Ipsos MORI
Social Research Institute

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National Cancer Survivorship Initiative

Evaluation of Adult Cancer Aftercare Services - Wave 1 Report

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Executive Summary

This report presents the findings from the first wave of a service evaluation study commissioned by NHS Improvement, which aims to provide a baseline for the 11 tumour projects within the seven Test Communities (TCs) which are currently testing a new model of care which includes risk stratified care pathways in Adult Cancer Survivorship services, as part of the National Cancer Survivorship Initiative.

The research was conducted using a quantitative methodology. A 12-page postal questionnaire was sent to 1,862 eligible patients across 11 tumour projects at 7 TCs. A total of 1,301 completed questionnaires were received back, representing an adjusted response rate of 70%. Further details can be found in the methodology section.

Overall quality of care

Overall, patients were positive about the quality of care and services they had received, since their initial treatment finished. Almost six in ten (59%) rated it as ‘very good’ or ‘excellent’. However, with the service provided to patients particularly important, the six percent of patients who felt that they had received, at best, a poor service should not be overlooked.

In particular, prostate cancer patients were less likely to say that they had received a ‘very good’ or ‘excellent’ service. Only half reported this (53%), compared to two-thirds (66%) of colorectal cancer and three-fifths (61%) of breast cancer patients.

Patients cited a range of issues that could lead to improvements in overall care, such as more information or advice (9%) or improvements to care, aftercare or care plan (5%).

Patients’ need for advice and support

Positively, almost eight in ten patients felt that they did have all the information, advice and support they needed in order to manage their health (78%).

Beyond this, large proportions of patients had not had, but did not need information, advice or support to:

- Help them to continue living in their own home (74%).
- Cope with their financial issues (71%).
- Help them with the other practical things (71%).

However, there appears to be an information deficit in terms of providing patients with all the information they need about the signs of symptoms of the cancer. More than one third (37%) did not feel that they had all the information they need to identify the signs and symptoms of the cancer coming back.

Only a very small proportion of patients (5%) said that they have received any information too late for it to be of use.

Self-managed care

Overall, a large majority of patients (83%) said that they were confident managing their own health.

Across a range of problems that patients had experienced, either since their initial diagnosis for cancer or since their initial treatment had finished, patients displayed a greater ability to self-manage some problems.

For example, more than four in ten patients (42%) who did less physical activity or exercise, since their diagnosis, had taken action themselves to do more. Similarly, a third (34%) of patients who had noticed a change in their weight, compared to pre-diagnosis, had taken action themselves to deal with this.

However, patients are much less able to deal with some other issues, namely:

- Around one in eight (12%) who have experienced a fear that the cancer will come back have dealt with this by themselves.
- Only one in ten (10%) experiencing a change in their interest in sex (that they were not happy with) have taken action themselves to improve this.
- Just five-percent (5%) of patients who have had problems with erectile function since before their diagnosis have taken action themselves.

Indeed, more than four in ten (45%) of patients who have experienced erectile function problems since their diagnosis have not done anything in particular and continued to have problems.

Contact with health professionals

Only around one in five (21%) patients reported having a care plan. However, of those who did have a care plan, the overwhelming majority (84%) did say that it is useful. The presence of a care plan is a factor in a number of different aspects of patients' experience of aftercare services.

Over three-quarters of patients (77%) said they did know who to contact during office hours if they have a concern related to their cancer or their treatment for it, and a further ten per cent said they do not know, but would know how to find out. Almost half of patients (47%) had contacted somebody during office hours – and seven in ten (71%) had contacted their cancer hospital nurse, whilst two-fifths (38%) have contacted their GP.

When it comes to contact out of hours, a much lower proportion of patients said they do know who to contact (only 38%), although one in five (20%) do know how to find out. Only one in seven (14%) had ever had to contact somebody out of office hours with a concern related to their cancer or their treatment for it. Almost six in ten (59%) had contacted the hospital whilst approaching three in ten (28%) had contacted their GP or out of hours service.

More than half of patients (53%) had not contacted their GP in the last 6 months with a concern about their cancer or treatment for it, whilst 38% had done so between one and five times.

Background and Objectives

Background and Objectives

Background

Ipsos MORI was commissioned by NHS Improvement in January 2011 to conduct a service evaluation of Adult Cancer Survivorship services. This was part of an ongoing programme testing a new and improved model of care, for the National Cancer Survivorship Initiative (NCSI), as part of the wider Cancer Programme NHS Improvement is currently engaged in.

NHS Improvement was established in 2008 and works across the NHS with clinical teams to improve quality, impact and effectiveness of service delivery. The Cancer Programme is one of NHS Improvement's five main programmes, and seeks to deliver the aims of good practice, increased impact and value for money within the specific field of cancer treatment.

The Cancer Survivorship Initiative is one of the Cancer Programme's three national priorities for 2009-2010 which is considering a range of approaches to survivorship care and how these can best be tailored to meet individual patients' needs. The focus of Cancer Survivorship is on helping people who have been diagnosed with cancer beyond their treatment; to adapt to any health consequences and to monitor symptoms that might indicate reoccurrences or other associated health problems. The initiative is promoting 'five key shifts':

- a cultural and attitudinal shift to focus on health and recovery;
- a shift towards improving information;
- a shift towards assessment and care planning;
- to shift towards providing tailored care pathways based on risk of future problems associated with the type of cancer, the type of treatment and the particular circumstances of the individual;
- a shift towards improved measurement through patient reported outcome and experience measures.

These 'shifts' are reflected in the work of a number of test communities which have been piloting survivorship projects during 2009 and 2010 and which have led to the development of ' care pathways', which commenced in December 2010 in seven Test Communities (TCs). These TCs are testing risk stratified pathways of care with the aim, where appropriate, of shifting from a medical to a supported self-management model of care. As with all exploratory projects it is essential that the effectiveness and impact of the pathways is systematically evaluated, and this study is one of a range of activities being undertaken to make sure all learning is captured and interpreted.

These new, risk stratified pathways of care were launched across the TCs in April 2011, just prior to the launch of this survey.

Objectives

The overarching objective of this research project is to evaluate the seven TCs established as part of the National Cancer Survivorship initiative. In order to do this a quantitative survey is being conducted. This will be conducted in two waves. The first wave is designed to establish a ‘baseline’ level of findings, against which results achieved in the follow-up wave can be compared. This report presents the findings from the initial baseline survey.

The study was designed to collect information on several broad areas of patient experience of aftercare:

- the **care patients received;**
- **contact between patients and the NHS during aftercare;**
- to what extent patients feel able to and are comfortable in **managing their own health**; and
- The **need for information** amongst patients – do any areas have an information deficit or overload?

In addition, the research is designed to compare and contrast the approaches being taken across the 3 pathways and the 7 TCs trialling the new method of aftercare service delivery.

Methodology

Methodology

A quantitative approach was chosen as the most appropriate methodology with which to collect the robust data necessary to evaluate the improvement programmes being implemented by the TCs. In this chapter we detail the sampling approach taken, along with information on data collection and advice on interpretation and analysis of results.

The survey was conducted across a total of eleven cancer pathways, across the seven TCs involved in this study. Below we detail the cancer pathways considered at each TC for the purpose of this evaluation, but it is important to note that these are not the only tumour groups treated at each of these sites.

- **Brighton and Sussex University Hospitals NHS Trust** – Breast Cancer;
- **North Bristol Hospital NHS Trust –** Breast Cancer, Colorectal Cancer, and Prostate Cancer;
- **Guy's and St Thomas' NHS Foundation Trust** – Colorectal Cancer;
- **Hillingdon Hospital NHS Trust** – Breast Cancer and Prostate Cancer;
- **Hull and East Yorkshire Hospitals NHS Trust** – Breast Cancer;
- **Ipswich Hospital NHS Trust –** Breast Cancer and Prostate Cancer; and
- **Luton and Dunstable NHS Foundation Trust** – Prostate Cancer.

Throughout this report we refer to the cancer types and hospitals involved at three different levels, defined here as follows:

- **Tumour Group** - this is the cancer type a patient has been treated for, in this case breast cancer, colorectal cancer or prostate cancer;
- **Test Community (TC) –** each of the seven sites involved in the study; and
- **Tumour Project** – this is the tumour group at an individual TC. For example, the TC at Bristol consists of 3 tumour projects.

Sampling of Patients

Sampling was conducted by the TCs, following instructions, advice and guidance provided by Ipsos MORI. The TCs were directed to randomly select 180 patients within each cancer pathway[1]. A step-by-step guide on how to draw a random sample is drawn was sent to each test site.

Once the initial sample of 180 patients had been drawn, a DBS[2] check was then performed in order to ensure, as far as possible, that any patients who had recently passed away were excluded from the survey. In addition, Ipsos MORI asked that each TC requested a DBS check to be run on all of the selected patients prior to the dispatch of each reminder letter, and any patients were removed from the sample.

Data Collection

Fieldwork was conducted between 21 April 2011 and 2 September 2011, using a 12-page paper questionnaire. The questionnaire was designed in collaboration between Ipsos MORI and NHS Improvement, and the final version of the questionnaire is included in the appendices to this report. All questionnaires were sent out with a personalised cover letter, which was signed by a person with appropriate authority within each TC, such as the Lead Oncologist for example, and a pre-paid Business Reply Envelope.

Prior to the beginning of fieldwork, the questionnaire was cognitively tested by Ipsos MORI. A total of five patients (2 Breast, 1 Colorectal and 1 Prostate) from across the pathways were observed completing the draft questionnaire, and then had the opportunity to discuss the content, wording and layout with a member of the Ipsos MORI research team. This feedback was taken into consideration when producing the final version of the questionnaire.

Ipsos MORI produced the questionnaires for all TCs. Ipsos MORI also produced and dispatched the covering letters for Bristol, Hull and Luton, whilst the TCs themselves chose to produce the personalised letters at Brighton, Guy's and St Thomas', Hillingdon and Ipswich, and dispatch their own questionnaire packs.

Fieldwork began on a staggered basis, with Hull being the first to be dispatched on 21 April 2011, whilst Ipswich was the final TC to go into field on 27 July 2011, due to the differing timescales involved with the preparation of the sample from each TC. Two reminder letters,

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[1] In order to ensure that once a Demographics Batch Service (DBS) check had been run, a sample of

[2] The DBS check enabled PTCs to ensure that patients who had passed away at home, or in the care of another NHS Trust or private facility had also been excluded from the sample.

complete with questionnaires, were sent out to all non-respondents at intervals during the fieldwork period.

Mail out	Number of returns	% of returns	% of sample
Initial (1)	928	71%	50%
First reminder (2)	272	21%	15%
Second reminder (3)	101	8%	5%
Total	**1,301**	**100%**	**70%**

The sample sizes and response rates for each of the cancer pathways across each of the seven TCs. Sample sizes have been adjusted by removing any patients included who were subsequently found to be ineligible for the survey[3]. As the table illustrates, all pathways achieved a response rate of at least 60%.

Test Community	Pathway	Adjusted Sample size	Valid Returns	Response Rate
Brighton	Breast	176	**127**	**72%**
Bristol	**TC Overall**	**499**	**372**	**75%**
	Breast	169	**121**	**72%**
	Colorectal	164	**121**	**74%**
	Prostate	166	**130**	**78%**
Guys	Colorectal	171	**108**	**63%**
Hillingdon	**TC Overall**	**334**	**210**	**63%**
	Breast	165	**105**	**64%**
	Prostate	169	**105**	**62%**
Hull	Breast	157	**107**	**68%**
Luton	Prostate	172	**119**	**69%**
Ipswich	**TC Overall**	**353**	**258**	**73%**
	Breast	179	**129**	**72%**
	Prostate	174	**129**	**74%**
OVERALL		**1,862**	**1,301**	**70%**

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[3] 'Ineligible' patients include those who had since passed away, or patients who notified us that they had received their treatment and aftercare from a site outside of the PTC at which they had been diagnosed.

Presentation and Interpretation of Quantitative Data

A further explanation of statistical reliability is appended, but it should be remembered at all times that a sample, rather than the entire population of patients across the TCs, has taken part in the survey. As a consequence, all results are subject to sampling tolerances, which means that not all differences are significant. Only differences that have been tested to be statistically significant at the 95% level of confidence are reported.

By way of illustrating this, the margin of error for the overall quality of care question is shown in the table below.

Question	Patients reporting “excellent/very good”	Confidence Interval
Overall, how would you rate the quality of care and services you have received since your initial treatment finished?	59%	+/- 2.3 percentage points

Throughout the report, where percentages do not sum to 100, this may be due to computer rounding, the exclusion of “don’t know” or “not stated” categories, or multiple answers. Throughout the report an asterisk (*) denotes any value of less than half of one per cent, but greater than zero. Where reference is made to “net” figures, this represents the balance of opinion on attitudinal questions, and provides a particularly useful means of comparing the results for a number of variables.

In addition, the data has been cleaned, and edited, as is necessary in all postal surveys, in accordance with the routing on the questionnaire, as well as to correct for other issues that emerged during the course of data processing. Further details of the data editing that has been applied to the data set are included in the appendices to this report.

Answers to the five free-text questions have been assigned to codes, and included in the figures.

No weighting has been applied to the data.

Acknowledgements

Ipsos MORI would like to thank Gilmour Frew, Anne Wilkinson, and Vanessa Brown at NHS Improvement for their assistance and guidance in developing the questionnaire and their continued input throughout the project. In addition, Adam Glasser at NHS Improvement provided valuable input to the design of the questionnaire. We would also like to thank the staff at each of the seven Test Communities for their assistance in compiling patient lists. In

addition, we also extend our thanks to all those patients who took part in our project, both in the cognitive testing stage, and by completing the survey, without whom this project would not have been possible.

Publication of findings

Our standard Terms and Conditions apply to this, as to all studies we carry out. Compliance with the MRS Code of Conduct and our clearing is necessary of any copy or data for publication, web-siting or press releases which contain any data derived from Ipsos MORI research. This is to protect your reputation and integrity as much as our own. We recognise that it is in no-one's best interests to have findings published which could be misinterpreted, or could appear to be inaccurately, or misleadingly, presented.

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Checked & Approved:	*Josh Keith*
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Overall quality of care

Overall quality of care

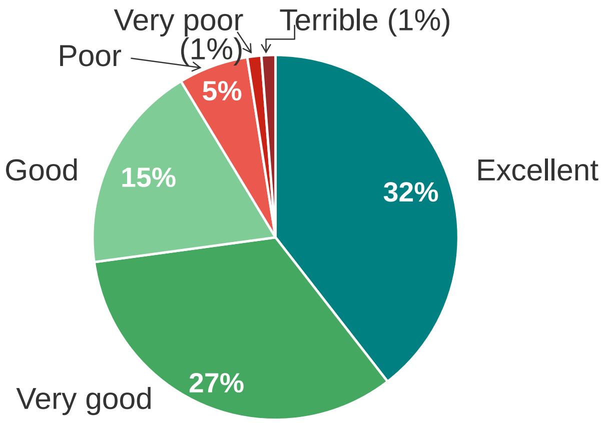
At the beginning of the survey, patients were first asked to think about the overall quality of the care and services that they had received since the completion of their initial treatment for cancer. This was asked before respondents were prompted to think in detail about the different aspects of their care. In this chapter we examine patients' thoughts on their care, first at the overall level, then across the three tumour types, and then finally between each of the seven TCs.

Care overall

Overall, patients reported being happy with the quality of care and services that they had received as part of their aftercare programme, that is, since the end of their initial treatment. A high proportion of patients, almost six in ten (59%), rated the care and services they received as 'excellent' or 'very good'. If this is extended to include those rating their care as 'good', then the proportion rises to almost three-quarters (74%) of patients. However, it is important not to overlook the small, but nonetheless important, minority who rated their care as 'poor', 'very poor', or 'terrible' (6%)[4].

Overall quality of care

Overall, how would you rate the quality of the care and services you have received since your initial treatment finished?



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

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[4] Please not that the figures in the chart do not sum to 100 as 19% of patients who responded chose not to answer this question.

Tumour Group

There are marked differences in the quality of care received by patients in different tumour groups. The data collected shows significant differences in how patients rate the quality of their care based on the tumour they were treated for. Both breast (61% excellent or very good) and colorectal (66% excellent or very good) cancer patients were more positive about the quality of their care than prostate cancer patients (53% excellent or very good). Furthermore, male patients were less positive about the quality of their care than female patients, reflecting the lower score amongst prostate cancer patients, a group composed entirely of male patients.

Test Community Differences

The highest performing TC on this initial measure is Hull, three-quarters (74%) of whose patients thought their care had been excellent or very good. Ipswich has the lowest score, with under half (42%) of patients rating their care as excellent or very good. The fact that Ipswich and Luton are the lowest scoring TCs can be partially linked to these being two of the only three TCs at which prostate cancer patients were included. As we have already illustrated above, prostate cancer patients were less positive. In addition it is important to consider the high proportion of prostate cancer (and therefore Ipswich and Luton) patients who chose not to answer this question[5]. Given the high ratings other patients gave to their care and services, it is possible that this reflects an underlying unwillingness to report dissatisfaction amongst patients. This is certainly worthy of further investigation.

At first examination, TC appears to have more effect on perceived quality of care than tumour group. When examining the results within the TCs, there are no significant differences across the pathways for those TCs that deal with more than one tumour group.

However, when comparing the same tumour groups from the different TCs, there are some significant differences, reflecting the differences between TCs at the overall level.

- **Breast cancer** – ranges from 74% (Hull) to 63% (Brighton);
- **Colorectal cancer** – ranges from 68% (Guy's) to 64% (Bristol); and
- **Prostate Cancer** – ranges from 62% (Bristol) to 40% (Ipswich).

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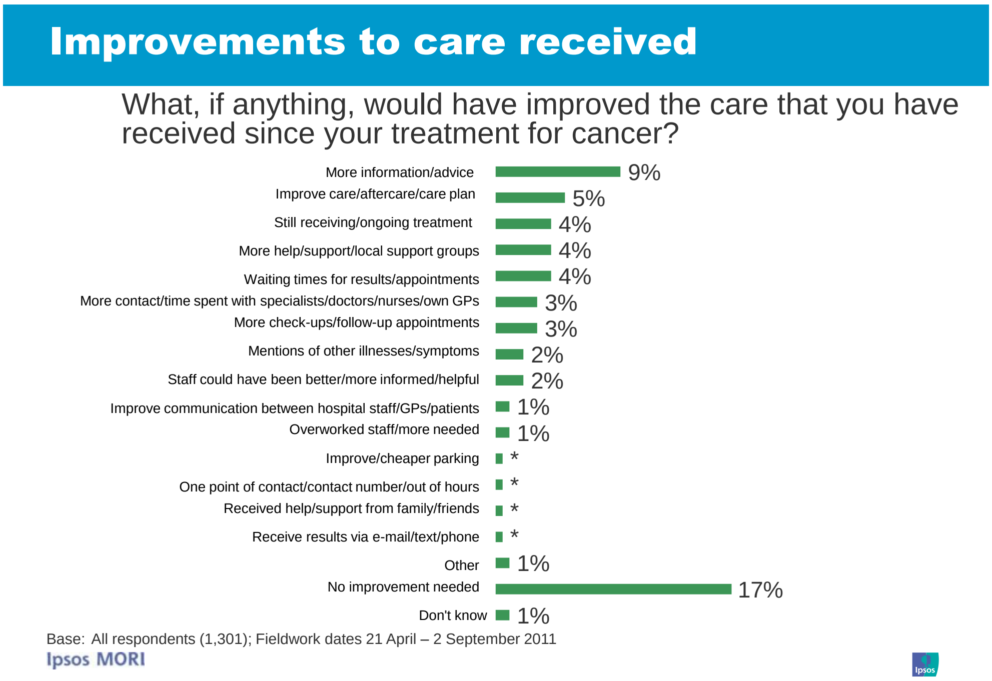
[5] 38% of patients at Ipswich, 24% of patients at Luton, and 24% of Prostate cancer patients overall did not answer this question.

This indicates that while tumour group does indeed have an impact on patients' perception of care, when this is controlled for, the TC does indeed have a significant role in shaping satisfaction.

Improvements to care

Respondents were given the opportunity to suggest what, if anything, would have improved the care they had received since the completion of their treatment for cancer. The very positive attitude of the majority of patients taking part in this study is reflected in the proportion of patients who either did not answer this question (55%), or who gave an answer that falls into the category that "No improvement is needed" (17%).

However, of those who suggested improvements, several focussed on the nature of contact between patients and healthcare specialists. For example, approaching one in ten (9%) of patients reported that they would have liked **more information/advice**, and this is a theme that we will examine in greater detail in the following chapter. Other improvements suggested are more general, such as **improve care/aftercare/care plan** (5%).


Improvements to care received

What, if anything, would have improved the care that you have received since your treatment for cancer?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

There are some differences across the demographic sub-groups, for example, Female patients were more likely than men (2%), and patients overall (4%), to say they would have liked more help/support/local support groups (5%). Additionally, patients aged 36-60 were more likely to identify this aspect as in need of improvement (6% compared to 4% of patients overall).

By comparing answers to this question with response from other key questions in the survey, we are able to gain more understanding of the results, and how perceptions of the quality of care could be improved. Patients rating the overall quality of their care as good (15%) were more likely than patients who rate their care as very good/excellent (6%) and patients overall (9%) to say they would have liked more information/advice. Similarly, patients who did not recall having a care plan and those who said they are not confident in managing their own health were more likely to want more information/advice than patients overall (11%, 14% and 9% respectively).

Tumour groups and Test Communities

Suggested improvements to care are very similar across both the tumour groups and the TCs, with one of the very few significant differences being that patients treated at Luton are more likely to have said that improving care/aftercare/care plan would have improved the overall quality of their care.

Thus, the overall picture is a positive one, but so far the data has provided little insight to the issues that patients face during aftercare, and how each of these is dealt with. We begin to reflect on this in the following chapter, where we examine patients' need for advice and support, and who delivers it.

