

CANCER CONTROL 2019

CANCER CARE IN EMERGING HEALTH SYSTEMS



EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH
FOREWORD BY **DR TEDROS ADHANOM GHEBREYESUS**, DIRECTOR-GENERAL, WORLD HEALTH ORGANIZATION

GLOBAL CANCER INITIATIVES • CANCER PREVENTION AND TREATMENT
TRAINING AND EDUCATION • INCTR UPDATE

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IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

CANCER CONTROL 2019

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Network for Cancer Treatment and Research
Editor-in-Chief: Dr Ian Magrath

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Cancer control and universal health coverage

Dr Tedros Adhanom Ghebreyesus, Director-General, World Health Organization



Dr Tedros Adhanom Ghebreyesus was elected as WHO Director-General for a five-year term by WHO Member States at the 70th World Health Assembly in May 2017, the first person from the WHO African Region to become WHO Director-General. Dr Tedros served as Ethiopia's Minister of Foreign Affairs, 2012–2016, and Minister of Health, 2005–2012. Born in Asmara, Eritrea, Dr Tedros holds a PhD in Community Health from the University of Nottingham and a Master of Science in the Immunology of Infectious Diseases from the University of London. He has published numerous articles in prominent scientific journals, and received awards and recognition from across the globe.

The global landscape in cancer prevention and control has evolved radically in the past decade since the initial publication of *Cancer Control*. What was previously considered a disease of high-income countries is now rightly seen as a global public health crisis. Approximately one in five people will develop cancer before the age of 75, and a majority of cases will arise in low- and middle-income countries where survival is unacceptably low.

The global community has been put on alert, and the political response has been robust. Reduction of premature mortality from cancer and other non-communicable diseases (NCDs) is now a global target in the WHO Global Action Plan for the Prevention and Control of NCDs, as well as the UN Agenda for Sustainable Development. We have had numerous High-Level Meetings and World Health Assembly resolutions defining a global agenda to provide cancer care for all.

Now is the time to convert political commitments into

action. Every minute, over 30 people around the world are diagnosed with cancer. We cannot wait longer to provide care for the child in Guatemala with leukaemia or the mother in Zambia with cervical cancer.

Universal health coverage (UHC) is the vehicle we must use to prevent and manage cancer. I have made it a priority for WHO to support governments in achieving UHC. In alignment with this, we have invited the global community to participate in major initiatives to eliminate cervical cancer and improve survival for childhood cancers. Policy-makers can take immediate steps to further prioritize cancer prevention and control in the context of efforts to strengthen primary and broader healthcare systems. My hope and expectation is that the future issues of *Cancer Control* will be able to highlight the successful integration of cancer prevention and control into the UHC agenda, with many more lives saved. ■

Welcome to Cancer Control 2019

This is the sixth edition of our annual publication *Cancer Control*. This edition, *Cancer Control 2019*, happily coincides with the twentieth anniversary of our partners, the International Network for Cancer Treatment and Research (INCTR). The Network was founded in Brussels and is dedicated to helping to build capacity for cancer control in low- and middle-income countries (LMICs) to diagnose and treat cancer promptly, with the ultimate goal of improving survival rates and quality of life of all cancer patients. It is still headquartered in Brussels today, but now has branches all over the World and operates programmes in nearly 31 countries. To mark this anniversary, we have a specially expanded INCTR section, which details INCTR's mission and achievements over the last 20 years, and carries special in-depth reports from four of its branches including Brussels, Brazil, Canada and France, who work in a broad range of LMICs.

We are also pleased to have a foreword from Dr Tedros, the Director-General of the World Health Organization who introduces the importance of universal health coverage to cancer control; how this approach can be an enabling one. In fact, we carry a case study from one of our sponsors whose programme seeks to widen access for those suffering with cancer to treatment in Dubai through alliances with an insurance company and the health authority. The subject of universal health coverage is bound to enter into cancer control more and more.

There are other new initiatives which we follow in this edition. The Economist Intelligence Unit has produced a Cancer Preparedness Index, to which the Head of INCTR's Canadian branch offers some accompanying thoughts. HRH Princess Dina Mired of Jordan, newly installed as President

of the UICC, calls for greater action post the UN High-Level Meeting she addressed and we cover the UICC's "City Cancer Challenge" and "Treatment for All" initiatives. The International Agency for research on Cancer (IARC) describes the progress made on its Cancer Screening Five Continents (CanScreen5) programme to improve screening in LMICs and the International Atomic Energy Agency charts the future for its important role. A smaller initiative in Uganda shows how safety can be improved in Chemotherapy treatment even in a low-resource setting.

Education and training is never far from our agenda and in this edition we look at cascaded training in East Africa carried out under the guidance of the Royal College of Physicians in the UK; how the US National Cancer Institute is using telemonitoring to advance cancer control in Africa and how the European School of Oncology aims to even up the disparities between Western and Central/Eastern Europe via its educational programmes.

Therefore, we very much hope you will find this edition of *Cancer Control* useful in your work. We would be delighted to have your feedback and suggestions. *Cancer Control 2019* can be accessed online at www.cancercontrol.info together with the five previous editions. You can also find information about INCTR and its programmes, as well as details on how to join. ■

Dr Ian Magrath, Editor-in-Chief, Cancer Control and President, INCTR

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There is no time to lose: An urgent call for meaningful action to reduce NCDs

HRH Princess Dina Mired of Jordan, President of the Union for International Cancer Control (UICC)



This article is based on the keynote speech delivered by Princess Dina Mired to delegates at the Third United Nations High-Level Meeting on Non-Communicable Diseases (NCDs) in 2018 as “Eminent Champion of NCDs”. Princess Dina, President of UICC, reflects upon the progress that has been made since 2011, the signing of the first Political Declaration on NCDs and where we still need concerted action to reduce the tremendous burden of cancer and other NCDs in countries around the world.

In September 2018, I was invited to speak at the United Nations for the Third High-level Meeting (UNHLM) of the General Assembly as “Eminent Champion” on the prevention and control of non-communicable diseases (NCDs). This was the second time that I addressed the General Assembly on this important health issue.

Seven years and seven days before my 2018 speech, I gave the keynote speech at the first High-level Meeting on NCDs. At the time, in 2011, standing at the solemn podium, I felt the gravity of the occasion, not just as a keynote speaker on behalf of civil society, but as the voice of 36 million souls worldwide who were dying from the leading diseases of our time: cancer, diabetes, heart disease, chronic respiratory disease and mental illness. I thought especially of those living in low- and middle-income countries (LMICs), who bear the brunt of the global NCD burden with very little access to global resources. And yet despite the solemnity of the task, during the preparation of my speech, words poured out so easily. In fact, it felt like my speech literally wrote itself in one go.

In 2011, we had to debunk the myth that NCDs only affect high-income countries, and we had to impress upon world leaders to add a new acronym to the big list of UN acronyms. When we spelled out the letters “N”, “C”, “D”, we etched non-communicable diseases front and centre on our list of diseases to address immediately. We, the passionate, committed players in civil society, all felt that we had finally hit the big league.

However, this time around, I confess that I struggled to develop my speech. I wrote, rewrote and crumpled many papers and was altogether at a loss for words, driven by deep bafflement as well as great concern about the slow progress since the UNHLM in 2011.

In fact, according to a recent study entitled “NCD

Countdown 2030,” published by *The Lancet* with collaboration from the World Health Organization (WHO), the NCD Alliance and Imperial College London, UK, we know that more than half of all countries are not on track to meet the Sustainable Development Goal (SDG) 3.4 target to reduce premature mortality from NCDs by one-third; and mortality from the four NCDs included in SDG target 3.4 has stagnated or increased since 2010 among women in 15 (8%) countries and men in 24 (13%) countries (1).

Furthermore, in 2018, it was estimated that there were 18.1 million new cancer cases and 9.6 million deaths from cancer (2). This alarming growth in cancer incidence and mortality, from 14.1 million and 8.2 million respectively in 2012, underscores the urgency at hand. Certainly, these are disheartening statistics, given the enormity of the challenge and the encompassing injustice wreaked on the afflicted.

What is puzzling is that this current grim landscape prevailed even though since the first UNHLM in 2011, civil society organizations and WHO have worked tirelessly to support countries in their fight against NCDs. We advocated hard for the framework to have global targets with the overarching goal to reduce premature mortality 25% by 2025. Then, we argued that NCDs are a development issue and not simply a health issue, making the political and economic case for them to enter the club of the SDGs. Together, we reframed our call to action in dollar terms, to ensure that finance ministers would understand that investing in NCD prevention, treatment and cure is not only a sound economic decision but also a high-yielding investment. We have shown that investing US\$ 1.27 now on NCD prevention will yield a return of US\$ 7 per year in 2030, totalling US\$ 350 billion dollars (3).

We advocated for an investment in health systems so that individuals can access the services they need through the life

course and along the continuum of care, from prevention and early detection of NCDs to treatment and care, as well as palliative care and survivorship.

In parallel, we have supported and developed evidence-based tools and guidance documents, as well as initiatives such as the Global Initiative for Cancer Registries (GICR) and the RESOLVE initiative. We even rolled up our sleeves and put boots on the ground through initiatives like the City Cancer Challenge founded by UICC and the Bloomberg Partnership for Healthy Cities, which support cities in developing strong, sustainable and impactful cancer and NCD programmes at city levels. The work of our colleagues at WHO have given us a suite of “Best Buys” for all countries based on the best available scientific research to take efficient and cost-effective action on NCD prevention, treatment and care no matter their income levels.

With these actions, we erased the assumption “we don’t know what to do”, we erased the “no money argument”, and we nullified the notion of the impossible, the challenging and the complex. Yet, 15 million people are still dying prematurely every year right before our eyes (4). It is for these reasons that I was at a loss for words. After all, how many times does one need to explain the obvious and the urgent to spur serious and meaningful action? What else should we do to get the political and economic attention needed for implementation on the ground?

We understand the challenges that heads of states and health ministers face, especially in resource-challenged countries, can be formidable. A health minister who for so long only focused on communicable diseases like malaria, Tuberculosis and HIV must now find the funds to purchase medicines and technologies, as well as provide quality human resources, to manage NCDs, often without a global-type fund or other international assistance.

Sometimes, it seems that it is easier to fund weapons to wage war that destroys human lives than it is to financially support the actions that will save them. But, as Martin Luther King Jr said, “We refuse to believe that the bank of justice is bankrupt”.

While we understand the often competing and difficult decisions that governments face with scarce available resources, we have also walked in the uncomfortable and distressed shoes of patients who must make the unconscionable decision about whether to put food on the table or to get their lifesaving medications, and that is if that medicine is even available, affordable or accessible. As President of UICC and the former Director General of the King Hussein Cancer Foundation, I have witnessed this inequity at first hand during visits to various developing countries.

We need to understand what it is that is paralyzing some

countries from doing more of the right thing? Perhaps, we all have to remind ourselves that we cannot simply wish these diseases away. These diseases are here to stay unless we act to stop them. I often say that NCDs are the “serial killers” of our time. They are non-discriminate, expansive, consistent, swift, strategic and certainly very comprehensive and universal in their approach. But what accelerates their deadly work is our own fragmented, indecisive and inactive approach.

And yet, there are a multitude of new opportunities available to us to take decisive action on NCDs. We must seize these opportunities to implement the programmes and services in cancer and other NCDs and make a real difference in people’s lives, both to limit the likelihood that people develop NCDs and to manage them effectively.

As I stood on the podium at the 2018 UNHLM, I did not want to focus my speech only on how and why we were not meeting our global commitments, but also to bring forward some of the recommendations of civil society organizations working on NCDs in communities around the world.

These recommendations include the following:

➔ Let us advocate for universal health coverage (UHC).

UHC has emerged as an international policy priority in health and development. UHC seeks to ensure that people access the health services that they need, that are of high quality and efficacy, and that people are not put into financial difficulty in accessing them. This is welcome news for cancer control, as well for other NCDs. Many countries around the world are developing national UHC plans, which will include essential health services across communicable and non-communicable diseases.

It is possible for every country, regardless of income level, to include some cancer control interventions in the national UHC package. For example, in countries with high breast cancer and cervical cancer rates, HPV vaccination campaigns can be rolled out along with cervical screening and/or breast cancer awareness in conjunction with other services at primary healthcare level, such as family planning, maternal and child health programmes and HIV/AIDS programmes. In this way, UHC can be progressively achieved so governments do not have to cover “everything at once”.

➔ Let us heed the global call to action by the Director General of the World Health Organization in May 2018 to eliminate cervical cancer.

To achieve its elimination, we need action on three fronts: 1) to increase the coverage of vaccination against human papilloma virus (HPV); 2) to increase cervical screening coverage with rapid and appropriate management of women who screen as positive; and 3) to reduce deaths from cervical

cancer through promoting early access to treatment and care, including palliative care.

This global initiative on cervical cancer - one of the most preventable cancers - can transform the lives of girls and women and render cervical cancer once and for all to the annals of history.

- ➔ Let us ensure that NCDs are a priority item on the cabinet ministers' agenda, not just the health minister, the whole of the government's agenda.
- ➔ Let us develop and implement national NCD plans, as well as National Cancer Control Plans (NCCP), in all countries. These plans should be endorsed by the Head of State and contain a detailed budget, as well as targets and time-bound commitments.
- ➔ Let us achieve an increase in the level of funding available at national level for NCDs from all sources, including domestic, bilateral, multilateral and innovative financing by 2025.
- ➔ Let us invest seriously in NCD prevention to stop the factories of disease. Also, let us invest in early detection and treatment interventions that we know are effective in reducing the burden of NCDs. These are detailed in WHO's evidence-based "Best Buys" to fight NCDs.
- ➔ Let us make vaccinations available in all countries to reduce the incidence of infection-based cancers.
- ➔ Let us tax the industries that break us, instead of giving them a tax break. Let us implement the regulatory and fiscal measures such as front-of-pack labelling; marketing restrictions on foods and drinks to children; healthy fiscal policies, including taxes on sugary drinks and subsidies on fruit and vegetables; and the promotion of healthy environments that guarantee physical activity and access to safe drinking water and healthy food.
- ➔ Let us legislate against industries that are intent on profiting at the expense of our health. Starting with the tobacco industry. Let us call for full implementation of the Framework Convention on Tobacco Control (FCTC) to stop them owning the best real estate in the world - the millions of youthful lungs consuming their deadly product.
- ➔ Let us invest in NCD surveillance data to track, monitor and report in 2025 on the progress we have made.

Yes, it can be done. We have seen some shining examples of what can be achieved with political will. Many countries have already established NCD plans, and a growing number of countries have "operational plans," which means that plans are "off the shelf" and being implemented.

In the 15 years I spent as Director General of the King Hussein Cancer Foundation, as part of the team that saw the

transformation of cancer care in Jordan, I experienced first-hand what political will, planning, organization, systemization and hard work can accomplish.

Seeing 59 Heads of State present at the 2018 UNHLM on NCDs gave me renewed hope and sent a resounding message to all NCD patients and their families that the global community does care about NCDs. I began to see the possibilities for a world where children diagnosed with leukemia in LMICs do not have to accept the inevitability of a measly 10% survival rate for a disease that can be cured in a high-income country. A world, where refugees who have escaped the violence of war do not have to be subjected again to the violence of inaction on NCDs, receiving little or no treatment for their cancer, heart disease or diabetes. A world where refugees are not seen as a special superhuman breed who are only in need of basic emergency services.

I reminded delegates that every letter and every word they agreed to in the political declaration would translate into something real for people living with NCDs. Each delegate can provide insulin, palliative care or essential cancer medications for millions at an affordable price, or, adversely, with a simple pen stroke, can take it all away from those who need it most. Yes, it is very personal and very real.

The writing is on the wall. We are moving decidedly towards an unhealthy and injurious future unless we resolve today to deliver on our promises and accelerate progress. I reminded the delegates that we must ask ourselves what legacy we want our generation to be remembered for. The one that watched the NCD epidemic destroy the lives of our children and our children's children, or the generation that said enough is enough and took remedial action? The weight of this seminal decision is on all our shoulders, including government, civil society organizations and the multitude of patient organizations who can provide experience and insight into what a patient-centred approach to NCDs looks like.

As Nelson Mandela, one of my heroes, aptly said: "It always seems impossible until it is done". Let the 2018 UNHLM be the seminal meeting that will finally start to deliver on the ground. ■

HRH Princess Dina Mired of Jordan is a mother of a cancer survivor and is a well-known and respected advocate for Cancer Control and Non-Communicable Diseases. HRH Princess Dina was elected as President of the Union International for Cancer Control (UICC) in 2018. Prior to that, Princess Dina established and led the King Hussein Cancer Foundation (KHCF) from 2002-2016. Princess Dina transformed the non-profit foundation into the most successful advocacy and development organization and fundraiser for all cancer control efforts in Jordan and the region.

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BASMAH gives new hope for cancer patients



BASMAH is a first of its kind initiative created as part of a partnership between the Dubai Health Authority (DHA), Roche Pharmaceuticals and AXA-Gulf Insurance to provide full coverage for breast, colon and cervical screening and treatment for all Dubai residents. This initiative reflects UAE Vision 2021 which aims to provide the highest quality of medical care to patients with chronic diseases, promote a culture of early detection and raise awareness about the importance of regular check-ups.



Under the BASMAH initiative, 4.6 Million Dubai residents will be covered for breast, colon and cervical cancer screening and treatment, irrespective of the cost and duration, in dedicated Centres of Excellence (CoE) allocated by the Dubai Health Authority (DHA), including Dubai Hospital. CoE are being built throughout Dubai, with dedicated healthcare practitioners who will oversee patients using the initiative.

BASMAH includes a seamless and successful process which is ensured through training the primary healthcare physicians and a third party "TruDoc 24X7" accompanying patients throughout their entire journey. The process includes home visits from doctors for patient onboarding, a medical call centre that is available 24/7 in multiple languages, an interactive mobile application with medication and appointment reminders, wellness tips and push notifications. The patient support programme will also have monthly reporting for insurance companies and the DHA.

HE/ Humaid Al-Quttami
Director General – Chairman of the Board
Dubai Health Authority



The three partners – Dubai Health Authority, Roche and AXA – presenting the BASMAH initiative in the presence of Dubai Government officials, the management of the main hospitals and healthcare influencers

The BASMAH initiative aims to expand the existing treatment coverage for patients to ensure access to the most effective treatments available, while developing an effective process for early detection of cancer through regular screening.

Two actions were developed in order to combat the disease. Firstly, a dedicated cancer fund where AED 19 from every health insurance policy in Dubai will be directed to a common fund which will be utilized by the insurance company when the cover limit is met.

Additionally, coverage will be required to meet a minimum acceptable limit for the treatment of cancer.

Secondly, coverage for cancer screening will be a compulsory element of every health insurance policy. Cancer screening is now covered as part of all insurance benefit plans under the DHA Mandate, including the basic one, as early detection has proved to result in a higher survival rate.

The name “BASMAH”, meaning smile in Arabic, was chosen because the initiative aims to build a healthy, hope-filled and happy cancer-free community where people can carry on with their lives with a “BASMAH”.

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The Cancer Preparedness Index: Objectives, methods and dissemination

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The differences in cancer incidence, mortality and survival between countries can at least partly be traced back to varying national policies and infrastructures. The Cancer Preparedness Index – with its 45 indicators clustered into three domains – is designed to highlight differences in policy and systems between countries and how they relate to outcomes. The Index was built via a literature review and expert input. The results will be presented during the 2019 War on Cancer conferences.

Cancer is the world's second biggest killer, causing one in six deaths. It is also one of the leading global causes of morbidity. As well as the human cost, there is the significant financial burden—cancer was estimated to cost the world a staggering US\$ 1.16 trillion in 2010 (1). While much of this cost is felt in high income countries, the burden of cancer care will increasingly fall on lower- and middle-income countries, in which 70% of cancer deaths already occur (2). The economic consequences are likely to be devastating, particularly for those countries just climbing out of poverty.

Cancer is no longer always a death sentence, and cancer survivorship is on the rise (3). This presents new and growing challenges for national health systems and wider society. Cancer is still primarily a disease of the elderly, and with longer life expectancies, increasing incidence rates and improved survival, people live longer with cancer—or under its shadow. Improved survivorship is a good news story, providing hope for many individuals and their families, but it can create difficulties for policy-makers, healthcare professionals and patients.

There are large differences in cancer incidence, mortality and survival between countries. These differences reflect a combination of factors: prevalence of underlying risk factors, variations in susceptibility, and differences in cancer detection, reporting, classification systems, treatment, and follow-up. There is a need to reinforce healthcare infrastructure, strategies and policies to reduce incidence and improve outcomes. Health policies and systems need to be better prepared to meet the challenge of cancer; to reduce human suffering for individuals and economic costs for society. How well prepared are countries today, and what could they be doing better?

Why an index?

The goal of reducing incidence and improving outcomes is one

easily agreed by all stakeholders. The more challenging issue is how can this be done within limited healthcare budgets; what are the inputs that offer the best “bang for the buck”, and who is leading the way in implementing evidence-based policy and systems?

There is good evidence around “what works” when it comes to cancer policy. For example, screening and early detection programmes have been well researched: cervical cancer incidence has shown a marked decrease with the advent of screening programmes in several high-income countries (4). Similarly, previous research here at the EIU has found an association between that quality of cancer care plans and the percentage change in DALY: the better the plan, the bigger the fall in DALYs (unpublished). To summarize the state of knowledge, WHO have put together a list of policy “best buys” in tackling NCDs, including cancer (5). The document ranks the relative effectiveness of interventions ranging from vaccinations to smoking cessation programmes to advertising bans. However, even though the evidence is often clear, a brief look across different countries will show that there is often little consistency in the formulation and implementation of policy.

The Cancer Preparedness Index is designed to highlight how policies vary from country to country, how well they're implemented, and how associated they are with cancer outcomes. The Index will be able to monitor the progress of countries across the globe in their fight against cancer and be a tool for advocating change where it is needed.

Methods

The Index is effectively a collection of policy indicators associated with high-quality outcomes. Scores for each indicator—after normalization and weighting—are summed

to give an overall score for each country. These composite country scores will be used to rank countries according to their success in promoting and funding best-practice strategies and initiatives, and in delivering care through suitable health-system infrastructure. We describe here the five key stages of the research: 1) literature review, 2) expert panel, 3) index development, 4) data collection, and 5) index finalization.

1) Literature review: The literature review, performed by experience health information specialists, was used to define the research question, key concepts, and the aims of the study. The search covered both published (including MEDLINE, PubMed and Embase) and grey literature. Our review synthesized evidence-based recommendations and descriptions of good practice, and was used to develop a draft index framework. The draft framework consisted of potential domains and indicators, along with a draft scoring schema for each indicator.

2) Expert panel: Once the draft index framework was completed we convened an expert panel. The panel included high-level stakeholders from the Union for International Cancer Control, the World Bank, the European Society for Medical Oncology, the Brazilian Ministry of Health, the Joint Action innovative Partnership for Action Against Cancer, the Colombian League against Cancer, and Youth Cancer Europe. Through critique of the draft framework, the panel advised on the design of the index, the selection of indicators and the scoring system. We used input from the meeting to refine the index framework, including the specification of domains, indicators and weights, and the development of scoring guidelines and scales. The panel did not, however, “sign off” the framework; all editorial decisions remained in the hands of the researchers.

3) Index development: With the finalized draft framework in hand, we then performed a data audit. The audit identified which indicators had pre-existing data sources we could use from multilateral organizations such as the WHO and the World Bank, NGOs, or published research in the literature. For those indicators where data sources were not available, we set down what research was needed and the likely sources, be it in the literature or via interviews of national experts. We also developed scoring guidelines: some indicators have simple binary scores (e.g. yes/no) while others allow for more discrimination (e.g. yes/no/partial). The final framework (“the Index”) was then shared with the expert panel for their final comments.

4) Data collection: The Economist Intelligence Unit has a network of country contributors that we were able to use to score individual countries. Indicators were scored through a combination of desk research and interviews. Desk research included a review of national policies, plans and

strategies, a search of the healthcare literature, and trawling for quantitative and qualitative information from regional or international sources. Alongside the desk research, country contributors performed interviews of national experts to obtain a more nuanced assessment of a country’s activity in its fight against cancer. National authorities are beset with forms and requirements from national and international organizations; in order not to add to their workload the research for the Index was performed solely by the Economist Intelligence Unit and its contributors.

5) Index finalization: Scores were peer reviewed by the research team; where there was uncertainty we asked for more information or clarification from the country contributor. In the case of disagreement scores were finalized via discussion and consensus within the project team. Scores were normalized on a scale of 0 to 100, where 0 is the lowest score and 100 the highest. The final scores were collated and categorized in an Excel workbook, where we were able to conduct sensitivity analyses and perform a final sense check (against other studies and through comments received from the expert panel). Further functionalities were then added to the workbook such as interactive weight profiles, country and region comparison tools, and heat maps.

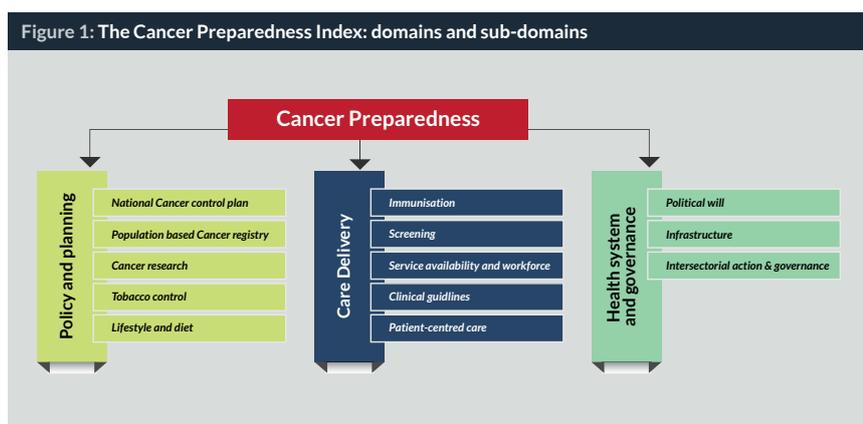
The Index

The Cancer Preparedness Index has three domains: 1) policy and planning, 2) care delivery, and 3) health system and governance. The first domain focuses on levers that are mostly in the hands of policy-makers. It examines whether countries are taking the necessary steps to effectively understand and manage their cancer burden; also, are they acting to reduce cancer incidence through reducing risky behaviors. The second domain looks at the delivery of cancer-specific activities within health systems themselves, starting with immunization and screening campaigns and working through to the delivery of care for cancer sufferers and survivors. The accessibility of drugs and technologies are included here, along with indicators scoring the comprehensiveness of clinical guidelines and the use of patient-centered care. The final domain acknowledges that cancer cannot be defeated by cancer-focused activities alone. It looks at factors such as political will and intersectoral action, and the provision of universal healthcare and the promotion of a health-enabling environment.

Each of the three domains consists of a number of sub-domains (Figure 1). The first two domains have five sub-domains each, while the third domain has three; we therefore decided to weight the three domains 40:40:20.

Each sub-domain consists of two or more indicators. There are a total of 45 indicators in the Index: 17 in the policy and planning domain, 20 in care delivery and 8 in health system

Figure 1: The Cancer Preparedness Index: domains and sub-domains



is growing fastest: in upper- and lower-middle income countries. We hope to extend the research to more countries in future iterations of the index—including to low income countries (where access to data can be more of a challenge).

Dissemination and next steps

The Index and associated research and dissemination programme is designed to drive dialogue and action by policy-makers around the world. It focuses on

and governance. Normalized indicator scores will be summed to give a sub-domain score, which again will be normalized and summed to give domain scores. These weighted sum of these normalized domain scores will give an overall score for each country—from 0 to 100—allowing them to be ranked.

Table 1 provides an example of a scoring schema for one of the indicators. The example is taken from the policy and planning domain; the sub-domain is national cancer control plans. For this sub-domain there are four indicators, each one with its scoring scheme. This example demonstrates that, in the case of national cancer control plans, it's not just whether a country has a plan, but also the quality of the plan (such as the presence of explicit timeframes, implementation plans and funding sources) that is important. Other indicators follow a similar pattern, by rewarding not only presence or absence of certain activities or policies but, where possible, issues of quality or implementation too.

Data will be collected for 28 lower-middle, upper-middle and high income countries (Table 2). Included countries are from Europe, Asia-Pacific, Latin America, North America, Africa and the Middle-East. We wanted to not only capture the diversity in policy adoption and implementation in high income countries, but also include comparisons from where the burden of cancer

how healthcare systems can be better prepared to deal with the cancer challenge. The programme will seek to attract global media interest and to engage other important stakeholder groups, such as payers, physicians and care providers.

The initial results of the index will be launched at The Economist's War on Cancer events throughout 2019. The Economist has invited policy-makers and industry leaders to a global series of thought-provoking events aimed at mobilizing policy, financing, capacity-building and partnerships to confront the enormous challenge cancer presents since 2015. These conferences, under the War on Cancer banner, serve as an ideal opportunity to disseminate the results of the index.

The Economist Group will also put together a custom-built, online microsite to host the Index and all of the campaign content. The index will be downloadable as an Excel workbook with functionality to allow the user to plot results against background indicators, generate heat maps, alter indicator weightings and other functionality. The microsite will be interactive and accessible for desktop, tablet and mobile users. A promotion and amplification plan will drive awareness of the microsite and stimulate engagement and, we hope, repeat visits.

In addition to the Index results we shall be researching

Table 1: Example of scoring schema from four indicators in the National Cancer Control Plan sub-domain

Sub-domain	Indicators	Scoring schema
National cancer control plan	Existence of operational policy/strategy/action plan for cancer	No plan = 0 Part of NCD plan = 1 National cancer control plan (NCCP) = 2
	Comprehensiveness of cancer plan	Cancer targets and indicators +1 Coverage of continuum of cancer care services - prevention (+1), early detection and diagnosis (+1), treatment (+1), supportive and palliative care (+1), patient-centred care (+1)
	Implementation framework for cancer plan	Leadership for plan implementation +1 Timeframes (start and end dates) +1 Financial resources for plan activities +1
	Monitoring and evaluation of cancer control plan	Cancer control governance (as per national plan) +1 Health information systems for monitoring plan activities +1

Table 2: The 28 countries included in the Index, organized by World Bank income group

High income	Australia; Canada; France; Germany; Italy; Japan; Netherlands; Saudi Arabia; South Korea; Spain; Sweden; UK; USA
Upper-middle income	Argentina; Brazil; Chile; China; Colombia; Mexico; Romania; Russia; South Africa; Thailand; Turkey
Lower-middle income	Egypt; India; Indonesia; Kenya

and publishing a white paper. This will summarize the global findings of the research, offer analysis of the Index results, and provide insights and conclusions on how effectively systems are prepared for cancer. Because the Index is a comparative tool, all countries are scored using the same schema. However, countries will naturally have differing priorities, depending on their income level, demographic profile and other factors; for example, it may not be cost-effective for some countries to fund screening programmes. It's therefore important to see the results in context, which is what the white paper will do. The paper will include qualitative analysis from 11 in-depth interviews with high-level cancer experts, including clinicians, policy-makers and patients. It will be available on the hub alongside the downloadable Index, and together we hope they will help advocate for effective policy development in the field of cancer control and preparedness.

