



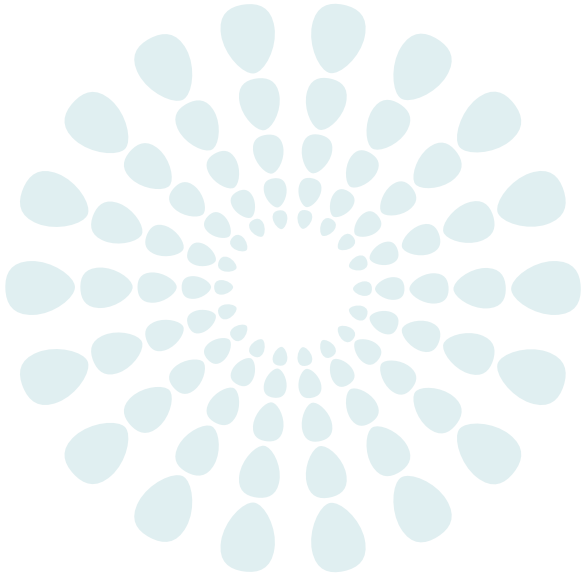
OVARIAN CANCER: BETTER DATA, BETTER OUTCOMES

Virtual Meeting Report



GLOBAL
OVARIAN
CANCER
CHARTER
a World Ovarian Cancer
Coalition initiative

OVARIAN CANCER: BETTER DATA, BETTER OUTCOMES



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INTRODUCTION

This report summarises the virtual meeting, Ovarian Cancer: Better Data, Better Outcomes, which took place on 18th November 2020 as part of the Global Ovarian Cancer Charter Summit Series. Recordings of the individual elements of the meeting are available on [our website](#).

The purpose of the meeting was to highlight key challenges and opportunities for improving ovarian cancer data collection, with a view to improving cancer control and planning, and improving outcomes.

The format for the meeting included a variety of live and pre-recorded material on three key themes:

- The importance of population-based cancer registries, and experiences of setting up the African Cancer Registry Network
- How data that is routinely collected on women with ovarian cancer can be used to improve outcomes for women, with examples from England and Australia (2 interviews)
- Why diversity in data, particularly clinical trials and location of trials is essential, and how improvements in data diversity might be achieved.

The context for these discussions was the Global Ovarian Cancer Charter launched in September 2020 and the specific Goal that calls for improvement in the diversity and quantity of ovarian cancer data. In particular it was noted that just one in five low- and middle-income countries have the necessary data to drive cancer policy.

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 100 registrants, 65 live participants from close to 20 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 organisations to improve the quantity, quality and diversity of ovarian cancer data.

CHARTER
SUMMIT SERIES

Ovarian Cancer:
Better Data, Better Outcomes

November 18, 2020 | 1:00pm UTC

an initiative of the World Ovarian Cancer Coalition
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MEETING CONTENT

The meeting was introduced by Clara MacKay, Chief Executive Officer of the World Ovarian Cancer Coalition. Participants and key themes from the discussions are highlighted below.

CANCER REGISTRIES

- Dr Max Parkin and Biying Liu from the African Cancer Registry Network
- Isabelle Soerjomataram, Deputy Section Leader from the International Agency on Cancer Research (IARC)

Professor Max Parkin outlined the role of population-based cancer registries. A population-based registry collects data on all cancer cases in a community, not just those who are treated in hospital, so it is useful for epidemiology and public health purposes, not just for evaluating hospital services. It describes the size of the issue, the types of cancer, and helps define the main priorities. The registry can help monitor interventions in terms of cancer control.

The World Health Assembly resolution, as far back as 2005, and updated more recently states that all countries should have mechanisms for monitoring cancer and evaluating cancer control programmes. All ministers of health put their names to this, so this should be an important tool.

