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England

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Protecting and improving the nation's health

Living with and beyond womb 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 Patient Reported Outcome Measures 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
NHS England

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

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

- improve understanding of health-status related quality of life outcomes for people following womb 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 one and five years after a diagnosis of womb 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 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
- 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 womb (uterine) cancer, and is published alongside similar summaries of the results of the PROM pilots for cervical 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 womb cancer, and 654 completed questionnaires were returned, a response rate of 52%. There were statistically significant differences in response rate by age at diagnosis, by deprivation quintile and by years since diagnosis.

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 respondents 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. For womb 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 654 questionnaires were returned completed, a response rate of 52% (Table 1). In 225 cases (18%) the patient opted out or was too ill to take part (212, 17%), had died (4, <1%) or was otherwise ineligible (9, 1%). A small number of questionnaires were returned undelivered (4, <1%).

There was evidence of a difference in response rate by age at diagnosis ($p = 0.017$). The 60 to 69 age group was most likely to respond, with response rate lower for other age groups. The oldest age group had a particularly low response rate (46%).

There was strong evidence of a difference in the response rate by deprivation quintile ($p < 0.001$). Those in more deprived quintiles were less likely to respond, with a very low response rate in the most deprived quintile (35%).

There was evidence of a difference in response rate by the number of years after diagnosis the questionnaire was sent ($p = 0.011$). The response rate for women in their first year after diagnosis (60%) appeared to be higher than for women 2 to 5 years after diagnosis (47% to 52%).

Table 1. Response rates for women with womb cancer

	Completed questionnaire		Returned undelivered		Patient deceased		Too ill/opt out		Other ineligible		No response		Total
Total	654	52%	4	0%	4	0%	212	17%	9	1%	369	29%	1,252

Age at diagnosis													
16-49	46	51%	0	0%	1	1%	6	7%	1	1%	36	40%	90
50-59	174	54%	2	1%	0	0%	35	11%	1	0%	110	34%	322
60-69	258	57%	2	0%	0	0%	73	16%	3	1%	120	26%	456
70-99	176	46%	0	0%	3	1%	98	26%	4	1%	103	27%	384

$p = 0.017$

Deprivation quintile

(1 – least deprived, 5 – most deprived, based on the income domain of the Indices of Multiple Deprivation 2010)

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1	160	56%	0	0%	1	0%	54	19%	2	1%	69	24%	286
2	156	57%	1	0%	0	0%	45	17%	2	1%	68	25%	272
3	148	57%	1	0%	0	0%	42	16%	1	0%	67	26%	259
4	123	50%	1	0%	1	0%	45	18%	1	0%	76	31%	247
5	66	35%	1	1%	2	1%	26	14%	3	2%	88	47%	186

$p < 0.001$

Years after diagnosis													
1	187	60%	1	0%	1	0%	44	14%	0	0%	80	26%	313
2	148	47%	1	0%	3	1%	54	17%	5	2%	102	33%	313
3	164	52%	1	0%	0	0%	60	19%	2	1%	86	27%	313
5	155	50%	1	0%	0	0%	54	17%	2	1%	101	32%	313

$p = 0.011$

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

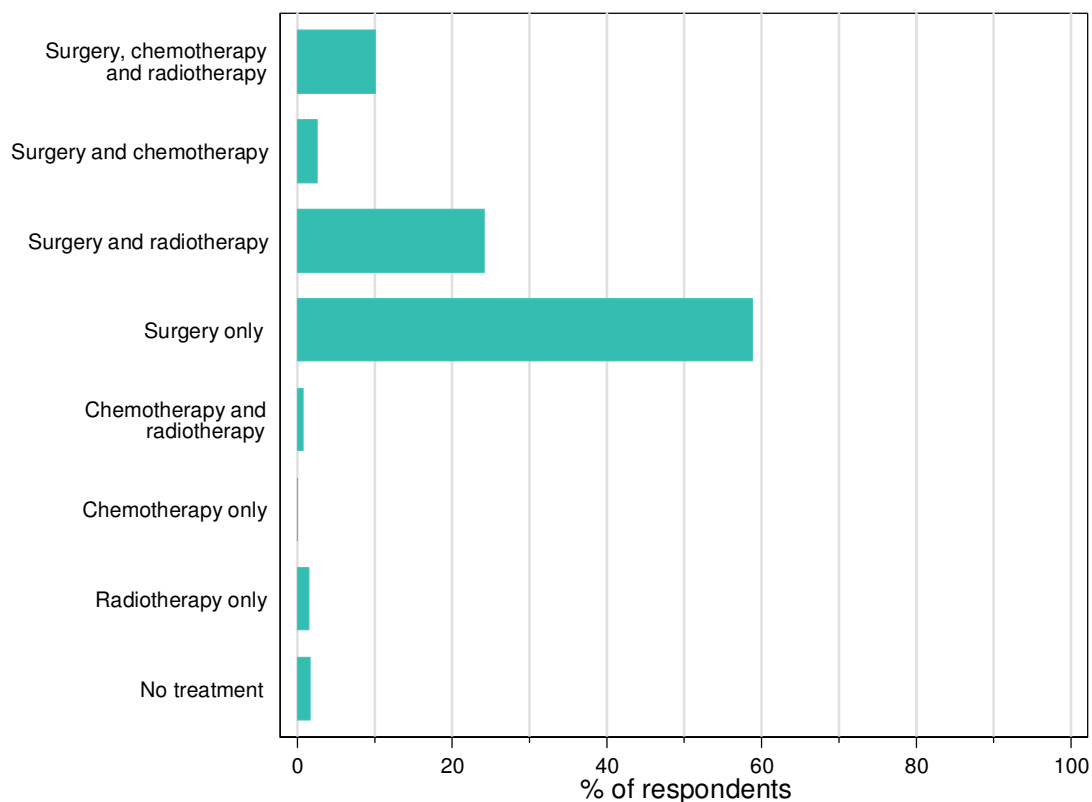
Treatment

Almost all respondents (627 of 654, 96%) were treated with surgery (Table 2; Figure 1), with the majority of respondents (385, 59%) receiving surgery only, although around a quarter (159, 24%) of respondents received both surgery and radiotherapy. Eleven respondents (2%) did not report receiving any treatment.

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

	N	%
Surgery	627	96%
Chemotherapy	89	14%
Radiotherapy	240	37%
Total	654	
Did not answer	0	

Figure 1. Treatment received by respondents to the survey



Most respondents (466 of 637, 73%) 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 womb cancer? (Q2)

	N	%
I am still having my initial treatment	11	2%
It is less than 3 months since my initial treatment	5	1%
It is between 3 and 12 months since my initial treatment	66	10%
It is between 1 and 5 years since my initial treatment	466	73%
It is more than 5 years since my initial treatment	87	14%
Don't know / can't remember	2	0%
Total	637	
Did not answer	17	

Almost all respondents (548 of 600, 91%) were in remission (Table 4).

