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Protecting and improving the nation's health

Living with and beyond cervical cancer

A descriptive summary of responses to a pilot of patient reported outcome measures for gynaecological cancer



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About NHS England

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The organisation encourages patient and public participation in the NHS, treats everyone respectfully and puts patients' interests first. It empowers and supports clinical leaders at every level of the NHS through clinical commissioning groups, networks and senates, within NHS England itself and in providers of NHS services. NHS England helps everyone to make genuinely informed decisions, spend the taxpayers' money wisely and provide high quality services for all, now and for future generations.

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Foreword

This report offers a descriptive summary of responses to a pilot of patient reported outcome measures (PROMs) for gynaecological cancers and provides a much needed insight into the health and wellbeing of women living with and beyond cervical, womb and ovarian cancer.

I congratulate the gynaecological oncology community for focusing its attention on survivorship issues, and on the formation of the PROM development group set up to develop PROMs on behalf of the British Gynaecological Cancer Society (BGCS) and the Gynaecology Clinical Reference Group of the National Cancer Intelligence Network (NCIN).

Overall 1,832 women responded to the three pilot surveys, sent out in 2013, to women with cervical, womb and ovarian cancer; most of whom had their initial treatment between 1 and 5 years before filling in the questionnaire.

As a result of having gynaecological cancer and undergoing the associated treatments such as radiotherapy, chemotherapy and surgery; the health and wellbeing of those women affected by it can potentially be significantly reduced. Respondents reported issues such as anxiety and depression, body image, urinary and sexual problems and a lack of good information and advice.

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

- improve understanding of health-status related quality of life outcomes for women following treatment for gynaecological 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
- 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
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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 (DH) 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 5 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 gynaecological oncology community has also focused attention on survivorship issues, and formed the PROM development group to develop patient reported outcome measures on behalf of the British Gynaecological Cancer Society (BGCS) and the gynaecology site-specific clinical reference group of the National Cancer Intelligence Network (NCIN).

The cervical cancer pilot PROMs survey was commissioned in late 2013, along with similar surveys of women with uterine and ovarian cancer. These surveys were undertaken by Picker Institute Europe on behalf of NHS England.

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

- improve understanding of health-status related quality of life outcomes for people following cervical cancer treatment
- 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
- 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

Methodology

The survey described in this report was commissioned by NHS England 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 English National Cancer Registration Service, and comprised 1,252 people (aged 16 and over) between 1 and 5 years after a diagnosis of cervical 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 European Organisation for Research and Treatment of Cancer (EORTC) questionnaires. This included the cancer generic tool EORTC QLQ-C30. A pragmatic decision was made to create a gynaecological cancer generic tool from the existing gynaecological cancer site specific tools (EORTC QLQs CX24, OV28 and EN24). This meant that the same questionnaire could be presented to all gynaecological cancer patients.

The content of the questionnaires was agreed by the British Gynaecological Society PROMs Development Group. Detailed cognitive testing of the full questionnaires was undertaken using volunteer patients.

The survey was conducted by post, with 2 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
- before the second reminder

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

Results

This report is a descriptive summary of the results of the gynaecological cancer PROM pilot for cervical cancer, and is published alongside similar summaries of the results of the PROM pilots for uterine and ovarian cancer. These descriptive results will form the basis for detailed analysis of the gynaecological cancer PROM pilot, which will consider the impact of demographics and other parameters. Such comparisons and analyses are excluded from this report.

Therefore, this report provides a brief summary of the 106 questions in the questionnaire, and there is no executive summary.

The questionnaire was sent to 1,252 women who had been diagnosed with cervical cancer, and 493 completed questionnaires were returned, a response rate of 39%. There were statistically significant differences in response rate by age at diagnosis and deprivation quintile.

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

- response rates
- 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
- overall support and care
- demographics

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 9 in 10 of those who returned the questionnaire gave an answer. For cervical cancer, the main exceptions were questions which were not applicable, such as those about experience of sexual activity for those who had not been sexually active, or pain in scars made during surgery for those who had not had surgery.

Other results are presented in tables showing the number and percentage of responses with each answer and the number of non-respondents.

Response Rates

Overall, 1,252 questionnaires were sent out and 493 questionnaires were returned, a response rate of 39% (Table 1). In 106 cases (8%) the patient opted out or was too ill to take part (92, 7%), had died (6, 0.5%) or was otherwise ineligible (8, 1%). A small number of questionnaires were returned undelivered (22, 2%).

There was evidence of a difference in response rates by age at diagnosis ($p = 0.044$), with younger age groups less likely to have responded to the questionnaire than older age groups. The response rate for the 16 to 29 age group was 32%, in comparison to a response rate of 44% for the 50 to 99 age group.

Deprivation quintile was assigned using the income domain of the indices of multiple deprivation 2010. There was evidence of a difference in the response rate by deprivation quintile ($p = 0.021$). Those in more deprived quintiles appeared to be less likely to respond than those in less deprived quintiles, with the most deprived quintile having a response rate of 34% compared to 48% in the least deprived quintile.

There was very weak evidence of a difference in response rate by the number of years after diagnosis the questionnaire was sent ($p = 0.084$).

Table 1. Response rates for women with cervical cancer

	Completed questionnaire	Returned undelivered	Patient deceased	Too ill/opt out	Other ineligible	No response	Total
Total	493 39%	22 2%	6 0%	92 7%	8 1%	631 50%	1,252

Age at diagnosis							
16-29	73 32%	6 3%	0 0%	7 3%	1 0%	138 61%	225
30-39	149 38%	7 2%	0 0%	22 6%	0 0%	210 54%	388
40-49	114 40%	4 1%	2 1%	18 6%	3 1%	142 50%	283
50-99	157 44%	5 1%	4 1%	45 13%	4 1%	141 40%	356

$p = 0.044$

Deprivation quintile

	Completed questionnaire	Returned undelivered	Patient deceased	Too ill/opt out	Other ineligible	No response	Total
(1 – least deprived, 5 – most deprived, based on the income domain of the Indices of Multiple Deprivation 2010)							
1	92 48%	1 1%	1 1%	14 7%	2 1%	83 43%	193
2	84 41%	2 1%	0 0%	21 10%	1 0%	98 48%	206
3	103 42%	6 2%	2 1%	16 7%	2 1%	114 47%	243
4	97 36%	6 2%	0 0%	18 7%	0 0%	150 55%	271
5	113 34%	7 2%	3 1%	23 7%	0 0%	183 56%	329

$p = 0.021$

Years after diagnosis							
1	135 43%	3 1%	4 1%	24 8%	4 1%	143 46%	313
2	119 38%	6 2%	1 0%	19 6%	2 1%	166 53%	313
3	132 42%	6 2%	1 0%	18 6%	1 0%	155 50%	313
5	107 34%	7 2%	0 0%	31 10%	1 0%	167 53%	313

$p = 0.084$

The p-value is the probability of observing questionnaire completion rates among people sent the survey at least as varied as those above when the true response rate does not vary across groups

