



WORLD
OVARIAN
CANCER
COALITION

*Challenges and
opportunities in improving
access and affordability
of essential medicines in
low- and middle-income
countries*

THE JOURNEY TO MORE EQUITABLE OVARIAN CANCER CARE

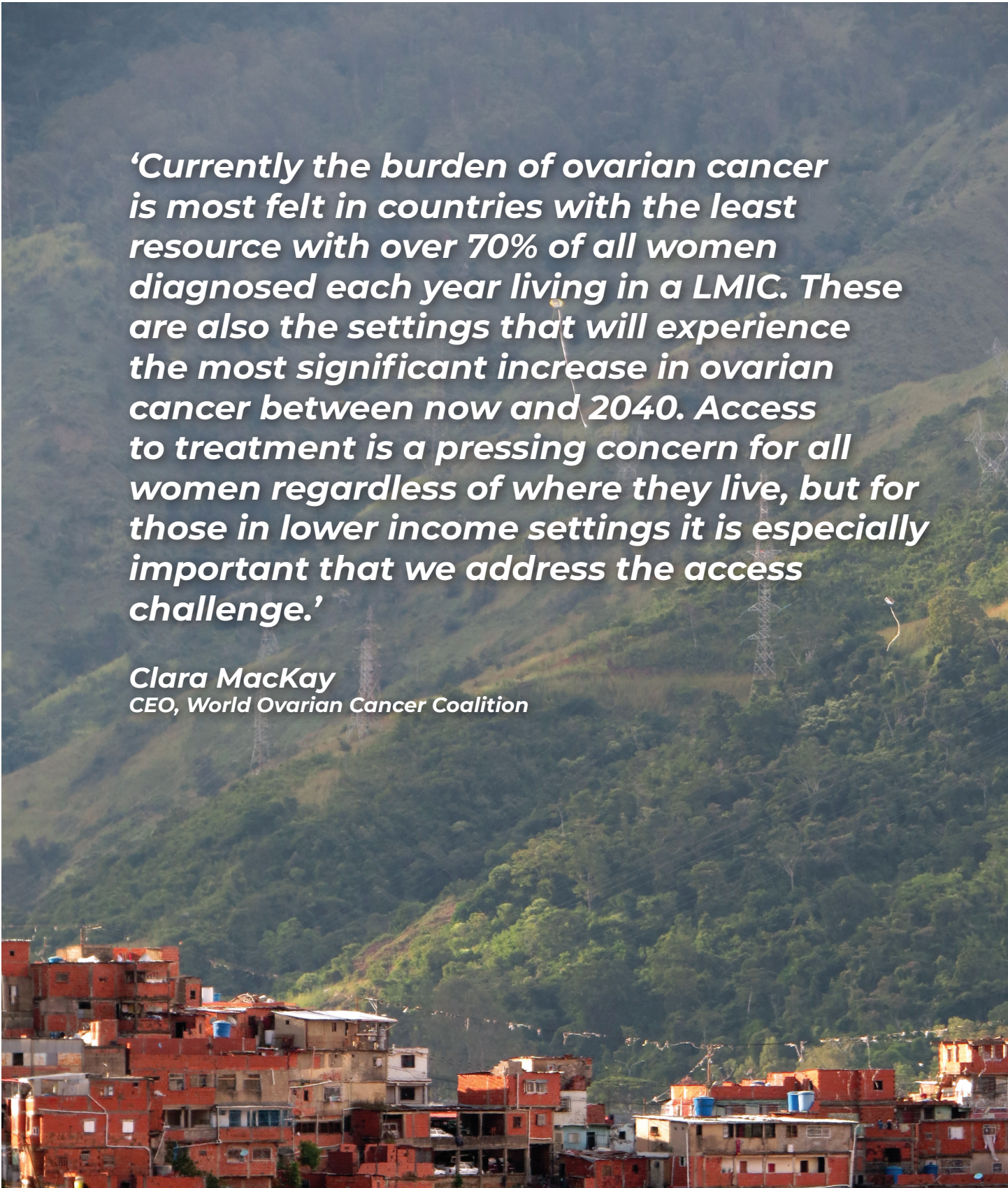
**ACCESS TO ESSENTIAL MEDICINES ROUNDTABLE (APRIL 2022)
REPORT - SEPTEMBER 2022**

In April 2022, the World Ovarian Cancer Coalition invited global experts including clinicians, policy experts, NGOs and ovarian cancer patient advocates from countries across the income spectrum to identify challenges and opportunities to improve access to essential medicines in ovarian cancer and to inform the Coalition on actions it could take to support members to advocate for better access and affordability of medicines locally. This report summarizes the findings from this Roundtable.



GLOBAL
OVARIAN
CANCER
CHARTER
a World Ovarian Cancer
Coalition initiative

**NO
WOMAN
LEFT
BEHIND**



‘Currently the burden of ovarian cancer is most felt in countries with the least resource with over 70% of all women diagnosed each year living in a LMIC. These are also the settings that will experience the most significant increase in ovarian cancer between now and 2040. Access to treatment is a pressing concern for all women regardless of where they live, but for those in lower income settings it is especially important that we address the access challenge.’

Clara MacKay
CEO, World Ovarian Cancer Coalition

EXECUTIVE SUMMARY

LACK OF UNDERSTANDING OF THE CANCER ENVIRONMENT AND MEDICINES' OPTIONS

Health systems in low- and middle-income countries (LMICs) have been geared towards addressing the significant burden of communicable diseases and still lack the full understanding, infrastructure and human capital required for routine delivery of comprehensive cancer management. Fragmented diagnostic, treatment and palliative care services result due to deficits from both a national policy and local health delivery perspective.

The cancer community must do more to engage with decision makers to highlight the very different challenges for provision of quality cancer care compared to the communicable diseases environment, and press for a more integrated health systems approach to address all cancers and availability of cancer medicines, rather than siloed approaches to individual cancer types.

THE WHO ESSENTIAL MEDICINES LIST (EML)

The World Health Organization (WHO) model EML is a valuable guide for policymakers and governments in selecting the best mix of cancer medicines for national needs and supporting routine procurement and financing mechanisms. This is especially true in those countries that do not have formalised health technology appraisal processes.

However, there remain significant barriers in LMICs in accessing essential cancer medicines even for common chemotherapies and hormone treatments that have been in use for over 40 years. Governments need to prioritise equitable access, align their own national EMLs with the WHO EML and look to routine

availability and affordability for their respective populations.

POOR DATA AND ITS IMPACT IN LMICs

Many cancer registries in LMICs, where they even exist, are underfunded and under-prioritized, severely weakening the data required for good planning on cancer patient volumes and stage at diagnosis. As a result, selection, procurement, and financing decisions are often skewed towards high burden cancers with newer medicines the focus of discussion. Well-established generic treatments are then passed over and synergies of availability of cancer medicines that are used in several indications are missed. Further, scarcity of data and planning hampers the development of localized cancer treatment guidelines that would help support equitable access and quality of treatment services.

As advocates, we must challenge the inaction on lack of local data. Data sets from the World Health Organization and International Agency for Research on Cancer (IARC) are a robust starting point and international guidelines such as those by the National Comprehensive Cancer Network (NCCN) are now tailored to less developed settings. However, while these tools and the technical assistance WHO provides should be well known, many countries are still not aware of these opportunities to improve the affordability and availability of cancer medicines. Collaboration between clinicians, the research community, and patient and civil society groups is needed to drive processes and to showcase the key role data systems play.

