The financial impacts of cancer

Methodological Appendix

University of Bristol's Personal Finance Research Centre
and
TNS BMRB

April 2012

University of BRISTOL
Personal Finance Research Centre

TNS BMRB
TNS

Contents

The study methods and all study materials were designed by the Personal Finance Research Centre and TNS BMRB in collaboration with Macmillan Cancer Support. An internal steering group, which included cancer patients in its membership, was also set up by Macmillan for the duration of the study. This group oversaw and inputted to the design of the study and study materials at each stage.

1. Depth interviews

24 qualitative depth interviews for this study were undertaken in May 2012 with people who had been diagnosed with cancer.

Purpose and rationale

The primary purpose of the qualitative depth interviews was to inform the development of the quantitative survey. In particular, the findings from the depth interviews were used to develop the content of the questionnaire. Clearly, the scope of the potential areas of additional cost that individuals and households might have incurred is very broad and it was not possible in practice to account for all possible scenarios in a quantitative survey without placing undue burden on participants. A primary purpose of the depth interviews therefore was to prioritise which questions to ask, in order that the questionnaire can adequately cover the main and the most expensive areas of additional costs to individuals with a cancer diagnosis and their household. The findings from the depth interviews also helped inform the response categories for these questions and the language that used to ask them.

Although their main purpose was to inform the design of the survey, the depth interviews were additionally used to supplement the findings from the quantitative survey. The value of using qualitative methods of research is not to provide findings that can be generalised as being representative of a population as a whole, as is often the intention of using quantitative (e.g. survey) methods.[1] Instead, the particular strength of qualitative research value lies in its ability to provide a depth of insight on specific and often complex and inter-related issues. It explores research questions and concepts in people's own terms and language and can provide new perspectives on old or assumed constructs, often challenging existing assumptions about the social work and developing new theories in doing so.

The sample design for this stage of the study reflected these two particular needs of the study.

Recruitment and sample selection

Although geographical location generally plays a far smaller role in financial outcomes than age and income, some degree of geographical spread was nonetheless included in the design, taking account of the different financial costs associated, for example, with how far people need to travel in order to access public, health and other services. Interviews were undertaken across three different geographical locations: the 'home counties', West Sussex and south Wales in May 2012.

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[1] For a detailed consideration of social research methods see for example: Bryman, A (2008) *Social research methods* (3rd edition). New York: Oxford University Press

The participants were 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. Macmillan provided the Personal Finance Research Cente with extracts of the database covering callers living in the three regions of England and Wales. The database was encrypted and password protected. The extracts were limited to people with cancer who had agreed to be contacted about taking part in research undertaken on Macmillan's behalf.

Within each of these three locations, callers living in a particular postcode locations, which were selected to provide good urban and rural coverage within reasonable travel distance of a PFRC qualitative interviewer, were invited to opt-in to an hour-long depth interview via a short postal screening questionnaire and consent form (see Document A). From approximately 240 invitations and screening questionnaire issued, approximately 70 positive returns were received. An advert was also posted on Macmillan's Opportunities Exchange forum, through which five positive responses were received.

The potential effects of self-selection, particularly where participants were recruited via the Exchange, were considered. However, this was deemed not to have an undue effect on the study, particularly as the depth interviews were largely intended to inform the quantitative phase and that people who were motivated to volunteer for the research through these recruitment methods may be more likely to have experienced a broader range of costs than others who are otherwise comparable to them, thereby providing richer qualitative data.

A final sample of 24 participants was selected from the positive returns received. The selection was based on location (again ensuring a good mix of urban and rural area) and was undertaken purposively to represent a range of people by cancer type, stages and time since diagnosis, as well as gender, age group, and family status (see Table 1). Those who were not selected to take part in the interviews were sent a letter thanking them for their interest and advised that their contact details would not be retained.

Each participant was sent a leaflet providing them with more information about the study and the name of the interviewer who would contact them (see Document B). The interviewer called shortly thereafter by phone to arrange an appointment. In most cases the interview was undertaken in-home or another location as specified by the participant. In two instances the interview was undertaken by telephone. In some cases, the participant's partner also participated in the interview.

A financial incentive was not offered to depth interview participants due to the potential for undue influence on participants, an ethical (and practical) consideration.[2] Macmillan made arrangements to reimburse participants for any out-of-pocket expenses incurred as a result of their participation.

Interviewers were briefed in full on the purpose and scope of the depth interviews. The hour-long interviews were informed by a topic guide (see Document C), which explored:

- The nature of the financial costs arising in relation to their diagnosis;

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[2] See for example Grant, RW and Sugarman, J (2004) Ethics in Human Subjects Research: Do Incentives Matter? *Journal of Medicine and Philosophy, 29*(6): 717–738.

- 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 interview was audio-recorded (with the permission of the participant) and transcribed in full. A full debrief of the interviews was undertaken and interim analysis was undertaken to inform the design of the survey (see section 2). Analysis of the interviews for the final report was undertaken thematically using QSR NVivo 9.

Ethical Approval

Ethical approval for the qualitative phase of the study was sought and received via the University of Bristol's School of Geographical Sciences Ethics Committee which works to the standards of the ESRC Research Ethics Framework and in accordance with University Policy and Procedure.

Table 1: Characteristics of qualitative sample

	Male	**Female**
	11	**13**
Age		
18-44	1	3
45-59	6	6
60+	4	4
Family status		
Has partner	7	8
No partner	4	5
Dependents		
Children under 16	5	5
No children under 16	6	8
Stage		
Receiving treatment	5	2
Up to 12 months since treatment	2	4
More than 12 months since treatment	3	6
Other	1	1
Cancer Type		
Breast Cancer	0	7
Blood/Lymphatic/lymphoma	3	2
Oesophageal	2	1
Prostrate	2	0
Urinary tract	0	2
Bowel	1	1
Other	3	0

Document A: Letter and screening questionnaire

WE ARE MACMILLAN. CANCER SUPPORT

University of BRISTOL

PERSONAL FINANCE RESEARCH CENTRE
School of Geographical Sciences
University of Bristol
University Road
Bristol BS8 1SS

Tel : 0117 928 9713

<Title/Initial> <surname>
<Address>
<Address>
<Address>
<Address>
<Address>

date

Dear <Title> <surname>

Understanding the financial impacts of cancer

I am writing to ask if you would be willing to take part in a new piece of research that aims to increase our understanding of the financial impacts that people with cancer face as a result of their condition.

The University of Bristol has been asked to undertake this research by Macmillan Cancer Support. As someone who has contacted the Macmillan Support Line and expressed potential interest in helping with research, Macmillan passed on your contact details to us solely for the purpose of inviting you to take part in this study.

For this study, we are looking to recruit people to take part in one-to-one in-depth interviews. The purpose of the interview is to understand the different types of financial costs incurred following a cancer diagnosis, how these arise and the effect they can have on people affected by cancer and their households. The findings will help to inform the design of a survey questionnaire that will be used in a later phase of the research. They will also be used to supplement the findings from the survey in the final report. The research will inform policy, the support services that Macmillan provides and campaigns. No individuals will be identifiable in the final report.

The interview will last up to one hour and will be undertaken in-home (or another location, as preferred). It will be carried out by a professional interviewer, who will phone you to arrange a suitable date to visit you. They will send you written details about the aims of the study and a contact at Bristol University in case you have any queries.

We are looking for 24 research participants in total. To get a broad understanding of the types of costs incurred and their impacts we would like to recruit people from a mixture of backgrounds. Therefore, if you would be willing to take part in this study, please complete the details on the following page, returning it in the envelope enclosed with this letter by **25 April 2012**.

Many thanks for your time.

Yours sincerely

Andrea Finney, Research Manager

If you are willing to take part in this research please complete this page and return it in the stamped addressed envelope enclosed with this letter

Please note that your details will only be held for the purposes of this research study. They will not be passed to Macmillan Cancer Support. They will be destroyed on completion of the study.

<Name>
<Address>
<Address>
<Address>
<Address>
<Address>

1. What is your age? Please tick (✓) one box:

Under 18 years............ ☐ 18 to 44............. ☐ 45 to 59............ ☐ 60 or over......... ☐

2. Do you have a partner/spouse who is living with you? Please tick (✓) one box:

Yes.............................. ☐ No..................... ☐

3. Do you have any children who are aged 16 or under? Please tick (✓) one box:

Yes.............................. ☐ No..................... ☐

4. Which of the following stages most accurately describes your current situation in relation to your cancer treatment? Please tick (✓) one box:

Receiving treatment..... ☐ up to 12 months post-treatment .... ☐ more than 12 months post-treatment ☐

Other.......................... ☐ If other, please give details:_______________________________

5. Please write below the type of cancer that you have been diagnosed with:

____

6. Finally, please write below the best telephone number for the researcher to reach you on:

Best: ____

Alternative (optional): _______________________________

Document B: Depth interview information leaflet

Description of cost What does the cost relate to?	Notes e.g. How much did it cost? How did it arise? Who paid? Was it expected, or a surprise?	When did it arise? e.g. before, during or after treatment
Continue on a separate sheet if necessary		

Understanding the financial impacts of cancer

Thank you for agreeing to take part in this important new study.

This leaflet explains about the aim of the study and what you should expect from the interview. It also confirms the day and time of the interview that has been arranged with you by phone, and the name of the person who will interview you.

The aim of the research

Previous research by Macmillan Cancer Support has shown that transport and parking costs can be a burden on people affected by cancer. However, we believe that these costs are only a small part of the overall picture.

This new research study aims to improve our understanding of the types of costs that are incurred by people with a cancer diagnosis, how and when these costs arise, the sums of money involved and what impact, if any, they have on the financial situations of individuals and their households.

The findings will help Macmillan build on our ongoing work to reduce the financial impacts of cancer through our campaigns and through the information and support services we offer.

Your appointment

Time and date	**Name of interviewer**
	Phone number

If you need to change your appointment time or day, please contact the interviewer on the number shown.

Our research partners

Macmillan has asked the University of Bristol's Personal Finance Research Centre to carry out this study on our behalf. This is a leading research centre that undertakes high quality research. Their research has been influential in informing government, charities like ours and other organisations about how best to develop services and policy to help improve the financial situations of individuals and households. The researchers that they appoint to carry out the interviews are professional interviewers with several years of experience.

The research interview: what is involved?

The interview will last about one hour. It will take place in your home, unless you have agreed with the interviewer to meet somewhere else.

The purpose of the interview is to hear about your experiences and your views. There are no right or wrong answers and the interview will be informal. The interviewer will use a topic guide to ensure that they ask all the right questions to fully understand your situation, the costs you may have incurred and any impact this has had on you or others close to you.

To avoid having to take lots of notes, the interviewer will voice record the interview, with your permission. The recording will be destroyed as soon as the research is complete. No individual will be identifiable in the final report.

If you would like to have a friend, family member or carer with you during the interview they would be very welcome to sit in. You can also stop the interview at any time if you feel unwell or uncomfortable.

Finally, if the interview is taking place in another location we will arrange to repay your out-of-pocket expenses, up to a maximum of £10. The interviewer will explain how you can claim this.

Questions or queries

If you have any questions about the research, please contact **Andrea Finney**, the research manager at Bristol University. Andrea can be reached on **0117 9289713** (or andrea.finney@bristol.ac.uk) during office hours. If she isn't available to take your call, please leave a message and she will get back to you as soon as she can.