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

	N	%
My cancer has responded fully to treatment	548	91%
My cancer has been treated but is still present	7	1%
My cancer has not been treated at all	8	1%
My cancer has come back after it was treated	12	2%
I am not certain what is happening with my cancer	25	4%
Total	600	
Did not answer	54	

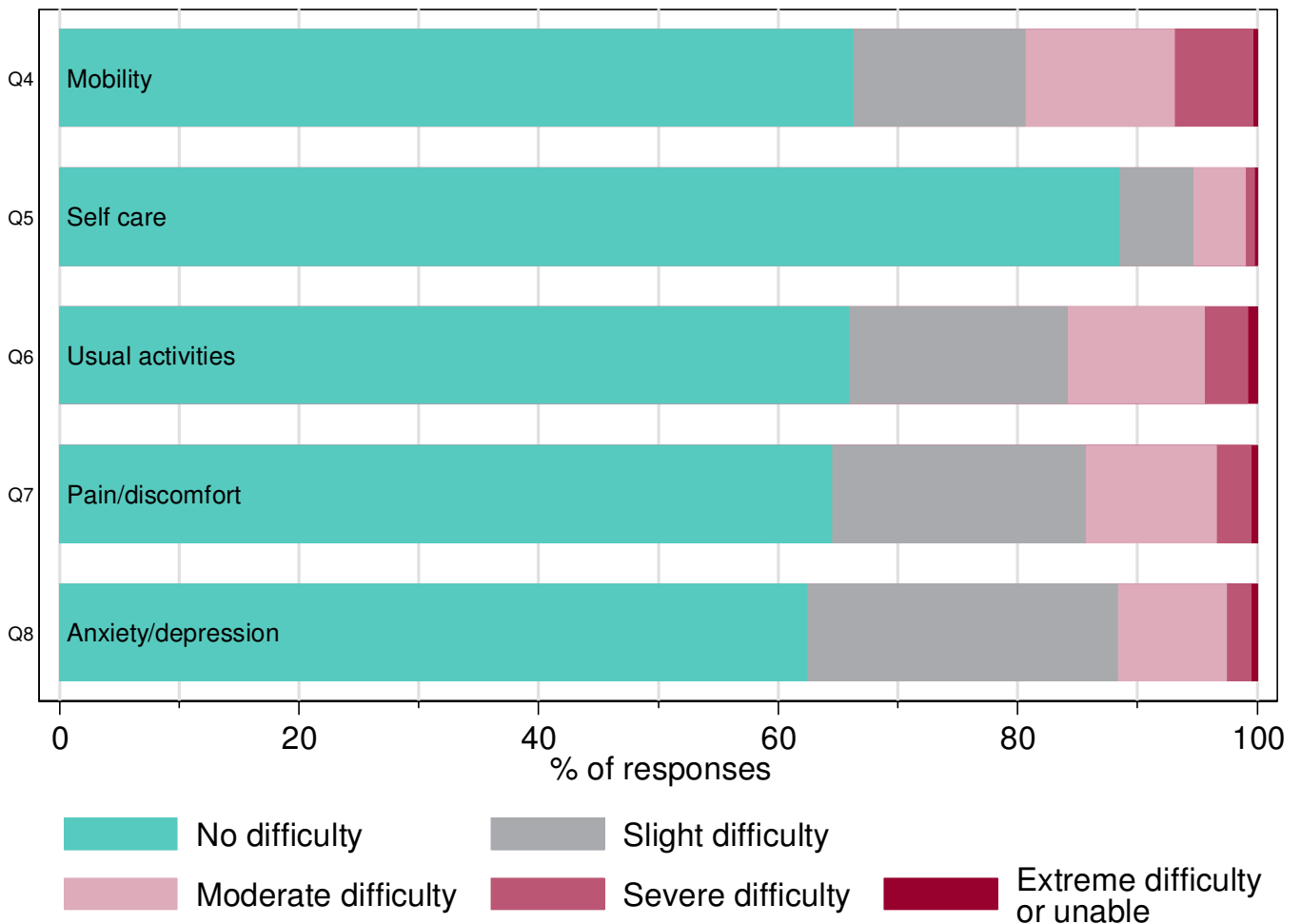
Health and wellbeing today

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, usual activities, pain/discomfort and anxiety/depression.

The most common problem was with anxiety or depression, with 241 of 641 responses (38%) reporting at least a slight problem and 75 (12%) reporting they were moderately, severely or extremely anxious or depressed on the day they filled in the questionnaire.

Mobility was a problem for many women, with 44 of 641 responses (7%) reporting severe problems with walking about, or that they were unable to walk about.

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



Health and wellbeing in the past week

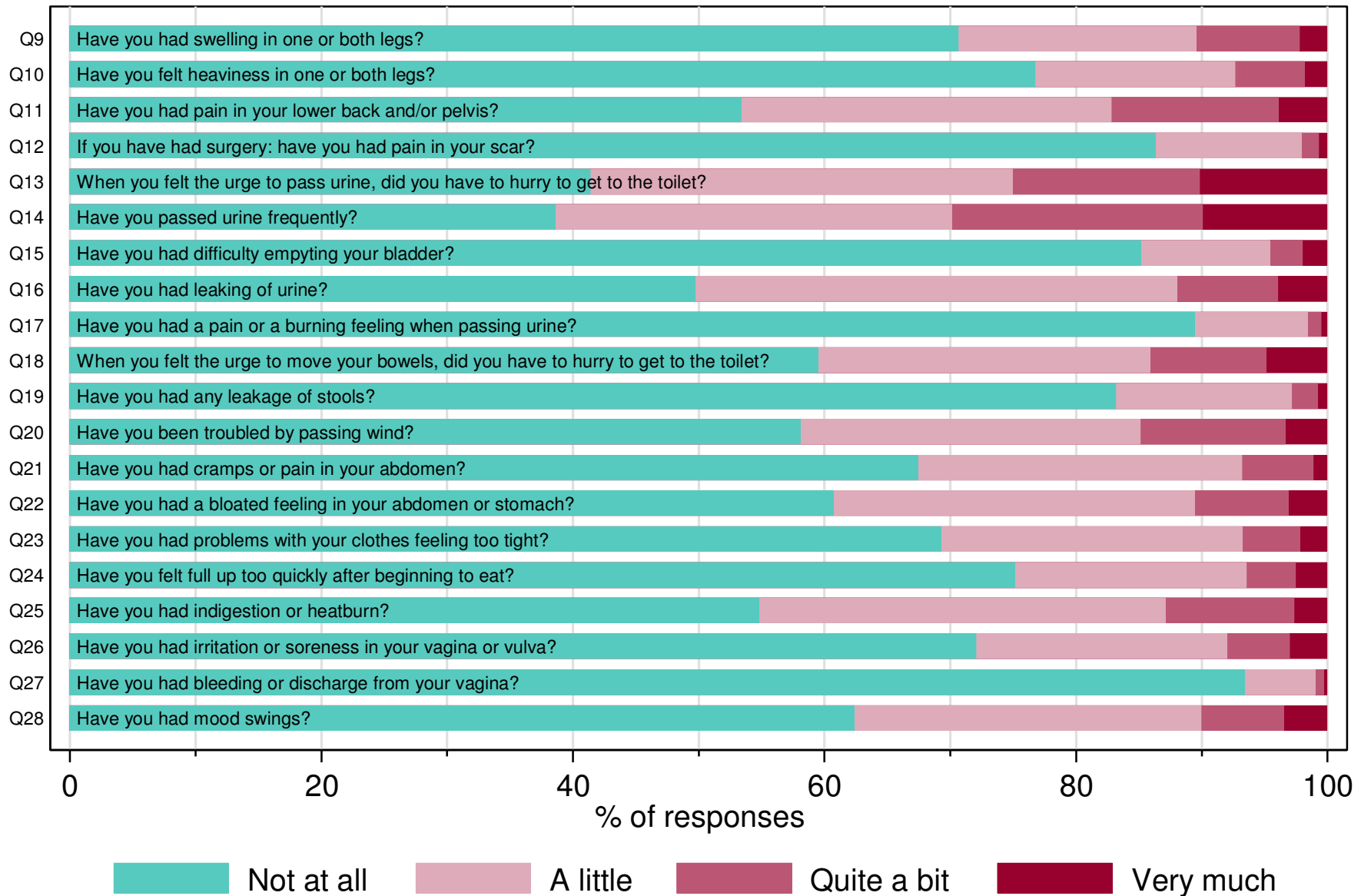
The most common problem reported in the week before filling in the questionnaire was aches and pains in muscles or joints, with 257 of 641 responses (40%) reporting that this was occurring a little bit, and 168 responses (26%) reporting that this was occurring quite a bit or a lot (Figure 3). Lower back or pelvis pain was also quite common, with 287 of 616 responses (47%) reporting at least a little bit of such pain.