Biying Lui has worked with Dr Parkin on the development of the [African Cancer Registry Network](#), which began in 2009 with registries in Uganda and Kenya. A variety of funding sources over the years have helped expand the members to 35 in 25 countries 2020. The aim is to have registries in all Sub-Saharan countries and intermediate objectives include increasing the number of countries meeting internationally accepted standards with respect to completeness and validity of data relating to incidence, stage and survival

To be a member, each registry must initially cover at least 50% of their population base, rising to 70% within a couple of years. A population base may be regional or national. They must also contribute to the database annually. The AFCRN works with the [IARC](#), [Union for International Cancer Control \(UICC\)](#) and the [Global Initiative for Cancer Registry Development](#).

AFCRN have several functions including providing training, technical, and scientific support to participating members, advocating the cause of cancer registration in the region, and coordinating international research projects and papers. They do not fund the development of registries. Their data contributes to publications, larger studies such as SurvCan 3, and is used to develop manuals such as staging manuals to reflect the local health environments where data is often handwritten or missing. The local registrars have to assign stage to cases they find which are not routinely collected but this requires training. AFCRN data also contributes to [Globocan](#) data where they are of sufficiently high quality. They have had to pivot their training to offer online/video modules due to COVID-19.

Whilst there has been little work done directly on ovarian cancer, this presents an opportunity, subject to funding sources and interested researchers. This could include a randomised selection of sample regions to obtain information on vital status, stage and/or treatment information. They have worked on an as yet, untested essential TNM staging for ovarian cancer (working with UICC and IARC) and are seeking doctors or registrars who could check the accuracy of the registrar's staging.

Isabelle Soerjomataram is working on an IARC project on staging in cancer, which will include ovarian cancer, comparing survival in low and middle-income (SURVCAN), with high-income countries (SURVMARK). She stressed the importance of good quality cancer data as a means of monitoring progress and planning for the future, to inform action. The recording of stage allows

you to explore several different aspects such as women's behaviour and awareness, referral procedures and hospital treatments at a population level.

Data collection is an iterative and slow process – one of continuous improvement. It is important not only to involve the registries but multiple stakeholders including doctors in hospitals. Networks of registries are important to help drive improvements in the collection of cancer data, that is becoming more and more usable by a number of different stakeholders.

All participants agreed that it was rewarding to work with registries in low- and middle-income countries, as a little resource can go a very long way and drive important changes.

Max felt that ovarian cancer has been a somewhat neglected cancer (for example like bladder cancer in men) because of the challenges of diagnosing and treating it, even in higher-income countries, and because the focus has been mainly on breast and cervical cancer. Isabelle confirmed that this has been the case. She called on ovarian cancer patients and patient groups to demand use of the data – and stress the importance of the data for research and decision making. Biying spoke of the stories of patients, realising how hard it can be for them to recount their experiences, but that there is a real opportunity to let patients know how important their information can be for others in the future.

THE OVARIAN CANCER AUDIT FEASIBILITY PILOT (ENGLAND)

- Andy Nordin, Gynaecologic Oncologist, Past President of the British Gynaecological Cancer Society, and a clinical advisor to the National Cancer Registration Service (NCRAS) in England

Andy outlined why England was a good setting for a project such as this. This included having low survival rates when compared to other high-income countries, despite some improvements in recent years through the organisation of cancer services into specialist centres. As part of this, certain cancer data has been collected routinely – Cancer Outcomes and Services Data (COSD) including type, stage, and performance status should be recorded by their teams. Pathology data and imaging is also stored. Other collected data include SACT (Systemic anti-cancer therapy), surgery, and radiotherapy data.

The ambition of the audit was to use the data that was routinely collected, see how much quality data there was and how it could be used to drive improvements. It was important that it captured every case, not selective samples with a risk of selection bias. This is all of the data on all of the patients, warts and all. There have been other clinical cancer audits in England, but they are very expensive to run as they require staff to upload new data to a registry and chase data, including the risk of case selection. This pilot was to see what could be extracted from existing data, and potentially offer a blueprint for similar schemes with other cancers. It is important that the data is used in a meaningful way for clinicians, patients and patient groups to drive improvements in care.

