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Ipsos MORI
Social Research Institute

National Cancer Survivorship Initiative

Evaluation of Adult Cancer Aftercare Services - Follow-up Survey Report

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Executive Summary

This report represents the findings from the follow-up wave of a service evaluation study commissioned by NHS Improvement. This builds on the first wave conducted in 2011 across seven existing Test Communities (TCs) who were implementing new risk stratified pathways of care. A further seven new TCs have now started to implement the pathways and the follow-up survey was conducted across all 14 TCs. Results from the existing and new TCs have been analysed separately.

The research was conducted using a quantitative methodology. A 12-page postal questionnaire was sent to 4,313 eligible patients across 30 tumour projects at 14 TCs. A total of 2,648 completed questionnaires were received back, representing an adjusted response rate of 60%. Further details can be found in the methodology section.

Overall quality of care

Existing Test Communities

Amongst patients at the existing TCs, more patients now rate the aftercare they have received as ‘excellent’ or ‘very good’ than in 2011 (68% compared to 59% at the baseline). However, it is important not to overlook the very small proportion rating their care as ‘poor’, ‘very poor’ or ‘terrible’. The differences between the tumour groups have narrowed somewhat since the baseline, although breast cancer patients remain the most positive.

New Test Communities

Results amongst patients at the new TCs are similarly positive, with more than seven in ten (71%) rating their care as ‘excellent’ or ‘very good’. Worth noting again is the small minority (4%) who rate their care as ‘poor’ or worse. Colorectal patients are more positive than other patients about the quality of care.

Patients’ need for advice and support

Existing Test Communities

There has been a slight reduction in the proportion of patients at the existing TCs who feel that they have all the information, advice or support they need to help manage their health. This has fallen to just under three-quarters (74% vs 78% in 2011).

However, there has been good progress made to address the information deficit identified in the baseline survey regarding the signs and symptoms of cancer. Two-thirds (66%) of patients now feel that they have the information they need, compared to 54% in the baseline. Patients remain well informed about the effects of their treatment (74%), and a very small minority of patients reported have received information too late for it to be of use (6%).

New Test Communities

Reflecting results at the existing TCs, a majority (73%) of patients appear to have all the information, advice and support that they need to manage their health. However, patients appear to need more information regarding the signs and symptoms of cancer. Around six in ten patients (61%) feel that they have all they need about the signs and symptoms of cancer.

As with patients at the baseline communities, patients are relatively well informed about the effects of treatment (73%), and only a very small proportion (7%) have received information too late for it to be useful.

Self managed care

Existing Test Communities

Overall, a large majority of patients (84%) are confident managing their own health, remaining in line with the baseline. Patients also feel confident managing the impact of their cancer on their health, though slightly less so at 75%. This was not asked at the baseline, so this provides some useful additional information.

We saw in the baseline that patients displayed a greater ability to self manage some problems and issues than others. Some progress has been made in relation to support for patients suffering from tiredness, weakness or fatigue. The proportion of patients reporting that they have not had any advice or support here has fallen to less than one in five (18%).

Around one third of patients experiencing this problem have taken action themselves to deal with it (32%).

There are a number of issues where patients still appear less able to deal with them on their own:

- Around one in eight (14%) who are scared that the cancer will come back have dealt with this on their own.

- Only around one in ten (11%) experiencing a change in their interest in sex (that they were not happy with) have taken action themselves to improve this.

- Just seven per cent of patients who have had problems with erectile function since treatment have taken action themselves.

Other aspects of self managed care have experienced little or no change since the baseline. Patients appear most able to take action themselves in relation to changes in weight (33%) and decrease in physical activity (38%).

New Test Communities

At the new TCs, as with the existing, the vast majority of patients feel confident in managing their own health (84%). A slightly lower, but still high, proportion (78%) feels confident managing the impact of their cancer on their health.

Patients are able to self manage some issues better than others. In particular, more than four in ten (42%) patients who have suffered a decrease in their level of physical activity and exercise have taken action themselves that has helped. Around a third of patients also took action themselves that helped with feeling tired, weak or fatigued; a change in weight; or feeling low or down (34%; 32%; 33%).

As in the existing TCs, issues where patients have more trouble include:

- Dealing with a change in their interest in sex – almost half (49%) have not done anything and still have problems;
- Change in erectile function – more than four in ten (46%) have not done anything and still have problems; and

- Being afraid that the cancer will come back – a quarter (25%) have not done anything and still have problems, while only around one in eight (14%) have taken action themselves that has helped.

Contact with health professionals

Existing Test Communities

Representing one of the most significant changes since the baseline survey, more than one third of patients now have a care plan (35%). This has increased from just one in five (21%) previously. However, there has been a seven percentage point decrease in the proportion of patients who find this care plan to be useful (84% to 77%).

A large majority (78%) again report knowing 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 say that they do not know, but would know how to find out. Both of these figures are very similar to the baseline. More than four in ten (44%) patients have contacted somebody during office hours – and the cancer hospital nurse remains the most frequently cited, followed by more than a third who have contacted their GP.

As with the baseline survey, outside of office hours a much lower proportion of patients say they know who to contact (37%), while almost a quarter (24%) would know how to find out. Only around one in ten (11%) have ever had to do so, most frequently contacting their hospital.

New Test Communities

Three in ten patients (30%) have a care plan, which is higher than at the existing TCs during the baseline survey. Encouragingly, more than four in five of these (84%) think their care plan is useful.

A high proportion of patients know who to contact during office hours, while just over four in ten (43%) have done so. As we would expect, those who have contacted somebody have most frequently contacted their cancer hospital nurse. A much lower proportion know who to contact outside of office hours (35%), and only around one in eight (12%) have done so. Almost half of these patients (49%) have contacted their hospital department.

Implications

The work of the NCSI and the Test Communities involved over the last 3 years, and the survey work conducted to evaluate this, can be considered to have implications on three levels. First of all, the findings serve to inform the future work of the hospitals involved as Test Communities, providing guidance for areas that still require attention. Secondly, there are implications for the wider cancer survivorship agenda, as the NCSI Vision continues to 2015, and cancer aftercare more generally. Finally, there is some learning that can be taken from this work and applied to the wider agenda regarding the treatment and management of long term conditions.

Overall, while the findings are encouraging and broadly positive, they illustrate some key issues that remain and require further attention. In particular, it is important that continuing efforts are made to ensure that all patients have all the information they need about the signs and symptoms of their cancer. There has been good progress made here, but there is room for further progress to be made. The issues of fatigue and physical activity also represent areas requiring further attention. While various initiatives have been implemented at several of the existing Test Communities to try and help patients increase their levels of physical activity, there has been little sign of improvement since the baseline survey. This indicates that further work is required to demonstrate to patients the importance of physical activity and exercise.

It is frequently male patients who appear the least likely to seek help or take action themselves across various issues, which perhaps indicates that healthcare professionals need to tailor their conversations with patients and encourage men in particular to seek help.

As we have mentioned throughout this report, whether or not patients have a care plan is often a key factor in whether patients have had the necessary information and support to deal with various issues. However, the reduction in the proportion of patients finding their care plans useful since the baseline survey is intriguing. This indicates that there may be further work needed to understand how best care plans should be used with patients, and how patients might benefit from the care plan and planning process surrounding this.

Furthermore, a wider implication is that patients without a care plan are more likely to contact their cancer doctor, and therefore increasing the proportion of patients with a care plan may further reduce the frequency of this contact, reducing the burden on cancer doctors.

Ultimately, this survey illustrates the good work that the Test Communities have been involved in, whilst also highlighting some areas where there is room for further improvement as they continue their work over the coming years. In addition, there is much that can be learnt to help ensure the efficacy of any future survivorship initiatives, whether at the national level, or undertaken by individual hospitals.

1. Background & objectives

1. Background & objectives

1.1 Background

Ipsos MORI was commissioned by NHS Improvement in January 2011 to conduct a baseline survey as part of an 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).

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

The Cancer Survivorship Initiative was one of the Cancer Programme’s three national priorities for 2009-2010 which considered a range of approaches to survivorship care and how these could best be tailored to meet individual patients’ needs. The focus of cancer survivorship was 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 promotes ‘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;
- a 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 commencement of the baseline survey.

In September 2012 Ipsos MORI was again commissioned by NHS Improvement to conduct a follow-up survey amongst the seven TCs participating in the baseline survey (‘existing’ TCs). In addition, since the baseline survey eight ‘new’ TCs had joined the programme, and therefore the survey was also conducted with patients from these TCs, to provide information on the current experiences of their patients.

1.2 Objectives

The overarching objective of this research project is to evaluate the new model of care implemented in the TCs. In order to do this a quantitative survey was conducted. This has been conducted in two waves. The first wave was designed to establish a ‘baseline’ level of findings, against which results achieved in the follow-up wave could be compared, for those TCs who took part in the baseline survey. For those TCs who have joined the programme since the baseline survey, the second wave provides information on experiences at the current time, and effectively provides them with a set of baseline data.

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 three tumour groups involved in the initiative (breast, colorectal and prostate cancer).

This report contains the findings from the follow-up survey, with comparisons drawn with the baseline survey where appropriate.

1.3 Structure of this report

The main body of this report is divided into two sections. In the first section, we focus on the results from the follow-up survey at the 7 existing TCs. Beginning with an overview of the baseline survey, this section is then divided thematically to cover: overall quality of care; patients' need for information and advice; self managed care; and care plans and contact with health professionals. Within each of these chapters, our main focus is on problems, issues, information or service gaps identified by the baseline study, and examining what progress, if any, has been made against the baseline.

In the second section of the report we move on to examine the results obtained by the new TCs, following the same thematic structure. Whilst it is not possible to make direct comparisons to the results obtained at the existing test communities, where useful, broad overarching comparisons are drawn.

2. Methodology

2. Methodology

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

The follow-up survey was conducted across a total of thirty cancer pathways, across the fourteen 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. For each of the existing TCs, a new patient sample was drawn, and therefore while some of the same patients may have taken part in both the baseline and follow-up survey, they were not sampled in this way, and it is not possible to make any longitudinal comparisons.

Existing Test Communities

- **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.

New Test Communities

- **Dorset County Hospital NHS Foundation Trust –** Breast Cancer, Colorectal Cancer, and Prostate Cancer;
- **Ipswich Hospital NHS Trust –** Colorectal Cancer[1];

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[1] Ipswich added colorectal cancer to their programme following the baseline survey.

- **The North West London Hospitals NHS Trust** – Breast Cancer, Colorectal Cancer, and Prostate Cancer;
- **Royal Marsden NHS Foundation Trust** – Breast Cancer, Colorectal Cancer, and Prostate Cancer;
- **Royal United Hospital Bath NHS Trust** – Breast Cancer, Prostate Cancer;
- **Salford Royal NHS Foundation Trust –** Colorectal Cancer[2];
- **St George's Healthcare Trust** – Breast Cancer, Colorectal Cancer, and Prostate Cancer; and
- **West Hertfordshire Hospitals NHS Trust –** Breast Cancer, Colorectal Cancer, and Prostate Cancer.

Throughout this report we refer to the cancer types and hospitals involved at two 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; and
- **Test Community (TC)** – each of the seven sites involved in the study.

2.1 Sampling of patients

Sampling was conducted by the TCs, following advice and guidance provided by Ipsos MORI. The TCs were directed to randomly select 160 patients within each cancer pathway[3]. A step-by-step guide on how to draw a random sample was sent to each TC Patients who had been diagnosed with their cancer between March 2009 and March 2012 were eligible for selection.

Once the initial sample of 160 patients had been drawn, a Demographics Batch Service (DBS)[4] 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

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[2] Salford began work as a Test Community following the baseline survey, but before the other new Test Communities had commenced.

[3] In order to ensure that once a Demographics Batch Service (DBS) check had been run, a sample of up to150 patients per pathway per PTC remained.

[4] 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.

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 removed from the sample.

2.2 Data collection

Fieldwork was conducted between 11 January 2013 and 20 March 2013, using a 12-page paper questionnaire. The questionnaire was based on that used in the baseline survey, in order to maintain comparability, with a small number of amendments. 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, and a pre-paid Business Reply Envelope.

The baseline questionnaire had been cognitively tested with patients by Ipsos MORI, and feedback from this exercise informed the final questionnaire design.

Ipsos MORI produced the questionnaires for all TCs. Ipsos MORI also produced and dispatched the covering letters for the majority of TCs, whilst the TCs themselves chose to produce the personalised letters at Guys and NW London, and dispatch their own questionnaire packs.

Two reminder letters, complete with questionnaires, were sent out to all non-responders at intervals during the fieldwork period. The following table shows the numbers of returns for each mail out.

Mail out	Number of returns	% of returns	% of sample
Initial (1)	1966	74%	46%
First reminder (2)	558	21%	13%
Second reminder (3)	124	5%	3%
Total	**2,648**	**100%**	**61%**

The response rates vary for each of the cancer pathways across each of the seven TCs. As the following table illustrates, all pathways achieved a response rate of at least 47%.

Test Community	**Pathway**	**Adjusted Sample Size**[5]	**Valid Returns**	**Response Rate**
Brighton	Breast	139	86	62%
Dorset	**TC Overall**	**408**	**293**	**72%**
	Breast	143	97	68%
	Colorectal	118	88	75%
	Prostate	147	108	73%
Guys	Colorectal	140	77	55%
Hillingdon	**TC Overall**	**293**	**146**	**50%**
	Breast	149	89	60%
	Prostate	144	83	58%
Hull	Breast	147	107	73%
Ipswich	**TC Overall**	**438**	**288**	**66%**
	Breast	148	108	73%
	Colorectal	**145**	92	63%
	Prostate	145	88	61%
Luton	Prostate	137	92	67%
North Bristol	**TC Overall**	**433**	**263**	**61%**
	Breast	149	81	54%
	Colorectal	134	91	68%
	Prostate	150	91	61%
NW London	**TC Overall**	**445**	**233**	**52%**
	Breast	148	80	54%
	Colorectal	148	83	56%

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[5] Base sample sizes have been adjusted to account for ineligible patients, which included those who had since passed away, patients who notified us that they had received their treatment and aftercare from a site outside of the TC at which they had been diagnosed, or patients whose address was not valid.

	Prostate	149	70	47%
Royal Marsden	**TC Overall**	**438**	**274**	**63%**
	Breast	148	92	62%
	Colorectal	142	88	62%
	Prostate	148	94	64%
RUH Bath	**TC Overall**	**295**	**192**	**65%**
	Breast	147	100	68%
	Prostate	148	92	62%
Salford	**TC Overall**	150	98	65%
	Colorectal	150	98	65%
St Georges	**TC Overall**	433	247	57%
	Breast	142	77	54%
	Colorectal	143	76	53%
	Prostate	148	94	64%
West Hertfordshire	**TC Overall**	417	226	54%
	Breast	137	76	55%
	Colorectal	142	76	54%
	Prostate	138	74	54%
OVERALL		**4,313**	**2,648**	**61%**

2.3 Presentation and interpretation of quantitative data

A further explanation of statistical reliability is appended, but it should be remembered 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**
Existing TCs	Overall, how would you rate the quality of care and services you have received since your initial treatment finished?	68%	+/- 2.9 per centage points
New TCs		71%	+/- 2.2 per centage points

Throughout the report, where per centages 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 three free-text questions have been assigned to codes, and included in the figures.

No weighting has been applied to the data.

2.4 Acknowledgements

Ipsos MORI would like to thank Gilmour Frew, Anne Wilkinson, and Julia Ozdilli at NHS Improvement for their help throughout the project. We would also like to thank the staff at each of the fourteen TCs for their assistance in compiling patient lists. In addition, we also extend our thanks to all those patients who took part in our project, without whom this project would not have been possible.

2.5 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:	*Anna Quigley*
	Josh Keith
	Harry Carr

Part one: existing TCs

3. Overview of the baseline survey

Before discussing the findings of the follow-up study which forms the main focus of this report, this chapter provides a brief overview of the baseline quantitative survey.[6] This provides essential background before considering what progress, if any has been made across the existing TCs in the follow-up survey. It will also provide useful context when considering the baseline results for the new TCs, to see how they are currently performing in comparison to existing TCs when they first began work.

3.1 Overall quality of care

Overall, patients in the baseline survey were positive about the quality of care and services they had received since completing their initial treatment. Almost six in ten (59%) rated it as 'very good' or 'excellent'. However, the six per cent 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 with two in three (66%) colorectal cancer patients and three in five (61%) breast cancer patients.

Patients cited a range of issues that could lead to improvements in overall care, the key ones being 'more information or advice' (9%), 'improvements to care, aftercare or care plan' (5%), 'more help/support/local support groups' (4%), and 'waiting times for results/appointments' (4%).

3.2 Patients' need for advice and support

Positively, almost eight in ten patients felt that they had 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 said they did not need information, advice or support to:

- help them continue living in their own home (74%);

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[6] For further details please refer to the full baseline survey report available from: http://www.improvement.nhs.uk/cancer/survivorship/Home/AdultSurvivorship/Resources/Publications/tabid/313/Default.aspx

- cope with their financial issues (71%); or
- help them with the other practical things (71%).

However, there appeared to be an information deficit in terms of providing patients with all the information they needed about the signs and symptoms of cancer. Almost two in five (37%) did not feel that they had all the information they needed to identify the signs and symptoms of the cancer coming back.

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

3.3 Self managed care

Overall, more than four in five patients (83%) said that they were confident managing their own health.

Patients displayed a greater ability to self manage some problems than they did others. For example, more than two in five patients (42%) who did less physical activity or exercise since their diagnosis had taken action themselves to do more. Similarly, one in three (34%) patients who had noticed a change in their weight since their diagnosis had taken action themselves to deal with this. However, patients appeared to be much less able to deal with some other issues, namely:

- Around one in eight (12%) who had experienced a fear that the cancer would come back had dealt with this by themselves. Others had done nothing in particular but still felt afraid that the cancer would come back (28%), whilst one in six (17%) had received advice or support that had helped them to feel less afraid that the cancer would come back.
- Only one in ten (10%) experiencing a change in their interest in sex (that they were not happy with) had taken action themselves to improve this, while more than half (52%) hadn’t done anything in particular despite their interest in sex not having returned to how it had been before diagnosis.
- Just one in twenty (5%) patients who had problems with erectile function since their diagnosis had taken action themselves. Indeed, more than four in ten with such problems (45%) had not done anything in particular and continued to have problems.

These points indicate that, at the time of the baseline survey at least, there were some problems where patients were not getting the necessary advice, help or support.

3.4 Care plans and contact with health professionals

A personalised care plan is a written document that should be offered to all patients at the beginning of treatment, focusing on their individual needs, and reviewed at key trigger points on the care pathway. Care planning was one of the key principles[7] of the *National Cancer Survivorship Initiative Vision* (2010)[8] for improved care and support for people living with and beyond cancer.

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 was useful.

Over three-quarters of patients (77%) said they knew who to contact during office hours if they had a concern related to their cancer or their treatment for it, and a further ten per cent said they did 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%) had contacted their GP.

A much lower proportion of patients said they knew who to contact out-of-hours (only 38%), although one in five (20%) did 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 three in five (59%) had contacted the hospital, while almost three in ten (28%) had contacted their GP or out-of-hours service.

Knowing who to contact in the event of a concern is a key aspect of aftercare. These findings show patient preference for contacting their cancer nurse, which is a theme that also emerged during the qualitative work conducted around issues of care co-ordination.

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[7] *Effective follow-up: Testing risk stratified pathways*, NHS Improvement – Cancer (2011), http://www.improvement.nhs.uk/LinkClick.aspx?fileticket=piHHerH%2fYd0%3d&tabid=56

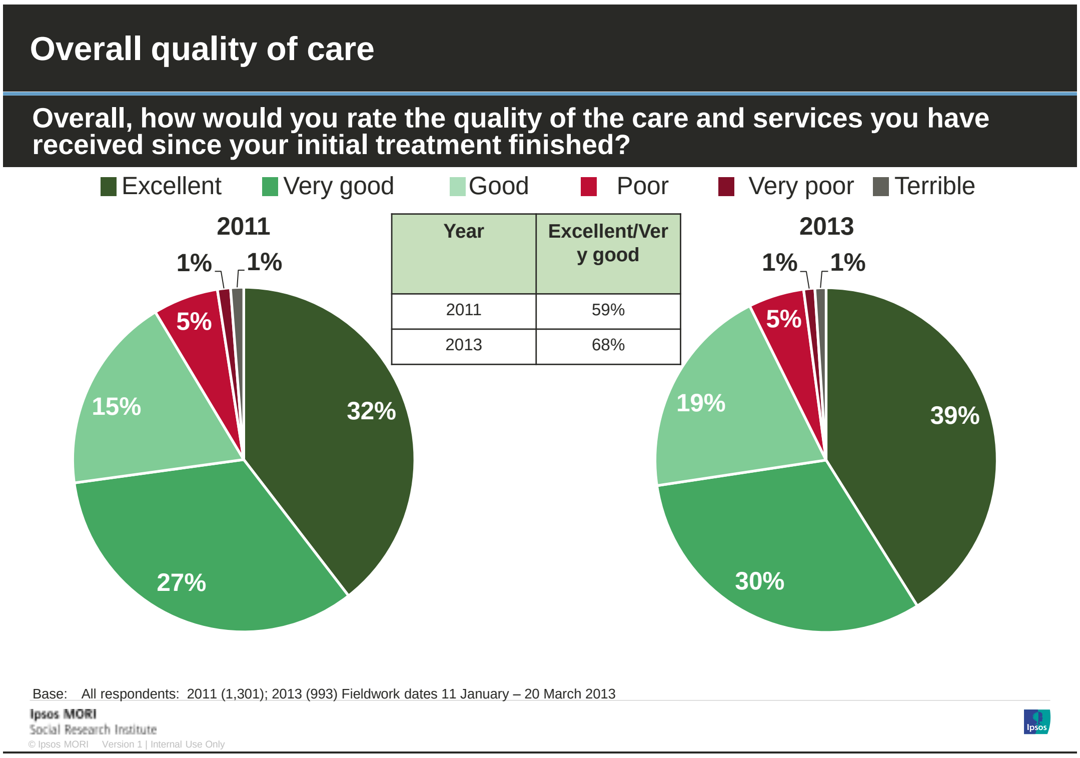
[8] *National Cancer Survivorship Vision,* NCSI (2010), www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf

4. Overall quality of care

This chapter considers patients' perceptions of the overall quality of aftercare received at the existing TCs, comparing between the baseline and follow up waves of research.

4.1 Quality of care

We know from other surveys, such as the *2012 National Cancer Patient Experience Survey*[9] that cancer patients in general are very positive about the quality of the care they receive (88% answered 'excellent' or 'very good'[10]). The baseline survey showed that satisfaction with *aftercare* was also good amongst the TCs. It was already high amongst patients surveyed in 2011 and has improved in 2013. An even higher proportion of patients, almost seven in ten (68%), now rate the services that they have received after completing their treatment as 'excellent' or 'very good'. If we extend this to include those rating the care as 'good' or better, this figure rises to 88% (compared to 74% at the baseline). However, there is again a small but very important minority who rate their care as 'poor', 'very poor' or 'terrible (6%). The fact that there has been no decline in the size of this group illustrates that there is still room for improvement.



Overall quality of care

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

Year	Excellent/Very good
2011	59%
2013	68%

Base: All respondents: 2011 (1,301); 2013 (993) Fieldwork dates 11 January – 20 March 2013

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[9] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf

[10] Please note that patients in the National Cancer Patient Experience Survey were rating their care from diagnosis to present.

In the baseline survey we saw that breast and colorectal cancer patients were more positive than prostate cancer patients about the quality of the care they had received. However, this pattern has not been repeated in 2013. Breast cancer patients remain the most positive; more than four in ten (42%) rate their care as ‘excellent’, compared to just under four in ten (39%) overall and one-third (33%) of prostate cancer patients. Colorectal patients fall in between, four in ten rated their care as excellent (40%).

Beyond tumour group comparisons, there are differences in the perceived quality of care depending on the length of time a patient has been in the aftercare system. Both those patients diagnosed in the first section of our sampling window (March 2009 – February 2010) and those who reported finishing their initial treatment more than two years ago[11] are more likely to rate their care as ‘excellent’ or ‘very good’ than patients overall (76%, 75% and 68% respectively). While it is not possible to make any causal links here, it is nonetheless interesting, and positive, that the longer patients have been interacting with the aftercare services, the more positive they are about the care they have received.

The baseline survey demonstrated the importance of care plans, and that effect is again evident in the follow-up survey. Almost eight in ten (78%) patients who have a care plan rate the overall quality of their care as ‘excellent’ or ‘very good’, while this falls to just over six in ten (62%) amongst those patients without a care plan.

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[11] There will be significant overlap between these two groups of patients.

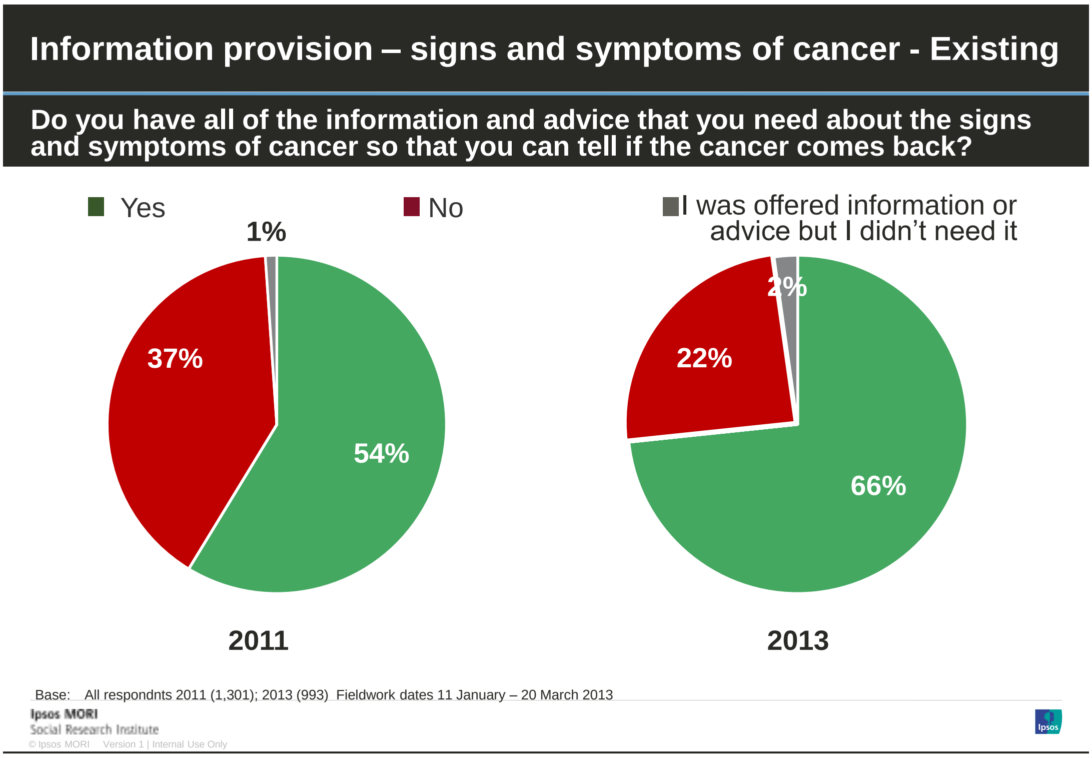
5. Patients' need for information and advice

Having established that patients at the existing TCs report a high perceived quality of overall care, this chapter moves on to look at patients' need for information and advice. In particular, we focus on those areas of information and advice identified as issues at the baseline survey, and assess what progress, if any, has been made in this regard.

5.1 Signs and symptoms of cancer

The baseline survey showed that a significant minority of patients were not well equipped to be able to tell whether their cancer had returned. Almost two in five patients (37%) reported that they did not have all the information or advice that they needed about its signs and symptoms. This represents a significant information gap, especially under a system where it is intended that patients would be taking more responsibility for monitoring their own health.

Therefore, it is positive that fewer patients now report that they do not have all the necessary information and advice. This proportion has fallen to under one quarter (22%), a decrease of fifteen percentage points. This appears to be linked to the role of care plans. Patients who report having a care plan are more likely than those without to say they have all the information and advice that they need in this regard (79% vs 60%).



Information provision – signs and symptoms of cancer - Existing

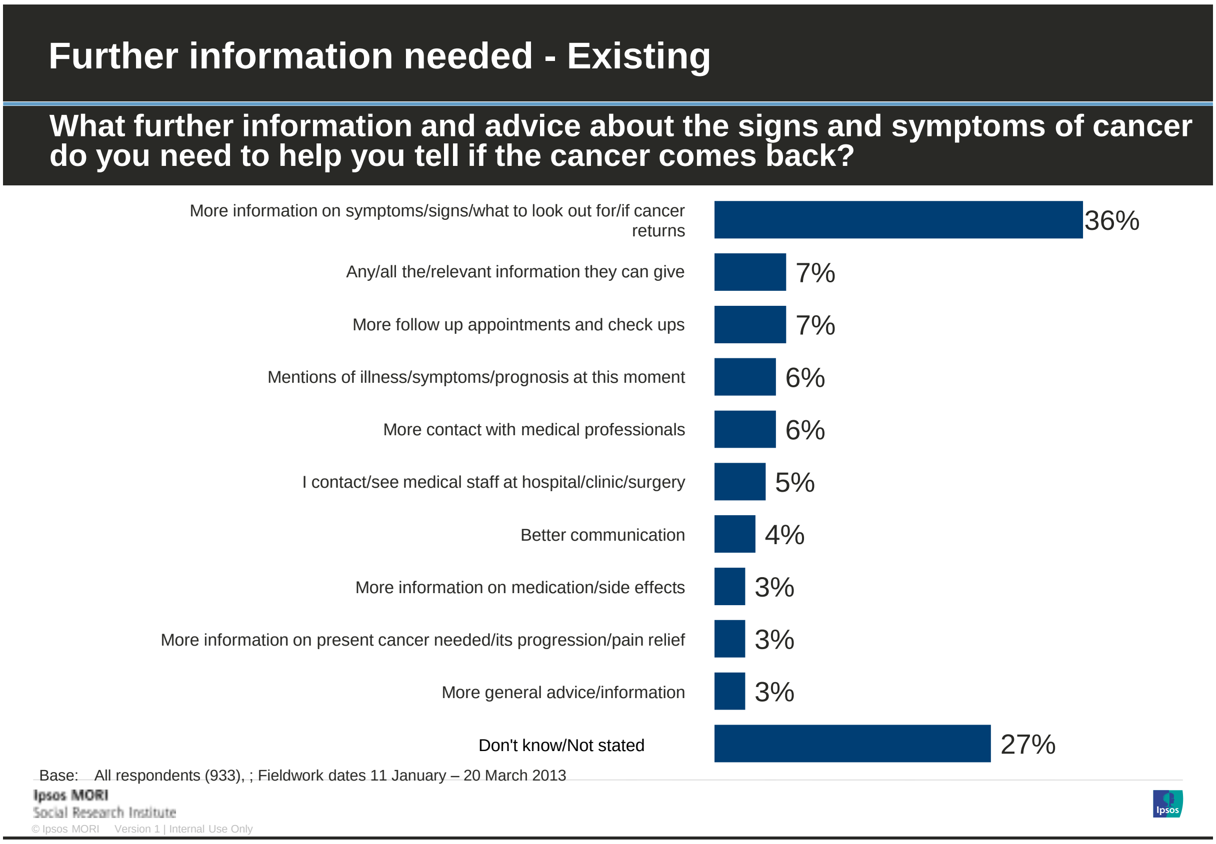
Do you have all of the information and advice that you need about the signs and symptoms of cancer so that you can tell if the cancer comes back?

