, with a growing number of councils tightening their eligibility criteria for receipt of services (Audit Commission, 2011).

To the best of our knowledge, this is the first study that has attempted to link data on primary care, hospital and local authority funded social care use with data held by cancer registries. This has allowed us to explore a range of questions, which has not been possible previously.

We have shown that there is a social care response for people with cancer, both following a cancer diagnosis and towards the end of life. Our results have shown that use of health and social care by people with cancer may be required for a significant period after diagnosis. We have also shown the differing trajectories in health and social care costs before and after a cancer diagnosis, and at the end of life.

This report raises a number of questions that warrant further investigation. In particular, we have found that only ten per cent of people diagnosed with cancer were assessed by local authority social services in the period immediately after diagnosis, and a similar percentage received services in the 12 months after diagnosis. It is impossible to say whether these figures are appropriate, or whether they are indicative of a lack of access to services. Another significant gap is in the contribution of NHS and voluntary sector community nursing and palliative care services. While a significant proportion of people who use these services has cancer, the degree to which they complement or substitute local authority social care, and their possible effects on hospital activity, are unclear. Other avenues for further work include investigating regional variation in the availability and use of services, long-term patterns of usage, and the interaction between health and social care.

The lack of knowledge about their need for, and use of, social care is a critical bar to ensuring that services are commissioned that are accessible and meet the needs of the growing number of people living with and beyond cancer. This report has attempted to begin to explore gaps in our understanding of what services are used by people with cancer, when, by whom and how much they cost. It has shown how existing information streams can be used to provide a much greater level of detail about what services are being used by people with cancer. Clearly, these types of analyses need to be extended and repeated more widely to inform local decisions about the planning and commissioning of services.



# 1. Introduction

There are estimated to be around two million people living with cancer in the UK, with improved survival rates, earlier detection and an ageing population leading to cancer incidence increasing by around three per cent a year (Maddams and others, 2009). Given the growing number of people who are living with cancer, there has been a move from seeing it as a fatal illness, to a chronic one, where people may be in one of a number of possible stages, ranging from diagnosis, active treatment, remission and relapse to end of life. This shift has led to a growing focus on survivorship, and on the long-term needs of those living with and after cancer.

The health care needs of those with cancer have been studied extensively. For example, two recent studies in the UK looked at the use of inpatient hospital care by people previously diagnosed with cancer (Maddams and others, 2011a; 2011b). These studies showed that the use of hospital care was highest in the year after diagnosis, but there remained significant cancer-related inpatient activity up to three years after diagnosis, particularly for those with lung or colorectal cancer. They also found that those in the final year of life had the highest level of inpatient hospital use. Those both more than one year from diagnosis and more than one year from death had the lowest hospital use.

There is also relatively extensive evidence about the costs of cancer. These costs can be divided into three components (Bosanquet and Sikora, 2004):

- the direct costs of diagnosis, treatment and follow-up
- the morbidity costs to the state, patients and their families of living with a disease
- loss of income (and loss to the state of tax revenue) due to premature mortality.

Most attention has focused on direct health care costs. The Department of Health's Programme Budgets (which collate information on NHS spending) reported that in 2010/11, expenditure by primary care trusts in England on cancer care was over £5.8 billion (Department of Health, 2011). These data showed that breast and haematological cancers accounted for the largest share of health care spending. A report by a private health insurance company (Bupa, 2011) suggested that the cost of cancer diagnosis and treatment (including NHS, private and third sector provision) in the UK was around £9.4 billion in 2010, or around £30,000 per person, and that this will grow to over £15 billion by 2021.

Many studies have sought to estimate the direct or indirect costs of particular types of cancer (Bending and others, 2010; Broekx and others, 2011; Chirikos and others, 2002; Fleming and others, 2008; Fourcade and others, 2010; Hanly and others, 2012; Morris and others, 2009; O'Neill and others, 2012; Roehrborn and Black, 2011; Sangar and others, 2005; Tingstedt and others, 2011), predominantly focusing on the direct medical costs, or broader economic consequences (through loss of earnings).

However, as well as their health care needs, it is clearly likely that some of those diagnosed with cancer may also have emotional and practical needs associated with the illness or treatment, which require the involvement of social care services. These services range from home care or equipment/adaptations to assist with daily living, through to short- or long-term residential or nursing home care for those who cannot live independently. The need for these services is likely to vary according to a range of factors – including socioeconomic status and access to informal care from family and friends – and apply to people throughout the cancer journey.

Compared to research into health care use, there is a remarkable dearth of evidence about the use of social care by people with cancer. A previous study by the Nuffield Trust looked at the use of inpatient hospital and local authority funded social care by people at the end of life (Bardsley and others, 2010). One of the striking findings of the study was that people with cancer had very low rates of social care use compared with those with other conditions. One report estimated that the cost of health and social care at the end of life for people with cancer was approximately £1.8 billion (National Audit Office, 2008). That report also estimated the cost of voluntary sector hospices to be around £500 million – a significant proportion of those cared for in hospices have cancer (National Council for Palliative Care, 2012).

A report by Macmillan Cancer Support (2010) argued that local authority social services are not meeting the needs of people with cancer. It found that people were often not referred for assessment by social services and were unaware of services that might have been available. The report also found that organisations that commissioned social care services had limited understanding of the specific needs of cancer survivors. In a previous survey, Macmillan Cancer Support (2006) found that 35 per cent of those with cancer did not know how to access social care and support. A recent survey by the Department of Health (2010b) found that 19 per cent of people who needed help felt that they did not get enough support from health and social services after leaving hospital.

Given improving survival rates for many (but not all) cancers, and the increasing focus on cancer survivorship, the Nuffield Trust was commissioned by the Department of Health, as part of the National Cancer Survivorship Initiative (NCSI), to undertake a project to examine the use of health and social care services by people with cancer and the costs involved. This report describes analyses that explore first the use of health and social care by people living with cancer (excluding care at the end of life), and then the use of services in the final year of life. Some of the key questions we set out to address are as follows:

*Use and costs of health and social care for people living with cancer*

- What was the pre- and post-diagnosis use of health care and local authority funded social care in people with cancer? How did this vary by type of cancer?
- How did the use of health and social care by people with cancer following diagnosis compare with those without cancer? How did this vary by type of cancer?
- What were the predictors of the use of social care by people following a cancer diagnosis?

*Use and costs of health and social care for people with cancer at the end of life*

- What was the use of health and social care by people with cancer in the final year of life and what were the costs involved? How did these vary by type of cancer?
- How did the use of health and social care by people with cancer in the final year of life compare with other people at the end of life?



## 2. Methods

The analyses in this report are based on datasets that had previously been supplied to the Nuffield Trust for another project (Bardsley and others, 2010). We approached three sites in England to seek permission to re-use the linked hospital and local authority funded social care datasets that they had previously provided. All three sites agreed to allow their data to be used; however, one site had to be excluded as it no longer held the encryption key that had been used originally to pseudonymise their data (see below).

### Sites

The two sites whose data were used were a suburban area and a large county and cannot be considered representative of England as a whole. They had been used in the previous study based on the following pragmatic criteria:

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

### Datasets

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

- Secondary Uses Service (SUS) data on inpatient, outpatient and A&E hospital activity
- general practitioner (GP) registrations (information on the people registered with a general practice at any given time)
- information about the use of local authority funded social care
- code data from GP practice systems for one of the sites, which we had access to read.

All sensitive personal information was removed and key linkage fields were encrypted before datasets were transferred to the Nuffield Trust. This is in line with guidance from the Ethics and Confidentiality Committee of the National Information Governance Board (see Box 2.1).

The datasets were linked using the pseudonymised NHS number as the unique identifier. The pseudonymised identifier was created by an encryption algorithm that used a password that was unknown to the Nuffield Trust. This ensured that individuals were not identifiable. Within each site the same password was used to encrypt all datasets to ensure that individuals could be linked across datasets.

### **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. The size of the datasets involved meant that it would not be feasible to seek individual consent from people to use their data for the project. Informed consent is the fundamental principle governing the use of person-identifiable information by any part of the NHS or the research community. The only exception to this rule is for essential NHS activities that are in the interests of patients or the wider public, where anonymous information will not suffice, and where obtaining consent is not a practicable alternative. Applications to use data in this way must be submitted to the National Information Governance Board (NIGB) and are typically dealt with by its Ethics and Confidentiality Committee.

In this study we excluded sensitive information and used a process to pseudonymise key identifiers at source, that is, before transfer to the Nuffield Trust. The predecessor group (the Patient Information Advisory Group) had previously issued a ruling stating that the requirements of the above principles may be met by encrypting data in such a way that they are effectively pseudonymous, that is, they cannot be identified without a password (Patient Information Advisory Group, Department of Health, 2006). We obtained written confirmation from the NIGB that the pseudonymisation process and use of encrypted media that we planned to use would meet its requirements and that no application was necessary under Section 60 of the Health and Social Care Act 2001.

### **Health datasets**

We used admitted patient care, outpatient and A&E data supplied by the primary care trusts in the two sites. These data were taken from the routine Commissioning Data Set (CDS) submissions of record-level, patient, clinical and administrative data that are made by providers of NHS-funded care in England. These datasets covered the period from 2003 to 2008.

### **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 been developed primarily to fulfil local operational needs in managing care services commissioned by the local authority. There is currently no national dataset for social care, and so data models vary between local authorities. For the two sites we grouped together local descriptions under the following headings:

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

- telehealth/telecare
- assessments
- other.

Grouping services in this way allowed more consistency between the sites and allowed us to apply unit costs to each service type.

### **GP dataset**

Each site provided a GP registration file, containing a pseudonymised list of individuals who had been registered with a GP practice in the primary care trust, along with their registration date. This covered the period from 2003 to 2008.

For site A we additionally had information on GP contacts with patients extracted from GP practice systems. This information consisted of information on contact dates and all read codes recorded for each contact.

### **Cancer registration dataset**

Although we could have used the hospital records in the SUS datasets to identify people with cancer, this would have missed a significant proportion of cases. In particular, diagnoses are only recorded for inpatient and day case admissions. Some people with cancer will not have an inpatient admission, and therefore could not be identified using this method. In addition, SUS inpatient records do not contain the date of cancer diagnosis. An accurate date of diagnosis was required for this project, against which activity could be indexed.

Therefore we set out to link the health and social care datasets described above with data on cancer registrations from the National Cancer Data Repository (NCDR). The NCDR holds detailed diagnostic and basic treatment information on all registrable conditions (all malignant neoplasms or those of uncertain behaviour, plus some benign tumours based on data collected by the 11 UK cancer registries). Information on cancer registrations were provided by the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS).

### **What was not included in the datasets**

The datasets contained information on formal services only, but informal social care provided by families, friends or volunteers can form a significant part of social care provision (Health and Social Care Information Centre, 2010). In addition, not all formal services were represented in the datasets. The social care datasets only included information about care that was funded at least in part by the local authority. Care that was arranged privately was not included.

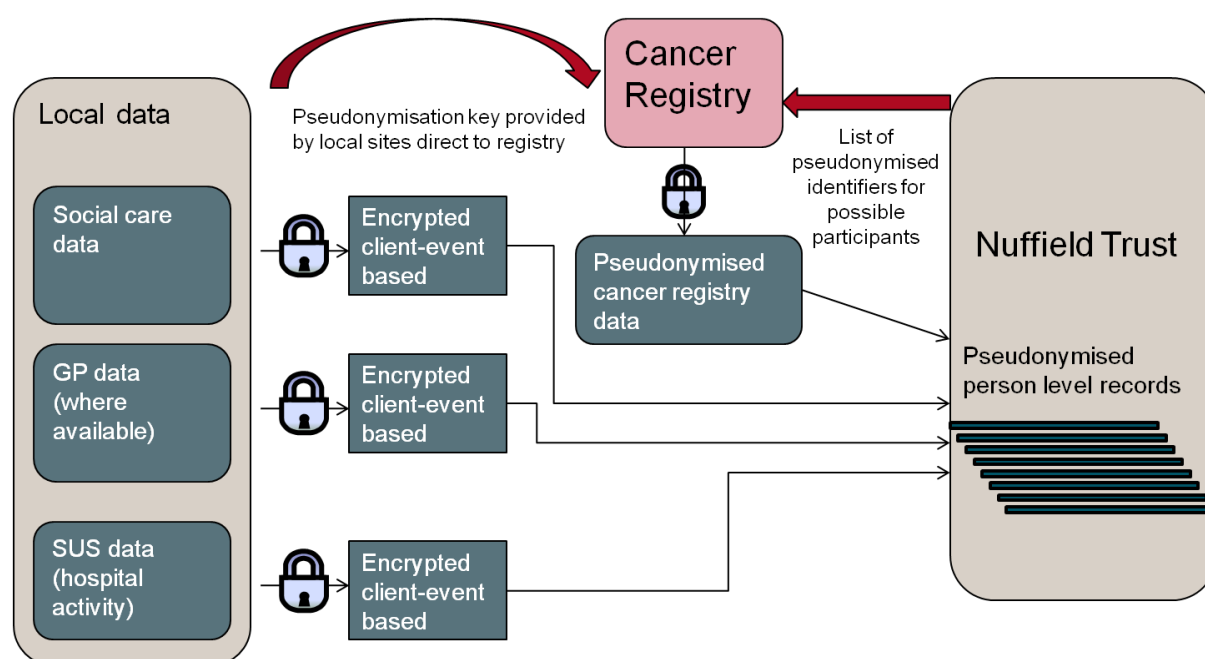
Also, we did not have access to data relating to hospice- and other non-hospital-based palliative care services. Potentially this is a significant component of care for people with cancer (particularly towards the end of life).

## Data linkage

A two-stage process was used to produce a list of all cancer registrations for people who were registered with a GP practice in either of the two sites. First, we provided NYCRIS with a list of pseudonymised NHS numbers for people registered with GP practices in the two sites at some point during 2003–08. This was from the GP registration data described above. Second, the two local sites shared their encryption password with NYCRIS, which was then able to encrypt the NHS number field in the cancer registration dataset, in order to identify any cancer diagnosis records for people who were in the GP registration datasets. NYCRIS then supplied us with a dataset of cancer diagnoses from 1990 to 2008 for people in the registration dataset, including diagnosis date, ICD-O-3 (International Classification of Diseases for Oncology, 3rd edition) diagnosis, basic treatment data, date and cause of death.

The process for supplying data to the Nuffield Trust from the two sites and the cancer registry is summarised in Figure 2.1.

**Figure 2.1: Summary of information flows needed to create longitudinal patient-level records**



## Sample

### People diagnosed with cancer

A member population was constructed based on people registered with a GP practice in the two sites in either April 2006 or April 2007. This gave a combined population of approximately 1.2 million people.

Using the cancer registration dataset, a subset of this population was identified who had their *first diagnosis* of cancer between January 2006 and June 2007 inclusive. This gave us one year of pre-diagnosis and up to 18 months of post-diagnosis health and social care data for all participants. Only those whose first diagnosis fell within the study period were included, to avoid confounding effects from previous cancer treatment. It is possible that some individuals might have had a cancer diagnosis before 1990, which would not have been included in the cancer registration dataset. However, this is unlikely to have affected a significant number of people.

### People with cancer at the end of life

We created a member file consisting of those in the population file (registered with a GP practice in the sites in either April 2006 or April 2007) who died between April 2006 and October 2008.

Using the cancer registration dataset we identified a subset of these people who had a cancer diagnosis between 1990 and 2008. We excluded those who had a benign cancer diagnosis or a diagnosis of basal cell carcinoma. Using the cause of death information recorded in the cancer registration data, only those people where a malignant cancer diagnosis was recorded as a cause of death were included, although we did not restrict it to cases where it was recorded as the underlying cause of death. This produced a cancer cohort of 7,936 people.

## Analytical approach

### Standardised rates for those living with cancer

Given that people with cancer were on average significantly older than the overall population of the two sites, we calculated standardised ratios of health and social care use. The standardised ratios were calculated as follows:

For each individual in the member file we calculated their use of health care (number of admissions/attendances) and social care (whether or not they received services) over six quarters, indexed from their earliest GP registration date (either April 2006 or April 2007). This allowed us to calculate quarterly rates of usage by age band and sex within each site. We then aggregated the quarterly figures together to calculate an overall usage rate over a quarter, by age, sex and site. For analyses by social care service type, we additionally standardised by the population use of each service type.

We applied this quarterly rate to the cohort of people diagnosed with cancer to produce quarterly expected rates of usage. The observed and expected rates of usage for the cancer cohort were constructed by quarter for 12 months before diagnosis and for 18 months after diagnosis (15 months for the hospital data as we did not have 18 months of post-diagnosis activity for everyone).

We have previously shown (using the same datasets) that there was a significant increase in health and social care use at the end of life, particularly in the last two or three months (Bardsley and others, 2010). For this part of the study we were interested in the use of services by cancer survivors, and so we were keen to minimise the effect of the use of services at the end of life. In order to do this we excluded activity that took place in the quarter in which an individual died when calculating both the observed and expected rates. We aggregated the observed and expected figures across the two sites as geographical differences were not a primary focus for this study.

We compared the use of social care in the cancer cohort with people with a range of other chronic conditions. For each individual in the member population of both sites, we identified whether or not they had various chronic conditions recorded on an inpatient admission in the three years before an index date. For those in the cancer cohort the index date was their date of diagnosis. For everyone else it was their earliest registration date in the GP member file (either April 2006 or April 2007).

The chronic conditions of interest were:

- diabetes
- hypertension
- congestive heart failure
- ischaemic heart disease
- cardiovascular disease
- angina
- asthma
- chronic obstructive pulmonary disorder (COPD)
- chronic renal failure
- arthritis and connective tissue disorders.

A categorical measure was then constructed, based on the number of chronic conditions that had been recorded previously. This measure had five levels: 0–3 and 4+ chronic conditions. Standardised usage rates for social care were then calculated over an 18-month period, standardised for age and sex to usage by the population of each site, as set out above. For those with cancer, the 18-month period covered the time after diagnosis. For the rest of the member population it covered an 18-month period from their index date.

### **Standardised rates for those with cancer at the end of life**

For the end of life analyses we calculated rates for the number of people using social care services in the final three complete months of life, standardised by age and sex to the usage in that period of all those who died within each site. For analyses by service type, we additionally standardised by the use of each service type by those in the end of life member file.

For hospital activity we calculated rates for the number of admissions/attendances in the final three full months of life, standardised by age, sex and activity type (elective admission/non-elective admission/outpatient/A&E) to the profile of usage of the whole end-of-life cohort.

## Predicting social care assessment and receipt of services

As well as comparing the use of health and social care, we also conducted multivariate analyses to explore the characteristics associated with social care assessment and social care use among cancer patients. Our method used a two-stage model. The first stage described the characteristics associated with undergoing an assessment for social care following diagnosis, while the second stage described the characteristics associated with receipt of social care, conditional on having first undergone an assessment. Almost all (98.4 per cent) of cancer patients who started to receive social care after diagnosis had a recorded assessment, so this model structure mimics the way patients moved through the system.

The second stage of the model was concerned with whether or not a patient received social care, rather than the amount of social care received. Our model was therefore an adaptation of the standard two-stage model, as both models were logistic regression models, rather than a combination of logistic and linear models. We chose time periods for defining our variables, and studied assessments occurring in the 90 days following diagnosis, and social care services received in the 180 days following diagnosis.

We excluded basal cell carcinoma cases from the multivariate analyses but included patients whose diagnosis was subsequently found to be an error or who had a benign tumour. A variety of variables were tested for inclusion in each model (see Table 2.1). Variable selection was based on an initial model that included all variables; variables were then successively removed based on a consideration of the Akaike information criterion, which is a measure of the relative goodness of fit of a statistical model.

**Table 2.1: Variables tested for inclusion as predictors in the multivariate analyses**

Variable	Notes
Site	Levels: Site. ( <i>reference = site B</i> )
Hospital provider, where patients were in hospital at date of diagnosis	Levels: Main NHS trusts. ( <i>reference = smaller NHS trust or out of hospital</i> )
Cancer site	Levels: Acute leukaemia, brain/CNS, breast, gynaecological, haematological, head and neck, lower gastrointestinal (GI), lung, other, prostate, sarcoma, skin, testicular, upper GI, urological, error/benign. ( <i>reference = error/benign</i> )
Treatment type	Levels: No treatment, non-surgical treatment, surgery only, surgery plus. ( <i>reference = no treatment</i> )
Age category	Levels: 0–44, 45–64, 65–74, 75–84, 86+. ( <i>reference = 45–64</i> )
Sex	Levels: Male, female. ( <i>reference = female</i> )
Deprivation score	Based on the 2004 Index of Multiple Deprivation (IMD) (Department for Communities and Local Government, 2010) attributed to the patient's general practice. Levels: 1st (least deprived), 2nd, 3rd, 4th, 5th quintiles. ( <i>reference = 1<sup>st</sup> quintile</i> )
Receipt of community-based social care in 180 days before diagnosis	Includes home care, day care, direct payments, equipment and adaptations, meals and other.
Care home in 180 days before diagnosis	Includes residential and nursing home care.
Social care assessment in 180 days before diagnosis	Any assessment.
Number of chronic health conditions	From inpatient hospital record. Includes angina, asthma, cerebrovascular disease, congestive heart failure, COPD, diabetes, hypertension, ischaemic heart disease, renal failure and sickle cell.
Diagnoses	Several variables were created based on three years of inpatient history up to and including the date of diagnosis: alcohol use, anaemia, angina, asthma, atrial fibrillation, cerebrovascular disease, congenital disorders,



	congestive heart failure, connective tissue disorders and arthritis, COPD, developmental disorders, diabetes, drug use, falls, hypertension, iatrogenic diseases, injury, ischaemic heart disease, mental health conditions, mild liver disease, non-rheumatic valvular disorders, peripheral vascular disease, respiratory infection and sickle cell.
In-hospital diagnosis	Various variables were created to indicate whether patients were diagnosed while admitted to hospital and whether the admission: <ul style="list-style-type: none"> <li>• was an emergency, regular elective or day case admission or other</li> <li>• cancer recorded on the inpatient dataset.</li> </ul>
Inpatient hospital admission before diagnosis	Three variables were created (7–30 days, 30–90 days or 90–180 days before diagnosis).
Inpatient hospital admission before diagnosis (cancer recorded in the inpatient datasets).	Occasionally cancer was recorded in the inpatient datasets before the date of diagnosis in the cancer registry. Three variables were created (7–30 days, 30–90 days or 90–180 days before cancer registry diagnosis).

## Costs

### *Inpatient spells*

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

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

### *Outpatient attendances*

As with inpatient costs, prices were either taken from the 2010/11 national tariff where there was a mandatory HRG or treatment specialty price, or otherwise derived from the 2007/08 reference costs. Costs of unbundled activity were included where applicable.

### *A&E attendances*

Unlike inpatient and outpatient costs, A&E visits were all costed using the 2010/11 national mandatory tariff. This provides a limited set of costs, which are still assigned by the HRG3.2 code of the visit.

### *Social care*

Social care costs were calculated for every episode of care for those in the cancer cohort that fell (at least in part) within a two-and-a-half-year period that spanned one year before diagnosis and



up to 18 months after diagnosis. The number of days of each type of service within each month or quarter was calculated, and the unit costs shown in Table 2.2 were applied at a daily rate. It should be noted that the estimated costs are purely indicative and do not relate to the actual amounts paid by each local authority.

**Table 2.2: Unit costs used to weight social care activity**

Service group	Unit cost	Source
Nursing care	£646 a week	National average across all councils (from provisional national returns PSSEX1 2010/11), plus an allowance for the NHS contribution to nursing care in nursing homes*.
Residential care	£529 a week	National average across all councils (from provisional national returns PSSEX1 2010/11).
Home care	£212 a week	Based on an average of 12.4 home care hours per older person* and an assumed cost of £17.10 an hour (national average across all councils: provisional PSSEX1 national returns 2010/11).
Respite	£529 a week	Assumed same as residential care.
Other accommodation	£529 a week	Assumed same as residential care.
Equipment and adaptations	£199 per installation	Calculation based on PSSEX1 and Referrals and Appraisals data.
Direct payments	£124 a week	National average across all councils (from provisional national returns PSSEX1 2010/11).
Day care	£106 a week	National average across all councils (from provisional national returns PSSEX1 2010/11).
Meals	£30 a week	National average across all councils (from provisional national returns PSSEX1 2010/11).
Assessments	Not costed	
Telehealth/telecare	Not costed	
Other	Not costed	

\* Source: Personal Social Services Research Unit 2010/11 unit costs of social care

### 3. Results – Part I: The use of health and social care by people living with cancer

#### Sample

Between January 2006 and June 2007, 11,795 people had a first diagnosis of cancer. In site B, a significant number of registry records were for people diagnosed with basal cell carcinomas. It was felt that these were not likely to be representative of people with cancer, and so they were excluded from the cohort of those with cancer. In addition, there were a significant number of benign tumour diagnosis records for both sites, and a small number of invalid diagnosis codes. We also excluded these from the cohort, with the exception of breast carcinomas *in situ* (ICD-10 code D05). This gave a final sample of 8,072 people. Characteristics of the populations of the sites and of the cancer cohort are shown in Tables 3.1 and 3.2 below.

**Table 3.1: Characteristics of the member population of the two sites**

	Site A	Site B	Overall
Total population	412,770	775,445	1,188,215
Mean age (standard deviation – SD)	36.8 (21.9)	42.8 (23.9)	40.7 (23.4)
% female	49.8%	51.2%	50.8%
Mean IMD (GP practice)	21.7 (7.6)	17.6 (4.1)	19.0 (5.9)

**Table 3.2: Characteristics of those with their first cancer diagnosis between January 2006 and June 2007**

	Site A	Site B	Overall
Number of people	2,022	6,050	8,072
Mean age (SD)	66.1 (16.0)	69.3 (14.6)	68.5 (15.0)
% female	49.4%	52.0%	51.3%
Mean IMD (GP practice)	20.8 (7.9)	17.2 (4.1)	18.1 (5.5)
% alive 12 months after diagnosis	72%	72%	72%

There were some differences between the two sites, with cancer patients in site A tending to be younger and from more deprived areas. This is not surprising as site A is an urban area, while site B is predominantly rural.

Table 3.3 shows the average age and GP practice IMD of the cancer cohort. Only seven per cent of the cancer cohort was aged less than 45, with 38 per cent aged 75 or older. Approximately 20 per cent of the 85+ age group had a diagnosis of skin cancer, while breast cancer made up over a quarter of cases in the 19–44 and 45–64 age groups.

**Table 3.3: Age and deprivation characteristics by cancer type**

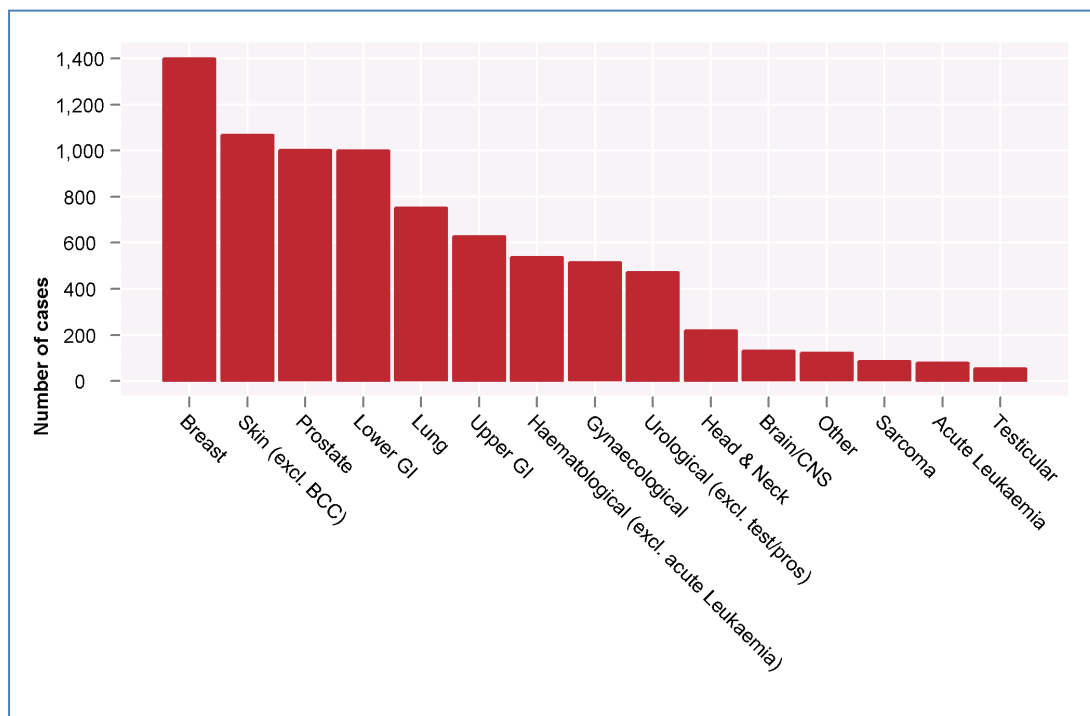
Cancer type	Average age (SD)	GP practice IMD (SD)
Other	74.7 (15.9)	19.1 (6.2)
Upper GI	72.5 (12.4)	18.3 (5.5)
Prostate	71.8 (9.8)	18 (5.7)
Lung	71.6 (11.6)	19.1 (6.2)

Lower GI	71.6 (12.7)	18 (5.3)
Urological (excluding. testes/prostate)	70.9 (13.8)	18.2 (5.4)
Skin (excluding basal cell carcinoma)	70.7 (16)	16.8 (4.8)
Haematological (excluding acute leukaemia)	66.6 (17.1)	18.2 (5.4)
Gynaecological	65.5 (15.3)	17.7 (5.1)
Sarcoma	65.1 (22.5)	19.4 (5.9)
Head and neck	64.6 (15.6)	18.5 (5.5)
Breast	63 (14.2)	18.4 (5.6)
Brain/CNS	60.8 (22.1)	17.8 (5.5)
Acute leukaemia	51.6 (28.1)	17.9 (5.2)
Testicular	37.2 (11.5)	18.8 (5.9)

We created broad cancer groupings in order to permit sub-group analyses. These groupings were constructed using ICD-10 codes and are broadly consistent with those used in Cancer Waiting Times (CWT) submissions (the only difference being that prostate cancers were categorised separately from other urological cancers). Figure 3.1 shows the distribution of cancer types across the two sites combined. Those classified as ‘other’ were predominantly cancers of unknown primary (CUPs).

The high number of skin cancer cases (once basal cell carcinomas were excluded) was unexpected. Of these cases, 85 per cent were from site B. Further investigation showed that 71 per cent of the skin cancer records were coded as non-melanoma skin cancer (ICD-10 code C44), the majority of which were classified as squamous cell carcinomas.

**Figure 3.1: People living with cancer, by cancer type**



Note: BCC = basal cell carcinoma.

## Longitudinal histories

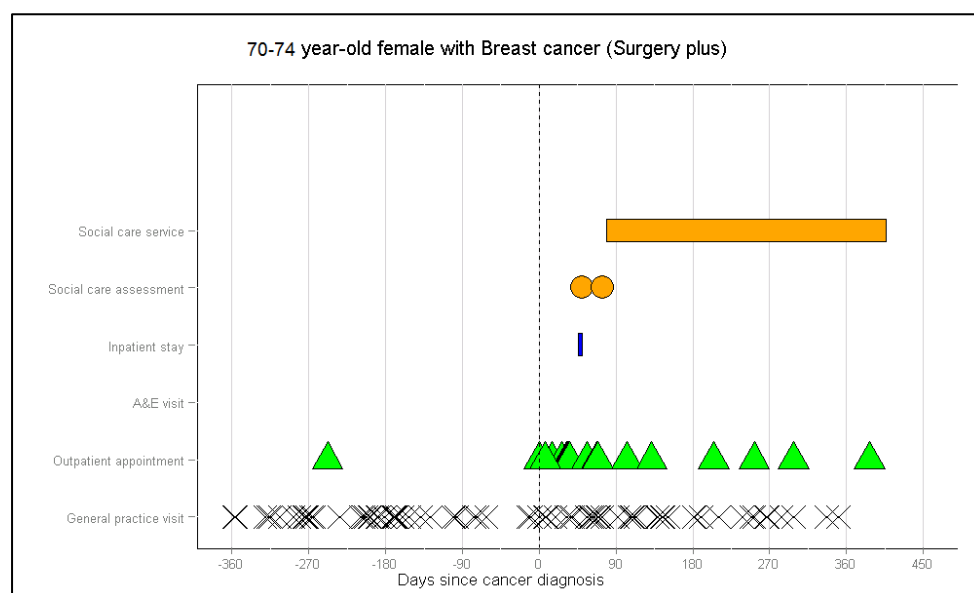
Having linked the datasets together, we were able to construct longitudinal histories for each of the 8,072 people with cancer diagnosed in the study period. These histories were indexed from the first date of cancer diagnosis recorded in the cancer registry and contained information about service use for 12 months before the diagnosis and for 15 months afterwards.

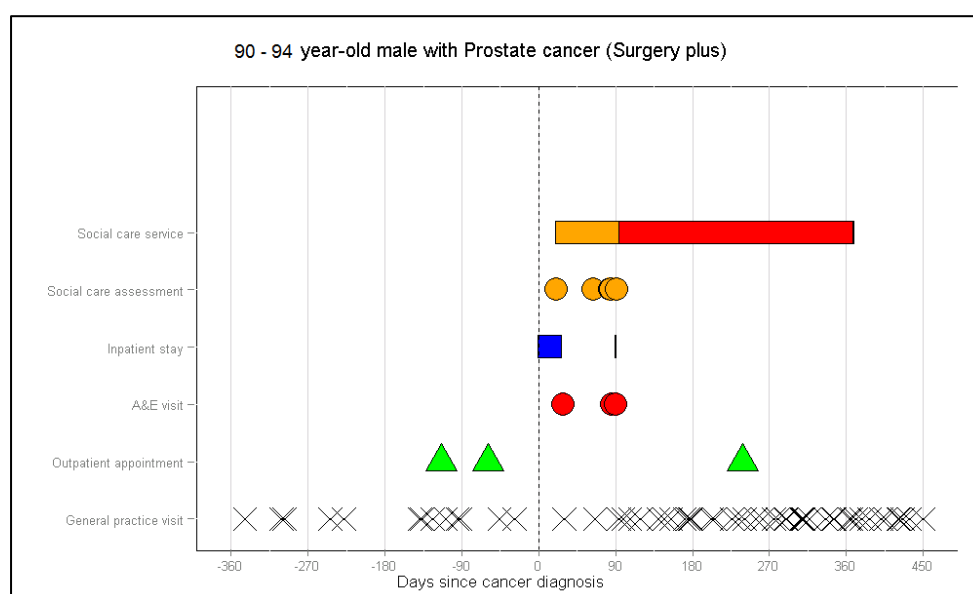
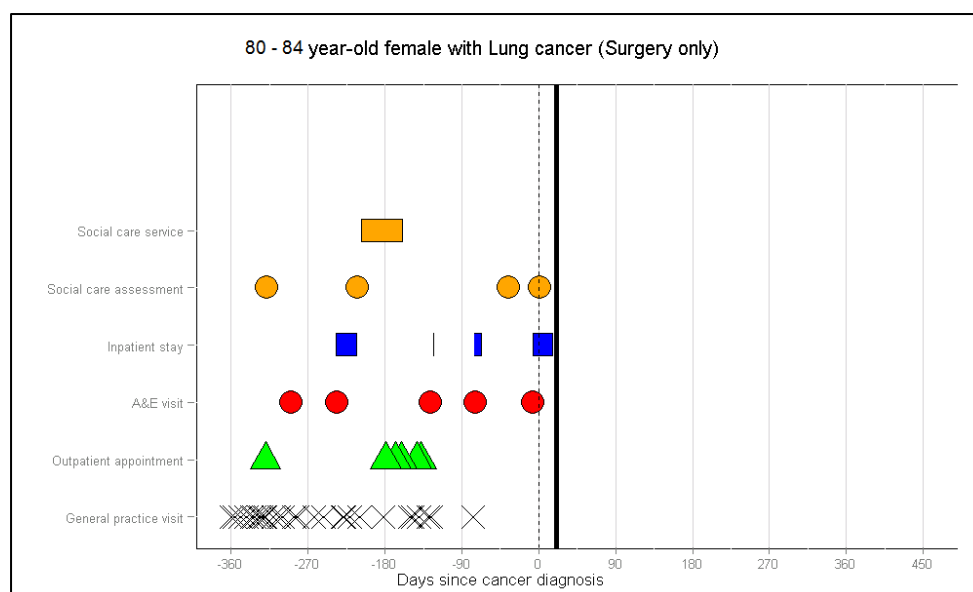
The histories of three people who used social care are illustrated in Figure 3.2.

