

The financial impacts of cancer

Final report

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1 Measuring the financial impacts of cancer

What, if any, are the additional financial costs that are associated with cancer? How and when do these costs arise, and how do they impact on the financial and wider wellbeing of adults with cancer and their households?

In spring 2012, Macmillan Cancer Support commissioned the University of Bristol's Personal Finance Research Centre and TNS BMRB to explore these questions and more in a landmark research study.

Previous research undertaken for Macmillan in 2006 highlighted the hidden costs of cancer (RDSi, 2006). Finding then that seven in 10 households faced extra costs just to get to their treatment and that a third also suffered a loss of income, the study concluded that families were dealing with a 'huge financial burden' as a result of a cancer diagnosis. Six years on and at a time when many households' finances are already squeezed by the increased cost of living and insecure incomes (Finney and Davies, 2011) any additional cost arising as a result of cancer has the potential to add significantly to that burden.

Recent research for Macmillan estimated that the average financial cost to people diagnosed with cancer in Wales was £5,800 in the first five years post-diagnosis. Costs associated with loss of income (where incurred) and travel were again the biggest drivers of the total cost and, linked closely to people's treatment programmes, the greatest share of the cost was incurred in the first year post-diagnosis (£2,100; Monitor Company Group).

About this research

This new study examined the cost of cancer through a wide lens, considering the cost arising through lost incomes and increased expenditure across a broad range of areas of expense. It

measured the total cost arising as a direct result of a diagnosis or treatment and explored the impact of this on households' financial wellbeing and quality of life.

Calculated and expressed as a monthly equivalent cost, the study cannot provide any in-depth assessment of the longevity of the different costs that arise as a result of cancer. Nonetheless, the study relates the costs of cancer and their impacts to people's demographic and socio-economic characteristics as well as their diagnosis and cancer journey. In this way, the findings help to identify which groups of people are most vulnerable to the costs of cancer, when and why.

The focus of the study was explicitly on adults with cancer and their households. The costs of cancer among children and young people were the subject of a recent study by CLIC Sargent (Gravestock, 2011).

The research was undertaken in two phases.

Phase 1: Depth interviews

This first phase of the research involved 24 qualitative depth interviews with people who had been diagnosed with cancer. The interviews took place in locations across the south of England and Wales in May 2012.

Volunteers to take part in the depth interviews were mostly recruited from a database of callers to the Macmillan Support Line, which offers advice, information and support to people with concerns about cancer across a range of issues.

The participants were selected purposively to represent a range of people by cancer type, stages and time since diagnosis, as well as gender, age group, and family status. The hour-long interviews explored:

- The nature of the financial costs arising in relation to their diagnosis;
- How and when these costs arose; their experience and perception of these costs; and

- How they impacted on individuals and their families, financially and in other ways.

The findings from the depth interviews were undertaken primarily to inform the design of the questionnaire. They are also used in this report to supplement and illustrate findings from the survey. Where names of participants are referred to, these have been changed (along with selected key demographic information) to protect individuals' identities.

Phase 2: National survey

The second phase of the study involved a survey of people with a cancer diagnosis. The fieldwork for this stage of the study, which covered England, Wales, Scotland and Northern Ireland, was undertaken in August to October 2012.

Survey respondents were recruited via two methods: from a database of callers to the Macmillan Support Line; and via a sample of Macmillan Information and Support Centres located in hospitals across the UK. Those opting into the study completed and returned a 16-page questionnaire comprising 33 mostly closed-response questions.

A total of 1,610 completed questionnaires were returned. These included people with a wide range of cancer types, diagnosed from as recently as within the last month to several decades previously, with a large majority, 69 per cent, being diagnosed within the last two years and 88 per cent in the last five years. Most (96 per cent) had received some treatment in relation to their cancer in the last six months, including 37 per cent who had undergone chemotherapy and 31 per cent who had undergone surgery (see Table 5 in the separate Methodological Appendix for more detail).

In addition to capturing information about respondents' demographic and socio-economic characteristics and details about their cancer diagnosis, the questionnaire covered:

- The additional financial costs associated with living with cancer relating to increased expenditure – on healthcare, treatment and support and day-to-day living costs – and loss of income;
- How their households were managing financially at the time of the survey, and how this had changed since diagnosis; and
- How the financial costs of cancer had impacted on people's quality of life.

All of these questions related to people's most recent (primary) cancer diagnosis.

The purpose of the survey was to measure the average additional financial burden on people with cancer, whether arising from extra expenditure or a loss of income, and the impact of this burden for them and their households. It captured the current financial impact on individuals with a cancer diagnosis of any kind and regardless of how long ago they received their diagnosis.

The results from the survey were weighted to be representative of all people with a cancer diagnosis in the UK by cancer type, age, country of residence and gender. Statistical testing was undertaken on the data and 'significant' differences and associations – i.e. those that can be confidently generalised from the sample to the population – are defined as those that are statistically significant at the five per cent level ($p < .05$). Except where stated, differences and associations are reported in the text only where they are statistically significant.

Even so, there are limits to how representative the sample can truly be said to be: because respondents were, by definition, people who had sought information or advice about cancer from Macmillan (although this could be on any topic, not just a financial concern); and because of the voluntary nature of participation (returning a response rate of 37 per cent), which results in a largely self-selecting sample. Social survey

methods also rely inherently on self-reporting by respondents which in this instance depends greatly on accurate recall. The potential effects of any systematic differences arising as a result of these methodological constraints on the substantive findings of the survey are unobservable and therefore unknown. These points are discussed further in Chapter 8 and the accompanying Methodological Appendix.

Ethical approval for both stages of the study was sought and received in accordance with the University of Bristol Policy and Procedure. A steering group, which included cancer patients in its membership, was set up by Macmillan to inform and oversee all stages of the project. For full details of the study methodology, see the separate Methodological Appendix.

About this report

The results of this study are presented in six substantive chapters. Chapter 2 describes the total financial impact individuals and their households incurred as a result of a cancer diagnosis. Chapter 3 looks specifically at the financial impact arising due to income loss. Chapter 4 considers presents the findings of the study in relation to increased expenditure arising as a result of a cancer diagnosis. Chapter 5 looks at how people had funded the income they had lost or increased expenditure they had incurred. Chapters 6 and 7 then consider the financial and wider wellbeing respectively of people with cancer and their households, and explores the role played by the financial impact of cancer within this.

Throughout these chapters, key methodological considerations are provided alongside the results to which they relate.

A final chapter, Chapter 8, summarises the results from across the chapters, discusses the strengths and limitations of the study, and considers the implications of the study for research and policy.

Technical note 1: Weighting and imputation

Weighting is employed to ensure that the respondents to a survey are representative as far as possible of the population to which they are generalising. Weights applied in this study, which adjusted for each cancer type, age band and country within gender, were created to correct for differing levels of response and to match the profile of the completed interviews back to the sample universe. The impact of the weighting on the effective sample size was particularly large for age-related characteristics (including age group, employment status and household composition) and some types of cancer.

Imputation is another technique that is often used in survey research. Imputation assigns replacement values for specific data points that are either missing or unusable (OECD, 2006). Its purpose is to make the data complete. Imputation of missing and extreme values was undertaken in the current study for those variables used in the calculation of the financial costs of cancer. The number of values that were imputed differed depending on the variable concerned. For example, 156 missing values were imputed for reduction in income and 98 were imputed for the costs of outpatient visits.

For more details, see the separate Methodological Appendix.

2 The financial impact of cancer

Following a cancer diagnosis, people are exposed to a wide range of potential new or increased costs, relating to different areas of expenditure, as well as a potential reduction in income through, for example, loss of earnings.

The national survey undertaken for this study asked respondents to provide information about the additional expenditure they (or their partner, on their behalf) had incurred as a direct or indirect result of their cancer diagnosis over the last six months or since their diagnosis if this was less than six months ago.

The questionnaire covered 28 components of expenditure altogether, across five broad categories:

- Costs associated with outpatient visits;
- Costs associated with inpatient stays;
- Other costs relating to healthcare, including medical treatment, supplementary healthcare and sundries;
- The cost of specialist clothing, equipment and modifications (to the home and car); and
- The added costs of day-to-day living.

In measuring the added costs of day-to-day living, respondents could also indicate where they had spent less, rather than more, on different types of expense, and this is taken into account in our calculations.

In addition to these five categories of expenditure, the questionnaire also asked respondents for their household's current weekly or monthly income. This was compared with their household income immediately prior to their diagnosis (adjusted for inflation) to provide a measure of absolute change in income since diagnosis. The resulting change in income was then adjusted to take into account the extent to

which the respondent attributed the change to their cancer diagnosis. See Chapter 3 for more information on how a change in income was measured.

In this chapter we consider the total financial impact to individuals and their households across all six categories of expenditure and income. In each instance, this is expressed as a monthly equivalent amount. As such, the measure of financial impact used here is based on the monthly financial burden of cancer calculated for each individual respondent at around the time they completed the questionnaire, reflecting closely where they were in their cancer journey at that time.

Because individuals responding to the survey were all at different points in their cancer journey at the time of the survey, their results – taken together – provide a snapshot of the average monthly financial impact of cancer on individuals and their households regardless of where people were in their cancer journey. In other words, the figures described here represent the *ongoing* monthly financial burden of cancer averaged across all individuals with cancer and across the cancer journey, albeit based on 2012 figures. However, this will vary from one individual to the next and will vary depending on where people are in their cancer journey. As such, as this chapter and subsequent chapters illustrate, the burden of this impact does not fall equally among individuals, with certain impacts also varying by cancer status and other characteristics associated with someone's diagnosis.

The total financial impact of cancer

The median total financial impact of cancer to an individual and their household was £103 per month. This means that a half of all UK adults with a cancer diagnosis incurred an additional impact of less than £103 per month (or even a negative sum) as a result of their diagnosis, while a half incurred more than £103 per month.

The mean total financial impact of cancer in 2012 was estimated as £450 per month. The mean takes the arithmetic average of all respondents. It is considerably higher than the median because a minority people in the sample incurred very large impacts compared with the rest.

In fact, not everyone incurred a financial impact as a result of their diagnosis. Our estimates show that 17 per cent of people had incurred no impact, or had even experienced a saving as a result of their diagnosis. For the 83 per cent of respondents who had incurred an impact, however, the median total impact increases to £187 (with a mean of £569).

The unequal distribution of the financial impacts of cancer across all respondents is illustrated in Table 1. This shows that for 25 per cent of people with cancer the additional burden incurred to their household was less than £13 per month. This includes the 17 per cent of people who had not incurred a financial impact.

Table 1: Financial impact of cancer: summary stats

| 25 th percentile | Median (50 th percentile) | 75 th percentile | Mean (Arithmetic average) |
|-----------------------------|--------------------------------------|-----------------------------|---------------------------|
| £13 | £103 | £489 | £450 |

Base is all respondents (n=1,610). Monthly equivalent cost.

Meanwhile, 75 per cent incurred an impact of less than £489 meaning that 25 per cent of them incurred £489 or more per month. These include some respondents who had experienced a financial impact of £1,000 or more additional per month and among them were individual respondents who reported several thousands of pounds worth of additional burden.

Regardless of whether the median or mean financial impact is considered, there is no doubt that people with cancer bear significant added burdens as a result of their diagnosis. We cannot rule out the possibility that people with greater burdens opted into the survey more than those

Technical note 2: Extreme cases

For each component of expenditure, the cost reported by individuals ranged widely, from those with no costs to those reporting several thousands of pounds in cost. Within this, the data are highly skewed, with preponderance for zero-value and low-value costs and a long tail of individuals with much higher costs. Extremely high values in samples are particularly problematic because they have a disproportionate influence on the arithmetic average (i.e. the mean).

In view of this, we have taken two precautions when producing these results. First, we have removed the influence of extreme cases, defined as those that are greater (or less than) than 3.29 standard deviations from the mean (representing the most extreme one per cent of cases in a normal distribution). The reported values for these cases were replaced with the median value among the non-zero cases (as the most parsimonious value).

This operation was undertaken at the level of the individual components of cost and their 'new' value was carried through when calculating the total costs. The effect of this operation was to reduce the value of the mean for each component and any combination of them, and thereby bring it closer in line with the average for the majority of respondents. Without this adjustment, the mean total cost of cancer would be estimated at £525 per month, while the median would be £105 per month.

While extreme values are problematic when producing survey statistics, they are not necessarily invalid or erroneous, as some of the examples given in the main body of the report help to illustrate.

Second, the median was produced alongside the mean for all analyses (see the separate volume of Appendix Tables). The median is the middle value in the data after all values have been ordered from lowest to highest. For data that are highly skewed like this, the median is the better measure of the 'typical' case, because it is unaffected by the size of the larger values; it is also more conservative. For this reason, all reporting of top-line results from the survey in the main body of this report leads with the median and considers the mean as only secondary to this.

Where comparisons are made between subgroups (for example when comparing the financial impact incurred by men and women, or by cancer type), the mean becomes the preferred measure, however. This is because the mean is amenable to significance testing, in which the differences observed between groups are assessed to see if they are the result of a genuine difference in the population. Only those differences that are found to be genuine (indicated with an ‘*’ in the Appendix Tables) are reported.

Even so, the mean remains susceptible to high values and should be treated with caution. As such, the medians are still reported in preference to the mean wherever possible. Where median costs are consistently zero across subgroups (which occurs wherever fewer than 50 per cent of people incur financial impacts), we default to reporting the mean.

with low or no costs or that some people may have over-reported impacts (although others may have under-reported them). It is important nonetheless to emphasise that certain financial impacts were not captured in the survey for methodological reasons (e.g. costs of eye care and spectacles, increased travel and private healthcare insurance premiums and any costs or income losses incurred on behalf of the respondent by someone other than their partner). Had they been included, the estimated financial impact would certainly have been higher (see Chapter 8 for a further discussion).

The financial impact of cancer by cancer type

The total financial impact of cancer varied significantly depending on the type of cancer an individual had been diagnosed with.¹

¹ Statistical significance has been undertaken based on the mean financial impact, rather than the median. We have used the analysis of the mean here to identify where significant differences exist between subgroups, but report the median values for these subgroups (as the median provide the more conservative estimate of impact).

Table 2 shows that those diagnosed with lymphoma, leukaemia or myeloma were at the high end of the range with a median financial impact of £181 (and mean of £500 per month). Similarly, those with an ‘other’ type of cancer had a median financial impact of £204 (and mean of £744 per month). These included people diagnosed with brain or testicular cancer or skin melanoma (and a range of other unspecified cancer types).

Table 2: Total financial impact of cancer, by cancer type

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|--|------------|----------|------|
| Cervix, ovary or uterus | 40 | 316 | 106 |
| Prostate | 52 | 264 | 159 |
| Kidney or bladder | 57 | 373 | 71 |
| Colorectal | 105 | 326 | 163 |
| Breast | 120 | 427 | 123 |
| Lung, bronchus or trachea | 118 | 376 | 472 |
| Oesophagus, stomach, pancreas or liver | 124 | 488 | 88 |
| Lymphoma, leukaemia or myeloma | 181 | 500 | 160 |
| Other | 204 | 744 | 155 |

Base is all respondents (n=1,610). Those who ‘did not state’ are not shown. Treat with caution any figures based on small sample sizes (shown in grey).

The monthly additional financial impact associated with cancer of the cervix, ovary or uterus, prostate, and kidney or bladder was comparatively low, the median financial impact for these, in turn, being £40, £52 and £57 per month.

While the total financial impact of cancer did not vary significantly by how long ago people had received their cancer diagnosis or the current stage of their cancer, there was some variation by whether or not people had received surgery or chemotherapy for their cancer in the last six months. This may partly reflect that the type of treatment received will vary depending on the type of cancer that someone is being treated for. The median additional burden incurred by those

who had had surgery was £181 (with a mean of £549) and chemotherapy was £220 (with a mean of £545; see Table A1 in the accompanying Appendix for full details).

The magnitude of the financial impact experienced by different subgroups of people tended to vary in line with the proportion of them who were exposed to any financial impact, regardless of that magnitude. As such, 92 per cent of people diagnosed with lymphoma, leukaemia or myeloma were exposed to some degree of financial impact, as were 89 per cent of those who had had surgery in the last six months. Even so, the majority of people in all subgroups had experienced some financial burden, those receiving their diagnosis more than five years ago being at the low end of the range (77 per cent, compared with the average of 83 per cent).

Total financial impact of cancer by type of impact

A median of £0 indicates that a large proportion of people with cancer did not experience a reduction in their household's income as a result of their diagnosis (Table 3). This was the case for 70 per cent of people with cancer (see Table A2).

Table 3: Total financial impact of cancer, by category

| Monthly equivalent cost | Median (£) | Mean (£) |
|--------------------------------------|------------|------------|
| Reduced income | 0 | 224 |
| Outpatient visits | 15 | 143 |
| Inpatient stays | 0 | 6 |
| Other healthcare | 0 | 17 |
| Clothing / equipment / modifications | 0 | 26 |
| Day-to-day living | 3 | 34 |
| Total cost | 103 | 450 |

Base is all respondents (n=1,610). The mean cost by category will always sum (subject to rounding) to the mean of the total cost. Because of the way the median cost is calculated, the median values for categories do not sum to the total median cost.

Nonetheless, reduced incomes accounted for the largest proportion of the total financial impact of

cancer. This is indicated by the mean values shown in Table 3.

The mean reduction in income as a result of a cancer diagnosis was £224 per month (Table A1), equivalent to almost a half of the total estimated financial impact of £450. If we only look at the 30 per cent who experienced an income drop, we find that their incomes were lower by a median of £567 (and mean of £860 per month).

A more detailed consideration of income loss due to cancer is the focus of Chapter 3.

Altogether, the estimated additional cost arising as a result of a cancer diagnosis from increased expenditure, as distinct from reduced income, totalled a median cost of £63 (and a mean cost of £226) per month. When considered in the context of a mean household total spend – across all areas of expenditure (not just those relating to cancer) – of £2,052 per month in 2010, this is not an insubstantial sum (ONS, 2011).

The costs associated with outpatient visits made up the largest share of additional expenditure (Table 3). This reflects that a large majority – 71 per cent – of people with cancer had incurred costs for this in the last six months. Overall, the median additional monthly financial burden incurred due to the cost of outpatient visits was £15 (and the mean was £143).

In contrast, inpatient stays involved much lower costs for those with cancer (and their partners) overall. Most (72 per cent) incurred no costs in this category, reflected in a monthly equivalent median cost of £0 (and a mean of £6).

Expenditure on other aspects of healthcare following a cancer diagnosis was also comparatively low, with a median value of £0 again indicating that a majority of people with cancer (59 per cent) did not pay for any supplementary treatment or healthcare (and an overall mean cost of £17 per month).

With most people (63 per cent) incurring no costs in relation to clothing or equipment or modification to the home or car, the median monthly equivalent amount spent on this category was £0 (the mean was £26 per household).

Finally, added costs of day-to-day living were more widely experienced (54 per cent had incurred some). Apart from the costs associated with outpatient visits, this was the next largest category of expenditure in terms of cost, with the median cost of cancer to individuals and their households being £3 (and the mean being £34 per month).

The component costs of each category of expenditure shown in Table 3 are revisited in more detail in Chapter 4.

The total financial impact of cancer by characteristics

There were some significant variations in the total financial burden people (and their households) incurred as a result of their cancer diagnosis depending on their socio-demographic and household characteristics (Table A4). These included age and household composition, along with several measures of the individual's and the household socio-economic status.²

Overall, the financial impact of cancer was lower among the over 60s. The median financial impact peaked at £463 per month among those in their 50s, dropping steeply away to £108 among those in their 60s at the time of the survey. Reflecting this, the burden was also high in families with dependent children (£318 in couple households and £395 in lone parent households). The median

² Statistical significance has been undertaken based on the mean financial impact, rather than the median. We have used the analysis of the mean here to identify where significant differences exist between subgroups, but report the median values for these subgroups (as the median provide the more conservative estimate of impact).

financial impact among those living in a home that was owned with a mortgage or rented privately was relatively high (at £235 and £175 per month respectively).

With a median of £350 per month, those who were working full time at the time of the survey incurred particularly high financial burdens, as did those who were in paid work at the time of their diagnosis (£378). When the breakdown by monthly household income is examined, those with the lowest incomes, of less than £430 (or £100 per week), incurred the largest median financial impact of £336.

However, the highest median financial impact overall was observed for the under 60s who were in work at the time of the survey. This group incurred an extra £486 (median) per month of financial burden as a result of their diagnosis. This underlines the finding that a loss of earned income is a major driver of the total financial impact of cancer (Table A4).

The median financial impact by country of residence ranged from £67 per month in Northern Ireland, through £83 in Scotland, to £103 per month in Wales and £105 in England (Table A3).³ The apparent variation in the *mean* financial impact incurred by nation (ranging from £288 per month in Northern Ireland to £640 in Wales) was not statistically significant, however. This may be because there is no real difference in the total financial impact of cancer depending on country of residence, or it may be because bigger samples within the individual countries would be needed to detect any differences that do exist.

³ Appendix Table A3 additionally shows the full breakdown of cost by country of residence. Significance testing of the median has not been undertaken as this would rely on 'nonparametric' tests, which are less able than 'parametric' tests to detect true differences that exist (Field, 2009). Therefore the mean (which is amenable to parametric tests) is relied upon to indicate the significance and hence reliability of any variation by characteristics.