Base: All respondnts 2011 (1,301); 2013 (993) Fieldwork dates 11 January – 20 March 2013

As discussed later in this report, the proportion of patients with a care plan has increased between the baseline and follow-up survey, and so this could explain why patients report being better informed.

There are some differences between tumour groups. Colorectal cancer patients are the most likely to report that they do not have all the necessary information. Almost one third (32%) say this, compared to less than a quarter (22%) of patients overall.

Where patients do not have the information or advice they need, they ask for a range of things. However, they most commonly cite a general desire for more information on symptoms/signs/ what to look out for if cancer returns, rather than anything more specific. This was mentioned by more than one third of patients (36%).



Further information needed - Existing

What further information and advice about the signs and symptoms of cancer do you need to help you tell if the cancer comes back?

Base: All respondents (933), ; Fieldwork dates 11 January – 20 March 2013

5.2 Information about effects of treatment

In the baseline survey, patients appeared to be better informed about the effects of their treatment than about signs and symptoms. Three-quarters (75%) reported that they did have all the information and advice they needed, and just one in ten (10%) said that they would have liked more information. While the proportion saying that they have all they need on the effects of treatment has not changed significantly since then, the proportion who feel they need more information or advice has fallen in the follow-up survey to seven per cent.

Do you have all of the information and advice that you need about the effects of your treatment?	***2011***	***2013***
Yes	75%	74%
I was offered information or advice but I didn't need it	2%	3%
No	6%	8%
No, and I would have liked information or advice about the effects of my treatment	**10%**	**7%**

As has been evident throughout, care plans make a difference here. Patients without care plans were more likely to report that they did not have all the information and advice they needed about the effects of their treatment (11% vs 4%).

5.3 Information needed to manage health

More than three-quarters of patients (78%) in the baseline survey reported that they had all the information, advice or support they needed to manage their health. Although this proportion has remained high in the follow-up survey, it has fallen to 74%. It will be important for TCs to ensure that patients are receiving this information if they are to be able to self-manage effectively.

5.4 Information received too late

In the baseline survey, a very small proportion of patients (5%) reported that they had received information, advice or support too late for it to be useful. Encouragingly, this has remained low in the follow-up survey (6%).

5.5 Advice or support with other issues

There were a number of issues covered in the baseline survey where patients did not generally express a need for advice. These results have not changed significantly in the follow-up survey and so are only covered briefly here:

- **Advice or support to help carry on working –** 60% of patients were already retired when diagnosed, and a further 16% have not had advice or support but *do not need it*. Only 3% of patients reported not receiving advice or support, and *would like to have*;
- **Advice or support to help continue living in own home –** 76% of patients have not had advice or support but *do not need it*, and just 2% of patients have not had advice or support and *would like to have*;
- **Advice or support with financial issues –** 72% of patients have not had advice or support but *do not need it*. Seven per cent of patients did not receive any advice or support with financial issues, and *would like to have*; and
- **Advice or support with other practical things –** 71% of patients have not had advice or support but *do not need it*, while only 6% of patients have not had advice or support but *do need it*.

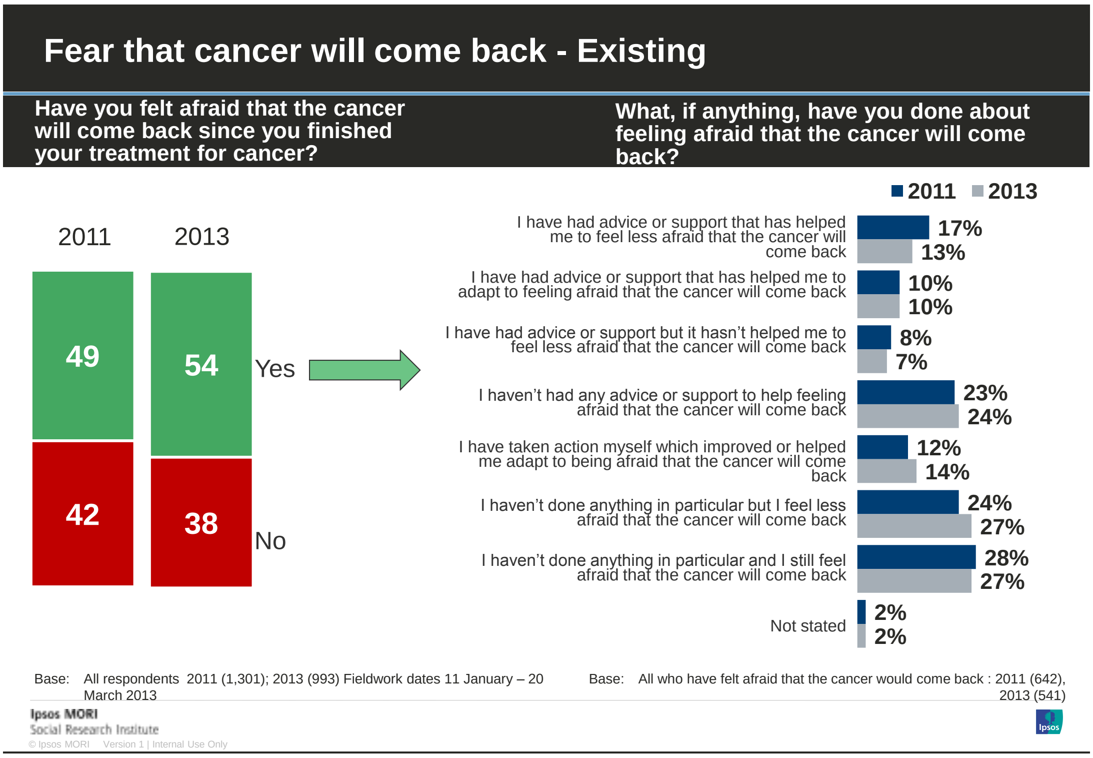
Although largely very positive, there is a very small, but nonetheless important, minority of patients who have not received the advice or support that would help them deal with these issues.

6. Self managed care

While largely returning encouraging findings, the baseline survey did identify a number of apparent information gaps for patients across the original seven TCs. These would need to be addressed if the move towards a greater degree of self managed care was to work for the patients involved. This chapter considers these key issues, to examine what progress had been made by the existing TCs. It then moves on to cover other elements of self managed care, where patients' needs were relatively lower.

6.1 Fear of cancer coming back

Overall, a greater proportion of patients in 2013 report feeling afraid that their cancer will come back after finishing treatment. This has increased from just under half of patients (49%) in the baseline survey to 54% in the follow-up survey. However, the key question is how patients have been able to deal with this fear. In this regard, there has been no significant change since the baseline. One in eight patients (13%) with these concerns has gone on to receive advice or support that has helped them to feel less afraid; this is broadly in line with the baseline survey finding. Perhaps more important though is the proportion of patients who report either that they have not had any advice or support (24%) or that they haven't done anything in particular and still feel afraid that the cancer will come back (27%). Neither of these measures have shown any improvement since the baseline. Indeed, in terms of self-management, there has also been no movement in the proportion of patients who report that they have taken action themselves that has helped, remaining at around one in eight (14%).



Fear that cancer will come back - Existing

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 2011 (1,301); 2013 (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have felt afraid that the cancer would come back : 2011 (642), 2013 (541)

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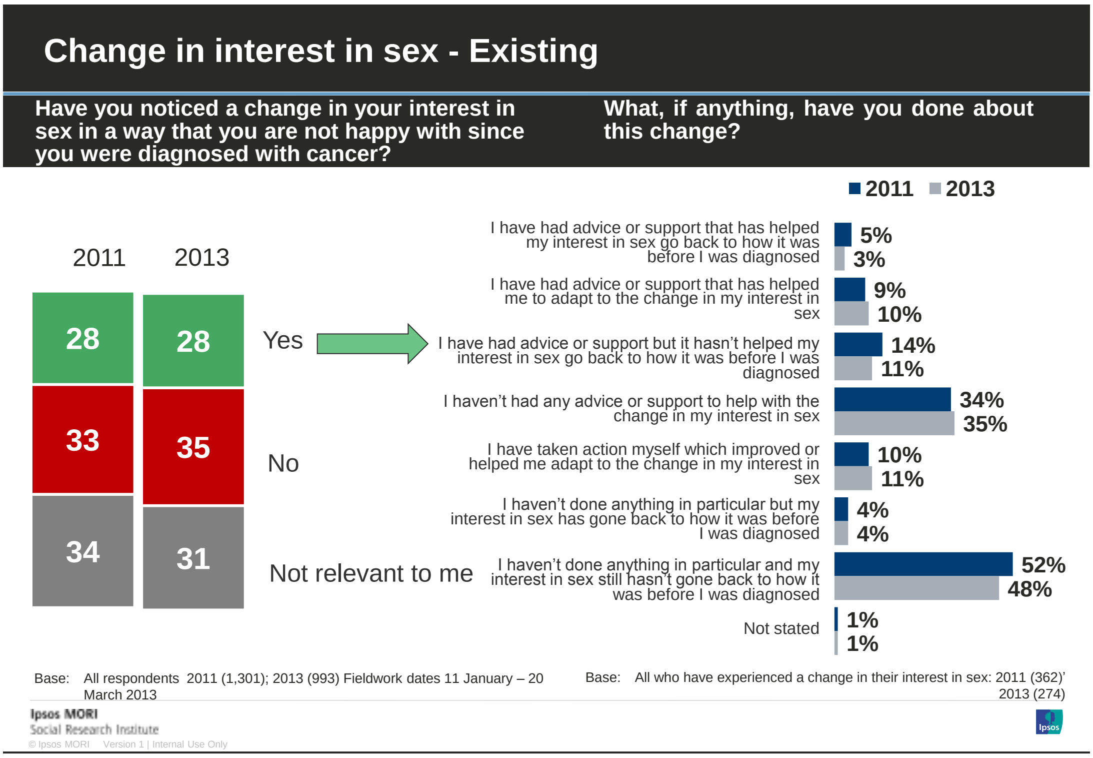
Those patients who are more confident in managing their own health are more likely to have taken action themselves (16%) that improved or helped them adapt to the fear that the cancer will come back (compared to 6% for those who are not confident). Furthermore, patients without a care plan are more likely to be lacking advice or support to help with feeling afraid that the cancer would come back (27% compared to 19% of those who do have a care plan).

6.2 Change in interest in sex

Another apparent gap identified in the baseline survey was amongst those patients who had noticed a change in their interest in sex since they were diagnosed with cancer. The proportion of patients reporting this issue has remained consistent at almost three in ten (28%). Almost half (48%) haven't done anything in particular and their interest in sex still hasn't returned to how it was pre-diagnosis, and more than one-third (35%) haven't had any advice or support to help. Only a small proportion (11%) of patients have taken any action themselves to help them deal with or adapt to this situation. These results are in line with those in the baseline survey.



Change in interest in sex - Existing

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?

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

Base: All respondents 2011 (1,301); 2013 (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have experienced a change in their interest in sex: 2011 (362)' 2013 (274)

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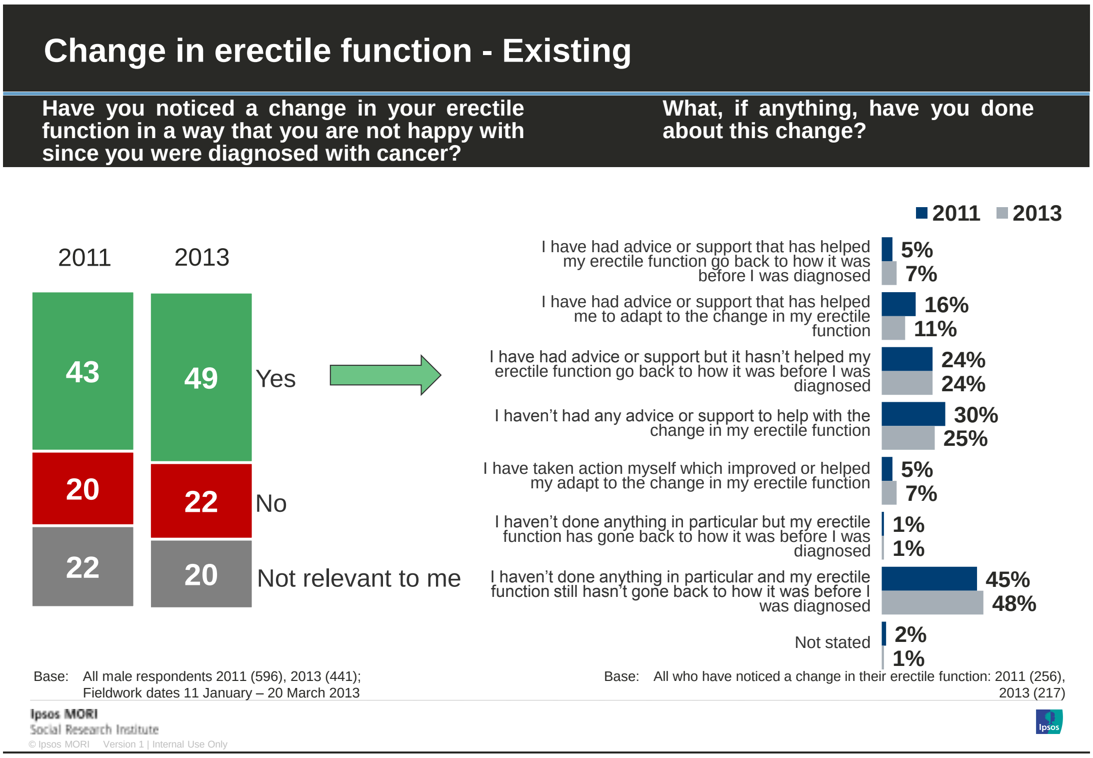
There were no differences to be seen across the tumour groups with regard to this issue.

6.3 Change in erectile function

For male patients during the baseline survey, one of the biggest information gaps seemed to be for those patients who reported having experienced a negative change in their erectile function. Almost half (49%) of male patients from the existing TCs reported having experienced this in the follow-up survey, which represents an increase of six per centage points since the baseline. Again, however, the key point is how patients have been able to deal with this. There is a great deal of consistency in the results compared to the baseline survey, with almost half (48%) reporting that they haven't done anything in particular and their erectile function still hasn't gone back to how it was before they were diagnosed. A quarter (25%) haven't had any advice or support. Only slightly more than one in ten (11%) report having had advice or support that has helped adapt to the change, and just 7% have had advice or support that has helped their erectile function return to how it was pre-diagnosis.



Change in erectile function - Existing

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

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

Base: All male respondents 2011 (596), 2013 (441); Fieldwork dates 11 January – 20 March 2013

Base: All who have noticed a change in their erectile function: 2011 (256), 2013 (217)

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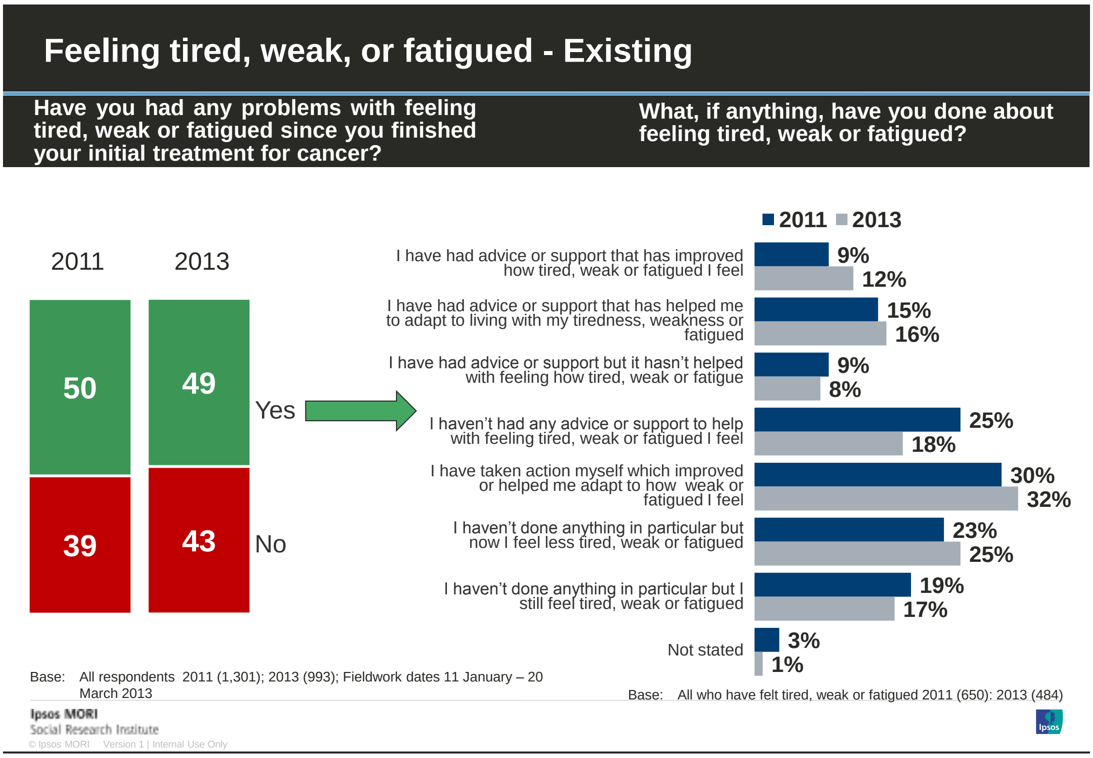
Given that the vast majority of patients who have experienced this issue were prostate cancer patients, there are no differences to be seen by tumour group here.

6.4 Feeling tired, week or fatigued

Tiredness appeared to be a significant problem for patients in the baseline survey. Half (50%) reported having problems with feeling tired, weak or fatigued since they had finished their initial treatment for cancer. The proportion is similar at the follow-up stage (49%). However, there has been some progress on whether this issue is being dealt with. In the baseline survey, one quarter (25%) of those who had reported problems had not had any advice or support to help with feeling tired, weak or fatigued. This has now fallen to one in six (17%).



Feeling tired, weak, or fatigued - Existing

Have you had any problems with feeling tired, weak or fatigued since you finished your initial treatment for cancer?

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

Base: All respondents 2011 (1,301); 2013 (993); Fieldwork dates 11 January – 20 March 2013

Base: All who have felt tired, weak or fatigued 2011 (650): 2013 (484)

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There are few differences between the tumour groups to be seen here. Breast cancer patients, however, more frequently report having taken action themselves which has improved or helped them adapt to how tired, weak or fatigued they felt (36% v 25% of prostate patients).

There are also some differences by age. Older patients (76+) are more likely to say that they haven't done anything in particular and still feel tired, weak or fatigued (29% compared to 16% of those aged 36-60, and 13% of those aged 61-75). On the other hand, younger patients, those aged 36-60, are more likely to have had advice or support that has helped them adapt to living with this problem (22% compared to 16% overall). The differences evident between age groups may also be linked to the fact that breast cancer patients are more likely to be aged 36-60.

Care plans will be discussed in more detail later in this chapter, but the results at this question again hint at their importance for patients. Those without a care plan are more likely to say they have not received any advice or support to help with feeling tired, weak or fatigued (23% compared to 12% of those who do have a care plan).

6.5 Other aspects of self managed care

Thus far we have looked at the aspects of self managed care where particular service gaps were identified in the baseline survey, to assess whether any progress has been made. We have also identified some other areas of self managed care where there is evidence of improved service and patient experience over time.This section now considers those areas where the baseline survey showed fewer gaps (relative to other areas) and which have shown little or no change at the follow-up stage:

- **Trouble sleeping at night, or through the night –** around four in ten (41%) patients report having trouble with this; two in ten (20%) of these patients have taken action themselves to help, whilst similar proportions have either done nothing and had less trouble or haven't had any advice or support (20% and 19%). Three in ten (30%) have not done anything in particular and still have trouble.

- **Decrease in physical activity or exercise –** the proportion of patients who report that they do less activity or exercise than they did prior to their cancer diagnosis has fallen from 44% to 38%. Generally patients seem able to deal with this, with almost four in ten (38%) reporting taking action themselves that has helped them. However, 37% haven't had any advice or support and still do less exercise than previously. Prostate cancer patients are the most likely to report having done nothing and still have problems (49%).

- **Frequency of physical activity** – Patients in the follow-up survey report doing 30 minutes or more of physical activity on an average of 2.5 days a week, compared to 2.7 for the baseline survey.

- **Change in weight** – In line with the baseline, more than four in ten patients (45%) have experienced a change in weight that they are not happy with. Again one third

(33%) have taken action themselves, while almost three in ten say they have not received any advice or support (28%) and the same proportion say they have not done anything but the problem remains (29%). Prostate cancer patients are more likely to have done nothing and still not be happy with their weight (36%).

- **Problems with bowel or urinary function –** four in ten (40%) patients report having problems with their bowel or urinary function. Almost three in ten (28%) say that they have received advice or support that has helped, and two in ten have received advice or support that has helped them adapt to the problems (21%) or have taken action themselves that has helped (20%). However, one in six (16%) has done nothing and still has problems. Problems are more prevalent amongst prostate and colorectal cancer patients (54% and 49%). On the other hand, breast cancer patients are more likely to have taken action for this issue themselves (26%) than prostate cancer patients (16%).

- **Feeling low or down –** slightly more than four in ten (45%) patients report often feeling low or down since finishing their initial treatment for cancer, in line with findings from the baseline survey. Of these, three in ten (30%) have taken action themselves, and around one in eight (12%) has received advice or support to help them adapt to feeling low or down, and to help them feel low or down less often. One in five (20%) has not had any advice or support. Female patients are more likely to report feeling low or down (54%).

For most of these additional aspects of self-managed care, those patients who report having a care plan are more likely to say they have received advice or support that has helped. This is less so for changes in weight, and also for feeling low or down, which indicates that there are some aspects of self managed care where the care plan itself is less useful.

6.6 Confidence managing own health

As with the baseline survey, a vast majority of patients (84%) report feeling confident about managing their own health.

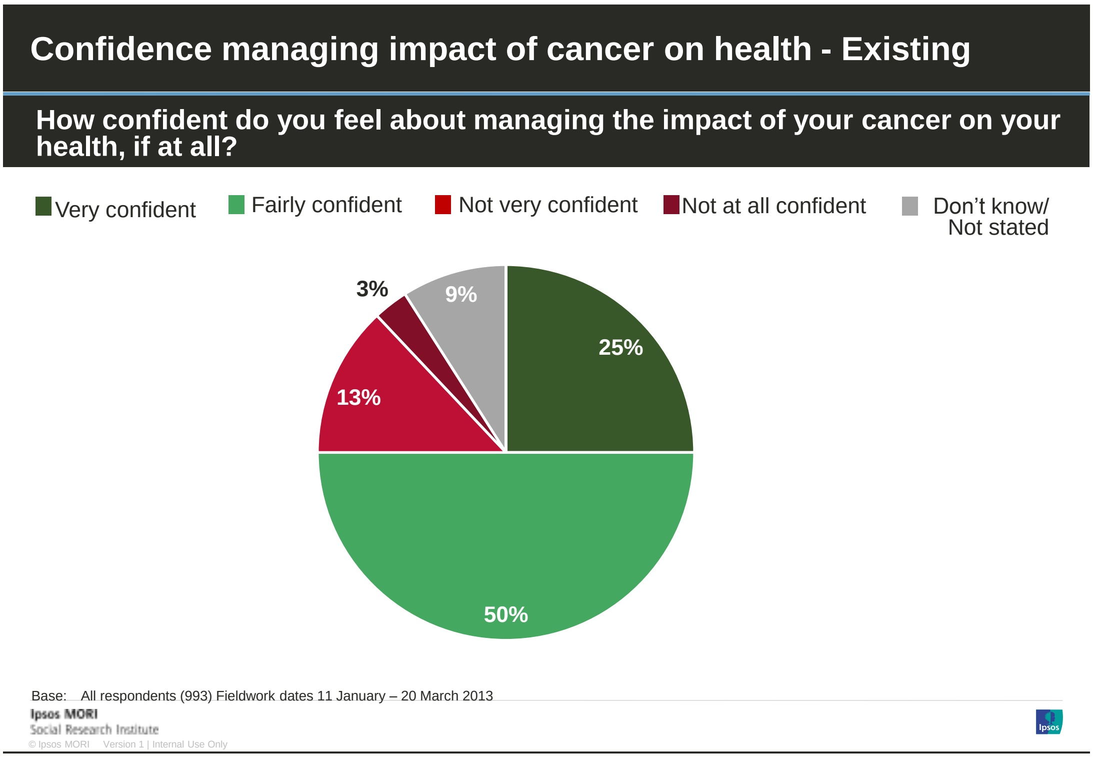
How confident do you feel about managing your health, if at all?	***2011***	***2013***
Very confident	30%	29%
Fairly confident	53%	54%
Not very confident	8%	9%
Not at all confident	2%	2%
Don't know/Not stated	5%	6%

In the follow-up survey, there were no differences in levels of confidence between patients in the different tumour groups.

The value of information provision is clear. Those patients with a care plan are more likely to report being confident (89%) than those without (83%). There is even more of a difference to be seen between those patients who feel that they have all the information they need to manage their health (93%) and those who do not (63%). Patients who report having all the information about the signs and symptoms of cancer are also significantly more likely to report feeling confident than those lacking information (90% v 74%).

6.7 Confidence managing impact of cancer on health

Patients appear slightly less confident about managing the impact of the cancer on their health. Still a majority of patients report feeling confident (75%), while one in six do not (16%)[12].



Confidence managing impact of cancer on health - Existing

How confident do you feel about managing the impact of your cancer on your health, if at all?

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

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There are no differences across the tumour groups in this regard. However, as we have seen throughout this chapter, patients with a care plan are more likely to feel confident managing the impact of the cancer on their health (83%) than patients without a care plan (73%). As would be expected, there is a strong correlation between the two aspects of managing health. Those patients who feel confident managing their health in general are far more likely to feel confident managing the impact of their cancer on their health (89% v 6% of those who do not feel confident).

Patients in the 36 – 60 year old age group are more likely than those aged 61 – 75 and patients overall to report not being confident (20%; 14% and 16%).

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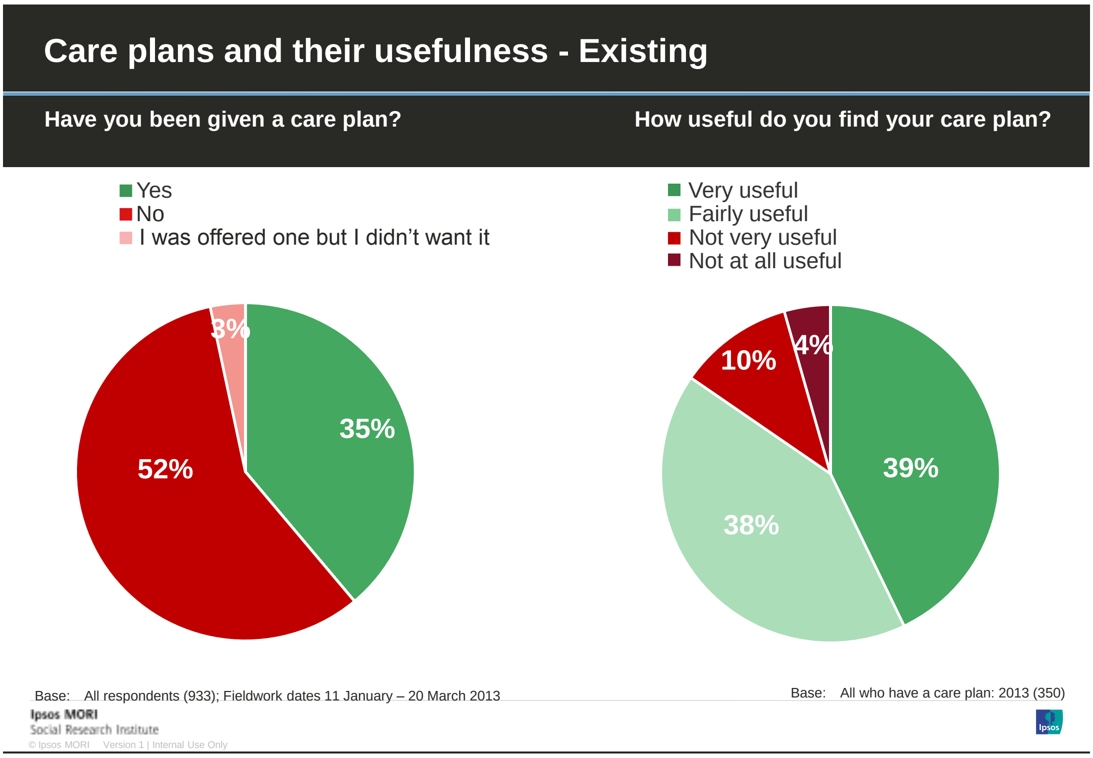
[12] This was a new question in the follow-up survey.

7. Care plans and contact with health professionals

This chapter moves on to look at whether or not patients have been given care plans, and how useful patients find them. We also examine patient reported experience of contacting healthcare professionals about their cancer, both during and outside office hours.

7.1 Care plans

The baseline survey highlighted the importance of a care plan. The results suggested that it may help give patients the confidence to manage their own health, and to enable them to try and deal with problems or issues that they had experienced since their cancer diagnosis. However, only around one in five (21%) patients reported that they had been given a care plan. Positively, this has increased to more than a third (35%)[13] of patients from existing TCs in the follow-up survey.


Care plans and their usefulness - Existing

Base: All respondents (933); Fieldwork dates 11 January – 20 March 2013

Base: All who have a care plan: 2013 (350)

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[13] 20% have received a care plan at diagnosis, while a further 15% received one upon finishing their treatment.

By way of context, according to the *2012 National Cancer Patient Experience Survey*[14] less than one-quarter (24%) of patients have been offered a written assessment and care plan.

In the follow-up survey, breast cancer patients are again the most likely to report having a care plan. More than four in ten (42%) have received one, compared to three in ten (30%) prostate and just over a quarter (26%) of colorectal cancer patients.

