

CANCER CONTROL 2021

CANCER CARE IN EMERGING HEALTH SYSTEMS



COMMISSIONING EDITOR: **MARK LODGE**, DIRECTOR, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH, UK

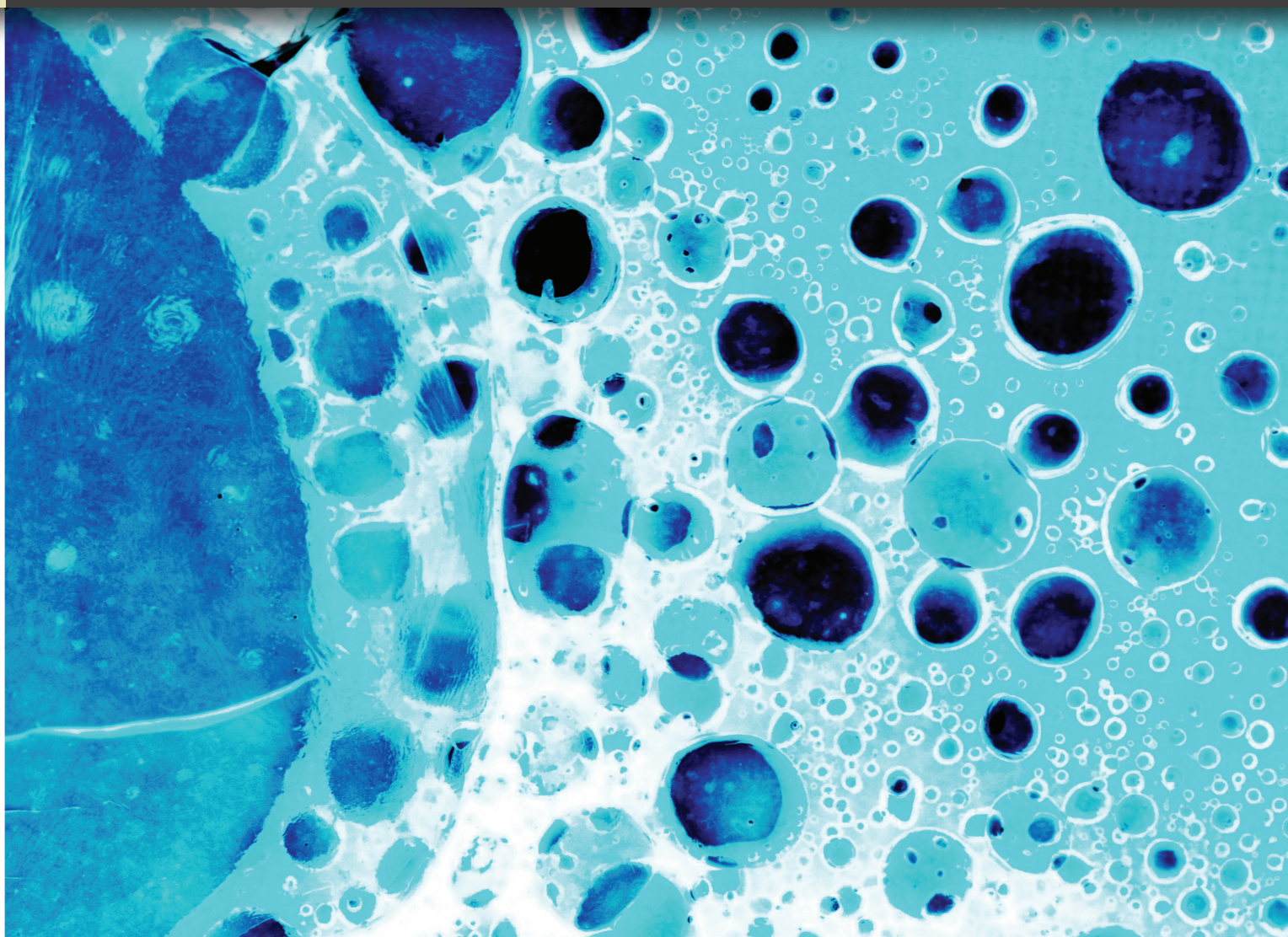
GLOBAL CANCER INITIATIVES • RESEARCH AND DEVELOPMENT
REGIONAL PERSPECTIVES • INCTR UPDATE

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CANCER CONTROL 2021

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Contents

05 Introduction

CANCER CONTROL INTERVIEW

06 Cancer Control interviews Dr Andre Ilbawi, WHO's Technical Officer for Cancer Control

André Ilbawi, MD, Technical Officer, Cancer Control; Department of Noncommunicable Diseases Division of Universal Health Coverage (Communicable and Noncommunicable Diseases) and World Health Organization

GLOBAL CANCER INITIATIVES

11 The strengths of partnerships in addressing AMR for better cancer care outcomes

Shalini Jayasekar Zurn, UICC; **Sonali Johnson**, UICC; **Helle Aagaard**, ReAct Europe; **Carina Alm**, Norwegian Cancer Society; **Jon Kirknes**, Norwegian Cancer Society and **Anna Zorzet**, ReAct Europe

16 The SIOP Global Mapping Programme: What we are learning and how it will benefit paediatric oncology care, support and families across Africa

Neil Ranasinghe, SIOP Global Health, International Society of Paediatric Oncology, London, UK; **Joyce Balagadde Kambugu**, Paediatric Oncology, Uganda Cancer Institute, Kampala, Uganda; **Lorna Renner**, Department of Child Health, University of Ghana; **Kathy Pritchard-Jones**, University College London (UCL) and Great Ormond Street Institute of Child Health, London, UK; **Alan Davidson**, Paediatric Haematology-Oncology Service, Red Cross War Memorial Children's Hospital, Cape Town, South Africa; **Maria El Kababri**, Department of Pediatric Hematology and Oncology, Children's Hospital, Rabat, Morocco; **Korede Akindele**, The Dorcas Cancer Foundation, Lagos, Nigeria; **Eric Bouffet**, Paediatric Neuro-Oncology Program, University of Toronto, Toronto, Canada; **Julia Challinor**, School of Nursing, University of California San Francisco, San Francisco, California, USA; **Laila Hessissen**, Paediatric Hematology and Oncology Unit of Rabat, Mohamed V University, Rabat, Morocco; **Jennifer Geel**, Division of Paediatric Haematology/Oncology, Faculty of Health Sciences, School of Clinical Medicine, University of the Witwatersrand, Johannesburg, South Africa

24 The development of global cancer networks in a time of pandemic, decolonization and climate change

Mark Lodge, Executive Director INCTR UK, Convenor London Global Cancer Week (LGCW) Oxford UK; **Kim Diprose**, Independent consultant, UK Global Cancer Network; **Richard Cowan**, Consultant in Clinical Oncology, The Christie School of Oncology, Manchester UK; **Susannah Stanway**, Medical Oncologist, London Global Cancer Week (LGCW) Steering Committee UK; **Danielle Rodin**, Director, Global Cancer Program, Princess Margaret Cancer Centre, Toronto Canada; **Rebecca Morton Doherty**, Director, Policy and Global Impact, City Cancer Challenge Switzerland and **Annie Young**, Emerita Professor of Nursing, Warwick Medical School, University of Warwick, UK

28 Updating the economics of the "War on Cancer": False metaphor and faulty economics

Smita Srinivas, India Lead and Co-Investigator, the Innovation for Cancer Care in Africa Project (ICCA), The Open University, Milton Keynes UK and the National Centre for Biological Sciences-Tata Institute of Fundamental Research (NCBS-TIFR) Bengaluru, India.

RESEARCH AND DEVELOPMENT

34 Women's cancers: do variations in patterns of care explain the worldwide inequalities in survival and avoidable premature deaths? The VENUSCANCER project

Dr Claudia Allemani, Professor of Global Public Health, Cancer Survival Group, London School of Hygiene and Tropical Medicine, UK

40 The importance of ancestry and diversity in cell line collection and analysis for people of African ancestry

Simone Badal, The University of the West Indies, Mona

REGIONAL PERSPECTIVES

46 Cancer control in the Eastern Mediterranean Region

Ibtihal Fadhil, President, Eastern Mediterranean NCD Alliance

49 Confronting inequitable access to health commodities for the acceleration of cervical cancer elimination goals within the Commonwealth

Dr Janneth Mghamba, Health Advisor, Commonwealth Secretariat; **Emily Gilmour**, Health Research Officer, Commonwealth Secretariat; **Yunus Mohammed**, Executive Director, SAPAM; **Victoria Rutter**, Executive Director, Commonwealth Pharmacists Association and **Layne Robinson**, Head of Social Policy Development, Commonwealth Secretariat

53 Addressing the need for palliative care in Nepal – the building of a hospice and palliative care education centre in Kathmandu

Max Watson, Consultant, Palliative Medicine Western Trust, Director of Project ECHO at Hospice UK; **Patricia Newland**, Executive Director, The Challenge Fund and Local Radio Presenter on Current Affairs, UK; **Rajesh Gongol**, Vice Chancellor, Patan Academy of Health Sciences, Founding President Hospice Nepal and **Stuart Brown**, Consultant, Palliative Medicine, Waikato Hospital, New Zealand

INCTR UPDATES

58 Mission, organization and achievements

62 INCTR Branches

63 INCTR Governing Council and partner institutions in developing countries

64 Partners: Past and present

Welcome to Cancer Control 2021

The COVID-19 pandemic is far from over, but healthcare professionals and policymakers are starting to look towards the way forward for cancer care, which has suffered as healthcare resources have been diverted to communicable diseases. In this edition look at the wider issues facing global health perspectives at this time: a more holistic approach to global cancer care; the need for networks that pool all the resources available (think of COVID-19) to improve cancer care in LMICs; to look at the emerging threats that cancer control faces; and finally, not to neglect R&D.

Our interview with Dr Andre Ilbawi does much to widen our horizons by considering the patient experience and how, perhaps, the clinical “War on Cancer” should be tempered by the other levers that are required to move forward. Not least those coming from the patient experience which may seem disconnected from such a bellicose approach. Smita Srinivas, from the Open University in the United Kingdom, also raises doubts the rhetoric of the “War on Cancer” and suggest that we should look at the economic concepts that drive healthcare and bring in some new perspectives.

A good illustration of how networks can be used is provided by the SIOP Global Mapping Programme for paediatric cancer in Africa. In this article, we break format as individual members of the programme focus on the areas that they had charge of which range from limited access to cancer care, establishing cancer societies, national cancer registries and many more. Here, we see the power of a network bringing results.

But where do networks come from? Another of our articles looks at the experiences of three different cancer network: the UK Global Cancer Network, which is mapping links between UK professionals and LMICs; the Canadian Global Cancer Network and the City Cancer Challenge, launched by the UICC in 2017. Their experiences, will be helpful and inspiring for those seeking to establish the cancer networks they argue are so necessary.

Keeping an eye on emerging problems is also important when all eyes are focuse on one crisis. The UICC issue a timely

reminder that we must take notice of growing antimicrobial resistance which poses a complex array of problems for those treating, and suffering, from cancer. Something we have been following in depth in our sister publication *AMR Control* (<http://resistancecontrol.info/>). We, also, have a report from Dr Ibtihal Fadhil on the Eastern Mediterranean Region, which has been hit by many geo-political problems beside COVID-19, which are not fully appreciated. Cancer Control will be publishing a special report on the region by the same author which will amplify what is discussed.

Finally, we should not forget research in these times and therefore we have re-established our R&D chapter with two articles: one looking at the developing VENUSCANCER study on disparities in women’s globally and another from the Dr Badel in the Caribbean looking at the racial content of cell lines and how it needs to be improved to achieve better outcomes. ■

We would be delighted to have your feedback at cancercontrol@globalhealthdynamics.co.uk. Please visit our website www.cancercontrol.info for updates and also to find out more information about INCTR and its programmes, as well as how to join.

Dr Ian Magrath, Editor-in-Chief, Cancer Control and President, International Network for Cancer Treatment and Research.

Tim Probart, MA, Publisher, Cancer Control and CEO, Global Health Dynamics.

Cancer Control interviews Dr Andre Ilbawi, WHO's Technical Officer for Cancer Control



André Ilbawi, MD, Technical Officer, Cancer Control; Department of Noncommunicable Diseases Division of Universal Health Coverage (Communicable and Noncommunicable Diseases) and World Health Organization

Andre, can we begin by asking about your background and how you got to WHO?

For many of my colleagues and for me, working at World Health Organization (WHO) is an unexpected privilege and not a planned outcome – it is a unique opportunity and responsibility to serve communities using a powerful platform and network of collaborators.

My background is as a cancer surgeon trained in the United States. During my training, I had the honour of taking three months to work at UICC as a fellow with support from the US National Cancer Institute and Breast Health Global Initiative. My wife, Shannon, came, on sabbatical from her faculty position in family medicine, to volunteer at WHO.

Upon returning to the United States, my wife and I were preparing to move to Africa to work as academic clinicians. An unexpected opportunity to work short-term at WHO opened up. We felt that we could come and help get something started then move to Africa. Six months became a year, two years and now six years.

But, it has been such a privilege to have worked at WHO, to interface with governments committed to action, to be inspired by partners and to be moved by advocates. We have seen a turning of the tide towards oncology being recognized now as a priority area within public health globally and, increasingly, an area in which governments are improving care. It has been a privilege to feel part of this shifting global narrative recognizing the urgency and humanity in cancer care.

The popular perception is that when it comes to cancer WHO is only interested in cancer prevention. Is this view correct?

WHO is the public health agency for the United Nations. Our primary objective, enshrined in our Constitution, is “the attainment by all peoples of the highest possible level of health as a fundamental right of every human being”. This inspiring ambition is important to understand our functions – that they

are not limited to prevention but extend from promotion to palliation.

When we look at progress in health, with what has driven improvements in life expectancy, the primary achievements have been achieved through public health policies and programmes. This same is true in cancer. A lot of our progress, particularly in high-income countries, has been reached because of risk factor reduction and the earlier detection of cancer.

But, this is not the only dimension. The cancer agenda, as part of the global public architecture, is broader. Millions of lives each year are saved because of improvements in access to quality care. This is the tenet of health for all as part of the 2030 UN Agenda for Sustainable Cancer.

We cannot achieve the SDGs without investing more in cancer control. And, our work at WHO reflects that reality – we have launched three global initiatives with partners around the world to catalyze immediate improvements in access to care and to save lives.

While many cancers can be prevented – and should be – the reality is an estimated 50%–70% of cancers cannot. There will be generations of people affected by cancer who deserve attention and care. And, that providing care, we can drive prosperity and development for all.

The popular misconception of regarding cancer as entirely a problem requiring clinical solutions is frustrating because so many of the buttons one needs to press lie beyond the control of clinicians.

Yes. You raise an important point. Cancer control, like all of health, requires a “whole-of-government, whole-of-society response”. This must be our approach to achieve the most meaningful success, because if we focus only on the areas that are frequently in the public discourse – whether it be cancer medicines or advanced technologies for screening – we miss the opportunity to have a holistic and person-centred response.

And, within this framework, we can understand where each of us fits and what we can do. In the prevention realm, for example, we can advocate for tobacco control through policies, regulation, taxation, counselling, knowledge sharing and more. Everyone has a role. And, as we consider the broader context of cancer prevention, we must remain vigilant to better understand carcinogens and to act on emerging risks such as air pollution using levers throughout the halls of government.

Health professionals and advocates are core to this dialogue. But, we must act in solidarity. There is not one button, there is no superior voice. We move as a unified, inclusive community.

Can you talk about some of the other challenges facing us in the cancer community?

We are at risk of losing our guiding beacon, losing steam and losing cohesion. What are we trying to achieve? What motivates our work?

It has been nearly 50 years since the war on cancer was declared. There have surely been major advancements, and we needed to be challenged as a global community to respond to this devastating disease.

But, perhaps it is time to focus on solidarity with a more person-centred understanding of how cancer affects individuals and communities. Let's be more attentive to the care requirements for people living with cancer and their families.

To start, investments in cancer should be more focused on improving access for all populations, driving forward universal health coverage and ensuring financial protection. There is a strong economic argument for doing so. But, even more important is the human justification.

Can we accept a world where, for decades, millions of people are dying unnecessarily from cancer because of where they live or how much money they have? This tears at the fabric of our souls and our bonds as a community. And, it is not a high-income versus low-income country phenomenon. This happens within zip codes, within neighbourhoods.

We also need to shift our language in how people with cancer experience care. There are a lot of questions that get triggered after a cancer diagnosis: why did this happen?, what are the options of treatment?, why has the cancer come back?. Cancer is a life-defining event that ultimately changes the trajectory of life - but it does not have to be something that you should wake up every day and think *'This cancer defines me. This cancer is going to dictate every decision I make.'*

People with cancer have shared with me that a philosophical shift towards cancer as part of life helps, that we begin to experience it as a chronic disease like diabetes or heart disease. Discussions on cancer care should be informed by a vision for tomorrow, not dictated by fears of death from today and the disappointment of losing a "war" against cancer.

So you are not signed up to The War on Cancer and the Moonshot?

That is a great question. There are dimensions of the War on Cancer that have saved countless lives. I am not advocating for less investments in cancer research and innovation.

But, for many in the cancer community, the bellicose language or survival at all costs has had unintended consequence. People living with cancer – the people we care for – are experiencing fear, poverty, isolation. Providers are feeling burnt out, exhausted. Inequities are rampant. Vulnerable populations are being ignored. This cannot continue.

What if the social context of cancer changes? What if we create a social context, based on equipoise, that addresses the harsh physical realities but balances it with systems designed to meet the broader needs of people with cancer – mental, social, spiritual and economic.

There would be great value in changing the narrative, but it is not easy to produce. Our investments reflect our priorities. It is time to ask if we are investing enough in the broader care needs of our communities and if we are ready to protect the social fabric of our communities by promoting equity and solidarity.

It is time to shift our understanding of cancer. Of all the things that I remember, from the hospital and all the people I talked to, I remember you encouraging me and telling me that it's okay, 'You can deal with this', in the same way that I'm dealing with my own high blood pressure, my own obesity, and it's not necessarily going to be a perfect solution around the corner. But it shouldn't make me live in fear."

There is a third option: that we maintain this fictional war on cancer while at the same time supporting people to come to terms with their diagnosis? It is close to double think.

Exactly. This is why it is so challenging. If you and I, people who have lived and breathed these questions for decades, feel the double speak in our internal thoughts how can we communicate to others? How can we help the patient who's sitting in a cancer ward focus on the future, on survival but also live each day abundantly. It is a paradox, and that does complicate how cancer is framed.

Cancer as a death sentence is still so real for so many people. And that fear does influence everything. Sometimes it's has positive consequences to motivate advocate, drive political decision making. And in that regard, how do we support people experience fear?

It is horrific to see someone suffer and die from cancer, especially when palliative care isn't available. But that goes back to where we can also spend more time as a community. How do we create an environment where the needs of cancer patients are being met in all domains of their life? The inability

to provide more holistic care is, in some ways, a moral failure.

And when we ask people with cancer four questions “Do you know what your prognosis is? Do you know why you’re receiving treatment? Do you know what are some of the complications of your treatment? Do you know what the financial implications of the treatment you’re receiving? ... Ask these four questions anywhere in the world, and the vast majority of cancer patients won’t be able to know? Now, please tell me isn’t that an absolute failure in creating a system that empowers cancer patients?”

How do you regard the current COVID-19 pandemic?

It has been devastating in health impact, but also devastating in its social impact. Health has become increasingly viewed in a political context, and trade-offs are positioned through a lens of tribalism rather than solidarity. We are losing an opportunity to show that health should promote social cohesion rather than exacerbate it.

These days carry the weight of history. It is a global gut check. The past year (2020–2021) has been so challenging because solidarity is being lost in so many communities. Going back to your question on what are some of the challenges for us in the cancer community. We are experiencing similar phenomena now with COVID-19 – divisions in priorities, motivation and objectives. And, it is triggering burnout and radical individualism that will harm the health agenda. We still have opportunities to emerge stronger and with new ways of working. But, we must acknowledge the massive human and economic costs of the pandemic.

We should all be thinking more about the political philosophy of cancer. What’s so instructive about cancer is that it makes you look afresh at Society and how we regard one another. If we only think about the medicine, and the scientific/clinical side of cancer we’re missing a large part of the story.

I totally agree. We all applaud the advances in cancer survival. But, at the same time, the social narrative and what cancer means to individuals and to communities has been lost on the focus on increasing survival at all costs. That’s where I agree with what you’ve said. The failure to create a philosophy of cancer results in a complete void of a coherent narrative behind it. Misinformation is rampant, creating situations in which the gut response to the word ‘cancer’, for too many people, is fear and misery not empowerment. And that is current predominant ‘the philosophy of cancer’.

If everyone’s so afraid of cancer, why haven’t we done better in terms getting it onto political agendas? If cancer is so commonplace why isn’t it a leading issue?

It is multi-factorial and is linked to the broader political context

of health. The general public often does not prioritize health in political dialogues, instead focusing on income and wealth, security, infrastructure. Our task is to make health seen as a communal good.

The promotion of health is further constrained by what people expect from governments in regulations to reduce risk exposure – that is, a ‘nanny state’ dialogue. And with cancer, we are further tasked with communicating the difference between risk and hazard.

Within the health agenda, cancer can feature prominently, particularly in high-income countries. It has featured in recent US elections as an example through political commitments. But, in the vast majority of countries, investments are not concomitant to the broader health, social and economic burden of the disease.

And, political commitments are only one step towards practical actions. After the UN High Level Meeting on NCDs in 2011, after all this energy went into preparation and into political engagement, progress has been sporadic and insufficient. There were 34 Heads of State at that Meeting and over 50 Health and Foreign Ministers. But, if we look at impact from available data, there has not been concomitant improvements in general government expenditure on NCDs before and after that 2011 event.