Thinking about costs: a memory jogger

This project will look across all the different types of cost that people can incur following a cancer diagnosis. We have included some ideas about the types of cost that can arise at the bottom of this page. You may have incurred some of these but not others, and you may have had to pay for something that we have not thought of. We are interested to hear about all of these. We are also interested to know when these costs arose, in relation to your diagnosis and any treatment received (shown in the diagram below), or if they are ongoing.

On the back of this leaflet, we have included a page for any notes you might like to make between now and the interview about particular costs you have incurred since your cancer diagnosis. Please don't feel you need to make comprehensive notes of all the costs you have incurred, only those things that spring to mind, large or small.

The note card is intended only as a memory aid for use in the interview. It is not a requirement of the study and you will still make a valuable contribution to the research if you have not made any notes on it.

parking phone bill transport

alternative therapy dietary supplements

private treatment reduced income

home help home modifications

medical equipment utility bills

food and drink care or convalescence

Document C: Depth interview topic guide

Macmillan Financial Impacts: topic guide

1. Introduction

- From PFRC, University of Bristol
- Independent research, commissioned by Macmillan
- Study of the costs that arise following diagnosis and their impact
- Confidential, anonymised
- Lasting around 60 minutes
- Recording to ease note-taking; destroyed once project is completed.
- Questions?

Note to interviewers: The topic guide sets out the topics that each interview should aim to cover. Please adapt the form of words you use as appropriate to the interview situation, and use your discretion in relation to the order in which the topics are covered.

2. Background

- Age
- Who live with
    - Number/age of children
- Housing tenure
- Any change in living arrangements/tenure since diagnosis?
    - Reasons for change – diagnosis or other

3. Diagnosis

- What type of cancer(s) do/did you have?
    - Distinguish primary and secondary, and recurrence
- When were you first diagnosed?
- What led to your diagnosis? (any length of time ill beforehand?)
- What cancer treatment are you having? (did you have)
    - frequency/duration
    - where received treatment (e.g. hospital, specialist centre)
        - how got/get there
        - how far
- How often do you have check-ups or other appointments (e.g. with GP; consultant)
        - how got/get there
        - how far

- How is your health generally at the moment?
    - Any other health issues related to the cancer diagnosis?
    - Any health issues not related to the cancer diagnosis?
- What are the main ways your diagnosis (or diagnoses) and/or treatment has affected you day-to-day?
- And how has it affected others you live with/other friends and family?
    - Who has mostly been helping or caring for you?

4. Current financial situation

- Overall what is your *current* total household income (showcard)
    - What makes up your household income e.g. earnings
    - Probe for what this was pre-diagnosis and at any other key points

- If shortfall in income, generally how have you coped with it e.g. savings/borrowed/cut back/)?
    - Probe for income/critical illness or product (e.g. mortgage) protection. Was this used or not used, why?

- Overall, how are you managing financially *at the moment*?
    - Unprompted; then prompted (show card)
    - Probe for how this has changed since pre-diagnosis/ treatment/ post treatment stages

Employment

- What is your current working status?
    - Job type, role,
    - Employee or self-employed
    - Hours worked
    - Main earner?
- Has this changed since your diagnosis (including role, hours)?
    - If yes, in what way? What was status prior to diagnosis?
    - Why? As a result of illness/treatment (partly, wholly) or for other reasons (e.g. retirement)?
    - How sudden or gradual have these changes been? Particular crunch points (e.g. in relation to cancer journey)?
    - Periods of unpaid leave taken (how long)?
- What impact has it had on your own/household's income?
    - Probe for approximate figures if possible, prior to diagnosis and at key points since then
- Covered/used accident, sickness and unemployment insurance? How helpful?
- And has there been any change to the working status of anyone else in your household as a result of your diagnosis and/or treatment or for any other reason?
    - In what way?
    - Why?
    - Sudden or gradual change?
    - Impact on household's income (probe for approximate figures)

Benefits and tax credits

- Are you (or your partner) currently entitled to any benefits and how has this changed since before your diagnosis?
    - Income replacement e.g. Income Support, Jobseeker's Allowance?
    - Tax credits
    - Other (DLA; Carers allowance; Employment and Support Allowance/Incapacity Benefit)
- What effect have these benefits/tax credits had on your household income?
    - To what extent did they offset the loss of income (if applicable)

Other income changes

- Any other changes in income? (e.g. started to receive pension)

5. Additional costs

- What are the main additional costs you have incurred since diagnosis? (spontaneous then use prompt list / note card)?

- For each one, explore the following [where there are lots of costs mentioned, use discretion to focus on bigger costs and/or more unusual ones]:
    - One-off cost or recurring?

        - If recurring, how frequently/regularly incurred; whether still ongoing?
    - Roughly how much was the cost?
        - If recurring, each time incurred; and roughly how much in total or how many times incurred
    - When did you incur this cost (prompt in relation to diagnosis, treatment and time since treatment)
    - Who covered the cost? (yourself/ partner/ family/ friend/ grant)
        - Have they been reimbursed (e.g. hospital parking charges reimbursed by hospital)?
    - How was the money for the extra costs found?
        - From income/household budget
        - Savings (how much remain)?
        - Borrowing from family
        - Commercial credit (which type?), or released equity from property?
        - What are the total amounts drawn down/borrowed
        - Has been any knock-on effect from these?

    - Was the cost expected? Why/ Why not?
    - How essential was the cost?
        - Was an alternative available or considered?
        - What would have been the effect of going without?
    - Did you feel the cost was fair (amount; that you had to pay for it)?

- What have been the indirect costs incurred by you? (e.g. lost time/earnings due to taking time off for appointments or because feeling unwell)
    - When? (probe in relation to cancer journey)
    - Have others incurred these on your behalf (e.g. appointments, to look after you)?
        - Who covered these costs (them, you or someone else)?

- Have/ did any day-to-day costs reduce as a result of your diagnosis or treatment?
    - Why/how?
    - By how much?
    - Impact?

6. Overall financial impact

- What costs overall have had the biggest impact on your financial situation?
    - One large item, or
    - Cumulative effect of smaller costs?
- Have any been notable for any other reasons (e.g. unexpected/unfair)?
- Were there any particular crunch points in terms of coping with these costs?
    - Why?
    - When? (probe in relation to cancer journey)
- Have you had any (other) financial concerns (money worries) since your diagnosis?
    - What were these? (e.g. not being able to afford to travel, pay bills, having to borrow, lose savings)
    - When? (probe in relation to cancer journey)
- How well have you managed/any problems with:
    - Housing payments (rent/mortgage)
        - Any lender/landlord forbearance;

        - Any mortgage protection insurance held/used?
    - Heating or food bills
    - Other day-to-day expenditure

- Overall, what effect has the diagnosis had on your life and family financially (standard of living/quality of life)
    - Since diagnosis (probe in relation to cancer journey)
    - Currently
    - Looking ahead to the future

- Do you feel that you are as well-off financially as you could be, considering your diagnosis?
    - Why/why not?

7. Other impacts

- Overall, how has the diagnosis affected you and your family?
    - Family/ relationships
    - Work
    - General outlook
- What has been the role of additional costs and/or lost income in this?
    - In adjusting to these costs what impact has this had more generally (e.g. emotionally, psychologically, anxiety, worry) on you and your family?

8. Help and advice

- Since your diagnosis, have you received any advice on financial matters (inc. benefit entitlement)?
    - If yes, where from?
    - When? (probe in relation to whether pre-emptive or already in difficulty)
    - What advice was given?
    - How useful was it?
    - How satisfied with quality of advice?
    - How did it affect choices/decisions made?
    - Did you follow the advice?
        - If yes, feel better (or worse) off financially as a result?
        - If no, why not?
- What information/ advice would you like to have received/ would have been useful, and when (eg in cancer journey)?
    - On financial issues
    - On other issues
- If someone else was in the same situation, what information or advice about financial matters would you give them?

9. Anything else you would like to add?

THANK YOU

Queries can be directed to Andrea Finney, the research manager at Bristol University (0117 9289713).

Showcard 1: Income

Roughly how much income do you (and your partner) have in total? Please include take home pay from paid work or self-employment, social security benefits including Child Benefit, tax credits or any other regular income.

Please read out the letter that applies

	Per week:	**Per month:**
A	Less than £100	Less than £430
B	£100 - £199	£430 - £859
C	£200 - £299	£860 - £1299
D	£300 - £399	£1300 - £1719
E	£400 - £499	£1720 - £2149
F	£500 - £999	£2,150 - £4,299
G	£1,000 - £1,999	£4,300 - £8,699
H	£2,000 or more	£8,700 or more

Showcard 2: How managing financially

Which of these best describes how well you are currently keeping up with all of your household bills and credit commitments?

Please read out the letter that applies

A	**Keeping up without any difficulties**
B	**Keeping up but it is a struggle from time-to-time**
C	**Keeping up but it is a constant struggle**
D	**Have fallen behind with some of them**
E	**Have fallen behind with many of them**

2. Survey

A national survey of 1,610 people was undertaken in late summer and early autumn 2012.

Overall survey design considerations

The primary purpose of the quantitative survey was to enable the quantification of the additional costs and financial losses incurred by individuals and households as a result of a cancer diagnosis, the financial and other impacts of these additional costs, and which groups of people are most affected by these. In considering the best approach to surveying cancer patients three possible approaches were identified:

- Screening within the general population to identify eligible patients
- Using NHS cancer networks to recruit patients
- Using Macmillan's own networks and resources to recruit patients for the research.

The first of these approaches – general population screening – appears to have several advantages over the other two approaches. First, it would not require NHS ethical approval, enabling the fieldwork to commence more quickly. Second, it has the potential to deliver a sample that is most representative of the population since it will cover patients who may not be identified through the other two approaches (e.g. cancer patients in remission who are not currently accessing any services).

To assess the feasibility of a general population screening approach, we estimated the likely eligibility (or prevalence) rate within the general population. We defined the population as all patients within the UK diagnosed with cancer in the last five years. Based on a relatively recent article in the British Journal of Cancer,[3] we calculated prevalence rate for cancer diagnoses within the last five years in the UK of 1.2 per cent among males and 1.25 per cent among females. This suggested that in order to identify 2,000 eligible patients (to achieve 1,000 interviews) it would be necessary to screen some 160,000 people.

Prevalence is highly skewed by age so screening could be made more efficient by targeting particular age groups. TNS-BMRB maintains a resource called the 'Demographics Database' which would help us to target screening to, for example, particular age groups. Based on the journal paper referenced above, we estimate that prevalence of people diagnosed with cancer in the last five years ranges from around 0.17-0.18 per cent in the 0-44 age group to 4-6 per cent in the 65+ age group. Using a resource like the Demographic Database we could target screening towards the 65+ age group. While this would reduce the volumes of people it would be necessary to screen, we would still need to screen around 100,000 to achieve a robust enough sample for all age groups.

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[3] Maddams, J, Brewster, D, Gavin, A, Steward, J, Elliott, J, Utley, M and Møller, H (2009) Cancer prevalence in the United Kingdom: estimates for 2008 *British Journal of Cancer 101*, 541–547.

Based on this analysis the project team concluded that general population screening would not be a feasible approach to take, given the available budget.

