WORLD OVARIAN CANCER COALITION | IGCS INTERNATIONAL GYNECOLOGIC CANCER SOCIETY

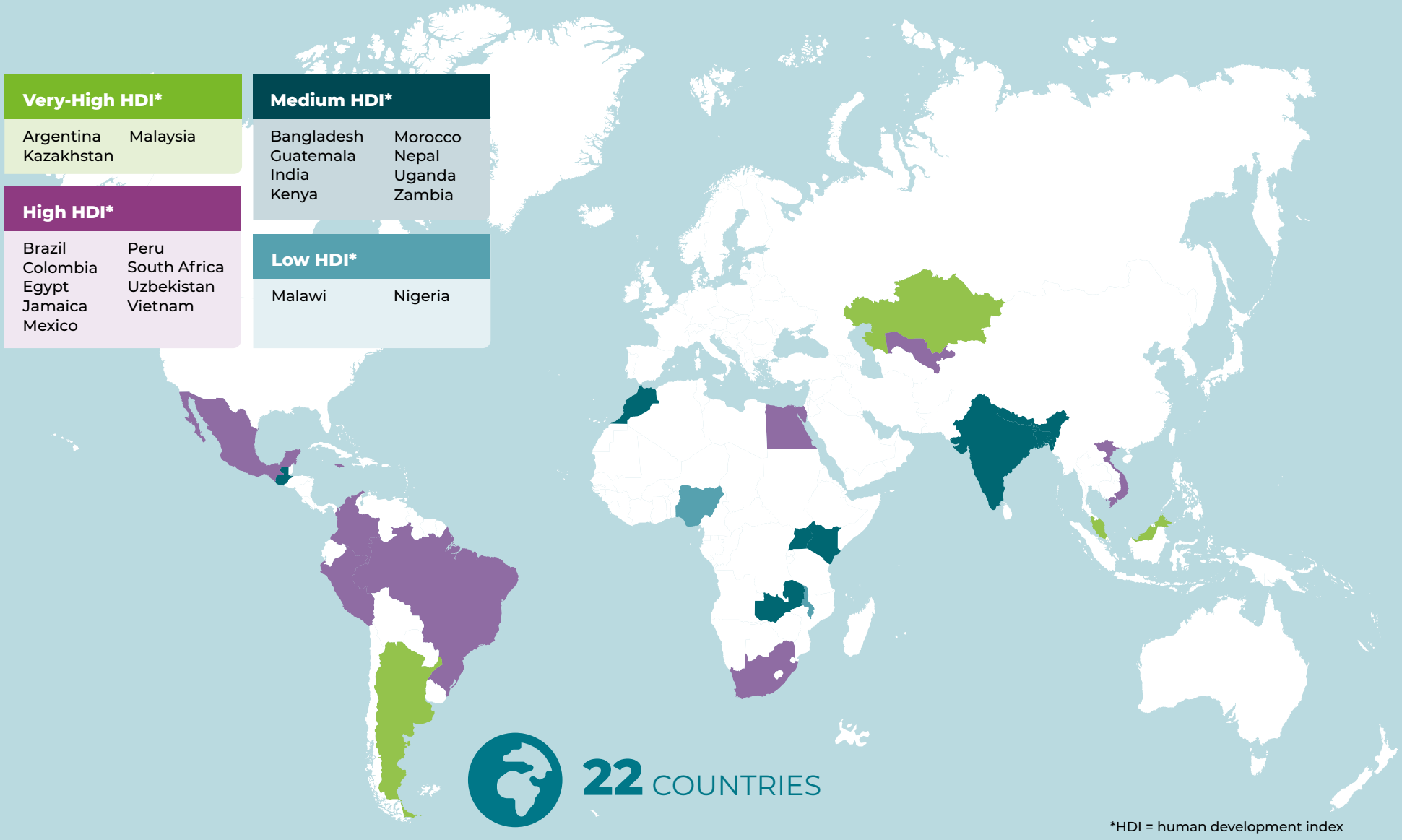
A JOINT INITIATIVE FOR WOMEN

THE EVERY WOMAN STUDY™

LOW- AND MIDDLE-INCOME EDITION

REPORT

SEPTEMBER 2025



82 HOSPITALS

2446 WOMEN

28 LANGUAGES

METHODS OF PARTICIPATION

WhatsApp

63.8% SELF-COMPLETED THE SURVEY

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INTRODUCTION

THE WORLD OVARIAN CANCER COALITION

Formally established in 2016, the World Ovarian Cancer Coalition (the Coalition) is the only global not-for-profit focused on ovarian cancer. Working with over 220 patient advocacy organisations around the world, the Coalition's vision is to ensure that everyone living with, or at risk of, ovarian cancer has the best chance of survival and the best quality of life possible, no matter where they live. Our mission is to drive profound and equitable change for all those impacted by the disease through partnerships, evidence, advocacy and awareness.

THE INTERNATIONAL GYNECOLOGIC CANCER SOCIETY

The International Gynecologic Cancer Society's (IGCS) mission is to enhance the care of people affected by gynecologic cancers worldwide. We pursue this mission through education, training, public awareness, and global collaboration. Activities focus on raising awareness about early diagnosis and treatment, fostering professional connections, supporting research, and providing mentorship and training opportunities, with the ultimate goal of optimising care for women with gynecologic cancers.

THE EVERY WOMAN STUDY™

The Every Woman Study™ Low- and Middle-Income Edition is a valuable and much needed follow on to the study first carried out by the Coalition in 2018. The studies use patient experience to characterise the main challenges and opportunities to improve survival and quality of life for women with the disease. In 2018 some 1531 women from 44 countries participated in an online survey with the findings published in the International Journal of Gynecological Cancer in 2020 [1]. A set of common challenges were uncovered, from delays in diagnosis, lack of awareness, access to treatment, support needs and priorities, but the extent to which each was present varied by country. Although a global study, almost all of the respondents came from high-income countries (95%), when in fact just 30% of women with ovarian cancer live in these settings.

ORIGINAL **EVERY WOMAN™** STUDY IN 2018:

44 COUNTRIES

1531 WOMEN

95% CAME FROM HIGH-INCOME COUNTRIES

CHALLENGES

- Delays in diagnosis
- Lack of awareness
- Access to treatment
- Support needs & priorities

With a shared commitment to understanding the needs and struggles of patients in low- and middle-income countries, the IGCS and the Coalition joined forces to address this major data gap. The IGCS opened up its networks of clinicians in low- and middle-income countries, with the Coalition doing the same with its patient advocacy network and also providing its expertise in running such studies. Together we built an Oversight Committee of patients, advocates, clinicians and data experts.

We adapted the methodology to make the study much more accessible to women in LMIC, reaching them through hospital clinics [2]. Whilst we found that the experiences of women in LMIC had issues in common with the earlier study, we also saw crucial differences, particularly around access to services and the severe financial impact of securing a diagnosis and treatment, leaving many women and their families on the verge of financial ruin.

We believe the findings of this study have the potential to drive change at global, national and local levels, and country teams are already using their data to that effect. This work underscores the strength and impact of global collaborations that bring together clinicians, researchers, patients and advocates. With the increasing global burden of ovarian cancer expected to impact LMIC in particular, and the lack of data from these areas, this work is both vital and unique. Whilst we will always press for more research, for new advances, this joint piece of work has instilled in our organisations the importance of looking at what is happening for the majority and trying to ensure we do the very best we can, in the here and now. Women, especially in LMIC deserve no less.

Clara MacKay
CEO
World Ovarian Cancer Coalition

Mary Eiken
CEO
International Gynecologic Cancer Society

EXECUTIVE SUMMARY

The women who participated in this study were the ones who were able to navigate the significant hurdles to a diagnosis and opted for treatment.

Ovarian cancer is on the rise, and the biggest burden will be felt in LMIC where 70% of women with the disease live.

Message from the Co-Chairs of the Oversight Committee

As co-chairs of the Oversight Committee for the Every Woman Study™ LMIC edition, we have had the privilege of working with many amazing colleagues around the world, listening closely to the realities facing women diagnosed with ovarian cancer in LMIC and those who treat and care for them, some in the most challenging of circumstances. Without their considerable efforts, this study would not have happened.

This study of patient-reported data combined with clinical data is unparalleled in such settings and highlights the challenges and disparities women face. It is important to recognise that the results presented, from women recruited through hospitals, still represent the best possible case for that community. One of the biggest challenges is getting a diagnosis, and many women do not even make it to that point. The women who participated in this study were the ones who were able to navigate the significant hurdles to a diagnosis and opted for treatment.

Before laying out the results in more detail, we will draw your attention to our key findings and recommendations. Given the wide variability of data by country, they do not represent a blueprint for action in all places. It will be up to local clinical teams, advocates, policy makers and governments to determine the most appropriate actions based on local findings and to consider communities they may not have reached. The fact that there is so much variability means change is possible.

We have four important tenets that run through the findings and recommendations:

Ovarian cancer is on the rise and the biggest burden will be felt in LMIC where 70% of women with the disease live. In some countries cases will more than double by 2050.
Action is essential.

National data is crucial to targeting interventions appropriately and effectively.
Action must be evidence based.

The women in this study are vital members of society and economies, often at an age where they are working and/or caring for family.
Loss of life is far more costly to society than the cost of diagnosis and treatment.

Lower education and income levels, greater distance to hospital facilities, and lack of financial support for diagnosis and treatment are the biggest barriers to good care and outcomes.
Interventions must be designed with a view to address barriers that are outside of health service systems.

KEY FINDINGS

ABOUT THE STUDY PARTICIPANTS

One of the strengths of this study is the broad demographic mix among the women represented.

- The mean age was 49.9 years old. It was however lowest in the low HDI countries (46.0) and highest in the very HDI countries (52.3).
- A third of women either had no formal education (12.2%) or were educated only to primary school level (20.6%). A third said their household income was below average for the country (37.6%) with just one in 10 saying it was above average (8.6%).
- Most women were in formal or informal employment (57.9%) and most had some form of caring duties (51.3%).
- Distance to their treatment centre varied widely by country with a third of women travelling more than 2 hours, and one in six travelling more than five hours (14.6%). This places increased burdens in terms of cost and resource on families and there is some evidence to show it can delay diagnosis.

MEAN AGE
49.9
YEARS OLD

A third
of women either had no formal education or were educated only to primary school level

A third
said their household income was below average for the country

57.9%
of women were in formal or informal employment

51.3%
of women had some form of caring duties

A third
of women travelled more than 2 hours to their treatment centre

One in six
travelled **MORE THAN FIVE HOURS**

About their ovarian cancer

The type, stage and age of diagnosis all varied by country. This is why national data is so important.

Lack of information on the stage and type may indicate workforce issues such as understaffing or a lack of expertise in pathology, hindering access to the best possible care.

63.4% of women undertook the survey when their cancer was in remission. This indicates potential selection bias, meaning the results are likely to reflect healthier populations than might be seen in the clinics. Women who were too unwell to participate were excluded, and in some countries, women do not undergo treatment for recurrence due to the increased burden of cost.

Epithelial ovarian cancer is the most common form (82.6%), and in most countries, **high-grade serous** is the most common subtype (44.0%), except in countries where unspecified epithelial ovarian cancer levels are high

FACTORS OTHER THAN TYPE OF OVARIAN CANCER INFLUENCE THE STAGE AT DIAGNOSIS, SUCH AS **LEVEL OF EDUCATION** AND **AGE**

Rates of other types of ovarian cancer can vary between countries and will influence stage profiles. The following graphic shows countries with higher-than-average rates for different types of ovarian cancer.

COUNTRIES WITH HIGHER-THAN-AVERAGE RATES OF CANCER

Clear Cell	Endometrioid	Mucinous	Germ Cell	Granulosa
Guatemala*	Vietnam	Zambia	Bangladesh	Jamaica*
Malaysia	Malaysia	South Africa		Kenya
		Kenya		Uganda

For all types of ovarian cancer,

4 in 10

women were diagnosed with early-stage disease (I and II, 39.4%). For those with high-grade serous that figure fell to 20.9%

One in ten women had an unspecified type of epithelial ovarian cancer. This varied by country from 0% to 50% and reflects issues with pathology services.

*LOW SAMPLE SIZES

About their families

Lack of awareness of family history may be leaving women at risk. One in six women did not know about their family history of breast or ovarian cancer (15%) but this varied widely by country. Only one third of women were aware that having a family history of cancer might increase an individual's risk of the disease (34.3%). Of the women in this study, one in four had at least one relative with a history of breast and/or ovarian cancer (24.2%).

AWARENESS OF OVARIAN CANCER

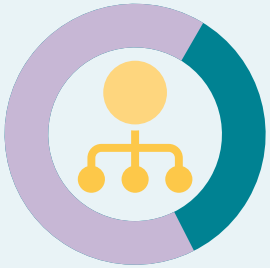
Knowledge of ovarian cancer is low. Just one in four women said they had heard of ovarian cancer and knew something about it (26.1%). This varied by country (from 3.3% to 63.2%). Those with some knowledge were more likely to be better educated, in higher income families, and from a higher HDI country.

SYMPTOMS EXPERIENCED

Almost all women experienced one or more symptoms associated with ovarian cancer, regardless of their stage of diagnosis (90.9% of all women, 85% stage I, 95.5% stage IV).

Pelvic and/or abdominal pain was the most reported symptom (65.6%), followed by increased abdominal size and/or persistent bloating (58.6%). Three-quarters of women were concerned by their symptoms (77.2%).

ONE IN SIX WOMEN
DID NOT KNOW ABOUT THEIR FAMILY HISTORY OF BREAST OR OVARIAN CANCER



34.3%

ONE THIRD OF WOMEN
WERE AWARE THAT HAVING A FAMILY HISTORY OF CANCER MIGHT INCREASE AN INDIVIDUAL'S RISK OF THE DISEASE

Just 1 in **4**
women said they had heard of ovarian cancer and knew something about it

Almost all women
experienced symptoms associated with ovarian cancer

of all women | **of those stage I** | **of those stage IV**

REPORTED THAT THE FIRST DOCTOR THEY SAW TOOK THEIR CONCERNS SERIOUSLY (58.1%).

This level of concern was associated with shorter times to diagnosis

FACTORS AFFECTING TIME TO DIAGNOSIS INCLUDED

increasing age

lower family income

lower levels of awareness

longer travel times

ROUTE AND TIME TO DIAGNOSIS

Most women seek help for their symptoms, but their first visit varies by country. Most visit either a family doctor or gynecologist, but In Uganda, herbal prescribers were the most common first consultation. Almost six in 10 reported that the first doctor they saw took their concerns seriously (58.1%). This level of concern was associated with shorter times to diagnosis.

Overall, the median time from experiencing symptoms to starting treatment was three months, but this varied by country from one (Vietnam) to seven months (Kenya). For the quarter of women in the study who experienced the longest times to diagnosis, this was at least six months but varied by country from two months (Vietnam) to 11 months (Uganda). It is clear that times to diagnosis can and should be shortened at a national level, particularly for those who experience the longest waits.

Factors including increasing age, lower family income, lower levels of awareness and a trend towards longer travel times were associated with the longest times to diagnosis.

The range of diagnostic tests used was very wide. Malawi was a particular outlier, with one in ten women proceeding to surgery after only a manual examination, but in general, use of abdominal and/or transvaginal ultrasound was much lower than would be expected, given guidelines. It is clear also that in many of the countries there are significant patient costs associated with diagnostic tests and this, together with workforce issues, may be impeding diagnosis.