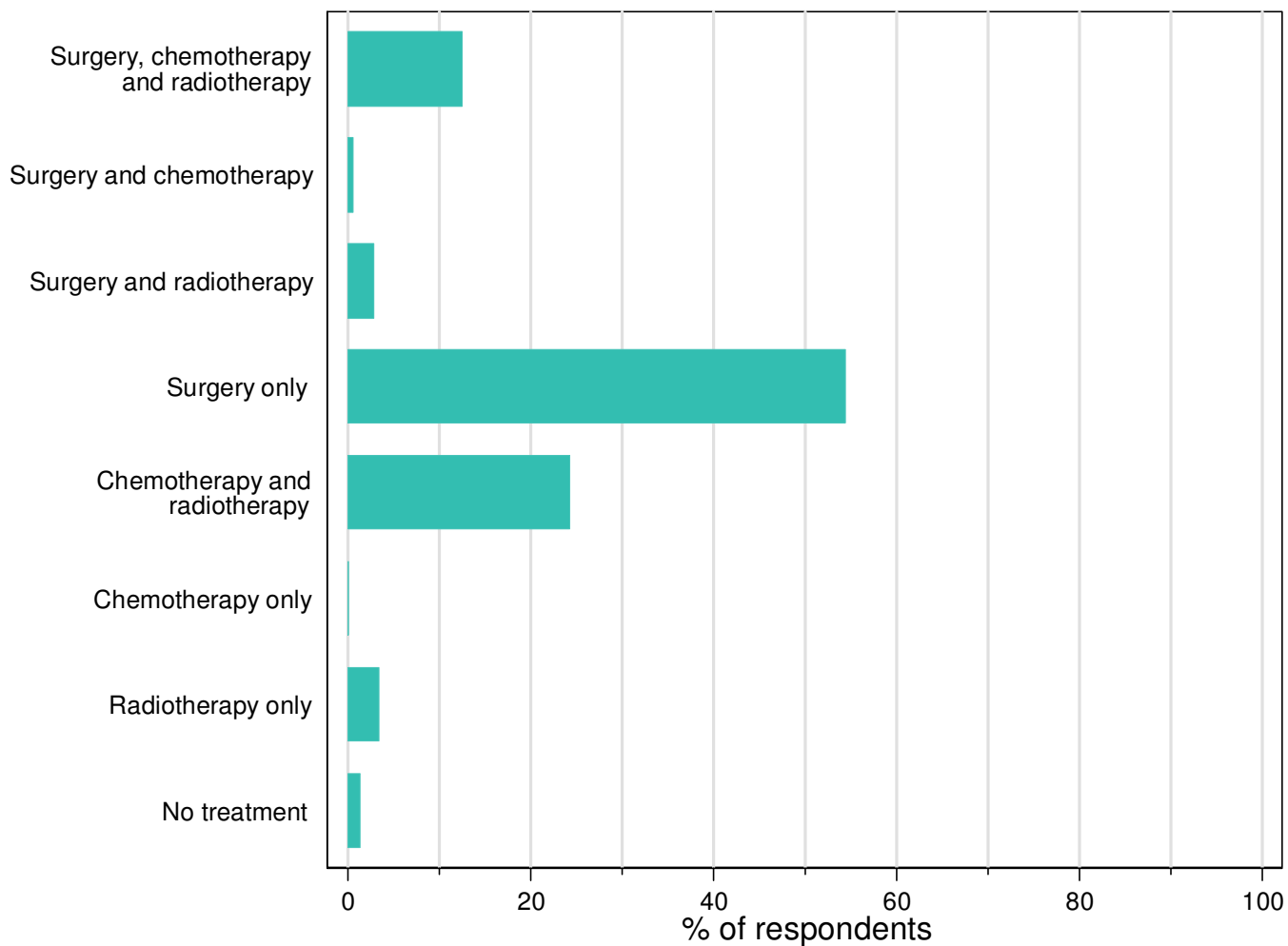
Treatment

Most women (348 of 493, 71%) were treated with surgery (Table 2; Figure 1), with the majority of respondents (269, 55%) receiving surgery only. One in eight respondents (62, 13%) received surgery, chemotherapy and radiotherapy, while a quarter (120, 24%) received chemotherapy and radiotherapy, but not surgery. Seven respondents (1%) did not report receiving any treatment.

Table 2. What treatment have you received for your cancer? (Q1)

	N	%
Surgery	348	71%
Chemotherapy	186	38%
Radiotherapy	213	43%
Total	493	
Did not answer	0	

Figure 1. Treatment received by respondents to the survey



Most respondents (367 of 485, 76%) had their initial treatment between 1 and 5 years before filling in the questionnaire (Table 3).

Table 3. How long is it since you completed your initial treatment for cervical cancer? (Q2)

	N	%
I am still having my initial treatment	1	0%
It is less than 3 months since my initial treatment	3	1%
It is between 3 and 12 months since my initial treatment	62	13%
It is between 1 and 5 years since my initial treatment	367	76%
It is more than 5 years since my initial treatment	51	11%
Don't know / can't remember	1	0%
Total	485	
Did not answer	8	

Almost all respondents (422 of 480, 88%) were in remission (Table 4).

Table 4. How has your cervical cancer responded to treatment? (Q3)

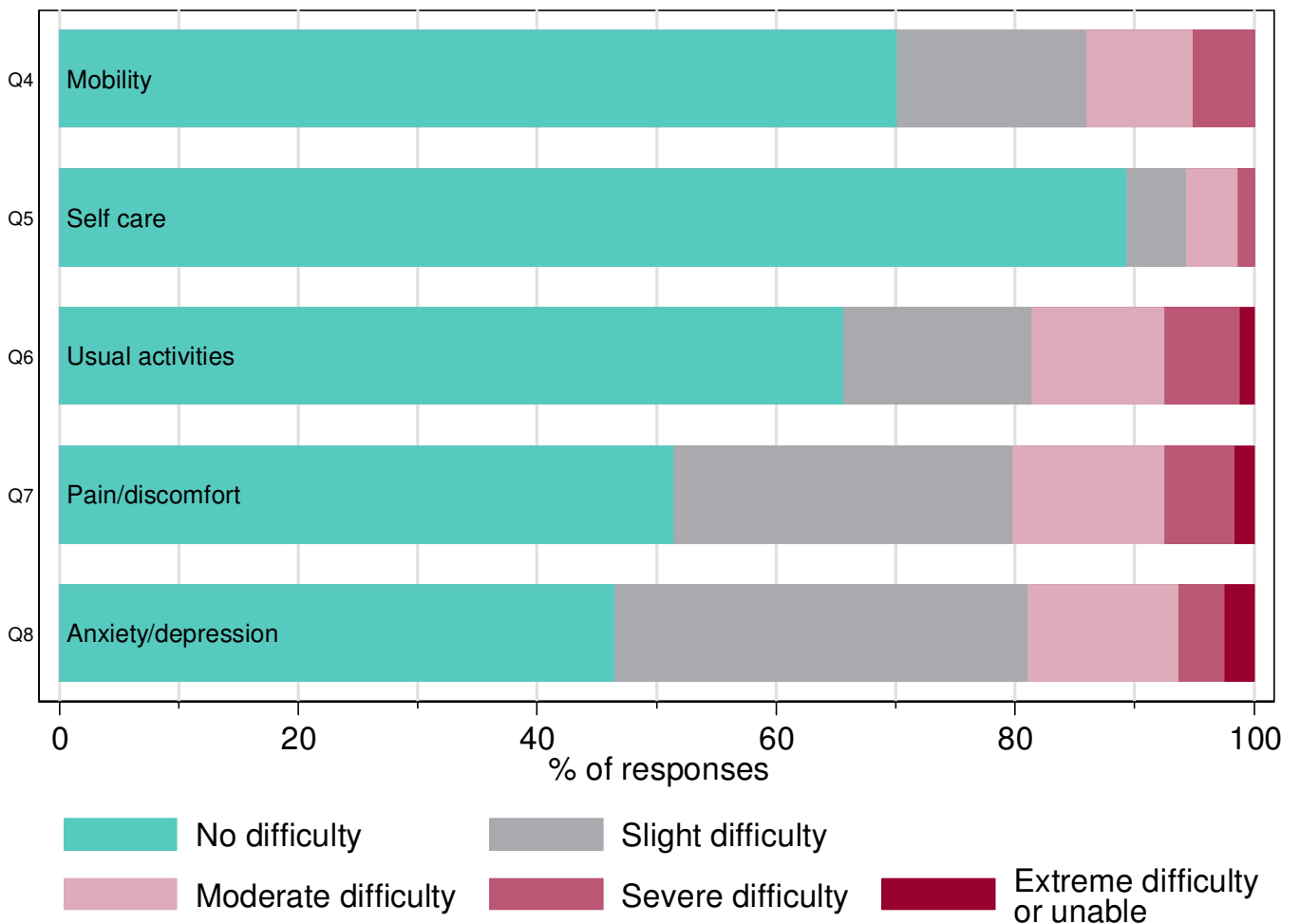
	N	%
My cancer has responded fully to treatment	422	88%
My cancer has been treated but is still present	13	3%
My cancer has not been treated at all	2	0%
My cancer has come back after it was treated	11	2%
I am not certain what is happening with my cancer	32	7%
Total	480	
Did not answer	13	

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 2). More than 60% of women reported no problems on each question about mobility, self care or usual activities.