The second option involved using NHS cancer networks, an approach that has been used successful by the research team in the past. With this option, we would have selected cancer clinics across the UK to aim to cover a representative cross-section both by geographical location and by cancer type. In theory, this approach would enable a representative sample of cancer patients currently receiving treatment to be recruited, although for practical reasons our selection would have been limited to the larger clinics and to those where key staff were most positive about the research and most willing to engage with the project. In each clinic, all patients would ideally be asked to take part in the research. The main disadvantage of this approach, particularly given the busy clinic setting in which staff might struggle to recruit participants, was the possibility of a high level of self-selection at the recruitment stage. As a result, it was agreed that this was not a feasible approach for this study.

The third option involved recruitment of cancer patients via the network of Macmillan Information and Support Centres, of which 170 are located across the UK, including 120 in hospitals. Although the sample would, by default, by limited almost exclusively to patients visiting these centres, as most were located in hospitals where cancer treatment takes place, it was initially intended that recruitment would extend to those centres located in the community, and mobile centres visiting different locations, enabling recruitment to be include patients no longer receiving treatment at a hospital. However, in order to produce sufficient sample numbers within the parameters of the project timetable and costs, only larger centres (those with estimated throughput of around 1000 or more patient enquiries per year) could be considered for inclusion. All of these were based in hospitals.

The main advantages of using the centres for recruitment were: 1) the setting will be more relaxed and supportive than during a clinic appointment, making it easier for staff to introduce the research to patients and answer any questions they have about it, 2) staff at the centres will be Macmillan employees or volunteers, and will therefore be much more motivated to assist with the research, and 3) patients who have been given information or assistance by staff at a centre are also likely to respond favourably to a request to take part in the research, thus increasing the level of take-up. Indeed, very high opt-in levels had been achieved by Macmillan in a previous study, and based on this, the design was expected to return the target sample numbers for this study.

After detailed consideration, this third option that was agreed as the way forward and progressed into the field. In the event, however, there were insufficient numbers of centres (particularly larger centres) to provide the target sample numbers in the Celtic nations of the UK (defined here as Scotland, Wales and Northern Ireland). A decision was therefore taken in collaboration with Macmillan to boost the sample numbers in these nations using an alternative recruitment method. Subsequently, as recruitment via the centres in England was also lower and slower than anticipated, the same decision was taken to boost sample numbers in England. This was achieved by using the Macmillan Support Line (MSL) database as a source of additional sample. Subsequent sections in this note provide more detail about the implementation of the survey in the field.

While largely driven by convenience and the large sample frame the MSL database provided, this decision was partly taken based on the successful use of the MSL for recruiting participants to the depth interviews, which indicated a response rate in the region of 30 per cent. The decision also took into account the rich mix of sample the database would likely to produce in terms of socio-demographic characteristics, (again as indicated by the depth interview recruitment process) and, while confining the sample frame by definition to information- and advice-seekers, ensuring that any potential bias towards people with financial concerns being recruited to the sample was minimised (since enquiries made to the MSL covers all issues relating to cancer, not just financial issues; see below).

A particular concern about the use of two different sample frames in the study was the potential for it to introduce systematic differences within the sample that affected the survey findings. For example, the Centre sample may be expected to include more people currently under the direction of a consultant and in treatment – in turn potentially reflecting how long ago they were diagnosed and the status of their cancer. As such, initial exploratory analysis was undertaken on receipt of the final data to explore whether the survey findings varied depending on which sample respondents belonged to. This analysis found sample source was not a significant determinant of the survey findings and therefore did not need to be controlled for.

Sample design and recruitment

As described above, a two-stage design was carried out whereby individuals eligible to participate in the survey (i.e. those who had received a cancer diagnosis) were recruited:

- via the network of Macmillan Information and Support Centres;
- or by re-contacting individuals who had phoned the Macmillan Support line and had agreed to take part in future research.

The aim was to achieve a sufficiently large sample in each nation of the United Kingdom to allow for separate country analyses to be carried out. The target sample sizes in each country were as follows:

England	975
Wales	175
Scotland	175
Northern Ireland	175
United Kingdom	1,500

Selection of participating centres and sampling eligible respondents

Macmillan provided TNS BMRB with a list of Macmillan Information and Support Centres present across the UK, along with information on the number of individual’s visiting the centre each year that had been diagnosed with Cancer. In cases where this information was missing, estimates were provided by Macmillan where appropriate.

Prior to selecting the sample a number of centres were removed this included:

- Centres attached to hospices, as it was not felt to be appropriate to recruit in these locations.

- Centres with fewer than 1,000 eligible visitors per year where the throughput was unlikely to make the exercise worthwhile, although due to the small number of centres present within the Celtic nations two of the centres selected received fewer than 1,000 visitors per year.
- Centres without any information on the number of eligible visitors (actual or estimated)

A total of 32 centres were selected across England and 5 centres across the Celtic nations (Wales, Scotland and Northern Ireland) to help recruit eligible individuals visiting the centres.

Initial contact with the centres was made by Macmillan and each selected centre was asked if they would be willing to help with the research. A total of 24 English centres and one centre in each of Scotland, Wales and Northern Ireland agreed to help with recruitment.

Centres were asked to introduce the research to all eligible individuals visiting the centre, where it was deemed appropriate and sensitive to do so.

Macmillan Support Line Database

In order to boost the number of individuals recruited to take part in the research a second sample frame, the Macmillan Support Line (MSL), was used. This sample frame was used to boost sample numbers across England, Scotland, Wales and Northern Ireland.

The MSL is a service provided by Macmillan for people with cancer, their friends, family or carers, or anyone else with concerns about cancer. It is widely advertised – on Macmillan's website, in their information leaflets and other literature and through television, radio and poster campaigns – and is available via a freephone number. Crucially, it provides information, advice and support on any matter relating to cancer, not just in relation to financial matters or money worries (Macmillan's records show that around 37 per cent of enquiries relate to financial matters, including 15 per cent on 'financial issues' and 22 per cent on 'welfare rights').

Sample from the MSL consisted of individuals with a cancer diagnosis who had phoned the MSL and were happy to be contacted by post for research.

Sample in England was drawn based on individuals who had contacted the MSL most recently, which stretched back over a 3 month period. All eligible individuals who had called the MSL during the 3 months prior to the sample selection were selected.

To draw sufficient sample within the Celtic nations it was necessary to draw sample spanning over a longer time period and so records went back to 2010. A simple random selection was made to draw the sample.

Questionnaire design and testing

The questionnaire, which was designed and developed to capture a comprehensive measure of cost and drew wherever possible on survey questions used successfully in previous surveys, was administered by post. Two data collection modes were considered as being appropriate to the study: telephone and postal surveys. A postal survey was considered the better approach than a telephone survey on balance, for three main reasons. First, there are clearly cost advantages in conducting a postal survey over a telephone survey. Second, a postal survey is the least intrusive form of research and it was considered the most appropriate methodology in this instance because a proportion of respondents were potentially vulnerable or elderly. Finally, although postal surveys are often rejected because they tend to have a lower response rate compared with other methods, in this case we expected a postal survey to generate a good response. This was partly because we were using an opt-in approach (for recruitment via centres), and because the survey should have a high salience for those invited to take part.

Although problems associated with the quality and validation of data are inherent to all survey methods that rely on self-report, an additional advantage conferred by using postal surveys is that respondents can take more time when considering and completing their answers (more so than for any other mode of survey administration, including interviewer-administered face-to-face and telephone surveys). This improves the material accuracy of the responses provided not least because respondents are better able to consult their own notes and records and discuss particular issues with partners, carers or other individuals. Indeed, the qualitative interviews indicated clearly that many respondents had full records of their appointments, and in some cases expenses, and that they were prepared to consult these in order to provide the study with the most accurate information possible. The main limitation of postal surveys in terms of data quality and validation, however, is that it is very difficult to build checks into the data collection process and the point of data collection. To mitigate this, systematic checks were made of the questionnaire responses post-hoc during data preparation to identify and deal with wherever possible out-of-range responses (see below).

Another mechanism used to help mitigate erroneous reporting involves ‘designing-out’ the scope for it to happen in the first place. This was partly achieved by ensuring that questions included in the survey conformed to best practice in question construction,[4] and by drawing on questions that had been used successfully in previous surveys. It was also achieved through external testing of the questionnaire, which was undertaken in two phases. First, five people who had taken part in the depth interviews were approached to review the questionnaire. All agreed and a draft questionnaire was sent out by post to them. Participants were asked to complete the questionnaire as best they could, and were called by telephone, by arrangement, to discuss any problems or issues that they came across. Participants were also asked a series of standard questions as part of a cognitive testing process, which was designed to ensure that key questions had been understood and answered as intended. A small number of changes were made as a result of this stage of testing.

Second, a small pilot was undertaken at one Macmillan Information and Support Centre, with full agreement of that centre. Over the course of two days, people visiting the centre were invited to help with the research. Eight people in total completed the draft questionnaire in the presence of a TNS BMRB researcher who observed the ease with which they completed the questionnaire and addressed any problems arising. A small number of changes were made as a result of this stage of testing.

Measuring financial impacts

In addition to answering questions about their demographic and socio-economic status and aspects of financial wellbeing and quality of life, a large part of the survey was dedicated to meeting the

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[4] Czaja, R and Blair, J (1996) *Designing Surveys: A guide to decisions and procedures*. London: Sage

primary objective of the study, i.e. to quantify the financial impact (or costs) of cancer, covering costs to individuals and their households arising from additional expense and/or reduced incomes.

Reduced incomes

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 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 the best available proxy for a point estimate of total income.

Second, respondents were asked, using the same income bands, to indicate what their (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 they 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.

Increased 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. Respondents were asked 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.

As a result, the additional expense arising is expressed throughout the report 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.

Ethical Approval

This survey design was reviewed by The National Research Ethics Service (NRES) who classified it as service evaluation and development, meaning that there was no requirement to undertake a Research Ethics Committee (REC) review. Ethical approval was therefore sought via the University of Bristol as the lead research organisation. The study was referred to the University of Bristol's Ethics Committee and Government Office which was satisfied with the judgment made by NRES and approved the study.

Fieldwork

Recruitment via Macmillan Information and Support Centres

Within each centre a single person was identified to act as the key contact for the recruitment, in terms of co-ordinating the recruitment, monitoring progress and returning opt-in cards. This individual was primarily the centre manager.

Each centre agreeing to help with the research was sent a briefing pack that explained the nature of the research, how we would like their assistance and details outlining what we wanted them to do. The centre manager also took receipt of the materials needed for recruitment (see Document A) and made sure these were circulated to everyone working within the centre.

Each centre was asked to carry out the following tasks:

1. Introduce the possibility of taking part in the survey to all patients, except in situations where it was felt inappropriate to do so
2. Hand out the patient leaflet explaining the research, and ask willing participants to fill out an opt-in card (name and address)
3. Collect back the opt-in cards and send these back to TNS BMRB (the research agency) on a weekly basis. Pre-paid envelopes were provided for this purpose.

Due to lower levels of opt-ins than originally anticipated the recruitment period was extended from 5 weeks to a 10 week period, from early August to early October 2012.

Fieldwork period and staging

Fieldwork for sample recruited via Macmillan Information and Support Centres was undertaken on a rolling basis, with sample loaded weekly. Postal questionnaires were dispatched on a weekly basis to all those who had opted into the research.

Fieldwork for sample selected from the MSL database was undertaken in 3 separate batches, the first two batches were made up of sample from the Celtic nations and the final batch sample from England.

Fieldwork took place between 17th August and 21st October 2012.