TREATMENTS FOR OVARIAN CANCER

Most women in the study underwent surgery to treat their disease, but the level varied by country, as did the rates of optimal cytoreduction. Factors beyond age and stage of diagnosis impact the likelihood of optimal cytoreduction, namely, lower HDI status of the country, lower household income, self-payment for care, longer distances travelled and lower levels of awareness.

Basic chemotherapy regimens were generally available throughout the study, but interruptions in supply affected access in two countries during the period of data collection.

Hormone treatments are not always available in countries to treat low-grade serous or endometrioid ovarian cancer. Whilst almost all countries have access to bevacizumab, its usage is quite limited, often due to cost.

Use of PARP inhibitors in LMIC is very low at present, hindered by cost and the lack of genetic testing. No African woman in the study received a PARP inhibitor. This contrasted with 12% of women in Argentina and 3.6% of the women in the study overall.

1.7%
of the women in the study underwent genetic testing prior to diagnosis

15.6%
of the women in the study underwent genetic testing post diagnosis

LATIN AMERICA

AFRICA

% of women who underwent genetic testing

1/3rd of women have used herbal, complementary or alternative treatments

GENETIC TESTING

Rates of genetic testing are very low, and almost non-existent in terms of determining risk. This limits access to PARP inhibitors and highlights missed prevention opportunities.

Only 1.7% of the women in the study underwent genetic testing prior to their own diagnosis, and just 15.6% post diagnosis. These rates were strongly driven by region, with Latin American countries having rates of 2.5% and 40% respectively, contrasting with Africa where the rates were 0.4% and 1.4%. Clinicians have attributed high costs and lack of genetic testing facilities for these low rates [3].

IMPACT OF OVARIAN CANCER DIAGNOSIS ON WOMEN AND THEIR FAMILIES

A diagnosis and treatment for ovarian cancer has wide reaching implications for women and their families. Again, these vary by country, as do potential solutions, hence the importance of local data.

Side effects

When asked which were the two most problematic side effects, 'tiredness and fatigue' (37.9%), and 'feeling or being sick' (24.9%) were most cited.

Nearly a third of women have used herbal, complementary or alternative treatments not prescribed by their doctor to try and control their cancer, or any pain experienced associated with the cancer and its treatment.

Support needs

EMOTIONAL SUPPORT NEEDS

Emotional support needs vary widely by country as does the extent to which women get support, and from whom. Women surveyed relayed a range of emotional stresses including fear of recurrence or dying, as well as stigma and abandonment.

There was a greater burden on doctors and family members than on trained mental health professionals to meet these needs.

Only one in six women receive professional help (16%), driven by rates in Latin America. Overall, women who felt they received the support they needed (professional or otherwise) were more likely to have higher family incomes and higher levels of education. One in ten women (10.4%) said their emotional needs were not met in any meaningful way and a further four in ten said they were only met to some extent (39.2%).

Less than one in ten women had been part of a cancer support group.

Half of women said their emotional support needs were not met (49.6%).

45.9%
Family finances affected greatly

29.5%
Family finances affected to some extent

1/3rd of women said family income had fallen below what they needed to live on.

PRACTICAL SUPPORT NEEDS

Help with daily chores, transportation, and treatment, travel and food costs are amongst the common forms of practical help needed. Families bear the greatest burden.

FINANCIAL IMPACT

Three-quarters of women say their family finances have been affected either greatly (45.9%) or to some extent (29.5%). For almost a third of women in the study, their family income fell below what they needed to live on (29.4%). This varied by country from just 2.8% in Argentina, to 64.8% in Mexico.

INFORMATION NEEDS

There are large gaps in information provision, and the burden falls on doctors. Women would like hospitals to provide information about treatment and diagnosis. The role of charities or NGOs is very small in this respect, but they could perhaps increase their role. Just four in ten women got the information they needed when they needed it (41.3%). The internet is not widely used, even though most women have access to it.

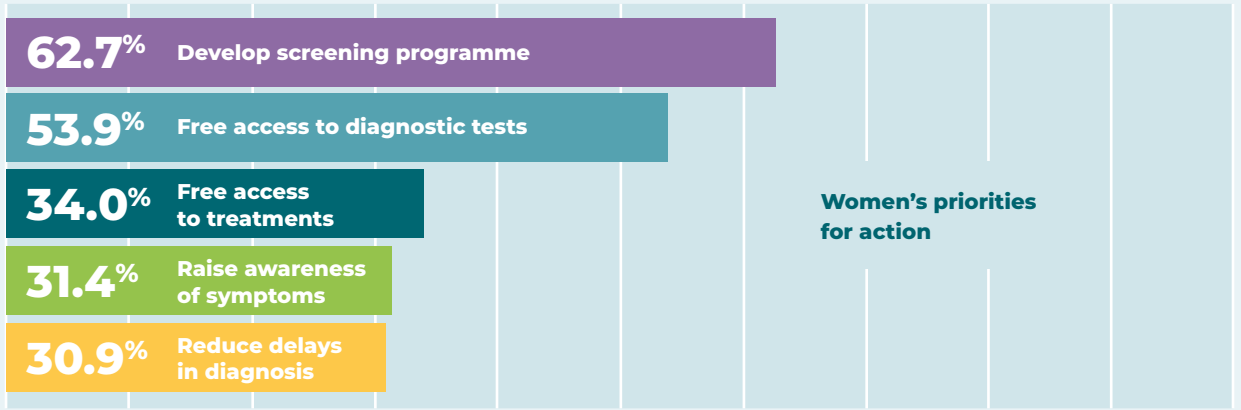
Women's priorities

Women's physical health (82.1%), followed by their mental wellbeing (60.8%) are important drivers of their quality of life. The importance of mental wellbeing varies by region (77% in Latin American to 37.7% in African respondents).

Most believe that their governments should be doing more to improve the lives of women with ovarian cancer. In terms of priorities for action, women are focused on improving diagnosis and reducing the financial burden of both diagnosis and treatment.

"Satisfied with treatment received in this center and doctors involvement in treatment. But our financial condition is very bad, it would be great if we get free treatment."

Participant, India



RECOMMENDATIONS

Priorities for action will be determined by local results, resources and shared decisions amongst stakeholders. Actions may be targeted at a national level, or more locally to address specific matters and will require involvement by governments, policy makers, cancer advocacy organisations, clinical communities and women.

"Build more hospitals for people with ovarian cancer to have easy access to treatment."

Participant, Zambia

"Help raise awareness about early symptoms of ovarian cancer so that women present to the hospital early."

Participant, Zambia

DATA IS NEEDED TO DRIVE CANCER CONTROL PLANS AND LOCAL ACTION

It is imperative that ovarian cancer data be routinely included in cancer registries at a local, regional and/or national level, and that ovarian cancer should be factored into national cancer control plans. This will enable appropriately targeted actions.

LOCATION OF SERVICES AND WORKFORCE EXPERTISE/WORKLOAD MUST BE CONSIDERED

Location should not be a barrier to accessing diagnostics and appropriate treatment. Models of working may need to be adapted, and workforce recruitment, training and retention considered to ensure adequate provision for the growing number of cases. This should include services such as diagnostics, as well as skilled pathologists, surgeons, oncologists and psychologists, if need be including new ways of delivery such as shared services where resource is scarce.

REDUCE TIME TO DIAGNOSIS AND MAKE IT AFFORDABLE FOR ALL

Women face barriers to diagnosis due to costs and delays in the process. It is essential that countries endeavour to reduce the cost of getting a diagnosis and the component parts of delay meaning:

- Women know when to seek appropriate and timely medical care for symptoms through increased awareness of symptoms.
- Doctors know when to seek appropriate and timely diagnostic tests for symptoms through increased awareness of symptoms, and improve access to tests.
- Health or payment systems do not hinder access to timely assessment. This could be achieved if diagnostics were included on the World Health Organisation Essential Medicines List.

ENSURE WOMEN GET AFFORDABLE ACCESS TO THE BEST POSSIBLE TREATMENT

Optimal cytoreductive surgery is one of the main drivers of good outcomes. This requires access to specialists, facilities and resources.

All the chemotherapy and hormone treatments currently used for ovarian cancer are included on the World Health Organisation's Essential Medicines List, and as such should be accessible in every country. High levels of financial toxicity are experienced by women who must pay directly for these treatments.

Newer treatments, such as bevacizumab and PARP inhibitors which are transforming the care of women with ovarian cancer in higher-income countries, are very rarely available to those in LMIC where these medicines are either self-funded or only covered by state health insurance in very rare circumstances. Linked with genetic testing, the gap between high- and lower-income countries will only widen in terms of outcomes unless access to tests and drugs improves in terms of availability and affordability. This finding underscores the importance of initiatives such as the Union for International Cancer Control's Access to Oncology Medicines Coalition (ATOM) [4].

IMPROVE SUPPORT FOR WOMEN

Access to psychological support, good basic information provided by treatment centres and/or civil society based on local women's needs, and low- or no-cost access to treatment and healthcare centres, will provide women a better quality of life.

EDUCATE ABOUT RELEVANCE OF KNOWING FAMILY HISTORY

Women do not realise the importance of knowing their family history, and health systems fail women by ignoring the potential that genetic testing can have on prevention.

Dr Tracey Adams
Co-Chair Oversight Committee, EWS LMIC
Associate Professor Subspecialist Consultant in Gynaecological Oncology Groote Schur Hospital, Cape Town, South Africa

Robin Cohen
Co-Chair Oversight Committee, EWS LMIC
Chair, World Ovarian Cancer Coalition
CEO The Sandy Rollman Ovarian Cancer Foundation, Pennsylvania USA

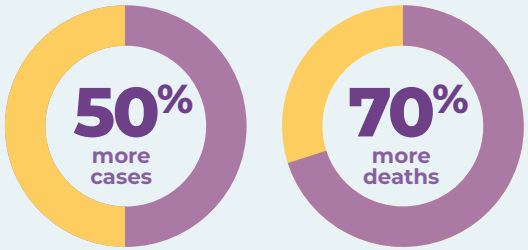
ABOUT OVARIAN CANCER

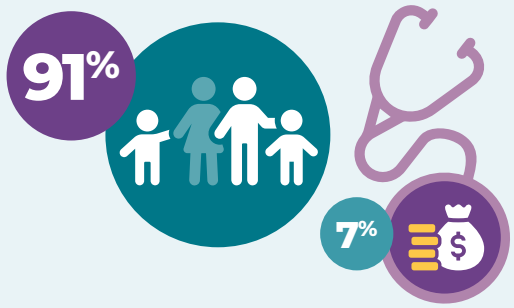
If current trends continue, based on 2022 Globocan mortality rates

8,000,000

women are projected to die from ovarian cancer by 2050.

This represents an increase of:





The biggest component of socioeconomic burden of the disease (91%) is attributable to the loss of life, many times more than the direct health costs of diagnosing and treating the disease (7%). This provides a very strong imperative to do more to save lives.

Ovarian cancer is a worldwide concern, and more needs to be done to address it comprehensively. If current trends continue, based on 2022 Globocan mortality rates, nearly eight million women are projected to die from ovarian cancer globally by 2050, with the heaviest burden falling on LMIC where 70% of those diagnosed live [5]. By this time there will be over half a million new cases of the disease diagnosed each year (503,448) and over 350,000 deaths. This represents an increase of more than 50% in cases and 70% in terms of mortality.

The Coalition's recent Socioeconomic Burden of Ovarian Cancer in 11 Countries Study highlighted that by far the biggest component of socioeconomic burden of the disease (91%) is attributable to the loss of life, many times more than the direct health costs of diagnosing and treating the disease (7%) [6]. This provides a very strong imperative to do more to save lives.

Ovarian cancer is a challenging disease. The majority of women are diagnosed at an advanced stage (III or IV) [7]. Large scale studies such as Concord 3 show five-year survival rates are less than 50% [8]. As yet, there are no screening tools [9]. Findings from the first The Every Woman Study™ unearthed variations in key metrics by country that mean it should be possible to drive improvements in timely diagnosis, genetic testing, and access to treatments such as PARP inhibitors which are bringing prolonged progression free survival [1].

A companion piece of qualitative research with clinicians leading the Every Woman Study™ in LMIC highlighted the lack of data to drive policy changes, together with the impact of cultural norms, and the effects of inter- and intra-country inequities in terms of access to diagnostics and treatments [3].

5 YEAR SURVIVAL RATES ARE LESS THAN 50%

AS YET THERE ARE NO SCREENING TOOLS

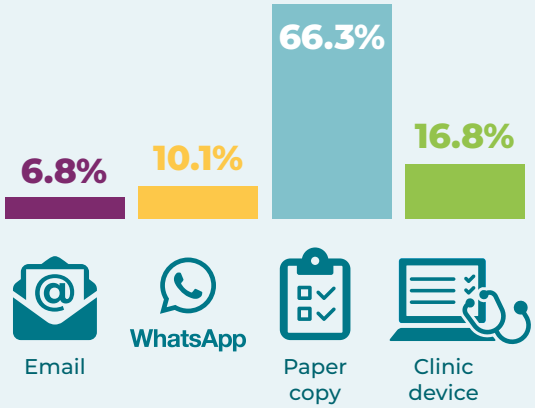
LACK OF DATA TO DRIVE POLICY CHANGE

THE WOMEN IN THIS STUDY

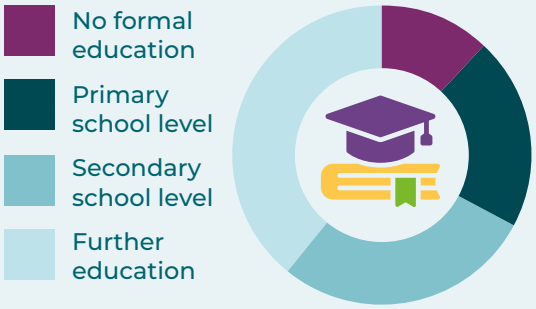
"Having ovarian cancer has been a painful and traumatic experience affecting me and my family members financially and my general well-being."

Participant, Nigeria

HOW THE WOMEN PARTICIPATED



WOMEN'S LEVEL OF EDUCATION



Data from 2446 women in 22 LMICs were included in the study. Eligible participants were aged 18 or over at the time of the survey and had been diagnosed within the previous five years. Due to the various timeframes in obtaining ethics approvals and preparing for the study, data collection took place between June 2022 and May 2024, with almost all the 82 participating hospitals completing their own data collection within one year of starting. Women had the choice of participating by email (6.8%) or WhatsApp/Telegram links (10.1%), by filling out a paper copy of the survey (66.3%), or accessing it on a clinic device (16.8%). The survey was available in 28 languages. Preferences varied widely between countries. Two-thirds of the women (63.8%) self-completed the survey. The remainder were interviewed mainly by members of the study teams, and some by a family member.

The results represent the best possible case. Before we share the results, we should highlight that the women who participated were those who had the means (financial and otherwise) to get a diagnosis and undergo treatment at appropriate centres, and were physically and mentally well enough to take part. The results are therefore likely to represent the best possible case. Fifteen of the 22 countries achieved sample sizes based on their five-year prevalence, that were big enough to make broad statements about care in their setting (95% CI, +/- 10%). When combined however the data becomes much more powerful, highlighting significant differences in many aspects of diagnosis, care and support.

