

THE **EVERY WOMAN** STUDY™

LOW- and MIDDLE-INCOME EDITION



WORLD
OVARIAN
CANCER
COALITION

IGCS



A JOINT INITIATIVE FOR WOMEN

An overview
August 2022

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 \(2018\)](#)

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The Project Team



Frances Reid
Programme
Director,
Coalition

Study Lead



Mary Eiken
CEO, IGCS



Clara Mackay
CEO, Coalition

**Luna Benvenisti-
Zarom**
Study Assistant,
Coalition

Anmol Bajwa
Study Assistant,
Coalition

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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*

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Oversight Committee

Name	Role
Tracey Adams	Co-Chair (Clinical)
Robin Cohen	Co-Chair (Advocacy)
Isabelle Soerjomatram	Global Data Expert IARC
Asima Mukhopadhyay	South Asia (Clinical)
Rafe Sadnan Adel	South Asia (Advocate)
Ngoc Phan	East Asia (Clinical)
Iren Lau	East Asia (Advocate)
Dilyara Kaidarova	Central Asia and Europe (Clinical) - joint
Raikhon Bolatbekov	Central Asia and Europe (Clinical) - joint
Eva Maria Stromsholm	Central Asia and Europe (Advocate)

Basel Refky	Middle East and North Africa (Clinical) - joint
Sara Nasser	Middle East and North Africa (Clinical) - joint
Florencia Noll	Latin America (Clinical)
Annie Vaillant	Latin America (Advocate)
Martin Origa	Africa (Clinical)
Runcie CW Chidebe	Africa (Advocate)
Garth Funston	Primary Care Specialist

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The **EVERY WOMAN** STUDY™ 2018



THE
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WORLDWIDE LAUNCH
OCT 18, 2018
MUNICH, GERMANY

 **1531** WOMEN

 **44** COUNTRIES

 **15** LANGUAGES



THE
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INTERNATIONAL JOURNAL OF
GYNECOLOGICAL CANCER



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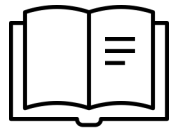


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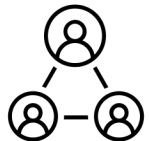
OBJECTIVES OF THE LMIC EDITION



- 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.

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WHERE DO WOMEN WITH OVARIAN CANCER CURRENTLY LIVE, VS PARTICIPATION IN EWS 2018?



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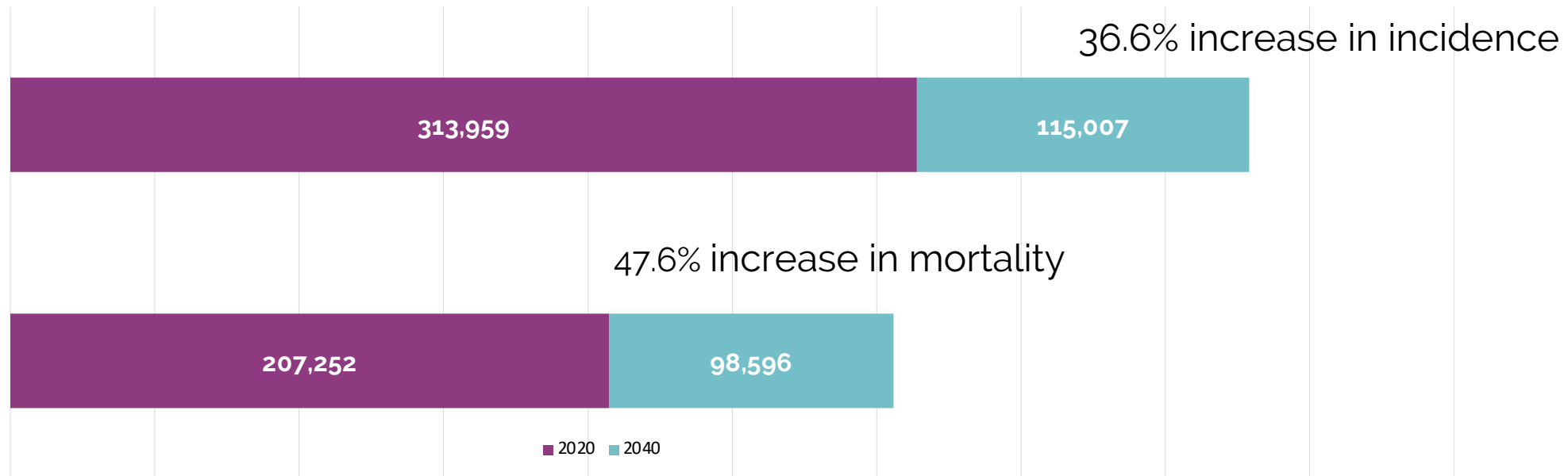


