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Living with and beyond bladder cancer

A descriptive summary of responses to a pilot of Patient Reported Outcome Measures for bladder cancer

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Living with and beyond bladder cancer

A descriptive summary of responses to a pilot of Patient Reported Outcome Measures for bladder cancer

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Foreword

This report offers a descriptive summary of responses to a pilot of Patient Reported Outcome Measures (PROMs) for bladder cancer and provides a much needed insight into the health and wellbeing of people living with and beyond bladder cancer.

I congratulate the bladder clinical community for focusing its attention on survivorship issues. Overall 673 people responded to the pilot survey which was carried out in 2013 and sent to people with bladder cancer; most of whom had their initial treatment between 1 and 5 years before filling in the questionnaire.

As a result of having bladder cancer and undergoing the associated treatments such as radiotherapy, chemotherapy and surgery; the health and wellbeing of those affected by it can potentially be significantly reduced. Respondents reported issues such as urinary and sexual problems, anxiety and depression, difficulties with general activities of daily living and fear of their cancer coming back.

The information in this report will be of vital importance to:

- Improve understanding of health-status related quality of life outcomes for people following treatment for bladder cancers;
- Consider variations in outcomes, for example for different age groups or for those with comorbidities;
- Start to enable health and care services, at a national and local level, to measure the impact of interventions for people living with and beyond cancer over time; and
- Link with Hospital Episode Statistics, cancer registration and other data sets to begin to understand the relationship between health-status related outcomes and types of cancer treatment.

I hope this report enables clinical teams and other stakeholders to use the high level findings presented here as a focus for further local investigation in order to address the issues identified in this PROM survey.



Sean Duffy
National Clinical Director for Cancer

1 Introduction

Quality of life among cancer patients has been assessed in the context of clinical trials, but relatively little is known about quality of life in representative cohorts of people living with and beyond cancer. The Cancer Reform Strategy (2008) included a commitment to improve care and support for the 1.8 million people living after a diagnosis of cancer in England.

In September 2008, the Department of Health launched the National Cancer Survivorship Initiative (NCSI). This was a partnership between DH and Macmillan Cancer Support and was supported by NHS Improvement. NCSI aimed to ensure that those living with and beyond cancer got the care and support they needed to lead as healthy and active a life as possible, for as long as possible.

In January 2010, the NCSI published a document describing the emerging vision for improved care and support for people living with and beyond cancer. This vision document set out five key shifts, which the NCSI identified as necessary to achieve improved care and support for cancer survivors. These included a move from an emphasis on measuring clinical activity to an emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures (PROMs) in aftercare services.

The NCSI supported the routine collection of PROMs in cancer aftercare to measure progress in improving care and support for cancer survivors, and initiated a longer-term development programme to demonstrate the value of using outcome measures to show improvements in care and quality of life of people living with and beyond cancer.

Further support for PROMs was provided by Living With and Beyond Cancer: Taking Action to Improve Outcomes (2013), which informed the direction of survivorship work in England to 2015. This document was designed to support commissioners, providers and others to take the actions necessary to improve survivorship outcomes. It set out what has been learnt about survivorship, including: people's needs; their experience of care; and the impact cancer and treatment has upon their lives.

The bladder cancer pilot PROMs survey was commissioned in 2012 with data collected January to March 2013. These surveys were undertaken by Picker Institute Europe on behalf of the Department of Health. Responsibility for the PROMs was later transferred to NHS England.

The aims of the pilot bladder cancer PROMs survey were to:

- improve understanding of health-status related quality of life outcomes for people following treatment for bladder cancer;
- consider variations in outcomes, for example for different age groups or for those with comorbidities;
- start to enable NHS England nationally, and health and care services at a local level, to measure the impact of interventions for people living with and beyond cancer over time; and

- link with Hospital Episode Statistics, cancer registration and other data sets to begin to understand the relationship between health-status related outcomes and types of cancer treatment.

2 Methodology

The survey described in this report was commissioned by the Department of Health and conducted by Picker Institute Europe. 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.

The sample for the survey was identified with the aid of the Eastern Cancer Registration and Intelligence Centre (now part of the National Cancer Registration Service within PHE), and comprised 1,252 people (aged 16 and over) between one and five years after a diagnosis of bladder cancer.

The survey questions, wherever possible, were based on well validated generic or cancer-specific quality of life tools, although their specific use in this format has not yet been fully validated.

The EQ5D was selected as a generic measure of quality of life to facilitate comparisons with other patient groups and with the population of 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.

Detailed cognitive testing of the full questionnaires was undertaken using volunteer patients.

The survey was conducted by post, with two reminders (to non-responders only). Standard questionnaires, covering letters and reminder letters were used. Picker Institute Europe provided a national Freephone helpline for patients and supported completion of the survey through textphone and language translation facilities. Picker Institute Europe conducted checks for deceased patients at three specified time points in the survey process. These were:

- before initial send out;
- before the first reminder; and
- before the second reminder.

These checks were undertaken with the assistance of the Medical Research Information Service.

3 Results

This report is a descriptive summary of the results of the PROM pilot for bladder cancer. These descriptive results may form the basis of detailed analysis of the bladder cancer PROM pilot, e.g considering the impact of demographics and other parameters. Such comparisons and analyses are beyond the scope of this report.

Therefore, this report provides a brief summary of the 99 questions in the questionnaire, and there is no executive summary.

The questionnaire was sent to 1,252 people who had been diagnosed with bladder cancer, and 673 completed questionnaires were returned, a response rate of 54%. There were statistically significant differences in response rate by age at diagnosis, but differences in response rate by deprivation quintile did not reach statistical significance.

Results are presented in the order of the questions in the questionnaire, which breaks down into sections covering:

- response rates and demographics;
- treatment;
- health and wellbeing on the day of the questionnaire;
- health and wellbeing in the week before the questionnaire;
- health and wellbeing in the month before the questionnaire and
- overall support and care.

Most questions were on similar frequency or agreement scales, and where possible these are presented in stacked bar charts showing the percentage of responses. This makes for easier comparison across questions, but may be misleading where many questionnaires left the question blank. For most questions presented in such bar charts, more than nine in ten of those who returned the questionnaire gave an answer. Other results are presented in tables showing the number and percentage of responses with each answer and the number of non-respondents.

