



# THE EVERY WOMAN STUDY

SUMMARY REPORT



WORLD  
**OVARIAN**  
CANCER  
COALITION

THE  
**EVERY**  
**WOMAN**  
STUDY™



# PARTICIPATING COUNTRIES



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**USA** MEXICO **UK**

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CAYMAN ISLANDS **IRELAND** DENMARK

PUERTO RICO NETHERLANDS **G**

COLOMBIA **BELGIUM**

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ARGENTINA **BRAZIL** FRANCE SWITZERLAND

PORTUGAL **SPAIN** CROATIA

MOROCCO **ITALY**

GHANA NIGERIA GREECE

**AUSTRALIA**

This report has been produced and funded by the World Ovarian Cancer Coalition

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October 2018

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Professor Neerja Bhatla and Annwen Jones



**INLAND JAPAN**  
**ORWAY**  
**ARK LITHUANIA MONGOLIA**  
**ERMANY**  
**SLOVENIA HUNGARY**  
**ERLAND LEBANON CHINA**  
**DATIA ISRAEL INDIA**  
**ROMANIA**  
**E SOUTH AFRICA**  
**A NEW ZEALAND**  
**PHILIPPINES**

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# THE WORLD OVARIAN CANCER COALITION

The World Ovarian Cancer Coalition is a not-for-profit organization, established in 2016 by a group of international ovarian cancer patient advocacy leaders. It builds on the resounding success of World Ovarian Cancer Day, the annual ovarian cancer awareness campaign launched in 2013. Our mission is simple: to ensure the best possible chance of survival, and the best quality of life for every woman with ovarian cancer – wherever she lives.

Today, the Coalition works with 135 individual patient advocacy organizations from 37 countries around the world. Since 2013, the World Ovarian Cancer Day campaign has reached well over 1,000,000 - with people taking part from at least 50 countries and in 45 different languages – and each year its reach and impact grows.

In 2017 we made the decision to address the evidence gap relating to the experiences of women with ovarian cancer globally, and to identify what needs to be done to tackle this deadly, often overlooked cancer not just for women in more developed countries, but right around the world. The World Ovarian Cancer Coalition Every Woman Study is the result of that decision. Members were surveyed about their priorities for action, and a literature review formed the basis of the World Ovarian Cancer Coalition Atlas, bringing together for the first time evidence around incidence, mortality and survival as well as attitudes and practices. A series of interviews amongst women and clinicians in 16 countries was conducted. The findings informed the development of the Every Woman Study Online Survey available in 15 languages, and was completed by 1531 women in 44 countries between March and May 2018. A total of 37 clinicians in 15 countries contributed to the clinician interviews and online consultations. All reports are available on our website [www.worldovariancancercoalition.org](http://www.worldovariancancercoalition.org).



At every stage, the work has been overseen by an Expert Advisory Panel (see page 38), with global representation. We thank them for their time and expertise. We would also like to pay tribute to the many women who have been interviewed or taken part in the survey, some of whom have since lost their lives to the disease. Their determination to share their insight, their fears and hopes, has been invaluable. A number of member organisations and other supporters have also provided essential support without which we would not have been able to reach out so far and wide. There remains much to be done.

The recommendations from the Every Woman Study present so many opportunities now to transform survival and wellbeing for women with ovarian cancer. Action is vital. This is why as a Coalition we are developing the first Global Ovarian Cancer Charter. To be launched in 2019, it will help drive the changes we need to fulfil our collective mission of ensuring the best possible chance of survival, and the best quality of life for every woman with ovarian cancer – wherever she lives.

# EXECUTIVE SUMMARY

## MESSAGE FROM THE CO-CHAIRS OF THE EXPERT ADVISORY PANEL



**ANNWEN JONES**



**PROFESSOR NEERJA BHATLA**

*“You make everything a little bit better than it is, and you make a big difference. I don’t think there is one magical thing that you can do.”*

**PROFESSOR IAIN McNEISH, UK**

With some 600,000<sup>1</sup> women living within five years of their diagnosis of ovarian cancer, slow progress in improving low survival rates when compared to other cancers and incidence set to grow 55% by 2035, efforts to improve survival and quality of life for these women is an ever-increasing and pressing global challenge.

The World Ovarian Cancer Coalition is dedicated to that task. The findings of the Every Woman Study, the largest ever consultation of women with the disease, with contribution from the international clinical community, provide a compelling and wide-eyed lens which will lay to rest misconceptions about the disease, stimulate further research and most importantly motivate women, clinicians, patient groups, and policy makers to act as a matter of urgency.

1531 women with ovarian cancer in 44 countries took part and the results present a devastating litany of the challenges they and those who care for them have faced at every turn: from ignorance of the disease and key symptoms; inaction around family history; major challenges in getting a correct diagnosis; to effective treatment and support. It is not news that ovarian cancer is a ‘difficult disease’, but the findings from the Study reveal wide variations between countries in terms of what they achieve well, and what is most challenging for them in tackling this disease.<sup>†</sup>

No one country has all the answers, and whilst there is still an urgent need for a step-change in the level of investment in research for better treatments and tools for early diagnosis, there are significant opportunities to improve survival and quality of life for women in the immediate and short-term to make a series of marginal gains if these variations are addressed by individual countries.

Looking at the key findings of the study it becomes clear that countries have significant potential to learn from each other:

- Women in Germany had the shortest time to diagnosis, but much less access to specialist clinicians that are key to successful treatment.
- Women in the UK have almost universal access to specialists but the lowest proportion of women diagnosed within a month of visiting a doctor.
- Women in Japan had one of the shortest times to diagnosis, but very little access to genetic testing, and were least likely to get the emotional support they needed.
- Women in the USA were most likely to wait more than three months before consulting a doctor about symptoms, but most likely to receive genetic testing.
- Women with ovarian cancer in Hungary were most aware of ovarian cancer before their diagnosis, but were much less likely to be offered surgery to treat their disease.

<sup>†</sup> Given the good health, age and affluence of participants and the contrasting short-term mortality statistics the Expert Advisory Panel believe these findings represent an ‘optimistic’ view of the true picture.

## EXECUTIVE SUMMARY

*"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 I was before... actually I was taken away from my reproductive apparatuses, and for me I remain half a woman, unfinished not complete, and psychologically I cannot live as before....I have very strong pains... but they tell me everything is normal...for me nothing [is] as before. In front of others I'm happy, I laugh, I'm joking, but inside I died on [the date of her diagnosis]."*

**SURVEY PARTICIPANT, ITALY**

Each year there are an estimated 239,000 women diagnosed with ovarian cancer. Less than half are likely to survive to five years post-diagnosis, and in some countries the figure is much lower.<sup>2</sup> Shockingly, using data from two studies,<sup>3,4</sup> it is also estimated (conservatively) that one in six women (40,000) lose their lives within three months of being diagnosed. With incidence on the rise, predicted to reach 371,000 a year by 2035, there needs to be a united and concerted effort to drive progress. Raising awareness of the disease will play an invaluable part of building support and funding for this challenge as two-thirds of women we surveyed had never even heard of ovarian cancer or know anything about it.

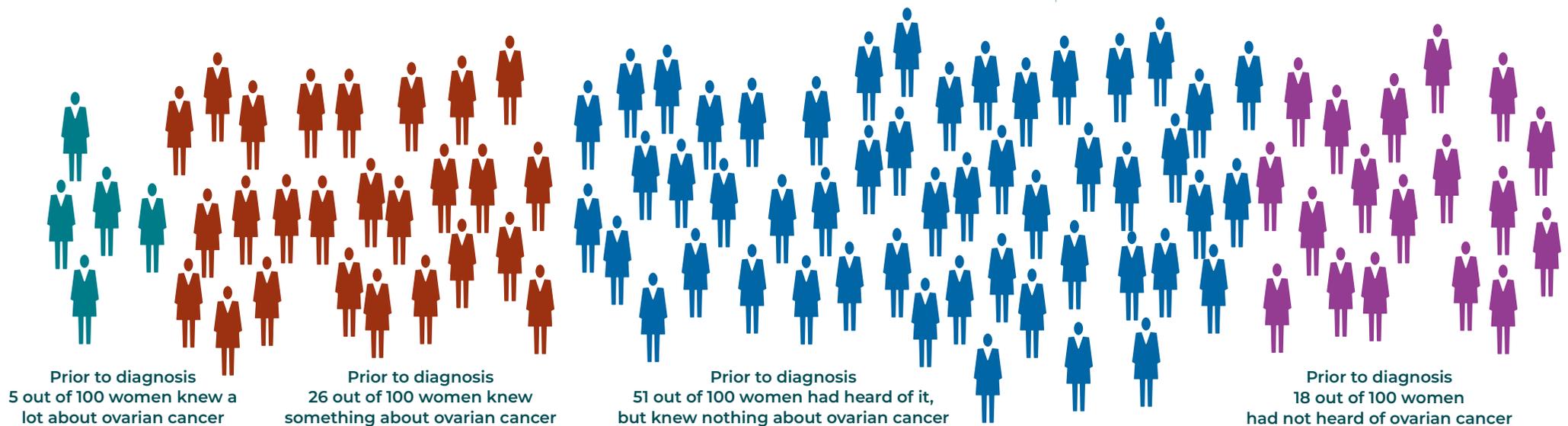
The numbers are shocking enough, but one participant from Italy highlighted how terrible the impact of this disease can be.

Our commitment is to help women no matter where they live, not just to live, but to have a better quality of life living with this disease. This report highlights what can be done here and now to start to make that a reality, and to give them hope for the future.

Hope and belief is important, as interviewee Nanci in Brazil outlined.

*"Once I asked one of these doctors, 'So what are my chances?', and she answered 'Your chances are very minimal'. I answered back, 'I will surprise you.' And I have surprised her. Be faithful and try new things, it means everything. Allow yourself to be open to new things....Never give up despite the challenges, it is wonderful to live."*

**NANCI, BRAZIL**



## EXECUTIVE SUMMARY

With an estimated 600,000 women living within five years of an ovarian cancer diagnosis, results in this study achieve a confidence level of 95% with a confidence interval of +/- 2.5% where n=1350.

Where country comparisons are made, the significance threshold is set with  $p < .01$ , unless marked \* in which case  $p < .05$ .

## KEY FINDINGS

### AWARENESS AND DIAGNOSIS

1. Over two-thirds of women had not heard of ovarian cancer, or knew anything about it prior to their own diagnosis, with wide variations between countries.
2. Nine in 10 women experienced multiple symptoms prior to diagnosis irrespective of stage of diagnosis or type of ovarian cancer.
3. Of these women, eight in 10 consulted a doctor about symptoms, but the time to do so varied widely, and on average fewer than half went within a month. One in 10 waited more than six months. The estimated time from visiting a doctor to diagnosis also varied widely, and for one in 10 it took over a year to be diagnosed. The time from experiencing symptoms to diagnosis varied by more than three months between different countries.
4. Clinicians who contributed to the Study were of the firm view that delays in diagnosis could be reduced, thereby improving a woman's ability to undergo and tolerate treatment and that this could potentially lead to improvements in five-year survival. They felt strongly that a lack of awareness of symptoms on the part of women and family doctors and/or gynecologists contributes to delays in diagnosis.

### FAMILY HISTORY

1. Opportunities are being missed to identify women at risk of developing ovarian cancer because of their own family history. Of those with two or more relatives with ovarian cancer in their family, 80% had not had genetic testing prior to their own diagnosis. In the absence of screening, knowing your own genetic susceptibility is a potentially vital source of primary prevention.
2. Levels of testing pre-diagnosis varied widely, with Germany having the highest rate: 34% of women with one or more family members affected were tested, compared to an average of 16.1% for all countries.
3. Women are potentially missing out on new targeted treatments described as a 'game changer' because they are not receiving genetic testing post-diagnosis. Combined figures for pre- and post-diagnosis testing vary widely by country from 9.6% in Japan to 80.6% in the USA, with an average for all of 54.7%. This also means that the opportunity to find others at risk in the family is lost.

## EXECUTIVE SUMMARY

### ACCESS TO SPECIALIST TREATMENTS IN A TIMELY MANNER

1. Despite published evidence of the benefit of assessment, surgery and treatment by ovarian cancer specialists in high volume centres,<sup>5,6</sup> the proportion of women receiving this level of care varies widely around the world and the organisation of specialist services is seen by members of the clinical community as a vital step to improving outcomes.
2. Delays accessing test results, operating room space, and drugs can impact on the care women receive and vary between and within countries.
3. Rates of certain procedures such as primary surgery, surgery for recurrence and intraperitoneal chemotherapy can vary widely by country.
4. Women are very positive about the care they receive, but where women have to pay for their own treatments, the financial impact can be devastating on families.

