MAKING OVARIAN CANCER A GLOBAL PRIORITY

Virtual Meeting Report

GLOBAL
OVARIAN
CANCER
CHARTER
a World Ovarian Cancer Coalition initiative

MAKING OVARIAN CANCER A GLOBAL PRIORITY

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INTRODUCTION

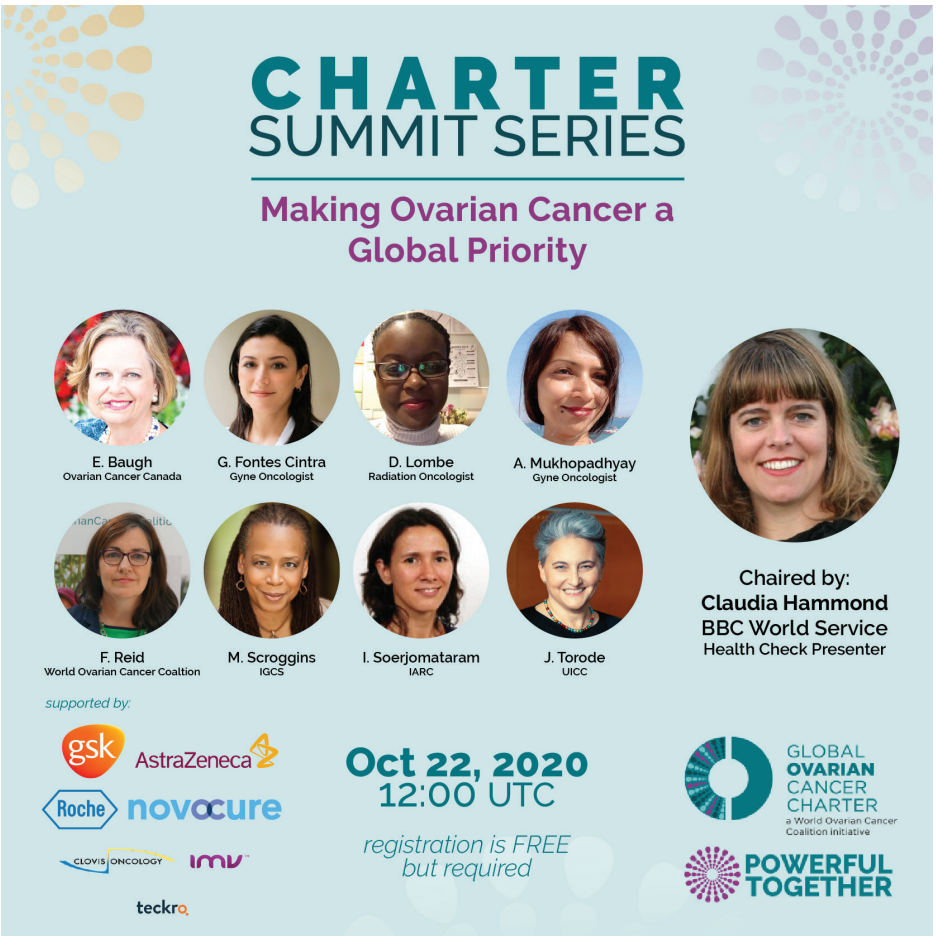
This report summarises the virtual meeting, 'Making Ovarian Cancer a Global Priority', which took place on 22nd October 2020 as part of the Global Ovarian Cancer Charter Summit Series. A recording of the meeting is available on the World Ovarian Cancer Coalition website.

The purpose of the meeting was to highlight key challenges and opportunities for improving survival and quality of life for women with ovarian cancer and to explore in particular the gap between care for women in high resource settings compared to those living in low- and middle-resource settings.

The format for the meeting was an expert panel of individuals with diverse experiences and expertise. The context for the discussion was the Global Ovarian Cancer Charter launched in September 2020 and the specific Goal that calls for ovarian cancer to become a global priority. The discussion was also informed by the World Ovarian Cancer Coalition launch of an updated Global Atlas that includes projections for an increase in incidence in of ovarian cancer of 47% by 2040, with developing countries likely to face the greatest burden.

