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Protecting and improving the nation's health

Living with and beyond ovarian 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.

NHS England works in partnership with a number of other bodies including the Care Quality Commission, Monitor, NHS Trust Development Authority, Public Health England, NICE, Health Education England and the Health and Social Care Information Centre, each of which has distinctive responsibilities within the health and social care system.

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

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

- improve understanding of health-status related quality of life outcomes for people following ovarian 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; 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.

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 ovarian 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; and
- 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 ovarian cancer, and is published alongside similar summaries of the results of the PROM pilots for uterine and cervical 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 ovarian cancer, and 685 completed questionnaires were returned, a response rate of 55%. There was a statistically significant difference in response rate by age at 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 ovarian 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 685 questionnaires were returned, a response rate of 55% (Table 1). In 204 cases (16%) the patient opted out or was too ill to take part (177, 14%), had died (14, 1%) or was otherwise ineligible (13, 1%). A small number of questionnaires were returned undelivered (4, <1%).

There was strong evidence of a difference in response rate by age at diagnosis ($p = 0.001$). The 50 to 59 age group had the highest response rate (65%).

There was no evidence of a difference in the response rate by deprivation quintile ($p = 0.221$).

There was no evidence of a difference in response rate by the number of years after diagnosis the questionnaire was sent ($p = 0.748$).

Table 1. Response rates for women with ovarian cancer

| | Completed questionnaire | Returned undelivered | Patient deceased | Too ill/opt out | Other ineligible | No response | Total |
|-------|-------------------------|----------------------|------------------|-----------------|------------------|-------------|-------|
| Total | 685 55% | 4 0% | 14 1% | 177 14% | 13 1% | 359 29% | 1,252 |

| Age at diagnosis | | | | | | | | | | | | | |
|------------------|-----|-----|---|----|---|----|----|-----|---|----|-----|-----|-----|
| 16 to 49 | 149 | 50% | 4 | 1% | 1 | 0% | 22 | 7% | 1 | 0% | 119 | 40% | 296 |
| 50 to 59 | 194 | 65% | 0 | 0% | 3 | 1% | 28 | 9% | 4 | 1% | 71 | 24% | 300 |
| 60 to 69 | 181 | 54% | 0 | 0% | 3 | 1% | 62 | 18% | 2 | 1% | 90 | 27% | 338 |
| 70 to 99 | 161 | 51% | 0 | 0% | 7 | 2% | 65 | 20% | 6 | 2% | 79 | 25% | 318 |

$p = 0.001$

| Deprivation quintile | | | | | | | | | | | | | |
|---|-----|-----|---|----|---|----|----|-----|---|----|----|-----|-----|
| (1 – least deprived, 5 – most deprived, based on the income domain of the Indices of Multiple Deprivation 2010) | | | | | | | | | | | | | |
| 1 | 154 | 60% | 1 | 0% | 1 | 0% | 39 | 15% | 1 | 0% | 62 | 24% | 258 |
| 2 | 166 | 54% | 1 | 0% | 3 | 1% | 56 | 18% | 4 | 1% | 78 | 25% | 308 |

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| | | | | | | | | | | | | | |
|---|-----|-----|---|----|---|----|----|-----|---|----|----|-----|-----|
| 3 | 137 | 52% | 0 | 0% | 5 | 2% | 38 | 14% | 2 | 1% | 84 | 32% | 266 |
| 4 | 128 | 58% | 2 | 1% | 0 | 0% | 25 | 11% | 0 | 0% | 67 | 30% | 222 |
| 5 | 96 | 51% | 0 | 0% | 5 | 3% | 19 | 10% | 1 | 1% | 68 | 36% | 189 |

$p = 0.221$

| Years after diagnosis | | | | | | | | | | | | | |
|-----------------------|-----|-----|---|----|---|----|----|-----|---|----|----|-----|-----|
| 1 | 176 | 56% | 0 | 0% | 6 | 2% | 41 | 13% | 6 | 2% | 84 | 27% | 313 |
| 2 | 176 | 56% | 0 | 0% | 3 | 1% | 42 | 13% | 2 | 1% | 90 | 29% | 313 |
| 3 | 165 | 53% | 2 | 1% | 3 | 1% | 47 | 15% | 1 | 0% | 95 | 30% | 313 |
| 5 | 168 | 54% | 2 | 1% | 2 | 1% | 47 | 15% | 4 | 1% | 90 | 29% | 313 |

$p = 0.748$

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

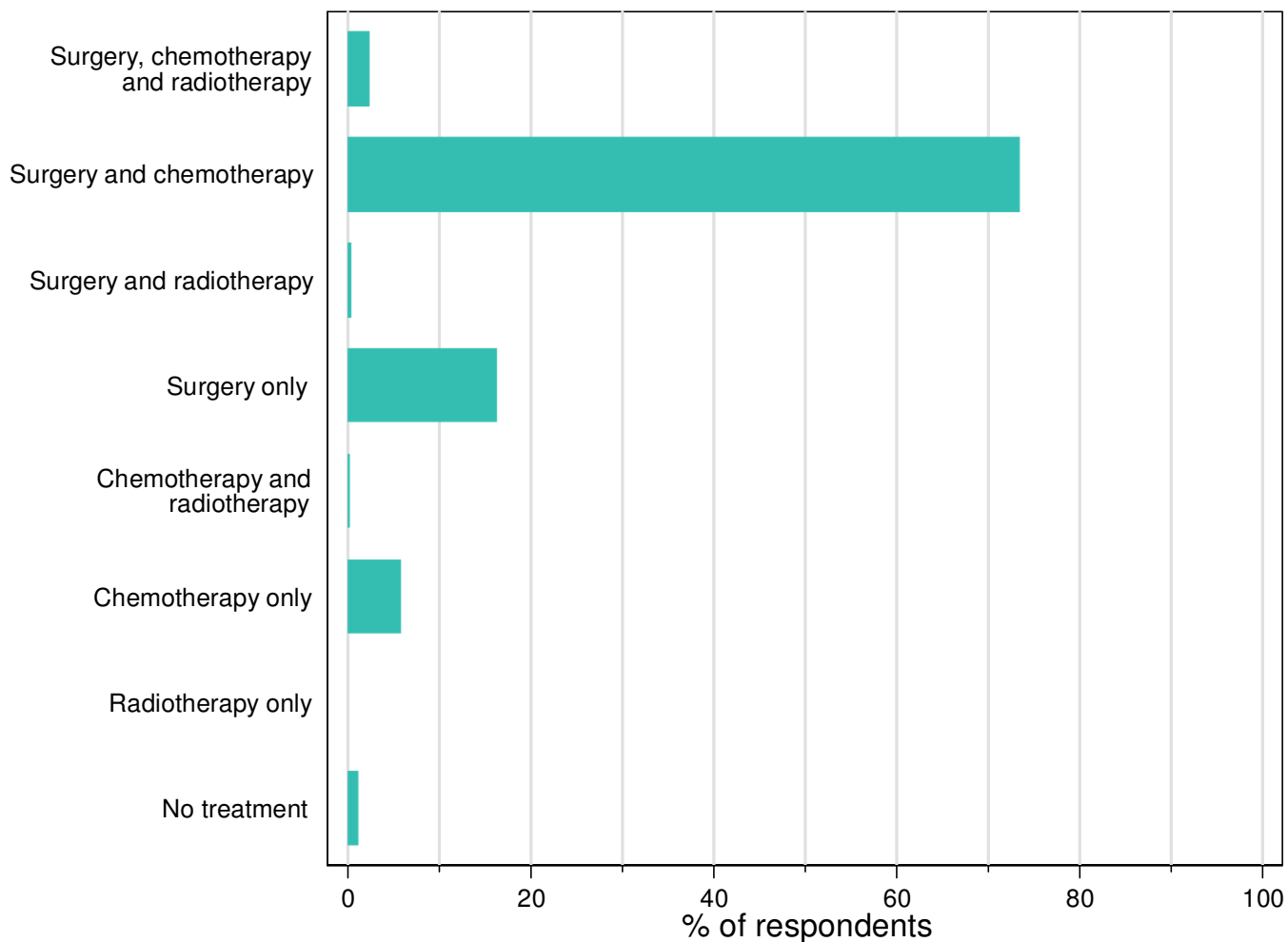
Treatment

Almost all respondents (635 of 685, 93%) were treated with surgery (Table 2; Figure 1), with the majority of respondents (503, 73%) receiving both surgery and chemotherapy but not radiotherapy. Eight respondents (1%) did not report receiving any treatment.