- The first person undergoes two assessments of her social care needs after being admitted to hospital for surgery for breast cancer. She receives home care for a period of nearly a year and has regular outpatient appointments.
- The second person has a history of social care use as she received a meals service. She also has a history of emergency admissions to hospital related to her diabetes and her hospital record indicates senility. She also has extensive contact with her GP practice in the year before her cancer diagnosis. She is diagnosed with lung cancer while in hospital, and experiences pneumonia and urinary tract infection. She dies in hospital.
- The third person is diagnosed with prostate cancer. He does not have a history of social care use, but after diagnosis his social care needs are assessed four times. He initially receives a home care with meals service, before experiencing a further inpatient admission with stroke and being admitted to residential care.

Although individual illustrations such as these are powerful ways of representing experiences of the health and social care system, they are necessarily limited to a small number of individuals.

**Figure 3.2: The care history of three people with cancer who used social care\***





\* 'Surgery plus': Surgery plus either one or more of chemotherapy, radiotherapy and hormone therapy, or surgery plus a non-surgical treatment.

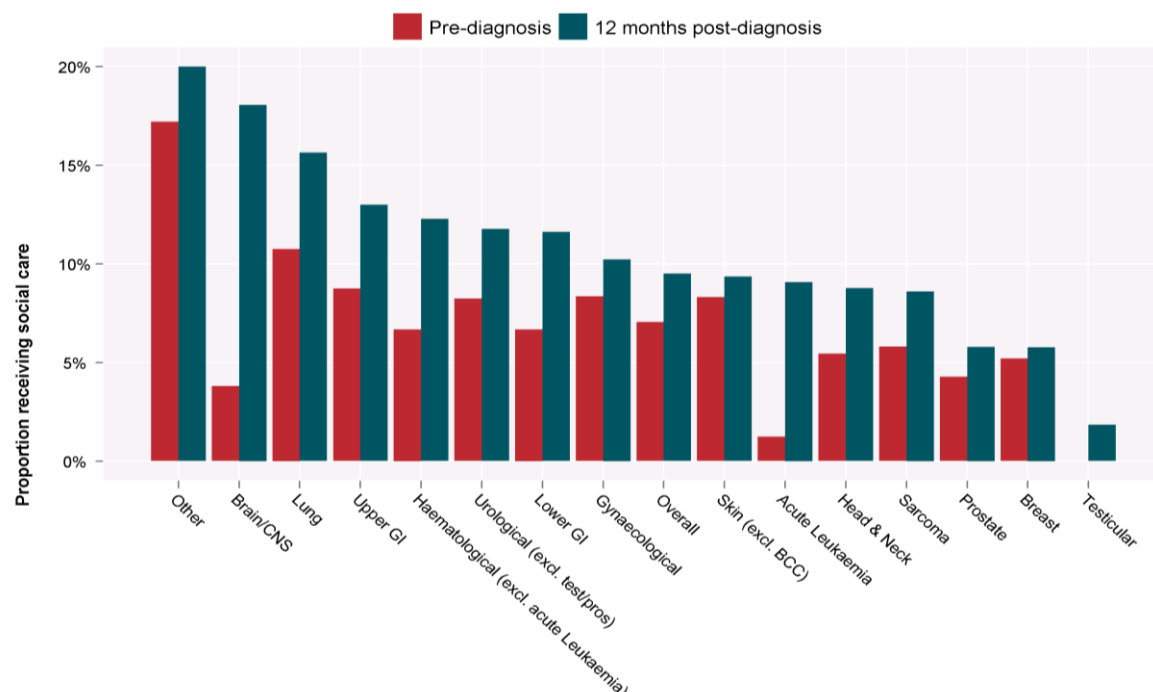
## Social care use

*What proportion of people with cancer used social care? Was this higher or lower than the rest of the population?*

Overall, the use of local authority funded social care by people with cancer was relatively low, with 7.1 per cent receiving a service (excluding assessments) in the year before the date of their cancer diagnosis, and 9.5 per cent using services in the 12 months after diagnosis. Of the people with cancer, 16 per cent received an assessment in the year after being diagnosed with cancer, with 9.6 per cent being assessed in the 90 days after diagnosis. However, this varied significantly by cancer type, with only three per cent of those with skin or breast cancer being assessed within three months of diagnosis, compared with 18 per cent of those with upper GI cancers, 27 per cent of those with lung cancer and 31 per cent of those with brain/CNS tumours. Figure 3.3

shows the percentage of people with cancer who used social care in the 12 months before and after diagnosis.

**Figure 3.3: Use of social care by people with cancer before and after diagnosis**



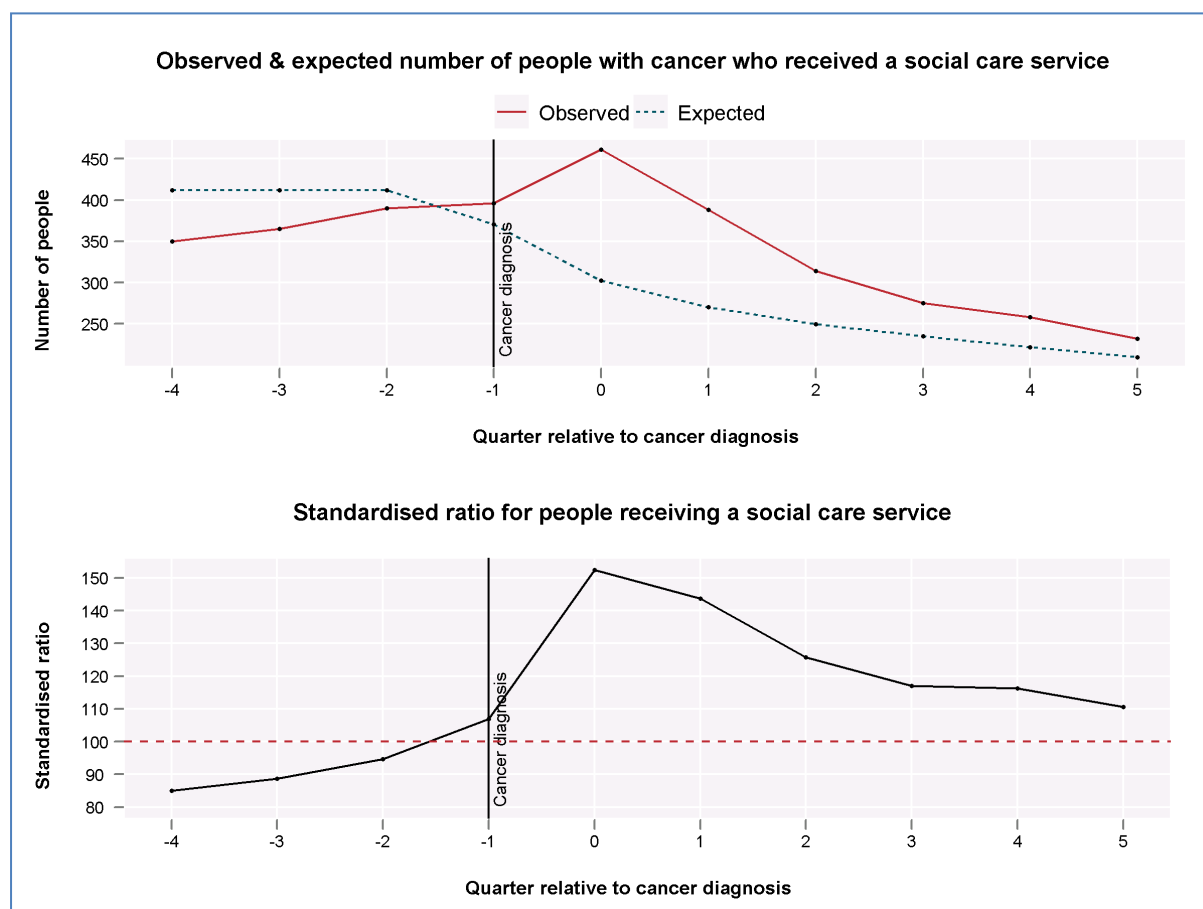
Those with unknown or ill-defined cancers had the highest level of social care use both before and after diagnosis. Those with brain/CNS tumours had low levels of use before diagnosis, but a high level of use in the year after diagnosis. Those diagnosed with lung cancer had a relatively high level of use before diagnosis (perhaps not surprising as these people would be likely to have a range of other comorbidities that might require social care). Among other common cancers, those with breast or prostate cancers did not show a pronounced change in social care use following a diagnosis of cancer.

The top part of Figure 3.4 shows the observed and expected number of people with cancer receiving a local authority funded care service by quarter, relative to the date of cancer diagnosis. Standardised rates were calculated relative to the date of cancer diagnosis. The lower part of the figure shows the data expressed as a ratio (observed/expected\*100). A value of 100 means that the observed level of usage was the same as would be expected based on the population structure. As explained above, at each time point the observed and expected figures were based on people alive at that point.

The results show:

- in the 12 months before diagnosis, there were fewer people using social care than expected, although the number steadily increased over time
- a large increase in social care just after diagnosis, with 50 per cent more people than expected receiving a service in the three months after diagnosis
- a subsequent decline in usage, although with uptake still ten per cent higher than expected 18 months after diagnosis.

**Figure 3.4: Standardised use of social care by people with cancer, compared with overall use in the two sites\***



\*Note vertical line indicates the start of the month in which cancer diagnosis made

*Were there differences in the use of social care by cancer type?*

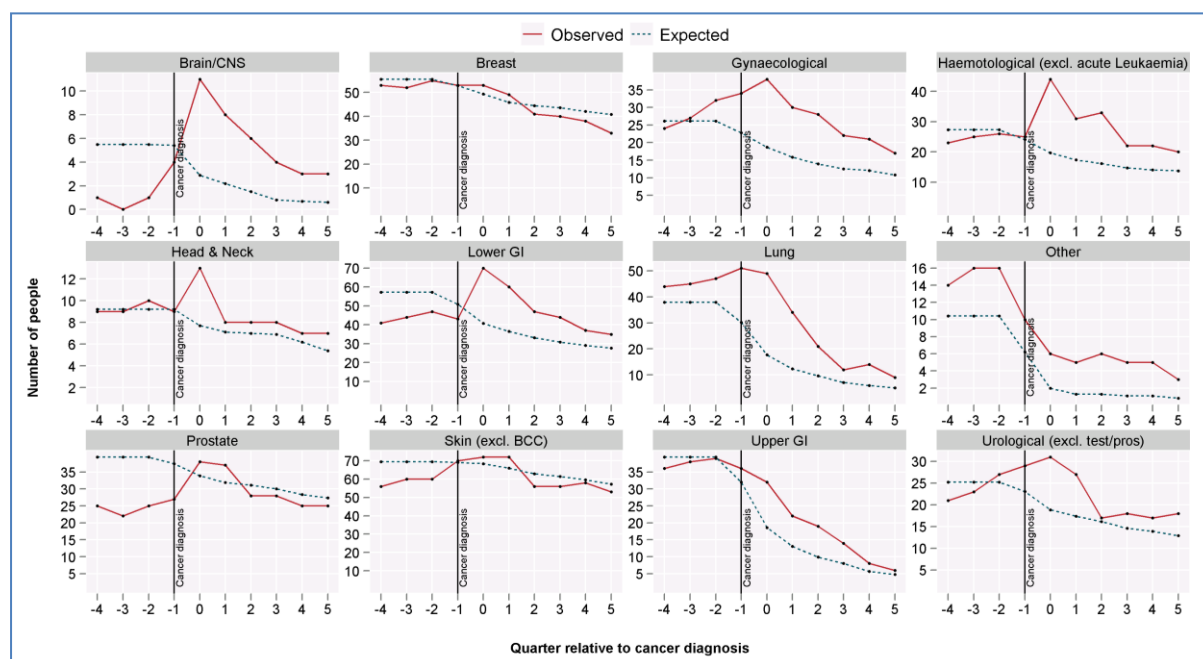
Differences in incidence by age, as well as treatment options and likely prognosis, mean that social care use is likely to vary between cancers. Figure 3.5 shows observed and expected figures for use of social care, split by cancer type.

The pattern of social care use varied noticeably by cancer type, although there were a few common patterns:

- low usage before diagnosis, with a sharp rise in the number of people receiving social care immediately after diagnosis – brain/CNS, prostate and lower GI cancers
- higher than expected use before diagnosis – lung and other cancers
- use broadly in line with expectation, with little evidence of a spike following diagnosis – breast, skin (to some extent) and upper GI cancers
- pre-diagnosis use in line with the population, but a sharp increase in use after diagnosis – non-leukaemic blood cancers and head and neck cancer
- increasing use through the year before, peaking in the three months after diagnosis – gynaecological and urological cancers.

The sharp decline in the expected number of people for some cancers (in particular lung, other and upper GI) reflects a high mortality rate in those groups.

**Figure 3.5: Observed and expected number of people with cancer who received social care, by cancer type**



*What types of social care were used by people with cancer?*

The analyses above showed that fewer people than expected used social care in the year before being diagnosed with cancer, but with higher than expected use over 18 months after diagnosis. This raises the question of which services were used, and whether this varied by time from diagnosis.

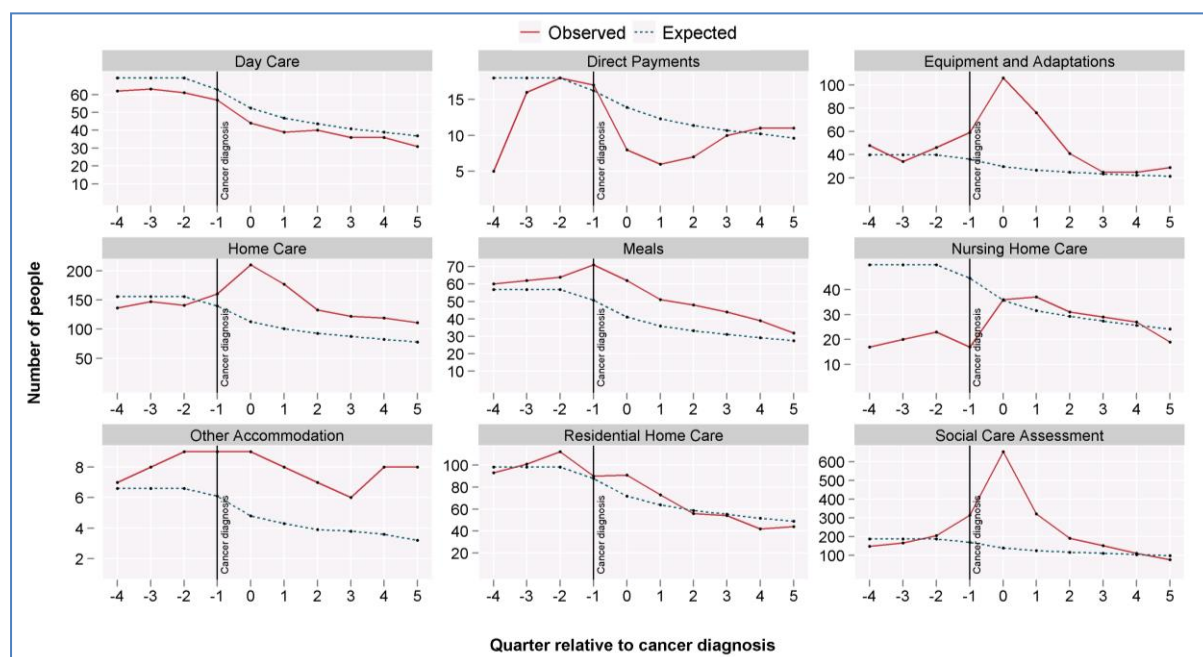
Figure 3.6 shows the observed and expected numbers of people using different types of local authority funded social care among those diagnosed with cancer. It should be noted that the expected rates were calculated by standardising by age, sex and, additionally, the usage of each service type within each site.

A number of points are clear from this:

- The lower than expected use of social care in the year before cancer diagnosis seems to have been driven largely by low use of direct payments, and most notably extremely low rates of use of nursing home care.
- Although the number of people in local authority funded nursing home care was significantly lower than expected before diagnosis, it jumped in the quarter after diagnosis and thereafter tracked the expected level of use.
- Use of residential care broadly tracked the expected rate through the period.
- Significant spikes were seen in the number of people receiving equipment/adaptations and home care following diagnosis. For equipment/adaptations this declined back to the population level of use after around 12 months, while use of home care remained more than 40 per cent higher than expected 18 months after diagnosis.
- The number of people receiving meals was higher than expected before diagnosis, and remained higher throughout the 18-month period after diagnosis.
- There was a threefold rise in assessments in the three months following diagnosis.



**Figure 3.6: Observed and expected number of people with cancer receiving selected types of social care**



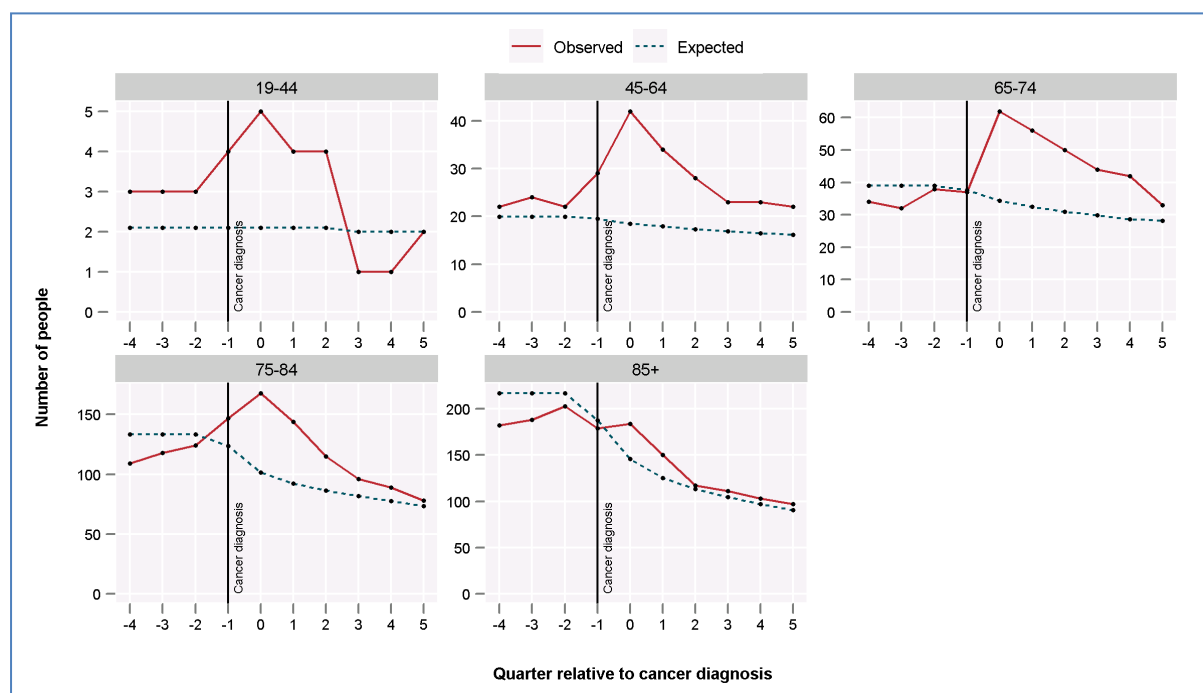
*Were differences in social care use linked to age?*

Given the clear differences in use of social care between those diagnosed with cancer and the wider population of the two sites in this study, such as the much lower numbers of people in nursing home care, we investigated whether the pattern of social care use varied by age. Figure 3.7 plots observed and expected levels of use of social care by age band.

The results show that:

- The fewer than expected people receiving social care before diagnosis was primarily accounted for by older people, with fewer people aged 75+, and particularly the very elderly, receiving local authority funded social care.
- The sharp rise in the use of social care after diagnosis was seen in all age groups except for the very elderly, where post-diagnosis usage broadly tracked the expected rate.

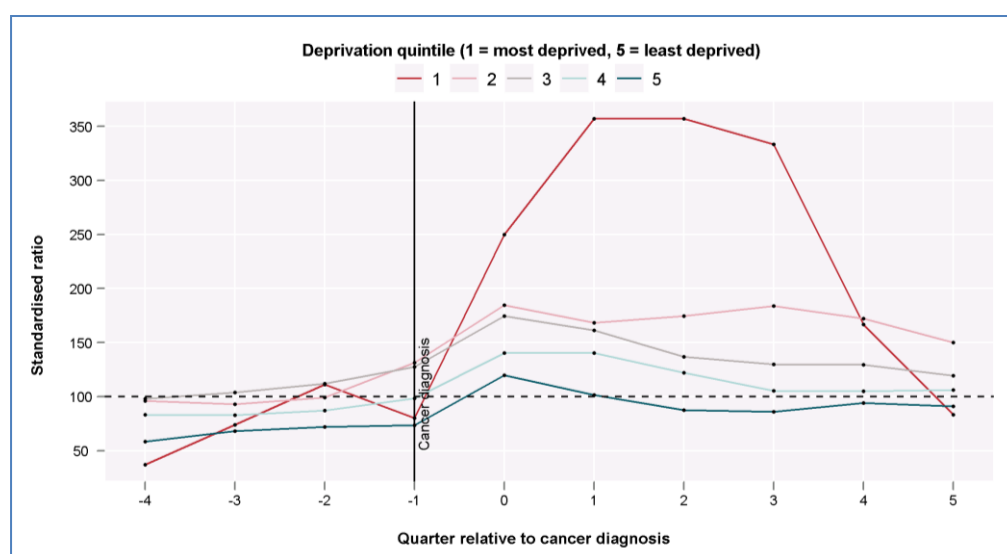
**Figure 3.7: Observed and expected number of people with cancer receiving social care, by age band**



*Were there differences in social care use according to level of deprivation?*

We were surprised by the lower than expected use of social care before diagnosis by people in the cancer cohort. One possible explanation might be that it reflects an effect of deprivation. Figure 3.8 plots standardised ratios for the number of people receiving social care, by deprivation quintile (deprivation calculated at GP practice level). The Figure shows that pre-diagnosis usage was lower in less-deprived quintiles. The extreme values seen for the most deprived quintile are due to very few people in this quintile in the cohort.

**Figure 3.8: Standardised ratios for social care use, by deprivation quintile, standardised by site, age band and sex**



Given that the gap in social care use seemed to be particularly pronounced in older groups, Table 3.4 shows the proportion of people with cancer aged 75+ who received social care in the period from 12 to 3 months before diagnosis, and the proportion in the rest of the population of the two sites (aged 75+) over an equivalent period. This shows that fairly consistently, people subsequently diagnosed with cancer used slightly less social care than those who were not in the cancer cohort.

**Table 3.4: Use of social care among people aged 75+, by deprivation quintile**

Quintile	Cohort	No social care	Social care	% receiving social care
1 (most deprived)	Cancer cohort	20	2	9.1%
	Others	441	94	17.6%
2	Cancer cohort	190	28	12.8%
	Others	6,693	1,227	15.5%
3	Cancer cohort	959	164	14.6%
	Others	31,456	5,341	14.5%
4	Cancer cohort	1040	139	11.8%
	Others	32,242	4,512	12.3%
5 (least deprived)	Cancer cohort	469	55	10.5%
	Others	14,561	1,906	11.6%

*Were there differences in the use of social care according to the type of treatment?*

The National Cancer Data Repository (NCDR) dataset holds information on curative treatments given within six months of diagnosis. Using this information, we classified people into three categories according to the type of treatment they received:

- no treatment
- surgery only
- non-surgical/surgery plus (either one or more of chemotherapy, radiotherapy and hormone therapy, or surgery plus a non-surgical treatment).

Figure 3.9 shows the number of people with cancer, by cancer type and treatment received. Overall, 22 per cent were recorded as not receiving any active treatment. Among those who did not receive active treatment, the most common cancers were prostate (20 per cent), lung (17 per cent) and upper GI (17 per cent). Those who received no treatment were also significantly older than others (mean age 75.7 years versus 66.5 for those who were treated), and also had shorter life expectancy following diagnosis (mean 7.5 (SD 11) months versus (16.4 (SD 13) months), and nearly 60 per cent died within six months of being diagnosed with cancer.

**Figure 3.9: Number of people living with cancer, by cancer type and treatment received**

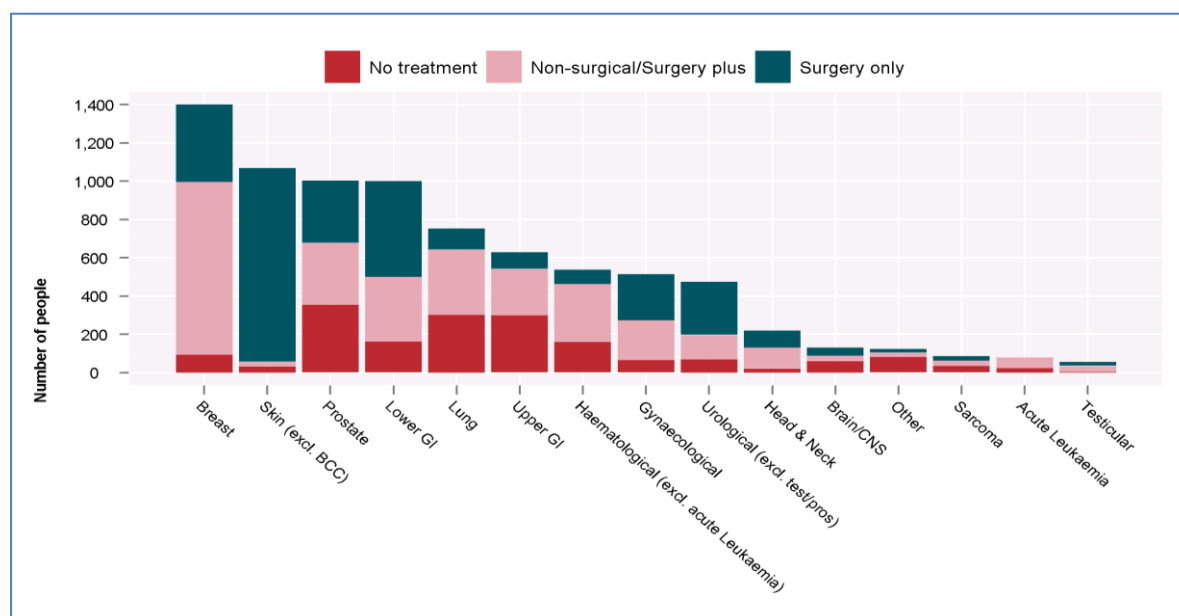
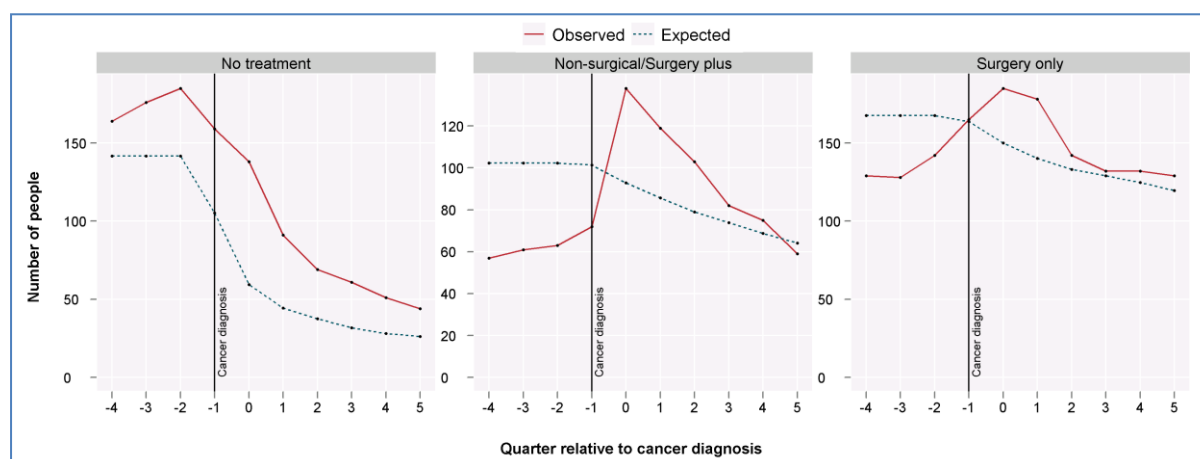


Figure 3.10 shows the observed and expected overall use of social care according to the type of treatment received. Those who did not receive active treatment consistently were more likely to use social care than expected, both before and after diagnosis. Those receiving active treatment (of any type) had lower than expected use of social care before diagnosis, with a sharp increase after. Those receiving non-surgical treatment seemed to use social care for longer after diagnosis.

**Figure 3.10: Observed and expected use of social care by people with cancer, by treatment type**

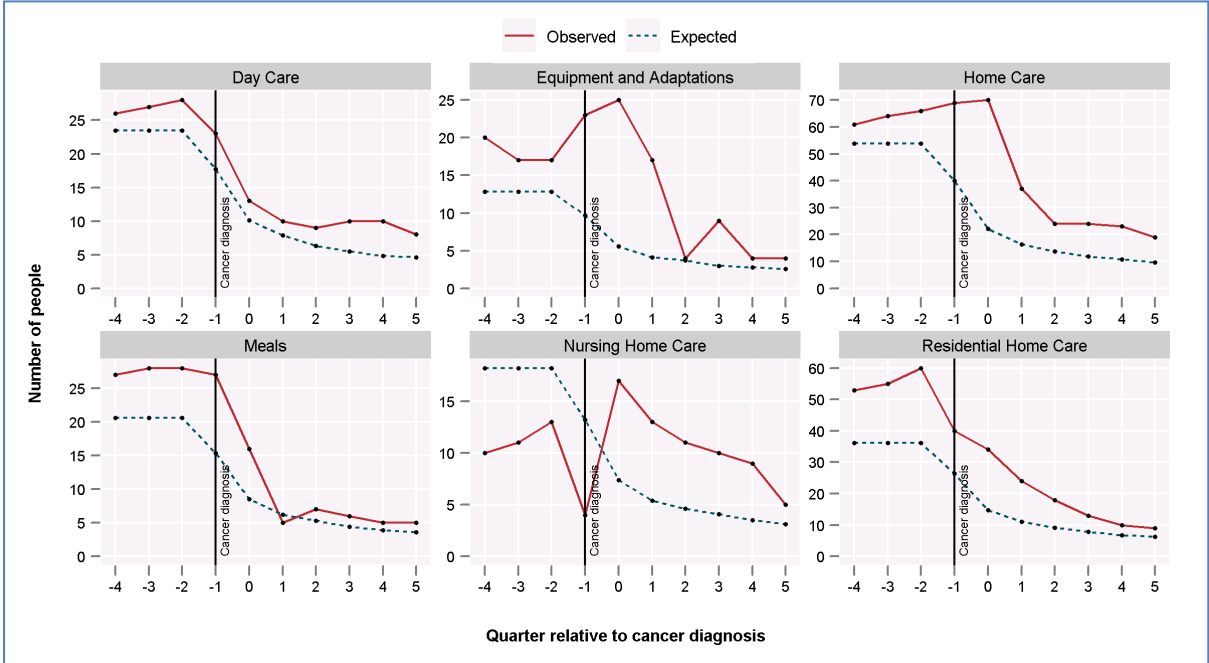


Figures 3.11 to 3.13 show the use of different social care services according to the type of treatment. Among people who did not receive active treatment, more than expected used most forms of social care. An interesting exception was nursing home care, where fewer people were in a nursing home before diagnosis than expected, with a dip in the period leading up to diagnosis, followed by a sharp rise and higher than expected use after diagnosis.

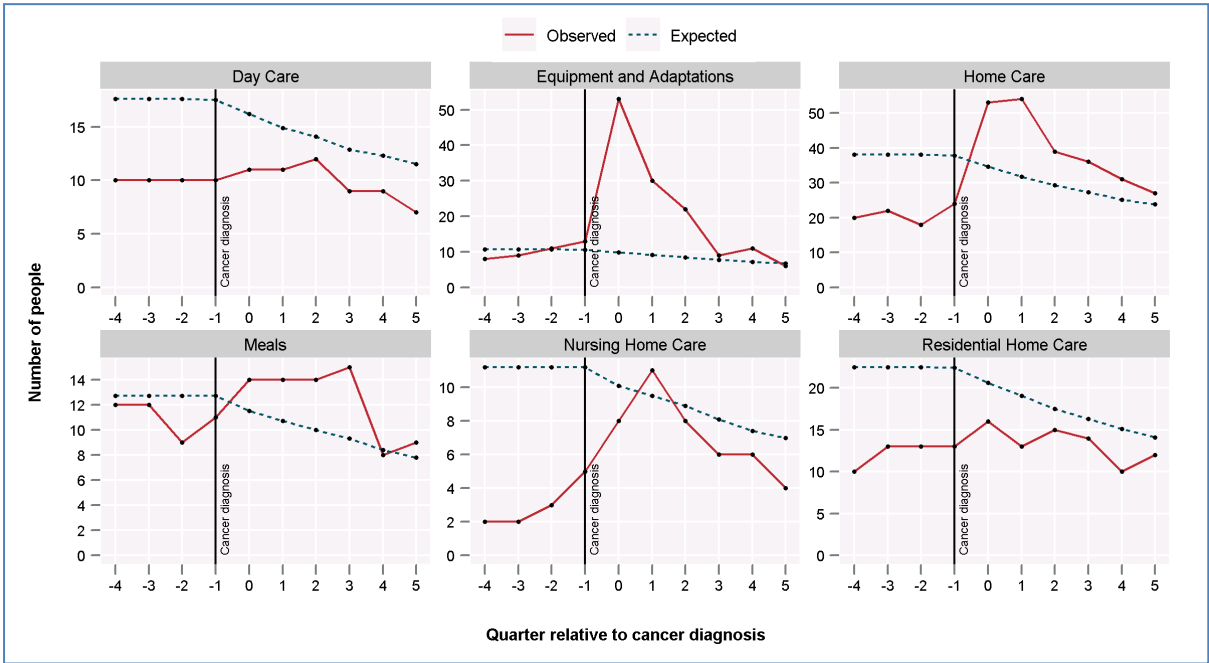
Among people who were treated, those who had surgery only had higher levels of use of equipment/adaptations and home care after diagnosis, but consistently lower levels of use of day care and nursing home care. A similar pattern was seen for those who had some form of non-

surgical treatment, although fewer people used most forms of social care before diagnosis in this group.