The World Ovarian Cancer Coalition is using the information from this meeting to inform our programme of Global Charter activity, including the development of the Every Woman Study™ that will be piloted in low- and middle-income countries.

Attendance at the meeting was diverse with over 160 registrants, 90 live participants from over 25 countries, including patient advocates and patient advocacy organizations, policy makers, clinicians and industry. We hope that those who attended, participated, or have since engaged with the content will be inspired to explore what more they can do as individuals and organisations to make ovarian cancer a priority in their country and beyond.



MEETING CONTENT

The meeting was introduced by Clara MacKay, Chief Executive Officer of the World Ovarian Cancer Coalition, and the discussion was hosted by BBC World Service Health Check and the Evidence presenter Claudia Hammond.

The panel included:

- **Isabelle Soerjomataram**, Deputy Section Head of the International Agency on Cancer Research (IARC)
- **Julie Torode**, Special Projects Director at the Union for International Cancer Control (UICC), Switzerland
- **Dicey Scroggins**, Advocate and Director of Global Outreach and Engagement at the International Gynecologic Cancer Society (IGCS), USA
- **Elisabeth Baugh**, Chair of the World Ovarian Cancer Coalition and CEO of Ovarian Cancer Canada
- **Dorothy Lombe**, MD, clinical and radiation oncologist, Cancer Diseases Hospital, Zambia
- **Asima Mukhopadhyay,** Consultant and Honorary Associate, NGOC, Gateshead and Newcastle University, UK, Honorary consultant, Chittaranjan National Cancer Institute, Kolkata, India
- **Georgia Fontes Cintra**, Gynecologic Oncologist, Hospital Sírio Libanes, Brasilia and IGCS International Mentor in Mozambique

BACKGROUND

The meeting started with presentations outlining the most up-to-date information on ovarian cancer incidence, mortality and survival as as a clinical overview of advances in ovarian cancer treatment.

THE WORLD OVARIAN CANCER COALITION ATLAS 2020

- Frances Reid**,** Programme Director, World Ovarian Cancer Coalition

This review of global ovarian cancer incidence, mortality, and survival is an update of a report produced in 2018 to inform the first Every Woman Study™. The full 2020 report can be found here.

Key points from the presentation:

- There were just under 300,000 cases of ovarian cancer in 2018 and three-quarters of a million women living within five years of a diagnosis.
- Two-thirds of these women live in low- and middle-income countries where cancer has been seen as a disease of the rich. While cervical cancer currently presents the greatest burden and challenge, the new WHO cervical cancer elimination strategy, with vaccination and screening, has great potential to combat this.
- Just one in five low- and middle-income countries have the necessary data to drive cancer

policy

- Age-standardised incidence rates are highest in high-income countries, but rates rise as countries, or regions within a country, develop economically
- Ovarian cancer is not one disease, nor is the way it spreads described in a consistent fashion. This creates challenges when trying to describe and plan how to tackle the burden of disease
- Existence of, and adherence to, guidelines on diagnosis and treatment vary widely, even in high-income countries. Many adapted guidelines for low-income countries are still too complicated, or not suited to local resource to allow for widespread implementation
- Access to treatment varies, especially to new PARP inhibitors and targeted medicines such as Bevacizumab. Genetic testing is also similarly challenged. Many low- and middle-income countries do not have access to these new developments, and also can struggle to access the basic chemotherapy drugs, which have been the mainstay of ovarian cancer treatment for more than 30 years. In a number of low-and middle-income countries patients have to pay some or all of the cost of their treatment, and even when they don't there are many associated costs that will have a catastrophic effect on a family's finances
- Studies such as the International Cancer Benchmarking Partnership Study or the Concord studies provide insight into the variations in survival around the world. Caution should be exercised when comparing one country's survival rates within another, except within studies or highly comparable studies
- Incidence rates are set to rise 47% by 2040. Those in developing countries will be hardest hit. For example, in Africa cases are set to rise 98% in that timeframe, whereas in Europe, the figure is 10%
- These figures add to the urgency to ensure the gap between high- and low and middle-income countries does not widen.

