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Defining opportunities to improve survival and quality of life for women with ovarian cancer in 24 low- and middle-income countries: The Every Woman Study™

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Projected increases in cases and deaths from ovarian cancer are due to hit developing countries hardest by 2040, yet many of them lack sufficient data to advocate and drive effective change to deal with this challenging disease. This novel collaboration brings together advocates and clinical teams from 24 low- and middle-income countries, with the World Ovarian Cancer Coalition and the International Gynecologic Cancer Society to show the experience of women being treated at hospitals in these locations, as a way of identifying local, national and global priorities for action.

Ovarian cancer

By the year 2040, the Global Cancer Observatory (GLOBOCAN) predicts that there will be 428,966 cases of ovarian cancer each year, and 305,858 annual deaths, representing increases of 36.6% and 47.6%, respectively, over 2020 (Figure 2) (1).

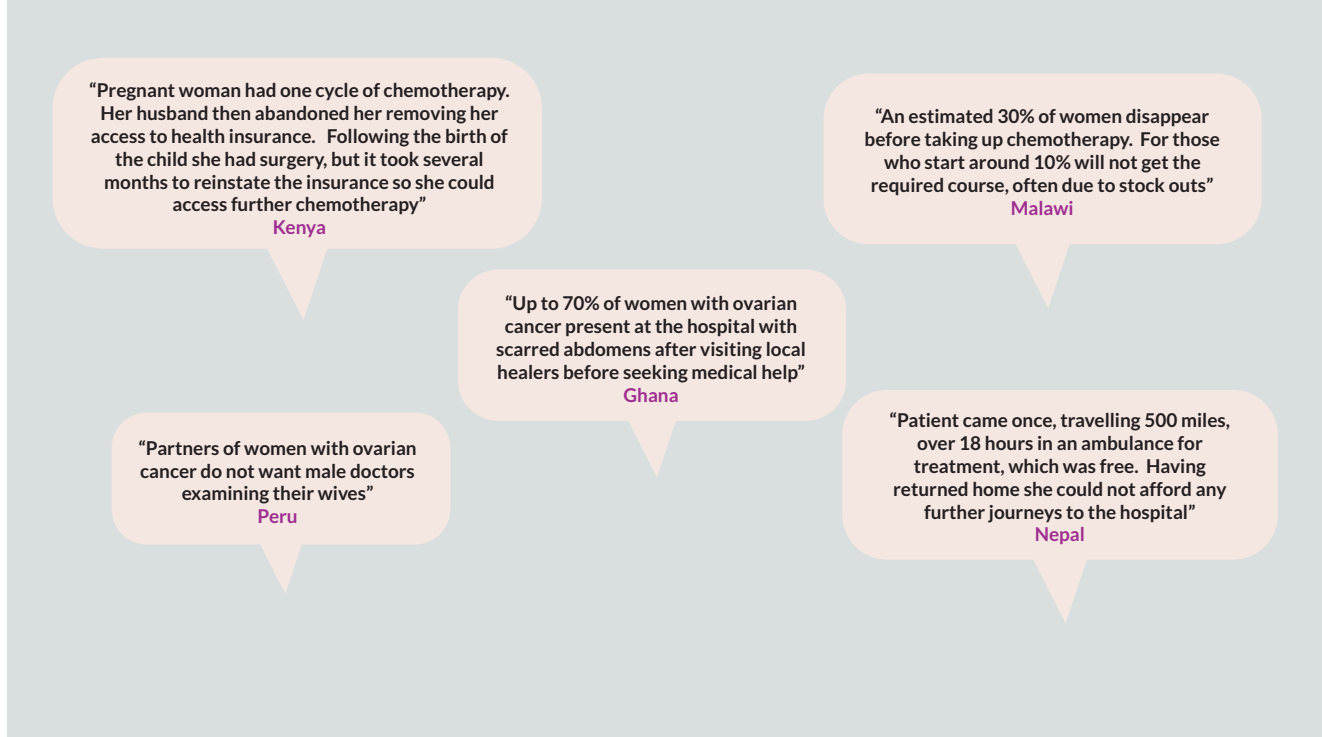
Currently more than 823,000 women live within five years of their diagnosis. Additionally, GLOBOCAN states the greatest increases will be in low, lower- and upper-middle income countries (LMICs), where 70% of women with the disease currently live (2). Across the African continent alone, cases are expected to almost double (Figure 3).