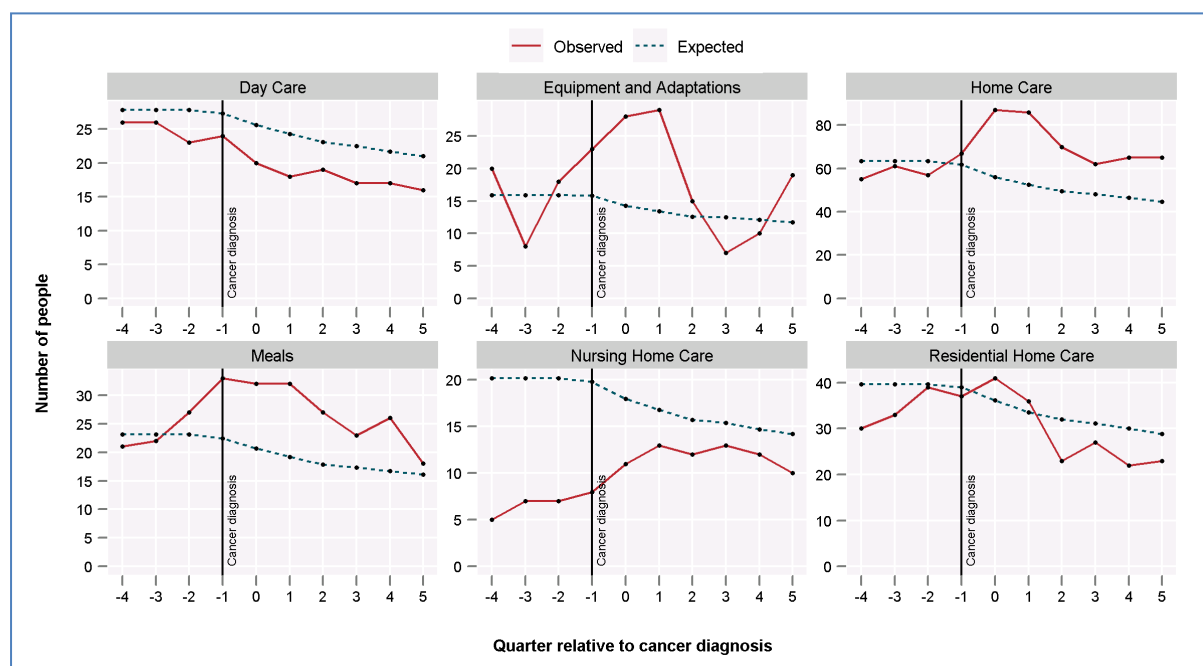
**Figure 3.11: Observed and expected numbers of people using social care, by service type, for those receiving no active treatment only**



**Figure 3.12: Observed and expected numbers of people using social care, by service type, for those receiving non-surgical treatment or surgery plus other treatment**



**Figure 3.13: Observed and expected numbers of people using social care, by service type, for those receiving surgical treatment only**



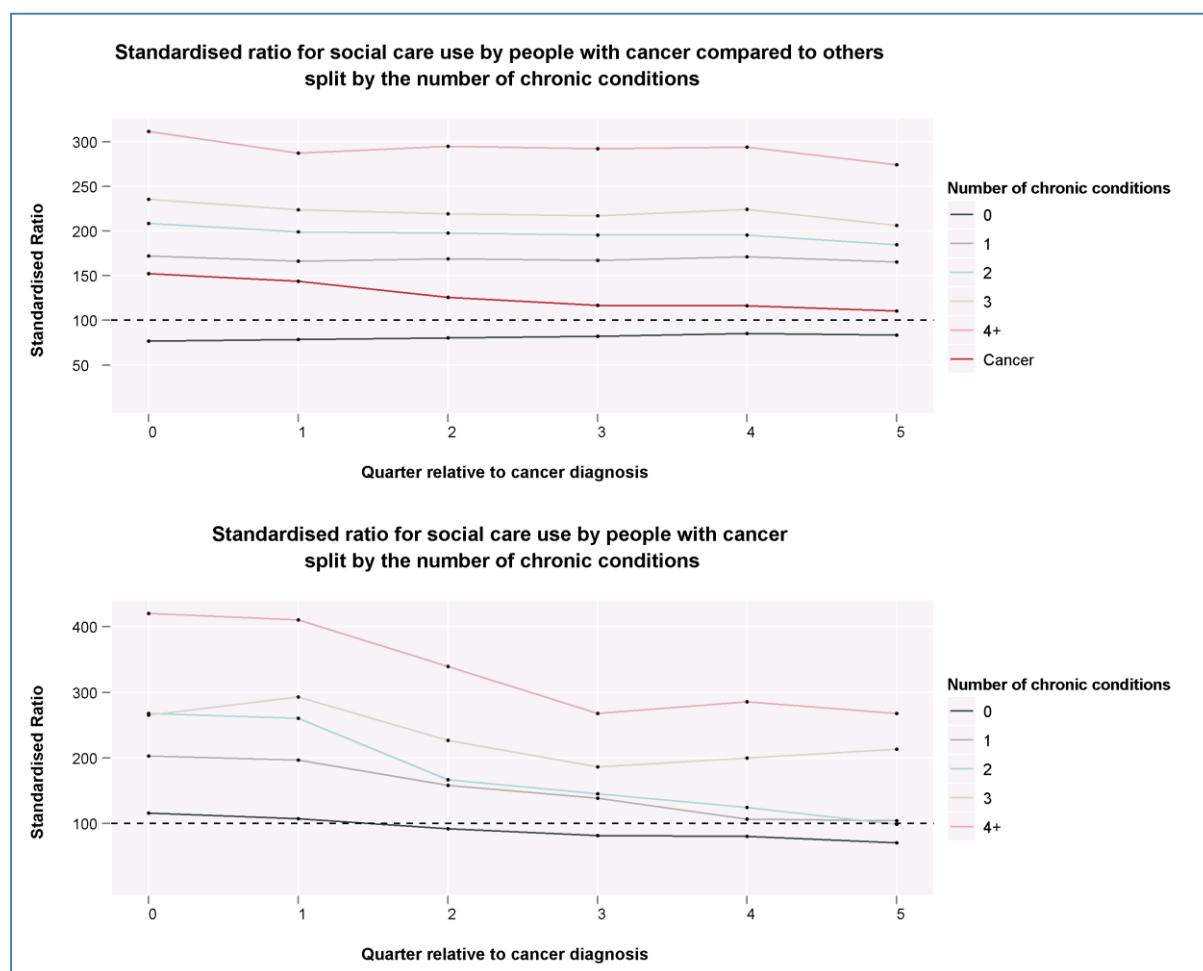
*How did the use of social care by people with cancer compare with people with other chronic conditions? Did the presence of other chronic conditions affect the use of social care by people with cancer?*

The top part of Figure 3.14 shows the standardised ratio for social care use over 18 months, by people with cancer, and by other people with and without chronic conditions. For those with cancer the data cover the 18-month period after diagnosis. After diagnosis those with cancer were more likely to use social care than people without any chronic conditions. However, fewer people with cancer used social care than those with any chronic illnesses recorded.

We were also interested in whether social care use by people with cancer was affected by the presence of other comorbid chronic conditions. The lower part of Figure 3.14 plots the standardised ratio of social care use of the cancer cohort, according to the number of chronic illnesses. In the period after diagnosis, social care use was consistently higher for people with comorbid chronic conditions.

It should be noted that usage for the wider population was calculated over a fairly arbitrary 18-month period. Had we indexed from an inpatient admission (for example), it is likely that usage rates would have been even higher.

**Figure 3.14: Impact of comorbid chronic conditions on social care use**



*What characteristics were associated with use of social care among people with cancer?*

The analyses described above have shown that characteristics such as cancer type, age and treatment type are associated with social care use. However, other factors will also be important, such as need, living situation, support networks and service provision in the area. Further, many of these factors are likely to have a combined effect, in that they are correlated with each other.

In order to distinguish between the independent effects of characteristics on social care use, we used a multivariate approach. Thus, we aimed to estimate the effect of each characteristic when other characteristics were held constant. As described earlier, our method used a two-stage model. The first stage described the characteristics associated with undergoing an assessment for social care following diagnosis, while the second stage described the characteristics associated with receipt of social care, conditional on having first undergone an assessment.

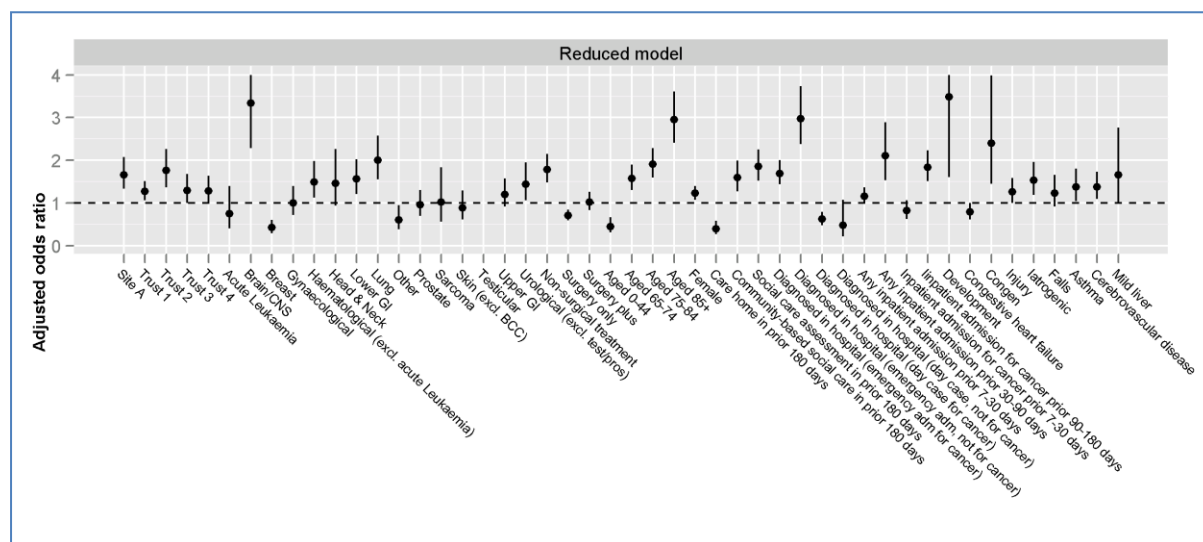
The results are shown here as odds ratios, where a value greater than one means that the variable was associated with an increased likelihood of receiving an assessment, while a value of less than one means that it was linked to a reduced likelihood of an assessment.

The results of the first-stage model, for social care assessment, are shown in Figure 3.15. Key features were as follows:

- Assessment was more common among those with cancer in site A than in site B, and among people seen in four NHS trusts.
- Age and being female were also associated with assessment for social care.
- Brain/CNS, haematological, lower GI, lung and urological cancers were associated with assessment, while breast cancer and other cancers were negatively associated with assessment.
- Non-surgical treatment types (consisting primarily of radiology and chemotherapy) were associated with assessment.
- Prior use of community-based social care and prior assessments were associated with social care assessment following discharge, while prior care home stays were negatively associated.
- Diagnosis while in hospital was associated with assessment for social care, provided the admission was an emergency. Diagnosis in day case settings was negatively associated.
- Some comorbidities (developmental disorders, congenital disorders, injuries, iatrogenic diseases, asthma, cerebrovascular disease and mild liver disease) were associated with assessment. Falls were associated with assessment, and improved the fit of the model, although were not quite significant at the standard five per cent level.

The model had strong discriminatory ability with an area under the curve of 0.82. That is, given two patients, one of whom underwent assessment and the other did not, the model will give a higher risk score to the patient who underwent assessment approximately 82 per cent of the time.

**Figure 3.15: Characteristics associated with undergoing social care assessment within 90 days of cancer diagnosis (first-stage model)**



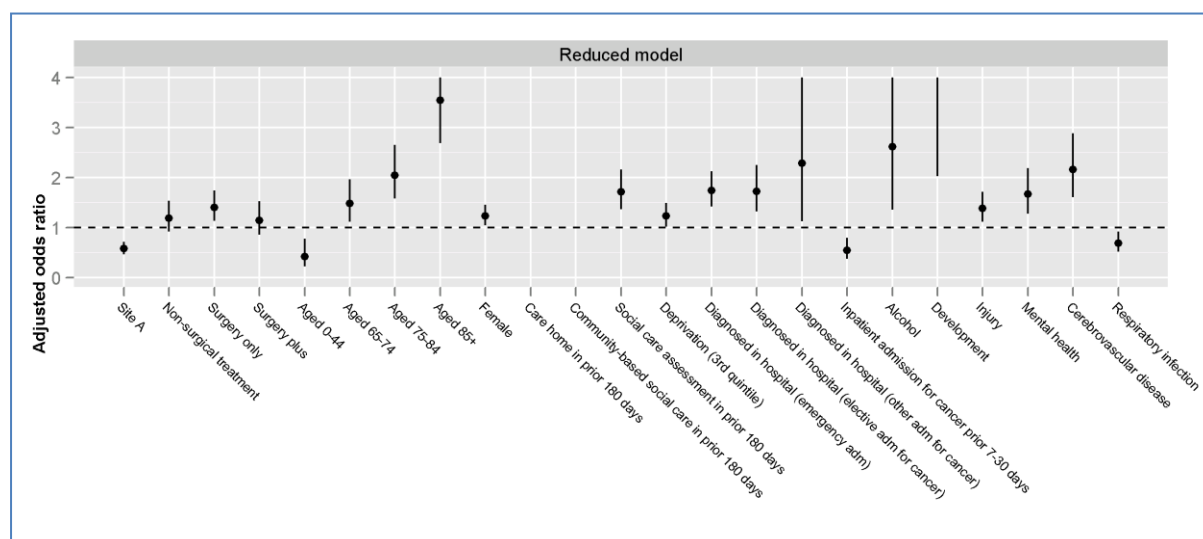
By comparison, fewer variables were identified that were predictive of social care service use, conditional on having undergone assessment (the second-stage model):

- The characteristics most associated with social care use related to prior social care use. Odds ratios are not shown in the Figure because of the different scale: 52.5 for care homes (95 per cent confidence interval 36.2, 76.1); 26.1 for community-based social care (19.9, 34.3). Prior social care assessment was also positively associated with social care use after diagnosis.



- People with cancer in site A were less likely to receive a service conditional on assessment, even though they were more likely to undergo an assessment in the first place.
- Age and being female were associated with social care use, but there was no strong association with a practice-level deprivation score.
- There were no significant differences in social care use by cancer type, over and above those described for assessments.
- Patients with certain comorbidities (alcohol use, developmental disorders, injuries, mental health conditions, cerebrovascular disease and respiratory infection) were more likely to use social care conditional on the other factors. Respiratory infection was negatively associated.
- Diagnosis in hospital after emergency admission was associated with social care use, as well as diagnosis during ‘other’ admission with a diagnosis of cancer.
- Prior diagnosis of cancer on hospital datasets was negatively associated with social care use.

**Figure 3.16: Characteristics associated with use of social care within 180 days of cancer diagnosis, conditional on having received an assessment within 90 days (second-stage model)**

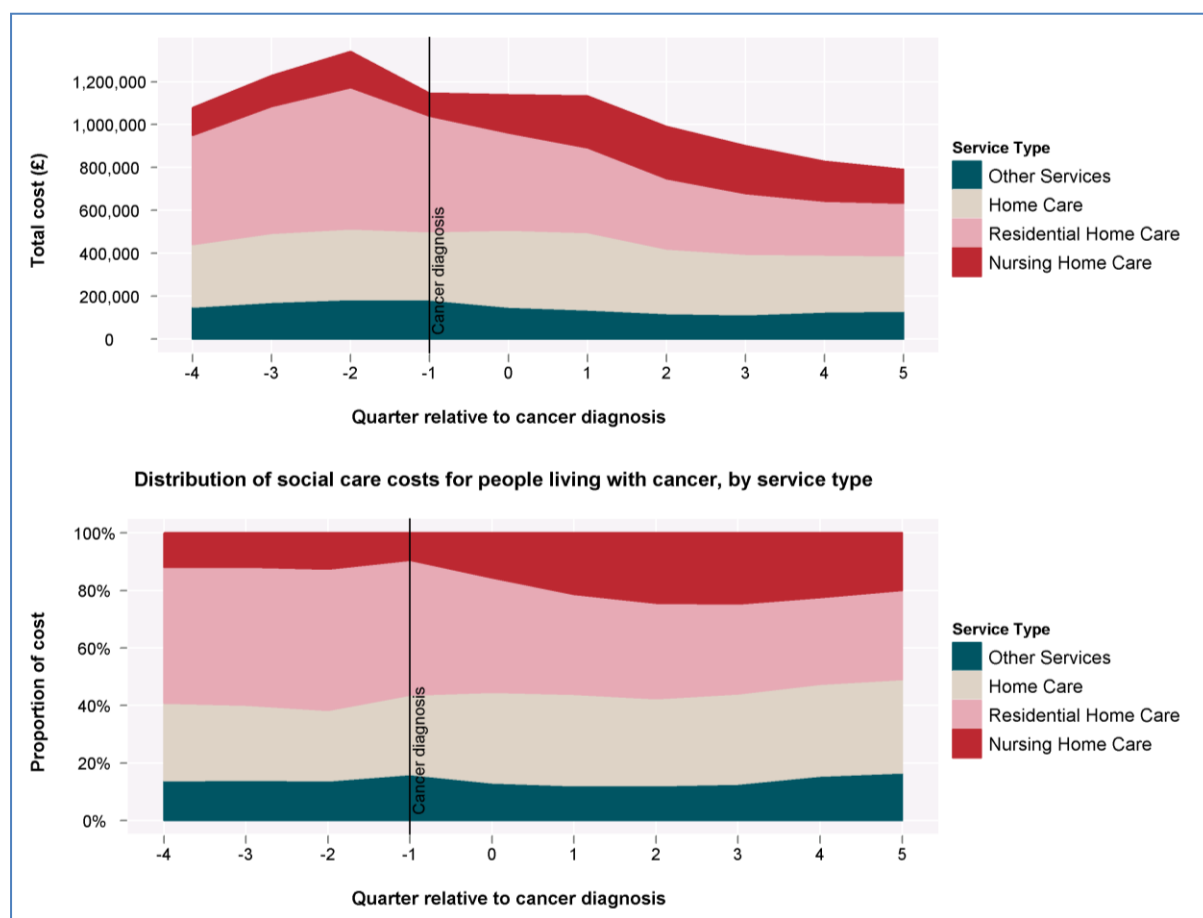


*What were the costs of social care for those living with cancer?*

In total, the notional cost of local authority funded social care for people diagnosed with cancer, covering a year before diagnosis and up to 18 months after, was more than £10,580,000. Of this, 45 per cent was spent in the year before diagnosis. Of the cost of social care after diagnosis, 71 per cent was accounted for by activity in the first 12 months. Costs of social care peaked around three months before diagnosis, and then gradually fell to £800,000 18 months after diagnosis. It is notable that while the number of people with cancer receiving social care peaked after diagnosis (see Figure 3.4), there was not a similar rise in costs.

A breakdown of social care costs by service type (see Figure 3.17) shows that nearly half of the costs in the year before diagnosis were due to residential care homes. However, after diagnosis the proportion accounted for by residential care fell to around a third of the total, while the proportion spent on nursing home care rose to over 20 per cent.

**Figure 3.17: Costs of social care for people living with cancer, by service type**

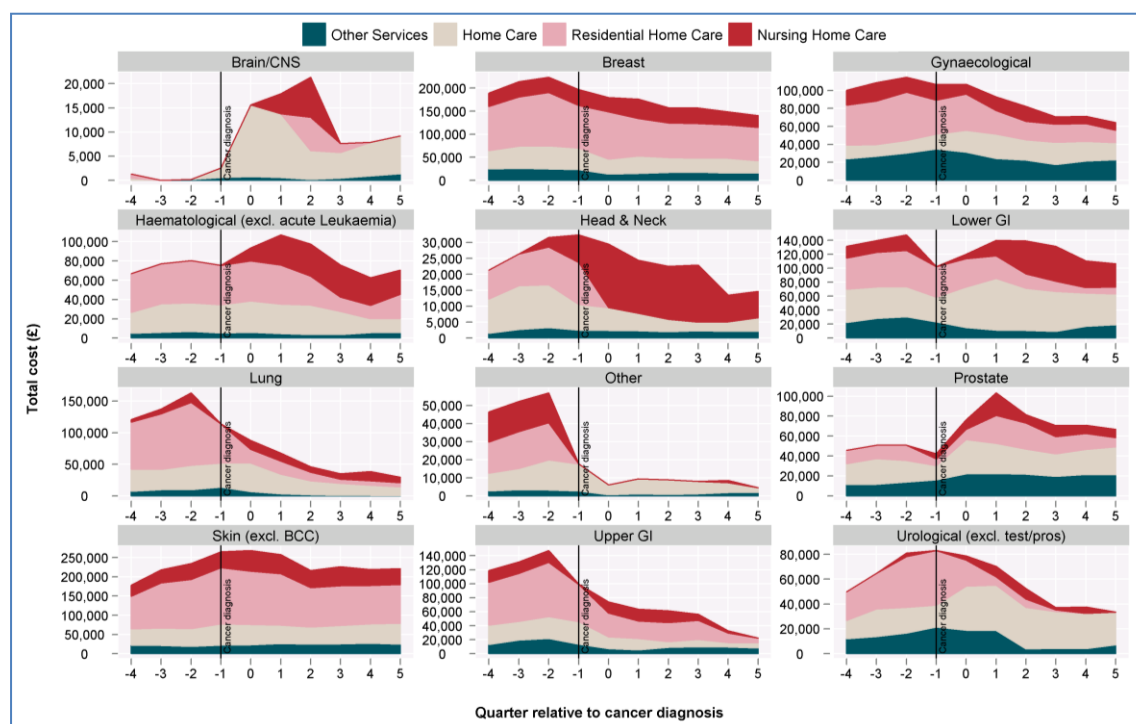


It is clear that the bulk of the decline in costs over time is explained by a fall in spending on residential care. As the unit costs can be thought of as a weighted activity measure, it is clear that this represents a fall in use of residential care. Both home care and nursing care showed a rise in costs after diagnosis, indicating greater usage. However, the rise in home care costs (13 per cent) in the three months after diagnosis was noticeably less than the 32 per cent increase in the number of people who used home care in that period (Figure 3.6). This suggests that many of these people may have used home care for relatively short periods, therefore not incurring high costs.

Of the total social care cost, 22 per cent was accounted for by people diagnosed with skin cancer, while 17 per cent was accounted for by those with breast cancer. For patients with skin, breast, lung or upper GI cancer, residential care accounted for nearly half of the social care costs over the whole period.

Figure 3.18 shows the total cost of social care for people living with cancer, by cancer and service type over time. This shows some very interesting patterns. For several cancers, for example, head and neck, lung, upper GI and urological cancers, the amount spent on residential care fell very rapidly in the months after diagnosis. For head and neck cancer there was an interesting cost shift from residential care to nursing care.

**Figure 3.18: Total cost of social care for people with cancer, by cancer and service type**



Earlier we showed that the number of people receiving local authority funded social care increased sharply after receipt of a cancer diagnosis. Figure 3.19 shows the average cost of social care per person with cancer who received some sort of service (excluding assessments) in each quarter, by service type. The split by service type should be interpreted with caution as the denominator is the number, by cancer type, who received *any* service in the quarter, as opposed to the number who received the specific service.

In contrast to the pattern seen for the number of people using services, the average cost per user declined in the quarters immediately before and after diagnosis, before increasing again. This may reflect many people receiving low-cost services such as equipment and adaptations. However, it may also reflect people in residential and nursing care being discharged if they were admitted to hospital for diagnosis or treatment, and therefore not incurring care costs. Looking at the data for selected cancer types, it is notable that the decline in average cost around the time of diagnosis is particularly marked for those with upper and lower GI cancers.

**Figure 3.19: Average cost of social care per person with cancer who used services, by service type**

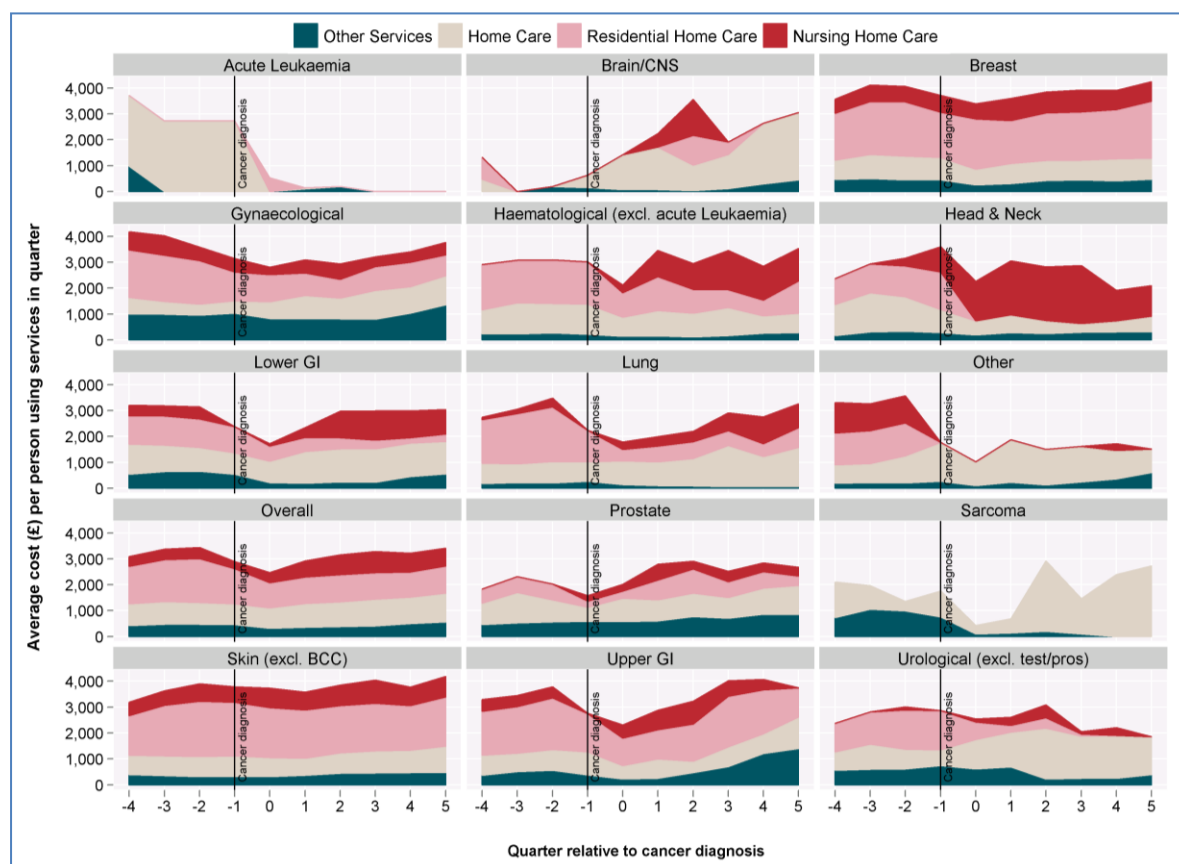
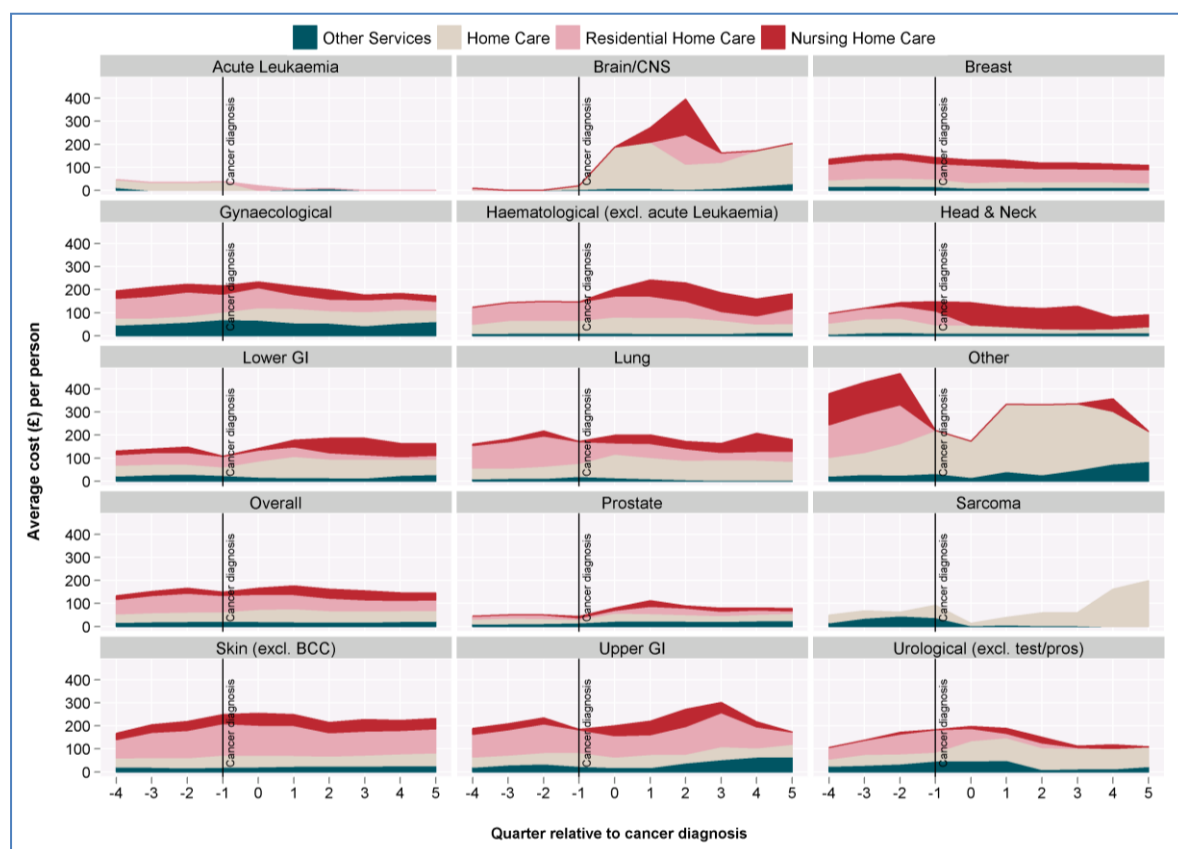


Figure 3.20 shows the average cost of local authority funded social care per person living with cancer (regardless of whether or not they received social care). The average cost was very stable, varying from £140 to £180 per quarter. There was some variation by cancer type, with those diagnosed in the 'other' category being relatively expensive, along with people diagnosed with skin and upper GI cancers. Conversely, the average cost for those with prostate or breast cancer was lower.

**Figure 3.20: Average cost of social care per person with cancer, by service type**



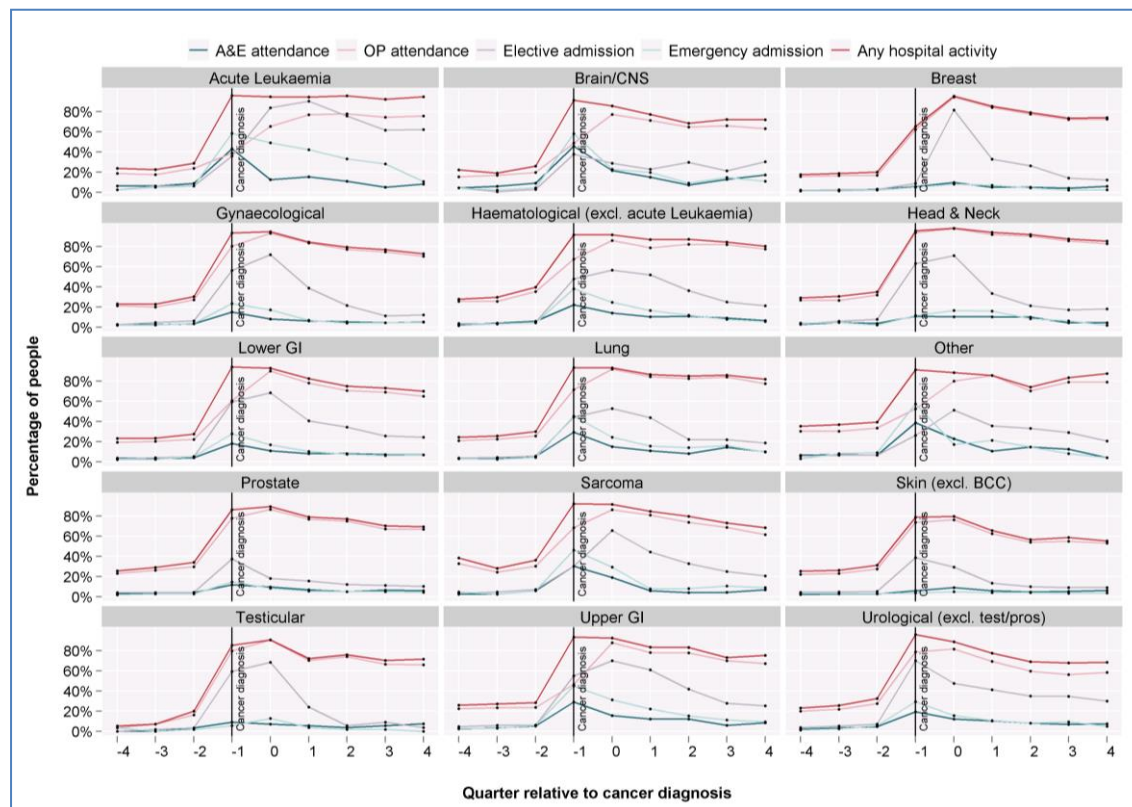
## Hospital care

*What was the level of hospital activity by people diagnosed with cancer? How did this compare with others in the population?*

It is clearly very likely that being diagnosed with cancer will lead to increased hospital activity. However, hospital use before and after formal diagnosis is likely to be influenced by a range of factors, such as the route to diagnosis, age, cancer type and treatment.

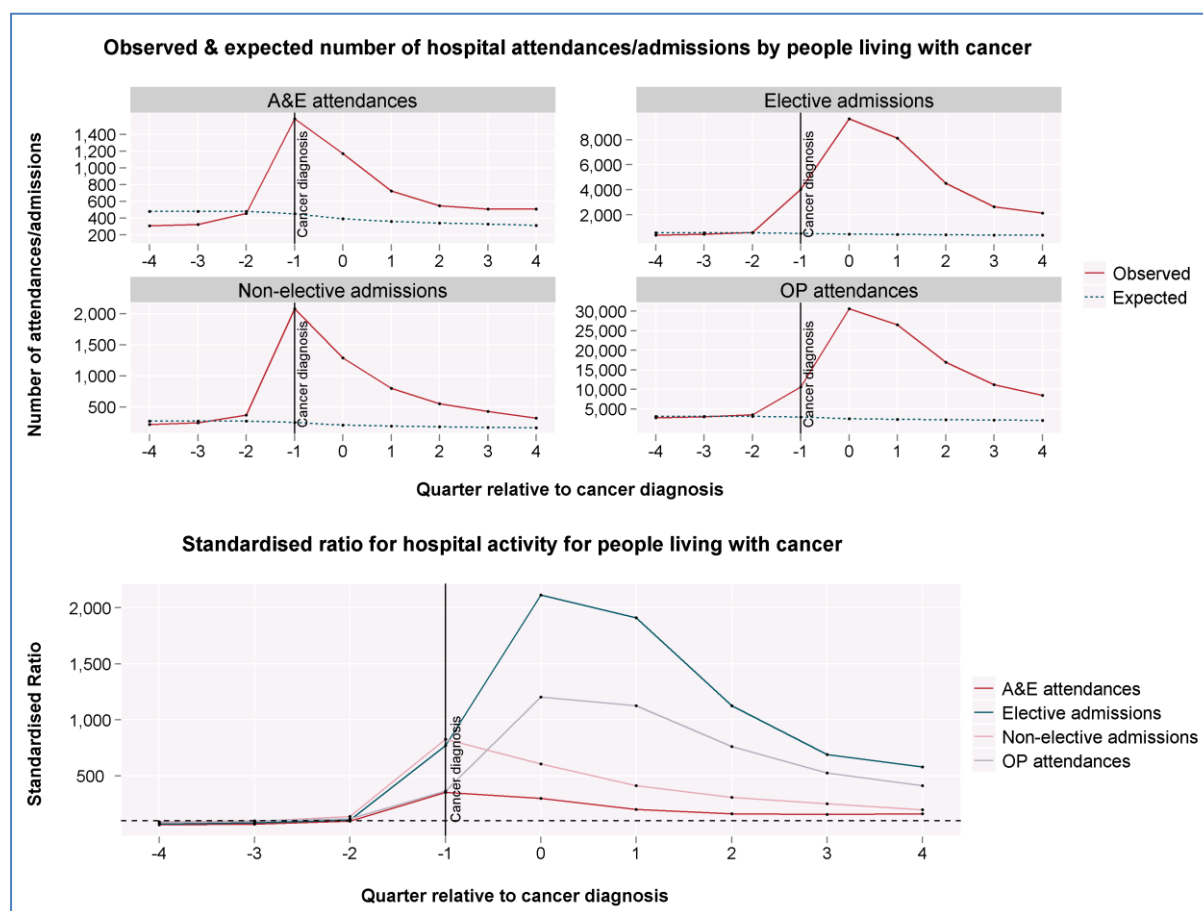
Figure 3.21 shows the percentage of people with cancer who used hospital care in each three-month period, by cancer type. Results are only shown up to 15 months (five quarters) after diagnosis to ensure equal coverage of all individuals. There was some variation between cancer types, with higher levels of pre-diagnosis use for those with 'other' cancers (predominantly cancer of unknown primary – CUP) and sarcomas. Over 90 per cent of those with acute leukaemia continued to have hospital care up to 15 months after diagnosis, while for other cancers, for example testicular, prostate and urological cancers, the corresponding figure was around 70 per cent, and for skin cancer it was just over 50 per cent.

**Figure 3.21: Percentage of people with cancer who used hospital care, by cancer type**



One would expect that the level of hospital activity after diagnosis for people with cancer would be significantly higher than for the wider population. Figure 3.22 plots observed and expected numbers of hospital attendances and admissions for those diagnosed with cancer (OP = Outpatients). The expected figures were standardised as set out earlier and, as with all analyses presented here, both observed and expected figures exclude activity in the quarter in which a person died. It should be noted that we included regular day attendees in elective admissions – it is likely that this is how attendances for the administration of chemotherapy were recorded in some trusts.

**Figure 3.22: Standardised use of hospital care among people with cancer, by activity type**



Hospital activity in the three to 12 months before diagnosis was in line with the wider population, with the exception of A&E attendances, where use was noticeably lower than expected. Both A&E and emergency (non-elective) admissions peaked in the quarter leading up to diagnosis. Elective and outpatient activity rose sharply leading up to diagnosis, and peaked in the three months after.

