

# Quality of Life of Cancer Survivors in England

Report on a pilot survey using Patient Reported  
Outcome Measures (PROMS)

**DH INFORMATION READER BOX**

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Report undertaken by Quality Health for the Department of Health

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# Foreword

The publication of this report represents an important milestone in the evaluation of outcomes for cancer patients in England. The report demonstrates that it is feasible to collect detailed information on the quality of life of cancer survivors, using cancer registries to identify patients who are between one and five years post diagnosis. The high response rate (66%) and the willingness of large numbers of patients to provide free text comments on their quality of life, and on their experience of care, demonstrates the acceptability of this approach.

Progress on cancer survival and mortality (Domain 1 of the NHS Outcomes Framework) has been measured and reported in this country for many years. More recently measurement of patient experience (Domain 4) has become possible through the cancer patient experience surveys. Lengths of stay and readmission rates have been used as measures of recovery (Domain 3) and 30 day mortality following some forms of cancer surgery have been published as an indicator of patient safety (Domain 5). This report shows the potential to measure quality of life in representative cohorts of cancer survivors, thereby enabling us to measure progress on Domain 2 of the NHS Outcomes Framework. By scaling these surveys up we can now potentially compare quality of life following a diagnosis of cancer for patients treated at different hospitals. This will be trialled for colorectal cancer in the coming year.

The headline findings from the current survey show that the majority of cancer survivors report no problems on each of the five items on the EQ5D. However, between 8% (self care) and 22% (mobility and usual activities) report moderate or severe problems on each of these items. In line with expectations, quality of life was closely related to disease status (e.g. remission vs. recurrent cancer) and the presence of other long term conditions.

Fear of recurrence and fear of dying were reported by a relatively large proportion of cancer survivors at one year (47% and 27% respectively). Although reductions in these fears were observed over time, they were reported by 42.5% (fear of recurrence) and 22% (fear of dying) at five years.

In relation to individual cancers, key findings were that 19% of colorectal cancer patients had difficulty controlling their bowels and that these patients were more than twice as likely as others to report lower quality of life. Amongst prostate cancer patients around 38% reported urinary leakage and this was associated with lower quality of life scores.

We now need to extend the measurement of quality of life to other cancer types, in order that a focus on this important outcome is maintained and further developed. I congratulate all concerned with this initiative.



Professor Sir Mike Richards  
National Cancer Director  
Director Domain 1  
National Commissioning Board

# 1. Executive Summary

## Introduction and Aims

- 1.1 Around 1.8 million people in England are currently living with or beyond a diagnosis of cancer. One of the overarching aims set out in 'Improving Outcomes: A Strategy for Cancer' (2011) is to ensure that everything is done to allow cancer survivors to live as healthily as possible. However, little is currently known about the long term quality of life of cancer survivors in this country.
- 1.2 This survey was commissioned by the Department of Health as part of the National Cancer Survivorship Initiative (NCSI). The survey was conducted by Quality Health in conjunction with three cancer registries in England.
- 1.3 The first aim of the survey was to assess the feasibility and acceptability to cancer survivors of collecting information on quality of life (QoL) through the use of Patient Reported Outcome Measures (PROMS). The second aim was to assess the overall quality of life of representative samples of cancer survivors with four different tumour types (breast, colorectal and prostate cancer and non-Hodgkin's lymphoma (NHL)) and at four different time points after diagnosis (approximately one, two, three or five years). The third aim was to assess the contribution of demographic, disease-related, and other, factors to quality of life.
- 1.4 The current report provides results for each of the individual items used in the survey, together with simple comparisons between tumour types (where relevant) and time points post diagnosis. Univariate comparisons between different patient groups (e.g. based on age, gender, ethnicity or sexual orientation) are also reported. Additional reports will be published in parallel with this report. These provide more information on the inter-relationships between different factors (e.g. disease status or the coexistence of other long term conditions) and overall quality of life and on the free text comments made by respondents.

## Patients

- 1.5 An initial sample of 4,992 patients was identified by three participating cancer registries (West Midlands, East of England and Thames). This sample comprised 312 patients in each of the four tumour groups at each of the four time points.
- 1.6 In total 3,300 responses were obtained, giving a response rate of 66%. Response rates were broadly similar across the tumour groups and between time points, with around 200 patients responding in each tumour group at, each time point.

## Survey instruments

- 1.7 Overall quality of life was assessed using the EQ5D. This instrument has five items covering problems with walking about, washing or dressing, doing usual activities, pain or discomfort and anxiety or depression. The EQ5D was selected in order to facilitate comparisons with other patient groups assessed through survey programmes in this country.
- 1.8 Other survey items used for all tumour groups were selected to cover:
- Demographics
  - Treatment details
  - Disease status (e.g. remission, relapse, uncertain)
  - Long term conditions (one item)
  - Physical activity (one item)
  - Social difficulties (11 items)
  - Psychological issues (nine items)
  - Work status (one item)
  - Experience of care (six items)

Wherever possible these questions were drawn (with permission) from previously validated survey instruments such as the Social Difficulties Inventory (SDI).

- 1.9 Tumour-specific questions were drawn from the relevant Functional Assessment of Cancer Therapy (FACT) questionnaires (with permission). A total of 43 questions were common to all tumour groups, with around 20-30 additional questions depending on tumour type. Detailed cognitive testing of the full questionnaires was undertaken using volunteer patients.

## Headline Findings

- 1.10 The high response rate (66%) demonstrates the feasibility and acceptability of collecting information on quality of life (QoL) from cancer survivors, including those who are five years post diagnosis. Around one third of respondents also chose to provide free text comments. However, lower response rates were observed amongst older people (aged 85+) and those who were more deprived.
- 1.11 The median age for the 3,300 respondents was 69 years, of whom 52% were males. More than one half (55%) reported that their cancer was in remission, with 17.5% reporting the presence of disease and 15% being uncertain.
- 1.12 On each of the five items of the EQ5D – mobility, self-care, usual activities, pain and anxiety/depression – the majority of patients reported no problems at all in any of these areas (notably, 51% reported no pain at all; whilst 81% reported no problems at all with self care). However, between 8% (self care) and 22% (mobility and usual activities) reported moderate or severe problems on each of these items.

- 1.13 Overall quality of life (based on the EQ5D summary score) was significantly associated with:
- The presence and number of concurrent long term conditions
  - Disease status
  - Age (with 65-74 year olds having the best quality of life)
  - Physical activity
- 1.14 Four of the five items in the EQ5D did not appear to change significantly over time since diagnosis (pain, mobility, usual activities and self care). However, the percentage of patients reporting anxiety or depression decreased significantly over time.
- 1.15 Almost half (47.3%) of respondents reported fear of recurrence at one year. Although this decreased significantly over time, fear of recurrence was reported by 42.5% of patients at five years. A similar pattern was observed for fear of dying (27% at one year decreasing to 22% at five years).
- 1.16 Around one fifth of participants reported taking 30 minutes, or more, of physical activity at least five days a week (in line with the Chief Medical Officers' recommendations). Overall almost 30% of patients reported doing no physical activity. Prostate cancer survivors were the most likely to undertake recommended levels of physical activity, and least likely to do no physical activity.
- 1.17 Increasing physical activity was associated with improved quality of life as measured by the EQ5D.
- 1.18 Findings relating to individual tumour types include the following:
- Colorectal (bowel) cancer: around 19% had difficulty controlling their bowels. These patients were more than twice as likely as others to report lower QoL. The presence of a stoma or urinary leakage were not significantly associated with QoL.
  - Prostate cancer: 58% reported they were unable to have an erection, with a further 11% reporting difficulty having, or maintaining, an erection. 38.5% reported some degree of urinary leakage and 13% reported difficulty controlling their bowels. Urinary leakage was significantly associated with poorer QoL, whereas erectile dysfunction and difficulty controlling bowels were not, amongst respondents with prostate cancer.

## Commentary

- 1.19 This is the largest survey of cancer survivors covering multiple cancer types, to have been conducted in Europe. The feasibility of using cancer registries to identify relevant samples of patients has been demonstrated.
- 1.20 The relatively high response rate, low level of missing data and low number of calls to the dedicated helpline suggest that this approach is acceptable to the majority of cancer survivors. However, the lower response rates amongst the oldest age group (85 years +) and those who are most deprived, should be noted.
- 1.21 The findings linking QoL to presence or absence of ongoing cancer, or long term conditions, were in line with expectation and provide face validity.

- 1.22 In univariate analyses, QoL appeared to improve with time since diagnosis. However, on closer examination this is likely to be due to the relatively higher proportion of survivors at five years who reported that they were in remission.
- 1.23 The survey has highlighted the relationship between poor bowel control and poorer quality of life for patients with colorectal cancer and the relationship between urinary incontinence and poorer QoL for patients with prostate cancer. Larger surveys would facilitate analysis of factors contributing to poor bowel control or urinary incontinence in survivors of these cancers. Such surveys would also enable comparisons to be made between provider Trusts.
- 1.24 The impact on QoL of having a coexisting long term condition has been highlighted by this survey. For 40 of the 43 questions that were common to all four tumour groups, significant differences were observed between those with, and without, long term conditions. In every case, those with a long term condition were less positive than those without one. A similar pattern was observed for those questions which related to specific tumour groups.



## 2. Introduction

- 2.1 Although quality of life (QoL) amongst cancer patients has been assessed in the context of clinical trials, relatively little is known about QoL in representative cohorts of cancer survivors.
- 2.2 One of the key aims of current cancer strategy in England is to ensure that everything is done to enable cancer survivors to live as healthy a life as possible. Measurement of quality of life amongst cancer survivors is an essential prerequisite for this. The survey described in this report was commissioned by the Department of Health, and conducted by Quality Health. The development of the survey methodology was overseen by the Cancer Patient Experience Advisory Group, co-chaired by Professor Sir Mike Richards and Professor Jessica Corner.
- 2.3 The first aim of the programme was to assess the feasibility of acquiring information on quality of life from patients who were around one, two, three or five years post diagnosis of cancer. Four tumour groups were chosen (breast, colorectal, prostate and non-Hodgkin's lymphoma), as these tumour groups represent large numbers of cancer survivors. Patients were identified through three cancer registries.
- 2.4 The survey questions were, wherever possible, based on well validated generic or cancer-specific quality of life tools.
- 2.5 The EQ5D was selected as a generic measure of quality of life to facilitate comparisons with other patient groups and with the population in England. The Social Difficulties Inventory (SDI) was also used for all patients. Items relating to individual cancer types were drawn, with permission, from the relevant Functional Assessment of Cancer Therapy (FACT) questionnaires.
- 2.6 The second aim was to assess the overall quality of life of respondents and to compare responses between tumour types, and over time. The third aim was to assess the contribution of demographic, disease-related and other factors to overall quality of life.
- 2.7 For clarity, respondents' responses have been rounded to the nearest whole number. In some cases, this will mean that figures do not add up to 100%.

### 3. Response rate and helpline calls

A total of 4,992 patients were taken from three Cancer Registries for the Cancer Survivorship Pilot Survey: Eastern Cancer Registration and Information Centre (ECRIC), Thames Cancer Registry (TCR) and West Midlands Cancer Intelligence Unit (WMCIU). The samples were equally split between four cancer types (breast, colorectal, NHL and prostate). Within each cancer type the sample was again divided equally between four time cohorts: one year, two years, three years and five years from diagnosis.

#### Response rate

- 3.1 During the survey process Demographics Batch Service (DBS) checks were undertaken on three occasions to remove deceased patients: before the first send out, before the first reminders were sent and before the second reminders were sent. Patients were also removed arising from calls to the helpline and via postal communications that were received. These included additional deceased patients, those who had moved and could not be traced, and other ineligible patients. This produced a final sample of 4,866.
- 3.2 The overall response rate was 66% (3,300/4,992). The response rate, after removal of those who had moved, were ineligible or had died, was 68% (3,300/4,866). The response rates were broadly similar between the three cancer registries.

**Table 3.1: Response rates by Cancer Registry**

| Registry | No. completed questionnaires | No. moved/ deceased/ineligible | Total no. sent | Response rate (after exclusions) |
|----------|------------------------------|--------------------------------|----------------|----------------------------------|
| ECRIC    | 904                          | 62                             | 1,396          | <b>68%</b>                       |
| Thames   | 1,418                        | 45                             | 2,169          | <b>67%</b>                       |
| WMCIU    | 978                          | 19                             | 1,427          | <b>69%</b>                       |
|          | <b>3,300</b>                 | <b>126</b>                     | <b>4,992</b>   | <b>68%</b>                       |

3.3 Table 3.2 shows response rates by cancer type and year of diagnosis.

**Table 3.2: Response rates by cancer type**

| Tumour group      | Total no. sent | No. moved, deceased, ineligible | No. completed questionnaires | Response rate |
|-------------------|----------------|---------------------------------|------------------------------|---------------|
| Breast            | 1,248          | 28                              | 854                          | 70%           |
| Colorectal/gastro | 1,248          | 27                              | 802                          | 66%           |
| NHL               | 1,248          | 56                              | 778                          | 65%           |
| Prostate          | 1,248          | 15                              | 866                          | 70%           |

**Table 3.3: Response rates by cancer type and time cohort**

| Tumour Group       | Time Cohort        | No. completed questionnaires | No. moved/ deceased/ineligible | Total no. sent | Response rate |
|--------------------|--------------------|------------------------------|--------------------------------|----------------|---------------|
| <b>Breast</b>      | <b>one year</b>    | 215                          | 4                              | 312            | <b>70%</b>    |
|                    | <b>two years</b>   | 212                          | 3                              | 312            | <b>69%</b>    |
|                    | <b>three years</b> | 204                          | 14                             | 312            | <b>68%</b>    |
|                    | <b>five years</b>  | 223                          | 7                              | 312            | <b>73%</b>    |
| <b>Colo-Gastro</b> | <b>one year</b>    | 202                          | 3                              | 312            | <b>65%</b>    |
|                    | <b>two years</b>   | 215                          | 8                              | 312            | <b>71%</b>    |
|                    | <b>three years</b> | 195                          | 3                              | 312            | <b>63%</b>    |
|                    | <b>five years</b>  | 190                          | 13                             | 312            | <b>64%</b>    |
| <b>NHL</b>         | <b>one year</b>    | 197                          | 9                              | 312            | <b>65%</b>    |
|                    | <b>two years</b>   | 187                          | 28                             | 312            | <b>66%</b>    |
|                    | <b>three years</b> | 207                          | 12                             | 312            | <b>69%</b>    |
|                    | <b>five years</b>  | 187                          | 7                              | 312            | <b>61%</b>    |
| <b>Prostate</b>    | <b>one year</b>    | 234                          | 3                              | 312            | <b>76%</b>    |
|                    | <b>two years</b>   | 220                          | 5                              | 312            | <b>72%</b>    |
|                    | <b>three years</b> | 200                          | 3                              | 312            | <b>65%</b>    |
|                    | <b>five years</b>  | 212                          | 4                              | 312            | <b>69%</b>    |

3.4 As can be seen from table 3.3, response rates remained fairly consistent across the time cohorts without significant drop off from those individuals with longer time since diagnosis, as might have been expected.

3.5 Quality Health provided a dedicated survey helpline staffed by trained, in-house operators. 64 calls were made to the helpline; these included calls which fell into the following categories:

- Patients calling for general advice about completing the questionnaire
- Patients calling to say they were too ill or did not want to participate
- Relatives calling to report deceased patients
- Patients reported as having moved
- Patients calling for help with translation facilities

- 3.6 As soon as calls were received, the nature of the call and any required action was logged on the database to ensure that, in particular, patients who were deceased, or did not want any further communication, did not receive survey reminders. Patients who raised queries about their health status were offered information about the Macmillan Cancer Support website and helpline, or referred to their originating Trust, if this was appropriate.
- 3.7 Further information about patient status was received via letters (11) and NHS Trusts (two).
- 3.8 A full report on helpline activity was produced for the NCSI committee.

## 4. Patient demographics

The samples for the survey were taken from three Cancer Registries (ECRIC, TCR, and WMCIU) and included patients in four time cohorts. A sampling manual was developed to ensure that all patients in the samples met stringent criteria in relation to their ICD10 coding.

- 4.1 Cancer patients often make a number of visits to a hospital or hospitals for a variety of treatments or consultations in a short period of time. To ensure that patients were not sent more than one questionnaire, checks were undertaken on all samples for the survey to ensure that patients appeared on the list, only once. Further checks were made between Registries to ensure that patients did not appear on the lists of more than one Registry.
- 4.2 The table below shows the number and percentage of respondents by tumour group.

**Table 4.1: Tumour group by number of respondents**

| <b>Tumour Group</b>               | <b>Number of respondents</b> | <b>Percentage of respondents</b> |
|-----------------------------------|------------------------------|----------------------------------|
| Breast                            | 854                          | 25.9%                            |
| Colorectal/lower gastrointestinal | 802                          | 24.3%                            |
| NHL                               | 778                          | 23.6%                            |
| Prostate                          | 866                          | 26.2%                            |
| <b>Total</b>                      | <b>3,300</b>                 | <b>100%</b>                      |

- 4.3 The tables below show the percentage and number of respondents by gender, age, ethnicity, sexual orientation and long term condition.

**Table 4.2: Respondents by gender**

| <b>Gender of respondents</b> | <b>Number of respondents</b> | <b>Percentage</b> |
|------------------------------|------------------------------|-------------------|
| Male                         | 1,613                        | 52%               |
| Female                       | 1,514                        | 48%               |

**Table 4.3: Respondents by age group**

| Age of respondents | Number of respondents | Percentage |
|--------------------|-----------------------|------------|
| 16-25 years of age | 3                     | 0%         |
| 26-35 years of age | 23                    | 1%         |
| 36-50 years of age | 242                   | 8%         |
| 51-65 years of age | 925                   | 30%        |
| 65-75 years of age | 1,017                 | 33%        |
| 76+ years of age   | 873                   | 28%        |

**Table 4.4: Respondents by ethnicity**

| Ethnicity of respondents              | Number of respondents | Percentage |
|---------------------------------------|-----------------------|------------|
| White (British, Irish or other white) | 2,734                 | 93.6%      |
| Asian or Asian British                | 99                    | 3.1%       |
| Black or Black British                | 82                    | 2.4%       |
| Mixed background                      | 16                    | 0.5%       |
| Other                                 | 215                   | 0.4%       |

**Table 4.5: Respondents by sexual orientation**

| Sexual orientation of respondents * | Number of respondents | Percentage |
|-------------------------------------|-----------------------|------------|
| Heterosexual                        | 2,832                 | 94.4%      |
| Bisexual                            | 7                     | 0.2%       |
| Gay or lesbian                      | 16                    | 0.5%       |
| Other                               | 16                    | 0.5%       |

\*4% of patients said they preferred not to answer this question, and a further 9% of all respondents to the survey did not answer the question at all.

**Table 4.6: Respondents with long term conditions**

| <b>Respondents with long term conditions*</b> | <b>Number of respondents</b> | <b>Percentage</b> |
|---|------------------------------|-------------------|
| Alzheimer's disease or dementia               | 26                           | 1%                |
| Angina  | 132                          | 4%                |
| Arthritis                                     | 886                          | 27%               |
| Asthma or other chronic chest problem         | 321                          | 10%               |
| Blindness or visual impairment                | 136                          | 4%                |
| Deafness or hearing impairment                | 432                          | 13%               |
| Diabetes                                      | 420                          | 13%               |
| Epilepsy                                      | 24                           | 1%                |
| Heart condition                               | 391                          | 12%               |
| High blood pressure                           | 1,040                        | 32%               |
| Kidney disease                                | 75                           | 2%                |
| Learning difficulty                           | 18                           | 1%                |
| Liver disease                                 | 28                           | 1%                |
| Long term back problems                       | 535                          | 16%               |
| Long-standing mental health problem           | 73                           | 2%                |
| Long-standing neurological problem            | 56                           | 2%                |
| Another long-standing condition               | 400                          | 12%               |
| None of these conditions                      | 727                          | 22%               |

\*40% of patients said they did not have a long-standing condition other than cancer. The table shows the percentage and number of patients saying they had one or more of each of the long-standing conditions specified.

**Table 4.7: Treatment by cancer type**

| <b>Treatment by cancer type</b> | <b>Breast</b> | <b>Colorectal</b> | <b>NHL</b> | <b>Prostate</b> |
|---------------------------------|---------------|-------------------|------------|-----------------|
| <b>Radiotherapy</b>             | 72%           | 19%               | 32%        | 43%             |
| <b>Chemotherapy</b>             | 36%           | 47%               | 75%        | 3%              |
| <b>Surgery</b>                  | 84%           | 90%               | 24%        | 26%             |

## 5. Overview of the generic questions

**This section of the report describes the results for all those questions in the survey which were common to all cancer types. Cancer specific questions are reported in a separate section.**

- 5.1 The text of each question is displayed followed by a description of the results. All four PROM surveys about living with and beyond prostate, breast and bowel cancer, and non-Hodgkin's lymphoma (NHL) are available in Appendix A.
- 5.2 For each question key scores were calculated after removing any patients who said that the question did not apply to them or said they did not need a particular type of information, who ticked 'don't know/can't remember' or who did not answer at all.
- 5.3 The key score for each question is shown firstly as an overall percentage of all relevant respondents to the survey; this same key score is then used to highlight variations between tumour groups. Where the key score has been constructed from more than one response option to a particular question (e.g. questions with response options of disagree, strongly disagree), then the response options that make up that key score are described.
- 5.4 There are two types of chart in this section, those showing the key scores by cancer type and those showing the key scores by time cohort. In each of these charts the overall score for all respondents (the national average) is shown as a red line.
- 5.5 For each question, significance tests were used to establish whether particular cancer types or time cohorts have scores at variance from the overall group of respondents. Where differences were significant, this is specified below, in the relevant chart.
- 5.6 The questions in this section of the survey were about the patient's perception of their own health on the day that they completed the questionnaire. Questions from this section of the questionnaire, which related to specific tumour groups, are reported in section 6.

### Length of time since completion of treatment

**How long is it since you completed your initial treatment for ... cancer?**

#### Overall findings

- 5.7 5% of patients said they were either still having their initial treatment (4%) or that it was less than three months since their initial treatment (1%).
- 5.8 14% said it was between three and 12 months, 66% one to five years, and 14% more than five years.
- 5.9 1% did not know or could not remember.



## Cancer responding to treatment

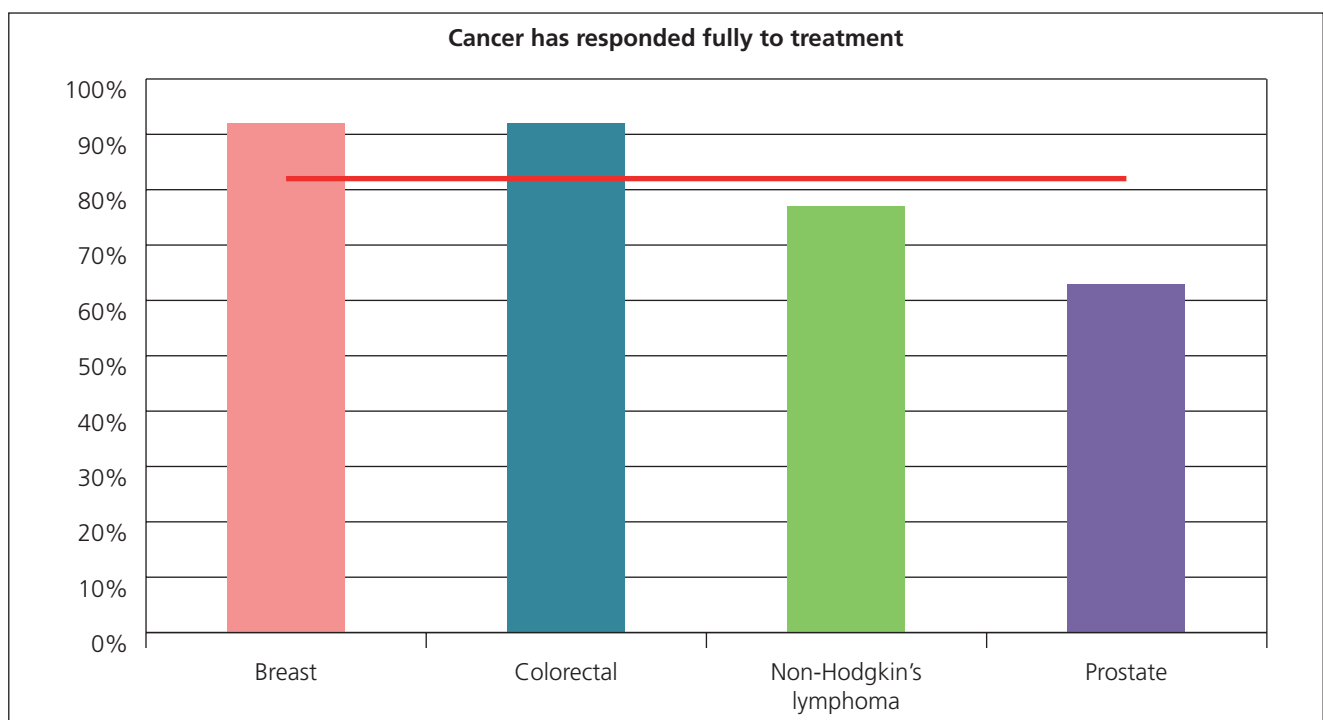
### How has your .... cancer responded to treatment?

#### Overall findings

- 5.10 82% of those patients who were certain what was happening said their cancer had responded fully to treatment; 10% said it had been treated but was still present, 5% said it had not been treated at all and 3% said it had come back after it was originally treated.
- 5.11 12% of patients overall, were not certain what was happening with their cancer.

## Your health today

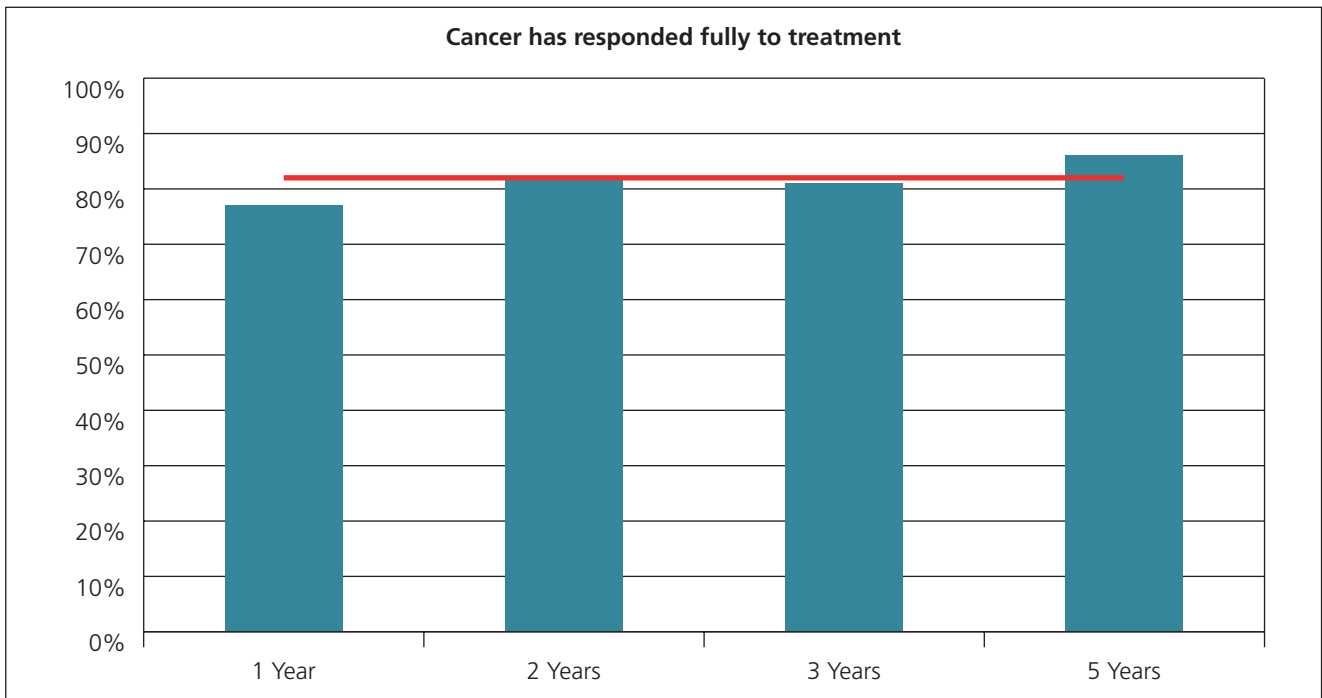
**Chart 5.1: Findings by Tumour Group**



- 5.12 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

## Your health today

**Chart 5.2: Findings by Time Cohort**



5.13 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

### EQ-5D-5L questions

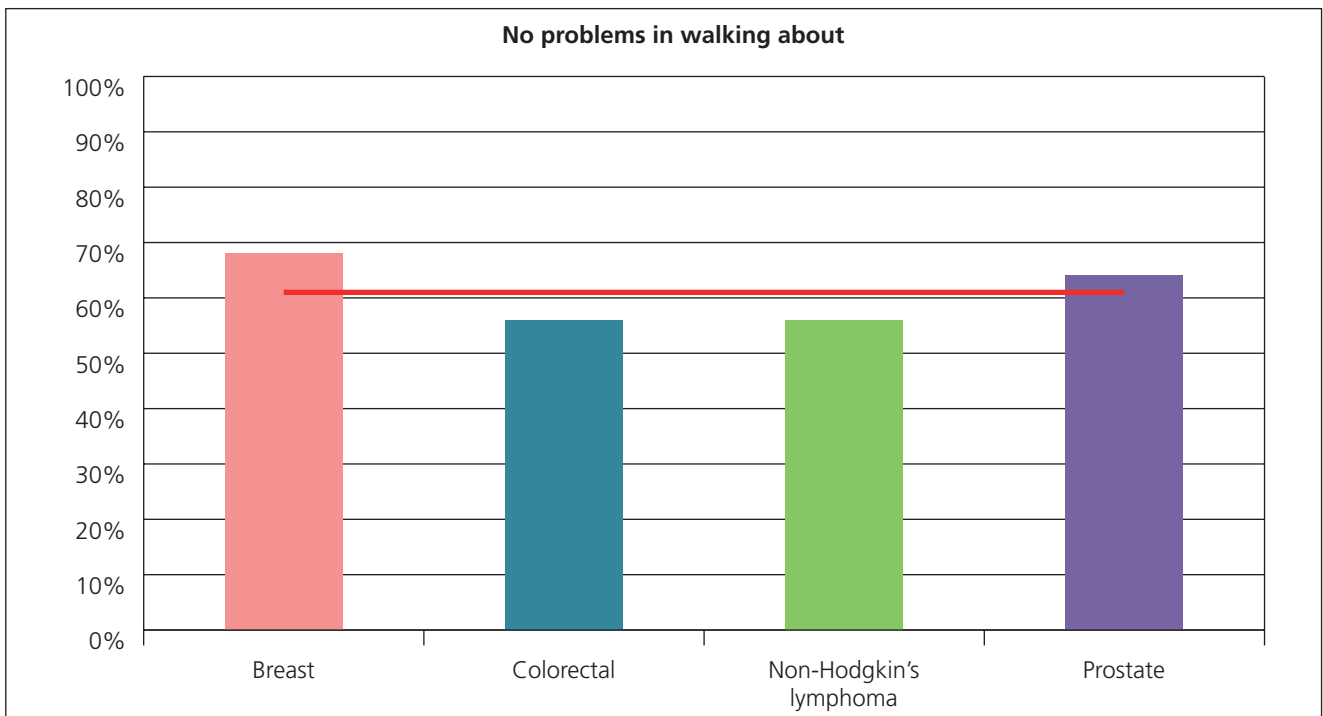
5.14 Patients were asked to tick one box that best described their health today on each of five health topics.

#### Mobility

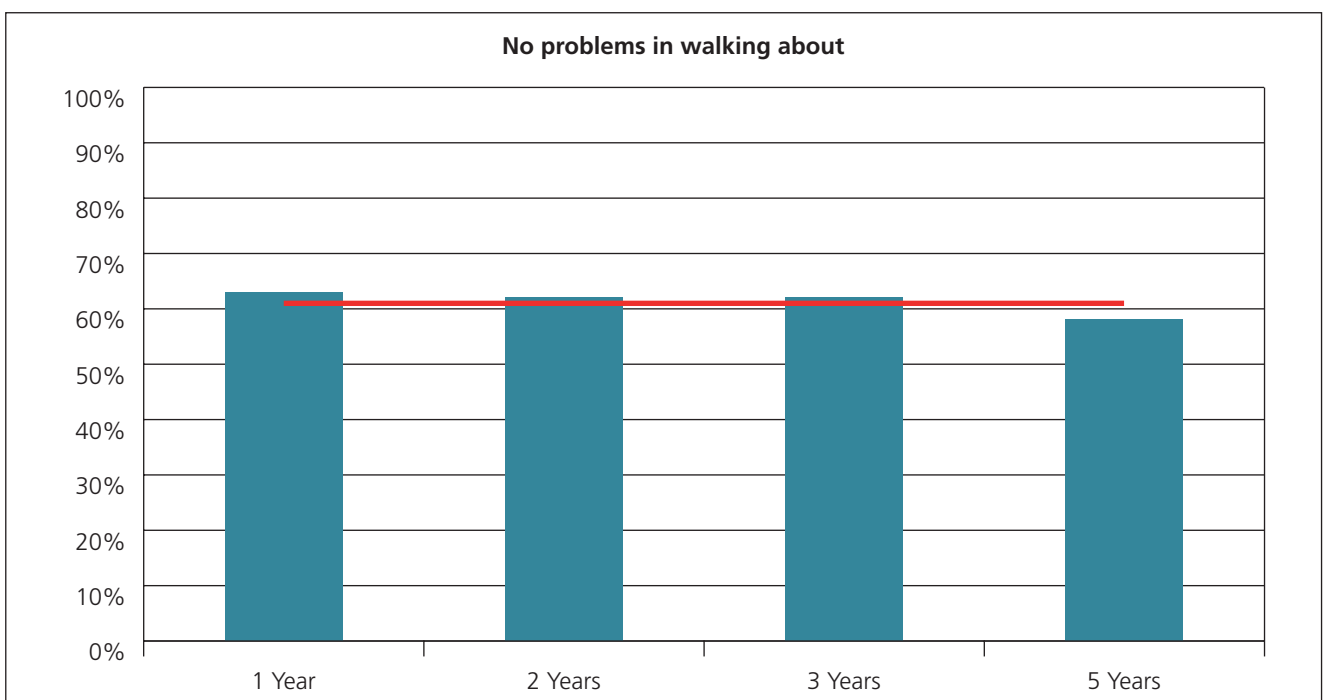
#### Overall findings

5.15 61% of patients said they had no problems walking about; 17% said they had slight problems, 14% had moderate problems and 8% had severe problems. 1% said they were unable to walk about.

**Chart 5.3: Findings by Tumour Group**



**Chart 5.4: Findings by Time Cohort**



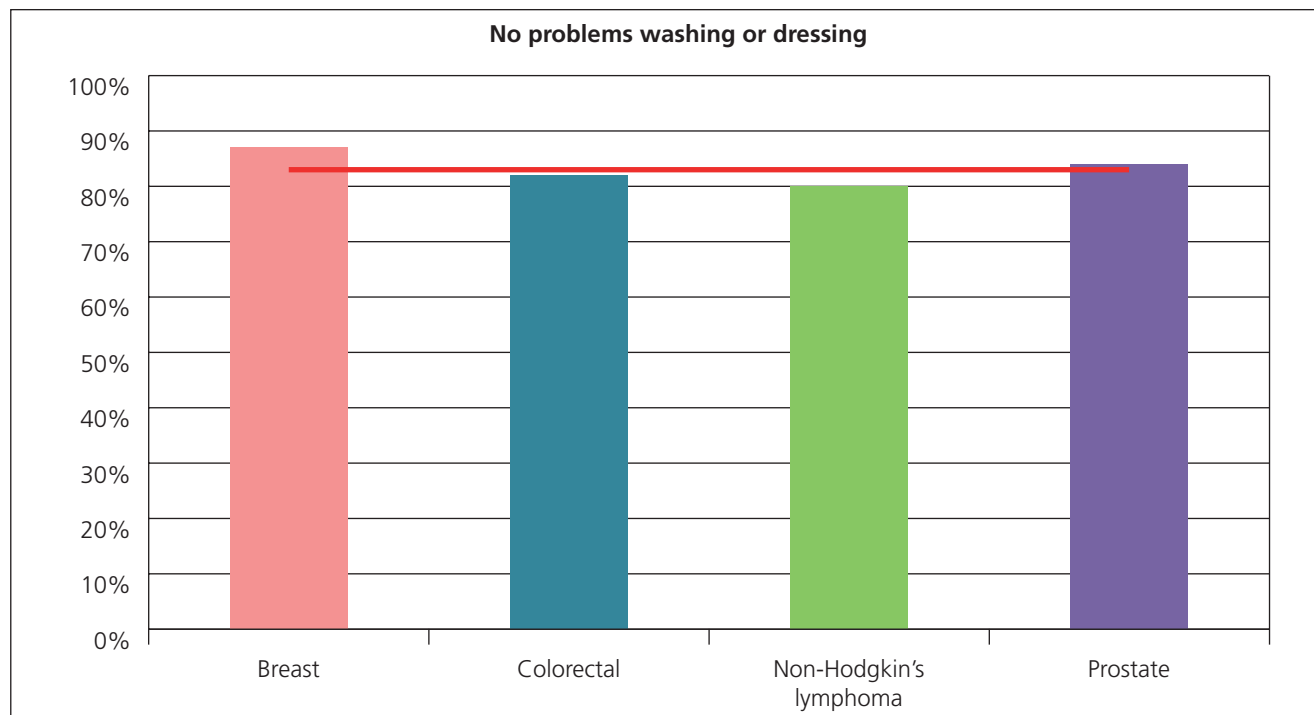
5.16 There were significant differences between the five year cohort and all other time cohorts.

## Self Care

### Overall findings

5.17 83% of patients said they had no problems washing or dressing themselves; 8% said they had slight problems, 6% had moderate problems and 2% had severe problems. 1% said they were unable to wash or dress themselves.

**Chart 5.5: Findings by Tumour Group**



**Chart 5.6: Findings by Time Cohort**

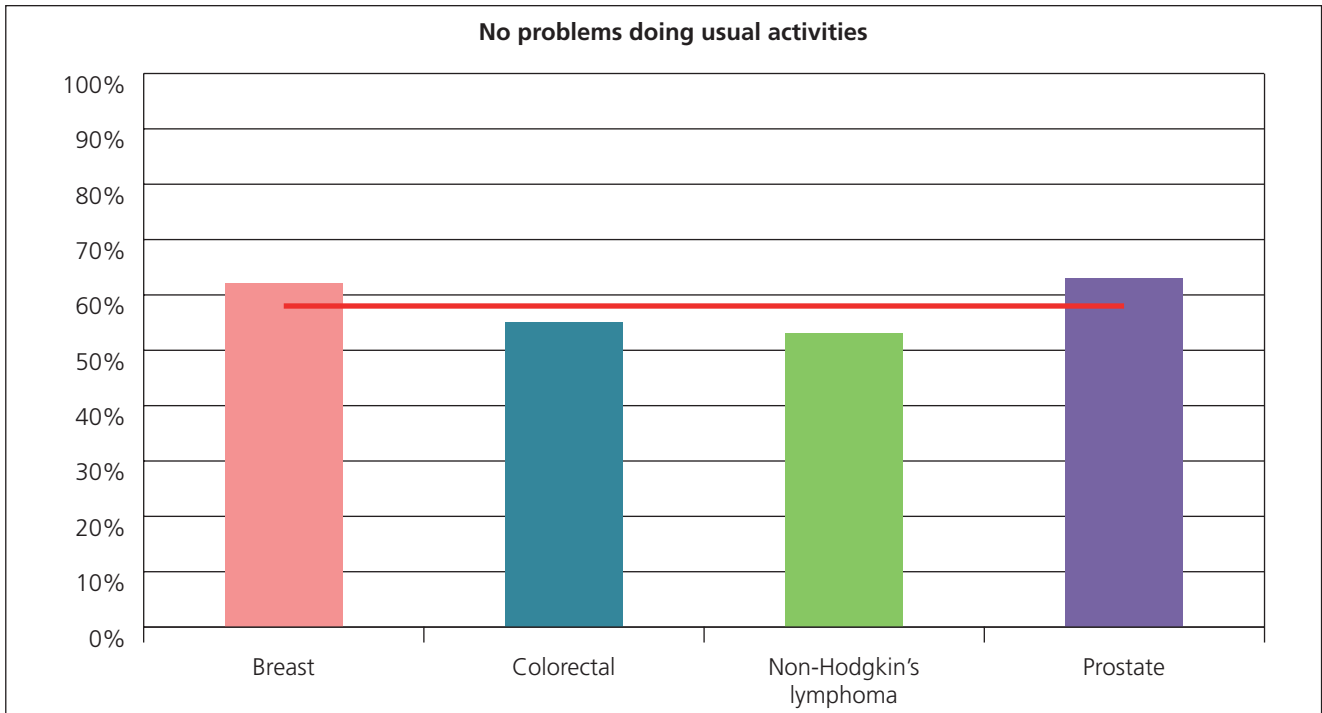


## Usual activities

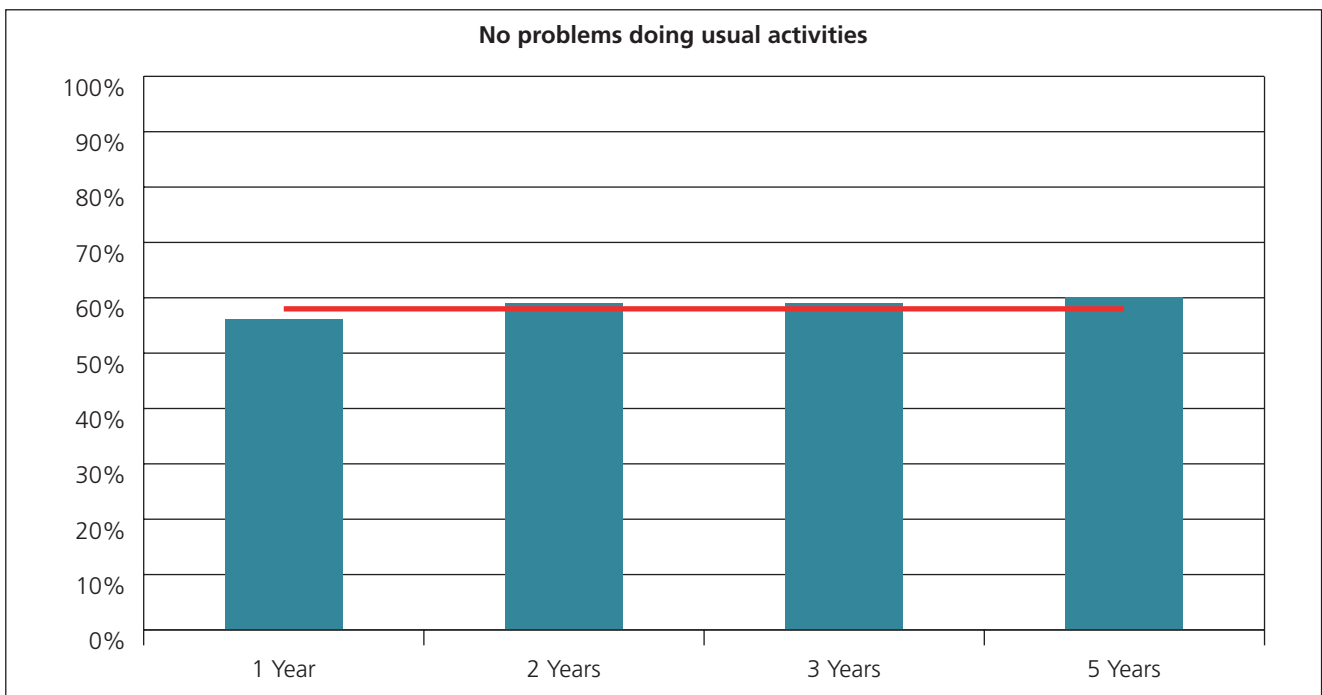
### Overall findings

5.18 58% of patients said they had no problems doing their usual activities; 20% said they had slight problems, 14% had moderate problems and 5% had severe problems. 2% said they were unable to do their usual activities.

**Chart 5.7: Findings by Tumour Group**



**Chart 5.8: Findings by Time Cohort**

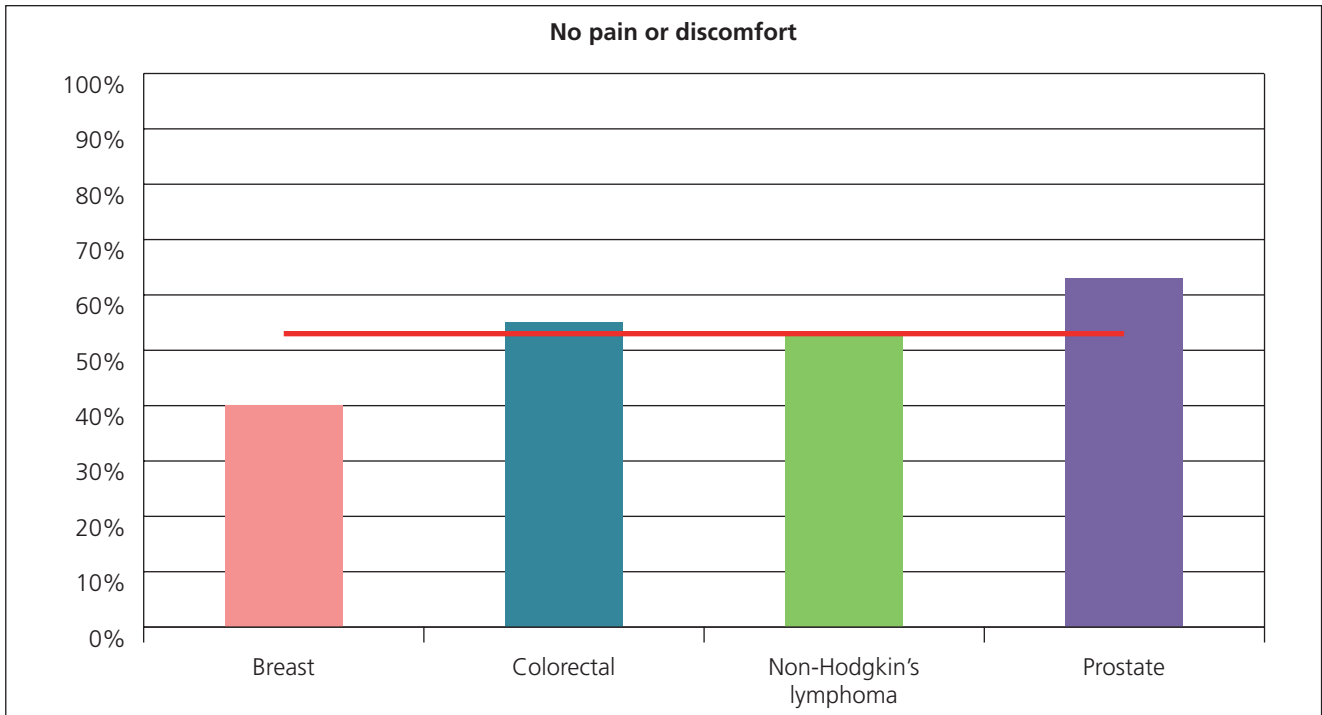


## Pain/discomfort

### Overall findings

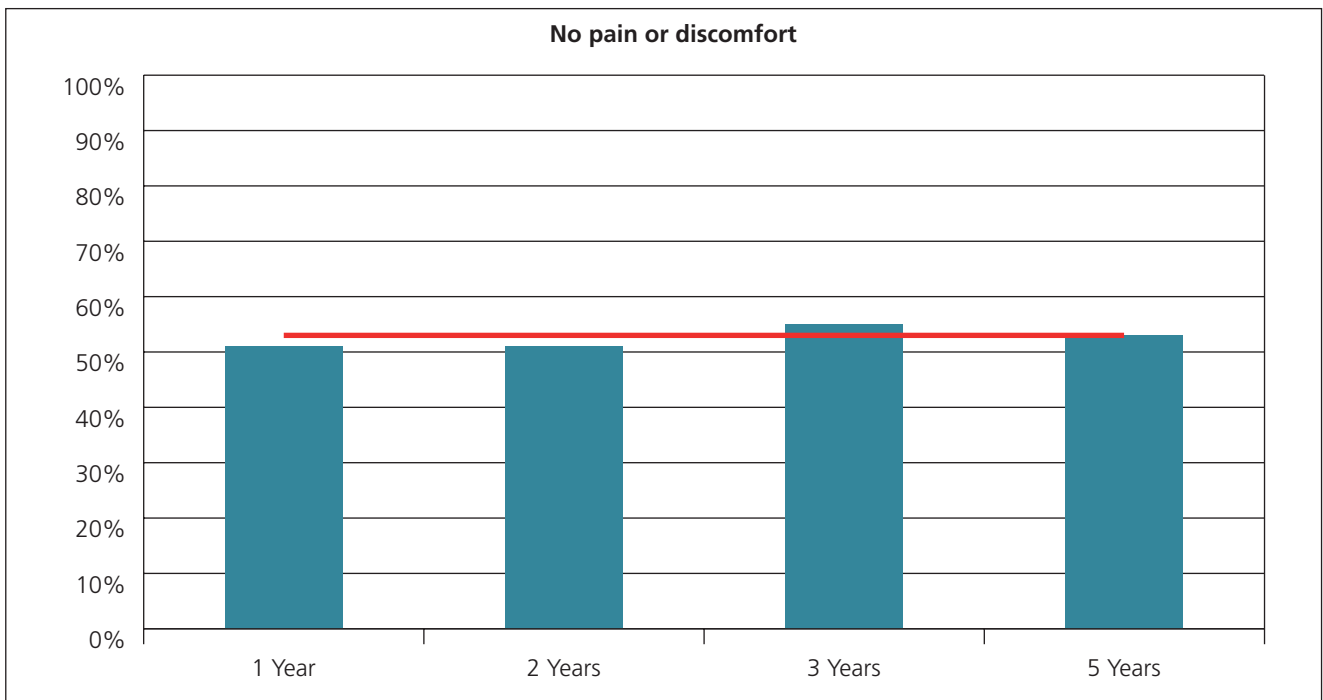
5.19 53% of patients said they had no pain or discomfort; 28% said they had slight pain or discomfort, 13% had moderate pain or discomfort, 5% had severe pain or discomfort and 1% had extreme pain or discomfort.

**Chart 5.9: Findings by Tumour Group**



5.20 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.10: Findings by Time Cohort**

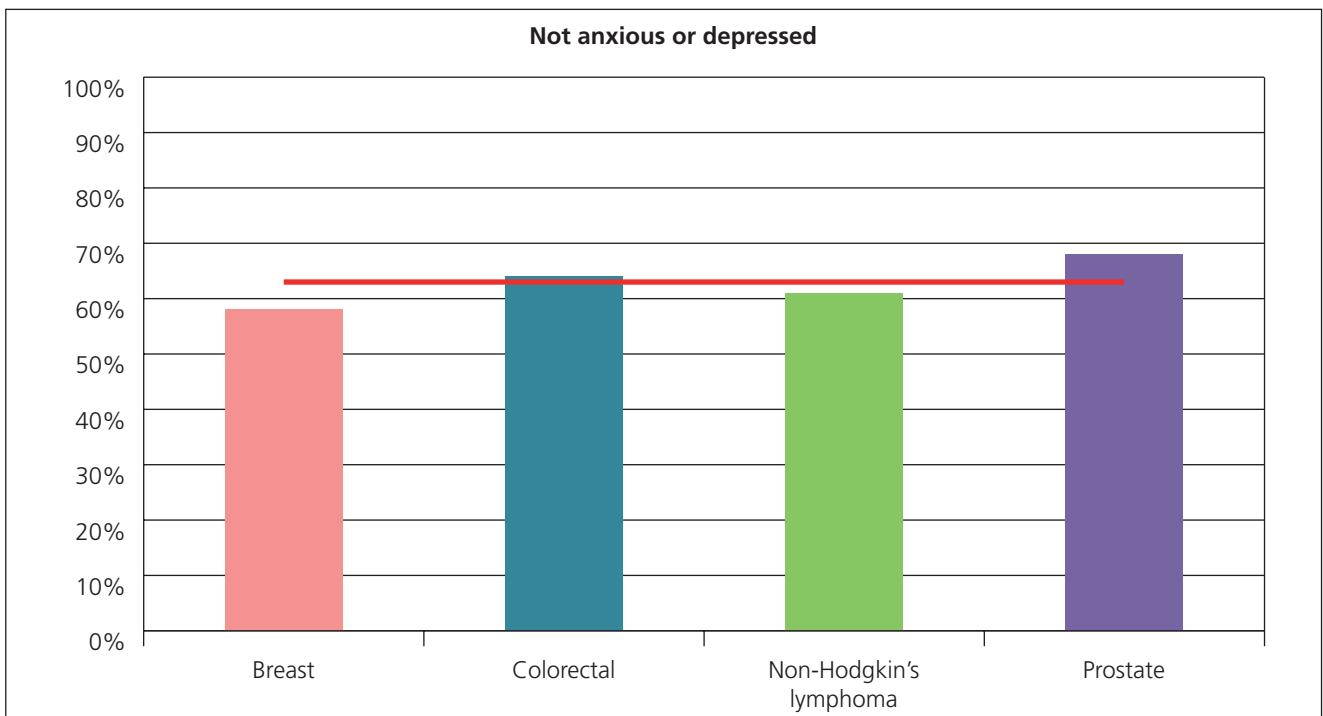


**Anxiety/depression**

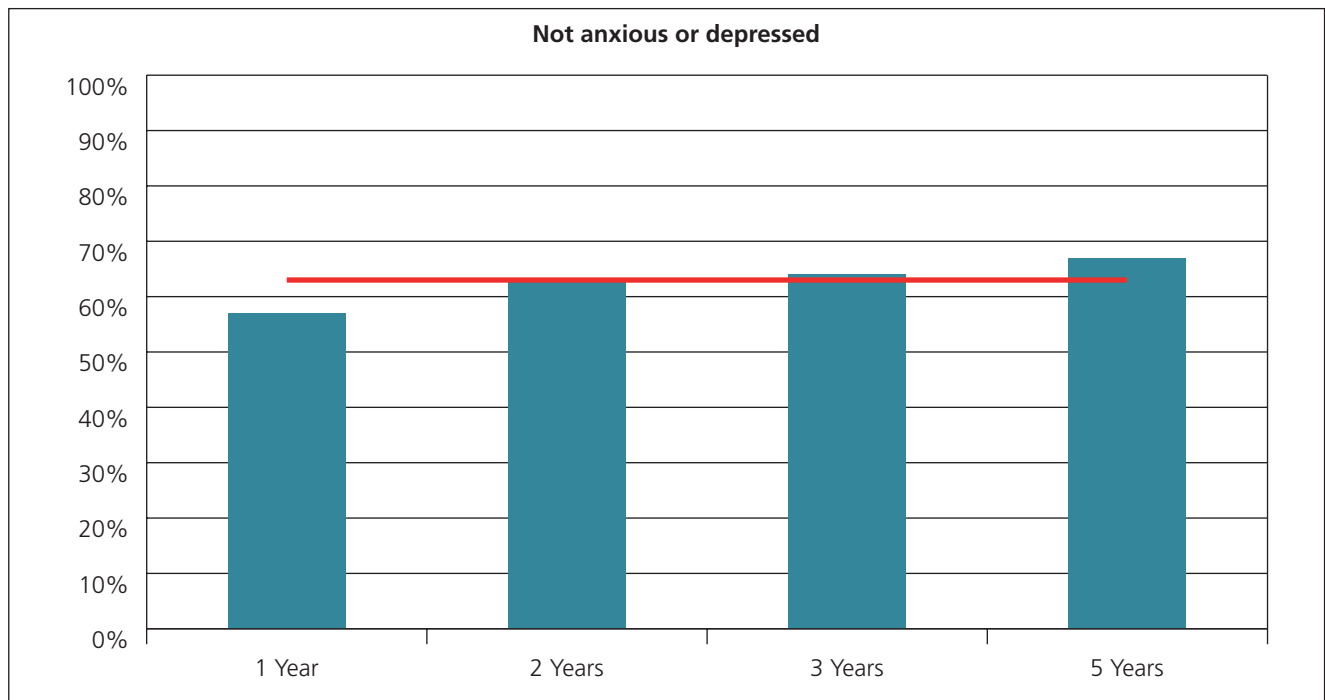
**Overall findings**

5.21 63% of patients said they were not anxious or depressed; 25% said they were slightly anxious or depressed, 10% were moderately anxious or depressed, 2% were severely anxious or depressed and 1% were extremely anxious or depressed.

**Chart 5.11: Findings by Tumour Group**



**Chart 5.12: Findings by Time Cohort**



5.22 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## Exercise

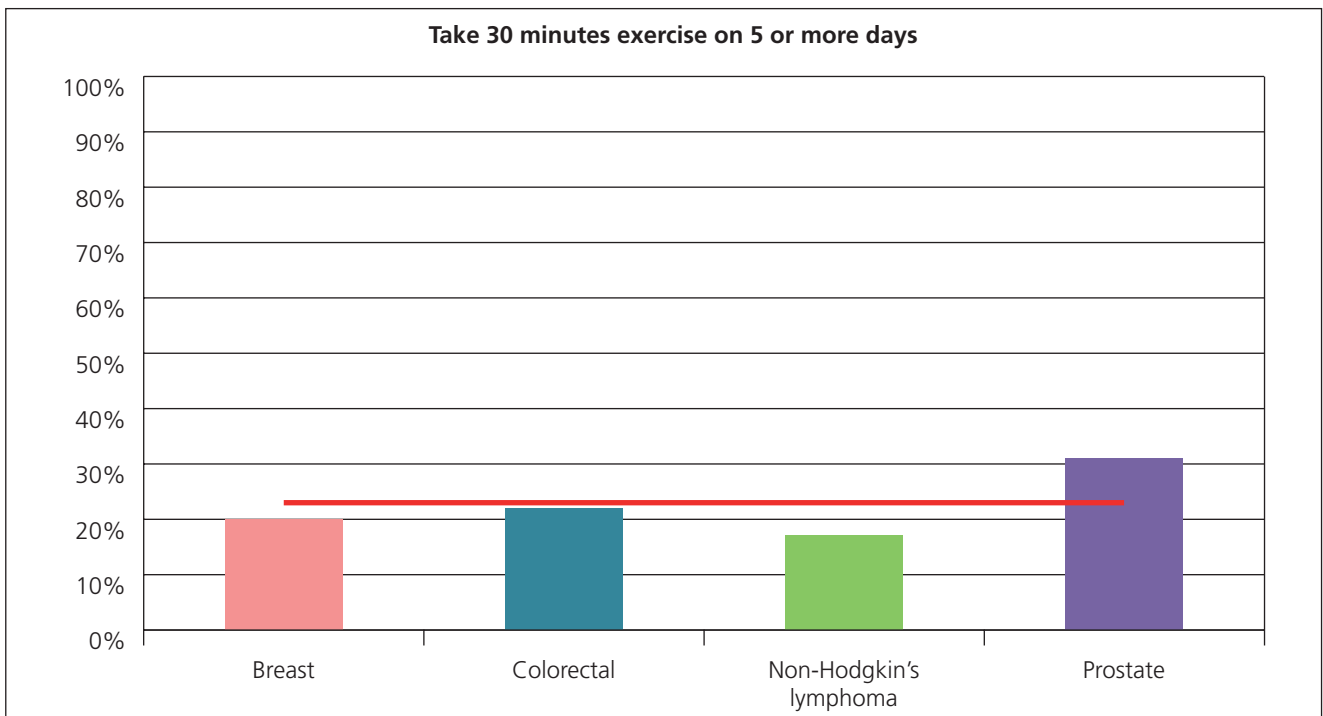
**In the last week, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate?**

### Overall findings

5.23 23% of patients said they did five days or more (8% did five days, 3% did six days and 11% did seven days); 10% said they did one day, 15% did 2 days, 14% did three days, and 8% did four days. 31% said they did no exercise in the past week.

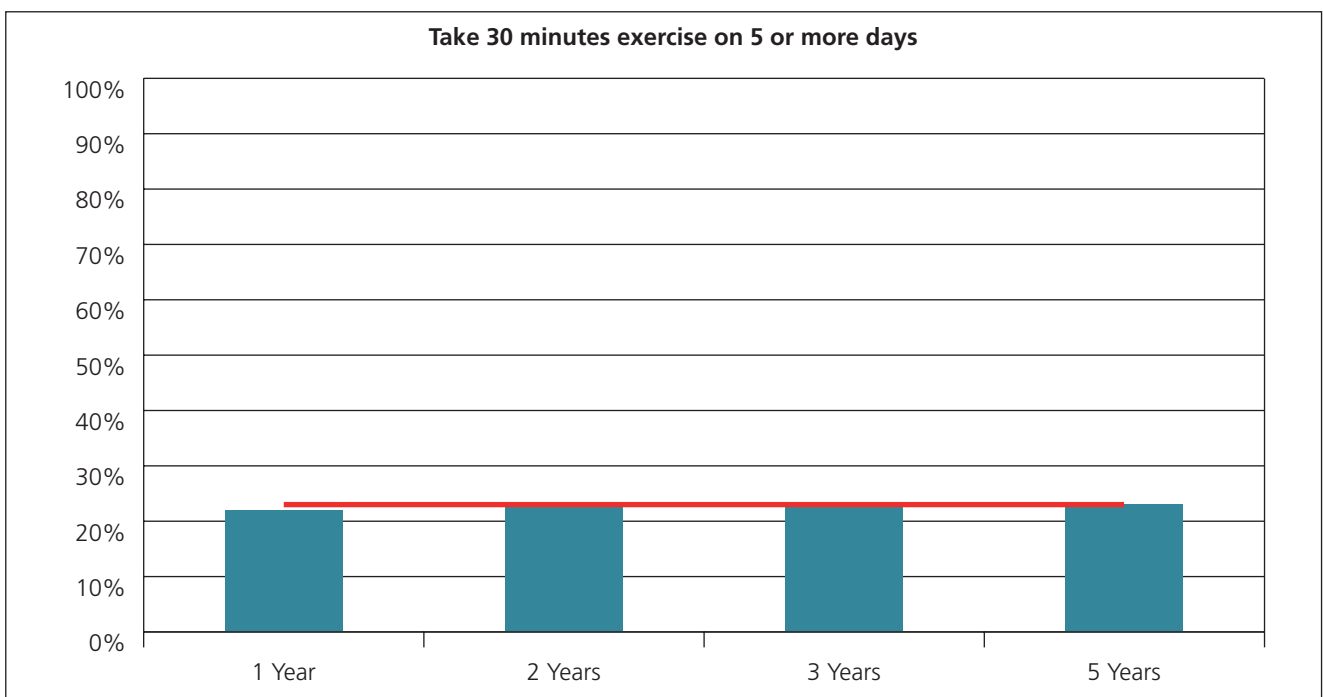


**Chart 5.13: Findings by Tumour Group**



5.24 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.14: Findings by Time Cohort**



## Your health and well being in the last month

5.25 The questions in this section of the survey were from the Social Difficulties Inventory and included an additional response option 'does not apply' which was added for the purposes of this questionnaire. The second set of questions were developed to address issues about fears and health problems that patients might experience.