Whether at the time of diagnosis, after treatment, upon recurrence or receiving the news their cancer is incurable, many women are not getting the information they need. Most information they are given is verbal and rarely goes beyond generic and treatment specific information.



### RECOMMENDATIONS

This Study provides powerful evidence relating to the significant challenges facing women with ovarian cancer around the world. The Expert Advisory Panel believe this work provides a solid basis for setting a course for global, transformational change that needs to involve the whole ovarian cancer community.

#### 1. AWARENESS

The panel were shocked by the lack of knowledge of the disease worldwide. They recognise that this must change in order to build support and funds for action to achieve profound and long-lasting change for women with ovarian cancer. They were also of the firm belief that raising awareness of the disease and key symptoms is essential to reducing unacceptable delays in diagnosis, so that:

- a. Women do not delay seeking help, or tolerate delays once they have sought help for symptoms they are experiencing.
- b. General practitioners, family doctors, emergency physicians and gynecologists are better able to determine who needs prompt diagnostic tests and specialist assessment.

#### 2. SHORT-TERM MORTALITY

The ovarian cancer community needs a greater understanding of short-term mortality. This requires highlighting and encouraging further research including investigations about the biological and performance/treatment status of women who die very quickly, but also ways to determine their experience prior to their diagnosis.

#### 3. FAMILY HISTORY

The lack of knowledge about the importance of family history and genetic testing must be addressed amongst women, health professionals and policy makers. In particular:

- a. The importance of both the mother's and father's side of the family.
- b. The role of timely genetic testing and counselling to enable primary prevention and access to new targeted therapies.

#### 4. SPECIALIST TREATMENT

It is essential women receive prompt specialist assessment. This can be done by:

- a. Letting women know that specialist assessment and treatment is likely to offer them the best chance of successful treatment and survival.
- b. Providing or facilitating information for family doctors and gynecologists as to who should be sent for specialist assessment.
- c. Highlighting variation around the world, the benefits of specialist treatment and how countries/regions approach the challenges of implementing such a system.

## EXECUTIVE SUMMARY

In our introduction we have chosen to focus on our top priority areas for action, but ask you also to consider the areas of information, mind and body, clinical trials and diversity in data which are discussed in this report.

As co-chairs of the Expert Advisory Panel we urge you to think back to Nanci's words. We hope that if the results of this report surprise you, you will be motivated to try new strategies in the quest to improve survival, and hold on to the belief and knowledge that desperately needed progress can be made. The World Ovarian Cancer Coalition will be launching a Global Ovarian Cancer Charter in 2019 and we urge you to be proactive participants in improving the lives of hundreds of thousands of women right around the world, and to transform the future for those yet to be diagnosed.

### ANNWEN JONES

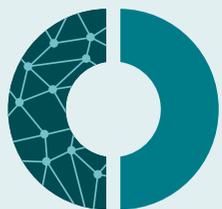
Chief Executive Target Ovarian Cancer, UK.

Vice-Chair of the World Ovarian Cancer Coalition.

### PROFESSOR NEERJA BHATLA

Department of Obstetrics & Gynecology,  
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Chairperson, FIGO Committee for  
Gynecologic Oncology.



WORLD  
**OVARIAN**  
CANCER  
COALITION

To join the World Ovarian Cancer Coalition  
please visit our website:

[www.worldovariancancercoalition.org](http://www.worldovariancancercoalition.org)

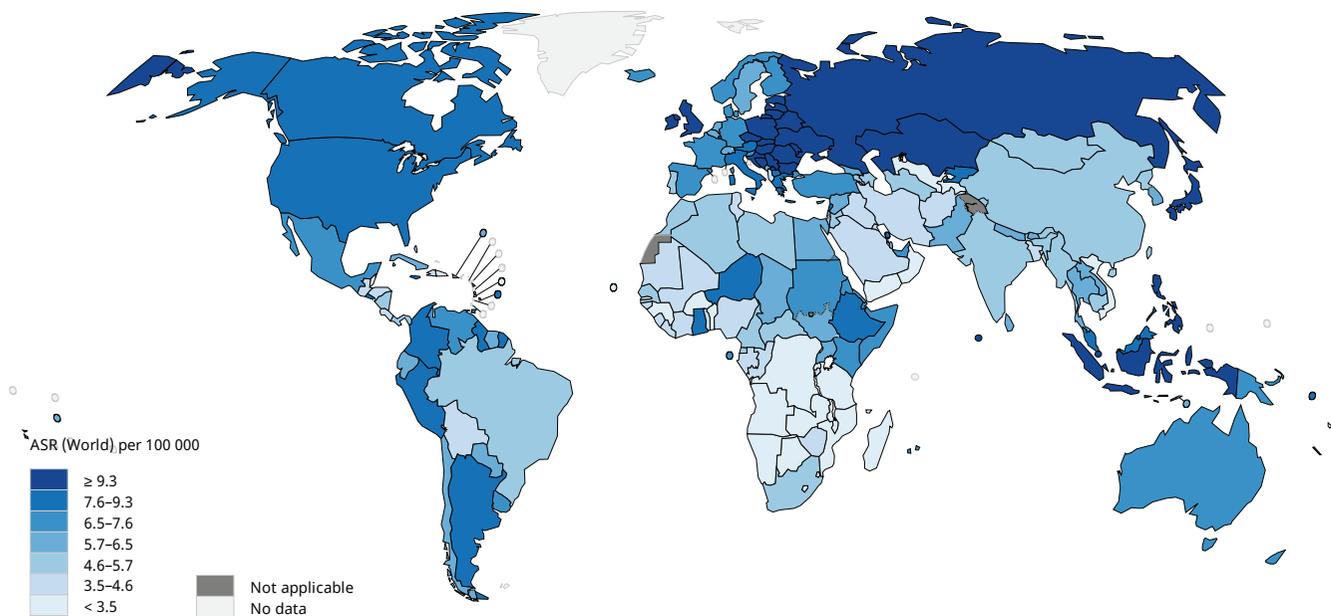
# ABOUT OVARIAN CANCER

Ovarian cancer is the 7th most common cancer, and the 8th most common cause of death from cancer in women in the world. The Globocan study<sup>1</sup> estimated there were 239,000 cases and 152,000 deaths from the disease in 2012. It predicts that by 2035 there will be a worldwide increase of 55% in incidence to 371,000 and an increase in deaths of 67% to 254,000.

Age standardised rates of incidence and mortality are highest in developed parts of the world, with risk rising as a country develops economically. This together with expanding populations and increase in life expectancy drive the future projections, adding to the urgency to address globally poor survival rates. In addition to where women live, other risk factors are age, family history and hormonal factors. Whilst serous epithelial ovarian cancer is the most common type of the disease worldwide and within countries, other types vary more widely according to country, as does the average age of diagnosis.

Population sizes however mean that most women with ovarian cancer live in less developed parts of the world (58%). In terms of countries: China has the largest number of women living with ovarian cancer, followed by India, USA, Russian Federation, Indonesia, Japan, UK, Germany, Italy and Brazil.

## ESTIMATED AGE-STANDARDISED INCIDENCE RATES (WORLD) IN 2018, OVARY, FEMALES, ALL AGES



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Estimations of survival rates vary widely depending on which types of ovarian cancer are included, the completeness of cancer registration, and how background mortality is calculated. This makes comparisons between countries inadvisable, unless within a research study. The Concord 3 Study (2018) analysed data on over 865,000 women with ovarian cancer in 61 countries diagnosed between 2010 and 2014.<sup>2</sup> Using data it considered reliable, 24 countries had five-year survival in the 40-49% range, and 19 countries in the 30-39% range. India had the lowest calculated figure of 15.6%. Compared to their data for women diagnosed between 1995 and 1999, survival rates in Japan increased by 20%, 2 countries by more than 10% and 14 countries between 5 and 10%.

# THE WOMEN IN THIS STUDY

There were 1531 responses from women in 44 countries, who were diagnosed since January 2013. Six countries had more than 100 respondents (Australia, Canada, Germany, Japan, UK, USA).<sup>†</sup> The single biggest ethnic group were Caucasians (57.2%) followed by East Asian (13.6%) and Latino/Hispanic (8.23%). 9.1% of women chose not to disclose their ethnic status, and 8.6% said other.

Epithelial serous ovarian cancer was the most common type of ovarian cancer in almost all countries including Japan with approximately one-third of cases (34%). Endometrioid and clear cell ovarian cancers were the next most common (approximately 10% each), but were more common in Japan (approx. 22% each) and less common in some other mainly European countries. The figures also showed that 12.5% did not know what type of ovarian cancer they had, in Hungary this figure was 29.3%.

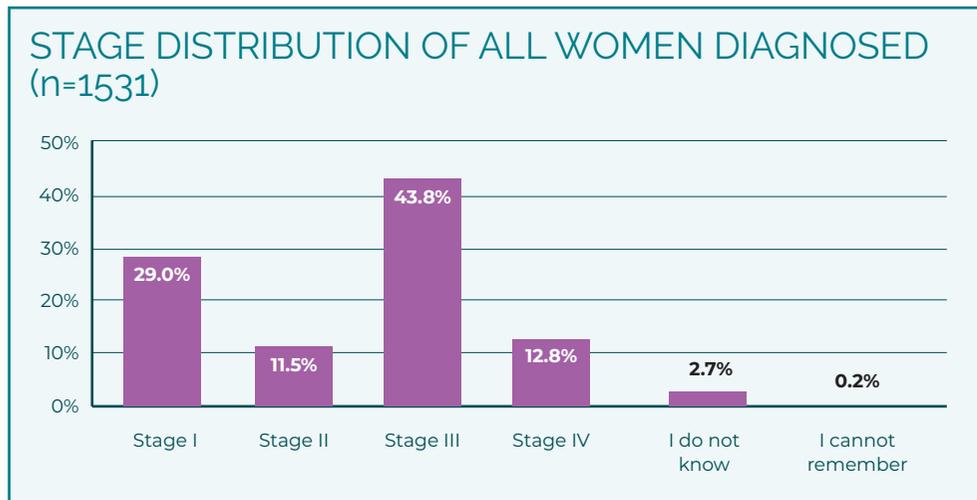
Almost a third of women were in each of the 41-50, and 51-60 age brackets, with the remaining third roughly between older and younger participants. Age and stage of diagnosis were shown clearly to be affected by the type of ovarian cancer, but women in Japan experienced endometrioid, clear cell and serous ovarian cancers on average a decade earlier than women with the same types in the USA and Canada.

Women with serous ovarian cancer were least likely to be diagnosed at stage I in the UK<sup>‡</sup> than the average for other countries. For clear cell and endometrioid ovarian cancer, Japan was more likely to diagnose at stage I than the average for all, and the USA less likely.<sup>§</sup> Japan was less likely to diagnose at stage III than the average, and the USA more likely.<sup>§§</sup>

Almost two-thirds of women had not experienced a recurrence of their ovarian cancer. Recurrence was more common in women with serous or primary peritoneal ovarian cancer, and in women diagnosed before 2016, which represented half of all respondents.

It is unsurprising given the age profile of respondents that many were in employment prior to their diagnosis (75.8%), and whilst 50.6% described their household income as average for their country, 31.4% said it was above average.

The Expert Advisory Panel noted that the respondents were on the whole younger than expected, and from the data supplied, they were more affluent on the whole and from developed economies. Given this and the low rates of recurrence, it is a reasonable assumption to say these women are in better general health than expected, and as such the results of this study reflects a potentially more positive situation than that which exists in reality.



<sup>†</sup> Australia 120, Canada 167, Germany 141, Japan 250, UK 176, USA 248

<sup>‡</sup> 3.1% vs average for all serous of 9.4%

<sup>§</sup> Japan 69.7%, average 57.2%, USA 37.2% \*

<sup>§§</sup> Japan 11%, average 18.9%, USA 39.5% \*

# AWARENESS AND DIAGNOSIS

## KEY FINDINGS

Over two-thirds of women had not heard of ovarian cancer or knew anything about it prior to their own diagnosis with variations by country ranging from 50.0% to 86.4%.

