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Marti, J, Hall, PS, Hamilton, P et al. (5 more authors) (2015) The economic burden of cancer in the UK: a study of survivors treated with curative intent. *Psycho-Oncology*. ISSN 1057-9249

<https://doi.org/10.1002/pon.3877>

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The economic burden of cancer in the UK: a study of survivors treated with curative intent

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The authors declare that they have no conflict of interest.

Acknowledgements

The electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) study was funded by Macmillan Cancer Support. We would like to thank the Corporate Finance Department of the National Health Service Leeds Teaching Hospitals Trust (LTHT) including Wendy Allott and Joe Selfridge who provided data from the LTHT Patient Level Information and Costing System.

Abstract

Objective: To describe the economic burden of UK cancer survivorship for breast, colorectal and prostate cancer patients treated with curative intent, one year post-diagnosis.

Methods: Patient-level data were collected over a three-month period 12-15 months post-diagnosis to estimate the monthly societal costs incurred by cancer survivors. Self-reported resource utilisation data were obtained via the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system and included community-based health and social care, medications, travel costs and informal care. Hospital costs were retrieved through data linkage. Multivariate regression analysis was used to examine cost predictors.

Results: Overall 298 patients were included in the analysis, including 136 breast cancer, 83 colorectal cancer and 79 prostate cancer patients. The average monthly societal cost was \$US409 (95%CI:\$US316-\$US502) [mean:£260, 95%CI:£198-£322] and was incurred by 92% of patients. This was divided into costs to the National Health Service (NHS) (mean:\$US279, 95%CI:\$US207-\$US351) [mean:£177; 95%CI:£131-£224], patients' out-of-pocket (OOP) expenses (mean:\$US40, 95%CI:\$US15-\$US65) [mean:£25; 95%CI:£9-£42] and the cost of informal care (mean:\$US110, 95%CI:\$US57-\$US162) [mean:£70; 95%CI:£38-£102]. The distribution of costs was skewed with a small number of patients incurring very high costs. Multivariate analyses showed higher societal costs for breast cancer patients. Significant predictors of OOP costs included age and socioeconomic deprivation.

Conclusions: This study found the economic burden of cancer survivorship is unevenly distributed in the population and that cancer survivors may still incur substantial costs over 1 year post-diagnosis. In addition, this study illustrates the feasibility of using an innovative online data collection platform to collect patient-reported resource utilisation information.

Keywords: oncology, cancer survivorship, costs, out-of-pocket expenses, informal care, economics.

Introduction

Cancer is becoming increasingly survivable thanks to advances in treatment and early detection. Better prognosis and a growing population in high-incidence age groups have led to a rising number of cancer survivors. There are approximately two million cancer survivors in the UK and this figure is expected to double by 2030 [1,2], which warrants a better understanding of the economic consequences of cancer survivorship.

It has been shown that 80% of UK cancer patients are more than one year away from both diagnosis and death and had not used any cancer-related acute health care in a given year [3]. While a substantial portion of costs is incurred during the first year following diagnosis [4-6], cancer may impose a significant economic burden on patients and the health system in the longer-term. Survivors may require continuing inpatient and outpatient care and support from relatives. While in the UK, the National Health Service (NHS) may cover costs such as community-based care and prescribed medications, other costs, such as travel to appointments or child care are mostly incurred by patients. In addition, informal care is time-consuming and has often been overlooked in economic evaluations in cancer [7,8].

Cost-of-illness studies in cancer vary widely in methodology, data type and level of aggregation making cross-study comparisons challenging. Most existing studies have focused on direct medical costs during the initial period of care and have been conducted in the United States or in other countries with disparate health systems with varying levels of direct financial participation from patients [9-19]. As the UK health system is predominantly publicly funded and mostly free at the point of use, results from most of these studies are not generalizable to the UK. Notable exceptions are studies conducted in Canada whose health system is also mainly public. Overall, there is a dearth of UK studies on the cost of cancer and, in particular, on the cost of cancer survivorship and related informal care. An exception is Macmillan's recent unpublished prospective study of over 1,600 cancer patients which found 83% incurred an average monthly economic loss following diagnosis of \$US900 (£570), with lost earnings and out-of-pocket (OOP) expenses accounting for the largest share of the burden [20]. While informative, this study had a low response rate (37%) and a heterogeneous sample that included both recently diagnosed patients and long-term survivors with multiple cancer types. The full economic impact of cancer survivorship on the UK NHS and on society as a whole is therefore not fully understood.