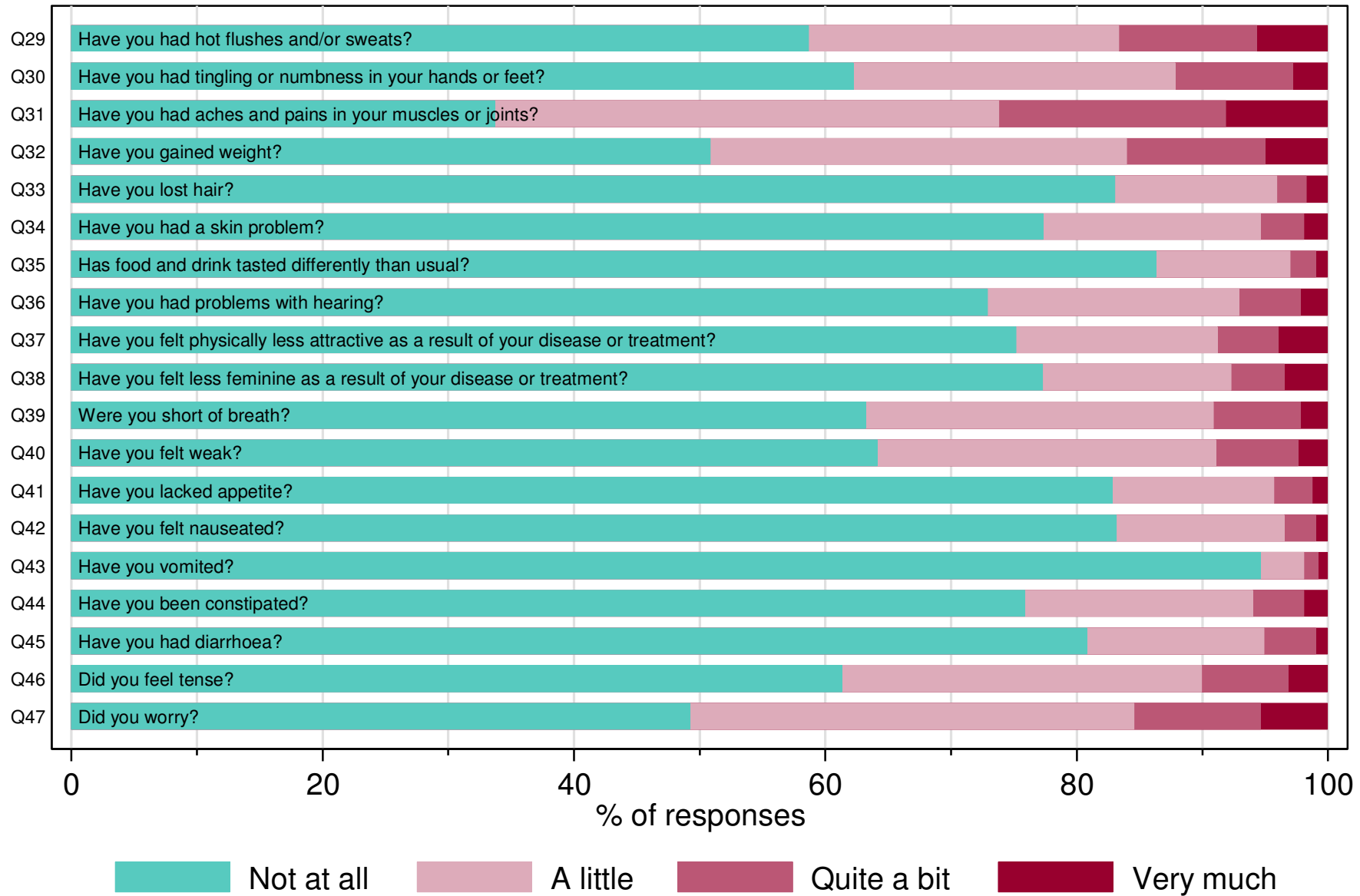
The majority of respondents (378 of 616, 61%) reported having passed urine frequently at least a little bit in the week before filling in the questionnaire, with 184 women (30%) reporting urinating somewhat or very frequently. A similar majority (363 of 619, 59%) reporting having to hurry at least a little bit to get to the toilet when they felt the urge to pass urine, with 155 women (25%) reporting they had to hurry quite a bit or a lot. Half the respondents (316 of 628, 50%) reported at least a little bit of leakage of urine, with 75 (12%) reporting that this had occurred quite a bit or a lot.

A slight majority (322 of 634, 51%) 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.