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GLOBOCAN PROJECTIONS OVARIAN CANCER WORLDWIDE TO 2040

Globocan Cancer Today and Cancer Tomorrow

(26th July 2021)



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GREATEST BURDEN OF INCREASE

Globocan Cancer Today and Cancer Tomorrow (26th 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%

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KEY DIFFERENCES 2018 - 2022

	2018	2022 LMIC
Women recruited	Via social media, patient groups	At clinics/hospitals (up to 10 per country)
Number of participants	1531 from 44 mainly high-income countries Just 72/1531 (0.05%) responses came from the proposed countries for 2022	Approx 2,570 women from up to 30 countries (LMIC)
Method of completion	Online, self completed (largely)	Online or on paper, at clinic/hospital Self completion or administered according to woman's needs/wishes
Time in field	8 weeks	Up to a year
Length of survey	148 questions, one hour to complete	56 questions, 20 minutes. Additional input from clinical staff
Areas completed		Broadly similar, less detail.

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STUDY LOCATIONS (confirmed ☒)

UPPER-MIDDLE INCOME		
Argentina	<input checked="" type="checkbox"/>	
Brazil	<input checked="" type="checkbox"/>	
Colombia	<input checked="" type="checkbox"/>	
Guatemala	<input checked="" type="checkbox"/>	
Mexico	<input checked="" type="checkbox"/>	
Peru	<input checked="" type="checkbox"/>	
Jamaica	<input checked="" type="checkbox"/>	
Malaysia	<input checked="" type="checkbox"/>	
Kazakhstan	<input checked="" type="checkbox"/>	
South Africa	<input checked="" type="checkbox"/>	

LOWER-MIDDLE INCOME		
Ghana	<input checked="" type="checkbox"/>	
Kenya	<input checked="" type="checkbox"/>	
Nigeria	<input checked="" type="checkbox"/>	
Zambia	<input checked="" type="checkbox"/>	
Philippines		
Vietnam	<input checked="" type="checkbox"/>	
Egypt	<input checked="" type="checkbox"/>	
Morocco		
Tunisia	<input checked="" type="checkbox"/>	
Bangladesh	<input checked="" type="checkbox"/>	
India	<input checked="" type="checkbox"/>	
Nepal	<input checked="" type="checkbox"/>	
Uzbekistan		

LOW-INCOME		
Malawi	<input checked="" type="checkbox"/>	
Mozambique	<input checked="" type="checkbox"/>	
Uganda	<input checked="" type="checkbox"/>	

Minimum sample size 2,066 based on minimum sample sizes per confirmed country (5-year prevalence, 95% CL, +/- 10%)

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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

确诊罹患卵巢癌之前，您有以下哪些症状？
请勾选所有适用的选项。

<input type="checkbox"/>	腹部（胃）疼痛
<input type="checkbox"/>	尿频
<input checked="" type="checkbox"/>	进食困难
<input checked="" type="checkbox"/>	排便习惯改变（如腹泻或便秘）
<input type="checkbox"/>	极度疲劳
<input type="checkbox"/>	腹部增大
<input type="checkbox"/>	感觉饱满
<input type="checkbox"/>	不明原因的体重下降
<input checked="" type="checkbox"/>	尿急
<input type="checkbox"/>	骨盆疼痛
<input type="checkbox"/>	持续腹胀
<input type="checkbox"/>	其他症状
<input type="checkbox"/>	无上述症状

Dalam masa sebelum diagnosis kanser ovari anda, yang manakah, jika ada, gejala berikut yang anda alami?
TANDAKAN SEMUA YANG BERKENAAN.