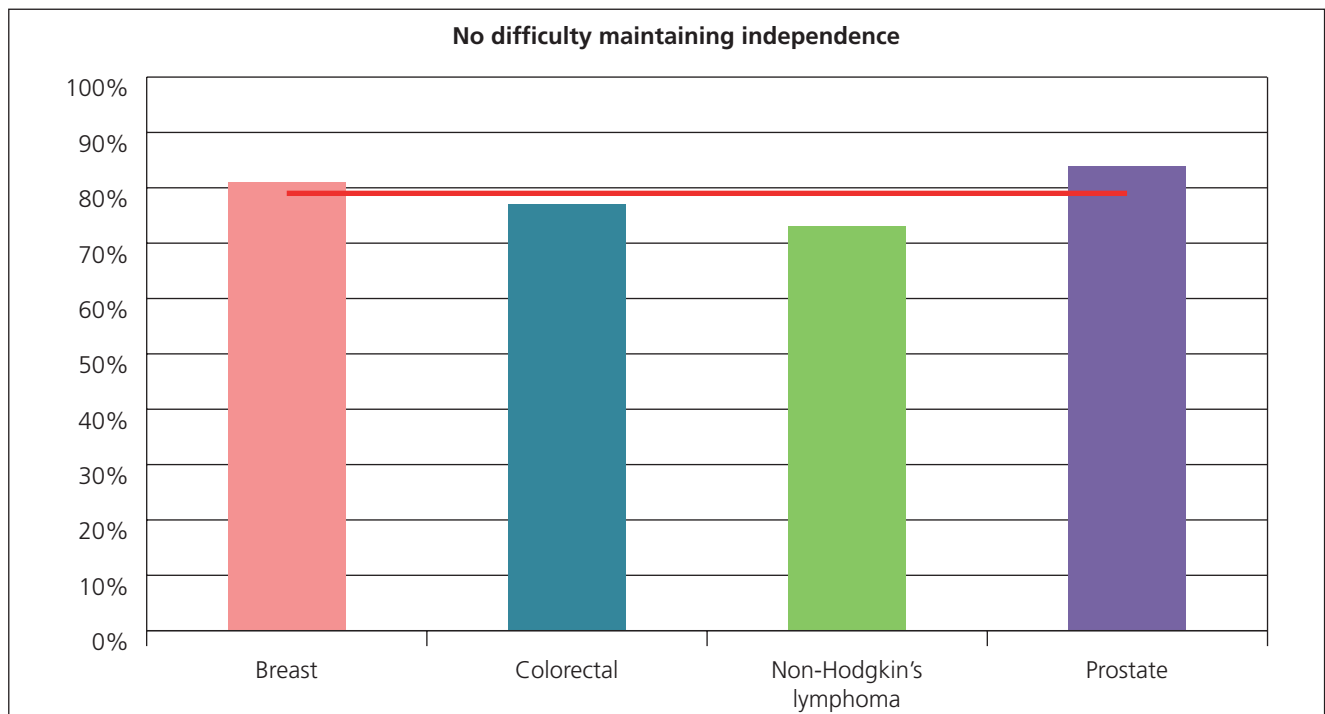
### Social Difficulties Inventory

#### Have you had any difficulty in maintaining your independence?

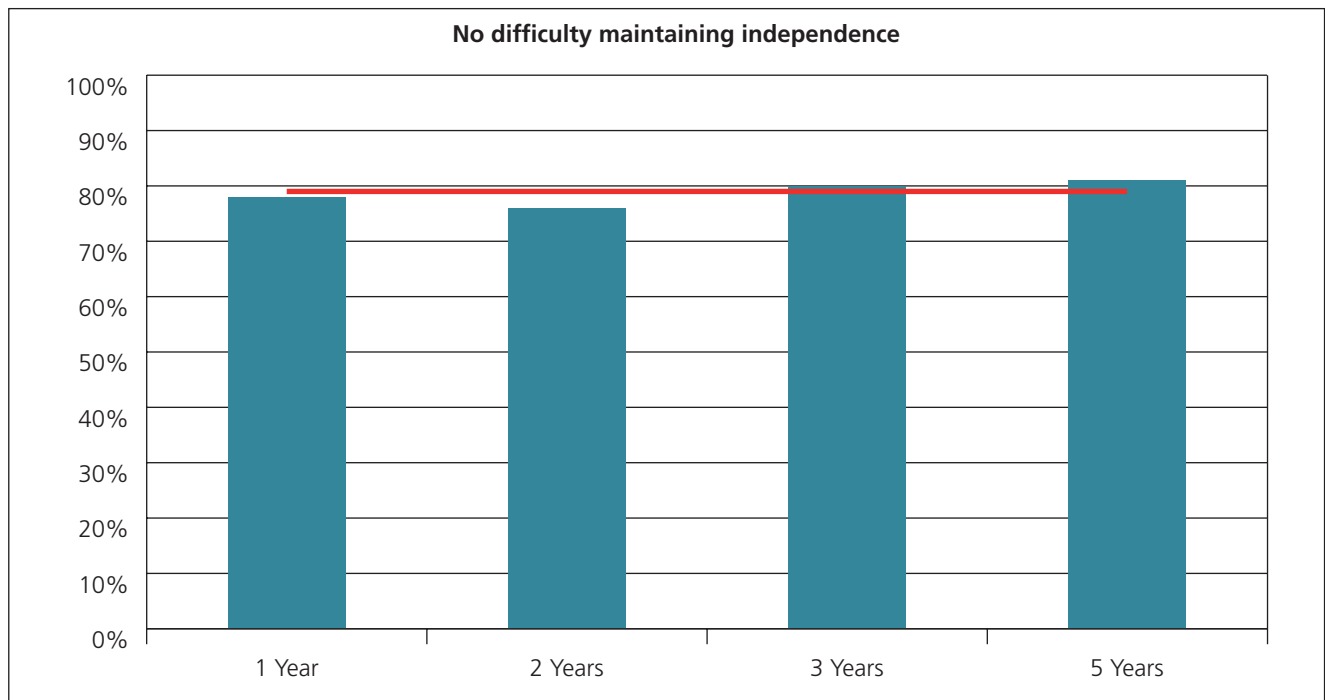
##### Overall findings

5.26 79% of patients said they had no difficulty maintaining their independence; 13% had a little difficulty, 5% said quite a bit, 3% said very much, 2% said this did not apply to them.

**Chart 5.15: Findings by Tumour Group**



**Chart 5.16: Findings by Time Cohort**

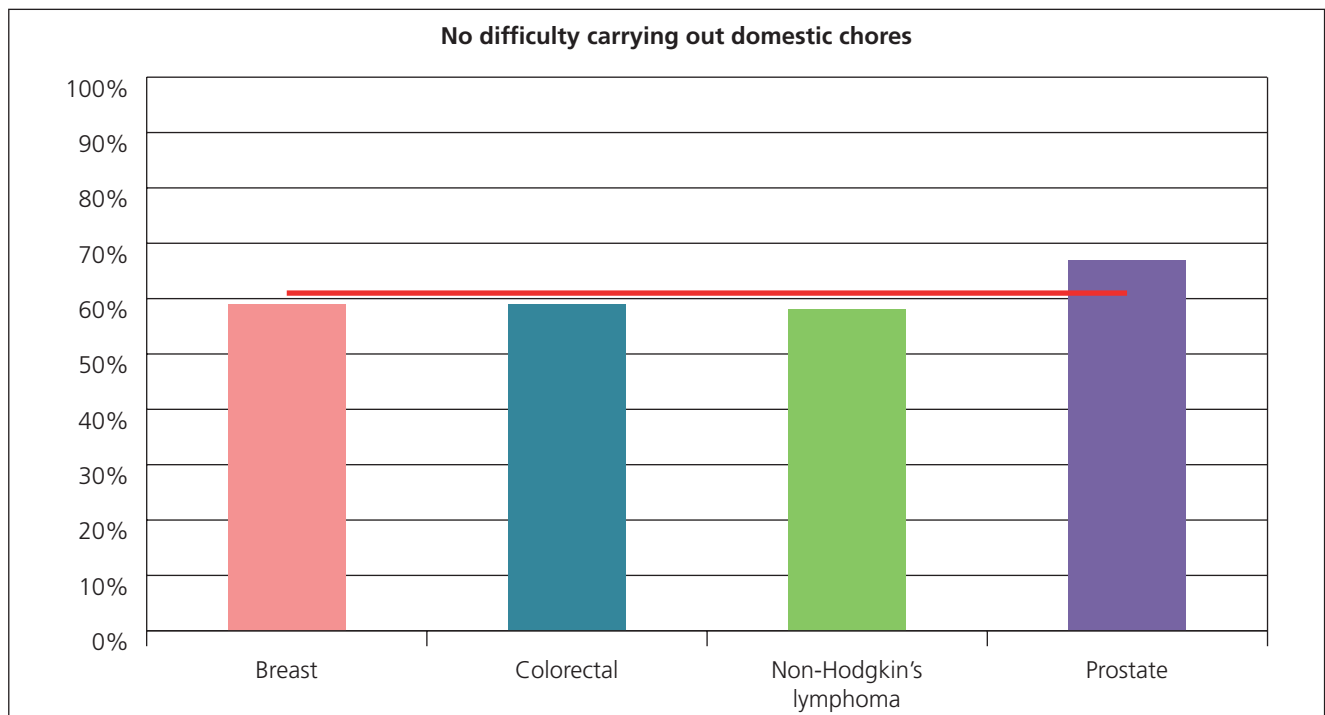


**Have you had any difficulty in carrying out your domestic chores?**

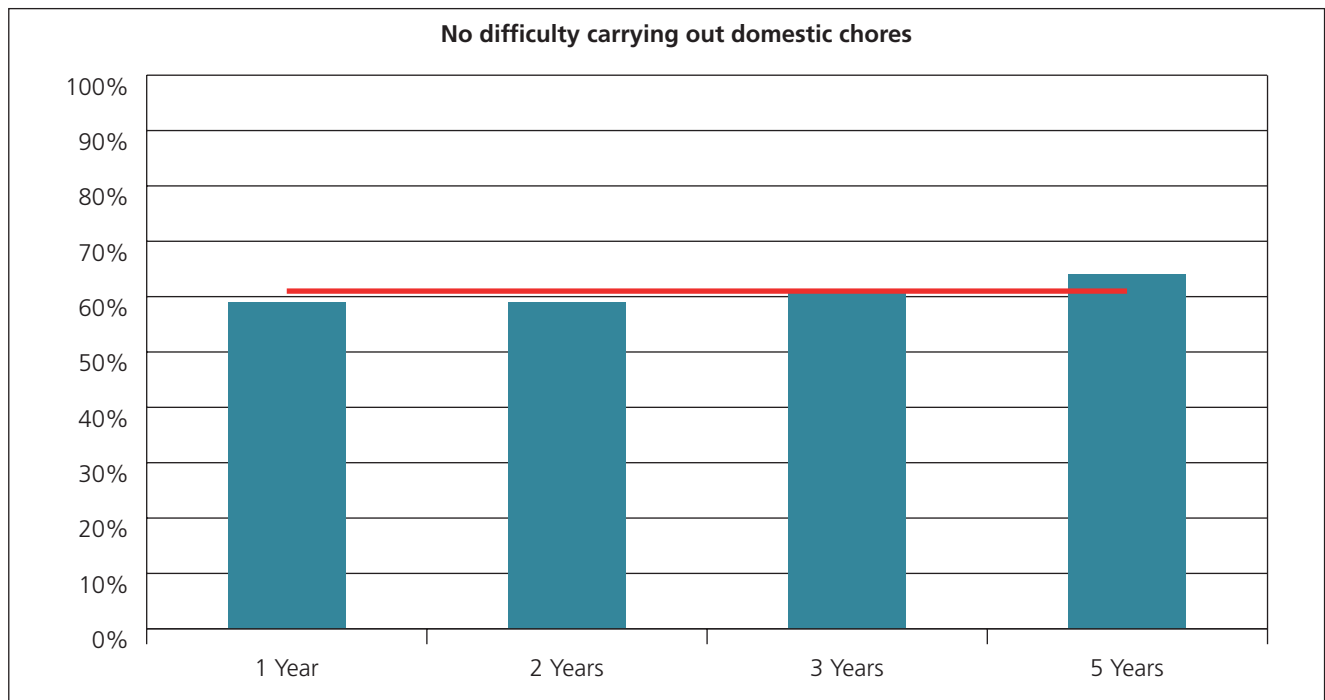
**Overall findings**

5.27 61% of patients said they had no difficulty carrying out their domestic chores; 22% had a little difficulty, 11% said quite a bit, 7% said very much, 2% said this did not apply to them.

**Chart 5.17: Findings by Tumour Group**



**Chart 5.18: Findings by Time Cohort**

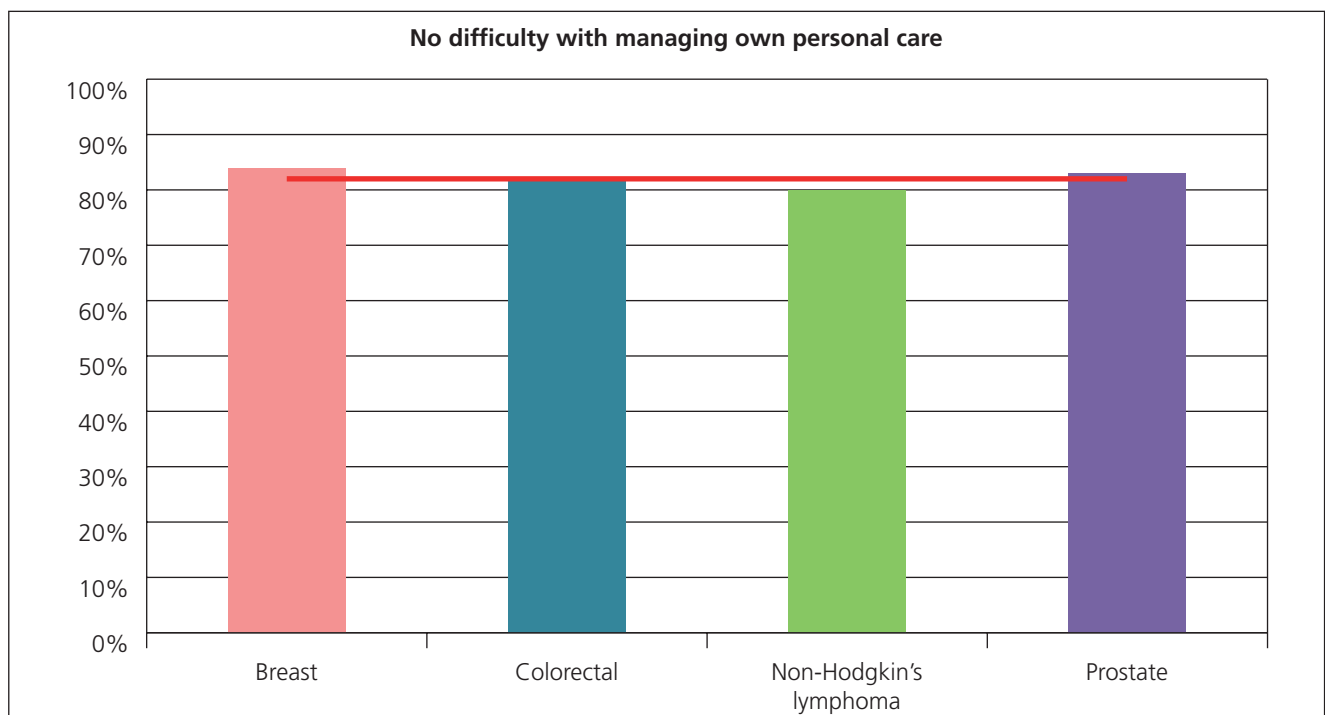


**Have you had any difficulty with managing your own personal care?**

**Overall findings**

5.28 82% of patients said they had no difficulty managing their own personal care; 11% had a little difficulty, 4% said quite a bit, 3% said very much, 1% said this did not apply to them.

**Chart 5.19: Findings by Tumour Group**



**Chart 5.20: Findings by Time Cohort**



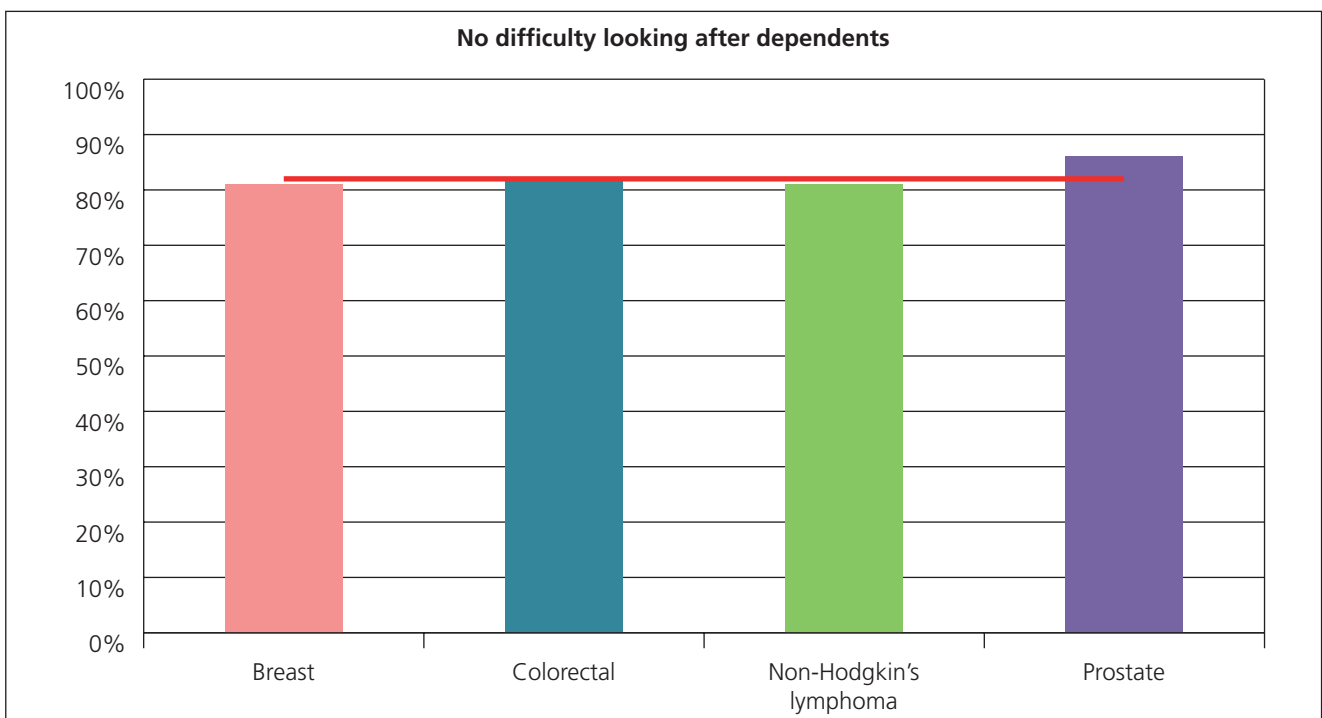
**Have you had any difficulty with looking after those who depend on you?**

**Overall findings**

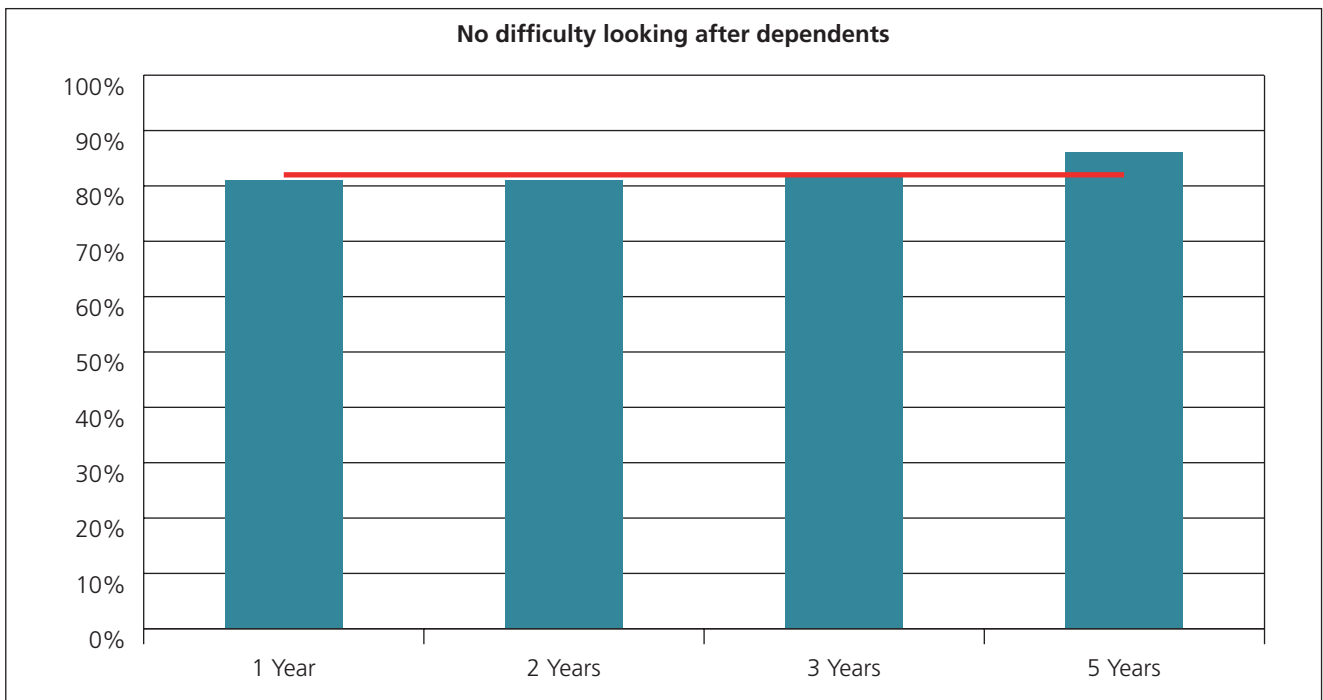
5.29 82% of patients said they had no difficulty looking after those who depended on them;

5.30 10% had a little difficulty, 4% said quite a bit, 3% said very much, 26% said this did not apply to them.

**Chart 5.21: Findings by Tumour Group**



**Chart 5.22: Findings by Time Cohort**



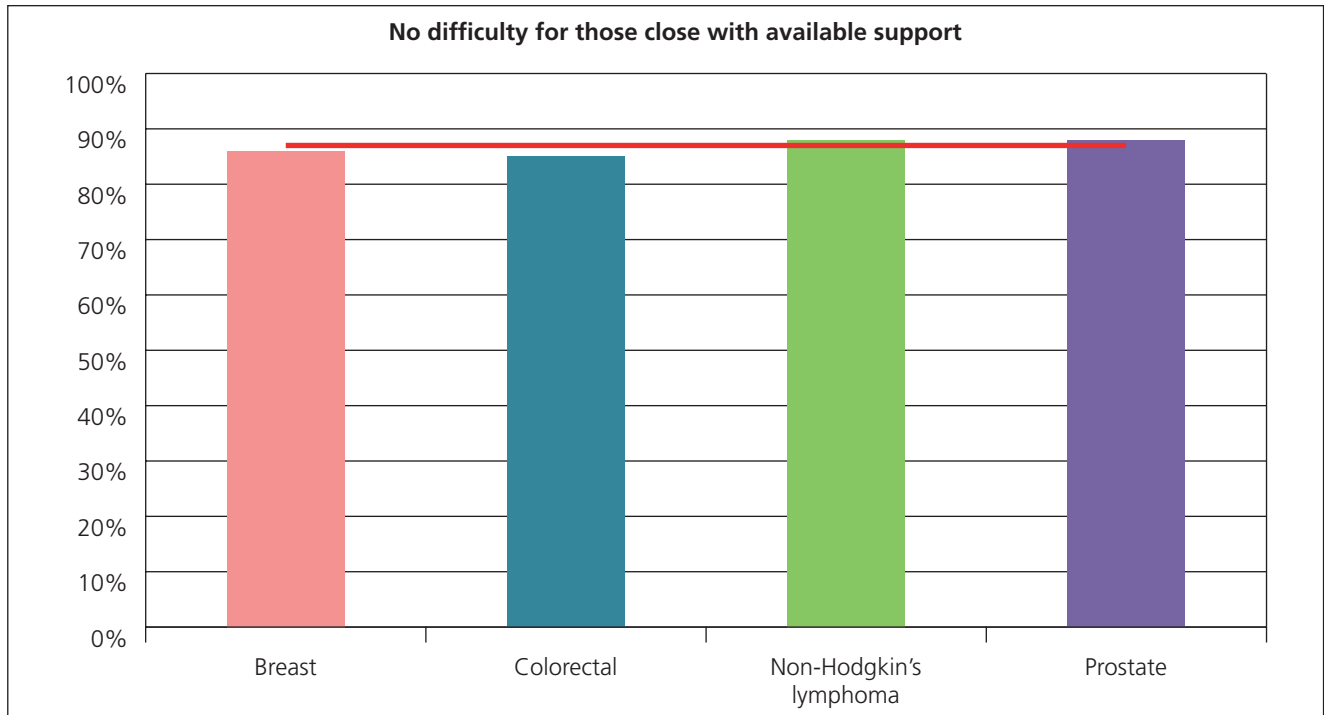
5.31 There were significant differences between the five year cohort and all other time cohorts.

**Have any of those close to you had any difficulty with the support available to them?**

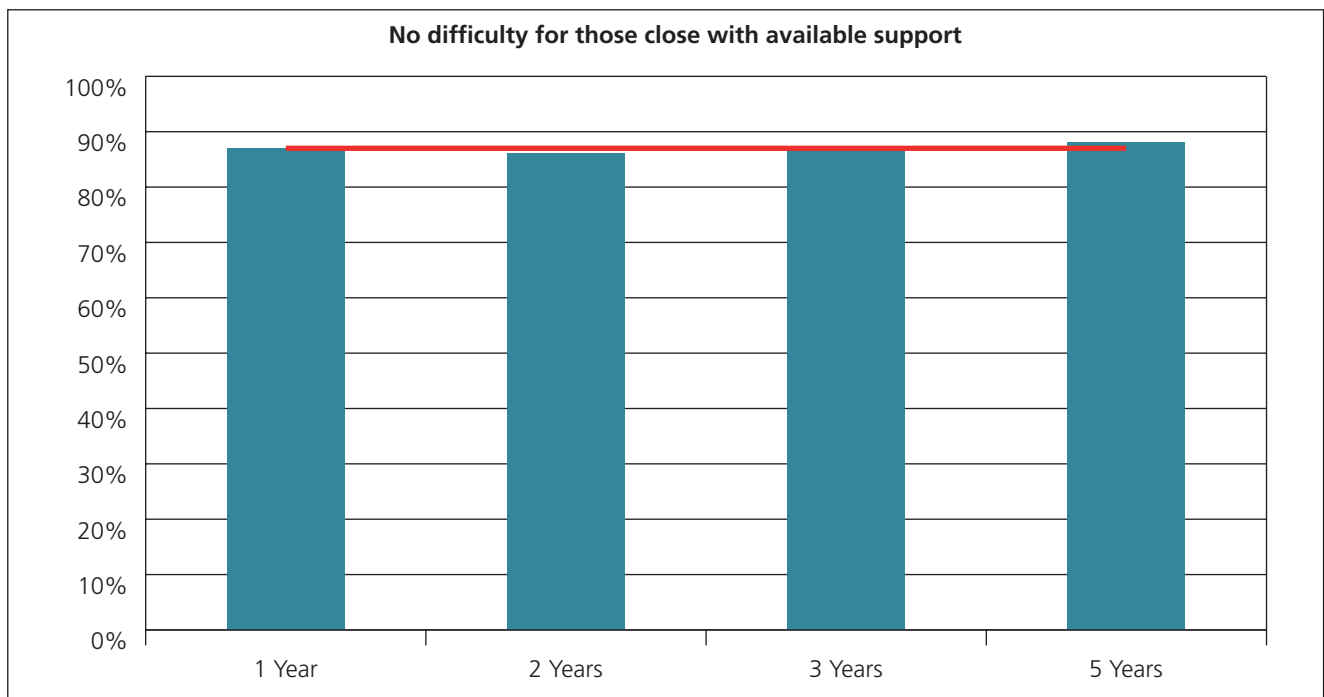
**Overall findings**

5.32 87% of patients said those close to them had had no difficulty with the support available to them; 7% had a little difficulty, 3% said quite a bit, 3% said very much, 30% said this did not apply to them.

**Chart 5.23: Findings by Tumour Group**



**Chart 5.24: Findings by Time Cohort**

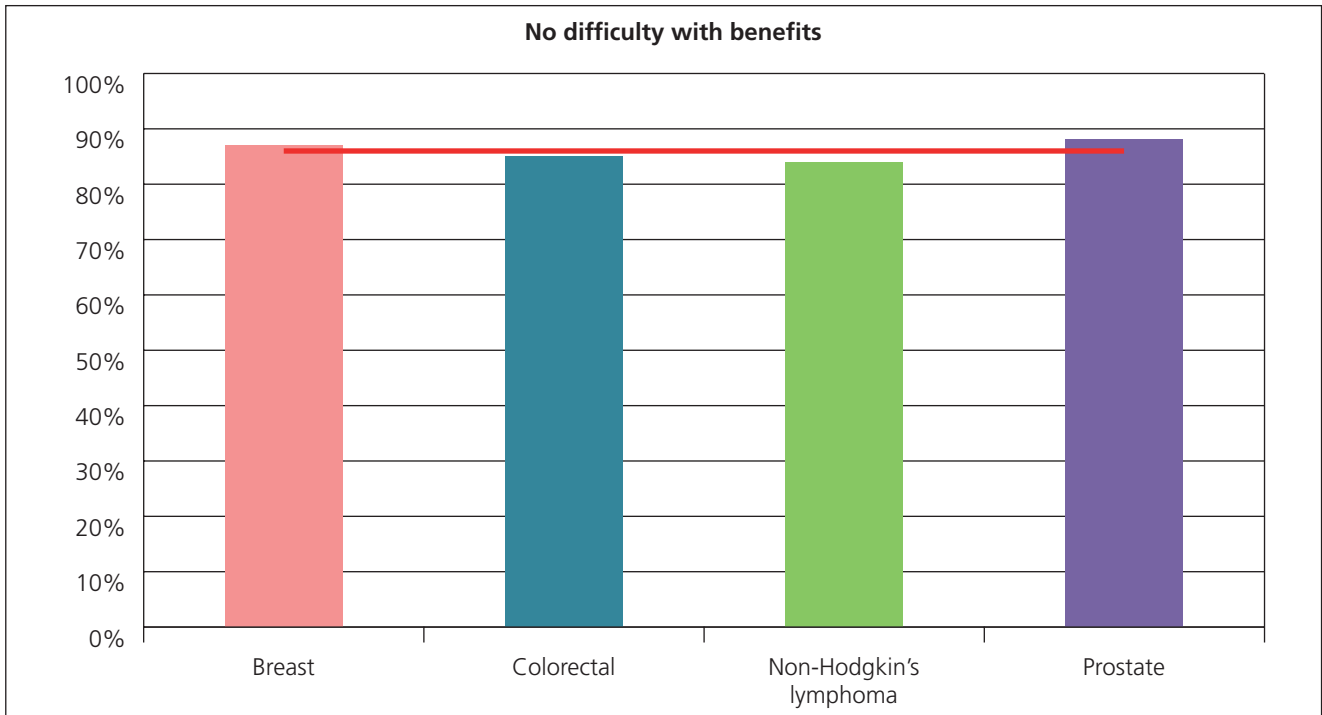


## Have you had any difficulty with benefits?

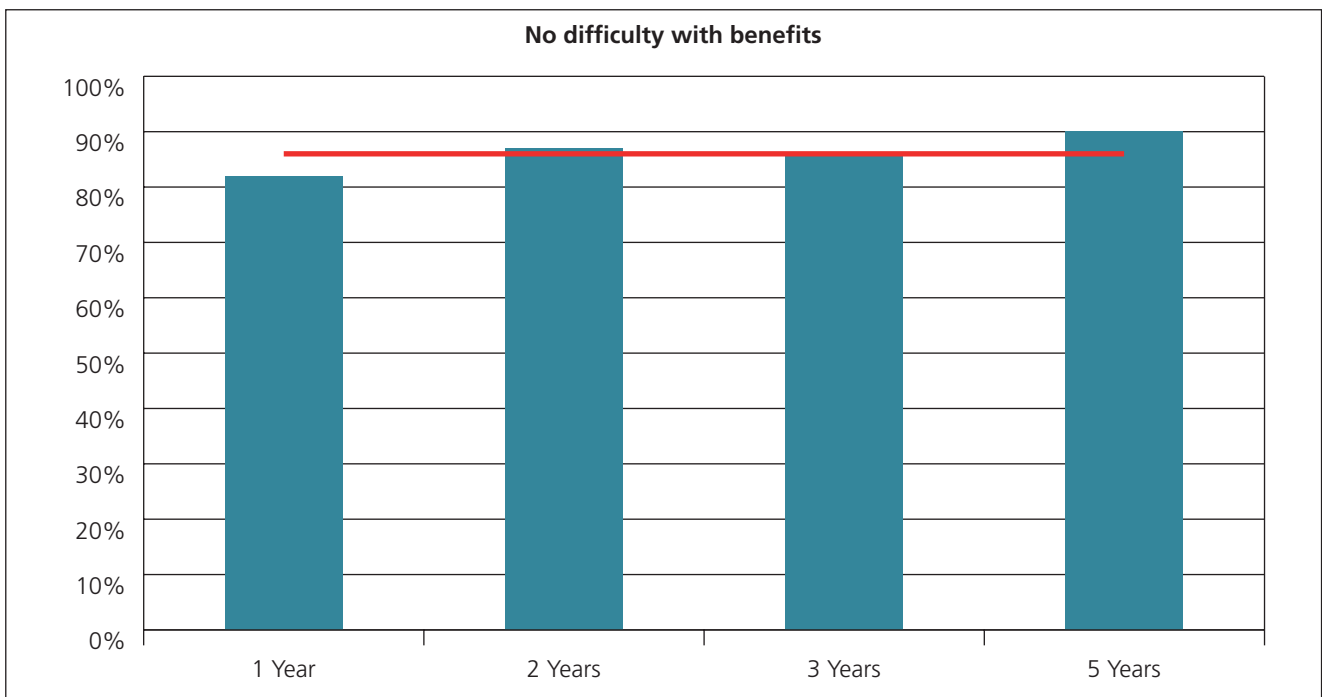
### Overall findings

5.33 86% of patients said they had no difficulty with benefits; 6% had a little difficulty, 3% said quite a bit, 5% said very much, 40% said this did not apply to them.

**Chart 5.25: Findings by Tumour Group**



**Chart 5.26: Findings by Time Cohort**



5.34 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

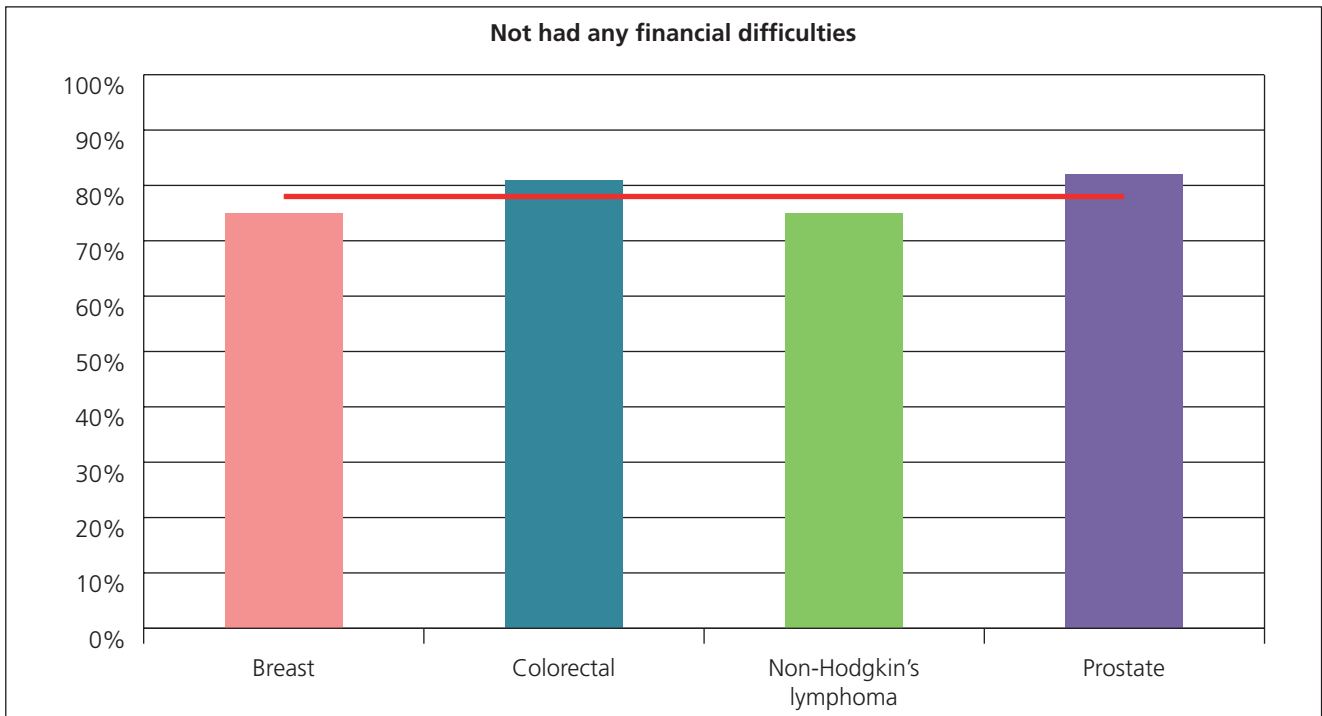


## Have you had any financial difficulties?

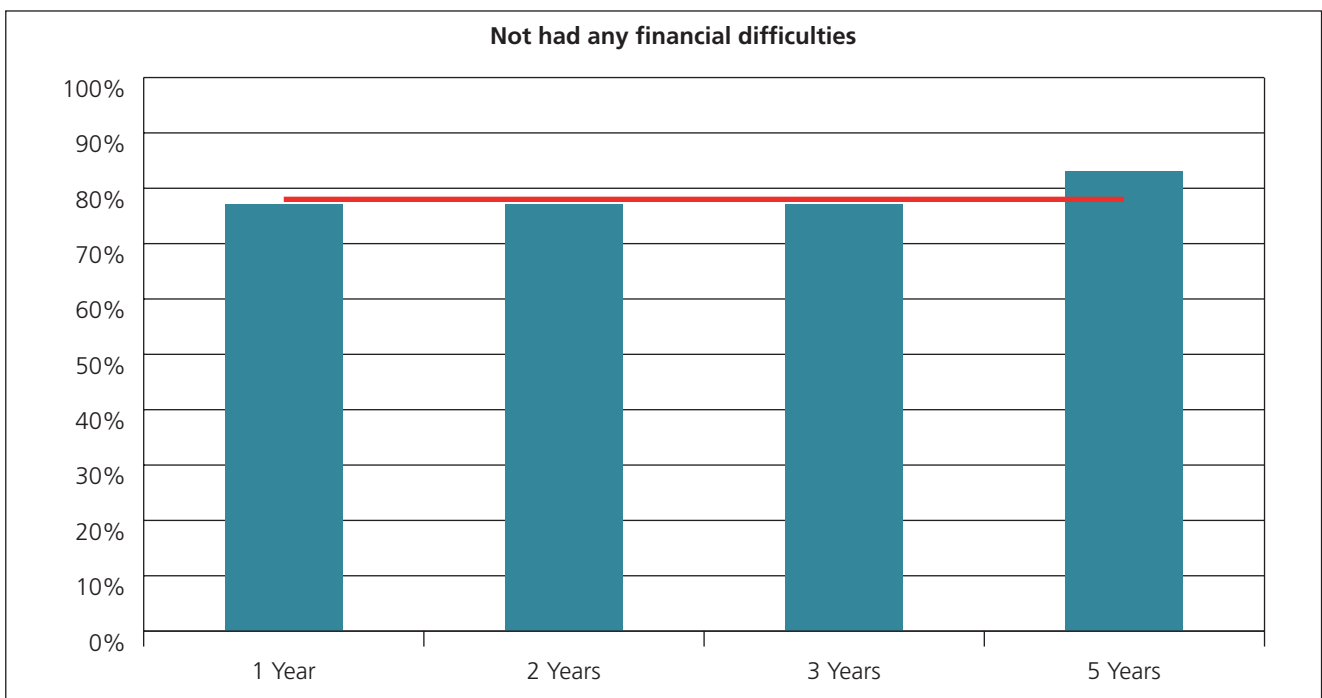
### Overall findings

5.35 78% of patients said they had no financial difficulties; 13% had a little difficulty, 4% said quite a bit, 4% said very much, 13% said this did not apply to them.

**Chart 5.27: Findings by Tumour Group**



**Chart 5.28: Findings by Time Cohort**

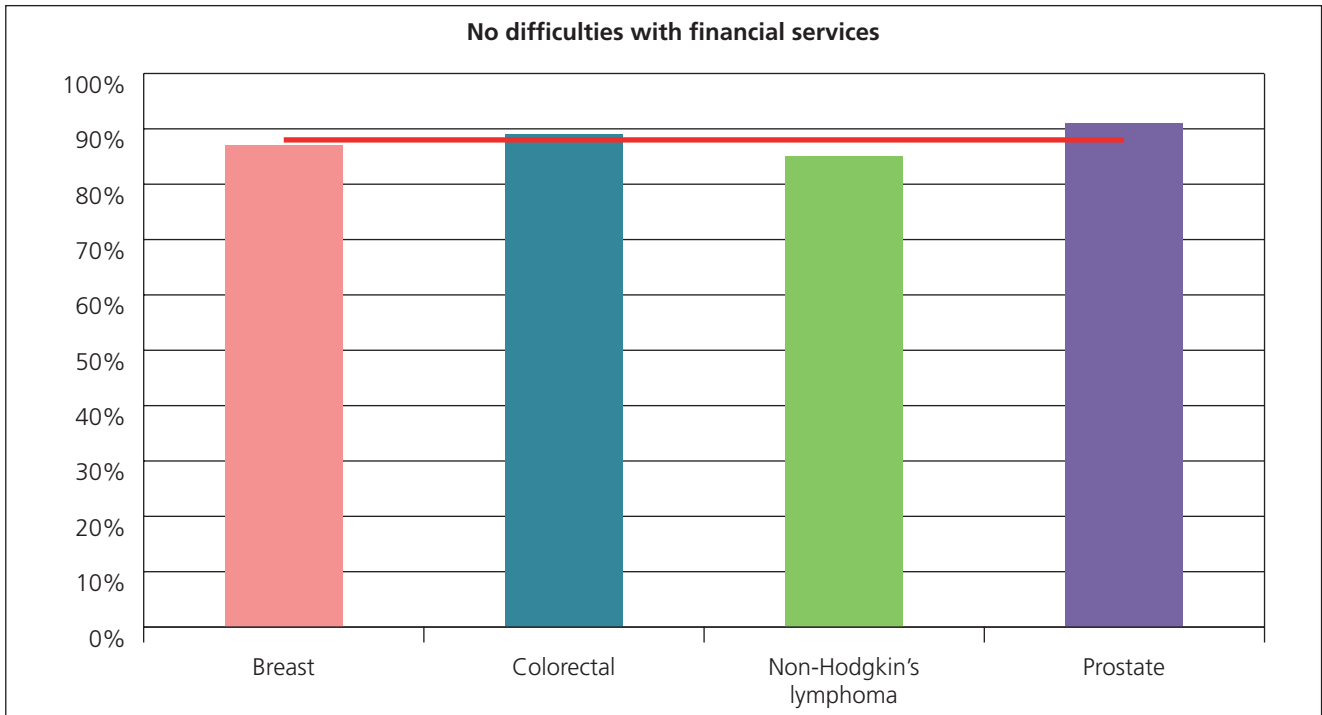


## Have you had any difficulty with financial services?

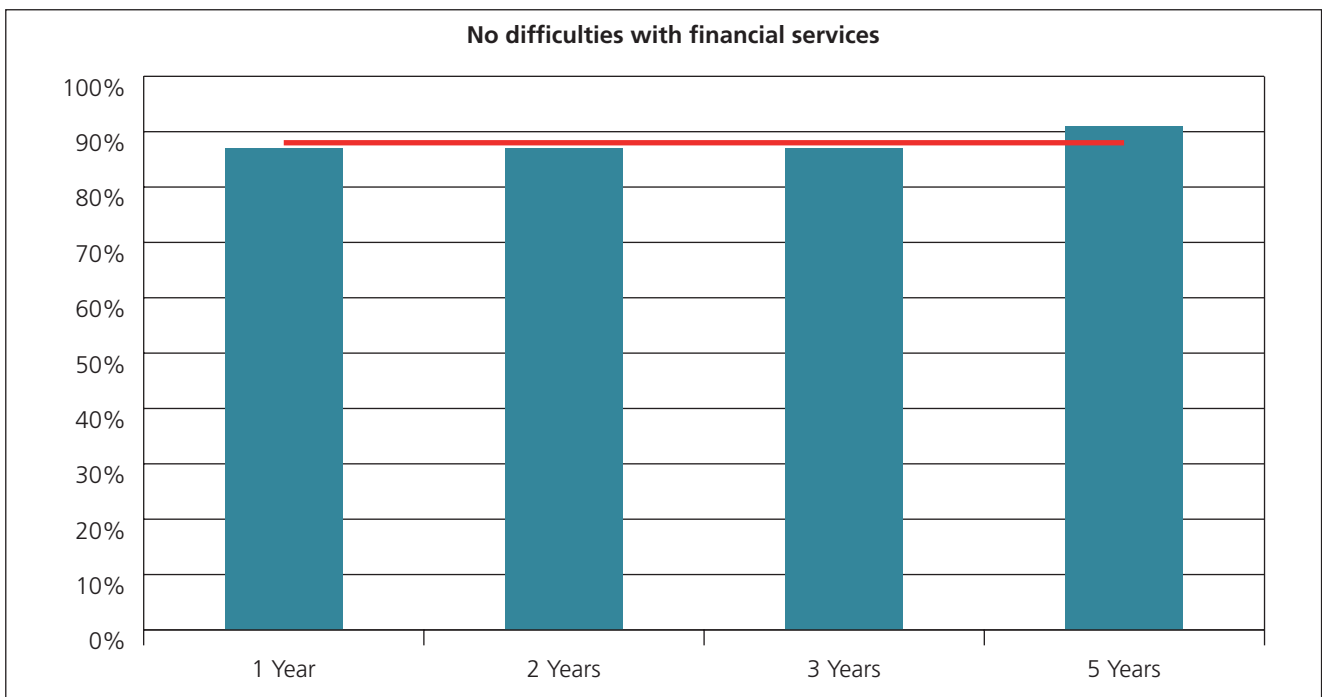
### Overall findings

5.36 88% of patients said they had no difficulty with financial services; 7% had a little difficulty, 2% said quite a bit, 3% said very much, 23% said this did not apply to them.

**Chart 5.29: Findings by Tumour Group**



**Chart 5.30: Findings by Time Cohort**



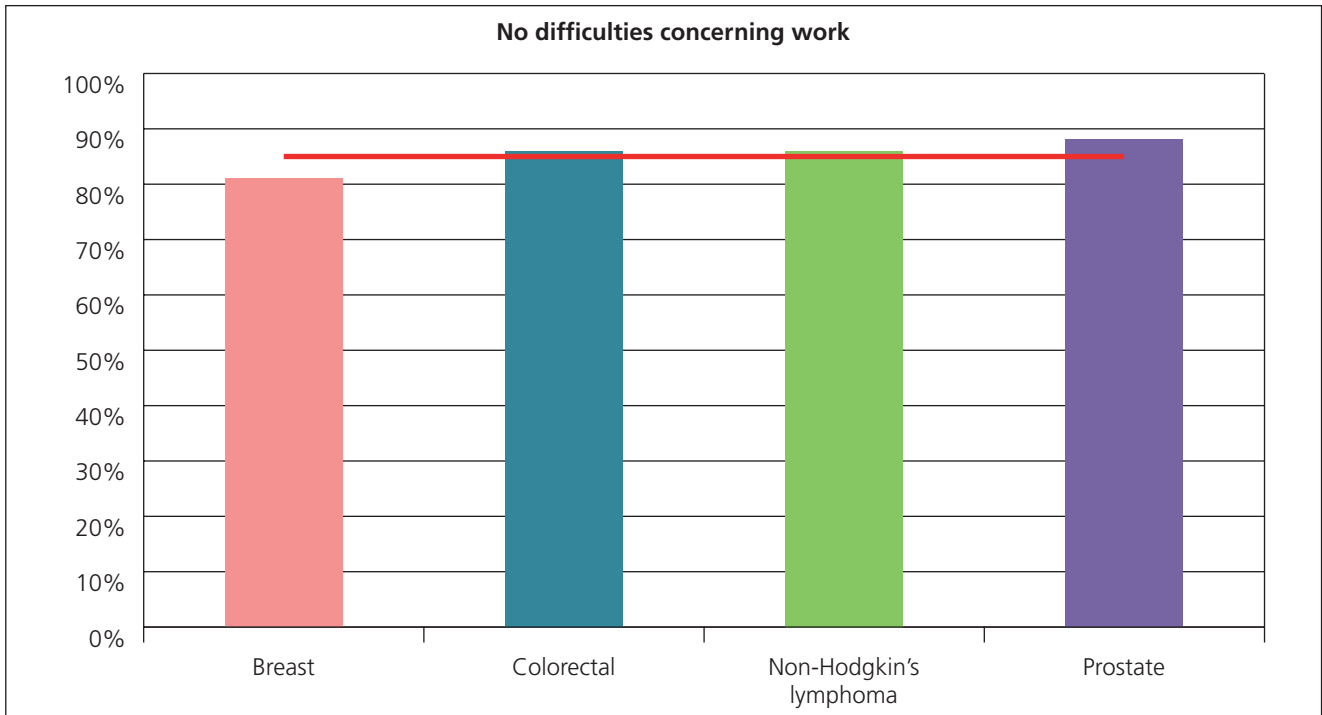
5.37 There were significant differences between the five year cohort and all other time cohorts.

## Have you had any difficulty concerning your work?

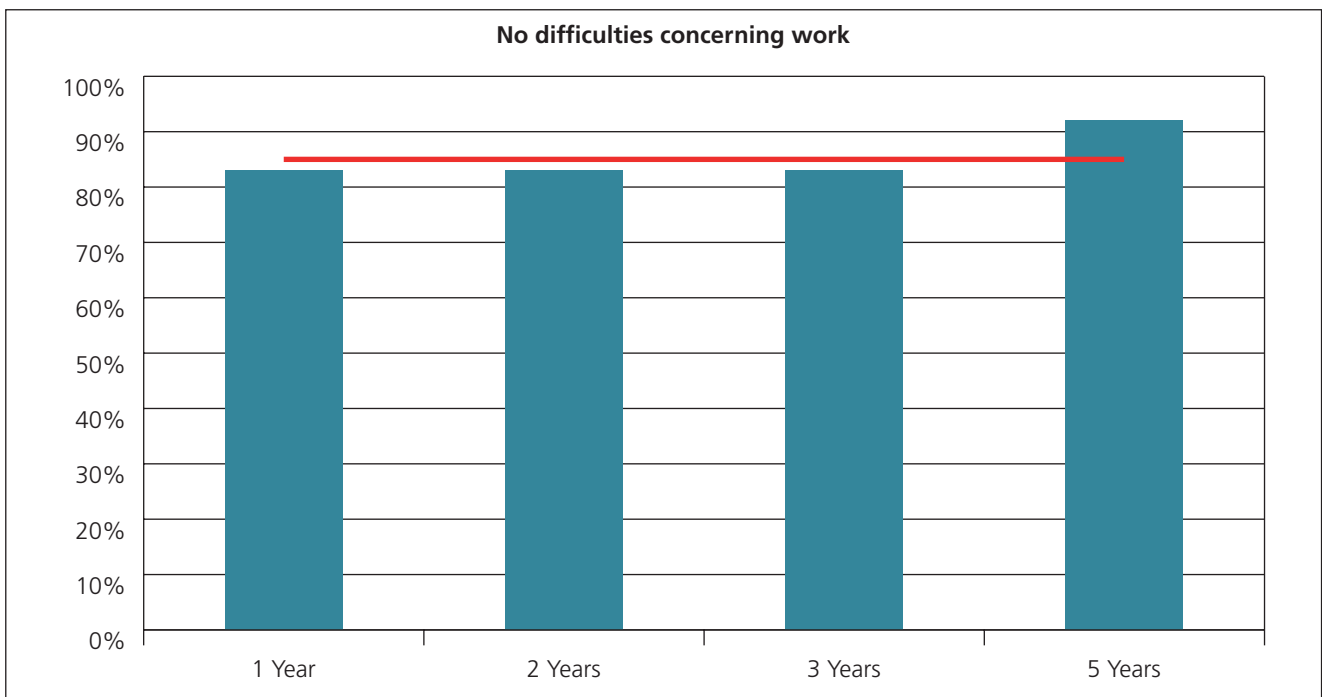
### Overall findings

5.38 85% of patients said they had no difficulty concerning their work; 9% had a little difficulty, 3% said quite a bit, 3% said very much, 47% said this did not apply to them.

**Chart 5.31: Findings by Tumour Group**



**Chart 5.32: Findings by Time Cohort**



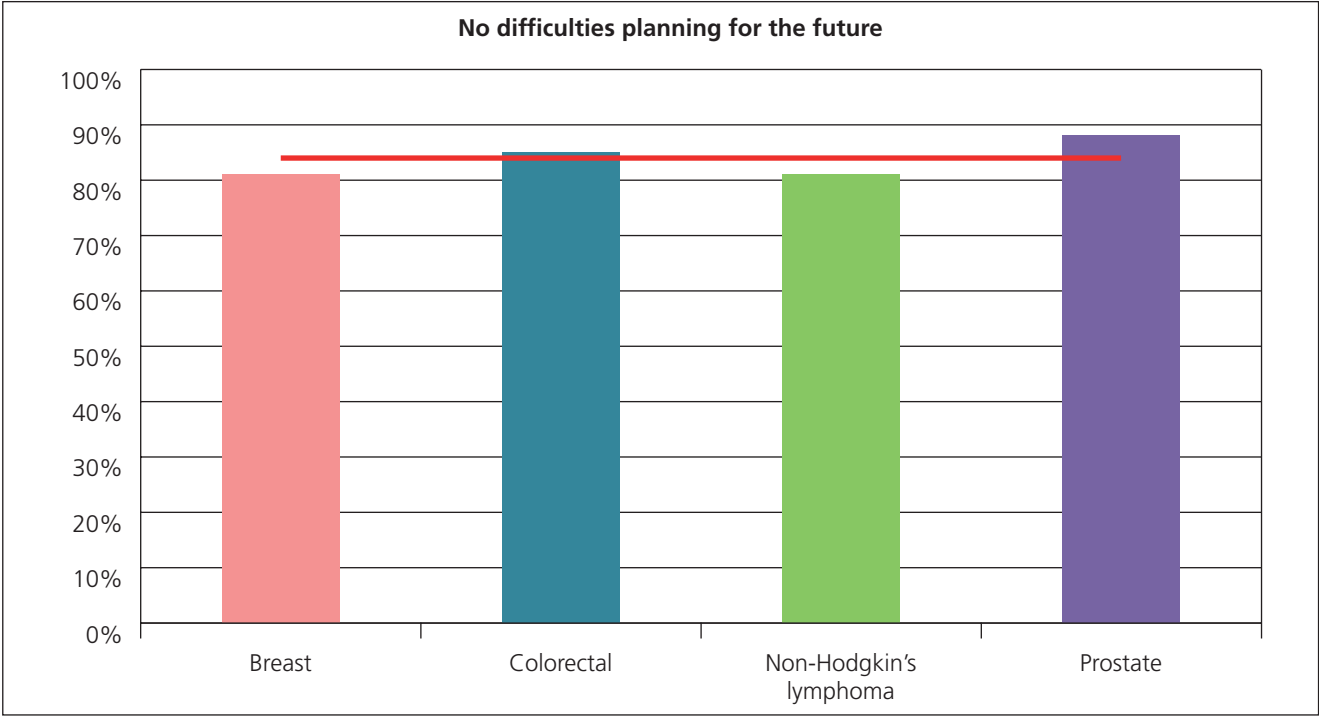
5.39 There were significant differences between the five year cohort and all other time cohorts.

**Have you had any difficulty with planning your own or your family's future?**

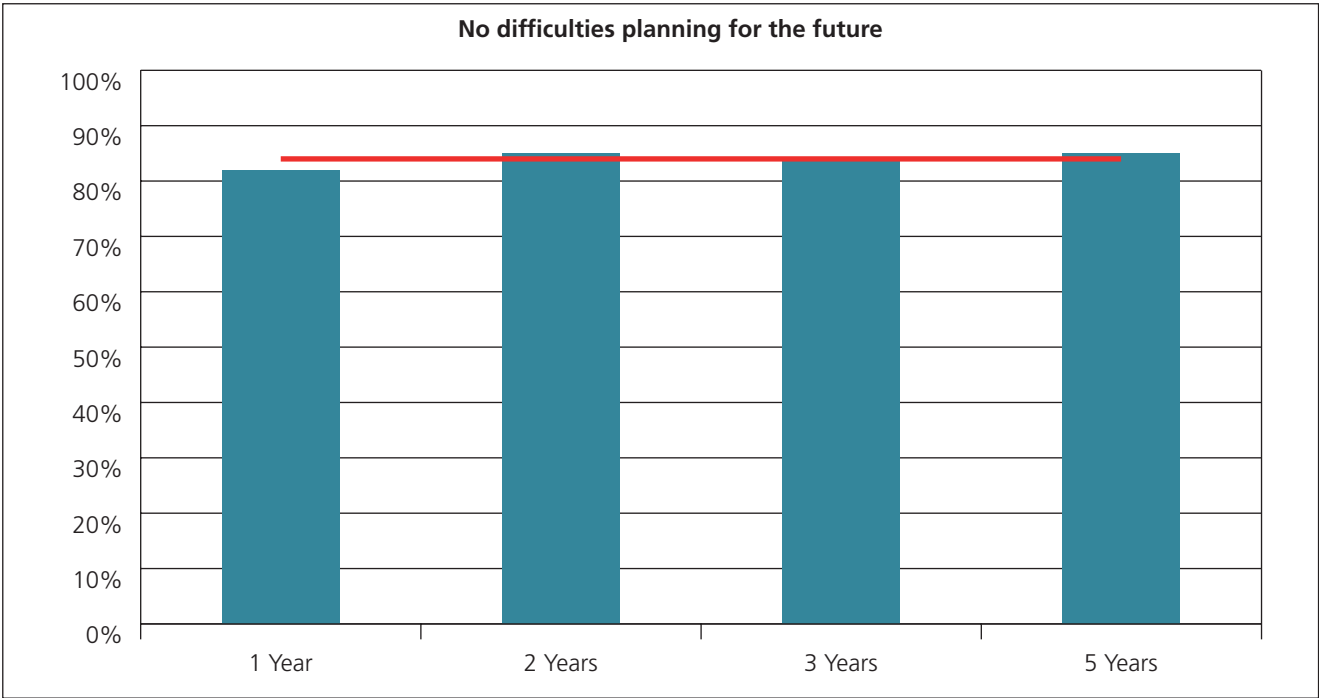
**Overall findings**

5.40 84% of patients said they had no difficulty with planning the future; 10% had a little difficulty, 3% said quite a bit, 3% said very much, 26% said this did not apply to them.

**Chart 5.33: Findings by Tumour Group**



**Chart 5.34: Findings by Time Cohort**

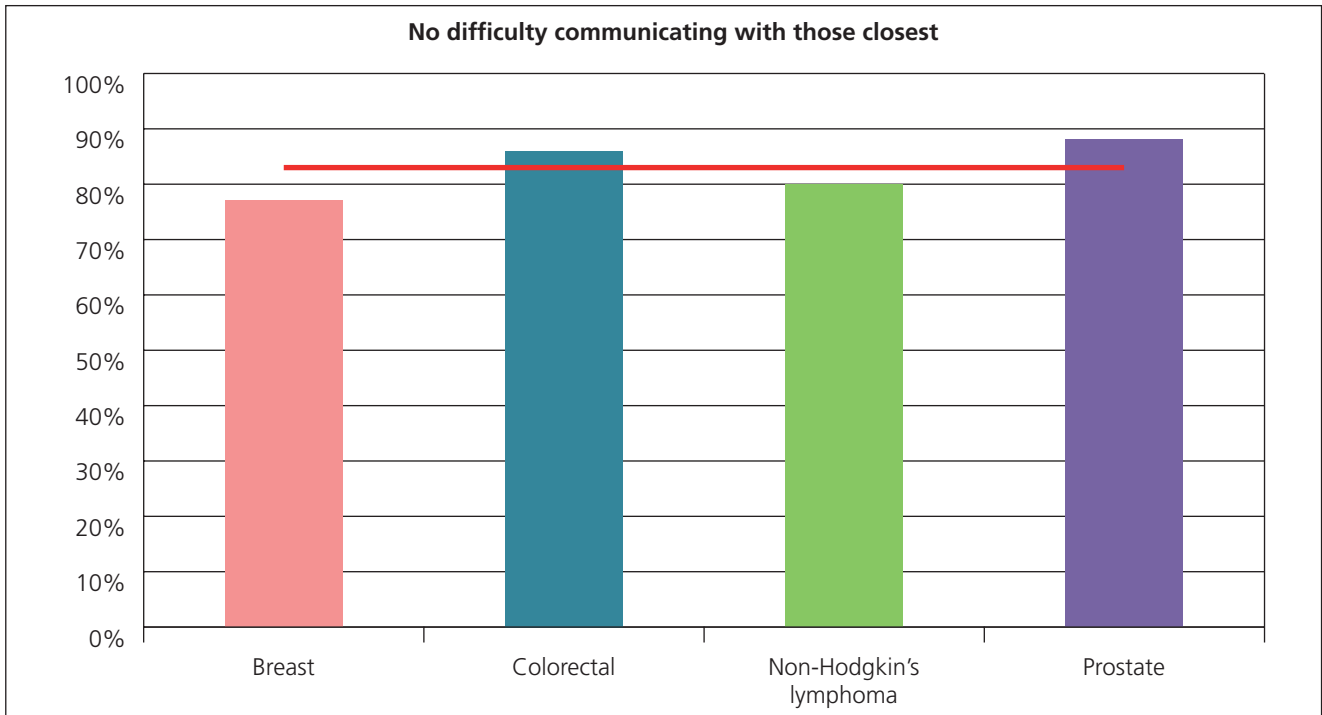


## Have you had any difficulty with communicating with those closest to you?

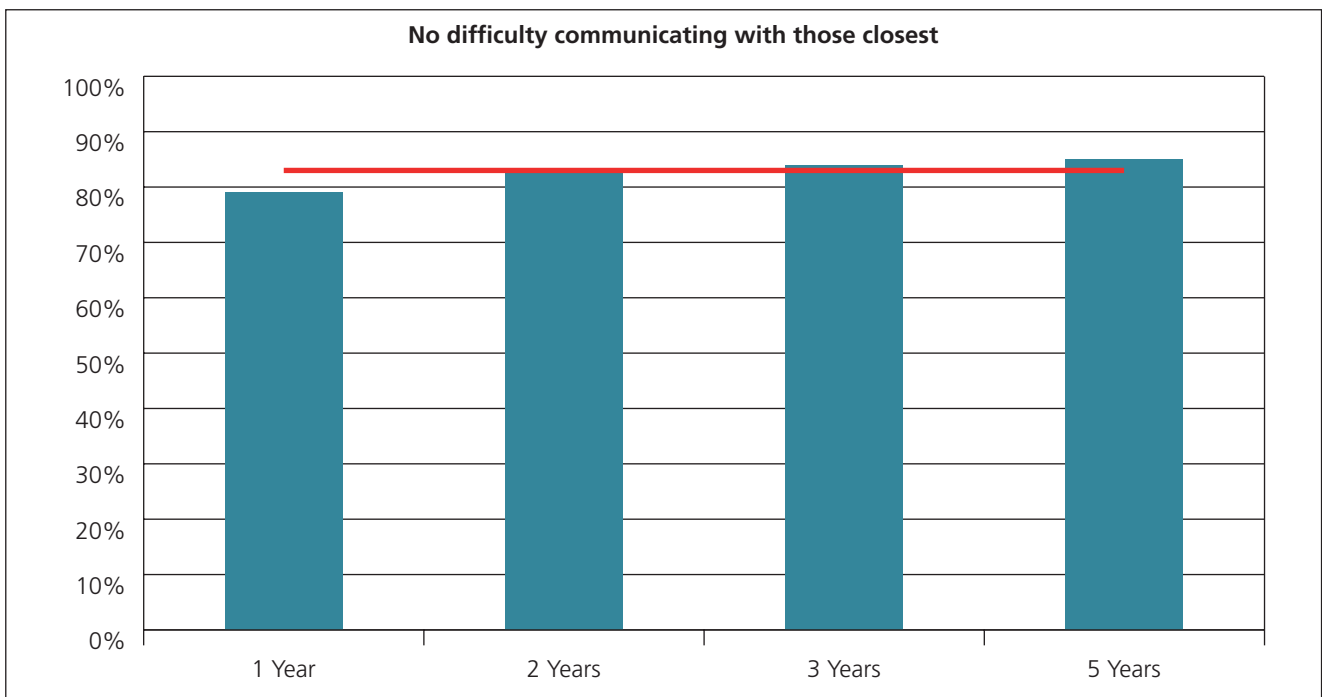
### Overall findings

5.41 83% of patients said they had no difficulty communicating with those closest to them; 12% had a little difficulty, 4% said quite a bit, 2% said very much, 3% said this did not apply to them.