3 The impact of cancer on income

The impact of a cancer diagnosis on household incomes can be substantial. Three in 10 people with cancer were exposed to a reduction in their household's income as a result of their diagnosis. Having a low income (at the time of the survey) and being in work when diagnosed are key factors in determining those at greatest risk of incurring an income loss, with cancer type also playing an important role.

In this chapter we consider which types of cancer patients are more likely to experience a drop in income as a result of their diagnosis and explore how and why this occurs. We also report the loss of income by country of residence, the nature of an individual's cancer diagnosis and their socio-demographic characteristics. We draw primarily on the results from the national survey, supplemented with findings from the depth interviews.

The measure of income used in the survey took into account the income of the respondent and that of their partner (if they had one), whether from employment, benefits or other sources of regular income. We refer to this throughout this report as total household income. It is important to capture income for the household as a whole because incomes are expected to be pooled between partners to some degree. Additionally, the depth interviews found that a cancer diagnosis for one partner could lead to important employment decisions for the other partner. Total household income is also taken into account in eligibility for certain types of benefits.

Under normal circumstances, incomes in households of working age would be expected to increase over time (an underpinning principle of economics known as the 'life-cycle hypothesis'). However, following a cancer diagnosis, people

Technical note 3: Measuring a change in income due to cancer

The challenge of capturing a change in income in a cross sectional survey and, over and above this, attributing that change retrospectively to a major life event such as a cancer diagnosis, is a significant one. We approached this in the current survey in three steps.

First, we asked respondents to tell us which of a set of income bands most closely matched respondents' (and their partner's, if they had one) total income, from take home pay, benefits or any other regular income. Given constraints of questionnaire length and the potential for high levels of missing or erroneous data, it was not possible to ask respondents for exact income figures. Instead the mid-point of the band was used post-hoc as a proxy for a point estimate of total income.

Second, respondents were asked, using the same income bands, to indicate what their income (and their partner's, if they had one) was immediately prior to diagnosis. Again, the mid-point of each band was used as a substitute for a precise income level. This mid-point was then adjusted (upwards) to control for the effect of inflation using published Retail Price Index multipliers (via safalra.com). The appropriate multiplier was applied based on the year the respondent told us they received their diagnosis. The absolute change in income was then calculated.

Third, in order to take account of changes to income that were not related to respondents' diagnoses, respondents were asked to rate, on a five-point scale, the extent to which any difference (positive or negative) in their income since diagnosis was due to their diagnosis. Respondents' answers to this question were used to adjust the calculated absolute change in income proportionately: where a score of 5 ('entirely') took a factor of 1.0; 4 took a factor of 0.75; 3 ('partly') took a factor 0.5; 2 took a factor of 0.25; and 1 ('Not at all') took a factor of 0.0. Finally, those not giving an answer to this question were assigned a factor of 0.5. Those who did not complete either income question were assigned the value of the median adjusted change in income for the sample as a whole.

might need to take unpaid leave, change their jobs and even exit work altogether. As such there are complex reasons why household incomes may decrease over time following a cancer diagnosis.

Loss of income

Table 4 shows that, at the time of the survey, the largest proportion of people had experienced no measurable change in their household incomes as a result of their cancer diagnosis. A large minority, some 30 per cent, had experienced a reduction in their household's income attributable to their diagnosis (Table 4).

Table 4: Proportion experiencing a (net) change in income due to cancer

| Column percentages | % |
|-----------------------|-------|
| Lower | 30 |
| No measureable change | 64 |
| Higher | 7 |
| Base | 1,610 |

Base is all respondents (n=1,610).

This reflects the findings of research undertaken for Macmillan in 2005-06 in which 36 per cent of people had suffered a loss of income as a result of cancer (RDSi, 2006). Only a small minority had higher incomes following (and as a result of) their diagnosis.

Survey respondents were additionally asked to indicate whether particular types of changes had affected their total household income at any time since their diagnosis. The results are shown in Table 5. Overall, nearly one in five had stopped working permanently. This was not necessarily the direct (or indirect) result of the respondent's diagnosis. Reflecting the wording of the survey question, it could also have been for an unrelated reason such as passing into retirement age, or a combination of factors.

Another 15 per cent had stopped working temporarily on reduced or no pay, perhaps during prolonged treatment. Only small minorities of people had reduced the hours they worked or

taken unpaid leave or moved to a lower paid job, even if they later recovered their full earnings.

Table 5: Proportion experiencing types of income change at any time since diagnosis

| Column percentages | % |
|--|-------|
| Stopped working permanently (e.g. left job, made redundant, retired) | 18 |
| Stopped working temporarily on reduced or no pay (e.g. taken sick leave) | 15 |
| Reduced hours worked or taken unpaid leave | 8 |
| Partner leaving the household (eg. marital separation, death) | 4 |
| Moved to a lower paid job | 1 |
| None of these | 55 |
| Not stated | 6 |
| Base | 1,610 |

Base is all respondents (n=1,610).

Predictors of income loss

Regression analysis showed that household income at the time of survey and whether or not the patient was working at the time of their diagnosis were strongly associated with a drop in household income independently of other characteristics available from the survey (Table A5).

Regression analysis is a multivariate analysis technique which identifies which characteristics are related to an outcome of interest, in this case a loss of income, while simultaneously holding constant the influence of other characteristics that may also be related to that outcome. It is a useful technique because it separates out the unique (or 'independent') influence of individual characteristics on the outcome when some of those characteristics may themselves be correlated (e.g. household income and home ownership). The strength of the independent relationship each factor has with the outcome is also assessed in the analysis, and those characteristics that are statistically significant (as in this case, household income) are said to 'predict' the outcome of interest. A higher or lower propensity to have experienced that outcome for one category of people (e.g. those

with a low household income) compared with others is expressed as an odds ratio. An odds ratio of greater than 1.0 for any category of interest indicates that the odds of experiencing a loss of income are higher for this category relative to a reference category; where they are less than 1.0 the odds are lower relative to the reference category.⁴ A further explanation of regression analysis can be found immediately following Table A5.

As such, we find that the odds of experiencing a loss of income were seven times higher among those with the lowest incomes (of less than £430 per month, or £100 per week) than those with the highest incomes (of £2,150 per month, or £500 per week, or more; Table A5). They were also seven times as high among those who were working at the time of their diagnosis compared with those who were not. And they were higher for partnered households than for single adult households.

Type of cancer was also highly significant in the regression analysis. All other things being equal, those with cancer of the oesophagus or stomach, and pancreas or liver were particularly likely to have experienced a loss of income. The odds were lowest among those with an ‘other’ type of cancer.

Notably, gender, age, country and area of residence were not predictive in the analysis. Cancer status and treatment received in the last six months were also not independently related to experiencing an income loss.

⁴ The type of regression used here is a single entry binary logistic regression. Note that ‘odds’ and ‘likelihood’ are similar but not identical concepts. While an odds ratio of greater than 1.0 signifies increased likelihood (and an odds ratio of less than 1.0 indicates a decreased likelihood) odds and likelihoods are not measured on equivalent scales and therefore cannot be described in the same way.

In keeping with the results of the regression analysis, the *amount* of income lost – as expressed by the mean – varied significantly by several socio-economic measures and household composition (Table A6).⁵ The mean is used here to illustrate the variation in where the burden of income loss is disproportionately felt. Except where stated, the corresponding median for each subgroup is £0.

The mean loss was particularly high among those working full time at the time of the survey (£592; Table 6). Related closely to this, large losses of income were experienced by people aged under 60 and in work at the time of the survey (mean of £584 and median of £161 per month) and those who were working when they were diagnosed (mean, £564; median, £213 per month; Table A6).

Table 6: Reduction in household income due to cancer by employment status

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|--|------------|----------|------|
| Working full-time ¹ | 0 | 592 | 342 |
| Working part-time ¹ | 0 | 345 | 241 |
| Retired | 0 | 67 | 594 |
| Unable to work due to permanent ill-health or disability | 0 | 336 | 264 |
| Other situation | 0 | 620 | 121 |

Base is all respondents (n=1,610). Those with missing employment status information are not shown. 1. Employed or self-employed, including being temporarily off work due to ill health or maternity leave.

Also consistent with the findings of regression analysis, people living in the lowest-income households suffered particularly high income losses on average, with a mean loss of £660 per

⁵ This analysis uses significance testing of the mean to identify sub-groups incurring a higher burden of loss in comparison to others. The mean is also relied on heavily here to illustrate these differences, given the large number of sub-groups incurring median income losses of £0 (reflecting that fewer than 50 per cent of people had incurred *any* loss). However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high loss.

month (and a median loss of £11 per month (Table A6). And couples with dependent children also incurred a disproportionately high mean income loss (of £551 per month)

A number of other measures that were not significant in the regression analysis were significant when the actual loss of income was considered. This is partly because the latter takes account of the full range of values of the income loss, whereas the former looks just at whether or not someone suffered an income loss at all (i.e. the outcome measure is different). However, it is also partly because the regression analysis controls for any natural correlation that exists between pairs of measures. For example, working status and age are naturally correlated quite highly with each other, because they are both linked to people's life stage.

As such, we find that the mean loss of income varied significantly by age, with those in their 40s (£481 per month) and 50s (£596) incurring the greater losses. The median loss of income for these age groups was also high (£64 and £32 per month respectively); this denotes the finding that these groups were particularly likely to have incurred an income loss of any magnitude (52 per cent compared with the average of 30 per cent). Similarly, with a mean of £469 per month, those owning their homes with a mortgage also faced high income loss on average when compared with other tenure groups; 46 per cent of these had reduced incomes as a result of the respondent's diagnosis.

More striking still, however, is the finding that some 56 per cent of those working at the time of their diagnosis had incurred some reduction in income (with a mean loss of £564 and a median of £213 per month). As the next section discusses, this is intuitive because those in work at the time are likely to have higher incomes than people who are not in work, including those who are retired; in other words, they had more income to potentially lose. However, in addition to this, we

also find that 55 per cent of people aged under 60 and working at the time of the survey had incurred an income loss (with a mean cost for this subgroup of £584 and a median of £161). This implies that the impact of a diagnosis on earned income exists even where people continue to be in (or have subsequently returned to) work.

The mean loss of income among men was £275 per month compared with £173 among women. And the monthly loss of £395 in income among people from non-White backgrounds was significantly higher than the mean loss of £219 among people from White backgrounds.

The actual loss of income also did not vary depending on where people lived.

In contrast to the regression analysis, there was no significant variation overall depending on the nature of people's cancer diagnosis (Table A7). So while people with certain types of cancer were more likely than others to have incurred any income loss, all other things being equal, the actual loss did not vary significantly by cancer. Nonetheless, the mean among those diagnosed with cancer of the oesophagus, stomach, pancreas or liver was an estimated £309 per month. Among those with lymphoma, leukaemia or myeloma it was £278 per month, and for other types of cancer it was £287. This compares, for example, with a mean loss of £117 per month among people with cancer of the lung, bronchus or trachea. The median in each case was £0, testifying to the fact that less than a half of people in each of these subgroups experienced income loss. In other words, the impact of income loss was felt fairly equally by people with different types of cancer and at different stages in their cancer journey.

Pathways to income loss

A loss of income was naturally a big cause for concern among many of the people interviewed in depth for the study, and it was experienced as one of the biggest financial impacts of cancer for

those affected. The ways in which income was lost, and the effect of the loss depended on life stage and household circumstances and how temporary or long-lasting the income loss was.

In the depth interviews, it was common for people who were working as employees at the time of their diagnosis to have spent at least a period of time receiving only Statutory Sick Pay. In some cases the length of time people needed to take off work meant that their entitlement to Statutory Sick Pay had also ended, leaving some with no income at all.

Diagnosis could also result in temporary financial loss among people who were self-employed, during periods when they were too poorly to work.

The people we spoke to in depth who had returned to work had been able to manage despite the temporary loss of income. However, a cancer diagnosis could also result in a permanent loss of earnings, with very serious negative consequences for a household's finances. This could be as a direct result of a cancer diagnosis: there were examples of people who were dismissed from their jobs while receiving or recovering from treatment or recovery period. Coupled with the emotional damage caused by these events, some felt they were less employable following a cancer diagnosis:

'In the interim, while all this was going on I then sent my CV out to other companies...I say look I've got health issues and they say what's that and I say, you know, I've been given the all clear but I had cancer. And it goes very, very quiet and they then say things like well, you know, it's a very stressful job...are you prepared to work weekends.

I was saying "well no I'm not prepared to work weekends", you know.'

Elsewhere, a cancer diagnosis was a compounding factor in continuing to be out of work. Some people did not feel up to looking for new employment after a cancer diagnosis while others

were still in treatment and not yet well enough to work again.

A cancer diagnosis could also lead to a drop in a partner's income. Among the depth interviewees, this included cases where a partner took unpaid leave (or a self-employed partner took time away from their business) to provide care and support. In other instances, partners had taken a drop in earnings because they decided not to take overtime or work long distances from home in order to spend more time at home.

Loss of income compounding loss of income

Mike was diagnosed with brain cancer in early 2011. During his treatment he felt well enough to work and his employers gave him the option of working from home whenever he needed to. This helped him greatly as the company only offered limited sick pay and this arrangement enabled him to keep on working initially. Over time, however, Mike's treatment left his immune system compromised and a number of minor illnesses meant he used up all of the sick leave on full pay that he was entitled to. Now recovering from shingles he receives only Statutory Sick Pay and has also dropped to part-time hours to take the pressure off when he is well enough to work.

On top of this, Sally, Mike's wife, also lost income as a result of his Mike's treatment. Sally took time out of her work to take Mike for radiotherapy every weekday for six weeks. As a self-employed hairdresser, Sally had to honour her appointments and paid someone else to cover them:

'Well I had to take you [addressing Mike] to appointments and I just couldn't carry on so I paid people to do my shifts and do some of the work... I'd have to work it out, but yes, a fair bit of money.'

Source: depth interviews

A household's ability to weather an income loss influenced how depth interviewees felt about their work situations. One woman, a relatively high earner with a husband who also worked, felt her priorities had changed following her diagnosis. As a result, she was happy to accept a lower paid

part-time job in exchange for a better quality of life. Another was sufficiently well-off to manage while her husband took two months unpaid leave to support her.

Those whose household finances were less secure often faced difficult decisions about work: reluctantly returning to work before they felt fit enough; or deciding that they could not afford for a partner to take unpaid leave to provide care and support.

Having an understanding employer came through in the depth interviews as another important factor in determining the impact of a cancer diagnosis on earned income. There were examples of people receiving financial help from employers in the form of bursaries or extended sick pay. Other employers offered flexible working to enable the person with cancer to keep working, or a phased return to work following treatment.

People who were already retired or unable to work at the time of their cancer diagnosis faced less disruption to their income, because it did not depend on being able to work.

4 The impact of cancer on expenditure

Increased expenditure arising due to a cancer diagnosis can be considerable. The costs associated with outpatient visits contribute the most to the total cost people incur on average, followed by the added cost of day-to-day living due to cancer. These costs were not evenly distributed across the population, however, and while some people incur no added expense within a category others incur a large burden of additional costs.

In this chapter the focus turns to the increased expenditure that can arise as a result of a cancer diagnosis. We consider the five categories of expenditure in turn, define the component costs that make up these categories and explore which factors determine the extent to which people are affected by them. We start, however, by giving an overview of the total added expense people with cancer are estimated to incur and identifying the types of people that are exposed to the greatest costs.

Total expenditure

The estimated additional cost from expenditure of any kind totalled a median cost of £63 (and a mean cost of £226) per month. When considered in the context of a mean household total spend – across all areas of expenditure (not just those relating to cancer) – of £2,052 per month in 2010, this is not an insubstantial sum (ONS, 2011). Here we briefly consider the types of people (and households) exposed to the greatest burden of expenditure as a result of cancer. Subsequent sections consider the groups that are exposed to the specific categories of cost making up total expenditure.

Overall, the strongest predictors of incurring any added expenditure were socio-economic in nature (Table A8). The odds were particularly high among those living in medium- and high-income

Technical note 4: Measuring expenditure

Respondents to the survey were asked to provide details of additional expenditure incurred by them (or their partner on their behalf) arising as a result of their cancer diagnosis or treatment. We asked respondents to exclude any expense that was paid for by others, such as costs paid for by the NHS, any insurance they held or their local authority.

The questionnaire deliberately excluded any additional costs that may have been incurred by family members other than a partner or other individuals, such as friends and neighbours. This decision was taken following the depth interviews, which indicated that respondents were not always clear about the costs others had incurred and could therefore not easily quantify them. As such, the costs presented here reflect a narrow measure of cost. Nonetheless, we cannot rule out the possibility that some respondents may have included such costs.

For each component, cost was asked in relation to the previous six months (or since diagnosis if this was less than six months previously). Our decision to capture costs over this reference period was driven by the results of the depth interviews.

One key objective of the depth interviews was to gain an understanding of when costs tended to arise following a diagnosis and the extent to which people could remember these costs. Recall of costs was ostensibly fairly strong, particularly as significant events such as treatment dates were, if not recorded on calendars, highly memorable to people. It was clear, however, that some of the more significant costs arose during or shortly after treatment, when people may be more physically and emotionally drained, and potentially less able or inclined to complete a questionnaire. A 12-month reference period was considered too long to be able to relate cost to cancer status, and so a six-month reference period was agreed.

Here, the additional expense arising is expressed as a monthly equivalent amount. In other words, the costs people reported to the survey were divided by six or, where someone was diagnosed with cancer fewer than six months previously, by the number of months that had passed since their diagnosis.

households. For example, the odds of incurring any increased costs as a result of cancer were 2.5 times higher among people with middle-to-high incomes (of £1,700 to £2,149 per month) than those on the lowest incomes (of less than £430 per month).

When controlling for income (and other factors), the risk of incurring extra expense was particularly high for people who were retired at the time of the survey. Owning the home outright or with a mortgage also carried higher odds of incurring extra expense, when compared with those renting from a social landlord.

Turning to the actual costs incurred by these groups, middle-to-high incomes incurred particularly high costs, with a median of £97 (and mean of £457) per month compared with the overall median of £63 (and £226) per month (Table 7; Table A9). This may partly be driven by the ability of better off households to afford greater additional costs.

Table 7: Total expenditure by monthly household income

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|-------------------------|------------|----------|------|
| Less than £430 | 88 | 236 | 128 |
| £430 to £849 | 43 | 191 | 334 |
| £850 to £1,299 | 78 | 196 | 381 |
| £1,300 to £1,699 | 77 | 202 | 242 |
| £1,700 to £2,149 | 97 | 457 | 193 |
| £2,150 or more | 58 | 205 | 246 |

Base is all respondents (n=1,610). Those with missing income information are not shown.

More than nine in ten of people in this income category had incurred some cost (91 per cent, compared with 85 per cent overall). Interestingly, those on the lowest incomes also incurred relatively high actual costs as indicated by the median (of £88 per month) and about average costs as indicated by the mean (of £236). This suggests that the costs incurred by those on the lowest incomes (by the 81 per cent incurring any) are fairly tightly clustered around the median and

below the mean, whereas they are much more wide-ranging for people with the middle-to-high incomes. Apparent differences in the actual costs incurred by employment status and housing tenure were not statistically significant.

Demographic characteristics played only a small role in determining which types of people were at risk of incurring any added expense overall. In the regression analysis, ethnicity was the only factor that predicted incurring any extra expense (Table A10). All other things being equal, people from a White background were more likely to have done so. When looking at the actual costs incurred, only age group and household composition produced statistically significant variations in the mean. Here, people aged in their 40s and 50s incurred the greater costs overall (with a median cost of £180 and £113 respectively and a mean cost of £442 and £528), as did lone parents (with a median of £117 and mean of £1,138).

Characteristics relating to the respondent's cancer diagnosis were also important drivers of incurring any added cost, with certain types of treatment and cancer status being significant in the regression. The odds were twice as high for people undergoing surgery or chemotherapy in the last six months compared with those who had not. They were also high among people with advanced, secondary or metastatic cancer or cancer that had recurred or relapsed at the time of the survey.

A different pattern emerges when considering the actual costs incurred, however. Here there were significant variations in the cost (as represented by the mean) incurred by cancer type, when the respondent received their diagnosis and receiving radiotherapy in the last six months. The cost incurred was particularly high among people with 'other' types of cancer (which includes brain and testicular cancer and skin melanoma) with a median of £83 per month (and a mean of £457), those diagnosed in the last six months (with a median of £84 and a mean of £345) and those

undergoing radiotherapy in the last six months (with a median of £89 and a mean of £359). In addition to these, comparatively high median costs were observed among people with cancer of the lung, bronchus, pancreas or liver (£104 per month), those diagnosed between six and 12 months previously (£89, reflecting that some 91 per cent of them had incurred some added cost), and those undergoing chemotherapy (£118, again reflecting that 91 per cent had incurred these).

The disparity between the results of the regression and the mean costs is likely to partly reflect the different measures that are considered (exposure to *any* cost and the actual cost), as well as the relationships that are likely to exist between the various diagnosis characteristics. When these relationships are stripped out in the regression analysis the true, independent, effect of an individual characteristic is identified.

Costs due to outpatient visits

The survey captured the costs associated with outpatient visits in three components: travel costs, parking costs and incidental costs such as food and drink and phone calls. These were captured on a per-visit basis with respondents also asked to indicate the number of visits they had taken for each different healthcare practitioner or support group they had seen.

Table 8: Component cost of outpatient visits

| Monthly equivalent cost | Median (£) | Mean (£) |
|-------------------------|------------|----------|
| Travel | 10 | 118 |
| Parking | 0 | 14 |
| Incidentals | 0 | 12 |
| Total cost | 15 | 143 |

Base is all respondents (n=1,610). The means do not sum correctly due to rounding.