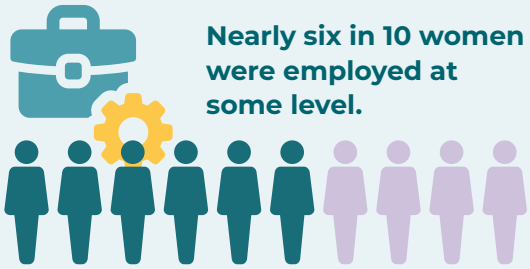
We present an overview of the results, and note that important variations occur between countries in almost every domain. Therefore, we cannot emphasize enough the importance of national data to inform cancer planning and efforts to improve outcomes.

OVERVIEW

Participants represented a range of demographics. The mean age at diagnosis was 49.9 years, but this varied from 46 in the low HDI countries, to 52.3 in the very high HDI countries.

A third of women had caring responsibilities for a child or children under the age of 18 (33.5%), and a further one in 10 cared for elderly relatives (12%). Just under half said they had no caring responsibilities (48.7%).

A third of women had either no formal education (12.2%) or only educated to primary school level (20.6%), just under a third were educated to secondary school level (28.2%), and the remainder completed education beyond secondary school level (technical college, university, post-graduate, 39%).

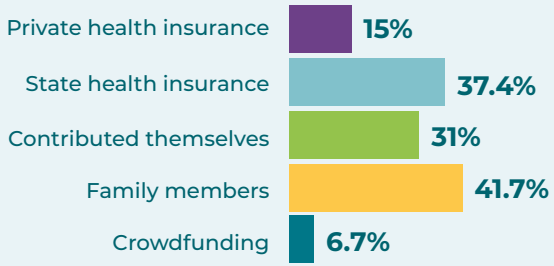


Nearly six in 10 women were employed at some level.

1/3rd of women described their income as 'below average'.

1/2 of women described their income as 'average'.

COVERING COSTS



"Currently using herbs because travelling for treatment will be costly."

Participant, Malawi

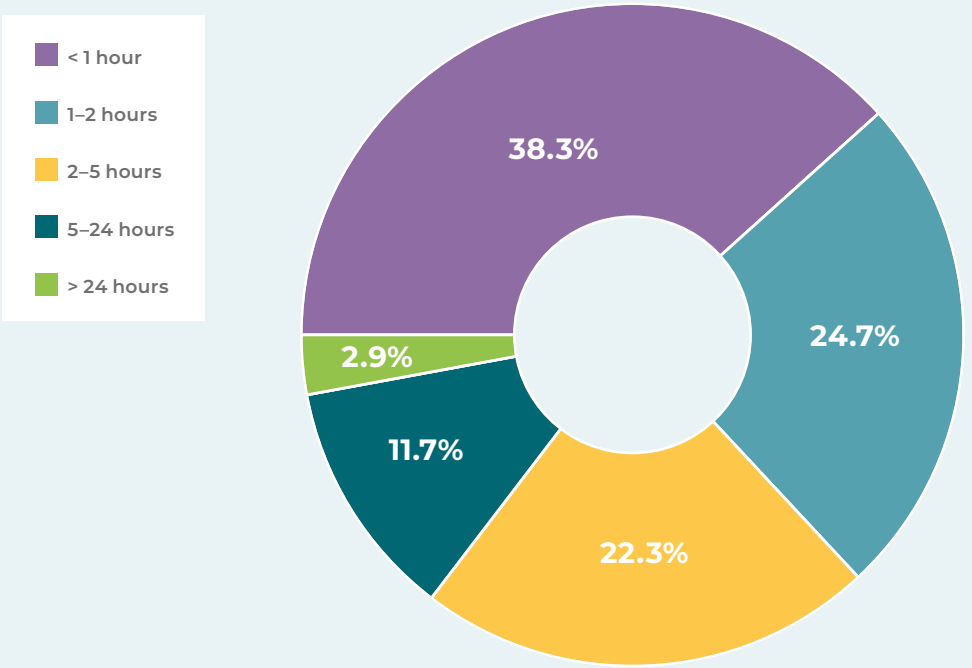
Nearly six in ten women were employed at some level (57.9%), just over three in ten said they had no formal or informal employment (31.8%), and one in ten described themselves as retired (10.8%).

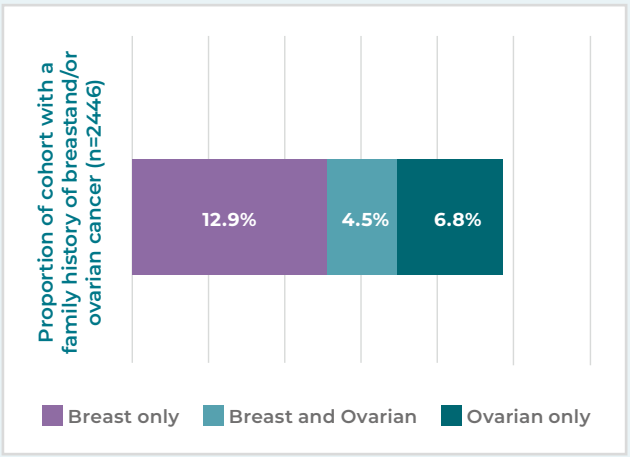
In terms of household income, over a third (37.6%) described their income as 'below average for their country', around a half 'average' (47.8%), and less than one in ten 'above average' (8.6%). Six percent of women did not want to disclose their income level.

In many LMIC, cancer diagnosis and care can bring associated costs. In terms of how these are covered, just 15% said they had private health insurance, nearly four in ten said there was state health insurance (but this may not cover all costs, 37.4%), a third said they had contributed themselves (31.0%) with four in ten saying family members had paid (41.7%). 6.7% of women had resorted to crowdfunding or getting money from charities to help cover their costs.

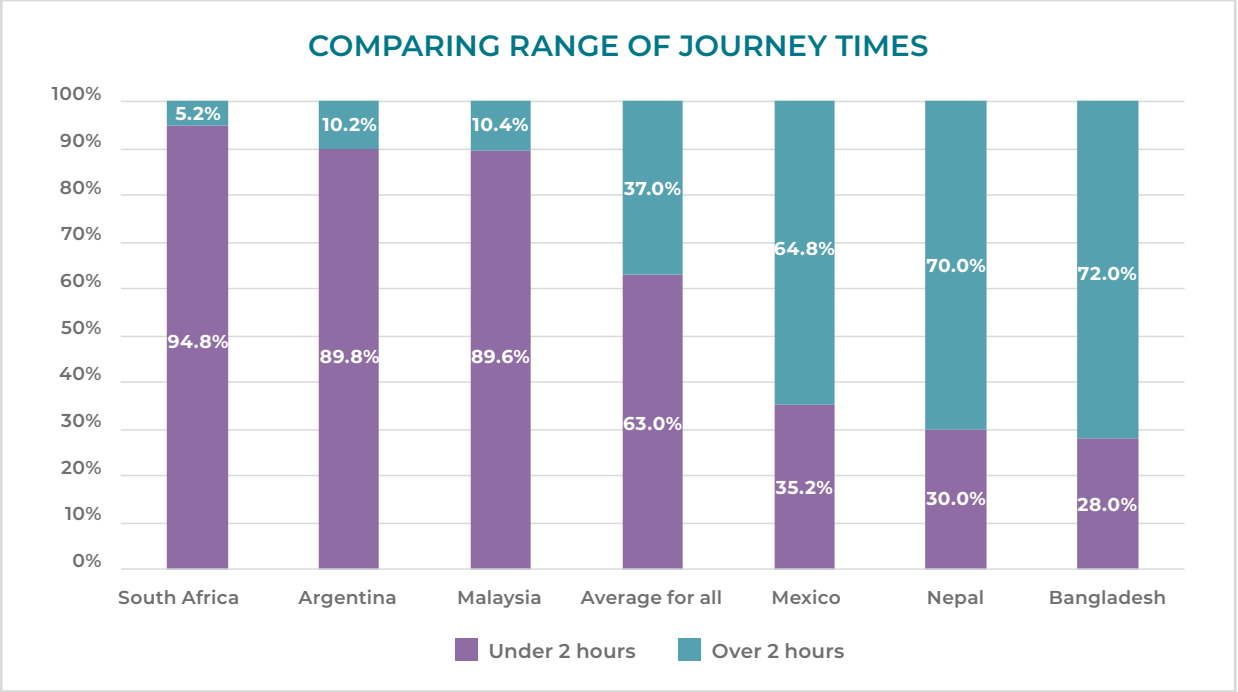
Just over a third of the women lived within one hour of the hospital where they are seen for their ovarian cancer, a quarter live between one and two hours, and a third of women are more than two hours away, some with very long journeys.

TIME TAKEN TO TRAVEL TO HOSPITAL (n=2434)





Looking at the proportion of patients who took up to two hours to reach their hospital you can see there is very wide country variation.



Distance to hospital can be a barrier to access in terms of journey time, access to transportation and cost. In some countries there is only one cancer treatment centre, such as in Zambia and Uganda. It is likely that some patients who live far away do not have the resources to make such journeys. It can also affect how local teams organise their services to try and ensure as much can be done at one hospital appointment as possible.

FAMILY HISTORY

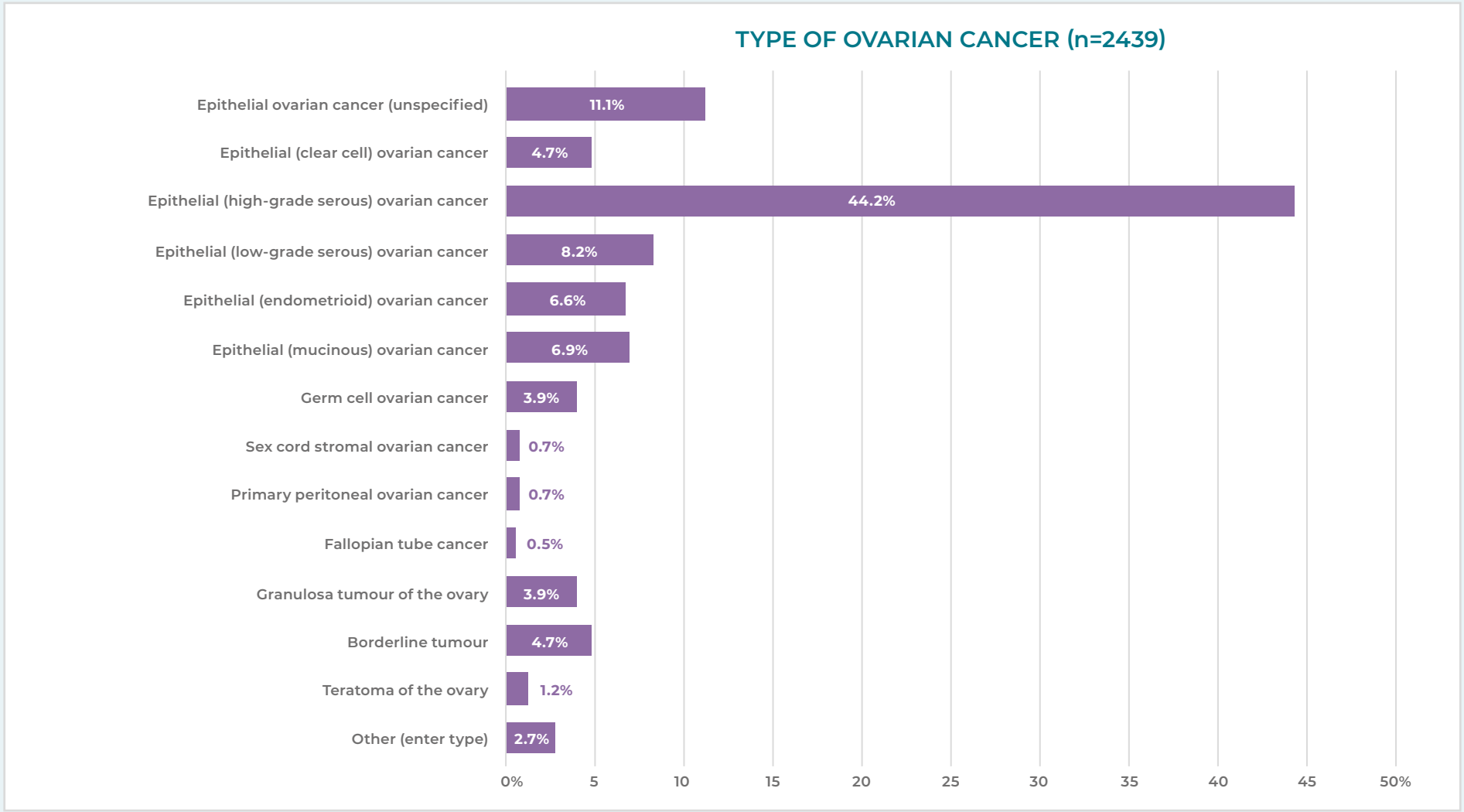
Lack of awareness of family history of cancer and the associated risks are significant. Around one in six women had no idea about their family history of cancer (15%), varying by country from 4% in Mexico to over 40% in Kazakhstan.

One in four women had at least one relative with either breast and/or ovarian cancer (24.2%). Just over one in 10 had a family history of ovarian cancer (11.3%). Half of the participants in Argentina reported one or more close relatives with ovarian and/or breast cancer (50%), compared to just 6% in Malawi.

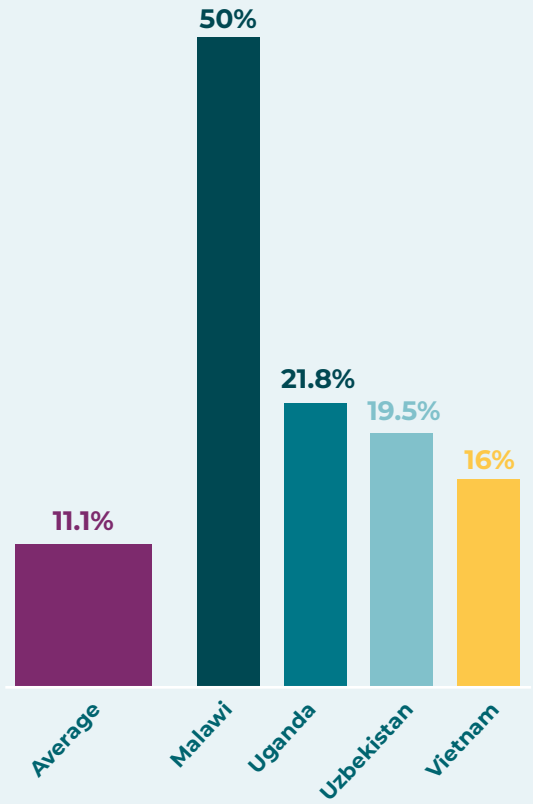
TYPE OF OVARIAN CANCER

Overall, epithelial subtypes including unspecified account for between 60% and 96% of each country's cases and 82.6% of the study population.

Epithelial high-grade serous ovarian cancer is the most common type of ovarian cancer seen in the study with nearly half the patients having this subtype (44.0%). This ranged from 11.5% in Zambia to 76.9% in Egypt.



UNSPECIFIED CASES BY COUNTRY %



Issues with pathology can prevent women from getting the appropriate treatment.