But we all felt better afterwards?

Yes, we did feel better. It was not a failure per se. But, it begs the question of what constitutes success? And, for whom? Similar to ‘shooting for the stars for cancer cure’, are we also ‘shooting for the stars’ that every government is only prioritizing cancer? Would that be well situated in the reality of where cancer fits in a broader health agenda?

Once you start saying cancer is the most important issue.... I’ve always felt very uncomfortable with that. There’s a woman in a field somewhere struggling with a breech birth, are you really telling me that your five-year randomized control trial getting an extra six weeks of life is more important? One wants to say: “Guys, where’s your humanity?”

That was perfectly said. For all of us in the cancer community, it is the a driving purpose for our lives, how we spend our time and energy. At the same time, there’s a lot of unrelated poor health and suffering in the world.

We can start by shifting away from heavily focused investments on curative therapy at all costs. Yes, it is absolutely important that we innovate, that we drive progress. But, we can also see how supporting the broader health agenda will also benefit cancer community and save millions of lives each year while doing it. Investments in primary healthcare and universal health coverage improve cancer care. That is a fact

and that should be a priority.

And, the value of a broader integrated approach is also founded on evidence. For example, integrating palliative care improves quality of life and longevity when compared to focusing on systemic therapy alone.

If we can shift our emphasis toward broader investments in health systems, that will accelerate progress in all domains of health and promote solidarity. We have seen some advocates take this approach, and I think it is transformative.

And, by broadly investing in health, we enable economic growth and prosperity for all. I remember, when I was in college (my goodness!), a professor challenged the common perceptions of investing in health. He said, “The United States is criticized for spending 12%–13% of its GDP on health. Why is that a problem?” It is an extremely important point. The United States now spends nearly 18%. Effective investments in health yield dividends in productivity, human capital development, social cohesion to drive prosperity for all.

These are difficult value judgments to make. But, increasingly, we’re able to show definitively that loss of health – and cancer is a very good surrogate – has a ripple effect across the broader community and economy. The consequences for people with cancer are often that their lives are uprooted, their out-of-pocket expenditures are high, the indirect costs are substantial, marital stability suffers, the health and well-being of the children and family suffers. As a community, we should document these impacts and talk more about what to do about it. We are failing to create the narrative that captures the broader impact of cancer – on our lives and on the lives and well-being of our loved ones.

As a species, for much of our lives we generally don’t think too much about our own death. That’s a problem for ‘later on’. But when we get a cancer diagnosis, we can hear Death knocking on the door, and that’s where the shock is, not just the fear of it, but actually the fear of the whole darkness.

I remember when I first started in medicine, meeting people with cancer was overwhelming. My first day on the ward, I met a young woman dying from cervical cancer, in the room with her young children and husband. It was devastating.

Over time, my perspective changed. People with cancer understand Life in a way that we should all understand it. And the more time I spent in cancer, the more humbled and blessed I have felt to be part of the community that understood Life. And that, for me, is the value in the cancer community setting a new narrative. That’s why, if we can put the people who are going through cancer in the centre – truly in the centre – and actually listen to the experiences that they’re having, then we can begin to understand where cancer fits in Society.

If people with cancer are seen as a population who we invoke

pity on, or for whom we create an environment of fear, then we’re doing them and ourselves a disservice because we’re losing the lessons that they are best positioned to guide us on: Trust, Solidarity, Mortality, Death with Dignity, Purpose. This is what matters.

I have a hope for cancer, because it’s such a relatable disease, regardless of where you are in the world. Cancer means something to a family and to a community, so if there’s anything that will yield solidarity, it should be this disease that we have dedicated our lives to.

Cancer lays out why Health matters in Life for all to see, contained in one irreplaceable experience. That’s where we can all draw our inspiration as a community. And that’s why, I think it’s such an important thing to discuss these things here in Cancer Control and during London’s Global Cancer Week. Let us pause. Innovation is where we need to think; progress for tomorrow is where we need to be. But let’s listen to the lessons of yesterday and today, or we’re not going to know what the value is of the better tomorrow. ■

Dr André Ilbawi is a medical doctor, specialized and double-board certified in surgical oncology. Dr Ilbawi joined the World Health Organization in 2015 and now serves as the focal point for the cancer programme at WHO Headquarters in Geneva, Switzerland.

In his current position, Dr Ilbawi is responsible for implementation of the 2017 World Health Assembly resolution on cancer prevention and control. He was Executive Editor of the 2020 WHO Report on Cancer and has supported additional WHO publications on broad topics ranging from guidance on cancer prevention to access to cancer health products. Dr Ilbawi also led the development of the WHO/IARC priority setting tool for cancer control, workforce optimization strategies, and other tools to support capacity building. He led the launch of the WHO Global Initiative for Childhood Cancer (2018), now being implemented in 30+ countries, as well as supported the launch of WHO Global Breast Cancer Initiative (2021) and implementation of the WHO Cervical Cancer Initiative based on the World Health Assembly resolution on the Global Strategy to Accelerate the Elimination of Cervical Cancer (2020).

Global Cancer Initiatives



The strengths of partnerships in addressing AMR for better cancer care outcomes

Shalini Jayasekar Zurn, UICC; **Sonali Johnson**, UICC; **Helle Aagaard**, ReAct Europe; **Carina Alm**, Norwegian Cancer Society; **Jon Kirknes**, Norwegian Cancer Society and **Anna Zorzet**, ReAct Europe



SHALINI JAYASEKAR ZURN



SONALI JOHNSON



HELLE AAGAARD



CARINA ALM



JON KIRKNES



ANNA ZORZET



Helge's story

- Helge was 21 years when he was diagnosed with Leukaemia.
- Over a 5-year period, he endured several chemotherapy cycles, a stem cell transplant and a lung transplant to survive.
- Due to the stem cell transplant, he was in isolation and dependent on antibiotics, without which he would never have been able to receive the necessary treatments that saved his life.
- It was a combination of the cancer treatments and the antibiotics that saved his life.
- He is doing well today and is a strong advocate for addressing antimicrobial resistance.

Source- Norwegian Cancer Society

Matilda's story (name changed)

- Matilda is nine years old and is living with cancer. She was initially treated with a chemotherapy protocol but relapsed and is now getting more aggressive chemotherapy at the hospital. Matilda is a happy child and surrounded by her family and friends.
- She is now on antibiotics for an ongoing fever.
- Unfortunately, within a short time, her heart rate starts to increase, and the residents get called. She starts to look progressively unwell and within 12 hours her blood pressure drops, she has trouble breathing and is taken to the intensive care unit (ICU), intubated and put on a ventilator. Twelve hours later despite everything the ICU doctors and nurses try to do she dies.
- The blood culture that was taken at the start of the whole episode shows that it was a gram-negative bacterium (*klebsiella pneumoniae*) resistant to most antibiotics including the ones she was taking.

One in six deaths is due to cancer (1) and this number will increase. In order to ensure higher rates of survival and a better quality of life, effective cancer control must include raising awareness, effective prevention strategies, early detection, access to effective treatments and palliative care. Ensuring access to timely and appropriate cancer treatment includes access to antimicrobials to address infections. These are a crucial element in the arsenal of cancer

treatment modalities.

Infections in cancer patients are a common occurrence, making the use of antibiotics can be lifesaving in the treatment of these patients (2). As many as 1 in 5 cancer patients undergoing treatment will need antibiotics at some point (frequently multiple times) during their treatment (3).

Cancer patients are at a higher risk of infections due to the lowering of immune defences resulting from their treatment, in

particular radiation therapy, chemotherapy (4). Infections may also be related to an immunosuppressed state due to changes in the immune system caused by some haematologic malignancies (5). In the case of solid tumours many factors contribute to an increased risk of infection, including obstructions caused by the tumour itself and the disruption of natural barriers such as skin and mucosal membranes (6). Furthermore, surgery, catheters and other devices used in treatment often increase the risk of infections (7). Sepsis and Pneumonia are among the most common causes for admission to intensive care units for cancer patients. It is estimated that 8.5% of cancer deaths are due to severe sepsis (8).

AMR and its impact on cancer care outcomes

Antimicrobial resistance is a global public health problem, especially as antimicrobial treatment options are becoming limited. Antimicrobial resistance (AMR) happens when microorganisms (such as bacteria, fungi, viruses and parasites) change and are still able to grow, even when they are exposed to antimicrobial medicines that are meant to kill or limit their growth (such as antibiotics, antifungals, antivirals, antimalarials and anthelmintics). As a result, the medicines become ineffective and infections persist, increasing the risk of spread to others. Currently, an estimated 750,000 people die every year from drug-resistant infections (9).

Although multi-country studies to provide comparable data on a global level is lacking, several in-country hospital surveillance studies suggest an increase in AMR in cancer patients. For example, a study in India showed that 73% of patients with blood cancers were colonized with carbapenem-resistant bacteria in the gut (10). A 2017 study in Ethiopia, showed that bacterial infections in cancer patients was 19.4%, and that multi-drug resistance was not uncommon (11). These studies indicate that key advances in medicines, including the newer targeted therapies for cancer patients, could be undermined by the increasing threat of AMR.

To address the impact AMR has on negative cancer care outcomes, a series of actions have to be put in place to ensure that cancer patients have access to the right treatment at the right time. For this to happen, we need to build strong and effective partnerships.

Better addressing AMR for improved cancer care outcomes through partnerships

The critical need to address AMR to improve cancer care outcomes is finally starting to get the attention it deserves. However, the current global response is still far from reaching the scale and urgency required to address the problem of AMR effectively. For this reason, the Union for International Cancer Control (UICC), which is one of the oldest and largest

nongovernmental organizations dedicated to cancer control, has prioritized AMR and is committed to addressing this issue within the cancer community and beyond.

Three priorities for UICC have been identified, which need to be addressed simultaneously. These are (i) evidence generation that effectively mobilizes policymakers, (ii) raising awareness and increasing knowledge within the cancer community and (iii) uniting the cancer and infectious diseases communities towards a joint goal in supporting access to affordable medicines and responsible use of antibiotics (neither overuse nor misuse).

In 2020, UICC and the Wellcome Trust participated in the London Global Cancer Week (LGCW), an annual event (12) that provided the ideal platform to bring together experts from the fields of cancer and AMR to discuss what action needs to be taken. The objective was to raise awareness on AMR and ensure its prioritization in the global cancer agenda. At this event, the UK Government's Special Envoy on AMR, the Norwegian Cancer Society, the International Society for Paediatric Oncology (SIOP), the Wellcome Trust and others called for increased collaboration to raise awareness and ultimately ensure strategies are in place to control AMR, including access to and rational use of treatments.

Partnerships to improve and disseminate data on AMR and cancer care

Review of the existing evidence shows a lack of data on the impact of AMR on treatment outcomes for cancer patients. A recent report commissioned by the Wellcome Trust found that cancer patients who developed drug-resistant infections had a greater risk of dying and were more likely to need additional medical support. But the report also mentioned that this evidence was weak and more systematic research is needed to quantify the impact of AMR on cancer care outcomes (13). It is important that clinicians and policymakers know which negative outcomes including mortality in cancer care are due to AMR and how often these occur (14). This data is needed not only to help shape a more comprehensive response at the political level and clinical level, but to also increase awareness at grassroot and patient levels (15).

Many initiatives and partnerships are aimed at addressing AMR, such as the UK's Fleming Fund which supports low- and middle-income countries (LMICs) with building laboratory and surveillance capacity to ensure quality data (16). The Fund has provided training and laboratory equipment to a number of countries to strengthen national AMR surveillance systems (17). In 2015, the World Health Organization (WHO) launched the Global Antimicrobial Resistance and Use Surveillance System (GLASS) to improve knowledge through surveillance and research. It is the first global collaborative effort to standardize AMR surveillance. However, Dr. Abdul Ghafur,

an infectious disease specialist from Apollo Hospitals in India, pointed out at the LGCW event that many countries have yet to implement systems to feed national data into GLASS. High quality data is needed to back up advocacy efforts and convince policymakers that this issue needs action now.

Other smaller initiatives between governments, private foundations and the pharmaceutical industry have also been established towards this end.

Such data collection should also be used to capture the impact of AMR on cancer care in order to understand the depth of the issue and reinforce anecdotal evidence from cancer patients and oncologists who deal with AMR on a frequent basis, with real-world data.

A Longitude Prize survey among 100 oncologists from across the United Kingdom, showed that 95% worry about increasing drug resistance and how it will impact cancer care. In addition, more than 7 out of 10 believe that drug-resistant infections will make some cancer treatments obsolete within 10 years (18).

Partnerships in raising the profile of AMR and cancer

Research collaborations to improve data collection and surveillance, showcasing the evidence-based data through effective communication, needs to be combined with raising awareness among the public and policymakers. Currently, knowledge and awareness within the cancer community of how drug resistant infections affect cancer care outcomes are low. It is urgent that the cancer community, oncology professionals, cancer advocates, programme managers, patient groups and other stakeholders working in the field of cancer understand and address the factors that contribute to the development and spread of AMR (19).

This is a multi-sectoral issue and in order to bring about policy change through tailored strategies and guidelines, the infectious diseases community and cancer community should come together. In this regard, addressing AMR is a priority for UICC and a task force of experts was convened in 2019 to support evidence generation, identify research gaps in knowledge of cancer and AMR, share best practices, and ultimately engage the cancer community to work together and bring about policy change. Since AMR has become a UICC priority, UICC and the UICC-led task force on AMR and cancer care have been very active in raising awareness on AMR among the cancer community and beyond, through various platforms, including LGCW and the Cancer Control series.

Partnerships for ensuring access to antimicrobials

Antimicrobials are a key and indispensable part of cancer treatment. However, access to treatments for infections is not always a reality. Medicines to treat infections are not available in many parts of the world. Of the 25 antibiotics developed

between 1999 and 2014, only 12 had registered sales in more than 10 countries (20). Shortages and lack of access to older antibiotics in many countries is also a chronic problem, and the reasons for this includes fragile – sometimes single-source – supply chains, regulatory challenges and the lack of commercial incentives to manufacture, register and distribute these medicines. Ensuring access to these existing treatments need to be addressed urgently.

In addition, recent years have seen huge advances in cancer care, including the new targeted therapies and immunotherapy for cancer treatment. Similar prioritization of R&D for newer therapies to address infectious pathogens, which undermine the effectiveness of both old and new cancer treatments, is urgently needed.

A number of initiatives do exist that specifically support new medicines and R&D such as the UK's Global AMR Innovation Fund (GAMRIF), R&D-funders like CARB-X, non-profit drug developers such as GARDP and the industry-funded AMR Action Fund. New approaches to R&D investment and more collaborative approaches are needed. Several legislative proposals in Europe and the United States (various subscription models and the PASTEUR and DISARM acts) have been put forward to try to incentivize R&D for new therapies. There is, however, considerable concern that these initiatives will not take a global nor an end-to-end approach that could ensure sustainable access for all. These proposals and other novel collaborative mechanisms should be expanded to ensure equitable and affordable access in LMICs and HICs alike, so that cancer patients everywhere receive the medicines they need.

While the current global COVID-19 pandemic has shown the importance of multi-sectoral cooperation, with active participation of relevant stakeholders i.e. governments, civil society, research institutions and industry, the crucial importance of government leadership should however not be understated. As the WHO's newly established "Council on the Economics of Health for All" stated in its recent publication on the governance of health innovation for the common good: "The development of multiple coronavirus disease 2019 (COVID-19) vaccines in less than a year shows how much can be accomplished when human ingenuity and solid medical research and development capabilities are given extensive public support. It further notes however that "...this experience also demonstrates that unless innovation is governed for the common good, many people remain excluded from its benefits, limiting the positive impact of health interventions, and creating unacceptable inequities that potentially exacerbate the health needs that it is supposed to address".

There is an urgent need for key players to come together and explore innovative ways to fund R&D for new antibiotics, increase collaborative networks and ensure there is a

sustainable supply of medicines and diagnostics (existing and new) for cancer patients, especially in LMICs.

Against this background a more in-depth discussion on access to antimicrobials for cancer patients will take place during the forthcoming 3rd LGCW in November 2021. The focus of this session will be access to medicines and diagnostics. Taking forward the messages from LGCW 2020, speakers at this session will elaborate on and provide insight into possible partnerships in ensuring equitable access to treatments globally. The session is once again a partnership between UICC, the Wellcome Trust, the Norwegian Cancer Society and will include UICC task force members, SIOP and ReAct along with insights from the industry. ■

Research areas that need urgent attention and collaboration

- ➔ Strengthening surveillance capacity to ensure quality data on the impact of AMR.
- ➔ Evidence generation on the impact of AMR on cancer care outcomes.
- ➔ Evidence-based resources to increase knowledge and awareness on AMR across communities to influence policy change.
- ➔ Ensuring equitable access to novel therapies.

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Sonali Johnson is Head of Knowledge, Advocacy and Policy at the Union for International Cancer Control (UICC). Her main area of work is to ensure that cancer prevention, treatment, and care is positioned within the global health and development agenda, including plans for universal health coverage (UHC). During her professional career, Sonali has worked on a range of public health issues including cancer control, gender and HIV/AIDS, reproductive and sexual health, gender based violence, knowledge translation, research ethics and health and human rights.

Sonali holds a PhD and post-doctorate diploma in public health and policy from the London School of Hygiene and Tropical Medicine and an MSc in Gender and Development from the London School of Economics and Political Science.

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The SIOP Global Mapping Programme: What we are learning and how it will benefit paediatric oncology care, support and families across Africa

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JENNIFER GEEL

We present the state of care for children/adolescents with cancer across Africa and highlight key aspects of treatment from a parent's perspective. Survey data was collected from the Global Mapping Programme of the International Society of Paediatric Oncology (SIOP) made possible by support from the Sanofi Espoir Foundation. While previous surveys document global disparities in cancer care and resources, most do not identify available treatment services and facilities. This Programme data informs paediatric oncology clinicians, civil society organizations, families and other stakeholders of available treatment options and support whilst being mindful of the children/adolescents and families that we serve.

My daughter was diagnosed with acute lymphoblastic leukaemia when she was three years old. She was treated at four hospitals across London at various stages of her treatment. Fortunately, she has made a full recovery and has just finished her second year studying physics at university. As a member of the SIOP Global Mapping Programme Core Team, I have been well aware of published statistics highlighting the differences between care for children across the globe, and in particular what happens to children in resource-limited settings. However, there are similarities between her cancer journey and critical support resources that are offered to our family in England and those available in countries in Africa, and these are highlighted here.

(Neil Ranasinghe, parent of Anne)

Background

Childhood cancer is a growing burden in high-income countries (HIC) as well as low- and middle-income countries (LMIC) (1). Survival rates are up to 85% for most diseases in HIC, however this cure rate is not achieved across the rest of the world where >80% of children live (2). In general, children with cancer in HIC are diagnosed in an early stage of their disease, which improves their chance for cure. This is not the experience of most children in LMICs, where all levels of medical professionals may be unfamiliar with the symptoms of childhood cancer, referral processes are weak and tertiary-level care is limited to the capital or perhaps one other large city (3). Africa has a population of close to 1.34 billion (4), but as of 2021, only includes one HIC (Seychelles) and seven UMICs (5). As the rate of infectious disease decreases across Africa and other resource-limited settings, the noncommunicable disease burden (e.g., cancer) increases and is receiving global attention as reflected by government representatives at the WHO seventy-fourth World Health Assembly (6). Economic development in the recent past across Africa has been improving steadily despite contraction due to the 2020 global pandemic (7). Nevertheless, regional economic recovery (albeit variable) is expected as vaccines become available, and children/adolescents continue to receive treatment for cancer across this continent.

In 2018, SIOP initiated a Global Mapping Programme for childhood cancer to determine available services and support for childhood cancer treatment especially in continents with many LMICs. The first continent surveyed was Africa since little documentation of the level of available treatment and family support services was available. The Global Mapping Programme provides an up-to-date picture of resources, staffing, and facility-level capacity to i) advocate for more resources; ii) enable collaboration to share data, and if appropriate, join clinical trials; and iii) produce an online map of childhood cancer treatment facilities. The survey methodology is described in detail by Geel et al., 2021 (8).

Key elements of successful childhood cancer programmes

This article reflects on childhood cancer across Africa as documented in the first phase of the SIOP Global Mapping Programme. Here, we address access to and importance of key elements of childhood cancer care. The first author, parent of a survivor of childhood cancer, identified specific survey data to highlight disparities and commonalities in treatment in the United Kingdom compared to countries in Africa from a parent perspective. We hope the findings and commentary presented here provide a baseline portrait of achievements to date, as well as a roadmap for moving forward locally and

in collaboration with global efforts, e.g., the WHO Global Initiative for Childhood Cancer (GICC). The GICC aims to improve childhood survival to 60% by 2030 worldwide (1). Selected key elements of childhood cancer care presented here are essential to achieving this goal and making a difference in the lives of children/adolescents with cancer in LMICs. Current disparities and gaps in childhood cancer care must be documented to be successfully eliminated – this is the purpose of the SIOP Global Mapping Programme.

What happens if there is no or limited childhood cancer treatment in your country?

Neil Ranasinghe, parent of a survivor of childhood leukaemia, and member of the SIOP Global Health Network, and SIOP Global Mapping Programme Core Team member

African data from the SIOP Global Mapping Programme showed a wide disparity in services and facilities available to children/adolescents with cancer and their families. Some hospitals are well equipped and offer chemotherapy, radiotherapy and specialised surgery, whilst others only provide basic cancer care. Some countries have no paediatric oncologists meaning that adequate cancer therapy is extremely difficult to provide.

