WHAT IS THE EVERY WOMAN STUDY™ - LMIC EDITION?

The Every Woman Study™ is:

• A joint initiative of the World Ovarian Cancer Coalition and the International Gynecologic Cancer Society, to identify the challenges and opportunities to improve survival and quality of life for women with ovarian cancer in low- and middle-income countries.

• A unique study involving up to 300 hospitals in 31 low-, lower-middle, and upper-middle income countries around the world exploring women's experiences of ovarian cancer from pre-treatment to post-diagnosis, revealing their needs and priorities. An oversight committee drawn from the regions is an equal mix of patient advocates and clinicians.

• An adapted version of the EVERY WOMAN STUDY (2018).
The Project Team

Frances Reid  
Programme Director, Coalition

Mary Eiken  
CEO, IGCS

Clara Mackay  
CEO, Coalition

Luna Benvenisti-Zarom  
Study Assistant, Coalition

Anmol Bajwa  
Study Assistant, Coalition

Study Lead
Co-Chairs of the Oversight Committee

Robin Cohen
CEO, Sandy Rollman Ovarian Cancer Foundation and Gynecologic Nurse Oncologist in Philadelphia, USA

Tracey Adams
Gynaecological Oncologist, Groote Schur Hospital, Cape Town, South Africa

Both served on the Expert Panel for the 2018 Study
## Oversight Committee

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracey Adams</td>
<td>Co-Chair (Clinical)</td>
</tr>
<tr>
<td>Robin Cohen</td>
<td>Co-Chair (Advocacy)</td>
</tr>
<tr>
<td>Isabelle Soerjomatram</td>
<td>Global Data Expert IARC</td>
</tr>
<tr>
<td>Asima Mukhopadhyay</td>
<td>South Asia (Clinical)</td>
</tr>
<tr>
<td>Rafe Sadnan Adel</td>
<td>South Asia (Advocate)</td>
</tr>
<tr>
<td>Ngoc Phan</td>
<td>East Asia (Clinical)</td>
</tr>
<tr>
<td>Iren Lau</td>
<td>East Asia (Advocate)</td>
</tr>
<tr>
<td>Dilyara Kaidarova</td>
<td>Central Asia and Europe (Clinical) - joint</td>
</tr>
<tr>
<td>Raikhan Bolatbekov</td>
<td>Central Asia and Europe (Clinical) - joint</td>
</tr>
<tr>
<td>Eva Maria Stromsholm</td>
<td>Central Asia and Europe (Advocate)</td>
</tr>
<tr>
<td>Basel Refky</td>
<td>Middle East and North Africa (Clinical) - joint</td>
</tr>
<tr>
<td>Sara Nasser</td>
<td>Middle East and North Africa (Clinical) - joint</td>
</tr>
<tr>
<td>Florencia Noll</td>
<td>Latin America (Clinical)</td>
</tr>
<tr>
<td>Annie Vaillant</td>
<td>Latin America (Advocate)</td>
</tr>
<tr>
<td>Martin Origa</td>
<td>Africa (Clinical)</td>
</tr>
<tr>
<td>Runcie CW Chidebe</td>
<td>Africa (Advocate)</td>
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<tr>
<td>Garth Funston</td>
<td>Primary Care Specialist</td>
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</table>
The EVERY WOMAN STUDY™ 2018

1531 WOMEN
44 COUNTRIES
15 LANGUAGES

WORLDWIDE LAUNCH
OCT 18, 2018
MUNICH, GERMANY

CANADA
USA
UK
FINLAND
JAPAN
GERMANY
HUNGARY
BRAZIL
FRANCE
SWITZERLAND
LIBANON
CHINA
PORTUGAL
SPAIN
CROATIA
ISRAEL
INDIA
MOROCCO
ITALY
ROMANIA
GHANA
NIGERIA
GREECE
SOUTH AFRICA
NEW ZEALAND
AUSTRALIA
PHILIPPINES

INTERNATIONAL JOURNAL OF GYNECOLOGICAL CANCER

THE EVERY WOMAN STUDY™
LOW- AND MIDDLE-INCOME EDITION

A JOINT INITIATIVE FOR WOMEN
OBJECTIVES OF THE LMIC EDITION

• National and regional data on a range of key patient experience issues that will provide direction on practice and can be used to advocate for national and system change