KEY ADVANCES IN OVARIAN CANCER TREATMENT OVER THE LAST DECADE

- Georgia Fontes Cintra

Georgia outlined the main challenge with ovarian cancer – that approximately 70% of women will have repeated recurrences of their disease, at increasingly shorter time intervals until treatment no longer works. This suggests that what has been offered in the past decades is not really suitable. However, three recent key developments are offering the potential to transform outcomes for women:

- It has been shown that advances in surgery can impact on women's outcomes. Goals have changed from trying to reduce any residual disease to less than 1cm, to trying to remove all sites of the disease. This involves really aggressive surgery, and it was right that women and clinicians questioned whether it was worth putting someone through that, but the results show that it can be. But in order to be able to do such aggressive surgery a surgeon needs specialist training and work in a high volume, specialist centre
- A greater understanding of genetic mutations that can cause ovarian cancer is leading to a better understanding and treatments for the disease. Initially it was thought that younger women were most affected by these forms of the disease, but it is now known to be more spread across the ages, and that not all have a significant family history. Guidelines have

changed to say all women with epithelial ovarian cancer should be tested, which then allows other affected family members to take preventative action with prophylactic surgery

- Use of new targeted drugs, such as PARP inhibitors for those with BRCA mutations or HR deficiency, together with drugs such as Bevacizumab are offering the real hope of turning the disease from a life limiting disease to a chronic disease, with patients even with stage 3 disease living 60 months and beyond.

PANEL DISCUSSION - KEY THEMES

The following highlights the key themes raised during the panel discussion.

The key challenges in low- and middle-income countries

Throughout the discussion there were many examples of the multiple challenges women with ovarian cancer face in low- and middle-income countries. They can vary somewhat between countries and include but are not limited to:

- Very late diagnosis (lack of awareness, challenges of getting a diagnosis)
- Access to imaging and specialist pathology to make correct diagnoses
- Access to basic chemotherapy drugs, either because patients cannot afford to pay if it is not covered by the state or insurance, or supplies are erratic
- Very different experiences between private and public hospitals and whether or not there is access to health insurance
- Access to new targeted treatments and genetic testing
- Lack of skilled surgeons, anaesthetists, access to theatre and ICU space
- 'Half treatment' in the community because more general doctors do not have enough knowledge, and can be disastrous for women in terms of their outcomes and finances
- Lack of clinical trials to drive up standards and assess treatments for local populations and lack of associated infrastructures
- Follow up can be erratic as patients often live a very long way away from cancer centres and often choose not to return
- The need for sustainable approaches to system improvements, rather than a sudden initiative for two years that fades away.

Georgia highlighted that many doctors, outside the direct field of gynecologic oncology, still view ovarian cancer as a death sentence, and that this pessimism in some way restricts their willingness to do more for women. There is a need to let them know that there are now opportunities to make progress, and potentially allow women to return to contributing great value to societies through their work, caring, or family commitments. Georgia said that in her country, many doctors do not speak English, and their knowledge of ovarian cancer is from text books in their native language that are often considerably out of date. We should not give up on the women, and need the whole team behind this change in approach.

Both Georgia and Dorothy were very keen to also highlight the possibility of improving palliative care for women. There is perhaps a culture of 'too much too late'. Dicey highlighted the importance of palliative care beginning at diagnosis, helping women to optimise their wellbeing.

Dorothy highlighted that even if she cannot do much to cure or extend life, she can be there to make women's final days or months more bearable. Georgia expressed concern at the backlash in her country of the use of opioids, because of the potential for addiction and misuse. Julie highlighted important work in progress by the Commission of Narcotic Drugs, with UICC and ESMO aiming to balance regulation with access for medicinal purposes, but at present this has yet to percolate down to daily practice. Advocates can help to make a difference with this.