The most common problem was with anxiety or depression, with 259 of 484 responses (54%) reporting at least a slight problem and 92 (19%) reporting they were moderately, severely or extremely anxious or depressed on the day they filled in the questionnaire. Pain/discomfort was at least a slight problem for nearly half of women (235 of 483, 49%).

Figure 2. Health and wellbeing on the day of filling in the survey among respondents



Health and wellbeing in the past week

The most common problem reported in the week before filling in the questionnaire was passing urine frequently, with 105 of 471 women (22%) reporting urinating a little frequently, and 205 (44%) reporting urinating somewhat or very frequently (Figure 3). A similar majority (275 of 483, 57%) reporting having to hurry at least a little bit to get to the toilet when they felt the urge to pass urine, with 160 women (33%) reporting they had to hurry quite a bit or a lot. Half the respondents (233 of 485, 48%) reported at least a little bit of leakage of urine, with 90 (19%) reporting that this had occurred quite a bit or a lot.

Nearly half of women (226 of 482, 47%) reported having to hurry to get to the toilet when they felt the urge to move their bowels at least a little bit in the week before filling in the questionnaire, although only one fifth of respondents (92 of 481, 19%) reported any difficulty with leakage of stools.

The majority of respondents (288 of 485, 59%) reported having aches and pains in muscles or joints, with 160 responses (33%) reporting that this was occurring a little bit, and 128 responses (26%) reporting that this was occurring quite a bit or a lot (Figure 2). Lower back or pelvis pain was also common, with 270 of 482 responses (56%) reporting at least a little bit of such pain.

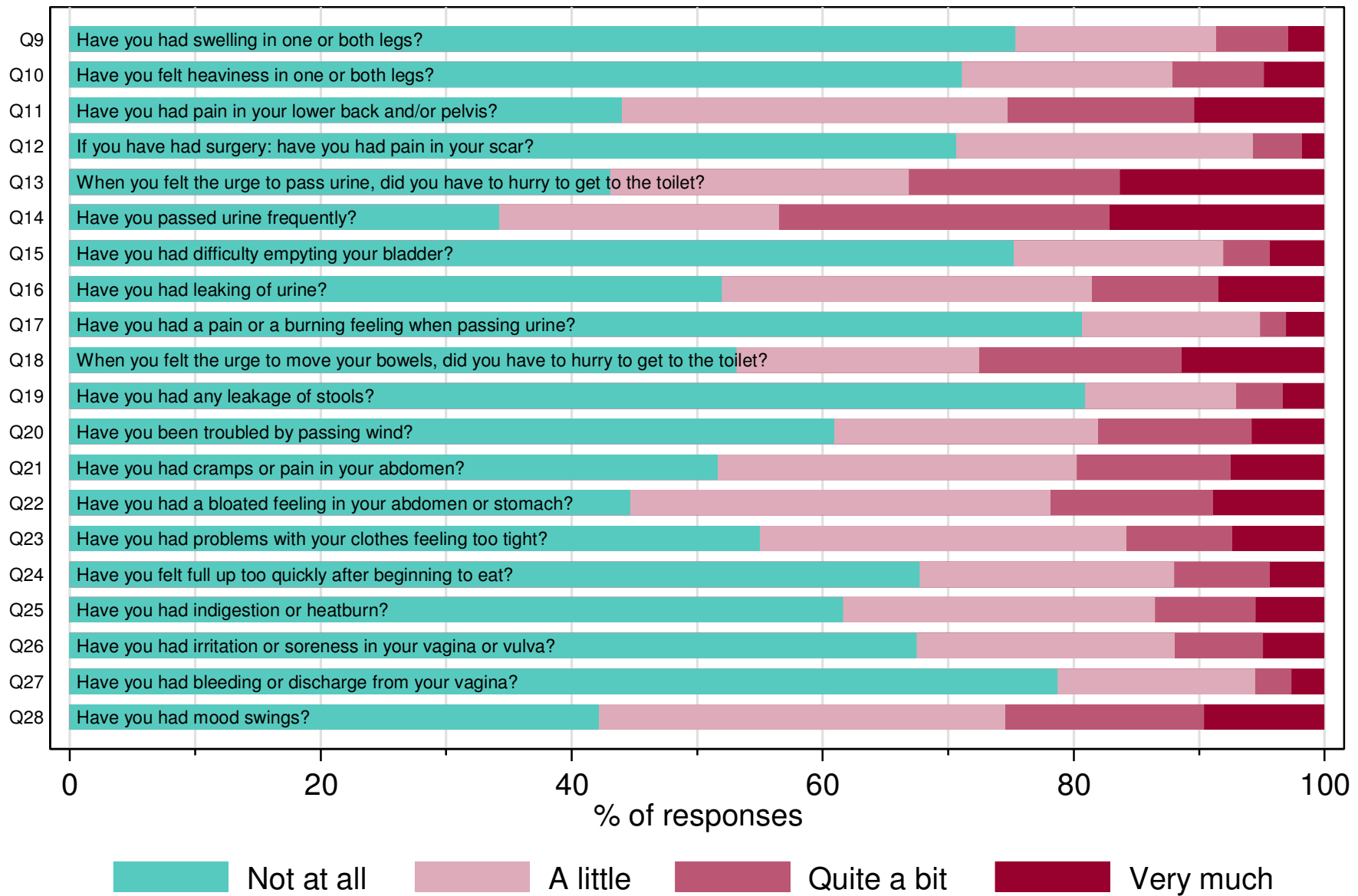
Three fifths of women (282 of 485, 58%) reported having worried at least a little bit in the past week, reflecting the reported issues with anxiety or depression on the day of the questionnaire. The same number of women (282 of 487, 58%) had issues with mood swings.

More than half of respondents (268 of 484, 55%) reported having had a bloated feeling in their abdomen or stomach a little in the week before filling in the questionnaire, with a similar number (233 of 481, 48%) reporting cramps or pain in their abdomen.