• Opportunities for all to publish key findings at **national and international levels** to add to the literature and knowledge base of ovarian cancer

• Comparability between other low- and middle-income countries at national and regional levels, and by country income status

• Opportunities for clinicians, and women who have ovarian cancer, to work together to inform and promote advocacy efforts and foster new, or develop existing relationships with local non-governmental organisations

• More widely, the Study protocol and survey will be made available to others who wish to use a standardised approach to benchmark local patient experience and contribute to the evidence base relating to the experiences of women with ovarian cancer.
WHERE DO WOMEN WITH OVARIAN CANCER CURRENTLY LIVE, VS PARTICIPATION IN EWS 2018?

- High-income
- Upper-middle income
- Lower-middle income
- Low-income

Proportion of women with ovarian cancer living in these settings (Globocan August 2021)

EWS 2018 participation

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GLOBOCAN PROJECTIONS OVARIAN CANCER WORLDWIDE TO 2040 Globocan Cancer Today and Cancer Tomorrow (26th July 2021)

- 47.6% increase in mortality
- 36.6% increase in incidence
# Greatest Burden of Increase
Globocan Cancer Today and Cancer Tomorrow (26th July 2021)

<table>
<thead>
<tr>
<th>Region</th>
<th>Incidence 2020</th>
<th>Incidence 2040</th>
<th>% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asia</td>
<td>170,759</td>
<td>235,360</td>
<td>38.8%</td>
</tr>
<tr>
<td>Europe</td>
<td>66,693</td>
<td>72,916</td>
<td>9.4%</td>
</tr>
<tr>
<td>North America</td>
<td>26,630</td>
<td>33,510</td>
<td>25.9%</td>
</tr>
<tr>
<td>Latin America and Caribbean</td>
<td>24,263</td>
<td>34,974</td>
<td>49%</td>
</tr>
<tr>
<td>Africa</td>
<td>25,513</td>
<td>45,302</td>
<td>86.9%</td>
</tr>
<tr>
<td>Oceania</td>
<td>2,101</td>
<td>3,006</td>
<td>44.6%</td>
</tr>
<tr>
<td>World</td>
<td>313,959</td>
<td>428,966</td>
<td>36.6%</td>
</tr>
</tbody>
</table>
### KEY DIFFERENCES 2018 - 2022

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2022 LMIC</th>
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<tbody>
<tr>
<td>Women recruited</td>
<td>Via social media, patient groups</td>
<td>At clinics/hospitals (up to 10 per country)</td>
</tr>
<tr>
<td>Number of participants</td>
<td>1531 from 44 mainly high-income countries</td>
<td>Approx 2,570 women from up to 30 countries (LMIC)</td>
</tr>
<tr>
<td></td>
<td>Just 72/1531 (0.05%) responses came from the proposed countries for 2022</td>
<td></td>
</tr>
<tr>
<td>Method of completion</td>
<td>Online, self completed (largely)</td>
<td>Online or on paper, at clinic/hospital Self completion or administered according to woman’s needs/wishes</td>
</tr>
<tr>
<td>Time in field</td>
<td>8 weeks</td>
<td>Up to a year</td>
</tr>
<tr>
<td>Length of survey</td>
<td>148 questions, one hour to complete</td>
<td>56 questions, 20 minutes. Additional input from clinical staff</td>
</tr>
<tr>
<td>Areas completed</td>
<td>Broadly similar, less detail.</td>
<td></td>
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<tr>
<td>UPPER-MIDDLE INCOME</td>
<td>LOWER-MIDDLE INCOME</td>
<td>LOW-INCOME</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Argentina</td>
<td>Ghana</td>
<td>Malawi</td>
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<tr>
<td>Brazil</td>
<td>Kenya</td>
<td>Mozambique</td>
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<tr>
<td>Colombia</td>
<td>Nigeria</td>
<td>Uganda</td>
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<td>Guatemala</td>
<td>Zambia</td>
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<tr>
<td>Mexico</td>
<td>Philippines</td>
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<td>Peru</td>
<td>Vietnam</td>
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<td>Jamaica</td>
<td>Egypt</td>
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<tr>
<td>Malaysia</td>
<td>Morocco</td>
<td></td>
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<tr>
<td>Kazakhstan</td>
<td>Tunisia</td>
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<tr>
<td>South Africa</td>
<td>Bangladesh</td>
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<td></td>
<td>India</td>
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<td></td>
<td>Nepal</td>
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<td></td>
<td>Uzbekistan</td>
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Minimum sample size 2,066 based on minimum sample sizes per confirmed country (5-year prevalence, 95% CL, +/-10%)
So far....