The levels of unspecified cases vary by country, with higher levels indicating issues in identifying the type and most appropriate treatment course. Overall the rate was 11%, with the highest rates of unspecified epithelial ovarian cancer in Malawi (50%) followed by Uganda (21.8%), Uzbekistan (19.5%) and Vietnam (16%). This contrasts with Egypt, Kenya and Peru who were able to identify every patient's type of epithelial ovarian cancer (0%).

In terms of other types of epithelial ovarian cancer and non-epithelial ovarian cancer, several countries had significantly more cases of certain types than the average for all:

- **Clear cell ovarian cancer:** Guatemala* (30.8%) and Malaysia (13.6%) had the highest rates compared to all countries (5.3%).
- **Endometrioid ovarian cancer:** Vietnam and Malaysia had the highest rates (28% and 14.4% respectively, vs. 6.7%).
- **Mucinous ovarian cancer:** Zambia, South Africa and Kenya had the highest rates (19.7%, 14.6% and 13.5% respectively vs. 7.3% for all).
- **Germ cell tumours:** Bangladesh had the highest rate (10.4% vs 3.8% for all)
- **Sex cord stromal:** Egypt* had the highest rate (3.8% vs 0.9% for all).
- **Granulosa tumours:** Jamaica* had the highest rates, followed by Kenya and Uganda (25%, 18.3% and 12.7% vs 4.8% for all).
- Overall borderline accounted for 4.7% of all cases, but several countries did not record any cases. This seemed to depend on how borderline cases are handled in the relevant countries, with some being dealt with in secondary rather than tertiary centres.

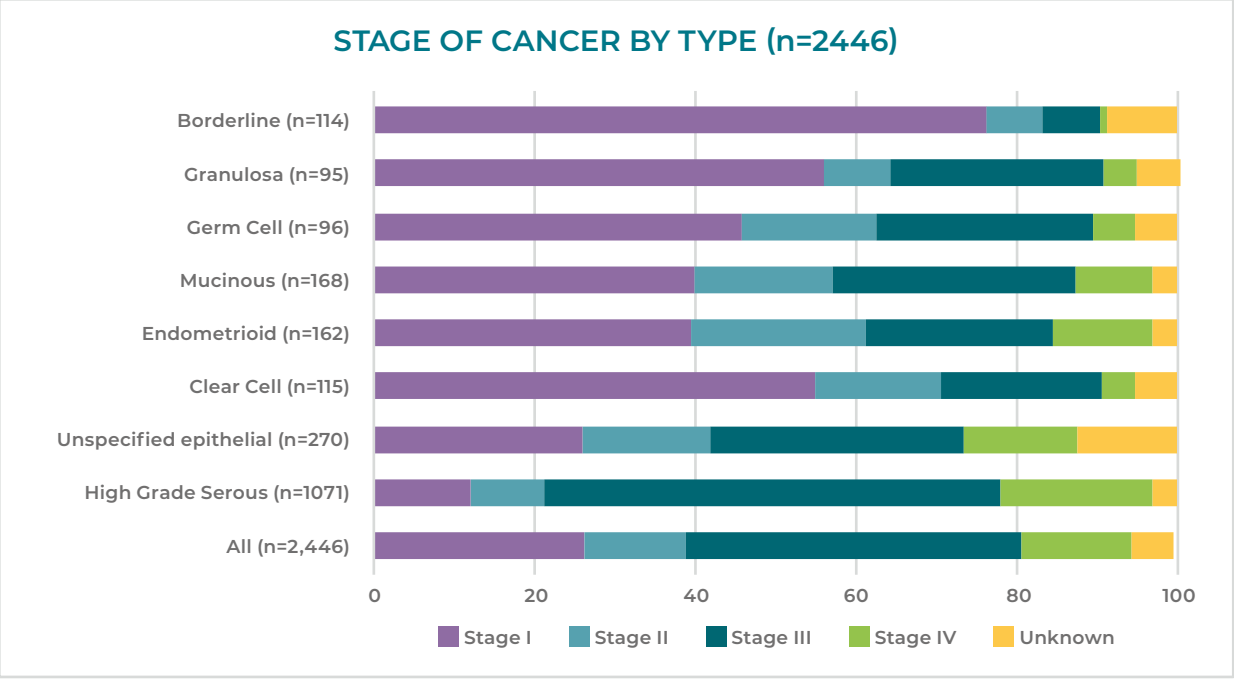
COUNTRIES WITH HIGHER-THAN-AVERAGE RATES OF CANCER

Clear Cell	Endometrioid	Mucinous	Germ Cell	Granulosa
Guatemala*	Vietnam	Zambia	Bangladesh	Jamaica*
Malaysia	Malaysia	South Africa		Kenya
		Kenya		Uganda

*LOW SAMPLE SIZES

STAGE AT DIAGNOSIS

Stage at diagnosis can be linked to the subtype of the disease, with endometrioid, clear cell, low-grade serous and mucinous more commonly diagnosed with early-stage disease (stage I or II). This will affect a country's pattern of stage distribution.



Stage at diagnosis can be affected by a range of factors. Our preliminary analysis shows that a woman is more likely to be diagnosed at a late stage if she is above the age of 60, has no formal education, and lives in a lower HDI country. For women diagnosed with high-grade serous, compared to all the women in the study, you can see a large difference.

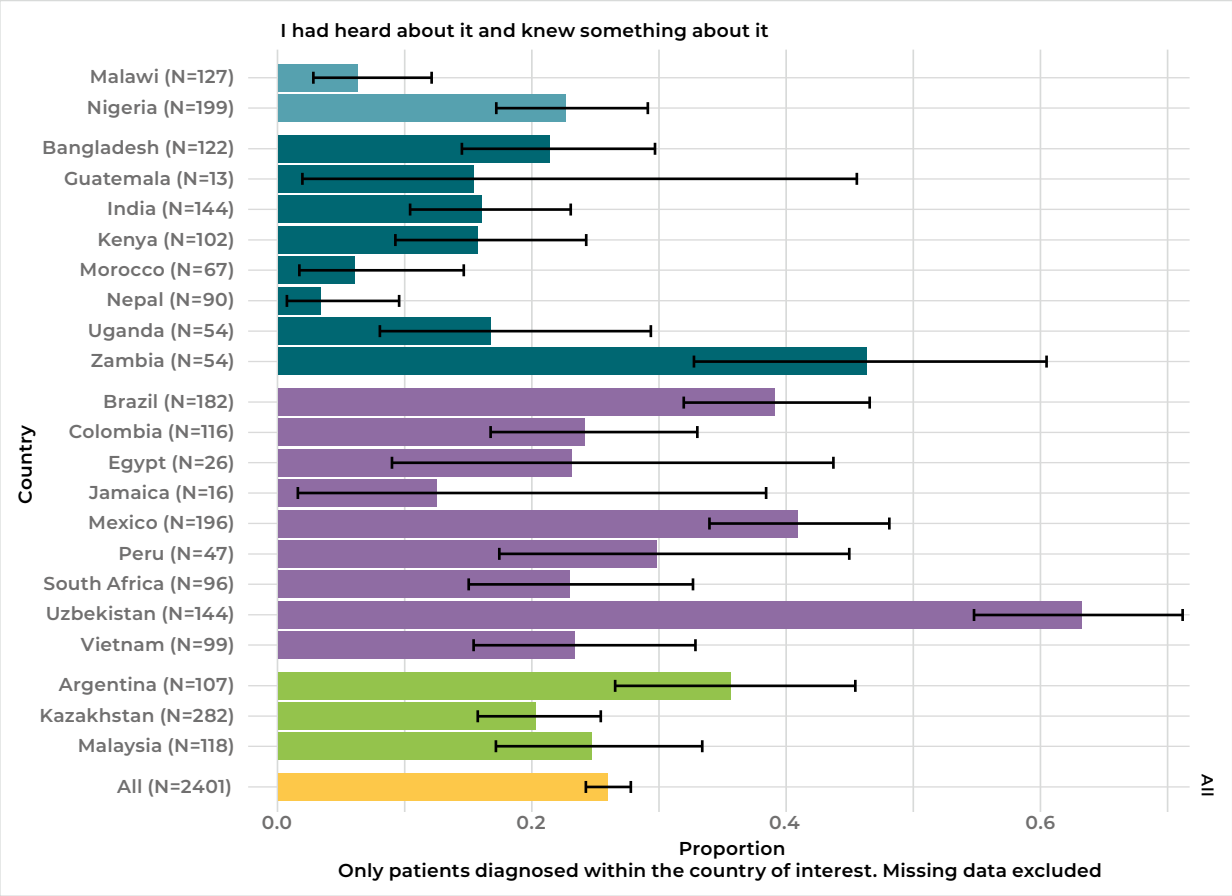
	All women with high-grade serous	All women in the study
Stage I	12%	26.7%
Stage II	8.9%	12.7%
Stage III	57%	41.8%
Stage IV	19%	13.6%
Unknown	3.1%	5.2%

There were very low levels of recurrence amongst participants (17.1%). This was most likely driven by the fact that at least 75% of the women had taken part in the study within three years of their diagnosis and potential recruitment bias. The inclusion criteria and local selection favoured women who were in better physical and mental health.

AWARENESS

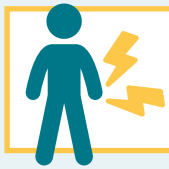
Knowledge of ovarian cancer is low. Only 26.1% of women had heard of ovarian cancer and knew something about it. Levels varied widely between countries from 3.3% in Nepal to 63.2% in Kazakhstan. Factors associated with higher knowledge included higher educational level, higher family income and greater HDI level of the country.

AWARENESS – HAD HEARD OF OVARIAN CANCER AND KNEW SOMETHING ABOUT IT

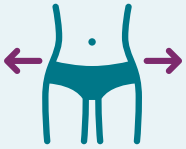


Morocco, Malawi, Nepal, Kenya and Bangladesh had the highest rates of never having heard of the disease.

SYMPTOMS ASSOCIATED WITH OVARIAN CANCER



65.6% reported experiencing pelvic or abdominal pain



58.6%

Persistent bloating

34.1%

Difficulty eating

23.5%

Fatigue

20.1%

Urinary urgency

23.3%

Unexpected weight loss

22.7%

Changes in bowel habits

Five out of the seven symptoms examined were more strongly associated with late-stage diagnosis – eating related symptoms, bloating, bowel related symptoms, fatigue and weight loss.

SYMPTOMS EXPERIENCED

A large majority of women experienced multiple symptoms of ovarian cancer prior to their diagnosis, regardless of stage and type.

90% Ninety percent of women had one or more symptoms of possible ovarian cancer prior to their diagnosis. This included 85% of women who had stage I disease and 95.5% of women with stage IV.

Over half of respondents reported experiencing abdominal/pelvic pain (65.6%) and increased abdominal size and/or persistent bloating (58.6%), while over a third experienced feeling full and/or difficulty eating (34.1%) and one in five reported urinary urgency or frequency (20.1%). Of those reporting symptoms (n=2,223), most symptomatic women (78.2%) reported having multiple symptoms (median: 2, range 1–7). Five out of the seven symptoms examined were more strongly associated with late-stage diagnosis in logistic regression models, namely eating related symptoms, bloating, bowel related symptoms, fatigue and weight loss. After adjusting for confounding factors, women with late-stage diagnosis were more likely to report multiple symptoms compared to those with early-stage diagnosis.

3/4 Three-quarters of women were concerned about their symptoms. Of the women who experienced any symptoms, half said they were concerned (49.4%), and another quarter said they were somewhat concerned (27.8%). A further 14.2% not very concerned and approximately one in 20 said they were not at all concerned (6.5%).

Half of the women in Nepal reported that they were either not at all concerned, or not very concerned (50%). This contrasted strongly with women in Egypt, Malawi, Nigeria, Vietnam and Morocco who had the highest rates of being concerned or somewhat concerned (88.4%, 100%, 92.4%, 92.8% and 93.6%).

For the women who did not experience symptoms prior to their diagnosis (n=130), most were discovered during a routine scan (36.2%), routine examination (33.1%) or whilst being treated for something else (26.9%). They were mostly diagnosed with epithelial high-grade serous cancer (43.8%) followed by mucinous and borderline (both 9.2%). The women in this group were twice as likely to have private health insurance as for the total cohort (29.5% vs 15%), but similar proportions of state medical insurance (40.3% vs 37.4%). They or their families were less likely to have paid themselves (16.3% and 26.4% vs 31% and 41.7%) than the total cohort. Women were also much more likely to be diagnosed with stage I or II disease (59.2%) than with stage III or IV (36.1%), but their age profile was like the study cohort.

"Your health is in your own hands, so if you experience the slightest symptoms, consult a doctor immediately."

Participant, Uzbekistan

"[There were] delays in assigning appointments with the clinician, difficulty expressing the symptoms in a short consultation time, shame in reiterating the symptoms after clinical recommendations such as "it's stress, go to a therapist, you have to play sports." If I didn't go in on call and with the advice of my gynecologist who was alerted about an ultrasound, the cancer control and care would be delayed for another month. Other exogenous factors such as holidays, availability of tomographers. The feeling of "getting lucky" in the process was truly hostile."

Participant, Argentina

HELP SOUGHT FOR SYMPTOMS

Most women sought advice about their symptoms (86.4%). Mexico (99%), India (98.6%), Uganda (98.1%), Egypt (96.2%), Morocco (95.1%) and Nigeria (90.2%) had the highest rates. Kenya, Argentina, Uzbekistan and Guatemala had the lowest rate of seeking advice. At this point we could not determine any factors linked to this (such as age, stage, family income, level of awareness or types of symptoms).

Countries have differing norms for the type of appointments women might seek. In some countries the first consultation would most likely be with a general practitioner (family doctor), (0% to 74.5%) and in others it might be a gynecologist (10% to 66.7%).

One in 25 women first sought help from a local healer (4.2%) across all surveyed countries, but in India, this rose to one in four women (25%). In Malawi, 47.6% of women first consulted an Alternative Health Practitioner, who in the context of the country prescribes and sells preprepared herbal remedies. Brazil had the highest proportion of first visits to an emergency doctor (19.2%), and in Jamaica, India, Argentina and Colombia this rate was above one in ten.

Women who first sought help from a local healer (n=87) were less likely to have private medical insurance (3.4%) than the cohort as a whole (15%), and much more likely to have had family members pay for their care (80.5% vs 39.4% for the whole cohort). Below average family income, and no formal education were also potential factors.

Women report that most doctors took their concerns very seriously. The median number of visits to a medical doctor prior to their diagnosis was three with an interquartile range of two to four based on 1,401 respondents. Women reported that most doctors were likely to take their concerns very seriously (58.1%).

TIME TO DIAGNOSIS AND TREATMENT

In this study we have taken the approach of examining three major components of the Aarhus checklist which is a resource for early cancer diagnosis [10]. It explores the time from the patient first experiencing changes to their body and their subsequent help seeking behaviour, otherwise called 'the patient interval', the time from first presenting to a health professional about the changes, through investigations to the point of diagnosis – 'the diagnostic interval', and 'the treatment interval', being the time from diagnosis to treatment starting.

All the times are patient reported in months. Incomplete data from symptomatic patients were excluded, as were entries that clearly had some level of error, for example seeking help for a symptom, before it started. Patients who were diagnosed in another country, also had their data excluded.