A slight minority (313 of 637, 49%) 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)



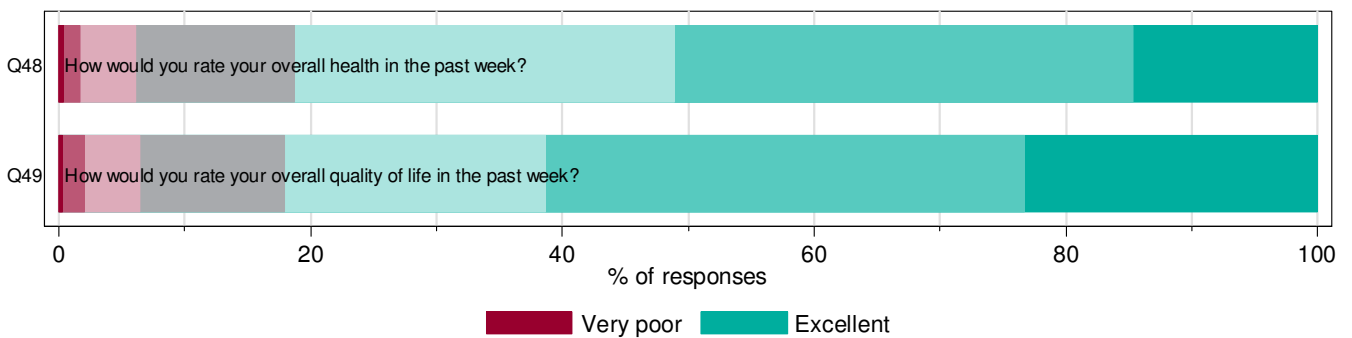


On a seven point scale, where one was very poor and seven was excellent, 519 of 639 respondents (81%) rated their overall health rated as 5 or above, and 523 of 638 respondents (82%) rated their quality of life as 5 or above (Table 5; Figure 4).

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	3	0%	2	0%
2	8	1%	11	2%
3	28	4%	28	4%
4	81	13%	74	12%
5	193	30%	132	21%
6	233	36%	242	38%
7 - excellent	93	15%	149	23%
Total	639		638	
Did not answer	15		16	

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



The majority of respondents (382 of 634, 60%) 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 nearly a third of respondents (204, 32%) 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	204	32%
1 day	73	12%
2 days	105	17%
3 days	98	15%
4 days	60	9%
5 days	50	8%
6 or 7 days	44	7%
Total	634	
Did not answer	20	

Health and wellbeing in the past month

In the month before filling in the questionnaire, 209 of 585 respondents (36%) reported at least a little interest in sex, and a similar number, 179 of 585 respondents (31%), reported that they were at least a little sexually active (Figure 3).

A substantial number of women reported problems such as:

- their vagina feeling dry during sex (125 of 235 respondents, 53%)
- their vagina feeling short or tight during sex (84 of 238 respondents, 35%)
- feeling pain during sex (70 of 231 respondents, 30%)

The majority of respondents (158 of 219, 72%) 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.

The most common more general problems reported were:

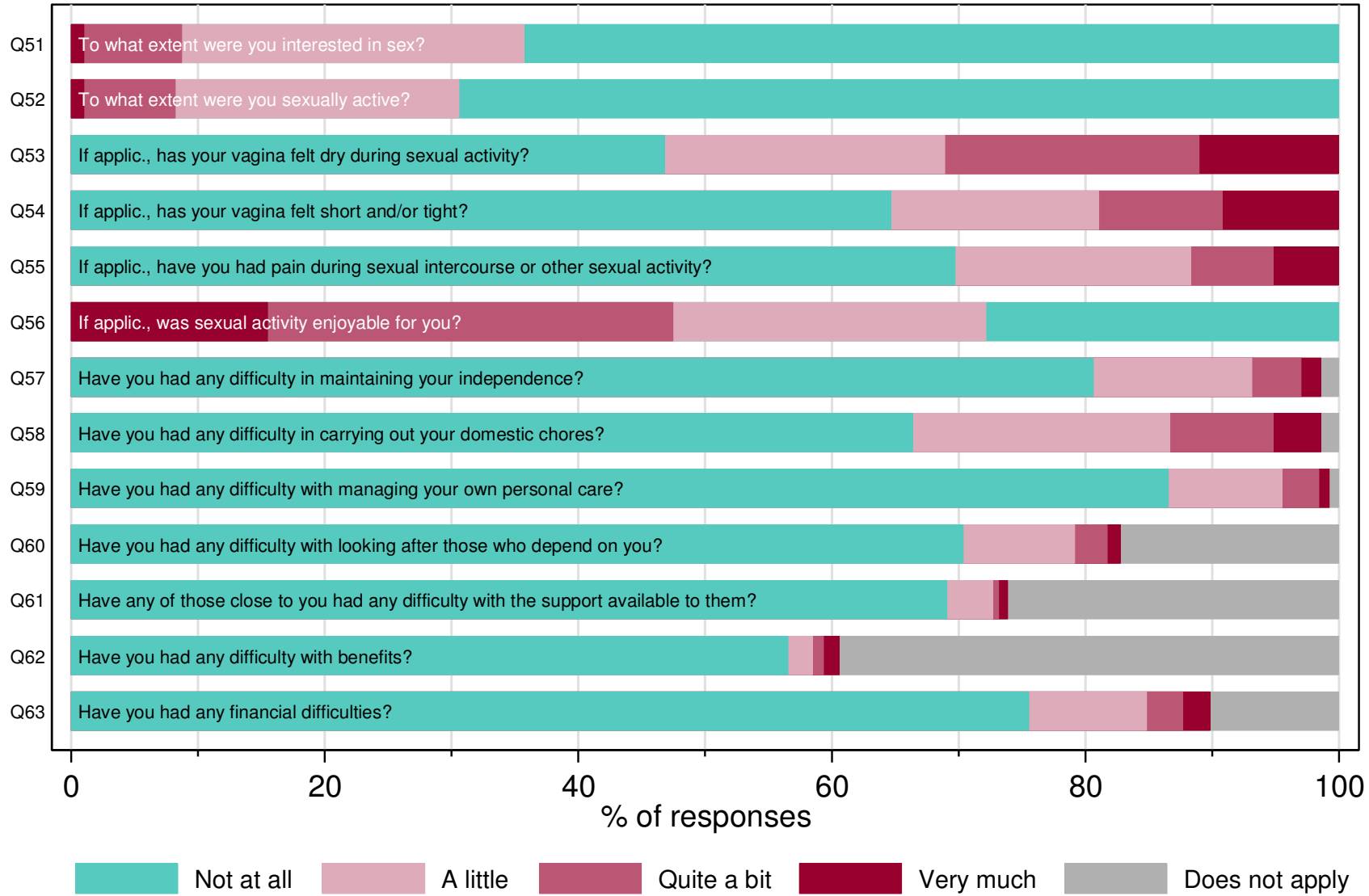
- difficulty with domestic chores (205 of 636 respondents, 32%)
- difficulty with body image (168 of 613 respondents, 27%)
- feeling isolated (159 of 618 respondents, 26%)

Most women only reported minor issues, with 5% or fewer reporting that they 'very much' had difficulty for any of questions 57 through 77.

Slightly more than half of respondents (325 of 623, 52%) said that they either strongly agreed or agreed with the statement "I have fears about my cancer coming back" (Figure 4).

Two fifths (261 of 616, 42%) agreed or strongly agreed with the statement "I have trouble sleeping" and a similar proportion (240 of 613, 39%) agreed or strongly agreed with "I always feel tired", however, while there was a moderate and statistically significant correlation between responses to these two questions, many of the women who agreed with "I always feel tired" did not agree with "I have trouble sleeping", and vice versa.