3.1 Response Rates and Demographics

Overall, 1,252 questionnaires were sent out and 673 questionnaires were returned, a response rate of 54% (Table 1). In 260 cases (21%) the patient opted out or was too ill to take part and 21 (2%) had died. A small number of questionnaires (7, <1%) were returned undelivered and 9 (<1%) were otherwise ineligible. The response rate, after removal of those who had moved, were ineligible, too ill, opted out or had died, was 70% (673/955).

Of those who replied 500 (76%) were men and 162 (24%) were women. Response rates by deprivation and age do not take into account the exclusions described above so should only be compared with the overall response of 54%.

Table 1. Response rates

Completed questionnaire	Returned undelivered	Patient deceased	Too ill/opted out	Ineligible	No response	Total
673 54%	7 <1%	21 2%	260 21%	9 <1%	282 23%	1,252

Year	No. questionnaires sent (after exclusions)	No. completed questionnaires	Response rate (after exclusions)
2007	233	170	73%
2008	252	180	71%
2009	237	160	68%
2010	233	163	70%

Quintile of income deprivation	No. questionnaires sent (total)	No. completed questionnaires	Response rate (total)
1 (Least deprived)	250	156	62%
2	282	154	55%
3	285	152	53%
4	225	102	45%
5 (Most deprived)	210	98	47%

Age at diagnosis	No. questionnaires sent (total)	No. completed questionnaires	Response rate (total)
Under 40	15	3	20%
40-49	41	21	51%
50-59	114	60	53%
60-69	353	216	61%
70-79	423	235	56%
80 or over	306	127	42%

The earliest year of birth for people who answered question 90 (What year were you born?) was 1916 and the most recent was 1983, with a mean year of birth of 1939. The recorded year of birth in cancer registry data was the same as that reported by respondents in all except 4 cases, there were 17 respondents who did not fill out their year of birth.

About 1/3 (32%) of those who responded were aged 60-69 (216 of 673) and around another 1/3 (35%) were aged 70-79 (235) (Table 2).

Table 2. Respondents' age at diagnosis

Age at diagnosis	Number	Percentage
Under 40	3	0%
40-49	21	3%
50-59	60	9%
60-69	216	32%
70-79	235	36%
80 and over	127	19%

Almost a quarter (23%) of respondents (144 of 629) said they were a carer to a family member, friend or neighbour (Q92).

Most respondents (91%) said they were heterosexual/straight (563 of 619, 1% (7) answered lesbian or gay, 1% (4) answered other, <1% (3) answered bisexual, and 7% (42) preferred not to say (Q93).

Around three quarters (76%) of respondents (497 of 653) live with a partner, spouse, friend or their family, while 2% (11) live alone and 1% (5) live in a nursing home; hospital or other long term care home. Seven respondents said that they had other living arrangements (Q94).

Three-fifths (62%) of respondents (388 of 624) reported a long-standing health condition other than cancer. Figure 1 shows the frequencies of various conditions which respondents had. The most common were high blood pressure (36%) and arthritis (29%).

Figure 1. Long term conditions among respondents (Q95)