• 23 countries already participating
• 2 countries have started recruiting, many others about to start
• 110 sites confirmed
• No issues so far with any ethics approvals
• 8 languages uploaded to REDCap so far, at least 15 more to come
EACH CENTRE WILL....

• Co-ordinate activities with their **Country Lead**
• Decide how best to get optimal participation (choice of administrator/method of administration based on local circumstance and individual women's needs)
• Identify one or two women to assist with testing, feedback, and advocacy efforts
• Will receive an honorarium funded by IGCS and the World Ovarian Cancer Coalition ($300-$500US) once ethics approval has been obtained. Pre-approved costs for translation and submission fees will be met by IGCS/the Coalition
• Collectively commit to recruiting their country's minimum sample size, based on Globocan five-year prevalence (usually 75-95 per country), but larger samples will deliver more robust national results.
QUESTIONS FOR WOMEN (between 38 and 56 questions based on their responses)

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How eligible women can participate

• It will be most efficient if women self complete the survey, but testing has shown this needs to be in a quiet, undisturbed location in the clinic (online or on paper), or at home (online). Women can be given a unique link via email or WhatsApp

• For women who do not have the language/literacy skills or need support to complete the survey, the administrator will take women through the questions and record their answers. Any paper copies of the survey will need to be uploaded locally to REDCap

• Consent will be in clinic, or at the start of the online survey. Consent should not be sought over the phone

Resource intensity: Lower to higher
OTHER INFORMATION ENTERED BY ‘ADMINISTRATOR’

<table>
<thead>
<tr>
<th>Eligibility Criteria Instrument</th>
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<tbody>
<tr>
<td>Year of diagnosis, age at diagnosis</td>
</tr>
<tr>
<td>Type of ovarian cancer and stage on diagnosis</td>
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<tr>
<td>Current status (initial treatment, remission, relapse, palliative, other)</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Participant Clinical Data Instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic tests</td>
</tr>
<tr>
<td>Surgery and drug treatments</td>
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<tr>
<td>Genetic testing</td>
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</table>

National context provided by country’s Lead Clinician. This will be provided through completion of a standardized report during 2022.

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A JOINT INITIATIVE FOR WOMEN
Local context – Country Lead

• Each Country Lead will also be responsible for providing information and perspectives on a wide range of topics relating to ovarian cancer in their country, such as:
  • Access to diagnostics, route to diagnosis
  • Access to treatments and pain control
  • Workforce
  • Cultural aspects impacting on patient experience
  • Impact of COVID on ovarian cancer care
  • Mix of centres involved in the study

• The findings will form a standalone report, but also be used for context in terms of global and national analysis/papers
TIMESCALE

2021
- Finalise survey and protocol
- Translation and submission to ethics

2022
- Translation and submission to ethics
- Translation and submission to ethics
- Data collection starts, country lead surveys
- Data collection and OC Review. Early publication prep

2023
- Data Collection
- Data collection closes end June 2023
- Analysis
- Preparation for publications
EARLY OUTCOMES

The Women’s Coalition Against Cancer in Malawi approached the Health Ministry about the Study – and have had a very positive response about formal participation and engagement. The Health Ministry is now coordinating activity.

Clinicians and women with ovarian cancer in Malaysia have already set up their first patient group to look at support and advocacy – Ovarian Cancer Malaysia – with great press coverage!

Early coverage includes
• nature.com (https://www.nature.com/articles/d41586-021-03719-5)
• International Journal of Gynecologic Cancer as part of their ‘Corners of the World’ feature
• forthcoming presentations at UICC World Cancer Congress, International Gynecological Cancer Society Meeting, London Global Cancer Week,
• forthcoming article in Cancer Control 2022
Thank you for your interest

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And Clara MacKay, CEO, World Ovarian Cancer Coalition
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