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.



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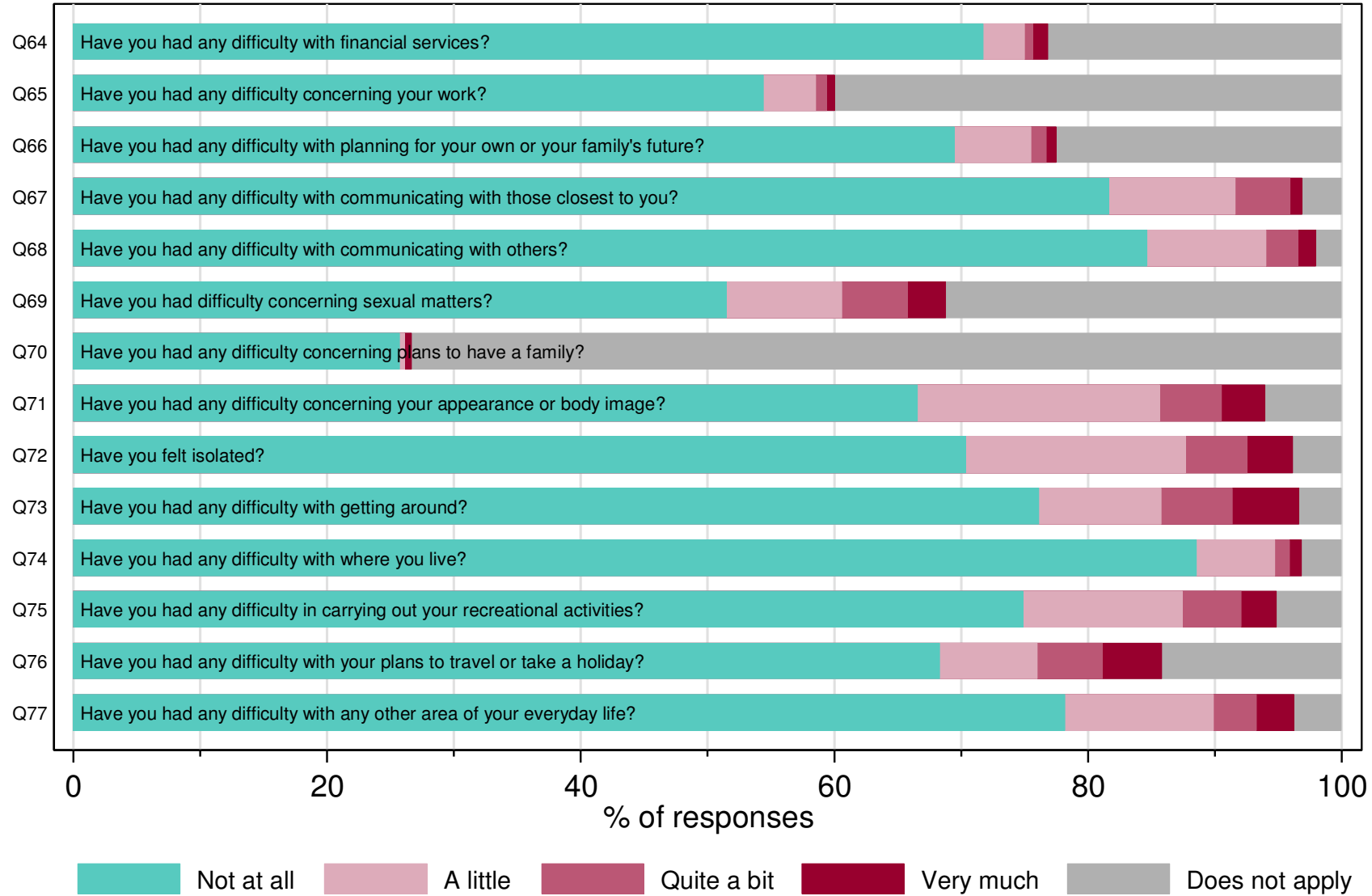
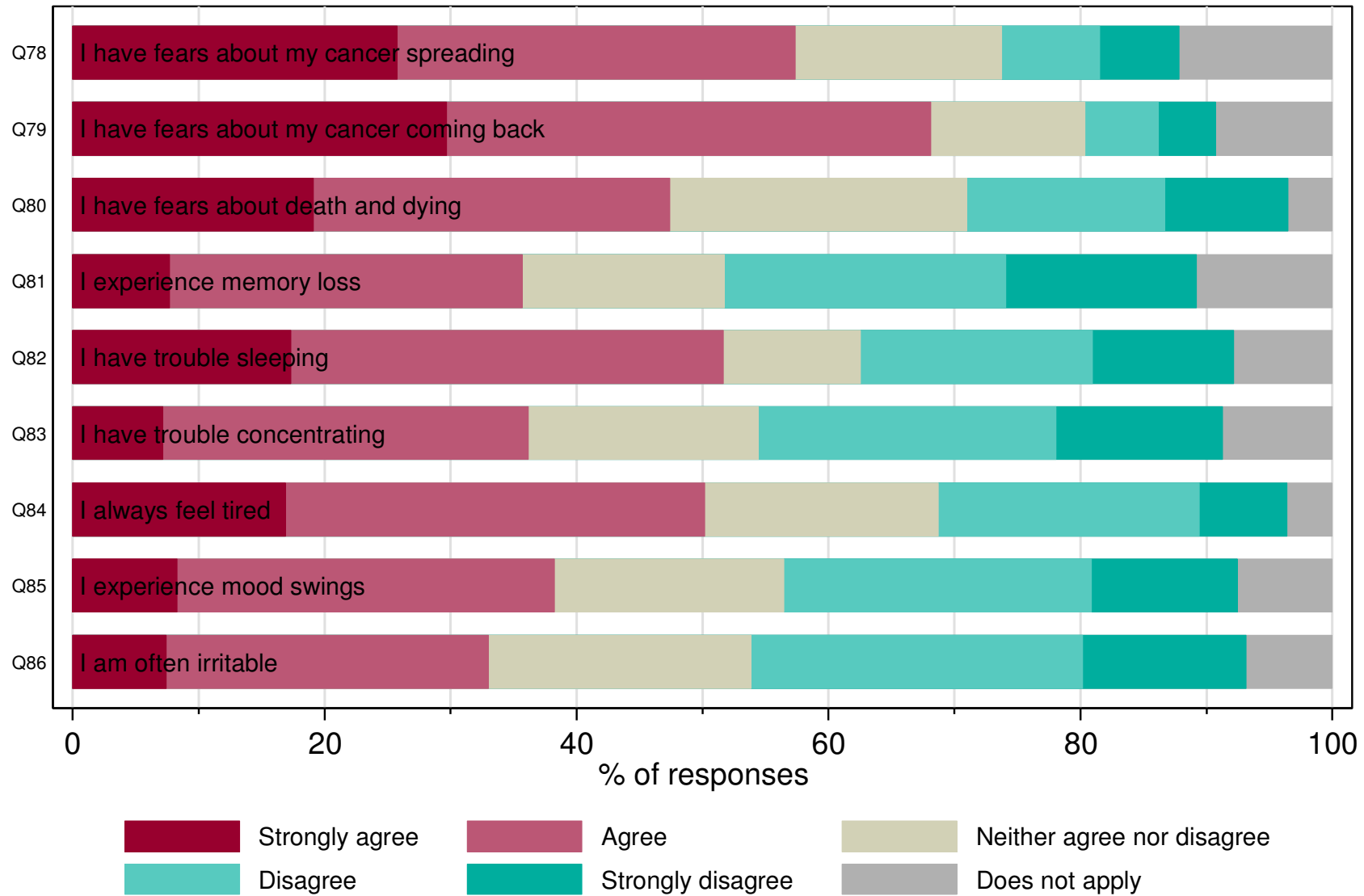