Asima highlighted that breast and cervical cancers were now being noticed and acted on more in low- and middle-income countries, for example with the establishment of clinical trials, but there has been little interest hitherto from governments in funding ovarian cancer research. The cost of treating an ovarian cancer patient versus a cervical cancer patient was a barrier and that it was important to overcome the issues and perceptions.

She also highlighted that research in India showed that a lot of younger women were getting ovarian cancer, 10-15 years earlier than in the UK, and that up to 30% of the cases involve a BRCA mutation. Reflecting on the large increases in future years she said that significant numbers of family members were at risk of developing breast, or ovarian cancer. As such it was important that BRCA testing should be part of the funding mechanisms for governments, and part of the policy effort. She is helping develop low cost alternative approaches to genetic testing through their NUGENA programme (nurse led) in India and Nepal. Whilst PARP inhibitors currently are prohibitively expensive in countries such as India, there are opportunities for primary prevention strategies. Having worked on the development of one of the PARP inhibitors (Rucaparib) and now setting up trials of low dose treatments in Kolkata, she described it as heart-breaking to see almost 80% of women not have access to such new treatments.

The importance of data

The panel agreed about the importance of data as a means to cancer planning, control, and improvement. Isabelle highlighted the low level of data in low- and middle-income countries, and that without data it is impossible to start advocating for changes, take decisions, and even really talking about ovarian cancer. Whilst collecting data in such settings may not be easy, even basic level cancer data would start the process of making it a priority, working together. Differences in data, for example in ovarian cancer incidence and survival provide opportunities to identify gaps, and can help point to solutions. Gaps can occur between countries, but also between ethnic groups, age groups, and socioeconomic groups.

Asima reinforced the need for data to drive change. She cited the challenges she had as a surgeon to convince hospital authorities that it was worth allowing extra operating theatre time to undertake more complex operations, both in the UK and India. Surgeons are always under time pressure from hospitals, and it takes some convincing to persuade them that four extra hours in theatre, and four extra days in intensive care (ICU), may provide a woman with four years extra life.

Elisabeth spoke about variations within a country, and how Ovarian Cancer Canada's version of the Every Woman Study™ is now digging deeper into local and regional differences, across the different provinces in Canada, so that all women have access to the best possible care.

An audience member highlighted that some rarer forms of ovarian cancer are not researched, and receive less attention and resource. Georgia highlighted that in these situations it was really important to pool data from as wide a range of countries as possible otherwise it would be impossible to determine the best way to manage these patients, and that giving them generalised treatments was definitely not optimal. Isabelle, who is undertaking a study on survival in ovarian cancer highlighted the challenges of getting data on the rarer types, which ultimately means that they do not have enough information to be presented and published. She confirmed the value of meetings such as this to get the message across and bring people together to tackle such issues.

The importance of a whole-system approach

Julie commented that many of the challenges highlighted were not unique to ovarian cancer and were in fact common health system challenges that need to be solved for all cancers.

To achieve the goal of optimising outcomes for patients and countries, well-oiled systems are needed: Referral, with informed primary care, and referral pathways to centres that can confirm a diagnosis, treatment and palliative care given in a timely manner. There is a lot of work to be done to achieve this in low- and middle-income countries.

The 2017 Cancer Resolution embraced the ambition of improving cancer health systems adopted by all countries, and it is a useful document and a fantastic hook to raise the issues in the Charter with policy makers, reminding them of the obligations they have made in the resolutions. Many countries have since upgraded their cancer plans. These are the routes to secure progress, there is a website to find a country's own cancer plan and partners who have similar aims to drive improvements. Julie is happy to introduce ovarian cancer advocates to partners in their own countries to reinforce these national efforts.

Julie highlighted that many decision makers of today in low- and middle-income countries did their training in communicable diseases, and may therefore not be so well informed about good cancer control measures. It takes time to build trust and get messages across. She acknowledged that in the past there has been too much of a focus on medicines alone, and that the UICC and wider cancer community was pushing forward on surgery, radiotherapy, and now diagnostics. The package needs to be put together as a whole. Whether it is a small, medium, or large package depends on a nation's ability to pay, but even so there should be a connectivity of care, a sustainable complete care pathway for a set number of cancer types. She advised starting small, and build over time, and that cancer advocates have a vital role to play in bringing about these changes.

