



WORLD  
**OVARIAN**  
CANCER  
COALITION

THE  
**EVERY**  
**WOMAN**  
STUDY™

# **EVERY WOMAN STUDY** **WOMEN'S SURVEY 2018** **FULL RESULTS REPORT**

This report has been produced and funded by the World Ovarian Cancer Coalition  
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# THE EXPERT ADVISORY PANEL

Our sincere thanks go to the members of our Every Woman Study Expert Advisory Panel for their oversight and input.

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## EXECUTIVE SUMMARY

The mission of the World Ovarian Cancer Coalition is to ensure the best possible chance of survival and the best possible quality of life for every woman with ovarian cancer, no matter where she lives.

The Every Woman Study aims to bring together an authoritative evidence base that speaks to the views of women with ovarian cancer across the globe, and medical staff caring for them. It involves a literature review, and both qualitative and quantitative work with women, clinicians and patient organisations. The findings from the study will form the basis of the Global Ovarian Cancer Charter to be launched in 2019.

This report summarises the findings of the quantitative work carried out amongst women who were diagnosed with ovarian cancer since the beginning of 2013. It provides up to date information that can be presented to governments and healthcare providers about the national situation in the global context, and offers opportunities to drive forward progress.

A total of 1531 women from 44 countries took part in the online survey between 5<sup>th</sup> March and 8<sup>th</sup> May 2018. It was available in 15 languages including English, chosen to reflect significant population groups of women with ovarian cancer, and where partner organisations were keen to support the process. You can read further information about the methodology employed in the Appendix, and notes about using statistics from this report immediately just before the summary findings. It should be noted that the respondents to the survey could be considered to be 'the best possible', in other words the findings have not captured many women from lower income countries, those who are not well enough to get to treatment, or those who lack the computer and/or literacy skills to participate and seek information. The population for this study:

- Is richer than the population in general.
- Is less diverse than the global population.
- Live mainly in higher income countries.
- Is in reasonable health, with half of the group within 2 years of diagnosis with low levels of recurrence.
- Is a younger than expected cohort (even accounting for different disease profiles).

The findings present a devastating litany of the challenges women face in getting a correct diagnosis and effective treatment and support. They include widespread ignorance of the disease and its symptoms, delays in diagnosis, variations in treatments, lack of clinical trials, lack of genetic testing for women with a family history, to the unmet support and information needs at every turn. These challenges present themselves in varying proportion in different countries.

There are no simple answers, nor did we expect to find any. What the study does show however is that within each of these challenges there are real and tangible opportunities to make progress. Different countries do certain things to a greater or lesser extent. Understanding the variations can provide a focus for governments, health care providers, charities/support organisations and women themselves to make an extraordinary difference.

It isn't all about new resource, though clearly that plays an important role. We should all have hope for the future not least because this report shows that:

- No matter where you live, there are ways to work towards improving quality of life and survival for women with ovarian cancer.
- There is more and less diversity than previously understood. The study provides an excellent snapshot, with fertile ground for future work and research.
- There are some incorrect generalisations about ovarian cancer, particularly in terms of symptoms, stage and types of ovarian cancer. These can now be refuted and the evidence used to help improve delays in diagnosis.
- For the first time we have a quality of life indicator for women with ovarian cancer.

### Interpreting the results

Given the total number of survey individual responses, the confidence level and intervals were calculated. The population size was taken as the world wide 5-year prevalence of ovarian cancer<sup>i</sup> which is 586,624. The number of survey entries (1,531) gives results with 95% confidence level, and a margin of error of +/- 2.5%. Not every woman answered every question, and in these instances the margin of error increased. Where just 500 women answer a question, the margin of error is +/- 4.4%.

Where comparisons are made between groups of respondents, the threshold for significance is set at  $p < .01$ . All percentages quoted in comparisons are valid at this level unless marked with an asterisk\* in which case  $p < .05$ . Comparisons are made against the average for all respondents unless otherwise stated. As response numbers per country fall, the chances of identifying significant variations diminishes, unless the variation appears very wide. There were sufficient responses from Australia, Canada, Germany, Japan, UK and USA to feature widely in the analysis, with Spain, Italy, Brazil and Hungary appearing less often. Only the significant variations are shown for each country.

## SUMMARY FINDINGS BY SECTION ABOUT THE WOMEN

A total of 1531 women took part in this online survey, from 44 different countries around the world. Responses were dominated by women in more developed nations, and those who described their ethnicity as Caucasian (57%). Whilst half of the respondents described their household income as average for their country, a higher proportion (31%) described their income as 'higher than average' than 'lower than average' (11%). Three-quarters of the women were in some form of employment.

The average age of diagnosis was 50, but there were significant variations by country. Even when the variations in type of ovarian cancer were considered, there remained different age profiles. When compared to known age profiles for particular countries, it can be seen that this sample is in general younger than might be expected, mediated perhaps by the online nature of the study, promoted by email and social media.

Just over half of the women (50.9%) were diagnosed since the start of 2016. When the group was asked about rates of recurrent ovarian cancer, almost two-thirds (63.6%) of women said their ovarian cancer had not returned.

In terms of who paid for treatment and care, there is wide variation by country. Nearly a quarter of all respondents had to contribute directly themselves to the cost of their treatment and care.

The caveats then for interpreting the results are as follows:

- They represent a more affluent, younger population than would be expected.
- The lower proportion of recurrence when compared to overall long-term survival rates, means it is a fair assumption to say the respondents are broadly speaking in better health. These results would be very unlikely to include any women at risk of very early death. In the UK, it has been shown that 15% of women die within two-months of diagnosis, and nearly a third within the first year (30%, any stage on diagnosis). Age, emergency presentation and sub-type are drivers of this<sup>ii</sup>. In the USA 43% of women diagnosed with stage III or IV disease die within the first year<sup>iii</sup>.
- As such, the results of the survey reflect a potentially more positive situation than that which exists in reality.

### Key findings<sup>1</sup>

- Epithelial serous ovarian cancer was the most common type of ovarian cancer in almost all countries including Japan, accounting for a third (34%) of cases. The proportion of other types of ovarian cancer varied between countries, and independent of type of ovarian cancer, so did the age on diagnosis.
- Stage on diagnosis varied widely between types of ovarian cancer, but can also vary within a type, by country.
- On average more than one in ten women did not know what type of ovarian cancer they had, but this varied by country (between 2.2% and 29.3%). Of the women who were told, nearly a third had to ask for the information.
- The diagnosis of ovarian cancer has a major impact on a woman's ability to work.

### Recommendations<sup>2</sup>

- It is appropriate to examine what can be done to improve diagnosis at an early stage in any country, for any of the types of ovarian cancer.
- Consideration should be given as to understanding the experience of those who survive for only a short time.
- That a focus for future work is to gather data from ethnic groups and/or less developed countries.
- Consistent use of internationally agreed classifications of types and subtypes of ovarian cancer would make comparability of future data analysis more robust.

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<sup>1</sup> Highlighted findings are results carried forward into the summary report.

<sup>2</sup> Recommendations in bold are carried forward in the summary report.

- Collation and publication of more detailed information about age, stage, short-term mortality, ethnicity and types of ovarian cancer should be a goal for each country to inform strategy.
- Knowing their type of ovarian cancer would help women access the most appropriate information, and treatment.

## FAMILY HISTORY AND GENETIC TESTING

The data showed wide variation by country. This may be for a variety of reasons. Research studies to date show that common founder mutations differ between countries, and remain to be identified in others. Genetic testing, and number of women identified with genetic mutations, and indeed the proportion of relatives affected by breast or ovarian cancer all differ by country.

### Key findings

- 80% of women who had two or more members of their close family affected by ovarian cancer had not been tested for mutations in genes connected to familial breast and ovarian cancer prior to their own diagnosis. This proportion varied by country, with Germany having the highest rate of testing (34% of women with one or more cases).
- Paternal family history was equally important at the second-degree relative level (i.e. women had similar proportion of maternal and paternal grandmothers affected).
- Levels of genetic testing post diagnosis varied widely by country, which means some women are at risk of not getting the appropriate treatment, and that members of their own family may remain unaware that they too are at increased risk of developing the disease.
- The proportion of respondents who were found to have genetic mutations varied widely by country from a very low proportion in Japan (3.2%) to 58.7% in Italy. On average one in five women had a genetic mutation linked to breast and ovarian cancer (20.2%).
- The balance of genetic mutations differs by country.

### Recommendations

- Genetic testing and associated counselling should be more widely available for women with a family history of breast and or ovarian cancer.
- Where appropriate (by type), women with ovarian cancer should be offered testing post-diagnosis regardless of family history to ensure appropriate treatment and offer the potential for primary prevention.
- It is imperative to raise awareness amongst women and doctors of the importance of including family history from the father's side of a family.
- Further research is needed into the prevalence of different genetic mutations by country and work to identify the main founder mutations.

## KNOWLEDGE OF SYMPTOMS

### Key findings

- Over two-thirds of the women had not heard of ovarian cancer or did not know anything about it prior to their own diagnosis. Almost one in five had never heard of it, and a half had heard of it, but knew nothing about it.
- Just 13.9% of respondents had known increased abdominal size was a potential symptom of ovarian cancer. This was the symptom most commonly recognised.

### Recommendations

- There is an urgent need to improve women's awareness of ovarian cancer, and the symptoms most commonly associated with the disease.

## SYMPTOMS EXPERIENCED AND THE LEAD UP TO DIAGNOSIS

### Key findings

- More than 90% of women reported experiencing multiple symptoms prior to diagnosis. This was true for all types of ovarian cancer where there were more than 40 responses. Women with stage I disease were more likely not to have had symptoms but this remained a very small proportion (12.6% vs 8.7% for all stages).
- There was no significant difference in the number of symptoms reported by type of ovarian cancer, all reported between 4 and 5 symptoms. Women with stage IV ovarian cancer were more likely to report having had 5 symptoms as opposed to 4 symptoms for all other stages, including stage I.
- A quarter of women waited more than 3 months before visiting their doctor, and over 10% waited more than 6 months.
- There were only marginal differences between the types of symptoms reported between different ovarian cancer types. Only fallopian tube cancer showed a number of variations, with less women reporting pain in the abdomen or pelvis, persistent bloating, urinary urgency and changes in bowel habit. 3.3% of respondents reported having this form of the disease.
- Women who knew lots about ovarian cancer were more likely to visit a doctor within three months of experiencing symptoms (85.4%\* vs 74.8%).
- A significant proportion of women (23.6%) also reported symptoms other than those most closely associated with ovarian cancer. In fact, symptoms that fell into this category were often the ones that caused most concern for women. They were grouped under one category of 'other'.
- Over a quarter of women were very concerned about symptoms (26.4%) and one in three women (34%) were fairly concerned. There was no variation in levels of concern between women diagnosed with different stages or types of ovarian cancer, or between women of different ages.
- Despite experiencing symptoms, one in five women did not consult a health professional about their symptoms and something else led to their diagnosis. Women who have to pay some or all of their medical costs themselves were less likely to



consult a health professional than the cohort as a whole, and much more likely if they said the state paid some or all of their medical costs.

## Recommendations

- When women present with symptoms, doctors should clearly be looking for the symptoms most likely to indicate of ovarian cancer. However, the presence of other symptoms should not mean they dismiss the possibility.
- Awareness campaigns need to stress the importance of visiting a doctor about symptoms.

## ROUTE TO DIAGNOSIS

### Key findings

- 40% of women felt their doctors did not take their concerns seriously.
- Less than half of women were diagnosed within a month of visiting a doctor (average for all 43.2%) but this varied between countries from 30% in the UK to 56.3% in Japan and 62.3% in Italy. Women who knew lots about ovarian cancer were more likely to be diagnosed within a month of visiting the doctor (58.3%\* vs 43.2%)
- For one in ten women, their diagnosis took more than a year from first visiting a doctor about symptoms. This was just 2.8% in Japan.
- The two most common first diagnostic tests are CA125 (25.4%) and Transvaginal ultrasound (21.2%). There were a number of significant variations by country. In Japan the most common first tests were CT (21.8%) and MRI (21.6%).
- A third of women had to visit the doctor they first consulted more than twice before being referred on (if indeed they were referred on).
- At this point fewer than one in five women were aware that the doctor suspected cancer. Most doctors were considering other diagnoses.

### Recommendations

- There is considerable room for improvement in terms of speeding up the time to diagnosis, and the extent to which doctors recognise the potential symptoms of ovarian cancer.
- There is scope to further understand how different countries are organising their initial assessment of women who may have ovarian cancer.

## DIAGNOSIS

### Key findings

- Most women are shocked to be told they have ovarian cancer (59%). Given that many know nothing about the disease this is perhaps not surprising.
- Over 50% of women reported spending less than 15 minutes with the doctor giving them this life altering information.

- More than half of all women did not feel they were given all the information they needed at the time of diagnosis, and 8% were not given any information (written or verbal). This varied by country.
- Only 37.3% of women were given written information, and only around one in ten women received information about living with ovarian cancer and sources of support.
- Women were much more likely to report getting the information they needed if either of the following was true: the doctor telling them their diagnosis spent more than 15 minutes with them, and/or they were given written information.

## Recommendations

- Even if the time that doctors can spend with women is very limited, there is much they can do to improve women's experience around the time of diagnosis. Good quality written information about the disease, living with it, and information on sources of support are vital to help women at this most vulnerable time
- There is potential to consider how nurses (who are less involved at this time) could perhaps assist in information provision, whether they are specialists or not, and how the role of patient support charities could assist.

## SURGERY

### Key findings

- Most (over 90%) women underwent surgery for ovarian cancer, again suggestive that this is a cohort of women who were well enough to undergo surgery. The one strong outlying country is Hungary where less than six in ten women had surgery. There were no variations by stage, or age of diagnosis across all countries.
- Although the overall rates are low, there are wide variations however in the rates of surgery for recurrent cancer, second surgery because the first surgery did not remove enough of the cancer, and in terms of the proportion of women receiving chemotherapy before their surgery.
- Just under half of all women have their surgery within half an hour of home, but for 10% they have to travel more than 2 hours to have their surgery. This may well be influenced by the proportion of women undergoing treatment by a specialist gynecological cancer doctor.

## CHEMOTHERAPY

### Key findings

- There is a wide variation in the use of intra-peritoneal chemotherapy by country, ranging from 0.7% in the UK to 23.2% in Spain and 22.5% in the USA, with 9.8% on average for all countries.
- Just one respondent did not experience side effects from chemotherapy treatments. For just under 3 in 10 women, health professionals were able to successfully reduce the side effects to a great extent, and for 6 in 10 women, they were reduced to some

extent. The most commonly cited 'difficult' side effects are largely ones that could be improved with management (tiredness, fatigue, being or feeling sick, constipation).

- For both surgery and chemotherapy, whilst most women said the experience was 'something of what they expected' there is considerable room to improve their expectations (less than half say it was as expected).

### Recommendations

- There is scope for further understanding variations in treatment modalities in different settings, and in particular what proportion of women are operated on by a specialist surgeon trained in gynecological oncology.

## TREATMENT IN GENERAL

### Key findings

- Women are generally very positive about the care they get, saying they are treated with dignity and respect. But there are some variations, and the countries generally map into how women report being always involved in decision making about their treatment, which varies from 22.8% in Japan to 59.6% in Australia.
- Women's choices of treatment (if they have any) is very driven by hope of a cure, prolonging life and quality of life.
- Almost all women are left with long-term side effects (nine out of ten women), some of which could potentially be managed or reduced (tiredness, fatigue, lack of interest in sex, anxiety).
- There is a wide range in the proportion, by country, of women wanting or being able to get a second opinion.

### Recommendations

- Efforts are made to acknowledge and address long-term side effects, either through medical management and/or information and support for the non-physical symptoms.
- Where possible there is a real need to develop effective treatments that allow women to get on with living their lives after treatment without a continual reminder and legacy of the treatment they have endured.

## CLINICAL TRIALS

### Key findings

- Almost two-thirds of women (64.3%) report never having had a discussion about clinical trials, this varied from 47% in Germany to 80% in Japan. On average just one in four women were asked by their **doctor** about clinical trials. This is in stark contrast to women's willingness to consider trials (92%). Issues such as travelling to another hospital to take part in trials are not necessarily a barrier.
- The overall participation in clinical trials by respondents was just 12%.

### Recommendations

- There is a major need for more clinical trials in ovarian cancer, and for a much higher proportion of women to be offered the opportunity to take part in them.
- Consideration should be given as to whether there are suitable trials for women at other hospitals if none are suitable at their current hospital.

## SUPPORT NEEDS

### Key findings

- Fewer than one in 10 women (8.9%) said there was no particular time that they needed emotional support. They were allowed to select different options, and on average they selected 2. The most common times were at the point of diagnosis (65.9%) and after the treatment has ended (46.8%).
- Responses were different in some countries, for example Japan, where recurrence or incurable disease were more commonly cited than the average for all.
- Unsurprisingly issues around fertility affected younger women more, but also body image (age 31-40), and increasing issues with fear of dying/cancer returning with age (over 50s).
- Only just over a quarter of women were offered help by a health professional (28%), and for one in five they were neither offered help, nor sought help. Women relied heavily on family and friends for support (emotional, practical). Women in Japan had the highest proportion not getting the help and support they needed.
- One in five women have never met another woman with ovarian cancer (in person or online). In Japan this is 30%. Just over half of women had met another woman with ovarian cancer in person, one in four have met women online, and just 2% by telephone. Only 7.5% of the women who had not met anyone did not want to meet other women. Those who had met other women were positive about the benefits, but did find it hard when someone they knew had a recurrence or died. But for them the positives outweighed the benefits.
- Women face a considerable financial burden when diagnosed with ovarian cancer, both in direct costs of treatment and indirect costs such as increased expenditure travelling to and from hospital. Two-thirds of women said it impacted to a great or some extent (31% and 37% respectively). There are variations by country and those who were working in paid full time employment had a higher proportion saying their finances were greatly affected (36% vs 31%).
- Almost one in three women have had to use personal savings to fund treatment and care (28.8%).
- Those who reported that their household income was below average for their country were more likely to report a great impact (56% vs 31%).

### Recommendations

- There is a real need for women to have more opportunities to meet other women with ovarian cancer, either in person or online. This will help reduce feelings of isolation and help them find out tips for living with the disease, sources of support and information. Care should be taken to help women with any difficult feelings that arise, but this should not be a barrier to action.

- If hospitals cannot provide mechanisms for support, then they should look to signpost women to any organisations that can help them cope at critical points such as diagnosis, end of treatment, recurrence and news of terminal disease. Hearing from other women that they find this valuable would encourage those who are not sure.

## INFORMATION NEEDS

### Key findings

- Fewer than one in five women always found the information they needed at any time (18.7%) and this varied by country from 4.2% in Japan to 34.7% in Italy.
- Doctors, followed by websites were the most important sources of information for women, however nearly a third of women found information on the internet very scary. Nurses seemed underutilised a source of information (both general nurses and specialist nurses).
- Information needs to cover a wide range of topics, from general information and information on treatments, to living with ovarian cancer, dealing with recurrence, spotting recurrence, genetic testing to other aspects of support.

### Recommendations

- There is a significant unmet need in terms of information. Charities, support groups and nurses could play an important role in this. There could be potential for the World Ovarian Cancer Coalition to provide a curated information hub signposting people to other organisations who may be able to share information for local translation.

## QUALITY OF LIFE

### Key finding

- The extent to which women feel mentally well is as important as the extent to which they feel physically well in terms of how they rate their quality of life, and these were the two most important factors.
- Findings were consistent in the 'by country' analyses.
- The strong support for the list of factors (produced from the qualitative interviews) provides the potential for not only a quality of life indicator, but also the basis for tips for women and doctors that might help them women cope with their feelings.

### Recommendations

- Much more consideration should be given to the mental wellbeing of women going through diagnosis and treatment for ovarian cancer as a means to improve their quality of life.

## GOVERNMENT EFFORT AND PRIORITIES

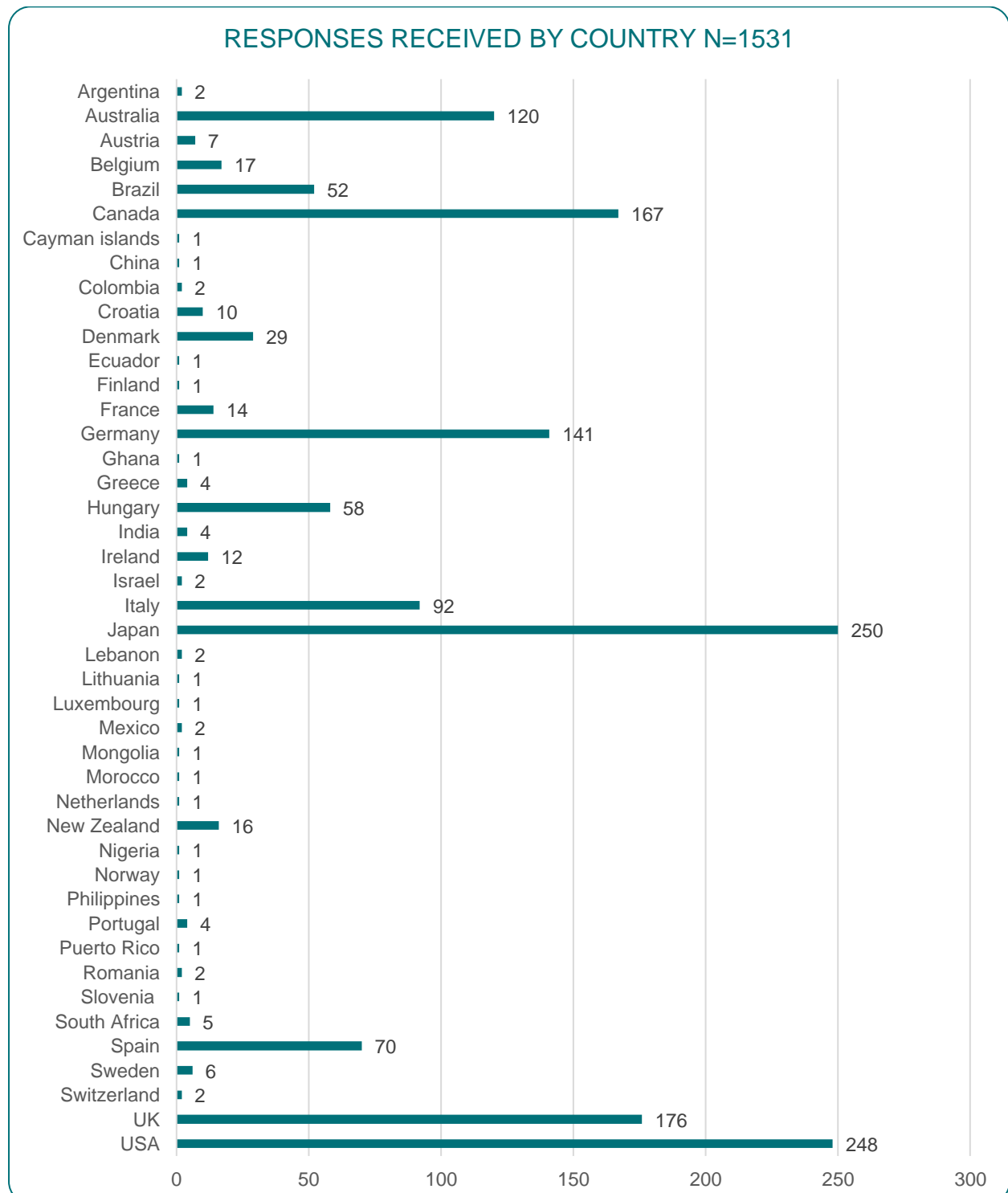
### Key findings

- Whilst there are some variations by country, in general women do not believe their own governments are doing nearly enough to improve survival and quality of life for women affected by ovarian cancer. The average score was 4.3 out of 10, ranging by country from 3 (Brazil) to 5.4 (Australia).
- Overwhelmingly women's priorities for action focus on early diagnosis. Given a list of 15 priorities including the option 'other', the top six were
  - Finding an effective screening tool.
  - Raising awareness of symptoms.
  - Reducing delays in diagnosis.
  - Prevention of ovarian cancer.
  - Improving diagnostic tests.
  - Ensuring access to gynecological cancer specialist doctors.

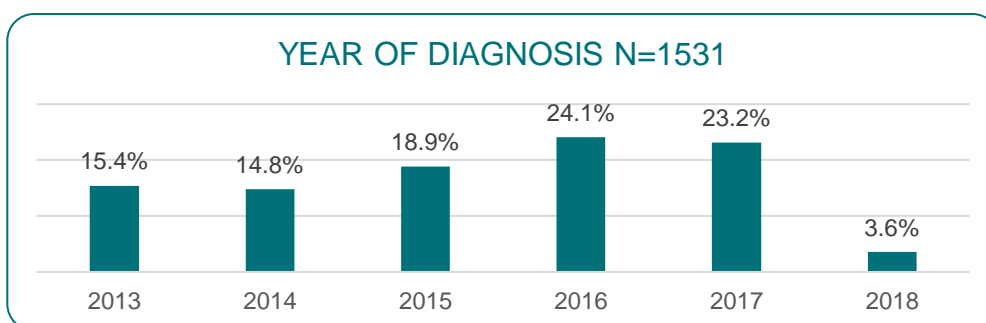
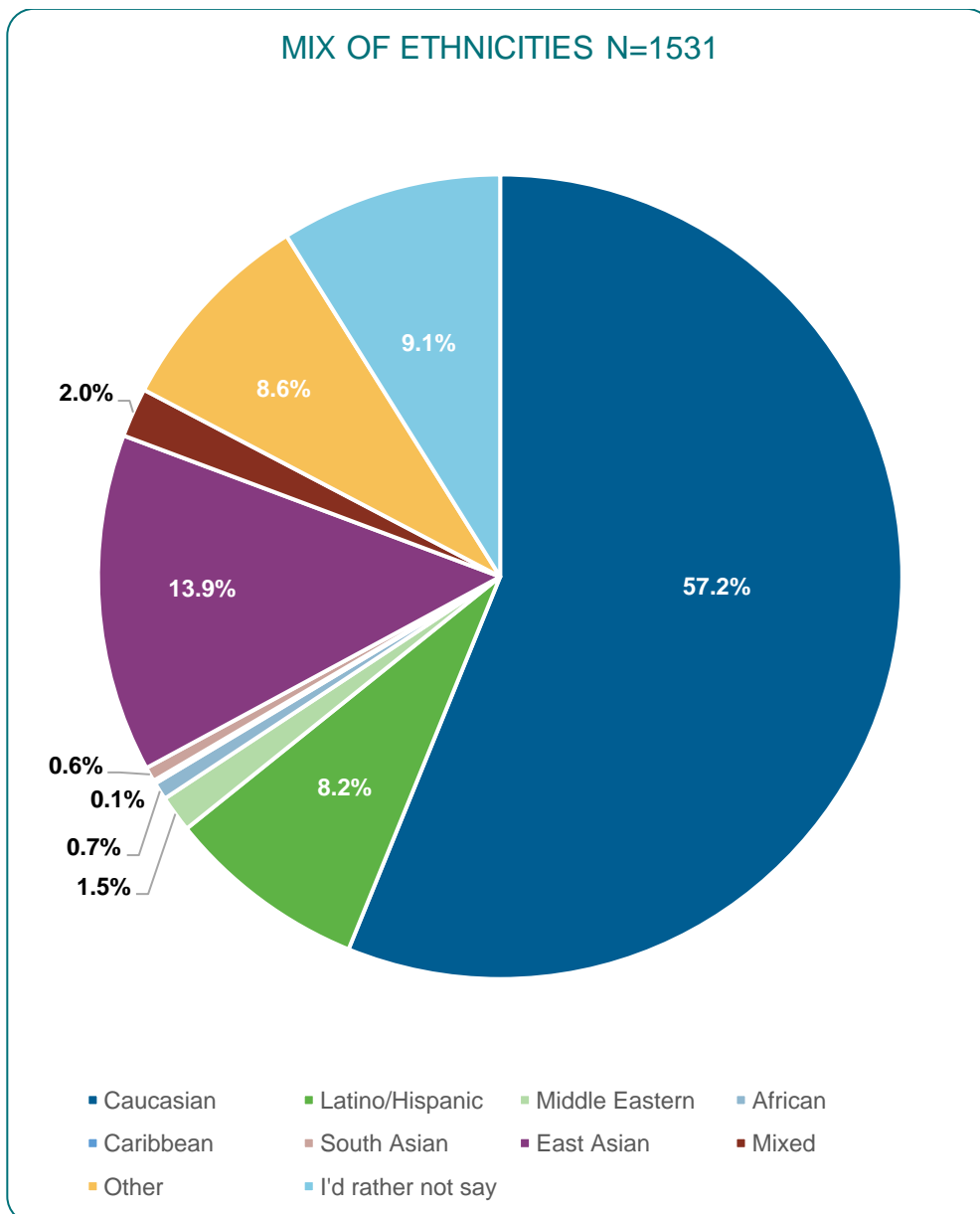
# FINDINGS IN FULL

## ABOUT THE WOMEN BACKGROUND INFORMATION

Of the answers received, 96.7% were from women with ovarian cancer, with the remaining 3.3% (n=51) of answers being completed on behalf of women. Of these the large majority were family members (78% n=40). Responses came from women in a total of 44 countries as shown below.



The biggest single ethnic grouping was Caucasian (57.2%). Women were only able to participate if they had been diagnosed during or since January 2013. Over 50% had been diagnosed since the beginning of 2016.





Only 15.8% of respondents describe themselves as living in the countryside or a village, with the remainder living in more urban areas. Most women 39.3% live less than 3 miles from their nearest hospital. Just over 15.3% live more than 12 miles from their nearest hospital.

The most common age for leaving formal education was 18 (16.8%), followed by 22 (13.1%), but varied from aged 10 to 30, with another 8.5% of women describing their leaving age as 'other'. By far the majority of women were married or living with a partner at the time of diagnosis (71.5%) with 12.9% describing themselves as never married. At the time of diagnosis, most women (59.2%) did not have any caring responsibilities. 21.8% had children or a child under the age of 18, whilst 10.5% cared for an elderly relative.

Just before they were diagnosed, 11% described their household income as below average for their country, 50.6% as average, 31.4% as above average, with the remaining 7% preferring not to say.

## EMPLOYMENT

By far the majority of women were in some sort of paid employment or were self-employed (75.8%) prior to diagnosis. 10.5% were not in paid or self-employment, and 13.6% were retired. Women in Japan were much more likely not to have retired than the average (4.4%) and in Australia they were much more likely to be retired (24.2%).<sup>3</sup>

Of those who were in some form of work, by far the majority altered their working hours. They either took time off for treatment (61.8%), decided not to return (13.4%), retired (8.8%), or were not allowed to work (8.4%). 7.6% of women did not take any time off for treatment. This varied from 0% of women who had been working in Australia, 2.9% of women in Japan, 3% of women in the UK, to 16.6% of women in the USA.<sup>4</sup>

Of those who decided not to return to work, the greatest proportion (25.3%) were in the 61-70 age bracket. Stage at diagnosis was also relevant across all ages, increasing from 9.2%\* of those diagnosed with stage I disease, to 23% of those diagnosed with stage IV, versus the average of 13.4%.<sup>5</sup>

Of those who took time off but returned to work only 39.5% returned to their normal working hours. 24.6% returned on reduced hours. The remainder returned but then either had to have more time off, reduce hours, or give up altogether. The side effects of treatment were the most common factor for this group of women changing hours or deciding to leave work once they had returned (56%), but for 25.6% of women, they had to alter their work arrangements as their cancer came back.

## AGE, STAGE AND TYPE OF OVARIAN CANCER

The most common age brackets for diagnosis were 51-60 (32%) and 41-50 (31.6%). This however varied between countries. Results were examined for countries where there were

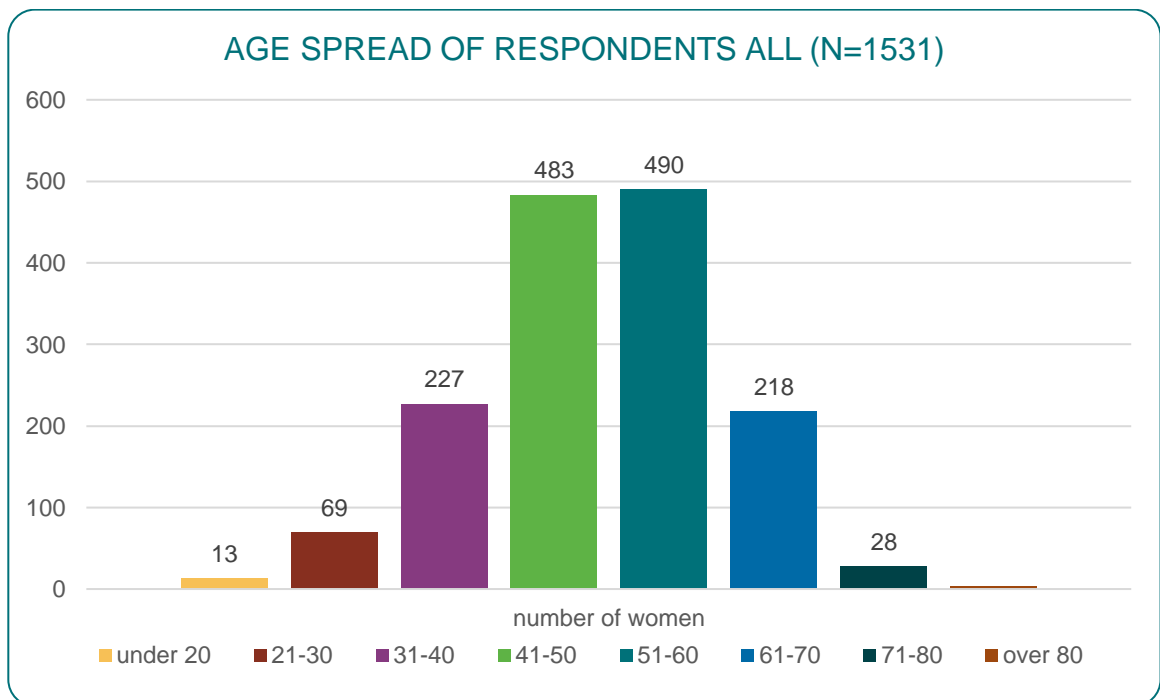
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<sup>4</sup> BY COUNTRY CROSS TAB NUMBERS Q14

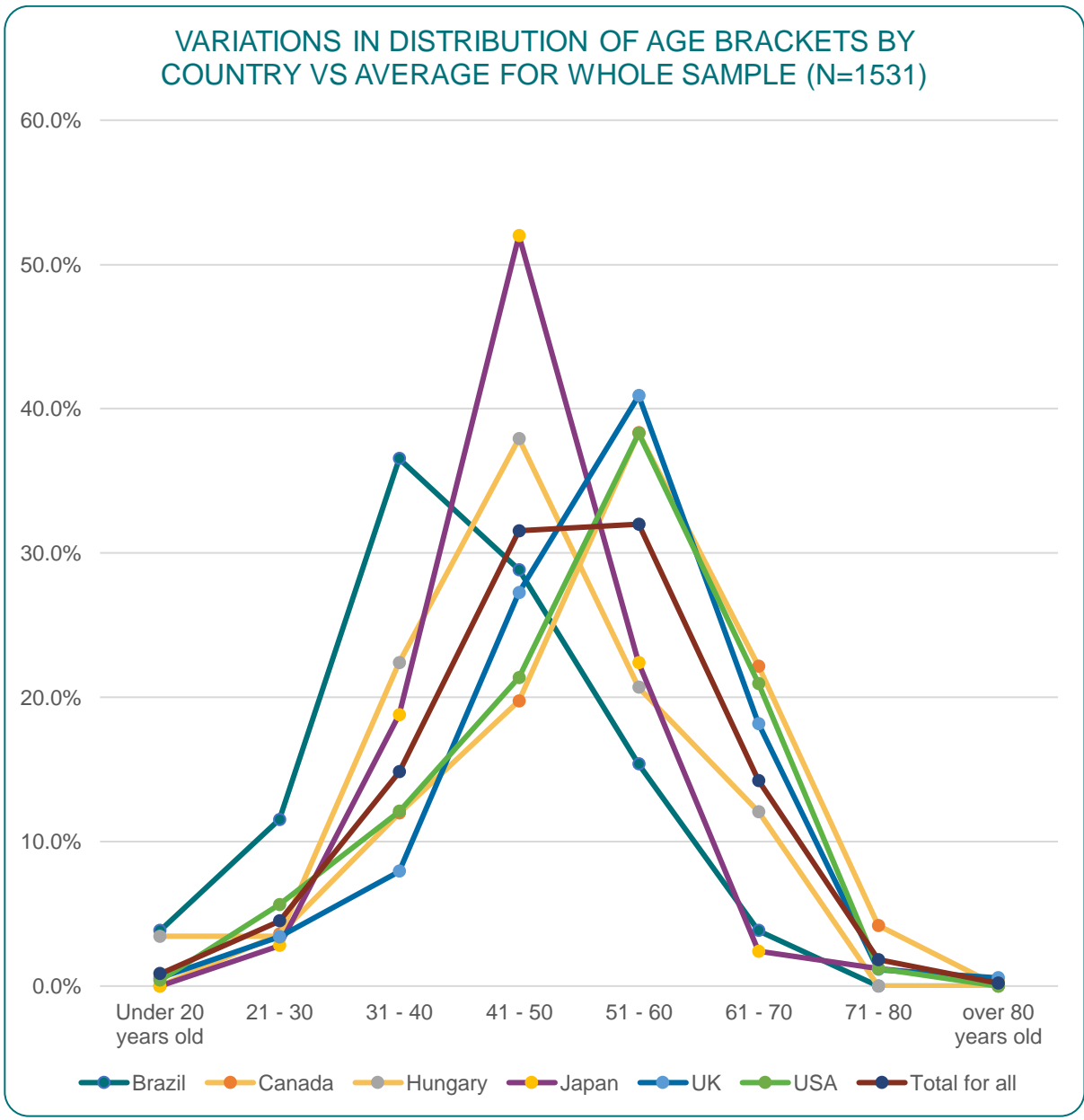
<sup>5</sup> BY STAGE CROSS TAB NUMBERS Q14

more than 40 respondents, and for age brackets that had more than 40 respondents<sup>6</sup>. The significant findings are highlighted below, and for those countries where significant findings exist, the plot of age distribution is shown for information.