It has been a two-year project, funded by the [British Gynaecological Cancer Society](#), [Target Ovarian Cancer](#) and [Ovarian Cancer Action](#), who have also been involved in the development of the work.

One of the key drivers for the project was the release of [National Cancer Information Network \(NCIN\)](#) data which revealed that some 15% of women in England, diagnosed with ovarian cancer, die within 2 months of their diagnosis, and that 31% die within 12 months. He described this as a “fall off the chair moment”. These patients in particular were elderly, and had come via emergency admissions into hospital rather than a primary care doctor. There appeared to be variations about the country in terms of these proportions, and this led to the pilot.

Outcomes of the pilot include a profile report, looking at changes in survival since 2000, a report on variation in survival in England, across the 19 cancer alliances in England. This showed

extensive variation in one- and five-year survival. The main body of work has been a treatment report, published just ahead of this event. It covers over 17,000 women, all those diagnosed over a three-year period, all women. He described this as warts and all data. 21.9% did not get access to any treatment surgery or chemotherapy. Almost another fifth (18%) did not get any surgery. This must be contributing to 31% dying within 12 months. There is a large variation by region. The data is available in raw and adjusted forms for Cancer Alliances and hospital Trusts. As much as possible is published, [available to all](#), and the data for each hospital available behind the National Health Service firewall. Age is an important factor (raw and adjusted) in whether women get treatment or not.

He also discussed the importance of co-morbidities, and performance status, which is as yet, not complete in many cases (30-40%). He says this is more important than the stage at diagnosis in determining outcomes and likelihood of treatment, given the vast range of disease within stage 3. They are working to ensure doctors improve recording of performance status.

Andy described how his own hospital is using the data to explore why so few women are getting treatment. There are many reasons why this may happen, including age, stage, performance status, but also delays in getting to the specialist teams, either by primary care delay or delays within secondary care, for example women on other wards in the hospital having investigations. Other factors might be willingness to do surgery, nutrition available for women, and other factors.

Prior to the end of the pilot they are going to do further work on regional variation in short-term mortality data, and hope to set the foundations for a surgical audit looking at those who get surgery, developing a score to assess surgical complexity score in other words look at the extent of radical surgery and how that might relate to survival. They hope the pilot will be successful in terms of attracting national funding for this work in future as a cost-effective way of utilising data that is already routinely collected.

In terms of advice for clinical or advocacy groups in other countries where data collection is not good or non-existent, he recognises the challenges in non-centralised services. His view is that a little bit of data on everyone is more valuable than a lot of data on a select number of cases, in terms of looking at access to care and what is happening. Complex data requirement will mean only major centres will participate which will skew the results, so population-based cancer data is key.

THE NATIONAL GYNAE-ONCOLOGY CANCER REGISTRY (AUSTRALIA)

- Natalie Heriot, Co-ordinator of the National Gynae-Oncology Cancer Registry.

Following a successful pilot, which was funded by [Ovarian Cancer Australia](#), and developed by Monash University, the go-ahead for a full scale [gynae-oncology registry](#) has been given with funding from the Australian Government. The population of just over 1,500 women diagnosed with ovarian cancer each year in Australia and New Zealand is spread out over a vast geographic area, and there are just over 50 gynae-oncologists who can treat them. So there has been real concern that not enough women are being seen and treated by specialists. In particular women in rural centres may not be receiving best practice care and there is the potential even within specialist centres for different practices.

The pilot involved 10-12 centres over three years, with around 600 women with epithelial ovarian cancer involved. This will now expand. The registry started with a new model, sourcing data from existing data sets, or records at public hospitals. Previously everyone collected their own data which made it difficult to compare and contrast across hospitals. The registry pulls together stage and treatment data. As part of developing the model, clinicians gathered to debate best possible care, and this revealed for example variation in imaging strategies.