<input checked="" type="checkbox"/>	Sakit di bahagian abdomen (perut)
<input type="checkbox"/>	Kekerapan kencing
<input checked="" type="checkbox"/>	Kesukaran makan
<input checked="" type="checkbox"/>	Perubahan dalam kebiasaan usus (cth., cirit-birit atau sembelit)
<input type="checkbox"/>	Kepenatan keterlaluan
<input type="checkbox"/>	Bertambah saiz abdomen
<input type="checkbox"/>	Rasa kenyang
<input type="checkbox"/>	Penurunan berat badan yang tidak dapat dijelaskan
<input checked="" type="checkbox"/>	Tak tahan kencing
<input type="checkbox"/>	Sakit di bahagian pelvis
<input type="checkbox"/>	Kembung perut yang berterusan
<input type="checkbox"/>	Gejala-gejala lain
<input type="checkbox"/>	Tiada satu pun di atas

EACH CENTRE WILL....

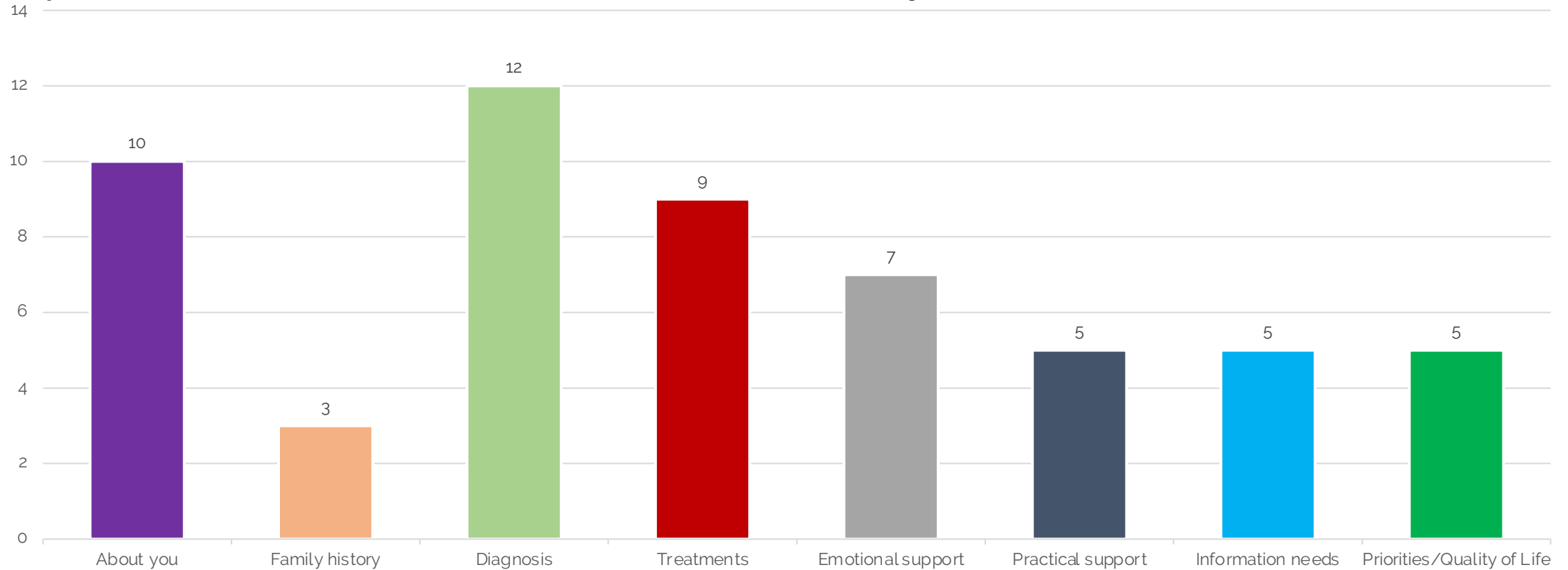
- Co-ordinate activities with their **Country Lead**
- Decide how best to get optimal participation (choice of administrator/method of administration based on local circumstance and individual women's needs)
- Identify one or two women to assist with testing, feedback, and advocacy efforts
- Will receive 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.

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QUESTIONS FOR WOMEN (between 38 and 56 questions based on their responses)



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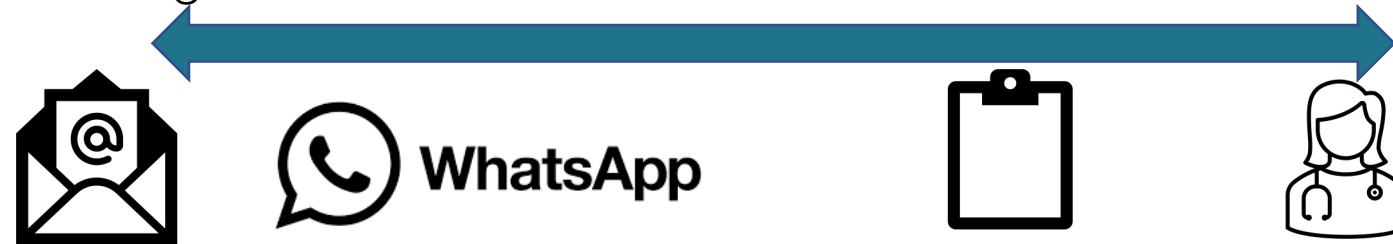