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

| | N | % |
|----------------|----------|----------|
| Surgery | 635 | 93% |
| Chemotherapy | 562 | 82% |
| Radiotherapy | 22 | 3% |
| Total | 685 | |
| Did not answer | 0 | |

Figure 1. Treatment received by respondents to the survey



Most respondents (434 of 668, 65%) 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 ovarian cancer? (Q2)

| | N | % |
|--|-----|-----|
| I am still having my initial treatment | 24 | 4% |
| It is less than 3 months since my initial treatment | 12 | 2% |
| It is between 3 and 12 months since my initial treatment | 99 | 15% |
| It is between 1 and 5 years since my initial treatment | 434 | 65% |
| It is more than 5 years since my initial treatment | 96 | 14% |
| Don't know / can't remember | 3 | 0% |
| Total | 668 | |
| Did not answer | 17 | |

Two thirds of respondents (433 of 645, 67%) were in remission, but 74 respondents (11%) said their cancer had been treated but was still present, while 89 respondents (14%) had had their cancer come back after treatment (Table 4).

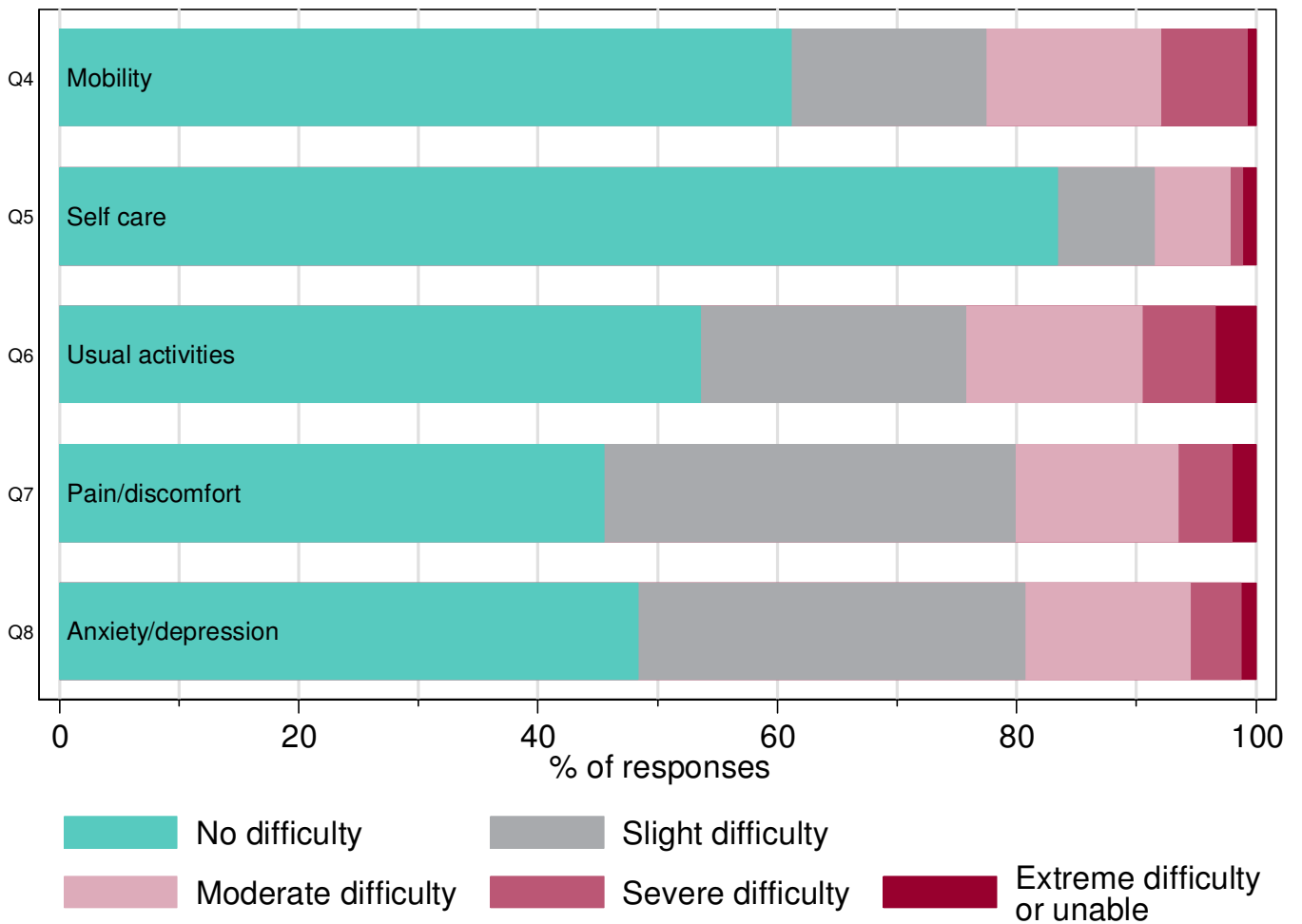
Table 4. How has your ovarian cancer responded to treatment? (Q3)

| | N | % |
|---|-----|-----|
| My cancer has responded fully to treatment | 433 | 67% |
| My cancer has been treated but is still present | 74 | 11% |
| My cancer has not been treated at all | 1 | 0% |
| My cancer has come back after it was treated | 89 | 14% |
| I am not certain what is happening with my cancer | 48 | 7% |
| Total | 645 | |
| Did not answer | 40 | |

Health and wellbeing today

Around half of women reported that they had had no difficulty on each question about mobility, usual activities, pain/discomfort and anxiety/depression (Figure 2). Four fifths of respondents (565 of 677, 83%) had no difficulty with self care, but problems carrying out usual activities, with pain/discomfort and with anxiety/depression were more common with around a quarter of women having slight difficulty with each of these and around a quarter having moderate, severe or extreme difficulty.

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 272 of 677 responses (40%) reporting that this was happening a little bit, and 184 (27%) saying this was happening quite a bit or very much (Figure 3). Lower back and/or pelvis pain was also reported by many women (345 of 658 responses, 52%).

The second most common problem was being worried, with 411 of 675 responses (61%) saying they had worried at least a little bit in the week before filling in the questionnaire. Perhaps similarly, almost half of respondents (325 of 668, 49%) reported feeling tense.

The majority of respondents (382 of 663, 58%) reported having passed urine frequently at least a little bit in the week before filling in the questionnaire, with 200 women (30%) reporting urinating somewhat or very frequently. Around half the respondents (324 of 639, 51%) reporting having to hurry at least a little bit to get to the toilet when they felt the urge to pass urine, with 135 women (21%) reporting they had to hurry quite a bit or a lot. Two fifths of the respondents (270 of 657, 41%) reported at least a little bit of leakage of urine, with 63 (9%) reporting that this had occurred quite a bit or a lot.