Interestingly, and perhaps reflecting an increased emphasis on care plans amongst the TCs, patients diagnosed in the final 12 months of our sampling window (March 2011 – March 2012) are more likely to report that they were given a care plan on diagnosis (26%) than patients diagnosed between March 2009 – February 2010 (17%) or March 2010 – February 2011 (19%).

Whilst the proportion of patients receiving a care plan has increased, there has been a decrease in the proportion of patients who describe their care plan as useful. In the baseline survey, over eight in ten patients who had a care plan reported finding it useful (84%). However, this figure has now dropped to just over three-quarters (77%). Whilst this still means that the majority of patients find their care plan useful, the decrease is of some concern nonetheless. Without further investigation it is difficult to establish with any degree of certainty why this may be. However, it does raise a question as to whether the drive to increase the proportion of patients receiving a care plan has been at the expense of ensuring that the care plans meet the exact needs of the patients. As we have seen through the qualitiative work conducted around care coordination, it is often the care planning process, rather than the care plan document itself that is of most help to a patient.

This may also go some way to explaining why the increase in the proportion of patients with a care plan has not had quite the impact on driving improvement in other measures as it might have done.

7.2 Contact with healthcare professionals during office hours

In line with the findings from the baseline survey, more than three-quarters (78% v 77% in 2011) of patients at the existing Test Communities say that they would know who to contact during office hours if they had a health concern related to cancer or their treatment. Positively, a further one in ten (10%) says that although they do not know, they would know how to find out. A similar proportion as seen in the baseline survey (44% v 47% in 2011)

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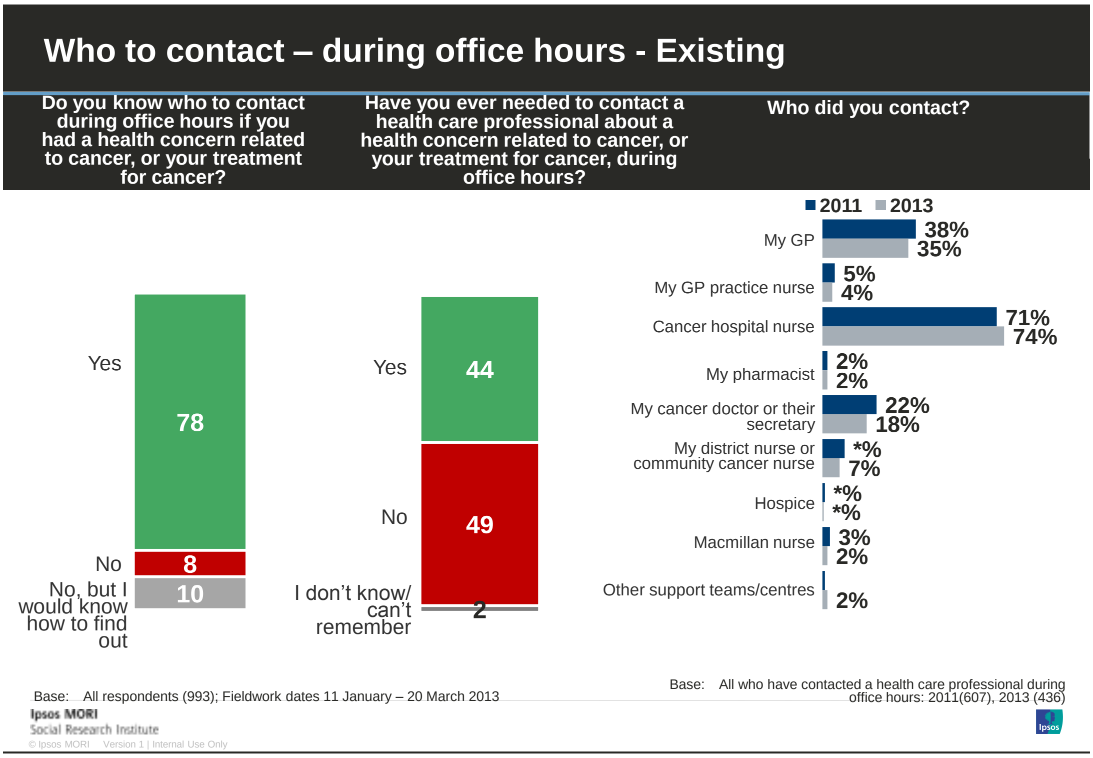
[14] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf

report that they have needed to contact a health care professional about their cancer or treatment during office hours. As the chart below illustrates, those who have contacted a healthcare professional again most frequently contacted a cancer hospital nurse (74%), their GP (35%) or their cancer doctor [or secretary] (18%). This is consistent with the findings from the baseline survey. The frequency with which patients report contacting their cancer hospital nurse can further be understood by considering some data from the *2012 National Cancer Patient Experience Survey*[15]*.* According to this almost nine in ten (87%) cancer patients have been given the name of a Clinical Nurse Specialist (CNS) who would be in charge of their care. Of these, three quarters (75%) find it easy to contact their CNS, while the vast majority (91%) find that they get answers they can understand 'all or most of the time' when they ask important questions of their CNS.



Who to contact – during office hours - Existing

Do you know who to contact during office hours if you had a health concern related to cancer, or your treatment for cancer?

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?

Who did you contact?

Base: All respondents (993); Fieldwork dates 11 January – 20 March 2013

Base: All who have contacted a health care professional during office hours: 2011(607), 2013 (436)

Breast cancer patients are again the most likely to know who to contact (84% v 78% overall), and to say that they have contacted a healthcare professional (53% v 44% of patients overall). In terms of who patients contacted, there are very few differences to report on across the three tumour groups, with the exception that both breast and colorectal[16] patients are more likely to contact their cancer hospital nurse (77% and 80%) than prostate cancer patients (62%).

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[15] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf

[16] Please note the small base size here (79).

As would be expected, patients who have a care plan (89%), those who found it useful (91%), those confident in managing their health (82%) and those with all the information they need to help manage their health (85%) were more likely than patients overall to know who to contact (78%).

There are likely to be a number of factors contributing to the patient's decision on who to contact, such as personal preference, and the nature of their concern. However, there do appear to be several underlying themes present in the data:

- Patients **without a care plan** are more likely to have contacted their cancer doctor [or secretary] than patients **with a care plan** (23% v 11%);
- Patients **confident in managing their own health** are more likely to have contacted their cancer hospital nurse (77%) than those **not confident** (61%[17]);
- Patients **not confident in managing their own health** are more likely to have contacted their GP than those **who are confident** (48%[18] v 33%);
- Patients **who don't have all the information they need to help manage their health** are more likely to have contacted their pharmacist (5%[19]) than those who **do have all the information** (1%);
- Patients who **do have all the information about signs and symptoms of cancer** are more likely to have contacted their cancer hospital nurse (77%) than those who **do not have all the information** (65%).

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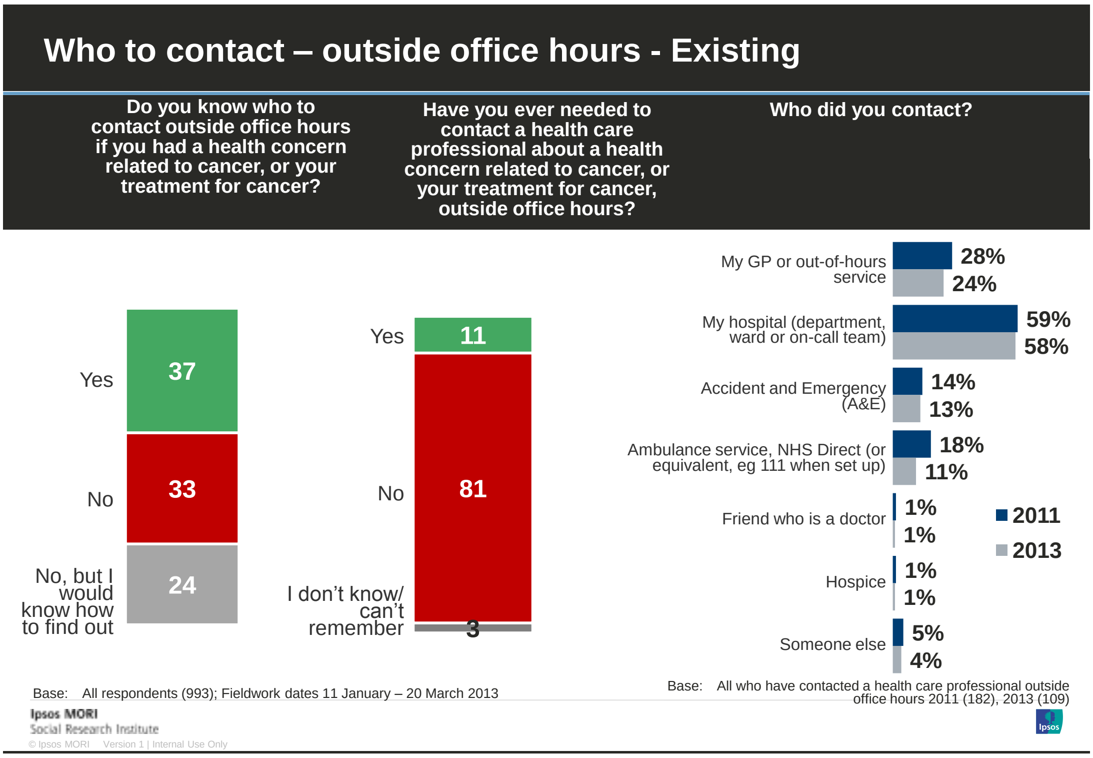
[17] Please note the small base size here (69).
[18] Please note the small base size here (69).
[19] Please note the small base size here (91).

7.3 Contact with healthcare professionals outside office hours

Patient reported experience of contacting healthcare professionals outside office hours is consistent with the baseline findings. One third of patients do not know who to contact in this situation (33%). A smaller proportion (11%) report having had to contact a healthcare professional about their cancer or its treatment out-of-hours, falling from more than one in eight (14%) in the baseline survey.



Who to contact – outside office hours - Existing

Do you know who to contact outside office hours if you had a health concern related to cancer, or your treatment for cancer?

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?

Who did you contact?

Base: All respondents (993); Fieldwork dates 11 January – 20 March 2013

Base: All who have contacted a health care professional outside office hours 2011 (182), 2013 (109)

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Of those who say that they have contacted someone, the largest proportion have again contacted their hospital (58%), while almost one-quarter have contacted their GP or out-of-hours service (24%), again in line with the 2011 baseline survey.

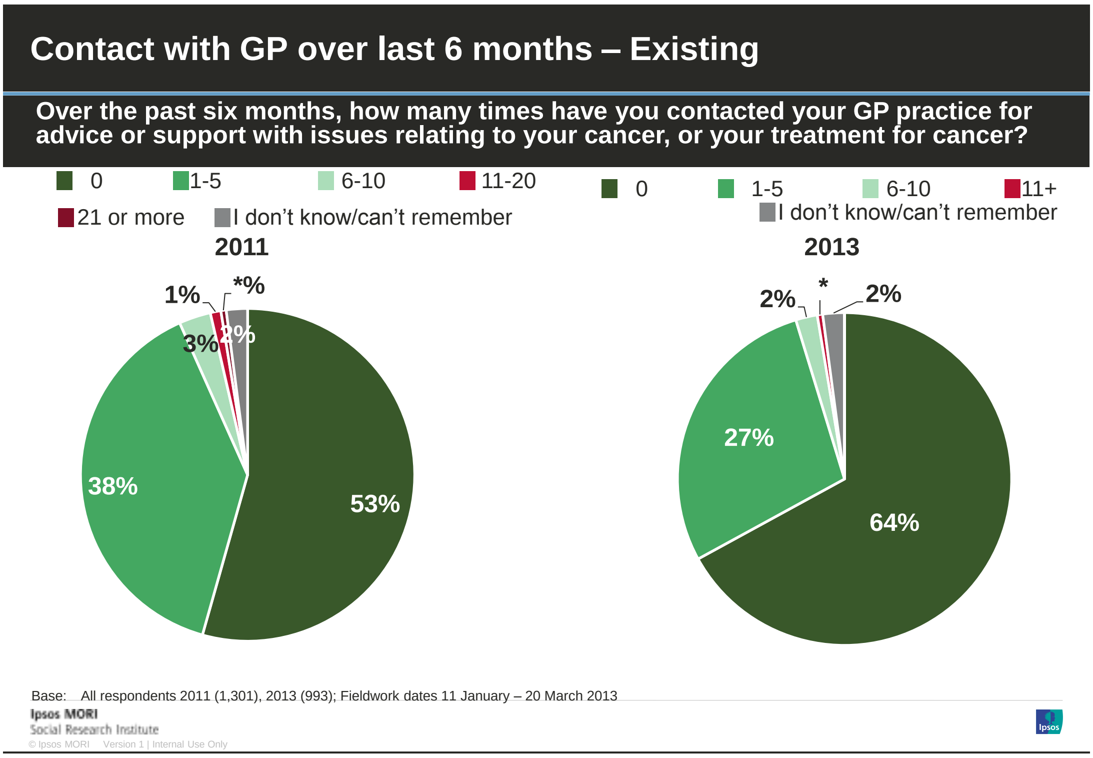
Again, a higher proportion of prostate cancer patients (40%) than breast (31%) and colorectal (24%) report not knowing who to contact outside office hours. Colorectal patients are more likely to have had to contact somebody (17% vs 11% overall).

As we have seen consistently throughout, those with a care plan (47%), those who found it useful (54%), those who are confident in managing their own health (40%) and who have all the information they need to do so (43%) are more likely to know who to contact (37% overall).

These groups are also less likely to have had to contact anybody outside of office hours. Therefore, given the higher proportion of patients with care plan in 2013, this may explain why the proportion of patients reporting having contacted somebody outside of office hours has fallen.

7.4 Contact with GP

Patients in the follow-up survey appear less likely to have contacted their GP practice for advice about their cancer or its treatment. Almost two-thirds (64%) of patients report that they have not done so at all, and this represents an increase of eleven per centage points since 2011.



Contact with GP over last 6 months – Existing

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 2011 (1,301), 2013 (993); Fieldwork dates 11 January – 20 March 2013

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Unsurprisingly, patients who report being confident in managing their own health (68%), having all the information they need to help manage (67%) and all the information they need about the signs and symptoms of the cancer (69%) are more likely not to have contacted their GP in the last 6 months in relation to their cancer than patients overall (64%).

Part two: new TCs

8. Overall quality of care

Having covered the TCs who participated in the baseline survey in the foregoing chapters, the following four chapters will focus solely on results for new TCs. While strict comparisons can not be drawn with the existing TCs, it is interesting to note how the results for new TCs compare with those for existing ones now and in 2011[20]. In this chapter we examine how care is currently rated by patients, before moving on in later chapters to consider specific aspects of their aftercare.

8.1 Quality of care

Patients at the new TCs generally rate the quality of the care and services they have received after their initial treatment highly. Two in five rate their care and services as ‘excellent’ (39%), with a further third describing their care as ‘very good’ (32%). In total, nine in ten patients think the quality of the care and services they received as either ‘good’, ‘very good’ or ‘excellent’ (89%). These results are in line with those of the existing TCs in the follow up survey, illustrating how positive they are. However, it should not be overlooked that a small but significant group still rate their care as ‘poor’, ‘very poor’, or ‘terrible’ (four per cent).

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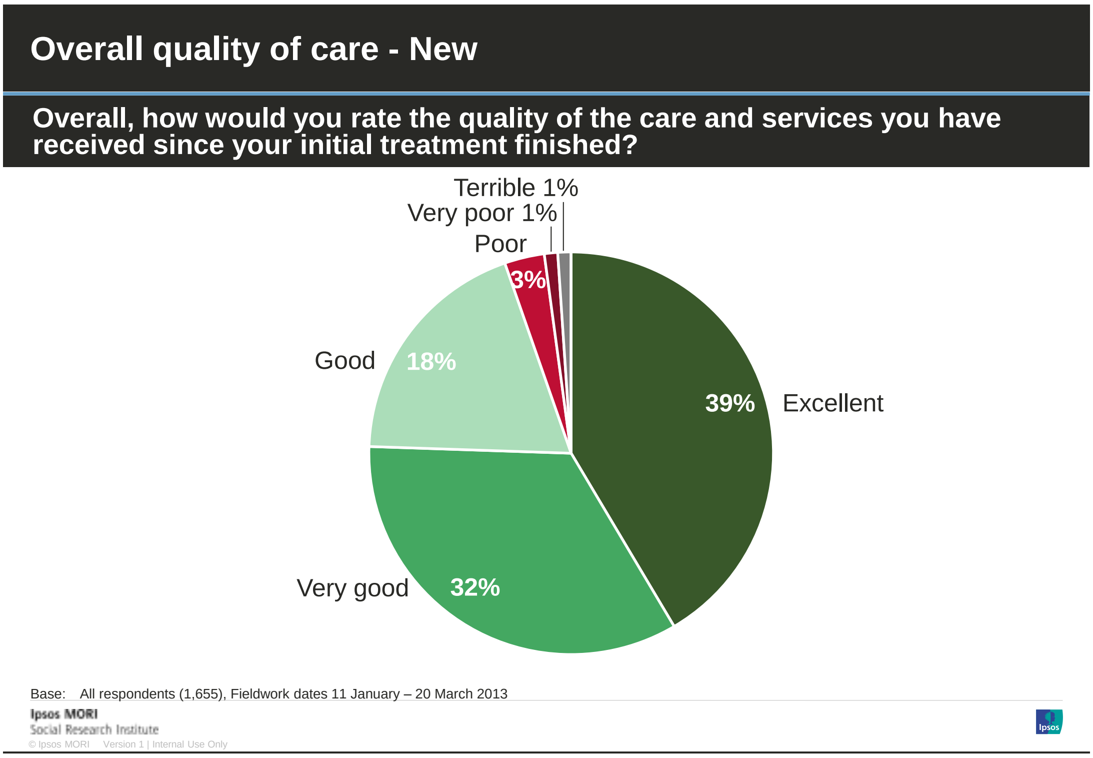
[20] These comparisons are provided for context only and should be treated with caution, as the profile of new and existing TCs differs.



Overall quality of care - New

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

Base: All respondents (1,655), Fieldwork dates 11 January – 20 March 2013

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There are significant differences between tumour groups regarding the perceived quality of aftercare. Care for colorectal cancer is rated more positively than both breast and prostate cancer, with three quarters (75%) rating this care as ‘excellent’ or ‘very good’ (compared to 70% and 68% respectively).

Patients with longer-term experience of aftercare appear to rate it more highly, as is also the case amongst the existing TCs. Those patients diagnosed earliest (between March 2009 and February 2010) are more likely to say their care was ‘excellent’ or ‘very good’ than those diagnosed later (76% of these patients, compared with 71% overall). Similarly, those for whom it had been more than two years since their initial treatment finished are also more likely to be positive about their care (77% compared with 71% overall)[21].

Care plans appear to be effective in the new TCs at this early stage. Patients with a care plan are more likely to rate their care as ‘excellent’ or ‘very good’ (81% vs 67% of those with no care plan).

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[21] There will be siginificant overlap between these two groups.

9. Patients’ need for advice and support

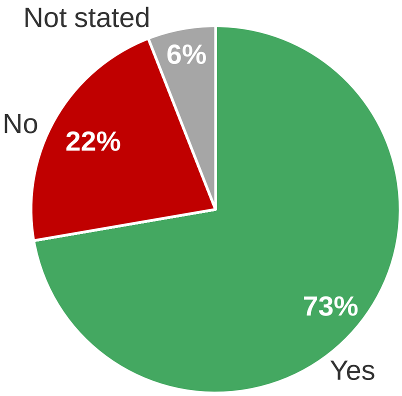
In this chapter we consider a range of issues where patients might need advice or support. We examine the need for advice on the issue, the provision of advice, and how helpful the advice was where provided.

9.1 Managing health

A significant minority of patients appear to need more support to help them manage their health. While almost three in four say that they have all the information, advice and support needed to manage their health (73%), just over one in five feels they do not (22%).

Information provision – managing health - New

Do you have all the information, advice or support you need to help you manage your health?

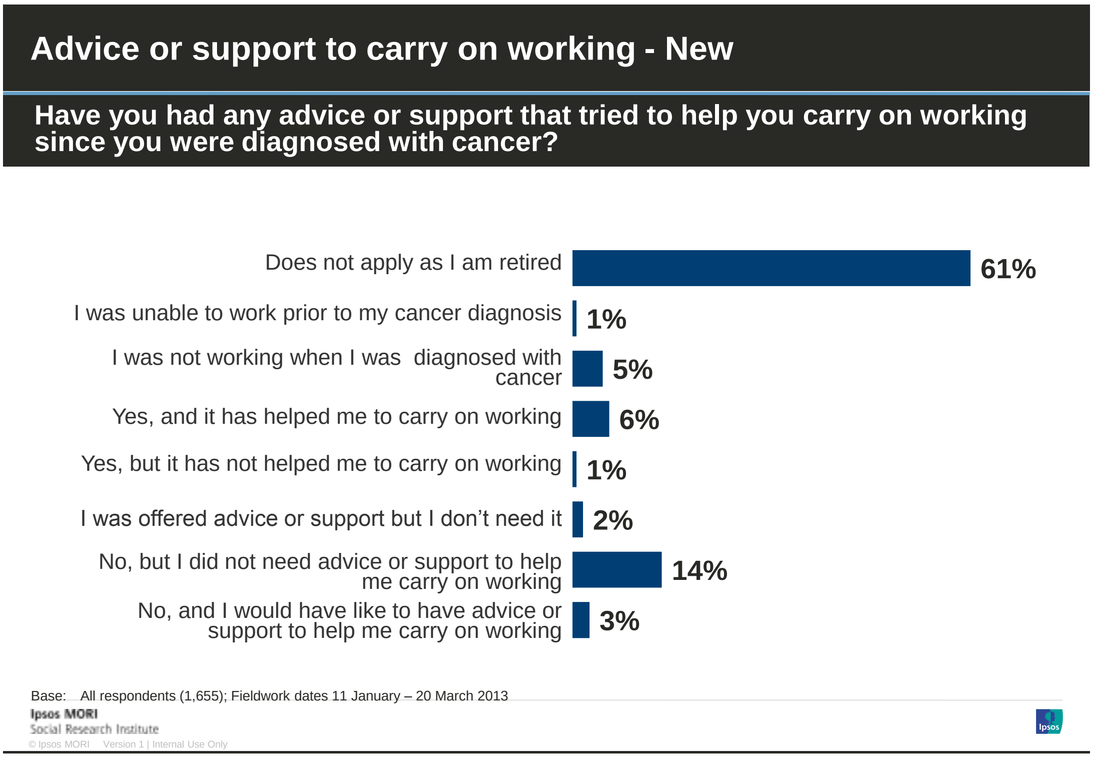


Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

Tumour group does not appear to play a role here, with no significant differences across different groups. However, those with a care plan are again more positive, with 87% agreeing that they have enough information, compared with 67% of those who do not have a care plan.

9.2 Help to carry on working

While most patients say they do not need advice to help them carry on working (mostly because they were retired), six per cent say they have received advice or support that has helped them to remain in work, with a further one per cent receiving advice that has not helped. A small number say they would have liked advice but have not received it (three per cent).



Advice or support to carry on working - New

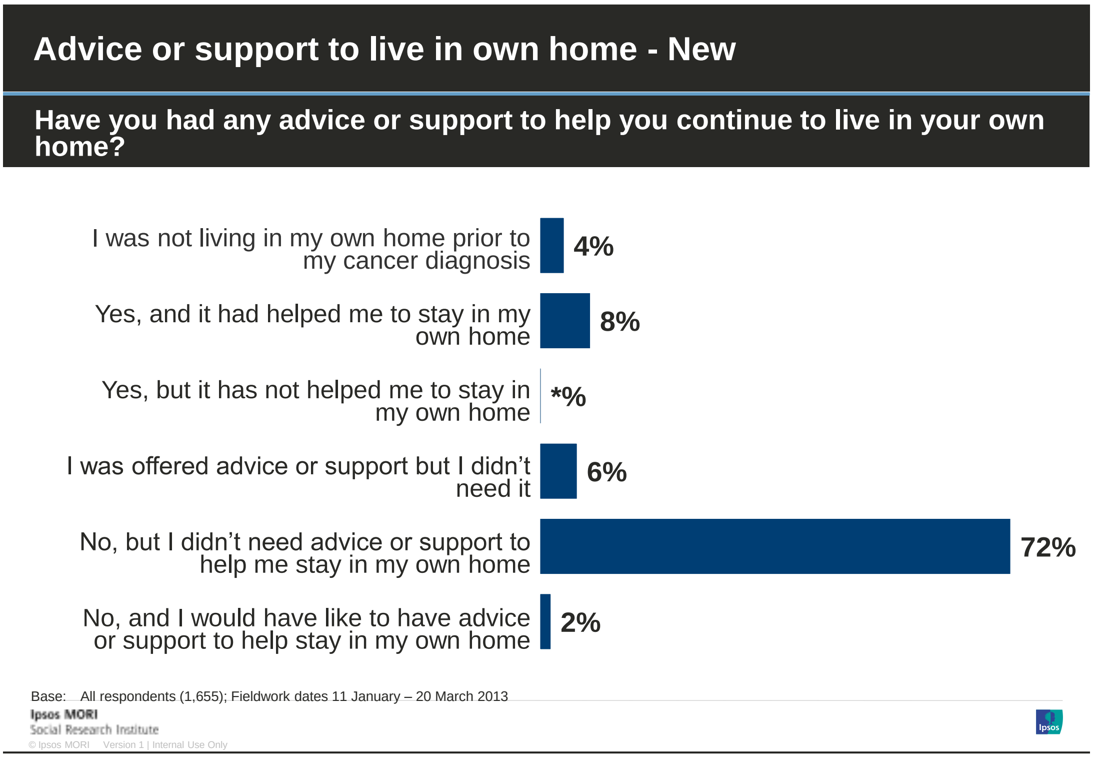
Have you had any advice or support that tried to help you carry on working since you were diagnosed with cancer?

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

Breast cancer patients are more likely to have had support that has helped them carry on working (10% compared with six per cent overall). This is also reflected in a greater proportion of women receiving help to carry on working than men (eight per cent compared with five per cent of men). This may be explained by the fact that significantly fewer women and breast cancer patients say that they are retired than other groups. Just over half of female patients are retired (55%) compared with two thirds of males (66%), while 47% of breast cancer patients are retired, compared with 61% overall.

9.3 Help to continue living in own home

The majority of patients has not received advice or support to continue living in their own homes, but also do not need it (72%). Just under one in ten has received support that has helped them stay at home (eight per cent). Two per cent have not have such support and would have liked it, while the number who have had advice that did not help is negligible.


Advice or support to live in own home - New

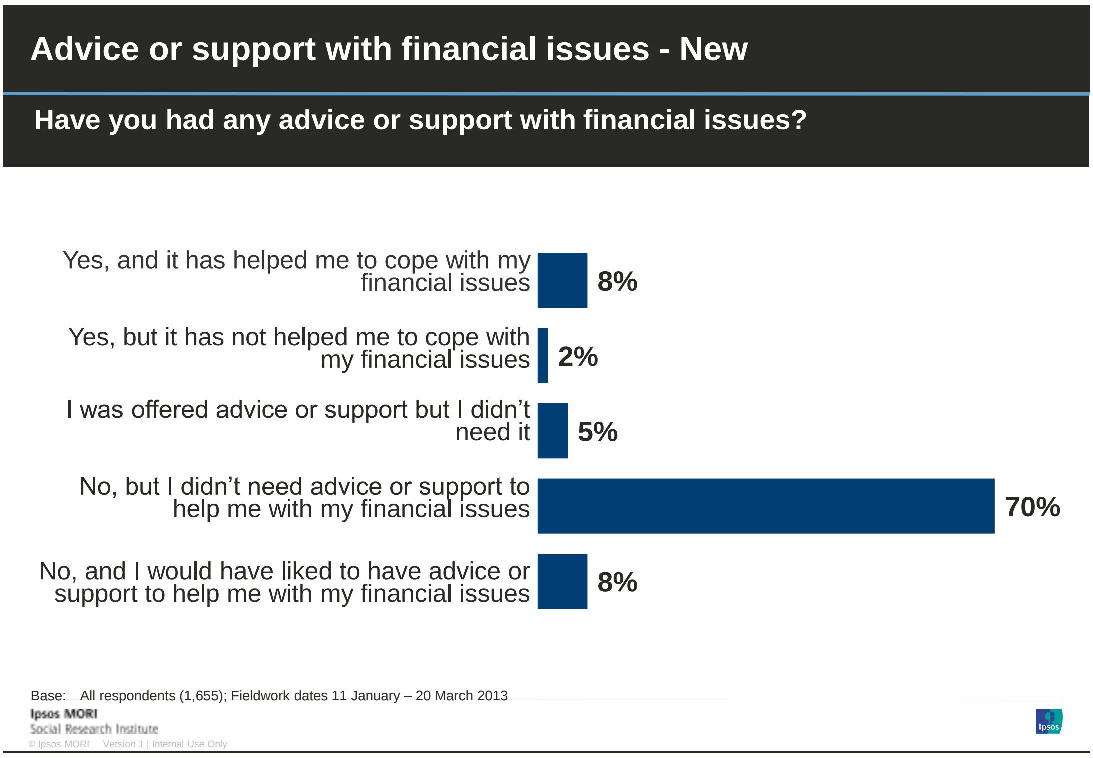
Have you had any advice or support to help you continue to live in your own home?

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

Perhaps unsurprisingly, it appears that help to continue living in their own home is particularly important for older patients. Patients aged 76 or over are more likely to have had support that helped them stay in their own home (13% compared with eight per cent on average).

9.4 Help with financial issues

The majority of patients are confident in dealing with any financial issues, with seven in ten saying that they have not received advice or support with financial issues, but do not need any (70%). However, amongst those who do require advice or support, almost half have not received it. Overall, just under one in ten has had support that helped them cope with their financial issues (eight per cent), and the same proportion would have liked such support but have not received it (also eight per cent).



Advice or support with financial issues - New

Have you had any advice or support with financial issues?

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

Younger patients are considerably more likely to require help with financial issues. Those aged 36-60 are far less likely to say they didn't need advice, whether they were offered it or not (58% neither needed nor received financial support compared with 70% overall, and seven per cent were offered support but did not need it compared with five per cent overall). This may be explained by the fact that this group are more likely to be affected by loss or reduction of salary after diagnosis where they have to leave work or reduce their hours – as well as having had less time to potentially build up savings for such an eventuality.

There is some variation across tumour groups here. Prostate cancer patients are more likely to have neither wanted nor received financial support (74% compared to 65% of breast cancer patients). Breast cancer patients were more likely to have wanted support but not received any, however – 11%, compared with eight per cent overall.