In total, the median cost associated with outpatient visits was £15 per month. Taking into account the fact that some people incurred relatively large outpatient costs, the mean across all adults with cancer was £143 per month, the largest category of expenditure in terms of cost.

Technical note 5: Calculating travel costs

Respondents were invited to record their travel costs either as a total cost per round trip or, if they travelled by car, the round trip mileage. The decision to allow people to report mileage was again driven by results from the depth interviews, in which participants often knew the mileage rather than the cost.

In converting mileage into financial costs we have assumed 25 pence per mile. This is based on figures published by the AA (2012) relating to the running cost per mile for mid-priced petrol and diesel cars.

Where respondents provided detail about the travel cost and the mileage, we have disregarded mileage in preference for cost. See the Methodological Appendix for more information.

The largest component of the cost of outpatient visits related to the expense of travel (Table 8). With most people having incurred this type of cost (69 per cent), the median cost overall was £10 per month (and the mean was £118 per month).

Several survey respondents said they had relied on taxis more to get them to and from their GP and hospital treatment, either because they were too tired to drive or were advised not to use public transport because of their weakened immune systems.

In comparison, most had not incurred any costs relating to parking (62 per cent) or incidental expense (72 per cent) during any outpatient visits in the last six months. As such, the median cost for both was £0, with an overall mean monthly equivalent cost of £14 and £12 respectively.

This partly reflects that hospitals throughout Wales and most in Scotland have introduced free parking. Elsewhere hospital parking may be free or charged at reduced rates for certain types of patients. Even so, the number of visits for treatment that people made meant even the most nominal parking cost could present a financial burden, as one depth interview explained:

'So it's £1 [for a parking coupon] every time and it doesn't seem a lot but when you haven't got £1 it is a lot of money.'

Among the depth interviewees, there was a strong sense that it was unfair that people with cancer (or any serious illness) were charged to park at a hospital or treatment centre. People resented paying parking charges, however much the amount, because it was an unavoidable cost associated with cancer diagnosis and treatment.

'I still think if somebody's got cancer they should be able to park for free, it's only going in the Council's pocket, you know, why should they have it when people are struggling to make ends meet on their lousy sick pay?'

Additionally, people may still need to pay for parking when attending appointments at locations other than a hospital or treatment centre and cancer patients may not be able to make use of the free parking spaces hospitals do provide.

One person interviewed in depth explained that while her blue badge qualified her to use the free designated blue-badge spaces at her hospital, these were over-subscribed and rarely available. She normally ended up paying for parking elsewhere in the hospital grounds.

Predictors of outpatient costs

There were several strong predictors of incurring outpatient costs, including age, employment status and household income at the time of the survey (Table A11). The odds of incurring outpatient costs were considerably higher among 18 to 39 year olds compared with all other age groups. Meanwhile those who were retired and those on middle-to-high incomes were also at the high end of the range. Those who described themselves as White had three times the odds of those who were non-White of incurring outpatient expense.

Where people lived also made a difference. In comparison with those living in Scotland, people in England, Wales and Northern Ireland all had around twice the odds of incurring outpatient expense. And all other things being equal, those living in rural areas were more likely to have experienced outpatient costs than those in urban areas.

Cancer type was another strong predictor, with those diagnosed with kidney or bladder and brain cancer being at the high end of the range. This may reflect the ongoing risk of infection among those with cancer of the kidney or bladder and the difficulty in managing brain cancer at home.

Those who had received surgery or chemotherapy to treat or manage their cancer in the last six months were also more likely, all things being equal, to have incurred any outpatient costs. In relation to cancer status, those with advanced, secondary or metastatic cancer had the highest odds of incurring expense as an outpatient.

One survey respondent had flown to London from Edinburgh several times for specialist treatment for her cancer. She and her husband had needed to stay overnight in hotels on a number of these occasions, adding greatly to their costs. She felt this could have been avoided had her appointments times accommodated her exceptional travel needs.

When we examine the actual costs incurred from outpatient visits, a familiar pattern emerges, with significant variations by age and various measures of socio-economic status (Table A12).⁶ The mean is used here to illustrate the variation in where the burden is disproportionately felt. For

⁶ This analysis uses significance testing of the mean to identify sub-groups incurring a higher burden of cost in comparison to others. The mean is used here to illustrate these differences. However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs.

completeness the median is also shown. Sometimes the mean and median do not vary in line with each across subgroups. This apparent inconsistency normally arises either because the proportion of people incurring any cost varies from group to group, or because a small minority of people within a group incurred particularly high costs, or a combination of both.

So, when considering the *actual* cost incurred from outpatient visits, this was again high among people aged 18 to 39 (with a mean of £319 per month and, reflecting the results of the regression described above, a median cost of £56; Table 9, Table A12). This partly reflects that the vast majority of 18 to 39 year olds had incurred these costs (93 per cent). The mean cost was higher still among those in their 40s (£423 per month). However, with fewer people in their 40s incurring these costs (83 per cent) the median, at £24 per month, was somewhat lower than for people aged under 40, suggesting that a small minority of people in their 40s had incurred particularly high outpatient costs.

Table 9: Outpatient costs by age

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|-------------------------|------------|----------|------|
| 18 to 39 | 56 | 319 | 89 |
| 40 to 49 | 24 | 423 | 229 |
| 50 to 59 | 28 | 140 | 494 |
| 60 to 69 | 20 | 133 | 491 |
| 70 or over | 9 | 98 | 305 |

Base is all respondents (n=1,610). Those with missing age information are not shown. Treat with caution any figures based on small sample sizes (shown in grey).

The cost was also high among those working full-time when interviewed (with a median of £36 and mean of £289 per month) and, in keeping with this, among the in-work under 60s (median, £34; mean, £289 per month).

Those with middle-to-high household incomes incurred large costs on average, with a mean of £383 per month (and a moderate median of £17). Those receiving health-related benefits also

incurred larger outpatient costs (with a mean of £170 and a median of £20 per month) compared with those not in receipt of them (£128 and £14 respectively).⁷

However, it was single adults with dependent children (i.e. lone parents) who were at the higher end of the range across all groups, albeit based on a small sample. These incurred a mean monthly equivalent cost of £1,024 (with a median cost of £28; Table A12).

Despite some marked variation in the estimated mean cost by country of residence these differences were not statistically significant. Outpatient costs also did not vary significantly by area of residence, despite the large share of outpatient costs that is comprised of travel expense and the finding that people in rural areas were more likely to incur some outpatient costs. In other words, people in rural areas were at greater risk of incurring some outpatient costs but not necessarily higher costs, all-tolled, than people in urban areas.

Aspects of people's cancer diagnosis were significant however in predicting the amount of outpatient costs they faced (Table A13). Those with 'other' types of cancer had an estimated mean monthly cost of £325 (and a median of £22), while those who did not state the type of cancer they had (including some who did not yet have a diagnosis) incurred a mean additional cost of £227 due to outpatient visits (and a median of £28). So, while people diagnosed with kidney or bladder and brain cancer were among the people most likely to incur any outpatient costs, where those with 'other' and unspecified types of cancer were incurring costs these were likely to be high.

⁷ Defined as the respondent receiving Employment and Support Allowance, Incapacity Benefit, Attendance Allowance or Disability and Living Allowance; or the partner receiving carer's allowance, whether or not these related to the respondent's cancer diagnosis.

The costs were also high among those with recent diagnoses, at an estimated £236 per month (mean) among those diagnosed within the last six months (and a corresponding median of £33). This is likely to reflect that the most intensive period of treatment would also have occurred within the last six months, along with the costs of potentially lengthy testing and diagnosis process.

In keeping with this, the mean cost among those receiving radiotherapy was £298 per month (with a median of £35 per month). Although there was no significant variation in the mean cost depending on whether or not people had received chemotherapy for their cancer in the last six months, the *median* cost among those receiving chemotherapy (£40) was also notably high, with a high proportion having incurred any cost (80 per cent). This possibly reflects that a relatively large proportion of these patients were making repeat outpatient trips for these types of treatments.

Cost due to inpatient stays

In capturing the total cost of inpatient stays relating to people’s cancer diagnosis or treatment, the survey also asked about the costs associated with travel, parking and incidentals. This included any costs arising from partners visiting respondents during their stays as an inpatient.

Table 10: Component cost of inpatient stays

| Monthly equivalent cost | Median (£) | Mean (£) |
|-------------------------|------------|----------|
| Travel | 0 | 2 |
| Parking | 0 | 1 |
| Incidentals | 0 | 2 |
| Total cost | 0 | 6 |

Base is all respondents (n=1,610). The means do not sum correctly due to rounding.

Overall, only 28 per cent of people had incurred any costs associated with inpatient stays for their cancer within the last six months. Since most treatment will be administered during day visits, inpatient stays will tend to be the exception and might only occur occasionally if at all within a six month period. As a result, the median cost of

inpatient stays was £0. The mean was also low at just £6 per month, comprised of £2 in travel costs, £2 in incidentals and £1 in parking costs (the amounts do not sum to £6 due to rounding).

Despite these low means, where costs were incurred they could be significant. Among those incurring any parking costs, one in 10 had incurred the equivalent of £20 per month or more, rising to £23 among those incurring any travel costs and £25 for those incurring any incidental costs.

One survey respondent commented that his wife had travelled the 52-mile round trip to see him twice a day during an extended hospital stay.

Predictors of cost due to inpatient stays

There were no statistically significant variations in the costs associated with inpatient stays by country of residence (Table A3).

Cancer type, receiving certain types of treatments and cancer status were all significant predictors of incurring inpatient costs (Table A14).

As we saw in relation to outpatient costs (see earlier in this chapter), the odds of incurring inpatient costs were at the high end of the range among people with cancer of kidney or bladder and brain and also, in this instance, those with lymphoma, leukaemia or myeloma. The odds of were twice as high among those with advanced, secondary or metastatic cancer compared with those whose cancer was localised or stable, in remission or unknown or undergoing diagnosis. Those who had received chemotherapy, radiotherapy and especially surgery in the last six months were more likely to have incurred inpatient costs, all things being equal, than those who had not received this type of treatment.

Variations in the *actual* cost incurred by diagnosis characteristics were also significant (Table A15).⁸ The mean is used here to illustrate the variation in where the burden of inpatient costs is disproportionately felt. Except where stated, the corresponding median for each subgroup is £0.

At the high end of the range, the mean cost incurred as an inpatient among those with colorectal or an ‘other’ type of cancer and those with diagnosed in the last six months was £9 per month (Table 11).

Table 11: Costs relating to inpatient visits by cancer type

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|---|------------|----------|------|
| Breast | 0 | 5 | 472 |
| Prostate | 0 | 2 | 159 |
| Cervix, Ovary, Uterus | 0 | 3 | 106 |
| Colorectal | 0 | 9 | 163 |
| Lung, bronchus or trachea | 0 | 2 | 123 |
| Oesophagus, stomach, pancreas or liver | 0 | 5 | 88 |
| Kidney or bladder | 0 | 4 | 71 |
| Lymphoma, leukaemia or myeloma | 0 | 5 | 160 |
| Other | 0 | 9 | 155 |
| Not stated / not known / undergoing diagnosis | 0 | 6 | 113 |

Base is all respondents (n=1,610). Those with missing cancer type information are not shown. Treat with caution any figures based on small sample sizes (shown in grey)

Among those with advanced, secondary or metastatic cancer it was £10 per month. And among all those who had had surgery in the last six months the mean inpatient cost was the

⁸ This analysis uses significance testing of the mean to identify sub-groups incurring a higher burden of loss in comparison to others. The mean is also relied on heavily here to illustrate these differences, given the large number of sub-groups incurring median inpatient costs of £0 (reflecting that fewer than 50 per cent of people had incurred *any* such cost). However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high cost.

equivalent of £12 per month; a median cost of £1 per month derives from the finding that a substantial 51 per cent of them had incurred at least some cost due to inpatient stays (compared with 28 per cent overall).

Some demographic and socio-economic characteristics were also important predictors of incurring any inpatient costs in the regression (Table A14). The odds decreased steadily with increasing income levels. People with partners were more likely to incur inpatient costs than single adults living alone, possibly reflecting the cost to partners of visiting them as an inpatient. And those aged 70 or over were least likely, all other things being equal, to have incurred inpatient costs.

Consistent with this, there were also significant variations by age, household composition and household income in the actual cost associated with inpatient stays (Table A16). Those bearing the highest costs included the under 40s (£10 per month; albeit based on a small sample), those with the lowest household incomes (of less than £430 per month; incurring £9 per month in inpatient costs) and those with incomes of £1,300 to £1,699 (£11 per month). Couples with dependent children also incurred comparatively high costs with a mean of £15 per month, revealing that considerably more couples with dependent children had incurred any cost due to inpatient stays than the average (41 per cent compared with 28 per cent).

Country and area of residence were not important factors in the inpatient costs people had incurred.

Other healthcare costs

Other healthcare costs captured in the survey ranged from dietary supplements and dressings, through private treatment to nursing and personal care provided in the home.

A majority of people with cancer (59 per cent) had not paid for any supplementary treatment or

healthcare within the last six months. As such, the median cost of this category (and its component parts) is estimated at £0 across the population of people with cancer as a whole. The mean total cost incurred across these components was £17 per month (Table 12).

Although the mean cost for this category is fairly small when compared with other categories of cost, an additional expense of £17 is not insubstantial when we consider that the mean UK household spends £22 per month on healthcare (ONS, 2011).

Table 12: Component cost of other healthcare

| Monthly equivalent cost | Median (£) | Mean (£) |
|--|------------|-----------|
| Over-the-counter or prescription medicines | 0 | 2 |
| Dietary supplements | 0 | 2 |
| Dressings | 0 | 1 |
| Private treatment or healthcare | 0 | 5 |
| Dental surgery or care | 0 | 3 |
| Nursing care provided in-home | 0 | 1 |
| Personal care provided in-home | 0 | 3 |
| Total cost | 0 | 17 |

Base is all respondents (n=1,610).

Private treatment and healthcare (such as surgery, medications, consultations and convalescent or therapeutic stays not covered by insurance or the NHS) comprised the largest share of the mean cost of other healthcare. The mean cost to people with cancer overall was £5 per month. This was despite only four per cent of people incurring these costs. Among this small proportion who did incur private treatment or healthcare costs, the median cost incurred was equivalent £33 per month for the last six months, (with a mean cost of £112 per month; Table A2).

Dental surgery and care contributed a mean cost of £3 per month to the total. This varied significantly by country of residence, with people in Scotland and Wales spending £8 per month (mean) compared with £2 per month spent by those in England and Northern Ireland (Table A3).

Overall, eleven per cent of people had actually incurred dentistry costs; among this subset of the population, the median cost was £9 per month (and the mean was £28; Table A2).

Personal care provided to people in their homes also contributed a mean cost of £3 per month overall to the total cost. While only five per cent had paid for this type of care, the median amount this subset spent each month was £28 (with a mean expense of £56 per month; Table A2).

Other components which contributed only small amounts to the total cost of other healthcare were: over-the-counter or prescription medicines and dietary supplements; dietary supplements such as tablets and nutritional drinks; and dressings, such as wound dressings, stay dry pads or sanitary wipes (Table 12). Even so, small proportions of people did incur these (see Table A2), as the following case illustrates:

One survey respondent had continued to pay for her prescriptions after her diagnosis, only finding out belatedly – and by chance – that she qualified for free prescriptions for any medications relating to her cancer or the effects of her treatment.

In addition to these costs, some other costs relating to healthcare that were not captured, as they had not been anticipated as an additional area of expenditure but were mentioned by the survey respondents, included eye tests, spectacles and lenses.

Predictors of other healthcare costs

There were several strong predictors of incurring any other healthcare costs (Table A17). Among them were characteristics relating to an individual's diagnosis.

Having had surgery or chemotherapy in the last six months and having advanced, secondary or metastatic cancer, recurrence or relapse were strongly related to incurring such costs, independently of other characteristics.

Cancer type was also predictive. Among those most likely to have incurred other healthcare costs, all other things being equal, were those diagnosed with cancer of the lip, mouth, pharynx or larynx. This may reflect the costs associated with dentistry described above or due to a greater need for dietary supplements, given the nature of these types of cancer. It was also high among those with breast cancer, cancers of the reproductive system, pancreas or liver, colon or rectum, and lung bronchus or trachea (Table A17).

Table 13: Other healthcare costs by cancer status

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|-------------------------------------|------------|----------|------|
| Advanced / secondaries / metastatic | 0 | 33 | 219 |
| Recurrence / relapse | 3 | 19 | 65 |
| Not known / undergoing diagnosis | 0 | 17 | 230 |
| Localised or stable | 0 | 11 | 462 |
| Remission or cancer-free (cured) | 0 | 17 | 431 |

Base is all respondents (n=1,610). Those with missing cancer status information are not shown. Treat with caution any figures based on small sample sizes (shown in grey).

The actual costs associated with different characteristics of the diagnosis ranged from a mean of £8 per month among those with colorectal cancer to £33 per month among those with advanced, secondary or metastatic cancer (Table 13; Table A18).⁹ People diagnosed with breast cancer spent £28 per month (mean) and those with lung, bronchus or trachea incurred £25. When considering these variations we rely here greatly on the mean to illustrate them because the median for almost all subgroups was £0 (because fewer than 50 per cent had incurred

⁹ Variation in the actual cost between subgroups is indicated by significance testing of the mean. The mean is also relied on here to illustrate these differences, given the large number of sub-groups incurring median other healthcare costs of £0 (reflecting that fewer than 50 per cent of people had incurred *any* such cost). However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs.

them). However, reflecting the finding that 51 per cent of people with cancer of the cervix, ovary or uterus or cancer that had recurred or relapsed had incurred these costs, the median cost for these subgroups was £1 and £3 respectively.

Although the number of people in the sample who had received no treatment at all for their cancer in the last six months was small, the mean amount they had spent on other healthcare was large at £66 per month. This reflects the finding that a comparatively high proportion of them (53 per cent) had incurred some cost in this category. In keeping with this, the median cost of supplementary healthcare and sundries to those receiving no treatment was £3 per month. This does not seem to reflect that they had received the diagnosis a long time ago; instead it might reflect that these respondents had opted for alternative therapies or were paying privately for palliative care.

Some demographic and socio-economic characteristics were also important predictors in the regression analysis (Table A17). Housing tenure, for example, was a strong predictor with those owning their homes or renting privately being at the high end of the range. The likelihood of having incurred these costs was also high among those with high incomes. These findings appear to reflect the ability of better-off households to afford to pay for alternative or supplementary healthcare.

Additionally, people aged under 40 were more likely than all other age groups, all other things being equal, to have incurred other healthcare costs and it was also higher among living in rural areas than those in urban areas.

Even so, the actual costs incurred did not vary significantly by any of the demographic or socio-economic characteristics examined (Table A19). There was also no variation in the actual cost incurred depending on where people lived, by country or type of area. It was, however,

particularly common for the under 40s (58 per cent) and those under 60 and working (56 per cent) to have incurred some cost, and this is reflected in the medians costs of £3 and £2 per month respectively for these subgroups.

The cost of clothing, equipment and modifications

The survey included a category of expenditure intended to capture larger one-off costs that can arise due to a cancer diagnosis or treatment. These range from replacement clothing due to weight change or discomfort through wigs and other head coverings (for example, because of hair-loss following chemotherapy) to buying specialist equipment or modifying the home or car.

Table 14: Component cost of clothing, equipment and modifications

| Monthly equivalent cost | Median (£) | Mean (£) |
|--------------------------------------|------------|----------|
| Wigs, hair-pieces, head coverings | 0 | 2 |
| Fabric supports | 0 | 1 |
| Clothing | 0 | 9 |
| Modifying the home | 0 | 12 |
| Specialist equipment for home or car | 0 | 2 |
| Total cost | 0 | 26 |

Base is all respondents (n=1,610).

Most people (63 per cent) did not incur *any* costs in this category. As such, the median cost for this category of expenditure (and each of its components) was £0. The mean monthly equivalent amount people spent across these components was £26. When considering the mean, the largest component cost of clothing, equipment and modifications was from making modifications to the home, such as installing an accessible bath or shower, handrails or stair lift or widening doorways or replacing flooring (Table 14).

Although a large majority of people did not incur any cost from making modifications to the home (96 per cent), high costs incurred those who did led to an overall mean of £12 per person per

month. Among the four per cent who did, the median cost was £67 per month (with a mean cost was £326; albeit based on small numbers; Table A2). These relatively high costs are illustrated by Sian’s story below.

Costly modifications to the home

Sian was diagnosed with cancer in 2009. Her home, which she rents from a local Housing Association, had damp problems that predated her diagnosis. But it was only after her diagnosis that she became concerned and eventually discovered that a leak had been making all her carpets damp. The landlord fixed the leak but would not replace the carpets, which remained damp, and in Sian’s view, unhygienic. Such were her concerns as she started chemotherapy, Sian had all her carpets replaced, at a cost of several hundred pounds, with new hard flooring that would be more hygienic and easier to keep clean.

Source: depth interviews

Costs relating to replacement clothing also made up a large share of this category, with a mean of £9 per month. In comparison, wigs and other head coverings (£2 per month), specialist equipment for the home or car (£2 per month) and fabric supports such as surgical brassieres or abdominal and spinal supports (£1 per month) made up only small shares of the overall cost, reflecting the more specialist nature of these costs.