Key to the success of the pilot was the clinical and Ovarian Cancer Australia patient advocacy group engagement. This was a new way of leading the project, and felt very different to a government or a research approach. Involving the clinicians in this so early on, it was a more positive approach. Now they are looking to recruit all the specialist centres which should happen within the next 12 months, and then in future other hospitals that treat women with ovarian cancer in larger centres, and then more rural sites, where ovarian cancer can be an incidental finding, which results in secondary, delayed surgery. This will take up to five years.

The registry will not just collect hospital and registry data but collect patient reported outcome measures and patient experience and psychological measures (PROMS and PREMS), so will have a much more focused consumer aspect. The Prostate Cancer Registry in Australia has been an inspiration to this project, which has been developed over the last 10 or so years. It has been able to identify issues at particular sites, and resolve them, for example in one centre they had shorter surgeries and more radiotherapy. This was examined more closely and it was discovered that due to scheduling, more junior doctors were doing the surgeries, not properly supervised, which led them to taking less tissue. The registry is not about naming and shaming, but about encouraging improvements in care. The registry does not have power to intervene, but will let hospitals know how they perform against other data, but not other hospitals. These variations may be due to various reasons, but opens up the discussion.

One ethos of the registry, is to give something back to patients, in return for giving their information, so it is hoped that women can be signposted more effectively to support services.

In terms of ensuring success, ensure you have a multi-disciplinary approach: clinicians to determine best practice in that setting (not just guidelines), the health services support, consumer support so they can determine the most important outcomes for them, and then have a really good idea of how site governance and ethics works in your country. That was a major challenge in this project, with different approaches in different areas. Natalie is happy to answer any queries by email ngor@monash.edu.

DIVERSITY IN CLINICAL TRIALS

This live panel discussion, led by Clara MacKay, CEO of the World Ovarian Cancer Coalition and focused on two key areas: improving diversity of those who participate in trials and improving the geographic location of trials.

The panel:

- Sudha Sundar, Professor of Gynaecological Cancer, University of Birmingham, England, Consultant Gynaecological Oncologist, Birmingham and President of the British Gynaecological Cancer Society
- Tomi Akinyemiju, Associate Professor, Vice-Chair for Diversity, Equity and Inclusion, Duke University Medical School of Medicine, USA
- Rose Anorlu, Professor of Obstetrics and Gynaecology, University of Lagos, Nigeria and President Elect of the African Organisation for Research and Training in Cancer (AORTIC)
- Runcie Chidebe, Founder and Executive Director, Project Pink Blue, Nigeria, Member, Ministerial Committee on the Implementation of the National Cancer Control Plan, Federal Ministry of Health, Nigeria
- Mary McCormack, Consultant Clinical Oncologist, University College Hospital, London and Immediate Past Chair of the Cervical Cancer Research Network

The session opened with Clara reading a quote from Sudha Sundar in an interview for the World Ovarian Cancer Coalition's Every Woman Study in 2018. Sudha works in one of the most diverse

population groups in England, and carries out research in India as well.

“What we do know, for breast cancer too, is that these women (Asian, black) tend to get ovarian cancer a whole decade younger, but nobody understands this, what happens to these people. The literature is extremely dominated by Caucasian people. I’m not sure we have equity of access, or equity of knowledge certainly.”

Sudha welcomed discussion of this key issue, as she feels it is often not present in people’s minds. She had been involved in searching for data on issues such as prevalence of genetic mutations in women from Asian subcontinent backgrounds, but very little data existed and was often from skewed populations. She highlighted the importance of discovering whether the proven age difference between African and Asian women developing ovarian cancer was an epidemiological or biological factor, and how this might impact on treatments. Even working in such a diverse centre, Sudha had to resort to getting leaflets on genetic testing translated in the Punjab for use with women she sees. She urged people to reflect on whether they were truly serving the population they treat.