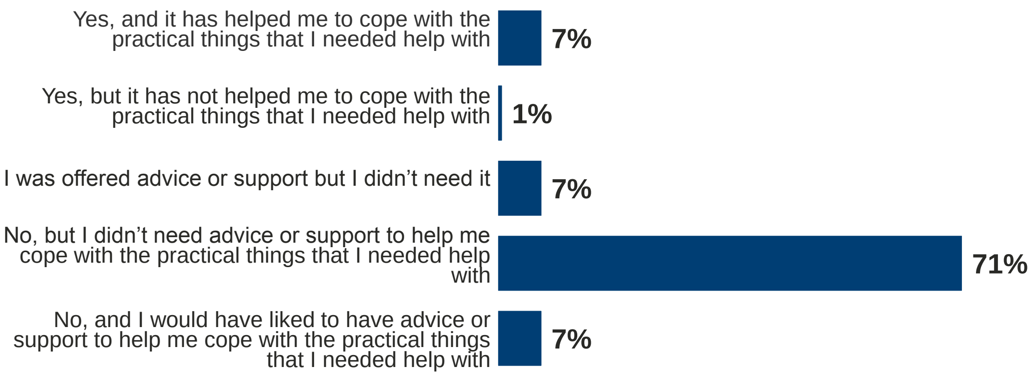
These differences are also reflected in differences across genders. Men are more likely to neither want nor receive financial support (73%, compared with 67% of women). Women, meanwhile, are more likely to have wanted but not received such support (10%, compared with seven per cent of men). Again, this may be linked to age, as the profile of breast cancer patients is slightly younger than the other tumour groups.

9.5 Help with other practical things

Most patients do not say they require support in areas such as personal care, doing housework or shopping; seven in ten neither need nor receive such support (71%). However, around one in seven says they do need this support. Of those that do, the proportions are evenly split as to whether they have received it or not – seven per cent of patients have received support that helped them cope, while a further seven per cent say they wanted such help but were not provided with any. One per cent has had advice that did not help.

Advice or support with other practical things - New

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 (1,655); Fieldwork dates 11 January – 20 March 2013

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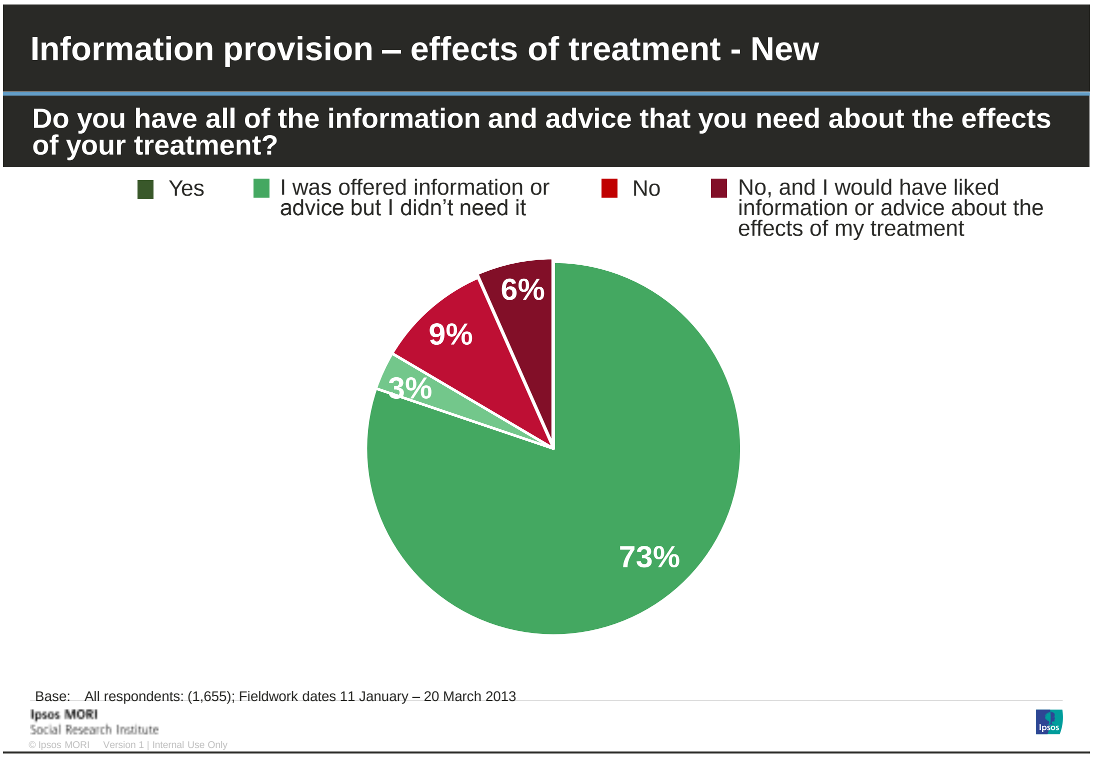
There were no significant differences in results across tumour groups for this question.

9.6 Information about the effects of treatment

The majority of patients are happy with the information provided about the effects of their treatment. Three quarters say that they have all of the information and advice they need (73%), with a further three per cent saying that they were offered information or advice but didn't need it. However, almost one in five does not have this information (17%).



Information provision – effects of treatment - New

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

Base: All respondents: (1,655); Fieldwork dates 11 January – 20 March 2013

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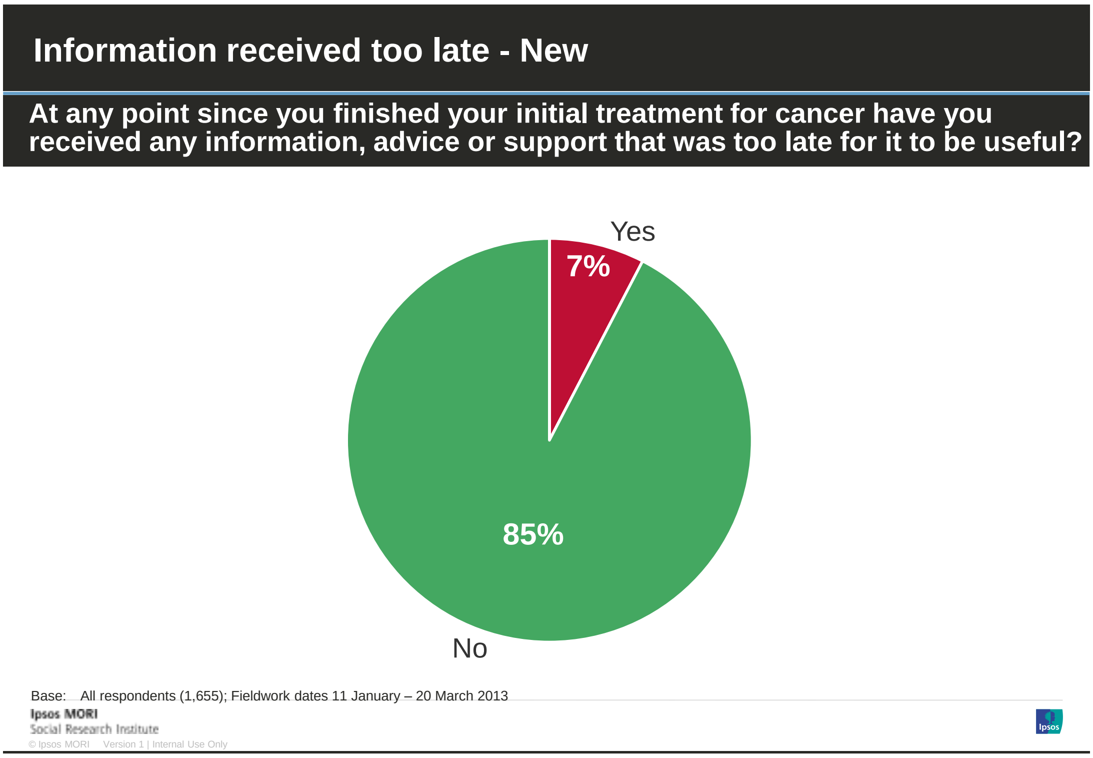
Younger patients are less satisfied with the information provided about the effects of their treatment. Thirteen per cent of 36-60 year olds say that they would have liked information about these effects but did not receive any, compared with 10% of 61-75 year-olds, and six per cent of those aged 76 or over.

Those with care plans are more likely to feel they have been given the all the information they needed. Almost nine in ten patients with care plans say that they have all the advice they needed (86%) compared with less than seven in ten of those who do not (69%).

There are no significant differences across tumour groups on this question.

9.7 Support provided too late for it to be useful

Most patients appear to receive information, advice or support in a timely fashion. However, a small but noteworthy group say they have received information too late for it to be useful (7%).



Information received too late - New

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?

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

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Information provision again appears to be key to patients' confidence in managing their own health. One in six patients who say they are not confident in managing their health feel they have been given support too late for it to be useful (16%), compared with seven per cent overall.

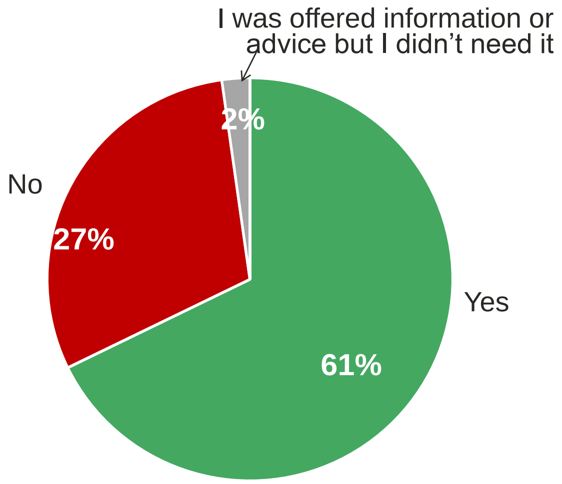
There are no significant differences in results across tumour groups for this question.

9.8 Information on signs and symptoms

Most patients do have all the information needed about the signs and symptoms of cancer so they can tell if it comes back, but a sizeable minority do not. Just over a quarter do not feel they have what they need (27%).

Information provision – signs and symptoms of cancer - New

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 (1,655); Fieldwork dates 11 January – 20 March 2013

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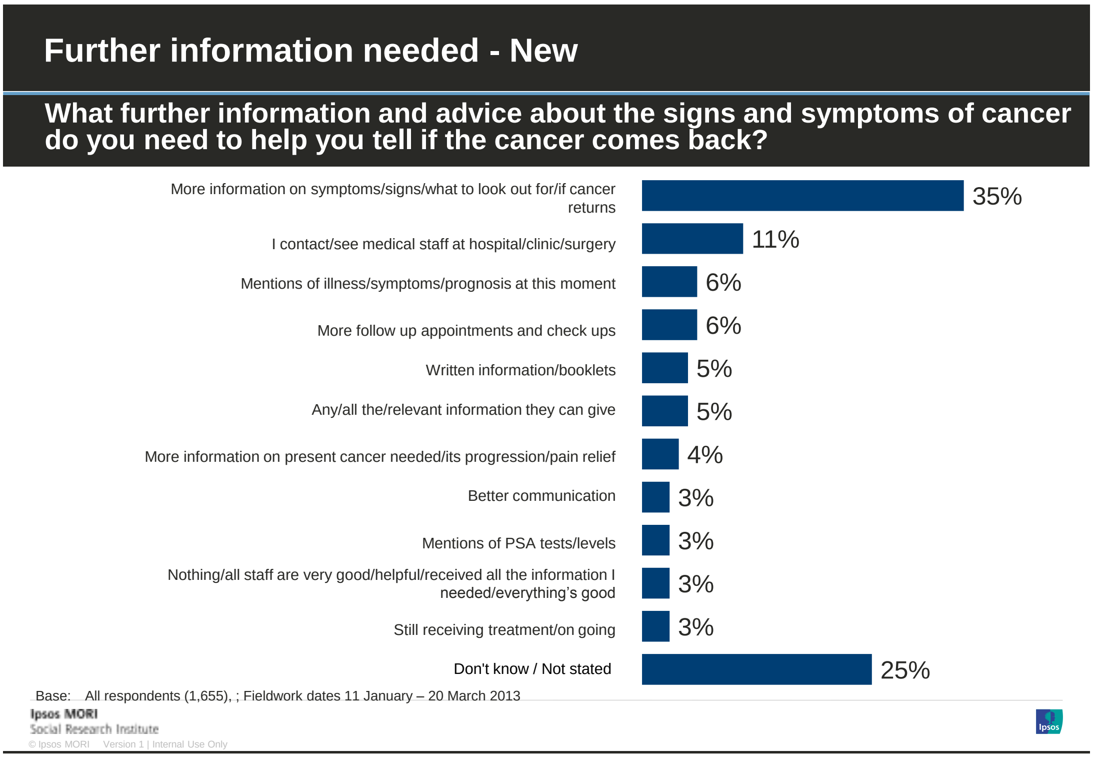
Patients who have been in aftercare for a longer period of time tend to feel better informed about the signs and symptoms of their cancer. For example, seven in ten patients whose initial treatment finished over two years ago (71%) have this information, compared with six in ten overall (61%), and 55% of those who had finished their treatment less than six months previously.

Again, care plans appear useful. Patients with a care plan are more likely to have the information they need (72% vs 57% of those with no care plan).

Where patients do not have all the information they need, they do not tend to ask for specific types of information. They most commonly ask for general information on what to look out for if the cancer returns, and this makes up 35% of responses.



Further information needed - New

What further information and advice about the signs and symptoms of cancer do you need to help you tell if the cancer comes back?

Base: All respondents (1,655), ; Fieldwork dates 11 January – 20 March 2013

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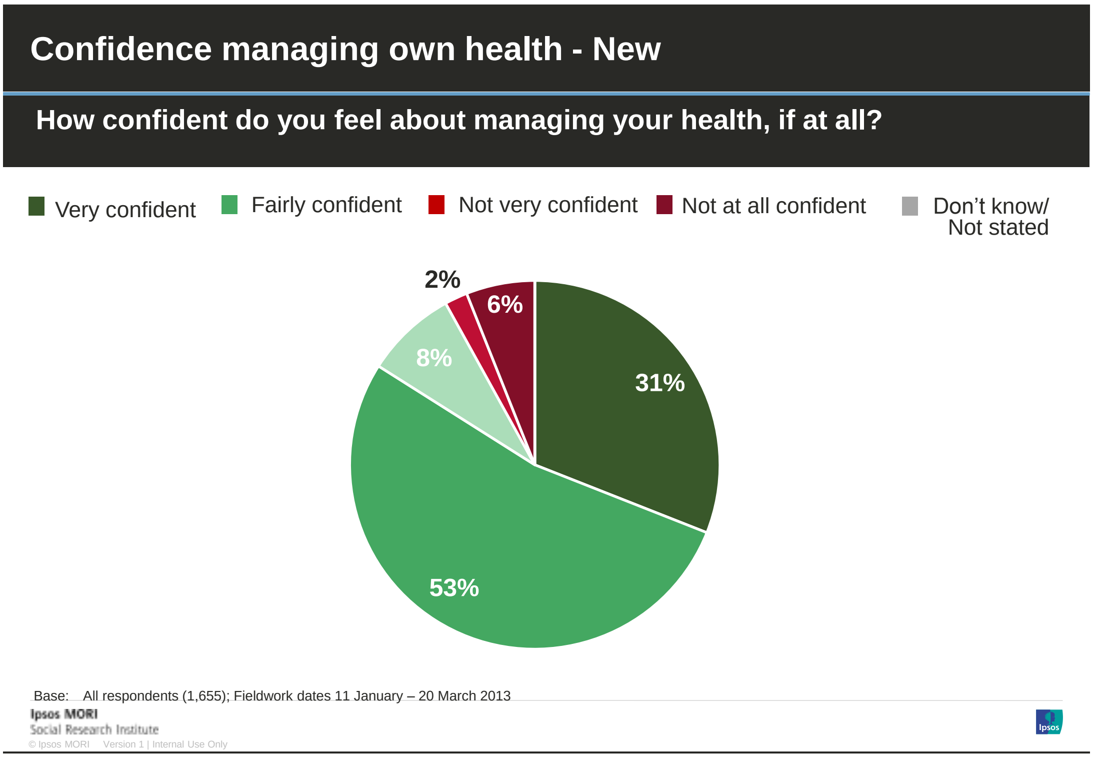
10. Self-managed care

There are a wide range of aspects of patients’ ability to self-manage, In this chapter we will consider each issue in turn, examining its prevalence and the way the problem has been tackled, if at all.

For the majority of these issues (and as seen with the existing TCs), there are correlations with information provision and (to a lesser extent) care plans. Throughout this chapter the most compelling examples are indicated, but this pattern is repeated in almost every case.

10.1 Confidence in managing health

As is the case in the existing TCs (both at the baseline and follow-up stages), most patients feel confident in managing their health, with three in ten saying they are very confident.


Confidence managing own health - New

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

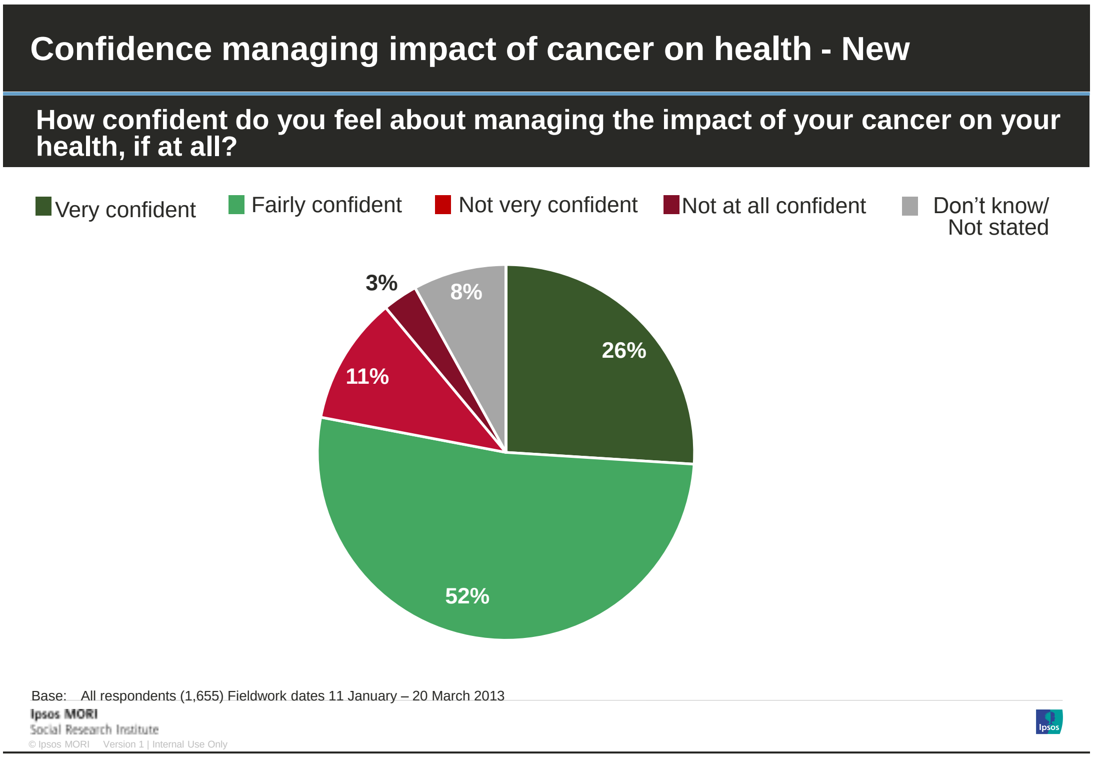
Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

However, some groups of patients are less confident than others. For example, 81% of prostate cancer patients are confident, compared with 84% overall.

Patients with care plans are more likely to feel confident managing their health; 90% are confident, compared with 84%of those without care plans.

10.2 Confidence in managing the impact of cancer on health

Patients are slightly less confident in managing the impact of cancer on their health, than their health in general, though the majority still say they are confident (78%).



Confidence managing impact of cancer on health - New

How confident do you feel about managing the impact of your cancer on your health, if at all?

Base: All respondents (1,655) Fieldwork dates 11 January – 20 March 2013

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Women express more concern here; 17% of women say that they do not feel confident, compared with 11% of men.

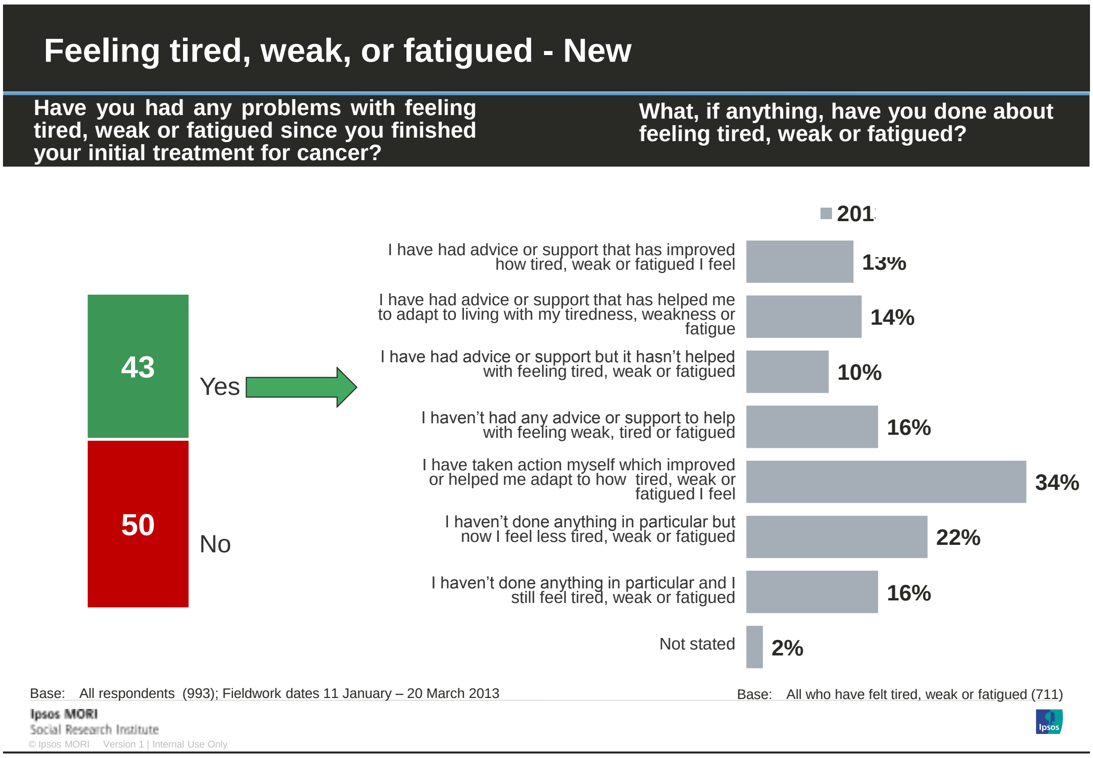
As seen in the existing TCs, care plans and information provision appear to help. Almost nine in ten (87%) of those with care plans are confident, compared with three quarters (76%) of those without care plans. Similarly, almost nine in ten of those who feel they have the information they need to recognise of the cancer has returned (88%) are confident in managing the impact of cancer, compared with two thirds (66%) of those who do not have this information.

There were no significant differences between tumour groups on this question.

10.3 Feeling tired

Just over two in five patients have felt tired, weak or fatigued since their initial treatment for cancer (43%). Positively, a third of these patients have taken action themselves that has improved the problem (34%) and one in five has not done anything in particular, but now feels less tired (22%). Where patients have received advice or support regarding their problems, similar proportions say that it has improved how they felt and that it has helped them adapt to their tiredness (13% and 14% respectively).

However, one in ten says that the advice has not helped (10%) and a further 16% haven't done anything in particular but still feel tired.



Feeling tired, weak, or fatigued - New

Have you had any problems with feeling tired, weak or fatigued since you finished your initial treatment for cancer?

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

Base: All respondents (993); Fieldwork dates 11 January – 20 March 2013

Base: All who have felt tired, weak or fatigued (711)

There are differences by tumour group, and related to this, by gender. For example, women are more likely to have taken action to improve how they feel – 38% have done so, compared with 30% of men. However, breast cancer patients are also more likely than other patients to feel better despite not having taken any action (26% vs 22% overall).

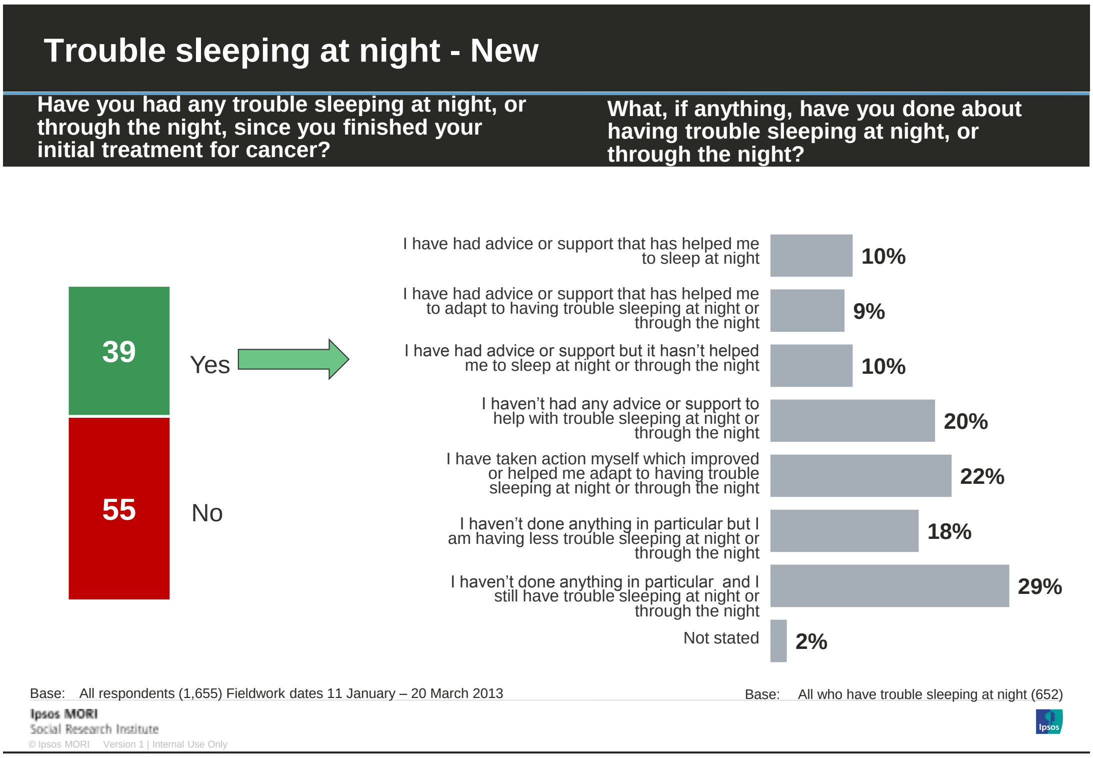
Age is also important, with older patients over the age of 75 more likely to have done nothing but still feel tired (27% vs 16% overall). This may indicate that these patients are more willing to accept the problem, thinking that it cannot be helped.

10.4 Trouble sleeping

Four in ten patients have had trouble sleeping at night since they finished their initial treatment (39%), with breast cancer patients most likely to suffer from this (46%).

Patients who have trouble sleeping are particularly passive regarding this problem – three in ten (29%) have done nothing and still have these problems. A further 18% say they haven't done anything but the problem has resolved itself.

Three in ten have had advice regarding the problem, split evenly between those where the advice has helped them sleep (10%), helped them adapt to having trouble sleeping (9%), or not helped (10%). One in five has taken action themselves that has helped them sleep (22%).



Trouble sleeping at night - New

Have you had any trouble sleeping at night, or through the night, since you finished your initial treatment for cancer?

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

Base: All respondents (1,655) Fieldwork dates 11 January – 20 March 2013

Base: All who have trouble sleeping at night (652)

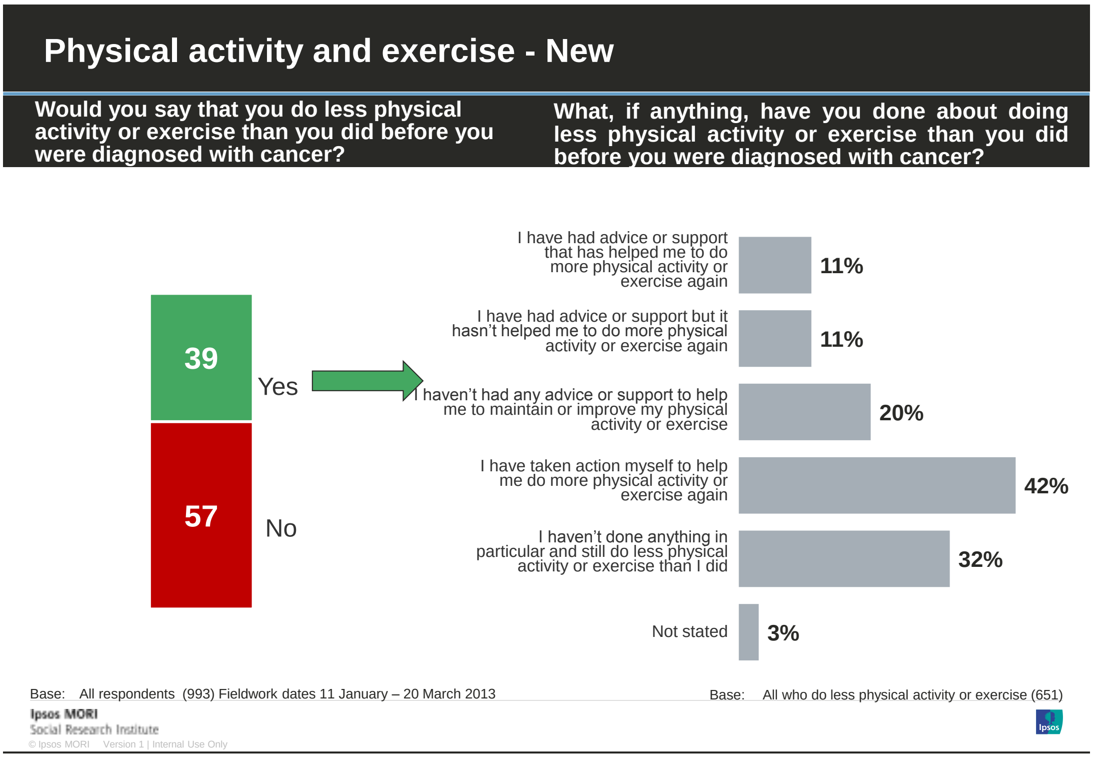
As with problems with tiredness, patients over 75 are more likely to have not done anything and still have trouble sleeping. Over a third (35%) of this group have done nothing and still struggle to sleep, compared with less than three in ten (29%) overall.

