CANCER CONTROL 2025

CANCER CARE IN EMERGING HEALTH SYSTEMS

EDITOR-IN-CHIEF: **PROFESSOR SIMON SUTCLIFFE**, PRESIDENT, TWO WORLDS CANCER COLLABORATION
COMMISSIONING EDITOR: **MARK LODGE**, CHAIR, UK AND IRELAND GLOBAL CANCER NETWORK

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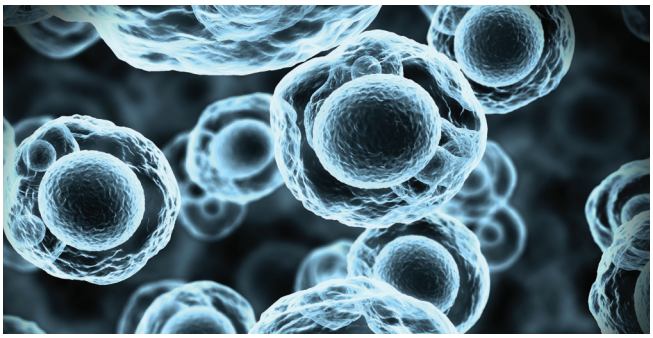

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Is the bell tolling for global health?

Dr Simon Sutcliffe, Editor-in-Chief, *Cancer Control*

The burden of chronic diseases, including cancer, continues to rise. Implementing solutions now assumes new relevance as support for global health agencies is being withdrawn; foreign aid – both general and programme-specific – has been reduced or abandoned; direct and indirect support for academia, innovation, and research is under threat; and established relationships between countries are being dissolved or renegotiated.

For the high-resource world, the privilege of choice regarding our health and wellbeing is due to ~200 years of improvement in the public's health – controlling communicable diseases and risk factors – and ~75 years of improvement in the public's illnesses through medical interventions directed to the causes and treatment of disease. The result has been the creation of wealth and a civil society that values and provides social protections for its citizens. By contrast, billions of people in lesser-resourced countries endure poverty, pain, misery, and suffering. This is their children's inheritance. Who our parents are, where they live, and how we grow up determines our choices, our lives, and predicts our outcomes

Despite being "cut from the same genomic cloth", neither equity nor equal opportunity prevail. We value the same things – happiness and wellbeing, standard of living, health, education, fairness, trust, generosity, etc. However, socio-emotional competence, the value of culture and community, humanity and human development are eroding. The elitism of imperialism, colonialism, ethnicity, and race is being replaced by the elitism of nationalism, populism, social media, transactional relationships, and return-on-investment.

Disruption is good if it results in constructive thought and action to address existing problems. John Kerry's words (March 2024) remain prescient: "If we did the things we could do, that we know how to do, and that we have the technologies for – we could actually do it. We're just not. We're not doing it on a global basis. And everybody seems to be locked into a place of indifference". Indifference must now be replaced by a new direction – social, economic, political, and medical advance, particularly now in a time of increased political and financial uncertainty.

The fundamental belief in decency, hard-work and the health of self, society, and the planet is now challenged by contrasting political philosophies, polarizations within society, and materialism undermining interdependence, global collaboration, and mutual support. High-resource nations increasingly prioritize "individualism", personal achievement, and independence, rather than "collectivism", social cohesion, and interdependence. Continuing human development in low- and middle-income countries will require national and global social investment, not just external "foreign aid". Could external debt repayment be exchanged for investment in social determinants of health? Could repeated cycles of emergency and disaster relief be replaced by investment in resilient infrastructure and sustainable development? Could foreign aid be aligned with improvements in population health, more complete universal health coverage, social protections, and stronger, more resilient societies?

John Donne (1573–1671) recognized interdependence, the importance of community and social responsibility in times of religious and political upheaval in "For Whom the Bell Tolls":

"Each man's death diminishes me, for I am involved in mankind. Therefore, send not to know for whom the bell tolls. It tolls for thee".

Rather than contest or debate the "rights and wrongs" of evolving global politics and finances, the healthy now must be "what must we now do to advance global health", "can we?" and "will we?" ■

THE *CANCER CONTROL* CONSULTATION

Health and well-being: What matters and whose opinion counts?

We live longer, but do we live better? Do we value a longer life – achieving our natural life expectancy and beyond? Or the realization of a functional life – fulfilling a productive physical, mental, and social life? Or is it the enjoyment of living – relationships: personal, family, work, community, and society; satisfaction, contentment, and being remembered with respect and affection?

Although humans have been on earth for over 3 million years, it is only in the last 200+ years that life expectancy at birth has doubled – the gain of an extra life. Through the control of premature death, we live longer, create wealth, achieve a decent standard of living, value education, and promote freedom of choice through a civil society that values individual and societal well-being. In the Westernized world, we have established choice regarding our health and well-being – the resource whereby we realize aspirations, satisfy needs, cope with a changing environment, and appreciate the value of living.

However, we relinquish one-third of our gain in longevity (our lifespan) through compromise to our physical, mental, emotional, spiritual, and societal well-being (our healthspan). How do we view the balance between the things that threaten our living – our "lifespan" – and the things that threaten our days – living well, our "healthspan"?

Our genes, environment or circumstances are conferred by our parents. Irrespective of birth circumstances, the common principles underlying health and well-being: a decent standard of living; education and opportunity; a fair, just and caring society; a healthy life expectancy; freedom to make life choices; and the value systems underlying wise choices: generosity and trust; community vitality; and a safe and secure environment. We choose what we value, and choice depends upon options and the ability to pursue them. Living, dying, caring, and grieving impact us all, no matter what our circumstances. They are shaped by the socio-cultural-economic and political contexts in which we live.

If the goal is "a good life" and "a good death", as individuals, caregivers, and community/society, how do we value fully informed choice, prioritizing the person as well as disease, and social justice, social protections, and quality healthcare for all? ■

Professor Simon Sutcliffe, Editor-in-Chief, Cancer Control

RESPONSES

Bahija Gouimi, *President and Founder, AMAL Association, Morocco and* ***Zainab Shinkafi Bagudu,*** *CEO, Medicaid Cancer Foundation and President-Elect, Union for International Cancer Control*

In a digital age where technology, therapeutic advances, and artificial intelligence are at their peak, how do we understand care? Do we see it as cure of a disease or as healing in a more holistic sense? What about the much-touted patient-centred approach and quality of life? Are these just slogans, trends, buzzwords… or a tangible reality? Today, a person living with cancer is not merely seeking a treatment that might extend their life further into old age. They long for care that treats them with dignity – care that respects their humanity, meets their needs, soothes their fears, understands and relieves their suffering, and, above all, listens to their dream of living better, of living a "normal" life.

A healthcare system must be attuned to the real, complex, and multidimensional needs of people living with cancer. They are not just vessels for treatment, a medical file, a hospital bed, a statistic, or a cost to be reduced in a budget. They are individuals, each experiencing their own unique life situation.

And every life has value. Every person carries a unique story, voice, expectations, doubts, and personal challenges. They want personalized answers. They want to be heard, respected, supported, and involved – regardless of their illness, age, gender, location, language, origin, or beliefs.

A person living with cancer is not just "a patient" but a legitimate partner who must always be valued in the design of care pathways – not only to improve their health, but also to

enrich their quality of life.

In many low- and middle-income countries, countless people living with cancer still lack access to treatment due to distance, centralized care, or lack of resources. Entire families collapse under the mental burden, the psychological, social, and financial pressure of a cancer diagnosis. People feel alone, invisible, voiceless.

What truly matters?

What matters is being treated with fairness, being included in the solutions, having their stories heard, their experiences respected, and health policies designed not just for them, but with them.

We cannot always emphasize the length of a person's life. What we know from people who have experienced cancer is that the quality of their life is hugely important to them and to their families.

Health is not just the absence of disease. Health is, above all, a sense of safety, support, and dignity. Unfortunately, when cancer is detected very late, where there is not access to treatment or pain relief, where there are unclear care pathways, and where people spend their life savings to secure the treatment and care they need, these principles fall by the wayside. A person in pain feels their dignity being stripped away. When a person is treated as a medical case only, they are stripped of their humanity.

The Union for International Cancer Control (UICC) is proud to launch the global World Cancer Day campaign for 2025–2027: "United by Unique", which calls for a fundamental shift in how we approach cancer care and health systems around the world. As advocates and patient representatives, we urge the cancer community to ensure that services are delivered at the right time, in the right place, and in the right way. This requires actively engaging individuals and communities in decisions about their own health – and upholding their dignity and well-being as central to every aspect of care.

If a life is marked by delayed diagnoses, lack of information, insufficient support, treatment disruptions, inequality, stigma, indifference to my suffering, long waits, and unclear care pathways… then that's not LIFE – it's mere SURVIVAL.

RESPONSES

Annie Young, *Professor Emerita, Warwick Medical School, University of Warwick, and Co-Founder, Global Power of Oncology Nursing*

Well-being is intrinsically linked to the basic human rights of mental and physical health, and a decent standard of living, as Simon Sutcliffe points out.

We now have robust evidence on how to improve healthspan; we have the measurements (for example, the new WHO Well-Being Index: WHO-5) nonetheless, we now need to get a GRIP (getting research into practice) to help us close the gap between lifespan and healthspan. Genes aside, if we only perform what we already know, including striving for an active social life, keeping mentally engaged, eating well, exercising, and sleeping well, we may succeed.

In countries of mid to high human development, a diagnosis of cancer or other serious condition is sometimes a trigger to make a fresh start – to work towards a productive as possible physical, mental, and social life, enjoy spending more time with family and colleagues; and give something back to the community towards a more compassionate society. These are not mutually exclusive.

As cancer healthcare professionals, we learn to listen and value the opinion of a person with a cancer diagnosis in front of us and, if their relationship is good, listen to the caregivers. They tell us what life is really like. We not only listen but hear their words and concerns, act on what is within our sphere of influence and strive to keep in touch.

Now is the time to move outside our comfort zones – to lobby for interventions known to improve the subjective well-being of people – to be added to the list of public health measures crucial to personal, community, and socioeconomic development. Nevertheless, putting the list into practice is all down to first-rate personalized care and also setting an example ourselves. In addition, as global healthcare professionals, we will not be shy to speak out about people who are denied these basic human rights; for example, people who live in areas of conflict and have no choice over their healthspan, not to mention their lifespan. We will shout loud for some form of basic healthcare, social justice, and social protection, including publishing the facts.

Currently, we live longer and do not live better. We can change this for the collective good. What matters is acting on the voice of the individual wherever they may live; their opinion counts.

RESPONSES

Jane Ross *has worked for many international and Canadian organizations supporting the physical, mental, and emotional support of people with disabilities and challenges. She is now retired.*

Scientific research, emergent technologies and therapeutics, and evidence-based medicine have dramatically expanded detection and treatment of cancer. Survival has improved, lifespan is longer. However, research is costly, slowly translated, and of limited reach to all who could benefit.

Cardiotoxicity (heart damage from treatment) impacting the health of cancer survivors is the second leading cause of death following diagnosis. Thirty percent of those surviving cancer struggle with cardiotoxicity and its long-term effects. Yet, worldwide, cardio-oncology services are non-existent or of limited availability despite telemedicine, machine learning, and integrative technologies to embed AI (as Augmented Technology) into clinical practice.

The study of survivorship, whilst not new, grows as the number of survivors grows, as does the suffering and the side effects – cardiotoxicity, post-surgical, radiation late effects, hormonal changes, and physical, mental, emotional, social, and spiritual distress.

Once strong community life has "taken a back-seat" in the quest for individual cures. Human and cultural factors are ignored – human hearts cry out for attention and loving kindness. Despite the appeal of compelling medical science and technology, has the value of efficacious local practices, places, and healing sights, sounds and smells once familiar and collectively shared within thriving social communities been eroded? My wise teacher, UK-educated Dr Thomas Kargbo of Sierra Leone, said "no Western doctor has ever cured an African. While my people may seek Western medicine for symptom relief and treatment, there can be no cure without the engagement of indigenous healers tending to the socio-cultural and spiritual reasons for illness and misfortune". In the global context, this lack of appreciation for the sacred and familiar is not unusual, nor is it conducive to improving the human condition *(1)*.

The special needs of children with cancer are reflected on by David Morley (Founder, Institute for Child Health, UK), who states, "When we diagnose a medical problem and perform a procedure to correct it, we do not just resolve a problem experienced by a patient – we impact his life, his family, his community, and the world. This patient will go on to make the world a better place" *(2)*.

This Consultation explores personal and collective questions of vital importance. The realities and threats of climate change – that "rapidly growing risks outpace corrective actions" - invites citizen engagement, knowledge integration, comprehensive collaboration, and practical application of research to communities worldwide. Local and global change means we must act differently; we need to think big and small, embrace innovative changemakers, and encourage fresh strategies in rural and urban communities alike. As the anthropologist Margaret Mead instructed, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has".

1. McGilchrest, Iain. *The matter with things. Perspectiva Press.* 2021.
2. Krive, Marianna. *Personal communication.* 2025

CANCER CONTROL SURVEY 2025

How have recent external events affected your work in cancer control?

AFRICA

"The recent decline in global health funding, because of increasing entrenchment and reactionary politics in the West, is expected to affect funding of many cancer researchers and cancer projects in Africa. Despite this bleak outlook, many cancer researchers and policymakers are optimistic that this decline in global funding is a unique opportunity and will spur African governments to deliver on two commitments: on health spending and on research and development (R&D) spending. On 27 April 2001, African Union (AU) governments adopted the Abuja Declaration, a commitment to allocate at least 15% of national budgets to the health sector. In 2006, a second commitment was made by member countries of the AU to spend 1% of their GDP on R&D. African governments continue to significantly fall short of honouring these two commitments. There is now hope in the continent that the shocks of declining global health funding, and the increasingly complicated and tenuous geopolitical ecosystem, will bring about the necessary reckoning that only through local spending on health and research, and through local innovation, will African countries create the infrastructure needed for locally relevant upscaling of health systems and noncommunicative disease (NCD) response, including cancer control."

Professor Nazik Hammad, Division of Hematology-Oncology St Michael's Hospital, University of Toronto

ARGENTINA

"The current global health crisis is significantly disrupting the international agenda. In Latin America, this is evident through delays, budget constraints, and limited progress in national cancer plans. Ongoing initiatives and research funded by US organizations are also almost paralyzed. Many collaborations and discussions are on hold, pending clarity on future measures. For instance, in Argentina, the government has effectively shut down the National Cancer Institute and, following the US decision, resigned from the World Health Organization (WHO) system. Similar adverse decisions are emerging across the region. While streamlining global health efforts may enhance efficiency and cut costs, such actions must be grounded in strategic, well-informed decisions, rather than rushed or unconsulted measures."

Professor Eduardo Cazap, Founder and President, Latin American and Caribbean Society of Medical Oncology (SLACOM)

COLOMBIA

"As a researcher, I work with vulnerable women's communities, aiming to strengthen their ability to prevent cervical and breast cancer. Over the past decade, Colombia's research landscape has experienced a complete disruption. Universities relied solely on external funding to conduct research that integrated regional communities. Tragically, all opportunities to apply for these external funds ceased suddenly at the start of this year. This has utterly dismantled research groups; many expectations have been put on hold, and it has become incredibly difficult to motivate students to pursue their careers."

Professor Gloria Sanchez, Co-ordinator, Infection and Cancer Group, Faculty of Medicine, University of Antioquia, Medellin, Columbia

THE COMMONWEALTH

"Recent geopolitical instability and declining official development assistance (ODA) have placed considerable strain on cancer control efforts in many Commonwealth low- and middle-income countries. These external pressures are forcing governments to make difficult health spending decisions, often to the detriment of NCD programmes, including cancer. In response, the May 2025 Commonwealth Health Ministers Meeting discussed innovative financing strategies aimed at building more resilient and sustainable health systems. Together with these, the forthcoming Lancet Oncology Commission on Cancer in the Commonwealth, which is expected to be published by autumn 2025, is another opportunity, as it will provide timely, evidence-based guidance tailored for resource-constrained settings. With budgets

tightening, equitable partnerships and coordinated action across the Commonwealth remain key to sustain meaningful progress in cancer control."

Janneth Mghamba, Health Advisor, Commonwealth Secretariat

DENMARK

"Its 'a time of trouble'. The withdrawal of US contributions to WHO has had a real knock-on effect. Faced with the need to make severe cuts, WHO's European Office (EURO) has decided to deprioritize NCD control, keeping only primary prevention teams on alcohol, tobacco, and nutrition, but ending the work on early detection, diagnosis, and treatment of cancer, cardiovascular disease, diabetes, and respiratory disease, as well as disease-specific control plans, with termination of the relevant staff contracts. Formerly, EURO held the responsibility for attending to the NCD control needs of 53 countries, including the EU, Western Balkans, and former Soviet Union countries. Ending this important assistance may be an unintended consequence of President Trump's policy."

Marilys Corbex, WHO Europe Office Copenhagen

EASTERN MEDITERRANEAN REGION

"Ongoing armed conflict and humanitarian crises have severely disrupted cancer care in our region. This year has seen increased damage to health facilities and more frequent attacks on healthcare workers, while substantial reductions in global health aid have further strained already fragile systems. These challenges have caused significant delays in treatment, leading to more advanced disease and higher mortality rates. Continued blockades and limited humanitarian access further restrict essential cancer services, and without urgent international intervention, disparities in cancer care within conflict zones will continue to grow."

Ibtihal Fadhil, President, Eastern Mediterranean Region NCD Alliance

EGYPT

"Persistent geopolitical instability around Egypt has reinforced the case for national, self-reliant cancer programmes. Launching population screening is capital-intensive, and return on investment may not appear for several years, therefore challenging within the current context. Conflict-driven displacement obliged us to extend screening and treatment to refugee communities. These stresses accelerated the uptake of AI-enabled diagnostics to curb costs and turnaround times. Sustaining progress now depends on close partnership with nongovernmental organizations across the cancer control continuum."

Khaled Kamal, Egypt

FRANCE

"Recently, with the suppression of US AID programmes, it seems more difficult to obtain some funds from donors for cancer programmes. Private donors are solicited to give money to replace USAID for the struggle against hunger or to maintain vaccination programmes. For this reason, less funds are available to support care and research on cancer. It is hoped that African governments will understand the need for more support from the ministries of health in each country."

Laurence Desjardins, President, Alliance Mondiale Contre Le Cancer (AMCC)

INDIA

"The COVID-19 pandemic posed significant challenges to cancer control programmes in India. The Government of India has a strong commitment to comprehensive cancer care, encompassing prevention and screening, treatment, and palliative care. The universal coverage approach, through Ayushman Bharat and state schemes, remains a cornerstone of the nation's commitment to equitable cancer care.

However, the pandemic led to hospital overloads, postponed routine cancer screenings, and delayed many critical treatments. Healthcare providers at my place of work, particularly in palliative care, observed a concerning rise in patients presenting with advanced-stage cancers and prolonged suffering for many months to come. This was particularly distressing among children with potentially curable cancers who, due to missed follow-ups, returned with more aggressive disease that could have been prevented with timely intervention.

These disruptions exposed vulnerabilities and reminded us of the need for stronger preparedness strategies to withstand the shock of any future pandemics, disasters, or wars."

Gayatri Palat, Associate Professor, Pain and Palliative Medicine, MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad, India

JAMAICA

"While I haven't been directly impacted by current changes, I face uncertainty regarding future research funding accessibility. The ongoing governmental shifts appear aimed at restructuring research approaches rather than restricting specific research

areas – a reset I understand and support. However, this transition period creates challenges in identifying stable funding sources for cancer research, particularly for projects addressing disparities in underserved populations. Despite this uncertainty, I remain optimistic that these changes will ultimately strengthen cancer control efforts through more efficient resource allocation and clearer research priorities."

Simone Badal, Senior Lecturer Department of Basic Medical Sciences, The University of the West Indies

LEBANON

"Lebanon's cancer care is destabilized by economic collapse, political conflicts, and global supply disruptions. The recent regional war resulted in drug shortages, increased reliance on aid, and delayed access to treatment. In war zones, destroyed homes, damaged infrastructure, and disrupted transport have displaced patients and affected cancer care delivery. These factors combined have further weakened Lebanon's already fragile healthcare infrastructure and depleted essential resources."

Ali Shamseddine, Professor of Hematology-Oncology, American University of Beirut Medical Center, Lebanon

"The regional and local conflicts, economic collapse, and donor fatigue have critically impacted cancer control in Lebanon. Medication shortages, reduced government funding, and mass healthcare migration jeopardize access to lifesaving cancer treatments, especially for children. While resilience is often praised through the work of civil societies like the Children's Cancer Center of Lebanon (CCCL), it should not replace urgent health services structural solutions and coverages. We urgently need increased global solidarity with local cancer communities, governmental and international institutions' investment in sustainable systems, and prioritization of affordable, high-quality medicine to ensure that cancer care is not an ongoing casualty of regional instability."

Mrs Hana Chaar Choueib, General Manager, Children's Cancer Center of Lebanon

MALAYSIA

"The honest truth is that recent global events are not affecting me or my country, so I would have to say that work goes on as usual. Whether or not the tariffs have caused prices of drugs and medical supplies to increase is not apparent yet. Maybe it will become more apparent later."

Dr Yip Cheng Har, Consultant Breast Surgeon, Ramsay Sime Darby Health Care, Malaysia, and Lead Clinician, Breast Cancer Research Programme, Cancer Research Malaysia

NIGERIA

"Recent external events, such as COVID-19, and shifts in global development funding have created significant challenges for cancer control efforts. This shift is driven by growing nationalism in Europe and the United States. The changes have led to a substantial decline in funding for NCDs, including cancer.

Overall, there is a growing demand for increased domestic resource mobilization, and Nigeria is responding positively to this; however, the long-term effects are likely to disrupt the research, care, and treatment pipeline."

Professor Isaac F Adewole, Chairman, National Task Force on Cervical Cancer Elimination, National Institute for Cancer Research and Treatment (NICRAT), Nigeria

SOUTH AFRICA

"Recent geopolitical developments, including US trade sanctions and USAID funding cuts to HIV control programmes and medical research programmes, have strained South Africa's health programmes. A sluggish economy further strains resources, with the result that the government may redirect limited funds from cancer control to HIV care. Cancer control non-profit organizations are under pressure, facing fierce competition for resources, reduced funding, and increased service demands, prompting strategies including diversified funding, strengthening financial oversight and stakeholder engagement, and collaborations with partners to sustain cancer control efforts. Advocacy for equitable health policies and protecting vulnerable populations remain critical in this challenging environment."

Elize Joubert, CEO, The Cancer Association of South Africa (CANSA)

UICC

"Addressing the growing cancer burden requires sustained investment in research and global collaboration. Cutting funding and withdrawing support from major international organizations threaten the progress made in cancer and put lives at risk. Countries that have led in cancer research and invested in health systems, especially in low- and middle-income countries, must reflect on the long-term consequences. Beating cancer demands strong and sustained efforts, because no one should die from a preventable cancer, and everyone deserves access to essential treatment and care."

Shalini Jayasekar Zurn, Senior Advocacy Manager, Union for International Cancer Control (UICC)

UK

"The US withdrawal from global health and development, as well as reductions in high-income overseas development assistance (as these countries pivot to defence spending), has triggered the largest contraction and re-organization of health aid for decades. The "perfect storm" of post pandemic, conflicts, and US withdrawal has resulted in some US$ 10 bn being wiped off the last 10-year average, with a decline of some 40% in 2025. For many countries, money earmarked for cancer will now be re-allocated to other more urgent priorities. Looking forward, countries will need to rely on their domestic resource mobilization, along with an increasing reliance on multi-lateral development bank support through a mixture of grants blended with concessional loans."

Professor Richard Sullivan, Cancer Policy & Global Health, Kings College London, UK and Director, Kings Institute of Cancer Policy, UK

"Events around the world impact greatly on our work in cancer control for children. Disruption, along with limited access to treatment for children, has increased the need for palliative care. Yet access to palliative care is challenging due to a lack of essential medicines, trained personnel, and resources. We are having to learn how to provide palliative care in humanitarian crises settings due to armed conflict, climate change, migration, and uncertainty, along with strengthening existing and developing new collaborations."

Professor Julia Downing, Chief Executive, International Children's Palliative Care Network (ICPCN)

"The current situation is extremely concerning and is impacting the doctors who we work with across the world. The slashing of cancer control and global health initiatives is shocking and depressing. People are trying to adjust to a new reality that they hope won't last too long. ecancer.org is receiving record numbers of visitors, with our free educational resources aiming to offer whatever support we can. We all hope for a more positive future."

Danny Burke, CEO, ecancer.org

"The impact that the conflicts in Ukraine, Gaza, and other areas of the world are having on cancer patients is catastrophic. In the European Cancer Organisation's Focussed Topic Network on Emergencies and Crises we have been working together in a coalition of the willing to ensure that cancer patients do not become the innocent victims in conflict zones throughout the world."

Mark Lawler, Professor of Digital Health, Queen's University Belfast and Co-Chair, European Cancer Organisation's Focussed Topic Network on Emergencies and Crises

USA

"For 30 years, I have supported childhood cancer professionals and parent stakeholders with limited resources to attend international conferences, share their experiences, and have a voice in refining treatment to achieve the most effective care in their settings. Since 2024, xenophobia-driven restricted travel policies, rising costs of protectionist taxation, and ongoing conflicts and humanitarian emergencies mean far fewer can travel, thus adversely affecting our community's efforts to strive for worldwide equity in successful childhood cancer care. "

Julia Challinor, consultant for multiple international projects on childhood cancer and pediatric oncology nursing

"The all-out attack on biomedical sciences, global health and equity research, and anything to do with sex and gender has felt like a massive gut-punch to all who work in cancer research and global women's health. However, it also serves to remind us of the fragility of all things, and our duty to carry on, one way or another!"

Ophira Ginsburg, Provost's Visiting Professor of Global Cancer Equity, Imperial College London, UK

"Recent external events have had a major impact on our work on cancer control. The biggest impact has been in delays of funding. Trainees and collaborators have also been impacted by uncertainties. However, new opportunities have also emerged, including major investment in the use of AI and quantum technology tools that will reshape the future of global cancer control."

Wil Ngwa, Director, Global Health Catalyst

ACCESS TO MEDICINE FOUNDATION

"At the Access to Medicine Foundation, we closely track how pharmaceutical companies are progressing on access, particularly in low- and middle-income countries. Recent global events including political efforts that undermine the FDA and threaten NIH-funded research are not just a domestic issue. These shifts risk slowing the pace of innovation and disrupting the global R&D ecosystem, with knock-on effects for access to life-saving cancer treatments in underserved communities."

Jayasree K Iyer, CEO, Access to Medicine Foundation, The Netherlands

Cancer Control interviews Dr Miriam Mutebi, President of AORTIC

Dr Miriam Mutebi is a Consultant Breast Surgical Oncologist and Assistant Professor in the Department of Surgery at the Aga Khan University Hospital in Nairobi, Kenya. She is also a clinical epidemiologist and health systems researcher with a research focus on understanding barriers to access for women with cancers in sub-Saharan Africa and in designing interventions to mitigate those barriers.

She is the President of the African Organization for Research and Training in Cancer (AORTIC), a member of the education and training committee for AORTIC and past-President of the Kenya Society of Hematology and Oncology (KESHO) and on the board of directors of the Union for International Cancer Control (UICC). She is also the co-founder of the Pan African Women's Association of Surgeons (PAWAS – www.africanwomensurgeons.org) and is part of the Kenya Association of Women Surgeons.

She is also co-Chair of the National Cancer Taskforce in Kenya, Chair of the Commonwealth Taskforce for the elimination of Cervical Cancer and a Commissioner on three Lancet commissions. She is a lead on the African Cancer Survivorship Working Group that is dedicated to developing continental research that reflects patient reported outcomes and quality of life and has developed and helped implement both local and regional cancer policy.

CANCER CONTROL: Dr Miriam Mutebi, you're the first female breast cancer surgeon in Kenya and the co-founder of the Pan African Women's Association of Surgeons. You're the president of African Organizational Research and Training in Cancer (AORTIC) and last year you were awarded the ASCO Humanitarian award. How did you get here? How does anyone get to that position? Tell us your journey.

MIRIAM MUTEBI: Probably a whole lot of stubbornness, I guess. You know, growing up in Nairobi, one of the things that I probably, like most people after high school wondered about, was how to start…. You asked "What's my journey?" Somebody else had that same question asked to them in an interview, and they started with this song: "I was born by the river in a little tent… And just like that river I've been running ever since..."

CANCER CONTROL: Sam Cooke! He wrote that. Change is gonna come.

MIRIAM MUTEBI: Exactly, "a change is gonna come". I love that guy. Anyway, hopefully, we won't go that far back to my beginnings. But you know, like every bewildered teenager, by the time they finish high school they have ten million different things they want to do. For me, I always had. And for me, I always had five different things that I wanted to do. I wanted to do law. I wanted to do pharmacy. I wanted to do medicine. I wanted to write. I've even tried my hand at bad poetry and prose in my youth! And architecture. So it was, okay, I like all of these. I'm good at them. How do I decide on which direction I really want to go in?

CANCER CONTROL: How did you decide?

MIRIAM MUTEBI: By talking to my parents and listening to their advice. Because we usually have a gap year and that allowed me to spend a bit of time at each of these professions and kind of decide what it is that I wanted to do. And so, I ended up working at a publishing firm. I ended up shadowing a pharmacist and helping to count pills behind the counter. I got time at a law firm and at an architectural firm, and then I ironically actually got to volunteer at the Aga Khan University Hospital..

CANCER CONTROL: Where you are working now?

MIRIAM MUTEBI: Yes, this is my current employer. So I got to spend a bit of time trying different things. At the end of it all, it came down to the two things: medicine and writing. And so, I go back to my Dad. And I'm like "Dad, what do I do? I want to do medicine, and I want to write". And he says "Well, if you do medicine, you can still write. If you write, you might not be able to do medicine." And so that's kind of how I got into medicine.

CANCER CONTROL: And so you went to medical school. What was that like?

MIRIAM MUTEBI: I was in medical school in the early 2000s, just as we were coming to the tail end of the HIV epidemic, but we still weren't having much access to antiretrovirals. So it was actually a very grim time, I would say. This is certainly not the case currently with better programmes and with a lot more access to antiretrovirals, with normalization of HIV, which has become like any other chronic illness. But when I was in medical school, then there was still a lot of stigma around a diagnosis and unfortunately some patients would get abandoned at the hospital. So, you could find in the medical wards – and we'd have, maybe, six wards in total – that maybe the first few wards were full of patients who were having acute medical conditions like pneumonia or renal dysfunction, who were being treated actively. And then a significant number of the remaining wards had patients who had been abandoned by their families. They were basically getting supportive care and were at different stages of succumbing to the disease or its complications. And that was pretty grim, because then they didn't necessarily have access to as many medications and antiretrovirals. It's a totally different experience for those doing these rotations currently.

CANCER CONTROL: How did that feel?

MIRIAM MUTEBI: I would say there was a sense almost of helplessness, maybe even hopelessness, in that setting. Then one would go three floors down to the surgical ward where a patient comes in and they have an acute abdomen problem. You take them in, they have surgery, they go home, and they're like "Thanks Doc!" And for me, it was like "Where can I make an impact?" And so that's how I wandered into surgery. Which is probably a very different experience now because HIV is like anything else – you treat it. You wouldn't even be able to tell who's suffering unless they disclose it. But that's what shifted me into surgery.

CANCER CONTROL: What led you to specialize in breast cancer surgery?

MIRIAM MUTEBI: In surgery we have what we call "end-of-rotationitis", where you complete a rotation and you're like "Ooh, I want to do that". You do orthopaedics and you're: "Ah, I want to do this".. You do urology and you're like: "No, I want to do this". For me, I think the striking thing was when I was in my breast rotation. In all the books I had read the description of who gets breast cancer was basically a lady in her sixth or seventh decade. At the time, the poster child for breast cancer was the "Nulliparous Nun", a woman who never had children and had never breastfed – all of which are supposed to be traditionally protective factors – and maybe in her sixties or seventies. And I'm sitting in on clinics and I'm seeing patients in their thirties and forties with multiple children all breastfed, with none of the traditional sort of risk factors. And I asked myself "What is going on? Somebody needs to get to the bottom of this."

CANCER CONTROL: So, what did you do to address this?

MIRIAM MUTEBI: We used to do two things at my institution where I trained. The first was a monthly screening by the nurses where we would have ladies coming in, getting a clinical breast exam (CBE) and if there's any concern, they get them sent and seen by the doctor. As the resident, you frequently drew the short straw, and had to sit in for the duration of these monthly weekend screenings. But then I started to realize that a significant number of the referrals were inappropriate. Somebody being told "You have bilateral breast masses" and you're examining the breast and you can't feel anything. And you're like "Okay, this is clearly a problem." Right? A problem even within the healthcare workforce around what is a good CBE? And so, for me, I'd think this is a space that really needs to be developed and expanded on.

And then the second thing was that we, as obliging residents, used to volunteer to do a lot of talks and public awareness work, especially with our cancer support groups. And what stood out for me was one time when I was talking about the complications of mastectomy. I'm sitting there, giving them the rundown, saying "Your surgeon will have told you about this, that, and the other..." and you can always tell when you're giving a talk and you're reading the room and everybody's kind of looking a little like they're staring into the headlights. And you're wondering "What is going on?" But you still give the talk, and you think maybe I'm making it too technical. No, I'm communicating in fairly simple language. But they still have this look…

CANCER CONTROL: Yes.

MIRIAM MUTEBI: But then, later on, after the talk, a group of ladies called to me and they pulled me aside, and they said "You know, Doc, you're telling us this fairy tale about where your surgeon actually talks to you and explains what's going to happen with surgery!" And I'm thinking that's not right.

I had a 65-year-old, a lovely lady. She had a DCIS and, unfortunately, she had a modified radical mastectomy, which is a lot more aggressive surgery than we would usually do. But she had really horrible lymphoedema, and she said that she was 65 (she's much older now) and the way she was told her cancer diagnosis was "Listen, you have a cancer. We're going to take you to theatre tomorrow and chop off your breast since

you clearly don't need it." And she was like "Who says because I'm 65, I don't need my breast?" Right? And so, I was like "Okay, here we have a ton of problems!"

It's really about the perceptions of the worth and utility of women and their contribution. And the perception that "Well, you know, since you're clearly past childbearing…" Nobody wakes up one day and says this is a good day to lose my breast. So for me, it was really about how do we ensure that our patients are seen, heard, and respected. Somebody needs to be able to provide that service for women. And that's really how I wandered into breast surgery.

CANCER CONTROL: This explains so much of what I've seen written about you and what you've said.

MIRIAM MUTEBI: Healthcare professionals need to be educated or informed as much as the patients.

CANCER CONTROL: I imagine the response you were getting from your audience – the eyes of a deer looking into the headlights – was just a blank stare. Like "I don't recognize this …This never happened to me?"

MIRIAM MUTEBI: Yes, exactly. Exactly.

CANCER CONTROL: And your assumption that it had is interesting. I wonder if it's a generational thing? That your generation found that older generations weren't doing all the things you know are good practice?

MIRIAM MUTEBI: I would say, in fairness, there's almost been a shift – and not just in Africa but everywhere – away from the almost paternalistic approach to the practice of medicine. You know, when we literally came down from the mountain and told you to swallow two tablets. Right?

CANCER CONTROL: Ah, "the good old days".