AGE BRACKET	COUNTRIES WITH LESS THAN AVERAGE IN THIS AGE BRACKET	AVERAGE	COUNTRIES WITH MORE THAN AVERAGE IN THIS AGE BRACKET
21 - 30		4.5%	
31 - 40	UK 8.0%	14.8%	Brazil 36.5%
41 - 50	Canada 19.8% USA 21.4%	31.6%	Japan 52%
51 - 60	Brazil 15.4% Hungary 20.7%* Japan 22.4%	32%	UK 40.9%
61 - 70	Brazil 3.9% Japan 2.4%	14.2%	Canada 22.2%* USA 21%*

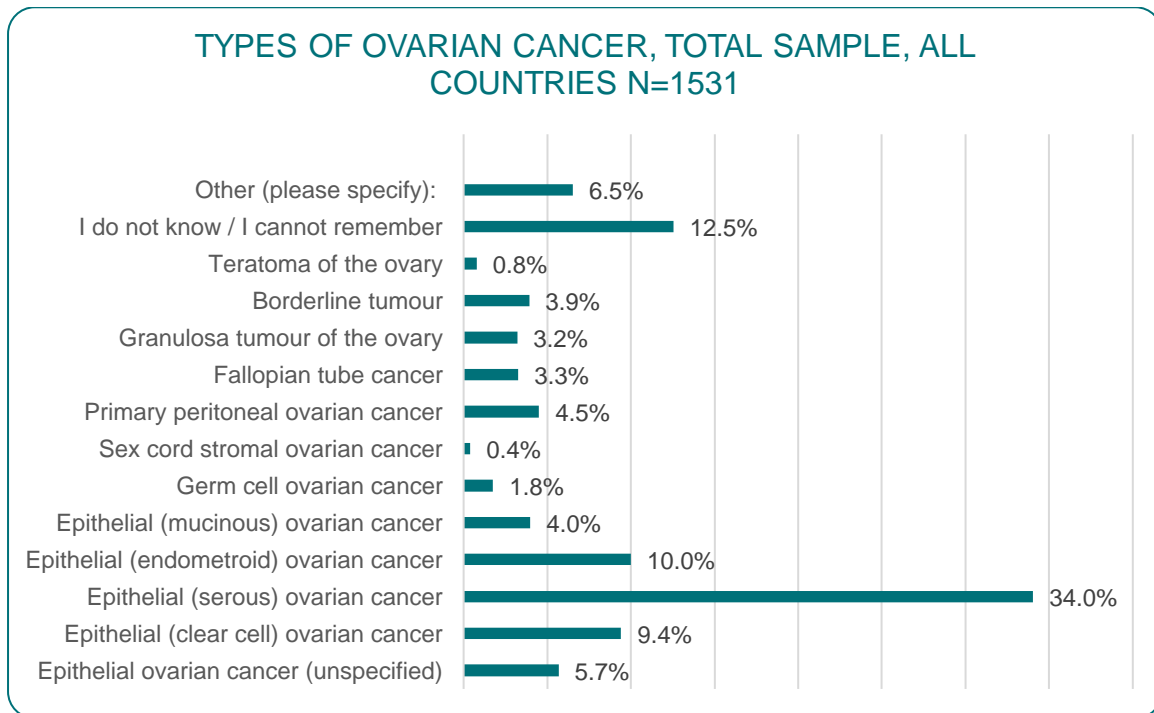
<sup>6</sup> BY COUNTRY CROSS TAB NUMBERS Q17



Women were given a list of 12 types of ovarian cancer and asked to indicate which type they had. They were also given the option of 'I don't know', and 'other' where they were asked to specify which types. In the initial data clean, this list was examined, and where it was clear that the respondent had one of the listed type, the answer was assigned appropriately. There were a considerable number of significant variations in proportions of type (where there were more than 40 responses in total), by country<sup>7</sup>. More than one in ten did not know or could not remember which type of ovarian cancer they were diagnosed with (12.5%). Both Germany and Japan had very low rates of women not knowing what type of ovarian cancer they had and very low rates of unspecified epithelial ovarian cancer. Care should

<sup>7</sup> BY COUNTRY CROSS TAB NUMBERS Q17

also be taken in interpreting some results as it seems clear in some countries that specific types of ovarian cancer may not be ‘specified’, for example fallopian tube cancer (Brazil, Hungary, Italy), or mucinous (Italy), or clear cell (Hungary), or it may be that clinicians in some countries are less likely to tell women. Hungary in particular had the highest proportion of ‘I don’t know’, with nearly one in three women unclear as to what type of ovarian cancer they had been diagnosed with (39.3% vs 12.5%). On the other hand, their nil returns may just mean none were recorded in this study sample. As with other studies that look at the morphology of ovarian cancer in different countries, each uses different classifications to break down the different types so it is very hard to compare our findings accurately to previously run studies.



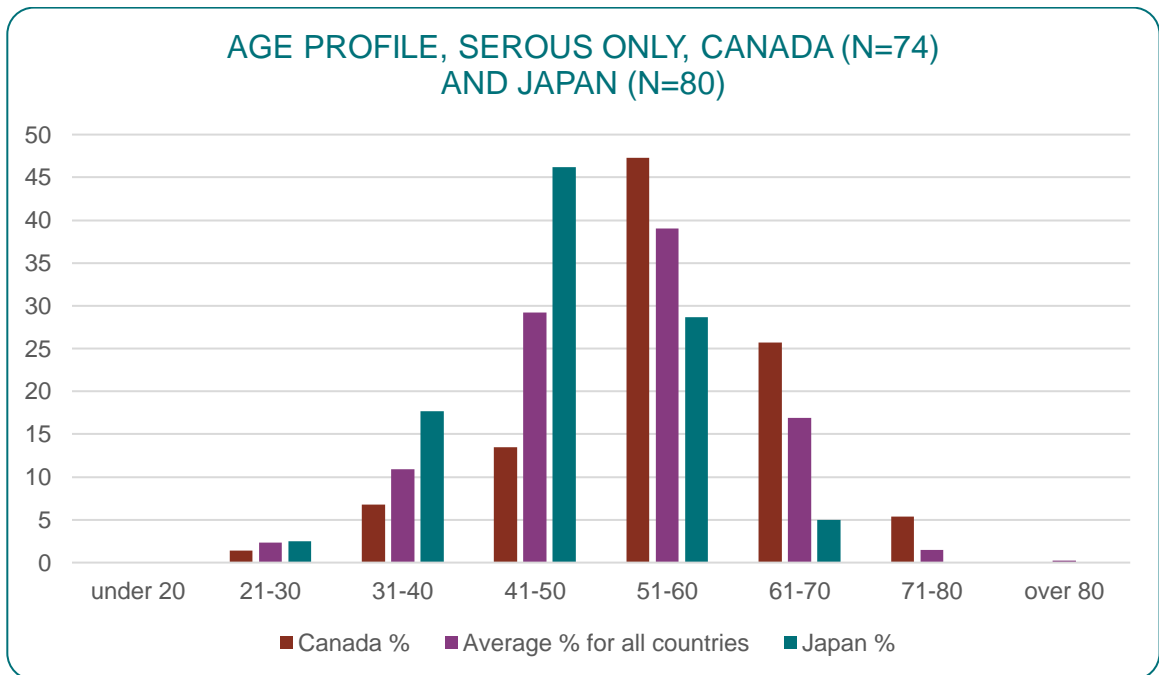
TYPE OF OVARIAN CANCER WHERE THERE WERE 50 OR MORE RESPONDENTS	LOWER PROPORTION	AVERAGE FOR ALL	HIGHER PROPORTION
EPITHELIAL OVARIAN CANCER (UNSPECIFIED)	Germany 0.7% Japan 2.4%	5.7%	
EPITHELIAL (CLEAR CELL) OVARIAN CANCER	Australia 5%* Brazil 1.9% Germany 3.6%	9.4%	Japan 22%

	Hungary 0%		
EPITHELIAL (SEROUS) OVARIAN CANCER	Hungary 17.2%	<b>34%</b>	Canada 44.3%*
EPITHELIAL (ENDOMETROID) OVARIAN CANCER	Germany 2.8% UK 5.7%	<b>10%</b>	Japan 21.6%
EPITHELIAL (MUCINOUS) OVARIAN CANCER	Italy 0%	<b>4%</b>	
PRIMARY PERITONEAL OVARIAN CANCER	Australia 1.7%* Brazil 0% Japan 0.8%	<b>4.5%</b>	Germany 10.6%*
FALLOPIAN TUBE CANCER	Brazil 0% Hungary 0% Italy 0%	<b>3.3%</b>	
BORDERLINE TUMOUR	USA 1.2%	<b>3.9%</b>	Brazil 17.3%*
I DO NOT KNOW / I CANNOT REMEMBER	Brazil 3.9% Germany 2.2% Italy 5.4% Japan 4%	<b>12.5%</b>	Hungary 29.3%

From our findings, it can be seen that the age profile of women in particular countries varies, as does the mix in proportions of different types of ovarian cancer. To see if there were underlying variations in age alone, two particular comparisons were made (where country sample size for the type of ovarian cancer was greater than 40).

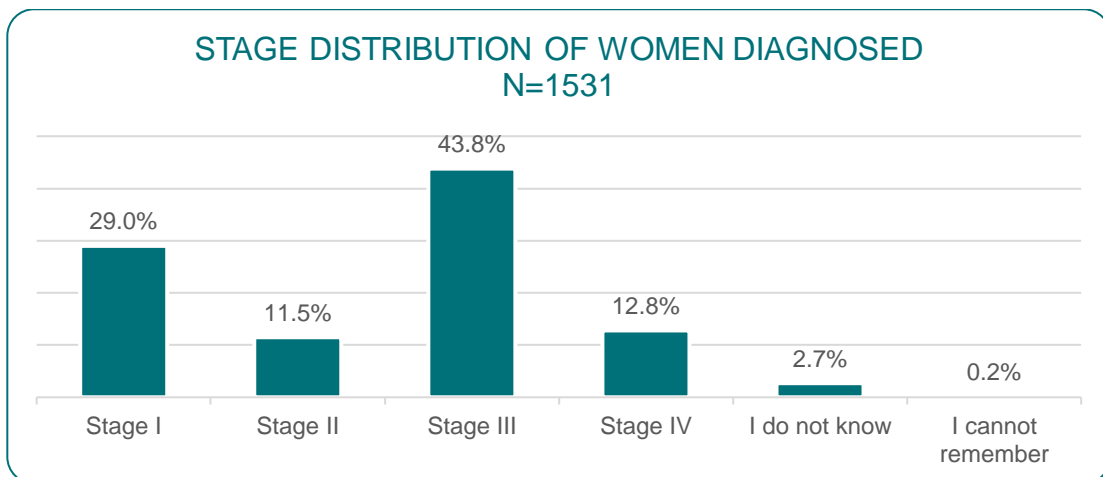
There were statistically significant differences between women in Japan and the US who had either clear cell or endometrioid ovarian cancers in the 41-50 age bracket (US 23.3%, average for all countries 43.4%, Japan 58.7%) and the USA had a higher proportion of women in the 51-60 age bracket than the average (58.8%\* vs 29.3%). Japan had a similarly younger profile for serous ovarian cancer, with statistically significant differences seen again in the 41-50 age bracket when compared to women in Canada (Canada 13.5%, average for

all 29.2%, Japan 45.2%) and a lower proportion of women in the 61-70 age bracket (5% vs average for all of 16.9%)<sup>8</sup>.



In terms of how they found out about the type of cancer they had, 63.3% were told without asking, but 28% asked for the information.

The stage at which women were diagnosed was as follows:



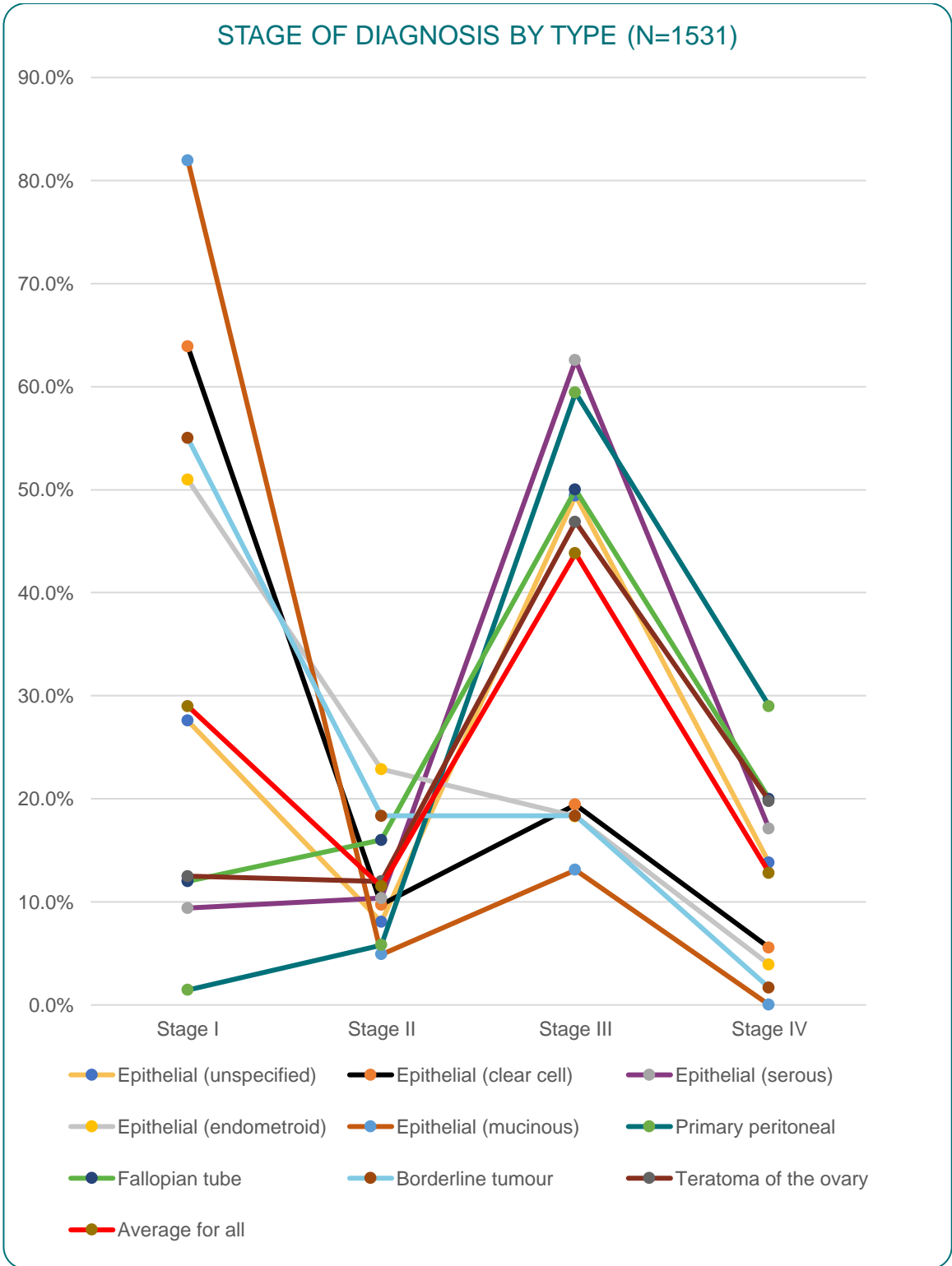
<sup>8</sup> Additional Analysis Statistical Checks – by country age and type tab, data from cross tab all results filtered by types (serous, clear cell and endometroid).

The data was examined to explore any link between type of tumour and stage on diagnosis. For this cohort, stage at diagnosis is very much driven by the type of ovarian cancer as shown by the chart on the next page.

The data was examined to see if there were differences in stage of diagnosis by country. However, we already know that some countries are more likely to have certain types of ovarian cancer than others, so looking at the stage by country for all types does not elicit useful information. Instead as a comparison, stage spread was compared for serous ovarian cancer between the different countries. There were sufficient respondents to compare Canada, Germany, Japan, UK and USA to the average for all respondents. The UK was less likely to diagnose at stage 1 (3.1%\* vs average for all of 9.4%). For clear cell and endometrioid, only Japan and USA were compared against the average for all countries. Japan was more likely to diagnose at Stage 1, and the USA less likely than the average to diagnose at stage 1 (Japan 69.7%, average 57.2%, USA 37.2%\*). The USA was more likely than the average for all to diagnose at stage 3, and Japan less likely (USA 39.5%\* average for all 18.9%, Japan 11%)<sup>9</sup>.

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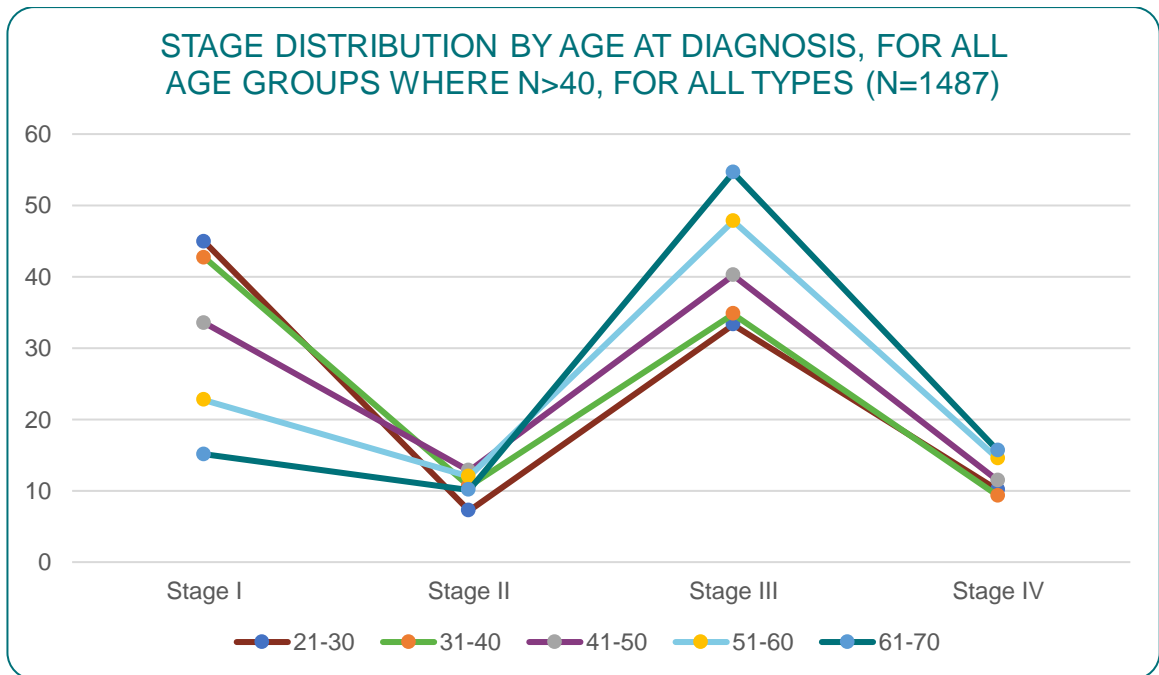
<sup>9</sup> Additional Analysis Statistical Checks – by country stage and type tab, data from cross tab all results filtered by types (serous, clear cell and endometrioid).



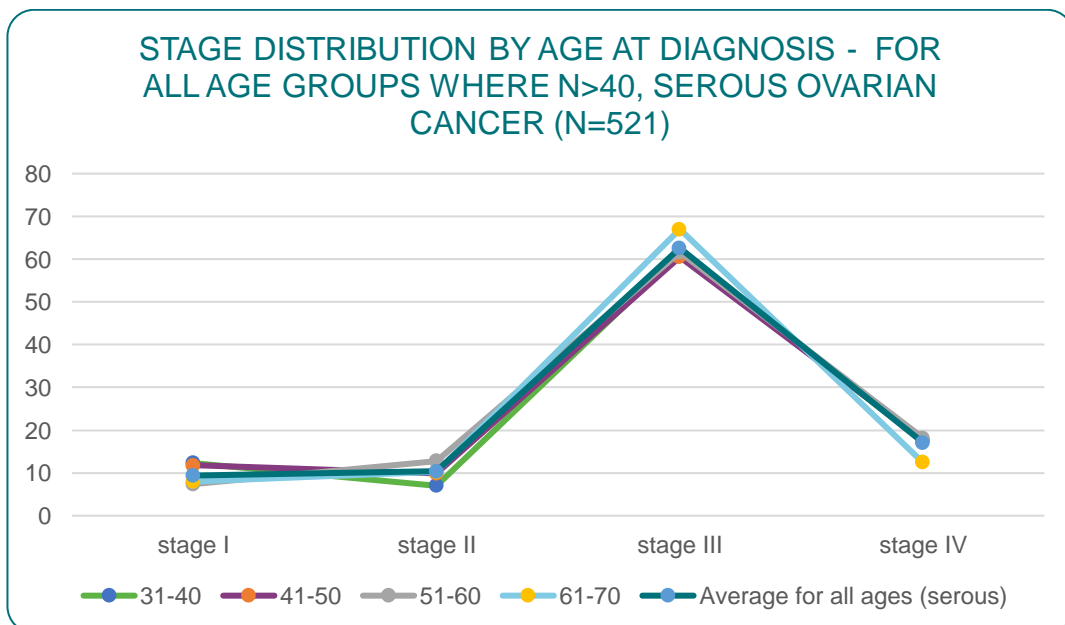
There appeared to be variations in age and stage mix. Women who were under the age of 40 were more likely to be diagnosed with Stage I disease (21-30 age group 44.9%, 31-40 age group 42.7% vs average for all of 29%) and women over 50 less likely to be diagnosed with stage I disease (51-60 age group 22.6%, 61-70 age group 15.1% vs average of 29%). Women aged 31-40 were less likely to be diagnosed with stage III, (34.8% versus the



average of 43.8%) and women in the 61-70 age bracket more likely to be diagnosed with stage III than the average for all ages (54.6% vs 43.8%)<sup>10</sup>.



However, examining the data for serous only, there were no statistically significant differences between age and stage diagnosed, therefore the trend seen above (for all types) is likely to be driven by the age and stage profile of certain cancer types grouped together and should not be used as a generalisation.



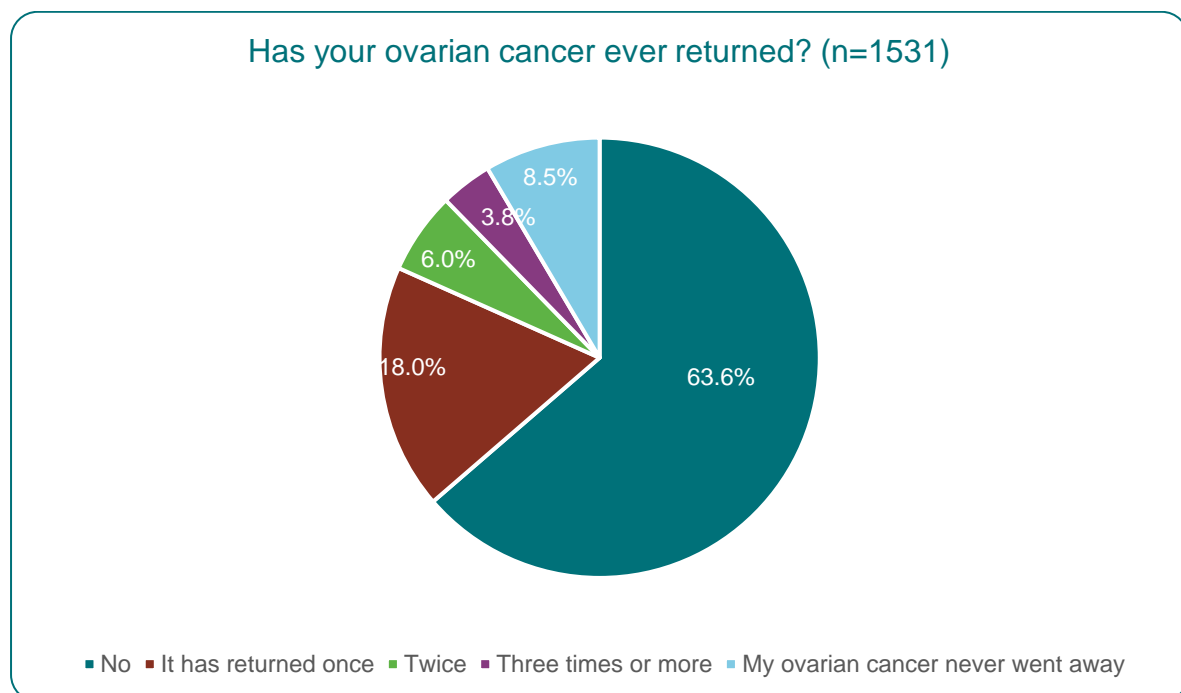
<sup>10</sup> BY STAGE CROSS TAB NUMBERS Q17

Once again in terms of how women found out about their stage of diagnosis, 64% were told without asking, 21.9% asked directly, and 12% read it in their notes.

## CURRENT STATE OF TREATMENT

In terms of where they are in their treatment, just 32.9% of respondents were currently receiving treatment, either for a recurrence (22.2%), or newly diagnosed disease, (10.7%). 55% of respondents said they were in remission and their cancer was not active.

Women were asked if their cancer had ever returned. The answers for the full sample was as follows.



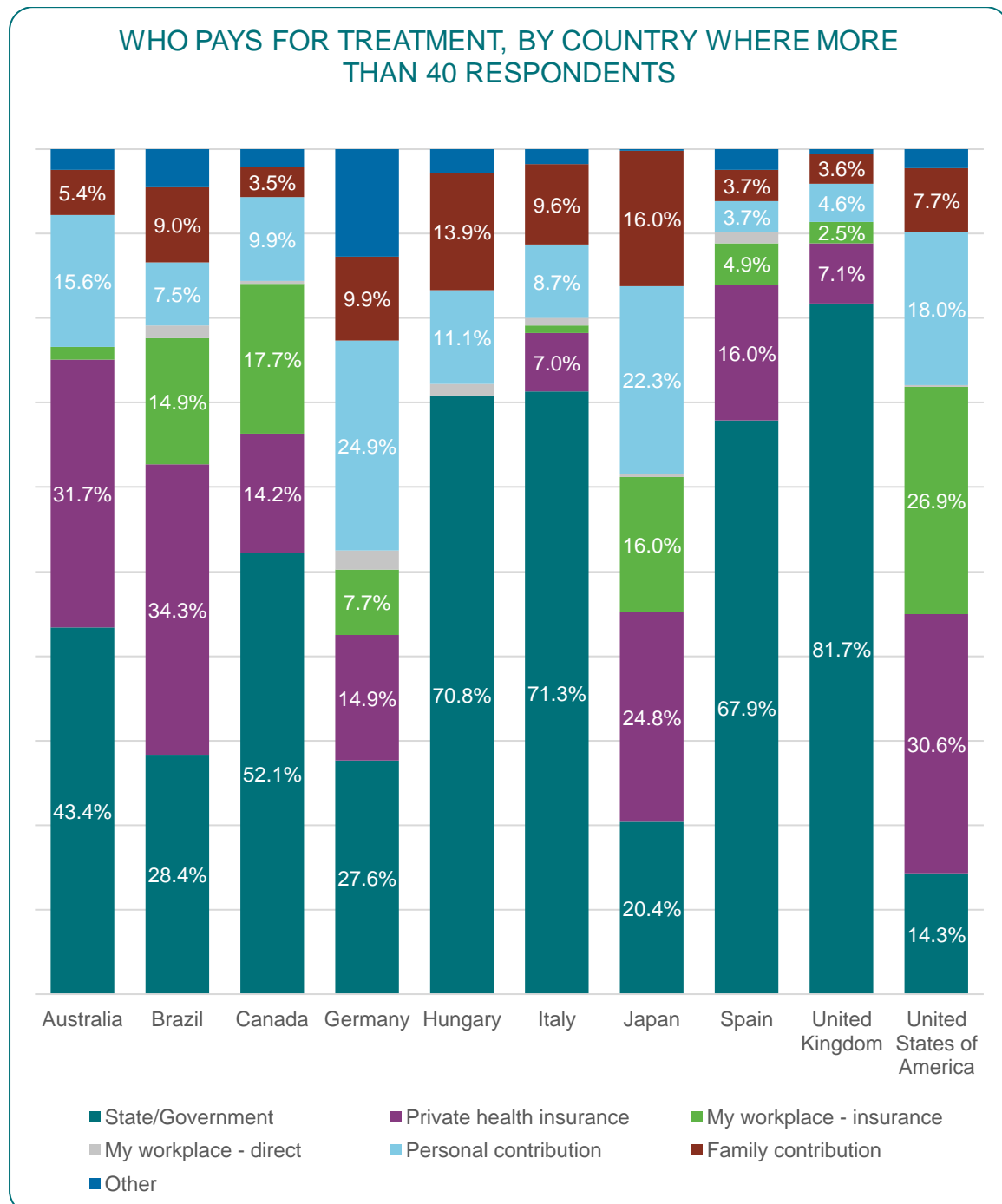
By looking at when these women were diagnosed, the proportion of those who had been diagnosed in 2013, whose cancer had not returned was 51.3%. When looking at women diagnosed with endometrioid and clear cell cancer, the figure was 72.3% and for serous ovarian cancer 44%.

Examining different types of ovarian cancer in more detail by subtype where there were more than 40 responses, clear cell (81.2%), endometrioid (83.2%), mucinous 93% and borderline (79%) were all more likely not to have returned. Serous (52.5%) and primary peritoneal cancer (38.7%) were less likely not to have returned, for any year of diagnosis. Endometrioid (3.7%), mucinous (1.8%) and borderline (1.7%) were less likely to have 'never gone away' versus the average 8.5%<sup>11</sup>.

<sup>11</sup> BY TYPE OF OVCA CROSS TAB Q23

## WHO PAYS FOR TREATMENT

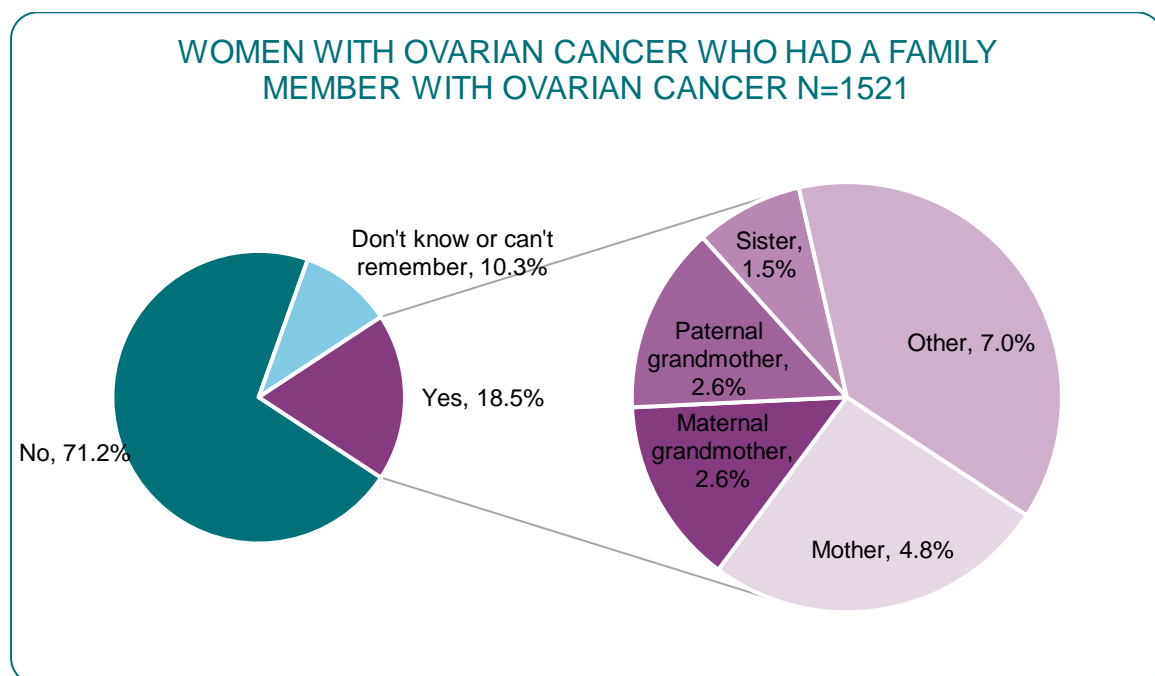
Given the global nature of the survey it is not surprising that women in different countries have their treatment funded in different ways, from the State or insurance companies paying, to relatives or workplaces contributing to the cost of care. The balance can vary widely as is shown in the following chart for countries who had more than 40 participants.



Just over 10% of women have either applied for state or charitable funding or contested the costs an insurance company will cover. For 12.4% of these women, making the application or contesting a decision delayed the start of treatment (n=21).

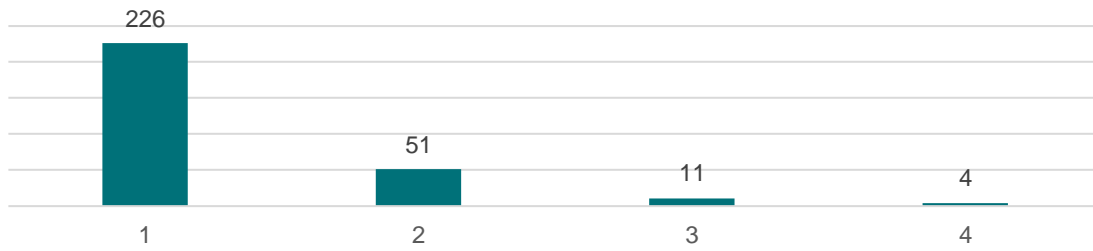
## FAMILY HISTORY AND GENETIC TESTING OVARIAN CANCER

Women were asked if they had blood relatives who had developed ovarian cancer. 71.2% said no, and 10.3% said they did not know or could not remember. This left 18.45% of women with a positive response in terms of having a close relative with ovarian cancer (n=281). Of this group, 26% had a mother who had developed ovarian cancer, 14% a maternal grandmother, and 14% a paternal grandmother. Just under 8% had a sister with the disease. Most women had just one family member with ovarian cancer. The mean number of relatives was 1.3. The breakdown is represented below with the proportion of family members out of the whole sample group, but note that women may have had a grandmother and a mother etc. Women in Brazil (85%\*), Japan (82.8%) and Canada (82%) were most likely not to have a close relative with ovarian cancer<sup>12</sup> compared to the average for all (71.2%).



<sup>12</sup> BY COUNTRY CROSS TAB NUMBERS Q27

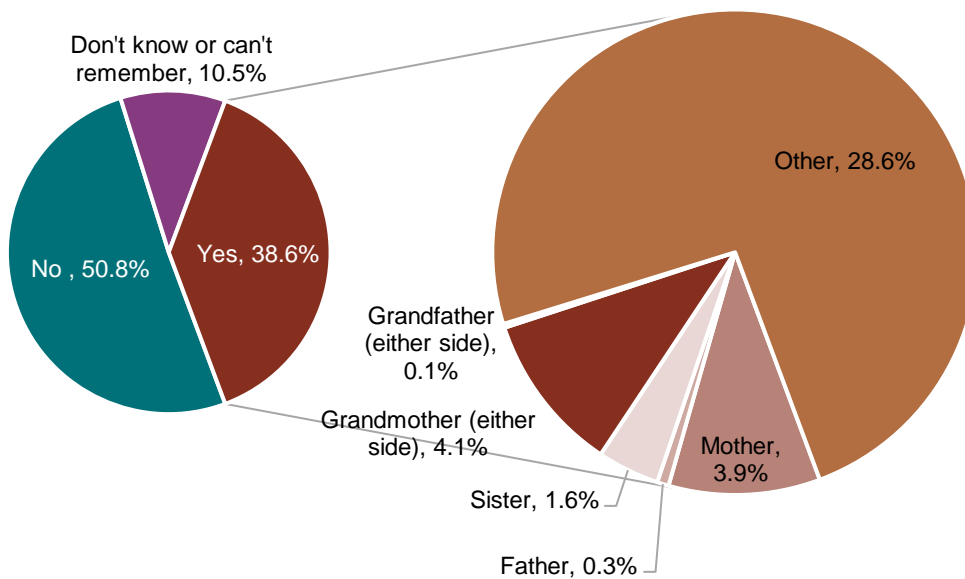
### NUMBER OF RELATIVES AFFECTED BY OVARIAN CANCER (N=292)



### BREAST CANCER

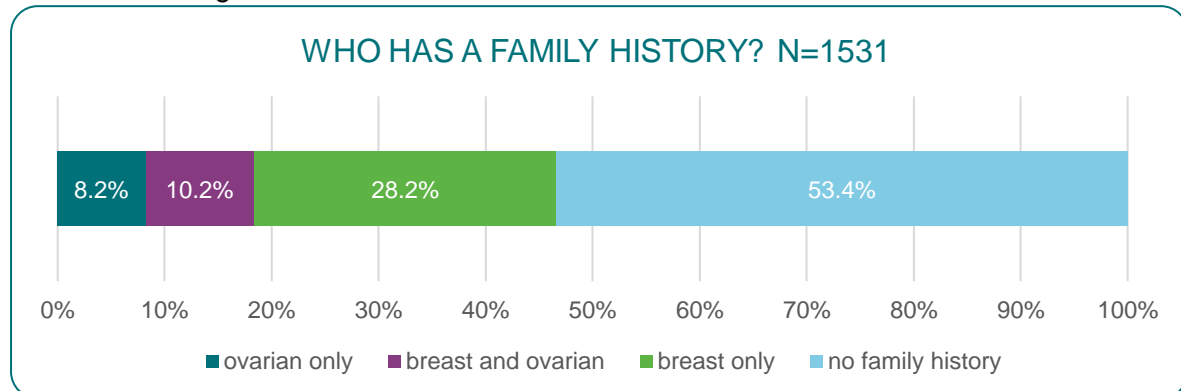
38.6% of women said they had a history of breast cancer in close family relatives (male and female, n=588). Of those with a history, 27.9% had a mother or father with the disease, 11% had a brother or sister, and 28.2% had a grandparent (either side). Most women had just one relative, with the mean number of relatives affected by breast cancer 1.4. The breakdown is represented below. 50.8% said they did not have a close family relative affected by breast cancer. This varied by country, with 67.5%\* of women in Brazil saying they did not have a close relative with breast cancer, 61.8% of women in Japan and just 41% of women in the USA.

### WOMEN WITH OVARIAN CANCER WHO HAD A FAMILY MEMBER WITH BREAST CANCER (N=1517)



## BREAST AND OVARIAN CANCER

Of those who had family history of breast or ovarian cancer, 21.9% had a history of both breast and ovarian cancer (n=156), 432 had a history just of breast cancer, 125 a history of only ovarian cancer. In terms of the total sample it can be seen that the women surveyed had the following<sup>13</sup>:



## GENETIC TESTING – PRIOR TO DIAGNOSIS

Almost all women had not had a test for BRCA1 or 2 gene defects prior to their diagnosis (91.5%). With 0.9% not sure or not remembering, just 7.6% of the total sample were tested prior to their diagnosis. Germany was the only country with a significantly higher proportion (15.6%\*)<sup>14</sup>.