Our study aimed to fill this gap by: (1) describing the economic burden of cancer survivorship in the UK from a societal perspective for breast, colorectal and prostate cancer patients (three of the four most common UK cancers and the largest survivor groups [2]) treated with curative intent and (2) examining independent cost predictors.

Materials and methods

Framework for analysis

We used a standard cost-of-illness framework [21] such that we estimated direct medical costs and informal care time costs, and labelled the sum of all cost categories as societal costs. Direct medical costs are the actual expenditures related to health care utilisation for cancer treatment, continuing care and rehabilitation that are borne either by the NHS or paid directly OOP by the patient. The former include hospital costs, the use of community-based health and social care, and the use of medications reimbursed by the NHS. The latter include medications paid OOP, travel costs to and from appointments and extra expenses (e.g. child care). Informal care time costs were evaluated with the human capital approach [22] by assigning the relevant market value to the time spent by family and friends to provide care. In this study, we were not able to quantify patients' productivity losses (or indirect costs). See Figure 1 for an overview of the cost categories.

Data and sample

Multiple data sources were linked to obtain relevant patient-level clinical and financial information for a three-month period 12-15 months post-diagnosis. Non-hospital resource use data were collected as part of a feasibility study to test a novel electronic system for collecting patient-reported outcomes online; the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system. Comprehensive accounts of the design and development of the ePOCS system [23], the protocol [24] and results [25] of the feasibility study have been published open-access. The ePOCS study received NHS ethical approval (ref.10/H1306/65). In the study, adult patients were recruited from Leeds Teaching Hospitals NHS Trust (LTHT) and Calderdale & Huddersfield NHS Foundation Trust (CHFT) and were eligible to participate if diagnosed with potentially curable breast, colorectal or prostate cancer within the last 6 months, and if English literate. Recruitment was undertaken by NHS clinicians and research nurses. Efforts were made to approach all consecutive eligible patients. Patients in the feasibility study completed quality-of-life questionnaires using the ePOCS system at three time-points; within 6 months of diagnosis (T1), and at 9 (T2) and 15 (T3) months post-diagnosis. At T3 patients completed a financial cost of cancer (FCC) questionnaire about the resources they had used as a result of cancer and its treatment in the previous three months (see supplemental appendix). The ePOCS system allowed patients' questionnaire responses to be linked with their sociodemographic and clinical cancer registry data. We used information on gender, age at diagnosis, diagnosis (breast, colorectal or prostate cancer), treatment (i.e. chemotherapy, surgery, hormone therapy, radiotherapy) and level of socioeconomic deprivation measured via the index of multiple deprivation (IMD) calculated from patients' postcodes [26]. Hospital costs were obtained through linkage with the pilot database of the National Patient-Level

Information and Costing System (PLICS) using patients' NHS numbers. PLICS provides new opportunities for the calculation of the complete hospital-based cost of care, and offers an improvement over current methods which rely on coded Human Resource Groups (HRGs) and assigned national standard tariffs.

Costing analysis

We used a micro-costing approach where we first collected information on resource utilisation at the individual level and then, where appropriate, applied standardised unit costs to obtain patient-level costs [22].

In the FCC questionnaire (see supplemental appendix), patients were asked to report the number of contacts over the previous three months with various different health professionals (e.g. GP, practice nurse), as well as where each contact took place (e.g. on the phone, at the hospital, etc.). The unit cost of each contact type was obtained from the Personal Social Services Research Unit of Health and Social Care [27]. Patients were asked to provide information on their medications (e.g. name, dose) and whether they paid for their prescriptions. The price of each medication was obtained from the British National Formulary [28]. The cost of medication to the NHS was calculated depending on whether patients paid for their prescriptions. If a patient paid for their prescription this was taken at a cost of \$US12.10 (£7.65) per item and this charge was taken off the total cost of that medication accrued over the three-month period. Patient OOP medication costs included the cost of over the counter medications and the cost of prescriptions if patients paid for them. The cost of travel to appointments was based on the distance travelled by car by the patient to and from appointments at a price of \$US0.35 (£0.22) per mile [29] and on the total cost of using public transport and taxis. Extra costs included all patient-reported OOP expenses incurred by them or their carers as a result of cancer over the three-month period, such as paying for additional heating, childcare or incontinence pads. Patients were then asked to report the average number of hours per week family and friends had given them practical help as a consequence of cancer over the previous three months. This number was multiplied by the number of weeks (12) and the median hourly wage of home care workers (\$US11 (£7)) to obtain a conservative estimate of the economic value of informal care [27]. Because the patient FCC questionnaires were completed over a one-year time period (August 2011-October 2012), costs were not discounted.