MIRIAM MUTEBI: We're a lot more collaborative now, and it's more patient centred. In oncology we've gone through the whole spectrum where now it's really about shared decision-making. It tends to be the same, I would say, in many other specialities. There's been a shift from "Doctor knows best" to "We're partners in your health and giving you the information that you need in order to make the best decision". There's generally more openness to being questioned, but it's still a learned skill.

CANCER CONTROL: In what sense?

MIRIAM MUTEBI: In the sense that sometimes where there is a lack of openness to being questioned you have to do a deeper dive into where that stems from.

CANCER CONTROL: Where does that stem from?

MIRIAM MUTEBI: Sometimes it stems from ignorance. Like "Don't ask me questions, because if you ask me questions, then you're going to shine a spotlight and show that I don't know." And I think maybe some of the older clinicians had a very big problem with saying "I don't know." Whereas you'd find nowadays people are a lot more open; probably going a little to the other extreme where on occasion, your doctor is "googling" your responses sometimes in front of you. Which is why my patients sometimes tell me "I don't trust that doctor! They were Googling in front of me." But generally doctors are a little more open and things are better. I don't have a problem telling my patients "I don't know the answer to that. I would have to look at it. I would have to read up around it, or even refer you to maybe somebody who knows, or who has this as their speciality."

CANCER CONTROL: You're suggesting the doctor-patient relationship has mostly changed?

MIRIAM MUTEBI: I would say traditionally doctors were highly revered as the single source of knowledge, whereas now, with technology and the Internet and everything, there has been a democratization of knowledge. Our role has become less as a censor, more as custodians of how to make the best proper decisions. But even with the newer generation it's… "I'm sorry I'm going off on a tangent, but bear with me…"

CANCER CONTROL: Go ahead.

MIRIAM MUTEBI: One of the things we have had to reflect on as clinicians, maybe the one thing that we may have lost along the way, is our humanity. One of the things that we're trying to think about as educators which we never had to address before is: "How do you teach empathy?" Because we used to regard our training in medicine as almost like an apprenticeship. You mirror your seniors, and you practise how they practise. I think somewhere along the way, medicine started to become a "9 to 5", and we've almost come to the end of the spectrum where we're treating medicine like just a job. And that, I think, is also a problem. Don't get me wrong. In surgery and other fields, regulating the work hours has definitely made a difference. We would often do 72-hour shifts.

CANCER CONTROL: Brutal.

MIRIAM MUTEBI: Yes, it was not great, but I would say now

that there is sometimes, an overinterpretation of regulated hours. It doesn't mean for instance, because it is it's five o'clock, you should leave the operating theatre… You should leave the patient on the table because you need to clock out. I would say that there's generally a trend towards less patient ownership.

When we were in medical school, even as a medical student, when you admit the patient to the ward, they were yours until discharge. You had to follow up the patient. You had to get the labs, you had to do the other things. But what we find now, sometimes due to the regulated hours, you find is that continuity of care only happens with the attending physician or surgeon. You're the only one who pretty much has a sense of what's actually happening to the patient, because everybody else is checking in and checking out for their areas, whereas for us it doesn't matter as the buck ultimately stops with you. Yes, it might be a little uncomfortable having to stay a little longer, but at the end of the day the patient has given you the privilege, for want of a better word of operating on them or caring for them when they're most vulnerable. And that does come with a certain trade off.

CANCER CONTROL: The privilege of having the patient's trust in you?

MIRIAM MUTEBI: Exactly. I think that's where we've swung the pendulum to the other extreme. It's one of those things we're trying to think about collectively: how do we reinstall empathy in our training? This is not just a nine-to-five job. This is a person. This is somebody. Having said that, I have often worked with very diligent and conscientious residents. The question is how do we amplify this across the board?

CANCER CONTROL: We're now clearly heading towards talking about AORTIC and research and training in cancer. Is the message here "Look, medicine and the care of patients is special?" That there's nothing else like this. It's unique. And we might have set hours and we might have shifts and so on, but actually it's special and you should remember that as healthcare professionals, there's no one else in the world doing this job except you?

MIRIAM MUTEBI: Exactly. And just wrapping up the journey, as a practicing surgeon, when you're treating women across the continuum and realizing that not only are many of them getting diagnosed with advanced disease, they're often not completing their care. And so really trying to think strategically around what is going on and how do we solve that? So that is why I had to go back to school because I had to learn more about this. That's why I decided to get my training in epidemiology and health systems research and to look at what are the barriers to care? And how can we design interventions that address those barriers?

AORTIC's mission is to look at how we can transform cancer care or cancer control in Africa, through collaborations in research, education, and advocacy to provide equitable and timely care to patients. Then, its broader aspiration is looking at how do we get patients, irrespective, of where they are in Africa, accessible, affordable, timely cost-effective quality care. This is really the ask.

CANCER CONTROL: How can this transformation be achieved?

MIRIAM MUTEBI: I would say AORTIC's strategy has been through three main pillars that almost reflect the three barriers or "buckets" to care that patients face.

The first bucket is financing, which is a major barrier because quite a number of patients are paying out of pocket for access to cancer care. We recently did work with the *Lancet Commission on Women, Power and Cancer* looking at what is the percentage of household expenditure that women in low- and middle-income countries face versus women in high-income countries. The women in high-income countries spent about 30% of their annual household expenditure on cancer care. I wonder if you have any idea about the amount women in low- and middle-income countries might spend?

CANCER CONTROL: Several times more.

MIRIAM MUTEBI: Yes, it's about 160% of annual household expenditure. So, is it any wonder that people are not completing their care? Don't get me wrong, there have been some attempts to try and improve patients completing their care. I remember when I was an intern, we would have to give chemotherapy as prescribed by the internist, because again, there weren't enough oncologists at the time. You would get a patient getting the first cycle of chemotherapy and just disappearing. And then they would come back six months later, and they're super excited because they've raised enough money for the next cycle.

CANCER CONTROL: When it was too late?

MIRIAM MUTEBI: Totally. And so I would say the significant thing that made a difference, at least in Kenya, was the social insurance that provides cover for some of the costs of the treatment, whether it's surgery, chemotherapy, or radiotherapy. So we're actually getting more patients to the finish line. Another challenge, when we're looking at finances, is that there's only so much leverage one has in the absence of

enabling policy.

The second bucket is addressing the health system itself. We know that, on average, anyone in sub-Saharan Africa is going to see from four to six healthcare providers before a definitive diagnosis of their cancer is made. That's why we're moving the language away from "late presentation" because that's almost like blaming the patient for the late diagnosis when we know that patients are ping-ponging through our health systems before help is secured.

I've had numerous episodes where patients go to healthcare providers and they're in their thirties or forties, and again, people are still having that poster mentality where unless the lady is in her sixties and seventies, she can't possibly have anything related to cancer. Because most of them are of childbearing age; I would say 30% to 40% of my patients are under 40. So, they're coming in with lumps and are being told "It's nothing!" Or maybe they're breastfeeding at the time or pregnant, and so it's "No, no. This is nothing to worry about." And they're the ones self-advocating and coming back and saying "This is still growing." Or "something's not right." And sometimes they actually have to push in, in order for them to get the care that they need. There's really a gap that needs to be addressed at the primary healthcare setting, because these are the gatekeepers to care.

And then, of course, when you do get into the system, even when you're getting to navigate the system, you find maybe that's missing the agency, and the lack of skills. You're still not necessarily getting the quality care that you need in order to get you to the full treatment. And those are really some of the areas that are major barriers for patients.

The third bucket, that perhaps we don't talk about as much, is the social-cultural barriers that exist.

CANCER CONTROL: Are we talking stigma here? Or class?

MIRIAM MUTEBI: Yes. Stigma, which, to be completely honest, we found has nothing to do with levels of education.

CANCER CONTROL: Really?

MIRIAM MUTEBI: We did a study looking at both private and public hospitals in Kenya and Tanzania, and what we realized was that it really didn't matter about the levels of education or socioeconomic status. We interviewed patients in private hospitals and I've had patients who have been told: "Don't come home. You're literally half the woman you used to be!" I think that my assumption/hypothesis going in was that this was to do with levels of education, but this was not so. The reality is that there are many partners who are not supportive, regardless of education or socioeconomic status. But then, any chronic illness/condition sort of unmasks the underlying tensions in a relationship, and it almost acts as a trigger for some of these.

CANCER CONTROL: Is there data on this?

MIRIAM MUTEBI: I believe there have been small studies in Nigeria for instance and other parts of Africa. One such study looked at women three years into their cancer diagnosis. Eighty percent of women who'd been in a relationship prior to their diagnosis were actually either divorced or separated. These are staggering figures, albeit from a small sample, but it kind of tells of a trend happening in many parts of Africa. There are also some cultural elements. Sometimes there's a lot of cancer fatalism, where there's the belief that you're going to die from cancer; that you go to the hospital to die, which paradoxically is self-fulfilling when people get a cancer diagnosis and are using alternative therapies, and then only go to hospital when they're in extremis. That is how the myth is perpetuated, because you go in and you don't come out and people say "Why would I come in if I genuinely believe that cancer is not treatable?"

CANCER CONTROL: In our 2023 edition there was an excellent article on the language of cancer communication in Africa written by Hannah Simba and Valerie McCormack at IARC and yourself. Can you tell us what part language plays as a cultural barrier to cancer control?

MIRIAM MUTEBI: This is part of the work that we're doing with AORTIC and in collaboration with IARC, looking at the language of cancer. Kenya, for instance, has about 65 different dialects and Ethiopia probably has around 85 or so, but there isn't necessarily a specific word in dialect for cancer. What happens is that the many dialects would interpret it in direct translation with negative connotations as "the wound that never heals" or "the thing that will kill you". So if you're thinking about cancer as the wound that never heals, or the thing that would kill you, why, for heaven's sake, would you come to the hospital to get care, right? It doesn't make sense. You believe that you are going to die anyway. So, there's still a lot of cancer fatalism that needs to be addressed.

We've been trying to do that through advocacy and this includes to healthcare providers. The language we use can have either positive, neutral, or negative connotations and we're trying actively to get to the neutral definitions without negative connotations. The language that we use, from the health system perspective, is incredibly powerful and one has to be mindful of what the local interpretation of the screening and treatment process might be like, for example.

CANCER CONTROL: But our language about cancer isn't neutral, is it? We have reserved the term "malignant" solely for its description, and that is because we recognize its wickedness; its propensity to return after we believe we have been cured. If you're looking for an enemy, it's an enemy of all of us. We're all cell-based.

MIRIAM MUTEBI: Exactly. What I mean by "neutral" is that you don't want to oversell it, in the sense that you're having positive connotations to it, but you do want to avoid the negative connotation and just get to a neutral space so you're able to have a balanced conversation.

There's a real push back, at least from the people with lived experience, against the enemy or battle connotations. Some individuals may not want to be called "warriors" and some people have a real concern with the word "survivor". But, to answer your point, recognizing that it's definitely not benign and it is an intense experience, it's important to be respectful of that. These are things that do need to be acknowledged, even as we communicate to patients. I always like to joke and say "I'm in the hope business", because for the longest time, at least in Africa, it was basically cancer equals death. But I'm also not giving false hope. It's really giving a practical, balanced view that there is treatment at any stage of cancer and that the treatments are available that can potentially cure or control the disease and improve the quality of life.

CANCER CONTROL: You spoke earlier about empathy. I think it's normal for people to find it difficult to deal with someone else's suffering. It may not be part of one's natural set of responses. You actually have to be taught how to do it and, even then, I'm not sure how successful one is. You see suffering and you have to respect it. But it's finding the words… Sometimes, you don't need words, just holding a hand.

MIRIAM MUTEBI: Exactly. Beyond having to teach formal empathy, some of it is just basic common sense.

CANCER CONTROL: But the teaching of healthcare is a brutal thing. The hours, the work; you're brutalized to a certain extent. You come in with the best of intentions, all bright-eyed and bushy-tailed, and after five years…

MIRIAM MUTEBI: Yes, you find 80 patients waiting in your queue and you're thinking, how do I provide this? I have a colleague who's an anaesthetist, and he's like "You know, you're seeing 80 patients in a day, but the patient is only seeing one doctor, right? And so, for that one patient, are you giving one hundred percent?"

I know it's a big call to ask from us, but patients unfortunately do not have the luxury of seeing all the colleagues who do what you do. For them "For them you are it." And so, for that brief interaction of 15, 10, or even five minutes all you can say to yourself is 'How do I manage to infuse this interaction with "I see you. I hear you. I know this is tough, but we can do it if we go through 1, 2, 3?" And that may not take more than two or three extra minutes.

Part of the strategies that we've been looking at are communications strategies for healthcare providers seeing patients. Nobody says you have to do it all. Maybe the patient spends five to 10 minutes with you and a longer time with the breast care nurse going over some of the things that have been discussed, just so that at the end of the day the patient will feel heard, respected, and supported.

And so people have looked at what are the different models of communication, even bringing the caregivers on board and trying to get them to understand. Because that brings me to the third aspect of the cultural variance of Africa. In Africa, there's a vibrant sense of community and I always say that I love that about Africa. It doesn't matter where you are on the continent, people will welcome you and will support and feed you. But sometimes it becomes a double-edged sword, when it affects patient agency.

I'll give you an example. I have a patient who because of the size of the lesion would probably either have breast conservation therapy or a mastectomy. Usually we would lean toward breast conservation. Let's say then, you would advise the patient of the same, but you still have to go through the options. And sometimes patients will go home because they want to have a think about it. And then, two weeks later, they sometimes come back with a clan, you know? And the family spokesperson is saying: "We have decided…" And I'm like "Wait, wait, hang on a minute. Who's we?" And then it's like "We have decided she's going to have a mastectomy." And, you know, you're looking at this, and you're thinking "I know what the patient wants, because we've had this conversation. Why should she lean towards having a mastectomy?" But the patient says "Well, it doesn't matter what I want. They're the ones who are paying for it, so they get to decide."

CANCER CONTROL: Harsh.

MIRIAM MUTEBI: Yes. So it's really not just about giving women a voice. We talk about agency and ask "What does the patient want?" It's also about the financial support to ensure that her decisions are actually supported if she can't pay for it. Traditionally, in many parts of Africa, women are often not the primary determinants of the health seeking behaviour so they need either financial support, or sometimes even permission, in order for them to access care. It's a bit of a disaster where

you're saying "Hey, you know all about agency, but we can't back it up with a system that's going to support your decision." So those are really some of the aspects that we do need to think about tweaking, even as we think about fully supporting our patients' wishes.

CANCER CONTROL: This ties in with your work on the *Lancet Commission on Women, Power, and Cancer*, and also your position at AORTIC. One of the questions I have to ask you – and it's an official question – is: Madame President, what are your plans for AORTIC?

MIRIAM MUTEBI: I could be cheeky and say "Plans for our patients to prosper. Plans to give them hope and the future."

CANCER CONTROL: And lo, right in front of our eyes she changes into a polished politician!

MIRIAM MUTEBI: But then, seriously, I will tell you about how we're actually doing that. As I was explaining earlier, we have three main arms: education and training, research, and advocacy. Through the education and training part we've been training clinicians all the way across the continuum of care. Right now, in collaboration with partners we are training primary healthcare providers, teaching them the basics of the signs and symptoms of high burden cancers, which in our setting are breast, cervical, prostate, colorectal, oesophageal, gastrointestinal (GI), and childhood cancers. And, going beyond that, getting them to appreciate the intricacies of the referral pathways in their setting, and also patient navigation. So that we actually do get and retain patients into the system.

Part of the additional training and education we're also doing, through a webinar-based series, and other in person modalities, is getting the healthcare workforce to really improve on the quality of care that they're providing; having ongoing conversations about things like magnitude of benefits. Because again, we have a young emerging workforce and there's a lot of enthusiasm to emulate other settings. How do we get all these shiny new toys in? And so we're always taking a pragmatic approach, saying "What are the basics of care delivery that one needs?" We can't be pushing for, say, complex immunotherapies when we don't even have the basics of chemotherapy. It doesn't mean that we don't push for that, but we do need to look at how we get the basics in place first, then build on that. So that's part of the conversation that we've been having, how to push for both, but prioritize needs.

I've just came from the AORTIC Best of ASCO Africa meeting in Addis Ababa, which was the first in-person, conference that we've had in this series, around access to quality care and customising solutions for Africa, that we have had. To be completely honest, I was just blown away. Our theme was around innovations and access to technologies and we had a simple mandate. What we did for these young oncologists was we said "This is the latest evidence. What we want you to do is interrogate this evidence and ask 'What does this look like for my patients? What are the implications? And what am I going to do when I travel back from Addis to my hospital?"

It was such a brilliant event! People were sitting down and discussing things like "These are my challenges. These are the things and opportunities I see. Does this make sense for my patients? No. Why not?" And this was because of 1, 2, 3. It was basically just discussing real-world practice, the challenges that we're having, and, more importantly, what are the opportunities?

For instance there's a brilliant study around exercise, improving our long-term outcomes for colorectal cancer patients. And so, of course, this was a little more complex, using some apps and other strategies. And we're like "Okay, but what does this look like for your urban or rural patients? How do you contextualize this evidence for your practice and for your settings? And honestly, I was just sitting there, watching them deconstruct then adapt and rebuild science for our settings and I was having a proud "Mother Hen" moment, thinking "These are my babies, Africa is in good hands!"

In that sense, I think the future of Africa is safe if these are the people who are going to move this forward; a hundred percent. It was such an inspiring meeting. It was so good to see people engaging with work, and really trying to see "How do we break this down and make this relevant to our settings?"

CANCER CONTROL: Those are the best sort of meetings – you want to go on and on!

MIRIAM MUTEBI: Yes, and we were saying "Listen guys we have to cut the session short and move on to the next session!"

CANCER CONTROL: What was the take-home message?

MIRIAM MUTEBI: I think, for me, it's really around "How do we tap into that and amplify that on a continental scale?" I mean, we definitely are having the forums and things that we're providing but then how can we collectively amplify those efforts? That's really part of the educational scope beyond the traditional didactic. It's really about pragmatic ways of delivering quality care in our setting, and I think pushing back against the maxim that low resources equals suboptimal care. And that's something that I definitely do not accept, because we know that any setting has resources. We need to talk about resource optimization and misuse, under-use, and over-use, and what that looks like in our setting. Simple things like

avoiding serial CT scans every three months for patients who are on survivorship or follow-up care and the financial toxicity that brings. Because there's no support for that and patients are breaking the bank trying to get money to do that.

CANCER CONTROL: Well, the ghost of Universal Health Coverage is haunting all of us. Since the beginning of this year, with everything else that's happened, it seems to have receded as a possibility. People aren't talking about UHC so much anymore, which brings me on to the next question. *Cancer Control* is conducting its annual survey… we haven't approached you because we are already having this interview…. but the question is the same: "How have recent external events affected your work in cancer control?" What would be your answer?

MIRIAM MUTEBI: I'm probably going to sit on the fence a little bit, in saying that this is pretty much an evolving or moving target. We will probably have a little more clarity on the downstream effect and true impact of all of this in the next couple of years, but I would say the immediate impact has definitely been a pausing of many global oncology activities. So, whether it's research or collaborations or whatever, that has been the immediate effect. There's still a lot of uncertainty. Nobody is really sure. Is this definite? Is this going to be long term? Are there some things that are continuing to work, or some things that are not working at all? And so I would say it's a little early to reflect on what the implications are.

But it is important to get ahead of any disruptions to systems and you know, as we always say, make lemonade, or look for the silver lining. Perhaps it's an opportunity, like the pandemic, for us all to take stock and look at how we could do things differently in the future? I think it's forced us to an inflection point where we do need to sit down and think about how we can maybe do things differently, or in a more sustainable manner that encompasses a global approach to care going forward. I think we did that with the pandemic, so perhaps we need to think about how we could have a global approach to trying to solve the granular issues of local oncology in different settings. We haven't really engaged with that question as robustly as we needed to. I think we've sort of done things a certain kind of way for a while, and, like the pandemic, this is forcing us to take a beat and think about "Well, how can we work together differently? And how can we build back better?"

Because whether we look at it from a health system perspective or a geopolitical perspective, the truth is that the world is changing so we need to think about how we can change better, or evolve better, to support this changing world. And so that for me, is a real opportunity that we can leverage on. I think the downstream effects will emerge in time but the idea is for us to be proactive, and to use this moment to really rethink our paradigms.

CANCER CONTROL: Yes, the commonality between what we've had happening this year and the SARS-CoV-2 pandemic is that both have shown our vulnerabilities.

MIRIAM MUTEBI: Absolutely. Maybe this is a nice segue into one of the other initiatives we're doing, which is around research. One of the things that I'm most excited about, my biggest push at the moment, is trying to develop our continental research infrastructure. We do know that as a whole, cancer research in Africa is only about 8% of all African biomedical research, right? And if you put that in a global context, it's probably much lower. The work we've done at AORTIC, in collaboration with King's College London, is looking at the representation of cancer research in Africa, where I would say almost 67% of all African cancer research is being generated by five countries, mostly in North Africa. And so that begs the question: what is happening to the remaining 49? It's clearly an opportunity to start to shift this.

And, anecdotally we've had all these stories about how medications don't work as expected. We are looking at guidelines, and supported by trials and data that have been based predominantly on Caucasian populations. And so there's a real opportunity for us to try and think about how can we develop, generate, and get sustainable data that we can use for policies in our setting. And that's a really big part of the push that I've been trying to work on over this period.

A large part of what we've been trying to do in AORTIC over the last two years is to establish the Cancer Foundation to look at how to generate funding and support for micro-grants that can help answer basic health systems questions. And why that's important is because, for the longest time, research has not been something that's necessarily been intuitive in our curricula, as you will find in many medical schools across the globe. Outside Africa, even as an undergraduate, you would maybe do a year of research or at least have some dedicated research time.

In many training centres in Africa what happens is you'll get your first encounter with research probably as a postgraduate, where you have to develop a dissertation. Your supervisor is somebody who's done something similar, so their exposure and expertise is probably not as optimal as it could be. So how do we expand that infrastructure? Because even as we compete globally, we've realized that the questions that we want answered are not necessarily in tandem with the funding streams that exist.

I'll give you an example. We tried to look at what the continental priorities are? What are the burdens of cancer and

what is the research that's being generated? We were able to compare those and we found with high burden cancers, like cervical, prostate, oesophageal, and GI, hardly any research was being done around these, whereas breast cancer and blood cancers almost have a commensurate level of research. There's a clear gap and opportunity to change this.

If we look at cervical cancer, where we have a 90% mortality, clearly there's a need to figure out what can we try to do to resolve this and ask "What is the main difference between the 49 countries and these top five countries that are leading cancer research in Africa? Who's paying for this?" What you realize is that the ones that have the highest research output are the countries that are having country-led initiatives or at least having skin in the game in terms of funding their own research.

In terms of looking at the priorities, which is something we also did, we looked at research priorities across the globe. We looked at Africa, Latin America, and Europe, and if you look at those charts there's no difference. What does that tell us? It tells us that there is no difference between Europe, Latin America, or African priorities, which is clearly not true. It just means that the funding streams are dictating the focus of research rather than the actual needs on the ground dictating the research. But at the end of the day it's "who pays the piper". If you're bringing in the money I can't tell you that you can only do research on my priorities. You're going to do it according to your priorities.

And so we need to think about how we get to a model where we're generating grassroots research that speaks to the needs on the ground? And how do we then find a way of tweaking the current funding streams to reflect that? How do we shift efforts so that we can get alignment between local researchers and local and international funders?

This is now part of our work because our young oncologists have said that the work they want to do is not necessarily of interest to anyone else. For instance, they want to answer simple, basic questions – and you would think that this is fairly basic, but we don't even have the data on what's happening to their patients. What are the outcomes? So, somebody writes a nice small grant "I'm working at my setting, and I would like to know what's happening to my patients, and what are their outcomes ?" and they are in the global competition pool where they're going neck to neck with somebody who's working with an innovative new molecule. I mean, this research may not reflect a global hot priority, but may be essential to cancer control and planning in that ecosystem. Don't get me wrong, it is important to have both questions answered, but we're fundamentally saying how do we then create the platform or the ecosystem that actually generates this local data? And that's through the micro-grants that we have launched.

We had the first call in September. It's all about trying to answer basic health system questions in a cohesive manner that actually builds up the collective of that data and providing a way that we can then collate that data to make real fundamental change.

CANCER CONTROL: This sounds eminently sensible. Who's funding the micro-grants?

MIRIAM MUTEBI: So, I'm hoping to get this plug in because we're going to use this platform to get more funding. We have two partners so far: BioUsawa, which is an African-based company that are trying to produce their own monoclonal antibodies on the Continent; and collaborations through the Henry Ford Center, through their Precision Medicine for Advanced Breast Cancer collaboration. But we're definitely trying to get more funding for the next run. You would think that this makes sense but people are always sceptical, so that sometimes you have to show proof of concept. That's what we're trying to do with this initial run, and trying to see whether we're able to encourage more partnerships and support for this. This is the direction AORTIC is going be heading and in support of that in another couple of months we will hopefully be launching the AORTIC journal.

CANCER CONTROL: Sorry? The AORTIC journal?

MIRIAM MUTEBI: Yes, fresh off the press – you heard it here first! Part of the thinking behind the micro-grants is also the capacity building. So it's not just giving you some seed funding to answer basic questions. It's providing you with support for "How do I write a grant? How do I share my findings? How do I translate that into manuscripts? How do I disseminate that to a regional audience?"

CANCER CONTROL: And now you've got a journal to publish the results.

MIRIAM MUTEBI: Now we've got a journal to help facilitate these learnings, exactly.

CANCER CONTROL: Excuse me while I stand on my soapbox for a moment, but you were talking about the bibliometric exercise that Ajay and Richard and the guys at King's were helping you with. I looked at this, oh gosh! many, many years ago, and it was abundantly clear even then that Africa, as a continent, was still massively underrepresented in the published journals. It really is a case of you've got to grow your own, because otherwise you're always dependent on some guy in Phoenix, Arizona, or Tavistock Square or wherever.

MIRIAM MUTEBI: Absolutely... but then it is equally important to invite the same guys from Phoenix, etc., to collaborate and develop opportunities for bidirectional learning.

CANCER CONTROL: You began by saying "These breast cancer patients didn't look at all like what I was expecting. They were meant to be like 60-year-old nuns, and she's under 40 and she's got a child at the breast…." And that's because the published research had shown that two-thirds of breast cancer patients were over 65. Sure, in our country. But not in yours.

MIRIAM MUTEBI: Exactly! The context matters and this is why I'm really pushing for the journal, because… I'll give you an example.

A few years ago, we did a study on breast cancer patients and tried to look at the 5-year survival. We honestly searched across the continent, and we couldn't find anybody who had that kind of data. And so we submitted to an eminent journal – which shall remain nameless – and their response was, "Oh, gosh, I think you should try and do some kind of multicentre study. As a global community, we're moving towards multicentre collaborative work…."

And we were like "You don't get it. You just don't get it." Because anybody in Africa is like "Wow! How did you manage to get this data?" Because nobody, for a myriad of reasons at the time, had any significant data for patients beyond one or two years. This is because a large number of patients dropped out of care, tracking mechanisms were not robust and so on. This was from a well-meaning, but not optimally informed, external editor.

And I'm thinking, I'm sorry, but you don't get it and rather than arguing with you we should change the game and see how we can provide platforms where people are generating prevalence data that we can learn from, and have opportunities to collaborate on. So, the journal is part of the opportunity for expanding a platform that provides an area where people can disseminate data, use that, and really build that sort of research ecosystem.

CANCER CONTROL: This is a good point to segue into the third arm of what AORTIC does: the advocacy.

MIRIAM MUTEBI: I think it's a universally acknowledged truth that at the end of the day, any sustainable cancer control efforts still come down to finance: "who's paying the piper?" And so there's clearly a need to have a more nuanced approach to advocacy. I think, initially, in African oncology at least, our perception of advocacy was basically to hold up a placard and demand our rights. What isn't commonly known about AORTIC is that it has a long history of developing advocacy. In fact, when I first joined AORTIC in 2013, it was as a cancer advocate. They were giving a masterclass in cancer advocacy training and I signed up for that.

It's really worth thinking about what are the different aspects of advocacy that need to happen? One is political advocacy in the sense that we do need to talk to our policy leaders in a language they understand.

As clinicians we tend to give facts and figures and then notice that their eyes are glazing over. Or sometimes, from a civil society or lived experience perspective, you find the contribution around advocacy would be sharing stories. This is an incredibly powerful tool, but needs to be harnessed and this hasn't been defined.... better in order to move the needle. And so, training CSOs and people with lived experience around political advocacy is some of the ongoing work that AORTIC is doing in collaboration with partners. Questions such as "How do you consolidate your 'ask' to policymakers? How do you use your stories to support the 'ask'? How do you move the needle forward?" And that's really one of the strong aspects that AORTIC is championing.

We've also done research advocacy training where we have trained CSOs and people with lived experience to sit on IRBs; how to ask the right questions, how to ensure that the research community still has that tie-in to the communities they are studying. How to ensure the research is truly participatory. So, there's really a lot of advocacy efforts that are ongoing. We've recently revived our Advocacy Special Interest Group and those are some of the areas that we are looking at.

Of course, there are other aspects of advocacy that we want to expand, along with partners, because there's still quite a bit of legal advocacy that's needed in our setting. We have patients getting fired from their jobs because of their cancer diagnosis, with employers saying "Oh, you're taking too many days off" or that they just can't be bothered.

CANCER CONTROL: That's really the financial cultural change that's necessary.

MIRIAM MUTEBI: Exactly. Because people still need to have their chemo or other treatments and they will have to pay for it, and you shouldn't be in a position of having to have either chemo or pay your rent or pay for your meals. And we do need to develop things like the "right to be forgotten". That's not a conversation we've even started to engage with yet. But as we're seeing more and more patients getting through treatment successfully and living for years on end, these are real issues that we have to start to manage proactively.

CANCER CONTROL: Do you think the policymakers are aware of the likelihood of there being quite a steep increase in cancer

incidence over the next 30 years? That's what IARC data are showing. And the financial consequences of that? Because, as you know, the cost implications of a cancer diagnosis ripple out across and beyond families into the economy. Do they recognize that this is coming down track, or are they like our politicians, thinking mainly in the short term?

MIRIAM MUTEBI: I would say there is a general awareness, especially, for instance, in Kenya where there's been a definite effort towards building systems, decentralizing care, and expanding the workforce, but there's a lot of heterogeneity that exists from country to country. I think that there has been a definite increase in the awareness of policymakers lately around cancer as an emerging problem. And how do we know this? We've seen this in the number of national cancer control plans that have been developed within the last 10 years, which have increased by almost 50%.

Where we would probably need to work with policymakers is, for the want of a better word, "eradicating" the sense of cancer fatalism, because quite a number of them still believe "Well, you're going to die, why are we spending money?"

And the second challenge is that cancer, compared to other medical conditions, is also expensive to treat. So, when they say "Yes, we acknowledge it's a problem, but we don't have the money for cancer care", I think we need to push back against the all or nothing mentality. Because sometimes the mentality is "Well, if I can't have the most state-of-the-art scanning equipment, then I can't come up with any sort of cancer control programme."

So it's really about shifting the narrative around to health as an investment rather than an expenditure. and emphasizing the early prevention strategies; showing policymakers the benefits of savings earned. If we take, for instance, something like breast cancer or even women's cancers in general, the causes of every two out of three women's premature deaths, that's women under 50 years who are the majority of the blue-collar workers in many countries; who are basically supporting the economy. How does it make sense not to invest in getting screening and detecting this early, starting treatment early? And we don't even have to talk about maternal orphans caused by female cancers and that sort of downstream effect on the family and economy. It's about getting them to rethink approaches. How do we deconstruct this daunting term cancer control? How do we break it down into doable portions and phased approaches that make sense for the setting?

I know WHO worked with the Kenyan government to look at an investment case for early detection strategies. They were looking at mammogram as opposed to CBE and they showed a minimal difference in doing a CBE versus doing mammography in terms of stage shifting when deployed as an early detection strategy. But if you look at the difference in capital required for mammography screening versus coordinated CBE exam, it's chalk and cheese. So, it's about looking at how do we build systems that we want within the resources that we have, what is the value added that we can develop and amplify?

And again, with policymakers we're also trying to emphasize looking at regional approaches rather than single country approaches because, for now, every country cannot have PET scans or state-of-the-art technology across the board. But if we look at how we increase fluidity of resources related to the workforce across these different borders, irrespective of where they are, or facilities that ease the movement of healthcare professionals across regions, then we're able to build truly regional centres of excellence in key areas that can support a lot of different dimensions, and that sometimes actually helps.

Then even things like basic access or procurement of medications. You might not know this, but currently African patients pay three to four times the cost of a drug in a similar low- and middle-income country. And if you take a deeper dive into the reasons why, the manufacturers are saying "Well, it's a small market…" and so on. So, we're saying how about we develop regional agreements and procurement, so that we're able to negotiate and start telling policymakers and industry "Listen, projections suggest we're going to be your biggest market in the next 10 years. It makes sense that we start to engage in a sustainable manner. We're not asking for a handout, No, no, no! Let's make a sustainable investment case so that you're benefiting. You still need to run your company and ensure supply. How do we provide treatment at a cost that's not going to break the bank and that keeps you sustainable enough for you to run your business and continue to generate these medications that are going to be increasingly needed, and ensure a constant and consistent supply where needed?"

CANCER CONTROL: Yes, because if nothing else changes the future will be harder than it is now and that is a poor inheritance to leave to the next generation.

MIRIAM MUTEBI: This is a real issue. Africa is a young continent. People getting cancer are technically youths; roughly 40% of our patients are under 40. So what are we doing about that? Looking at the projection of this growing cancer burden, it is imperative that we think about how we're going to leverage innovations and technology to mitigate some of the gaps in terms of the workforce. Because if we only go through the traditional route of training in colleges and workforce expansion, that takes you anywhere from 10 years or so from start to finish. But between and beyond that, how are we using technology or innovation to plug into the health system gaps?

CANCER CONTROL: Thank you so much for sparing the time to talk with us. You have been extraordinarily generous. I only have a couple more questions, if you have the time. The first is: having said all you have said about what can be done in Africa, do you feel positive about the future?

MIRIAM MUTEBI: A hundred percent. A hundred percent, after my "Mother Hen" moment! I really feel that there's so much going for the continent. We have the fastest growing economies. We have a vibrant and expanding workforce. Everybody's enthusiastic about making a change and making a difference. It's just thinking through how to cohesively consolidate efforts that help us to gain traction. But I would say there's been a general awakening enthusiasm to impact care and so it's really about, just thinking strategically how to tap into that, expand that and amplify that in a broader regional setting that I believe is really, truly going to make a difference.

And it's not just the health workforce. Even from the grassroots level there's been so much more engagement from civil society organizations, normalizing conversations around cancers and their management. We've seen growth and momentum in different countries. I reference Kenya, because that's my closest reference, where the CSOs have expanded and actually come under a single umbrella body KENCO. KENCO coordinates all the cancer-related advocacy activities for the country. What we realized was that everybody was focusing on screening. So we were saying "Let's take a step back. How do we have some people advocating for survivorship? How do we have some people advocating for diagnostics or treatment? Because it shouldn't be just screening, screening, screening; it's the entire patient journey.

Also, there's been such a big movement that states currently any technical working group of the Ministry has to have at least people with lived experience or cancer advocates serving on the technical groups for the Ministry, and that's huge as their contributions are invaluable

CANCER CONTROL: That's a huge advancement.

