

Use of health and social care by people with cancer

Research summary

Xavier Chitnis, Adam Steventon, Adam Glaser and Martin Bardsley

May 2014

There are estimated to be around two million people living with cancer in the UK. Improved survival rates, earlier detection and an ageing population have led to the incidence of cancer 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 shift from seeing it as a fatal illness to a chronic one, where people may be at different stages, ranging from diagnosis, active treatment, remission, relapse or 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. To find out how this impacts on the use of health and social care services, we used data linkage methods to track the patterns of service use across health and social care in the year after people were diagnosed with cancer.

Key points

- We studied the primary, secondary 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. We believe this is the first study that has attempted to link data on primary care and social care use with data held by cancer registries. This linkage allows exploration of a range of questions that previously it would not have been possible to address.
- The results show 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 (compared with seven per cent receiving care in the year before diagnosis). 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. However, we noted that social care use for those with cancer was less than for those with some other chronic diseases.
- Those subsequently 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.
- 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 per quarter. There was some variation between cancer types, for example, costs for people with skin or breast cancer tended to be higher compared with those with prostate cancer.
- Hospital use remained high for some time after diagnosis. Fifteen months after diagnosis, people with cancer had 60 per cent more Accident & Emergency (A&E) attendances, 97 per cent more emergency admissions, four times as many outpatient attendances and nearly six times more elective admissions than would be expected in

a population of the same age/gender. A similar pattern was seen for GP visits, with cancer survivors having 50 per cent more contacts than expected 15 months after diagnosis.

- We were able to analyse information on health and social care usage for 7,936 people where cancer was mentioned on the death certificate. Of this group 42 per cent were assessed by social services in the final year of life, with greater numbers being assessed in the months closer to death. In total, we found that 27 per cent of cancer patients received some form of local authority-funded social care in the final year of life.
- 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 estimated average cost per person of social care for the final 12 months of life was £1,600, and rose only slowly over that 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.



Background

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 due to cancer (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 can also have other emotional and practical needs associated with the illness or treatment, that require the involvement of social care services. These services might range from home care, equipment or adaptations to assist with activities of daily living, or 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 report by Macmillan Cancer Support argued that, ‘Cancer should be as much a social care concern as it is a health priority’ (Macmillan Cancer Support, 2010). It uses pseudonymised health, social care, GP and cancer registration data covering the period 2003 to 2008. It found that social services in the UK are not meeting the needs of people with cancer. People were often not referred for assessment by social services and did not know the sort of services that might have been available to them. The research also found that organisations who commissioned social care services had limited understanding of the specific needs of cancer survivors. In a previous survey, Macmillan Cancer Support found that 35 per cent of those with cancer did not know how to access social care and support (Macmillan Cancer Support, 2006).

This study 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. The analysis was based on linkage of existing records from cancer registry and hospital records; for full details of the methods used, see our accompanying research report (Chitnis and others, 2014). As a result, we were able to construct anonymised care histories at person level for over 8,000 people diagnosed with cancer. Figure 1 gives an example of the care histories for three people. These datasets cover the period up until 2008. Though the datasets are relatively dated, the general principles underlying their value and applicability can still be demonstrated. The research report that accompanies this summary (Chitnis and others, 2014) describes a range of analyses looking at patterns of service use before and after a cancer diagnosis. We also separately examined the subset of people that died. Our study examined questions such as:

- What was the pre-and post-diagnosis utilisation of health care and local authority-funded social care in people with cancer? How does this vary by type of cancer?
- How did the utilisation of health and social care by people with cancer following diagnosis compare to those without cancer? How does this vary by type of cancer?
- What was the use and cost of health and social care by people with cancer in the final year of life? How does this vary by type of cancer?