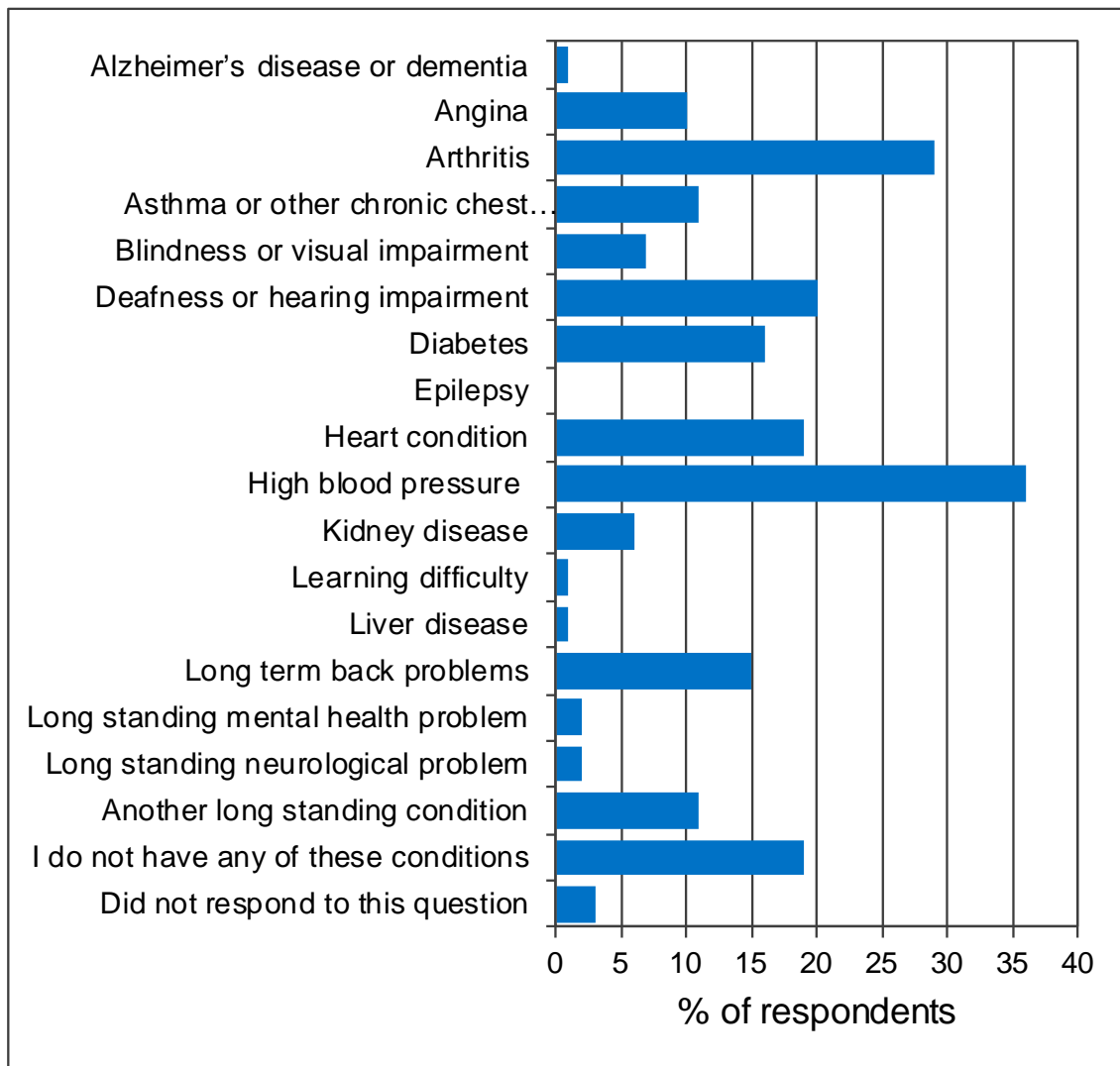


Figure 2 shows employment status for people at the time of the survey and before their diagnosis with cancer. The majority of respondents were retired both before diagnosis (440 of 643) and at the time of the survey (500 of 630). 18% (118 of 643) of respondents were in full time employment before diagnosis but this dropped to 9% (56 of 630) at the time of the survey, as a third of the cohort were in the 60-69 age bracket this may be at least partly attributed to them reaching pension age since diagnosis. The majority of currently employed people (54%) who answered the question said that they were working their usual hours (68 of 126), with a similar number of people (12%) working less hours than usual (15), and a few working more hours than usual (9) (Table 3).

Figure 2. Employment status before diagnosis with cancer and current employment status

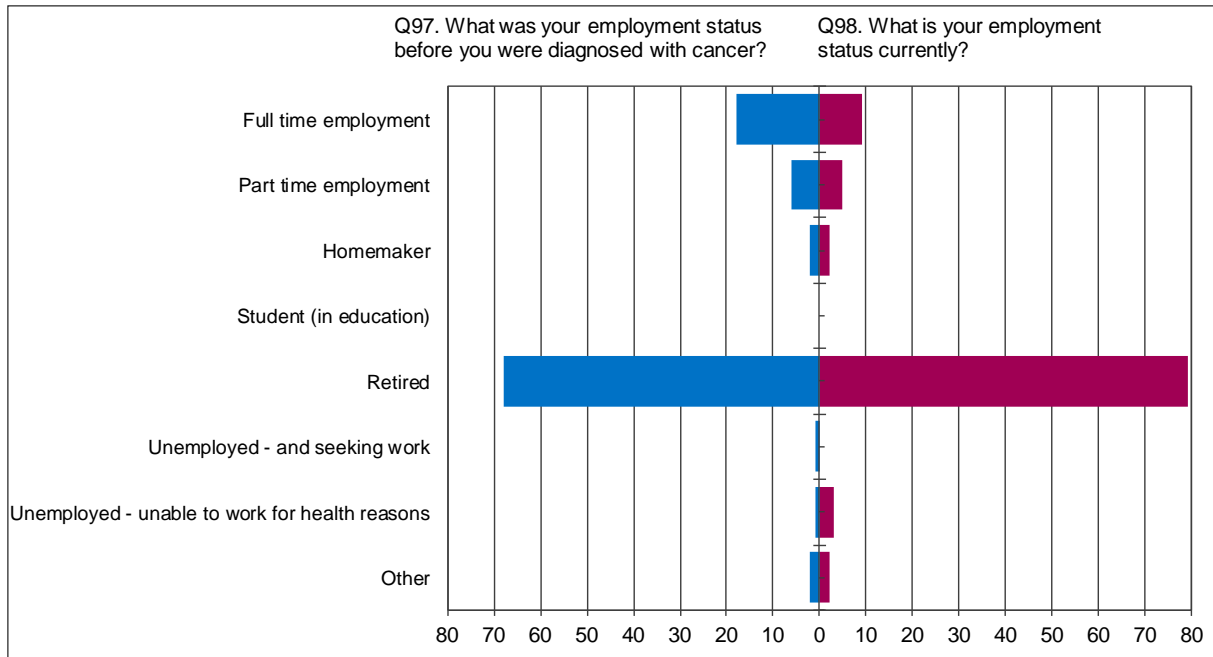


Table 3. Current hours of work, for people currently employed (Q99)

Employment	Number	Percentage
Not working at all	34	27%
Working less hours than usual	15	12%
Working your usual hours	68	54%
Working more hours than usual	9	7%
Total	216	
This question does not apply to me	375	
Did not answer	172	