There were huge spikes in use of A&E and emergency admissions in the three months before diagnosis. Elective and outpatient activity also rose at this point, although to a much lesser degree; their activity peaked in the quarter following diagnosis. Use of all types of hospital care remained significantly higher than expected up to 15 months after diagnosis, with 60 per cent more A&E attendances than expected, and more than five times as many elective admissions.

*Did hospital use vary by cancer type?*

It is likely that the pattern of hospital use differs significantly between cancer types. This might be due to a number of factors such as how people are initially diagnosed (e.g. GP referrals/population screening versus patients presenting at A&E) and the nature of treatment.

Figures 3.23 to 3.26 plot observed and expected levels of hospital activity, by cancer type.



Figure 3.23: Observed and expected A&E attendances for people with cancer

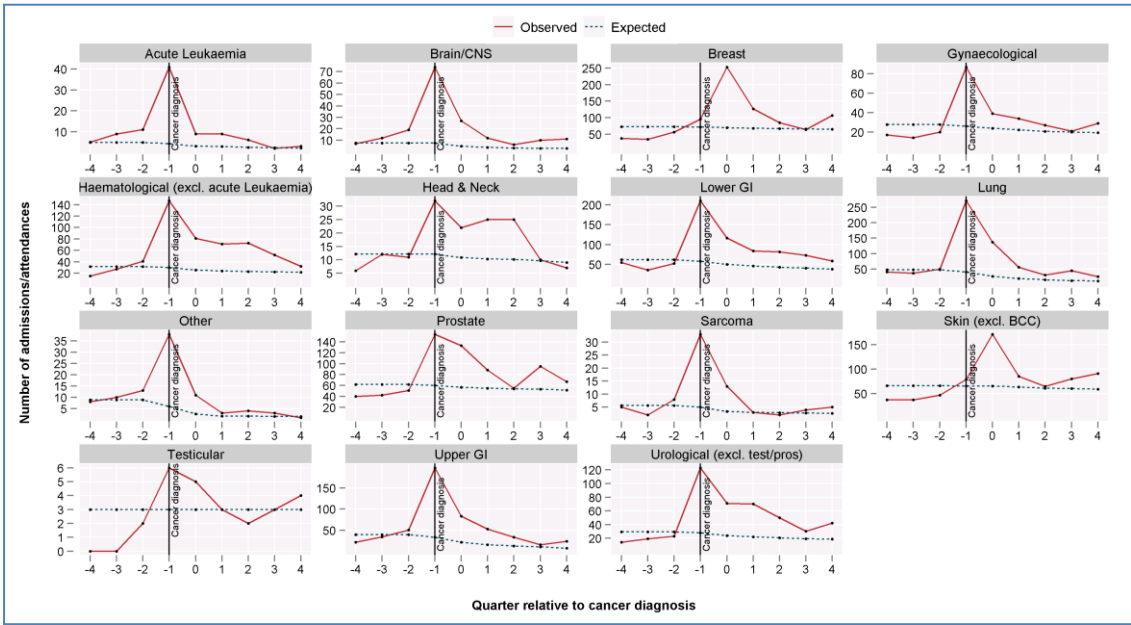
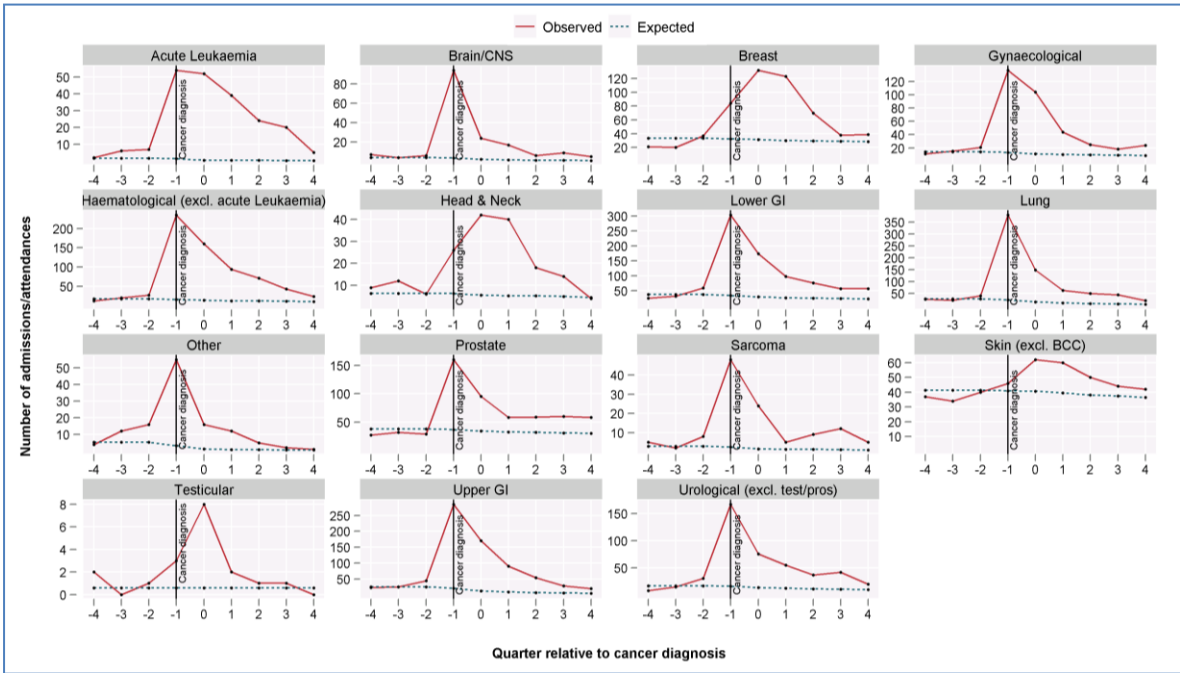
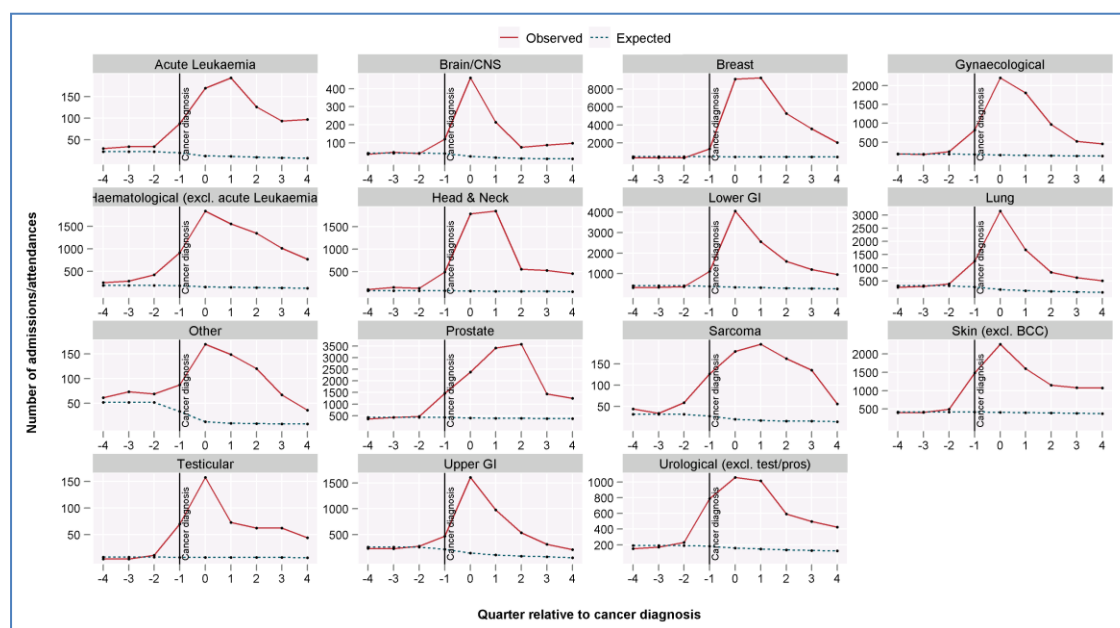


Figure 3.24: Observed and expected emergency admissions for people with cancer

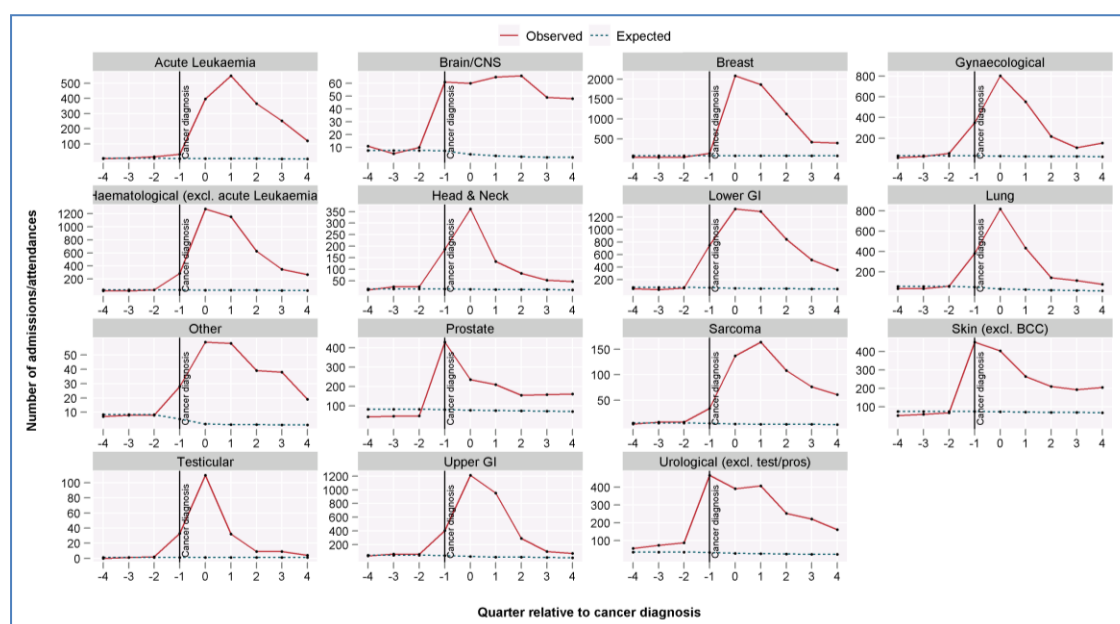




**Figure 3.25: Observed and expected outpatient attendances for people with cancer**



**Figure 3.26: Observed and expected elective admissions for people with cancer**



For most cancers, A&E attendances peaked in the quarter before diagnosis. The exceptions were breast and skin cancers where the rates peaked in the three months after diagnosis.

Unsurprisingly the pattern was very similar for emergency admissions. However, for some cancer types, for example acute leukaemia, breast, skin, and head and neck cancers, emergency admissions either peaked after diagnosis or were consistently high over the six months straddling diagnosis. The high rates after diagnosis may reflect admissions due to complications of cancer treatment.

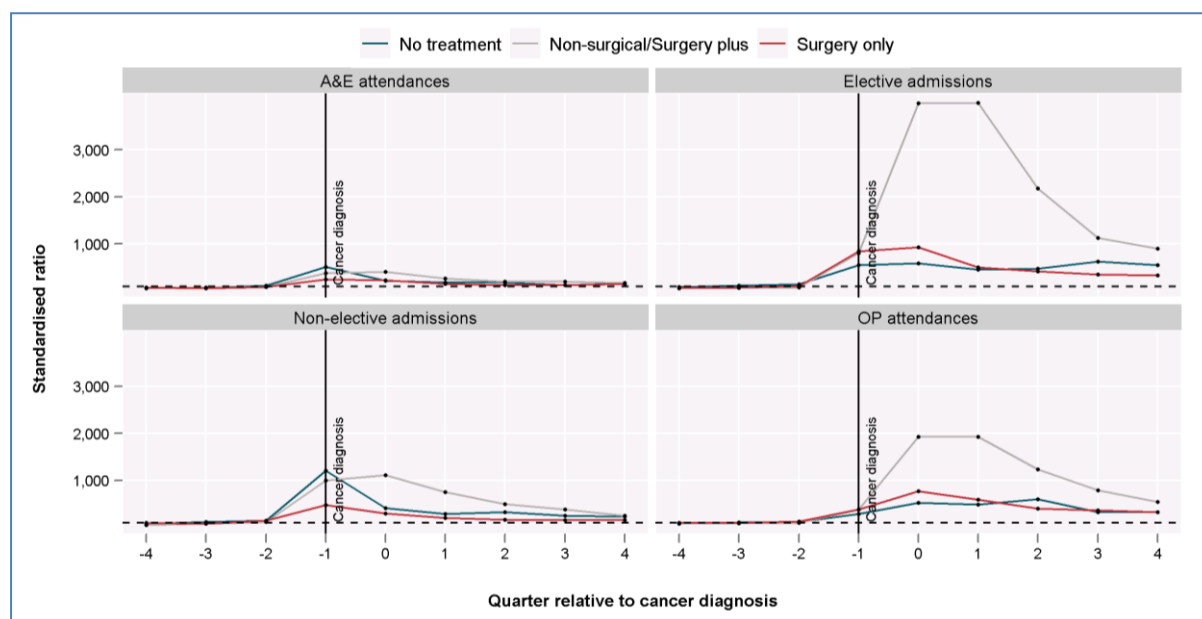
For most cancer types, elective admissions and outpatient attendances peaked in the three months after diagnosis. It is interesting that for some cancers, for example brain/CNS, sarcoma and urological cancers, elective admissions remained at a high level 15 months after diagnosis.

#### *How did type of treatment affect hospital use?*

As with social care use, we were interested in the extent to which the use of hospital care varied by the type of cancer treatment received (if any). One might expect that people receiving chemotherapy and/or radiotherapy would have significantly higher levels of hospital contact than those who only had surgery.

Figure 3.27 plots the standardised ratios (observed/expected\*100) for inpatient, outpatient and A&E activity. A ratio of 100 indicates hospital use in line with expectation. Those who did not receive active treatment had the highest standardised ratio for both A&E attendances and non-elective admissions in the three months leading up to diagnosis. Those who only had surgery had peaks in elective and outpatient activity in the three months after diagnosis, although their usage was still significantly higher than expected more than a year after diagnosis. Those who had some form of non-surgical treatment (alone or in addition to surgery) had the highest level of inpatient and outpatient activity. Interestingly, their emergency (non-elective) admissions and A&E attendances had fallen by 15 months after diagnosis to similar levels to the other treatment groups, while their planned activity remained significantly higher.

**Figure 3.27: Standardised ratios for hospital care among people with cancer, by activity type**

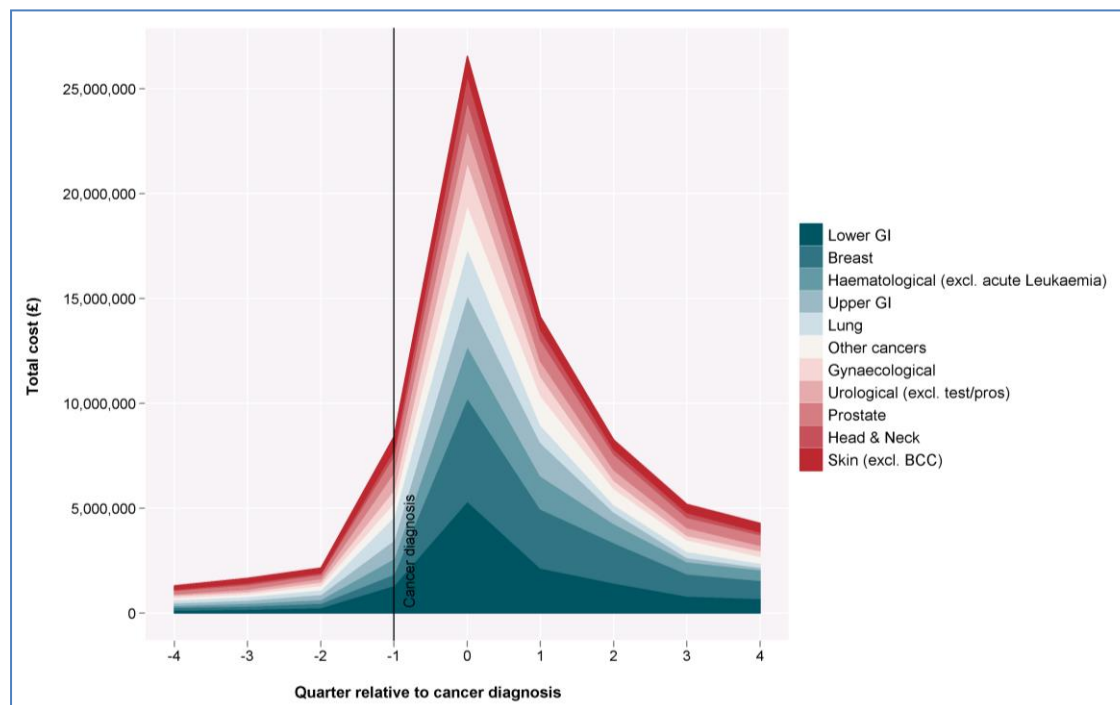


#### *What were the costs of hospital care for people living with cancer?*

The notional cost of hospital care (excluding activity around death) for people living with cancer was more than £72 million for the period covering one year before diagnosis and up to 15 months after diagnosis. Figure 3.28 shows that people with breast or lower GI cancer accounted for the largest share of costs, representing 18 per cent and 17 per cent of the total respectively. Overall, 81 per cent of hospital costs were incurred in the period after diagnosis; however, this varied significantly by cancer type. For people with breast cancer, less than ten per cent of the

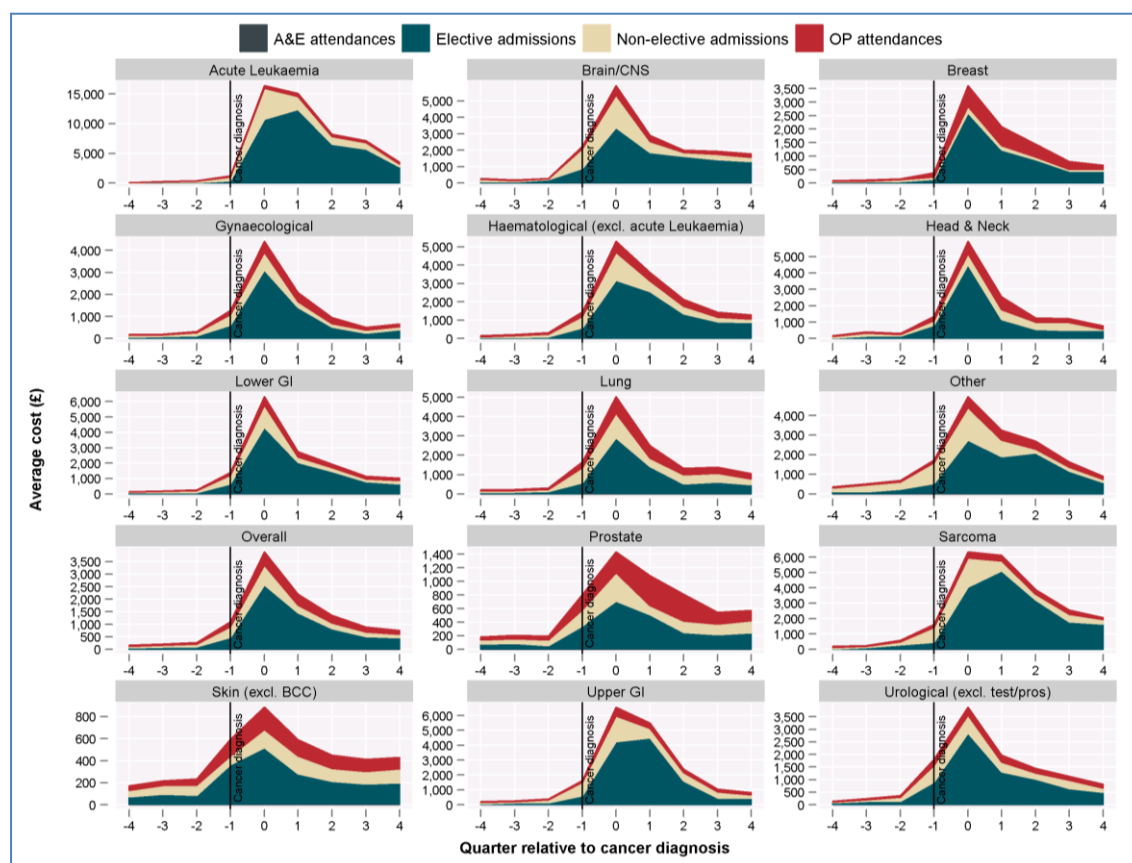
total hospital cost was accumulated before diagnosis. Conversely, around 30 per cent of the cost of hospital care for those with lung or skin cancer was due to activity before diagnosis.

**Figure 3.28: Total cost of hospital care for people with cancer (excluding activity at the end of life), by cancer type**



Unsurprisingly, the average cost of hospital care per person varied significantly between cancers, as did the expenditure on different types of care. Patients with acute leukaemia were by a wide margin the most expensive in terms of hospital care, peaking at around £12,000 per person per quarter in the six months after diagnosis. At the other end of the spectrum, those with skin or prostate cancer had relatively low hospital costs, peaking at £800 and £1,100 pounds respectively. For some cancers, for example haematological neoplasms, brain/CNS, lung, 'other' and sarcomas, a relatively high proportion of expenditure was accounted for by emergency admissions. Conversely, for those with prostate, skin or breast cancer, outpatient activity made up a much larger share of the average expenditure (see Figure 3.29).

**Figure 3.29: Average cost of hospital care per person with cancer, by activity type**



*What was the relative pattern of hospital and social care costs?*

Figure 3.30 plots the average hospital and social care costs per person in the cancer cohort. It is clear that before diagnosis hospital and social care costs were very similar, but started to deviate significantly in the run-up to diagnosis. The relative lack of change in average social care costs after diagnosis is clear. Figure 3.31 shows the same data but split by cancer type. With the exceptions of acute leukaemia, prostate and skin cancers, the pattern was remarkably similar across cancers, although the actual values varied.

Figure 3.30: Average costs of hospital and social care per person living with cancer

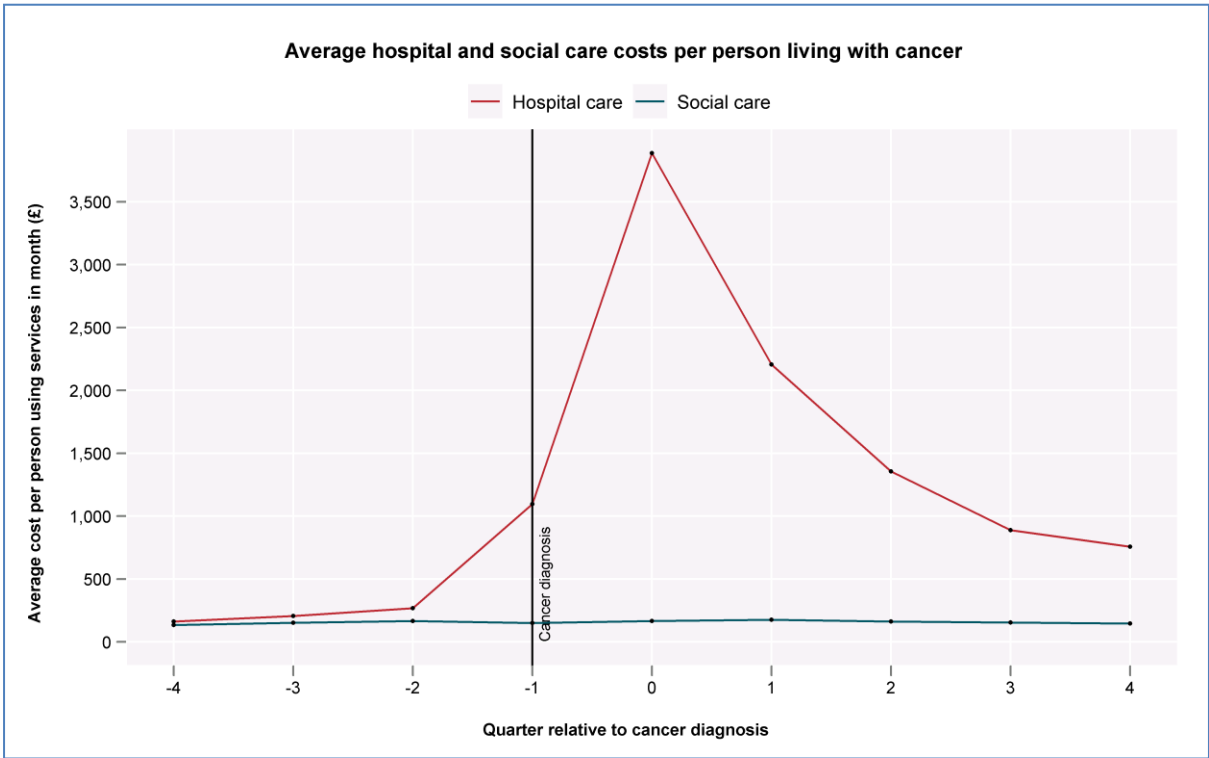
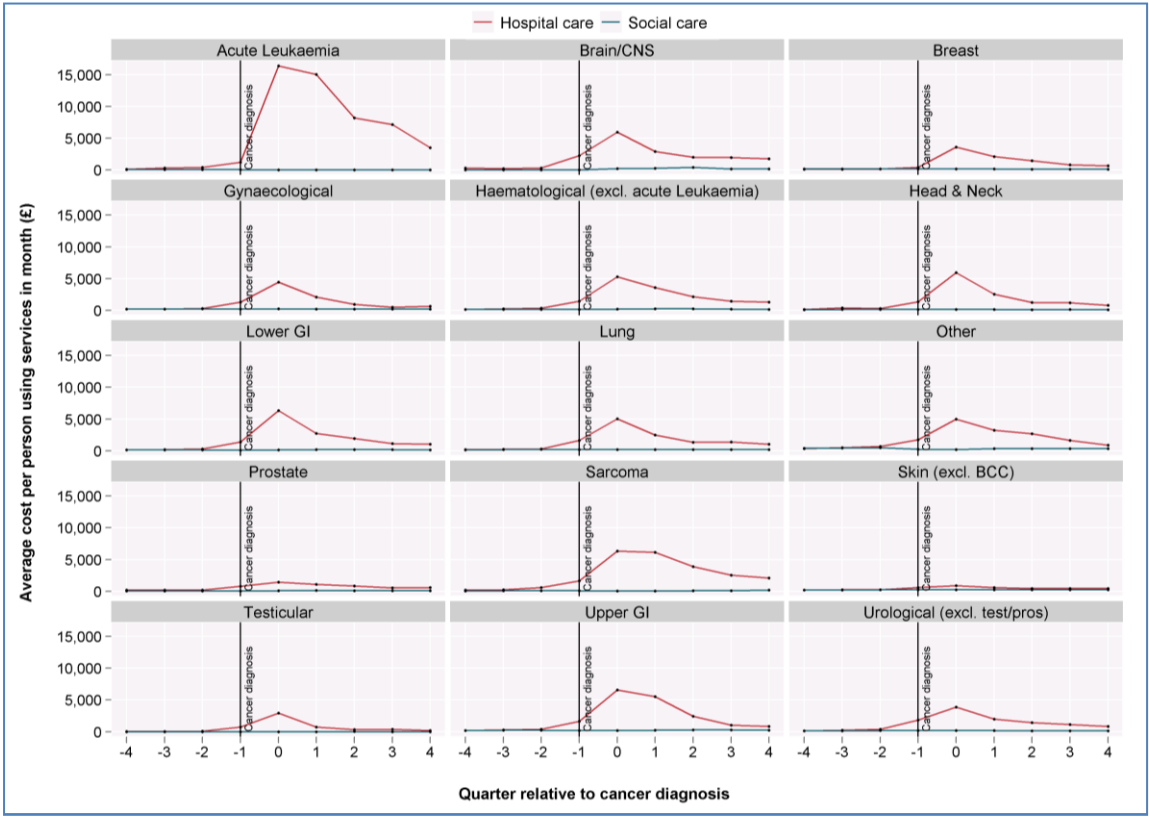


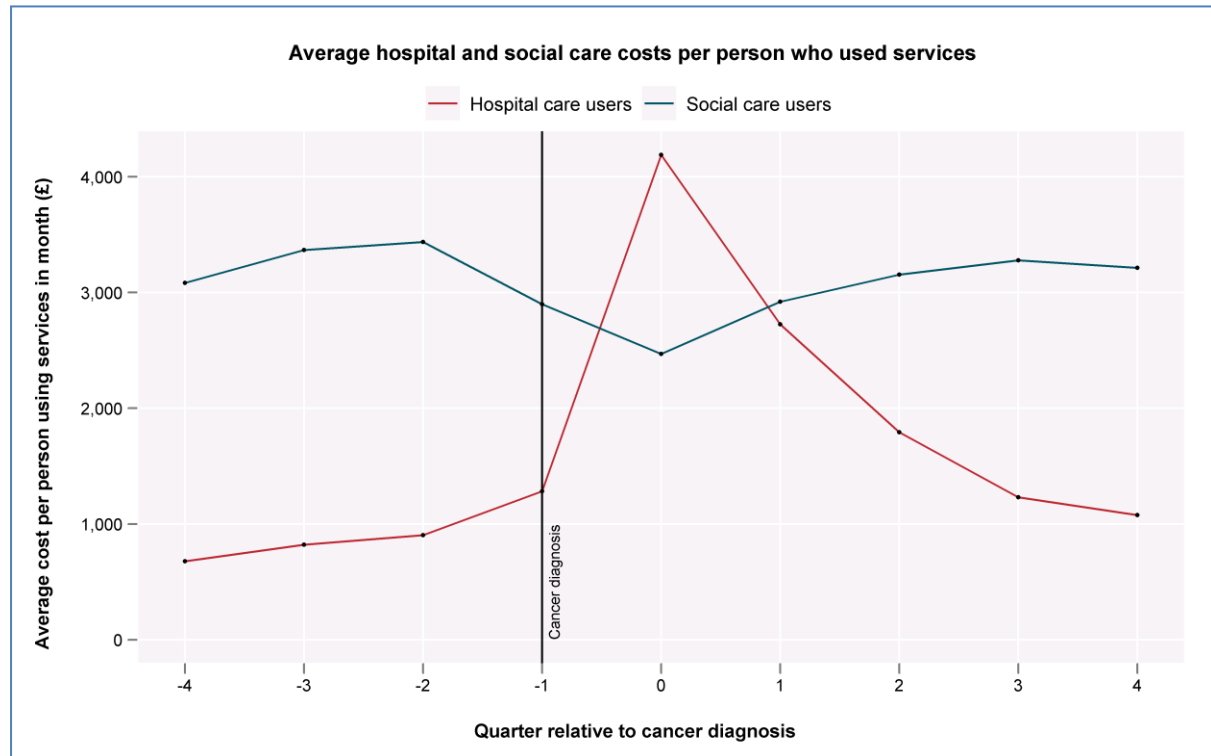
Figure 3.31: Average costs of hospital and social care per person, by cancer type



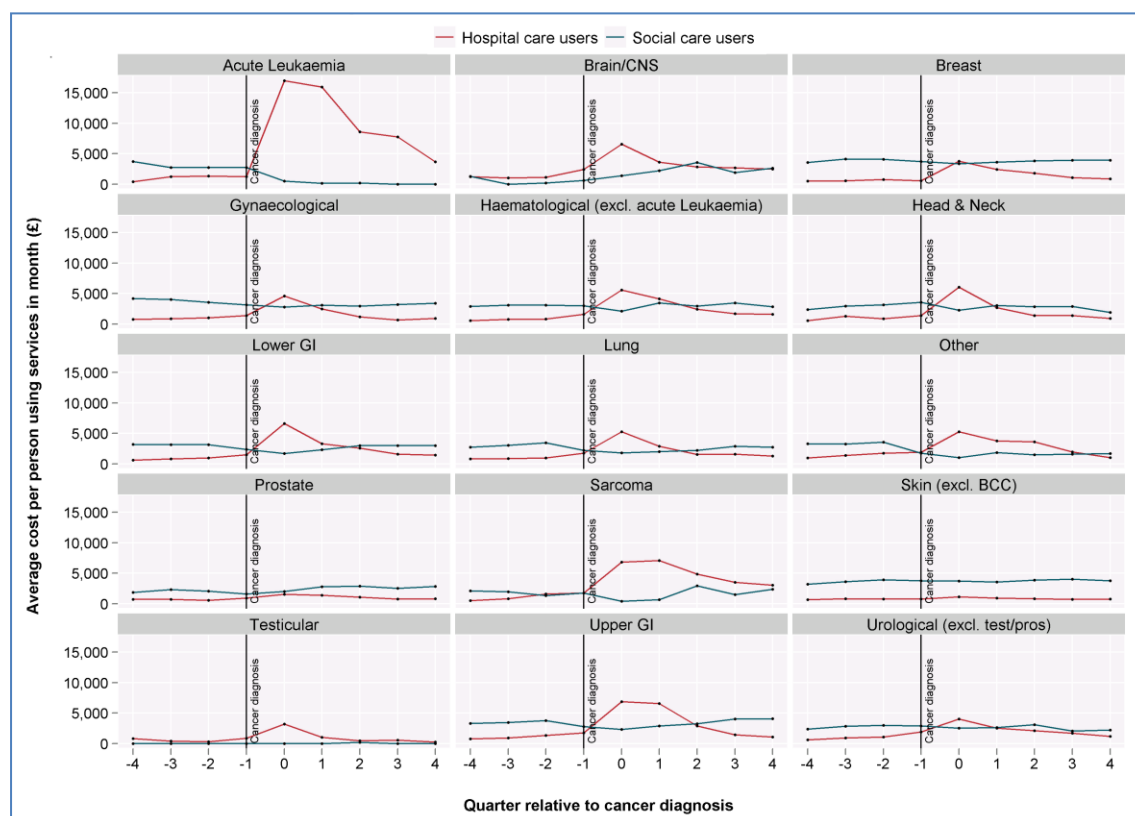
Figures 3.32 and 3.33 plot average costs for people with cancer who used services (hospital care or social care). Here the pattern is very different from that seen above. For those using social

care, their costs were much higher before diagnosis than the hospital costs of those who used secondary health services. However, the pattern changed after diagnosis, with the average costs of those using hospital care outstripping the social care costs of those receiving such services, before the original profile resumed by six months after diagnosis.

**Figure 3.32: Average costs of hospital and social care per person with cancer who used services**



**Figure 3.33: Average costs of hospital and social care per person who used services, by cancer type**



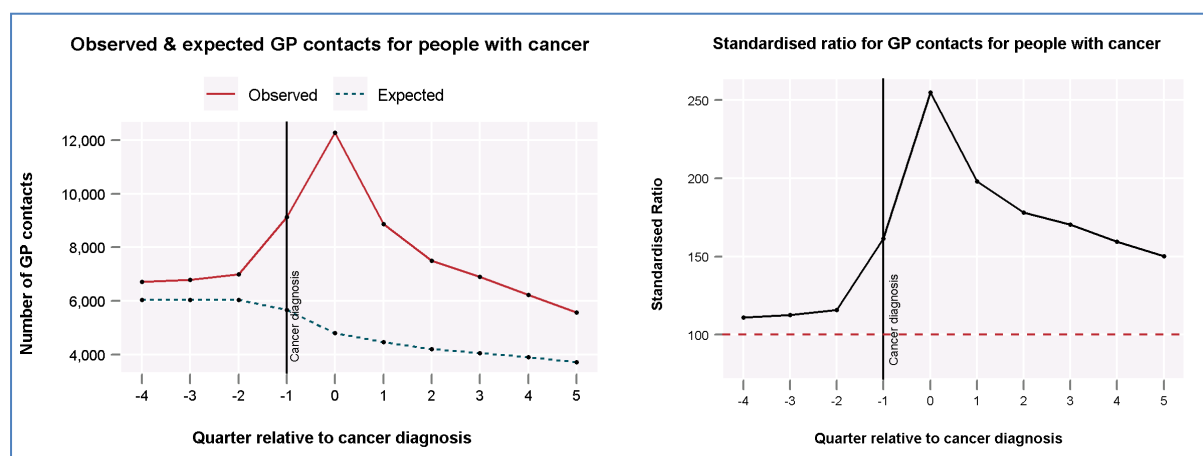
## Primary care

*To what extent did people with cancer use primary care?*

For site A, we obtained permission to use data recorded on GP practice systems. Of those people who were diagnosed with cancer, 11.4 per cent had no record of GP contact in the 12 months before their diagnosis. This is slightly higher than a recent audit by the Royal College of General Practitioners (RCGP, 2011), which found that 9.5 per cent of patients did not consult with their GP before diagnosis (counting consultations for problems linked to the patient's cancer). However, this audit was based on GP practice identification of those diagnosed with cancer. Looking at those cancers with at least 50 cases, we found that lung cancer patients were the least likely to have visited their GP (83 per cent had a record of a visit).