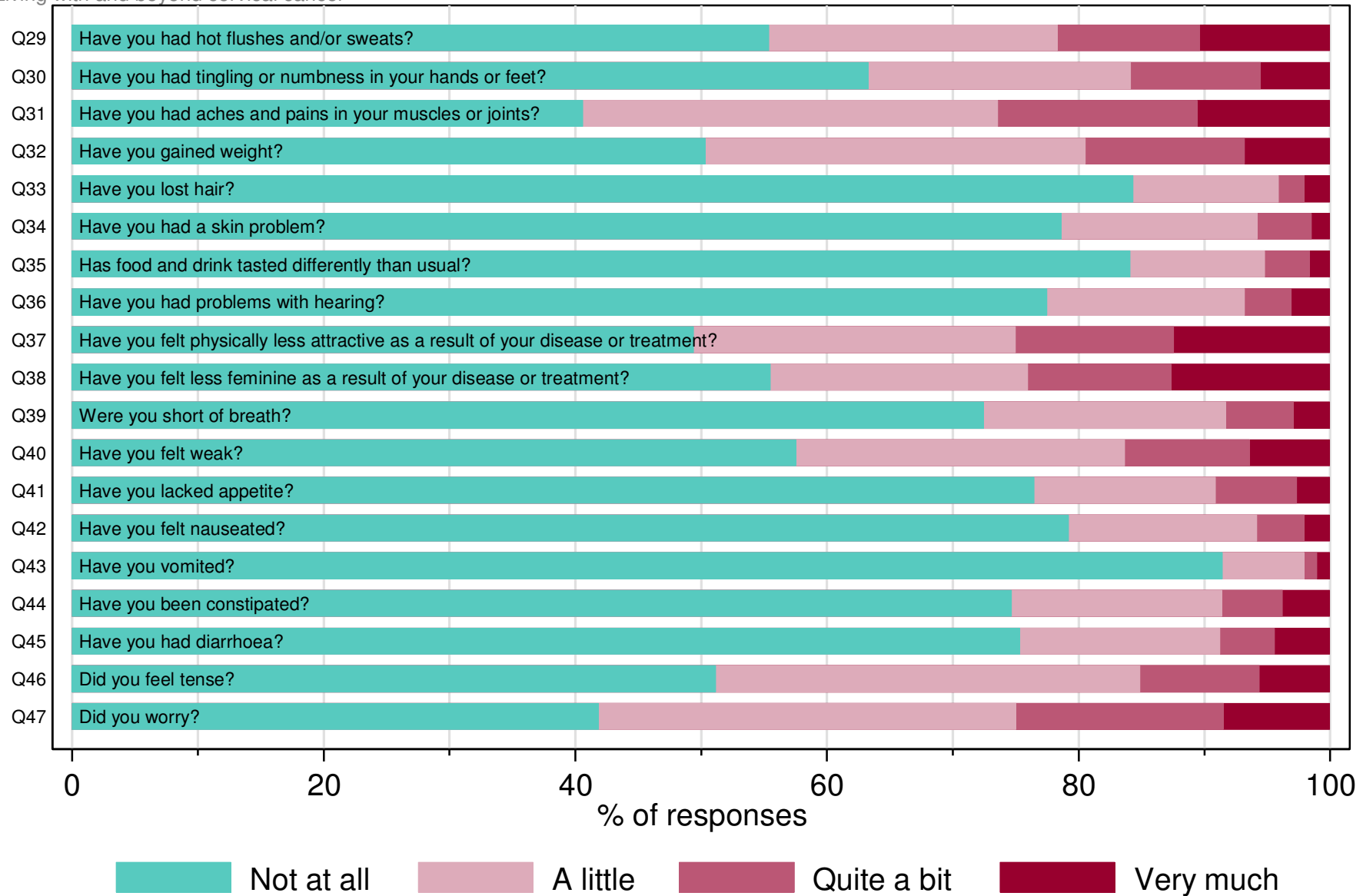
Women also commonly reported feeling physically less attractive (245 of 484, 51%) or less feminine (215 of 483, 45%) as a result of their disease or treatment, with a quarter of women feeling quite a bit or very much less attractive (121, 25%) or less feminine (116, 24%).

Half of women (240 of 483, 50%) reported having gained at least a little bit of weight in the past week.

Figure 3. Health and wellbeing among respondents in the week before filling in the survey (frequency scale questions)



Living with and beyond cervical cancer

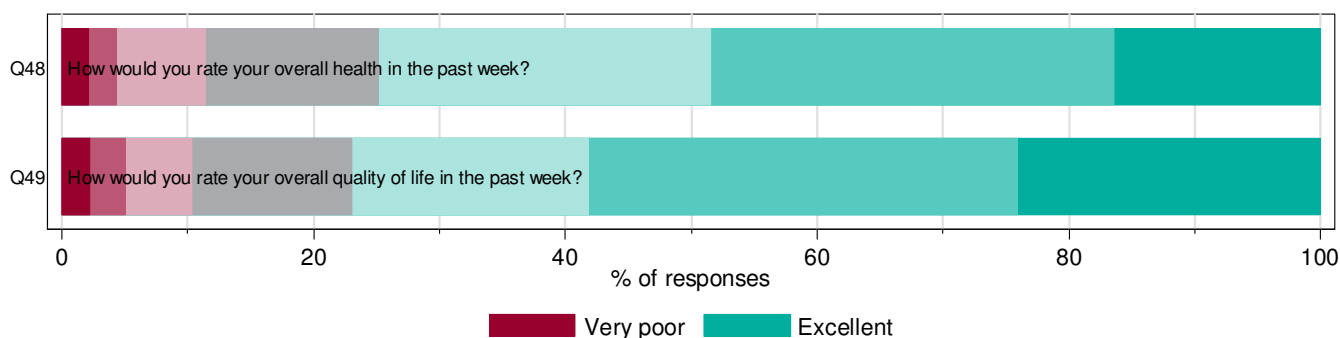


On a 7 point scale, where 1 was very poor and 7 was excellent, 360 of 481 respondents (75%) rated their overall health rated as 5 or above, and 370 of 481 respondents (77%) rated their quality of life as 5 or above (Table 5).

Table 5. Respondents’ self-reported overall health and quality of life in the week before filling in the survey, from questions 48 (How would you rate you overall health in the past week?) and 49 (How would you rate your overall quality of life in the past week?)

	Q48		Q49	
	N	%	N	%
1 - very poor	10	2%	11	2%
2	11	2%	13	3%
3	34	7%	26	5%
4	66	14%	61	13%
5	127	26%	90	19%
6	154	32%	164	34%
7 - excellent	79	16%	116	24%
Total	481		481	
Did not answer	12		12	

Figure 4. Respondents’ self-reported overall health and quality of life in the week before filling in the survey



The majority of respondents (275 of 478, 58%) reported only having done 30 minutes or more of physical activity which was enough to raise their heart rate on 2 or fewer days in the past week, with nearly a quarter of respondents (110, 23%) reporting no physical activity at all (Table 6). These questionnaires were completed between February and April 2014, and the cold and wet weather in this period may have contributed to the lack of physical activity.

Table 6. 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? (Q50)

	N	%
None	110	23%
1 day	81	17%
2 days	84	18%
3 days	72	15%
4 days	41	9%
5 days	38	8%
6 or 7 days	52	11%
Total	478	
Did not answer	15	

Health and wellbeing in the past month

In the month before filling in the questionnaire, 235 of 470 respondents (50%) reported at least a little interest in sex, and a similar number, 245 of 469 respondents (52%), reported that they were at least a little sexually active (Figure 5).

A substantial number of women reported problems such as:

- their vagina feeling dry during sex (160 of 302 respondents, 53%)
- their vagina feeling short or tight during sex (167 of 309 respondents, 54%)
- feeling pain during sex (152 of 303 respondents, 50%)

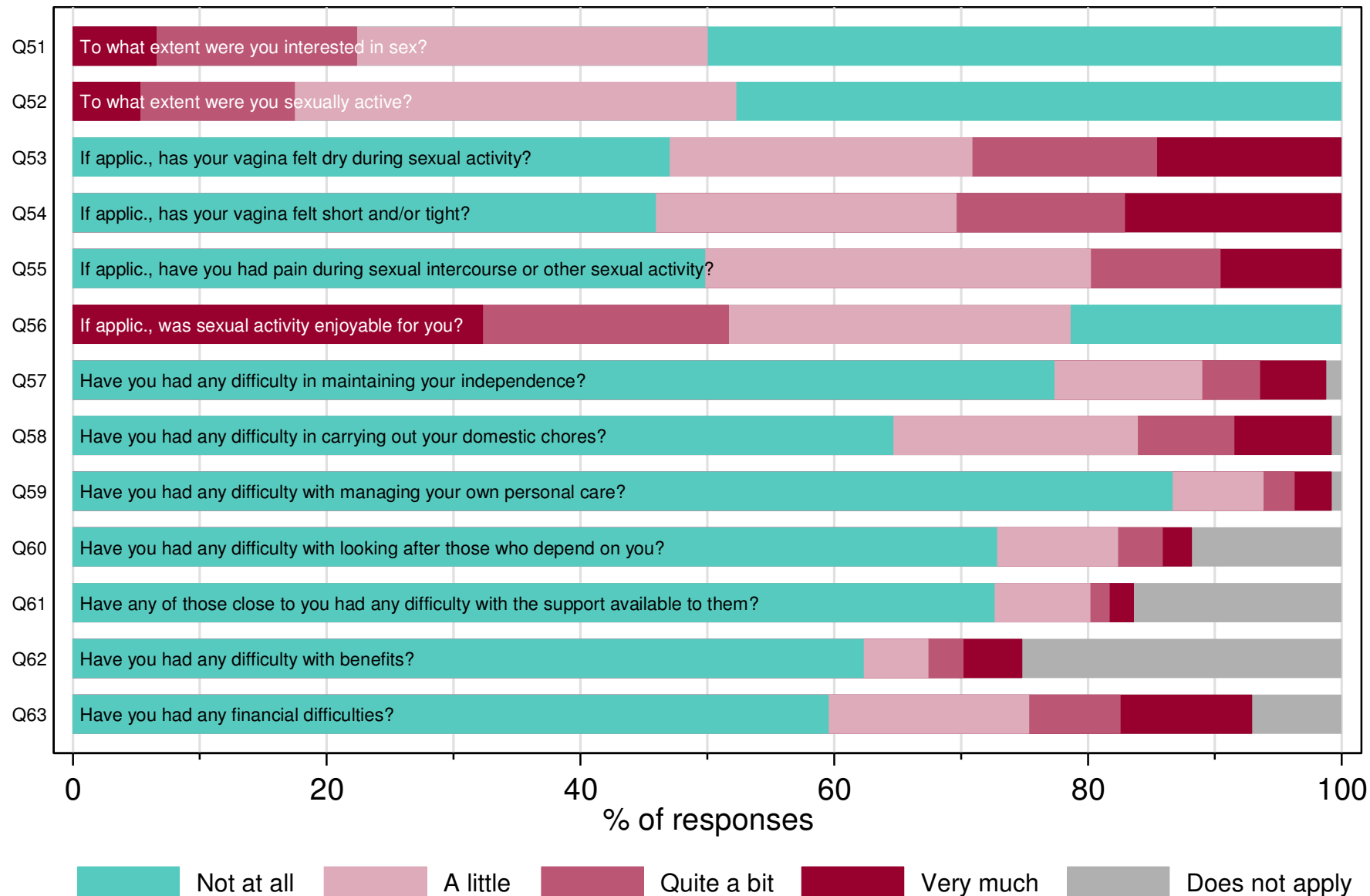
The majority of respondents (231 of 294, 79%) reported that they found sex enjoyable. Some of the women who answered these questions reported that they had not been sexually active in the previous month. A large minority of women (181 of 474, 38%) reported some difficulty concerning sexual matters, with 61 women (13%) saying they had very much had difficulties.