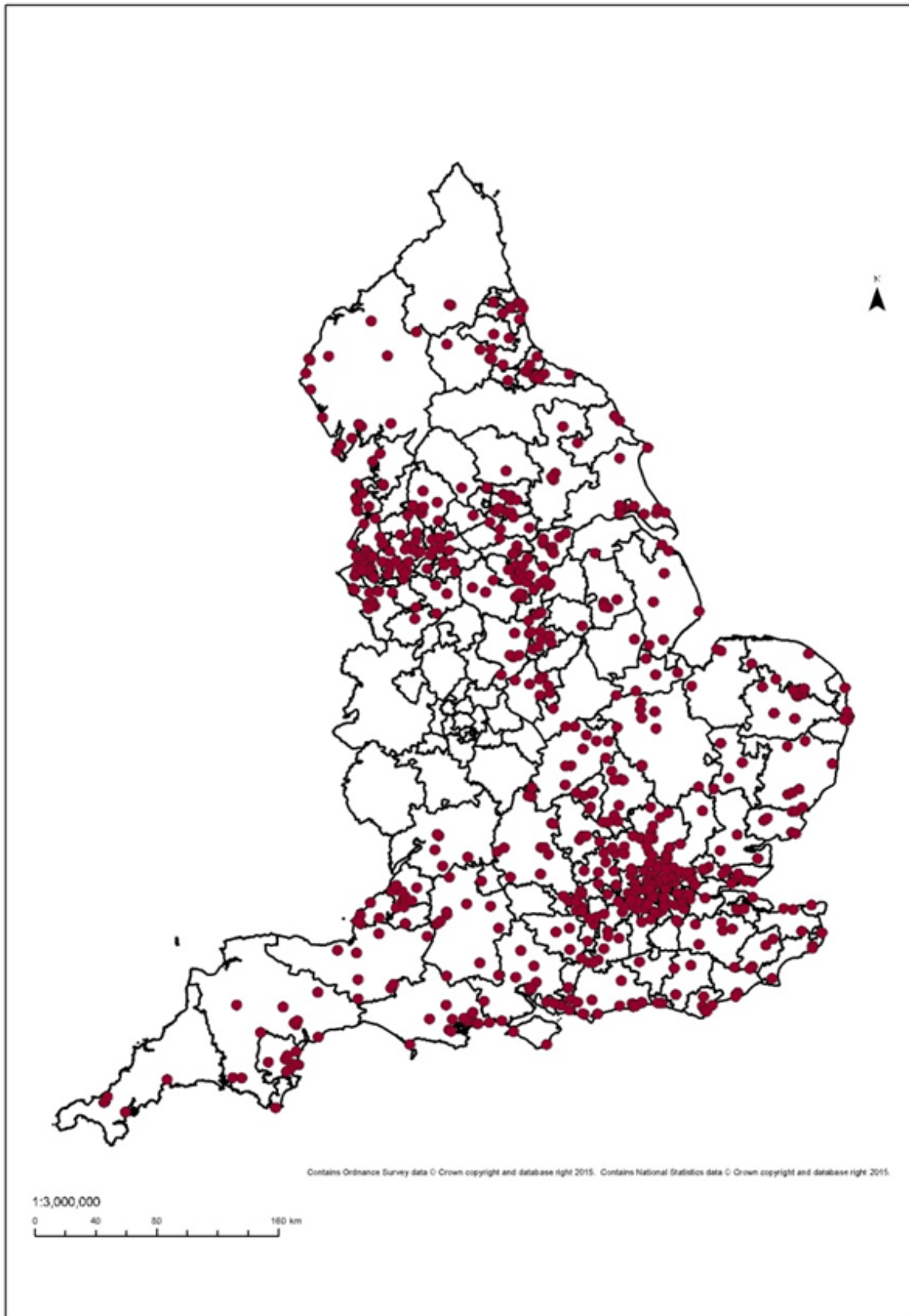
The majority of respondents (97%) classified themselves as British (626 of 646) (Table 4). This is a higher proportion of cases than the overall ‘White British’ population, which was 80% at the 2011 census. Although the intention of the survey was that ‘British’ represented the same category as ‘White British’ in the census it is possible that respondents were confused between ethnicity and nationality. It should be remembered that the proportion of population identifying as ‘White British’ increases with age. In the 2011 census 91% of those aged 60 and over were in this group, and 84% of respondents to the bladder cancer PROMS pilot were 60 or older.

Table 4. Ethnicity of respondents (Q100)

Ethnic group	Number	Percentage
British	626	97%
Irish	7	1%
Any other White background	7	1%
Any other Mixed background	1	0%
Indian	1	0%
Pakistani	1	0%
Bangladeshi	1	0%
Any other Asian background	1	0%
Chinese	1	0%
Total	646	
Did not answer	27	

Respondents were dispersed across England (Figure 3). It is clear that no people from the West Midlands were surveyed. This is a potential source of bias, not least because the West Midlands has a larger than average ethnic minority population. A large number of cases were from the North West area, around Manchester and Liverpool, but these areas have the highest rates of bladder cancer in England.

Figure 3. Approximate locations of respondents in England



3.2 Treatment

Table 5 shows the majority (77%) of respondents (494 of 644) were treated with telescopic/endoscopic bladder tumour surgery, the next most frequent treatment (30%) was chemotherapy into the bladder (257). Radiotherapy was less frequently used than surgery or chemotherapy with 16% (105) of respondents being treated with it.

Table 5. What treatment have you received for your cancer? (Q1)

Treatment	Number	Percentage
Telescopic/Endoscopic bladder tumour surgery	494	77%
Radical cystectomy	127	20%
Chemotherapy into the bladder	257	30%
Intravenous chemotherapy	81	12%
Radiotherapy	105	16%
Total	644	
Did not answer	29	

The understanding of treatments delivered should be considered alongside the time since diagnosis. The people surveyed were deliberately chosen to be at a range of times since their first diagnosis, as bladder cancer frequently recurs and/or progresses there is a greater chance of respondents having multiple treatments with time. 67% of respondents (419 of 623) had their initial treatment between 1 and 5 years before filling in the questionnaire (Table 6).

Table 6. How long is it since you completed your initial treatment for bladder cancer? (Q2)

Time since treatment	Number	Percentage
I am still having my initial treatment	31	5%
It is less than 3 months since my initial treatment	12	2%
It is between 3 and 12 months since my initial treatment	119	18%
It is between 1 and 5 years since my initial treatment	419	65%
It is more than 5 years since my initial treatment	60	9%
Don't know/can't remember	7	1%
Total	648	
Did not answer	25	

Most respondents (434 of 513) were in remission (Table 7).

Table 7. How has your bladder cancer responded to treatment? (Q3)

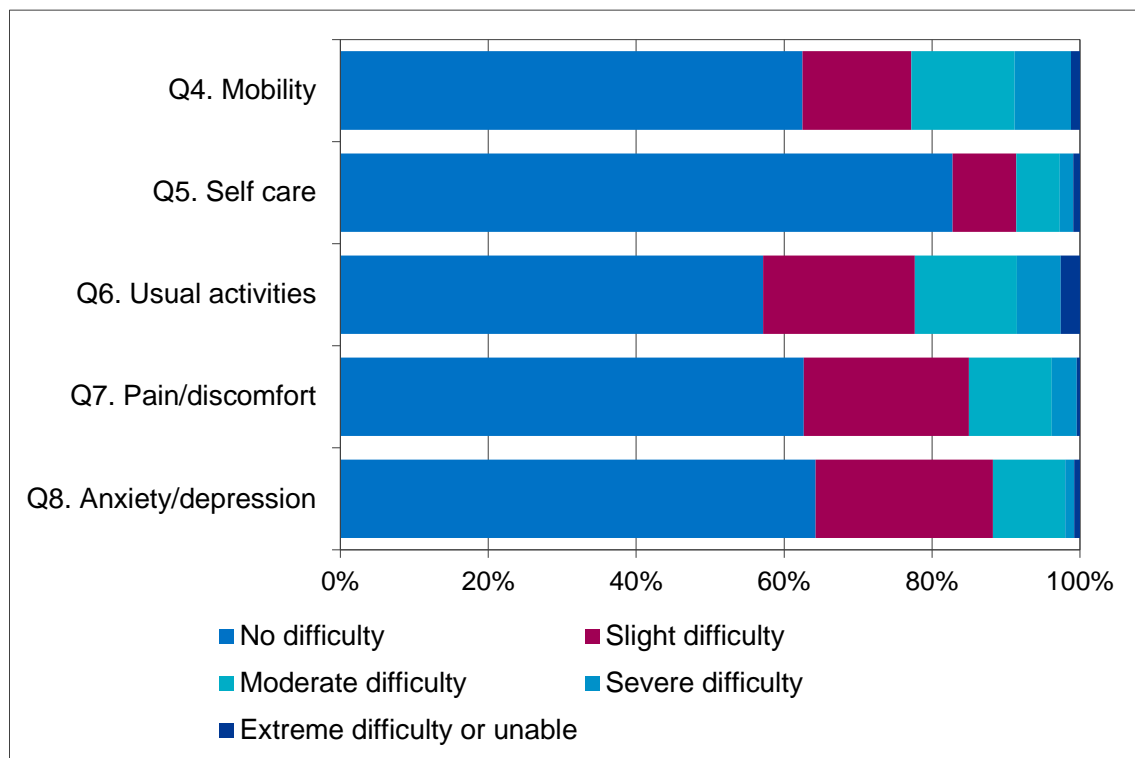
Time since treatment	Number	Percentage
My bladder cancer has responded fully to treatment	434	73%
My bladder cancer has been treated but is still present	41	7%
My bladder cancer has not been treated at all	2	0%
My bladder cancer has come back after it was treated	30	5%
I am not certain what is happening with my bladder cancer	85	14%
Total	593	
Did not answer	80	