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Preparing for cancer II – Cancer control plans: Being prepared and ready to implement

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Cancer preparedness cannot be seen as just as medical issue. In this companion piece to the previous article, the author considers the factor outside of government policy-making and National Cancer Plans, that need to be thought about – such as culture, leadership, responsibility, local context and the abilities to collaboration effectively – when considering “Preparedness”.



"Would you tell me, please, which way I ought to go from here?" said Alice
"That depends a good deal on where you want to get to." said the Cat.

Approximately 9.6 million people die of cancer each year (1). Cancer incidence is estimated to increase by 50% by 2035 (2). The disease burden is greatest in low- and middle-income countries (LMICs), where 70% of cancer deaths occur; the number of cancer cases is rising most rapidly due to demographic change, and where health systems are neither well prepared nor equipped to manage this growing burden. While an estimated 59% of cancer cases occur in LMICs, only 6% of global spending on cancer is directed to these countries

(3). Furthermore, only 1% of global health financing is directed to non-communicable diseases (NCDs), which include cancer (4). The growth in oncology cost is expected to rise 7%–10% annually throughout 2020, when global oncology costs will exceed US\$ 150 billion (5).

The institution of large population national cancer control plans (NCCPs) has been accepted as a critical and necessary step to address this challenge for all nations, recognizing that the greatest challenge for low-income countries (LICs) and middle-income countries (MICs) is to build the capacity necessary, whereas for the high-income countries (HICs), the greater challenge might be to sustain the capacity that has been built. For all, NCCPs represent a way to “know where we are going, and how to get there”.

The content of NCCPs

Comprehensive cancer control (CCC) addresses cancer across the continuum of prevention to end-of-life care, rather than as one cancer site, or one aspect of care delivery (e.g., prevention). It brings together partners from multiple sectors to collectively address the cancer burden in a community by leveraging and sharing existing resources and identifying and addressing cancer-related issues and needs.

The ICCP (International Cancer Control Partnership) hosts an online multilingual inventory of NCCPs from every world region at www.iccp-portal.org. All registered NCCPs have been reviewed by the ICCP over the last year to provide guidance upon their content and to highlight where further development might be appropriate. Unsurprisingly, given that the knowledge and data underlying NCCPs is available through similar websites, international meetings and publications (i.e., “the evidence is the evidence”), these plans have much in common. Although most UN member countries have an NCCP,

Table 1: Contextual components of preparedness for implementing cancer control

The Disease Control Plan	Contextually appropriate content aligned to goals and targets
Data: Information Public Policy	Registry: Surveillance: Outcomes: Projection: health economic data. Equity: Fairness: Integration: "Greatest good for the greatest number..."
Societal Responsibility	Disease as an "all of society" issue: inclusivity: engagement: priorities: mobilization & participation
Leadership and Governance Organizational Structure	Coherent, comprehensive, leadership & stewardship Relationships, reporting, responsibilities, accountabilities
Health Workforce	Supply: skills appropriateness: retention: incentivization
A Financial Plan and Budget Sustainability	Secure new, re-allocated or transferrable funds Ethical, professional, socio-economic accountability and sustainability
Collaboration Communication	All disciplines, institutions, organizations and sectors (PPP). All of government; all of society (political, professional; public & private)

relatively few have actually put their plan into implementation, notwithstanding entirely appropriate content. There are good plans in implementation, e.g., Australia, France, New Zealand, United Kingdom, Canada, etc.; more commonly in high-resource countries. The challenge with NCCPs is that medical and scientific content and validity are essential, but insufficient to implement an NCCP. Knowing what the route forward should be is not synonymous with undertaking, or even understanding, what the journey will entail.

The context and collaborations of NCCPs

Understanding country context and the availability of collaboration and relationships are necessary prerequisites for implementation of NCCPs. Contextually, the issues of culture, population composition, levels of literacy and poverty, health infrastructure, geography, climate, economy, human resources, technology are amongst the key determinants of whether a country could actually put what is known and desired into implementation. But knowing whether the constituencies whose participation is necessary to implement the plan are present, constructively engaged and actively collaborating to achieve population goals proves to be equally important. NCCPs are societal plans requiring engagement and action by all constituents of society. They are not the plan of any one constituency – the government, the ministry of health, or the medical profession, etc. They are society's plan to control cancer in their population and they must be owned and supported by all components of society.

Whether NCCPs are likely to be implemented successfully or not has less to do with the content of the plan and more to do with the state of preparedness and readiness to implement the NCCP. This is more about functions, structures, funding and execution (a strategic plan, a business plan, an operating plan, a budget, a governance structure, leadership, an executive and operational structure, reporting and accountability), and the existence of an understanding between necessary

collaborating entities (government, MoH, institutions, academia, NGOs, advocacy groups, patients, advocates, public and private sector) as to how they will relate, contribute and hold themselves accountable for delivering the elements of the plan.

The Cancer Preparedness Index described elsewhere in this publication identifies Policy & Planning, Care Delivery and Health System & Governance attributes as key determinants of understanding preparedness for implementation of NCCPs (6). Whilst the authors at the Economist Intelligence Unit (EUI) position the value of the Index primarily in terms of government policy formulation and comparability between nations in their level of preparedness to enact NCCPs, an understanding of preparedness and readiness by each of the partners in the execution of an NCCP is fundamental for collaborative implementation.

Which begs the question "What does 'preparedness and readiness' look like? What does it mean from the perspective of each partner?" Some of the possible components are presented in Table 1.

A key issue, however, notwithstanding preparedness, is to identify the individual or group who is both capable and willing to take on the responsibility of overseeing that the strategy delivers the outcomes for which it has been created. Finding such a steward can be as challenging as the task itself. Who is able to coordinate the "content" – the medical and scientific enterprise – with the "context" – the socio-political enterprise? Who will convene, facilitate and enable the necessary "collaboration" between the multiplicity of different, independent parties and at the same time align strategic, business (financial) and operational implementation? Who is sufficiently trusted, respected and knowledgeable across the elements of the strategy, while at the same time independent of individual, organizational or institutional pre-set mission agendas. Who is focused, responsible and prepared to be 100% accountable to the stakeholders for the

implementation of a plan that is directed towards improved population health/cancer control outcomes? These are some of the considerations that underlie the choice of “steward and stewardship”.

Preparedness and readiness requires being able to demonstrate, step by step, the feasibility of the developments that are imperative for implementing a NCCP. The strategic plan (the “why” and the “what”) must become a business plan (“how”, “how funded”, “by whom”); the business plan must align to the financial plan; implementation must align with an annual operating budget (“what activity will we be doing tomorrow and how is it being paid for?”). Interestingly, this is more readily apparent for countries with one national policy and budget, rather than for “federated” countries, for whom implementation requires the determination of “added value for all without competition with any.”

In addition, two fundamental and critical issues – culture and leadership – require an “up-front” consideration. Is there a culture of collaboration between science, medicine, public health, health services and the institutions/enterprises whose engagement is necessary to achieve improved population health outcomes? Why would the NCCP be more implementable and effective now than may have hitherto been the case to date? Globally, government indifference and/or change of political leadership represents a major impediment to national efforts to control cancer/NCDs. The public expression of support, including policy and funding is necessary. What might leadership look like at a national, state or municipal level?

Leadership can be demonstrated by other players besides elected politicians; such as by:

- NGOs: aligning organizational priorities (organizational well-being, competitive advantage and fundraising imperatives) and societal priorities attained through integrated and collaborative solution(s)?
- Academia: aligning academic and health service needs, particularly health human resource needs, training and mentorship, curriculum development, and fostering the changes in health practice underlying good, progressive change in healthcare universities, faculties of medicine, schools of public health, schools for health professional disciplines, and professional societies.
- Health sector authorities and institutions/hospitals/ community services: enacting the necessary shifts from acute, tertiary, facility-based, high-tech, high professional resource-based care to more sustainable models appropriate for chronic and non-communicable diseases in an ageing population, including the reallocation of resources within operating budgets.
- Patients, advocates and advocacy: mobilizing advocacy

for cancer control, rather than reactively for single diseases, with patients and advocates becoming “owners” of the problem and its solution, rather than “arms-length” observers?

- Public/civil society: shifting the balance from an illness-focus to a health, wellness and illness management perspective, in which personal choices, behaviours and actions are integral components of necessary change.
- Private sector/health industry: engaging and harnessing the value, expertise and influence of the private sector whilst honouring the principles and practices of universal healthcare systems and balancing principles with the practical realities of sustainable healthcare.

If we define collaboration as “the pursuit by multiple, independent organizations, of a common vision and purpose to achieve a shared greater goal” then “true collaboration”, would be ideal, but unlikely. Independent organizations have distinct governance, proscribed purposes, funding mechanisms and obligations to stakeholders/shareholders/funders. “True collaboration” would require the subjugation of individual mandates to a common “higher” and shared purpose.

Short of this ideal, but more realistic in practice, are lesser levels of collaboration; e.g., “sharing” – providing information with, or without, any necessary expectation of attention or action; “co-ordinating” – determining where mutual agendas can come together, in person or remotely, to exchange information that is relevant to purpose; or “cooperating” – working together on defined areas of mutual activity to the greater gain of all parties.

In principle, host nations and collaborating partners may expect benefit through any level of collaboration, but in practice, the increasing commitment through sharing, coordinating, cooperating and truly collaborating is the investment that host and partner(s) make in trust and mutual respect, time, and reconciling individual goals to a shared common purpose (sharing common “turf”) (7).

Coherence and constructive collaboration between the “owners of the plan” – not just the steward (the person or organization with responsibility and accountability to oversee the implementation of the NCCP), but rather those whose leadership, influence, support and visible profile provide the impetus for a societal plan to be effective. The role of the steward is to foster and nurture this culture, environment and relationship, to enable the plan to be implemented in a contextually-appropriate manner, and report and demonstrate the results of collective action for control cancer at a population level.

We know which countries have NCCPs and we know which global organizations are taking the lead with assistance or

technical development on components of NCCPs. What we do not have is a ready source of knowing “who is doing what, how and where”?

There will be others, of whom we are unaware:

- ➔ pursuing the same purpose, within the same country, with a different set of partners, but without knowledge of others’ activities;
- ➔ pursuing the same purpose, in countries with different contexts and cultures;
- ➔ pursuing different aspects of cancer control, unaware of “how the whole could be of greater value and relevance than the sum of the parts” to the host country.

Irrespective of country, or aspect of cancer control, the key opportunity is to learn why, under what circumstances (contexts), and through what relationships and understandings (collaboration) are cancer control interventions implemented successfully, or not. What determines success, or failure, when content (NCCPs) is similar?

Could we achieve greater gain more effectively and quickly through collective knowledge than by individual endeavour? Who could/would serve this role for global cancer control – the source of information regarding ‘who is doing what, where and with whom’ – the resource to facilitate collaborations to strengthen, rationalize and reduce duplication within aspects of cancer control, within and between countries? Who could be the “honest broker” of information that would benefit all parties, expedite partnerships and foster collective action?

Who might, should or could assume the role of steward to advance the many initiatives to advance global cancer control?

Conclusions

Controlling cancer, or any NCD, is not solely a medical issue – it is a societal issue where the solutions come from the informed actions of multiple, relevant constituencies, each of which has a role and a level of influence through which the goals of improved population-based cancer (NCD) control can be reached. Proving that implementation of NCCPs causes improved outcomes of cancer control will be challenging inasmuch as there is no control group and no ability to rigorously compare the value of the interventions within a contemporaneous non-intervention population. Furthermore, population cancer/NCD control outcomes will continue to improve without an NCCP so long as social determinants of health continue to improve. Notwithstanding, the implementation of NCCPs is associated with improved cancer/NCD outcomes. To that end, NCCPs represent a direction that is consistent with where we want to get to. Knowing the destination is essential for the journey. However, to arrive at the right destination requires not only the map (content), but also knowledge of what one must be prepared for (context), and the level of readiness to optimize the likelihood of arrival (collaborations). Determining how we collaborate is our decision to make. ■

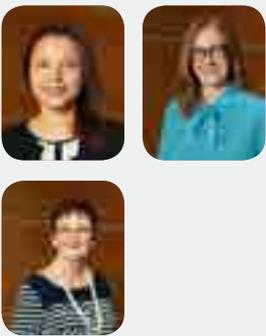
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City Cancer Challenge: Delivering sustainable, local solutions for cancer care

Rebecca Morton (top left), Head, Policy and Global Impact; **Dr Susan Henshall** (top right), CEO and **Professor Sanchia Aranda** (bottom), Chair, City Cancer Challenge (C/Can), Union for International Cancer Control (UICC)



City Cancer Challenge (C/Can) is a global, multisectoral initiative launched by the Union for International Cancer Control (UICC) in Davos, Switzerland, in January 2017. C/Can aims to build a collective movement of cities, supported by a network of global and local partners, to deliver quality, equitable, and sustainable cancer treatment solutions for all. This article provides an overview of the C/Can approach, highlighting early successes, as well as opportunities for future engagement by the cancer community and beyond.

Cities as health policy “entrepreneurs”

Today, more than half of the world’s population live in urban environments. By 2030, a projected 662 cities will have at least one million residents with 95% of urban expansion predicted to take place in low- and middle-income countries (LMICs) (1). The scale and speed of this urbanization means cities are facing unprecedented pressures on the urban environment, and the health and wellbeing of their populations. This challenge is compounded in LMICs, where the non-communicable disease (NCD) burden is the highest, and where already fragile health systems are struggling to provide equitable access to quality healthcare, particularly for the most vulnerable populations.

In response, city leaders are emerging as champions of new initiatives and platforms for health promotion, and, in many cases, “policy entrepreneurs” in NCD prevention and care, developing models that are scalable at the national level.

Tbilisi City Hall, for example, has been supporting screening programmes for breast, cervical, colorectal and prostate cancer since 2008. In 2016, based on latest registry data showing breast cancer to be the most common malignancy, Tbilisi City Hall decided to allocate resources to ensure full financial coverage for women in Tbilisi with HER-2 positive breast cancer to undergo a full course of targeted treatment. The City of Kigali has been partnering with local businesses and NCD organizations on the Kigali “car-free day” initiative to raise awareness around NCD risk factors, promote physical activity, and deliver a variety of health promotion services to

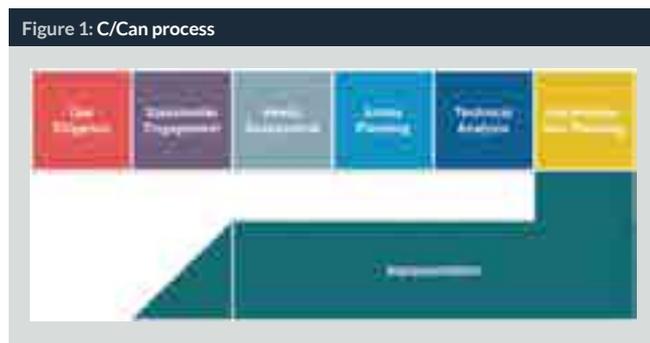
Kigali citizens twice a month.

These and similar city-led initiatives are in turn creating powerful networks of city leaders who are shaping the global urban health and development agenda (2). Building on this momentum, and recognizing the untapped potential of an integrated, systems approach to Sustainable Development Goals (SDGs) 3.4 (non-communicable diseases), 11 (safe and sustainable cities) and 17 (partnership to deliver the goals), City Cancer Challenge (C/Can) was launched by the Union for International Cancer Control (UICC) in 2017 to empower cities to design, plan and implement quality, equitable, sustainable cancer care solutions for all. Now a standalone foundation, C/Can aims to reach 20 cities by 2020, as a first step towards creating a global movement of cities working together to improve cancer control.

The C/Can process: An adaptable blueprint for transformation

C/Can is now operational in seven cities – Cali, Colombia; Asunción, Paraguay; Yangon, Myanmar; Kumasi, Ghana; Porto Alegre, Brazil; Kigali, Rwanda; and Tbilisi, Georgia – and will be announcing a new group of cities in 2019.

C/Can cities are supported to undertake a 2-year process that is shaped around six sequential phases (see Figure 1), with each phase delivering an agreed set of outputs. This provides cities with a systemized framework, which begins with a needs assessment to identify priority interventions for improving access to quality cancer care. These priorities are then further



refined and translated into concrete plans for implementation, which the city leads.

Stakeholder engagement: The power of partnerships

Once a city formally joins C/Can (3) the first step is to map and engage all appropriate stakeholders in the C/Can process, including city leadership, regional/national government, cancer care providers and decision-makers in both the public and private sectors. This results in the establishment of a multisectoral C/Can City Executive Committee - the main decision-making body throughout the process, responsible for the setting of priorities, the approval of city plans and activities, and the oversight of implementation activities. Representation from key actors in the local, regional and national health system, including the national and regional ministries of health who most often administer the delivery of cancer care services in each city is critical. Whilst C/Can is leveraging cities as a key non-state actor in a health systems response, it is important that this response is integrated and coordinated across local, national and international levels.

Needs assessment: Understanding the unique the city context

A key component of the C/Can approach is to empower local city leaders to define their own needs and craft solutions that reflect an understanding of the unique local context. During this phase of the process, data are collected using C/Can's City Needs Assessment Questionnaire with the aim of providing in-depth information on the current state of delivery of cancer treatment and care services in a city. Developed in 2017 by a global multidisciplinary team of experts and partners (4), the questionnaire is designed to obtain critical operational and administrative data from the principal institutions that provide cancer care services in the city, covering core diagnostic and clinical services, as well as the management and quality of these services. The questions also address the extent to which patients are placed at the centre of care by assessing community access and integration of care within the city, considering the perspective of institutions, civil society and patients.

The data collection process is coordinated by a group of between 20 and 25 local technical experts who each convene

ASUNCIÓN'S CITY EXECUTIVE COMMITTEE ADVANCES A NATIONAL CANCER LAW

In October 2018, the Paraguayan senate unanimously approved a National Cancer Law recognizing access to cancer prevention, treatment and care as a right, and establishing a National Programme for Cancer Control. The government has since allocated US\$ 50 million for implementation in Year 1, with an additional US\$ 100 million under discussion for Year 2.

The process to develop the law and garner support was spearheaded in May 2017 by the multisectoral City Executive Committee established as part of the C/Can process in Asunción. The city needs assessment highlighted the highly fragmented nature of the local health system which had resulted in a lack of inter-institutional coordination, inequality and high cost of cancer care. These findings prompted the Committee to prioritize a review of the legal framework in Paraguay and the drafting of a new cancer law.

working groups comprised of topic experts in each area in the questionnaire (e.g., palliative and supportive care) with different expertise and professional profiles (e.g., treating physicians, nurses, pharmacists, social workers, technicians, psychologists, administrators) from participating institutions. This group of technical experts is also tasked with consolidating city-wide data in their respective fields to produce a short Diagnostic Report summarising findings and recommending priority areas for action.

This city-wide analysis is now complete in the first four C/Can cities (Asunción, Cali, Kumasi and, Yangon) with data contributed from over 90 institutions, 800 health professionals and 650 patients, across 1,100 data points (see Figure 2).

Planning and technical analysis: Data-driven decision-making

During these phases of the process, city needs are further refined and structured into a set of high-level objectives

Figure 2: Snapshot of C/Can progress



with activities, which are further refined and validated. City stakeholders then commit to conduct an in-depth technical assessment to provide robust and validated data on each of the major topic areas to inform project planning. This is considered critical to ensure that city activity plans are data-driven and that all partners and stakeholders, including international organizations and development agencies, can provide a targeted response to the needs.

Implementation

During this final phase, implementation moves ahead on a project basis, with clear definition of the institutions/persons responsible, resourcing needs activity timeline and time-bound targets and metrics to measure progress and impact.

Addressing needs through technical assistance

Over 50 international public and private organizations have been mobilised as City Cancer Challenge partners to deliver technical assistance to the cities. This includes government agencies, international organizations (e.g., IAEA), professional associations and private companies. Partnerships with health professional associations (e.g., American Society for Clinical Pathology and the American Society of Clinical Oncology) are already creating opportunities to respond to some key common areas of need, for example, strengthening the quality of pathology services, and building capacity to deliver multidisciplinary cancer management through access to education and training opportunities. These early learnings with partners will be critical in developing a model of technical assistance that can be replicated and sustainably scaled to other cities.

New collaborations driving change

Through the C/Can needs assessment and prioritization process, several cancer care gaps that can be addressed through stronger collaboration and cooperation between key stakeholders without needing significant financial investment have been identified.

Looking ahead: Building a community of cities

Working with a small but diverse group of 20 cities over the next two years, C/Can aims to validate and refine a series of capacity-building tools, guidance documents and technical assistance packages to ensure they are meaningful and relevant in cities across different regions, income settings and cancer care contexts, and can support scale-up to a wide global community of cities. Lessons learned in the cities will also be used to explore the potential for both greater inter- and intra-regional cooperation and collaboration with specific efforts being made to build networks and platforms that support knowledge exchange and peer-to-peer learning.

A JOINT INDUSTRY RESPONSE TO SPECIFIC NEEDS IN CALI

In Cali, Colombia, for example, working via La Asociación de Laboratorios Farmacéuticos de Investigación y Desarrollo (AFIDRO), the pharmaceutical industry has agreed to join efforts and provide a collective response (funding and technical assistance) to a set of specific priority needs. Work is currently underway to finalize this joint industry proposal for support. In addition, AFIDRO are financing a local expert to provide project planning and project management expertise to advance the planning of city projects in Cali.

EARLY WINS IN KUMASI AND CALI THROUGH THE C/CAN PROCESS

In Kumasi, for example, bringing together the city, traditional leaders and the teaching hospital through the C/Can process has resulted in a decision from the city to allocate an unused state building to house the cancer registry and provide a local office space for C/Can activities.

In Cali, Colombia, one of the key gaps identified through the needs assessment was the urgent need to increase the number of regular blood donors. Blood banks across the city are working together with the departmental and municipal government to review current public policy around blood donation and to explore coordinated strategies to increase voluntary donation.

Underpinning this effort is an evidence-based approach to monitoring, evaluation and learning (MEL) that will be critical to creating a solid foundation for long-term planning, implementation and ensuring sustainable results. C/Can's MEL framework includes a comprehensive set of metrics designed to track progress and impact at city and global levels, as well as mechanisms to feed lessons learned into adaptive, iterative planning for city and global activities.

Ensuring city "readiness" to join C/Can

One of the critical learnings from the first C/Can cities is that there are a number of common drivers for success in the C/Can process. These have been captured and used to develop a set of "readiness criteria" for cities considering engagement in C/Can. These include:

- ➔ political commitment to improved cancer control at city, regional and national level;
- ➔ the existence of local champions for improved cancer care;
- ➔ robust and coordinated civil society;

- ➔ open and transparent dialogue between cancer care stakeholders across a city;
- ➔ examples of multisectoral collaborations between government, private sector and civil society for the improvement of cancer treatment and care;
- ➔ a National Cancer Control Plan in which C/Can activities can be anchored;
- ➔ accurate cancer data from a population-based cancer registry to inform the design, planning and monitoring of cancer solutions;
- ➔ basic capacity and availability of core cancer services that can be built on and accelerated through the C/Can process.

These criteria are outlined in more detail in the C/Can City Checklist (5). The Checklist is designed to support ministers of health, mayors and city leaders, civil society organizations, industry partners and others to gauge a city's eligibility and readiness to join C/Can; identify areas that may need to be strengthened before applying, and what resources are available to help address these areas. For example, embedding civil society into the C/Can process has proven to be vital in ensuring that the right local stakeholders are engaged, that a strong linkage to the local community is maintained, and that the patient perspective is included. It is therefore important that civil society organizations are coordinated and able to collaborate effectively. The Checklist highlights UICC's Treatment for All advocacy initiative, that is: working with and supporting UICC members, partners and its network to mobilize and equip civil society with the skills to identify advocacy priorities and translate global cancer commitments into effective national action (6). Similarly, for cities where cancer planning and data need to be strengthened, the Checklist highlights the International Cancer Control Partnership (ICCP) Portal for access to cancer planning and capacity building resources (7), as well as IARC's Global Initiative for Cancer Registry Development (GICR) (8).

As C/Can continues to grow, engaging new cities, partners, and supporters, it is uniting around a shared vision of improving access to equitable quality cancer treatment and care with the support of a network of local, regional and global partners who bring technical assistance, and complementary resources and

competencies to enable sustainable solutions. ■

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Dr Susan Henshall is currently the CEO of the City Cancer Challenge. Prior to this, Dr Henshall led a translational cancer research programme at the Garvan Institute of Medical Research in Sydney, Australia, for over a decade, focusing on the identification and validation of markers of cancer outcome and drug response. Over the course of her career, she has held senior faculty appointments at the University of New South Wales in Australia and Georgetown University in the United States. She also played a key role in the funding and development of the Kinghorn Cancer Centre, a dedicated translational cancer research and clinical centre which opened in Sydney in 2012.

Professor Sanchia Aranda is Chair of C/Can: City Cancer Challenge. She was appointed CEO of Cancer Council Australia in 2015. Professor Aranda leads cancer policy and advocacy development, ensuring a strong evidence base informs Australian cancer control. She is a registered nurse and has held roles in healthcare, research, tertiary education and government prior to joining the not-for-profit sector. Her leadership roles nationally and internationally include eight years on the Advisory Council for Cancer Australia (2006–2015), 16 years on the board of the ISNCC, including four as President (2006–2010) and eight years on the board of UICC, including two as President (2016–2018). She is a board member for the International Collaboration on Cancer Reporting and the Clinical Oncological Society of Australia.

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VCS FOUNDATION PRESENTS AN INTEGRATED SOLUTION TO SUPPORT CERVICAL CANCER ELIMINATION FOR ALL



VCS Foundation is a not for profit organization established in 1964 with the goal of achieving cervical cancer control in Australia. We believe that cervical cancer elimination should be for all, no matter where you live.

Our three operational pillars; VCS Population Health, VCS Pathology and VCS Digital Health are an integrated solution to assist you in the design and delivery of screening and vaccination strategies to support cervical cancer prevention for all.

We work locally, regionally and internationally. We understand the complexities of population health and the importance of delivering services to improve the health of communities in ways that are safe, acceptable and cost effective.

We work effectively in collaboration with stakeholders and in partnerships.

VCS Population Health provides public health operations and advice to support the delivery of screening and vaccination services. We established Australia's first cervical screening registry over 25 years ago and our team of public health practitioners and health information managers know how to design and deliver high quality registry operations. High quality integrated data flows provide the information that you and every person involved in the delivery of your program need to support participants and optimize its reach and results. As well as delivering excellence in operational public health practice, we also excel in policy-relevant research design and delivery to ensure that programs continually improve and progress.

VCS Pathology is our specialist clinical laboratory providing excellence in HPV testing, cervical cytology, histopathology and testing for sexually transmissible infections. We are leaders in self-collected HPV tests, pioneering a service supporting self-collection for cervical screening. In our 50 years of operation we have reported over 12 million cervical screening tests. Our Medical Education Unit develops and delivers accredited training and education materials to support medical professionals to conduct high quality screening in practice settings. As a not for profit reference laboratory service, we can consult with you about all aspects of quality testing supporting screening to the highest standards.

VCS Digital Health has over 25 years of successful service delivery in developing, operating and supporting highly scalable, configurable and secure digital platforms and eHealth solutions.



CanSCREEN® is an award winning contemporary technology platform that has been designed to securely support population health management services across a spectrum of health programs, including screening and vaccination. We work with you to support your large and small scale health service program requirements, and to cost effectively improve health outcomes.

Project ROSE, highlighted elsewhere in this issue, is an example of our ability to innovate and adapt to different settings to achieve health for all.

VCS Foundation is proud to be a key partner of Australia's National Health and Medical Research Council (NHMRC) funded Centre of Research Excellence (CRE) in Cervical Cancer Control. The work of the Centre for Research Excellence in Cervical Cancer Control will ensure the future of cervical cancer prevention is underpinned by world class research.

The Compass Trial, is a large scale randomized controlled trial, being conducted by VCS Foundation and Cancer Council NSW. This significant study is important for Australia's National Cervical Screening Program and globally for understanding the implementation and impact of HPV based screening.

Australia is a world leader in achieving cervical cancer control in our population and it is time to extend that leadership to supporting cancer prevention globally.

The unique combination of our integrated services can cost effectively support you in responding to the global call to action to eliminate cervical cancer.

We invite you to join us in a new partnership to save more lives.

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The Commonwealth and cervical cancer: Time for collective action

Mark Lodge (left), Director, International Network for Cancer Treatment and Research UK, Oxford, UK; **Therese Lethu** (middle), Founder, Global Health Objectives and **Dr Ophira Ginsburg** (right), Director, High-Risk Cancer Genetics Program, Perlmutter Cancer Center and Associate Professor, Section for Global Health, Department of Population Health, New York University School of Medicine, USA



A significant proportion of deaths from cervical cancer occur in Commonwealth countries where the effectiveness of strategies to prevent or treat the disease is variable, particularly in the low- and middle-income member countries. The global campaign to eliminate cervical cancer provides the Commonwealth with a unique opportunity to act collectively in the prevention, treatment and research of cervical cancer.

The Commonwealth is a voluntary association of 53 independent countries that work together to pursue common goals promoting development, democracy and peace. It has a combined population of 2.4 billion; equivalent to around one third of the global population. Significantly for cancer control, the Commonwealth is a heterogeneous, multicultural, multilingual grouping that includes both advanced and developing economies, encompasses every climate and continental region (Africa: 19 countries; Asia: 7; the Caribbean and Americas: 13; Europe: 3; and the Pacific: 11) and the extremes of topography and demography. In its councils, the Pacific nation of Nauru, the smallest Commonwealth member country, with a population of about 10,000, has the same voting power as India, its most populous member country with over 1.2 billion people.

Cervical cancer is a mostly preventable disease and its elimination is generally regarded as “low-hanging fruit” in discussions around Sustainable Development Goals. Nevertheless, in 2018, 13 women died every hour in the Commonwealth from cervical cancer and over 425,000 women were living with cervical cancer. Commonwealth member countries carry a 34% share of the global cervical cancer incidence burden (191,685 new cases) and 38% of global cervical cancer mortality (118,708 deaths). Globocan estimates indicate that by 2030 the Commonwealth’s share will have increased to 38% of global incidence (265,627 new cases) and 42% of global mortality (168,012 deaths (1).