Dorothy emphasised the importance of focusing on infrastructure, laboratory support and new technologies and that solving issues in low- and middle-income countries must not happen in silos. Medicines on the WHO Essential medicines list must be made available. There is no point gaining access to PARP inhibitors in Zambia if there is not the laboratory support for genetic testing. The global health community needs to stop defining where we stop and start, and needs to be a blanket improvement in the type of services offered in cancer care. Multi-disciplinary care is improving, but technology is lagging behind.

Ovarian cancer as a woman's health issue

Julie felt that the global health community still has much more to do to boost the profile of women's health beyond maternal and reproductive health. There are some excellent pieces of work emerging to show the impact of the loss of women's lives on families, communities and economies. These should help ovarian cancer advocates, and find allies to champion the issues, such as focusing on the rights of women, empowerment of women and women's health. Show yourself as a trusted source of high-quality information to start the dialogue.

Julie thought that the ovarian cancer community should consider talking more about women's cancer as a whole vs ovarian cancer specifically. She pointed to the WHO's plan to formally launch its Global Cervical Cancer Elimination Strategy on November 17th as an example of where there may be great opportunities to strengthen health systems that could also benefit women with ovarian cancer.

The importance of advocacy

This was a particularly strong theme in the discussion, both in terms of patient advocacy and clinical community advocacy.

Dicey outlined the benefits of advocacy, both in terms of helping women feel they are not alone, connecting them to others, and the extraordinary effect it can have on research, support, and education. She describes it as a 'high touch enterprise' and one that requires training, resources and dedication to bring about tangible results. As an ovarian cancer advocate for over 20 years since her own diagnosis, Dicey said she is now able to bring to IGCS a deeper understanding of how this important activity, which they have always recognised, can be further embedded into their activities it in different ways. She also highlighted that some of the issues in low- and middle-income countries are as valid in low resource settings even within higher income economies. She said that there is no country on the planet that cannot develop robust advocacy and see the rewards from it.

Elisabeth, who has also been involved in the sector for over 20 years, highlighted how much had changed in that time in Canada. She described how the community had not been connected. Many women were very ill, recurring, and dying. Building their advocacy movement had taken 10-15 years, connecting them, putting them in touch with each other and building belief that they can make a difference. She learnt much from the HIV/Aids and breast cancer communities in how to get people organised to move forward, galvanise government, get policies changed and backed by funding. It was important to support advocates, often giving vital time when they are ill, and time limited, and factor this in to advocacy plans, spreading the load so others can step in.

Dicey said it was important that lessons be learned from mistakes made in higher income countries, and that there be a bi-directional flow of education, so it's not just about women learning about their condition, but that clinicians learn from patients to ensure developments that are most important to women. Dorothy described the importance of listening to local experts, the women who experience the disease.

Both Georgia, Asima, and Dorothy spoke of the need for advocacy amongst the clinical community, aimed at colleagues in the same or related disciplines, and health providers and policy makers. This includes improving knowledge of the condition, the value of specialist treatments, and building knowledge about the importance of research programmes, clinical trials, and quality control. An audience member highlighted the need to involve the media in reaching out to policy makers and government officials.

Julie reiterated the importance of advocacy, using as many tools (provided by groups such as the World Ovarian Cancer Coalition and the Union for International Cancer Control as possible, but tailoring them to local need, and working alongside others who have similar aims.

The importance of coming together to tackle these issues

Coming together on issues is vital, and strengthens any call to action immeasurably. Elisabeth cited the four-year campaign working with clinicians, researchers and advocates to call for greater research funding, resulting in $10 million (Canadian) for key projects. She outlined the importance of getting everyone 'on the same page', then training the volunteers and establishing the key messages that were consistent over the years. They showed the politicians what wasn't working, the need, the gaps, challenges and opportunities. She also stressed the importance of partnering with the right people, and that the World Ovarian Cancer Coalition had been very fortunate to have positive relationships with UICC and a strategic partnership with the IGCS.