3.3 Health and wellbeing today

The majority of respondents did not report particular problems with their health and wellbeing on the day they completed the questionnaire (Figure 4). More than 55% reported no problems on each question about mobility, self-care or usual activities.

Levels of anxiety or depression correlated closely with levels of pain reported, with 24% (157 of 655) of respondents feeling slightly anxious or depressed and 22% (147 of 659) experiencing slight pain whilst 12% (77 of 655) reported they were moderately, severely or extremely anxious or depressed and 14% (99 of 659) reported they were in moderate, severe or extreme pain on the day they filled in the questionnaire.

Figure 4. Health and wellbeing on the day of filling in the survey among respondents



3.4 Health and wellbeing in the past week

84% of respondents (507 of 602) reported that they did not feel ill although a lower percentage, 68%, (409 of 602) reported having no pain (Figure 5).

89% (384 of 431) said they had not lost hope in the fight against their illness though a lower number (65%) said they were not worried about dying (286 of 439). 61% said they were nervous in general (270 of 445).

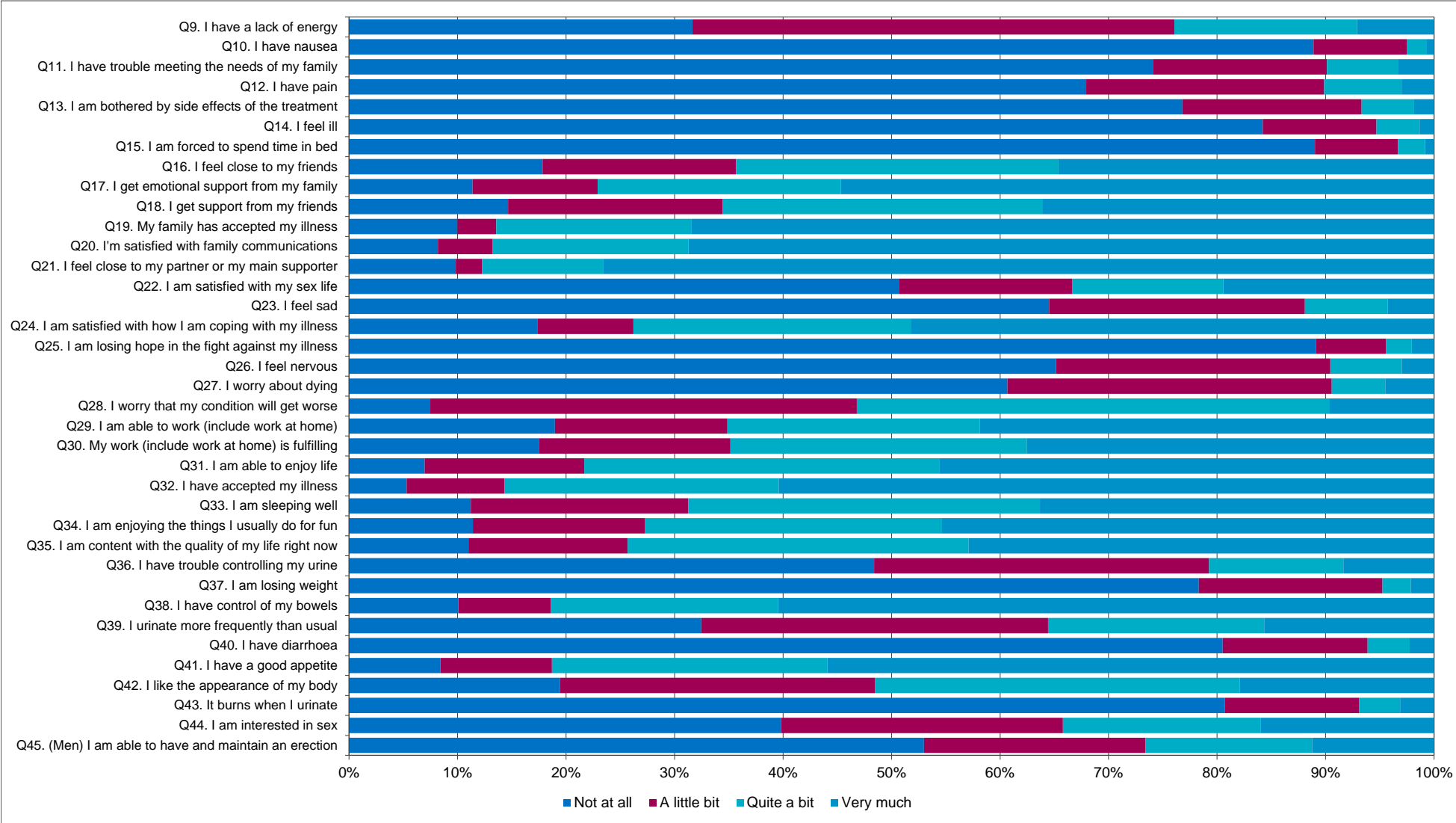
89% of respondents said they were sleeping well (562 of 633), content with the quality of their life right now (558 of 627), enjoying the things they usually do for fun (543 of 613) and getting at least a little bit of emotional support from their family (522 of 589). Similar levels were also seen in other positive aspects such as being able to

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enjoy life, feeling close to their main person of support, getting support from friends and family, family's acceptance of their illness and family communication.