The principal cause of most cases of cervical cancer is infection with oncogenic human papilloma virus (HPV). HPV infection is transmitted through skin to skin contact, which includes most sexual activity for men and women. Infected cells lining the cervix gradually develop pre-cancerous lesions

that later may turn into cancer. There are around 200 different types of HPV virus, of which 15 types are classified as high risk for cancers (HR-HPV type). Of all the HR-HPV types HPV16 and HPV 18 are the most commonly associated with invasive cervical cancer (2) and are responsible for about 70% of all cervical cancer cases worldwide. There is growing evidence of HPVs also being a relevant factor in other anogenital cancers (i.e., anus, vulva, vagina and penis) as well as head and neck cancers.

After infection with HPV the most common risk factors for cervical cancer are a weakened immune system and smoking. The immune system is important in destroying cancer cells and slowing their growth and spread. Human immunodeficiency virus (HIV) damages a woman’s immune system and puts them at higher risk for HPV infections. In women with HIV, a cervical pre-cancer might develop into an invasive cancer faster than it normally would.

Women in Commonwealth countries with high prevalence of HIV – for example, South Africa, Tanzania and Zambia (3,4,5,6,7) – are therefore especially at risk and this is reflected in their higher age-standardized incidence and mortality rates from cervical cancer.

Smoking is also a risk factor for the development of cervical

RISK FACTORS FOR CERVICAL CANCER

- HIV infection
- Weakened immune system (HIV)
- Smoking
- STDs (Chlamydia, Herpes simplex)
- Age <17 at first full term pregnancy
- Multiple sexual partners
- Multiple pregnancies
- Diet low in fruit and vegetables
- Overweight

cancer. Women who smoke are about twice as likely as non-smokers to get cervical cancer while the time since quitting is associated with a two-fold reduced risk (8). Tobacco by-products have been found in the cervical mucus of women who smoke (9). Researchers believe that these substances damage the DNA of cervix cells and may contribute to the development of cervical cancer (10). Other risk factors include chlamydia infection, a diet low in fruit and vegetables, excess weight and having multiple pregnancies. If a woman is younger than 17 years at first pregnancy, she is also more inclined to developing cervical cancer later in life than women who have waited to get pregnant until they were 25 years or older (11).

Cervical cancer incidence and mortality in the Commonwealth

Cervical cancer is the fourth most frequent cancer in women, with an estimated global incidence of 569,847 new cases in 2018 and – most critically for domestic family budgets – the second most frequent female cancer in the 16–49 year age range. In that year 1,474,265 women were living with cervical cancer (five-year prevalence). Cervical cancer is also the fourth most frequent cause of cancer deaths in women. Globocan 2018 reports 311,365 deaths from cervical cancer worldwide; more than 85% of which occurred in low- and middle-income countries (1).

The Globocan 2018 data presented in Table 1 shows that within the Commonwealth cervical cancer is the leading female cancer in 10 member countries, the second-most common female cancer in 16 member countries, and the leading, or second-highest cause of death from cancer, in females in 29 member countries. The five Commonwealth member countries with the highest number of cervical cancer cases and deaths are India, Nigeria, Tanzania, Bangladesh and South Africa. The data reveals the strong association between national wealth and cervical cancer. Of the 26 Commonwealth countries where it is the leading or the second-most common female cancer, none are classified as high-income countries by the World Bank and only seven as “Upper-Middle Income”. The same pattern applies to mortality. Of the 29 Commonwealth member countries where cervical cancer is either the leading or the second-most common cause of female cancer deaths, only one is a high-income economy and seven are upper-middle income countries. The Globocan data suggests that the Commonwealth’s incidence of cervical cancers will rise by 38% in the 13 years between 2018 and 2030 in line with population growth, and that the number of deaths from cervical cancer will increase by 42% (from 118,708 p.a. to 168,012 p.a.) in the same period. These total figures mask the wide disparity between the increases predicted for the high-income countries (e.g., the UK’s 13% increase in mortality) and that expected in

the lower-middle and low-income countries (Nigeria 45% and Mozambique 47% respectively).

Prevention of cervical cancer

There are two ways cervical cancer can be prevented: 1) by immunizing girls, boys and young women at an early age against the infections that can cause premalignant lesions that may develop into malignancy and 2) by finding and destroying the precancerous lesions before they can become cancerous. The first strategy calls for vaccination with corresponding community education and social mobilisation as key components to enhance uptake; the second for screening and treatment of precancerous lesions (“screen and treat”) across the life course of the women. The most efficient formula for cervical cancer prevention (P) is a combination of the two strategies: Vaccination (V) plus Screen and Treat (ST), or P= V + ST.

➔ Primary prevention of cervical cancer by vaccination (V)

Human papilloma virus (HPV) infection through skin to skin contact – predominantly sexual – is the principle cause of almost all cervical cancers, with HPV 16 and HPV 18 being linked to 70% of all cervical cancers. There are three barriers to eliminating cervical cancer by vaccination:

- 1) Politics: Historically, resource allocation on LMIC health agendas has been skewed towards communicable diseases, maternal and neonatal mortality and nutritional poverty rather than non-communicable diseases (NCDs), such as cancer.
- 2) Uninformed or misinformed public and professional knowledge about cervical cancer and a low level of awareness about the dangers of HPV infection and how it can be prevented. Five common issues have been identified: medical misconceptions about the HPV vaccination; fear of the unknown; need for prior desensitisation to resolve cultural barriers; a rural-urban divide in health awareness; and economic concerns associated with access to the HPV vaccination.
- 3) Cost - The cost of HPV vaccines and of immunization: HPV vaccines are available to GAVI countries and to all PAHO member countries in the Caribbean and Americas region at a discount through the PAHO Revolving Fund, although for some of the Commonwealth’s small countries this price may still be unaffordable. Additional costs – of storage, transportation, delivery and promotion – are also incurred.

➔ Secondary prevention of cervical cancer by screening and treatment of precancerous lesion (ST)

Prevention by screening and treatment is possible because cervical cancer is preceded by a long latent period when

Table 1 : Cervical Cancer Incidence, Mortality and Prevalence 2018 – 2030

	World Bank	Incidence	Cervix Ca	Incidence	Est. 2018	Deaths	Cervix Ca	Deaths
	Class 2018	2018	rank	2030	Prevalence	2018	rank	2030
Australia	HI	924	13	1,047	3,438	331	16	410
Bahamas	HI	29	4	35	85	23	2	30
Bangladesh	LMI	8,068	2	11,481	17,702	5,214	3	7,629
Barbados	HI	38	4	43	106	27	3	33
Belize	UMI	46	2	68	122	25	1	37
Botswana	UMI	333	1	479	852	166	1	249
Brunei	HI	52	4	66	168	14	4	21
Cameroon	LMI	2,356	2	4,998	4,566	1,546	2	2,333
Canada	HI	1,434	13	1,586	5,049	586	15	714
Cyprus	HI	45	11	55	143	18	14	24
eSwatini (formally Swaziland)	LMI	380	1	539	774	238	1	351
Fiji	UMI	124	2	145	354	94	2	121
Gambia	LI	184	1	284	310	132	1	208
Ghana	LMI	3,151	2	4,761	6,857	2,119	1	3,235
Guyana	UMI	124	2	150	298	64	1	81
India	LMI	96,922	2	128,291	225,689	60,078	2	81,113
Jamaica	UMI	486	3	569	1340	361	2	452
Kenya	LMI	5,250	2	8,335	10,963	3,286	1	5,478
Lesotho	LMI	477	1	595	876	346	1	430
Malawi	LI	4,163	1	6,621	7,770	2,879	1	4,587
Malaysia	UMI	1,682	3	2,402	4,898	944	4	1,436
Malta	HI	11	16	12	34	7	22	9
Mauritius	UMI	120	3	147	342	56	3	75
Mozambique	LI	4,291	1	6,308	6,965	3,376	1	4,956
Namibia	UMI	236	2	344	544	135	1	200
New Zealand	HI	190	12	214	677	72	17	88
Nigeria	LMI	14,943	2	21,528	29,601	10,403	2	15,085
Pakistan	LMI	5,601	3	8,075	11,659	3,861	3	5,621
Papua New Guinea	LMI	1,024	2	1,406	2,075	663	2	931
Rwanda	LI	1,304	1	2,048	2,410	921	1	1,472
Saint Lucia	UMI	15	3	18	40	12	2	16
Samoa	UMI	10	6	12	27	6	5	7
Sierra Leone	LI	299	2	431	474	242	2	350
Singapore	HI	429	7	697	1,318	208	8	313
Solomon Islands	LMI	55	2	78	114	39	1	55
South Africa	UMI	12,983	2	16,240	34,170	5,595	1	7,322
Sri Lanka	LMI	1136	2	1404	3183	643	2	844
Tanzania	LI	9,772	1	15,213	19,332	6,695	1	10,449
Trinidad and Tobago	HI	140	4	156	414	97	2	120
Uganda	LI	6,413	1	10,342	12,337	4,301	1	6,961
United Kingdom	HI	3,430	12	3550	12,575	1,033	17	1,169
Vanuatu	LMI	21	2	28	46	13	2	17
Zambia	LMI	2,994	1	4,826	6,407	1,839	1	2,980
		191,685		265,627	437,104	118,708		168,012
% increase 2018 - 2030				38.5				42
WORLD		569,847		691,129	1,474,265	311,365		394,561
Commonwealth % of World totals		34%		38%	30%	38%		43%

persistent HPV infection leads to the development of asymptomatic precancerous lesions. Left untreated or undetected, these precancerous lesions may develop into cancer over a 5 – 30 year period whereas, if detected, they can be removed, preventing the development of cancer in the future and saving costly interventions. Systematic screening of women with an organized population-based approach has contributed to the reduction in cervical cancer incidence by up to 80% in developed countries.

Precancerous lesions can be detected by (i) performing cytological (Pap) smears; (ii) visual inspection with acetic acid (VIA); or (iii) HPV testing. While all three modalities are considered by WHO to be “very cost-effective interventions” or “Best Buys” (13), WHO does not recommend starting or scaling-up cytology-based screening in countries that have not yet done so. Rather, the emphasis is on HPV as the primary screening modality, although costs are currently prohibitive in many countries. Screening levels remain variable throughout the Commonwealth and dependent on the availability of resources and infrastructure. Screening and pre-cancer treatment algorithms are being optimized (14,15) in many countries with the availability of HPV testing, the known difficulties with accuracy and quality assurance for VIA (12) and challenges in taking VIA as a primary screen, and cryotherapy as the primary pre-cancer treatment method to scale.

Most high-income Commonwealth member countries have population-based screening programmes, with Australia recently replacing cytology with HPV DNA detection tests to screen women aged 25 to 74 years every five years and New Zealand and the UK following in this direction. A recent report predicts that in the coming two decades Australia could eliminate cervical cancer as a major public health issue, which the authors suggest is the same as the accepted annual incidence for a “rare” cancer, that is <4 cases/100 000 per year, by 2021-2035 (16).

Elsewhere, screening coverage is variable. Although the Commonwealth member countries in the Caribbean and Latin America region have all implemented opportunistic conventional cytology-based cervical cancer screening programmes, screening has achieved limited success there due to the lack of an organized population-based approach, poor quality control and low population coverage. Despite its lack of resources, Belize has demonstrated that screening for cervical cancer and precancerous lesions can be combined with delivering STD counselling. India shares one-fourth of the global burden of cervical cancer. The Fourth National Family Health Survey (NFHS-4) (17), a nationally representative survey including 699,686 Indian women aged 15–49 years that was conducted at the district level during 2015–2016 found

that lifetime cervical cancer screening prevalence was low (29.8%) and varied by geographic region, ranging from 10.0% in the Northeast Region to 45.2% in the Western Region.

Opportunistic screening programmes provide free Pap smear services to the women at all the public health facilities in Malaysia and at the women’s wellness clinics in Sri Lanka. In South Africa, the national programme has had little impact on disease burden; by 2014 it had reached only 14% of the target population. In comparison, a screening pilot study has been successfully scaled-up to 75 government-run health facilities across Zambia’s 10 provinces and supported by rigorous quality assurance.

Treatment of cervical cancer

Treatment for invasive cervical cancer is dependent on ‘Stage’ as defined by the International Federation of Gynaecology and Obstetrics (FIGO). For Stage 1A cancers, surgery is the preferred treatment. 74% of cervical cancer cases will need this modality at some point in the management pathway (18). Current capacity and capability for delivering the range of pelvic procedures that are required to manage cervical cancer from a surgical perspective varies widely across Commonwealth countries.

For high-income populations in some upper middle-income member countries, surgical availability and outcomes mirrors that found in the high-income countries. However, this only covers some 6% of women with cervical cancer in Commonwealth countries. For the remainder, access remains both geographically and financially poor (19), reflecting the reality that women with cervical cancer need to travel an average of 100km to access a health facility capable of carrying out a surgical biopsy, a major contributor to late presentation (20,21). In many Commonwealth LMICs a scarcity of appropriately trained pelvic surgeons, the shortage of operating rooms, and a low operating volume can conspire to deliver an often unsafe surgical environment (22).

For Stage 1 tumours greater than 4cms in size and for all other Stages, the standard primary treatment is concurrent chemotherapy and radiation, although for Stage 4, disease treatment is determined by performance status. Several challenges to the equitable provision of radiotherapy services in LMI Commonwealth countries have been identified, with many populations having little or no access to publicly-funded radiotherapy services. These general barriers to the provision and delivery of radiotherapy include the lack of: adequate human and financial resources; equipment that meets IEC standards or equivalent national device standards; preventive maintenance and repair contract and funds and quality assurance (QA) equipment, treatment planning systems and simulation equipment for assuring

Figure 1: Reports of research published in 2016 relevant to cervical cancer control in Commonwealth member countries, listed by institutional/country affiliation of first authors

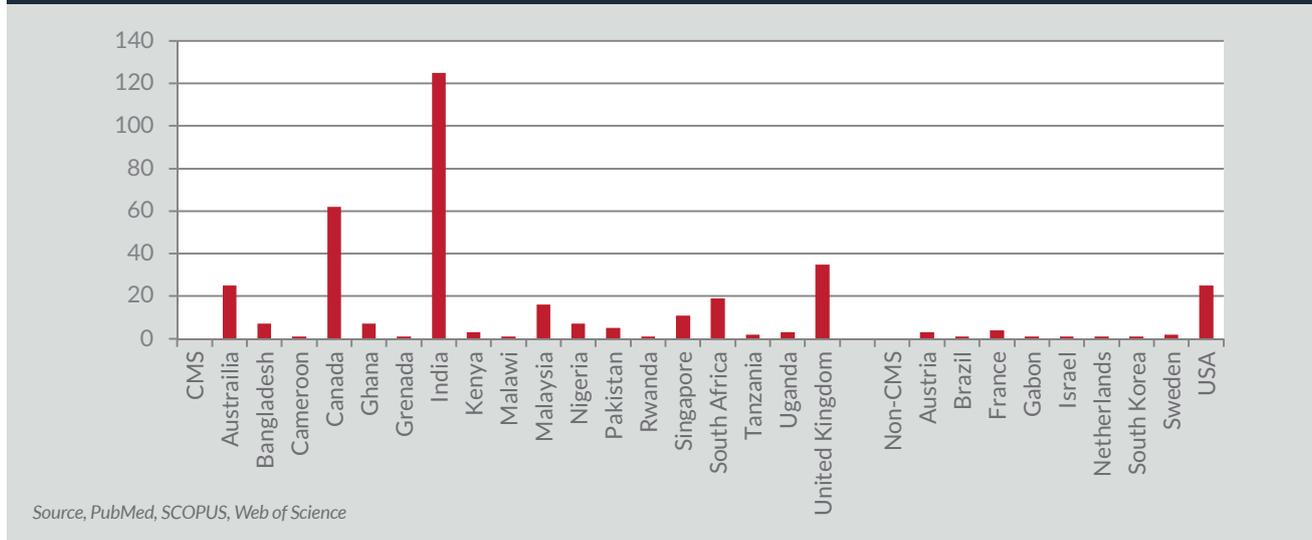
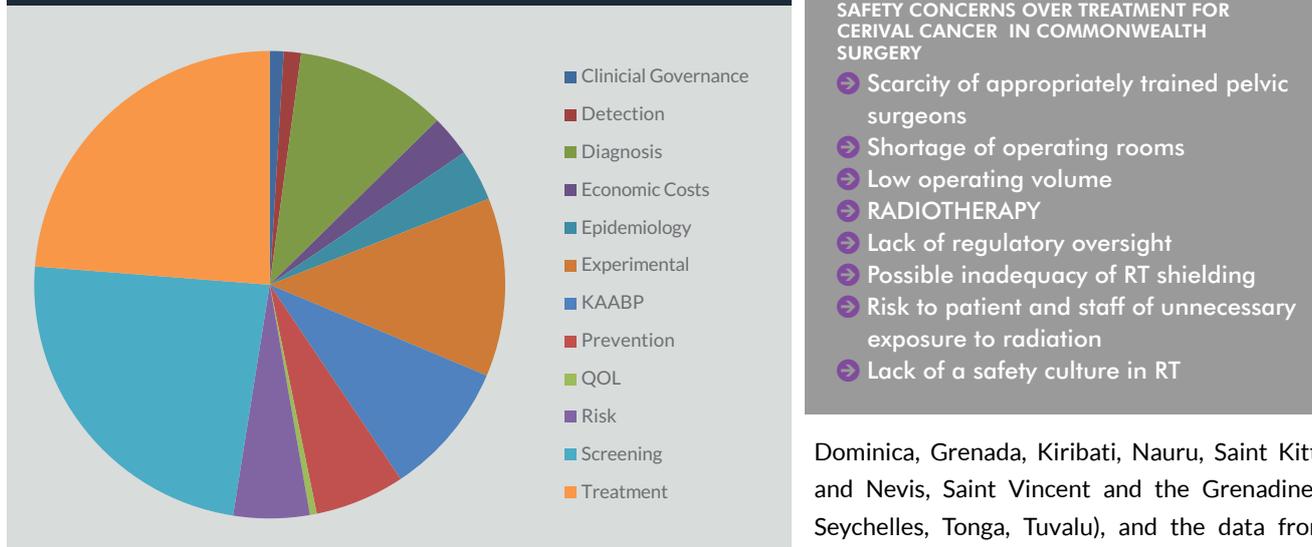


Figure 2: Topics addressed in research papers on cervical cancer in the Commonwealth (2016)



optimized radiotherapy treatments. There is concern over the availability of brachytherapy equipment in countries with no regulatory authority as the IAEA Code of Conduct on the Safety and Security of Radioactive Sources (23) would prevent the exportation of sources to countries without adequate regulatory oversight. In some countries the lack of regulatory authority with expertise in authorization and inspection of radiotherapy may be putting the patient, worker and public at risk to unnecessary exposure to radiation.

Cervical cancer research in the Commonwealth

Epidemiological data from population-based registries and scientific data from clinical trials and studies are two of the foundation stones of evidence-based cancer control. The International Agency for Research on Cancer’s Globocan 2018 database does not include data from 10 Commonwealth small countries with LMI economies (Antigua and Barbuda,

countries that are presented in Table 1 may be underpowered.

An African Cancer Registry Network (24) has been established to improve the effectiveness of cancer surveillance in sub-Saharan Africa by providing expert evaluation of current problems and technical support to remedy identified barriers, with the long-term goal of strengthening health systems and creating research platforms for the identification of problems, priorities, and targets for intervention. AFCRN works with cancer registries in Botswana, The Gambia, Ghana, Kenya, Malawi, Mauritius, Mozambique, Namibia, Nigeria, Seychelles, South Africa, Swaziland, Uganda, and Zambia and acts as the African Regional Hub for cancer registration as part of IARC’s Global Initiative for Cancer Registry Development in Low and Middle Income Countries framework.

The incomplete and of variable quality of the data reported by their cancer registries is compounded by the difficulties in retrieving reports of cancer research conducted in low-

or middle-income Commonwealth member countries. An electronic search of four bibliographic databases (Pubmed, Embase, African journals Online and WHO's African Index Medicus) conducted in 2017 by INCTR UK for evidence published between 2000 and 2016 relevant to cervical cancer and other HPV-linked cancers in sub-Saharan Africa identified 1,656 reports of research, of which 1,414 (85%) reports related to populations or patients in African Commonwealth countries (25). A second sample search of PubMed; SCOPUS and Web of Science, for reports of cervical cancer research relevant to Commonwealth members published in 2016 (the most recent complete year) identified 370 reports from 18 Commonwealth countries and 9 non-Commonwealth countries (Figure 3), of which 45 reports (12%) were by first authors located in African countries.

The most frequently researched topics were Screening (100 publications) and Treatment (100 publications) Experimental medicine (52 publications, of which 36 had first authors in India), Diagnostics (44 publications) and Prevention (26 publications). Knowledge, Awareness, Attitude, Behaviour and Practice (KAABP) issues relating to cervical cancer were addressed in 39 publications (Figure 4). Twelve papers considered cost and resource management in the management of cervical cancer, but only two papers looked at the quality of life of patients receiving treatment for cervical cancer.

Discussion

Because the majority of cervical cancers start with pre-cancerous changes caused by HPV infection, the high mortality rate from cervical cancer can be reduced through a comprehensive approach that includes prevention, early diagnosis, effective screening and treatment programmes. For the foreseeable future, cervical cancer prevention will require both HPV vaccination and screening, providing opportunities to improve primary healthcare systems and reduce cancer disparities (26). Allocation of resources and the provision of skilled healthcare professionals are essential for effective cervical cancer control. Included in the package of care should be access to HPV vaccination for girls aged 9–12 years. Similarly, screening programmes should be initiated for women over 30 years, aiming for the widest coverage and ensuring that all women with abnormal cytologies be offered either further assessment or treatment with follow-up. Zambia's successful roll out of screening serves as an example of achievement through political will.

Surgery and radiotherapy are essential components of effective cancer treatment; it is not possible to offer comprehensive cancer care without them. The increase in the number of women screened for cervical cancer is driving a huge demand that is not being matched by investment in

the surgical supply side to manage both malignant disease and benign pelvic pathology that is incidentally picked up (27). 80% of Commonwealth cervical cancer patients require radiotherapy as part of their treatment protocol (28). Health systems in LMI Commonwealth countries do not yet have adequate RT facilities to provide these services.

Policy-makers require reliable evidence in order to make informed decisions (29). Without reliable and robust data from population-based registries, Health Ministries cannot know whether their vaccination and screening programmes are succeeding or failing. Similarly, progress in healthcare is based on the evidence from painstaking and rigorous research that provides an insight into the impact of interventions on specific communities where country-level data disaggregation has formerly been poor. Its size, geographical spread, economic diversity and heterogeneous genetic composition gives the Commonwealth unique advantages in research into the causes of cancer and various strategies for its control, in different healthcare settings and as the testing ground for anticancer policies and treatments (30).

The identification of 370 reports published in one year provides a helpful freeze-frame picture of what was being researched in the area of cervical cancer at the time, but it cannot begin to represent the full magnitude of the Commonwealth's contribution to research in this area. A more substantial body of reports of scientific research studies relevant to the populations of low- or middle-income Commonwealth countries lies scattered across the international literature in a multitude of regional databases, online journals and libraries; a large reservoir of scientific wealth generally unread and unreferenced because it is expensive to find in terms of time and cost. Ignorance is not strength. Creating and sharing a knowledge base of the research conducted across the Commonwealth into the prevention and treatment cervical cancer is a prerequisite for evidence-based cancer control. Healthcare interventions and policy strategies that prove to be effective across the diversity of the Commonwealth member countries offer gains for the global economy.

Conclusions

In his Call to Action to Eliminate Cervical Cancer on 19 May 2018, WHO Director-General Dr Tedros Adhanom Ghebreyesus emphasized that most women who die of cervical cancer live in the low- or middle-income countries that are the least prepared for managing the increasing burdens of cancer and other non-communicable diseases. Collective action by the Commonwealth countries to address the deficits outlined in this article will represent a good investment by governments, given the impact of cervical cancer on premature death and disability, with its long-lasting

“Cervical cancer strikes women in the prime of life. These women are raising children, caring for their families and contributing to the social and economic fabric of their communities. Nine in 10 women who die from cervical cancer are in poor countries. This means some of the most vulnerable women in our world are dying unnecessarily. That cannot be fair or just. But it doesn’t have to be this way. Cervical cancer is one of the most preventable and treatable forms of cancer, as long as it is detected early and managed effectively.”

Call to Action to Eliminate Cervical Cancer
 Dr Tedros Adhanom Ghebreyesus, WHO Director-General
 19 May 2018

social, financial and economic consequences for the affected women, their immediate families and their wider community. The establishment of a Commonwealth Cancer Fund would be a useful innovation.

Addressing the issue of cervical cancer can illuminate the way to move forward and to protect health systems from the high expense and ravages of malignant diseases. This is a unique leadership opportunity for the Commonwealth to act as a global and regional catalyst for pulling together major stakeholders involved in the fight against, not just cervical cancers, but all cancers. If taken, it will have an impact extending far beyond the boundaries of its member countries. ■

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Therese Lethu is a global health specialist with more than 25 years of experience working with organizations such as WHO, the Global Business Coalition (GHHealth) and the French Ministry of Foreign Affairs, with a focus on Africa. Thérèse’s expertise is very much related to helping fight non-communicable diseases, especially cervical cancer, as one of the most preventable forms of cancer. She founded a Swiss-based NGO, Global Health Objectives, to advocate for accelerating the elimination of cervical cancer according to the global strategy of WHO.

Dr Ophira Ginsburg is a medical oncologist and global women’s health researcher with technical and policy expertise in non-communicable diseases prevention and management. She is the Director of the High-Risk Cancer Genetics Program and Associate Professor in the Section for Global Health, Department of Population Health at New York University School of Medicine. Formerly based at the University of Toronto, from 2015 to 2016 she was a Medical Officer at WHO, and continues to serve as a consultant to several UN agencies, providing technical assistance to Member States on national cancer control planning and policies. She is leading a new study funded by the US National Institutes of Health (“Cancer Moonshot” programme), to improve access to cancer genetics services through primary care clinics in the New York area.

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My Child Matters: An initiative of the Sanofi Espoir Foundation



Sara Calmanti, Valentine Leuenberger, Laure Poirat, Laurence Bollack, Valérie Faillat
and Anne Gagnepain-Lacheteau, Sanofi Espoir Foundation

The Sanofi Espoir Foundation was created in October 2010 to consolidate more than 20 years of commitment to national and international solidarity.

To fulfill its mission of reducing inequalities in health, the Sanofi Espoir Foundation focuses its activities on the child (childhood cancer in low- and middle-income countries) as well as on the mother-child unit (maternal and neonatal health because inequalities start even before birth) and on the family-child unit (especially in situations of very great vulnerability: conflicts, population displacements, precariousness).

The Foundation naturally responds to humanitarian emergencies, but focuses primarily on long-term partnerships to act on such recurrent issues as education and prevention, training and access to care.

Its action is based on the vision that a three-pronged demographic, climatic and epidemiological transition is changing the framework of humanitarian aid (emergency interventions), social action (reintegrating lost individuals into their society and, above all caring for them) and human development (the structured approach to education, health and social protection). It is also driving the Foundation to initiate changes of its own: strengthening its approach by using new technologies such as development tools (e.g. e-Health) and cultivating a global, transnational and horizontal approach to combat global phenomena that are highly interdependent and interconnected.

The Sanofi Espoir Foundation provides:

- ➔ Financial support, for health projects developed by humanitarian associations or NGOs that are Foundation partners.
- ➔ Donation of health products, framed by a charter based on

the guiding principles of the World Health Organization, as part of the response to health crises.

- ➔ Contribution of expertise – provision of internal Sanofi Group experts or external synergies to aid projects and partners supported by the Foundation.
- ➔ Human resource input – involvement of Group employees in actions supporting the Foundation's partners.

The origin and purpose of the My Child Matters programme

The Sanofi Espoir Foundation, which is involved in the development of specific health programmes in emerging countries, conceived in 2005 a unique international initiative, the My Child Matters programme, which is entirely devoted to helping children with cancer in low- and middle-income countries in Africa, Asia, Latin America, Oceania and Europe to benefit from early diagnosis and access to care according to the international standards.

Why paediatric oncology?

The incidence of paediatric cancers is estimated at 300,000 new cases each year. Focusing on paediatric oncology in low- and middle-income countries could appear as a paradox in countries where basic health services such as primary care are still unaffordable for the majority of the citizens. Nevertheless, structuring services devoted to children affected with cancer means conceiving a comprehensive holistic system able to reply to complex healthcare needs which are the result of clinical (diagnosis, treatment, pain control, end of life) to psychosocial

(schooling, family socio-professional environment, etc.) characteristics/parameters. Structuring a paediatric oncology offer is therefore a pedagogic exercise leading to a healthcare model that can be adapted and modulated in other fields because the services are structured on the basis of patient needs on not on their organizing principles.

What can My Child Matters do?

My Child Matters aims to accompany and support teams willing to build up a paediatric oncology strategy and implementation programmes in low- and middle-income countries all over the world. Through a call for proposals process, the support provided translates into expertise on the projects submitted, ad hoc training in leadership and project management for the candidates, sharing knowledge on global initiatives, favouring communication actions such as participation in congresses and scientific publications.

In each country that benefited from its support, My Child Matters is considered as the first milestone of a structuring approach in the paediatric oncology environment.

Who is My Child Matters?

A dedicated team (Medical Director and Programme Manager) pilot this action. Several partners are also involved, in particular SIOP (International Society of Pediatric Oncology), the City Cancer Challenge, the St. Jude Children's Research Hospital AMCC (International Alliance Against Cancer), GFAOP (Franco-African Pediatric Oncology Group), and other international organizations involved in fighting childhood cancers.

An Expert Committee has an advisory board role. It comprises international experts in the field of paediatric oncology. During the call for the proposal evaluation process it is convened to propose strategic recommendations, to assess the progress of each on-going project and validate the funding release for the next year.

A mentor is assigned to each project awarded: he/she accompanies each leader in order to achieve the successful implementation of their objectives.

Where is My Child Matters in 2019?

To date 58 projects in 42 countries have been supported. In several countries the impacts of this initiative has been proved and are the subject of publications in prestigious journals such as *Lancet Oncology* (1). Of the 26,861 children per year who develop cancer in the ten index countries with My Child Matters projects, that were evaluated in 2006, an estimated additional

Figure 1: The My Child Matters network and its successes



Figure 2: My Child Matters project leaders and mentors from all over the world. Paris, March 2019



1,343 children can now expect an increase in survival outcomes. In Paraguay, the projects supported by My Child Matters have reduced the drop-out rate to zero (2).