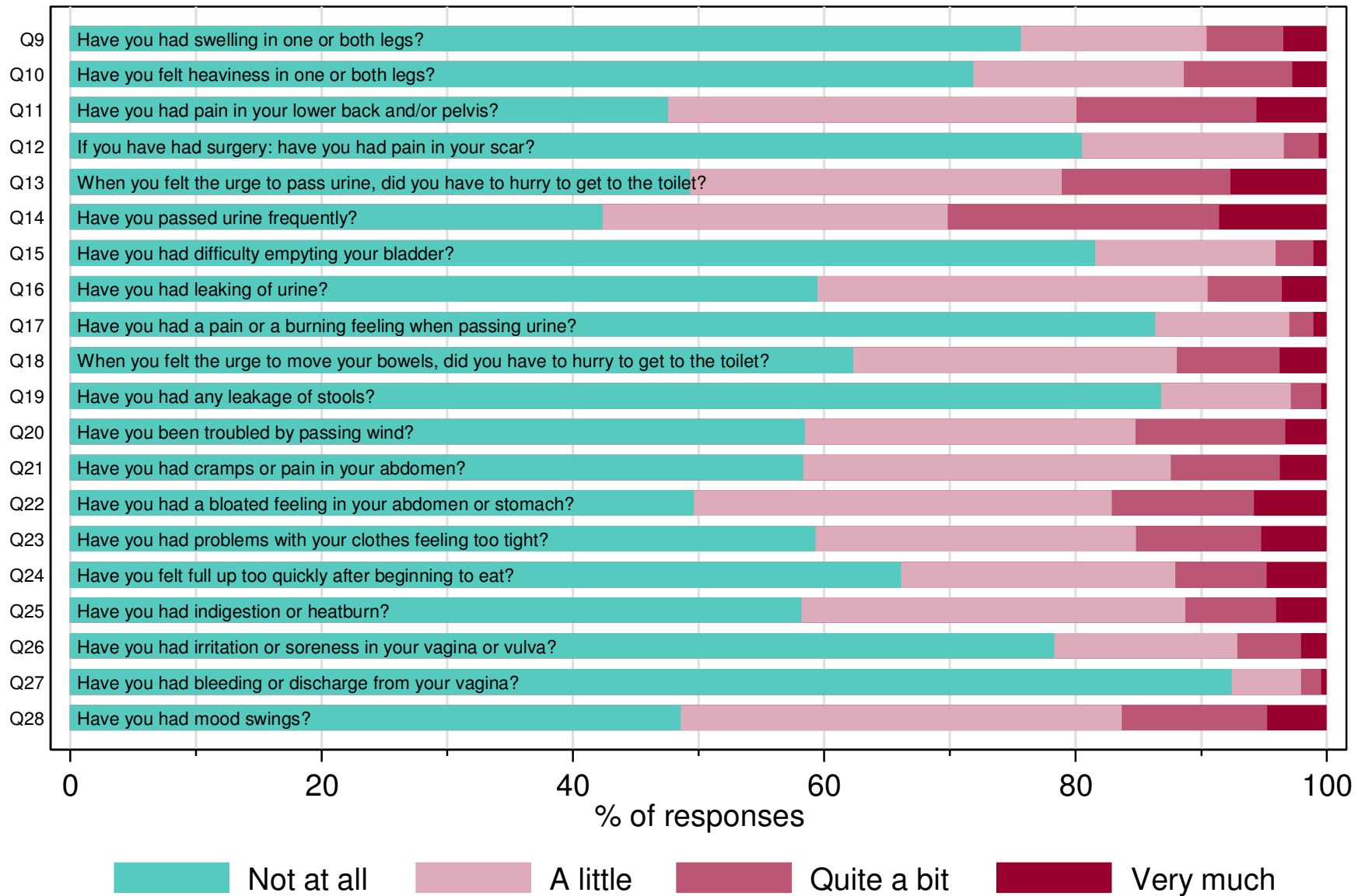
Almost half of women (332 of 673, 49%) had felt at least a little less attractive as a result of their treatment, and two fifths of women (256 of 677, 38%) had felt at least a little less feminine as a result of their treatment.

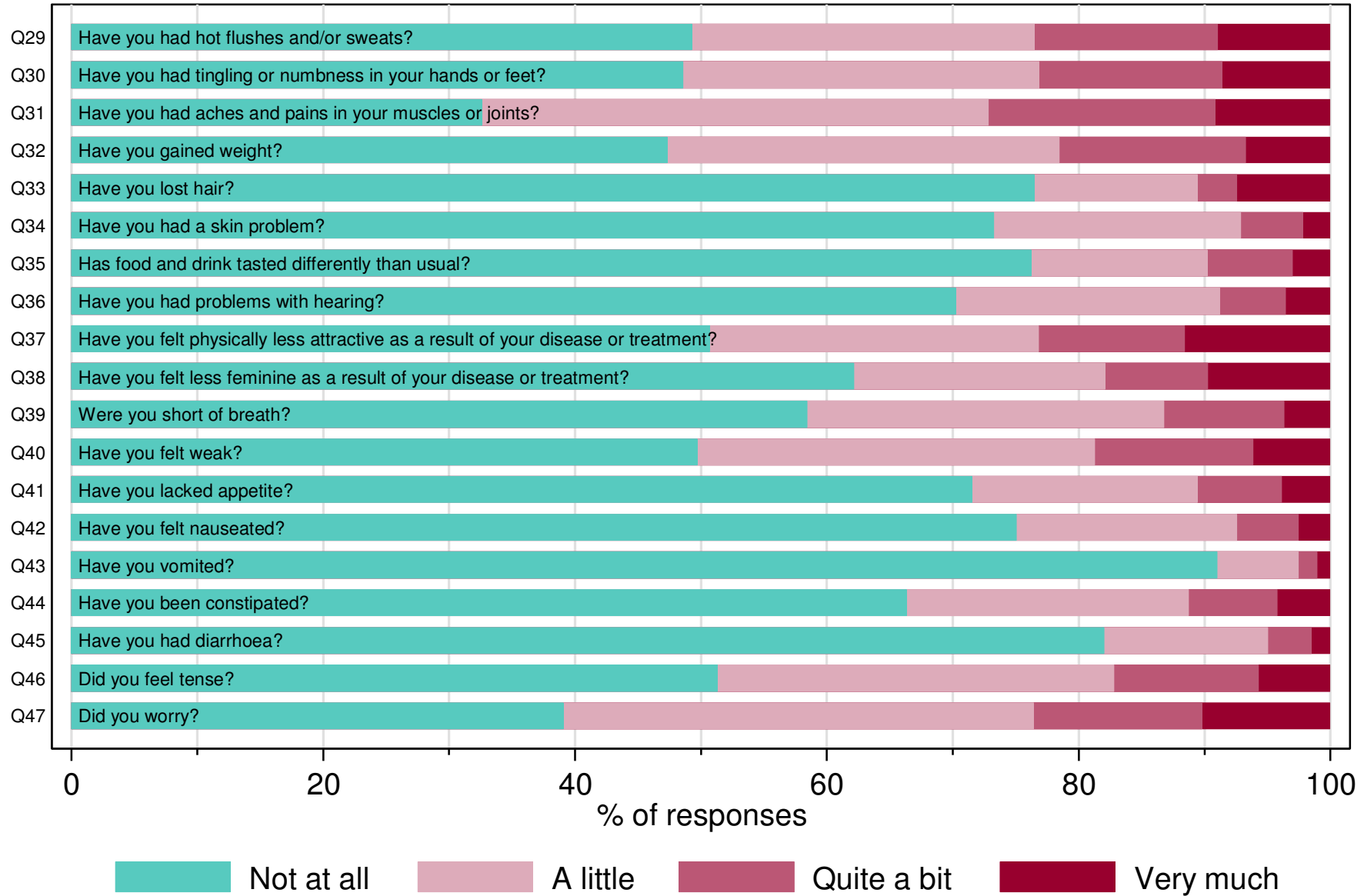
Around half of respondents had also had problems with:

- a bloated feeling in their abdomen or stomach (338 of 671, 50%)
- mood swings (346 of 675, 51%)
- hot flushes and/or sweats (341 of 672, 51%)
- tingling or numbness in their hands or feet (347 of 675, 51%)
- weight gain (354 of 672, 53%)
- feeling weak (338 of 672, 50%)

The responses to questions 9 through 47 showed that problems affecting health and wellbeing were common in women who had been diagnosed with ovarian cancer. The only problems which affected fewer than 10% of respondents were vomiting (60 of 669, 9%) and bleeding or discharge from their vagina (51 of 675, 8%).

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



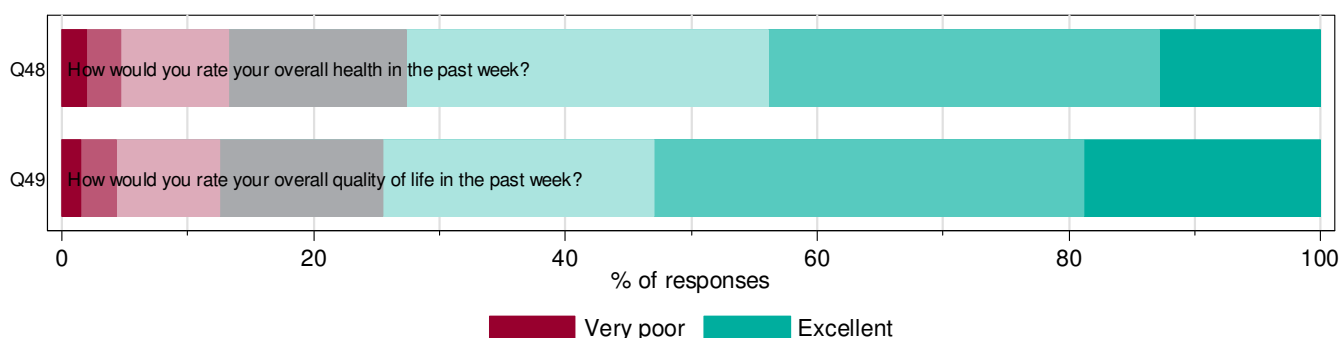


On a seven point scale, where one was very poor and seven was excellent, 492 of 677 respondents (73%) rated their overall health rated as 5 or above, and 507 of 681 respondents (74%) rated their quality of life as 5 or above (Table 5; Figure 4).

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 | 13 | 2% | 11 | 2% |
| 2 | 19 | 3% | 19 | 3% |
| 3 | 58 | 9% | 56 | 8% |
| 4 | 95 | 14% | 88 | 13% |
| 5 | 195 | 29% | 146 | 21% |
| 6 | 211 | 31% | 233 | 34% |
| 7 - excellent | 86 | 13% | 128 | 19% |
| Total | 677 | | 681 | |
| Did not answer | 8 | | 4 | |

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



The majority of respondents (407 of 668, 61%) 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 more than a third of respondents (238, 36%) 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 | 238 | 36% |
| 1 day | 68 | 10% |
| 2 days | 101 | 15% |
| 3 days | 90 | 13% |
| 4 days | 62 | 9% |
| 5 days | 45 | 7% |
| 6 or 7 days | 64 | 10% |
| Total | 668 | |
| Did not answer | 17 | |

Health and wellbeing in the past month

In the month before filling in the questionnaire, 196 of 620 respondents (32%) reported at least a little interest in sex, and a similar number, 172 of 613 respondents (28%), 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 (149 of 252 respondents, 59%)
- their vagina feeling short or tight during sex (100 of 246 respondents, 41%)
- feeling pain during sex (96 of 240 respondents, 40%)

The majority of respondents (162 of 234, 69%) 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:

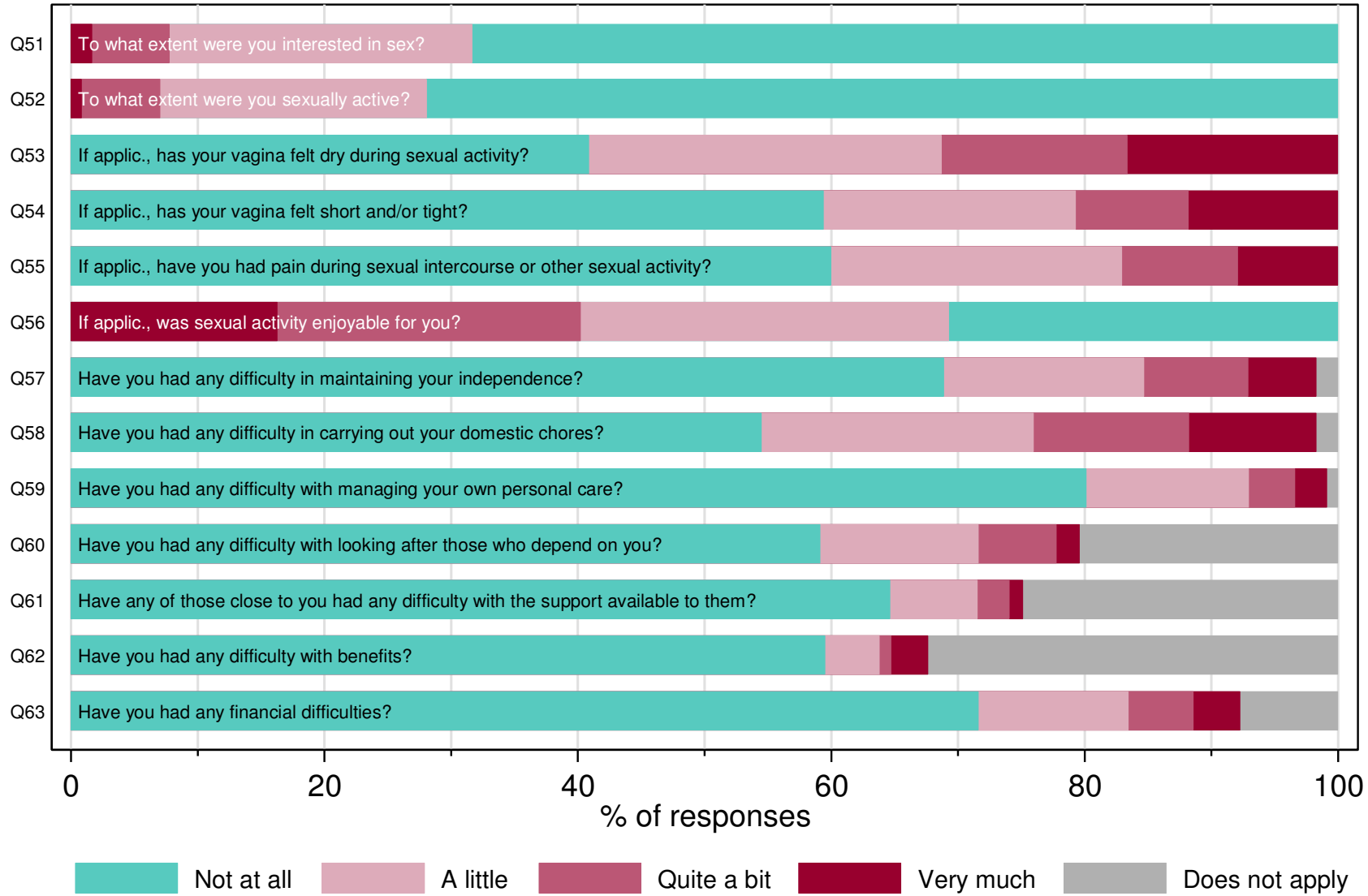
- difficulty with body image (315 of 663 respondents, 48%)
- difficulty with domestic chores (297 of 679 respondents, 44%)
- feeling isolated (253 of 668 respondents, 38%)
- difficulty with recreational activities (228 of 665 respondents, 34%)
- difficulty with travel plans (209 of 660 respondents, 32%)