68% (410 of 607) reported that they needed to urinate more frequently than usual, 52% (321 of 622) reported at least some trouble controlling their urine and 19% reported that it burns when they urinate (117 of 607). 19% of respondents said they had no or little control of their bowels (118 of 642) and the same percentage had problems with diarrhoea (121 of 621). The majority of patients (78%) had not lost any weight (477 of 619) and 82% reported still having a quite good or 'very much of' an appetite (522 of 642) in the past week.

Figure 5. Health and wellbeing among respondents in the week before filling in the survey (frequency scale questions)



Of the respondents 20% reported having a stoma: of those 51% (53 of 103) said they were not embarrassed at all by it and 59% (62 of 105) said it was not difficult to care for the stoma.

Table 8. Do you have a stoma appliance? (Q46)

Stoma appliance	Number	Percentage
Yes	108	20%
No	437	80%
Total	545	
Did not answer	128	

Table 9. Responses to questions on feelings about stomas from question 47 (I am embarrassed by my stoma appliance) and question 48 (Caring for my stoma appliance is difficult)

Response	Q47		Q48	
	Number	Percentage	Number	Percentage
Very much	14	14%	5	5%
Quite a bit	11	11%	9	9%
A little bit	25	24%	29	28%
Not at all	53	51%	62	59%
Total	103		105	
Did not answer	5		3	

The majority of respondents (357 of 635) reported only having done 30 minutes or more of physical activity which was enough to raise their heart rate on two or fewer days in the past week, with 34% of respondents (217) reporting no physical activity at all (Table 10).

Table 10. In the past week, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate? (Q49)

Days physically active	Number	Percentage
None	217	34%
1 day	60	9%
2 days	80	13%
3 days	83	13%
4 days	48	8%
5 days	46	7%
6 or 7 days	101	16%
Total	635	
Did not answer	38	

3.5 Health and wellbeing in the past month

In the month before filling in the questionnaire the most common problems where respondents reported at least 'a little' difficulty were;

- difficulty with domestic chores (240 of 651, 37%)
- difficulty with your plans to travel or take a holiday (215 of 647, 33%)
- difficulty concerning sexual matters (52 of 594, 9%)
- difficulty concerning sexual matters (168 of 594, 28%), although 37% (218) of respondents said this question did not apply to them
- feeling isolated (178 of 648, 27%)
- difficulty with getting around (178 of 653, 27%)

The statement for which the greatest proportion of respondents answered 'very much' was 'difficulty for those close to you (e.g. partner; children; parents) with the support available to them' (161 of 620 respondents, 26%); 34% of respondents (213) reported at least 'a little' difficulty (Figure 6).

47% (297 of 635) said that they either agreed or strongly agreed with the statement "I have fears about my cancer coming back" (Figure 7) whilst 37% (233 of 632) either agreed or strongly agreed with the statement "I have fears about my cancer spreading".

Figure 6. Respondents' health and wellbeing in the month before filling in the survey (frequency scale questions)