Patients' need for advice and support

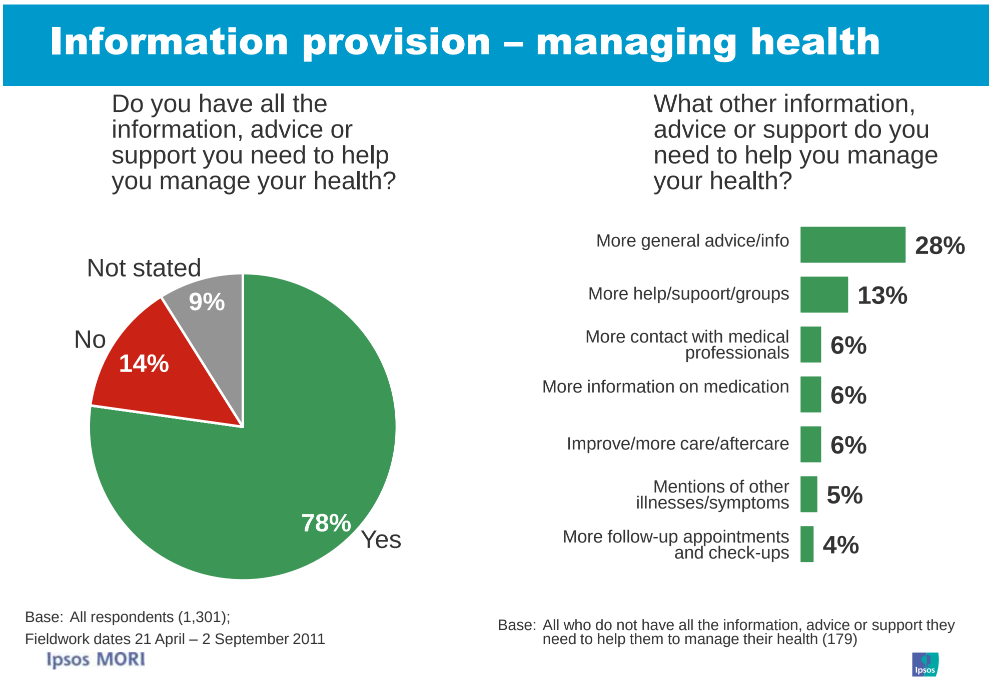
Patients’ need for advice and support

In a system that is moving towards increased dependency on patients’ self-managing their aftercare, it is important to establish the gaps in information and what types of advice and support patients currently make use of. This is our main concern in this chapter, and as we examine each issue we will first present the overall picture, before looking at the three tumour groups and finally the seven TCs. This will also enable us to begin to understand the factors contributing to the overall satisfaction with the care received.

Information provision

Patients taking part in the survey were asked whether they felt that they had all of the information, advice or support that they need to help manage their health. And, overall more than three-quarters (78%) of patients agreed that they do. This is roughly comparable to the almost nine-tenths (88%) of respondents to the National Cancer Patient Experience Survey (2010) who reported that they had been given ‘the right amount’ of information about their condition and treatment[6].

Those patients who did not feel that they had all the information, advice or support necessary to help them manage their own health were asked to specify what they thought to be lacking. The most frequently cited improvement is more general advice/information (28%), whilst one in eight patients (13%) felt that they needed more help/support groups.



Base: All respondents (1,301);
Fieldwork dates 21 April – 2 September 2011

Base: All who do not have all the information, advice or support they need to help them to manage their health (179)

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[6] National Cancer Patient Experience Survey (2010) available from http://www.quality-health.co.uk/images/stories/pdfs/NCPES4.pdf - last accessed on 28 September 2011

Beyond this, the other main issues also focussed on quantity of information provided or frequency of contact.

There are some differences between the genders here, female patients were significantly more likely to say that they needed **more help/support/groups,** with one-fifth (20%) of female patients reporting this compared to less than one in ten male patients (7%) and only an eighth of patients overall (13%)[7]. The role of a care plan in helping to ensure patients received the necessary information, advice and support is evident here. More than nine in ten (93%) patients with a care plan felt they did have all the information, advice or support to help them manage their health, compared to three-quarters (76%) of patients who said they don't have a care plan (and 78% of patients overall).

Tumour Groups

Tumour group does not have an impact here with patients across all three equally likely to feel that they do have all of the necessary information to manage their health. In terms of the information needs that are not being met, there is also no variation across the tumour groups.

Test Communities

When TC is taken into account a few differences emerge. Patients at Brighton were the most likely to feel that they do have all the information, advice or support that they needed to manage their own health. Well over eight in ten (86%) reported this, compared to 78% overall, 77% at Hillingdon, and 76% at both Bristol and Ipswich.

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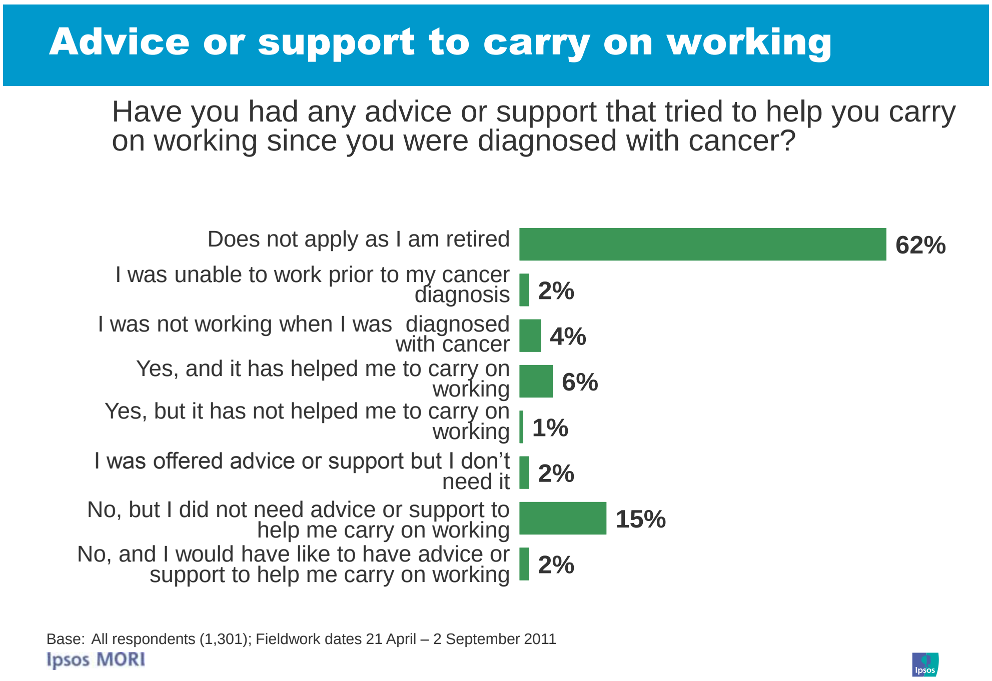
[7] N.B. Base sizes are under 100 so please use caution when interpreting the results.

Help to carry on working

Only, a very small proportion (7%) of patients had received any advice or support to help them carry on working since they were diagnosed with cancer. A large proportion of patients, almost seven in ten (68%), reported that they were either already retired, already unable to work or were not working when they were diagnosed with cancer.

Furthermore, whilst around one in six patients (17%) reported either that they did not receive any advice or support to continue working, only 2% said that they would have liked to receive advice or support on this issue.

As would be expected, patients who did not feel confident managing their own health were more likely to say that they would have liked advice or support to help them continue working than patients who were confident managing their own health (7% compared to 2% of patients who are confident in managing their own health).



Advice or support to carry on working

Have you had any advice or support that tried to help you carry on working since you were diagnosed with cancer?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

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Tumour Groups

There is only one difference appearing across the tumour groups. Patients who had been treated for breast cancer were more likely to say that they did receive advice or support that helped them to carry on working (8% compared to 6% overall).

Test Communities

There are few differences of note across the TCs. Patients at Brighton were the most likely to feel that they did not receive any advice or support, but that they did not need it (24% compared to 15% overall). At Hull, on the other hand, more patients feel that they were offered advice or support to help them carry on working that they did not need (5% compare to just 2% overall). Whilst only a very small proportion, this perception of excess information is important, and will be essential to revisit in Wave 2. If patients receive more information than they need, the risk of them overlooking an important piece of information may well increase.

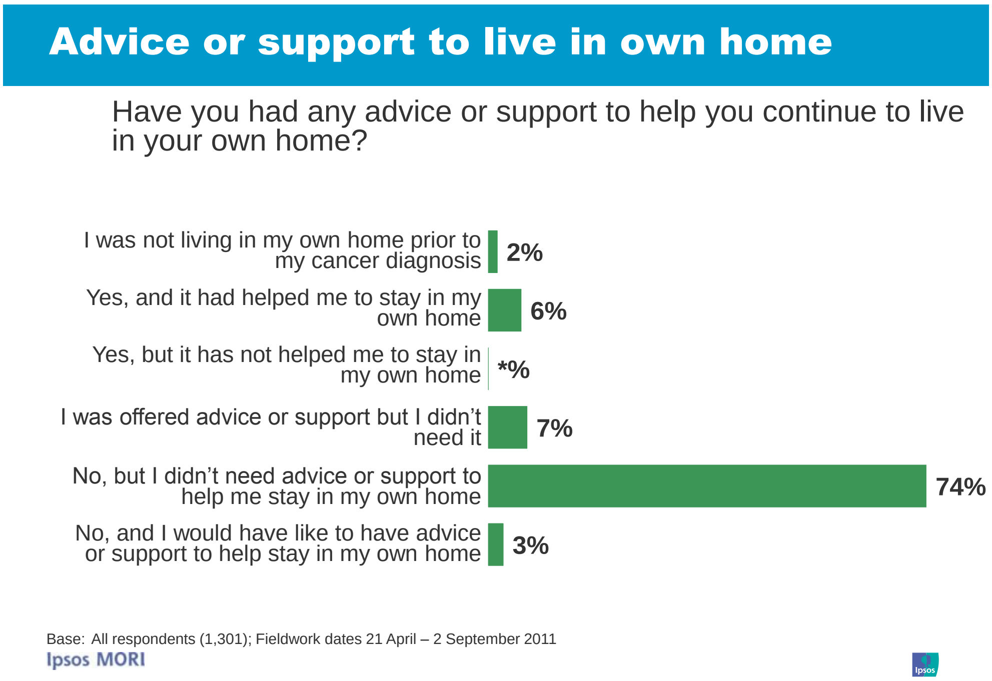
Around one in twelve breast cancer patients from Hillingdon (8%) reported that they did not receive advice or support to help them carry on working and would have liked to. This is compared to just 2% of patients overall, and between 1% and 3% across the other pathways at each TC.

Living in own home

As with the need for advice or support to help patients continue working, a large proportion of respondents did not feel that they needed any help to continue to live in their own home, almost three-quarters (73%) don’t.

Only a small minority of patients reported that they did not receive advice or support on this issue and that they would have liked to have done so (3%), and patients not confident managing their own health were more likely to be in this group (9%).

Furthermore, patients with a care plan are more likely to have reported having received advice or support that helped them to stay in their own home (8%) than those without a care plan (5%). The issue of care plans and how useful patients have found these will be discussed in greater deal later in this report, but these findings indicate that they are important.


Advice or support to live in own home

Have you had any advice or support to help you continue to live in your own home?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

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Perhaps unsurprisingly, patients aged 76+ were the most likely to have received advice or support that had helped them to continue living in their own home (11% vs 6% overall).

Tumour Groups

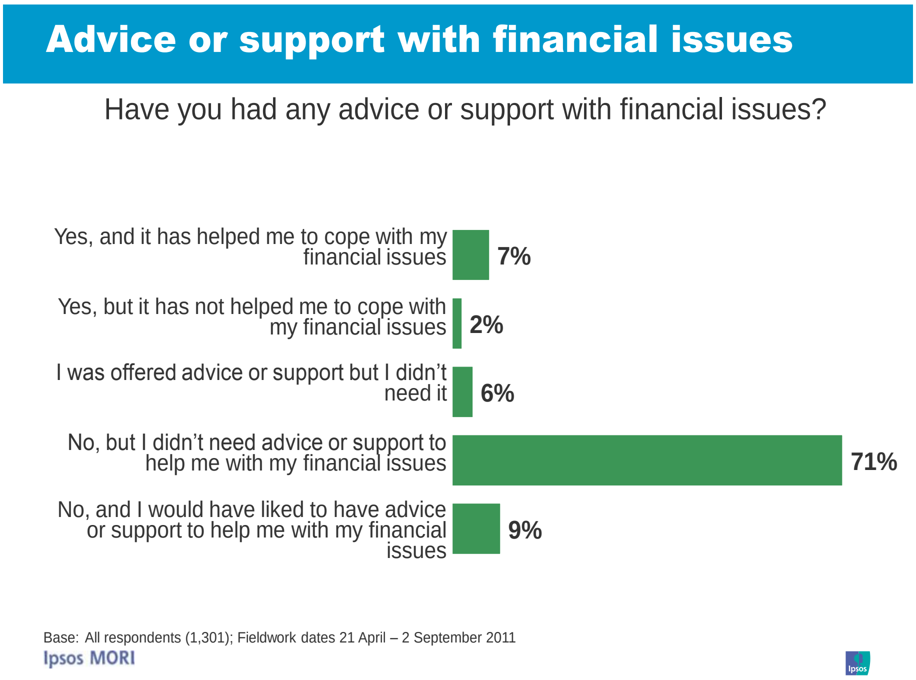
There is not a large amount of variation across the tumour groups. However, breast cancer patients were more likely to report not having received any unnecessary advice or support to continue living in their own home (77%) than patients overall (74%). One in ten colorectal cancer patients (10%) reported that they were offered advice or support but didn't need it (compared to 7% overall).

Test Communities

At the TC level, patients treated at Guy's and St Thomas' (13%) were more likely than patients overall (7%), or at Bristol (6%), Ipswich (6%) and Luton (5%), to have been offered advice or support that they did not need.

Advice with financial issues

On the whole, patients appeared to be happy dealing with any financial issues. More than seven in ten patients (71%) said that they did not receive any advice or support with financial issues, but did not need any. However, almost one in ten (9%) did not receive any advice or support **and would have liked to**. Patients aged 36-60 (17%) were more likely to report this than patients overall. The majority of this age-group is likely to be in work or have been in work before being diagnosed. This means that they need help coping with loss of salary through leaving work or reducing their hours, and the knock-on effect this can have on mortgage payments, amongst other things.



Advice or support with financial issues

Have you had any advice or support with financial issues?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

By way of comparison here, a similar question was asked on the National Cancer Patient Experience Survey in 2010. Half (50%) of respondents reported that they did not receive information from hospital staff about how to get financial help or benefits, and would have liked to[8].

As we have seen previously, confidence is important. A higher proportion of patients confident in managing their own health said that they didn't need help to cope with their financial issues than patients who are not confident (75% vs 58%).

Another positive point is that the proportion of patients who received advice or support that **did not** help them with their financial issues is very small (2%).

Tumour Groups

Across the tumour groups colorectal cancer patients (16%) were more likely than patients overall (9%) and patients of the other two pathways (breast 10%; prostate 6%) to say that they didn't receive advice or support with their financial issues, but that they would have liked to.

Test Communities

Patients being treated at Guy's and St Thomas' were more likely to feel that they didn't receive the advice or support that they needed to help with their financial issues, than patients being treated at almost all of the other TCs. More than one in five patients at Guy's and St Thomas' (22%) reported this compared to less than one in ten overall (9%).

Comparing the different tumour projects across the TCs helps us better understand what is shaping this feeling –colorectal cancer patients at Guy's and St Thomas' were more likely to feel this (22%) than colorectal cancer patients at Bristol (11%). Thus while colorectal cancer patients are more likely to lack the support they need, this difference is exacerbated by TC. Breast cancer patients at Hull were more likely than patients overall (6% vs 2%) to have received advice or support that did not help them to cope with their financial issues.

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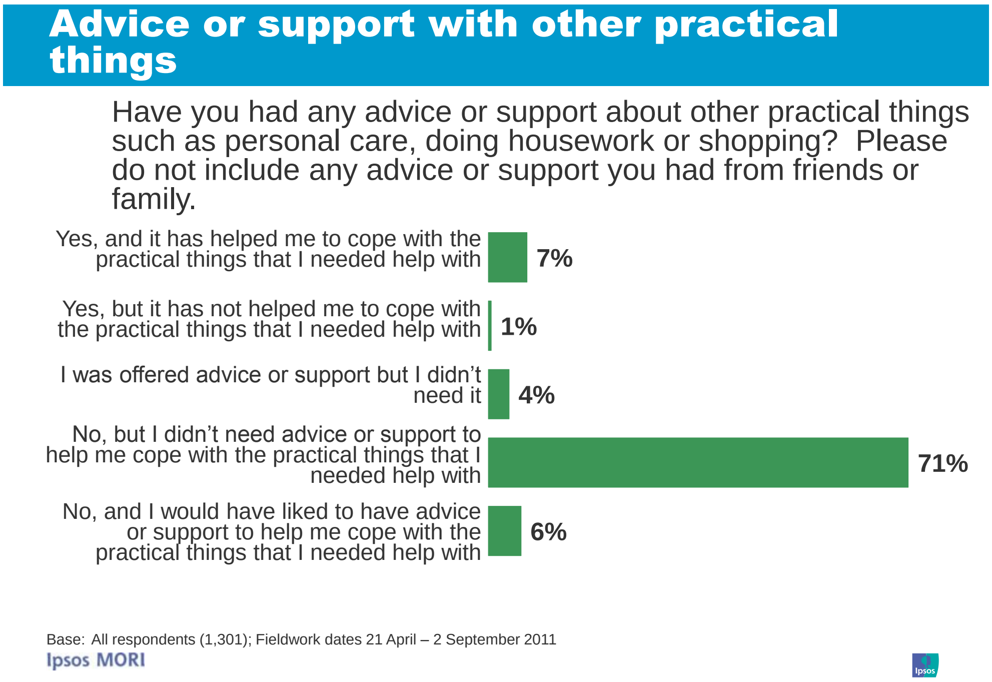
[8] National Cancer Patient Experience Survey (2010) available from http://www.quality-health.co.uk/images/stories/pdfs/NCPES4.pdf - last accessed on 28 September 2011

Advice for practical things

More than seven in ten (71%) patients felt that they have not received any advice or support to help them cope with practical things, such as housework or shopping, but that they have not needed any. A small minority (6%) didn't receive any advice or support and would have liked some.



Advice or support with other practical things

Have you had any advice or support about other practical things such as personal care, doing housework or shopping? Please do not include any advice or support you had from friends or family.

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

As with the other issues discussed in this chapter, the confidence of a patient in managing their own health is linked to whether or not they feel that they have received the necessary advice or support, or if they have needed any. More than three-quarters (77%) of patients confident managing their own health didn't receive any advice or support but didn't need any, compared to just over half (52%) of those who are not confident.

Tumour Groups

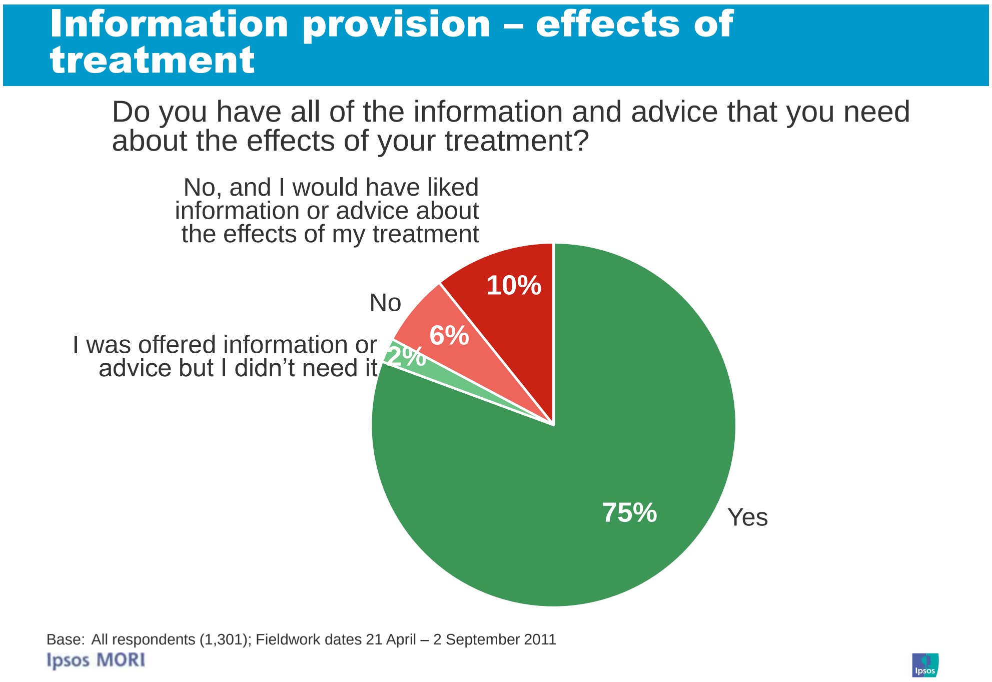
At the tumour group level, the only difference of note is that colorectal cancer patients were the most likely to have been offered advice or support but not needed it (10%) compared to 6% of patients overall.

Test Communities

There were little differences between the TCs on this measure, but patients at Guy's and St Thomas' were the most likely to report that they have received advice or support that has helped them cope with practical things (15%) compared to 7% overall. This reflects the fact that Guy's and St Thomas' is a colorectal tumour group only TC.

Information on effects of treatment

Continuing the general theme that patients appear to feel that they do have the necessary information and advice – three-quarters (75%) felt that they have all the information and advice they need about the effects of their treatment.



Information provision – effects of treatment

Do you have all of the information and advice that you need about the effects of your treatment?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

However, a fairly small yet important minority (16%) of patients felt that they did not have all the information that they need. Those patients who said they are not confident managing their own health feel that they would have liked more information or advice about the effects of their treatment. More than one-quarter (27%) of patients who were not confident managing their own health felt that they didn't receive information but would have liked some, compared to ten percent (10%) overall.

Tumour Group

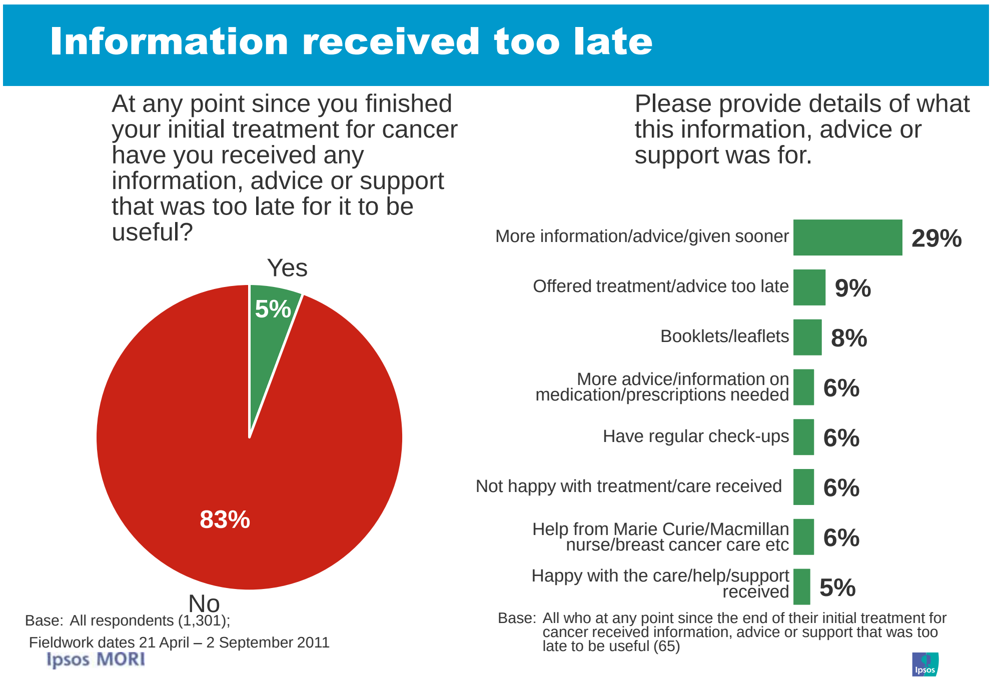
Breast cancer patients felt the most informed about the effects of their treatment (81% say they have all the information compared to 75% overall).