Figure 1: Anonymised examples of the care history of three people with cancer who used social care



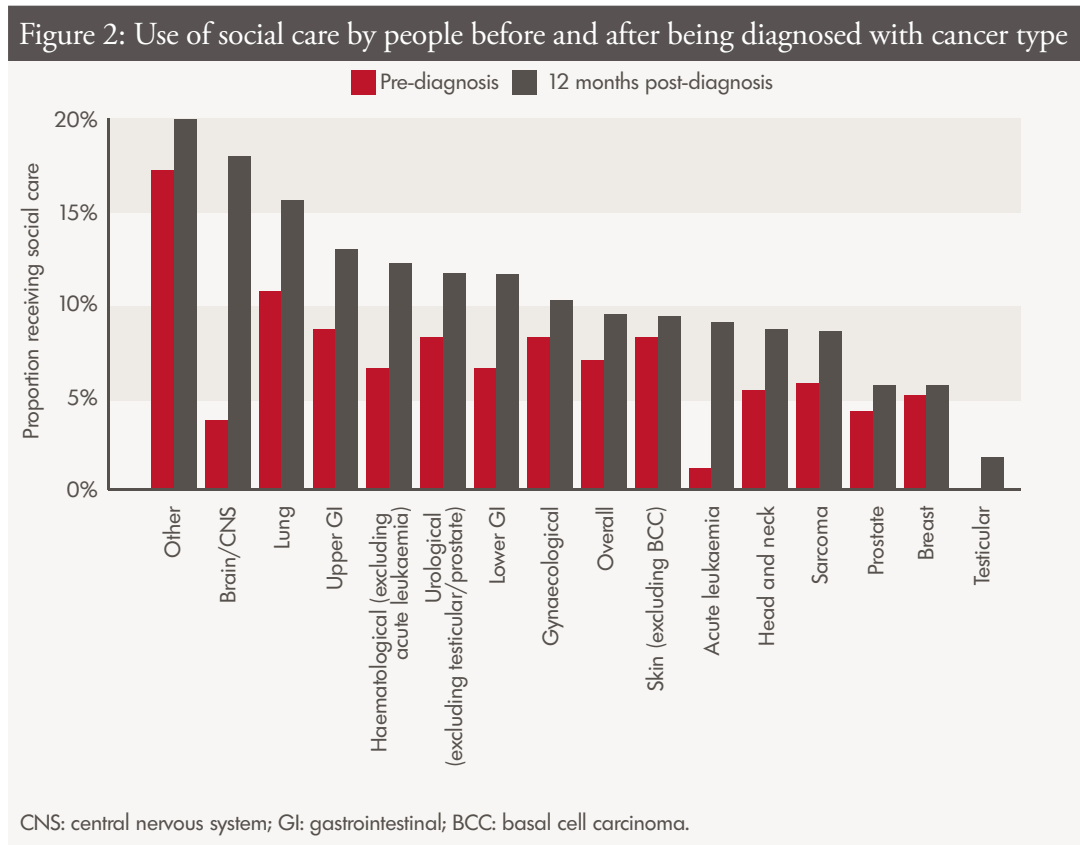
* Surgery plus either one or more of chemotherapy, radiotherapy and hormone therapy, or surgery plus a non-surgical treatment.
 † Patient died shortly after diagnosis. Vertical bar on diagram indicates time of death.

Findings

Use of social care for those living with cancer

We analysed the primary, secondary 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. 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. The use of resources at the end of life were analysed separately, including during this time period.

Our results showed clear evidence of a social services response to a person being diagnosed with cancer. Ten per cent of people received some form of local authority-funded social care service in the year after diagnosis, although we note that almost seven per cent of cases were also receiving care in the 12 months before diagnosis (see Figure 2). There were large differences in social care use by cancer type. All cancers showed an increase in social care use after diagnosis, although there was less evidence of this among those with lung, breast or skin cancer.