Nine in 10 women experienced symptoms prior to their diagnosis. On average women experienced four or more symptoms, mainly, but not exclusively those most commonly associated with ovarian cancer. This was irrespective of country, stage and type of ovarian cancer.

Of these women, eight in 10 consulted a doctor about symptoms, but the time taken to do this varied widely by country. On average less than half visited a doctor within one month, and one in 10 waited more than six months. Knowing lots about ovarian cancer increased the likelihood a woman would visit her doctor within three months of experiencing symptoms.

The time from this visit to diagnosis also varied widely by country. For one in 10 women it took more than a year to be diagnosed. This offers much room for improvement. The estimated total time from experiencing symptoms to diagnosis varied from just under 22 weeks (Japan), to 36.5 weeks (USA) with an average of 31 weeks for all women in the study.

Almost all of the clinicians who were consulted felt that lack of awareness of symptoms amongst women, family doctors, gynecologists and physicians contributed to delays in diagnosis. They felt that addressing these delays could certainly improve women's ability to undergo and tolerate treatment, and could potentially lead to improvements in five-year survival.

The Expert Advisory Panel noted that the cohort of women in our study were younger and in better health than they had expected, so the results of the survey may represent the best possible current position. They noted that the clinicians' report and academic literature have highlighted the shocking data that a considerable proportion of women die within the first three months of diagnosis (up to 26%), potentially around 40,000 women globally each year. Research into short-term ovarian cancer mortality is very limited but points to increasing age, emergency presentation, lack of specialist care, and co-morbidities playing a part.

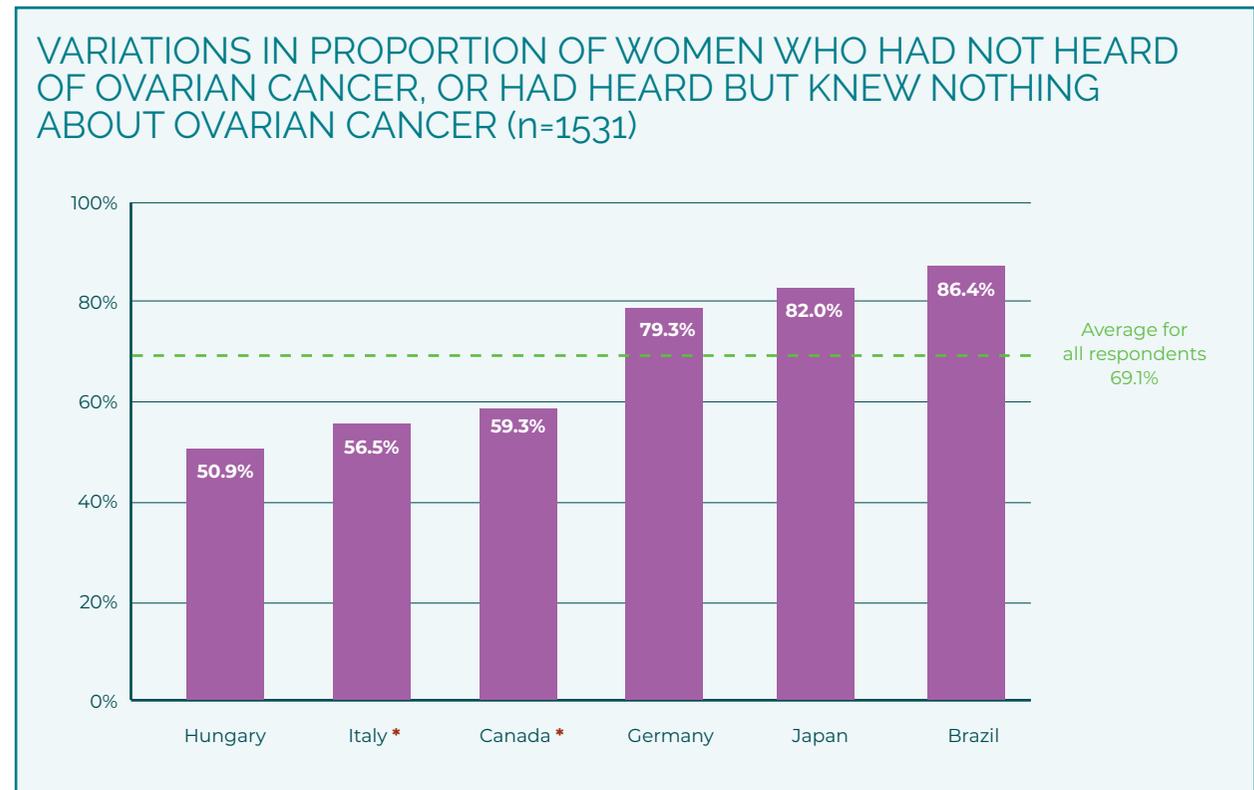
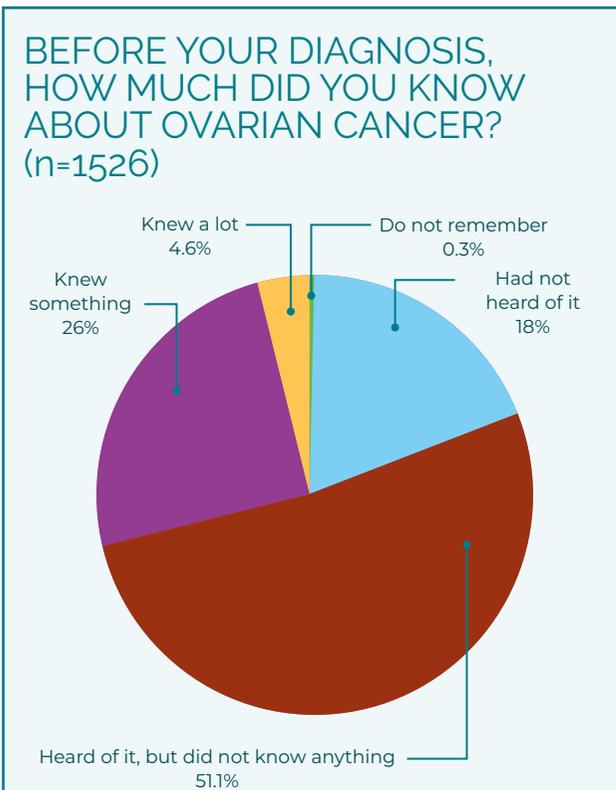
## AWARENESS AND DIAGNOSIS

Over two-thirds of women had not heard of ovarian cancer or knew anything about it prior to their own diagnosis with wide variations between countries. Just under 14% of the total sample had known that increased abdominal size, or persistent bloating could be a symptom of ovarian cancer and these were the most commonly recognised symptoms.

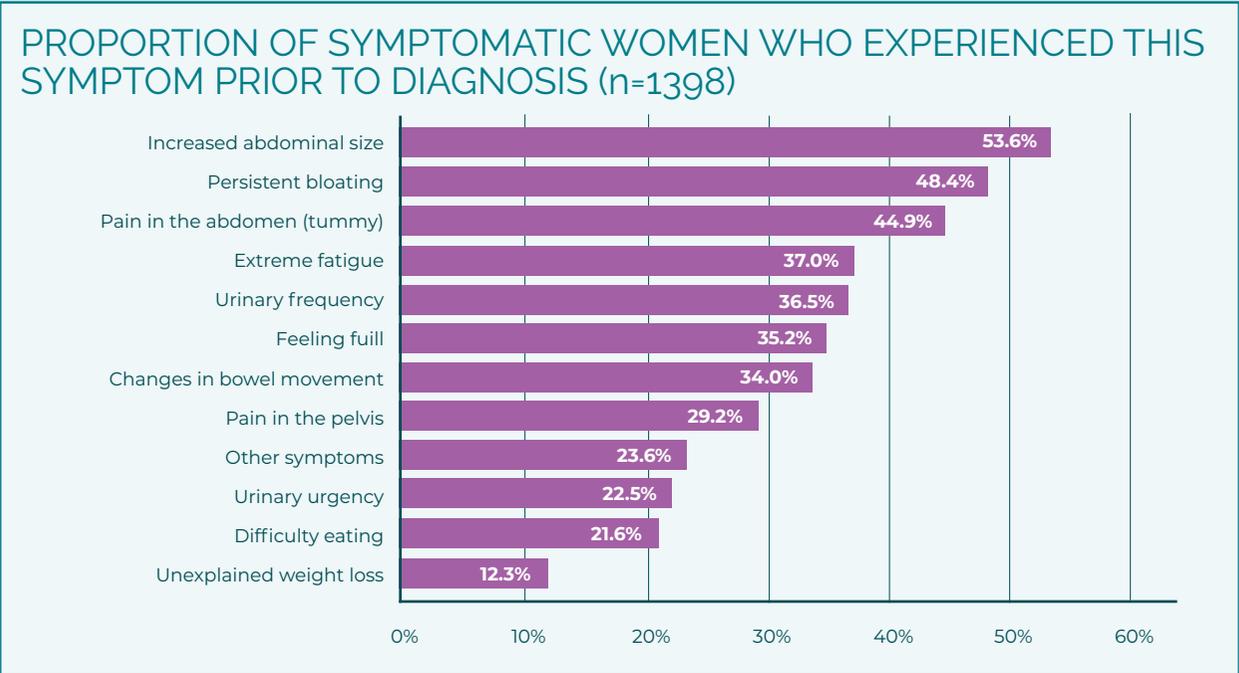
More than 90% of women reported experiencing multiple symptoms prior to their diagnosis. Of the women with stage I disease, 87.4% reported experiencing symptoms. On average women experienced four or more symptoms (including the category 'other') from the following list irrespective of country, stage, and type of ovarian cancer. Women with stage IV disease were more likely to report five or more symptoms.

*“There needs to be... 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.”*

**SURVEY PARTICIPANT, UK**

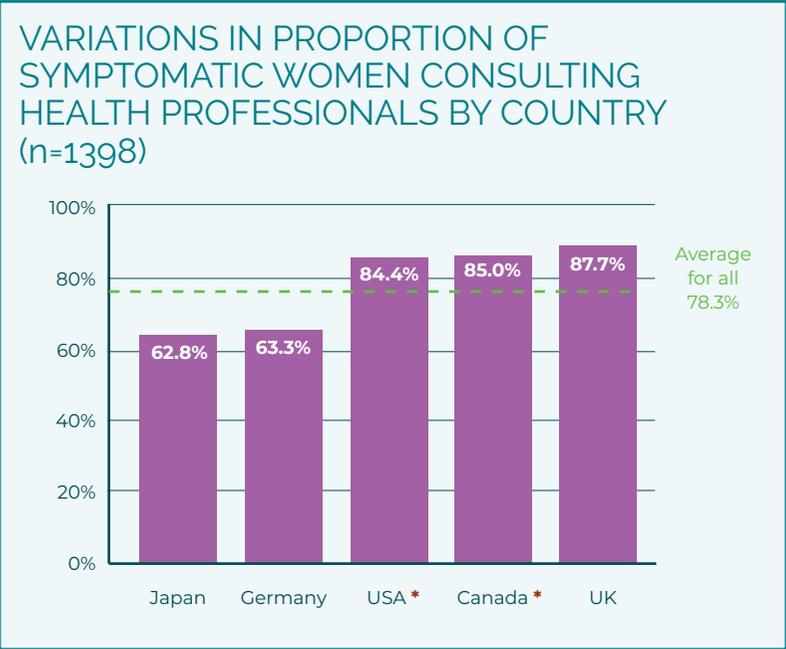


# AWARENESS AND DIAGNOSIS



Symptoms experienced were broadly similar for all types of ovarian cancer. Only fallopian tube cancer showed a number of variations, with fewer women reporting pain in the abdomen or pelvis, persistent bloating, urinary urgency and changes in bowel habit, but there were no significant increases in any other symptoms.

Despite more than 90% of women reporting multiple symptoms prior to their diagnosis, not all consulted a health professional about these symptoms. This varied widely by country, with an average for the study as a whole of 78.3%.