Costs of hospital care were extracted from PLICS for each of the patients within the study over the time period of interest. PLICS records costs at the patient level for hospital-based accident and emergency department visits, outpatient attendances and inpatient stays. Individual care episodes are coded using the national HRG version 4 codes. HRG costing uses a mixture of: (a) top-down costing – where cost pools are allocated to HRGs using the total cost of that cost pool weighted for each HRG based upon the best available data and, (b) bottom-up costing – which builds up the costs of an HRG from known local expenditure HRGs

[30]. The costs contained within the PLICS database are derived entirely by bottom-up costing.

Statistical analyses

We used descriptive statistics to summarise societal costs, including NHS costs, patients OOP expenses and the costs of informal care. To facilitate interpretation and ensure comparability with earlier studies, we present monthly costs in each cost category. We examined associations between monthly costs and age (>70), gender, IMD (least deprived category), cancer site, treatment type, and hospital using two-part models to account for the high proportion of patients that incurred zero costs and for the skewness of the positive cost distribution. The first part of the model examines the probability of experiencing any cost using logistic regression, and the second part models the level of cost among those who have positive costs using generalized linear model with gamma family and log link [31,32]. The models were estimated for all cancer sites combined.

Results

Patients' characteristics

Of 1,152 eligible patients invited to join the ePOCS feasibility study, 636 (55.2%) consented to participate. Participants were significantly younger and more affluent than declining patients, although there were no differences by gender, diagnosis or time post-diagnosis. The majority of patients who offered a reason for non-participation cited technology-related issues (e.g. no computer/Internet access, do not like computers) [25]. We identified patients in the ePOCS study (N=636) who had not experienced a recurrence of their cancer and who had completed the FCC questionnaire 15 months post-diagnosis (n=397). As PLICS data were not available for CHFT patients, these patients were excluded from the analysis (n=83). Finally, we excluded 16 patients who had missing information on most items in the FCC questionnaire. Overall, 298 patients were included in the analysis. Table 1 provides information on patients' sociodemographic and clinical characteristics. Compared to the 'baseline' sample (N=636), patients who completed the FCC questionnaire were younger, more likely to have prostate cancer, less likely to have colorectal cancer and lived in less deprived areas.

Costs

Costs in each category are presented in Table 2. The mean monthly societal cost was \$US409 (95%CI:\$US316-\$US502) [mean:£260, 95%CI:£198-£322]. This comprised costs to the NHS (mean:\$US279, 95%CI:\$US207-\$US351)[mean:£177; 95%CI:£131-£224], patient OOP expenses (mean:\$US40, 95%CI:\$US15-\$US65) [mean:£25; 95%CI:£9-£42] and informal care (mean:\$US110, 95%CI:\$US57-\$US162) [mean:£70; 95%CI:£38-£102]. Hospital costs and informal care costs accounted for 47% and 27% of total societal costs respectively. A large number of patients incurred little or no societal cost although a small proportion had very high costs (see supplemental appendix). The proportion of patients incurring any cost differed by cost category, with some relatively frequently incurred (68%) but lower costs (e.g. travel costs) and others less frequently observed (19%) but higher costs (e.g. cost of informal care).

Costs in the three main categories were estimated by cancer site (Table 3). Results show that breast cancer patients incurred significantly higher monthly costs, mainly due to higher NHS costs. Costs for prostate cancer patients were lower in all cost categories. Seven patients incurred monthly costs above \$US3,160 (£2,000). The main cost driver was hospital costs for five of these patients and informal care for two patients who required extensive support from family and/or friends (>90 hours per week). Although the mean OOP cost is relatively low in this sample at \$US40 (£25), 11 (3.7%) patients incurred more than \$US158 (£100) a month in OOP expenses over the period. The majority (54.5%) of these patients had breast cancer

and main cost drivers were non-prescription medicines (e.g. Glucosamine, Vitamin E), and extra costs (e.g. child care and additional heating).