The level of social care use is strongly related to age, so we compared the use of social care for different cancer groups to the expected levels based on care use for people of the same age and sex – in some analyses we compared the observed and expected in the form of a standardised ratio (values greater than 100 indicate the observed numbers were higher than expected). Figure 3 charts the patterns for different cancer types; it

shows the differences in the baseline levels of social care and changes around diagnosis. For some cancers (lower gastrointestinal (GI) tract, skin including squamous cell carcinoma, prostate and brain/central nervous system (CNS)), rates of social care use before diagnosis were slightly lower than expected. However, the overall picture is that amongst survivors, people with cancer were more likely to be receiving social care 18 months after diagnosis. This seemed to be particularly due to people receiving home care. Consistent with our previous work (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 conditions were more likely to use social care than those without.

We also examined the factors associated with a greater likelihood of receiving a social care assessment. We found rates of assessment varied between the two sites studied, 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.

“ Fifteen months after diagnosis, people with cancer had 60% more A&E attendances and 97% more emergency admissions than would be expected in a population of the same age/gender

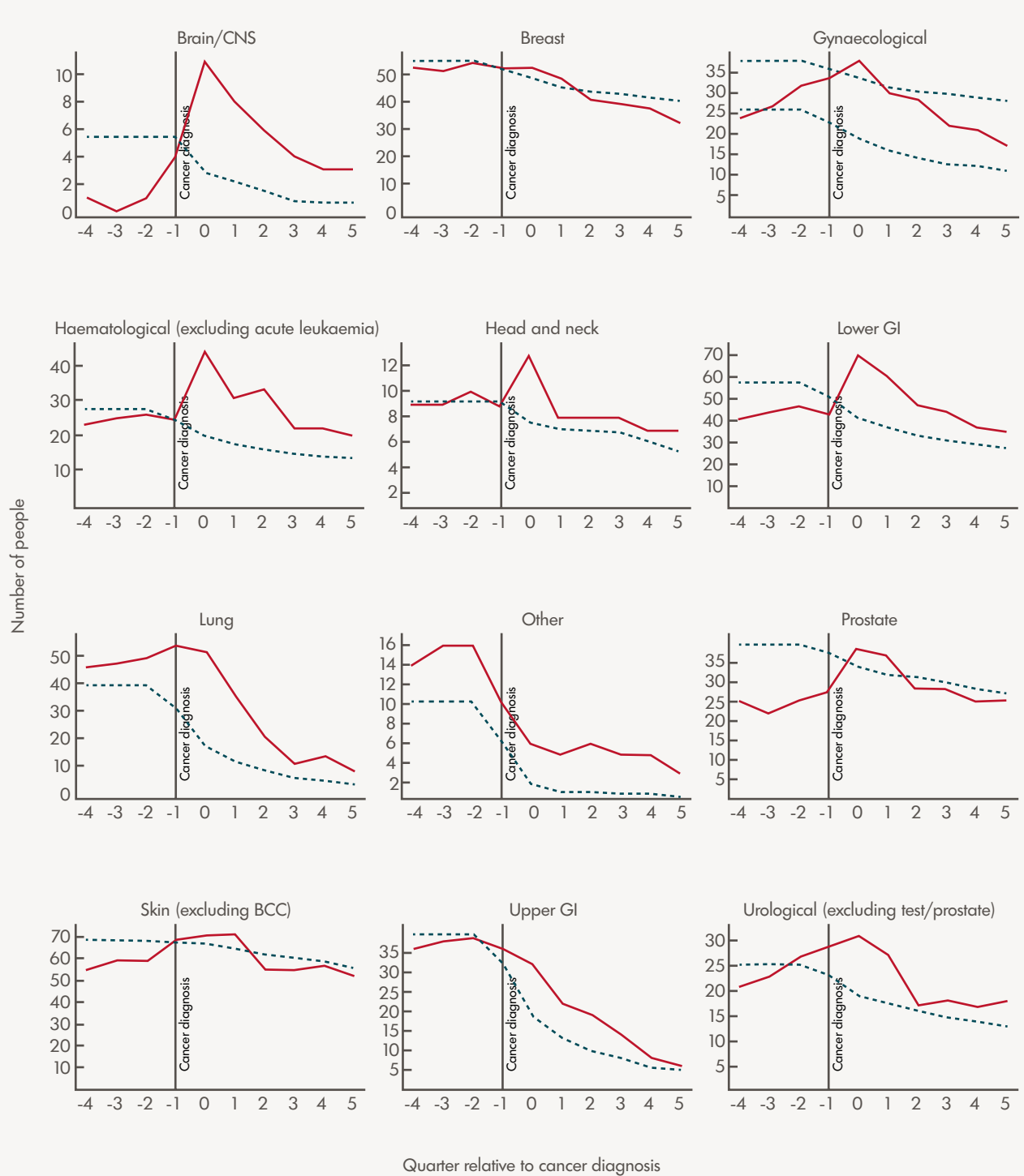
The total cost of social care in the period after diagnosis for those living with cancer was around £5.8 million. The corresponding figure for hospital care was over £48 million. The average cost of social care per person was relatively stable over time at around £140 to £180 per quarter. There was some variation between cancer types; the costs for people with skin or breast cancer tended to be higher 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 per 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.