Looking at those who had a family history of either breast or ovarian cancer, or breast and ovarian cancer the following can be seen:

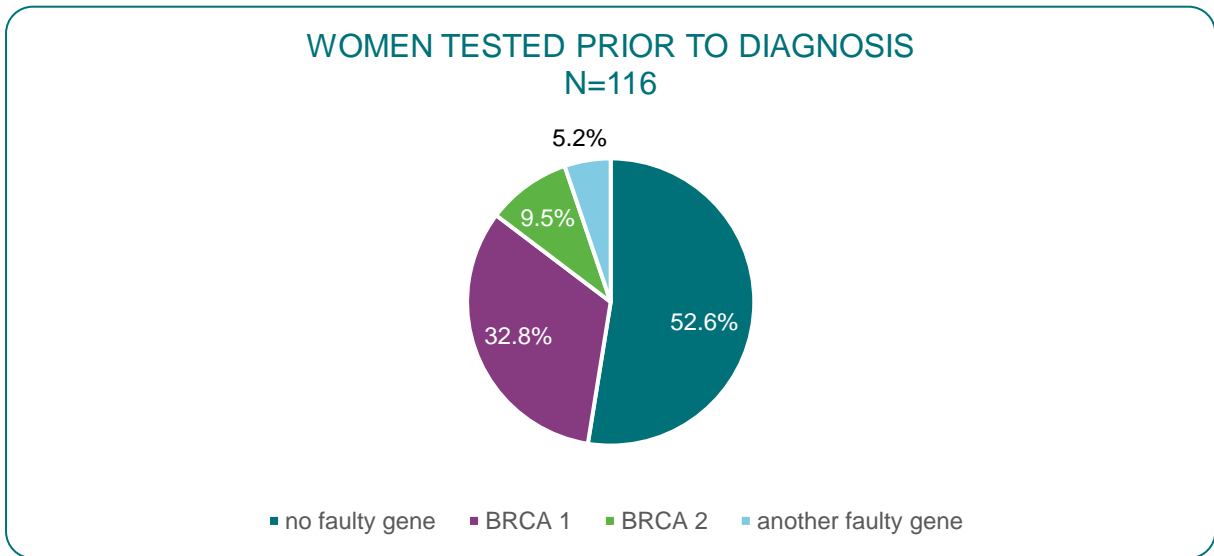
FAMILY HISTORY	PROPORTION RECEIVING TESTING PRIOR TO DIAGNOSIS	SIGNIFICANT VARIATIONS
Ovarian cancer family history (one or more cases)	16.1%	Germany 34%
Ovarian cancer family history (one case only)	15%	
Ovarian cancer family history (two cases)	20% <sup>15</sup>	
Ovarian and/or breast cancer family history (one or more)	10.9%	Germany 22.4%*
Ovarian and breast cancer family history (two or more cases)	21%	

<sup>13</sup> Additional Analysis Statistical Checks GENETIC TESTING SHEET. Data drawn from MeasurementMattersAnalysis/Family History Analysis

<sup>14</sup> Additional Analysis Statistical Checks GENETIC TESTING SHEET. Data drawn from MeasurementMattersAnalysis/Family History Analysis

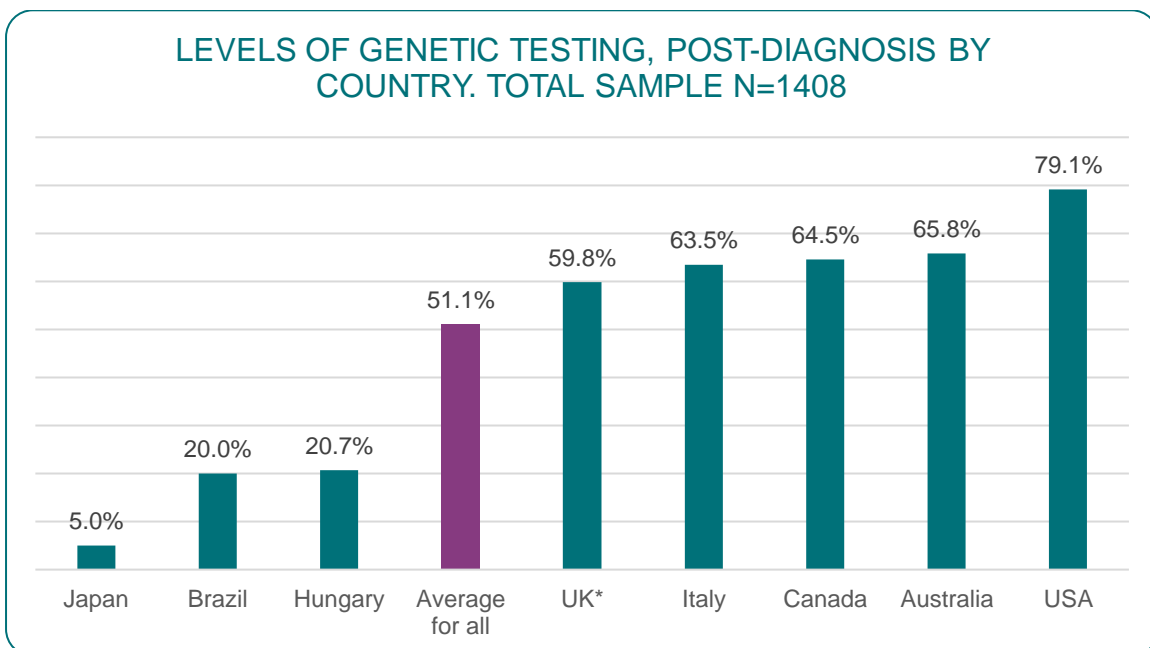
<sup>15</sup>MeasurementMattersAnalysis/FamilyHistory-Analysis\_2

It is concerning that despite having two cases of ovarian cancer, or a case of ovarian cancer and breast cancer in close family relatives, testing prior to diagnosis was still only occurring for one in five women. There were 4 women who each had 4 family members diagnosed with ovarian cancer, but only one of these women was tested pre-diagnosis. Returning to the full sample, for those who were tested before diagnosis (n=116), no faulty gene was found in just over half the women (52.6%).

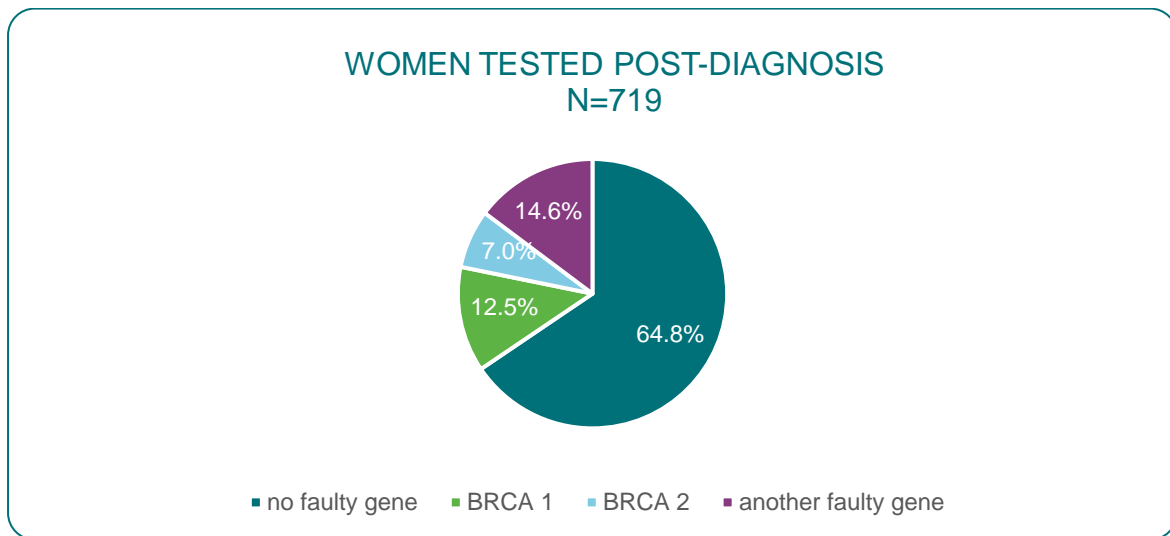


## GENETIC TESTING POST-DIAGNOSIS

Those women who were not tested prior to their diagnosis were asked whether they had been tested for faulty genes after their diagnosis. 51.1% were tested (regardless of family history n=719). This varied by country, from 5% in Japan to 79.1% in the USA.



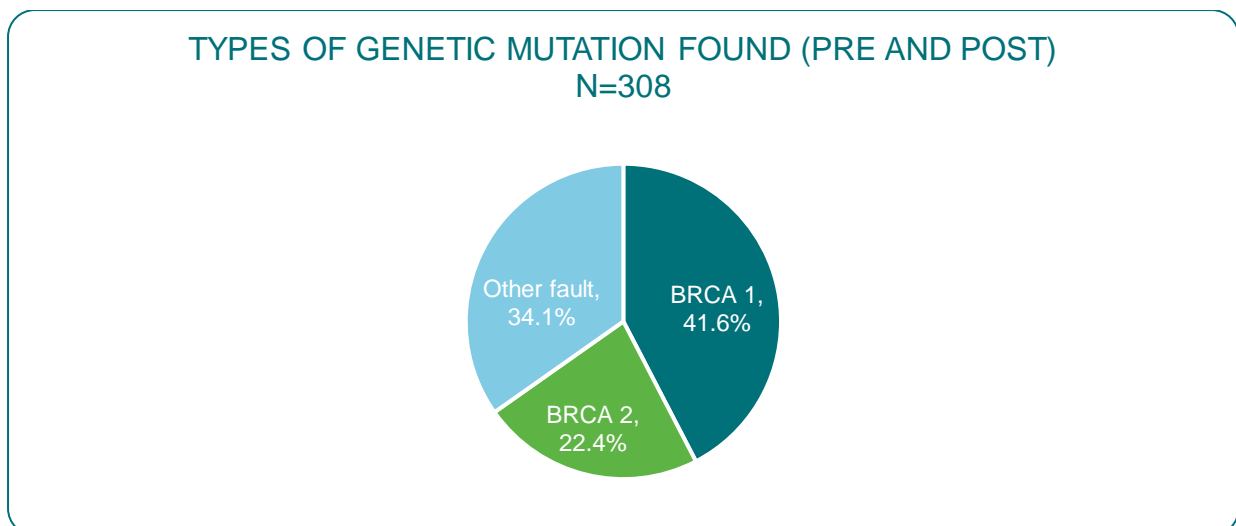
Of those who were tested post-diagnosis, the breakdown of the results was as follows:



663 of the total sample did not receive genetic testing at all (43%). Of these 92 women (6% of total sample) remain untested despite having a family history of ovarian cancer (at least one relative), and 231 women (15% of the total sample) indicated they had a family history of breast cancer (at least one relative).

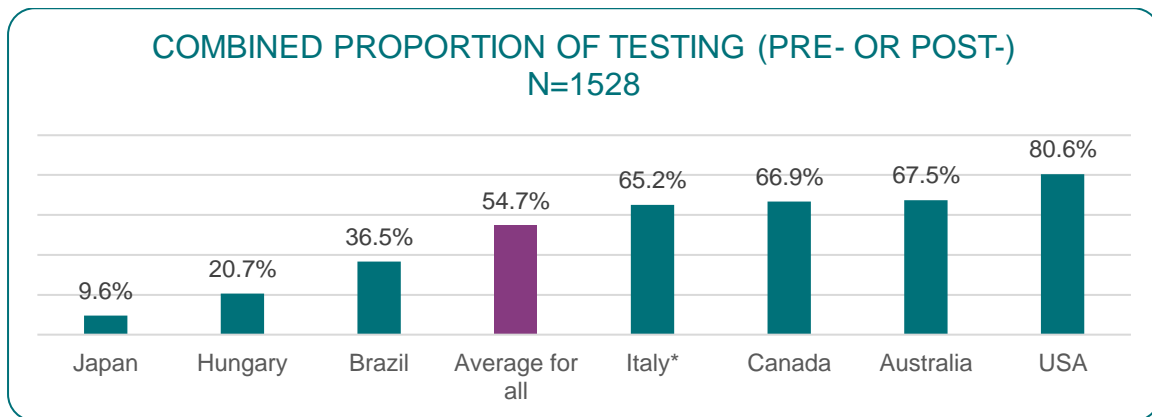
## OVERALL GENETIC TESTING

Combining tests pre- and post-diagnosis, then globally 54% of women with ovarian cancer were tested for faulty genes. Of this group 36.9% tested positive for a faulty gene (n=308), representing 20.1% of the total sample. The break down was as follows.

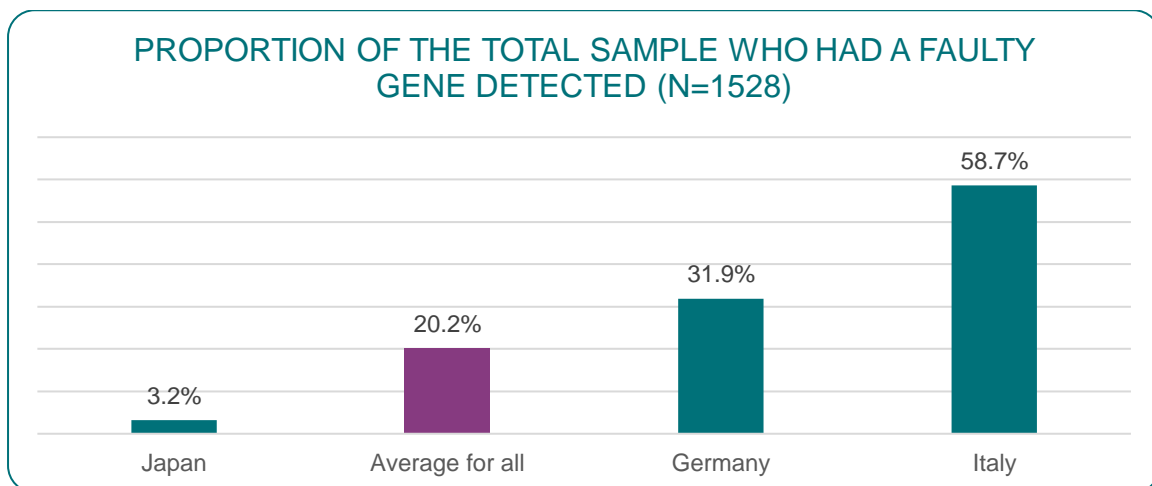




The proportion of women tested either pre- or post-diagnosis varies widely by country<sup>16</sup>. Women in Japan and Hungary are much less likely to undergo genetic testing (9.6%, 20.7%, average 54%). In the Every Woman Study Clinician Report, one Japanese clinician said women have to pay for their genetic tests. Other women are much more likely to undergo testing in the US (80.7%), Australia (67.5%) and Canada (66.9%). Earlier it was flagged that Germany had a much higher proportion of women tested pre-diagnosis, but a lower proportion of testing post-diagnosis balances this out.



There were statistically significant variations in the proportion of the total responses in the Study who had a faulty gene identified, by country, varying from 3.2% to 58.7%, with an average of 20.2%.



In testing post-diagnosis, as a proportion of all their respondents, Italy had over three times the number of women with BRCA1 mutations when compared to the proportion for all countries (23% vs 6.4%) and Italy and Germany had by far the highest proportion in tests

<sup>16</sup> BY COUNTRY CROSS TAB NUMBERS Q30

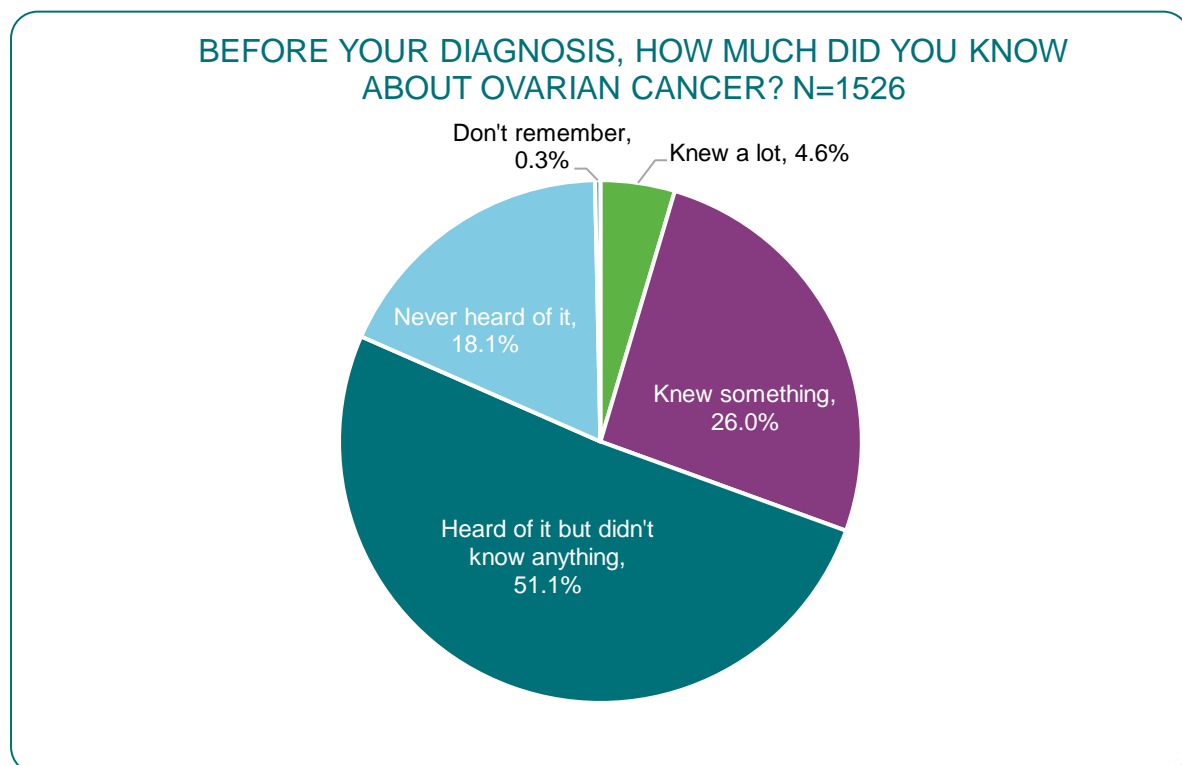
post-diagnosis where 'other' faulty genes were found. This ranged from 0% in Japan, 0.9% in Australia and 2.4% in the UK, to 18.5% in Germany and 31.8% in Italy.

For most women (60%) the tests (before or after) were paid for by the State, insurance companies paid for 27.6% and 7.5% of tests were paid for by the women or a relative. Most countries had women responding in each category.

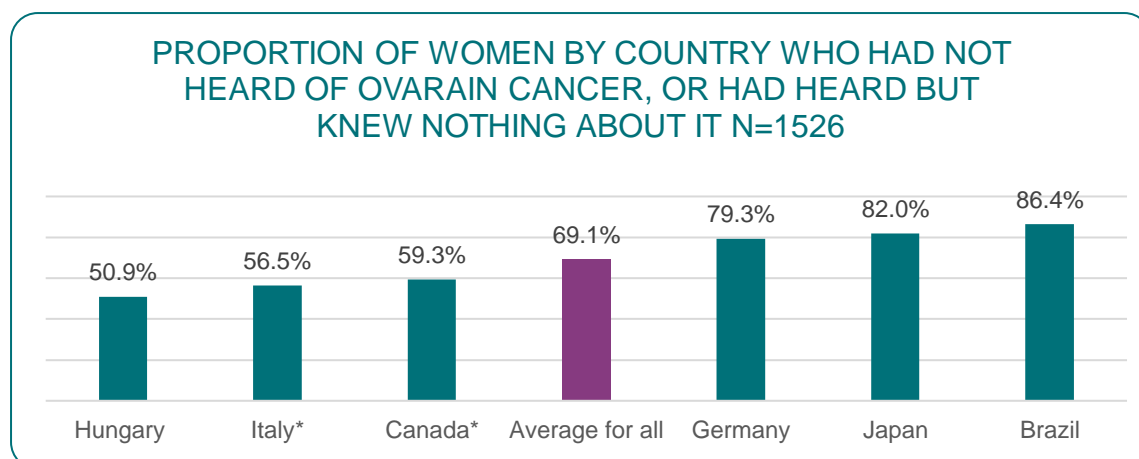
## SYMPTOMS AND LEADING UP TO DIAGNOSIS

### KNOWLEDGE OF SYMPTOMS

Over two-thirds of women who developed ovarian cancer had either never heard of ovarian cancer, or had heard of it but knew nothing about it (69.2%). Just over half of women (51.1%) had heard of ovarian cancer but did not know anything about it. 18.1% had not even heard of it. Just 4.6% said they knew a lot about it. In Brazil this figure was 0%.



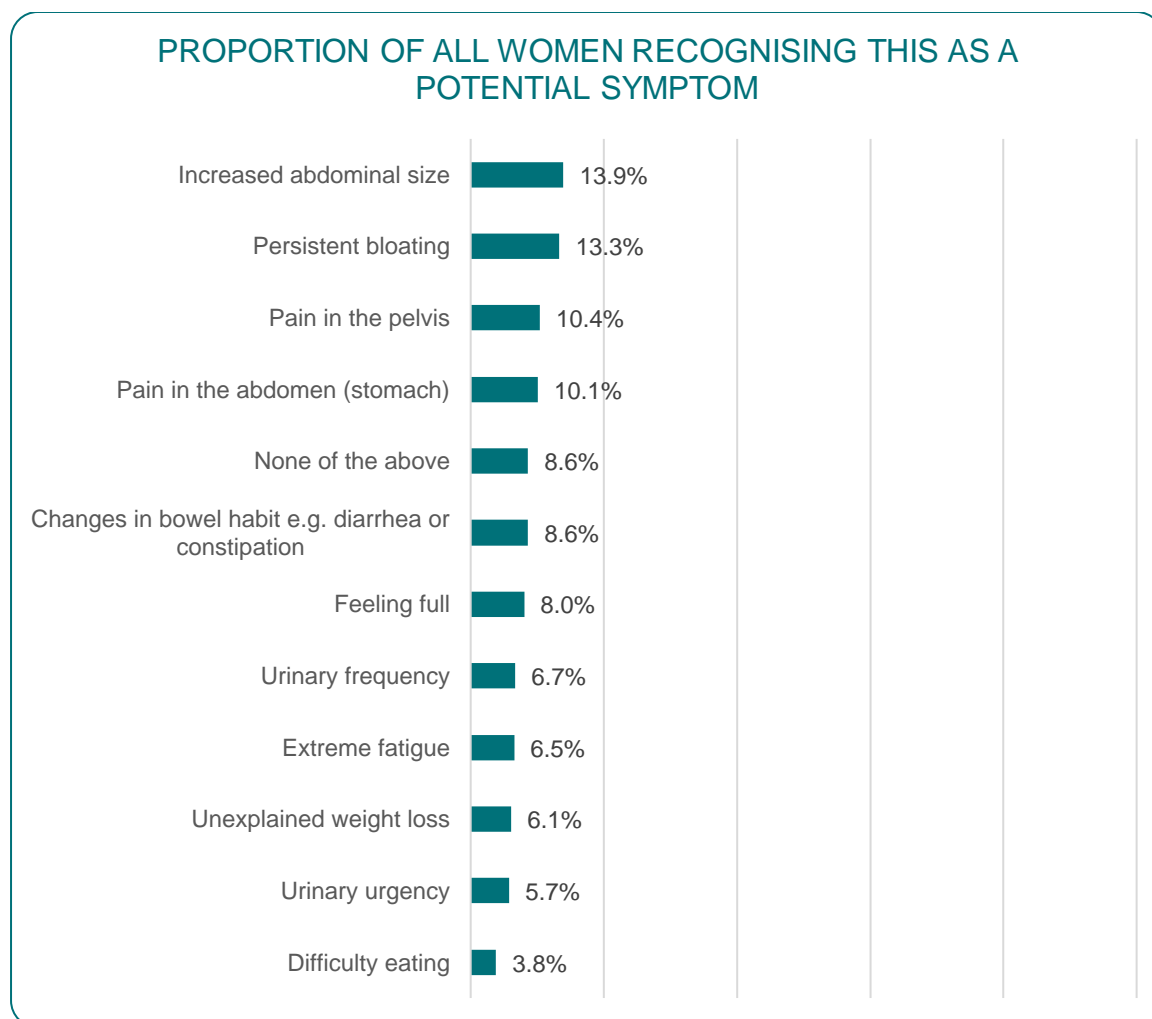
There were variations by country in the proportion not knowing or having heard of ovarian cancer.<sup>17</sup>



<sup>17</sup> BY COUNTRY CROSS TAB NUMBERS Q32

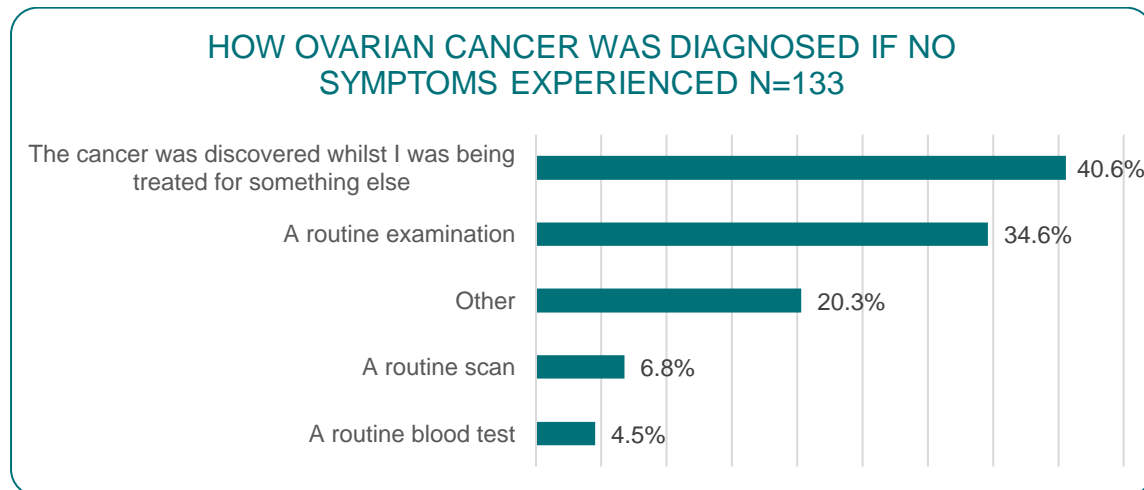
Those women who said they knew something or a lot about ovarian cancer were asked which if any of the following symptoms, if experienced frequently could indicate someone might have ovarian cancer. They were asked to tick all that they knew. On average they recognised 3 of the symptoms listed below. The most commonly cited was increased abdominal size. It should be noted that despite saying they knew a lot or something, 28% of this group responded 'none of the above'.

As a proportion of the total sample size this means that just under 14% of women recognised the most commonly recognised symptom.

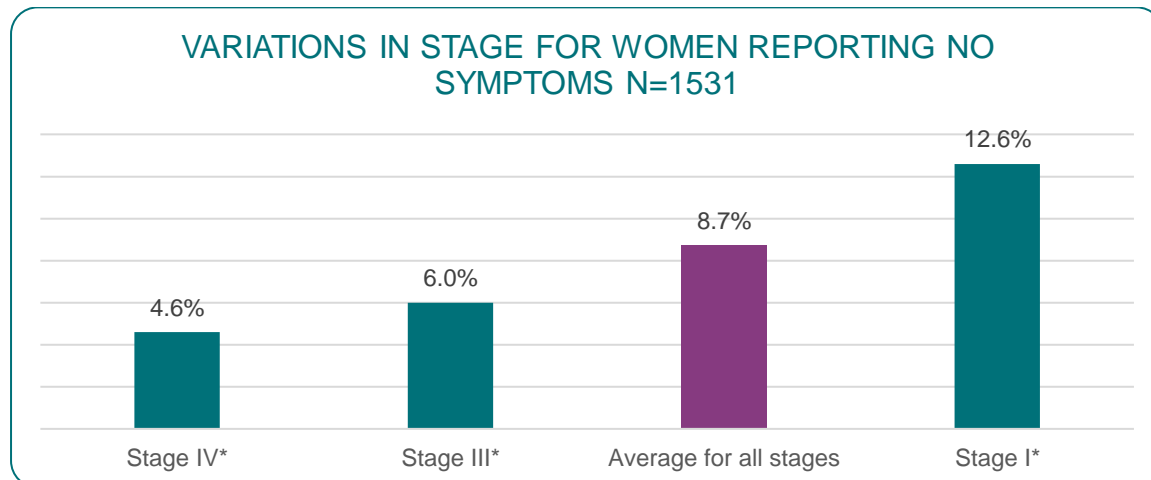


## SYMPTOMS EXPERIENCED PRIOR TO DIAGNOSIS

Just 8.7% of women did not experience any symptoms prior to their diagnosis. For these women, their cancer was most commonly found whilst they were being treated for something else, or during a routine examination (n=133).



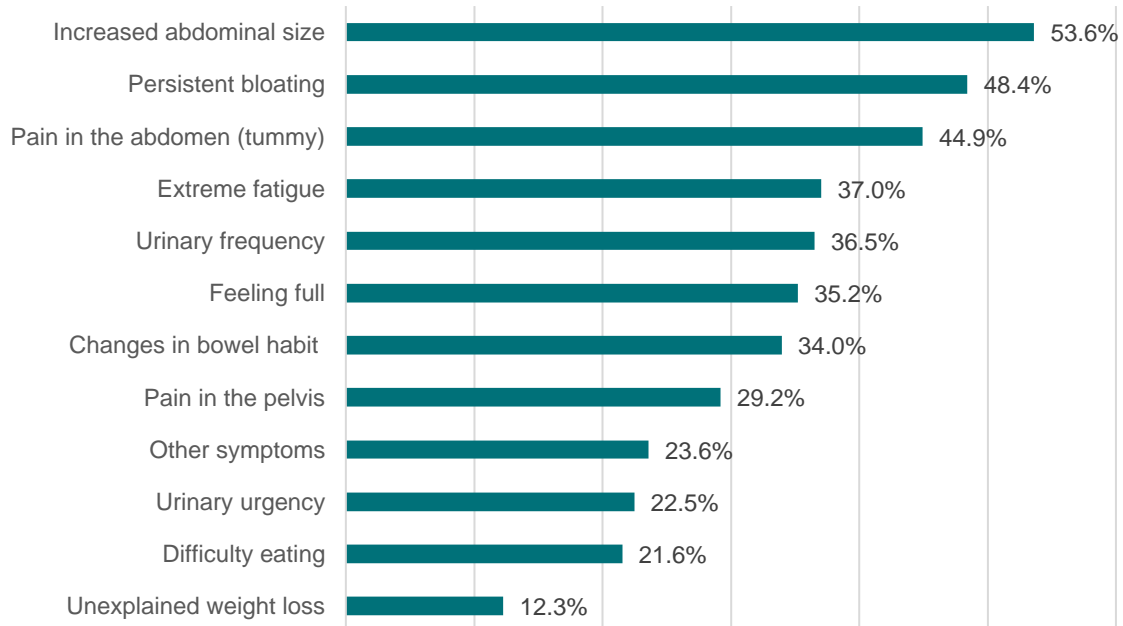
Women who were diagnosed with stage I disease were more likely to report no symptoms compared to the average, and women with stage III or IV disease less likely<sup>18</sup>. This still meant that 87.4% of women with stage I disease experienced symptoms.



Excluding the responses for 'other symptoms', those who experienced symptoms experienced on average 4 symptoms from the list below (mean=4.4).

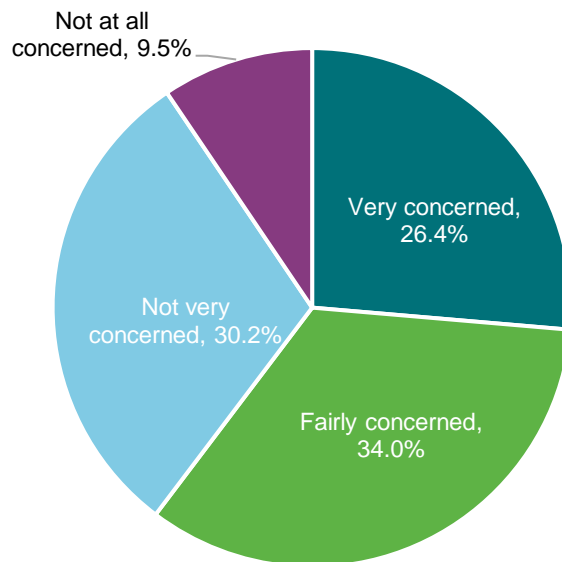
<sup>18</sup> BY STAGE CROSS TAB NUMBERS Q34

**PROPORTION OF SYMPTOMATIC WOMEN WHO SAID THEY HAD THIS SYMPTOM PRIOR TO DIAGNOSIS N=1398**



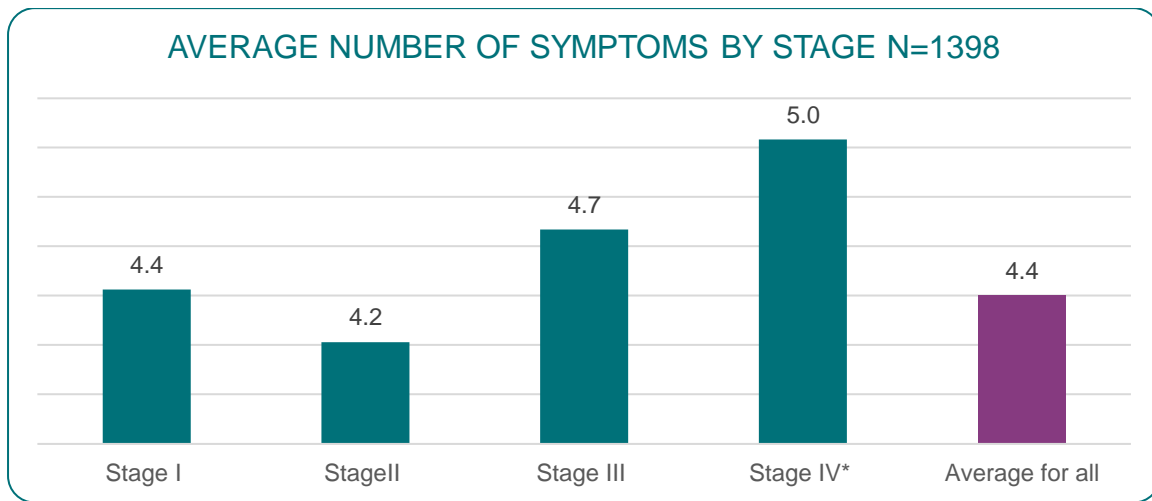
Just over a quarter of women described themselves as being very concerned about their symptoms, with 60% in total saying they were very or fairly concerned (n=1396).

**LEVEL OF CONCERN ABOUT SYMPTOMS N=1396**



There were no statistically significant variations found in levels of concern between women diagnosed with different stages or types of ovarian cancer, or between women of different ages.

The average number of symptoms by stage of diagnosis was as follows: Women with stage IV ovarian cancer were likely to report a higher than average number of symptoms (5.0 vs 4.4), but only one more symptom than for the other stages. Women with stage I, II and III disease on average experienced between 4 and 5 symptoms from the list.



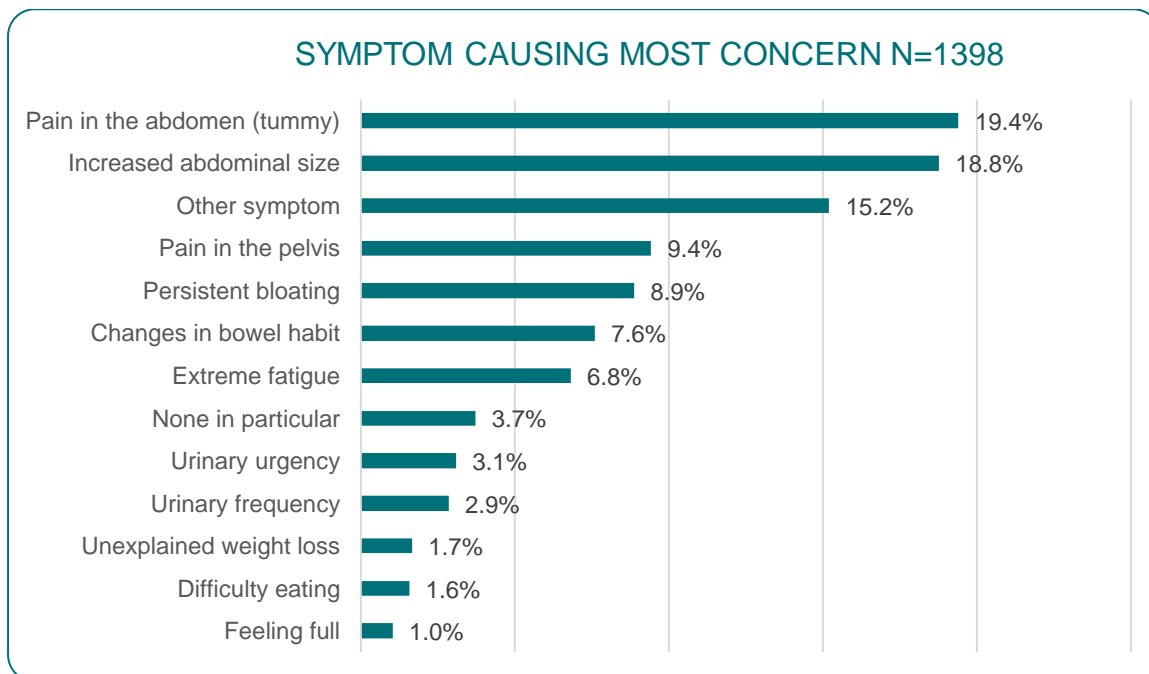
There were no statistically significant differences seen in the average number of symptoms reported by type of ovarian cancer<sup>19</sup>. There were some but not many differences in the type of symptoms reported by cancer type, where 50 or more women had that type. Germ cell, sex cord stromal, granulosa and teratoma were consequently excluded. Fallopian tube cancers had more variation than any other type.