There are countries with literally no facilities treating children/adolescents with cancer (9). In some cases, e.g., Eswatini, the children are sent to neighbouring South Africa for treatment, however, this is disruptive to the families' lives and leaves siblings and other family members at home who would normally serve as a support system for the child and parent.

Many childhood cancer care actions and treatments can be implemented at a national level in Africa and are not prohibitively expensive (10). Outcomes for children/adolescents with cancer across Africa will not improve without a well-trained paediatric oncology health workforce. Other factors that significantly improve outcomes includes appropriate medical imaging, universal health coverage, locally relevant research, cancer registries and support from non-governmental organizations (NGOs). The SIOP Global Mapping Programme provides updated documentation of capacity in the region. The following addresses each of these elements of childhood cancer care, written by an African or international expert on the selected topic.

Access and importance of medical imaging for childhood cancer across Africa

Dr Joyce Balagadde Kambugu, Head of Paediatric Oncology, Uganda Cancer Institute

Limited access to imaging is one of several contributors to poor outcomes of childhood cancer in Africa. While this can be attributed to inadequate resource allocation to healthcare

Table 1: Major antibiotic resistance in Iran between 2013–2014 (WHO, 2014)

Payment of care in your setting at facility level	Responses			
	Fully subsidised by state/donors	Partially subsidised by state/donors	Paid for by the family of the patient	No answer
Answers	36 (33%)	39 (36%)	24 (22%)	10 (9%)

Note: Totals may not add up to 100% due to rounding.

in general especially noncommunicable diseases, under-appreciation of the essential role of imaging in treatment outcome should also be noted. Imaging is important at every step in the continuum of cancer management – detection, diagnosis, staging, treatment planning, assessment of treatment response and long-term follow up. Moreover, the authors of the *Lancet Commission on Imaging and Nuclear Medicine* (2021) showed significant cost saving advantages with good imaging services overall (11). On its own, purchase of expensive imaging equipment will not have the desired effect on cancer treatment outcome. There must be a robust maintenance plan for the equipment, continuous availability of consumables such as films, reagents etc., and skilled human resource to deliver the service holistically. Otherwise, the expensive equipment will sit in facilities unused.

The SIOP Global Mapping Programme in Africa showed significant disparities in access to imaging both between countries and within countries. Not surprisingly, for basic imaging, at least one respondent in 44 (94%) of 47 countries reported having access to X-Ray, and 45 (96%) have access to ultrasound. More advanced technologies (e.g., computed tomography) were only reported as available in 79% (37) of 47 countries. Still, at this point in Africa, models referred to in the *Lancet Commission on Imaging and Nuclear Medicine* suggest that the largest survival advantage may be brought about by scaling up access to conservative imaging rather than to newer modalities like PET.

Access and importance of universal health coverage

Lorna Renner, Associate Professor, Department of Child Health, University of Ghana

In order to achieve the target of the WHO GICC, countries will have to make all efforts to improve outcomes by, amongst other strategies, ensuring access to effective treatment and reducing treatment abandonment. The implementation of Universal Health Coverage (UHC), which should include childhood cancer care, would be an important approach to achieve this. According to the WHO, “Universal health coverage means that all people have access to the health services they need, when and where they need them, without financial hardship” (12).

Unfortunately, with regards to childhood cancer, this has not

been fully achieved in several LMICs. Evidence from the SIOP Global Mapping Programme undertaken in Africa showed that only a third of the respondents from 47 countries affirmed full treatment cover by the state or donors (see Table 1). Fifty-eight percent had partial cover or families having to pay solely out of pocket. This is a reality, for example, from personal experience in Ghana, families have to pay out of pocket to access life-saving treatment for their child who has cancer. Countries have committed to UHC but advocacy at the local level is still required for childhood cancer care to become a priority and for adequate health financing. There is strong evidence to support advocacy efforts showing the cost-effectiveness of childhood cancer treatment in LMIC globally and in Africa in particular (10,13,14).

Importance of active paediatric oncology clinical research programmes

Kathy Pritchard-Jones, President of SIOP, Professor of Paediatric Oncology, University College London (UCL) and Great Ormond Street Institute of Child Health, London, UK

It is widely accepted that improvements in childhood cancer survival rates go hand in hand with active participation in clinical research, including observational studies and registries (15–17). However, most of the evidence supporting ‘best practice’ treatment recommendations for children and young people with cancer living in resource-limited countries comes from research studies performed in HIC (18). Yet, there are many other determinants of outcomes in LMICs including treatment toxicity and abandonment, drug shortages, sub-optimal diagnostic facilities, poor access to specific treatments such as radiotherapy. Therefore, clinical research performed in LMICs, which deal with these context-specific issues and constraints, is essential to define the optimal therapeutic strategies to improve cure rates and decrease short- and long-term toxicities (19).

The SIOP Global Mapping Programme survey for Africa investigated the current status of clinical research activity across the continent, with 23 low-income countries (LIC), 23 lower-middle-income countries (L-MIC), 7 upper-middle-income countries (UMIC) and one HIC. It is encouraging that 31% (34/109 units) and 49% (23/47 countries) reported

having an active clinical research programme (24). The finding compares to 82% of 35 European countries reporting a national childhood cancer research society or network when surveyed by SIOP Europe in 2013 (16). LMICs offer a great potential for patient recruitment to observational studies, including those that define priority areas for intervention to improve survival rates and those that investigate tumour biology and genetics in the local population.

Units that are active in clinical research and cancer registration processes are more likely to generate local evidence on safety and efficacy of treatments used. When available, parents/caregivers should be offered the opportunity to have their child participate in relevant clinical trials and studies that aim to improve the optimal treatment for all children/adolescents with cancer. The best example on how information coming from LMICs could influence treatment worldwide comes from Hodgkin lymphoma. In the 1970s, it was treated with combined radiotherapy and chemotherapy in HICs. However, the lack of availability of radiotherapy in LMICs made it impossible to administer radiotherapy with chemotherapy to patients, and results later confirmed, that such combination regimens were unnecessary for many patients in all countries (20,21). Therefore, this is a two-way road in knowledge generation (22). Nevertheless, barriers to oncology clinical trials in LMICs have been well documented and calls for funding and capacity building are on-going (19,23-25).

Treatment of cancer in children and young people is constantly being refined and the best “standard of care” is widely recognized as inclusion in a clinical trial or study, even for newly diagnosed patients. Treatment protocol recommendations need to be regularly updated, consistent with the latest research findings. Optimal treatment should be widely encouraged by a national childhood cancer research network including across LMICs.

Importance of national cancer registry

Professor Alan Davidson, Head of the Paediatric Haematology-Oncology Service, Red Cross War Memorial Children's Hospital and the University of Cape Town, South Africa

It is estimated that 41% of Africa's population (26) are under 15 years. Based on northern hemisphere data (140/m/year), this means 77,000 new cases of paediatric cancer annually. Recent data on survival for childhood cancer in sub-Saharan Africa reveal some of the lowest survival rates in the world for malignancies that in HIC have good rates of cure, including retinoblastoma and Wilms tumour. A barrier to improving these outcomes is the lack of accurate, population-based data from LMICs on childhood cancer incidence, stage at diagnosis and survival (27).

According to *The Cancer Atlas*, only 5.3% of childhood cancer

in Africa is registered (compared to 66% in Europe and 97% in the United States) (28). Registries help to track the incidence of new cancers in childhood, assess the extent and severity of disease at diagnosis and evaluate outcomes. Hospital-based cancer registries contribute to patient care by providing accessible information on patients with cancer, the treatment received and the outcomes. Specialized registries collect and maintain data on particular types of cancer. Population-based cancer registries (PBCR) collect data on all new cases of cancer occurring in a well-defined population, usually a defined region or country, and the emphasis here is on epidemiology and public health (29). As the most important form of PBCR, National Cancer Registries provide an invaluable resource of information for policy planning and research (30). They will enable us to tackle inequalities in access to appropriate care, ultimately leading to earlier diagnosis, better management, and improved outcomes for children with cancer in Africa. In the SIOP Global Mapping Survey, responses were received from 47/54 African countries, and 25 of these reported having a national cancer registry.

Importance of national paediatric oncology societies

Dr Maria El Kababri, Assistant Professor, Department of Pediatric Hematology and Oncology, Children's Hospital, Rabat, Morocco

A paediatric oncology society is an association of all professionals working with children/adolescents with cancer (e.g., paediatric oncologists, surgeons, radiation oncologists, radiologists, pathologists, biologists, nurses, and researchers) dedicated to the prevention, screening, diagnosis, treatment, and follow-up of paediatric cancers. Its missions are:

- ➔ Develop recommendations on therapeutic prescriptions and the organisation of paediatric oncology care.
- ➔ Promote research at national and international level.
- ➔ Create a space for dialogue between the various actors in paediatric oncology and with the supervisory authorities.
- ➔ Contribute to the education and continuing training of professionals and the evaluation of practices.
- ➔ Participate in the information and support of parents of children/adolescents with cancer.

In Africa, the role of a national paediatric oncology society is essential in the development of paediatric oncology, especially if its action is focused on the specific problems of the continent's countries and other similar contexts: continuous training of personnel, facilitating access to care and essential drugs, early diagnosis of paediatric cancers, and follow-up of patients under treatment to prevent treatment abandonment and reduce mortality. In addition, these societies organize and coordinate multidisciplinary treatment networks for childhood cancers.

Table 2: National paediatric oncology societies data from 109 facilities across 47/54 African countries from SIOP Global Mapping programme

National paediatric oncology society	Responses			
	Have society	Don't have one	Don't know	No answer
Answers (109 hospitals)	23 (21%)	11 (10%) 2 (2%)	73 (67%)	10 (9%)

Note: Totals may not add up to 100% due to rounding.

Table 3: Non-profit organizations data of 109 facilities across 47/54 African countries from SIOP Global Mapping programme

Non-profit organisations that support children with cancer treated at your hospital?	Responses				
	1	2 or more	None	Don't know	No answer
Number of non-profit organizations Answers (109 hospitals)	48 (44%)	25 (23%)	4 (4%)	3 (3%)	29 27%

Note: Totals may not add up to 100% due to rounding.

These societies also play a social role by providing support to families of children with cancer through advocacy for the cause of children with cancer. They are major players in the implementation and development of the WHO GICC

The SIOP Global Mapping Programme showed that only 13 African countries have a dedicated society (see Table 2); eight dedicated to paediatric oncology (Algeria, Morocco, Tunisia, Cameroon, Congo, Egypt, Nigeria, South Africa) and five for general oncology (Benin, Kenya, Mauritius, Uganda, Tanzania). However, few of them actively communicate on social networks through a website or other communication tools. It is clear that the development of paediatric oncology societies in Africa should be encouraged as a driver for the development of the discipline in a country and as an essential partner for the implementation of the WHO global initiative.

It should be noted since the time of the survey, some countries (e.g., Ghana) have formed a national paediatric oncology professional society as part of their activities to focus the country to implement the WHO GICC.

Importance of non-profit organisations (NGOs) for childhood cancer across Africa

Korede Akindele, Head of Programmes, The Dorcas Cancer Foundation, Lagos, Nigeria

Cancer is a bully. Much worse than the playground bully, cancer does not try to steal children's lunch money. Cancer tries to steal their futures.

The role of NGOs cannot be over-emphasized when it comes to caring for cancer in Africa. Many of these NGOs such as The Dorcas Cancer Foundation have been at the forefront of awareness and advocacy mainly to ensure that children are brought in for treatment early, ultimately reducing both morbidities, and mortality related to cancer. Financial constraints and challenges have also been major obstacles. Cancer treatment is undeniably expensive, more so in a resource-poor setting like Nigeria and many other African

countries. NGOs are taking bold steps to bridge this financial gap between patient and treatment, by raising funds to pay for care, involving kind-hearted individuals, community, corporate organisations, and government in making sure that no child has to suffer cancer without access to care.

We know a cancer diagnosis is a toll beyond just the physical and financial, but also impacting the psycho-social aspects of the child's life, confusing, and traumatic for patients and family alike. NGOs support this process and help these families get through by creating support group programmes.

Advocacy programmes in rural and urban communities, media awareness (TV and radio), and social media have also been effective tools used by NGOs across Africa region especially in Nigeria to combat childhood cancer. For the SIOP Global Mapping Programme data on African NGOs supporting childhood cancer, see Table 3.

Importance of the SIOP Global Mapping programme

Professor Eric Bouffet, past president of SIOP, Director of the Paediatric Neuro-Oncology Program, University of Toronto, Professor of Paediatrics Academic of Lyon, France

Many statements on the situation of paediatric oncology in the world start with the following comment: "Over 80% of children with cancer live in low and middle-income countries where survival rates are much lower than high-income countries" (24). However, although this statement is both heart-breaking and compelling, it is difficult to figure out the exact situation of these countries, the reasons for the poor outcomes and the solutions to improve survival. The SIOP Global Mapping of Africa has been an eye-opening experience, showing for example that in 15 countries, there was no trained paediatric oncologist or that the provision of chemotherapy was appropriate in only half of the continent (9). The collection of such detailed information offers many advantages, and in particular an opportunity for advocacy and targeted interventions aiming at improving training for the treating teams and access to care for patients.

Such work should not be limited to Africa. Further collection of information is critical in other continents where resources are limited, and a similar survey is ongoing in South and Central America and soon in South Asia. In addition, regular updates are needed to offer the most accurate information and measure progress over time.

Conclusion: A better understanding, and providing help to families

The SIOP Global Mapping Programme has provided a much better understanding of how children/adolescents with cancer are treated across Africa. This is enabling collaboration with WHO GICC and assisting SIOP and local stakeholders including NGOs, to advocate for resources, equipment, and specialized paediatric oncology health workforce where it is needed most. The programme has highlighted that in many African countries, chemotherapy is not continuously available (9), which allows for local, regional, and international advocacy by all stakeholders, including parents. This article has shown what is needed, why it is needed and what is already working. The SIOP Global Mapping Programme is not just an academic exercise but is helping families across the continent identify where their child may receive treatment, resources for support during treatment and demonstrates the essential role played by NGOs in supporting these families. As a parent of a child who survived a childhood cancer, I confirm that the elements of childhood cancer care addressed here were essential to my daughter's recovery. All children/adolescents with cancer and their families deserve optimal care no matter their geography. ■

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Korede has impacted thousands of people, healthcare professionals, leaders and individuals in Africa and Middle East, improving understanding of the importance of early detection and proper treatment of childhood cancer.

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The development of global cancer networks in a time of pandemic, decolonization and climate Change

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Independent of governments and major institutions, grassroots Global Cancer Networks are leveraging their international relationships to make a difference to the lives of people with cancer worldwide along the continuum of cancer care. This article describes three examples of how different types of Networks are addressing the shared problem of cancer across low- and middle-income countries and the challenges they face in this time of pandemic, decolonization and climate change.

Cancer is a leading cause of death worldwide with the majority of cancer deaths occurring in low- and middle-income countries (LMICs) (1). In response, the academic discipline of “Global Oncology” has developed as an area of practice, research, education and advocacy that aims to improve outcomes and achieve health equity across the cancer continuum, with a special emphasis on underserved populations around the world. In parallel, global cancer networks addressing the shared problem of cancer across countries are forming independently as a social phenomenon involving people and relationships with the ability to capitalise on the strengths of their relationships and to make a difference to the lives of people with cancer worldwide along the continuum of cancer care.

Global networks are shaped by their social context. The current situation represents a triple jeopardy with the increasing burden of cancer on top of the COVID-19 pandemic and the local effect of global climate change impacting the health and livelihoods of vulnerable communities. This paper describes three different approaches in the development of global cancer networks that have a shared aim of building capacity in cancer control and addressing global inequities.

UK Global Cancer Network

The UK has embarked upon a two pillar approach. Building on

the foundations of the pioneering annual one-day meetings on global health and cancer organised by the Royal Society of Medicine's Oncology Section 2016–2019, an extended week-long event – London Global Cancer Week (LGCW) – has been established providing an international platform for wide ranging and influential discussions around global oncology and the challenges presented by rising cancer incidence in LMIC (2). Despite the interruption from the COVID-19 pandemic, the development of LGCW as a first supporting pillar for UK global cancer activity has been rapid. Evolving from seven events in 2019, through 22 events in 2020 with an attendance of more than 2,000 people from 97 countries, to 39 planned events in 2021 with 101 speakers from 47 countries. Aspiring to be more than a conventional peer-to-peer conference, LGCW is outcome focused and encourages its event hosts to think strategically how their participation can not only further their own missions but also help create new opportunities and spaces in global cancer.

One successful outcome has been the setting up of the UK Global Cancer Network (UKGCN) (3), providing the second pillar of the UK approach. Launched on the first day of the second LGCW on 15 November 2020 as an independent not-for-profit network of UK-based individuals and institutions already working in partnership with colleagues in LMICs,

this multidisciplinary grouping is dedicated to encouraging and facilitating active collaborations between the UK cancer community and partners in LMICs (4). In its first year UKGCN has carried out a rapid mapping exercise to identify UK colleagues who are active or interested in working with LMIC partners in the projects that strengthen cancer control through a variety of means such as research and education in poorer resourced settings. Smaller specialist multi-disciplinary groups are being formed to strengthen UK input to collaborative projects led by LMIC partners.

Canadian Global Cancer Network

In November 2020, the Canadian Partnership Against Cancer (CPAC) and the Princess Margaret Global Cancer Centre hosted a Canadian Global Oncology Workshop to bring together over a hundred Canadian leaders in global oncology and to discuss opportunities for pan-Canadian collaboration in the field. This workshop was the first step in the development of the Canadian Global Cancer Network to connect individual global cancer initiatives led by Canadians and to develop a coordinated approach to advocacy, funding and priority-setting. Canadians have a long history of engagement in global cancer control initiatives, including significant contributions to global efforts on health equity, access to treatment and universal health coverage, education and leadership development, and advocacy around the psychosocial needs of cancer patients and the need to address the patient's experience along the full continuum of care.

The Canadian Global Cancer Network is in its early stages of development and is focused on establishing a governance structure that is inclusive of investigators across the country engaged in different areas of global cancer control and that engages those with the lived experience of cancer disparities, including those from LMICs. The second Canadian Global Oncology Workshop is planned for December 2021 to provide a forum for Canadian cancer professionals to convene, share ongoing work and discuss key issues in the field. This workshop is also designed to provide an opportunity for networking and mentorship, with a focus on including junior investigators and trainees interested in developing a career in this field. Specific sessions for brainstorming along key thematic areas (e.g. health services research, clinical trials, education and health professional development) are planned to facilitate joint proposals along these themes. These proposals are aimed to leverage and build upon the infrastructure of existing partnerships between Canadian investigators and international organizations and will demonstrate to federal funding agencies that global oncology is a unique programmatic area in need of support. Through this pan-Canadian collaboration, a philosophy of international partnership that addresses inequities in cancer control and that considers the concepts of

privilege and allyship will be developed (5).

City Cancer Challenge: A multisectoral city-led partnership for improving access to quality cancer care

Launched by the Union for International Cancer Control (UICC) in 2017, City Cancer Challenge (C/Can) is a growing network of cities and partners from across sectors working together to improve access to quality cancer care. Established as a standalone Foundation in 2019, C/Can is now operational in nine cities across Africa, Asia, Eastern Europe and Latin America, and is preparing to take on a new cohort of cities throughout 2022 and 2023.

A key factor of the C/Can city engagement process (6) is to support and connect cities through a growing portfolio of technical cooperation and capacity development programmes including international expert consultations, twinning arrangements, peer exchange, and scientific visits.

For example, in Cali, Colombia, resource-appropriate guidelines for the management of breast, cervical, prostate and colorectal cancers were developed by local experts in collaboration with the National Cancer Institute of Colombia and with support from experts designated by C/Can partners including The American Society of Clinical Oncology, American Society of Clinical Pathology, International Society of Nurses in Cancer Care, Oncology Nurse Society and the Latin-American Palliative Care Association.

Despite the unique challenges presented by the global health pandemic, cities like Cali have shown remarkable resilience and adapted quickly, including by harnessing digital solutions. For example, the Rwanda Biomedical Centre is leading a new collaboration to establish information systems that can work together to ensure cancer data connectivity in Kigali, Rwanda. Other notable progress in C/Can city projects over the last 18 months (7) include: completion and dissemination of a quality control manual for pathology labs across Cali (8), and development of a Quality Assurance Programme for radiotherapy services in Kumasi, Ghana.

One of the enduring challenges is ensuring the sustainability and scalability of projects. The pandemic has reinforced the criticality of engaging local sustainability partners early in the process. Part of this is providing tangible ways to foster the continued exchange of best practices and peer-to-peer discussion among cities, such as through C/Can's online TeleECHOTM programme. As C/Can is demonstrating, convening networks of cities, partners and people with a shared commitment to cancer control can be a powerful driver in accelerating local action for sustainable impact.

Discussion

There is a growing awareness worldwide of the rapidly enlarging

gap between the needs of cancer patients in LMICs and the resources and infrastructure available to meet their needs. For some years individuals and institutions in high-income countries (HICs) committed to this cause have been working alongside colleagues in LMICs to address these inequities and have made important local progress. However, these projects have tended to work in isolation and have struggled to create sustainable models to address these problems.

The three types of Global Cancer Networks described in this paper provide examples of how individuals and institutions can be drawn together to develop collaborations in which expertise, commitment and resources are shared to make a more strategic and sustainable partnerships in global cancer control.