Use of health services for those living with cancer

The patterns of health care services showed a clear increase in use after diagnosis – as might be expected. There were also some signs that the level of hospital and GP activity was increased before the time of a cancer diagnosis. Unplanned (emergency) hospital activity peaked for most cancers in the period around diagnosis, while elective admissions and outpatient attendances were generally at their highest in the three months after diagnosis (Figure 4). Use of hospital care varied by the type of treatment: those who only had surgery had many fewer admissions and attendances than those who had non-surgical treatment. Hospital use remained high for some time after diagnosis. Fifteen months post-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 would be expected in a population of the same age/gender. A similar pattern was seen for GP visits, with cancer survivors having 50 per cent more contacts than expected 15 months after diagnosis.

The costs of hospital care – based on the costs to commissioners – was very much higher than for social care and showed a clear peak in the three months after diagnosis. The additional costs associated with cancer tended to carry on, and were still visible in surviving patients after 12 months.

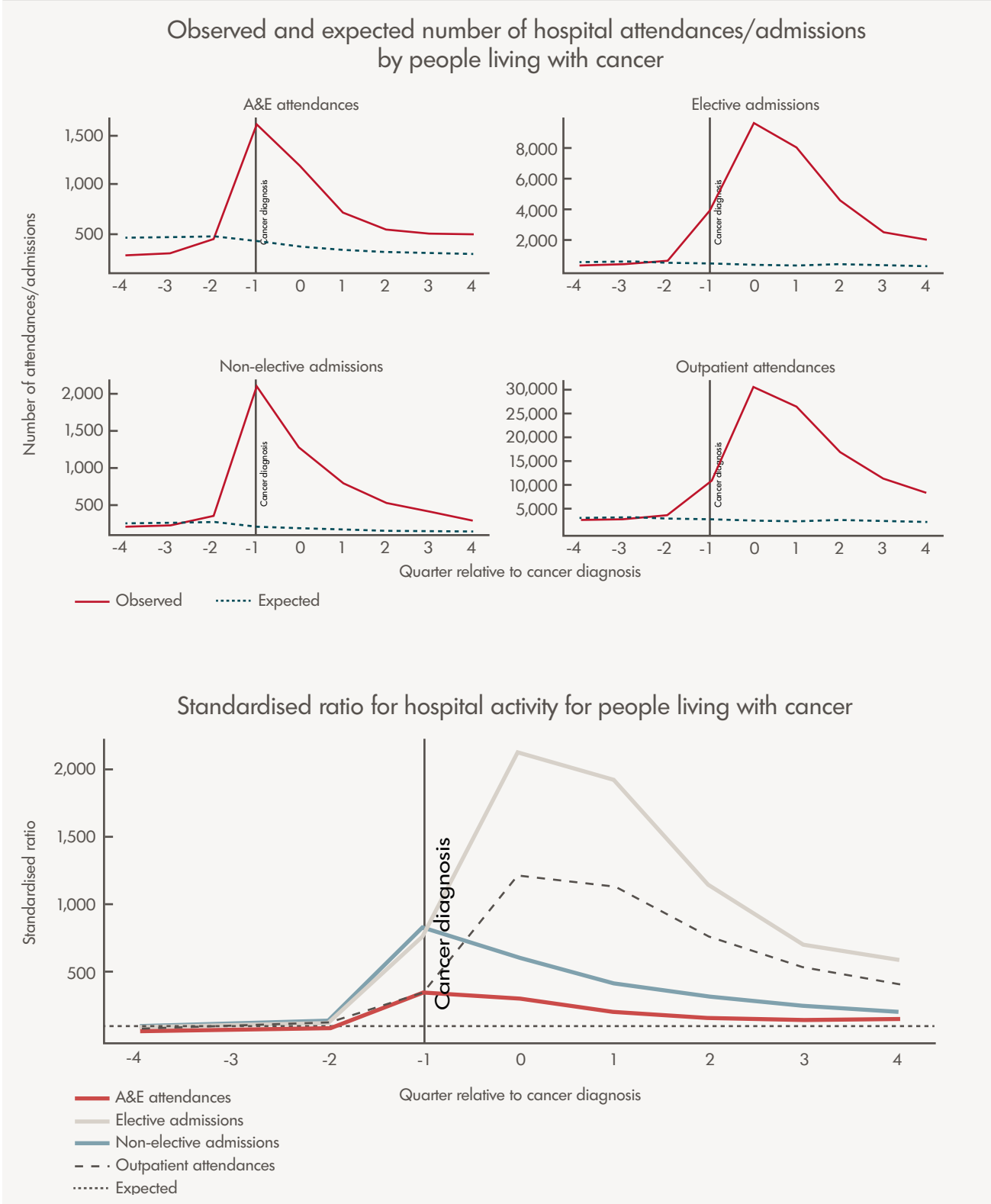
Figure 3: Observed and expected rates for use of social care by cancer type