LESS LIKELY	TYPE OF SYMPTOM REPORTED ON AVERAGE (N=1531)	MORE LIKELY
Fallopian tube 28%	Pain in the abdomen 44.9%	
Clear cell 16.7% Fallopian tube 18%*	Pain in the pelvis 29.2%	
Fallopian tube 30%	Persistent bloating 48.4%	Borderline 66.7%
	Increased abdominal size 53.6%	Mucinous 67%*
	Feeling full 35.2%	
	Difficulty eating 21.5%	
	Urinary frequency 36.1%	

<sup>19</sup> BY TYPE OF OVCA CROSS TAB Q34

Fallopian tube 12%*	Urinary urgency 21.8%	
Clear cell 23.6%	Changes in bowel habit 34%	
Fallopian tube 22%*		
	Extreme fatigue 37%	
Mucinous 3.3%	Unexplained weight loss 12%	
	Other symptoms 23.6%	
	No symptoms reported 8.7%	

Women were asked which one symptom caused them most concern:

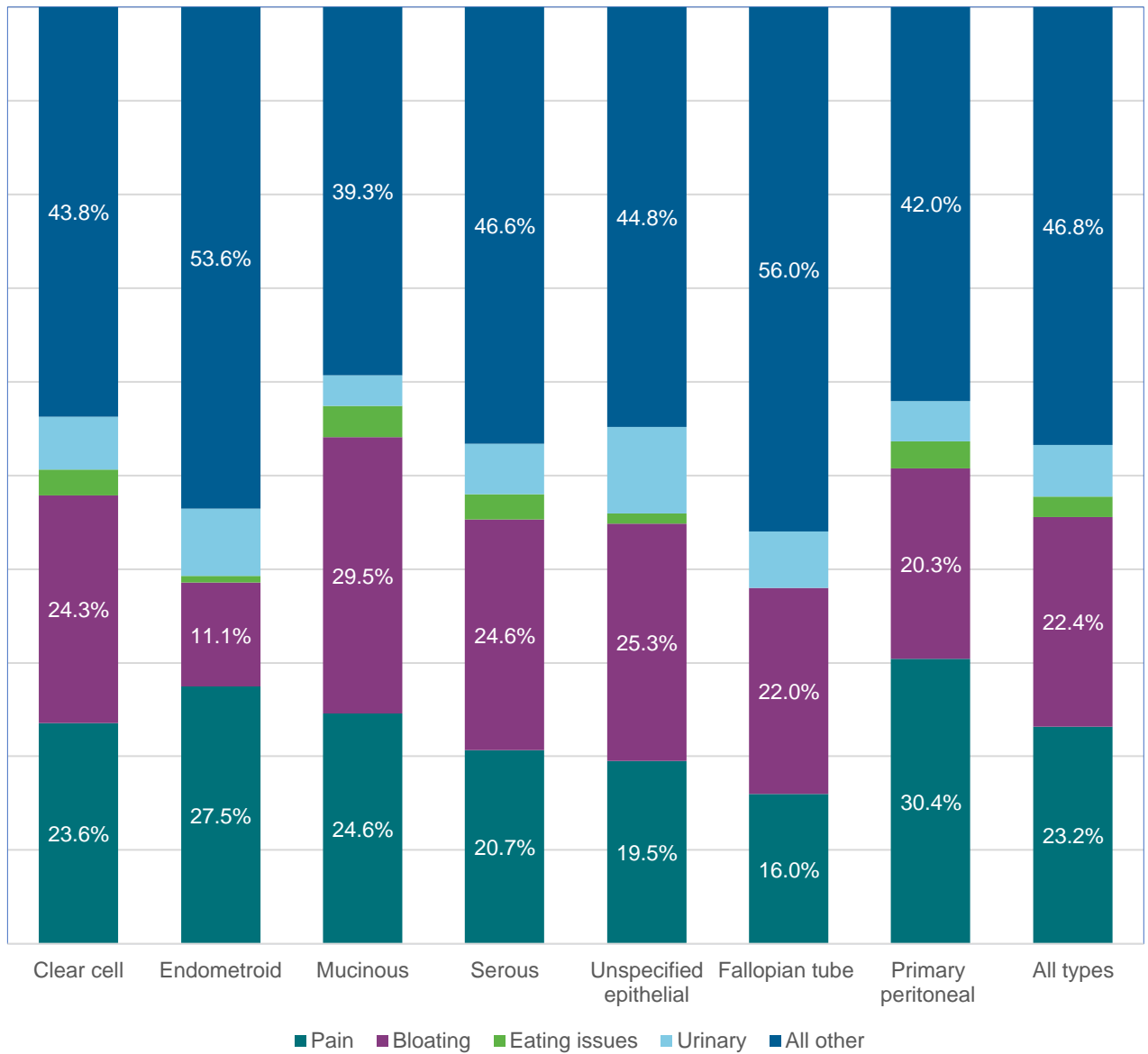


As some women may have reported for example both bloating and increased abdominal size, or difficulty eating and feeling full, the symptoms were then grouped into more generic types, and duplicate entries not counted. For example, if a woman reported both bloating and increased abdominal size, this counted as one rather than two entries. The categories were: pain, bloating, eating issues and urinary. Statistically significant differences were seen in the grouped symptoms for endometrioid ovarian cancer:<sup>20</sup> For endometrioid ovarian cancer women were much less likely to report bloating as the symptom of greatest concern (11.1% vs 22.4% for all types), and less likely to report eating issues as the symptom of greatest concern (0.7%\* vs 2.2% for all types).

<sup>20</sup> ADDITIONAL ANALYSIS STATISTICAL CHECKS/SYMPTOMS



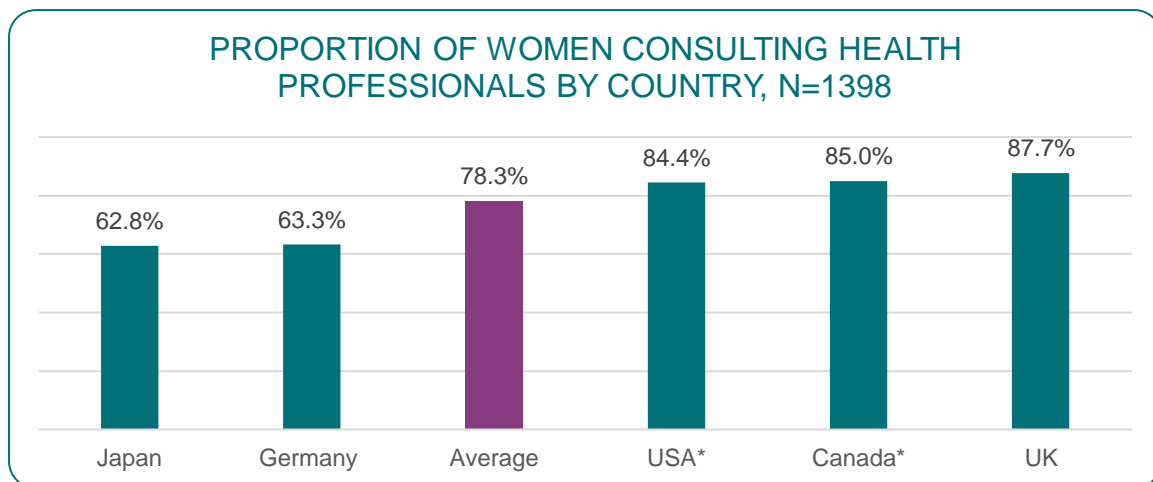
PROPORTION OF PRIMARY SYMPTOM OF CONCERN GROUPED,  
FOR CANCER TYPES WHERE N>50 TOTAL SAMPLE N=1221



## ROUTE TO DIAGNOSIS

78.3% of women consulted a health professional about their symptoms. For the remainder (21.7%) something else led to their diagnosis. Women who were diagnosed with stage I cancer were more likely not to have consulted a health professional about symptoms (28.1%\*) and those with stage IV cancer less likely not to have consulted a health

professional (15%\*)<sup>21</sup>. There were also variations by country<sup>22</sup>:



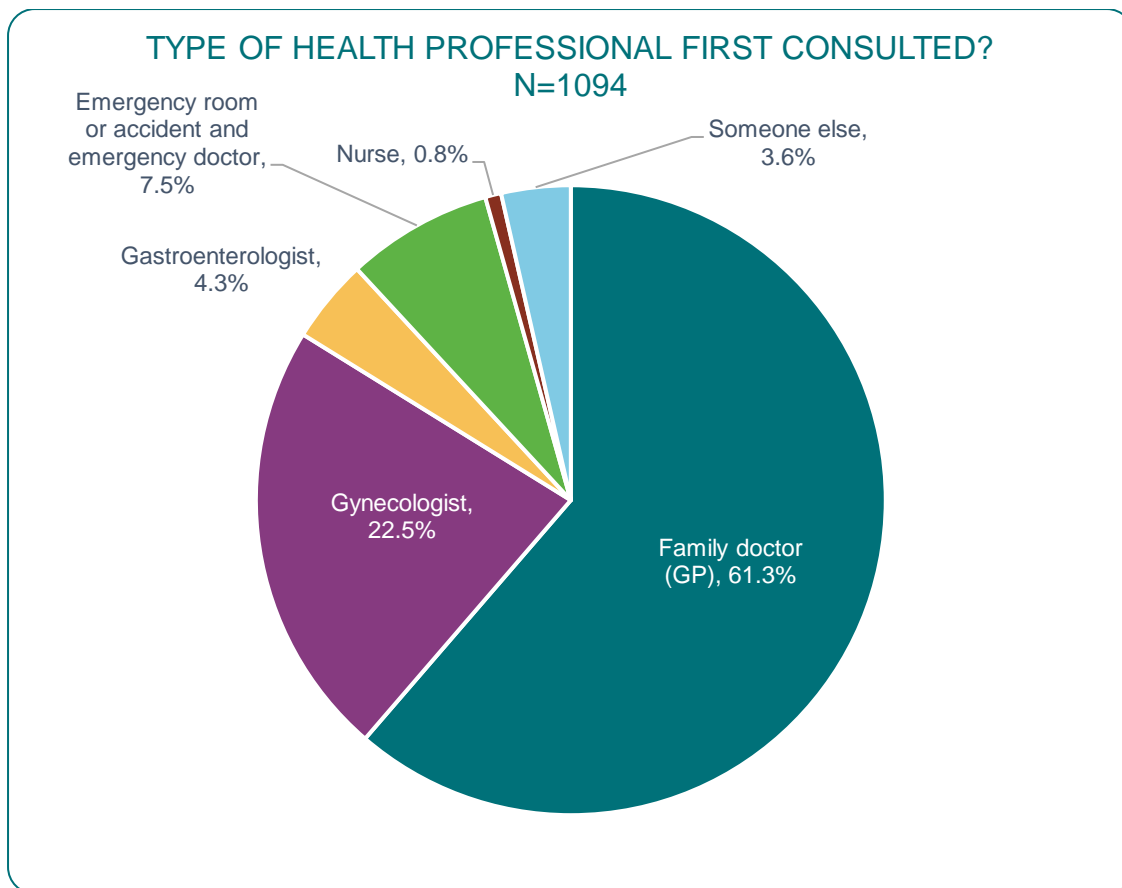
Women who said that the state paid some or all of their medical costs were more likely to consult a health professional (81.6%) and women who said that they had to pay some or all of their medical costs themselves were less likely have consulted a health professional (72.2%\*)<sup>23</sup>.

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<sup>21</sup> BY STAGE CROSS TAB NUMBERS Q38

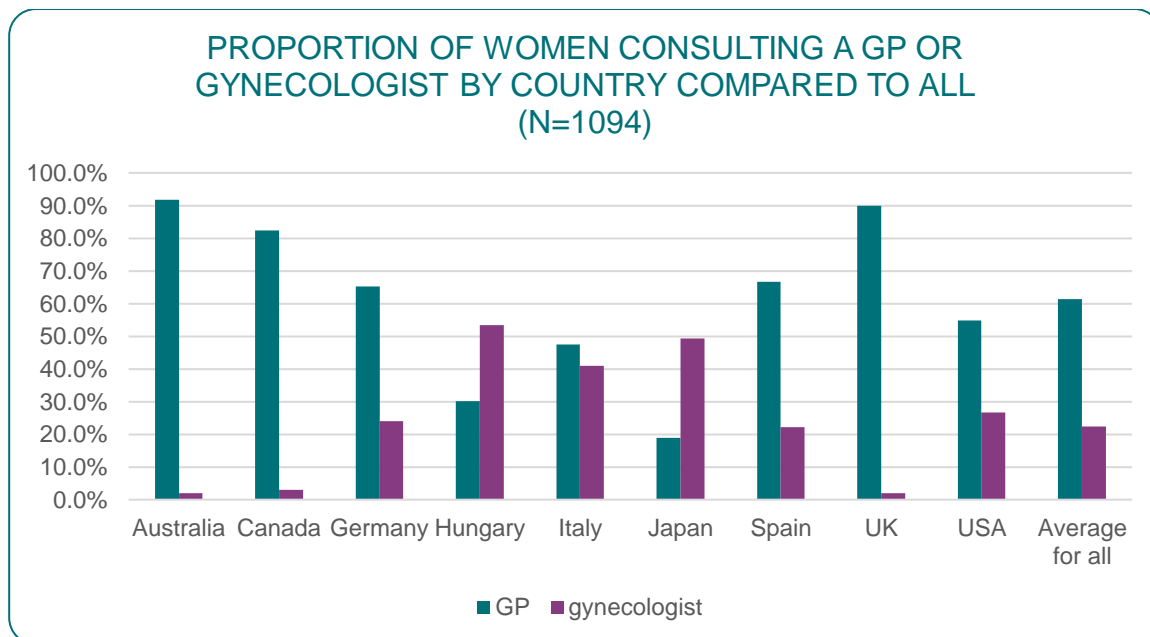
<sup>22</sup> BY COUNTRY CROSS TAB NUMBERS Q38

<sup>23</sup> ADDITIONAL ANALYSIS STATISTICAL CHECKS/PAYMENT



Most women who consulted a doctor consulted a family doctor (61.3%). When looked at by breakdown of country (where  $n > 40$ ), there were statistically significant differences for women visiting GPs or gynecologists<sup>24</sup>. In Australia, Canada and the UK women are much more likely to consult a GP than a gynecologist. In Brazil, Hungary and Japan women are much more likely to consult a gynecologist, and in the US and Italy the picture is more mixed. In Brazil, women were more likely to first consult an Accident and Emergency doctor than in other countries (23.7%\* vs 7.5%). The low reporting of visits to A&E may reflect or two factors, that this is a relatively well cohort (A&E diagnosis is more highly associated with short term mortality), and that this question asks about the first visit to a doctor.

<sup>24</sup> BY COUNTRY CROSS TAB NUMBERS Q39



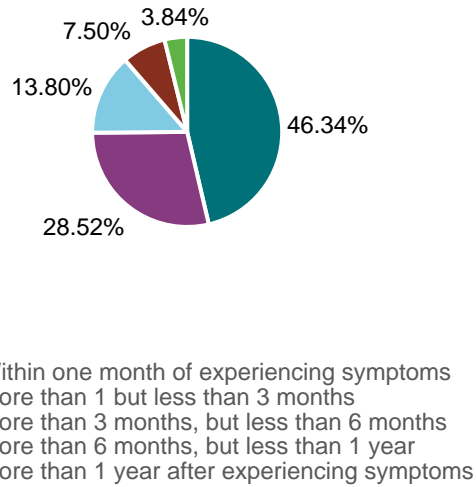
Looking at who has contributed towards health care costs, and the type of doctor or health professional first seen the following variations were seen<sup>25</sup>:

- Women who said the State paid for some or all of their care were more likely to consult a family doctor or GP than the average for all (67.6% vs 57.9%)
- Women whose family had contributed towards some or all the costs of their care were less likely to consult a GP or family doctor (42.4% vs 57.9%)
- Women who said the State paid for some or all of their care were less likely to consult a gynecologist than the average for all (17.9% vs 24.3%)
- Women whose family had contributed towards some or all the costs of their care were more likely to consult a gynecologist (33.5% vs 24.3%)

Women were asked how quickly they visited that health professional after experiencing symptoms. 46.3% of women went within one month, and a further 28.5% going within 3 months. A quarter of women waited over 3 months (25.1%) and over 10% of women waited more than 6 months (11.3%).

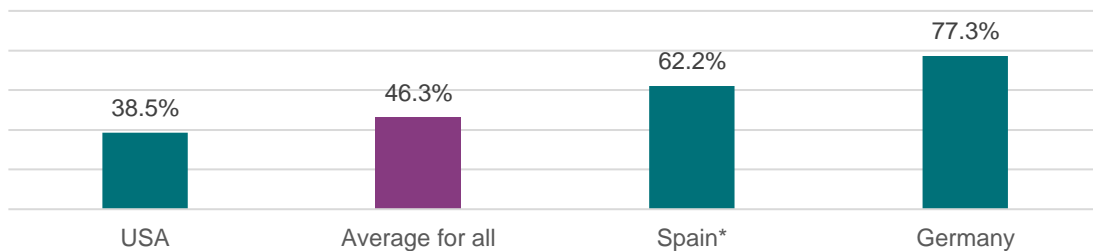
<sup>25</sup> ADDITIONAL STATISTICAL ANALYSIS CHECKS/ PAYMENT

HOW SOON AFTER EXPERIENCING SYMPTOMS DID YOU VISIT A HEALTH PROFESSIONAL? N=1094

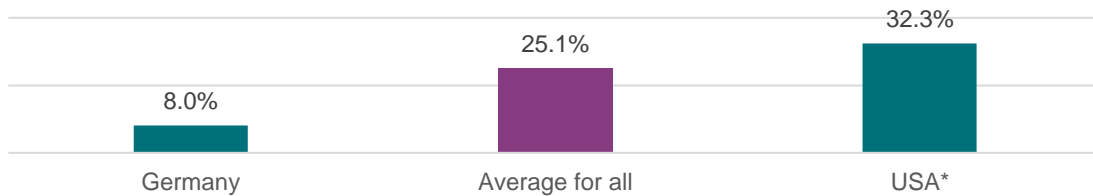


There were some variations between countries:<sup>26</sup>

PROPORTION OF WOMEN WHO VISITED A HEALTH PROFESSIONAL ABOUT SYMPTOMS WITHIN ONE MONTH N=1094



PROPORTION OF WOMEN WHO VISITED A HEALTH PROFESSIONAL ABOUT SYMPTOMS MORE THAN 3 MONTHS AFTER THEY STARTED N=1094

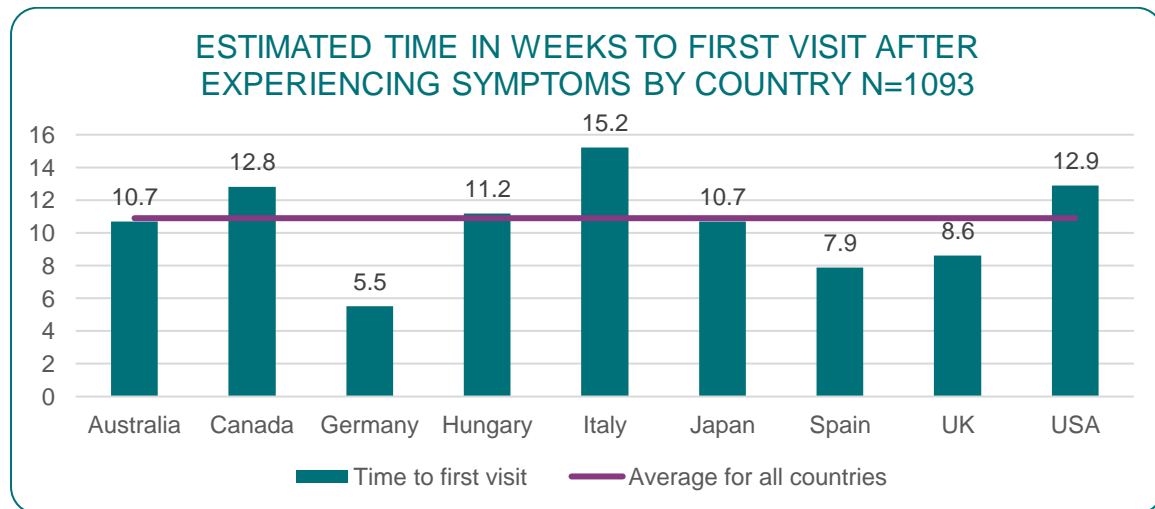


There were no statistically significant variations when looking at the time to visit the doctor and stage on diagnosis apart from women diagnosed with stage IV were more likely to have visited the doctor within a month of experiencing symptoms (56%\* vs 46.3%). Women who

<sup>26</sup> BY COUNTRY CROSS TAB NUMBERS Q40

knew lots about ovarian cancer were more likely to visit a doctor within the first three months of experiencing symptoms (85.4%\* vs 74.8%).<sup>27</sup>

An average time to visit a health professional in weeks was calculated by allocating the mid-point of each time period. For example, 'up to one month' was given a nominal figure of 2 weeks, 1-3 months was 8 weeks, etc. This gives an indication of how countries might vary. Only countries with more than 40 responses were considered. The average time period to visit a doctor using this method (for all countries) was 10.9 weeks.

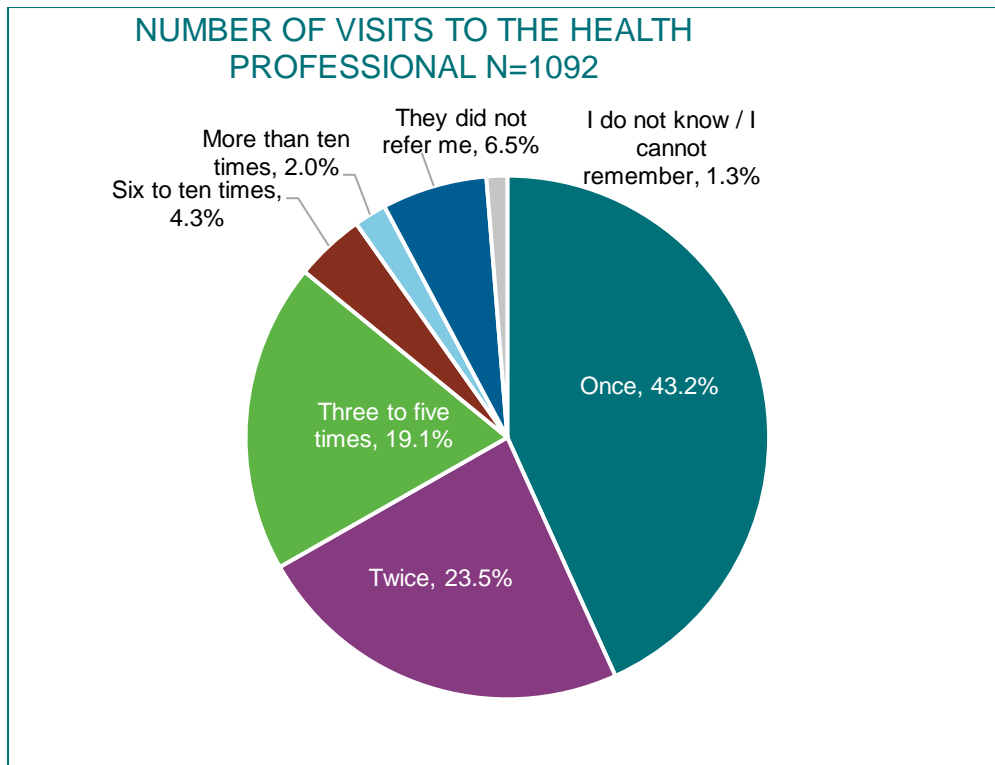


37.4% of the health professionals took women’s concerns very seriously, with a further 22.5% taking them fairly seriously. Just under 40% (39.5%) of women felt that health professionals did not take their concerns very seriously, or not at all seriously. No significant differences were found between types of health professionals consulted and how seriously the professional took the women’s concerns. In Germany women were more likely to report that their concerns were taken very seriously (52%\* vs 37.4%) and less likely to report their concerns were taken not at all seriously (9.3% vs 19.2%)<sup>28</sup>.

There were also a few differences in the number of times women saw that health professional before being referred on. 43.2% of women were referred after their first visit: However, for around a third of women, it took three or more visits before being referred on.

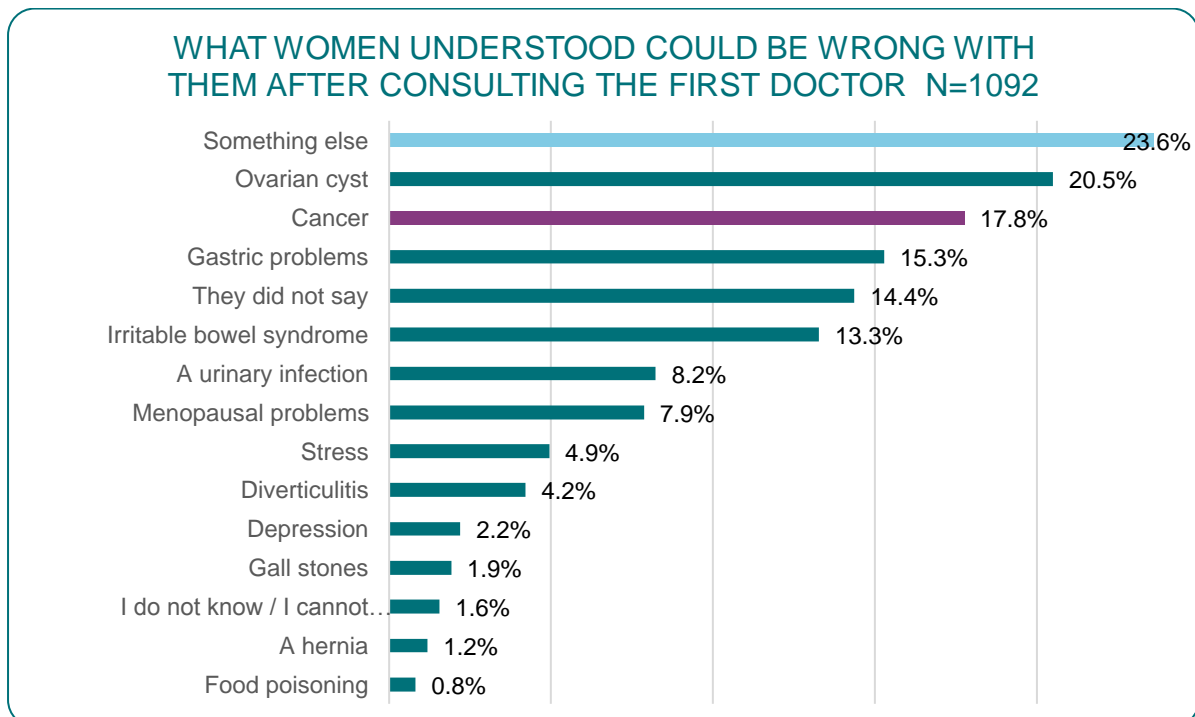
<sup>27</sup> ADDITIONAL STATISTICAL CHECKS/KNOWLEDGE CROSS TAB Q32 AND Q40

<sup>28</sup> BY COUNTRY CROSS TAB NUMBERS Q41



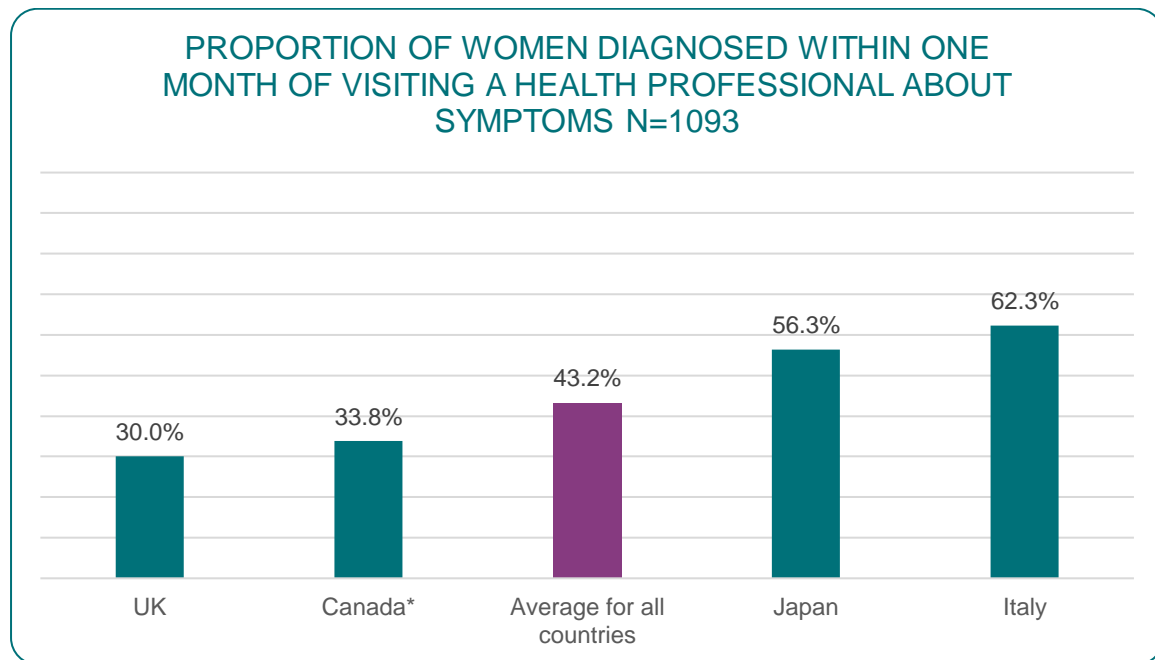
In Canada a higher proportion were referred after their second visit (33.8%\* vs 23.5%) and in the US a lower proportion were referred after their second visit (16.9%\*).

For the health professionals the women first saw, just 17.8% indicated they thought cancer was the cause of their symptoms. More doctors indicated ovarian cysts 20.7%, and irritable bowel syndrome, gastric problems and other diagnoses were each indicated in more than 10% of cases.



In addition to the first person they saw, women then saw a range of other healthcare professionals including most commonly gynecologists, other family doctors, or accident and emergency doctors.

Women were asked how long it took from first visiting a doctor about symptoms until their diagnosis. On average 43.2% were diagnosed within a month of first visiting a doctor. There were no variations by type of ovarian cancer (looking at type where there were more than 40 respondents). Women who knew lots about ovarian cancer were more likely to be diagnosed within a month of visiting their doctor (58.3%\* vs 43.2%)<sup>29</sup>. There were also country variations:<sup>30</sup>



For one in ten women (11.3%) their diagnosis took more than a year. Japan was the only country where women were statistically much less likely to be diagnosed more than a year after visiting a doctor 2.8%.<sup>31</sup> Women with clear cell ovarian cancer were less likely to be diagnosed more than a year after visiting a doctor (5.1%\*). No significant variations were found between time to diagnosis, and stage of ovarian cancer diagnosed, i.e. a similar proportion of women with stage I cancer were diagnosed within 1 month, as women with stage IV, and likewise for diagnosis occurring after a year.

An average time from first visiting a health professional to diagnosis was calculated. An error in the programming of the survey, meant the time period for three to six months was excluded, which was not picked up on testing, or highlighted by anyone completing the survey. The results were adjusted by taking one-third of the one to three months, and one-

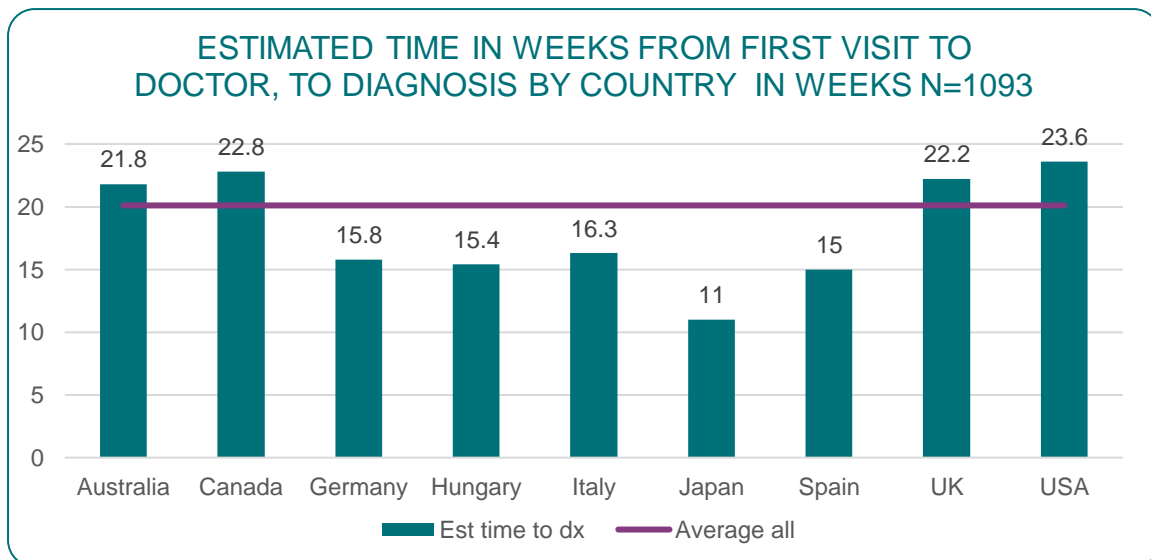
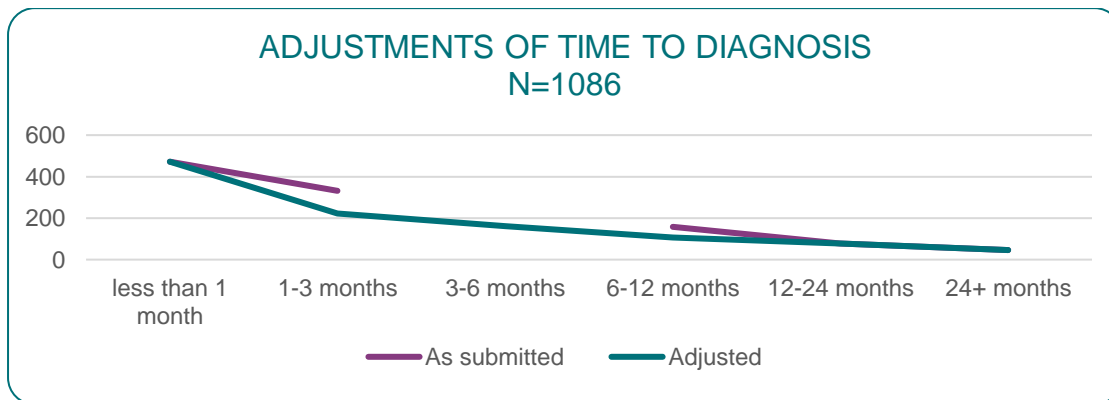
<sup>29</sup> ADDITIONAL ANALYSIS STATISTICAL CHECKS/KNOWLEDGE CROSS TAB Q32 AND Q45

<sup>30</sup> BY COUNTRY CROSS TAB NUMBERS Q43

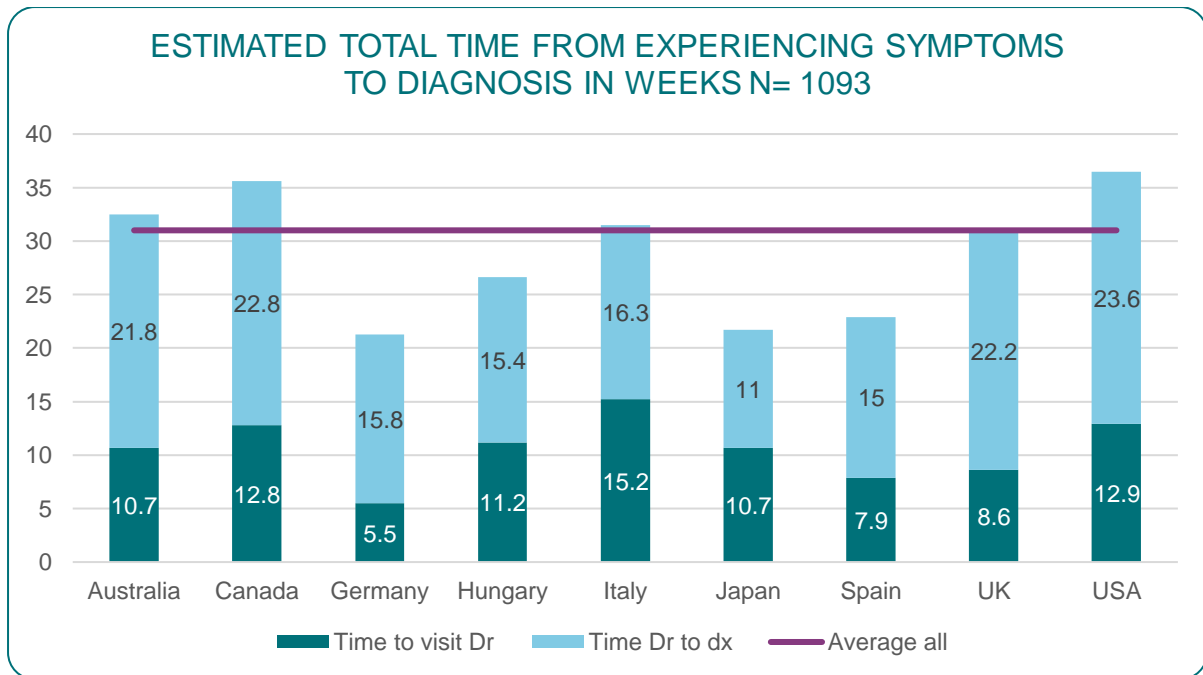
<sup>31</sup> BY COUNTRY CROSS TAB Q45



third of the six to twelve months, and combining those. The data for less than one month and more than twelve months was left untouched. The mid-point of each time period was used to calculate an average time to diagnosis. There was minimal variation in the average time between that submitted and the adjusted figure (19.6 weeks vs 19.7 weeks).



Looking at the estimated times to visit a doctor, and then to get a diagnosis provides a clear indication of the level of variations that can exist, and what factors might be contributing. They are however not to be taken as an actual representation.



The average was 31 weeks for all women in the study who experienced symptoms in any country, and 28.8 weeks for women in the countries above.

Women were asked which the first tests were that were carried out as part of their diagnosis. Some women gave one answer, and others two. There were variances between countries as follows when examining the proportion of first tests carried out<sup>32</sup>.