There are no differences between tumour groups regarding action taken to trouble sleeping.

10.5 Physical activity

Four in ten patients say they do less exercise than they did before they were diagnosed with cancer (39%) and this appears to affect older patients more. For example, half of patients over 75 say they are doing less exercise now (50%). Rectal patients are also particularly likely to be doing less physical activity; more than half (52%) do less physical activity than before their diagnosis, compared with two fifths of patients overall (39%).

This is one area where patients appear more proactive about their problems. Two in five have taken action themselves to help do more exercise (42%). Advice and support seem less forthcoming than for other problems though; one in five has received advice, with half finding this useful (11% say it has helped and the same proportion say it has not). However, one in three (32%) has not done anything and still does less exercise than before.



Physical activity and exercise - New

Would you say that you do less physical activity or exercise than you did before you were diagnosed with cancer?

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

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

Base: All who do less physical activity or exercise (651)

Despite the fact that this appears to be more of a problem for older patients, they again seem more willing to accept the problem. More than two in five patients aged 76 or over say they have done nothing about it (43% vs 32% overall).

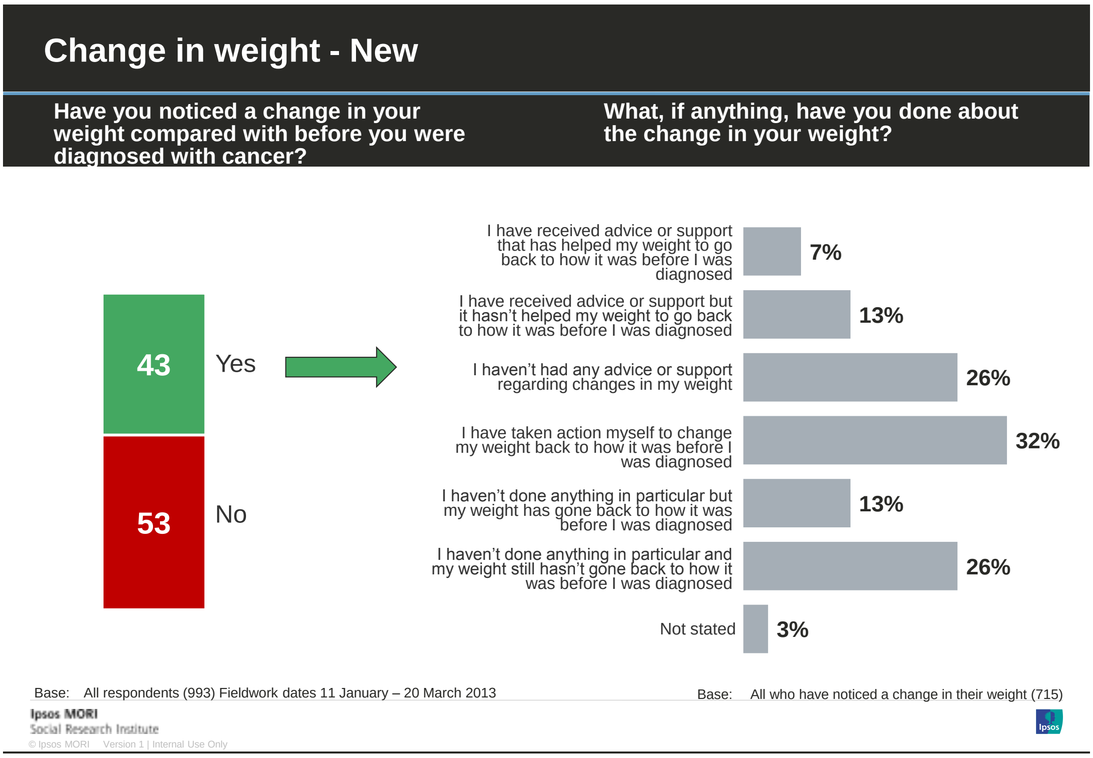
Patients were also asked about levels of physical activity, in order to provide some contextual understanding. While some patients are doing exercise[22] regularly, a quarter (26%) of patients say they have done no exercise in the past week. This rises to one in three patients over the age of 75 (36%).

10.6 Change in weight

Just over four in ten patients (43%) report noticing a change in their weight since their diagnosis. Women are more likely to have noticed a change in their weight (47% compared with 41% of men).

Patients do not appear to benefit from advice on this subject as they do regarding other problems. Only seven per cent have had advice that has helped, while 13% have had advice that has not helped. One in four (26%) has not had any advice regarding their weight change.

A third of those who have noticed a change in their weight have taken action themselves to deal with it (32%), while 13% have not done anything but their weight has gone back to what it was before their diagnosis.



Change in weight - New

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

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

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have noticed a change in their weight (715)

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[22] Defined as 30 minutes of activity which was enough to raise heart rate

There are differences across tumour groups here. Breast cancer patients are more likely to have taken action themselves (39% vs 32% overall), while colorectal patients are more likely than other patients to have done nothing in particular but their weight has returned to what it was pre-diagnosis (18% vs 13%).

Again older patients seem more reluctant to take action to deal with their problem (35% of those aged over 75 say they have done nothing and their weight has not gone back to what it was before).

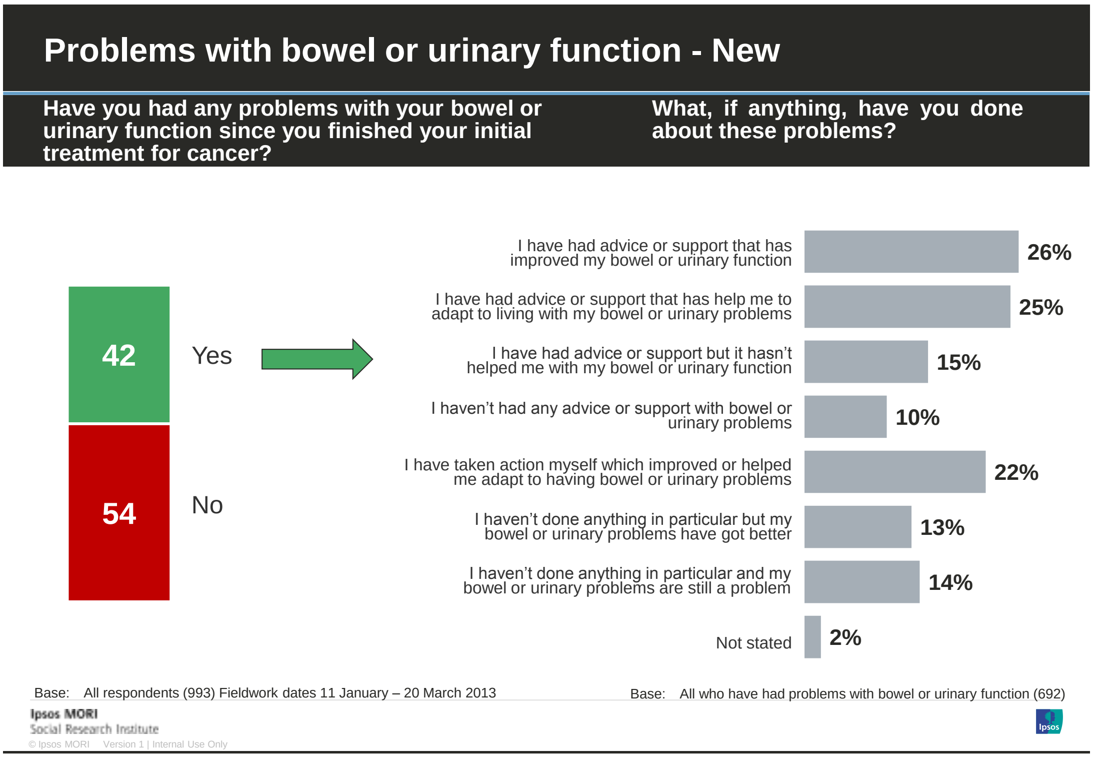
This is another area where care plans seem to be important. Three in ten of those who do not have a care plan (31%) have not had advice regarding their weight change, compared with 15% of those who do have a care plan.

10.7 Problems with bowel or urinary function

Four in ten patients (42%) have had problems with bowel or urinary function since the end of their initial cancer treatment, more commonly among colorectal and prostate cancer patients. One in five breast cancer patients (22%) has had bowel or urinary problems, compared with a third of colon cancer patients (35%) and more than half of rectal cancer patients (52%) and prostate cancer patients (54%).

Advice appears to be more readily available for these problems. Two thirds of patients (66%) have received advice or support – 26% have had support that has improved their bowel or urinary function, 25% have had advice that has helped them adapt to their problems, but 15% have had advice that has not helped.

One in five patients with bowel or urinary problems has taken action themselves which has improved or helped them to adapt to their problems (22%) and some have found that the problems have resolved themselves (13%). However, 14% have done nothing and their problems remain.



Problems with bowel or urinary function - New

Have you had any problems with your bowel or urinary function since you finished your initial treatment for cancer?

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

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have had problems with bowel or urinary function (692)

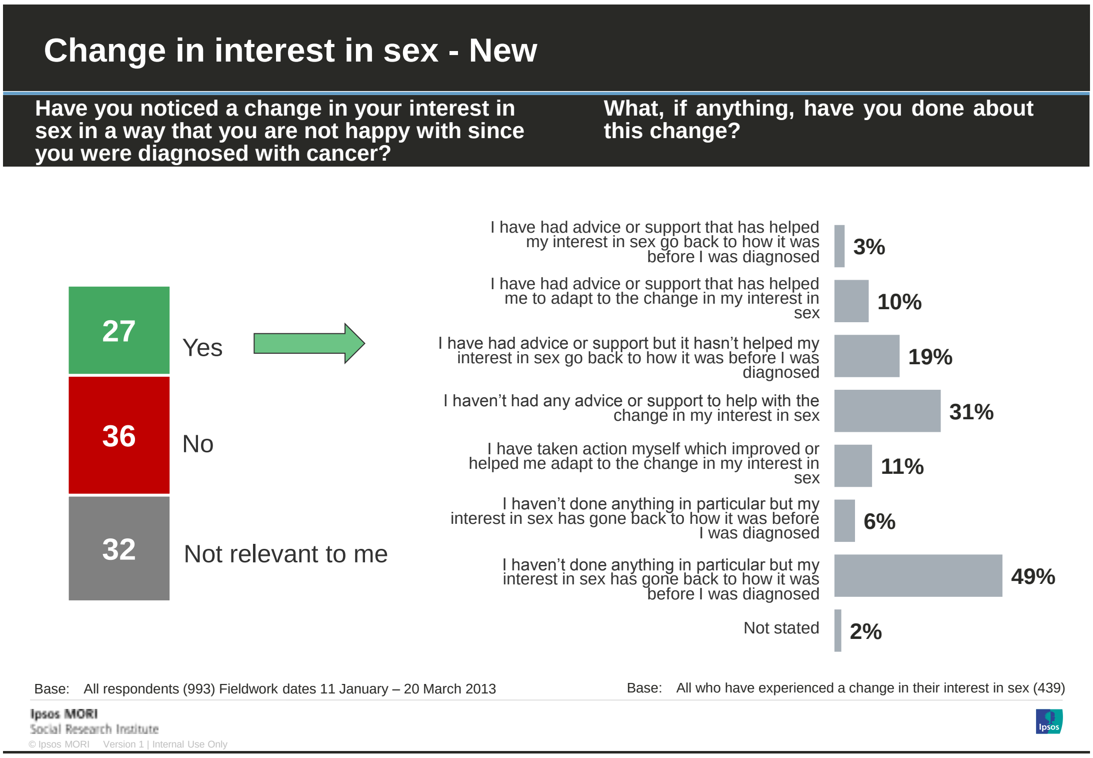
Women tend to be more proactive in their reaction to these problems. Three in ten women (29%) have taken action themselves to improve their bowel or urinary function, compared with 19% of men. Again, those aged over 75 are less likely to have taken action themselves (15% vs 22% overall).

10.8 Change in interest in sex

Fewer people report a change in their interest in sex as a problem. Just over a quarter of patients have noticed a change in their interest in sex since diagnosis in a way they aren't happy with (27%). This is far more prevalent among prostate cancer patients (44% have noticed a change), and far less prevalent among colon cancer patients (11% noticed a change). Younger patients are more likely to have noticed a change, while older patients are more likely to say that this issue was not relevant to them.

Patients are particularly unlikely to be proactive in addressing this issue – and it is far less likely to resolve itself on its own. Half of those suffering from changes in sexual interest have done nothing about it and have seen no improvement (49%).

Advice appears relatively ineffective in dealing with changes in patients' interest in sex. One in five patients has received advice that has not helped (19%), while only three per cent have received advice that has helped to return their interest to what it was pre-diagnosis and 10% have had advice that has helped them to adapt to change in their interest in sex.



Change in interest in sex - New

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?

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

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have experienced a change in their interest in sex (439)

There are some differences across tumour groups regarding action taken to change in sexual interest. For example, prostate cancer patients are more likely to have had advice that has helped them adapt to their change in sexual interest (16% compared with 10% overall), but also to have had advice that has not helped (27%, compared with 19% overall).

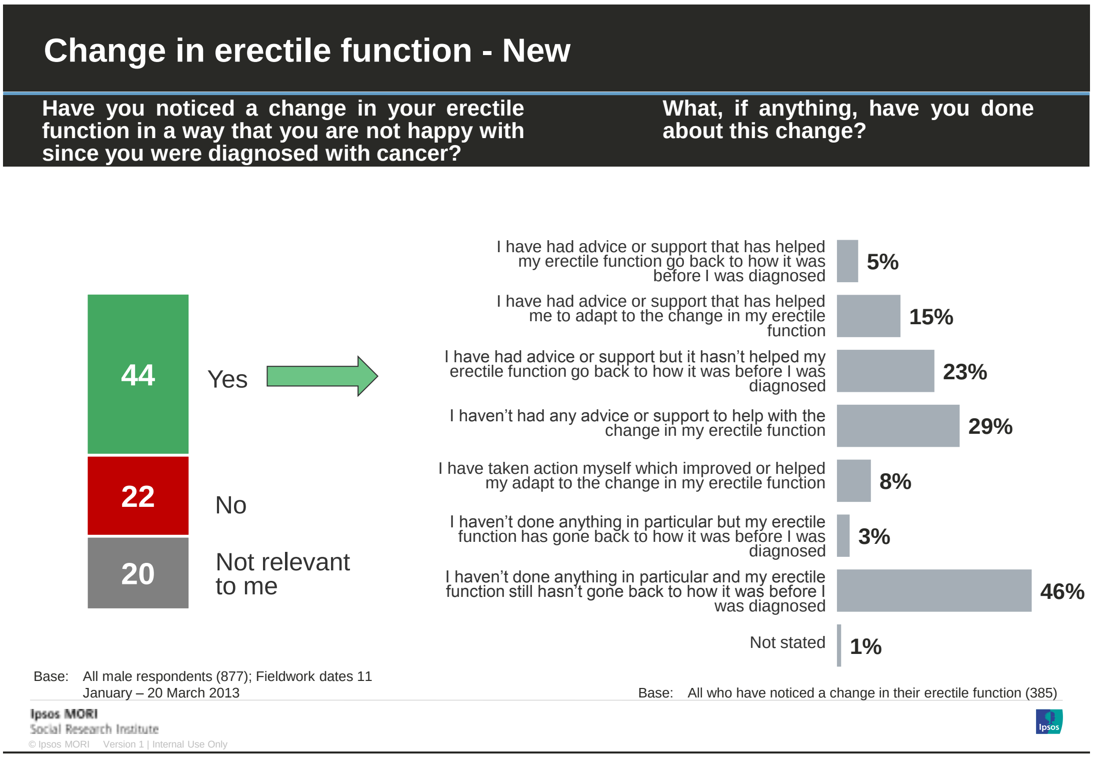
As with previous issues mentioned in this chapter, the over-75s are more likely to have done nothing, with their problem not improving (58% compared with 49% overall).

10.9 Change in erectile function

More than four in ten men have noticed a change in their erectile function since their diagnosis that they aren't happy with (44%) and this rises to more than half of prostate cancer patients (55%). Colon patients are by far the least likely group to have noticed such a change (19%).

As with interest in sex, patients with erectile function problems are particularly unlikely to do anything about it – and it is particularly unlikely to be solved without action. Almost half (46%) of those who have erectile problems have done nothing about it, and it hasn't got better. Eight per cent have taken action themselves which has improved their erectile function.

Where advice has been provided, it appears relatively ineffective. Just over four in ten have had advice regarding their erectile function problems (43%) – five per cent have had advice that helped their erectile function, 15% have had advice that helped them adapt to the change, while 23% have had advice that has not helped.



Change in erectile function - New

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

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

Base: All male respondents (877); Fieldwork dates 11 January – 20 March 2013

Base: All who have noticed a change in their erectile function (385)

10.10 Feeling afraid

A concern that the cancer will come back plagues around half of patients (49%). The level of fear varies widely by tumour group. Nearly two thirds of breast cancer patients have been afraid (63%), compared with half of colorectal patients (50%) and a third of prostate patients (34%).

This difference may be linked to the fact that more women say they are afraid than men. Three in five (62%) women say they have felt afraid, as opposed to two fifths (38%) of men.

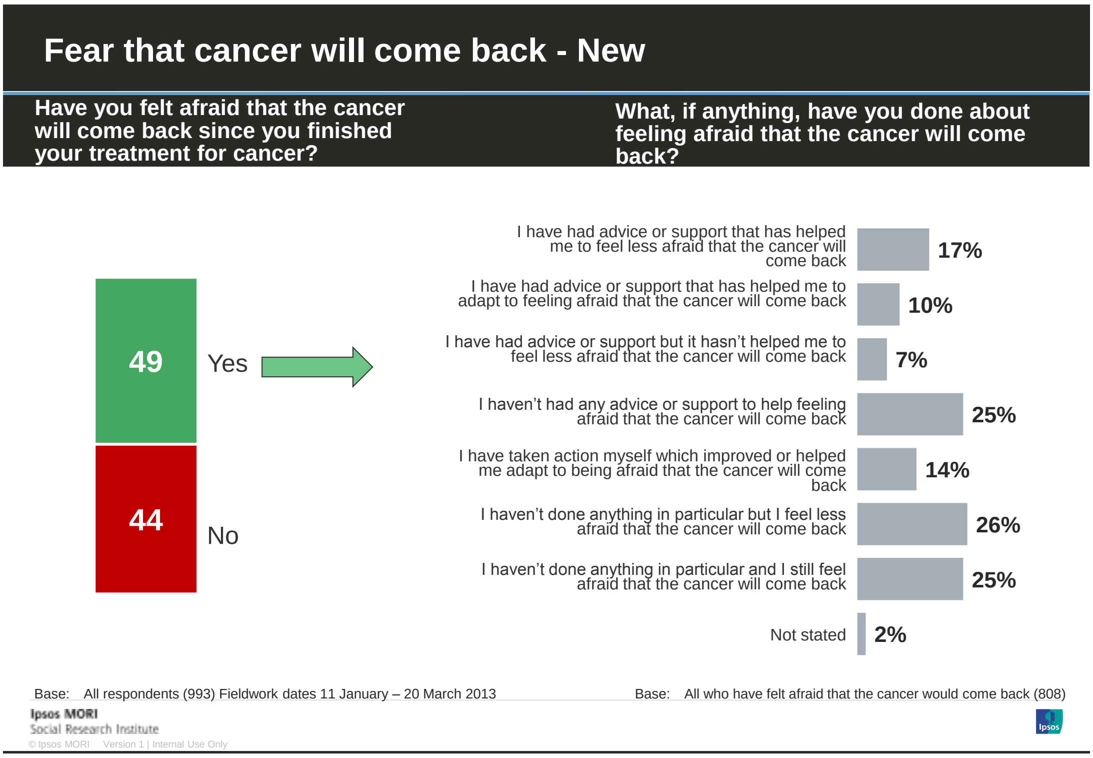
Younger patients are also more likely to be worried than older patients. Almost three quarters of 36-60 year-olds have felt afraid (73%), compared with half of 61-75 year-olds (49%) and a third of those aged over 75 (33%). While women patients in the survey tend to be younger, this does not completely explain this – younger people do appear to suffer more from a fear of cancer returning than older patients. For example, amongst both women with colorectal cancer and women with breast cancer, the likelihood of being afraid of the cancer returning decreases with age.

As we have seen in the existing TCs, patients with general information on managing their health and on the signs and symptoms of their cancer are less likely to be worried about it coming back. For example, 64% of those that do not feel they have enough information about the signs and symptoms have felt afraid, as opposed to 48% of those who do.

Having a care plan also appears to make a significant difference to patients' fear of cancer returning – 53% of those without a care plan had felt afraid, compared to 46% of those with a care plan.

Advice is comparatively effective in dealing with these fears. A third of people who have felt afraid have received advice (34%) – 17% have received advice that has helped them feel less afraid, 10% have had advice that has helped them adapt to feeling afraid, while seven per cent have had advice that hasn't helped.

Some have taken action themselves which has helped their fear or helped them adapt to it (14%), and fear has subsided among some without action. A quarter haven't done anything in particular but now feel less afraid, perhaps with the passage of time (26%). A similar proportion have done nothing though and still feel afraid (25%).



Fear that cancer will come back - New

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 (993) Fieldwork dates 11 January – 20 March 2013

Base: All who have felt afraid that the cancer would come back (808)

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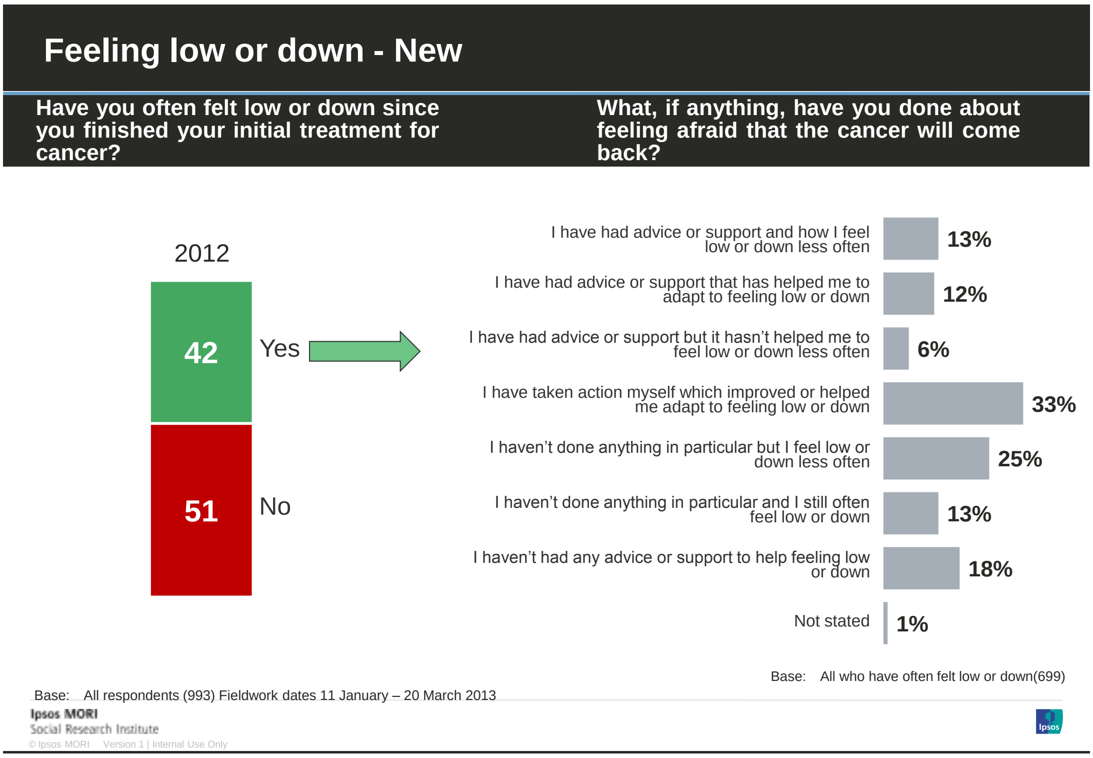
As with previous issues mentioned in this chapter, women (17%) are more likely to have taken action themselves. Again, care plans appear to contain advice on this, or at least those patients who receive a care plan also receive advice. One in three (28%) of those without a care plan have not had any advice regarding their fear, and this falls to one in five (18%) of those who do have one.

10.11 Feeling low or down

Two in five patients say they have often felt low or down since they finished their initial treatment for cancer (42%), and this rises to just over half of women (51%).

Feeling low is more likely than other issues mentioned in this chapter to resolve itself without action. One in four (25%) haven't done anything in particular but now feel down less often. However, more than one in ten (13%) haven't done anything in particular and they still often feel down. A third of people have taken action themselves that has helped them feel low less often, or helped them to adapt to feeling low (33%).

Almost a third of those who report that they have often felt low have had advice regarding their problem (31%) – 13% have had advice that has helped them feel low less often, 12% have had advice that has helped them adapt to feeling low, while six per cent have had advice that hasn't helped.



Feeling low or down - New

Have you often felt low or down since you finished your initial treatment for cancer?

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

Base: All who have often felt low or down(699)

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

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Tumour group does make some difference here with prostate cancer patients more likely not to have done anything in particular, but still have problems (18% vs 13% overall).

11. Contact with health professionals

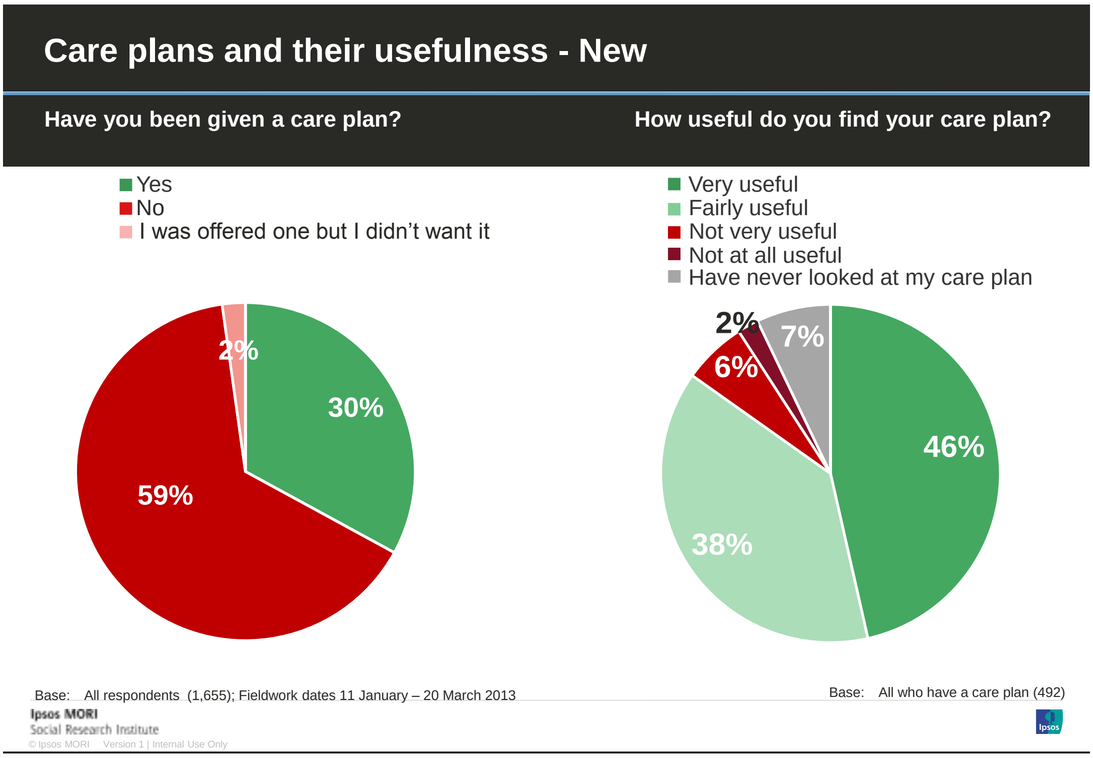
In this chapter we examine patients’ contact with health care professionals, assessing the provision of care plans and their usefulness, and contact with health care professionals during and outside of office hours.

11.1 Care plans

Findings in previous chapters (both for new and existing TCs) indicate that having a care plan is correlated with patients having access to the information, advice and support they need in dealing with issues related to their cancer and its treatment.

Three in ten patients in the new TCs (30%) report having a care plan – 19% when they were diagnosed and 11% when they finished their treatment. This is encouraging as it is higher than seen in the baseline survey amongst existing TCs (21%).

Ratings of the care plans’ usefulness is also positive. More than four in five (84%) think their care plan is useful (46% very useful).



Care plans and their usefulness - New

Have you been given a care plan?

How useful do you find your care plan?

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

Base: All who have a care plan (492)

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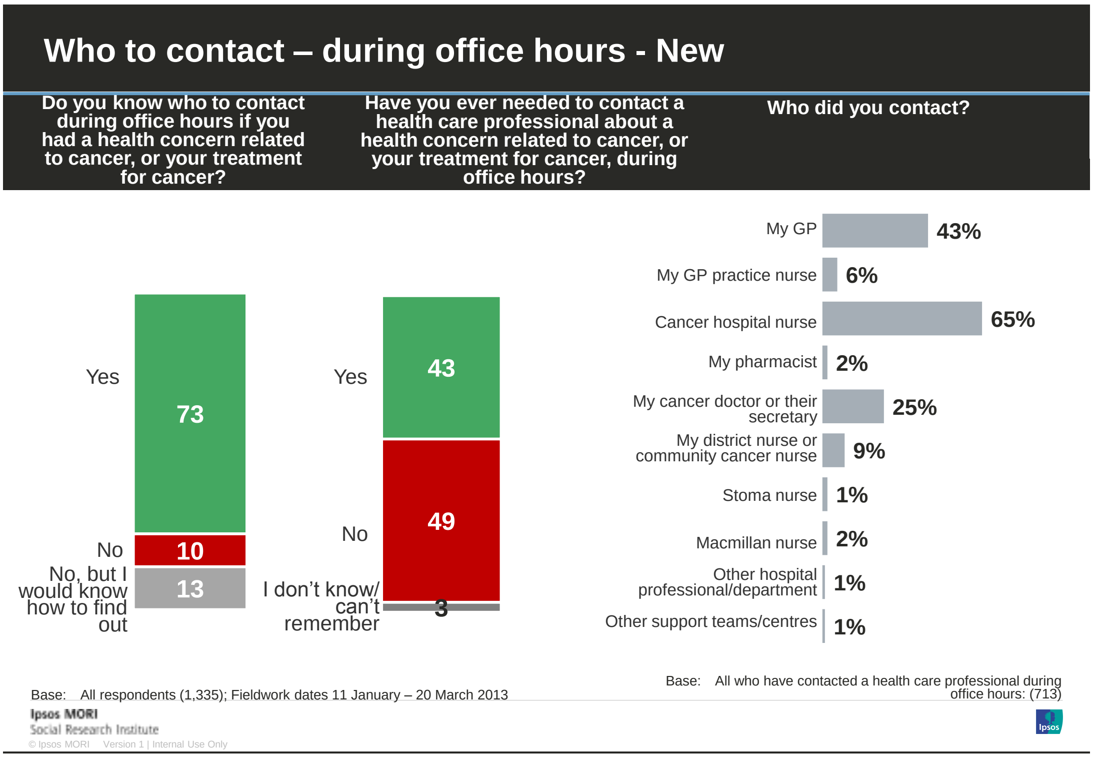
There is some variation between tumour groups – prostate cancer patients are most likely to have a care plan (34%), compared with 30% of breast cancer patients and 26% of colorectal cancer patients.