The UKGCN, the Canadian Global Cancer Network and the City Cancer Challenge, in addition to having similar goals, share important characteristics. Firstly, they are all organizations which have been developed by workers in the field who have recognized the advantages of such partnerships. They have emerged from “the coal face” rather from national or governmental initiatives. Secondly, they recognize the importance of equal partnership between colleagues in HICs and LMICs. There is increasing evidence that those from HIC health backgrounds who engage in global health activities benefit from enhanced knowledge, motivation and leadership skills. Thirdly, the three networks all emphasise the importance of interdisciplinary cooperation in delivering healthcare. Finally, they all share the ethos of enabling and supporting current successful work in the field and have no desire to influence or interfere with cancer collaborations which are working well. They see the potential for sharing good practice between ongoing projects and acting as a catalyst and an enabler for new programmes.

Different networks inevitably will have differing approaches to attaining their goals. Rather than this being a drawback, this is something to be encouraged. Each will bring their own perspective and experience, and the variety will enrich the whole.

Where do these global cancer networks stand in relation to the COVID19 pandemic, the challenge of climate change and the drive towards decolonization? COVID-19, Climate change and conflict are all disrupters of cancer care across the world. Whereas conflict almost entirely has a negative effect, COVID-19 has illustrated to us our global interdependency in healthcare and our ability, when forced to develop a rapid and effective response. Global cancer networks should draw on the same principles to effectively tackle global cancer. The need to recognize our global interdependency was further demonstrated at the recent COP26 summit meeting in Glasgow. Climate change represents a significant threat to

health and healthcare delivery, particularly in low-resourced health settings where cancer is an increasing problem. Global cancer networks with their multidisciplinary ethos are well placed to draw on the full breadth of appropriate professional expertise (e.g. health economists, environmentalists, agronomists) to address these challenges.

In the past, HIC /LMIC collaborations had a tendency for the balance of the agenda to be weighed in the direction of the HIC rather than meeting the needs of the LMIC. Nowhere is this more clearly illustrated than in the field of research where leadership, authorship and acknowledgement have primarily sat with the high-income country partner. Here, a global cancer network, free from the restrictions and responsibilities of a single institution, can ensure that the LMIC partner takes on the leadership role and that their projects focus entirely on the needs of the LMIC. Similarly, the polarity of fellowships travelling almost entirely in the direction of the HIC could be reversed by initiatives driven by global health networks. As Paul Farmer has noted (9):

“Cancer is everywhere and we need to treat it where we find it. Eighty percent of the burden of disease in your specialty falls on the developing world. The pathologies are the largely the same, and the treatments can be the same, too. The diagnostic and therapeutic advances of the past half-century have been astounding, particularly in oncology. The challenge, of course, is delivery. So, we need to meet it. We need to deliver high-quality care, and we need to deliver on our promise to care for patients to the best of our ability and training.”

By investing effort in helping build capacity, global cancer networks can play their part in redressing the balance from cancer control to cancer care. Cancer is an example of what can be achieved to improve health by cooperation, collaboration, and mutual learning across the globe. ■

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Updating the economics of the “War on Cancer”: False metaphor and faulty economics

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The “War on Cancer” is undoubtedly a poor metaphor. Cancer is a complex biological process, not a single target for bellicose action; science is not organized on war strategy principles; and the winners and losers in a military war reflect neither the experiences nor the choices of cancer patients and scientists. A more fundamental problem exists: the economics of the so-called “war” are faulty. The first section of this article discusses the false war metaphor and its faulty economics. The second describes a more dynamic economic context that draws on evolutionary and institutional perspectives.

Wars come and go and some unfortunately last a long time in the imagination. The so-called “War on Cancer” is faulty on many fronts: metaphorically, one cannot wage a war on cancer because cancer reflects complex biological processes whose science is still being understood, thus any “war” is certain to be “lost”; the costs of better prevention and early treatment combined are vital to understanding the long-run quality of life losses to patients; and that the “war” itself has many fronts including geography, gender, income, and other social divisions and differences (1). The metaphor of war is best seen as a simplistic approach to politics and financing – for industry, for politicians, NGOs, and scientists (2,3). It assumes that led by political will, laboratory science proceeds from R&D to patients in a determined march, partnering with national institutes of health, an active set of industrial firms, and an array of non-profits, with beneficial effects for the economy and rewards for firms. Similar to the “linear model” of science, which used shorthand rhetoric to concentrate investments during the Second World War and establish the supremacy of science, the “War on Cancer” directed investment and claimed an inevitable role for science and industry (4).

One problem with the “war” metaphor is that social priorities are not directly translated as if by a camp of military strategists with a clear finger on the map, tracing the most directly effective path to an outcome. Yet, while the metaphor has been recognized as flawed, the health economics is not always updated (5). Another problem is that a “standard model” of cancer science(s) is not neatly organized on standardized institutional fronts and acts as only one, albeit

powerful, source of knowledge and industrial transformation (6). Other sources may be engineering firms, patient networks, “traditional” systems of science, non-profit advocacy, or clinical “applied” research. With multiple biological and social causes and correlates, cancer stakeholders extend well outside the lab-based model.

Industrial organization and technological efforts (both technical and organizational) are thus a fundamental feature of cancer care response from diagnostics to treatment, palliation to rehabilitation. If it becomes easy to identify and abrade a tumour through better laser optics and miniaturization, clinical skills will change. Conversely, making it easier for researchers to study tissue samples can stimulate more ambitious prototyping to advance the design of patient-friendly miniature optics or handheld diagnostics.

A dynamic economics for cancer and health

A dynamic economy is not accurately described as actors under a command and control military tent; neither a linear march to success, nor paths entirely driven by the efficient intentions of a heartless industrial complex. Institutions are the social norms, customs, guidelines, standards, rules, regulations, and laws which, through specific organizations such as government agencies, business firms, or universities, define the scope of the economy. Different institutional combinations exist in all societies. Because these combinations are dynamic and change over time, an older static, non-equilibrium, analysis of technological change is entirely misleading.

The “War’s” foundational metaphor arguably reflects a time when cancer was less well understood and the economics

of learning and innovation were nascent. Yet, advances in evolutionary and institutional economics in the last 50 years have revolutionized the study of technological change (7). These changes dislodge an equilibrium perspective and emphasize an uncertain search and learning process of firms with no “best” technology (8). One simple heuristic suffices to show different pathways: three domains of an “institutional triad” of production, demand, and delivery can distinguish national health industries, each of which has a distinct technological history (9). “Health policy” and “industrial policy” are separated in this heuristic (10). Laboratory science also historically emerges as only one type of institutional combination, not a universal paradigm. For example, India’s cancer profile where a significant incidence is preventable, needs a rethinking of its economics and policy design, with science channelled and publicly supported in priority areas, and firms and other organizations with their ears to the ground, encouraged to assess health problems and learn, create, and adapt technologies or service solutions.

Countries with greater industrial self-reliance can more confidently shape their health priorities. While there is no inevitable link between health policies and industrial policies, there may well be a jostling for power by some dominant firms to create and protect the institutional combinations that favour them e.g. intellectual property, market design, technical standards or even their “brand” as friends to NGOs or other communities, or other favourable business strategies. Competition can thus prove to be critical in differentiating effective firms by technology, price, quality, or other patient-friendly features and rejecting expensive solutions by building value-based strategies. At the same time, other social institutions such as welfare regimes and an ethos of assistance should be encouraged alongside individual lifestyle shifts. This attention to real-world variety, complexity and uncertainty against an artificial “rigour” of clinical and economic evaluation is also supported by clinicians who study the variable nature of health interventions (11).

The benefits of viewing cancer through evolutionary and institutional lenses

I have argued that the health industry is best seen as multiple markets and combinatorial problems requiring close attention to non-market institutions. That the social determinants of health might include industrial organization and especially industrial policy is a relatively new acknowledgement, also supported by the need to appreciate the complexity of health interventions (12). Successful supplier countries are those with active firms (public, private, hybrid) and other organizations (non-profits, grassroots, or cooperatives) which will generate new problems and where new markets have to be constituted,

regulated, phased out, or cancer priorities addressed through non-market means. Notably, countries with wider health knowledge systems and home-grown abilities to prototype, develop hybrid organizations, and develop treatments or equipment, are a special case of countries, and democracies an especially important sub-group. This is not a normative view but informed by the different historical pathways of nations and products, and far removed from the idea that an “invisible hand” of efficient markets should dominate society. With this conceptual shift comes uncertainty and the need for new methods, but provides a historically more accurate approach toward realistic long-term health policy and plans driven by robust problem-solving (13).

The pharmaceutical industry’s history is based largely on chemical industry progression, while biotechnology has had its own evolution (14). Mixed together as they are in cancer science and clinical treatment, there is no definable trajectory of a single industrial pathway, but there certainly can be priorities for accelerating access, accuracy, and humane care. Neither are the dynamic features of industrial organization easily collapsed into a traditional profit-driven description of a “medical-industrial complex”, because there are increasingly more actors in the health industry world – public hospitals, non-profits, hybrid platforms and service organizations, charities, or others, who play often invisible search, learning, and solution provider roles, and whose primary motivation may not be profit. Moreover, different sub-sectors have their own learning and regulation requirements, with equipment manufacturers and generic pharmaceuticals difficult to compare; the former suffering industrial rules devised for the latter (15). Similarly, the measures of industry impact and scale have to be context-driven: the degree of vertical integration and industry diversification goals can then be used to assess whether the policy goal is greater numbers of start-ups in handheld devices for breast cancer diagnostics, “big data”, fewer cases altogether, or something else entirely.

The industrial foundations of “choosing wisely”

Articles I and V of the Alma Ata Declaration 1971 require a commitment from governments that policy design will ensure responsibility for improvements in population health. Cancer response is therefore shaped by which demand institutions ensure such improved and judicious consumption of care and treatment. Therefore, industrial policies will need to situate cancer strategies beyond a single disease and its clinical management goals to a context-driven industrial response for health enhancements and universal healthcare commitments. At the same time, cancer-generating and multi-industry challenges such as environmental toxicity can be framed within industrial and systemic drivers of health (16).

A technologically contingent approach emphasized that societies need continuous problem-solving capabilities to resolve production, demand and delivery challenges and to clarify what knowledge systems serve them best. Industrial churn in cancer technologies can originate outside cancer. During COVID-19, countries under strict lockdowns or import curbs have behaved in unexpected ways in highly compressed timelines to produce PPE or COVID-19 diagnostic kits and which now shape how their cancer treatment is addressed (17,18).

How institutions and organizations come together illustrates the dynamic problem of morphine production for cancer palliation (19). India has in principle a complete supply chain but in practice one with several production, demand and delivery gaps, from opium cultivation to final opioids availability. Dramatic improvements are certainly possible: industrial gaps between agricultural production, procurement quotas and licences to align with technology upgrading for opium processing; and alignment of national programmes, state bureaucracies, or leading hospital procurement systems to track and anticipate the demand of palliative care morphine. This requires procurement systems to match decentralized district-level networks of regional hospitals and clinics which can see the urgency of morphine availability hiding in plain sight (20,21). Patients are also often unaware that doctors and medical bureaucrats may unwittingly undermine pain management with misplaced worries about addiction or trafficking. Medical and science education, and the training of bureaucrats need updates in dynamic industry models of global and national opioids supply chains, and exposure to economics, engineering, law and ethics.

A second example, Choosing Wisely India, demonstrates why and how traditional US, UK, or Canadian technology priorities for scanning or chemotherapy may need to be reassessed in Indian or African contexts (22,23). Choosing Wisely India fits within the ambitious National Cancer Grid of India (NCG) with tumour boards and expert panels and Vishwam Connect which combines Indian cancer standards with growing overseas requests (24). If extended to the industrial side, these initiatives can usher in sensible minimum thresholds for standardized imports, identify priority innovations, specify local content requirements that dovetail

with economic plans, establish quality or safety standards, and iteratively develop agile procurement or malpractice systems. In turn, such clarity on size and regulation of markets can aid firms in areas such as materials, scanners, lasers, dosage forms, optics, plastic molding and 3-D printing. This departure from cancer's US or European industrial histories, more accurately reflects domestic cancer data as well as domestic technological capabilities.

Conclusion

Major changes in the economics of technological change have emerged in the last half century which can move us beyond unrealistic war metaphors. COVID-19 has also revealed fundamental industrial gaps in global distributed manufacturing, fair pricing for imports or adjudication rules for technology transfer. Global policies in cancer should therefore support, not drive, national dialogues on priorities and evaluation. Health policy and industrial policies are rarely analysed as essentially intertwined. We hope that the Innovation for Cancer Care in Africa (ICCA) project can provide a preliminary body of research to analyze these linkages and improve cancer care in the coming years. ■

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Forthcoming publication

CANCER CONTROL FRANCOPHONE 2021

PRISE EN CHARGE DU CANCER PÉDIATRIQUE DANS LES SYSTÈMES DE SANTÉ DES PAYS FRANCOPHONES ÉMERGENTS



INTRODUCTION PAR LE PROFESSEUR ERIC BOUFFET, HÔPITAL POUR ENFANTS DE TORONTO, CANADA
COORDINATEUR ÉDITORIAL: FRANÇOIS DESBRANDES, RESPONSABLE DU
PROGRAMME D'ONCOLOGIE PÉDIATRIQUE « MY CHILD MATTERS », FONDATION SANOFI ESPOIR

INITIATIVES ET PROGRAMMES DE LUTTE CONTRE LE CANCER
FACTEURS DE RISQUE
DIAGNOSTIC
TRAITEMENTS DES CANCERS
FORMATION ET E-LEARNING
REGISTRE DES CANCERS ET ACCOMPAGNEMENT

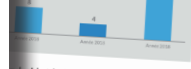
SANOFIESPOIR
FOUNDATION

Cette édition a été rendue possible grâce au soutien de la Fondation Sanofi Espoir en accord avec Global Health Dynamics

FORMATION ET E-LEARNING

Cours disponible sur la plateforme e-learning de 2020

Nombre de nouveaux cours
en ligne sur la plateforme
e-learning par année



Le 02 avril 2020 pour IOS. Elle a
été téléchargée 140 fois pour Android
et 140 fois pour IOS. Le nombre de
visites de la plateforme a été de 9 937
visites et 5 911 visites ont été
effectuées au 31 décembre 2021.

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Tableau 1: Indicateurs socio-démographiques des répondants de l'enquête

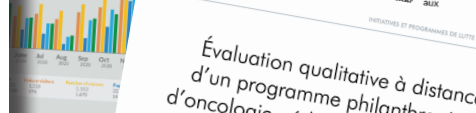
Age	25-30	30-40	+40	TOTAL
Sex				
Homme	1	15	15	31
Femme	3	22	11	36
Total	4	37	26	67

Tableau 2: Origine géographique des répondants de l'enquête de satisfaction du projet e-learning

Pays	Nombre de participants
Maroc	24
Niger	6
RDC	6
Senegal	4
Benin	3
Côte d'Ivoire	3
Mali	3
Algérie	2
Burundi	2
Cameroon	2
Republique Centre Afrique	2
Mauritanie	2
Burkina Faso	1
Gabon	1
Guinée	1
Madagascar	1
Tchad	1
Yogo	1
Tunisie	1
Total	67

d'accord ou tout à fait d'accord avec les points liés aux aspects techniques et pédagogiques de la plateforme (tableau 3). Les commentaires écrits incluaient le désir de voir une extension des cours offerts via la plateforme, d'avoir un forum de discussion et de développer la rubrique bibliothèque pour inclure les travaux de recherche des anciens candidats du DUCP. La plateforme a été visitée presque 10 000 fois en 2020 et nous espérons doubler ce chiffre pour 2021. L'application a été téléchargée 223 fois.

Le tableau 3 montre que les participants ont été généralement satisfaits par les aspects techniques et pédagogiques de la plateforme et ne semblent pas avoir eu beaucoup de difficultés à accéder aux



Le programme « My Child Matters » de la Fondation Sanofi Espoir a été évalué en 2020 et 2021. L'évaluation a été réalisée par une équipe de professionnels de la santé et de la recherche. Les résultats de l'évaluation ont été présentés lors d'une conférence de presse en 2021.

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Research and Development



Women's cancers: do variations in patterns of care explain the worldwide inequalities in survival and avoidable premature deaths? The VENUSCANCER project

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VENUSCANCER is a European Research Council (ERC)-funded worldwide study designed to explain the global inequalities in survival from breast, cervical and ovarian cancers, the three most common cancers in women. The goal is to provide levers for health policy to reduce or eliminate avoidable differences in survival from these cancers.

Opening the World Cancer Congress in Paris (2016), the French President, François Hollande, insisted that women should be at the heart of cancer control, “because they are victims of inequality in access to prevention, treatment and screening in every country in the world”.

Cancers of the breast, ovary and cervix are a major public health problem worldwide. Every year, approximately 2.5 million women are diagnosed with one of these cancers, and they account for over 900,000 deaths (1). Many of these deaths are avoidable, even in low- and middle-income countries (LMICs), where cancers in women represent a major economic burden, both to families that lose a mother, but also to the national economy (2).

Reducing the numbers of cancer deaths in women will require improvements in prevention, but also more effective health systems, to improve the survival of women who do develop one of these cancers (3). Yet access to safe surgery varies widely between the richest and poorest countries (4), and in more than 30 of the poorest countries, radiotherapy services are not available at all (5,6).

Differences in survival from these three cancers between high- and low-income countries are striking (7). Inequalities in survival also exist between high-income countries (8), and even between regions within those countries. The problem has been succinctly summarised: “political toleration of unfairness in access to affordable cancer treatment is unacceptable” (9).

In 2015, the CONCORD programme established worldwide surveillance of trends in 5-year survival over the 15-year

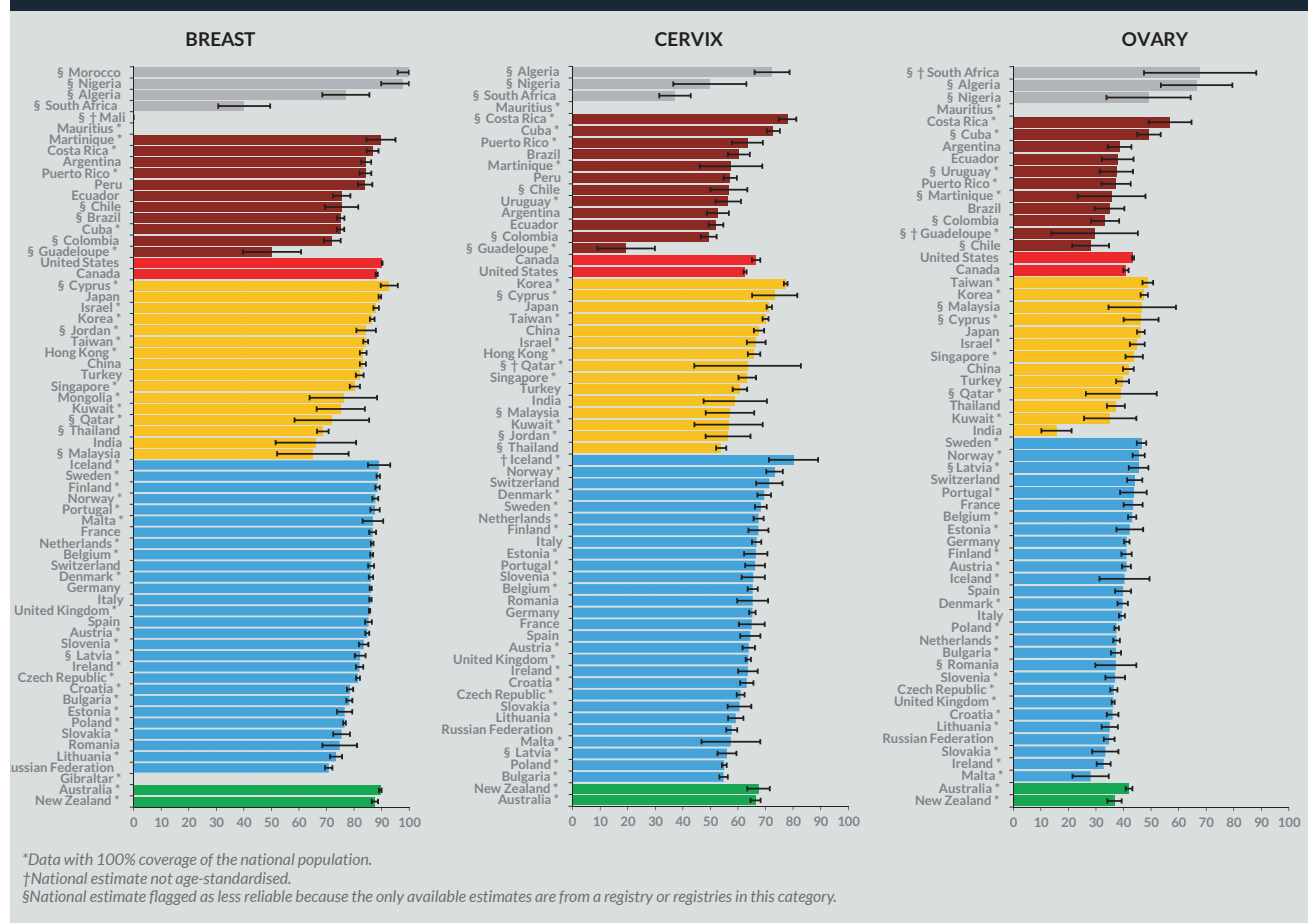
period 1995–2009 (10). It documented for the first time the very wide global differences in survival trends for most of the common cancers, including breast, cervical and ovarian cancers. In 2018, the third cycle of the CONCORD programme updated worldwide trends in survival for patients diagnosed up to 2014. In 2010–2014, age-standardized 5-year net survival for breast cancer varied from 66% in India to 91% in the United States; from 52% in Ecuador to 77% in Korea for cervical cancer, and from 16% in India to 57% in Costa Rica for ovarian cancer (Figure 1) (7).