We calculated standardised usage rates for GP contacts as set out earlier. Figure 3.34 plots observed and expected numbers of GP contacts for people with cancer and the standardised ratio. Overall, those who went on to be diagnosed with cancer had ten per cent more GP contacts than expected up to three months before diagnosis. In the period immediately before diagnosis, the number of GP contacts increased rapidly, and this continued into the subsequent quarter. Although the number of contacts then declined, 18 months after diagnosis it remained 50 per cent above expected.

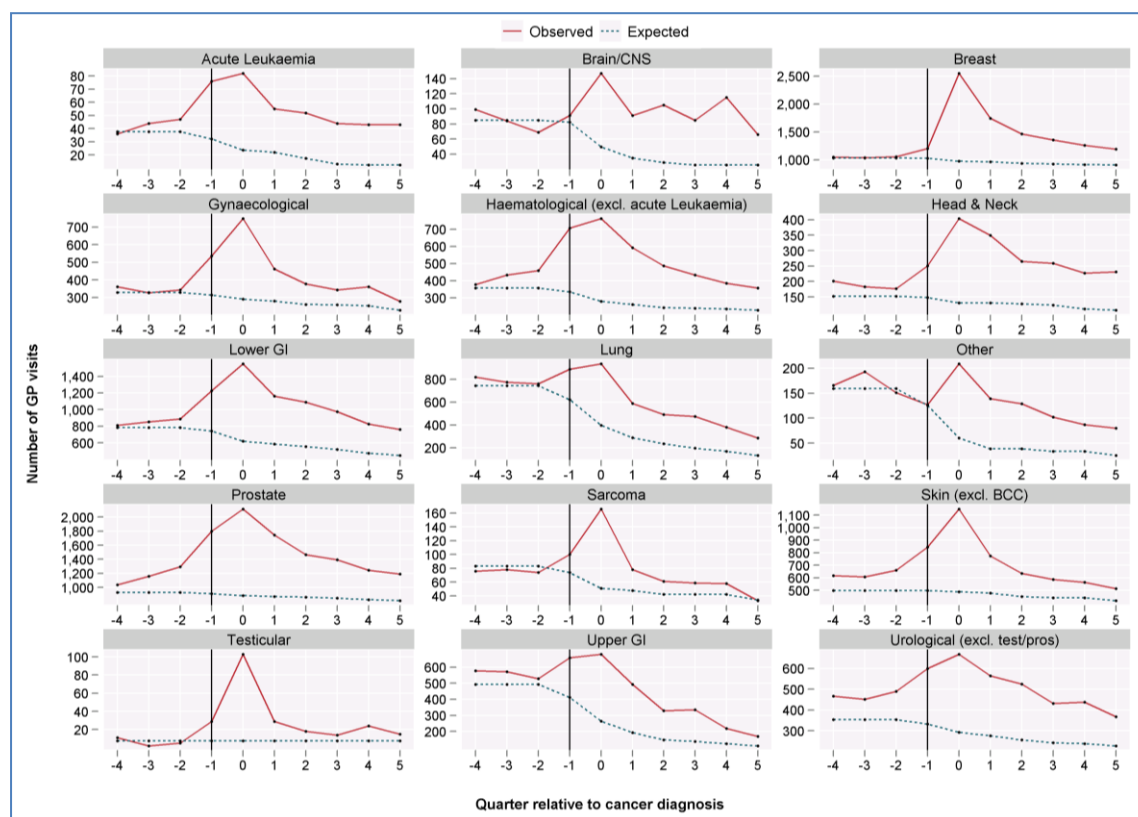
**Figure 3.34: Standardised GP activity for people with cancer**



*How did primary care usage vary by cancer type?*

Figure 3.35 plots the observed and expected figures for GP surgery visits, by cancer type. Broadly, all cancer types showed a significant increase in primary care contacts following diagnosis, although the level of increase was much smaller for upper GI and lung cancers than others.

**Figure 3.35: Observed and expected number of GP surgery visits, by cancer type**

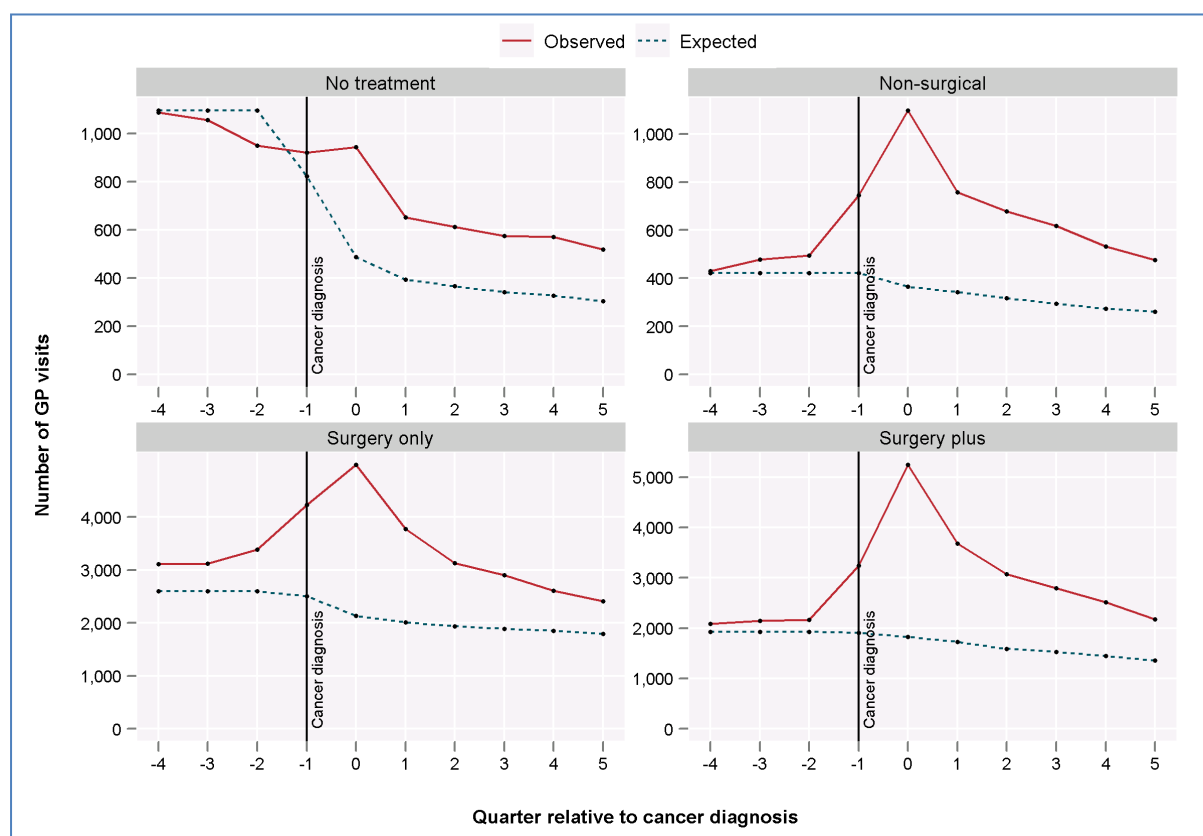




*Was primary care use affected by the type of treatment?*

We were interested in whether people's use of primary care was linked to the type of cancer treatment (if any). Figure 3.36 shows observed and expected numbers of GP surgery visits according to the type of treatment received. People receiving active treatment showed a significant increase in GP activity following diagnosis that remained higher than expected after 18 months. Interestingly, those not receiving treatment had slightly lower levels of primary care contact than expected before diagnosis, in contrast with those who went on to be treated.

**Figure 3.36: Observed and expected number of GP surgery visits, by treatment type**



## 4. Results – Part II: What was the use of health and social care by people with cancer at the end of life?

### Sample

Tables 4.1 and 4.2 show the demographic characteristics of the end of life population of the two sites, and of those in the cancer cohort. Those where cancer was mentioned as a cause of death were younger than the broader end-of-life cohort, and were more likely to be male.

**Table 4.1: Characteristics of the end-of-life population of the two sites**

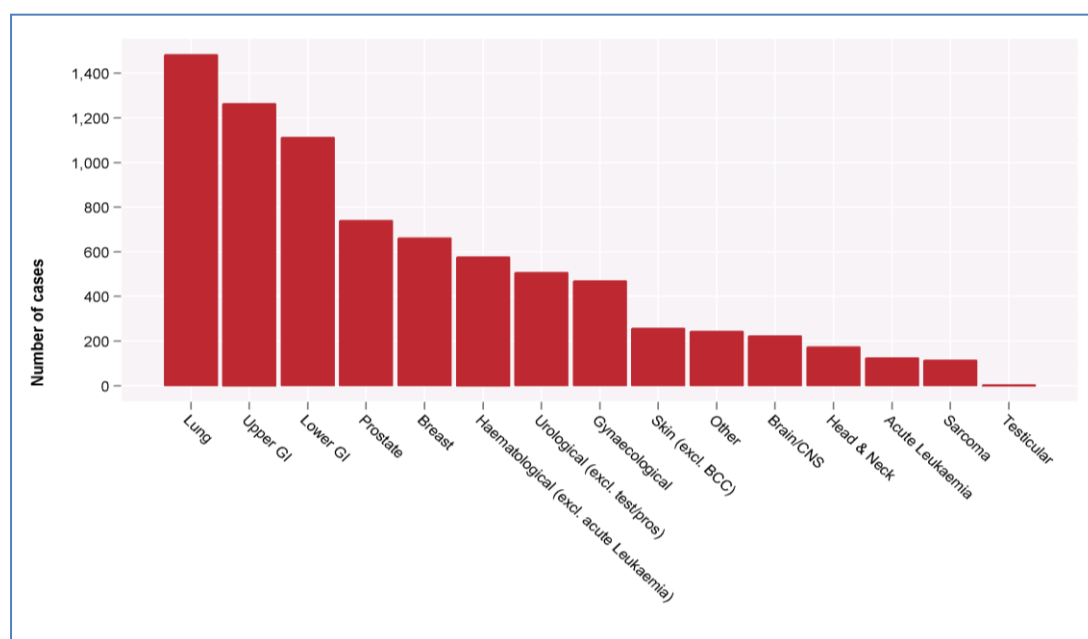
	Site A	Site B	Overall
Number of people	6,162	18,358	24,520
Mean age (SD)	77.1 (15.1)	80.1 (13.2)	79.4 (13.8)
% female	51.7%	53.0%	52.7%
GP practice deprivation (IMD)	20.9 (7.8)	17.5 (4.2)	18.3 (5.5)

**Table 4.2: Characteristics of the end-of-life cancer cohort of the two sites**

	Site A	Site B	Overall
Number of people	1,899	6,037	7,936
Mean age (SD)	73.7 (13.6)	75.6 (12.4)	75.1 (12.7)
% female	46.3%	47.3%	47.0%
GP practice deprivation (IMD)	20.7 (7.9)	17.3 (4.0)	18.1 (5.4)

Figure 4.1 shows the breakdown of the cancer cohort by cancer type. Just under half of the deaths were accounted for by people diagnosed with upper or lower GI or lung cancer.

**Figure 4.1: Number of people in the end-of-life cancer cohort, by cancer type**



On average, the cancer cohort was diagnosed 21.4 months before death (SD = 33.5). This ranged from five months for people with testicular cancer to 40 months for those with prostate cancer (see Table 4.3). It should be noted that this was calculated using the most recent diagnosis date for each person. This was to avoid using a diagnosis from many years previously. However, some people had more than one recorded cancer diagnosis.

There were significant differences in the age profile of the cancer cohort. Nearly 40 per cent of those with prostate, skin and other (predominantly metastatic) cancers were aged 85+. Those with brain/CNS, head and neck, and breast cancers tended to be younger. Overall, nearly 60 per cent of the cancer cohort was aged 75 or older.

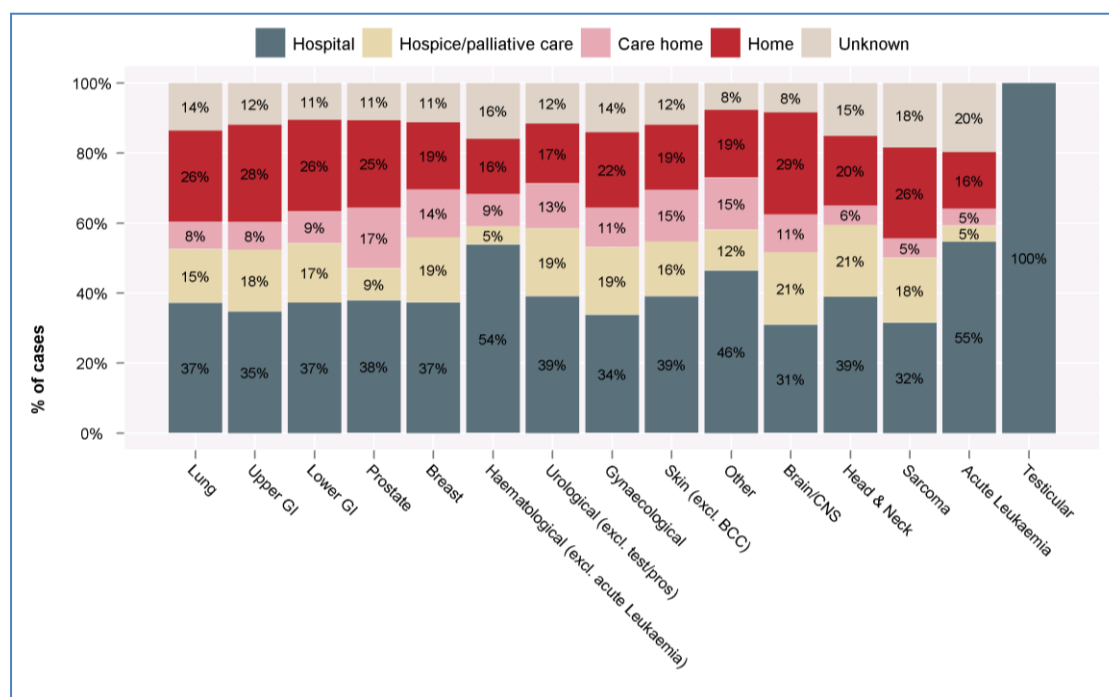
**Table 4.3: Population characteristics, by cancer type**

Cancer type	Average age (SD)	GP practice IMD (SD)	Average number of months from last diagnosis to death
Prostate	80.9 (8.8)	17.8 (5.1)	39.8 (41.3)
Skin (excluding basal cell carcinoma)	77.5 (13.7)	17.1 (4.7)	33.8 (40.5)
Other	77.4 (13.1)	18.4 (6)	5.1 (13.4)
Urological (excluding testes/prostate)	77.1 (10.6)	17.6 (5)	21.2 (33.2)
Haematological (excluding acute leukaemia)	76.4 (12.3)	17.6 (5)	30.4 (41)
Lower GI	76.3 (11.7)	17.7 (5.4)	20.4 (28.7)
Upper GI	74.7 (11.9)	18.2 (5.4)	9 (15.1)
Lung	73.8 (11.2)	18.9 (5.9)	8.3 (14.7)
Breast	73.8 (15.1)	18.2 (5.4)	53.9 (51.5)
Gynaecological	73.6 (13.1)	18.1 (5.1)	21.4 (26.7)
Head and neck	70.8 (14.2)	19.1 (5.3)	22.5 (31.4)
Acute leukaemia	70.4 (18.1)	17.9 (6.1)	12.1 (26.4)
Sarcoma	69.5 (17.3)	18 (4.7)	16 (24.8)
Brain/CNS	65 (16.8)	17.5 (5.7)	13.8 (25.9)
Testicular	52.7 (20.6)	19.2 (9.5)	5 (6.2)

## Place of death

We also had information on place of death, supplied by the cancer registry. This field was blank for 99 per cent of records in site A, but was relatively well completed in site B (only 12 per cent unknown). Therefore we only included people from site B in analyses of place of death. Overall, 38 per cent of those with cancer in site B died in hospital, 23 per cent at home, 15 per cent in a hospice or palliative care unit and only ten per cent in a care home (see Figure 4.2). People with haematological cancers were most likely to die in hospital (>50 per cent). Among the high-volume cancer types, for example GI and lung cancers, a relatively small proportion of people were recorded as having died in a care home, while a high proportion died at home. Deaths at home were also common among those with brain/CNS and prostate tumours and sarcomas. People with prostate or skin cancer were the most likely to die in a care home. This is unsurprising as these cancer groupings had the highest proportion of very elderly people.

**Figure 4.2: Place of death for the end-of-life cohort, by cancer type**



## Longitudinal trajectories

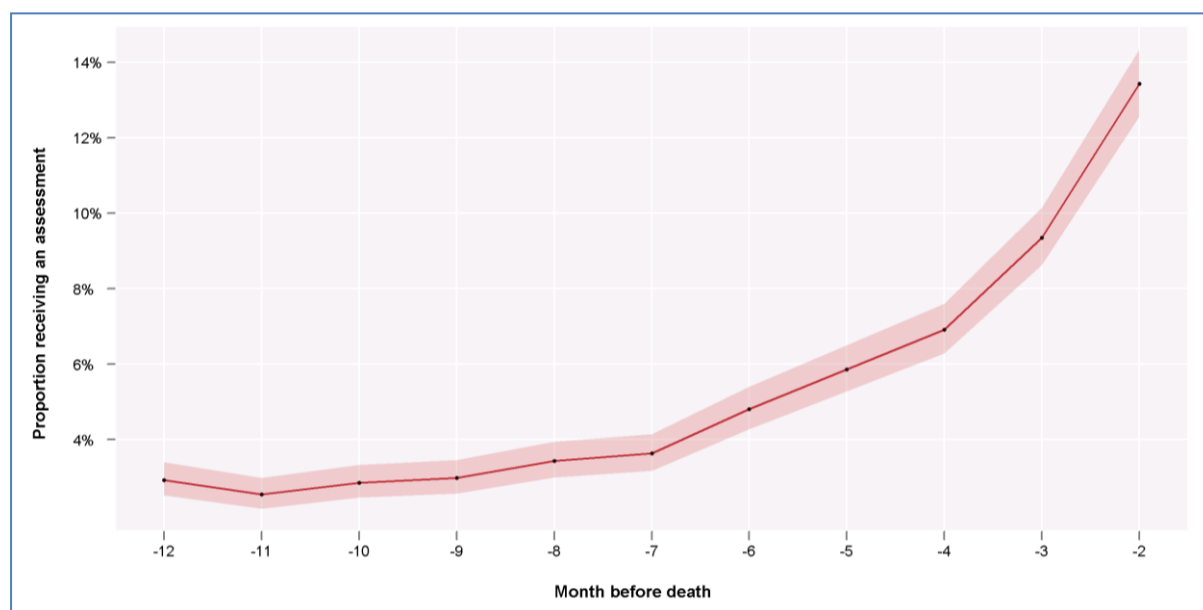
### Social care use

*How many people with cancer used social care in the final year of life? How did this vary by age and cancer type?*

Information on assessments for the last year of life was available for 5,698 people (72 per cent) in the cancer cohort. Overall, 42 per cent of those with cancer had a local authority social care assessment in the last 12 months of life. This varied from 36 per cent of those with skin cancer to 52 per cent of those with prostate cancer. Figure 4.3 shows that the rate of assessment increased sharply as death approached, growing from around three per cent of people a year before death, to over 13 per cent in the penultimate month of life.

Note in the following graphs we do not show a value for the last month of life because the data we had did not give us the precise date of death, therefore we cannot say if somebody died at the start or end of the month.

**Figure 4.3: Proportion of people with cancer who received a social care assessment in the final year of life**



Overall, 27 per cent of those in the cancer cohort used some form of social care in the final year of life. This is broadly consistent with a previous study by the Nuffield Trust (Bardsley and others, 2010), which found that 24 per cent of cancer patients used social care in the final year of life (albeit identifying cancer cases in a different way). There were significant variations in the use of social care by cancer type (see Figure 4.4), ranging from over 30 per cent for breast, testicular and prostate cases, to just over ten per cent for acute leukaemia cases. Interestingly, upper GI and lung cancer cases comprised a significant number of deaths, but were at the lower end of social care use in the final year of life.

**Figure 4.4: Use of social care by people with cancer in the final year of life, by cancer type**

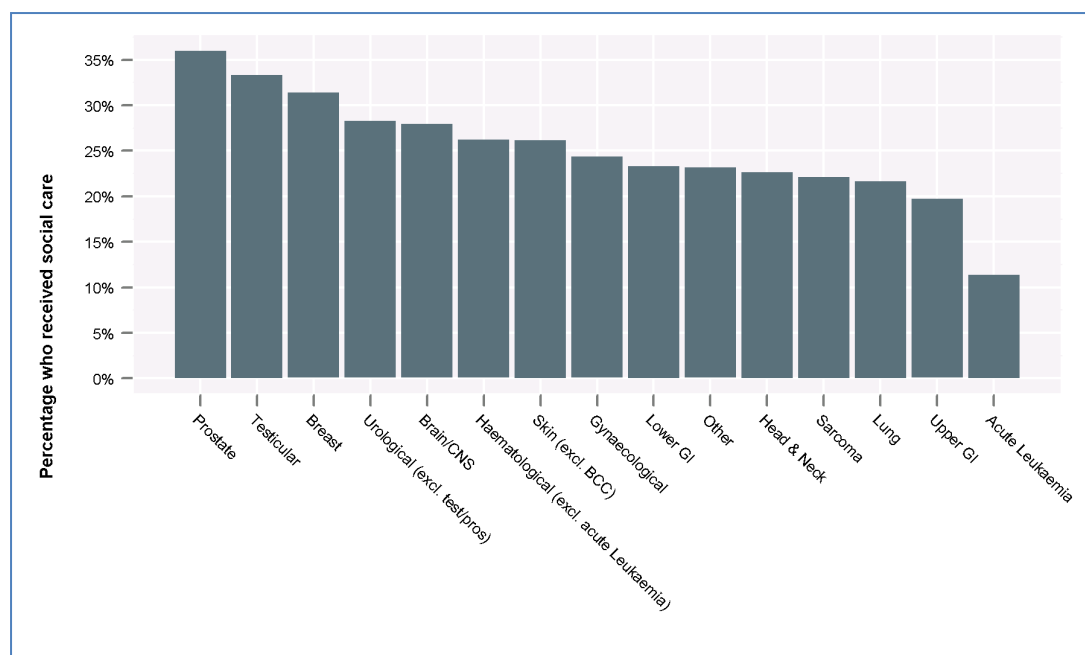
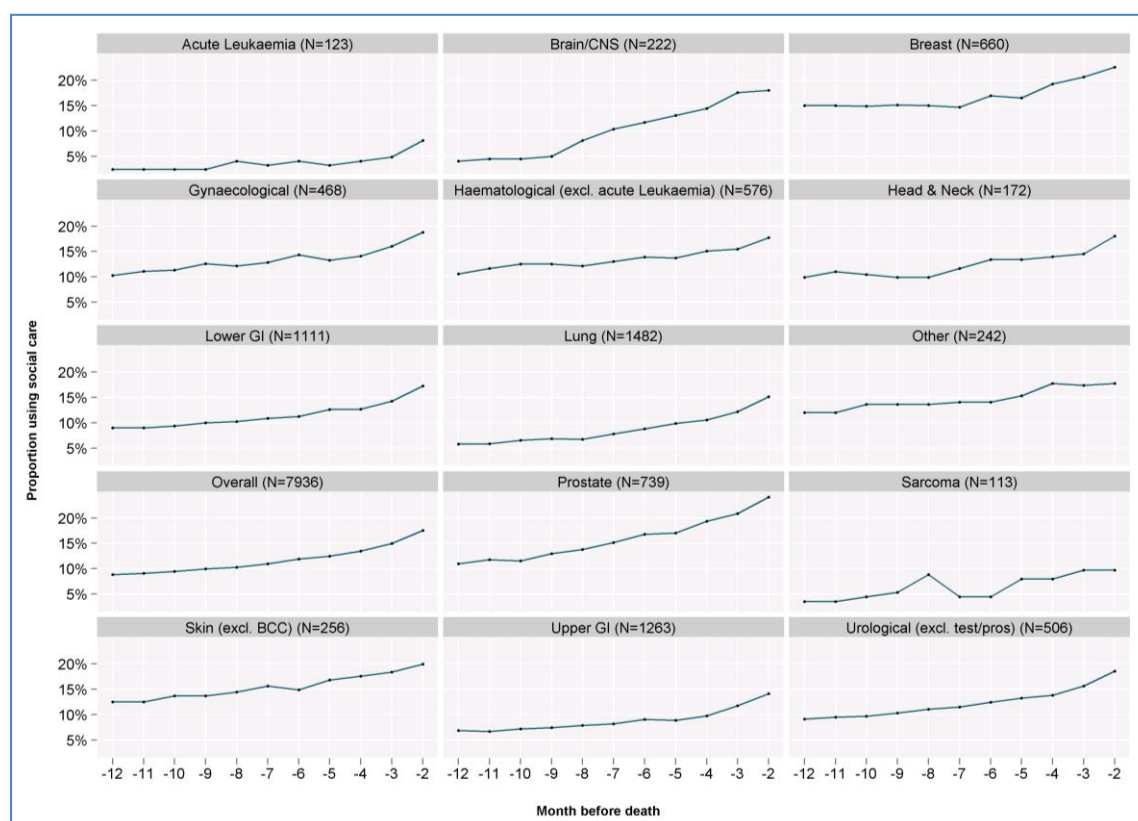


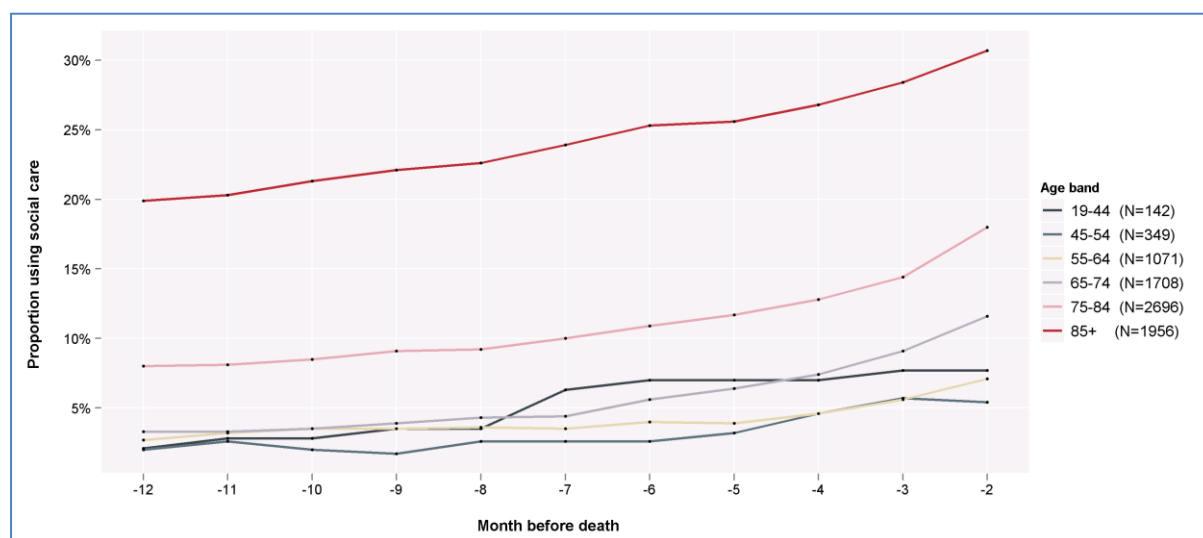
Figure 4.5 below plots the proportion of people in the cancer cohort who used social care over the final 12 months of life. Usage rose from nine per cent a year before death to over 17 per cent in the month before death. Although the number of people receiving local authority funded social care rose over the last year of life for all types of cancer, there were significant variations. The number of people with brain/CNS tumours who used social care rose rapidly over the last year from a very low base. People with breast, prostate and ‘other’ cancers generally were more likely to use social care, while those with sarcomas or acute leukaemia were the least likely. Among the high-volume cancers (in terms of numbers of deaths), the proportion of lung and upper GI cancer patients who used social care was slightly lower than for other cancers.

**Figure 4.5: Use of social care over the final 12 months of life, by cancer type**



Looking at activity by age band (see Figure 4.6), use of social care by people with cancer rose in line with age (with the exception of those aged 19–44, although there were relatively few cases in this band). More than 30 per cent of those aged 85+ were in receipt of local authority funded social care in the month before death.

**Figure 4.6: Use of social care over the final 12 months of life, by age band**



*What social care services did people with cancer use in the final year of life?*

The results above showed a clear increase in the use of social care in the final year of life by people diagnosed with cancer. Obvious questions are what services they used, and how the profile of service use changed during the final months. Figure 4.7 shows the proportion of the cancer cohort who received selected services by month over the final year of life. Use of nursing home care, meals and equipment all doubled or trebled over the course of the year, albeit from very low levels. There was an increase in use of residential care, although to a lesser degree. The use of residential and nursing care was very low, particularly compared with the usage figures that were found in the previous end-of-life study by the Nuffield Trust (Bardsley and others, 2010). We return to this later. Most notable, however, was the very sharp increase in use of home care, particularly in the final three full months of life.

The overall pattern seems to be relatively consistent across cancer types. Figure 4.8 plots of the proportion of people using selected services by cancer type. Home care was consistently the most used service, with around one in eight people with brain cancer receiving home care in the penultimate month of life. People with breast or prostate cancer were slightly more likely to use local authority funded residential and nursing home care than those with other cancer types.

Figure 4.7: Use of selected social care services by people with cancer over the final 12 months of life

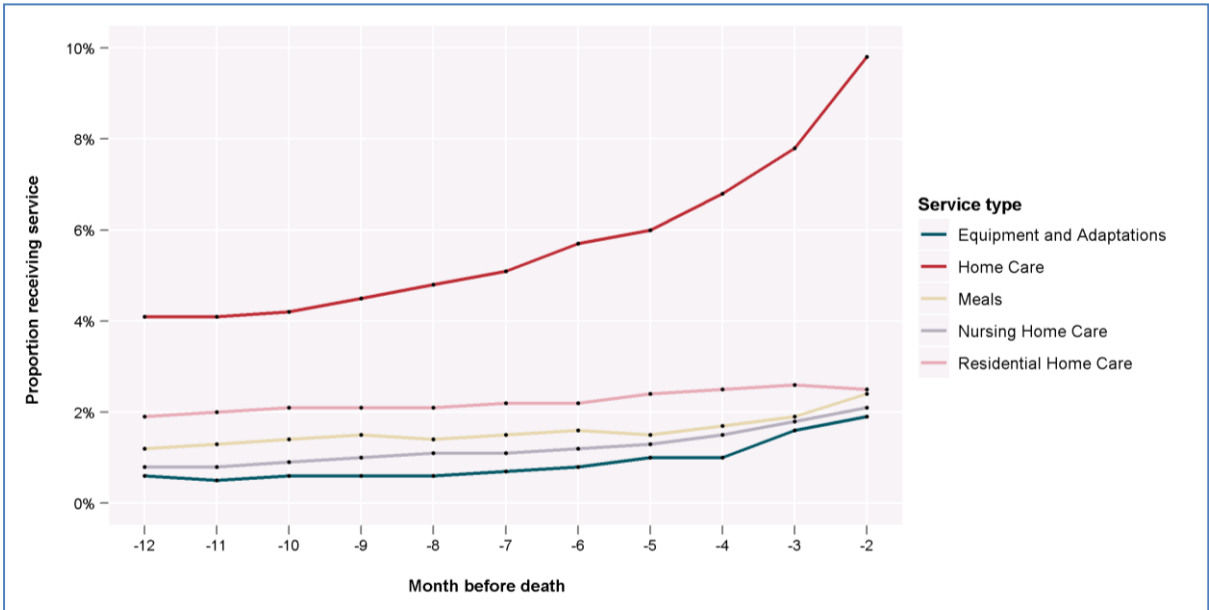
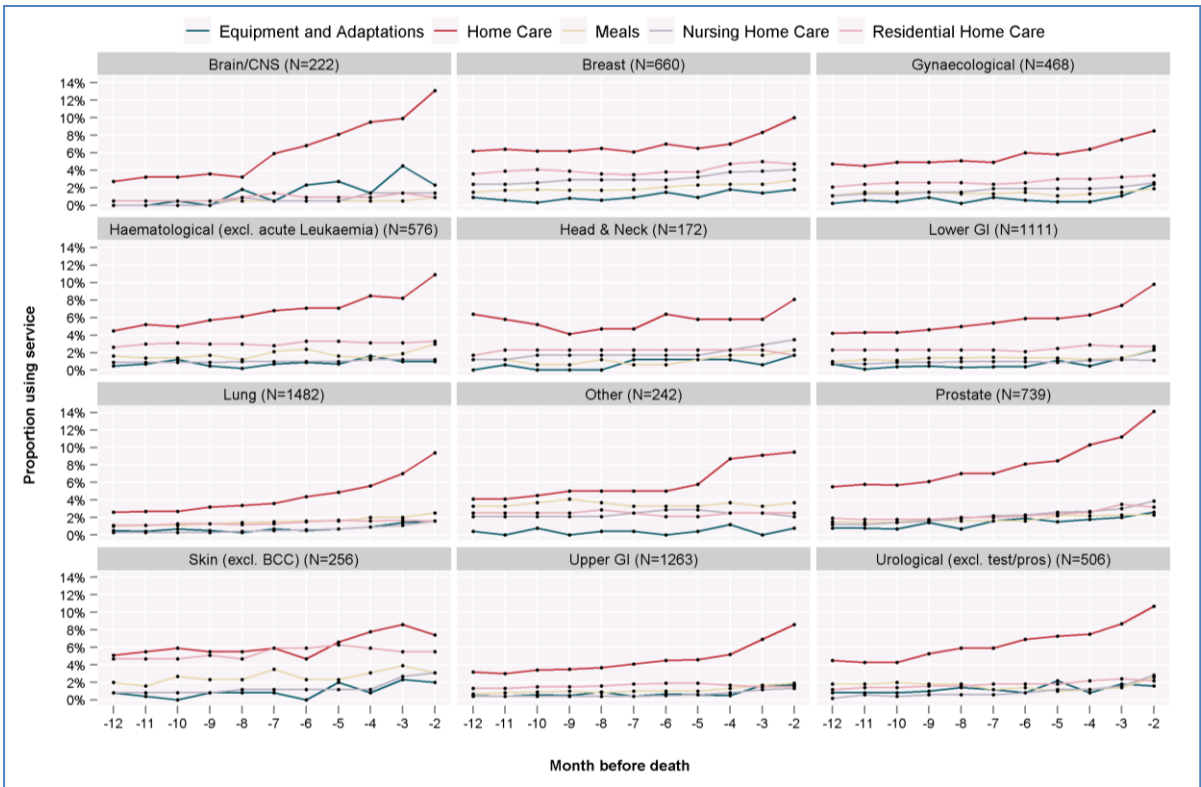


Figure 4.8: Use of selected social care services over the final 12 months of life, by cancer type

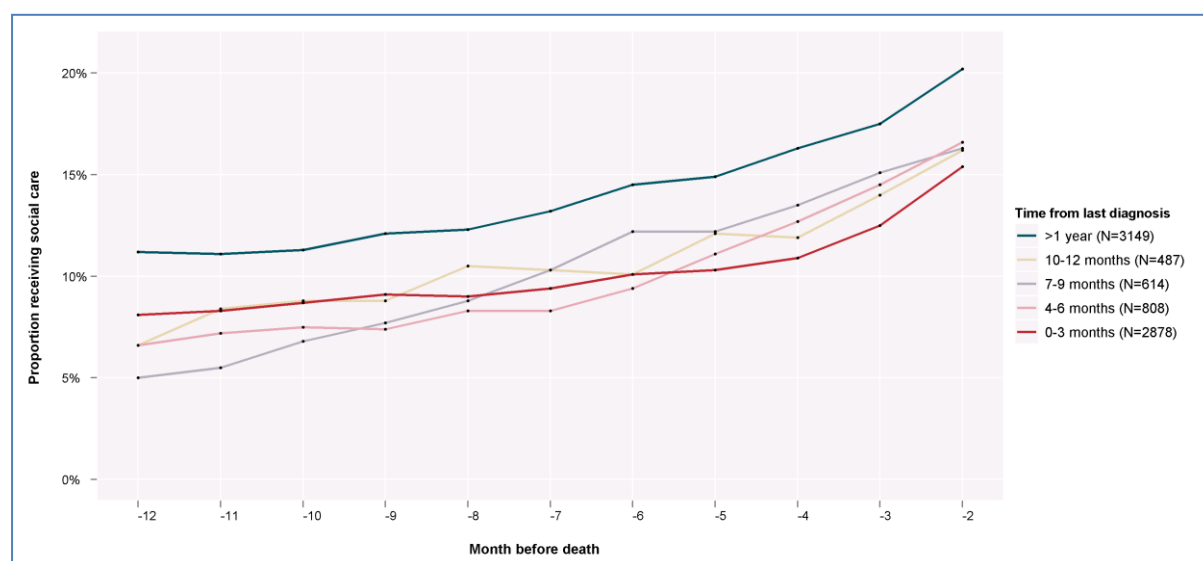




*Was social care use by people with cancer at the end of life affected by time from diagnosis?*

We were interested in finding out to what degree the length of time between diagnosis and death might influence use of social care in their final year of life. Figure 4.9 shows the percentage of people who used social care in each month in their final year of life, grouped by the time between diagnosis and death. Those diagnosed more than one year before death consistently had the highest level of use throughout the final year, while differences for the other groups narrowed over the final year of life. However, it should be noted that this chart is potentially confounded by being indexed against the last cancer diagnosis date, as described earlier.