Even in high-income countries, ovarian cancer is difficult to diagnose and treat. Ninety-percent of women experience

symptoms, regardless of stage or type of disease (3). The American Cancer Society cites 2020 five-year survival figures for epithelial ovarian cancer at 49%, with 59% diagnosed at the most advanced stages (4). The Concord-3 study showed high-income country five-year survival rates of between 30% and 49% (5).

Family history, in addition to age, is the most significant risk factors for ovarian cancer, with between 13% (6) and 18% (7) of women found to have BRCA 1 or BRCA 2 genetic mutations, varying by country. Lynch Syndrome also confers a family risk. Genetic testing identifies optimal treatments and family members who may be at risk, but discussing family history can often be taboo, and access to genetic testing is either non-existent or minimal and very costly in LMICs.

Figure 1: Country vignettes provided by Every Woman Study Country Leads



It is widely acknowledged that there is a lack of robust data in many LMICs to drive effective cancer control plans (8,9) and up until recently the focus of health policy has been on communicable diseases. The Cervical Cancer Elimination Strategy and HPV vaccines have introduced opportunities for the improvement of cancer detection and care in women. For many LMICs, whilst the challenges from this huge killer are far from over, they should reduce significantly over time. This provides the opportunity to minimize the devastating impact ovarian cancer has on individuals and societies, and it is vital that ovarian cancer is not neglected in national cancer plans.

The Every Woman Study™ (2018)

The World Ovarian Cancer Coalition’s vision is a world where every woman with ovarian cancer has the best chance of survival, and the best quality of life, wherever she may live. This is to be achieved by empowering the global ovarian cancer community, through knowledge, collaboration and action. In 2018, the Coalition developed the first Every Woman Study™, an online survey shared by social media and advocacy

Figure 2: GLOBOCAN, Cancer Tomorrow, predicted increases in annual incidence and deaths. Accessed 26 July 2021

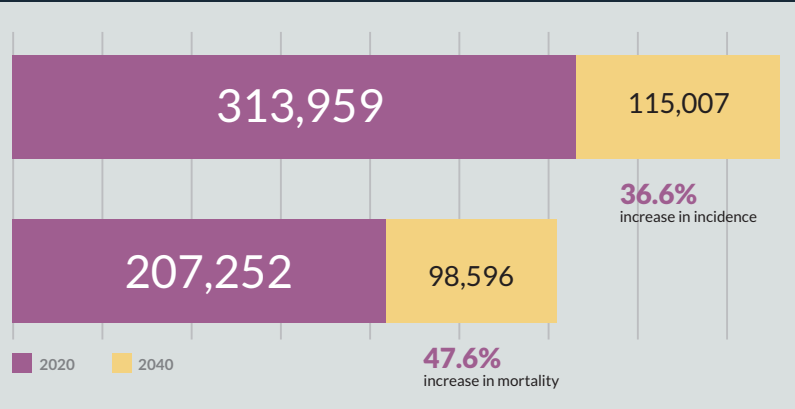


Figure 3: Burden of increase; GLOBOCAN Cancer Tomorrow. Accessed 26 July 2021

	Incidence 2020	Incidence 2040	% Increase
Asia	170,759	235,360	38.8%
Europe	66,693	72,916	9.4%
North America	26,630	33,510	25.9%
Latin America and Caribbean	24,263	34,974	49%
Africa	25,513	45,302	86.9%
Oceania	2,101	3,006	44.6%
World	313,959	428,966	36.6%



groups, to find the challenges and opportunities to improve survival and quality of life for women with ovarian cancer (Figure 4).

The results published in 2020 (10) defined a set of common obstacles and problems, but also revealed that each country varied in the extent to which particular challenges were an issue. No one country was without significant challenges, from women’s knowledge of ovarian cancer, patient, doctor and system delays in diagnosis, access to surgery, trials, treatment and genetic testing, and levels of information and support. This revealed important opportunities for progress.

However, one key limitation of the study was that 95% of respondents to the 2018 study lived in high-income countries, reflective of the approach taken to recruitment (Figure 5). Globally, just 30% of women with ovarian cancer live in these settings (11).