Results from the two-part models showed that prostate cancer patients were less likely to incur any societal cost than breast cancer patients and that, among those with costs, observed costs were lower. Patients who underwent radiotherapy were more likely to incur any societal and NHS cost, but they incurred lower costs on average. Models for NHS and OOP costs indicated that both colorectal and prostate cancer patients were less likely than breast cancer patients to incur any cancer-related costs. The second part of the OOP model showed that patients in the older age group incurred lower OOP costs, and that patients who live in the least deprived areas (i.e. lower quintile of socioeconomic deprivation) had higher OOP costs (see supplemental appendix).

Discussion

This paper analysed multiple data sources to estimate the economic burden of cancer survivorship at the patient level in the UK. Our estimates will inform economic evaluations of alternative technologies and practices in supportive cancer care. We found an average monthly societal cost of \$US409 (£260) among this sample of breast, colorectal and prostate cancer patients one-year post-diagnosis. The recent unpublished Macmillan study found an average monthly cost of \$US900 (£570), but their survey included both recently diagnosed patients and survivors, and included productivity losses in the analyses [20]. Other estimates yielded higher monthly costs, but were focused on direct costs in the intensive phase of care (\$US526 (£333)/month) [33] or on more severely ill patients (\$US1,513 (£958)/month) [34]. Our analysis showed that societal costs are mainly attributable to NHS and informal care costs, rather than patients' OOP expenses. Importantly, a majority of patients experienced little or no cost, but a small number of patients incurred very high costs, as previously found [20]. When comparing costs across cancer sites, we found that breast cancer patients had higher costs, mainly due to high NHS costs, which was confirmed in the multivariate analysis. These results contrast with previous findings from the US and Canada where studies found higher health system costs for colorectal cancer patients compared to breast and prostate cancer patients [4-6,35]. It is worth noting these studies relied mostly on population-based samples whereas we analysed a small sample, which may not be representative of the UK population of cancer survivors. In addition, three of these studies focused on the initial treatment period, up to 12 months post-diagnosis [4-6], and the other study included patients 65 years and older only [35], making direct comparisons difficult. The time frame of interest is important as most patients in all three groups are likely to have completed expensive primary treatment by twelve months post diagnosis. In addition, these previous studies include older data. In recent years new and relatively costly drugs

have been introduced for some groups of breast cancer patients following primary NHS treatment (e.g. Herceptin).

Overall, even in this sample of relatively healthy patients, the societal costs are not negligible and substantial support from family and friends was required. Our findings echo those of recent studies that highlight the importance of time cost for informal care in cancer survivorship [7,8]. In our sample, the main drivers of societal costs were costly hospital stays and extensive recourse to informal care. A possible explanation for this may be the presence of multiple long-term conditions in this patient group. While we do not have information on comorbidities, recent research has shown that more than half of cancer patients report having at least one other long-term condition [36]. Multivariate analyses showed that prostate cancer patients had consistently lower societal costs than breast cancer patients. When OOP expenses were analysed, we found that patients living in more deprived areas and who were older were less likely to incur high OOP expenses. While difficult to explain with the data at hand, the lower OOP costs among less affluent patients may be due to shorter distances travelled for inpatient treatments in this group [37]. An alternative explanation indicated by several observations in our sample is the more frequent use of non-prescription medicines among higher income breast cancer patients [38]. Regarding age, while older people may have accumulated assets over a lifetime, they are likely to have relatively low disposable income. In addition, some services such as travel on public transport that are costly for younger patients may be free at older age.

We were able to collect detailed information on NHS costs, OOP expenses and support from family and friends. The novelty of our approach lies in the use of new data collection platforms. The estimation of detailed hospital costs was performed using a new patient-level costing system and the patient-reported information on resource use was collected via the innovative web-based ePOCS system [23-25]. However, this study has several limitations that should be noted. First, we estimated societal costs based on data collected over a three-month period and hence have described only a “snapshot” of the burden of cancer survivorship. However, the focus on a short and recent time period will have likely enhanced recall accuracy among patients. Recall time frame and data collection platform are important determinants of recall accuracy in self-reported use of health care services [39]. A three-month period offers a good trade-off between accuracy and the risk of fluctuation of costs. Overall, our figures are likely to reflect a conservative estimate of the economic burden of cancer as it has been shown that patients often underreport resource utilisation [39]. Second, while respondents were asked to report specifically “resources used as a result of cancer and cancer treatment”, we cannot rule out that our estimates reflect some non-cancer-related costs. Third, the ePOCS feasibility study was restricted to English-literate patients and, as is often the case in research studies [40], those who joined were younger and more affluent than non-participants; this may limit the generalizability of our findings. Fourth, we were unable to recover detailed information on patients’ productivity losses. Recent estimates