VENUSCANCER

VENUSCANCER, embedded in the CONCORD programme, aims to examine in much greater depth why these enormous differences in survival up to five years after diagnosis still persist for women diagnosed in the most recent years for which data are available in cancer registries. Results from this project will enable us to see how much of the differences in survival between high- and low-income countries can be explained, whether by the biological characteristics of the cancers, or by the health care women receive, or by broader aspects of society, such as women's socio-economic status or level of education. This is the first aim of VENUSCANCER.

The second aim is to examine trends in *avoidable premature deaths*, in relation with each country's gross domestic product and total national expenditure on health. In this context, avoidable premature deaths are defined as deaths that occur within five years of a cancer diagnosis in a given country that

Figure 1: Global distribution by continent and country of age-standardised 5-year net survival for women (15–99 years) diagnosed during 2010–14 with breast, cervical or ovarian cancer



would not be expected to occur if survival from that cancer in that country were as high as in another country, typically in the same world region.

The overall aim of VENUSCANCER is to provide actionable evidence for health policies to reduce the burden of women's cancers worldwide.

Protocol

The protocol for data collection has been developed in collaboration with over 300 cancer registries worldwide. This has been a major undertaking in its own right.

Three VENUSCANCER Working Group meetings to discuss the protocol were held during major international conferences in Arequipa, Peru (12 November 2018) at the International Association of Cancer Registries (IACR) conference; in Vancouver, Canada (12 June 2019), during the North American Association of Central Cancer Registries (NAACCR), and in Moscow, Russian Federation, during the Second International Forum of Oncology and Radiology (23 September 2019). The discussion focused on the first aim of the project, to collect detailed demographic, biological and clinical data for women diagnosed with breast, ovarian or cervical cancer during the

most recent year for which data are available, and in as many countries as possible.

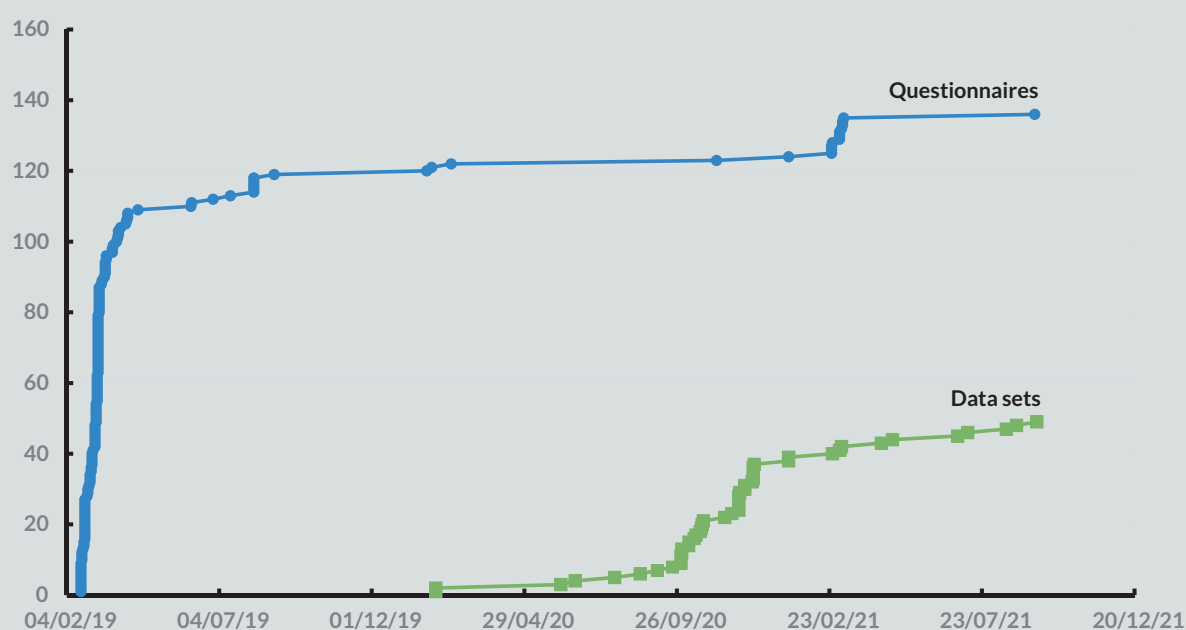
The ERC Consolidator grant enabled support to be provided for visa, travel, accommodation and conference fees for six colleagues from LMICs (Brazil, Cuba, Nigeria, Russian Federation, South Africa, and Thailand), who would not otherwise have been able to participate in these meetings.

Three questionnaires were developed to help refine the protocol for data collection. The questionnaires were designed:

- To identify cancer registries that are willing to contribute to this challenging part of the VENUSCANCER project.
- To identify which registries have data at the required level of completeness.
- To identify which registries are willing to increase the completeness of their data.
- To select cancer registries in LMICs that would be eligible for financial support for data collection.

The questionnaires were presented during the VENUSCANCER Working Group meetings. My research team helped our colleagues to complete the questionnaires, and we discussed which variables were more likely to be collected and

Figure 2: Number of registries that have submitted questionnaires or data



complete in their registry.

In February 2019, over 300 cancer registries were invited to complete online questionnaires to identify those which have data at the required level of completeness, or were willing to improve their data. Analyses of the questionnaires were presented in Lisbon, Portugal (May 2019), in Vancouver, Canada (June 2019) and in Moscow, Russian Federation (September 2019). By September 2019, 123 cancer registries in 42 countries (4 lower-middle-income, 14 upper-middle-income, 24 high-income) had submitted at least one questionnaire, but most registries (80%) submitted all three.

Cancer registries have continued to submit questionnaires to be considered for participation. By mid-September 2021, we had received 374 questionnaires from 136 cancer registries (Figure 2). The impact of the COVID-19 pandemic is visible.

For most of the data items that we wish to examine, the answer as to whether they are collected routinely was categorised as “Yes”, “No” or “Unknown” and, if “Yes”, the expected level of completeness was categorised as less than 25%, 25%–49%, 50%–74%, 75%–100%, or unknown. Several questions invited free-text replies.

The questionnaire on breast cancer included 71 questions, which produced more than 300 separate data items (variables). The questionnaire on cervical cancer included 62 questions (300 variables), while the questionnaire on ovarian cancer included 54 questions (over 250 variables).

We will include cancer registries with the highest availability and completeness of the required data. Following analysis of the questionnaires for each cancer, the data collection

protocol was finalised in November 2019. The protocol enables cancer registries to start their own database for the study, but following rigorous agreed rules.

We defined “basic information” as demographic data (e.g., age) and tumour data (e.g., the anatomic site and microscopic appearance of the tumour). We evaluated three criteria for the inclusion of cancer registries in VENUSCANCER:

- Basic information, plus data on stage at diagnosis and treatment: for all three cancers, slightly more than 50% of cancer registries collected these data with adequate completeness.
- Basic information, plus data on stage at diagnosis, treatment and molecular biomarkers: for all cancers, around 30% of cancer registries collected these data with adequate completeness.
- Basic information plus data on stage at diagnosis, molecular biomarkers, treatment *and* socioeconomic status: for all cancers, only 5% of cancer registries collected these data with adequate completeness.

However, after considering the willingness of colleagues to collect additional data for individual women from clinical records, these percentages rose to 76%–79%, 44%–51%, and 9%–14%, respectively.

If we include only registries that can provide all the variables we want to analyse at the required level of completeness (option 3), the worldwide scope of the project would be severely constrained. Therefore, we selected the criteria that will enable us to conduct a study on patterns of care with the

widest possible geographic scope (option 1). Nevertheless, we will also perform parallel analyses by tumour sub-type for those registries that can provide data on biomarkers (option 2), and analyses by socioeconomic status for the small proportion of registries that aim to submit this information (option 3).

Over 100 registries submitted questionnaires for each cancer; incidence for 2015–2017 was complete in over 90 of these registries. Data completeness was high for stage, staging procedures and treatment, only moderate for molecular biomarkers, and low for comorbidities and socioeconomic status.

Most cancer registries were willing to improve their data completeness before submitting their data to VENUSCANCER. Results for breast cancer are shown in Figures 3–5. Similar results are available for cervical and ovarian cancers (data not shown).

The call for data was issued on 21 December 2019. The original deadline for data submission was 30 June 2020. Due to the COVID-19 pandemic, this deadline was postponed to September 2020. Since the pandemic has been affecting the various areas of the world at different times, data collection is still ongoing. By mid-September 2021, we had received data sets from 49 cancer registries: 44 data sets for breast cancer, 42 for cervical cancer and 27 for ovarian cancer (Figure 2). We expect to receive more data sets in the coming months.

Expected results

Health policymakers need good evidence on the reasons for international disparities in cancer survival, in order to focus

their policy initiatives.

Such evidence can come from “high-resolution” studies, in which detailed clinical data that are not systematically captured at cancer registration are obtained directly from the medical records, such as the stage of disease at diagnosis, the investigations carried out to identify the stage of disease, and the types of treatment provided for each patient. Analysis of these data can show the extent to which international differences in survival are likely to be due to differences in stage at diagnosis or, for example, to under-treatment in the elderly.

High-resolution studies can thus identify the key drivers of inequalities in cancer survival.

VENUSCANCER will be a particularly important high-resolution study, because it is both population-based and worldwide. It will provide details of the biological and molecular characteristics of tumours in all women diagnosed with cancer of the breast, ovary or cervix in a given country or region, and on patterns of care, as well as short- and medium-term survival, in over 40 countries.

Analysis of the VENUSCANCER data will highlight the strengths and weaknesses of the health system in providing care for all women diagnosed with one of these three common cancers in each country.

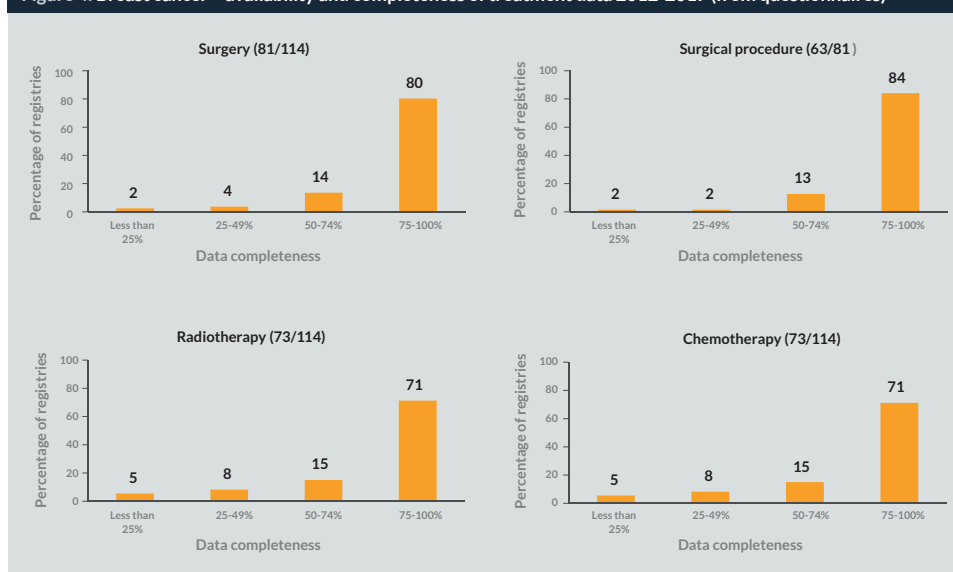
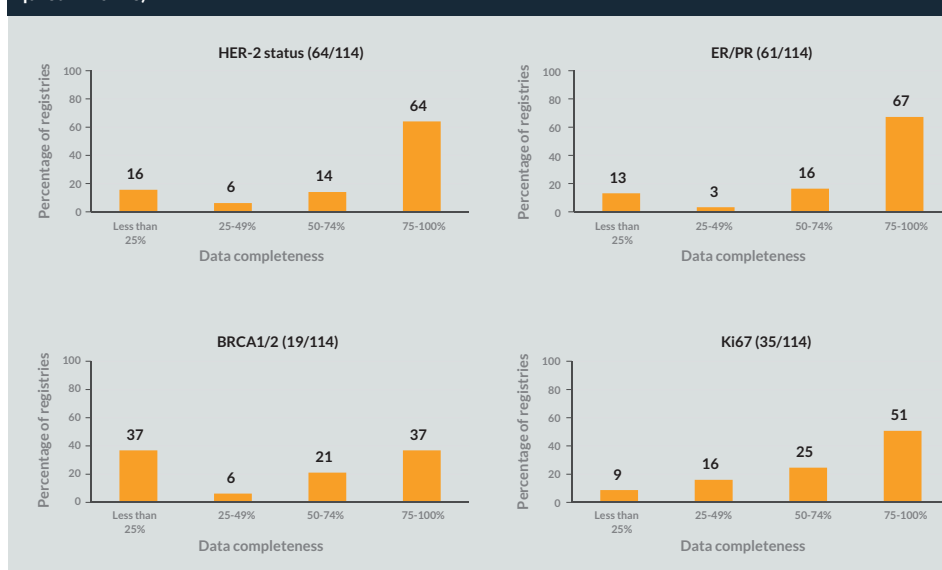
Trends over time in the number of avoidable premature deaths among cancer patients will offer a powerful contrast with outcomes in better-performing health systems in neighbouring countries. They stimulate policymakers to plan more appropriate cancer control strategies. Avoidable

premature deaths are a powerful way to express inequalities in survival as a single number that is suitable for policymakers: “Politicians do not like to do things that are too difficult. Simple, clear messages are important” (Baroness Delyth Morgan, Breast Cancer Now).

Even in the twenty-first century, safe and effective surgery is not yet available in many countries in the world. In some countries, radiotherapy may be considered a luxury, or may simply be unavailable (4). Examination of recent trends in cancer survival, and in the number of avoidable premature deaths, in the light of the distribution of patterns of care, will contribute key evidence for

Figure 3: Breast cancer - stage availability by year of diagnosis (from questionnaires)



Figure 4: Breast cancer – availability and completeness of treatment data 2012-2017 (from questionnaires)**Figure 5: Breast cancer – availability and completeness of data on molecular biomarkers 2012-2017 (from questionnaires)**

planning appropriate cancer control strategies to guarantee equal access to cancer prevention, screening and treatment to women in every country in the world.

The evidence from this research will help drive policy to reduce inequalities in survival from the most common cancers in women. This work will involve targeted dissemination of the findings to scientists, policymakers, cancer patients and the general public. Results from VENUSCANCER will also be used by the Organisation for Economic Co-operation and Development (OECD) in its *Health at a Glance* series, and for the WHO Global Breast Cancer Initiative.

COVID-19 pandemic: ethical, legal and administrative issues

The COVID-19 pandemic of 2020–2021 has changed many aspects of our lives, including research. Many technical and

administrative problems have arisen, both at the London School of Hygiene and Tropical Medicine (LSHTM) and among cancer registries around the world.

One of the most important features of this ERC consolidator grant, offering financial support to cancer registries in LMICs, has turned out to be more difficult than we expected, due to the need to set up legal contracts between LSHTM and each registry or its host institution. Other difficulties have arisen because English is not the mother tongue for most of our colleagues in LMICs, and because it has proved impossible for some cancer registries even to open a bank account, or if that is achieved, to receive financial support from another country, in this case the United Kingdom.

The United Kingdom's exit from the European Union (EU) also did not help. In many European countries, where the General Data Protection Regulation (GDPR) was already mis-interpreted or over-interpreted by administrators,

it has become much more difficult to obtain essential data for research, e.g., full dates of birth, diagnosis or last known vital status. Similar regulations have created problems in releasing detailed data in North America.

Despite the difficulties posed by the COVID-19 pandemic and by Brexit, we have finalised the legal contracts to permit the transfer of funds for data collection to selected cancer registries in LMICs, and data-sharing agreements with cancer registries in the 27 EU Member States to enable transmission of sensitive personal data in compliance with the EU GDPR. Nevertheless, this was an extremely time-consuming exercise.

Unless cancer control policies are to be based on statistical projections from data that are scanty or of average quality, or even, where data are non-existent, modelled on the basis of untestable assumptions from data collected in other countries, action is urgently required to create population-based cancer

registries that can provide a continuous stream of high-quality data in most countries. This would imply availability of adequate resources to register all patients with cancer in a timely fashion, the right to access up-to-date national or regional death records to establish their vital status, the legislative stability to operate efficiently over the long term, and the autonomy to deploy all their data for research. ■

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The importance of ancestry and diversity in cell line collection and analysis for people of African ancestry

Simone Badal, The University of the West Indies, Mona



People of European ancestry tend to receive greater benefit from anticancer treatments than people of African ancestry. The recent attention on these different outcomes in patients globally with cancer is uncovering potential sources for these biases as significantly poor representation persists for Blacks when using cell line models. Similar observations are seen at the clinical level. To close the gaps and to ensure equal benefit for both Blacks and Whites with cancers, increased representation of cell lines needs to be achieved. A focused push from funding agencies, journal editors and policymakers can aid in this outcome.

Many drug leads for cancer treatment have emerged from the application of preclinical studies that have utilized cancer cell lines as 2D and 3D models and as xenografts in specialized mouse models. The application of cell lines in cancer research spans more than 70 years, a period that has generated many discoveries in cancer treatment towards improved patient survivorship (1). Yet, the methodologies employed to generate cell lines remain lacking given the less than 10% success rates. This continues to stifle the advancement of cell lines; a requisite for the optimal application of these preclinical tools. While cell lines continue to pave the way for drug discoveries, the genetic drift encountered from the incessant propagation in vitro is an area warranting attention to advance drug leads with a personalized approach.

Cell lines representative of myriad tumours across various ethnicities are crucial to this end. Research by Barretina et al. (2), and Garnet et al. (3), have together shown gene-drug specificity across more than 1,000 cell lines exposed to almost 150 anticancer drugs. Similar findings were obtained by the NCI-60 study (4) whereby various cell line panels representative of different cancer subtypes yielded more effective drug leads than the usage of single cell lines for different cancers. Cell line panels typically provide representation of different tumour subtypes for specific cancers, and these are believed to be more effective in drug prediction than single cell lines (1). Of the two main global suppliers for cell lines, American Type Culture Collection (ATCC) and The European Collection of Authenticated Cell Cultures (ECACC), cell line panels are only offered by ATCC, and of the 24 panels (Figure 1), representation for Blacks is only observed among three. While ECACC does not offer specific cell line panels, their offering

of categories of different types of cancers (Table 1) shows majority representation for Caucasians as of September 2021.

The questions surrounding cancer disparities has forced an inquest into in vitro research models. Both socioeconomic factors and biological drivers play a role in the higher incidence and mortality rates for Black men and women with cancer. African American men have 25% higher incidence and 43% higher mortality rates than White American men with cancer (5). Although, African American women have lower cancer incidence rates than White American women, they have a 20% higher mortality rate (6). In general, the top two cancers of concern for African American men are prostate and lung while for African American women, they are breast and lung. Similar trends are observed in the Caribbean and Africa (7). Of these cancers of concern (breast, lung and prostate), Black representation among the ATCC cell line panel is only observed for breast cancer and among the various cancer cell lines (colorectal, esophageal and neurobiology) offered by ECACC, there are no known representation for Blacks.

The most emphasized cancer disparity is observed for prostate cancer, especially in light of the global decline in mortality rates irrespective of the pervasive incidence and mortality rates for Black men in the Caribbean and Africa (7) and the two and a half times higher mortality rates for African American men compared to European American men (8). One could argue that Blacks tend to make up most of the lower income status population but even when assessed grade for grade and stage for stage, survivorship for Whites is better than Blacks (7). Despite the observed disparity, no prostate cancer cell line panel exists for Blacks among the ATCC cell line panel (9). Moreover, more than 97% of the prostate cancer cell lines available at ATCC are Caucasian in origin. If cell lines

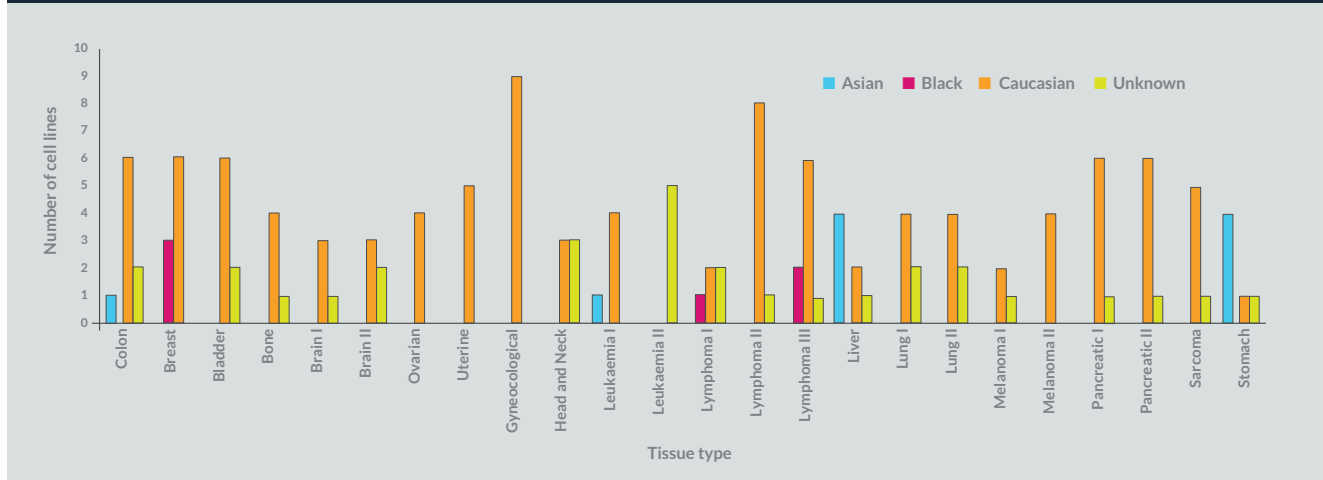
Figure 1: The ethnic representation of panels of cancer cell lines according to tissue specificity on ATCC's website. Taken from Badal et al., (9)

Table 1: The distribution of ethnicities of human cell lines offered by ECACC categorized by cancer type. Of the thirty-eight cell lines listed, representation for Blacks is 0%. ECACC also has other categories of human cell lines not shown in the table, serum free (4), induced pluripotent stem cells (1700), GPCR, Hybridoma collection (400), Chromosomal abnormality, HLA-Type Collection (430) and Human Random Collection, (700 all Caucasian)

Cancer	Ethnicity
Colorectal	
GP5d	Caucasian
MDST8	Unknown
HCA-46	Unknown
HCA-24	Unknown
HCA-2	Unknown
HCA-7	Unknown
HCA-7 Colony 29	Unknown
HT29 gluc C1	Caucasian
HT115	Unknown
HT55	Unknown
HT29/219	Caucasian
CACO-2	Caucasian
LS180	Caucasian
SW 620	Caucasian
LoVo	Unknown
LS174T	Caucasian
COLO 320DM	Caucasian
COLO 205	Caucasian
SW 1116	Caucasian
Neurobiology	
BE(2)-C	Caucasian
BE(2)-M17	Caucasian
SK-N-BE(2)	Caucasian
SK-N-DZ	Unknown
SH-SY5Y	Unknown
Oesophageal	
ESO26	Caucasian
ESO51	Caucasian
KYAE-1	Caucasian
KYSE-270	Asian
KYSE-30	Asian
KYSE-410	Asian
KYSE-70	Asian
OACM5.1 C	Caucasian
OACP4 C	Caucasian
OE19	Caucasian
OE21	Caucasian
OE33	Caucasian
SK-GT-2	Hispanic
SK-GT-4	Caucasian

are used in drug discovery, this begins to explain the enhanced responsiveness to chemotherapy drugs experienced among Whites compared to Blacks (10,11). Of note, is that majority of prostate cancer deaths occur among men with advanced disease.