Isabelle reinforced this message, saying there was much to learn from different communities, stakeholders, advocates, clinicians, and advocacy groups. It is important to work better with different groups, coming together around common goals, than to work alone.

Opportunities and priorities for action

The following were identified as opportunities and priorities for action:

- Data: Improve data collection, via cancer registries and patient experience to inform advocacy campaigns. The Every Woman Study™ (for low- and middle- income countries) may offer one way forward.
- Prevention: Genetic testing an important way forward to identify those at risk in the future, low cost options are being trialled
- Centres of expertise, focus on developing centres of expertise with appropriate infrastructure, and communicate the potential of these approaches. They exist in other disease areas (for example fistula in Addis Ababa). Adopt new online strategies to target blocks (such as access to specialist pathology)
- Improving the availability of specialist surgery (with associated longer operating and ICU times)
- Building an advocacy community, of patients, advocacy groups, and clinicians, and join forces with groups working on similar issues in relation to health infrastructure (access to essential medicines, universal health coverage, palliative care, opioid use, women's health/ rights) and making sure advocacy efforts are heard, using different formats including media, and social media, as well as face to face meetings.
- Existing tools, make the most of existing tools such as the 2017 Cancer Resolution, national cancer plans, and the WHO Cervical Cancer Elimination Strategy to align arguments

Panel members: take-home messages/priorities

Dicey: The importance of health literacy, and the role advocates can play with this, and linking it women's health and wellbeing in a holistic way. And the importance of cancer registries to develop reliable and sustainable data, knowing that this is achievable.

Isabelle: The importance of cancer registries and data. Everyone of us can do something. We always think of so many advocacy routes, but start with yourself, what can I do about it, learn from others. Don't think of it as a big mountain in front of you but lots of little steps till you reach the top of the mountain.

Elisabeth: What has been really striking is the capacity, commitment, and variety of expertise that is willing to come together to make a difference. The World Ovarian Cancer Coalition should continue to drive the enabling environment to build advocacy, to advance health literacy. We can push forward on this.

Dorothy: Education – invest more in learning about the different aspects of the spectrum of ovarian cancer problems. My take away from low- and middle- income countries where cervical cancer is a problem now is that HIV control underway, cervical cancer will be eliminated but ovarian cancer will be a problem and we better have the solutions before that happens.

Georgia: I have learnt so much today, we have so much energy and effort to help these women. When we gather like today it gives us focus, clears our mind to know exactly the next steps. What I learn is that I need to gather more with other clinicians who treat women so we can come up with better ideas on how to treat these women and improve their lives, and to educate doctors and patients. Patients sometimes develop early symptoms but they often think it is nothing. They should know that if its persistent they should seek help.

Julie: The energy and different stakeholders was great, showing how much we already know to address the gaps. I really encourage you to bring together all your stakeholders to develop a national advocacy plan and I can help with connections, palliative care networks, research networks, surgery networks. Bringing these in now into your work will give it good momentum – you are not starting from scratch in some of these areas.

Asima: It is a wakeup call. Great to have so many people from different backgrounds talking about the same thing. We now know if you can get people together and motivate (such as with coronavirus) you can do things – having everyone concentrating on some goals. With concerted effort things will improve.

CONCLUSION

This event provided an opportunity for the global community to come together, take stock of the ovarian cancer landscape and discuss the gaps that inhibit the kind of care needed to achieve greater equity for women in all resource settings. The presentations, panel discussion and contributions from participants highlighted the many different challenges but also much by way of agreement of the steps we can take now to tackle this issue.

Encouragingly the event had resulted in new connections and collaborations for us – as well as for many of those that attended. In itself, this is an important achievement. The event has also given us a greater understanding of the complexities that many countries and low resource settings face which will help inform our work on plans to undertake a version of the Every Women Study that specifically looks at these settings.

We owe an enormous thank you to all that joined us for this event. We hope that has provided new perspectives and inspiration for global action.

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