"The delay was too much. I was even crying for them to operate [on] me. I had to patronize prayer houses, and the abdomen kept increasing."

Participant, Nigeria

"The first doctor could have taken symptoms and results more seriously, to have a quicker diagnosis. Wishes that she could have been aware what her symptoms could mean, and go to an appropriate doctor and get treated earlier."

Participant, Malaysia

"To assist women with ovarian cancer [to] get early diagnosis and treatment, sensitize women on [the] importance of enrolling for the national health insurance fund NHIF."

Participant, Kenya

Most of the women in the study visited a doctor and were assessed promptly. However, for a significant proportion there were multiple delays. These vary by country and cause.

	Patient interval (variation by country range)	**Diagnostic interval (variation by country)**	**Treatment interval (variation by country)**
Median time in months	1 month (0 to 2 months)	1 month (0 to 2 months)	Within 1 month (0 to 1 month)
For 25% of the women this part of the process took:	More than 2 months (1 to more than 5 months)	More than 2 months (1 to more than 4 months)	More than 1 month (0 to more than 2 months)
Overall time from symptom to treatment in months	On average 3 months (1 to 7 months)		
For 25% of women, the whole process took:	More than 6 months (2 to more than 11 months)		

Initial analysis has explored some of the factors associated with the different intervals. Only one factor was shown to affect all women – the level of concern of the doctor they first saw, with lower levels of concern meaning a longer time from first seeking help to diagnosis. This underscores the need for clinical education. However, other factors did appear to be contributing to the length of time for the 25% of women with the longest times.

Lower income, awareness, and longer distances travelled are associated with the slowest times to diagnosis.

Interval	**Affecting all**	**Affecting the 25% of women with the slowest times**
Patient		Increasing age associated with longer time to seek help
Diagnostic	Level of concern shown by first doctor – higher level associated with shorter time to diagnosis	Lower income, lower awareness and a trend for longer distances travelled associated with longer time from seeking help to diagnosis
Treatment		Those who were less concerned about their symptoms had a shorter treatment interval

"What stressed me the most was the delay from the EPS (public health insurance plan) in authorizing my treatment."

Participant, Colombia

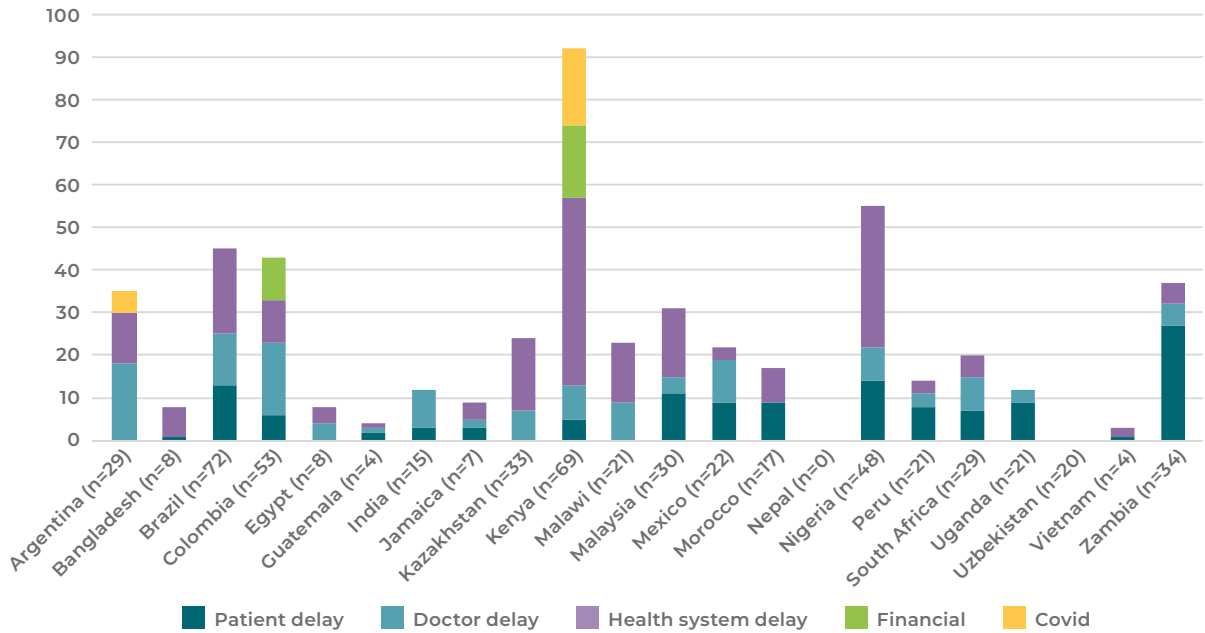
"Could not get a gynae appointment, as all doctors were booked up. Had to wait for tests and health system appointments. Health care staff not taking my concerns seriously. I admitted myself to the trauma unit to get seen."

Participant, South Africa

Almost four in ten women say their time to diagnosis could have been shortened. Most common delays were due to health system issues (tests/appointments/results), misdiagnosis or lack of awareness on the part of the doctors, and thirdly, lack of patient awareness of symptoms, or fear.

Symptomatic women were asked whether their time from experiencing symptoms to diagnosis could have been shortened, and if so how. For almost four in ten women (38.4%) the answer was yes, with a further third (34.7%) saying they were unsure. Only a quarter said their time to diagnosis could not have been shortened (26.8%)[1]. A total of 565 comments were left and were categorised into themes at a country level. Some women left more than one comment. Further refining of categories brought the data together. Looking at the variations by country helps understand which are the priority areas for action.

MOST COMMON REASONS FOR DELAYED DIAGNOSIS BY COUNTRY (n=565)



Uzbekistan stood out in terms of the comments, framing the importance of proactive behaviour on the part of women, the importance of seeking specialist advice and assessment, and the importance of regular check-ups (20 in total). This was an interesting finding given the context that Uzbekistan had one of the shortest times to diagnosis treatment.

[1] Where necessary Google Translate was used

Of the 82 participating hospitals, 2 were classified as basic, and the rest were a mix of limited and enhanced.

Guidance on standard diagnostic tests *(ASCO Stratified Guidelines for Ovarian Cancer, Vanderpuye et al) [11].*

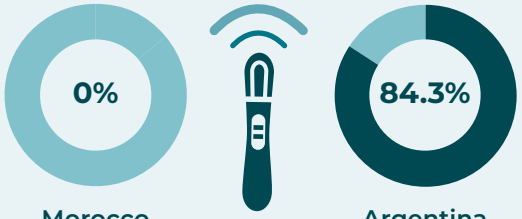
Procedure	
Clinical examination	All sites (Basic, Limited, Enhanced)
CA125 test	All sites (Basic, Limited, Enhanced)
Combination of abdominal and pelvic ultrasound (transvaginal)	All sites (Basic, Limited, Enhanced)
CT	Limited and Enhanced sites
MRI	Enhanced sites, if it will affect clinical management

USE OF CA125 BLOOD TESTS

Malawi

Guatemala, Jamaica and Uganda

USE OF TRANSVAGINAL ULTRASOUND



Morocco

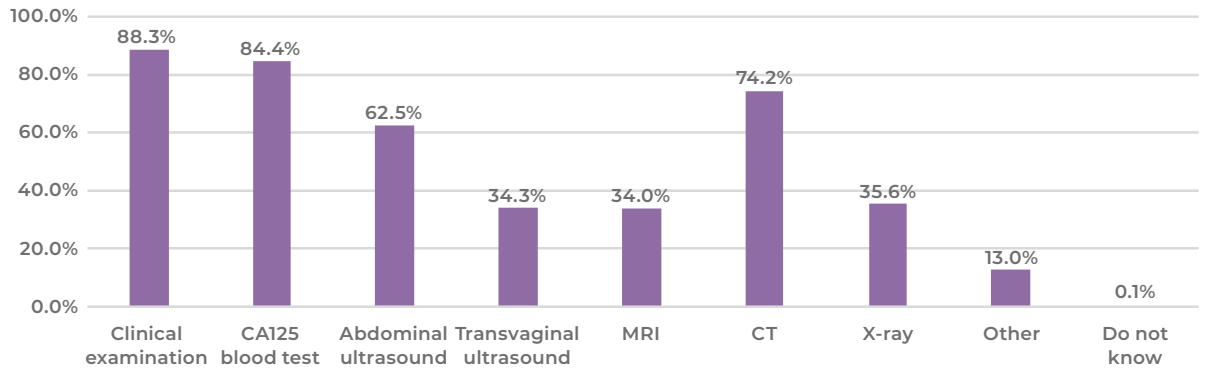
Argentina

DIAGNOSTIC TESTS

Access to imaging tests can be very varied. This may be due to lack of financial and human resource, but also the cost of tests being met by many patients.

The use of diagnostic tests varied by country, but overall, the use of transvaginal ultrasound was low at 34.3% which was surprising given that this is recommended in diagnostic guidelines. Clinicians have said that it is most commonly due to lack of equipment, or lack of trained operators, and that where resources are limited, they would rather progress to CT or MRI which might have more of an impact on treatment decisions. There is also the issue that in many countries, patients have to pay for diagnostic procedures. The following data were collected from the patient records.

TESTS UNDERTAKEN DURING DIAGNOSTIC PROCESS (n=2443)



- Rates of clinical examination varied by country from two in three women in Colombia and Uzbekistan (64.7%, 65.8%) to every woman who took part in the study in Egypt, Guatemala, Jamaica, Nepal, Peru and Uganda.
- Malawi had the lowest use of CA125 blood tests, with just one in seven women receiving one (14.1%), followed by Colombia where six in ten women received one (62.9%). This contrasted with every woman in the study from Guatemala, Jamaica and Uganda.
- Transvaginal ultrasound use varied very widely, with Argentina and Kazakhstan having the highest rates (84.3% and 83.1% respectively), and extremely low or no rates in Morocco (0%), Kenya (1%), Nepal (1.1%), Zambia (3.3%), Uganda (5.5%) and India (6.1%).
- CT scan was the most common imaging used (74.2%), varying from almost all study participants in Mexico (98%) to one in seven in Malawi (14.1%). MRI was another option, but even in Malawi, this was low. Further analysis showed that for one in three patients in Malawi, the only diagnostic tests they underwent were clinical examination and/or abdominal ultrasound (37.5%) with a further one in ten receiving only a clinical examination (9.4%).

TREATMENTS FOR OVARIAN CANCER

Most commonly, women with ovarian cancer will be treated with surgery, followed, or sometimes preceded by chemotherapy.

RECOMMENDATIONS FOR TREATMENT

The goal of surgical management of stage III and IV ovarian cancer is to perform optimal tumor cytoreduction, which is achieved by resecting all visible tumor to < 1 cm and ideally to no visible tumour (ASCO Stratified Guidelines for Ovarian Cancer [11]). Chemotherapy is likely to be given in most cases, except for borderline ovarian cancer, or low risk stage I disease (stage IA). The recommended treatment includes two different types of chemotherapy: carboplatin and pactlitaxel. The ASCO Stratified Guidelines also suggest that targeted therapies such as PARP inhibitors and antigenic drugs such as bevacizumab may be offered in the most resourced settings, but warn of potential for financial and physical toxicity.

In some cases, especially where it may be difficult to achieve optimal cytoreduction, due to advanced stage of disease, a course of neo-adjuvant chemotherapy is recommended, to shrink the tumour prior to surgery (interval debulking) taking place.

Some women may not be able to undergo surgery due to the extent of their disease or ill health.

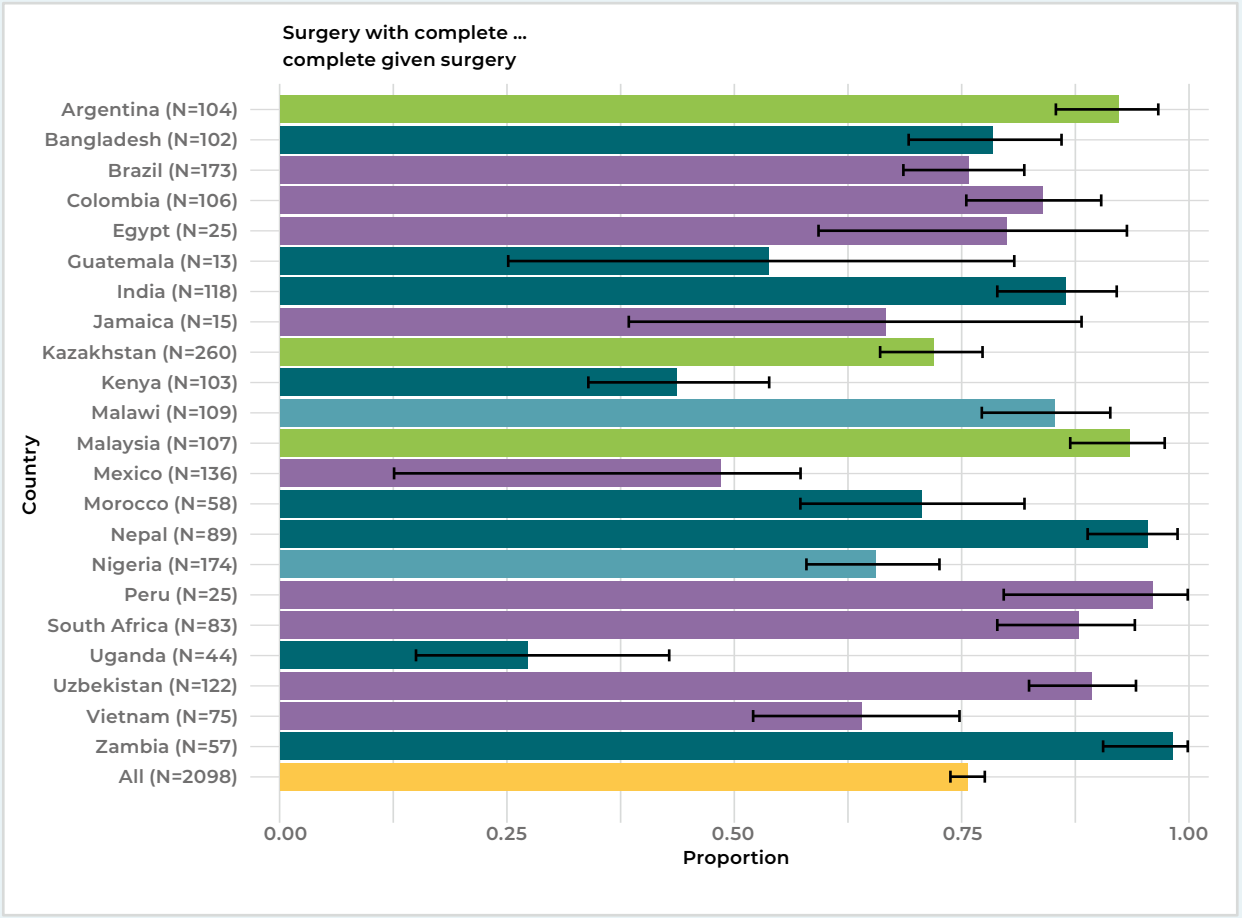
We have taken care in the analysis to check the impact of recent diagnoses on the reported figures. A woman undergoing neoadjuvant chemotherapy would not have had surgery, and a woman who recently underwent surgery may not have started chemotherapy.