Up to two mailings were sent to individuals from either sample source:

- The initial mailing consisted of a cover letter, a questionnaire (with full instructions), and a reply paid envelop. All respondents were asked to return the questionnaire by a specific date;
- After 3-4 weeks a target reminder was sent to those who had not replied to the first mailing, This contained another copy of the questionnaire and a cover letter.

Given the nature of the survey and the individuals sampled it was not felt to be appropriate to send more than two mailings to potential respondents to ensure the survey was not too intrusive.

See Document B for copies of the materials sent to potential respondents.

Response rates

Table 2 gives details of response by country. Overall, 1,610 questionnaire returns were received across both types of sample which represented a response rate of 37%. Response rates ranged from 39% in England to 33% in Scotland and Northern Ireland.

Table 2: Response rates by country and sample type

	England	Wales	Northern Ireland	Scotland	Total
Centres					
Opt ins received	244	2	10	6	262
Questionnaires sent out	244	2	10	6	262
Questionnaires received	133	1	7	3	144
Response rate (%)	55	70	70	50	55
MSL					
Questionnaires sent out	2,577	507	433	583	4,100
Questionnaires received	963	173[1]	137	193[1]	1,466
Response rate (%)	37	34	32	33	36
All					
Questionnaires sent out	2,821	509	443	589	4,362
Questionnaires received	1,096	174	144	196	1,610
Response rate (%)	39	34	33	33	37

Notes: 1. Note that 17 respondents from the Wales MSL sample 2 from the Scotland MSL sample lived in England, all in postcodes very close to the border. These were not re-classified in the data.

The slightly lower response rates achieved across the Celtic nations can perhaps be attributed to the following reasons:

- The longer time period elapsing between contacting the MSL and being contacted for the research.
- A smaller proportion of sample was recruited via the centres which achieved higher response rates.

Given the cancer population tends to have higher than average mortality rates, some patients may have died in between opting in to the survey or agree to take part in future research and being sent a paper questionnaire. This was a particular concern with the Celtic nations MSL sample frame, where in some cases there may have been a time lag of 2 to 3 years. In order to deal with this situation sensitively a box was added to the front of the questionnaire, which could be crossed if there was no longer anyone within the household who had been diagnosed with cancer. In total 57 questionnaires were returned for this reason.

There were a small number of refusals to participate (8) which included questionnaires returned with an explicit refusal or a refusal via telephone. The biggest category of non response, by far was individuals who did not reply to any of the mailings. Across the United Kingdom, 59%of the sample did not reply. This could have been because they did not wish to take part in the survey, or because they had moved address so may never have received a questionnaire or they may have passed away.

Table 3: Proportion of returns considered deadwood, compared to questionnaire returns and no contact

Status of returns	Numbers	Percentage of questionnaires issued
Complete questionnaire	1,610	37
Partially completed	25	0.6
Returned blank	55	1.3
Returned by Post Office	52	1.2
Refusal	8	0.1
No longer anyone in the household with cancer	57	1.3
Incorrect details	20	0.5
No response	2,587	59

Data scan checks and preparation

All returned paper questionnaires were scanned and a number of edit checks were conducted on the scanned data. This ensured that where individuals had multi-coded questions the scan image was checked to ensure the correct code was assigned in the data. Edits were also carried out on all questionnaires collecting numerical data and any answers falling out of the predefined ranges were checked by the research team and edited where necessary.

All verbatim answers at open-ended questions were inspected by coders. This resulted in some additional codes being added to the code frames of some questions.

Data weighting

Weighting was employed to ensure the survey respondents are representative as far as possible of the population to which they are generalising. The weights were created to correct for differing levels of response between different groups of individuals, and to match the profile of the completed interviews back to the sample universe.

Cancer population data was obtained from Cancer Incidence and mortality in the UK 2007-2009.[5] This showed cancer incidence for individual countries for males and females separately within the UK. Data providing breakdowns within age and gender were obtained from Cancer Research UK,[6] who collated cancer prevalence by age for all countries within the UK from national bodies such as ONS. Together these sources included information on cancer incidence rates within gender for each cancer type, age group and country. These incidence rates, multiplied by the general population,[7] gave survey population targets for which to weight the survey to.

The use of incidence rates was preferred over prevalence rates because the available prevalence statistics do not provide adequate breakdowns by age. The effect of using incidence rates over preference rates is likely to be the under-representation of cancer types which carry longer survival rates (such as breast and prostate cancer) compared with those types of cancer with shorter survival rates (such as lung cancer). However, regression analysis – where used – will tend to control for this.

Some respondents were not able to/ chose not to divulge the type of cancer they had. For the weighting purposes a multinomial logistic regression model was created that imputed the most probable type of cancer they had based on all other survey data.

Rim weighting was used to calibrate to these targets and therefore the weighted data matches the population on type of cancer, age distribution, country and gender.

Capping was applied to the weight to limit extreme weights and damage to the effective sample size. Minimum and maximum caps were set at approximately the 4th and 96th percentiles respectively. Table 4 below displays the effective sample size and maximum and minimum caps that were applied to each weight.

Table 4: Effective sample size and weight caps

Weight	Effective sample size	Minimum weight	Maximum weight
WgtAGE	808	0.13	3.91

Sample composition

A breakdown of the sample by socio-demographic and diagnosis characteristics is shown in Table 5.

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[5] Cancer Incidence and mortality in the UK, 2007-2009: http://www.ons.gov.uk/ons/dcp171778_259504.pdf

[6] http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/age/

[7] http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-213833

Table 5 Characteristics of the sample

	Unweighted sample		Weighted sample (scaled)	
	Number in sample	Proportion of total	Number in sample	Proportion of total
Gender				
Male	657	41	841	52
Female	940	58	752	47
Not stated	13	1	17	1
Age group				
18 to 39	89	6	62	4
40 to 49	229	14	107	7
50 to 59	494	31	228	14
60 to 69	491	30	438	27
70 or over	305	19	774	48
Not stated	2	-	1	-
Ethnicity				
White	1,507	94	1,496	93
Non-White	69	4	75	5
Not stated	34	2	39	2
Household composition				
Single adult living alone	431	27	496	31
Partnered, no children	776	48	863	54
Partnered with dependent children	185	11	105	7
Single adult with dependent children	76	5	37	2
Single adult with other adults	130	8	99	6
Not stated	12	1	10	1
Area type				
Rural	384	24	371	23
Urban	1,226	76	1,239	77
Nation within the UK				
England	1,096	68	1,322	82
Scotland	196	12	150	9
Wales	174	11	87	5
Northern Ireland	144	9	51	3
Housing tenure				
Owns home outright	604	38	771	48
Owns home with a mortgage	427	27	282	18
Renting from a private landlord	158	10	143	9
Renting from a social landlord	366	23	353	22
Some other arrangement	48	3	48	3
Not stated	7	-	13	1
Employment status				
Working full-time[1]	342	21	208	13
Working part-time[1]	241	15	150	9
Retired	594	37	959	60
Unable to work due to permanent ill-health or disability	264	16	171	11
Other situation	121	8	71	4
Not stated	48	3	51	3
Age combined with working status				
Under 60 and working	475	30	230	14
Under 60 and not working	317	20	159	10
Over 60	796	49	1,211	75
Missing	22	1	9	1
Whether working at time of diagnosis				
Yes	818	51	596	37
No	717	45	915	57
Missing	75	5	99	6

Continues...

Table 5 (continuation) Characteristics of the sample

Monthly household income now				
Less than £430 (Less than £100pw)	128	8	90	6
£430 - £849	334	21	359	22
£850 - £1,299	381	24	390	24
£1,300 - £1,699	242	15	243	15
£1,700 - £2,149	193	12	205	13
£2,150 - £4,299	212	13	185	12
£4,300 - £8,649	30	2	26	2
£8,650 or more (£2,000pw or more)	4	-	2	-
Not stated	86	5	111	7
Monthly household income at time of diagnosis (not adjusted for inflation)				
Less than £430 (Less than £100pw)	80	5	64	4
£430 - £849	247	15	303	19
£850 - £1,299	283	18	323	20
£1,300 - £1,699	223	14	219	14
£1,700 - £2,149	227	14	201	13
£2,150 - £4,299	354	22	273	17
£4,300 - £8,649	66	4	55	3
£8,650 or more (£2,000pw or more)	20	1	17	1
Not stated	110	7	155	10
Respondent (or partner) receiving income-replacement benefits or tax credits				
Yes	377	23	349	22
No	1,233	77	1,261	78
Respondent receives health-related welfare benefits or partner receives carers allowance				
Yes	620	39	578	36
No	990	61	1,032	64
Cancer type				
Breast	472	29	266	17
Prostate	159	10	206	13
Cervix, Ovary, Uterus	106	7	68	4
Colorectal	163	10	180	11
Lung, bronchus or trachea	123	8	188	12
Oesophagus, stomach, pancreas or liver	88	5	128	8
Kidney or bladder	71	4	81	5
Lymphoma, leukaemia or myeloma	160	10	121	8
Other	155	10	227	14
Not stated / not known / undergoing diagnosis	113	7	144	9
When received diagnosis				
In the last 6 months	504	31	535	33
6 months but less than 12 months ago	317	20	328	20
1 year but less than two years ago	291	18	240	15
2 years but less than 5 years ago	312	19	264	16
5 or more years ago	142	9	182	11
Not stated	44	3	62	4
Cancer status				
Advanced / secondaries / metastatic	219	14	236	15
Recurrence / relapse	65	4	64	4
Not known / undergoing diagnosis	230	14	269	17
Localised or stable	462	29	484	30
Other	14	1	15	1
Remission or cancer-free (cured)	431	27	350	22
Not stated	189	12	191	12
Received surgery in the last six month				
No	1,116	69	1,148	71
Yes	494	31	462	29
Received radiotherapy in the last six months				
No	1,273	79	1,248	78
Yes	337	21	362	22

Continues...

Table 5 (continuation) Characteristics of the sample

Received chemotherapy in the last six months				
No	1,018	63	1,050	65
Yes	592	37	560	35
Received hormonal therapy in the last six months				
No	1,305	81	1,353	84
Yes	305	19	257	16
Received any other treatment in the last six months				
No	1,445	90	1,476	92
Yes	165	10	134	8
Received no treatment in the last six months				
No	1,542	96	1,524	95
Yes	68	4	86	5
All	1,610	100	1,610	100

Notes: 1. Employed or self-employed, including being temporarily off work due to ill health or maternity leave.

A comparison between the unweighted frequencies and the weighted frequencies shows the effect of the weighting on the sample. The comparisons for the four variables used in the weighting – gender, age group, cancer type and country – show that men, people living in England (by virtue of the sampling design) and especially people aged 70 and over – were particularly under-represented in the unweighted sample. The effect of the weighting was therefore to increase the contribution of these and other under-represented groups to the analysis and decrease the relative contribution of the groups (such as those with a breast cancer diagnosis) that were over-represented in the sample. The effect on other characteristics was generally more muted, although it is notable that retirees were particularly under-represented in the sample (reflecting that people aged 70 or over was also under-represented).

The overall effect of weighting on the current sample was to reduce the effective sample size (as shown in Table 4 above) and therefore the precision of the estimates produced, particularly by age group.

Analysis and estimates

All analysis was undertaken on weighted data. However, and despite the care taken in designing sample strategies (as described above), practical limitations mean no sample can ever said to be truly representative of the population to which it relates (also known as the ‘sample universe’). A particular limitation of any survey research is the voluntary nature of participation.