have shown lost earnings account for more than 25% of the economic cost of cancer survivorship [20]. More data about the number of cancer-related working days lost would have been required to produce a comparable estimate. Another limitation is the lack of staging information included in the analysis. It is difficult to make comparisons between diagnostic groups using the different types of stage and the sample sizes were too small to perform the analyses by cancer type. In addition, staging information was missing for more than 10% of patients.

Given the increasing number of patients living with and beyond cancer, more research is needed to obtain a comprehensive understanding of the economic burden of cancer survivorship. In particular, as family and friends seem to provide crucial support for cancer survivors, studies which provide a more detailed account of the economic burden of informal care in cancer survivorship are needed [7,8]. As health care utilisation information is costly to routinely collect, especially in a chronic disease setting, a web-based system such as ePOCS could facilitate collection of the information required to undertake comprehensive economic analyses.

References

1. Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *Brit J Cancer* 2009;**101(3)**: 541-7.
2. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Brit J Cancer* 2012;**107**:1195-1202
3. Maddams J, Utley M, Møller H. Levels of acute health service use among cancer survivors in the United Kingdom. *Eur J Cancer* 2011;**47(14)**:2211-20.
4. Warren JL, Yabroff KR, Meekins A, Topor M, Lamont EB, Brown ML. Evaluation of trends in the cost of initial cancer treatment. *Journal of the National Cancer Institute* 2008;**100(12)**:888-897.
5. de Oliveira C, Bremner K, Pataky R, Gunraj N, Haq M, Chan K, Cheung W, Hoch J, Peacock S, Krahn M. Trends in use and cost of initial cancer treatment in Ontario: a population-based descriptive study. *Canadian Medical Association Journal Open*, **1**: E151-E158; published online December 9, 2013, doi:10.9778/cmajo.20130041
6. de Oliveira C, Bremner K, Pataky R, Gunraj N, Chan K, Peacock S, Krahn M. Understanding the costs of cancer care before and after diagnosis for the 21 most common cancers in Ontario: a population-based descriptive study *Canadian Medical Association Journal Open*. **1**:E1-E8; published online January 16, 2013, doi:10.9778/cmajo.20120013
7. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer* 2009;**115(S18)**:4362-4373.
8. Hanly P, Ceilleachair AO, Skally M, O'Leary E, Kapur K, Fitzpatrick P, et al. How much does it cost to care for survivors of colorectal cancer? Caregiver's time, travel and out-of-pocket costs. *Support Care Cancer* 2013;**21(9)**:2583-92.
9. Gordon L, Scuffham P, Hayes S, Newman B. Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psycho-oncol* 2007;**16(12)**:1130-9.
10. Guy GP, Ekwueme DU, Yabroff KR, Dowling EC, Li C, Rodriguez JL, et al. Economic burden of cancer survivorship among adults in the United States. *J Clin Oncol* 2013;**31(30)**:3749-57.
11. Tsimicalis A, Stevens B, Ungar WJ, McKeever P, Greenberg M, Agha M, et al. A prospective study to determine the costs incurred by families of children newly diagnosed with cancer in Ontario. *Psycho-oncol* 2012; **21**:1113-1123.
12. Lauzier S, Levesque P, Mondor M, Drolet M, Coyle D, Brisson J, et al. Out-of-pocket costs in the year after early breast cancer among Canadian women and spouses. *J Natl Cancer I* 2013;**105(4)**:280-92.
13. Mols F, Thong MS, Vissers P, Nijsten T, van de Poll-Franse LV. Socio-economic implications of cancer survivorship: results from the PROFILES registry. *Eur J Cancer* 2012;**48(13)**:2037-42.