## AWARENESS AND DIAGNOSIS

*“Women need to get to know their own body. Especially in Brazil, private health insurance is so expensive and the public health system not very good. We don’t get regular check-ups so we need to be alert 24/7.”*

**AMANDA, BRAZIL**

*“Had they spotted the signs, it might have made a difference. She started on a losing wicket.”*

**ANAND, ABOUT HIS WIFE  
ANUJA’S DIAGNOSIS, INDIA**

*“Government 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!”*

**SURVEY PARTICIPANT,  
AUSTRALIA**

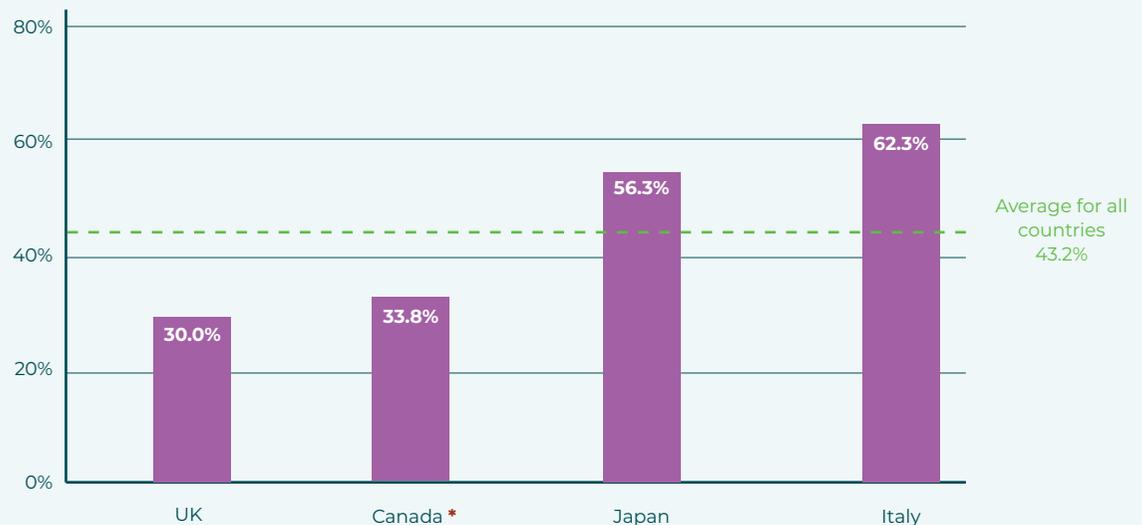
A quarter of women waited three months or more before visiting a doctor with their symptoms. One in 10 waited more than six months. Those who contribute directly towards their own healthcare costs were least likely to seek help from a doctor (of any type).

Women in Germany and Spain were most likely to visit a doctor within a month, and women in the USA less likely.<sup>†</sup> Women in the USA were most likely to wait more than three months and women in Germany least likely.<sup>‡</sup> Women who knew lots about ovarian cancer were more likely to visit their doctor within three months (85.4%\* vs 74.8% for all).

Just over a quarter of women described themselves as being very concerned about their symptoms, with a total of 60% saying they were very or fairly concerned. There were no variations in levels of concern for women with different stages or types of ovarian cancer, or by their age. Once they had sought help, four in 10 women said their doctor did not take their concerns seriously.

The proportion who were diagnosed within one month of visiting a doctor varied by country from 30% in the UK, to 56.3% in Japan and 62.3% in Italy. The average was 43.2%. For women who knew lots about ovarian cancer, that figure was 58.3%\*.

### VARIATIONS BY COUNTRY IN PROPORTION OF WOMEN DIAGNOSED WITHIN ONE MONTH OF VISITING A HEALTH PROFESSIONAL ABOUT SYMPTOMS (n=1093)

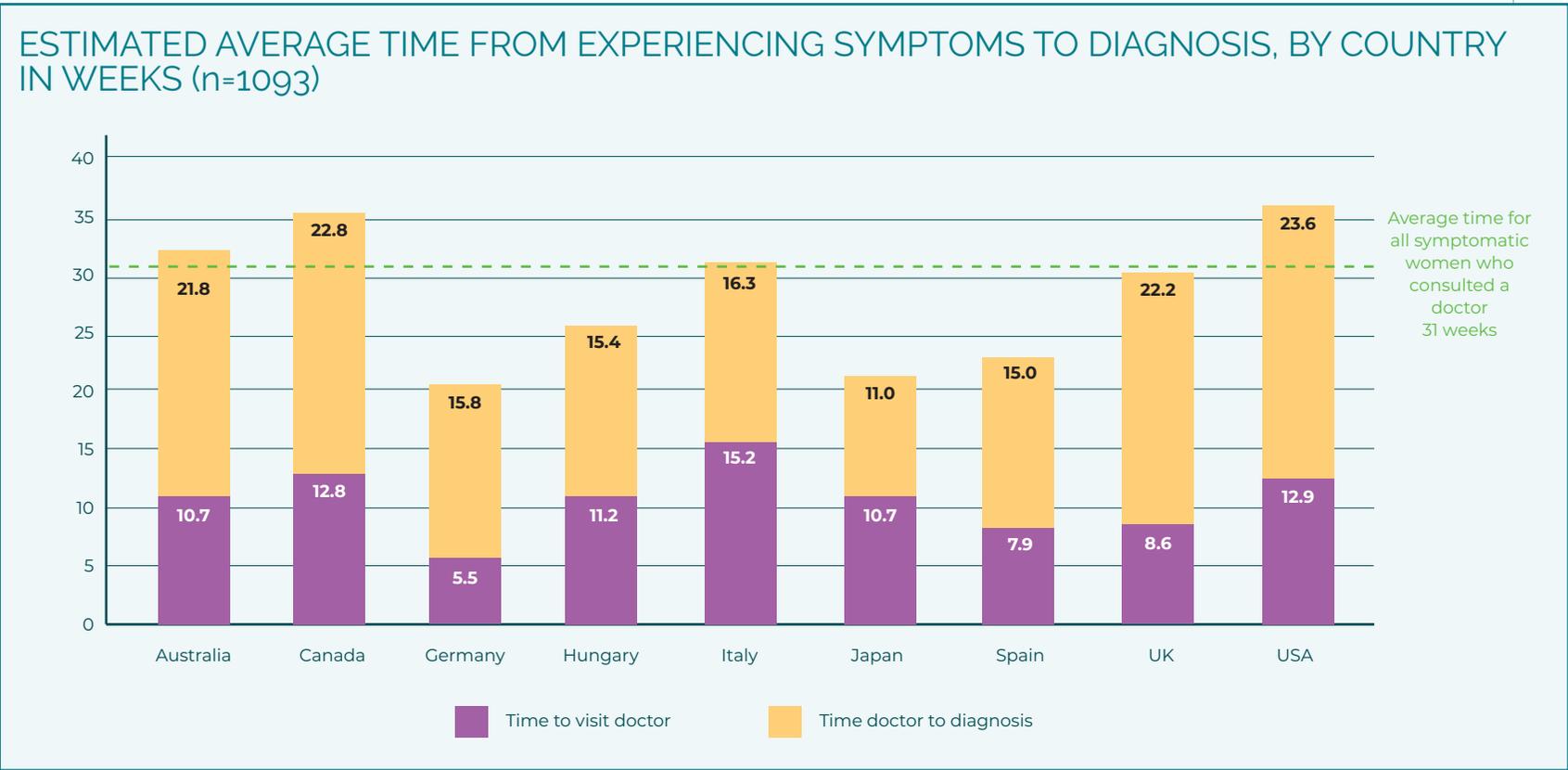


<sup>†</sup> Germany 77.3%, Spain 62.2%\*, Average for all 46.3%, USA 38.5%. <sup>‡</sup> USA 32.3%\*, Average 25.1%, Germany 8%

# AWARENESS AND DIAGNOSIS

*Kayoko from Japan was diagnosed very promptly after seeking help. She had noticed a lump the size of a golf ball whilst lying on her stomach trying to read. She had been very busy with work so left it a week or so but it was getting bigger. She went to see a gynecologist – this was easy to arrange as there was a clinic close to work, so she went one evening without an appointment. By this time her tummy was swelling and she looked pregnant. The clinic said it was beyond them and sent her to a major hospital as an emergency. She was diagnosed that day.*

In terms of estimated total time from first symptoms experienced to diagnosis, Germany (21.3 weeks), Japan (21.7) and Spain (22.9) were the quickest. The USA (36.5), Canada (35.6) and Australia (32.5) took the longest. 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 below.



## AWARENESS AND DIAGNOSIS

There were wide variations in women’s reporting of the first two diagnostic tests they had been given. Overall, the CA125 blood test was the most common cited by one in four women, followed by transvaginal ultrasound and CT scan (both one in five), but this varied by country:

TEST	MORE LIKELY THAN THE AVERAGE TO HAVE HAD THIS AS ONE OF THE FIRST TWO TESTS	AVERAGE PROPORTION OF WOMEN REPORTING THIS AS ONE OF THE FIRST TWO TESTS THEY HAD	LESS LIKELY THAN THE AVERAGE TO HAVE HAD THIS 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 (TVU)	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% USA 3.8% Canada 4.4% *
CT	Italy 28.6% * USA 25.1% *	19.3%	Hungary 11.2% UK 13%
X-RAY		3.8%	

Given the extremely low levels of awareness of the disease and its symptoms, and the clearly challenging paths to diagnosis demonstrated in this study, it is perhaps unsurprising that when asked about priorities for future action, women focused almost exclusively on getting a diagnosis as quickly as possible, ahead of working on new drug treatments or surgical procedures. Given 14 options developed from the interview phase, the top five priorities were:

1. Finding an effective ovarian cancer screening tool.
2. Raising awareness of the symptoms of ovarian cancer.
3. Reducing delays in diagnosis.
4. Prevention of ovarian cancer.
5. Improving diagnostic tests.

It was not just the women who had a clear focus on the need to improve diagnosis. Late stage diagnosis and reducing delays in diagnosis were very strong themes amongst the clinicians who were consulted, with them highlighting the devastating impact.

*“Late stage diagnosis is a catastrophe – we don’t have much success in treating this ugly disease if it is discovered in the advanced stage....all the other challenges have secondary importance in relation to this.”*

**DR ZOLTÁN NOVÁK, HUNGARY**

## AWARENESS AND DIAGNOSIS

*“About 20% of women don’t receive any treatment at all because we are not diagnosing them in time. They don’t need a stage shift, they don’t even need to have lower tumour volume though this is always presented (talked about) – but if we can diagnose them with a better performance status then we will improve mortality.”*

**MRS SUDHA SUNDAR, UK**

*“In most of the cases (presenting as an emergency) the patients are not fit enough to receive any part of the management pathway – to see the good effect of treatment we need to be able to make the patient bear the two modalities of treatment, but in many instances the general health is not permitting, so we are defeated in the first place – upsetting for patients and us.”*

**DR MANAS CHAKRABARTI,  
INDIA**

*“The dream is a screening programme that works, but I think we are many many many many years from that. So what can we do in the first instance? It’s going to be about rapid access to diagnosis, which involves patient, public and GP education..... I know that women often present with symptoms when the cancer is advanced, but there can be a big difference [even within stage 3c disease]. You can be fit and well, but four weeks later you can be absolutely ‘gubbed’ – that’s a Glaswegian expression for really, really sick. One thing I’ve observed, having now worked in several cancer centres around the UK, is that for women going to the GP, the time that it then takes to be diagnosed can be painfully long.”*

**PROFESSOR IAIN McNEISH, UK**

Of those clinicians who responded to the online consultation, almost all felt that the time to diagnosis could be reduced. Guidance for GPs, family doctors, gynecologists and emergency doctors on who should have specialist assessment, accredited training programmes for GPs or family doctors, and campaigns to alert women of the symptoms of ovarian cancer were considered high or medium priority by 83% of those who responded.

Whilst there was some difference in opinion amongst clinicians as to whether this would improve overall survival or bring about a shift in stage of diagnosis, it was almost universally acknowledged that it would mean more women would be able to undergo or tolerate treatment, and may well impact five-year survival rates positively.

The issue of those women who are too unwell to be treated was picked up on by the Expert Advisory Panel. They noted a lack of data on women who die very quickly following their diagnosis, unable to receive any treatment, but highlighted two studies which show the devastating effect of this issue:

A report by the National Cancer Registration and Analysis Service (NCRAS) in England highlighted short-term ovarian cancer mortality as a particular issue, with 15% of women with ovarian cancer dying within 2 months of their diagnosis.<sup>4</sup> Three risk factors were identified for death within a year of diagnosis:

- Emergency presentation (56% died in first year).
- Advanced age - 43% of those aged 70-79 died in first year, and 70% of over 80s.
- Tumour morphology – those who had ‘unclassified epithelial ovarian cancer’ or ‘miscellaneous or unspecified’ morphology.