Weighting cannot control for this. This is because weighting can control for only those variables that can be observed by the researcher, for example age, sex, country of residence and potentially attitudinal variables, and where a reliable external source of data exists for the sample universe against which the sample characteristics can be calibrated. Self-selection into a survey, and the characteristics that drive this, is not normally observable, and this was true of this study. It is important that the estimates produced by this survey are understood in this context.

In addition to weighting and the data cleaning process described above, other adjustments were made to the data imputation using imputation.

Imputation

Following initial exploratory analysis, imputation was undertaken to correct for instances of missing and implausible data in the final run of analysis. The purpose of undertaking imputation is to make the data complete. Even where data are missing (or implausible) for only isolated cases for any one component of cost, where key outcome measures (such as the total financial impact of cancer) are dependent on combining different component costs, cases with missing data on any component must be omitted from any composite measures, even if their data are otherwise complete (this is known as casewise deletion). In this study, there were around 30 component costs of cancer meaning that casewise deletion would have meant substantially lowering the valid sample size for key measures, not to mention 'wasting' a significant amount of otherwise valid data our respondents had so kindly given. Imputation of cost data was undertaken in the event of extreme and missing values.

Extreme values

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). While extreme values are not necessarily invalid or erroneous they are problematic when producing survey statistics.

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 (imputed) with the median value among the non-zero cases (this is the most parsimonious value as it represents the 'typical' value and because it minimises the effect of the imputation on the distribution of the data). In practice, this typically affected considerably fewer than one per cent of cases per component cost and only those at the top of the distribution. For example it affected eight cases in relation to outpatient travel costs, two cases in relation to over-the-counter or prescription medicines and 10 cases in relation to extra (or less spent on food and drink day-to-day.

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.

Missing values

Respondents who did not answer any individual survey question relating to the cost (including where they did not indicate 'not applicable') were assigned a value of zero for the components making up that question. This decision reflects that the questionnaire invited respondents to leave a question blank if they did not feel it applied to them. It is also a conservative approach which adds caution to the calculation of costs. This applied to 98 cases for Q20 (outpatient visits), 286 for Q21 (inpatient stays), 138 for Q22 (treatment and healthcare, specialist of replacement clothing, specialist equipment and modifications) and 120 for Q23 (day-to-day living; see Document C below). Where respondents had completed some component costs at Q22 and Q23 but not others, the value also defaulted to zero for those that were not completed.

Where incurring travel costs, respondents were only required to provide *either* the mileage (if travelling by car) or the cost associated with this. Where respondents gave *both* for any entry at Q20 or Q21, the cost was taken in preference over the mileage. This decision was taken on the basis that someone may have included mileage where they had not travelled by car. This affected 136 cases in relation to Q20 (outpatient visits) and 52 in relation to Q21 (inpatient stays).

When estimating income lost as a result of cancer, respondents (156 cases) who did not complete either component (income before diagnosis, income now) were assigned the value of the median adjusted change in income for the sample as a whole. The 87 cases who did not answer Q13 (rating the extent to which any change in income was due to cancer) were assumed the middle value (‘partly’).

Document A: Fieldwork materials for Macmillan Information and Support Centres

UK Office
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ
Tel 020 7840 7840

Dear [TNS to insert contact name]

Thank you for agreeing to take part in Macmillan's landmark study on the financial impacts of a cancer diagnosis. Your help is much appreciated.

Please find enclosed a briefing pack from the research agency (TNS BMRB) with recruitment information for you to help us carry out this research and to answer any question you may have. Please check that your briefing pack contains all the instructions and materials listed on the recruitment information sheet as they will be necessary for carrying out the study.
After reading the instructions and information, should you have any additional questions, please contact Emma Coleman on freephone 0800 158 2952 or email emma.coleman@tns-bmrb.co.uk.

We would like to thank you in advance for your help with this important research. Macmillan knows that financial concerns are a continuing issue for the majority of people with cancer and the findings from this research will help Macmillan build on the work we have already been doing to support people affected by cancer.

With thanks on behalf of Macmillan and the research team.

Yours sincerely

J Mitchell

Jennifer Mitchell
Policy Manager
Macmillan Cancer Support

Research: Understanding the financial cost of a cancer diagnosis

Recruitment information

Thank you very much for agreeing to help us with this important research. This document provides an outline of what we would like you to do for us and hopefully helps to answer some of the questions you may have.

In addition to this recruitment information, you will also have received the following within your recruitment briefing pack:

- Poster advertising this research opportunity to patients
- Opt-in cards for patients
- Patient information leaflets about the research
- Pre-paid envelopes

How can I help?

We would like your centre to help us recruit people who have been diagnosed with cancer to take part in the research. This will involve the following three steps:

1. Introducing the possibility of taking part in the survey to all patients, except in situations where you feel it is inappropriate to do so
2. Handing out the patient leaflet which explains the research, and asking willing participants to fill out an opt-in card (copies of the leaflet and opt-in card are included in your recruitment pack)
3. Collect back the opt-in cards and send these back to TNS BMRB (the research agency) on a weekly basis (every Friday if you can). Pre-paid envelopes have been provided for this purpose within your recruitment pack

TNS BMRB will then send a postal questionnaire to participants who opt-in to the research to complete at their leisure. They are free to opt-out of the research at any stage. If you would like a copy of the questionnaire for your reference, please contact TNS BMRB (contact details can be found at the end of this document).

Please turn over to find out more about the research and some answers to common queries.

Overview of the survey

- Macmillan is undertaking this UK-wide research project to better understand the financial costs of a cancer diagnosis on patients and their household.

- Macmillan will use the results of the research to identify solutions to the financial problems that people affected by cancer face. It will help us to improve the services, information and advice we offer and strengthen our case for the need for this type of help and support. Macmillan will be launching a public-facing campaign next year calling on policy makers to address the financial difficulties faced by people with cancer.

- Macmillan is working with the Personal Finance Research Centre (PFRC) based at the University of Bristol and TNS BNS to undertake this research. TNS BMRB is an independent research agency specialising in social research and will be managing the survey on behalf of Macmillan. Further information about TNS BMRB and PFRC can be found at the end of this document.

Who is eligible to take part?

- We are interested in the views and experiences of anyone aged 18 or over who has been diagnosed with cancer.

- It does not matter when they received their diagnosis, what their financial situation was then or what it is now. We want to include a broad range of people with different experiences.

- Please note that we are not asking you to screen patients in or out of this research – the research is open to all those aged 18 or over who have had a cancer diagnosis.

- Information about the research will be contained in the patient leaflet, along with a helpline number that people can call to find out more or to ask questions. So you don’t need to talk patients through the research in a lot of detail.

- We appreciate that it may not be appropriate to introduce the survey in all situations and so feel it is best left down to your discretion.

Recruitment Period

- We would like you to recruit individuals over a five week period or until you run out of opt-in cards (providing this is still within the 5 week period). Please start the recruitment as soon as you receive this recruitment pack.

- Depending on the number of returns we receive in total, this period may be extended. We will inform you if this is the case.

What happens once the opt-in card is completed?

- For data security purposes we ask that you store the completed opt-in cards in a locked cupboard/draw and send them to TNS BMRB once a week in the pre paid envelopes supplied within the recruitment pack. There are enough envelopes to cover the 5 week recruitment period plus a couple spare. If this is going to be problematic, please contact TNS BMRB to discuss alternative arrangements.

- Once TNS BMRB have received the completed opt in cards, a paper questionnaire will be sent to the individual at the address they have given. This will allow them to fill out the questionnaire in their own home and in their own time.

- If TNS BMRB have not received a completed questionnaire back within 3-4 weeks, a full reminder pack, containing a questionnaire, will be sent to the address. No further contact will be made if no questionnaire is received after this.

Can someone else fill out the paper questionnaire on the patient's behalf?

- If participants require any help to complete the questionnaire then it is fine for them to ask a family member, friend or carer. However, we would like to hear their views, not the views of the person helping them to fill the questionnaire out.

Does the survey have Ethical Approval?

- The National Research Ethics Service (NRES) has reviewed this study and classified it as service evaluation and development, meaning that there is no requirement to undertake a Research Ethics Committee (REC) review. Ethical approval has therefore been sought and approved via the University of Bristol as the lead research organisation.

Data security

- TNS BMRB is committed to ensuring that all information including personal and sensitive information is protected at all times. TNS BMRB are compliant with the 1998 Data Protection Act, The Market Research Society (MRS) Code of Conduct, The ISO 2025:2006 and The ISO 9001:2008. All personal information collected for this survey will be securely stored and the information can only be accessed by a limited number of staff members.

- The results of this survey will not be released to Macmillan in any format that would enable them to link responses to individuals without prior permission from the participant.

Who should I contact for more information?

- For general enquires please contact Emma Coleman at TNS BMRB on freephone 0800 158 2952 or email emma.coleman@tns-bmrb.co.uk

- If you would like a copy of the final research report when it is completed, please contact David Collings on 0177 9288634 or david.collings@bristol.ac.uk

TNS BMRB and The Personal Finance Research Centre

- TNS BMRB is one of the largest independent research organisations in Britain. TNS-BMRB provides knowledge that helps Government, the private sector and the Third Sector plan and care for society. Their expertise includes the provision of national statistics, public policy analysis, public service performance measurement and improvement, and communications evaluation.

- The Personal Finance Research Centre is an independent research centre that specialises in robust social research across all areas of personal finance, mainly from the consumer's perspective. The Centre undertakes high-profile research for a range of stakeholders including government policymakers, charities and consumer groups and the financial services industry.

Will my taking part in this study be kept confidential?

Yes. The results of the survey will not be released to Macmillan in any format that would enable them to link responses to individuals.

Contact for further information

If you wish to find out more about the survey itself, or you have any questions about it, please feel free to contact Emma Coleman at TNS BMRB on freephone 0800 158 2952

If you would like more general information or support regarding cancer then you can ring the freephone Macmillan Cancer Support helpline: 0808 808 00 00