Test Communities

At the TC level, the tumour group differences are further reflected; patients at Brighton were most likely to feel that they have all the information and advice about the effects of their treatment that they needed (87% compared to 75% overall). On the other hand, colorectal cancer patients at Bristol were more likely to feel that they did not have all the information or advice that they needed (14%). However they did not necessarily feel that they would have liked more information or advice.

Information received too late

As well as receiving sufficient information, it is also very important that patients receive the information they need in a timely fashion. Information being received too late to enable any action to be taken would be a cause for concern.



Base: All respondents (1,301);

Fieldwork dates 21 April – 2 September 2011

Base: All who at any point since the end of their initial treatment for cancer received information, advice or support that was too late to be useful (65)

Positively, more than four-fifths of patients (83%) reported that they had not received any information that has been too late to be useful. However the five percent answering ‘yes’ still warrants addressing.

Of those reporting that they had received information too late, around three in ten (29%) simply said that it was more information/advice/given that should have been given sooner. Almost one in ten (9%) felt that they were offered treatment or advice too late.

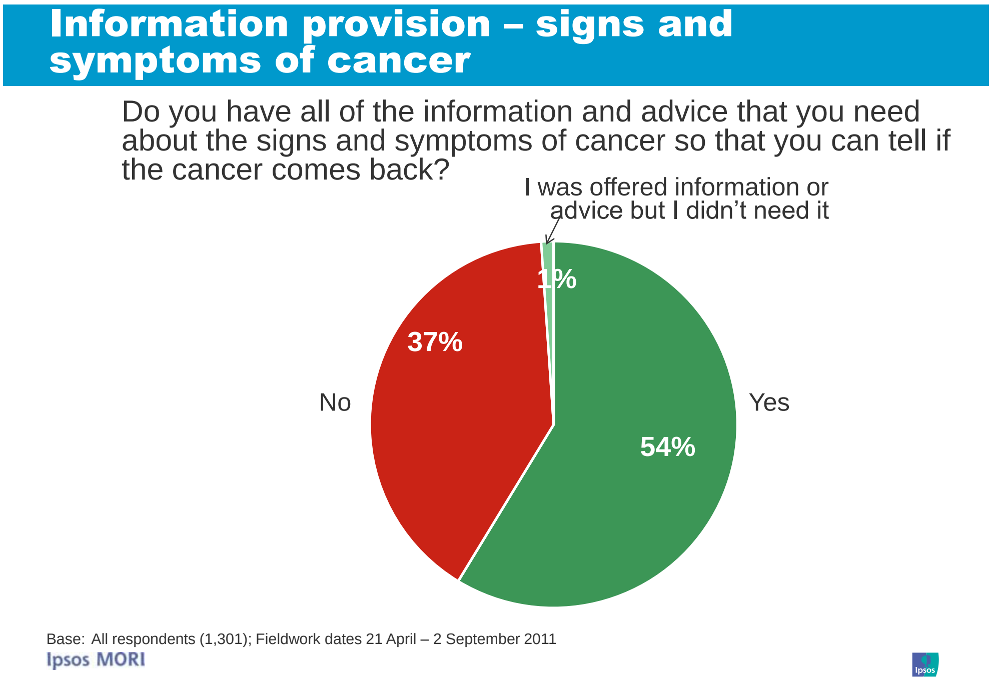
Tumour Groups and Test Communities

No difference is evident between tumour groups or TCs, but there is some variation across the tumour projects. Breast cancer patients at Hull were more likely to report that they have received information or advice that was too late to be useful (9%) compared to patients overall (5%), breast cancer patients at Brighton (3%) and prostate cancer patients at Ipswich (2%).

However, due to the small number of patients reporting that they had received information, advice or support too late for it to be useful, sub-group analysis of the types of information, advice or support that this related to is not possible.

Information on signs and symptoms of cancer

One area where information provision does seem to be less satisfactory is around the signs and symptoms of cancer. Over one-third (37%) of patients did not feel that they had all the information and advice that they need about this so that they can tell if the cancer comes back.



Information provision – signs and symptoms of cancer

Do you have all of the information and advice that you need about the signs and symptoms of cancer so that you can tell if the cancer comes back?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Tumour Group

The only difference existing across the tumour groups is that breast cancer patients felt the best informed about the signs and symptoms of cancer (62% vs 54% overall).

Test Communities

Across the TCs, patients at Guy's and St Thomas' felt the least well-informed about the signs and symptoms of cancer, with over half (51%) feeling that they did not have all of the necessary information. Looking at the different tumour projects breast cancer patients at Bristol and Ipswich were the most likely to feel that they did have all the necessary information (63% and 65% respectively compared to 54% overall).

Thus far we have established what need patients have for information, and which are the key areas for improvement identified by patients taking part in this study. This leads us into our next key concern, which is the degree to which patients are able to cope with any issues that have arisen since they finished their treatment for cancer.

Self-managed care

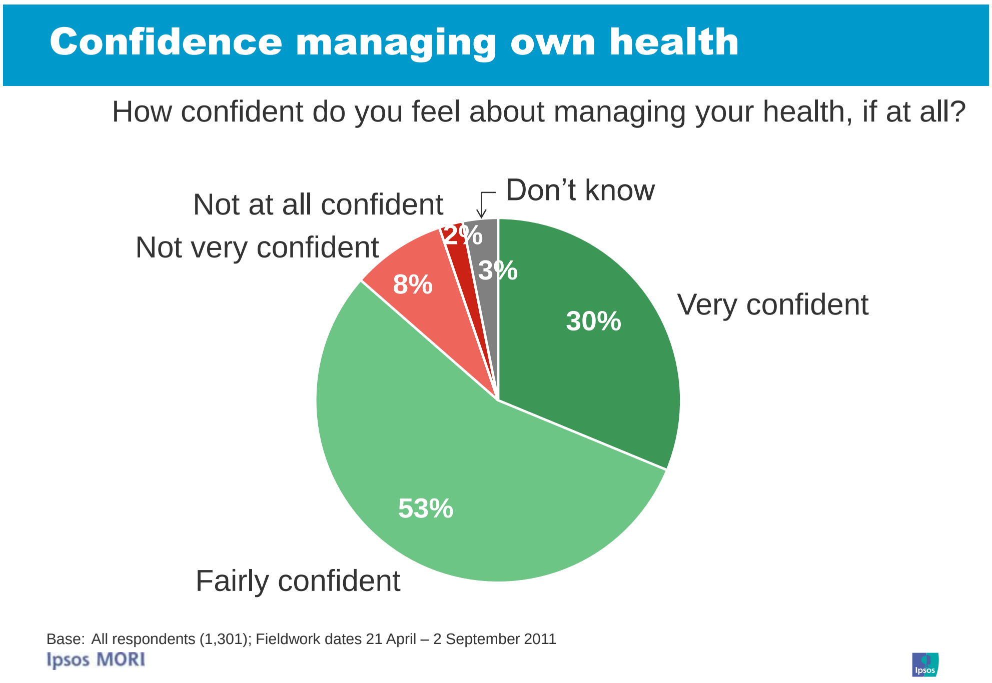
Self-managed care

Patients were asked to think about several problems or issues, whether they had experienced them and how they dealt with them. We consider each problem in turn, looking first at the overall picture, and subsequently at the impact of tumour group, then TC on patients' views. Then we also consider a number of key relationships to try and build a more detailed picture of how these issues are inter-related.

One of the key themes that we will focus-in upon is the degree to which patients reported self-managing their care, and finding solutions to their problems without having to seek professional advice or support.

Confidence in managing own health

As we have seen throughout this report so far, and will become more evident in this chapter in particular; is that confidence patients managing health often seems to be very important, indeed it appears to be one of the contributing factors, to how people deal with any issues. Therefore, it is important to examine this before we begin to look at the problems patients have and how they deal with them.


Confidence managing own health

How confident do you feel about managing your health, if at all?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

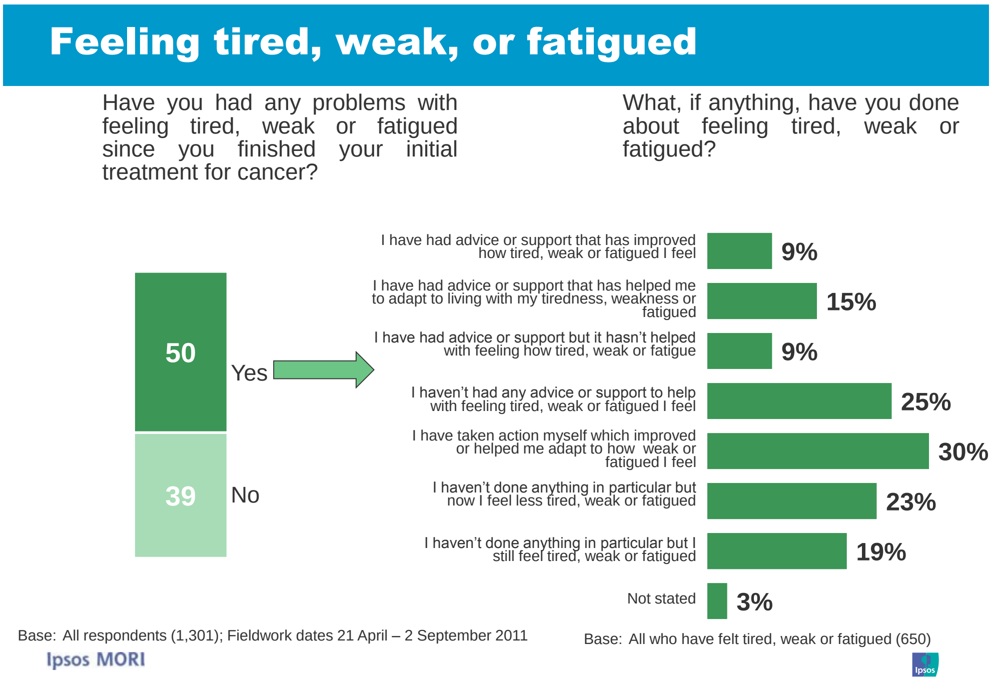
As a group, the patients who took part in our survey reported being confident in managing their own health, over four-fifths (83%) reported that they are fairly or very confident (with 30% of those very confident).

Tumour Group and Test Communities

Beyond the overall group, feelings of confidence were consistent across the three tumour groups, the seven test sites, and the eleven individual tumour projects. There were a small number of potentially interesting differences, such as the fact that prostate cancer patients at Bristol were more likely to report being very confident (35%) than their counterparts at Ipswich (19%). This could be worthy of further exploration to identify the reasons behind these differences and any learning that could be applied across the TCs.

Tiredness

Since they finished their initial treatment for cancer, one in two patients (50%) reported having had some problems with feeling tired, weak or fatigued - three in ten patients (30%) experiencing this problem had taken action themselves which had improved or helped them to adapt to how tired, weak or fatigued they felt. However, only a relatively small proportion (15%) reported having had advice or support that had helped them adapt to living with their tiredness, weakness or fatigue, whilst less than one in ten (9%) had received advice or support that had improved how tired, weak or fatigued they felt.



At this initial level, the figure that perhaps poses the most cause for concern is the small but not insignificant group (19%) reporting that they had not done anything in particular and still had problems feeling tired, weak or fatigued.

In this aspect, it is possible to see the impact of both the care plan, and the level of confidence patients feel in managing their own health on how they have dealt with their weakness, tiredness and fatigue. Patients with a care plan were more likely than patients without to have had advice or support that had either improved how they felt (16% v 7%) or helped them to adapt to living with the issue (25% v 13%). Patients who felt confident in managing their own health, were more likely to have taken action themselves that had improved or helped them adapt to how tired, weak or fatigued they felt (34%) than those who were not confident, and patients overall (12% and 30% respectively). This will be a recurring theme throughout this chapter.

Tumour Group

Breast cancer patients were more likely than patients overall to report problems feeling tired, weak or fatigued since their treatment finished (56% v 50%). Prostate cancer patients, on the other hand, were more likely than patients of the other two tumour groups and patients overall to report not having any problems (45%).

In terms of the actions that had been taken to resolve or deal with this issue, there were several differences across the three tumour groups. First of all, prostate cancer patients were the most likely to report that they had received advice or support that had not helped with their feeling tired, weak or fatigued (14% compared to 9% overall). On the other hand, breast cancer patients were more likely to report having done nothing in particular, which led to feeling less tired, weak or fatigued (27% v 23% overall)

Test Communities

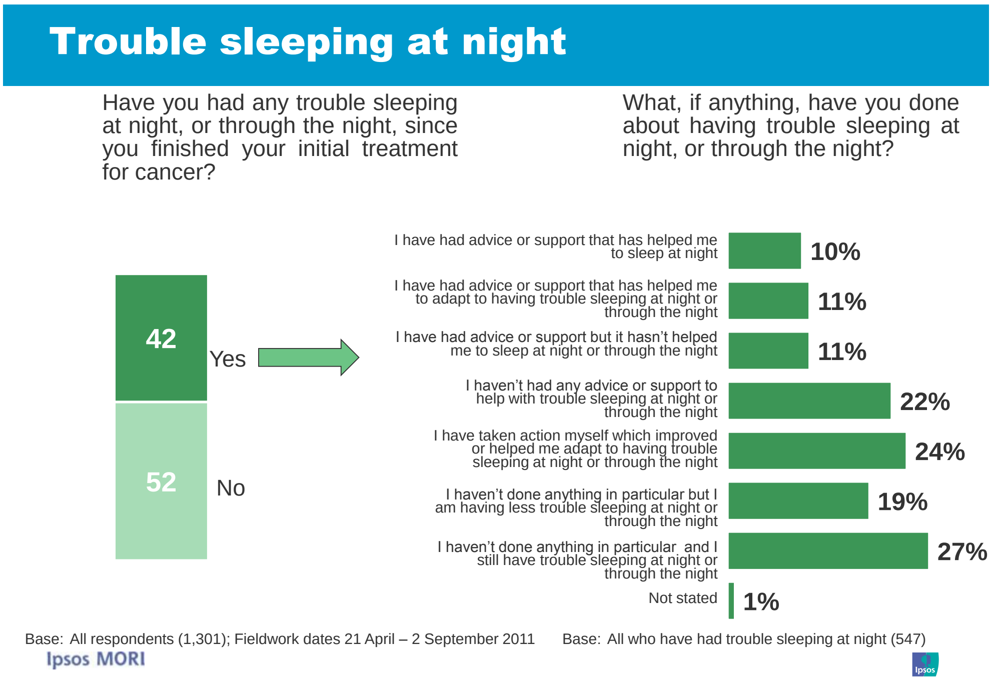
Looking at the data at the TC level, at Hull more than three-fifths (63%) of patients reported having had problems, compared to half overall (50%). However, this likely reflects the fact that at Hull, for the purpose of this service evaluation, only Breast cancer patients were considered. Indeed, patients at Hull were more likely to report this, than patients at Bristol, Ipswich and Luton (50%, 41% and 43% respectively).

There are few differences worth drawing out in how patients across the TCs have approached their issues. Patients at Hillingdon were more likely to have had advice or support that had helped them to adapt to living with this problem (24% compared to 15% overall) but also more likely to have had advice or support that had not helped with how tired, weak or fatigued they felt (18%), compared to patients overall (9%). One-quarter of patients (25%) at Bristol reported having done nothing in particular, but still feeling tired, weak or fatigued, whilst just under one in five (19%) reported this overall.

When we look at the differences between the different tumour projects across the TCs, there are some differences it is useful to draw out[9]. For example, prostate patients at Hillingdon were more likely than patients across a number of the other tumour projects to report having had advice or support that hasn't helped (30%) the most interesting comparison is perhaps that this is significantly higher than the 10% of breast cancer patients at Hillingdon who reported this.

Sleeping

Following a similar theme to the issues of tiredness, weakness or fatigue – patients were asked about trouble they have had sleeping at night, or through the night. Overall, slightly more than four in ten (42%) patients reported that they have had trouble with this since they had finished their initial treatment for cancer.



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have had trouble sleeping at night (547)

Yet, more than one-quarter of patients (27%) who had issues with this reported that they had not done anything about it, and were still experiencing the problem. This could be indicative of patients' feeling towards this issue, perhaps hinting at an underlying feeling that there is just a problem they have to live with. It is also possible that they were experiencing problems sleeping at night prior to their diagnosis and treatment for cancer.

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[9] However, when breaking the sample down to this level, the base sizes for the individual tumour projects are small (43-68) and therefore results should be treated with caution.

A relatively high proportion of patients reported self-managing this issue (24%). Furthermore, as we would expect, patients who said they were confident in managing their own health were more likely to have taken action themselves which has helped (26% v 13%[10]).

In addition, patients with a care plan were more likely to have had advice or support that had helped them adapt to the problem than patients without one (17% v 9%). This further underlines the role the care plan can, and does, play in ensuring patients have access to the necessary information and advice.

Tumour Group

Across the tumour groups, breast cancer patients (46%) were more likely than prostate cancer patients (37%) and patients overall (42%) to report that they have had problems sleeping at or through the night.

In terms of the actions taken to deal with this, reporting across the tumour groups was fairly consistent. However, one difference worth commenting on is that one-third (33%) of prostate cancer patients reported having taken no action and still having trouble with sleeping, which is higher than the percentage (27%) of patients overall who reported this.

Test Communities

Across the TCs, Ipswich patients were more likely than patients overall to report not having had any problems with sleeping (58% compared to 52% overall). Indeed, once the different tumour projects at each TCs are broken down, prostate cancer patients at Ipswich are more likely to report this than patients overall (60% v 52%).

Actions taken by patients are consistent across the TCs, although the base sizes at some TCs are fairly small.

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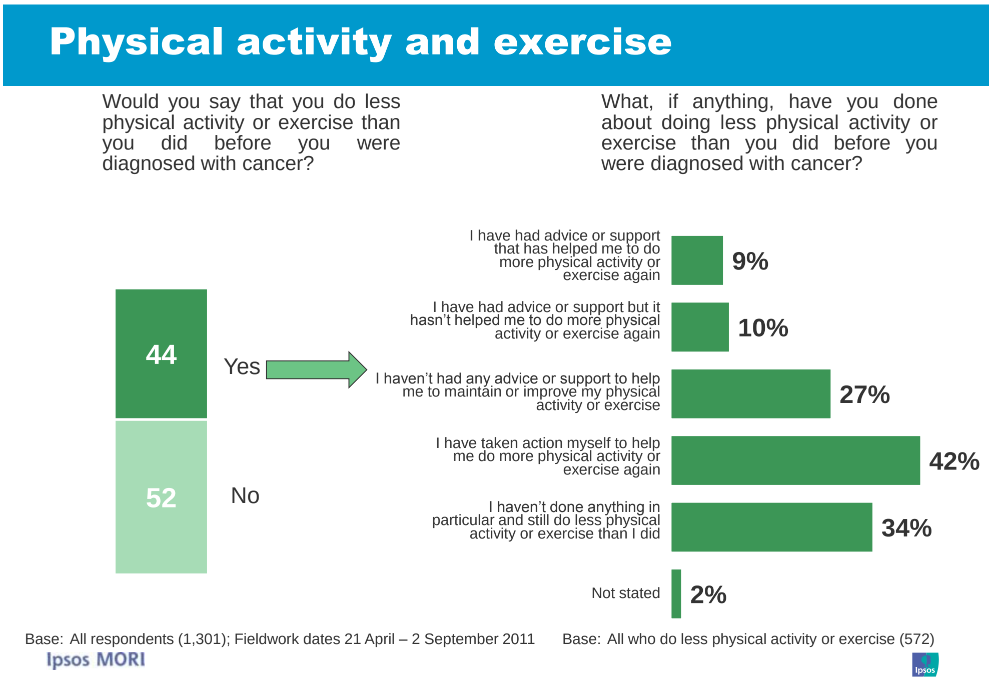
[10] Please note that the base size for people not confident managing their own health is less than 100.

Exercise

When asked to consider whether they do more less physical activity or exercise than they did before they were diagnosed with cancer, over two-fifths of patients (44%) said that they do.



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who do less physical activity or exercise (572)

For this problem in particular there was a very high incidence of patients taking action to help themselves to do more physical activity or exercise, with more than two-fifths (42%) having done so. An yet a lack of physical activity is clearly a problem for some as over one-third (34%) reported that they had not done anything about this issue and still do less physical activity, and also over one-quarter (27%) had not had any advice or support to help them maintain or improve their levels of physical activity or exercise.

A higher proportion of patients who were being confident in managing their own health reported taking action to help themselves do more physical activity or exercise than those who were not confident (48% v 24%). And, as we have already highlighted, it is patients without a care plan who felt ill-informed. Patients without a care plan were more likely to have not received any advice or support on this issue compared to patients with a care plan and patients overall (32%, 18% and 27% respectively).

Tumour Group

Colorectal cancer patients were more likely to report doing less physical activity or exercise than before their diagnosis (57% v 44% of patients overall). They were also the least active of the tumour groups (Breast – 42%; Prostate – 40%). It is possible that this is related the more invasive nature of surgery for colorectal cancer. In addition, colorectal cancer patients were more likely to be aged 75+, at which age a serious disease such as cancer may have a more detrimental long-term effect on health. The incidence of secondary cancers was also found to be higher amongst colorectal cancer patients, which may also have had an effect on the general health of the patients. Colorectal cancer patients were more likely to report having been diagnosed with a secondary cancer than breast or prostate cancer patients and patients overall (14% compared to 7%, 8% and 9% respectively).

Breast cancer patients were more likely to report that they took action themselves (49% v 42%). Whereas prostate cancer patients were more likely to report doing nothing and still doing less physical activity or exercise (40%) than patients overall (34%).

Test Communities

Results across the TCs were relatively consistent, although the base sizes at this level are relatively small. However, there is one significant difference; patients at Guy's and St Thomas' were more likely to report having had advice or support that has helped them to do more physical activity or exercise (18%[11] compared to 9% overall).

Prostate cancer patients at Bristol were more likely to have done nothing in particular and still be doing less physical activity (49%[12] v 34% overall).

At this point, it is useful to look at how much physical activity the patients responding to this study reported doing currently, in order to add some context to these figures.

As the chart below highlights, one-quarter of respondents (25%) said they do 30 minutes or more of physical activity on no days per week. Whereas one in ten (11%) reported doing so every day of the week.