Figure 6. Respondents' health and wellbeing in the month before filling in the survey (agreement scale questions)



Overall support and care

Half of respondents (310 of 624, 50%) reported that they do not need a care plan (Table 7), while only one in twenty (27, 5%) reported that they definitely had or thought they had a care plan. Two fifths of respondents (270 of 630, 43%) did not have a named nurse they could contact with worries about their cancer care, and a further 42 (7%) did not know if they had one.

Nearly one in five respondents (105 of 627, 17%) 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	17	3%	318	50%	295	47%
Yes, I think so	10	2%			227	36%
No	256	41%	270	43%	105	17%
I don't need a care plan	310	50%				
Don't know	31	5%	42	7%		
Total	624		630		627	
Did not answer	30		24		27	

Three quarters of respondents (479 of 635, 75%) reported that hospital staff did everything they could to support them following their cancer treatment (Table 8). A small minority (10 respondents, 2%) reported that they never received support, while 78 women (12%) reported that hospital staff provided all the support they could only some of the time.

A substantial minority of respondents (129 of 623, 21%) 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 41 respondents (7%) reporting their GP practice never provided support. However, more women (270, 43%) 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	479	75%	270	43%
Only some of the time	78	12%	76	12%
Never	10	2%	41	7%
My general practice is not involved			129	21%
I do not need any support	68	11%	107	17%
Total	635		623	
Did not answer	19		31	

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

	N	%
Yes, definitely	126	20%
Yes, to some extent	67	11%
No	74	12%
Don't know / can't remember	359	57%
I did not need help from health or social services	3	0%
Total	629	
Did not answer	25	

Three quarters of respondents (478 of 641, 75%) considered themselves to be non-smokers (Table 10), although 19 of these women had smoked in the past, but more than five years previously. This explains how more women responded in Table 11 than considered themselves to be ex-smokers. Few women considered themselves to be smokers currently (27 of 641, 4%).

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

	N	%
Smoker	27	4%
Ex-smoker	136	21%
Non-smoker	478	75%
Total	641	
Did not answer	13	

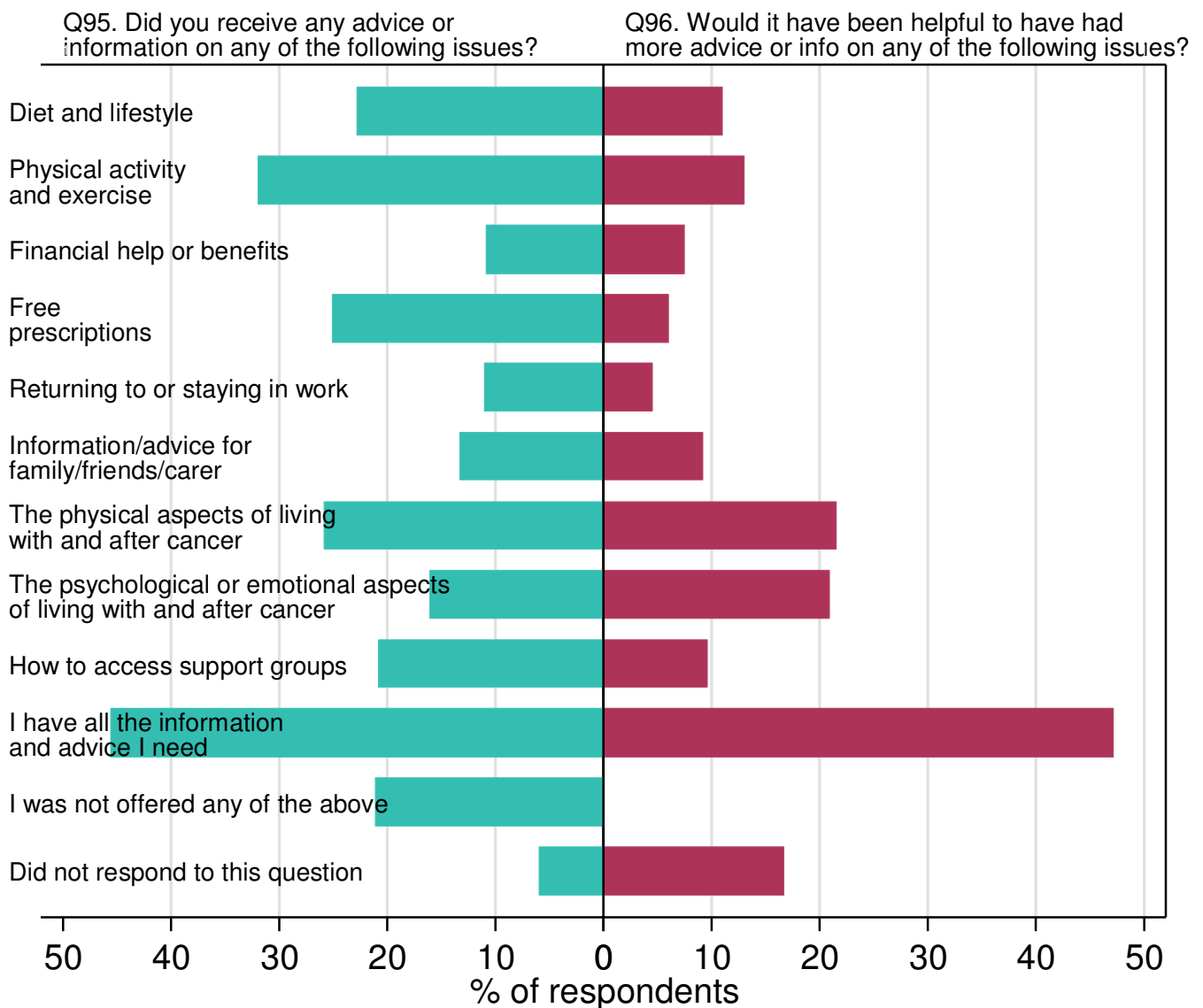
Table 11. If an ex-smoker, how long ago did you stop? (Q94)

	N	%
Less than 1 year	7	5%
Less than 2 years (and more than 1 year)	5	3%
Less than 3 years (and more than 2 years)	4	3%
Less than 4 years (and more than 3 years)	6	4%
Less than 5 years (and more than 4 years)	2	1%
More than 5 years	130	84%
Total	154	
Did not answer	500	

Of the 654 women who had been diagnosed with womb cancer contacted, only 298 to 309 (46% to 47%) reported that they had received all the advice and information they needed. Around a fifth of women (138, 21%) said they had not received any information or advice on any of the topics mentioned (Figure 7). Around one in five women would have found more advice or information on the physical (141, 22%) and psychological or emotional (137, 21%) 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, a number of women said that more information on support groups for womb cancer and on symptoms that might indicate the return of the cancer would have been helpful. There was a general feeling that support, particularly psychological support, was lacking for living after cancer.