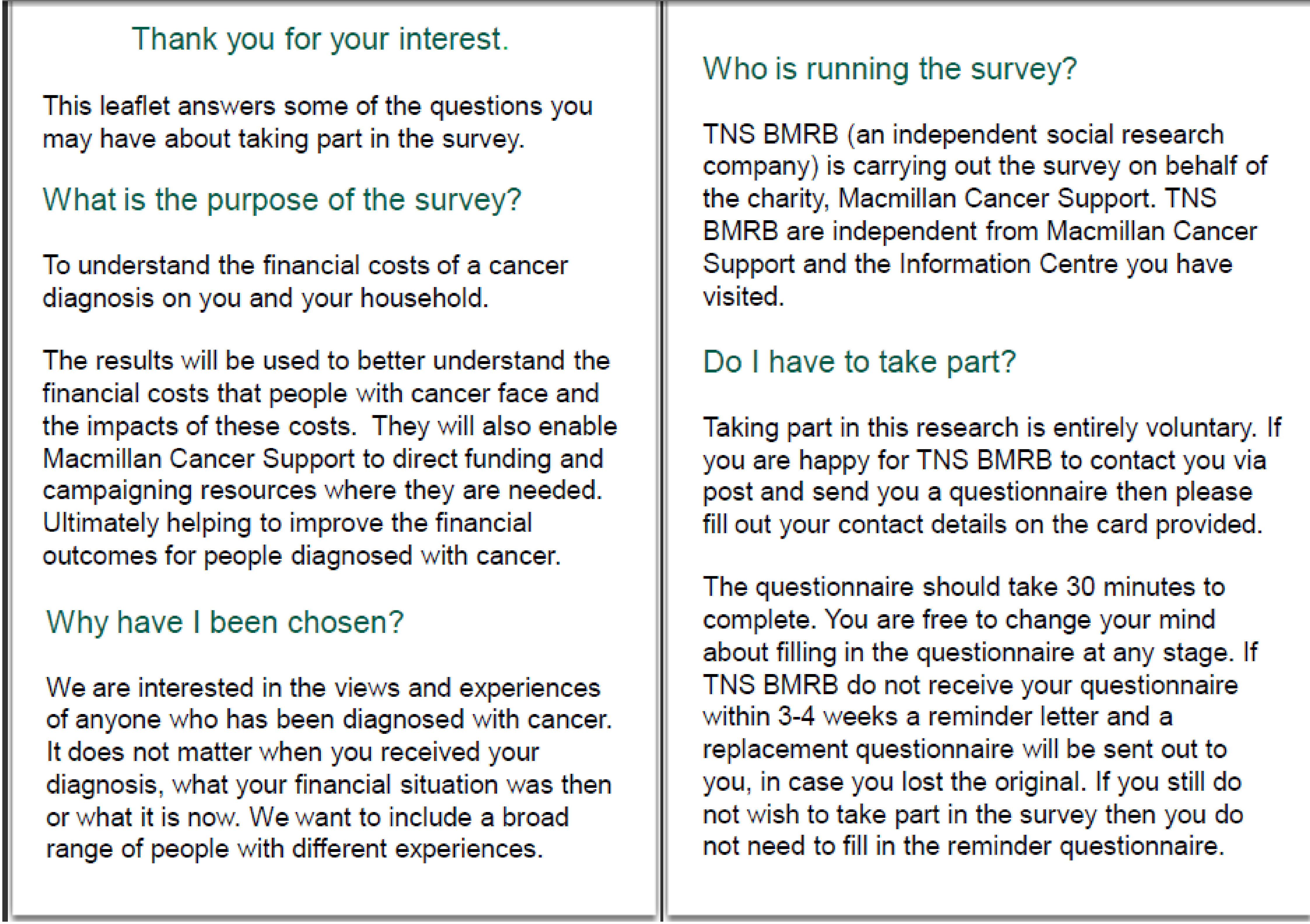
Thank you for reading this information sheet. We hope you are able to help.

Understanding the financial cost of a cancer diagnosis

Survey
Information leaflet

TNS

WE ARE MACMILLAN.
CANCER SUPPORT



Thank you for your interest.

This leaflet answers some of the questions you may have about taking part in the survey.

What is the purpose of the survey?

To understand the financial costs of a cancer diagnosis on you and your household.

The results will be used to better understand the financial costs that people with cancer face and the impacts of these costs. They will also enable Macmillan Cancer Support to direct funding and campaigning resources where they are needed. Ultimately helping to improve the financial outcomes for people diagnosed with cancer.

Why have I been chosen?

We are interested in the views and experiences of anyone who has been diagnosed with cancer. It does not matter when you received your diagnosis, what your financial situation was then or what it is now. We want to include a broad range of people with different experiences.

Who is running the survey?

TNS BMRB (an independent social research company) is carrying out the survey on behalf of the charity, Macmillan Cancer Support. TNS BMRB are independent from Macmillan Cancer Support and the Information Centre you have visited.

Do I have to take part?

Taking part in this research is entirely voluntary. If you are happy for TNS BMRB to contact you via post and send you a questionnaire then please fill out your contact details on the card provided.

The questionnaire should take 30 minutes to complete. You are free to change your mind about filling in the questionnaire at any stage. If TNS BMRB do not receive your questionnaire within 3-4 weeks a reminder letter and a replacement questionnaire will be sent out to you, in case you lost the original. If you still do not wish to take part in the survey then you do not need to fill in the reminder questionnaire.

WE ARE MACMILLAN. CANCER SUPPORT

TNS

We would like your help

You are invited to take part in a survey for Macmillan Cancer Support. The survey looks at the costs people may face as a result of their cancer diagnosis. We would like to send you a questionnaire by post for you to fill in.

The UK wide research will help Macmillan to better understand the financial challenges that people affected by cancer face. We can then work to improve the support and advice provided to people along their cancer journey.

If you would **like** to take part, please indicate this by ticking the box below **and** writing your name and address in the space provided**.** TNS BMRB (an independent research company) will then send you the questionnaire and ask you to return it to them. A **freepost** envelope will be provided for you to do this. All your answers will be treated in the strictest of confidence.

If you would like to know more about the survey, please see the information sheet provided or you can contact Emma Coleman on freephone 0800 158 2952

I would like to take part in the survey so please pass my name and address on to TNS BMRB ☐

Please tick if appropriate

Name (please print in capitals)

Address (please print in capitals)

House Name/Number

Street

Street 2

Town

County

Country

Postcode

Thank you

Reference:

Document B: Questionnaire and cover letters

WE ARE MACMILLAN.
CANCER SUPPORT

TNS BMRB
TNS

Reference Num:
Mr/Mrs/MISS/MS [SURNAME]
Street
Town
Postcode

DATE]

Dear Mr/Mrs/MISS/MS [SURNAME]

Understanding the costs of cancer: a national survey

Thank you for taking the time to complete the enclosed questionnaire. Your replies will help Macmillan Cancer Support increase its understanding of the financial costs that people with cancer face and the impacts of these costs. Even if you feel you have not experienced any increased costs, we would still like to hear from you.

Macmillan has asked TNS BMRB and the University of Bristol to undertake this survey on their behalf. This is a national survey and the results will inform policy, the support services that Macmillan provides and its campaigns. Your response is very important to us.

The questionnaire should take about 30 minutes to complete. Depending on your situation, a number of the questions might not be relevant to you.

Your responses to this questionnaire are anonymous. Your name and contact details will never be attached to the information you give us and no individuals will be identifiable in the final report.

Please return the completed questionnaire in the envelope provided by Monday October 15th – **no stamp is needed**. If you have any questions about the survey or questionnaire please get in touch with Emma Coleman at TNS BMRB on freephone 0800 158 2952 or email: Emma.Coleman@tns-bmrb.co.uk.

Please see the reverse of this letter for further information.

Many thanks again

Emma Coleman
TNS BMRB

University of
BRISTOL
Personal Finance
Research Centre

Understanding the costs of cancer: Further information

Would you like to receive a copy of the research report?

Our research partners at the University of Bristol will be pleased to send you a copy of the research report when it is published. If you would like to receive a copy, please email David Collings at david.collings@bristol.ac.uk or call him on 0117 9288634 giving your name and postal address (or your email address if you would prefer to receive the report via email). Your contact details will not be passed on to any other organisation or used for any other purpose.

Would you like to be a media case study for Macmillan?

Macmillan would like to talk to people who have faced particular financial hardship (for example with housing, borrowing and other household commitments) as a result of cancer, to see if they may be willing to share their experiences with the media.

If you are willing to consider being a Macmillan media case study please contact Alison Davies, Macmillan's Case Study Officer on aldavies@macmillan.org.uk, including an outline of your experiences.

Alison will get in touch to explain more about what may be involved if you are selected to be a case study, and check if you are happy to take part. None of the information you provide to Alison will be shared outside Macmillan without your permission and you can change your mind at any time.

The information you have provided in the questionnaire will not be passed on to Macmillan with your contact details and it will not be possible for them to identify your answers in any way.

Many thanks for your help

WE ARE MACMILLAN.
CANCER SUPPORT

TNS BMRB
TNS

Reference Num:
Mr/Mrs/MISS/MS [SURNAME]
Street
Town
Postcode

[DATE]

Dear Mr/Mrs/MISS/MS [SURNAME]

Understanding the costs of cancer: a national survey

I would like to invite you to take part in an important new survey for Macmillan Cancer Support about the financial costs of cancer. Your replies will help Macmillan increase its understanding of the financial costs that people with cancer face and the impacts of these costs.

We hope you can help. Even if you feel you have not experienced any increased costs as a result of your diagnosis, we would still like to hear from you.

Macmillan has asked TNS BMRB and the University of Bristol to undertake this survey on their behalf. This is a national survey and Macmillan will use the results to help develop the information, advice and support services they provide and improve the financial outcomes of people affected by cancer.

The enclosed questionnaire should take about **30 minutes to complete**, although this may be longer or shorter depending on your circumstances. Depending on your situation, a number of the questions might not be relevant to you.

All the answers you give will be treated in the strictest of confidence in accordance with the Data Protection Act.

We would be grateful if you could return the completed questionnaire in the prepaid envelope provided by Monday October 15th. If you have any questions about the survey or questionnaire, please get in touch with Emma Coleman at TNS BMRB on freephone 0800 158 2952 or email: Emma.Coleman@tns-bmrb.co.uk.

Please see the reverse of this letter for further information.

Thank you for taking the time to complete this questionnaire.

Emma Coleman
TNS BMRB

University of
BRISTOL
Personal Finance
Research Centre

Understanding the costs of cancer: further information

Why have I been chosen to take part in this survey?
We are interested in the views and experiences of a broad range of people who have been diagnosed with cancer. You have been chosen at random from a list of people who have contacted the Macmillan Support Line. It does not matter when you received your diagnosis, what your financial situation was then or what it is now, we would still like to hear from you.

Who is running the survey?
TNS BMRB (an independent social research company) is carrying out the survey on behalf of the charity, Macmillan Cancer Support. TNS BMRB is independent from Macmillan Cancer Support. Researchers from the University of Bristol will produce the results from the survey.

Do I have to take part?
Taking part in this research is entirely voluntary. If TNS BMRB do not receive your questionnaire within 3-4 weeks a reminder letter and a replacement questionnaire will be sent out to you in case you have lost the original. If you still do not wish to take part in the survey then you do not need to fill in the replacement questionnaire.

Will my taking part in this study be kept confidential?
Yes. The results of the survey will not be released to Macmillan in any format that would enable them to link responses to individuals.

Would you like to receive a copy of the research report?
Our research partners at the University of Bristol will be pleased to send you a copy of the research report when it is published. If you would like to receive a copy, please email David Collings at david.collings@bristol.ac.uk or call him on 0117 9288634 giving your name and postal address (or your email address if you would prefer to receive the report via email). Your contact details will not be passed on to any other organisation or used for any other purpose.

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Many thanks for your help

WE ARE MACMILLAN.
CANCER SUPPORT

TNS BMRB
TNS

Reference Num:
Mr/Mrs/MISS/MS [SURNAME]
Street
Town
Postcode

[DATE]

Dear Mr/Mrs/MISS/MS [SURNAME]

Understanding the costs of cancer: a national survey

You may remember receiving a letter and questionnaire a couple of weeks ago about an important survey for Macmillan Cancer Support. To the best of our knowledge we have not yet received a reply from you.

If you have already returned your questionnaire then please ignore this letter. I apologise for bothering you again and thank you for taking part in this important research.

If you have not returned your questionnaire we would still very much like to hear your views. It is important that we are able to understand the financial costs faced by people with cancer, and the impacts of these costs.

The questionnaire should take about 30 minutes to complete. Depending on your situation, a number of the questions might not be relevant to you.

Your responses to this questionnaire are anonymous. Your name and contact details will <u>never</u> be attached to the information you give us and no individuals will be identifiable in the final report.