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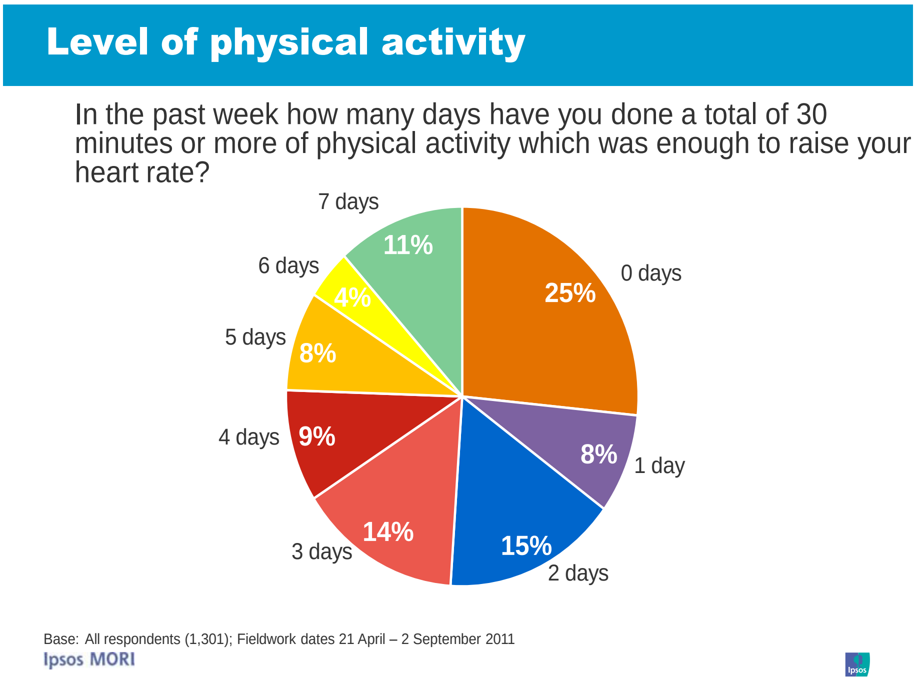
[11] Base size is 66 so please treat results with caution.
[12] Base size is 49 so please treat results with caution.



Level of physical activity

In the past week how many days have you done a total of 30 minutes or more of physical activity which was enough to raise your heart rate?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Breast (29%) and colorectal (30%) cancer patients were more likely than prostate cancer patients (19%) to have not done 30 minutes or more of physical activity or exercise.

Indeed, one in seven prostate cancer patients (14%) reported having exercised everyday in the week prior to completing the survey. This is in line with national data, which shows that men do more physical exercise than women, and therefore explaining why prostate cancer patients do higher levels[13].

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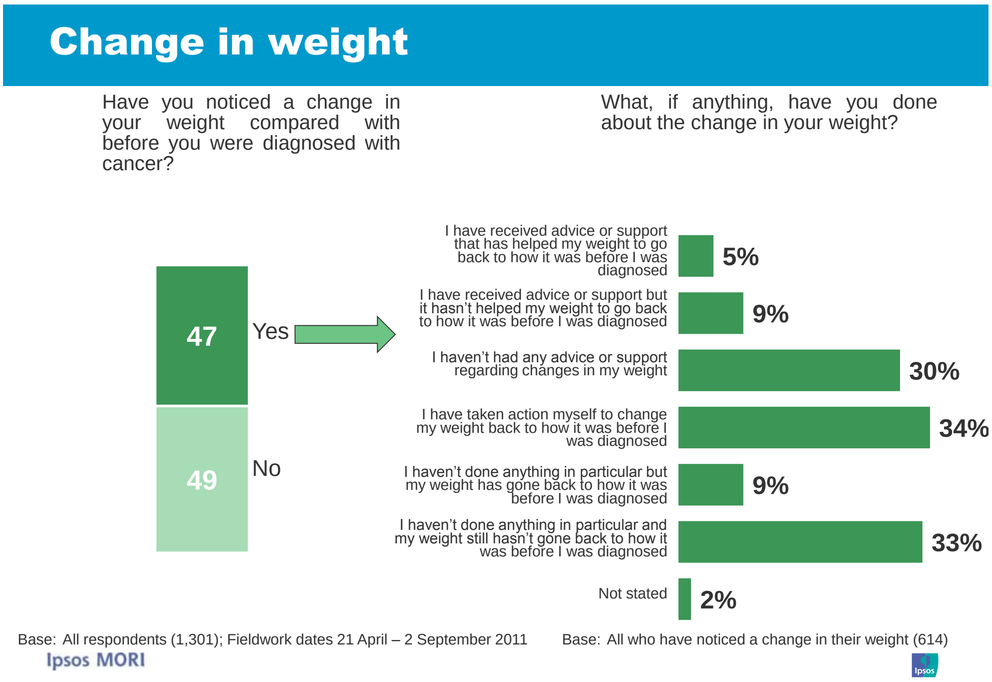
[13] 39% of men do 30 minutes of moderate or vigorous activity at least 5 days a week, compared to 29% of women (Social Trends 41, ONS, http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-218733 last accessed 21 September 2011)

Weight

Just under half of patients (47%) responding to our survey said that they had noticed a change in their weight compared to before they were diagnosed with cancer. This could either be weight-gain or weight-loss.



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have noticed a change in their weight (614)

As with exercise, patients report high incidences of taking action themselves, with more than one-third doing so (34%). Significant numbers of patients also report having done nothing in particular (33%) and still having not returned to the pre-diagnosis weight, or having had no advice or support (30%).

Again we find that patients confident managing their health were more likely to report taking action themselves (36%). Whilst those without a care plan were more likely to report not having had any advice or support (34% compared to 30% overall, and 22% of patients with a care plan). Additionally, those with a care plan were more likely to have had advice or support that had helped their weight go back to how it was before their diagnosis.

Tumour Group

Colorectal cancer patients were the most likely to have noticed a change in their weight (56%, compared to 48% of breast and 41% of prostate cancer patients reporting the same).

In terms of actions taken in order to deal with this change in weight, colorectal cancer patients were more likely to report having had beneficial help or advice (10% compared to 5% overall). This group of patients was also the most likely to have taken no action, with their weight to have gone back to previous levels (16%) compared to less than one in ten (9%) overall.

Prostate cancer patients were the most likely to have taken no action and to be still having trouble with their weight not returning to how it was previously. Two-fifths (40%) report this, whilst only one-third (33%) of patients do overall.

Test Communities

Patients being treated at Guy's and St Thomas' were the most likely to report a change in weight, but this likely reflects the fact that Guy's is only a TC in relation to colorectal cancer, and as previously illustrated colorectal patients were more likely to report a change in their weight.

Again, we see that there is not much variation amongst the TCs on this measure, with the exception that approaching one in five (18%[14]) patients at Guy's and St Thomas' reported having received advice or support that has helped. This was higher than the five percent of patients overall, and the findings for a number of other TCs (Brighton – 5%; Bristol - 1%; Hillingdon – 5%; Ipswich – 2% and Luton – 4%[15]).

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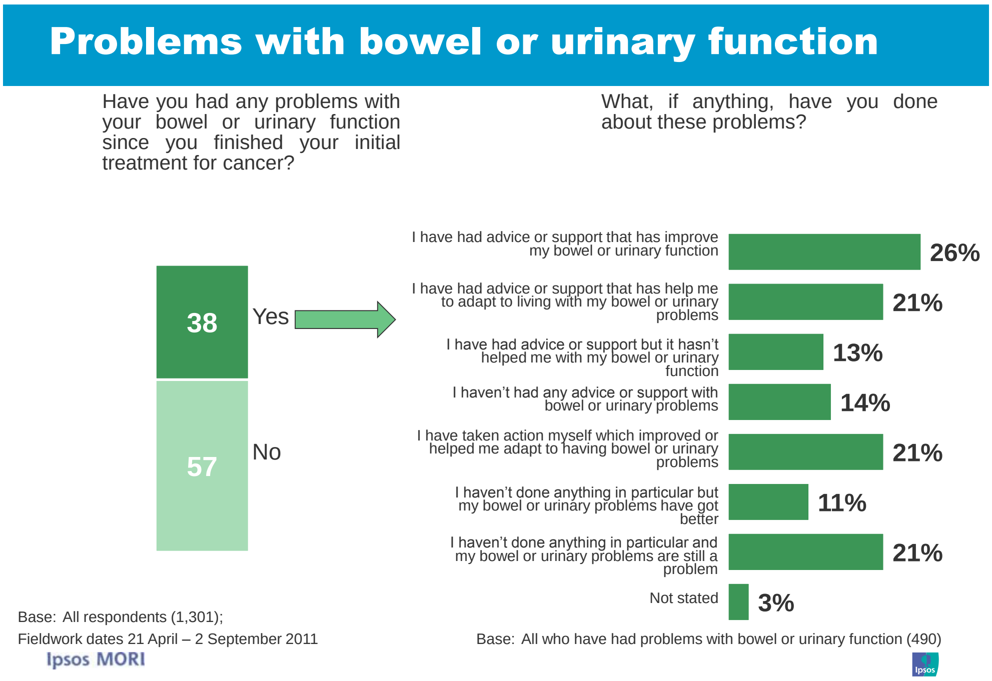
[14] Please treat this result with caution due to the small base size (65).

[15] Some of these figures have small base sizes, please treat with caution (Brighton – 66; Hillingdon – 95; and Luton – 54).

Bowel/Urinary Function

The number of patients who reported that they have had problems with bowel or urinary function since they finished their initial treatment for cancer was lower than for some of the other measures we have seen so far. Just under two-fifths (38%) reported this issue. It is possible that this is related to bowel and urinary function problems being more closely linked to certain tumour types, such as prostate and colorectal, than to breast.



Base: All respondents (1,301);
Fieldwork dates 21 April – 2 September 2011

Base: All who have had problems with bowel or urinary function (490)

Tumour Group

As would be expected, prostate and colorectal cancer patients were both more likely to report having problems with their bowel or urinary function than breast cancer patients (55%; 51% and 18% respectively). Of those breast cancer patients who did report having trouble with their bowel or urinary function, almost three in ten (29%) had taken action themselves that had helped them to deal with these issues. This is in comparison to just a fifth of patients overall (21%). Colorectal cancer patients were most likely to have had advice or support that had helped them (29% v 21% overall).

Test Communities

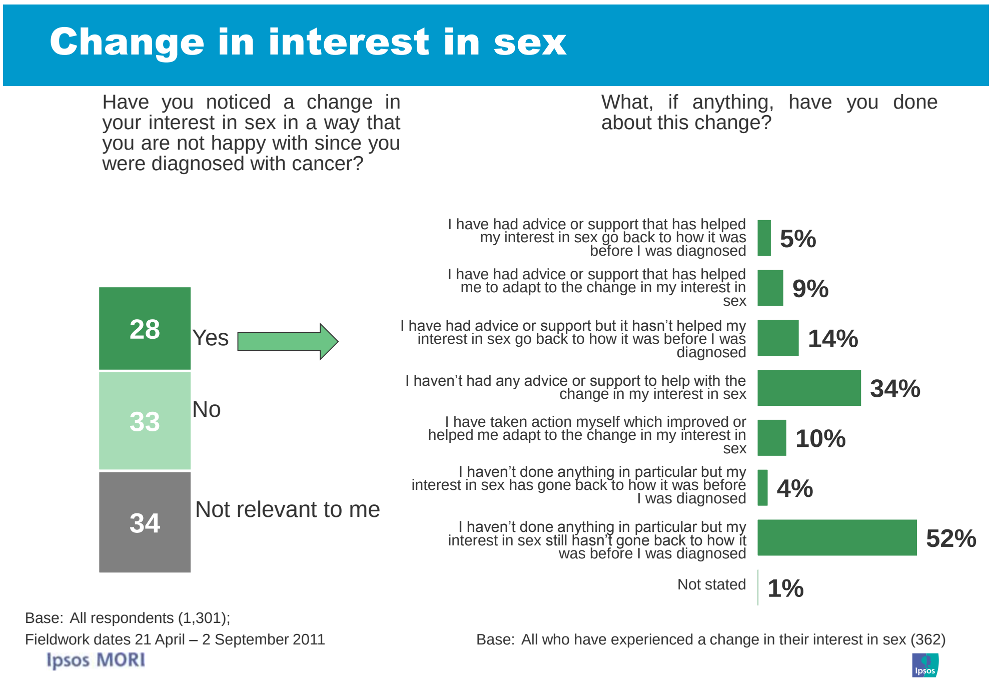
Again the impact of tumour type probably outweighs the effect of TC here, those TCs involving a prostate or colorectal tumour project were more likely to have patients reporting having problems with bowel and urinary function. For example three-fifths of patients (63%) at Luton had experienced problems with their bowel or urinary function, compared to almost two-fifths overall (38%), and just one in seven (14%) at Hull, a breast cancer tumour project.

Splitting the results down between the different tumour projects, shows that colorectal cancer patients at Guy's and St Thomas' were more likely to have had advice or support that had not helped than colorectal patients at Bristol (27%[16] v 11%[17]), whilst at Bristol colorectal cancer patients were more likely to have had advice or support that had helped than their counterparts at Guy's (39%[18] v 17%[19]).

Sex drive and sexual function

Sex drive

Respondents were also asked whether or not they had noticed a change in their interest in sex, that they were not happy with, since their diagnosis with cancer. A significant proportion, (34%), felt that this issue was not relevant to them, especially elderly (76+) respondents[20], and colorectal cancer patients[21].



Base: All respondents (1,301);
Fieldwork dates 21 April – 2 September 2011

Base: All who have experienced a change in their interest in sex (362)

Of those who said they had experience a change in their interest in sex that they're not happy with, over half (52%) reported not having taken any action, and still having problems with their interest in sex. A further third (34%) reported they have had no advice or support, and only a very small minority (5%) had had any advice or support that had helped their

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[16] Please treat result with caution due to small base size (52).
[17] Please treat result with caution due to small base size (64).
[18] Please treat result with caution due to small base size (64).
[19] Please treat result with caution due to small base size (52).
[20] 61% compared to 37% of patients aged 61-75, 44% aged 36-60 and 34% overall.
[21] 45% compared to 36% of breast cancer patients, 26% of prostate cancer patients and 34% overall.

interest in sex return to its pre-diagnosis level, with one in seven (14%) who had advice or support that had not helped.

Tumour Group

Prostate cancer patients were the most likely to report having undergone a change in their interest in sex (42% compared to 28% overall). However, there are very few differences to be seen across the tumour groups in how patients attempted to deal with this issue. Prostate cancer patients were both more likely to have received advice or support that had helped, and to have had advice or support that has not helped. What can perhaps be interpreted from this, is that prostate cancer patients are more likely to seek advice for issues regarding interest in sex.

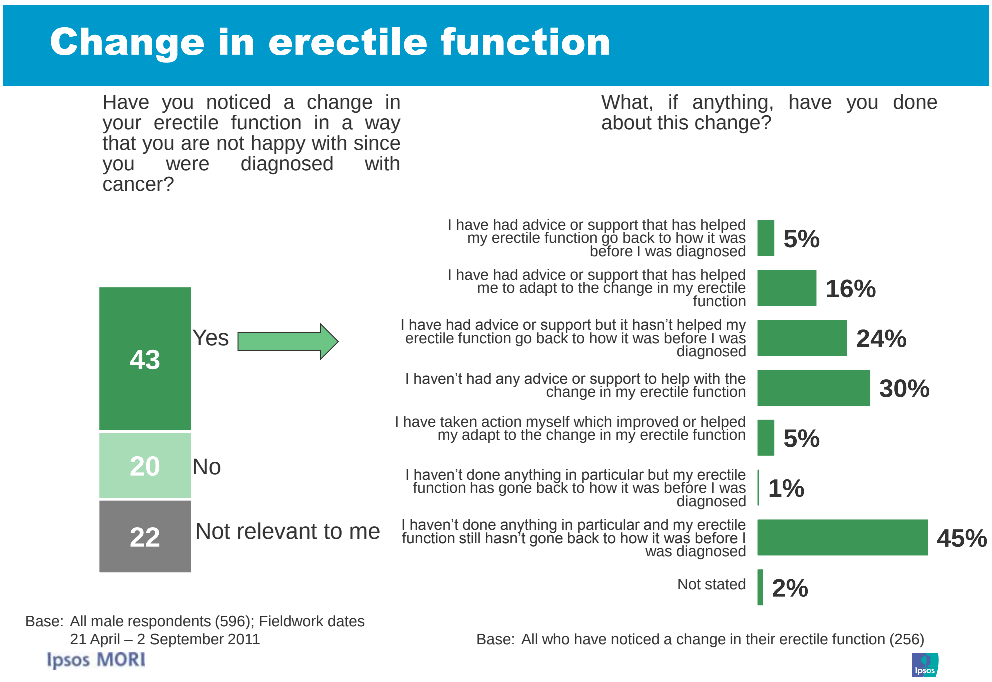
Test Communities

Closely linked to the level of reporting problems with interest in sex amongst prostate cancer patients, Luton patients were more likely to report an issue here (49%) than patients overall (28%). This is worthy of further investigation to understand if Luton is offering a particularly accessible information source on this issue.

When looking at how patients across the TCs tried to deal with this problem, there is consistency across all of the TCs.

Sexual Function

Following on from this question, all male respondents were asked whether they had noticed any change in their erectile function, in a way that they are not happy with. Just over two-fifths male patients (43%) said that they had noticed such a change.



Base: All male respondents (596); Fieldwork dates 21 April – 2 September 2011

Base: All who have noticed a change in their erectile function (256)

Tumour Group

Prostate cancer patients were more likely to have experienced issues with their erectile function than colorectal cancer patients (45% vs 31%), as might be expected from the nature of the two different tumour types.

As the majority of patients reporting a problem with their erectile function are prostate cancer patients, it is not possible to draw out any differences in how this is dealt with across the tumour groups.

Test Communities

In terms of proportions of male patients reporting issues with their erectile function, there is consistency across the TCs, with the exception of the sole colorectal only TC, Guy's and St Thomas', whose patients are more likely to report not having any issues with their erectile function, than patients overall (32% compared to 20%).

There are only a small number of patients at each TC reporting unwelcome changes in their erectile function, which makes meaningful comparison difficult. However, patients at Bristol are more likely than patients overall to have had advice or support that has not helped their erectile function to return to previous levels (38%[22] compared to 24% overall).

The answers to these two questions, and in particular the higher proportion of patients who had sought no help or taken no action to deal with issues surrounding interest in sex or erectile function suggest that this is something that people find more difficult to discuss, that they are not aware that the problems they are having are linked to their cancer, or that they assume nothing can be done about them.

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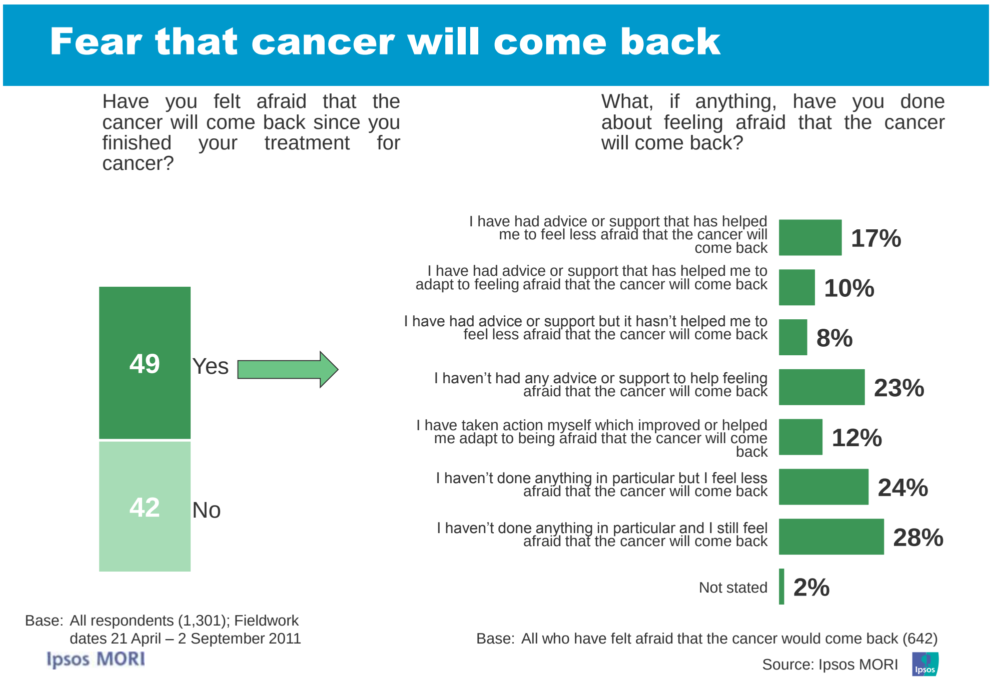
[22] Please not the base size at Bristol is 82

Anxiety about cancer returning

Almost half of patients (49%) said they have felt some level of anxiety or fear that their cancer will return.


Fear that cancer will come back

Have you felt afraid that the cancer will come back since you finished your treatment for cancer?

What, if anything, have you done about feeling afraid that the cancer will come back?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have felt afraid that the cancer would come back (642)

Source: Ipsos MORI

This fear is notably higher amongst those who said they are not confident managing their own health (72%) than it is amongst those with confidence (48%). Conversely, the incidence of fear is lower amongst patients who felt that they had received a very good or excellent service overall and quality of care.

More than one-quarter (28%) of respondents said they had not done anything in particular and still felt afraid that their cancer will return, and one-quarter (23%) reported not doing anything. Almost one-quarter (24%) had done nothing in particular, but felt less-afraid than they did previously. Positively, 17% said that they had received advice or support, and that this had helped them to feel less afraid.

Patients confident in managing their own health were more likely to have taken action themselves that had helped (13%) than patients overall (12%) and those not confident in managing their own health (5%[23]).

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[23] Please note the small base size for this figure (96)

Tumour Group

Breast cancer patients were the most likely to be afraid that their cancer would come back (64%) compared to one-third of prostate cancer patients (34%), and over two-fifths of colorectal cancer patients (46%).

There is a high degree of consistency across the three tumour groups, although prostate cancer patients were more likely to have had advice and support (23%) that had helped them feel less afraid than patients overall (17%). More than one in three of breast cancer patients (31%) reported that they had not done anything and still feel afraid, whilst around a quarter (28%) reported this overall.

Test Communities

Reflecting the higher incidence of fear amongst breast cancer patients, patients at the two breast cancer only TCs, Brighton and Hull, were more likely than patients overall to have experienced this fear (66% and 64% respectively, compared to 49% overall).

Patients at Hull were more likely to have done nothing and still feel afraid (41%[24]) than patients overall (28%) whilst Ipswich patients were more likely to have done nothing but feel less afraid (33%) than patients overall (24%).