Going forward, from early 2021, her hospital will be working to train genetic liaison workers to go into mosques, temples and churches to increase the understanding of the importance of genetic testing, and they are working to develop better communications materials and techniques. Additionally, she is involved in a study comparing groups of Indian women with ovarian cancer from Birmingham, with matched groups in India to see what differences there are. She believes that much more can be done locally and globally to increase knowledge of ovarian cancer in diverse populations and improve equity in access.

Sudha chose to use genetic counselling as an example, describing the work as ‘pretty monotone’, assuming everyone comes from the same sorts of background and failing to acknowledge unexplored cultural overlays. She said that in the UK there was a danger of entrenching inequality because the knowledge gap would widen.

Tomi spoke about the motivating study that led to her current work, funded by the National Cancer Institute in the United States, looking at racial disparities and access to treatments for women with ovarian cancer. The study looked at five-year survival for white women in the US, compared to African American women. It is widely acknowledged that treatments have improved, and the expectation was to see that survival over the period 1975 to 2009 had improved. For the complete data set, that was true, with a rise from 34% to 47%. Despite expectations that there might be disparity when it came to looking at the women by ethnicity, the study team did not expect to find that in fact, for black women the survival rates had decreased 27%. However, when they examined the pattern in other cancers, the same findings were found, especially for cancers where there were amenable (effective) treatment strategies.

Using a framework of a health economist from the 1970’s her team have been looking at five key areas:

- Finance – relating to insurance/co-pays
- Availability of treatment (are there hospitals, cancer centres, specialists near you)
- Acceptability – relating to the interaction between patient and health care provider. Do you trust your doctor? Do they treat you with empathy?
- Accommodation – if there are services, are they available at a time and place that is easy for you to access
- Accessibility - how many buses/train journeys, time to drive?

SEER data showed that in fact, and this is true for other cancers too, that black women are more likely than white women to live in an area with hospitals, specialist centres etc.). Some of this may be due to the fact that few black women live in rural areas.

Examining the other issues, the team showed that whilst finance did present some issues, the biggest factor that affected whether or not women attended appointments was 'acceptability'. Women did not get a sense of empathy from their health care provider, and did not fully trust them. There were issues with the way they were 'spoken to', so there was a sense of mistrust, and lack of respect. This then affects other aspects of care such as access to clinical trials.

Rose spoke of some of the challenges of bringing cancer research to women in Nigeria. She acknowledged that ovarian cancer was becoming a bigger problem, and that the evidence on the ground did not necessarily match what text books might predict. For example, it's quite common to have women presenting, even when they have had 6-10 children. Part of the reason ovarian cancer may appear to be increasing could be that more women are aware of cancer per se and so are coming forward to seek help. Because care in Nigeria is so spread out in terms of access to specialists, Rose is fairly certain that there are many women, particularly in rural areas where a significant proportion of the population live, who never come forward and get diagnosed. The main barriers being lack of awareness, distance to centres and a lack of funds. Women in Nigeria have to fund their own chemotherapy.

She spoke of the lack of data and funds for research, but that more needed to be done for women with ovarian cancer. Reflecting on the discussions around genetic testing she said that this almost impossible in Nigeria due to cost. She was in favour of epidemiological studies to get basic data as a starting point. There has been an increasing focus on cervical cancer, with the WHO Elimination Strategy, but almost no NGO focus on ovarian cancer and that needs to change.

Runcie highlighted that in Nigeria and more widely in Africa, that cancer is rarely discussed from a patient perspective. The face of cancer is someone dying, not living. The aim of Project Pink Blue is to bring a live face to cancer in Africa, and he has realised that patients must be at the forefront much more. There are now many people working on 'resilience' (survivorship), and many positive stories to tell. His goal is to bring patients to lead on advocacy in relation to treatments and research, to bring about a change, and greater focus on non-communicable diseases such as cancer. With communicable diseases there have been many patients, an increasing amount of treatment but often still poor outcomes because medicines are not tested in communities.

In relation to ovarian cancer, Runcie commented that it is clear the data for Nigeria is under-reported, much of it is missing.