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How eligible women can participate

- 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'

Eligibility Criteria Instrument

Year of diagnosis,
age at diagnosis

Type of ovarian
cancer and stage
on diagnosis

Current status
(initial treatment,
remission, relapse,
palliative, other)

Participant Clinical Data Instrument

Diagnostic tests

Surgery and drug
treatments

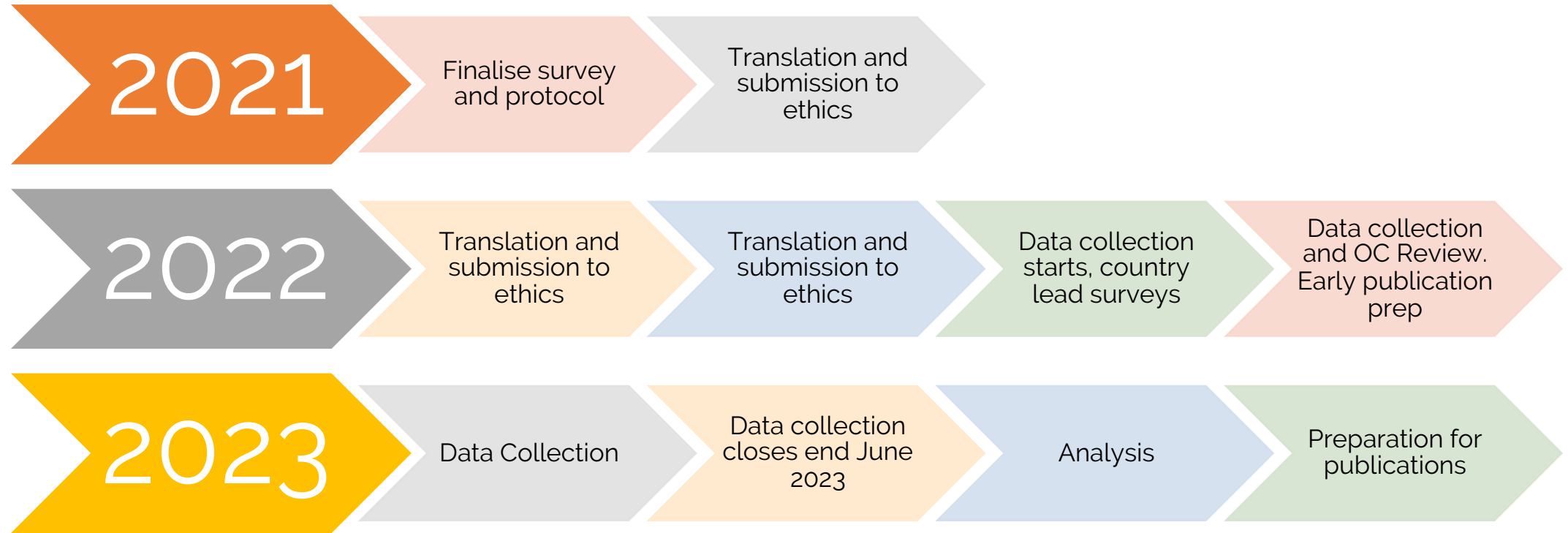
Genetic testing

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

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



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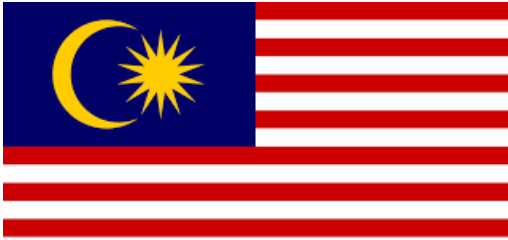


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EARLY OUTCOMES



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

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Thank you for your interest



Frances Reid, Study Director

frances@worldovariancancercoalition.org



And Clara MacKay, CEO, World Ovarian Cancer Coalition

cmackay@worldovariancancercoalition.org

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