Women who had more than one of these risk factors had an even higher chance of dying quickly.

## AWARENESS AND DIAGNOSIS

An American study concluded from a sample of over 9,000 women with either stage III or IV disease that 43% died within the first year, 26% of the cohort within the first 90 days.<sup>3</sup> Older age, increased co-morbidity, stage IV disease, lack of a visit to a gynecologic oncologist and surgery were all associated with an increase in 90-day mortality .

In the context of the stage mix of women in this study (page 12), were the two study figures (both from high income economy countries) replicated globally, it was estimated around 40,000 women die within three months of their diagnosis. This could be seen as an underrepresentation of the real figure.

### RECOMMENDATIONS

The Expert Advisory Panel were cognisant of the fact that respondents to the women's survey represented a younger, more healthy population with lower rates of recurrence than expected. Therefore, the findings in the study survey are likely to represent the 'best possible' picture at this point in time and may mask the importance of some issues.

The Expert Advisory Panel recommend that the World Ovarian Cancer Coalition, partner organisations, and members of the wider clinical and patient community have a strong focus on reducing delays in diagnosis. In particular:

- Raising awareness of the disease and key symptoms amongst women so they do not delay seeking help, or tolerate delays once they have sought help.
- Raising awareness of the key symptoms with clinicians (GPs, family doctors, emergency physicians, gynecologists), so they are better able to determine who needs prompt diagnostic tests and specialist assessment. This could be achieved by highlighting current accredited educational tools, encouraging member organisations to consider such programmes, supporting advocacy for national clinical guidelines for the diagnosis of ovarian cancer, and targeted communications with specialist press highlighting best practise.

The Expert Advisory Panel also recommend that the World Ovarian Cancer Coalition highlight the issue of short-term mortality, and encourage further research studies that investigate not only the biological and performance/treatment status of women who die within three months of diagnosis, but find a way to explore their experiences prior to diagnosis. This may reveal to what extent morphology/late diagnosis/lack of specialist treatment/performance status play a part in these devastating statistics.

# FAMILY HISTORY AND GENETIC TESTING

## KEY FINDINGS

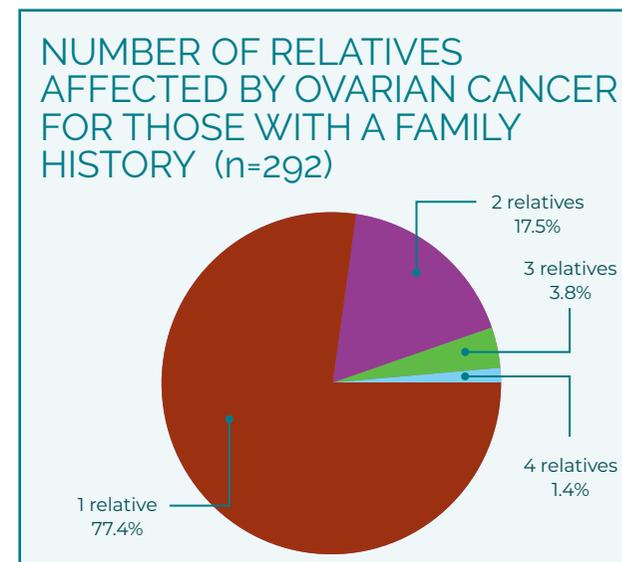
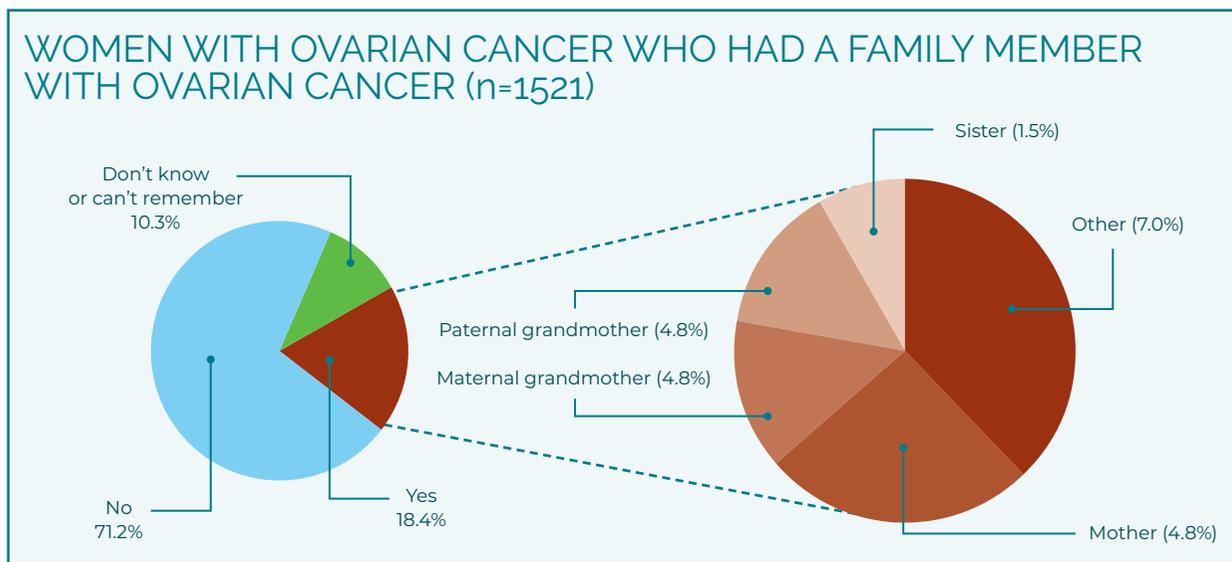
Family history of ovarian cancer is one of the most significant risk factors for developing the disease due to faulty BRCA or other genes that are passed between generations. Despite this, 80% of women in the study who had two or more close relatives affected by ovarian cancer prior to their own diagnosis, had not been tested for faulty genes.

Genetic testing (combined figures for pre- or post-diagnosis) varies widely by country, from 9.6% in Japan to 80.6% in the USA, with an average for all of 54.7%. This potentially means women are missing out on receiving new targeted treatments, and on the opportunity to prevent future family cases developing.

Of the respondents to the women’s survey, 18.4% had a family history of ovarian cancer prior to their own diagnosis and 10.3% did not know. Women in Brazil, Japan and Canada were more likely to report not having a relative affected compared to the average for all countries.†

Most women had just one relative with the disease, on one or other side of their family, and 38.4% had family members with breast cancer on one or other side. Paternal family history is as important as maternal family history with similar proportions of maternal and paternal grandmothers affected for both breast and ovarian histories.

† Brazil 85%\*, Japan 82.8%, Canada 82%, vs 71.2% for all countries.



## FAMILY HISTORY AND GENETIC TESTING

*"I was denied a genetic test for BRCA back in 2004 as I wasn't considered 'high enough risk' as no mother or aunts 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 have been 6 further family members diagnosed with BRCA1."*

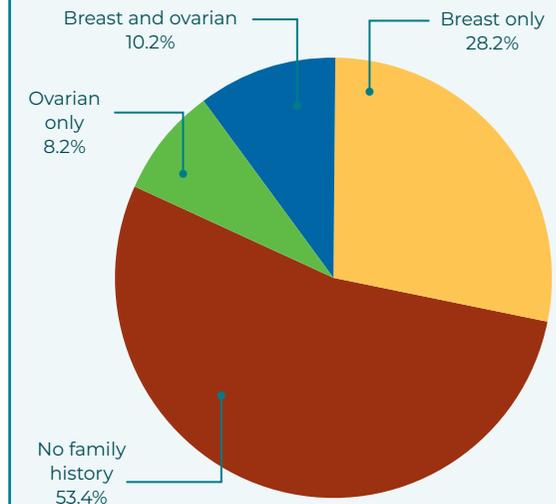
**SURVEY PARTICIPANT,  
AUSTRALIA**

*Nusrat, a single mother from India in her 40s, was never offered information or testing despite her mother and sister dying of ovarian cancer. As a hospital nurse, she became concerned about abnormal bleeding and was able to consult a doctor, and scans led to her diagnosis of advanced ovarian cancer.*

Opportunities are being missed to identify women at risk of developing ovarian cancer because of their own family history. Of those with two or more relatives with ovarian cancer in their family, 80% had not been tested prior to their own diagnosis. In the absence of screening, knowing your own genetic susceptibility is a potentially vital source of primary prevention. Levels of testing pre-diagnosis varied widely, with Germany having the highest rate (34% of women with one or more family members affected) compared to an average of 16.1% for all countries.

Of the clinicians who took part in discussions, there was strong support for the potential of genetic testing to help not only with primary prevention but also targeted treatments. They describe it as one of the most important recent developments.

### WHO HAS A FAMILY HISTORY? (n=1531)



*"Understanding that 10-15% of women with high grade serous ovarian cancer will have a germline BRCA1 or 2 mutation has been a game changer. We are now offering testing to everyone with high grade serous ovarian cancer, then not only can we identify those who could benefit from parp inhibitors, but we can also identify daughters, sisters, nieces who may be at risk. We [his Scottish group] are just publishing our experience of open access genetic testing, and half the people we found with a germline mutation had no family history – they would have failed the test for accessing the test based on family history. Parp inhibitors will certainly help. Whether we cure, we don't know, but we can certainly help them live longer."*

**PROFESSOR IAIN McNEISH, UK**

## FAMILY HISTORY AND GENETIC TESTING

*“There are national guidelines (2015) which allow women with ovarian cancer to be tested independent of their family history for BRCA mutations...Health government is not central. There are 20 health regions, and each region adopts its own health rules and can decide what they will pay for. Some are paying for it, some are not because of financial issues.”*

**DR SANDRO PIGNATA, ITALY**

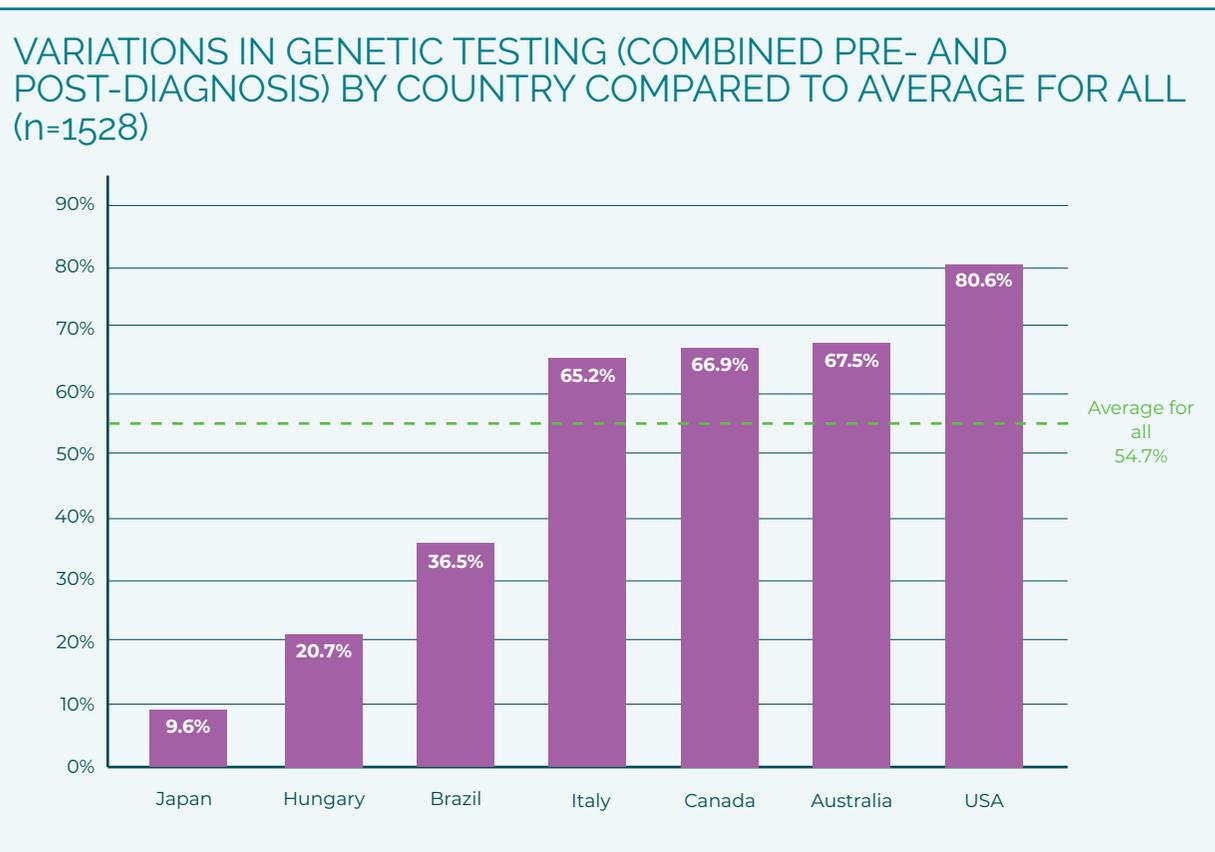
*“We put referrals in when we have the pathology, but it takes nine months to get counselled. We will be in trouble if we have upfront parp inhibitors approved for treatment... as the waiting times are so long. The whole process will have to be condensed. We only have blood testing (not tumour testing, which would be quicker – but they are not validated in the Ontario setting – there are very few labs approved for testing). We are ok for second line treatment, as they will have had their genetic counselling by the time they need this treatment.”*

**DR LAURIE ELIT, CANADA**

Access and delays though are significant issues for the clinical community. In Romania, access to genetic testing is provided by a pharmaceutical company, and in other countries such as Italy, other factors affect access to tests.

