Objective

This briefing note aims to provide a succinct understanding of the global ovarian cancer landscape, with a particular emphasis on key epidemiological data, challenges and opportunities in various resource settings, economic implications, lived experiences of patients and healthcare providers, and the World Ovarian Cancer Coalition's strategic priorities.

1. Global Burden of Ovarian Cancer

Ovarian cancer presents a significant global health challenge, impacting women worldwide with considerable mortality and morbidity.

- **Current Incidence and Mortality:** Ovarian cancer is the eighth most common cancer in women globally and the eighth leading cause of cancer death. In 2020, approximately 314,000 women were diagnosed with ovarian cancer, and 207,000 died from the disease. Unless there are changes to how we respond to ovarian cancer, it is estimated that the disease will claim more than 8 million lives from 2022 to 2050. These figures highlight ovarian cancer's high lethality and the need for enhanced focus and resources.

- **Projected Trends:** The global burden of ovarian cancer is expected to grow substantially. By 2050, the incidence is projected to increase by 55%, and mortality by almost 70%, primarily driven by population growth and aging. The highest increases are expected in low- and middle-income countries (LMICs), where healthcare infrastructure is already frail resulting in even greater struggles to cope with the rising burden.

- **Regional Disparities:** The distribution of ovarian cancer cases is uneven, with approximately 70% of cases occurring in LMICs. These regions face significant barriers in terms of healthcare access, early diagnosis, and treatment options, leading to poorer outcomes compared to high-income countries (HICs). While progress has been made with new targeted treatments and innovative therapies, ovarian cancer remains one of the most challenging cancers to treat, with five-year survival rates showing stark disparities between HICs and LMICs.

  In HICs, the five-year survival rate ranges between 40% to 50%, supported by earlier diagnosis, access to surgery, and advanced treatments. In

contrast, survival rates in LMICs can drop as low as 20% to 30% due to late diagnoses, limited healthcare infrastructure, and reduced access to advanced therapies. Notably, progress in improving survival rates for ovarian cancer lags behind other cancers, such as breast cancer, where five-year survival rates often exceed 85% in HICs. Breast cancer has benefited from more effective screening programs and broader access to treatment options, while ovarian cancer lacks a reliable screening programme, leading to later-stage diagnoses and poorer outcomes. The contrast between these cancers underscores the need for enhanced early detection and access to comprehensive care globally as ovarian cancer increasingly becomes a major public health challenge.

2. Challenges and Opportunities

Addressing ovarian cancer effectively requires understanding both the distinct challenges unique to different resource settings and the common issues they share. While each setting faces its specific obstacles, a prevalent challenge across both high and low-resource environments is low awareness and poor health literacy, as highlighted in the 2018 Every Woman Study™ (EWS) and the Every Woman Study™: Low- and Middle-Income (LMIC) Edition.

High-Income Countries (HICs)

- **Challenges:**
    - **Late Diagnosis:** Despite the availability of advanced healthcare systems, many ovarian cancer cases in HICs are still diagnosed at a late stage. This is largely due to low levels of awareness about ovarian cancer symptoms among women and healthcare professionals, coupled with health system delays and the non-specific nature of the disease's symptoms. According to data from GLOBOCAN and the International Agency for Research on Cancer (IARC), the majority of ovarian cancer cases are diagnosed at advanced stages (Stage III or IV), where survival rates are significantly lower. Only about 15-25% of cases are detected at Stage I, when the disease is more treatable, with five-year survival rates as high as 90%. In contrast, when diagnosed at advanced stages, survival rates drop to around 30% or lower.

- **Screening:** There are no screening methods such as those that exist for breast, cervical or colon cancer, that will detect asymptomatic ovarian cancer cases. CA-125 blood tests and transvaginal ultrasound, which are used to diagnose symptomatic women, are not sufficiently specific or sensitive to pick up asymptomatic cases to the extent that disease mortality is reduced..