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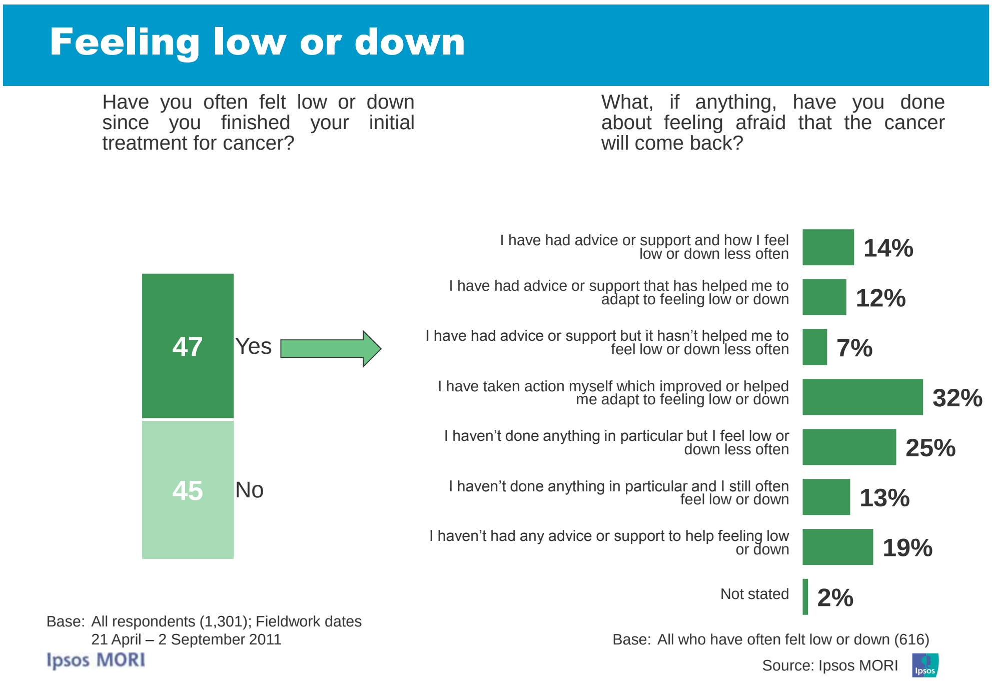
[24] Please not the small base size at Hull (68).

Feeling low or down

Slightly fewer than half of respondents (47%) reported that they had often felt low or down since finishing their initial treatment for cancer.



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Base: All who have often felt low or down (616)

Source: Ipsos MORI

A patient's confidence in managing their own health appears to be an influencing factor here, four-fifths (82%) of those who said they are not confident reported often feeling low or down, compared to around two-fifths of patients(44%) who did feel confident.

A significant degree of self-management of care is also demonstrated here, with almost one-third (32%) of patients reporting that they had taken action themselves that had improved how they feel or helped them to adapt to their feelings. However, small, but nonetheless important, proportions of patients reported either doing nothing and still often feeling low or down (13%) or having had no advice or support to help with feeling low or down (19%).

Tumour Group

Prostate cancer patients were the least likely to have felt this way, more than half (53%) said "No" compared to two-fifths (40%) of breast and colorectal cancer patients and over two-fifths (45%) of patients overall. However, those prostate cancer patients who had felt this way were more likely than patients overall to have not had any advice or support (25% compared to 19%).

Test Communities

Approaching six in ten (58%) patients at Hull reported often feeling down or low, compared to just under half (47%) overall.

By and large, the results across the TCs are again fairly consistent in terms of how patients have dealt with feeling low or down. There are a few differences to draw out, for example Hillingdon patients were more likely to have had advice or support that had not helped (12%) than patients overall (7%). Almost one-quarter (23%[25]) of patients at Brighton who had often felt low or down reported having received advice or support and now feeling low or down less often. Only one in seven (14%) of patients overall reported this.

Relationships between problems

It is possible to interrogate the data further to highlight a number of apparent inter-relationships appearing in the data. This also helps to illustrate the knock-on effects that some problems can have.

First of all, patients who reported having trouble sleeping at night were more likely (65%) to do less physical activity or exercise than both those who had not had trouble sleeping (16%) or patients overall (44%).

Related to this, seven in ten (72%) patients who said they have had trouble sleeping at night reported feeling tired, weak or fatigued since they finished their treatment for cancer, compared to a third (35%) of those who had not had trouble sleeping, and half of patients overall (50%).

Thirdly, patients who reporting having problems with bowel or urinary function were more likely to say they did less physical activity or exercise (53%) than those who had not (39%) and patients overall (44%).

Finally, patients who did not feel that they had all the necessary information and advice about signs and symptoms of cancer were more likely to say that they had been afraid that the cancer will come back (57%) than those who felt well informed (48%) and patients overall (49%).

Whilst it is difficult to establish cause and effect, it is nonetheless interesting to look at these relationships, which further underlines the importance of helping patients to deal with any problems they have, as this may in turn help alleviate other related problems.

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[25] Please note small base size (62)

In this chapter we have seen that patients displayed a high level of self-management across a range of problems, in particular with problems related to weight, decreases in physical activity and exercise, or feeling tired weak or fatigued.

However, there appear to remain substantial unresolved patient need with regard to problems sleeping at or through the night, interest in sex and problems with erectile function. Additionally, as well as being two of the problems most frequently addressed by patients themselves, change in weight and decreases in physical activity or exercise also have comparatively high proportions of patients who had taken no action and continued to have a problem.

It is worth considering these latter two problems, especially with the move towards self-management of care, to ensure that this group does not grow. Examining why patients persist in having problems here is something that warrants further investigation.

Now that we have established patients' ability to self-manage their care, we can now move to a closely linked issue, contact with health professionals, and specifically who patients contact if they have any health concerns related to their cancer or their treatment for it.

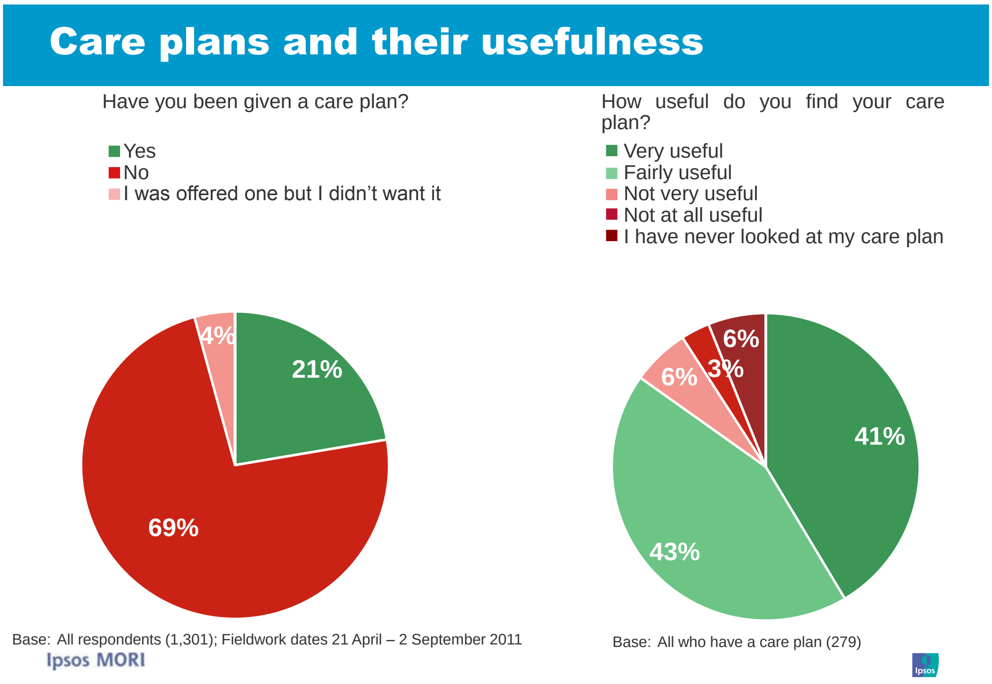
Contact with health professionals

Contact with health professionals

In this chapter we examine the level of contact between patients and health professionals, looking at the usefulness of care plans (and whether patients are aware of them), and follow-on by establishing who patients contact, during and outside office hours, and how frequently they have contacted their GP in the last six months. As in previous chapters, for each of these subjects, we first examine the data as a whole, before breaking it down to examine differences across the tumour groups, and then at the TC level.

Care Plans

The previous chapters of this report have demonstrated that the presence of a care plan appears to be an important factor in determining whether or not patients had been able to access the information, support and advice they needed to deal with any problems or issues related to their treatment.



Care plans and their usefulness

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have a care plan (279)

When asked whether or not they had been given a care plan, almost seven in ten (69%) said that they did not have one. Whilst only slightly more than one in five (21%) reported that they did, encouragingly the vast majority of these (84%) did find the care plan useful. However, the small proportions saying that either they found their care plan to be not useful (9%) or that they have never looked at their care plan (6%) should not be overlooked. It is also possible that the relatively small proportion of patients reporting having a care plan was partly driven by a difference in terminology, or formality of care planning. Patients may have been through a care planning process, without it being referred to as such. This would be a very useful issue to explore during the qualitative phase of this project.

Patients who said they were confident managing their own health (23%) were more likely to have a care plan than patients overall (21%). Almost one-quarter of patients who felt that their overall care and services had been excellent or very good (24%) had a care plan.

Tumour Group

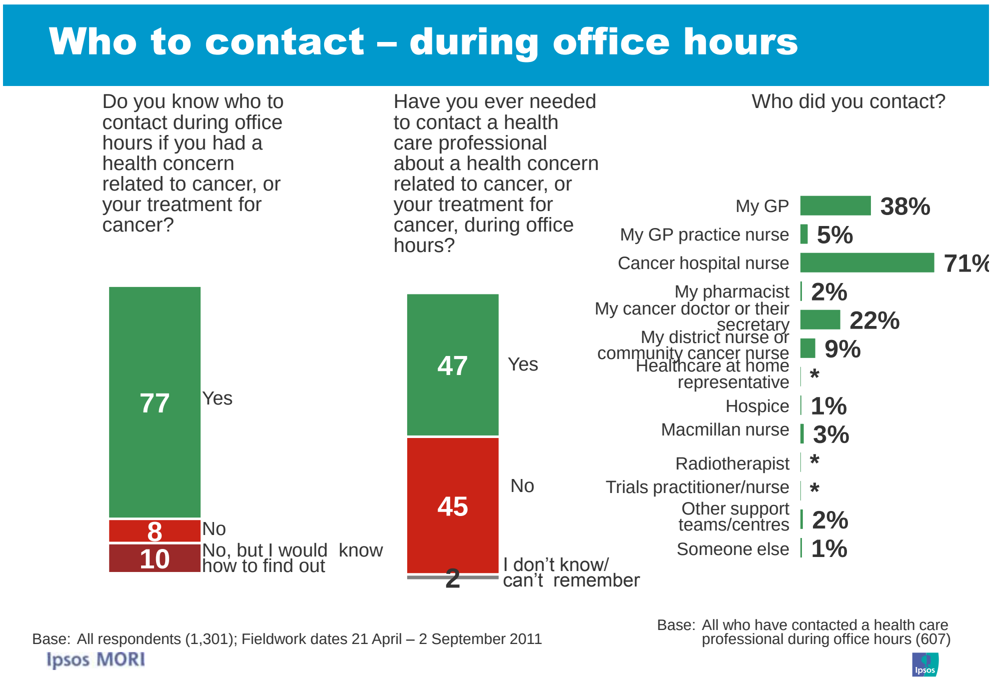
Breast cancer patients were more likely than prostate cancer patients and patients overall (24% vs 19% and 21%) to report having a care plan. However, in terms of how useful these patients found their care plans to be, there were no significant differences between the tumour groups.

Test Communities

At the TC level there were very few differences to be seen in terms of who had a care plan, almost three in ten (29%) of patients at Hillingdon had a care plan (21% do overall), whilst approaching three-quarters (74%) of patients at Bristol did not have a care plan (69% overall). Interestingly, there were one or two differences within the TCs – namely that breast cancer patients at Ipswich were more likely to have a care plan than prostate cancer patients there (28% and 15% respectively). This reflects the lower incidence of care plans amongst prostate patients as a whole.

Who do patients contact during office hours?

It is important that patients know who they need to contact during office hours if they should have a health concern related to their cancer or its treatment. Positively, more than three-quarters (77%) said they did, and a further one in ten (10%) felt that they would know how to find out. Less than half of respondents (47%) said they have had to contact a health care professional about a health concern related to their cancer or its treatment (during office hours). Those who did most often, contacted a cancer hospital nurse (71%), their GP (38%) or their cancer doctor [or their secretary] (22%).



Who to contact – during office hours

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have contacted a health care professional during office hours (607)

Tumour Group

Breast cancer patients were more likely than patients overall (83% v 77%) to say they did know who to contact during office hours, and were also more likely than all other tumour groups to have had to contact a health professional about a concern. More than half of breast cancer patients (55%) had done so compared to under half (46%) of colorectal cancer patients and under two-fifths (37%) of prostate cancer patients.

Of patients who said they had contacted a health professional, over three-quarters (77%) of breast cancer patients contacted a cancer hospital nurse, compared to seven in ten (71%) overall, whilst one in three prostate cancer patients contacted their cancer doctor or secretary, compared to a fifth (22%) overall.

Test Communities

Patients at Hull were more likely to know who to contact during office hours (85% compared to 77% overall) reflecting the fact that this is a breast cancer only TC. However, when looking at whether contact had been made, patients at Brighton, another TC where only breast cancer services are being considered for the purposes of this evaluation were more likely to have done so (60%) when compared to patients overall (47%).

In terms of who patients had contacted, over four fifths (84%) of patients at Hillingdon had contacted their cancer hospital nurse compared to seven in ten (71%) overall, whilst a fifth (20%[26]) of patients at Luton had contacted their district nurse or community cancer nurse, compare to nine percent overall.

Who a patient will contact can often depend on their personal preference, their personal relationship with the individual, and who they feel comfortable contacting. It will also often depend on the nature of their concern, it is logical to assume that the more concerned a patient is the more likely they will be to want to speak with a clinician such as their GP or cancer surgeon.

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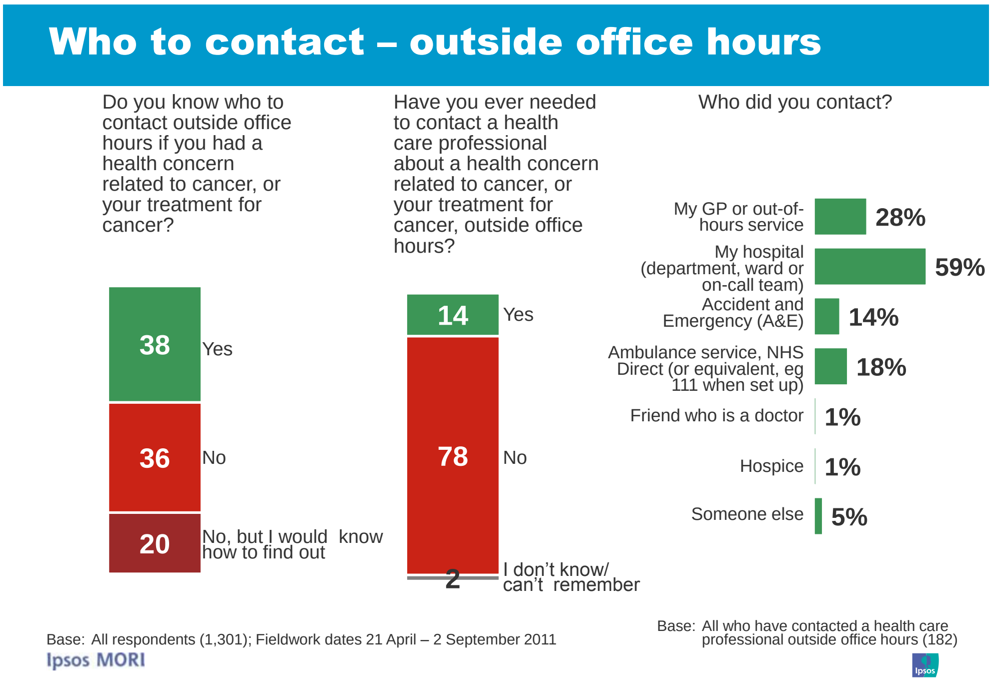
[26] Please note that this is based on a small base size (40) so please treat result with caution.

Who patients contact outside of office hours

It is also important that patients know who they should or can contact outside office hours if they have a health concern related to their cancer or their treatment for it. A much higher proportion here did not know who to contact in this situation (36%).



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Base: All who have contacted a health care professional outside office hours (182)

Although this is perhaps linked to the fact that only one in seven (14%) patients reported ever having to contact a health professional out of hours due to a cancer-related health concern. For those who said they had contacted someone, almost three-fifths (59%) contacted their hospital (including their ward, or A&E). Approaching one in three (28%) reported that they contacted their GP or out of hours service.

Tumour Group

A higher proportion of prostate cancer patients (41%) than breast (34%), colorectal (32%) and patients overall (36%) reported not knowing who to contact outside of office hours. As we found for office hour contact, breast cancer patients were more likely than patients overall to have contacted a health care professional out of hours (16%) compared to 14% of patients overall and just 11% of prostate cancer patients.

In terms of who was contacted, the small base sizes prevent detailed subgroup analysis, but significant differences are found in terms of the proportion of breast cancer patients who contacted their hospital (78%) compared to patients overall (59%) and prostate (35%) and colorectal (43%) patients[27].

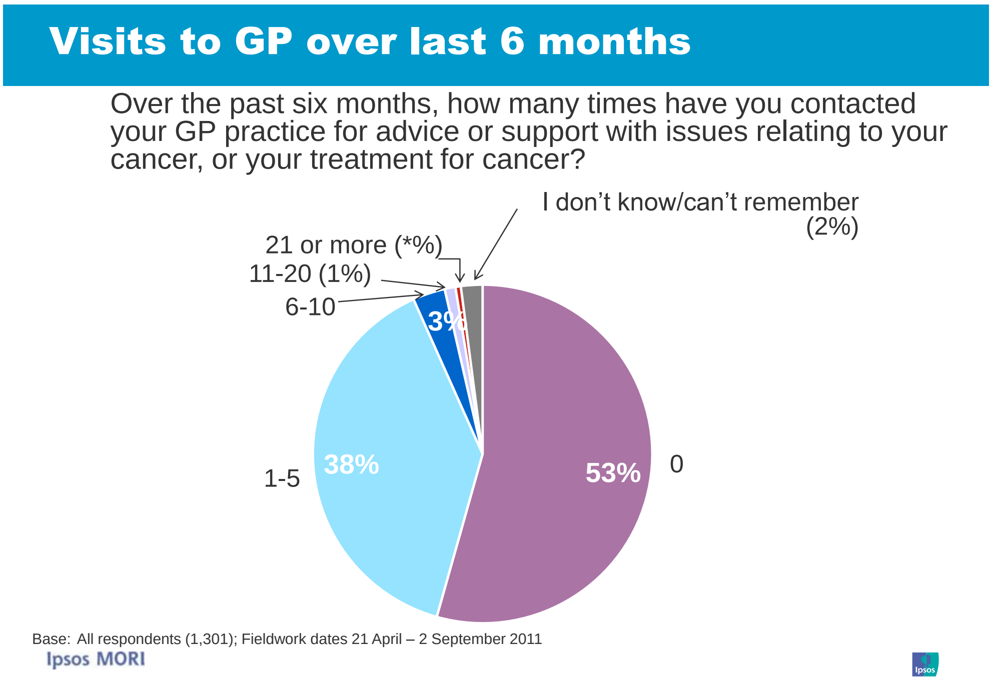
Test Communities

Positively, patients across the TCs were equally likely to feel that they knew who to contact outside of office hours, with the exception of Bristol, where more than four-tenths of patients (41%) were not aware who to contact compared to thirty-six percent of patients overall (36%). On the other hand, patients at Hull were more likely to have contacted somebody out of hours (23%) than patients overall (14%) and at Bristol, Ipswich and Luton (12%, 10% and 11% respectively).

The person who was most frequently contacted by patients is consistent across all of the TCs.

Visits to GP

Respondents were also asked to think about how many times over the last 6 months they have contacted their GP for advice or support relating to their cancer or their treatment for it. More than half (53%) of patients reported that they had done so on zero occasions, whilst just under two-fifths (38%) had done so on between one and five occasions.



Visits to GP over last 6 months

Over the past six months, how many times have you contacted your GP practice for advice or support with issues relating to your cancer, or your treatment for cancer?

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

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[27] Please note the small base sizes here: Breast (96), Colorectal (35) and Prostate (51).

Tumour Group

Prostate cancer patients were more likely than breast cancer patients and patients overall to have contacted the GP one to five times in the last six months to seek advice or support about their cancer or treatment (44% compared with 33% and 38% respectively).

Test Communities

Reflecting the higher propensity of prostate cancer patients to have contacted their GP, patients at Luton were more likely to have contacted their GP one to five times. More than half (51%) had done so compared to two-fifths (38%) overall.

When the eleven different tumour projects are looked at individually, there are some differences between the TCs. Breast cancer patients at Hillingdon were more likely to have contacted their GP one to five times than breast cancer patients at Bristol and Hull, over two fifths (46%) from Hillingdon had done so, compared to three in ten (29%) at both Bristol and Hull.

This measure is something that it would be interesting to compare when results are obtained from Wave 2 of the study. If the incidence of patients contacting their GPs with concerns related to their cancer or its treatment were to increase, then this may be indicative of self-management shifting the contact from the TC to the GP – rather than enabling patients to manage their own care.

This chapter shows that whilst the majority of patients were clear about who they would or should contact during office hours, there was a much lower level of awareness about who the appropriate person to contact outside of office hours is. However, this may be driven by the smaller proportion of patients who reported contacting a health professional outside of office hours.

Conclusions and Next Steps

Conclusions and Next Steps

Conclusions

Overall, the current picture is a positive one with patients positively rating the quality of the care and services they had received since their initial treatment for cancer (59% very good or excellent).

However, whilst many patients had experienced issues and problems relating either to their cancer or to their treatment for cancer, not all patients had been able to deal with their problems to the same level. Whilst a significant proportion of patients were already self-managing their care and taking actions themselves to deal with the problems they had experienced, there were still relatively high numbers of patients who were neither taking any action, nor receiving any advice or support and for whom some of the problems persisted. The level of confidence a patient has in managing their own health appears to be an important factor here.

We have seen throughout this report, that both tumour group and TC can be important factors in determining whether a patient has experienced an issue, and how they were able to deal with it. Beyond this however, the role of the care plan often appeared to be influential.

As you move towards an approach where higher levels of self-management are expected, it is clear there is still work to be done in order to facilitate self-management by patients.

Most patients felt that they had sufficient information, or did not need any, to manage their own health, remain in their own home, cope with financial issues or other practical elements of their day-to-day lives. A much larger proportion of patients did not have all the necessary information about the signs and symptoms of cancer to enable them to tell if it comes back. Given that almost half (49%) of patients had felt afraid that the cancer will come back, and over a quarter (28%) of these still did, this is clearly an important issue for patients.

Steps should be taken to increase patients' confidence in managing their own health, and part of this is ensuring that they feel that they have the necessary knowledge to do so. This includes knowing who to contact, and being given the right levels of information, and in a timely fashion.

Next Steps

Quantitative research is highly informative, enabling the collection of the views of a large number of patients, and providing robust data which will provide valuable comparisons once the follow-up survey has been conducted. However, the limited frequency with which a number of patients come into interaction with health professionals at their TC, perhaps only attending clinics a few times each year, means that conducting the follow-up quantitative survey between January to March 2012, as originally envisaged, will likely be too early to be able to gauge fully the impact of the risk stratified pathways being tested.