In terms of research in the country, Runcie described it as 'helicopter research' – people flying in to do research, take the data and head off. He said it was time to rethink global cancer research and investment. In 2015/16 there had been some 10,000 research organisations in global cancer research but over 5,000 were based in the USA, Canada and the UK. Less than 10% were located in Africa. Nigeria has the highest cancer burden in Africa yet there were only 6 current trials across all cancers.

Often the excuse of a lack of capacity and infrastructure is used to defend the lack of work in such areas, but Runcie says it is time that global oncology investment should move beyond a focus just on data, but also include developing infrastructure and facilities.

Mary was asked about her experiences in setting up the Cervical Cancer Research Network, which was initially founded in 2012 to bring colleagues in lower- and middle-income countries into research trials, given the heavy burden the disease has in these areas. She said initially they were naïve in thinking it would be relatively easy.

There was no shortage of enthusiasm but key challenges included:

- A lack of infrastructure and support to start trials
- A lack of funding, people to collect data, space to conduct trials
- Insurance and indemnification issues

- Difficulties working across national and regional boundaries and data sharing

However, there are now 27 sites in 14 countries and this is continuing to grow. The network now includes sites in Russia, Mexico, India and China. They have evolved their thinking about the network and now also include projects to develop data skills and collection, and have a small grants programme about to launch to encourage more lower- and middle-income resource settings to participate.

The geographic and cultural backgrounds are extremely important when getting involved in research and trials. It is imperative to ensure the results and treatments are safe and acceptable in the various healthcare settings and to populations. The cultural and logistical issues vary widely by country. Trust is a big issue, and this was a big impact in Romania with the roll out of the cervical vaccine, where take up was less than 5%. This came from a mistrust of political declarations, with the population having previously lived under a dictatorship rule. It highlighted the need to engage with local champions, health care professionals and the general population to build trust.

The panel went on to discuss some of the issues raised. Sudha highlighted that groups she was involved in such as the NIHR global surgery initiative shows the value of non-‘helicopter’ research, enabling local surgeons to brainstorm ideas for studies, then supporting them to develop methodologies, so was very much about capacity building. She urged people to look at the website globalsurg.org which contains a lot of free educational materials on good practice and recruitment into trials. She also cited studies she has been involved with globally to develop locally sustainable nutrition packs for patients undergoing surgery. The National Cancer Grid in India also runs workshops about the development of trials. So the issue is not that global research cannot be done, rather that the global cancer community has been less willing than others to take on board the issues, and that there has been less of an understanding about the need for resource stratified care, rather than focusing on the latest, most cutting edge care. Trials need to be useful. The launch of the Cervical Cancer Elimination Strategy, which was 20 years in development, shows it can be done. But it’s important that the global oncology community realise that diversity matters and diverse populations matter.


Tomi wanted to stress that a lot of the initiatives and strategies discussed in this meeting are not complicated. Building trust takes time and some effort, but not money, yet it has a powerful impact on patients’ wellbeing, their willingness to participate in trials and ultimately in outcomes. Building more hospitals and teams is not the priority, but building trust is, with diverse teams. After that you can look at trials, infrastructure and so on.

Rose reiterated the importance of good data and epidemiological studies ahead of studies into biology and genetics, and that teams in Nigeria and across Africa were willing to collaborate on this.

Runcie revisited trust as an issue, not just between patients and doctors, but also the need to build trust and relationships with local researchers. It is vital because without sufficient oncology research in Africa, women with ovarian cancer will continue to die.

Mary’s final comments were around the need to support people to deal with the most pressing issues in their community, and to recognise that this might not align with what people in other settings think is important. There needs to be more cooperation and discussion, and diverse teams involved in devising trials. She said that COVID-19 had shown what could be achieved in just 8 months, dealing with an unknown disease, bringing together regulatory bodies, global researchers, healthcare professionals and engagement in communities. With this anything is possible.

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For more information on the
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