The other cancer with a focused attention on its disparity is breast. Unlike prostate, the incidence rate for breast cancer among African American women is lower than White American women, yet the mortality rates are higher among Black women. Of concern is that no treatments existed for the most aggressive breast cancer, triple-negative breast cancer (TNBC) until recently, the most common type of breast cancer in Black women with 30% higher incidence rates (12) and 42% higher mortality rates (13). A similar pattern is observed for the availability of breast cancer cell lines, although representation for Blacks is observed among the six-breast cancer cell line panels on ATCC, more TNBC panels are needed for Black women with TNBC. TNBC cell line panel for Blacks is approximately 20% and there is a 14% representation for breast cancer cell lines overall. A larger gap was observed for breast cancer cell lines offered by ECACC as 94% were of European ethnicity and the remaining for Blacks. Similarly, poor representation of Blacks is observed at clinical trial accounting for less than 10% in general even for trials geared at TNBC (14).

The other cancer of concern for both Black men and women is lung cancer and like prostate cancer, there is an overall reduction in incidence and mortality rates, but Blacks have roughly twice higher incidence rates than Whites and higher mortality rates (15). While socioeconomic factors play a large role in this, with Blacks being less likely to receive optimal treatments including surgeries compared to Whites (16,17), research has linked biological drivers that contribute to the disparities (18). There is evidence that Blacks experience inferior treatment response to chemotherapy drugs and more severe toxicity to platinum-

based chemotherapy drugs (19) which contributes to poorer patient survivability. Irrespective of the burden lung cancer presents and the noteworthy disparity that exists, there is no representation for Blacks among the cell line panels on ATCC for lung cancer. Furthermore, of the 64 lung cancer cell lines available, representation for Blacks is roughly 14% and for Whites, roughly 80%.

Research with a focus on primary cancers of concern for Blacks is lacking and cell lines when applied appropriately will guide the development of drug leads with a targeted approach. Organizations like, African Caribbean Cancer Consortium, (AC3 <https://ac3online.org>), Prostate Cancer Transatlantic Consortium (CaPTC) and Human Hereditary and Health in Africa (H3A <https://h3africa.org/>) are engaged in research efforts to understand cancers specific among the Black population in Africa, the Caribbean and America. It is believed that these research initiatives at the genome, transcriptome and proteome levels taking lifestyle factors into account will contribute to advancing more effective anticancer therapies for Black men and women with cancer. However, needs to be increased representation in cell line panels and among cell lines in general from major suppliers such as ATCC and ECACC, to better understand cancers of concern for Blacks. Towards this end, our lab (AntiCancer Research Jamaica, www.acrj.org.jm) has developed a methodology used to develop the first cell line, ACRJ-PC28 (a prostate cancer cell line) from the Caribbean, a region with high Black representation. We believe this methodology will expand the representation of all cancers of concern for Blacks. Concomitantly, there needs to be a concerted effort among funding agencies, journal editors and policymakers to steer the direction of research towards a more inclusive approach. ■

Authors' Note

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Regional Perspectives



Cancer control in the Eastern Mediterranean Region

Ibtihal Fadhil, President, Eastern Mediterranean NCD Alliance



This profile considers the state of cancer control in the Eastern Mediterranean Region and the trends driving a worrying increase. It also considers the challenges as well as the priorities of those addressing them.

Cancer is a leading cause of morbidity and mortality in the EMR. It is the fourth leading cause of death and the second cause of non-communicable disease-related death in the Region (2). According to the International Agency for Research on Cancer (IARC), approximately 733,965 new cancer cases and over 458,625 deaths were reported in the EMR in 2020; a number that is projected to double by 2040, making this region the one with the highest estimated increase in cancer burden compared to all six WHO regions (3).

This increasing trend is mainly related to ageing and population growth, but it is also due to a higher exposure to risk factors such as tobacco use, unhealthy diets, air pollution, physical inactivity and infections. The prevalence of obesity in adults in the EMR remains high, particularly among women

and children (4) with a high body mass index (BMI) and this is expected to increase the incidence of colorectal, liver and gastric carcinoma, particularly among males, and breast cancer incidence among females (5).

Cancer control challenges

Currently over half of the EMR countries do not yet have operational National Cancer Control Plans (NCCPs) (6). The development of cancer programmes has been gravely affected by political instability and humanitarian crises. Over half of the EMR region is affected with acute and chronic emergencies and political unrest, resulting in waves of migration, displacement and the destruction of health services with negative impacts on all cancer services (7).

Figure 1: Map of the EMR region



A continuous “brain drain” of specialists caused by the unrest and political instability in the region has resulted in serious challenges to health services continuity and shortcomings in a region facing an increasing incidence of cancer. Most countries in the EMR are still challenged by weak public health systems, fragmentation of services, scarcity of resources, increased costs, limited access to cancer medicines and an overdependence on the private sector.

Cancer priorities

Prevention is a priority in the EMR where many of the common cancers can be prevented by feasible and cost-effective public health interventions (e.g. the implementation of FCTC recommendations to reduce lung cancer; increased coverage of hepatitis-B vaccinations to reduce liver cancer; reducing exposure to occupational carcinogens through stringent industrial safety norms to reduce bladder cancer, etc.), the adoption of healthy lifestyle and improvements in physical activities also needs to be prioritized in the region.

The early detection of common cancers is another key cancer control priority in the EMR. Screening for breast, cervical, colorectal and lung cancer is a complex and resource-intensive public health initiative. An “Early Diagnosis” approach, which can be effective for all common cancers and is logistically simpler to implement, and should be an integral component of all cancer control programmes in EMR countries

The cost of cancer treatment varies among EMR countries. The rate of “out of pocket” expenditure (OOP) is lower in high-income countries (25%), where governments fund more than 65% of the current health expenditures (CHE) of patients. By comparison, (OOP) is about 70% in low-income countries and government funding varies from 18% in Sudan to over 40% in Tunisia, Syria, and Morocco (8).

The generation of robust cancer data is a priority in the EMR countries where reliable population-based cancer registry and mortality data are used to monitor cancer incidence time trends, geographical patterns, and patient’s survival at the population level. There is considerable variation across the region, both in terms of population-based cancer registry coverage and quality, reflecting the varying degrees of developments in the region (9). While more than half of the 22 countries in the region (64%) have functional cancer registries in place (both regional and national), about 14% of EMR countries do not have any type of cancer registration system (9).

Palliative care in the EMR

When most cancer cases present at advanced stages (10), the provision of palliative care (PC) services becomes a necessity to reduce the suffering and improve quality of life

. Several initiatives and best practices have been developed in the region, yet the majority of EMR countries have not yet considered PC as a public health need and therefore have not included it in their health agenda. The EMR has a vast variation in laws, religious affiliations, and access to healthcare. Because of this, there is a great variability in PC policies and access to controlled medications; especially i.v. medications such as morphine or fentanyl. A majority of countries in the EMR have a much lower consumption of opioids than the global consumption of opioids which has been on a steady rise. There are many reasons for this, the most significant reason being the lack of access to opioids for both patients and healthcare professionals (11).

Impact of COVID-19

Unfortunately, the COVID-19 pandemic has further complicated the situation of cancer prevention and control in the region and has adversely affected all cancer services, from planning to PC, with the low-income countries being the most affected. According to the WHO survey in 2020,

cancer services were reported as being disrupted in more than 40% of countries in EMR (12). These disruptions to cancer services, including the suspension of screening programmes, delays in diagnosis and treatment (including palliative care), are likely to exacerbate the current situation with an increase in advanced-stage diagnoses and as a result an increase in potentially preventable cancer mortality. Countries continue to mitigate the disruption of service; the extent of the effects of the pandemic are still ongoing and yet to be fully evaluated and measured.

WHO/EMRO Regional Framework for Action

To help countries scale up their cancer control programmes, WHO/EMRO has developed a Regional Framework for Action (RFA) on cancer prevention and control (13).

This RFA aims to support countries in developing a more systematic approach to cancer control and to reduce mortality from common cancers. Moreover, WHO has also embarked on three major global initiatives in the past three years:

- ➔ the Global Initiative for Childhood Cancer (GICC);
- ➔ the Global Strategy to Accelerate the Elimination of Cervical Cancer;
- ➔ the Global Breast Cancer Initiative.

The adaptation of these strategic interventions, and prioritization guided by WHO initiatives, will require a far higher level of political commitment and sustained funding by EMR governments, and better evaluation of their existing programmes. ■

This editorial summarises the findings of the report *Cancer Control Eastern Mediterranean Region Special Report* (Fadhil I et al, in press Global Health Dynamics 2021) and is linked to the London Global Cancer Week presentation Learning lessons from COVID-19 – *Building better cancer control in the Eastern Mediterranean Region* at 9 a.m. - 11 a.m. GMT on Sunday 14 November 2021.

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Prior to this, Dr Fadhil served as Regional Adviser, Noncommunicable Diseases at World Health Organization, EMRO (2008–2016). She has also held various academic and clinical positions during the last 36 years on national and international levels. Working as NCD consultant for ministry of health in United Arab Emirates, Bahrain, Jordan and Iraq.

Dr Fadhil has served as a member of several national and international medical committees and public health associations, and has published as the main author or co-author of articles in several scientific journals.

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Confronting inequitable access to health commodities for the acceleration of cervical cancer elimination goals within the Commonwealth

Dr Janneth Mghamba, Health Advisor, Commonwealth Secretariat; **Emily Gilmour**, Health Research Officer, Commonwealth Secretariat; **Yunus Mohammed**, Executive Director, SAPAM; **Victoria Rutter**, Executive Director, Commonwealth Pharmacists Association and **Layne Robinson**, Head of Social Policy Development, Commonwealth Secretariat



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LAYNE ROBINSON

As part of the Commonwealth efforts to eliminate cervical cancer, and in alignment with the WHO's 2020 Global Strategy to Accelerate the Elimination of Cervical Cancer, the Commonwealth Secretariat has developed a new database that will provide member states with access to information and pricing of quality essential medicines. With greater access to fair and transparent pricing, governments will be able to make more informed procurement decisions and in turn, a reduction in inequities and disparities for low- and middle- income countries. Whilst the COVID-19 pandemic has threatened major global health goals, it is critical that governments take collection action to increase equitable access to health commodities to ensure that no country is left behind.

The Commonwealth is disproportionately affected by cervical cancer. Whilst the Commonwealth represents 30% of the world's population, it carries a 36% share of the global cancer incidence burden, and 39% of the global mortality burden (1). This sizable burden can be in part attributed to a greater proportion of being low- and middle-income countries (LMICs) in the Commonwealth, with many countries being further impacted due to a lower survival rate for cervical cancer in LMICs (2).

The Commonwealth carries a significant cervical cancer burden, particularly in LMICs. Whilst the causes of high incidence and mortality rates are multifaceted, a considerable challenge that member states face relates to equitable access to health commodities. Although 94% of cases are seen as preventable, LMICs continue to face inequities with regards to cancer prevention and control measures (3). Public health measures such as the establishment of cancer prevention and early detection programmes through increased cervical cancer screening, public health education programmes promoting safe sex to reduce risks of sexually transmitted infections

such as HPV and HIV, and the introduction of affordable HPV tests, medicines and vaccinations are critical in reducing global cervical cancer disparities, particularly among women in LMIC developing countries.

This article provides an overview of the cervical cancer landscape in the Commonwealth and explores the key challenges to equitable access to cervical cancer medicines and vaccines. In the following discussion potential strategies for address the issue, in alignment with the WHO's 2020 Global Strategy to Accelerate the Elimination of Cervical Cancer are considered.

Burden of cervical cancer in the Commonwealth

The 2018 Globocan Estimates on Cancer Incidence and Mortality Report indicates that Commonwealth's incidence of cervical cancer will rise by 38% by 2030 in line with population growth, in addition to the deaths increasing by 42% (4). It is important to note that these figures incorporate the varying scales of health systems across the Commonwealth.

The five Commonwealth member states with the highest

Table 1: Number of cervical cancer Incidences and deaths per Commonwealth region

Region	Incidence (#)	Deaths (#)
Africa	66,655	41,449
Asia	113,208	83,450
Caribbean	2,312	6,426
Europe	4,396	1,058
Pacific	5,342	3,057

Globocan, 2018

cases and deaths are Bangladesh, India, Nigeria, South Africa and Tanzania. Furthermore, data shows the highest regional incidence and mortality rates per population in the Commonwealth are seen in the Africa region, with the rates elevated in Southern Africa and Western Africa. Relatively speaking, the rates are 7 to 10 times lower in North America, Australia/New Zealand and Western Asia (5). Moreover, 7 of 8 sub-Saharan African countries – all of which are part of the Commonwealth – including the Gambia, Kenya, Malawi, the Seychelles, South Africa, Uganda and Zimbabwe, have experienced uniform rises in mortality rates (6). It is clear that the large part of success in North America, Australia, New Zealand and Western Asia is due to the effects of population-based cytological screening programmes in which have helped with declines in cervical cancer rates upon their implementation in the aforementioned countries.

Few LMICs have implemented country-wide HPV vaccination programmes, the factors of which are complex and multi-faceted. As of May 2020, less than 30% of LMICs had implemented national HPV vaccination programmes, compared with more than 80% of high-income countries (7). Further, in LMICs, just 44% of women have had at least one screening for cervical cancer, with the median range in sub-Saharan Africa at the country level being 16.9 percent (8). These higher incidence rates typically occur in countries with a high prevalence of HPV and human immunodeficiency virus (HIV), a lack of population wide cervical cancer screening programmes and often low uptake where they are established), and a lack of HPV vaccination programmes (9).

Research has indicated that widespread coverage of both the HPV vaccination and cervical cancer screening has the potential to avoid 13 million cervical cancer cases globally by 2069 (10). Implementing such initiatives is critical, with figures showing that in the absence of effective cancer preventive and control programmes, countries have experienced rapid increases in premature cervical cancer mortality in recent generations. Furthermore, to help accelerate cancer elimination strategies, there is a need for an uninterrupted supply of quality-assured and affordable HPV vaccines, screening tests, as well as palliative care medicines and other strategic commodities.

Challenges to equitable access to health commodities

One of the major factors contributing to global cervical cancer disparities is the challenge of access to oncology health commodities. Access to oncology health commodities can be assessed across three major dimensions: availability, affordability, and accessibility (11). Availability, typically requires marketing authorization for a product followed by launch of the medicine by the company. Accessibility encompasses the ability to obtain a prescription for the medicine and also factors associated with the pharmaceutical supply chain. Affordability includes the coverage status of the medicine and the insurance status of the patient, as well as other out-of-pocket costs and individual drug prices.

On the affordability of medicines, a report launched in 2020 from the WHO found that cancer medicine prices are disproportionately higher than other types of pharmaceuticals and therapies, and that the price of cancer drugs is continuing to increase at a rapid and alarming rate (12). Whilst HPV vaccination is predicted to be cost-effective, further addressing of the affordability issue requires countries to have good policies in place to improve health infrastructure and financing, as well as mechanisms to ensure that there is also a rational use of medicines (12). Whilst favourable policies seem to be a precursor, equally important is for countries to have reliable information on medicine prices and availability, from both the pharmaceutical industry as well as countries, to assist them in constructing sound medicine pricing policies and to also evaluate whether their expenditure on medicines is comparable to that of other countries, which can subsequently lead to governments making negotiations for cheaper prices.

With high rising prices of cancer drugs and other health commodities including those for cervical cancer, it is clear that for the achievement of elimination and attainment of the WHO's 90-70-90 target, the affordability of essential medicines, vaccines and health technologies needs to be addressed adequately as countries approach 2030 (13).

In recognition of this challenge, Commonwealth Health Ministers at the 2018 Commonwealth Health Ministers Meeting (CHMM) called for collective action to invest in cervical cancer prevention and treatment strategies, including to reduce the cost of medicines and address shortages of vaccines. Health Ministers deliberated on sharing pricing information through the creation of a Commonwealth database which could detail the prices of essential medicines, vaccines and health technologies.

Developing a Commonwealth-led solution to inequitable access

Given the Commonwealth's significant burden of cervical cancer, the Commonwealth Secretariat has made greater

commitments, in alignment with the WHO's Global Strategy for Cervical Cancer Elimination, to reduce and ultimately eliminate cervical cancer in the Commonwealth. Part of this effort has been the development of a new voluntary information and price-sharing database – the Voluntary Information and Price-sharing Database (VIPSD).

The VIPSD is an output from the 2018 CHMM, to take collective action on health priorities including cervical cancer, such as reducing the costs of essential medicines, vaccines and health technologies. This initiative is the result of a collaboration between the Commonwealth Secretariat, consultants from the South African Programme on Access to Medicines and Diagnostics (SAPAM), the Southern African Development Community (SADC) and the Organization for Eastern Caribbean States (OECS). The platform is modelled on a similar initiative created by SADC, and has now been launched to be used across The Commonwealth.

The database has been designed primarily as a means for countries to share information on the pricing of medicines and medical commodities. The platform is an easy way to identify areas where countries have made or can make savings in the procurement of essential medicines. In alignment with priorities of the Commonwealth Health Ministries, the key objectives of the VIPSD are to:

- ➔ Reduce manufacturer net selling price for member states.
- ➔ Improve efficiency of forecasting and price negotiation process for members.
- ➔ Provide a readily searchable database of verified supply information to ease decision making for procurement processes.
- ➔ Allow provision of data driven price analysis and insight for key stakeholders.

The launch of the VIPSD will help to provide a greater degree of transparency for member states, helping them to make more informed decisions about procuring medicines and vaccines. Furthermore, acknowledging that many member states face challenges in accessing quality and affordable cervical cancer medicines and vaccines, it is expected that the VIPSD will reduce inequities and disparities for LMICs. Is it premature to say how many LMIC Commonwealth members have joined this initiative?

Moving forward – how greater access will support elimination

It is clear that the elimination of cervical cancer will not be achieved only through greater access to fair and transparent pricing alone. Rather, the solution is multifaceted, and will require many arms of government to build effective policies and mechanisms, in addition to harnessing collective

multilateral strategies. These strategies include strengthening countries supply chain management, addressing procurement practices, tax and tariff policies, and strengthening national drug regulatory authorities.

To strengthen collective efforts, Commonwealth member states must take the necessary steps to emphasize the inclusion of cervical cancer in national health sector plans, and to utilize population registries to build robust surveillance data, on areas such as HIV-status, other cancers, vaccination status and screening results. The integration of cervical cancer services into existing primary health care and public health services will help to provide greater access to cervical cancer screening and treatment for women across the Commonwealth.

Whilst progress has been made over the last decade, it is evident, particularly taking into consideration the COVID-19 pandemic, that member states must sustain and expand on existing cervical cancer elimination efforts. The Commonwealth Secretariat is keen to continue supporting member states on the next steps towards fair and transparent pricing for cervical cancer medicines, including reviewing procurement legislation, medicine regulation and registration, with a view to harmonization. The race towards the elimination of cervical cancer within the Commonwealth is underway, with a line of sight on 2030. ■

Dr Janneth Mghamba is the Health Advisor for the Commonwealth Secretariat. A medical doctor and epidemiologist, Janneth has over 15 years of experience in global health and developing national health systems, with a particular focus on NCDs. Prior to joining the Commonwealth Secretariat, Janneth worked as the Assistant Director for the Epidemiology and Disease Control section of Tanzania's Ministry of Health.

Emily Gilmour is a mixed-methods researcher and global health policy professional with over six years of experience designing and managing social research projects. She currently works as a Health Researcher at the Commonwealth Secretariat, working across a range of global health priorities including reducing the burden of noncommunicable diseases, COVID-19 response and health security and resilience.