EXECUTIVE SUMMARY

THE VALUE OF INVESTING IN CANCER CONTROL

The understanding and defining of the value of cancer treatment, including cancer surgery and radiotherapy is absent from the global cancer control narrative. While the WHO has been working with local stakeholders to make the national case for investment in cancer services not just in terms of more efficient use of health system resources, but also in demonstrating the wider societal benefits of tackling cancer, there is little conversation about clinical benefit of individual treatment options. Treatments with marginal clinical benefit are simply exposing vulnerable cancer patients to toxicity with no gain. Lived-experience and quality of life are critical elements, including the concept of time toxicity (i.e. time spent searching for information that is not readily available that could otherwise be spent with loved ones).

Ovarian cancer treatments have good examples of regimens that have been established for decades still delivering good clinical benefit for women living with this disease. These treatment decisions must be made in line with the local context, with advocates building their own understanding of “value” and stimulating a national debate to establish assessment mechanisms.

STRUCTURAL AND CULTURAL CHALLENGES OF THE HEALTH ENVIRONMENT

LMICs face significant health systems challenges and also wider infrastructure and cultural barriers that impact how cancer services and medicines are delivered. A broader perspective would create a more enabling environment, for example addressing transport challenges could improve treatment adherence and lower the cost for patients in remote

communities. Detecting cancers early is critical in giving cancer patients the best opportunity to do well in treatment and possibly be cured. Accurate diagnosis and treatment monitoring is equally critical to good patient outcomes but they require robust diagnostic and pathology services. Further, research into public perceptions about cancer and addressing social taboos could be a lever for reducing stigma, particularly for women living with cancer and would support health seeking behaviour and adherence to treatment.

THE IMPORTANCE OF CIVIL SOCIETY, CLINICIANS, AND INDUSTRY

Each stakeholder group has unique and specific insights that together should form a powerful narrative when engaging with governments, while at the same time making the most of each group’s resources. Clinicians, the research community, advocates, industry and policymakers can form closer relationships to ensure better understanding and communication of the value of cancer control. In particular, with their unique insights and by harnessing the patient voice, NGOs can help to improve the debate on access to medicines so that policymakers have a full understanding of the specificities of cancer. This will in turn lead to tangible actions through more countries addressing core issues in their national universal health coverage (UHC) plans such as diagnosis, treatment, and care for cancer.

The Coalition wishes to thank the clinicians and experts who contributed to the Roundtable and this report and to its industry partners for their feedback to our findings.



‘The Coalition is keen to contribute to the wider ongoing debate about access to cancer medicines. In addition to the Roundtable discussion, and under the direction of the participants, we have drawn on several global policy reports on medicines’ access challenges to supplement the report and offer recommendations to policy-makers to ensure that ovarian cancer is recognised as a priority that requires action at a global and national level.’

Clara MacKay

CEO, World Ovarian Cancer Coalition

INTRODUCTION

BACKGROUND

In April 2022, the World Ovarian Cancer Coalition (Coalition) hosted a Roundtable of global experts to discuss the challenges facing low and middle-income countries (LMIC) in accessing ovarian cancer treatments, some of which have been in existence for over 40 years, are generic, widely available, and affordable. Participants included clinicians, policy experts and ovarian cancer patient advocates from countries across the income spectrum as well as experts from the broader cancer community.

The Roundtable is a follow-on activity from research carried out in 2021 by the Coalition that looked into the availability of ovarian cancer treatments in 13 high- to low-income countries based on World Bank classifications. The Coalition consulted clinicians in each of these countries and created a list of 15 treatments (drawn from 5 classes) routinely required for management of ovarian cancer. These ranged from well-established chemotherapies and hormone treatments to the newer VEGF-A and PARP-inhibitors (PARPi). All but one class of the treatments are already on the World Health Organization's Essential Medicines List (WHO EML). The research also investigated who was paying for the treatments. However, structural factors beyond availability and funding were out of scope. Many of these 'essential' ovarian cancer treatments have been available since the 1970s and 80s but the Coalition's research showed a stark contrast in routine availability of these medicines across the countries surveyed. Most significantly, patients in lower-middle income countries face major out of pocket expenses when accessing these drugs; in effect, even if EML treatments are available in their country, the majority of women with ovarian cancer cannot afford to be treated.

By bringing together ovarian cancer advocates and the global cancer community, the Roundtable aimed to identify challenges and opportunities to improve access to essential medicines in ovarian cancer and to inform the Coalition on actions it could take to support partner organizations to advocate for better access and affordability of cancer medicines in their own countries.

PRE-MEETING POLL AND DISCUSSION FORMAT

The Roundtable followed a presentations-and-questions format and was introduced by Clara MacKay, CEO of the World Ovarian Cancer Coalition and moderated by Dr. Julie Torode, visiting scientist at the Institute of Cancer Policy, King's College London and long term advocate on access to cancer medicines.

Designed with the support of Dr. Torode, the Coalition distributed a poll to attendees in advance of the session. This was to gauge levels of understanding, experience and confidence levels among civil society and expert participants regarding access issues and to assess where there is scope for closer alignment between the two stakeholder groups. Results were presented at the start by Frances Reid, Director of Programmes for the Coalition, and the key findings were:

- All respondents had at least some experience in advocating on access issues to some extent and had worked with clinicians on access issues at a local or national level and most had worked with industry and with other cross-cancer collaborations.
- Overall, there was a high level of personal confidence in discussing the issue of medicines access.

INTRODUCTION

- The poll also asked participants about the understanding of four pre-determined areas - universal health coverage (UHC); procurement and supply [of medicines]; weak health systems and; pricing policy frameworks – and their views on the most impactful opportunities to improve access for women with ovarian cancer in these areas.
- Among the civil society respondents specifically, there were high confidence levels in understanding of UHC and weak health systems, mid-level confidence of procurement and supply issues and low confidence on pricing policy frameworks.
- In terms of the most impactful opportunities to improve access for women with ovarian cancer in participant's countries, among civil society respondents, low scores were recorded for procurement and supply and UHC and higher scores for weak health systems and pricing policy frameworks.
- For global experts higher scores were recorded for procurement and supply and pricing policy frameworks, an indication of where better alignment can be worked on.

This report captures the key messages from each of the presentations, bringing them together under overarching themes and ends with conclusions and recommendations for next steps.


THE IMPORTANCE OF MEDICINES ACCESS FOR WOMEN WITH OVARIAN CANCER

Before exploring the detail of each of the participant's contributions, it is first worth briefly noting the context of cancer medicines access with specific reference to ovarian cancer,

and the specificities of LMICs in terms of the projected cancer burden over to 2040.

Access to quality cancer medicines has been a key discussion point among policymakers, clinicians, and advocates for many years. Until now, much of the debate and media coverage has centred on access to the newer drugs and other treatments in high-income countries.

However, there is a growing burden in the lower resourced regions of the world where countries are faced with immense structural and market challenges. For ovarian cancer, this is especially concerning as over 70% of women diagnosed with ovarian cancer live in LMICs.



70%
of
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countries**

INTRODUCTION

Overall, the global burden of cancer is set to increase by more than 60% by 2040, from 18.1 million new cases in 2018 to a projected 29.4 million cases in 2040.¹ According to Globocan's 2020 projections, by 2040 the number of women around the world diagnosed with ovarian cancer will rise almost 42% to 445,721. The number of women dying from ovarian cancer each year is set to rise to 313,617, an increase of over 50% from 2020.² Although five-year ovarian cancer survival rates are not available in all settings, they currently range from 36% to 46%. It is suspected that in some countries the figure is much lower. Furthermore, based on 2020 mortality rates, if nothing changes, by 2040 it is estimated that over four million women will die from ovarian cancer worldwide³, with the majority of those lost from LMICs.