Test	More likely to use as one of the first two tests	Proportion of first tests including this (average for all)	Less likely to use as one of the first two tests
CA125	UK 39.9% Italy 38.5% Hungary 36.7%*	25.4%	Germany 13.6% Japan 18.8% USA 20.5%*
Abdominal ultrasound	Germany 28.8% Canada 24.6% UK 23.4%	13.7%	Brazil 3.9% Italy 5% Hungary 6.1% Japan 8.3%
Transvaginal ultrasound	Hungary 32.7%* USA 25.8%	21.2%	Spain 14%* UK 15.5%*
MRI	Japan 21.6% Brazil 16.7%*	7.7%	Italy 0.6% Australia 1.1% UK 2.5%

<sup>32</sup> BY COUNTRY CROSS TAB NUMBERS Q46

			USA 3.8% Canada 4.4%*
CT	Italy 28.6%* USA 25.1%*	19.3%	Hungary 11.2% UK 13%
X-ray		3.8%	

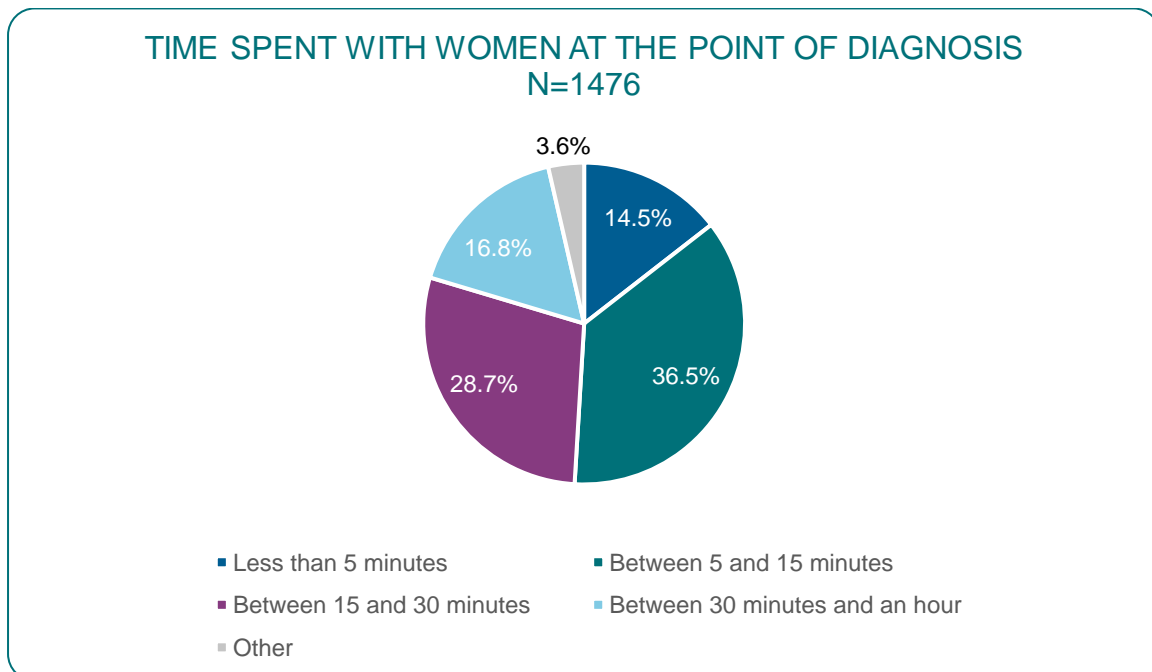
Just over half of women (52.9%) were able to always get answers to any questions they had in connection to tests leading up to their diagnosis. Just over 10% of women either could not ask questions or did not get any answers they understood (11.4%).

### AT THE POINT OF DIAGNOSIS

It was a gynecologist who most commonly told women about their diagnosis 43.6%. By far the large majority of diagnoses were delivered face to face (88.5%), with 10.5% of women getting their diagnosis by telephone.

Most women (66.9%) were able to have someone (family or friend) with them at the time of diagnosis, but 31.9% of women were alone.

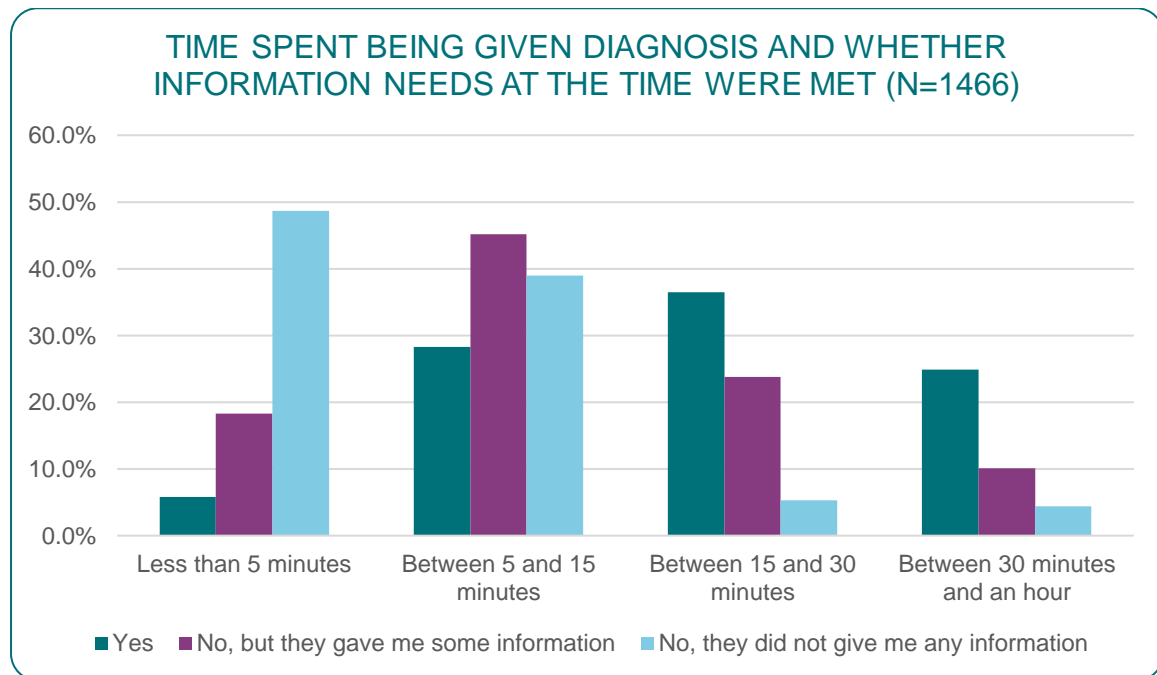
The most common period of time spent with women was between 5 and 15 minutes when they were given their diagnosis (36.5%). For 14.5% of women, the person giving them their diagnosis spent less than 5 minutes with them.



More than half of all women did not get all the information they needed at the time of diagnosis. Just under half of all women felt they were given all the information that they needed at that time (46.9%), with a further 41% saying they had been given some

information. 7.9% were not given any information. Only 1.4% said they did not want or need information.

Women who responded that they were given all the information they needed at the time of diagnosis were much more likely to respond that the person giving them their diagnosis spent between 15-30 minutes, or 30-60 minutes with them. Women who said they were given no information were more likely to respond that the person giving the diagnosis had spent less than 5 minutes with them, or 5-15 minutes<sup>33</sup>.



Of those women who were given any information, 92.5% were given verbal information, and just 37.3% of women were given written information. Some women were given both verbal and written information. Taking this into account, 27.5% of all information received was written, and 68.4% was verbal.

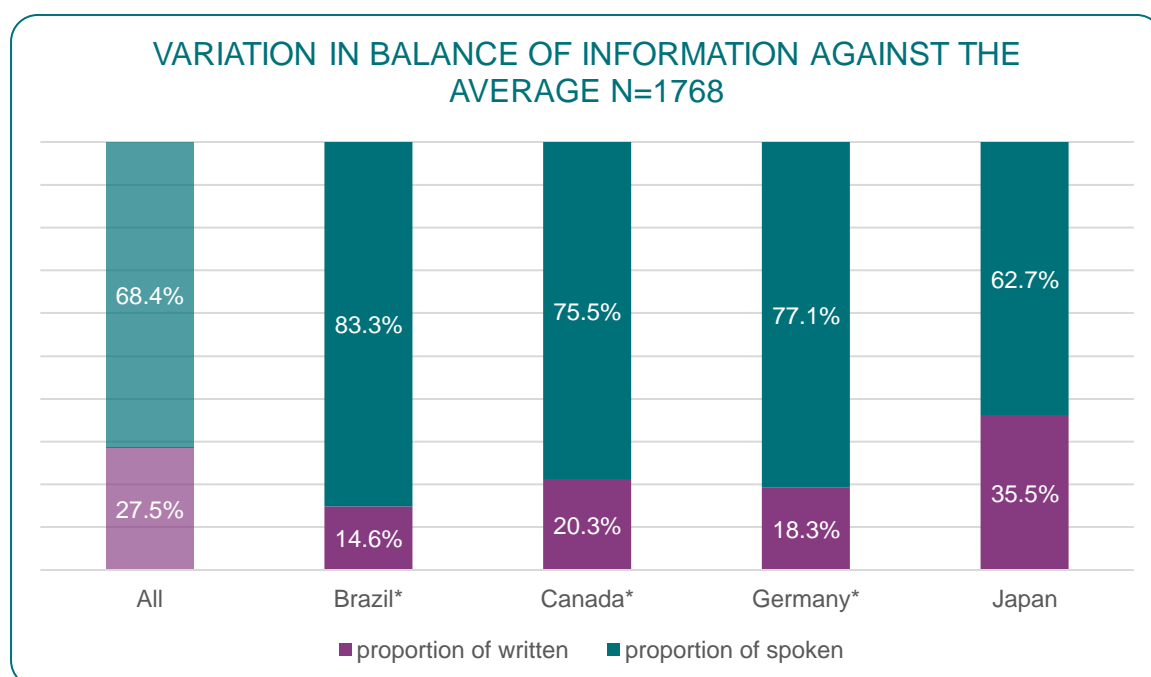
Examining those women who were given any information women who were given written information were statistically much more likely to say they had received all the information they needed (65.7%), and less likely to report having only received some of the information (34.4%).<sup>34</sup>

<sup>33</sup> INFO GIVEN CROSS TAB % Q51

<sup>34</sup> BY TYPE OF INFO ON DX CROSS TAB Q52

When countries were analysed the following was seen<sup>35, 36</sup>

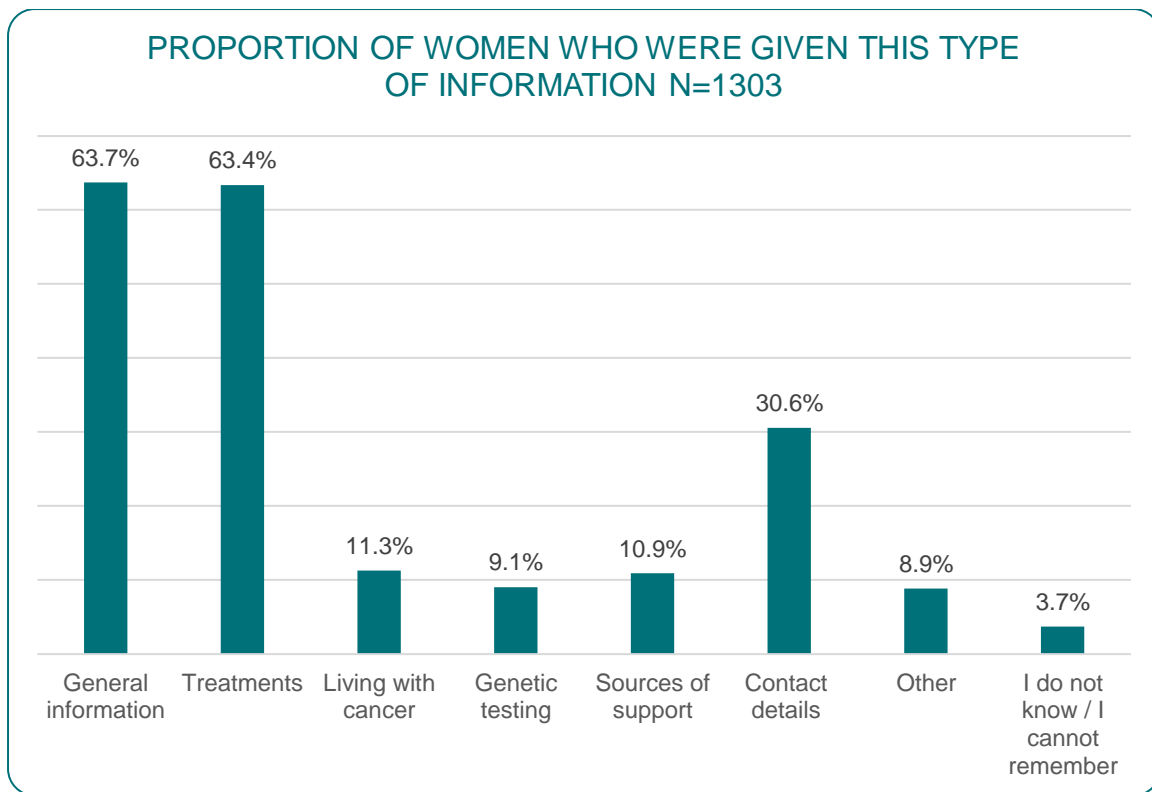
- In terms of the overall findings, respondents in Spain (63.6%) and Italy (62.2%) were more likely to have been given all the information they needed (average 46.9%), and Canada less likely (29.1%). Respondents in Canada were more likely to have been given no information at all (13.9%\* vs 7.9%) at the point of diagnosis.
- Japan was much more likely to have a higher proportion than the average of written information (35.8%) vs spoken (62.5%).
- Germany, Brazil and Canada were more likely to have a higher proportion of spoken information and a lower proportion of written information than the average.



Just under two-thirds of women who received verbal or written information were given general information about the disease (63.7%), and treatments (63.4%). Just 30.6% of women were given contact details for the health professionals caring for them. Only 11.3% received information about living with cancer, and even less (10.9%) were given information about sources of support for women with ovarian cancer.

<sup>35</sup> BY COUNTRY CROSS TAB NUMBERS Q52

<sup>36</sup> BY COUNTRY CROSS TAB NUMBERS Q53

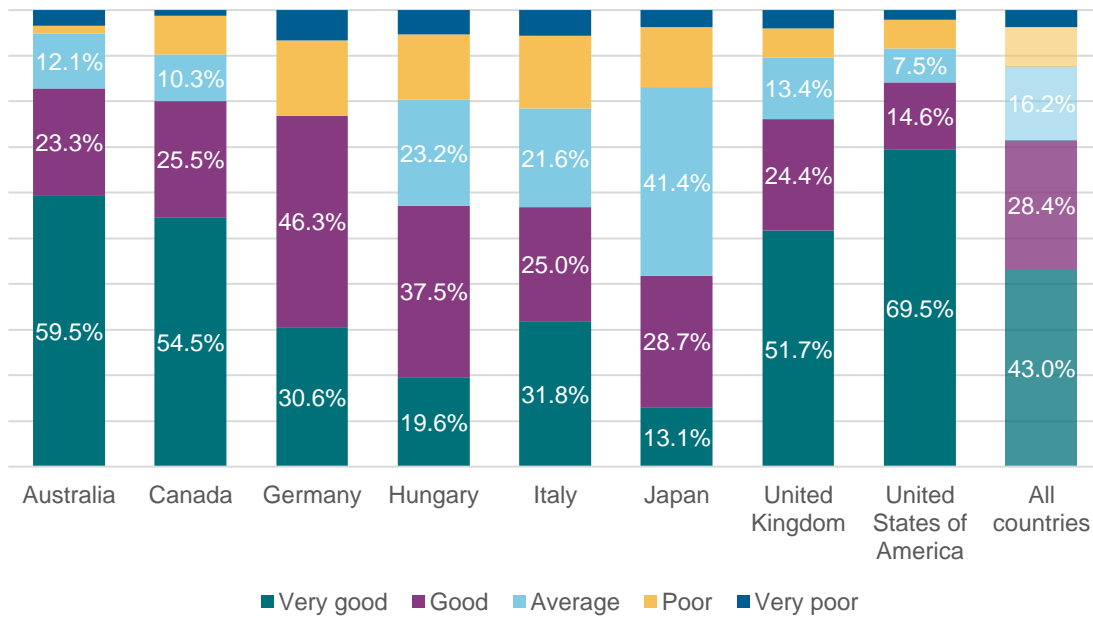


Overall women were very positive about the quality of care they received around the time of their diagnosis, with 43% saying it was very good, and 28.3% saying it was good. Looking at the analyses by country, the statistically significant variations were as follows<sup>37</sup>:

- Women in Australia, Canada, UK\* and USA were more likely to report their care around diagnosis as very good.
- Women in Germany, Hungary, Italy\* and Japan were less likely to report their care as very good.
- Women in Germany were more likely to report their care around diagnosis as poor when compared to the average.

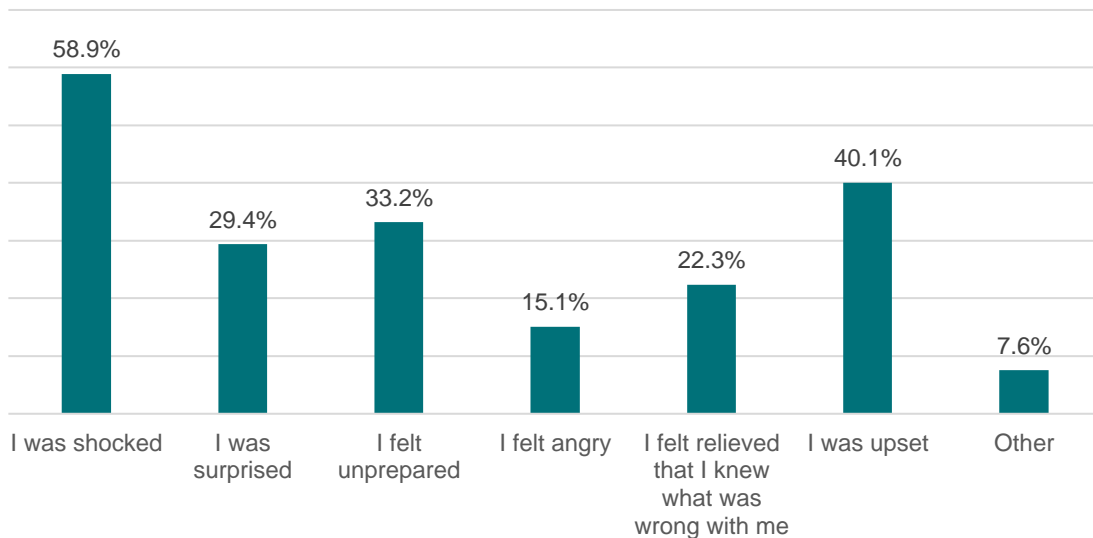
<sup>37</sup> BY COUNTRY CROSS TAB NUMBERS Q55

### HOW WOMEN REPORT THEIR CARE AROUND THE TIME OF DIAGNOSIS N = 1474



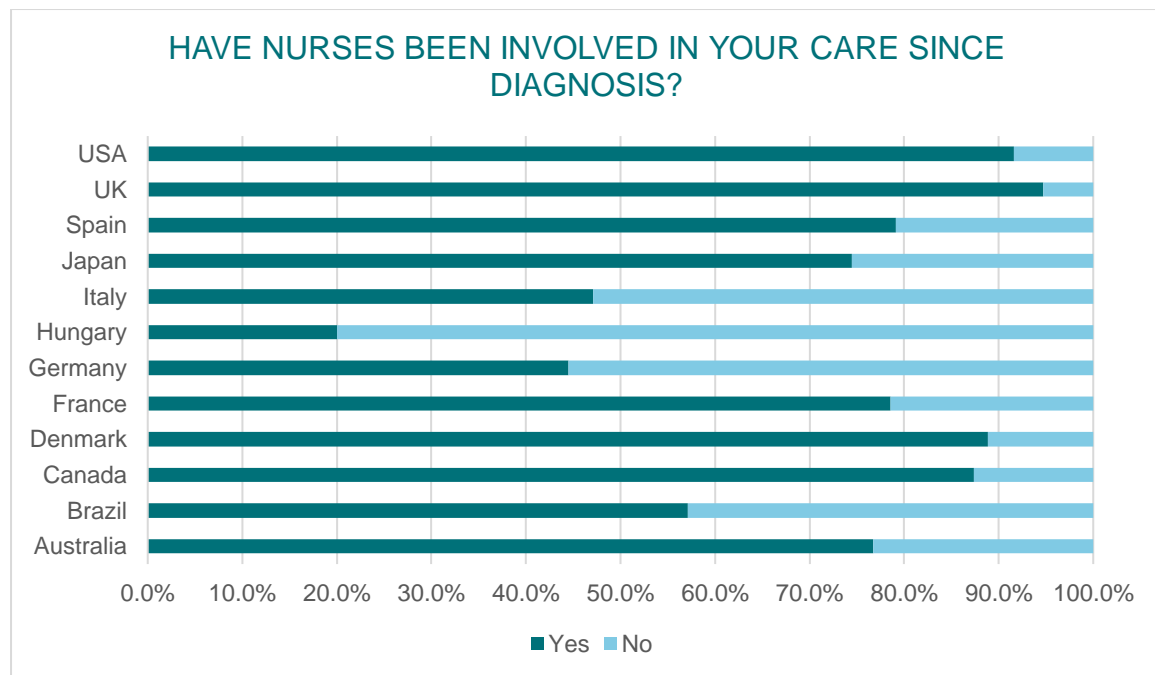
Needless to say, being given a diagnosis of ovarian cancer brings about negative emotions. Women could select more than one option. A total of 1478 women submitted a response.

### PROPORTION OF WOMEN EXPRESSING THIS REACTION N=1478



## NURSES INVOLVEMENT IN CARE OF WOMEN

Almost 75% of women have had contact with nurses since their diagnosis. The proportion is affected by the country in which they live.



Where nurses are involved in care, on the whole they are involved in most aspects of care from diagnosis, surgery, chemotherapy, follow up and acting as a contact point. They are more likely to be specialist nurses around the time of chemotherapy (78%), follow up (57%) and answering questions between appointments (60%), than on diagnosis (43%) or at surgery (48%).

The most common time period nurses are reported spending with women is between 5 and 15 minutes (51.0%), with a further 19.6% of women saying on average nurses spend between 15 and 30 minutes with them.

Comments about nurses' involvement are largely positive, with their ability to provide continuity of care the most commonly reported (51.6%). For around a third of women they report that:

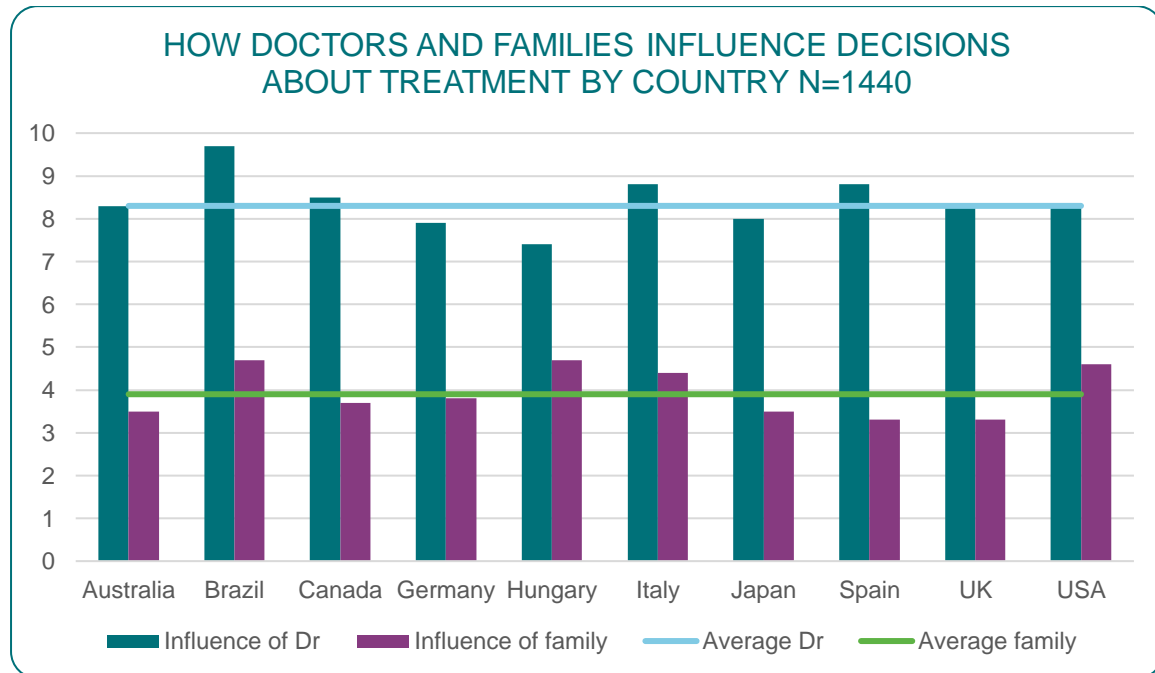
- They are a good source of information about ovarian cancer (35.5%).
- The nurses spend more time with them than the doctors (33.8%).
- They signpost women to other services (31.1%).
- Women feel able to ask them questions they find hard to ask the doctors (30.7%).

The most common negative statement was that women almost never see the same nurse (15.1%). Around 10% of women feel they wish nurses would help them access services they might need (11.25%) and that nurses do not have enough time to spend with them (10%), and that they could give more information about ovarian cancer (10%).



## TREATMENTS FOR OVARIAN CANCER

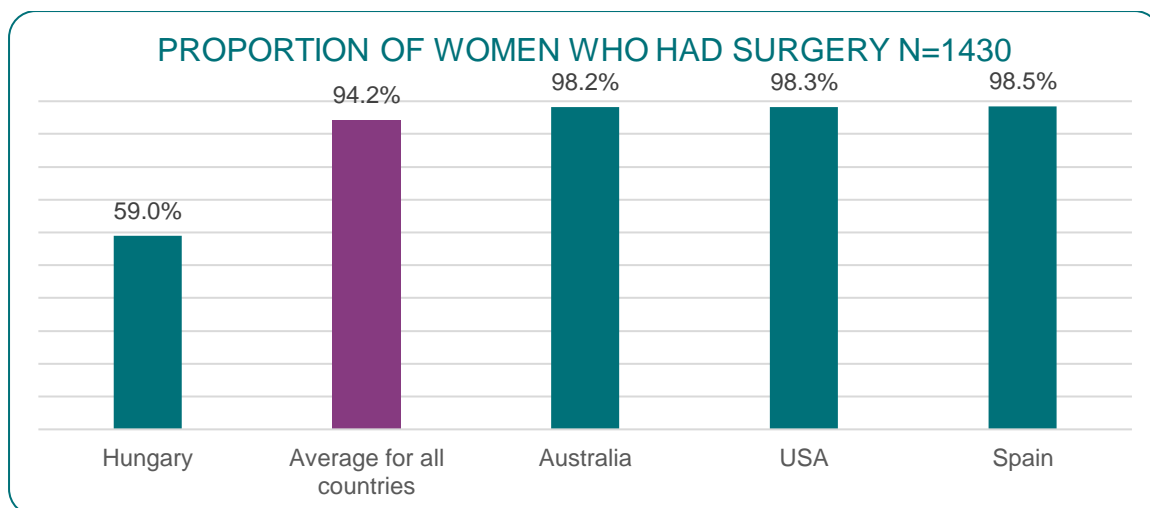
Women were asked, on a scale of 0 to 10 to rate how much influence a doctor had on their decisions about treatment. A score of 10 would indicate they trusted the doctor totally. For the sample as a whole, the average score was 8.3. Women were also asked, on a scale of 0 to 10, to rate how much influence their family had on decisions about their treatment, with 10 indicating the family were wholly responsible for the treatment. The average score was 3.9.



## SURGERY

94.2% of women had surgery to treat their ovarian cancer. No statistically significant differences were found when comparing age bracket on diagnosis, or stage of diagnosis across all countries. There were however statistically significant differences between countries. Women in Australia, Spain and the USA were more likely to report having surgery (98.2%, 98.5%, 98.3%), and women in Hungary much less likely to report having surgery (59%)<sup>38</sup>.

<sup>38</sup> BY COUNTRY CROSS TAB NUMBERS Q63



On average 20.7% of women had chemotherapy before their first surgery. Women in the UK (29.8%\*) were statistically more likely to have chemotherapy before surgery and in the USA they were less likely (14.8%\*).

On average 9.6% of women have had surgery for recurrent ovarian cancer. Once again this varied by country. Women in Hungary were statistically much more likely to undergo surgery for recurrent cancer (28.1%), and women in the UK less likely (4.3%).

Some women (12%) had a second operation because the first surgery did not remove enough of the cancer. Women in Brazil were much more likely to undergo such a procedure (31.6%)<sup>39</sup>.

The greatest proportion of women (47.1%) had surgery in a hospital within 30 minutes travelling time from their home. For 5.9% of women, surgery took place between two- and four-hours travelling time from home, and for 4.4% it was over four hours. Combining these two proportions gives the average responses (10.3%) in terms of having to travel more than two hours from home for surgery. Women in Italy (30.1%) were much more likely to have to travel more than two hours from home for surgery, and much less likely in Japan (1.5%). In Italy, the result was particularly stark for those travelling more than four hours (20.5% vs 4.4%)<sup>40</sup>.

For just over a third of women, their surgery took place in a different hospital to the one in which they had any chemotherapy (36.5%). Women in the UK (46%) were more likely to have their surgery in a different hospital as were women in Hungary (56.2%\*)<sup>41</sup>.

By far the majority of women (92.1%) felt that health professionals gave them enough time to ask questions about surgery with 62.7% saying yes always, and 29.4% saying yes some of the time. Women in the USA were more likely to say they were always given enough time

<sup>39</sup> BY COUNTRY CROSS TAB NUMBERS Q64

<sup>40</sup> BY COUNTRY CROSS TAB NUMBERS Q66

<sup>41</sup> BY COUNTRY CROSS TAB NUMBERS Q67

(73.3%), and women in Japan were less likely to say they were always given enough time to ask questions about surgery (51.5%).<sup>42</sup> Of those who felt they were given time to ask questions, 65.3% said they understood the answers all of the time, with 34.5% saying they understood the answers some of the time.

The majority of women (69.8%) were given written information about their surgery that they could understand. 15% were not given any information.

In terms of the risks and benefits of surgery, some 6.4% of women said it was not discussed with them. For 81.1%, the risks and benefits were discussed and understood.

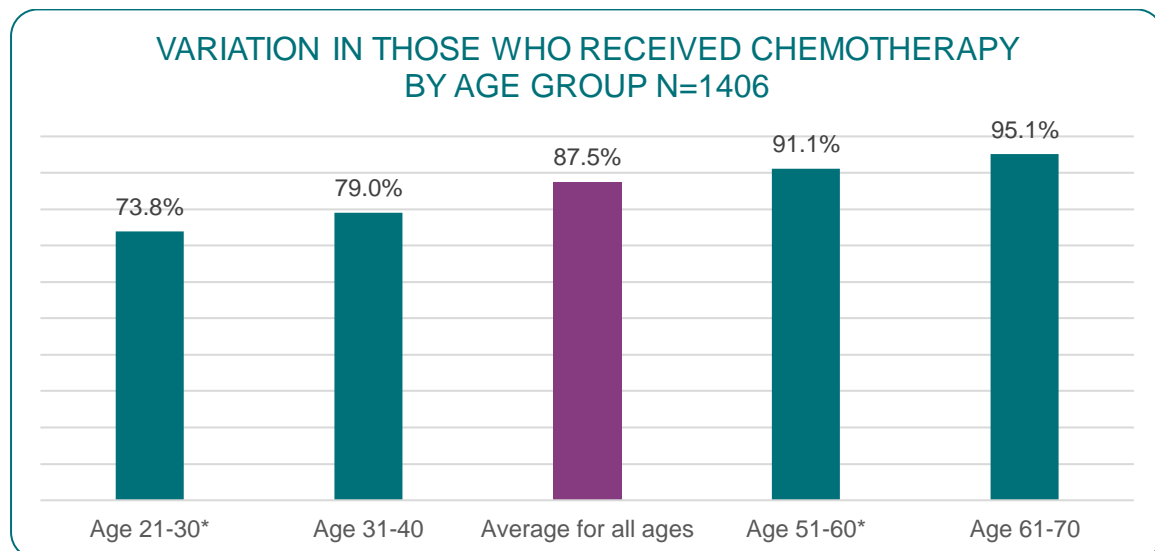
75.8% of women were given information about danger signals to look for after they had gone home from surgery. For some 16.6% of women it was not discussed at all. 82.4% of women were given information about recovering from surgery.

Whilst levels of information giving were high, just 42.2% of women reported that their experience of surgery was as they had expected from the information given. 39.9% said it was as expected 'to some extent'.

Half of all women reported that their surgeon spent between 5 and 15 minutes with them following the operation. For 26% of women it was between 15 and 30 minutes. For 12.5% of women, the surgeon spent less than 5 minutes with them.

## CHEMOTHERAPY

87.5% of women have received chemotherapy to treat or control their ovarian cancer. There were variations by age group.



<sup>42</sup> BY COUNTRY CROSS TAB Q68

There was also an association with type of ovarian cancer, with women less likely to receive chemotherapy if they have mucinous (63%), granulosa tumour (47.8%), and borderline (31.5%). All women who had primary peritoneal ovarian cancer received chemotherapy, and almost all women with epithelial (serous) (97.9%) or fallopian tube cancer (98%). Sample sizes for other types of tumour with low chemotherapy rates were too small to produce statistical significance (sex cord stromal, germ cell, teratoma).<sup>43</sup>

Earlier we showed there were variations in the types of tumour by country, but despite this, the only significant difference in rate of women receiving chemotherapy was that in the USA they were statistically more likely to receive chemotherapy (92.1%).

Women were asked about how many courses of chemotherapy they had undertaken to treat their ovarian cancer. In testing this question proved difficult in terms of differentiating between courses and cycles of chemotherapy and was amended to include a more detailed explanation. In this survey 35% responded they had undertaken one course, falling steadily down to 2.5% reporting 5 courses. Then there was a large jump to 34.5% reporting more than 5. On examining the data by type of ovarian cancer, this jump was evident in every type bracket, so the only conclusion that can be reached is that some women still did not understand the term 'course' despite the explanation.

Half of all respondents who have had chemotherapy started their last or only course since the start of 2017 (50.3%).

Women were more likely to have their chemotherapy within an hour's travelling time of home, when compared to the travelling time for surgery (83% vs 73.7%) and less likely to have to travel more than 2 hours for their chemotherapy (4.2% vs 10.3%).

Just 17.8% of women have ever been given a choice of chemotherapy drugs. Women with germ cell tumours or borderline cancers were less likely to receive a choice of drugs (4.8%\*, 5.9%\*)<sup>44</sup>.

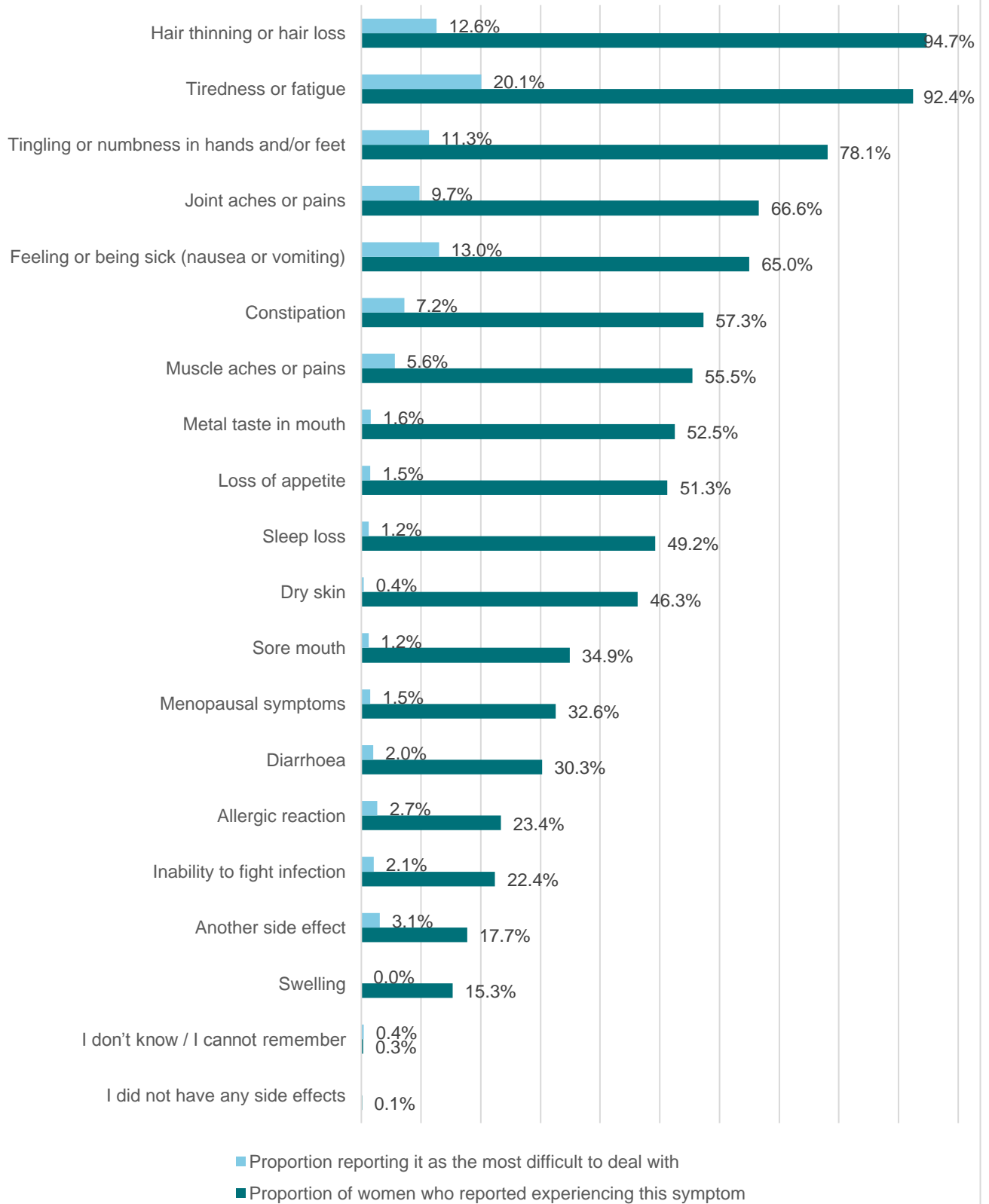
Of the 1230 women who had chemotherapy, 1217 women submitted details on side effects. Just one woman did not experience any side effects from chemotherapy. 94.7% experienced hair thinning or loss, 92.4% experienced fatigue or tiredness. Tingling or numbness in hands and/or feet was experienced by 78.1%, and joint aches and pains by 66.6%.