Variations in the cost of clothing, equipment and modifications by characteristics

With an estimated mean cost of £103 in Wales, the total cost of clothing, equipment and modifications was particularly high (Table A3).¹⁰ This was largely accounted for by a high mean of £89 per month in relation to home modifications. It is important to note, however, that this could

¹⁰ Variation in the actual cost by country is indicated by significance testing of the mean. However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs.

be the result of one or two very large values in the sample, which may not be representative of the broader picture.

There were also statistically significant variations in the mean cost by country for clothing and wigs and head-coverings. The cost of clothing was at the low end of the range in England (£8 per month; see Table A3) compared with other nations of the UK. Conversely, the estimated cost relating to wigs and hair-coverings was at the high end of the range for people living in England (£3 per month). The median (and mean) cost for this component in Wales was £0. This most likely reflects that charges for wigs (along with charges for appliances and other prescription charges) were abolished for people in Wales in 2007.

Conversely, however, the finding that country was not statistically significant in regression analysis predicting whether or not people had incurred any clothing, equipment or modification costs, suggests that this is most likely a spurious finding that is not attributable *per se* to living in Wales (Table A20) but one or more other factors that relate indirectly to this.

One survey respondent had needed to replace the wig she used following her treatment on several occasions, with the NHS only paying for the first of them.

In keeping with previous sections, characteristics relating to people's diagnosis were particularly important in predicting whether or not people had experienced any costs associated with clothing, equipment and modifications (Table A20).

Cancer type was strongly predictive. All other things being equal, people with breast cancer were more likely than people with many other types of cancer to have incurred any such costs. This may reflect the particular costs of surgical brassieres, or the need for seat-belt protection for example. This is borne out in the estimated *actual* costs (Table A21), for which people with breast

Technical note 6: The cost of a new car or moving home

The questionnaire asked respondents to say whether or not they had moved home as a result of their diagnosis or treatment in the last six months or bought a new or replacement car. Overall, four per cent of people had moved home and nine per cent had bought a 'new' car.

While it was important to capture the effect of cancer on these large one-off costs, the costs associated with these, where incurred, were expected to be very variable. The costs of moving home would also be difficult for some respondents to estimate and the cost of any new car or home might include an element of choice that did not relate directly to someone's diagnosis.

Therefore, rather than asking respondents to estimate the costs associated with these major events, the costs have been assumed based on published averages. The costs of moving home were based on figures published by Lloyd'sTSB (2012) and the Resolution Foundation (Darian, 2011):

- Home owned outright: £7,846
- Home owned with mortgage: £8,922
- Private rented sector, one adult:¹ £1,309
- Private rented sector, two adults:¹ £1,346
- Social rented sector: £1,110

1. Deposits were not included as these represent a displacement of resources rather than a true cost.

The assumed cost of buying a new or replacement car was based on figures published by Auto Trader (2012) and took the average cost of a used car under three years old:

- Cost of car: £15,010

Because these costs have been assumed they have not been included in the total for clothing equipment and modifications reported here or in the total financial impact of cancer reported in Chapter 2. If they were included the median cost of clothing equipment and modifications would remain at £0, but with new estimated mean of £240 per monthly equivalent. The new median total financial burden of cancer would be £137 with a mean of £664 per month.

cancer incurred a median cost of £5 per month for this category.

Having received chemotherapy, surgery or radiotherapy in the last six months also increased the odds that people had incurred costs in this category. Those with advanced, secondary or metastatic cancer and those whose cancers had recurred also had an increased propensity to have incurred these costs, taking account of their other characteristics.

Despite some wide variation in the actual (mean) cost incurred due to clothing, equipment and modifications by diagnosis characteristics, this variation was not generally statistically significant (Table A21). The one exception was that people who had not had any treatment had far higher than mean costs, with a mean of £102 per person per month (albeit based on a small sample).¹¹

Because it is amenable to significance testing, we look to the mean as the better indicator of whether any apparent variation is large enough to conclude that differences do genuinely exist in the population. It is notable nonetheless that the median cost incurred in this category of expenditure was £5 among people with breast cancer, £5 among those with relapsed or recurring cancer, and £4 among those receiving chemotherapy in the last six months; the median cost for all other subgroups was £0. This is due to the finding that just over a half of people in these subgroups had incurred some additional cost in this category, compared with 37 per cent overall (Table A21).

Demographic and socio-economic characteristics appeared to play a smaller role than we saw in relation to other healthcare costs (see earlier in this chapter). Age and gender were both

¹¹ Variation in the actual cost by different subgroups is indicated by significance testing of the mean. However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs.

significant, however, with women being more likely than men to have incurred clothing, equipment and modifications costs (even after taking into account the finding that breast cancer was also linked with incurring these costs), and the odds falling steady with increasing age.

Costs after breast cancer

Carol is in her forties and a mother with two young children. Diagnosed with breast cancer in 2011, Carol was surprised by some of the costs that came up for her as a result of her treatment. These included needing to buy a water-proof sleeve to keep her wounds dry when showering and specialist bras which she had needed to replace on more than one occasion:

'I had to buy a number of bras during the chemo stuff, because they did the reconstruction and then I had [sic], before I had radiotherapy it meant that this bust changed a lot because of the silica.'

Because the drains from her surgery limited what she could wear, new pyjamas and comfortable clothes also had to be paid for. And she needed to change her shampoo, moisturisers and other toiletries while she was having chemotherapy to make sure she was only using products that did not have any perfume in them.

In addition to these unavoidable costs, Carol spent considerable sums of money on other things which, to her, were also important. She chose not to wear the wig provided to her by the NHS, and instead bought hats and scarves that she thinks cost £100 all-tolled. And she bought a lot of makeup to compensate for hair loss during chemotherapy:

'I know I didn't have to but actually that made me feel a lot more human.'

Being comfortably off, Carol recognised the degree of choice she had in spending her money on these items. She was resentful, however, about the cost of buying the medical supplies she could not have managed without.

Source: depth interviews

Employment status and household income were also important. Here it was those who were in retirement and those on middle incomes at the

time of the survey who were most prone to these costs (Table A22).

Furthermore, those receiving health-related benefits were more likely, all things being equal, to have incurred these costs. This may indicate a high level of health and support intervention required by these individuals. Variation in the actual cost for this measure was also significant, with those in receipt of health-related benefits spending a mean cost of £48 per month compared with £12 among those who were not. Still, less than a half of them had incurred any cost in this category (56 per cent), resulting in a median cost of £0 (Table A22).

The added cost of day-to-day living

Apart from the costs associated with reduced income and outpatient visits, the next largest category of expenditure in the survey related to the added costs of day-to-day living. The median cost incurred following a cancer diagnosis was £3 per month (54 per cent had incurred any), and the mean cost incurred was £34 per month. This takes into account the fact that respondents to the survey could indicate where they had incurred lower rather than higher day-to-day living costs as a result of their cancer, for example, because they were less active socially or were eating less than they previously needed to.

Components of increased daily living costs

Eight component costs were taken in consideration when measuring the added cost of day-to-day living (Table 15). No single component cost was incurred by more than a half of respondents to the survey, resulting in a median cost for each component of £0.

When considering the mean cost instead, the largest share of the additional £34 that people were paying towards their daily costs each month as a result of their cancer came from household fuel bills and help around the home or garden. Overall, each of these components contributed a mean of £8 per month to the total. For fuel bills in

particular this is likely to be an underestimate because the survey was undertaken in late summer and early autumn. Had winter fuel costs been taken into account, when the demand on heating (and lighting) would be greater, the mean would almost certainly have been higher. Even so, each of these additional costs affected less than a half of households (33 per cent and 25 per cent respectively), as reflected in the median values of £0 (Table 15).

The overall mean additional cost of £8 per month compares with an average total spend on fuel bills across the population of the UK as a whole (regardless of having a cancer diagnosis) of £93 per month (ONS, 2011). In contrast the additional £8 per month paid for help around the home or garden as a result of cancer compares with a national average cost of £10 per month (ONS, 2011).

Table 15: Components of the added cost of day-to-day living

| Monthly equivalent cost | Median (£) | Mean (£) |
|--------------------------------|------------|-----------|
| Food and drink | 0 | 5 |
| Household items | 0 | 1 |
| Household fuel bills | 0 | 8 |
| Telephone or internet bills | 0 | 4 |
| Travel costs | 0 | 3 |
| Television or books | 0 | 3 |
| Help around the home or garden | 0 | 8 |
| Child care | 0 | 1 |
| Total cost | 3 | 34 |

Base is all respondents (n=1,610). Means do not sum correctly due to rounding.

The depth interviews highlighted how these additional costs impacted on the households that were affected.

As in Mary's case, below, the effects of cancer and its treatment meant that people could be particularly susceptible to the cold, which in turn could add significantly to their heating bills. Others in the depth interviews could no longer perform basic tasks around their home such as

cleaning and gardening due to their illness and treatment. Where they bore the full cost of buying-in this help, depth interviewees expressed a certain amount of frustration and resentment that there was no financial assistance available to them. We examine how people funded the additional costs of cancer in more detail in Chapter 5.

Turning the heating up after cancer

The burden of additional heating costs following a cancer diagnosis was raised by several of the people interviewed in depth. Mary estimated that she spent an extra £200 on heating in the first winter alone following her diagnosis. A widow living on a modest fixed pension, Mary reflected that this cost in particular *'hit me hard'*.

Having the heating turned up higher was partly because Mary was still in recovery after her surgery. But it was also because her cancer treatment had led to considerable weight loss, which in turn left her feeling the cold much more than she had ever done before. For Mary, this added cost was simply unavoidable:

'It was absolutely necessary because I just...I just couldn't cope with the cold.'

Source: depth interviews

Additional spending on food and drink amounted to a mean of £5 per month. In the depth interviews, this was attributed to making a concerted effort to eat more healthily. This additional cost is small when compared with an average total spend on food and drink of £231 per month across all UK households (ONS, 2011), but no less a potential added burden.

The remaining components contributed rather smaller amounts to the total added cost of living of £34 per month as measured by the mean: telephone and internet bills contributed a mean of £4 per month; extra travel costs, for example due to increased use of the car or public transport to get about in daily life, added £3 per month; spending on television, books or other leisure activities contributed £3 per month; and

household items (such as cleaning products) added £1 per month.

One depth interviewee told us that he was entitled to travel free on public transport. However, because he and his wife both used wheelchairs – and the bus could only accommodate one of these at a time – he had had to resort to travelling by car to get about.

Another £1 per household (mean) was also spent each month on child care as a result of people's diagnosis or their treatment. This low cost reflects that only one per cent of people in the sample incurred child care costs as a result of their diagnosis or treatment, though the cost to those incurring any child care costs would be considerably higher. Like some of the other costs described earlier, depth interviewees with young children expressed a degree of resentment that there was no financial help available to people with cancer to help them meet the costs of childcare when they were not well enough to care for their children themselves. Some had paid for professional childcare. Others had relied on help from family or friends because they did not want

Predictors of increased daily living costs

The two day-to-day living costs which accounted for the largest share of the total varied significantly by country of residence.¹² The additional cost of fuel bills varied from £7 per month among those living in England to £18 per month among those in Northern Ireland. The higher cost in Northern Ireland is likely to reflect a greater dependence on oil for heating the home here, which tends to be more expensive than gas (which is widely available via the grid in other countries of the UK; The Consumer Council, 2012). The cost of help around the home also ranged

¹² Variation in the actual cost by country is indicated by significance testing of the mean. However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs. For completeness, the median is also provided where relevant.

from £7 per month in England to £19 per month in Northern Ireland (Table A3).

As a result of these variations, the total added cost of day-to-day living was also high for people living in Northern Ireland (with a mean of £58 per month and a median of £8) compared with an estimated mean of £31 per month among those living in England (and a median of £2). The mean cost among those in Wales was £43 and for those in Scotland it was £45 per month (with medians respectively of £2 and £8).

The effect of country of residence held true in regression analysis. All other things being equal, the propensity to have any additional costs was higher in Northern Ireland and Scotland compared with England (Table A23).

Another strong predictor in the regression was household income, whereby those with the lowest incomes were least likely overall to have incurred extra costs (Table A23). This may reflect the extent to which people can afford to spend more, rather than their needs or preferences. This is supported by the finding that, all other things equal, people living in a home that was owned outright were more likely to have had additional day-to-day living costs than those who rented their homes from a social landlord. However, households receiving health-related benefits were also likely to have incurred added costs suggesting that the help they were receiving from benefits were helping to ease the burden of cost (Table A23).

There was also some variation by household composition, whereby single adults living alone were more likely than childless couples to have incurred added daily living costs. Even after controlling for this and other characteristics, those aged under 40 were still more likely to have incurred added costs than those aged over 60 (Table A23). The actual, median cost incurred by people aged under 40 was £10 per month (with a mean of £58 per month). This may reflect the

more active lifestyles of younger people and single adults living alone or the higher relative cost to live as a single adult rather than a couple (where certain costs can be shared). However, the actual costs incurred were considerably greater where people had dependent children (see Table 16). This may indicate a particular desire or determination in households with children not to compromise their living standards.

Table 16: Added costs of day-to-day living by household composition

| Monthly equivalent cost | Median (£) | Mean (£) | Base |
|--------------------------------------|------------|----------|------|
| Single adult living alone | 5 | 39 | 431 |
| Partnered, no children | 2 | 29 | 776 |
| Partnered with dependent children | 8 | 49 | 185 |
| Single adult with dependent children | 10 | 56 | 76 |
| Single adult with other adults | 1 | 30 | 130 |

Base is all respondents (n=1,610). Cases with missing household composition information are not shown. Treat with caution any figures based on small sample sizes (shown in grey).

Finally, cancer type and certain types of treatments were also significant in the regression analysis. For this category of cost, people with breast cancer or an 'other' type of cancer were at the low end of the range. Compared with these, the odds of incurring added daily living costs were significantly higher among those with cancer of the pancreas or liver, kidney or bladder, lung, bronchus or trachea and brain, and those diagnosed with lymphoma, leukaemia or myeloma (Table A23).

The effect of having had surgery in the last six months was also strong, the odds of incurring extra daily costs being 2.3 times higher among those who had compared with those who hadn't. The odds were also higher among those who had had chemotherapy, but they were lower among those who had had radiotherapy in the last six months.

Notably, cancer status was not independently related to incurring extra living costs (Table A23). However, when looking at the actual cost incurred the variation in the mean across this measure was statistically significant (Table A24). Variation in the actual cost by different subgroups is indicated by significance testing of the mean. However, the precise values of the means should be treated with caution as they are influenced by isolated cases incurring very high costs. As such, and, for completeness, the median is also provided here.

The mean cost of cancer among people with cancer of the lung, bronchus or trachea was relatively high at £40 per month (with a median of £7), rising to £48 per month (and a median of £17) among those with oesophagus, stomach, pancreas or liver and £49 (median of £5) among those with an 'other' type of cancer.

More striking still is the finding that people with advanced, secondary or metastatic cancer were spending an extra £57 per month (mean, with a median cost of £15). This relates to the finding that 64 per cent of these patients had incurred some additional cost relating to day-to-day expense. In turn, this may partly reflect that these individuals had particular types of cancers, or were having certain types of treatment, that were also likely to be associated with incurring costs. For example, the actual cost incurred by people who had had chemotherapy in the last six months was also comparatively high, with a mean cost of £43 per month, a median of £10, and 64 per cent of this group incurring any cost (Table A24). In comparison, only 38 per cent of people who had received no treatment at all in the last six months had experienced additional day-to-day living costs (resulting in a median of £0), although those who had appeared to have incurred relatively high costs given the overall mean cost for this subgroup of £65 per month.

Additional analysis found that the mean cost varied significantly for many of the demographic and socio-economic measures that were

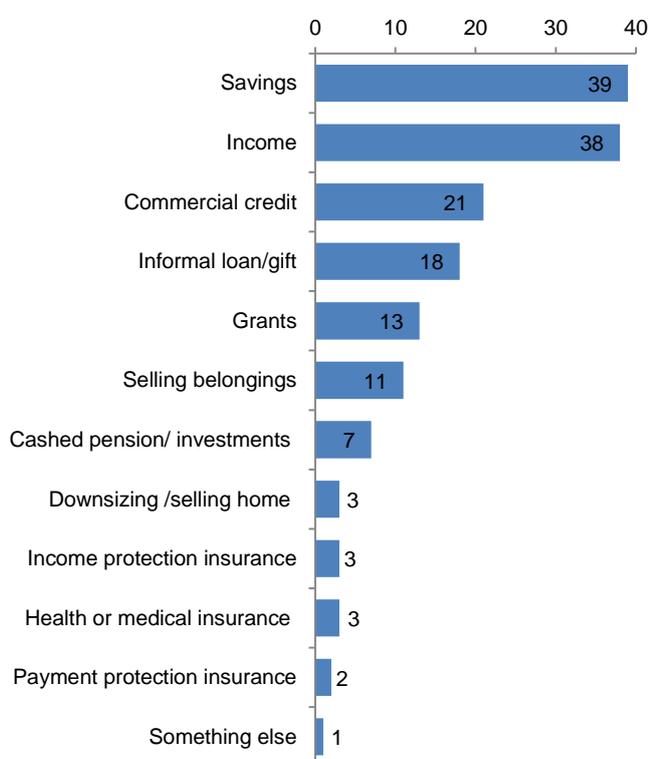
significant in the regression analysis that predicted whether or not any added daily living costs were incurred (Table A25). These include age, household composition, income and the receipt of health-related benefits. Of particular note is that the mean cost to people describing themselves as unable to work due to ill-health was £64 per month, and the median cost was £17 per month. Some 66 per cent of this group had incurred some additional day-to-day living costs.

5 Funding the financial impact of cancer

The burden of additional expense or loss of income resulting from cancer led most people to need to draw on resources other than their regular income at some point since their diagnosis. For many, this involved using up savings, turning to commercial borrowing or accepting financial help from friends or family.

Survey respondents were asked to consider which, from a list of different sources of funding, they (or their partner) had used at any time since their diagnosis to help pay for any increased costs resulting from their diagnosis or treatment. Most (72 per cent) had used one or more sources. Which source people had used did not vary significantly by country of residence (Table A26). The individual sources of funding people said they had used are shown in Figure 17.

Figure 17: Sources used to help pay for increased cost: percentages



Base is all respondents (n=1,610). More than one response was allowed. 28 per cent overall had used 'none'.

As we might expect a large number – nearly four in 10 – said they had used regular incomes, such as income from earnings, pensions or social security benefits.

If we consider the sources of regular income people said they (or their partner) received at the time of the survey, income from state pensions (21 per cent) and private pensions (18 per cent) made up a considerable share, reflecting the older age of people with cancer on average. Income from earnings were used by 14 per cent of people overall (Table A27).

Similar proportions received Attendance Allowance or Carers Allowance (14 per cent) and income-replacement benefits or tax credits (13 per cent). The propensity to have used either of these regular sources of income varied considerably by country of residence, being higher in Northern Ireland (30 per cent and 35 per cent respectively) compared with elsewhere (Table A27).

The depth interviews found that people with cancer were not always aware of the welfare benefits they might be entitled to. Some people had experienced considerable financial hardship before they found out by chance that they were eligible for financial assistance from the state. We go on to discuss people's experiences of advice in relation to money and debt in Chapter 6.

Sources of funding other than regular income

Overall, 60 per cent of people had used sources other than their regular income to help meet any extra costs arising due to cancer. A large proportion had used savings to meet these increased costs, possibly from the income generated by savings or possibly from the capital itself (Figure 17). This may partly reflect the bias towards older people among those diagnosed with cancer, who may have been drawing on money they had put aside for their later years during their working lives. Due to constraints on

the scope of the survey and the length of the questionnaire we do not know what level of savings respondents had when they started to draw on their savings or what they currently had.

The depth interviews showed that, where people had drawn on savings, these were used to cover larger costs or to help compensate for a loss of earned income. Some people were reluctant to use up their savings in these ways. Instead they decided to either go without things or else turned to family or friends for help. They resented the fact that they had to draw on their own assets at all, and felt that financial help should have been available to them, either from the state or from other organisations like Macmillan.

The survey found that one in five people had used commercial credit (21 per cent) in order to help pay for the increased costs arising because of their diagnosis or treatment. Overdrafts and credit (or store) cards were the most commonly used sources of commercial borrowing for these costs (Table A28). This reflects the picture for the general population of adults, where overdrafts and credit cards have consistently been popular forms of credit over recent years (ONS, 2012). Again, due to constraints on the scope of the survey and the length of the questionnaire, respondents' levels of general borrowing (including for uses other than funding the cost of cancer) was not collected.

In comparison, it was unusual for people to say they had turned to other types of formal borrowing, including an unsecured loan from a bank, building society or finance household (three per cent) or a secured loan or second mortgage (one per cent). Only small proportions of people with cancer had used home credit (three per cent), or a loan from a payday lender or pawnbroker (two per cent) to help pay for increased costs since their diagnosis. This is consistent with low rates of use of alternative forms of credit in the general population (Collard et al., 2012 forthcoming). Borrowing from

unlicensed lenders (i.e. loan sharks) was also very unusual among people with cancer, being reported by less than one per cent.

Almost as many people had taken a loan or gift of money from friends or family (18 per cent) as had borrowed commercially in order to help pay for the increased costs of cancer. The depth interviewees revealed the other types of support that family and friends provided to people with cancer. These are easily overlooked but often played an important role in offsetting the costs of cancer. They included family or friends driving people with cancer to hospital or other health-related appointments. This could mean that a working partner did not have to take (more) time off work. Help also came in the form of informal childcare, helping out with the school run or cleaning. Where help was provided by family members, this was generally felt to be part of the give-and-take of family life. Gifts were sometimes given to friends or family in appreciation of their help and support. It is not possible to say from this study how common these types of support are.