Based on the number of ovarian cancer deaths in 2020, if nothing changes, by 2040 over

4 MILLION women will be lost to the disease.

Global policymakers and governments continue to underappreciate the impact of ovarian cancer on women, their families, their societies, and economies⁴. However, hope is on the horizon as the tide is beginning to turn for some women's cancers, as is the case with the WHO's Cervical

Cancer Elimination Initiative. Launched in 2018, this strategy focuses not only on prevention, but also on treatment and palliative care. Alongside the prioritisation of breast cancer by policymakers and the World Health Assembly's Cancer Resolution in 2017, the cancer community now has an opportunity to align arguments for action in ovarian cancer under the broader umbrella of women's cancer. It is hoped that this would lead to a more targeted and effective use of advocacy resources.

THE SPECIFICITIES OF LOW- AND MIDDLE-INCOME COUNTRIES

Policymakers and advocates must contend with the unique challenges facing LMICs if they are to improve access to medicines and patient outcomes. In West, East, Middle, and Southern Africa, cancer is among the three leading causes of premature death (at ages 30–69 years) in almost all constituent countries⁵, and is responsible for one in seven premature deaths overall and one in four deaths from non-communicable diseases (NCDs)⁶. Critically, the burden is expected to nearly double in the region during the next 20 years because of population growth and ageing, reaching 1.5 million new cases and 1 million deaths by the year 2040⁷ – a sobering projection which should encourage policymakers to act. These trends are mirrored in all emerging economies: in Southern, South-Eastern and Eastern Asia, 8.2 million new cancer cases and 5.2 million cancer deaths were estimated in the region in 2018, corresponding to around half of the cancer burden worldwide⁸. In Latin America and the Caribbean about 1.3 million new cancer cases and 666,000 cancer deaths were estimated to have occurred in 2018.⁹

‘There is an opportunity for the cancer community to align arguments for action in ovarian cancer under the broad umbrella of women’s cancer, and make the best use of our advocacy resources’

*Julie Torode,
Institute of Cancer Policy,
King’s College, London.*

ROUNDTABLE DISCUSSION

1. PERSONAL STORY

THE CANCER SITUATION IN BANGLADESH – ADEL'S AND MONOARA'S STORY

Rafe Sadnan Adel's (Adel) mother died from ovarian cancer in 2014, and their experience in Bangladesh is illustrative of the journey patients and carers in lower-income countries need to take while navigating a cancer diagnosis. As a result of challenges in accessing basic information and support in their own language, Adel personally spent an enormous amount of time doing research, while at the same time caring for his ailing mother. So profound was his experience that Adel was inspired to establish an online resource (www.cancerbd.net) to support Bengali cancer patients by providing basic information about their disease and treatment options. By doing so, others in a similar situation will not have to experience 'time toxicity' and will instead be able to spend precious time with their loved ones. Adel's initiative demonstrates that civil society can play a significant role in supporting patients and carers.

Adel's mother, Monoara, went through a 4-year struggle with ovarian cancer and was faced with costly medicines, poor health system infrastructure and a lack of basic information including knowledge about treatment side effects. Monoara and Adel's experience captures many of the frustrations and stresses of what women and carers face in lower income countries including the double-whammy of 'time toxicity' – time diverted away from loved ones focused on finding much-needed information - and also

'financial toxicity' - having to suffer out of pocket expenses for treatments that would likely be available in most high-income countries. As a family, they had to resort to crowdfunding to try and raise the necessary funds for treatments that might not even have been available locally in the prescribed format due to supply issues. Monoara and Adel's striking story encapsulates how health systems are failing patients and their families, particularly in poorer parts of the world, while also offering hope in how to overcome these challenges.



ROUNDTABLE DISCUSSION

2. KEYS TO ROUTINE ACCESS

SHALINI JAYASEKAR-ZÜRN KNOWLEDGE, ADVOCACY & POLICY TEAM, UICC

Ms. Jayasekar-Zürn highlighted several barriers to access medicines identified during the UICC World Cancer Leaders' Summit in 2019 which aligned with the four domains for improving access. In particular, the perennial challenge of medicines listed on the WHO EML not being available due to various factors, including inadequate pricing policies, procurement and supply challenges and access to companion diagnostics. Potential solutions include a move towards more sustainable pricing (including discussions on reimbursement) and addressing the challenges of procurement and supply chain by bringing together all the relevant stakeholders to ensure a reliable supply of equipment and other services are provided.

'There is a huge capacity building component in diagnostics and pathology which are so vital yet often don't get the attention they deserve.'

Shalini Jayasekar-Zürn
UICC

Also, building capacity in diagnostics and pathology services are vital yet often don't get the attention they deserve - so the Essential Diagnostics List (EDL) and the EML must be aligned at country level to ensure access to appropriate treatment.

Shalini concluded by touching on the leading role that civil society can play in making the case for access to medicines by pointing out the influence exerted by advocates campaigning for direct acting antivirals (DAAs) for Hepatitis C patients in India and how this should serve as inspiration for cancer advocates.

PROFESSOR CHRIS BOOTH MD THE CANCER RESEARCH INSTITUTE, QUEEN'S UNIVERSITY, CANADA

Prof. Booth gave a formal overview of the role of the WHO model Essential Medicines List, which serves as a guide to policymakers and governments to shape their own national EMLs and formularies. Additionally, in recent years a formal working group was established to advise the WHO on implementation of the EML, creating a touchpoint for the cancer community to influence the content. He reiterated the role that civil society can play in encouraging more active engagement in national processes of translating WHO advice into a national cancer EML.

Chris highlighted the findings of the Desert Island Project¹⁰, in which oncologists around the world largely agreed on the 20 priority cancer medicines they would choose to take with them to a desert island, irrespective of where they worked. Unfortunately, for the vast majority of patients worldwide those same 20 medicines are not routinely available. For example, carboplatin in LMIC is only universally available without significant financial impacts on patients for just one-third of women, one-third of oncologists said they could prescribe the drug but it would lead to significant financial toxicity for their patients and another one-third said they could give it to their patients but it would result in catastrophic financial ruin.

ROUNDTABLE DISCUSSION

2. KEYS TO ROUTINE ACCESS

RUNCIE C.W. CHIDEBE
EXECUTIVE DIRECTOR PROJECT PINK
BLUE AND WORLD OVARIAN CANCER
COALITION BOARD MEMBER

Mr. Chidebe discussed access to cancer medicines in Africa with specific reference to Nigeria, providing a brief overview of the health system challenges in the latter. Barriers to accessing medicines include the transport infrastructure and the location of hospitals, and the additional problems these present to cancer patients. For example, many patients can't afford even the bus fare to their hospital. This is particularly problematic in a geographically large and populous country like Nigeria where over 30% of the population are over 4 hours away from a comprehensive cancer treatment centre¹¹. Very few Nigerians can afford cancer treatment, with less than 5% of the population covered by health insurance and as much as 90% of health expenses are paid out-of-pocket.¹² The transport and other infrastructure reality in Nigeria could easily apply to other countries in Africa and, in many others, the situation is actually worse, demonstrating the need for governments to consider wider investment beyond the confines of health care services if this reality is to change for the better.

'For many patients, finding the bus fare to travel to a cancer centre is beyond them.'

Pat Garcia Gonzalez
CEO, The Max Foundation



'Very few Nigerians can afford cancer treatment, with less than 5% of the population covered by health insurance and as much as 90% of health expenses are paid out-of-pocket.'

Runcie C.W Chidebe
Project Pink Blue, Nigeria



ROUNDTABLE DISCUSSION

3. MOVING THE NEEDLE

MEGAN O'BRIEN VICE-PRESIDENT GLOBAL CANCER TREATMENT, AMERICAN CANCER SOCIETY

Ms. O'Brien described how access barriers can be broken using a 'leaky pipeline' as an apt metaphor for highlighting the complexity of the access to treatment conundrum. There are challenges at every step and even if one of the leaks is plugged, patients can get lost at the next step in the journey – therefore interventions must be multi-modal in scope. The American Cancer Society have seen centres staffed and full of patients, yet there are no available treatments, leading to many patients seeking medicines from private pharmacies where they pay significantly more or resorting to black market sources with the high risk of counterfeit products.