But being successful does not mean that we should stop thinking about how to improve the support provided by this programme for the benefit of children affected with cancer. For example, following the last call for proposals, 24 projects have been selected for being potentially accompanied. Among them, several came from teams which have been already supported thus suggesting the possibility of developing a sustainability strategy by the Foundation for the local teams. Furthermore, thanks also to this programme, the standards of care in the selected countries have tended to improve. This is witnessed by the increased quality in terms of the scientific profile of the submitted projects. Nevertheless, this process gives rise to a more competitive call probably generating a gap between low- and middle-income countries. Should we therefore conceive an *ad hoc* strategy addressed to low-income countries?

Another issue is also to capitalize the experience achieved by favouring the exchanges within the My Child Matters community and the emergence of an international network to share knowledge, skills as well as tools. ■

1. <https://www.ncbi.nlm.nih.gov/pubmed/29726390>

2. <https://www.ncbi.nlm.nih.gov/pubmed/25929610>

My Child Matters Nursing Awards 2015-2018

Sanofi Espoir Foundation with acknowledgements to Julia Challinor and Christina Baggott,
International Society of Paediatric Oncology (SIOP) Nursing Group

Building on the successful “My Child Matters” funding program for children and adolescents with cancer in low- and middle-income countries (LMIC) initiative launched in 2006, the Sanofi Espoir Foundation announced at the 2015 International Society of Paediatric Oncology (SIOP) summit in Toronto a new initiative for “My Child Matters” funding for nurses in these settings in collaboration with SIOP. Applicants were requested to develop and highlight innovative approaches to nursing service and practice, to improve the care and quality-of-life of children with cancer by focusing on education, professional practice or research. Applications were accepted in French, Spanish and English and reviewers with expertise in these settings and fluent in these three languages were identified from the SIOP nursing network.

As one of the few supporters of paediatric oncology nursing care in LMICs, the Sanofi Espoir Foundation, in partnership with SIOP, has shown leadership in the improvement of nursing care for the 80% of children and adolescents with cancer who live in resource-poor areas around the world. The nurses who received the funding have highlighted the wide range of nursing practice areas for improvement and demonstrated that positive change is possible in the quality of life of the patients and families they attend.

➔ **2015 – 10 Award winners.** They were announced at the SIOP Annual Conference in Cape Town and a second round of awards launched.

In the first call for applications 38 were received from 25 LMICs. Led by the SIOP Nursing Committee Chair, the applications were reviewed by a paediatric oncologist and expert paediatric oncology nurses who lived in LMICs or had experience working in those settings. The top scoring projects were selected for funding and included nurses from the United Arab Emirates (UAE), Cameroon, Pakistan, India, Ghana, the Democratic Republic of the Congo, China, Mexico, GFAOP (consortium of 18 Francophone African countries) and Burkina Faso.

➔ **2016 – 10 Award winners.** Presentation of two completed My Child Matters Nursing Awards on the projects’ success and impact were given during SIOP Annual Conference in Dublin and the third round of Awards were to be given for a two-year period instead of only one-year.

Figure 3: Map of countries that have received nursing funding through “My Child Matters Nurses Awards” since 2015.



A total of 27 eligible applications were received from 19 countries, all were reviewed and top scoring abstracts from Mexico, Colombia, India, Ghana, Iraq, GFAOP, Central African Republic, Pakistan and Indonesia were awarded funding as follows.

➔ **2017 Presentation of two completed My Child Matters Nursing Awards** on projects’ success and impact during SIOP Annual Conference in Washington, DC and launch of the third round of Awards.

➔ **2018 – 5 Award winners for two-year projects.** Announcement at the SIOP Annual Conference in Kyoto and presentations by two 2016 awardees on the projects’ success and impact.

63 applications were received from 33 countries, so a decision was made to exclude upper-middle-income countries from eligibility. The review committee selected the following highest scoring projects to receive the Sanofi Espoir Foundation awards from Zimbabwe, Vietnam, El Salvador, Tanzania and Cambodia.

➔ **2019** The Sanofi Espoir Foundation will launch the fourth round of Nurses Awards at SIOP Annual Conference in Lyon, France in October this year. If you are interested in submitting your project, make use the contact details below

Sanofi Espoir Foundation – 262 boulevard Saint Germain –
75007 Paris, France FoundationSanofiEspoir@sanofi.com

Establishing a tertiary care cancer hospital in a developing country: The story of the Shaukat Khanum Memorial Cancer Hospital and Research Center

Professor Nausherwan K Burki, Professor of Medicine, University of Connecticut Health Center, USA; Chief Medical Advisor and Member, Board of Governors, Shaukat Khanum Memorial Cancer Hospital and Research Center, Pakistan

A first-hand account of establishing a tertiary care cancer hospital in Pakistan, a low- and middle-income country, and the decision-making and challenges behind this. The article looks at how the concept was arrived at, funding concerns, how the hospital was to be administered, the medical staffing of the hospital at all levels and the how the medical services were organized to provide the diagnostic and therapeutic functions, as well as patient care and information. Finally, the article touches on research and the future for the hospital.

Modern cancer care requires a highly trained workforce, sophisticated equipment and facilities, expensive drugs and public awareness. It is not surprising, therefore, that poorer countries lag far behind advanced, developed countries in providing adequate care – diagnostic, therapeutic or palliative – for cancer patients.

Until the early 1990s, Pakistan had no organized focus on cancer patients, even though the country has highly trained physicians and surgeons. Diagnostic equipment was lacking, very few standard chemotherapy drugs were in use and cancer treatment was provided in the general wards of general hospitals by non-specialist physicians and surgeons. It was in this vacuum that a tragedy brought Imran Khan to the cancer scene. In 1990, Imran was an international cricketing celebrity, having captained the Oxford University cricket team and the Pakistan cricket teams; in the same year, his mother died of cancer and he was horrified by the lack of adequate cancer care and palliation that she received. Realizing that if the level of care for someone who could fully afford it was so poor, the care given to the vast majority of Pakistanis who could not afford it must be even worse, Imran determined to build a tertiary care cancer hospital, named for his mother, the Shaukat Khanum Memorial Cancer Hospital and Research Centre, in Lahore, Pakistan, as a model for Pakistan. Because of his cricketing celebrity status, donations began to pour in, but he was not sure where to start.

In 1990, he approached me for assistance in developing the project, while I was a Professor of Medicine at the University of Kentucky in the United States. We agreed on four things –

it would be a non-profit charitable institution, it would strive to provide the best, most advanced diagnostics and treatment for cancer, with free or subsidized treatment to all cancer patients who could not afford it, and there would be no direct government involvement.

To develop a master plan for a tertiary care, state-of-the-art, cancer institution in a developing country was a daunting task. No reliable statistics on cancer incidence in Pakistan were available in 1990, concepts of modern hospital management did not exist in the country, nursing training had not kept up with modern trends and there was a dire shortage of trained ancillary health staff. Thus I was presented with a *tabula rasa* to develop what would be a unique experiment in the country.

I was fortunate when I advertised for a hospital design architectural firm in finding Messrs Arrasmith, Judd, and Rapp of Louisville; their principal, Graham Rapp, was well-versed in hospital design and in working overseas, having designed and built a hospital in Turkey. Most importantly, since our funds were very limited, Mr Rapp stated that fees were not a major concern. I am very pleased to say that the firm has been working with us ever since, and is currently designing our new hospitals in other cities. With this architectural firm, and in discussions with a wide array of friends and experts, we developed a master plan. Not knowing the cancer incidence in the country, one had to pick figures and projections out of the air: recognizing that modern cancer treatment is primarily outpatient based, I projected that in the first year we would have 25,000 outpatient visits and planned accordingly. The master plan was in three phases

– starting with 60 inpatient beds with all ancillary services and increasing the inpatient beds to 250 by the end of 10 years. In the event, the timeline was too optimistic, and the phases have stretched out over 20 years, rather than the proposed 10 years. The hospital has been built according to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards and United States' hospital building codes. Hospital building codes are foreign to most doctors and were to me as a clinician/research worker; over the last 20 years in my role of developing and overseeing this hospital, I have learnt an enormous amount. The Shaukat Khanum Memorial Cancer Hospital opened its doors to patients in December 1994, even while some of the construction work had not been completed.

A major problem in developing such an institution in Pakistan, or any developing nation for that matter, is the absence of supporting facilities – we could not simply rely on available diagnostic and specialty services in the community or region; there were no trained oncologists, adult or paediatric, intensivists, cytopathologists, etc. In 1990, there was no MRI machine in the region; medical radioisotopes and blood products were generally not available. We were therefore constrained to develop virtually all the necessary diagnostic and treatment infrastructure within the institution.

Financial concerns

The hospital concept was based entirely on donations, since it had been decided that no government involvement would be allowed to avoid bureaucratic or political interference. It was a great surprise, and very heartening, that the Pakistani public, both within and outside Pakistan, has responded enthusiastically, in no small part because of the credibility of Imran Khan and his celebrity status. Imran worked tirelessly soliciting funds around the country and abroad, and people responded enthusiastically. These donations have continued and indeed increased over the years, with publicity campaigns and fundraisers: currently 56% of the hospital budget comes from donations.

Administration

Given the absence in Pakistan of trained staff familiar with modern hospital administration, we decided from the outset that in the initial stages a hospital administrator trained and working in the United States' would be required. Hospital administrators working in the United Kingdom's NHS in 1990 were not considered ideal, since most had no experience of running a freestanding, non-profit, nongovernment hospital. Accordingly, the first two hospital administrators were from the United States'. These Hospital Directors recruited local staff for the different administrative functions, some of which had never existed or were rudimentary in the regional hospitals – materials management, management information systems, facilities

Figure 1: The Hospital opened on 29 December 1994



management, central sterile supply and laundry department, etc. Many of the local staff underwent on the job training and today are highly accomplished in their various administrative fields.

In the first year that the hospital opened, I took a sabbatical from my university and ran the hospital as CEO for 14 months. This allowed me to put in place certain procedures, which are now set in stone. Today, 25 years later, the hospital runs smoothly and efficiently due in large part to these workers.

Nursing

At the outset, we noted that nursing training and nursing procedures appeared to be petrified in the 1950s and if the hospital was to function at international levels, it was essential to improve nursing services and bring them up to modern standards. Accordingly, I determined to initially have a Nursing Director from Europe or the United States', who would develop a cadre of nurses to train the local nurses. The Nursing Director, Barbara Messer, from California, recruited a small group of nurses from the United Kingdom, Ireland and South Africa who formed a core for training and supervising locally recruited nurses. A number of highly-trained nurses were recruited from the Phillipines by Ms Messer for nurse manager positions in crucial areas of the hospital – the operating suites, the intensive care unit, the chemotherapy unit, etc. This core group developed a re-training programme, consisting of class work, didactic lectures and hands-on bedside training for the recruited nurses. A diploma programme for oncology nursing – the first in the Middle East/South Asia region – was instituted. The result of this planning and training is that the hospital now has highly-trained Pakistani nurse administrators and nursing services comparable to any hospital in the world; in addition, the hospital has the only group of trained oncology nurses in the region.

Medical services

It was decided at the outset to recruit physicians who were currently trained in Europe or the United States' to bring the latest techniques and concepts to cancer care at the hospital. While we advertised for all physicians of any nationality, Pakistan is fortunate in having a large diaspora of highly-trained

physicians. It is also a curious fact that virtually all members of this diaspora yearn to return to their homeland, especially when their children come of school age. Thus, I was able to recruit a number of physicians who had just completed their fellowship specialty training in various fields in the United States, Britain and Ireland. Their fresh knowledge was a boon, but their lack of administrative experience needed to be nurtured. It is very heartening that now, 25 years later, they form a mature, experienced group, responsible for excellent results at the hospital. In this regard, Dr Faisal Sultan and Dr Aasim Yusuf are to be singled out for exemplary service. Dr Faisal Sultan, an infectious disease specialist, has been the CEO for more than 15 years and Dr Aasim Yousuf, a gastroenterologist, has been the Medical Director and now Chief Medical Officer for the same time. They have guided the hospital to Joint Commission accreditation (in 2018) and they continue to oversee excellence at the Hospitals of the Shaukat Khanum Trust.

Initially, I had hoped that certain specialty services – neurosurgery, nephrology, orthopaedic surgery, urology, etc., could be provided by part-time visiting surgeons and physicians from the community. However, this turned out to be impractical and now the hospital has a full complement of full-time medical and surgical specialties.

Diagnostic services

Laboratory and imaging services had to be developed from scratch and were fortunate in being able to recruit accomplished pathologists and radiologists. In 1994, cytology services did not exist in Pakistan; on hospital opening day, an Australian tourist happened to be present. It turned out that she was a cytology technician and she agreed to stay on and train our technicians. She stayed with us for one year and established the cytology services. Molecular biology and genetic services became available with the development of our research services (see below).

The hospital installed the first MRI machine in the region in 1994. Subsequently, we installed the first (and still the only) PET scanning unit in the region. Unlike in advanced, developed countries, we were forced to install our own cyclotron for manufacture of radioisotopes because of non-availability and the short half-life of radioisotopes.

Today, the hospital has a full complement of diagnostic laboratory and imaging services, which include CAT scanning, ultrasound facilities, PET/CT scanning and nuclear medicine. The pathology laboratory subscribes to the College of American Pathologists (CAP) quality control programme to ensure accurate results.

Therapeutic services

As cancer treatment takes three forms – chemo- or immunotherapy, surgery, and radiation therapy – all three

modalities needed to be available.

The hospital provides adult and paediatric oncology services, with a full backup of associated specialties – intensive care, pulmonary medicine, gastroenterology, infectious diseases, etc.

Chemotherapy:

The Hospital plan includes a 30-bed chemotherapy bay (20 adult and 10 paediatric beds), plus a further 10 beds on an inpatient floor, providing 130 chemotherapy and transfusions daily. Further expansion of this area is in progress. When the hospital opened, the majority of standard chemotherapeutic drugs were not available in Pakistan. Over time, after negotiations with multinational pharmaceutical manufacturers, these drugs have become available and now the latest, most effective drugs are provided to the patients.

Radiation medicine:

At the time of planning the hospital, all radiation facilities in Pakistan were under the control of the Federal Atomic Energy Commission (AEC), and the only radiation therapy units that existed were in freestanding government-run facilities, many with outdated equipment. The Shaukat Khanum Memorial Cancer Hospital & Research Center, Lahore, became the first hospital to install radiation equipment, approved by the AEC. Currently, with five linear accelerators, radiation treatment is provided to 207 patients daily (Table 2).

Palliative care:

The concept of palliative care did not previously exist in Pakistan. A palliative care unit was established at the hospital for cancer patients and provides appropriate care to these patients.

Hospital pharmacy and blood bank:

The concept of an integrated hospital pharmacy was a foreign concept in Pakistan. The Shaukat Khanum Memorial Cancer Hospital & Research Center was the first institution to establish a proper hospital pharmacy, with pharmaceutical advice on drug interactions, dosages and toxicity available to the doctors.

Similarly, at the time of establishing the hospital, blood product usage in the country was very basic, with most patients receiving whole blood when necessary. The hospital established its own blood bank and brought in the concept of blood products and donor testing for hepatitis and HIV, etc. This has now been emulated in many institutions in Pakistan.

Hospital information services

Over the years, the hospital has developed its own comprehensive software, with a Hospital Information System department of 15 software engineers. The hospital is now essentially paperless. This system has been provided free of cost

to government hospitals, particularly in the Northern province of Khyber Pakhtunkhwa.

Patient care

At the outset, given that this was to be a non-profit hospital dependent on donations from the public, two concepts were enforced:

The most important of these is the concept of patient registration based on first come, first served. In developing countries like Pakistan, rules are elastic and the wealthy and influential usually manage to override them to their own benefit. However, we made this a rigid rule, and because it was apparent that I would not budge from this rule, there were very few attempts to circumvent this, including by some from the highest in the land, and today the registration system functions smoothly on this basis.

A second absolute rule is that once a patient is registered into the system there is no distinction in services provided to non-paying versus full-paying patients. The outpatient facilities, the inpatient rooms and facilities, the chemotherapy and diagnostic services are all equal for all patients. In fact, inpatients in the 2-bed rooms (all the inpatient rooms are 2-bed rooms) are frequently completely unaware of the paying status of their companion patient.

In this regard, there were some difficult moral decisions to be made. Since the hospital was predicated on providing cancer treatment regardless of the ability of the patient to pay, it became clear in the first year that we would run out of funds.

The oncologists were therefore requested to decide at what stage of a given cancer, treatment becomes palliative rather than curative, at which point only palliative care would be provided. This was a difficult decision for the oncologists, since by training it is their wont to continue maximum treatment to the end. However, they agreed and this policy was instituted.

This brought another dilemma: the fully paying patients demanded to continue treatment with certain expensive drugs, which they could afford, despite explanations of the advanced stage of their cancer and the long-term futility of the use of these drugs. Was it morally justified to withhold treatment with drugs (that were only available in the hospital pharmacy having been directly imported) that the patient could afford and that might have some temporary benefit or provide peace of mind? This dilemma brought a major shift in hospital function which, in the long run, has been very helpful: patients who are willing to pay the full cost of treatment are registered separately; however, the criteria for admission into the system remains the same for them as for the indigent patients. Once they are admitted into the system for treatment, no distinction is made between them and the indigent patients in terms of diagnosis, treatment or facilities.

A second dilemma surfaced early: as the reputation of the hospital and the quality of its laboratory and diagnostic services spread, many non-cancer patients wanted to use these services. At first, it was felt that since all the donations had been made for cancer treatment, non-cancer patients could not be entertained. However, two considerations came to the fore: it was not considered morally acceptable to withhold diagnostic services from patients willing to pay the full charge, especially since we had excess capacity and in some cases, for example MRI services, the only diagnostic capability in the region. The income from these services would help to provide better care for the cancer patients. Therefore, the diagnostic laboratory and imaging services were opened to non-cancer patients with the proviso that this would in no case jeopardise the availability or timeliness of these services for the cancer patients. The same considerations were then applied to the available medical expertise and the medical staff were permitted to see non-cancer patients on the same basis.

These decisions have led to the opening of more than 200 diagnostic collection centers around the country, where patients can have blood or urine samples taken and sent to the main laboratory, and in the majority of cases have the results available to them on the web the same day. This is now not only a significant medical resource to the country, but a significant source of funds for the hospital.

We had projected that in the first year there would be 25,000 outpatient visits; in the event there were 23,500.

The most common cancers seen at the hospital are shown in Table 1. Since breast cancer is the most common cancer seen at the hospital, there are three specialized breast surgeons who also provide breast reconstructive services. Neurosurgery, gynaecology, ophthalmology, orthopaedics, head and neck surgery, thoracic and general oncologic surgery services are provided.

The number of outpatient visits and treatments given over the years are shown in Table 2.

Research

A fundamental concept of the hospital, enshrined in its name, is cancer research. As a fledgling institution this was difficult to start, but a major boost was given by the German Cancer Research Center (*Deutsches Krebsforschungszentrum* – DKFZ) in 1996. Under the leadership of Nobel prize-winner, Professor Zur Hausen, the DKFZ undertook to train our scientists and help in establishing our molecular and basic research laboratories. They have continued to collaborate with us, especially Professor Ute Haman, with the publication of a number of research papers.

Current status

The commonest cancers seen at the hospital are listed in order

Table 1: Cancer incidence in Pakistan

ESTIMATED 2018 NEW CANCER INCIDENCE IN PAKISTAN (GLOBOCAN)

New cancers ADULTS (Age >15 years):
168,615 (162 per 100,000 POPULATION)

New Cancers CHILDREN (age < 15 years):
5,322 (7.6 per 100,000 POPULATION)

SHAUKAT KHANUM HOSPITAL BASED CANCER STATISTICS 2017

New cancers in ADULTS (>18 years): 5433 (90.6%)
New cancers in CHILDREN (< 18 years): 563 (9.4%)

TOP FIVE CANCERS BY CANCER SITE

Adult male	Adult female
Prostate 312 (12.3%)	Breast 1,242 (42.1%)
Colorectum 248 (9.8%)	Cervix Uter 197 (6.7%)
Lip and Oral Cavity 167 (6.6%)	Uterus 53 (5.2%)
Testis 165 (6.5%)	Esophagus 138 (4.7%)
Stomach 140 (5.5%)	Colorectum 130 (4.4%)

Children

Hodgkin Lymphoma	124 (22.0%)
Acute Lymphoblastic Leukemia	93 (16.5%)
Non-Hodgkin Lymphoma	61 (10.8%)
Retinoblastoma	48 (8.5%)
Nephroblastoma	46 (8.2%)

of frequency in Table 1, as well as the estimates for the country as a whole.

In 2017–2018, 72% of patients at the hospital were treated entirely free of charge. Another 13% received partially free treatment. Only 15% of patients bore the full cost of treatment.

On a daily basis, approximately 700 outpatients are seen at the Lahore hospital. Chemotherapy is given to an average of 130 patients daily (Table 2).

The future

The advent of the Shaukat Khanum Memorial Cancer Hospital & Research Center, Lahore, has had a major impact in Pakistan, not only on clinical cancer services, but on hospital management, nursing services, pharmacy services and general health management. Regional health facilities have sent observers to the hospital and applied our hospital systems to their institutions. Nurses from these hospitals and pharmacists from other hospitals rotate through the SKMCH and return to their institutions to apply what they have learnt.

The hospital received recognition from the Joint Commission on 20 April 2018. It has been a long journey and it is continuing.

Because of the significant number of patients travelling from the north of the country and Afghanistan, in 2015, a new hospital with 250 beds was built and opened in the city of Peshawar, applying the same principles. This hospital currently provides diagnostic and chemotherapy services and will soon become a fully-fledged cancer hospital with surgical and radiation services.

A new hospital building has started in Karachi, the largest city in Pakistan, and is planned to open in 2021.

The Shaukat Khanum Memorial Cancer Hospital & Research

Center, Lahore, is now able to offer training in nursing, hospital administration and hospital pharmacy services to people from other countries. In addition, clinical attachments are available in various disciplines to medical students and doctors, with on-site accommodation (website: shaukatkhanum.org.pk).

It is our belief that with dedication and focus, and with public support, it is possible to build similar institutions in all developing countries and improve cancer care worldwide. ■

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Table 2: Shaukat Khanum Memorial Cancer Hospital and Research Centre

Year	New registrations	Ambulatory visits	Inpatient admissions	Chemotherapy visits	Radiation therapy
Dec.1994 – Dec. 1999	25,862	125,009	9,092	57,400	79,373
2000	3,014	40,325	2,599	9,600	17,033
2001	3,656	49,511	3,102	9,322	22,170
2002	3,093	49,270	3,309	11,690	25,059
2003	3,486	54,190	3,668	12,839	26,149
2004	4,219	69,023	4,177	15,377	32,318
2005	6,570	76,736	4,910	15,868	36,326
2006	7,696	87,534	5,134	18,206	39,545
2007	9,125	112,714	6,023	23,719	41,463
2008	9,529	119,037	6,079	23,709	43,143
2009	7,981	124,372	6,545	26,448	43,307
2010	9,120	130,165	6,783	27,588	42,888
2011	9,480	141,806	7,618	31,367	44,540
2012	9,542	156,766	8,613	31,198	51,865
2013	9,211	172,236	9,949	33,783	53,451
2014	9,536	185,018	10,654	39,044	56,444
2015	10,253	205,313	11,352	42,559	65,132
2016	10,203	236,351	12,576	52,843	65,759
2017	9,004	243,663	12,054	47,983	64,885
2018	9,878	247,508	13,213	47,669	64,737
Total	170,458	2,626,547	147,450	578,212	915,587

Cancer Screening in Five Continents (CanScreen5) – a project designed to improve the quality of cancer screening programmes

Eric Lucas (top left), **Dr Andre L Carvalho** (top right) and **Dr Partha Basu** (bottom), Screening Group, International Agency for Research on Cancer, Lyon, France



The Cancer Screening in Five Continents project (CanScreen5) of the International Agency for Research on Cancer (IARC) is designed to uniformly collect, analyse, store and disseminate information on the characteristics and performance of cancer screening programmes in different countries, with the core objective of motivating and supporting the countries to collect and use cancer screening data in a consistent manner on a regular basis using an effective information system. A web-based open access platform will be created to reflect data from the screening programmes across the globe and allow the screening programmes to compare their performance over time and with other similar programmes. The new initiative will impress upon the programme managers the value of monitoring and quality improvement of cancer screening programmes and also support capacity-building in this area.

Cancer screening programmes are complex and resource-intensive but can have huge benefits when implemented in the right manner. Systematic screening of the population at risk for some of the common cancers can significantly reduce the mortality from the disease. However, this requires appropriate planning, adequate financial, human and technical resources and high level of organization of the health services (1). Lack of governmental commitment to provide the requisite sustainable resources can be a serious barrier to successful implementation of cancer screening programmes (2). Countries that do not have adequate resources, infrastructure and health system coordination to implement cancer screening should prioritize early diagnosis of symptomatic individuals linked with prompt and good-quality treatment (3). Currently, population-based screening is recommended only for cancers of breast, cervix, colorectum and oral cavity (4). Following the success of cancer screening in high-resourced countries, many of the countries with limited resources have included population-based cancer screening in their national cancer control plans. Romero et al. reported that already 133 countries included cervical cancer screening and 120 included breast cancer screening in their national plans (5). However, few of them included adequate budget allocation, a comprehensive implementation plan and a strategy for quality assurance.

Many of the countries in Europe have heavily invested in implementing cancer screening programmes over the last few decades. In 2003, the Health Ministers of the European Union (EU) adopted a set of recommendations on cancer screening delineating the key principles of planning, implementing and evaluating quality-assured programmes, and invited all member states to implement breast, cervical and colorectal cancer screening using a population-based approach. The European Guidelines were published to provide evidence-based recommendations to the Member States and also to highlight the necessity of regular monitoring and evaluation (6,7,8). The International Agency for Research on Cancer (IARC) in Lyon, published the reports on the status of implementation of cancer screening programmes in the EU in 2008 (first report) and 2017 (second report) (9,10). These reports described the protocols, level of organization, status of implementation and performance of the screening programmes in the EU region. Similar reports are regularly published by the screening programmes in Australia, Canada and some of the countries in Europe outside the EU. However, the vast majority of countries in low- and medium-resourced settings do not have sufficiently organized screening programmes to report the status of implementation and performance on a regular basis (11). In 2016, the World Health Organisation (WHO) launched the non-communicable diseases (NCD) document repository,

which provides access to over 2,900 documents containing NCD targets, policies and guidelines submitted by Member States to WHO, including cancer control guidelines for some countries (12). However, there is a lack of a global database that uniformly gathers and stores information on cancer screening programmes in a standardized manner that could reflect data from the real world and would allow comparisons between countries. The cancer screening in five continents (CanScreen5) project of IARC proposes to build such a global repository reference of accurate information on the cancer screening programmes and their performance worldwide.

Aims and objectives of CanScreen5

CanScreen5 is a global project designed to collect, analyse and disseminate information on cancer screening programmes and activities in different countries with the core objective of motivating and supporting countries to collect and utilize cancer screening data in a consistent manner on a regular basis, utilizing an effective information system. Capacity-building of service providers and programme managers in collecting good quality data for better programme evaluation and quality improvement is a major focus of CanScreen5. The specific objectives are:

- ➔ Periodically report the status of implementation of cancer screening programmes at national and sub-national levels in different countries in five continents;
- ➔ Evaluate the population-based cancer screening programmes in different countries using standardized process and outcome indicators;
- ➔ Share the information with policy-makers, programme administrators, researchers and other stakeholders with an objective to improve the quality of cancer screening programmes;
- ➔ Report the use of novel screening tests, screening algorithms and population-based approaches followed by different cancer screening programmes;
- ➔ Impart training on monitoring, evaluation and quality assurance to the programme coordinators, data managers and other personnel involved in monitoring and evaluation; and
- ➔ Support collaborative research aiming towards the evaluation of efficient and effective approaches to population-based cancer screening.

Methodology

The CanScreen5 project is founded on the IARC experience

Figure 1: Capture of the CanScreen5 platform



in preparing the two status reports on the implementation cancer screening in the EU (9,10). The tools and strategies for data collection developed to prepare the reports have been further refined to make them suitable for different resource settings, especially for LMICs. A web-based open access portal is developed with technical support from CPO Piemonte, Italy. All data published in the second EU report on implementation of breast, cervical and colorectal cancer screening from the 28 European Member States are migrated and available on the platform. The synthesized data is presented for a given cancer type (cancer fact sheets), for a selected country (country fact sheets) or through the analysis tools (tables, graphics or map format) (Figure 1). We plan to officially launch the CanScreen5 platform by middle of 2019, initially only the data from the 28 European Member States will be available. After the launch of the platform, we will invite the representatives from the Ministry of Health, programme coordinators and researchers involved in managing and/or supervising cancer screening programmes in different countries to collect and share qualitative and quantitative information on their respective programmes. The data-providers should obtain a mandate from the Ministry or national authorities to share the data. The selected data providers will be trained on the functionality of the CanScreen5 platform, the data collection methods, the standard definition of the performance indicators and their significance in programme quality assurance before they are given password-protected access to the platform to upload their data. Expected information to be collected comprise those on national policies, protocol for screening

Table 1: The performance indicators for the breast cancer screening programmes in European Union (EU) and Morocco. The screening programmes in the EU are mammography based and the mean values have been estimated for 50–69 year old women. The programme in Morocco uses clinical breast examination (CBE) to screen the women between 45 and 69 years of age. The data are not directly comparable because the programme in Morocco does not collect age-stratified data. Many of the indicators could not be estimated for Morocco as they do not have a system of invitation and some of the data are not collected by the programme

Performance indicators recommended by the European guidelines for quality assurance	EU mean estimates (10)	Morocco estimates(18)	Comments
Invitation coverage of annual target population	78.9%	Not applicable	Breast cancer screening programme in Morocco does not invite the eligible women systematically
Examination coverage of annual target population	49.2%	86.6%	
Participation rate to screening (out of the total women invited)	60.2%	Not applicable	Breast cancer screening programme in Morocco does not invite the eligible women systematically
Further assessment rate	4.4%	3.2%	
Further assessment participation rate	97.3%	34.7%	The CBE positive women in Morocco are examined by a clinician and are referred to mammography only if the clinician detects any abnormalities. The programme only collects the number of women undergoing mammography following repeat CBE by clinician. So the rate is underestimated in Morocco
Treatment referral rate	6.0/1,000	Not available	The information is not collected by the Moroccan programme
Detection rate of invasive cancer	4.6/1,000	1.0/1,000	The programme in Morocco does not separately collect data for invasive cancer and carcinoma in situ (CIS) detected
Detection rate of CIS	0.9/1,000	Not available	The programme in Morocco does not separately collect data for invasive cancer and carcinoma in situ (CIS) detected
% of CIS of all cancers	16.9%	Not available	
Positive predictive value of further assessment to detect CIS and invasive cancer	11.4%	8.7%	The value has been over-estimated in Morocco as the denominator includes only the women undergoing mammography but not the number of women undergoing further assessment by clinician
Benign surgical biopsy rate	0.7/1,000	Not available	The Moroccan programme does not collect the number of women undergoing surgical biopsy and the outcome of the biopsy
Benign / malignant ratio	0.13	0.66	

and diagnosis, programme management, financing, inviting the target population, screening practices, quality assurance planning, including screening registries, etc. A cancer site-specific quantitative data collection questionnaire will be used by the data-providers to collect aggregated data related to the number of invitations sent, number of individuals screened, number further assessed and further assessment results. Once such data are uploaded on the CanScreen5 platform, the inbuilt data analysis software will automatically estimate the process indicators (population coverage, participation rate, compliance to further assessment, etc.) and the outcomes indicators (screening test positivity, detection rate of disease, predictive values of tests, etc.).