- **Opportunities:**

  - **Research and Innovation:** HICs are uniquely positioned to lead the charge in ovarian cancer research and innovation. Ongoing investment in cutting-edge research is crucial for developing new diagnostic methods, including biomarker discovery and advanced imaging techniques. For instance, studies have shown that biomarkers such as CA-125, HE4, and others hold promise for earlier detection, although further research is needed to improve sensitivity and specificity. Advances in imaging technology, such as enhanced MRI and transvaginal ultrasound techniques, are also being explored for their potential to detect ovarian cancer earlier, before it progresses to advanced stages. Continued investment in these areas can pave the way for breakthroughs in early detection, which is crucial for improving survival rates and reducing healthcare costs in the long term.

  - **Targeted Treatments:** HICs benefit from access to advanced treatments, including targeted therapies such as PARP inhibitors and immunotherapy, which have shown substantial success in treating ovarian cancer, especially in patients with BRCA1/2 mutations. According to a study published in The Lancet Oncology, PARP inhibitors like Olaparib have demonstrated significant efficacy in prolonging progression-free survival in ovarian cancer patients, particularly those with germline BRCA mutations. Expanding genetic testing for BRCA mutations can help tailor these treatments to the individuals who are most likely to benefit. Research also suggests that increasing the availability of genetic testing could have a profound impact on improving ovarian cancer outcomes by enabling earlier, more personalized treatments. Immunotherapy is another promising area, as checkpoint inhibitors and CAR-T cell therapies continue to be explored in clinical trials for ovarian cancer. Continued research and innovation in HICs are essential to

expanding the arsenal of treatment options available to patients worldwide, particularly as these therapies become more accessible globally. Additionally research needs to involve diverse populations to ensure timely access to all patient groups.

Low- and Middle-Income Countries (LMICs)

- **Challenges:**
    - **Lack of Awareness and Education:** In LMICs, a critical barrier to early diagnosis and treatment of ovarian cancer is the low level of awareness about the disease. Women often lack knowledge about the symptoms, which can be non-specific and easily mistaken for less serious conditions. Studies show that up to 70% of women in LMICs are diagnosed at an advanced stage because they were unaware of the warning signs or delayed seeking medical help. Additionally, healthcare providers in these regions may have limited familiarity with ovarian cancer due to the lack of specific training and resources. Cultural stigma and misinformation further exacerbate the situation, leading to a reluctance among women to seek medical attention, particularly in regions where discussing reproductive health issues is taboo. Furthermore, the high cost to patients and families of diagnostic procedures can also delay women seeking help.
    - **Inadequate Healthcare Infrastructure:** The healthcare infrastructure in LMICs presents another significant obstacle in managing ovarian cancer. Limited access to diagnostic tools, treatment facilities, and trained healthcare professionals severely hampers the ability to diagnose and treat the disease effectively. According to the World Health Organization (WHO), many LMICs lack basic diagnostic capabilities like CA-125 blood tests and transvaginal ultrasounds, which are vital for more rapid diagnoses. Even when diagnostic tools are available, long waiting times, outdated equipment, and overburdened healthcare systems often delay diagnosis and treatment. Furthermore, the absence of specialized oncologists and gynecologic cancer surgeons means that women may not receive optimal care.
    - **Limited Access to Existing and New Ovarian Cancer Treatments:** LMICs face significant barriers to accessing even basic treatments