**Chart 5.35: Findings by Tumour Group**



**Chart 5.36: Findings by Time Cohort**



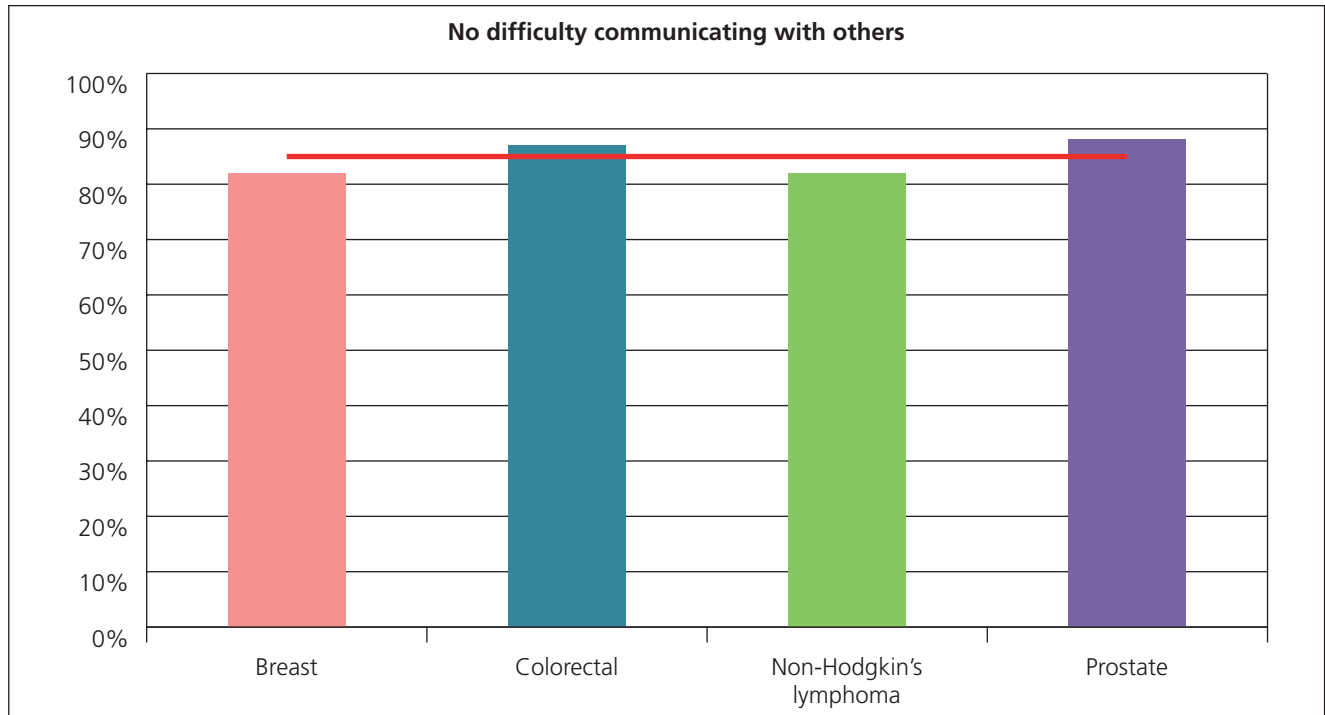
5.42 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## Have you had any difficulty with communicating with others?

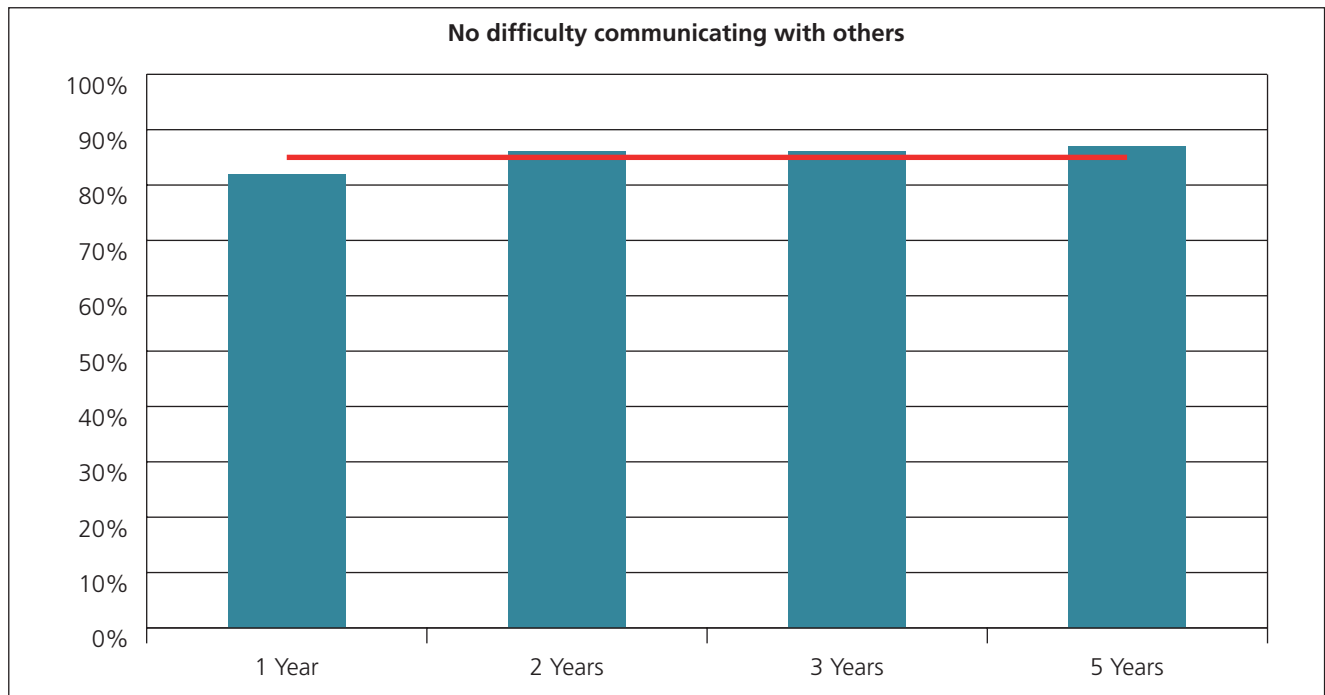
### Overall findings

5.43 85% of patients said they had no difficulty communicating with others; 11% had a little difficulty, 3% said quite a bit, 1% said very much, 2% said this did not apply to them.

**Chart 5.37: Findings by Tumour Group**



**Chart 5.38: Findings by Time Cohort**



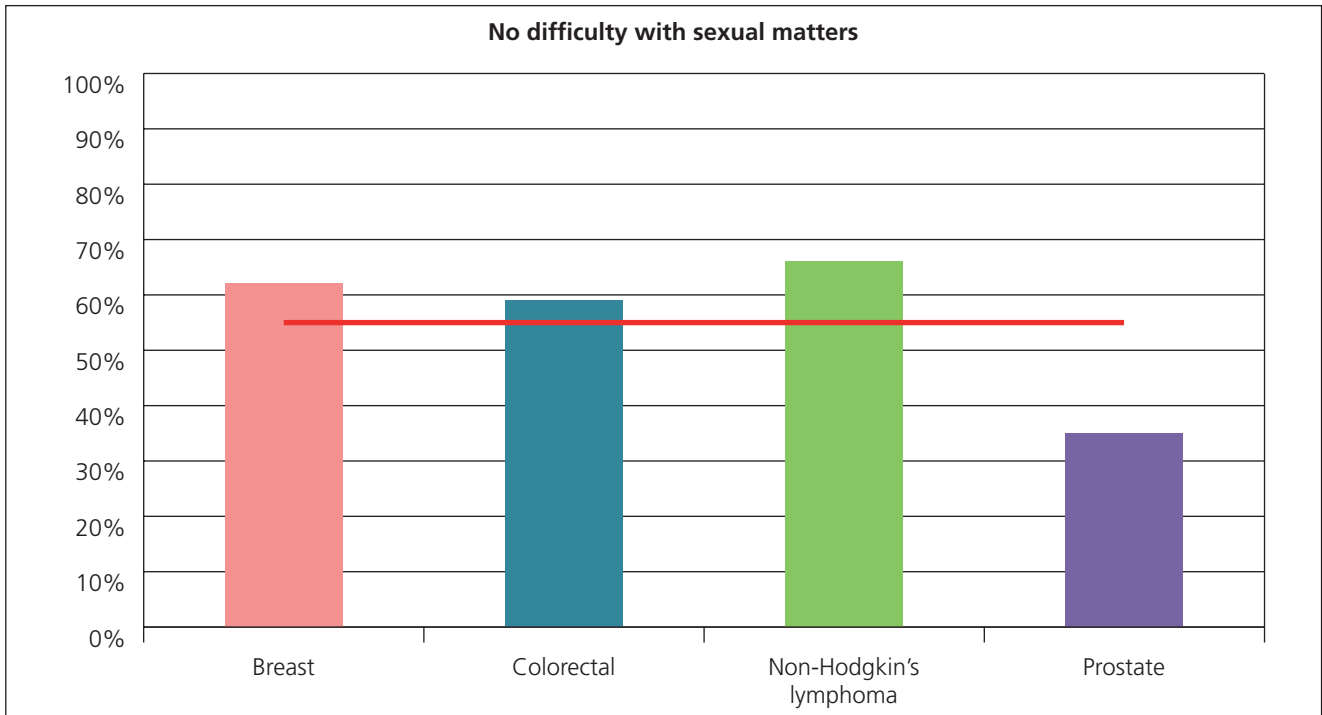
5.44 There were significant differences between the one year time cohort and all other time cohorts.

## Have you had any difficulty concerning sexual matters?

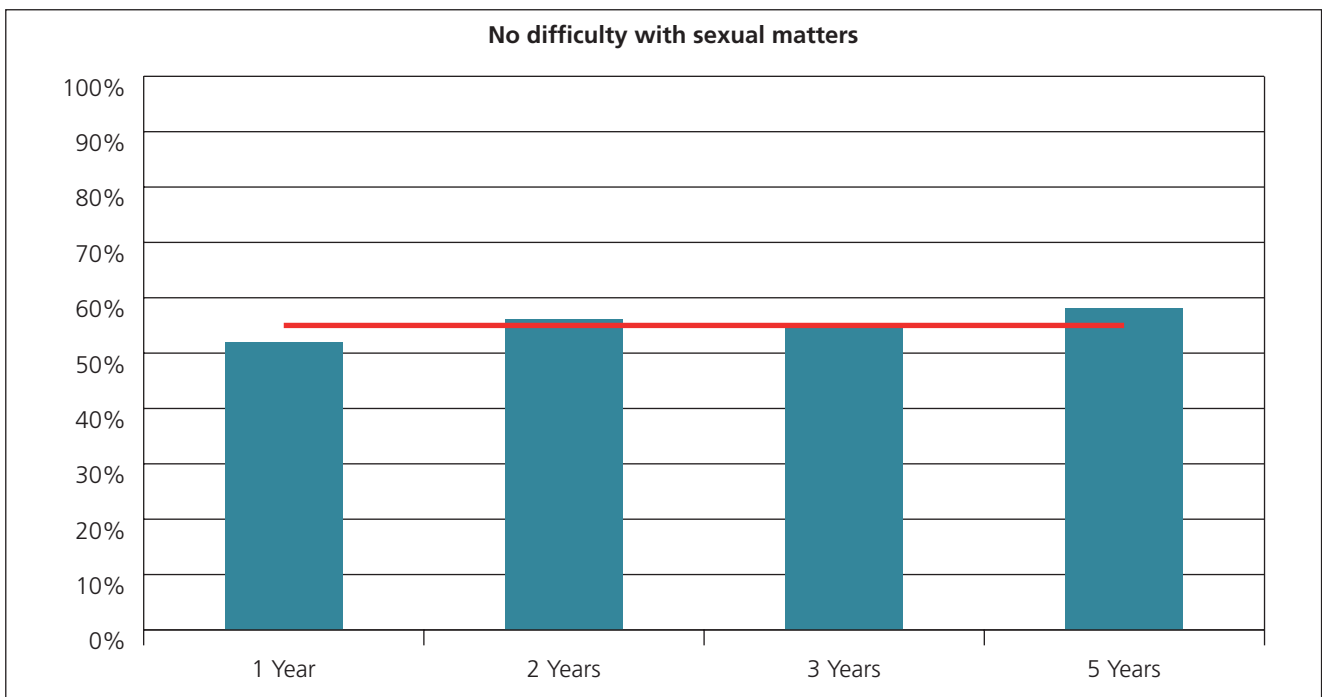
### Overall findings

5.45 55% of patients said they had no difficulty concerning sexual matters; 18% had a little difficulty, 11% said quite a bit, 16% said very much, 30% said this did not apply to them.

**Chart 5.39: Findings by Tumour Group**



**Chart 5.40: Findings by Time Cohort**

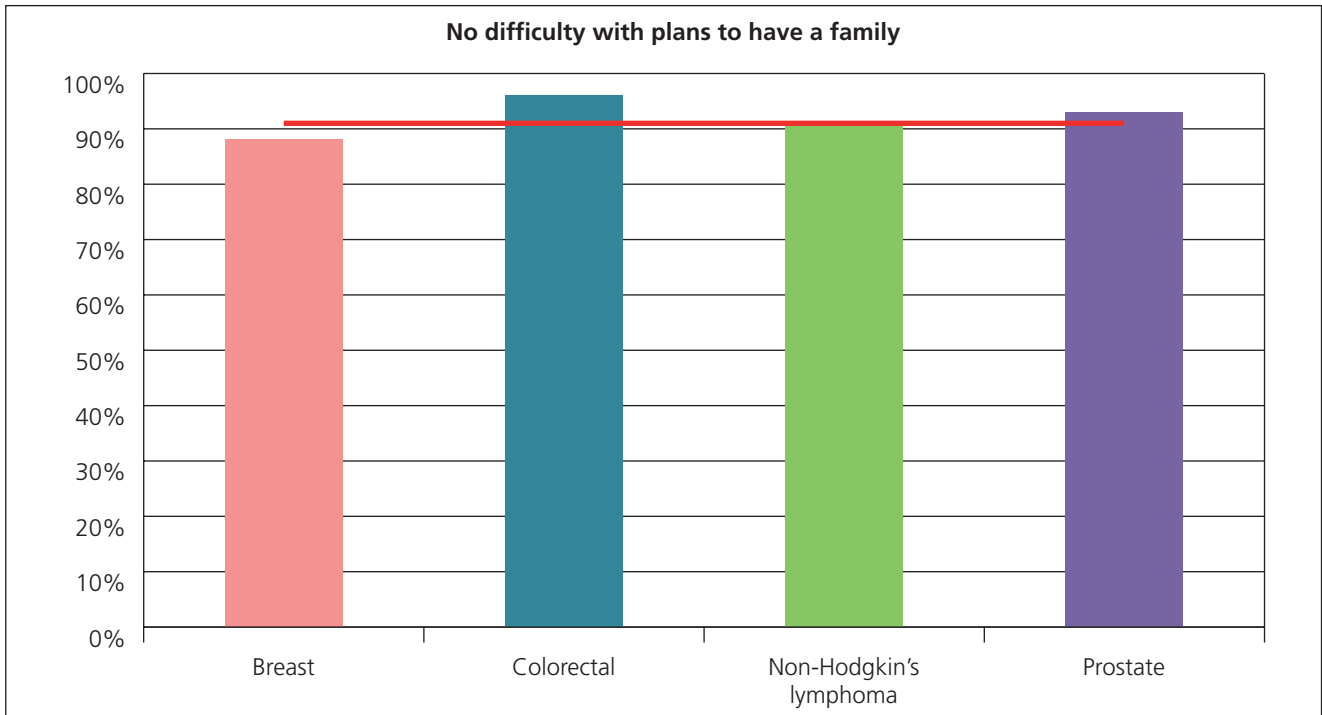


## Have you had any difficulty concerning plans to have a family?

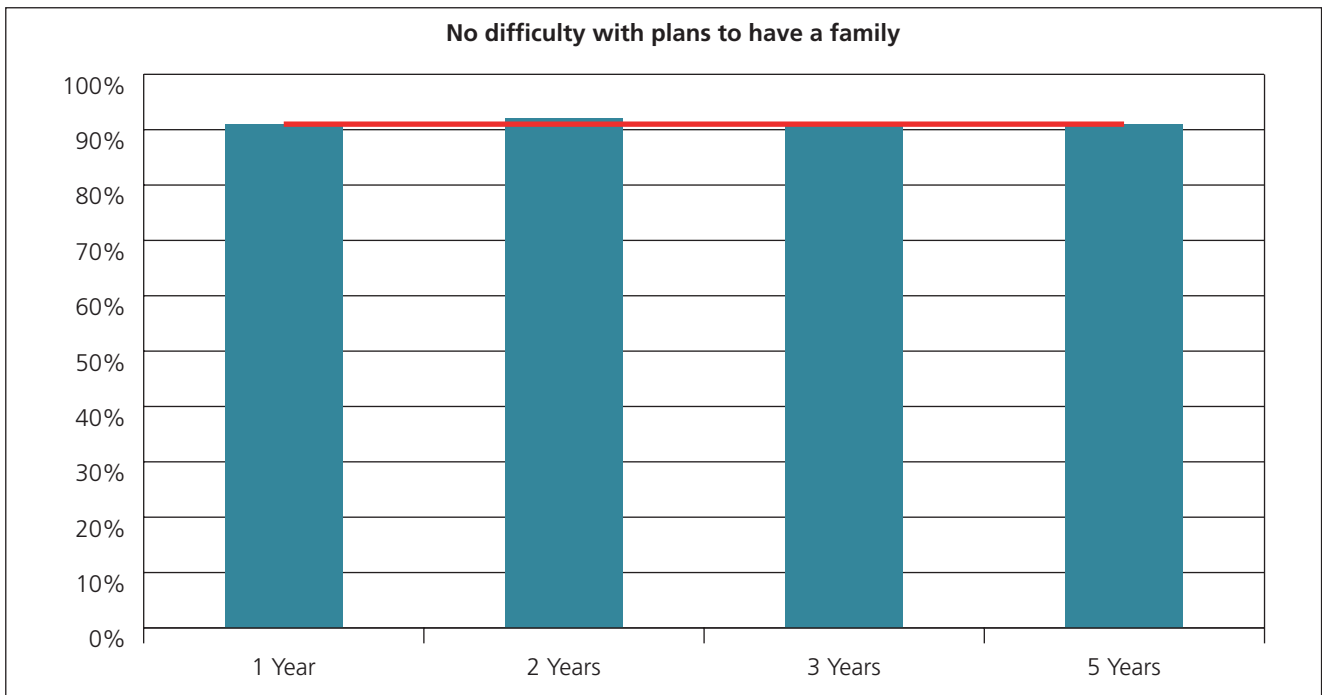
### Overall findings

5.46 91% of patients said they had no difficulty concerning plans to have a family; 3% had a little difficulty, 1% said quite a bit, 4% said very much, 75% said this did not apply to them.

**Chart 5.41: Findings by Tumour Group**



**Chart 5.42: Findings by Time Cohort**



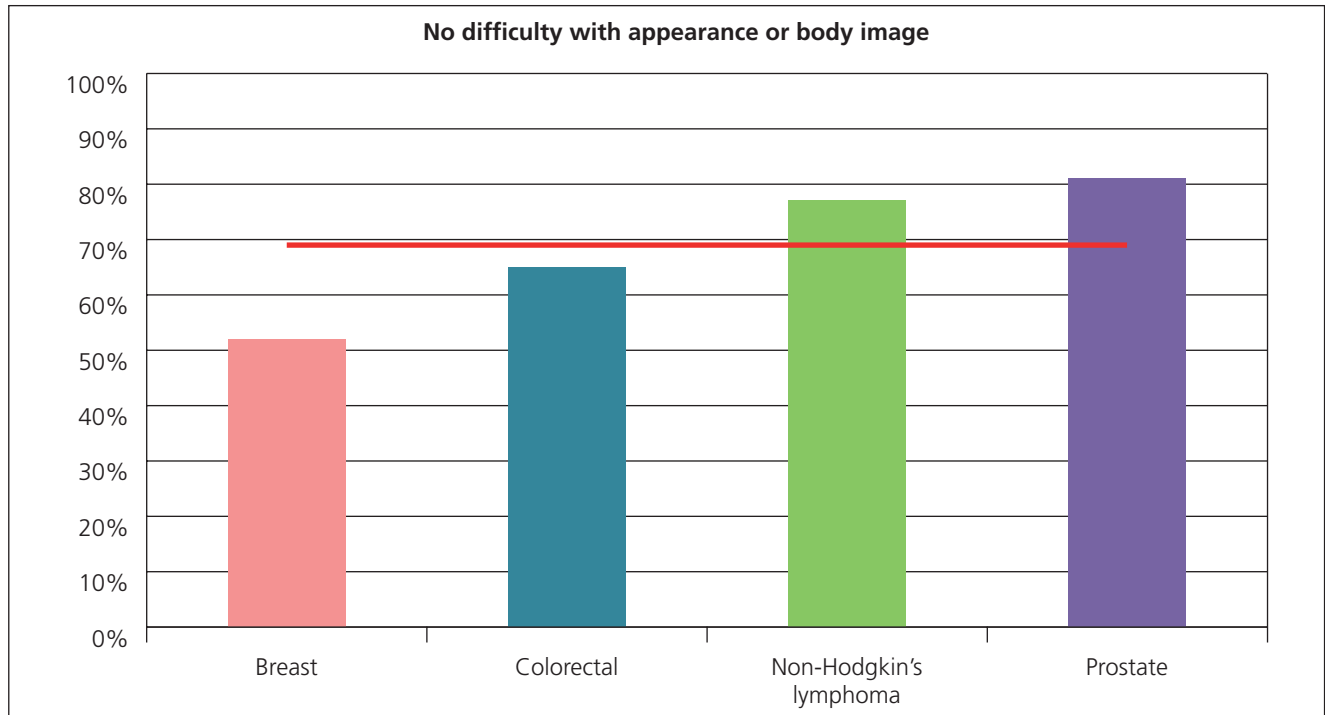


## Have you had any difficulty concerning your appearance or body image?

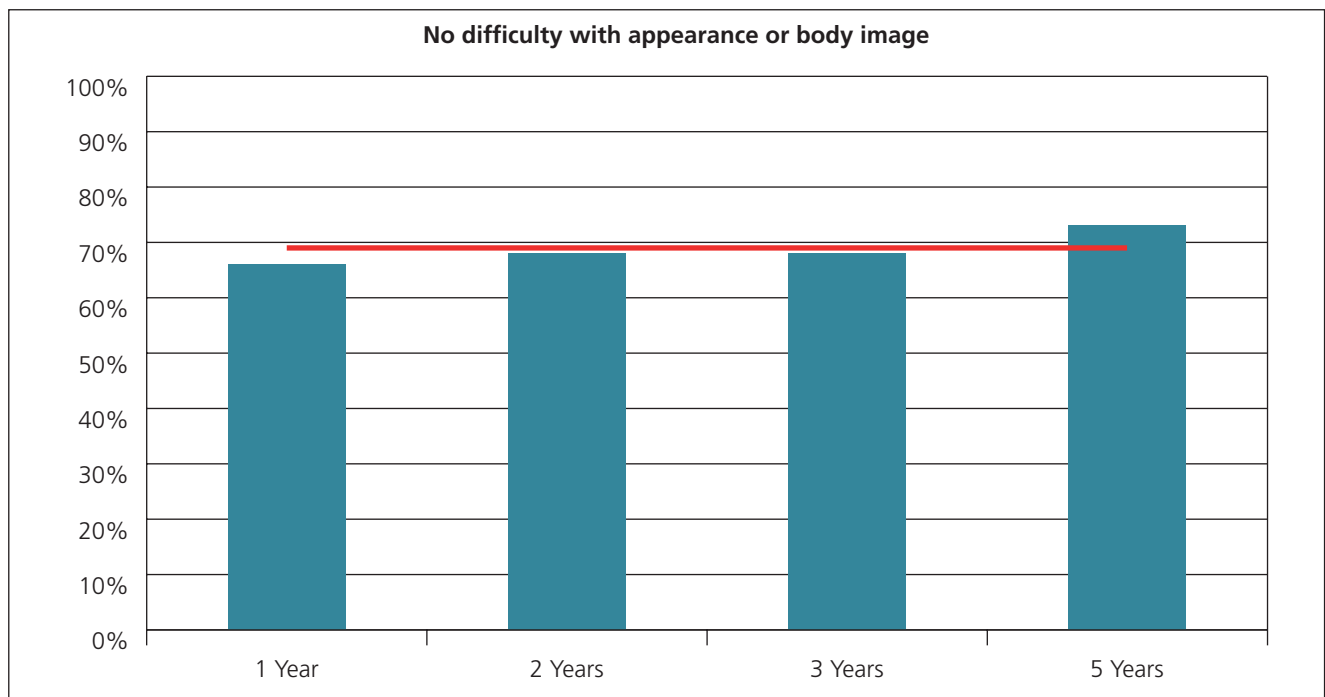
### Overall findings

5.47 69% of patients said they had no difficulty concerning their appearance or body image; 19% had a little difficulty, 7% said quite a bit, 5% said very much, 8% said this did not apply to them.

**Chart 5.43: Findings by Tumour Group**



**Chart 5.44: Findings by Time Cohort**



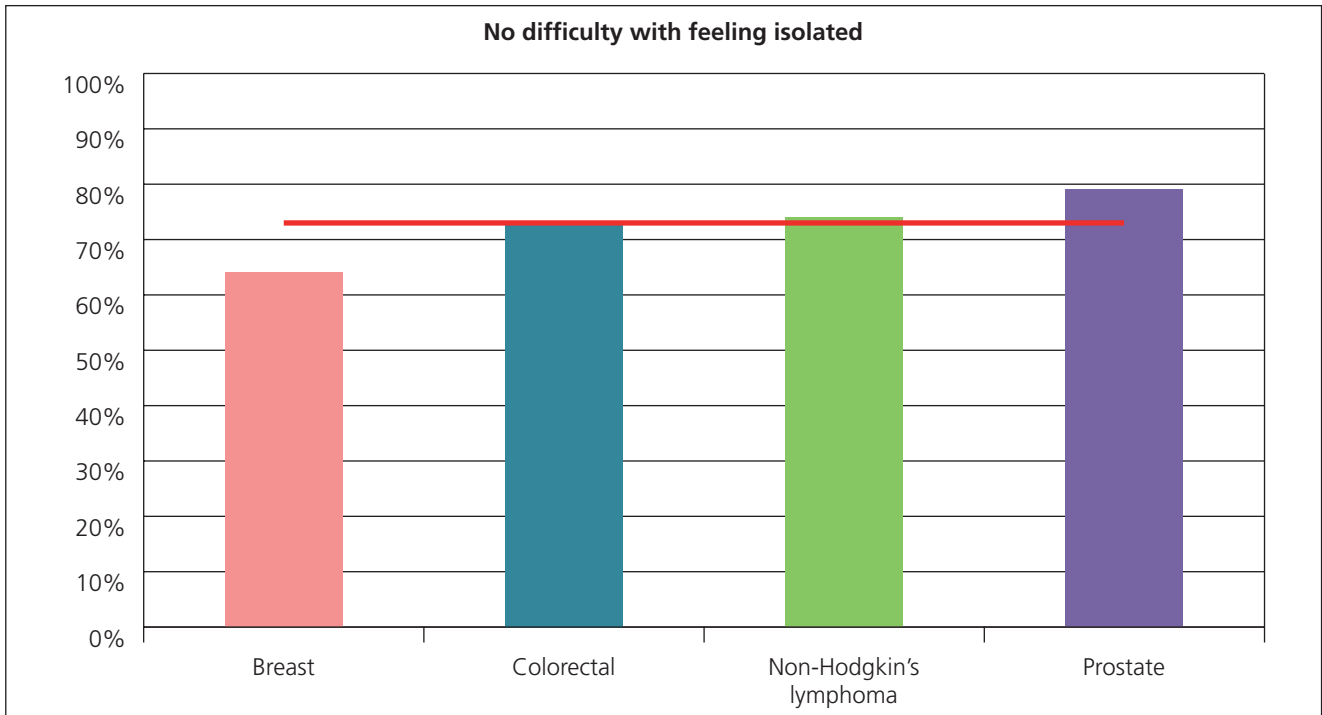
5.48 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## Have you felt isolated?

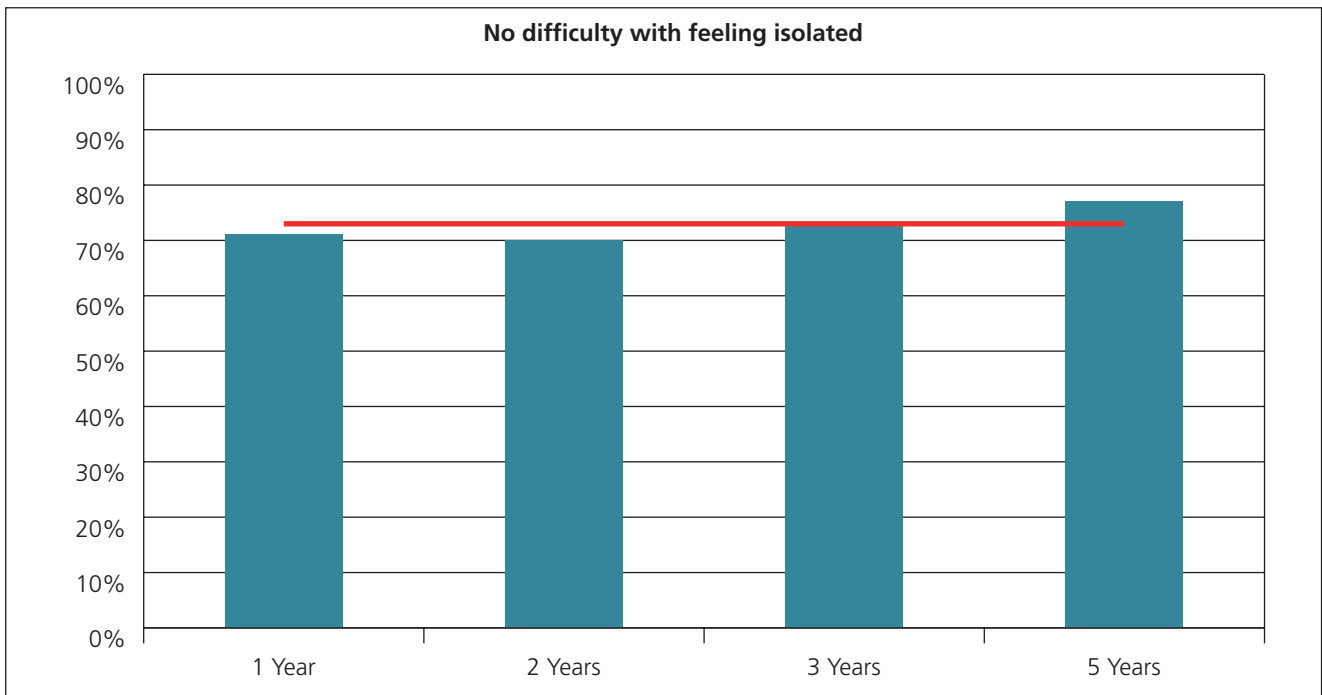
### Overall findings

5.49 73% of patients said they had no difficulty feeling isolated; 17% had a little difficulty, 6% said quite a bit, 4% said very much, 7% said this did not apply to them.

**Chart 5.45: Findings by Tumour Group**



**Chart 5.46: Findings by Time Cohort**



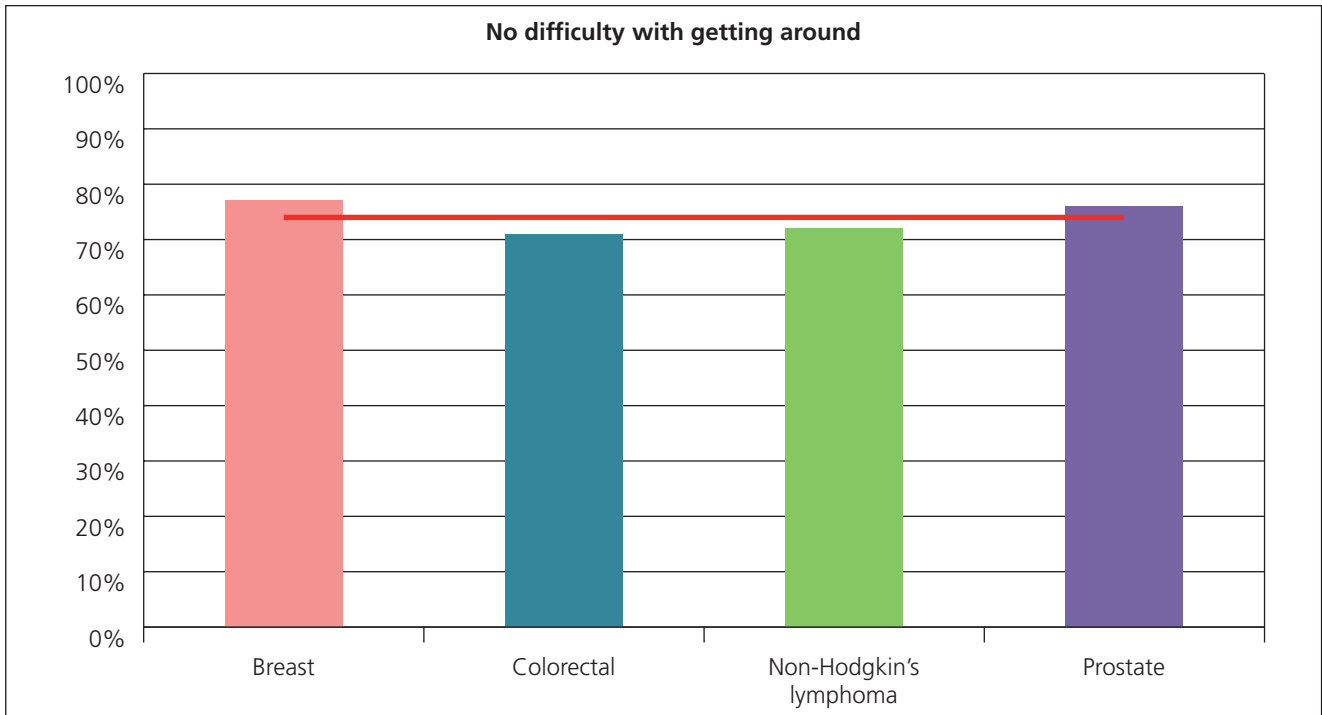
5.50 There were significant differences between the five year cohort and all other time cohorts.

## Have you had any difficulty with getting around?

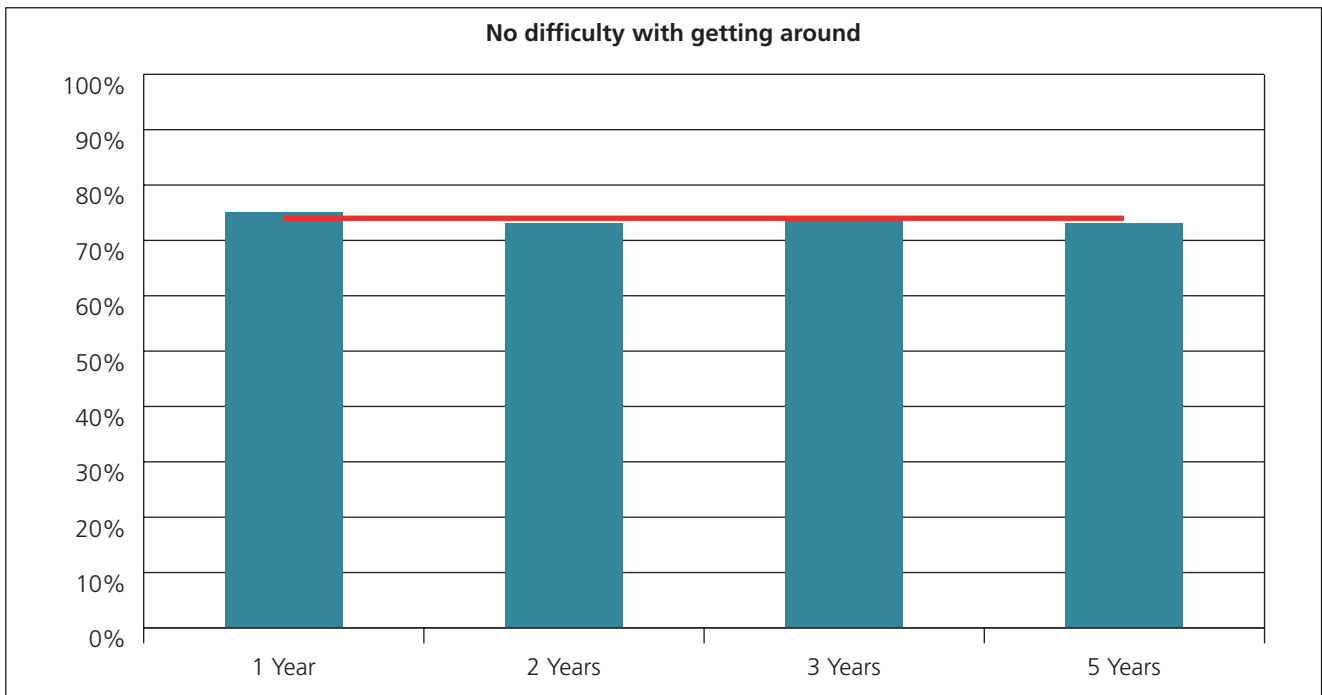
### Overall findings

5.51 74% of patients said they had no difficulty getting around; 14% had a little difficulty, 6% said quite a bit, 6% said very much, 3% said this did not apply to them.

**Chart 5.47: Findings by Tumour Group**



**Chart 5.48: Findings by Time Cohort**

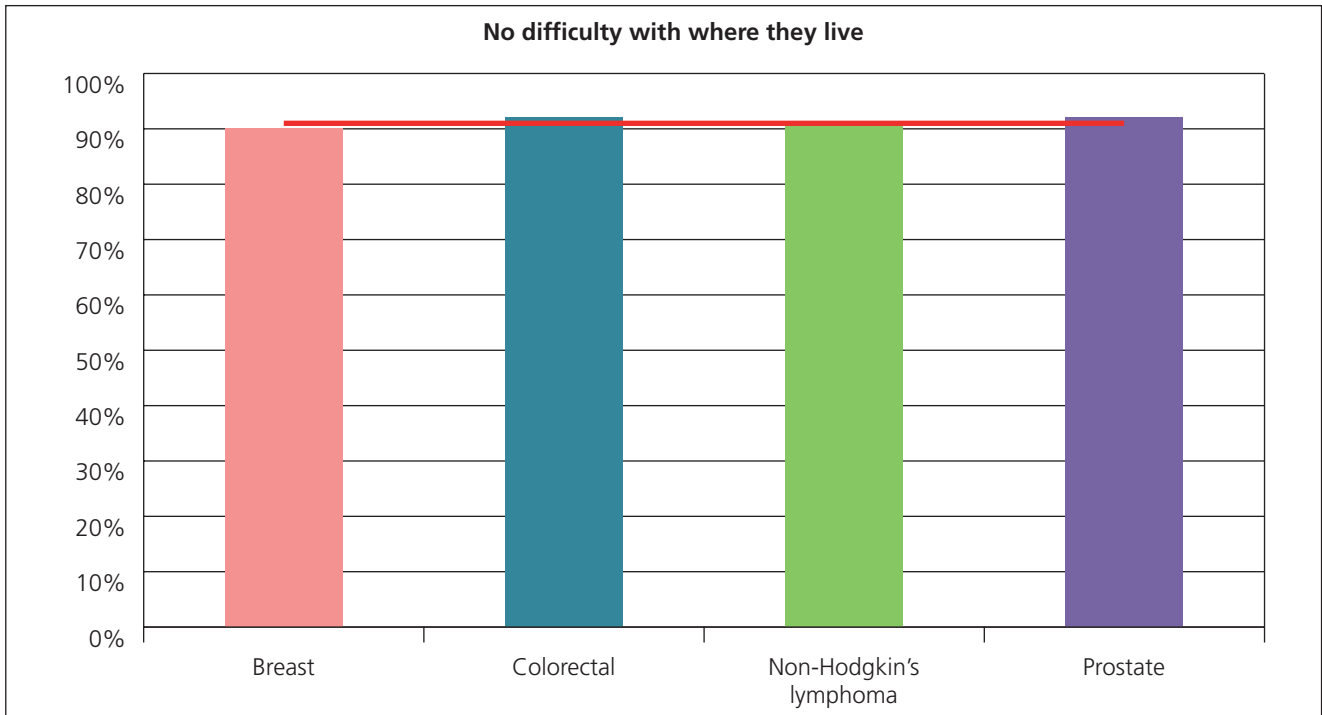


## Have you had any difficulty with where you live?

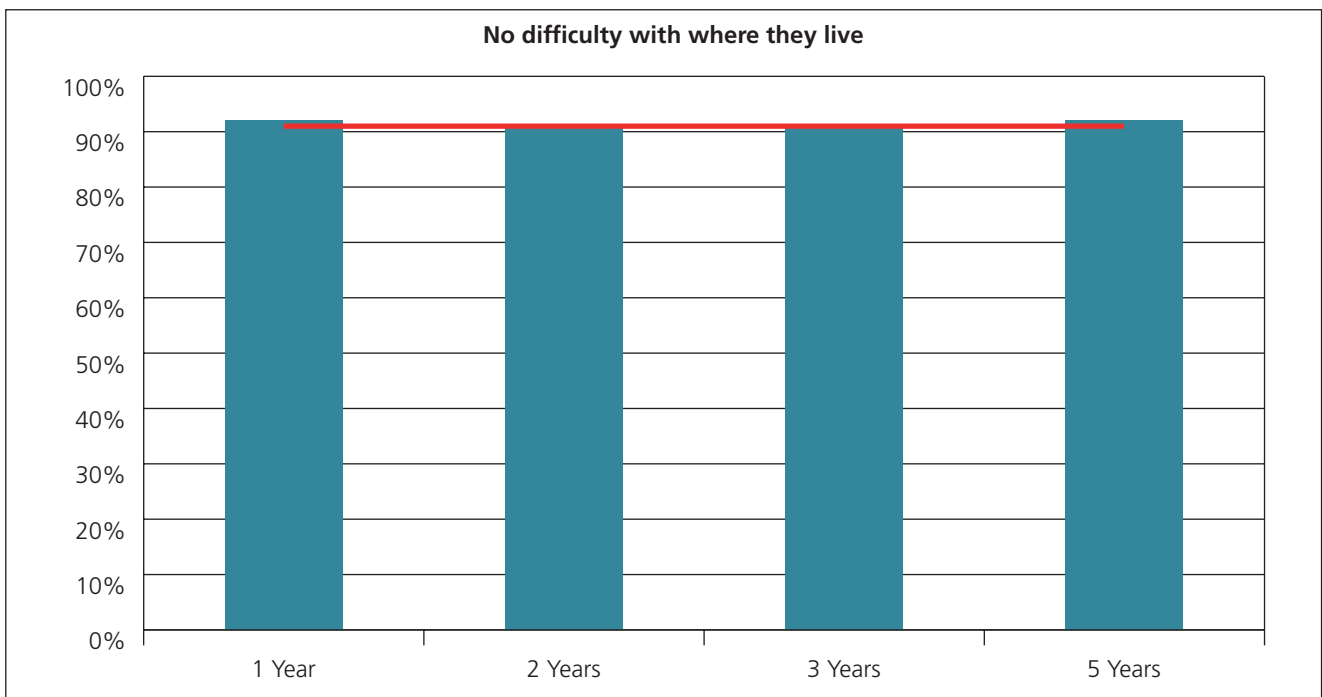
### Overall findings

5.52 91% of patients said they had no difficulty with where they lived; 5% had a little difficulty, 2% said quite a bit, 2% said very much, 4% said this did not apply to them.

**Chart 5.49: Findings by Tumour Group**



**Chart 5.50: Findings by Time Cohort**

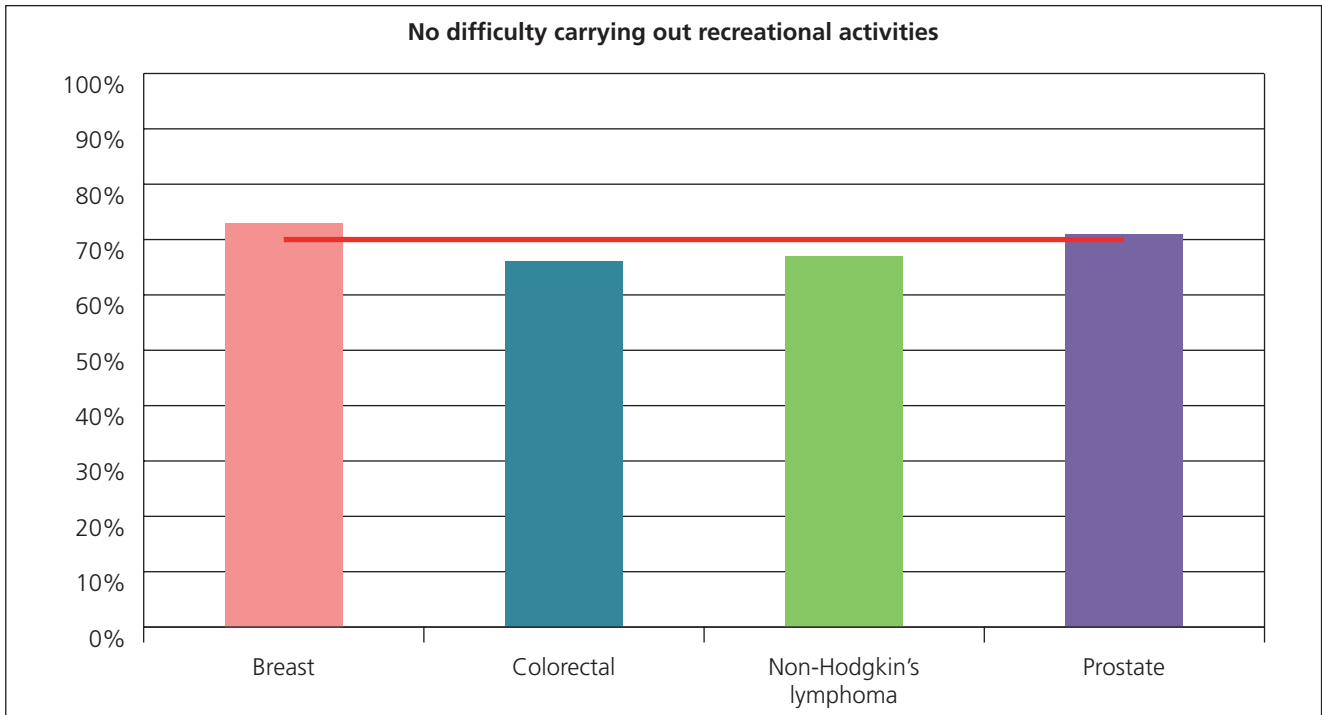


## Have you had any difficulty carrying out your recreational activities?

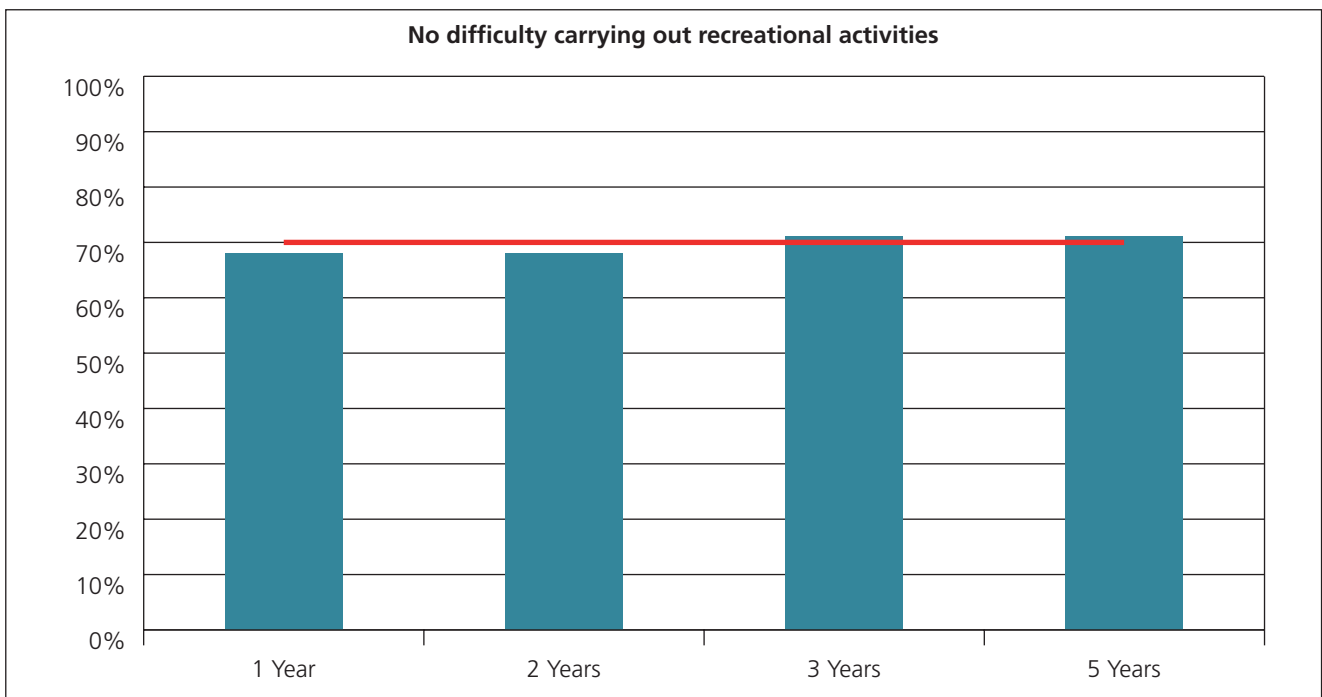
### Overall findings

5.53 70% of patients said they had no difficulty carrying out their recreational activities; 17% had a little difficulty, 7% said quite a bit, 7% said very much, 5% said this did not apply to them.

**Chart 5.51: Findings by Tumour Group**



**Chart 5.52: Findings by Time Cohort**

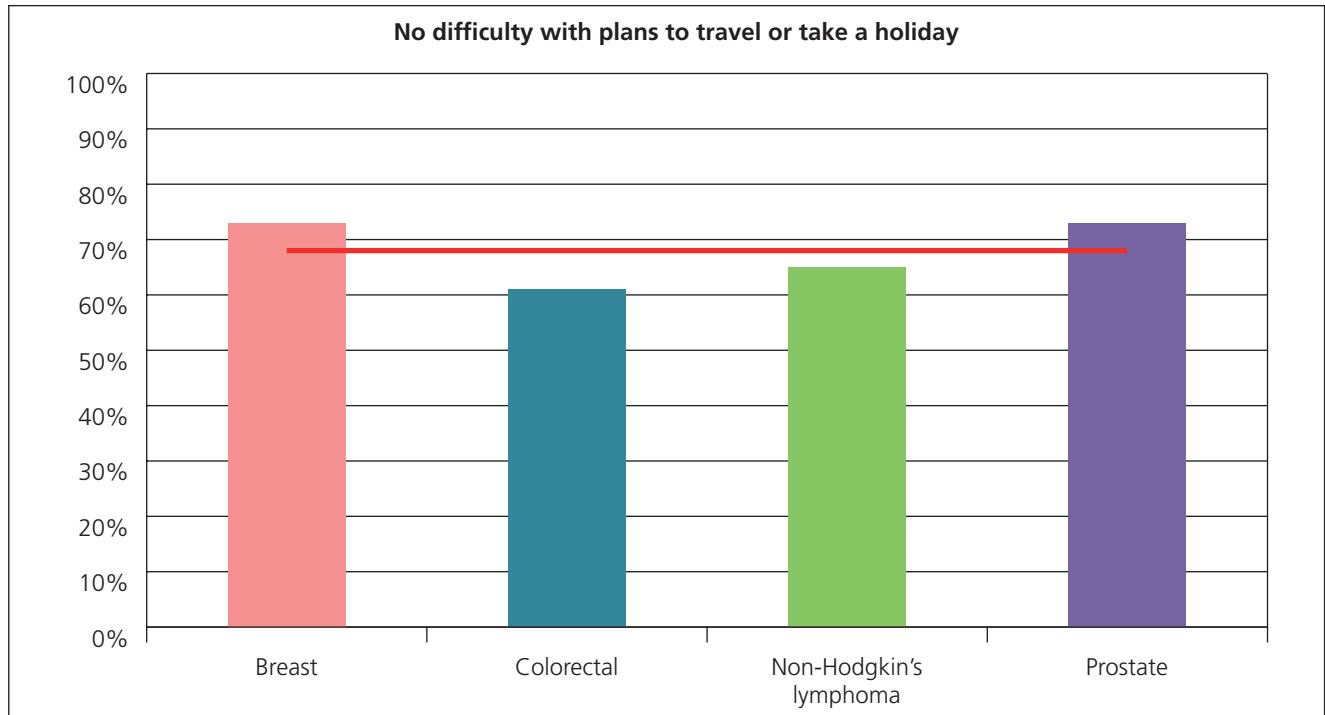


## Have you had any difficulty with your plans to travel or take a holiday?

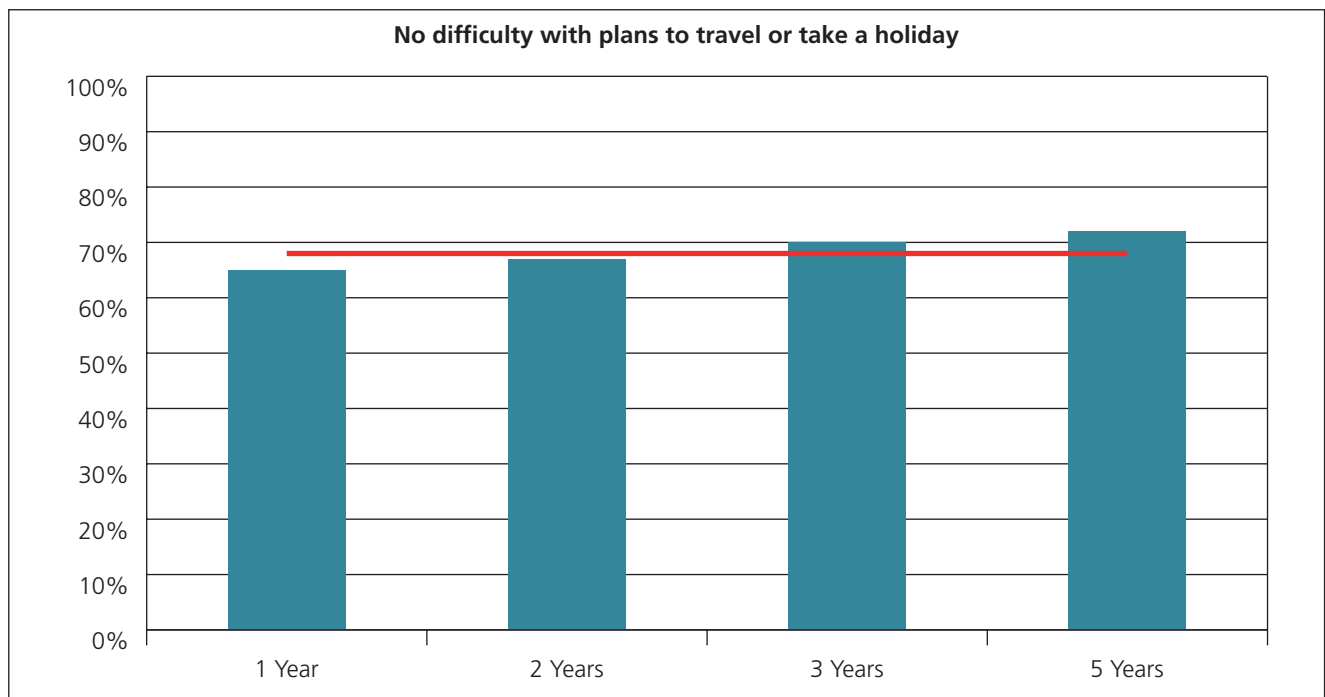
### Overall findings

5.54 68% of patients said they had no difficulty with plans to travel or take a holiday; 14% had a little difficulty, 8% said quite a bit, 10% said very much, 11% said this did not apply to them.

**Chart 5.53: Findings by Tumour Group**



**Chart 5.54: Findings by Time Cohort**



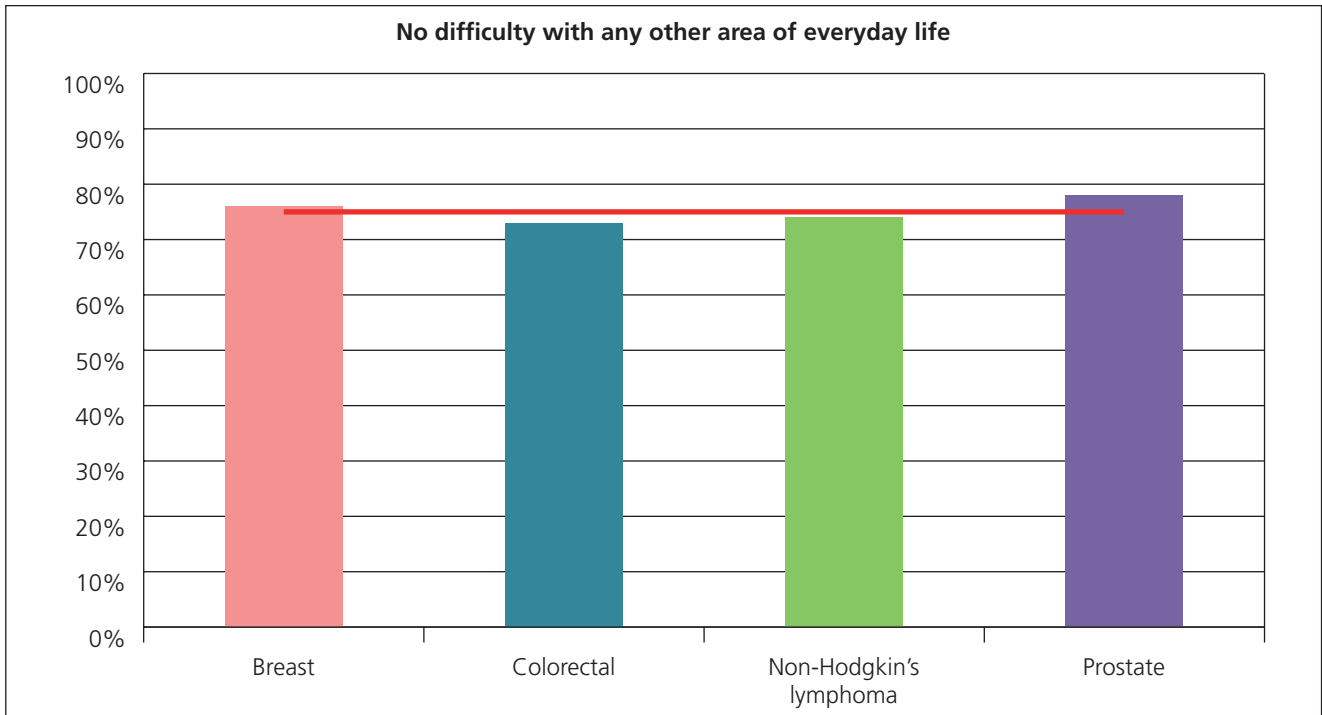
5.55 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## Have you had any difficulty with any other area of your everyday life?

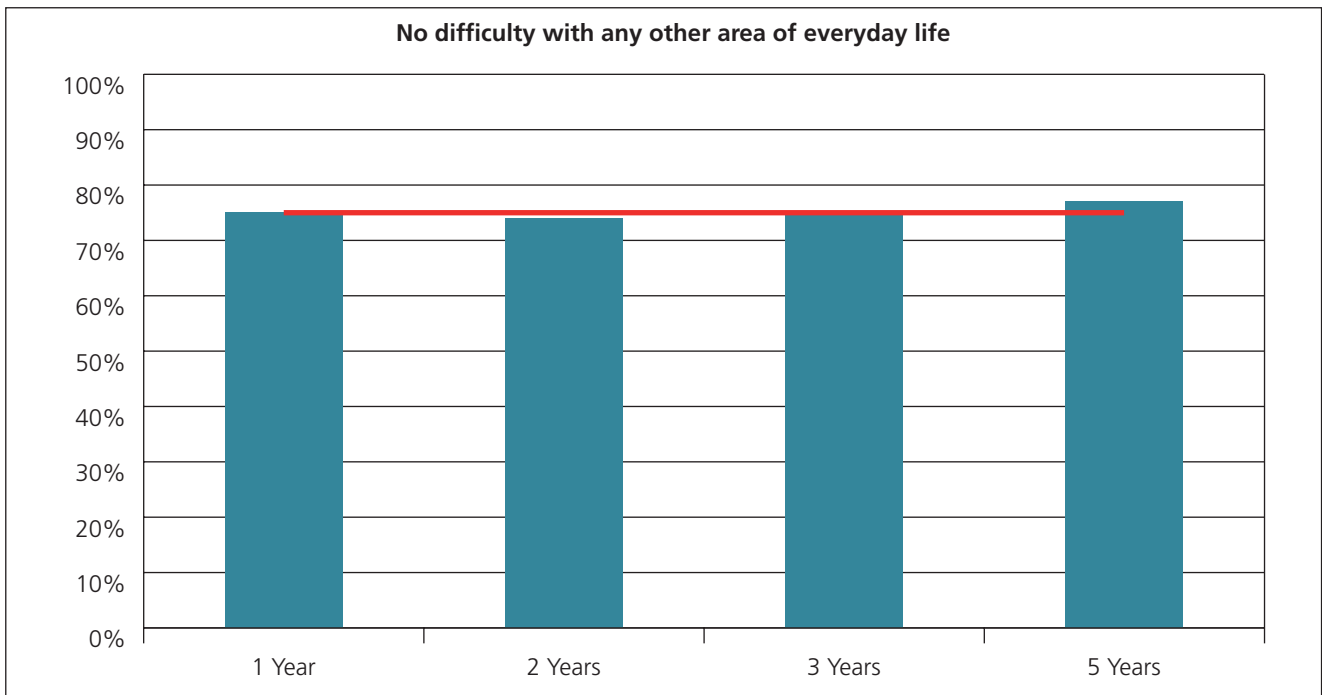
### Overall findings

5.56 75% of patients said they had no difficulty with any other area of their everyday life; 16% had a little difficulty, 5% said quite a bit, 4% said very much, 4% said this did not apply to them.