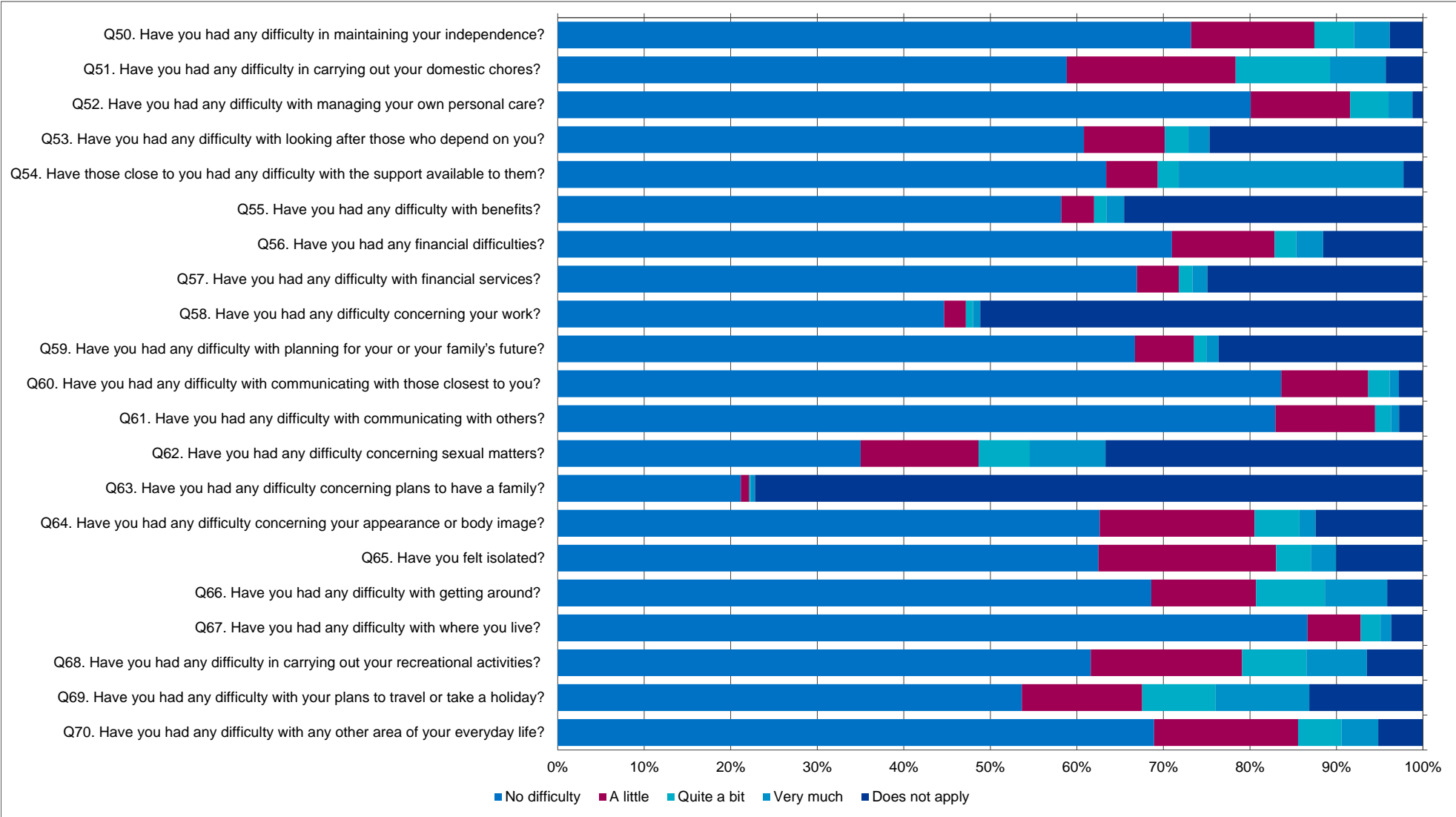
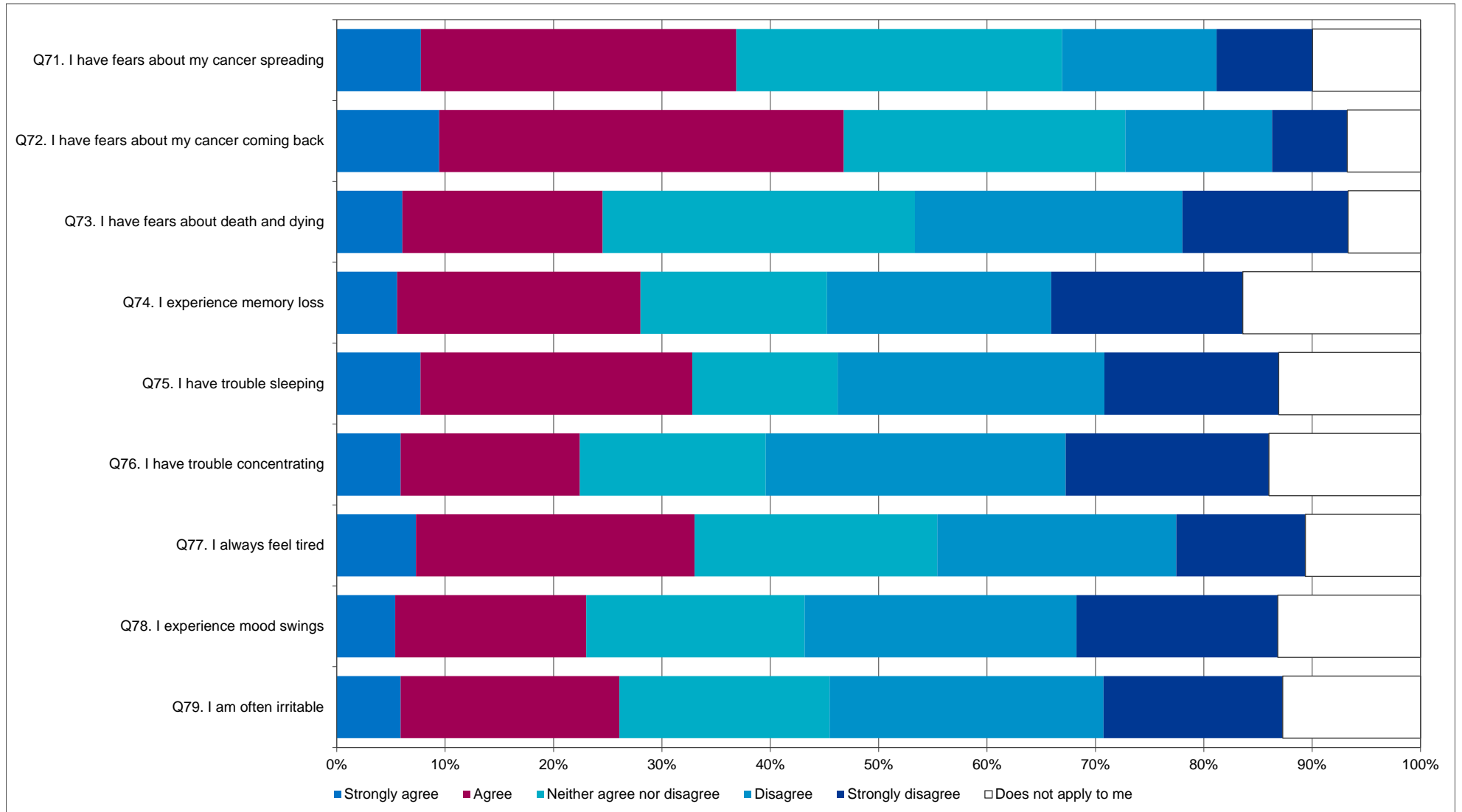


Figure 7. Respondents' health and wellbeing in the month before filling in the survey (agreement scale questions)



3.6 Overall support and care

Table 11 shows that 27% of respondents (171 of 639) reported that they do not need a care plan (Table 8), whilst 11% (72 cases) reported that they definitely had or thought they had a care plan. Two fifths of respondents (292 of 657) did not have a named nurse they could contact with worries about their cancer care, and a further 7% (45) did not know if they had one.

One quarter of respondents (164 of 656) did not know who to contact if they had any concern about any aspect of living with cancer.

Table 11. Responses to questions on care plans and contacts, from question 80 (do you have an up to date written care plan?), question 81 (do you have a named nurse who you can contact if you have a worry about your cancer care?) and question 82 (do you know who to contact if you have a concern about any aspect of living with cancer?)

Response	Q80		Q81		Q82	
	Number	Percentage	Number	Percentage	Number	Percentage
Yes, definitely	29	5%	320	49%	243	37%
Yes, I think so	43	7%			249	38%
No	367	57%	292	44%	164	25%
I don't need a care plan	171	27%				
Don't know	29	5%	45	7%		
Total	639		657		656	
Did not answer	34		16		17	

Three quarters of respondents (495 of 658) reported that hospital staff did everything they could to support them following their cancer treatment (Table 12). A small minority of 2% (12 respondents) reported that they never received support, while 85 people (13%) reported that hospital staff provided all the support they could only some of the time.