Megan showcased several joint initiatives working with other NGOs, such as the Clinton Health Access Initiative, professional bodies such as the NCCN and the African Cancer Coalition to harmonize cancer guidelines in Africa to address the shortage in treatment guidelines across the continent.

'Every access program needs to consider supply and demand - we often solve a supply issue but then see the medicine expire on the shelf.'

Megan O'Brien
VP Global Cancer Treatment
American Cancer Society

Megan concluded by outlining key lessons learned including that advocacy is most effective when it is paired with well-developed solutions and specific 'asks', and that every access program has to look at both supply and demand. Finally, governments and health officials often lack the understanding of the cancer environment and need technical support with a critical role for local cancer experts to play in bridging that knowledge gap.

DR. ASIMA MUKHOPADHYAY GYNAECOLOGICAL ONCOLOGIST

Dr. Mukhopadhyay presented a summary of how her specialist centre and research group in India (KolGoTrg) is engaging professionals throughout the patient journey using academic clinical trials with an emphasis on making best use of the available and limited resources (a resource adapted patient and professional advocacy approach). A contrast was made between high- and low-income settings, in which she also has extensive experience. In higher resource settings, there is a clearer pathway of treatment for women starting with surgery, chemotherapy and the option of the latest treatments, such as PARPi, as well as processes in place to help you recover and survive your cancer. In lower resource settings the pathway will be patchy and in practice will require a more flexible and innovative or creative use of treatment options, with the aim of making the most of the limited available resources. For example, in India, KolGoTrg has initiated implementation studies where existing healthcare professionals, like nurses, are being trained to carry out counselling as part of their genetic testing services in the cancer setting (NuGenA), or developing low cost HRD assays and introducing proof of concept trials for affordable approaches for PARPi therapy (IPIROC, Intermittent dosing for PARPi).

ROUNDTABLE DISCUSSION

3. MOVING THE NEEDLE

PAT GARCIA-GONZALEZ CEO, THE MAX FOUNDATION

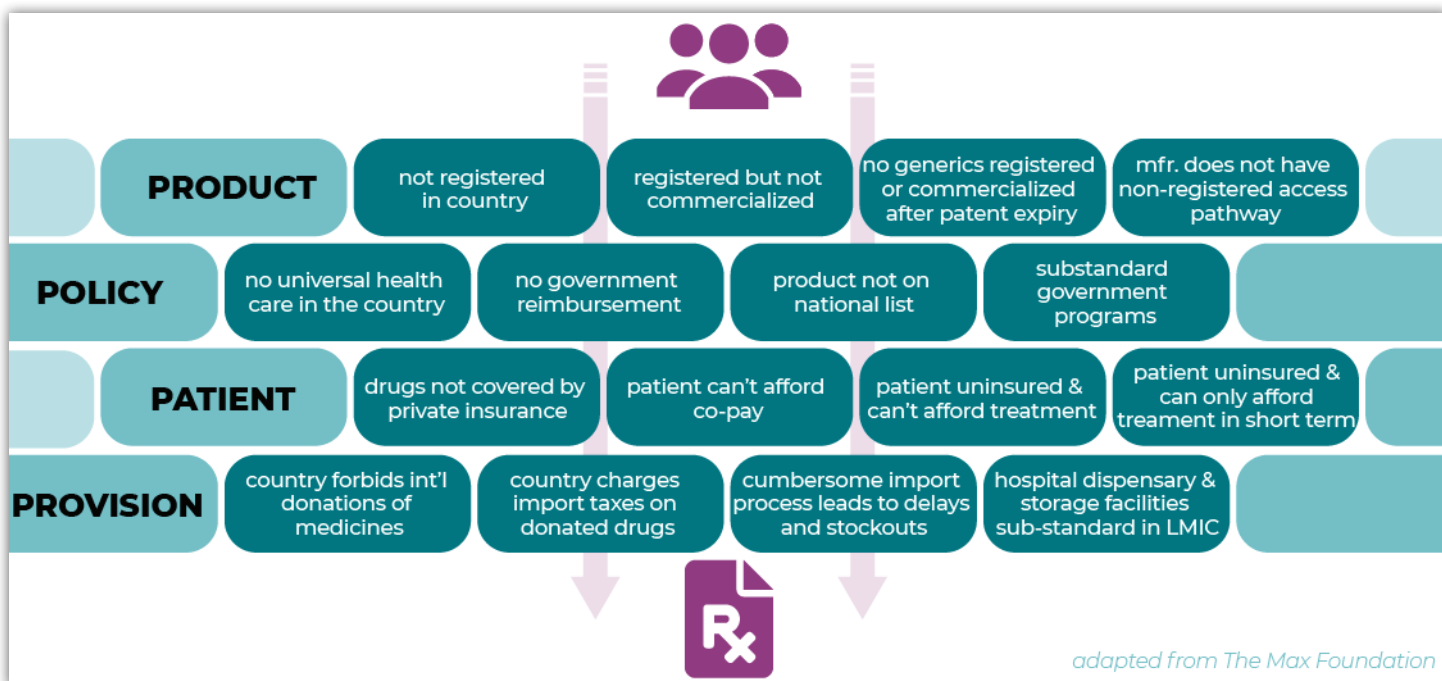
The Max Foundation runs a number of cancer programs in LMICs, including providing medicine to patients at no cost, for as long as they are needed. Ms. Garcia-Gonzalez described the seemingly endless access barriers faced in terms of a “brick wall.” Each brick presents a different barrier, and once a way to get through this layer is found, the next layer is revealed. For example a product may struggle to be registered in a LMIC, or if it is, it is not commercialized even after loss of exclusivity provided by its patent. If this ‘brick’ is removed, the next layer that patients face is their inability to afford their medicines, sometimes due to a lack of health insurance. If attempts are made to donate products, import duties are levied or it is government policy not to allow the gifting of products - South Africa being an example. If products, having overcome all these layers, do eventually find a route to patients, other socio-

economic and cultural barriers emerge, such as the stigma of certain diseases and the lack of agency for some women in their ability to make their own healthcare decisions.

However, through an effective network of volunteers and building long term partnerships with stakeholders, the Max Foundation has come up with effective solutions. In 2017, a new model of access to treatment called Max Access Solutions was created, made up of four pillars:

1. Shipping & logistics;
2. Healthcare provider network;
3. Medicines; and
4. In-country Max Team providing services to patient organisations and clinicians in local settings.

To date, 27 million doses of medicines to over 39,000 patients in 70 countries have been delivered.