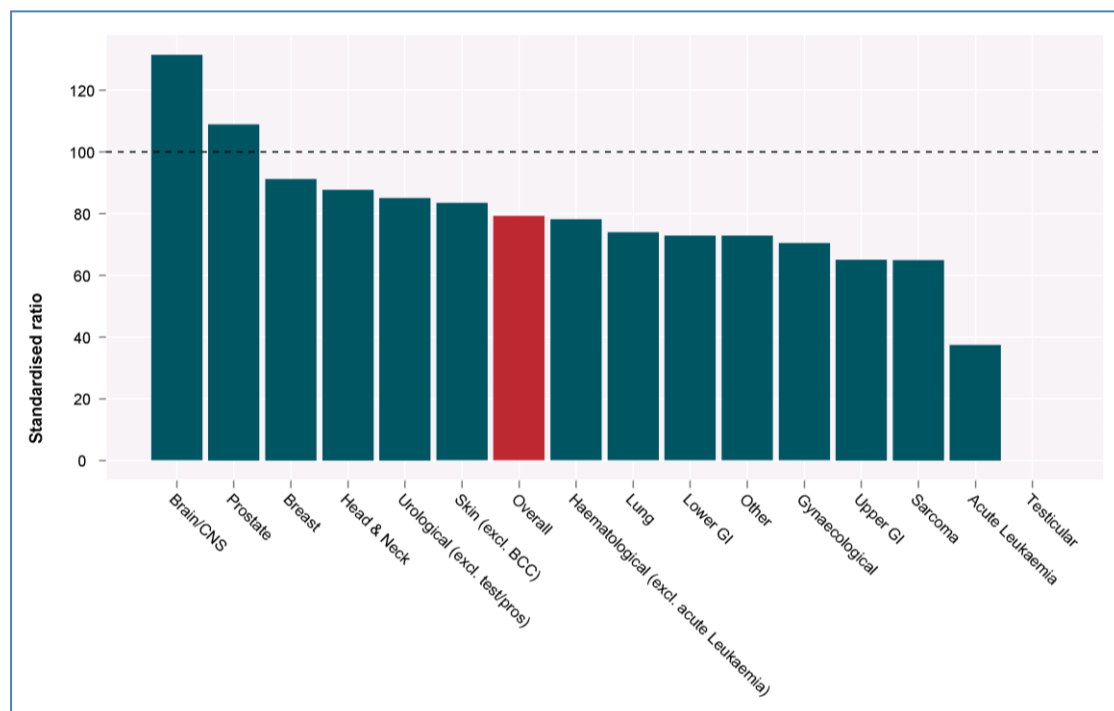
**Figure 4.9: Use of social care over the last 12 months of life, by time from last diagnosis**



*How did the use of social care by people with cancer compare with use by other people at the end of life?*

We calculated standardised rates of health and social care use in the final three full months of life based on all those who died between April 2006 and October 2008. Figure 4.10 shows the standardised ratio for the number of people who used social care in the final three full months of life. Across all cancer types, 20 per cent fewer people than expected used local authority funded social care. Only people with prostate or brain/CNS cancer were more likely to use social care than the wider population at the end of life, while use was notably lower among those with common cancers such as upper and lower GI and lung cancers.

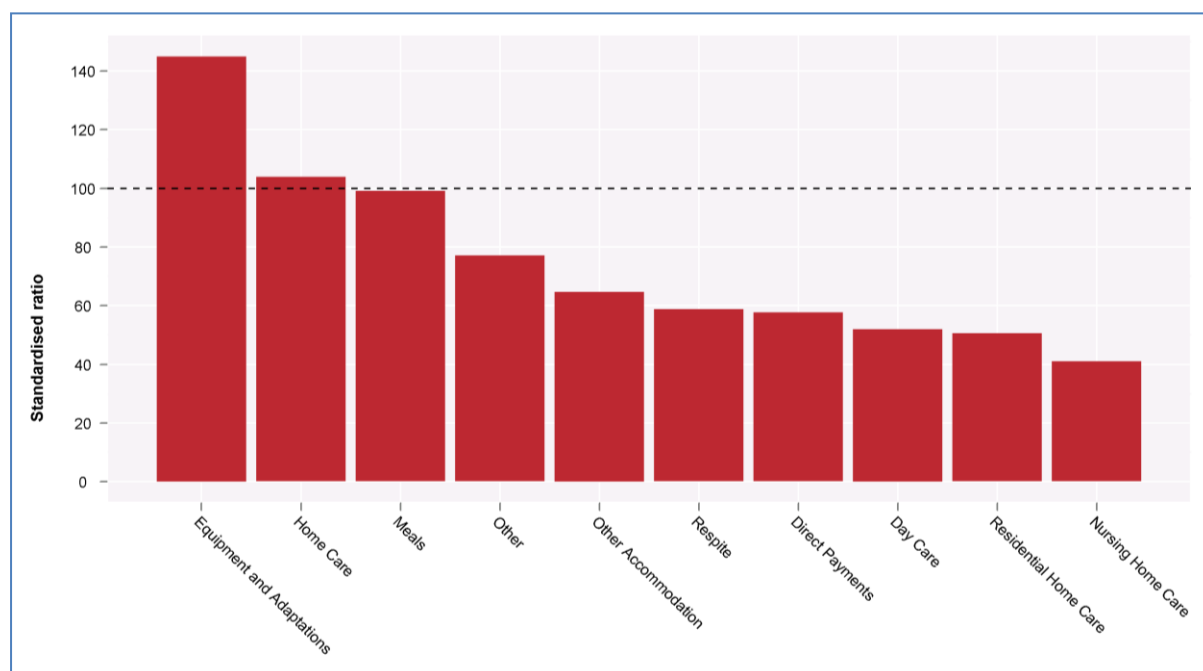
**Figure 4.10: Standardised ratio for use of social care in the last three months of life, by cancer type**



*How did the use of different social care services by people with cancer compare with use by others at the end of life?*

Although fewer people with cancer than expected used social care at the end of life, we were interested in whether this was a general pattern or seen to a greater extent for certain services. We calculated standardised usage rates by service type in the final three months of life, and the results for selected service types are shown in Figure 4.11. The pattern is very interesting, with over 40 per cent more people than expected receiving equipment and adaptations, and slightly more receiving home care. However, use of residential care homes was only 50 per cent of the expected rate, while nursing home use was even lower at just over 40 per cent of the expected number of people.

**Figure 4.11: Standardised ratio for use of particular social care services in the final three months of life**



The very low level of use of residential and nursing home care among those recently diagnosed with cancer is very striking. This again raises the question of whether this was consistent across cancer types. To test this we calculated standardised rates of use of selected service types in the final three full months of life for six cancers, and compared them to all other cancers combined. We combined the other cancers together in order to maximise numbers; however, there are likely to be differences within this group that are obscured by this analysis. The results are shown in Figure 4.12.

People with prostate, breast or lung cancer were more likely to be in receipt of meals than expected. Across all cancer types, more people than expected received equipment/adaptations, although this was most prominently seen among those with a brain/CNS tumour. Use of residential and nursing home care was lower for all cancer types, although generally higher among breast and prostate cancer patients. However, most striking were the very low levels of use of nursing home care among people with GI cancers.

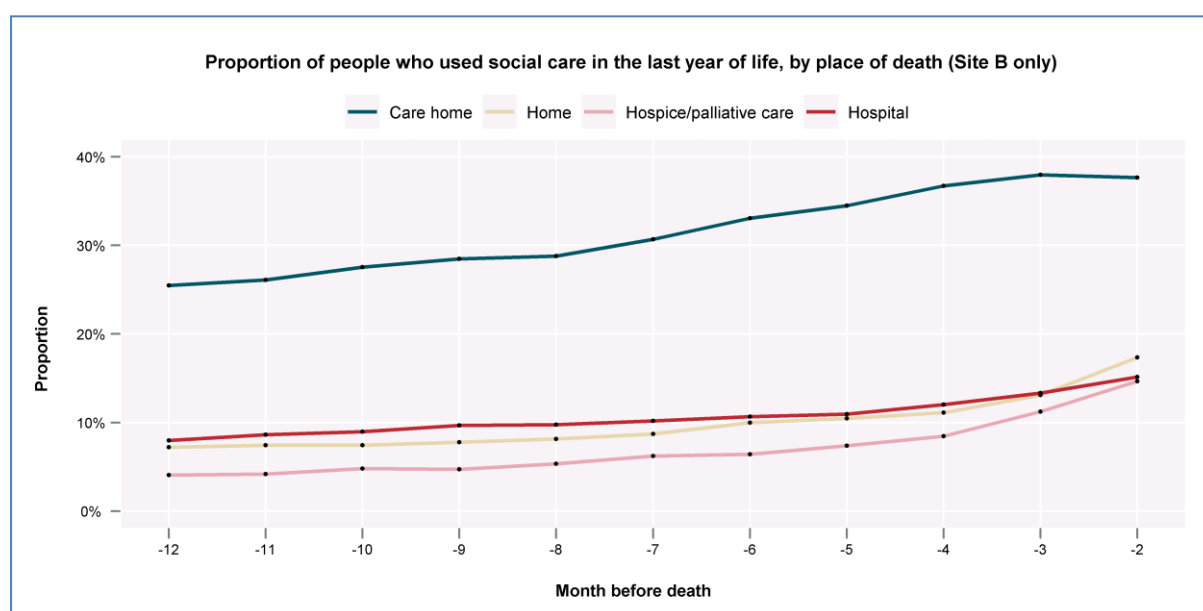
**Figure 4.12: Standardised ratios for use of particular services in the last three months of life, by selected cancer types**



*Was use of social care affected by where people died?*

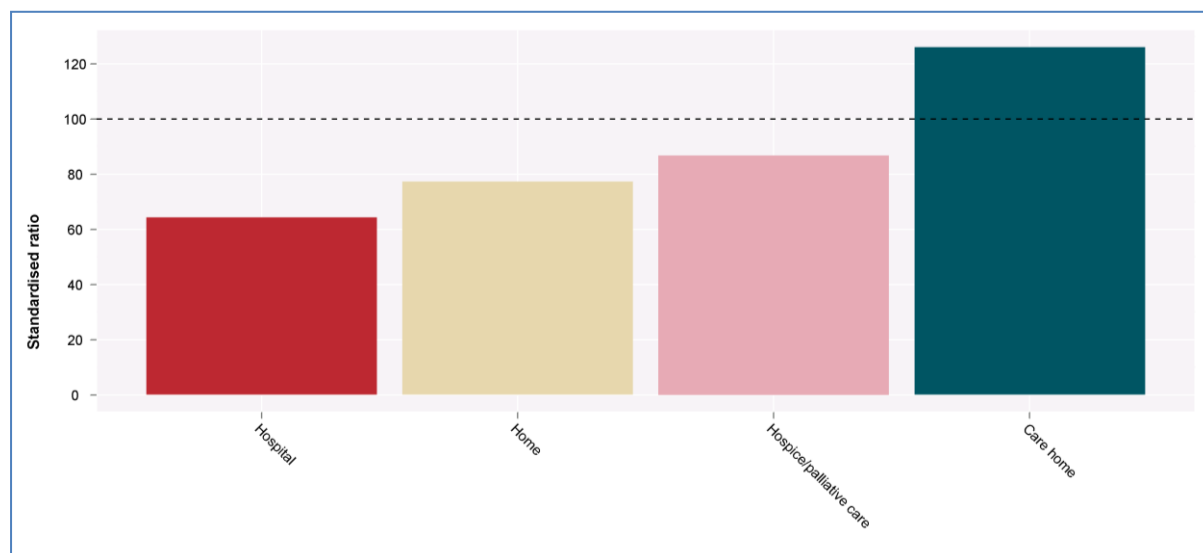
Unsurprisingly, those people with cancer in site B who died in a care home were, by a wide margin, the most likely to use social care in the final year of life, with over a third receiving local authority funded care. Those who died in a hospice or other specialist palliative care facility were the least likely to use services throughout the final year, although their use increased noticeably in the final couple of months (see Figure 4.13).

**Figure 4.13: Use of social care in the last 12 months of life, by place of death (site B only)**



Age- and sex-standardised ratios for the number of people in receipt of local authority funded social care by place of death showed that, as would perhaps be expected, those who died in hospital were much less likely to use social care at the end of life than was expected (see Figure 4.14). Conversely, those who died in a care home were much more likely to use local authority funded social care. Interestingly, those who died at home or in a hospice or specialist palliative care unit were somewhat less likely to use social care than expected.

**Figure 4.14: Standardised ratio for use of social care, by place of death**



*What was the cost of social care for people with cancer in the final year of life?*

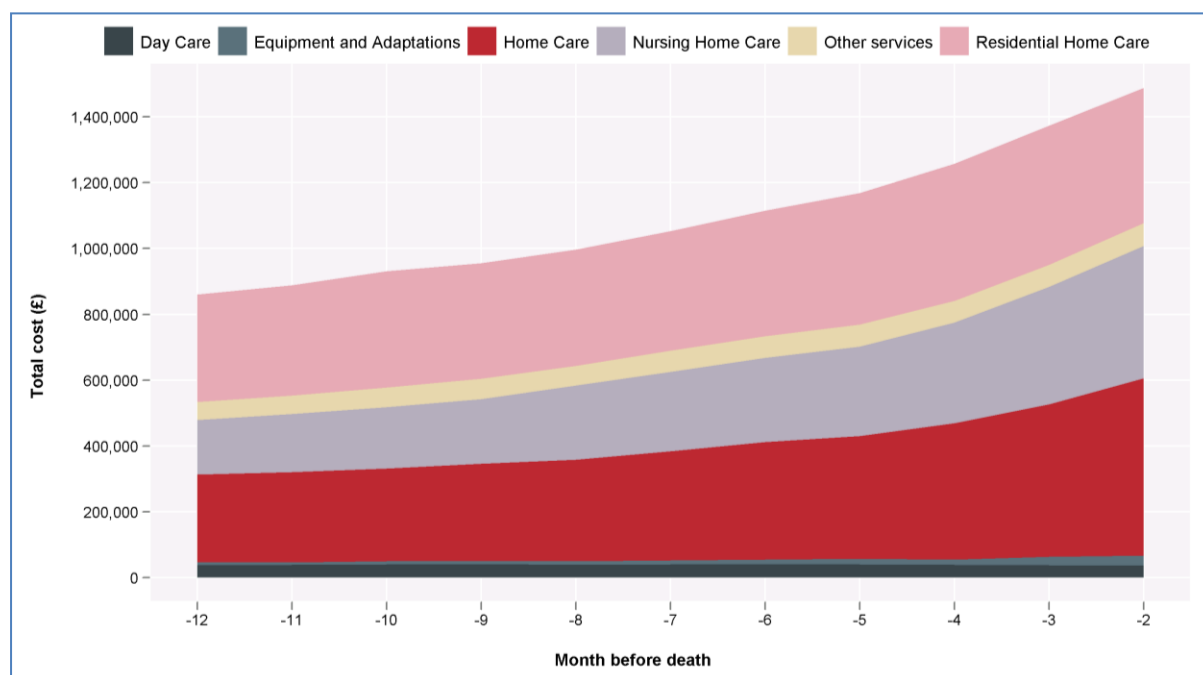
Overall, 27 per cent (N=2,123) of the cancer cohort used local authority funded social care in the final year of life. The total cost of this care was £12.9 million across the two sites, although the cost of usage ranged widely between individuals from £0 to more than £33,000. The average cost of social care per person who used services was over £6,000; however, there was a noticeable difference between the sites. Across both sites the average cost of social care per death (that is, including those who did not use social care) in the final year was around £1,600 (see Table 4.4).

**Table 4.4: Average cost of social care for people with cancer in the last year of life**

	Site A	Site B	Overall
Average cost per service user	£5,166	£6,370	£6,080
Average cost per death	£1,390	£1,701	£1,626

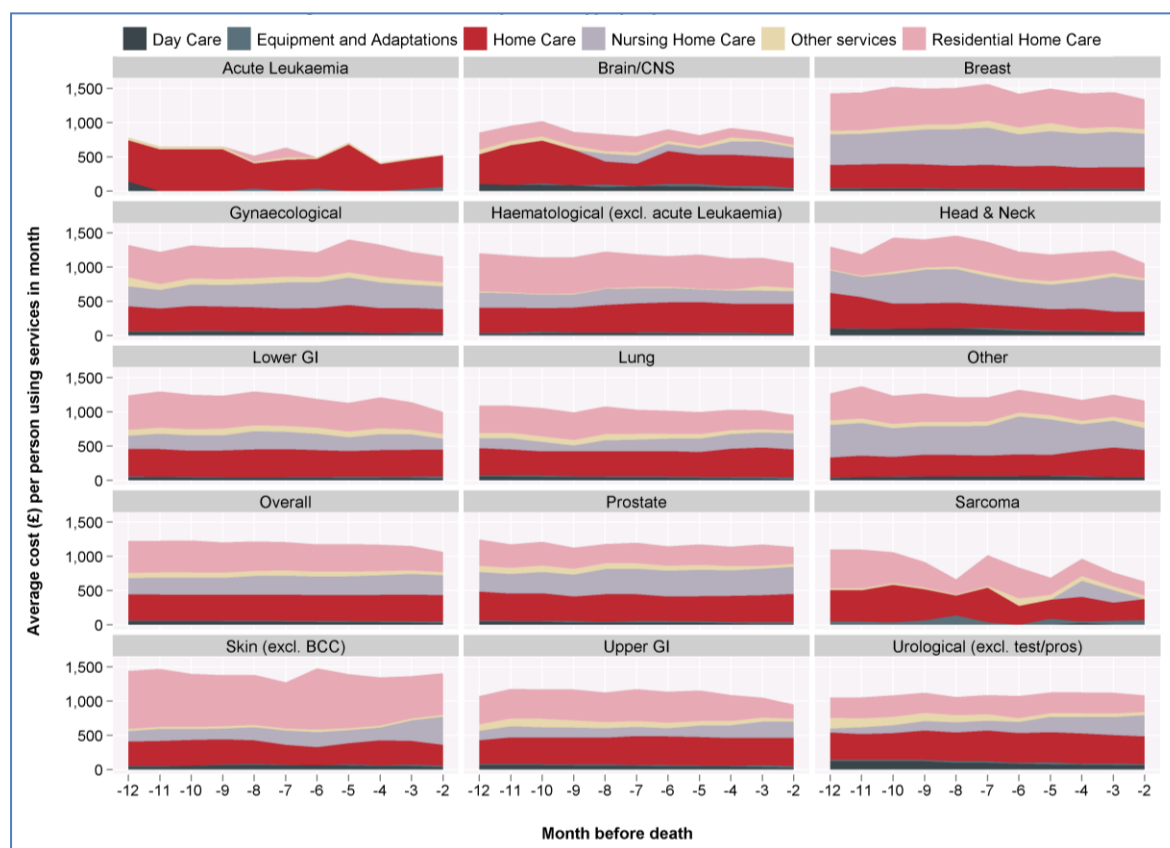
Total social care costs rose by around 75 per cent over the final year of life, to over £1.4 million in the penultimate month. As can be seen in Figure 4.15, this rise was due to increased use of nursing home care, and particularly to greater use of home care.

**Figure 4.15: Total social care costs for people with cancer over the final 12 months of life, by service type**



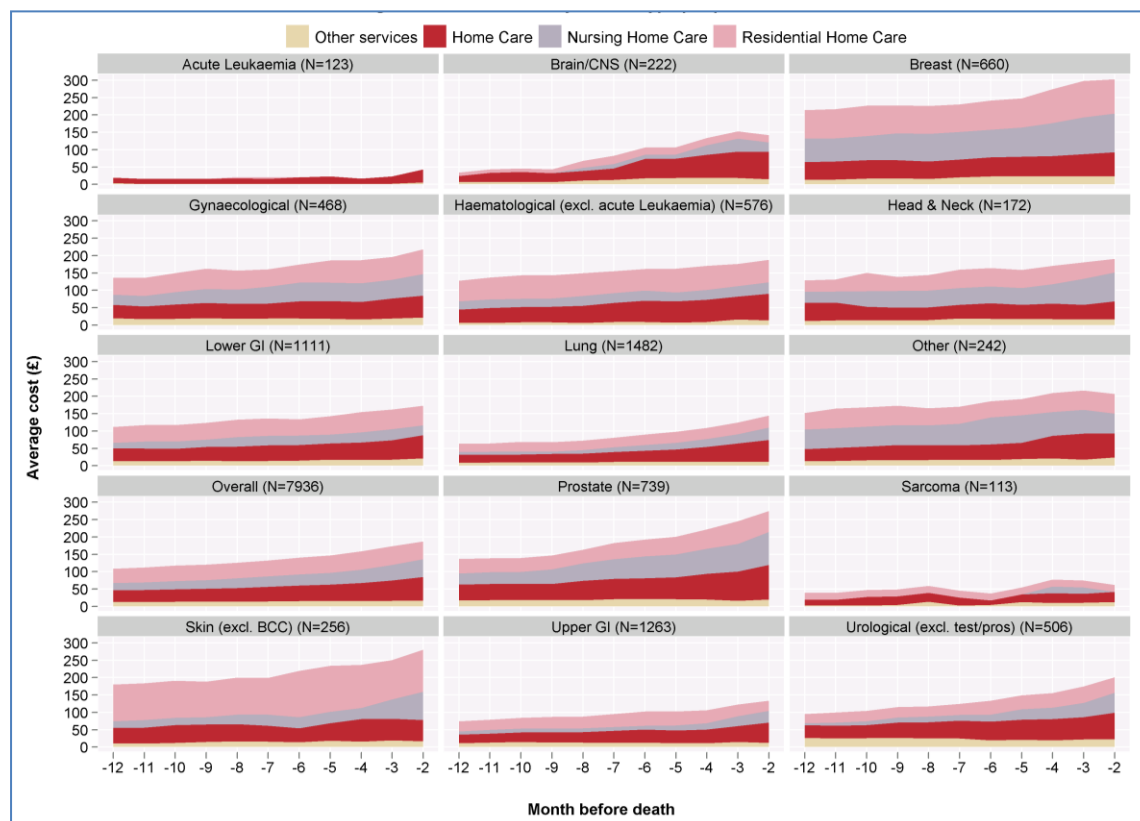
We calculated the average cost of social care per person with cancer who used services in each month in the final year of life. Across all cancer types, the average cost per person per month fell slightly over time, from around £1,225 to £1,070, with a small growth in average expenditure on nursing home care, but a reduction in the amount spent on residential care. Although the average cost per person using services was relatively stable through the last year of life, one obvious question is whether the relative spend on different services changed. Figure 4.16 plots the average cost each month per person who used social care services, by cancer and service type. It is notable that the average amount spent on nursing home care rose significantly over the year for people with brain/CNS, head and neck and urological neoplasms.

**Figure 4.16: Average social care costs over the final 12 months of life per person who used services, by cancer and service type**



We also calculated the average cost of social care in the final year of life per person, including those who did not use services. The results are shown by service type in Figure 4.17. Across all cancer deaths, the average cost per month increased from just over £100 per month a year before death to around £190 in the penultimate month. There were significant variations by cancer type, with skin and breast cancer patients having a far higher average cost than others, for example, lung and GI cancers. This is due to their higher rates of usage of residential and nursing home care. The fact that the average cost per death increased significantly over the course of the last year of life, while the average cost per person receiving services remained static, indicates that the increase in total costs was due to more people receiving services, not primarily to people receiving more expensive services as death approached.

**Figure 4.17: Average social care costs per person over the last 12 months of life, by cancer and service type**

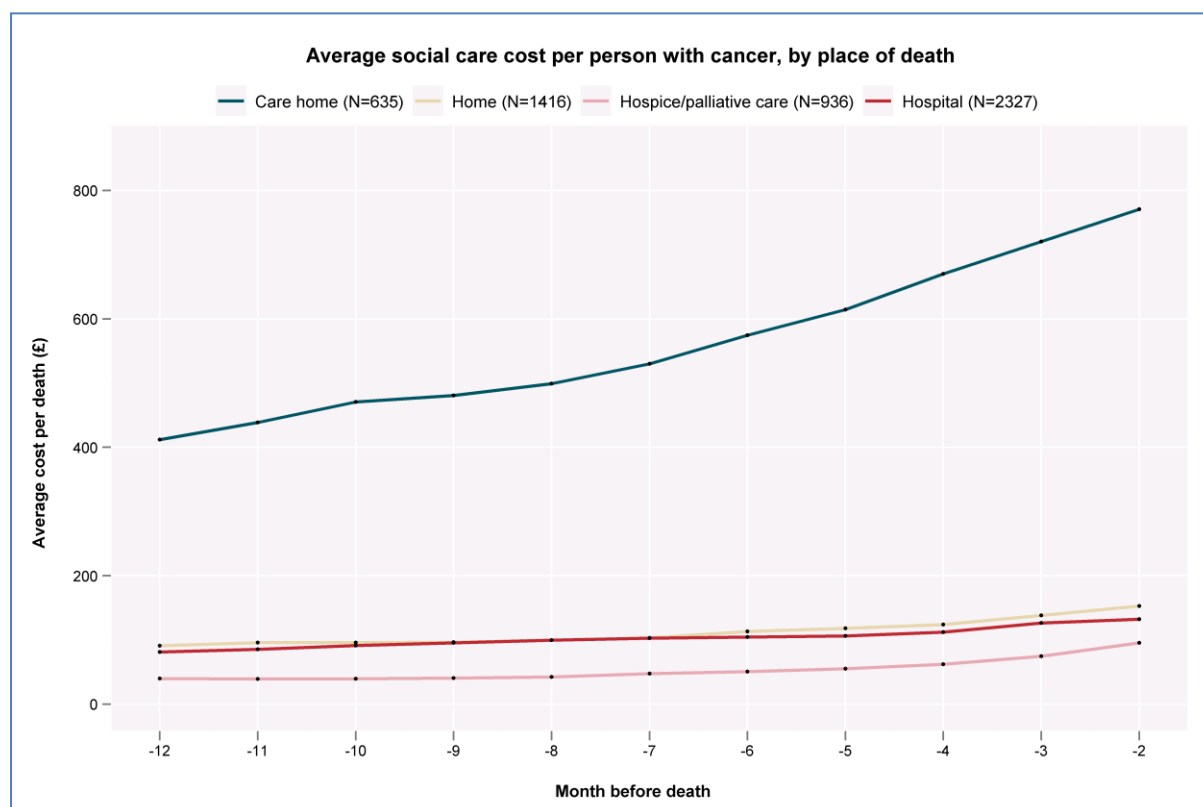


*How was the cost of social care affected by place of death?*

The average cost of local authority funded social care per person for those who died in a care home was approximately five times larger than for those who died in other settings, and rose fairly steadily through the last 12 months. The cost per person for those who died in hospital or at home was broadly similar throughout the last year of life. The lowest average cost was for those who died in a hospice or palliative care unit (see Figure 4.18).

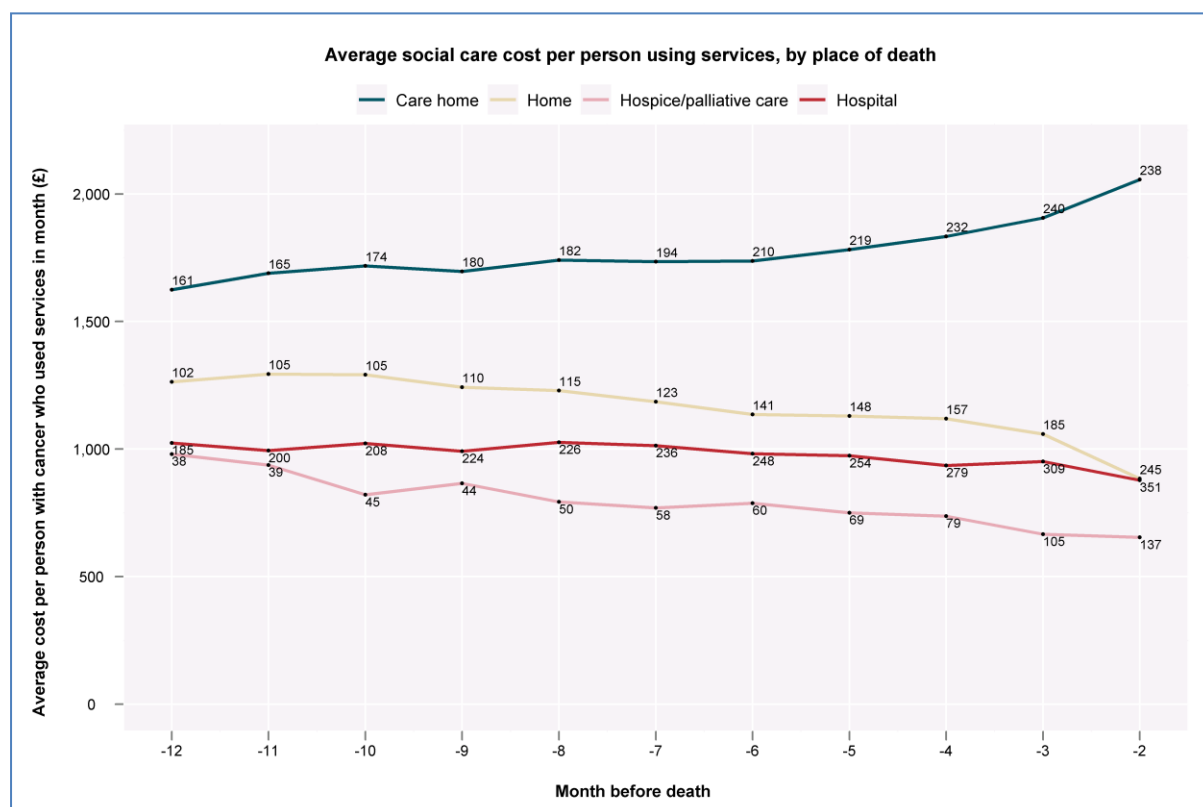


**Figure 4.18: Average social care cost per person with cancer over the last 12 months of life, by place of death**



Interestingly, the average cost of social care per person who used services shows quite a different pattern (see Figure 4.19). For those who died in a care home the average social care cost per service user rose from £1,600 to £2,100 over the course of the final year of life. However, for those who died at home, in hospital or in a hospice, the average social care cost fell over the course of the final year. This is perhaps surprising. For those who died in a hospice/palliative care unit, the increase in usage over the last year of life was particularly seen in the provision of equipment and meals, with the relative proportion receiving residential or nursing care falling. A similar pattern was seen for those who died in the hospital, with the growth in activity predominantly accounted for by equipment, meals and home care, with little change in the number receiving residential or nursing home care. Therefore, the decline in average costs seems to be driven largely by greater provision of lower-cost services towards the end of life.

**Figure 4.19: Average social care cost per person with cancer who used services over the last 12 months of life, by place of death**

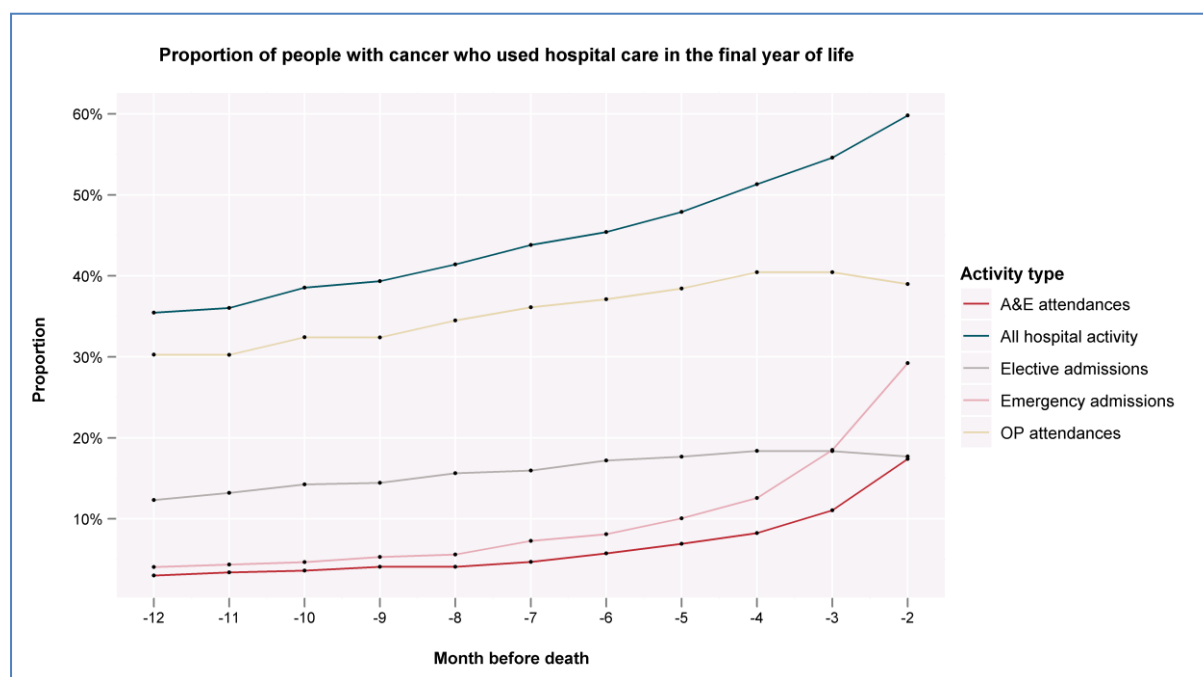


## Hospital care

*What proportion of people with cancer used hospital care in the final year of life?*

Compared with those who died from conditions other than cancer, there was much greater use of hospital care than social care for people with cancer in the final year of life (see Figure 4.20). The proportion of people who had a hospital attendance or admission increased substantially from 35 per cent a year before death to 60 per cent in the penultimate month of life. The trends for A&E attendances and emergency admissions paralleled each other, remaining fairly stable in the first few months, but rising very sharply in the final three months. It is notable that 30 per cent of people with cancer had an emergency admission in the penultimate month of life.