In the survey, 13 per cent of people with cancer overall said they received a grant from a charitable body to help them meet their increased costs. Because the survey respondents were sampled via Macmillan (which provides grants), this may well be an over-estimate.

As we saw with benefit entitlement earlier in this chapter, the findings from the depth interviews suggested that people may only access the grants that may be available to them by chance. Not surprisingly, the most common grant mentioned by depth interviewees was the income-related grant available from Macmillan, which is on average £250. While those on lower incomes who had received the Macmillan grant were very grateful for it, others expressed frustration that they did not qualify for this help because it was income-related. In their view, this type of financial help should be available to all people with cancer,

not just those on lower incomes, *'because we all need help'*.

A large minority (11 per cent) of people with cancer had sold belongings (such as personal items or a car) to help them pay for the additional financial costs following a cancer diagnosis.

Figure 17 also shows the less common ways people had funded the additional costs arising from cancer. A small proportion (seven per cent) had cashed in pensions or other investment. Very few had sold their homes or downsized in order to meet any increased costs (three per cent). It was also unusual for people to have had any financial help from insurance policies.

A few people in the depth interviews had benefited from insurance policies, which helped to replace lost income or (in the case of private health insurance) to cover the cost of particular treatments.

Predictors of common alternative sources of funding

Regression analysis explored which characteristics were important predictors of drawing on savings, commercial borrowing, help from friends or family or selling belongings – some of the more common sources of funding except for regular income – to help fund the cost of cancer. The same measures that were used in regressions reported in previous chapters were used here, with the additional inclusion of the total financial impact of cancer individuals had incurred (in five groups based closely on quintiles of cost).

For each of the four sources of funding, the total financial impact of cancer was a strong, if not the strongest, predictor, with the odds of having used each source increasing steadily as the total financial impact increased. For example, compared with those incurring a total burden of less than £10 per month, the odds among those with a financial impact of £1,000 or more were seven times higher for using savings and for commercial borrowing, five times higher for those

selling belongings and they were three times higher for taken a loan or gift of money from friends or family (Tables A29-A32).

Apart from this the predictors varied depending on the source of funding considered.

Drawing on savings

Other important drivers of using savings to help pay for increased costs were household income and housing tenure (Table A29). The odds of drawing on savings tended to decrease as income increased, albeit peaking among those with low-to-middle incomes (i.e. those with incomes of between £860 and £1,299 per month). This is likely to reflect two things: that there is a reduced need to draw on savings in the presence of higher incomes; but that the availability of (or inclination to use) savings is low among those with the lowest incomes. This is supported by the finding that single adults with dependent children or living with adults other than a partner were unlikely, all other things equal, to draw on savings to fund the cost cancer.

Once household income and other factors were taken into account, the odds of drawing on savings were also fairly high among people owning their homes outright. Again, this may reflect a greater tendency for people without housing costs to have had more capital to draw on. Not being in receipt of health-related benefits at the time of the survey also increased the odds of drawing on savings at any time since diagnosis as a result of costs incurred.

There were no variations in the propensity to draw on savings depending on where people lived.

Finally, cancer type was also related to drawing on savings to help fund the cost of cancer when other factors were taken into account. Notably, those with cancer of the pancreas or liver and brain were at the high end of the range. The odds were also significantly higher among those who

had *not* had surgery for their cancer in the last six months than those who had.

Use of commercial borrowing

Gender, housing tenure and not being in receipt of income-replacement benefits were strong predictors of using commercial borrowing to help pay for the increased cost arising from cancer (Table A30).¹³ All other things equal, women were more likely than men to have used this source as were people who were living in rented or mortgaged homes and those not receiving of income-replacement benefits. The odds of borrowing as a result of cancer were also higher among people from a non-White background than those describing themselves as White.

There were no variations in the propensity to use commercial borrowing depending on where people lived.

Characteristics of people's cancer diagnosis played a fairly small part. Only cancer type was significant in the analysis, and even then it was not a strong predictor. Here, people with cancer of the kidney or bladder and lip, mouth, pharynx or larynx were at the high of the range.

Financial help from friends and family

In contrast, cancer type was a strong predictor of people turning to friends or family for help (Table A31). The odds were particularly high among those with cancer of the lip, mouth, pharynx or larynx. They were also high among people with colorectal cancer, breast cancer and cancers of the reproductive system.

Other strong predictors of drawing on loans or gifts of money from family or friends related to people's socio-economic status. Again, people

living in rented or mortgaged homes and those on the lowest incomes were more likely, all other things equal, to have turned to family or friends for help. This might be expected, since friends and family tend to be a last resort when other sources of money (particularly savings and commercial borrowing) have become limited (see, for example, Finney and Davies, 2011). However, being in receipt of income-replacement benefits lowered the odds that people had turned to commercial borrowing, possibly because this type of credit was less available to them (or only at excessive cost).

Most notably, however, the odds of getting help from family or friends were particularly high among those who described themselves as unable to work due to permanent ill-health or disability. In contrast, they were low among people aged 60 and over, all other things being equal.

Although country of residence was not a significant predictor, there was some variation depending on whether people lived in an urban or rural area. Those living in a rural area were somewhat more likely, all other things being equal, to have drawn on financial help from family or friends.

Selling belongings

The characteristics driving the selling of belongings to fund the cost of cancer were in many cases similar to those predicting drawing on friends or family for help. As such, the odds of selling belongings were very high among people with cancer of the lip, mouth, pharynx or larynx (Table A32). However, they were also higher among people for whom their cancer status was not known or undergoing diagnosis compared with those either in remission or, conversely, with advanced, secondary or metastatic cancer. Where people had received surgery or some 'other' treatment for their cancer in the last six months, the propensity to have sold belongings was also high compared with those who had not received these types of treatments.

¹³ Respondents were defined as receiving 'income-replacement benefits', as distinct from 'health-related benefits' if they were receiving any of the following: Income Support, Job Seeker's Allowance, Tax Credits or Pension Credits.

As we saw in relation to having financial help from friends and family earlier in this chapter, socio-economically it was people who were permanently unable to work due to illness or disability who were most likely – all other things being equal – to have sold belongings. The odds were also high among all housing tenure groups who did not own their homes outright, compared with those who did, rising to 3.3 times the odds among those renting privately.

While country of residence did not predict selling belongings to fund the cost of cancer it was significantly higher among people living in rural areas than urban ones. This might partly reflect the success of online auction sites for second-hand goods in recent years and the continued expansion of retail stores that buy and sell second-hand goods into provincial towns.¹⁴

The percentage of people using these four sources of funding broken down by the full range of socio-demographic and diagnosis characteristics in shown in Tables A33-A34.

¹⁴ See for example Reuters (2012) and Cash Converters (2012).

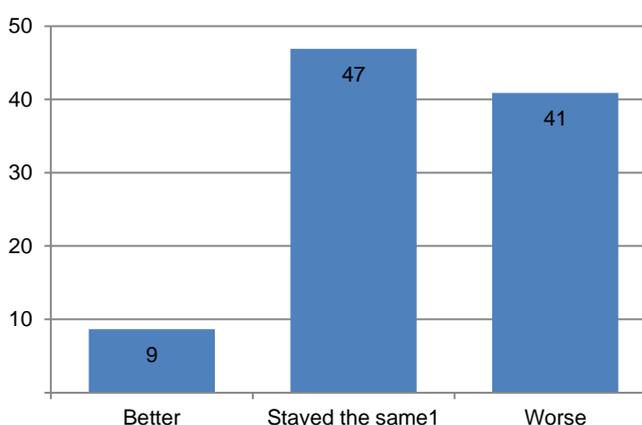
6 The impact of cancer on financial wellbeing

For a substantial minority of people with cancer, their general financial situations had got worse since their diagnosis. The added costs households incurred as a result of a cancer diagnosis strongly predicted which households were struggling financially at the time of the survey. In many cases, however, money and debt advice had had a positive impact on households' situations.

An important aim of the study was to understand the impact a cancer diagnosis has on households' financial wellbeing, particularly (though not exclusively) where this arises as a result of the financial cost of cancer.

Survey respondents were asked to say whether their general financial situation had got better, worse or stayed about the same since their diagnosis. For almost a half of people, their situation had broadly stayed the same (or that it was too difficult to say). A further one in 10 felt that their situations had got better. Four in 10 considered that their financial situations had got worse since their diagnosis (Figure 18). This did not vary significantly by country of residence (Table A35).

Figure 18 Change in general financial situation since diagnosis: percentages



1. Includes those saying 'too difficult to say'. An additional four per cent did not state. Base is all adults (n=1,610).

The changes people had experienced, whether their situation had got better or worse, may or may not have been related to their diagnosis. Indeed, deterioration in the financial health of households since a diagnosis, particularly a diagnosis occurring several years previously, could have happened for any number of reasons. This is particularly true given the difficult economic climate the UK has experienced since the financial crisis first hit in 2007. However, as the next section describes, the total burden households had incurred as a result of a cancer diagnosis was an important driver of someone feeling that their household's general financial position had got worse.

Predictors of being worse off financially since diagnosis

In regression analysis, the total financial burden people and their households incurred as a result of cancer – through loss of income, increased expenditure or both – was highly predictive of reporting a worse general financial situation since diagnosis (Table A36). The odds were higher among all groups incurring a total financial impact of £10 or more per month compared with those incurring less than this, and they increased steadily as the impact rose. As such, the odds were some 11 times higher among those incurring a total financial impact of £325 per month and 22 times higher among those with a burden of £1,000 per month or more. This provides strong evidence that the financial impact of cancer is a contributing factor to households worsening financial situations.

Once the financial burden someone had incurred was taken into account, a few other characteristics also predicted reporting being worse off financially since diagnosis (Table A36). These included housing tenure and household income at the time of the interview and work status at the time the respondent was diagnosed. The odds of feeling worse off were higher among people living in rented or mortgaged homes

compared with those owning their homes outright, and they were higher among those with lower incomes than higher incomes. They were also rather higher if people had been not been working prior to their diagnosis compared with where they had. This may be because any change following a diagnosis, however small, may have greater significance where fewer resources were available in the first place.

Those receiving health-related benefits were also more likely than their counterparts who were not receiving them to report that their situations had got worse since diagnosis. This suggests that these benefits only went some way towards helping people offset the costs they faced. It may also reflect the fact that some health-related benefits are means tested, meaning that those receiving them were probably worse off to start with than those without them.

Household composition was significant in the analysis but where people lived was not (Table A36).

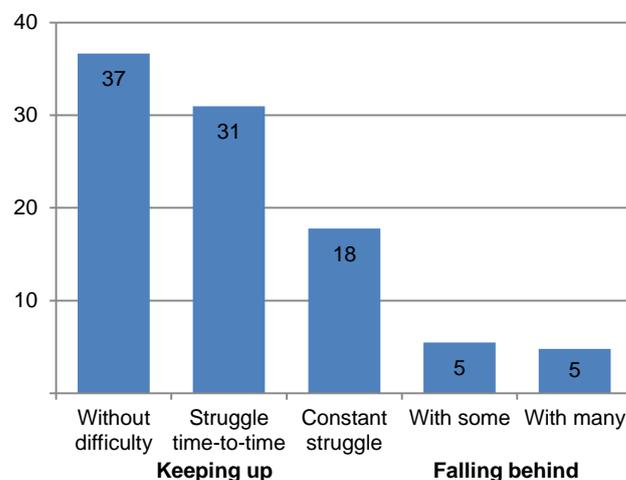
The full breakdown in the propensity to report being worse off is shown in Tables A31 and A33.

Predictors of struggling to meet financial commitments

Survey respondents were asked to select from a list of statements which one best described how well they (and their partner) had been able to keep up with their household bills and credit commitments over the last 12 months.¹⁵ More than two-thirds of people (68 per cent) said they were keeping up without difficulty or that they were keeping up albeit with a struggle from time-to-time (Figure 19). However, a large minority of people with cancer (28 per cent) said that it had either been a constant struggle to keep up (18 per cent) or that they had actually fallen behind with

some or many commitments in the last 12 months (10 per cent).

Figure 19: How well keeping up with household bills and credit commitments: percentages



An additional four per cent did not state. Base is all respondents (n=1,610).

Again, households' ability to meet their financial commitments – or the extent to which they were in financial difficulty – is not necessarily a reflection of or attributable to the respondent's diagnosis. We can, however, place these findings in the context of other research that has studied the population as a whole. In an online survey undertaken in Britain in 2009/10, 23 per cent of people overall said that they either constantly struggled to keep up with bills and payments or were falling behind (BIS, 2011). And in response to a national face-to-face survey undertaken on behalf of the Bank of England in September 2011, 7.5 per cent of people said they were falling behind with some or many bills at the moment (Kamath et al., 2011). As such, and although the figures for the population as a whole are not directly comparable (because of different methodological approaches), the finding that 28 per cent of people with cancer had at least struggled constantly and that one in ten had fallen behind nonetheless seems high in this context.

As might be expected, socio-economic characteristics are important determinants of finding it at least a constant struggle to keep up with financial commitments, if not actually falling

¹⁵ This question has been used extensively in previous surveys. See for example, Atkinson et al (2006), ECRI and PFRC (2008) and Kamath et al (2011).

behind with them. In regression analysis, the odds of struggling in this way were high among those who were unable to work due to permanent ill-health or disability, those renting or paying a mortgage on their homes, and those with low household incomes.

People who had been working prior to their diagnosis were also more likely than others, all things being equal, to have found their commitments at least a constant struggle as were those receiving income-replacement benefits (Table A38). As discussed in Chapter 2, the findings from the depth interviews suggested that where people were struggling financially this reflected a permanent (or at least persistent) loss of income, whereas those with more temporary losses had been able to manage during that time.

Gender and household composition also played a role, with men being more likely than women and lone parents being more likely than all other groups to have struggled, all other factors being equal. Where people lived was not significant.

But, again, the total financial impact of cancer incurred was also strongly predictive, pointing clearly to the contributory role that this plays in the financial difficulties households experienced.

Even when these and other characteristics were taken into account, having had surgery or some 'other' treatment for cancer in the last six months also increased the chances of being in difficulty compared with those who had not had these types of treatments. This also points quite clearly to the indirect effect a diagnosis has on households' ability to manage financially.

The full breakdown in the propensity to report being in financial difficulty is shown in Tables A35 and A36.

Arrears on consumer credit and household bills

A follow up survey question sought to understand which particular types of bills and other financial

commitments households had missed in the last 12 months due to a lack of money, if any. This also took into account being unable to meet the minimum payment on a credit or store card and – as a proxy for missing payment on overdrafts – use of an unauthorised overdraft. Again, this may or may not have arisen either as a direct or indirect result of the respondent's cancer diagnosis.

The purpose of the question was to identify the extent to which respondents' households had fallen into arrears due to over-indebtedness.¹⁶ It is important to note that households may have missed payments for other reasons, for example, inadvertently missing a payment date, being disorganised or disputing a payment (Dominy and Kempson, 2003).

When specified in this level of detail, a quarter of people overall (25 per cent) had missed at least one payment in the last 12 months. This included 17 per cent who had been unable to meet one or more household bills and 17 per cent who had got into difficulties with unsecured credit commitments (an instalment loan, credit or store card or overdraft); nine per cent had missed payments on both types of commitments.

This is broadly comparable to estimates for the population of Britain as a whole, albeit now dated, in which 22 per cent of households had missed payments on one or more commitments in the previous 12 months (Kempson, 2002).

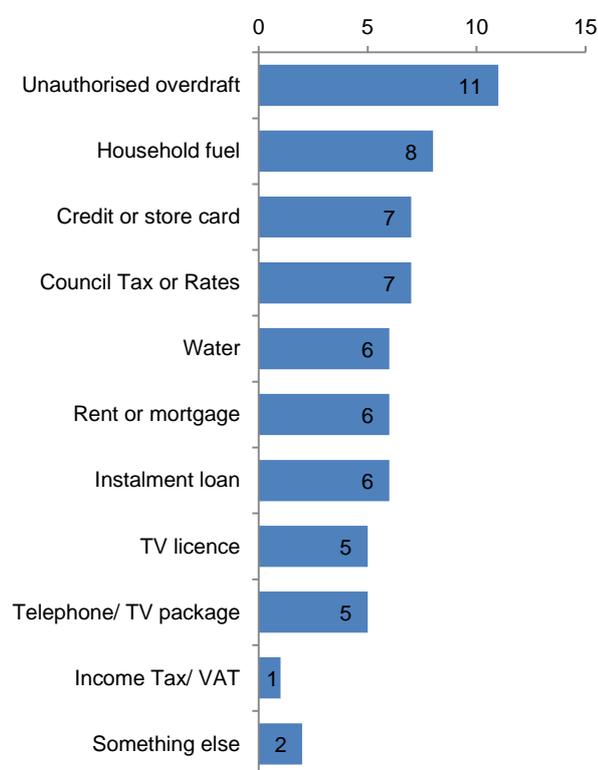
The most common commitment people with cancer got into difficulty with was an overdraft on a current account (Figure 20). 11 per cent of households had drawn on an unauthorised overdraft on at least one occasion within the last year. This partly reflects the wide usage of overdrafts in the general population and among people with cancer. Seven per cent had been unable to make the minimum payment on a credit

¹⁶ See for example, European Commission (2008).

or store card and six per cent had missed an instalment on a loan from a bank, building society or other lender.

Eight per cent of households overall had missed one or more payments on their household fuel bills (e.g. gas or electricity) because of a lack of money. Given the value people placed on keeping warm following a cancer diagnosis and spending increased lengths of time at home, this is particularly striking. Indeed, the difficulty people

Figure 20: Types of payments missed in last 12 months due to lack of money: percentages



An additional 73 per cent had not missed payments and one per cent did not state. Base is all respondents (n=1,610).

had meeting these bills may directly reflect the increased amount they were spending each month as a result of their diagnosis (estimated at a mean of £8). It was also not uncommon for people to have missed one or more payments for their Council Tax or Rates (seven per cent), water or housing costs (six per cent respectively). One in 20 had not been able to pay for their TV licence or a telephone or TV package on time and a very

small number (one per cent) had failed to pay their Income Tax or VAT bill on time.

Like household fuel, these are also priority bills, so called because the consequences of defaulting on them can be serious – ranging from loss of service, through losing one’s home to a visit from bailiffs or a court appearance – meaning they should be prioritised over unsecured consumer credit commitments (StepChange, 2012).

For most types of commitments, any apparent variation in the propensity to have missed a payment by country of residence was not statistically significant. However, the likelihood of having falling behind with Council Tax or Rates did vary significantly, with households in Scotland being particularly likely (12 per cent) to have done so (Table A41).

Predictors of arrears on household bills

Like self-reported financial difficulties (described in the previous section), default on essential household bills was driven by socio-economic characteristics and household composition (Table A42). The total financial impact of cancer was also significant in the regression analysis, evidencing the contributory role played by the increased costs and income loss arising as a result of a cancer diagnosis.

In addition, ethnicity and country of residence (but not type of area) also played a role. People from a non-White background had nearly three times the odds of having missed household bill payments compared with those describing themselves as White. And people in Scotland were significantly more likely, all other things equal, to have missed one or more such payments than people living in England.

The full breakdown in the propensity to report being worse off is shown in Tables A39 and A40.

Worry about money

The depth interviews indicated that, in the early stages of diagnosis and treatment, people gave relatively little thought to the extra costs they were incurring. Not surprisingly, they were most concerned about the illness and its impact on their health.

'I just didn't think about cost, you know, it was just all about survival really in the first year.'

Although people often reflected on those costs later, typically only once treatment was complete, they had not become a source of worry where people had been able to absorb them with their regular income, savings or through a timely return to work.

For some people, in fact, their illness had led them to worry less about money. For them, worry about their health took priority and other aspects of life were seen in a new light:

Depth interviewee: *'My way of thinking has altered slightly and in a good way because I don't worry as much, you know.'*

Interviewer: *'About money?'*

Depth interviewee: *'Well anything, money, anything generally, you know, because you realise that you're mortal.'*

There were some for whom money had become a source of concern, however. This included someone who had taken on unmanageable debts to pay for private treatment and others who had lost incomes and who had either not been able to adjust to their new circumstances or, as yet, establish their eligibility for social security benefits. Although these concerns tended to come at crunch points, such as when people were transitioning between earned incomes and income from benefits, people's main focus of worry was how they would manage in the long term. Worry added to people's levels of stress and

reduced their ability to cope emotionally at these times:

'I've always managed to maintain a reasonable high sort of mental focus, if you like but when I can't see where my next penny's coming from and I can't see what's around the corner and you're, you know, you're feeling pretty bad from the treatment that you're getting as well, and then your stress levels go up and it's just you feel unbelievably, almost suicidally [sic], low.'

For some people, the legacy of their diagnosis also made it particularly difficult to know how to plan for the future financially, as Gerald's case illustrates, because their planning horizon had become distorted.

Distorted time horizons make financial planning difficult after cancer

Gerald is in his early 50s and a lone parent of one. He was eventually diagnosed with follicular lymphoma in summer 2011. This had been difficult to detect and took several months of blood tests, scans and two lumbar puncture procedures.