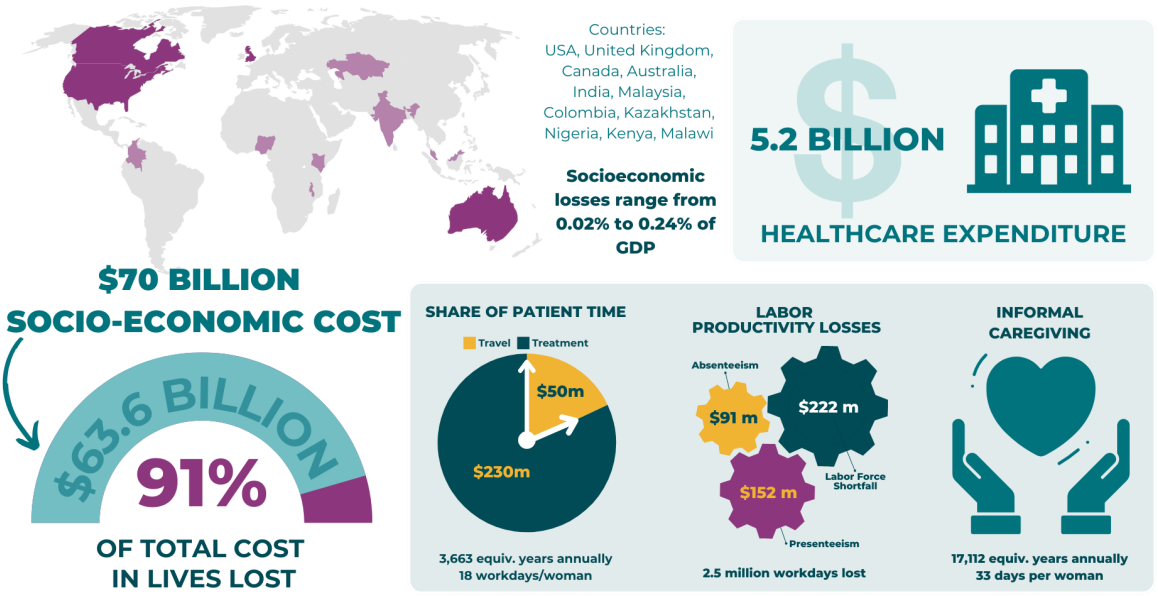
listed on the World Health Organization's Essential Medicines List, with newer advancements such as PARP inhibitors largely out of reach for the majority of women. The lack of access to public or private healthcare insurance exacerbates the situation, as many women in these regions are forced to pay out-of-pocket for diagnostics and treatments. This financial burden often leads to devastating consequences, pushing families into almost certain financial ruin.

- **Opportunities:**
    - **Community-Based Awareness Programs:** Initiatives that educate communities about ovarian cancer symptoms and encourage early medical consultation can significantly improve detection rates. A recent study published in *JAMA* highlights the critical role of symptom-triggered testing in achieving earlier diagnoses.

      Research suggests that increasing community awareness about these early, subtle symptoms—such as bloating, pelvic pain, and urinary issues—can shift the trend toward earlier diagnosis. By raising awareness and encouraging women to seek testing when these symptoms appear, community-based programs could lead to earlier interventions and improved survival rates. Leveraging local media, community leaders, and healthcare workers, these programs can empower women to recognize the signs early and seek medical attention before the cancer advances, ultimately reducing the number of late-stage diagnoses.

    - **Partnerships and Funding:** international partnerships are vital in delivering the resources, expertise, and training needed to elevate ovarian cancer care in low- and middle-income countries (LMICs). By collaborating with global health organizations, these partnerships can bridge critical gaps in healthcare infrastructure and empower local healthcare systems. These collaborations facilitate the introduction of cost-effective diagnostic and treatment options, ensuring that even resource-limited settings can adopt advanced, yet affordable, interventions for ovarian cancer.

3. The Economic Impact of Ovarian Cancer



Ovarian cancer imposes a significant economic burden, affecting both healthcare systems and individuals. According to the World Ovarian Cancer Coalition's *Socioeconomic Burden of Ovarian Cancer in 11 Countries Study*, the socio-economic impact of ovarian cancer across the 11 countries alone is estimated to be around $70 billion, with a staggering 91% of that cost attributed to lives lost. This highlights the devastating personal and economic toll of the disease. The infographic above, drawn from the study, illustrates the economic burden by breaking down healthcare expenditures, labor productivity losses, and informal caregiving costs.