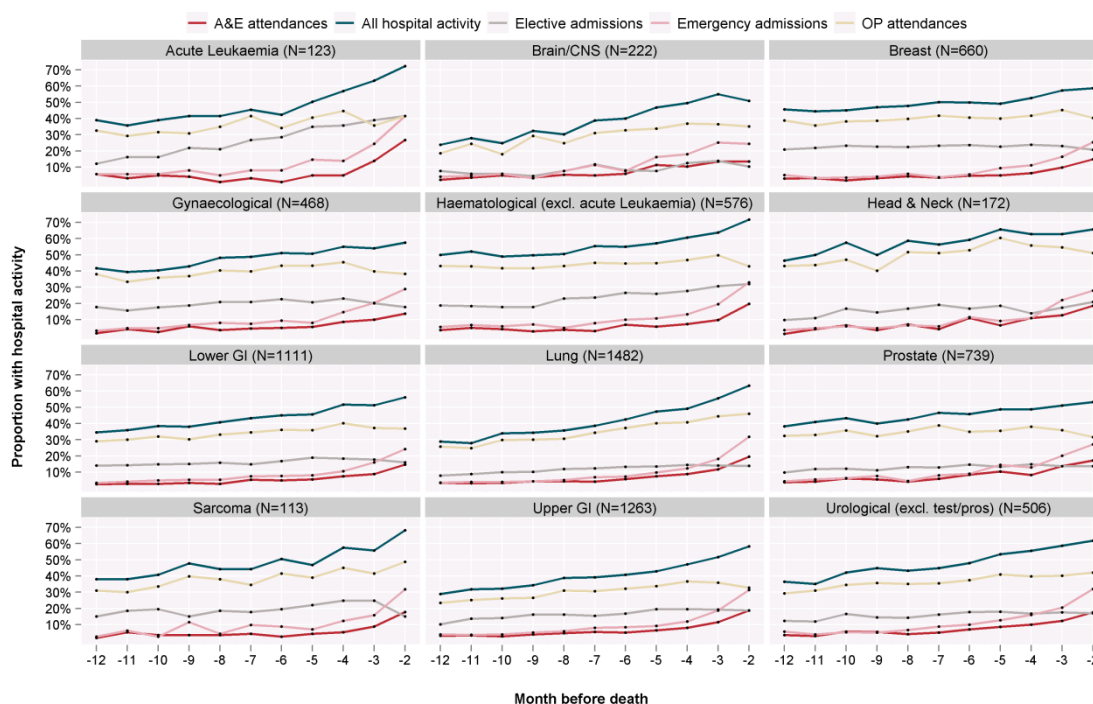
**Figure 4.20: Use of hospital care over the last 12 months of life, by activity type**



OP: outpatient

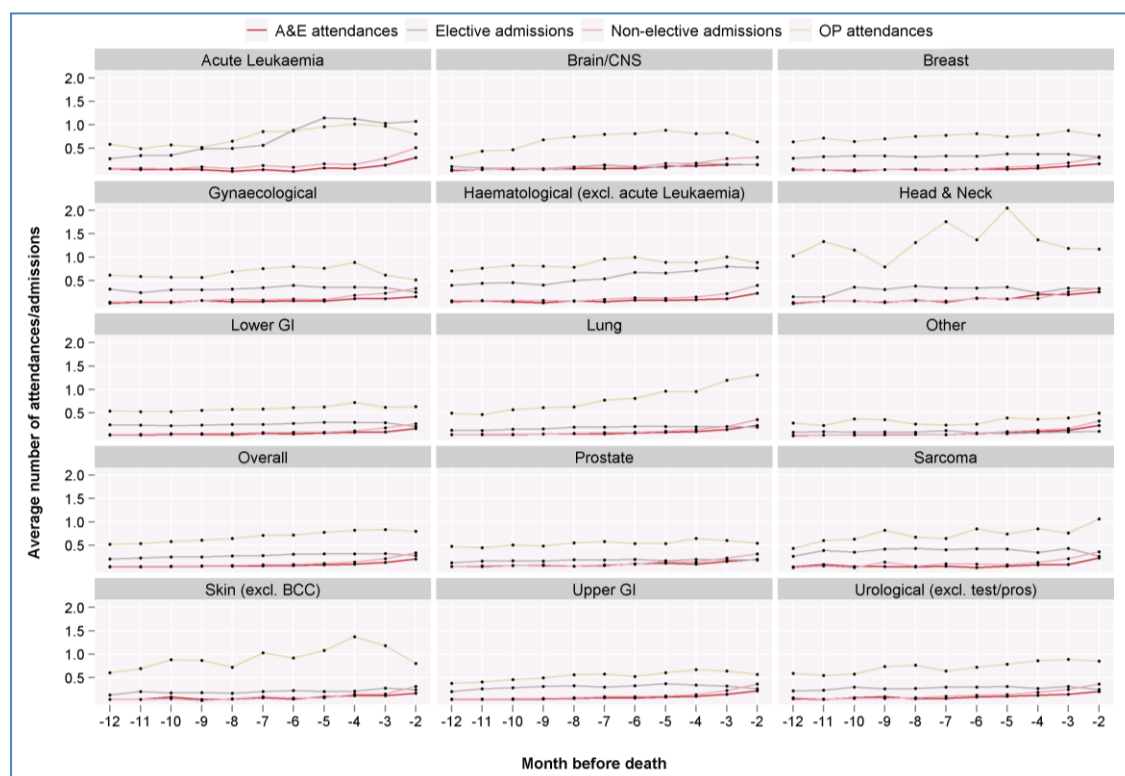
Figure 4.21 shows the proportion of people who accessed hospital care by cancer and activity type. Broadly, the pattern was fairly similar across cancer types, although patients with acute leukaemia were the most likely to have hospital activity, and more of those patients had elective admissions than patients with other cancers.

**Figure 4.21: Use of hospital care over the last 12 months of life, by cancer and activity type**



The intensity of hospital usage by cancer type in the final year of life is shown in Figure 4.22. It can be seen that people with head and neck, skin or lung cancer had significantly more outpatient attendances per person than those with other cancer types. Not only did a higher proportion of patients with haematological cancers attend hospital, they also had significantly more elective admissions per person than those with other types of cancer.

**Figure 4.22: Average number of hospital attendances/admissions over the last 12 months of life, by cancer type**



Of course, not all hospital activity for people with cancer is likely to have been related to their cancer. These people were generally relatively elderly, and thus some might be expected to have other conditions requiring inpatient or outpatient care. We looked at the main specialty (or treatment function where the main specialty was not recorded) for every outpatient attendance for the cancer cohort in the final year of life. It should be noted that in site B, 16 per cent of outpatient attendances (11 per cent of the combined sample) did not have a valid mean specialty or treatment function code. Over 25 per cent of all outpatient attendances in the final year of life were recorded against main specialty code 800 (clinical oncology), while a further 12 per cent were for medical oncology. The figures for the final three months of life were very similar.

High levels of outpatient activity were particularly seen for those with head and neck, skin or lung cancer. For head and neck cancer, 21 per cent of outpatient attendances were in clinical oncology, four per cent were in medical oncology, while another 26 per cent were in either ear, nose and throat (ENT) or oral surgery. Of the remainder, 15 per cent were under an invalid specialty, and 13 per cent of attendances were with allied health professionals.

For skin cancer, 19 per cent of attendances were for clinical oncology, 11 per cent for plastic surgery, seven per cent for medical oncology and six per cent for dermatology; specialties might conceivably be relevant to the treatment of skin cancer. Unfortunately, 29 per cent of attendances did not have a valid specialty code.

Among those with lung cancer, 26 per cent of outpatient attendances were in respiratory medicine, 24 per cent in clinical oncology and a further 11 per cent in medical oncology. Given that a high proportion of those with lung cancer would also have comorbidities including asthma and COPD, the high number of respiratory medicine attendances is not surprising.

We also looked at the extent to which hospital admissions were cancer-related. We checked whether or not a cancer diagnosis was recorded in any of the 14 diagnosis fields on the inpatient record. Using this approach, 78 per cent of emergency admissions had a cancer diagnosis recorded, while this figure rose to 83 per cent of emergency admissions in the last few months of life. Eighty-eight per cent of elective admissions had a cancer diagnosis recorded for the spell, rising to 90 per cent of admissions in the final three full months before death. For both emergency and elective admissions, those with ‘other’ cancers (mainly unknown primary or secondary neoplasms) had the lowest proportion of cancer-related admissions. This might reflect that these cases are often difficult to diagnose, and so patients may be recorded with a range of symptoms, before a diagnosis is finally made.

#### *How much time did people with cancer spend in hospital in the last year of life?*

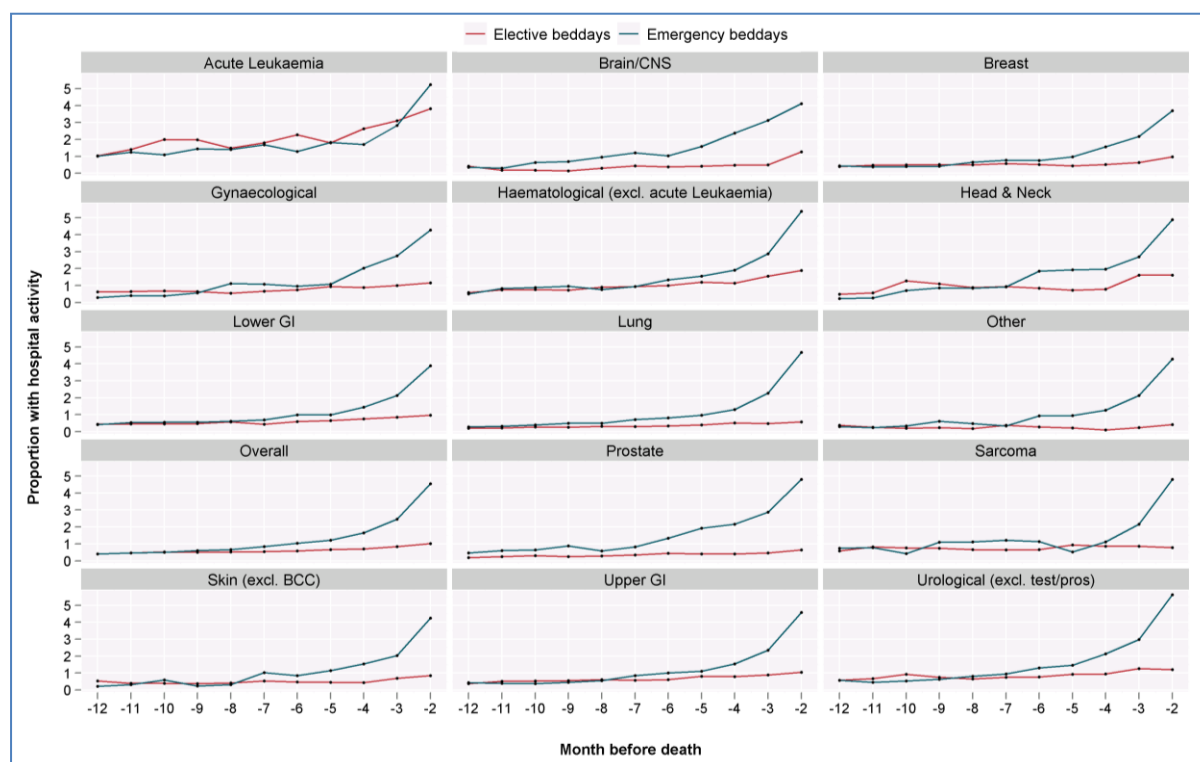
We calculated the number of days that each person with cancer spent in hospital in each month during the last year of life. On average, people in the cancer cohort spent 25 days in hospital in the last year, with two thirds of these being during emergency admissions. People with acute leukaemia spent the greatest proportion of time in hospital, split evenly between emergency and elective spells. Table 4.5 shows the mean number of hospital bed days for each cancer type in the year before death.

**Table 4.5: Average number of hospital bed days for each cancer type in the year before death**

Cancer type	Elective bed days	Emergency bed days	All bed days
Acute leukaemia	25.4	25.1	50.5
Brain/CNS	5.3	18.9	24.2
Breast	6.8	15.5	22.2
Gynaecological	9.3	18.2	27.5
Haematological (excluding acute leukaemia)	12.5	23.0	35.5
Head and neck	11.7	20.5	32.2
Lower GI	7.5	15.7	23.2
Lung	4.3	16.1	20.4
Other	3.3	15.7	19.0
Prostate	4.5	20.6	25.1
Sarcoma	9.3	18.1	27.4
Skin (excluding basal cell carcinoma)	6.1	15.9	22.0
Testicular	5.3	6.3	11.7
Upper GI	8.0	16.8	24.7
Urological (excluding testes/prostate)	10.2	20.9	31.2
<b>Overall</b>	<b>7.4</b>	<b>17.8</b>	<b>25.2</b>

Figure 4.23 shows the average number of days people spent in hospital by month through the last year of life. Across all cancer types there was a rise in emergency bed days, particularly in the last three full months of life.

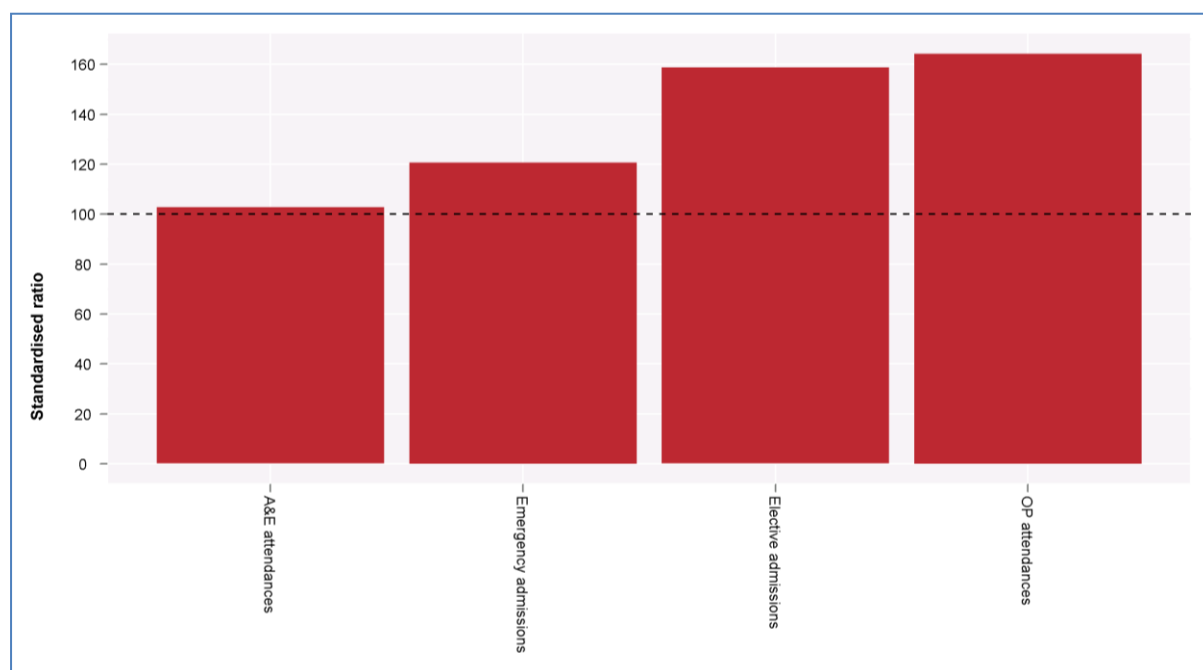
**Figure 4.23: Average number of hospital bed days over the last year of life, by cancer type**



*How did hospital activity by people with cancer compare with hospital activity by others at the end of life?*

We calculated standardised ratios for the number of hospital admissions and attendances in the final three months of life (excluding the month in which a person died). These showed that use of all types of secondary care activity was higher in cancer patients in the final three months of life than expected (see Figure 4.24). This was most clear for elective and outpatient activity where cancer patients had more than 50 per cent more admissions and attendances than expected. They also had 20 per cent more emergency admissions and slightly more A&E attendances.

**Figure 4.24: Standardised ratios for hospital use in the final three full months of life**



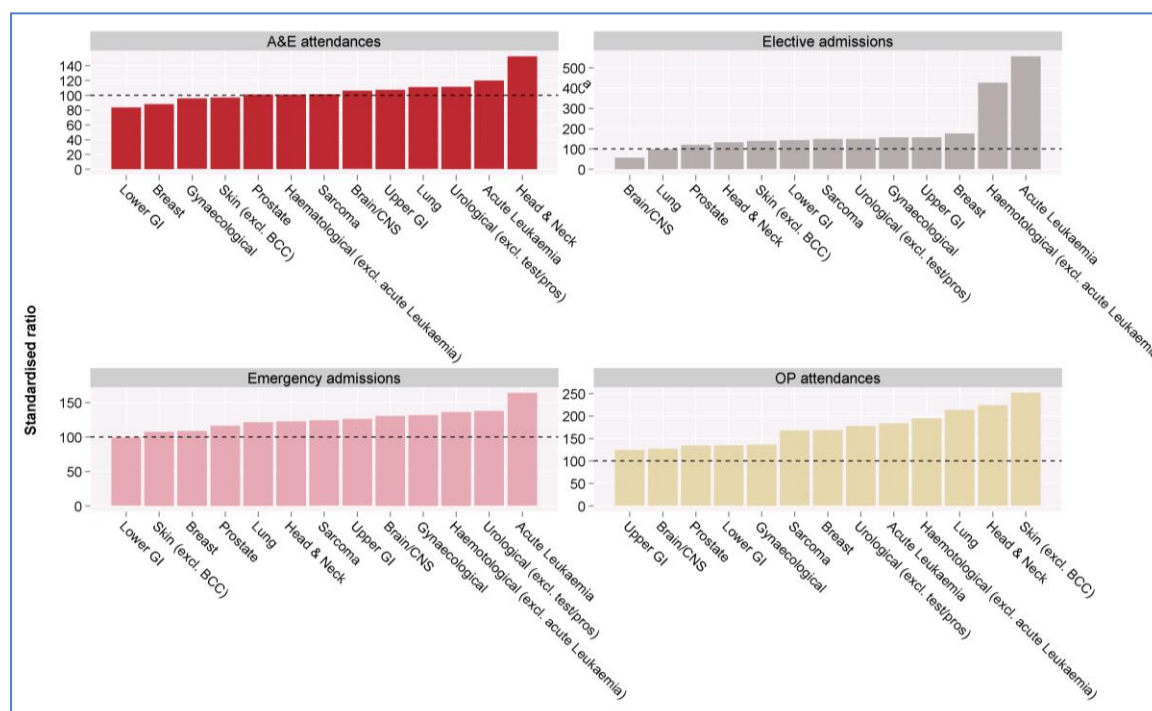
OP: outpatient

Breaking this down by cancer type, it is clear that A&E attendances were broadly in line with expectation for most cancer types, with the exception of head and neck cancer patients. Elective admissions were higher for all cancer types (with the exception of brain/CNS cancer), but most significantly higher among patients with haematological neoplasms. The numbers of emergency admissions and outpatient attendances were consistently higher than expected across all cancer types (see Figure 4.25).

We looked further into the elective admissions for people with cancer, to try to understand what the admissions were for. Of the elective admissions in the last three full months of life, 61 per cent were day cases, 25 per cent were inpatient admissions and 14 per cent were regular day or night attendances.

Thirty-eight per cent of day case admissions were recorded under specialty code 800 (clinical oncology), suggesting that they related to radiotherapy treatment, while 15 per cent were recorded against medical oncology. Nearly 30 per cent of day cases were recorded against clinical haematology, with over 90 per cent of these for people with haematological cancers.

**Figure 4.25: Standardised ratios for hospital use in the final three full months of life, by cancer and activity type**

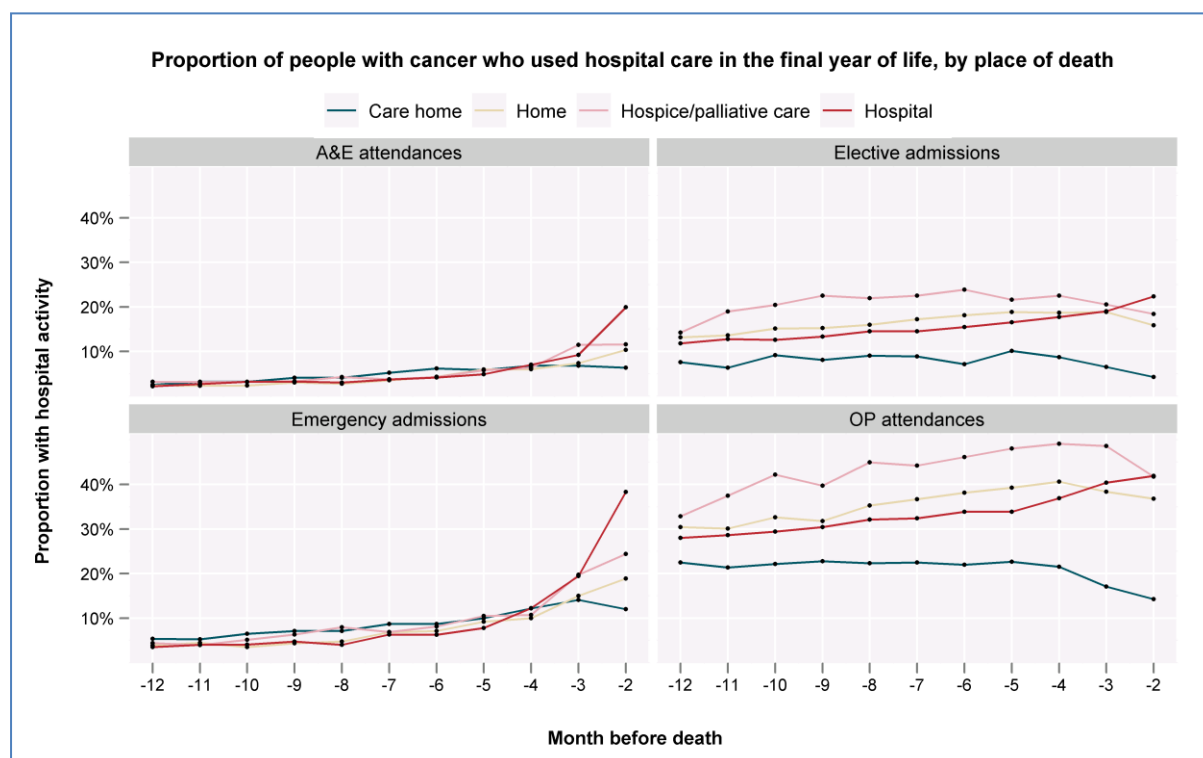


*Was use of hospital care affected by where people died?*

For site B, the proportion of people using hospital care in the final year of life varied significantly according to their place of death (see Figure 4.26). Those who died in a care home were least likely to have planned hospital care, and there was little evidence of an increase in the number using hospital care as death approached. Those who died in hospital had the highest level of hospital use, with a very sharp increase in the proportion with an emergency admission towards the end of life. Interestingly, a relatively high proportion of those who died in a hospice/palliative care unit had planned hospital activity throughout the final year of life.

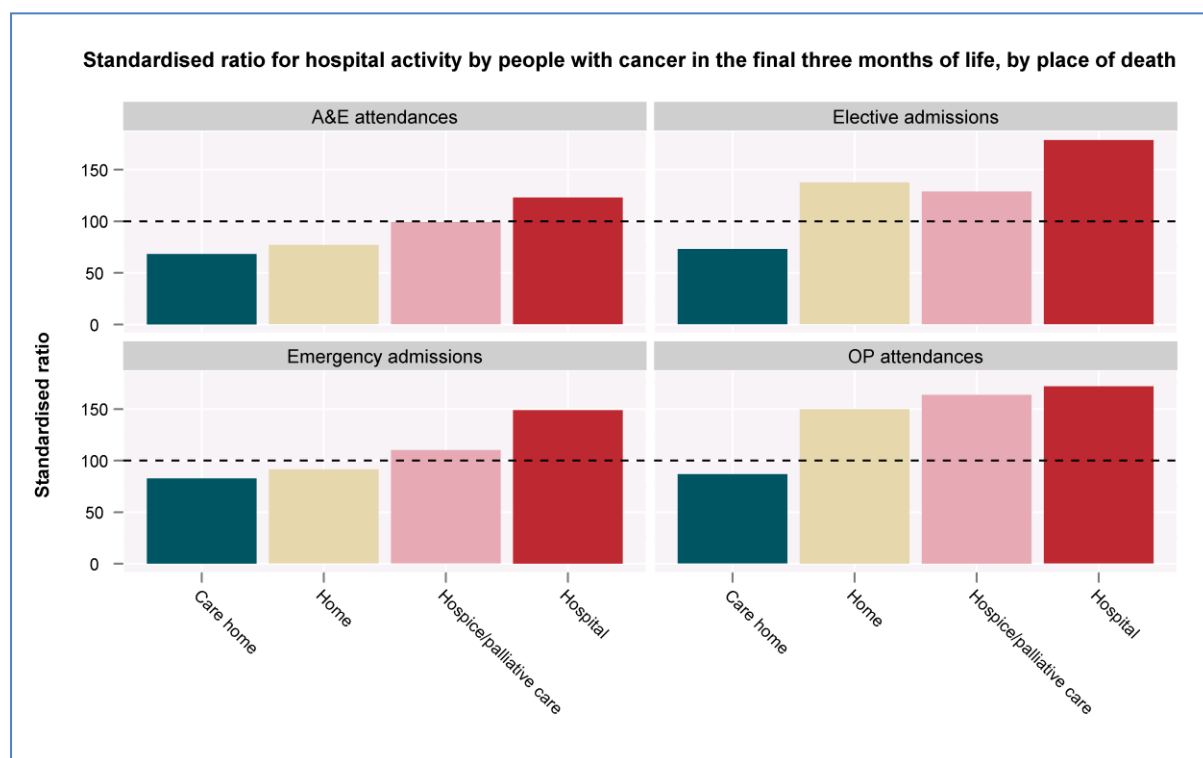


**Figure 4.26: Use of hospital care by people with cancer over the last year of life, by activity type and place of death**



While it is likely that people who die in hospital will have higher hospital usage at the end of life than others, it would be interesting to know whether dying elsewhere is associated with lower hospital usage. For site B, we calculated standardised ratios for hospital admissions and attendances in the final three months of life, by place of death. Unsurprisingly, those who died in hospital had the highest levels of all types of activity (see Figure 4.27). Interestingly, those who died in a care home had consistently lower than expected hospital activity. People with cancer who died at home had lower than expected A&E and emergency admissions, while those who died in a hospice had slightly increased rates of emergency admissions.

**Figure 4.27: Standardised ratios for hospital use at the end of life, by activity type and place of death**

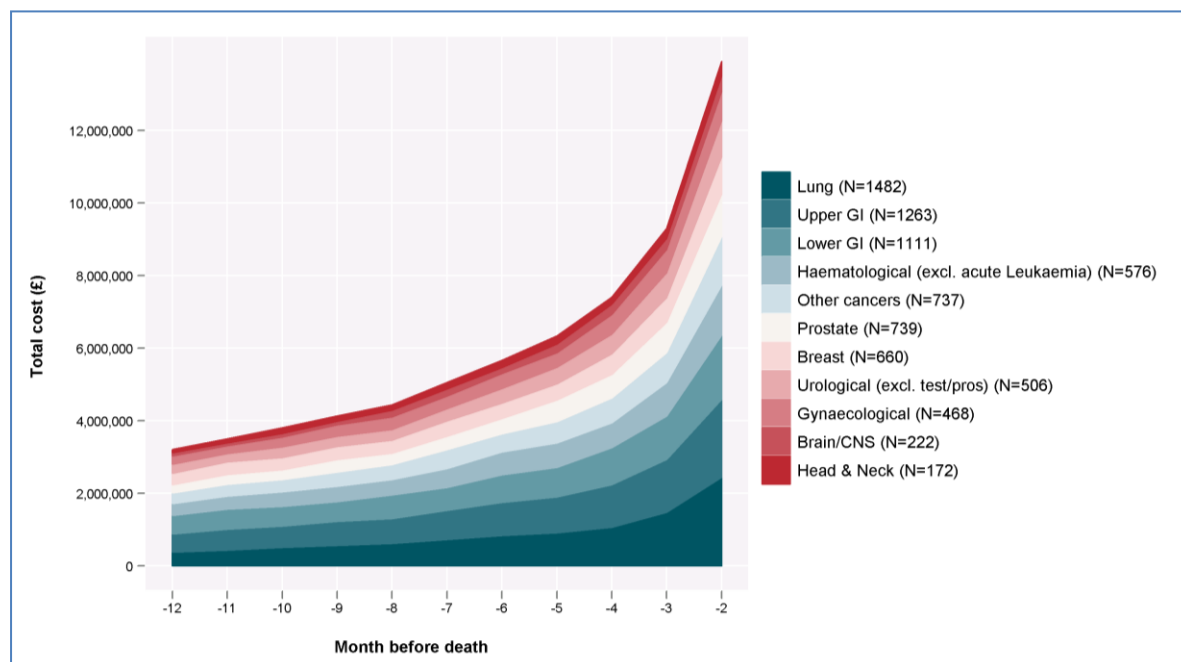


OP: outpatient

*What were the hospital costs for people with cancer in the final year of life? How did costs vary by cancer type?*

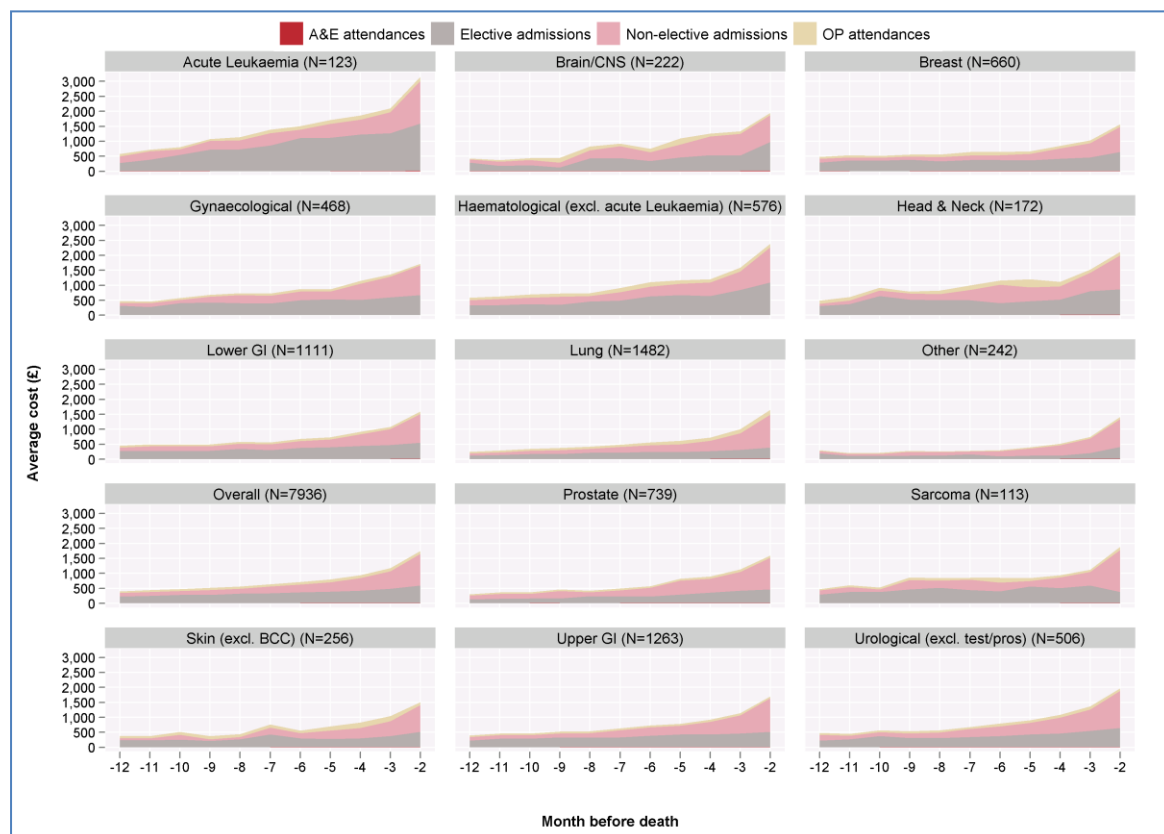
The total estimated hospital cost in the final year of life for the 7,936 people where cancer was recorded as a cause of death was over £78 million. The cost increased significantly over the final year, from around three per cent of the total 12 months before death (£3.2 million), to nearly 18 per cent (£13.9 million) in the penultimate month of life. The largest proportions of the total expenditure were accounted for by those with lung and GI cancers (see Figure 4.28). On average, the cost of hospital care for each person with cancer was around £9,800 in the last year of life.

**Figure 4.28: Total cost of hospital care in the last year of life for people with cancer, by cancer type**



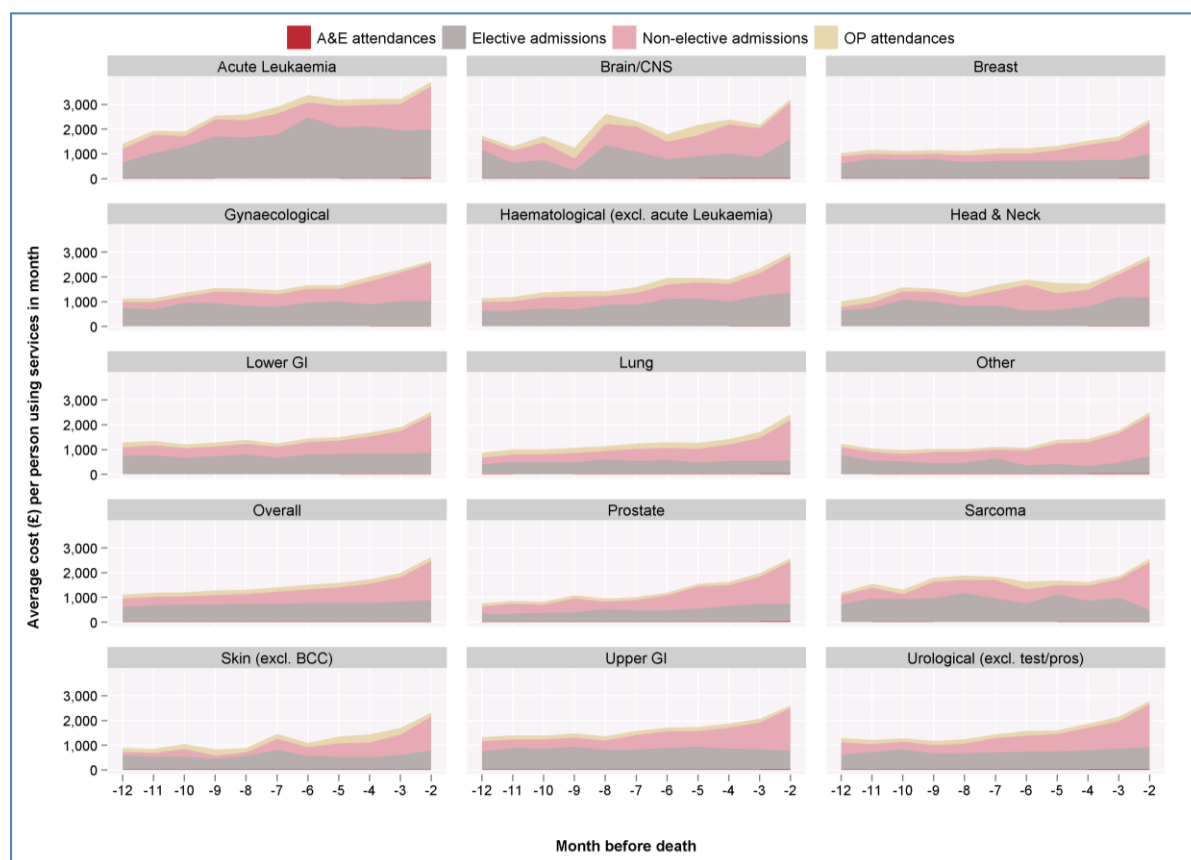
Earlier we showed that social care costs in the final year of life varied significantly by cancer type. Interestingly, this was much less evident for hospital costs. Across all those with cancer, the average hospital cost per person tripled over the course of the last 12 months of life. For patients with blood cancers the hospitals costs were significantly higher than for other cancers. For other cancer types, the hospitals costs were remarkably similar – rising from around £500 to £1,500 over the last year. This is surprising, and the reasons for this consistency are not clear. Across all cancer types the increase in hospital costs over the last year of life was predominantly due to non-elective admissions (see Figure 4.29).

**Figure 4.29: Average cost per person of hospital care in the last year of life, by cancer and activity type**



For social care we found that average costs per person who used social care were very stable over the final year of life. Perhaps unsurprisingly, the pattern of average costs for those who used hospital care was very different, with an increase in the average cost over the last year of life for all cancer types (see Figure 4.30).