Two thirds of respondents (440 of 646, 68%) said that they either strongly agreed or agreed with the statement “I have fears about my cancer coming back” (Figure 6), and more than half (367 of 640, 57%) agreed or strongly agreed with the statement “I have fears about my cancer spreading”.

Half (342 of 662, 52%) agreed or strongly agreed with the statement “I have trouble sleeping” and a similar proportion (332 of 662, 50%) 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.

Almost half of respondents (307 of 648, 47%) agreed or strongly agreed with the statement “I have fears about death and dying”.

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.



Living with and beyond ovarian cancer

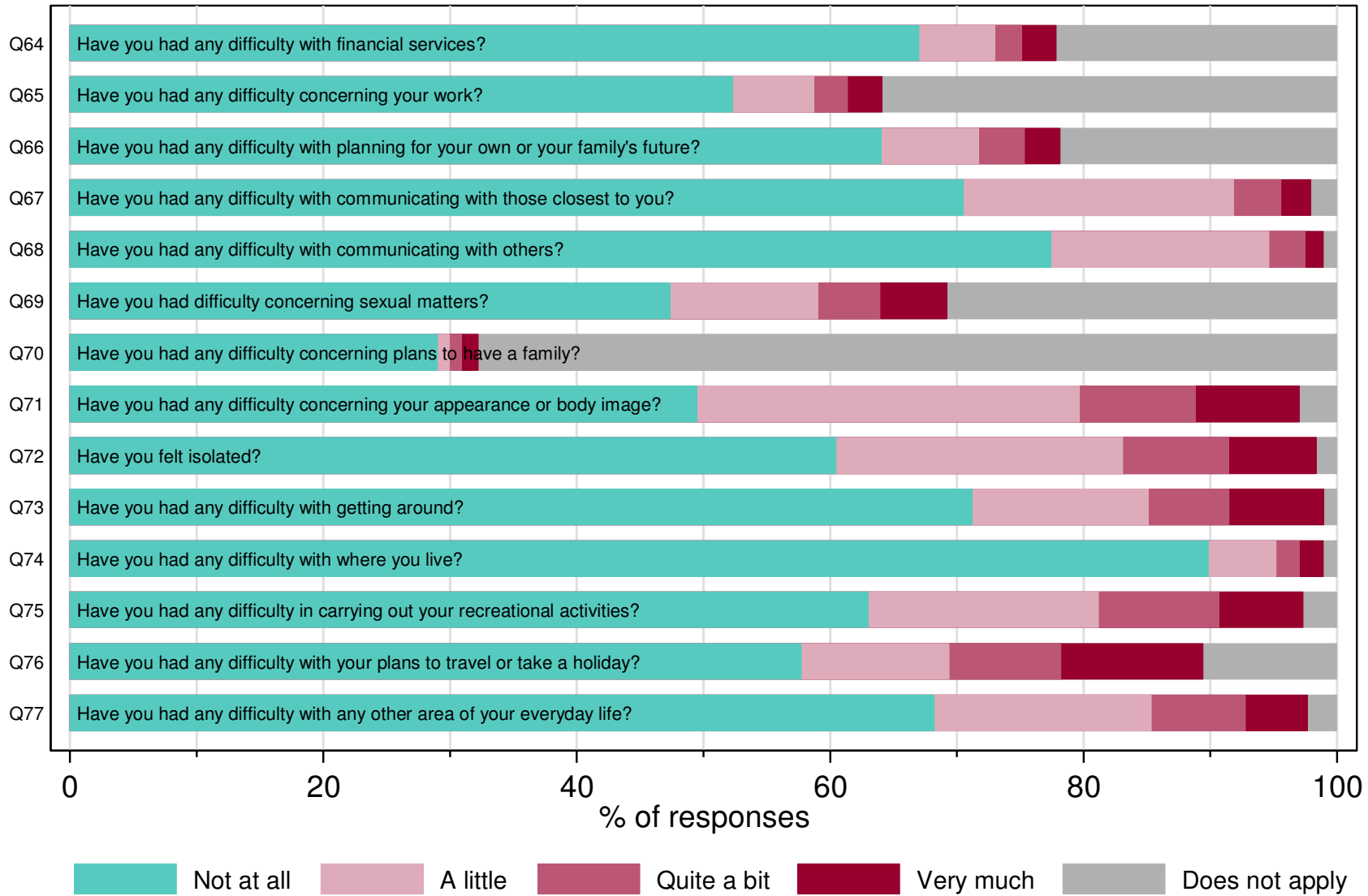
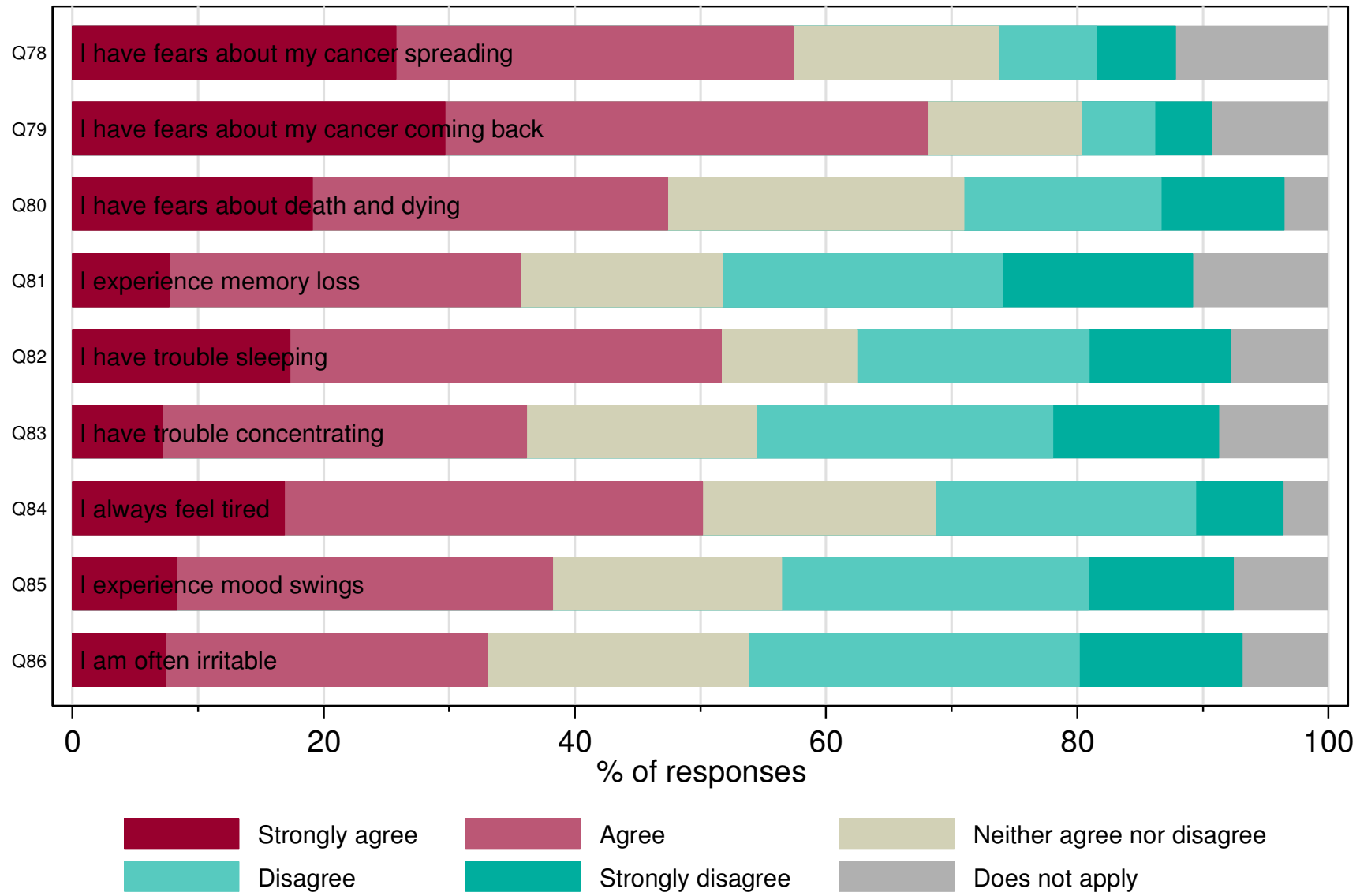