CNS: central nervous system; GI: gastrointestinal; BCC: basal cell carcinoma.

— Observed - - - - - Expected

Figure 4: Standardised use of hospital care among people with cancer, by activity type



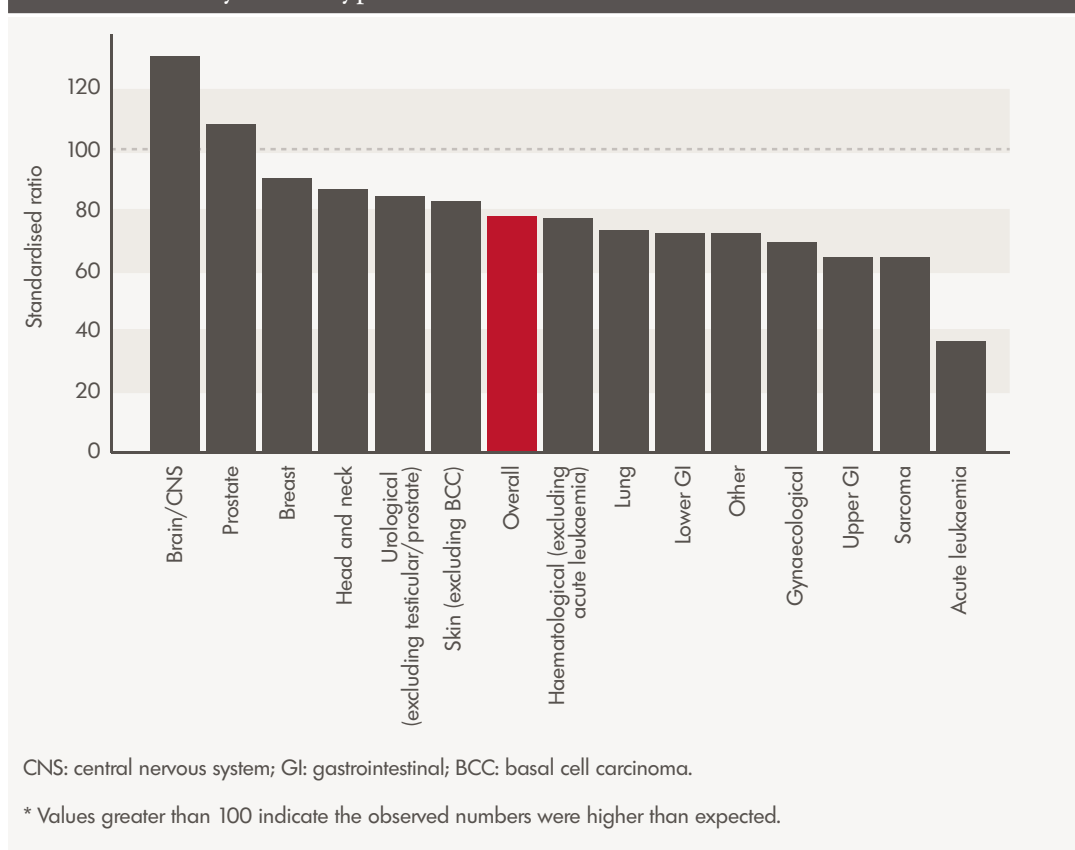
Use of services for people with cancer at the end of life