SURGERY

Surgery is the most common form of treatment for the disease. Of those surveyed, only 13.2% did not have surgery. This contrasted with just 1.0% in Kenya, 2.2% in Nepal, 3.7% in Argentina and 4.9% in Brazil. Only seven in ten women in Mexico had surgery (69.4%), but they had one of the highest rates of late-stage diagnosis (85.7%).

Of the 2,098 women who received surgery, rates of optimal cytoreduction varied widely by country. Overall, three-quarters of these women had optimal cytoreduction (75.5%, n=1588). Highest rates occurred in Nepal (93.5% of their total cohort of 91), Zambia (91.8% of their total cohort of 61) and Argentina (88.9% of their cohort of 108). Lowest rates were in Uganda, Mexico, Kenya and Vietnam.

COMPLETE CYTOREDUCTIVE SURGERY



Initial analysis shows several factors associated with rates of optimal cytoreduction. As expected, older age and higher stage ovarian cancer were very strongly associated with lower rates of optimal cytoreduction. However novel findings of the study show that other factors have an association as well:

- Lower household income
- Lower HDI status of the country
- Longer distances travelled
- Self-payment for care
- Lower levels of awareness

Other factors that may impact on optimal surgery include a lack of access to operating theatres, intensive care facilities and the skillset of the surgeon.

"Feeling better – ...[she] doesn't see the need to start treatment."

Participant, Malawi

RATES OF SECOND SURGERY AND SURGERY FOR RECURRENCE

Of the women who had surgery (n=2,098), just over one in ten underwent a second procedure because the first operation had not removed enough of the cancer. The countries with the highest rates were Mexico, Guatemala and Peru, where over one in four underwent such operations.

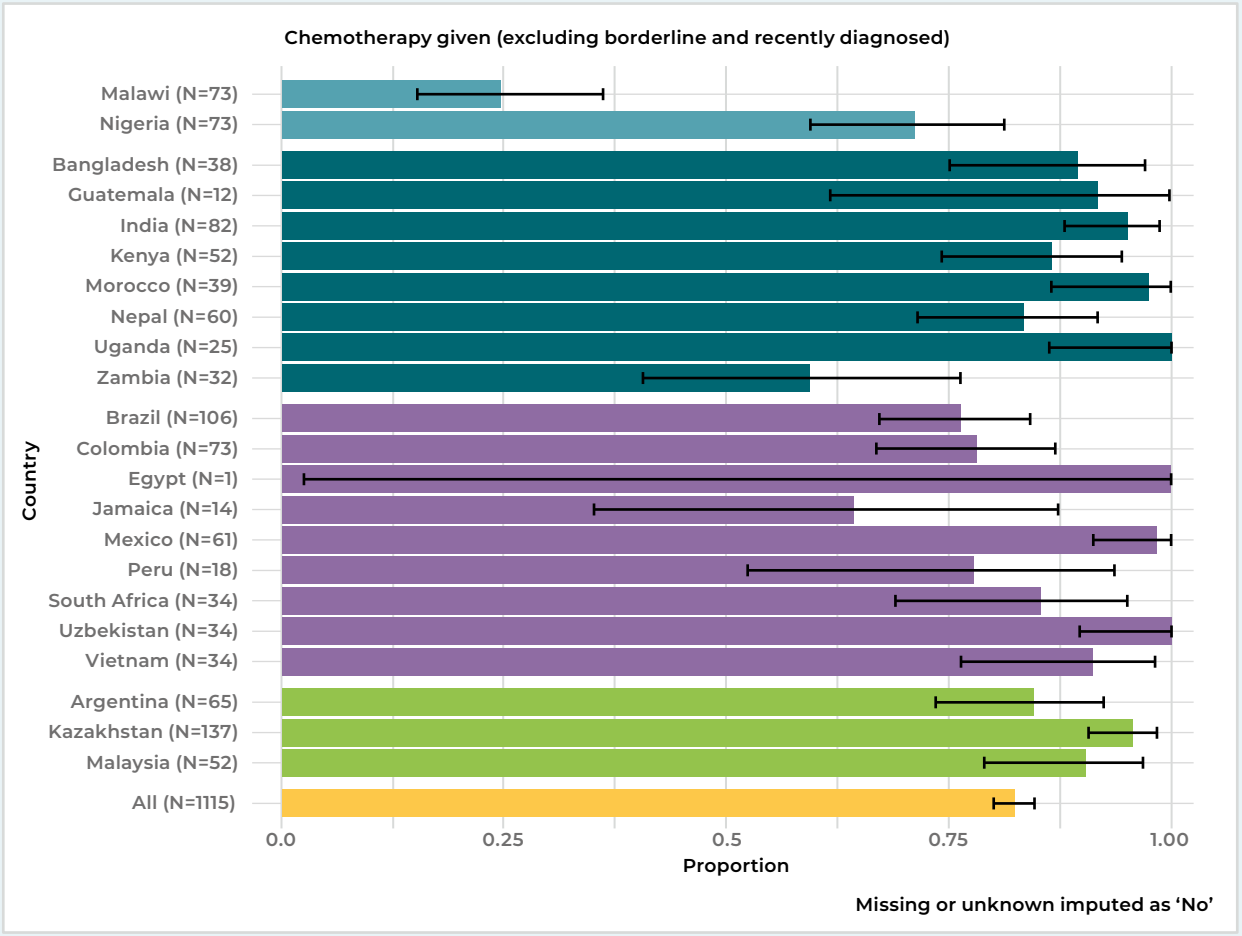
One in 20 women underwent a second surgery to address a recurrence of their ovarian cancer. No such procedures occurred for the women in the study from Uganda or Zambia.

CHEMOTHERAPY

For the study cohort, 76.6% of women received chemotherapy (n=2,420). Overall, reasons for not receiving chemotherapy included a very recent diagnosis, recovering from surgery, or diagnosed with stage IA or borderline ovarian cancer. Rates by country varied very widely from 22.6% in Malawi, to 98.2% in Uganda. On occasion women said they did not want chemotherapy as it would make them feel unwell, or they felt better after surgery so did not want it.

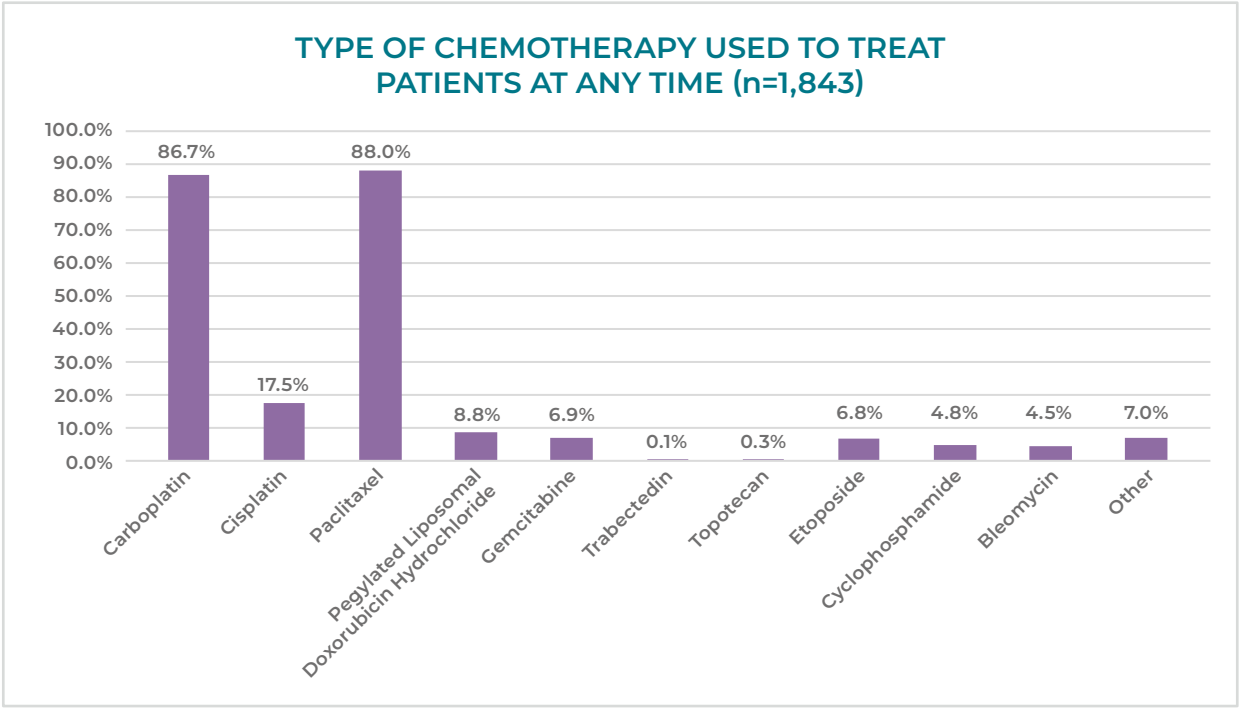
The data was also examined excluding those with borderline, and those with a recent diagnosis. There was still wide variation by country.

CHEMOTHERAPY GIVEN (EXCLUDING BORDERLINE AND RECENTLY DIAGNOSED)



A third of the women who received chemotherapy had neoadjuvant treatment, prior to their surgery (32.7%). In Egypt, this was all women, whereas rates in Kenya and Malawi were extremely low.

Carboplatin and paclitaxel, the mainstay of chemotherapy treatment are available in most countries, but shortages can occur. Carboplatin together with paclitaxel should be given as the standard of care for women with epithelial ovarian cancer, and a combination of bleomycin, etoposide and cisplatin are used for non-epithelial tumours. Other drugs were used if there was a lack of supply, or for recurrent disease.



For those women who received chemotherapy, Zambia (26.7%) and Uzbekistan (51.8%) had the lowest rates of Carboplatin usage, and the country leads confirmed this was due to shortages in supply. In Uzbekistan this was resolved during the study period.

OTHER DRUG TREATMENTS

Hormone treatments such as letrozole, anastrozole or tamoxifen can be used in conjunction with other chemotherapies to treat low-grade serous ovarian cancer, clear cell, and some non-epithelial types. Egypt, Nepal, Malawi and Uganda reported that these drugs are not available in their countries. Some of the other countries had varied access to some of the drugs. Of the study cohort, 2% of patients received tamoxifen, 1% received anastrozole, and 1.4% letrozole.

Availability of drugs such as bevacizumab does not mean it is accessible. Bevacizumab is technically available in all countries in the study except South Africa, though access may vary between sites within a country, and over a given time period. The proportion of patients who have received bevacizumab varies widely. Usage is often determined by cost or payment mechanism. For the study, 12.8% received the drug. Rates varied between 0% in Egypt and Jamaica, under 5% of patients in Bangladesh, Brazil, Kenya, Malawi, Malaysia Nepal, Peru, Uganda and Uzbekistan contrasting with the highest levels of usage in Guatemala (61.5%), Morocco (47.1%), Zambia (32.8%) and Argentina (29.6%). Within countries there was also variation.

Overall, in Nigeria a quarter of women received the drug, but by far the majority all came from one treatment site in Gombe where access is by a charitable scheme.

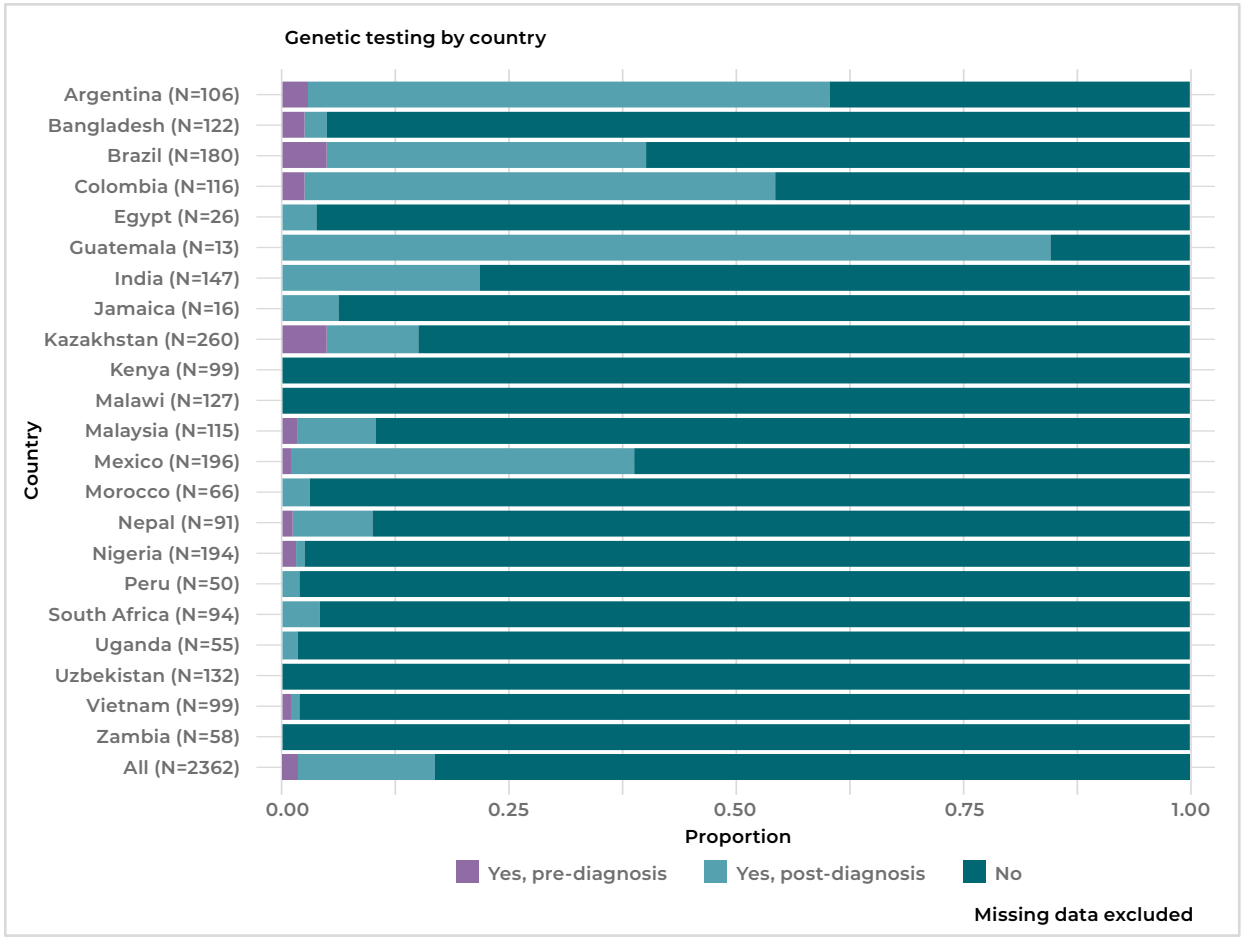
Use of PARP inhibitors in the study was very low and varied by region and country. No women in Africa in the study received this type of drug. In terms of PARP inhibitors (olaparib, rucaparib, and niraparib), olaparib is most commonly available, but usage varies widely. PARP inhibitor usage is more common in Latin American countries, particularly Argentina (12% of patients received it), Colombia (8.6%) and Brazil (6.6%). Overall, just one in 40 patients received olaparib (2.5%), fewer than one in 200 received rucaparib (0.4%), and fewer than one in 100, niraparib (0.7%). Overall, fewer than one in 25 women received these types of drugs (3.6%).