The data submitted by the data providers will undergo quality checks before the analysed data is displayed and disseminated through the web platform. The project

secretariat at IARC will perform the initial review to check for consistency, completeness, and validity of the aggregated data. The compiled and analysed data will be shared for further validation with the CanScreen5 Scientific Committee for final validation.

The project will be implemented in phases, initially targeting the countries having a reasonable degree of organization of the cancer screening programme and a functioning health information system (HIS). Tailored approaches to data collection will be formulated for the countries not having efficient screening registry or health information system. However, appreciating the challenges that might be encountered in the majority of the countries to collect data of adequate quality and completeness, the Scientific Committee members will decide on the most pragmatic way to collect authentic information from the different countries and the

“minimum dataset” that needs to be collected from reliable sources for performance evaluation. The countries failing to provide the “minimum dataset” will only have the qualitative information collected and analysed. The CanScreen5 project will collect data from population-based programmes, opportunistic programmes or pilot/demonstration projects, and population surveys and categorize them according to the quality and reliability of source.

A partnership will be developed with major international cancer organizations and foundations involved in supporting and evaluating cancer screening programmes and initiatives.

Discussion

Earlier studies have highlighted the low quality or complete lack of data to evaluate the cancer screening programmes in Latin America and other regions, in spite of the large volume of screening activities in many of them (13). The European experience demonstrated the significant contribution of screening registries to improve the data quality and completeness and better organization of the programmes (14). It is now well-recognized that a robust health information system is extremely critical for the success of a cancer screening programme. The screening programme information system (screening registry) should consist of a minimum dataset, comprising individual information, screening test findings, confirmation/clinical assessment outcomes, referral for treatment, final histopathology diagnosis and stage of cancer. A working group chaired by Dr A Anttila in 2011, recommended the procedures, the data items needed and the coding structures for a systematic individual-level registration of cancer screening programmes (15). The working group also provided a set of key performance indicators that could be relevant for the European screening programmes and defined them. The CanScreen5 project adapted the performance indicators and the methodology of estimating them from these European recommendations but simplified and refined them to be globally relevant. We expect that by encouraging the systematic reporting of the characteristics and the outcomes of the screening programmes, monitored and evaluated using performance indicators against a set of standards, the CanScreen5 project will help continuous quality improvement of the programmes, reduce inequity and harm and promote better utilization of the resources.

LMICs have many difficulties in implementing organized population-based cancer screening programmes; these hurdles include sociocultural and educational barriers, access to healthcare, lack of trained health professionals, fragmented healthcare systems and financial cost, among others, but also the lack of systematic collection of performance indicators that could be used as the basis for continuous quality

improvement of the programme (3,16,17). In absence of a computerized information system, some of the LMICs use ingenious methods to collect aggregate performance data to monitor the programmes. However, due to the heterogeneity in the definition of the indicators and the method of estimating them, the data are often difficult to compare (Table 1) (18).

The CanScreen5 project will develop guidelines to improve data collection and evaluate the screening programmes using predefined indicators. The portal will have an e-learning platform to train the data providers and ensure harmonization of data collection across the countries. The dissemination of the qualitative and quantitative data collected from the countries will be through easily interpretable fact sheets (by countries and by cancer sites), interactive tables, maps and charts displayed on the CanScreen5 web platform. The programme managers will be able to identify the gaps and take corrective actions not only from the analysed data from their own programmes, but also from the comparative data submitted by the other countries.

Conclusion

The CanScreen5 platform is a freely accessible web-based platform designed to uniformly gather and store information on cancer screening programmes and initiatives across the globe and will reflect data from the real world. It provides the requisite data collection tools, the standardized methodology for estimating the performance indicators and the facility to compare the indicators with national and international standards. By providing a freely accessible platform to visualize the performance data analysed with a common set of indicators, CanScreen5 allows the cancer screening programmes to compare their performance over time and with other similar programmes. We expect this initiative to impact the capacity-building in monitoring and quality improvement of cancer screening programmes around the world. ■

Disclaimer

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Responding to the call for “Treatment for All”: Examples from Indonesia, Mexico and Uganda

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In response to the growing cancer burden and building on the cancer resolution adopted at the World Health Assembly in 2017, the Union for International Cancer Control (UICC) launched a global campaign calling for “Treatment for All”. National activation of Treatment for All refers to civil society’s guided engagement with this campaign in their country context. This article presents preliminary examples and lessons learned in the initial project phase from civil society in three countries: Indonesia, Mexico and Uganda.

Despite growing attention to the impact of non-communicable diseases (NCDs) on global health, the burden of cancer rose in 2018 to 18.1 million new cases and 9.6 million cancer deaths (1) each year, from 15.2 million and 8.8 million respectively in 2015. While in recent years governments have increasingly worked with national stakeholders, such as civil society organisations, to implement interventions, particularly at primary care level, including vaccination, screening programmes, supportive and palliative care, there is still a wide equity gap in cancer survival rates. Cancer mortality is especially high in LMICs, countries which, despite having almost 80% of the burden as measured by disability-adjusted life years, are estimated to have a less than 5% share of resources for cancer (2), with poorer outcomes linked to limited availability of data and access to diagnosis, treatment and care.

In May 2017, Member States reaffirmed cancer control as a critical health and development priority (3) with the adoption of the World Health Assembly (WHA) resolution on *Cancer prevention and control in the context of an integrated approach* (4). The resolution drew upon the Global Action Plan for the Prevention and Control of NCDs (5) and the Sustainable Development Goals (SDGs) to establish the case for increasing national investment and action on cancer.

Building on the unanimous approval of the resolution, the Union for International Cancer Control (UICC) launched the global advocacy campaign “Treatment for All” in 2018, which aims to decrease premature deaths from cancer worldwide by calling on the international cancer community to close the global equity gap in access to cancer services by addressing the four pillars of Treatment for All:

➔ Improved quality of cancer data for public health use

- ➔ Increased number of people with access to early detection and accurate cancer diagnosis.
- ➔ Timely and quality treatment for early and metastatic disease for all.
- ➔ Basic supportive and palliative care service for all.

In 2018, three civil society organizations joined the ‘national activation’ of Treatment for All as “Country Champions”, working with UICC to translate global commitments into national responses most suited to their country’s needs: Indonesian Cancer Foundation, Indonesia; Salvati AC, Mexico; and Uganda Cancer Society, Uganda. Their efforts were used to inform a broader initiative aiming to engage up to 40 Country Champions by 2020. In the following sections, we outline the main features of the national advocacy campaigns, as well as some insights gleaned through the initial phase of developing the advocacy priorities, which may be helpful for civil society organizations working to advance health sector priorities in their countries.

Indonesia Cancer Foundation: Urging a stronger response to improve palliative care

Country background

Indonesia is a large archipelago of more than 17,000 islands and over 260 million people. In 2018, male cancer mortality was over 100,000, while female cancer mortality exceeded 450,000 (6). Leading cancer types include breast, cervix uteri, lung, colorectum and liver cancers. The Ministry of Health in Indonesia has forecast that approximately 240,000 new cases of cancer will arise each year, 70% of these already at an advanced stage (7). Few screening and early detection programmes are available for cervical, breast and prostate

cancer at the primary healthcare level, and access to palliative care is also limited (8).

While the government has a national cancer control programme (NCCP) and a commitment to universal health coverage (UHC), implementation of the programme has been challenging due to the sheer size of the population, and the need to address other existing health priorities, including infectious diseases and maternal and child health. However, palliative care was identified as an increasingly important and crosscutting demand, particularly given only 1% of the population has access.

A focus on palliative care

Established in 1977, Indonesia Cancer Foundation (ICF) is comprised of 96 branches focused on increasing public awareness and implementing preventive and supportive activities, with emphasis placed on palliative care. Given many cancer cases present at late-stage disease, ICF is building on their existing home-based palliative care training programme for family and caregivers to shape a national advocacy campaign, calling for the improved support of palliative care services by local and national government.

Although palliative care is included in their NCCP and the Indonesian Ministry of Health has launched a palliative care policy as of 2007 (9), services are only available in some larger cities, including Jakarta and Surabaya. Identified barriers to palliative care include a limited understanding amongst healthcare professionals, the difficult and dislocated geography of the country and limited access to opioid medicines (10). In order to begin addressing barriers in access to palliative care, ICF advocates for their home-care training to become certified and recognized, with an extended reach through “train the trainer” workshops in different localities and increased training of healthcare professionals. Paired with these activities, ICF calls on government to draft hospice care regulations this year.

Salvati AC: Budget advocacy for implementation of their NCCP

Country background

Mexico has a population of over 130 million. In 2018, male and female cancer mortality was approximately 40,000 per sex, with breast, prostate, colorectum, thyroid and cervix uteri cancers as the leading cancer types (11).

For the past years, with leadership from the National Cancer Institute in Mexico, a UICC member, there have been several roundtable meetings between health professionals, local authorities, legislators and civil society to establish the guidelines and goals of the NCCP, which focuses on prevention, screening and early detection, treatment, palliative care,

rehabilitation, research and financing, without much success in moving adoption and implementation of the plan forward, particularly with the appropriate budget.

Notably, the 2017 World Cancer Leaders’ Summit in Mexico triggered strong involvement of Mexican stakeholders in the field of cancer control and led to further reinforcement of the plan in 2018. The National Cancer Institute has since been appointed to lead the implementation of the plan, integrating cancer management into all levels of care and the health sector to avoid fragmentation of health services (12). A national cancer committee has also been established, with representation from civil society. Also in 2018, a law to regulate the functioning of a national population-based cancer registry was passed, following a strong call for improved data for public health planning (13).

An NCCP co-driven by civil society

Founded in 2011 with the objective to support low-income people living with cancer, Salvati AC is one of the founding members of Mexico’s national cancer coalition of more than 50 organizations, Juntos Contra el Cáncer.

Leadership from Salvati participates in the national cancer committee, and they intend to represent the voice of patients and civil society comprising Juntos Contra el Cáncer, working alongside partners such as the National Cancer Institute. Building on momentum seen in the past two years for cancer control, despite the political transition to a new government in 2019 (14), Salvati is currently shaping a national “Treatment for All” campaign focused on adequate funding for implementation of an NCCP that puts patients’ needs first. To support this work, they co-hosted the Second Congress for Juntos Contra el Cáncer and the First Congress for Patients in November 2018. Efforts are currently focused on ensuring cancer control is a fundamental part of the upcoming five-year National Development Plan, which will secure adequate government funding for the entire length of the NCCP’s implementation.

Uganda Cancer Society: Coordinating multi-stakeholder engagement to ensure the development of an NCCP

Country background

Uganda has a population of 44,270,565, with male and female cancer mortality over 10,000 per sex. The leading cancer types include cervix uteri, Kaposi sarcoma, breast and prostate cancer, as well as non-Hodgkin lymphoma (15).

While Uganda has one of the most established cancer registries in its region (17), as well as an expired cervical cancer screening programme (18), it does not yet have an NCCP. This means that there is no strategic direction guiding cancer control interventions in the country, which also limits

the amount of funding allocated to cancer. For the most part, screening, early detection and treatment are not available, with only one centralized cancer centre, the Uganda Cancer Institute, providing treatment to patients (18).

A multi-stakeholder approach to drafting an NCCP

In 2011, Uganda Cancer Society (UCS) was established as an umbrella body bringing together different civil society organizations in order to systematically contribute to effective cancer control through advocacy, awareness creation, capacity-building, research and patient support.

UCS seeks the development of an NCCP that will reduce cancer incidence and mortality through implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment and palliation, while making the best use of available resources. To bring different stakeholders to the table on this issue, UCS, alongside the Uganda Cancer Institute, launched a National Cancer Symposium in 2018, calling for an urgent response to address cancer and NCDs.

Building on the launch of this symposium, Uganda has developed a national “Treatment for All” campaign focused on the drafting of their NCCP by February 2020 and will follow up the launch of their symposium with another event this year.

Discussion

UICC worked with all three civil society organizations to better understand their unique cancer control landscapes and determine advocacy goals in line with Treatment for All. Indonesian Cancer Foundation chose to focus on one specific pillar of Treatment for All – palliative care – whereas Salvati AC and Uganda Cancer Society chose to focus on the drafting, budgeting and implementation of their NCCPs. This is well grounded in a recent global analysis on NCCPs, which indicated that, as countries move toward UHC, greater emphasis is needed on developing NCCPs that are evidence-based, financed and implemented to ensure robust national responses (19).

While the Treatment for All national campaigns are only just underway, UICC acknowledges a few crosscutting lessons

learned. Firstly, across all three Country Champions, UICC saw the value of coalition building. Whether the organisation had many branches, served as an umbrella organisation or founded an official alliance, each Country Champion determined their advocacy goal based on collective agenda shaping to represent a more comprehensive set of stakeholders. On this point, we also saw the importance of convening platforms to bring stakeholders and decision-makers together to generate momentum for accelerated policy development, including the Second Congress of Juntos Contra el Cáncer and Uganda’s National Cancer Symposium. Each Country Champion also acknowledged the importance of international partnerships, with UICC and one another, to bolster a more holistic response to address cancer and to link to the notion of a global movement on cancer control, underpinned by a set of global commitments, including the Global Action Plan on NCDs and the cancer resolution.

As efforts across Country Champions continue, UICC plans on setting up key metrics to measure the impact of the national activation of Treatment for All, paving the most meaningful path to reach global cancer control, health and development targets together. As more engage, UICC also aims to establish regional connections for the sharing of best practices and the development of shared solutions. This global campaign calls on all stakeholders, everywhere, with a connection to cancer control to commit to promoting greater equity in access to data, early detection, treatment and care for the robust health system coverage needed to reduce the growing global cancer burden. ■

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Global cancer control: The role of the International Atomic Energy Agency and future perspectives

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The global burden of cancer is rapidly growing worldwide and there is a low level of preparedness to assess the disease, especially in LMICs. The International Atomic Energy Agency (IAEA) is committed to providing all the required support, to introduce, expand and improve the peaceful use of radiation in medicine, through its inter-institutional partnerships and its different technological tools.

The global burden of cancer is rapidly growing worldwide (1), with an estimated number of 18.1 million new cases and 9.6 million cancer deaths globally in 2018. These numbers are expected to rise to 24.1 million new cases and 13 million deaths by 2030 (1). Among the global challenges in addressing this disease are its variability, differing epidemiology between regions and countries, multiple risk factors associated with different types of cancer, pressure on all components of national health systems from promotion, prevention, access to early diagnoses and treatment as well as the palliative care and survivorship programmes.

The International Atomic Energy Agency (IAEA) was created in 1957 as an independent, intergovernmental organization in the United Nations System with a main objective to "... seek to accelerate and enlarge the contribution of atomic energy to peace, health and prosperity throughout the world. It shall ensure, so far as it is able, that assistance provided by it or at its request or under its supervision or control is not used in such a way as to further any military purpose". (IAEA Statute) (2).

As part of the achievement of this objective and in concordance with the sustainable development goals, the IAEA is committed to providing all the required support, to introduce, expand and improve the peaceful use of radiation, this includes the safe and sustainable use of radiation in medicine, including radiotherapy, diagnostic radiology, nuclear medicine and medical physics. Since its creation, the IAEA has

strongly supported and advanced research, staff training and the design of quality radiation facilities for low- and middle-income countries (LMICs).

Over time the different approaches used to address the growing needs of Member States included the use and development of different technological tools to facilitate training and education of professionals in radiation medicine worldwide, as well as to create a collection of important data that can help identify and address gaps in a timely manner.

Coordination of efforts worldwide

The IAEA, aware of the growing burden of cancer worldwide, has coordinated efforts with different international institutions and other UN organizations to tackle the global challenges that need to be addressed. Cervical cancer is the second most common cancer in women in LMICs, where 80% of the cases occur. In response, seven UN agencies (IAEA, WHO, IARC, UNAIDS, UNFPA, UNICEF and UNWomen) have joined efforts to create the UN Joint Global Programme on Cervical Cancer Prevention and Control (UNJGCP), working together through joint missions, and supporting the development of joint work plans that address cervical cancer all the way from prevention and HPV vaccination, to diagnosis, treatment, and palliation (3).

The Programme of Action for Cancer Therapy (PACT) was created in 2004 as an IAEA global initiative to confront the cancer crisis, with the vision of a global public-private

Figure 1: A dashboard representing the different information available for radiotherapy decision-making, as an example of the use of the technological tools available



partnership and fund, a joint programme for cancer control in collaboration with the World Health Organization (WHO) the International Agency for Research on Cancer (IARC), the Union for International Cancer Control (UICC) and other key international organizations was developed, with the main objectives of building a global partnership of interested organizations committed to address the challenge of cancer in LMICs; to mobilize resources to assist LMICs in the development and implementation of their radiation medicine capacities, within a national cancer control programme (NCCP); and to ensure the effective and sustainable transfer of radiation medicine technologies and technical knowledge to LMIC Member States.

As a tool to achieve all these goals the IAEA, in coordination with WHO and IARC, have established the ImpACT Review Missions, to help LMICs with a baseline situation analysis as well as a set of recommendations to help them prioritize and guide their decisions and the cancer control planning from the establishment of a cancer registry, prevention, early detection, diagnoses, treatment and palliative care. Since 2005, IAEA has conducted over 90 ImpACT review missions to its Member States. Recent published data (4) summarize some of the results obtained from these ImpACT review missions.

Diagnosis and treatment for paediatric cancers is another issue the IAEA has taken on. In June 2018, a new cooperation agreement between Childhood Cancer International (CCI) and the IAEA was signed, to ensure the best possible access to treatment and care for children with cancer worldwide. CCI brings together 188 organizations in 93 countries, representing parents and young cancer survivors working to promote best practices. Together with other institutions, the IAEA has joined WHO to strengthen the diagnosis and treatment in paediatric radiation oncology to support this

especially sensitive group of patients.

Knowing the geographic distribution of radiotherapy centres, nuclear medicine and radiology equipment available worldwide helps to clearly identify the population-based shortfalls in equipment and staffing. With its already well-established role in providing technical guidance at every step involved in the implementation and use of radiation medicine, the IAEA has maintained a Directory of Radiotherapy Centres (DIRAC) since 1968, with an online edition available since 1995. Data on facilities is obtained from several sources and is being continuously updated, including 7,269 radiotherapy centres in 147 countries, with 12,000 teletherapy machines. There is a similar database for nuclear medicine facilities, NUMDAB, and current inter-

institutional efforts are being made to establish a radiology database.

The IAEA also encourages research in Member States by creating a framework that supports scientific and technical exchanges between countries, bringing together research institutions from high-income countries and LMIC to research topics of common interest for both. The results of the Coordinated Research Projects (CRPs) are available to Member States as well as the international scientific community through dissemination in the IAEA's scientific and technical publications and in other relevant international or national journals.

IAEA CRPs in human health have a broad scope, ranging from quality assurance (5-7), radiation biology (8,9) and diagnostic imaging (10) to hypofractionated treatments in head and neck cancers (11-13), central nervous system tumours (14-15), lung cancer (16), cervical carcinoma (17, 18) among other pathologies, as well as educational CRPs, focusing, for example, on the global evaluation of an electronic blended tool for contouring (19). Current CRPs include new technological approaches, such as Stereotactic Body Radiation Therapy (SBRT). The IAEA is developing a new secure data management and repository system, called International Research Integrated System (IRIS), that will allow the IAEA not only to monitor every step of data collection to ensure high-quality data from its CRPs, but will also provide a dynamic schema that allows further analysis of the data and mega data collection as a step towards a medical artificial intelligence tool.

Artificial intelligence

The use of artificial intelligence is increasing rapidly around the world and the IAEA has embraced this new development

and is working to improve some of its processes by the implementation and integration of artificial intelligence systems in the working rhythm of the IAEA's Dosimetry Laboratory (DOL), that would allow it to predict better the time windows between receipt and delivery of the Dosimetry sets and the final receipt at DOL, with an expected improvement in the scheduling of the deliveries and a continuous workflow allowing no delays in the results.

Virtual tumour boards

The shortage of radiation professionals, added to the scarcity of access to new evidence-based approaches in clinical practises in some isolated centres in LMICs, encouraged the IAEA to look for a different solution that could fit their needs. The implementation of virtual tumor boards (VTB) started in 2012 as a response for those isolated centres, with limited access to up-to-date publications or difficult cases with no access to a second opinion or further case discussions. The Africa Radiation Oncology Network (AFRONET), started as a pilot telemedicine project that included 14 centres. To date, more than 70 sessions have been organized with a presentation of cases, as well as evidence-based data and expert opinions. AFRONET provides an electronic, easy to install, cost-free application that allows the interaction of all the participants and strengthens the bonds among the participating countries. The IAEA is in the process of expanding this successful project, with the creation of other VTBs in francophone Africa, Asia-Pacific, Latin America and Russian-speaking countries.

IT-based education

Taking in to account the need to facilitate the access to already available learning material, the IAEA created the Human Health Campus (20), now available through desktop and mobile devices. The Human Health Campus is an electronic tool designed to work as an essential informative resource for all health professionals in nuclear medicine, radiopharmacy, radiation oncology, medical physics, nutrition. Having access to a modern learning environment that allows users to download the learning material available, that includes a wide variety of different types of publications: from a set of technical guidelines on setting radiotherapy infrastructure (21-23), guidelines for the treatment of common malignancies (24-27), recorded webinars in nuclear medicine and radiotherapy, atlases for nuclear medicine and radiology (28-29), updated educational syllabi for professionals in radiation medicine (30-34) and digital training material (35-44). All these learning materials are constantly being updated and are freely downloadable.

The IAEA's Cyber Learning Platform for Network Education and Training (CLP4NET) is a machine learning environment, that allows easy access from anywhere in the world to the

broad collection of educational material available. It provides an interactive online learning platform that allows users to find educational resources easily. It contains distance-assisted training online, with instructor-led courses and e-learning self-study resources to enhance the self-directed learning experience and expand it to a wider audience. The use of the IAEA's platform is provided as a cost-free service by the IAEA.

Among the learning material available is a distance-learning course in Applied Sciences of Oncology (ASO)(45). The ASO provides the learner with an introduction to the applied sciences of oncology. It is designed to supplement textbooks with practical information and examples, and to give an overview of knowledge not easily gained from any one textbook. The course has been produced for the IAEA to provide cancer education for doctors and other radiotherapy professionals in countries where there is little currently available. The course covers eight subject areas and within each subject there are a few individual modules. The materials include interactive text and illustrations that require the students to answer questions before they can progress to the next module. Another distance learning course available is the Advanced Medical Physics Learning Environment (AMPLE) another IAEA-developed platform that provides medical physicists with guided learning materials and remote mentorships to enhance their clinical training in hospitals, as the lack of clinical training in Medical Physics has been identified as a weakness in the Medical Physicist curricula in several LMIC. AMPLE was initially launched in 2004 and since then it has been widely used in Asia and the Pacific, providing a structured, instructor-led learning environment focused on key competencies, in the different areas of medical physics (radiation medicine, nuclear medicine, diagnostic radiology and radiotherapy).

The IAEA launched the TNM cancer staging application in 2015. With it, the user can select characteristics of the disease, such as presence of metastases in the lymph nodes, and the application would provide the correct staging via their mobile devices.

Automated remote quality assurance

Knowing that in every process a good quality assurance system is mandatory to guarantee the expected results, to assess this important keystone of radiation medicine the IAEA has worked overtime in the development of quality assurance guidelines for radiotherapy (QUATRO) (46), nuclear medicine (QUANUM) (47), and radiology (QUAADRIL) (48). These tools have been broadly used in expert missions carried out by the IAEA and have been adopted in several countries as a national framework for internal audits (49).

Since 1969, the IAEA/WHO introduced a postal dosimetry audit system for radiotherapy centres offered to Member

States eligible for TC programme support. It is a cost-free service to participants and it checks the calibration of megavoltage machines (Cobalts and Linacs) with small dosimeters sent by mail, providing the results within eight weeks. The centre receives a certificate if the results are within the 5% tolerance limit. Outliers receive another set of dosimeters and are contacted if additional verifications are needed (50).

Aware that all beams used to treat cancer patients should be verified by an independent national, regional or international auditing organization, as well as the scarcity of auditing centres, in 2010 the IAEA established a Dosimetry Audits Network Database (DAN) (51), to be able to provide a network of the available centres to exchange information and compare results, and also to provide countries the opportunity to identify the available auditing centres. Through this network, the IAEA has identified that there are still not enough auditing centres and encourages the setting up of more auditing centres.

Efforts have been made by the IAEA also in the field of radiology to establish methodology and guidelines (52) from a remote quality control on planar imaging, that allows those centres with no regular availability to a Medical Physicist to perform the quality control on a regular basis, with a mechanism that allows a remote and automated regular quality control.

The IAEA, through its Human Health Division, understands the need to take advantage of the multiple data available, as well as the new technological advances that present themselves as a tool for decision-making, an engine for the identification of new opportunities, and an opportunity to reach out to those countries in need through the different networks and applications available. ■

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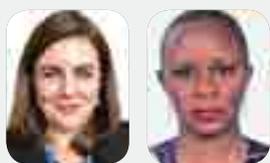
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Improving the safety of chemotherapy treatment for cancer patients in Uganda

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As the burden of cancer in low- and middle-income countries assumes greater priority for global health workers, attention must be paid to ensuring safety and quality in novel practice. Following on from a longstanding collaboration between the UK and Uganda, we implemented a quality improvement project focusing on safe practice in chemotherapy delivery at a cancer centre in Mbarara, which delivered noticeable improvements for both patients and staff.

The burden of cancer is increasing across the globe. Whilst in high-income countries the resources and infrastructure exist to address this burden, in low-middle income countries the disproportionate number of patients affected by cancer is compounded by a need for far greater investment in the necessary tools to address prevention, treatment and palliation. As progress is undeniably being made in addressing cancer in underserved settings, it is imperative that measures are put in place early to ensure that the quality of novel services is optimal and the safety of patients is paramount. The intensive nature of cancer treatments – often with a relatively narrow therapeutic window – means that attention to safe practice is of particular importance. Treatment modalities used in oncology are inherently potentially hazardous – chemotherapy drugs (or cytotoxics), for example, can cause significant harm if not handled or administered correctly. With this in mind, on the back of an existing partnership between Bristol, UK and Mbarara, Uganda, we conducted an 18-month quality improvement collaboration, to focus on improving the safety of chemotherapy delivery to adult and paediatric cancer patients in Mbarara, as Uganda's countrywide cancer services expand.

Uganda's capital, Kampala, hosts the Uganda Cancer Institute, founded in 1967, and treating approximately 200 cancer patients a day. In a country of 93,000 square miles, with a population of 44.3 million, there has increasingly been a need to expand cancer services to "satellite units" in further corners of the country. Mbarara lies approximately 200 miles southwest of Kampala and is the largest town in Uganda's western region, with a population of approximately 195,000. Mbarara's Regional Referral Hospital (MRRH), a public

hospital founded by the Ministry of Health, provides medical services to the local and regional population, with a catchment of approximately 10 million people. It also serves as a teaching hospital for the Mbarara University of Science and Technology (MUST).

History of the Bristol-Mbarara partnership

In 2000, the University of Bristol and MUST established a paired institutional partnership with support from the Tropical Health & Education Trust (THET) to establish postgraduate training in internal medicine in Mbarara. This was complemented by a formal Memorandum of Understanding between University Hospitals Bristol (UHB) and MUST. The Master's in Medicine (MMed) programme proved highly successful; a number of doctors who graduated from this initial programme continue to work as lecturers at MUST delivering the current MMed curriculum.

In 2012, as non-communicable diseases assumed increasing priority following the successful implementation of HIV programmes, oncology formally became part of the curriculum for postgraduate doctors undertaking the MMed qualification in Mbarara. Oncologists from UHB began to engage regularly with the department of medicine at MUST, providing teaching in the discipline of oncology and liaising with the department to support the future vision of an oncology service at MRRH for cancer patients.

It had become clear that the existing HIV clinic at MUST was seeing an increasing number of patients suffering from Kaposi's sarcoma, an HIV-associated malignancy which, although sometimes manageable with anti-retroviral therapy alone, often requires the use of cytotoxic chemotherapy for

adequate palliation. Paediatric malignancies – particularly haematological malignancies identified after communicable diseases such as malaria had been ruled out – were also evident, and as cancer awareness in the general population increased, so the demand for treatment grew.

What started as a small service quickly expanded, and the cancer clinic at MRRH became the first Satellite Cancer Centre affiliated with UCI, treating patients with a variety of malignancies. UHB supported the development of the clinic with more than 10 inter-institution exchange visits, providing education to nurses and doctors at MUST during this time of expansion. The exchanges took the form of “expert missions” – where experienced staff travel to the recipient’s institution to provide training, advice and “fellowships”, and where recipients travel to host institutions for training and education. Examples of the types of support provided include:

- ➔ Nine expert missions by consultant oncologists for teaching and clinic development.
- ➔ Expert mission by consultant paediatric oncologist for teaching.
- ➔ Expert mission by consultant chemotherapy pharmacist for teaching.
- ➔ Fellowship for MMed trainee from Mbarara to Bristol for oncology training.
- ➔ Fellowship for MMed lecturer from Mbarara to Bristol for oncology training.
- ➔ Procurement of funds for refurbishment of designated space in Mbarara for oncology clinic, chemotherapy storage and preparation, MDT meetings and chemotherapy delivery areas for adults and children.
- ➔ Procurement of funds for a biosafety cabinet, for preparation and re-constitution of cytotoxic agents.