The Every Woman Study™: LMIC Edition

The lack of data from women in LMICs about their ovarian cancer experience was a key driver for the new study. However, it was clear that the online approach would not deliver sufficient numbers to provide robust information at a global or national level. To address this, the Coalition decided to partner with the International Gynecologic Cancer Society (IGCS) because of their established networks in many LMICs, and their strong public commitment to health equity.

An Oversight Committee was formed with equal representation from clinicians and patient advocates from the six major geographic regions. In addition to adapting the original survey and extending the reach of the Study, they gave, and continue to provide, invaluable insight on the care of women with ovarian cancer in their region.

Women, attending appointments at participating hospitals within five years of their diagnosis, will be invited to participate in a 30-minute survey. Questions cover the time from pre-diagnosis through to post-treatment and include knowledge of ovarian cancer prior to diagnosis, experience of symptoms, the diagnosis, treatment decisions, the long-lasting physical, emotional, and financial effects of the disease, and the impact of COVID-19 on care. Depending on their location, language, literacy skills and digital connectivity they can self-complete the survey by email, WhatsApp or on paper, or have someone interview them and record their answers. Where possible

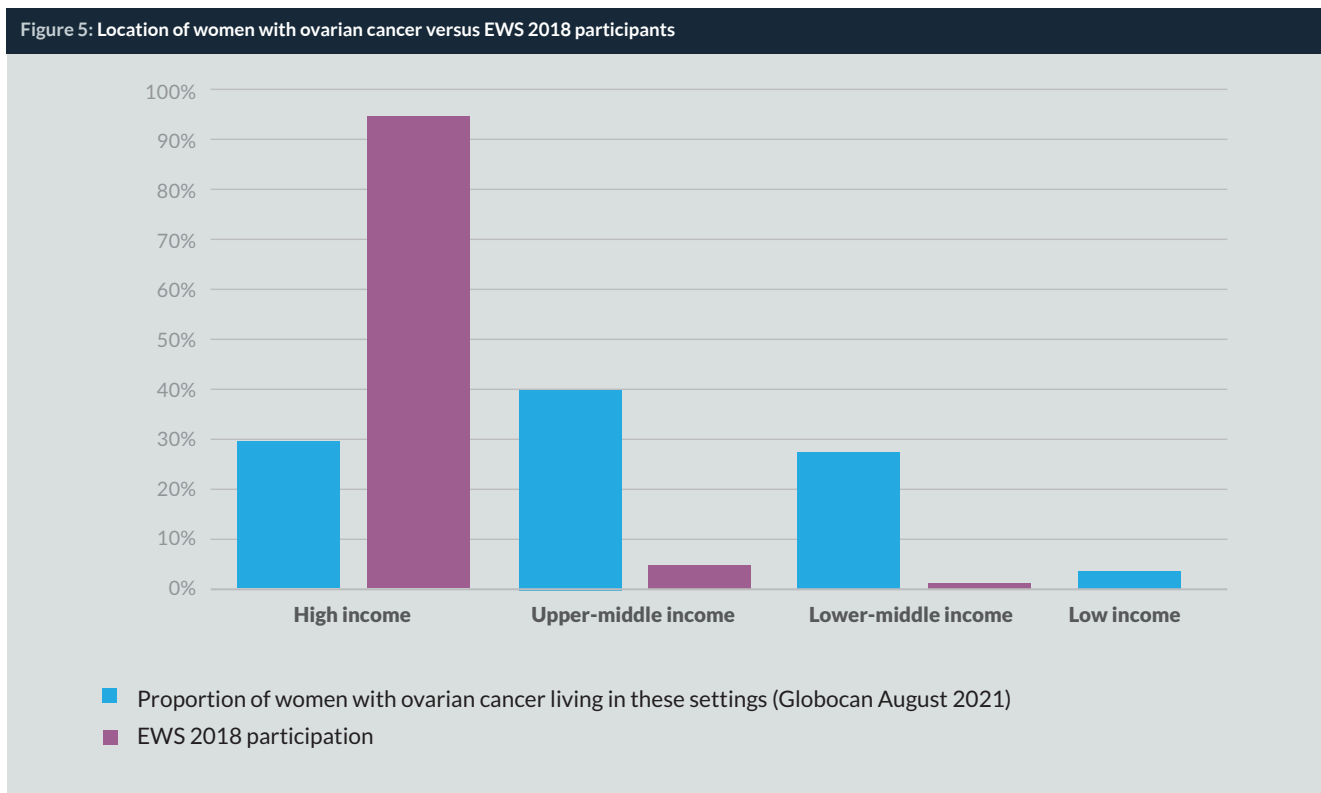
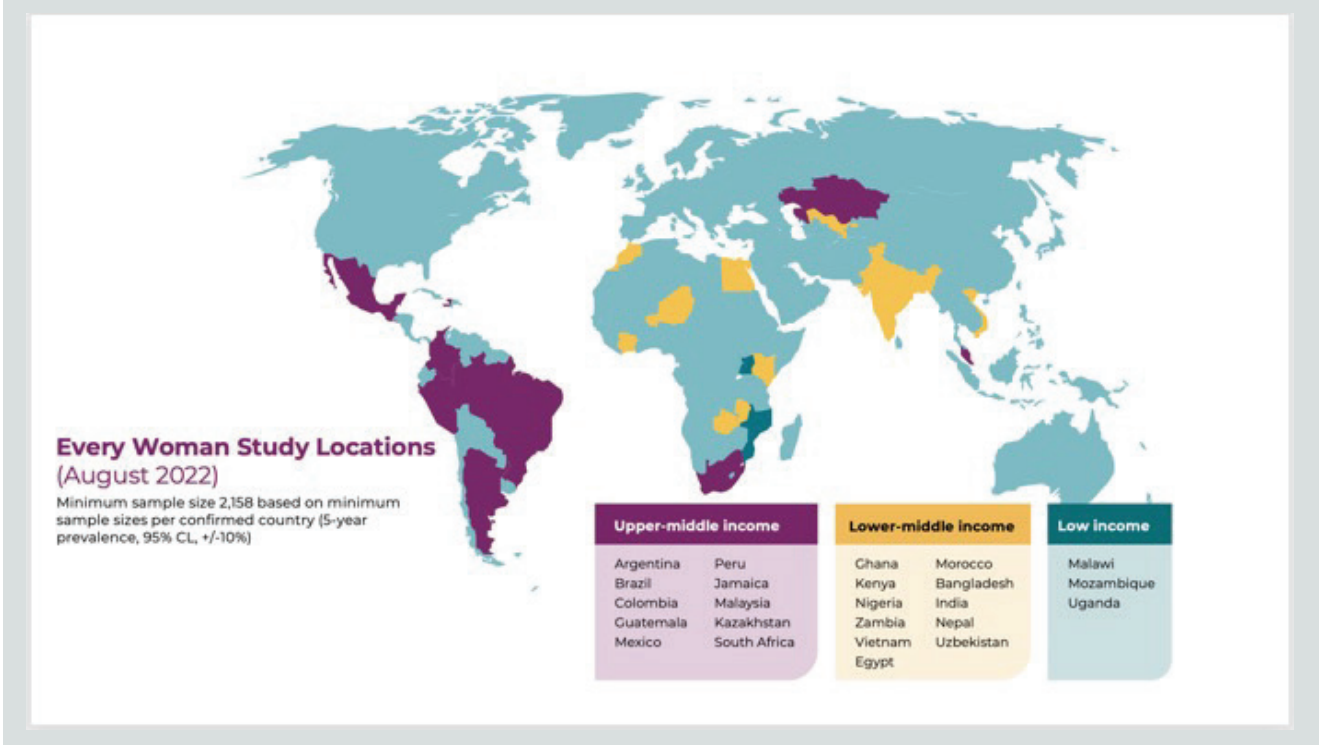


Figure 6: Every Woman Study: LMIC locations, August 2022



they are provided with details of local nongovernmental organizations that can provide a variety of support.

From an initial target list of 31 low, lower-middle and upper-middle income countries, there are now 24 countries either already collecting data or waiting for ethics approval (Figure 6), with translations in 27 languages (Figure 7).

Country specific contexts

As part of the Study, participating Country Lead Clinicians are interviewed about their experiences of caring for women with ovarian cancer in their country.