19% of respondents (126 of 653) reported that their general practice was not involved with supporting them after treatment. A lower percentage (49%) of the respondents (322) felt their GP practice was doing everything possible to give them support, and 28 respondents (4%) reported their GP practice never provided support. 99 people (15%) felt that their GP practice provided all the support they could only some of the time (Table 13).

Although the levels of respondents reporting the hospital and GP practices giving no support were low, 13% of respondents felt they had not been given enough care and help from health and social services (86 of 653); however nearly half of respondents (312) felt they did not need any help from health and social services.

Table 12. Responses to questions on hospital and GP support, from question 83 (do you think that hospital staff did everything they could to support you following your cancer treatment?) and question 84 (do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?)

Response	Q83		Q84	
	Number	Percentage	Number	Percentage
Yes, all of the time	495	75%	322	49%
Only some of the time	85	13%	99	15%
Never	12	2%	28	4%
My general practice is not involved			126	19%
I do not need any support	66	10%	78	12%
Total	658		653	
Did not answer	15		10	

Table 13. Following your initial cancer treatment have you been given enough care and help from health and social services? (Q85)

Response	Number	Percentage
Yes, definitely	149	23%
Yes, to some extent	101	15%
No	86	13%
Don't know/can't remember	5	1%
I did not need help from health or social services	312	48%
Total	635	
Did not answer	20	

10% of respondents considered themselves to be current smokers (64 of 658). Half of respondents (334 of 658) considered themselves to be ex-smokers (Table 14) and another 40% (260) considered themselves non-smokers. Of the ex-smokers three quarters had quit more than 5 years ago (276 of 366).

Table 14. Respondents' self-reported smoking status (Q86)

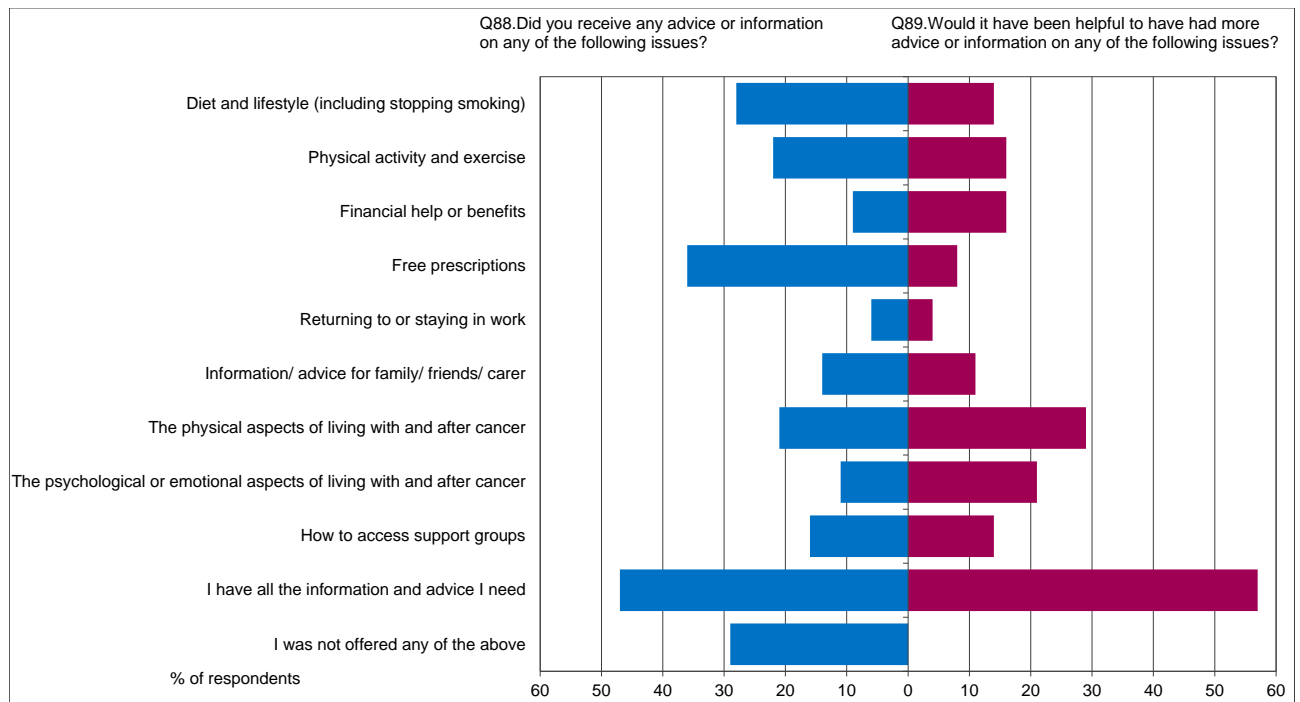
Smoking status	Number	Percentage
Smoker	64	10%
Ex-smoker	334	51%
Non-smoker	260	40%
Total	658	
Did not answer	15	

Table 15. If an ex-smoker, how long ago did you stop? (Q87)

Quitting status	Number	Percentage
Less than 1 year	23	6%
Less than 2, but more than 1 years	20	5%
Less than 3, but more than 2 years	17	5%
Less than 4, but more than 3 years	19	5%
Less than 5, but more than 4 years	11	3%
More than 5 years	276	75%
Total	366	
Did not answer	307	

47% of respondents (302 of 646) reported that they had received all the advice and information they needed. 29% (189) said they had not received any information or advice on any of the topics mentioned (Figure 8). 29% (164 of 560) would have found more advice or information on the physical aspects of living with or after cancer helpful, and 21% (119) would have found more advice or information on the psychological or emotional aspects of living with or after cancer helpful; these were the most common topics people would have liked more advice on.

Figure 8. Issues on which advice and information was received by respondents, and issues where respondents would have found it helpful to have had more advice or information



4 Summary

This report provides a high level summary of the findings of the PROMs pilot for bladder cancer. The data generated by this pilot may form the basis for more detailed analysis and validation. Clinical teams and other stakeholders may wish to use the high level findings presented here as a focus for further local investigation.

5 Acknowledgements

Thanks go to Picker Institute Europe for administering the survey and the National Cancer Registration Service for compiling participant lists and storing data

This is a joint report by NHS England and Public Health England, with data provided by NHS England and analysis by Public Health England. Context and clinical perspective was provided by members of the National Cancer Intelligence Network (NCIN) urological cancer site-specific clinical reference group.