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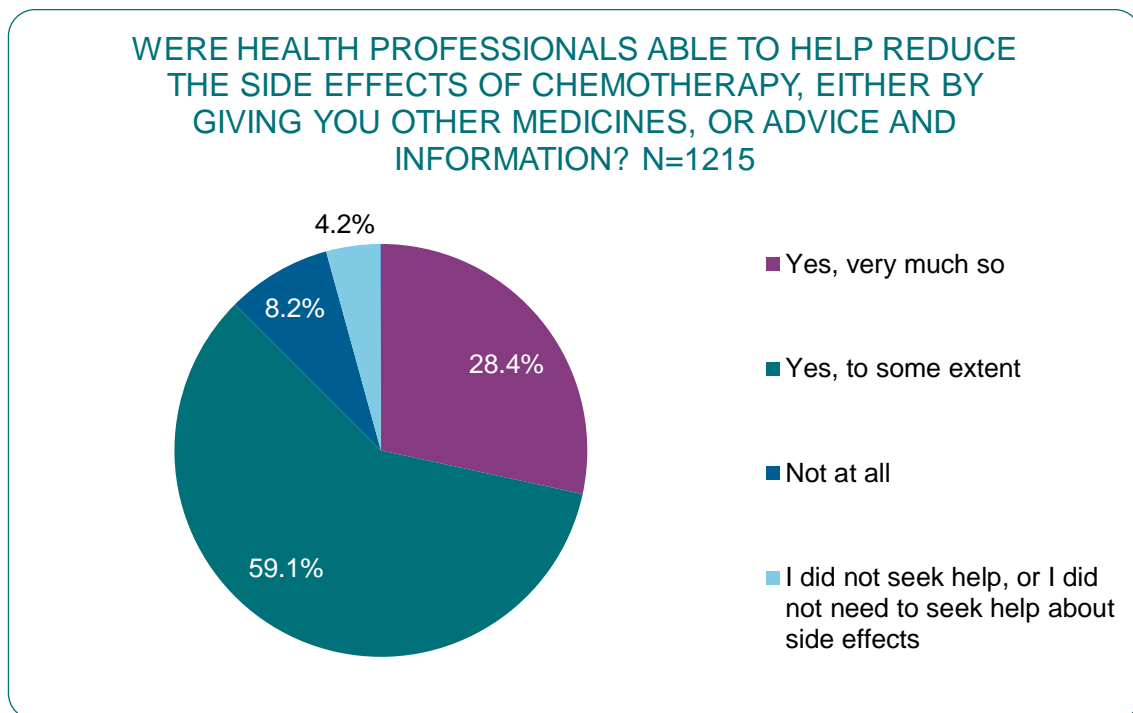
<sup>43</sup> BY TYPE CROSS TAB NUMBERS Q76

<sup>44</sup> BY TYPE CROSS TAB NUMBERS Q80

PROPORTION EXPERIENCING THIS SIDE EFFECT AND WHICH WAS MOST DIFFICULT SIDE EFFECT TO DEAL WITHN=1230



Most women, at least to some extent, were able to get help from health professionals to alleviate symptoms.



91% of women had been treated with Carboplatin, and 88.7% with Paclitaxel. Just 14.8% had received Cisplatin, 14% Pegylated Liposomal Doxorubicin Hydrochloride, and 9.8% Gemcitabine.

9.8% of women had received intraperitoneal chemotherapy (IP), delivered directly into their pelvic cavity. There were country variations. Most countries no matter how small the numbers had one or more patients who had received it.

- Women in the US (22.5%) and Spain (23.2%\*) were much more likely to receive IP therapy.
- Women in the UK (0.7%), Germany (2.5%) Japan (3.7%) and Italy (4.1%\*) were less likely to receive it.<sup>45</sup>
- Of the women who were treated with IP therapy (n=119), 28.9% were given treatment with the hypothermic IP therapy.

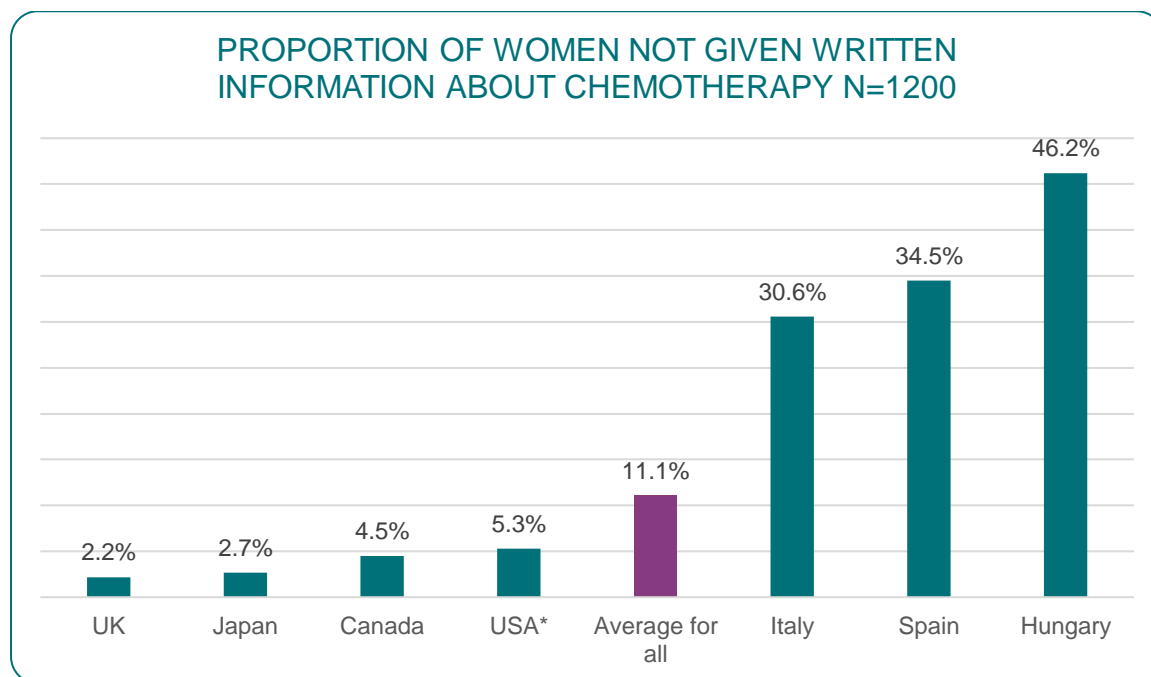
64.8% of women felt health professionals always gave them enough time to ask questions about chemotherapy, with 29.5% saying they were given enough time, some of the time. Women in the USA (77.9%) were more likely to say they always had enough time to ask questions about chemotherapy, and women in Japan (43.6%) and Hungary (41%) less likely to say they always had time. There were no statistical differences by country for the proportion of women who said they never had enough time (4.1%). The results are very

<sup>45</sup> BY COUNTRY CROSS TAB NUMBERS Q85

similar to the same question about surgery, including the variations in the USA and Japan<sup>46</sup>. There was no significant difference between who contributes towards healthcare costs.

Just over two-thirds of women always understood the answers they were given (68.9%) with almost all the remainder understanding the answers some of the time (30.7%).

77.7% of women were given understandable written information about chemotherapy before it began. 8.3% reported being given information but not understanding it all. 11.1% of women did not get any written information about chemotherapy but this varied widely by country<sup>47</sup>.



The countries in which women were much more likely not to have been given any written information were Hungary (46.2%), Spain (34.5%) and Italy (30.6%). The countries where women were less likely not to have been given written information were US (5.3%), Canada (4.5%), Japan (2.7%) and the UK (2.2%).

8.9% of women reported that the risks and benefits of chemotherapy had not been discussed with them, but for 77.3% they were, and were fully understood.

9.3% of women reported not being given information about danger signals to watch out for following chemotherapy, but 87.1% were. In terms of being given information about recovering from chemotherapy and its side effects, 81.7% of women said they were given information.

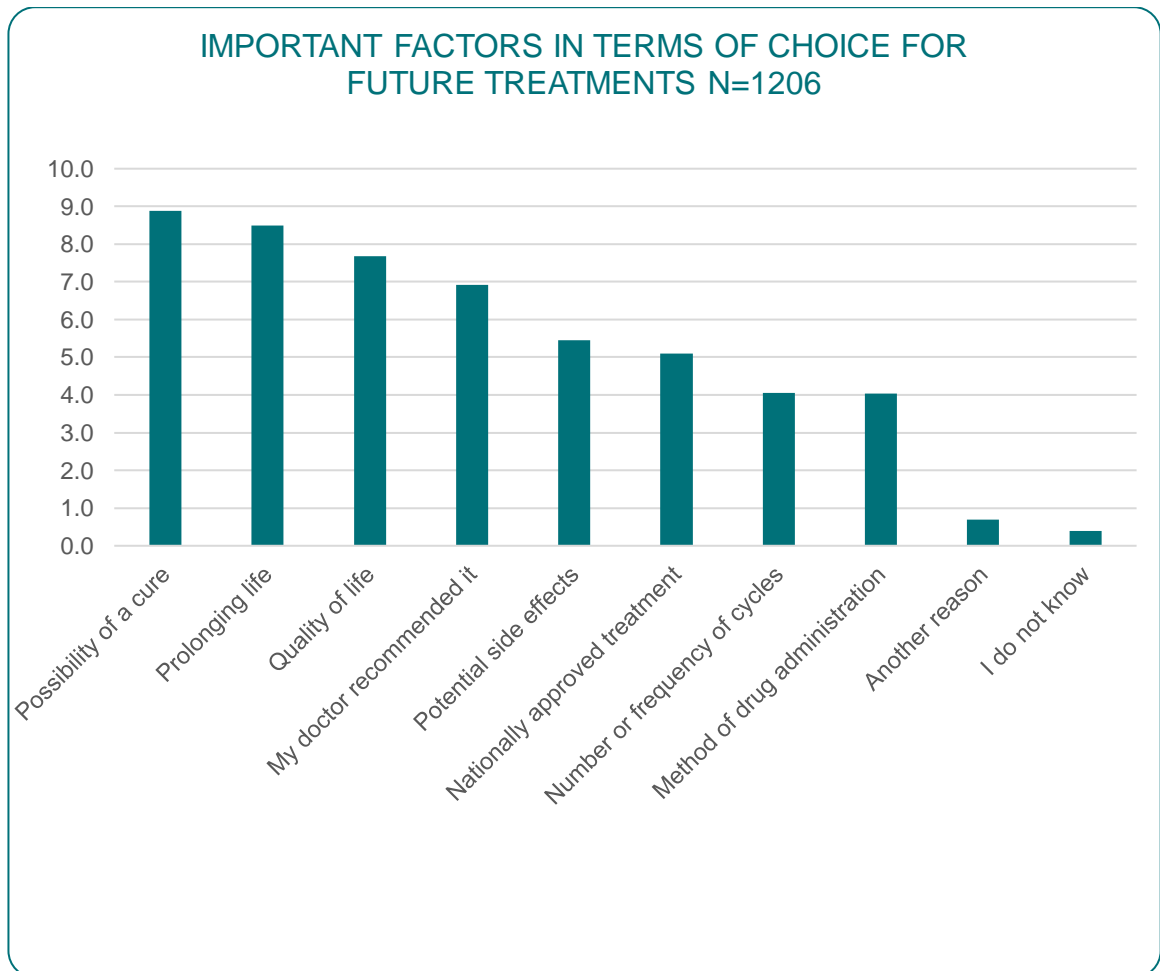
In terms of the experience of chemotherapy being as expected from information they had received, 38.1% said it was, and 46.5% said it was to some extent.

<sup>46</sup> BY COUNTRY CROSS TAB NUMBERS Q87

<sup>47</sup> BY COUNTRY CROSS TAB NUMBERS Q89

As with surgery, the most common time period chemotherapy doctors spent with women was between 5 and 15 minutes (52.1%). 11.3% reported that the chemotherapy doctor spent on average less than five minutes with them.

Women were asked if they had a choice in the future of the type of chemotherapy they could have in the future, what would be most important to them. They were asked to score between 0 (not at all important) and 10 (the most important).



## BIOLOGICAL THERAPIES

Women were asked if they had ever been offered a biological therapy to treat ovarian cancer. 11.7% said they had, 9.2% said they did not know or could not remember, and 79.6% said no. Given that no drug names were given at this point in the survey this may be an under-representation, as when women were asked previously which chemotherapy drugs they were given, drugs such as Avastin and Olaparib were included on sizeable proportion of the entries under 'other'.

Over half of the women who had been offered a biological therapy were given treatment with Avastin (56.3%). 13.3% had treatment with Olaparib, and Niraparib was the most common 'other' biological therapy (8/27). Women who were offered biological therapies were more likely to feel they always understood the answers to any questions than for chemotherapy

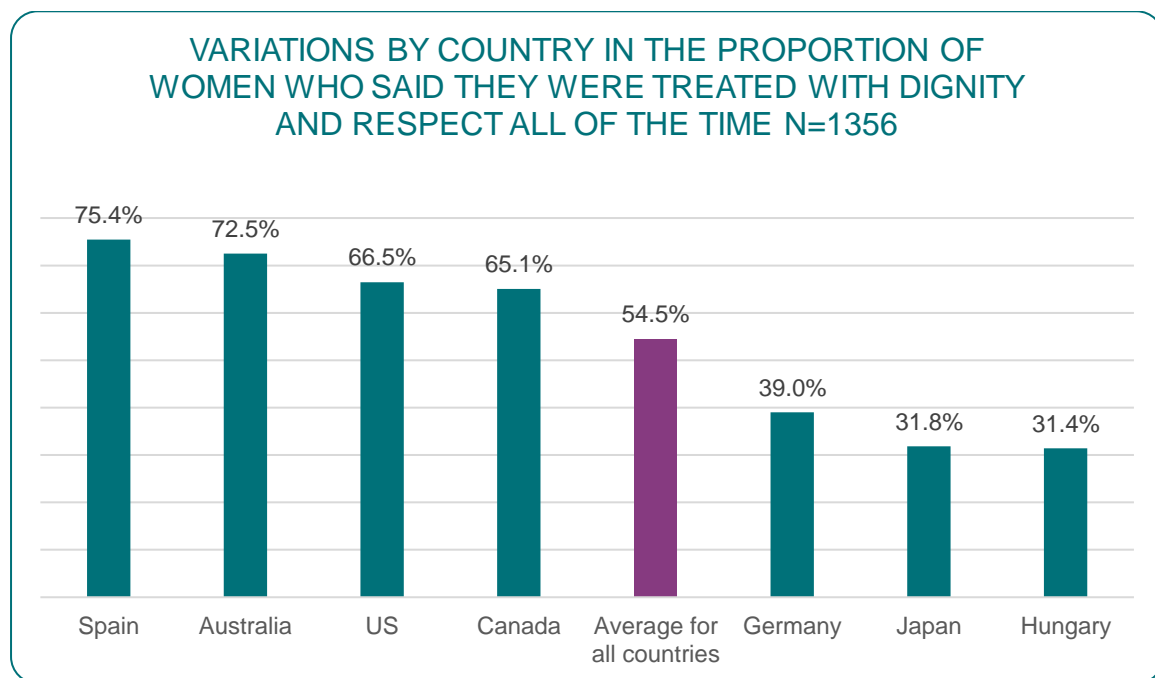


and surgery (84.2% vs 68.9% and 65.3%), however nearly a quarter of women (23.7%) were not given any written information about their biological therapy (more than twice the rate for chemotherapy and 1.5 times the rate for surgery).

## HOSPITAL TREATMENT IN GENERAL

Almost all women were very positive about the care they received during treatment. 91.5% felt they were treated with dignity and respect all or most of the time. Just 6.6% said they were treated with dignity and respect only some of the time, and just 1.25% said not at all.

There were some variations from the average in the number of women who said they were treated with dignity and respect (54.5%) by country all of the time<sup>48</sup>.



All women in Australia felt that they had been treated with dignity and respect, to some extent.

85.5% of women rated their care as good (30.7%) or very good (55.1%) with just 2.6% of women saying their care was poor.

45.3% of women felt they had always been involved to the extent they wished to be in decisions about treatment, and 39.4% said this was the case most of the time.

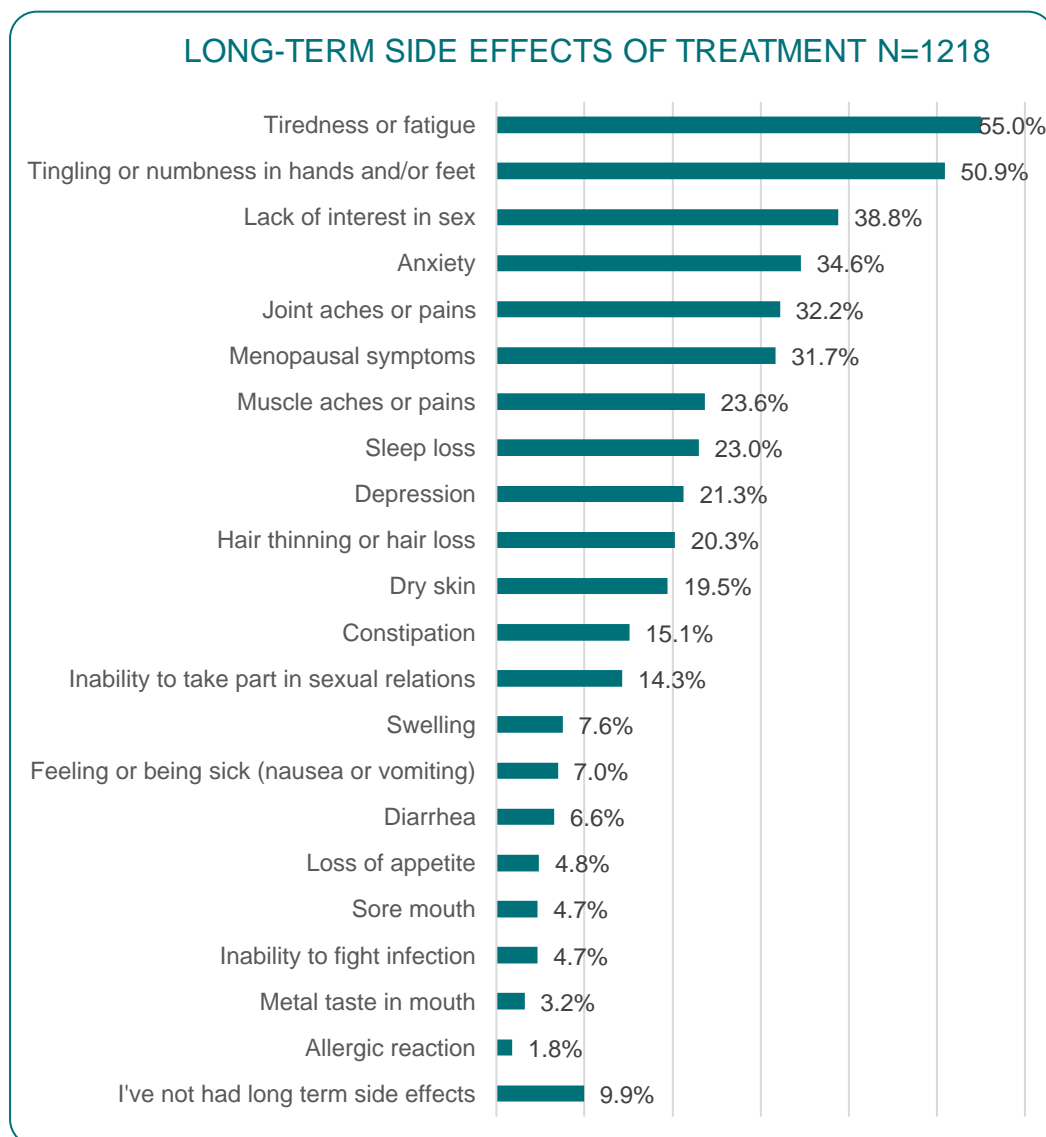
- Women in the US were more likely to report they had always been involved (63.8%) and less likely to say they'd been involved only some of the time (4.9% vs 11.2%) or not at all (0.9% vs 3.25%).
- Women in Hungary were much less likely to say they'd always been involved (11.8% vs 45.3%), and more likely to say they'd only been involved some of the time (25.5%\*vs 11.2%).

<sup>48</sup> BY COUNTRY CROSS TAB NUMBERS Q111

- Women in the UK and Australia were more likely to report always being involved (58.5% and 59.6%), with women in Japan and Germany much less likely to report always being involved (22.8% and 28.5%)<sup>49</sup>.

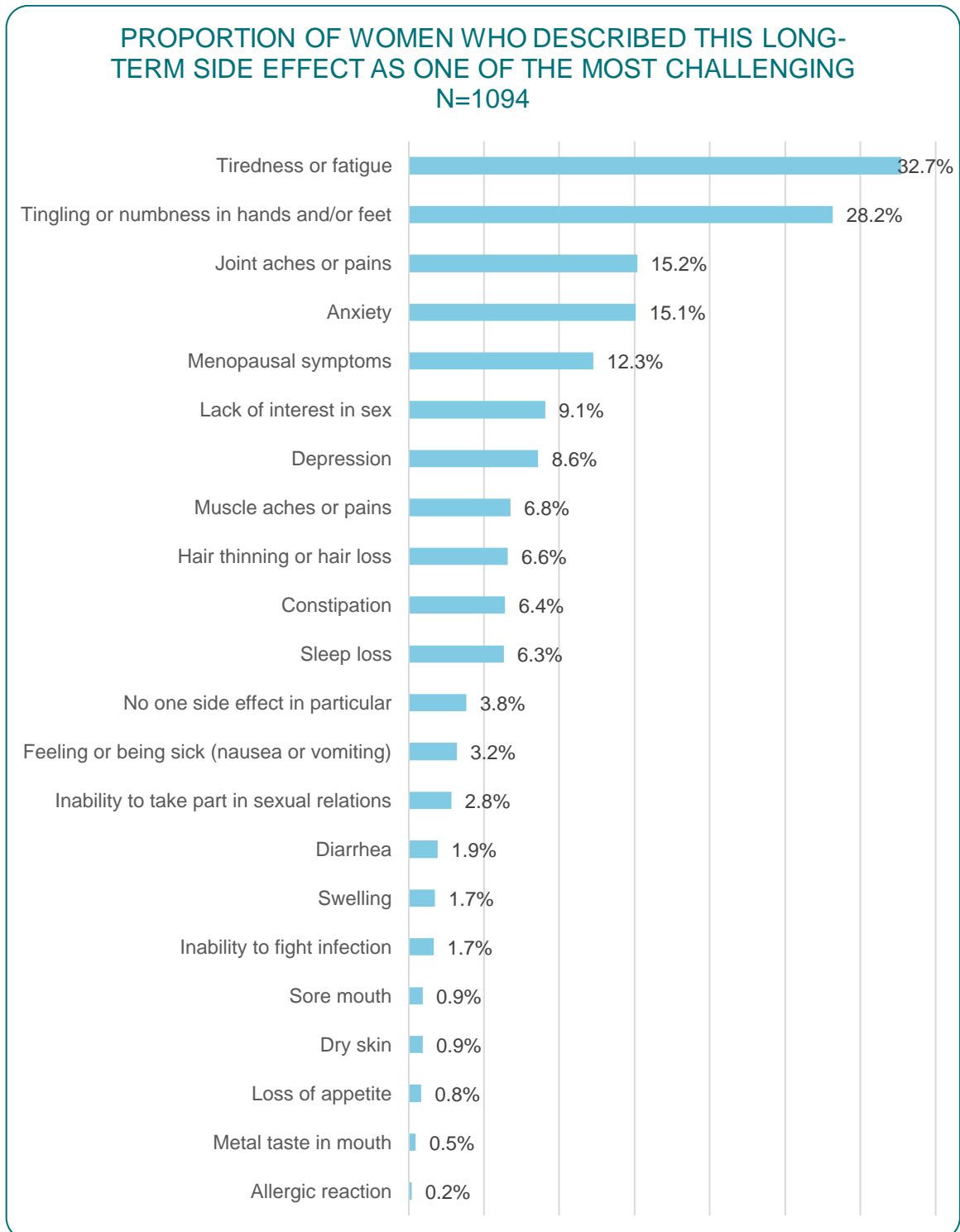
## LONG-TERM SIDE EFFECTS

Women were asked about long-term side effects of treatment. After excluding those who were still in their first course of treatments, it was clear that almost all women are left with long-term side effects. Just under 10% have not experienced long-term side effects. The extent to which women report these side effects are below.



<sup>49</sup> BY COUNTRY CROSS TAB NUMBERS Q112

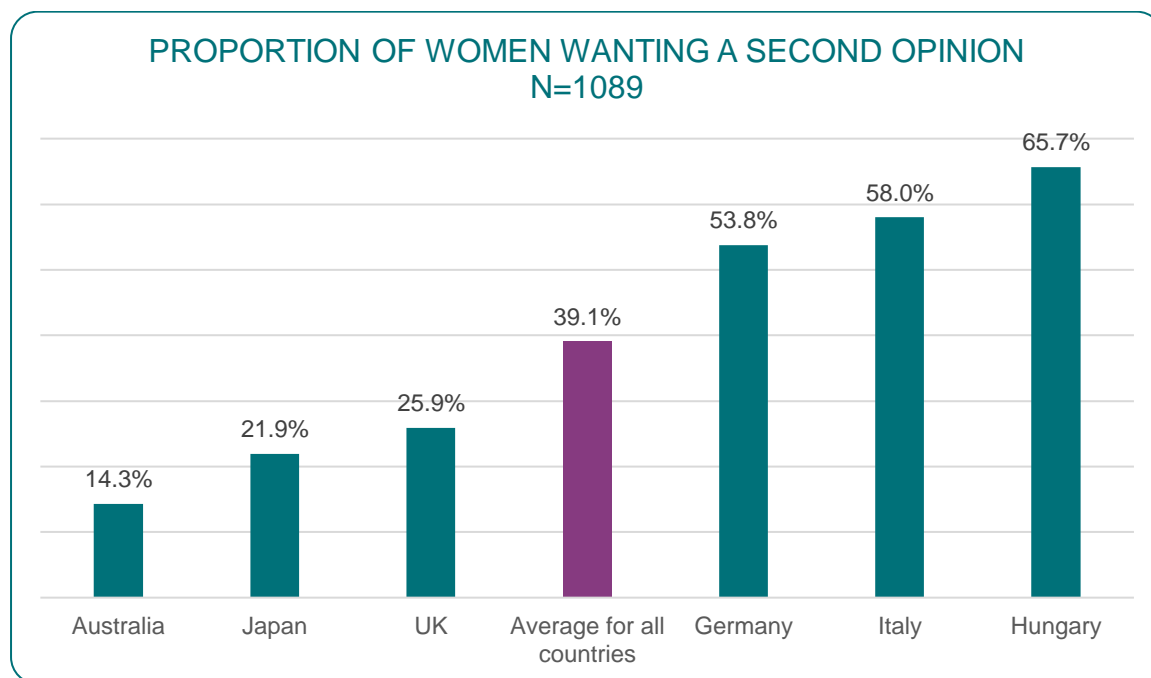
Women were then asked which long-term side effects were most difficult to deal with. They were allowed to select up to two options.



The rates of reporting anxiety and/or depression as one of the most challenging long-term side effects were checked against stage at diagnosis, but no statistically significant variations were found. Stage at diagnosis had no impact on the likelihood of depression or anxiety being a major long-term side effect.

## SECOND OPINIONS

Two fifths of women (39.1%) questioned indicated that at some point they have wanted to get a 'second opinion' from another ovarian cancer doctor. There was a wide variation between countries<sup>50</sup>.



Of the 679 women who answered the question, 'Were you able to get a second opinion', 54% responded yes. Women in Italy (68.5%\*) and Germany (71.6%) were more likely to be able to get a second opinion than the average<sup>51</sup>.

## CLINICAL TRIALS

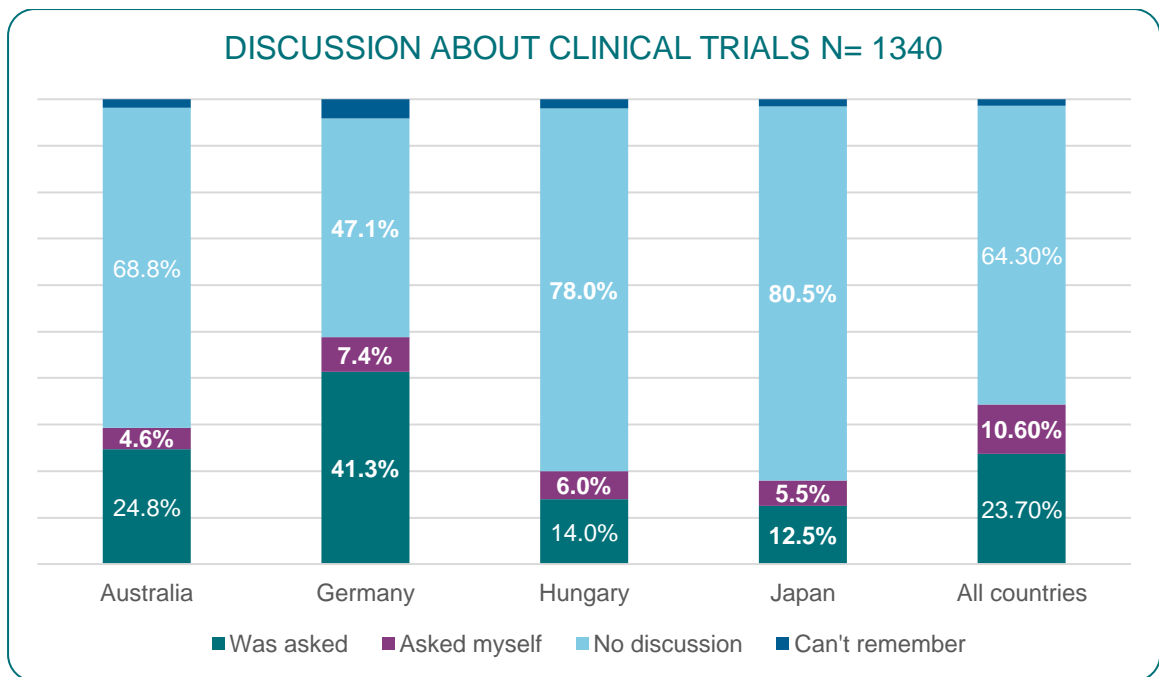
Just 23.7% of women were asked about joining a clinical trial. A further 10.6% asked about joining a trial. Almost two-thirds of women (64.3%) had no discussions about clinical trials. There were variations by country:

- Women in Japan had the highest proportion of women who had no discussion about trials (80.2%) followed by Hungary (78%\*).
- Women in Germany were more likely to have been asked about trials (41.3%) and less likely to have had no discussion about trials (47.1%).
- Just 12.5% of women in Japan had been asked about clinical trials.
- Australia had the lowest proportion of women who asked about trials themselves (4.6%).<sup>52</sup>

<sup>50</sup> BY COUNTRY CROSS TAB NUMBERS Q115

<sup>51</sup> BY COUNTRY CROSS TAB NUMBERS Q116

<sup>52</sup> BY COUNTRY CROSS TAB NUMBERS Q117

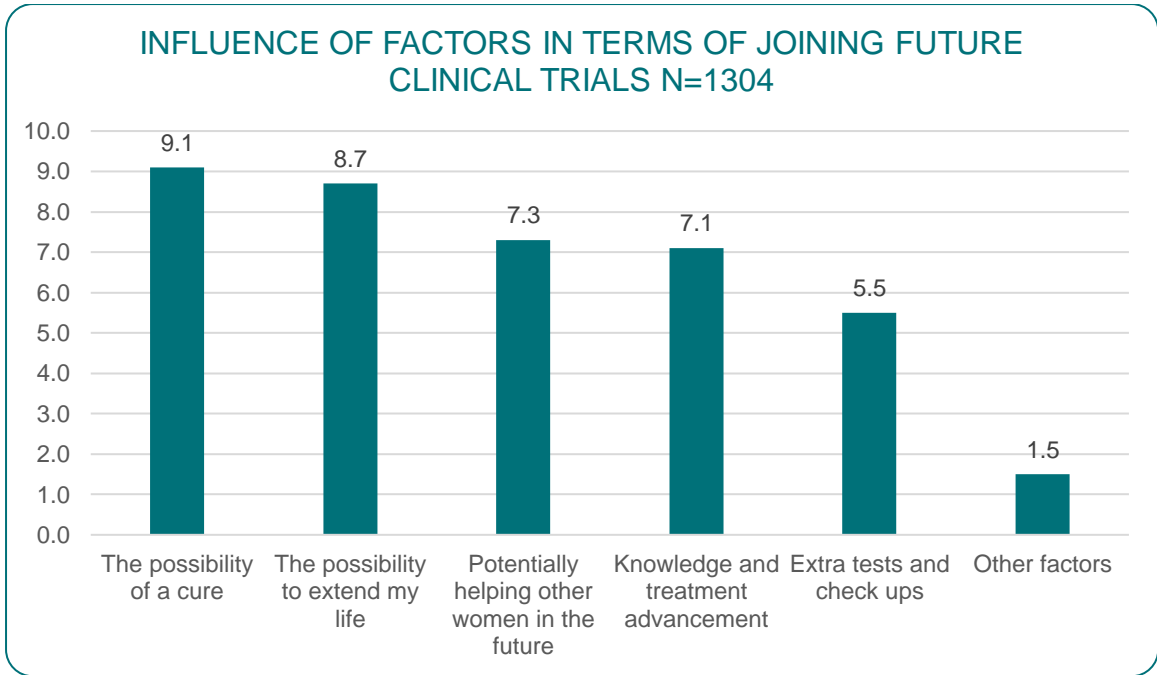


Of those women who were asked, or asked themselves (n=462), just under half (48.5%) of them said there were clinical trials they were eligible to join. No statistically significant results were found between countries.

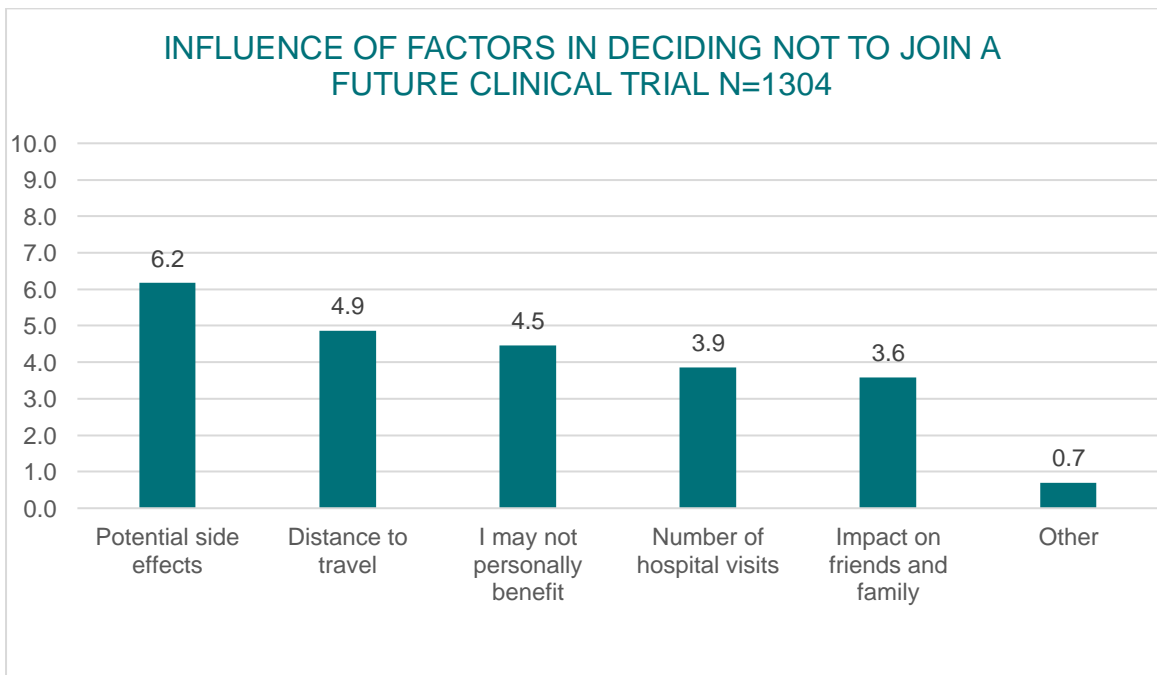
For these women, 89.3% said they were given understandable information about the clinical trial. 74.8% took part in the clinical trial they were eligible for. This represents just 12.4% of women who began answering questions about clinical trials (n=1340).

1340 women responded to the question “In future, if you were offered a clinical trial, would you be prepared to go to another hospital so you could take part?” Just 2.69% of these respondents said they did not want to participate in clinical trials at all. A further 5.2% said they would not participate in trials at another hospital. This left 92.2% of the respondents inferring they would be interested in participating in clinical trials. 33% said definitely yes to considering another hospital, 49.4% said they may be interested in going to another hospital, and 9.8% indicated they possibly might not want to go to another hospital. Clearly there is a very large mis-match between women being offered trials, and women interested in taking part, either at their local or another hospital.

Women were asked how important a range of factors might be in terms of the benefits of joining a clinical trial. Women could score 10 for the most important or a very important factor, and zero for not at all. There were 1304 responses, and all categories scored a minimum of 0 and a maximum of 10.



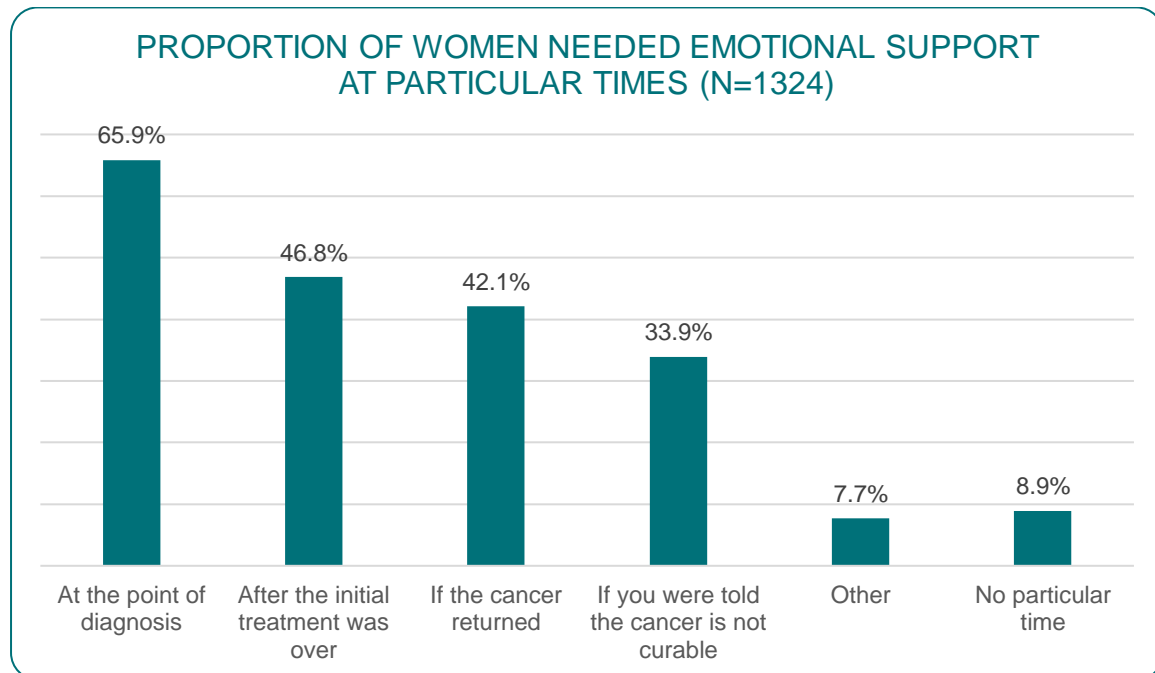
Women were also asked to rate the importance of the following factors in terms of them potentially deciding not to join a clinical trial. 10 would be a very important factor, and zero means it would not be important at all. Apart from the potential side effects, all the factors which may influence a decision not to join a future clinical trial scored lower than all the factors that might influence a decision to join a future clinical trial.