We were able to analyse information on health and social care usage for 7,936 people where cancer was mentioned on the death certificate. Of this group, 42 per cent were assessed by social services in the final year of life, with greater numbers being assessed in the months closer to death. In total, we found that 27 per cent of cancer patients received some form of local authority-funded social care in the final year of life. This varied by cancer type and 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.

We compared service use in those with cancer to a general population group who died to estimate what would have been expected for people of the same age. We found that 20 per cent fewer people with cancer received social care in the last three full months of life than would have been expected in a population of the same age. This was true of almost all cancer types, except brain/CNS and prostate cancer (Figure 5).

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).

Figure 5: Ratio of observed to expected levels of social care use in the last three months of life, by cancer type*



We found that people with cancer had significantly greater use of hospital care than people with other health problems at the end of life. In the last three full months, those with cancer had 20 per cent more emergency admissions, and over 60 per cent 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.

We estimated that for our overall group of people who died, the total cost of social care for those with cancer in the final year of life was £12.9 million, while the hospital costs were over £67 million. The average cost per person of social care was £1,600 for the final 12 months of life, and rose only slowly over the last year. For hospital care, the average cost was around £8,500 per person, and the costs rose much more sharply, particularly in the final two or three months of life. It is important to note that these costs are based on what commissioners would pay, that is they are derived from health services tariffs, mainly for hospital care. The actual cost of hospital may not equal the tariff the hospital was paid. In addition, there are other health care costs in the primary, community and voluntary sectors that are not included.

“ 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 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, and they also used less hospital care than those who died elsewhere. This is consistent with other previous work (Bardsley and others, 2012), which found that those who died in a care home used much less of all forms of hospital care than did those who died in other settings.

Conclusion

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. Until now there has been a lack of information about service use, particularly in relation to social care (Macmillan Cancer Support, 2010), but this study has demonstrated how existing information streams can be used to address this knowledge gap. Though the sample was opportunistic, we believe it is still the largest study 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.

The results of our analyses showed that there was evidence of a response by social services triggered by a cancer diagnosis, with a 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. For some people, receipt of social care is critical to their ability to retain independence and participate in society. Social care can also have important financial implications for service users due to the means-tested funding system that currently exists in England. These types of analyses may help patients to understand the possible implications of a cancer diagnosis. In addition, they provide a starting point for policy-makers and commissioners when considering the balance of resourcing required. However, it is difficult for us to judge whether the observed level of social care use is appropriate. That would require a further study that takes account of the impact of different services on patient outcomes.