Dr Afrin Fatima Shaffi, Gynaecologic Oncology Fellow at Moi Teaching and Referral Hospital in Kenya:

“There are some very significant challenges. One of the biggest is the very late presentation of women at the specialist centres, and the fact that many women never make it that far. They often do not realise they are sick, and may try many herbal remedies first. Often, they will need permission from their husband or elders to pursue medical treatment options, and many face stigma that their illness is related to witchcraft, and are suspicious of medical treatments. Cost can be a huge barrier, even US\$ 5 for health insurance can be 20–25% of monthly income, and many need to travel, often hundreds of kilometres, to the nearest cancer hospital. Consequently, treatment is often interrupted or abandoned.

On a systems level we need more hospitals to care for cancer

Figure 7: Word cloud of 27 available translations



patients, nearer where they live to improve the uptake of treatment, and a bigger workforce. Often there may be just three doctors seeing 60 patients in a day at the cancer clinic. We have limited options to treat relapse, and there is no access to trials.

As clinicians we need to build rapport with our communities, so people trust in the care we can give. We need to empower and educate women to seek help in a timely fashion, and we need policy-makers, stakeholders, and government to get on board with us to tackle these challenges, as we are seeing increasing numbers of ovarian cancer cases.”

Dr Shaffi's reflections are shared by many of her counterparts, but as with the original Study a picture is emerging of variations between countries on the most pressing issues. So far, other key themes include:

- ➔ lack of cancer registry data makes planning for care difficult;
- ➔ even where costs of treatments are reimbursed, there can be a lack of accessible and affordable diagnostics meaning women never reach the point of diagnosis and care;
- ➔ drug supplies can be patchy with regular stockouts, challenging adherence to treatment regimes.

For some clinicians there is a considerable personal toll caring for women when they know most of them will die from their disease, especially in settings where there is a mistrust of or a disbelief in modern medicine, and where women are unable to access medical care and treatments freely, or where there is civil unrest. This has included but not been limited to:

- ➔ contributing personally to help fund care (e.g., funding blood supplies);
- ➔ advocating on behalf of women with local faith leaders, and family members so treatment can start or continue;
- ➔ knowing that many women "disappear" during treatment, unable or unwilling to bear the direct or indirect costs of care;
- ➔ lack of pathology services and genetic testing;
- ➔ having to go into hiding because of the risk of kidnapping and local unrest or just deciding to emigrate because they feel they cannot tolerate the situation any longer.

Unsurprisingly, COVID-19 had a devastating impact on clinicians' ability to care for women, especially in the early pandemic phase when local or national lockdowns meant women could not travel for treatment. As a result, many women just "disappeared" and have not been seen since.

In Nigeria, the Country Lead reported that diagnosed cases in 2020 fell to below 30% of the previous year. Hospitals and clinicians were repurposed to the pandemic effort, and to this day there is a legacy of COVID-related delays, and significantly greater numbers of late-stage diagnosis. However, the pandemic delivered benefits for some, including better resourced intensive care units and more streamlined approaches to care.

The Every Woman Study™ in action

Data collection is underway in several countries but the complexity of managing 125 participating sites in 24 countries, means that start dates are staggered. Data collection will end in June 2023.

Malaysia was the first country to start collecting data for the Study, offering the survey in English, Bahasa Malay and

Figure 8: Ms Lee Sze Yue (left) and Dr Rubandra Kalimuthu (centre) obtaining consent from Ms Tay Siew Kiok (right), the first patient to join The Every Woman Study™ 2022 at the University of Malaya Medical Centre daycare facility



Chinese. To date, their lead centre at the University of Malaya Medical Centre, Kuala Lumpur, has already collected data on 50 women (Figure 8).

Professor Yin Ling Woo, University of Malaya Medical Centre, Kuala Lumpur, Malaysia

"This collaboration has created opportunities for us in Malaysia. While we have spearheaded many 'firsts' in terms of research here in South East Asia, there has not been any real advocacy specifically for women with ovarian cancer. When we were approached, we were very excited. More importantly, the Study led to a collaboration with the World Ovarian Cancer Coalition, leading us to consider a dedicated ovarian cancer patient support group in Malaysia allowing us to work hand-in-hand with ovarian cancer warriors. The Coalition has provided us with guidance, and as a result, the Malaysian Ovarian Cancer group was established. Although MyOvaCa group is in its infancy, it is already serving women as a platform for peer support, education and in time, to advocate for their own needs. We are grateful for the education and social media materials from the Coalition which has helped us to accelerate our own webinar series and social media content creation.