# SUPPORT NEEDS

## EMOTIONAL SUPPORT

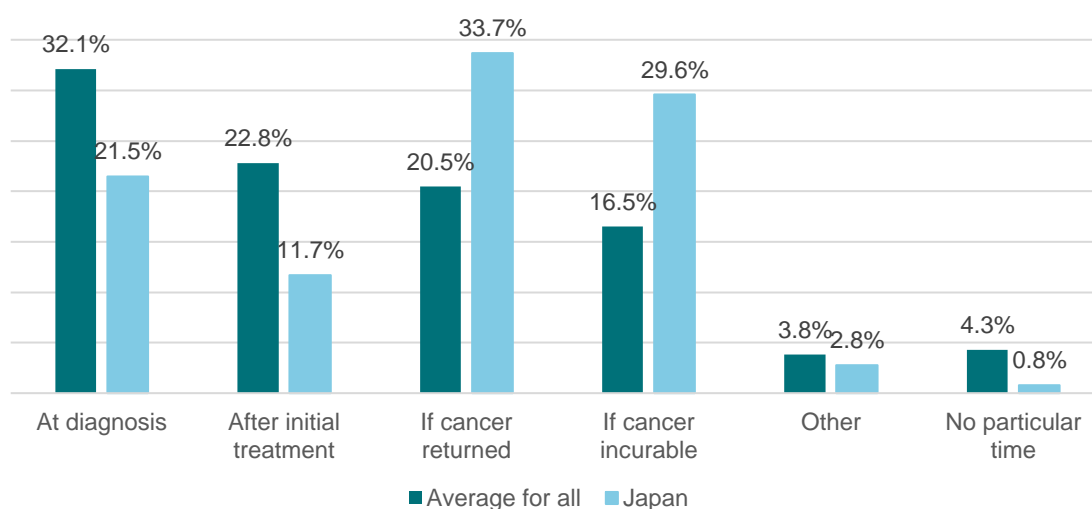
Just under 10% of women who responded (8.9%) said there was no particular time when they felt in need of emotional support. Women were allowed to select more than one option. On average they selected 2 options (2.05). The most common points they needed support was at the point of diagnosis (65.9%) and after treatment had ended (46.8%) closely followed by if the cancer returned (42.1%).



There were some interesting variations between countries<sup>53</sup>. Most striking were the responses from women in Japan, who were less likely to report having had a need for emotional support at the time of diagnosis, as a proportion of all their emotional needs, or after treatment ended (21.5% of all responses from Japan vs 32.1% of all responses, 11.7% vs 22.8%). However, they were far more likely to include a response of needing help if the cancer returned or they were told the cancer was not curable (33.7% vs 20.5%, 29.6% vs 16.5%). They were also less likely to say there was no particular time when they needed support (0.8% vs 4.3%).

<sup>53</sup> BY COUNTRY CROSS TAB NUMBERS Q124

### EMOTIONAL SUPPORT NEEDS JAPAN (N=198) COMPARED TO THE AVERAGE FOR ALL (N=1324)

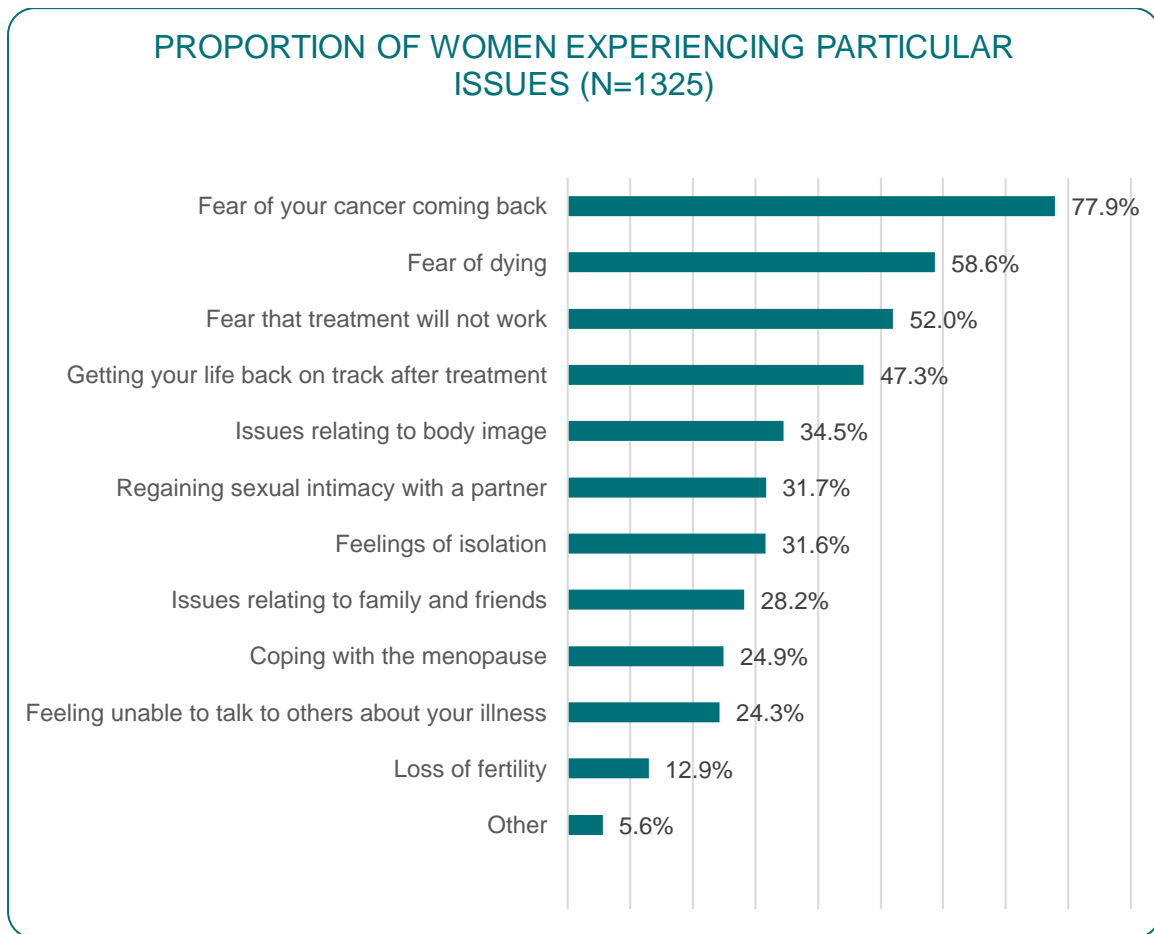


The complete set of statistically significant variations were as follows:

LESS LIKELY TO BE REPORTED IN THE MIX THAN THE AVERAGE	SUPPORT NEEDED AT PARTICULAR TIMES AS A PROPORTION OF ALL EMOTIONAL SUPPORT NEEDS 2718 responses from 1325 women	MORE LIKELY TO BE REPORTED IN THE MIX THAN THE AVERAGE
Japan 21.5%	On diagnosis 32.1%	Italy 45% Spain 43.9%* Germany 39.7%*
Japan 11.7%	Once treatment had ended 22.8%	
Germany 14.1% Spain 12.3%*	If the cancer returned 20.5%	Japan 33.7%
Spain 4.1% Italy 3.6%	If told the cancer incurable 16.5%	Japan 29.6%
Japan 0.8%	No particular time 4.3%	



Women were asked to select particular issues that they had faced. They could select multiple options. On average they selected 4 or 5 options. Just 2.5% of women said they had faced no particular issue, and 5.6% said there were other issues they faced in addition to any others they had selected.

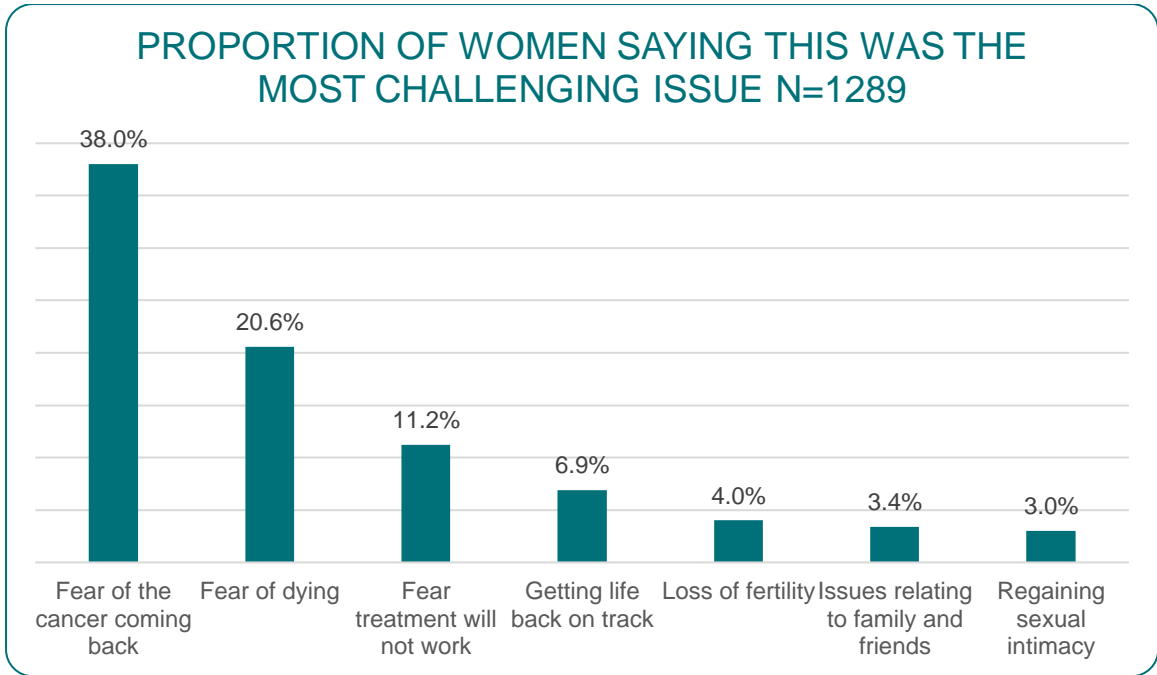


As a proportion of all the responses women gave there were some variations by age, that were statistically significant<sup>54</sup>.

<sup>54</sup> BY AGE CROSS TAB NUMBERS Q125

LESS LIKELY TO REPORT THIS IN THE MIX	PROPORTION EXPERIENCING THIS ISSUE AS A PROPORTION OF ALL THEIR RESPONSES BY AGE GROUP  5725 responses from 1325 women	MORE LIKELY TO REPORT THIS IN THE MIX
Fear of cancer returning (11.9% vs 18%) Fear treatment will not work (8.1% vs 12%) Fear of dying (9.9%* vs 13.6%)	21-30	Loss of fertility (10.6% vs 3%)
Fear of cancer returning (14.8% vs 18%) Fear treatment will not work (9.1% vs 12%) Fear of dying (11.2%* vs 13.6%)	31-40	Issues relating to body image (10.1%* vs 8%) Loss of fertility (8.2% vs 3%) Coping with the menopause (9% vs 5.8%)
Loss of fertility (1.8% vs 3%)	41-50	Coping with the menopause (8.6% vs 5.8%)
Loss of fertility (0.2% vs 3%) Coping with the menopause (2.9% vs 5.8%)	51-60	Fear treatment will not work (14%* vs 12%) Getting life back on track after treatment (11.8%* vs 11%)
Regaining sexual intimacy (5.4%* vs 7.3%) Loss of fertility (0%) Coping with the menopause (0%)	61-70	Fear treatment will not work (16.5% vs 12%)

Women were asked which issue they found most challenging and could only select one option. Fear dominated the top three categories.



In terms of seeking out support, the greatest proportion of women sought help from family and friends (37.3%). 28% of women were offered help by a health professional, and a similar proportion (27.8%) sought help from a health professional. Women could tick more than one response, most selected one or two options (mean = 1.2).

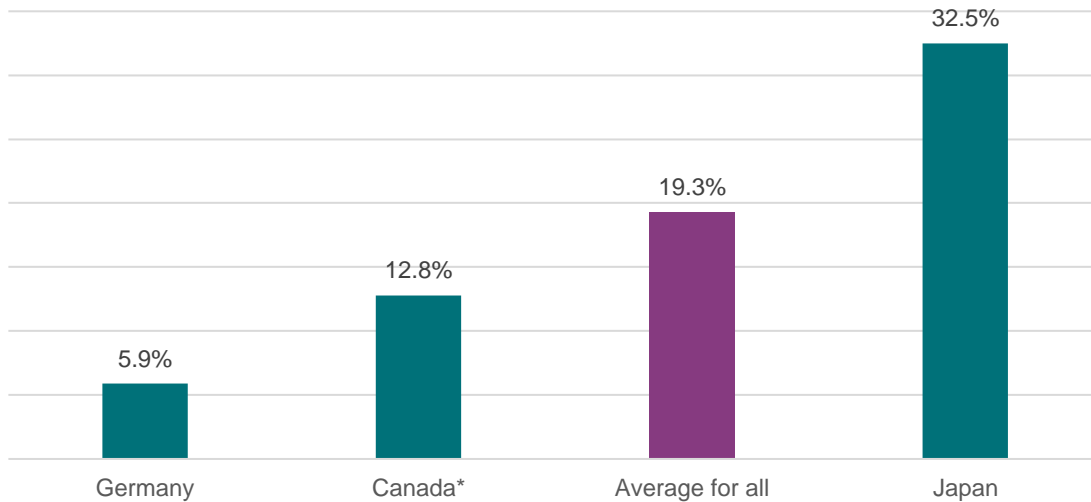
Yes, I sought help from a health professional	27.8%
Yes, I was offered help from a health professional	28%
I sought help from family and friends	37.3%
I neither sought help, or was offered help	19.3%
Other	4.5%

As a total proportion of the possible answers (i.e. including multiple answers), women in Germany were more likely to have reported seeking help from a health professional (31.7%\* vs 23.8%), and women in Japan were much less likely to have reported seeking help from a health professional (14.4% vs 23.8%).

Almost one in five (19.3%) said they did not seek help or were not offered help. There were variations by country:<sup>55</sup>

<sup>55</sup> BY COUNTRY CROSS TAB NUMBERS Q127

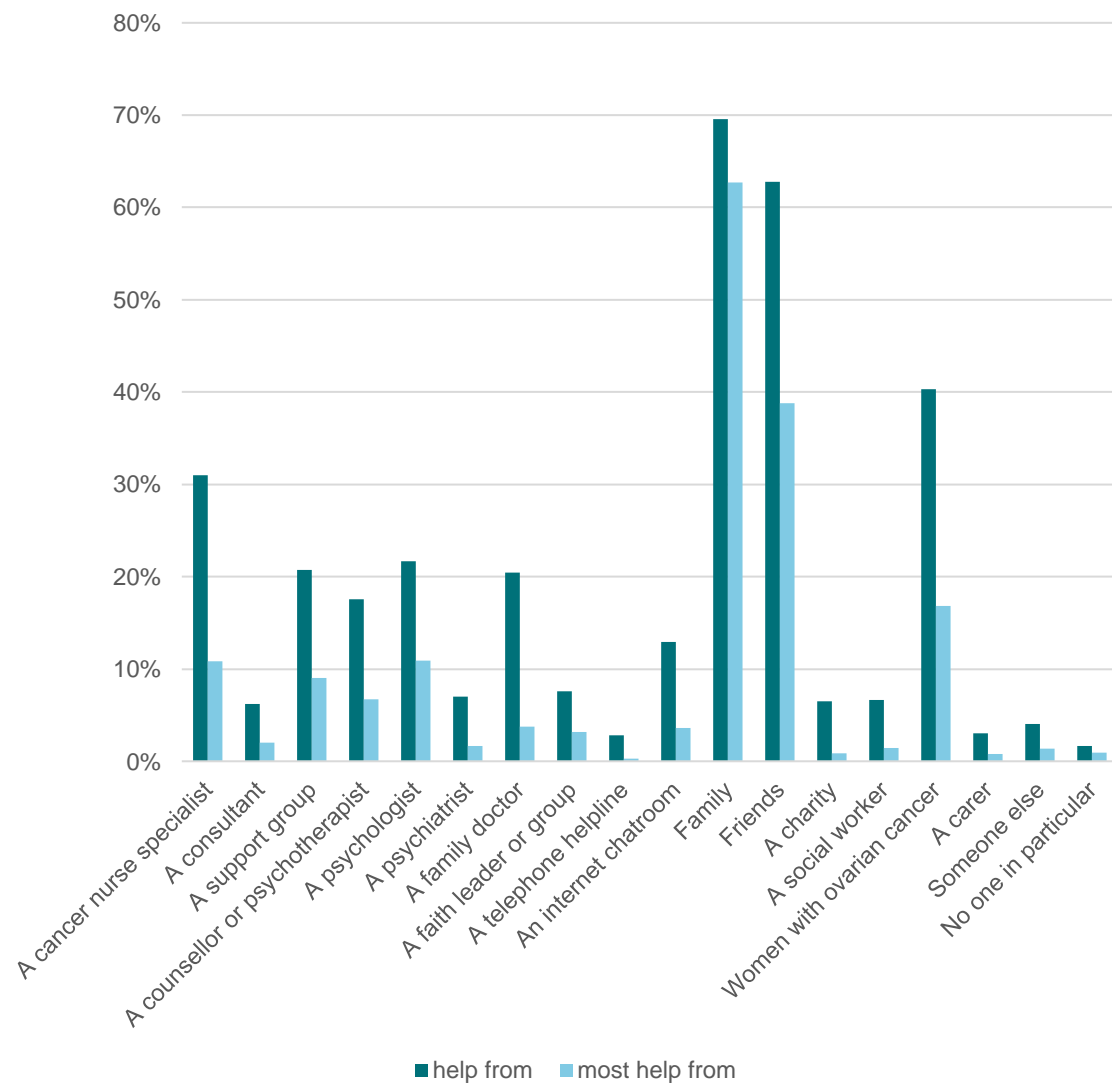
## VARIATIONS IN WOMEN SAYING THEY DID NOT SEEK OR WERE NOT OFFERED HELP N=1321



Women were then asked who gave them support and were allowed to select multiple options. Family and friends were the most commonly reported in the mix (69.5% and 62.3% respectively of all respondents included this), followed by other women with ovarian cancer (40.3%), and a cancer nurse specialist (31%). Women were asked if they got the help they needed from them. 47.3% said yes, very much so, and 49.7% said yes to some extent.

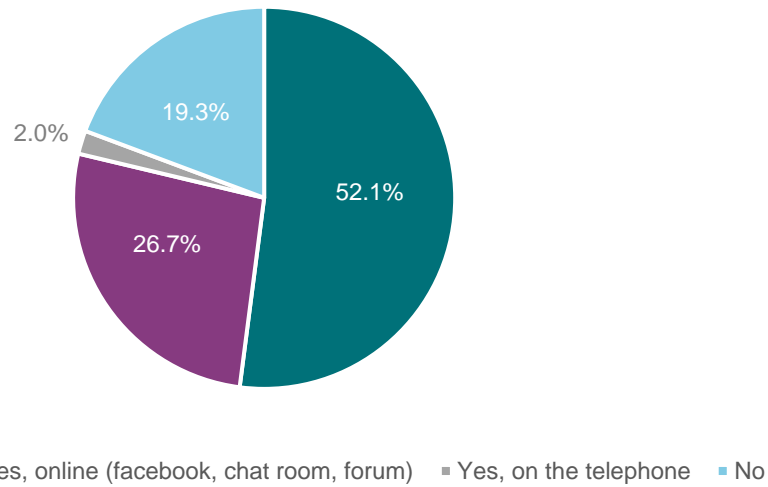
The graph below includes all the responses (the bar chart), with scores for those who gave most emotional support (women were allowed to select two options for this aspect).

**SOURCES OF SUPPORT FOR WOMEN N=1046**  
 ALLOWED MULTIPLE RESPONSES FOR SOURCE OF SUPPORT,  
 AND 2 RESPONSES FOR MOST SUPPORT



Nearly one in five women with ovarian cancer have never met another woman, or group of women who have also had ovarian cancer (19.3%). Just over half of women have met someone in person (52.1%), 26.7% have met online, and 2% by telephone.

## HAVE YOU MET ANOTHER WOMAN WITH OVARIAN CANCER? (N=1136)



There were variations by country:

- Women in Japan were more likely not to have met another woman with ovarian cancer (29.7% vs 19.3%), and less likely to have met a woman online (11.3% vs 26.7%).
- Women in the UK were less likely to have met other women in person (43.2%\* vs 52.1%) and more likely to have met someone online (42% vs 26.7%).
- Women in Germany were less likely not to have met another woman online (8.5% vs 19.3%) and were more likely to have met someone in person (61.9% vs 52.1%).
- Women in Australia were more likely not to have met someone (28.3%\* vs 19.3%), and less likely to have met someone online (17% vs 26.7%).
- Women in Hungary were less likely to have not met anyone (10.2%\* vs 19.3%), and more likely to have met someone online (44.9% vs 26.7%).
- Women in Canada were less likely to have met someone online (18.6%\* vs 26.7%). The same was true for women in Italy (15.6%\*), whilst women in Brazil were more likely to have met someone online (55.8%).

Of the 255 women who had not met anyone (either in person or online), just 7.5% said they did not want to meet others. 54% said they definitely would, and the remainder 38.4% said they were not sure.

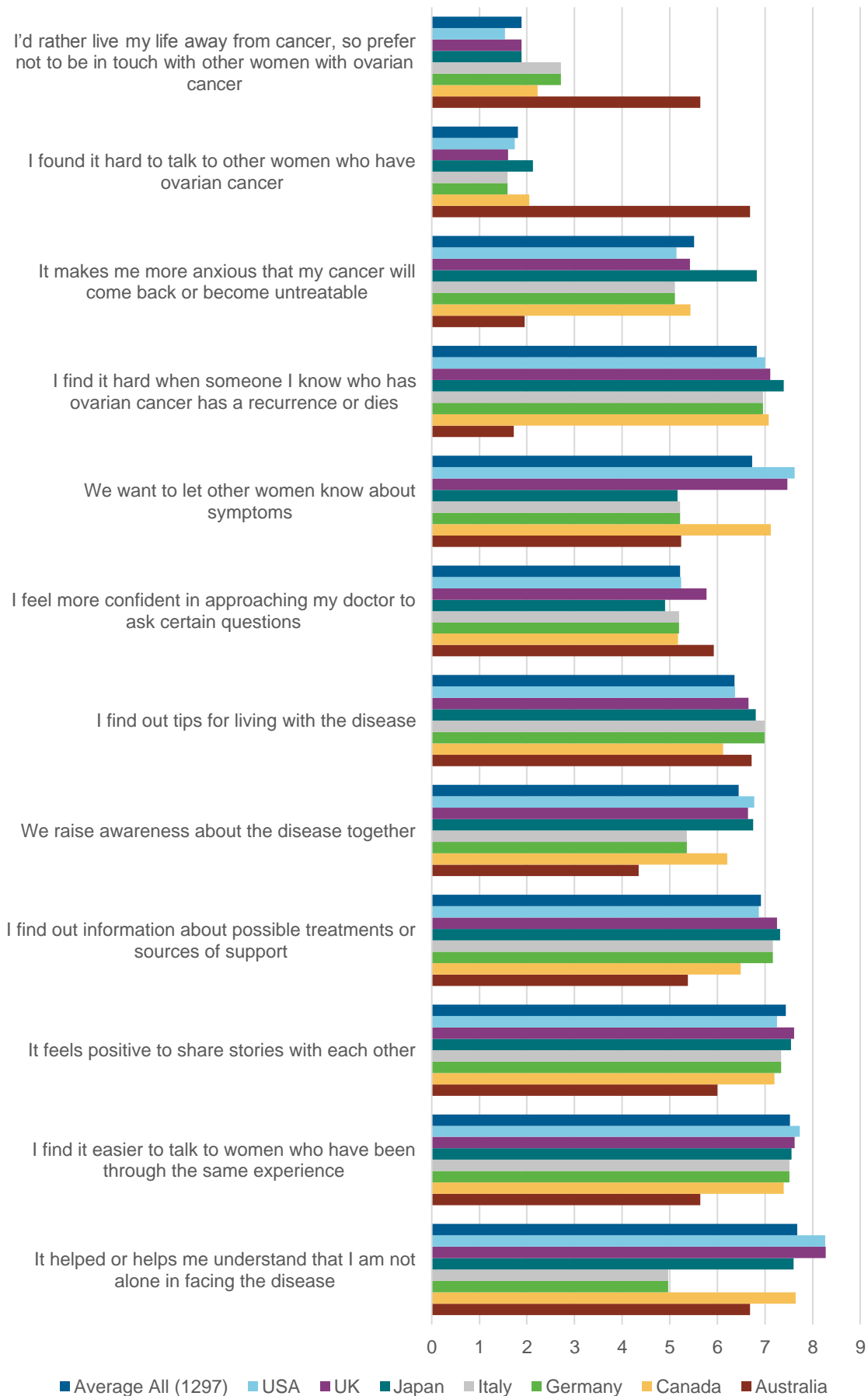
Women were given a mix of positive and negative statements about meeting women with ovarian cancer. Scoring 10 for a category would mean they totally agreed, 0 totally disagreed, and 5 would mean neither agree or disagree. There were some variations by country (where more than 40 respondents)<sup>56</sup>.

<sup>56</sup> DATA EXTRACTED FROM FULL SUMMARY REPORT AND COUNTRY FILTERS Q133

## SUPPORT (OUT OF 10) FOR STATEMENTS ABOUT MEETING OTHER WOMEN WITH OVARIAN CANCER N=1297



## HOW WOMEN FEEL ABOUT MEETING OTHER WOMEN WITH OVARIAN CANCER (N=1297)



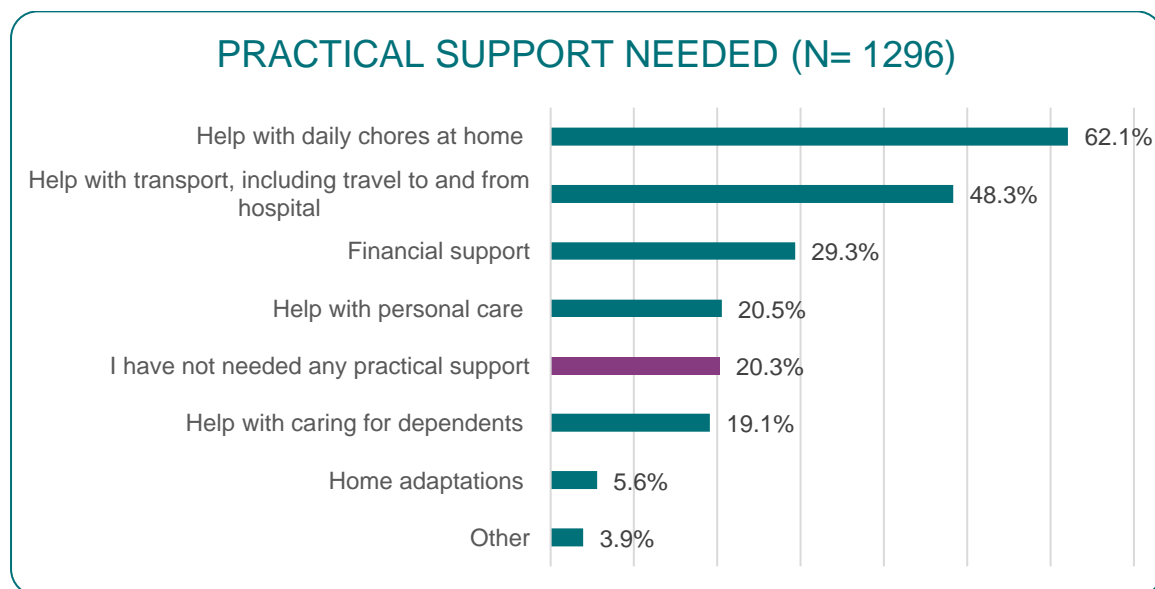


By far the largest majority of women (70.4%) said they would prefer to meet with other women who had ovarian cancer, as opposed to other women with any cancer (9.4%) or any person with cancer (12%). Just 8.2% said they did not want to meet any other people with cancer (n=1277).

## PRACTICAL SUPPORT NEEDS

Just one in five women (20.3%) said they had not needed any practical support since their diagnosis. By far the most common category of help required was that relating to daily chores at home, (shopping, cleaning, gardening, preparing food) with three in five women needing this form of support (62.1%). Help with transport, including travel to and from hospital needed by almost half of the respondents (48.3%). Financial support was the third most common category with almost one in three women saying they needed it (29.2%).

The mean number of categories ticked was 2.1, with Japan's average slightly lower at 1.9.<sup>57</sup>



There were variations in the proportion of help needed according to age on diagnosis for age groups where there were more than 40 respondents.<sup>58</sup>

<sup>57</sup> BY COUNTRY CROSS TAB NUMBERS Q135

<sup>58</sup> BY AGE CROSS TAB NUMBERS Q135

LESS LIKELY TO REPORT THIS AS PART OF THE PRACTICAL SUPPORT MIX	AGE GROUP	MORE LIKELY TO REPORT THIS AS PART OF THE PRACTICAL SUPPORT MIX
Do not need practical support (5.8%* vs 9.7%)	21-30	Financial support (21.3%* vs 14%)
Do not need practical support (6.8%* vs 9.7%) Home adaptations (0.9% vs 2.7%)	31-40	Help looking after dependents (14.6% vs 9.2%)
	41-50	
Help caring for dependents (6.5%* vs 9.2%)	51-60	Do not need practical support (12.8%* vs 9.7%)
Help caring for dependents (4.6% vs 9.2%) Financial support (7.4% vs 14%)	61-70	
Help caring for dependents (1.9% vs 9.2%) Financial support (5.7%* vs 14%)	71-80	

In terms of variation by country where there were more than 40 respondents:

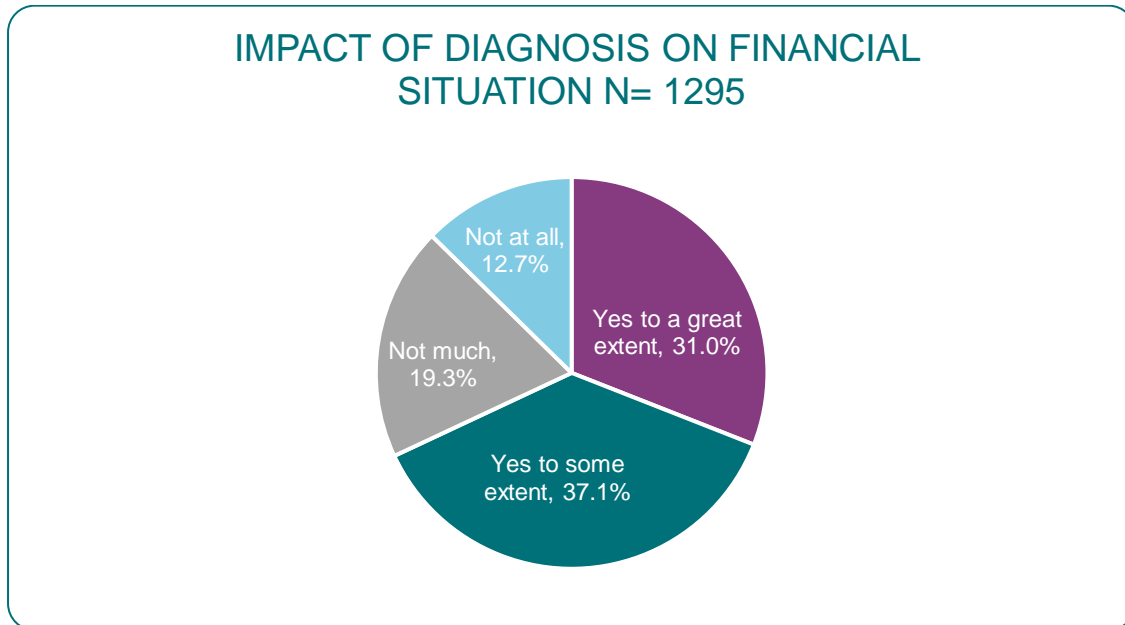
- Women in Japan were much less likely to need help with daily chores as part of their support mix, (20.7% vs 29.7%), and with personal care (4.5% vs 9.8%), but were much more likely to say that they needed financial support as part of the support mix (26.8% of responses vs 14%).
- In Germany, women were more likely to need home adaptations (30.5%\* vs 23.1%), and less likely to say they did not need practical support (2.2%).

Women who had practical support needs were asked if they had received help (n=1027). On average 16.3% of women did not receive any practical help despite needing it. This proportion varied widely by country. Very few women in Canada (3%), Italy (2.7%) and the USA (1.7%) reported not getting any practical help, but in Japan, the figure was 53%.

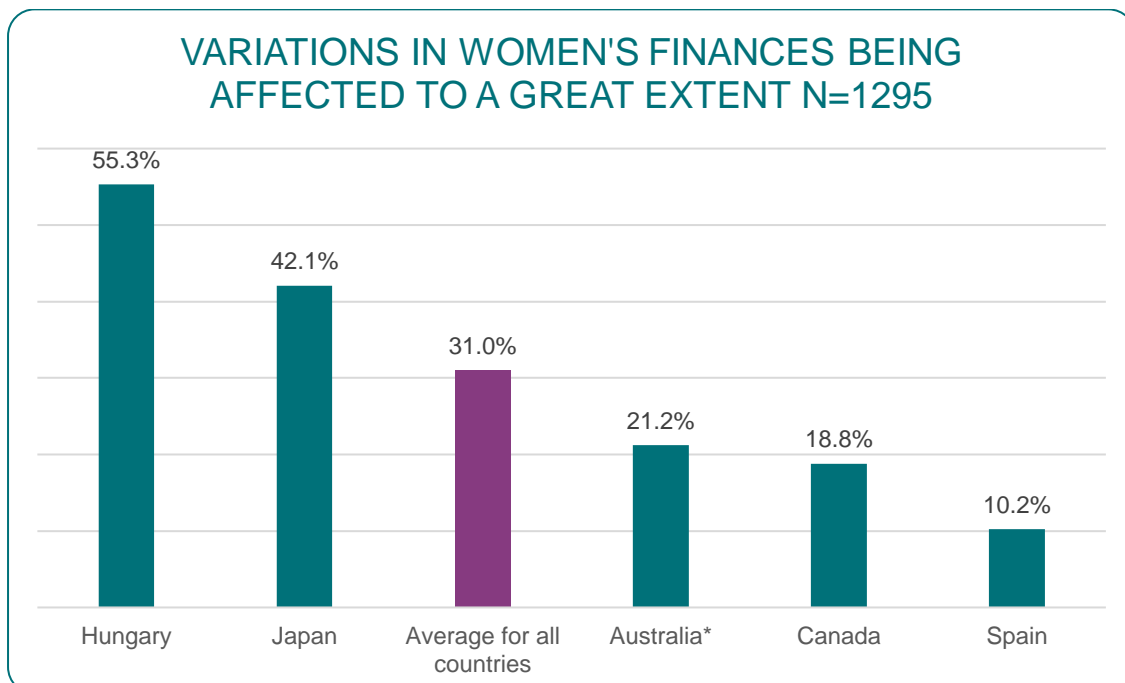
Almost all help that was given, was provided by family members (78.7%), with friends the second most common category (14.8%). All other categories were less than 2% each.

## FINANCIAL SUPPORT NEEDS

Women were asked whether having a diagnosis of ovarian cancer had impacted on their financial situation. Just 12.7% said it not impacted at all. And for two thirds of women, the effect was considerable:



On average 31% of women said their finances had been impacted to a great extent. This varied by country from 10.2% in Spain to 55.5% in Hungary<sup>59</sup>.



<sup>59</sup> BY COUNTRY CROSS TAB NUMBERS Q138

Women in Brazil (4.7%\*) and Japan (5.1%) are less likely to report that their finances had not been impacted at all (average for all is 12.7%).

