Building opportunities to improve quality of life for women with ovarian cancer in low- and middle-income countries: the Every Woman Study

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According to the International Agency for Research on Cancer, the incidence of ovarian cancer will rise to 40% by 2040,\(^1\) with the greatest load falling on countries within low and medium human development indexes (Figure 1).

Currently, the available statistics on mortality and incidence rates for ovarian cancer vary critically from region to region of the world. The estimated number of new cases in Latin America, Asia, and Africa are usually below the average compared with those of high-income settings.\(^1\)

While the risk of developing the disease is highest in high-income countries, there is a marked gap in terms of women dying from the condition in low- and middle-income settings. In such countries there are further challenges including the availability and quality of data collection about the burden of ovarian cancer. In 2019, according to the WHO, more than one-third of countries did not have cancer registries, a unique tool to measure the size and assess the nature of the burden of illness on a healthcare system. In the context of ovarian cancer specifically, most countries do not have the required data to design accurate strategies. There is also a lack of information on the pathway to diagnosis and treatment, as well as data on quality of life among women with ovarian cancer.

In order to address the gap in the evidence related to the experience of women with the disease, the World Ovarian Cancer Coalition along with the International Gynecologic Cancer Society are developing a survey protocol that aims to gather information from up to 300 hospitals in 30 low- and middle-income countries (Figures 2–3).

The aim of the study is to provide a first-hand patient experience evidence base for women with ovarian cancer living in these settings, detailing patients’ experience from diagnosis to treatment, and assessing how many women are affected by the disease, so as to identify the key challenges and opportunities that may improve survival and quality of life.

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**Country Leads**

**February 2022**

<table>
<thead>
<tr>
<th>Country</th>
<th>Lead Clinician</th>
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<th>Lead Clinician</th>
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<td>Fatou Mekonnen Assie</td>
<td>India</td>
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<td>Brazil</td>
<td>Celine Balabço and Matias de Carvalho and Celine Banaba</td>
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<td>Bente T polys and Silvia Lucio Rodriguez-Castillo</td>
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<td>Mexico</td>
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<td>Zambia</td>
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<td>Peru</td>
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<td>Egypt</td>
<td>Besnik Bel</td>
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<td>Namibia</td>
<td>Lamo Uyembo</td>
<td>Morocco</td>
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<td>Benin</td>
<td>Delia Akonsi and Jocelin Sambou</td>
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<td>Nga Pil</td>
<td>Nigeria</td>
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<tr>
<td>Malaysia</td>
<td>Yip Ling Liu</td>
<td>Singapore</td>
<td>Participation and leads still to be confirmed</td>
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</tbody>
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**Figure 2** Participating countries and country leads 2022. Reproduced from: Every Woman Study: Low- and Middle-Income Edition, World Ovarian Cancer Coalition/International Gynecologic Cancer Society, 2022, with permission.

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**Figure 1** Estimated number of new cases of ovarian cancer from 2020 to 2040, females, age 0–85+ years. HDI, human development index. Reproduced from CancerTomorrow, International Agency for Research on Cancer/WHO, 2022, with permission.
The survey will cover topics including women’s prior knowledge of ovarian cancer, family history, experience of symptoms, time and routes to diagnosis, the care received including treatments and access to clinical trials, and quality of life issues such as long-term side effects, support and information needs, and priorities for action.

Looking back to the previous study, we found substantial variation in women’s experience through the healthcare system; for example, the time to diagnosis across countries ranged from 21 weeks in Germany to 40 weeks in Brazil. The extent to which each challenge was an issue in each country varies widely, providing key learning points and opportunities for progress.

In low- and middle-income regions, this project is a major opportunity to gather novel evidence on patient experience at a country and global level, to drive national and international patient and clinical advocacy efforts, and to develop policies to improve patient care.

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REFERENCES

Figure 3 The oversight committee of the ground-breaking Every Woman Study: Low- and Middle-Income Edition.