Figure 6. Respondents' health and wellbeing in the month before filling in the survey (agreement scale questions)



Overall support and care

Half of respondents (303 of 657, 46%) reported that they do not have a care plan (Table 7), while two fifths (255, 39%) reported that they do not need a care plan; only 56 (9%) thought they had or definitely had an up to date written care plan. One third of respondents (216 of 664, 33%) did not have a named nurse they could contact with worries about their cancer care, and a further 39 (6%) did not know if they had one.

Nearly one in five respondents (127 of 668, 19%) 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 | 26 | 4% | 409 | 62% | 327 | 49% |
| Yes, I think so | 30 | 5% | | | 214 | 32% |
| No | 303 | 46% | 216 | 33% | 127 | 19% |
| I don't need a care plan | 255 | 39% | | | | |
| Don't know | 43 | 7% | 39 | 6% | | |
| Total | 657 | | 664 | | 668 | |
| Did not answer | 28 | | 21 | | 17 | |

Three quarters of respondents (502 of 667, 75%) reported that hospital staff did everything they could to support them following their cancer treatment (Table 8). A small minority (14 respondents, 2%) reported that they never received support, while 122 women (18%) reported that hospital staff provided all the support they could only some of the time.

A substantial minority of respondents (110 of 658, 17%) 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 38 respondents (6%) reporting their GP practice never provided support, however, more women (325, 49%) 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 | 502 | 75% | 325 | 49% |
| Only some of the time | 122 | 18% | 126 | 19% |
| Never | 14 | 2% | 38 | 6% |
| My general practice is not involved | | | 110 | 17% |
| I do not need any support | 29 | 4% | 59 | 9% |
| Total | 667 | | 658 | |
| Did not answer | 18 | | 27 | |

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

| | N | % |
|--|------------|----------|
| Yes, definitely | 163 | 25% |
| Yes, to some extent | 112 | 17% |
| No | 96 | 15% |
| Don't know/can't remember | 284 | 43% |
| I did not need help from health or social services | 7 | 1% |
| Total | 662 | |
| Did not answer | 23 | |

Two thirds of respondents (460 of 675, 68%) considered themselves to be non-smokers (Table 10), although 17 of these women had smoked in the past, but more than five years previously. This, along with the one woman who considered herself to be a smoker but had very recently stopped smoking, explains how more women responded in Table 11 than considered themselves to be ex-smokers. Few women considered themselves to be smokers currently (49 of 675, 7%).

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

| | N | % |
|----------------|----------|----------|
| Smoker | 49 | 7% |
| Ex-smoker | 166 | 25% |
| Non-smoker | 460 | 68% |
| Total | 675 | |
| Did not answer | 10 | |

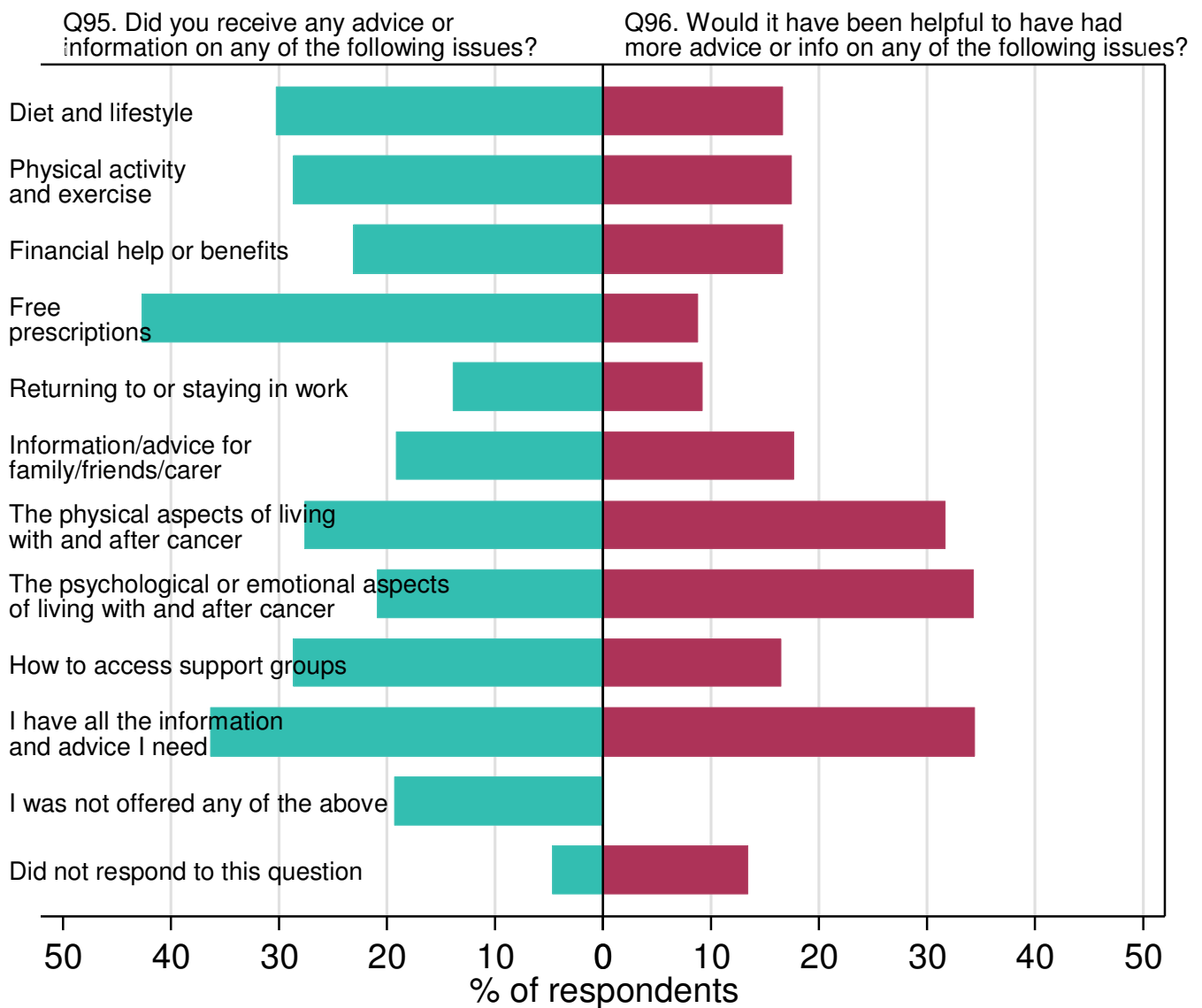
Table 11. If an ex-smoker, how long ago did you stop? (Q94)