MIRIAM MUTEBI: Exactly, in terms of getting people out there. There's more global recognition of the value of having people with lived experience sitting in and sharing their insights. And so I would say, that's why I'm super optimistic. Yes, the burden is rising. Yes, challenges exist, but there are clear opportunities and the drive and enthusiasm to make a difference. As I said earlier "I am in the hope business." Yes, I'm truly optimistic.

CANCER CONTROL: The next question is, can you talk about this yen for flying. Are you going for a pilot's licence?

MIRIAM MUTEBI: Yes, yes. I'm getting in my hours, but the challenge is that, in order to get your private pilot's licence, you need to sit the ground exam and that takes time. I've talked to my trainers, and you need at least three to six months' dedicated reading, because it's a whole lot of the things that you've kind of run away from since high school: physics, geography, map reading, and so on. And then, of course, a lot of the exam relies on you knowing international air law and local law, so I'm thinking I need a little more dedicated time to close on this. I haven't quite gotten it yet, but I'm hoping to.

In the meantime, I'm still trying to get my hours in. It's one of those things I had as a child, a life-long bucket list, and somehow what was always at the top of that was becoming a flying doctor. And I blame my folks because where I grew up in Nairobi was a place called Langata.

CANCER CONTROL: Near the airport?

MIRIAM MUTEBI: Yes, very near what they call the Wilson Airport, where they used to have Amref, which is the African Medical Relief services. There used to be flying doctors that would go around different parts of the country.

CANCER CONTROL: That's so cool!

MIRIAM MUTEBI: Exactly. The reason that I actually joined medicine initially was because I wanted to be a flying doctor. And so, I look at my bucket list at 10, I look at my bucket list at 20 and at 25, and it's still to become a flying doctor. So I said to myself "Come on, Miriam, let's actually do it."

CANCER CONTROL: I thought that it was just to be a pilot, but actually you can't shake it off, you need to be a flying doctor!

MIRIAM MUTEBI: And because we also do quite a bit of breast outreach in different settings. If there's a quicker way of getting there, rather than a 10 to 15 hour journey by road, if I can get there in an hour or less, then, you know…

CANCER CONTROL: One more question, then we really will finish. What advice would you give Miriam aged 17 years, if you could?

MIRIAM MUTEBI: Oh, wow! I think the first thing I would probably say is "Believe in your vision and believe in yourself. Because sometimes what happens is that not everyone can see your vision or your direction. And that's okay."

I think growing up iteratively, you have things that you want to do, but then you talk to people who discourage you. Sometimes it doesn't mean that they're not well-meaning. It's just that they don't necessarily have the context, or see

what you're getting at. So I would say "Have faith and belief in your vision and what you want to accomplish." There's going to be a lot of people waiting to talk you out of it, and for every person saying something can be done, there are at least 10 people telling you exactly how and why it can't. So I would just say, you know, "Believe in yourself and keep going!"

The other thing I would say is, fortunately, or unfortunately there is no substitute for hard work. There's always going to be an opportunity cost to what you want out of life, but there are benefits. You know, sometimes I think we're living in the age of instant gratification. Yes, we may have gotten a little more efficient at doing certain things, but in order for you to be really good or really engaged with something, you do need to put in the time and effort.

CANCER CONTROL: And it does reward you.

MIRIAM MUTEBI: Yes, exactly. And you can't cut corners, or figure "I'm just going to take shortcuts." You do need to put in the time, and that's the reality. Nothing in life is ever… well, at least my experience…nothing in life is handed to you on a golden platter. You have to actively go and do the time. Do the work in order to get to where you want to be.

But also, what I would say is enjoy the process and the journey, because sometimes we have tunnel vision. We're so focused on where we want to get that we forget that Life actually happens in the gentler parts of the process and the journey. That's where you do, or get, most of your learning and experience. And when you look back, it's not about where you've got to, but how you got there that really makes a difference.

CANCER CONTROL: It's also on the journey that you make your friends.

MIRIAM MUTEBI: Exactly, and where you interact, iterate. And where you learn to fail and rise. As Samuel Beckett says, you know, "Fail again. Fail better."

CANCER CONTROL: I've heard it said about luck, that it's surprising how much more luck you get from working hard. The harder you work, the more luck you get.

MIRIAM MUTEBI: I can't remember who it was that said "Chance favours the prepared mind."

CANCER CONTROL: It was Louis Pasteur.

MIRIAM MUTEBI: It's quite right. It's the intersect of hard work and opportunity. That's what we're really labelling as "luck".

CANCER CONTROL: Well, we've been very lucky indeed, having this opportunity to speak with you, Miriam. Thank you for giving up so much of your time.

MIRIAM MUTEBI: No worries. It was nice catching up and having the opportunity to, how do I say, pontificate about the subjects I like best! Thanks for the chance. ■

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The 2025 UN High-level Meeting on NCDs and Mental Health: The art of negotiation

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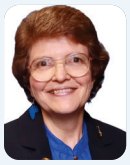
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The fourth United Nations High-level Meeting (HLM4) on Non-communicable Diseases and Mental Health in September 2025 was the culmination of months of consensus-building and was an important moment for global and national policy on NCDs. The statements by governments at HLM4, and the accompanying Political Declaration, provide all those working on NCDs and mental health with a direction of travel for global cancer advocacy to 2030 and beyond.

Every year during the General Assembly of the United Nations in New York City, high-level meetings (HLMs) are convened to bring together world leaders and governments to discuss specific health, development, and security issues. They are an important opportunity to secure commitments, build political will, and attract increased funding at the very highest level, while raising broader public and policymaker awareness of the need for action on global priorities. The first health-related HLM was on HIV/AIDS in 2001; others have included Ebola, antimicrobial resistance, tuberculosis, and universal health coverage *(1)*.

The fourth HLM on Non-Communicable Diseases (NCDs) and Mental Health (HLM4) was held on 25 September 2025 *(2)*. Its focus was on mental health and NCDs as a whole, rather than the individual diseases – with cancer being one of the five main conditions that the World Health Organization (WHO) includes within this agenda (alongside cardiovascular disease, diabetes, chronic lung disease, and mental health conditions), along with five shared risk factors (unhealthy diet, tobacco use, physical inactivity, alcohol use, and air pollution).

This meeting, like the previous three NCD HLMs (in 2011, 2014, and 2018), highlighted the prevention and control of NCDs worldwide, including a focus on their social and economic impacts. NCDs are a major challenge to sustainable development, threatening both individual health and the economies of many countries, leading to increased inequities. Taken together, NCDs and mental health conditions are the leading cause of death and disability in the world. Right now, someone aged under 70 dies from an NCD every two seconds, with 86% of these premature NCD deaths occurring in low- and middle-income countries *(3)* – and yet the majority of NCDs can be prevented or delayed. "Grappling with NCDs is a fundamental pillar in our development strategy," said the Minister of Health and Human Services for Somalia.

Every HLM sees the adoption of a Political Declaration (PD), prepared and negotiated in the preceding months. This sets out a consensus position and acts as both catalyst and guide for future action. The drafting was led by government "co-facilitators" (Luxembourg and St Vincent and the Grenadines), who published the Zero Draft of the PD in May 2025 *(4)*. This initial version was a significant step forward on the previous (2018) Declaration, including global targets to help drive accountability, and a number of commitments for the first time to reform the prevention and care of mental-health conditions – but with notable gaps, including concerningly little on the need for meaningful engagement of civil society and people living with NCDs.

For over a year, non-governmental organizations, including

the UK Working Group on NCDs, advocated to governments on how to build on the commitments set out in the 2018 PD. This intensified after the release of the first (zero) draft of the 2025 PD, in the face of significant lobbying by the private sector (notably, the alcohol and unhealthy food industries)*(5)*.

In some ways, the final PD *(6)* is an advance on the 2018 PD, including (for cancer) a clear focus on childhood, liver and cervical cancers, and on building more responsive cancer-control systems. However, lobbying, combined with today's challenging political climate, has led to the weakening of some key aspects, particularly on health-promoting environments *(7)*. "Compromises have denuded commitment," the Prime Minister of St Maarten for the Kingdom of the Netherlands commented.

For example, the original target on the number of countries with strong health taxes on tobacco and alcohol was removed (and inclusion of sugar-sweetened beverages removed entirely), and a proposed ban on tobacco advertising softened to merely a recommendation. Language such as "as appropriate" became scattered throughout, reducing the urgency and universal need for action. The only reference to "equity" that remains is in the title of the PD. The wording "harmful" use of alcohol is retained, despite evidence showing that there is no safe level of alcohol use either for brain health *(8)* or for cancer risk, and alcohol is a class-1 carcinogen *(9)*.

Although the PD is a document reached by consensus, the statements made by governments during the HLM itself (see also Box 1) revealed important areas of global agreement, with several noting that they, too, had wished to see a more ambitious final text. There was wide acknowledgement of the scale of the crisis, with a strong focus on the need for "all-of-society engagement" and a cross-sectoral approach. A fully integrated primary healthcare (PHC) system was recognized as a necessity for NCD and mental-health care. As the Prime Minister and Minister for Finance from the Bahamas put it, "Treating the body without treating the mind leaves people only half cared for."

Despite time-keeping efforts to hold speakers to a maximum of three minutes, not everyone wishing to speak was able to do so during the eight hours of plenary – which is indicative of the impact of NCDs and mental health on every country in the world. Negotiating blocs are likely to have impacted how negotiations unfolded, given geopolitical priorities, with some speakers either identifying with or formally aligning their delegation to groupings including Small Island Developing States (SIDS), the G77, and the European Union.

Nine Heads of Government spoke, including seven from SIDS, which are particularly harshly affected by NCDs: "This is not a silent epidemic: it is an emergency that chips away at our resilience daily," said the Deputy Prime Minister of Samoa.

Box1: Recurring themes from the plenary statements

- There is a pressing need to address mental-health conditions on the same level as NCDs, especially amongst young people.
- NCDs and mental health are development issues and their financial impacts have a strongly negative effect on national and global economies.
- There is a continued need to commit to sustainable financing for NCDs and mental health – both prevention and control – at all levels (national/state/regional/global) and for dedicated international development assistance.
- The prevention and early detection of NCDs and mental-health conditions must be integrated within PHC, with PHC being fundamental to achieving universal health coverage.
- Addressing NCDs and mental health conditions requires an all-of-government approach.
- The necessity of multisectoral engagement and partnership, including government, the private sector, and civil society.
- Effective prevention is a priority, validating the use of fiscal measures and regulations limiting exposure to known risk factors such as tobacco, use of alcohol and foods with high fat, salt or sugar content.
- The importance of protecting young people, including through tobacco and vaping control and by providing alternatives to unhealthy food.
- There is continued widespread support for WHO.

Two panels ran in parallel with the plenary, on tackling determinants of NCDs, and on strengthening health systems and financing. These were an additional opportunity to hear from more member states and were an important forum for the voice of civil society organizations.

Throughout, there was overwhelming support for the World Health Organization (WHO). The exceptions were the United States and Argentina, whose objections were no surprise. Their rejection of the PD forced it to a formal vote in the General Assembly in the weeks after the HLM, which at the time of publication is still to take place.

However, the plenary also highlighted critical gaps in global ambition. There was an imbalance in the care continuum, focusing extensively on the need to address prevention but with little on reducing morbidity, and only a couple of statements mentioned palliative care (despite palliative care being mentioned five times in the PD). The life-course perspective was unbalanced: there was welcome attention on children and youth (especially mental health and childhood cancers) but a concerning lack of focus on diversity, gender, disability, and ageing more broadly.

Notably, there was an alarming lack of commitment to meaningful engagement of people living with NCDs, with only a few honourable mentions, such as by South Africa. However, this imbalance was partially addressed by the final speech of the plenary, given by a spokesperson from the WHO Civil Society Working Group on NCDs. Kwanele Asante offered a powerful framework, using the language of citizenship to remind member states of their legal duties to respect, promote, and fulfil fundamental health and human rights, part

of which are stringent regulations to prevent health harms of the alcohol, unhealthy food, and tobacco industries.

The PD may be a consensus document, but the true test for action lies in national implementation. HLM4 has clarified that the fight is no longer about agreeing on goals, but about demanding that governments fulfil their duties by translating global ambitions into robust, regulated, equitable national health policy. All those in the NCD and cancer communities should seize the opportunity that this provides, on the understanding that the PD acts as the floor and not the ceiling when it comes to advancing the global NCD agenda, ahead of and beyond the Sustainable Development Goals horizon of 2030. ■

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From influence to persuasion: How cancer misinformation has altered on short video platforms like TikTok

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DR STEPHANIE ALICE BAKER

TikTok is a short video platform that has grown rapidly since its launch in 2016. Increasingly used as a search engine by younger demographics, TikTok is an important source of health information that can inform decision-making about illness, treatments, and remedies for disease. In this article I draw on empirical research to show that there has been a shift from influence to persuasion in the ways that cancer misinformation circulates online. I argue that TikTok incentivizes cancer misinformation due to the prominence of the algorithm on the user experience, the capacity for unknown creators to gain visibility, and the accessibility of monetization on the app.

Ten years ago, I began researching health and wellness misinformation following the Belle Gibson scandal *(1)*. Gibson, a former Australian wellness influencer, established a loyal following by documenting her alleged battle with a rare form of terminal brain cancer online. Initially, Gibson's story was publicly shared on a blog, The Whole Pantry, subsequently developed into a book for Penguin and an app for Apple. Legitimized by these global corporations, and amplified by the media, Instagram was the primary social media site where she built her brand. Employing the handle @healingbelle, Gibson curated her cancer journey online, sharing the ups and downs of her recovery, photos of her child in nature, and innocuous health advice. Gibson was young, friendly, and relatable. She didn't fit the stereotypical image of a cancer patient and in many ways that was part of her appeal. She became a beacon of hope for her followers, a sign that they too could overcome illness and disease through adopting a healthy lifestyle and eschewing impure foods.

Gibson is an interesting example to commence with as she exemplifies the ways in which influence formerly operated online. She was one of the original wellness influencers on Instagram, even though the term was not part of contemporary parlance at the time. Gibson's personal brand was carefully curated through a series of self-presentation techniques that conveyed the appearance of accessibility, authenticity, and autonomy *(2)*. Together, these "three A's" have become the foundation on which health and wellness influencers establish trust and intimacy with their followers online *(3)*. Social media provides the capacity for direct exchange between a celebrity and their followers in the form of replies, reposts, and likes. By occupying the same social media sites as her followers, Gibson gave the impression of accessibility; by disclosing her personal struggles and setbacks she gave the impression of authenticity. Crucially, as an alleged cancer survivor, whose lived experience of recovery was premised on rejecting conventional medicine, she gave the impression of autonomy from institutional power and the medical establishment. Together, this appearance of accessibility, authenticity, and autonomy created a compelling brand. However, it took time for Gibson to establish an online following, and a degree of skill, luck, and perseverance involving regular posts, and carefully curated captions and photographs.

A decade later, the ways in which cancer misinformation spreads online have profoundly changed. Much of this is due to the popularity of short video platforms, such as TikTok, YouTube Shorts, and Instagram Reels. TikTok is a short video-sharing platform that has grown rapidly since its launch in 2016. Launched as Douyin in China then rebranded as TikTok in other regions following its international launch in 2017, reaching 1.59 billion monthly active users in 2025 *(4)*. TikTok is popular among younger demographics. The dominant age group is 18–24, accounting for 39% of users *(4)*. According to Pew Research, most US teens use the platform, with about 6-in-10 teens aged 13 to 17 (63%) using TikTok, including 57% who use it daily and 16% who say they're on it "almost constantly" *(5)*. Renowned for dance videos, challenges, and compilations, the platform has become a popular mode of communication among younger demographics. Although the platform presents itself as an entertainment site with the "mission is to inspire

creativity and bring joy" *(6)*, TikTok is increasingly used as a search engine among younger demographics *(7)*. The app hosts user-submitted videos and provides a platform for people to share content about a range of topics from celebrities to politics and mental health. TikTok affords users the capacity to search, livestream, and be recommended content on the app *(8)*. The app enables users to comment on other videos through three technological affordances: the Green Screen, the Stitch, and the Duet, which allows users to incorporate clips of another user's content into their videos. Despite incorporating features of older social media apps (e.g., Vine's looping videos), what makes TikTok unique is the prominence of the algorithm on the user experience *(9)*. On TikTok, the user experience is driven by the "For You" algorithm *(10)*. When a user opens that app, the first thing they encounter is the "For You Page" (FYP) where the algorithm recommends an endless scroll of popular videos that become more personalized as it detects which content engages the user. Unlike Facebook, Twitter, and Instagram, which originally adhered to a friend and follower-based network involving users actively following accounts, TikTok's algorithm determines which content is surfaced to users on their feed and by whom. The result is that users are frequently exposed to content by unknown creators and those they do not actively follow. The algorithm has a disproportionate impact on TikTok users because unlike other social media apps, viewing video content characterizes the user experience.

TikTok has altered the scale of cancer misinformation that people are exposed to online. A study I conducted in 2024 to assess the quality of cancer cure videos on TikTok found that most cancer cure videos promoted unproven cancer remedies: soursop tea, apricot kernels, oils, and Fenbendazole (dog dewormer) *(11)*. The study simulated someone diagnosed with cancer using TikTok to search for cancer remedies, analysing the top 50 videos each week for four weeks when searching for "cancer cures" on the app. In total, 200 TikTok videos were analysed. Of these 200 posts, 163 (81%) depicted unproven cancer remedies. The techniques employed to legitimize these alleged cures included the following:

- personal anecdotes of cancer survivors sharing their stories of recovery;
- contrarian doctors revealing a miracle cure for cancer;
- conspiracy theories exposing the truth about corrupt medical institutions and miracle cures being suppressed by the establishment;
- spiritual messages about the importance of faith, religion, and mindset to overcome illness and disease; and
- informative posts relaying information, frequently via a voice over, to sell a product or service. Posts in this category often featured visual references to nature and an account with an authoritative sounding name (e.g., the Institute for Heath).

These five overlapping codes provide insight into the ways in which content creators legitimize their claims and, more specifically, the modes of persuasion employed to encourage users to purchase unproven cancer cures.

Cancer misinformation on TikTok exemplifies the shift from influence to persuasion. When Belle Gibson established her personal wellness brand in 2013–15, her social media profiles comprised evocative blog posts and carefully curated captions and photographs that were used to communicate her story. Together, these written and visual modes of communication contributed to her online persona and the parasocial relationship she cultivated with her followers: a one-sided emotional and imaginary relationship that public figures establish with their audience via the media. Short video platforms, such as TikTok conversely, prioritize brevity. In 2024, the average length for a TikTok video was 35–55 seconds *(12)*. The brevity of videos affords users the capacity to create and consume a higher volume of content, algorithmically recommended by a variety of content creators, many of whom are unknown to the creator. Very few cancer cure videos on TikTok feature influencers or celebrities. Most are produced by relatively unknown creators, who gain visibility by employing a strong emotional hook to engage viewers and game the recommender algorithm. Rhetorical questioning featured in my study as a common mode of persuasion and an emotional hook, employing the content creator's cancer survival story (e.g., "Do you want to know how to heal cancer?", "Do you know how I know you can beat the odds?") as evidence to legitimize their miracle cancer cure. Informative posts similarly used rhetorical questions to pique curiosity and interest: "Did you know that soursop leaves kill cancer cells naturally without any side effects?", "Have you ever used RSO [Rick Simpson Oil] to cure a disease?", "Struggling with cancer? Discover the power of Source App! Transform one leaf into a cancer fighting elixir: Soursop leaf is 10,000 times better than chemotherapy". Conspiracy theories were a persuasive way to capture attention because they implied that there was a cure for cancer that was being suppressed by the medical establishment: "The cure for cancer has always existed, but the truth is hidden away from you for a reason", "The cure for cancer was discovered 42 years ago, but has been suppressed several times", "This is soursop fruit and it cures cancer but the health industry doesn't want you to know that because they make billions from chemo than helping you recover from chemo", "This man found a cure for cancer…He cured cancer and was jailed for healing people with herbs…He had beaten the High Priests of Medicine". Videos of this kind are often accompanied by evocative music and

feature a viral hook to create intrigue and attract attention: "I leaked it", "He knew too much".

Another significant shift regarding the prevalence of cancer misinformation on TikTok is the numerous routes to monetization. Health and wellness influencers typically earn money through a combination of advertorials, sponsored posts, and affiliate marketing for commercial brands *(13)*. Those promoting cancer misinformation, like Belle Gibson, capitalized on selling their own products and services in the form of books, courses, and apps *(1,2)*. Prior to the launch of TikTok, it was uncommon to see prominent health and wellness influencers using social media to sell alternative medical treatments directly to their followers. As public figures, doing so would risk content moderation, demonetization, and suspension. Content creation has fundamentally changed with TikTok and the emergence of short video platforms. TikTok provides a variety of different avenues for content creators to earn money. TikTok's creator fund enables popular creators to monetize their content. In addition to earning revenue from subscriptions, affiliate marketing, and partnering with brands, another opportunity for monetization is the TikTok shop: an e-commerce store where creators can sell products directly through the app. In 2025, TikTok Shop's global gross merchandise value reached US$ 18.6 billion, driven by direct in-app purchases and live commerce *(4)*. Popular product categories include beauty, technology, and fashion, marketed by creator-led content. In my own research, I found that numerous videos on TikTok relay the content creator's personal story of recovery from cancer to verify the efficacy of a product or claim. Most cancer cure videos on TikTok simultaneously centre the viewer through reference to the second person singular/plural: "You" (e.g., "Do you want to know how to heal cancer?"), using an emotional hook to capture attention before directing users (often via a flashing caption) to a link in their bio to purchase a product or service. Linktree was the most common tool used to sell unproven cancer cures. Linktree is a "link in bio" tool. Launched in 2016, it enables users to link their social media profiles and unify digital ecosystems through the link-in-bio category (URL or QR code) that acts as a personalized landing page. Linktree functions as a creator's website to sell products and services. It enables creators to monetize their audience by selling products, requesting payments for services, and collecting revenue from affiliate links on their Linktree. As a direct form of monetization, Linktree facilitates online sales because customers do not need to leave the app to purchase a product. Most products advertised on cancer cure videos on TikTok were direct sales for alternative health products: soursop tea, apricot kernels, and natural oils. Online coaching services promising to cure cancer were also prevalent on the app. Some links directed users to conspiratorial books to purchase on Amazon, and others directed users to their GoFundMe donations page where they could fundraise for a particular cause. Tracing how cancer cures are monetized on TikTok demonstrates the intricate ways in which misinformation spreads online.

In the last decade, there has been a shift in the techniques used to promote cancer misinformation online. Health and wellness influencers traditionally used social media platforms, such as Instagram, to build a compelling brand. Their capacity to influence their followers to purchase a product or service relied less on a single post and more on the parasocial relationship they cultivated with their audience over time. Influencers still occupy a central part of the creator economy. The launch of TikTok in 2016, and other short video platforms has, however, altered the ways in which cancer misinformation spreads online. Rather than spend years building an influential personal brand, content creators spreading cancer misinformation on TikTok use a series of persuasive techniques to capture and monetize attention. Brief, simple messaging makes content stick by distilling a concept into 60 seconds or less. Visual and verbal hooks are used to create curiosity, drama, and intrigue and make content compelling. Many of the creators identified in my study violate TikTok's community guidelines and terms of service. Although they can be suspended and demonetized, what makes regulating these accounts more challenging is that they are managed by an industry of content creators rather than a small number of prominent influencers. The barriers to entry to create an account and sell unproven cancer cures are lowered on TikTok because the algorithm enables a new account with a small number of followers to gain the same level of visibility as an established account with hundreds of thousands of followers. The result is a shift from influence to persuasion, from a smaller number of influencers promoting cancer misinformation to an industry of relatively unknown creators who use persuasive hooks and platform features to monetize unproven products and services as miracle cures for cancer. ■

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What can tobacco control teach us about vested interests in food and nutrition?

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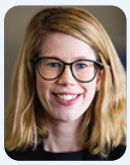
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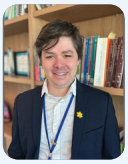
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Twenty years after the World Health Organization Framework Convention on Tobacco Control came into force, a clear achievement of the tobacco control movement has been to highlight the role of the tobacco industry as a vector of the tobacco epidemic and propose enforceable limits on its engagement in policy. What can we learn from tobacco control for preventing food industry interference in law and policymaking for healthy diets?

What can tobacco control teach us about vested interests in food and nutrition?

Twenty years after the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC) came into force, a clear achievement of the tobacco control movement has been to draw attention to the role of the tobacco industry as a vector of the tobacco epidemic. Although tobacco remains one of the world's largest preventable causes of death, global tobacco use prevalence among people aged 15 years and older has declined from about one in three people in 2000 to about one in five people in 2022, with a key factor in this decline being the implementation of regulatory measures under the WHO FCTC *(1)*. The denormalization of the tobacco industry has been one of the main enablers of these developments, with the progressive exclusion of the tobacco industry from tobacco control policymaking at WHO and nationally setting the stage for the progress we see today *(2,3)*.

By contrast, no country is on track to halt the rise in obesity. Between 1990 and 2022 the worldwide prevalence of obesity more than doubled, and the prevalence of overweight and obesity in children aged 5–19 rose from 8% to 20% over the same time period, with childhood obesity in the same age group quadrupling from 2% to 8% *(4)*. A significant driver of these trends is unhealthy food systems: food systems are dominated by transnational companies *(5)*; trade, investment and commercial practices entrench obesogenic food environments *(6,7)*; and food marketing is becoming ever more sophisticated and embedded within addictive and manipulative digital environments *(8)*. There is an urgent need to examine the power of private sector actors in the food industry and to regulate them to ensure that health takes priority over profits. How can we apply the lessons from tobacco control on the importance of governance, influence, and voice to achieve evidence-based public health policies and better manage vested interests in food and nutrition?

International obligations to prevent tobacco industry interference

The WHO FCTC is unique among international treaties in containing specific international obligations to address the role of vested interests in causing harm. Article 5.3 of the WHO FCTC requires that, in setting and implementing their public health policies with respect to tobacco control, Parties shall act to protect these policies from commercial and other vested interests of the tobacco industry in accordance with national law. This provision reflects decades of experience with the tobacco industry's denial of the health harms of smoking, funding of research and front groups, delay tactics, and aggressive litigation and lobbying to prevent regulation. It is implemented through guidelines that establish clear

expectations around good governance and transparency in dealings with the tobacco industry, and has been cited by the High Court of England and Wales as part of an "evidence base" demonstrating the duplicity of the tobacco industry and the need for vigilance and transparency in dealing with them.

Article 5.3 is not perfect – it requires national laws and policies to implement, and its implementation globally is uneven. Tobacco industry interference remains a key barrier to the adoption of tobacco control laws *(10)*. Countries can also protect against industry interference without international treaty provisions, by passing laws and policies appropriate to their context.

But Article 5.3 establishes a clear norm recognizing that tobacco industry interference is a problem requiring international cooperation to address. It is unique in establishing binding obligations to address the harm caused by commercial entities. For example, despite increasing awareness of the commercial determinants of health and documented use of similar tactics of denial and delay as the tobacco industry, fossil fuel companies collectively have a larger presence at climate Conference of the Parties (COPs) than any country delegation and civil society campaigns to remove them have not yet been successful *(11,12)*, while efforts to establish a legally binding treaty on the human rights responsibilities of transnational corporations have been ongoing since the 1970s, with the most recent round of negotiations on a business and human rights treaty having been in progress since 2014 *(13,14)*.

Food industry interference as a barrier to action on healthy diets

In food and nutrition, too, industry interference is a well-documented barrier to the adoption of evidence-based laws and policies. Producers of unhealthy food expend significant resources to oppose public health regulation; shape scientific evidence and public discourse through sponsored research and public relations; and externalize the cost of the harms they cause onto people and their environments *(15)*. For example, the global soft drink industry has embraced self-regulation as a key component of its strategy to position itself as "part of the solution" to obesity *(16)*. Food and beverage companies name and shame countries that pass mandatory regulations, such as taxes on sugar-sweetened beverages (SSBs). In 2016, the International Food and Beverage Alliance (IFBA) presented a global "pressure map" tagging countries that passed mandatory SSB taxes as "red", meaning they were labelled as "discriminatory" or "exerting undue pressure" on the food industry, while countries that passed "industry-friendly" policies were tagged "green" *(17)*. The IFBA continues to challenge the effectiveness of SSB taxes to promote health in its 2022 comments submitted to the WHO on the WHO Global Noncommunicable Disease (NCD) Action Plan 2013–2030, while advancing self-regulation, voluntary commitments to reformulate their products, and healthy lifestyle promotion as viable alternatives *(18)*, despite evaluations of self- or quasi-regulation largely reporting these approaches as ineffective *(19)*.

In Brazil, a systematic plan and strategies by food and beverage companies to weaken front-of-pack labelling policy was leaked to the public. These plans were aimed at the policy to be passed by the Brazilian public health agency, ANVISA, and included generating their own evidence on labelling schemes that favoured industry *(20)*. The resulting front-of-pack label adopted in Brazil was weaker because of the industry interference than the measure initially proposed by ANVISA. It included industry proposed measures, such as selecting a magnifying glass rather than a stop sign as the shape of the label, much smaller dimensions, and a focus on a weaker nutrient profile that included a smaller number of foods identified as being high in sodium, saturated fats, and sugars *(21, 22)*.

Two industries, two approaches

There has clearly been a significantly different approach to what are essentially similar tactics by vested interests of delaying, dividing, deflecting, and denying in tobacco control compared to nutrition *(23)*. While tobacco advertisements were bought out of professional sport decades ago in many countries *(24,25)*, Coca Cola's agreement to sponsor the Olympics was recently renewed until 2032 *(26)*. It would be unthinkable for tobacco companies to be present at major tobacco control conferences, yet multinational food companies with significant "junk food" businesses received prominent speaking slots at the United Nations (UN) Food Systems Summit and are part of multistakeholder initiatives such as the Scaling Up Nutrition partnership *(27,28)*.

One example of this contrast can be seen when looking at another major WHO instrument – the WHO International Code of Marketing Breast-Milk Substitutes. Despite infant manufacturer tactics in marketing breast-milk substitutes resulting in significant increases in infant and child deaths, infant food manufacturers were actively involved in consultations for the WHO International Code of Marketing Breast-Milk Substitutes. Industry were also invited as "equal participants" with government delegates in the 1979 WHO and UNICEF *Meeting on Infant and Young Child Feeding*, which was a key preparatory meeting in the lead-up to the development of the WHO Code *(29)*. The resulting non-legally binding code considers "*that manufacturers and distributors of breast-milk substitutes have an important and constructive role to play in relation to infant feeding, and in the promotion of the aim of this*

Code and its proper implementation" and Article 9 envisages an important role for manufacturers and distributors in labelling breast-milk substitutes.

The global normative framework on food industry interference

Unlike Article 5.3 of the WHO FCTC and its guidelines, normative guidance on industry interference in food, such as the WHO's draft approach for the prevention and management of conflicts of interest in nutrition *(30)*, largely reflects a contextual, process-based approach, centring around due diligence and the balancing of risks and benefits of engagement, in light of the reasons for engagement and the type of food industry actor involved. Similarly, while the WHO's Framework of Engagement with Non-State Actors has clear exclusions for tobacco and arms, it notes only the need to exercise caution in relation to food and alcohol industry engagement *(31)*.

These differences in approach reflect legitimate differences between tobacco and food as risk factors, including a greater diversity of private sector entities in the food sector, the potential to reorient at least some food producers towards more health-promoting options, and the greater range of food systems governance functions, including in areas such as food safety, undernutrition, and procurement, where interaction may be necessary and where there is more potential for alignment between public and private interest. Essentially, while the tobacco industry is a clear-cut villain, the food industry is a more complex character.

The last decade, however, has seen some recognition of the primary importance of government-developed public health policies and laws for food and nutrition. For example, Codex Guidelines on Front-of-Pack Nutrition Labelling adopted in 2021 recognize that while all interested parties, including the private sector, may have a role in consultations for front-of-pack labelling, the measure "should be government led" *(32)*.

Further lessons from tobacco control on food industry interference

What then, if anything, can the nutrition community learn from the experience in tobacco? There is significant literature on this question *(33,34)*, and our aim is not to provide a comprehensive review here. However, some key lessons from tobacco control specific to addressing industry interference in food lawmaking and regulation might include:

- Private sector entities have an obligation to their shareholders to make profits. They therefore have a strong interest in halting, delaying, and undermining laws and policies that might threaten those profits. It is important to take their efforts to do so seriously as a barrier to implementation.
- Evidence-based laws and policies that are government led and mandatory have been shown to be more effective than self-regulatory or voluntary approaches *(35)*. There is a need for clearer guidance on the difference between appropriate and inappropriate interactions with the food industry. Article 5.3 of the WHO FCTC limits interactions with the tobacco industry to those that are strictly necessary to regulate them, provided those interactions are transparent. In food, there is far less consensus on where to draw the line, and much more complexity in identifying who should be covered by it, given the diversity of food producers and types of food sold. Nevertheless, some areas can clearly be identified as high risk – such as policy and legislative development and standard-setting. Policymakers should think through the relative risks of different types of food producers, retailers, and distributors (as well as individuals and experts who might represent food industry interest or have other conflicts of interest), appropriate reasons to consult, and the appropriate time for consultations, and develop these as more specific guidelines for their national context. Further, while in some areas of food policy, such as food safety, food industry engagement may be needed for technical reasons, it is important to make sure these relationships between industry and regulators do not bleed over to areas where they are more problematic, such as setting of nutrition standards.
- Where policymakers decide to engage, transparency over who is consulted, when, and why is core to ensuring appropriate scrutiny and debate over public health policy – providing this information on a website is one mechanism from tobacco control that could be adapted to food *(36)*; a more general solution is publishing diaries of ministers and senior decision-makers to ensure public availability of this information.
- Different sectors of government need to be aligned on how and when engagement is appropriate – for example, tobacco industry interference is more challenging to address in non-health ministries, such as trade or customs *(37)*, where it may be more common to consult private sector stakeholders and which may not have the same sensitization to the need to prevent industry interference. Responsibility for food policy is often split across health and food/agriculture ministries, an even wider range of ministries touches on food, and food systems are also highly globalized, so having a set of common expectations across ministries regarding private sector engagement is even more important in food policy.
- Clear guidance to countries on which policies work can

help cut through obfuscation by vested interests – a key role of the WHO FCTC has been to provide countries with a clearly enumerated list of policies that are known to work across a wide variety of contexts and detailed guidance for implementing them. The legal weight of the WHO FCTC is important for this, but the technical cooperation behind the WHO FCTC's provisions is important too. In this regard, the recently updated NCD best buys for health and WHO's technical packages on food have an important role to play, especially as they are recognized by UN human rights mandates as being an important means of implementing legal obligations on the right to health *(38)*.

Each of the above suggestions is compatible with existing guidance on conflict of interest in nutrition and recognizes that they might apply differently to different contexts, as befits the differences between tobacco and food as risk factors. But they reflect a difference in emphasis – a recognition that when asking questions about the risk/benefits of private sector engagement, the answer must ensure that there remains public oversight of questions of public interest.