Identification of need for quality improvement

With more patients attending the cancer clinic in Mbarara came increasing complexity of disease presentations and the subsequent necessary treatment regimens. Staff were delivering multidrug protocols, with complex dosing and critical time-bound delivery requirements. At the same time, they were tasked with handling, preparing, re-constituting and accurately administering these unfamiliar and potentially hazardous drugs, with no formal safety training.

Chemotherapy delivery requires logistical, clinical and administrative support, and in most centres worldwide is managed by a multidisciplinary team of highly-trained specialist professionals. Cytotoxic medications are, by their nature, inherently dangerous drugs which require safe handling, meticulous attention to detail during preparation, and thorough checks of dose calculations and prescriptions. Infusion rates, timing of administration and even the order

in which multidrug regimens are administered must also be strictly adhered to, to ensure the safety of patients and staff. In the treatment of cancer, whether curative or palliative, chemotherapy must be given with the most stringent attention to these safety measures. While both under-dosing and over-dosing can lead to serious consequences for the patient, even giving the appropriate dose incorrectly or ineffectively can lead to adverse consequences – for example, an increased risk of treatment toxicity and risks of harm related to drug spillages, extravasation or drug reactions.

The increasing demand for patients in Mbarara to have access to cancer treatment reflected the progressive shift in prominence of non-communicable diseases in LMICs in recent years. However, the evolution of underlying governance frameworks and specialist training structures required to provide these tertiary services lagged behind the upfront clinical demand, and, despite the positive progress made in Mbarara and the impact of the longstanding partnership with Bristol, challenges remained. Areas that were particularly identified as requiring focus were:

- ➔ No opportunity for specialist training of nurses.
- ➔ No formal role for a chemotherapy-trained pharmacist in cancer clinic.
- ➔ No embedded policy for observing or updating chemotherapy dose protocols.
- ➔ No formal requirement for staff to acquaint themselves with emergency procedures in the event of acute chemotherapy reactions.
- ➔ No benchmark of competency for handling, preparing or administering cytotoxic drugs.

Critical incidents, including failure to follow protocols, inaccurate calculations and dosing, inappropriate fluid regimens and incorrect drug formulations for intrathecal administration, had been observed, with the frequency unknown because of a lack of reporting protocols.

The commitment to providing a safe and effective cancer service in Mbarara was evident from the dedication of the staff working at the clinic and was supported by colleagues from UCI. Regular attendance from UCI’s medical oncologist and chemotherapy pharmacist was instrumental in supporting the growth of the service. However, local training in cytotoxic administration and the associated safety procedures was not formalised and UCI staff had commitments and heavy workloads in Kampala. With ongoing input from colleagues in Bristol, in 2016 a quality improvement project was devised, with the specific aim of improving safety measures in the clinic for the benefit of both staff and patients.

Funding was sought from the UK Government’s Department for International Development, through the THET’s Health

Partnerships Scheme, and ultimately a grant of £80,000 was awarded to support the implementation of the project.

Aims

We specifically aimed to address training in the safe handling, preparation and administration of chemotherapy, to both adult and paediatric patients, in order to work towards providing a safe and accountable chemotherapy service. This required the input of professional staff from various disciplines, including doctors, nurses, pharmacists and pharmacy technicians. A series of bilateral training fellowships and expert missions were arranged, with input from the head of the department of Medicine at MUST, the director of the Uganda Cancer Institute, the chief chemotherapy pharmacist from UCI and all local cancer clinic staff in Mbarara.

Our aim was to provide training which could positively impact the day-to-day running of the clinic, whilst providing a firm foundation of guidelines, standard operating procedures (SOPs), training manuals and other educational materials for future reference. Given the time-bound nature of the project, with finite funding, we planned to create a broad-based, sustainable training structure involving a variety of health professionals, utilizing both formal teaching and practical experience of safety procedures, in order that these staff members could propagate their expertise to future incoming staff, in a waterfall fashion.

Training methods

For practical training, we devised several workplace-based assessment tools, utilising logbooks and sign-off sheets, which allowed staff to practice their skills and ultimately achieve competency in unsupervised practice. In this way, we taught safe cannulation for delivery of cytotoxics, safe set-up of chemotherapy infusions, management of acute complications, such as extravasation and anaphylactic reactions, and safe disposal of cytotoxic waste. Large posters detailing emergency procedures and other useful clinical algorithms for common procedures were placed around the clinic. A laptop computer was provided and training materials, such as PowerPoint presentations, posters, chemotherapy protocols and sample SOPs, were stored there for all staff to access at any time.

We delivered a series of lectures to each cadre of staff, providing training in the basic science of oncology (particularly for newer staff with limited experience of treating cancer patients), and, over time, teaching increasingly specialised material suitable for healthcare providers working in this setting.

Practical demonstrations of procedures and scenarios also formed part of the programme, particularly for emphasising the importance of safe handling of cytotoxic medications

during spillage or leakage incidents. Personal Protective Equipment (PPE) kits were provided, consisting of gloves, gowns, masks and goggles, so that contact with potentially harmful medications was limited in the event of spillage incidents.

Impact and outcomes

An important part of this quality improvement project – and the historical partnership as a whole – was the maintenance of a strong professional relationship between healthcare professionals at our institutions. A key aspect of the project's structure was the inclusion of training fellowships for Ugandan staff in Bristol, through which our oncology teams forged stronger friendships and expanded professional networks. Colleagues from Uganda were able to see the context in which oncology is practised in a westernized, state-funded healthcare system, and to reflect on some of the aspects of care that could be transferred back to the clinic in Mbarara. During the fellowships, we provided practical, on the ground training in aseptic services, pharmacy, chemotherapy delivery and inpatient settings. Doctors also attended clinics and MDT meetings, and all visiting staff spent time on our inpatient ward. For each staff member coming to Bristol, we planned a series of activities through which we aimed to encourage reflection on both the differences and similarities of the journey of the cancer patient in the UK and Uganda. Participating staff reported significant benefits from their visits. Activities that were noted as being particularly beneficial were:

- ➔ Handover meetings – providing an opportunity for shift staff to discuss patient care and managements plans.
- ➔ Documentation practices – accurately recording treatment decisions, chemotherapy prescriptions and drug administration, and any adverse events.
- ➔ Routine double-checking of chemotherapy prescriptions (by pharmacists) and drug administration (by nurses).

These activities were highlighted as priorities for introduction into the clinic in Mbarara, as a way of addressing continuous improvement in safety standards.

The role of the oncology pharmacist was a further specific focus of this quality improvement intervention. One pharmacist was working in the Mbarara clinic, who had general pharmacy training but no chemotherapy-specific formal qualifications. UCI's chief chemotherapy pharmacist had been very involved in the development of the clinic and continued to engage with the team throughout our project. A major focus of the local pharmacist's training was the correct use and maintenance of the bio-safety cabinet that was previously procured for the clinic, but had not been utilised effectively due to a lack of training. We therefore worked closely with our pharmacist

and pharmacy technicians from Bristol to devise a simplified training manual, relevant to the local setting, so that any nurse or pharmacist required to prepare cytotoxic medication was able to use the cabinet and maintain safety requirements. Practical demonstrations and supervised chemotherapy preparation sessions provided useful training, and gave staff a sense of empowerment to use this unfamiliar equipment. A maintenance and cleaning log for the cabinet was drawn up to ensure its continued reliable functioning.

Once this had been established as a fundamental part of the safe workflow process, our team from Bristol concentrated on enhancing the clinic pharmacist's role. We introduced routine screening of chemotherapy prescriptions, looking for dose calculation errors and inaccuracies, and encouraged the pharmacist to take a more prominent role in the clinic. His engagement with the doctors during consultations and when making treatment decisions gave him further confidence in his role and has been a major factor in the improved running of the clinic.

At the end of our 18-month period of planned activities, significant improvements had been made in the day-to-day running of the clinic from a safety perspective. The doctors and pharmacist enjoyed a good working relationship where dose calculations and prescriptions were queried and double-checked without fear of criticism or judgment. An audit of prescription charts showed an encouraging increase in the rate of documented chemotherapy prescriptions which were correctly administered to patients, when compared with the baseline data at the start of the project.

Nursing staff showed demonstrably improved confidence in handling and administering chemotherapy, which motivated them to continue to learn and encourage their colleagues to adhere to safety guidelines. Our institutions remain in close contact and further fellowships and expert missions continue.

Conclusions

Our collaborative experience has highlighted some of the

challenges faced at the grassroots level when addressing the needs of cancer services in LMICs and provided insight into some of the day-to-day activities that can be incorporated into standard practice in these settings to provide safe and effective cancer care to patients. We achieved a noticeable improvement in safety practices within the 18 months that the project was running and with sustainable investment in teaching materials and a close ongoing professional relationship, we envisage further progress and maintenance of high standards in the cancer clinic in Mbarara.

We believe there is a need for other health partnerships and collaborators to report and publish similar experiences of quality improvement efforts, to highlight the needs of individual cancer centres and to provide contextual evidence of their benefits. With greater emphasis placed on the importance of quality improvement and strict adherence to safe practice in cancer centres globally, we can take steps in the right direction across the globe towards effective cancer care for those who need it most. ■

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Addressing the burden of cancer in East Africa through cascaded training

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Background: The Medical Training and Fellowship (METAF) programme aims to improve early detection and treatment of cancer in East Africa.

Methods: Needs assessment, followed by "train the trainer" workshops and cascaded training courses facilitated by local trainers, supported by expert faculty.

Results: 13 clinical training activities have been delivered and 289 doctors trained across East Africa.

Conclusions: The TOT solution to the need for a rapid cascade of knowledge has been well received.

In late 2015, the Royal College of Physicians (RCP) was invited to act as technical partner on an East African Development Bank-funded project designed to increase the early detection and treatment of cancer in East Africa. Following a needs assessment in January 2016, the Medical Training and Fellowship (METAF) programme was born. This article provides an overview of the programme's background, aims, progress to date, successes and challenges.

Background

The majority of global cancer incidence and deaths occur in low- and middle-income countries (1). Deaths attributed to cancer in Africa are rising at an alarming rate and should current trends continue, it is estimated there will be 1.4 million new cases and 1 million deaths from cancer by 2030 (2).

Late-stage diagnosis has been identified as a key factor associated with Africa's high cancer mortality rate, with approximately 80% of patients beginning treatment when the disease is at an advanced stage (3). For example, five-year female breast cancer relative survival rates are 46% in Uganda, compared with 90% in the United States (4). Across East Africa there is a growing burden of cancer with 60% more Africans now dying from cancer than from malaria (2). The gradual epidemiological transition towards non-communicable diseases (NCDs) means that strengthening capacity in the specialty of oncology is more important than ever.

It was in recognition of these challenges that the East African Development Bank's (EADB) Medical Training and Fellowship (METAF) programme was founded. The METAF programme is a four-year project (2016–2020), funded by the EADB and delivered in partnership by the British Council and the Royal College of Physicians (RCP).

The METAF programme and partnership is heavily aligned with the United Nations' 2030 Agenda for Sustainable Development and the associated Sustainable Development

Goals, which came into force in at the beginning of 2016, recognizing NCDs as a major challenge for sustainable development and supporting the use of partnerships and collaboration across countries and organizations to tackle these challenges and to meet these goals (5).

Aims and objectives

The METAF programme aims to improve early detection, research and treatment of cancer in East Africa by: increasing the levels of awareness of cancer amongst the medical officers at district and regional hospitals; increasing early referrals and diagnosis of cancer patients; empowering medical officers at district and regional hospitals to deliver care and manage urgent symptoms of cancer; and developing networks and linkages for cancer care among different strata of healthcare workers in Kenya, Tanzania and Uganda.

The programme covers short clinical training courses across Kenya, Tanzania and Uganda delivered by selected physicians from the RCP alongside senior faculty-based physicians across East Africa. Through the delivery of clinical training courses, participants are equipped to better undertake acute triage of cancer presentation and to manage urgent symptoms of cancer within their own district or regional hospital.

Methods

Needs assessment

In 2016, the programme partners conducted a week-long needs assessment, holding meetings with national representatives in oncology from across Kenya, Tanzania and Uganda to assess health needs, potential risks, and to refine the project details to ensure alignment with the national priorities. The needs assessment also involved focus group discussions with identified oncology trainees and contacting the Ministries of Health in each of the participating countries. The needs assessment concluded that a cascade model of training was

Figure 1: Agenda 2030 – 17 goals sustainable development goals

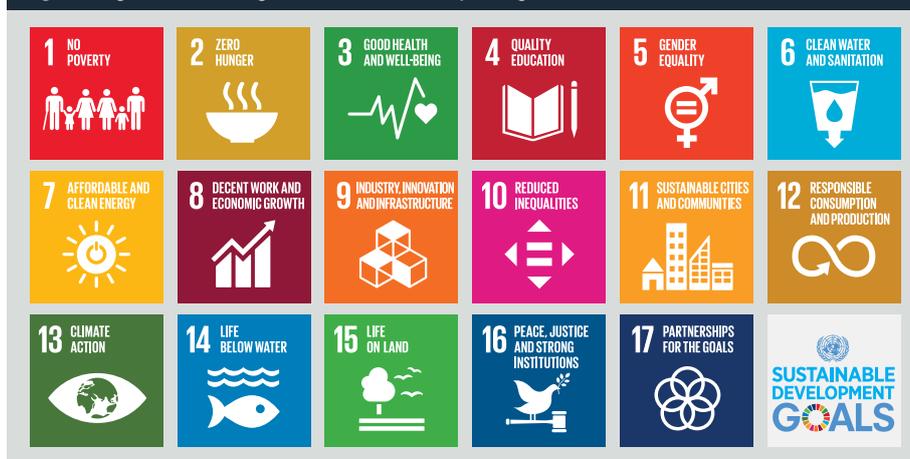


Figure 2: Map of the East African region



Figure 3: Oncology training course, Bagamoyo, Tanzania (September 2017)



required, to allow for rapid dissemination of information, as well as country-specific content and sustainability. Therefore, it was determined that a “train the trainer” component should be incorporated to reinforce teaching expertise and maximise reach. The aim of the training would be to increase capacity to undertake acute triage of cancer presentation within a district or regional hospital and to manage urgent symptoms

of cancer. An initial series of “Training of Trainers” (ToT) courses would be delivered to participants with a Master of Medicine (MMed) or those currently within a MMed programme. A selection of the participants would be identified as trainers to deliver subsequent cascaded courses across all participating countries. It was also determined that priority should be given to applicants deployed, or soon to be deployed, outside of major urban centres.

From the needs assessment,

local senior oncology consultants were nominated as course leaders (course convenors) to lead on course curriculum, design and content, and to advise and support the recruitment of local course teaching faculty and course participants. Local oncology faculty were recruited along with faculty from the RCP to develop and deliver the ToT oncology workshops.

Training of Trainers oncology workshops

After the official launch of the programme in August 2016, a series of residential ToT oncology workshops were delivered. The contents of the ToT oncology workshops were designed to upgrade the participant’s knowledge of cancer epidemiology; how common cancers in East Africa present and are diagnosed and managed; and how to perform acute triage of cancer patients, manage urgent symptoms and refer without delay. The aim was also to equip the participants to teach and share experience acquired through this course with other health workers at lower health facilities.

The curriculum involved the participant delivering case-based discussions, e.g., “A man with urinary symptoms”, supplemented by a limited number of generic lectures delivered by the RCP and local faculty (“Palliative Care”, “Treatment Toxicities”, “HIV and Cancer”, etc.). Each of the 20 case-based discussions were developed to reflect the most common cancers in each of the participating countries. The content was designed to encourage participant involvement and allow flexibility for local faculty expertise and interests. Each trainer practised delivering a case-based discussion and was given feedback on presentation and teaching methods by both local and RCP oncology education experts. Evaluation of knowledge and confidence gained was measured by pre- and post-tests, as well as post-course discussions with local and RCP faculty.

Cascaded oncology training course

After the delivery of three ToT workshops, a cohort of 39

Figure 4: Oncology training course, Nairobi, Kenya (September 2018)



Figure 5: Refresher ToT course, Entebbe, Uganda (April 2018)



trainers across Kenya, Tanzania and Uganda were trained to facilitate the future “cascaded” oncology training courses. Following feedback from both the trainers and faculty, the course content was amended to reduce the amount of background information and make the curriculum as interactive as possible.

Each cascaded oncology training course was facilitated by approximately five trainers who had participated in the previous ToT workshops, supported by local and RCP faculty. The content again consisted of clinical cases to illustrate common cancers in East Africa with a strong emphasis on symptom management and appropriate decision-making, taking into account local medical resources. Each trainer would ask the course participants what they would look for on examination, how to investigate and how to treat the presenting patient. The RCP and local faculty members on each case had prepared a PowerPoint slide set to facilitate discussion and to add more detail, particularly around epidemiology, treatment and priorities of care. The trainers facilitating each case answered the majority of the question, with the floor opened to the other delegates after each session.

Throughout the courses, emphasis was made on the acute triage of patients ensuring that the right cancer and the right patients were referred to relevant referral centres (Uganda Cancer Institute, Ocean Road Cancer Institute and Kenyatta National Hospital). Emphasis was made on performance status of the patient, identification of symptoms and palliation in those patients unfit for treatment.

Within the oncology training in Kenya, the concept of “Cancer

Mashinani”, cancer care at the grassroots level, is emphasized. Group discussion was encouraged to help identify ways of strengthening referral pathways. The residential model of the training allowed for the course participants to have open discussion with faculty and trainers during break and evening meals, and encouraged the building of cancer healthcare and professional networks.

Refresher ToT workshops

In 2018, a refresher ToT workshop was held for the trainers in Uganda to regroup and share experiences from the cascaded courses held in Soroti and Mbarara, and to discuss the impact of the programme on the trainer’s practice and how to improve future trainings. Within the refresher ToT, the facilitators also highlighted areas that had not been included in the initial curriculum including: communication skills; breaking bad news; effective PowerPoint presentation skills; cancer myths and misconceptions; and cancer screening. Following this insightful workshop, a post-course “Knowledge, Attitudes and Practice” survey was developed to be circulated to both trainers and course participants.

Results

The monitoring and evaluation framework draws from management information systems, participant feedback and trainer/faculty feedback.

Management information systems

Data gathered from application forms records indicate numbers attending the courses, the demographic makeup of participants and the geographical spread of practice. Since the launch of METAF in 2016, 13 oncology training activities have been delivered; four ToT oncology workshops and nine cascaded oncology training courses. The total number of doctors having completed an oncology training workshop or course across East Africa is 289 (Table 1).

Feedback, gathered by participant feedback forms, suggests that over 1,500 clinical staff will benefit from the knowledge gained on the training courses through mentoring by course participants at home facilities. In addition to high numbers of participants, demographic data collected from application forms suggest a wide geographical spread across Kenya, Tanzania and Uganda.

Multiple choice tests were completed at the beginning and end of each training and the test scores compared to evaluate a change in knowledge. Compared pre- and post-test scores suggest an average 12% increase in clinical knowledge (Table 2).

Participant feedback

Evaluation forms were circulated to course participants at

Table 1: : Number of participants

Clinical courses	Kenya	Tanzania	Uganda	Rwanda	Total
ToT, Nairobi, Kenya	15	12	0	0	27
ToT, Kampala, Uganda	0	0	19	0	19
ToT, Dar es Salaam, Tanzania	10	7*	0	0	10*
Oncology (cascaded) Training course, Soroti, Uganda	0	0	17	0	17
Oncology (cascaded) Training course, Bagamoyo, Tanzania	0	19	0	0	19
Oncology (cascaded) Training course, Machakos City, Kenya	29	0	0	0	29
Oncology (cascaded) Training course, Mbarara, Uganda	0	0	20	0	20
Oncology Refresher ToT Course, Entebbe, Uganda	0	0	12*	0	0*
Oncology (cascaded) Training Course, Mbeya, Tanzania	0	23	0	0	23
Oncology (cascaded) Training Course, Machakos, Kenya	32	0	0	0	32
Oncology (cascaded) Training Course, Nairobi, Kenya	42	0	0	0	42
Oncology (cascaded) Clinical Training Course, Entebbe, Uganda	0	0	21	0	21
Oncology (cascaded) Clinical Training Course, Mwanza, Tanzania	0	30	0	0	30
Total	128	84*	77*	0	289

ToT = Training of Trainers.

*Not counted in total, refresher training for those that have already completed ToT

convenors, local trainers and RCP faculty to gather feedback on the structure of the programme and delivery of the curriculum. The feedback seeks to capture the observations of the trainers and faculty, identify key challenges and lessons learned. The reported feedback from trainers and faculty have contributed to the continued revision of the curriculum content and design. Feedback suggests that valuable partnerships have been formed and that the exchange in knowledge across geographies has benefited both RCP faculty and local faculty.

“Observing healthcare in a resource-poor environment was hugely influential to me and made me realise how much UK and Tanzanian doctors can learn from each other. In the District Hospitals of Tanzania, clinical acumen is often the only tool for diagnosis. While we are lucky in the UK to have access to state-of-the-art facilities, it is essential to retain fundamental medical skills and the art of complex decision-making in the absence of diagnostic tests.”

Dr Georgina Wood, RCP volunteer

Challenges and limitations

Owing to the variety of partners involved in the project and the multitude of stakeholders both at the country and regional levels, the

Table 2: : Average percentage increase between the pre- and post-course test scores

Clinical courses	Average percentage increase
ToT, Nairobi, Kenya	32%
ToT, Kampala, Uganda	19%
ToT, Dar es Salaam, Tanzania	12%
Oncology (cascaded) Training course, Soroti, Uganda	19%
Oncology (cascaded) Training course, Bagamoyo, Tanzania	17%
Oncology (cascaded) Training course, Machakos City, Kenya	31%
Oncology (cascaded) Training course, Mbarara, Uganda	17%
Oncology Refresher ToT course, Entebbe, Uganda	N/A
Oncology (cascaded) Training Course, Mbeya, Tanzania	11%
Oncology (cascaded) Training Course, Machakos, Kenya	12%
Oncology (cascaded) Training Course, Nairobi, Kenya	7%
Oncology (cascaded) Clinical Training Course, Entebbe, Uganda	19%
Oncology (cascaded) Clinical Training Course, Mwanza, Tanzania	12%
Total	12%

ToT = Training of Trainers.

the end of each training to elicit feedback on the quality of training and logistical organization. Post-training surveys were circulated to and completed by course participants to highlight how they have implemented the knowledge gained into their everyday practice. These post-training surveys are also used as an opportunity to learn more about resource availability and the expected level of dissemination of information within participant's local facilities, which can be used to inform and improve future trainings. The feedback gathered within the evaluation forms and post-course surveys suggests a self-reported higher index of suspicion for cancer, increase in referrals and confidence in managing patients with cancer.

Trainer/faculty feedback

Training reports are also completed by the local course

implementation of the METAF programme has not been without challenges. Challenges have ranged from fully understanding the structure of healthcare in each of the participating countries to political and workforce changes in both East Africa and the United Kingdom.

Other challenges have varied from getting the right people involved (faculty, trainers, government stakeholders, etc.), time, communication, politics, geography and infrastructure.

However, the most significant limitation of the programme is how its impact can be effectively measured. The implemented methods of monitoring and evaluation (post-course surveys; refresher ToTs, focus group discussions) all mainly reply on self-reporting from participants and trainers. Given the remit of the programme, it is not possible to equate self-reported increases in knowledge and confidence to patient outcomes.

Conclusions

Across Kenya, Uganda and Tanzania there is a growing burden of NCDs and cancer. The growing burden of cancer in East Africa means that strengthening capacity in the specialty of oncology is more important than ever. The METAF programme and partnership between the EADB, British Council and RCP has aimed to strengthen capacity in cancer care in Kenya, Tanzania and Uganda through a unique training model. The METAF training model, with the curriculum design and delivery teams drawing expertise from both the RCP and East Africa, has guaranteed both world-class approach and content while still ensuring contextual relevance. The ToT and a cascade model of training courses has allowed for rapid dissemination of information, maximising reach and increasing teaching capacity. The programme has been well received by participating doctors, trainers and faculty and has been demonstrated to be effective within this multinational programme. While the complex programme has endured several challenges, the methodology may be applicable to similar needs in other low- and middle-income countries.

Thanks and acknowledgements

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Use of telementoring to advance cancer control: The 2018 Africa Cancer Research and Control ECHO[®] Programme

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Cancer, a leading cause of death globally, disproportionately affects low- and middle-income countries (1). The National Cancer Control Plan (NCCP) is a key tool for planning evidence-based cancer prevention and control interventions; however, policy-makers and programme implementers in limited-resource settings face NCCP implementation challenges. Use of telementoring, as part of a comprehensive approach to planning, provides a platform for knowledge sharing and multi-directional learning to support implementation of NCCPs for countries and international partners alike.

Cancer is expected to be the leading cause of death worldwide in the twenty-first century. In low- and middle-income countries (LMICs), cancer incidence is on the rise, due in part to an increase in modifiable risk factors, such as obesity, tobacco and alcohol use, and to longer lifespans due to the increase in the control of infectious disease. Cancers like cervical, prostate and breast, which have relatively high survival rates in high-income countries, are among the highest causes of mortality in LMICs (1,2). The number of countries with a Non-Communicable Disease Plan (NCD) that includes cancer, or a National Cancer Control Plan (NCCP), has grown to 87% of countries, and 224 cancer-related plans from 93 countries are available on the International Cancer Control Partnership (ICCP) portal (3). However, there is evidence that countries do not always operationalize their NCCP; thus, there is an increasing demand for dissemination of best practices and solutions to common implementation barriers for NCCPs. For example, while a recent global analysis of NCCPs found that there is reference to a leadership mechanism for implementation in 79% of NCCPs, only 7% referenced who would be accountable for implementation. While 37% of reviewed plans mention costing the NCCP, just 7% have an implementation strategy for costing (3).

From 2013–2017, the Center for Global Health at the US

National Cancer Institute (NCI/CGH), together with global cancer control experts in the ICCP (4), convened regional Cancer Control Leadership Forums (CCLF) to increase the capacity of participating countries to initiate or enhance evidence-based cancer control planning and implementation (5). Ten country teams from the Africa region participated in an in-person CCLF in Lusaka, Zambia, in 2014 and/or a subsequent online, virtual CCLF in 2017. Evaluation data demonstrated the effectiveness of the 2014 and 2017 programmes, including positive reception of the virtual format of the 2017 CCLF and the preference from country teams to learn best practices from others working in the region (6). Based on these evaluation data, and on the need for a sustainable and cost-effective method for convening stakeholders, NCI/CGH explored utilization of the telementoring platform Project ECHO[®] (Extension for Community Health Outcomes) to continue the knowledge exchange of evidence-based best practices for overcoming barriers to effective NCCP implementation.

Project ECHO was developed in 2003 by Dr Sanjeev Arora at the University of New Mexico as a method to improve equitable access to healthcare and provide technical capacity. The platform uses technology for combined case-based and didactic, multi-directional learning (7). Each Project ECHO session consists of case presentations from participants,

discussion and feedback from fellow participants and technical experts, and a brief didactic presentation on a relevant technical topic. Sessions are held on the Zoom videoconferencing platform, negating the need for travel and disruption of daily work. Project ECHO has been effectively implemented in many clinical settings and increasingly in non-clinical settings in the United States and internationally. There are many cancer-related ECHO clinics in the Project ECHO Cancer Collaborative (9). For example, the University of Texas MD Anderson Cancer Center (MD Anderson), has 11 cancer-related programmes, including several focused on cervical cancer - two for cervical cancer prevention in Medically Underserved Areas in Texas and Mozambique (sessions held in Portuguese); as well as ECHO programmes for clinical management of gynecologic cancers with 10 countries in Latin America (sessions held in Spanish), and radiation oncology-focused sessions with Zambia (8). In an evaluation of ECHO to extend knowledge after a hands-on cervical cancer training in the Texas-Mexico border programme, preliminary data showed that post-training ECHO participants maintained or increased their level of knowledge and self-efficacy as a result of participation in the ECHO, demonstrating that these complementary interventions are effective to deliver cervical cancer control capacity building. MD Anderson serves as a training centre (Superhub) to help other organizations become ECHO hubs.

Seeing the potential to use the Project ECHO model to continue the cancer control evidence dissemination efforts in previous CCLFs, NCI/CGH, in partnership with the ECHO Institute at the University of New Mexico and the MD Anderson Cancer Center, launched three regional ECHOs, including the 2018 Africa Cancer Research and Control Project ECHO Program (Africa ECHO). The Africa ECHO aimed to increase familiarity and utilization of national cancer control planning principles and strategies, and to strengthen the interactions of those working in cancer control programs with researchers, advocates, and regional and international partners. NCI/CGH utilized an evaluation survey approach to measure impact and contribute to the evidence about potential effectiveness of ECHO to strengthen national cancer control planning and implementation.

Methods

The Africa ECHO included participants from the 2014 and 2017 Africa CCLFs, and additional stakeholders as referred from regional and international partners. These participants represented Ministries of Health, academic institutions, health facilities, and non-governmental organizations. Global and regional partners who participated in the Africa ECHO included global cancer control experts, implementing partner

organizations and academic institutions.

Session topics were planned with input from stakeholders and participants, with an emphasis on commonly reported challenges from past evaluations of CCLFs. Unlike in clinically-focused ECHOs where patient cases are presented, the Africa ECHO case presentations were on cancer control planning challenges, such as tobacco control, resource mobilization and building human resource capacity. Each session was 90 minutes in length, with time split evenly between case presentations, didactic presentations, and discussion (see Table 1 for full list of session topics).

The Africa ECHO was designed to be time-limited to pilot the ECHO model and to measure its effectiveness in advancing and strengthening cancer control planning in the region. A pre-post survey method was used to help NCI/CGH determine the impact and measurable outcomes of the ECHO programme when utilized in a cancer control context (10). Baseline and endpoint questions covered participant level of knowledge, utilization of cancer control planning strategies, partner engagement, and feedback on the ECHO model. Additionally, participating partners and didactic speakers completed an endpoint survey with questions covering usefulness of the ECHO model to their engagement with in-country stakeholders, and level of collaboration resulting from ECHO engagement.

Results

A total of 48 participants from 12 countries registered for the Africa ECHO, with sector representation by primary responsibility from Ministries of Health (25), non-governmental organizations (9), research/academia/clinical care (8), and technical partners to Ministries of Health (6) (Table 2). Approximately one-third of participants attended at least four of the seven monthly sessions, and an average of 18 participants (38%) attended each session. An average of 10 partners and guests (one-time attendees and speakers) attended each session.