ROUNDTABLE DISCUSSION

3. MOVING THE NEEDLE

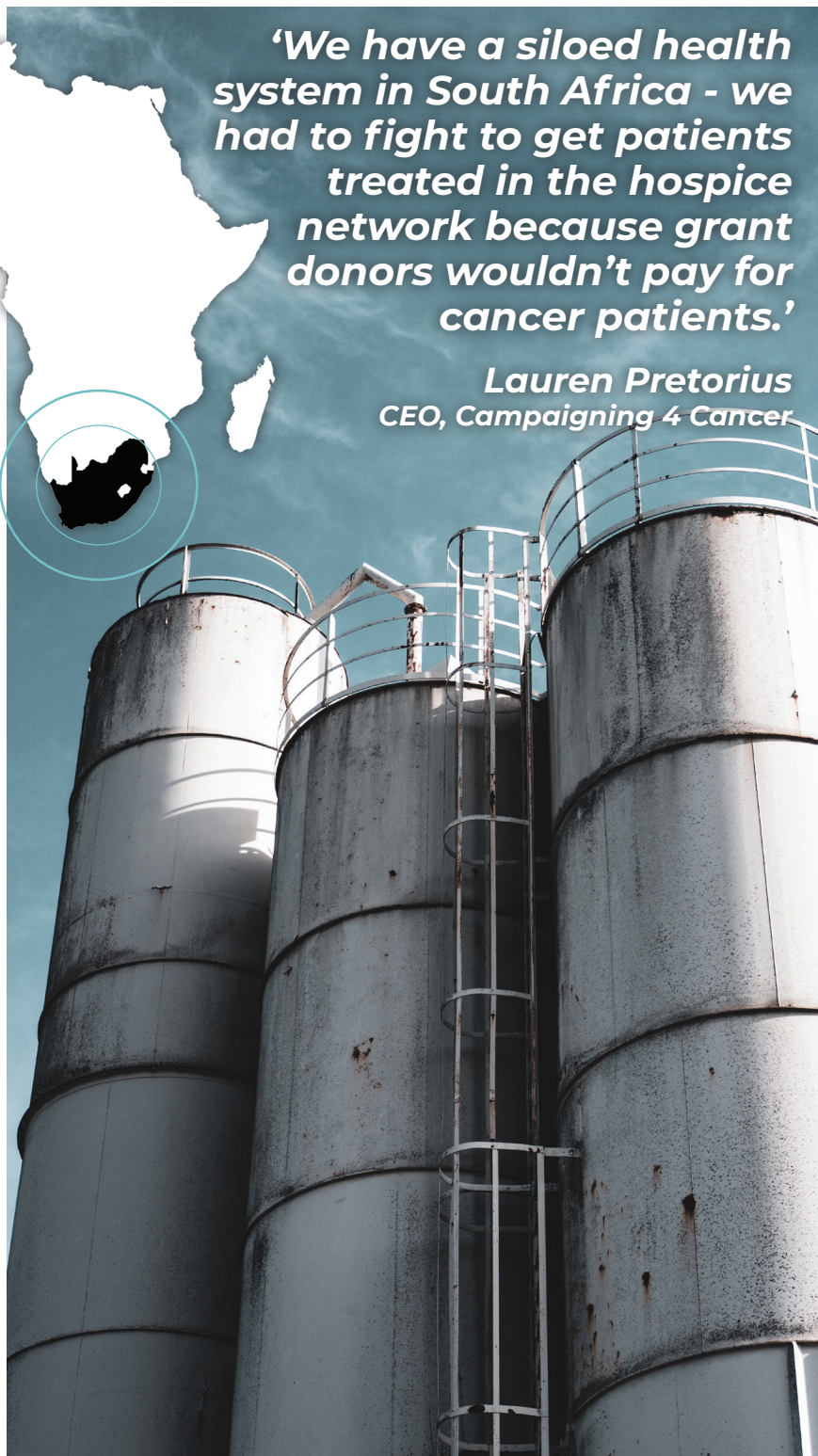
LAUREN PRETORIUS CEO CAMPAIGNING FOR CANCER

Ms. Pretorius spoke from a pan-cancer advocacy perspective in South Africa. She mentioned that emphasis on price seems to dominate discussions about medicines while innovative ways of financing are ignored. Lauren posed the question: How do we entrench capacity building to determine value in a particular country, which would be a huge tool to help LMICs particularly where the capability to assess that value does not exist? As well, existing protocols, formularies and guidelines are created without the flexibility to adapt to a patient's precise needs and as such negate the idea of precision medicine. Therefore, systems that assess this more effectively are required as are financial plans that delivers patients.

Finally, Lauren raised the point about the 'siloed' healthcare systems in South Africa, where HIV and communicable diseases are kept apart from NCDs due to grant and donor funding. Specifics of grant conditions result in NCD groups not being able to access the skills which means a few health conditions are prioritised over each other (e.g., NCD). This needs to be addressed with donors.

'We have a siloed health system in South Africa - we had to fight to get patients treated in the hospice network because grant donors wouldn't pay for cancer patients.'

Lauren Pretorius
CEO, Campaigning 4 Cancer



ROUNDTABLE DISCUSSION

3. MOVING THE NEEDLE

JAYASREE IYER CEO, ACCESS TO MEDICINE FOUNDATION


The Foundation manages the Access to Medicines Index, a tool for driving change in the pharmaceutical industry that identifies practice, tracks progress, and shows where critical action is needed to improve access to medicine for the poor. Jayasree provided key insights and an update on the next iteration of the Index and explained how they work with industry on how they perceive challenges in LMIC.

Pharmaceutical companies find that the barriers to access are similar in nature to those already raised during the Roundtable discussion and find it difficult to see how these can be overcome. There is an opportunity to exchange knowledge between companies and local advocates and clinicians to address the lack of understanding in industry about the demand and volume of consumption for medicines in lower income countries. This would enable companies to build a case internally for a genuinely global access strategy.

LORNA WARWICK, CEO, LYMPHOMA COALITION

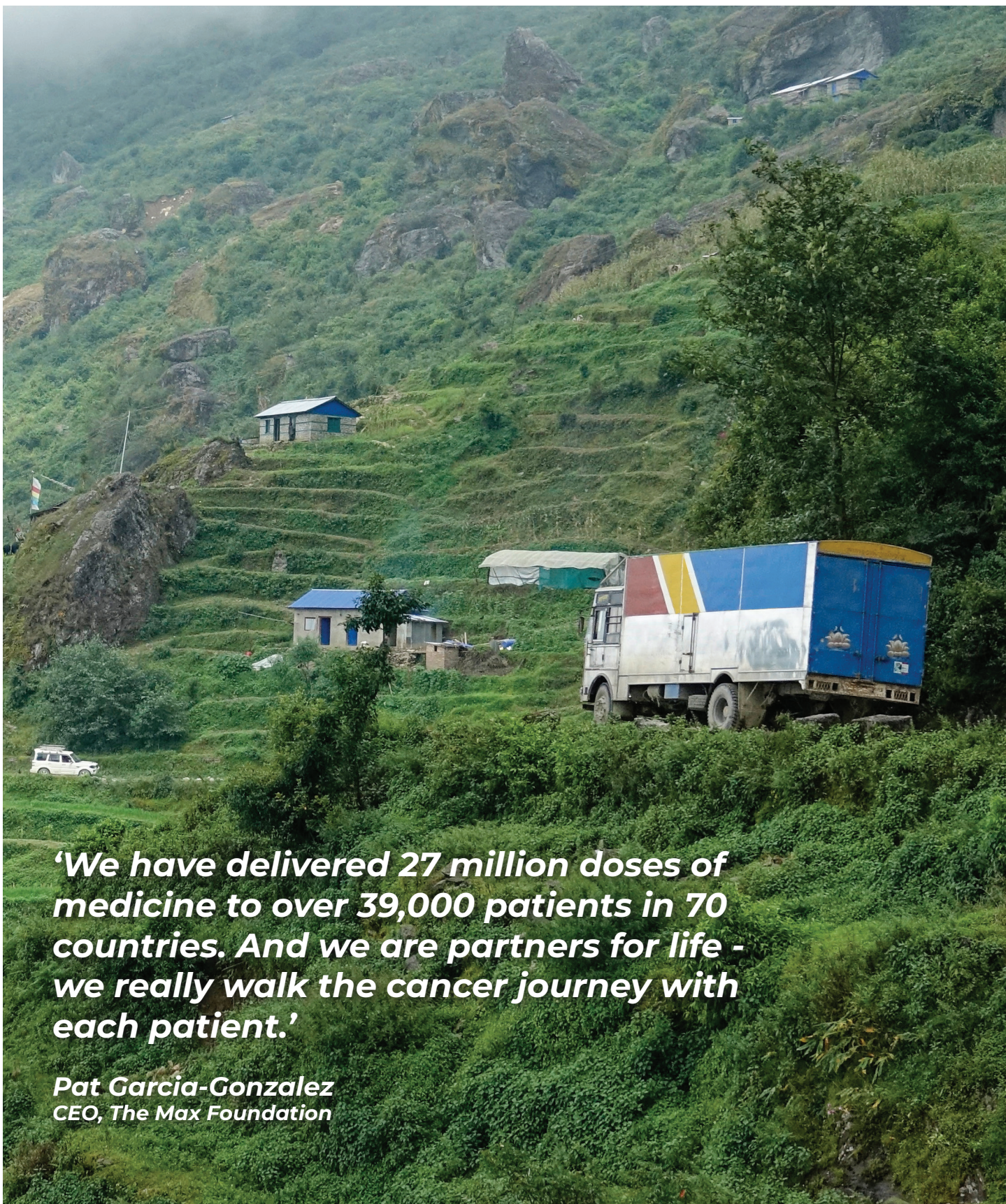
The Lymphoma Coalition is a global patient organisation with experience in supporting their advocacy network. A key learning is that country-level organisations have come about for their own specific reasons and advocacy is not necessarily a priority for all of them. As such, the Lymphoma Coalition have had the most impact where they have supported those of their members who are willing to participate in the advocacy process through training and working alongside them.