I enclose a further copy of the questionnaire together with a reply paid envelope and would be grateful if you would complete it and return it by <u>Thursday October 25th</u> – **no stamp is needed**.

If you have any questions about the survey or questionnaire please get in touch with Emma Coleman at TNS BMRB on freephone 0800 158 2952 or email: Emma.Coleman@tns-bmrb.co.uk.

Please see the reverse of this letter for further information.

Many thanks again

Emma Coleman
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University of BRISTOL
Personal Finance Research Centre

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Many thanks for your help

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CANCER SUPPORT

TNS BMRB
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Emma Coleman
TNS BMRB

University of BRISTOL
Personal Finance
Research Centre

Understanding the costs of cancer: further information

Why have I been chosen to take part in this survey?
We are interested in the views and experiences of a broad range of people who have been diagnosed with cancer. You have been chosen at random from a list of people who have contacted the Macmillan Support Line. It does not matter when you received your diagnosis, what your financial situation was then or what it is now, we would still like to hear from you.

Who is running the survey?
TNS BMRB (an independent social research company) is carrying out the survey on behalf of the charity, Macmillan Cancer Support. TNS BMRB is independent from Macmillan Cancer Support. Researchers from the University of Bristol will produce the results from the survey.

Do I have to take part?
Taking part in this research is entirely voluntary. If you still do not wish to take part in the survey then you do not need to fill in this replacement questionnaire.

Will my taking part in this study be kept confidential?
Yes. The results of the survey will not be released to Macmillan in any format that would enable them to link responses to individuals.

Would you like to receive a copy of the research report?
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Many thanks for your help

WE ARE MACMILLAN. CANCER SUPPORT

TNS BMRB
TNS

Understanding the costs of cancer: A national survey

Thank you for taking the time to complete this questionnaire. **It should take about 30 minutes to complete.**

If you require any help to complete the questionnaire then it is fine to ask a family member, friend or carer. Please remember however that we would like to hear your views – not the views of the person who is helping you.

If, for any reason, there is no longer anyone in your household who has been diagnosed with cancer, please cross the box below and return the questionnaire to us so we do not trouble you further.

☐ There is no longer anyone in the household who has been diagnosed with cancer

How to fill in the questionnaire

1. Most questions on the following pages can be answered by putting a cross in the box next to the answer that applies to you, like this: ☒

   Or by writing in a number like this

£			5

2. Occasionally a question will ask you to **"cross all that apply."** Please cross as many boxes as apply to you when you see this instruction.
3. Please try to answer every question. If you cannot remember, do not know, or the question does not apply to you then please cross the relevant box where shown or leave the question blank.
4. If you change your mind about an answer you have given, completely block out the box you have crossed like this, ■ and then put a cross in your preferred box.

Where can you get help?

✉ Emma.Coleman@tns-bmrb.co.uk ☎ Survey helpline 0800 158 2952

Reference:

Section 1: About you

1. Are you male or female?

Please cross one box only

☐ Male

☐ Female

2. What is your current age, in years?

Please cross one box only

☐ 18 to 29

☐ 30 to 39

☐ 40 to 49

☐ 50 to 59

☐ 60 to 69

☐ 70 to 79

☐ 80 or older

3. Who normally shares your home with you?

Please cross all that apply

☐ No-one else

☐ Wife, husband or partner you live with as a couple

☐ Children aged under 16

☐ Children aged 16-18 who are at school or college

☐ Other adult children

☐ Parents or parents-in-law

☐ Other adults who share meals or living room with you

4. Which one of the following best describes your housing situation?

Please cross one box only

☐ Own your home outright

☐ Own your home with a mortgage (including shared ownership)

☐ Rent your home from a private landlord

☐ Rent your home from a local authority or housing association

☐ Live with your adult children

☐ Live with your parents

☐ Other – please write in here:

5. And which one of the following best describes your current employment situation (and that of your partner, if you have one)?

Please cross one box only for you (and one for your partner)

You	**Partner**	
☐	☐	Full-time employed/self-employed – including temporarily off work due to ill health or maternity leave
☐	☐	Part-time employed/self-employed – including temporarily off work due to ill health or maternity leave
☐	☐	Retired
☐	☐	Unemployed and looking for work
☐	☐	In full-time or part-time study
☐	☐	Looking after the home/caring for family
☐	☐	Unable to work due to permanent ill-health or disability
☐	☐	Other situation

Section 2: About your cancer diagnosis

6. What type of cancer have you been diagnosed with most recently?

We would like to know the site of the primary cancer that you have been diagnosed with. This is usually named after the part of the body where the cancer first started to grow (even if it may have spread to other areas). Please tell us about your most recent primary diagnosis if you have had other cancers in the past.

We have listed the four most common types of cancer below. If the cancer you were diagnosed with is not on the list, please write it in the space provided.

Please cross one box only

- ☐ Breast
- ☐ Prostate
- ☐ Colorectal/bowel
- ☐ Lung, bronchus or trachea (throat)
- ☐ Not known/undergoing diagnosis
- ☐ Other – please write in here: ☐

7. When was this cancer diagnosed?

Please enter the month and year below

☐☐ Month

☐☐☐☐ Year

8. Which of the following best describes the current status of this cancer?

Please cross all that apply

☐ Localised or stable

☐ Advanced / secondary / metastatic

☐ Recurrence / relapse

☐ Remission or cancer-free (cured)

☐ Not known/undergoing diagnosis

☐ Other – please write in here: ☐

9. Which of the following treatments have you had for this cancer at any time since your diagnosis? Please also tell us which you have had in the last 6 months and any you are receiving at the moment.

Please cross all that apply

At any time	Last 6 months	At the moment	
☐	☐	☐	Surgery
☐	☐	☐	Radiotherapy
☐	☐	☐	Chemotherapy/chemo
☐	☐	☐	Hormonal therapy (e.g. Tamoxifen, Flutomide)
☐	☐	☐	Any other treatment
☐	☐	☐	Don't know
☐	☐	☐	None

Section 3: Your household's financial situation

This section asks about your household's total income, how you are managing financially at the moment, and how this compares to the time immediately before your cancer diagnosis.

The answers you give us in this section will help us to understand the extent to which any change in your household's situation is due to the diagnosis, whether directly or indirectly, or if it is due to other factors.

When we refer to your 'diagnosis', please think about **your most recent (primary) cancer diagnosis**.

10. Which of the following sources of income do you (and your partner) currently receive?

Please cross all that apply to you (and your partner, if you have one)

You	Partner	
☐	☐	Income from employment/self-employment (including sick pay)
☐	☐	State Pension
☐	☐	Income from personal or occupational pensions
☐	☐	Tax Credits or Pension Credit
☐	☐	Income Support or Jobseeker’s Allowance
☐	☐	Employment and Support Allowance or Incapacity Benefit
☐	☐	Attendance Allowance or Disability Living Allowance
☐	☐	Carers Allowance
☐	☐	Any other benefit (e.g. Housing Benefit)
☐	☐	Other: please write in:
☐	☐	None of these

11. Which of the following most closely matches the income you (and your partner) currently receive in total?

Please include take home pay from paid work or self-employment, social security benefits including Child Benefit, tax credits and pension credits or any other regular income.

By take home pay we mean pay after tax and any other deductions made at source.

Please cross one box only

	Per week:	**Equivalent per month:**
☐	Less than £100	Less than £430
☐	£100 - £199	£430 - £849
☐	£200 - £299	£850 - £1,299
☐	£300 - £399	£1,300 - £1,699
☐	£400 - £499	£1,700 - £2,149
☐	£500 - £999	£2,150 - £4,299
☐	£1,000 - £1,999	£4,300 - £8,649
☐	£2,000 or more	£8,650 or more

12. And which of the following most closely matches the total income you (and your partner) typically received immediately before your diagnosis?

Again, please include take home pay from paid work or self-employment, social security benefits including Child Benefit, tax credits and pension credits or any other regular income.

Please cross one box only

	Per week:	**Equivalent per month:**
☐	Less than £100	Less than £430
☐	£100 - £199	£430 - £849
☐	£200 - £299	£850 - £1,299
☐	£300 - £399	£1,300 - £1,699
☐	£400 - £499	£1,700 - £2,149
☐	£500 - £999	£2,150 - £4,299
☐	£1,000 - £1,999	£4,300 - £8,649
☐	£2,000 or more	£8,650 or more

13. On a scale of 1 to 5, to what extent would you say that any change in your total income now compared with before your diagnosis is because of your cancer diagnosis or treatment?

Please cross the box that most closely reflects your situation

Not at all		Partly		Entirely
1	2	3	4	5
☐	☐	☐	☐	☐

☐ Not applicable / No change

14. Have you experienced any of the following changes at any time since your diagnosis?

For example, if you reduced the hours you worked please cross this box even if you later increased your hours. Or, if you reduced your hours and later stopped working permanently due to retirement, please cross both of these boxes.

Please include **changes arising for any reason,** not just those relating to your diagnosis.

Please cross all that apply

- ☐ Your partner leaving the household (e.g. marital separation, death)
- ☐ Stopped working temporarily on reduced pay or no pay (e.g. taken sick leave)
- ☐ Reduced hours worked or taken unpaid leave
- ☐ Moved to a lower paid job
- ☐ Stopped working permanently (e.g. left job, made redundant, retired)
- ☐ None of these

15. <u>Overall,</u> has your general financial situation got better, worse or stayed about the same since your diagnosis?

Please cross <u>one</u> box only

☐ Better

☐ Worse

☐ Stayed the same

☐ Too difficult to say

16. Thinking about the last 12 months, which of the following statements best describes how well you (and your partner) are keeping up with your household bills and credit commitments?

Please cross <u>one</u> box only

☐ Keeping up with all of them without difficulty

☐ Keeping up with all of them but it is a struggle from time-to-time

☐ Keeping up with all of them but it is a constant struggle

☐ Falling behind with some of them

☐ Having real financial problems and falling behind with many of them

17. Which (if any) of the following types of payments have you (or your partner) missed at any time in the last 12 months due to a lack of money? Please include any payments where you have fallen into arrears.

Please cross <u>all</u> that apply

☐ Rent or mortgage

☐ Council Tax or Rates

☐ Electricity, gas or other fuel bills

☐ Water bill

☐ Telephone bill or TV package (including mobile phone/broadband)

☐ TV licence

☐ Income tax or VAT

☐ The minimum payment on a credit (or store) card

☐ An instalment on a loan from bank, building society or other lender

☐ Other – please write in here: ☐

☐ None of these

18. In the last 12 months, have you used an unauthorised overdraft on any of your current accounts?

Please cross one box only

☐ Yes

☐ No

☐ Not applicable/No current account

19. Finally, in the last 12 months, which (if any) of the following things have you (and your partner) gone without due to a lack of money?

Although not all of the items may be relevant to your situation, this question is based on a standard question used in Government surveys to assess standards of living. Please cross all items that you have gone without partly or entirely due to a lack of money.

Please cross all that apply

☐ A week's annual holiday away from home

☐ Buying new, rather than second hand, clothes

☐ Keeping your home adequately warm in winter

☐ Having friends or family for a drink or meal once a month

☐ A hobby or leisure activity

☐ Replacing a major electrical appliance (e.g. fridge)

☐ Keeping your home in a decent state of decoration

☐ None of these

Section 4: Additional costs arising because of your cancer

In this section, we would like to know about **the costs that you have incurred (or your partner, if you have one, has incurred on your behalf)** as a direct or indirect result of your diagnosis. We do not need to know about any costs that were paid for by someone other than you (or your partner), such as costs paid for by the NHS, insurance or your local authority.