Clinicians also reported varying times for testing and counselling to be carried out, from 14 days (reported by a clinician in the USA), three to four months for an Australian respondent (the main reason being delays in counselling), and two to three months for a UK respondent, who said delays were largely with blood test results. A Japanese clinician highlighted that often in Japan, women have to pay for the test themselves, and that getting the National Health Insurance in Japan to pay for the test should be a priority.

Variations in levels of testing post-diagnosis were clearly seen in the women’s survey results, and the combined figures calculated. They varied from 9.6% in Japan, and 20.7% in Hungary, to 80.6% of women in the USA. The average was 54.7%.

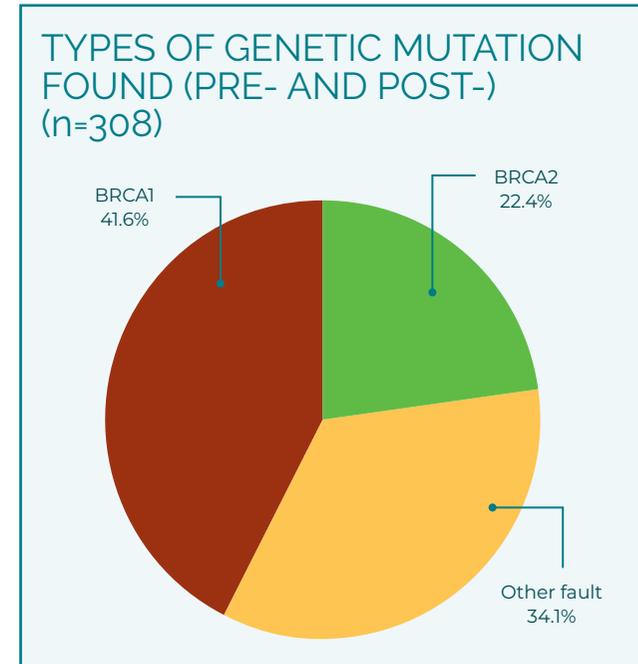


## FAMILY HISTORY AND GENETIC TESTING

One in five of all survey participants knew they had a genetic mutation linked to ovarian cancer identified. Of those with a fault, the breakdown was as shown.

Clearly there is a need to improve access to and timing of genetic testing, but with the recognition that mutations occur at different points in the gene depending on tumour types and populations, so detection is not always straightforward. For example, in women of Ashkenazi Jewish descent, founder mutations occur mainly in three sites,<sup>7</sup> whereas in different populations mutations can occur at many different points. A recent study by Rebbeck et al has shown that the risks may vary by type and location of the BRCA mutation.<sup>8</sup>

In conclusion, women are clearly not being identified as 'at risk' when they have a family history. They are not getting access to timely genetic testing either ahead of a diagnosis which offers the potential to prevent their disease, or after a diagnosis, which means they are potentially denied access to targeted and proven treatments. It is also imperative that women are supported through the genetic testing process.



### RECOMMENDATIONS

The Expert Advisory Panel recommend that the World Ovarian Cancer Coalition play a strong role in raising awareness of issues around family history and access to genetic testing.

It advises the World Ovarian Cancer Coalition and wider community to raise awareness of the importance of family history on both the mother's and father's side of the family, and the role of timely genetic testing and counselling pre- and post-diagnosis to allow for opportunities to prevent future cases, and access to new targeted therapies. This should target not only women, but clinicians as well.

# ACCESS TO TREATMENTS

*“Women should not fall into poverty because of illness.”*

**SURVEY PARTICIPANT, GERMANY**

*“I was lucky to have some of the world's best doctors.... While Australia has medicare, there are huge problems for people like me who cannot afford health cover... and are not eligible for the aged pension or health care card.... My husband is 73 and still has to work. I had to pay for my own chemo, it's a pretty bad place to be in.”*

**SURVEY PARTICIPANT, AUSTRALIA**

*“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 it would be devastating to my mental health...”*

**SURVEY PARTICIPANT, USA**

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

**SURVEY PARTICIPANT, USA**

## KEY FINDINGS

Despite published evidence of the benefit of assessment, surgery and treatment by ovarian cancer specialists in high volume centres,<sup>5</sup> the proportion of women receiving this level of care varies widely around the world and organisation of specialist services is seen by members of the clinical community as a vital step to improving outcomes. Additionally, delays in accessing test results, theatre space, and drugs can impact on the care women receive and vary between and within countries. In general women are very positive about the care they receive, but where women have to pay for their own treatments, the impact on their finances can be devastating.

Overall women were very positive about their care during treatment with 91.5% saying they were treated with dignity and respect all or most of the time, but there were differences between countries. The variability of care within countries, and between state and private sector was highlighted by women in the interviews with very contrasting stories. Nanci in Brazil said she knew many women who had moved considerable distances to access treatment, because the protocols and services offered are very different (state to private, region to region) and some are very behind.

Nusrat, a single mother of two from Mumbai in India travelled two hours each way by train and bus, so she could have free treatment with Carboplatin. However, Anuja, also from India had her many treatments paid for by her employer, over the five years she lived with ovarian cancer. Her husband Anand felt that in this instance professionals saw her as a money-making machine, but that they lost interest when there was no hope.

*“Her life was already over....there was no concept of care, only of cure. For them it was a question of victory or defeat, and once they realised they were on the losing side, they quit. They seemed to forget there was a human involved, and that is very hard for a carer to see.”*

**ANAND, INDIA**

Where countries do not provide free health care, there can be hugely negative consequences for women who have to pay for their own treatments.

In general, 30.9% of women reported that their finances had been affected to a great extent by their diagnosis, with women in Hungary and Japan more likely to be impacted, and Spain, Canada and Australia less likely.<sup>†</sup>

<sup>†</sup> Hungary 55.3%, Japan 42.1%, Spain 10.2%, Canada 18.8% Australia 21.2%\*, average for all 30.9%.

## ACCESS TO TREATMENTS

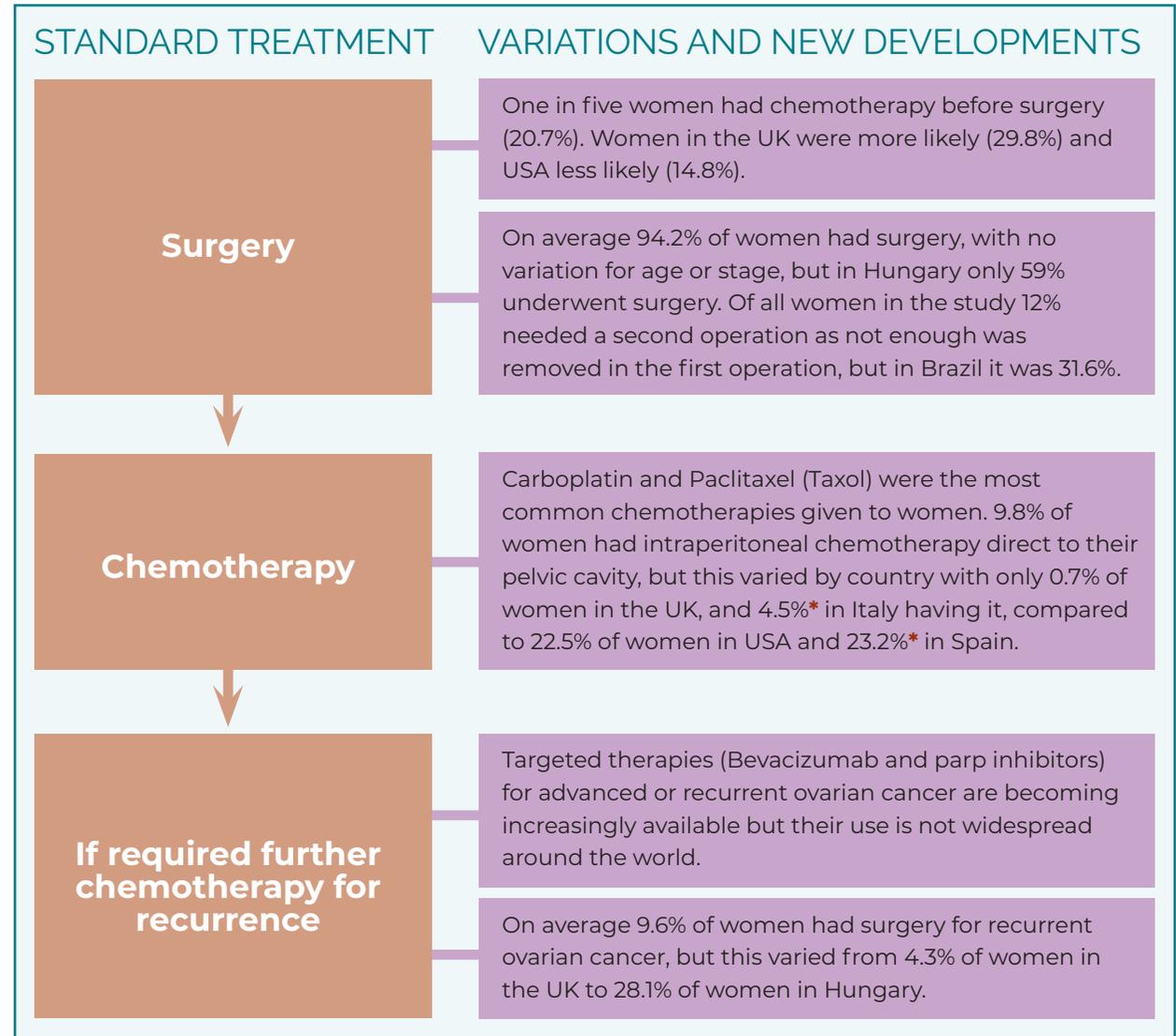
*“We need to let gynecologists know the latest evidence, so they understand that the very best approach to treat women with ovarian cancer is by specialist surgeons operating as part of a multidisciplinary team... Some women prefer the obstetricians who delivered their children, many of them are desperate to start treatment, and think there is no time to find a specialist, and some do not know that gynecologic oncologists exist. Others have economic difficulties for moving to another city for treatment, or the ‘ego’ of some physicians without special training in cytoreductive surgical techniques.”*

**DR LUCAS MINIG, SPAIN**

*“There is huge variability in knowledge. We have a lot to do in terms of educating our gynecological colleagues as to what they should or shouldn’t take on... It would be really helpful to have a manuscript, guidelines or book which says for the wider world ‘this is what you need to look out for – these are high risk patients that should be managed at a cancer centre from the outset!’”*

**MRS SUDHA SUNDAR, UK**

The main treatments for ovarian cancer remain surgery, followed by chemotherapy (Carboplatin and/or Taxol). If the cancer recurs then those drugs or others may be offered. Some countries now have access to targeted therapies such as Bevacizumab for advanced or recurrent ovarian cancer, or parp inhibitors for women with identified BRCA mutations.



For the clinicians who were consulted, one of the strongest themes to emerge was that not enough women receive appropriate specialist treatment by gynecologic oncologists.