| | N | % |
|---|----------|----------|
| Less than 1 year | 14 | 8% |
| Less than 2 years (and more than 1 year) | 11 | 6% |
| Less than 3 years (and more than 2 years) | 14 | 8% |
| Less than 4 years (and more than 3 years) | 5 | 3% |
| Less than 5 years (and more than 4 years) | 6 | 3% |
| More than 5 years | 128 | 72% |
| Total | 178 | |
| Did not answer | 507 | |

Of the 685 women with ovarian cancer, only 236 to 249 (34% to 36%) reported that they had received all the advice and information they needed. Around a fifth of women (132, 19%) said they had not received any information or advice on any of the topics mentioned (Figure 7). Around a third of women would have found more advice or information on the physical (217, 32%) and psychological or emotional (235, 34%) 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 ovarian cancer would have been helpful, and that support groups for younger women did not seem to exist. Several women said isolation was their biggest problem.

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 1924 and the most recent was 1996, with a mean year of birth of 1951. The recorded date of birth was the same as in registry data in all except 9 cases.

A quarter of respondents (163 of 647, 25%) said they were a carer to a family member, friend or neighbour (Q98).

Most respondents said they were heterosexual/straight (602 of 638, 94%), with 30 (5%) preferring not to say, 4 (1%) being lesbian or gay and 2 (<1%) being other (Q99).

Around three quarters of respondents (510 of 672, 76%) lived with a partner, spouse, friend or their family, while 153 (23%) lived alone. Only 1 woman lived in a nursing home, hospital or other long term care home. Eight respondents said that they had other living arrangements (Q100).

Half of respondents (324 of 640, 51%) 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 arthritis (169, 25%) and high blood pressure (161, 21%).

Figure 8. Long term conditions among respondents

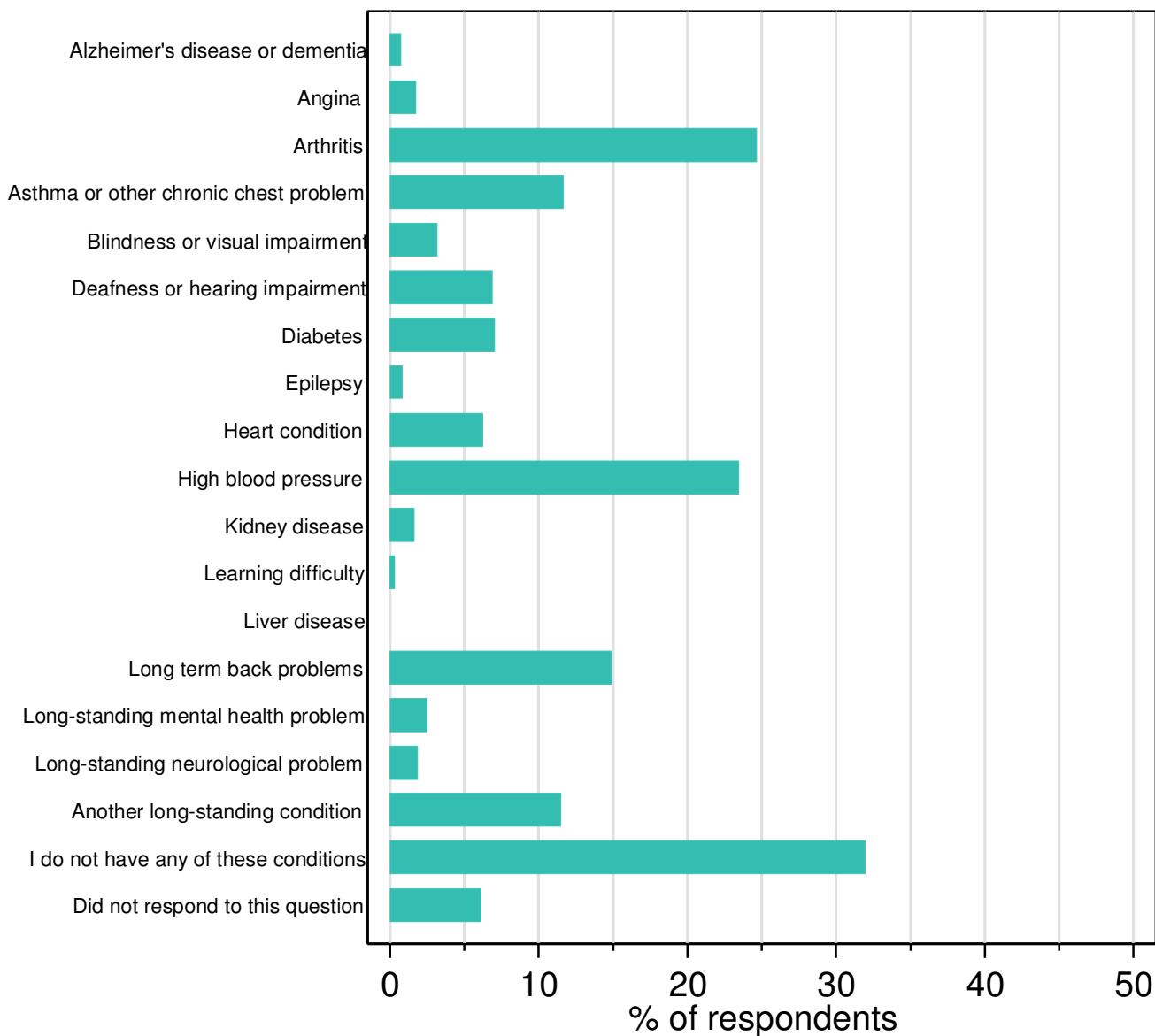


Figure 9 shows employment status for respondents currently and before their diagnosis with cancer. The observed differences might be explained by women retiring either naturally or due to health reasons. The majority of currently employed women who answered the question said that they were working their usual hours (143 of 243, 59%), with slightly more women working less hours than usual (43, 18%) than were working more hours than usual (15, 6%) (Table 12).