However, there are no significant differences across tumour groups or other demographics regarding the usefulness of care plans.

11.2 Contact during office hours

The majority of patients know who to contact during office hours if they have a health concern related to cancer, or their treatment for cancer. Three quarters (73%) of patients know who to contact, while 13% say they would know how to find out. This does leave one in ten patients who appear not to have an easy route back into the system should they need it.

When patients have needed to contact a health professional about their cancer, they are most likely to have contacted their cancer hospital nurse (65%). This emphasises the importance of this role for patients – something that has been seen in the baseline survey, the qualitative work on care coordination and in the national cancer patient experience survey. Four in ten contacted their GP (43%), and a quarter contacted their cancer doctor [or their secretary] (25%).



Who to contact – during office hours - New

Do you know who to contact during office hours if you had a health concern related to cancer, or your treatment for cancer?

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?

Who did you contact?

Base: All respondents (1,335); Fieldwork dates 11 January – 20 March 2013

Base: All who have contacted a health care professional during office hours: (713)

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There is some variation among tumour groups. Breast cancer patients are most likely to know who to contact (78%), compared with 73% of colorectal cancer patients and 67% of prostate cancer patients. In line with this, women are also more likely to know who to contact (76% vs 70% of men).

The professional contacted varied widely across tumour groups:

Prostate cancer patients are more likely than other patients to have contacted their GP. More than half (55%) contacted their GP, compared with four in ten breast patients (42%) and just over a third of colorectal patients (36%).

Breast cancer patients are most likely to have contacted their cancer hospital nurse. Three quarters of breast cancer patients (75%) contacted their cancer hospital nurse, compared with two thirds of colorectal cancer patients (67%) and less than half of prostate cancer patients (46%).

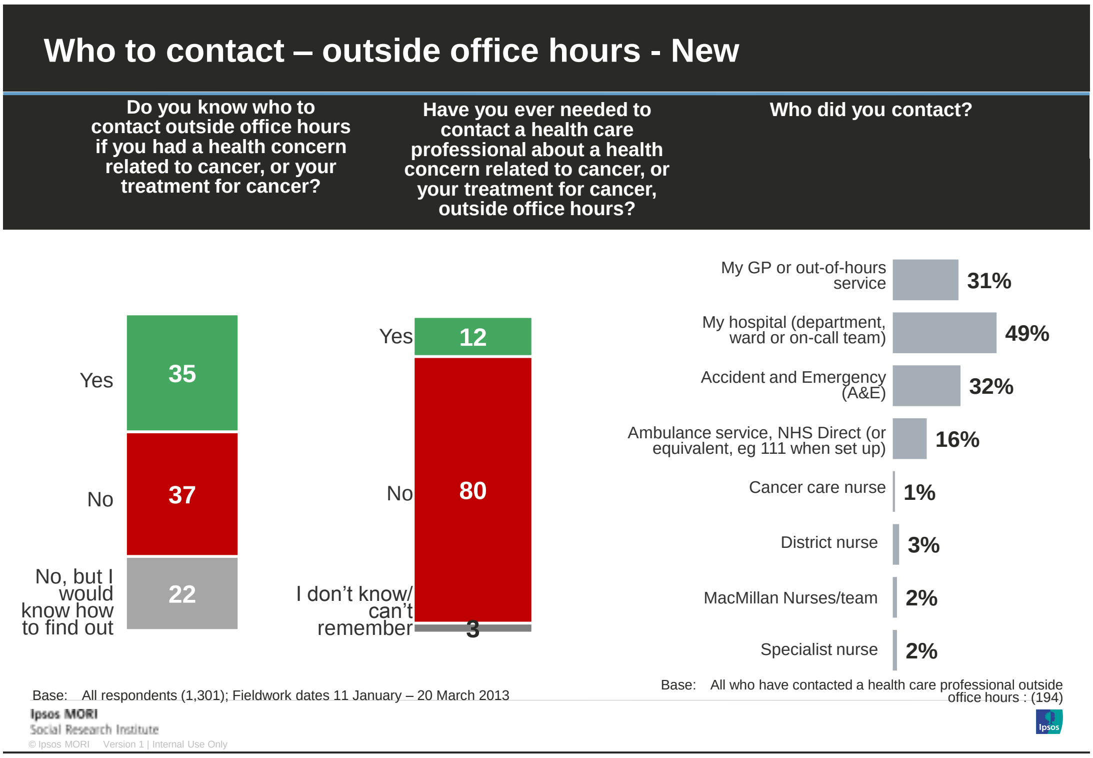
Colorectal cancer patients are more likely to talk to their cancer doctor than other groups. A third of colorectal cancer patients talked to their cancer doctor (33%), compared with a quarter of prostate cancer patients (23%) and a fifth of breast cancer patients (19%).

This is one area where a care plan appears particularly important, as 86% of those with a care plan know who to contact during office hours (compared with 70% of those who do not have a care plan).

11.3 Contact outside office hours

Patients are less likely to know who to contact outside office hours. Just over a third (35%) say they know who to contact, with a further fifth saying they know how to find out (22%). This leaves a significant minority who do not know who they should be contacting at all (37%).

One in ten patients (12%) have needed to contact someone out-of-hours, most commonly contacting their hospital (49%). A third contacted their GP or out-of-hours service (31%), with the same proportion contacting an A&E department (32%). One in six (16%) contacted the ambulance service, NHS Direct or 111.



Who to contact – outside office hours - New

Do you know who to contact outside office hours if you had a health concern related to cancer, or your treatment for cancer?

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?

Who did you contact?

Base: All respondents (1,301); Fieldwork dates 11 January – 20 March 2013

Base: All who have contacted a health care professional outside office hours : (194)

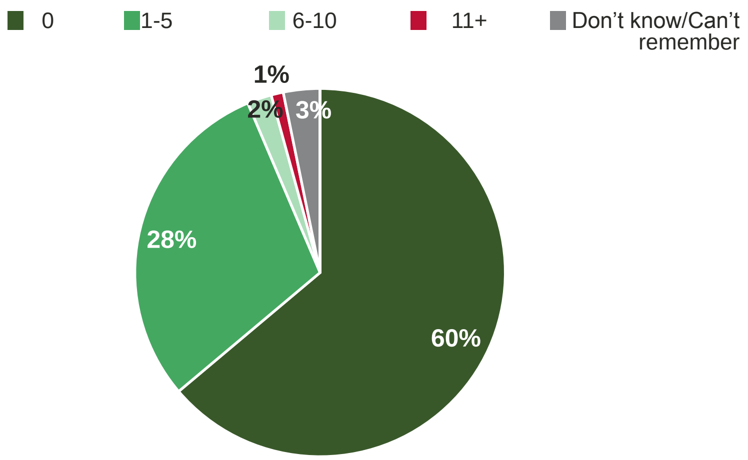
Again, patients with care plans have better knowledge of who to contact (44% vs 30% of those without a care plan).

11.4 Contact with GPs

As shown in this chapter, patients do contact their GPs about their cancer or its treatment. However, most patients have not done so – and where they have, their contact has been relatively infrequent. Three in five patients have not contacted their GP at all (60%). Three in ten have contacted their GP between one and five times (28%), two per cent have contacted them between six and ten times and one per cent has contacted them more than eleven times.

Contact GP over last 6 months - New

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 (1,655); Fieldwork dates 11 January – 20 March 2013

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Prostate cancer patients are significantly more likely than other tumour groups to have contacted their GP. Well over a third (37%) have contacted their GP between one and five times, compared with less than three in ten (28%) overall. Colon cancer patients are least likely to have contacted their GP in the last six months – seven in ten (72%) had not done so, compared with six in ten (62%) overall.

Unsurprisingly, those more confident in managing their own health, and those who feel they have all the information needed to manage their health and recognise cancer symptoms are less likely to have contacted their GP. For example, two thirds (65%) of those confident in managing their health have not seen their GP in the last six months, compared with less than half (44%) of those who are not confident.

Conclusion and Implications

Conclusions and Implications

In this final chapter, we first present a summary of the key conclusions from this piece of research, highlighting areas of progress whilst also recognising the issues that still remain to be addressed. This then leads on to a discussion of the implications of the findings presented, in part to help inform the future work of the Test Communities.

Conclusions

- Results for the new and existing Test Communities (TCs) are very similar and generally very positive. We have seen some progress from the baseline for existing TCs – especially in terms of perceived overall quality of care since the end of treatment, which has increased by seven percentage points since 2011.

- At the baseline stage we saw the important role that a care plan had to play in ensuring that patients were able to access the advice and support that they need. Given this, it is positive that we have seen a fourteen percentage point increase in the proportion of patients with a care plan in the follow-up survey among existing TCs (2011: 21%; 2013: 35%). This is to be expected given that care planning was one of the key principles of the *National Cancer Survivorship Initiative Vision* (2010).

- However, whilst more patients at existing TCs have care plans, the proportion of these who find them to be useful has fallen by seven percentage points (from 84% to 77%), although a majority do still find them useful. If care plans have been more widely offered to patients, then it is possible that this has contributed to the reduction in their perceived usefulness.

- Patients at new TCs are more likely to have care plans than existing TCs were at the baseline stage (existing TCs 2011: 21%, existing TCs 2013: 35%, new TCs 2013: 30%).

- Care plans are seen as useful in new TCs this year by the same proportion of patients as found them useful at existing TCs at the baseline stage (84%). The challenge will be to maintain this (or improve it) as care plans are offered more widely in the new TCs.

- A significant information gap identified at the baseline was the proportion of patients who said they did not have all of the information and advice they needed about the signs and symptoms of cancer. Addressing this issue was going to be a key aspect of a move further towards self management, and therefore it is encouraging to see that this group has fallen at existing TCs to account for less than a quarter of patients in the follow-up survey. This group accounted for just over a quarter of new TCs – more than for existing TCs this year, but significantly less than existing TCs at the baseline stage.

- Another issue where a degree of improvement at existing TCs is evident at the follow-up stage is with patients who have had problems feeling tired, weak or fatigued. The proportion of patients reporting that they haven't had any advice or support here has fallen from one quarter to less than one in five (25% to 18%). This proportion is at a similar level at the new TCs (16%), again illustrating that the new TCs are starting from a better position than the existing TCs in 2011.

- Despite the progress made, there has been no reduction in the proportion of patients who have been afraid that their cancer will come back at existing TCs. Rather, this has increased to more than half of patients. Again, more than one quarter (27%) of these patients haven't done anything and still feel afraid that the cancer will come back.

- There remain some other issues for which patients are not receiving the advice or support they need, and demonstrate less ability to self manage. Significant numbers, almost half in both cases, of patients who have experienced a change in their interest in sex, or in their erectile function have not done anything in particular and are still experiencing problems. This is true of both sets of TCs.

- As with the baseline survey, most patients feel that they have 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. Again, this is true of both sets of TCs.

- A vast majority of patients already felt confident managing their health at the baseline, and, unsurprisingly given the minimal room for improvement, there has been no change over time at existing TCs.

- A majority of patients do know who to contact during office hours, and those who have done so again contacted their cancer nurse. This is true of both sets of TCs, and was also true of existing TCs at the baseline stage.

Implications

The work of the NCSI and the Test Communities involved over the last 3 years, and the survey work conducted to evaluate this, can be considered to have implications on three levels. First of all, the findings serve to inform the future work of the hospitals involved as Test Communities, providing guidance for areas that still require attention. Secondly, there are implications for the wider cancer survivorship agenda, as the NCSI Vision continues to 2015, and cancer aftercare more generally. Finally, there is some learning that can be taken from this work and applied to the wider agenda regarding the treatment and management of long term conditions.

Overall, while the findings are encouraging and broadly positive, they illustrate some key issues that remain and require further attention. In particular, it is important that continuing efforts are made to ensure that all patients have all the information they need about the signs and symptoms of recurrence. There has been good progress made here, but there is room for further progress to be made. The issues of fatigue and physical activity also represent areas requiring further attention. While various initiatives have been implemented at several of the existing Test Communities to try and help patients increase their levels of physical activity, there has been little sign of improvement since the baseline survey. This indicates that further work is required to demonstrate to patients the importance of physical activity and exercise.

It is frequently male patients who appear the least likely to seek help or take action themselves across various issues, which perhaps indicates that healthcare professionals need to tailor their conversations with patients and encourage men in particular to seek help.

As we have mentioned throughout this report, whether or not patients have a care plan is often a key factor in whether patients have had the necessary information and support to deal with various issues. However, the reduction in the proportion of patients finding their care plans useful since the baseline survey is intriguing. This indicates that there may be further work needed to understand how best care plans should be used with patients, and how patients might benefit from the care plan and planning process surrounding this.

Furthermore, a wider implication is that patients without a care plan are more likely to contact their cancer doctor, and therefore increasing the proportion of patients with a care plan may further reduce the frequency of this contact, reducing the burden on cancer doctors.

Ultimately, this survey illustrates the good work that the Test Communities have been involved in, whilst also highlighting some areas where there is room for further improvement as they continue their work over the coming years. In addition, there is much that can be learnt to help ensure the efficacy of any future survivorship initiatives, whether at the national level, or undertaken by individual hospitals.

Appendices

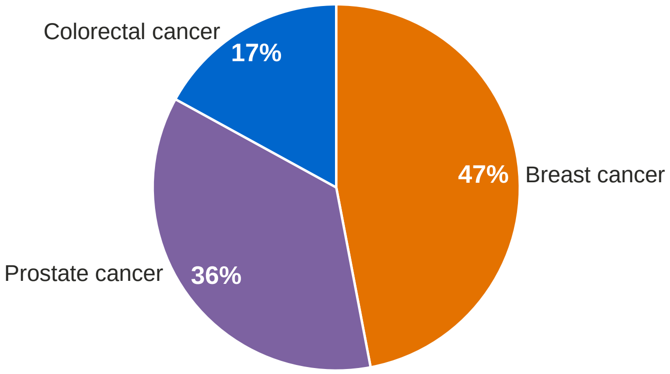
Appendices

Appendix 1: Profile of Respondents

Amongst existing Test Communities, almost half (47%) of patients responding had been most recently diagnosed with breast cancer, whilst colorectal patients accounted for 17% of patients. These results mirror those seen in the baseline study (45% and 18% respectively).

Cancer pathway - Existing

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



Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

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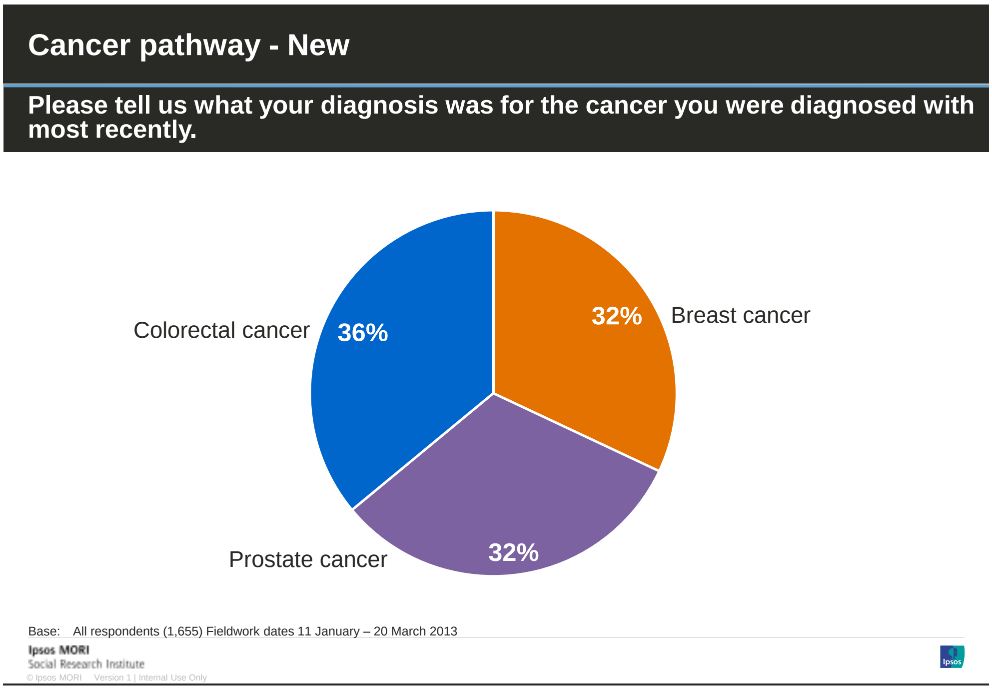
The distribution of patients responding for specific cancer types within the new Test Communities only was more evenly split across the three tumour groups, reflecting the fact that more of the new Test Communities were involved for all three tumour groups.



Cancer pathway - New

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

Base: All respondents (1,655) Fieldwork dates 11 January – 20 March 2013

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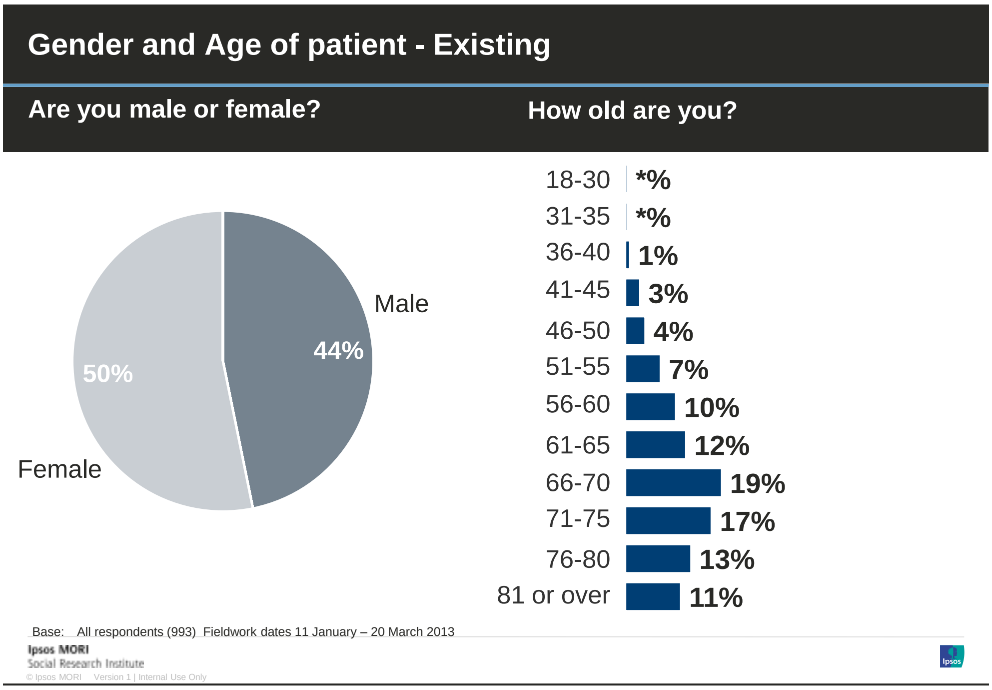
Little change was observed in the gender and age profile of cancer patients in existing Test Communities since the baseline study. Overall, there is an even split in terms of patient gender (44% male and 50% female) and the majority of patients responding are over 60 years of age.



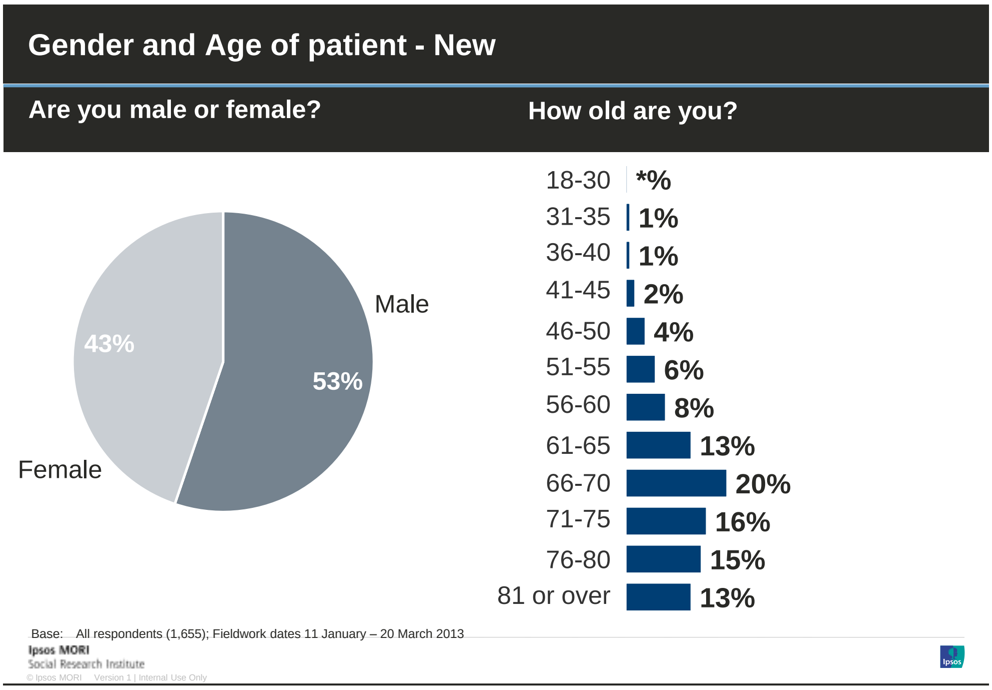
Gender and Age of patient - Existing

Are you male or female?

How old are you?

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

In the new Test Communities a slightly different gender distribution was seen, with over half (53%) respondents being male and 43% female, due to more new TCs involving prostate cancer patients. The age of respondents is still skewed towards an older generation.



Gender and Age of patient - New

Are you male or female? **How old are you?**

Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

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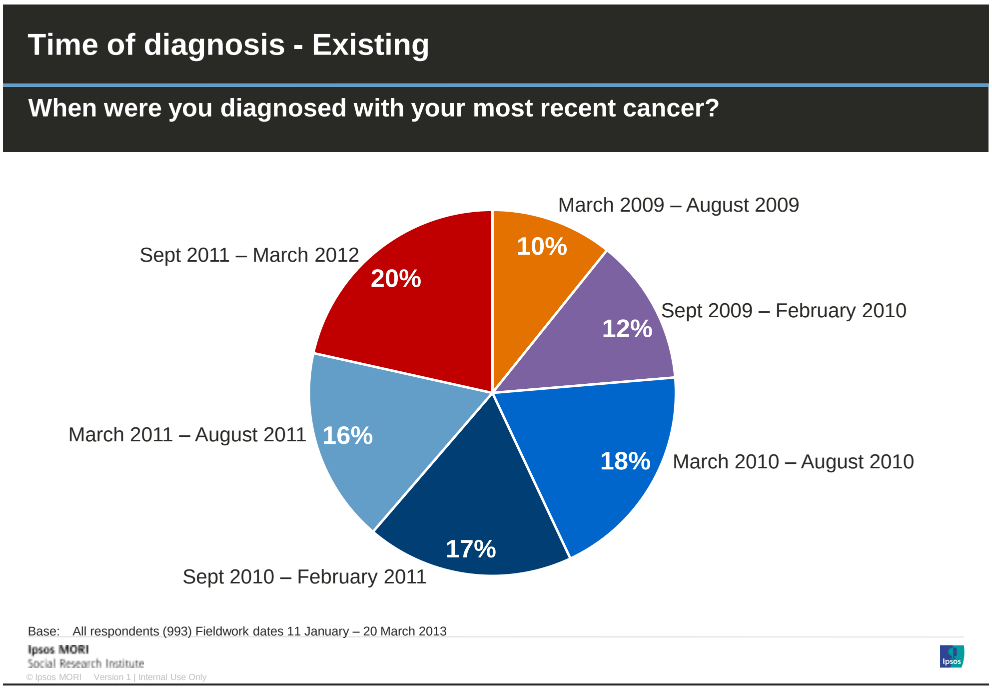
In accordance with the sampling strategy, the majority of respondents were diagnosed with their most recent cancer between in 2009 and 2012, in both the existing and new Test Communities.



Time of diagnosis - Existing

When were you diagnosed with your most recent cancer?

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

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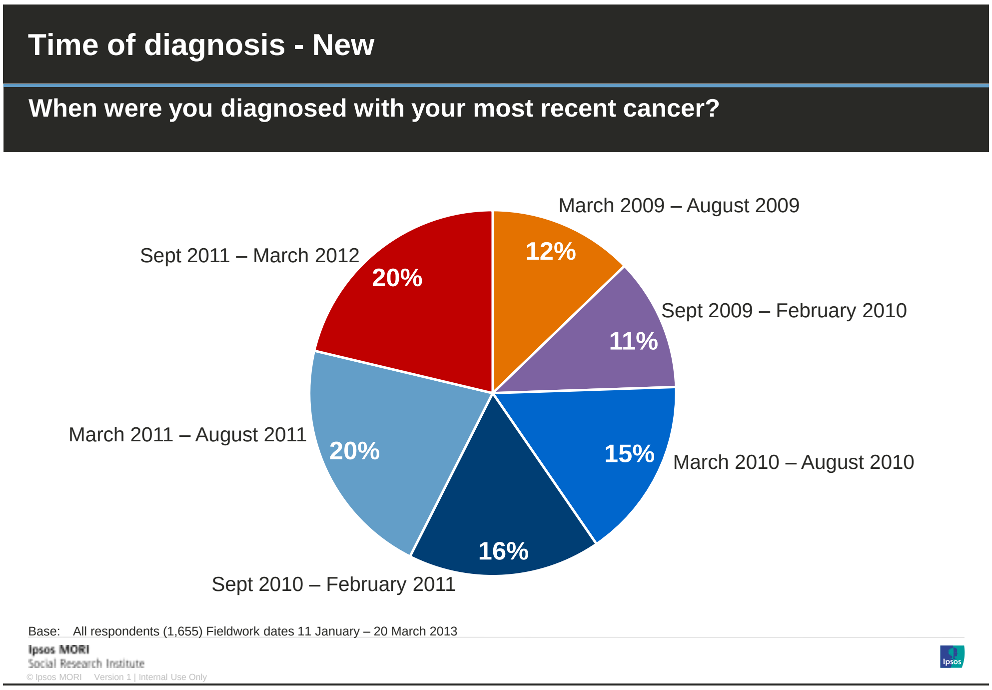

Time of diagnosis - New

When were you diagnosed with your most recent cancer?

Base: All respondents (1,655) Fieldwork dates 11 January – 20 March 2013

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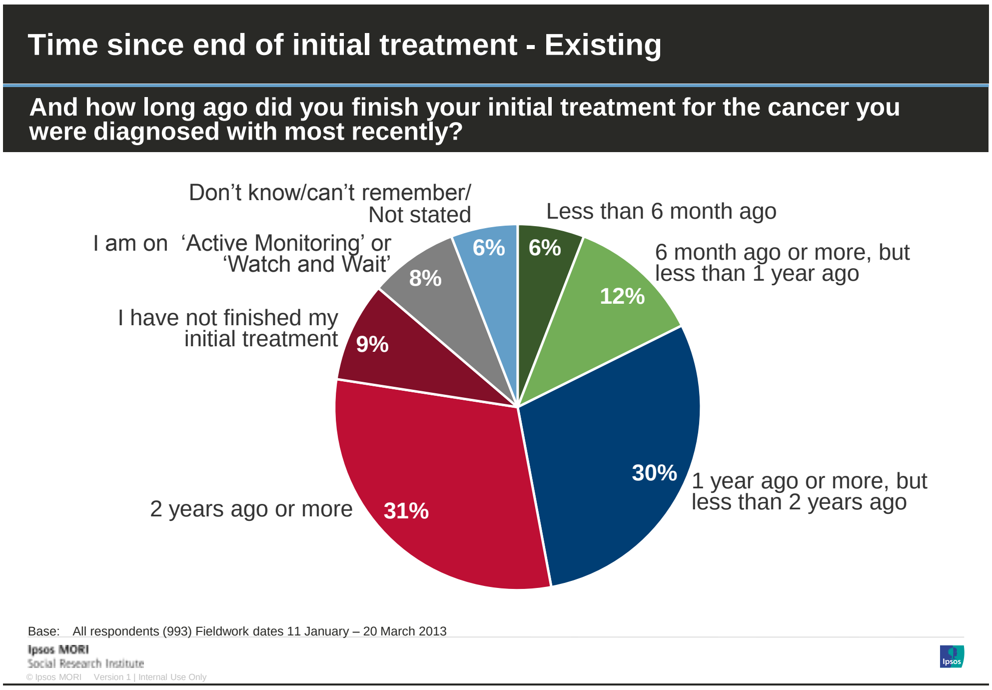
Results from existing Test Communities since the baseline survey indicate a shift in the number of patients who completed their initial therapy over 2 years ago; with almost one third of patients now accounting for this group (31% vs 6% in baseline survey). Conversely, a smaller proportion of patients responding to the survey had not finished their initial treatment compared to the baseline survey (9% vs 17% in baseline survey), reflecting a change in the sampling strategy.