The baseline survey was completed by 37 participants (77.1%) from 11 countries, and 21 participants (43.8%) from nine countries completed both the baseline and the endpoint surveys. Most survey respondents represented Ministry of Health, clinical care, advocacy, and research. A total of 10 individuals completed the partner and speaker survey (the total number of partners varied throughout the programme).

Usefulness of ECHO to address cancer control challenges

At baseline, survey respondents were asked to identify cancer control-related challenges they wanted to address in the Africa ECHO®. At endpoint, 20 survey respondents (95%) reported that their cancer control-related challenges had been

Table 1: 2018 Africa ECHO session topics and presenters (by institution)

Date	Topic	Case presenter institution(s)	Technical presenter & moderator institution(s)
April 2018	Initial findings from the global analysis of National Cancer Control Plans	N/A	World Health Organization
May 2018	Tools to prioritize cost-effective cancer control programmes and to finance the National Cancer Control Plan	Ministry of Health, Ethiopia Ministry of Health, Kenya	International Agency for Research on Cancer World Health Organization
June 2018	Financing the implementation of the National Cancer Control Plan: Mapping resources, engaging experts, utilizing communities of practice, partnering with the private sector	Uganda Cancer Institute, Uganda Ministry of Health, Zambia	International Atomic Energy Agency
July 2018	Building human resource capacity for cancer research and control through partnership and mentorship	African Esophageal Cancer Consortium, East and Southern Africa Rwanda Biomedical Center, Rwanda	World Health Organization Istituto Europea di Oncologia New York University
August 2018	Getting ahead of the curve on tobacco control in the Africa region	Ministry of Health and Childcare, Zimbabwe University of Cape Town, South Africa	Center for Tobacco Control in Africa American Cancer Society
September 2018	Integration of cancer into existing health services (Part I)	Ministry of Health and Wellness, Botswana Jhpiego, Botswana	University of Washington
November 2018	Integration of cancer into existing health services (Part II)	Clinton Health Access Initiative/ Ministry of Health, Nigeria National Cancer Institute, Kenya	Albert Einstein College of Medicine Harvard Medical School/ Massachusetts General Hospital

addressed, and 14 respondents (66%) identified additional cancer control-related challenges that were identified over the course of their participation in the Africa ECHO (including funding for cancer control; monitoring and evaluation; and, access to services, among others). All 21 endpoint survey respondents stated that the virtual platform was suitable to their learning style. The primary logistical challenge with the Project ECHO virtual platform was internet connectivity.

When asked to describe how the Africa ECHO helped them address their cancer control-related challenges, the primary response was the sharing of experiences and best practices by countries in the region (10 respondents, 50%), followed by technical guidance (7 respondents, 35%), and the application of learning to move cancer control planning forward in their setting (4 respondents, 20%). As a result of participation in the Africa ECHO®, survey respondents reported an increase in utilization of cancer control planning resources, such as the International Cancer Control Partnership portal (ICCP), the World Health Organization cancer control planning tools, and the Union for International Cancer Control resources for

cancer planning and control.

Changes in level of cancer control planning knowledge

Survey respondents were asked to rank their level of knowledge about 15 cancer control planning strategies, such as building political will, forming partnerships for financial support and using evidence-based resources to inform strategy. Endpoint survey respondents reported an increase in knowledge for all 15 cancer control strategies as a result of participation in the ECHO. Respondents reported the greatest increase in knowledge in: incorporating monitoring and evaluation into plans and programmes; engaging multisector partners in the cancer community; and engaging members of the NCD, women's health, infectious disease fields and partners outside the health sector.

Building regional partnerships

Endpoint survey respondents reported on number of new partnerships by stakeholder group developed as a result of participation in the Africa ECHO. Respondents reported

Table 2: Africa ECHO registered participants

Country	Total #	Total by sector (primary responsibility)				
		Ministry of Health	Non-governmental organization	Research/Academia	Technical partner to Ministry of Health	Clinical
Botswana	4	2	0	0	2	0
Ethiopia	4	2	1	1	0	0
Kenya	7	2	2	3	0	0
Kingdom of eSwatini	2	2	0	0	0	0
Malawi	2	2	0	0	0	0
Namibia	3	1	0	1	1	0
Nigeria	1	0	0	0	1	0
Rwanda	3	2	1	0	0	0
Tanzania	4	2	0	0	1	1
Uganda	9	6	2	1	0	0
Zambia	4	2	0	1	1	0
Zimbabwe	5	2	3	0	0	0
TOTAL	48	25 (52.1%)	9 (18.8%)	7 (14.6%)	6 (12.5%)	1 (2.1%)

To experience on-line cancer control learning opportunities on a continuous basis that was broadening my field of cancer control knowledge; also the opportunities to learn from other countries who are having similar challenges.”

ECHO participant

forming the highest number (6 or more) of new partnerships with clinical/hospital partners (8 respondents), the Ministry of Health (7 respondents), and community groups (7 respondents). Respondents also reported that the greatest increase in stakeholder support for their activities came from stakeholders outside of their organizations in their own countries (19.2% increase in reporting “very supported”) and stakeholders from the region (17.1% increase in reporting “very supported”). Anecdotally (not captured in the survey), participants also reported an increase in ease of connection with the global cancer control experts who participated in the Africa ECHO. For example, one participant reported via email that he met one of the World Health Organization experts at a regional conference and that the Africa ECHO connection allowed him to immediately connect and network.

Reflections on bi-directional learning

Of the 10 partners and speakers who responded to the endpoint survey, 7 responded that they had served as a speaker or moderator during the Africa ECHO. Of these, 6 (86%) reported that the experience was very useful or useful to them, and 4 (40%) reported developing new collaborations.

Discussion

The Africa ECHO was designed to pilot and measure the ECHO platform’s effectiveness in advancing and strengthening cancer control planning in the region. The findings from baseline and endpoint surveys indicate that the Africa ECHO was largely successful. The main challenges the participants

wanted addressed were cancer control planning strategies, such as building political will, forming partnerships for financial support and using evidence-based resources to inform strategy. Endpoint survey results show an increase in level of knowledge, indicating the usefulness of ECHO as a learning platform.

The most often reported source of learning was from best practices shared by regional colleagues. The benefit of learning from real-world experiences was underscored in various ways in the survey, and informally by participants, and reflects similar findings from other ECHOs that local and regional expertise and locally-relevant knowledge are both vital sources of information for programme implementers (11). The value of South-South exchanges in building regional capacity has been shown in other models (12–16), and the Africa ECHO adds to the evidence that demonstrates the value of this type of exchange. For programme implementers with limited time and capacity to build networks to help them with problem solving, the Africa ECHO provided brief live interactions that opened doors for further engagement offline. This is underscored by the fact that participants reported that the highest increase in support for their cancer control activities came from stakeholders from other sectors or from within the region (not within their own organizations).

At the same time, the informal setting created by using the Zoom platform allowed participants to interact with regional and global experts in cancer control, some of whom were instrumental in development of the global cancer control resources and implementation research findings accessed by the ECHO participants. The ability to ask direct and sometimes

provocative questions to global leaders in cancer research and control resulted in dynamic discussion. The ECHO Institute describes this as “the democratization, or demonopolization, of knowledge” (17). Direct engagement between participants and experts brought tools and resources to life and provided opportunities for further networking. These connections were bi-directional, as partners and speakers also reported an increase in number of partnerships at the country-level resulting from ECHO engagement.

Participants demonstrated an increase in technical knowledge as a result of participation in the Africa ECHO in various cancer control planning principles and strategies. This finding is consistent with another study that used Project ECHO as a telementoring tool for healthcare professionals’ knowledge and self-efficacy in pain management (18). This contributes to the evidence of Project ECHO’s application for strengthening knowledge at the clinical, as well as policy and planning levels. The areas where participants reported the higher levels of increased knowledge mirror the cancer control topics covered in the sessions, demonstrating that a specific ECHO curriculum focused on evidence translation to policy and programmes can result in a high impact in addressing cancer control challenges. New challenges that were identified in the course of participation may be a result of exposure to new challenges as presented in the case-based learning format (11). The additional technical topics listed are the natural “next steps” to the knowledge pieces gained in this ECHO – for example, building research capacity or monitoring and evaluation. Notably, these topics mirror some of the recommendations outlined in the global analysis of NCCPs (3).

Limitations

The Africa ECHO was a positive learning, knowledge-exchange, and partnership-building experience for the participants and technical experts alike. However, the time-limited structure of the programme, and pre-post survey method only provides short-term outcome data based on programme participation (10). Longer-term engagement would help to highlight the ability of participants to apply acquired knowledge, to identify barriers and challenges, and to provide sustained opportunities for cross-regional knowledge exchange. The pre-post survey demonstrated an increase in knowledge and familiarity with cancer control strategies and principles. However, there was lower overall session participation compared to registrant numbers, and lower response rate to the endpoint survey than the baseline survey. Both factors are key limitations to these findings.

Conclusion

The adoption of this model of mentoring in cancer control

planning, implementation and monitoring, is recommended. The ECHO model should continuously be developed and evaluated in terms of its impact, not only on cancer stakeholders’ knowledge and skills, but on cancer control plan implementation and health outcomes. To that end, it is recommended that future ECHOs in the policy arena include a longer-term impact evaluation be conducted at regular intervals of three to five years to gauge if and how participation in ECHO impacts the effectiveness of implementation of NCCPs or other policies. Effort is required to enhance participation and response rates in future evaluations and to ensure that future ECHO® networks meet the needs of the population using them. This should address minor technological issues to enhance audiovisual quality and connectivity.

One of the outcomes of demonopolized knowledge is the emergence of technical leaders in regions where knowledge exchange is taking place. Following the six-month Africa ECHO engagement convened by NCI/CGH, a steering committee representing four countries in the region has emerged to move the Africa ECHO programme forward. This group will continue to convene scientists, planners and policy-makers from the region to share best approaches and challenges in cancer control. Opportunity exists to continue to accelerate recent progress in cancer control in the region, which has included strengthening of cancer surveillance and prevention services (3). Challenges remain, especially in the areas of financing and resourcing NCCPs, and in building human resource capacity for equitable cancer control. The experience of the 2018 Africa ECHO indicates that Project ECHO and telementoring, as part of a comprehensive approach, can play an important role in improving health outcomes.

For information about partnership opportunities, contact the Project ECHO Cancer Collaborative. ■

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Challenging cancer inequalities within Europe through education and training: ESO's vision

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Disparities in cancer incidence and mortality between Central and Eastern Europe (CEE) and Western Europe persist. Among the causes are a lack of a timely diagnosis and lack of access to trained specialists. The European School of Oncology (ESO), a non-profit provider of education in cancer medicine, has been operating in CEE since the 1980s. This article provides an overview of the challenges in cancer care faced in CEE and of ESO's activities to improve inequalities.

Cancer incidence and mortality differ significantly within Europe. Although the incidence of many cancer types is higher in Western Europe, mortality per incidence rate is generally higher in Central and Eastern Europe (1). And while mortality has been decreasing in Western Europe (WE), this trend is not seen in most countries in Central and Eastern Europe (CEE) (2,3,4,5). The causes of these disparities are multifactorial, including but not limited to risk factor exposure, health system and cancer care infrastructure, availability of medication, late stage at diagnosis and lack of access to trained oncology specialists. The last two factors are those on which the non-profit European School of Oncology, with its mission "to contribute through education to reducing the number of cancer deaths and to ensuring early diagnosis, optimal treatment, and holistic patient care", has been focusing its activities to advance cancer care in CEE.

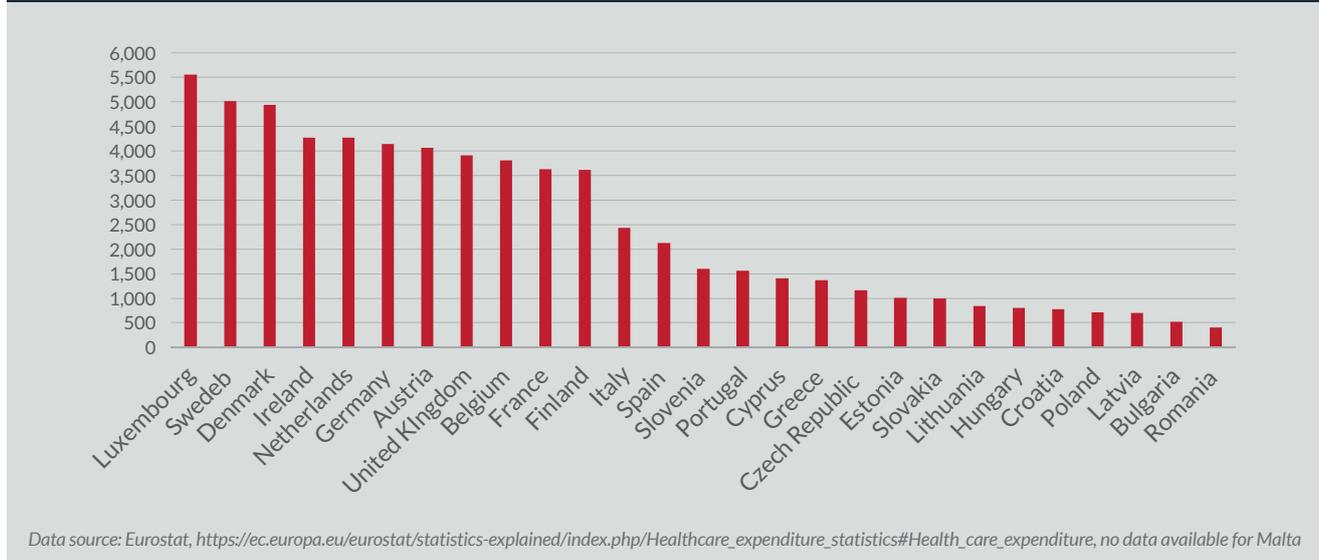
ESO's vision and philosophy are encapsulated in its motto, "learning to care". Founded in 1982, ESO provides evidence-based, patient-oriented oncology education to health professionals, including clinical and medical oncologists, radiation therapists, surgeons, pathologists, nurses, patient advocates and medical students. Due to its financial

independence, ESO can set its own priorities, paying attention to developing the transfer of knowledge in areas that are disadvantaged, such as countries and regions with limited economic resources. This article highlights the challenges in cancer care faced in Central and Eastern Europe, and ESO's current and future activities which address these challenges.

Challenges in cancer care in Central and Eastern Europe

Central and Eastern European (CEE) countries represent the group of countries comprising Albania, Bulgaria, Croatia, the Czech Republic, former Yugoslavian countries, Hungary, Moldova, Poland, Romania, Slovakia, and the three Baltic states: Estonia, Latvia and Lithuania. Due to their similar economic background in the post-communist system, these countries are usually analysed together. Ten CEE countries are currently part of the European Union; however, healthcare and its management are a national responsibility in the EU and the lowest rates of healthcare spending per capita in 2015 were reported in "new" European Union countries (6) (Figure 1). In many CEE countries, the collection of health outcome data and cancer registry data are limited, making it difficult to assess

Figure 1: Per capita healthcare expenditure (in EUR) in European Union Member States in 2015



access to care (7). However, there are important limitations across CEE in the availability and access to the services required for qualitative management of cancer patients. These limitations cover the entire spectrum from research to palliation and together lead to worse clinical outcomes in the region.

Complete and accurate pathology is crucial for making optimal treatment recommendations, and testing for molecular markers has significantly impacted clinical practice. While diagnostic pathology and immunohistochemistry are usually available in academic centres in the main cities of Eastern Europe, these resources are frequently not available in smaller centres (8); testing for molecular alterations is only patchily available in most of the CEE countries (9). Multigene panel testing has become available in CEE countries, but costs must be covered by the patients, while medical oncologists often lack the expertise needed for interpreting the results.

Research is underrepresented in CEE, with the negative economic trend across the CEE region leading to a sustained migration of trained researchers to Western Europe. Clinical research is mainly carried out by pharmaceutical companies, and due to issues concerning access to newer therapies, Eastern Europe has a high recruitment potential. While new therapeutic options have become available through clinical trials, access to these medicines is often delayed for patients in CEE: one study showed delays of up to 10 years in certain CEE countries between EMA approval of trastuzumab and its reimbursement (10).

Several countries in CEE have centralized cancer centres that provide all cancer surgical procedures, while even basic surgery may be in shortage or not available at all in distant rural areas (11). And although radiotherapy is a critical component of comprehensive cancer care, most CEE countries do not have

the quality or quantity of radiotherapy needed for an adequate service to their population. Under-capacity rates in the region, i.e., the percentage of patients in the county who would not have access to radiotherapy, range from 20% to 70% (12).

Across CEE countries, the paradigm for palliative care is slowly shifting towards the integration of supportive and palliative care throughout the continuum of cancer care. However, limited resources, centralization of services, lack of patient-oriented information, limited registries and absent or inadequate national cancer control plans lead to a situation in which many patients who live with advanced cancer are in dire need of palliation services.

Challenges in training and education

To inform its strategic plan for the coming years, ESO has gathered input from oncologists from Central and Eastern Europe on the challenges their countries face in the training and education of oncology professionals. These inputs provide a snapshot of oncology training across a diverse landscape of healthcare systems.

While some countries offer specializations in medical oncology, radiation oncology and surgical oncology, in others, resident training either covers all oncology fields or even splits time between internal medicine and oncology. Regardless of their country’s model, many professionals reported a lack of training in specific, highly needed fields of oncology, such as molecular oncology, immunotherapy, molecular diagnostic tests and their application, genetic counselling and advanced radiotherapy techniques. In some CEE countries, continuing medical education, which could bridge this gap, is either not well organized, has a highly limited budget or does not exist at all. Limitations in available equipment and therapies also limit educational opportunities for oncology residents. Worryingly,

Figure 2: Countries in Central and Eastern Europe in which ESO has carried out training activities



access to medical journals and even textbooks constitutes a problem in some CEE countries.

The expert panel also reported that while residents in some countries have only limited access to patients and spend their residency mostly as “observers”, residents in others are used to “make life easier” for oncologists, thereby either limiting practical exposure or the time available for further training. In some countries, residents rarely participate in clinical trials and research. A lack of mentorship, with many mentors underprepared and undervalued for their role, was described by most experts. On a more systemic level, several experts described multidisciplinary teams as either non-existent, especially outside major cities, or non-functional.

ESO’s activities in Central and Eastern Europe

After more than 35 years in operation, ESO is the oldest organisation exclusively dedicated to increasing the knowledge of health professionals in all fields of cancer medicine. ESO has a dedicated Eastern Europe and Balkan Regions programme to coordinate educational activities in the area, as well as a Eurasia programme focused on Russia, the Baltic region, and the surrounding geographical area.

ESO’s mission in CEE is to promote and secure independent academic education of all professions involved in cancer care, boost education on the multidisciplinary cancer care approach, support the training of young oncologists in the region, establish leadership programmes and foster professional and scientific collaboration between countries.

ESO has been operating in the Balkan region since 1989.

Since 2001, ESO has been running a series of training courses in different countries in CEE, focusing not only on developing the skills of qualified oncologists, but also of oncology residents, oncology nurses, general practitioners and medical students.

In 2011, ESO organized the first Masterclass in Clinical Oncology in the Balkan region. “ESO Masterclass” is an interactive, highly specialized, residential course for young oncologists and oncologists in-training. The ESO EEBR Masterclass in Clinical/Medical Oncology is designed for physicians in medical oncology, radiation oncology and surgical oncology wishing to improve their skills in the management of cancer patients. The programme exposes 50 selected participants from the region to a full spectrum of issues in clinical oncology, with plenary lectures on state-

of-the-art clinical evaluation and treatments, with reference to clinical guidelines. Practical training is offered through clinical case presentations with interactive discussions. In 2018, ESO, together with EONS, organized the first EEBR Masterclass in Oncology Nursing, specifically designed to meet the needs of cancer nurses in CEE countries. Masterclasses are also held for the Baltic region and Eurasia. In all cases, priority is given to applicants practicing in the relevant countries and experts are drawn from the area to facilitate the exchange of experience.

Since 2014, ESO has been organizing refresher courses on specific cancer types for qualified medical and clinical oncologists in Central and Eastern Europe. Refresher courses are aimed at previous participants of Masterclasses and provide an update on state-of-the-art therapeutic options and an overview of the latest advances in the field for the 45 selected participants

All authorized presentations from ESO events are made available on the ESO website. More e-learning materials are offered through e-ESO, including CME-accredited live e-sessions that provide the opportunity to interact with international experts.

The visiting professorship meeting (VPM) programme was established in 2012 to enable knowledge transfer between opinion leaders in specific fields of oncology, local experts and young oncologists. Each year, ESO supports five meetings between visiting professors and clinical institutes in the Eastern European and Balkan Region, and two VPMs in the Eurasian region. The VPM focuses on a tumour type and

discipline. It is organised for up to 50 participants from the host clinical institute, as well as from other institutes in the region or country, and promotes the best possible cancer care given the specific local situation.

ESO offers fellowship programmes for doctors and nurses at clinical training centres. This programme, which is open to applicants also from CEE, offers oncologists and oncology nurses the opportunity to spend up to six months in a clinical setting that is specifically designed to increase knowledge, improve professional development and encourage mobility. A structured educational programme tailors the experience to the individual fellow's needs and specialisations.

The Eurasia programme aims to create a specific educational programme for Baltic and Eurasian countries. The main focus is to organize courses on cancer types that are considered a priority issue for the population of each country and address all stakeholders involved in cancer care, from specialised doctors and nurses to hospital managers and administrators. Since 2014, four Masterclasses in Clinical Oncology have been held in the region. The "Eurasia Courses" are clinically-oriented courses for young oncologists focused on specific cancer types and have been running since 2015. ESO also holds sessions during the annual International Oncology Forum "White Nights" in St. Petersburg, Russia.

In 2016, ESO started a cooperative programme in Kyrgyzstan, with the aim of improving breast cancer diagnosis and treatment. This has already resulted in the setting up of an immunohistochemistry laboratory in Bishkek, as well as personnel exchange and shared educational programmes between Kyrgyzstan, Switzerland and Italy. This successful cooperation will serve as a model for setting up diagnostic and treatment packages and for providing structured educational pathways to doctors, nurses and patient advocates.

Overall, ESO has provided training activities in 18 countries in Central and Eastern Europe. Through the nine Masterclasses organised in the Balkans since 2011, two refresher courses per year since 2014, and several visiting professorship programmes, more than 1500 young oncologists and oncologists in-training from the Balkans will have received high-quality speciality training by ESO over a period of eight years. Many more professionals will have been trained through ESO's e-learning activities in the region.

How can ESO improve training in Central and Eastern Europe?

The input from oncologists from countries in CEE will inform ESO's future strategy for educational activities that address so-far unmet needs in the region. As countries in the region face different challenges, individual activities may be more relevant to a subset of countries. A specific presentation on

access to care issues is included in each Masterclass to provide participants with specific information that can be used to lobby their health authorities to improve care. Development of leadership skills and capabilities for engaged professionals from different countries is a special priority for ESO to help in the creation of a future generation of leaders that will catalyse improvement of care delivery.

To improve knowledge about state-of-the-art oncology, ESO may widen its educational offerings in CEE to residents and medical students. Masterclasses in Oncology Basics for residents, as well as focused courses on select topics especially relevant for CEE or which are so far lacking in national curricula (creating functional MDTs, creating National Cancer Control Plans) are planned. Official recognition of ESO courses by countries in CEE may improve participation and visibility. ESO may achieve a comparatively big impact on resident education, with relatively low investment, by providing or improving access to medical journals and textbooks, which is particularly an issue in LMICs.

Improving the education and involvement of supervisors, particularly in areas where mentors are not adequately prepared for their role, is another aim of ESO. This will include dedicated courses on mentorship, leadership programmes, as well as activities to promote adherence to established curricula.

Within the Clinical Training Centres programme, ESO offers trainee oncologists the opportunity to spend several months in a reputable clinical centre. However, this training opportunity is currently offered only at centres in Western Europe and language barriers may hinder interaction, especially with patients. Fellowships in centres in the Eastern European and Balkan region may also improve cooperation between regional centres and, due to cultural and historical similarities, may address challenges similar to those faced by fellows in their home countries and centres.

A structured educational plan, not limited in applicability to CEE, will point residents towards appropriate courses and training possibilities. This could be developed into an ESO residency, allowing young oncologists to build their personal career pathways within ESO. ESO offers a broad range of e-learning materials, partly CME accredited, as well as all authorized presentations from ESO events. Efforts will be made to improve the visibility of this option, which is particularly relevant in regions where CME is underserved.

Conclusions

According to EUROCARE-5, cancer survival has improved across Europe, starting in 2000, due to access to better diagnosis and treatment. However, differences in outcomes are still evident, comparing CEE with the rest of the EU (13).

ESO uses its position as a financially-independent provider of evidence-based, patient-oriented education in all fields of cancer medicine to drive access to knowledge, particularly in traditionally underserved regions, such as Eastern Europe, the Balkans and Eurasia. ESO's strategic vision for the next three years will stipulate an enhancement of educational activities in this region, with a focus on improving the training of future leaders in oncology. ■

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Dr Aapro chaired the scientific and organizing committees

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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 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 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

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

Figure 1: Disease burden and resources



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.

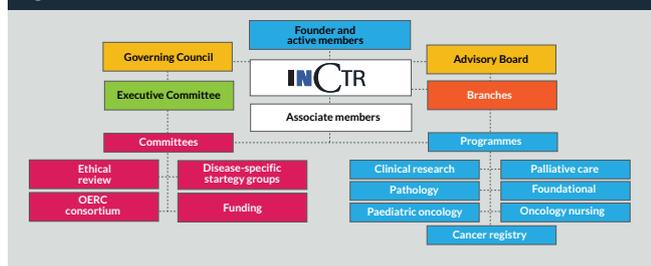
Resource development, administration and programmes (e.g., adult oncology, paediatric oncology, cancer registries, pathology and palliative care) are supervised by an Executive Committee or directly by the branches. The Executive Committee is responsible to INCTR's Governing Council. Programmes and projects 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.

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

Figure 1: Disease burden and 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

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

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 Cancer
Av Nove de Julho, 4275
Jardim Paulista, CEP 01407-199
São Paulo, SP, Brasil
➔ President: Dr Sidnei Epelman
Contact: inctr@inctrbrasil.org

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

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

UNITED KINGDOM

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

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

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 STATES

INCTR USA
5111 Ambergate Lane
Dallas, Texas
75287 -5405
USA
➔ President and Chairman:
Dr Madhavan 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 (Lubumashi, 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)
- ➔ Shaukat 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 Oncologico 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

Improving the outcome of children with Burkitt Lymphoma in sub-Saharan Africa

Dr Ian McGarth, President, International Network for Cancer treatment and Research (INCTR) and Melissa Adde, Director, INCTR Clinical Research Programme

The International Network for Cancer Treatment and Research (INCTR) is an international not-for-profit organization based in Brussels, Belgium. INCTR is dedicated to helping to build capacity for cancer control by increasing the ability of partners in low- and middle-income countries (LMICs) to diagnose and treat cancer promptly, with the ultimate goal of improving survival rates and quality of life of all cancer patients. One of INCTR's major programmes is in paediatric cancer. While other branches of INCTR such as *Alliance Mondiale Contre le Cancer* and INCTR Brazil conduct their own specific projects in childhood cancer that contribute to this programme, INCTR Brussels has its own projects that are also part of the overall paediatric oncology programme. The main project is the treatment and characterization of Burkitt lymphoma (BL) in Africa.

Background

BL, a relatively rare childhood cancer in the United States and Europe, is common in equatorial Africa and accounts for approximately half of all childhood cancers in this world region. It is one of the few cancers that can be cured with chemotherapy alone. In order to improve the outcome of young patients with BL in Africa, INCTR, through its African BL Strategy Group comprised of doctors from Africa, implemented a standard treatment protocol in 2004. The protocol was initially conducted by four institutions – the Ocean Road Cancer Institute in Dar es Salaam, Tanzania, the Kenyatta National Hospital in Nairobi, Kenya, the Obafemi Awolowo University Teaching Hospitals Complex in Ile-Ife, Nigeria and the University College Hospital in Ibadan, Nigeria. In 2010, St Mary's Hospital Lacor (LH) in Gulu, Uganda joined the study. Over 800 patients have been entered on the study. It is presently on-going at LH.

The treatment protocol

The INCTR protocol for BL is relatively simple, affordable, and can be safely delivered in the context of sub-Saharan Africa where there are limited resources for treatment and supportive care. The protocol consists of a First-Line regimen (FL) for newly diagnosed, previously untreated patients

which is comprised of cyclophosphamide, vincristine and methotrexate (MTX) (COM) plus intrathecal (IT) therapy with MTX and cytarabine (ara-C). For patients who fail to respond to FL or who relapse early following completion of FL, there is a Second-Line regimen (SL) which consists of ifosfamide, etoposide, ara-C and IT therapy with MTX and ara-C.

Results

The majority of patients who have been treated are young children – with a median age of seven years. Over 90% of all patients had multiple sites of disease at the time of initial presentation. The most common sites of disease at presentation were abdominal and pelvic masses (62%), followed by jaw tumours (54.5%), orbital tumours (18.8%) and lymph node involvement (18.7%). The majority of patients (76.5%) had a complete response (CR) to FL and 16% had either a partial response or no response to FL. An additional 7.5% of patients could not be evaluated for response because of early deaths within the first cycle due to infection, tumour lysis syndrome, bleeding, sudden respiratory arrest or progressive disease. Seven patients who could not be evaluated for response were lost to follow-up. At the time of relapse or when PR or NR was determined, SL therapy was administered to 129 patients – and 41.1% of these patients went on to achieve a CR. Unfortunately, no treatment was given at the time of disease progression to 25% of this group of patients. With this protocol, overall survival (OS), when calculated using appropriate statistical methods, is 65% at two years. This protocol demonstrates that it is possible to cure children – even those who relapse or who do not respond to initial therapy.

Challenges encountered by families of children with BL

Families of children with BL are faced by many challenges. Families are often rural subsistence farmers who live on a less than two US\$2 a day. They may exhaust what financial resources they have in trying to obtain help at nearby health centres. The centres that they often consult are unable to diagnose, let alone treat children with BL. The majority of families live long distances from the hospitals capable of treating them. Travel can be expensive and difficult, particularly when roads



and more efficient means of transportation are difficult to access. Once they arrive at a hospital capable of diagnosing and treating their child, they must bear the costs associated with treatment, including blood tests, x-rays and ultrasound examinations, biopsy and spinal needles and they must have sufficient funds to support the costs of accommodation and food during treatment.