Conclusion – the importance of voice, influence, and representation in public health policymaking

More needs to be done to help policymakers and public interest groups counter the power, resources, and lobbying of the food industry. Unlike tobacco, all of us eat and interact with the food system. Regulating the food industry therefore requires a much more fundamental consideration of the role of private sector in society. This is understandably a more difficult conversation, particularly when private sector interests in relation to nutrition include not only purveyors of unhealthy food and drink, but those that sell foods that are healthier (or claim to be), pharmaceutical companies that make weight loss drugs, sellers of diet products, and a whole ecosystem of groups and individuals that represent some or all of the above, including lobbyists, lawyers, marketing and public relations companies, paid experts, social media influencers, and industry groups. But the lessons of the WHO FCTC, particularly Article 5.3, are not just about tobacco, but about governance – a question of who is given voice, influence, and representation in matters of critical public policy. Keeping these questions front of mind will help to make sure that we can learn from tobacco control to ensure healthy diets for all. ■

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CANCER AND AMR

40 Can the burden of antimicrobial resistance be lowered for immunocompromised cancer patients? A narrative review and call to action
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44 The overlooked intersection: AMR's consequences for cancer patients
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Can the burden of antimicrobial resistance be lowered for immunocompromised cancer patients? A narrative review and call to action

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Heavily immunocompromised cancer patients are at heightened risk from antimicrobial resistance (AMR). A narrative review by the Menarini Group of 214 recent publications has identified the broad burdens of AMR for affected patients and healthcare systems. These include excess mortality, effective treatment of underlying conditions, additional economic costs, and long-term damage to patients' lives. This review also sets out the initiatives needed to reduce these burdens, including more research on the patients' experience, more education for healthcare professionals, rapid diagnostic testing and standardized screening, changes to clinical procedures, a better understanding of AMR cost implications, and more investment in antibiotics.

The complete, original article can be found in https://link.springer.com/journal/40121/volumes-and-issues/14-9

Antimicrobial resistance (AMR) is a growing threat to global health security. In 2021 it was associated with 4.7 million deaths worldwide, with 1.1 million of these deaths due to bacterial-resistant infections. Cancer patients are at particular risk from bacterial infections because of their immunocompromised status, frequent hospitalizations, invasive procedures, and the widespread use of antibiotics in their treatment. In the US population, cancer patients are three-times more likely to die from infection, and in the UK a survey of 100 oncologists found that 46% believed that chemotherapy might become unviable because of AMR.

In August 2025, the Menarini Group conducted an important narrative review, published in *Infectious Diseases and Therapies (1)*, to find out how researchers writing in recent publications (2018–2023) described the burdens faced by immunocompromised cancer patients, and their healthcare systems, from bacterial AMR. Following an initial review of 410,088 publications on AMR, 214 publications were selected following a screening process to compile this review, which was then considered by a virtual steering committee.

The results of this review were particularly focused on how recent publications reported on the current epidemiology and mortality caused by AMR; cancer tumours and AMR; patient perspectives on the impact of AMR; how clinical management practices were changing; and the costs of AMR for patients, healthcare systems, and global society. The review also included transplant patients and those with haematological malignancies.

Epidemiology and mortality

The narrative review found the frequency of AMR in cancer and transplant victims with bacterial infections to be approximately 10% to 30% globally, which is consistent with previous estimates. However, some centres reported a zero susceptibility to ß-lactams and fluroquinolones when used as prophylaxis, revealing a growing threat of AMR. There were also reports of multidrug resistance, where bacteria were resistant to one agent in three or more antibiotics classes, which could range from 1% to 73.8% of the samples taken.

The impact of AMR on mortality also varied, ranging from

3.0% to 64.4% for 30-day mortality and 8.7% to 75% for time-points beyond one year. These wide gaps reflect variations in underlying disease types, treatment intensity, and patient comorbidities, as well as tolerance to specific antimicrobial regimes and access to treatment.

Another key factor contributing to AMR-associated mortality was inappropriate empiric antibiotic therapy (IEAT), where a prescribed antibiotic is known to be ineffective against a pathogen but is still given to the patient. Rates of IEAT range from 16.8% to 68.6%, but are a modifiable risk factor. Poor outcomes were also reported for carbapenem-resistant bacteria because of limited treatment options.

Cancer tumours and AMR

Infection remains a leading cause of death for patients with solid tumours, with worse overall survival rates for AMR versus no AMR. The narrative review found that median overall survival in AMR-compromised patients was just 6.0–17.0 months compared with 23.9–50 months for non-colonized patients with cancer.

The lowest prevalence of AMR in patients with solid cancers was in pre-surgery patients with gynaecological cancer and the highest in patients with cholangiocarcinoma (CCA). One study found that 71.7% of patients undergoing resection of extrahepatic CCA had resistant bacterial infections.

Despite the high levels of AMR, the review found that there is a lack of infectious disease specialists involved with cancer patients. A recent Spanish study of cancer patients with pneumonia reported that only 26% were evaluated by an infectious disease specialist.

The narrative review also highlighted the problems that continue to exist in assessing the impact of infection on cancer mortality, which include under-reporting on death certificates due to comorbidities, and the long-term impact of treatment delays on disease control and survivorship.

Patient perspectives

The narrative review was particularly concerned with understanding the cancer patient's experience of AMR and this was made difficult by differences in patient populations, study designs, local epidemiology, and microbiological practices. The review makes it clear that there needs to be greater consistency and standardization in testing and reporting to accurately identify the patient burdens caused by AMR.

Some significant burdens for cancer patients were highlighted by the review:

- Social isolation due to long periods of care in hospital intensive care units (ICUs) and the enforced lack of contact with relatives and close social connections to control infection;
- Increased anxiety, particularly if there are additional burdens such as mechanical ventilation;
- Invasive AMR management, such as amputations to control infection in leukaemia, even when the underlying cancer was successfully treated;
- Central venous catheter (CVC) infections which require the removal of a catheter can complicate treatments like chemotherapy and lead to delays or incomplete treatments;
- Poor communication about the risks of AMR to patients, which, if improved, could help minimize the frequency of infections.

Comment

Dr Fatima Cardoso, Senior Medical Oncologist and President of the Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal

Our narrative review clearly shows the additional burden that AMR places on cancer patients, who are already facing considerable difficulties from the treatment of their underlying condition. The major problem is the fact that AMR leads to delays in oncological treatment, which can have serious consequences. But AMR is also associated with other problems that deeply impact the patients' quality of life. These can include social isolation from being in an ICU or being kept away from friends and relatives for long periods, new invasive treatments unrelated to the cancer and associated side effects, and increased anxiety and distress.

It is fundamental that all oncologists are very aware of AMR and its related complications. We must increase our understanding and awareness of AMR in order to be able to adequately care for cancer patients. AMR education and awareness must become part of our training, as well as part of our communication with cancer patients, particularly those who are immunosuppressed.

As oncologists, we are often focused on the consequences and outcomes of treating the cancer itself and may consider the risks of AMR as secondary. However, as described above, the consequences of AMR may be equally severe and are intertwined with the oncological care. It is therefore crucial that we integrate prevention and management of AMR with cancer care, to improve patient outcomes.

Coordination of care between hospital departments is also fundamental. Often, antibiotics prescription is performed by different specialists, without a central coordination. This increases the risk of AMR. Each medical area draws upon their separate procedures and traditions, when a cross-functional approach might lead to better stewardship practices and a deeper knowledge of how antibiotics are being used within a complex institution.

Awareness, education and collaboration between specialists, with involvement of the hospital infection control commission, can be difference between life and death for cancer patients.

Clinical management practices

The studies reviewed suggest that many prophylactic regimens were inadequate in oncology settings and that it was important for antibiotic treatment to be tailored to local epidemiology. Some studies also point to the use of targeted therapy in countries with a prevalence for carbapenem resistance, such as Greece, Italy, Spain, Poland, Portugal, and Turkey. However, the best course of management is not always clear because of a lack of high-quality evidence, which again points to the need for standardization in screening and reporting. The emergence of rapid diagnostic tests is starting to help by giving clinicians rapid access to microbiological results, as well as being a key step in improving AMR screening.

A key clinical management practice is antibiotic stewardship, as prolonged use of antibiotics exacerbates AMR trends. Some studies showed that the use of broad-spectrum antibiotics for short durations has been shown to reduce the pressures that drive AMR, and this is a relatively simple modification.

Direct and indirect costs of AMR

If a cancer patient develops an AMR infection, the review showed that this can increase the cost of treatment in several ways:

- The duration of stay in the hospital can be extended and time in ICUs or on ventilators will drive up costs. An AMR infection can extend the stay to up to 30 days and increase the costs by $US 50,000;
- Surgical revisions and central line-associated blood stream infections have caused an additional direct cost of EUR 8,810 per patient;
- Targeted antibiotics regimes can also increase direct costs substantially. The cost of using targeted antibiotics against vancomycin-resistant enterococci was estimated at US$ 1,604 to US$ 27,000, and US$ 8,542 to US$ 31,811 for targeted therapy against P. aeruginosa. These figures are similar to the US$ 31,338 cost of treating bloodstream infections (BSI) due to methicillin-resistant *Staphylococcus aureus* (MRSA) in US hospitals.

Infection control must also be seen in the context of managing a patient's underlying condition. For example, in the United States, cancer treatment has a cumulative cost of US$ 77,339 to US$ 225,270 for treating colorectal, lung, and female breast cancer over 23 months. Depending on the cancer treatment, direct costs can rise to over US$ 1 million per patient. The high cost of these underlying treatments suggests that investing more in infection control and management will lead to a cost saving for the healthcare system as additional costs of fighting the infection will not be encured.

Microbial stewardship programmes have also been shown to generate cost savings of US$ 732 per patient.

Limited study data from the review means that indirect costs are less well understood. Indirect costs can, however, come from several areas:

- The inability to work. The World Bank has estimated that indirect costs could rise in line with the growing presence of AMR and so cost the global economy more than US$ 6.1 trillion (3.8% of GDP) due to lost economic output;
- AMR infections can delay treatments, making outcomes worse, including higher mortality rates;
- Hospitals become less efficient, as witnessed during the COVID-19 pandemic, and precious resources are depleted or diverted.

There is an unmet need for a more comprehensive cost-effectiveness analysis of the impact of AMR on vulnerable patients and society. This would be useful in guiding policymakers towards a complete picture of the AMR situation. It may well also support the case for incentives to increase the development of new antibiotics.

Conclusion

The spread of AMR is a growing and complex societal problem, which places healthcare systems under stress and burdens the patient population with treatment delays, invasive management, social isolation, poorer outcomes, and reductions in quality of life.

This narrative review has shown that to address these challenges, everyone needs to be involved. There should be greater education for clinicians and healthcare professionals, including nurses and pharmacists, to promote the use of appropriate antibiotics and effective stewardship, to make use of rapid diagnostic tools for faster analysis, and to implement more consistent and standardized screening.

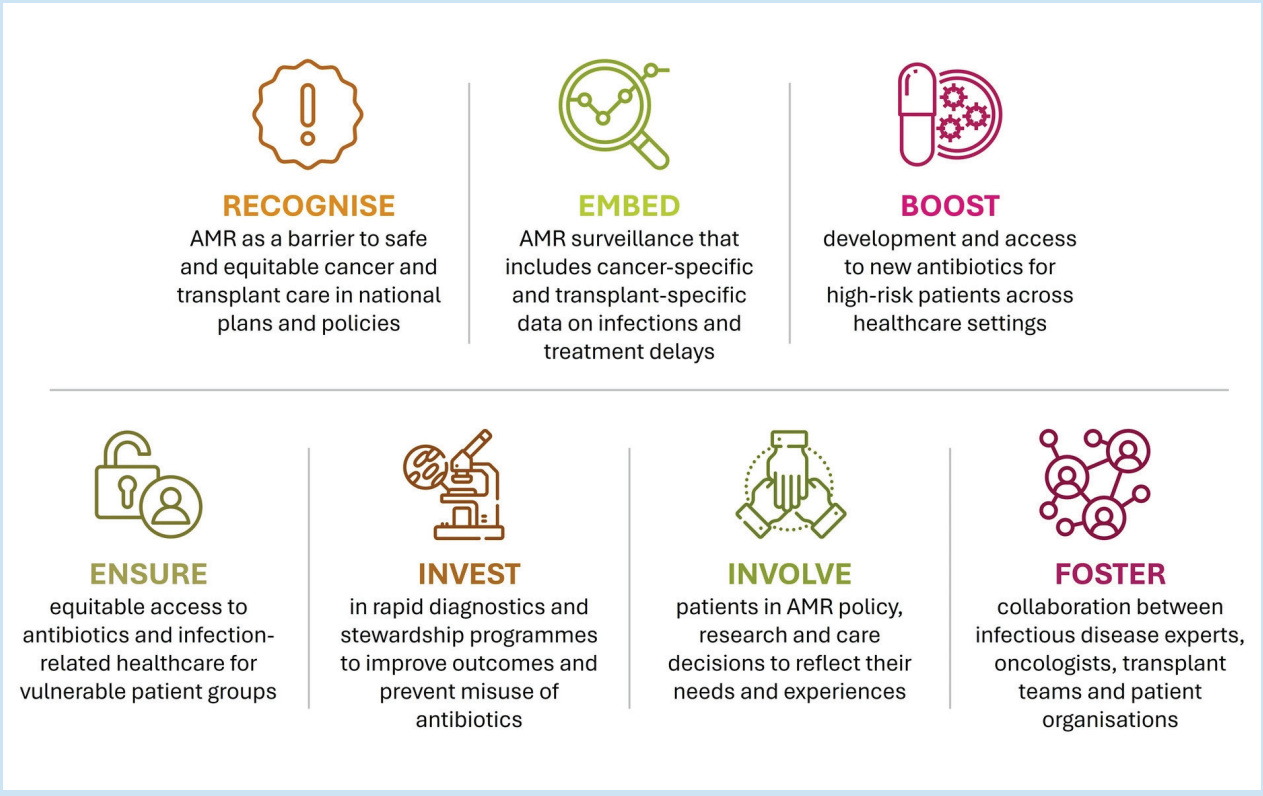
Patients should be involved, as well as being assessed frequently for AMR pathogens, and their treatment with antibiotics adjusted to the shortest possible duration. Patient access should not only be to antibiotics, but also to screening and laboratory facilities. Integrating the patient voice into AMR policy, stewardship design, and care planning is essential. Education is imperative for patients at high risk from AMR. Also vital is the need for patients to feel confident about reporting symptoms to their healthcare providers.

Finally, this narrative review emphasizes the pressing need to strengthen the antibiotic pipeline with appropriate financial incentives, increase research and development, and implement stewardship programmes. A coordinated approach is required to protect future health security and to preserve the benefits of effective antibiotic treatment for patients with cancer. ■

Call to Action: Safeguarding cancer care from AMR

The authors of the narrative review propose that the following actions should be prioritized:

- Recognize AMR as a barrier to safe and equitable cancer care, and incorporate it into national cancer plans and critical medicines policies.
- Embed AMR surveillance systems that collect cancer-specific data, including information on treatment delays, infection outcomes and mortality.
- Boost the development of new antibiotics and establish access mechanisms to ensure these treatments are available to high-risk patients in all healthcare settings.
- Ensure equitable access to antibiotics and infection-related healthcare services by implementing targeted access strategies tailored to high-risk patient groups.
- Invest in rapid diagnostic testing and antimicrobial stewardship programmes within oncology services to improve patient outcomes and reduce unnecessary antibiotic use.
- Involve patients in AMR policymaking, research and healthcare planning to ensure their experiences and needs inform decision-making and care delivery.
- Foster stronger collaborations between infectious disease specialists, oncologists and patient organizations to coordinate care pathways and drive sustained action on AMR.
- Develop and implement appropriate financial incentives to strengthen the antibiotic pipeline.



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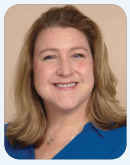
The overlooked intersection: AMR's consequences for cancer patients

Diane Flayhart, Director, Global Public Health, BD (Becton, Dickinson, and Co), Sparks, Maryland, USA


DIANE FLAYHART

Antimicrobial resistance (AMR) poses a critical threat to cancer patients, who are especially vulnerable due to immunosuppression and frequent infections. Recent large-scale studies reveal significantly higher AMR rates in both inpatient and outpatient cancer populations, leading to increased morbidity, mortality, and healthcare costs. This article highlights the urgent need for targeted infection prevention, diagnostic stewardship, and global collaboration to mitigate AMR's impact on oncology care and safeguard treatment outcomes.

Patients with noncommunicable diseases (NCDs) are vulnerable to other health threats, including infectious diseases. COVID-19 brought this into stark reality, but viral pandemics, while devastating and disruptive, are not the only concern. Antimicrobial resistance (AMR) is a real and current threat, already associated with approximately five million deaths a year and trillions of dollars in healthcare costs. As a result of AMR, antibiotics, antifungals, and other medicines become ineffective and infections become difficult or impossible to treat *(1,2)*.

Most alarmingly, its burden is felt in vulnerable populations, including people living with NCDs. In patients with cancer, the estimated risk of an infection-related death is >2.9 times that in the non-cancer population *(3)*, and the hospital mortality rate for cancer patients with sepsis in intensive care is 62% *(4)*.

Infections remain a leading cause of morbidity and mortality among cancer patients, many of whom are immunocompromised due to chemotherapy and other medical interventions. It is estimated that one in five cancer patients undergoing treatment are hospitalized due to infection, and antibiotics are the main line of defence. The global rise in AMR complicates infection management by reducing the effectiveness of standard therapies. This situation leads to prolonged hospital stays, increased healthcare costs, and higher mortality rates.

Figure 1: Burden of antimicrobial resistance in adult hospitalized patients with cancer: A multicenter analysis

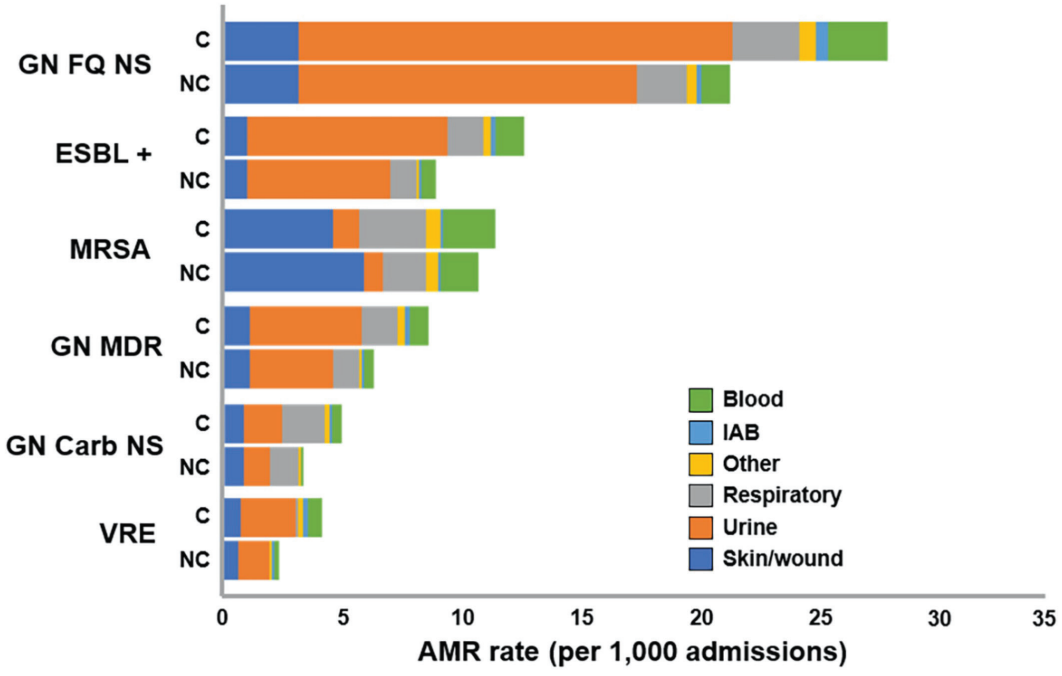


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Figure 2: **Visual abstract of outpatient data, produced by *The Lancet Oncology***

Recent publications highlight the impact

In people with cancer, infections have a primary or secondary role in over half of deaths. However, there have not been large studies or meta-analysis completed to understand the impact of AMR in the cancer population.

In a recent study in *Cancer Medicine*, research indicates that people with cancer had a heightened risk of drug-resistant infection. The study showed that cancer patients receiving care in the inpatient setting have 1.5–2x risk of having an AMR pathogen than non-cancer patients *(5)*. The study analyzed data from more than 4.6 million admissions across 168 US hospitals. Most pathogen-AMR combinations showed a higher incidence of AMR rates in cancer, except for *Acinetobacter sp.* The analysis included Gram-negative pathogens analyzed for multidrug resistance, ESBL production, and resistance to fluoroquinolones and carbapenems. For Gram-positive pathogens, methicillin resistance for *S. aureus* and vancomycin resistance for *Enterococci sp.* were analyzed (Figure 1).

In the second study, published in *The Lancet Oncology*, research looking at the outpatient setting found that AMR rates among key pathogens were one to three times higher, and up to five times greater with some specific pathogen-source combinations in outpatient cancer patients *(6)*. The study, which included 1,655,594 unique bacterial isolates collected from outpatients attending 198 facilities, is, to our knowledge, the first time a large multicentre study quantifying AMR in outpatients with cancer in the United States has been published. A significantly higher prevalence (% NS) of AMR and rate of AMR (per 1,000 pathogen isolates) among US patients with cancer compared to those without cancer in most evaluated pathogens, regardless of the culture site, was seen (Figure 2). Particularly alarming were the findings in blood and urine cultures. In blood, fluoroquinolone-resistant and ESBL+ pathogens, as well as vancomycin-resistant Enterococcus (VRE), were markedly more prevalent in cancer outpatients. In urine samples, cancer outpatients exhibited elevated resistance to carbapenems, fluoroquinolones, ESBL-producing organisms, methicillin-resistant Staphylococcus aureus (MRSA), and VRE.

Taken together, the two studies, which are believed to be the first large multicentre studies to quantify AMR among cancer patients in the United States, offer some of the strongest evidence to date that superbugs or drug-resistant pathogens pose a substantial risk to cancer patients across a variety of settings.

The increased rates of AMR in patients with cancer in both the inpatient and outpatient settings highlights the need for enhanced infection prevention programmes and focused

antibiotic and diagnostic stewardship efforts to improve timely AMR identification and antibiotic prescribing among patients with cancer. This includes:

- increasing the use of rapid diagnostic tools in the outpatient setting prior to antibiotic prescription;
- adjusting hospital-level guidelines on empiric antibiotic choice based on real-time antibiograms, as well as prompt de-escalation, escalation, or switch in antibiotics based on susceptibility testing even in the outpatient setting; and
- implementing antimicrobial stewardship protocols as they are critical for the management of patients with cancer.

A scoping review in *The Lancet Oncology* found the prevalence of AMR bacterial infections from seven World Health Organization (WHO) priority pathogens in patients with haematological malignancies was 35%, with 65% of the studies in the meta-analysis showing higher mortality rates associated with AMR infections *(7)*. Bloodstream infections were the most common, particularly involving resistant strains such as third-generation cephalosporin-resistant Enterobacterales, MRSA, and VRE. The findings underscore the urgent need for improved surveillance, standardized reporting, and targeted interventions, especially in underrepresented low- and middle-income regions.

The commentary by Shropshire et al in *The Lancet Oncology* highlights the growing threat of AMR across the cancer care continuum, particularly in outpatient settings *(8)*. Historically confined to hospitals, AMR has expanded into the community, posing significant risks to cancer patients, who are especially vulnerable to infections. The commentary published alongside the publications referenced above noted that the findings underscore the need for improved infection control measures in outpatient oncology care, which currently lack the rigour of inpatient protocols. The commentary also emphasizes the importance of integrating microbiome-based strategies and environmental surveillance to prevent AMR transmission. Ultimately, the authors call for targeted research and sustainable interventions to mitigate AMR's impact on cancer treatment outcomes.

Together, these studies demonstrate the need for action

While significant advancements have been made in the treatment of patients with cancer, additional attention to AMR research and prevention is necessary to maintain this progress and reduce the adverse impact of AMR on this highly vulnerable population.

Learnings from an AMR Insights roundtable

A roundtable, hosted by AMR Insights, brought together international experts from academia, clinical practice, and microbiological research, each providing a unique lens on the complex intersection between AMR and oncology *(9)*. Below are the key takeaways published in a white paper summarizing the roundtable discussion.

- **Dr Debbie Goff,** an infectious disease pharmacist and global stewardship expert, highlighted the transformative implications of the recent data. She emphasized the underestimated burden of AMR in outpatient settings, pointing out that the trend of shifting cancer care from inpatient to outpatient environments has not reduced infection risks as previously assumed. Dr Goff advocated for developing cancer-unit-specific antibiograms to detect AMR patterns more precisely. She also stressed the importance of diagnostic stewardship, urging healthcare systems to implement rapid diagnostic testing in ambulatory care settings, where empiric prescribing is most vulnerable to failure.
- **Dr Margaret Lubwama,** a clinical microbiologist at Makerere University College of Health Sciences, presented findings from Uganda that align with the global data. She underscored that AMR rates among cancer patients in sub-Saharan Africa are significantly high, with over 80% of ESBL-producing E. coli showing resistance to fluoroquinolones and other frontline antibiotics. Dr Lubwama's research extended to environmental swabbing in oncology wards, revealing the presence of multidrug-resistant organisms on surfaces such as toilet bowls, which suggests potential transmission via environmental reservoirs. Her proposed next steps include whole genome sequencing to identify cross-transmission routes, co-designing infection prevention protocols with hospital staff, and integrating community stakeholders in policy formulation.
- **Dr Afreenish Amir,** a medical microbiologist, speaking from her experience in Pakistan's national AMR surveillance initiatives, stressed the importance of comprehensive metadata in AMR analysis for cancer patients. She emphasized that understanding the context – hospitalization history, antibiotic usage, immune status, and facility type – is critical for policy relevance. Dr Amir proposed a framework linking microbiological data with antimicrobial usage and outcome indicators to inform empirical treatment guidelines, essential medicines lists, and national stewardship strategies. She also called for alignment with global AMR initiatives such as Global Antimicrobial Resistance and Use Surveillance System (GLASS) and the WHO Research Agenda on Human Health.
- **Dr Vikas Gupta,** Senior Director of Clinical Affairs (Q-linea), emphasized the strategic decision to publish in

oncology journals. He noted that traditional infectious disease channels fail to reach the oncology community, where AMR awareness is often limited. By engaging oncologists directly through their literature and professional networks, Dr Gupta and colleagues aim to foster recognition of AMR as an oncologic risk factor. He encouraged replication of these studies in other countries, particularly low- and middle-income countries, to broaden the evidence base. He also called for coordinated international efforts to monitor AMR trends in oncology and adapt stewardship practices accordingly.

The roundtable served not only to disseminate new data but also to galvanize a global call to action for safeguarding cancer care against the rising tide of AMR.

Action is needed today

AMR is a core threat to vulnerable patients. Through political declarations, partnerships, and programmes, we must recognize the devastating impact of AMR on health systems and acknowledge that AMR undermines cornerstone medical procedures such as surgery, cancer treatment, and organ transplants. Working together we can improve access to the tools needed to slow AMR, improve cancer outcomes, and support people's overall wellbeing.

Learn more about the AMR and the impact to vulnerable populations at the AMR: Combat Antimicrobial Resistance and Cancer And AMR Consortium | AMR. ■

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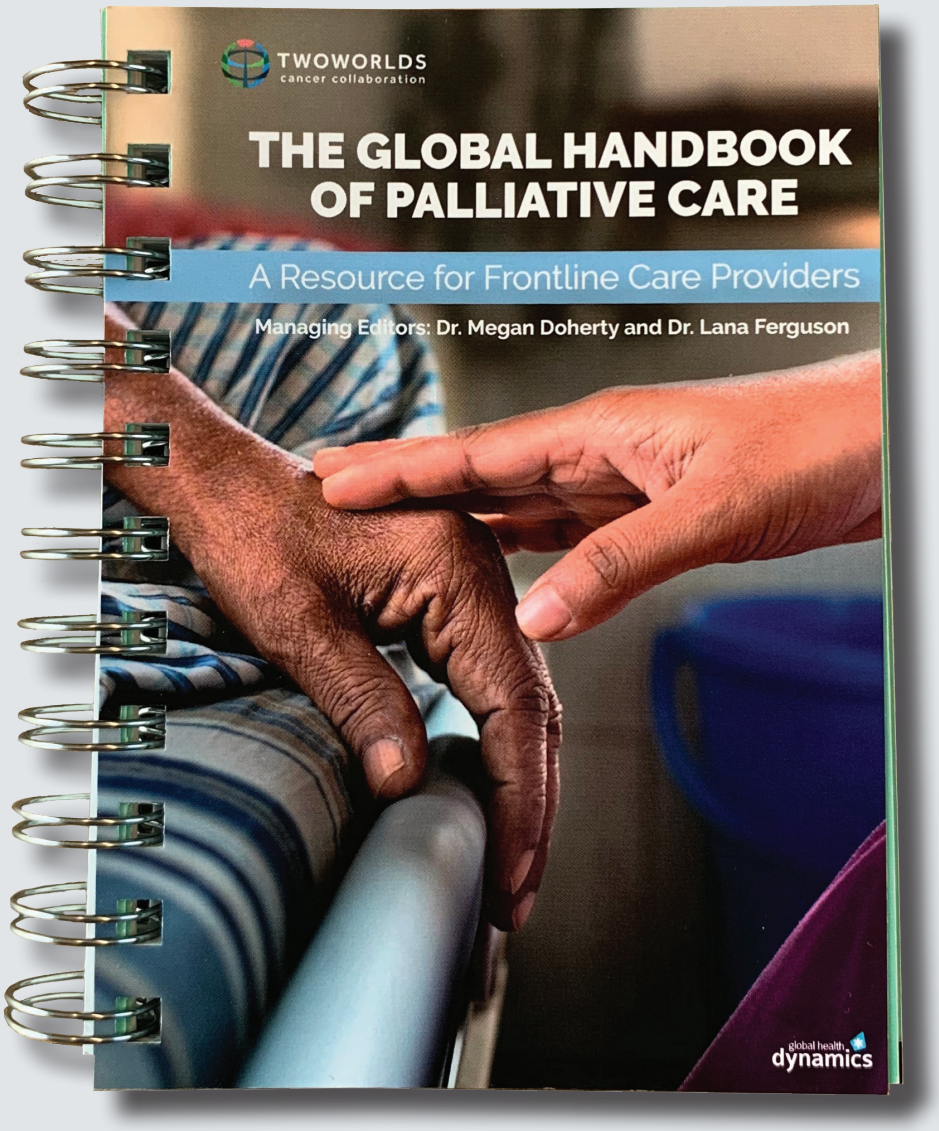

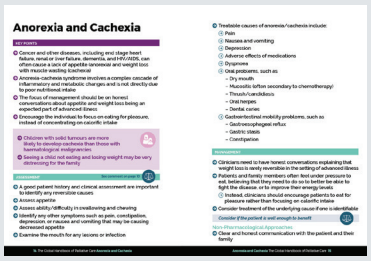

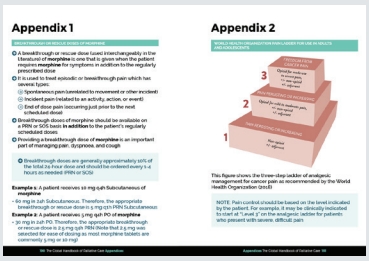

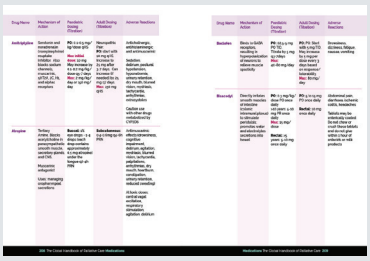

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50 Care amidst crisis: Advancing palliative care in the WHO Eastern Mediterranean Region

Nahla Gafer, Consultant, WHO EMRO, Cairo, Egypt; **Atika Al Musalami,** Palliative Medicine Consultant, Royal Hospital, Muscat, Oman; **Fara h Demachkieh,** Head of Quality, Research and Development Unit, SANAD, Beirut, Lebanon; **Sami Al Shamry,** Palliative Medicine Consultant and National Palliative Care Leader, King Fahad Medical City, Riyadh, Saudi Arabia; **Heba Al Sawahli,** Consultant, WHO EMRO, Cairo, Egypt; **Jihan Azar,** Consultant, WHO EMRO, Cairo, Egypt; **Asmus Hammerich,** Director, Noncommunicable Diseases and Mental Health, and Healthier Populations Department (HNM), WHO EMRO, Cairo, Egypt; and **Lamia Mahmoud,** Regional Adviser, WHO EMRO, Cairo, Egypt

57 Beyond the dispensary: Rethinking the role of pharmacists in low- and middle-income countries through co-learning, collaboration, and ethical practice

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Care amidst crisis: Advancing palliative care in the WHO Eastern Mediterranean Region

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Palliative care is a human right and a moral imperative, offering holistic relief for patients and families facing serious illness, yet in the World Health Organization (WHO) Eastern Mediterranean Region (EMR) millions are left without access to essential palliative care. In addition, the region hosts nearly half of the world's displaced population, with cancer and chronic disease rates rising rapidly, compounded by conflict-related psychosocial issues, injuries, and trauma.

The EMR Expert Network in Palliative Care is contributing to policy development and culturally sensitive capacity building on service models, including home-based care. The WHO/EMR office is taking great steps in involving Member States in order to integrate palliative care services within the different health systems.

Palliative care is a holistic approach to alleviating health-related suffering, regardless of a patient's disease stage or prognosis *(1)*. It represents a return to the core purpose of healthcare: person-centred care for patients and their families, addressing not only physical problems, but also emotional, social, and spiritual distress. Palliative care is recognized under the human right to health *(2)* and is a moral imperative in response to those grappling with tremendous burdens and suffering due to a serious illness.

Despite its universal relevance, the implementation of palliative care varies significantly across regions *(3)*, and particularly in the World Health Organization (WHO) Eastern Mediterranean Region (EMR), where complex challenges – namely humanitarian crises, fragile health systems, and limited resources – hinder its integration. While the principles of palliative care emphasize dignity, relief from suffering, and holistic support, these ideals are often difficult to uphold in settings marked by instability, scarcity, and unrecognition of palliative care. In the EMR, protracted conflicts, displacement, and strained healthcare infrastructures have exacerbated the need for palliative care, particularly for vulnerable populations facing life-limiting illnesses, trauma, and severe pain without adequate relief *(4)*. Despite gradual advances in palliative care over recent years, the disrupted health systems in many countries of the region have compromised substantial progress. This article aims to shed light on the situation and the need for palliative care in the EMR amid conflict settings.

The need for palliative care in the EMR

The EMR is experiencing one of the fastest increasing rates of cancer and other chronic diseases globally, with cancer projected to rise significantly over the next 15 years *(5)*. Most cancer cases are diagnosed late, resulting in poor survival rates and a high demand for palliative care services to manage advanced disease *(6-8)*. An estimated 2.4 million people in the EMR require palliative care annually; the majority suffering from advanced cancer, cardiovascular diseases, chronic respiratory conditions, inherited haemoglobinopathies, and progressive neurological and metablic disorders *(9)*. However, these numbers fail to capture the hidden toll of conflict-related injuries, burns, and trauma which have created a surge of patients with severe, long-term pain and disability. The intersection of chronic disease and conflict creates a detrimental situation: patients who might have managed their conditions with early intervention now face unmitigated suffering due to bombed hospitals, medication shortages, and hyperinflated prices.