Shortly after returning to work following his treatment, Gerald was laid off from his job. Out of work and lacking the right qualifications he's not able to return to similar work without further training. Though currently in remission, a relapse seems likely and, now trying to decide what to do for the best, Gerald's future looks uncertain:

'So I've got to think outside of the box and think about what I'm going to do and I don't know really...you're thinking short-term, I may not be here for very long, however I may be here until 75 and the way things are going at the moment, I won't retire until I'm 70, so technically I've still got 18 years employment'.

Source: depth interviews

Seeking money or debt advice

Respondents to the survey were asked to say which from a list of advice providers they had received advice from in relation to money or debt

since their diagnosis, and to rate the helpfulness of the advice they had received. Based on this, it was estimated that six in 10 people diagnosed with cancer had sought such advice (Table 21). As survey respondents were recruited via Macmillan information and advice services (which include money and benefits advice among a wide range of other topics) this may well be an over estimate.¹⁷

Of the remaining four in 10, most had not wanted advice about money or debt. However, a small proportion (four per cent) had wanted advice but not received any, including two per cent who wanted advice but didn't seek any and another two per cent who sought advice but didn't receive any.

Table 21: Whether sought and received advice: percentages

| | Percentage (%) |
|---------------------------------|----------------|
| Advice received | 58 |
| Wanted advice but none sought | 2 |
| Sought advice but none received | 2 |
| No advice wanted | 32 |
| <i>Unweighted base</i> | <i>1,610</i> |

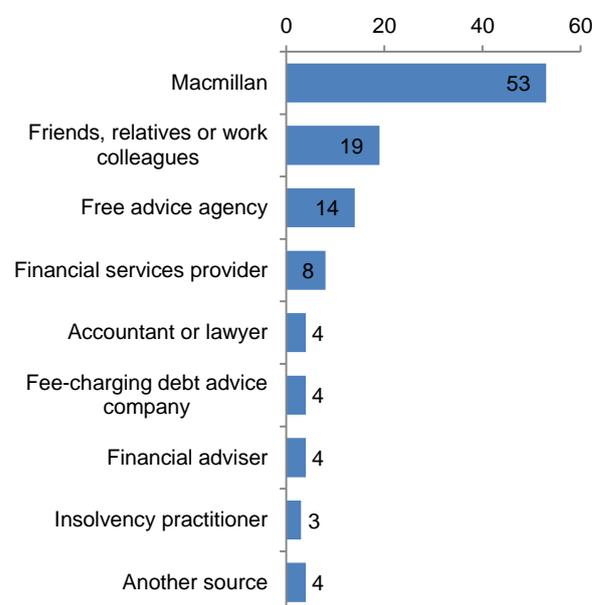
An additional seven per cent did not state. Base is all respondents (n=1,610). Figures do not sum correctly due to rounding.

Where people had sought advice, this was most commonly from Macmillan (again, this is likely to be an artefact of the sample recruitment method; Figure 22). Apart from this, the most common sources of advice about money and debt were friends, relatives or work colleagues (19 per cent) or a free advice agency (such as a Citizens Advice Bureau, debt advice agency or law centre; 14 per cent). One in twelve had sought advice from a bank, building society or other financial services provider and very few had sought advice from any other source.

Of these, the only variation by country of residence related to receiving advice from an

accountant or lawyer. This was somewhat higher in Scotland (seven per cent) and Northern Ireland (eight per cent) than in England (three per cent) or Wales (one per cent; Table A45).

Figure 22: Sources of advice: percentages



Base is all respondents (n=1,610).

Advice needs

Although the survey did not ask for details of the specific money issues that people sought advice about, the survey analysis suggests that at least some would have sought help with debt problems. In the depth interviews, welfare benefits also came through strongly as an issue that people had sought help (or wanted help) with, particularly in cases where they had experienced a drop in earned income as a result of their illness.

Three quarters of people who had received advice from Macmillan or friends, relatives or work colleagues said they found the advice helpful (Table A46). Thirteen per cent of people using these sources found the advice they received unhelpful, the remaining finding it neither helpful nor unhelpful. People who spoke to a bank, building society or other financial services provider were particularly likely to find the advice they received unhelpful (32 per cent).

¹⁷ See the Methodological Appendix for more details.

Depth interviewees reported mixed experiences of getting advice about welfare benefits and other financial support. The overall impression was of a fractured system that people found difficult to navigate – even those who had successfully applied for help.

The complexity of the benefits system meant that people occasionally received seemingly contradictory advice from different sources, and did not always know how to proceed when this happened. Delays in receiving the benefits they were eligible for, or realising they could have been receiving these benefits for several years if only they had known about them was frustrating, especially when people were in dire need of the money. A few people were unhappy about the way they had been treated by local civil servants when they applied for welfare benefits.

'They're not very helpful, the majority of them [Jobcentre Plus advisers], it's like their own money and they don't want you to have it.'

Where people were told they weren't eligible for any financial help at all, this could be a source of considerable frustration, even resentment.

Impact of advice on financial situations

Respondents who had received any advice (taking account of advice received from more than one source) were asked whether it had had a positive or negative impact on their household's general financial situation. Nearly a half (47 per cent) said that it had had a positive impact.

Notably, however, one in 10 (10 per cent) said that the impact on their general financial situation had been negative and an additional three in 10 (30 per cent) felt it had had no impact. While this seems high, it might be because the advice people received could not have had a material effect on their households' finances. For example, people may have hoped they were entitled to welfare benefits or other financial help but discovered they were not. The depth interviews evidenced

that this could breed resentment where people felt the status of their illness – rather than their financial circumstances – ought to qualify them for help:

'Yes I think the unfairness of it is if... you've got one person that says oh yes I'm getting all this, this and this, okay I'll try that and you actually get "no your cancer's, you know, you're not, you're not entitled to that" but she is, how does that work out then?'

Often unfamiliar with the benefits system, the depth interviews found that people did not know what welfare benefits or other state support there was, whether they would be eligible to receive it, or how to go about applying for it.

'Novices like us, you know, we're bumbling around at the bottom and don't know what we're doing.'

There was a large element of chance in terms of how people came across information on these matters, for example from talking to people in a hospital waiting room or from friends who had also experienced serious illness.

In addition, it often took people a considerable amount of time to piece together bits of information they had got from different sources.

Based on their own experiences, the depth interviewees felt that there should be better mechanisms for making sure people with cancer were given the information they needed, preferably early on in their diagnosis and treatment. Ideally, they wanted to be able to access all the information and help they required from one organisation, such as Macmillan, which also understood their illness. The idea of having one leaflet or website that provided guidance about the sort of help available to people depending on their symptoms or on the type or stage of their cancer was also appealing.

The other types of help that people would welcome included assistance to fill in application

forms for welfare benefits, to maximise their chances of success by including all the relevant information, because, *'if you don't tick the right box it's refused'*:

'I couldn't fill the forms in because I haven't got a clue... I've always worked all my life, I haven't got a clue how the system works.'

Some people would have welcomed a more holistic review of their finances in the early stages of their diagnosis and treatment – like a financial health check. This was often tied up with a strong desire to 'get their house in order' because of the serious nature of their illness and uncertainty about the future. This type of financial health check would cover benefit entitlement, grants, things like hospital transport and prescription charges, but also issues such as employment options (e.g. flexible working) and basic money advice like contacting creditors if faced with a drop in income. As one person described it, they would have liked *'a proper chat with a proper professional'* over the course of an hour or so, in their own home where the necessary paperwork was at hand.

Regardless of what it comprised or how it was delivered, it was important that information and help was provided in a sympathetic, understanding and positive way.

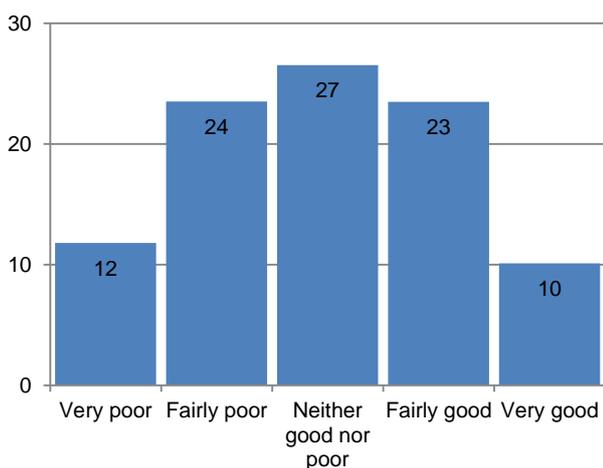
7 Financial impacts in quality of life outcomes

For a substantial minority of people with cancer, a poor quality of life was attributable, at least in part, to the financial impacts of their cancer diagnosis. The cost of cancer and a vulnerability to these costs contributed strongly to a decline in people’s quality of life following a diagnosis. The same factors were also important for explaining deprivation among people with cancer.

A key objective of this study was to cast new light on the extent to which the financial impacts of cancer affect people’s quality of life more generally. This dimension was explored in both the survey and in the depth interviews.

Survey respondents were first asked to rate, on a scale of one (very poor) to five (very good), their quality of life at the moment.¹⁸ This question was asked without reference to the effect of respondents’ diagnoses.

Figure 23: Quality of life at the moment: percentages



An additional five per cent did not state. Base is all respondents (n=1,610).

¹⁸ This question was based on an item asked in the World Health Organisation’s Quality of Life assessment instrument (WHOQOL-BREF).

A third of people overall rated their quality of life as good, including one in 10 who felt it was very good (Figure 23). When compared with a similar life satisfaction measure for the UK as a whole – for which a large majority of people reported medium and high levels of satisfaction (ONS, 2012b) – this appears low.

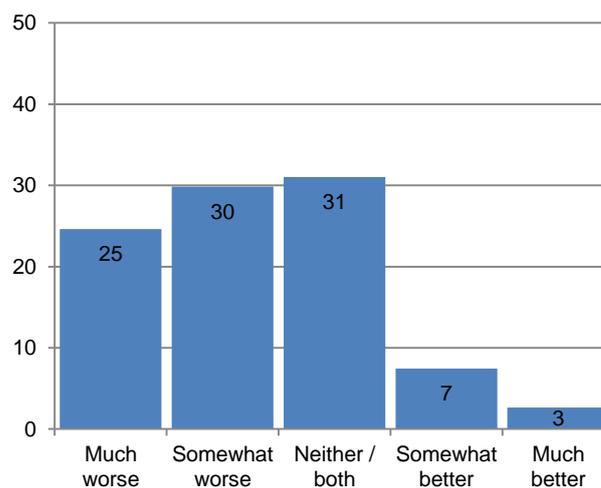
While a further one in four people with cancer felt their quality of life was neither good nor poor at the moment, a third overall described it as poor or very poor.

Role of diagnosis in quality of life

Two follow-up questions asked survey respondents to say whether they felt their quality of life was worse or better as a result of their cancer diagnosis and whether it was worse or better as a result of the financial impacts of their cancer diagnosis. The results for the first of these are shown in Figure 24.

As might be expected, it was unusual for people to say that their quality of life was better as a result of their cancer diagnosis (10 per cent).

Figure 24: Quality of life worse or better due to diagnosis: percentages



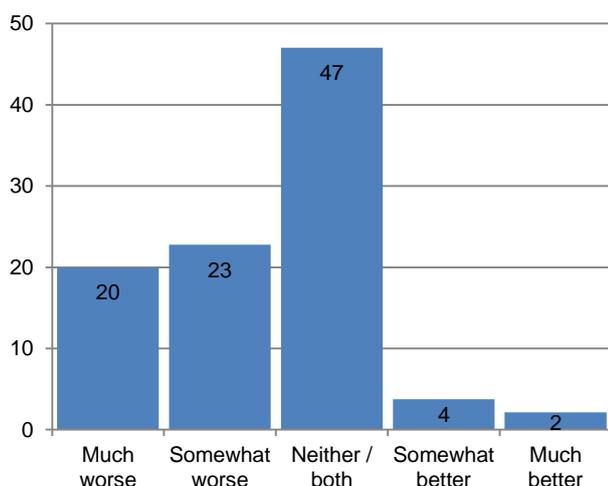
An additional four per cent did not state. Base is all respondents (n=1,610).

As we saw in relation to money worries in chapter 6, the depth interviews suggested that where this was the case it was because a potentially life reducing illness had helped them to re-focus on

the positives of life and value what they did have, particularly in the form of family relationships.

The more common picture (55 per cent) was that a cancer diagnosis had made people’s quality of life worse, including a quarter who felt it was much worse. A further one in three people felt that their diagnosis had not made their quality worse or better, or that it had made some aspects worse and other aspects better.

Figure 25: Quality of life worse or better due to financial impact of diagnosis: percentages



An additional four per cent did not state. Base is all respondents (n=1,610).

In comparison, the financial impact of a cancer diagnosis was felt to have made quality of life neither worse nor better overall among nearly a half of people (Figure 25). However, more than four in 10 people felt their quality of life was worse as a result of the financial impacts of cancer.

Again, a few people felt their situations had got better (six per cent). It is not clear from the study why this might be, but the reasons might include benefiting from income protection or payment protection insurance following their diagnosis or becoming entitled to welfare benefits that they had not previously received.

Role of financial impact of cancer in quality of life

Looked at another way, if we consider only the subset of people who said their quality of life was poor or very poor at the moment, 89 per cent of them attributed this at least in part to their cancer diagnosis and 65 per cent could attribute it, at least in part, to the financial impact of their diagnosis or treatment. This means that 23 per cent of people with cancer overall had a poor quality life due, at least in part, to the financial impact of cancer.

Compared with the overall average (43 per cent), the propensity to report a worse quality of life as a result of the financial impacts of cancer was particularly common among people who were unable to work due to permanent ill-health or (70 per cent), who had an ‘other’ employment situation (70 per cent) and those with the lowest household incomes (71 per cent; Table A47). It was also prevalent among people in their 40s (72 per cent) and lone parents (75 per cent).

There were also statistically significant variations depending on the nature of people’s cancer diagnosis. As might be expected, the most marked variation was in relation to the cost people had incurred as a result of their cancer, where we find that 72 per cent of people incurring costs of more than £1,000 per month felt the financial impact had made their quality of life worse, compared with only 21 per cent among those incurring costs of less than £10 per month (Table A48).

We might expect respondents to the survey to conflate the impact of their cancer diagnosis per se on their quality of life with the effect the financial impacts of cancer had had on their quality of life. When the influence of reporting a worse quality of life due to a cancer diagnosis was controlled in regression analysis, the total financial impact of cancer still strongly predicted a worse quality of life due to the financial impacts of cancer (Table A49). The odds increased steadily as impact rose, such that they were some 12

times higher among those incurring the greatest burdens than those incurring the lowest. This further evidences a direct and strong detrimental effect of the financial impact of cancer on the wider wellbeing outcomes for people with cancer.

Cancer type and having recently had surgery for cancer were also independently related to reporting that the financial impacts of cancer had made people's quality of life worse, with people diagnosed with brain cancer being at the high end of the range. However, the influence of these factors was relatively weak.

In contrast, socio-economic characteristics were particularly important for explaining why some people's quality of life had been impacted by the costs of cancer and others had not. Household income, housing tenure and employment status now and at the time of diagnosis were all significant in the regression analysis.

All other things being equal, those on lower incomes and those living in social rented accommodation (itself a strong indicator of a low income) were more likely than better-off people to report a poorer quality of life because of the financial impact of cancer, regardless of the size of the actual cost. And they were three times higher among those unable to work at the time of the survey due to ill-health than those who were retired.

Taken together, these findings paint a clear picture of how the financial impacts of cancer disproportionately affect the quality of life outcomes for those who are most vulnerable to the costs of cancer by virtue of their socio-economic status. Conversely, demographic characteristics and where people lived did not

independently influence this quality of life outcome (Table A49).¹⁹

However, another important factor was people's socio-economic situations prior to their diagnosis. The odds of reporting a poorer quality of life as a result of the financial impact of cancer were twice as high among those in paid work at the time of their diagnosis than those who were not. This reflects the finding that people who were in work at the time of the diagnosis were more vulnerable to loss of earned incomes that can seriously affect people's quality of life. In contrast, those already relying on benefits or pensions were unlikely to see their basic incomes being impacted in the same way.

Mitigating factors in the impact of a cancer diagnosis on quality of life

The in-depth interviews found that two factors seemed to have a material effect on the quality of life experienced by people with cancer. These were understanding from their or their partners' employers (which we go on to discuss below) and the support of family. A sign of the support that some received from their partners was in the fact that some of the depth interviewees were accompanied by their partner in the interview, as illustrated by Nigel's story described over the page.

Even the financial help that the extended families of some participants were able to provide could in turn have a big effect on people emotionally;

'My sister phoned up one night and said I've put £50 into your bank for you and I just burst into tears, because the pressure just felt that much then.'

Conversely, losing a partner during treatment, either due to their death or marital breakdown,

¹⁹ Gender was statistically significant in the analysis but only because of the influence of the small number of people who did not state their gender.

could also add strain on people's quality of life, not only in its own right but also as a result of the financial impacts of those events. In some instances the participant's cancer diagnosis was felt to have contributed to these events.

Support through adversity

Nigel is in his 40s and is living with cancer long-term. Nigel lost his job as a result of his cancer, and his wife, Helen is registered disabled. They are struggling for money, which at times has left them worrying about their ability to meet the payments on their mortgage.

Family is at the heart of what is keeping Nigel and Helen going. They see Nigel's cancer as something they will get through together. Helen even joined Nigel in the interview for this research. The support of wider family, including their parents and their adult son, has also played a key role. Nigel and Helen are now focussed on the future with a forthcoming wedding to go to and the arrival of their new granddaughter to look forward to.

Source: depth interviews

Although people who were in work at the time of their diagnosis were at significant risk of a downturn in their quality of life, the depth interviews highlighted how big an impact gestures of support from an employer could have on people, not just financially, but emotionally.

The most common type of support employers provided was in being as flexible as possible to the employee, whilst also reassuring them that they would have a job to go back to. A few were paid fully for their whole time off. Although others lost some wages, the benefit to them lay in feeling accommodated by their employers. For example, one took into account the lack of sick leave in previous years to pay full time wages for as long as possible. One employer insisted on a staged return to work for one woman, which, although meant her losing more income than she would have done had she made an immediate return to work, made her feel more considered by her employer:

'The duty of care towards me has been outstanding.'

Support was also extended to the friends and family members of the depth interviewees by some employers. This included allowing small amounts of time off on full pay, or larger amounts of unpaid leave while keeping their jobs open and allowing people to rearrange their hours in order for them to meet caring responsibilities to the person with cancer. Valued highly, these supportive gestures were often completely unexpected:

'The following week after I'd been settled in hospital, he [partner] went back to work and he filled in a holiday form and gave it to the boss and his boss just ripped it up and said, no it's on us.'

Level of material and social deprivation

The depth interviews highlighted how the added cost of cancer often meant people 'making do' in other areas, rather than turning to commercial borrowing, help from family or friends or any available savings to afford these costs. Examples of things depth interviewees had gone without because they could not afford them included certain types of (healthier) food, having family visit them in hospital, having the heating on high enough (and instead wrapping up in blankets) and help around the home.

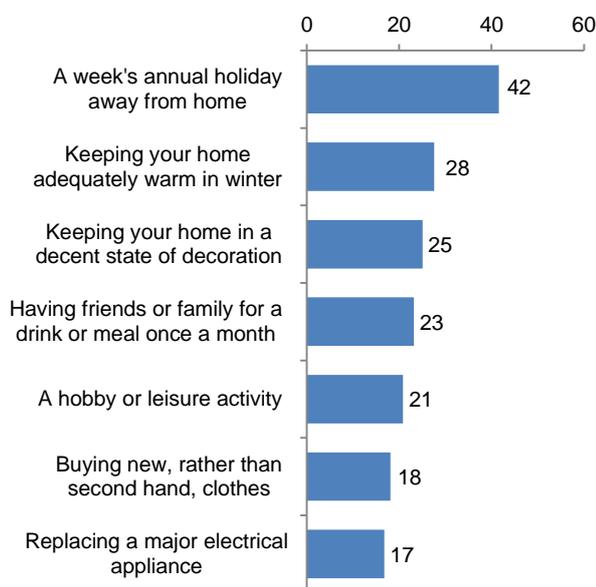
One survey respondent volunteered that he had gone without dental treatment because it was not affordable. Initially the cost of the treatment had been in the region of £2,000, but having stopped working because of his cancer he could not afford to have the treatment. Meanwhile the cost had escalated to some £8,000 because his treatment had not been timely.

The survey sought to measure the extent to which people with cancer had gone without a range of items in the last 12 months that many people take for granted. These ranged from a hobby or leisure activity through replacing a major electrical appliance to keeping the home adequately warm

in winter. Crucially, the question asked whether people had gone without these items due to a lack of money.

The items that people with cancer were asked to consider are shown in Figure 26. These were based closely on a larger set of items used by the Department for Work and Pensions to understand levels of material and social deprivation as part of their suite of measures to monitor poverty in the UK (DWP, 2012). They in turn have been identified through extensive research as items fundamental to people’s material wellbeing and an adequate standard of living (McKay, 2011).

Figure 26: Items people with cancer went without in the last 12 months: percentages



An additional said ‘none of these’ and 2 per cent did not state. Base is all respondents (n=1,610).

Overall, 58 per cent of people with cancer had gone without one or more of the items listed due to a lack of money. The item that most people had gone without was a week’s annual holiday away from home. In comparison, 17 per cent had gone without replacing a major electrical item such as a fridge.

In DWP’s suite of measures, greater importance is assigned to items that are available to a larger proportion of the population. In DWP’s latest monitoring report, a holiday away from home

carried a low weight compared with other items, as did a hobby or leisure activity, which one in five people with cancer had gone without. Having friends or family around for a drink or meal at least once a month, which nearly a quarter of people with cancer had gone without, carried a moderate weight.