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 1920 and the most recent was 1986, with a mean year of birth of 1947. The recorded date of birth in cancer registry data was the same as that reported by respondents in all except 4 cases.

Almost a third of respondents (181 of 607, 30%) said they were a carer to a family member, friend or neighbour (Q98).

Most respondents said they were heterosexual/straight (559 of 604, 93%), with 37 (6%) preferring not to say and 8 (1%) being bisexual (4), lesbian or gay (1) or other (3) (Q99).

Around three quarters of respondents (458 of 637, 72%) live with a partner, spouse, friend or their family, while 171 (27%) live alone. Only one respondent lived in a nursing home, hospital or other long term care home. Seven respondents said that they had other living arrangements (Q100).

Three fifths of respondents (389 of 610) 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 high blood pressure (254, 39%) and arthritis (206, 31%).

Figure 8. Long term conditions among respondents

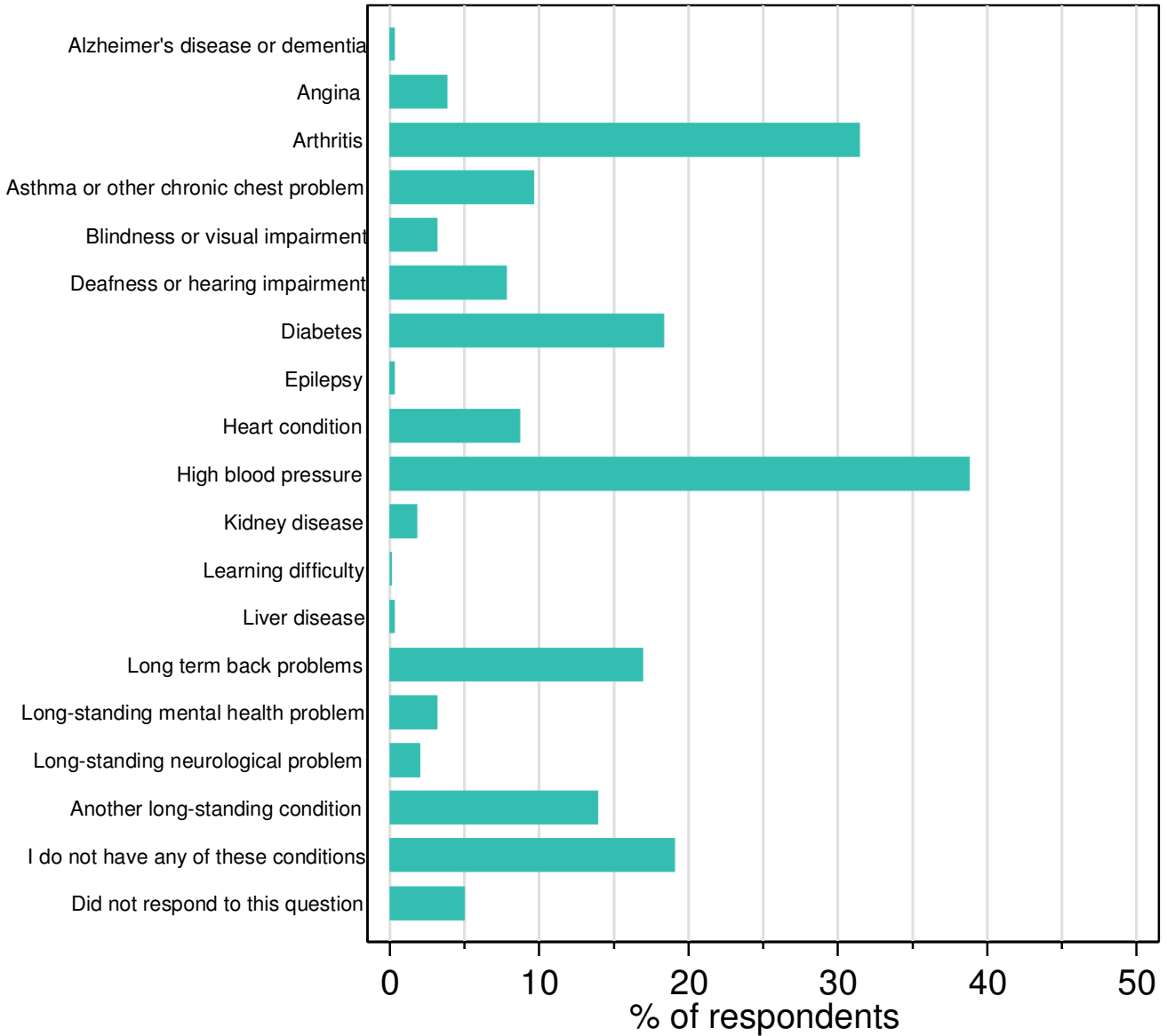


Figure 9 shows employment status for people currently and before their diagnosis with cancer. The observed differences might be explained by women retiring either naturally or due to health reasons. The majority of currently employed women who answered the question said that they were working their usual hours (120 of 172, 70%), with slightly more women working less hours than usual (19, 11%) than were working more hours than usual (10, 6%) (Table 12).