**Chart 5.55: Findings by Tumour Group**



**Chart 5.56: Findings by Time Cohort**



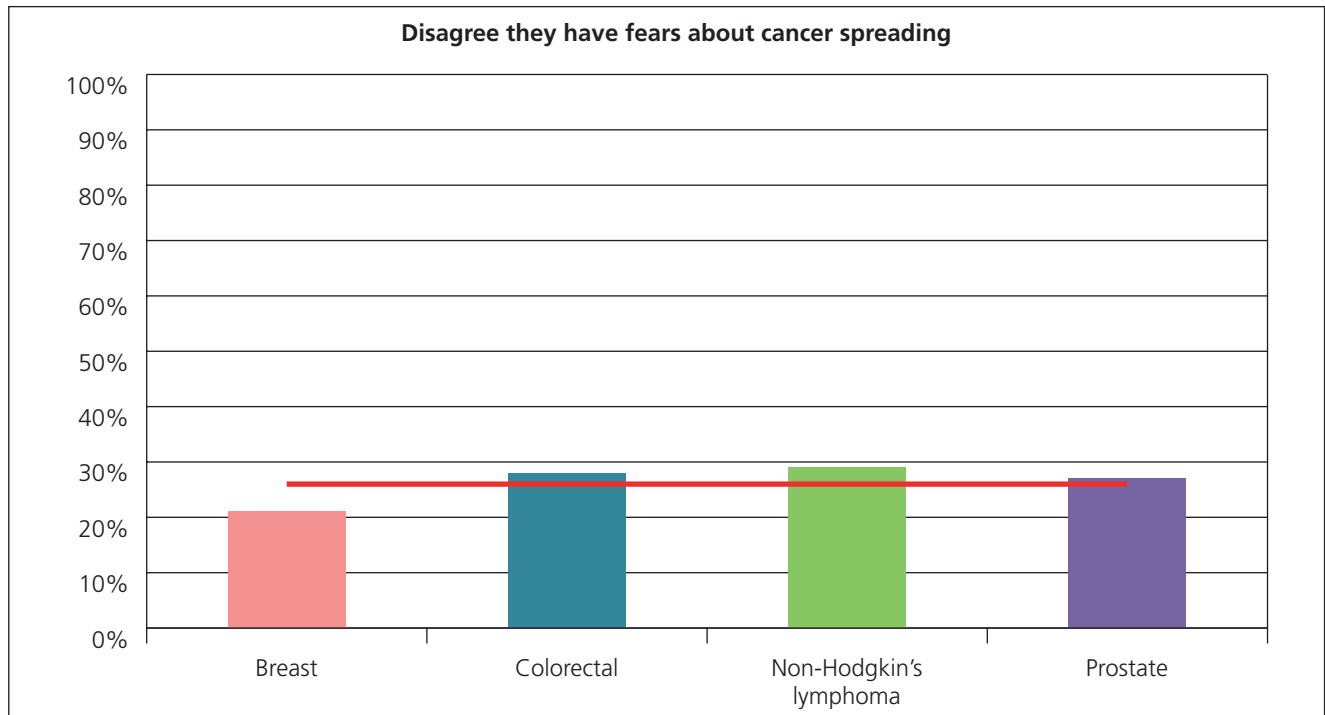
## Fears and other health issues

### I have fears about my cancer spreading

#### Overall findings

5.57 26% of patients said they disagreed (16%) or strongly disagreed (10%) that they had fears about their cancer spreading; 13% strongly agreed, 32% agreed, and 29% neither agreed nor disagreed. 12% said this did not apply to them.

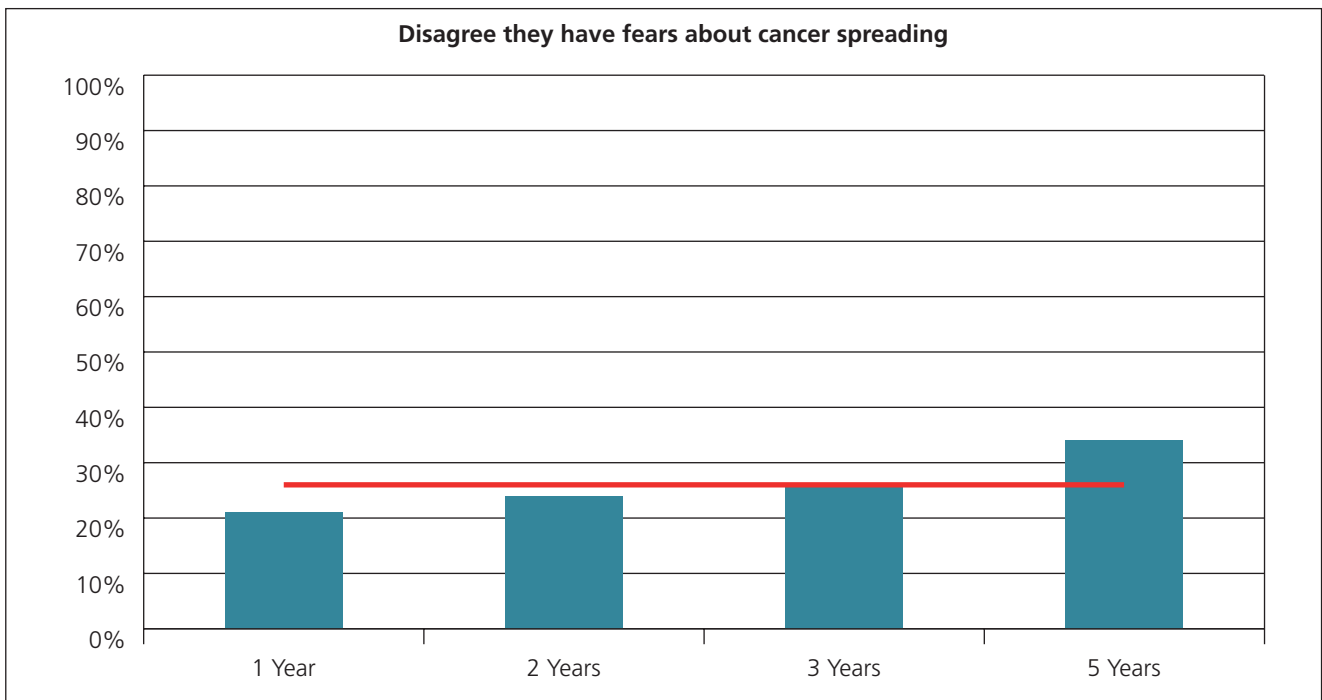
**Chart 5.57: Findings by Tumour Group**



5.58 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.



**Chart 5.58: Findings by Time Cohort**



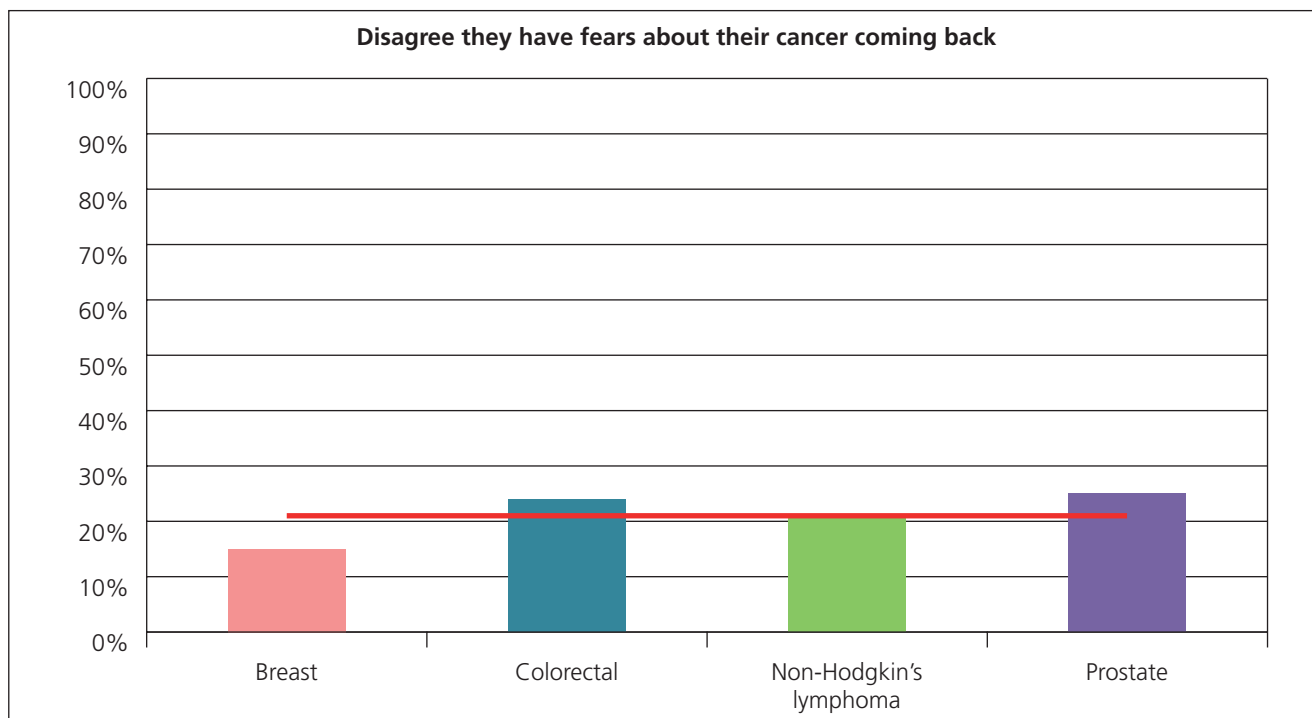
5.59 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

**I have fears about my cancer coming back**

**Overall findings**

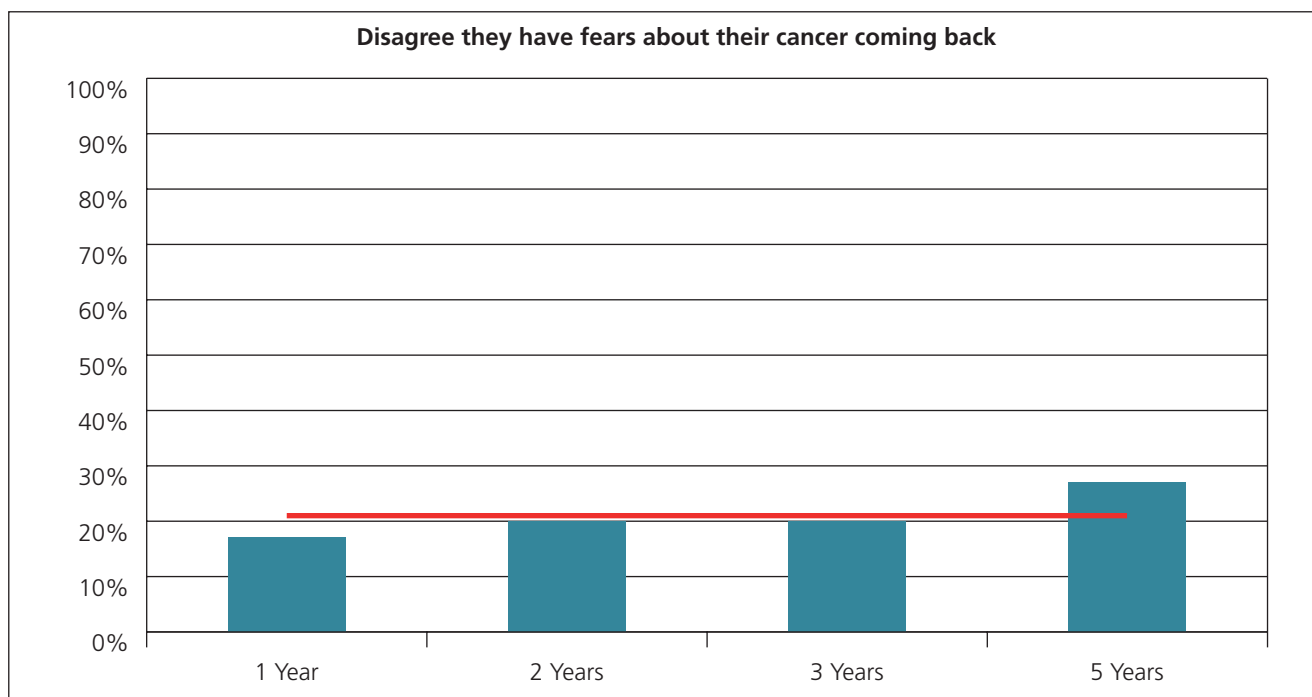
5.60 21% of patients said they disagreed (13%) or strongly disagreed (8%) that they had fears about their cancer coming back; 17% strongly agreed, 40% agreed, and 23% neither agreed nor disagreed. 12% said this did not apply to them.

**Chart 5.59: Findings by Tumour Group**



5.61 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.60: Findings by Time Cohort**



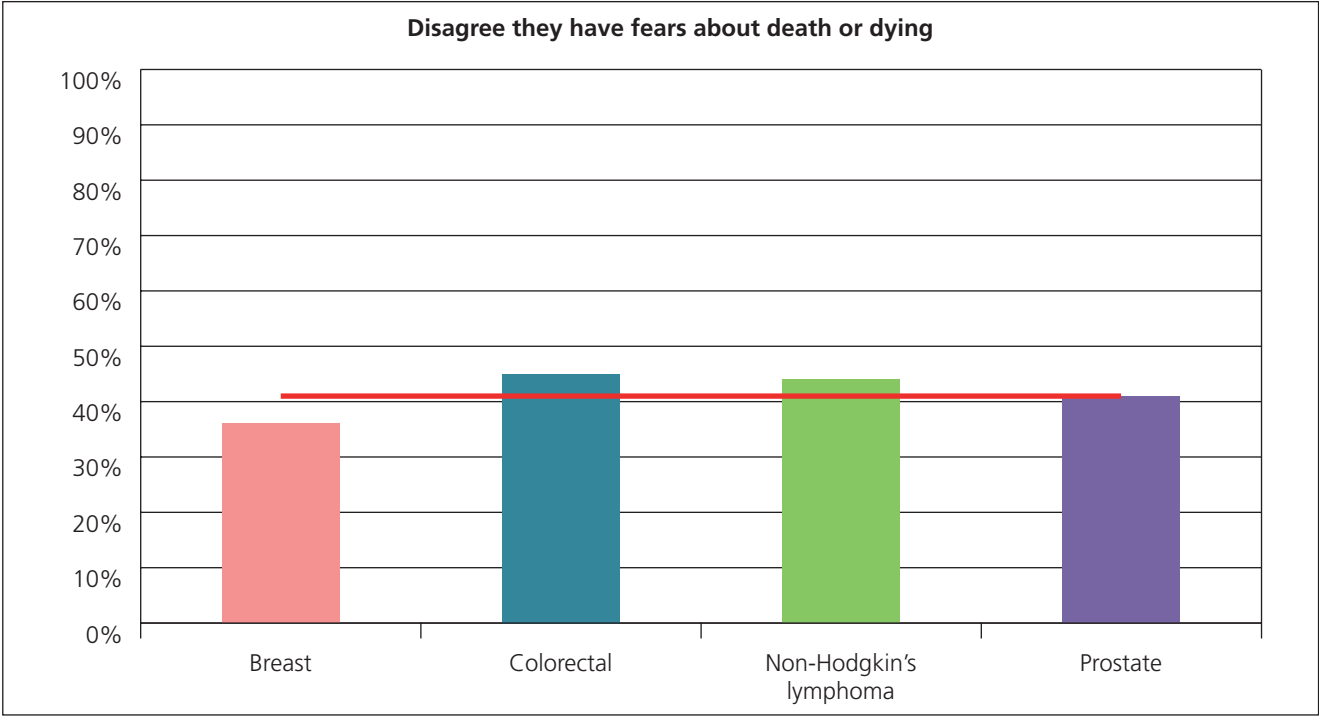
5.62 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

**I have fears about death and dying**

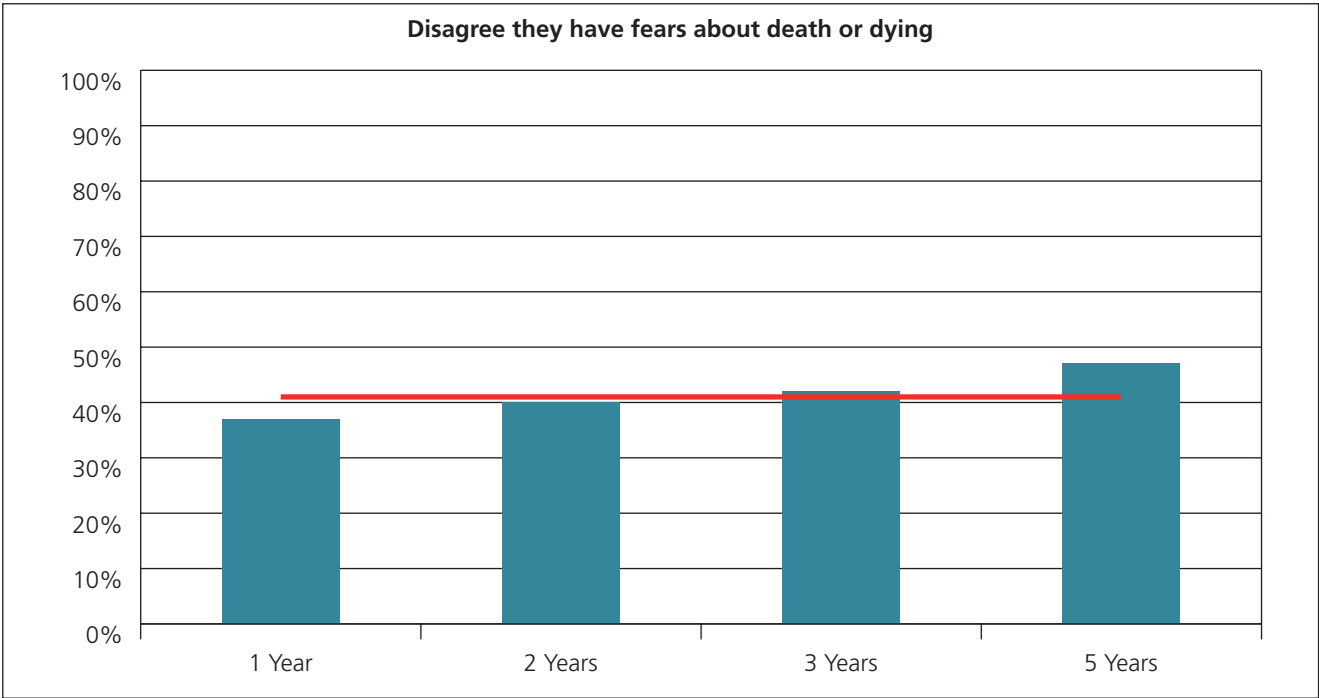
**Overall findings**

5.63 41% of patients said they disagreed (23%) or strongly disagreed (18%) that they had fears about death and dying; 8% strongly agreed, 20% agreed, and 30% neither agreed nor disagreed.

**Chart 5.61: Findings by Tumour Group**



**Chart 5.62: Findings by Time Cohort**



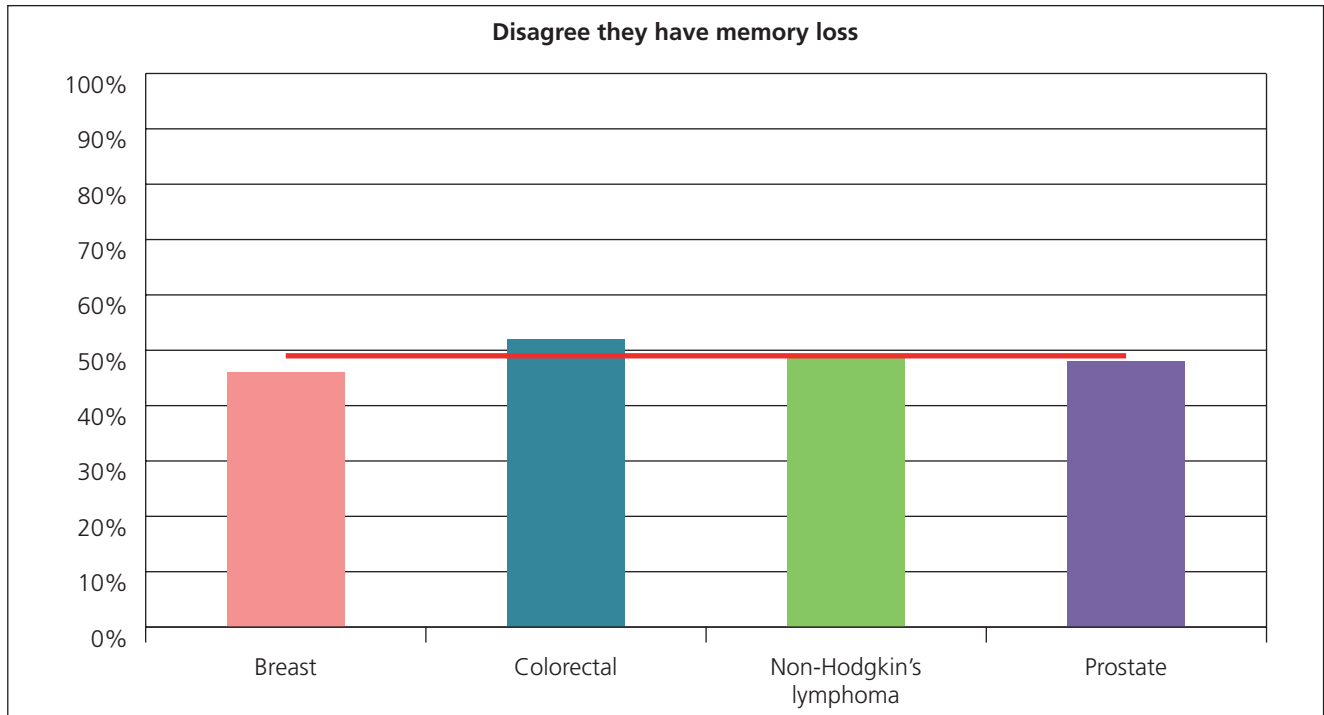
5.64 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## I experience memory loss

### Overall findings

5.65 49% of patients said they disagreed (26%) or strongly disagreed (23%) that they experienced memory loss; 7% strongly agreed, 27% agreed, and 18% neither agreed nor disagreed.

**Chart 5.63: Findings by Tumour Group**



**Chart 5.64: Findings by Time Cohort**



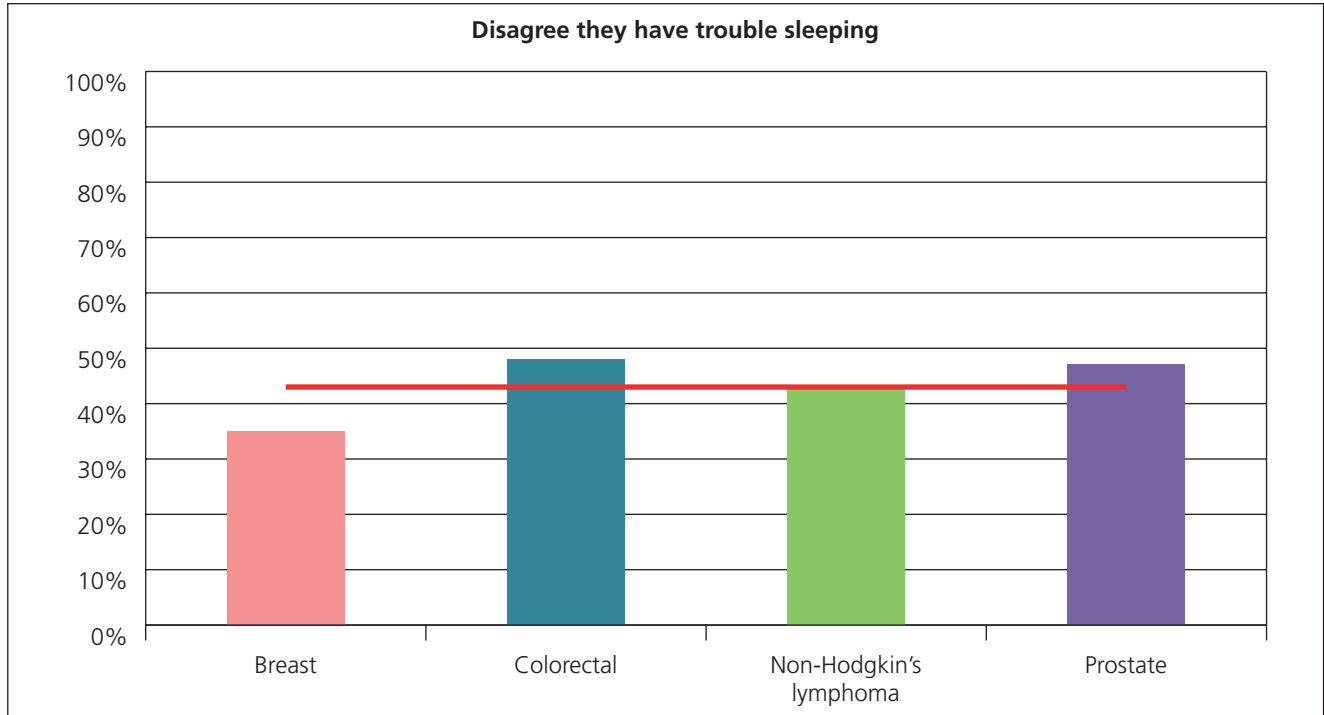
5.66 There were significant differences between the five year cohort and all other time cohorts.

## I have trouble sleeping

### Overall findings

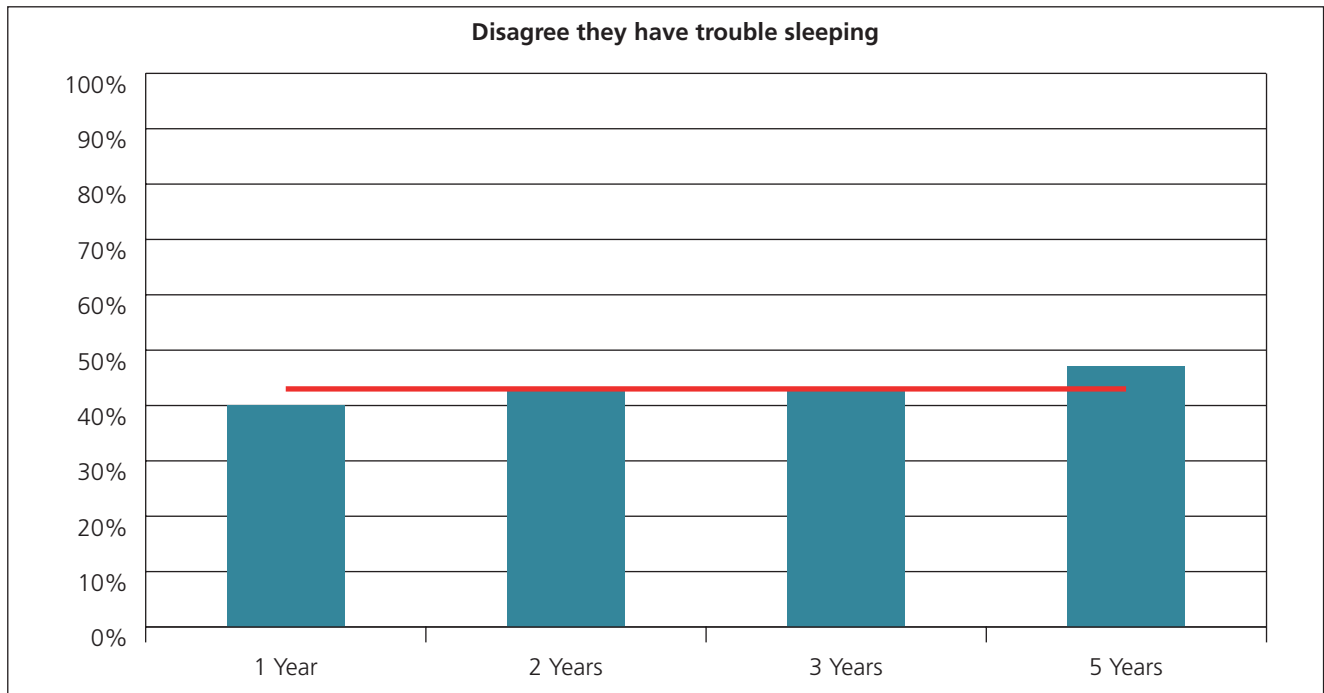
5.67 43% of patients said they disagreed (23%) or strongly disagreed (20%) that they had trouble sleeping; 13% strongly agreed, 30% agreed, and 15% neither agreed nor disagreed.

**Chart 5.65: Findings by Tumour Group**



5.68 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.66: Findings by Time Cohort**



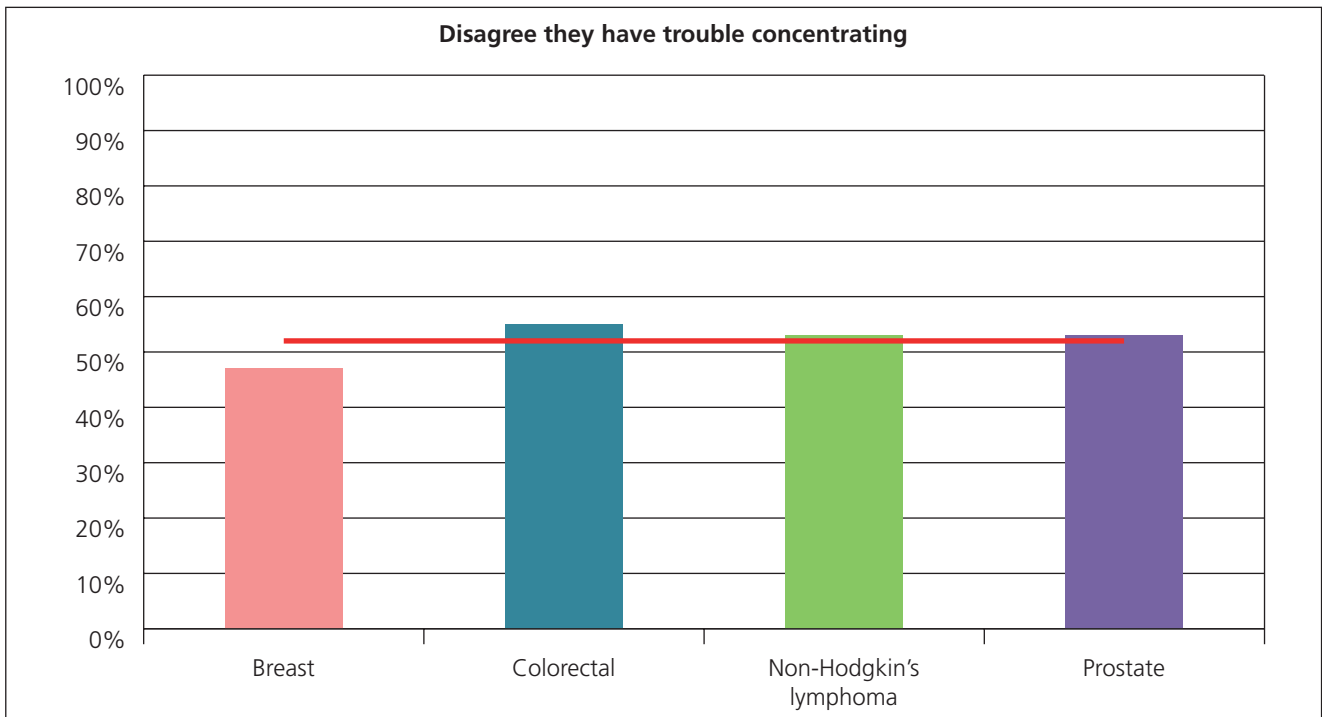
5.69 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

**I have trouble concentrating**

**Overall findings**

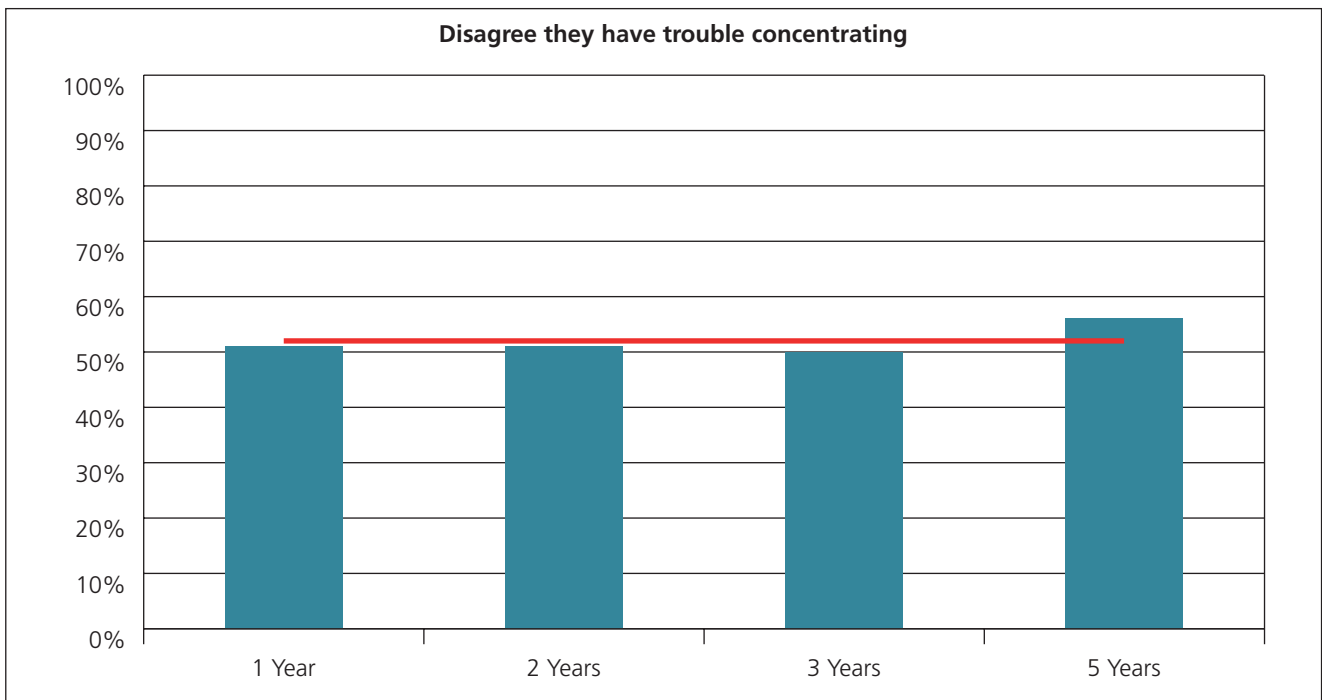
5.70 52% of patients said they disagreed (30%) or strongly disagreed (22%) that they had trouble concentrating; 7% strongly agreed, 23% agreed, and 18% neither agreed nor disagreed.

**Chart 5.67: Findings by Tumour Group**



5.71 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.68: Findings by Time Cohort**



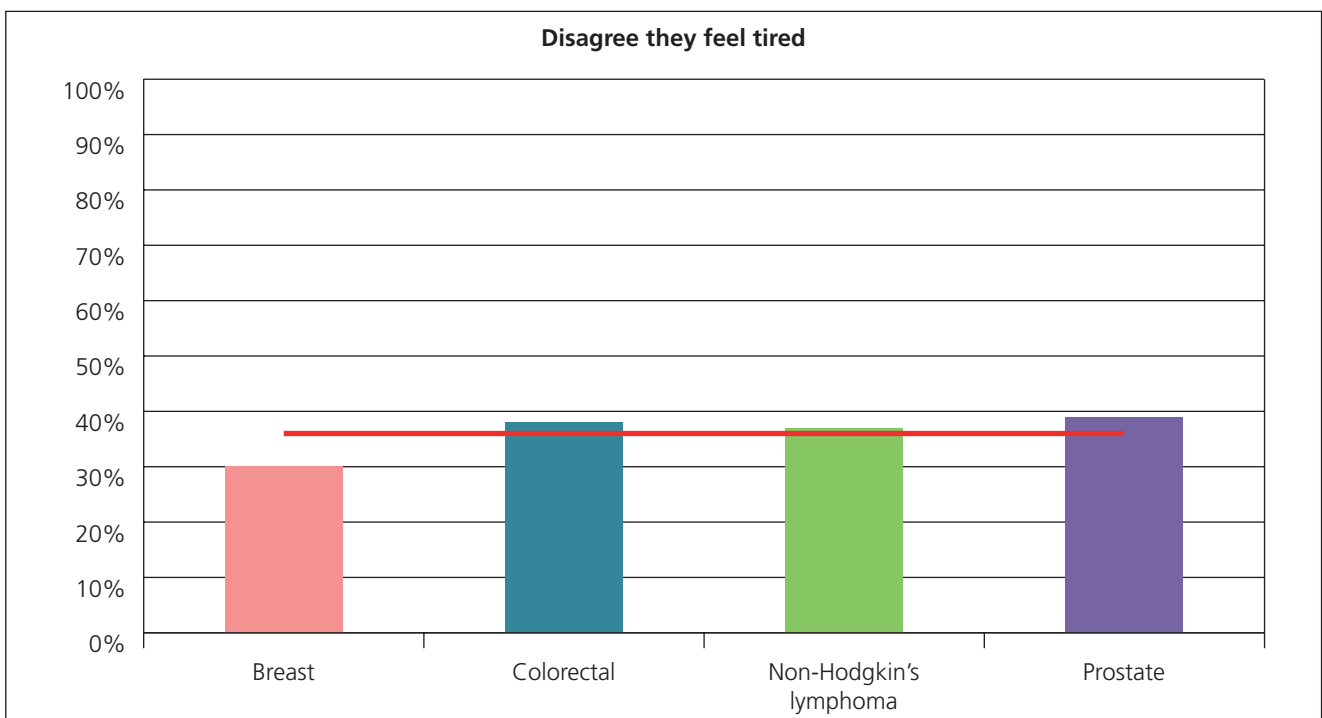
5.72 There were significant differences between the five year cohort and all other time cohorts.

**I always feel tired**

**Overall findings**

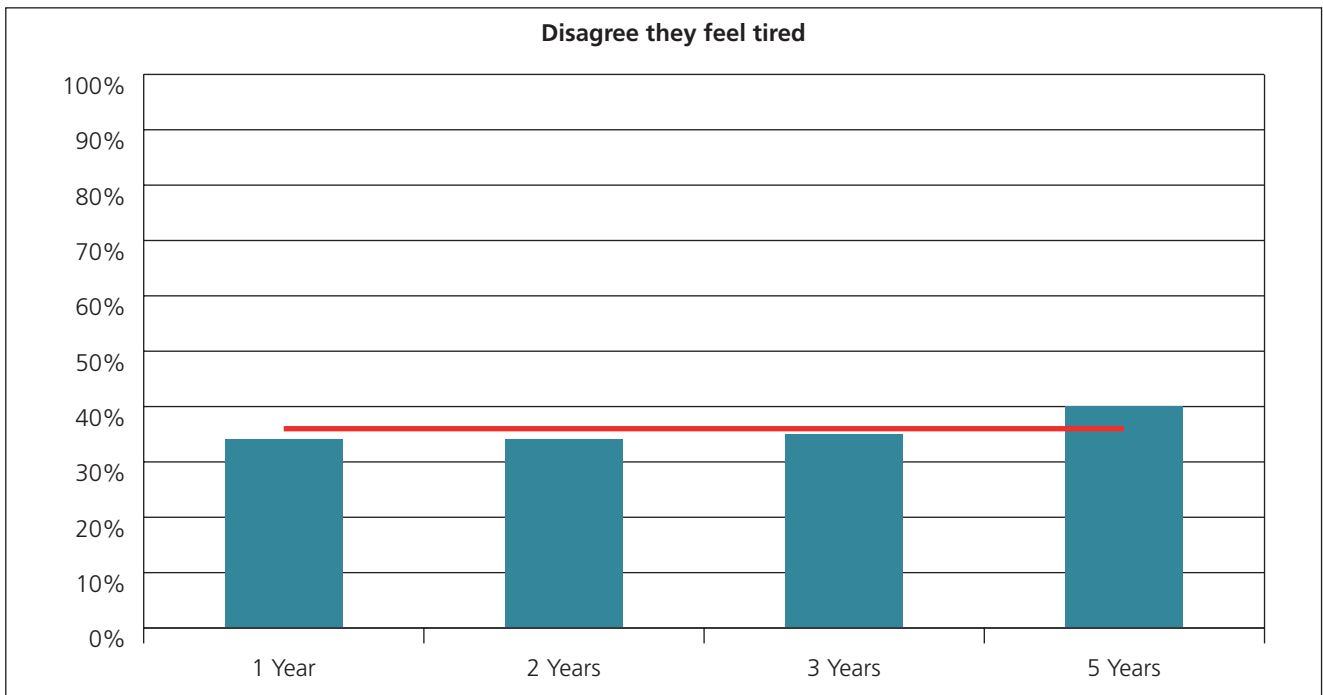
5.73 36% of patients said they disagreed (23%) or strongly disagreed (13%) that they always felt tired; 14% strongly agreed, 29% agreed, and 21% neither agreed nor disagreed.

**Chart 5.69: Findings by Tumour Group**



5.74 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.70: Findings by Time Cohort**



5.75 There were significant differences between the five year cohort and all other time cohorts.

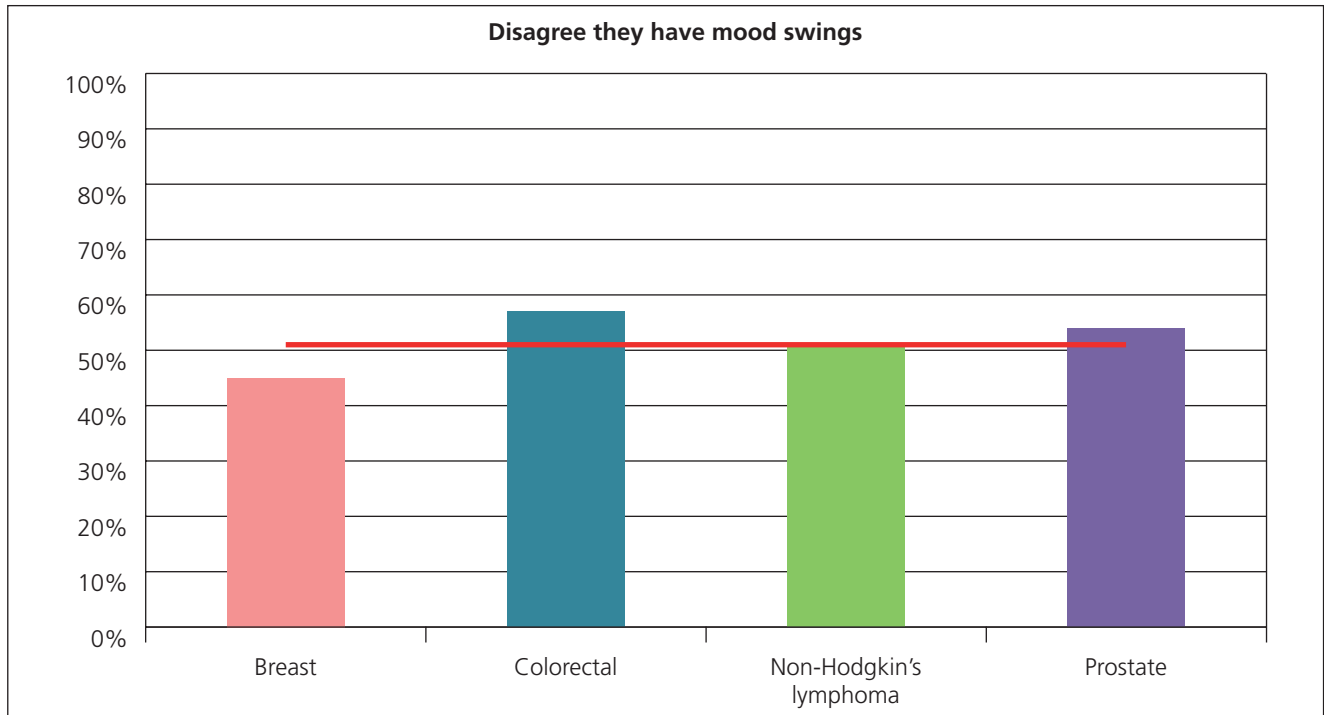


## I experience mood swings

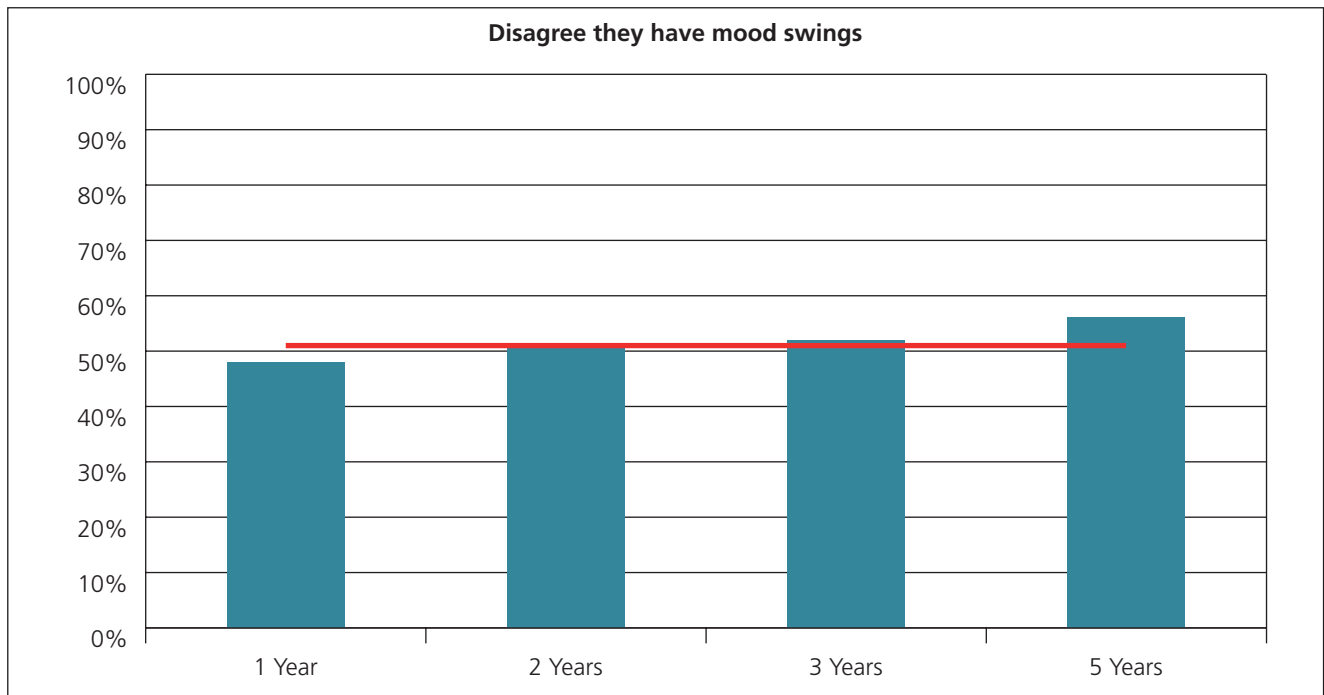
### Overall findings

5.76 51% of patients said they disagreed (29%) or strongly disagreed (22%) that they experienced mood swings; 7% strongly agreed, 24% agreed, and 17% neither agreed nor disagreed.

**Chart 5.71: Findings by Tumour Group**



**Chart 5.72: Findings by Time Cohort**



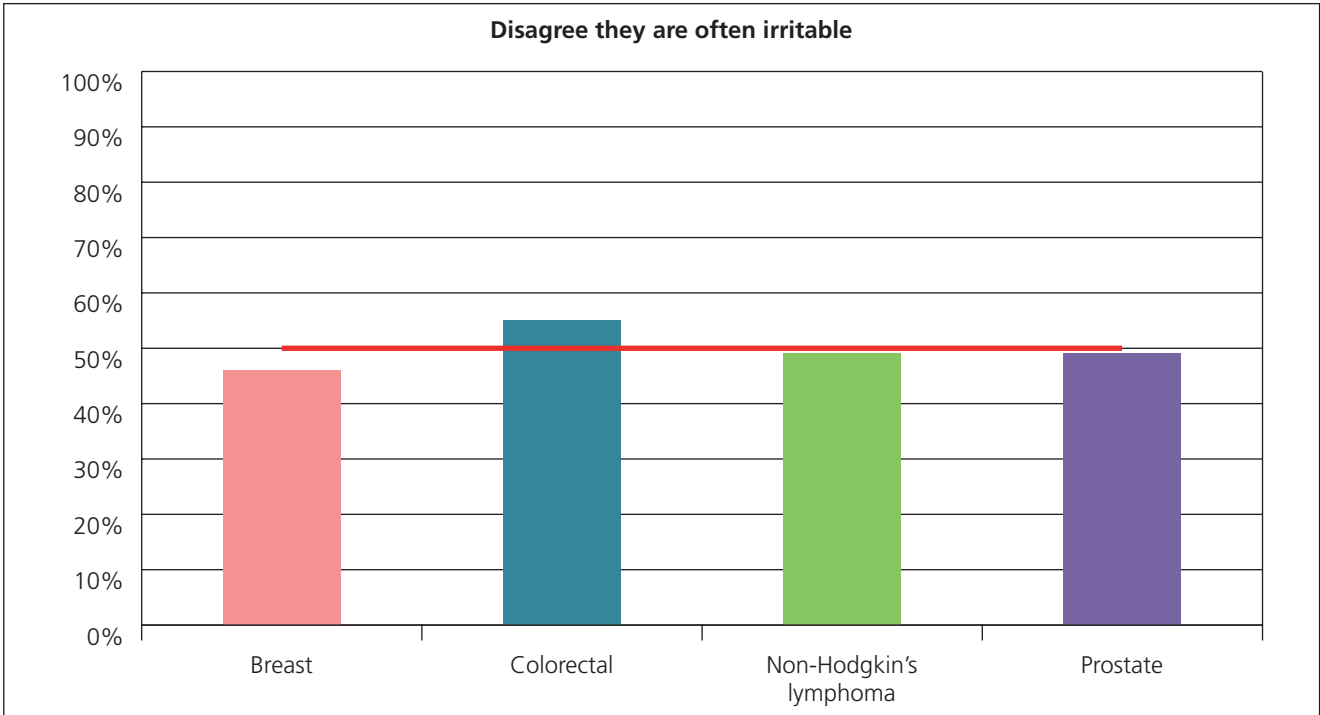
5.77 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

## I am often irritable

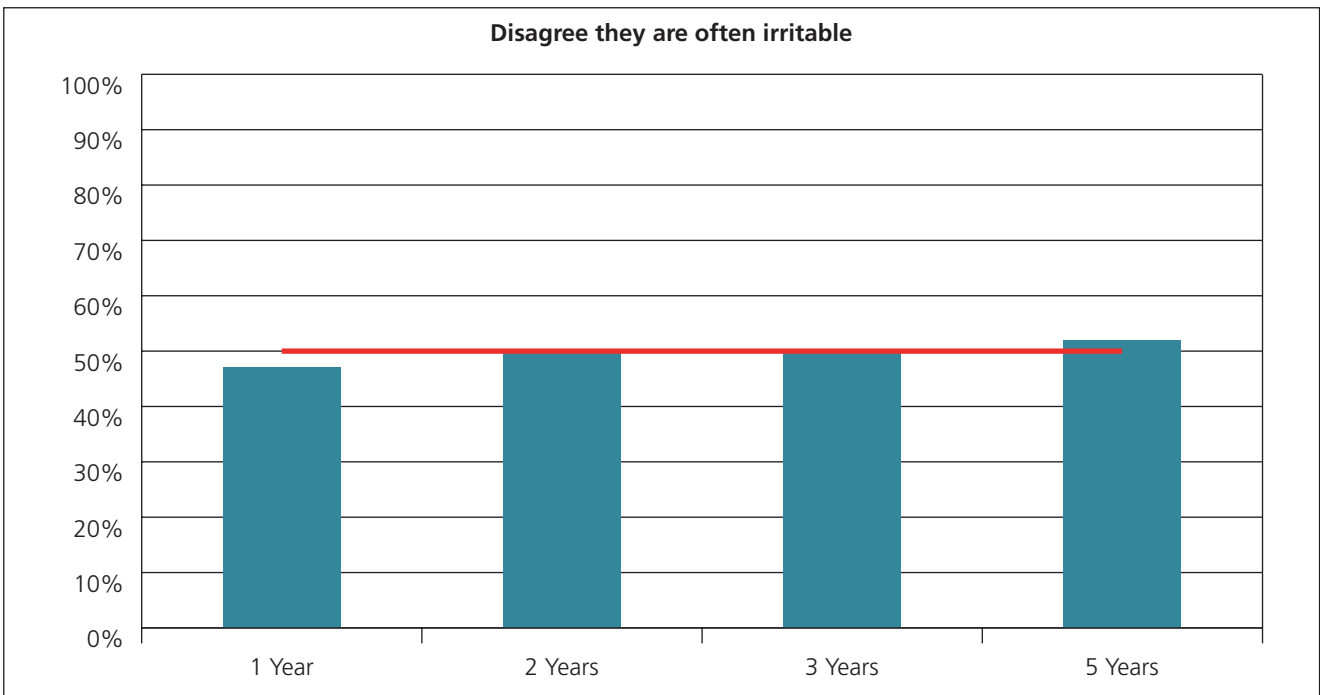
### Overall findings

5.78 50% of patients said they disagreed (29%) or strongly disagreed (21%) that they were often irritable; 7% strongly agreed, 23% agreed, and 20% neither agreed nor disagreed.

**Chart 5.73: Findings by Tumour Group**



**Chart 5.74: Findings by Time Cohort**



## Overall support and care

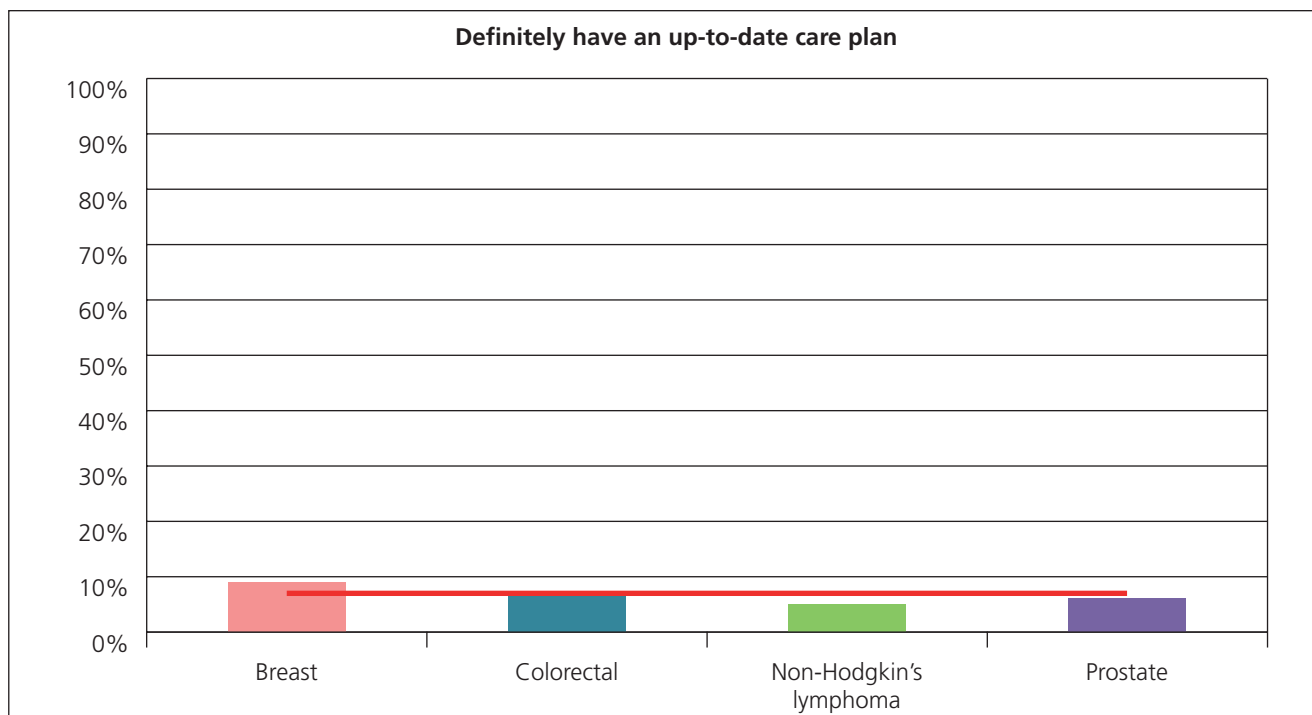
The questions in this section concerned overall patient perceptions about care plans, contact points, care in the community and information.

### Do you have an up-to-date written care plan?

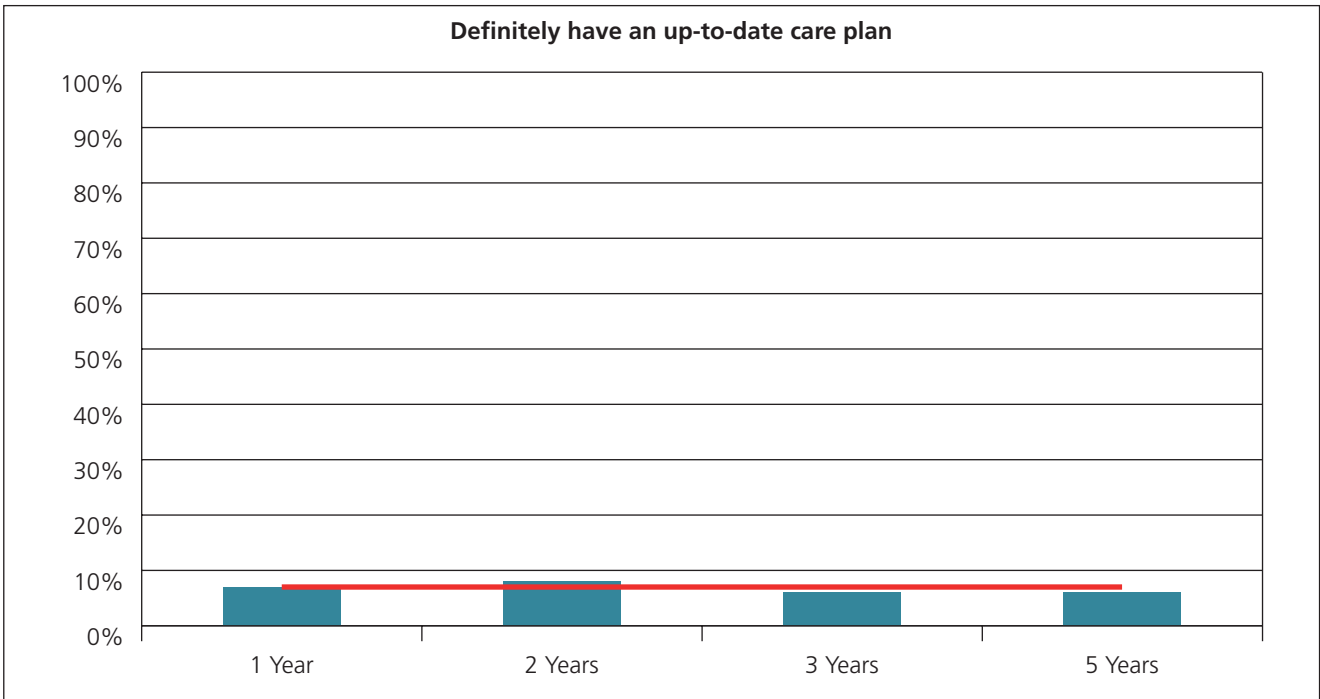
#### Overall findings

5.79 7% of patients said they definitely had an up-to-date care plan; 9% said they thought they did and 84% said they did not have one. 36% said they did not need a care plan and 5% said they did not know.

**Chart 5.75: Findings by Tumour Group**



**Chart 5.76: Findings by Time Cohort**

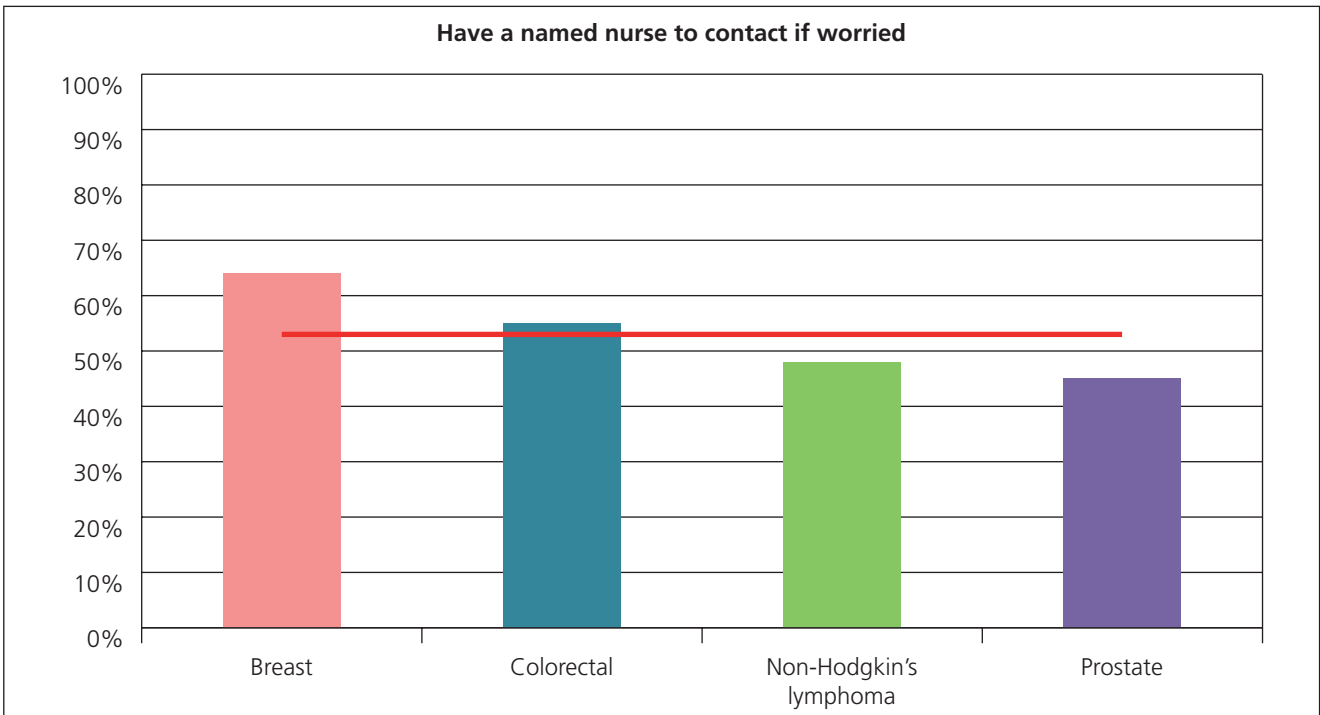


**Do you have a named nurse who you can contact if you have a worry about your cancer care?**

**Overall findings**

5.80 53% of patients said they did have a named nurse; 47% said they did not have one. 7% said they did not know.

**Chart 5.77: Findings by Tumour Group**



5.81 There were significant differences between the scores for tumour groups on this question when tests for difference were applied across all tumour groups.

**Chart 5.78: Findings by Time Cohort**



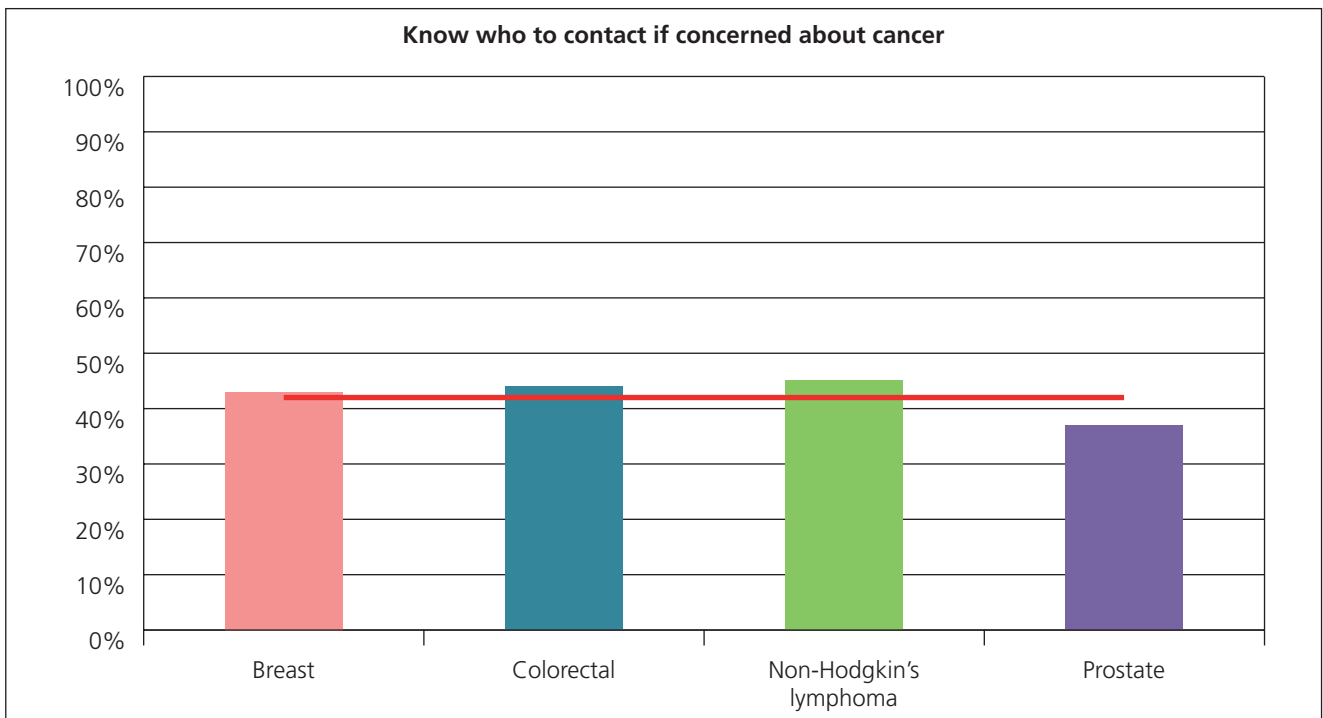
5.82 There were significant differences between the one year time cohort and all other time cohorts. There were also significant differences between the five year cohort and all other time cohorts.