14. De Oliveira C, Bremner KE, Ni A, Alibhai SMH, Laporte A, Krahn MD. Patient time and out-of-pocket costs for long-term prostate cancer survivors in Ontario, Canada. *J Cancer Surviv* 2013; doi:10.1007/s11764-013-0305-7
15. Yabroff KR, Borowski L, Lipscomb J. Economic studies in colorectal cancer: challenges in measuring and comparing costs. *JNCI Monographs* 2013;**2013(46)**:62-78.
16. Foster, T.S., et al., The economic burden of metastatic breast cancer: a systematic review of literature from developed countries. *Cancer treatment reviews* 2011; **37(6)**: p. 405-415.
17. Roehrborn, C.G. and L.K. Black, The economic burden of prostate cancer. *BJU international* 2011;**108(6)**: 806-813.
18. Short PF, Moran JR, Punekar R. Medical expenditures of adult cancer survivors aged <65 years in the United States. *Cancer* 2011; **117(12)**: 2791-2800.
19. Bernard DSM, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *Journal of Clinical Oncology* 2011; **29(20)**: 2821-2826.
20. Macmillan Cancer Support (2013). Cancer's hidden price tag: revealing the costs behind the illness. Available at: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf> (accessed March 2014)
21. Akobundu E, Jing J, Blatt L, et al. Cost-of-illness studies: a review of current methods. *Pharmacoeconomics* 2006; **24(9)**: 869-90
22. Brouwer W, Rutten F, Koopmanschap M. Costing in economic evaluations. In *Economic Evaluation in Health Care: Merging Theory with Practice*, Drummond M, McGuire A, (eds.). Oxford University Press: Oxford, 2001; 68–93.
23. Ashley L, Jones H, Thomas J, Forman D, Newsham A, Morris E, et al. Integrating cancer survivors' experiences into UK cancer registries: design and development of the ePOCS system (electronic Patient-reported Outcomes from Cancer Survivors). *Br J Cancer* 2011;**105**:S74–S81.
24. Ashley L, Jones H, Forman D, Newsham A, Brown J., Downing A, Velikova G, Wright P. Feasibility test of a UK-scalable electronic system for regular collection of patient-reported outcome measures and linkage with clinical cancer registry data: the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system. *BMC Med Inform Decis Mak* 2011; **11**: 66.
25. Ashley L, Jones H, Thomas J, Newsham A, Downing A, Morris E, Brown J, Velikova G, Forman D, Wright P. Integrating patient reported outcomes with clinical cancer registry data: a feasibility study of the electronic Patient-Reported Outcomes from Cancer Survivors (ePOCS) system. *J Med Internet Res* 2013; **15(10)**: e230. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24161667>.

26. Department for Communities and Local Government. English Indices of Deprivation: Guidance Document. London; 2010. URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6222/1871538.pdf (accessed March 2014)
27. Curtis, L 2012. Unit Costs of Health and Social Care. *Personal Social Services Research Unit*.
28. BNF. British National Formulary 65. London: BMJ Publishing Group; 2013.
29. AA running cost (petrol car) 2012. Available at: <http://www.theaa.com/resources/Documents/pdf/motoring-advice/running-costs/petrol2012.pdf> (accessed March 2014)
30. Department of Health Payment by Results team (2012) A Simple Guide to Payment by Results (London).
31. Manning W. Dealing with skewed data on costs and expenditures. *In The Elgar Companion to Health Economics*, Jones A (ed.). Edward Elgar Publishing: Cheltenham, 2012;473-480.
32. Mullahy J. Econometric modeling of health care costs and expenditures: a survey of analytical issues and related policy considerations. *Medical care* 2009;**47(S1)**:S104-S108.
33. Fourcade RO, Benedict Á, Black LK, Stokes ME, Alcaraz A, Castro R. Treatment costs of prostate cancer in the first year after diagnosis: a short-term cost of illness study for France, Germany, Italy, Spain and the UK. *BJU international* 2010;**105(1)**:49-56.
34. Remak E, Brazil L. Cost of managing women presenting with stage IV breast cancer in the United Kingdom. *British Journal of Cancer* 2004;**91(1)**:77-83.
35. Yabroff KR, Lamont EB, Mariotto A, et al. Cost of care for elderly cancer patients in the United States. *J Natl Cancer Inst* 2008;**100**:630-41.
36. Glaser, AW, Fraser LK, Corner J, Feltbower R, Morris EJ, Hartwell G, Richards M, Wagland R. Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey. *BMJ Open* 2013; **10**: 3(4).
37. Propper C, Damiani M, Leckie G, Dixon J. Impact of patients' socioeconomic status on the distance travelled for hospital admission in the English National Health Service. *J Health Serv Res Po* 2007; **12(3)**: 153-159.
38. Catt S, Fallowfield L, Langridge C. What non-prescription treatments do UK women with breast cancer use? *Eur J Cancer Care* 2006; **15(3)**: 279-285.
39. Bhandari A, Wagner T. Self-reported utilization of health care services: improving measurement and accuracy. *Medical Care Research and Review* 2006;**63(2)**:217-235.
40. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA* 2004; **291**: 2720-2726.