Furthermore, the quantitative data produced by this survey, and presented in this report, has raised a number of issues, and questions, that merit being studied in much greater detail. Whilst quantitative data is very useful, and the medium/long-term plan should continue to be to conduct the follow-up wave of the postal survey at a point suitably distant from now, in the short-term the interests of the initiative and patients would be best served by an interim qualitative study.

A qualitative study would offer a much greater level of understanding of how patients and staff feel about the care delivered to adult cancer patients, and the changes that are being made. Moreover, it will help to understand what is shaping the results here; for example understanding the difference in how TCs and individual tumour projects deliver their care currently, and how they are building towards risk stratified pathways. This will help to share best practice, and in turn contribute to an improvement in service all round.

Whilst there is much more work to be done some of the initial themes that would be served well to further explore with both patients and staff are:

- Absence of care plans – is this explained by a difference in terminology, and what do staff at the TCs think about care plans and their usefulness?
- How patients feel about self-management of care – do they want to be responsible for managing their own care?
- What is currently driving patients who are self-managing their care and problems – is this their preferred option, or is there a lack of support?
- Those groups who have had problems but have not done anything about it – by moving towards a greater degree of self-management do we risk this group increasing.

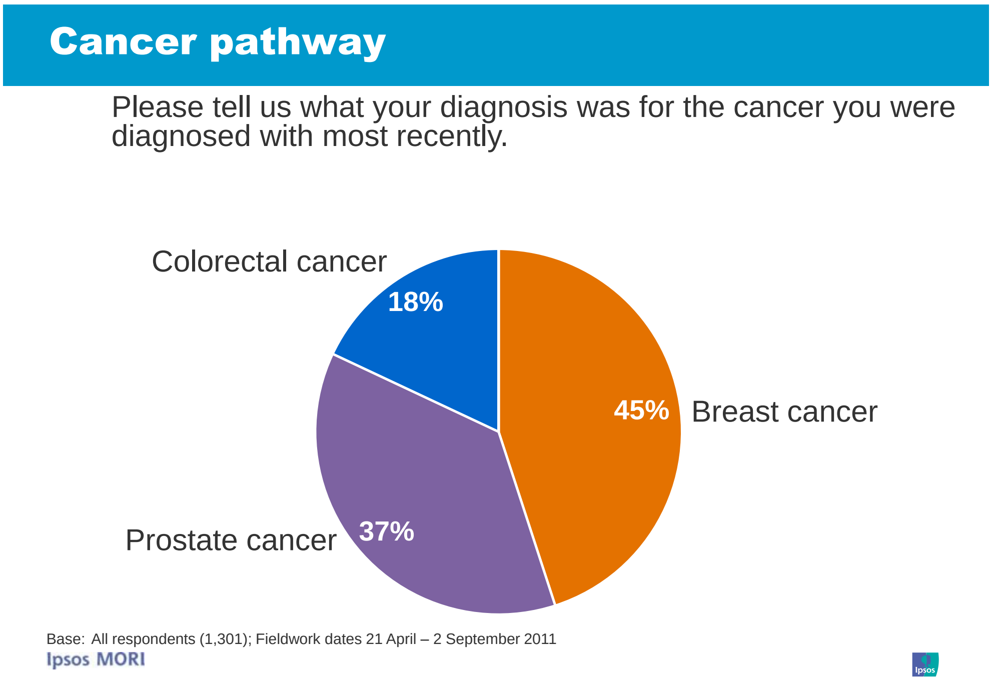
This survey has produced valuable and insightful data, which will ultimately prove to be the baseline against which the impact of the TCs is measured as the programme develops. In the meantime, it also provides a great foundation with which to build on with further qualitative work, which will help to add depth of understanding and perspective to the raw figures presented here.

Appendices

Appendices

Appendix 1: Profile of Respondents

More than four in ten (45%) of patients responding were breast cancer patients, whilst colorectal cancer patients made up the smallest group. This reflects the number of tumour projects within each pathway that are taking part in this evaluation (5 breast cancer, 4 prostate cancer and 2 colorectal cancer projects).



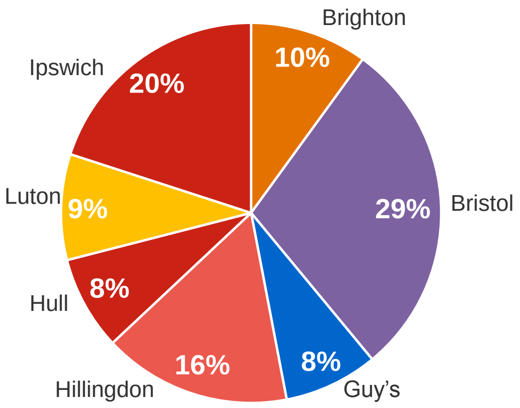
Cancer pathway

Please tell us what your diagnosis was for the cancer you were diagnosed with most recently.

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

The largest group of patients was made up by those TCs with more than one tumour project, Bristol (3 tumour projects), Ipswich and Hillingdon (2 tumour projects each).

Test Site

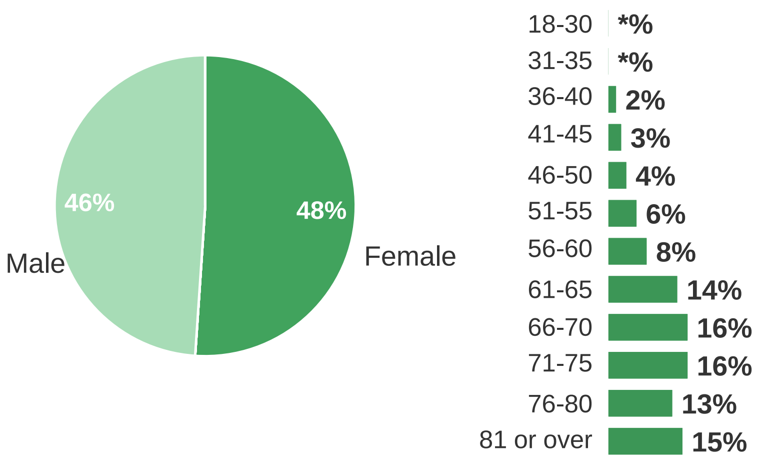


Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011
Ipsos MORI

There is a fairly even split in terms of patient gender, whilst the majority of patients responding are aged 60 or over, which most likely reflects the higher incidence of cancer amongst older members of the population.

Gender and Age of patient

Are you male or female? How old are you?

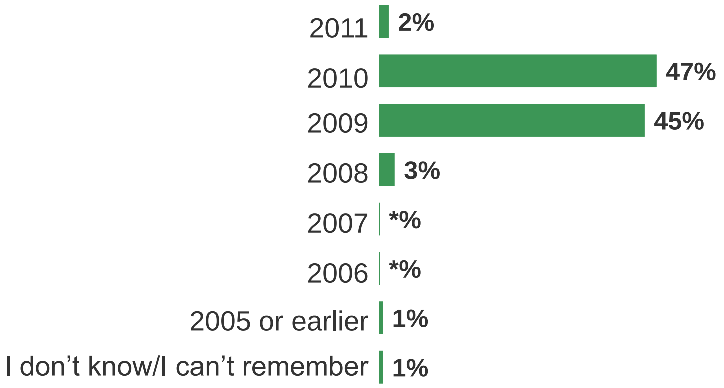


Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011
Ipsos MORI

In accordance with the sampling strategy, most respondents were diagnosed with their most recent cancer between in 2009 or 2010.

Year of diagnosis

In what year were you diagnosed with your most recent cancer?

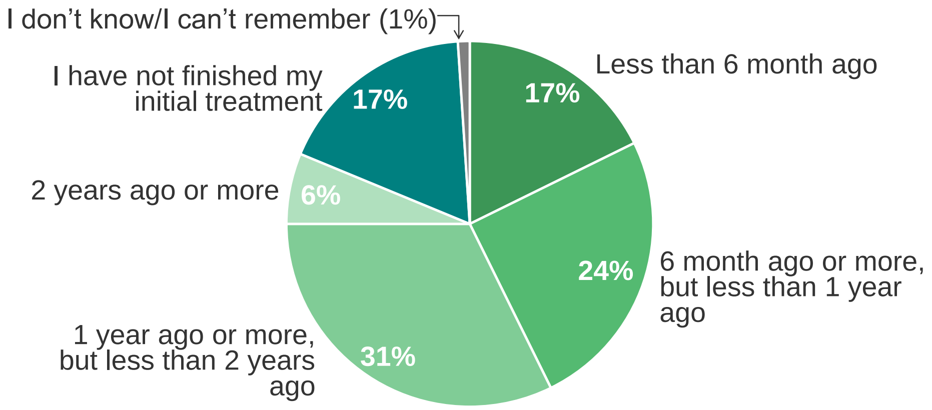


Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

One in six patients (17%) responding to the survey had not yet finished their initial treatment. However, it is likely that this group includes a large proportion of patients in receipt of hormone therapy, which in the case of breast cancer patients in particular can continue for up to five years after the other initial treatments (surgery, radiotherapy or chemotherapy) have finished. As such they would still be receiving aftercare services.

Time since end of initial treatment

And how long ago did you finish your initial treatment for the cancer you were diagnosed with most recently?

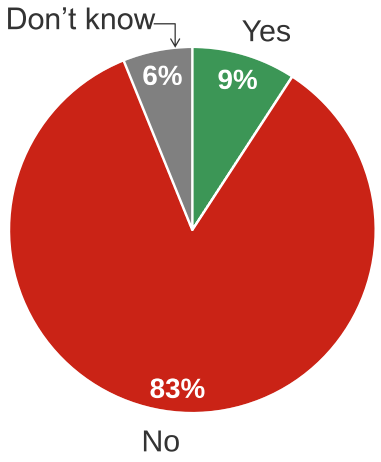


Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Less than one in ten (9%) of patients responding had been diagnosed with a subsequent secondary cancer.

Diagnosis of secondary cancer

Have you been diagnosed with a secondary cancer?



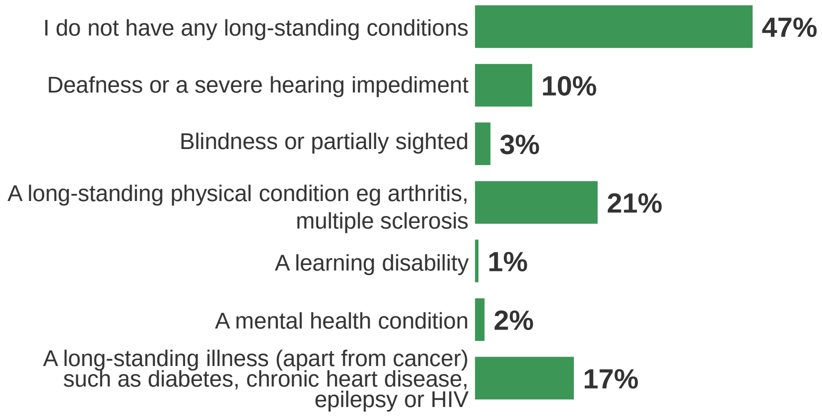
Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Almost half of patients responding (47%) did not have any long-standing conditions, whilst long-standing physical conditions (such as arthritis, or multiple sclerosis) were the most commonly cited.

Long-standing conditions

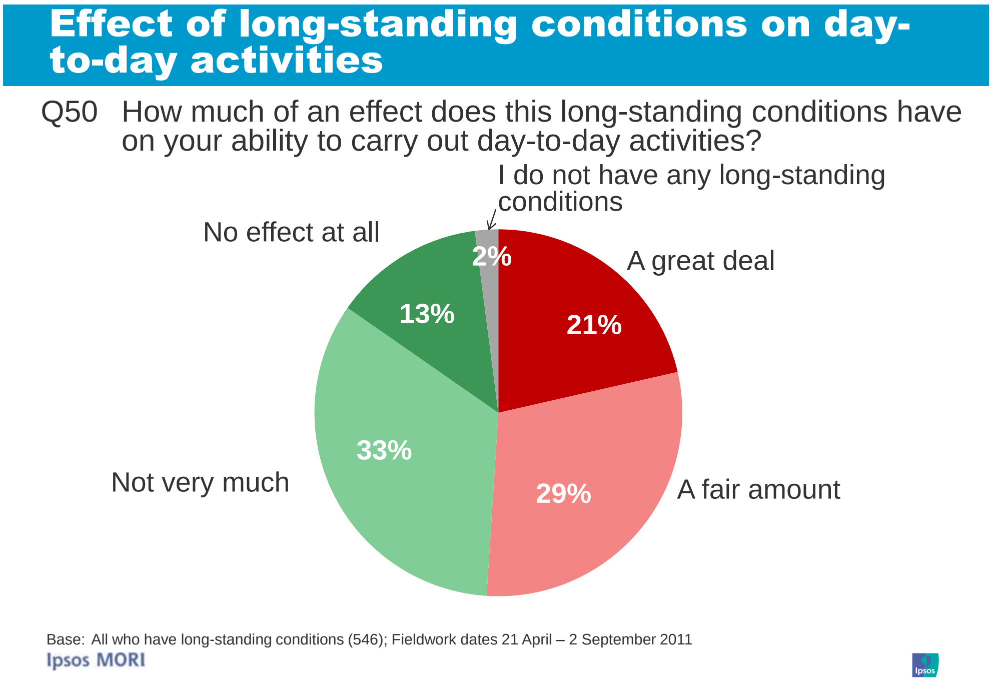
Do you have any of the following long-standing conditions in addition to your cancer diagnosis?



Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

For those patients who do have a long-standing condition, half (49%) reported that this had at least a fair amount of an effect on their ability to carry out day-to-day activities.



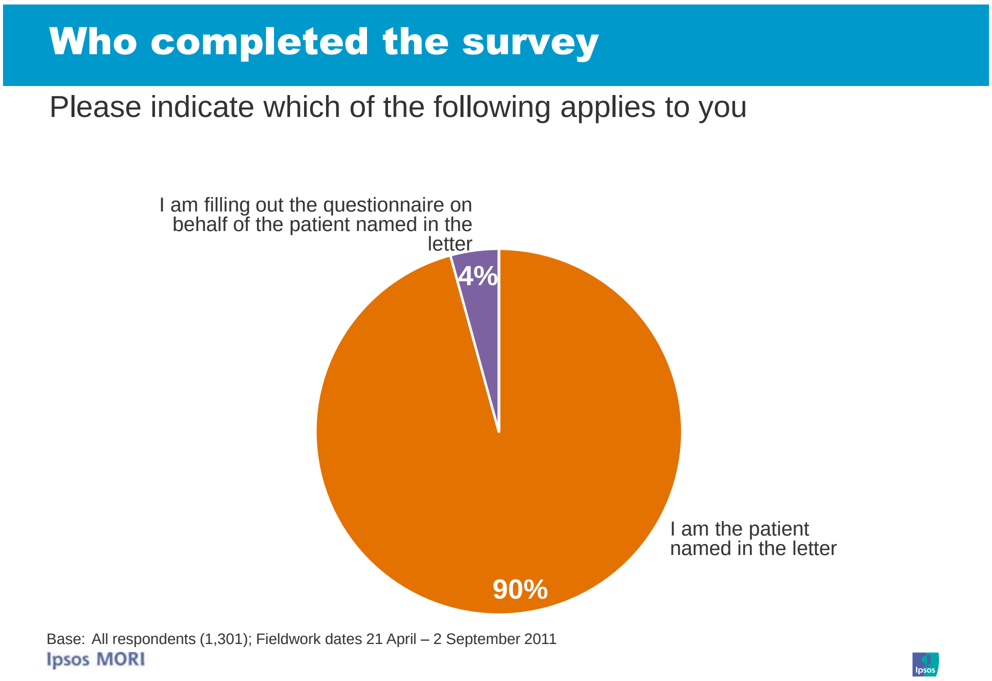
Effect of long-standing conditions on day-to-day activities

Q50 How much of an effect does this long-standing conditions have on your ability to carry out day-to-day activities?

Base: All who have long-standing conditions (546); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Nine-tenths of patients (90%) completed the survey themselves.



Who completed the survey

Please indicate which of the following applies to you

Base: All respondents (1,301); Fieldwork dates 21 April – 2 September 2011

Ipsos MORI

Appendix 2: Note on Data Editing

As mentioned in the methodology chapter of this report, a number of edits were applied to the data set as it was finalised. In the interests of full disclosure these are detailed below:

- If a respondent returned two questionnaires then the earliest returned questionnaire was accepted only;
- Questionnaires returned with no answers were excluded from the dataset;
- Question 1 - If cancer type was left blank, multi-coded, or did not match the tumour group (cancer type) which they were sampled for this was edited to match the sample. e.g. any patients responding “colorectal cancer” who were sampled as part of the Brighton breast cancer project were changed to “breast cancer”;
- Question 1 and Question 47 - If cancer type was given as Prostate and gender was given as female – this was changed to male;
- If any single-code question was multi-coded, all of these answers were dropped, and the respondent was counted as “not stated” for that question;
- Question 49 – if a respondent answered has said “I don’t have any long-standing conditions” but then selected a long-standing condition the “I don’t have any long-standing conditions” was ignored and any conditions selected were prioritised;
- Question 50 – this question was rebased to exclude those who selected “I don’t have any long standing condition” at Q49 and those figures were reported here. The data tables contain both iterations of data for this question;
- Question 25 and Question 26 – if a respondent answered “Yes” at Q25 and “I do not have a care plan” at Q26, then their response at Q25 was edited to “No” and Q26 answer blanked;
- Editing was applied based on the routing in the questions as displayed in the questionnaire; and
- When added in the coding questions editing was applied, for example for an answer coded at Q36 as both “receive results sooner” and “Don’t know” the “Don’t know” code was blanked.

Appendix 3: Statistical Reliability

The patients who took part in our survey are only a sample of the total "population" of patients, so we cannot be certain that the figures obtained are exactly those we would have if everybody had responded (the "true" values). We can, however, predict the variation between the sample results and the "true" values from knowledge of the size of the samples on which the results are based and the number of times a particular answer is given. The confidence with which we can make this prediction is usually chosen to be 95% - that is, the chances are 95 in 100 that the "true" value will fall within a specified range. The table below illustrates the predicted ranges for different sample sizes and percentage results at the "95% confidence interval":

Size of sample on which survey result is based	**Approximate sampling tolerances applicable to percentages at or near these levels**		
	10% or 90% ±	30% or 70% ±	50% ±
100 responses	6	9	10
200 responses	4	6	7
300 responses	3	5	6
500 responses	3	4	4
800 responses	2	3	4
1,000 responses	2	3	3
1,301 responses	2	3	3

For example, with a sample size of 1,301 where 30% give a particular answer, the chances are, 19 in 20, the "true" value (which would have been obtained if the whole population had been interviewed) will fall within the range of ±3 percentage points from the survey result (i.e. between 27% and 33%).

When results are compared between separate groups within a sample, different results may be obtained. The difference may be "real," or it may occur by chance (because not everyone in the population has been surveyed). To test if the difference is a real one - i.e. if it is "statistically significant", we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume "95% confidence interval", the differences between the results of two separate groups must be greater than the values given in the table below:

Size of samples compared	Differences required for significance at or near these percentage levels		
	10% or 90%	30% or 70%	50%
	±	±	±
100 and 100	8	13	14
100 and 400	7	10	11
200 and 200	6	9	10
200 and 400	5	8	9
300 and 300	5	7	8
400 and 400	4	6	7
500 and 500	4	6	6
500 and 1,000	3	5	6

Appendix 4: Questionnaire

Your experiences of aftercare

HOW TO COMPLETE THE SURVEY

BEFORE YOU FILL IN YOUR SURVEY PLEASE READ THE INFORMATION BELOW

All the questions require 'tick box' responses.

Please read each question carefully and tick the box ☑ that comes closest to your views, checking you have answered all questions. Answer the next question unless asked otherwise.

If you have received aftercare for your cancer from more than one NHS Hospital Trust, please think about where you received your care most recently when answering the questions.

In most cases you will only have to tick one box but please read the questions carefully as sometimes you will need to tick more than one box.

This questionnaire consists of 12 pages and should take no longer than 20 minutes to complete. Thank you in advance for your time.

What is the survey about?

The survey asks about the care you have received from the NHS since you finished your initial treatment for cancer. Your answers to this survey will help us to improve these services.

Q1 **Please tell us what your diagnosis was for the cancer you were diagnosed with most recently.**

Please only tick ✓ one box

☐ Breast cancer
☐ Prostate cancer
☐ Colorectal cancer

Q2 **In what year were you diagnosed with your most recent cancer?**

Please only tick ✓ one box

☐ 2011
☐ 2010
☐ 2009
☐ 2008
☐ 2007
☐ 2006
☐ 2005 or earlier
☐ I don't know / I can't remember

Q3 **And how long ago did you finish your initial treatment for the cancer you were diagnosed with most recently?** By initial treatment, we mean the surgery, radiotherapy, chemotherapy or hormone therapy that you received**.**

Please only tick ✓ one box

☐ Less than 6 months ago
☐ 6 months ago or more, but less than 1 year ago
☐ 1 year ago or more, but less than 2 years ago
☐ 2 years ago or more
☐ I have not finished my initial treatment
☐ I don't know / I can't remember

Q4 **Have you been diagnosed with a secondary cancer?**

Please only tick ✓ one box

☐ Yes ☐ No ☐ I don't know

These questions are about the care that you have received after your initial treatment for cancer was finished. By initial treatment, we mean the surgery, radiotherapy, chemotherapy, or hormone therapy, which you received.

Q5 **Overall, how would you rate the quality of the care and services you have received since your initial treatment finished?** **Please only tick ✓ one box**

☐ Excellent	☐ Poor
☐ Very good	☐ Very poor
☐ Good	☐ Terrible

We are now going to ask you some questions about your health and how your health has been since you finished your initial treatment. For each question, please tick the box that best describes how you feel.

When we say information, advice or support, we mean information, advice or support you have received from the NHS or other organisations, such as charities. Please do not include information, advice or support you have received from friends and family.

Feeling tired, weak or fatigued

Q6 **Have you had any problems with feeling tired, weak or fatigued since you finished your initial treatment for cancer?** This includes any problems that you do not have any more.

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q7** ☐ No **PLEASE GO TO Q8**

Please answer Q7 if you have had any problems with feeling tired, weak or fatigued since you finished your initial treatment for cancer. If you have not had any problems, please go to Q8.

Q7 **What, if anything, have you done about feeling tired, weak or fatigued?**

Please tick ✓ as many boxes as apply

- ☐ I have had advice or support that **has improved** how tired, weak or fatigued I feel
- ☐ I have had advice or support that **has helped me to adapt** to living with my tiredness, weakness or fatigue
- ☐ I have had advice or support but **it hasn't helped** with feeling tired, weak or fatigued
- ☐ **I haven't had any advice or support** to help with feeling weak, tired or fatigued
- ☐ **I have taken action myself** which improved or helped me adapt to how tired, weak or fatigued I feel
- ☐ I haven't done anything in particular but now **I feel less** tired, weak or fatigued
- ☐ I haven't done anything in particular and **I still feel** tired, weak or fatigued

Please can everyone answer this question.