**Do you know who to contact if you have a concern about any aspect of living with or after cancer?**

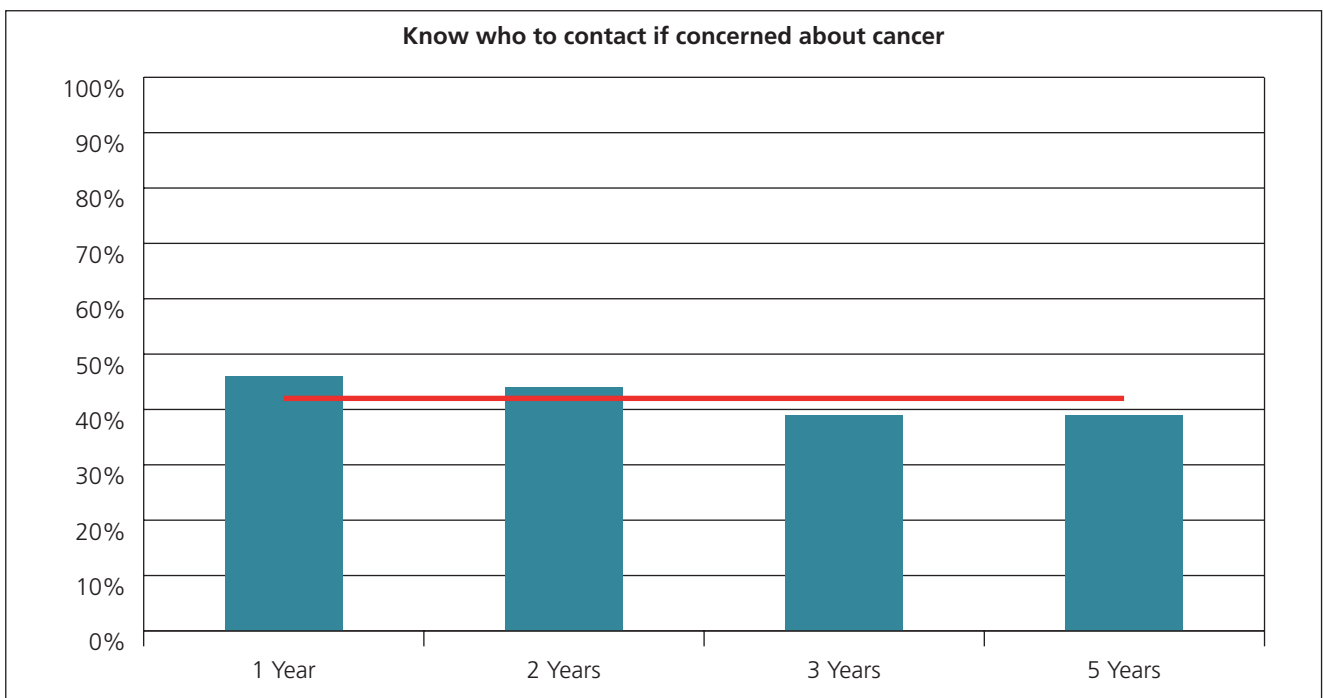
### Overall findings

5.83 42% of patients said they definitely knew who to contact; 34% said they thought they did and 24% said they did not know who to contact.

**Chart 5.79: Findings by Tumour Group**



**Chart 5.80: Findings by Time Cohort**



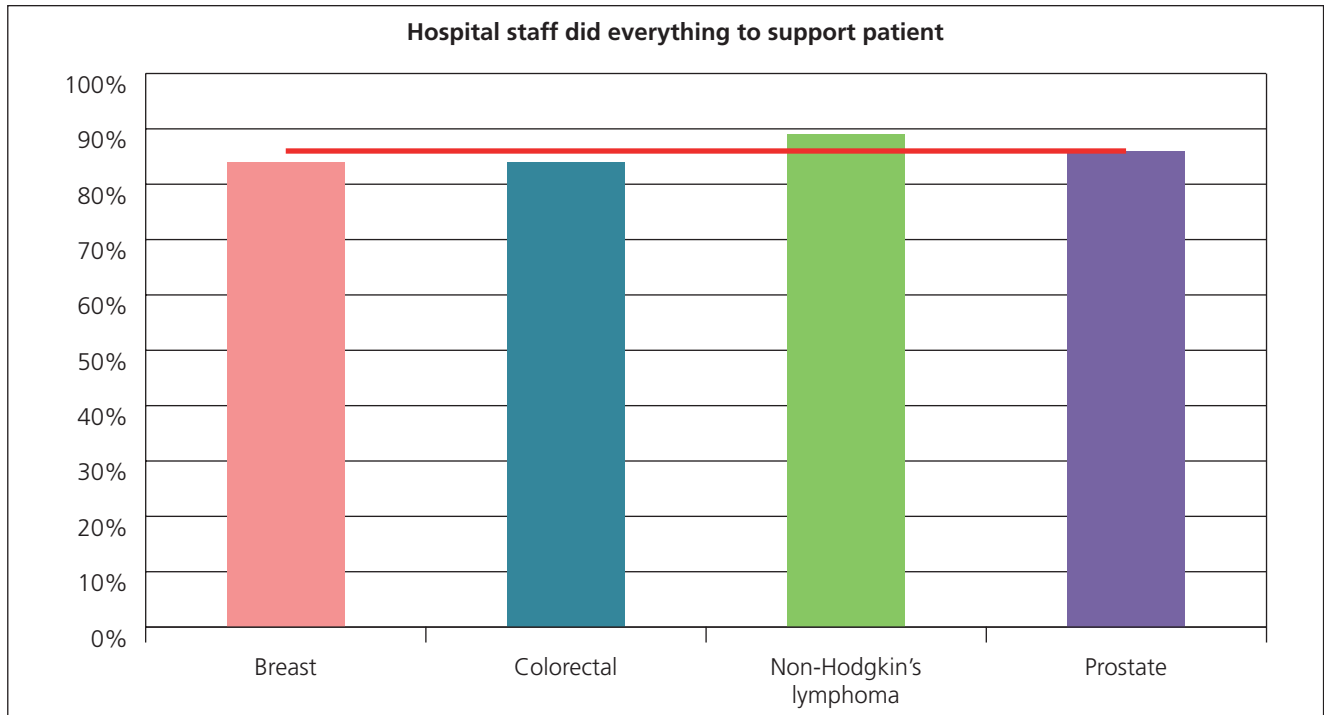
5.84 There were significant differences between the one year time cohort and all other time cohorts. There re also significant differences between the five year cohort and all other time cohorts.

**Do you think that hospital staff did everything they could to support you following your cancer treatment?**

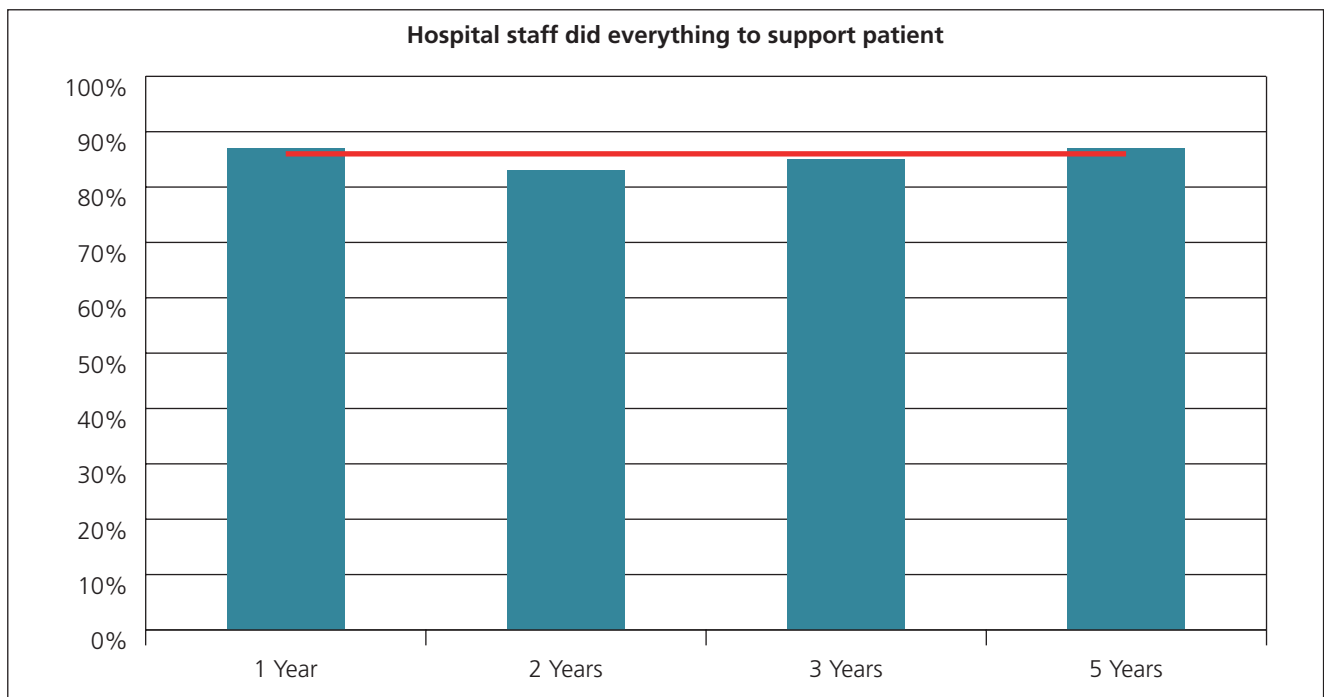
**Overall findings**

5.85 86% of patients said that hospital staff supported them all of the time; 12% said they did only some of the time and 2% said they never did, 12% said they did not need any support.

**Chart 5.81: Findings by Tumour Group**



**Chart 5.82: Findings by Time Cohort**

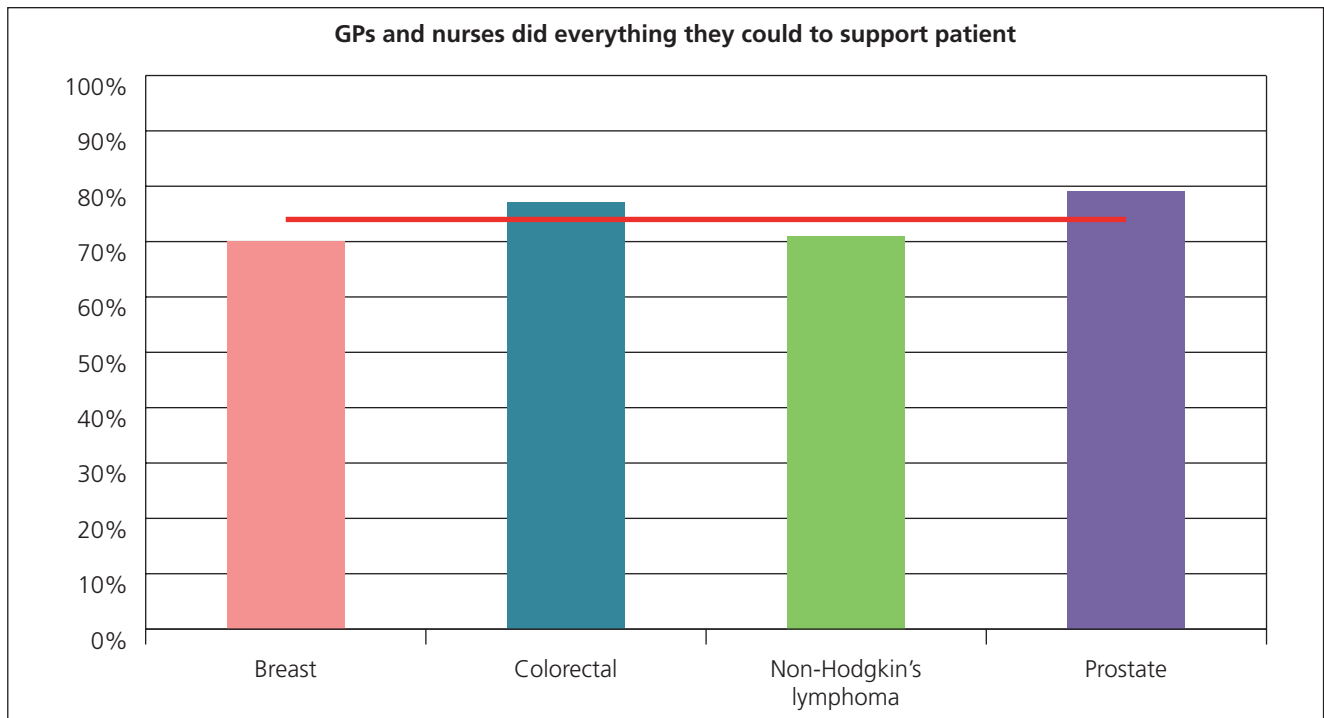


**Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?**

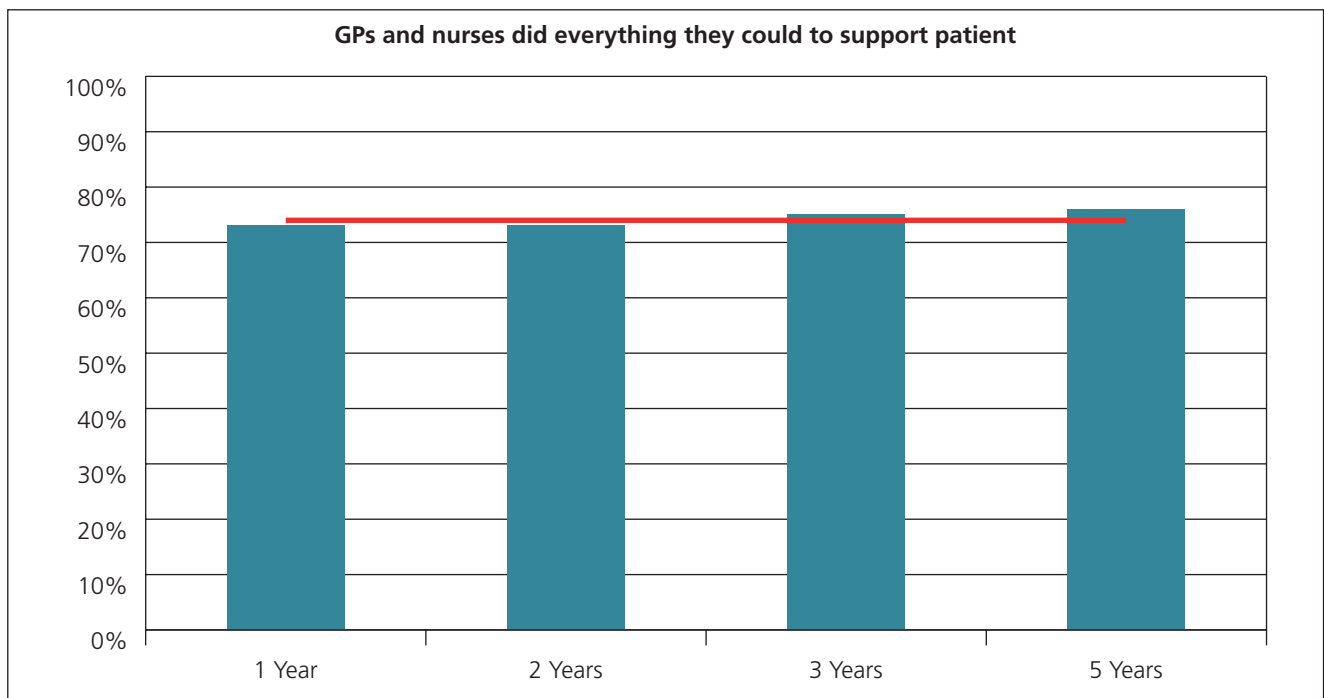
**Overall findings**

5.86 74% of patients said that GPs and nurses supported them all of the time; 19% said they did only some of the time and 7% said they never did, 20% said their general practice was not involved and 11% said they did not need any support.

**Chart 5.83: Findings by Tumour Group**



**Chart 5.84: Findings by Time Cohort**



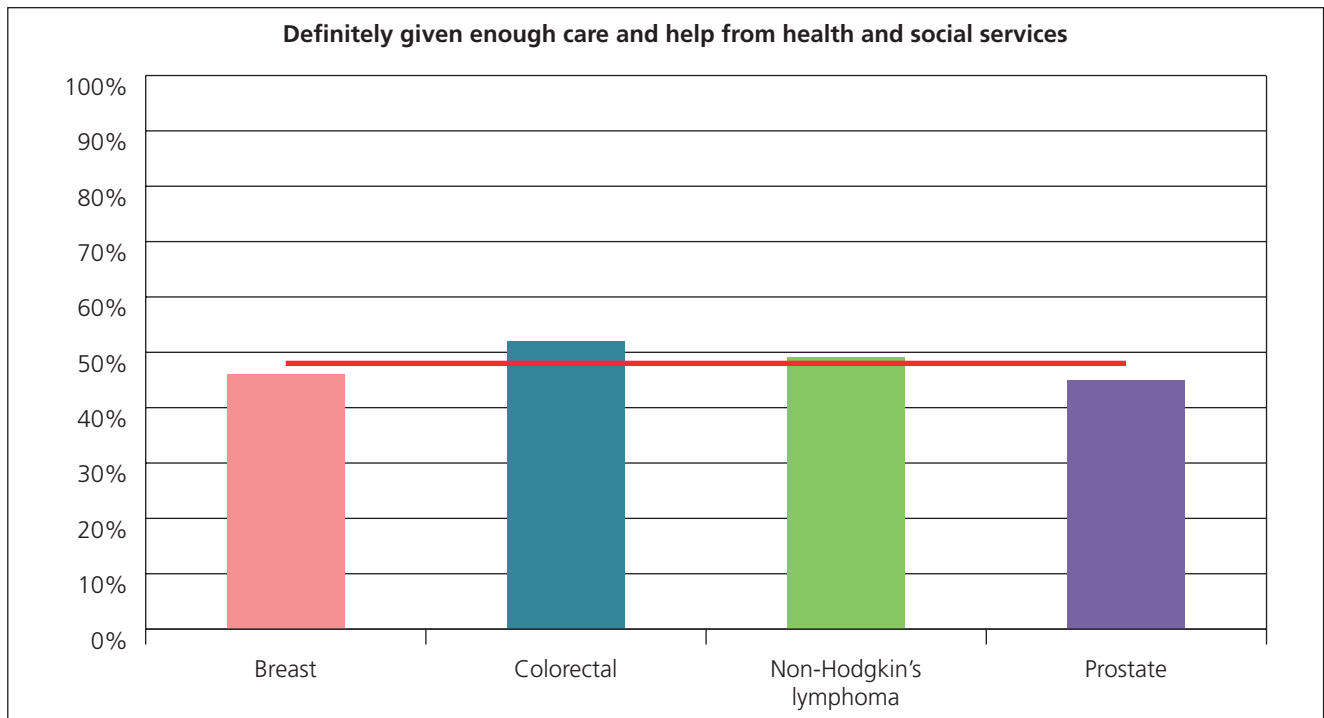


**Following your initial cancer treatment, have you been given enough care and help from health and social services?**

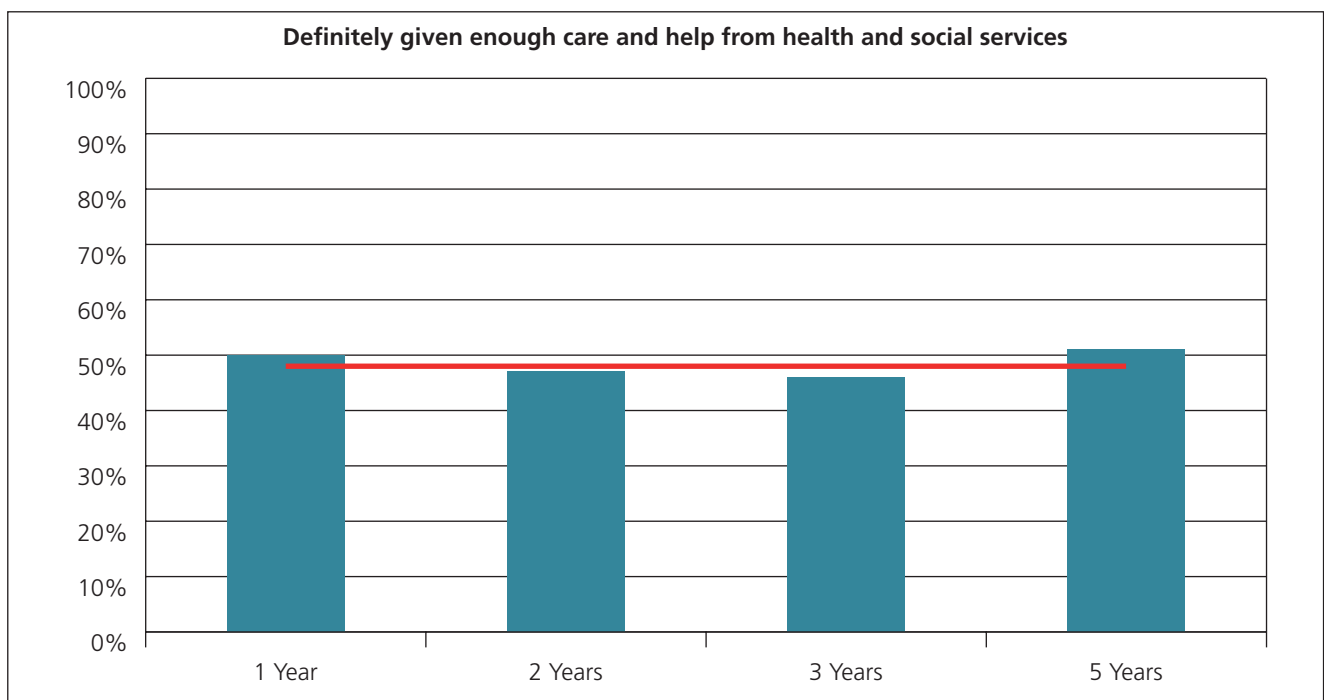
**Overall findings**

5.87 48% of patients said they had definitely been given enough care and help from health and social services; 25% said they had to some extent and 26% said they had not been given enough help. 48% said they did not need any help and 1% said they did not know.

**Chart 5.85: Findings by Tumour Group**



**Chart 5.86: Findings by Time Cohort**

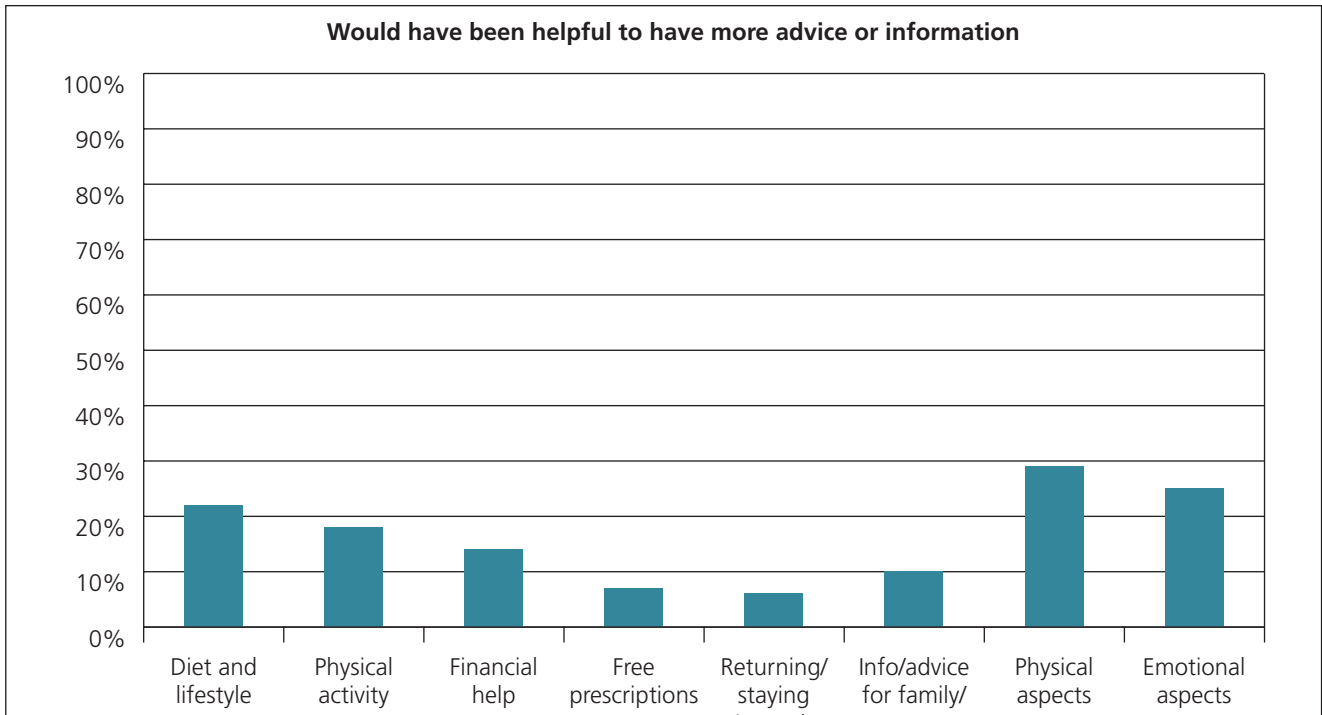


**Would it have been helpful to have had more advice or information on any of the following issues.**

**Overall findings**

5.88 The chart shows the proportions of patients who said that it would have been helpful to have had more advice or information on the issues listed.

**Chart 5.87:**



5.89 Patients said that it would have been helpful to have had more advice or information on the physical aspects of living with and after cancer, the emotional aspects and diet/lifestyle.

## 6. Cancer specific questions

This section of the report describes the results for all those questions in the survey which were specific to particular cancer types. All questions were displayed in the same format as the generic questions.

### Breast Cancer

#### Questions about treatment and procedures

##### **What treatments have you received for your breast cancer?**

###### Overall findings

6.1 72% of patients said they had received radiotherapy, 36% had received chemotherapy, 46% had hormone treatment, and 84% surgery.

##### **If you have had breast surgery, do any of the following apply to you?**

###### Overall findings

6.2 57% of patients said they had had a lumpectomy, 38% had a mastectomy, and 12% had had breast reconstruction. 4% said they were waiting to be considered for breast reconstruction. 8% said they had had none of the listed procedures.

## Functional Assessment of Cancer Therapy (FACT) questions

6.3 This set of questions was taken from the FACT-B questionnaire specifically for breast cancer patients.

### I have been short of breath

#### Overall findings

6.4 64% of patients said they had not been short of breath at all, 23% said they were a little, 7% somewhat, 4% quite a bit, and 2% very much.

**Chart 6.1: Findings by Time Cohort**

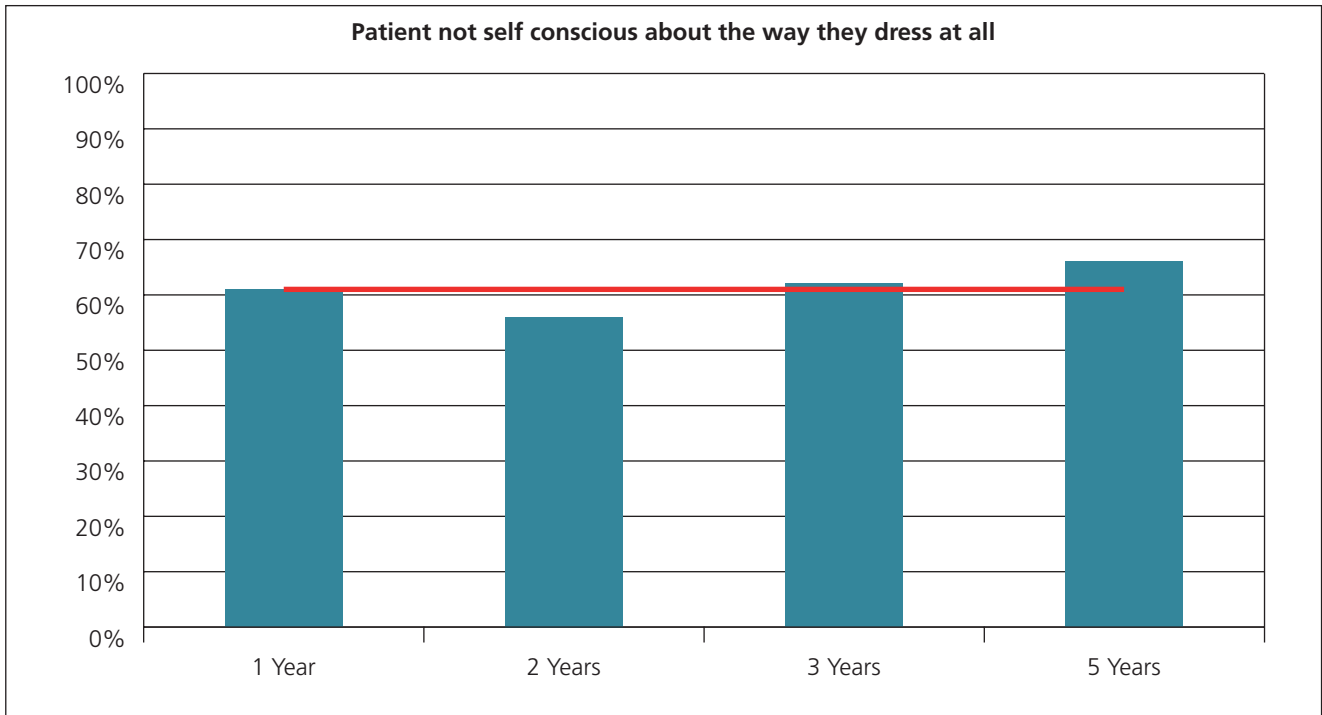


## I am self conscious about the way I dress

### Overall findings

6.5 61% of patients said they were not self conscious about the way they dressed at all, 19% said they were a little, 7% somewhat, 7% quite a bit, and 5% very much.

**Chart 6.2: Findings by Tumour Group**



## One or both of my arms are swollen or tender

### Overall findings

6.6 72% of patients said their arms were not at all swollen or tender, 16% said they were a little, 5% somewhat, 5% quite a bit, and 2% very much.

**Chart 6.3: Findings by Time Cohort**

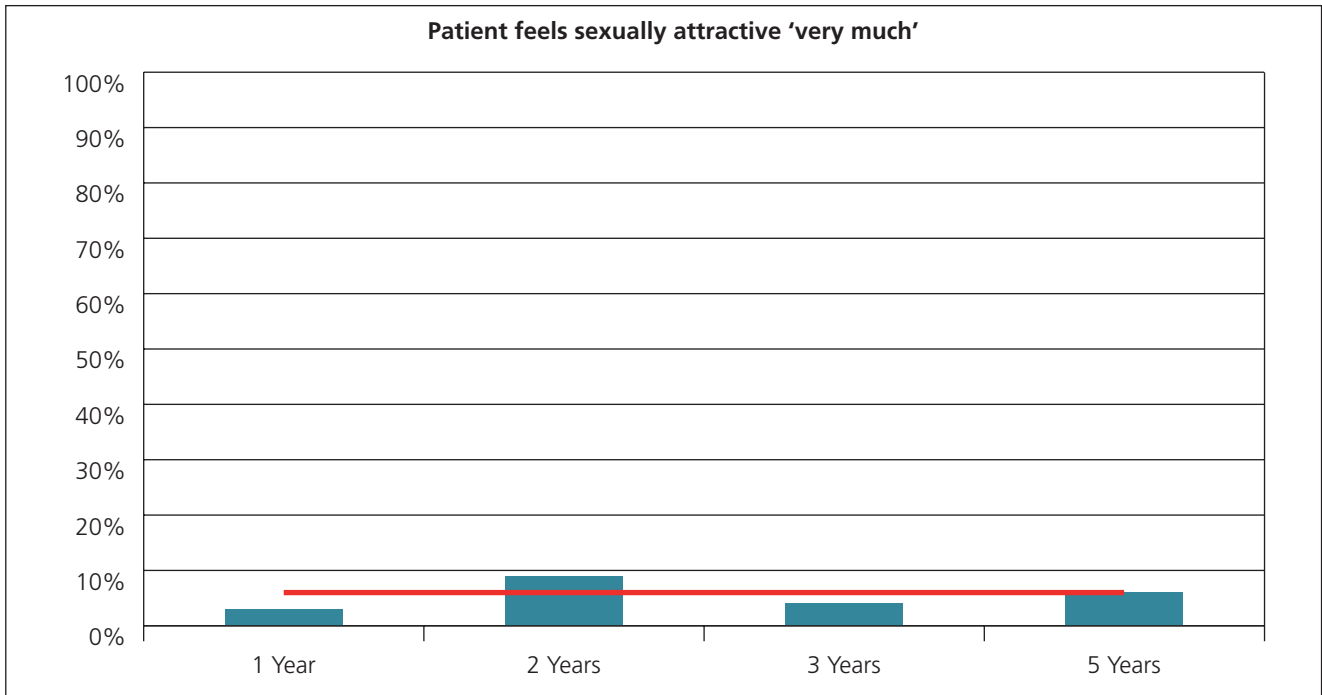


## I feel sexually attractive

### Overall findings

6.7 6% of patients said they felt sexually attractive 'very much', 9% said they did quite a bit, 21% somewhat, 22% a little bit, and 42% not at all.

**Chart 6.4: Findings by Time Cohort**

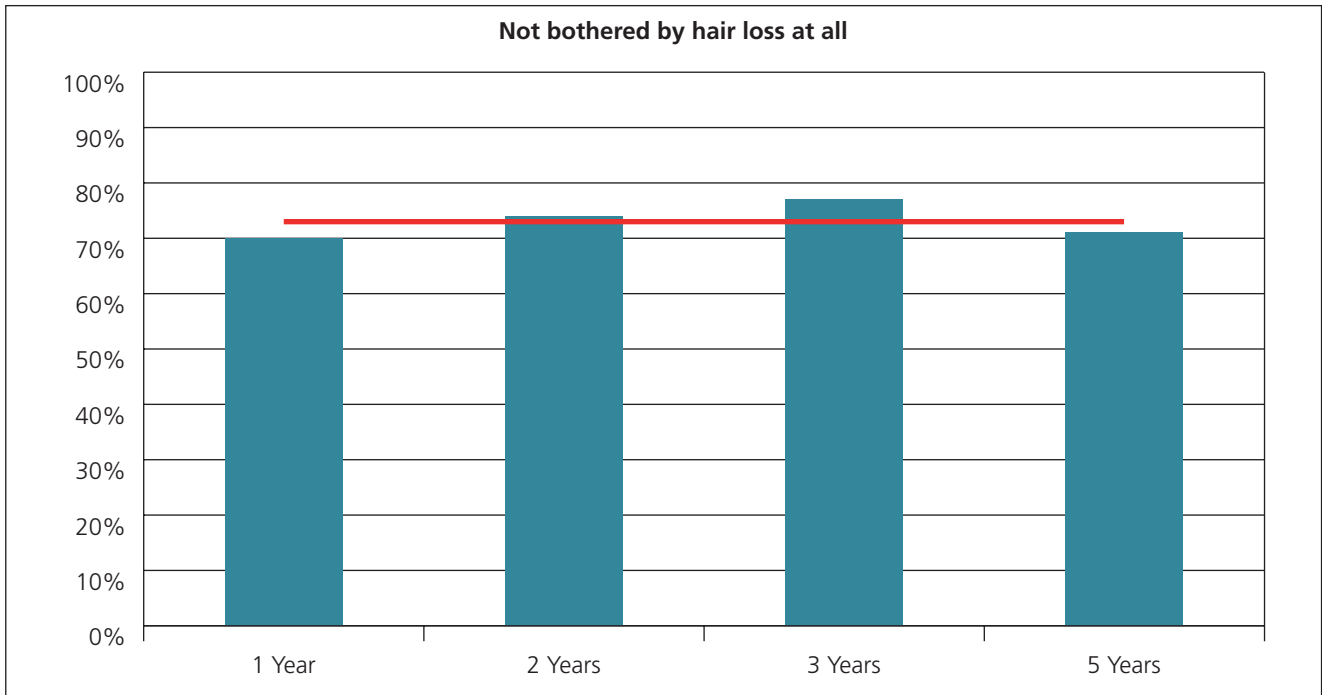


## I am bothered by hair loss

### Overall findings

6.8 73% of patients said they were not bothered by hair loss at all, 13% said they were a little, 5% somewhat, 3% quite a bit, and 6% very much.

### Chart 6.5: Findings by Time Cohort



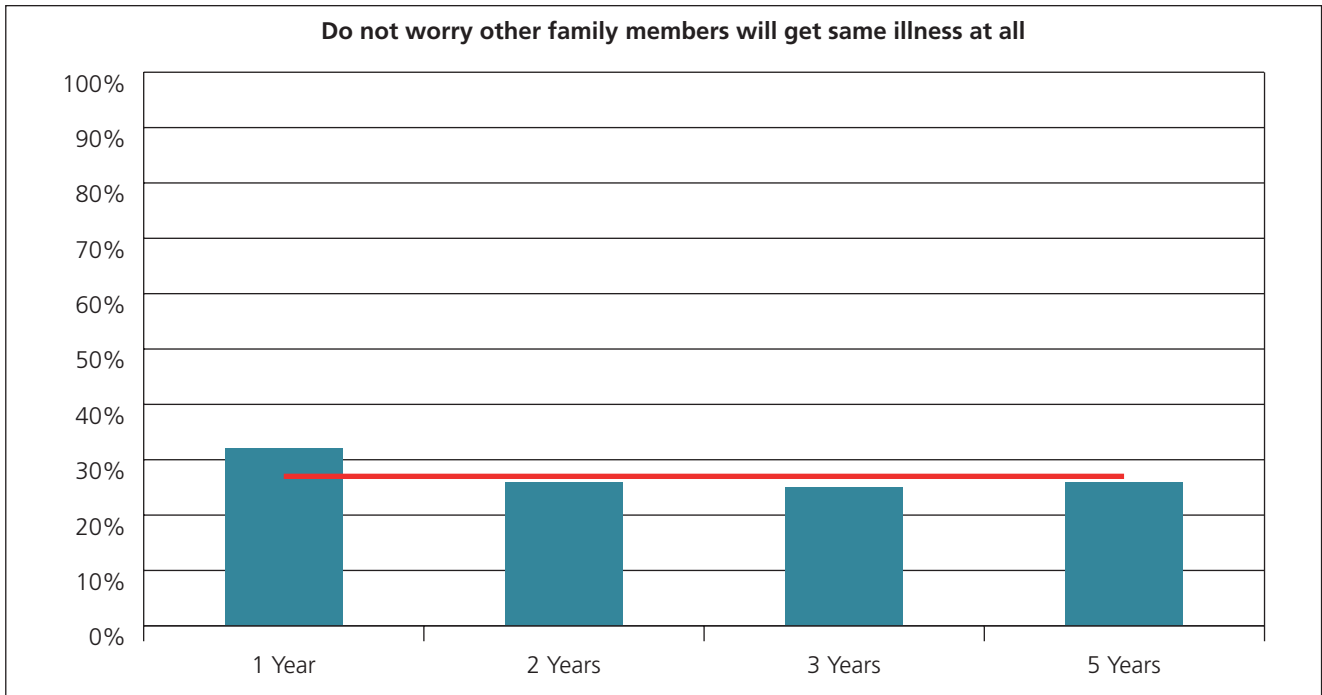


## I worry that other members of my family might someday get the same illness I have

### Overall findings

6.9 27% of patients said they were not at all worried that other members of their family might someday get the same illness, 30% said they were a little, 11% somewhat, 12% quite a bit, and 19% very much.

**Chart 6.6: Findings by Time Cohort**

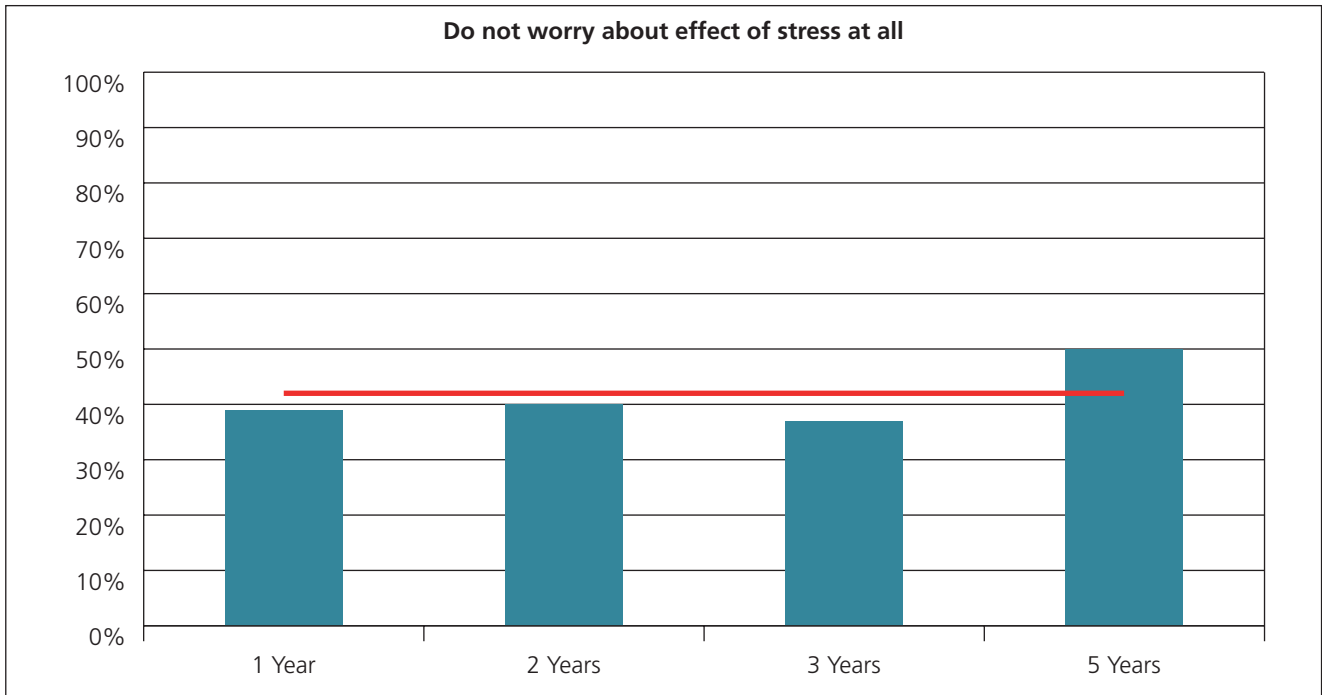


## I worry about the effect of stress on my illness

### Overall findings

6.10 42% of patients said they were not at all worried about the effects of stress on their illness, 25% said they were a little, 12% somewhat, 13% quite a bit, and 9% very much.

### Chart 6.7: Findings by Time Cohort

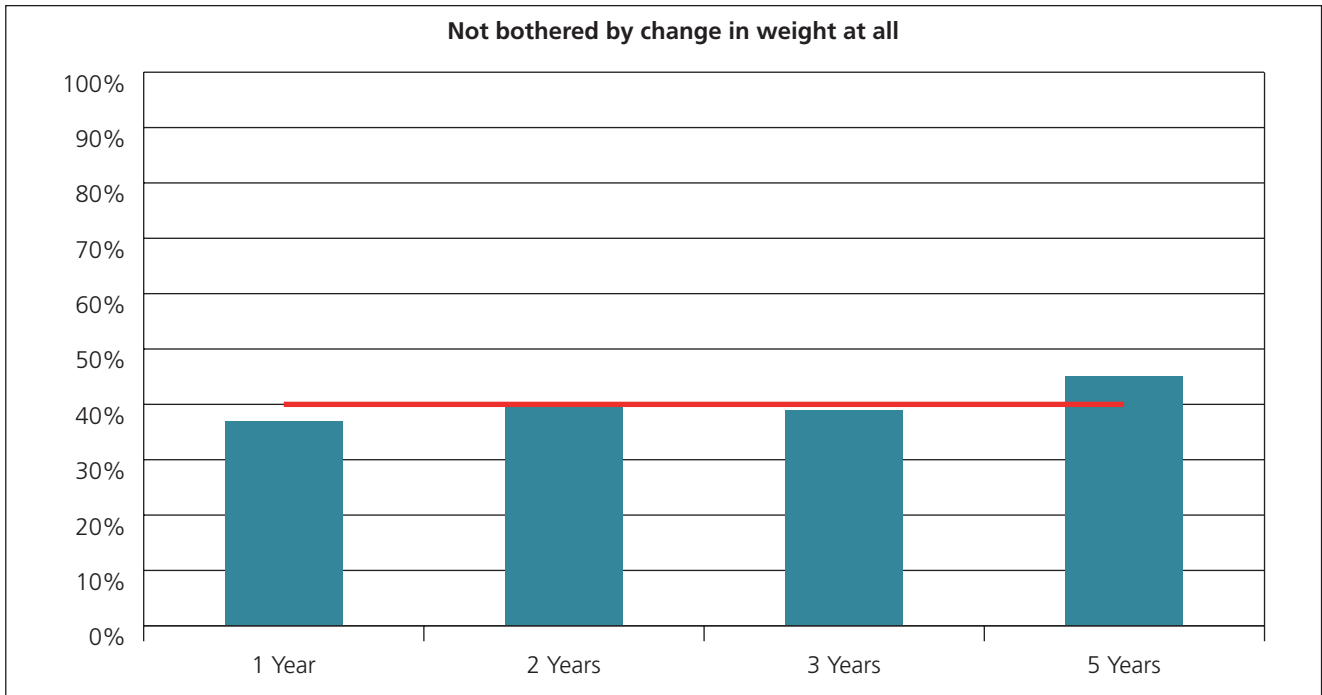


## I am bothered by a change in weight

### Overall findings

6.11 40% of patients said they were not at all bothered by a change in weight, 25% said they were a little, 11% somewhat, 11% quite a bit, and 13% very much.

**Chart 6.8: Findings by Time Cohort**

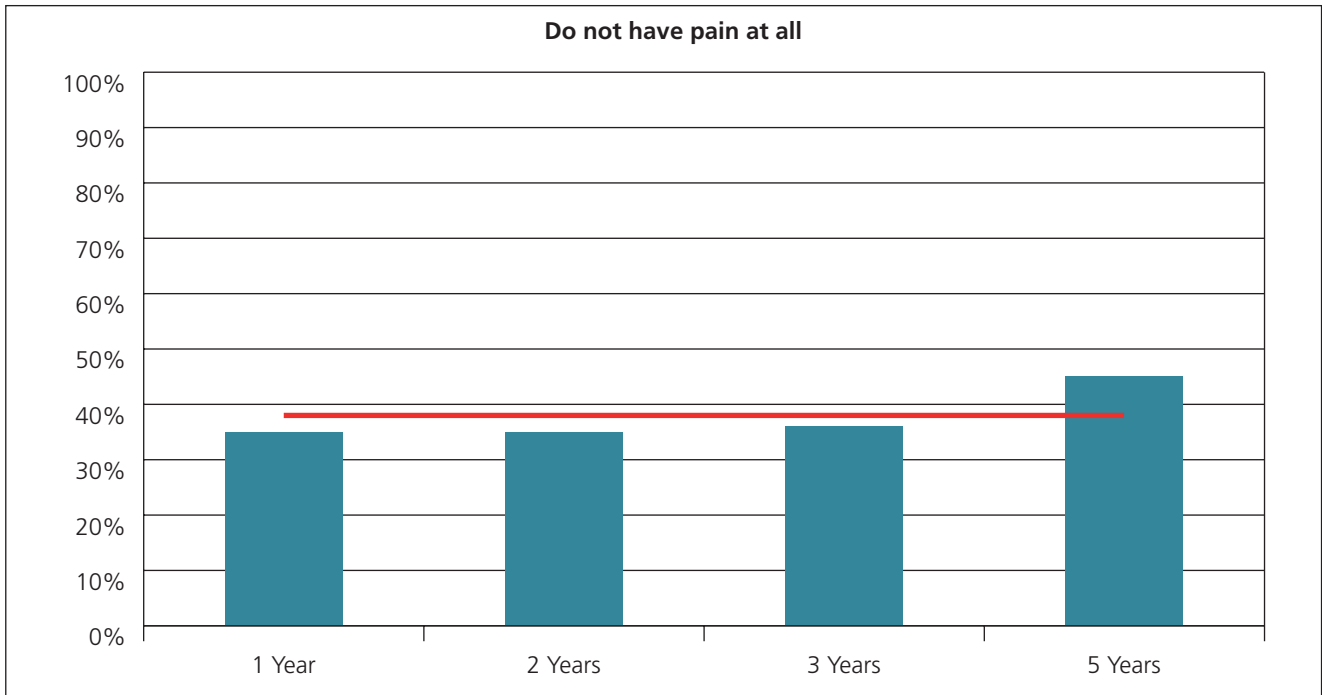


## I have certain parts of my body where I experience pain

### Overall findings

6.12 38% of patients said they did not have certain parts of their body where they experienced pain at all, 30% said they did a little, 14% somewhat, 9% quite a bit, and 9% very much.

**Chart 6.9: Findings by Time Cohort**



# Colorectal Cancer

## Questions about treatment and procedures

### What treatments have you received for your colorectal/GI cancer?

#### Overall findings

6.13 19% of patients said they had received radiotherapy, 47% had received chemotherapy, and 90% surgery.

### If you have a stoma (e.g. colostomy) is it:

#### Overall findings

6.14 22% of patients said their stoma was still present and 18% said it was reversed. 60% said this did not apply to them.

## Functional Assessment of Cancer Therapy (FACT) questions

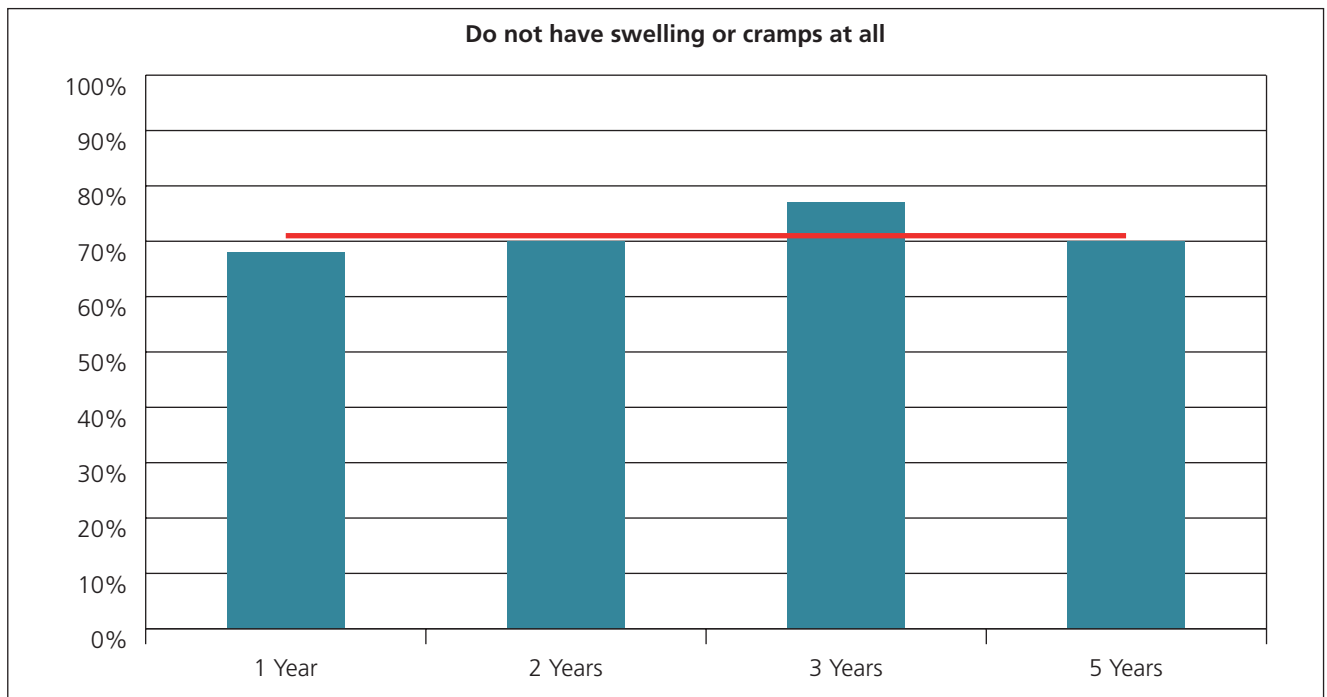
6.15 This set of questions was taken from the FACT-C questionnaire specifically for colorectal cancer patients. Some changes and additions were made to these questions.

### I have swelling or cramps in my stomach area

#### Overall findings

6.16 71% of patients said they did not have swelling or cramps at all, 17% said they did a little, 5% somewhat, 5% quite a bit, and 2% very much.

**Chart 6.10: Findings by Time Cohort**

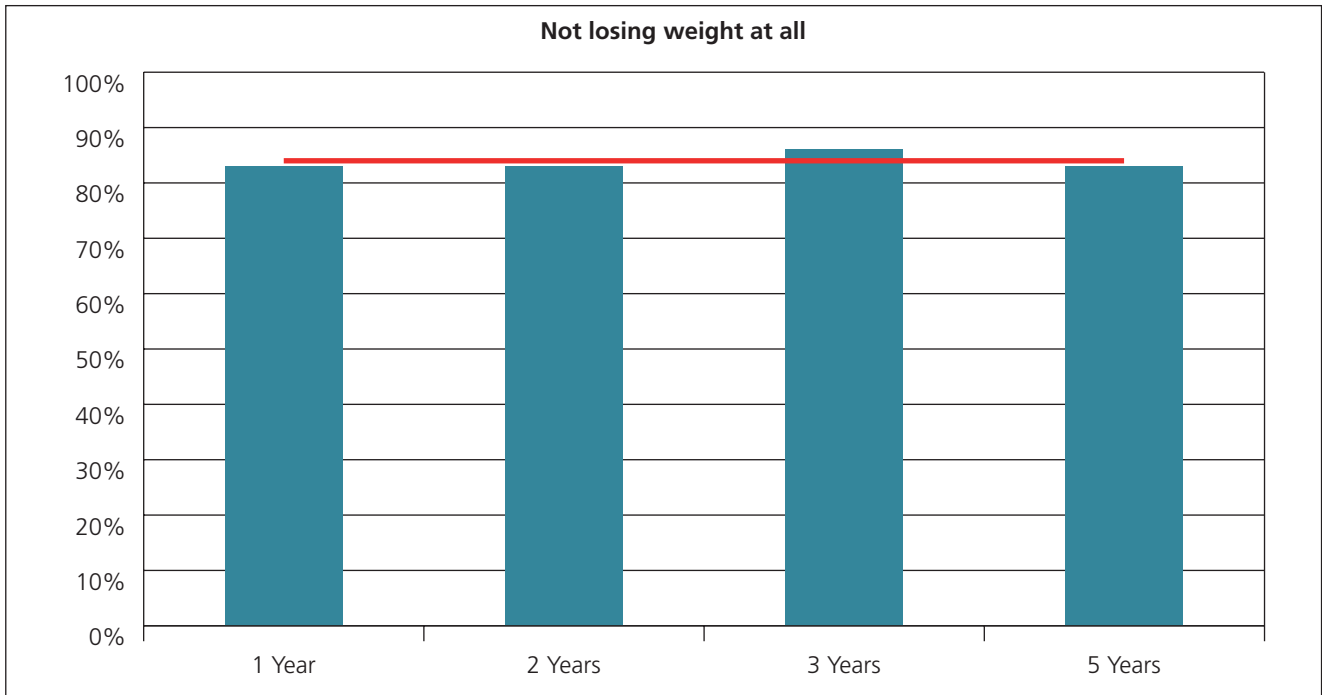


## I am losing weight

### Overall findings

6.17 84% of patients said they were not losing weight at all, 10% said they were a little, 3% somewhat, 2% quite a bit, and 1% very much.

**Chart 6.11: Findings by Time Cohort**

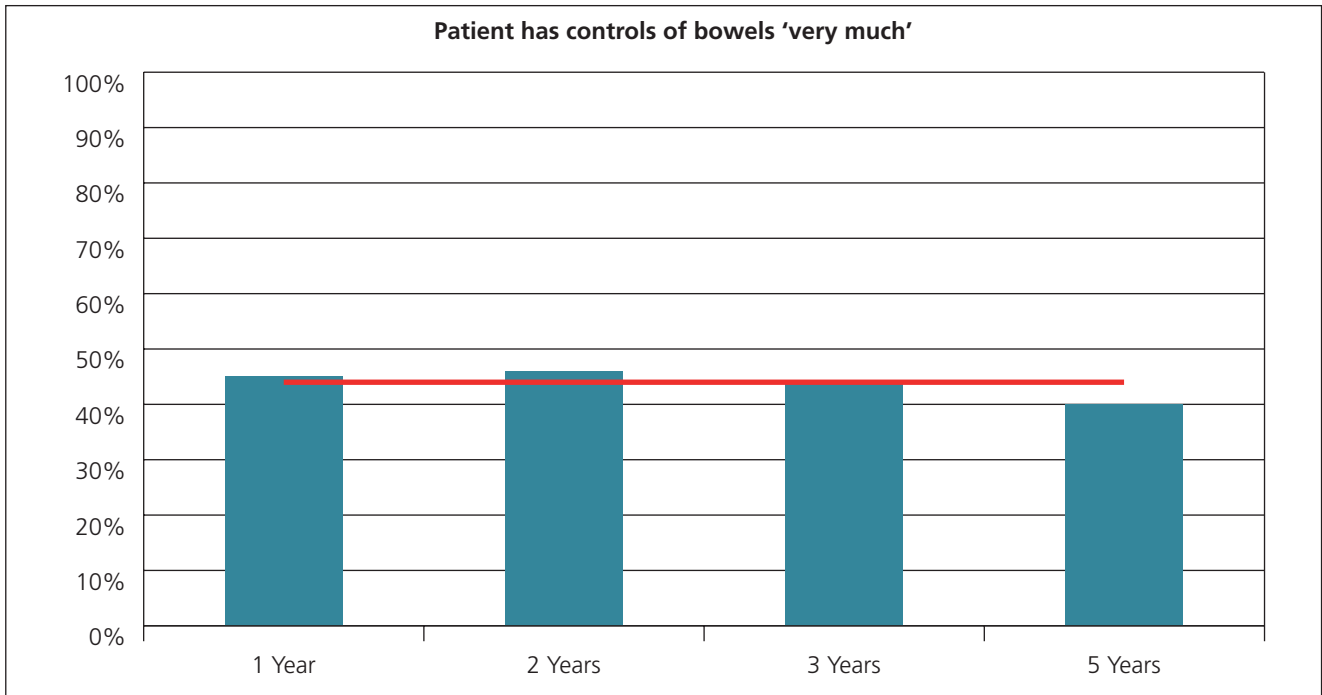


## I have control of my bowels

### Overall findings

6.18 44% of patients said they had control of their bowels 'very much', 17% said they did quite a bit, 13% somewhat, 6% a little bit, and 21% not at all.

**Chart 6.12: Findings by Time Cohort**

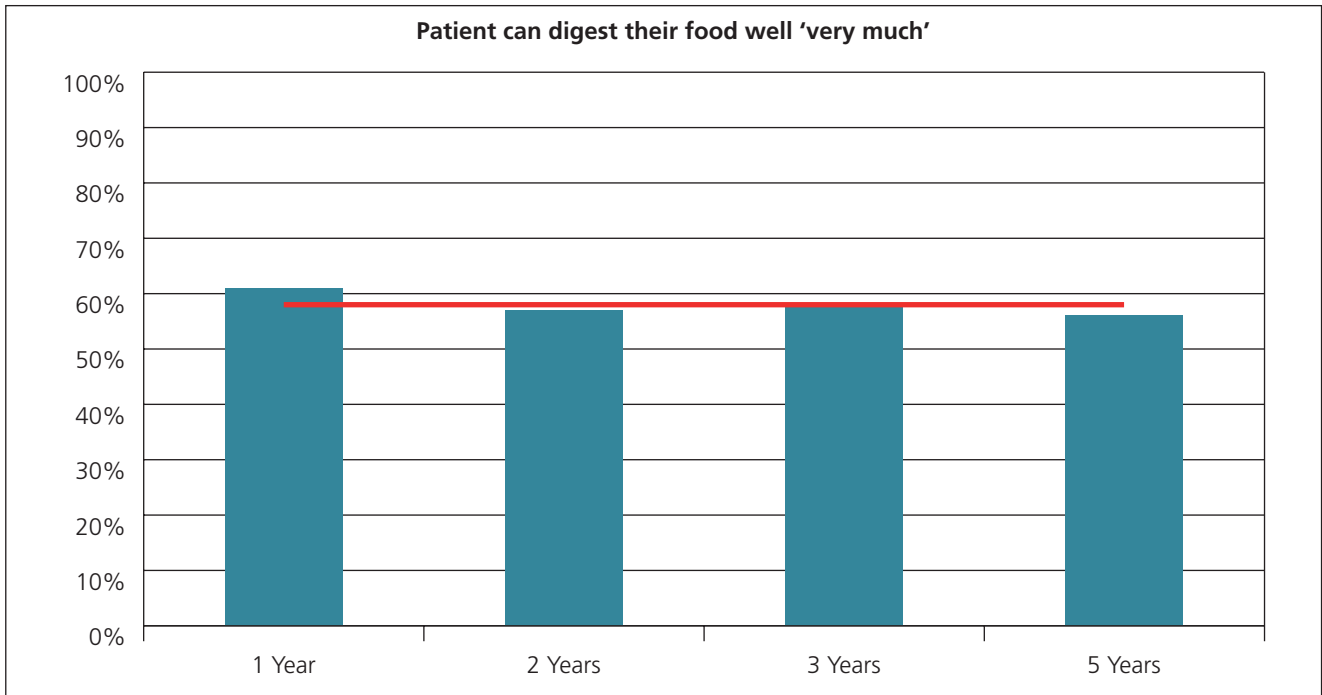


## I can digest my food well

### Overall findings

6.19 58% of patients said they could digest their food well 'very much', 16% said they could quite a bit, 9% somewhat, 4% a little bit, and 14% not at all.