Table 1: Patient characteristics

	Full sample (n=298)	Breast (n=136)	Colorectal (n=83)	Prostate (n=79)
Gender (%)				
<i>Male</i>	134(45.0)	0(0)	55(66.3)	79(100)
<i>Female</i>	164(55.0)	136(100)	28(33.7)	0(0)
Age at diagnosis (%)				
<i>0-50</i>	54(18.1)	43(31.6)	10(12.0)	1(1.3)
<i>51-60</i>	77(25.8)	41(30.1)	21(25.3)	15(19.0)
<i>61-70</i>	122(40.9)	40(29.4)	32(38.6)	50(63.3)
<i>70+</i>	45(15.1)	12(8.8)	20(24.1)	13(16.5)
Employment status at interview (%)				
<i>Employed (full-time)</i>	76(25.5)	44(32.4)	14(16.9)	18(22.8)
<i>Employed (part-time)</i>	45(15.1)	34(25.0)	5(6.0)	6(7.6)
<i>Unemployed</i>	9(3.0)	1(0.7)	6(7.2)	2(2.5)
<i>Retired</i>	142(47.7)	41(30.1)	51(61.4)	50(63.3)
<i>Other</i>	20(6.7)	13(9.6)	5(6.0)	2(2.5)
<i>Missing</i>	6(2.0)	3(2.2)	2(2.4)	1(1.3)
Treatment (%)				
<i>Chemotherapy</i>	130(43.6)	87(64.0)	43(51.8)	0(0)
<i>Surgery</i>	196(65.8)	119(87.5)	60(72.3)	17(21.5)
<i>Hormone therapy</i>	56(18.8)	48(35.3)	0(0)	8(10.1)
<i>Radiotherapy</i>	113(37.9)	61(44.9)	12(14.5)	40(50.6)
<i>No treatment</i>	31(10.4)	1(0.7)	7(8.4)	23(29.1)
Socioeconomic status (%)				
<i>1 (most deprived IMD^a quintile)</i>	44(14.8)	19(14.0)	18(21.7)	7(8.9)
<i>2</i>	50(16.8)	22(16.2)	16(19.3)	12(15.2)
<i>3</i>	48(16.1)	21(15.4)	11(13.3)	16(20.3)
<i>4</i>	79(26.5)	37(27.2)	19(22.9)	23(29.1)
<i>5 (least deprived IMD^a quintile)</i>	77(25.8)	37(27.2)	19(22.9)	21(26.6)
Breast cancer stage (%)				
<i>Stage 1</i>		69(50.7)		
<i>Stage 2</i>		42(30.9)		
<i>Stage 3</i>		10(7.4)		
<i>Stage 4</i>		1(0.7)		
<i>Missing</i>		14(10.2)		
Colorectal cancer stage (%)				
<i>Duke's A</i>			17(20.5)	
<i>Duke's B</i>			23(27.7)	
<i>Duke's C</i>			26(31.3)	
<i>Duke's D</i>			2(2.4)	
<i>Missing</i>			15(18.1)	
Prostate cancer Gleason score (%)				
<i>6</i>				24(30.4)
<i>7</i>				40(50.6)
<i>8</i>				1(1.3)
<i>9</i>				6(7.6)
<i>Missing</i>				8(10.1)

^aIndex of Multiple Deprivation

Table 2: Monthly costs over the 12-15 months post-diagnosis period (2012 \$US)