## ACCESS TO TREATMENTS

*“There are currently in Hungary around 150 hospitals treating or operating on women with ovarian cancer, where the total population is under 10 million... ESGO guidelines would suggest centralising to five or so centres... This is my personal goal to fight for this in the future... I am hopeful I can persuade the powers that be. I need to believe in this!”*

**DR ZOLTÁN NOVÁK, HUNGARY**

*“As in the great majority of countries, the treatment is non-centralised... We are now working closely with other colleagues in our State [Valencia]... to centralise treatment at least in our area because it has been demonstrated to be the most powerful tool to obtain beneficial results for women.”*

**DR LUCAS MINIG, SPAIN**

Clinicians in the UK estimated that nowadays 90% of women are assessed and treated by specialists but it has taken several years to reach this level. Countries such as Australia and Canada are currently finding that there are major delays in terms of accessing operating theatre space in these tertiary centres (which also deal with other specialist conditions), to the extent it can influence the order of treatment a woman receives, ahead of what may be best for her. Germany have developed a specialist centre model, but as yet estimates of the proportion of women seen in this way is much lower (around 50-60%). In Brazil, a clinician estimated that just 20% of women were seen in a specialist setting, and said doctors were routinely taken away from their specialist duties to deal with emergency medicine cases. They reported delays of 8-12 weeks to start treatment. Whilst some national groups have implemented specialist care, in other countries it is down to individuals or small groups.

Sheer distance to travel can be an issue, and in Romania it was highlighted that the road network was of very poor quality making travel difficult. In Australia there are efforts to run a ‘hub and spoke’ system where specialist clinicians travel out to triage women, though very little major gynecologic oncology surgery is carried out in rural regional towns.

An insufficient workforce is also a major issue. Whilst respondents in some countries felt there were enough gynecologic oncologists and medical/clinical oncologists to meet the needs of women with ovarian cancer, others said the situation was very different. For example, in Romania there are very few centres to treat women and there is no formal training programme for gynecologic oncologists. In India there is currently a dire shortage of gynecologic oncologists, and almost all who are there have been trained in other countries. Those who are trained locally often end up working in private practise, as can happen in South Africa. There was also recognition that other professionals were needed in the context of multidisciplinary team working to support women in their recovery (both body and mind). Only the German clinicians who responded felt they had the appropriate and varied workforce within their MDTs.

There is frustration when delays in test results and treatment occur, and when some countries do not have access to treatments that other countries have. Dr Tracey Adams in South Africa talked of how only Carboplatin and Paclitaxel were routinely available for state funded patients. No targeted drugs (for example, Bevacizumab, parp inhibitors) are available to her, except in the research setting which is

*“Despite this system, there are a number of ovarian cancer patients who are never given the chance to have an MDT (Multi-Disciplinary Team) assessment, or told they could have the option to have it discussed. They are diagnosed outside of a gynecological oncology unit – you are totally dependent on the person treating them to refer them in. There is no guarantee that will happen.”*

**PROFESSOR PETER GRANT, AUSTRALIA**

## ACCESS TO TREATMENTS

*"In Canada the biggest challenge for me is access to various agents for chemotherapy or biologic therapy for treatment. Canada is pretty restricted, and you have to have a high level of evidence to get it approved, and then to get it funded, there is a whole other level of process at the provincial level to get it covered for patients. For example, we have only just got access to Bevacizumab for women who are sub-optimally debulked for upfront treatment, or as 2nd line treatment for platinum sensitive women. Canada is only just looking at parp inhibitors, and currently they are only available on compassionate release or clinical trials."*

**DR LAURIE ELIT, CANADA**

We are pleased to note that since this interview in early 2018 parp inhibitors are now approved in most provinces.

uncommon. Other drugs have to be 'motivated for', i.e. via appeal, and are often not available. She also highlighted that in some very rural areas in her country, people hold different beliefs about their illness and treatment, based on cultural and religious factors. Some women decline treatment believing that God will heal them and others seek treatment from sangoma (witch doctors or shamens), and she as a doctor must respect their views. Difficulty in accessing drugs is not necessarily limited to developing or lower income countries, with Canada highlighted as a case in point.

## RECOMMENDATIONS

The Expert Advisory Panel recommends that there is a need to emphasise the importance and value of specialist treatment in a timely manner including:

- Highlighting variation around the world, and experiences of implementing a specialist approach locally/nationally.
- Encouraging women to seek specialist assessment.
- Encouraging members to work with clinicians in their own countries to promote the importance of specialist care.
- Providing or facilitating information demonstrating why the approach is important aimed at 1) family doctors, physicians and gynecologists and 2) policy makers.

# INFORMATION

## KEY FINDINGS

More than half of all women do not get all the information they need at the time of diagnosis, and only one in five women say they have found all the information they need (at whatever point). Verbal information is more common than written information, and rarely goes beyond generic and treatment specific information.

*“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.”*

**SURVEY PARTICIPANT, JAPAN**

*“My first port of call was Google, but the messages were very, very awful... terrible, and scared me.”*

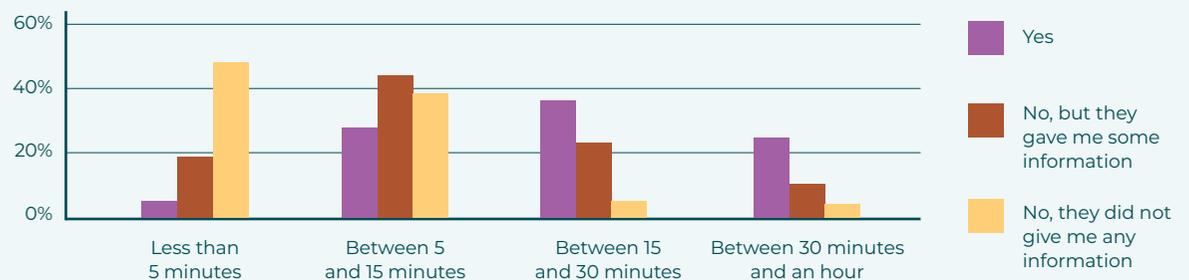
**NANCI, BRAZIL**

Given the challenges so many women faced in terms of getting a diagnosis, and their lack of awareness of the disease, it is unsurprising that six in ten women were shocked to be told they had ovarian cancer. More than half of all women did not get all the information they needed at the time of diagnosis.

The interviews conducted with women prior to the survey identified information as an important issue, and was a common source of distress. The interviewees all experienced a lack of information at the time of diagnosis, and some said there was inadequate communication with their (overworked) doctors. The point was raised that cultural norms would mean some women would not necessarily question their doctor about what they were being told, and the general lack of information and desire to question impacts women’s ability to access or think about the possibility of clinical trials. Some had turned to the internet, but found it hard.

The women’s survey highlighted that for one in seven (14.5%), the doctor who told them they had ovarian cancer spent less than five minutes with them breaking the news. The most common time period was between five and 15 minutes (36%). Those who felt they did get all the information they needed were more likely to have had a longer time period with the doctor (15-30 minutes (28.7%)) or they were more likely to have been given written information (rather than be given information verbally).

TIME SPENT BEING GIVEN DIAGNOSIS AND WHETHER INFORMATION NEEDS AT THE TIME WERE MET (n=1466)



## INFORMATION

*“There is one thing that confronts me... the lack of explanation that this is not one disease... the community information and perception are lacking... there is a vast difference. It causes a lot of confusion and concern for women about their long-term outlook.”*

**PROFESSOR PETER GRANT,  
AUSTRALIA**

*“My tumour was extremely rare and it was very difficult to make a decision about the right therapy as doctors do not know the tumour much. There was not much information on the internet.”*

**SURVEY PARTICIPANT, GERMANY**

Just one in five women said they were able to find all the information they needed (at any time). This varied from 4.2% of women in Japan to 34.7% in Italy (the average was 19.7%). Only 11.3% of women received information about living with ovarian cancer, and 10.9% received information about sources of support.

### VARIATIONS BY COUNTRY IN PROPORTION OF WOMEN WHO FOUND ALL THE INFORMATION THEY NEEDED (n=1193)



The clinicians who were consulted reflected that they did not usually have information to give women about clinical trials and quality of life issues. There was also comment that information was generic.

Nearly a third of women reported finding information on the internet that was very scary (29.6%), but most of the women (73.2%) had found some good quality information on the internet. They also found support groups and other women with ovarian cancer who they meet in person or online to be a good source of information.

## RECOMMENDATIONS

The Expert Advisory Panel recommends that the World Ovarian Cancer Coalition consider how it can help member organisations access good quality accredited information, either by sharing information from other members, or where necessary producing information which can be used by members, preferably in women’s first language as relevant.

This information can be used with and outwith the hospital setting and should cover not only general information and treatments, but also information about living with the disease and the associated challenges, and access to sources of support.

For time-strapped clinicians it is even more important that they can provide women with good quality written information in relation to their diagnosis and that member organisations and/or the World Ovarian Cancer Coalition assist in that role.

# MIND AND BODY

## KEY FINDINGS

**Mental health is as important to women with ovarian cancer as their physical health in terms of their quality of life, yet this is often overlooked.**

Following in-depth interviews with women about what affected their quality of life as a result of their ovarian cancer, a number of statements were tested with women in the survey. The extent to which women feel mentally well and physically well were the most important factors for them (8.9 and 8.8 out of 10). Other key factors included having a sense of purpose (7.5), the ability to engage in hobbies and activities (7.5) and the ability to 'return to normal' (7.4).

Most women said they had needed emotional support at certain times since their diagnosis.

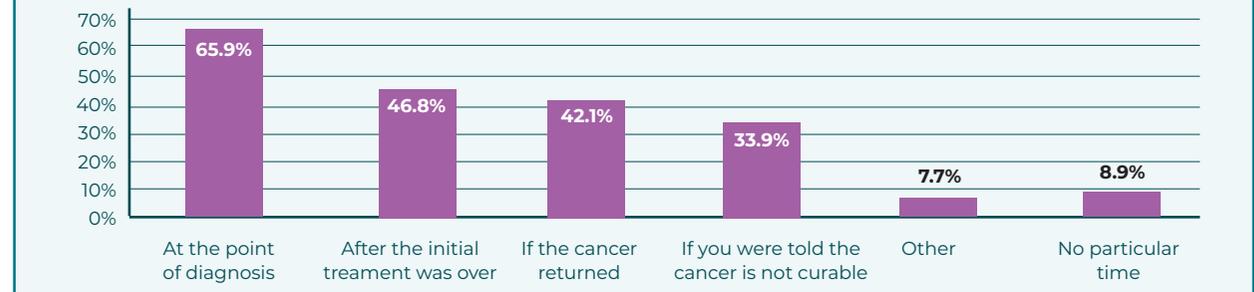
*"My personality trait is to show a strong face to people, to say I am completely fine but that is not always the case and it is very exhausting... so I spend a lot of time at home on my own doing this [felting and sewing] to calm myself down."*

**KAYOKO, JAPAN**

*"I think I am a strong woman aware of what happened to me... but I can say that I am no longer the person I was before... [physically and psychologically].. in front of others I'm happy, I laugh, I'm joking, but inside I died [after her diagnosis]."*

**SURVEY PARTICIPANT, ITALY**

### PROPORTION OF WOMEN WHO NEEDED EMOTIONAL SUPPORT AT PARTICULAR TIMES (n=1324)



Japan stood out as a country where support needs were greatest if the cancer returned or became incurable, and as a country where support needs were least likely to be met. The proportion of women who said they did not seek or were not offered help for emotional support varied from 5.9% in Germany to 32.5% in Japan, with 19.3% being the average. In the interviews with women, all those from Japan displayed a strong sense of wanting to be seen to 'get on with life' even when friends and family are concerned. Kayoko said this was the most challenging aspect of living with ovarian cancer.

That sense of hiding the true self was present in women in other countries too.

Nine out of 10 women (90.1%) have been left with long term side effects of treatment which include both physical and mental health issues. Tiredness or fatigue is the most commonly experienced long-term side effect (55%) followed by tingling or numbness in hands and feet (50.9%). Nearly four in 10

## MIND AND BODY

women have a lack of interest in sex, over a third (34.6%) suffer with anxiety, and one in four suffer from depression, and a similar proportion suffer sleep loss.

The clinicians who were consulted believed there was a growing focus on quality of life issues for women, and that this was important to carry forward in research and in terms of trying to access help for them, but many acknowledged it was hard in their hospital setting to access professional support. The clinicians in India and South Africa also highlighted that in some areas there is still a significant social stigma associated with a cancer diagnosis.