The most common more general problems reported were:

- difficulty with body image (229 of 484 respondents, 47%), with 61 respondents (13%) saying they had very much had difficulties with body image
- feeling isolated (200 of 485 respondents, 41%)
- difficulty with domestic chores (167 of 484 respondents, 35%)
- financial difficulties (161 of 482 respondents, 33%)
- difficulty communicating with those closest to them (149 of 485, 31%)

Three quarters of respondents (354 of 481, 74%) said that they either strongly agreed or agreed with the statement “I have fears about my cancer coming back” (Figure 6).

Figure 5. Respondents' health and wellbeing in the month before filling in the survey (frequency scale questions)
 Ordering is reversed for questions where 'very much' is the ideal response.



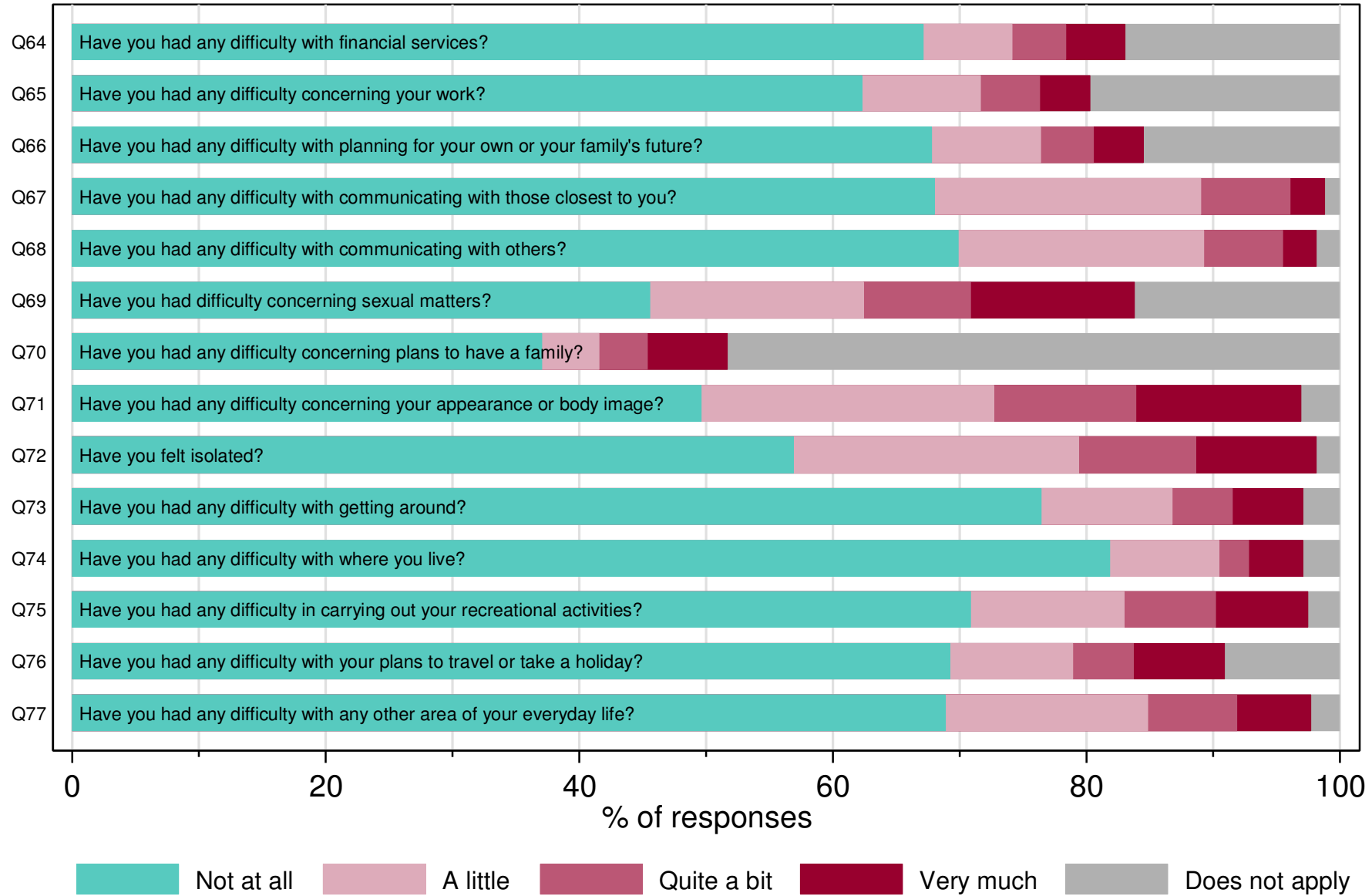
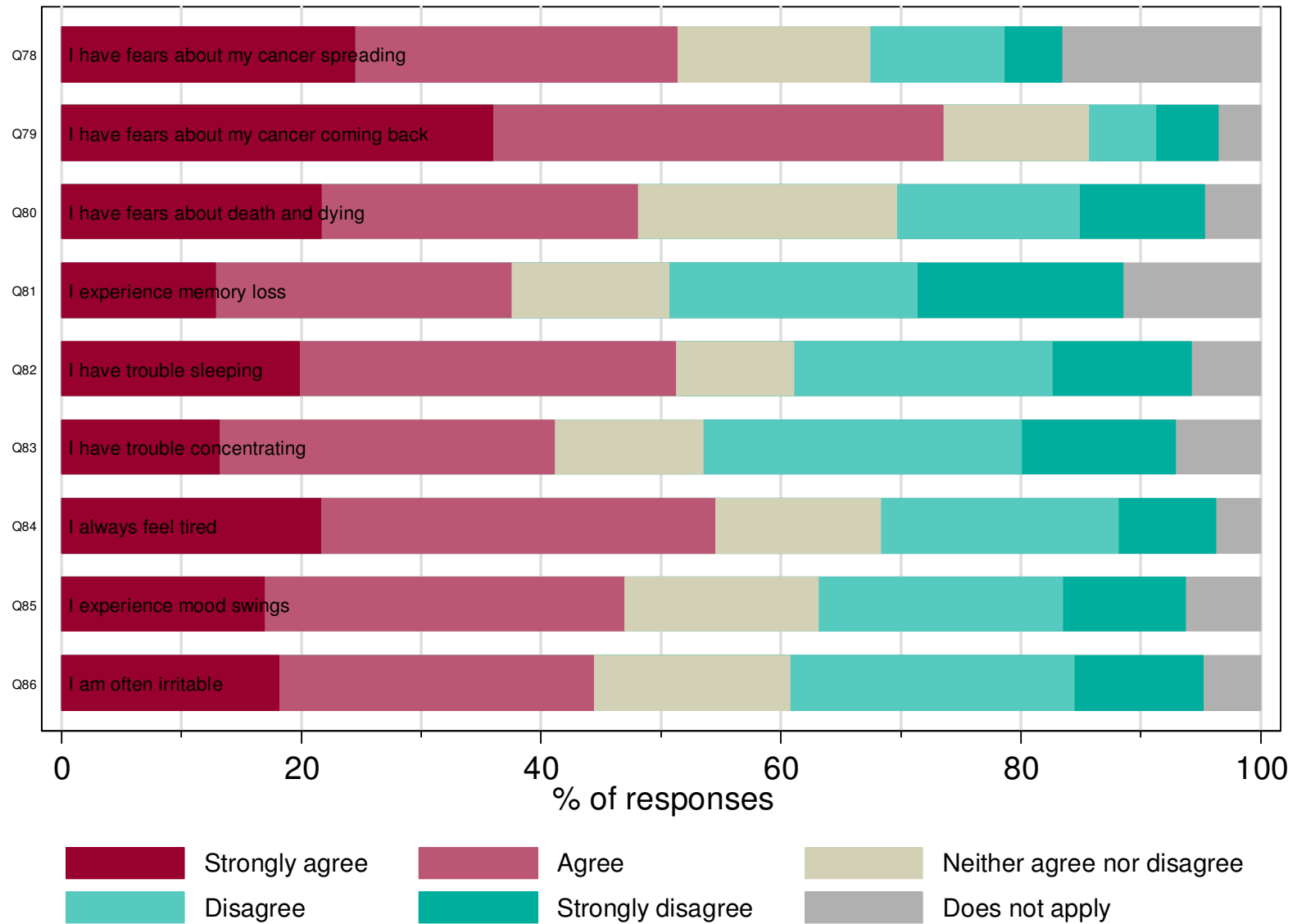