However, we note a finding from the recent review by Macmillan Cancer Support that ‘Many people with low to moderate social care needs fall outside the social care system and rely on friends and family to provide the emotional and practical support that they need’ (Macmillan Cancer Support, 2010). Furthermore, an increasing amount of studies are showing the potential for substitution between health and social care. (Bardsley and others, 2012; Forder, 2009). Therefore, it is possible that the relatively low use of social care is leading to greater use of the health care system.

“ For some people, receipt of social care is critical to their ability to retain independence and participate in society

There was also 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 incurred much lower costs. 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 outweighed those of social care, and this remained the case over a year after diagnosis. These types of analyses can help to estimate the likely levels of resources needed according to the type of patient treated when comparing or planning services.

Although people with cancer incur significant costs across care sectors, use of social care services and overall costs were relatively modest and demonstrated differential patterns in response to diagnosis. Further, there was shift of costs away from social care

following diagnosis. This demonstrates the importance of understanding the long-term needs of cancer patients across both health and social care services for service planning, funding and assessing intermediate outcomes.


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 both the number of people receiving an assessment and some sort of care package (with a particularly significant rise in home care use) as death approached. 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 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.


As we continue to see significant financial constraint in health and social care funding, obtaining the information needed to make informed choices about care costs has become more important. Future work should seek to address the optimal design and integration of health and social care services for people with cancer, and the long-term social cost implications of these.

References

- Bardsley M, Georghiou T, Chassin L, Lewis G, Steventon A and Dixon J (2012) 'Overlap of hospital use and social care in older people in England', *Journal of Health Services Research & Policy* 17(3), 133–9.
- Bardsley M, Georghiou T and Dixon J (2010) *Social Care and Hospital Use at the End of Life*. Nuffield Trust.
- Bending MW, Trueman P, Lowson KV, Pilgrim H, Tappenden P, Chilcott J and Tappenden J (2010) 'Estimating the direct costs of bowel cancer services provided by the National Health Service in England', *International Journal of Technology Assessment in Health Care* 26(4), 362–9.
- Bosanquet N and Sikora K (2004) 'The economics of cancer care in the UK', *The Lancet Oncology* 5(9), 568–74.
- Broekx S, Den HE, Torfs R, Remacle A, Mertens R, D'Hooghe T, Neven P, Christiaens MR and Simoens S (2011) 'The costs of breast cancer prior to and following diagnosis', *European Journal of Health Economics* 12(4), 311–7.
- Chitnis X, Steventon A, Glaser A and Bardsley M (2014) *Describing the Use of Health and Social Care by People With Cancer. Research report*. Nuffield Trust.
- Forder J (2009) 'Long-term care and hospital utilisation by older people: an analysis of substitution rates', *Health Economics* 18(11) 1322–38.
- Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M and Moller H (2009) 'Cancer prevalence in the United Kingdom: estimates for 2008', *British Journal of Cancer* 101(3), 541–7.
- Macmillan Cancer Support (2006) *Worried Sick: The emotional impact of cancer*.
- Macmillan Cancer Support (2010) *Do Social Care Services Meet the Needs of People Affected by Cancer?*
- Morris S, Cox B and Bosanquet N (2009) 'Cost of skin cancer in England', *European Journal of Health Economics* 10(3), 267–73.

For more information about the Nuffield Trust,
including details of our latest research and analysis,
please visit www.nuffieldtrust.org.uk

 Download further copies of this research summary
from www.nuffieldtrust.org.uk/publications

 Subscribe to our newsletter:
www.nuffieldtrust.org.uk/newsletter

 Follow us on Twitter: [Twitter.com/NuffieldTrust](https://twitter.com/NuffieldTrust)

Nuffield Trust is an authoritative
and independent source of
evidence-based research and
policy analysis for improving
health care in the UK

59 New Cavendish Street
London W1G 7LP
Telephone: 020 7631 8450
Facsimile: 020 7631 8451
Email: info@nuffieldtrust.org.uk

 www.nuffieldtrust.org.uk

Published by the Nuffield Trust.
© Nuffield Trust 2014. Not to be reproduced
without permission.