Having trouble sleeping at night, or through the night

Q8 **Have you had any trouble sleeping at night, or through the night, since you finished your initial treatment for cancer?** This includes any trouble sleeping that you do not have any more.

Please only tick ✓ one box

☐ Yes PLEASE GO TO Q9 ☐ No PLEASE GO TO Q10

Please answer Q9 if you have had any trouble sleeping at night or through the night since you finished your initial treatment for cancer. If you have not had any problems, please go to Q10.

Q9 **What, if anything, have you done about having trouble sleeping at night, or through the night?**

Please tick ✓ as many boxes as apply

☐ I have had advice or support that **has helped** me to sleep at night
☐ I have had advice or support that **has helped me to adapt** to having trouble sleeping at night or through the night
☐ I have had advice or support but it **hasn't helped** me to sleep at night or through the night
☐ **I haven't had any advice or support** to help with trouble sleeping at night or through the night
☐ **I have taken action myself** which improved or helped me adapt to having trouble sleeping at night or through the night
☐ I haven't done anything in particular but I am **having less** trouble sleeping at night or through the night
☐ I haven't done anything in particular and I **still have** trouble sleeping at night or through the night

---

Please can everyone answer this question.

Physical activity or exercise

Q10 **Would you say that you do less physical activity or exercise than you did before you were diagnosed with cancer?** Physical activity or exercise includes many activities e.g. housework, walking, gardening, running going to the gym among other things.

Please only tick ✓ one box

☐ Yes PLEASE GO TO Q11 ☐ No PLEASE GO TO Q12

Please answer Q11 if you have done less physical activity or exercise than you did before you were diagnosed with cancer. If you have not had any problems, please go to Q12.

Q11 **What, if anything, have you done about doing less physical activity or exercise than you did before you were diagnosed with cancer?**

Please tick ✓ as many boxes as apply

☐ I have had advice or support that **has helped** me to do more physical activity or exercise again
☐ I have had advice or support but it **hasn't helped** me to do more physical activity or exercise again
☐ **I haven't had any advice or support** to help me to maintain or improve my physical activity or exercise
☐ **I have taken action myself** to help me do more physical activity or exercise again
☐ I haven't done anything in particular and **still do less physical activity or exercise** than I did

Please can everyone answer this question.

Q12 **In the past week on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate?**

This may include sport, exercise, brisk walking or cycling for recreation or to get you to and from places, but should not include housework or physical activity that is part of your job.

Please only tick ✓ one box

☐ 0 days ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 days

Change in your weight

Q13 **Have you noticed a change in your weight compared with before you were diagnosed with cancer?**

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q14** ☐ No **PLEASE GO TO Q15**

Please answer Q14 if you have noticed a change in your weight compared with before you were diagnosed with cancer. If you have not noticed a change, please go to Q15.

Q14 **What, if anything, have you done about the change in your weight?**

Please tick ✓ as many boxes as apply

☐ I have had advice or support that **has helped** my weight to go back to how it was before I was diagnosed

☐ I have had advice or support but **it hasn't helped** my weight to go back to how it was before I was diagnosed

☐ **I haven't had any advice or support** regarding changes in my weight

☐ **I have taken action myself** to change my weight back to how it was before I was diagnosed

☐ I haven't done anything in particular but my weight **has gone back** to how it was before I was diagnosed

☐ I haven't done anything in particular and my weight **still hasn't gone back** to how it was before I was diagnosed

---

Please can everyone answer this question.

Bowel or Urinary function

Q15 **Have you had any problems with your bowel or urinary function since you finished your initial treatment for cancer? This includes any problems that you do not have any more.**

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q16** ☐ No **PLEASE GO TO Q17**

Please answer Q16 if you have had any problems with your bowel or urinary function since you finished your initial treatment for cancer. If you have not had any problems, please go to Q17.

Q16 **What, if anything, have you done about these problems?**

Please tick ✓ as many boxes as apply

- ☐ I have had advice or support that **has improved** my bowel or urinary function
- ☐ I have had advice or support that has **helped me to adapt** to living with my bowel or urinary problems
- ☐ I have had advice or support but **it hasn't helped** with my bowel or urinary problems
- ☐ **I haven't had any advice or support** with bowel or urinary problems
- ☐ **I have taken action myself** which improved or helped me adapt to having bowel or urinary problems
- ☐ I haven't done anything in particular but my bowel or urinary problems **have got better**
- ☐ I haven't done anything in particular and my bowel or urinary problems **are still a problem**

Please can everyone answer this question.

Change in your interest in sex

Q17 **Have you noticed a change in your interest in sex in a way that you are not happy with since you were diagnosed with cancer?**

Please only tick ✓ one box

☐ Yes	☐ No	☐ Not relevant to me
PLEASE GO TO Q18	PLEASE GO TO Q19	PLEASE GO TO Q19

Please answer Q18 if you have noticed a change in your interest in sex since you were diagnosed with cancer. If you have not noticed any change or this is not relevant to you, please go to Q19.

Q18 **What, if anything, have you done about this change?**

Please tick ✓ as many boxes as apply

- ☐ I have had advice or support that has helped my interest in sex **go back** to how it was before I was diagnosed
- ☐ I have had advice or support that has helped me to **adapt to the change** in my interest in sex
- ☐ I have had advice or support but **it hasn't helped** my interest in sex go back to how it was before I was diagnosed
- ☐ **I haven't had any advice or support** to help with the change in my interest in sex
- ☐ **I have taken action myself** which improved or helped me adapt to the change in my interest in sex
- ☐ I haven't done anything in particular but my interest in sex **has gone back** to how it was before I was diagnosed
- ☐ I haven't done anything in particular and my interest in sex **still hasn't gone back** to how it was before I was diagnosed

Please can male respondents answer this question.

Change in your erectile function

Q19 **Have you noticed a change in your erectile function in a way that you are not happy with since you were diagnosed with cancer?**

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q20**

☐ No **PLEASE GO TO Q21**

☐ Not relevant to me **PLEASE GO TO Q21**

Please answer Q20 if you have noticed a change in your erectile function since you were diagnosed with cancer. If you have not noticed any change or this is not relevant to you, please go to Q21.

Q20 **What, if anything, have you done about this change?**

Please tick ✓ as many boxes as apply

☐ I have had advice or support that has helped my erectile function **go back** to how it was before I was diagnosed

☐ I have had advice or support that has helped me to **adapt to the change** in my erectile function

☐ I have had advice or support but **it hasn't helped** my erectile function go back to how it was before I was diagnosed

☐ **I haven't had any advice or support** to help with the change in my erectile function

☐ **I have taken action myself** which improved or helped me adapt to the change in my erectile function

☐ I haven't done anything in particular but my erectile function **has gone back** to how it was before I was diagnosed

☐ I haven't done anything in particular and my erectile function **still hasn't gone back** to how it was before I was diagnosed

---

Please can everyone answer this question.

Fear about the cancer coming back

Q21 **Have you felt afraid that the cancer will come back since you finished your treatment for cancer?** This includes any fear that you do not feel any more.

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q22**

☐ No **PLEASE GO TO Q23**

Please answer Q22 if you have felt afraid that the cancer will come back since you finished your initial treatment for cancer. If you have not felt afraid of this, please go to Q23.

Q22 **What, if anything, have you done about feeling afraid that the cancer will come back?**

Please tick ✓ as many boxes as apply

☐ I have had advice or support that has helped me to **feel less afraid** that the cancer will come back

☐ I have had advice or support that has helped me to **adapt to feeling afraid** that the cancer will come back

☐ I have had advice or support but **it hasn't helped** me to feel less afraid that the cancer will come back

☐ **I haven't had any advice or support** to help with feeling afraid that the cancer will come back

☐ **I have taken action myself** which improved or helped me adapt to being afraid that the cancer will come back

☐ I haven't done anything in particular but I **feel less afraid** that the cancer will come back

☐ I haven't done anything in particular and I **still feel afraid** that the cancer will come back

Please can everyone answer this question.

Feeling low or down

Q23 **Have you often felt low or down since you finished your initial treatment for cancer?** This includes any time that you have felt low or down since you finished treatment, even if you do not feel like that any more.

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q24** ☐ No **PLEASE GO TO Q25**

Please answer Q24 if you have often felt low or down since you finished your initial treatment for cancer. If you have not felt this way, please go to Q25.

Q24 **What, if anything, have you done about often feeling low or down?**
Please tick ✓ as many boxes as apply

☐ I have had advice or support and now **I feel low or down less often**
☐ I have had advice or support that has helped me to **adapt to feeling low or down**
☐ I have had advice or support but **it hasn't helped** me to feel low or down less often
☐ **I have taken action myself** which improved or helped me adapt to feeling low or down
☐ I haven't done anything in particular but I feel low or down **less often**
☐ I haven't done anything in particular and **I still often feel** low or down
☐ **I haven't had any advice or support** to help feeling low or down

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Section 2: Staying in touch with the NHS

A care plan

A care plan is a written document that sets out what you need and what support you get to help you manage your condition. It is a plan agreed between you and the people providing or supporting your care.

Q25 **Have you been given a care plan?**
Please only tick ✓ one box

☐ Yes ☐ No ☐ I was offered one but I didn't want it

Q26 **How useful do you find your care plan?** **Please only tick ✓ one box**

☐ Very useful
☐ Fairly useful
☐ Not very useful
☐ Not at all useful
☐ I have never looked at my care plan
☐ I don't have a care plan

Making contact

Q27-33 are about contact with services following your initial treatment for cancer

Q27 Do you know who to contact during office hours if you have a health concern related to cancer, or your treatment for cancer? **Please only tick ✓ one box**

☐ Yes ☐ No ☐ No, but I would know how to find out

Q28 **Have you ever needed to contact a health care professional about a health concern related to cancer, or your treatment for cancer, <u>during office hours</u>?**
Please only tick ✓ one box

☐ Yes ☐ No ☐ I don't know / I can't remember

Please answer Q29 if you have contacted a health care professional about a health concern related to cancer, or your treatment for cancer, <u>during office hours</u>. If you have not, please go to Q30.

Q29 **<u>Who</u> did you contact?**

Please tick ✓ as many boxes as apply

☐ My GP
☐ My GP practice nurse
☐ Cancer hospital nurse
☐ My pharmacist
☐ My Cancer doctor or their secretary
☐ My district nurse or community cancer nurse
☐ Someone else **(please write who in the box)**

☐

Q30 **Do you know who to contact <u>outside office hours</u> if you have a health concern related to cancer, or your treatment for cancer?**
Please only tick ✓ one box

☐ Yes ☐ No ☐ No, but I would know how to find out

Q31 **Have you ever needed to contact a health care professional about a health concern related to cancer, or your treatment for cancer, <u>outside office hours</u>?**
Please only tick ✓ one box

☐ Yes ☐ No ☐ I don't know / I can't remember

Please answer Q32 if you have contacted a health care professional about a health concern related to cancer, or your treatment for cancer, <u>outside office hours</u>. If you have not, please go to Q33.

Q32 **<u>Who</u> did you contact?**
Please tick ✓ as many boxes as apply

☐ My GP or out of hours service
☐ My hospital (department, ward or on call team)
☐ Someone else **(please write who in the box)**
☐ Accident and Emergency (A&E)
☐ Ambulance Service, NHS Direct (or equivalent, e.g. 111 when set up)

☐

Q33 **Over the past six months, how many times have you contacted your GP practice for advice or support with issues relating to your cancer, or your treatment for cancer?**
Please only tick ✓ one box

☐ 0
☐ 1-5
☐ 6-10
☐ 11-20
☐ 21 or more
☐ I don't know / I can't remember

Q34 **How confident do you feel about managing your health, if at all?**
Please only tick ✓ one box

☐ Very confident
☐ Fairly confident
☐ Not very confident
☐ Not at all confident
☐ Don't know

When we say advice, we mean advice and support you have received from the NHS or other organisations, such as charities. Please do not include advice you have received from friends and family.

Q35 **Do you have all the information, advice or support you need to help you to manage your health?** **Please only tick ✓ one box**

☐ Yes **PLEASE GO TO Q37**
☐ No **PLEASE GO TO Q36**

Q36 **What other information, advice or support do you need to help you to manage your health?** **Please write your answer in the box below**

Please can everyone answer this question.

Q37 **Have you had any advice or support that tried to help you carry on working since you were diagnosed with cancer? Please do not include any advice or support you had from friends or family.**
Please only tick ✓ one box

☐ Does not apply as I am retired
☐ I was unable to work prior to my cancer diagnosis
☐ I was not working when I was diagnosed with cancer
☐ Yes, and it has helped me to carry on working
☐ Yes, but it has not helped me to carry on working
☐ I was offered advice or support but I didn't need it
☐ No, but I did not need advice or support to help me carry on working
☐ No, and I would have liked to have advice or support to help me carry on working

For questions 38 – 42 please think about any advice or support that you might have received since you finished your initial treatment for cancer.

Q38 **Have you had any advice or support to help you continue to live in your own home?** Please do <u>not</u> include any advice or support you had from friends or family.

Please only tick ✓ one box

☐ I was not living in my own home prior to my cancer diagnosis
☐ Yes, and it has helped me to stay in my own home
☐ Yes, but it has not helped me to stay in my own home
☐ I was offered advice or support but I didn't need it
☐ No, but I didn't need advice or support to help me stay in my own home
☐ No, and I would have liked to have advice or support to help stay in my own home

Q39 **Have you had any advice or support with financial issues?** Please think about any financial issues that may have arisen because of your diagnosis with cancer and do <u>not</u> include any advice or support you had from friends or family.

Please only tick ✓ one box

☐ Yes, and it has helped me to cope with my financial issues
☐ Yes, but it has not helped me to cope with my financial issues
☐ I was offered advice or support but I didn't need it
☐ No, but I didn't need advice or support to help me with my financial issues
☐ No, and I would have liked to have advice or support to help me with my financial issues

Q40 **Have you had any advice or support about other practical things such as personal care, doing housework or shopping?** Please do <u>not</u> include any advice or support you had from friends or family.

Please only tick ✓ one box

☐ Yes, and it has helped me to cope with the practical things that I needed help with
☐ Yes, but it has not helped me to cope with the practical things that I needed help with
☐ I was offered advice or support but I didn't need it
☐ No, but I didn't need advice or support to help me cope with the practical things that I needed help with
☐ No, and I would have liked to have advice or support to help me cope with the practical things that I needed help with

Q41 **Do you have all of the information and advice that you need about the effects of your treatment?**

Please only tick ✓ one box

☐ Yes
☐ I was offered information or advice but I didn't need it
☐ No
☐ No, and I would have liked information or advice about the effects of my treatment

Q42 **At any point since you finished your initial treatment for cancer have you received any information, advice or support that was too late for it to be useful?**

Please only tick ✓ one box

☐ Yes **PLEASE GO TO Q43** ☐ No **PLEASE GO TO Q44**

Q43 **Please provide details of what this information, advice or support was for.**
Please write your answer in the box below

Please can everyone answer this question.

Q44 **Do you have all of the information and advice that you need about the signs and symptoms of cancer so that you can tell if the cancer comes back?**
Please only tick ✓ one box

☐ Yes
☐ No
☐ I was offered information or advice but I didn't need it

Q45 **What, if anything, would have improved the care that you have received since you finished your treatment for cancer?** **Please write your answer in the box below**

Section 4: About you

The following questions will help us to see how experiences vary between different groups of the population. Your responses will only be used for analysis purposes and will be treated in confidence. If you would prefer not to answer these questions, please leave them blank.

Q46 **Please indicate which of the following applies to you.**
Please only tick ✓ one box

☐ I am the patient named in the letter
☐ I am filling out this questionnaire on behalf of the patient named in the letter

If you are filling in this questionnaire on behalf of someone else, please ensure the patient's details are entered here, not those of the person filling in the form. Please remember that "you" refers to the patient.

Q47 **Are you male or female?**
Please only tick ✓ one box

☐ Male ☐ Female

Q48 **How old are you?**
Please only tick ✓ one box

☐ 18-30
☐ 31-35
☐ 36-40
☐ 41-45
☐ 46-50
☐ 51-55
☐ 56-60
☐ 61-65
☐ 66-70
☐ 71-75
☐ 76-80
☐ 81 or over

Q49 **Do you have any of the following long-standing conditions in addition to your cancer diagnosis?**
Please tick ✓ as many boxes as apply

☐ I do not have any long-standing conditions
☐ Deafness or a severe hearing impairment
☐ Blindness or partially sighted
☐ A long-standing physical condition e.g. arthritis, multiple sclerosis
☐ A learning disability
☐ A mental health condition
☐ A long-standing illness (apart from cancer) such as diabetes, chronic heart disease, epilepsy or HIV

Q50 **How much of an effect does this long standing condition / do these long standing conditions have on your ability to carry out day-to-day activities?**
Please only tick ✓ one box

☐ A great deal
☐ A fair amount
☐ Not very much
☐ No effect at all
☐ I do not have any long-standing conditions

Thank you very much for taking the time to complete this questionnaire.
Please return it to us in the freepost envelope provided, or send it back to: FREEPOST PLUS RSHB-CCJE-EAUR, Aftercare Service Evaluation, Ipsos MORI, Research Services House, Elmgrove Road, Harrow, HA1 2QG

Appendix 5: Topline Results

10-054658-01

Ipsos MORI

NHS Improvement - Cancer Aftercare Service Evaluation
Wave 1

Topline Results

28 October 2011

Technical Note - Wave 1

Results are based on a total of 1,301 completed surveys received from patients at 7 Test Sites in England, representing an adjusted response rate of 70%. Fieldwork was conducted between 21 April 2011 and 2 September 2011.

In each of the 7 Test Sites there existed one or more the following cancer pathways: Breast, Colorectal, Prostate. The sample for the study was drawn for each pathway. We requested up to 180 randomly selected patients that had been diagnosed with their cancer more than 6 months, but less than 24 months prior to the date of sampling.

A paper questionnaire and covering letter was sent out to each patient sampled. Two subsequent reminders, complete with questionnaires, were sent out during the fieldwork period.

The Test Sites and pathways involved in this study are:
Hull: Breast
Ipswich: Breast, Prostate
Luton: Prostate
Hillingdon: Breast, Prostate
Guy's and St Thomas': Colorectal
Bristol: Breast, Colorectal, Prostate
Brighton: Breast

Results are based on all respondents (1,301) unless otherwise stated.

Interpreting the data
An asterisk (*) indicates a percentage of less than 0.5% but greater than zero. Where percentages do not add up to 100 this is due to computer rounding or multiple responses.

Base sizes of less than 100 should be treated with caution and these results seen as indicative only. Bases of less than 30 should be treated with extreme caution and seen as indicative only.

Weighting
The data are unweighted.

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	**1301**	**589**	**483**	**229**
Q1	**Please tell us what your diagnosis was for the cancer you were diagnosed with most recently.**				
	Breast cancer	45%	100%	-	-
	Prostate cancer	37%	-	100%	-
	Colorectal cancer	18%	-	-	100%
	Not stated	-	-	-	-
	Base size:	**1301**	**589**	**483**	**229**
Q2	**In what year were you diagnosed with your most recent cancer?**				
	2011	2%	1%	2%	2%
	2010	47%	50%	45%	44%
	2009	45%	44%	43%	48%
	2008	3%	2%	3%	3%
	2007	*	-	1%	-
	2006	*	*	1%	-
	2005 or earlier	1%	1%	2%	-
	I don't know/I can't remember	1%	*	2%	1%
	Not stated	1%	1%	1%	2%
	Base size:	**1301**	**589**	**483**	**229**
Q3	**And how long ago did you finish your initial treatment for the cancer you were diagnosed with most recently? By initial treatment, we mean the surgery, radiotherapy, chemotherapy or hormone therapy that you received.**				
	Less than 6 months ago	17%	17%	15%	19%
	6 months ago or more, but less than 1 year ago	24%	26%	22%	23%
	1 year ago or more, but less than 2 years ago	31%	34%	23%	39%
	2 years ago or more	6%	5%	6%	8%
	I have not finished my initial treatment	17%	15%	25%	7%
	I don't know/I can't remember	1%	*	2%	1%
	Not stated	4%	2%	7%	3%
	Base size:	**1301**	**589**	**483**	**229**
Q4	**Have you been diagnosed with a secondary cancer?**				
	Yes	9%	7%	8%	14%
	No	83%	88%	81%	73%
	I don't know	6%	5%	8%	9%
	Not stated	2%	*	3%	4%
	Base size:	**1301**	**589**	**483**	**229**
Q5	**Overall, how would you rate the quality of the care and services you have received since your initial treatment finished?**				
	Excellent	32%	34%	25%	38%
	Very good	27%	27%	28%	28%
	Good	15%	15%	17%	14%
	Poor	5%	5%	5%	7%
	Very poor	1%	*	1%	1%
	Terrible	1%	*	1%	1%
	Not stated	19%	18%	24%	12%
	Excellent/very good	**59%**	**61%**	**53%**	**66%**
	Very poor/terrible	**1%**	*****	**2%**	**2%**
	Net excellent/very good	**58%**	**61%**	**51%**	**63%**
	Base size:	**1301**	**589**	**483**	**229**
Q6	**Have you had any problems with feeling tired, weak or fatigued since you finished your initial treatment for cancer? This includes any problems that you do not have any more.**				
	Yes	50%	56%	41%	55%
	No	39%	35%	45%	36%
	Not stated	11%	9%	15%	9%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	**650**	**327**	**197**	**126**
Q7	**What, if anything, have you done about feeling tired, weak or fatigued?**				
	I have had advice or support that has improved how tired, weak or fatigued I feel	9%	11%	5%	10%
	I have had advice or support that has helped me to adapt to living with my tiredness, weakness or fatigue	15%	16%	13%	17%
	I have had advice or support but it hasn't helped with feeling how tired, weak or fatigued	9%	8%	14%	5%
	I haven't had any advice or support to help with feeling tired, weak or fatigued	25%	21%	30%	25%
	I have taken action myself which improved or helped me adapt to how tired, weak or fatigued I feel	30%	32%	31%	25%
	I haven't done anything in particular but now I feel less tired, weak or fatigued	23%	27%	17%	25%
	I haven't done anything in particular and I still feel tired, weak or fatigued	19%	15%	23%	22%
	Not stated	3%	2%	3%	3%
	Base size:	**1301**	**589**	**483**	**229**
Q8	**Have you had any trouble sleeping at night, or through the night, since you finished your initial treatment for cancer? This includes any trouble sleeping that you do not have any more.**				
	Yes	42%	46%	37%	41%
	No	52%	49%	54%	52%
	Not stated	6%	5%	8%	7%
	Base size:	**547**	**272**	**181**	**94**
Q9	**What, if anything, have you done about having trouble sleeping at night, or through the night?**				
	I have had advice or support that has helped me to sleep at night	10%	11%	7%	13%
	I have had advice or support that has helped me to adapt to having trouble sleeping at night or through the night	11%	11%	11%	10%
	I have had advice or support but it hasn't helped me to sleep at night or through the night	11%	8%	14%	14%
	I haven't had any advice or support to help with trouble sleeping at night or through the night	22%	22%	23%	19%
	I have taken action myself which improved or helped me adapt to having trouble sleeping at night or through the night	24%	27%	21%	20%
	I haven't done anything in particular but I am having less trouble sleeping at night or through the night	19%	18%	18%	21%
	I haven't done anything in particular and I still have trouble sleeping at night or through the night	27%	24%	33%	28%
	Not stated	1%	1%	-	2%
	Base size:	**1301**	**589**	**483**	**229**
Q10	**Would you say that you do less physical activity or exercise than you did before you were diagnosed with cancer? Physical activity or exercise includes many activities, e. g. housework, walking, gardening, running and going to the gym among other things.**				
	Yes	44%	42%	40%	57%
	No	52%	55%	54%	41%
	Not stated	4%	3%	5%	3%
	Base size:	**572**	**248**	**194**	**130**
Q11	**What, if anything, have you done about doing less physical activity or exercise than you did before you were diagnosed with cancer?**				
	I have had advice or support that has helped me to do more physical activity or exercise again	9%	10%	6%	12%
	I have had advice or support but it hasn't helped me to do more physical activity or exercise again	10%	10%	9%	13%
	I haven't had any advice or support to help me to maintain or improve my physical activity or exercise	27%	27%	29%	25%
	I have taken action myself to help me do more physical activity or exercise again	42%	49%	37%	39%
	I haven't done anything in particular and still do less physical activity or exercise than I did	34%	27%	40%	37%
	Not stated	2%	2%	3%	-