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

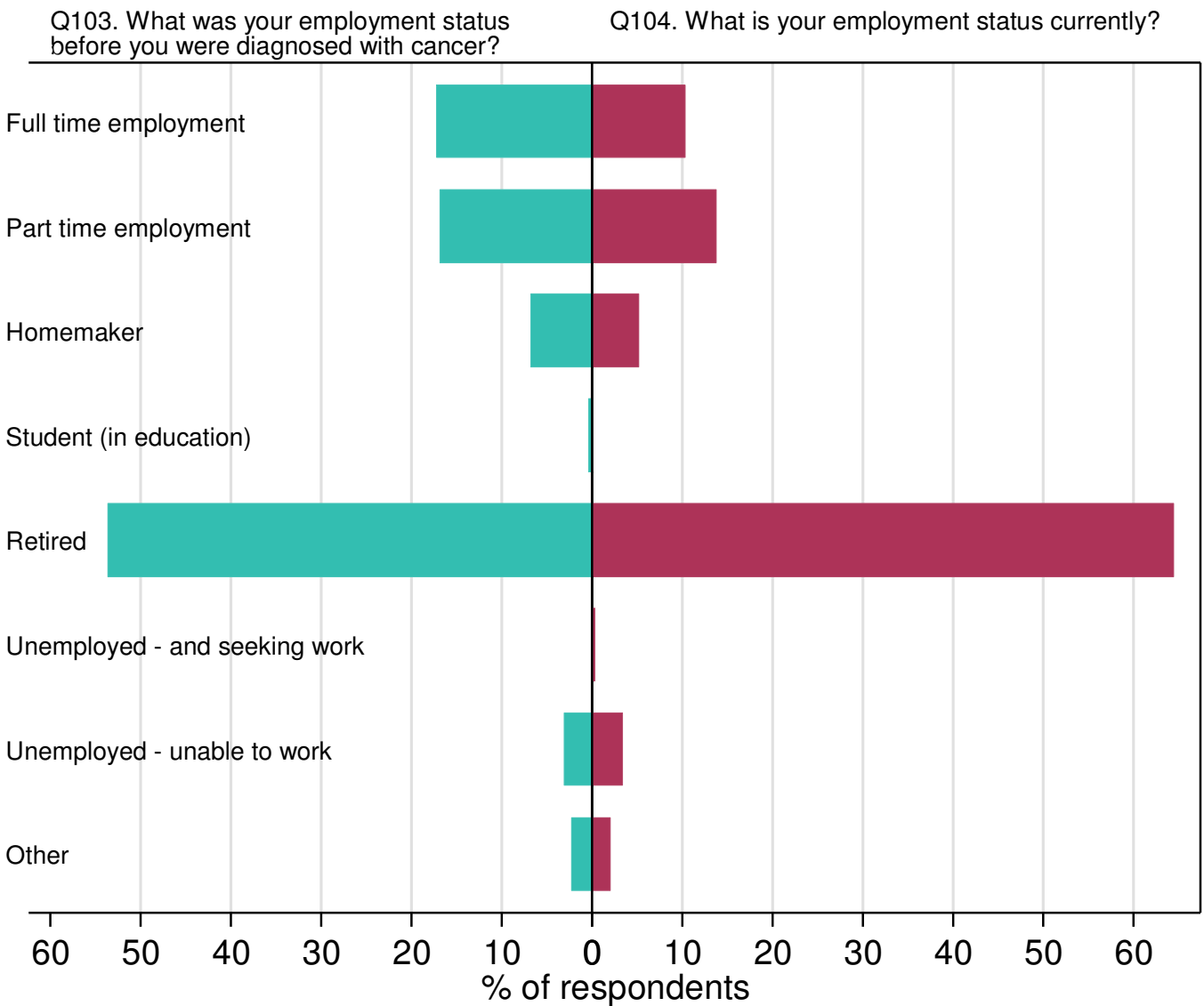


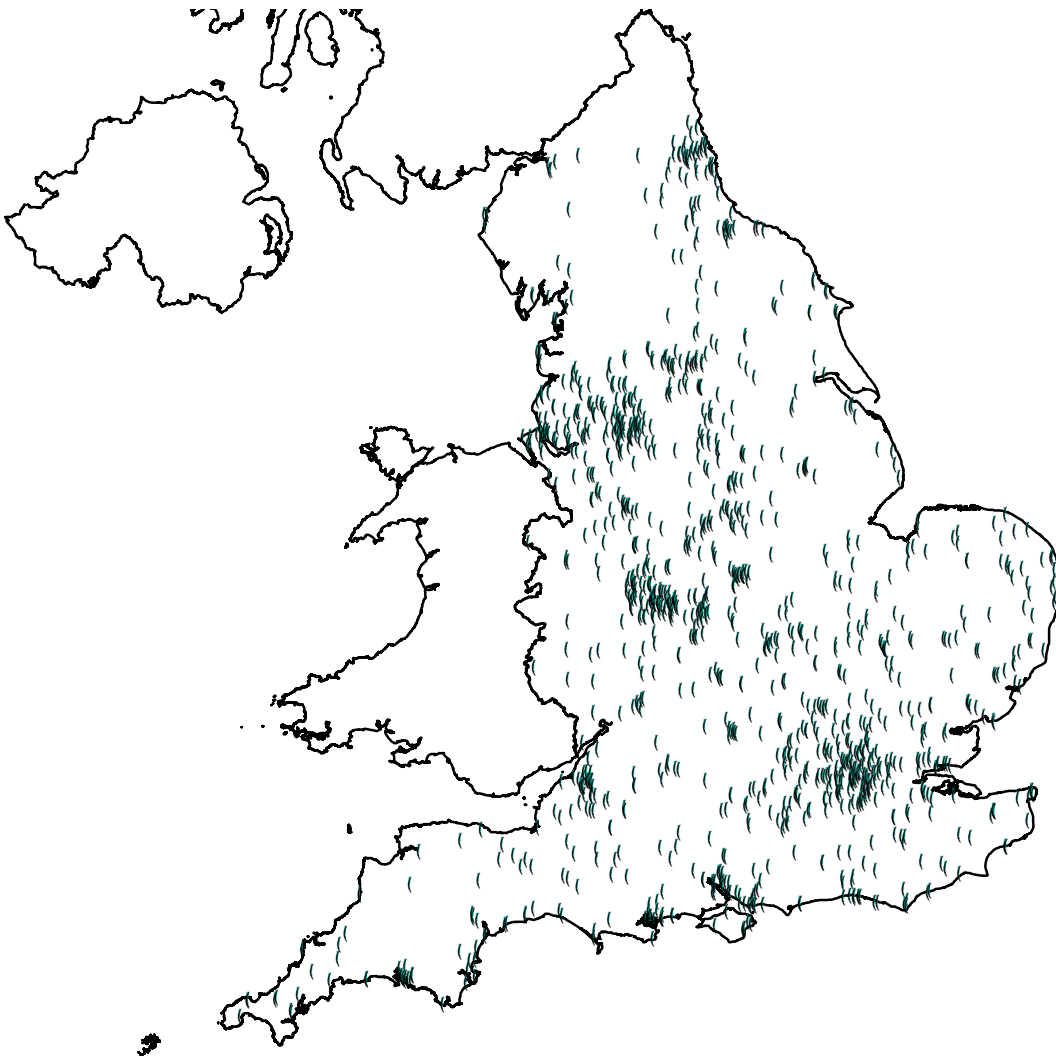
Table 12. Current hours of work, for people currently employed (Q105)

	N	%
Not working at all	23	13%
Working less hours than usual	19	11%
Working your usual hours	120	70%
Working more hours than usual	10	6%
Total	172	
This question does not apply to me	260	
Did not answer	222	

The majority of respondents classified themselves as white (623 of 639, 97%), with almost all of these (611 of 623, 98%) describing themselves as white British (Q106). One respondent was mixed white and Asian. Eight respondents were Asian or Asian British. Four respondents were black or black British. Three 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 womb 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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