Just 28% of women had been offered support by a health professional. Most commonly women have to turn to family (69.5%) and friends (62.3%) for support, and do get the most support from them, but also other women with ovarian cancer (40.3%).

Women were positive about the benefits of meeting other women with ovarian cancer. However, one in five women have never met another woman with ovarian cancer (either online or in person) and this varied by country. The most important benefit was helping them understand they were not alone in facing the disease. This was followed closely by the fact they found it easier to talk to someone who had been through the same experience, that it was positive to share stories, and find out information about possible treatments and sources of support. Women did acknowledge however that it can be difficult for them when women they have met face a recurrence or die.

Women would much rather be part of an ovarian cancer support group, than a gynecological cancer support group or a more general cancer support group. Clinicians however mainly reported that if their hospitals offer support groups, they cater for the latter two groups. Of the women who had not met anyone, only 7.5% said they did not want to meet with other women.

### RECOMMENDATIONS

The Expert Advisory Panel recommends that the World Ovarian Cancer Coalition promote the importance of mental wellbeing in addition to physical wellbeing and provide information to help:

- Women access information and sources of support.
- Encourage members to promote the importance of mental wellbeing.
- Health professionals advocate for the inclusion of professional support via multidisciplinary teams in women's care.
- Encourage health professionals and member organisations to promote the importance of support groups that focus on the needs of women with ovarian cancer as opposed to other types of cancer.

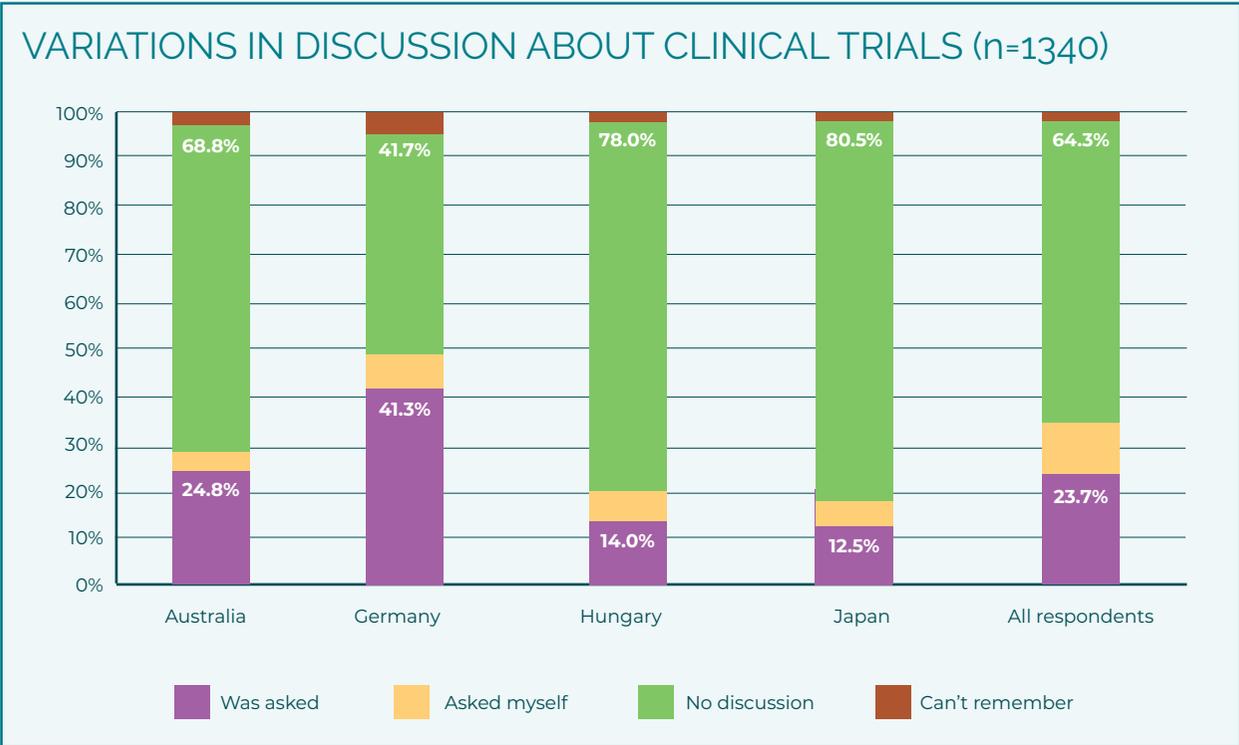
In addition, the Coalition could promote the idea of a 'quality of life index' as defined in the study, and share tips from other women about coping mechanisms.

# CLINICAL TRIALS

## KEY FINDINGS

Fewer than one in four women were asked about joining a clinical trial. One in 10 initiated the discussion themselves with their doctor. This is despite the fact that just 2.7% of women said they were not at all interested in taking part in future clinical trials. There is a clear mismatch between women's desire and the opportunity to take part in such studies.

Just under two-thirds of women (64.3%) had no discussion about clinical trials with a doctor. Women in Japan had the highest proportion of women who had not had any discussion about clinical trials (80.5%), and Germany the lowest proportion (47.1%). 23.7% of women were asked by doctors, and 10% initiated the discussion themselves. Of the women who did discuss clinical trials, just under half (48.5%) said there were clinical trials they were eligible to join. Almost all of these women (89.3%) felt they were given understandable information about the trial. In total just 12.4% of all respondents to the survey had taken part in a clinical trial.



## CLINICAL TRIALS

*“The hope is we can make them less complicated and less regulated. There have been improvements in Canada – Instead of everyone having a Research Ethics Board, they are becoming more centralised in the province. I’d like to see that too for the costings of trials (financial evaluation) – that would be great, because currently every hospital has to sign on and do their own financial evaluation as to whether they can do the trial or not. Clinical trials as a concept is great, but it’s the details where we struggle.”*

**DR LAURIE ELIT, CANADA**

*“There is a European law, which allows women to travel to another country to take part in trials if they are not available in her country, but it does not happen. I don’t know how to make this happen, but it’s important for women to have the chance to get the drugs. In Romania it’s not fair for a woman not to have access to a drug, just because she is not from Hungary or France.”*

**DR DRAGOS MEDIAN, ROMANIA**

Just 2.7% of women said they did not want to participate in clinical trials, and just 5.2% said they would not consider trials at another hospital. Eight in 10 women said they would consider travelling to another hospital to take part in a trial (82.4%).

In terms of factors that might influence women to join a clinical trial, they rated the possibility of a cure, or possibility to extend their life as the most important factors, scoring 9.1 and 8.7 out of 10. These ranked considerably higher than most common factors which may influence a decision not to join a trial such as side effects (6.2), distance to travel (4.9), or potential that they may not benefit personally (4.5).

Clinicians suggest a mixed picture with some countries having advanced systems for opening and including women in trials. Spain and Italy were noted for this. In other countries there were concerns about the difficulties involved in getting women into trials, from delays in pathology reporting, regulatory burden, reporting requirements and most importantly, lack of funding and lack of suitable trials.

Clinicians reported women’s participation rate in their hospital between 5% and 50% and highlighted a lack of suitable resources to give women about clinical trials.

*“The reporting requirements are stricter and increasing significantly which makes it harder to run – data collection is much more onerous and difficult. It requires personnel and funding.”*

**PROFESSOR PETER GRANT, AUSTRALIA**

## RECOMMENDATIONS

The Expert Advisory Panel recognised the mismatch between women’s desire to find out and potentially participate in clinical trials and the opportunities available to them.

The Panel recommended that more information be available to women about how to ask about clinical trials, or how to find out what trials might be available at their hospital or other hospitals in the region.

They also recommend that it is important for funding bodies to maintain an interest in ovarian cancer trials, and there is current concern that the numbers of trials are diminishing.

# DIVERSITY IN DATA

*“In Romania there is just one regional registry that covers less than 15% of the country, and this data is used to extrapolate figures for Globocan. Our country has tried to introduce national collection, they tried to put it on the doctors but they didn’t have time to complete the database....I would be curious how others have achieved national registration.”*

**DR DRAGOS MEDIAN, ROMANIA**

## KEY FINDINGS

Many studies reflect populations that are largely Caucasian or white North American in origin. As such, women may not be getting the optimal treatment for them, even if they reside in Europe or North America, because the findings may not be relevant to their local populations who display different characteristics in terms of age, presentation and treatment status.

Commentators on global cancer statistics are united in the call for better cancer registration around the world to improve the drive for cancer control. At present, particularly for mortality, data for many countries in the Globocan study is estimated and may mask the true extent of the impact of cancer on families and the relevant health economies.

The accumulation of global cancer data for any cancer type is a major challenge for those seeking to inform and develop cancer control policies, with huge variations in the registration of cancer incidence and mortality. A country is considered to have high quality registration when more than 50% of cases are recorded. For a considerable number of countries, statistics are estimated rather than based on fact, and it has been suggested that this leads to an underestimation rather than an overestimation of true figures.<sup>9,10</sup> It has been estimated that only one in five low- and middle-income countries currently have the necessary data to drive policy improvements.<sup>11</sup>

Of the clinicians consulted the majority said they wished to see more complete cancer registration. They would also like to see more data on basic biology and the different types of ovarian cancer, the proportion of which can vary by country. They highlighted that much of the research

*“Sometimes we are so embroiled in providing day to day care that we almost become consumers of science – we forget to contribute to it. The patients here have a different genetic profile to Caucasian women with the disease. We need powerful research in the local population. That is why after a tiring busy day looking after patients, I am here in the lab trying to forge some collaborations, and trying to persuade the government to listen. Look, we are following the research of the Western World. That is fine, but we need to make sure it is valid in our scenario too. Take for example the incidence of BRCA testing in our local population. We do not even know the local incidence. We need to sharpen all these to make the treatment meaningful for the patient.”*

**DR MANAS CHAKRABARTI, INDIA**

## DIVERSITY IN DATA

*“What we do know, for breast cancer too, is that these women (Asian, black) tend to get ovarian cancer a whole decade younger, but nobody understands this, what happens to these people, because the literature is extremely dominated by Caucasian people. I’m not sure we have equity of access, or equity of knowledge certainly. I’m sounding resentful here but we spend bucket loads of money providing an extra 2 weeks of progression free survival but we can’t be bothered to find out some of these basic issues that affect the vast majority of women in the world diagnosed with ovarian cancer, that today do not happen to be in the driving seat. That will change but it will take time.”*

**MRS SUDHA SUNDAR, UK**

literature is based on Caucasian or white American women and this may well mean the results do not reflect their own local populations.

The risk of developing ovarian cancer is highest in developed countries, and risk rises as countries develop economically. However, China and India have the largest numbers of women with ovarian cancer, and of the ten countries with most women, only five are Caucasian or white North American. As populations increase and economies grow, it will become ever more urgent to have the right data for effective cancer control.

The data from the women’s survey reinforces the difference in age profiles and types of ovarian cancer depending on women’s location. Whilst serous ovarian cancer was still the most common form of the disease in Japan (32%, average for all countries 34%), there was a significantly higher proportion of clear cell (22% vs 9.4% average for all) and endometrioid ovarian cancers (21.6% vs 10% average for all) than in other countries. Comparing women in Japan and Canada with serous ovarian cancer, the most common age bracket was 10 years younger in Japan. The same applied to endometrioid and clear cell cancers when comparing women in Japan to America.

Throughout the duration of the Study, from the initial reports and interviews, to the quantitative phase, the Panel has been mindful that the work of the coalition has sought to be more representative of communities and countries where the voices of women with ovarian cancer are not routinely heard. To this extent, the survey was translated into 15 languages. The Panel would support the Coalition’s continued work in this field to strive for more diverse data and participation.

## RECOMMENDATIONS

The Expert Advisory Panel supported the views expressed by the clinicians consulted and the conclusions of studies of academic data, that there is a significant shortage of data relevant to diverse populations. This relates not just to cancer registration in countries (for example in the whole of Africa), but also in relation to the diversity of ethnicities represented in trials, and the use of evidence as a basis for treatment. It recommends that this be included in research priorities.

The Panel also recommends that the World Ovarian Cancer Coalition supports broader initiatives such as the Union for International Cancer Control’s World Cancer Declaration which includes targets to increase population-based cancer registries and surveillance systems in all countries to measure the global cancer burden and the impact of national cancer control programmes.

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The data and results of this study remain the sole property of the World Ovarian Cancer Coalition.

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- Makiko Suzuki, patient representative, Japan.

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