"Through the interviews with women, we have come to realise how little women knew that their symptoms could be linked to cancer, how important families and religion can be in supporting women during this time, and how isolating it is for those without these forms of comfort. Many came to our hospital because of its affordability, but even so they need information about sources of assistance."



The formation of Ovarian Cancer Malaysia is an important early outcome for both the Study and the local team. In Malawi, the lead advocacy group, the Women's Coalition

Against Cancer (WOCACA) engaged with national policy-makers straight away, and the Ministry of Health have since supported implementation. A number of country teams have expressed an appetite to continue data collection even beyond the official cut-off date. For some, this is their first collaborative venture within their country, and some teams are already discussing how they could adapt the Study to cover other gynaecologic cancers.

Challenges of managing equity

Developing, co-ordinating and managing a study across a wide range of countries, and variety of hospitals is a complex task. Key challenges include:

- ➔ ensuring the participating centres reflect the variety of care within a country;
- ➔ accommodating the huge variability in language, literacy levels, and internet connectivity, ensuring women with least resource can participate;
- ➔ providing sufficient resource for core expenses (translation, ethics submission) and in those places with least resource, other essential items like data entry support;
- ➔ balancing countries' different needs within the study approach.

A unified approach among and even within some LMICs is not feasible. The Oversight Committee has provided invaluable guidance on tackling issues. A flexible, direct and pragmatic approach with local teams has proven essential when tackling inequity on this scale. This has added complexity to the Study and data analysis, but it is rewarding to see some early benefits as we enable voices from more women and clinicians from LMICs to be heard (Figure 9).

Results and beyond

Analysis will begin once data collection ends in June 2023 and key findings including variations between countries examined. Data at a national level will be jointly owned by the Coalition, IGCS, and the Country Lead, with country specific reports produced for each setting, highlighting variances from the global data set and helping identify national priorities. Participating country teams will be supported to submit for publication, and all participating clinicians will be listed as authors on all the papers.

The project team, Oversight Committee, and already many Country Lead Clinicians believe the Study is just the start of an important and ongoing journey. Potential sources of funding

Figure 9: Early outcomes from the Every Woman Study™: LMIC Edition



Dr Aisha Mustapha, Ahmadu Bello University Teaching Hospital, Kaduna State, Nigeria

"It has opened my mind to the possibilities of improving care for women with ovarian cancer in Nigeria. I believe that the Study will improve our understanding of key local issues and enhance our advocacy efforts. Taking part is also a gateway to initiating even more research in the future."

for a grants programme, based on national priorities, are currently being sought. ■

Frances Reid, MBA, is programme director for the World Ovarian Cancer Coalition. She has worked with women who have had ovarian cancer since 2003, advocating for improvements in survival and quality of life. Joining the coalition in 2017, she led the development of the Every Woman Study™ and is principal investigator for the LMIC edition.

Previously working in UK charities, she developed the Target Ovarian Cancer Pathfinder Study (2009, 2012, 2016) which led to the formation of the All-Party Parliamentary Group on Ovarian Cancer, the development of new national guidelines, and award-winning professional development tools for general practitioners.

Dr Tracey Adams is a clinician, specialist in Obstetrics and Gynaecology and a subspecialist in Gynaecological Oncology in the Department of Obstetrics and Gynaecology, Groote Schuur Hospital, Cape Town, South Africa. Her research interests include peri-operative care, HPV-associated multizonal disease in women and ovarian cancer. Her passion lies in advocacy and serving the women of South Africa in a resourceful yet respectful manner. She is affiliated to the SAMRC UCT Gynaecological Cancer Research centre (GCRC), as well as UCT Global Surgery. Tracey is Co-Chair

of the Every Woman Study™: LMIC Edition Oversight Committee, and Country Lead for South Africa.

Anmol Bajwa is undertaking a Masters in Health Policy and Management at Columbia University's Mailman School of Public Health focusing on health policy analysis. Her passion for public health and health equity began while developing health promotion programmes for menstrual hygiene and women's health in India. Her research interests include the role of analysis in the formation of health policy, cross-national comparisons of health systems, and how policies affect barriers and access to health care. She is working with the World Ovarian Cancer Coalition to undertake and analyse interviews with Country Lead Clinicians for the Every Woman Study™: LMIC Edition.