Even before political instability and displacement shattered many countries of the region, limited palliative care services in the EMR were mainly due to ignorance of its importance and its impact, compounded by restrictive policies, cultural stigma, and institutional indifference. Governments failed to integrate palliative care into national health strategies, leaving more than 80% of patients without access to essential pain relief *(10)*. Opioid regulations can be overly restrictive: morphine was often exclusive to cancer patients, with prescriptions limited to 3-day supplies or permitted only in inpatient settings, forcing terminally ill patients to repeatedly travel for medication refills or get admitted to a hospital bed just to relieve pain *(11)*. Meanwhile, training in palliative care was virtually non-existent; many medical schools offered zero hours of formal palliative education, and misconceptions about morphine addiction overshadowed its medical necessity *(12)*. Meanwhile, funding ignored the cost-efficiencies of palliative care and its ability to reduce hospitalizations and optimize treatment, leaving services concentrated in urban hubs, if at all existent. This systematic abandonment created a vicious cycle: without recognition, there was no funding; without funding, there was no training; and without training, there was no advocacy. These multifaceted challenges require balancing immediate humanitarian needs with sustainable health system strengthening, reflecting the unique challenges and opportunities present in the EMR.

The EMR represents a critical area of unmet need for palliative care – marked by significant health disparities, and exacerbated by persistent conflict, economic instability, and sociocultural barriers (Figure 1). Although palliative care is essential for the millions facing terminal conditions across the region, access remains challenging *(13)*.

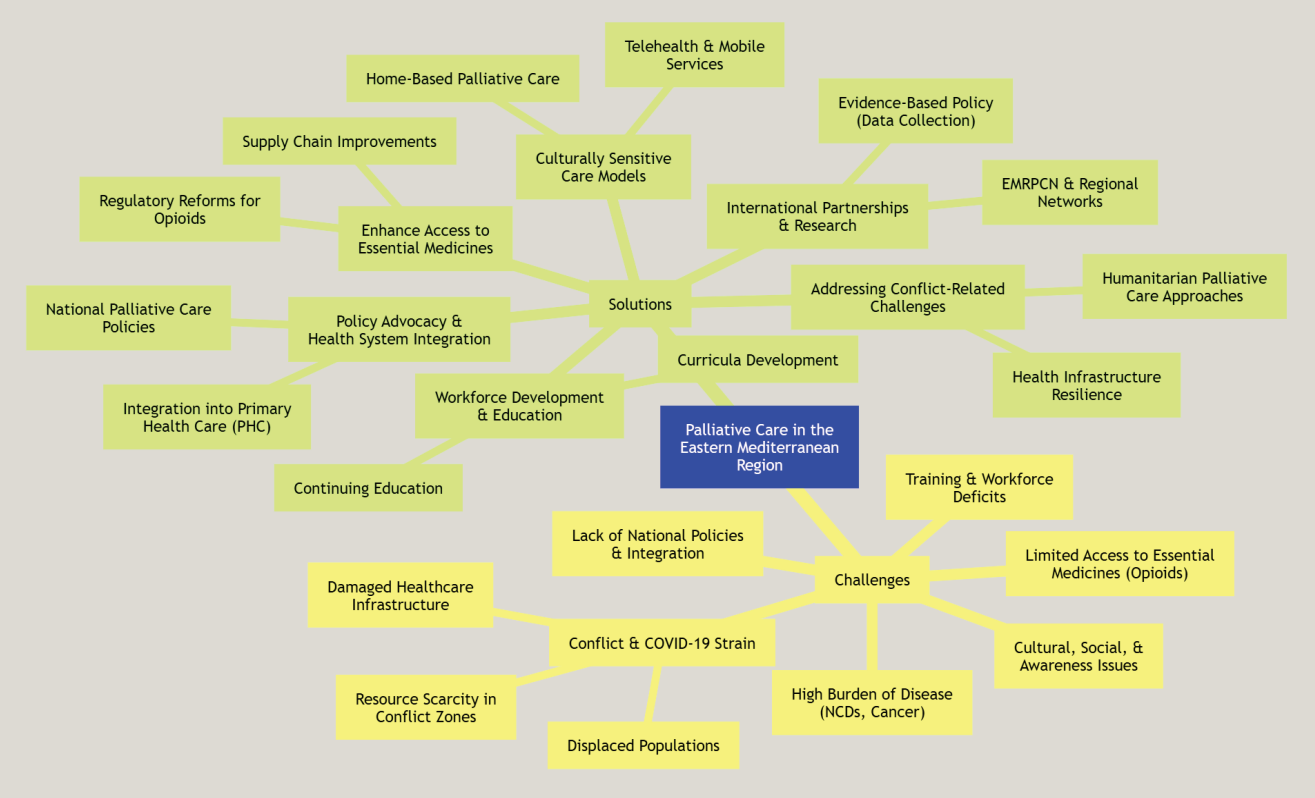
Addressing the palliative care imperative through timely provision

The wide range of systemic and contextual challenges collectively contribute to delayed referrals and limited palliative care service provision. The consequences of such late referrals include poor symptom control, increased emergency department visits and hospitalizations, and higher healthcare costs due to aggressive, futile treatments, notwithstanding the emotional distress for patients and families. Table 1 outlines the primary barriers to timely and effective palliative care, alongside actionable recommendations aimed at strengthening service delivery, enhancing integration into health systems, and improving patient outcomes. A fundamental goal is to reframe palliative care not as a service exclusive to the end of life, but as a core skill set for all healthcare professionals, integrated at all levels of practice – from generalist to specialist – and introduced early in the disease trajectory.

The EMR and conflict

The EMR is one of the world's most crisis-affected areas, with over 60% of its countries embroiled in armed conflict, political

Figure 1: A mind map illustrating the complex web of challenges (yellow) and interconnected solutions (green) for palliative care in the EMR



instability, or protracted humanitarian emergency *(14)*. In 2023, the region hosted nearly 30 million refugees and 40 million internally displaced persons, accounting for almost half of the global displaced population *(15)*. Countries including Syria, Yemen, Sudan, and Palestine-Gaza face catastrophic health system collapses, while host countries such as Egypt, Lebanon, Jordan, Libya, and Pakistan struggle with strained resources amid mass migration. This displacement crisis creates a double burden: fragile states cannot meet even basic healthcare needs, while host countries grapple with overcrowded facilities, exhausted staff, and funding deficits. For patients with chronic conditions this translates to unrelieved suffering.

Impact of conflict on healthcare systems, the healthcare workforce, and patients

Countries with armed conflicts have been witnessing detrimental effects on their healthcare systems, healthcare workforces, and patients with serious illnesses. The prevailing regional instability has been detrimental to the healthcare workforce, as documented in the WISH Report "In the Line of Fire: Protecting Health in Armed Conflict": targeted attacks, forced labour, and systemic collapse have decimated the medical workforce across conflict zones in the EMR. Those who remain face unimaginable risks; for example, a nurse kidnapped at gunpoint to treat a militia soldier, and a doctor executed after a commander died under his care. Even when they evade bullets and abduction, survival is a struggle, with salaries, if paid at all, rendered worthless by hyperinflation. Health professionals working in the public sector experience reduced wages during a crisis and after it *(16)*. Roads to clinics are either blocked or unsafe; pharmacies lack even basic antibiotics; and the psychological trauma of practicing "medicine without medicines" drives many to abandon their posts. Over 70% of Syrian healthcare workers fled the country after 2011, while in Sudan, 60% of hospitals lost staff within months due to direct violence and unsustainable conditions *(17)*. Within the first two weeks of the conflict, 26 hospitals in Khartoum were bombed, contributing to the war's catastrophic shutdown of 80% of Sudan's hospitals *(18)*, leaving cancer patients without access to basic care, let alone the sophisticated treatment modalities they desperately needed. Lebanon, which hosts the

Table 1: **Barriers to timely and effective palliative care, and recommendations for improvement**

Barriers to early palliative care	Recommendations for improvement
1. Education and awareness barriers - Many healthcare providers and patients/families associate palliative care only with end-of-life care, leading to delayed referrals	- Integrate palliative care principles and basics into the undergraduate and graduate education of healthcare disciplines (nursing, medicine, social work, psychology, pharmacy, etc.) - Train healthcare providers to assess palliative care needs, provide basic palliative care, and on referral to palliative care as early as possible - Integrate palliative care into orientation programmes and continuing education requirements - Public awareness programmes to destigmatize palliative care
2. Healthcare system barriers - Limited integration of palliative care into primary and secondary healthcare settings - Shortage of specialized palliative care teams and services	- Expand palliative care programmes to rural and underserved areas - Integrate palliative care into oncology, geriatrics, and chronic disease management - Ensure presence of palliative care teams at major hospitals, and their interaction with the different departments in terms of referral, training, and joint research - Build palliative care career pathways, compensations, and incentives for providing palliative care
3. Physician-related barriers - Some physicians hesitate to refer patients due to prognostic uncertainty, fear of taking away hope, and lack of training in palliative care communication	- Develop clear criteria for early palliative care referral for different conditions based on "need" and not based on "prognosis or disease progression" - Implement triggers in electronic health records for automatic palliative care consultations
4. Cultural and religious barriers - Families may resist palliative care due to misconceptions, preferring aggressive treatment until the very end - Cultural and religious beliefs may influence perceptions of death and dying, causing reluctance to discuss palliative care - Limited health literacy about the benefits of early palliative care	- Engage religious leaders (Ulama) to support discussions on palliative care within religious ethical frameworks - Design and integrate palliative care chaplaincy education into higher education systems - Encourage family meetings with palliative care teams to address concerns
5. Policy barriers - Lack of integration of early palliative care into national healthcare policies and funding schemes - Lack of standardized referral criteria across hospitals	- Government support for national palliative care policies and funding - More research on early integration of palliative care in health services in the EMRO region

highest refugee population per capita in the world, has endured several wars, conflicts, and crises, severely limiting access to essential medicines, healthcare facilities, and workforce, thereby burdening its fragile healthcare system *(19)*. The latest war on Lebanon resulted in 160 attacks on healthcare, 109 attacks on ambulances, 241 healthcare personnel killed and 295 injured, and the closure of three hospitals and 19 primary healthcare centres and dispensaries *(20)*. In Gaza, according to the latest situation update released by the WHO in August 2025, there have been 62,192 people killed and 157,114 injured. Only 50% of hospitals are partially functional and 39% of primary healthcare centres are functional. A total of 772 attacks on healthcare were documented, resulting in the killing of 929 peole, targeting 125 health facilities, including 29 hospitals damaged, and 197 ambulances. The malnutrition crisis remains dire and the infectious diseases threat persists. The ongoing attacks and resource shortages have severely weakened the health system – damaging or destroying 94% of hospitals, overwhelming the remaining partially functional ones, and disrupting essential health service delivery *(21)*.

Political instability and armed conflict have stalled cancer care across the EMR, transforming treatable malignancies into death sentences. Patients face significant treatment interruptions, whereby chemotherapy cycles are abandoned due to hospital shelling, radiation therapy halted by power outages, and life-saving surgeries cancelled due to fleeing medical staff *(22)*. In Syria alone, more than 11 years of war have left 1.5 million people living with permanent disabilities, many requiring ongoing palliative support *(23)*. Similarly, in Yemen, where healthcare systems have collapsed, the majority of cancer patients die without access to basic pain relief *(24)*. In Gaza, breast cancer survival rates have gone down and patients are suffering from a multitude of psychosocial issues *(25)*. In rural areas, a patient with multiple myeloma might endure a three-hour journey on the back of a cart, screaming in pain, only to reach an oncology centre with depleted morphine stocks. Radiotherapy, complex surgeries, and combined chemoradiotherapy (cornerstones of cancer management) require stable infrastructure, safe transportation, and precise timing, all obliterated by war *(26)*.

The consequences are dire: late-stage diagnoses surge as patients cannot reach functioning facilities, while those mid-treatment face relapses due to disrupted care. Another factor faced by the refugees and the displaced population is the psychological and social impact of the conflicts – loss of income, loss of housing, increased vulnerablility to sexual assault, loss of roles, grief and complicated grief, loss of country, being forced into a new society which might differ in culture and language. All these demand a holistic approach not only for individuals but for communities *(27)*. The result is a growing population of patients living – and dying – in agony from advanced disease, their suffering compounded by the near-total absence of pain management. This is where palliative care becomes not only an option, but a necessity.

The EMR Expert Network

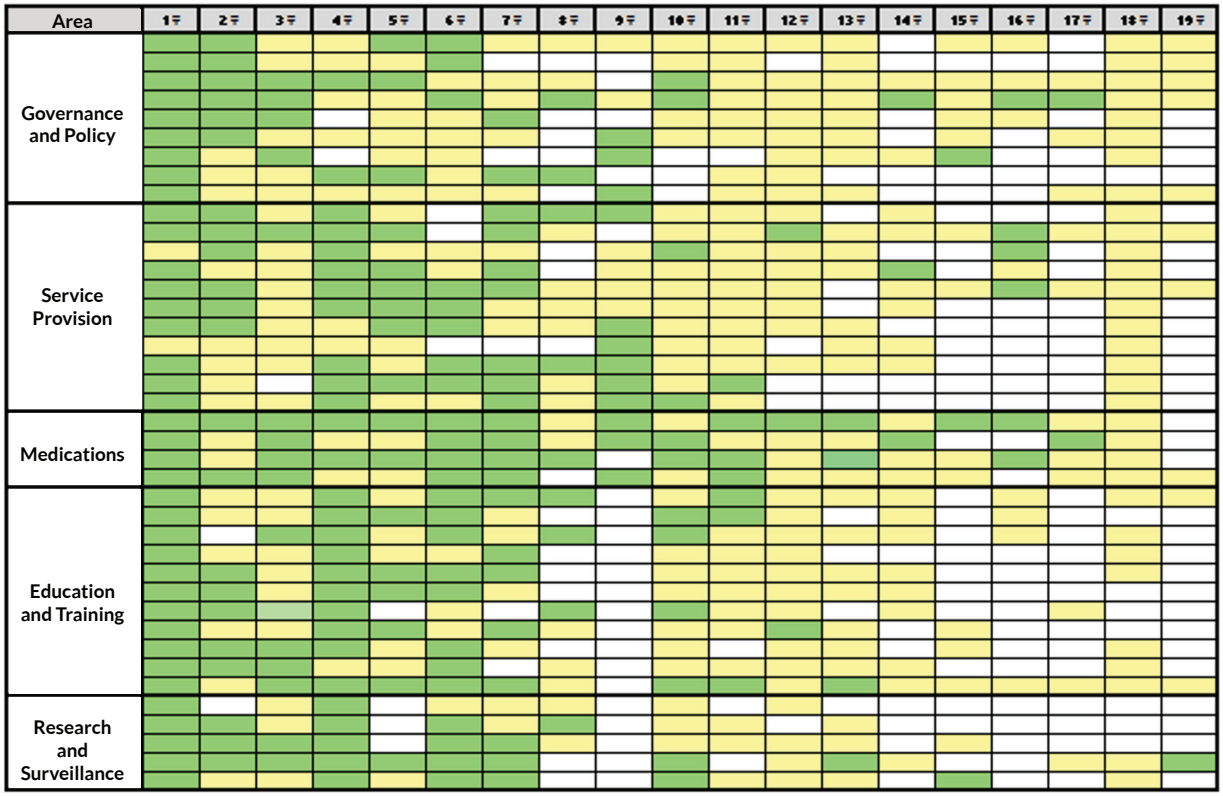
In 2019, the EMR Expert Network for Palliative Care (ENPC) was established by WHO/WHO Regional Office for the Eastern Mediterranean Region (EMRO) in collaboration with academic partners to create strategies for integrating palliative care into national systems. The network has developed a regional roadmap aligned with WHO guidelines aimed at policy development, workforce training, service implementation, and quality assurance *(28)*. Countries are encouraged to develop and adopt national palliative care policies to formally embed these services within health systems, including cancer control frameworks and primary care. This would ensure sustainable funding and coordination. Regulatory reforms are needed to improve the availability of opioid analgesics while ensuring safe and controlled use. Revising prescription laws and overcoming supply chain issues are priorities to expand pain relief access. Given the cultural and religious context in many EMR countries, home-based palliative care services are emphasized. These models facilitate care in patients' homes, respecting cultural values, and overcoming geographical and infrastructural barriers. The ENPC is also expanding palliative care training for physicians, nurses, and allied health professionals through curricula development and continuing education to support capacity building. Collaborations with international academic institutions and the WHO support facilitated knowledge exchange and the adaptation of global best practices. Ongoing research and monitoring help track progress and inform policy adjustments. The World Health Assembly Resolution 67.19 on palliative care *(29)*, the WISH report: How Can We Respond to 10 Years of Limited Progress? *(30)* and the Regional Framework for action addressing noncommunicable diseases in emergencies *(31)* provide guidance for the work of the ENPC.

Bridging the gaps: Advancing equitable access to palliative care in the EMR

The WHO Office for the Eastern Mediterranean Region is seeking to provide an overarching regional framework to guide its Member States towards strengthening palliative care. Priority actions that have been identified through the Member State consultations are shown in Table 2.

These priority interventions were identified based on an analysis of the prevailing situation in the region. Figure 2 provides a snapshot of the current status and feasibility of key strategic interventions across 19 countries that participated in a series of consultative stakeholder meetings that WHO EMRO conducted during the period May–June 2025.

Figure 2: Snapshot of the current status of palliative care in 19 EMR countries across five strategic areas in 2025. Columns represent Member States, and the shading reflects whether a strategic action is fully or partially available (green), or is considered implementable within 1–2 years (yellow), or needs more than two years to implement (white), according to the stakeholders in each country



The different rows indicate the following strategic actions respectively: a national palliative care policy; implement the palliative care strategy; appoint a dedicated focal person or taskforce within the Ministry of Health for palliative care development; include palliative care in cancer, NCD, HIV/AIDS, ageing, and UHC strategies; advocate for legal frameworks that support patient rights to palliative care and care choices; ensure palliative care services are defined within basic benefit packages and UHC; ensure dedicated budget lines for palliative care; promote public-private partnerships for palliative care services; and include palliative care in universal healthcare coverage plans.

Embed palliative care into primary healthcare, general hospitals, and tertiary-level services, ensuring consistent access; include palliative care in existing disease-specific programmes (e.g., oncology, HIV/AIDS, NCDs, geriatrics); develop comprehensive paediatric palliative care services within paediatric services; include children in adult palliative care programmes where appropriate; establish palliative care units or teams in tertiary and general hospitals; expand home-based and community palliative care services; develop national palliative care clinical guidelines; prepare health systems for palliative care in crises; identify and strengthen hospitals or institutions as model palliative care hubs and link them to academic institutions for capacity building and evidence generation; introduce referral and back-referral systems between institutes and homecare services; mobilize communities to support and be aware of palliative care.

Include essential palliative care medicines in national essential medical list; improve access to palliative care medicines, especially oral opioids; monitor national opioid consumption; revise laws and institutional regulations to enable safe and controlled access; include palliative care modules in undergraduate medicine, nursing, pharmacy, and social work education; develop postgraduate training and certification; regularly update practising health workers through CPD, short courses, and mentorship; build community and caregiver training capacity; train palliative care providers on home-based palliative care delivery; develop national standards and accreditation for palliative care training; recognize intermediate and specialist qualifications; support national professional development platforms; promote operational and implementation research in palliative care; integrate palliative care data into health information systems; and train physicians on proper pain management and safe opioid prescribing. Develop cost-effective models of care adapted to country context and health system infrastructure; establish patient-reported outcomes and feedback systems; conduct quality audits and service evaluations; track access to oral opioids and their consumption; and support participation in global and regional palliative care research collaborations.

Abbreviations: CPD, continuing professional development; NCD, noncommunicable disease; UHC, Universal Health Coverage.

Table 2: **Priority actions identified during Member State consultations for palliative care**

Area of Intervention	Challenges	Proposed solutions	Expected impact
Policy and governance	Lack of national policies, fragmented services, insufficient funding	Develop and adopt national palliative care policies; appoint a taskforce for palliative care development and avail funds	Formal recognition, sustainable funding, coordinated service delivery, equitable access
Medication access	Restrictive opioid regulations, supply chain barriers, stigma	Regulatory reforms for opioid availability; streamline supply chains; public awareness campaigns	Effective pain and symptom management, reduced suffering, improved quality of life
Workforce capacity	Shortage of trained professionals, limited educational opportunities	Expand training programmes (curricula, continuous education); recognize intermediate and advanced levels of palliative care training	Competent and compassionate healthcare providers, enhanced quality of care, increased number of staff providing palliative care
Service delivery models	Limited-service availability, inadequate infrastructure, geographical barriers	Promote culturally sensitive, home-based care; deploy mobile/telehealth services, especially in conflict zones; integrate palliative care in primary healthcare and in hospitals	Improved accessibility, continuity of care, patient-centred approaches; increased services at all levels of the health system
Public and cultural acceptance	Low awareness, stigma, cultural/religious sensitivities regarding end of life	Community engagement; education campaigns; involvement of religious leaders	Increased acceptance, earlier referrals, reduced psychological burden on families; increased social support

Conclusion

The EMR faces a critical and growing need for palliative care, exacerbated by intersecting crises of conflict, displacement, and fragmented health systems. Millions of patients with serious illnesses, trauma-related disabilities, and chronic conditions endure unrelieved suffering due to systemic barriers, including restrictive policies, workforce shortages, and cultural stigma. Yet, the region also presents opportunities for transformative change. By integrating palliative care into national health strategies, reforming opioid access laws, and prioritizing culturally sensitive service models, the EMR can uphold the fundamental right to relief from suffering, even amid instability.

Addressing these challenges requires a dual focus: immediate humanitarian action to deliver pain management and basic palliative services in conflict zones, and long-term system strengthening to embed palliative care into primary healthcare, oncology, and chronic disease programmes. Collaborative efforts, guided by WHO frameworks, regional networks like the ENPC, and community-led advocacy, can bridge gaps in awareness, training, and equity. The path forward demands political commitment, cross-sector partnerships, and innovative solutions tailored to the EMR's unique realities. Only then can the region ensure that no patient, whether in war-torn zone or an overcrowded refugee clinic, faces preventable suffering. ■

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Beyond the dispensary: Rethinking the role of pharmacists in low- and middle-income countries through co-learning, collaboration, and ethical practice

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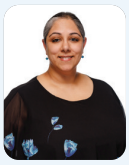
FATIMA LADHA


ANTHONY LAU

The widening of the pharmacist's role offers a vital opportunity to expand healthcare in low- and middle-income countries through increased learning, greater collaboration and better, more informed practice. This article describes the misconceptions that can hold this back and how to create the right environment for successful integration of the pharmacist's skills and learning – through first-hand experiences.

There is an unmistakable sense of excitement when pharmacists gather to discuss "making a difference globally". The ambition is clear, and the intentions are commendable. However, intention is just the initial step. Throughout this journey, we often field questions like "What works?" and "How can I help?", and these sincere inquiries merit honest replies. This article aims to reflect on our successes, challenges, and ongoing learning as we collaborate with pharmacists in low- and middle-income countries (LMICs).

We are privileged to contribute to the expanding role of pharmacy in global health through our work within Two Worlds Cancer Collaboration (TWCC) and The Sunflower Network, most recently through virtual education platforms, such as the Project ECHO model, and continent-spanning capacity-building linkages like the PallCHASE programme and our growing international palliative pharmacists' network.

Until recently, even in countries within North America and the United Kingdom, a pharmacist's role beyond dispensing was considered radical – it still is in some places. The concept of a clinical pharmacist is many decades old, yet it surprises other healthcare providers that we have the skills to perform physical assessments, independently prescribe, deprescribe, and coordinate medicine stewardship teams – and that these are authorized practices in high-income countries (HICs). Many of us want to share these advances internationally by promoting such clinical pharmacy models in LMICs.

However, what is defined as "progress" in one setting may be seen as an imposition elsewhere.

When Dr Fatima Ladha first started participating in TWCC-facilitated activities in 2013, she was excited to share the advancing practice skills with colleagues in other countries. However, it quickly became apparent that there are critical differences in practice environments beyond the ones we're familiar with in Canada. For instance, there were no clinical pharmacists onsite at any of the places where TWCC had a supportive role. When visiting the MNJ Institute of Oncology in Hyderabad, India, in 2014, she asked where the hospital pharmacist was, and healthcare team members looked confused as they informed her there might be a pharmacist working in the dispensary down the road from the hospital campus. Another example was that drug therapy counselling was provided to patients or their family members by the hospital or clinic team (i.e., nurse and/or physician) and not expected of the pharmacist. There was an assumption that Dr Ladha was there to observe and consult on the organizing and categorizing of the onsite inventory of medications. There was no notion that a pharmacist could be part of the interprofessional collaborative care teams onsite or contribute to clinical decision-making processes. Most of the healthcare workers were confused, asking "What can a pharmacist do here?"

Dr Ladha learned that the general perception of pharmacists

publicly and in healthcare settings within LMICs is that we are "drug traders" and like shopkeepers. This is despite the establishment of PharmD programmes (equivalent to the BPharm or BSc Pharm programmes in Canada at the time) in 2008 by regulatory bodies, including the Pharmacy Council of India, and graduates of such programmes are trained to work in direct patient care environments such as hospitals and clinics – like their counterparts in HICs.

However, over the past 10 years, the profession has gained traction, not only within India, but elsewhere in South and Southeast Asia and the Eastern Mediterranean regions. There are skilled clinical pharmacists established as respected members of care teams in many centres, yet independent pharmacist-driven decisions remain culturally or legally unviable. These realities challenge attempts to directly transfer knowledge and practice models across contexts.

When planning the pharmacotherapy modules for the inaugural year of the Fellowship in Pediatric Palliative Medicine Program for South and Southeast Asia, the faculty (with Dr Ladha as the only pharmacist on the team at the time) discussed with confidence that we could launch sessions designed as didactic-style lessons in clinical pharmacotherapy principles to prepare the fellows for their final Fellowship Program examination. The sessions were initially challenging, as fellows assumed she expected them to prepare long charts and tables regurgitating advanced chemistry lab concepts, molecular structures, and the like – concepts that even Dr Ladha had not learned in pharmacy training, nor utilized in her clinical practice. This was an unexpected reality check and culture shock: the fellows had never worked with pharmacists and had no notion of what our professional skillset and training includes. Dr Ladha quickly addressed this misunderstanding by sharing that the scope of pharmacists' practice includes being a paraprofessional clinician – as the pharmacy governing councils in the fellows' regions were also advocating. The sessions were then re-focused to be clinical discussions on complex therapeutic concepts the fellows faced in their daily practice and training. Now, several years into offering these modules for the Fellowship Program, we have changed our role to be more that of co-learners instead of instructors. As the perception of pharmacists has evolved positively in LMICs, thanks to efforts of the local regions' pharmacy advocacy campaigns, so too have the fellows' expectations of how pharmacists can contribute to healthcare teams and the outcomes they desire from these modules in the Fellowship Program.

It has become about sharing insights into how these practitioners work with conservative therapies using what is available locally, as they continue to advocate for expansion of medication formularies to match the World Health Organization (WHO) Essential Medicines List. These are challenges not typically encountered in North America, the United Kingdom, or Europe.

Highlighted as the most pressing issue by fellows in every cycle of the Program's pharmacotherapy modules is access to essential severe pain management with morphine or its equivalents for their patients: there are regulations, strong social and cultural stigma, no access to supply, and cost barriers to consider. Year after year, it remains a distressing issue. Other medications that are on the WHO List of Essential Medicines are also challenging to obtain. Yet, there are certain medicines which are manufactured in-country that we cannot even dream of accessing in Canada. After all, countries like India are in the forefront of pharmaceutical research and development and are global suppliers of pharmaceuticals.

These exchanges with the fellows emphasize the importance of innovation, resilience, and pragmatic adaptation to what is accessible. So, our aim for these modules continues to evolve and we shift priorities as needed. Rather than seeking to replicate North American models, we seek to equip these local leaders with adaptable tools and concepts, supporting context-specific solutions. The mutual mentorship and co-learning have become central to our work during these sessions. Our therapeutic conversations explore non-opioid analgesic alternatives available in the practitioners' regions, while still exploring the therapeutic benefits of opioids for palliative pain management. The overarching objective remains the same: to support the expressed need of fellows as they advocate on patients' behalf for access to essential medicines including morphine, fentanyl, and methadone. End-of-life pain management with opioids remains the gold standard of care and there cannot be any compromise on this fact – it remains the foundational theme in the pharmacotherapy sessions for each cycle of the Fellowship Program. To avoid discussions about this opioid crisis would be to perpetuate the unjust inequity millions of people face due to the other opioid crisis[1], which is irrelevant to the global palliative population.

Interest in global pharmacy grows with conferences, global health rotations offered by universities, and nongovernmental organizations seeking pharmacy expertise. Yet, certain realities require careful reflection.

Not all assistance is effective. We have seen clinical pathways falter without proper infrastructure, unused donations lost, and initiatives stopping after external support ends. Voluntourism can be valuable; but there are potential drawbacks if the plans

1. The opiod overuse crisis is prevalent globally and overshadows the palliative opioid crisis where thousands of adults and children are denied adequate government-regulated access to pain relief due to the stigma and fear of addiction (an irrelevant concept in palliative care) and is strongly influenced by societal misunderstanding of opioids in pain management.

do not include building long-term sustainable solutions for local healthcare systems to become independent of the need for external volunteers. Sustainability is complex. Without local ownership, projects fail, and externally funded interventions can foster dependency.

Ethical humility is crucial. Pharmacy, like other health professions, risks harmful paternalism when assuming superior knowledge or prescriptive approaches. For example, we originally assumed that we could share opioid stewardship[2] concepts with providers when planning our materials for Project ECHO sessions. However, it became apparent that doing so may propagate and empower the fear and stigma of opioids in LMICs – even amongst healthcare providers – and therefore inadvertently enable continuation of the palliative opioid crisis. The current definition of opioid stewardship, as it is understood by many healthcare colleagues worldwide, is that its aim is to reduce the use of opioids. After all, the concept developed in contextual response to promoting rational use of therapy, which happened to be predisposed by the emerging opioid overuse crisis at the time *(1)*. However, many overlook that opioid stewardship also includes discussion of opioid therapy benefits and the need for use in intractable pain situations, such as those seen in palliative care and cancer care settings. We recognized that any curriculum aiming to include opioid stewardship ought to reflect contextual readiness, social values, and local realities of whether the system in existence will be accepting of this equally important co-definition of opioid stewardship.

This complexity prompted a reflection for us: Are we providing meaningful support or simply projecting our own ideals for pharmacy practice?

Our most successful efforts have prioritized growth, attentive listening, and empowering local professionals to lead. Adaptation and respect for global diversity in pharmacy practice are vital.

Our international palliative pharmacists' network has grown. As of June 2025, we are 30 members strong, having grown from four members in 2023. This is attributable to many factors, such as the uptake in understanding the pharmacist profession's contribution to society and healthcare systems locally, and to introductions made through participation in the various Project ECHO series supported by TWCC and its partners. Practical topics such as drug supply logistics and therapeutic substitutions take precedence when our pharmacists meet. Sessions tailored for pharmacists and informal engagement on platforms like WhatsApp promote trust, peer support, and candid and genuine dialogue about issues such as burnout and advocacy.

Transformative and sustainable outcomes are found in our collaborative dialogue, because we invite participants to openly share their local pressing issues, such as managing severe pain in the context of limited opioid availability and addressing the stigma associated with recommending opioid medications, a global concern that is often more pronounced in LMICs. We work with the saying: "A problem shared is a problem halved"; and so our role through TWCC currently is to provide access to tools like Zoom™ and WhatsApp™, to references such as *The Global Handbook of Palliative Care*, and maybe to provide education sessions on complex topics such as refractory symptom management. But ultimately, it is us creating the space for those desirable conversations to happen.

While we may not have all the answers, we are committed to asking better questions. We have realized that our greatest contributions come from standing in solidarity, not offering prescriptive solutions.

These experiences reinforce that evidence-based frameworks, though valuable, are not always transferable. Practices common in one region of the world are impractical in others. Well-intentioned "westernized" initiatives risk defaulting to "best practices" that do not fit local contexts. Even strong evidence requires contextual relevance.

The key lesson is that sustainable global pharmacy initiatives begin with understanding local systems, which demands curiosity, humility, and time. Assuming to fill gaps with external solutions (like sending in skilled volunteers to work onsite) often overlooks deeper systemic issues such as policy, licensing, drug access, professional dynamics, or lingering colonial influences.

External support ought to supplement, not replace, local systems. Meaningful progress happens when local pharmacists lead, with external partners as supporters. Our facilitating local mentorship networks are an example of this: we have supported pharmacists to connect, share strategies, and advocate on their own terms.

A persistent challenge is distinguishing collaboration from charity. Excessive focus on knowledge transfer from "developed" to "developing" settings reinforces hierarchies. We continually question whether we are fostering true collaboration or inadvertently assuming authority, and if local leadership is empowered or dependency is created.

True partnership involves co-learning, valuing local expertise, and recognizing that innovation thrives despite constraint. It means sharing credit with, and promoting the visibility of, partners.

Political instability will dictate global health initiatives. Shifting policies can rapidly reverse progress made in capacity building, especially regarding drug therapy access. The recent

2. An approach in HIC healthcare systems in response to opioid overuse crisis which aims to minimize negative impacts such as overdose and other adverse drug effects.

restrictions of funding by the United States to organizations such as the WHO and United Nations Human Rights Council (UNHRC) is an example of immediate impacts on the ability of frontline workers to consistently and reliably support capacity building in local regions, because other countries have paused or pulled out their support to those initiatives in response. It is our hope that local teams will find resilient solutions for partnerships and suppliers that can bring stability for their suffering palliative populations.

Thus, sustainability must be central from the outset.

The future of global pharmacy relies as much on relationships, respect, and solidarity as on guidelines and toolkits. Empathy, humility, and authentic engagement are crucial.

Across regions, pharmacists are innovating, driven not by imported models, but by local needs and creativity.

As we continue to grow our international palliative pharmacists' network, we invite colleagues who are the leaders of our profession, living and working in resource-constrained regions, to share their stories. The greatest learning comes from these inspiring voices, and we stand in solidarity with them by inviting them to convey their experiences. We hope that our next publication will be the platform for their voices and sharing of experiences. ■

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REGIONAL FOCUS

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RINC: The rise and fall of a regional cooperation network for cancer control

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Recognizing the increasing population burden of cancer, the *Red de Institutos e Instituciones Nacionales de Cáncer* (RINC, the Network of National Cancer Institutes and Institutions) was established in 2011 under the governance of the Union of South American Nations (UNASUR), a regional intergovernmental organization fostering broader political, economic, social, and cultural integration. Notwithstanding relevant collective medical achievements, RINC ultimately failed due to political ideology and terms of office, politically-determined medical institutional leadership change, variable and insecure governance, inconsistent medical leadership support, and insecure, unsustainable financial commitment. Population-based cancer control plans require strategic medical content; implementation necessitates contextual, cultural, and collaborative relationships amongst all stakeholders.

In the 2015 edition of *Cancer Control*, Zoss and Santini published an article entitled "Regional cooperation in Latin America for cancer control: Moving from commitment to implementation" *(1)*. That article presented an overview of how Latin American countries had come together four years earlier establishing a fledgling *Red* ("Network" in Spanish) to support each other in cancer control plans and actions, with the aim of reducing cancer incidence and mortality in the region.