Figure 6. Respondents' health and wellbeing in the month before filling in the survey (agreement scale questions)



Overall support and care

Half of respondents (221 of 479, 46%) reported that they do not need a care plan (Table 7), while only 1 in 14 (35, 7%) reported that they definitely had or thought they had a care plan. Two fifths of respondents (201 of 482, 43%) did not have a named nurse they could contact with worries about their cancer care, and a further 36 (7%) did not know if they had one.

One quarter of respondents (137 of 481, 28%) did not know who to contact if they had any concern about any aspect of living with cancer.

Table 7. Responses to questions on care plans and contacts, from question 87 (do you have an up to date written care plan?), question 88 (do you have a named nurse who you can contact if you have a worry about your cancer care?) and question 89 (do you know who to contact if you have a concern about any aspect of living with cancer?)

	Q87		Q88		Q89	
	N	%	N	%	N	%
Yes, definitely	12	3%	245	51%	175	36%
Yes, I think so	23	5%			169	35%
No	187	39%	201	42%	137	28%
I don't need a care plan	221	46%				
Don't know	36	8%	36	7%		
Total	479		482		481	
Did not answer	14		11		12	

Three quarters of respondents (343 of 486, 71%) reported that hospital staff did everything they could to support them following their cancer treatment (Table 8). A small minority (16 respondents, 3%) reported that they never received support, while 99 women (20%) reported that hospital staff provided all the support they could only some of the time.

A substantial minority of respondents (90 of 483, 19%) reported that their general practice was not involved with supporting them after treatment. In general, fewer people felt their GP practice was doing everything possible to give them support, with 56 respondents (12%) reporting their GP practice never provided support, however, more women (191, 40%) felt that their GP practice did everything possible than felt otherwise.

Table 8. Responses to questions on hospital and GP support, from question 90 (do you think that hospital staff did everything they could to support you following your cancer treatment?) and question 91 (do you think that GPs and nurses at your general practice do everything they can to support you following your cancer treatment?)

	Q90		Q91	
	N	%	N	%
Yes, all of the time	343	71%	191	40%
Only some of the time	99	20%	99	20%
Never	16	3%	56	12%
My general practice is not involved			90	19%
I do not need any support	28	6%	47	10%
Total	486		483	
Did not answer	7		10	

Table 9. Following your initial cancer treatment have you been given enough care and help from health and social services? (Q92)

	N	%
Yes, definitely	98	20%
Yes, to some extent	61	13%
No	94	20%
Don't know / can't remember	5	1%
I did not need help from health or social services	224	46%
Total	482	
Did not answer	11	

Half of respondents (243 of 483, 50%) considered themselves to be non-smokers (Table 10), although 6 of these women had smoked in the past, but more than 5 years previously. One in six women considered themselves to be smokers currently (77 of 483, 16%), although 3 of these women also reported having stopped smoking. This explains how more women responded in Table 11 than considered themselves to be ex-smokers.

Table 10. Respondents' self-reported smoking status (Q93)

	N	%
Smoker	77	16%
Ex-smoker	163	34%
Non-smoker	243	50%
Total	483	
Did not answer	10	

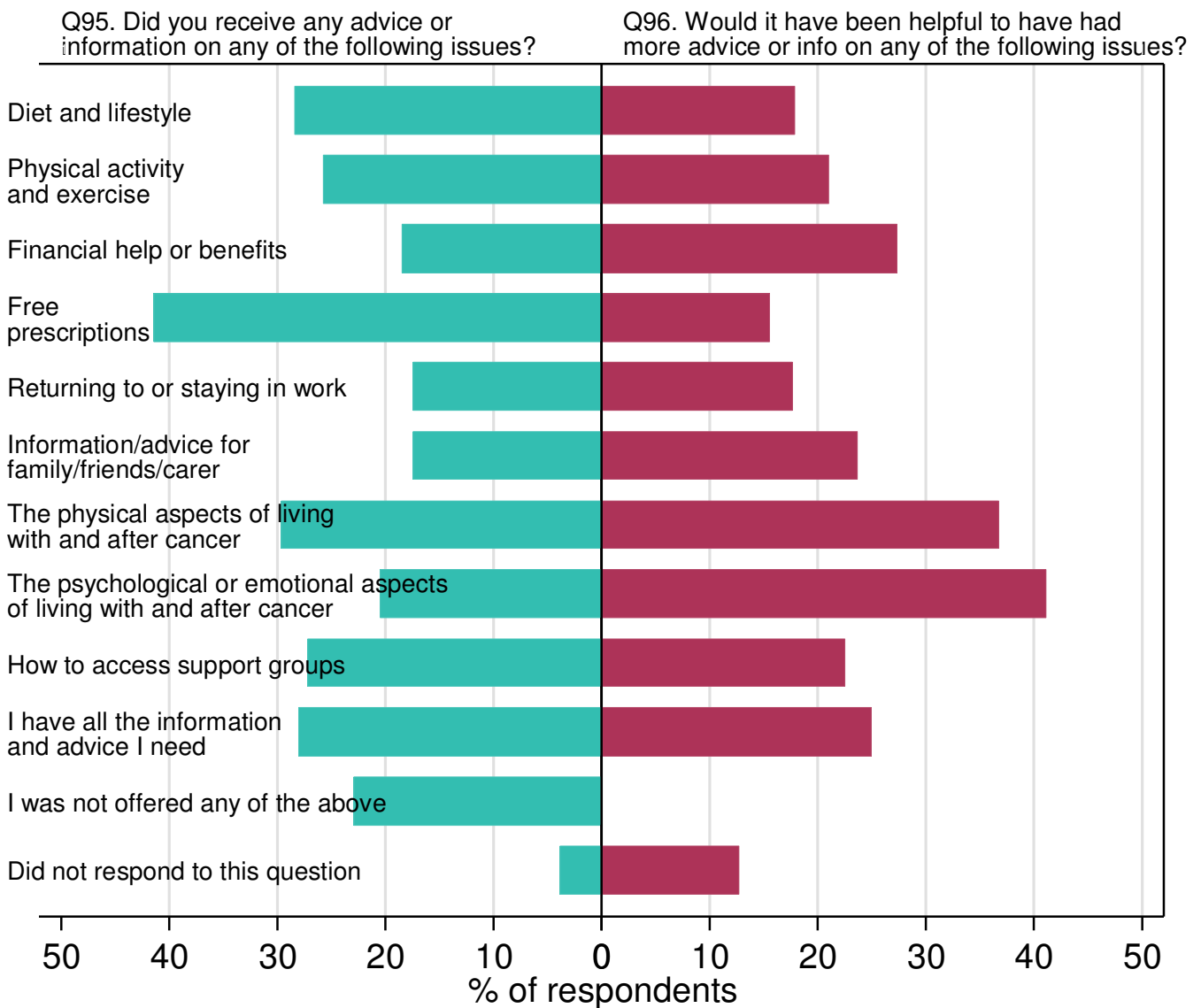
Table 11. If an ex-smoker, how long ago did you stop? (Q94)