In a similar vein, very few patients received intraperitoneal chemotherapy (IP) (0.6%) or hyperthermic intraperitoneal chemotherapy (HIPEC) (0.6%). For IP, just seven of the 22 countries were able to offer the treatment (Argentina, Colombia, India, Kazakhstan, Nepal, Uzbekistan and Vietnam, and seven countries could offer HIPEC (Argentina, Bangladesh, Colombia, India, Jamaica, Kazakhstan and Mexico).

GENETIC TESTING

Rates of genetic testing are very low, and almost non-existent in terms of determining risk. This limits access to PARP inhibitors and highlights that prevention opportunities are being missed.

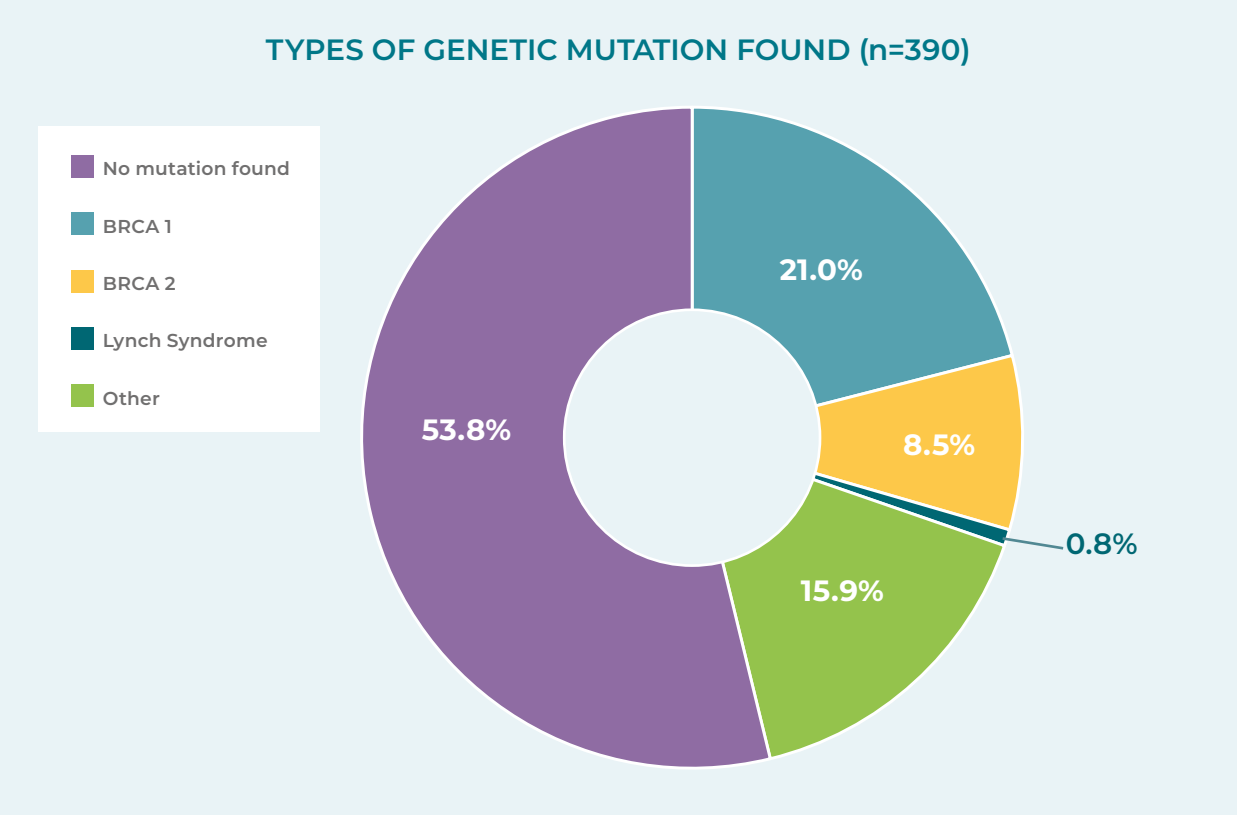
Of course, use of PARP inhibitors is dependent on genetic testing to determine BRCA status. Whilst the remit of PARP inhibitors is now also extending into those women who have positive homologous recombination deficiency status, the ability to do genetic profiling (somatic, germline) is very important, and potentially presents treatment and wider family prevention options. Rates of genetic testing are low, especially pre-diagnosis. For the study cohort just 1.7% had been tested prior to their diagnosis, and one in six, post-diagnosis (15.6%). This varied very widely by country with Latin American countries driving the overall figures, and African countries having the lowest rates.



"Years before my diagnosis I tried to undergo genetic analysis, but it was financially inaccessible to me. When I was diagnosed with cancer, the hospital, in agreement with a laboratory, performed a genetic study on me and I have a mutation in BRCA1. If I had known this before, I would have decided to perform the operation to remove my ovaries. I already had my two children."

Participant, Argentina

Of the 390 women who underwent genetic testing, BRCA 1 was the most common mutation found (21%). For over half of the women undergoing tests (predominantly after diagnosis, to determine potential treatments) no mutation was found. In terms of the study population (2,446), just 180 women had a genetic mutation identified (7.4%), which is well below expectations in terms of the population.



PARP inhibitor access is driven by private health insurance. Of the 115 women who had a BRCA 1 or BRCA2 mutation, 88 received treatment with a PARP inhibitor (76.5%). Women who received a PARP inhibitor were much more likely to have private health insurance (43.2% vs 15.0% for the study as a whole) or were likely to live in countries where state health insurance was present (46.9% vs 37.4%).

EFFECTS OF TREATMENT

Women were asked for the two most difficult side effects of treatment. The responses varied by country. Overall, tiredness and fatigue was the most reported category, recorded by over a third of patients (37.9%), followed by feeling or being sick in one in four women (24.3%). Hair thinning or hair loss, loss of appetite, and anxiety all scored over 15% in this ranking.

When asked if health professionals have been able to reduce the impact of side effects with other medicines, advice or information, most women said either 'Yes, very much so' (46.3%) or "Yes, to some extent (41.7%). However, one in 25 women said not at all (4%). The greatest resolution of side effects was seen in Mexico (73.7%), India (72.5%) and Uzbekistan (71.1%), and the countries with the highest proportion where the impact of side effects were not at all reduced were Jamaica (20%), Zambia (18%), South Africa (14.5%) and Egypt (13%) though there were very small sample sizes in Jamaica and Egypt.

Approximately one-third of women have used herbal, complementary or alternative treatments not prescribed by their doctor to control their pain or cancer. Just under one in 20 said they used them all the time (6.9%), and a further group had used them at some point (23.7%). Peru and Uzbekistan had the highest rates of use 'all the time' (14%, 11.9%), and Malawi, Peru, and Guatemala had the highest rates of 'at some point' (57.5%, 54%, and 53.8% respectively).

SUPPORT NEEDS

Emotional support needs vary widely by country, but most women do need support. Fear of recurrence or dying are very common features. Issues such as stigma and abandonment vary by country and region.

Most women felt the need for emotional support at some point since their diagnosis. This was predominately at the point of diagnosis (61.4%) and/or during treatment (55.6%). Overall, just 17.1% said they had not had any particular emotional support needs. Given the low rates of recurrence in the study, it should not be assumed that needs on recurrence or news of terminal prognosis do not require support.

Needs varied by country, with Colombia, Brazil, Malawi, Jamaica and India reporting the highest levels of 'I have not needed any emotional support' (47.4%, 42%, 39.4% 37.5% and 34% respectively). In contrast, emotional support needs were extremely high in Zambia where almost every woman needed support at diagnosis (96.7%), and no women reported 'I have not needed any emotional support'.

BIGGEST EMOTIONAL SUPPORT NEEDS

Fear of dying

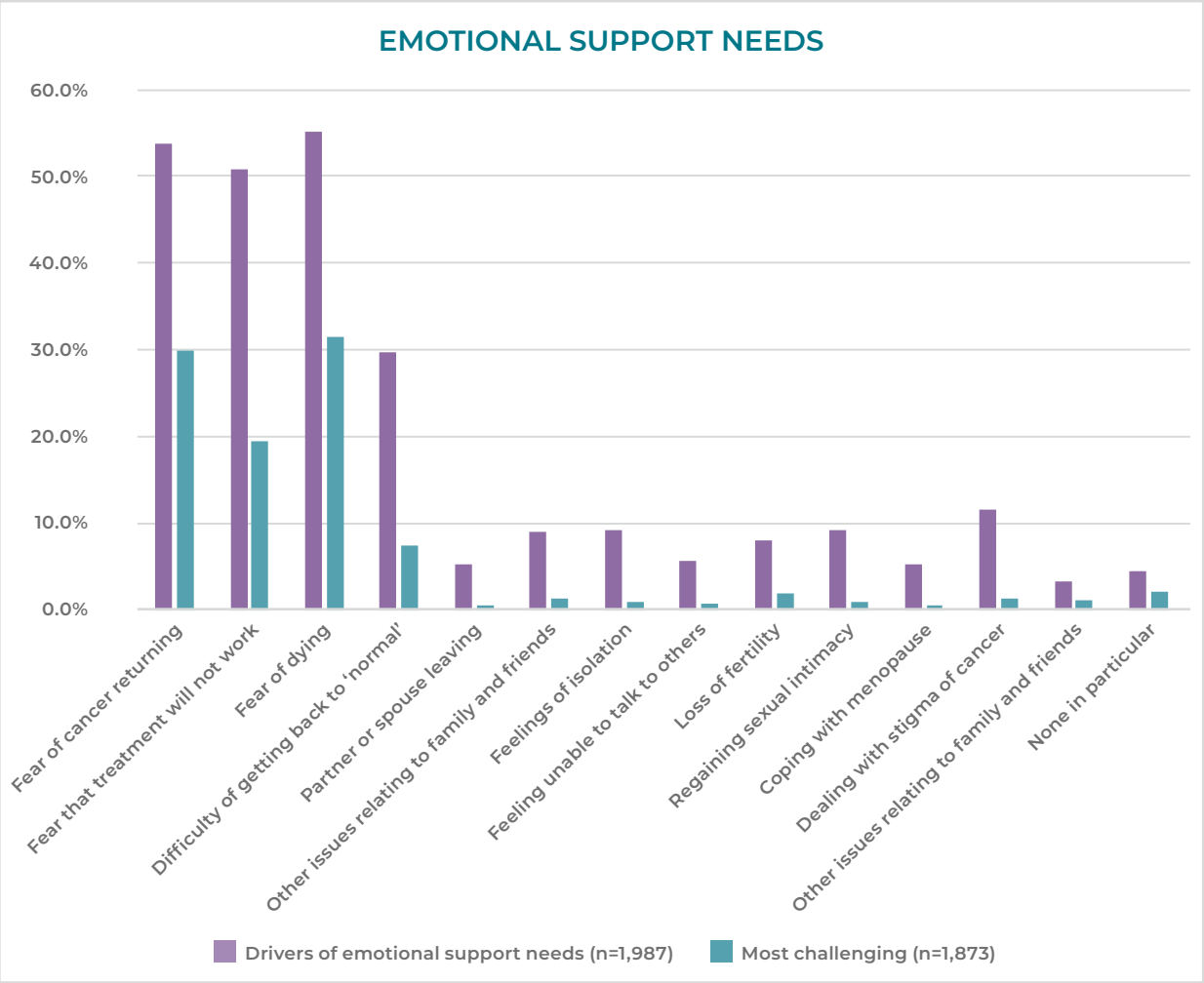
Fear of cancer returning

Fear of treatment not working

1 in 10
women reported difficulty dealing with the stigma of a cancer diagnosis

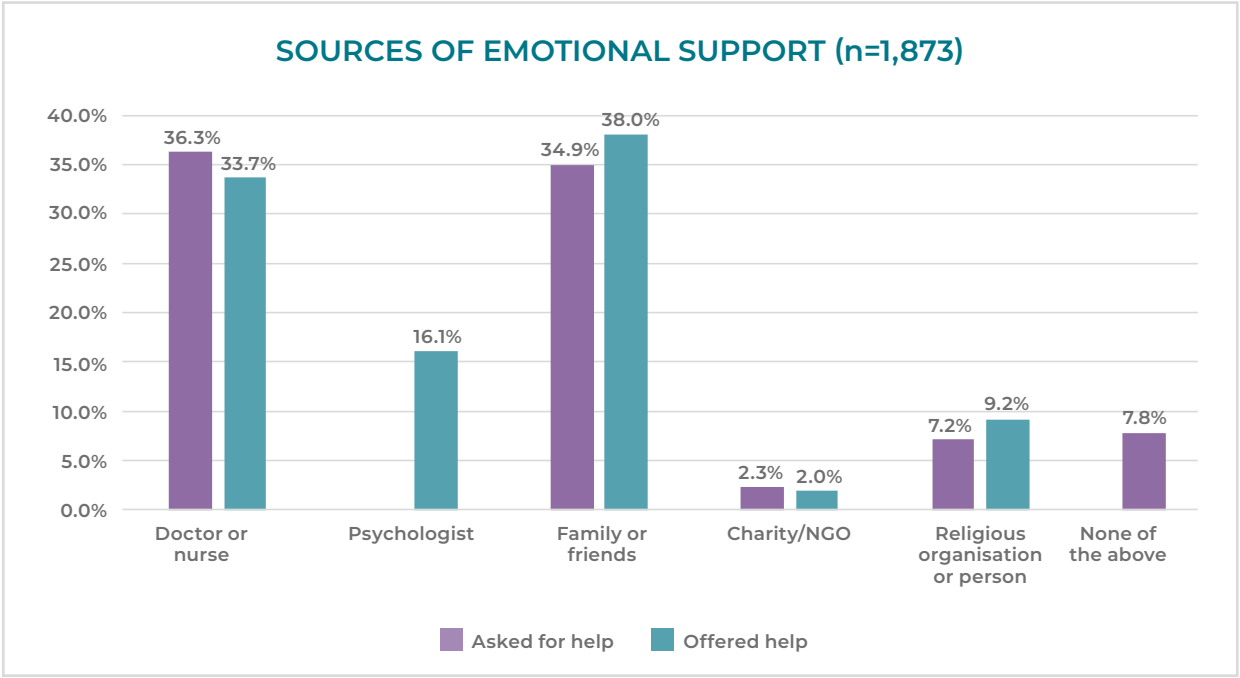
1 in 20
women experienced abandonment by their partner

Fear is by far the largest driver of emotional support need and is the issue women find the most challenging. This can include fear of the cancer returning, treatment not working and/or dying.



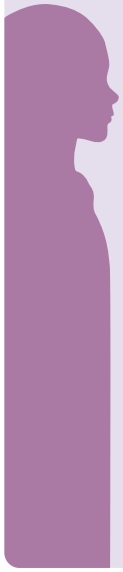
Variations occurred between countries as to the extent each was experienced. Overall, one in ten women reported difficulty dealing with the stigma associated with a cancer diagnosis (11.7%), but this varied mainly by country, with Brazil and Guatemala reporting the highest levels (33.7% and 38.5% respectively) within Latin America, the highest scoring region overall (21.8%) compared to Africa (10.2%) and Asia (1.7%). Overall, one in 20 women experienced abandonment by their partner, but the rate was at least one in 10 women in Peru, Jamaica, Guatemala, Colombia and Morocco.