**Chart 6.13: Findings by Time Cohort**



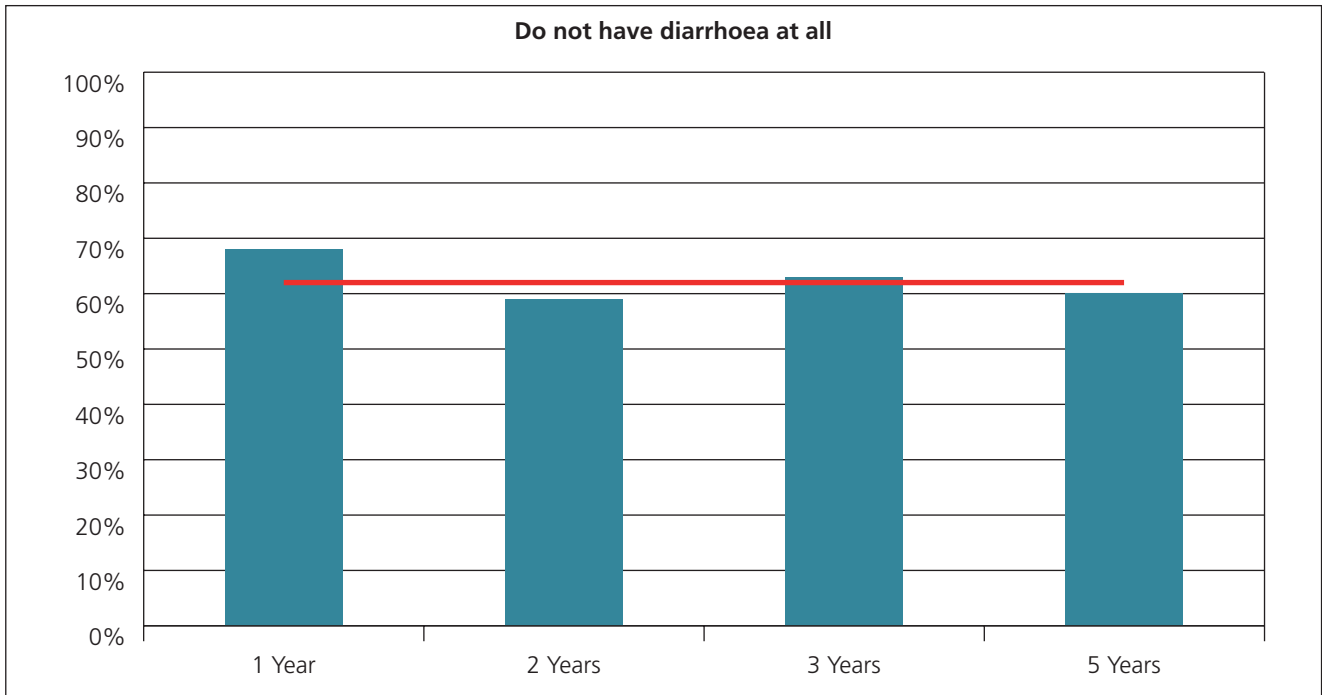


## I have diarrhoea

### Overall findings

6.20 62% of patients said they did not have diarrhoea at all, 22% said they did a little, 6% somewhat, 6% quite a bit, and 3% very much.

**Chart 6.14: Findings by Time Cohort**

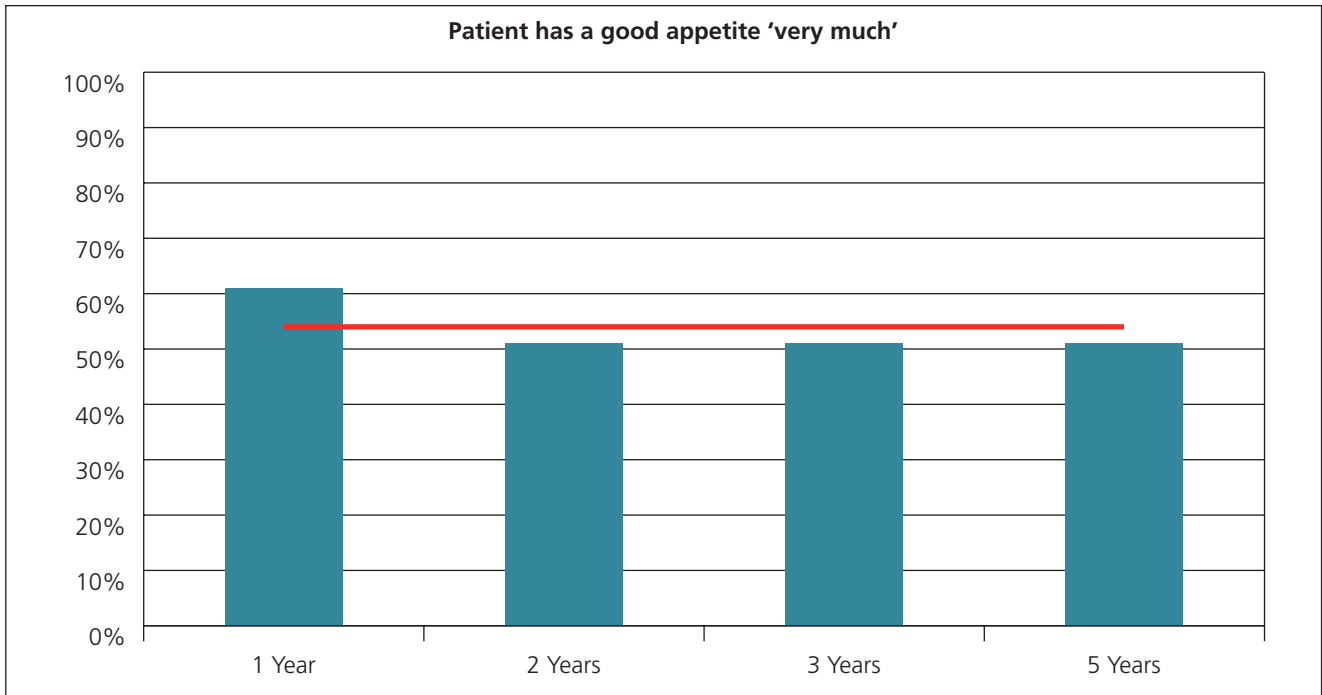


## I have a good appetite

### Overall findings

6.21 54% of patients said they had a good appetite 'very much', 16% said they did quite a bit, 12% somewhat, 5% a little bit, and 14% not at all.

**Chart 6.15: Findings by Time Cohort**

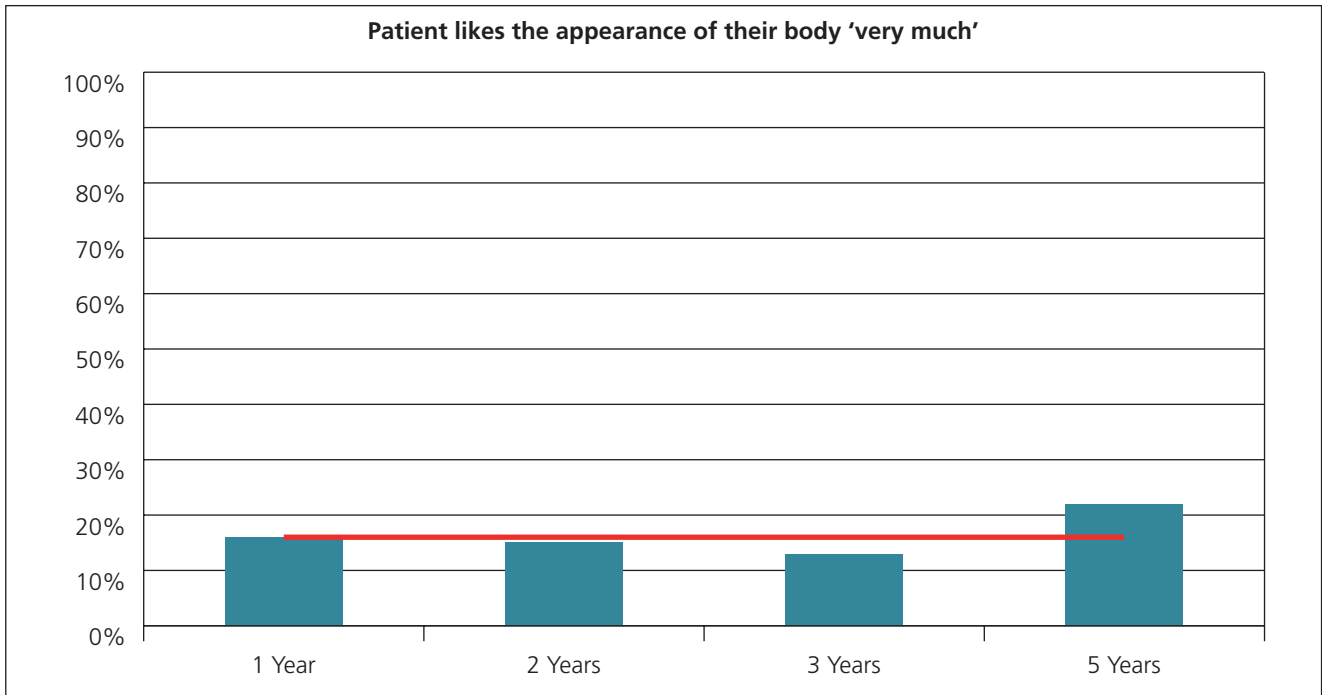


## I like the appearance of my body

### Overall findings

6.22 16% of patients said they liked the appearance of their body 'very much', 18% said they did quite a bit, 25% somewhat, 17% a little bit, and 23% not at all.

**Chart 6.16: Findings by Time Cohort**

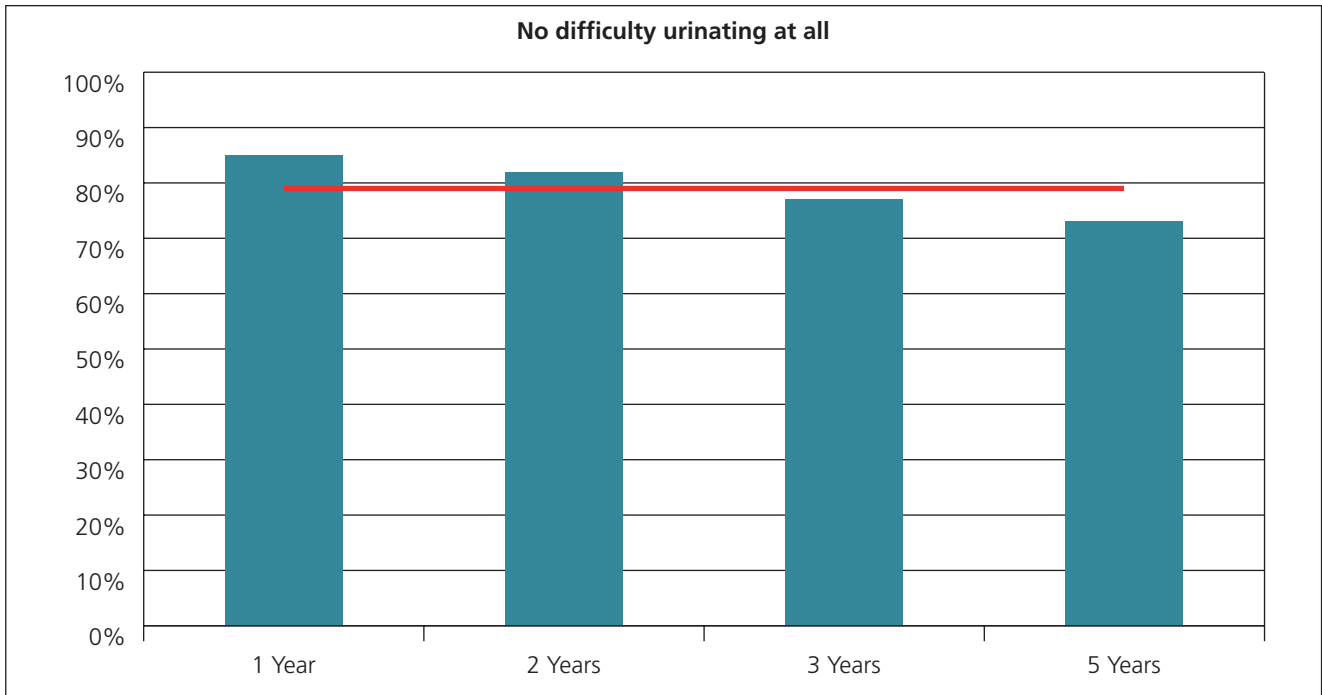


## I have difficulty urinating

### Overall findings

6.23 79% of patients said they did not have difficulty urinating at all, 14% said they did a little, 3% somewhat, 2% quite a bit, and 2% very much.

**Chart 6.17: Findings by Time Cohort**

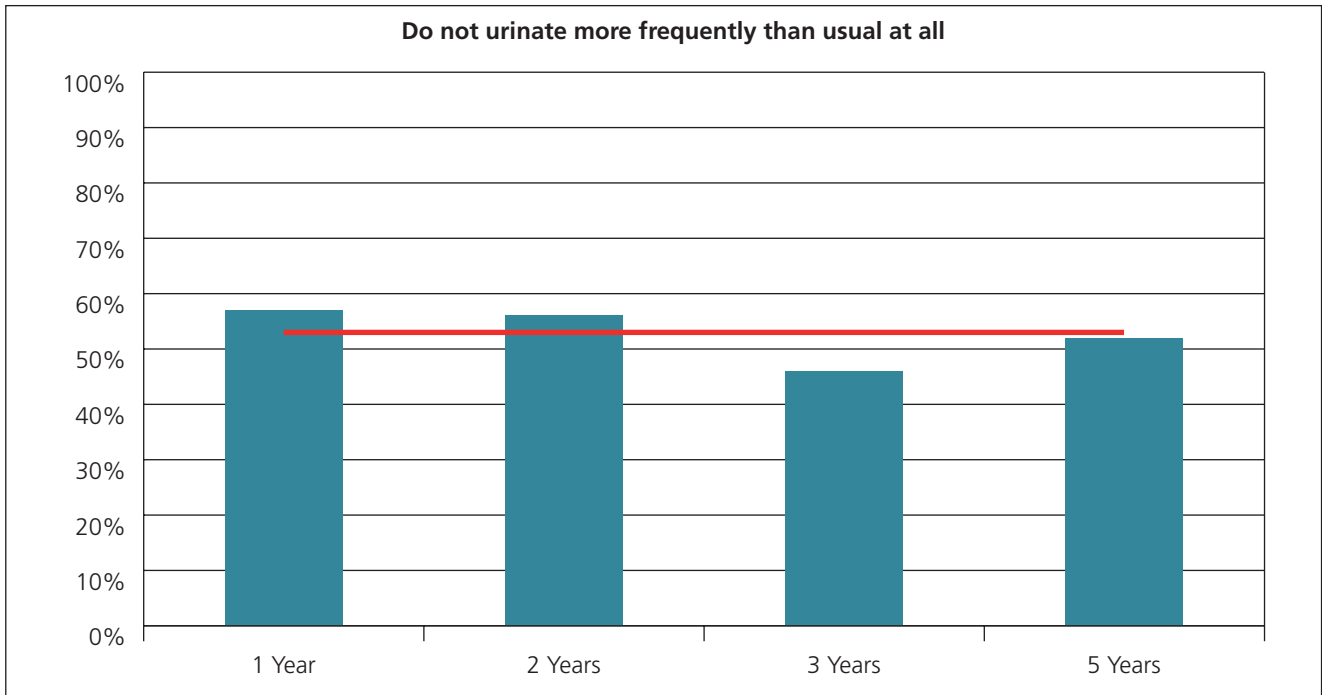


## I urinate more frequently than usual

### Overall findings

6.24 53% of patients said they did not urinate more frequently than usual at all, 25% said they did a little, 9% somewhat, 8% quite a bit, and 4% very much.

**Chart 6.18: Findings by Time Cohort**

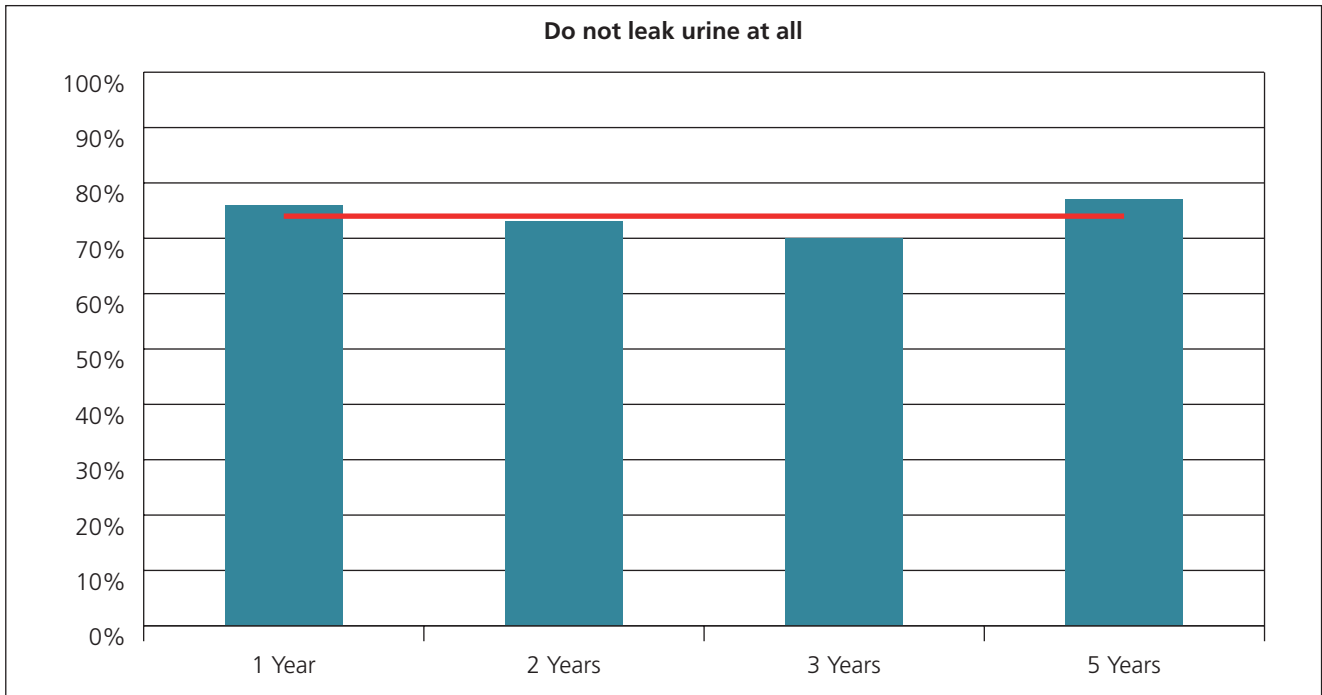


## I leak urine

### Overall findings

6.25 74% of patients said they did not leak urine at all, 18% said they did a little, 4% somewhat, 2% quite a bit, and 2% very much.

**Chart 6.19: Findings by Time Cohort**



## Do you have an ostomy appliance/stoma?

### Overall findings

6.26 20% of patients said they did have an ostomy appliance/stoma, 80% said they did not.

## I am embarrassed by my ostomy appliance/stoma

### Overall findings

6.27 44% of patients said they were not embarrassed by their ostomy appliance/stoma at all, 30% said they were a little, 10% somewhat, 5% quite a bit, and 12% very much.

**Chart 6.20: Findings by Time Cohort**

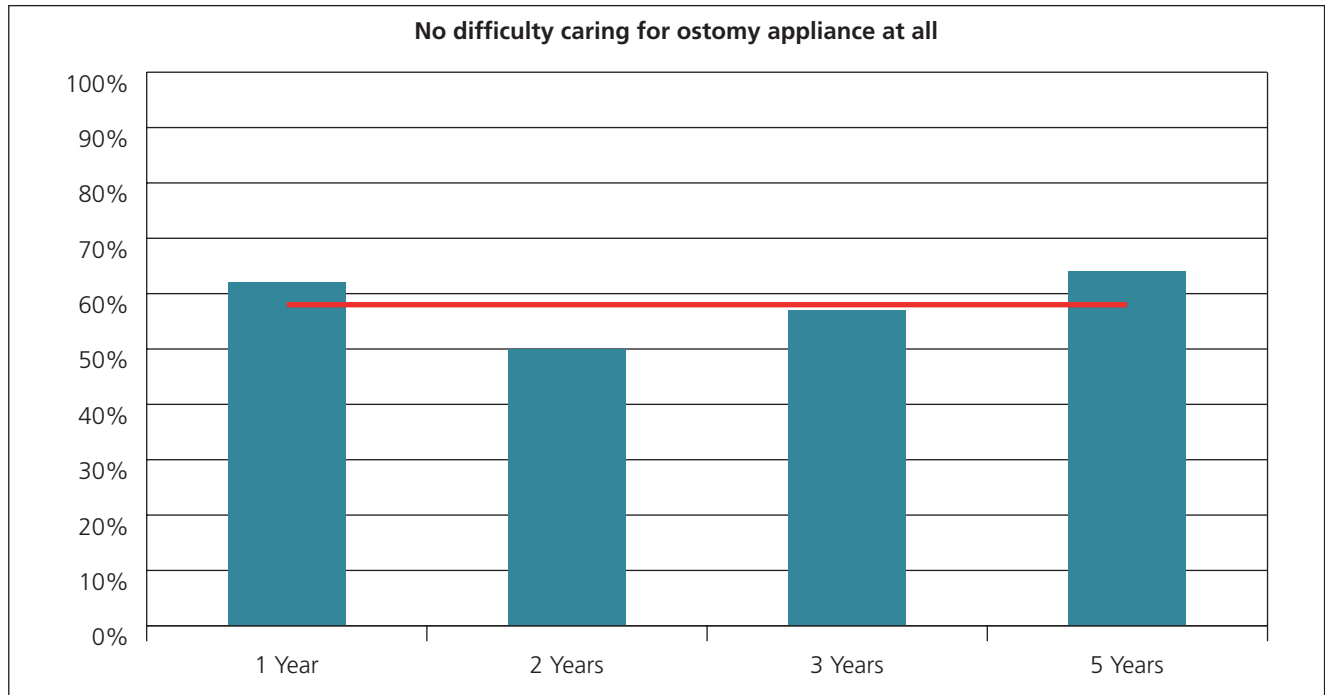


## Caring for my ostomy appliance/stoma is difficult

### Overall findings

6.28 58% of patients said caring for their ostomy appliance/stoma was not at all difficult, 25% said it was a little, 9% somewhat, 4% quite a bit, and 4% very much.

**Chart 6.21: Findings by Time Cohort**



## Do you have any difficulty in controlling your bowels?

### Overall findings

6.29 74% of patients said they did not have difficulty in controlling their bowels, 26% said they did.

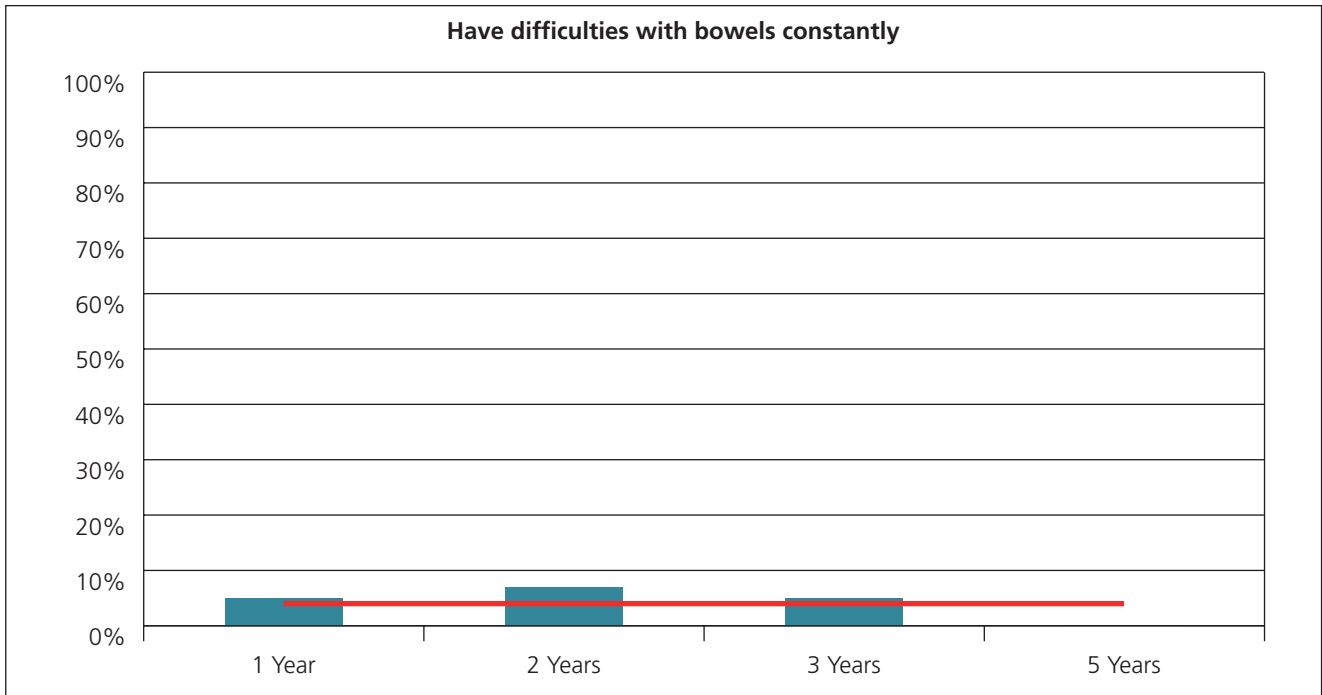


## If yes, how often do you have difficulties?

### Overall findings

6.30 4% of patients said they had difficulties constantly, 7% said daily, 13% weekly, and 10% monthly. 66% said that it varies.

**Chart 6.22: Findings by Time Cohort**



# Non-Hodgkin's lymphoma

## Questions about treatment and procedures

### What treatments have you received for your non-Hodgkin's lymphoma (NHL)?

#### Overall findings

6.31 32% of patients said they had received radiotherapy, 75% had received chemotherapy, 24% had surgery, 20% had antibody therapy and 5% had stem cell transplant.

#### Functional Assessment of Cancer Therapy (FACT) questions

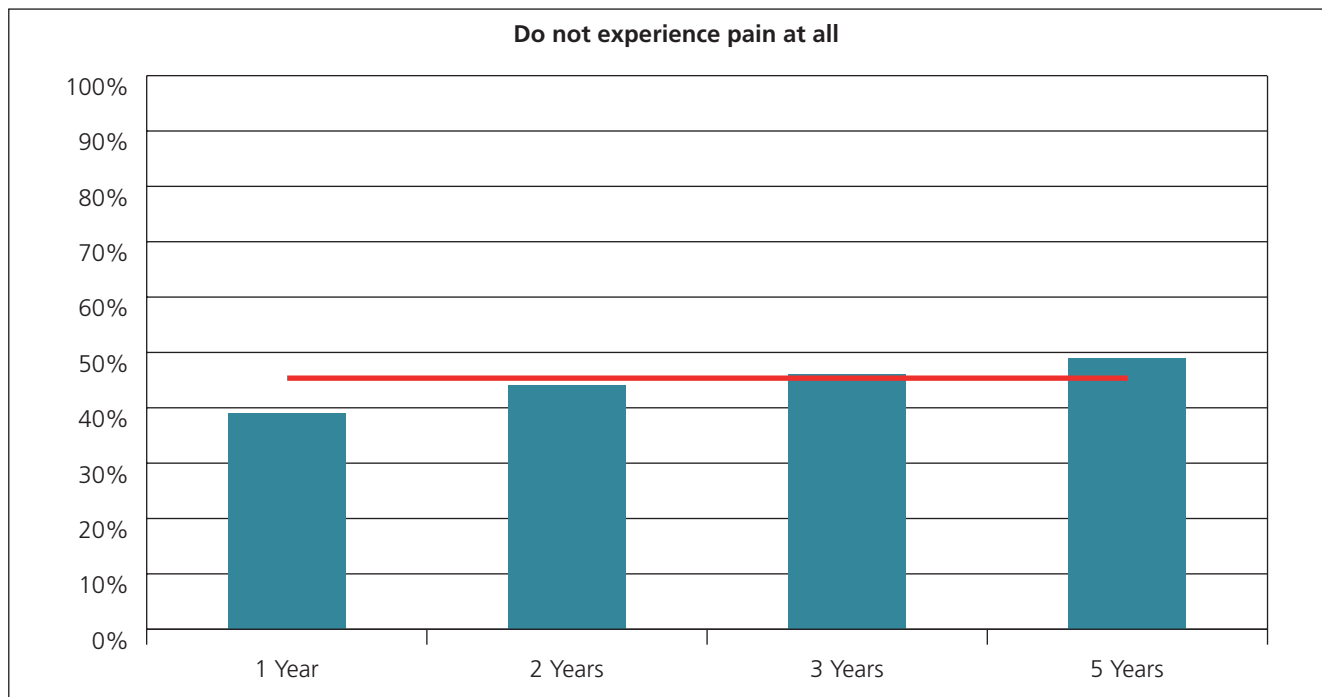
6.32 This set of questions was taken from the FACT-Lym questionnaire specifically for NHL patients.

### I have certain parts of my body where I experience pain

#### Overall findings

6.33 45% of patients said they did not have certain parts of their body where they experienced pain at all, 26% said they did a little, 12% somewhat, 12% quite a bit, and 6% very much.

**Chart 6.23: Findings by Time Cohort**

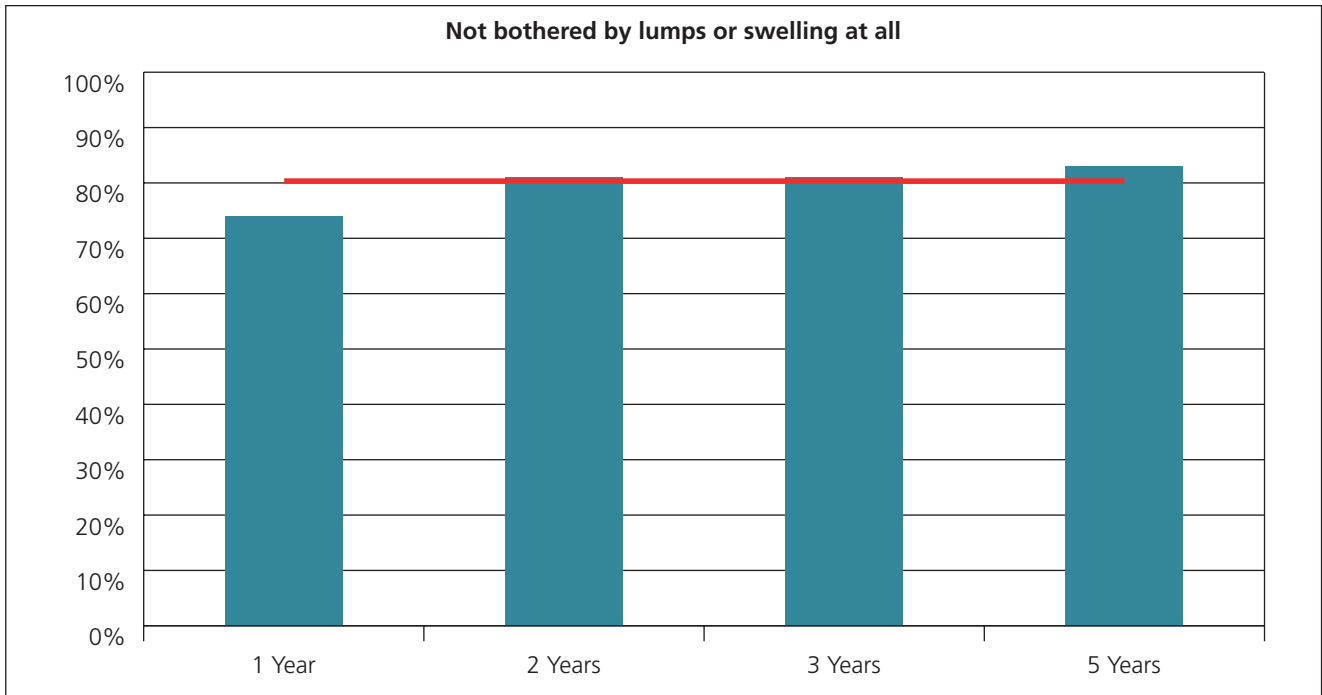


## I am bothered by lumps or swelling in certain parts of my body

### Overall findings

6.34 80% of patients said they were not bothered by lumps or swelling in certain parts of their body at all, 11% said they were a little, 4% somewhat, 3% quite a bit, and 2% very much.

**Chart 6.24: Findings by Time Cohort**

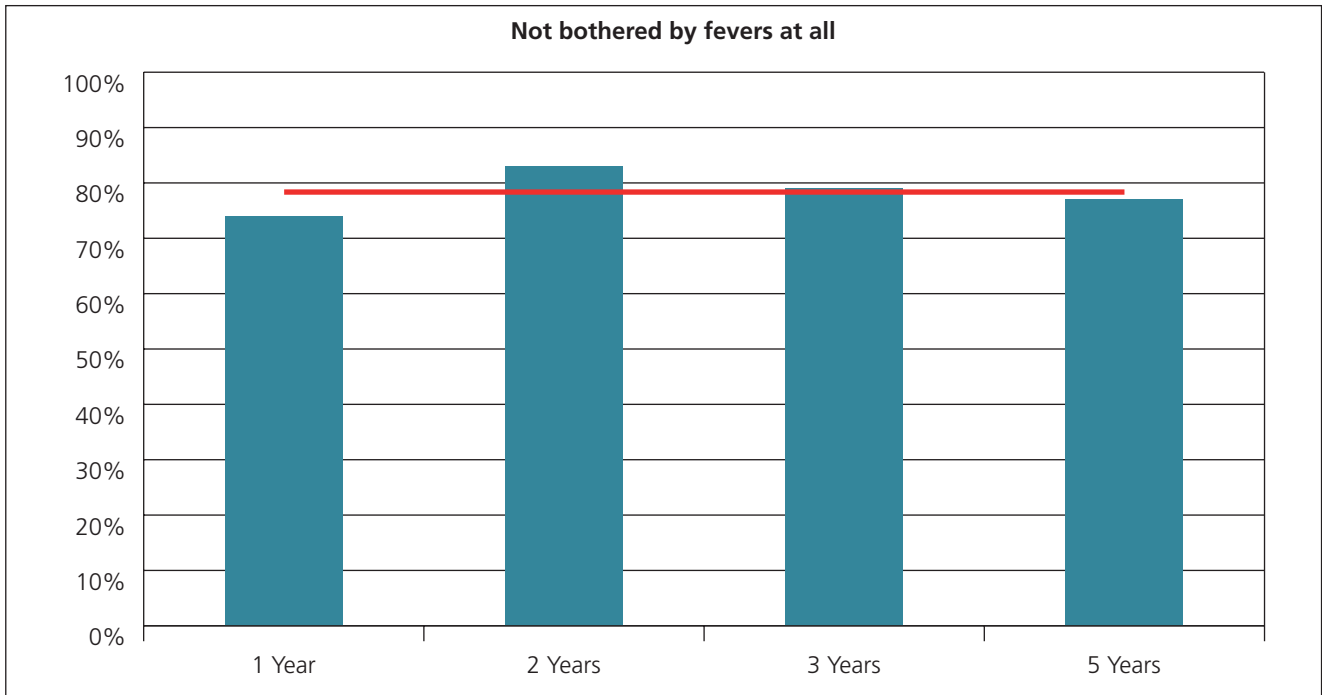


## I am bothered by fevers

### Overall findings

6.35 78% of patients said they were not bothered by fevers at all, 10% said they were a little, 5% somewhat, 4% quite a bit, and 2% very much.

**Chart 6.25: Findings by Time Cohort**

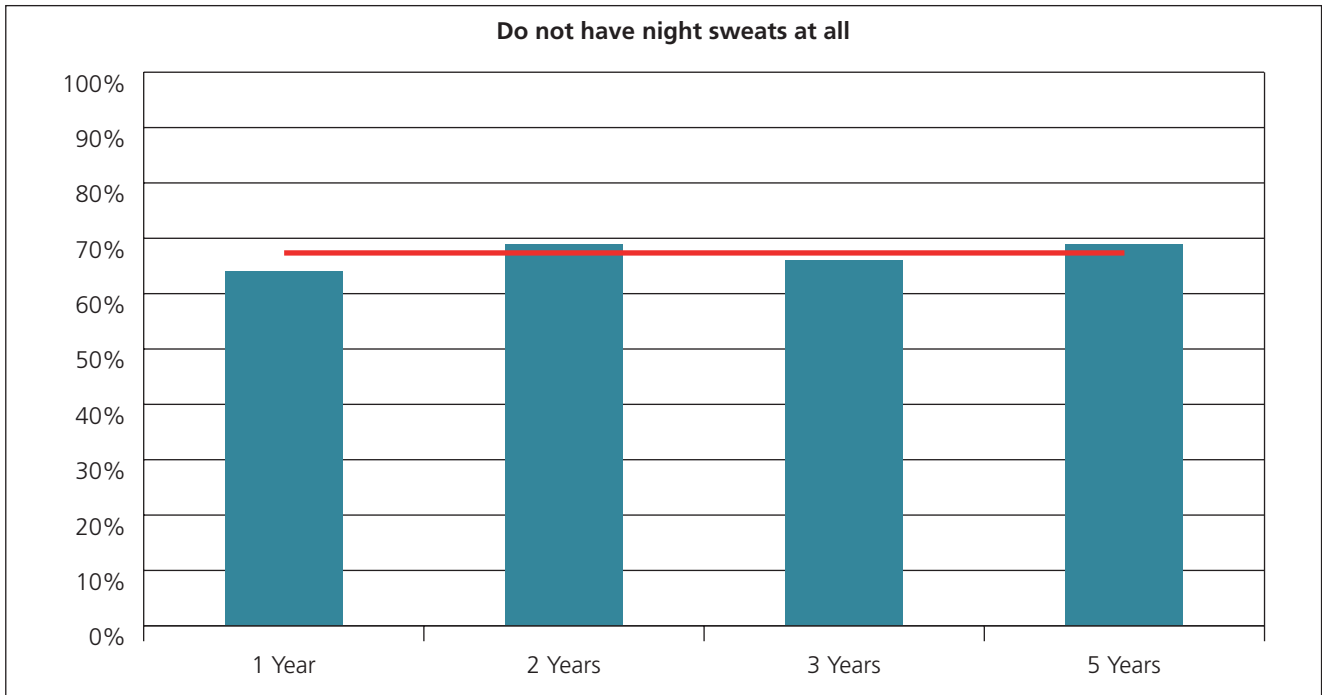


## I have night sweats

### Overall findings

6.36 67% of patients said they did not have night sweats at all, 20% said they did a little, 5% somewhat, 5% quite a bit, and 3% very much.

**Chart 6.26: Findings by Time Cohort**

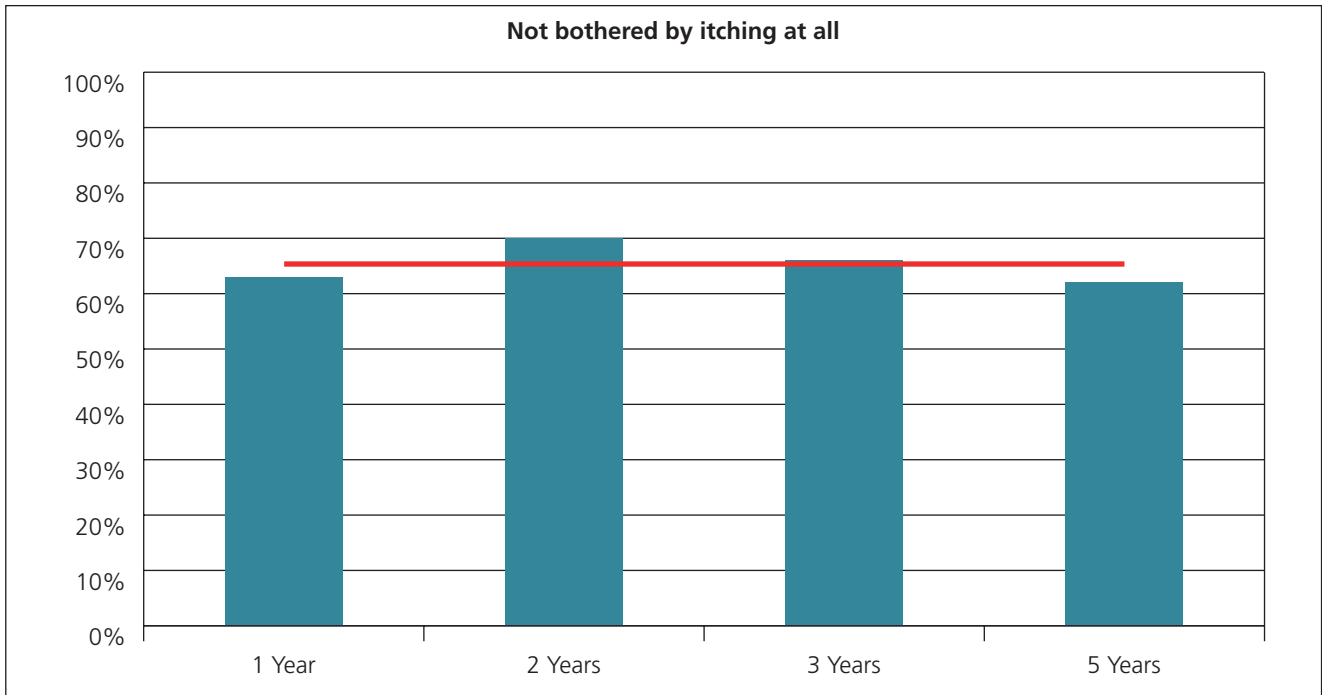


## I am bothered by itching

### Overall findings

6.37 65% of patients said they were not bothered by itching at all, 22% said they were a little, 6% somewhat, 4% quite a bit, and 2% very much.

**Chart 6.27: Findings by Time Cohort**

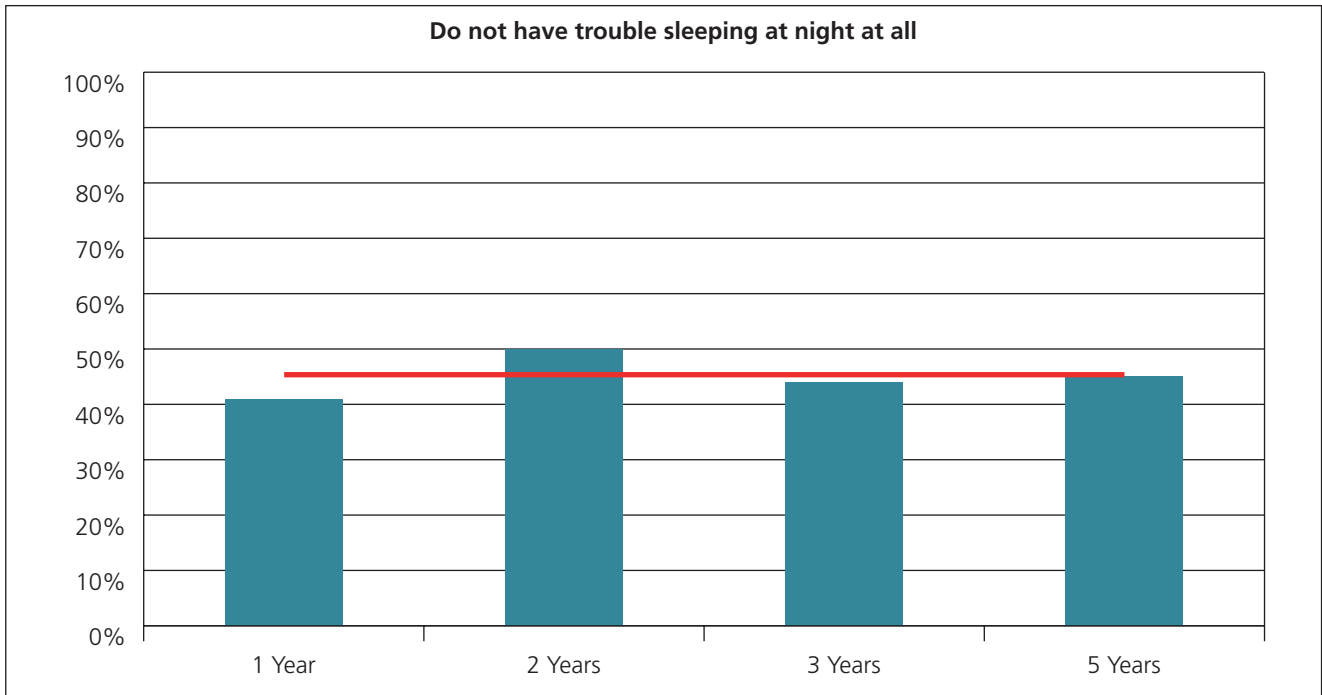


## I have trouble sleeping at night

### Overall findings

6.38 45% of patients said they did not have trouble sleeping at night at all, 26% said they did a little, 12% somewhat, 12% quite a bit, and 6% very much.

**Chart 6.28: Findings by Time Cohort**

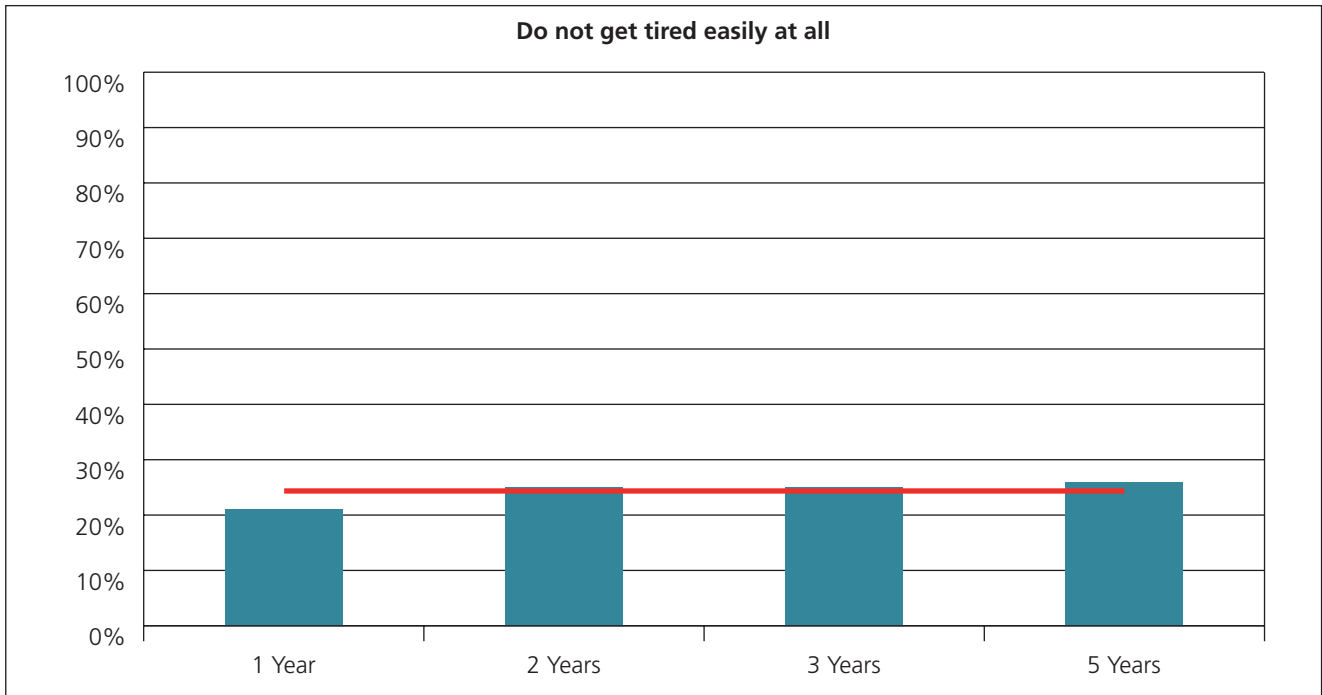


## I get tired easily

### Overall findings

6.39 24% of patients said they did not get tired easily at all, 31% said they did a little, 15% somewhat, 18% quite a bit, and 12% very much.

**Chart 6.29: Findings by Time Cohort**



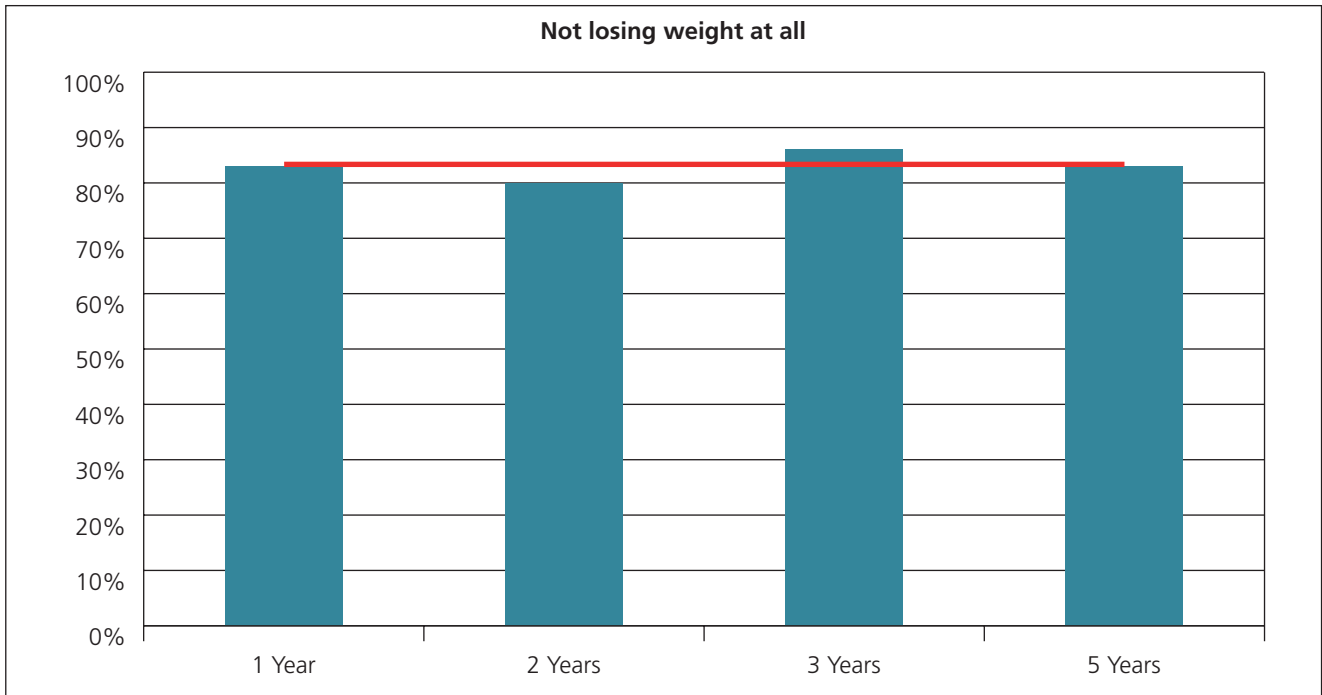


## I am losing weight

### Overall findings

6.40 83% of patients said they were not losing weight at all, 10% said they were a little, 3% somewhat, 2% quite a bit, and 2% very much.

**Chart 6.30: Findings by Time Cohort**

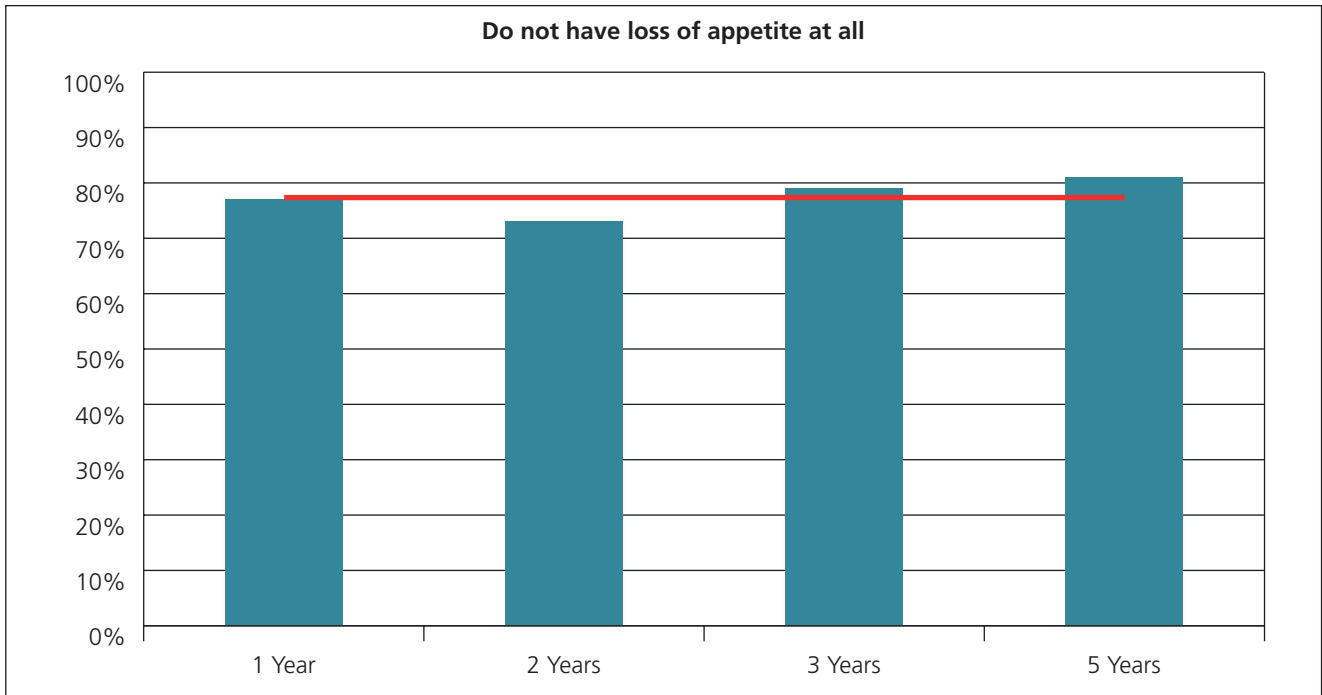


## I have a loss of appetite

### Overall findings

6.41 77% of patients said they did not have a loss of appetite at all, 14% said they did a little, 5% somewhat, 3% quite a bit, and 2% very much.

**Chart 6.31: Findings by Time Cohort**

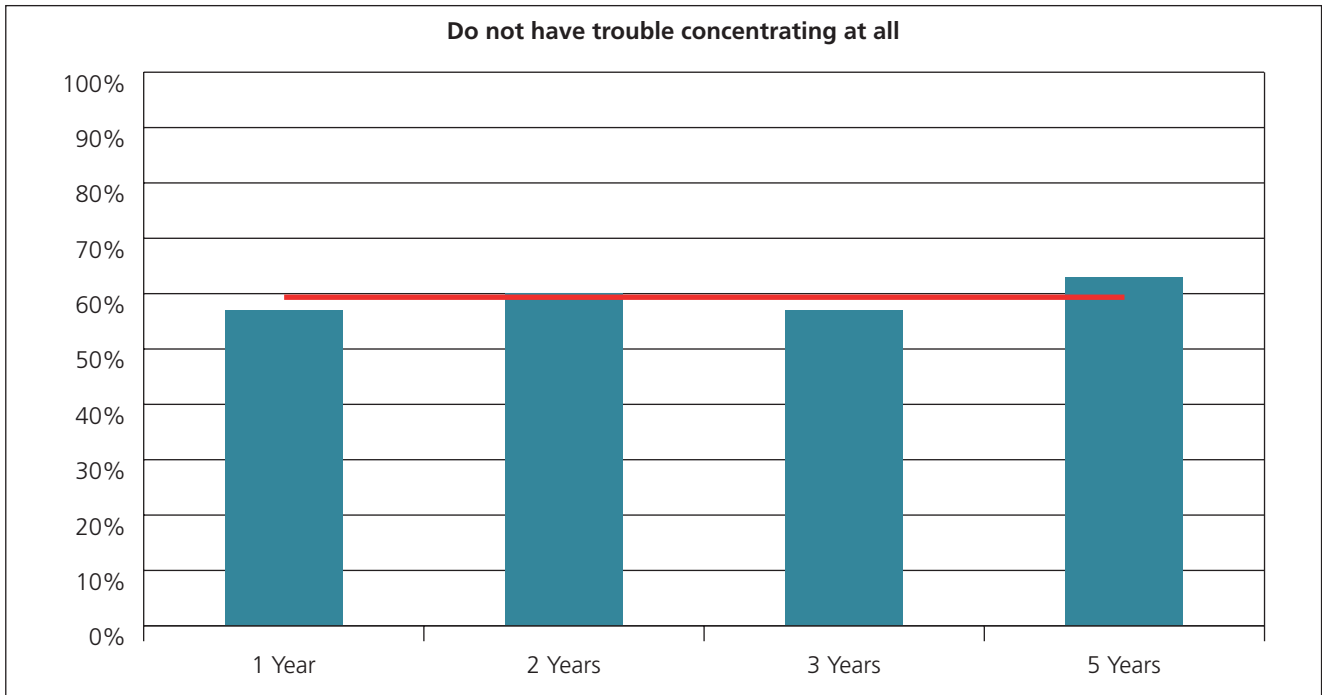


## I have trouble concentrating

### Overall findings

6.42 59% of patients said they did not have trouble concentrating at all, 25% said they did a little, 8% somewhat, 6% quite a bit, and 3% very much.

**Chart 6.32: Findings by Time Cohort**

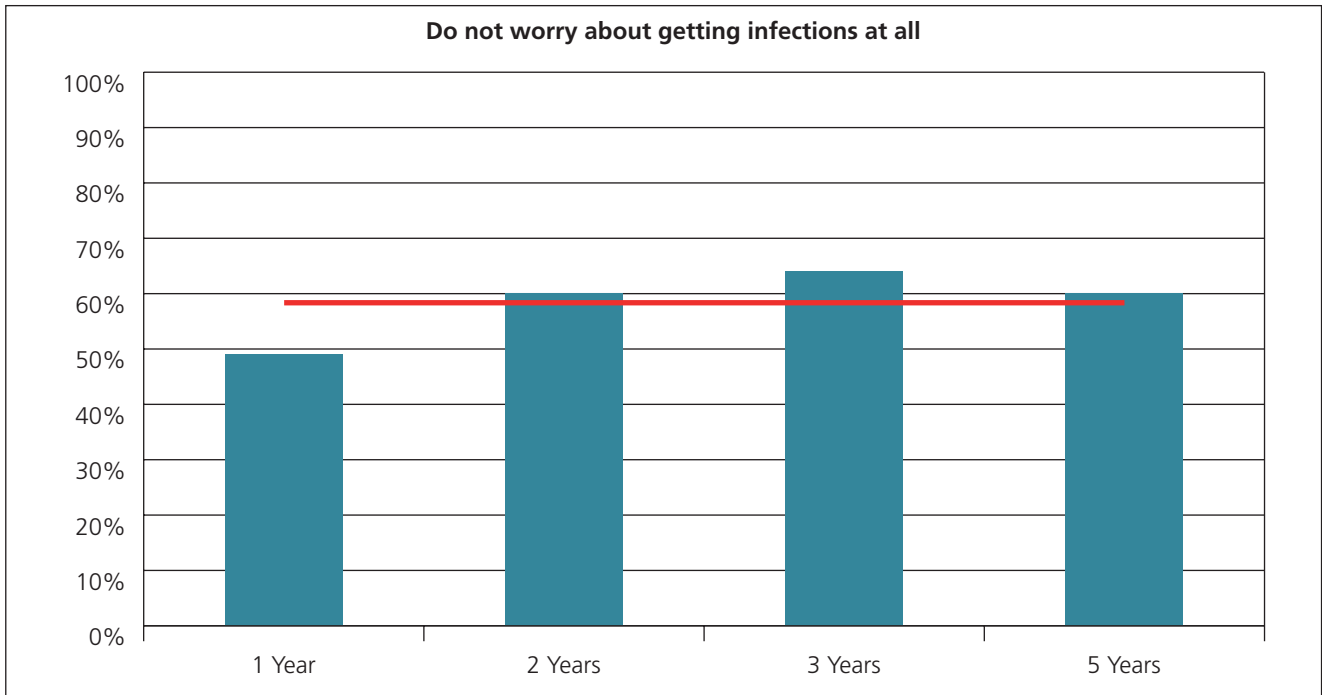


## I worry about getting infections

### Overall findings

6.43 58% of patients said they were not worried about getting infections at all, 24% said they were a little, 8% somewhat, 6% quite a bit, and 4% very much.

**Chart 6.33: Findings by Time Cohort**

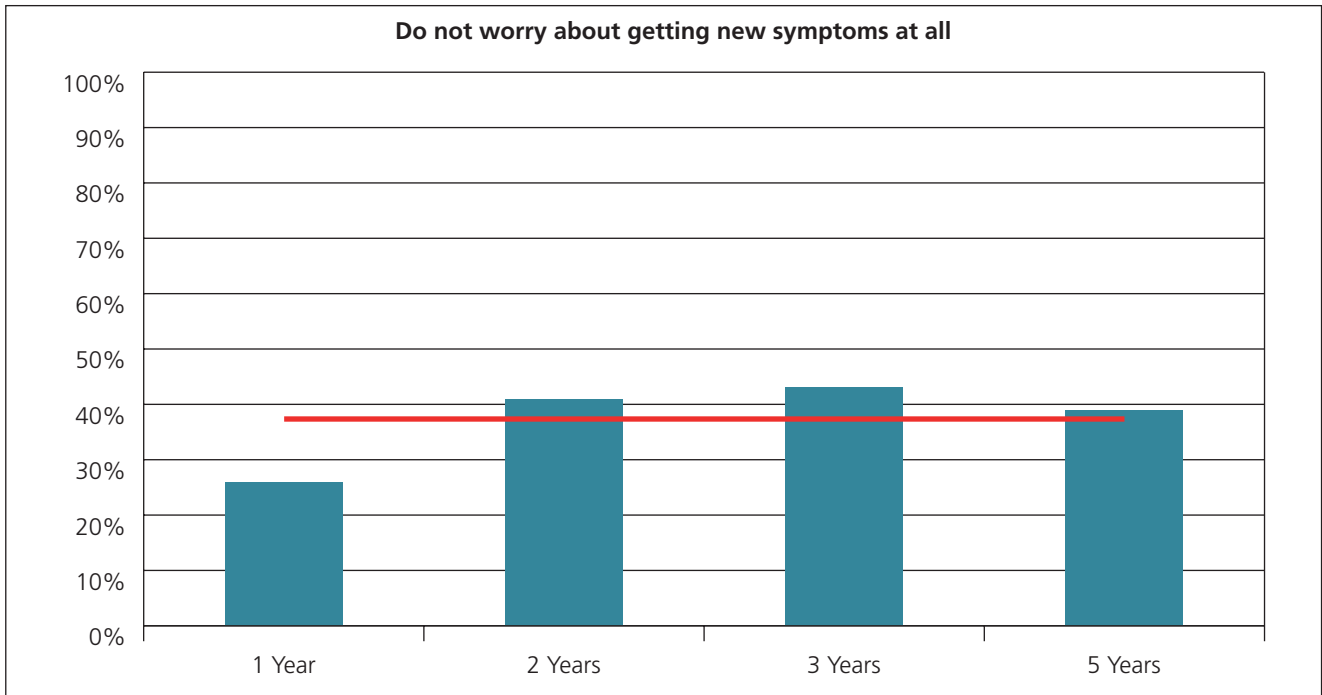


## I worry that I might get new symptoms of my illness

### Overall findings

6.44 37% of patients said they did not worry that they might get new symptoms at all, 34% said they did a little, 14% somewhat, 8% quite a bit, and 6% very much.