Original data to support advocacy plans is an important tool they provide their network. This is created through their Global Patient Survey on Lymphomas & CLL, which provides comparisons on the patient experience in countries on access to medicines and clinical trial activity amongst other areas. In summary, the value of a global coalition resides in their provision of training where there is local capacity, and providing the evidence base to more effectively make the case for action.



'We can help equip those local advocates [with data] so they can have those high quality discussions without struggling to find the information.'

Lorna Warwick
CEO, Lymphoma Coalition



‘We have delivered 27 million doses of medicine to over 39,000 patients in 70 countries. And we are partners for life - we really walk the cancer journey with each patient.’

Pat Garcia-Gonzalez
CEO, The Max Foundation

KEY THEMES IDENTIFIED FROM THE DISCUSSION

LACK OF UNDERSTANDING OF THE CANCER ENVIRONMENT AND MEDICINES' OPTIONS

A common thread running through the discussion centred on the impact of underdeveloped health systems in LMICs that are mainly geared towards addressing communicable diseases driven by genuine global health concerns. As a case in point there is a pressing need to address rates of maternal, infant and child mortality – which in Nigeria and India accounted for almost a third of all deaths in children under 5 in 2020¹³. This focus also reflects a lack of health system processes and the stark reality of meagre local resources.

Because of this, policymakers and health system managers in many LMICs will have poor knowledge and understanding of the specificities of cancer treatment not limited to the diagnostic processes, the range of cancer treatment options, and workforce challenges. To underscore this point, during the discussion the Max Foundation highlighted a list of LMICs that have limited ability to treat cancer, most of which are in West, East, Middle, and Southern Africa.

The lack of basic understanding of cancer is a major structural challenge and will require a concerted long-term effort by the cancer community to explain that cancer has very different challenges from communicable diseases and is made up of multiple different tumour types with a large range of treatment options.

THE WHO ESSENTIAL MEDICINES LIST

A valuable tool in understanding the most effective medicines for cancer patients is the WHO's Essential Medicines List (EML). Although global in nature, it is in practice used more in LMICs where formal health technology

appraisal systems do not exist, and as a guide to policymakers and governments in procuring medicines for their citizens.

There are major barriers in access to core cancer medicines worldwide.

However, as evidenced by the Coalition's Treatment Mapping exercise and recent publication of analyses undertaken by Chris Booth as part of the 'Desert Island Project', access to vital cancer treatments on the EML is not wide-spread. The Project examined global access to essential cancer medicines¹⁴ and showed 'striking barriers to access, even old cheap medicines in LMICs' and risk of substantial out-of-pocket expenditures even in higher income countries not trivial'. They concluded that there were major barriers in access to core cancer medicines worldwide, with one reason for this being that these medicines are not adequately prioritized by country-level access policies. This has led to insufficient levels of expertise and data gathering processes required to understand the value medicines bring, a point touched on below. The Project concluded that there was a need to 'challenge the feasibility of adding additional expensive cancer medicines to the EML'.¹⁵

KEY THEMES IDENTIFIED FROM THE DISCUSSION

POOR DATA IN LOWER INCOME COUNTRIES

A third theme that emerged from the discussion was the paucity of data at multiple levels, including few cancer registries and a lack of recent studies showing the efficacy of older treatments such as chemotherapies and hormone treatments. This is due in part to the poor health system infrastructure and that universal protocols do not exist for cancer data generation to flourish. Data poverty leads to an overreliance on anecdotal clinician feedback when making decisions about resource allocation. A recent research article by scientists from the International Agency for Research on Cancer (IARC)¹⁶ argues that investment in the primary source of information – population-based cancer registries – equips individual countries with the continuous data necessary to plan and inform national cancer services.

Data poverty leads to an overreliance on anecdotal clinician feedback when making decisions...

Although local level data is sub-optimal, there are significant data sets that are generated at an international level, such as well-developed WHO databases, the IARC, and the National Comprehensive Cancer Network (NCCN) based in the US. However, despite ongoing efforts

by these organisations and others to work with local clinicians and advocates in Africa, awareness of these data sets is low. As these data sets have the potential to be a highly effective tool for those advocating for better access, efforts to make better use of these locally through the global cancer community's network should be explored.

Highlighted during our discussion were initiatives being undertaken to engage with countries on a data driven approach connecting their data with assessment analysis utilising many of their existing data tools such as their knowledge Action Portal, IARC Global Cancer Observatory and impACT reviews report amongst others. The American Cancer Society also presented their extensive work with the NCCN, African oncologists and African cancer centres to adapt current NCCN guidelines (which are the most commonly used cancer guidelines in West, East, Middle and Southern Africa), for better use in those areas. The 2019 UICC Cancer Leaders' Summit also stressed the need to invest in clear and reliable data systems.

THE VALUE OF INVESTING IN CANCER CONTROL

Our fourth theme is that of understanding the value of action. One consequence of poor data is an inability to articulate the value of cancer control in lower income countries. Due in part to the focus on communicable diseases, the value of all treatment options, including surgery and other interventions such as cancer drugs, are not fully recognised.

Through various country-level initiatives, the WHO is helping to define the value of cancer control with countries by connecting their data sets to carry out a thorough needs analysis and helping to build the case for investment in both economic and social terms, linking this

KEY THEMES IDENTIFIED FROM THE DISCUSSION

SUSTAINABLE DEVELOPMENT GOALS

3 GOOD HEALTH AND WELL-BEING



closely to the Sustainable Development Goals 3.4 and 3.8. This should not only highlight the number of lives that can be saved but how this translates into the contribution to society that those surviving a cancer diagnosis can go on to make, such as continuing employment, and by extension generating tax revenues, as well as reducing the burden on health systems by having healthier lifestyles.

The value that cancer medicines such as carboplatin, cisplatin and paclitaxel can bring to women with ovarian cancer is potentially huge and more can be done to educate local policymakers and clinicians, a fact recognised by the WHO and its EML Cancer Working Group who are now focusing more on implementation of the EML locally.

A cautionary note was raised at the meeting about the existing narrative that espouses 'more drugs, faster', which bypasses the fact that the greatest benefit for patients in lower income countries can be achieved if older, cheap chemotherapy and hormone treatments were understood and used. The 'Desert Island Project' highlighted during the discussion posed several questions and concluded that the WHO EML is an accurate reflection of which medicines matter most to clinicians¹⁷, yet these medicines are not sufficiently prioritized by country-level access policies¹⁸.