	N	%
Less than 1 year	30	17%
Less than 2 years (and more than 1 year)	19	11%
Less than 3 years (and more than 2 years)	18	10%
Less than 4 years (and more than 3 years)	0	0%
Less than 5 years (and more than 4 years)	17	10%
More than 5 years	90	52%
Total	174	
Did not answer	319	

Of the 493 women with cervical cancer, only 123 to 138 (25% to 28%) reported that they had received all the advice and information they needed. Around a fifth of women (113, 23%) said they had not received any information or advice on any of the topics mentioned (Figure 7). Around 2 in 5 women would have found more advice or information on the physical (181, 37%) and psychological or emotional (203, 41%) aspects of living with or after cancer helpful; these were the most common topics women would have liked more advice on.

In free text comments there was a general feeling that support, particularly psychological support, was lacking for living after cancer. Some women would have appreciated more advice and support around the fertility implications of treatment, and help with changes in sex drive.

Figure 7. 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



Demographics

The earliest year of birth (Q97) for women who reported this was 1919 (although, this was probably a transcription error, as this patient had a year of birth of 1979 in cancer registry data) and the most recent was 1989, with a mean year of birth of 1966. The recorded date of birth in cancer registry data was the same as that reported by respondents in all except 7 cases.

Almost a quarter of respondents (107 of 479, 22%) said they were a carer to a family member, friend or neighbour (Q98).

Most respondents said they were heterosexual/straight (451 of 479, 94%), with 16 (3%) preferring not to say and 12 (2%) being bisexual (4), lesbian or gay (5) or other (3) (Q99). Percentages do not sum to 100% due to rounding.

Around four fifths of respondents (388 of 483, 80%) live with a partner, spouse, friend or their family, while 86 (18%) live alone. Nine respondents said that they had other living arrangements (Q100).

Two fifths of respondents (182 of 477, 37%) reported a long-standing health condition other than cancer (Q101). Figure 8 shows the frequencies of various conditions which respondents had. The most common were long-term back problems (63, 13%) and high blood pressure (52, 11%).

Figure 8. Long term conditions among respondents

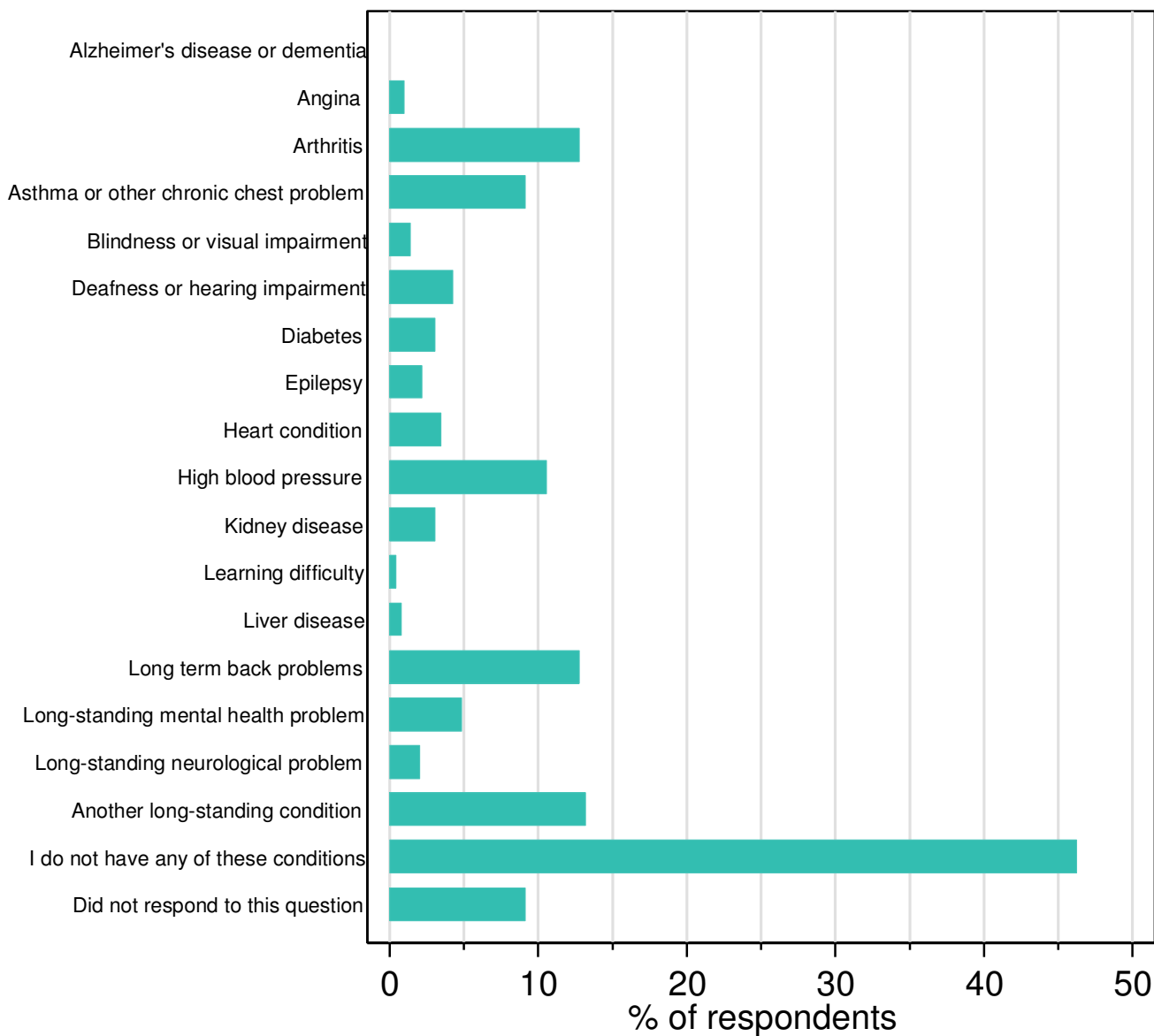


Figure 9 shows employment status for people currently and before their diagnosis with cancer. The majority of currently employed women who answered the question said that they were working their usual hours (206 of 299, 69%), with the same number of women working less hours than usual as working more hours than usual (32, 11%) (Table 12).