Meanwhile, replacing a major electrical item, having enough money to keep the home in a decent state of decoration and keeping the home adequately warm in winter carry high weights in DWP’s analysis, indicating that a large proportion of the population can afford these items.

We have already seen that 17 per cent of people with cancer had gone without replacing a major electrical item due to a lack of money. A quarter had gone without keeping their home in a decent state of decoration and nearly three in 10 had gone without keeping their homes adequately warm in winter.

Although the way the two sets of measures were collected are not directly comparable, levels of material and social deprivation among people with cancer appear similar if not lower for the items that carry a lower DWP weighting, when compared with the picture for the population as a whole. For example, compared with 23 per cent of people with cancer having gone without having friends or family around for a drink or meal at least once a month, 38 per cent of all adults of working age had gone without this and, on a similar measure, 24 per cent of people of pensionable age (over 65) had not gone out to socialise with friends or family at least once a month (DWP, 2012).

However, for the more highly weighted items, it appears that people with cancer were disproportionately more likely to have gone without. Most notably, the research for DWP found that 11 per cent of all adults of working age and three per cent of all pensioners had gone without keeping their home adequately warm in

winter; compared with an estimated 28 per cent among those with cancer.

Predictors of going without things essential to material wellbeing

Overall, 44 per cent of people with cancer had gone without at least one of the three most highly weighted items: replacing a major electrical item, having enough money to keep the home in a decent state of decoration and keeping the home adequately warm in winter. The propensity to have gone without one or more of them varied consistently by the total financial impact of cancer people had incurred and socio-economic characteristics. There were also significant variations by age and household composition whereby people in their middle, family-rearing years, and lone parents were particularly likely to have gone without (Table A50-A47).

Many of these characteristics were also *independently* related to having gone without at least one of these items. In regression analysis, all aspects of people's socio-economic status were strong predictors. Women were also more likely than men, all other things being, to have gone without (Table A52).

Again, however, the total financial impact people had incurred as a result of their cancer was an important predictor of having gone without these items. Compared with those incurring less than £10 per month as a result of cancer, the odds were significantly higher among all those incurring a burden of £100 per month or more. All things equal, people whose cancer was unknown or in the process of being diagnosed were particularly likely to have gone without these things, as were those with brain cancer and those who had had surgery or some 'other' treatment in the last six months.

8 Summary and conclusions

This report has considered the impact of cancer on a range of financial outcomes for individuals with a cancer diagnosis and their households. It has shown that the financial impact of cancer and the burden this has on the wellbeing of those households is not felt equally, falling disproportionately among certain groups. Policies and practices that helped people to manage the adverse financial impacts of a cancer diagnosis would improve their financial and general wellbeing.

This chapter looks across the results from each of the previous chapters to summarise the main findings and consider the extent to which different groups are impacted financially as a result of cancer and in what ways. The limitations of the study and its implications for research and policy are also considered.

The financial impact of cancer

The total financial impact of cancer on individuals and their households is estimated at £103 per month. This represents the typical (median) impact people with a cancer diagnosis incurred each month, averaged across all individuals in the UK, regardless of the nature of someone's cancer diagnosis, status, how long ago they were diagnosed and other key factors such as where people live and their socio-economic characteristics. The corresponding mean cost (which is the arithmetic average) is estimated at £450. This is considerably higher than the median because the arithmetic average is influenced greatly by a small minority of people who incurred very high costs.

The total cost is derived from income loss and increased costs across five categories of expenditure. A large proportion of the total impact derived from two of these categories: income loss and the cost of outpatient visits. Although only 30 per cent of people with cancer

experienced a reduction in their household income as a result of their diagnosis, among those who did the typical (median) loss amounted to an estimated £567 per month. The mean loss across the population as a whole, including those who did not incur any, was £224 per month.

Costs associated with outpatient visits (travel, parking and incidental costs) were experienced by a majority of people with a cancer diagnosis (71 per cent). The typical (median) cost incurred through outpatient visits overall – including those with £0 costs – was £15 per month (with a mean of £143). Among the subset incurring outpatient costs, the median burden was £37 per month.

The other area of additional cost that people with cancer commonly incurred related to the cost of day-to-day living. 54 per cent incurred these, with a typical (median) cost of £32 per month among this subset. Across all individuals with cancer, this equated to a typical (median) cost of £3 per month (and a mean of £34).

Most people did not incur costs from inpatient stays, clothing, equipment or modifications to their home or car, or other healthcare costs associated with their diagnosis. Nonetheless, once these and other costs associated with increased expenditure were taken into account the median impact from expenditure – all tolled – was £63 per month across all individuals with cancer in the UK (with a corresponding mean of £226 per month).

The role of the financial impact of cancer in wellbeing

When switching the focus to other aspects of individuals' and households' wellbeing, the role played by the financial impact of cancer on these outcomes was clear. The financial impact of cancer was the strongest driver of feeling worse off financially since diagnosis, and strongly predicted household financial difficulty and arrears on essential bills.

The financial impact of cancer also played a strong role in perceptions of quality of life for people

with cancer. While more than a half of people with a cancer diagnosis felt their quality of life was worse as a result of their diagnosis itself (55 per cent), four in ten also felt it was worse because of the financial impact of their diagnosis specifically (43 per cent).

The size of the actual total financial impact people had incurred (as measured in the survey) strongly predicted whether or not they felt their quality of life was worse as a result of the financial impacts of cancer. Importantly, this held true regardless of whether or not people felt their quality of life was worse as a result of their diagnosis generally. While intuitive, this is an important finding because it demonstrates that the actual financial impact incurred is 'felt' subjectively by individuals, which in turn impacts negatively on how people feel about their quality of life.

Determinants of financial impacts and their implications for wellbeing

When considering which types of people incur the greatest financial impact as a result of a cancer diagnosis a complex picture emerges. Overall, it was younger people (the under 60s but especially those in their 40s) who incurred the greatest total financial impact, and, consistent with this, those with dependent children and mortgages to pay (Table A4). Whether or not someone was working at the time of their diagnosis was also important, with those who were working estimated to have incurred three times the burden of those who were not.

People diagnosed with lymphoma, leukaemia or myeloma also tended to incur a higher than average burden, as did those with 'other' diagnoses and those who did not report their cancer type to the survey (including where the specific type of cancer was undergoing diagnosis). A greater financial impact was also experienced among those who had undergone surgery or chemotherapy within the last six months than those who had not.

When the focus turns to people's socio-economic status at the time of the survey, the greatest burden fell on both the better-off households (those with middle-to-high incomes) *and* the poorest households (those with the lowest incomes of less than £430 per month), rather than those with either moderate or very high incomes. Similarly, the greater burden was incurred by respondents working full-time at the time of the survey as well as those unable to work due to permanent ill-health or disability. This, sometimes polarised, picture emerges because the importance of different characteristics tends to vary depending on the nature of the financial impact considered.

Overall, when looking across the different categories of financial impacts, the nature of someone's cancer diagnosis plays a particularly important role (an overview is provided in the Table 27). The socio-economic status of the person with the diagnosis (and their household) is also important and tends to play a much bigger role in determining these impacts than their demographic characteristics such as gender, ethnicity and even where in the UK people are living. As such, we start by considering the role of the nature of the cancer diagnosis in the financial impacts of cancer in more detail, before turning to key socio-economic factors and finally socio-demographic and geographical ones.

The nature of the cancer diagnosis

The type of cancer someone had been diagnosed with and whether or not they had undergone surgery or chemotherapy in the last six months emerged consistently as important factors in determining the extent of the financial impacts individuals and their households had incurred.

Cancer type

People diagnosed with *lymphoma, leukaemia or myeloma* tended to incur a higher than average burden as did those with 'other' diagnoses. But exposure to the financial impact of cancer by

Table 27 Key groups incurring particularly high financial impacts: an overview

| | Total | Income loss | Outpatient visits | Inpatient stays | Other healthcare | Clothing/ equipment/ modifications | Day-to-day living |
|--|-------|-------------|-------------------|-----------------|------------------|------------------------------------|-------------------|
| Characteristics of the cancer diagnosis | | | | | | | |
| Breast cancer | | | | | | | ✓ |
| Colorectal cancer | | | | ✓ | | | |
| Lung , bronchus or trachea cancer | | | | | ✓ | | ✓ |
| Oesophagus or stomach cancer | | | | | | | ✓ |
| Lymphoma, leukaemia, myeloma | ✓ | | | | | ✓ | |
| 'Other' type of cancer | ✓ | | ✓ | ✓ | | | ✓ |
| Surgery in last 6 months | ✓ | | | ✓ | | | |
| Chemotherapy in last 6 months | ✓ | | | | | | ✓ |
| Radiotherapy in last 6 months | | | ✓ | | | | |
| No treatment in last 6 months | | | | | ✓ | ✓ | ✓ |
| Advanced, secondary or metastatic cancer | | | | ✓ | ✓ | | ✓ |
| Received diagnosis in last 12 months | | | ✓ | | | | |
| Received diagnosis in last 6 months | | | | ✓ | | | |
| Socio-economic characteristics | | | | | | | |
| Working at the time of diagnosis | ✓ | ✓ | | | | | |
| Under 60 and in work at time of the survey | ✓ | ✓ | ✓ | | | | |
| Under 60 and not working at time of survey | ✓ | ✓ | | | | | ✓ |
| Working full-time work at time of the survey | ✓ | ✓ | ✓ | | | | |
| Unable to work at time of survey due to permanent ill-health or disability | | | | | | | ✓ |
| Lower household income | ✓ | ✓ | | ✓ | ✓ | | |
| Medium or high household income | ✓ | | ✓ | ✓ | | | ✓ |
| Socio-demographic characteristics | | | | | | | |
| Male | | ✓ | | | | | |
| Female | | | | | | ✓ | |
| Non-White ethnic background | | ✓ | | | | | |
| Aged under 60 | ✓ | ✓ | | | | | ✓ |
| Aged under 50 | | | ✓ | | | | |
| Aged under 40 | | | | ✓ | | | ✓ |
| Couple with dependent children | ✓ | ✓ | | ✓ | | | ✓ |
| Lone parent | ✓ | ✓ | ✓ | | | | ✓ |
| Where people live | | | | | | | |
| Scotland | | | | | ✓ ¹ | | |
| Wales | | | | | ✓ ¹ | ✓ | |
| England | | | | | | ✓ ² | |
| Northern Ireland | | | | | | | ✓ ³ |

These characteristics are identified by looking at the mean financial impact incurred. See Appendix Tables A1, A4, A6-7, A12-13, A15-16, A18-19, A21-22, A24-25. 1. Dental care component only. 2. Wigs and head coverings component only. 3. Category, plus household fuel and help around the home or garden components.

cancer type varied considerably depending on the category of cost or income loss concerned. People with lymphoma, leukaemia or myeloma were particularly likely to incur any cost associated with outpatient visits (all other things being equal) and incurred particularly high costs in relation to clothing, equipment and modifications. The chronic (long-term) nature of these types of cancers (as well as the treatment) and comorbidity may play a part in this. They were also highly likely to feel that their household's financial situation was worse now compared with prior to their diagnosis.

When other factors are controlled, people with *brain cancer* stand out as having been more likely than others to have incurred inpatient and outpatient costs, to feel that their quality of life was worse as a result of the financial impact of cancer and to have gone without things considered essential for an adequate standard of living. This may be because brain cancer can be particularly hard to manage at home, requiring more inpatient and outpatient visits. Mobility may also be more difficult, limiting people's ability to have a full and independent lifestyle.

Cancer of the *kidney or bladder* also predicted exposure to inpatient and outpatient costs. This may reflect that these types of cancer require more ongoing appointments, particularly to manage the risk of infection.

People with *breast cancer* were particularly susceptible to added expense from other healthcare costs and clothing, equipment and modifications. Findings from the depth interviews suggested that this was a result of the combination of treatments received (e.g. surgery and chemotherapy) and the particular expense of buying surgical bras and new bras as body shapes changed. The costs associated with other healthcare and day-to-day living were also comparatively high among those with *lung cancer*.

All other things being equal, income loss was particularly common among those with cancer of the *oesophagus or stomach* and *pancreas or liver*. This may reflect the debilitating nature of these illnesses and, particularly in the case of pancreatic cancer, poor prognosis. People with these cancer types were also exposed more than others to the added costs of day-to-day living, and those with cancer of the oesophagus or stomach incurred high costs on average in relation to clothing, equipment and modifications.

Cancers of the *lip, mouth, pharynx or larynx* are the final group of note. People with these types of cancer were particularly likely to have incurred other healthcare costs, all other things being equal. This may be because they may have a greater need for dietary supplements, given the nature of their cancer. In addition, they were particularly likely to have borrowed commercially, had financial help from friends and family and sold belongings to help fund the cost of cancer and, when other factors were controlled, they were particularly likely to feel that their quality of life had worsened as a result of the financial impacts of cancer. It is not clear from this study why this would be the case.

Treatment received

The extent to which people had incurred financial impacts as a result of their diagnosis varied consistently depending on whether or not they had undergone particular types of treatment in the last six months, notably surgery and chemotherapy. There was also some variation for particular categories of impact depending on whether or not people had had radiotherapy or 'other' types of treatment and no treatment at all. Notably, undergoing treatment in the last six months, regardless of type of treatment, did not appear to be a factor in income loss (now compared with prior to their diagnosis).

Without exception, *surgery* and *chemotherapy* were important determinants of incurring some additional expense across all categories of cost,

holding true regardless of other influences. Among those undergoing surgery the actual (mean) cost associated with inpatient stays was also higher and among those undergoing chemotherapy the added cost of day-to-day living was notable. The former speaks for itself, as more intrusive surgeries will tend to involve inpatient stays. In turn, the latter finding may reflect the tendency for chemotherapy to make people prone to tiredness and weakened immunity on an ongoing or cyclical basis thereby increasing dependence on central heating, indoor leisure activities and help around the home or garden. The actual (mean) total financial burden was also higher among people receiving surgery or chemotherapy in the previous six months compared with those who had not.

Undergoing *radiotherapy* in the last six months was also associated with higher outpatient costs and it predicted whether or not people had incurred any costs associated with inpatient stays. This is likely to reflect the nature of radiotherapy treatment, which can involve short daily treatments or (in the case of whole-body radiotherapy, for blood-related cancers for example) intensive treatment that may be administered on an inpatient basis over the course of several days. Radiotherapy was also a determinant of cost from clothing, equipment and modifications.

Finally, not having undergone *any* treatment in the last six months was also associated with a higher cost on average from supplementary healthcare and treatment, clothing, equipment and modifications, and day-to-day living. These respondents may have been paying for alternative therapies or making structural and lifestyle changes to help them manage their cancer (or the after-effects of cancer or its treatment) going forwards. However, undergoing no treatment in the last six months did not predict the propensity to incur these costs at all, suggesting that other factors (such as work status, income, and cancer

type and status) were the more important determinants.

Cancer status

In addition to cancer type and treatment received, there were significant variations in the cost people incurred depending on the status of their cancer (for example whether localised, recurring or advanced) in relation to inpatient stays, supplementary healthcare and treatment and day-to-day-living. For each of these costs, respondents describing their cancer as *advanced*, *secondary* or *metastatic* incurred the greater costs. This most likely reflects the intensity of any treatment and care needed at this particularly difficult time in a cancer journey. For many of the areas of increased expenditure, exposure to these costs held true when other characteristics (of the diagnosis, individual and their household) were taken into consideration, with those with advanced secondary or metastatic cancer remaining at greatest risk.

Despite this, the total financial impact of cancer did not vary depending on cancer status. Notably, cancer status did not impact significantly on income loss. It also did not play a large role in individuals' and households' wellbeing.

Time since diagnosis

Compared with other characteristics relating to people's diagnoses, the time elapsed since diagnosis played a much smaller role in the financial impacts of cancer. The total financial impact incurred did not vary significantly by how long ago someone was diagnosed. This may partly reflect the myriad ways in which people may be affected by their diagnosis and that each person's cancer journey is unique. For some people, for example, their treatment and care may be most intensive only several years after their first diagnosis, after their cancer has recurred or become advanced. However, the cost from expenditure (totalled across all five categories) did vary and this was driven by the larger costs people

with more recent diagnoses (of less than a year) incurred from outpatient visits and inpatient stays.

Socio-economic characteristics

Apart from the nature of someone's cancer diagnosis, socio-economic factors were generally the strongest predictors of the financial impacts of cancer.

Employment status

The total financial burden incurred by *people aged under 60 and in work at the time of the survey* was more than double that of the average. As mentioned above, the financial impact was particularly high among those in full-time work. This masks some quite important differences by category of financial impact, however.

People in full-time work also incurred particularly high (mean) impacts relating to income loss and outpatient visits. While they were somewhat more likely than the average to have incurred *any* income loss or outpatient costs, this did not hold true when other factors were taken into account suggesting that other factors (such as household income and age) were more important determinants than employment status per se.

In contrast, being *retired* did significantly predict whether or not people had incurred costs from outpatient visits. Retired people were also more likely to have incurred costs from clothing, equipment and modifications to the home or car, all other things being equal.

Costs from inpatient stays and other healthcare costs did not vary significantly at all by employment status; although the cost of day-to-day living did. People describing themselves as *unable to work due to permanent ill-health or disability* incurred much higher day-to-day costs than the average, and they were more likely to have incurred these once the influence of other factors was taken into account.

However, the story does not end there for this group. Regression analysis found that, all other things being equal, people who were unable to work due to poor health were more likely than others to: have called on financial help from friends or family or sold their belongings to fund the cost of cancer; describe their household as being in financial difficulties; have missed payments on essential household bills; and feel that their quality of life had worsened as a result of the financial impacts of cancer. It would be wrong to assume that someone's inability to work due to ill-health or disability was the result of their cancer; it may have related to any condition that pre-existed or followed their cancer diagnosis. Even so, the findings paint a clear picture of vulnerability within this group, highlighting that, regardless of the actual financial impact incurred as a result of cancer, that impact is 'felt' disproportionately by certain types of individuals and households.

As mentioned above, whether or not someone was *working at the time of their diagnosis* was also important, with those who were working estimated to have incurred three times the burden of those who were not; this was due entirely to the effect of their diagnosis on income loss. This is intuitive because those with earned incomes at the time of their diagnosis have the greatest scope for income loss should they be unable to work as a result of their diagnosis or treatment.

Household income

Household income in the survey captured the respondent's income as well as their partner's (if they had one). As such, the measure is in turn affected by the respondent and partner's work status; and the depth interviews evidenced how a cancer diagnosis for one partner could not only impact their own earnings but potentially also those of their partner.

As mentioned above, the total financial impact of cancer varied significantly by household income.

But it was those with both the *lowest* and *medium-to-high incomes* (of £1,700 to £2,149 per month) who incurred the greater financial burdens on average.

Household income was a strong determinant of income loss and cost across all categories. People living in a household with *medium or high* incomes incurred the greater burden of costs from outpatient visits, clothing, equipment and modifications and day-to-day living. This may indicate a degree of flexibility and choice in these areas of expenditure. In other words, those who are better off are able to afford to pay for the added expense involved and do so.

Those with *low-to-medium* household incomes incurred higher than average costs from supplementary healthcare. People with medium incomes also incurred higher than average costs from inpatient stays; as did those with the lowest household incomes.

Those on the *lowest incomes* were also estimated to have incurred the greatest income losses; they were also more likely than other groups to have incurred any income loss, all other things being equal. This is counter-intuitive, as those on higher incomes would potentially have greater scope to lose income. However, the measure of household income relates to income at the time of the survey. As such, this would seem to suggest either that those with low incomes have even lower incomes following a diagnosis; or that reductions in income due to a diagnosis can be so substantial as to render those previously on moderate or even high incomes to low incomes.

The disproportionate burden of any income loss on poorer households is evidenced by the finding that patients from lower-income households were more likely than those from better-off households to: feel that their household was worse off financially since their diagnosis; report that their household was in financial difficulties at the time of the survey; and feel that their quality of life was

worse because the financial impacts of their diagnosis. While people with lower incomes would normally be more pre-disposed to financial difficulties (see for example, Atkinson et al., 2006) the opportunity offered by this study to place this within the context of a cancer diagnosis and the financial impacts incurred as a result of that diagnosis brings it into sharp focus.

Socio-demographic characteristics

In contrast to socio-economic status, demographic characteristics generally played much smaller roles (if any) in the financial impacts of cancer. Even so, there was some variation in the financial outcomes of people with cancer depending on their demographic characteristics.

Gender

The influence of gender on the financial impacts of cancer was confined to just two categories: income loss and the cost of clothing, equipment and modifications. *Men* were no more likely than women to have experienced a reduction in income as a result of cancer when other factors such as employment status and household income were taken into account. The actual (mean) loss incurred by men was significantly higher (by an estimated £100 per month) than women, however. The disproportionate impact on men's incomes may explain why men were more likely than women to describe their household as being in financial difficulty at the time of the survey.

Women, in contrast, were more likely than men (all other things being equal) to have incurred costs from clothing, equipment and modifications to the home or car. It is not clear why this would be the case, and further research would be needed to help explore the underlying reasons. They were also more likely than men to have turned to financial help from friends and family or commercial borrowing to fund the cost of cancer, and they were more likely to have gone without

items deemed by Government as fundamental to an adequate standard of living.