Parents have other children who remain at home and whose care has to be provided for during their absence. While one parent may remain with a child at a hospital during treatment because of the time it takes to travel back and forth, this proves costly for families in that there are lost wages from the one parent. Even if discharged in between treatment cycles, parents can be confronted with difficult choices such as losing income during harvest season or delaying subsequent therapy for their child so that not only the parents, but also their child with BL, if well enough, can assist with the harvest.

Ways in which INCTR supports children with BL

Over the years, INCTR has supported the participating hospitals and the children in a variety of ways. INCTR has provided training and education to the staff about the protocol as well as providing salary support for medical, nursing and data management staff. It has also ensured that diagnoses made can be more accurate through training of pathology staff and by providing the necessary reagents for more sophisticated tests such as immunohistochemistry that can be performed on diagnostic specimens. The importance of an accurate diagnosis cannot be emphasized enough because without it, children may receive therapy for a malignancy that they do not have. To ease the burden on families, INCTR has provided the funds required for the chemotherapy and for other medicines, patient travel, food and local accommodation. This has been possible from funds raised by a variety of sources – including grants and charitable donations. One fund-raising strategy has been to post a project that is hosted by GlobalGiving (a US-based 501c not-for-profit organization) which is entitled,

“Cure 250 Children with Burkitt Lymphoma in Africa”. GlobalGiving requires INCTR to post reports about the project every three months. These reports go more into depth about specific patients, their stories and the challenges that they have encountered. All reports related to this project can be accessed on INCTR’s project page on GlobalGiving via this link: <https://goto.gg/9630>. Each report conveys meaningful messages about the care of children with BL – intended for both lay-people and healthcare professionals.

Lessons learned and future directions

INCTR continues its collaboration with LH. The INCTR protocol for BL at LH led to other positive changes for all children with cancer seen at LH. A family home, funded by an Italian NGO and staffed by a local NGO, was built on the hospital’s grounds such that families living too far away from LH had accommodation and food. The family home also provides psychosocial support. INCTR made the decision to support a teacher for the children because, due to prolonged periods of time away from home, they were falling behind in their education. Supportive care practices to manage treatment-related complications – the most frequent being febrile neutropenia – were established for all children with cancer. Professional education about the signs of childhood cancer were conducted by LH and included healthcare professionals within the northern part of the country. Public awareness through community engagement has been carried out. And, for many years, LH had dedicated staff involved in the care of paediatric cancer patients. Due to the departure of key personnel, it seemed timely to review how best to train and educate new staff about childhood cancer care. And, while BL remains the most common cancer seen by LH, the care and treatment of the other most common childhood malignancies – Wilms tumour and rhabdomyosarcoma – needs to be addressed. Therefore, using the lessons learned by the implementation of the BL treatment protocol, the mutual goal is to ensure that all children receive high quality cancer care. ■

100% committed to cure: Personalized medicine and advancing research towards the goal of finding a cure for paediatric cancer

Dr Sidnei Epelman, INCTR Brazil

The Brazilian branch of INCTR coordinates programmes in Latin America, particularly in paediatric oncology and palliative care. The branch has a major role in training and education in clinical trials management, and is currently developing a clinical, pathological and radiological review for Brazilian patients with brain tumours in partnership with SOBOPE Brazilian Society of Paediatric Oncology; as well as in promoting the development of healthcare professionals involved in the psychological and multidisciplinary support of cancer patients.

As associated institutions INCTR, Brazil, TUCCA - Association for Children and Adolescents with Cancer - and the Department of Paediatric Oncology at Santa Marcelina Hospital, put into practice INCTR's international directives, being a worldwide benchmark for paediatric cancer treatment, clinical research and palliative care.

Our ultimate goal is to achieve a 100% cancer cure. To this end, we have developed a Centre of Excellence for the Care of Children and Adolescents with Cancer in partnership with Santa Marcelina Hospital, aligned with INCTR's main global objectives.

The major achievements made at this Centre of Excellence

include the establishment of a state-of-the-art inpatient ward and outpatient department for children and adolescents with cancer at the Santa Marcelina Hospital that serves a population of some four million people in one of the poorer areas of São Paulo.

As a result of the research and personalized care offered by TUCCA, Santa Marcelina Hospital and INCTR Brazil, more than 70% of children and adolescents with cancer treated at our centre can now be cured. Unfortunately, this excellent result is not achieved in most centres in Brazil. But, while the results are similar to those obtained in North America and Europe, there remain some patients whose tumours are resistant to treatment. Care, however, is never withheld from children even when cure is not possible, and the very existence of a hospice - the first paediatric one in Brazil - reminds us that each of us has the right to die without physical pain and with dignity.

It provides comprehensive end-of-life care that is not limited to the required medical and nursing care, but also includes psychosocial support. Assistance is provided after death - which includes not only support, but also to ensure family wishes are respected when life ends.

The hospice is supported by funds raised by TUCCA and



donations from the business community. In spite of the poverty of the families who have lost a child, they too contribute in small ways to show their appreciation for the care they received at the hospice.

The branch has also a major role in the treatment of retinoblastoma. Sadly, retinoblastoma is commonly diagnosed at a late stage in countries with limited resources. Efforts aimed at early detection can reduce the stage at diagnosis, potentially improving cure, saving the eye (preserving vision) and enabling simpler and more cost-effective treatment.

Considering this challenging context, we have developed an international early diagnosis campaign translated to over twenty idioms, including African languages. More recently, we have succeeded in having 18 September declared as the “National Day of Awareness and Encouraging Early Diagnosis of Retinoblastoma”. To gain the attention of the Brazilian population of the importance of the need for early diagnosis of retinoblastoma, TUCCA and INCTR Brazil managed to send this message to the general public with the cooperation of many others. One of the most notable activities took place at night, when the lights that illuminate the monument of Christ the Redeemer, which stands some 124 feet high atop the Corcovado hill in Rio de Janeiro, were switched off for several minutes to draw attention to the blindness caused by retinoblastoma.

We also maintain an Integrated Retinoblastoma Care Centre in partnership with Santa Marcelina Hospital. It offers advanced therapeutic options, such as intraarterial chemotherapy. In most cases, the technique has allowed preservation of a child’s eye and vision, resulting in 70% of eyes being preserved.

Aligned with our mission, psychosocial support is provided in several ways:

- Psychosocial support and counselling are provided to



patients and their families at the time of diagnosis and continuing throughout the treatment.

- A lodging-house has been built for the parents and patients who live far away, where distance makes it difficult for them to go home in-between treatments.
- Daily transportation is provided for those who live locally, but who have difficulty accessing public transportation – either due to disability or who live long distances from points of access to public transportation.
- Transportation is also provided for patients who live in the cities outside Sao Paulo where cancer care is not available.
- Schooling is provided to children to ensure that they continue their education during treatment in classrooms at Santa Marcelina Hospital.
- A special kitchen where a locally famous chef teaches parents how to cook has been set up. This weekly session brings families together in a more relaxed atmosphere.

We are currently focusing on three major initiatives: a multi-institutional collaborative study on childhood leukemia, in partnership with the National Institute of Cancer (INCA), the development of a biobank aimed to have a double impact by providing country-specific access to personalized medicine and advanced research and a molecular pathology laboratory. Since its inception, the laboratory has been developing and performing state-of-the-art molecular-based tests to aid in the diagnosis and management of Medulloblastoma. All initiatives are highly cost-effective from a societal perspective and benefit patients with brain tumours, leukemia and retinoblastoma throughout the country, even those not treated at our centre.

Our vision for the future is to be able to ensure access to appropriate treatment and supportive care for children and adolescents with cancer, from all over the country, even those who are not yet diagnosed. We are 100% committed to cure. ■



Two Worlds Cancer Collaboration Foundation: INCTR – Canada

Dr Simon B Sutcliffe, Director, INCTR Canada: Two Worlds Cancer Collaboration Foundation, Vancouver, Canada

Mission and programme objectives

Two Worlds Cancer Collaboration Foundation (Two Worlds Cancer), also known as INCTR Canada, is a volunteer-based Canadian not-for-profit society and registered charitable foundation with a mission to improve cancer control by building capacity for leadership, skills development, high-quality cancer care, early detection and research in low- and middle-income countries through provision of leadership and the necessary infrastructure for programme implementation in urban and community settings. Two Worlds Cancer emphasizes long-term collaborations with medical institutions and qualified physicians and investigators in developing countries, including the conduct of clinical trials and research associated with clinical service, training and mentorship. Two Worlds Cancer also promotes alliances between cancer centres, hospitals and organizations, both within and between countries, to ensure that available expertise to support resource-poor countries is maximized.

Past and current initiatives

Two Worlds Cancer Collaborations' current activities are focused on supporting palliative care development in South Asia:

India

Through collaboration with the MNJ Institute of Oncology & Regional Cancer Centre (MNJ) and the Pain Relief & Palliative Care Society (PRPCS – a Hyderabad-based NGO), the programme focuses on the establishment of a strong core facility in Hyderabad, with the ability to create increased scope and scale for palliative care locally, nationally and globally. The elements are:

- ➔ Urban Centre (Hyderabad): inpatient, outpatient and hospital-based support for adults, adolescents and children with cancer; 24/7 home care (Life at Your Doorstep): a 28-bed inpatient hospice.
- ➔ Rural & Community (Telangana): a 30-village network of supportive care, with, in addition, four small rural hospices, soon expanding to eight across Telangana, linked and supported by MNJ through mobile outreach and video conferencing. A Government of Telangana Initiative has provided eight district-based palliative care centres in the state in the first phase to provide palliative care by means

of home and hospice care in the rural community. The programme is supported by MNJ and PRPCS.

- ➔ A six-week training programme for health professionals, comprising a core curriculum, conducted every two months.
- ➔ Development of fellowship programmes for future specialists in palliative care.
- ➔ Project ECHO Paediatric Palliative Care Course – an online educational platform – Project ECHO provides an interactive “distance” paediatric palliative care course developed as a collaboration between Hyderabad and Dhaka, Bangladesh, provided to participants from India, regions of South Asia and international locations.
- ➔ LäraNära Programme – A “distance” online training programme for residents in radiation oncology at MNJ.
- ➔ Collaboration and support for the community, home palliative care programme in Visakhapatnam, Andhra Pradesh.
- ➔ Establishment of a paediatric palliative care programme at the Niloufer State Children's Hospital, Hyderabad.
- ➔ A preliminary pilot study in oral cavity cancer early detection in a rural community in collaboration with Hyderabad-based, private and public dental institutions, MNJ, PRPCS, and the British Columbia Oral Cancer Prevention Program.
- ➔ Support for palliative care services with CHAI (Catholic Hospital Association of India) and St Mary's Hospital, Bangalore.
- ➔ Opening of the Hyderabad Centre for Palliative Care to coordinate programmes and to be a centre for advocacy.

Nepal

Through collaboration with NAPCare (Nepal Association for Palliative Care), Two Worlds Cancer Collaboration provides support for palliative care:

- ➔ Establishment of the Nepal Strategy for Palliative Care, approved by Government in April 2017, and now undergoing implementation.
- ➔ Infrastructure and administrative support for NAPCare.
- ➔ Support for health professional training through the Hyderabad Centre educational programmes and locally in Nepal through Two Worlds Cancer team members and our

local partners.

- ➔ Support for the establishment of a new Hospice Nepal.
- ➔ Ongoing collaboration and support with palliative care programmes at a number of sites, including Bhaktapur Cancer Hospital (Partners in Compassion), BPK Memorial Cancer Hospital, Nepal Cancer Hospital and Research Centre, Hospice Nepal, and Patan Medical School.
- ➔ Development of a rural palliative care programme, centred around female health workers.
- ➔ Development of children's palliative care programme.

Sri Lanka

Initial development of palliative care services in Northern Sri Lanka, comprising:

- ➔ Advice to local public health officials.
- ➔ Health professional education through the Hyderabad Centre training course.
- ➔ Conducting on-site training workshops.

Bangladesh

Through collaboration between Dr Megan Doherty (University of Ottawa, World Child Cancer & Dhaka Children's Hospital, Bangladesh), the Hyderabad Centre for Palliative Care and Two Worlds Cancer: Assisting in the development and delivery of an online, paediatric palliative care course – Project ECHO programme – No Pain Too Small – for participants from India, regions of South Asia and international locations.

The Programme funders

Two Worlds Cancer Collaboration receives 100% of its revenue from philanthropy, comprising individual donors, foundations, gala events and website donations.

Specifically, Two Worlds Cancer receives no direct funding from governments (national or provincial, Canadian or Indian/South Asian), or from registered health charities (NGOs).

Funding received from the private sector and industry is directly related to sponsorships and contributions in support of gala events.

Funding for the Two Worlds Cancer Collaboration programmes over the next five years approximates C\$550,000 per annum.

The countries/regions where we have been involved

Two Worlds Cancer Collaboration is currently present and active in South Asia: in India (MNJ Institute and Pain Relief & Palliative Care Society, Hyderabad), Nepal (NAPCare, Bharatpur Cancer Hospital and BPK Memorial Cancer Hospital, Kathmandu), Sri Lanka and Bangladesh.

The activities are conducted through core "hubs" (India and Nepal programmes), with alignment and linkage of palliative

care activities with Sri Lanka (training & education) and Bangladesh (paediatric palliative care/Project ECHO).

South Asian programmes are focused on palliative care (adult, adolescent and paediatric) with modest cancer control activity through radiation residency distance-education and pilot studies in oral cavity early detection.

Two Worlds Cancer Collaboration has previously been active in palliative care in Brazil and in Tanzania, and although it has no current initiatives or palliative care activity in these regions, there is the hope that previous efforts continue to benefit programmes and individuals locally.

The institutions and agencies that have been involved in our work

Two Worlds Cancer Collaboration is the Canadian branch of INCTR and is an active member of the network.

In India, Two Worlds Cancer works closely with the MNJ Institute and the Pain Relief & Palliative Care Society (Hyderabad).

NAPCare (Nepal Assn. for Palliative Care) is a programme partner in Nepal. A twinning project is in place between Bharatpur Cancer Hospital and Partners in Compassion, Nanaimo, BC. Formerly, BPK Memorial Hospital, Bhaktapur and the Victoria Hospice, BC, operated a twinning programme.

Collaborations exist with the Northern Province, Sri Lanka, and Dhaka Children's Hospital, Bangladesh.

Online educational initiatives are part of the Project ECHO global education initiative, operated on the ZOOM video conference platform.

Research collaboration exists with the University of Edinburgh, Scotland, and an active, funded programme has been initiated with the University of Virginia, the Fogarty Foundation and NAPCare in Nepal.

How the programmes have been run

The Canadian component comprises 16 volunteers: health professionals (12); fundraisers (1); communications/marketing/photojournalism (3) and three contracted staff – an Executive Director (0.5 p/t), an Admin/Operations Assistant (0.2 FTE); and Accounting, Audit & Payroll (2 p/t FTE).

Two Worlds Cancer Collaboration administrates and manages the operations as a virtual enterprise based in BC, Canada, engaging with the host partner by regular ZOOM video conferences, conducting monthly executive meetings of Two Worlds Cancer volunteers and staff by video conference, and being present onsite in South Asia for 2-4 weeks per year.

In India, Two Worlds Cancer pays the compensation for the Executive Director (1 FTE); Executive Assistant (p/t); Pediatric Palliative Care Consultant (1 FTE), Palliative Care Medical Officer (p/t) and PRPCS for programme in regions in Telangana.

PROGRAMME OUTCOMES AND ACHIEVEMENTS: A BRIEF REPORT (INDIA)

Activity statistics for the Hyderabad Palliative Care Program include:

MNJIO (2017-18)

Adult Palliative Care

New patients	Review patients
3,790	10,647

Morphine consumption

Adults	Pediatrics
Kg. 9.592	G. 482

No of 6 Week certificate courses: 7 courses

No of candidates trained:

Doctors: 29

Nurses: 38

Social Workers: 09

Pharma D/ Counsellors'/ ANMs/ Physiotherapists: 16

PAIN RELIEF AND PALLIATIVE CARE SOCIETY HOME-BASED PALLIATIVE CARE PROGRAM

Total Number of Registrations	Total New Visits	Total Review Visits	Bereavement Visits	Total Visits
550	495	2,534	91	3,120

PAIN RELIEF AND PALLIATIVE CARE SOCIETY KUMUDINI DEVI PALLIATIVE CARE CENTRE, HOSPICE

Male	Female	Children	Total
349	318	56	717

MNJ INSTITUTE PAEDIATRIC PALLIATIVE CARE

New Patients	Review Patients
418	6,157

DISTRICT-BASED PC PROGRAM (JUNE-AUGUST 2018)

Total Patients seen in IP- 406

Total patients seen in Home care- 1,893

Patients identified in Survey – 1,891

MNJ INSTITUTE & PAIN RELIEF AND PALLIATIVE CARE SOCIETY RURAL OUTREACH PROGRAM

For the Chevalla community palliative care programme, a sample of the capacity-building support provided by the Hyderabad palliative care programme is as follows (2017):

Clinical Services

- Physician consultation and management of pain and other symptoms and end-of-life care.
- Nursing care such as care of the bedridden, wound care, oral care, catheterization, administration of drugs.

- Daily ambulation for bedridden patients.
- Communication and education of patient/family by checking insight, setting up goals of care, eliciting expectations and clarifying concerns.
- Physiotherapy: exercises, training of the family to maintain exercises at home and efforts at rehabilitation.
- Multidisciplinary team activities, such as care plans and decision-making, homecare plan, reviews, referrals, reports, interactions with field support team and mortality meeting.

Educational activities in the team

- Visiting experts, Dr Gayatri Palat (PC physician), Mr Swaroop (PC nurse specialist).
- Thrice-weekly online learning sessions via ZOOM with topics including: nursing procedures, nursing care plans and managing oedema of the neck (Ryle's tube insertion and medication).

Other activities

- Awareness camp for caregivers of stroke patients in the community.
- Multi-purpose community health workers: house-to-house survey for palliative care patients in 948 houses, one awareness meeting and three focus group discussions on palliative care.
- Area Hospital: to improve the scope of care, there is a constant interaction and engagement of rural hospice team with the area hospital doctors and staff. Some of the efforts had been to facilitate the application of a morphine licence with the drug controller, creation of the essential drug list for palliative care working with the hospital pharmacist, laundry and bio-waste disposal services.

Future plans and goals for the period 2019-2023:

Programmes:

- Continue to build "core" institution-based strength (Hyderabad), and community "scale-up" and support for continuing development of palliative care programmes in Telangana and other locations in India, Nepal, Sri Lanka and Bangladesh.
- Develop the Hyderabad Centre for Palliative Care as an independently-governed resource for palliative care development in Telangana, India and South Asia through networked collaboration locally, nationally and internationally.

Two Worlds Cancer/INCTR-Canada:

- Strengthen infrastructure: administration, operations and fundraising through appointment of a dedicated fundraising professional, establishment of a Two Worlds Cancer Collaboration Board of Directors and strengthen governance.

Funds are transferred from Canada to those contracted and the PRPCS for periodic disbursement according to defined “milestones” and reported deliverables as set out in annual MoUs.

Two Worlds Cancer funds build capacity for palliative care through direct personnel compensation and programme development support.

The host partner in Hyderabad provides local programme administration, management and operations and submits regular reports on expenditure, activity statistics and relevant care outcomes.

All meetings (local and international in Canada or India) are conducted by internet using Zoom technology (funded by Two Worlds Cancer, including a part-time IT support person in Hyderabad). The ZOOM platform is also used to support the Project ECHO program in palliative care across South Asia.

Two Worlds Cancer employs a donor database, e-Tapestry, for donor management and receipt issuance.

The Two Worlds Cancer website is: twoworldscancer.ca ■

The Alliance Mondiale Contre le Cancer (AMCC): Programmes present and future

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The Alliance Mondiale Contre le Cancer (AMCC) has developed three programmes associated with clinical and research objectives. These programmes are in accordance with the objectives and goals of INCTR. They are undertaken with academic institutions, scientific societies and French and African charities linked to the local authorities of the African countries in which the projects take place. The three thematic areas are retinoblastoma early diagnosis and treatment, pain and palliative care and pathology.

The retinoblastoma programme

The objective of this programme is to develop a proof of concept through data, to demonstrate to healthcare authorities that children with early stage retinoblastoma (Rb) can often be cured with minimal relative expense compared to the high-stage disease, and also that these patients can be expected to become productive members of society as their vision can also be preserved in most bilateral cases. The hope is that the programme will succeed in demonstrating the cost-effectiveness of this initial intervention and that government and the Ministry of Health will then be willing to take up the expenses of this disease as a public health improvement effort. One of the components of this project is a real-time study of the cost of therapy for retinoblastoma patients.

In 2018, in addition to following up previously treated patients, the programme to improve early diagnosis, treatment and rehabilitation of children suffering from retinoblastoma in sub-Saharan African countries has continued to expand. This programme is active in Bamako (Mali), Lubumbashi (DRC), Abidjan (Ivory Coast), Dakar (Senegal) and Antananarivo (Madagascar). This programme is run in collaboration with GFAOP (Groupe Franco Africain d'Oncologie Pédiatrique), the Curie Institute, Prothelem, Retinostop and supported by a grant from Foundation Sanofi-Espoir, as well as funding from the French Health Ministry.

Current outcomes of AMCC's retinoblastoma programme are reported in presentations and publications from the Bamako team (1-4).

Besides the treatment, educational programmes are also

undertaken in several places, for example, in Bamako with the training of a second ophthalmologist, Dr Aichata Tal, who was trained at the Curie Institute in January 2017 and who returned in December 2018. She is now working with Dr Fatoumata Sylla at IOTA in a permanent position. A nurse anaesthesiologist from IOTA spent two weeks in Paris in 2018 to be trained for the specificities of anaesthesiology in young children with retinoblastoma.

At a fundamental research level, Dr M Keita, assistant in the pathology department (Professor Cheick Traore) in Bamako, Mali, is involved in a research project on the genomic abnormalities in Rb with the Curie Institute and funding from the French association, Retinostop. During 2018, 24 samples of Rb of good quality, were analysed by him with the team from the Curie Institute.

In 2017, with a special grant from the Sanofi-Espoir Foundation to accelerate and finalize the implementation of conservative treatments in Senegal, additional equipment and training for Dr Paule Ndoeye, Head of the Ophthalmology Department at Le Dantec Hospital in Dakar, provided techniques and indications on conservative treatments. It was also an opportunity to launch a media campaign on early diagnosis and to set up registration for all cases of retinoblastoma seen by the Dakar team.

For this programme, meetings were organized, the last of which was held at the Curie Institute in Paris on 22 November 2017 with Dr Rokia Berete, Abidjan and Marcel Ngoy, Lubumbashi to discuss the extension of early detection conservative treatments for Rb to other centres, as well as financial support for retinoblastoma treatment (a request to health ministries).

This will continue with a meeting planned in Paris for 2019, for the three teams (from Bamako, Abidjan and Dakar) who are now able to practice conservative treatments for the early stages of retinoblastoma, particularly in bilateral cases. The objective is that these three teams become reference centres for training other sub-Saharan African countries.

This will be the first step in our next programme (2019-2028) aimed at extending the retinoblastoma programme to all francophone sub-Saharan countries and also to some anglophone countries.

This programme will also allow presentations to be made at international congresses and in publications (1-4).

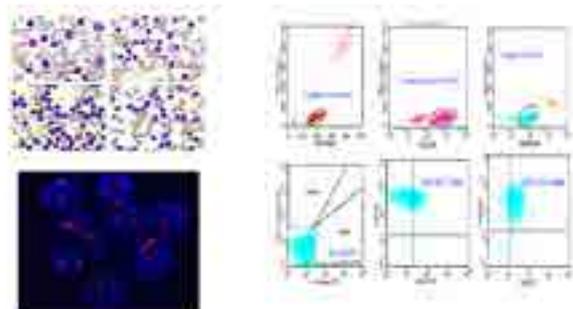
Figure 1: Retinoblastoma: a caritative concert organized by the Foundation Sanofi Espoir, My Child matters programme, with Dr Anne Gagnepain-Lacheteau, Medical Director of the Foundation



Figure 2: Palliative care: Preparation of oral morphine syrup



Figure 3: Cytological, immunophenotypical and cytogenetic analysis of a CLL from Senegal, using the platform i-Path, the pictures are sent for validation by experts. Small lymphocytes, expression of CD5, CD23, and low expression of slg, trisomy 12 detected by FISH



The pain and palliative care programme

This programme has two main objectives: (1) Advocacy for the fight against pain and discomfort in cancer and for the integration of palliative care into oncology programmes in sub-Saharan francophone countries and (2) Training competent teams with the objective of setting up reference centres to take care of patients and to train nurses and local healthcare professionals.

This programme is supported by the "Pierre Fabre" Foundation for five years and AMCC organizes an in-country workshop every two years. In 2017, the third oncology pain management workshop was held in Cotonou, Benin. The workshop was organized in partnership with the Association Francophone pour les Soins Oncologiques de Support (AFSOS), the French-Benin Association for the Fight Against Cancer (AFBLCC), the Beninese Association of Palliative Care (ABSP) and the Beninese Cancer Association (ALCC, Benin) with the support of the World Health Organization (WHO), Médecins Sans Frontières (MSF) and the Ministry of Health of Benin.

The scientific programme aimed at better integrating palliative care into oncology care at an early stage and focused on patients' pain assessment, use of analgesics, use of morphine, breaking bad news, management of wounds and paediatric palliative care.

A major event was the announcement of the delivery of a machine for the manufacture and dilution of morphine syrup and the imminent arrival of morphine powder in Benin in order to prescribe and distribute an effective oral analgesic.

Seven countries were represented in Cotonou and the

workshop was an opportunity to exchange best practices from countries including Benin, Ivory Coast, Togo, Senegal, Congo Brazzaville, Uganda and France.

The next workshop is planned for 2019 and should be organized in partnership with Bobo Dioulasso Medical University in Burkina Faso.

To complement the training, AMCC has launched a Palliafrique Forum (5) in April 2017 at the workshop in Cotonou. This Forum offers an exchange platform to all actors and associations active in the field of pain and palliative care in French-speaking Africa. It aims to support the creation of reference centres and to support training for pain care and palliative care in oncology. It can be accessed at www.forum-palliafrique.org.

This Forum, coordinated by Sabine Perrier-Bonnet, is mainly involved in palliative care training in Africa and is open to all healthcare professionals and students who want to improve their knowledge and/or exchange on palliative care and pain management issues. The Forum was presented at the Fourth International Francophone Congress of Palliative Care in Geneva in November 2017 and shows active exchanges between these different centers (6).

Pathology programme

In 2017 and 2018, the main activity of the pathology programme was the diagnostic support in hematopathology via telepathology with three actions:

- The extension of the network of the i-Path platform with the purchase of new microscopes for several centres: Abidjan (Ivory Coast), Bamako (Mali), Kinshasa (DRC),

Ouagadougou (Burkina Faso), Lubumbashi (RDC), Antananarivo (Madagascar) and Yaoundé (Cameroun). This was funded by grants from the Foundation Obelisque, Paris, and by the Foundation Sanofi Espoir in order to equip these new centres. The network of telepathology in French-speaking African countries now includes 10 centres (7). A first meeting on telepathology was organized in Paris on the 27 September 2018 at the Foundation Sanofi Espoir. Past and present experiences were presented as well as new equipment for the future with the possibility of digital pathology and whole slide scanning if standard techniques improve.

- ➔ Participation in the Treatment Protocol for Aggressive B-cell Lymphoma in Adults in Dakar, coordinated by Professor Saliou Diop (Hematology, Dakar) and Professor Pierre Feugier (Hematology, University Hospital Nancy) which began in September 2018. This protocol is supported by INCa (French National Cancer institute) and the role of AMCC is to coordinate and review the slides for patients enrolled in the protocol through the i-Path platform.
- ➔ Support in organizing the Pathology Committee of the GFAOP, which was launched in November 2017 during the GFAOP meeting. Dr Elisabeth Auburger, member of AMCC and Head of the Pathology Department of the General Hospital Simone Veil, Eaubonne, is the coordinator of the Committee. This Committee includes pathologists from francophone sub-Saharan countries and from Maghreb. The pathologists from the South are connected to the Path platform and they are invited to meetings for the review of slides of patients enrolled in therapeutic protocols for nephroblastoma, retinoblastoma and Burkitt lymphomas. These meetings are organized by Professor Aurore

Coulomb-L'Hermine (Head of the Pathology Department at University Hospital Trousseau, Paris).

Besides the diagnosis support, the pathology programme is also involved in more fundamental research. Research was developed during the PhD thesis at the University Cheick Anta Diop, Dakar, with Dr Abibatou Sall on lymphoproliferative disorders in Senegal in 2016. After a clinicopathological study of CLL cases from Senegal (8,9), (Figure 3), the analysis of immunoglobulin genes was undertaken by Professor Lorenzo Leoncini's team at the Department of Pathology, University of Siena. Material from Chronic Lymphocytic Leukemia (CLL) patients included in this study was analysed by NGS (New Generation Sequencing) and showed preferential usage of specific immunoglobulin heavy chain variable region with unmutated profile and advanced stage at presentation in Senegalese patients in comparison with Italian CLL patients suggesting diverse genetic and microenvironmental backgrounds (10).

In conclusion

The programmes developed by the AMCC are in line with the programmes of INCTR. In some Francophone African countries, they are mainly involved in paediatric oncology and conducted in collaboration with the GFAOP.

These programmes are supported by public and private institutions or foundations. The ultimate objective is to improve the care of cancer patients (adults and children).

These actions on retinoblastoma, pain and palliative care and pathology are ongoing with the objectives of education and training, early detection and treatments for malignancies, support diagnosis and research. ■

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*“Universal health coverage (UHC) is the vehicle we must use to prevent and manage cancer. I have made it a priority for WHO to support governments in achieving UHC. Policy-makers can take immediate steps to further prioritize cancer prevention and control in the context of efforts to strengthen primary and broader healthcare systems. My hope and expectation is that future issues of *Cancer Control* will be able to highlight the successful integration of cancer prevention and control into the UHC agenda, with many more lives saved.”*

Dr Tedros Adhanom Ghebreyesus, Director-General, World Health Organization
– foreword to *Cancer Control 2019*

“While we understand the often competing and difficult decisions that governments face with scarce available resources, we have also walked in the uncomfortable and distressed shoes of patients who must make the unconscionable decision about whether to put food on the table or to get their lifesaving medications, and that is if that medicine is even available, affordable or accessible. As President of UICC and the former Director General of the King Hussein Cancer Foundation, I have witnessed this inequity at first hand during visits to various developing countries.”

HRH Princess Dina Mired of Jordon, President of the UICC – *Cancer Control 2019*

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