	<i>% with cost</i>	Mean	Mean (without outliers) ^d	95%CI	Min (if cost>0)	Max
Costs to the NHS^a						
Hospital costs	34.2	\$194.2(£122.9)	\$169.2(£107.1)	\$127.5-\$206.7(£80.7-£165.0)	\$36.7(£23.2)	\$4045.3(£2560.3)
Community-based care	58.4	\$65.9(£41.7)	\$57.4(£36.3)	\$48.7-\$83.3(£30.8-£52.7)	\$11.5(£7.3)	\$1433.5(£907.3)
Cost of medications to the NHS	48.7	\$19.3(£12.2)	\$15.8(£10.0)	\$12.3-\$26.2(£7.8-£16.6)	\$0.09(£0.06)	\$541.6(£342.8)
Patients' out-of-pocket costs						
Cost of medications to the patient	9.1	\$11.9(£7.5)	\$5.4(£3.4)	\$-1.9-\$25.6(£-1.2-£16.2)	\$0.2(£0.1)	\$1473.8(£932.8)
Travel costs	68.1	\$7.1(£4.5)	\$6.0(£3.8)	\$4.9-\$9.2(£3.1-£5.8)	\$0.3(£0.2)	\$167.5(£106.0)
Extra costs	7.0	\$21.0(£13.3)	\$15.3(£9.7)	\$-1.3-\$43.6(£-0.8-£27.6)	\$5.2(£3.3)	\$3028.4(£1916.7)
Costs of informal care						
Value of carers' time ^b	18.9	\$69.4(£109.7)	\$80.3(£50.8)	\$58.3-\$161.0(£36.9-£101.9)	\$44.2(£28)	\$4645.2(£2940.0)
Total costs						
NHS costs	82.9	\$279.3(£176.8)	\$254.7(£161.2)	\$207.3-\$351.4(£131.2-£222.4)	\$0.3(£0.2)	\$4068.3(£2574.9)
Patient OOP ^c costs	69.5	\$39.8(£25.2)	\$26.9(£17.0)	\$14.5-\$65.3(£9.2-£41.3)	\$0.3(£0.2)	\$3028.4(£1916.7)
Informal care costs ^b	18.7	\$109.7(£69.4)	\$80.3(£50.8)	\$57.4-\$162.1(£36.3-£102.6)	\$44.2(£28)	\$4645.2(£2940.0)
Total societal costs^b	91.7	\$408.9(£258.8)	\$372.3(£235.6)	\$315.5-\$502.4(£199.7-£318.0)	\$0.3(£0.2)	\$5711.9(£3615.1)

^aNational Health Service; ^bBased on 288 observations with available carer time information; ^cOut-of-pocket;

^dOutliers are defined as patients with costs equal to or above the 99th percentile

Table 3: Mean (95%CI) monthly costs across cancer type (2012 \$US)

	Full sample (n=298)	Breast (n=136)	Colorectal (n=83)	Prostate (n=79)
NHS costs	\$279.3(\$207.3-\$351.4) <i>£176.8(£130.3-£223.3)</i>	\$394.2(\$261.5-\$526.9) <i>£249.5(£165.5-£333.5)</i>	\$218.4(\$118.5-\$318.4) <i>£138.2(£75.0-£201.5)</i>	\$145.5(\$77.9-\$213.1) <i>£92.1(£49.3-£134.9)</i>
Patient OOP ^a costs	\$39.8(\$14.5-\$65.3) <i>£25.2(£8.9-£41.6)</i>	\$49.0(\$12.2-\$86.0) <i>£31.0(£7.7-£54.4)</i>	\$52.0(\$-22.9-\$126.9) <i>£32.9(-£14.5-£80.3)</i>	\$11.4(\$3.6-\$19.0) <i>£7.2(£2.3-£12.0)</i>
Informal care costs ^b	\$109.7(\$57.4-\$162.1) <i>£69.4(£37.0-£101.9)</i>	\$111.9(\$37.0-\$186.8) <i>£70.8(£23.4-£118.2)</i>	\$187.5(\$64.3-\$310.8) <i>£118.7(£40.7-£196.7)</i>	\$25.9(\$-8.7-\$60.5) <i>£16.4(-£5.5-£38.3)</i>
Total societal^b	\$408.9(\$315.5-\$502.4) <i>£258.8(£197.4-£320.2)</i>	\$528.7(\$366.4-690.8) <i>£334.6(£231.9-£437.2)</i>	\$426.0(\$251.2-\$600.7) <i>£269.6(£159.0-£380.2)</i>	\$186.3(\$108.9-\$263.9) <i>£117.9(£68.9-£167.0)</i>

^aOut-of-pocket; ^bBased on 288 observations with available carer time information

Figure 1: Overview of the cost categories