**Chart 6.34: Findings by Time Cohort**

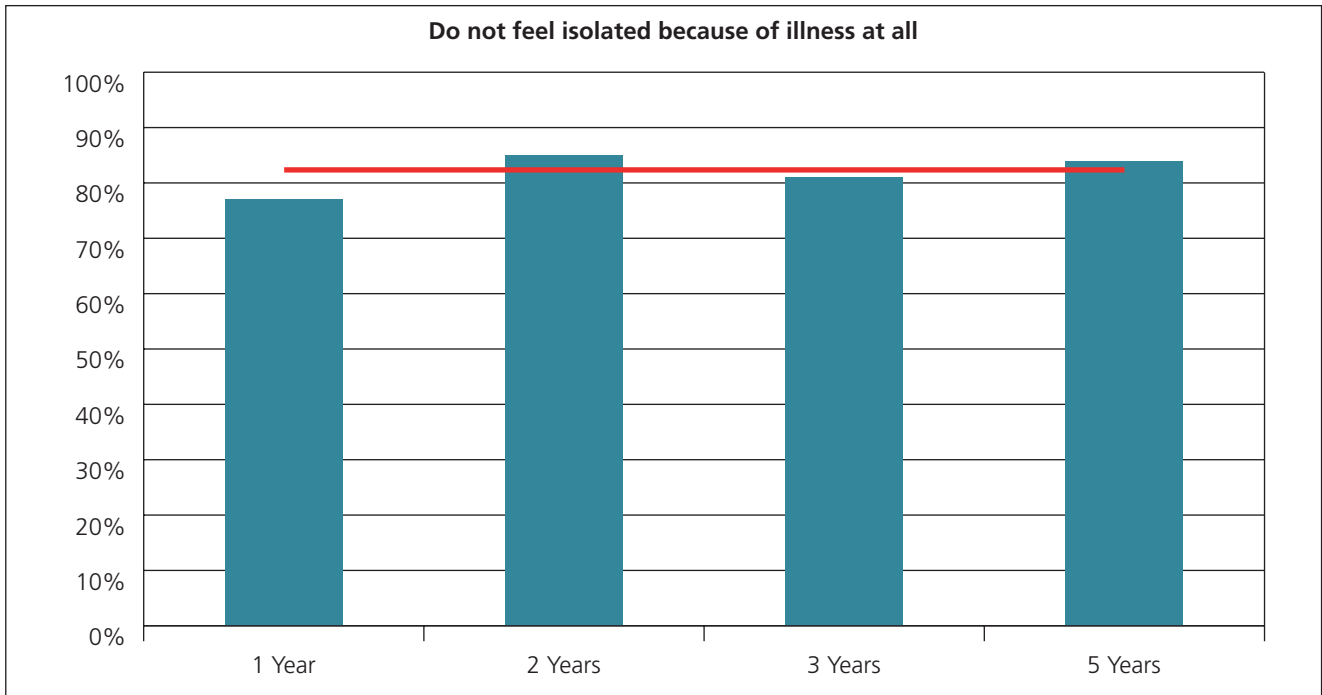


## I feel isolated from others because of my illness or treatment

### Overall findings

6.45 82% of patients said they did not feel isolated from others at all, 9% said they did a little, 4% somewhat, 3% quite a bit, and 3% very much.

**Chart 6.35: Findings by Time Cohort**

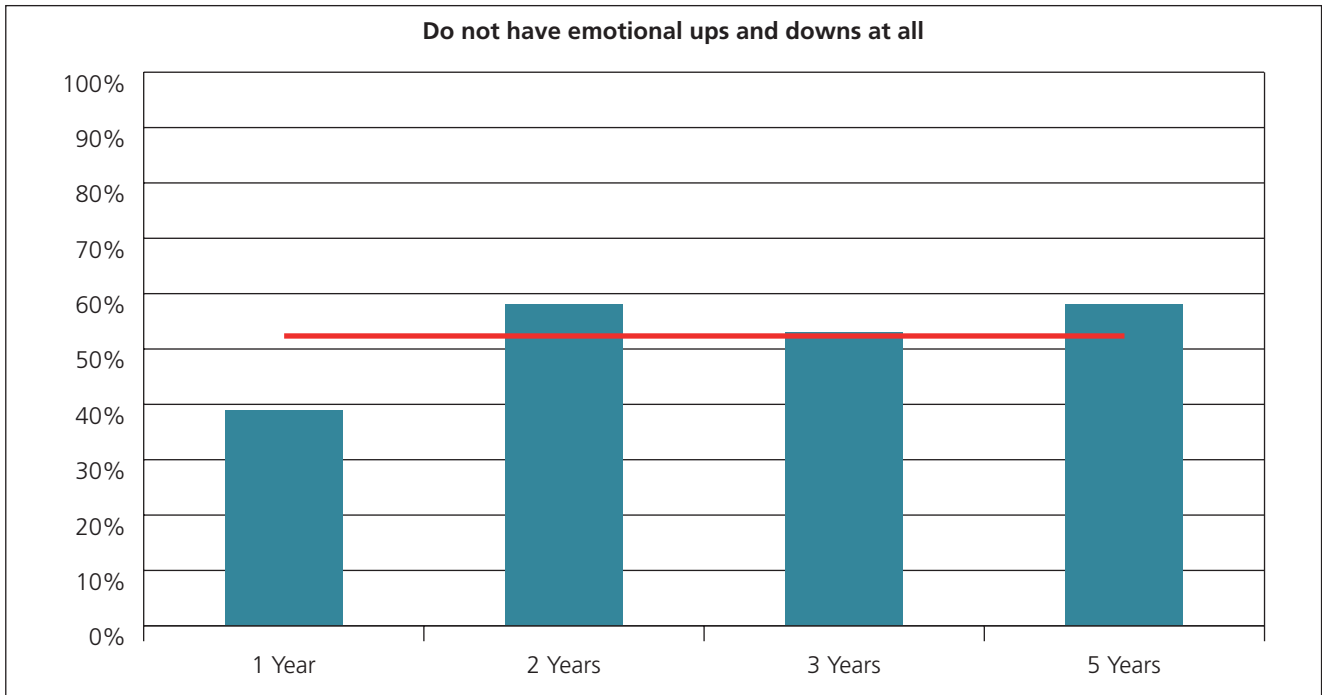


## I have emotional ups and downs

### Overall findings

6.46 52% of patients said they did not have emotional ups and downs at all, 26% said they did a little, 10% somewhat, 7% quite a bit, and 5% very much.

**Chart 6.36: Findings by Time Cohort**

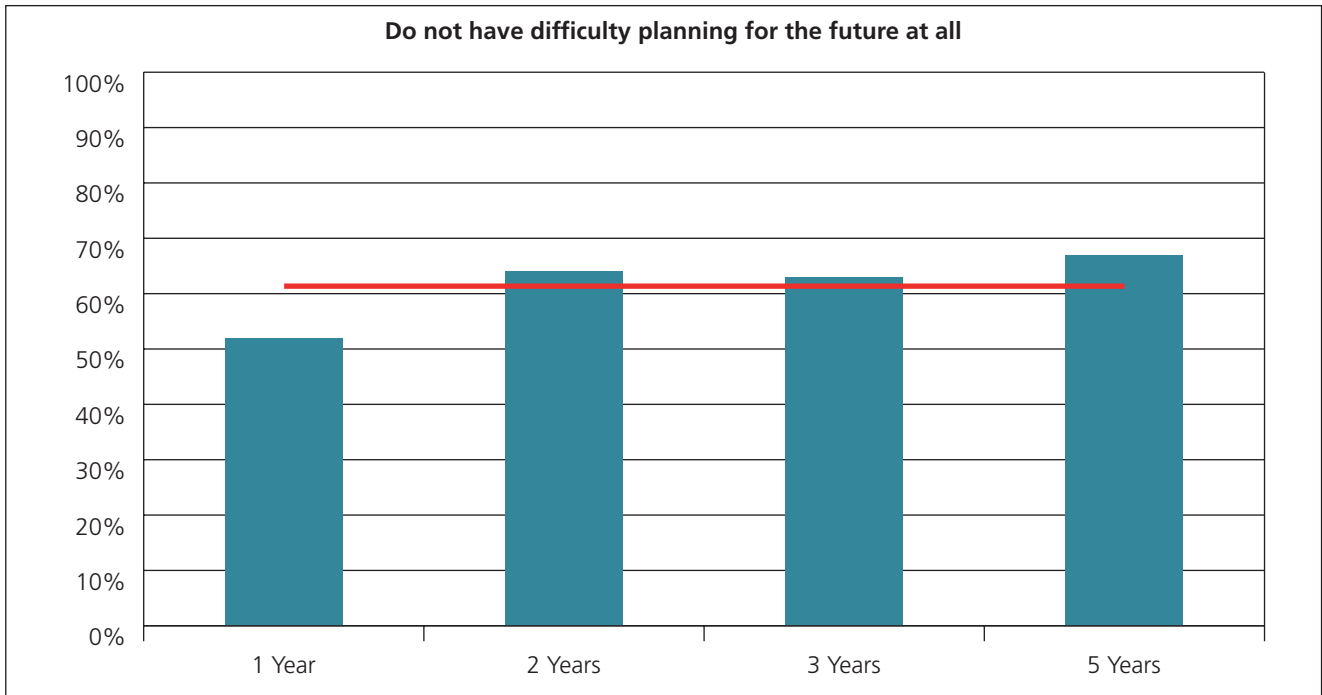


## Because of my illness, I have difficulty planning for the future

### Overall findings

6.47 61% of patients said they did not have difficulty planning for the future at all, 17% said they did a little, 8% somewhat, 6% quite a bit, and 7% very much.

**Chart 6.37: Findings by Time Cohort**





# Prostate Cancer

## Questions about treatment and procedures

### What treatments have you received for your prostate cancer?

#### Overall findings

6.48 43% of patients said they had received radiotherapy, 26% had had surgery, 43% had hormone treatment, 3% had chemotherapy, 1% had High Intensity Focused Ultrasound (HIFU), 1% had cryotherapy and 22% said monitoring with no current nor previous treatment.

#### Functional Assessment of Cancer Therapy (FACT) questions

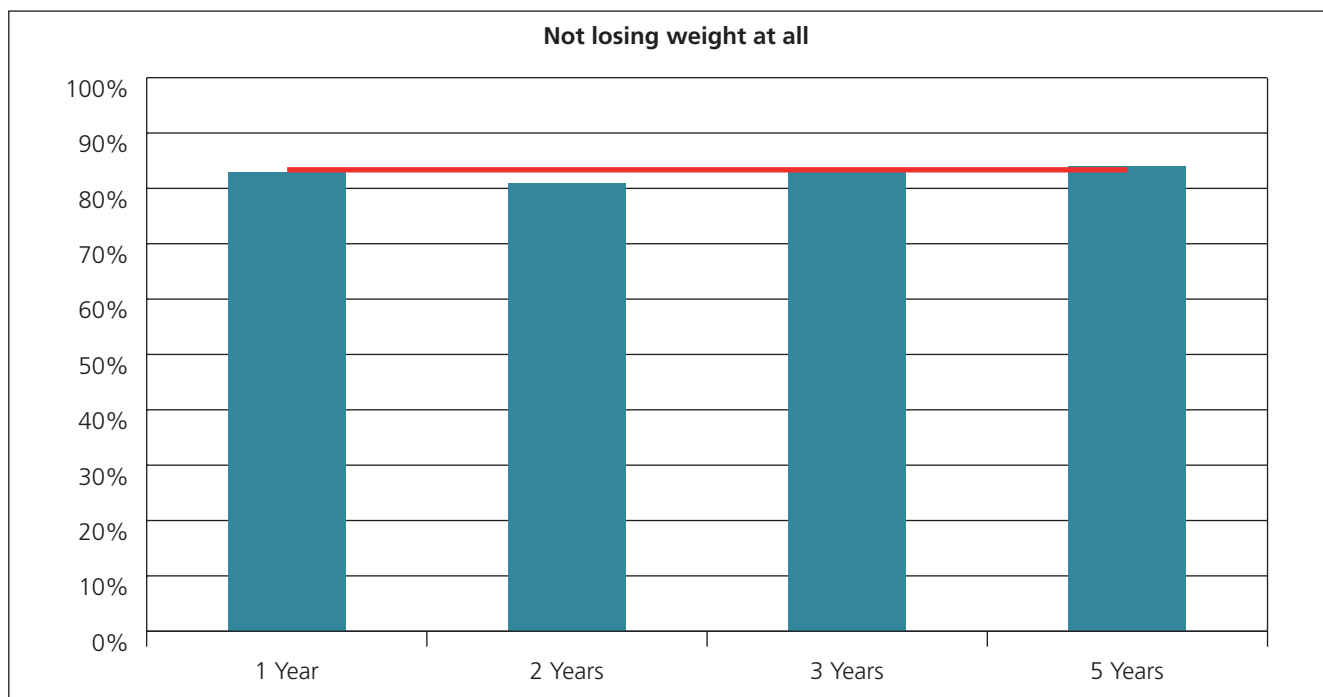
This set of questions was taken from the FACT-P questionnaire specifically for prostate cancer patients.

### I am losing weight

#### Overall findings

6.49 83% of patients said they were not losing weight at all, 13% said they were a little, 2% somewhat, 1% quite a bit, and 1% very much.

**Chart 6.38: Findings by Time Cohort**

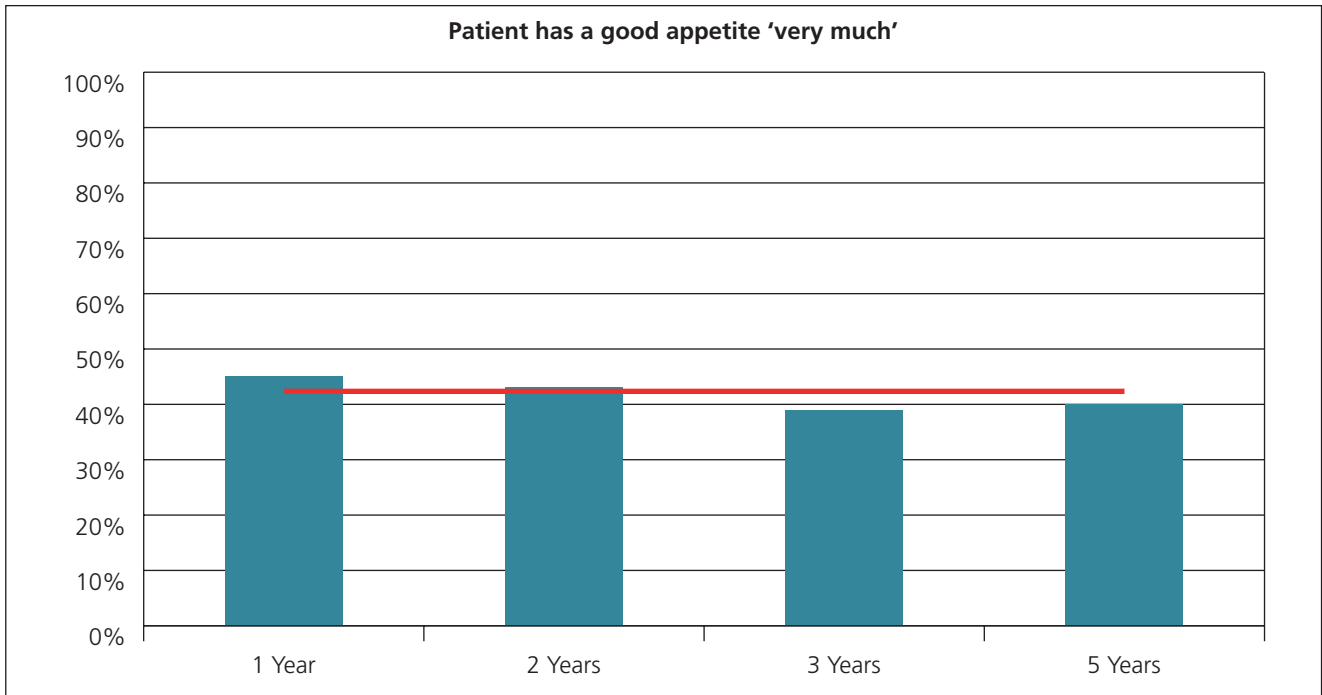


## I have a good appetite

### Overall findings

6.50 47% of patients said they had a good appetite 'very much', 20% said they did quite a bit, 11% somewhat, 6% a little bit, and 20% not at all.

**Chart 6.39: Findings by Time Cohort**

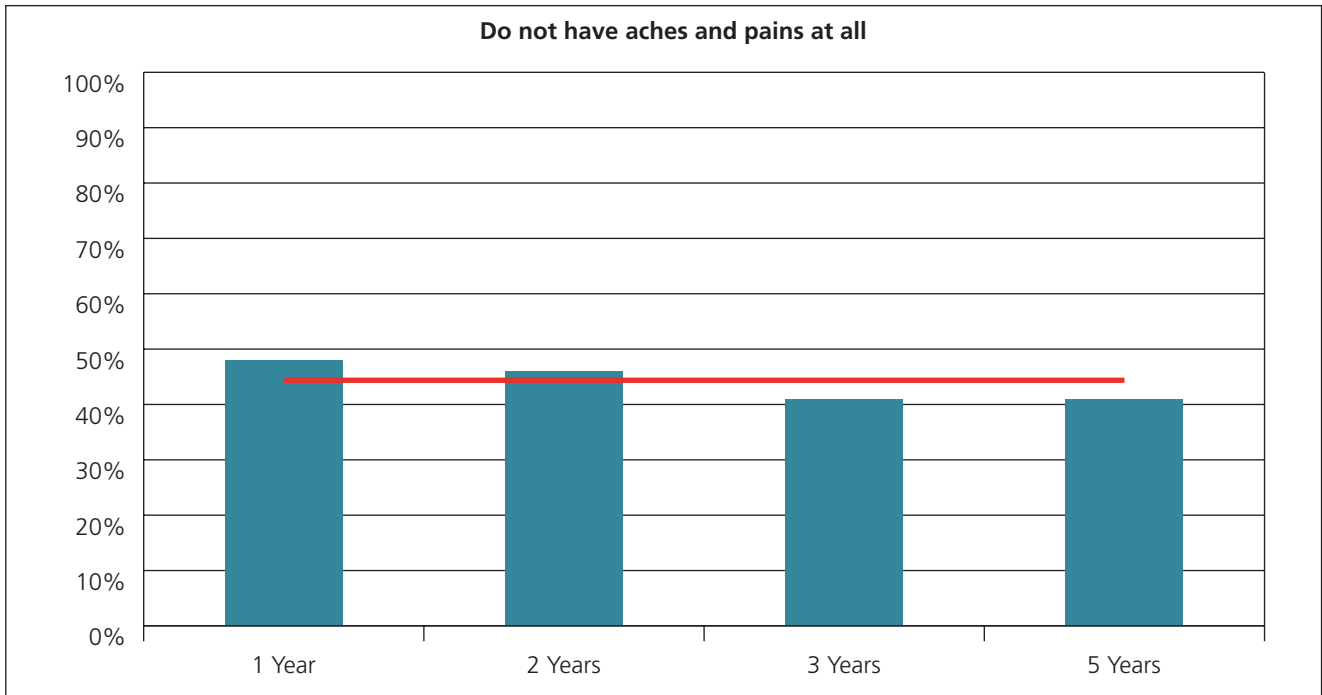


## I have aches and pains that bother me

### Overall findings

6.51 44% of patients said they did not have aches and pains that bothered them at all, 27% said they did a little, 12% somewhat, 12% quite a bit, and 5% very much.

**Chart 6.40: Findings by Time Cohort**

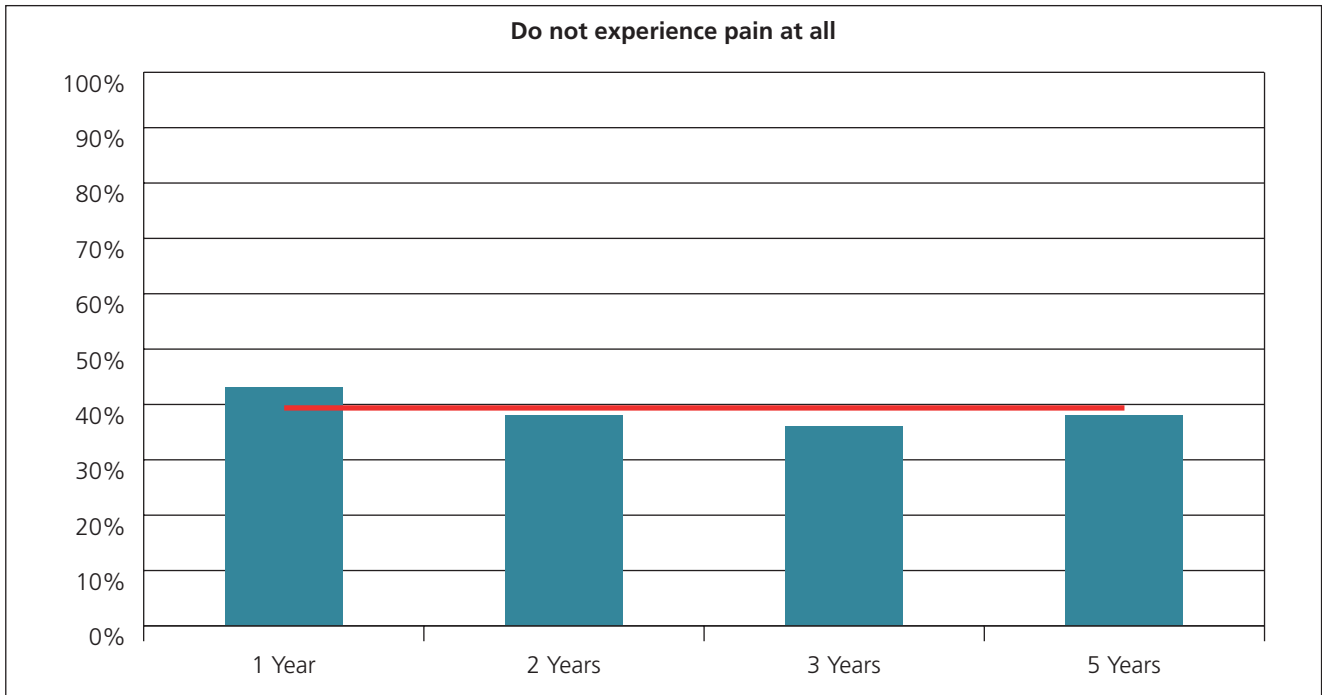


## I have certain parts of my body where I experience pain

### Overall findings

6.52 39% of patients said they did not have certain parts of their body where they experienced pain at all, 28% said they did a little, 13% somewhat, 12% quite a bit, and 7% very much.

**Chart 6.41: Findings by Time Cohort**

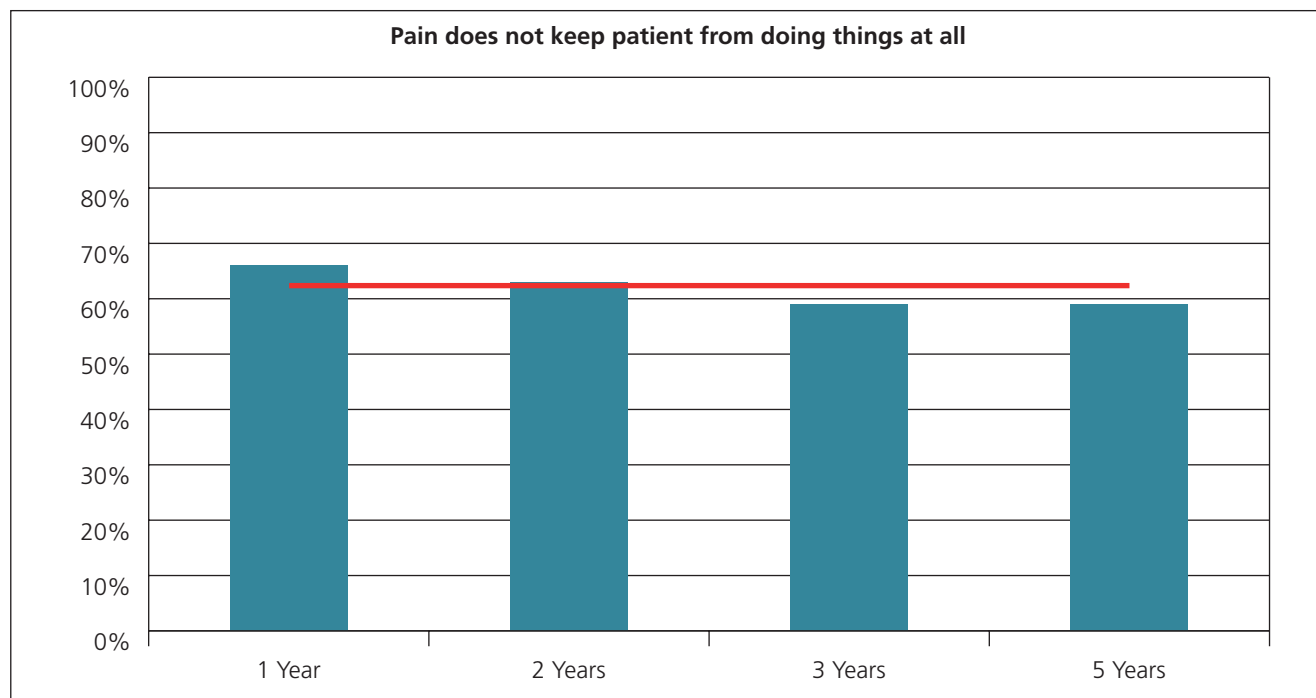


## My pain keeps me from doing things I want to do

### Overall findings

6.53 62% of patients said their pain did not keep them from doing things they want to do at all, 16% said it did a little, 8% somewhat, 7% quite a bit, and 7% very much.

**Chart 6.42: Findings by Time Cohort**

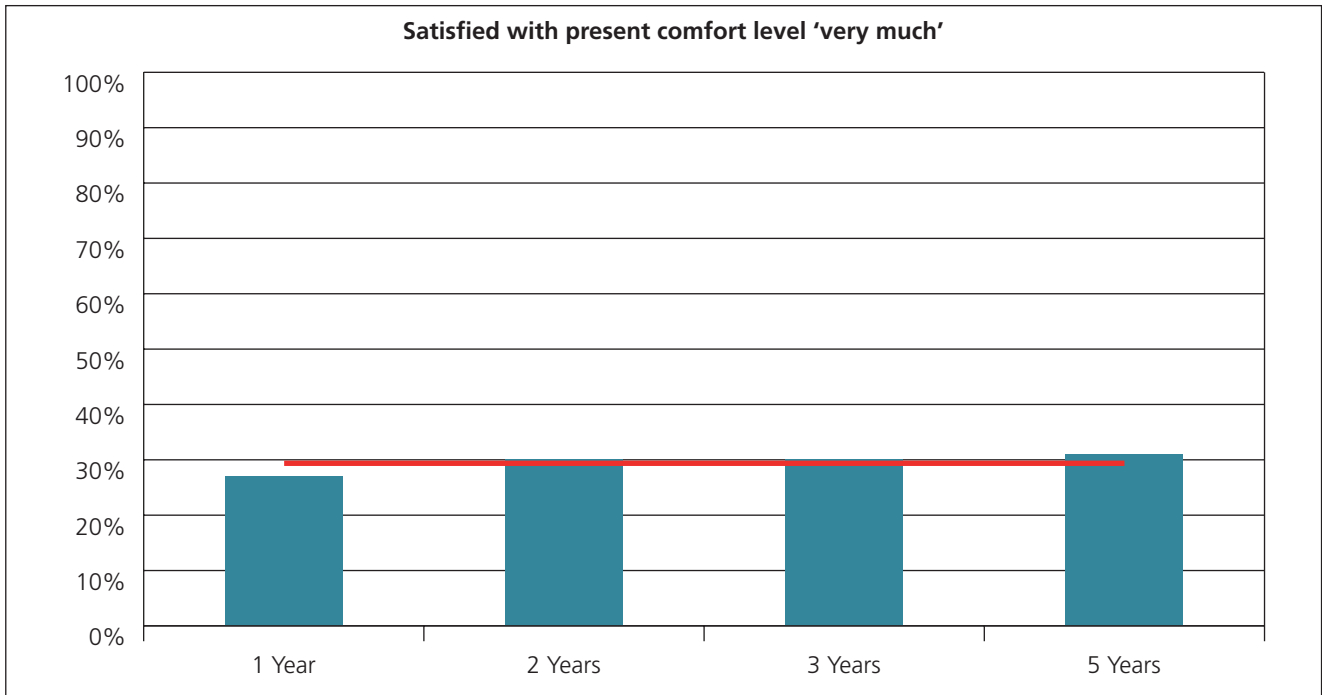


## I am satisfied with my present comfort level

### Overall findings

6.54 29% of patients said they were satisfied with their present comfort level 'very much', 14% said they were quite a bit, 17% somewhat, 10% a little bit, and 30% not at all.

**Chart 6.43: Findings by Time Cohort**

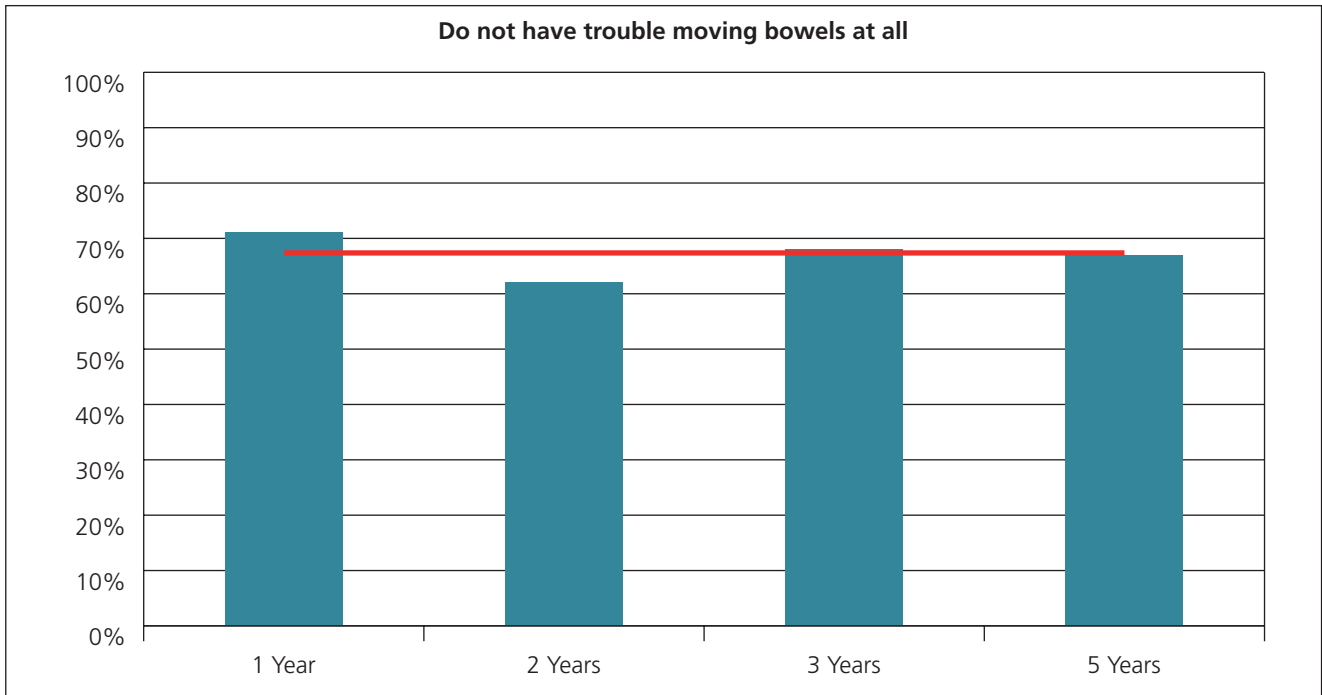


## I have trouble moving my bowels

### Overall findings

6.55 67% of patients said they did not have trouble moving their bowels at all, 18% said they did a little, 6% somewhat, 6% quite a bit, and 3% very much.

**Chart 6.44: Findings by Time Cohort**

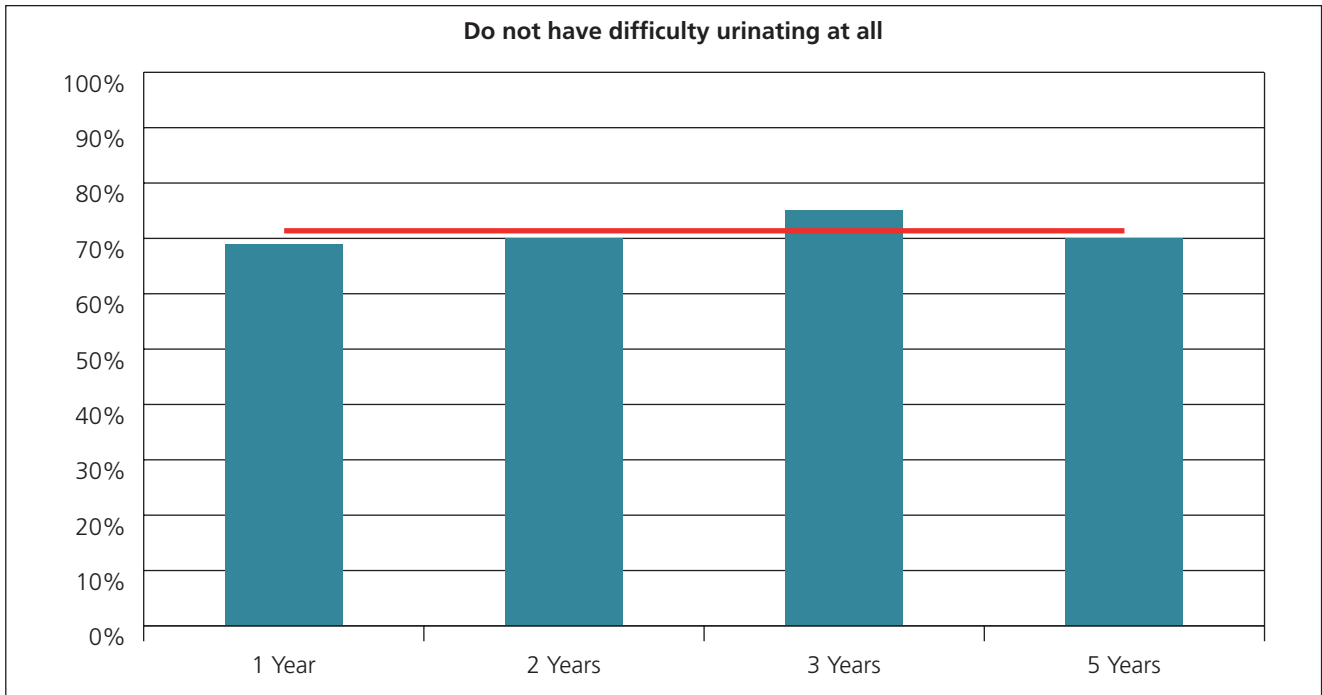


## I have difficulty urinating

### Overall findings

6.56 71% of patients said they did not have difficulty urinating at all, 19% said they did a little, 5% somewhat, 4% quite a bit, and 2% very much.

**Chart 6.45: Findings by Time Cohort**



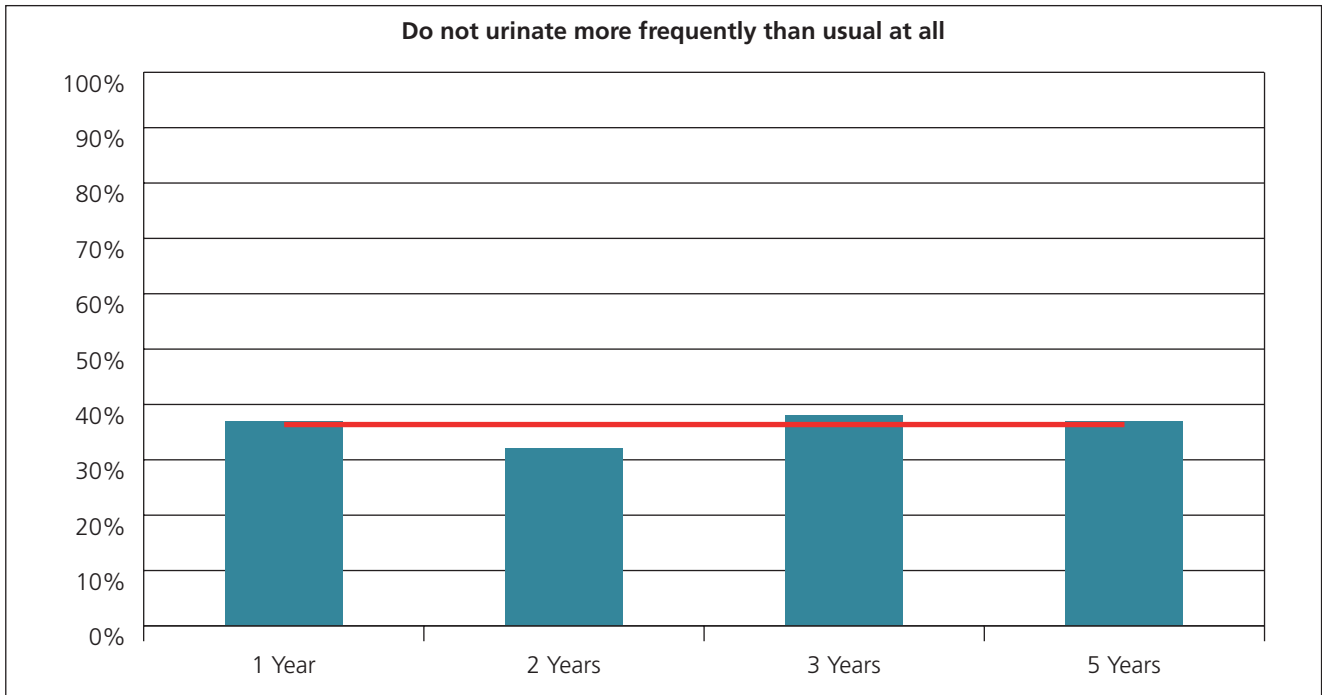


## I urinate more frequently than usual

### Overall findings

6.57 36% of patients said they did not urinate more frequently than usual at all, 31% said they did a little, 14% somewhat, 13% quite a bit, and 6% very much.

**Chart 6.46: Findings by Time Cohort**

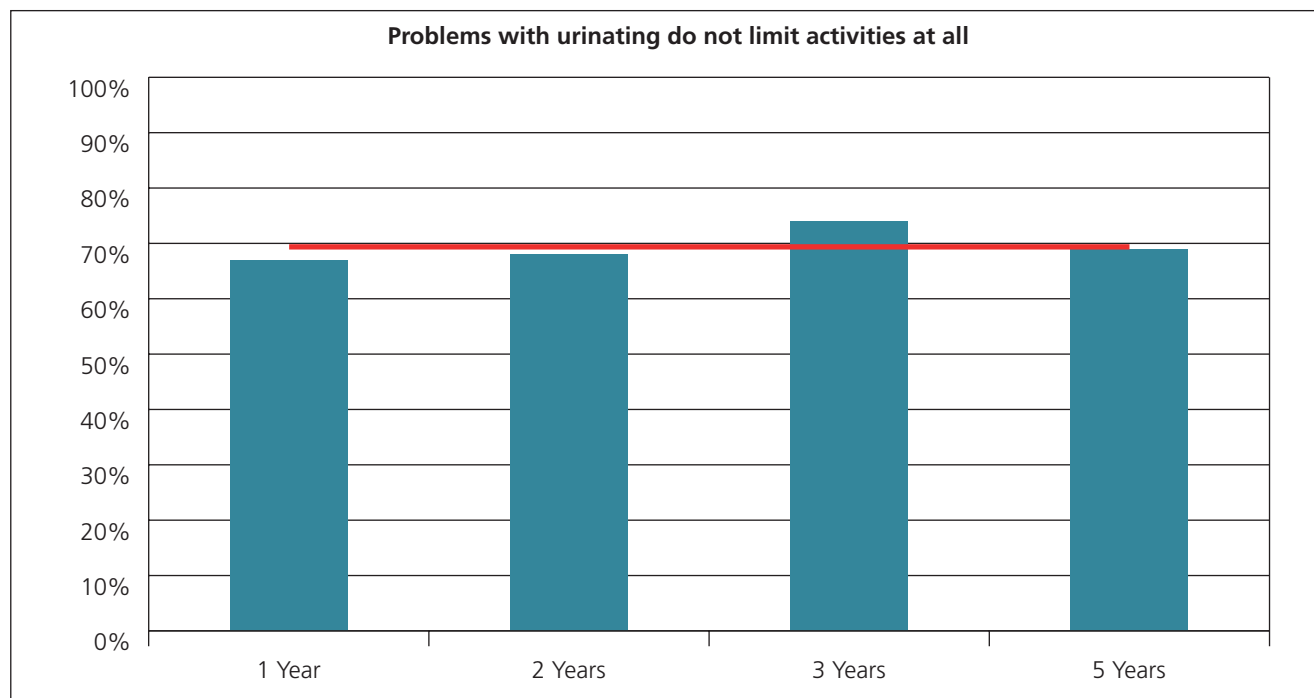


## My problems with urinating limit my activities

### Overall findings

6.58 69% of patients said their problems with urinating did not limit their activities at all, 17% said they did a little, 7% somewhat, 4% quite a bit, and 3% very much.

**Chart 6.47: Findings by Time Cohort**

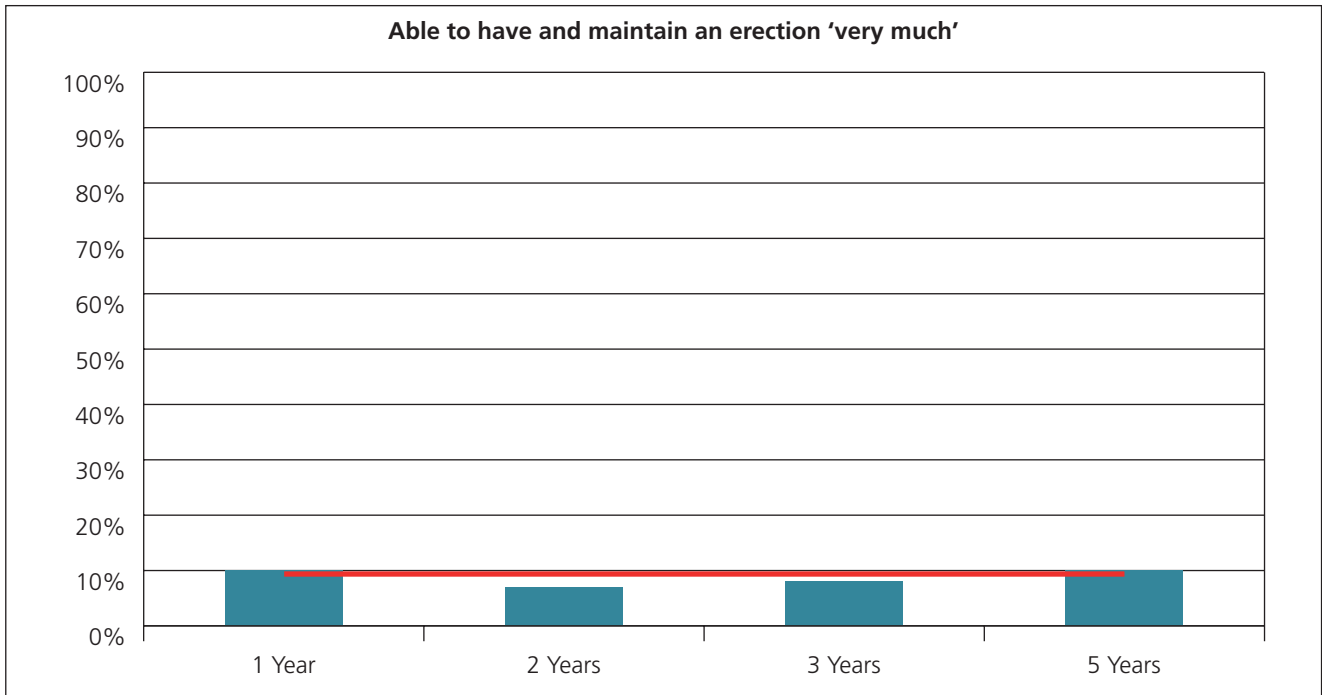


## I am able to have and maintain an erection

### Overall findings

6.59 9% of patients said they were able to have and maintain an erection 'very much', 6% said they were quite a bit, 10% somewhat, 12% a little bit, and 63% not at all.

**Chart 6.48: Findings by Time Cohort**

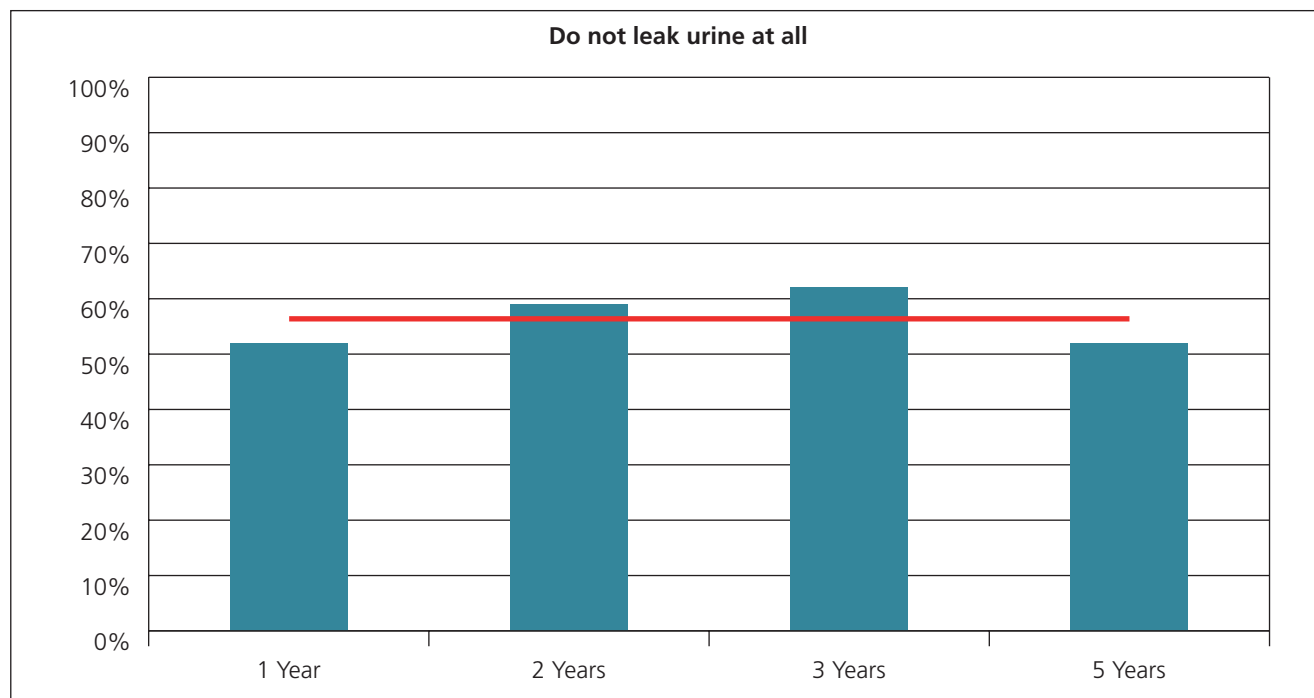


## I leak urine

### Overall findings

6.60 56% of patients said they did not leak urine at all, 31% said they did a little, 6% somewhat, 4% quite a bit, and 3% very much.

**Chart 6.49: Findings by Time Cohort**



## Do you have any difficulty in controlling your bowels?

### Overall findings

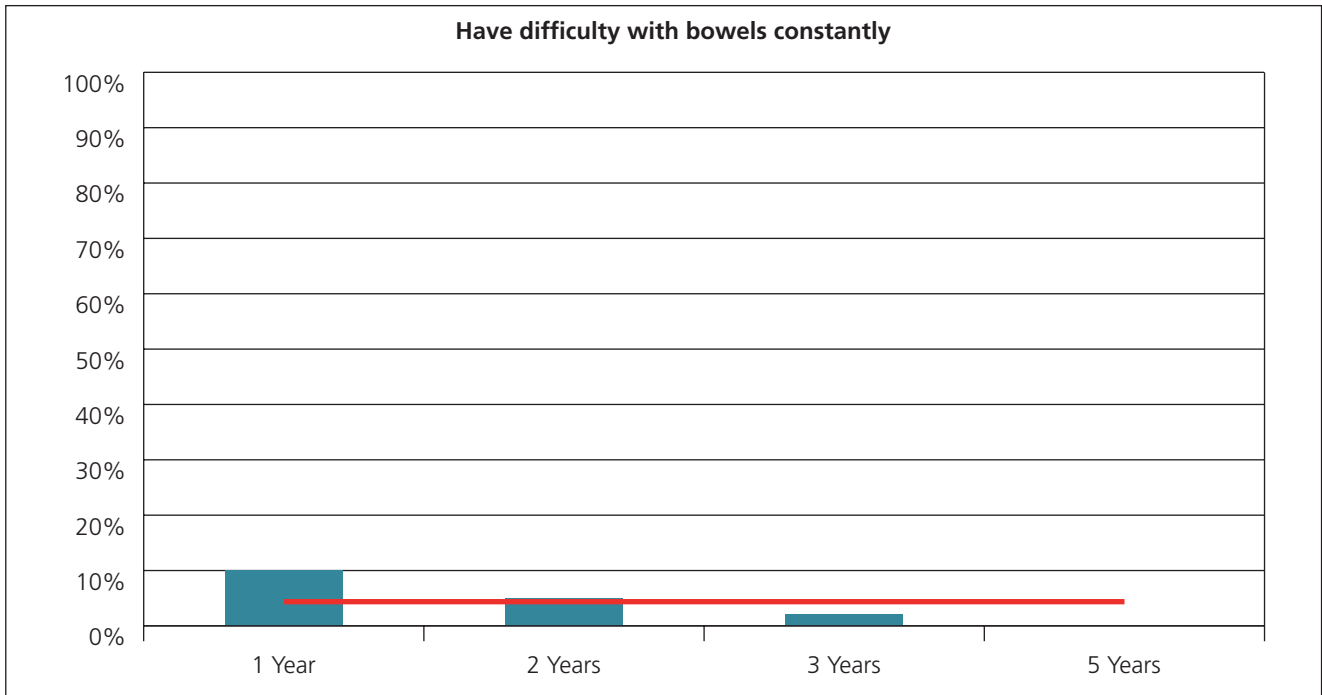
6.61 87% of patients said they did not have difficulty in controlling their bowels, 13% said they did.

## If yes, how often do you have difficulties?

### Overall findings

6.62 4% of patients said they had difficulties constantly, 15% said daily, 13% weekly, and 9% monthly. 59% said that it varies.

**Chart 6.50: Findings by Time Cohort**



## 7. Associations with chemotherapy and radiotherapy

7.1 Indicators were obtained from Cancer Registries in respect of whether a patient had received chemotherapy or radiotherapy; this was indicated in a flag field for each type of treatment in the sample dataset.

### Chemotherapy

7.2 Analysis of patients across all time cohorts and age bands was undertaken, with a separate analysis of patients by age band. These analyses demonstrated the following:

- When patients from all tumour groups and time cohorts are combined, the impact of chemotherapy from the patients' perspective is significantly negative on 15 questions, and positive on four questions. Significance tests demonstrated that on each of the 15 questions, patients who had had chemotherapy were less likely to have a positive view on that question than patients who had not had chemotherapy.
- The questions on which patients who had had chemotherapy are more negative than those who have not, are on difficulties with mobility; undertaking their usual activities; pain; having anxiety; maintaining their independence; carrying out domestic chores; having difficulty with benefits; having financial difficulties; having difficulty with financial services; having difficulties about work; having problems about appearance or body image; feeling isolated; carrying out recreational activities; plans to travel or holiday; and on having fears about cancer coming back.
- The questions on which patients who had had chemotherapy are more positive are as follows: their assessment of whether the cancer had responded to treatment; difficulties concerning sexual matters; having a named nurse; and knowing who to contact about living with or after cancer.

### Radiotherapy

7.3 Analysis was undertaken of patients across all time cohorts and age bands, with a separate analysis undertaken of patients by age band. The analysis demonstrated the following:

- When patients from all tumour groups and time cohorts are combined, the impact of radiotherapy from the patients' perspective is significantly negative on seven questions, and positive on two questions. Significance tests demonstrated that on each of the seven questions, patients who had had radiotherapy were less likely to have a positive view on these questions than patients who had not had radiotherapy.
- The questions on which patients who had had radiotherapy are more negative than those who have not are on having pain; having difficulties with their appearance or body image; having

fears about death and dying; having trouble sleeping; having trouble concentrating; experiencing mood swings; and being often irritable.

- The questions on which patients who had radiotherapy are more positive were as follows: their assessment of whether the cancer had responded to treatment; and on having no problems with mobility.
- Looking at any differences across age bands amongst patients who had had radiotherapy showed very few differences between these age bands. Only on two questions did tests reveal significant differences when scores from all age bands were analysed; and these questions were on having difficulties with mobility, where those aged 66 and over were significantly less positive than those who were younger; and on having fears about their cancer coming back, where older patients of 76 and over were more likely to say that they had no fears about their cancer coming back.

## Conclusions

- 7.4 The effect of chemotherapy on patients' attitudes is clearly more negative across a wider range of questions than the impact of radiotherapy on the attitudes of patients who experienced it.
- 7.5 The dataset informing the pilot survey did not contain information on when a patient had had chemotherapy or radiotherapy and it is not therefore possible to calculate an elapsed time from these kinds of treatment.
- 7.6 It is also the case that one of the Cancer Registries (Thames) recorded radiotherapy interventions for individual patients only within the first six months after diagnosis, whereas the remaining Registries recorded radiotherapy interventions at any point after diagnosis. It is not possible to establish whether this difference of policy had an impact on the survey findings.

## 8. Associations with stoma

- 8.1 The colorectal/lower gastrointestinal questionnaire asked patients whether they had a stoma; whether it had been reversed; and whether the question “did not apply”, i.e. they had never had a stoma.
- 8.2 On questions related to bowel control, sexual matters and body image, patients with a stoma in place were consistently less positive than were patients without a stoma. On 10 questions on which significance tests were conducted, all ten showed that patients with a stoma had significantly different attitudes from those without a stoma, and that in all these cases the perception of patients with a stoma was less positive. Examples of these differing attitudes are:
- Had control of my bowels “very much” in last seven days: those with stoma 23.7%; no stoma 49%
  - Had no difficulty controlling their bowels: those with stoma 62.1%; no stoma 79%
  - Like the appearance of my body in last seven days (very much): those with stoma 9.8%; no stoma 18.3%
  - Had no difficulty regarding sexual matters in last month: those with stoma 45.9%; no stoma 63.8%
  - Had no difficulty concerning appearance or body image in last month: those with stoma 52.6%; no stoma 69.5%
- 8.3 Patients were also asked whether they had had a stoma that had been reversed. On every question patients who had a reversal were significantly more positive than those with a stoma in place; and those who had had a reversal were almost as positive, on each question, as those patients who had never had a stoma. On one question patients who had experienced a reversal were marginally more positive than those who had never had a stoma (I like the appearance of my body, question 16).

### Conclusions

- 8.4 It is clear that the impact of a stoma is regarded as negative by many patients on a wide range of issues of importance to them. Having a stoma has a significant negative effect on patients’ ability to control their bowels; has a negative impact on their perception of their own body; and has a negative effect on their sex lives.
- 8.5 It is also clear that a stoma reversal largely recreates in those individuals the attitudes held by patients who have never had a stoma at all; and given the scale of negative attitudes towards stoma, the findings raise important issues of clinical policy for this group of colorectal patients.



## 9. Associations with physical activity

- 9.1 Patients were asked whether they undertook 30 minutes of physical activity, enough to raise their heart rate, and if so on how many days they had done so in the past week. Exercise was carefully defined in the question to include sport, brisk walking, or cycling, but respondents were instructed NOT to include physical activity such as housework or physical activity which was part of their job.
- 9.2 The question on physical activity was scored so as to comply with the Chief Medical Officer's guidance on such activity; accordingly, patients who undertook five or more days of such activity in the last week were scored positively, whereas other patients were not scored.
- 9.3 The association with regular exercise on the views of cancer survivors is one of the clearest outcomes of the pilot survey. Of the 43 scored common questions asked of survivors in each tumour group, 30 showed significant differences across all tumour groups with all time cohorts combined, as between those who did less than five days exercise a week, and those who did five days or more. In all the 30 instances where there were significant differences between these groups, those with the highest levels of exercise had more positive views than those with lower levels of exercise. In no cases, either across tumour groups or within them, was there an example where those who did less exercise were more positive than those who did more exercise.
- 9.4 These cross tumour group differences were also replicated within each tumour group, shown below:
- Breast: 20 differences where patients with higher levels of exercise were more positive than those who did less
  - Colorectal/lower gastrointestinal: 18 differences (as defined above)
  - NHL: 12 differences
  - Prostate: 22 differences
- 9.5 Exercise clearly made a substantial difference on questions related to mobility, self care, undertaking usual activities, maintaining independence, undertaking domestic chores, managing their own personal care, looking after those who depended on them, having difficulty getting around, and undertaking their usual activities. On all these questions, there were significant differences across all tumour groups, and within each of them, with those undertaking regular exercise being more positive. It is noticeable that on questions relating to communication, perceptions of body image, feelings of isolation, memory loss, having trouble sleeping, experiencing mood swings, and feeling irritable, the effect of exercise (although present in some tumour groups) is not as all pervasive as it is on other questions.
- 9.6 Examination of the issues on which there were no statistically significant differences between those who exercised, and those who did not, also shows an interesting pattern. There were nine

questions which showed no significant differences between those who exercised, and those who did less; and it is clear that some were on issues related to the financial environment (difficulty with benefits, or with financial services); some were on issues about prognosis and death (fears about cancer coming back, and fears about death and dying); and some were on the pattern of treatment they had received and their perceptions of NHS quality (having a written care plan; having a named nurse; hospital staff did everything they could to support them; and General Practitioner staff did everything they could to support them). One further question on which there was no difference by exercise level was on having plans to have a family.

## Conclusions

- 9.7 The association of regular exercise on the attitudes of patients is positive on many issues when we compare the group of patients who exercised regularly with those who did not.
- 9.8 This effect is most profound on issues related to managing the patient's own daily life and is rather less profound on some psychological issues such as feeling isolated, irritability, and having mood swings. Exercise has no measurable effect on patients' perception of financial issues and attitudes to the treatment they have had in the NHS.

# 10. Associations with gender

- 10.1 Gender related views of respondents were analysed in two separate ways:
- Across all tumour groups, looking at the differences between men and women in all groups; and
  - Within tumour groups, looking just at the different views of men and women in each tumour group separately.
- 10.2 The analysis showed a pattern familiar from surveys of NHS patients in all settings, whether they have been patients in acute hospitals, in community services, or in mental health. In summary, men are significantly more positive on many issues than are women, both when respondents from a gender are combined, across tumour groups, and when they are assessed for differences within particular tumour groups.
- 10.3 Specifically, the pattern of response from men and women showed the following characteristics when responses from all tumour groups were aggregated:
- There were 28 questions (out of 43 scored questions common to all tumour groups) on which there were statistically significant differences between the views of men and women. On 25 of the 28 questions, men were more positive than women; only on three, were women more positive than men.
  - The three questions on which women were more positive than men were on: whether their cancer had responded to treatment; having no difficulty on sexual matters; and on having a named nurse who they can contact.
  - The 25 questions on which men, across all tumour groups, were more positive were on: having no problems with pain; on having anxiety; on undertaking physical activity; on maintaining independence; on undertaking domestic chores; on looking after dependents; on having no financial difficulties; on having no difficulty with financial services; on having difficulty associated with work; on having difficulty planning for the future; on communicating with those close to them, or with others; having difficulty with their appearance or body image; on feeling isolated; having difficulties with where they lived; having fears about their cancer spreading; having fears about their cancer coming back; having fears about death and dying; having trouble sleeping; having trouble concentrating; always feeling tired; experiencing mood swings; feeling that hospital staff did everything they could to help them; feeling that GP staff did everything they could to help them; and being given enough care and help from health and social services.
- 10.4 Across the four tumour groups in the pilot respondent group, there were, of course, no women in the prostate tumour group, and in the breast tumour group there were only very small numbers of male respondents, as would be anticipated; the numbers of male respondents makes

it impractical to establish significance in responses between the genders within the breast tumour group. The gender analysis is therefore confined to the colorectal/lower gastrointestinal and non-Hodgkin's lymphoma groups. The pattern of response from men and women within these groups showed the following characteristics:

- Within the colorectal/lower gastrointestinal group, there are 16 questions on which there are statistically significant differences of views between male and female respondents. Only on one question where there is a significant difference were women more positive than men, and that was in respect of the question on having no difficulty regarding sexual matters. Men were more positive than women on pain; anxiety; undertaking physical exercise; independence; domestic chores; looking after dependents; feeling isolated; getting around; fears about cancer spreading; fears about cancer coming back; fears about death and dying; having trouble sleeping; knowing who to contact; hospital staff helping them; and on getting enough help from health and social services.
- Within the non-Hodgkin's lymphoma tumour group, there are 11 questions on which there are statistically significant differences of views between male and female respondents. Only on one question where there is a significant difference were women more positive than men, and as in the colorectal/lower gastrointestinal group, it was on having difficulty on sexual matters. Men were more positive than women on undertaking physical activity; maintaining independence; carrying out domestic chores; looking after dependents; appearance or body image; feeling isolated; having trouble sleeping; hospital staff doing everything they could to help them; GP staff supporting them; and being given enough help from health and social services.

## Conclusions

- 10.5 The pattern of responses between men and women is similar in the Survivorship Survey to that seen in both the Cancer Patient Experience Survey 2010<sup>1</sup> and the National Inpatient Survey<sup>2</sup> organised on behalf of the Care Quality Commission (CQC) in all acute NHS hospitals.
- 10.6 Men are, on many issues, more positive than women, both when all tumour group scores are aggregated, and when individual tumour groups are considered separately. However, women were more positive than men on difficulties with sexual matters; and the positivity on having a named nurse reflects the high concentration of Clinical Nurse Specialist (CNS) posts dealing with women in the breast cancer group.

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1 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_122516](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516)

2 [http://www.cqc.org.uk/search/apachesolr\\_search/inpatient%20survey](http://www.cqc.org.uk/search/apachesolr_search/inpatient%20survey)

# 11. Associations with age

- 11.1 On many NHS national surveys, there are significant differences in the view of patients based on the age group of the patient, with (in most cases) younger patients, especially those aged 16-24, being the most critical of NHS services. In the case of the survivorship survey pilot, age bands were concatenated to allow for the relatively small numbers of patients in the 16-50 age band; so the “youngest” age group in this context is 16-50, with further bands representing 51-65, 66-75, and 76+. Age was defined as being that identified by the patient as their age at the time of returning the questionnaire.
- 11.2 This tendency for “younger” patients to feel less positive than older ones, found in the national CQC survey programme, is not replicated in the Cancer Survivorship data. There are certain kinds of questions on which younger patients feel more positive than older ones, and vice versa. In total there were 14 scored questions, common to all tumour group questionnaires, where there were statistically significant differences seen across all age bands. In addition, there were differences within tumour groups as follows:
- Breast: four questions on which there were significant differences between the views of patients in different age bands
  - Colorectal/lower GI: two questions where there were significant differences
  - Non-Hodgkin’s lymphoma: three questions where there were significant differences
  - Prostate: no questions on which there were significant differences
- 11.3 There were two questions where there were significant differences across age bands within three of the four tumour groups: these were on having no problems with mobility; and on having fears that their cancer would come back. In all tumour groups, the oldest age group was the least positive on the mobility question; and in all tumour groups the oldest age group was the most positive on the question about fears that their cancer would come back.
- 11.4 The questions on which younger patients (16-50) are the most positive, and where the differences between age bands across all tumour groups are statistically significant, are as follows:
- Having difficulties with mobility (16-50s most positive, 76+ least positive)
  - Having difficulties undertaking their usual activities (16-50s most positive, 76+ least positive)
  - Having a named nurse to contact (16-50s most positive, 76+ least positive)
  - Undertaking domestic chores (16-50s most positive, 76+ least positive)
- 11.5 It is significant that the results on the named nurse question follow the pattern of response on the 2010 Cancer Patient Experience Survey (CPES), which demonstrated that access to a Clinical Nurse Specialist (CNS) was lowest amongst the oldest age group.

- 11.6 The questions on which younger patients were least positive, and where the differences between age bands across all tumour groups were statistically significant, are as follows:
- Having no problems with anxiety (16-50s least positive, 76+ most positive)
  - Having no financial difficulties (16-50s least positive, 76+ most positive)
  - Having no difficulty with their appearance or body image (16-50s least positive, 76+ most positive)
  - Having no difficulty with feeling isolated (16-50s least positive, 66-75+ most positive)
  - Having fears about their cancer coming back (16-50s least positive, 76+ most positive)
  - Having fears about death and dying (16-50s least positive, 76+ most positive)
  - Experiencing mood swings (16-50s least positive, 76+ most positive)
- 11.7 There were also a group of questions where the differences between age bands across all tumour groups were statistically significant, and on which the most positive scores were displayed by those in the mid range of the age distribution. These questions were as follows:
- Undertaking exercise five or more days a week (66-75s most positive)
  - Having memory loss (51-65 most positive, 76+ least positive)

## Conclusions

- 11.8 The data from the Cancer Survivorship survey does not follow the normal pattern related to age found in other national surveys, where younger patients are less positive than older ones on a wide range of issues.
- 11.9 In the Survivorship survey data, age differences can be seen to reflect the attitudes and concerns of patients at different stages in life, given that most cancer patients are over the age of 50. Therefore, we do not see the relative confusion about treatment and information which are obvious features of the CQC surveys age band data; instead we see evidence of greater levels of concern amongst younger cancer survivors about appearance and body image, and more fear about death and dying, than we see in older cancer survivors. Older cancer survivors were less positive about mobility, undertaking their usual activities, doing their domestic chores, and having a named nurse.