Ten years later, it is clear that the Network failed to achieve its objectives and, worse, the Network effectively dismantled itself. What went wrong?

Historical context for the rise of UNASUR and RINC

Established in 2011 as a regional geopolitical platform for the development and implementation of cancer control programmes and actions in Latin America, the *Red de Institutos e Instituciones Nacionales de Cáncer* (RINC, the Network of National Cancer Institutes and Institutions)[1] germinated out of two favourable conditions: 1) favourable political and ideological circumstances in the region, and 2) the inspiration of initiatives that followed the first two meetings of the International Cancer Control Congress (ICCC) in Vancouver, British Columbia, Canada, in 2005, and in Rio de Janeiro, Brazil, in 2007.

In 1991, several South American states established Mercosur, a regional common market modelled after the European Common Market. In 2008, South American countries established the Union of South American Nations (UNASUR), a regional intergovernmental organization that sought to foster broader political, economic, social, and cultural integration *(2)*. By late 2010, nine countries had ratified the UNASUR Constitutive Treaty *(3)*. This political union provided fertile ground for regional cooperation in various areas, including public health.

The ICCC, first held in Vancouver in 2005, took its population-based cancer control agenda to Latin America for its second congress. With support from Brazil's Ministry of Health, ICCC-2 was hosted by the National Cancer Institute (INCA) in Rio de Janeiro in November 2007.

Among the innovative ideas that emerged from the first two ICCCs was a pragmatic vision that regional approaches could accelerate the elaboration and implementation of national

[1] *The somewhat cumbersome title of the Network reflected the fact that not all participating countries have a National Cancer Institute (NCI), and even countries with an NCI often have agencies or offices within the Ministry of Health that have lead responsibility for population-based cancer control policies, programmes, and actions. Several delegations to RINC included representatives from a country's NCI and its Ministry of Health.*

cancer control policies and programmes into each country's public and private healthcare delivery systems by integrating evidence-based scientific and medical content within socially and financially achievable local contexts. Collaborative relationships among stakeholders and political support were viewed as a strategic ingredient.

This vision was crucial for the beginning of a coordinated strategy that culminated in the creation of the Latin American and Caribbean Alliance for Cancer Control. The strategic vision of the Alliance included establishing a collaborative work process, with one of its main characteristics being the construction of a regional community based on best practices, knowledge sharing, and programmes of common interest. Communication and regional cohesion were facilitated, given that most of the attendees from Latin American countries were Spanish or Portuguese speakers[2].

By 2011, UNASUR emerged as an opportunity to transform the Alliance into a Network of National Cancer Institutes and Institutions (RINC-UNASUR) and boost technical cooperation, bringing together national public institutions from the 12 South American countries that were formal members of UNASUR, as well as other Latin American and Caribbean nations.

With the formal support of governments, the new RINC-UNASUR geopolitical platform defined the following priorities:

- organizing a regional community of best practices for cancer control;
- exchanging information and knowledge related to the selected topics;
- identifying common needs, opportunities, and interests, and seeking shareable alternatives;
- promoting coordination among participating countries to strengthen the management and institutional development of national cancer institutes and institutions in the region; and
- promoting the commitment of governments at all levels to provide the authorizing legislation, budgetary commitments, and human resources necessary for the development and implementation of cancer control programmes.

The choice of cooperative programmes and actions to be developed by RINC-UNASUR was guided by 1) the most urgent cancer control priorities in terms of cancer morbidity and mortality, and 2) the greatest potential for achieving common goals through collective action as perceived by delegations from member countries. Initial priorities included the regional elimination of cervical cancer (the second most common cancer among women of all ages in Latin America), the reduction of breast cancer mortality, the expansion of population-based registries, and establishing a network of tumour tissue biobanks.

RINC made admirable initial progress and was recognized by international organizations such as the World Health Organization (WHO) and Pan American Health Organization (PAHO), the International Agency for Research on Cancer (IARC), and the International Atomic Agency Agency (IAEA) among others as an important milestone in health cooperation in Latin America. However, RINC faced significant structural challenges. UNASUR had some regional funds for projects, and whilst its resources were limited, UNASUR funding supported RINC to develop a Regional Cervical Cancer Control Plan in 2017 *(4)*, which was officially incorporated into the PAHO Action Plan for Central and South America.

UNASUR's precariousness and the impact on RINC

RINC's dependence on UNASUR as the primary source of sustainable long-term financing left the network vulnerable to political and economic fluctuations and rifts within the geopolitical bloc. The lack of adequate investment by member states in the South American Union's own infrastructure and operations prevented UNASUR's institutional structure from becoming sufficiently strong to overcome divergences and drive projects forward.

The vast majority of RINC's operations were funded by the NCIs of member states themselves, particularly by Brazil's National Cancer Institute (INCA), which from the outset provided a technical secretariat with specialists and support from within its own facilities. Resources were also made available by the Brazilian Ministry of Health through an agreement with PAHO, which administered the funds. In retrospect, financial circumstances certainly contributed to the weakening of UNASUR and, consequently, to the fragility of RINC's projects.

The bureaucracy of UNASUR and the governments of several of its member states also hampered the progress of RINC's work. The rigidity and slowness of internal processes of several member states compromised RINC's ability to implement RINC projects in a timely manner.

For a network such as RINC – formed under the auspices of a young regional multilateral union such as UNASUR – there were interesting potential benefits, such as the possibility for each member state's national mobilization for cervical cancer prevention (HPV immunization) and early detection (screening) to be part of a unified regional campaign, but there were also risks.

[2] *This emphasis on Spanish and Portuguese did not ignore the fact that the official language of Guyana is English and of Suriname is Dutch; nor did it ignore the fact that many UNASUR countries recognize indigenous people's dialects as official languages. French Guiana is a department and region of France, and thus is considered part of the European Union.*

The rotation of federal government power in individual member states, expected in democracies, inevitably brings ministerial and NCI leadership turnover, and often changes in policy and programmatic priorities. The change in priorities and political leadership in member countries led to the discontinuation of promising or successful programmes and actions, and waste of resources. The resultant instability challenged the ability to sustain long-term commitments and guarantee the ongoing implementation of multi-year strategic plans such as those encouraged by RINC.

UNASUR gradually began to suffer a process of erosion until its complete cessation in 2018, mainly due to the rise of centre-right and right-wing leaders in most South American governments alleging a "set of problems related to the organization's functioning". Six member countries – Brazil, Argentina, Paraguay, Colombia, Chile, and Peru – ultimately suspended their participation in UNASUR *(5)*. RINC was forced to immediately suspend its activities.

Over the following two years, with support from PAHO efforts were made to find a way to continue its activities reconstituted as RINC-Latin America and the Caribbean (RINC-LAC) *(6)*, but these efforts floundered, and in 2020 the Coronavirus pandemic dominated public health focus.

In 2022, thanks to the efforts of some remaining leaders of cancer care policy in the region, but without the participation of the NCIs and ministries of health, RINC managed to rebuild itself through cooperation with the Latin American and Caribbean Society of Medical Oncology (SLACOM). Today, RINC-SLACOM survives only as a consultative forum for discussing ideas and issues related to cancer control in the region.

Conclusion

RINC, which began as a platform for cooperation, collaboration, and technical coordination with unprecedented and unparalleled political reach, was progressively undermined by the gradual disintegration of UNASUR, its sponsoring body.

The initial cohesion and achievements of RINC – fostered under the auspices of UNASUR – demonstrate the value of the mutual support and reinforcement that regional cooperation initiatives can offer, but also highlight the importance of stability and sustainability of the political structures and budgetary commitments that support them. The decline of UNASUR not only weakened an ambitious regional integration project, but also calls into question the continuity of crucial efforts to control cancer in Latin America, a region that still faces significant challenges in this area. ■

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Dr Passman received his BSc in Life Sciences (Biology) and a Masters in Political Science (Health Policy) from the Massachusetts Institute of Technology. He was a Medical Scientist Training Program (MSTP) scholar at New York University where he received his MD and a PhD in Public Administration.

He completed a primary care track Internal Medicine residency at the UCLA Medical Center in Los Angeles, and then spent two years at the Universidade do Rio de Janeiro (UniRio) as a research fellow of the NIH Fogarty International AIDS Research Program.

From 1992 to 2001, he was an Assistant and then Associate Professor of Medicine at the UCLA School of Medicine. From 2001 until 2023 he has served as an Adjunct Associate Clinical Professor of Medicine. In Brazil, Professor Passman introduced standardized patients into the curriculum and taught at the School of Medicine of the Universidade do Grande Rio; he has also lectured in six graduate health management and health MBA programmes at public, private, and corporate universities.

Dr Simon B Sutcliffe, BSc, MD, FRCP, FRCPC, FRCR is a clinical oncologist with past practice in academic clinical medicine and research. A former CEO of Princess Margaret Hospital/ Ontario Cancer Institute (Toronto, Ontario) and the BC Cancer Agency (British Columbia, Canada), he is the President of Two Worlds Cancer Collaboration (formerly INCTR Canada), a nongovernmental organization focusing on compassionate care, palliative care, and cancer control in lesser-resourced countries. He is Editor-in-Chief of Cancer Control.

Dr Luiz Antonio Santini, MD, served as the Director General of Brazil's Instituto Nacional de Cancer (INCA) from 2005 to 2015. Under his administration, INCA implemented a new institutional technical-scientific model and started building a new campus. Much of Dr Santini´s early career was in clinical education at the School of Medicine of the Fluminense Federal University in Rio de Janeiro where he had completed a Residency Training in Thoracic Surgery. Dr Santini also completed a Fellowship in Public Health at the National School of Public Health at Fiocruz. He served three terms as Executive Director of the Brazilian Association of Medical Education (ABEM). Due to his regional leadership in Latin America, he served as Coordinator of RINC/UNASUR from 2011 to 2015. Dr Santini was elected three times as a UICC board member and represented Brazil on IARC´s Governing Council. Dr Santini is an Associate Researcher at the Oswaldo Cruz Institute Foundation (Fiocruz), and is most recently author (with Clovis Bulcão) of SUS: uma biografia: lutas e conquistas da sociedade brasileira (Editora Record, 2024), a biography of Brazil's universal public healthcare system.

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Cancer prevention and control in Peru: The role of the National Institute of Neoplastic Disease (INEN)

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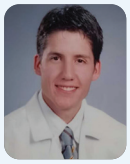
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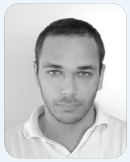
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Peru has had a national strategy for cancer control since 2012, known as the "Plan Esperanza", which has been strengthened by subsequent recent legislation. This article describes how this strategy had lead to significant progress in reducing cancer-related morbidity and mortality in Peru and has brought in universal access to cancer care, wider education and research, as well as providing an integrated approach to population-based cancer control.

Latin America and the Caribbean have an estimated cancer incidence rate of 186.5/ 100,000 and a mortality rate of 86.6/100,000 cases *(1)*. Cancer incidence will grow from 1.5 million new cases to more than 2.4 million by 2040, a 65% increase projected to be most pronounced in Central America (70%) and South America (65%) *(1–3)*. The International Agency for Research on Cancer (IARC) estimated 69,869 new cases and 34,976 deaths from cancer in Peru in 2022, with a cumulative risk of 17.02% for developing cancer *(4)*, placing Peru among the countries with an intermediate level of cancer incidence *(2,4)*. The Peruvian Death Information System (SINADEF) reports cancer mortality increasing by up to 26% in the last five years, from a ratio of 14.5 deaths per 100,000 people in the first half of 2019 to a ratio of 18.3 in the same period in 2024, reflecting failure of early detection, timely access to quality health services, and shortage of drugs for cancer treatment *(5)*. Cancer represents a growing problem for public health in Peru, with breast and cervical cancer control being a national priority *(4)*. Accordingly, public policies advancing population-based cancer control in Peru remain a health priority.

Public policies for cancer control

Established in 1939, the National Institute of Neoplastic Diseases (INEN), a decentralized public agency, has participated in various regulations for cancer control in Peru (Figure 1) *(6)*, becoming the leading institution for cancer prevention and control in Peru in 2006 *(7)*. Two regional centres have been established – in northern Peru in Trujillo, the Instituto Regional de Enfermedades Neoplásicas Norte (IREN Norte), and in Arequipa (Southern Peru), the Instituto Regional de Enfermedades Neoplásicas Sur (IREN Sur) *(8)*. In 2007, the "National Plan to Strengthen Cancer Prevention and Control in Peru" to reduce cancer incidence, morbidity, and mortality was published *(8)*.

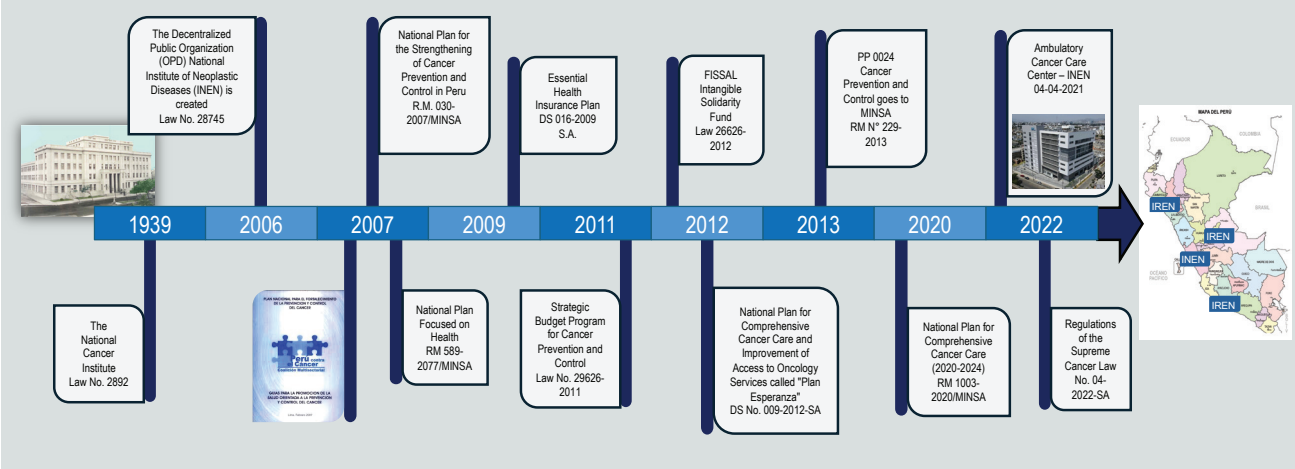
In 2012, the government approved "Plan Esperanza", a National Plan for Comprehensive Cancer Care and Improvement of Access to Oncology Services in Peru, to expand and improve access to oncology services throughout the country *(6)*. Plan Esperanza focused on promoting healthy lifestyles, cancer prevention, early detection, comprehensive care and treatment, and the decentralization of medical care for cancer patients through optimizing cancer care in all regions of Peru *(6)*. Between 2011 and 2012, the National Institute of National Endowment for National Health, with technical support from INEN, >7,000 health facilities were able to budget and allocate resources for cancer prevention, health promotion, and early detection of the five most common cancers – stomach, breast, cervical, prostate, and lung cancer – in 25 regions of Peru *(10)*. Publicly funded through Comprehensive Health Insurance (SIS), Plan Esperanza enabled equitable access to comprehensive health services, providing free basic and specialized prevention for the general population, particularly those living in poverty *(10)*. Overall, between 2009 and 2015, the total budget for cancer control increased more than sixfold, from 152 million soles to 936 million soles, an average annual growth of 35.4% *(10)*, with a total budget of 1.2 billion soles *(1)* for the fight against cancer by 2025 *(11)*.

An imPACT Review commissioned by the Ministry of Health (MINSA) in 2014 approved and validated the Plan Esperanza cancer control strategy and guidelines, recognizing the comprehensive, interdisciplinary, and cross-sectoral approach to cancer control in Peru; the importance of capacity expansion through decentralization, facility expansion, modernization and renovation of equipment, and training of health professionals; the focus on safety, quality, and standards of practice and care; and the value of social participation *(12)*. The review highlighted the need for effective leadership in cancer management (government, nongovernmental organizations, institutions, INEN, civil society), and emphasized the need for stable secure governance and financing as fundamental elements for implementation of an effective population-based cancer control strategy *(6)*.

National Plan for Comprehensive Cancer Care (2020–2024)

In 2020, MINSA, with INEN and other entities, approved the continuation of Plan Esperanza as a National Plan for Comprehensive Cancer Care (2020–2024) *(12)*. Based on 18 indicators of risk, mortality, and health services response determinants, MINSA conducted a territorial vulnerability analysis, identifying the most vulnerable regions for cancer prevention and control responses – Huánuco, Pasco, Ayacucho, Amazonas, Cajamarca, Loreto, and San Martín *(12)*. Short-term priority interventions were authorized to strengthen cancer prevention and control interventions *(12)*. The burden of leukaemia, represented by the number of years of healthy life lost (YHLL), exceeded that of cancers with higher incidence rates, e.g., stomach cancer, making treatment of leukaemia a priority in children and adolescents. According to the number of YHLL, cervical and breast cancer were third and

Figure 1: Public cancer control policies



fourth. Other cancer priorities included hepatocellular, lung, colorectal cancers, and lymphomas *(12)*.

The National Plan for Comprehensive Cancer Care recognizes the need to strengthen the decentralization of oncology services in Peru, allowing provision of oncology care in seventeen of the twenty-five regions, including the decentralization of oncology care in Metropolitan Lima itself, where oncology care is provided in 11 hospitals, in addition to INEN *(12)*. Centralization of human resources is reflected by 73% of the 204 medical or clinical oncology specialists, 67.9% of the 221 pathology specialists, and 82.6% of the 69 radiation oncologists registered nationwide being based in Lima and Callao. Per million inhabitants, the ratio of specialists in clinical oncology, surgical oncology, radiation oncology, and pathology is 1 per 6.4, 5.6, 2.2, and 6.9 *(12)*.

The redesign of the "Cancer Prevention and Control" budget 2024 seeks to strengthen strategic interventions in promotion, prevention, screening, and management of premalignant lesions, which have demonstrated a positive impact on cancer control with Plan Esperanza. The budget is also directed to cancer diagnosis and treatment (care for cervical, breast, stomach, prostate, leukaemia, lymphoma, lung, skin, liver, and colorectal cancers), with the incorporation of 0.5% of the total budget for palliative care *(13)*.

Integrated Network of Oncology Services

The National Integrated Network of Oncology Services, led by INEN, provides nationwide coverage for early detection, definitive diagnosis, staging, and treatment of cancer. Decentralization has been achieved through creation of the regional institutes in Huancayo/Junín (IREN Centro) and Iquitos/Loreto (IREN Oriente), supported directly through public investment. The National Oncology Network (RON) has established oncology units in each region of the country to promote the implementation of specialized comprehensive cancer care centres for adequate and timely care of cancer patients from different parts of the country, with the goal of decentralizing cancer treatment and follow-up [19]. Additionally, the Network ensures a referral and counter-referral system whereby cancer cases entering the health system through primary care can be referred to the nearest secondary-level hospitals, and then to the Regional Institutes of Neoplastic Diseases (IRENES). For highly complex cancer cases, referral is made to INEN.

The Childhood Cancer Law

Published studies reveal that 30% to 80% of paediatric patients suspend or abandon cancer treatment due to late diagnosis, drug toxicity, and difficulty accessing various treatments *(14,15,16)*. In 2019, Peru was chosen as an index country to combat the high dropout rate reported in the country (~50%) by the World Health Organization Global Initiative against Childhood Cancer *(17)*. In September 2020, the Law on Medical Emergencies for the Timely Detection and Comprehensive Care of Childhood and Adolescent Cancer was approved, ensuring universal coverage and referral to a tertiary care hospital within 72 hours for children and adolescents (<18 years of age) *(18)*. Social benefits are provided for parents of children with cancer, such as unpaid leave for up to one year from their workplaces, allowing for ongoing support and greater adherence to treatment.

The National Cancer Law

The National Cancer Law, based on the Plan Esperanza model, is promoted by the Peruvian Cancerology Society and INEN Medical Association and guarantees universal, free, and priority health services, ensuring equitable, accessible, comprehensive cancer services and coverage for cancer patients, and allowing immediate enrolment in Comprehensive Health Insurance (SIS) for patients without Social Health Insurance (EsSalud), private insurance, or insufficient health coverage *(19)*.

The law is implemented and financed through institutions that administer public or private health insurance funds, in addition to other public financing mechanisms, and guided by results-based budgeting for cancer prevention and control, among other related programmes. The Ministry of Health uses differentiated acquisition mechanisms (DAMs) for pharmaceutical products, medical devices, and health services necessary for the treatment of cancer, according to evidence supporting clinical effectiveness and safety compared to available conventional care *(19)*. The Executive Branch approves the acquisition of new technologies through the National Center for the Supply of Strategic Health Resources (CENARES) *(19)*.

Access to cancer medicines

The Pan American Health Organization (PAHO) has prioritized access to essential cancer medicines. The survival rate for paediatric cancer is over 80% in high-income countries, but does not exceed 30% in low- and middle-income countries, the difference being primarily due to the lack of access to cancer medicines.

In Peru (a middle-income country), cancer treatment is very expensive and practically unaffordable as an "out-of-pocket" cost. Furthermore, the Peruvian healthcare system is fragmented: each type of insurance has its own financing, budget, and independence. A Ministerial Resolution has allowed level III-2 health facilities to purchase and/or use medicines not approved in the National Single Request for Essential Medicines (PNUME), as long as they meet

two conditions: they must have prior approval from their institutional Pharmacotherapeutic Committee (CFT), and they must be contained in a Clinical Practice Guide (GPC) and/or regulatory document *(21)*. Since 2019, INEN has used this resolution for the approval of more than 50 oncological medicines validated by the CFT, and the development and/or updating of approximately 30 regulatory documents (CPGs) for various cancers, as well as for conditions or complications related to medical cancer treatment, thereby achieving access to innovative and more effective technologies *(22)*.

High-cost medicines for cancer treatment will be supplied for the first time in the hospitals of the MINSA networks in 2024 *(23)*.

Cancer Law Pathway: Health Technology Assessment (HTA)

Since 2012, with Plan Esperanza, the goal has been reducing out-of-pocket expenses related to access to oncology medications, ensuring that patients receive the necessary and effective innovative treatments through accessible, universal coverage for cancer treatment in Peru, especially those in vulnerable and impoverished situations; increasing the availability of evidence-based oncology medications and their use according to clinical practice guidelines nationwide; and achieving affordability, including coverage under the Public Insurance (Comprehensive Health Insurance – SIS). Additionally, a monitoring and evaluation system for the use of oncology medications managed by INEN has enabled unprecedented progress, with a focus on personalized and precision oncology transforming cancer treatment through personalized therapies based on the genetic characteristics of tumours – improving response and survival rates while optimizing the use of healthcare resources by reducing unnecessary treatments.

To further embed evidence-based decision-making and the adoption of HTA methodologies used in the country, the National Health Technology Network (RENETSA) was established in 2020 to conduct HTAs and economic evaluations. Up to 14 August 2024, RENETSA, using multicriteria evaluation (HTA-MCE) for pharmaceutical products for cancer, received 174 applications for 70 high-cost cancer medications with 38 opinions (18 in favour), and a list of HTAs of the rare and orphan diseases (ROD) with nine opinions. Guidelines for a standardized methodology leading to recommendations for the use of high-cost ETS have been published by the National Institute of Health (INS) *(25)*. Of 61 HTAs evaluated during the period 2022–2024, 33% of opinions were positive *(26)*.

Cancer prevention and health promotion: Ethnic and geographic diversity

In 2019, Peru recorded a loss of 518,176 years of healthy life (YYL) due to cancer *(27)*. Approximately 27% of the Peruvian population is Indigenous and faces lower cancer survival rates, attributable to late diagnosis and limited or no access to cancer treatments *(27)*, thereby highlighting the need for improved early detection strategies and equity in the provision of cancer care among the different populations of Peru.

Prostate, breast, stomach, colorectal, and cervical cancer represent 45% of cancers in Peru *(19)*. Currently, life expectancy in the Peruvian population is 74.6 years (72.0 in men and 77.3 in women), with an expectation that life expectancy will increase to 79 years by 2050, thereby increasing the cancer incidence rate *(27)*. The State encourages and promotes the equitable implementation of national health promotion, cancer prevention, and cancer control interventions *(21)*. Breast cancer is the most common cancer in women in Peru *(27)*. In 2022, 12.8% of women aged 30–59 years reported a clinical breast examination in the prior 12 months, 15% from the coastal, 9.2% from the mountains, and 9.1% from the jungle region *(27)*. For 40–59-year-old women, 8.9% had at least one mammogram in the past 24 months, 10.3% in urban and 2.4% in rural regions *(27)*. Cervical cancer is the second most common cancer in women in Peru: 10.6% of women aged 30–49 years have undergone human papillomavirus (HPV) molecular testing in the last three years, 11.2% in urban and 8.1% in rural areas *(27)*, with 9.6% knowing their results *(27)*. The goal for screening with HPV molecular tests for women between 30 and 49 years by 2030 is 70% *(27)*. Nationally, 47.5% of women aged 30–59 years have undergone Pap tests in the last three years, 49.6% in the coastal region compared to 44% in mountains and 43.7% in the jungle *(24)*. The highest rates for visual inspection with acetic acid (VIA), are in mountainous regions (Huánuco and Cerro de Pasco) and some districts in the jungle (Madre de Dios and San Martin) *(27)*. Laws directed to the control of consumption of tobacco products, nicotine, or substitutes exist to prevent the development of new generations of abusers and reduce morbidity and mortality secondary to their use *(27, 28)*.

Telemedicine

The National Cancer Law establishes the need for care and monitoring through telemedicine services for patients diagnosed with cancer, with special emphasis on older adults and those in vulnerable situations *(29)*. A significant barrier to accessing cancer care in Peru is the country's complex geography *(15)*. Nearly 50% of patients travel long distances for care in Lima at INEN; >75% of cases referred to Lima have advanced cancer requiring systemic treatment, usually chemotherapy *(16)*. A Peruvian retrospective study evaluating patients with hormone receptor (HR)-positive/HER2-negative advanced breast cancer (n=143) treated at INEN showed that almost 30% presented de novo disease at diagnosis, and

>50% of patients met "aggressive disease" criteria (including the following definitions from the RIGHT Choice trial: rapid disease progression, symptomatic visceral disease, markedly symptomatic non-visceral disease) and received first-line chemotherapy *(30)*. A satellite telechemotherapy centre was implemented in a second-level health facility in Lamas (jungle region), 1,100 km from the capital, from November 2015 to March 2018: 56 patients were treated remotely through telemedicine and telechemotherapy, the majority with breast cancer (73.2%), for a total of 232 chemotherapy courses (82% intravenous, 13% oral, and 5% hormone therapy), providing an effective treatment mitigating the geographical barriers hindering access to cancer care *(15)*.

National Biobank Network

Established in 2022 within INEN and supported by French-Peruvian cooperation (Institut de Recherche pour le Développement, IRD), a National Tumour Bank Network, overseen by INS in coordination with INEN, has been declared a public necessity *(29)*. The Biobank collects biological, clinical, and sociodemographic data on patients diagnosed with cancer, standardizing the procedures nationwide to provide biological samples for research under ethically and technically optimal conditions. Cancer registry data and biological samples are integrated, covering 5,992 cases of various types of neoplasia, providing a real-time platform linking regional and national tumour banks, updated data on cancer at the national level, and ensuring long-term preservation of samples to support cancer research to improve research and molecular oncology for cancer control and reduce genomic health inequalities through harmonized policies and governance *(31)*.

Research and the National Population-Based Cancer Registry

Clinical trial participation is low in Latin America, with Peru ranking sixth with 6.33% of all clinical studies conducted in the region. The National Cancer Law stipulates that the State promotes biomedical scientific research and education in cancer control at all three levels of government, as well as in all different entities of the National Health System, with the support of public and private universities, cancer patient organizations, and international technical cooperation *(16)*. The national benchmark for oncology research is INEN, supported by national and international technical and scientific institutions. Clinical data regarding etiology, risk factors, research, health planning, surveillance, and outcomes can be linked to the National Biobank Network.

Conclusions

Peru is a middle-income country in South America, comprising 34 million people, a nominal GDP per capita of US$ 8,500 per year, a Human Development Index of 0.762 (high), and a GINI coefficient of 40.2. Established in 1939, INEN formalized the intent towards population-based cancer control, pursuing public policies, social protections, and clinical practice advances to achieve equitable and affordable access to effective interventions to control cancer.

The Plan Esperanza, a national strategy for cancer control, was endorsed by the Peruvian government in 2012. It is now expanded and strengthened as the National Cancer Law (2021), providing prevention and comprehensive cancer care nationwide, guaranteeing universal access and coverage for cancer prevention, diagnosis, treatment, palliative care, and complementary support. In addition, the law promotes cancer education and research towards personalized and precision oncology, requiring specialized implementation and regulation by nationally competent institutions. The Childhood Cancer Law (2020) is directed to timely detection and comprehensive care for children and adolescents with cancer. Comprehensive Social Insurance (SIS) and Social Health Insurance (EsSalud) enable care provision and support without denial for financial reasons.

The Integrated Network of Oncology Services (INEN, IRENES, and oncology services in general hospitals) provides decentralized care through linked regional institutes and oncology services. INEN promotes enabling entities to support equitable, accessible, and affordable care, e.g., evidence-based clinical practice guidelines: developing and/or updating institutional regulatory documents; health technology assessment, including new drug evaluation and access to cancer medications; telemedicine and telechemotherapy services; and national cancer registration and linkage of registry with the National Biobank Network, providing optimal preservation of biological samples and supporting research. INEN is a benchmark for scientific research and cancer clinical trials, providing ongoing training and technical support to IRENES and RON.

Significant progress in reducing cancer-related morbidity and mortality in Peru has been achieved through system-wide collaboration: integrated care networks between home, community, secondary, and tertiary facilities; forums for patient and public input, opinion and guidance; and a system for population-based cancer control based on cooperation and collaboration between all levels of government, the Ministry of Health, social health insurance, publicly-funded institutions, academia, nongovernmental organizations, the private sector, patients, and the public. ■

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The realities of palliative care for cancer patients in Rwanda

Christian Ntizimira, Founder and Executive Director, African Center for Research on End-of-Life Care

CHRISTIAN NTIZIMIRA

Rwanda faces a severe shortage of specialists: with only 10 clinical oncologists, one paediatric oncologist, and a few trained palliative care professionals. Many healthcare workers report low confidence in delivering palliative care due to insufficient training. Palliative care in Rwanda is often stigmatized. The author, a pioneer physician of the palliative care programme in public health, advocates for "decolonizing" palliative care by reframing it through African philosophies. His "Safari Concept" uses animal metaphors to explain suffering and promotes "Ubuntu" to foster community engagement.

Palliative care, as defined by the World Health Organization (WHO), is an holistic approach that improves quality of life for patients and families facing life-threatening illness through the prevention and relief of suffering. This includes early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychological, or spiritual *(1)*. Globally, palliative care is recognized as a human right essential to dignity.

In Rwanda, and many low- and middle-income countries, palliative care is often misunderstood as end-of-life care. This narrow framing limits access to timely interventions that could otherwise support patients from the point of diagnosis. This article critically explores Rwanda's palliative care landscape for cancer patients, reviewing historical development, research findings, patient and caregiver experiences, and key policy recommendations.

Historical and policy context

Early developments and national policy

Before 2011, Rwanda had minimal access to strong analgesics such as morphine. In 2009, the government initiated a home-based care programme for terminally ill patients, largely delivered by family members, aligning with cultural preferences for home death *(2)*.

In 2011, Rwanda launched a standalone National Palliative Care Policy (NPCP), among the first in Africa. This policy sought universal access by 2020 and included the following strategic goals: access to essential medications, integration into all health levels, healthcare worker training, and monitoring mechanisms *(3)*.

By 2012, Rwanda began domestic production of oral morphine, easing concerns about opioid misuse. Nurses were authorized to prescribe morphine, enhancing access at the community level *(4)*.

Integration into broader health strategies

Palliative care is embedded in Rwanda's Health Sector Strategic Plan III and the National Cancer Control Plan *(5)*. These frameworks emphasize holistic cancer care, including symptom relief and psychological support, ensuring systemic integration rather than isolation *(5)*.

Decentralization and home-based care

Home-based care remains a primary delivery model. It resonates with cultural values and facilitates care for patients in rural areas. Rwanda's model reflects the Ubuntu philosophy, community-driven support for vulnerable individuals, which bolsters sustainability and cultural acceptability *(6)*.

Mukasahaha et al. *(7)* conducted a needs assessment in nine Rwandan hospitals. They found that 25% of inpatients had life-limiting illnesses, yet 99.2% had unmet palliative care needs. Only 8.1% were seen by palliative care services, highlighting a systemic gap between policy and practice. Despite domestic morphine production, barriers persist. Opiophobia, fear of opioid misuse, continues to affect prescription rates. Legal reforms have improved supply, but cultural beliefs and insufficient provider training hinder effective pain control *(8)*.

Rwanda faces a severe shortage of specialists: only 10 clinical oncologists, one paediatric oncologist, and a few trained palliative care professionals. Many healthcare workers report low confidence in delivering palliative care due to insufficient training *(9)*.

Twahirwa et al. *(10)* studied 120 home caregivers. Despite high exposure to pain education, 53.3% did not consistently apply pain management techniques. Patient satisfaction was low, and caregivers experienced significant emotional and financial burdens. Only 20% were educated on end-of-life signs.

The Safari Concept: Culture and metaphors in response to suffering

In Rwanda, there is a proverb that states: "When you are well, you belong to yourself, but when you are sick, you belong to your family". The "Safari Concept" employs animal metaphors to articulate experiences of suffering and promotes the principle of *Ubuntu* as a means of fostering community engagement *(6)*. This framework provides a novel lens for rethinking palliative care in Africa, rendering it more accessible, culturally relevant, and humane in alignment with the continent's values and lived realities. It exemplifies the importance of cultural sensitivity and innovative thinking in the development of care models that are truly centred on both patients and their families, thereby advancing the vision of palliative care as a universal right adapted to local contexts.

Within the Rwandan context, decision-making in healthcare is situated at the intersection of patient autonomy and community responsibility. This dual emphasis forms the foundation of clinical and ethical choices. The Safari Concept emerged as a response to four persistent challenges:

- The exclusion of family members from the decision-making process;
- Communication difficulties between healthcare professionals and families;
- Challenges in identifying the appropriate next of kin in hospital settings, given the broad cultural definitions of family; and
- The frequent neglect of the emotional and psychological needs of family members.

Experiences accumulated over the past decade, particularly through encounters with families, reveal profound suffering that has often gone unrecognized and unaddressed by healthcare professionals. The size of the family group involved in these discussions is determined by the family rather than by clinicians and may range from as few as five to as many as 60 individuals. Given the centrality of animal metaphors in Kinyarwanda, it became necessary to adapt medical discourse in ways that demystify and destigmatize palliative care.