Victoria Rutter was appointed as the first Executive Director of the Commonwealth Pharmacists Association in 2016. Her dedication has significantly increased the charity's footprint and work streams, supporting better access to and use of medicines in lower resource settings, including pioneering the highly commended Commonwealth Partnerships in Antimicrobial Stewardship programme. She has led advocacy for the profession in numerous high-level policy forums and is the civil society representative on the Commonwealth Advisory Committee on Health.

Yunus Mohammed has worked at various programme management levels, and is a qualified pharmacist with an MBA, project management certification and health technology development experiences. He has experience in development, strategy, pharmaceutical sector, healthcare sector, health technology, regulatory, intellectual property, and supply chain sectors. He continues to consult with the SADC Secretariat, Commonwealth Secretariat and other global partners, working regionally and internationally on access to medicines projects, and health systems strengthening.

Layne Robinson currently serves as the Head of Social Policy Development at the Commonwealth Secretariat. In this role, Layne leads the Commonwealth's work on Social Policy with particular focus on Youth, Education, Health and Sport policies, and provides technical advice to Commonwealth member states whilst working in partnership with relevant organisations to improve the lives of Commonwealth citizens.

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Addressing the need for palliative care in Nepal – the building of a hospice and palliative care education centre in Kathmandu

Max Watson, Consultant, Palliative Medicine Western Trust, Director of Project ECHO at Hospice UK; **Patricia Newland**, Executive Director, The Challenge Fund and Local Radio Presenter on Current Affairs, UK; **Rajesh Gongol**, Vice Chancellor, Patan Academy of Health Sciences, Founding President Hospice Nepal and **Stuart Brown**, Consultant, Palliative Medicine, Waikato Hospital, New Zealand



MAX WATSON



PATRICIA NEWLAND



RAJESH GONGOL



STUART BROWN

Sandwiched between India and China and with a population of over 29 million people, a quarter of whom earn less than US\$ 0.50 a day Nepal faces many challenges not least in healthcare. There is little palliative care provision for adults and children's palliative care is in the earliest stages of development. There is an urgent need for more hospice beds in Kathmandu as well as the expansion of the current palliative care outreach programmes into the rural regions of the country where 80% of the population reside. The number of trained palliative care health professionals is limited and key to the new hospice facility will be a state-of-the-art education facility.

Nepal is landlocked; located between India to the east, south and west and the Tibet Autonomous Region of China to the north. It has some of the most difficult terrain in the world, with 75% of the country being covered by mountains, meaning that access to the rural population to provide palliative care guidance and medication is extremely difficult.

Nepal has a population of over 29 million people with 60% of the population under 30 years of age. The average life expectancy has risen to 70 for men and 72 for women. The Ministry of Health is responsible for the support and administration of public health services including hospitals and clinics. The Nepalese government has approved a strategic plan for palliative care, but much work needs to be done to achieve the goals of this plan.

The burden of noncommunicable diseases is rising and patients with cardiovascular disease, cancer and respiratory conditions being most in need of palliative care (1). Patients with cancer have a high burden of symptoms such as pain, breathlessness and nausea and vomiting. Two common cancers in Nepal: oral cavity cancer and cancer of the cervix are known to have particularly severe symptoms which are difficult to alleviate (2).

Cancer incidence and survival rates in Nepal

Cancer incidence in Nepal is increasing and has become a major public health problem. It is now recognized that more attention should be paid to the need for palliative care - both in urban areas such as Kathmandu, but also among rural and remote communities. Lung cancer is the most common cancer among males followed by stomach, colorectal and oral cavity cancers. Among females, cervical cancer is the most common cancer followed by breast, lung and gallbladder cancers.

Comparing palliative care in Nepal and the United Kingdom

Dying in pain in Nepal is still a common occurrence. In the United Kingdom when a disease such as cancer is beyond curative treatments, patients rightly expect at least to receive effective pain relief, and many will be offered comprehensive hospice care. However, in low- and middle-income countries (LMICs), such as Nepal, the great majority of terminally ill patients have no access to pain relief medication and even less access to hospice care. As a result, many patients endure very painful deaths, causing both patients and their families immense suffering (Table 2).

Table 1: Number of cervical cancer Incidences and deaths per Commonwealth region

	Males	Females	Both genders
Population	13 348 435	15 788 373	29 136 808
Number of new cancer cases	8 943	11 565	20 508
Age-standardized incidence rate (world)	78.6	82.6	80.9
Risk of developing cancer before the age of 75 (%)	8.1	8.6	8.4
Number of cancer deaths	6 244	7 385	13 629
Age-standardized mortality rate (world)	56.1	53.9	54.8
Risk of dying from cancer before the age of 75 (%)	6.0	5.8	5.9
5-year prevalent cases	15 073	21 833	36 906
Top 5 most frequent cancers excluding non-melanoma skin cancer (ranked by cases)	Lung Stomach Colorectal Oral Cavity Thyroid	Cervix uteri Breast Lung Gallbladder Ovary	Lung Cervix uteri Breast Stomach Colorectal

Table 2: Palliative care in the United Kingdom versus Nepal

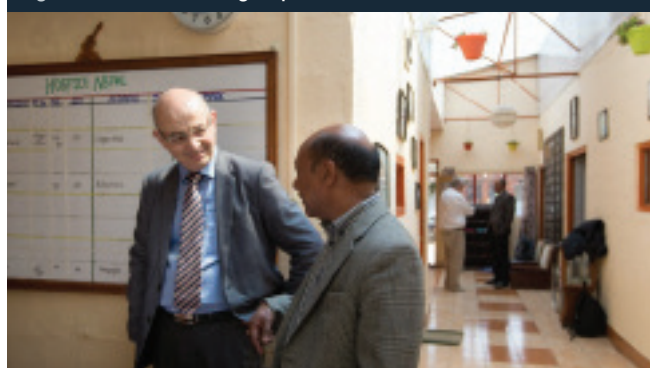
	United Kingdom	Nepal
Population	66,650,000	29,136,000
Those in receipt of palliative care in hospice each year	48,000	700
Those in receipt of palliative care at home each year	225,000	500
Number of adult hospice beds available	2,760	25
Total number of hospices	220	6
Number of dedicated children's hospices	58	0
Number of terminally ill patients with access to opioids	100%	9%

The Vision: Building a new Hospice Nepal and Palliative Care Education Centre in Kathmandu

Background:

Twenty years ago, four former Nepali schoolfriends got together and started the country's first hospice in Kathmandu. Today, from those very humble beginnings, Hospice Nepal has become an important centre for palliative care under the guidance of one of those four friends, Professor Rajesh Gongal, who is now the Vice-Chancellor of Patan Academy

Figure 1: Inside the existing hospice in Kathmandu



of Health Sciences (Figure 1). There is presently an 8 bed in-patient unit, a home based community programme in Kathmandu and a rural programme in the Makwanpur area (Table 3).

The hospice is run as a non-profit, non-governmental organization (NGO) registered with the Social Welfare Council in Lainchaur, Kathmandu. It is a registered charity overseen by a Board of Trustees. All NGOs in Nepal have to get certification from the Social Welfare Council which is subject to an annual audit and verification by the Tax Division of the Finance Ministry.

Aims

With the current demand for palliative care in Nepal outstripping the capacity of the present services, there is an urgent need to expand Hospice Nepal and include facilities for the care of children. Eighty percent of Nepal's population live rurally where transport links to Kathmandu and other major centres are often difficult decreasing access to central services. The need to expand Hospice Nepal's current

successful outreach programmes into more rural areas will thus be a major focus of the new hospice.

In particular, the provision for healthcare training and telementoring facilities are key to enable the leveraging of palliative care expertise across a wide population. It is planned to utilize the ECHO Programme which is a worldwide telementoring movement dedicated to the democratization of specialist knowledge which will enable clinicians to gain the expertise required to provide palliative care services and support (4,5). The ECHO network participants are able to learn new approaches for applying their knowledge across diverse cultural and geographical contexts (Figure 2). Patan University,

Table 3: Number of annual admissions to current hospice services

Year	In Patients	Kathmandu (urban community care)	Rural Community (in the Makwanpur area)
2017-2018	133	105	111
2018-2019	160	104	213
2019-2020	76	94	274

Figure 2: The ECHO programme



Two Worlds Cancer Collaboration Foundation (Canada) and the Hyderabad Centre for Palliative Care, India, have already successfully carried out ECHO programmes in adult and children's palliative care in Nepal. These organizations are partner organizations with Hospice Nepal.

Project Hospice Nepal

Those involved in the project come from Nepal, from across the globe and from a variety of backgrounds. Professor Max Watson and Dr Stuart Brown have been involved in various ways with Palliative Care development in Nepal and provide medical advice to the group, while there are other members from the commercial and voluntary sectors. There are ongoing fundraising campaigns in Nepal, the United Kingdom, New Zealand and Canada. The project was initiated by the Fairfield Rotary, Hamilton, New Zealand and in the United Kingdom, a registered charity, The Challenge Fund, has been actively campaigning to raise funds and to promote the project in order to attract as many supporters and donations as possible.

Fundraising has been slowed by the coronavirus pandemic – particularly in Nepal where the surges of Covid-19 have had a devastating impact across the country. However, whilst the pandemic has slowed the progress of fundraising, it has also highlighted even more starkly how important this project is to mitigate the suffering of thousands across the country who have died without access to palliative care support.

Phases of development

Phase 1: Land purchase

Plans for the construction of the new eco-friendly building have been drawn up and the land secured thanks to generous donations both from Nepal and overseas. Shortly before the onset of the pandemic, team members from the United Kingdom, New Zealand and Canada visited Nepal in order to view the site of the new hospice and to meet the Hospice board, the medical leadership and the project manager (Figures 4 and 5).

Phase 2: The build

The construction of the new building and associated areas will

Figure 4: Visit to the site by Project Hospice Nepal team members in February 2020



Figure 5: The land purchased for the new hospice



Figure 6: Hospice 3-D image



be overseen by Mr Om Rajbhandary, a well-respected Nepalese developer, and one of the original four friends involved with the creation of the current hospice. The quality of the building will be of the highest standard and meet stringent earthquake requirements, as laid down by the Government of Nepal who carry out regular inspections during the build. The building has been architecturally designed to be appropriate to Nepali culture and patient and family needs (Figure 6).

Phase 3: The fitting out

On completion of construction the fitting out phase will begin. It is envisaged that the new Hospice Nepal will consist of 25 beds with both individual rooms and small wards. There will be five dedicated paediatric beds with a play area for the children.

On the top floor there will be a “National Palliative Care Training Centre” where medical and nursing staff from across Nepal can receive training given by experts from Nepal and from other countries.

A lecture room and a small seminar room are planned along with IT facilities to enable tele-conferencing to support distance education and the ECHO networks.

Conclusion

Despite delays to the start of the project because of the devastating impact of the coronavirus in Nepal and around the world, pre-build work covering planning, detailed specifications, and tendering is underway.

The geographical diversity of the country will always pose a challenge, particularly with the coordination and delivery of palliative care into the more rural areas of the country. However, the new Hospice Nepal will provide increased access to care for adults and children both as in-patients and at home, becoming a state-of-the-art centre of excellence for the provision of palliative care, advocacy, and education. The unique collaboration between a proven committed team of palliative care pioneers, support from the Nepali Government and health service through the Palliative Care strategy, and the opportunity for collaboration with international supporters provides a strong platform for far reaching impact to improve the care of patients approaching the end of life across the country.

A new Hospice Nepal will be a central part of that development and it could serve as a blueprint for future collaborative initiatives both in Nepal and beyond. It is therefore vital that this opportunity to build capacity in palliative care for both adults and children progresses rapidly. ■

Further information on the project, together with details on all those involved, can be found on website www.projecthospicenepal.org.uk

Professor Max Watson is a Palliative Medicine Consultant in the United Kingdom and Director of Project ECHO at Hospice UK. He was formerly Medical Director of the Northern Ireland Hospice and Visiting Professor at the University of Ulster and Honorary Senior Lecturer at Queens University in Belfast. He is also Visiting

Professor, Virtual Academy at St Margaret's Hospice in Taunton and Honorary Consultant at Princess Alice Hospice, Esher. Professor Watson worked in Nepal throughout the 1990s and has returned regularly to teach there. He has authored and edited numerous books including the “Oxford Handbook of Palliative Care” and the “Palliative Adult Network Guidelines (PANG)” and has taught and lectured extensively across the world.

Dr Stuart Brown is a palliative care specialist at Waikato Hospital, New Zealand, where he is a Consultant in Palliative Medicine. He is a Rotarian and member of the Fairfield Rotary Club in Hamilton. Stuart has worked previously in Saudi Arabia in palliative medicine and later was Medical Director of the Tertiary Hospice and Palliative Care Unit at Abbotsford Regional Hospital in British Columbia, Canada. Since 2008, he has volunteered in Brazil, India, Nepal and Tanzania with the Palliative Access (PAX) Programme of the International Network for Cancer Treatment and Research (INCTR) and Two Worlds Cancer Collaboration, Canada.

Pat Newland is the Executive Director of the Challenge Fund, a UK registered charity, which fundraises for the treatment of cancer patients, particularly children, in low- and middle-income countries. Having gained a degree level qualification in modern languages, Pat has a background both in commerce and in politics having been a senior manager in the travel industry, served for 12 years as a Borough Councillor and is the owner and founder of a property business in London. She has always been active in the voluntary sector having been a school governor and a trustee of a number of charities including Druglink. She is a qualified radio presenter, producing and presenting current affairs programmes on local radio.

Professor Rajesh N Gongal is Vice Chancellor of the Patan Academy of Health Sciences (PAHS) in Kathmandu. He was the Founding Dean of the School of Medicine of PAHS. He is also the Founding President of Nepal Ambulance Service. He is the founding President of Hospice Nepal, the first palliative care centre in Nepal. He completed a fellowship in palliative care from Northern Ireland Hospice and Masters in palliative care from Ulster University. With colleagues, he has pioneered care teaching for doctors, nurses and rural healthcare workers across Nepal.

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INCTR Update



50 Mission, organization and achievements

54 INCTR Branches

55 INCTR Governing Council and partner institutions in developing countries

56 Partners: Past and present

Mission, organization and achievements

The International Network for Cancer Treatment and Research (INCTR) is an international nongovernmental organization (NGO) that was established to address a neglected global health problem – the ever increasing burden of cancer in developing countries. The founder members of INCTR included the former Institut Pasteur in Brussels and the International Union Against Cancer, now known as the Union for International Cancer Control (UICC). The National Cancer Institute in the United States provided financial and technical support and the organization began its activities in 2000. INCTR's headquarters are located in Brussels and it has offices and branches throughout the world. INCTR became an NGO in Official Relations with the World Health Organization (WHO) in January 2010.

The need for INCTR: Cancer in developing countries

Approximately 85% of the world's people live in low- or middle-income countries (LMICs). In 2012, Globocan estimated that there were approximately 14.1 million new cases of cancer and 8.2 million deaths from cancer in the world, with 65% of deaths occurring in LMIC. The number of cancer cases continues to rise across the world, but much faster in LMICs because development brings decreased mortality and with their higher fertility rates, this rapidly translates into population growth and increased numbers of patients with common diseases. The birth rate subsequently declines, although population growth continues since people live longer. Eventually birth and death rates stabilize at a much lower level of both than was the case prior to development. These demographic changes are accompanied by the adoption of unhealthy lifestyles practiced in high-income countries, particularly smoking, and increasingly, overeating and a sedentary lifestyle.

Resources of all kinds for treating cancer are limited in LMICs, such that patients who develop cancer frequently lack access to a facility capable of making an accurate diagnosis and providing appropriate therapy. There is a lack of drugs, a paucity of radiation therapy facilities and very few cancer specialists or other health care workers who are needed to effectively care for cancer patients. Diagnosis may be so delayed that there is little that can be done even if the patient does finally reach a facility competent to care for them. Terminal care is not widely available, and regulations and attitudes are still largely directed towards preventing the misuse of opioids rather than relieving the pain of

dying patients, such that most patients die without symptomatic relief or little or no mental or spiritual comfort. It is estimated, for example, that less than 1% of patients who need palliative care in India receive it.

INCTR is unique in that it focuses only on the developing world. It also works directly with its collaborators, sometimes visiting them many times in order to achieve its goal of helping to build sustainable capacity in LMICs in order to assist these countries in cancer prevention, early diagnosis, treatment and palliative care. It is not an advocacy organization, and all clinical projects are coordinated by a health professional. Its output is information collected in the field, lives saved by cancer prevention or treatment, and improved quality of palliative care.

Who INCTR works with

INCTR utilizes healthcare professionals familiar with the problems of developing countries to enable it to achieve its goals. See Box 1.

INCTR'S GOALS – MAKING A DIFFERENCE

- ➔ To reduce the incidence of cancer in resource-limited countries through public and professional education about the causes of cancer and how to use this information in cancer prevention
- ➔ To detect cancer early through public and professional education about the early signs of cancer and what to do if they appear
- ➔ To diagnose cancer accurately through pathology training and, where important and feasible, imaging techniques

INCTR develops local capacity within LMICs by training healthcare professionals to establish “centres of excellence” in the delivery of feasible, affordable and effective care, including palliative care, that is considered “best practice” so that they, in turn, can train others within their country or region.

INCTR works through its branches in implementing various programmes and projects conducted in collaboration with partner institutions in developing countries and monitored by field visits.

INCTR integrates research into its programmes by documenting and evaluating actual data (rather than projected economic or health benefits, for example). Such research may include a wide range of projects, from cancer education for the general public to developing treatment outcomes, including palliative care. This, in turn, enables healthcare professionals working in LMICs

Figure 1: Disease burden and resources

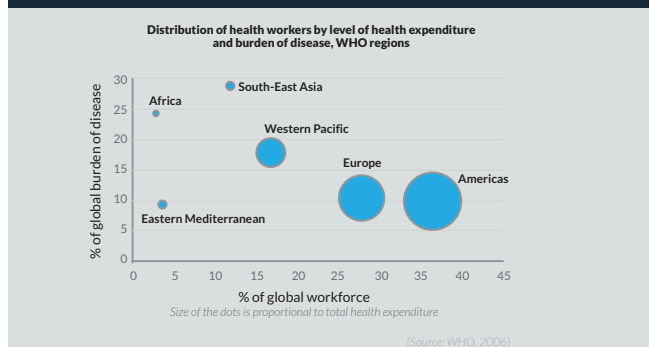
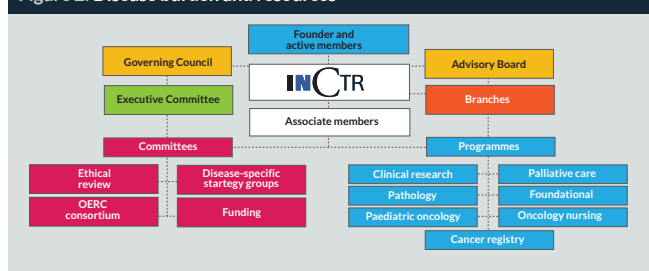


Figure 2: Disease burden and resources



to become familiar with the most pressing issues and to develop plans to improve efficiency and reduce cost. Although clearly many countries have limited health workforces and quantitation of such workforces can be valuable in terms of planning for the future, it realizes that many cancer plans have little impact because of the limited resources and great difficulty in expanding interventions to very poor populations which cannot “purchase” their own healthcare needs and which have little or no chance of expanding their present resources. Having a cancer plan is not enough. Successful cancer plans require knowledge and a budget in addition to educated health professionals.

INCTR's structure

INCTR has consultants and volunteers dedicated to the accomplishment of its goals. Although its headquarters are located in Brussels, it has branches in the United States, Canada, Brazil, United Kingdom, France, Egypt, Nepal and India. Branches are legally-established NGOs that contribute to and conduct programmes and projects that are relevant to INCTR's mission.

Resource development, administration and programmes (e.g., adult oncology, paediatric oncology, cancer registries, pathology and palliative care) are supervised by an Executive Committee or directly by the branches. The Executive Committee is responsible to INCTR's Governing Council. Programmes and projects are developed with the participation, input and advice of various INCTR committees and strategy groups, as well as independent scientific advisers. Programmes and projects are conducted in collaboration with partner institutions involved with cancer research, diagnosis and treatment, including palliative care and education in countries with limited resources.

STRATEGIES

- ➔ To build capacity for cancer prevention, diagnosis, treatment and palliation through professional education and training
- ➔ To conduct, or provide materials for the conduct of educational campaigns for the public and primary care doctors about the causes of cancer and living a healthier life
- ➔ To work with experts in-country to conduct locally relevant research on cancer control

Individuals, institutions or organizations often choose to serve as Associate Members who contribute financially to the work of INCTR.

What does INCTR do?

INCTR addresses all aspects of cancer control with the overall goal of lessening the morbidity and mortality from cancer. It emphasizes training and education of healthcare professionals in LMICs to ensure that “best practices” are instilled in cancer prevention, early diagnosis, treatment and palliative care. Research is an integral part of its work with its partners in LMICs in order to accurately document the cancer burden – including the types of cancer and extent of disease, the outcomes of prevention and early detection campaigns and the efficacy, toxicity and cost of treatment delivered. It also emphasizes public awareness of cancer, which is an essential component of early diagnosis. INCTR has a variety of programmes that are carried out in close collaboration with its branches as well as its partner institutions in developing countries. INCTR's current programmes include:

- ➔ adult oncology;
- ➔ clinical research;
- ➔ palliative care;
- ➔ pathology;
- ➔ cancer registry;
- ➔ foundational;
- ➔ paediatric oncology;

INCTR's projects and achievements

Each INCTR programme has goals and objectives in line with the overall mission of the organization, divided into separate projects. Many projects have been conducted or are on-going and include:

Adult oncology

- ➔ Prevention, early diagnosis, and treatment of selected cancers in poor urban areas and in rural and tribal regions in the state of Rajasthan in India.
- ➔ Cervical cancer screening using visual inspection in Nepal and Tanzania.
- ➔ Training of Bolivian healthcare professionals in cervical cancer screening by Peruvian experts.
- ➔ HPV vaccination of young girls in Nepal.