## 12. Associations with sexual orientation

- 12.1 There are only 41 respondents in the pilot across all tumour groups who described themselves as non-heterosexual, taking bisexual, gay, lesbian and other, together. It is not possible to draw reliable conclusions about the views of the non-heterosexual respondents because of the small size of this group, and further analysis of their views will not be possible until the Survivorship Survey is rolled out to a larger sample of patients. In the Cancer Patient Experience Survey, patients who described themselves as non-heterosexuals were less positive than were heterosexuals on a wide range of issues.

### Conclusion

- 12.2 No conclusions can be drawn at this point because of the lack of sufficient available data.

## 13. Associations with employment status

- 13.1 The survey contained two questions, commonly administered across all tumour groups and time cohorts, which asked about patients' employment status: one on their employment before being diagnosed with cancer (full time, part time, homemaker, student, retired, unemployed seeking work, unemployed and unable to work for health reasons, and "other"); and a second, with identical response options, which asked about their employment status at the time of returning the questionnaire.
- 13.2 A third question asked those who were currently employed at the time of returning the questionnaire, whether they were working their usual number of hours, or alternatively more or fewer. Of those in continuing employment post diagnosis, most respondents were working their normal hours but a significant proportion in all tumour groups and time cohorts were not working at all, or were working reduced hours.
- 13.3 Most respondents in all tumour groups and time cohorts categorised themselves as being in full time or part time employment, or in the retired category, when the measuring point was employment status before cancer was diagnosed.
- 13.4 The proportions of respondents in full time and part time employment was broadly stable across time cohorts and for each tumour group separately, when patients were referring to their employment status before being diagnosed with cancer. The numbers of respondents in full time employment was highest at this point, amongst non-Hodgkin's lymphoma respondents; and the proportion of retired respondents was highest amongst Prostate respondents.
- 13.5 In all tumour groups there was a significant decline in full time work between the two measuring points, i.e. pre-diagnosis, and at the time of returning the questionnaire, which was at least one year post diagnosis and in most cases considerably longer. This decline in employment participation was proportionately similar across the tumour groups but the non-Hodgkin's lymphoma respondents showed higher levels of full time employment both before diagnosis and at the time of response:

**Table 13.1: Decline in full time work by tumour group**

| Tumour Group        | Full time pre-diagnosis one year cohort | Full time currently one year cohort |
|---------------------|---|-------------------------------------|
| Breast              | 23%                                     | 15%                                 |
| Colorectal/lower GI | 20%                                     | 12%                                 |
| NHL                 | 32%                                     | 23%                                 |
| Prostate            | 24%                                     | 18%                                 |

- 13.6 It is clear therefore that the proportion of patients in employment, and very especially in full time employment, declines significantly after diagnosis by between a quarter and a third in each tumour group.



- 13.7 When we examine the views of respondents based on their prior employment status (i.e. prior to diagnosis) we find that there are virtually no significant differences between the views of respondents across employment status. On only one question (having no difficulty with mobility) were there significant differences when tests were run across employment categories. In this case those who were in full time employment were significantly more positive, with more respondents who were in full time employment having no problems with mobility.
- 13.8 It is clear that there are a greater number of significant differences when we look at the views of respondents in relation to their current employment status. There were 19 questions (out of 43 scored common questions) on which there were such significant differences; those with a current retired status were most positive of any group on having no financial difficulties, appearance and body image, fears of death and dying, on having mood swings and on feeling irritable. Those in full time employment were the most positive group on eight measures, including mobility, self care, undertaking usual activities, pain, anxiety, maintaining independence, undertaking domestic chores, and travelling/taking a holiday.
- 13.9 One of the most consistent findings in the survey results is that respondents who were neither in employment nor retired (i.e. homemakers, students, unemployed seeking work, and unemployed because of their health) were the least positive group on almost every one of the 43 common questions.

## Conclusion

- 13.10 It is clear from the data that participation in the employment market declines sharply after diagnosis with cancer, by between a quarter and a third in all the cancer groups surveyed.
- 13.11 At the point of completing the questionnaire, the largest scale differences in views were between those patients with differing employment status post diagnosis. Those in full time employment post diagnosis were more positive on a range of issues, whilst those who were neither in employment nor were retired were the least positive group on almost every question. This finding replicates findings from hospital inpatient surveys undertaken by Quality Health which have asked questions about employment status.

# 14. Associations with ethnicity

- 14.1 There were 208 respondents from black and minority ethnic backgrounds (BME), including mixed race backgrounds, to the Cancer Survivorship Survey pilot, across all tumour groups and time cohorts. This equates to 6.3% of all respondents.
- 14.2 However, when respondents from all BME and mixed race groups were disaggregated in to ethnic groups and compared with white respondents, no statistically significant differences were identified in their views. This is highly likely to be the product of very small numbers of respondents in each cell within a tumour group representing particular BME groups, even when time cohorts and ethnic groups are collapsed for the purposes of analysis.
- 14.3 The conclusion in respect of the pilot survey is therefore that there is insufficient data to enable potential differences of view to be identified. The Cancer patient Experience Survey (CPES) 2010 identified a large number of significant differences about cancer treatment held by different ethnic minority groups, and the working hypothesis for the Survivorship Survey was that those kinds of differences would be replicated, as indeed they are, in every national survey undertaken on behalf of the Care Quality Commission (CQC), in every sector of the NHS. Testing of this hypothesis will therefore be reserved until the Survivorship Survey is extended to further tumour groups, larger cohorts and wider locations.

## Conclusion

- 14.4 No conclusions can be drawn at this point because of the absence of sufficient available data.

# 15. Associations with long term conditions

- 15.1 There are approximately 15 million people with long term conditions (LTCs) in England, with prevalence rising on Quality and Outcome Framework Registers but self reported prevalence falling for most conditions<sup>1</sup>. It is expected that the number of people with a LTC will be stable over the next decade, but that the proportion having multiple LTCs will rise sharply during that period, partly due to the rising proportions of people over 60 in the population.
- 15.2 Long term conditions are not equally distributed in the population, with people in social class 5 having a 60% higher prevalence of LTCs and a 60% higher severity of conditions, than those in social class 1<sup>2</sup>. The impact of LTCs is powerful in employment, as those with a limiting LTC are half as likely to have a job as those with a non limiting LTC, or no LTC<sup>3</sup>. In this context, with a wealth of evidence demonstrating the powerful influence of long term conditions, it would be surprising if analysis did not show a substantial difference in the attitudes of those cancer patients with a LTC and those without one.
- 15.3 In the Cancer Patient Experience Survey 2010, the presence of self reported long term conditions (LTCs) had a significant impact on the views of patients about their care, and it was clear that of the LTCs analysed, those patients with a mental health issue or learning disability had the least positive views on a wide range of questions.
- 15.4 The evidence from the Cancer Survivorship survey shows strong relationships between the presence of long term conditions and poorer scores on most questions. In summary, we can say that:
- Of the 43 scored questions asked of all respondents in the survivorship survey, 40 showed a statistically significant difference between those patients who reported having a LTC of any kind and those who did not, when data from all patients across all four tumour groups was analysed. On every one of these 40 common questions, patients with a long term condition had lower positive scores than those without a LTC. On some questions, the differences between those with a LTC and those without were very large: for example, didn't have trouble sleeping (higher score more positive) – those with no LTC 52%; those with a LTC 38%.
  - The same pattern was evident when we analysed the questions specific to particular tumour groups in the Survivorship Survey. Of the 15 specific questions asked of non-Hodgkin's lymphoma patients, 14 showed statistically significant differences between those with a LTC and those who did not have one, and on all questions those with a LTC were less positive than those without one. On the 13 specific questions asked of Prostate patients, 11 showed significant differences, all of them showing LTC patients as less positive; on the nine specific

1 NHS Information Centre, and General Lifestyle Survey 2008

<http://www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles-related-surveys/health-survey-for-england>

2 General Household Survey 2006 <http://www.esds.ac.uk/findingData/snDescription.asp?sn=5804>

3 Labour Force Survey 2009

<http://www.ons.gov.uk/ons/guide-method/surveys/list-of-surveys/survey.html?survey=Labour+Force+Survey>

questions asked of Breast patients, four show significant differences, all of them with LTC patients being less positive; and on the 13 specific questions asked of Colorectal/lower gastrointestinal patients, 11 show significant differences, all of them with LTC Patients being less positive than those without a LTC.

# 16. Associations with social deprivation

- 16.1 The Cancer Patient Experience Survey 2010 (CPES) was analysed by quintiles based on the Index of Multiple Deprivation (IMD), with each deprivation level being based on 20% groupings within the 0-100% range; and in the case of the CPES no statistically significant differences were found between the quintiles as a whole.
- 16.2 The IMD deciles and quintiles are intended to provide range information in respect of the differences between the most deprived decile/quintile to the least deprived. Because of the counter intuitive nature of the findings in CPES when all quintiles were analysed across the dataset, with no significant differences found, and only one significant difference found when we moved the analysis to deciles, it was decided to reanalyse the data based on an assessment of the differences between the extreme cases – decile one (least deprived) to decile 10 (most deprived). This analysis showed something very different: there were 37 questions on which statistically significant differences between decile one and decile 10; but in 16 of the 37 cases of such difference, it was the most deprived decile who were the most positive.
- 16.3 However, there was a degree of consistency in the kinds of questions that were less well ranked by patients in the most deprived decile in CPES; 10 of the items related to information giving and understanding, and a further four items related to perceived feelings that the patient was being treated in an offhand way.
- 16.4 When we turn to the analysis of the Cancer Survivorship Survey, a rather different picture emerges. On 39 of the 43 scored common questions asked of patients in all tumour groups, there were statistically significant differences between the IMD quintiles with patients in quintile one (the least deprived) being more positive on every question than patients in quintile five, when significance tests were undertaken across all tumour groups. Even on the four questions that did not show significant differences between the quintiles, patients in quintile one were more positive than patients in quintile five.
- 16.5 When we examined the results of the IMD quintile analysis within each tumour group, the position was reinforced in this way:
- Breast: 16 of the 43 common questions showed significant differences, and on all these questions, patients in quintile one were more positive than those in quintile five.
  - Colorectal/lower GI: 21 of the 43 questions showed significant differences, and on all these questions, patients in quintile one were more positive than those in quintile five.
  - Non-Hodgkin's lymphoma: 25 of the 43 questions showed significant differences, and on all these questions, patients in quintile one were more positive than those in quintile five.
  - Prostate: 21 of the 43 questions showed significant differences, and on all these questions, patients in quintile one were more positive than those in quintile five.

- 16.6 There were a number of other points of interest in the IMD analysis, as follows:
- There were no significant differences between the IMD quintiles (across all tumour groups and within each of them) on the exercise question, measuring the number of days on which respondents undertook 30 minutes, or more, of sustained exercise
  - There were no significant differences between the IMD quintiles (across all tumour groups and within each of them) on the question relating to plans to have a family;
  - There were no significant differences on the care plan question (ie whether patients had an up to date written care plan);
  - There were no significant differences on the question asking whether hospital staff did everything they could to support the patient following their cancer treatment.
- 16.7 We also adjusted the IMD scores by removing the impact of age and gender; the effect of this was small but it did increase the number of statistically significant results as between quintiles one and five. We therefore concluded that on both adjusted and unadjusted scores, deprivation was a powerful factor in explaining differences of view between cancer survivors. The question remains: why should this be so when it seemed to be a less powerful variable in the CPES 2010?
- 16.8 The hypothesis that we believe comes closest to explaining the differences between the CPES 2010 data and that from the Survivorship Survey pilot is that in CPES, most questions were clearly about the patients' treatment for cancer by their GP, in hospital, and after discharge. If patients feel that, broadly speaking, all NHS patients are going to be treated equally by the system, then within each IMD decile or quintile there should be a similar distribution of views about the quality of such treatment. However, the questions in the Survivorship Survey were largely about the patients' health status as distinct from treatment, and it was noticeable that two of the questions where there were no significant differences between IMD quintiles were on care plans and support given by hospital staff, following cancer treatment.
- 16.9 What is clear is that there is a deprivation effect on the response rate on the Survivorship Survey between quintile one and quintile five, when all tumour groups and time cohorts are analysed. The quintile one response rate for all tumour groups and time cohorts was 82.4% for quintile one; and 77.8% for quintile five. This difference across all tumour groups was narrower than the difference between decile one and decile 10 on CPES, which was 71%-51%.

# Annex A: Living with and beyond Colorectal/ Gastro Intestinal Cancer



## **Patient Reported Outcome Measures 2012 Living with and beyond Colorectal / Gastro Intestinal Cancer**

This questionnaire is about your health and quality of life since completing this questionnaire last year. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

### **Who should complete the questionnaire?**

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view  not the point of view of the person who is helping.

### **Completing the questionnaire**

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

### **IMPORTANT INFORMATION**

To make sure information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

**By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:**

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future
- Information about you such as your address, held by the Personal Demographic Service, a central NHS register, may be checked before any further questionnaires related to your health status or NHS care and treatment are sent to you, specifically to make sure addresses are up to date and to ensure that letters are not sent inappropriately

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

**Published reports will not contain any personal details**

## YOUR HEALTH TODAY

*The questions in this section are all about your health and how you feel on the day you complete this questionnaire.*

1. What treatments have you received for your colorectal / GI cancer? **(Tick all that apply)**

- 1  Radiotherapy
- 2  Chemotherapy
- 3  Surgery

2. How long is it since you completed your **initial treatment** for colorectal / GI cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your colorectal / GI cancer.*

- 1  I am still having my initial treatment
- 2  It is less than 3 months since my initial treatment
- 3  It is between 3 and 12 months since my initial treatment
- 4  It is between 1 and 5 years since my initial treatment
- 5  It is more than 5 years since my initial treatment
- 6  Don't know / can't remember

3. How has your colorectal / GI cancer responded to treatment?

- 1  My colorectal / GI cancer has responded fully to treatment (I am in remission)
- 2  My colorectal / GI cancer has been treated but is still present
- 3  My colorectal /GI cancer has not been treated at all
- 4  My colorectal / GI cancer has come back after it was originally treated
- 5  I am not certain what is happening with my colorectal / GI cancer

4. If you have a stoma (e.g. colostomy) is it:

- 1  Still present
- 2  Reversed
- 3  This does not apply to me



## YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

### 5. MOBILITY

- I have no problems in walking about <sub>1</sub>
- I have slight problems in walking about <sub>2</sub>
- I have moderate problems in walking about <sub>3</sub>
- I have severe problems in walking about <sub>4</sub>
- I am unable to walk about <sub>5</sub>

### 6. SELF CARE

- I have no problems washing or dressing myself <sub>1</sub>
- I have slight problems washing or dressing myself <sub>2</sub>
- I have moderate problems washing or dressing myself <sub>3</sub>
- I have severe problems washing or dressing myself <sub>4</sub>
- I am unable to wash or dress myself <sub>5</sub>

### 7. USUAL ACTIVITIES (*work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities <sub>1</sub>
- I have slight problems doing my usual activities <sub>2</sub>
- I have moderate problems doing my usual activities <sub>3</sub>
- I have severe problems doing my usual activities <sub>4</sub>
- I am unable to do my usual activities <sub>5</sub>

### 8. PAIN / DISCOMFORT

- I have no pain or discomfort <sub>1</sub>
- I have slight pain or discomfort <sub>2</sub>
- I have moderate pain or discomfort <sub>3</sub>
- I have severe pain or discomfort <sub>4</sub>
- I have extreme pain or discomfort <sub>5</sub>

### 9. ANXIETY / DEPRESSION

- I am not anxious or depressed <sub>1</sub>
- I am slightly anxious or depressed <sub>2</sub>
- I am moderately anxious or depressed <sub>3</sub>
- I am severely anxious or depressed <sub>4</sub>
- I am extremely anxious or depressed <sub>5</sub>

## YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

*The questions in this section are about your health and how you have felt in the past 7 days.*

Please mark one box per line to give your response.

| <i>During the past 7 days:</i> |   | Not at all                    | A little bit               | Some-what                      | Quite a bit                | Very much                  |                            |                            |                            |
|--------------------------------|---|-------------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 10.                            | I have swelling or cramps in my stomach area  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 11.                            | I am losing weight  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 12.                            | I have control of my bowels   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 13.                            | I can digest my food well   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 14.                            | I have diarrhoea  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 15.                            | I have a good appetite  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 16.                            | I like the appearance of my body  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 17.                            | I have difficulty urinating   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 18.                            | I urinate more frequently than usual  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 19.                            | I leak urine  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 20.                            | Do you have an ostomy appliance / stoma?  | 1 <input type="checkbox"/> No |                            | 2 <input type="checkbox"/> Yes |                            |                            |                            |                            |                            |
|                                | If yes, please answer the next two items:   | Not at all                    | A little bit               | Some-what                      | Quite a bit                | Very much                  |                            |                            |                            |
| 21.                            | I am embarrassed by my ostomy appliance / stoma   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 22.                            | Caring for my ostomy appliance / stoma is difficult   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 23.                            | Do you have any difficulty in controlling your bowels (e.g. any accidents)?   | 1 <input type="checkbox"/> No |                            | 2 <input type="checkbox"/> Yes |                            |                            |                            |                            |                            |
|                                |   | Monthly                       | Weekly                     | Daily                          | Constantly                 | It varies                  |                            |                            |                            |
| 24.                            | If yes, how often do you have difficulties?   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |                            |
| 25.                            | In the <b>past week</b> , 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? <i>This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.</i> | None                          | 1 day                      | 2 days                         | 3 days                     | 4 days                     | 5 days                     | 6 days                     | 7 days                     |
|                                |   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> | 7 <input type="checkbox"/> | 8 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

***The questions in this section are about your health and how you have felt during the past month.***

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

**Please tick the response that best describes your answer.**

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 26. Have you had any difficulty in maintaining your independence?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 27. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 28. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)                                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 29. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 30. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 31. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 32. Have you had any financial difficulties?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 33. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 34. Have you had any difficulty concerning your work? (or education if you are a student)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 35. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 36. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)         | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 37. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 38. Have you had any difficulty concerning sexual matters?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 39. Have you had any difficulty concerning plans to have a family?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 40. Have you had any difficulty concerning your appearance or body image?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 41. Have you felt isolated?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 42. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 43. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)          | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 44. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 45. Have you had any difficulty with your plans to travel or take a holiday?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 46. Have you had any difficulty with any other area of your everyday life?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

*The questions in this section are about your health and how you have felt during the past month.*

Please tick the response that best describes your answer.

|  | Strongly<br>agree          | Agree                      | Neither<br>agree<br>nor<br>disagree | Disagree                   | Strongly<br>disagree       | Does<br>not<br>apply to<br>me |
|--|----------------------------|----------------------------|-------------------------------------|----------------------------|----------------------------|-------------------------------|
| 47. I have fears about my cancer spreading   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 48. I have fears about my cancer coming back | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 49. I have fears about death and dying       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 50. I experience memory loss                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 51. I have trouble sleeping                  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 52. I have trouble concentrating             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 53. I always feel tired                      | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 54. I experience mood swings                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 55. I am often irritable                     | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |

## OVERALL SUPPORT AND CARE

56. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

- 1  Yes, definitely  
2  Yes, I think so  
3  No  
4  I do not need a care plan  
5  Don't know

57. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

- 1  Yes  
2  No  
3  Don't know

58. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

- 1  Yes, definitely  
2  Yes, I think so  
3  No

59. Do you think that hospital staff did everything they could to support you following your cancer treatment?

- 1  Yes, all of the time  
2  Only some of the time  
3  Never  
4  I did not need any support

60. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

- 1  Yes, all of the time  
2  Only some of the time  
3  Never  
4  My general practice is not involved  
5  I do not need any support

61. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  I did not need help from health or social services  
5  Don't know / can't remember

62. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

- 1  Diet and lifestyle  
2  Physical activity and exercise  
3  Financial help or benefits  
4  Free prescriptions  
5  Returning to or staying in work  
6  Information / advice for family / friends / carer  
7  The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)  
8  The psychological or emotional aspects of living with and after cancer  
9  I have all the information and advice I need

## ABOUT YOU

*If you are helping someone to complete this questionnaire, please make sure this*

**information is the patient's and not your own.**

**63.** What year were you born?

(Please write in) e.g. 

|   |   |   |   |
|---|---|---|---|
| 1 | 9 | 4 | 4 |
|---|---|---|---|

|   |   |   |   |
|---|---|---|---|
| Y | Y | Y | Y |
|---|---|---|---|

**64.** Are you male or female?

- 1  Male  
2  Female

**65.** Which of the following best describes your sexual orientation?

- 1  Heterosexual / straight (opposite sex)  
2  Bisexual (both sexes)  
3  Gay or lesbian (same sex)  
4  Other  
5  Prefer not to answer

**66.** Which statement best describes your living arrangements?

- 1  I live with partner/spouse/family/friends  
2  I live alone  
3  I live in a nursing home, hospital or other long term care home  
4  Other

**67.** Do you have a long standing health condition? *Please include anything **other than your cancer** that has troubled you over a period of time or that could affect you over a period of time.*

- 1  Yes

2  No

3  Don't know / can't say

**68.** Which, if any, of the following conditions do you have? **(Tick all that apply)**

- 1  Alzheimer's disease or dementia  
2  Angina  
3  Arthritis  
4  Asthma or other chronic chest problem  
5  Blindness or visual impairment  
6  Deafness or hearing impairment  
7  Diabetes  
8  Epilepsy  
9  Heart condition  
10  High blood pressure  
11  Kidney disease  
12  Learning difficulty  
13  Liver disease  
14  Long term back problems  
15  Long-standing mental health problem  
16  Long-standing neurological problem  
17  Another long-standing condition  
18  I do not have any of these conditions

**69.** What was your employment status **before you were diagnosed with cancer?**

- 1  Full time employment  
2  Part time employment  
3  Homemaker  
4  Student (in education)  
5  Retired  
6  Unemployed and seeking work

7  Unemployed  unable to work for health reasons

8  Other

70. What is your employment status currently?  
*If on maternity or sick leave answer in relation to your **usual** employment status.*

1  Full time employment

2  Part time employment

3  Homemaker

4  Student (in education)

5  Retired

6  Unemployed  and seeking work

7  Unemployed  unable to work for health reasons

8  Other

71. If you are currently employed at the moment, are you:

1  Not working at all

2  Working less hours than usual

3  Working your usual hours

4  Working more hours than usual

5  This question does not apply to me

72. To which of these ethnic groups would you say you belong? (**Tick ONE only**)

**a. WHITE**

1  British

2  Irish

3  Any other White background  
(Please write in box)

**b. MIXED**

4  White and Black Caribbean

5  White and Black African

6  White and Asian

7  Any other Mixed background  
(Please write in box)

**c. ASIAN OR ASIAN BRITISH**

8  Indian

9  Pakistani

10  Bangladeshi

11  Any other Asian background  
(Please write in box)

**d. BLACK OR BLACK BRITISH**

12  Caribbean

13  African

14  Any other Black background  
(Please write in box)

**e. CHINESE OR OTHER ETHNIC GROUP**

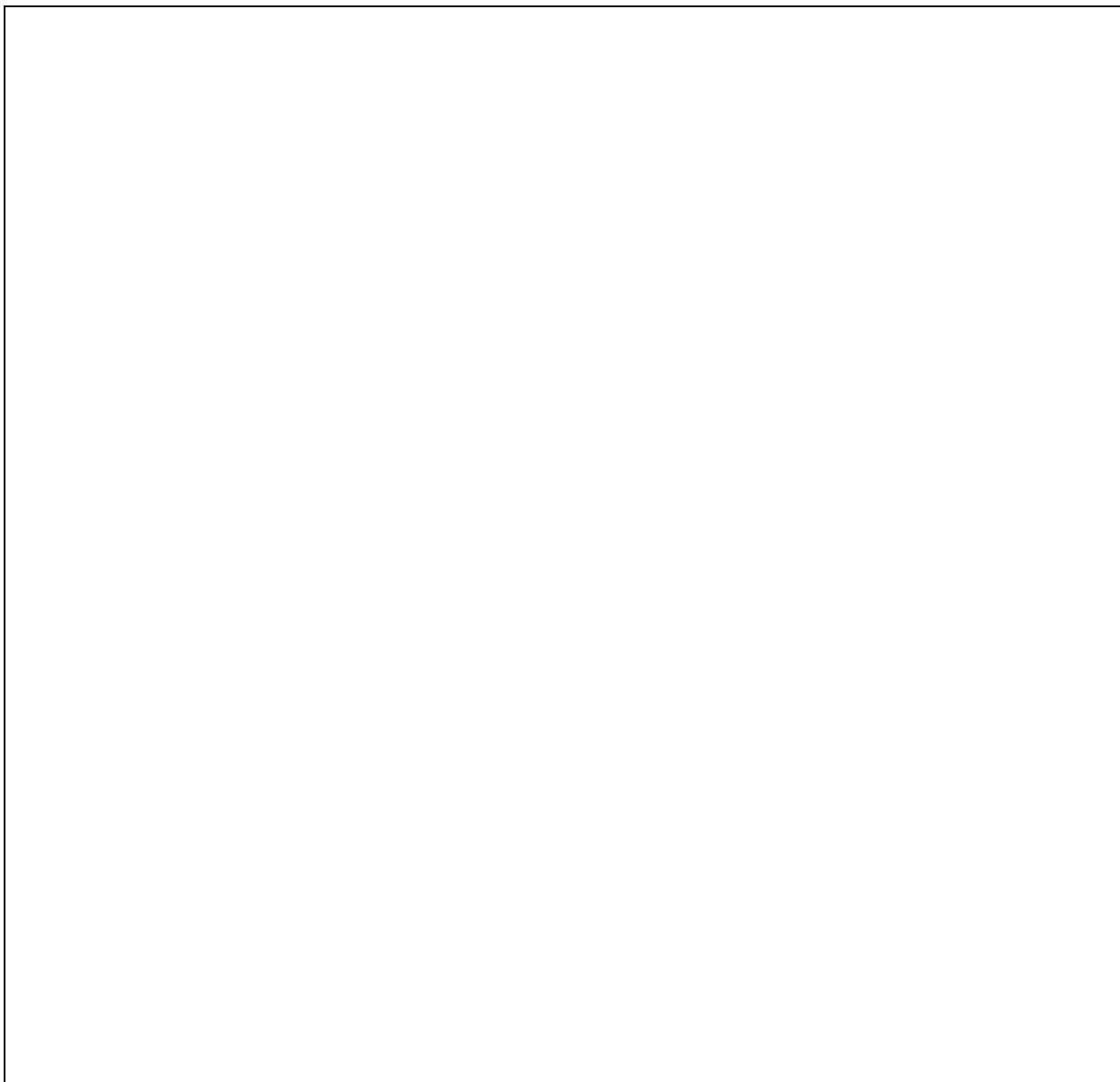
15  Chinese

16  Any other ethnic group  
(Please write in box)

**COMMENTS**



**If you have anything else you would like to tell us about any specific changes in how you feel about living with and beyond cancer since you completed the Patient Reported Outcome Measures survey in 2011, please do so here:**



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Questions 12 - 20 and 22 - 24 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 28 - 48 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

# Annex B: Living with and beyond non-Hodgkin's lymphoma



## Patient Reported Outcome Measures 2012 Living with and beyond Non Hodgkin's Lymphoma

This questionnaire is about your health and quality of life since completing this questionnaire last year. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

### Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view  not the point of view of the person who is helping.

### Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

### IMPORTANT INFORMATION

To make sure information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

**By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:**

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future
- Information about you such as your address, held by the Personal Demographic Service, a central NHS register, may be checked before any further questionnaires related to your health status or NHS care and treatment are sent to you, specifically to make sure addresses are up to date and to ensure that letters are not sent inappropriately

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

**Published reports will not contain any personal details**

## YOUR HEALTH TODAY

*The questions in this section are all about your health and how you feel on the day you complete this questionnaire.*

1. What treatments have you received for your Non Hodgkin's Lymphoma (NHL)?  
**(Tick all that apply)**
  - 1  Radiotherapy
  - 2  Chemotherapy
  - 3  Surgery
  - 4  Antibody therapy (including Rituximab)
  - 5  Stem cell transplant
  
2. How long is it since you completed your **initial treatment** for NHL? *Treatment includes any chemotherapy, radiotherapy, or surgery for your NHL. When answering this question please do not include antibody (Rituximab) treatment which you may have been given as a maintenance treatment following chemotherapy.*
  - 1  I am still having my initial treatment
  - 2  It is less than 3 months since my initial treatment
  - 3  It is between 3 and 12 months since my initial treatment
  - 4  It is between 1 and 5 years since my initial treatment
  - 5  It is more than 5 years since my initial treatment
  - 6  Don't know / can't remember
  
3. How has your NHL responded to treatment?
  - 1  My NHL has responded fully to treatment (I am in remission)
  - 2  My NHL has been treated but is still present
  - 3  My NHL has not been treated at all
  - 4  My NHL has come back after it was originally treated
  - 5  I am not certain what is happening with my NHL

## YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

### 4. MOBILITY

- I have no problems in walking about <sub>1</sub>
- I have slight problems in walking about <sub>2</sub>
- I have moderate problems in walking about <sub>3</sub>
- I have severe problems in walking about <sub>4</sub>
- I am unable to walk about <sub>5</sub>

### 5. SELF CARE

- I have no problems washing or dressing myself <sub>1</sub>
- I have slight problems washing or dressing myself <sub>2</sub>
- I have moderate problems washing or dressing myself <sub>3</sub>
- I have severe problems washing or dressing myself <sub>4</sub>
- I am unable to wash or dress myself <sub>5</sub>

### 6. USUAL ACTIVITIES (*work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities <sub>1</sub>
- I have slight problems doing my usual activities <sub>2</sub>
- I have moderate problems doing my usual activities <sub>3</sub>
- I have severe problems doing my usual activities <sub>4</sub>
- I am unable to do my usual activities <sub>5</sub>

### 7. PAIN / DISCOMFORT

- I have no pain or discomfort <sub>1</sub>
- I have slight pain or discomfort <sub>2</sub>
- I have moderate pain or discomfort <sub>3</sub>
- I have severe pain or discomfort <sub>4</sub>
- I have extreme pain or discomfort <sub>5</sub>

### 8. ANXIETY / DEPRESSION

- I am not anxious or depressed <sub>1</sub>
- I am slightly anxious or depressed <sub>2</sub>
- I am moderately anxious or depressed <sub>3</sub>
- I am severely anxious or depressed <sub>4</sub>
- I am extremely anxious or depressed <sub>5</sub>

## YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

*The questions in this section are about your health and how you have felt in the past 7 days.*

Please mark one box per line to give your response.

| <i>During the past 7 days:</i>  | Not at<br>all              | A little<br>bit            | Some-<br>what              | Quite<br>a bit             | Very<br>much               |                            |                            |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 9. I have certain parts of my body where I experience pain  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 10. I am bothered by lumps or swelling in certain parts of my body (e.g. neck, armpits, or groin)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 11. I am bothered by fevers (episodes of high body temperature)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 12. I have night sweats   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 13. I am bothered by itching  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 14. I have trouble sleeping at night  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 15. I get tired easily  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 16. I am losing weight  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 17. I have a loss of appetite   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 18. I have trouble concentrating  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 19. I worry about getting infections  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 20. I worry that I might get new symptoms of my illness   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 21. I feel isolated from others because of my illness or treatment  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 22. I have emotional ups and downs  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 23. Because of my illness, I have difficulty planning for the future  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 24. In the <b>past week</b> , 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? <i>This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.</i> |                            |                            |                            |                            |                            |                            |                            |
| <b>None</b>   | <b>1 day</b>               | <b>2 days</b>              | <b>3 days</b>              | <b>4 days</b>              | <b>5 days</b>              | <b>6 days</b>              | <b>7 days</b>              |
| 1 <input type="checkbox"/>  | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> | 7 <input type="checkbox"/> | 8 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

***The questions in this section are about your health and how you have felt during the past month.***

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

**Please tick the response that best describes your answer.**

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 25. Have you had any difficulty in maintaining your independence?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 26. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 27. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)                                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 28. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 29. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 30. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 31. Have you had any financial difficulties?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 32. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 33. Have you had any difficulty concerning your work? (or education if you are a student)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 34. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 35. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)         | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 36. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 37. Have you had any difficulty concerning sexual matters?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 38. Have you had any difficulty concerning plans to have a family?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 39. Have you had any difficulty concerning your appearance or body image?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 40. Have you felt isolated?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 41. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 42. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)          | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 43. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 44. Have you had any difficulty with your plans to travel or take a holiday?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 45. Have you had any difficulty with any other area of your everyday life?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

*The questions in this section are about your health and how you have felt during the past month.*

Please tick the response that best describes your answer.

|  | Strongly<br>agree          | Agree                      | Neither<br>agree<br>nor<br>disagree | Disagree                   | Strongly<br>disagree       | Does<br>not<br>apply to<br>me |
|--|----------------------------|----------------------------|-------------------------------------|----------------------------|----------------------------|-------------------------------|
| 46. I have fears about my cancer spreading   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 47. I have fears about my cancer coming back | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 48. I have fears about death and dying       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 49. I experience memory loss                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 50. I have trouble sleeping                  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 51. I have trouble concentrating             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 52. I always feel tired                      | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 53. I experience mood swings                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 54. I am often irritable                     | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |



## OVERALL SUPPORT AND CARE

55. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No
- 4  I do not need a care plan
- 5  Don't know

56. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

- 1  Yes
- 2  No
- 3  Don't know

57. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No

58. Do you think that hospital staff did everything they could to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  I did not need any support

59. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  My general practice is not involved
- 5  I do not need any support

60. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not need help from health or social services
- 5  Don't know / can't remember

61. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

- 1  Diet and lifestyle
- 2  Physical activity and exercise
- 3  Financial help or benefits
- 4  Free prescriptions
- 5  Returning to or staying in work
- 6  Information / advice for family / friends / carer
- 7  The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- 8  The psychological or emotional aspects of living with and after cancer
- 9  I have all the information and advice I need

## ABOUT YOU

**If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.**

62. What year were you born?

(Please write in) e.g. 

|   |   |   |   |
|---|---|---|---|
| 1 | 9 | 4 | 4 |
|---|---|---|---|

|   |   |   |   |
|---|---|---|---|
| Y | Y | Y | Y |
|---|---|---|---|

63. Are you male or female?

1  Male

2  Female

64. Which of the following best describes your sexual orientation?

1  Heterosexual / straight (opposite sex)

2  Bisexual (both sexes)

3  Gay or lesbian (same sex)

4  Other

5  Prefer not to answer

65. Which statement best describes your living arrangements?

1  I live with partner/spouse/family/friends

2  I live alone

3  I live in a nursing home, hospital or other long term care home

4  Other

66. Do you have a long standing health condition? *Please include anything other than your cancer that has troubled you over a period of time or that could affect you over a period of time.*

1  Yes

2  No

3  Don't know / can't say

67. Which, if any, of the following conditions do you have? (Tick all that apply)

1  Alzheimer's disease or dementia

2  Angina

3  Arthritis

4  Asthma or other chronic chest problem

5  Blindness or visual impairment

6  Deafness or hearing impairment

7  Diabetes

8  Epilepsy

9  Heart condition

10  High blood pressure

11  Kidney disease

12  Learning difficulty

13  Liver disease

14  Long term back problems

15  Long-standing mental health problem

16  Long-standing neurological problem

17  Another long-standing condition

18  I do not have any of these conditions

68. What was your employment status **before you were diagnosed with cancer**?

1  Full time employment

2  Part time employment

3  Homemaker

4  Student (in education)

5  Retired

6  Unemployed and seeking work

7  Unemployed unable to work for health reasons

8  Other

69. What is your employment status currently? *If on maternity or sick leave answer in relation to your usual employment status.*

1  Full time employment

2  Part time employment

- 3  Homemaker
- 4  Student (in education)
- 5  Retired
- 6  Unemployed  and seeking work
- 7  Unemployed  unable to work for health reasons
- 8  Other

70. If you are currently employed at the moment, are you:

- 1  Not working at all
- 2  Working less hours than usual
- 3  Working your usual hours
- 4  Working more hours than usual
- 5  This question does not apply to me

71. To which of these ethnic groups would you say you belong? (**Tick ONE only**)

**a. WHITE**

- 1  British
- 2  Irish
- 3  Any other White background  
(Please write in box)

**b. MIXED**

- 4  White and Black Caribbean
- 5  White and Black African
- 6  White and Asian
- 7  Any other Mixed background  
(Please write in box)

**c. ASIAN OR ASIAN BRITISH**

- 8  Indian
- 9  Pakistani
- 10  Bangladeshi
- 11  Any other Asian background  
(Please write in box)

**d. BLACK OR BLACK BRITISH**

- 12  Caribbean
- 13  African
- 14  Any other Black background  
(Please write in box)

**e. CHINESE OR OTHER ETHNIC GROUP**

- 15  Chinese
- 16  Any other ethnic group  
(Please write in box)

## COMMENTS

**If you have anything else you would like to tell us about any specific changes in how you feel about living with and beyond cancer since you completed the Patient Reported Outcome Measures survey in 2011, please do so here:**

Questions 4-8 are EQ-5D-5L. UK (English) v.2 © 2009 EuroQol Group. EQ-5D<sup>®</sup> is a trade mark of the EuroQol Group.

Questions 9 - 23 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 25 - 45 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

# Annex C: Living with and beyond Prostate Cancer



## Patient Reported Outcome Measures 2012 Living with and beyond Prostate Cancer

This questionnaire is about your health and quality of life since completing this questionnaire last year. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

### Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view  not the point of view of the person who is helping.

### Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

### IMPORTANT INFORMATION

To make sure information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

**By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:**

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future
- Information about you such as your address, held by the Personal Demographic Service, a central NHS register, may be checked before any further questionnaires related to your health status or NHS care and treatment are sent to you, specifically to make sure addresses are up to date and to ensure that letters are not sent inappropriately

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

**Published reports will not contain any personal details**

## YOUR HEALTH TODAY

***The questions in this section are all about your health and how you feel on the day you complete this questionnaire.***

1. What treatments have you received for your prostate cancer? **(Tick all that apply)**

- 1  Radiotherapy (including brachytherapy) (with or without planned hormonal treatment)
- 2  Surgery
- 3  Hormone treatment
- 4  Chemotherapy (not including hormones)
- 5  HIFU
- 6  Cryotherapy
- 7  Active surveillance (close monitoring but no current intervention)

2. How long is it since you completed your **initial treatment** for prostate cancer? *Treatment includes any chemotherapy, radiotherapy, or surgery for your prostate cancer. When answering this question please do not include hormone treatments.*

- 1  I am still having my initial treatment
- 2  It is less than 3 months since my initial treatment
- 3  It is between 3 and 12 months since my initial treatment
- 4  It is between 1 and 5 years since my initial treatment
- 5  It is more than 5 years since my initial treatment
- 6  Don't know / can't remember

3. How has your prostate cancer responded to treatment?

- 1  My prostate cancer has responded fully to treatment (I am in remission)
- 2  My prostate cancer has been treated but is still present
- 3  My prostate cancer has not been treated at all
- 4  My prostate cancer has come back after it was originally treated
- 5  I am not certain what is happening with my prostate cancer

## YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

### 4. MOBILITY

- I have no problems in walking about <sub>1</sub>
- I have slight problems in walking about <sub>2</sub>
- I have moderate problems in walking about <sub>3</sub>
- I have severe problems in walking about <sub>4</sub>
- I am unable to walk about <sub>5</sub>

### 5. SELF CARE

- I have no problems washing or dressing myself <sub>1</sub>
- I have slight problems washing or dressing myself <sub>2</sub>
- I have moderate problems washing or dressing myself <sub>3</sub>
- I have severe problems washing or dressing myself <sub>4</sub>
- I am unable to wash or dress myself <sub>5</sub>

### 6. USUAL ACTIVITIES (*work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities <sub>1</sub>
- I have slight problems doing my usual activities <sub>2</sub>
- I have moderate problems doing my usual activities <sub>3</sub>
- I have severe problems doing my usual activities <sub>4</sub>
- I am unable to do my usual activities <sub>5</sub>

### 7. PAIN / DISCOMFORT

- I have no pain or discomfort <sub>1</sub>
- I have slight pain or discomfort <sub>2</sub>
- I have moderate pain or discomfort <sub>3</sub>
- I have severe pain or discomfort <sub>4</sub>
- I have extreme pain or discomfort <sub>5</sub>

### 8. ANXIETY / DEPRESSION

- I am not anxious or depressed <sub>1</sub>
- I am slightly anxious or depressed <sub>2</sub>
- I am moderately anxious or depressed <sub>3</sub>
- I am severely anxious or depressed <sub>4</sub>
- I am extremely anxious or depressed <sub>5</sub>

## YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

**The questions in this section are about your health and how you have felt in the past 7 days.**

Please mark one box per line to give your response.

| <b>During the past 7 days:</b> |   | <b>Not at all</b>             | <b>A little bit</b>        | <b>Some-what</b>               | <b>Quite a bit</b>         | <b>Very much</b>           |                            |                            |
|--------------------------------|---|-------------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 9.                             | I am losing weight  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 10.                            | I have a good appetite  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 11.                            | I have aches and pains that bother me   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 12.                            | I have certain parts of my body where I experience pain   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 13.                            | My pain keeps me from doing things I want to do   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 14.                            | I am satisfied with my present comfort level  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 15.                            | I have trouble moving my bowels   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 16.                            | I have difficulty urinating   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 17.                            | I urinate more frequently than usual  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 18.                            | My problems with urinating limit my activities  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 19.                            | I am able to have and maintain an erection  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 20.                            | I leak urine  | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 21.                            | Do you have any difficulty in controlling your bowels (e.g. any accidents)?   | 1 <input type="checkbox"/> No |                            | 2 <input type="checkbox"/> Yes |                            |                            |                            |                            |
|                                |   | <b>Monthly</b>                | <b>Weekly</b>              | <b>Daily</b>                   | <b>Constantly</b>          | <b>It varies</b>           |                            |                            |
| 22.                            | If yes, how often do you have difficulties?   | 1 <input type="checkbox"/>    | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>     | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 23.                            | In the <b>past week</b> , 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? <i>This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.</i> |                               |                            |                                |                            |                            |                            |                            |
|                                | <b>None</b>   | <b>1 day</b>                  | <b>2 days</b>              | <b>3 days</b>                  | <b>4 days</b>              | <b>5 days</b>              | <b>6 days</b>              | <b>7 days</b>              |
|                                | 1 <input type="checkbox"/>  | 2 <input type="checkbox"/>    | 3 <input type="checkbox"/> | 4 <input type="checkbox"/>     | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> | 7 <input type="checkbox"/> | 8 <input type="checkbox"/> |



## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

***The questions in this section are about your health and how you have felt during the past month.***

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

**Please tick the response that best describes your answer.**

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 24. Have you had any difficulty in maintaining your independence?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 25. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 26. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)                                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 27. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 28. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 29. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 30. Have you had any financial difficulties?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 31. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 32. Have you had any difficulty concerning your work? (or education if you are a student)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 33. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 34. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)         | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 35. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 36. Have you had any difficulty concerning sexual matters?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 37. Have you had any difficulty concerning plans to have a family?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 38. Have you had any difficulty concerning your appearance or body image?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 39. Have you felt isolated?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 40. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 41. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)          | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 42. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 43. Have you had any difficulty with your plans to travel or take a holiday?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 44. Have you had any difficulty with any other area of your everyday life?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

*The questions in this section are about your health and how you have felt during the past month.*

Please tick the response that best describes your answer.

|  | Strongly<br>agree          | Agree                      | Neither<br>agree<br>nor<br>disagree | Disagree                   | Strongly<br>disagree       | Does<br>not<br>apply to<br>me |
|--|----------------------------|----------------------------|-------------------------------------|----------------------------|----------------------------|-------------------------------|
| 45. I have fears about my cancer spreading   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 46. I have fears about my cancer coming back | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 47. I have fears about death and dying       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 48. I experience memory loss                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 49. I have trouble sleeping                  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 50. I have trouble concentrating             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 51. I always feel tired                      | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 52. I experience mood swings                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 53. I am often irritable                     | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |

## OVERALL SUPPORT AND CARE

54. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No
- 4  I do not need a care plan
- 5  Don't know

55. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

- 1  Yes
- 2  No
- 3  Don't know

56. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No

57. Do you think that hospital staff did everything they could to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  I did not need any support

58. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  My general practice is not involved
- 5  I do not need any support

59. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not need help from health or social services
- 5  Don't know / can't remember

60. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

- 1  Diet and lifestyle
- 2  Physical activity and exercise
- 3  Financial help or benefits
- 4  Free prescriptions
- 5  Returning to or staying in work
- 6  Information / advice for family / friends / carer
- 7  The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- 8  The psychological or emotional aspects of living with and after cancer
- 9  I have all the information and advice I need

## ABOUT YOU

**If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.**

61. What year were you born?

(Please write in) e.g. 

|   |   |   |   |
|---|---|---|---|
| 1 | 9 | 4 | 4 |
|---|---|---|---|

|   |   |   |   |
|---|---|---|---|
| Y | Y | Y | Y |
|---|---|---|---|

62. Are you male or female?

1  Male

2  Female

63. Which of the following best describes your sexual orientation?

1  Heterosexual / straight (opposite sex)

2  Bisexual (both sexes)

3  Gay (same sex)

4  Other

5  Prefer not to answer

64. Which statement best describes your living arrangements?

1  I live with partner/spouse/family/friends

2  I live alone

3  I live in a nursing home, hospital or other long term care home

4  Other

65. Do you have a long standing health condition? *Please include anything other than your cancer that has troubled you over a period of time or that could affect you over a period of time.*

1  Yes

2  No

3  Don't know / can't say

66. Which, if any, of the following conditions do you have? (Tick all that apply)

1  Alzheimer's disease or dementia

2  Angina

3  Arthritis

4  Asthma or other chronic chest problem

5  Blindness or visual impairment

6  Deafness or hearing impairment

7  Diabetes

8  Epilepsy

9  Heart condition

10  High blood pressure

11  Kidney disease

12  Learning difficulty

13  Liver disease

14  Long term back problems

15  Long-standing mental health problem

16  Long-standing neurological problem

17  Another long-standing condition

18  I do not have any of these conditions

67. What was your employment status **before you were diagnosed with cancer**?

1  Full time employment

2  Part time employment

3  Homemaker

4  Student (in education)

5  Retired

6  Unemployed and seeking work

7  Unemployed unable to work for health reasons

8  Other

68. What is your employment status currently? *If on maternity or sick leave answer in relation to your usual employment status.*

1  Full time employment

2  Part time employment

## ABOUT YOU

**If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.**

61. What year were you born?

(Please write in) e.g. 

|   |   |   |   |
|---|---|---|---|
| 1 | 9 | 4 | 4 |
|---|---|---|---|

|   |   |   |   |
|---|---|---|---|
| Y | Y | Y | Y |
|---|---|---|---|

62. Are you male or female?

1  Male

2  Female

63. Which of the following best describes your sexual orientation?

1  Heterosexual / straight (opposite sex)

2  Bisexual (both sexes)

3  Gay (same sex)

4  Other

5  Prefer not to answer

64. Which statement best describes your living arrangements?

1  I live with partner/spouse/family/friends

2  I live alone

3  I live in a nursing home, hospital or other long term care home

4  Other

65. Do you have a long standing health condition? *Please include anything other than your cancer that has troubled you over a period of time or that could affect you over a period of time.*

1  Yes

2  No

3  Don't know / can't say

66. Which, if any, of the following conditions do you have? (Tick all that apply)

1  Alzheimer's disease or dementia

2  Angina

3  Arthritis

4  Asthma or other chronic chest problem

5  Blindness or visual impairment

6  Deafness or hearing impairment

7  Diabetes

8  Epilepsy

9  Heart condition

10  High blood pressure

11  Kidney disease

12  Learning difficulty

13  Liver disease

14  Long term back problems

15  Long-standing mental health problem

16  Long-standing neurological problem

17  Another long-standing condition

18  I do not have any of these conditions

67. What was your employment status **before you were diagnosed with cancer**?

1  Full time employment

2  Part time employment

3  Homemaker

4  Student (in education)

5  Retired

6  Unemployed and seeking work

7  Unemployed unable to work for health reasons

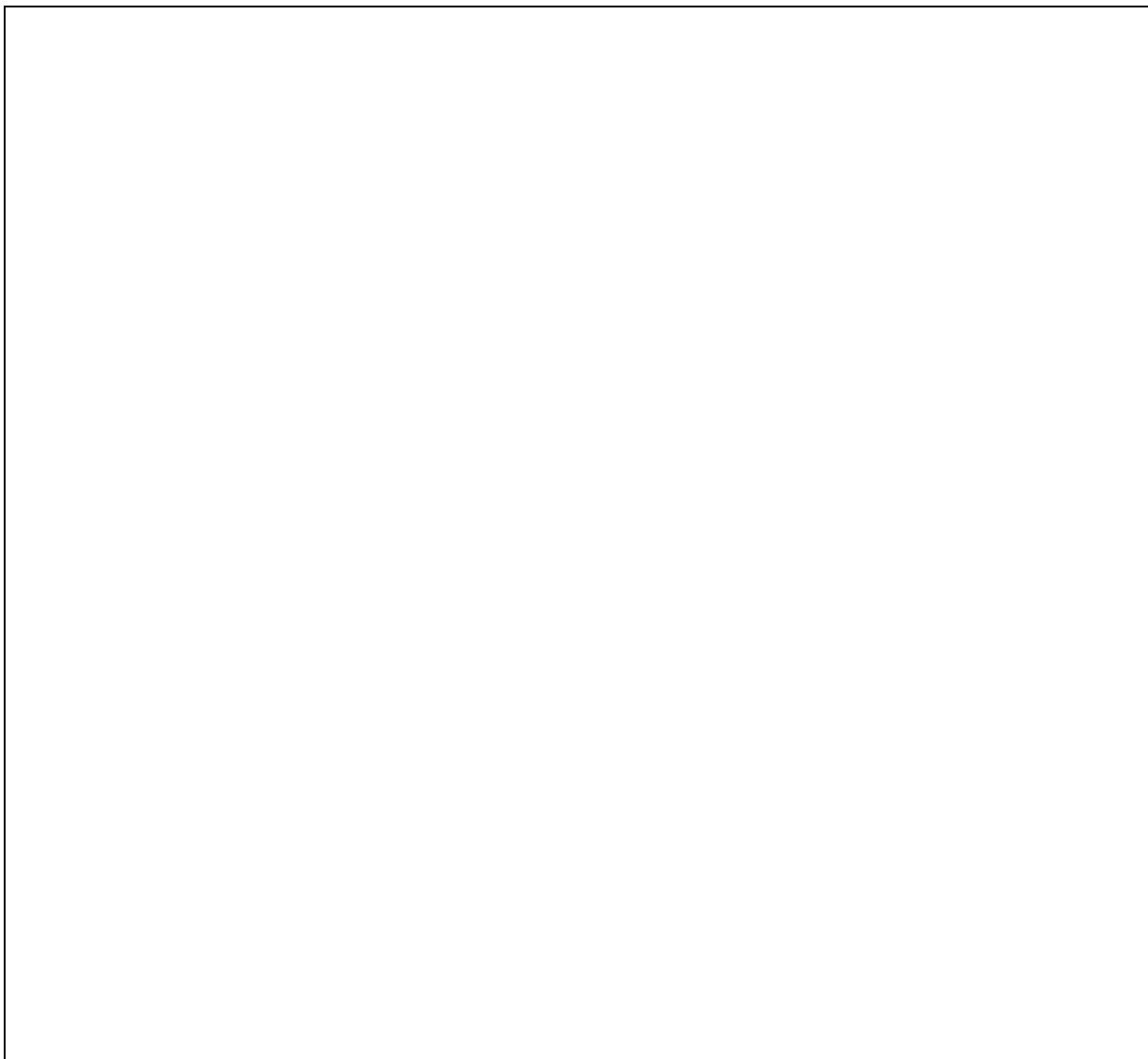
8  Other

68. What is your employment status currently? *If on maternity or sick leave answer in relation to your usual employment status.*

1  Full time employment

2  Part time employment

**If you have anything else you would like to tell us about any specific changes in how you feel about living with and beyond cancer since you completed the Patient Reported Outcome Measures survey in 2011, please do so here:**



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Questions 9 - 20 are taken from FACIT copyright 1987, 1997 by David Cella, PhD

Questions 24 - 44 are taken from the Social Difficulties Inventory. Originators of the Social Difficulties Inventory: Wright, E.P., Cull, A. and Selby, P.

# Annex D: Living with and beyond Breast Cancer



## Patient Reported Outcome Measures 2012 Living with and beyond Breast Cancer

This questionnaire is about your health and quality of life since completing this questionnaire last year. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

### Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view  not the point of view of the person who is helping.

### Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

### IMPORTANT INFORMATION

To make sure information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the quality of life for people who are living with and beyond cancer. These statistics will be used to compare the differences in quality of life for people treated for different types of cancer by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

**By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:**

- Your personal details and relevant health information can be held and used by an organisation contracted to the Department of Health to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service, Cancer Registries and other NHS databases can be held and used by an organisation contracted to the Department of Health to analyse the data
- Your personal details can be used to send you related follow-up questionnaires in the future
- Information about you such as your address, held by the Personal Demographic Service, a central NHS register, may be checked before any further questionnaires related to your health status or NHS care and treatment are sent to you, specifically to make sure addresses are up to date and to ensure that letters are not sent inappropriately

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Department of Health or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

**Published reports will not contain any personal details**



## YOUR HEALTH TODAY

*The questions in this section are all about your health and how you feel on the day you complete this questionnaire.*

1. What treatments have you received for your breast cancer? **(Tick all that apply)**

- 1  Radiotherapy
- 2  Chemotherapy (excluding hormone treatment)
- 3  Hormone treatment
- 4  Surgery

2. How long is it since you completed your **initial treatment** for breast cancer?  
*Treatment includes any chemotherapy, radiotherapy or surgery for your breast cancer. When answering this question please do not include hormone treatments such as Tamoxifen.*

- 1  I am still having my initial treatment
- 2  It is less than 3 months since my initial treatment
- 3  It is between 3 and 12 months since my initial treatment
- 4  It is between 1 and 5 years since my initial treatment
- 5  It is more than 5 years since my initial treatment
- 6  Don't know / can't remember

3. How has your breast cancer responded to treatment?

- 1  My breast cancer has responded fully to treatment (I am in remission)
- 2  My breast cancer has been treated but is still present
- 3  My breast cancer has not been treated at all
- 4  My breast cancer has come back after it was originally treated
- 5  I am not certain what is happening with my breast cancer

4. If you have had breast surgery, do any of the following apply to you? **(Tick all that apply)**

- 1  I have had a lumpectomy
- 2  I have had a mastectomy
- 3  I have had breast reconstruction
- 4  I am awaiting or considering breast reconstruction
- 5  None of these apply to me

## YOUR HEALTH TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

### 5. MOBILITY

- I have no problems in walking about <sub>1</sub>
- I have slight problems in walking about <sub>2</sub>
- I have moderate problems in walking about <sub>3</sub>
- I have severe problems in walking about <sub>4</sub>
- I am unable to walk about <sub>5</sub>

### 6. SELF CARE

- I have no problems washing or dressing myself <sub>1</sub>
- I have slight problems washing or dressing myself <sub>2</sub>
- I have moderate problems washing or dressing myself <sub>3</sub>
- I have severe problems washing or dressing myself <sub>4</sub>
- I am unable to wash or dress myself <sub>5</sub>

### 7. USUAL ACTIVITIES (*work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities <sub>1</sub>
- I have slight problems doing my usual activities <sub>2</sub>
- I have moderate problems doing my usual activities <sub>3</sub>
- I have severe problems doing my usual activities <sub>4</sub>
- I am unable to do my usual activities <sub>5</sub>

### 8. PAIN / DISCOMFORT

- I have no pain or discomfort <sub>1</sub>
- I have slight pain or discomfort <sub>2</sub>
- I have moderate pain or discomfort <sub>3</sub>
- I have severe pain or discomfort <sub>4</sub>
- I have extreme pain or discomfort <sub>5</sub>

### 9. ANXIETY / DEPRESSION

- I am not anxious or depressed <sub>1</sub>
- I am slightly anxious or depressed <sub>2</sub>
- I am moderately anxious or depressed <sub>3</sub>
- I am severely anxious or depressed <sub>4</sub>
- I am extremely anxious or depressed <sub>5</sub>

## YOUR HEALTH AND WELLBEING IN THE LAST 7 DAYS

***The questions in this section are about your health and how you have felt in the past 7 days.***

Please mark one box per line to give your response.

| <b><i>During the past 7 days:</i></b>   | <b>Not at<br/>all</b>      | <b>A little<br/>bit</b>    | <b>Some-<br/>what</b>      | <b>Quite<br/>a bit</b>     | <b>Very<br/>much</b>       |                            |                            |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 10. I have been short of breath   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 11. I am self conscious about the way I dress   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 12. One or both of my arms are swollen or tender  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 13. I feel sexually attractive  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 14. I am bothered by hair loss  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 15. I worry that other members of my family might someday get the same illness I have   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 16. I worry about the effect of stress on my illness  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 17. I am bothered by a change in weight   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 18. I have certain parts of my body where I experience pain   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |                            |                            |
| 19. In the <b>past week</b> , 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? <i>This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.</i> |                            |                            |                            |                            |                            |                            |                            |
| <b>None</b>   | <b>1 day</b>               | <b>2 days</b>              | <b>3 days</b>              | <b>4 days</b>              | <b>5 days</b>              | <b>6 days</b>              | <b>7 days</b>              |
| 1 <input type="checkbox"/>  | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/> | 7 <input type="checkbox"/> | 8 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

***The questions in this section are about your health and how you have felt during the past month.***

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These might be to do with things like their family life, social activities, finances and work.

**Please tick the response that best describes your answer.**

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 20. Have you had any difficulty in maintaining your independence?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 21. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 22. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)                                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 23. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)                           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 24. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 25. Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)                   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 26. Have you had any financial difficulties?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 27. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 28. Have you had any difficulty concerning your work? (or education if you are a student)   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 29. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

| <i>During the past month:</i>   | No difficulty              | A little                   | Quite a bit                | Very much                  | Does not apply             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 30. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)         | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 31. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)           | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 32. Have you had any difficulty concerning sexual matters?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 33. Have you had any difficulty concerning plans to have a family?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 34. Have you had any difficulty concerning your appearance or body image?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 35. Have you felt isolated?   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 36. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)                       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 37. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)          | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 38. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits) | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 39. Have you had any difficulty with your plans to travel or take a holiday?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| 40. Have you had any difficulty with any other area of your everyday life?  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |

## YOUR HEALTH AND WELL BEING IN THE LAST MONTH

*The questions in this section are about your health and how you have felt during the past month.*

Please tick the response that best describes your answer.

|  | Strongly<br>agree          | Agree                      | Neither<br>agree<br>nor<br>disagree | Disagree                   | Strongly<br>disagree       | Does<br>not<br>apply to<br>me |
|--|----------------------------|----------------------------|-------------------------------------|----------------------------|----------------------------|-------------------------------|
| 41. I have fears about my cancer spreading   | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 42. I have fears about my cancer coming back | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | 6 <input type="checkbox"/>    |
| 43. I have fears about death and dying       | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 44. I experience memory loss                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 45. I have trouble sleeping                  | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 46. I have trouble concentrating             | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 47. I always feel tired                      | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 48. I experience mood swings                 | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |
| 49. I am often irritable                     | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/>          | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |                               |

## OVERALL SUPPORT AND CARE

50. Do you have an up-to-date written care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer.*

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No
- 4  I do not need a care plan
- 5  Don't know

51. Do you have a named nurse who you can contact if you have a worry about your cancer care? *A named nurse is sometimes known as a Clinical Nurse Specialist or Specialist Cancer Nurse.*

- 1  Yes
- 2  No
- 3  Don't know

52. Do you know who to contact if you have a concern about any aspect of living with or after cancer?

- 1  Yes, definitely
- 2  Yes, I think so
- 3  No

53. Do you think that hospital staff did everything they could to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  I did not need any support

54. Do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?

- 1  Yes, all of the time
- 2  Only some of the time
- 3  Never
- 4  My general practice is not involved
- 5  I do not need any support

55. Following your initial cancer treatment have you been given enough care and help from health and social services (for example, district nurses, home helps or occupational therapists)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not need help from health or social services
- 5  Don't know / can't remember

56. Would it have been helpful to have had more advice or information on any of the following issues: **(Tick all that apply)**

- 1  Diet and lifestyle
- 2  Physical activity and exercise
- 3  Financial help or benefits
- 4  Free prescriptions
- 5  Returning to or staying in work
- 6  Information / advice for family / friends / carer
- 7  The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- 8  The psychological or emotional aspects of living with and after cancer
- 9  I have all the information and advice I need

## ABOUT YOU

***If you are helping someone to complete this questionnaire, please make sure this information is the patient's and not your own.***

57. What year were you born?

(Please write in) e.g. 

|   |   |   |   |
|---|---|---|---|
| 1 | 9 | 4 | 4 |
|---|---|---|---|

|   |   |   |   |
|---|---|---|---|
| Y | Y | Y | Y |
|---|---|---|---|

58. Are you male or female?

- 1  Male  
2  Female

59. Which of the following best describes your sexual orientation?

- 1  Heterosexual / straight (opposite sex)  
2  Bisexual (both sexes)  
3  Lesbian or gay (same sex)  
4  Other  
5  Prefer not to answer

60. Which statement best describes your living arrangements?

- 1  I live with partner/spouse/family/friends  
2  I live alone  
3  I live in a nursing home, hospital or other long term care home  
4  Other

61. Do you have a long standing health condition? Please include anything other than your cancer that has troubled you over a period of time or that could affect you over a period of time.

- 1  Yes  
2  No  
3  Don't know / can't say

62. Which, if any, of the following conditions do you have? (Tick all that apply)

- 1  Alzheimer's disease or dementia  
2  Angina  
3  Arthritis  
4  Asthma or other chronic chest problem  
5  Blindness or visual impairment  
6  Deafness or hearing impairment  
7  Diabetes  
8  Epilepsy  
9  Heart condition  
10  High blood pressure  
11  Kidney disease  
12  Learning difficulty  
13  Liver disease  
14  Long term back problems  
15  Long-standing mental health problem  
16  Long-standing neurological problem  
17  Another long-standing condition  
18  I do not have any of these conditions

63. What was your employment status **before you were diagnosed with cancer?**

- 1  Full time employment  
2  Part time employment  
3  Homemaker  
4  Student (in education)  
5  Retired  
6  Unemployed and seeking work  
7  Unemployed unable to work for health reasons  
8  Other

64. What is your employment status currently? *If on maternity or sick leave answer in relation to your usual employment status*

- 1  Full time employment  
2  Part time employment



- 3  Homemaker
- 4  Student (in education)
- 5  Retired
- 6  Unemployed  and seeking work
- 7  Unemployed  unable to work for health reasons
- 8  Other

65. If you are currently employed at the moment, are you:

- 1  Not working at all
- 2  Working less hours than usual
- 3  Working your usual hours
- 4  Working more hours than usual
- 5  This question does not apply to me

66. To which of these ethnic groups would you say you belong? (**Tick ONE only**)

**a. WHITE COMMENTS**

**If you have anything else you would like to tell us about any specific changes in how you feel about living with and beyond cancer since you completed the Patient Reported Outcome Measures survey in 2011, please do so here:**

- 1  British
- 2  Irish
- 3  Any other White background (Please write in box)

**b. MIXED**

- 4  White and Black Caribbean
- 5  White and Black African
- 6  White and Asian
- 7  Any other Mixed background (Please write in box)

**c. ASIAN OR ASIAN BRITISH**

- 8  Indian
- 9  Pakistani
- 10  Bangladeshi
- 11  Any other Asian background (Please write in box)

**d. BLACK OR BLACK BRITISH**

- 12  Caribbean
- 13  African
- 14  Any other Black background (Please write in box)

**e. CHINESE OR OTHER ETHNIC GROUP**

- 15  Chinese
- 16  Any other ethnic group (Please write in box)



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