From more than 800 family meetings, 12 distinct animal archetypes were identified, each representing a specific communication approach with families. These archetypes emerged through the questions posed by families and their expressed expectations of care. Each metaphor is rooted in pre-existing Rwandan cultural narratives used to describe circumstances or emphasize concepts requiring greater attention. During family meetings, the practitioner's role frequently entails identifying the most influential family figure, often metaphorically referred to as the "Lion" or "Lioness." This metaphor illustrates the dynamics of family hierarchy, enhances the effectiveness of communication, and informs subsequent communication strategies. Consequently, it is essential to observe how individuals introduce themselves, as this provides insight into the roles of family members in the decision-making process:

- Introductions proceeding from the eldest to the youngest suggest a traditional family hierarchy rooted in cultural values and strong traditions;
- Introductions beginning with the youngest and moving upward to the eldest indicate that hierarchy is determined by influence rather than tradition, and such meetings are likely to be more challenging to manage; and
- Introductions starting with females before males suggest that the meeting will proceed smoothly, although the decision-making process will likely involve extensive discussion.

Rwanda is a landlocked country characterized by both urban and rural settings, with the majority of the population residing in rural areas. In the context of palliative care, it is also critical to recognize the diversity of educational backgrounds, environments, and perceptions of care. These differences manifest as follows:

- **Urban families** often regard extensive medical evaluations and treatments as expressions of care, even when outcomes may be unfavourable. They also tend to believe that society evaluates them based on the location of their loved one's death; and
- R**ural families,** on the other hand, generally prefer their loved ones to die at home, surrounded by family and the broader community. While this preference may be shaped by cultural values, financial limitations, and logistical considerations, such as transportation and home care resources, it should not be misinterpreted as a reflection of poverty or lack of sophistication. In fact, rural families may be more educated than initially assumed.

After gathering this information, we categorized the observed behaviours emerging from discussions – including emotions and perceptions of medical facts – through the use of animal archetypes. These archetypes are employed not to depict the individual but to symbolize the type of suffering experienced. While multiple archetypes may emerge, it is generally the predominant one that reflects the principal form of suffering and its associated representation Selected examples include:

- **Giraffe suffering: Distance**
  - Behaviour: Families hold unrealistic expectations, disregarding available local resources.
  - Interpretation: This reflects scepticism about the

competence and expertise of the local healthcare team.
  - Management: Engage in confident yet humble dialogue without undermining the family's sense of dignity.
- **Hyena suffering: Conflict**
  - Behaviour: Unresolved intra-family conflicts manifest in the hospital setting, impeding decision-making.
  - Interpretation: The dual role of individuals as both patients and social connections produces inevitable tension.
  - Management: Collaborate with the family's leading figure to safeguard the patient's interests.
- **Tortoise suffering: Armour**
  - Behaviour: Families demonstrate a strong reliance on various potential cures, including religious beliefs, traditional healing practices, and philosophies.
  - Interpretation: This orientation reflects a desire for redemption or the fulfilment of unfinished responsibilities.
  - Management: Employ carefully chosen language to ensure respectful and effective communication.
- **Porcupine suffering: Haunting**
  - Behaviour: Families continually redirect present illness discussions towards past traumatic experiences.
  - Interpretation: This reveals a deep entanglement of past and present that complicates meaningful dialogue.
  - Management: Provide healthcare teams with education, training, and wellness support to strengthen resilience in the face of emotionally taxing interactions.

Lessons learnt

Traditional palliative care existed before modern palliative existed. The current model of palliative care comes from a different culture and understanding, which may harm patients' and families' choices. It is important to create a model that focuses on a community-centred approach beyond disease outcomes.

Context matters. The adaptation of existing tools or metrics should follow an adoption process based on the perceptions of care, instead of being transposed from a model to another context. For example, translating the five stages of Elisabeth Kubler-Ross into Kinyarwanda would be difficult to do, and mostly impossible to teach because of cultural differences. But using the Safari Concept tool, even for someone not familiar with palliative care, it resonates for the majority of Rwandans.

Terminology is crucial. The experiences with Rwandan patients revealed that the terminology "end-of-life care" has no meaning in the Rwandan philosophy of life. The appropriate term is "Life until the end", which reflects a deep connection with the person to the last breath, and that has to be done together with family members, not alone.

The way people die reflects how society lives. As Rwandan society is based on community, good death and bad death are not related to the disease outcomes or active treatments. Understanding suffering through the lens of African culture and community reveals a complex, interconnected web where the individual's experience is inextricably linked to their social, spiritual, and moral environment. For any intervention or care, particularly in fields like palliative care, a deep appreciation of these cultural nuances is not just beneficial but essential for providing truly person-centred and effective support. Ignoring these dimensions risks alienating individuals and communities from care that could otherwise be profoundly impactful.

Innovations and collaborations

Educational partnerships

Transnational collaborations have accelerated progress. The Human Resources for Health Program and Dana-Farber's Global Cancer Medicine Center have supported training, policy development, and the establishment of palliative teams at Butaro Cancer Center *(4)*.

Advance care planning (ACP)

Advance care planning is emerging as a key focus. Despite the NPCP, ACP is rarely practiced due to low awareness and training deficits. Efforts are underway to embed ACP into routine cancer care at both hospital and community levels *(9)*.

Research gaps and monitoring

While epidemiological data exist, research into context-specific models of care remains limited. The African Palliative Care Association calls for more implementation science to develop culturally adapted frameworks suitable for low- and middle-income countries like Rwanda *(11)*.

Conclusion and recommendations

Summary of achievements

Rwanda's pioneering NPCP, integration into national health plans, and domestic morphine production mark significant strides. Cultural alignment through *Ubuntu* and decentralized care enhances sustainability. However, challenges persist: unmet needs, opioid misconceptions, human resource deficits, and caregiver burdens.

Policy recommendations

- Strengthen legal frameworks to ease opioid access while ensuring safety.
- Systematically integrate palliative care into all health programmes and insurance schemes.
- Fund and expand community-based models aligned with cultural preferences.

Practice recommendations

- Scale up training across all health worker cadres.
- Establish ongoing mentorship and support for caregivers.
- Embed psycho-social services and ACP in standard care.

Research recommendations

- Invest in context-specific implementation science.
- Develop robust monitoring systems.
- Sustain mutually beneficial international partnerships.

By reinforcing these pillars, Rwanda can move beyond isolated success stories to a national framework that ensures dignity, alleviates suffering, and supports both patients and caregivers across the cancer journey. ■

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The retinoblastoma programme in Niger 2019–2029

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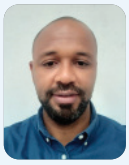
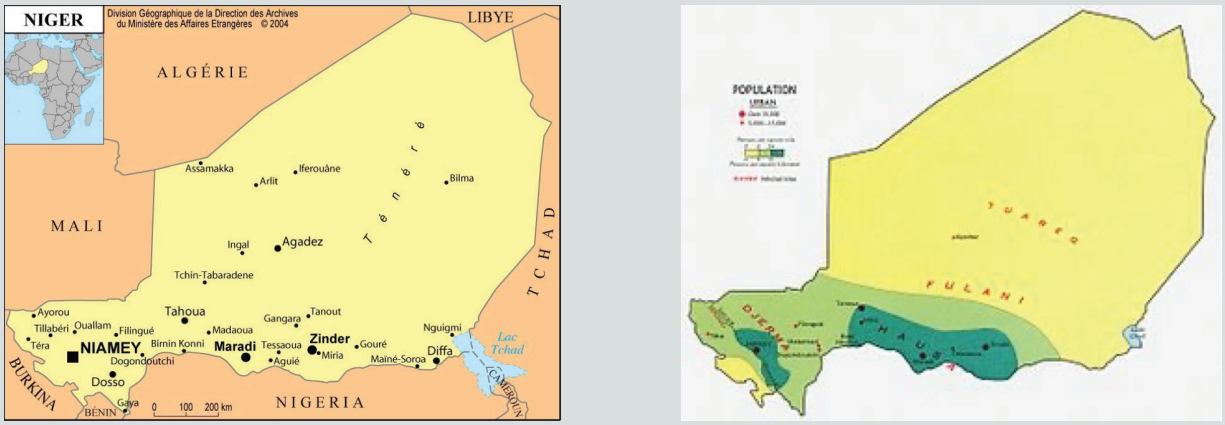

KARIM ASSANI

Retinoblastoma (RB) is a rare intraocular cancer. It can be unilateral or bilateral and affects young children before the age of five years. Early diagnosis and rapid management by a specialized multidisciplinary team achieves a 95% cure rate in developed countries, whereas in low- and middle-income countries mortality remains high. The Alliance Mondiale Contre le Cancer (AMCC), in partnership with the Franco African Group of Paediatric Oncology (GFAOP) and multidisciplinary African teams, has supported an RB programme in sub-Saharan Africa since 2011 to improve training of ophthalmologists and ocularists, equipment for conservative management, and programmes for early diagnosis and data collection. In 2019, this programme was extended to all French-speaking, and to some English-speaking and Lusophone teams".The programme was implemented in Niger in 2021 and a retrospective study of children with RB was recently conducted in Niamey. A total of 127 eyes with RB were observed, with 58 extraocular diseases at presentation. Three children with bilateral disease had one eye with conservative management. Early diagnosis campaigns are detailed. Retinoblastoma is still a diagnosis challenge in sub-Saharan Africa, and the creation of secondary centres is one way to facilitate early diagnosis. Local multidisciplinary teams face specific problems, such as socioeconomic difficulties, travelling problems, refusal of enucleation, and treatment abandonment.

Retinoblastoma (RB) is a rare type of eye cancer that affects young children under five years of age, affecting both eyes in approximately one-third of cases, and often appearing during the first year of life *(1)*. Approximately 8,500 new cases occur worldwide each year (of 8 billion inhabitants, 25% of whom are under 15 years of age), including 2,000 cases in sub-Saharan Africa, which has a population of approximately 1.2 billion, of which 40% are under 15 years of age *(2)*. A retrospective analysis of RB diagnosed in 40 European countries and 43 African countries shows that considering the frequency of RB to be one case for every 17,000 births, only 42% of expected cases are diagnosed in Africa versus almost 100% in Europe *(3)*. These facts were demonstrated in a larger study of 153 countries showing a further 49.1% of extraocular forms in low-income countries *(4)*. In these countries, such as Niger, survival remains below 20% due to late diagnosis or even no diagnosis, the small number of teams trained and equipped for treatment, training and equipment being costly for a limited number of cases, and countries having to face multiple other priorities *(5)*. Although it is not a public health problem, RB is exemplary today because it is easily curable in high-income countries (a 98% cure rate for more than 20 years, but for only 15% of global cases) with, for bilateral cases, preservation of at least one eye and useful visual acuity thanks to early diagnosis from the initial symptoms, rapid access to a competent team, well-codified treatments (enucleation + chemotherapy +/- local ophthalmological treatments) applied without delay, and complete insurance coverage with rehabilitation by prosthesis after enucleation *(2)*.

It is in view of this observation that the World Alliance Against Cancer (Alliance Mondiale Contre le Cancer [AMCC], cancer-amcc.org), in partnership with the African Francophone

Figure 1: Niger and its population



Group for Paediatric Oncology (GFAOP, www.gfaop.org) for French-speaking countries and the multidisciplinary team in Bamako, Mali, has led successive programmes since 2011 to "support early diagnosis, access to treatment, and rehabilitation for children with RB in French-speaking sub-Saharan Africa". A demonstration was provided by the dynamic team in Mali that the cure rate could exceed 80% in unilateral intraocular forms with prostheses manufactured locally, thanks to training (ophthalmologist and ocularist), the provision of additional equipment for ophthalmological procedures and anticancer drugs, assistance with early diagnosis campaigns, and support for the most deprived families *(6)*.

In 2019, a 2019–2028 programme was implemented on the same basis as the previous programmes but this time extended to most French-speaking sub-Saharan countries (Benin, Burkina Faso, Cameroon, Congo, Ivory Coast, Gabon, Guinea, Madagascar, Mali, Mauritania, Niger, Central African Republic, DR Congo, Togo, and Senegal), to some English-speaking countries (Ethiopia, Ghana, Kenya, Rwanda, Tanzania, and Uganda), and Portuguese-speaking countries (Mozambique and Angola), with a total of 1,400 new cases of RB expected in 2024 in the 23 countries concerned *(7)*. The objective of the programme is to contribute to curing at least 800 children with RB each year from 2030, in line with the World Health Organization's objective of curing 60% of childhood cancers. The Niamey team joined the programme coordinated by the AMCC in 2021.

Patients and methods

This is a retrospective study of children with RB in Niamey, Niger. Niger is a Central African country, covering 1.26 million km². It is home to 28 million inhabitants, with a high fertility rate (6 children/woman) and a projected population of 80 million by 2050. Currently, 47% of the population is under 15 years of age, and the number of new annual cases of RB, estimated at between 55 and 60 in 2024, will more than double by 2050. Routine care is free for children under five years of age, the age group at which RB is diagnosed (8).

Niger and its population: The population is mainly concentrated in the southwest of the country, with the capital, Niamey (nearly 2 million inhabitants), very remote. INS report, 2023 *(9)*.

- The implementation of the conservative treatment system and prostheses after enucleation was made possible thanks to the additional training in Bamako in 2021 and at the Curie Institute in 2024 of Dr Adam Nouhou Diori, an ophthalmologist at the Amirou Boubacar Diallo National Hospital (HNABD), which houses the referral ophthalmology department; and the training of an ocularist in Bamako in 2021. The paediatric oncologist at the National Cancer Centre in Niamey (CNLC), Dr Aîchatou Mahamadou, heads the paediatric oncological unit, which provides assessment and chemotherapy, and has been a member of the GFAOP since 2015 and a pillar of the multidisciplinary paediatric oncological team.
- Training has been supplemented by the allocation of equipment by the AMCC in recent years, including an enucleation box, indirect ophthalmoscope, diode laser plus helmet, cryode, fundus camera, prosthesis equipment; and the supply by the GFAOP of anticancer drugs for RB chemotherapy.

Thus, since the end of 2022, a dynamic and progressively well-equipped multidisciplinary team has been operational in Niamey. Enucleated children benefit from a prosthesis manufactured on site. Conservative treatments have been possible since 2023.

We conducted a retrospective study from 1 January 2022 to the end of December 2024 in the ophthalmology department of the HNABD in Niamey.

All children admitted to the HNABD and the Paediatric Oncology Department of the CNLC, diagnosed with retinoblastoma during the study period, were included.

Table 1: **Characteristics of eyes with retinoblastoma by year**

Year	2022	2023	2024
Number of children	35	35	35
Unilateral	31	26	26
Bilateral	4	9	9
Stage (number of eyes)	Intraocular: 24 Extraocular: 15	Intraocular: 17 Extraocular: 27	Intraocular: 28 Extraocular:16
Chemotherapy	Yes	Yes	Yes
Enucleation	23	13	14
Thermotherapy	0	2	1
Prosthesis	0	3	13

Of a total of 127 eyes with retinoblastoma over a 3-year period, the following were noted:
- 22 bilateral cases (44 eyes);
- 69 eyes with an intraocular stage; and
- 50 enucleated eyes, 16 of which were fitted with an ocular prosthesis.

A multidisciplinary consultation process was established: the team participates in a web conference coordinated by the AMCC every two weeks, where RB cases are discussed within the network of teams participating in the AMCC's RB programme using the RB-NET platform.

Actions are essential to promote early diagnosis. These actions must be repeated annually and involve training healthcare professionals and informing parents. Actions already taken are described in the results.

The 2029 objective is for at least 80% of incident RB cases in the country to reach the multidisciplinary team in Niamey, with most cases occurring at the early intraocular stage. The creation of a WhatsApp alert group including all ophthalmologists in Niger, extended to senior technicians, facilitates the arrival of cases in Niamey.

Data collection includes age, unilateral or bilateral form, stage at diagnosis, treatments used, and survival.

For conservative treatments, fundoscopy is performed at the start of active treatment every four weeks under general anaesthesia until complete response, then every month or every two months until one year of follow-up. All children, including unilaterally enucleated children, are followed every three months until two years of age, every four months until three years of age, then every six months until five years of age, and finally every year from the age of five.

The registries include consultation data, physical and electronic patient records from the paediatric oncology unit, as well as those from the ophthalmology department of the HNABD.

Respect for anonymity and confidentiality of patient identities, as per the Declaration of Helsinki, guarantees the ethics of our database.

Results

The actions carried out for early diagnosis are as follows:

- Training of general practitioners and paediatricians from

Table 2: **: Conservative management of three eyes**

Clinical cases	Case 1	Case 2	Case 3
Age	17 months	6 years	11 months
Gender	Female	Female	Female
Group of RB	OD: group A–B OG: group E	OD: group E OG: group C	OD: group A OG: group D
Results	OD: complete remission OG: enucleation	OD: Enucleation OG: complete remission of the main lesion with several recurrences producing a large retinal ischaemia	OG: complete remission OG: enucleation
Ocular prosthesis	Yes	Yes	Yes

all eight regions of Niger (25 participants) with the support of the Bamako team and the AMCC programme manager from 8–13 November 2021;

- Postgraduate Education Sessions (EPUs) organized in collaboration with the Nigerien Society of Ophthalmology (SNO): SNO Congress in 2022 with approximately 300 participants and EPUs on 23 February and 27 May 2023 and 1 June and 5 October 2024, which reached approximately 200 healthcare professionals;
- Local awareness-raising for healthcare practitioners in major referral hospitals in the capital (Niamey). In 2023, the National Hospital of Niamey brought together approximately 30 students, paediatricians, paediatric oncologists, and ophthalmologists in the paediatric staff room; and on 7 and 15 June 2023, the HNABD brought together approximately 50 participants, respectively, in their paediatric staff room.
- Training workshop for ophthalmology practitioners (ophthalmologists and senior ophthalmology technicians) from all regions in the recognition and referral of suspected cases of RB on 1–2 November 2023, with approximately 45 participants.

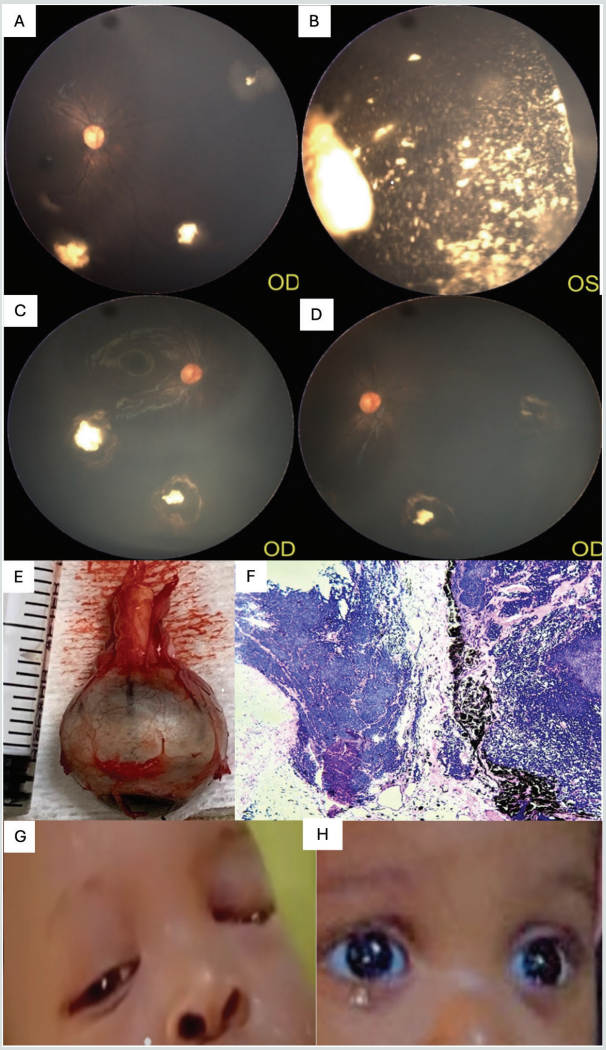
Children with extraocular forms (58 eyes) received palliative treatment following tumour spread, either orbital or cerebral.

Three children with bilateral retinoblastomas underwent conservative treatment of one eye with thermochemotherapy.

This treatment consisted of a combination of intravenous chemotherapy and local ophthalmic treatments (trans-pupillary diode laser thermotherapy and cryotherapy).

All three eyes were cured, although one eye experienced several local relapses after stopping chemotherapy, which required local ophthalmic treatment. (Figures 2, 3 and 4)

Figure 2: Clinical case number 1



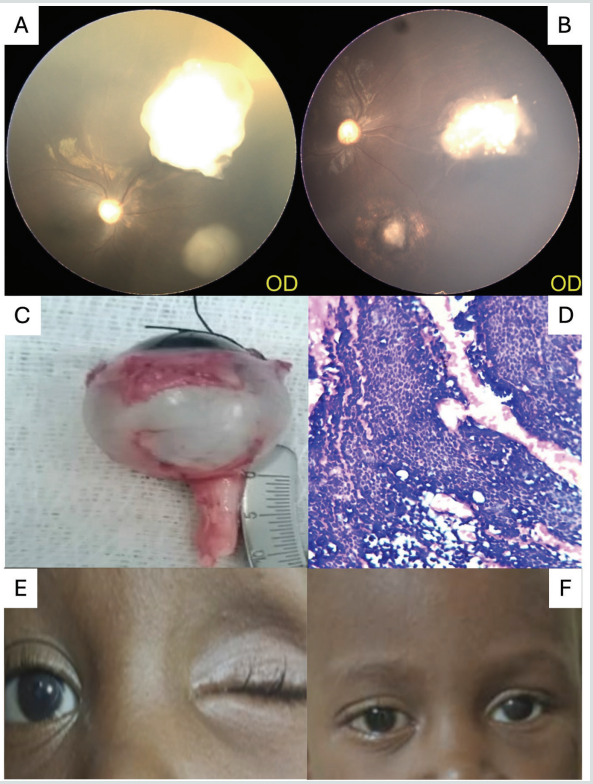
A. Fundus photography of the right eye at diagnosis. Two tumours are in the nasal part of the eye. B. Fundus photography of the same right eye after treatment by thermochemotherapy (six cycles of intravenous chemotherapy [vincristine, etoposide, carboplatin] and diode laser), showing calcified scars. C. Photography of the left enucleated eye. D. Histopathology sample of the left enucleated eye demonstrating the tumoral cells (hematoxylin and eosin staining). E. Aspect of the left orbit after enucleation, without ocular prosthesis. F. Satisfactory aesthetic rehabilitation after placement of the left ocular prosthesis.

Discussion

Retinoblastoma is a rare but highly curable tumour, which justifies the action taken by the AMCC since 2011 through a programme to support the management of RB in sub-Saharan Africa *(10)*. The possibility of rapid improvement in outcomes was demonstrated in Mali in 2018 thanks to support through training, additional equipment, and early diagnosis actions *(6)*. In Niger, in a recent study tracing the results of the service's activities from January 2016 to October 2022 (6 years 10 months), we found that most children arriving at the referral service are at a late stage that no longer allows for cure *(5)*. The conservative referral treatment centre in Niger was established in 2021, but it was not until May 2023 that the first case of bilateral RB meeting the criteria for conservative treatment was recorded. It should be noted that several challenges were overcome at different levels (logistics, training, etc.). Children with RB were able to benefit from free care for children under five years of age for certain aspects of treatment, even though the lack of financial means of parents of children with RB and the distance of localities from the reference centre were causes of delays in treatment *(11)*. Malnutrition and malaria were the main comorbidities among the children treated. Faced with all these challenges, it is sometimes necessary to know how to use personal relationships to facilitate the entry of equipment into the country, or to know how to innovate in order to adapt the equipment for our use.

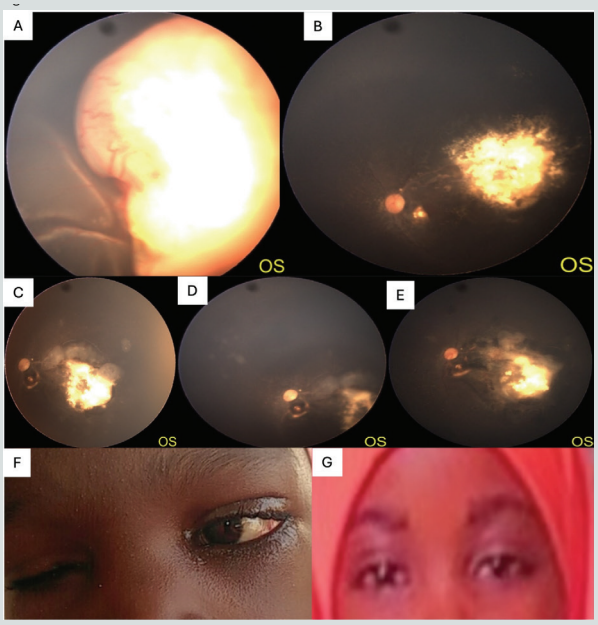
To facilitate early diagnosis, it was decided with AMCC to develop two secondary centres (Zinder and Maradi) in Niger so that a greater number of children can have access to early diagnosis.

Figure 3: Clinical case number 2



A. Fundus photography of the left eye at diagnosis, demonstrating a voluminous tumour at the posterior pole and a complete retinal detachment. B. Fundus photography of the same left eye after two cycles of intravenous chemotherapy (vincristine, etoposide, carboplatin), showing a retinal scar, without active disease. C and D. Fundus photography of the same left eye after initial treatment, demonstrating retinal recurrences and new lesions. E. Aspect of the fundus of the same eye after treatment of the active tumours by thermotherapy. E. Aspect of the right orbit after enucleation, without ocular prosthesis. F. Satisfactory aesthetic rehabilitation after placement of the right ocular prosthesis.

Figure 4: Clinical case number 3



A. Fundus photography of the right eye at diagnosis, demonstrating three retinal tumours. B. Fundus photography of the left eye at diagnosis, demonstrating a large retinal tumoral and a diffuse dense vitreous seeding. C and D. Fundus photography of the right eye after thermochemotherapy, demonstrating three retinal scars. E. Photography of the left enucleated eye. F. Histopathology sample of the left enucleated eye demonstrating the tumoral cells (hematoxylin and eosin staining). G. Aspect of the left orbit after enucleation, without ocular prosthesis. H. Satisfactory aesthetic rehabilitation after placement of the left ocular prosthesis.

Several actions are underway in 2025 including:

- Strengthening the multidisciplinary team in Niamey with the training of a second ophthalmologist at the IOTA University Hospital in Bamako to ensure continuity of conservative treatment, which was successfully initiated in 2023;
- Training ophthalmologists and senior ophthalmology technicians in Niamey on the diagnosis of RB, which is purely clinical, and on referral to the Niamey team;
- Informing primary health centre staff, who are the first point of contact for the population when faced with signs suggestive of RB (leukocoria, strabismus), and the appropriate actions to take within the framework of Ministry of Health programmes; and
- Identifying and training ophthalmologists (in Niamey) and senior ophthalmology technicians (onsite) in the two secondary centres in Zinder and Maradi.

Retinoblastoma is a rare malignant tumour of the retina that mainly affects young children *(12,13)*. In 90% of cases, the diagnosis is made before the age of five years, as in all three cases we report, even though cases of RB in older children have been reported in the literature *(12, 14, 15)*. On the other hand, bilateral or multifocal retinoblastomas are all hereditary, with autosomal dominant transmission. Retinoblastoma is unilateral in 70% of cases; the average age at diagnosis is approximately two years *(16)*. One of the cases we report became bilateral after five years of evolution in a unilateral form. In synchronous bilateral forms, the average age at diagnosis is about one year and tends to decrease in industrialized countries thanks to the screening of children in at-risk families by systematic examination of the back of the eye *(17)*. About two-thirds of stage A–C eyes can be saved by reduction chemotherapy alone coupled with focal treatments, compared to 25–30% of stage D eyes *(18)*.

Our three cases treated with this procedure healed. Hyperthermia is delivered by transpupillary infrared irradiation using a diode laser, at cytotoxic temperatures. It can destroy small tumours without vitreous swarming or subretinal fluid *(19)*. We performed transpupillary thermotherapy using a helmet and a 20-diopter lens, delivering continuous power calibrated to 350 mW for an average of 20 minutes on the tumours.

In the case of enucleation, the optic nerve must be severed as far as possible, over a length of at least 10mm for histopathological examination *(20)*. The most affected

eye was enucleated in all patients with a good section of the optic nerve of approximately 10mm. Very close specialized ophthalmological monitoring is necessary, because the reappearance of new tumour foci is part of the normal evolution of RB, especially the hereditary form *(21)*. One of the cases we followed had manifested several recurrences and relapses during his follow-up. Thanks to close and regular monitoring, the new tumours were able to be controlled.

Conclusion

Thanks to the considerable support of the AMCC, Niger, a low-income French-speaking sub-Saharan country, has been able to consolidate a multidisciplinary team for the organized care of children with RB, including conservative treatment allowing the preservation of one eye and useful vision in cases of bilateral RB. This is a young treatment centre, so several challenges remain to be addressed over time, especially in terms of early diagnosis as part of the public health actions of the country's health authorities. ■

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Declaration of Competing Interests

The authors declare no competing interests.

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CANCER RESEARCH

86 Revisiting the hallmarks of cancer: An interconnected hierarchy as illustrated by cancer-generated lactic acid

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93 The impact of the SIOP Programme for advancing research capacity on global childhood cancer research

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Revisiting the hallmarks of cancer: An interconnected hierarchy as illustrated by cancer-generated lactic acid

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Cancer is a complex disease characterized by diverse biological traits. Hanahan and Weinberg originally proposed six "hallmarks" to simplify and generalize the core features shared by all cancers. Over the past 22 years, this number has expanded to 14, reflecting our growing understanding of cancer biology. This continual expansion highlights a broader challenge: the proliferation of hallmarks without a clear hierarchy or conceptual framework that incorporates them in a coherent manner. As a result, the landscape of cancer traits has become increasingly complex and fragmented. To address this, we propose a functional reorganization of the hallmarks into a ranked hierarchy that clarifies their inter-relationships, rather than treating all traits as equally important. Specifically, we classify the hallmarks into three categories: 1) hallmarks essential for cancer cell survival, 2) hallmarks enhancing aggressiveness, and (3) cancer-enabling characteristics. We further illustrate this hierarchy and interconnectivity using cancer-generated lactic acid as a paradigmatic example. As a product of altered cancer metabolism, lactic acid simultaneously promotes immune evasion, supports cell survival, induces angiogenesis, and enhances metastatic potential. This reclassification of hallmarks provides a clearer conceptual framework to guide the development of foundational therapies targeting multiple cancer hallmarks in an integrated manner.

Cancer is a multifaceted and complex disease, with each subtype exhibiting its own unique characteristics and an array of distinctive molecular and genetic alterations. Nonetheless, common characteristics exist. Hanahan and Weinberg proposed the concept of the "hallmarks of cancer" in 2000 to provide a framework for generalizing these shared characteristics across cancers *(1)*. This concept distilled the essential traits that all cancers must acquire to thrive, regardless of their tissue of origin or their specific mutations. Twenty-two years later, the initial six hallmarks have now increased to 14, reflecting our growing understanding of the complexity of cancer biology. This continued expansion of hallmarks raises important questions: are all such characteristics equally essential to cancer survival and progression? Is the concept now overly complex, making generalizations about cancer biology more difficult?

Complicating the hallmarks landscape is the fact that these characteristics are frequently visualized as equal components around the outside of a circle, expanding as more hallmarks are introduced. While helpful, this representation can unintentionally lead to a misunderstanding of cancer biology. The hallmarks are not equal. Hanahan and Weinberg distinguished "hallmarks" from "enabling characteristics", the latter being phenomena that assist cancers in acquiring the more fundamental hallmark traits *(2)*. This distinction suggests an inherent hierarchy of importance, even if that is not obvious in the now-famous illustration. The side-by-side arrangement also fails to demonstrate the inter-relationship between the characteristics. Biologically, as noted originally by Hanahan and Weinberg, there is an indisputable connection between the various cancer traits, including from a signalling pathway perspective. Certain prominent oncogenes and tumour suppressors (such as c-Myc, Ras, and p53) can regulate multiple hallmark characteristics at the same time *(1)*. The hallmarks are thus interdependent and not isolated from one another.

This commentary revisits the hallmarks of cancer, exploring the nuances and interconnections between these cancer traits. We present a conceptual and visual reorganization

into three hierarchical categories based on their functional importance:

- hallmarks essential for cancer cell survival;
- hallmarks enhancing cancer cell aggressiveness; and
- cancer-enabling characteristics.

The traits essential for survival are the most fundamental – without life, there is no opportunity for development or progression. Moreover, these traits often serve as drivers that activate multiple downstream hallmarks and enabling characteristics. Cancer-generated lactic acid is an illustrative example of this interconnectivity, highlighting how one fundamental cancer trait can influence multiple additional hallmarks. Re-examining the hierarchy and interconnectivity of the cancer hallmarks will facilitate the development of new therapeutics that target multiple cancer characteristics simultaneously, potentially improving treatment efficacy.

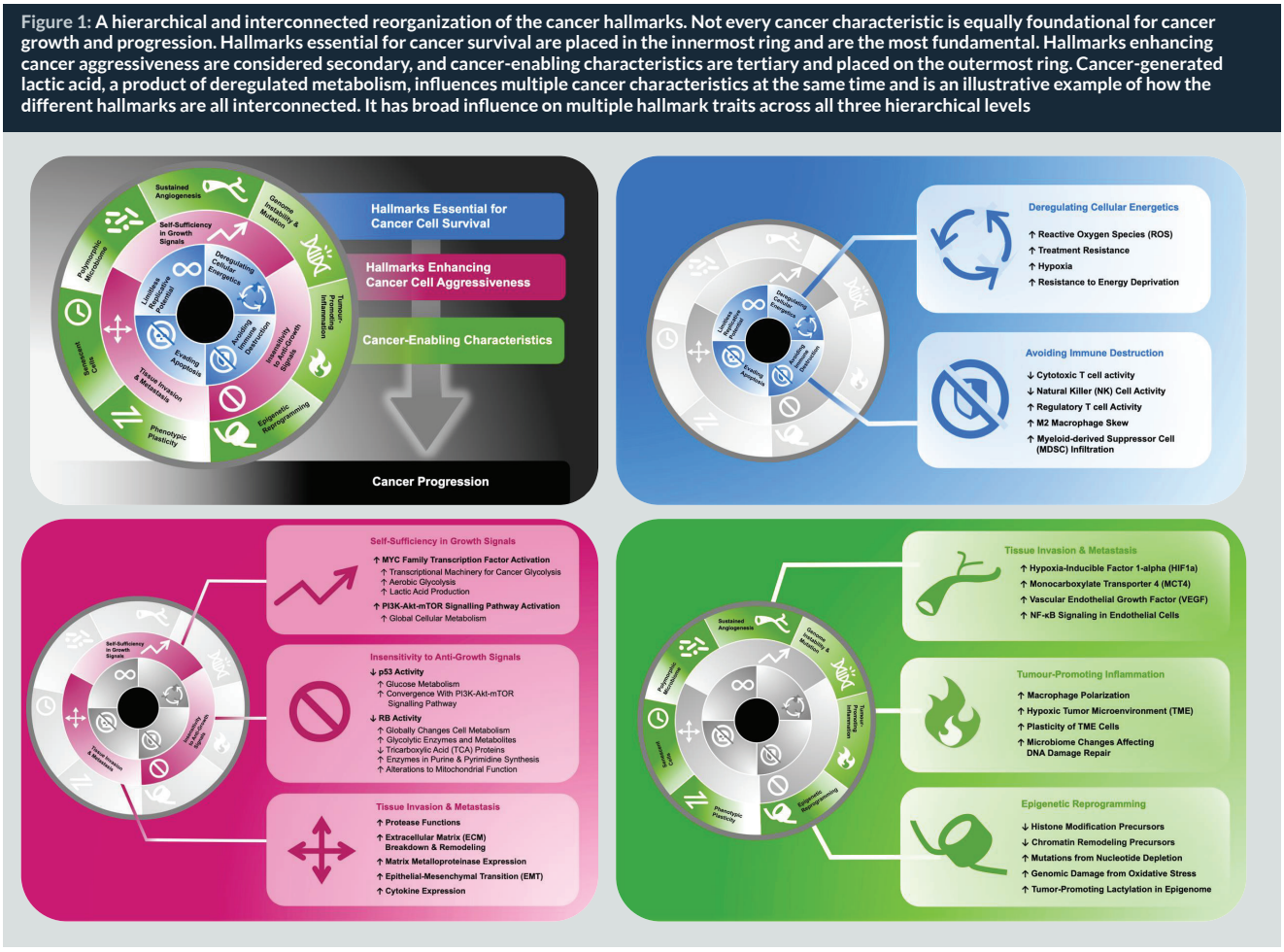
The evolution of cancer hallmarks

The initial hallmarks provided a unifying framework for describing the essential characteristics of cancers. These included self-sufficiency in growth signals, insensitivity to antigrowth signals, evading apoptosis, limitless replicative potential, sustained angiogenesis, and tissue invasion and metastasis *(1)*. Arising from an era of cancer research that emphasized mutational changes to various oncogenes and tumour suppressors, this novel conceptualization of cancer biology was groundbreaking and widely influential.