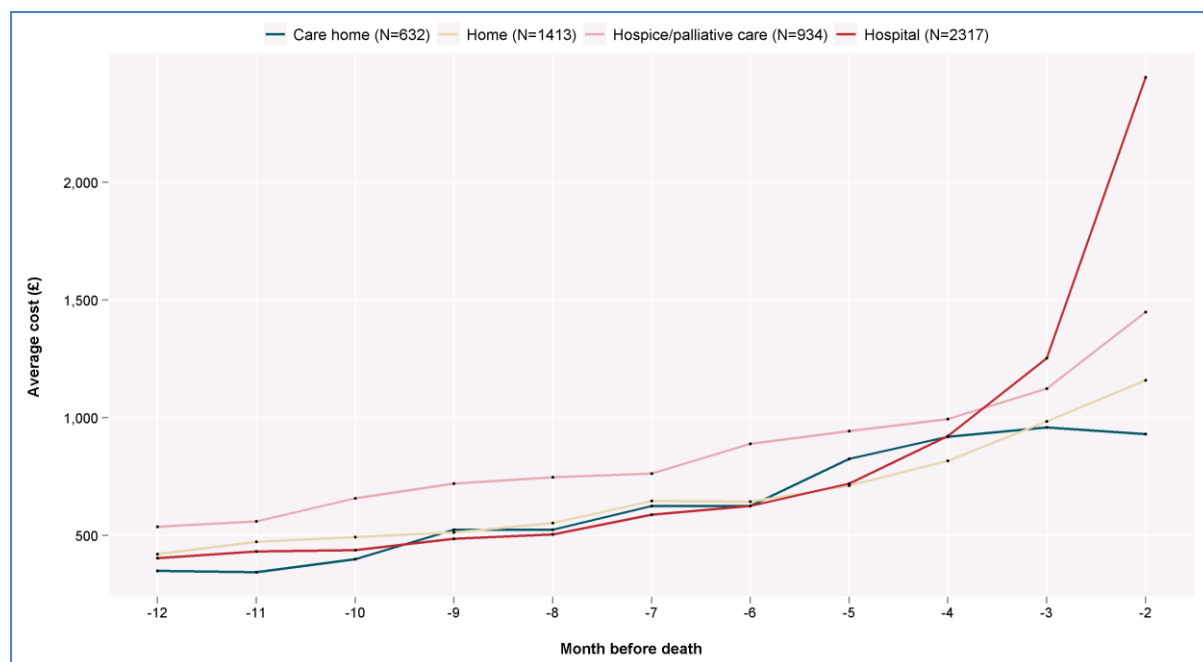
**Figure 4.30: Average cost of hospital care per person who used services in the last year of life, by cancer and activity type**



*How did costs of hospital care in the final year of life vary according to place of death?*

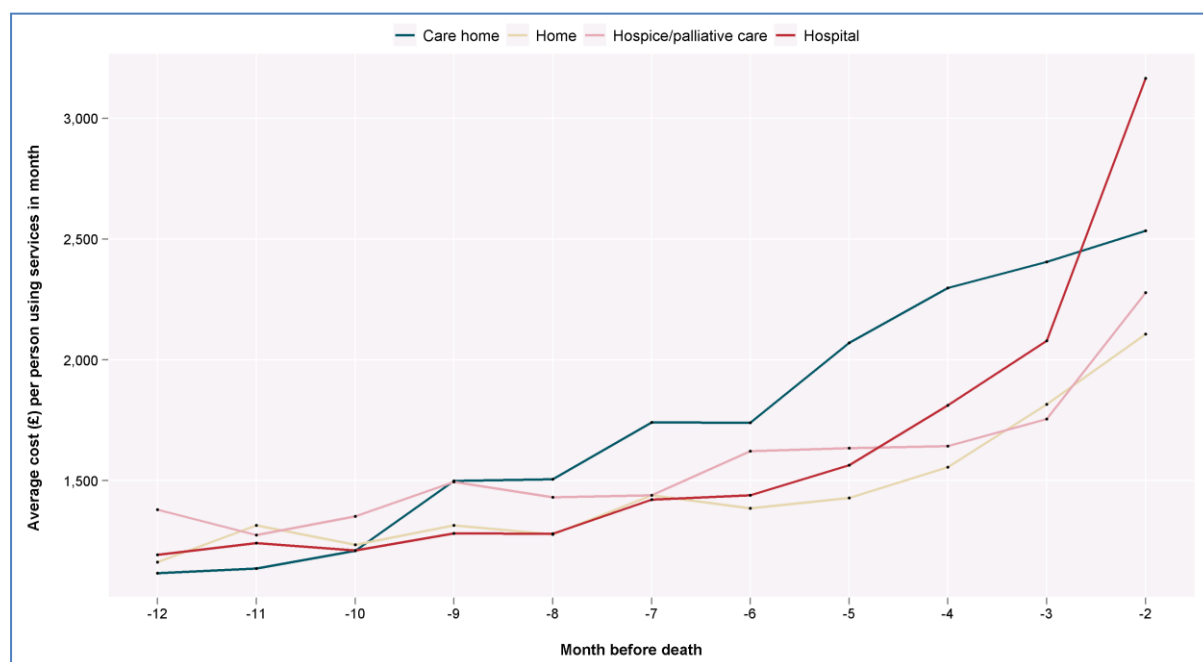
In site B, those who died in a hospice or specialist palliative care unit had slightly higher average hospital costs over much of the final year of life, compared with those with cancer who died elsewhere (see Figure 4.31). Those who died in hospital had a very significant increase in average hospital costs in the penultimate month of life, mirroring the pattern seen for the proportion of people who had an emergency admission.

**Figure 4.31: Average cost per person of hospital care over the last year of life, by place of death**



The average cost per person who received hospital care in each month rose from around £1,000 per month a year before death, to over £2,500 in the penultimate month of life for those who died in hospital. The average cost in the penultimate month for those who died outside hospital was between approximately £1,800 and £2,000 (see Figure 4.32).

**Figure 4.32: Average cost of hospital care per person who used services over the last year of life, by place of death**



*What was the relationship between hospital and social care costs in the final year of life?*

On average, the hospital and social care cost of each cancer death was approximately £11,400. Over 85 per cent of the cost of care in the last year of life was due to hospital care. There was significant variation between cancer types, with acute leukaemia cases incurring the highest cost per person, largely due to hospital care. Table 4.6 shows the average costs per death of hospital and social care in the final year of life, by cancer type.

**Table 4.6: Average costs per death of hospital and social care in the last year of life**

Cancer type	Hospital care	Social care	Overall
Acute leukaemia	£18,493	£263	£18,756
Haematological (excluding acute leukaemia)	£13,670	£1,812	£15,482
Head and neck	£13,279	£1,868	£15,147
Gynaecological	£10,980	£1,963	£12,943
Urological (excluding testes/prostate)	£10,836	£1,589	£12,426
Breast	£9,222	£2,865	£12,088
Brain/CNS	£10,925	£1,030	£11,955
Sarcoma	£11,294	£639	£11,934
Skin (excluding basal cell carcinoma)	£8,760	£2,497	£11,257
Lower GI	£9,547	£1,602	£11,149
Testicular	£11,009	£66	£11,075
Prostate	£8,651	£2,186	£10,837
Upper GI	£9,515	£1,151	£10,666
Lung	£7,994	£1,077	£9,071
Other	£6,302	£2,116	£8,418
<b>Overall</b>	<b>£9,767</b>	<b>£1,627</b>	<b>£11,393</b>

Figure 4.33 plots the average cost of hospital and social care per person in the cancer cohort. Twelve months before death, the average cost of hospital care was around 3.5 times the average social care cost. Over the final year of life the average social care cost rose slowly from £108 to £187, while the average hospital expenditure rose from below £400 to £1,750. Figure 4.34 shows these data broken down by cancer type. The pattern was broadly similar across cancer types, although average social care costs were higher for breast, prostate and skin cancer patients than for other cancer types.

Figure 4.33: Average cost per person of hospital and social care over the last year of life

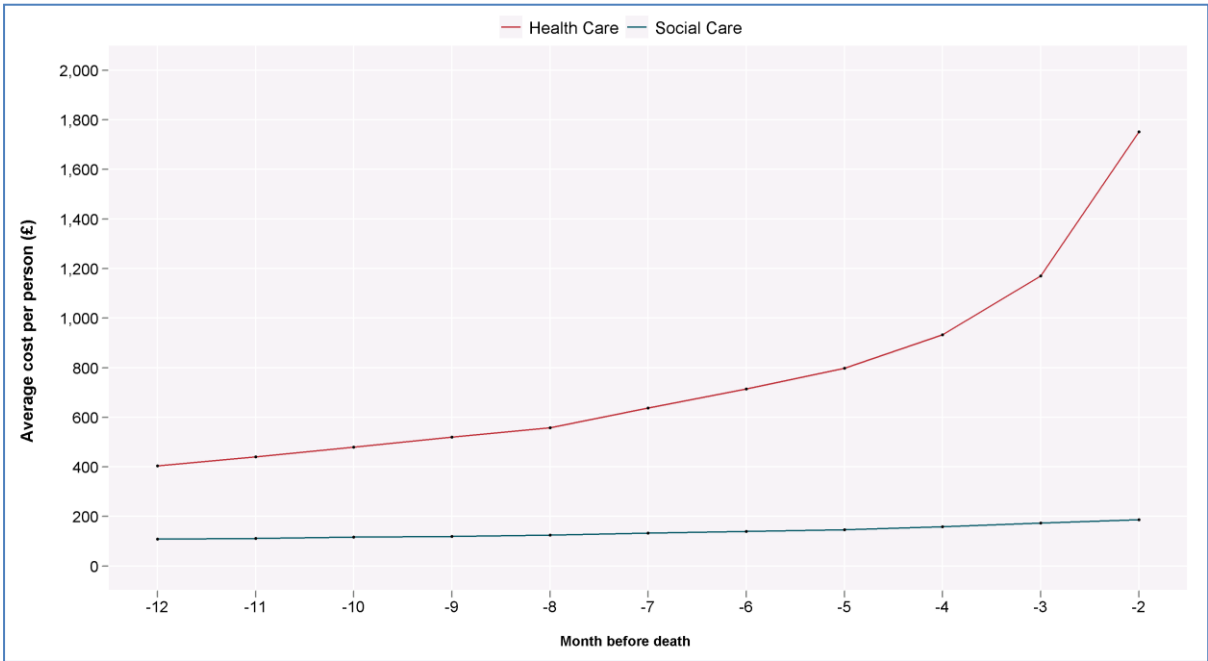
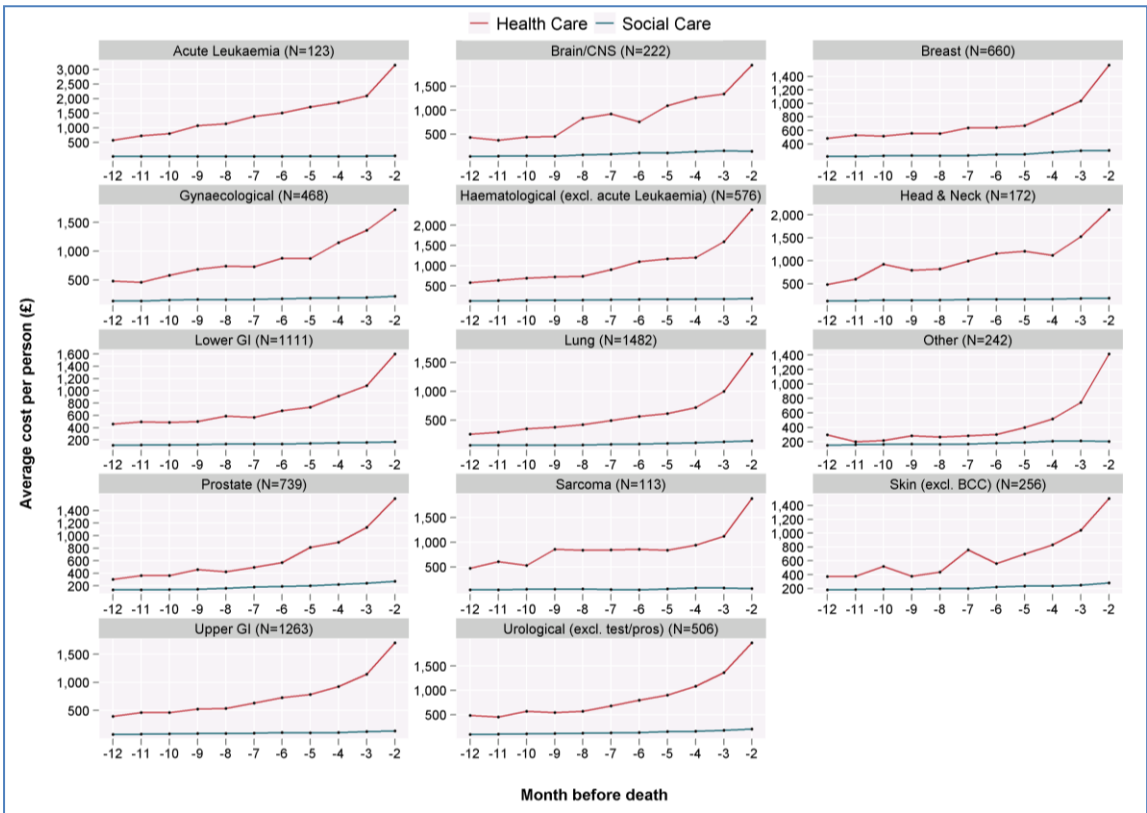


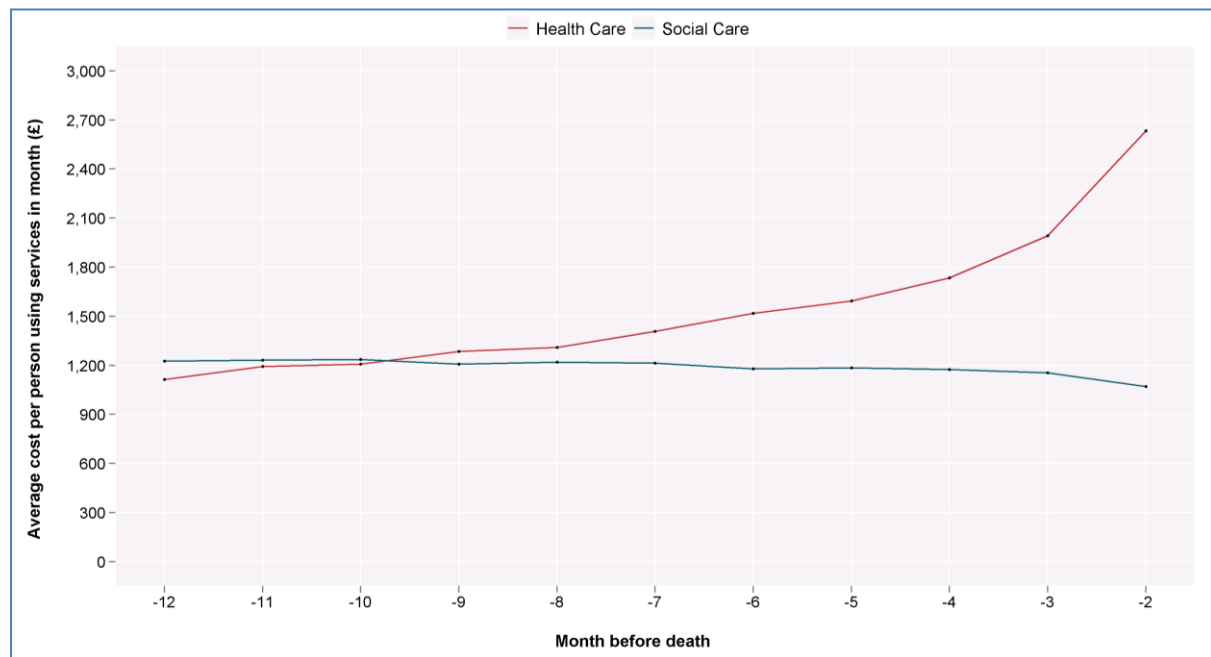
Figure 4.34: Average cost per person of hospital and social care over the last year of life, by cancer type



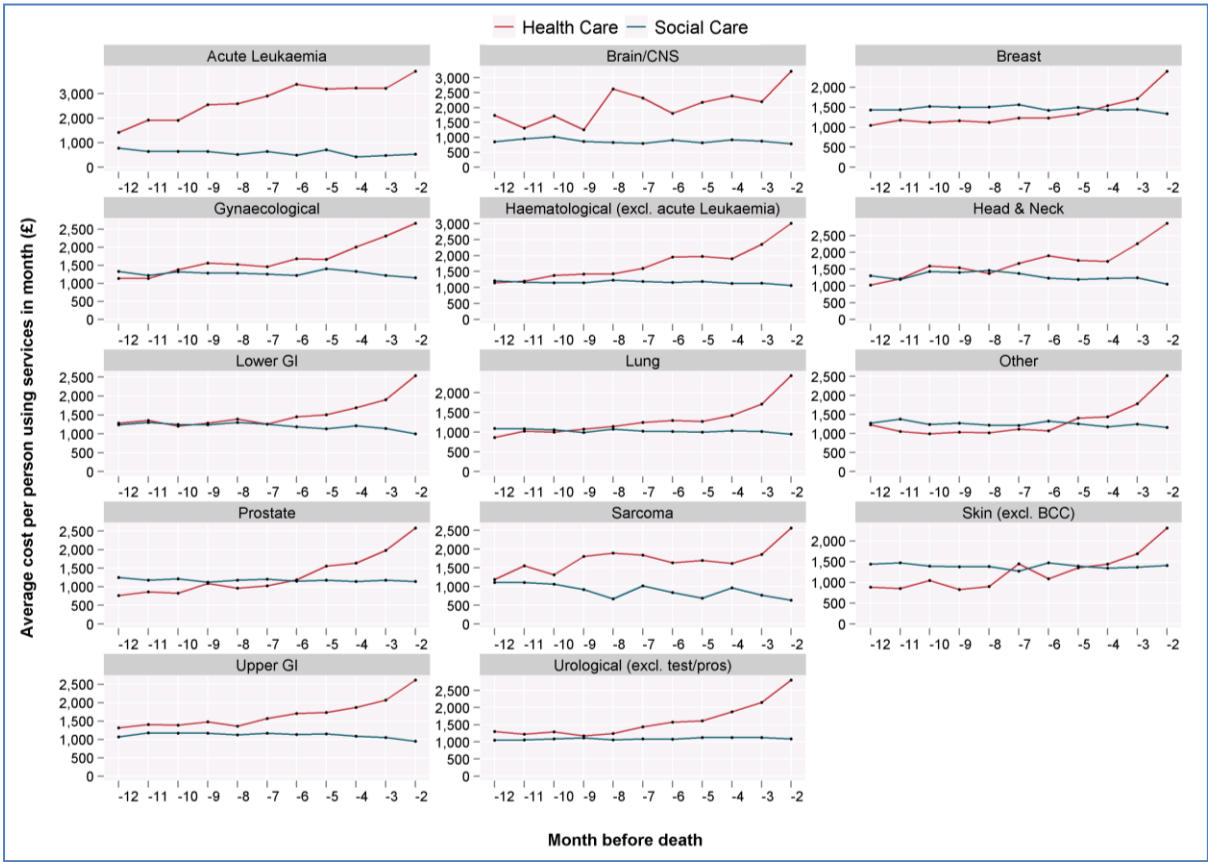


Looking at the average costs per person who received services and the pattern is slightly different (see Figures 4.35 and 4.36), with hospital costs slightly lower than social care costs a year before death. However, while the average social care costs fell slightly, the cost of hospital care rapidly grew and outstripped the average social care costs six months before death. There was much greater variation by cancer type. For patients with breast, prostate, skin or 'other' cancers, average social care costs were higher than hospital costs for much of the final year of life. For those with acute leukaemia, sarcomas or brain/CNS tumours, the average hospital costs were consistently higher than the social care costs.

**Figure 4.35: Average costs of hospital and social care per person who used services over the last year of life**



**Figure 4.36: Average costs of hospital and social care per person who used services over the last year of life, by cancer type**



## 5. Discussion

### Background

There are currently 1.8 million people in England living with and beyond a cancer diagnosis (Maddams and others, 2009). The next three to five years will see the NHS facing the major challenges of implementing new organisational structures arising from the Health and Social Care Bill 2011, and perhaps more importantly addressing the need to stay within increasingly constrained financial budgets (Smith and Charlesworth, 2011). In social care, a recent report found council spending on adult social services falling by 2.5 per cent in 2011/12, with 40 per cent of councils planning to make their criteria for receipt of services more stringent (Audit Commission, 2011).

Earlier diagnosis, more effective treatments and an ageing population are all contributing to an estimated three per cent annual increase in cancer incidence. With an increasing number of people surviving after a cancer diagnosis, there is a growing focus on the needs of cancer survivors, covering stages from diagnosis, active treatment and remission to relapse and end of life.

The health needs (particularly with respect to hospital-based care) of people with cancer are relatively well understood (Maddams and others, 2011a; 2011b), and other studies have attempted to quantify the inpatient direct health care and indirect economic costs of cancer (Bending and others, 2010; Broekx and others, 2011; Chirikos and others, 2002; Fleming and others, 2008; Fourcade and others, 2010; Hanly and others, 2012; Morris and others, 2009; O'Neill and others, 2012; Roehrborn and Black, 2011; Sangar and others, 2005; Tingstedt and others, 2011). However, there is an increasing recognition that people with cancer may have a range of broader social care needs, including help with activities of daily living (Macmillan Cancer Support, 2010). These needs may encompass a variety of services and may be both short-term (for example a home adaptation to assist with daily living) and long-term (for example admission to long-term residential or nursing care).

Recent work by the Nuffield Trust has shown that 14 per cent of people over the age of 75 use some form of local authority funded social care in one year (Bardsley and others, 2012), a figure that rises to 30 per cent of people at the end of life (Bardsley and others, 2010). We have also shown that the level of social care can be inversely related to hospital care in older people (Bardsley and others, 2012), and other studies have shown substitution between health and social care (Forder, 2009). However, despite the growing number of people living with cancer, to date there has been remarkably little research into the nature of social care that is needed by, and provided to, people with cancer (Macmillan Cancer Support, 2010). We also do not know what the balance of health and social care costs is for these people. Yet understanding the type and level of services accessed and the associated costs should be fundamental to decisions about planning, commissioning and provision of appropriate services at a population level. Without such a basic understanding, there is the danger that service cuts will create more harm and that investments may go to the wrong places.

### Observations on the process

To the best of our knowledge, this is the first study that has attempted to link data on primary care, hospital and local authority funded social care use with data held by cancer registries. This has allowed us to explore a range of questions, which has not been possible previously. We set

out to investigate two separate but related topics – the use and costs of health and social care by people living with cancer, and at the end of life.

In undertaking this work we have proven how operational datasets for people with cancer can be safely linked for whole populations to shown transitions across primary care, secondary care and social care. Moreover, linkage to basic cancer registry datasets shows that there is a route into the further details and precise information captured about people with cancer held by the National Cancer Intelligence Network.

Though the sample was opportunistic, we believe that this study is still the largest of its type in the UK, covering two sites with a combined population of approximately 1.1 million people, and around 11,800 cancer registry records.

## Living with cancer

This analysis looked at 8,072 people for 12 months before and up to 18 months after their first cancer diagnosis.

### Social care – key findings

- Ten per cent of people received a local authority social care assessment within three months of being diagnosed with cancer. This ranged from three per cent of those with skin or breast cancer, to 20 per cent of those with brain/CNS tumours.
- Ten per cent of people diagnosed with cancer received some form of local authority social care service in the year after being diagnosed with cancer. This ranged from six per cent of those with breast or prostate cancer, to 18 per cent of those with brain/CNS tumours.
- Eleven per cent fewer people than expected used social care six months before diagnosis, and 50 per cent more people than expected received social care in the three months after diagnosis, while ten per cent more people than expected used social care after 18 months.
- People with cancer were significantly less likely to use social care than people with other chronic conditions
- Fifteen months after diagnosis, people with cancer had nearly twice as many emergency admissions, four times as many outpatient attendances and over five times as many elective hospital admissions as expected.
- Access to social care was significantly higher in one site, and access to social care assessment varied between hospitals, and where people were diagnosed.

Our results showed that there was evidence of a response by social services being triggered by a cancer diagnosis, with a very sharp rise in the number of people being assessed immediately after diagnosis. Overall, ten per cent of people diagnosed with cancer received a social care assessment within three months of diagnosis. This ranged from three per cent to 31 per cent, and was highest in those with lung and brain/CNS tumours, and for those aged over 85. There were also factors that were less predictable. For example, people in one site were significantly more likely to receive an assessment, and there were differences by hospital – an indicator of differences in practice. Having surgery only was associated with a lower likelihood of receiving a social care assessment, while those patients diagnosed while admitted to hospital were more likely to be assessed, perhaps arising from the better communication between teams within the hospital environment. These differences existed even when adjusting for a wide range of confounding variables.

Moving beyond assessments to care services, there was a clear increase in the number of people receiving a social care service after diagnosis. However, the pattern of social service response varied significantly by cancer type. People with brain/CNS, gynaecological, head and neck, lower GI or urological cancer showed a sharp increase in the use of social care following cancer diagnosis. This spike was particularly due to more people receiving interventions such as equipment/adaptations and home care.

In contrast, people with cancer of the lung, breast or skin, or those with an unspecified cancer type, showed little evidence of a change in social care use after diagnosis. Those whose cancer was classified as lung or 'other' (predominantly cancer of unknown primary) were significantly more likely to be in receipt of social care both before and after being diagnosed with cancer. For those with lung cancer, this was likely to be due to the presence of comorbidities such as COPD, which might have led to earlier support from social services. Those whose cancer type was unknown or ill-defined were likely to have been complex cases presenting with a range of symptoms that made diagnosis difficult. It should be noted that both these groups also had high mortality rates within three to six months of diagnosis.

One intriguing observation was that people who went on to be diagnosed with cancer were less likely to use social care before diagnosis than the age-adjusted population average. This difference was predominantly accounted for by lower use of nursing home care, and, to a lesser extent, direct payments, and was found in older age groups. We cannot explain this finding fully but we suspect that it is a product of the cancer cohort being generally less deprived. This would mean that they were less likely to receive means-tested local authority services, but also that the prevalence of comorbid chronic conditions was slightly lower. This may in turn have led to greater premature mortality in the non-cancer group.

Conversely, across most cancer types, the rate of social care use 18 months after diagnosis was noticeably higher than expected. This seemed to be predominantly accounted for by people receiving home care, with 40 per cent more people than expected receiving home care up to 18 months after diagnosis. This effect was also seen for hospital care, particularly for planned inpatient and outpatient activity, and for GP surgery visits. Our main findings in relation to primary care and hospital activity are summarised above and so will not be discussed in detail here. However, it is worth noting that a previous study (Maddams and others, 2011a) found that people who had colorectal and lung cancer continued to have relatively high levels of inpatient hospital care in the second and third years after diagnosis.

The average cost of social care per person living with cancer remained remarkably stable over time, with the spike in social care usage not reflected in the costs. This is likely to have been due to lower use of residential care (possibly due to people being in hospital), countering the increased use of lower cost services such as home care and equipment/adaptations. There was also some evidence of a shift in expenditure over time from residential to nursing home care. Among those who received social care, the average cost varied by cancer type, with those with breast or skin cancer being relatively costly – mainly due these people tending to be older, and therefore being more likely to use expensive services such as residential care.

There was significant variation in the cost of hospital care by cancer type. People with acute leukaemia had the highest average cost by some considerable margin, while those with skin or prostate cancer were much less expensive. Across all those with cancer, the costs of hospital and social care were relatively similar for most of the year before diagnosis. However, after diagnosis, unsurprisingly the costs of hospital care far outstripped those of social care, and this remained the case over a year after diagnosis.

A number of questions arise from all of this, not least that the observation of these rates does not of itself tell us what constitutes good or appropriate care. However, we note a finding from the recent review by Macmillan Cancer Support (2010, p. 7) that ‘many people with low to moderate social care needs fall outside of the social care system and rely on friends and family to provide the emotional and practical support that they need’.

### **Health care – key findings**

- A&E attendances for those diagnosed with cancer peaked in the three months leading up to diagnosis, when they were 3.5 times higher than expected. Emergency admissions peaked in the same period (eight times as many as expected), but remained relatively high in the quarter after diagnosis.
- Elective admissions and outpatient attendances peaked in the three months after diagnosis, when patients were most likely to be in the midst of active treatment.
- Fifteen months after diagnosis, people with cancer had 60 per cent more A&E attendances, 97 per cent more emergency admissions, four times as many outpatient attendances, and nearly six times more elective admissions than expected.
- There were variations in hospital use by cancer type. Unlike most cancers, emergency admissions for people with breast, head and neck, or skin cancer peaked in the quarter after diagnosis. Elective admissions remained at a relatively high level for skin, brain/CNS and urological cancers for over a year after diagnosis.
- People who went on to be diagnosed with cancer consistently had around ten to 15 per cent more GP visits than expected in the year before diagnosis.
- As with hospital activity, contact with GPs peaked in the period immediately after diagnosis but remained consistently higher than expected up to 15 months after diagnosis, when those living with cancer still had 50 per cent more visits than expected.
- All types of cancer showed a rise in GP contacts after diagnosis, although the rise for those with lung and upper GI cancer was less than the spike that was seen for other cancers.

### **End of life**

Our analyses examined the use of health and social care by people with cancer over their last 12 months of life, and the key findings are summarised below.

### **End of life care – key findings**

- Forty-two per cent of people with cancer who died had a local authority social care assessment in the last year of life. This increased from three per cent who were assessed 12 months before death, to 13 per cent assessed in the last full month of life.
- Twenty-seven per cent of people received local authority funded social care in the final year of life. This ranged from ten per cent of those with acute leukaemia, to over 30 per cent of those with breast or prostate cancer.
- Nine per cent of people used social care 12 months before death, which almost doubled to 17 per cent in the penultimate month of life.
- Twenty per cent fewer people than expected used social care in the final three full months of life. Only people with brain/CNS or prostate cancer used more than expected.

- The number of people with cancer who used nursing care in the final three months of life was only 40 per cent of the expected level, while for residential care it was 50 per cent. These low rates were particularly seen for GI and lung cancers.
- Cancer patients had around 20 per cent more emergency admissions, and more than 60 per cent more elective admissions and outpatient attendances, compared with others in the final few months of life.
- Thirty-six per cent fewer than expected of those who died in hospital used social care in the last three months of life. For those who died at home it was 23 per cent lower, and for those who died in a hospice it was 13 per cent lower.
- People with cancer who died in a care home had 17 per cent fewer emergency hospital admissions in the final three months of life than expected, while those who died at home had eight per cent fewer admissions.
- Hospital costs accounted for 84 per cent of the total costs for cancer patients in the final year of life. The proportion of costs accounted for by social care ranged from 1.5 per cent for those with acute leukaemia, to 27 per cent for those with breast cancer.

Around 42 per cent of people with cancer who died received an assessment by social services, and 27 per cent received some form of local authority funded care service. There was a substantial increase in the number of people receiving both an assessment and some sort of care package (with a particularly significant rise in home care use) as death approached, indicating that services were responding to individuals' changing needs.

However, our findings broadly confirmed our previous research (Bardsley and others, 2010) in showing that *people with cancer used significantly less social care in the final three months of life* than did the wider population of people who died in the two sites. This difference was primarily due to very low numbers of people receiving residential or nursing home care, and was most striking for those with lung or GI cancers.

We believe that the most likely reason for the low level of social care use among people with cancer near the end of life is the use of voluntary sector nursing services provided by organisations such as Marie Curie, as well as NHS and voluntary sector palliative care services.

Our results showed a relatively high level of local authority funded social care use among those with brain/CNS cancer, with a high proportion (nearly 30 per cent) dying at home, but much lower levels of social care use in those with lung and GI cancers. The most recent survey of specialist palliative care services (National Council for Palliative Care, 2012) found that up to 90 per cent of people seen in such services had a cancer diagnosis. Of those, half of those admitted to specialist palliative units had digestive or respiratory cancer, while only three per cent had brain/CNS cancer.

Therefore, one possible explanation of the lower than expected use of residential and nursing care among people with GI or lung cancer is that they were much more likely to use specialist palliative care services towards the end of life. This might mean that they would have been less likely to require local authority funded social services. Conversely, those with, for example, brain/CNS cancer may have made much less use of specialist palliative services, and so may have relied more on local authority social care.

All forms of hospital use rose among people with cancer through the last 12 months of life, and were higher than the age- and sex-standardised expected rates in the final few months. Almost all cancers had a higher than expected number of emergency hospital admissions, and nearly a third of people with cancer had an emergency admission in the penultimate month of life. This may



raise questions about whether or not appropriate services were in place to try to reduce the need for emergency admissions towards the end of life.

People with haematological cancer were the most likely to die in hospital. This is consistent with other analysis, which reported a similar pattern (National Cancer Intelligence Network, 2011). A recent report (National End of Life Care Intelligence Network, 2012) found evidence of a significant link between deprivation and place of death. The authors found that people who died from cancer who were living in the least deprived quintile of areas were most likely to die in a hospice, care home or at home. Those who lived in the most deprived areas were most likely to die in hospital, while those in the least deprived areas were least likely to die while in hospital.

We found that those who died in a care home were much more likely to use social care in the last three months of life (25 per cent more people than expected). The opposite was true of those who died in hospital. Those who died at home or in a hospice were intermediate between the two, but less likely to use social care than the age-standardised population figure. This would be consistent with these groups receiving other support.

Those who died in hospital or in a hospice had higher than expected use of almost all forms of hospital care in the last three months of life. However, usage was consistently lower among those who died in a hospice. Those who died in a care home had consistently fewer hospital attendances and admissions. Those who died at home had lower unplanned hospital use (emergency admissions and A&E attendances).

While there was a substantial increase in the uptake of social care in the last 12 months of life, the associated cost gradient was far outstripped by the increase in hospital costs. The average cost of social care per person rose from £101 to £187 over the last year, the increase driven largely by home care and nursing home admissions. The average cost of health care rose from £350 to £1,750, driven mainly by emergency admissions. While the gradient of social care costs rose relatively steadily, although increasing towards the end of life, it was much steeper for hospital costs. The average cost per person nearly doubled from £792 to £1,500 in three months.

## Limitations

There are a number of limitations to the current study. First, it is based on data from only two areas. While we have no reason to believe that these are necessarily atypical, it is not possible to extrapolate the results more widely. Second, the analyses are based on data obtained from routine administrative systems and information flows. There are well-known limitations with using routine datasets, with possible question marks over data completeness and accuracy.

There are two sources of care about which we had no data. The lack of information on use of community nursing and specialist palliative care services by people with cancer represents a significant gap in this (and other) studies. Currently, person- and episode-level data is not routinely available for such services; however, there are moves towards the collection of such information from hospices and other palliative care providers (National Council for Palliative Care, 2012). This would be a significant step forward and would allow for the formation of a more complete picture of the use of care services towards the end of life.

We also only had access to data about services funded – at least in part – by local authorities. Social care support provided by local authorities is subject both to means-testing and eligibility



criteria. It is likely that some people in our samples self-funded social care that they required. However, the extent of such provision is hard to estimate.

Lastly, we know very little about the scale of need for social care among people with cancer. Routine council administrative systems have generally been relatively poor at recording individuals' needs. While we can use data on services provided as a proxy for need, this is far from adequate. Only a relatively small proportion of people with cancer in our sample were assessed for social care. Therefore it is possible that there might be significant numbers of people who would have benefited from some form of social care, but never received any. This may be because people did not know how to access such services or were unwilling to ask for help, their needs were not sufficient to meet councils' eligibility criteria, or they were not referred on to services for assessment (Macmillan Cancer Support, 2010).

## Implications

This work has shown how existing information streams can be used to provide a much greater level of detail about what services are actually being used by people with cancer. Moreover, by anonymised linkage across health and social care datasets we can see the timing of events and the interactions between services. Clearly these types of analyses need to be extended and repeated more widely to inform local decisions about the planning and commissioning of services.

We have shown that, although there is clearly a service response following the diagnosis of cancer for some patients, there is still a majority of cancer patients who are not assessed. Moreover, whether a patient gets a social care assessment or receives a service seems to vary between hospitals and areas – even when factors such as age, cancer type and deprivation are taken into account. What we cannot say is what the appropriate level of service should be.

Further research is required to explore the questions raised by this report. Possible avenues would include:

- Longer timescales – we have looked at health and social care use up to 18 months after a cancer diagnosis. Future work should extend this to understand long-term health and social care use.
- More geographical areas – this would allow us to develop a better understanding of variations in the availability and nature of social care provision to people with cancer, including the effect of different eligibility criteria.
- Social care needs and assessment – this report has identified (potentially) low levels of assessments by councils. However, future work should aim to further understand the reasons why people are or are not assessed, and what an appropriate level might be.
- Cancer stage – this report has not attempted to explore the effect of the stage at which an individual's cancer is detected. This is likely to be a significant factor in treatment options and therefore potentially in the possible need for social care.
- The interaction between care services and hospital use – given the drive to reduce unplanned hospital care, research should examine the degree to which community nursing services and other palliative care services can help to reduce emergency hospital admissions, particularly at the end of life.
- Use of primary care – the high level of use of primary care by cancer patients that was seen in one of the sites in this report is surprising. Further work would be needed to understand the reasons for this level of post-diagnostic activity.

- Influence of funding options – with an increasing drive for integrated care and pooled budgets, future work should aim to understand how different funding options for health and social care can improve integration and coordination of care for people with cancer.

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