Time since end of initial treatment - Existing

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

Base: All respondents (993) Fieldwork dates 11 January – 20 March 2013

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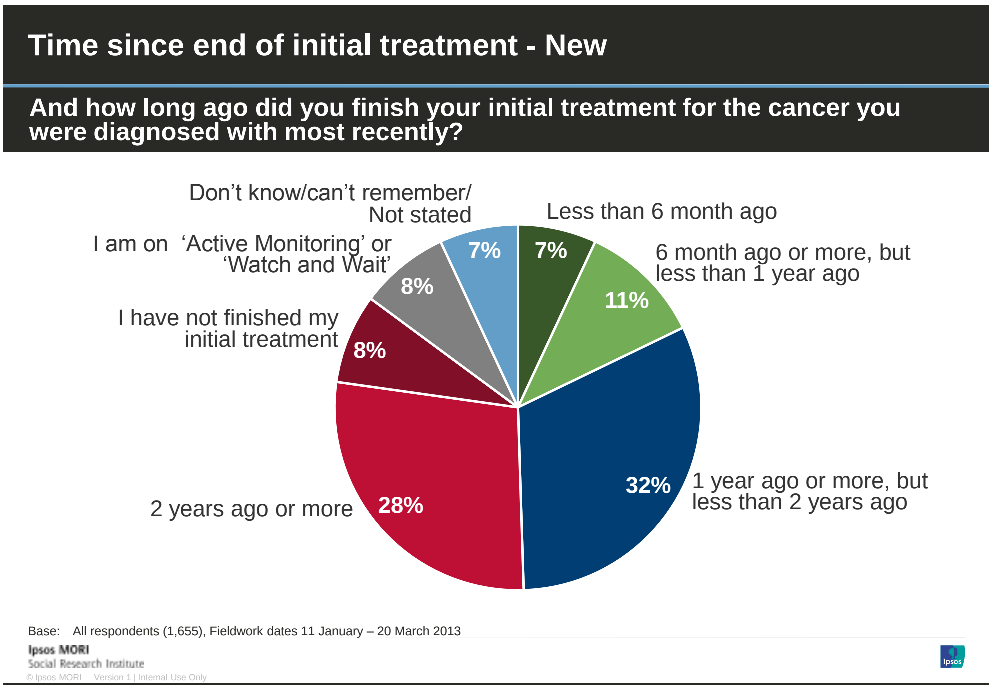
Results from the new Test Communities echo findings from the existing Test Communities for this question (28% completed initial treatment 2 or more years ago, 8% have not finished initial treatment).

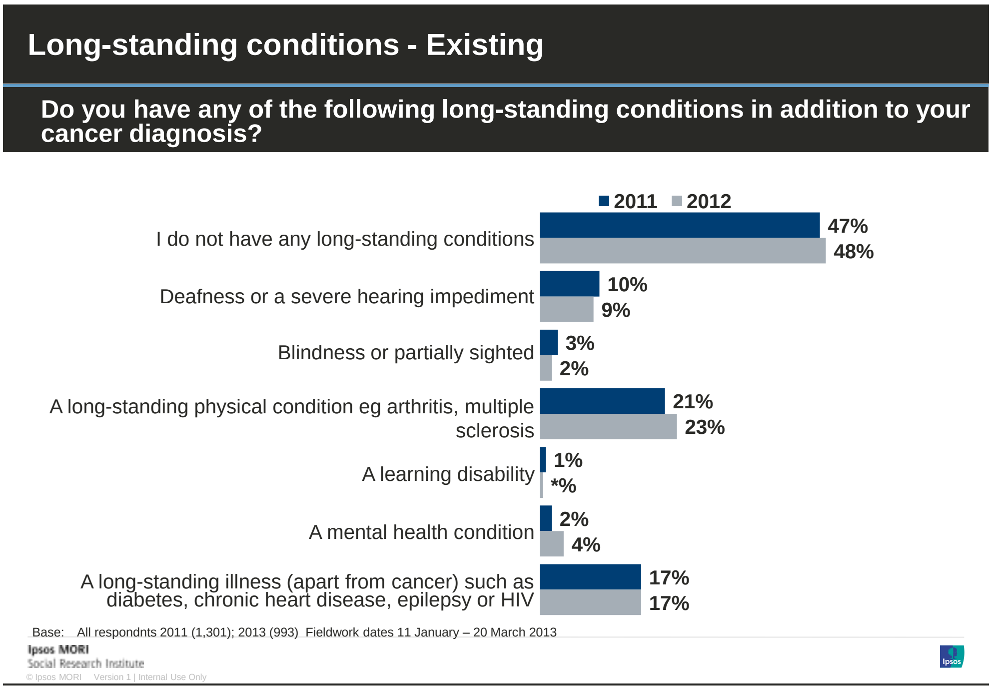


Time since end of initial treatment - New

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

Base: All respondents (1,655), Fieldwork dates 11 January – 20 March 2013

Almost half of patients responding from existing Test Communities (48%) did not have any long-standing conditions, a similar proportion to those in the baseline survey (47%). A long standing physical condition such as arthritis or multiple sclerosis was the most commonly cited (23%).



Long-standing conditions - Existing

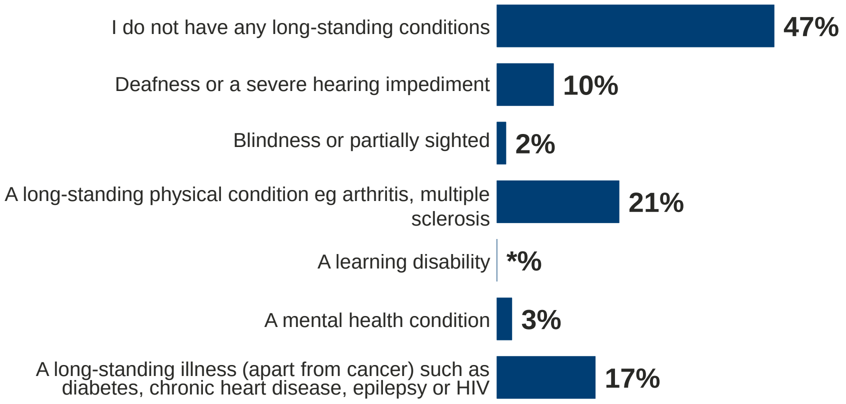
Do you have any of the following long-standing conditions in addition to your cancer diagnosis?

Base: All respondnts 2011 (1,301); 2013 (993) Fieldwork dates 11 January – 20 March 2013

Results for the new Test Communities replicate the findings in the existing Test Communities, with 47% of respondents reporting no long-term conditions and 21% citing a long term physical condition.

Long-standing conditions - New

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



Base: All respondents (1,655); Fieldwork dates 11 January – 20 March 2013

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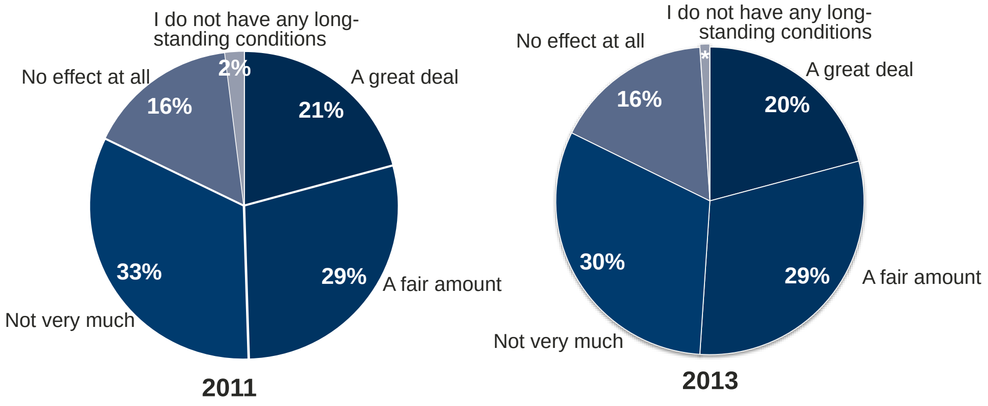
For those patients in the existing Test Communities who reported a long-standing condition, half (49%) said this affected them at least a fair amount in carrying out day-to-day activities. The same proportion reported at least a fair amount of an effect in the baseline survey for existing Test Communities.

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

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



Base: All respondnts 2011 (546); 2013 (411) Fieldwork dates 11 January – 20 March 2013

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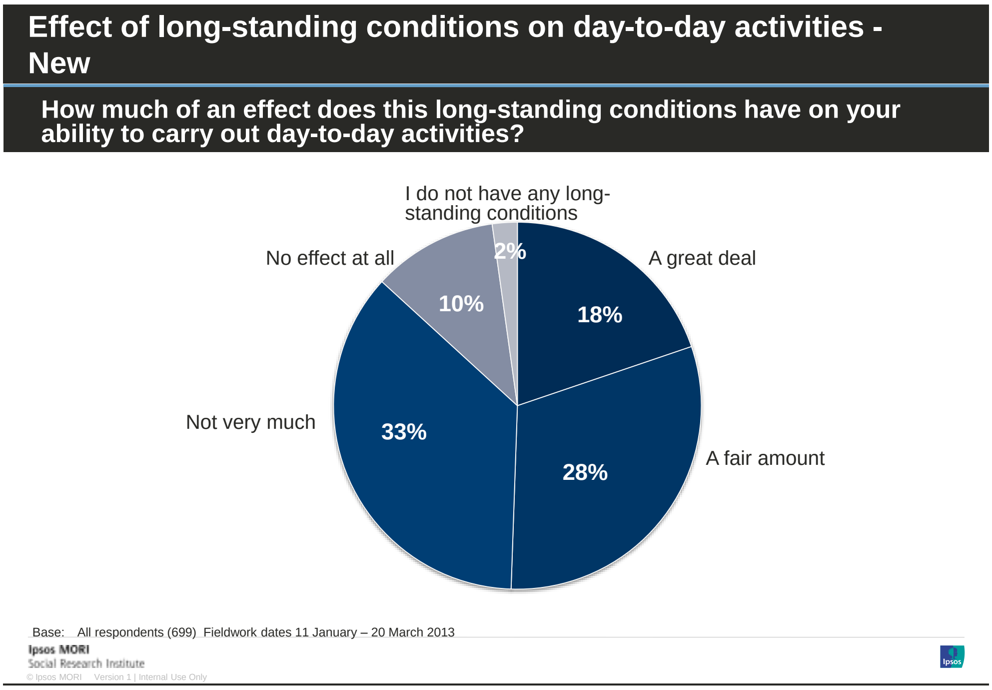
Results are similar across the new Test Communities for patients with a long-standing condition (46% great deal/fair amount of an effect on day-to day activities).



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

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

Base: All respondents (699) Fieldwork dates 11 January – 20 March 2013

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Across both existing and new Test Communities the vast majority of patients (91% and 92% respectively) completed the survey themselves. There is very little change in results for existing communities versus the baseline findings (90% completed survey themselves).

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 45 - If cancer type was given as Prostate and gender was given as female – this was changed to male. In addition, if 'Not Stated' gender was matched in where possible from the sample information;
- 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 48 – 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 48 – this question was rebased to exclude those who selected "I don't have any long standing condition" at Q47 and those figures were reported here. As with the baseline survey the data tables contain both iterations of data for this question;
- Question 24 and Question 25 – if a respondent answered "Yes" at Q24 and "I do not have a care plan" at Q25, then their response at Q24 was edited to "No" and Q25 answer blanked;
- Editing was applied based on the routing in the questions as displayed in the questionnaire; and

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
1,500 responses	2	2	3
2,000 responses	1	2	2
2,500 responses	1	2	2

For example, with a sample size of 1,000 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

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 (Please specify type)

If colorectal cancer please specify:

☐ Colon cancer
☐ Rectal cancer

Q2 **When were you diagnosed with your most recent cancer?**

Please only tick ✓ one box

☐ March 2009 – August 2009
☐ September 2009 – February 2010
☐ March 2010 – August 2010
☐ September 2010 – February 2011
☐ March 2011 – August 2011
☐ September 2011 – March 2012
☐ 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 initial surgery, radiotherapy, chemotherapy or when you started your hormone therapy**.**

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
☐ I am on ‘Active Monitoring’ or ‘Watch and Wait’

123456790

BARCODE

Section 1: Your care

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

Q4 **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

Q5 **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 Q6** ☐ No **PLEASE GO TO Q7**

Please answer Q6 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 Q7.

Q6 **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

Q7 **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 Q8** ☐ No **PLEASE GO TO Q9**

Please answer Q8 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 Q9.

Q8 **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

Q9 **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 Q10** ☐ No **PLEASE GO TO Q11**

Please answer Q10 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 Q11.

Q10 **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.

Q11 **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

Q12 **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 Q13 ☐ No PLEASE GO TO Q14

Please answer Q13 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 Q14.

Q13 **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

Q14 **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 Q15 ☐ No PLEASE GO TO Q16

Please answer Q15 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 Q16.

Q15 **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

Q16 **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
PLEASE GO TO Q17

☐ No
PLEASE GO TO Q18

☐ Not relevant to me
PLEASE GO TO Q18

Please answer Q17 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 Q18.

Q17 **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

Q18 **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	☐ No	☐ Not relevant to me
PLEASE GO TO Q19	**PLEASE GO TO Q20**	**PLEASE GO TO Q20**

Please answer Q19 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 Q20.

Q19 **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

Q20 **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 Q21** ☐ No **PLEASE GO TO Q22**

Please answer Q21 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 Q22.

Q21 **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

Q22 **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 Q23** ☐ No **PLEASE GO TO Q24**

Please answer Q23 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 Q24.

Q23 **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.

Q24 **Have you been given a care plan?**
Please tick ✓ all that apply

☐ Yes – when I was diagnosed ☐ Yes – when I finished my treatment ☐ No ☐ I was offered one but I didn't want it

---

Q25 **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

Q26-32 are about contact with services following your initial treatment for cancer

Q26 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

Q27 **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?**
Please only tick ✓ one box

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

Please answer Q28 if you have contacted a health care professional about a health concern related to cancer, or your treatment for cancer, during office hours. If you have not, please go to Q29.

Q28 **Who 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)**

Q29 **Do you know who to contact outside 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

Q30 **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?**
Please only tick ✓ one box

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

Please answer Q31 if you have contacted a health care professional about a health concern related to cancer, or your treatment for cancer, outside office hours. If you have not, please go to Q32.

Q31 **Who 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 111

Q32 **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+
☐ I don't know / I can't remember

Section 3: Managing your health

Q33 **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

Q34 **And how confident do you feel about managing the impact of your cancer on 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
☐ No

Please can everyone answer this question.

Q36 **Have you had any advice or support that tried to help you carry on working <u>since you were diagnosed with cancer</u>? Please do <u>not</u> 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 37 – 43 please think about any advice or support that you might have received since you finished your initial treatment for cancer.

Q37 **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.

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

Q38 **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.

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

Q39 **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.

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

Q40 **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

Q41 **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 ☐ No

Q42 **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 **PLEASE GO TO Q44**
☐ No **PLEASE GO TO Q43**
☐ I was offered information or advice but I didn't need it **PLEASE GO TO Q44**

Please answer Q43 if you don't have all the information and advice that you need about the signs and symptoms of cancer.

Q43 **What further information and advice about the signs and symptoms of cancer do you need to help you tell if the cancer comes back?** 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.

Q44 **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.

Q45 **Are you male or female?**
Please only tick ✓ one box

☐ Male ☐ Female

Q46 **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

Q47 **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

Please answer Q48 if you have a long-standing condition in addition to your cancer diagnosis.

Q48 **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 RSLE-ZGLU-ZYST, Aftercare Service Evaluation, Ipsos MORI, Research Services House, Elmgrove Road, Harrow, HA1 2QG

Appendix 5: Topline Results

12-062343-01

Ipsos MORI

NHS Improvement - Cancer Aftercare Service Evaluation - Follow-up Survey

Existing Test Sites

Topline Results

28 March 2013

Technical Note

Results are based on a total of 993 completed surveys received from patients at 7 Test Sites in England. Representing an unadjusted response rate of 61%. Fieldwork was conducted between 11 January and 20 March 2013.

In each of the 7 Test Sites there existed one or more of the following cancer pathways: Breast, Colorectal, Prostate. The sample for the study was drawn for each pathway. Up to 150 patients were selected at random from each cancer pathway at each Test Site. All patients had been diagnosed with their cancer between March 2009 and March 2012.

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 for which data is presented here 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 (993) 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:	993	471	354	168
Q1	**Please tell us what your diagnosis was for the cancer you were diagnosed with most recently.**				
	Breast cancer	47%	100%	-	-
	Prostate cancer	36%	-	100%	-
	Colorectal cancer	17%	-	-	100%
	Colon cancer	7%	-	-	42%
	Rectal cancer	6%	-	-	36%
	Base size:	993	471	354	168
Q2	**When were you diagnosed with your most recent cancer?**				
	March 2009 - August 2009	10%	9%	11%	9%
	September 2009 - February 2010	12%	13%	12%	11%
	March 2010 - August 2010	18%	21%	15%	14%
	September 2010 - February 2011	17%	18%	13%	20%
	March 2011 - August 2011	16%	17%	15%	15%
	September 2011 - March 2012	20%	18%	23%	21%
	I don't know/I can't remember	4%	2%	7%	4%
	Not stated	4%	3%	5%	6%
	Base size:	993	471	354	168
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 initial surgery, radiotherapy, chemotherapy or when you started your hormone therapy.**				
	Less than 6 months ago	6%	4%	8%	5%
	6 months ago or more, but less than 1 year ago	12%	11%	12%	14%
	1 year ago or more, but less than 2 years ago	30%	36%	21%	30%
	2 years ago or more	31%	38%	22%	30%
	I have not finished my initial treatment	9%	6%	14%	6%
	I don't know/I can't remember	1%	1%	1%	1%
	I am on 'Active Monitoring' or 'Watch and Wait'	8%	1%	17%	4%
	Not stated	5%	3%	5%	9%
	Base size:	993	471	354	168
Q4	**Overall, how would you rate the quality of the care and services you have received since your initial treatment finished?**				
	Excellent (6)	39%	42%	33%	40%
	Very good (5)	30%	27%	34%	28%
	Good (4)	19%	21%	17%	19%
	Poor (3)	5%	4%	5%	6%
	Very poor (2)	1%	1%	1%	-
	Terrible (1)	1%	*	1%	1%
	Mean	5.06	5.08	5.04	5.08
	Standard Deviation	0.98	0.99	0.96	0.99
	Standard Error	0.03	0.05	0.05	0.08
	Not stated	7%	4%	11%	6%
	Excellent/very good	68%	69%	67%	68%
	Very poor/terrible	1%	1%	1%	1%
	Net excellent/very good	67%	68%	66%	68%
	Base size:	993	471	354	168
Q5	**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	49%	56%	37%	52%
	No	43%	39%	51%	40%
	Not stated	8%	5%	12%	7%
	Base size:	484	266	130	88
Q6	**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	12%	10%	17%	11%
	I have had advice or support that has helped me to adapt to living with my tiredness, weakness or fatigue	16%	16%	17%	14%
	I have had advice or support but it hasn't helped with feeling how tired, weak or fatigued	8%	9%	5%	9%
	I haven't had any advice or support to help with feeling tired, weak or fatigued	18%	17%	18%	18%
	I have taken action myself which improved or helped me adapt to how tired, weak or fatigued I feel	32%	36%	25%	28%
	I haven't done anything in particular but now I feel less tired, weak or fatigued	25%	25%	21%	31%
	I haven't done anything in particular and I still feel tired, weak or fatigued	17%	15%	23%	15%
	Not stated	1%	1%	2%	-
	Base size:	993	471	354	168
Q7	**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	41%	48%	33%	40%
	No	52%	49%	56%	53%
	Not stated	7%	3%	11%	7%
	Base size:	412	228	116	68
Q8	**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	11%	11%	4%	19%
	I have had advice or support that has helped me to adapt to having trouble sleeping at night or through the night	10%	11%	10%	9%
	I have had advice or support but it hasn't helped me to sleep at night or through the night	10%	12%	9%	3%
	I haven't had any advice or support to help with trouble sleeping at night or through the night	19%	16%	26%	18%
	I have taken action myself which improved or helped me adapt to having trouble sleeping at night or through the night	20%	21%	19%	18%
	I haven't done anything in particular but I am having less trouble sleeping at night or through the night	20%	20%	20%	24%
	I haven't done anything in particular and I still have trouble sleeping at night or through the night	30%	29%	36%	22%
	Not stated	2%	1%	1%	4%
	Base size:	993	471	354	168
Q9	**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	38%	37%	36%	48%
	No	58%	61%	59%	45%
	Not stated	4%	2%	5%	7%

	Base size:	**380**	**172**	**127**	**81**
Q10	**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%	5%	14%
	I have had advice or support but it hasn't helped me to do more physical activity or exercise again	7%	9%	6%	6%
	I haven't had any advice or support to help me to maintain or improve my physical activity or exercise	23%	22%	23%	27%
	I have taken action myself to help me do more physical activity or exercise again	38%	46%	28%	40%
	I haven't done anything in particular and still do less physical activity or exercise than I did	37%	30%	49%	35%
	Not stated	4%	4%	6%	-
	Base size:	**993**	**471**	**354**	**168**
Q11	**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	28%	28%	23%	36%
	1	10%	10%	9%	11%
	2	15%	15%	15%	13%
	3	15%	16%	14%	13%
	4	8%	8%	8%	5%
	5	7%	7%	8%	4%
	6	4%	3%	5%	4%
	7 days	9%	8%	11%	7%
	Not stated	6%	4%	8%	7%
	Mean	2.5	2.4	2.7	2
	Base size:	**993**	**471**	**354**	**168**
Q12	**Have you noticed a change in your weight compared with before you were diagnosed with cancer?**				
	Yes	45%	49%	38%	50%
	No	50%	48%	55%	44%
	Not stated	5%	3%	6%	6%
	Base size:	**451**	**232**	**135**	**84**
Q13	**What, if anything, have you done about the change in your weight?**				
	I have had advice or support that has helped my weight to go back to how it was before I was diagnosed	8%	6%	10%	11%
	I have had advice or support but it hasn't helped my weight to go back to how it was before I was diagnosed	10%	10%	8%	15%
	I haven't had any advice or support regarding changes in my weight	28%	28%	33%	21%
	I have taken action myself to change my weight back to how it was before I was diagnosed	33%	37%	28%	30%
	I haven't done anything in particular but my weight has gone back to how it was before I was diagnosed	6%	6%	4%	11%
	I haven't done anything in particular and my weight still hasn't gone back to how it was before I was diagnosed	29%	27%	36%	21%
	Not stated	3%	1%	4%	5%
	Base size:	**993**	**471**	**354**	**168**
Q14	**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	40%	27%	54%	49%
	No	55%	70%	38%	46%
	Not stated	5%	3%	8%	5%
	Base size:	**397**	**125**	**190**	**82**
Q15	**What, if anything, have you done about these problems?**				
	I have had advice or support that has improved my bowel or urinary function	28%	22%	33%	27%
	I have had advice or support that has helped me to adapt to living with my bowel or urinary problems	21%	14%	20%	33%
	I have had advice or support but it hasn't helped me with my bowel or urinary function	14%	9%	15%	18%
	I haven't had any advice or support with bowel or urinary problems	14%	21%	13%	5%
	I have taken action myself which improved or helped me adapt to having bowel or urinary problems	20%	26%	16%	20%
	I haven't done anything in particular but my bowel or urinary problems have got better	11%	7%	16%	7%
	I haven't done anything in particular and my bowel or urinary problems are still a problem	16%	18%	15%	16%
	Not stated	2%	3%	1%	1%
	Base size:	**993**	**471**	**354**	**168**
Q16	**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%	21%	39%	23%
	No	35%	41%	28%	33%
	Not relevant to me	31%	34%	25%	38%
	Not stated	6%	4%	8%	6%
	Base size:	**274**	**99**	**137**	**38**
Q17	**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	3%	-	5%	3%
	I have had advice or support that has helped me to adapt to the change in my interest in sex	10%	8%	15%	-
	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	11%	9%	15%	5%
	I haven't had any advice or support to help with the change in my interest in sex	35%	35%	34%	37%
	I have taken action myself which improved or helped me adapt to the change in my interest in sex	11%	16%	7%	11%
	I haven't done anything in particular but my interest in sex has gone back to how it was before I was diagnosed	4%	4%	3%	11%
	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	48%	49%	46%	53%
	Not stated	1%	1%	-	3%
	Base size:	**441**	**6**	**354**	**81**
Q18	**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	49%	17%	54%	32%
	No	22%	33%	19%	36%
	Not relevant to me	20%	17%	20%	20%
	Not stated	8%	33%	7%	12%
	Base size:	**217**	**1**	**190**	**26**
Q19	**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	7%	-	8%	-
	I have had advice or support that has helped me to adapt to the change in my erectile function	11%	-	13%	-
	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%	-	26%	15%
	I haven't had any advice or support to help with the change in my erectile function	25%	100%	24%	31%
	I have taken action myself which improved or helped me adapt to the change in my erectile function	7%	-	6%	15%
	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	48%	100%	48%	50%
	Not stated	1%	-	1%	4%
	Base size:	**993**	**471**	**354**	**168**
Q20	**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	54%	64%	40%	58%
	No	38%	32%	47%	35%
	Not stated	8%	4%	13%	7%

	Base size:	541	303	140	98
Q21	**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	13%	14%	12%	11%
	I have had advice or support that has helped me to adapt to feeling afraid that the cancer will come back	10%	12%	11%	6%
	I have had advice or support but it hasn't helped me to feel less afraid that the cancer will come back	7%	7%	7%	6%
	I haven't had any advice or support to help with feeling afraid that the cancer will come back	24%	24%	21%	27%
	I have taken action myself which improved or helped me adapt to being afraid that the cancer will come back	14%	15%	13%	11%
	I haven't done anything in particular but I feel less afraid that the cancer will come back	27%	21%	34%	35%
	I haven't done anything in particular and I still feel afraid that the cancer will come back	27%	28%	26%	23%
	Not stated	2%	2%	3%	-

	Base size:	993	471	354	168
Q22	**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	45%	54%	34%	44%
	No	48%	42%	55%	49%
	Not stated	7%	4%	11%	7%

	Base size:	447	254	119	74
Q23	**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	12%	12%	14%	9%
	I have had advice or support that has helped me to adapt to feeling low or down	12%	13%	8%	16%
	I have had advice or support but it hasn't helped me to feel low or down less often	6%	6%	7%	3%
	I have taken action myself which improved or helped me adapt to feeling low or down	30%	30%	29%	30%
	I haven't done anything in particular but I feel low or down less often	24%	25%	22%	26%
	I haven't done anything in particular and I still often feel low or down	16%	15%	18%	14%
	I haven't had any advice or support to help feeling low or down	20%	19%	21%	20%
	Not stated	2%	1%	4%	-

	Base size:	993	471	354	168
Q24	**Have you been given a care plan?**				
	Yes - when I was diagnosed	20%	23%	20%	13%
	Yes - when I finished my treatment	15%	20%	10%	14%
	Yes	35%	42%	30%	26%
	No	52%	44%	56%	63%
	I was offered one but I didn't want it	3%	4%	3%	4%
	Not stated	10%	10%	11%	7%

	Base size:	350	200	106	44
Q25	**How useful do you find your care plan?**				
	Very useful	39%	35%	43%	43%
	Fairly useful	38%	43%	31%	34%
	Not very useful	10%	10%	13%	5%
	Not at all useful	4%	4%	3%	5%
	I have never looked at my care plan	9%	8%	8%	14%
	I don't have a care plan	-	-	-	-
	Not stated	1%	1%	2%	-
	Useful	77%	78%	75%	77%
	Not useful	14%	14%	16%	9%
	Net useful	63%	64%	58%	68%

	Base size:	993	471	354	168
Q26	**Do you know who to contact during office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	78%	84%	70%	76%
	No	8%	6%	11%	5%
	No, but I would know how to find out	10%	9%	11%	13%
	Not stated	4%	1%	8%	6%

	Base size:	993	471	354	168
Q27	**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	44%	53%	31%	47%
	No	49%	42%	60%	43%
	I don't know/I can't remember	2%	2%	3%	2%
	Not stated	5%	3%	7%	8%

	Base size:	436	249	108	79
Q28	**Who did you contact?**				
	My GP	35%	35%	36%	34%
	My GP practice nurse	4%	3%	3%	6%
	Cancer hospital nurse	74%	77%	62%	80%
	My pharmacist	2%	2%	2%	4%
	My cancer doctor or their secretary	18%	16%	23%	19%
	My district nurse or community cancer nurse	7%	7%	6%	9%
	Hospice	*	*	-	-
	Macmillan Nurse	2%	3%	1%	1%
	Other support teams/ centres	2%	2%	3%	1%
	Helplines/Hospital/ Cancer charity/advice line	*	-	1%	-
	Local hospital/A & E	*	*	1%	-
	Stoma nurse	1%	-	-	4%
	Specialist nurse	1%	1%	2%	1%
	Other hospital professionals/ departments	1%	*	2%	-
	Other	*	-	1%	1%
	Not stated	*	*	1%	-

	Base size:	993	471	354	168
Q29	**Do you know who to contact outside office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	37%	38%	33%	40%
	No	33%	31%	40%	24%
	No, but I would know how to find out	24%	27%	18%	25%
	Not stated	6%	3%	8%	10%

	Base size:	993	471	354	168
Q30	**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	11%	12%	6%	17%
	No	81%	83%	83%	71%
	I don't know/I can't remember	3%	2%	3%	2%
	Not stated	5%	2%	8%	10%

	Base size:	109	58	22	29
Q31	**Who did you contact?**				
	My GP or out-of-hours service	24%	19%	32%	28%
	My hospital (department, ward or on-call team)	58%	64%	41%	59%
	Accident and Emergency (A&E)	13%	9%	18%	17%
	Ambulance service, NHS Direct or 111	11%	3%	9%	28%
	Friend who is a Dr.	1%	2%	-	-
	Hospice	1%	2%	-	-
	Cancer care nurse	1%	-	5%	-
	District nurse	4%	2%	9%	3%
	Specialist nurse	1%	-	5%	-
	Other	4%	3%	5%	3%
	Not stated	10%	10%	14%	7%

	Base size:	993	471	354	168
Q32	**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	64%	70%	58%	58%
	05-Jan	27%	24%	31%	30%
	10-Jun	2%	2%	1%	2%
	11+	*	*	*	1%
	I don't know/I can't remember	2%	2%	3%	2%
	Not stated	4%	1%	7%	7%

	Base size:	993	471	354	168
Q33	**How confident do you feel about managing your health, if at all?**				
	Very confident	29%	30%	27%	33%
	Fairly confident	54%	56%	55%	49%
	Not very confident	9%	10%	8%	7%
	Not at all confident	2%	1%	2%	2%
	Don't know	2%	2%	2%	2%
	Not stated	4%	1%	6%	6%
	Confident	84%	85%	82%	83%
	Not confident	10%	11%	10%	9%
	Net confident	73%	74%	72%	74%

	Base size:	993	471	354	168
Q34	**How confident do you feel about managing the impact of your cancer on your health, if at all?**				
	Very confident	25%	26%	21%	31%
	Fairly confident	50%	50%	53%	43%
	Not very confident	13%	15%	12%	10%
	Not at all confident	3%	3%	4%	4%
	Don't know	4%	4%	4%	4%
	Not stated	5%	2%	7%	8%
	Confident	75%	77%	74%	74%
	Not confident	16%	17%	16%	14%
	Net confident	59%	59%	58%	61%

	Base size:	993	471	354	168
Q35	**Do you have all the information, advice or support you need to help you manage your health?**				
	Yes	74%	76%	73%	67%
	No	21%	21%	19%	25%
	Not stated	6%	3%	8%	8%