Phaedra Charlton is the Director of Communications and Marketing for the World Ovarian Cancer Coalition. She has had a varied career since receiving her BA in Communication Studies from Concordia University, Montreal, in 1997. Initially working for several years in the major motion picture industry in accounting, Phaedra looked for more fulfilling roles and transitioned into public administration and later entrepreneurship, always with a focus on communications, marketing and design. In addition to her work with the World Ovarian Cancer Coalition, Phaedra assists other charitable and publicly-minded organizations on an ad hoc basis with their messaging and marketing.

Robin Cohen is the CEO and Co-Founder of the Sandy Rollman Ovarian Cancer Foundation. She is a member of the Oncology Nursing Society, the Society of Gynecologic Nurse Oncologists and the Cambridge Who's Who. She has been recognized as one of the 75 Greatest Living Philadelphians, the 2016 recipient of the Cindy Melancon Leadership Award, and 2020 recipient of Cure Magazine's Ovarian Cancer Hero Award. She is Vice President of the Board of the Ovarian Cancer Research Alliance, Vice Chair of the Board of the World Ovarian Cancer Coalition and Co-Chair of the Every Woman Study™: LMIC Edition Oversight Committee.

Mary Eiken has been a senior association executive for over 24 years with experience in the field of association management, 19 years spent in gynecologic oncology. Mary became the first CEO of the International Gynecologic Cancer Society (IGCS). Her expertise in governance, policy, strategic planning, and volunteer engagement has brought incredible opportunities and positive change to the IGCS.

Through a variety of strategic partnerships, new programmes, engaging leaders globally, and diversifying revenue streams, IGCS has enhanced its global footprint significantly with a membership of over 3,300 and engaging with over 13,000 professionals internationally.

Clara MacKay, MPA, is CEO of the World Ovarian Cancer Coalition, and has nearly 20 years of experience in cancer advocacy, covering ovarian, pancreatic, bowel, prostate and breast cancer. She was a founding member of the World Pancreatic Cancer Coalition and Chair of Cancer 52 – a network representing the interests of rare and less common cancers. In 2015, she was appointed to an Independent Cancer Taskforce established by NHS England, UK, to develop a five-year strategy for cancer services. Now based in Nova Scotia, Canada, Clara is also Chair of Craig's Cause Pancreatic Cancer Society.

Dr Aisha Mustapha is a Consultant in Gynaecologic Oncology at Ahmadu Bello University Teaching Hospital, Zaria, Kaduna State Nigeria, and a Senior Lecturer at the affiliate University. She is involved in the clinical care of gynaecologic cancer patients in addition to teaching, research and advocacy. Her passion is to improve indices in the entire gynaecologic cancer care continuum in her home country through prevention, prompt diagnosis and evidence-based treatment.

She is the Nigeria Lead for The Every Woman Study™: LMIC Edition bringing together 12 hospitals to provide the much needed opportunity to improve care to these women.

Dr Afrin Shaffi is currently in the final year of gynaecologic oncology sub-specialty training at Moi University/Moi Teaching & Referral Hospital in Kenya and a Fellow of the International Gynecologic Oncology Society.

She maintains a special interest in improvement of gynaecologic cancer care through research and in addressing disparities in health care, making cancer care accessible to all. She is currently working on several research projects on cervical and endometrial cancer. Dr Shaffi has spearheaded various cervical cancer screening programmes in underserved communities in rural parts of Kenya.

Professor Woo Yin Ling is a Professor of Obstetrics and Gynaecology at University of Malaya and a Consultant Gynaecological Oncologist in University Malaya Medical Centre. She completed her specialist and subspecialty training in gynaecological oncology and postdoctoral research degree in the UK and was conferred her PhD by Cambridge University. As a clinician scientist, she describes her work as "Malaysian centric". Dr Woo has contributed to many OCAC (Ovarian Cancer Association Consortium)-led studies and is the main clinical lead for the MaGIC study (Mainstreaming genetic counselling for genetic testing of BRCA1/2 in ovarian cancer patients in Malaysia).

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