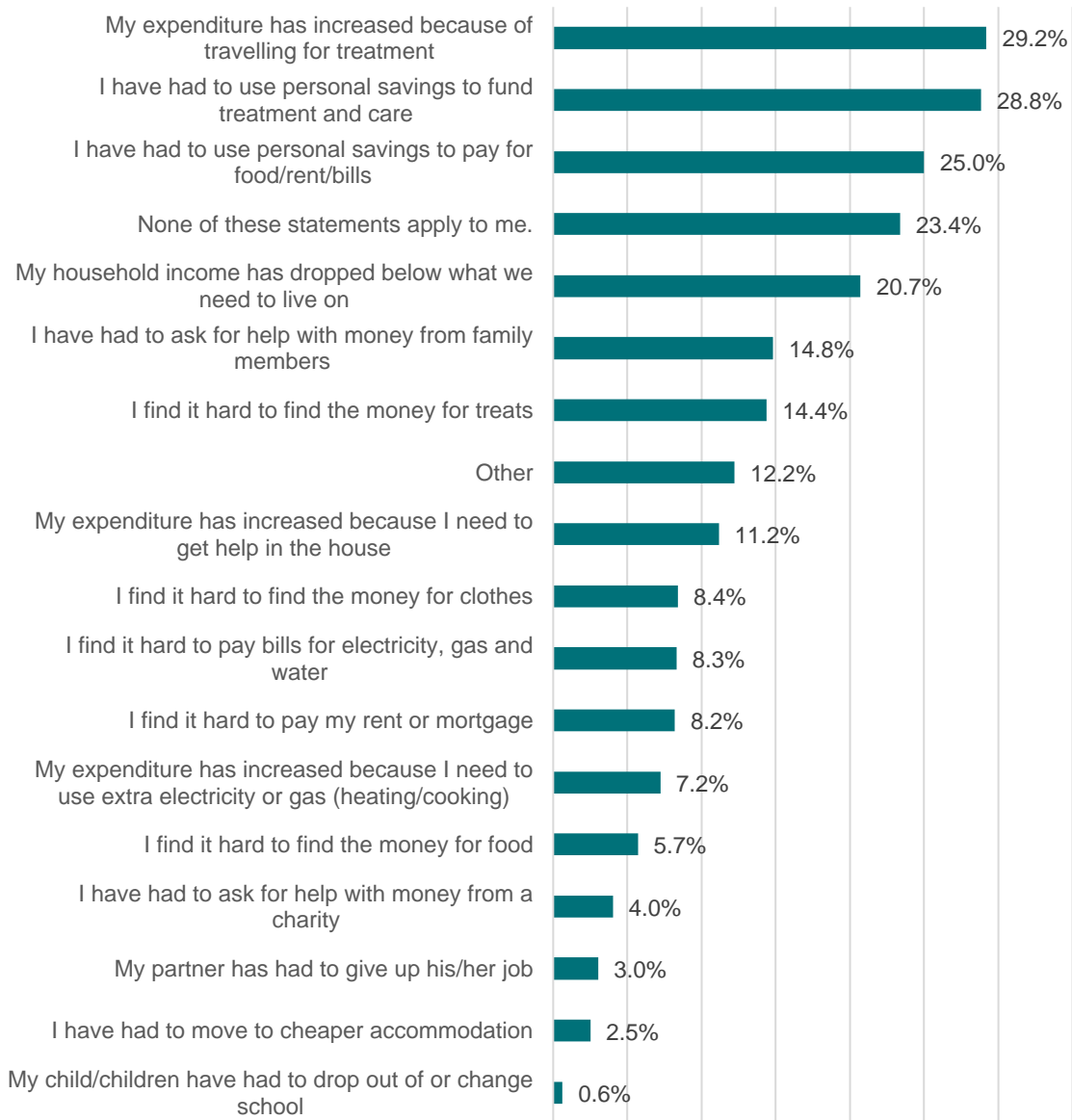
Women who had said their household income was below the average for their country were much more likely to report their financial situation had been impacted greatly than the average for all incomes (56% vs 31%), and those who reported that their income was above average less likely (21.9%). Women who were in paid full time employment were also much more likely to say their finances had been greatly affected (36%\* vs 31%) and those who were retired much less likely (11.7%).<sup>60</sup>

Women were asked in what way their finances had been affected by their diagnosis. Nearly three in ten women had to use personal savings to fund treatment and care (28.2%).

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<sup>60</sup> ADDITIONAL ANALYSIS STATISTICS CHECK/CROSSTAB Q13 AND 138

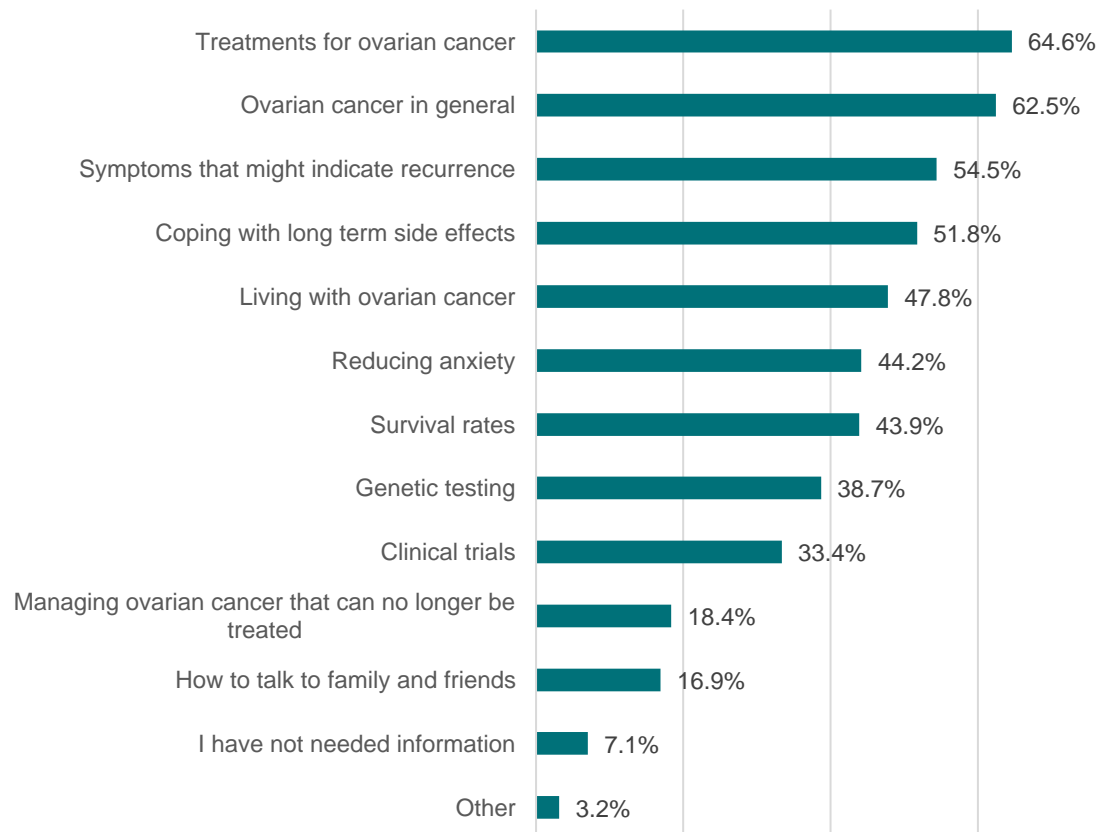
## WAYS IN WHICH THEIR FINANCES WERE AFFECTED N= 1120



## INFORMATION

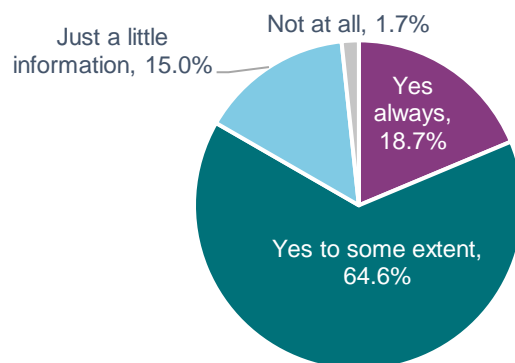
Women wanted information about a variety of issues, with just 7% of women saying they had not needed information since being diagnosed.

### PROPORTION OF WOMEN WANTING THIS TYPE OF INFORMATION N=1289

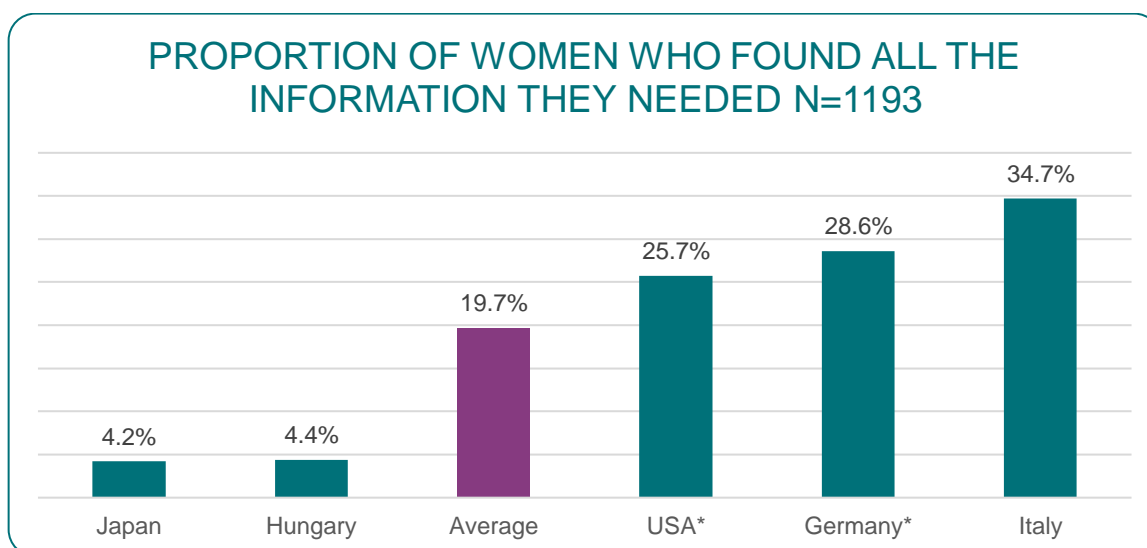


Just under one in five women (18.7%) of women always found the information they needed.

### Did you find the information you needed? n=1193



Variation occurred between countries, in relation to the proportion of women who found all the information they needed<sup>61</sup>.



Women with epithelial (endometrioid) ovarian cancer were less likely to find all the information they needed (11.7%\* vs 18.7%), and women with fallopian tube cancer more likely (34.2%\* vs 18.7%).

Women in the 31-40 age bracket were much less likely to get all the information they needed (8.4% vs 18.7%), whereas women in the 61-70 age bracket were much more likely to have had all the information they needed (32.2% vs 18.7%).

Doctors, followed by websites are the most important sources of information for women (62.4% cited their doctor, 56.2% said a website). Ovarian cancer support groups were the next most cited sources of information, and other women who have ovarian cancer (44.1% and 31.3%). Nurses were only cited by 18.2% of women.

Most women said they had searched for information on the internet about their diagnosis and found good information in their language (73.2%). However, 29.6% of women reported finding the information very scary. Women in Brazil were less likely to report having found good information in their own language (59.5%\* vs 73.2%)<sup>62</sup>.

<sup>61</sup> BY COUNTRY CROSS TAB NUMBERS Q141

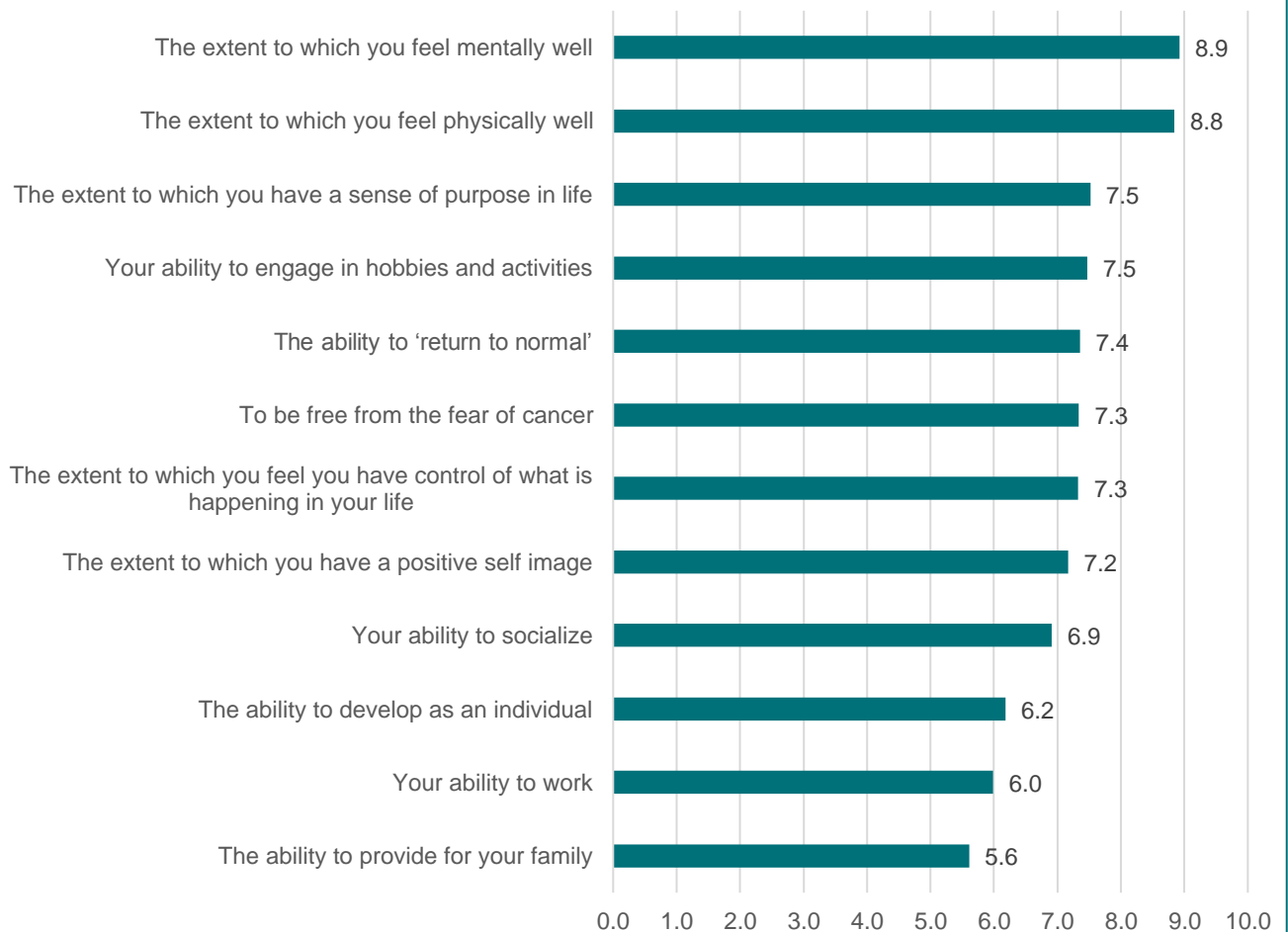
<sup>62</sup> BY COUNTRY CROSS TAB NUMBERS Q144

## QUALITY OF LIFE

Women were given a series of statements about quality life, derived from the qualitative interviews. They were asked to give each statement a score of between 0 and 10, with 0 being not at all important, and 10 the most important. All responses other than 'other', scored between 5.6 and 8.9.

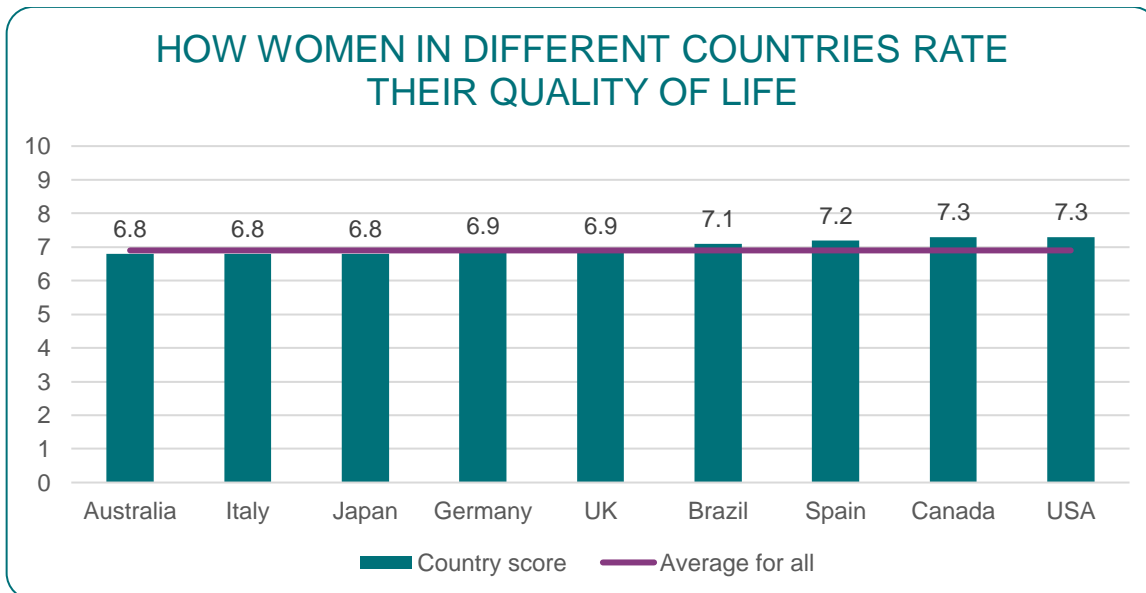
The extent to which women felt mentally well scored most highly (8.9), closely followed by the extent to which women felt physically well (8.8). This pattern was reflected consistently in the 'by country' analyses.

### MOST IMPORTANT FACTORS FOR QUALITY OF LIFE N=1270



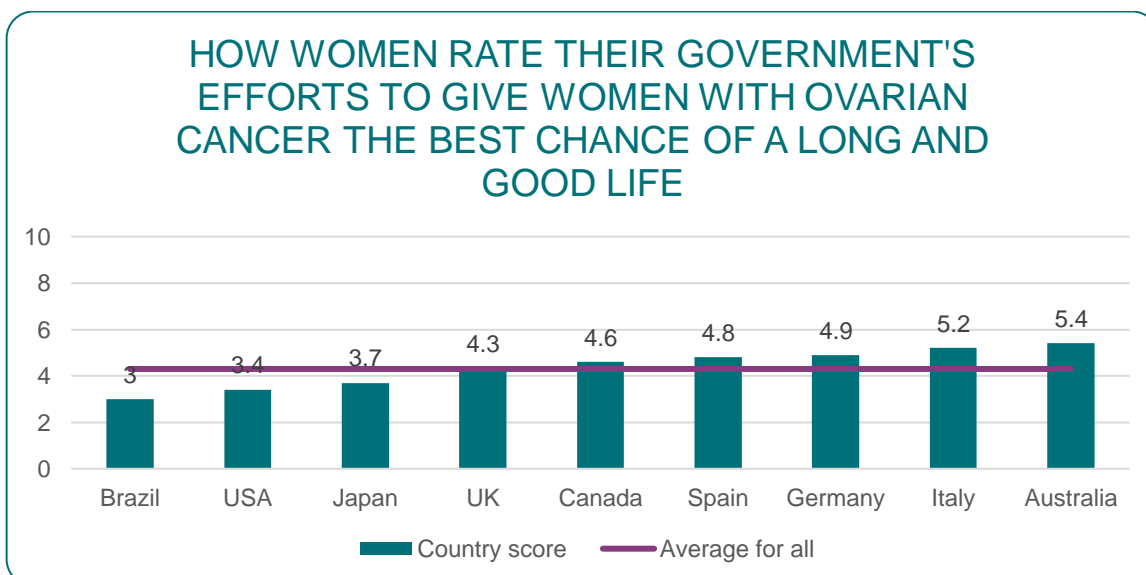


Women were then asked to rate their quality of life on the day they were completing the survey, with 10 being the best possible score. The Average was 6.9 (minimum score 0, maximum score 10, standard deviation 2.3, n= 1270). Countries with more than 40 responses were compared to the average<sup>63</sup>.



## GOVERNMENT EFFORT

Women were asked to rate the level of effort their government was giving to give women with ovarian cancer the best chance of a long and good life. 0 would mean they were doing nothing, 10 would mean they were doing all they can. The average for all respondents was 4.3 (minimum 0, maximum 10, standard deviation of 2.8, total responses n=1281).



<sup>63</sup> INDIVIDUAL COUNTRY REPORT

## IN THEIR OWN WORDS

Because the survey was undertaken in 15 different languages, there was deliberately very little opportunity to submit 'free text'. The penultimate question did include an option to comment following the rating of their government's action, and in addition a number of women chose to contact the Study Director by email. Approximately one in four left some form of comment. The following quotes are not comprehensive but reflect some of the range of comments received. The unprompted comments were predominantly negative. Many called for increased awareness and funding for research with a good proportion citing the amount of money going into breast cancer research, but there were also others that articulated some of the findings within the study, and others added perspective.

The women are only identified by the country in which they live. The comments are unedited except where identifying information has been removed. Google was used to translate the comments into English, but all the originals have been retained.

### Awareness

There needs to be more investment into effective screening for ovarian cancer. More widespread information about symptoms, if it wasn't for Ovarian Cancer month and word of mouth from ovarian cancer survivors then there would be even less knowledge out there. [UK]

Much more publicity is needed to bring awareness to the seriousness of this type of cancer. That information is not out there. A lot of work needs to be done. Women and their families only become aware when they are affected. Awareness and education will create more funding and research [Canada]

First of all, the knowledge of ovarian cancer is not widely spread in general. General information on disease of cancer is not accurately conveyed. Only the fear of cancer stands out. There is no information about safe medicine and care about treatment [Japan]

### Diagnosis

Govt needs to do more re GPs and their lack of diagnosis and lack of interest in their patients. After diagnosis I googled and all my symptoms were mentioned. GPs were not interested enough and made me feel like a hypochondriac. This went on for months! My stage 3 could've been a stage 1 or 2 if they cared enough. They were reluctant to do ct scans and Gynecologist disregarded U/S reporting of a bulky ovary. A Chinese medical practitioner detected abnormal amount of fluid in my abdomen before I insisted myself on better care from my Gynecologist.

I believe that the lack of early detection is very much dependant on our first point of contact - our GPs. I first reported on [...]and finally diagnosed [...nearly 4 months later 2017] by which time the pain and pressure on my bowel was unbearable. I visited 4 GPs, 2 specialists, a dietician, a Chinese Medical Practitioner and admitted myself to Emergency and no one even touched my belly to help diagnose my symptoms. This I find unacceptable. [Australia]

I saw 5 doctors - 2 GPs, a GYN at a pap clinic who is supposedly an expert in HPV, 2 internal medicine doctors and ended up diagnosing myself because not one of

them saw cancer in my obvious symptoms. The Government run system makes it impossible to see a GYN unless there is a problem detected by your GP. Until I moved to Canada I always had a GYN who I saw on a regular basis and he knew me. I can't help but wonder if having a GYN as part of my regular healthcare protocol would have gotten me diagnosed sooner. [Canada]

Neither my doctor or my gynecologist warned me that they felt my cyst was cancerous. I assume this was because my CA125 levels were normal. However an MRI showed that my cyst was complex...[because of what the gynecologist said] I realise he strongly suspected cancer but never warned me of this until after he completed my laparoscopic surgery. It was a shock to hear that news while feeling nauseated from anaesthesia and without my husband beside me. I wish there was a way to convey to the doctors that being open and honest with your patients makes it easier to discuss the ramifications of this disease. [Canada]

### **Health infrastructures**

I rate my country's efforts as zero. I was well treated as far as possible because I am from the health area and I have knowledge. I speak of equal to equal. Already people who were hospitalized with me without guidance, remained! You have to have a more humanized treatment. More searches. A hospital focused on this type of pathology. With professionals specialized in the subject. And with a psychological back, nutritionist, physiotherapy etc. [Brazil]

In Brazil, the government invests very little in research, structure, medicines and in the valuation of doctors. Many friends who depended on Sus [publicly funded healthcare system] died in the queue. [Brazil]

It should be forbidden to carry out any serious illness in non-specialized clinics. [Germany]

Doctors and especially nurses should not work under such a time pressure. This suffers the quality of work and errors arise - more time for patients would also be good for their psyche. [Germany]

### **Information**

My tumor was extreme seldom and it was very difficult to make a decision about the right therapy (if I should do Chemo or not) as doctors do not know the tumor much. There was not much Information in internet. [Germany]

The minute I learned [of my daughter's] diagnosis I spent countless hours online learning about this disease, studies, treatments – everything. People told me not to do this, that I would drive myself crazy, to ignore statistics, to calm down. NO! I wouldn't listen! Plus, I needed to learn what questions to ask the medical staff. I recommend this to all family members.....I joined online support groups, talked with other women undergoing treatment for ovarian cancer. I became a mini expert.....[USA]

## Impact of surgery

I have never seen an oncological gynecologist .... My oncologist who I love to the moon treats every type of cancer that there is. I think that would have been helpful, but I trust her.... Surgery to my colon... that was not mentioned at all in your survey and for me it was the most evasive and life altering treatment that occurred [having a bag].... I had so many accidents, so many emergencies having to go and not being near a bathroom....I live an hour from town up a mountain....(if I have to go on the way home).. I have to visit the woods with the bears and mountain lions. I couldn't go anywhere without being traumatized. I am now a month away from five year diagnosis and my cancer returned twice. I am having chemotherapy. My surgeon wants to do surgery again (third) but it would mean a permanent ileostomy. I told them I would rather have a gun – shoot me in the head than have that again. [USA]

I think I am a strong woman aware of what happened to me ... but I can say that I am no longer the same person as before ... actually I was taken away from my reproductive apparatuses ... and for me I remain a half woman ... unfinished not complete .... and psychologically I cannot live it as before ... sexually everything has changed ... And it's always worse ... I have very strong pains ... but they tell me that everything is normal .... for me nothing and as before ... and not even my physique since I have gained weight of 30 kilos ... in front of others I'm happy, I laugh, I'm joking, but inside I died after [date of diagnosis] 2014 [Italy]

## Drug therapies

New drug therapies need to be available to all women, example: Parp inhibitors that have had great success and is available to women in so many countries except Canada. [Canada]

Poor effort from the British government and the drug commissioning body in approving promising drugs, or removing drugs from the approved list. Ovarian cancer does not seem to have the same interest as other types of cancer - very disappointing. [UK]

Even though it looks Japanese government has tried to make a better environment for cancer patients, regional difficult is still remain. It's inconvenient for regional patients to have a second opinion [Japan]

## Genetic testing

They should support non-discrimination for genetic testing but they are disputing this [Canada]

I was denied a genetic test for brca back in 2004 as I wasn't considered 'high enough risk' as no mother or aunties had died of ovarian or breast (it was my paternal grandmother who died at aged 40 of breast cancer & she had 3 sons). I was estranged from my father at the time. Since my diagnosis of brca1/ ovarian/fallopian cancer there has been 6 further family members diagnosed with brca1 [Australia]

A case of HBOC, the surgery which female has to eliminate ovaries should be covered by insurance [Japan]

## Psychological support

There is still a lot to do to help many women who do not have the economic and psychological tools to face the cancer [Italy]

Physical support is good, but lack of mental support, as well as administrative support. [France]

Post treatment survivors need more support in the form of workshops on self-care and recurrence prevention as well as psychological support [Canada]

There seems to be a lack of screening for recurrence. I have never been given a PET scan, even though the use of PET in diagnosing recurrences is indicated in medical literature as making an impact on overall survival rates. CT scans are also not performed. I feel it makes it more difficult to remain confident as we can never truly know if we are truly disease free. [Canada]

I am a years survivor but live with chemotherapy side effects - Peripheral Neuropathy. My quality of life is greatly affected. I feel I was given the best treatment on offer. I have suffered anxiety and depression because of the effects and what I've been through to get where I am today. I have had counselling and at present on antidepressants. I go to a support group which I value dearly. [UK]

## Financial impact

Women should not fall into poverty because of illness. [Germany]

Especially about the employment support, the recognition of the world is low. In local cities, employment hiring will be cancelled if you know that you are sick. It is a situation I cannot even work part-time. In TV commercials we are aware that cancer patients work while being treated, but realistically it is not done in society. [Japan]

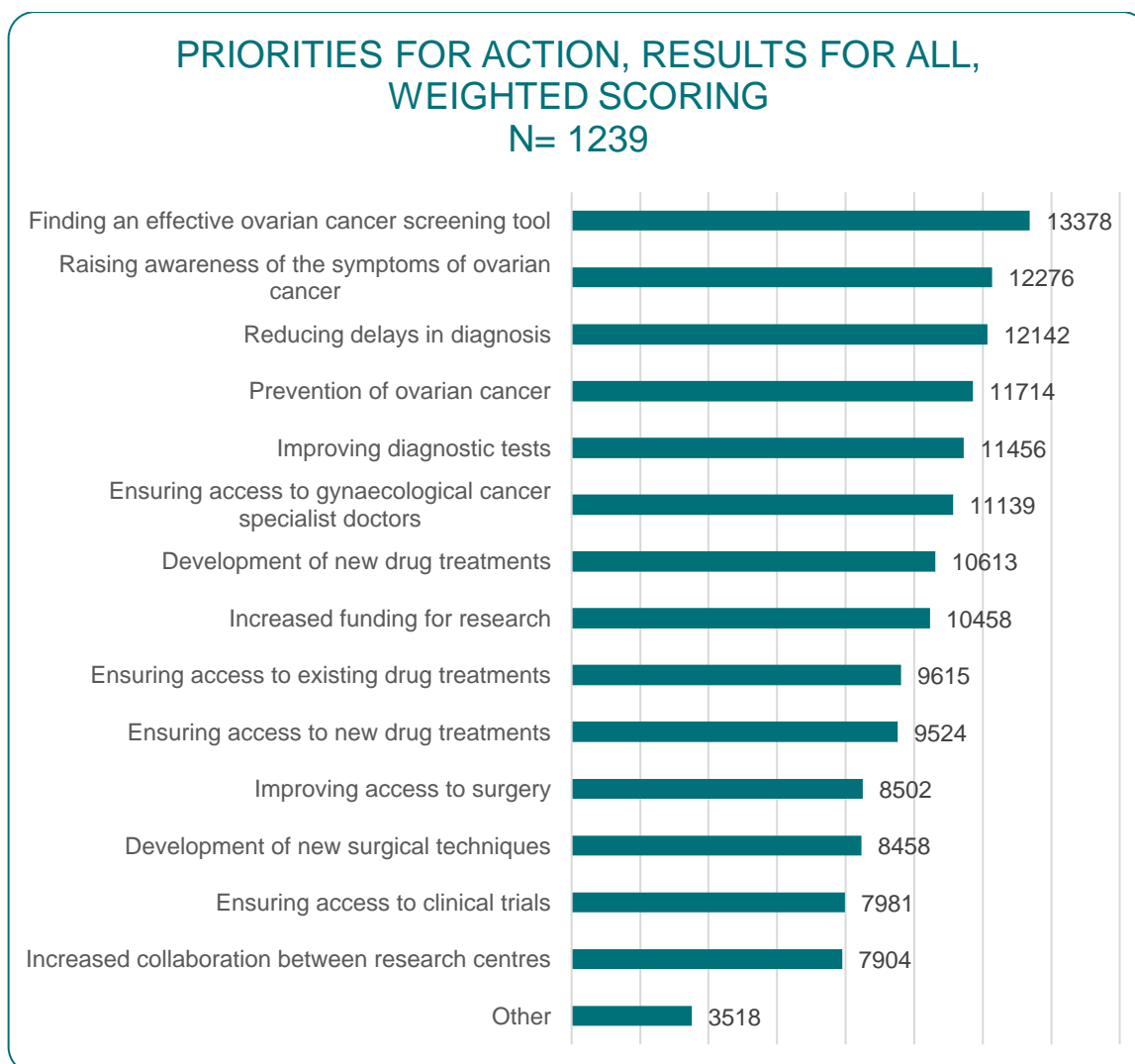
Because I'm a single woman very little help has been afforded to me financially. If it weren't for my church I would be so far behind financially that it would be devastating to my mental health. My government has done very little to assist me ...If I had children of my own I'd get all kinds of assistance but my cancer took that away from me. It seems unfair that my disability to be unable to have children be used against me in getting things like rent assistance, etc [USA]

Health insurance is a big deal in the US. If I re-occur and can't work will I be bankrupted because I have a pre-existing condition... it is a huge concern [USA]

I was lucky to have some of the world's best doctors. At the same time ovarian cancer is overlooked by the Australian Government with a clear focus on breast cancer. Also I had to pay for my chemotherapy. While Australia has medicare, there are huge problems for people like me who can't afford health cover (never earned enough for it so now have lifetime loadings) and aren't eligible for the aged pension or health care card. For us, we don't get to access health cover but don't get the benefits of the aged pension and health care card. My husband in 73 and still has to work. I had to pay for my own chemo. It's a pretty bad place to be in. [Australia]

## PRIORITIES FOR ACTION

The final question women answered explored their priorities for action in their country. The amalgamated results were as follows (having performed a weighted ranking):



There are some variations by country. The top three positions are highlighted for each country.

	Priority (all)	Australia	Brazil	Canada	Germany	Italy	Japan	Spain	UK	USA
Screening tool	1	1	7	1	2	1	1	2	1	1
Raising awareness	2	2	5	4	3	4	3	7	2	2
Reduce delays	3	5	1	2	8	2	4	1	3	6
Prevention	4	4	2	6	5	3	7	3	4	4
Improve diagnostic test	5	6	4	3	6	5	6	6	5	3
Access to specialist dr	6	7	3	7	1	7	5	5	6	7
Develop new drugs	7	8	10	8	4	8	2	10	9	8
Increase research funding	8	3	9	5	11	6	9	4	7	5
Access to current drugs	9	9	6	9	7	10	12	9	10	9
Access to new drugs	10	10	11	10	10	11	10	11	8	10
Access to surgery	11	11	8	11	12	9	11	8	14	12
New surgical techniques	12	14	13	14	9	12	8	12	11	14
Access to clinical trials	13	13	14	12	13	13	13	13	13	13
Increased research collaboration	14	12	12	13	14	14	14	14	12	11
Other	15	15	15	15	15	15	15	15	15	15

# Appendix 1

## METHODOLOGY

1. The questions for this survey were developed with the support of the Expert Advisory Panel, having reviewed the qualitative phase of the Every Woman Study (January 2018).
2. Member organisations have played an important role in participating in the member survey, sourcing interviewees, and testers, and promoting the Survey to women. Our thanks go in particular to:

Country	Organisation
Argentina	ACILCO
Australia	Cancer Voices Australia Ovarian Cancer Australia Royal Women's Hospital Australia (Deborah Neesham) St John Of God Subiaco Hospital Australia (Paul Cohen)
Brazil	Oncoguia Oncovida Rede Internationale
Canada	Ovarian Cancer Canada
Columbia	Fundacion Simmon
Croatia	Sve Za Nju
Denmark	KIU Women with Gynecological Cancer
Germany	Mamma Mia!
Hungary	Mallow Flower Foundation
India	Cachar Hospital (Dr Ravi Kannan) Cancer Patients Aid Association Colombia Asia Hospital Kolkata (Dr Manas Chakrabati) Indian Cancer Society Max Healthcare (Dr Swasti) Max Institute of Cancer Care (Dr Archit Pandit)
Ireland	Ovacare
Italy	Acto Alleanza Contro Il Tumore Ovarico Acto Onlus Loto Onlus
Japan	Smiley Patient Support Group
Portugal	Portuguese Association of Oncology Nurses



Puerto Rico	Sussoros Del Cancer Ovario
Romania	Romanian Federation of Cancer Patients Association
Spain	Asaco
Sweden	Gynecological Cancer Patients National Coalition Nätverket Mot Gynekologisk Cancer
United Kingdom	Ovacome Ovarian Cancer Action Target Ovarian Cancer
United States of America	Gynccsm Community Hope for Heather Ovar'coming Together Ovarian Cancer 101 Ovarian Cancer Project Ovarian Cancer Research Fund Alliance Sandy Rollman Ovarian Cancer Foundation

3. The draft survey was then tested in English online by 15 women from 9 different countries, in addition to 2 UK women who fed back on a paper draft (January 2018). The World Ovarian Cancer Coalition would like to thank:
  - Jan Rymer, UK
  - Anne Ainsworth, UK
  - Zrinka Ulovec, Croatia
  - Diane Gardiner Australia
  - Paola Ghitti, Italy
  - Silvana Simeoli, Italy
  - Brigitta Halász, Hungary
  - Susanna Quercoli, Italy
  - Sandra Balboni, Italy
  - Maria Lucia, Brazil
  - Amanda Luz, Colombia
  - Joana Yamagishi, Portugal
  - Sara Martinez Rios, Spain
  - Jenny Montresor, USA
  - Christie Lopez, Brazil
4. Member organisations who had participated in the member survey indicated a total of 13 different languages would be required. They were also asked if they were able to help with translations and testing. Following the EAP discussions about the prevalence of ovarian cancer in particular countries, and the seeking of offers of pro bono support for translation, the final draft of the survey was translated into 14 different languages: Bengali, Simplified Chinese, Croatian, Danish, Dutch, French, German, Hindi, Hungarian, Italian, Japanese, Portuguese, Punjabi, Spanish, Where required translation and checking was provided by Absolute Translations. Additional thanks to to Asako MacDougall, Birthe Lemley, Ecmín Otero, Ico Ildiko Nagy-Toth, Dr Manas Chakrabarti, Catherine Kirwin, Fulco Teunissen and Rafe Sadnan Adel for pro-bono translations or assistance checking translations.
5. We are grateful to the following sponsors for supporting the translation of the Every Woman Study Women's Survey: Merck Pfizer Alliance, Roche, Tesaro.

6. The final version of the survey went live on Monday 5<sup>th</sup> March and remained open for 2 months until World Ovarian Cancer Day on 8<sup>th</sup> May with the exception of the Indian Languages which went live on April 11<sup>th</sup>. Smart Survey hosted the survey.
7. A total of 1,531 valid survey answers were received by 9<sup>th</sup> May from 44 countries. To be valid, women had to have been diagnosed since the beginning of 2013, and answered questions at least up until the point of diagnosis (Q51). The following checks and amends were carried out:
  - All entries to 'other' for Q3 (in which country do you live) were assessed and reassigned if appropriate.
  - All entries to 'other' for Q16 (what type of ovarian cancer do you have?) were assessed. Where clear, they were reassigned to the given categories. Where unclear, they were left as 'other'.
  - The survey data was checked for duplicate IP addresses. These entries were then examined for duplicate responses. Where the entries were duplicates (for example someone may have partially completed the survey, and later completed the survey from scratch), the partial entry or a complete duplicate entry were deleted. Otherwise responses from duplicate IP addresses were kept where it was clear they were different respondents. A total of 40 duplicate responses were deleted.
8. All data is given to one percentage point (rounded up or down).
9. Most data were analysed using cross tables and filtered reports, with an A/B Testing significance calculator which calculated conversion rates, p values and significance. All the calculations that produced significant results are included in the cross-tab reports or associated documents. Dr Janet Townsend of Measurement Matters provided additional pro-bono pivot table analysis for some questions relating to family history, and symptom profiles.
10. All the data from the study is held exclusively by the World Ovarian Cancer Coalition
11. Funding for this study was drawn from general funds held by the World Ovarian Cancer Coalition.

## REFERENCES

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<sup>iii</sup> Renata R. Urban, Hao He, Raphael Alfonso, Melissa M. Hardesty, Heidi J. Gray, Barbara A. Goff Ovarian cancer outcomes: Predictors of early death, *Gynecologic Oncology*, Volume 140, Issue 3, 2016, Pages 474-480, ISSN 0090-8258, <https://doi.org/10.1016/j.ygyno.2015.12.021>.