	Base size:	993	471	354	168
Q36	**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	60%	52%	73%	53%
	I was unable to work prior to my cancer diagnosis	1%	2%	*	1%
	I was not working when I was diagnosed with cancer	4%	6%	1%	5%
	Yes, and it has helped me to carry on working	7%	8%	6%	7%
	Yes, but it has not helped me to carry on working	1%	1%	1%	2%
	I was offered advice or support but I didn't need it	3%	3%	2%	2%
	No, but I did not need advice or support to help me carry on working	16%	20%	8%	18%
	No, and I would have liked to have advice or support to help me carry on working	3%	4%	1%	4%
	Not stated	6%	3%	7%	8%

	Base size:	993	471	354	168
Q37	**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%	2%	2%	3%
	Yes, and it has helped me to stay in my own home	6%	6%	6%	8%
	Yes, but it has not helped me to stay in my own home	*	-	1%	1%
	I was offered advice or support but I didn't need it	6%	6%	5%	6%
	No, but I didn't need advice or support to help me stay in my own home	76%	80%	73%	71%
	No, and I would have liked to have advice or support to help stay in my own home	2%	2%	2%	2%
	Not stated	8%	4%	12%	10%

	Base size:	993	471	354	168
Q38	**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	5%	5%	4%	7%
	Yes, but it has not helped me to cope with my financial issues	3%	4%	2%	2%
	I was offered advice or support but I didn't need it	6%	8%	5%	4%
	No, but I didn't need advice or support to help me with my financial issues	72%	72%	74%	67%
	No, and I would have liked to have advice or support to help me with my financial issues	7%	7%	5%	10%
	Not stated	7%	3%	10%	10%

	Base size:	993	471	354	168
Q39	**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%	6%	5%	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	8%	9%	7%	7%
	No, but I didn't need advice or support to help me cope with the practical things that I needed help with	71%	71%	73%	67%
	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%	7%	3%	6%
	Not stated	8%	5%	10%	10%

	Base size:	993	471	354	168
Q40	**Do you have all of the information and advice that you need about the effects of your treatment?**				
	Yes	74%	79%	68%	73%
	I was offered information or advice but I didn't need it	3%	2%	4%	2%
	No	8%	7%	9%	7%
	No, and I would have liked information or advice about the effects of my treatment	8%	8%	8%	7%
	Not stated	7%	3%	11%	11%

	Base size:	**993**	**471**	**354**	**168**
Q41	**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?**				
	Yes	6%	7%	4%	9%
	No	84%	87%	80%	82%
	Not stated	10%	5%	16%	10%

	Base size:	**993**	**471**	**354**	**168**
Q42	**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	66%	76%	56%	55%
	No	22%	16%	25%	32%
	I was offered information or advice but I didn't need it	2%	1%	3%	2%
	Not stated	10%	7%	15%	11%

	Base size:	**218**	**74**	**90**	**54**
Q43	**What further information and advice about the signs and symptoms of cancer do you need to help you tell if the cancer comes back?**				
	More information on symptoms/signs/what to look out for/if cancer returns	36%	34%	29%	52%
	Any/all the/relevant information they can give	7%	11%	6%	6%
	More follow up appointments and check ups	7%	12%	4%	4%
	Mentions of illness/ symptoms/prognosis/of respondent at this moment	6%	4%	6%	7%
	More contact with medical professionals	6%	8%	4%	4%
	I contact/see medical staff at hospital/ clinic/surgery	5%	3%	7%	4%
	Better communication	4%	3%	6%	2%
	More information on medication/side affects	3%	7%	1%	2%
	More information on present cancer needed/ its progression/pain relief	3%	3%	3%	4%
	More general advice/ information	3%	1%	4%	2%
	Receive results sooner	2%	4%	2%	-
	Still receiving treatment/on going	2%	3%	-	6%
	Written information/ leaflets/booklets	2%	3%	1%	4%
	Nothing/all staff are very good/helpful/ received all the information I needed/ everything's good	2%	1%	2%	2%
	Mentions of PSA tests/ levels	1%	-	3%	-
	Mentions of other/ illnesses/symptoms	1%	-	1%	2%
	Improve/more care/after care	1%	-	1%	2%
	More dietary/lifestyle advice	1%	1%	-	2%
	Contact details if problems arise	1%	-	-	4%
	More help/support/groups	1%	1%	1%	-
	Advice on self examination	*	1%	-	-
	Improve scheduling of appointments/less waiting time/ cancellations	*	-	-	2%
	Receive help/support from other groups/ friends etc.	*	1%	-	-
	Counseling	-	-	-	-
	Other	2%	3%	1%	2%
	Don't know	2%	1%	3%	2%
	Not stated	27%	27%	33%	15%

	Base size:	**993**	**471**	**354**	**168**
Q44	**Please indicate which of the following applies to you.**				
	I am the patient named in the letter	91%	94%	89%	88%
	I am filling out this questionnaire on behalf of the patient named in the letter	4%	3%	4%	5%
	Not stated	5%	2%	6%	8%

	Base size:	**993**	**471**	**354**	**168**
Q45	**Are you male or female?**				
	Male	44%	1%	100%	48%
	Female	50%	91%	-	40%
	Not stated	5%	7%	-	11%

	Base size:	**993**	**471**	**354**	**168**
Q46	**How old are you?**				
	18 - 30	*	*	-	1%
	31 - 35	*	-	-	1%
	36 - 40	1%	1%	-	1%
	41 - 45	3%	6%	-	2%
	46 - 50	4%	6%	1%	4%
	51 - 55	7%	12%	1%	7%
	56 - 60	10%	12%	5%	13%
	61 - 65	12%	13%	12%	10%
	66 - 70	19%	18%	21%	17%
	71 - 75	17%	11%	23%	18%
	76 - 80	13%	11%	17%	11%
	81 or over	11%	8%	16%	12%
	Not stated	3%	2%	5%	5%

	Base size:	**993**	**471**	**354**	**168**
Q47	**Do you have any of the following long-standing conditions in addition to your cancer diagnosis?**				
	I do not have any longstanding conditions	48%	49%	44%	54%
	Deafness or a severe hearing impediment	9%	7%	12%	8%
	Blindness or partially sighted	2%	2%	2%	2%
	A long-standing physical condition, e. g. arthritis, multiple sclerosis	23%	26%	21%	16%
	A learning disability	*	*	*	-
	A mental health condition	4%	5%	2%	5%
	A long-standing illness (apart from cancer) such as diabetes, chronic heart disease, epilepsy or HIV	17%	15%	20%	15%
	Not stated	11%	10%	11%	13%

	Base size:	**993**	**471**	**354**	**168**
Q48	**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	9%	9%	8%	9%
	A fair amount	12%	13%	13%	11%
	Not very much	14%	13%	18%	10%
	No effect at all	10%	9%	9%	11%
	I do not have any longstanding conditions	12%	11%	12%	15%
	Not stated	43%	45%	39%	44%
	Great deal/fair amount	21%	21%	21%	20%
	Not very much/no effect at all	24%	22%	27%	21%
	Net great deal/fair amount	-3%	-1%	-6%	-2%

NHS Improvement - Cancer Aftercare Service Evaluation - Follow-up Survey

New Test Sites

Topline Results

28 March 2013

Technical Note

Results are based on a total of 1,655 completed surveys received from patients at 8 Test Sites in England. Representing an unadjusted response rate of 59%. Fieldwork was conducted between 11 January and 20 March 2013.

In each of the 8 Test Sites there existed one or more of the following cancer pathways: Breast, Colorectal, Prostate. The sample for the study was drawn for each pathway. Up to 150 patients were selected at random from each cancer pathway at each Test Site. All patients had been diagnosed with their cancer between March 2009 and March 2012.

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 for which data is presented here are:
Dorset: Breast, Colorectal, Prostate
Ipswich: Colorectal
North West London: Breast, Colorectal, Prostate
Royal Marsden: Breast, Colorectal, Prostate
RUH Bath: Breast, Colorectal, Prostate
Salford: Colorectal
St Georges: Breast, Colorectal, Prostate
West Herts: Breast, Colorectal, Prostate

Results are based on all respondents (1,655) 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:	1655	522	532	601
Q1	**Please tell us what your diagnosis was for the cancer you were diagnosed with most recently.**				
	Breast cancer	32%	100%	-	-
	Prostate cancer	32%	-	100%	-
	Colorectal cancer	36%	-	-	100%
	Colon cancer	21%	-	-	57%
	Rectal cancer	9%	-	-	25%
	Base size:	1655	522	532	601
Q2	**When were you diagnosed with your most recent cancer?**				
	March 2009 - August 2009	12%	14%	12%	9%
	September 2009 - February 2010	11%	15%	9%	8%
	March 2010 - August 2010	15%	18%	13%	16%
	September 2010 - February 2011	16%	14%	14%	18%
	March 2011 - August 2011	20%	16%	23%	20%
	September 2011 - March 2012	20%	18%	19%	21%
	I don't know/I can't remember	3%	2%	5%	2%
	Not stated	5%	3%	6%	5%
	Base size:	1655	522	532	601
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 initial surgery, radiotherapy, chemotherapy or when you started your hormone therapy.**				
	Less than 6 months ago	7%	5%	8%	7%
	6 months ago or more, but less than 1 year ago	11%	12%	11%	10%
	1 year ago or more, but less than 2 years ago	32%	34%	27%	35%
	2 years ago or more	28%	35%	19%	29%
	I have not finished my initial treatment	8%	8%	12%	4%
	I don't know/I can't remember	1%	1%	1%	1%
	I am on 'Active Monitoring' or 'Watch and Wait'	8%	2%	14%	7%
	Not stated	6%	3%	6%	8%
	Base size:	1655	522	532	601
Q4	**Overall, how would you rate the quality of the care and services you have received since your initial treatment finished?**				
	Excellent (6)	39%	35%	38%	44%
	Very good (5)	32%	34%	30%	32%
	Good (4)	18%	23%	18%	15%
	Poor (3)	3%	3%	5%	2%
	Very poor (2)	1%	1%	1%	*
	Terrible (1)	1%	*	1%	1%
	Mean	5.11	5.04	5.08	5.2
	Standard Deviation	0.95	0.92	0.98	0.94
	Standard Error	0.02	0.04	0.04	0.04
	Not stated	6%	3%	9%	6%
	Excellent/very good	71%	70%	68%	75%
	Very poor/terrible	1%	1%	1%	1%
	Net excellent/very good	70%	69%	67%	74%
	Base size:	1655	522	532	601
Q5	**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	43%	52%	37%	40%
	No	50%	42%	55%	53%
	Not stated	7%	6%	8%	7%
	Base size:	711	272	198	241
Q6	**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	13%	14%	10%	13%
	I have had advice or support that has helped me to adapt to living with my tiredness, weakness or fatigue	14%	15%	12%	14%
	I have had advice or support but it hasn't helped with feeling how tired, weak or fatigued	10%	9%	13%	10%
	I haven't had any advice or support to help with feeling tired, weak or fatigued	16%	13%	22%	15%
	I have taken action myself which improved or helped me adapt to how tired, weak or fatigued I feel	34%	37%	32%	33%
	I haven't done anything in particular but now I feel less tired, weak or fatigued	22%	26%	18%	20%
	I haven't done anything in particular and I still feel tired, weak or fatigued	16%	11%	22%	18%
	Not stated	2%	3%	3%	1%
	Base size:	1655	522	532	601
Q7	**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	39%	46%	37%	35%
	No	55%	50%	56%	58%
	Not stated	6%	4%	7%	6%
	Base size:	652	242	197	213
Q8	**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%	8%	10%	11%
	I have had advice or support that has helped me to adapt to having trouble sleeping at night or through the night	9%	7%	13%	7%
	I have had advice or support but it hasn't helped me to sleep at night or through the night	10%	9%	13%	9%
	I haven't had any advice or support to help with trouble sleeping at night or through the night	20%	21%	18%	20%
	I have taken action myself which improved or helped me adapt to having trouble sleeping at night or through the night	22%	23%	21%	20%
	I haven't done anything in particular but I am having less trouble sleeping at night or through the night	18%	21%	14%	19%
	I haven't done anything in particular and I still have trouble sleeping at night or through the night	29%	26%	33%	30%
	Not stated	2%	2%	2%	2%

	Base size:	**1655**	**522**	**532**	**601**
Q9	**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	39%	38%	39%	41%
	No	57%	59%	58%	55%
	Not stated	4%	4%	3%	4%
	Base size:	**651**	**197**	**205**	**249**
Q10	**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	11%	12%	12%	9%
	I have had advice or support but it hasn't helped me to do more physical activity or exercise again	11%	12%	10%	10%
	I haven't had any advice or support to help me to maintain or improve my physical activity or exercise	20%	19%	23%	18%
	I have taken action myself to help me do more physical activity or exercise again	42%	42%	42%	43%
	I haven't done anything in particular and still do less physical activity or exercise than I did	32%	31%	31%	34%
	Not stated	3%	3%	4%	2%
	Base size:	**1655**	**522**	**532**	**601**
Q11	**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	26%	29%	23%	26%
	1	10%	10%	9%	9%
	2	14%	16%	12%	13%
	3	16%	15%	16%	16%
	4	8%	9%	9%	7%
	5	8%	7%	10%	7%
	6	5%	3%	5%	6%
	7 days	9%	7%	10%	9%
	Not stated	6%	5%	5%	7%
	Mean	2.6	2.3	2.8	2.6
	Base size:	**1655**	**522**	**532**	**601**
Q12	**Have you noticed a change in your weight compared with before you were diagnosed with cancer?**				
	Yes	43%	45%	40%	45%
	No	53%	52%	57%	49%
	Not stated	4%	3%	3%	6%
	Base size:	**715**	**233**	**211**	**271**
Q13	**What, if anything, have you done about the change in your weight?**				
	I have had advice or support that has helped my weight to go back to how it was before I was diagnosed	7%	6%	7%	8%
	I have had advice or support but it hasn't helped my weight to go back to how it was before I was diagnosed	13%	13%	13%	12%
	I haven't had any advice or support regarding changes in my weight	26%	24%	31%	23%
	I have taken action myself to change my weight back to how it was before I was diagnosed	32%	39%	28%	28%
	I haven't done anything in particular but my weight has gone back to how it was before I was diagnosed	13%	7%	13%	18%
	I haven't done anything in particular and my weight still hasn't gone back to how it was before I was diagnosed	26%	28%	27%	24%
	Not stated	3%	3%	3%	3%
	Base size:	**1655**	**522**	**532**	**601**
Q14	**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	42%	22%	54%	48%
	No	54%	75%	41%	48%
	Not stated	4%	3%	5%	5%
	Base size:	**692**	**116**	**289**	**287**
Q15	**What, if anything, have you done about these problems?**				
	I have had advice or support that has improved my bowel or urinary function	26%	28%	29%	22%
	I have had advice or support that has helped me to adapt to living with my bowel or urinary problems	25%	16%	28%	26%
	I have had advice or support but it hasn't helped me with my bowel or urinary function	15%	9%	14%	18%
	I haven't had any advice or support with bowel or urinary problems	10%	10%	10%	9%
	I have taken action myself which improved or helped me adapt to having bowel or urinary problems	22%	32%	17%	23%
	I haven't done anything in particular but my bowel or urinary problems have got better	13%	8%	15%	15%
	I haven't done anything in particular and my bowel or urinary problems are still a problem	14%	16%	15%	13%
	Not stated	2%	3%	2%	1%
	Base size:	**1655**	**522**	**532**	**601**
Q16	**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	27%	22%	44%	16%
	No	36%	40%	27%	42%
	Not relevant to me	32%	34%	24%	36%
	Not stated	5%	4%	6%	6%
	Base size:	**439**	**113**	**232**	**94**
Q17	**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	3%	1%	3%	2%
	I have had advice or support that has helped me to adapt to the change in my interest in sex	10%	4%	16%	4%
	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	19%	8%	27%	11%
	I haven't had any advice or support to help with the change in my interest in sex	31%	39%	27%	33%
	I have taken action myself which improved or helped me adapt to the change in my interest in sex	11%	12%	10%	11%
	I haven't done anything in particular but my interest in sex has gone back to how it was before I was diagnosed	6%	4%	4%	11%
	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	49%	56%	47%	48%
	Not stated	2%	1%	2%	3%
	Base size:	**877**	**6**	**532**	**339**
Q18	**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	44%	50%	55%	26%
	No	31%	17%	19%	50%
	Not relevant to me	20%	33%	20%	20%
	Not stated	5%	-	5%	4%

	Base size:	385	3	294	88
Q19	**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%	-	6%	1%
	I have had advice or support that has helped me to adapt to the change in my erectile function	15%	-	19%	3%
	I have had advice or support but it hasn't helped my erectile function go back to how it was before I was diagnosed	23%	33%	26%	15%
	I haven't had any advice or support to help with the change in my erectile function	29%	33%	27%	39%
	I have taken action myself which improved or helped me adapt to the change in my erectile function	8%	33%	6%	14%
	I haven't done anything in particular but my erectile function has gone back to how it was before I was diagnosed	3%	-	2%	6%
	I haven't done anything in particular and my erectile function still hasn't gone back to how it was before I was diagnosed	46%	-	45%	51%
	Not stated	1%	-	1%	1%

	Base size:	1655	522	532	601
Q20	**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%	63%	34%	50%
	No	44%	34%	54%	43%
	Not stated	7%	4%	12%	7%

	Base size:	808	327	180	301
Q21	**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%	12%	22%	20%
	I have had advice or support that has helped me to adapt to feeling afraid that the cancer will come back	10%	10%	13%	9%
	I have had advice or support but it hasn't helped me to feel less afraid that the cancer will come back	7%	7%	7%	6%
	I haven't had any advice or support to help with feeling afraid that the cancer will come back	25%	28%	21%	24%
	I have taken action myself which improved or helped me adapt to being afraid that the cancer will come back	14%	19%	9%	13%
	I haven't done anything in particular but I feel less afraid that the cancer will come back	26%	26%	26%	26%
	I haven't done anything in particular and I still feel afraid that the cancer will come back	25%	28%	24%	24%
	Not stated	2%	2%	2%	2%

	Base size:	1655	522	532	601
Q22	**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	42%	53%	37%	38%
	No	51%	42%	55%	56%
	Not stated	6%	5%	8%	6%

	Base size:	699	278	195	226
Q23	**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	13%	15%	10%	13%
	I have had advice or support that has helped me to adapt to feeling low or down	12%	9%	12%	14%
	I have had advice or support but it hasn't helped me to feel low or down less often	6%	5%	5%	8%
	I have taken action myself which improved or helped me adapt to feeling low or down	33%	36%	31%	31%
	I haven't done anything in particular but I feel low or down less often	25%	25%	24%	25%
	I haven't done anything in particular and I still often feel low or down	13%	11%	18%	9%
	I haven't had any advice or support to help feeling low or down	18%	14%	23%	19%
	Not stated	1%	1%	1%	1%

	Base size:	1655	522	532	601
Q24	**Have you been given a care plan?**				
	Yes - when I was diagnosed	19%	20%	23%	14%
	Yes - when I finished my treatment	11%	9%	11%	12%
	Yes	30%	30%	34%	26%
	No	59%	61%	56%	61%
	I was offered one but I didn't want it	2%	2%	2%	3%
	Not stated	9%	7%	8%	10%

	Base size:	492	154	180	158
Q25	**How useful do you find your care plan?**				
	Very useful	46%	46%	42%	51%
	Fairly useful	38%	41%	42%	32%
	Not very useful	6%	5%	7%	5%
	Not at all useful	2%	1%	1%	4%
	I have never looked at my care plan	7%	6%	7%	6%
	I don't have a care plan	-	-	-	-
	Not stated	1%	1%	2%	2%
	Useful	84%	87%	83%	83%
	Not useful	8%	6%	8%	9%
	Net useful	77%	81%	76%	74%

	Base size:	1655	522	532	601
Q26	**Do you know who to contact during office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	73%	78%	67%	73%
	No	10%	8%	14%	10%
	No, but I would know how to find out	13%	11%	15%	12%
	Not stated	4%	3%	4%	5%

	Base size:	1655	522	532	601
Q27	**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	43%	55%	32%	43%
	No	49%	38%	60%	47%
	I don't know/I can't remember	3%	3%	3%	3%
	Not stated	5%	4%	5%	6%

	Base size:	713	286	169	258
Q28	**Who did you contact?**				
	My GP	43%	42%	55%	36%
	My GP practice nurse	6%	4%	8%	7%
	Cancer hospital nurse	65%	75%	46%	67%
	My pharmacist	2%	1%	4%	2%
	My cancer doctor or their secretary	25%	19%	23%	33%
	My district nurse or community cancer nurse	9%	6%	9%	12%
	Hospice	*	-	-	*
	Macmillan Nurse	2%	3%	1%	2%
	Other support teams/ centres	1%	1%	1%	1%
	Radiotherapist	*	-	1%	-
	Helplines/Hospital/ Cancer charity/advice line	*	1%	1%	-
	Local hospital/A & E	1%	1%	4%	*
	Stoma nurse	2%	-	-	5%
	Specialist nurse	*	*	1%	*
	Other hospital professionals/ departments	1%	1%	1%	*
	Other	*	-	1%	-
	Had no contact with anyone	*	*	-	*
	Not stated	1%	-	2%	2%
	Base size:	1655	522	532	601
Q29	**Do you know who to contact outside office hours if you have a health concern related to cancer, or your treatment for cancer?**				
	Yes	35%	32%	33%	38%
	No	37%	39%	39%	33%
	No, but I would know how to find out	22%	23%	23%	21%
	Not stated	6%	5%	6%	8%
	Base size:	1655	522	532	601
Q30	**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	12%	14%	8%	13%
	No	80%	77%	84%	77%
	I don't know/I can't remember	3%	4%	2%	4%
	Not stated	5%	4%	5%	6%
	Base size:	194	73	44	77
Q31	**Who did you contact?**				
	My GP or out-of-hours service	31%	32%	39%	26%
	My hospital (department, ward or on-call team)	49%	49%	41%	55%
	Accident and Emergency (A&E)	32%	34%	25%	35%
	Ambulance service, NHS Direct or 111	16%	8%	18%	22%
	No-one/not need to	1%	1%	-	-
	Cancer care nurse	1%	1%	-	-
	District nurse	3%	3%	5%	3%
	Macmillan Nurses/team	2%	4%	2%	-
	Specialist nurse	2%	-	2%	3%
	Other	1%	-	2%	-
	Not stated	6%	4%	5%	8%
	Base size:	1655	522	532	601
Q32	**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	60%	64%	49%	67%
	05-Jan	28%	27%	37%	22%
	10-Jun	2%	2%	3%	2%
	11+	1%	1%	1%	1%
	I don't know/I can't remember	3%	2%	4%	2%
	Not stated	5%	3%	5%	6%
	Base size:	1655	522	532	601
Q33	**How confident do you feel about managing your health, if at all?**				
	Very confident	31%	28%	31%	33%
	Fairly confident	53%	58%	51%	52%
	Not very confident	8%	8%	9%	7%
	Not at all confident	2%	1%	2%	2%
	Don't know	2%	2%	3%	2%
	Not stated	4%	2%	5%	5%
	Confident	84%	87%	81%	85%
	Not confident	9%	9%	11%	9%
	Net confident	75%	78%	70%	76%
	Base size:	1655	522	532	601
Q34	**How confident do you feel about managing the impact of your cancer on your health, if at all?**				
	Very confident	26%	22%	27%	29%
	Fairly confident	52%	56%	50%	50%
	Not very confident	11%	13%	11%	9%
	Not at all confident	3%	4%	3%	3%
	Don't know	4%	3%	6%	4%
	Not stated	4%	2%	5%	5%
	Confident	78%	78%	77%	79%
	Not confident	14%	17%	13%	12%
	Net confident	64%	61%	64%	68%
	Base size:	1655	522	532	601
Q35	**Do you have all the information, advice or support you need to help you manage your health?**				
	Yes	73%	75%	71%	71%
	No	22%	19%	23%	22%
	Not stated	6%	6%	5%	7%

	Base size:	1655	522	532	601
Q36	**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	61%	47%	66%	69%
	I was unable to work prior to my cancer diagnosis	1%	2%	1%	1%
	I was not working when I was diagnosed with cancer	5%	9%	3%	3%
	Yes, and it has helped me to carry on working	6%	10%	5%	4%
	Yes, but it has not helped me to carry on working	1%	2%	1%	*
	I was offered advice or support but I didn't need it	2%	3%	2%	2%
	No, but I did not need advice or support to help me carry on working	14%	18%	14%	11%
	No, and I would have liked to have advice or support to help me carry on working	3%	4%	2%	3%
	Not stated	6%	5%	6%	6%

	Base size:	1655	522	532	601
Q37	**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	4%	4%	3%	3%
	Yes, and it has helped me to stay in my own home	8%	6%	8%	10%
	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	6%	7%	5%	7%
	No, but I didn't need advice or support to help me stay in my own home	72%	75%	72%	70%
	No, and I would have liked to have advice or support to help stay in my own home	2%	2%	2%	2%
	Not stated	7%	5%	9%	7%

	Base size:	1655	522	532	601
Q38	**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	8%	9%	7%	7%
	Yes, but it has not helped me to cope with my financial issues	2%	3%	1%	2%
	I was offered advice or support but I didn't need it	5%	7%	5%	4%
	No, but I didn't need advice or support to help me with my financial issues	70%	65%	74%	71%
	No, and I would have liked to have advice or support to help me with my financial issues	8%	11%	7%	8%
	Not stated	7%	6%	8%	7%

	Base size:	1655	522	532	601
Q39	**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%	9%	5%	7%
	Yes, but it has not helped me to cope with the practical things that I needed help with	1%	1%	1%	1%
	I was offered advice or support but I didn't need it	7%	8%	6%	6%
	No, but I didn't need advice or support to help me cope with the practical things that I needed help with	71%	69%	73%	71%
	No, and I would have liked to have advice or support to help me cope with the practical things that I needed help with	7%	7%	5%	8%
	Not stated	7%	6%	9%	6%

	Base size:	1655	522	532	601
Q40	**Do you have all of the information and advice that you need about the effects of your treatment?**				
	Yes	73%	76%	72%	72%
	I was offered information or advice but I didn't need it	3%	3%	3%	4%
	No	8%	6%	9%	9%
	No, and I would have liked information or advice about the effects of my treatment	9%	10%	9%	9%
	Not stated	6%	4%	7%	6%

	Base size:	1655	522	532	601
Q41	**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?**				
	Yes	7%	6%	6%	7%
	No	85%	88%	84%	85%
	Not stated	8%	7%	10%	8%

	Base size:	1655	522	532	601
Q42	**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	61%	68%	57%	59%
	No	27%	24%	27%	30%
	I was offered information or advice but I didn't need it	2%	1%	3%	2%
	Not stated	10%	7%	14%	9%

	Base size:	449	126	143	180
Q43	**What further information and advice about the signs and symptoms of cancer do you need to help you tell if the cancer comes back?**				
	More information on symptoms/signs/what to look out for/if cancer returns	35%	37%	31%	36%
	I contact/see medical staff at hospital/ clinic/surgery	11%	6%	15%	12%
	Mentions of illness/ symptoms/prognosis/of respondent at this moment	6%	5%	6%	7%
	More follow up appointments and check ups	6%	9%	3%	5%
	Written information/ leaflets/booklets	5%	7%	3%	5%
	Any/all the/relevant information they can give	5%	6%	2%	6%
	More information on present cancer needed/ its progression/pain relief	4%	4%	6%	3%
	Better communication	3%	2%	3%	4%
	Mentions of PSA tests/ levels	3%	-	10%	-
	Nothing/all staff are very good/helpful/ received all the information I needed/ everything's good	3%	4%	2%	3%
	Still receiving treatment/on going	3%	2%	5%	2%
	More general advice/ information	2%	4%	2%	2%
	More information on medication/side affects	2%	2%	3%	1%
	Advice on self examination	2%	5%	-	1%
	Improve/more care/after care	1%	2%	1%	1%
	More contact with medical professionals	1%	2%	-	1%
	Contact details if problems arise	*	-	-	1%
	More dietary/lifestyle advice	*	-	-	1%
	More help/support/groups	*	1%	-	1%
	Mentions of other/ illnesses/symptoms	*	-	-	1%
	Receive results sooner	*	-	-	1%
	Receive help/support from other groups/ friends etc.	-	-	-	-
	Improve scheduling of appointments/less waiting time/ cancellations	-	-	-	-
	Counseling	-	-	-	-
	Other	1%	-	1%	2%
	Don't know	2%	2%	3%	2%
	Not stated	23%	21%	27%	21%

	Base size:	1655	522	532	601
Q44	**Please indicate which of the following applies to you.**				
	I am the patient named in the letter	92%	94%	91%	91%
	I am filling out this questionnaire on behalf of the patient named in the letter	3%	2%	4%	4%
	Not stated	5%	4%	5%	5%

	Base size:	1655	522	532	601
Q45	**Are you male or female?**				
	Male	53%	1%	100%	56%
	Female	43%	93%	-	37%
	Not stated	4%	6%	-	7%

	Base size:	1655	522	532	601
Q46	**How old are you?**				
	18 - 30	*	1%	-	*
	31 - 35	1%	1%	-	*
	36 - 40	1%	1%	*	1%
	41 - 45	2%	4%	*	1%
	46 - 50	4%	10%	1%	2%
	51 - 55	6%	11%	3%	3%
	56 - 60	8%	12%	7%	4%
	61 - 65	13%	14%	12%	13%
	66 - 70	20%	16%	22%	22%
	71 - 75	16%	9%	21%	18%
	76 - 80	15%	10%	19%	16%
	81 or over	13%	9%	14%	15%
	Not stated	3%	2%	2%	4%

	Base size:	1655	522	532	601
Q47	**Do you have any of the following long-standing conditions in addition to your cancer diagnosis?**				
	I do not have any longstanding conditions	47%	53%	42%	47%
	Deafness or a severe hearing impediment	10%	7%	13%	10%
	Blindness or partially sighted	2%	1%	2%	3%
	A long-standing physical condition, e. g. arthritis, multiple sclerosis	21%	23%	17%	24%
	A learning disability	*	*	1%	*
	A mental health condition	3%	2%	4%	2%
	A long-standing illness (apart from cancer) such as diabetes, chronic heart disease, epilepsy or HIV	17%	12%	22%	18%
	Not stated	10%	11%	11%	9%

	Base size:	1655	522	532	601
Q48	**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	8%	8%	7%	9%
	A fair amount	13%	12%	16%	12%
	Not very much	16%	14%	17%	17%
	No effect at all	9%	6%	12%	9%
	I do not have any longstanding conditions	14%	15%	13%	14%
	Not stated	40%	46%	36%	39%
	Great deal/fair amount	21%	20%	23%	21%
	Not very much/no effect at all	25%	20%	28%	26%
	Net great deal/fair amount	-4%	*	-6%	-5%