- **Healthcare Costs:** The total healthcare expenditure associated with ovarian cancer in the 11 countries is $5.2 billion, covering surgery, chemotherapy, hospitalization, and supportive care. In low- and middle-income countries (LMICs), these costs place immense strain on healthcare budgets, where resources are already scarce.
- **Out-of-Pocket Expenses:** In regions without universal healthcare, patients and their families often shoulder these medical costs. This

financial burden can lead to devastating consequences, pushing families into debt or exhausting their savings to cover treatment.

- **Productivity Losses:** Ovarian cancer also leads to significant labor productivity losses, estimated at $222 million annually. Women's ability to work is severely impacted, resulting in absenteeism, presenteeism, and long-term labour force shortages. This adds to the financial strain on families and the broader economy.

- **Informal Caregiving:** As shown in the infographic, informal caregiving adds an additional layer to the socio-economic burden, with caregivers often reducing work hours or leaving their jobs to support loved ones. An estimated 17,112 equivalent years of informal care are provided annually, further illustrating the enormous impact on households, particularly in LMICs.

4. Lived Experience: Insights from Patients and Clinicians

Understanding the lived experiences of those affected by ovarian cancer is crucial for developing patient-centered care strategies that reflect cultural, geographic, and resource specific challenges.

- **Patient Voices:** Women diagnosed with ovarian cancer often face a range of emotional, psychological, and practical challenges. Studies, including the Coalition's Every Woman Study™, have shown that many women lack awareness about ovarian cancer prior to their diagnosis, which can lead to delays in recognizing symptoms and seeking medical advice. This delay frequently results in a diagnosis at an advanced stage, limiting treatment options, impacting quality of life, and reducing survival rates.

The diagnostic process for ovarian cancer is often long,stressful, and can be costly, contributing to feelings of anxiety and uncertainty among patients. Many women report a significant gap between the onset of symptoms and receiving a diagnosis, during which time their condition may worsen. This prolonged uncertainty can lead to emotional distress,

fear about the future, and concerns about the availability of effective treatment options.

- **Challenges Faced by Clinicians:** As part of the Every Woman Study™: Low- and Middle-Income Edition, the Coalition gathered valuable insights from clinicians regarding the challenges and opportunities in ovarian cancer care and treatment. Healthcare providers in LMICs face significant obstacles, including limited resources, inadequate training, and a lack of diagnostic and treatment facilities, which hinder their ability to provide optimal care. These systemic limitations often lead to frustration among clinicians, who are aware of the gap between the care they can provide and the care their patients need.

  Despite these difficulties, clinicians also see these challenges as addressable opportunities for improvement, highlighting the potential for targeted interventions and resource allocation to enhance the quality of ovarian cancer care in these regions.

5. World Ovarian Cancer Coalition: Priorities, Key Messages, and Calls to Action

Strategic Priorities

The 2023-2026 Communications Strategy marks a shift from "Evidence for Action" to "Evidence to Action," focusing on using evidence-based insights to drive impactful communication and advocacy efforts. The Coalition's strategic priorities include awareness and health literacy, prevention, rapid diagnosis and best treatments, and access to data.

Major Initiatives by the World Ovarian Cancer Coalition

To support these strategic priorities, the World Ovarian Cancer Coalition has undertaken several key initiatives. These initiatives aim to address the challenges of ovarian cancer globally, particularly in low- and middle-income countries, and to advocate for better care and support for all women affected by the disease. The table below summarizes these major initiatives and their objectives:

Initiative	Description
2018 Every Woman Study™ (EWS)	A comprehensive global study conducted in 2018 that gathered insights from over 1500 women with ovarian cancer about their experiences, focusing on awareness, diagnosis, treatment, and support. The findings have informed advocacy and policy recommendations worldwide.
Every Woman Study™: LMIC Edition	An extension of the original study, this Edition focuses specifically on the challenges and needs of women with ovarian cancer in 22 low- and middle-income countries. It highlights disparities in care and access, aiming to guide targeted interventions in these regions.
Socioeconomic Burden Study (formerly known as Cost-of-Illness Study)	Analyzes the socioeconomic burden of ovarian cancer by way of impact on women, caregivers, healthcare systems and national economies across 11 countries. This study provides data to support policy changes and