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

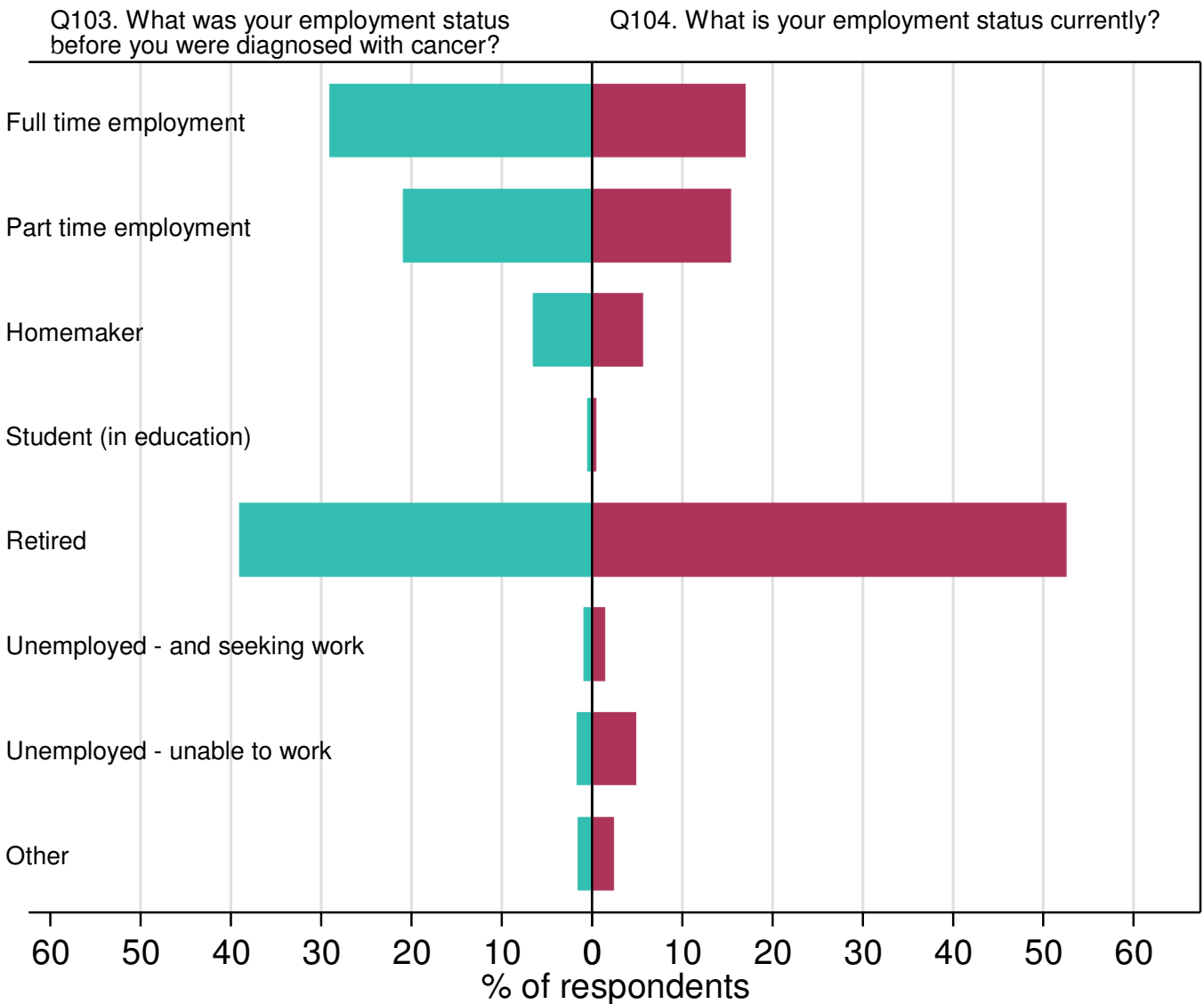


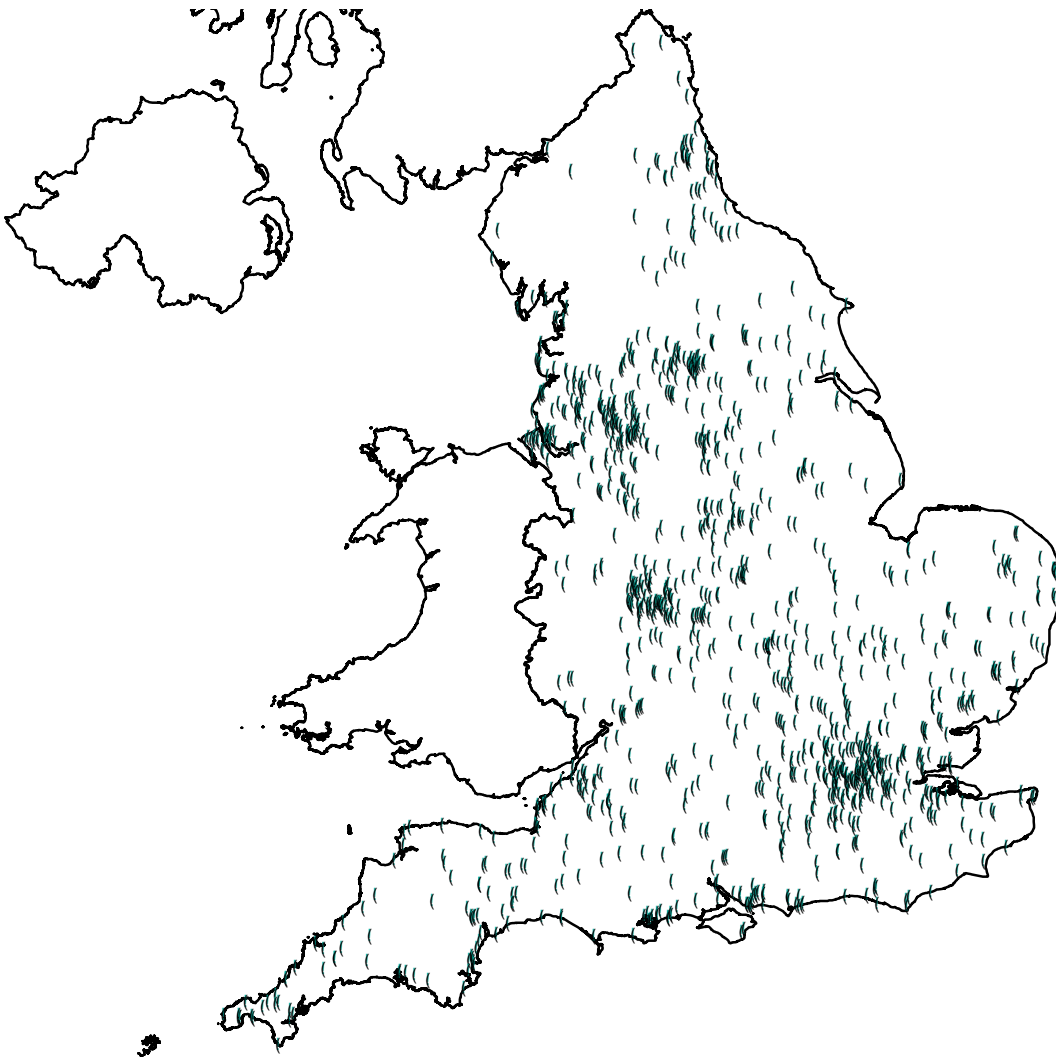
Table 12. Current hours of work, for people currently employed (Q105)

| | N | % |
|------------------------------------|----------|----------|
| Not working at all | 42 | 17% |
| Working less hours than usual | 43 | 18% |
| Working your usual hours | 143 | 59% |
| Working more hours than usual | 15 | 6% |
| Total | 243 | |
| This question does not apply to me | 253 | |
| Did not answer | 189 | |

The majority of respondents classified themselves as white (634 of 661, 96%), with almost all of these (614 of 634, 97%) describing themselves as white British (Q106). One respondent was mixed white and black Caribbean and two were mixed white and Asian. Eleven respondents were Asian or Asian British. Nine respondents were black or black British. Two respondents were Chinese and two had an other ethnic background.

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 ovarian 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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