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	1301	589	483	229
Q12	**In the past week on how many days have you done a total of 30 minutes or more of physical activity which was enough to raise your heart rate?**				
	0 days	25%	29%	19%	30%
	1	8%	9%	6%	8%
	2	15%	15%	15%	15%
	3	14%	14%	15%	13%
	4	9%	9%	10%	9%
	5	8%	8%	10%	7%
	6	4%	3%	5%	3%
	7 days	11%	10%	14%	8%
	Not stated	5%	4%	7%	6%
	Mean	**2.7**	**2.5**	**3.2**	**2.4**
	Base size:	1301	589	483	229
Q13	**Have you noticed a change in your weight compared with before you were diagnosed with cancer?**				
	Yes	47%	48%	41%	56%
	No	49%	49%	53%	40%
	Not stated	4%	3%	6%	4%
	Base size:	614	285	200	129
Q14	**What, if anything, have you done about the change in your weight?**				
	I have advice or support that has helped my weight to go back to how it was before I was diagnosed	5%	4%	3%	10%
	I have advice or support but it hasn't helped my weight to go back to how it was before I was diagnosed	9%	8%	9%	13%
	I haven't had any advice or support regarding changes in my weight	30%	32%	32%	22%
	I have taken action myself to change my weight back to how it was before I was diagnosed	34%	37%	33%	29%
	I haven't done anything in particular but my weight has gone back to how it was before I was diagnosed	9%	7%	8%	16%
	I haven't done anything in particular and my weight still hasn't gone back to how it was before I was diagnosed	33%	30%	40%	29%
	Not stated	2%	1%	2%	5%
	Base size:	1301	589	483	229
Q15	**Have you had any problems with your bowel or urinary function since you finished your initial treatment for cancer? This includes any problems that you do not have any more.**				
	Yes	38%	18%	55%	51%
	No	57%	78%	37%	45%
	Not stated	6%	4%	8%	4%
	Base size:	490	108	266	116
Q16	**What, if anything, have you done about these problems?**				
	I have had advice or support that has improved my bowel or urinary function	26%	21%	28%	27%
	I have had advice or support that has helped me to adapt to living with my bowel or urinary problems	21%	14%	21%	29%
	I have had advice or support but it hasn't helped me with my bowel or urinary function	13%	6%	13%	18%
	I haven't had any advice or support with bowel or urinary problems	14%	17%	13%	12%
	I have taken action myself which improved or helped me adapt to having bowel or urinary problems	21%	29%	18%	20%
	I haven't done anything in particular but my bowel or urinary problems have got better	11%	13%	11%	9%
	I haven't done anything in particular and my bowel or urinary problems are still a problem	21%	19%	21%	24%
	Not stated	3%	6%	3%	2%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	1301	589	483	229
Q17	**Have you noticed a change in your interest in sex in a way that you are not happy with since you were diagnosed with cancer?**				
	Yes	28%	20%	42%	17%
	No	33%	41%	25%	29%
	Not relevant to me	34%	36%	26%	45%
	Not stated	5%	3%	7%	8%
	Base size:	362	117	205	40
Q18	**What, if anything, have you done about this change?**				
	I have had advice or support that has helped my interest in sex go back to how it was before I was diagnosed	5%	1%	7%	5%
	I have had advice or support that has helped me to adapt to the change in my interest in sex	9%	5%	12%	8%
	I have had advice or support but it hasn't helped my interest in sex go back to how it was before I was diagnosed	14%	7%	19%	10%
	I haven't had any advice or support to help with the change in my interest in sex	34%	38%	31%	35%
	I have taken action myself which improved or helped me adapt to the change in my interest in sex	10%	13%	9%	5%
	I haven't done anything in particular but my interest in sex has gone back to how it was before I was diagnosed	4%	3%	3%	5%
	I haven't done anything in particular and my interest in sex still hasn't gone back to how it was before I was diagnosed	52%	59%	48%	53%
	Not stated	1%	2%	1%	-
	Base size:	596	6	483	107
Q19	**Have you noticed a change in your erectile function in a way that you are not happy with since you were diagnosed with cancer?**				
	Yes	43%	67%	45%	31%
	No	20%	17%	16%	38%
	Not relevant to me	22%	17%	21%	27%
	Not stated	15%	-	17%	4%
	Base size:	256	4	219	33
Q20	**What, if anything, have you done about this change?**				
	I have had advice or support that has helped my erectile function go back to how it was before I was diagnosed	5%	-	5%	6%
	I have had advice or support that has helped me to adapt to the change in my erectile function	16%	-	17%	9%
	I have had advice or support but it hasn't helped my erectile function go back to how it was before I was diagnosed	24%	-	24%	24%
	I haven't had any advice or support to help with the change in my erectile function	30%	25%	29%	36%
	I have taken action myself which improved or helped me adapt to the change in my erectile function	5%	-	6%	3%
	I haven't done anything in particular but my erectile function has gone back to how it was before I was diagnosed	1%	-	1%	-
	I haven't done anything in particular and my erectile function still hasn't gone back to how it was before I was diagnosed	45%	100%	44%	45%
	Not stated	2%	-	2%	3%
	Base size:	1301	589	483	229
Q21	**Have you felt afraid that the cancer will come back since you finished your treatment for cancer? This includes any fear that you do not feel any more.**				
	Yes	49%	64%	34%	46%
	No	42%	32%	52%	47%
	Not stated	9%	5%	14%	7%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	642	375	162	105
Q22	**What, if anything, have you done about feeling afraid that the cancer will come back?**				
	I have had advice or support that has helped me to feel less afraid that the cancer will come back	17%	15%	23%	16%
	I have had advice or support that has helped me to adapt to feeling afraid that the cancer will come back	10%	9%	12%	10%
	I have had advice or support but it hasn't helped me to feel less afraid that the cancer will come back	8%	8%	6%	11%
	I haven't had any advice or support to help with feeling afraid that the cancer will come back	23%	25%	21%	21%
	I have taken action myself which improved or helped me adapt to being afraid that the cancer will come back	12%	12%	12%	9%
	I haven't done anything in particular but I feel less afraid that the cancer will come back	24%	23%	23%	29%
	I haven't done anything in particular and I still feel afraid that the cancer will come back	28%	31%	24%	22%
	Not stated	2%	2%	4%	2%
	Base size:	1301	589	483	229
Q23	**Have you often felt low or down since you finished your initial treatment for cancer? This includes any time that you have felt low or down since you finished treatment, even if you do not feel like that any more.**				
	Yes	47%	54%	36%	53%
	No	45%	40%	53%	40%
	Not stated	8%	6%	11%	7%
	Base size:	616	321	174	121
Q24	**What, if anything, have you done about often feeling low or down?**				
	I have had advice or support and now I feel low or down less often	14%	17%	8%	14%
	I have had advice or support that has helped me to adapt to feeling low or down	12%	10%	11%	17%
	I have had advice or support but it hasn't helped me to feel low or down less often	7%	6%	8%	7%
	I have taken action myself which improved or helped me adapt to feeling low or down	32%	31%	29%	39%
	I haven't done anything in particular but I feel low or down less often	25%	27%	22%	26%
	I haven't done anything in particular and I still often feel low or down	13%	13%	16%	11%
	I haven't had any advice or support to help feeling low or down	19%	16%	25%	17%
	Not stated	2%	2%	1%	2%
	Base size:	1301	589	483	229
Q25	**Have you been given a care plan?**				
	Yes	21%	24%	19%	21%
	No	69%	66%	72%	69%
	I was offered one but I didn't want it	4%	4%	3%	3%
	Not stated	6%	6%	6%	7%
	Base size:	279	141	91	47
Q26	**How useful do you find your care plan?**				
	Very useful	41%	40%	37%	47%
	Fairly useful	43%	44%	42%	43%
	Not very useful	6%	6%	5%	9%
	Not at all useful	3%	3%	3%	-
	I have never looked at my care plan	6%	6%	10%	-
	I don't have a care plan	-	-	-	-
	Not stated	1%	1%	2%	2%
	Useful	**84%**	**84%**	**79%**	**89%**
	Not useful	**9%**	**9%**	**9%**	**9%**
	Net useful	**75%**	**76%**	**70%**	**81%**

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	**1301**	**589**	**483**	**229**
Q27	**Do you know who to contact during office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	77%	83%	69%	80%
	No	8%	4%	13%	10%
	No, but I would know how to find out	10%	10%	11%	6%
	Not stated	5%	3%	7%	4%
	Base size:	**1301**	**589**	**483**	**229**
Q28	**Have you ever needed to contact a health care professional about a health concern related to cancer, or your treatment for cancer, during office hours?**				
	Yes	47%	55%	37%	46%
	No	45%	39%	53%	44%
	I don't know/I can't remember	2%	2%	2%	3%
	Not stated	6%	4%	7%	7%
	Base size:	**607**	**322**	**179**	**106**
Q29	**Who did you contact?**				
	My GP	38%	36%	42%	35%
	My GP practice nurse	5%	3%	6%	8%
	Cancer hospital nurse	71%	77%	58%	74%
	My pharmacist	2%	2%	2%	4%
	My cancer doctor or their secretary	22%	17%	30%	23%
	My district nurse or community cancer nurse	9%	7%	13%	8%
	Health care at home representative	*	1%	-	-
	Hospice	1%	1%	1%	1%
	Macmillan nurse	3%	3%	2%	2%
	Radiotherapist	*	1%	1%	-
	Trials practitioner/ nurse	*	-	1%	-
	Other support teams/ centres	2%	2%	1%	2%
	Someone else	1%	1%	1%	1%
	Not stated	2%	2%	1%	4%
	Base size:	**1301**	**589**	**483**	**229**
Q30	**Do you know who to contact outside office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	38%	40%	33%	45%
	No	36%	34%	41%	32%
	No, but I would know how to find out	20%	22%	19%	19%
	Not stated	5%	5%	7%	3%
	Base size:	**1301**	**589**	**483**	**229**
Q31	**Have you ever needed to contact a health care professional about a health concern related to cancer, or your treatment for cancer, outside office hours?**				
	Yes	14%	16%	11%	15%
	No	78%	77%	81%	77%
	I don't know/I can't remember	2%	3%	2%	3%
	Not stated	5%	4%	7%	5%
	Base size:	**182**	**96**	**51**	**35**
Q32	**Who did you contact?**				
	My GP or out-of-hours service	28%	22%	35%	34%
	My hospital (department, ward or on-call team)	59%	78%	35%	43%
	Accident and Emergency (A&E)	14%	13%	18%	11%
	Ambulance service, NHS Direct (or equivalent, e. g. 111 when set up)	18%	10%	25%	26%
	Friend who is a doctor	1%	-	2%	3%
	Hospice	1%	1%	2%	-
	Someone else	5%	2%	8%	9%
	Not stated	10%	7%	14%	14%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	1301	589	483	229
Q33	**Over the past six months, how many times have you contacted your GP practice for advice or support with issues relating to your cancer, or your treatment for cancer?**				
	0	53%	59%	45%	53%
	1 to 5	38%	33%	44%	37%
	6 to 10	3%	2%	2%	3%
	11 to 20	1%	1%	-	1%
	21 or more	*	1%	*	-
	I don't know/I can't remember	2%	1%	4%	3%
	Not stated	4%	3%	5%	3%
	Base size:	1301	589	483	229
Q34	**How confident do you feel about managing your health, if at all?**				
	Very confident	30%	31%	28%	31%
	Fairly confident	53%	53%	53%	55%
	Not very confident	8%	8%	9%	8%
	Not at all confident	2%	3%	2%	1%
	Don't know	3%	2%	4%	2%
	Not stated	4%	3%	5%	3%
	Confident	**83%**	**84%**	**81%**	**86%**
	Not confident	**10%**	**11%**	**11%**	**9%**
	Net confident	**73%**	**74%**	**70%**	**76%**
	Base size:	1301	589	483	229
Q35	**Do you have all the information, advice or support you need to help you manage your health?**				
	Yes	78%	78%	77%	77%
	No	14%	14%	13%	15%
	Not stated	9%	8%	9%	8%
	Base size:	179	80	65	34
Q36	**What other information, advice or support do you need to help you manage your health?**				
	Better communication	2%	1%	3%	-
	Counselling	1%	1%	-	-
	I contact/see medical staff at hospital/ clinic/surgery	3%	3%	-	12%
	Improve/more care/ aftercare	6%	9%	3%	6%
	Improve scheduling of appointments/less waiting time/ cancellations	1%	3%	-	-
	Mentions of other/ illnesses/symptoms	5%	1%	9%	6%
	More contact with medical professionals	6%	5%	8%	3%
	More follow-up appointments and checkups	4%	4%	3%	9%
	More general advice/ information	28%	28%	28%	29%
	More help/support/groups	13%	21%	3%	12%
	More information on medication/side affects	6%	9%	-	9%
	Receive help/support from other groups/ friends etc.	1%	3%	-	-
	Receive results sooner	2%	1%	-	6%
	Still receiving treatment/ongoing	2%	-	2%	6%
	Other	3%	3%	5%	3%
	Nothing/all staff are very good/helpful/ recieved all the information I needed/ everything's good	8%	11%	8%	3%
	Don't know	1%	-	3%	-
	No answer/blank	1%	3%	-	-
	Not stated	35%	28%	40%	44%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	1301	589	483	229
Q37	**Have you had any advice or support that tried to help you carry on working since you were diagnosed with cancer? Please do not include any advice or support you had from friends or family.**				
	Does not apply as I am retired	62%	53%	72%	67%
	I was unable to work prior to my cancer diagnosis	2%	1%	1%	3%
	I was not working when I was diagnosed with cancer	4%	6%	1%	4%
	Yes, and it has helped me to carry on working	6%	8%	4%	4%
	Yes, but it has not helped me to carry on working	1%	2%	*	2%
	I was offered advice or support but I didn't need it	2%	3%	1%	2%
	No, but I did not need advice or support to help me carry on working	15%	19%	11%	10%
	No, and I would have liked to have advice or support to help me carry on working	2%	3%	1%	2%
	Not stated	6%	5%	7%	6%
	Base size:	1301	589	483	229
Q38	**Have you had any advice or support to help you continue to live in your own home? Please do not include any advice or support you had from friends or family.**				
	I was not living in my own home prior to my cancer diagnosis	2%	3%	2%	2%
	Yes, and it has helped me to stay in my own home	6%	5%	5%	7%
	Yes, but it has not helped me to stay in my own home	*	*	*	1%
	I was offered advice or support but I didn't need it	7%	6%	6%	10%
	No, but I didn't need advice or support to help me stay in my own home	74%	77%	73%	70%
	No, and I would have liked to have advice or support to help stay in my own home	3%	3%	3%	3%
	Not stated	8%	7%	10%	7%
	Base size:	1301	589	483	229
Q39	**Have you had any advice or support with financial issues? Please think about any financial issues that may have arisen because of your diagnosis with cancer and do not include any advice or support you had from friends or family.**				
	Yes, and it has helped me to cope with my financial issues	7%	6%	5%	10%
	Yes, but it has not helped me to cope with my financial issues	2%	2%	1%	1%
	I was offered advice or support but I didn't need it	4%	4%	4%	7%
	No, but I didn't need advice or support to help me with my financial issues	71%	73%	73%	59%
	No, and I would have liked to have advice or support to help me with my financial issues	9%	10%	6%	16%
	Not stated	7%	5%	11%	7%
	Base size:	1301	589	483	229
Q40	**Have you had any advice or support about other practical things such as personal care, doing housework or shopping? Please do not include any advice or support you had from friends or family.**				
	Yes, and it has helped me to cope with the practical things that I needed help with	7%	8%	4%	11%
	Yes, but it has not helped me to cope with the practical things that I needed help with	1%	1%	1%	*
	I was offered advice or support but I didn't need it	6%	6%	4%	10%
	No, but I didn't need advice or support to help me cope with the practical things that I needed help with	71%	72%	75%	61%
	No, and I would have liked to have advice or support to help me cope with the practical things that I needed help with	6%	6%	5%	8%
	Not stated	9%	6%	12%	9%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	1301	589	483	229
Q41	**Do you have all of the information and advice that you need about the effects of your treatment?**				
	Yes	75%	81%	70%	70%
	I was offered information or advice but I didn't need it	2%	2%	2%	3%
	No	6%	4%	7%	11%
	No, and I would have liked information or advice about the effects of r	10%	9%	12%	7%
	Not stated	7%	4%	10%	8%
	Base size:	1301	589	483	229
Q42	**At any point since you finished your initial treatment for cancer have you received any information, advice or support that was to late for it to be useful?**				
	Yes	5%	5%	4%	6%
	No	83%	87%	80%	81%
	Not stated	12%	7%	16%	13%
	Base size:	65	32	19	14
Q43	**Please provide details of what this information, advice or support was for.**				
	Booklets/leaflets	8%	6%	16%	-
	Happy with the care/ help/support I received	5%	6%	-	7%
	Have regular check-ups	6%	3%	16%	-
	Help from Marie Curie/ Macmillan nurses/breast cancer care etc.	6%	6%	-	14%
	Lack of support	3%	3%	5%	-
	Mentions of illness/ symptoms only	2%	-	-	7%
	More advice/information on medication/ prescriptions needed	6%	6%	-	14%
	More information/advice/ given sooner	29%	31%	32%	21%
	Not happy with treatment/care received	6%	13%	-	-
	Offered treatment/advice too late	9%	9%	5%	14%
	Still receiving/ongoing treatment	2%	-	5%	-
	Other	6%	3%	5%	14%
	Not stated	26%	22%	26%	36%
	Base size:	1301	589	483	229
Q44	**Do you have all of the information and advice that you need about the signs and symptoms of cancer so that you can tell if the cancer comes back?**				
	Yes	54%	62%	48%	46%
	No	37%	32%	40%	45%
	I was offered information or advice but I didn't need it	1%	1%	1%	2%
	Not stated	8%	5%	11%	7%
	Base size:	1301	589	483	229
Q45	**What, if anything, would have improved the care that you have received since you finished your treatment for cancer?**				
	Improve care/aftercare/ care plan	5%	5%	4%	6%
	Improve/cheaper parking	*	1%	*	*
	Improve communication between hospital staff/ GPs/patients	1%	1%	1%	*
	Mentions of other illnesses/symptoms	2%	1%	2%	3%
	More check-ups/follow-up appointment	3%	3%	3%	2%
	More contact/time spent with specialists/ doctors/nurses/own GP etc.	3%	3%	2%	4%
	More information/advice	9%	9%	11%	6%
	More help/support/local support groups	4%	5%	2%	5%
	One point of contact/ contact number/out of hours	*	1%	*	*
	Overworked staff/more needed	1%	1%	-	*
	Receive results via email/text/phone	*	*	*	-
	Received help/support from family/friends	*	1%	*	-
	Staff could have been better/more informed/ helpful	2%	2%	1%	3%
	Still receiving/ongoing treatment	4%	2%	7%	3%
	Waiting times/for results/appointments	4%	4%	3%	3%
	Other	1%	2%	1%	-
	No improvement needed	17%	18%	15%	18%
	Don't know	1%	*	1%	2%
	Not stated	55%	55%	55%	54%

Ipsos MORI

			Cancer pathway		
		Total	Breast	Prostate	Colorectal
	Base size:	**1301**	**589**	**483**	**229**
Q46	**Please indicate which of the following applies to you.**				
	I am the patient named in the letter	90%	93%	89%	87%
	I am filling out this questionnaire on behalf of the patient named in the	4%	2%	4%	7%
	Not stated	6%	5%	7%	6%
	Base size:	**1301**	**589**	**483**	**229**
Q47	**Are you male or female?**				
	Male	46%	1%	100%	47%
	Female	48%	88%	-	45%
	Not stated	6%	11%	-	9%
	Base size:	**1301**	**589**	**483**	**229**
Q48	**How old are you?**				
	18 - 30	*	*	-	-
	31 - 35	*	1%	-	*
	36 - 40	2%	4%	-	*
	41 - 45	3%	5%	*	1%
	46 - 50	4%	8%	1%	3%
	51 - 55	6%	10%	1%	4%
	56 - 60	8%	9%	6%	8%
	61 - 65	14%	15%	13%	10%
	66 - 70	16%	15%	18%	15%
	71 - 75	16%	9%	23%	16%
	76 - 80	13%	8%	16%	17%
	81 or over	15%	11%	16%	22%
	Not stated	4%	4%	4%	3%
	Base size:	**1301**	**589**	**483**	**229**
Q49	**Do you have any of the following long-standing conditions in addition to your cancer diagnosis?**				
	I do not have any longstanding conditions	47%	54%	42%	40%
	Deafness or a severe hearing impediment	10%	8%	13%	11%
	Blindness or partially sighted	3%	2%	3%	5%
	A long-standing physical condition, e. g. arthritis, multiple sclerosis	21%	22%	20%	21%
	A learning disability	1%	1%	1%	*
	A mental health condition	2%	2%	3%	3%
	heart disease, epilepsy or HIV	17%	12%	19%	27%
	Not stated	11%	11%	13%	8%
	Base size:	**546**	**207**	**219**	**120**
Q50	**How much of an effect does this long-standing condition/do these long-standing conditions have on your ability to carry out day-to-day activities?**				
	A great deal	21%	27%	17%	18%
	A fair amount	29%	27%	27%	34%
	Not very much	33%	35%	35%	28%
	No effect at all	13%	8%	14%	18%
	I do not have any longstanding conditions	2%	2%	2%	1%
	Not stated	3%	1%	5%	3%
	Great deal/fair amount	**49%**	**54%**	**44%**	**52%**
	Not very much/no effect at all	**46%**	**43%**	**49%**	**45%**
	Net great deal/fair amount	**3%**	**11%**	**-5%**	**7%**