Figure 9. Employment status before diagnosis with cancer and current employment status

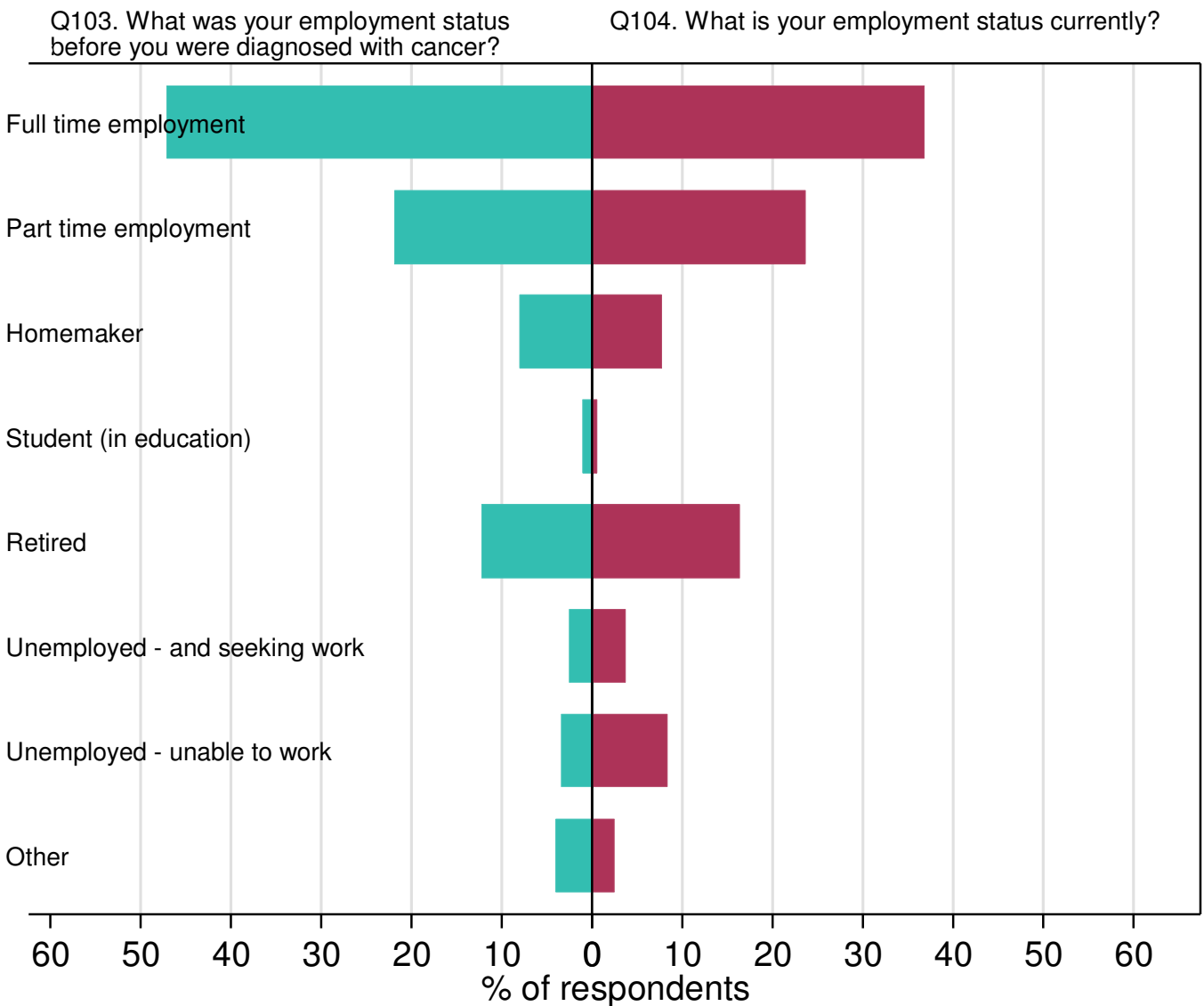


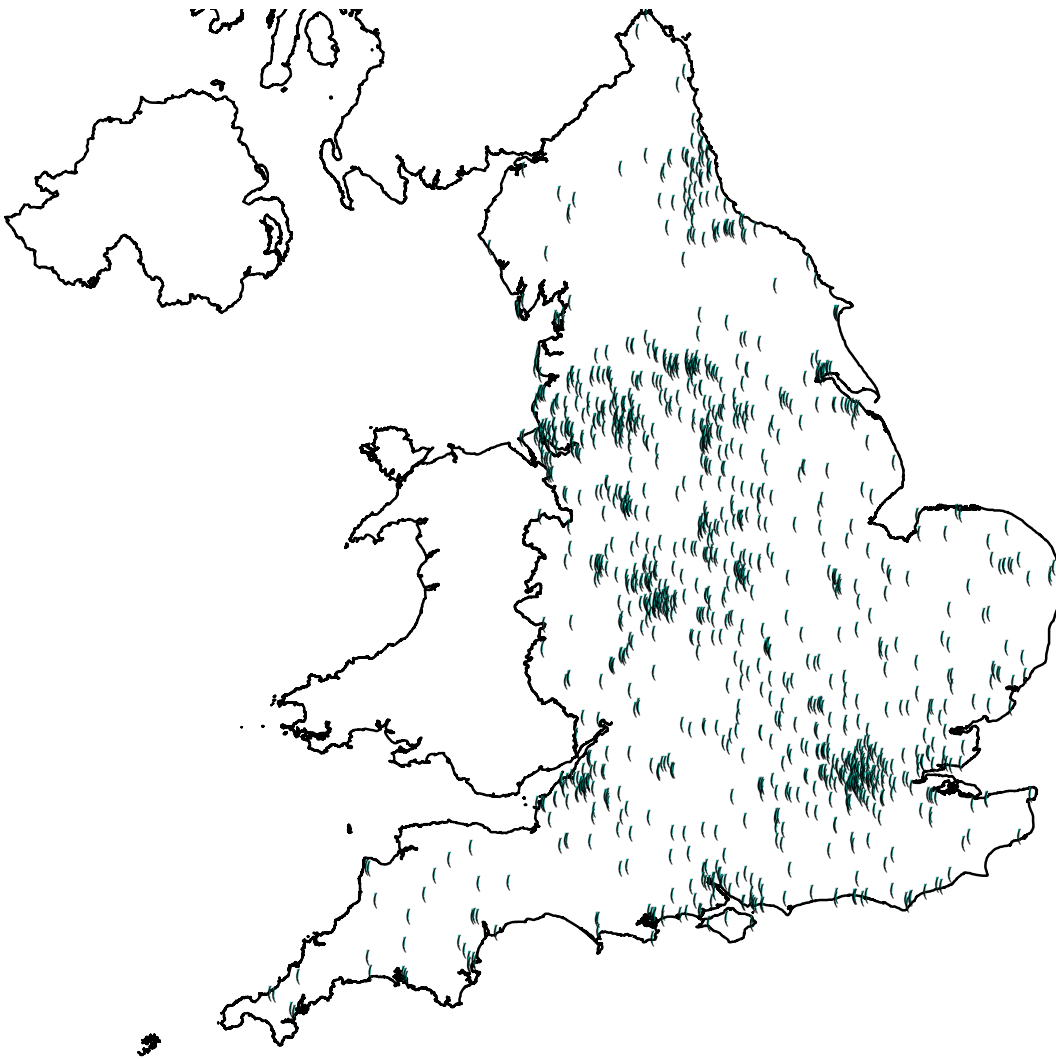
Table 12. Current hours of work, for people currently employed (Q105)

	N	%
Not working at all	29	10%
Working less hours than usual	32	11%
Working your usual hours	206	69%
Working more hours than usual	32	11%
Total	299	
This question does not apply to me	99	
Did not answer	95	

The majority of respondents classified themselves as white (462 of 479, 96%), with most of these (425 of 462, 92%) describing themselves as white British (Q106). Two respondents were from an other mixed background. Five respondents were Asian or Asian British. Six respondents were black or black British. Four respondents were Chinese.

Respondents were well dispersed across England (Figure 10). For each respondent from an upper-tier local authority, a point was plotted at one randomly-chosen postcode in that upper-tier local authority.

Figure 10. Approximate locations of respondents in England



Summary

This report provides a high level summary of the findings of the gynaecological cancer PROMs pilot for cervical cancer. The data generated by this pilot will form the basis for more detailed analysis and validation which will consider the impact of demographics and other parameters as well as critically analysing the questionnaires as functional PROMs tools. Clinical teams and other stakeholders may wish to use the high level findings presented here as a focus for further local investigation.

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