Although a detailed discussion on pricing of cancer medicines is not a central part of this report, the subject was raised several times during the discussion. Inadequate pricing policies have previously been raised as a major barrier to access and also an acknowledgement

that there are inadequate public funds to ensure universal access to essential medicines¹⁹. This has led to major out of pocket spending as identified in the Coalition's access project in 2021²⁰.

The Cancer Resolution adopted in 2017 by the 70th World Health Assembly²¹ reaffirmed cancer control as a critical health and development priority and led to the WHO Technical Report on the cost of cancer medicines demonstrating that countries consider cost a critical issue. The Report concluded that 'current pricing policy for cancer medicines has not adequately met health- and economic-related objectives' and that 'prices of medicines are high in both absolute and relative terms compared to other therapeutic areas'. It goes on to say that an ever growing list of medicines with annual costs in the hundreds of thousands is unsustainable, with action required by the global community to alter the status quo through 'system adjustments'²². As such, an open and honest debate is needed around reimbursement, alternative pricing mechanisms and taking forward the recommendations of the WHO technical report on pricing.

LACK OF EXISTING CANCER TREATMENT GUIDELINES HAMPER PLANNING AND PROCUREMENT

A further consequence of cancer not being a national priority in many lower income countries, is the lack of guidelines that have been developed, for example most countries in Africa do not have standard cancer treatment guidelines. This leads to poor quality, fragmented care and limits the ability to collaborate in training and research initiatives across countries, a point raised by the American Cancer Society. This fragmented approach to treatment can also be found within the same treatment centre with generational differences

KEY THEMES IDENTIFIED FROM THE DISCUSSION

in the way oncologists treat a particular cancer. Without a formal treatment framework procurement planning and forecasting become more difficult.

Harmonised guidelines developed by agencies such as the NCCN or the European Society of Medical Oncology have been adopted by some regions, for example, in West, East, Middle, and Southern Africa. However, these guidelines can be met by political resistance, especially if they do not fully take into account local issues and barriers.

‘If we don’t have quality affordable medicines on the shelf in the cancer centre, nothing else we do will matter.’

Megan O’Brien
VP Global Cancer Treatment
American Cancer Society

STRUCTURAL & CULTURAL CHALLENGES OF THE HEALTH ENVIRONMENT

As well as the major structural challenges healthcare systems in LMICs, there are wider infrastructure and cultural factors that will contribute to how healthcare, including medicines, is accessed.

The deep structural challenges of health systems in LMICs are significant, with non-

alignment with the WHO’s EML a common feature along with an insufficiently trained professional healthcare workforce. The UICC highlighted the need to address capacity building components to ensure sustainable access to cancer medicines for example, diagnostic and pathology services are vital and both EMLs and essential diagnostics need to be aligned at a country-level.

In terms of wider barriers, a country’s transport infrastructure and the location of treatment centres leave many patients behind as they cannot afford the bus fare to the hospital or the cancer centre is so far away that travel is simply unfeasible. Restrictions on the ability of some healthcare professionals²³ to prescribe drugs, such as pain medication for example, also leads to sub-optimal care. Other barriers highlighted include a lack of investment in manufacturing, the occurrence of natural disasters, and wars or conflicts in some areas – all of which are outside of the control of governments to varying degrees, even less so of health ministries. Additionally, social taboos that in some countries restrict a woman’s decision-making capabilities and health autonomy, can exacerbate problems and add a layer of complexity not easily addressed by policymakers.

THE IMPORTANCE OF CIVIL SOCIETY, CLINICIANS AND INDUSTRY

Our final theme centres on stakeholder collaboration. Patient advocacy groups and NGOs in high-income countries have made a significant contribution to raising the profile of cancer through not only raising funds and providing services to patients and carers, but also through the successful lobbying of governments. A study that looked at the breast cancer advocacy movement in 23 LMICs identified a number of challenges around trust,

KEY THEMES IDENTIFIED FROM THE DISCUSSION

knowledge gaps, stigma, sharing experiences, and sustainability. The study emphasised the importance of investment in three-way partnerships between health experts, civil society and political leaders and that advocates require evidenced-based solutions relevant to their local settings²⁴.

The Roundtable raised many of the same points, in particular the need for clinicians, NGOs/patient advocacy groups, industry, and policymakers to form closer relationships and have a coordinated approach in developing messages about the patient experience and the value of investment in cancer control. These relationships are essential in building a case for making treatments for ovarian cancer accessible and creating the necessary foundation for viable markets in LMICs.

Much can be learned from the experiences of civil society in other therapy areas, a point made by the UICC, who cited the impact of NGOs in convincing decision-makers in India to include direct acting anti-virals in providing a critical treatment option for patients with Hepatitis C. The Max Foundation also pointed to their collaboration with industry in making one of their products available for patients with chronic myeloid leukemia (CML).

As these examples illustrate, gains can be made if the relationship between civil society and industry is further developed; civil society offers unique insights into the patient experience, helps articulate the burden, quantify the need and can support industry to develop genuinely global access strategies. In addressing the complex challenge of access, we should direct our attention to three foundational areas. We need to first foster the development of robust, reliable local data that adequately quantifies patient need in each setting. We must nurture relationships with willing government partners

Advocates need evidence-based solutions relevant to their local settings.

who can set clear research and disease priorities supported by adequate funding and feasible regulatory processes. Finally, industry partners need to invest in the long-term development of sustainable and viable markets where they are weak or non-existent.

Additionally, in regions where resources are stretched, collaboration will be important in creating innovative practical solutions to everyday challenges, as well as a narrative that is convincing, has wide and informed support with a blended mix of carefully enlisted clinical expertise and the patient voice to provide a full picture. A gynaecological oncologist, who has experience of working in both high and LMIC countries, informed the group that the way they are addressing workforce gaps in India is by providing new skills for existing HCPs, such as addressing the lack of counsellors by training nurses to fill this role, as part of their genetic testing services.

'The greatest advance and benefit for most patients with ovarian cancer in the world... is ensuring patients have access to the core elements of treatment that provide large benefit. Safe, effective high quality surgery, access to carboplatin, cisplatin and paclitaxel, good supportive and palliative care.'

Chris Booth MD
Queen's University, Canada



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CONCLUSION AND RECOMMENDATIONS

WILLING AND ABLE

The rich discussion and passion displayed by the attendees at the Roundtable demonstrate there is no shortage of ability and willingness in the global cancer community to offer solutions that will improve access to medicines in LMICs.

The themes identified highlight the poor understanding among national policymakers about the complex nature of cancer care, and more specifically the potentially huge benefit older chemotherapy and hormone drugs can bring to women with ovarian cancer. A key reason for this is the lack of useful data systems that could better support the procurement and supply of medicines - as evidenced by lower income countries lacking a co-ordinated process that connects products with current guidelines and policies. Where no such systems exist, countries should be encouraged to use internationally created data as a starting point and as an example of good practice for national health systems to follow for the creation of sustainable data collection processes. Greater co-ordination is needed, including adoption of some of the work already achieved through harmonizing guidelines and access initiatives, such as those mentioned by American Cancer Society and the Max Foundation.

Many of the medicines that offer the greatest benefit to women with ovarian cancer, and indeed other cancers, have already been recognised and are on the WHO's EML. These include drugs that have been available for over 40 years, are off patent and inexpensive, yet to most patients are unavailable. Explaining the value of these drugs to policymakers will require a coordinated effort from multiple stakeholders - advocates, clinicians, and policymakers in order to widen their focus beyond NCDs and overcome their challenges in data collection. Underlying these impediments are the deep

rooted structural and cultural issues faced by LMICs, challenges that go far beyond health system infrastructure.