For each question we would like to know about costs arising **during the last 6 months** only (or during the time since your diagnosis if this was less than 6 months ago).

Depending on when you received your diagnosis, you may feel that the greater costs were incurred longer ago than the last 6 months. However, those costs will be reflected in the answers that other people – who will be at different stages since their diagnosis – give to the survey. Your answers, alongside those of others, will allow us to calculate the total costs people face and identify *when* the greatest costs occur.

We don’t need exact costs, just your best estimate, rounded to the nearest pound

If you feel a particular cost relates to more than one question, please only include it in one – the one you feel fits most closely.

20. In the last 6 months, how much have you (or your partner) spent on <u>visits</u> to see healthcare and other practitioners as an <u>outpatient</u> because of your cancer diagnosis or treatment?

These could relate to any kind of treatment, monitoring, tests or practical and emotional support. They could include visits to:

- A GP or other general practice staff, such as a nurse
- A consultant or specialist at a hospital or clinic
- A treatment unit, such as a chemotherapy day unit
- A physiotherapist, occupational therapist, counsellor or a support group
- A dentist
- Or any other practitioner you have seen on an outpatient basis.

For each place you have visited, please fill in the boxes below.

We would like to know the typical travel **costs <u>per visit</u>** (e.g. due to fares or petrol), and any parking or other incidental costs (e.g. drinks bought and phone calls <u>but not treatment</u>).

If you travelled by car and do not know the cost, please give the approximate mileage for each trip. We have included an example.

Place visited	Number of visits <u>in the last 6 months</u>	Travel (including fuel costs) per visit	Parking charges per visit	Incidental costs per visit
Example *GP surgery*	*4*	£ or *15* miles	£ *5*	£ *1*
		£ or miles	£	£
		£ or miles	£	£
		£ or miles	£	£
		£ or miles	£	£
		£ or miles	£	£

☐ Not applicable (x)

21. In the last 6 months, how much have you (or your partner) spent on <u>stays</u> in any hospital, clinic or hospice as an <u>inpatient</u> because of your cancer diagnosis or treatment?

These may have related to treatment, recovery or observation requiring an overnight stay. These might include the costs incurred by your partner (if you have one) in visiting you.

Please tell us the **total cost of <u>each stay</u>** due to travel, parking and any other incidental costs (e.g. food, drink, newspapers, and telephone or television cards).

Again, we have given an example.

If you travelled by car and do not know the cost, please give the approximate mileage for each stay.

Where you stayed	Travel costs per stay	Parking charges per stay	Incidental costs per stay
Example *Hospital*	£ *16* miles	£ *30*	£ *7*
	£ miles	£	£
	£ miles	£	£
	£ miles	£	£
	£ miles	£	£
	£ miles	£	£
	£ miles	£	£

☐ Not applicable (x)

22. In the last 6 months, how much have you spent in total on each of the following things because of your cancer diagnosis or treatment?

Please enter the cost, in £s, in the boxes below.

Treatment and healthcare	Cost	Not applicable (x)
Over-the-counter or prescription medicines (e.g. mouthwash, pain killers or skin creams. Please do not include any medications received on free prescription)	£	☐
Dietary supplements (e.g. tablets or nutritional drinks such as Scandishake or Ensure)	£	☐
Dressings (e.g. wound dressings, Stay Dry pads or sanitary wipes)	£	☐
Private treatment or healthcare (e.g. surgery medications, consultations, convalescent or therapeutic stays, not covered by the NHS or insurance)	£	☐
Dental surgery or care (e.g. any type of dental care not covered by the NHS or insurance)	£	☐
Nursing care provided to you in your home	£	☐
Personal care provided to you in your home (e.g. ‘home help’ or sleep-in or live-in care to help with things like bathing, cooking and shopping)	£	☐
Specialist or replacement clothing		
Wigs, hair-pieces or other head coverings	£	☐
Fabric supports (e.g. surgical brassieres or abdominal or spinal supports)	£	☐
Clothing (e.g. due to weight loss or gain or discomfort)	£	☐
Specialist equipment and modifications		
Modifying your home (e.g. installing an accessible bath/ shower, hand rails or stair lift or widening doorways, or replacing flooring)	£	☐
Specialist equipment for your home or car (e.g. specialist chairs or cushions, kitchen or bathroom aids, walking aids or seatbelt protection)	£	☐

23. And in the last 6 months, how much <u>extra</u> (or less) have you spent <u>in total</u> on each of the following day-to-day costs because of your cancer diagnosis?

Some people may have spent <u>less</u> on some of these things. Therefore at each question there is an option to indicate whether you have spent extra or less.

Please enter the cost, in £s, in the boxes below.

<u>Costs of day-to-day living</u>	Cost	Extra	Less	Not applicable
		(x)		(x)
Food and drink (e.g. because you have needed particular types of food or more food)	£ ☐☐☐☐	☐	☐	☐
Household items (e.g. cleaning products)	£ ☐☐☐☐	☐	☐	☐
Household fuel bills (e.g. electricity, gas) (e.g. because you need to have the heating or lights on more, for example because you are spending more time at home. Please do not include petrol)	£ ☐☐☐☐	☐	☐	☐
Telephone or internet bills (e.g. the use of a mobile phone, or increased use of the internet to keep in touch with family, friends or carers)	£ ☐☐☐☐	☐	☐	☐
Travel costs (e.g. driving or using public transport to get to the shops, see friends or work that you previously would not have needed to use. Please do not include visits to healthcare professionals)	£ ☐☐☐☐	☐	☐	☐
Television or books (e.g. increased use because you are less active or house-bound. This might extend to other leisure activities)	£ ☐☐☐☐	☐	☐	☐
Help around the home or garden (e.g. help with cleaning, and odd jobs around the home and garden that you might previously have done yourself)	£ ☐☐☐☐	☐	☐	☐
Child care	£ ☐☐☐☐	☐	☐	☐

24. In the last 6 months, have you needed to move home because of your cancer diagnosis or treatment?

Please cross one box only

☐ Yes

☐ No

25. And in the last 6 months, have you needed to buy a new car or other motor vehicle because of your cancer diagnosis or treatment?

Please cross one box only

☐ Yes

☐ No

Section 5: Meeting increased costs

This section asks about how you have managed to deal with any extra costs or loss of income you have told us about.

26. Which of the following sources, if any, have you (or your partner) used to help pay for any of the increased costs that you have told us about?

Please cross all that apply

☐ Income from earnings, sick pay, pensions or social security benefits
☐ Income protection insurance (e.g. accident, sickness and unemployment, or critical illness)
☐ Payment protection insurance (e.g. on a mortgage or loan)
☐ Cashing in a pension or other investments
☐ Savings
☐ Grants from charitable organisations, such as Macmillan or AgeUK
☐ Health or medical insurance (held privately or provided by your employer)
☐ A loan or a gift of money from friends or relatives
☐ Selling belongings (e.g. personal items or a car)
☐ Downsizing or selling your home
☐ Other – please write in here:
☐ None of these

27. Which of the following types of borrowing have you (or your partner) used to help pay for any of the increased costs that you have told us about?

Please cross all that apply

☐ A credit (or store) card that is not settled in full each month
☐ An overdraft
☐ An unsecured loan from a bank, building society or finance company (e.g. Norton Finance, Blackhorse)
☐ A loan from a company that collects payments from your home (e.g. Provident, Greenwoods)
☐ A loan from a payday lender or a pawnbroker
☐ A secured loan or second mortgage on your property
☐ A loan from an unlicensed lender who charges interest, such as loan shark
☐ Other – please write in here:
☐ None of these

28. And since your diagnosis, which (if any) of the following organisations have you sought any advice from about <u>money or debt</u>?

For each one you have used please <u>rate</u> how helpful you found the advice on the scale from 1 to 5. Please include any advice received in person, over the phone or online.

	Very unhelpful 1	2	Neither helpful nor unhelpful 3	4	Very helpful 5
Macmillan Cancer Support	☐	☐	☐	☐	☐
A free advice agency (e.g. Citizens Advice Bureau, debt advice agency, law centre)	☐	☐	☐	☐	☐
A bank, building society or other financial services provider	☐	☐	☐	☐	☐
A fee-charging debt advice company	☐	☐	☐	☐	☐
An insolvency practitioner	☐	☐	☐	☐	☐
A financial advisor (e.g. Independent Financial Advisor)	☐	☐	☐	☐	☐
An accountant or lawyer	☐	☐	☐	☐	☐
Friends, relatives or work colleagues	☐	☐	☐	☐	☐
Another source	☐	☐	☐	☐	☐

☐ Wanted advice but none sought
☐ Sought advice but none received
☐ None of these

→ GO TO QUESTION 30

29. And overall, has the impact of this advice on your household's general financial situation been positive or negative?

Please cross the box that most closely reflects your situation

Negative impact 1	2	Neither 3	4	Positive impact 5
☐	☐	☐	☐	☐

☐ Not applicable / no advice

Section 6: Your quality of life

This section asks about the impact of your cancer diagnosis on your quality of life.

For each question, please choose the answer that fits your situation the best. If you are unsure about which response to give to a question, the first response you think of is often the best one.

30. On a scale of 1 to 5, how would you rate your quality of life at the moment?

Very poor		Neither		Very good
1	2	3	4	5
☐	☐	☐	☐	☐

31. Overall, do you feel that your cancer diagnosis has made your quality of life worse or better?

Much worse		Neither/both		Much better
1	2	3	4	5
☐	☐	☐	☐	☐

32. And do you feel that the financial impact of your cancer diagnosis has made your quality of life worse or better?

Much worse		Neither/both		Much better
1	2	3	4	5
☐	☐	☐	☐	☐

Section 7: To finish

33. If there is anything that you would like to add about the financial costs or impacts that have arisen because of your diagnosis or treatment, please tell us in the box below.

For example, have we missed any particular costs or would you like to provide any further information about costs that you told us about?

34. For monitoring purposes, please indicate which one of the following best describes you.

Please cross one box only

- ☐ White – British
- ☐ White – Irish
- ☐ White – other White background
- ☐ Mixed
- ☐ Asian or Asian British
- ☐ Black or Black British
- ☐ Chinese
- ☐ Other
- ☐ Can't say/prefer not to say

Macmillan may like to undertake future research on the topics covered in this questionnaire. This research is likely to be conducted by a research organisation on their behalf.

35. Would you be happy to be contacted in relation to future research on related topics?

This would mean passing your contact details to Macmillan and a research agency for this purpose. Please be assured that your contact details will be held securely in accordance with the Data Protection Act and the Market Research Society code of conduct at all times. **Please note that you are not committing to take part in follow up research, only that you are happy to be contacted in relation to this.**

- ☐ Yes
- ☐ No

36. Would you be happy for Macmillan and the research agency to re-contact you based on the answers you have given in this questionnaire? This would mean linking your survey responses to your contact details (via a unique serial number) for this purpose.

Your contact details will be stored separately from your survey responses at all times and will be held securely in accordance with the Data Protection Act and the Market Research Society code of conduct. Any follow up will only be based on responses provided in this survey and not in relation to any other surveys.

- ☐ Yes
- ☐ No

Thank you for completing the questionnaire

Please return it to us in the envelope provided by Thursday 25th October