Ethnicity

In the sample responding to this survey, the total financial impact of cancer (as measured by the mean) did not vary by ethnicity, based on the broad categorisation available from the survey. Moreover, ethnicity was not – in its own right – an important factor in explaining variation in of the individual categories of cost or income, with one exception: people from a *non-White* background were more likely than their White counterparts to have incurred some outpatient cost. Non-Whites were also more likely to have experienced a reduction in their income as a result of cancer (and the mean loss they had incurred was greater) than among White people, but this did not hold true once the effect of other characteristics was taken into account.

A much clearer and more striking picture emerged when other financial outcomes for individuals and their households were considered. People from a non-White background were more likely than those from a White background to have funded the financial impact of cancer by drawing on savings and commercial borrowing. They were also more likely to have gone without things considered essential for an adequate standard of living due to a lack of money, to feel that their household's financial situation was worse since their diagnosis and be experiencing financial difficulty at the time of the survey. Moreover, the increased propensity to have missed payments on essential bills in the last 12 months held true when other factors were controlled in regression analysis.

Age

It was *younger people* (the under 60s but especially those in their 40s) who incurred the greatest total financial impact from a cancer diagnosis or treatment. The greater impact on younger people was felt more or less consistently

by these age groups across income loss and all of the categories of expenditure. Moreover, the disproportionate burden experienced by the under 40s from the costs of outpatient visits, supplementary healthcare and treatment, clothing, equipment and modifications and day to day living occurred independently of the other factors considered (such as employment status, household income and cancer type). The cost of inpatient stays was more likely to be experienced among the under 60s generally than older age groups, all other things being equal.

This could be driven by a range of factors, for example a more active lifestyle among younger people driving the desire for supplementary treatment or a better quality of living; further research would be needed to understand more fully the factors at play. However, it is interesting to note that the under 60s were more likely to see their households as being worse off financially since their diagnosis and to describe their quality of life as worse as a result of the financial impacts of cancer. Although these outcomes were not independent of other factors (such as income, employment status, and cancer type) they nonetheless point to a heightened degree of concern about the financial impacts of cancer on other areas of their wellbeing; while at the same time suggesting that the higher costs younger people incurred contributed to these outcomes.

The likelihood of having gone without certain things due to a lack of money and funding the impact of cancer with the help of commercial borrowing and financial support from friends and family also increased with decreasing age.

Household composition

The total financial impact people with cancer incurred was particularly high for *those with dependent children*, particularly for *lone parents*. To a large extent, this reflects the higher than average reduction in income that couples and lone parents with dependent children incurred (which will in turn reflect that these people are

likely to be of working age), and the particularly high cost from outpatient visits that lone parents incurred. Those living in a couple with children also incurred much higher than average inpatient costs.

The greater financial impact of cancer experienced by people with children carried through to how people felt about their and their household's situation. Both groups were more likely than average to see their quality of life as being worse as a result of the financial impact of their diagnosis. All other things being equal, partnered parents were particularly likely to feel that their household was worse off financially since their diagnosis. And lone parents were likely to report that their household was in some difficulty financially and that they had missed payments on essential bills; while it is not unusual for lone parents to be observed as being at particular risk of financial difficulties and arrears (see for example Daffin, 2009) the finding that this remains true in the context of a cancer diagnosis is alarming.

Regardless of whether or not people had children, *living in a couple* increased the risk of inpatient costs independently of other factors. This might be driven by the added cost incurred by partners visiting the patient in hospital (costs to other family members were not captured in the survey).

Household composition did not appear to influence the costs incurred from other healthcare or clothing, equipment or modifications. Being a *single adult* living alone or with other adults (for example in a house-share or with other adult family members) did increase the odds of incurring added day-to-day living costs compared with other groups. Meanwhile the actual cost was highest among partnered and lone parents *with dependent children*. The reasons for this are unknown, however one such reason might be a strong desire among single adults and those with children to maintain an adequate standard of

living and a quality of life that they had been accustomed to.

All other things being equal, household composition was not a factor in whether people had turned to friends or family, commercial borrowing or selling belongings to help fund the cost of cancer. Single adults were more likely than others to have drawn on savings.

Where people live

Overall, country and area of residence played only a small part in determining the financial impacts and other outcomes resulting from a diagnosis.

Country of residence

There was no significant variation in the total financial impact of cancer by country of residence. However, there were variations for particular categories and components. Compared with those living in *Scotland*, the risk of incurring outpatient costs was higher in England, Wales and Northern Ireland. Meanwhile cost incurred through dental care was particularly high in *Scotland and Wales*. This might reflect a greater dependence on private provision in those countries. The mean cost incurred through modifying the home were also higher than average in Wales. Regression analysis indicated that the higher cost in Wales was not attributable to living in Wales *per se* but to other (demographic or socio-economic) factors which also vary by country of residence.

In *England*, expense incurred from wigs and head coverings was relatively high compared with other countries. This may be because of the different subsidy arrangements under different administrative frameworks in the UK.

In contrast, people living in *Northern Ireland* were exposed to particularly high costs in relation to fuel bills and help around the home. The former is most likely explained by a greater reliance on oil for heating the home in Northern Ireland than gas which is more widely available in the other

countries via the grid (The Consumer Council, 2012).

Area of residence

The estimated financial impact of cancer did not vary significantly by the type of area in which people lived (urban or rural) for any of the six categories of financial impact nor indeed for the total cost. There were exceptional instances, however, where area of residence did predict (albeit weakly) whether or not someone incurred a cost independently of other factors. All other things being equal, outpatient costs and other healthcare costs were both more likely to be incurred by people living in *rural* areas. Area type also played a role in determining which people had drawn on help from friends and family or sold belongings in order to help fund the financial impact of cancer.

The findings in context: strengths and limitations of the study

A particular strength of using survey methods to estimate the financial impacts of cancer is that it allows for the direct measurement of those impacts from the very individuals and households affected by them. It also enables the implications of the financial impacts of cancer on wider wellbeing to be understood, taking account of the financial impacts incurred by the individual concerned and their household. By aggregating the findings from a carefully constructed and weighted sample, a picture emerges about the scale and nature of the financial impact of cancer on the population of people in the UK with cancer as a whole. In comparison with some other methods, survey estimation does not rely heavily on assumptions being made about individuals and their households based on external data sources; it therefore avoids the error that alternative study methods potentially introduce into the estimation process.

However, as with any study method, surveys have their limitations, and this study is no exception. First, in the absence of an accessible sample

frame that comprehensively covers all adults with cancer in the UK (such was available in the recent Ireland study), the sample of survey respondents in this study was drawn from Macmillan's own sources. Moreover, these sources, by definition, limited the pool of respondents to people (with a cancer diagnosis) who had sought information or advice from Macmillan, albeit on any cancer-related issue, not just financial ones. And they were people who had previously agreed to take part in research. For more detail, please see the Methodological Appendix.

Second, participation in the survey was entirely voluntary. This is reflected in the response rate of 37 per cent which, while relatively high for a postal survey, means that a majority of people did not respond. In other words, respondents to the survey were largely self-selecting, and this raises questions about how representative the sample is of the general population of people with cancer. We do not know why some people chose not to respond, and any systematic differences between those who did respond and those who did not, and whether or not these have any bearing on the findings from the survey, are unknown.

Steps were taken in the design and implementation of the study to mitigate the effect of these limitations. These include:

- Asking respondents to report any costs arising through increased expenditure as a result of cancer in the six months prior to completing the survey (or since their diagnosis if less than six months ago), thereby increasing the survey's ability to capture costs arising immediately following a diagnosis or during treatment when people might otherwise feel too poorly to take part.
- Encouraging respondents to take part regardless of how much or how little they had been affected financially by their diagnosis.
- Providing a background leaflet on the rationale and aims of the study and how and

why respondents had been selected to take part.

- Not over-burdening respondents by keeping the questionnaire as short and manageable as possible.
- Sending reminder questionnaires and providing freepost envelopes for the return of the questionnaires.
- Weighting the resulting sample to make it representative of the known population of people with cancer in the UK on key demographic and geographical dimensions.

Nonetheless, these precautions cannot eradicate entirely the effects of any potential biases in the sample. In particular, it is possible that people in the late stages of terminal cancer or those with particularly aggressive forms of cancer were under-represented as people in these situations may have been less inclined to opt in to the study.²⁰ The impact of the weighting on the effective sample for certain subgroups (particularly those reflecting age-related characteristics) further underlines the possibility that the financial impact of cancer may be better represented in the study for some patients than for others. As a result, the actual financial burden of cancer for adults with a cancer diagnosis in the UK may be greater or less than those estimated by the study.

Another limitation of the study relates to the reliance on respondents to recall and report factual detail accurately. To attempt to validate the costs would have been difficult and prohibitively expensive. Instead, precautions were taken to facilitate recall and accurate reporting. For example:

- Respondents were asked to report costs through increased expenditure as a result of

their diagnosis occurring only in the six months prior to the survey (or since their diagnosis if less than six months ago).

- Respondents were asked to report the cost of outpatient visits and inpatient stays on a per visit basis (an approach informed by the depth interviews to reduce the burden on respondents).
- The questionnaire content was informed by previous surveys and formative qualitative research with people with cancer.
- The questionnaire design was developed using best practice principles (for example, ensuring clear instructions, adequate font size and a maximum page limit).
- The questionnaire was tested and piloted to ensure that it was understood and completed by respondents as intended.
- A dedicated helpline was provided to answer any queries respondents had about completing the questionnaire.

Even so, the possibility remains that some respondents may have misreported certain financial impacts. As a result, the actual financial burden of cancer for adults with a cancer diagnosis in the UK may be greater or less than those estimated by the study.

For more details, please see the Methodological Appendix.

A fourth limitation of the survey relates to the way in which income lost as a result of cancer was calculated. First, it relied on respondents being able to accurately recall and report their household's current total income and what this was immediately prior to their diagnosis. These were collected in bands (income ranges) to encourage respondents to make a best estimate where they might not have known their exact incomes; the decision not to also collect exact incomes from those who may have known these was made due to the constraints on questionnaire length.

²⁰ Even so, respondents who described their cancer as secondary, advanced or metastatic comprised some 14 per cent of the sample suggesting that the sample may well have included some people in these situations.

However, the use of banded incomes reduced the precision with which change in income could be estimated. Assuming this imprecision is random, however, and not unequally distributed across the range for either measure (current income or previous income), then this approach is not expected to impact unduly on the estimates.

Attributing any change to the respondent's cancer diagnosis was also problematic. Asking respondents to calculate or even estimate the amount that was attributable to their diagnosis was not considered appropriate because of both the excessive burden this would place on respondents and risk of poor data quality. The approach that was instead adopted involved asking respondents to rate, on a five-point rating scale, the extent to which any change in their income now compared with prior to their diagnosis was related (directly or indirectly) to their diagnosis. Rating scales are widely used in surveys to measure difficult and abstract concepts. The points on the scales are often converted into 'scores' (see, for example, WHO, 1996).

In this case, the rating scale was used to adjust the absolute change in income (adjusted for inflation). Technical Note 3 on page 10 of this report and the separate Methodological Appendix provide more detail. As a fairly blunt scoring instrument this is likely to have introduced error into the estimation process for any one individual respondent. However, once aggregated up across individuals, this is assumed to cancel out.

A further limitation relates to the coverage of financial impacts captured in the questionnaire. Previous research and the qualitative interviews for this study informed the component costs captured in the survey. To attempt to capture an exhaustive list of costs would place undue burden on the respondent. The intention was however to capture a wide range of costs with a particular focus on the more common and larger areas of expenditure. Costs that would be difficult for

respondents to quantify (such as increased insurance premiums as a result of cancer) were excluded. Others were not included because the formative research had not identified them as an area of potential impact (e.g. costs associated with eye care and spectacles).

The questionnaire also deliberately excluded any additional costs or income loss that may have been incurred on the respondent's behalf by family members other than a partner or other individuals, such as friends and neighbours. This decision was taken following the depth interviews, which indicated that respondents were not always clear about the costs others had incurred and could therefore not easily quantify them. It was also outside the scope of the current study to measure the ongoing impact of cancer on households in those instances where the patient had died.

Had these areas of cost been included, the estimated total financial impact of cancer would certainly have been higher.

A final limitation relates to the achieved survey sample size. The practical and budgetary considerations that inform the design of all studies prevented larger numbers of people being sampled in this study. As such, a target sample size of 1,500 was identified to ensure – as the main priority of the study – reliable estimates of the financial impacts of cancer were produced for the UK as a whole, while also providing sufficient numbers for robust breakdowns by country of residence within the UK.

Nevertheless, a sample of this magnitude is relatively small. This has meant that we have been unable to explore the results for more detailed categorisations of particular sub-groups, for example for some discrete types of cancer and among the diverse ethnic groups that make up the non-White respondents. However, future studies might explore in more detail the financial impacts affecting these groups.

Implications of the study for future research

This study highlights the absence of a comprehensive sample frame for individuals with cancer in the UK that is available for use in research of this type. As we have described, this places limitations on the social research (and survey research in particular) that can be carried out with people with cancer at the moment.

For the first time, this study provides evidence about the relationship between the financial impacts of cancer, the nature of a cancer diagnosis, and socio-economic and demographic characteristics. The scope of the study precluded any detailed empirical examination of the dynamics of the financial impacts of cancer. As a result, there remain important questions about *why* factors such as socio-demographic characteristics (like age and gender) and cancer type, status and treatment result in particular financial impacts such as higher-than-average costs.

This study gives us a snapshot in time of the financial impacts of a cancer diagnosis. Only by conducting longitudinal research (following the same people with cancer over a period of time) can we fully understand how the financial impacts of cancer change and vary over time. Longitudinal research could also offer insight about how people with cancer think about and experience the financial costs of cancer at different points in their cancer journey. For example, someone's views may change once their prognosis (and the financial implications of that prognosis) is known.

The study has implications for future research on some quite specific issues as well:

The financial impact of cancer on families and social networks

This study looked in detail at the views and experiences of people with cancer and, where possible and appropriate, their partners. It was outside the scope of the study to examine in

detail the part played by people outside the household, such as wider family or neighbours in helping to fund the cost of cancer.

While it would almost certainly be impossible to quantify this wider help in any robust way, nonetheless further research could explore in more depth the views and experiences of people with cancer and the people outside the household that provide support – including the financial and non-financial benefits and costs involved.

Another important perspective to consider is the views and experiences of other household members who may be affected by the financial impacts of cancer, such as partners and children. For example, what affect does the financial cost of cancer have on their lives, and how do they feel about it?

Employment

The financial impact of income loss for people with cancer is striking. Research questions raised by this study include:

- How do people with cancer (and their partners) make decisions about work at different points in their cancer journey?
- What factors do people weigh up when making decisions about work, which factors are most important and why?
- How do people's views and experiences of state and employer support affect their decisions?
- From the employer's perspective, how does employer support for people with long-term health problems vary and why?

Information and advice

To inform the design and delivery of information and advice needs for people with cancer and their families, it would be useful to understand more about the drivers of people's positive and negative experiences of information, advice and support services. This study also begs the question of why survey respondents were more likely to be

unhappy about the advice they received from banks and other financial institutions than was the case with other sources of advice.

Financial services

Insurance was only mentioned by a very small proportion of respondents as a means of funding the costs of cancer. This raises the question of whether or not insurance could play a greater role in this respect; why people with cancer do or do not use insurance to fund or offset the financial impacts of cancer; and whether there are particular issues in terms of claiming on insurance policies that are specific to people with a cancer diagnosis.

Implications of the study for policy

This study indicates that helping people with cancer to manage the adverse financial impacts of a cancer diagnosis would result in a marked improvement in their financial and general wellbeing.

At the same time, one of the study's most striking findings is the wide variation in the financial impacts of cancer depending on the nature of the cancer diagnosis; socio-economic characteristics; and, to a lesser degree, demographic characteristics. This highly nuanced picture of the financial impacts of cancer presents challenges in translating evidence into policy and practice. It suggests that policy and practice should take into account the heterogeneity of the experiences of people with cancer, while at the same time recognising the financial and practical limitations of doing so.

The main components of the financial impact of cancer are loss of income and the outpatient costs that result from a cancer diagnosis. These have wide-ranging policy implications in relation to:

- The ability of people with cancer and their households to maintain a basic standard of living. In this respect, keeping the home warm in the light of continued upward pressure on

fuel bills is a particular issue which has implications for the current debate about how the government measures and addresses fuel poverty.

- Linked to this, the state support available to people with cancer, in the form of social security benefits but also help from local authorities such as grants for home modifications or help with travel costs.
- The support available from non-government organisations such as Macmillan.
- For people in work, the support available from employers, and whether there are good practice examples of financial and non-financial ways in which employers can help support employees with cancer that employers could be encouraged to take up.
- Country of residence is not generally a strong predictor of the financial impact of cancer. Nonetheless there are concerns about differences in relation to specific costs such as hospital parking charges, dental costs and fuel costs which merit attention.

This study also provides valuable information about the types of people most affected by the financial impacts of cancer, and by extension where resources should be targeted. So while the financial impacts of cancer are felt by people across the income range, it is people on low incomes who are worst affected. The other types of people who are vulnerable to adverse financial impacts are similarly those who are more likely to live on a low income, including single parents and people permanently unable to work due to illness or disability. Notably, it is exactly these types of people who will be most affected by the Coalition Government's welfare reforms.

These findings seem to validate strategies that target people on low incomes, for example grant schemes that are to some extent means-tested. At the same time, the qualitative research carried out for this study identified strong feelings of resentment and frustration among people with

cancer who were not eligible for any help and support. They questioned why, when they had the same serious illness and at face value seemed no better off than other people with cancer, they were deemed ineligible for help. In some cases, this was linked to a sense of entitlement because of the income taxes they paid when they were in work.

Finally, as well as the research implications described above, the study highlights policy implications in relation to the information and advice needs of people with cancer. Many of the issues around information and advice raised by this study are, sadly, by no means new. They do, however, attain a greater sense of urgency at the present time, in the face of unprecedented reform of the welfare benefits and tax credits system and the abolition of legal aid funding for welfare benefits advice and most debt advice.

- Compared with other sources of advice, people with cancer are more likely to find the advice they received from a financial institution unhelpful.
- People with cancer find it difficult to navigate the welfare benefits system, perceiving it to be complex and fragmented.
- They often do not know what help exists or what questions to ask. As a consequence, they come across information and sources of advice by chance.
- Friends, relatives and colleagues are a common source of advice for people with cancer. However, there is a risk that the advice or information they receive from informal, non-professional sources may be incorrect or partial.
- People with cancer ideally want to access information and advice across a range of subjects from one source, preferably one that also understands their illness, such as Macmillan.
- People like the idea of having one website or leaflet that tells them about the type of help

available depending on their symptoms or the stage of their cancer. In practice, this might be difficult to deliver and maintain in a simple and concise way.

Conclusions

At an estimated £103 per month, the typical total financial impact of a cancer diagnosis on individuals and their households is not insubstantial. The largest components of this impact derive from income loss and costs from outpatient visits (and specifically the travel costs associated with these). The added cost of day-to-day living following a cancer diagnosis also contributes a significant proportion of the total impact.

Overall, younger people (the under 60s but especially those in their 40s) incurred the greater total financial impact, and, consistent with this, those with dependent children and mortgages. Whether or not someone was working at the time of their diagnosis was also important, with those in work estimated to have incurred three times the burden of those who were not. This reflects the importance of income loss as a large component of the total financial impact, whereby those with earned incomes at the time of their diagnosis have the greatest scope to see their income fall.

People diagnosed with lymphoma, leukaemia or myeloma also tended to incur a higher than average burden, as did those with 'other' diagnoses and those who did not report their cancer type to the survey (including where the specific type of cancer was still undergoing diagnosis). A greater financial impact was also experienced among those who had undergone surgery or chemotherapy within the last six months than those who had not.

The greater burden of impact also fell on both the better-off households (those with middle-to-high incomes) *and* the poorest households, rather than those with moderate or very high incomes.

Similarly, particularly high financial impacts were found among people working full-time at the time of the survey as well as those unable to work due to permanent ill-health or disability. This polarised picture emerges because the importance of different characteristics tends to vary depending on the nature of the financial impact considered.

Overall, the nature of the individual's cancer diagnosis was particularly important regardless of the nature of the financial impact incurred. Socio-economic factors also tended to play an important role, more so than demographic characteristics such as gender, ethnicity and even where in the UK people live.

Over and above the financial impact individuals (and their households) had incurred as a result of their cancer, the detrimental knock-on effect that impact had on people's generally financial wellbeing and their quality of life has been clearly demonstrated by the study. Those incurring the greatest financial impacts and those most vulnerable to these impacts (because they were less able to afford them) were affected the most.

The limitations of the study have, nonetheless, highlighted the absence of any comprehensive sample frame of people with cancer in the UK that

is available for use in research of this nature. Important questions – about the dynamics of the financial impact of cancer across the cancer journey, why particular characteristics (including cancer type) influence the scale of that impact, and the effects on family members other than a partner and wider social networks – also remained unanswered.

The highly nuanced experience of the financial impact of cancer presents significant challenges to policy makers and practitioners in translating the findings into policy and practice. At the highest level, however, the findings from the study appear to validate strategies that protect and assist people on low incomes. Even so, they raise additional questions about the adequacy of policies to address fuel poverty, welfare benefits and grants to help with lumpy expenditure among people with cancer. They also underline the importance of accessible and timely money advice and information that is tailored to the needs of people with cancer. Because people with cancer do not always know what help exists or what questions to ask this information and advice (or signposting to it) needs to be proactively given by the full range of service providers people with cancer come into contact with.

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