TIME TO ACT

Amid the hurdles to improved access to medicines, there lies an opportunity for the ovarian cancer community to move forward. A concerted effort is required to raise cancer control up national agendas of low- and middle-income countries, and to build the infrastructure required to tackle the rising burden of cancer facing these regions as we move toward 2040 and beyond. This can only be achieved if advocates, NGOs, industry, and clinicians with an enhanced role articulate the value of cancer control and the key role medicines play for women with ovarian cancer, and indeed many other cancer patients. Through greater collaboration and learnings from other disease areas that have successfully campaigned for change, the ovarian cancer community can begin to offer solutions that are grounded in evidence and propose ways to allocate scarce resources more efficiently.

Given the priority placed in cancer control, specifically in cervical cancer by the WHO and World Health Assembly, now is the moment for the ovarian cancer community to streamline efforts and collaborate with cervical, breast and other cancer groups to educate and empower women, as well as healthcare professionals, to act on concerns. In addition, the development of national cancer strategies addressing early diagnosis and screening and Universal Health Care should be joined together with our 'calls to action' if a paradigm shift is to be achieved and address the growing burden in LMICs..

CONCLUSION AND RECOMMENDATIONS

THE COALITION'S COMMITMENT TO OUR MEMBERS AND THE OVARIAN CANCER COMMUNITY

The Coalition will support the ovarian cancer community by continuing to collaborate with global colleagues already working in this area and by indentifying areas of good practice.

The Coalition will also develop new information resources that provide a summary of the ovarian cancer treatments on the EML in relation to the benefits that they offer for use by partner organizations. We will also provide partner organizations with practical ideas based on their local needs, including advice on:

- Creation of a 'Value of Cancer Control' narrative
- Improving data collection, including capturing patients' experiences
- Engaging in the development and dissemination of the WHO's EML
- Collaborating with the wider community (e.g. Clinicians, other cancer NGOs) to amplify the patient viewpoint

Over the course of 2022 and 2023, the Coalition will address the challenges identified in this report and support stakeholders to provide solutions and ideas that will drive change for the benefit of all women. In particular, the Coalition would like to examine the specific challenges faced by women, the drugs they are able to access, and the impact this has on their wider well-being and long term recovery.

Additionally, in addressing the call for better data, the Coalition is reaffirming its commitment to the ongoing Every Woman Study™: Low- and Middle-Income Edition, which is a joint undertaking between the Coalition and the International Gynecologic

Cancer Society. Once complete, this Study will equip up to 30 low- and middle-income countries with robust and statistically relevant ovarian cancer data that can be used at a local level to advocate for change, while also providing a global evidence base for the Coalition to bring to international policymakers and thought leaders to further the case that ovarian cancer become a global priority.

THE **EVERY WOMAN** STUDY™ LOW- and MIDDLE-INCOME EDITION



More broadly, the Coalition will continue to engage with all of their stakeholders: clinicians, policy experts, NGOs, and industry at a global level, to articulate the issues that matter most to women with ovarian cancer – no matter where they live.

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APPENDICES

APPENDIX I: LIST OF PARTICIPANTS

Julie Torode

Visiting Scientist, King's College London -
Facilitator

Rafe Sadnan Adel

Founder Chairperson of Cancerbd.net
Bangladesh, member of World Ovarian Cancer
Coalition Board of Directors www.cancerbd.net

Christopher Booth

Medical Oncologist and Health Services
Researcher, Queen's University, Canada

Runcie C.W. Chidebe

Founder, Executive Director, Project Pink Blue,
member of World Ovarian Cancer Coalition
Board of Directors

Pat Garcia-Gonzalez

Chief Executive Officer, The Max Foundation
www.themaxfoundation.org

Megan O'Brien

Vice President, Global Cancer Treatment,
America Cancer Society. www.cancer.org

Shalini Jayasekar-Zürn

Knowledge, Advocacy and Policy team, UICC
www.uicc.org

Asima Mukhopadhyay

Gynaecological Oncologist (surgeon) and
clinician scientist, UK & India www.kolgotrg.org

René Pareja

Gynecologist and Obstetrician, Colombia

Lauren Pretorius

Chief Executive Officer, Campaigning For
Cancer, South Africa. campaign4cancer.co.za

Lorna Warwick

Chief Executive Officer, Lymphoma Coalition.
lymphomacoalition.org

Jayasree Iyer

Access to Medicines Foundation.
accesstomedicinefoundation.org

Clara MacKay

CEO, World Ovarian Cancer Coalition

Frances Reid

Programmes Director, World Ovarian Cancer
Coalition

Phaedra Charlton

Director of Communications & Marketing, World
Ovarian Cancer Coalition

Mikis Euripides

Policy & Patient Advocacy professional

APPENDIX II: FURTHER READING ON HEALTH SYSTEMS IMPACT ON MEDICINES ACCESS

Cancer and Universal health coverage

UICC World Cancer Leaders' Summit, 2019:
[www.uicc.org/sites/main/files/atoms/files/
WCLS2019-Report-Final.pdf](http://www.uicc.org/sites/main/files/atoms/files/WCLS2019-Report-Final.pdf)

WHO Technical Report on Pricing of Cancer Medicines and its Impacts

[apps.who.int/iris/bitstream/hand
le/10665/277190/9789241515115-eng.pdf](http://apps.who.int/iris/bitstream/handle/10665/277190/9789241515115-eng.pdf)

World Ovarian Cancer Coalition Ovarian Cancer Treatment Mapping Research

[worldovariancancercoalition.org/wp-content/
uploads/2022/08/Ovarian-Cancer-Treatment-
Access-World-Ovarian-Cancer-Coalition.pdf](http://worldovariancancercoalition.org/wp-content/uploads/2022/08/Ovarian-Cancer-Treatment-Access-World-Ovarian-Cancer-Coalition.pdf)

APPENDICES

APPENDIX III: CAMPAIGN EXAMPLES AND INFORMATION WEBSITES MENTIONED

www.pepal.org/njia

campaign4cancer.co.za/wp/project-ask

www.cancerbd.net

APPENDIX IV: WHO ESSENTIAL MEDICINES LIST (2021) - OVARIAN CANCER DRUGS

The following are ovarian cancer drugs that are on the WHO Essential Medicines List (2021 edition):

- Anastrozole (hormone treatment)
- Bevacizumab (VEGF-A inhibitor)
- Bleomycin (chemotherapy for non-epithelial ovarian cancer)
- Carboplatin (chemotherapy for epithelial ovarian cancer)
- Cisplatin (chemotherapy for non-epithelial ovarian cancer)
- Etoposide (chemotherapy for non-epithelial ovarian cancer)
- Gemcitabine (chemotherapy for epithelial ovarian cancer)
- Letrozole (hormone treatment)
- Paclitaxel (chemotherapy for epithelial ovarian cancer)
- Pegylated Liposomal Doxorubicin (chemotherapy for epithelial ovarian cancer)
- Tamoxifen (hormone treatment)
- Topotecan (chemotherapy for epithelial ovarian cancer)

The Coalition is grateful to these participating organizations:

**LYMPHOMA
COALITION**

 **The Max
Foundation**

 **American
Cancer
Society®**

 **uicc**
global cancer control

 **Cancerbd.net**

 **Project PINK BLUE**

**access to
medicine
FOUNDATION**

 **CAMPAIGNING
FOR CANCER**

 **Queen's
UNIVERSITY**



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**EMPOWERING THE GLOBAL OVARIAN CANCER COMMUNITY
THROUGH KNOWLEDGE, COLLABORATION AND ACTION.**

THE JOURNEY TO MORE EQUITABLE OVARIAN CANCER CARE
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Registered address:
205-145 Front Street East
Toronto, Ontario, Canada, M5A 1E3

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