	better resource allocation to address the socioeconomic impact of the disease.
Global Awareness Campaigns	Initiatives aimed at raising awareness of ovarian cancer symptoms and promoting early detection. These campaigns reach a global audience, emphasizing the importance of recognizing symptoms early to improve survival rates.
World Ovarian Cancer Day (WOCD)	An annual event to raise awareness and understanding of ovarian cancer. WOCD engages the public, healthcare providers, and policymakers in advocacy for improved care and support for women affected by the disease.
Partnerships with Healthcare NGOs	Collaborations with international non-governmental organizations, including the World Health Organization (WHO), International Gynecologic Cancer Society (IGCS) and the Nigerian National Institute of Cancer Research and Treatment (NICRAT) to enhance ovarian cancer care, particularly in LMICs.
Research Funding and Collaboration	Investing in and collaborating on research projects aimed at understanding factors impacting ovarian cancer care, treatment, and outcomes. The Coalition is building on epidemiologic data to understand patients' experiences and clinicians' perspectives. This supports innovation, enables inclusive policy making, and improves patient care.

Data Collection and Use	Promoting the collection and use of accurate and comprehensive data on ovarian cancer. This data is crucial for understanding the disease's impact, identifying gaps in care, and informing evidence-based strategies for better outcomes.

Key Messages and Calls to Action

- **Prevention (through testing):**
    - Governments should include genetic testing as part of their National Cancer Control Plans, to ensure women have access to appropriate, affordable and timely genetic testing and counselling wherever they live. Legal protections should be in place, and in LMIC in particular, access to testing needs to be stepped up by developing the necessary infrastructure, including access to counsellors and information available
    - In HIC, where genetic testing is more readily available, policy makers should tackle low awareness and uptake of testing and develop strategies to reduce the inequity of access between ethnic, geographic and income groups
- **Access:**
    - Funding to support accessible and affordable diagnostics needs to be prioritised so women can get an accurate diagnosis, and not endure unnecessary delay before receiving treatment. Every woman should have access to basic ovarian cancer treatments that are included on the WHO Essential Medicines List Ovarian cancer should be a global priority, so that the increasing burden and challenges of successfully treating women with ovarian cancer are recognized and planned for at local, regional, and national levels

- Every country should have a Cancer Control Plan that includes a clear strategy to address prevention, treatment and care for ovarian cancer, informed by quality data and with clear actions to reduce the disease burden
- In HIC, policymakers must address significant regional differences within countries in access to ovarian cancer treatment which persist

- **Data and Evidence:**
  - Policy makers must ensure that data used to develop cancer control plans and treatments reflects the diversity of local populations to ensure the best possible outcomes. And where no adequate data gathering systems exist, countries should be encouraged to use internationally created sources (e.g. WHO, IARC), as a starting point
- **Awareness and Health Literacy:**
  - Governments and civil society should raise awareness of the symptoms of ovarian cancer so women can seek appropriate help including diagnosis at the earliest opportunity, thus reducing morbidity and allowing more access to treatment, including access to clinical trials
  - Policy makers should work with NGOs and professional societies to encourage women with a family history of ovarian and certain other cancers to know about their risk

Conclusion

Ovarian cancer remains a formidable global health challenge, requiring coordinated efforts to address disparities in diagnosis, treatment, and support. A comprehensive approach involving genetic testing and prevention, early detection, equitable access to care, and robust patient support systems is crucial. Access to local and global data is crucial to support efforts to identify barriers and opportunities and the positive policy changes required to improve ovarian cancer survival and quality of life.

The World Ovarian Cancer Coalition, through its strategic priorities and calls to action, aims to drive meaningful change and improve the survival and quality of life for women with ovarian cancer worldwide. This briefing provides the necessary insights to engage with global stakeholders, to advocate for a comprehensive and inclusive approach to ovarian cancer care.

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