Family and friends play an important role, alongside medical professionals, in providing emotional support to women as the following results show. The rate of asking for help from medical professionals varied widely by country from 3.3% in Zambia to 82.4% in Uganda.



Approximately one in six women have been offered psychotherapy from a psychologist (16.1%), but this varies widely by country. Almost two-thirds of the women in Argentina have been offered this type of help, with Brazil and Colombia also seeing more than four in ten women in this category, compared to no women in Egypt, and less than one in 20 in Bangladesh, Nepal, Malaysia, Morocco, and Uganda.

The role of the church also varies widely, with women seeking support from religious organisations or people most commonly in Brazil, Guatemala and Jamaica. In Kenya and Zambia women reached out less, but help was offered to almost half of all women in this category.



"Psychotherapy helps me well, but psychotherapy services are expensive. Unfortunately, in our country psychotherapy is not covered by state health insurance. The hospital where I am undergoing treatment provides free psychological services, but one session lasts 30 minutes, this time was not enough for me."

Participant, Kazakhstan

One in ten women do not receive meaningful emotional support. Overall, just over half of those who had emotional support needs had them met (54.7%) and a further third had them met to some extent (35.1%). However, for one in ten women their needs were not met sufficiently or at all (10.2%). The women who had higher family income (above average) and increasing education levels were more likely to say that their emotional support needs had been met.

Cancer support groups (in person or online) do not reach many women. Over half of women in the study had met and talked to one or more women with ovarian cancer (58.3%), most commonly in person (47.5%) rather than as part of a cancer group (9.7%) or online (3.7%) or by phone (3.8%). Overall, the same proportion wanted to meet other women with the disease (58.7%). Women who had already met other women were keener to meet other women (70.1%, n=1400), and just 13.9% said no compared to the total cohort figure of 21.0%. This perhaps implies that the experience is generally more positive than some women fear.

PRACTICAL NEEDS

The biggest practical support women needed was help with daily chores at home (60%), financial support (43.7%), and help with transport including travel to and from hospital (39.5%). In each category, the level of help received was below that needed, and most marked in terms of transport and financial help. Family members gave the most practical support (95.6%), followed by friends (38.4%) and a religious organisation or person (9.1%) (n=2,107).

"The cost of treatment should be subsidised or free. My diagnosis and treatment was substantially delayed due to finances."

Participant, Kenya

"My family could not afford the cost of treatment and decided to go home for traditional medication. I signed against medical advice."

Participant, Nigeria

FINANCIAL IMPACT

Three-quarters of women say their family finances have been affected either greatly or to some extent. For almost a third of women in the study, their family income fell below what they needed to live on. Almost half of the women in the study said their family finances had been affected to a great extent (45.9%), and to some extent by another three in ten (29.5%). Just one in 10 said their financial situation had not been affected.

Three-quarters

of women said their family finances had been affected

Just 1 in 10

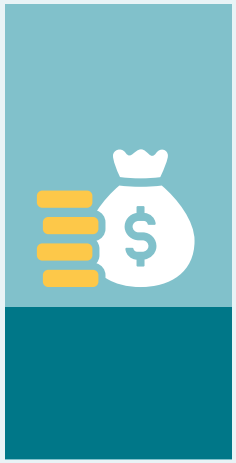
said their family financial situation had NOT been affected

"Satisfied with treatment received in this center and doctors involvement in treatment. But our financial condition is very bad, it would be great if we get free treatment."

Participant, India

"The disease has made me weak and unable to return to my work which was a source of income for my family."

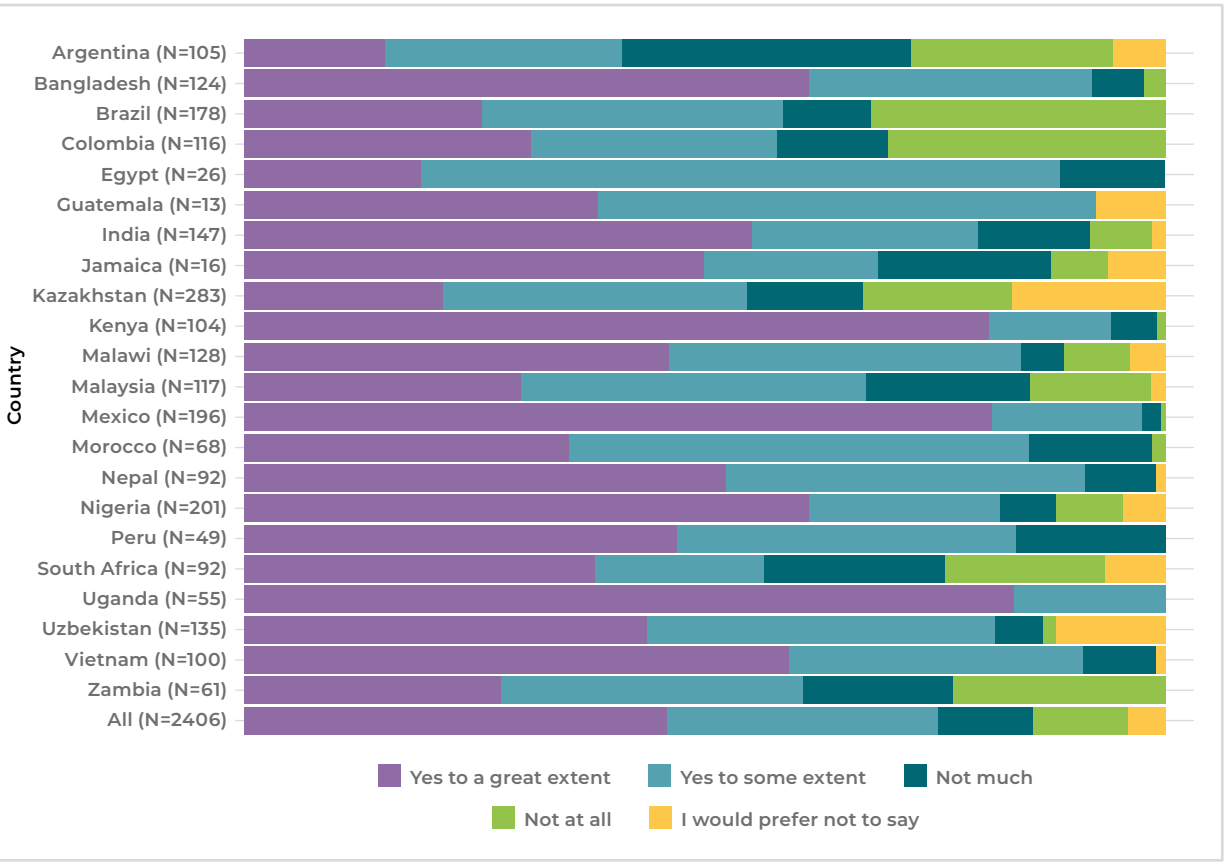
Participant, Uganda



A third

of women said their income had fallen below the level that they needed to live on

The extent to which family finances were affected greatly varied by country.



In terms of regions, over half of African women said their family finances had been affected to a great extent (53.5%), compared to 41.2% in Asia, and 43.5% in Latin America, and women in Latin America were more likely to say their family finances were unaffected (17.4%) when compared to Africa (7.6%) and Asia (7.7%).

For those whose finances were affected to a great or some extent, there were a variety of impacts relating to finance as follows, noting that for a third of respondents, their family income had fallen below the level they need to live on (36.1%). This represented 29.4% of the study cohort.

"In particular, I would ask specialized doctors to have more information at the time of diagnosis and cure, we do not understand their medical terms."

Participant, Peru

Only 4 in 10
got the information they needed when they needed it

MOST IMPORTANT SOURCES OF INFORMATION

97.3%
of women would like their hospital to provide information about living with ovarian cancer

INFORMATION NEEDS

There are large gaps in access to information, and the burden falls mainly on doctors. Women would like the hospitals to provide information about treatment and diagnosis. The role of charities or NGOs is very small in this respect.

Just four in ten women got the information they needed at the time they needed it (41.3%, n=2,023), meaning there is a large gap in terms of accessible information suited to women's needs at any given time.

Women were asked to select their two most important sources of information, and the burden lies heavily with the doctor treating the women (89.5%) followed by their nurse (27.4%). Just over one in six women cited a website as one of their important sources of information (17.7%) and the role of charities, NGOs, government agencies, and support groups was very small.

A third of women have never used the internet to search for information (34.9%). One in ten say they do not have easy access to the internet (9.4%), and a third of women said they found good information in their language on the internet (34.4%). One in six women (16.4%) found information that made them scared.

Almost all women would like their hospital to provide information about living with ovarian cancer (97.3%). Just one fifth (19.5%) said their hospital already supplied the information they needed. Most commonly women want information about treatment and diagnosis, living with ovarian cancer and what to expect, and information on how to manage physical and mental health.

WOMEN'S PRIORITIES

" Yes, the [operating] theatre needs more equipment, [and] Drs and nurses need professional and protected clothes for the theatre. Beds in the wards need more bedding and cleanliness improved. It seems there is shortage of nurses and doctors especially at the chemotherapy room: two nurses for more than 100 patients. This is tough for nurses moving from one room to another with less time to pay attention to patients, and to rest, causing stress. Expand the hospital to accommodate the waiting patients and improve cleanliness / hygiene in the wards."

Participant, Malawi

QUALITY OF LIFE

Quality of life is very much driven by good physical health followed by good mental health, but contributing factors vary by country and region.

Women were asked what factors would mean they had a good quality of life given they were living with ovarian cancer. Overwhelmingly, feeling physically well was most important (82.1%, n=2,409), followed by feeling mentally well (60.8%).

Good mental health was rated more highly in Latin America than in the other two regions. Just over three-quarters of women (77%) said feeling mentally well was an important aspect of quality of life. In Asia the figure was just under seven in ten women (66.9%) and it was lowest in Africa where just over a third of women rated it as an important part of quality of life (37.7%).

GOVERNMENT ACTION

Over 90% of women believe their governments could do more to help women with ovarian cancer live a long and good life (91.2%). This does vary by country. In Nepal, South Africa and Zambia, women are slightly less certain (70–80%).

WOMEN'S PRIORITIES

Women were asked to select up to three priorities for action in terms of improving the diagnosis and care of women with ovarian cancer in their country. Women prioritise the timely detection of the disease as important actions going forward.

Priorities (in order)	LMIC 2024
1	Develop screening programme (62.7%)
2	Free access to diagnostic tests (53.9%)
3	Free access to treatments (34.0%)
4	Raise awareness of symptoms (31.4%)
5	Reduce delays in diagnosis (30.9%)

THANK YOU

Our heartfelt thanks go to all the women who participated in the study, both in the testing phase, and data collection. We will continue to use your data and explore more of the intricacies of diagnosis and treatment of ovarian cancer in LMIC with a view to making progress.

None of this work would have been possible without the hard work of our 82 collaborating hospital teams, who tested translations, recruited women, retrieved clinical data and interviewed women. Anecdotally we know that for some of you, this process has been transformational, and is just the start of your efforts to do more for your patients.

And finally, an enormous thank you to our amazing Oversight Committee, statisticians and Country Leads. Your commitment over the last four years, to develop the study, get ethics approvals and build teams has been an inspiration, and we look forward to supporting you advance the care for women in your country.

Frances Reid
World Ovarian Cancer Coalition Director of Programmes, and The Every Woman Study™ Lead

THE OVERSIGHT COMMITTEE AND COUNTRY LEADS

OVERSIGHT COMMITTEE

Tracey Adams (**South Africa**) and Robin Cohen (**USA**), Co-Chairs, Asima Mukhopadhyay (**India**), Rafe Sadnan Adel (**Bangladesh**), Ngoc Phan (**Vietnam**), Iren Lau (**Malaysia**), Dilyara Kaidarova and Raikhan Bolatbekov (**Kazakhstan**), Eva Maria Stromsholm (**Finland**), Basel Refky (**Egypt**), Sara Nasser (**Germany**), Florencia Noll (**Argentina**), Martin Origa (**Uganda**), Runcie C W Chidebe (**Nigeria**), Isabelle Soerjomataram (**France**) and Garth Funston (**UK**)

We also remember the contributions of the late Dicey Scroggins (IGCS) and Celina May (Malaysia) who both served on the Oversight Committee as patient advocates

STATISTICIANS

Eileen Morgan (France) and Karen Kapur (Switzerland).

COUNTRY LEADS

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REFERENCES

[1] The World Ovarian Cancer Coalition Every Woman Study: identifying challenges and opportunities to improve survival and quality of life

Reid, Frances et al.

International Journal of Gynecological Cancer, Volume 31, Issue 2, 238–244

[2] The every woman study™ low- and middle-income countries edition protocol: A multi-country observational study to assess opportunities and challenges to improving survival and quality of life for women with ovarian cancer

Reid F, Adams T, Adel RS, Andrade CE, Bajwa A, et al.
(2024) The every woman study™ low- and middle-income countries edition protocol: A multi-country observational study to assess opportunities and challenges to improving survival and quality of life for women with ovarian cancer. PLOS ONE 19(5): e0298154.https://doi.org/10.1371/journal.pone.0298154

[3] Challenges and Opportunities in Ovarian Cancer Care: A Qualitative Study of Clinician Perspectives from 24 Low- and Middle-Income Countries.

Anmol Bajwa, Runcie C.W. Chidebe, et al.

Journal of Cancer Policy, 2025, 100582,

https://doi.org/10.1016/j.jcpo.2025.100582.

[4] https://gco.iarc.fr/en Accessed 10th April 2025

[5] https://www.uicc.org/atom/atom-coalition-home Accessed June 2025

[6] Socioeconomic Burden of Ovarian Cancer in 11 Countries

Brian Hutchinson et al.

JCO Glob Oncol 11, e2400313(2025).
DOI:10.1200/GO-24-00313

[7] Ovarian cancer statistics, 2018

Torre LA, Trabert B, DeSantis CE, Miller KD, Samimi G, Runowicz CD, et al.

CA Cancer J Clin. 2018 Jul; 68(4): 284–296. Epub 2018 May 29.
pmid:29809280; PMCID: PMC6621554.

[8] Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries

Allemani C, Matsouda T et al.

Lancet. 2018 Mar 17;391(10125):1023–1075. doi: 10.1016/S0140-6736(17)33326-3. Epub 2018 Jan 31. PMID: 29395269; PMCID: PMC5879496.

[9] Ovarian cancer population screening and mortality after long-term follow-up in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS): a randomised controlled trial

Usha Menon et al

The Lancet, Volume 397, Issue 10290, 2021,Pages 2182–2193

[10] The Aarhus statement on cancer diagnostic research: turning recommendations into new survey instruments.

Coxon, D., Campbell, C., Walter, F.M. et al.

BMC Health Serv Res 18, 677 (2018). https://doi.org/10.1186/s12913-018-3476-0

[11] Assessment of Adult Women With Ovarian Masses and Treatment of Epithelial Ovarian Cancer: ASCO Resource-Stratified Guideline.

Verna D. Vanderpuye et al.

JCO Glob Oncol 7, 1032-1066(2021).

DOI:10.1200/GO.21.00085

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A JOINT INITIATIVE FOR WOMEN

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