In 2011, two emerging hallmarks and two enabling characteristics were added: deregulating cellular energetics, avoiding immune destruction, genome instability and mutation, and tumour-promoting inflammation *(2)*. Recent advances were further outlined in the 2022 update, reflecting the continued discovery of new mechanisms involved in cancer development and progression. The addition of unlocking phenotypic plasticity, nonmutational epigenetic reprogramming, polymorphic microbiomes, and senescent cells brings the total number of cancer characteristics to 14*(3)*.

It is highly likely that additional cancer characteristics will be identified in the future. As our understanding of these mechanisms deepens, the framework of hallmarks should also evolve to better incorporate new scientific insights and reflect the biology being described. The current concept is limited by the omission of hierarchy and interconnection, thereby obscuring the true "systems biology" nature of cancer. This risks creating the impression that therapeutic

Figure 1: A hierarchical and interconnected reorganization of the cancer hallmarks. Not every cancer characteristic is equally foundational for cancer growth and progression. Hallmarks essential for cancer survival are placed in the innermost ring and are the most fundamental. Hallmarks enhancing cancer aggressiveness are considered secondary, and cancer-enabling characteristics are tertiary and placed on the outermost ring. Cancer-generated lactic acid, a product of deregulated metabolism, influences multiple cancer characteristics at the same time and is an illustrative example of how the different hallmarks are all interconnected. It has broad influence on multiple hallmark traits across all three hierarchical levels



strategies can be siloed into discrete and independent entities. Instead, significant synergistic effects may be achieved by simultaneously impacting multiple cancer hallmarks.

Reorganizing the cancer hallmarks

To provide clarity and strategic focus in cancer research and treatment, we propose a reorganization of the hallmarks into three hierarchical categories based on functional importance. Hallmarks fundamental to cancer cell survival form the foundation of this hierarchy, while traits that enhance aggressiveness and those that enable and support these processes occupy secondary and tertiary levels, respectively. This tiered structure not only reflects biological dependencies but also suggests a roadmap for prioritizing therapeutic targets.

The three categories (Figure 1) are:

- hallmarks essential for cancer survival;
- hallmarks enhancing cancer aggressiveness; and
- cancer-enabling characteristics.

Category 1: Hallmarks essential for cancer survival

Deregulating cellular energetics

Every living cell requires energy to survive. Cancer cells reprogramme their metabolism to supply energy (i.e., adenosine triphosphate [ATP]) and biomolecular building blocks necessary for rapid proliferation. The most widely observed alteration is a reliance on glycolysis even in the presence of abundant oxygen, a phenomenon known as aerobic glycolysis or the Warburg effect. Beyond glycolysis, cancer cells can also reprogramme additional metabolic pathways involved in glutamine, lipid, nucleotide, and lactic acid metabolism to sustain growth *(4)*. These adaptations not only fuel biosynthesis but also acidify the tumour microenvironment (TME), creating an immunosuppressive niche *(5)*. Understanding these metabolic shifts provides opportunities for metabolism-targeted therapies.

Avoiding immune destruction

Under normal circumstances, mutated cancer cells can be detected and eliminated by the body's immune system in a process known as immunosurveillance. However, as cancer cells continue to form and develop, they acquire the ability to avoid immune detection by downregulating antigen presentation, secreting immunosuppressive factors, and recruiting regulatory immune cells *(5-11)*. In addition, altered lactic acid metabolism leads to the overproduction of lactic acid and the acidification of the TME. This is a major immunosuppressive mechanism that allows cancer cells to evade immune destruction *(10)*. Immunotherapy, which enhances the immune response against cancer cells, has emerged as a promising therapeutic strategy directed at this hallmark.

Evading apoptosis

Cancer cell survival can be enhanced by evading programmed cell death (i.e., apoptosis). This can occur through mutations in apoptosis-related genes, overexpression of anti-apoptotic proteins, and dysregulation of cell death pathways such as autophagy and necroptosis.

Limitless replicative potential

Cancer cells maintain their ability to divide indefinitely by upregulating telomerase, an enzyme that extends telomeres, or by activating alternative lengthening of telomeres (ALT). This offers another direct avenue through which cancer cells can survive and continue to proliferate.

Category 2: Hallmarks enhancing cancer aggressiveness

Self-sufficiency in growth signals

Beyond the basic survival mechanisms that allow cancer to persist in a patient's body, cancer cells also constantly receive proliferation signals due to mutations in signalling pathways such as estimated glomerular filtration rate (EGFR) and Ras. These signals sustain further cancer growth. Ongoing replication also provides cancer cells with the opportunity to develop and accumulate additional aggressive characteristics.

Insensitivity to antigrowth signals

Tumour suppressor genes, such as p53, RB1 and PTEN, typically inhibit cell growth during normal cell division. Cancer cells often harbour mutations that inactivate these genes, allowing uncontrolled proliferation.

Tissue invasion and metastasis

Metastasis is the spread of cancer cells from the primary tumour site to distant organs. This process is facilitated by epithelial-mesenchymal transition (EMT), degradation of the extracellular matrix (ECM), and the establishment of a metastatic niche in the secondary tissue to support continued cancer growth. It is a primary indicator of aggressive disease and is associated with poor prognosis and death.

Category 3: Cancer-enabling characteristics

Sustained angiogenesis

Tumours form new blood vessels (i.e., angiogenesis) to supply oxygen and nutrients to fuel their growth. Anti-angiogenic therapies starve tumours by inhibiting blood vessel growth, although resistance mechanisms can limit their effectiveness.

Genome instability and mutation

Cancer cells exhibit high rates of genetic mutations, driving tumour evolution. This is frequently caused by defects in DNA damage repair pathways, allowing cancer cells to carry a higher

mutational burden and propagate these genetic alterations to the next generation of cancer cells.

Tumour-promoting inflammation

Chronic inflammation in the TME supports cancer progression by providing growth factors and survival signals, and by promoting genomic instability. This can be triggered by the death of healthy tissues surrounding tumour cells, and is frequently associated with pro-inflammatory cytokines such as NF-kB, STAT3, and TNF-α.

Unlocking phenotypic plasticity

Cancer cells exhibit remarkable phenotypic plasticity, allowing them to change their behaviours and adapt to diverse environmental or therapeutic pressures. Among the many possible mechanisms, the re-activation of embryonic developmental programmes and the reversion to less differentiated states during treatment may play significant roles in helping cancer cells acquire new traits and develop treatment resistance.

Non-mutational epigenetic reprogramming

Epigenetic modifications, such as DNA methylation and histone modifications, can drive cancer development and progression. They can functionally alter cancer cell behaviour by changing gene expression, without the need for genetic mutations.

Polymorphic microbiome

The microbiome influences cancer development and progression through interactions with the immune system, metabolism, and inflammation. Bacteria, fungi, or viruses may be directly carcinogenic, or they may have microenvironmental effects that modulate cancer growth, the anticancer immune response, or the efficacy of anticancer treatments.

Senescent cells

Senescent or dormant cancer cells, which have stopped dividing but remain metabolically active, contribute to the TME and promote later cancer progression. While they initially represent a barrier to tumourigenesis and a pause in tumour progression, they may eventually secrete cell–cell communication factors that promote the development and aggressiveness of neighbouring cancer cells. Alternatively, dormant cancer cells can also reactivate, becoming proliferating cells that fuel tumour relapse.

Interconnectedness of hallmarks: Cancer-generated lactic acid

It is clear, even from Hanahan and Weinberg's initial conception, that the various hallmarks are not independent entities *(1)*. The overproduction of cancer-generated lactic acid via altered cancer metabolism is an illustrative example of how these various hallmarks are intricately associated with each other *(5)*. There are many other possible examples.

Category 1: Hallmarks essential for cancer survival

Altered cancer metabolism results in excessive generation of lactic acid, which in turn leads to the acidification of the TME. This alteration results in a dramatic increase in glucose consumption, helping cancer cells maintain an adequate supply of precursor molecules for biosynthesis and allowing them to sustain their anabolic needs for rapid proliferation *(12-14)*. Recent research has demonstrated that the acidic TME created by excess lactic acid has multiple downstream cancer-promoting effects, impacting many other cancer hallmarks.

With respect to avoiding immune destruction, it is now well-established that an acidic TME inhibits anticancer effector immune functions while enhancing regulatory immune functions *(5, 10)*. Prior to 2013, few studies treated lactic acid as an immunomodulatory molecule *(11)*. It was considered a metabolic "waste product" instead. We were one of the first to hypothesize that lactic acid acts as a central immune-suppressive molecule in cancer *(5)*. The latest research has demonstrated that cytotoxic T cells and NK cells are less effective in an acidic environment *(15-18)*, while suppressive immune cells such as regulatory T cells are able to maintain their functionality *(19-23)*. An acidic TME can also skew macrophage differentiation towards the tumour-promoting M2 phenotype *(24-26)* and enhance the infiltration and function of immunosuppressive myeloid-derived suppressor cells *(27, 28)*. Inhibition of lactic acid secretion can enhance anticancer immunity, offering a promising therapeutic strategy for anticancer treatments *(29-32)*.

In relation to evading apoptosis, lactic acidosis can prevent apoptosis as induced by a variety of environment stressors, including therapeutic/chemotherapy treatment *(33-35)*, energy deprivation *(36)*, and hypoxia *(37)*. In particular, inhibition of lactate dehydrogenase A (LDHA), the primary enzyme converting pyruvate to lactate in the final step of aerobic glycolysis, can trigger the apoptosis cascade through increased generation of reactive oxygen species (ROS) *(37-40)*.

Category 2: Hallmarks enhancing cancer aggressiveness

Crosstalk occurs between glucose metabolism and growth/antigrowth signals *(41-45)*. Certain oncogenes, especially the MYC family of transcription factors, are primary regulators of glycolysis in cancer development. They can directly upregulate the transcriptional machinery that increases glucose metabolism, facilitates aerobic glycolysis, and increases lactic acid production *(46-48)*. Moreover, multiple oncogenic signals

can feed through the PI3K-Akt-mTOR signalling pathway, which also regulates cellular metabolism in a global manner *(49-51)*. Similarly, metabolic deregulation can also occur when tumour suppressors lose their functions. For example, the loss of p53 activity can upregulate glucose metabolism through signalling pathways that also converge on the PI3K-Akt-mTOR axis *(52-54)*. Depletion of the retinoblastoma (RB) gene product can result in global changes to cell metabolism, increasing glycolytic enzymes and metabolites, reducing tricarboxylic acid (TCA) cycle proteins, altering mitochondrial function, and increasing enzymes involved in purine and pyrimidine synthesis *(55-58)*.

Local tissue invasion and distant tumour metastasis are also promoted by an acidic TME through enhanced protease functions, facilitating the breakdown of the ECM and allowing cancer cells to migrate and metastasize *(59)*. Furthermore, reduced oxidative phosphorylation and increased glycolysis can enhance a cancer cell's metastatic potential, especially in terms of facilitating EMT and upregulating matrix metalloproteinase (MMP) and cytokine expression *(59, 60)*. As cancer cells travel in the bloodstream to colonize distant sites, altered metabolism can help circulating cancer cells survive *(61, 62)*.

Category 3: Cancer-enabling characteristics

There is a clear connection between cancer-generated lactic acid and enhanced angiogenesis, particularly in relation to hypoxia. The activation of HIF1a directly increases the expression of the lactic acid transporter MCT4, thereby facilitating increased glycolytic flux *(63)*. HIF1a also regulates multiple pro-angiogenic factors to promote angiogenesis *(64)*. Conversely, the accumulation of lactic acid may act upstream of hypoxia, leading to increased VEGF production and activation of endothelial NF-κB signaling *(65, 66)*.

The correlation between genome instability and cancer-generated lactic acid remains relatively underexplored. However, there are three primary mechanisms by which altered cancer metabolism may negatively impact DNA repair:

- depletion of metabolic precursors necessary for histone modifications and chromatin remodelling *(67-69)*;
- increased oxidative stress from altered cancer metabolism contributing to genomic damage via ROS *(70-73)*; and
- depletion of nucleotides needed for DNA repair increasing the propagation of mutations *(64)*. More studies are needed to fully elucidate how altered cancer metabolism impacts genomic instability.

Tumour-promoting inflammation and a polymorphic microbiome are both intricately linked to lactic acid metabolism through its relationship with anticancer immunity. Lactic acid can alter macrophage polarization, leading to cancer-promoting functions *(25)* Furthermore, both an immunosuppressive tumourigenic microenvironment and chronic inflammation are characterized by hypoxia and elevated levels of lactic acid *(75-77)*. Finally, the presence and depletion of various metabolites, including lactic acid, by bacteria and viruses can affect DNA damage repair *(78, 79)*.

Several mechanisms link metabolic changes to various aspects of phenotypic plasticity. An acidic TME can drive stem-like features in cancer cells *(80, 81)*. Similarly, lactic acid plays a crucial role in driving EMT, a key process in metastasis *(82)*. Altered glucose metabolism also significantly impacts the plasticity of cancer cells, cancer stem cells, and many surrounding non-cancer cell types within the TME *(83)*.

Finally, in addition to traditional methods of epigenetic reprogramming, increased intracellular lactate levels driven by altered cancer metabolism can alter gene expression through a relatively newly discovered epigenetic marker – lactylation. It can have wide-ranging impacts on the transcriptional machinery of cancer cells *(84-86)*, cancer-associated immune cells *(21, 26, 87)*, and other components of the TME *(88)*. Further, lactylation can directly impact various components of basic cellular machinery, broadly altering enzymatic functions as a post-translational modification. This affects PD-L1 *(89)*, p53 *(90)*, DNA repair *(91, 92)*, and glucose metabolism *(93, 94)*. Various lactyltransferases (AARS1/2) and epigenetic modulators (KAT8, HDAC1-3, SIRT1-3) function as important writers and erasers of cellular lactylation *(95-98)*. Lactylation is thus an important and highly relevant mechanism through which cancer-generated lactic acid exerts its cancer-promoting effects.

Conclusion

The hallmarks of cancer provide a framework for understanding the intricacies of cancer biology. The number of hallmarks has increased over the years, reflecting ongoing discoveries and deepening comprehension of cancer's complexity. It is important to reassess how hallmarks are categorized and understood. By reorganizing the hallmarks into a functional hierarchy of survival-critical, aggressiveness-enhancing, and cancer-enabling traits, we provide a framework that captures the intricate interplay driving cancer progression. This structured perspective not only deepens our biological understanding but also offers a strategic lens for developing multi-targeted therapeutic approaches aimed at the most influential drivers of cancer biology. Using the example of altered cancer metabolism, we illustrate how one fundamental trait can significantly influence and activate multiple other hallmark characteristics, highlighting the interconnected nature of these processes. Through this new, holistic perspective, innovative avenues for cancer research and

therapeutic development can be identified, ultimately leading to more effective cancer treatments targeting the core drivers of cancer progression.

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The impact of the SIOP Programme for advancing research capacity on global childhood cancer research

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Childhood cancer survival exceeds 80% in high-income countries (HICs) but remains far lower in many low- and middle-income countries (LMICs), where most affected children live and where little research occurs. Applying HIC protocols may lead to poorer outcomes in less well-resourced institutions, underscoring the need for context-specific evidence. Systemic barriers – fragile cooperative groups, underfunding, limited personnel, and regulatory complexity – further constrain LMIC research. To address this, the International Society of Paediatric Oncology (SIOP) launched the Programme for Advancing Research Capacity (PARC) in 2022, initially supporting cooperative groups in Latin America, Africa, and India. By strengthening infrastructure, training, and sustainability, PARC advances equitable paediatric oncology research and fosters long-term improvements in survival worldwide.

Addressing research disparities in childhood cancer

The survival gap

While significant progress has been made in childhood cancer, global outcomes remain markedly inequitable. In high-income countries (HICs), overall survival for children with cancer now exceeds 80% due to advancements made over the last 50 years through collaborative clinical trials and multidisciplinary care *(1)*. However, this success is not uniformly distributed. Childhood cancer survival rates in low- and middle-income countries (LMICs) are substantially lower, creating a major public health disparity. This profound imbalance is underscored by the paradox that over 90% of the world's children live in LMICs but less than 10% of childhood cancer research is conducted there *(2)*. This disproportionate allocation of research resources has resulted in a critical gap in locally relevant evidence, which is essential for developing, building up, and implementing effective treatment strategies.

The direct application of treatment protocols developed in HICs can lead to poorer outcomes in resource-limited settings *(3,4,5)*. A compelling example is the case of Burkitt lymphoma, where higher intensity chemotherapy regimens, which led to improved survival in HICs, resulted in unacceptable fatal toxicity when implemented in some LMICs *(4,5)*. This is often due to a higher proportion of patients presenting with advanced disease, as well as comorbidities such as malnutrition and chronic infections, and lower availability of intensive care support, which influence a patient's tolerance for intensive treatment. These outcomes highlight the critical need for context-adapted treatment protocols and the generation of local evidence for their clinical effectiveness *(6)*.

Systemic barriers to childhood cancer research

In LMICs, paediatric oncology research faces systemic barriers that go beyond clinical expertise. Because childhood cancers are rare, multicentre and often multinational collaborations are essential *(7)*. But cooperative groups in LMICs are typically fragile, underfunded, and unable to sustain long-term, high-quality research *(8,9)*. This financial instability is compounded

by a shortage of dedicated research personnel – such as study coordinators, research nurses, and data managers – leaving already overburdened clinicians to handle research tasks without institutional support or protected time *(8)*. As a result, research output remains limited, and fragile groups struggle to meet the demands of increasingly complex legal and regulatory requirements *(7)*. Together, these challenges make it extremely difficult to conduct rigorous clinical trials and generate the local evidence needed to improve outcomes for children with cancer (Table 1).

Table 1: PARC interventions to tackle the systemic challenges in paediatric oncology research in LMICs.

Systemic challenges in LMIC paediatric oncology research	PARC interventions
Organizational fragility Limited or no funding, fragile structures, and lack of legal status	**Legal formalization and governance** Grant support to formalize cooperative groups as legal civil society organizations
Lack of dedicated research personnel Work done by overstretched clinicians, no protected time or salary support	**Human resources and training** Funding for the addition of new personnel and training of key staff
Insufficient data management Lack of electronic data capture and secure platforms	**Data infrastructure** Supporting cooperative groups to develop their secure platforms for high-quality data capture
Lack of context-adapted evidence Direct application of HIC protocols leads to poor outcomes	**Enabling pragmatic protocols** Support for local groups to develop regionally-relevant clinical trials
Regulatory and administrative hurdles Complex laws for data and specimen sharing	**Legal and administrative expertise** Support for legal consultants and future consortium building to address shared barriers

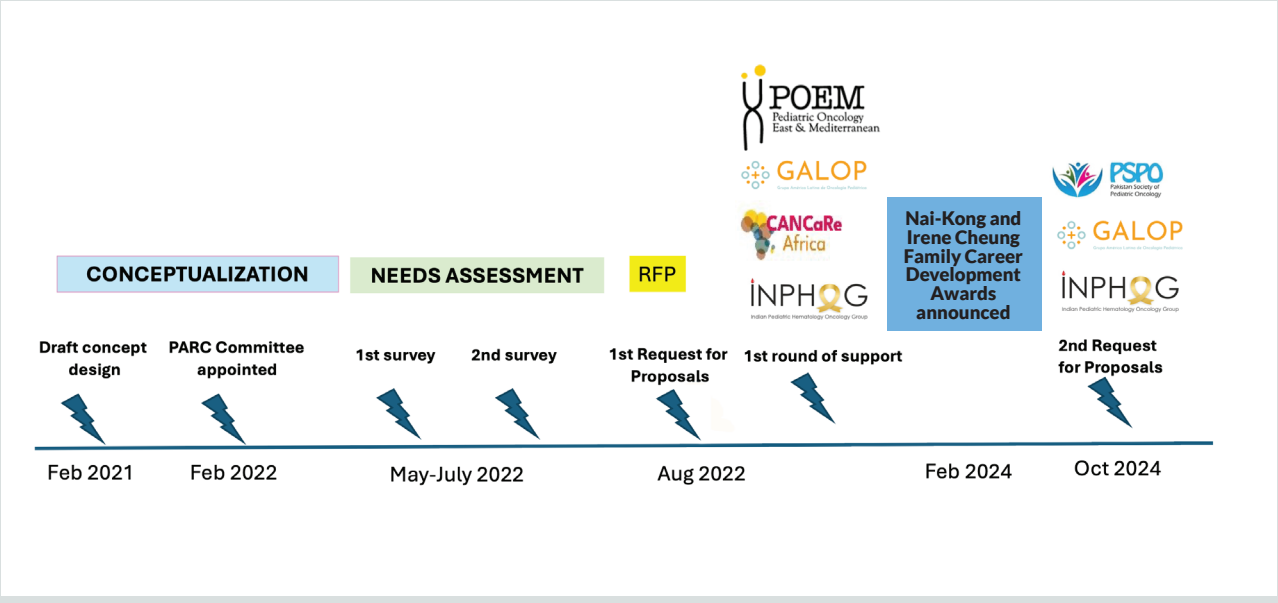
Abbreviations: LMIC, low- and middle-income countries; PARC, Programme for Advancing Research Capacity.

SIOP's support to childhood cancer research

A new model of intervention

In 2022, the International Society of Paediatric Oncology (SIOP) launched the Programme for Advancing Research Capacity (PARC) to address systemic challenges in paediatric oncology research in LMICs *(9)*. PARC's mission is to strengthen clinical research infrastructure so that local teams can generate evidence to guide treatment, improve care, and increase survival rates. This initiative aligns with SIOP's Strategic Plan, which identifies research support as a core pillar. Following a needs assessment in LMICs, PARC put this strategy into practice by supporting cooperative groups, enabling them to conduct research relevant to their settings (Figure 1). PARC is funded by Amazon, Foundation S, and private donors.

Figure 1: Timeline of PARC Programme development and groups funded – details available at https://siop-online.org/parc-committee/



The creation of PARC reflects the culmination of SIOP's long-standing commitment to its global membership. This evolution began in the 1990s with the Paediatric Oncology in Developing Countries programme, which helped bring professionals from LMICs into the Society and showcase their work. A milestone came in 2018, when SIOP was recognized as a non-state actor in official relations with the World Health Organization (WHO), strengthening its ability to advocate globally and contribute to the WHO Global Initiative for Childhood Cancer (GICC), where investment in cancer research infrastructure is a recommended priority action in the CUREALL implementation framework *(10)*. In 2022, WHO further emphasized the importance of building national research capacity through a key resolution *(11)*. Within this context, PARC represents the logical next step: moving beyond education and advocacy to provide direct funding and infrastructure support that will enable sustainable, locally driven paediatric oncology research (Figure 1).

The PARC Programme has three core objectives: 1) to enable SIOP members and partners to expand their clinical research capacity, 2) to advocate for the use of research to optimize outcomes, and 3) to mobilize resources for clinical research capacity development. Through grants, PARC supports international cooperative groups in Africa, Asia, and Latin America. A summary of the first three PARC-funded projects, implemented by cooperative groups, follows.

Latin American Group of Paediatric Oncology (GALOP)

GALOP made significant progress in strengthening its organizational and research foundations in a two-year-long project; it achieved legal recognition, enabling it to manage agreements, contracts, and funds effectively, while developing a standardized framework for data sharing and informed consent. It also built a member registry, recovered key documents from earlier initiatives, and created clear membership guidelines, consolidating its position as a formalized and collaborative research group. Furthermore, GALOP built research capacity by recruiting regional study coordinators, hiring a data manager, and securing a data platform. Extensive training strengthened technical expertise, while new Good Clinical Practice (GCP) certification requirements ensured research standards. Together, these actions not only exceeded initial goals but also created a scalable infrastructure for sustainable clinical research *(12,13)*.

GALOP also expanded its network, diversifying its membership, and launched new pragmatic clinical trials. Annual meetings bolstered collaboration, visibility, and partnerships across Latin America, while plans to integrate multidisciplinary specialists further enriched research capacity. Research networks for Wilms tumour and histiocytosis were consolidated, with new protocols designed, ethical approvals pursued, and registries developed to improve diagnostic and treatment practices. These initiatives, coupled with training and multidisciplinary collaboration, lay the groundwork for regionally adapted treatment protocols, ensuring GALOP's continued leadership in advancing paediatric oncology research and outcomes across Latin America.

Collaborative African Network for Childhood Cancer Care and Research (CANCaRe Africa)

CANCaRe Africa successfully strengthened research management and skills across its African research sites in a year-long project *(14)*. Dedicated local data managers were resourced at all nine centres, supported by a central data manager in Malawi who ensured quality oversight and mentorship. Regular monthly web meetings achieved high participation rates, focusing on data management and building research capacity. Training efforts exceeded expectations, with 230 Wilms tumour patients (vs 200 expected) and 400 SUCCOUR Phase 2 patients (vs 300 expected) enrolled, each with over 95% complete data, which is a remarkable achievement given the circumstances *(15–17)*. Continuous mentoring and monthly training sessions further improved data quality, coordination, and research skills across participating teams. All nine data managers and the CANCaRe Africa central data manager are still employed as data managers at their sites, demonstrating sustainability.

Progress on building grant development skills in core staff was more limited but still significant. Three proposals were submitted, including an ambitious and innovative strategy to reduce treatment abandonment *(18)*. Despite fewer regular online meetings than planned, a major in-person workshop in April 2023 gathered most site leaders and advisory members, allowing strategic discussions on ongoing projects, leadership transitions, and drafting seven planned publications, several of which are now published. These activities laid a solid foundation for future collaboration, capacity-building, and sustainability of paediatric oncology research in Africa.

The Indian Paediatric Haematology Oncology Group (INPHOG)

With limited funding, initial efforts built an ecosystem uniting centres for collaborative research studies, recruiting 13,182 children with cancer across 122 institutions in 24 INPHOG studies *(19)*. Formal PARC and other funding (2022–2024) has allowed INPHOG to make significant progress in strengthening paediatric oncology research capacity in India. A standardized paediatric cancer dataset was developed, and data capture software was piloted across multiple centres, with two studies already using the system. The Chennai population-based childhood cancer registry (PBCCR) and network of hospital-based childhood cancer registries (HBCCRs) study recruited

630 patients across 17 centres, and the national INPHOG HBCCR registry began enrolling patients after securing Clinical Trials Registry-India (CTRI) registration, with a goal of reaching 55 centres. Training for clinical research assistants (CRAs) was expanded: six full-time CRAs were initially hired and equipped, and capacity grew to 18; and CRA training workshops were held.

In parallel, interventional and retrospective studies advanced across six WHO Global Initiative for Childhood Cancer index cancers *(20,21)*. Recruitment was completed for 2,516 patients in the ICICLE 1 study on acute lymphoblastic leukaemia, followed by 421 patients enrolled in the ICICLE implementation study. Progress was also made in other cancers, with 700 patients recruited for Hodgkin lymphoma studies and more than 1,120 for retinoblastoma. New trials for Burkitt lymphoma and low-grade glioma are in preparation for 2025, while the Wilms tumour trial remains dependent on funding and regulatory approvals. In addition, a task force of civil society representatives was launched to ensure that patient and caregiver perspectives were integrated into research priorities and study design.

The PARC Programme has supported four more projects in the three continents, but at the time of publication of this article, activity information is not yet available. Furthermore, whenever possible, PARC collaborates on advocacy initiatives to promote the need for more paediatric cancer research in LMICs.

Fostering future leaders

The PARC Programme supports young researchers through the Nai-Kong and Irene Cheung Family Career Development Award. To date, two awards are helping nurture the next generation of researchers to establish successful patient-oriented research programmes with regional impact *(22)*.

The broader impact: Other capacity-building collaborations

The strategic principles of the PARC Programme are deeply aligned with the SIOP Strategic Plan and its emphasis on shepherding the research in childhood cancer. Furthermore, the Programme aligns with SIOP's broader mission to foster equitable "south-south partnerships" in settings where cooperative groups have not yet been established. This model emphasizes the prioritization of local needs, the cultivation of local expertise, and a commitment to truly equitable collaboration.

Strategic challenges and future directions

Navigating organizational and regulatory hurdles

The challenges faced by cooperative groups in LMICs are deeply ingrained and require sustained effort to overcome. As described above, insufficient funding, fragile organizational structures, and the lack of dedicated administrative and research personnel are persistent issues that PARC and its partners must continue to address. Furthermore, the complexity of legal and regulatory frameworks for data sharing and clinical trial implementation remains a significant hurdle. SIOP's own internal analysis of the PARC Programme's first funding cycle acknowledges these complexities.

A qualitative evaluation of the first four PARC Programme grants to cooperative groups is currently being conducted to understand the "complex, on-the-ground realities" of implementing capacity-building projects in LMICs. This study, which will involve semi-structured interviews and document reviews, aims to determine not just whether the grants met their goals, but "how and why those outcomes were – or weren't – achieved". This evaluation and the PARC Programme's commitment to learning demonstrate that SIOP recognizes that a simple, quantitative measure of success is insufficient. The Society is dedicated to understanding the nuanced, contextual factors that shape the implementation of cooperative groups' projects, and it will use these insights to guide future funding rounds and ensure that its approach remains grounded in the lived experiences of those involved.

Scaling impact and fostering sustainability

The future of the PARC Programme is focused on scaling the successes of the first funding cycle and building a truly sustainable research ecosystem.

In addition, a new major priority for the second round of PARC grants is the active engagement of "patients and civil society as active stakeholders in research." This will involve establishing formal partnerships with civil society organizations (CSOs), conducting educational workshops, and implementing communication strategies to foster collaboration and ensure research is aligned with patient needs. Crucially, the Programme will also help cooperative groups develop "long-term financial sustainability" by leveraging the fundraising experience of advocacy organizations. This shift from a focus on foundational infrastructure to an emphasis on building self-sustaining cooperative groups that are socially embedded and financially resilient is a testament to the Programme's long-term vision.

Conclusions and recommendations

PARC represents a significant and highly strategic intervention in the global effort to improve childhood cancer outcomes by fostering and strengthening sustainable regional clinical trial networks in LMICs. The Programme's unique approach, which targets the foundational infrastructure of research rather than individual trials, distinguishes it from conventional funding models. By providing grants for critical, often-overlooked

activities, such as legal formalization of cooperative groups, clinical research training and provision of human resources, as well as the development of data platforms, PARC is acting as a force multiplier, enabling the very existence of sustainable research in LMICs. ■

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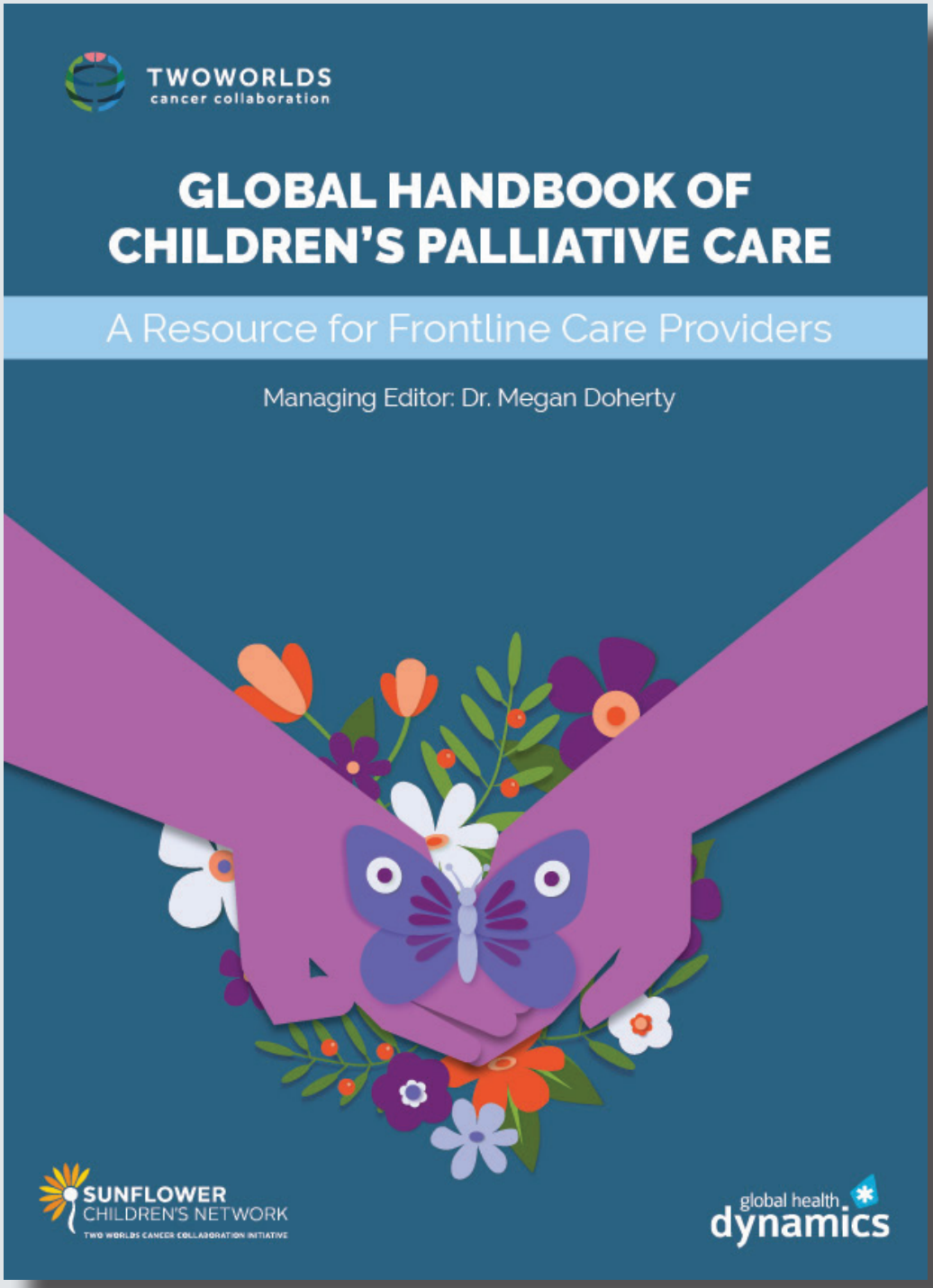

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