Cancer registries

- ➔ Establishing an East African Registry Network (EARN) that

subsequently became the African Cancer Registry Network (AFCRN). As part of the Global Initiative for Cancer Registry Development in LMICs, the Network acts as a consortium to provide a “regional hub” for cancer registries in sub-Saharan Africa. The AFCRN is supporting or assisting the development of 22 cancer registries in the region, including English- and French-speaking countries.

- ➔ Provision of training courses in cancer registration and the use of CanReg 5.
- ➔ Participation in collaborative international research.
- ➔ Visits of INCTR consultants to the Kingdom of Saudi Arabia to review cancer registration procedures and data quality and to Uganda to offer advice on setting up a cancer registry.

Clinical research

- ➔ The treatment and characterization of acute Lymphoblastic Leukemia in children, adolescents and young adults in India – over 450 patients have been treated by four institutions.
- ➔ The treatment and characterization of Burkitt Lymphoma – over 750 patients have been treated by seven centres in Nigeria, Democratic Republic of Congo, Uganda, Kenya and Tanzania. Survival is greater than 60% at 5 years.
- ➔ Understanding problems faced by parents of children with Retinoblastoma before treatment – 435 parents interviewed from institutions in 10 countries in Latin America, Asia and Africa.
- ➔ Situational analysis of breast cancer – 8,800 medical records of women treated for breast cancer in four institutions in Peru, Egypt, Pakistan and India.
- ➔ Studies carried out in Brazil, India, Pakistan and Turkey to determine delays in diagnosing and treating nasopharyngeal carcinoma and assess the role of consanguinity and familial history in this cancer.
- ➔ A new initiative to characterize the lymphoproliferative diseases in adults in Senegal with initiated in partnership with Universities in Dakar.
- ➔ Development of a pathological and radiological review for Brazilian patients with medulloblastoma in partnership with the Brazilian Society of Paediatric Oncology.

Foundational

- ➔ Accreditation Programme in the conduct of clinical trials in institutions in Brazil.
- ➔ Educating school children about cancer in Nepal.
- ➔ Evidence-based development through preparation of bibliographies of published literature from developing countries relevant to breast cancer and selected cancers in Egypt.
- ➔ Open Educational Resources for Cancer available online.
- ➔ Thematic workshops to discuss challenges in cancer control in East Africa.

- ➔ Webinars for e-learning.
- ➔ Publication of five annual editions of *Cancer Control* from 2013, with specialist healthcare publisher, Global Health Dynamics, looking at all aspects of cancer policy, prevention, detection, treatment and palliation.

Palliative care

- ➔ Training and educating healthcare professionals – doctors, nurses and social workers in the principles of palliative care – in Brazil, Cameroon, Burkina Faso, Sénégal, Mali, Tanzania, India and Nepal.
- ➔ Sensitization workshops for government officials and the public in Brazil, Tanzania, India and Nepal.
- ➔ Development of a centre of excellence in palliative care for both adults and children in Hyderabad, India.
- ➔ Lobbying governments to improve access to opioids for terminally-ill cancer patients – Nepal and India.
- ➔ Establishment of twinning programmes with hospices in Canada that support palliative care efforts in Nepal.
- ➔ Fostering the establishment of palliative care societies – in Nepal and Pakistan.
- ➔ Promoting paediatric palliative care in Pakistan.
- ➔ Publishing a palliative care handbook describing the management of a wide variety of symptoms in English, Portuguese, French and Turkish.
- ➔ Development of the “Life at Your Doorstep” home care programme offering extensive, 24/7 support for patients and families struggling with advanced and terminal illness in the cities of Hyderabad and Secunderabad.
- ➔ Organized training course for Francophone sub-Saharan Africa in Uganda. This was led by HASPF and the Institute of Hospice and Palliative care in Africa with expert input by Hospice Africa Uganda and Alliance Mondiale Contre le Cancer.
- ➔ Palliative care workshops and training courses for Francophone sub-Saharan Africa organized by AMCC in partnership with AFSO were held in Uganda and Ivory Coast.
- ➔ Establishment of palliative care centres of reference and training in sub-Saharan Francophone Africa (Mali, Cameroon, Ivory Coast).
- ➔ Canadian branch provides training in India for St Mary Hospital in palliative care and fosters a collaborative approach between palliative care and health care in Nepal.
- ➔ Development of palliative care programme in Rajasthan, India.

Paediatric oncology

- ➔ Establishment of centres of reference for the treatment of retinoblastoma – Mali and Democratic Republic of Congo.
- ➔ Mentoring of Indian paediatric oncologists in the

development of a common treatment protocol for Wilms Tumour.

- ➔ Conducting workshops and symposia on topics of relevance in developing countries.
- ➔ Promotion of the establishment of paediatric oncology societies – Philippines and Pakistan.
- ➔ Development of a centre of excellence in paediatric oncology at the Santa Marcelina Hospital/TUCCA in São Paulo, Brazil.
- ➔ Conducting a campaign for the early diagnosis of retinoblastoma including, but not limited to, the translation of a film showing a child with early retinoblastoma into 12 languages and distributing the film around the world (Brazil); development and wide dissemination and display of posters (Mexico and Brazil); and establishment of a retinoblastoma day (Turkey and Brazil).
- ➔ Ophthalmology nurses from the Democratic Republic of Congo trained in France to fit prosthetic eyes following enucleation (surgical removal of the eye) for the treatment of retinoblastoma.

Pathology

- ➔ Central pathology review of Burkitt Lymphoma in institutions participating in the treatment protocol for this disease in Africa.
- ➔ Training and education workshops for pathologists and clinicians.
- ➔ Training and education workshops for technicians and pathologists in techniques to improve diagnostic capabilities.
- ➔ Use of iPath – an internet telepathology programme – for consultation, training and education.
- ➔ Provision of training and education of haematopathologists in Francophone African countries (Cameroon, Democratic Republic of Congo, Sénégal).
- ➔ “What can we learn from Africa” pathology workshop held in Arusha, Tanzania for pathologists from Senegal, Benin and Democratic Republic of Congo to improve the ability of African haemato-pathologists to diagnose haematopathological neoplasms using the World Health Organization Classification.
- ➔ Setting up of a project to characterize lymphoproliferative disorders in adults in Senegal in partnership with local universities.
- ➔ Programme to improve pathologic and haematologic diagnostics established in Ethiopia using onsite and online training, education, and consultations.

Psychosocial support

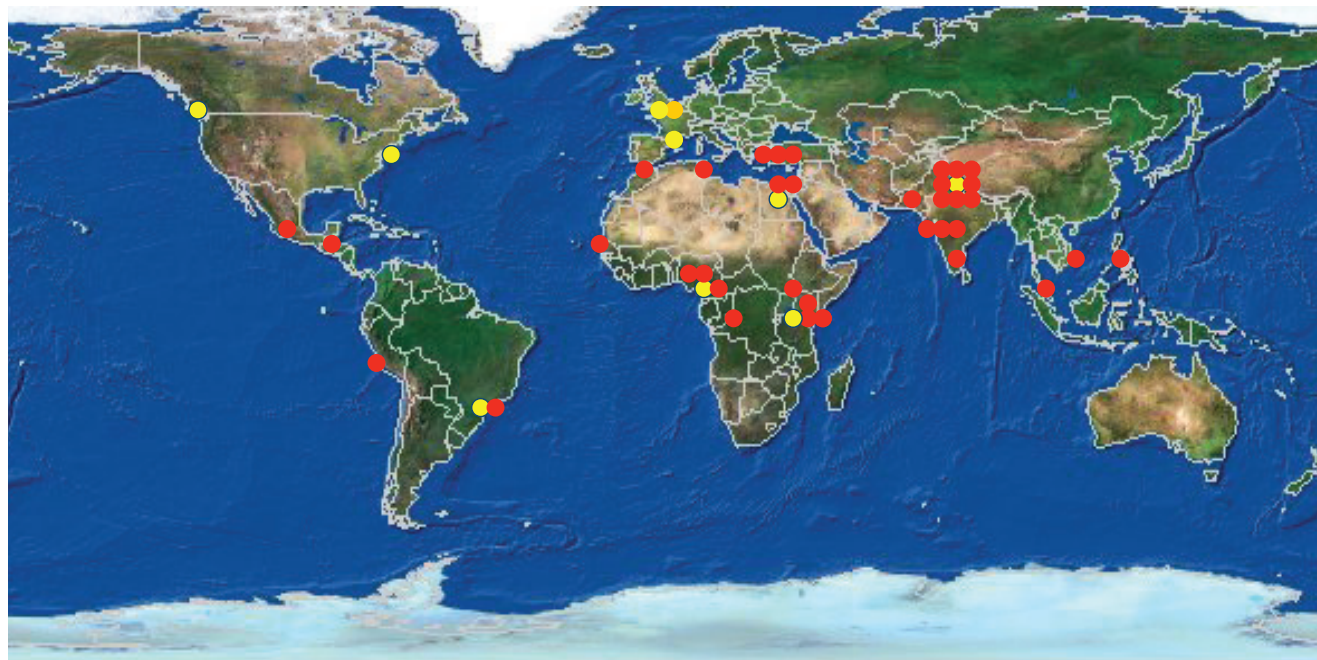
- ➔ Development of an educational programme relating to the psychosocial needs of cancer patients in conjunction with the Brazilian Society of Paediatric Oncology.

World Health Organization

- ➔ Organized the 2009 update of the WHO Essential Medicines List for Cancer.
- ➔ Participated in guideline updating and development (cervical cancer, Kaposi sarcoma and referral guidelines for breast and cervical cancer).
- ➔ Consultation with Dr Jean Marie Dangou, Head of AFRO (African Regional Office of WHO) on non-AIDS defining malignancies in HIV positive individuals.
- ➔ INCTR organized an advisory meeting for WHO AFRO relating to the issue of AIDS-related but non-AIDS defining cancers in Africa. A report was provided to AFRO.
- ➔ Advising EMRO on a planned high-level meeting in the region late in 2014.
- ➔ INCTR is participating in the development of recommendations for the management of cancer in the Eastern Mediterranean region. INCTR’s particular focus will be cancer information and the development of a tool that countries can use to identify their strengths and weaknesses with respect to cancer control, and develop or modify plans accordingly.

Considerable attention will be paid to the identification of methods of collecting and assessing the quality of data, the use of data in making scientific observations and/or the creation of evidence essential to establishing effective treatment programmes. INCTR will work more closely with governments in this regard, and funding for training, projects, scientific studies etc. will come from both within the country and outside the country. Every attempt will be made to ensure that programmes are self-sustaining after a reasonable time has passed.

INCTR Branches



● Offices and Branches

● Collaborating Units

Branches are established as legal non-profit organizations within the country in which they are located so that they may raise and disburse funds in support of INCTR's mission. Branches establish and maintain linkages with cancer centres or units, relevant professional organizations or elements of national or regional governments and coordinate ongoing INCTR programmes and projects within the country or region, if located in a low- and middle-income country. INCTR branches are listed below.

BRAZIL

INCTR Brazil

Associação Internacional para Tratamento e Pesquisa do Câncer
Av Nove de Julho, 4275
Jardim Paulista, CEP 01407-199
São Paulo, SP, Brasil
➤ President: Dr Sidnei Epelman
Contact: inctr@inctrbrasil.org

CANADA

INCTR Canada "Two Worlds Cancer Collaboration"

401-41 Alexander Street
Vancouver, British Columbia
V6A 1B2 CANADA
➤ President: Dr Simon Sutcliffe
➤ Treasurer: Dr Stuart Brown
➤ Secretary: Dr Fraser Black
Contact: cci-cancercontrol@shaw.ca
or Helen@torrance.com

EGYPT

INCTR Egypt

First Floor, app 10
2 Houd El Laban Street
Garden City, Cairo, Egypt
➤ President: Dr Hussein Khaled
➤ Executive Director: Dr Atef Badran
Contact: atef.badran@gmail.com

FRANCE

Alliance Mondiale Contre le Cancer

Institut Curie, 26 Rue D'Ulm
75005 Paris, France
➤ President: Professor Martine Raphaël
➤ Medical Director: Professor Pierre Bey
➤ Treasurer: Professor Jacques Rouëssé
➤ contact@cancer-amcc.org

INDIA

INCTR India

Swasthya Kalyan Bhawan
Narin Singh Road, Jaipur
302004 Rajasthan, India
Trustees:
➤ Dr Shivraj Singh (Managing Trustee)
➤ Mr Apurv Kumar
➤ Mr Rajiv Sahai

NEPAL

Nepalese Network for Cancer Treatment and Research INCTR

Nepal Ghokechaur Banepa 1, NEPAL
➤ Chairman: Dr Surendra B B Shrestha
➤ Vice Chairman: Dr Manohar Lal Shrestha
➤ Member Secretary: Radha Pyari Nakarmi
Contact: nnctr@ntc.net.np

UNITED KINGDOM

INCTR Challenge Fund

267 Banbury Road
Prima House, Oxford OX3 7HT
United Kingdom
Contact: max.parkin@cts.ox.ac.uk
➤ Chairman: Dr Max Parkin
➤ Administrator: Mrs Biying Liu
Contact: bliu@afcm.org

UNITED STATES

INCTR USA

5111 Ambergate Lane
Dallas, Texas
75287 -5405
USA
➤ President and Chairman:
Dr Madhaven Pillai
For information: info@inctr.be

Governing Council

Dr Sultan Al-Sedairy

Vice President for Development
Director, Research Centre, King Faisal Specialist Hospital
Riyadh, Saudi Arabia

Dr Robert Burton

Professor, School of Public Health and Preventative Medicine
Monash University
Melbourne, Australia

Dr Nausherwan Burki

Professor of Medicine, Division of Pulmonary

Medicine
University of Connecticut Health Center
Farmington, CT United States

Dr Sidnei Epelman

Director, Paediatric Oncology
Santa Marcelina Hospital, Sao Paulo, Brasil

Dr Ian Magrath

President, INCTR, Brussels, Belgium

Dr Donald Maxwell Parkin

Chairman of the Board,

INCTR UK Challenge Fund
Honorary Senior Researcher Fellow
CTSU – University of Oxford, United Kingdom

Dr Martine Raphael

President, AMCC, INCTR's French Branch
Hopital Bicetre
Paris, France

Mr Louis Schoofs

Secretary/Treasurer, INCTR
Former Chief Administrator
Institut Pasteur
Brussels, Belgium

Dr Simon Sutcliffe

President, Two Worlds Cancer Collaboration (INCTR Canada)
President, Canadian Partnership Against Cancer
Vancouver, BC Canada

Ambassador for Science

Dr Harald zur Hausen

Nobel Laureate in Medicine, Deutsches Krebsforschungszentrum, Heidelberg, Germany

Partner institutions in developing countries: Past and present

Africa

- ➔ Obafemi Awolowo University Teaching Hospitals Complex (Ile Ife, Nigeria)
- ➔ University College Hospital, Ibadan (Ibadan, Nigeria)
- ➔ Hôpital Général de Yaoundé (Yaoundé, Cameroon)
- ➔ Kenyatta National Hospital, University of Nairobi (Nairobi, Kenya)
- ➔ Bugando Medical Center (Mwanza, Tanzania)
- ➔ Muhimbili National Hospital (Dar es Salaam, Tanzania)
- ➔ Ocean Road Cancer Institute (Dar es Salaam, Tanzania)
- ➔ Tikur Anbessa Hospital, University of Addis Ababa (Addis Ababa, Ethiopia)
- ➔ St Mary's Hospital Lacor (Lacor, Uganda)
- ➔ Hôpital de Vanga (Vanga, Democratic Republic of Congo)
- ➔ Institut Ophthalmologique Tropical Africain, (Bamako, Mali)
- ➔ National Cancer Institute (Cairo, Egypt)

➔ Hôpital du Point G, Université de Bamako (Bamako, Mali)

- ➔ Centre Pasteur du Cameroun (Yaoundé, Cameroon)
- ➔ Université Cheikh Anta Diop (Dakar, Sénégal)
- ➔ CHU Mohammed VI (Marrakesh, Morocco)
- ➔ Clinique Universitaires, Faculté de Médecine de Kinshasa (Kinshasa, Democratic Republic of Congo)
- ➔ Clinique Universitaires, Université de Lubumbashi (Lubumbashi, Democratic Republic of Congo)

America

- ➔ Santa Marcelina Hospital (Sao Paulo, Brazil)
- ➔ Instituto Nacional de Pediatría (Mexico City, Mexico)
- ➔ Instituto Nacional de Enfermedades Neoplásicas (Lima, Peru)
- ➔ Universidad Francisco Marroquin (Guatemala City, Guatemala)
- ➔ El Instituto Oncologico Del Oriente Boliviano (Santa Cruz, Bolivia)

Asia

- ➔ Ankara University (Ankara, Turkey)
- ➔ Hacettepe University (Ankara, Turkey)
- ➔ Dokuz Eylül University (Izmir, Turkey)
- ➔ King Hussein Cancer Center (Amman, Jordan)
- ➔ King Faisal Specialist Hospital (Riyadh, Saudi Arabia)
- ➔ Children Cancer Institute, Ziauddin Medical University (Karachi, Pakistan)
- ➔ Jinnah Hospital Lahore – Allama Iqbal Medical College (Lahore, Pakistan)
- ➔ Shaikat Khanum Memorial Cancer Hospital and Research Centre (Lahore, Pakistan)
- ➔ All India Institute of Medical Sciences (New Delhi, India)
- ➔ Cancer Institute (WIA) (Chennai, India)
- ➔ Jaslok Hospital and Research Centre (Mumbai, India)
- ➔ MNJ Institute of Oncology

- (Hyderabad, India)
- ➔ Tata Memorial Centre (Mumbai, India)
- ➔ Nepal Institute of Health Sciences (Kathmandu, Nepal)
- ➔ B P Koirala Memorial Cancer Hospital (Bharatpur, Chitwan, Nepal)
- ➔ Bhaktapur Cancer Care Hospital (Bhaktapur, Nepal)
- ➔ Hospice Nepal (Kathmandu, Nepal)
- ➔ Kanti Children's Hospital (Kathmandu, Nepal)

- ➔ Shechan Hospice (Kathmandu, Nepal)
- ➔ Scheer Memorial Hospital (Banepa, Nepal)
- ➔ Patan Hospital (Kathmandu, Nepal)
- ➔ Philippine Children's Medical Center (Quezon City, Philippines)
- ➔ Shanghai Children's Hospital (Shanghai, China)
- ➔ Sarawak General Hospital and Sarawak Hospice Society (Kuching, Sarawak, Malaysia)

Latin America

- ➔ Santa Marcelina Hospital (Sao Paulo, Brazil)
- ➔ Instituto Nacional de Pediatría (Mexico City, Mexico)
- ➔ Instituto Nacional de Enfermedades Neoplásicas (Lima, Peru)
- ➔ Universidad Francisco Marroquin (Guatemala City, Guatemala)
- ➔ El Instituto Oncológico Del Oriente Boliviano (Santa Cruz, Bolivia)

Partners: Past and present

ORGANIZATIONS

World Health Organization (NGO in Official Relations)
 International Agency for Research on Cancer
 International Atomic Energy Agency/PACT
 Union for International Cancer Control
 European School of Oncology
 European Society of Medical Oncology

NGOs

American Cancer Society
 The Australian Cervical Cancer Foundation
 Augusta Victoria Hospital
 Breast Global Health Initiative
 Doris Duke Charitable Foundation
 Global Giving
 Hospice Africa France
 ICEDOC
 Jiv Daya Foundation
 Open Society Institute
 The Aslan Project
 TUCCA

PHARMACEUTICAL COMPANIES AND THEIR FOUNDATIONS

CIPLA Foundation
 Eli Lilly
 Glaxo Smith Kline
 Novartis Brasil
 Roche
 Sanofi-aventis – Fondation sanofi-espoir

ACADEMIC INSTITUTIONS

Georgetown University, Washington, DC USA
 Hopital Bicetre, Paris, France
 Imperial College, Hammersmith Hospital, London, UK
 Institut Curie, Paris, France
 King's College Health Partners, London, UK
 Nainamo Hospice, British Columbia, Canada
 National Cancer Institute of Brazil, Rio de Janeiro, Brazil
 National Cancer Institute of France, Paris, France
 University of Basel, Switzerland
 University of Ghent, Belgium
 University of Lund, Sweden
 University of Siena, Italy

GOVERNMENTS

Government of Australia, Australian Embassy, Nepal
 Government of Brazil
 Government of Ethiopia
 Government of Mali
 Government of Nigeria
 Government of Sénégal
 Government of Tanzania
 Government of Uzbekistan

COMMERCIAL COMPANIES

AGFA-Gaeverts
 ESMO
 Global Health Dynamics

Cancer Control

"The World Health Organization warmly welcomes this first annual publication on cancer control, with its laudable aim of improving cancer management in low- and middle-income countries. The publication deliberately seeks to apply the world's best expertise in cancer control, from renowned research institutes and international groups, to real conditions and needs in the developing world. It further benefits from the frontline experiences of initiatives addressing these needs and finding solutions to seemingly intractable problems."

DR MARGARET CHAN,
DIRECTOR-GENERAL, WORLD HEALTH ORGANIZATION

"It is a relief to many of us working in global health to see the momentum now gathering around the global movement against cancer and other noncommunicable diseases. This latest edition of Cancer Control reflects, and is an important part of, that movement"

DR ALA ALWAN,
WHO REGIONAL DIRECTOR FOR THE EASTERN MEDITERRANEAN