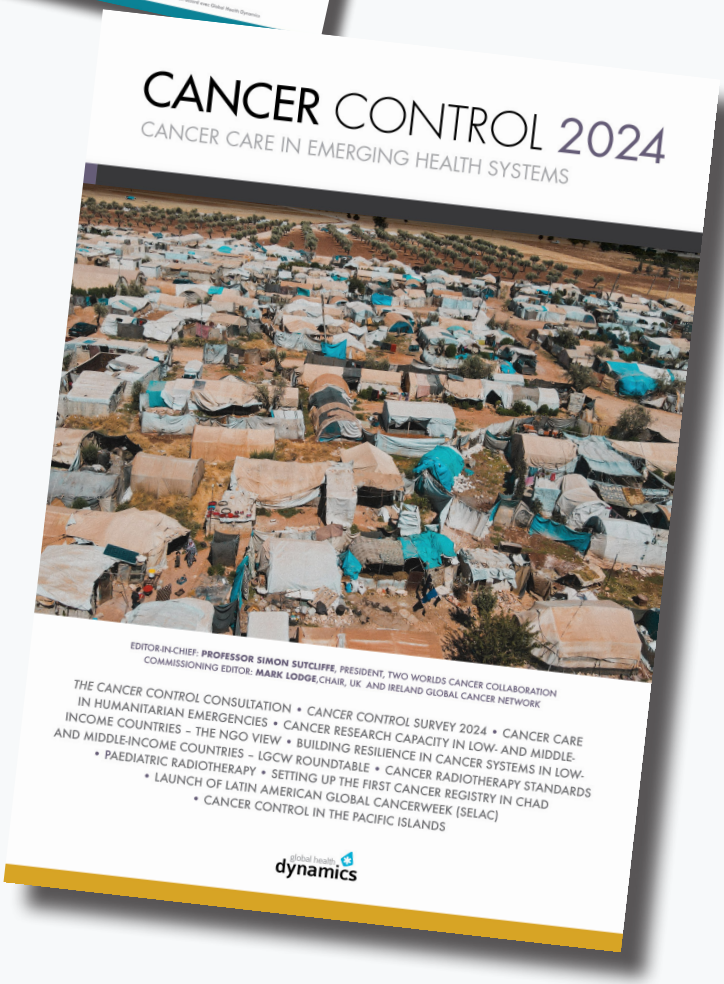
CANCER CONTROL 2026

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

THE *CANCER CONTROL* CONSULTATION ON CANCER CARE GOALS • GLOBAL SURVEY OF REACTIONS TO THE CURRENT HEALTHCARE SITUATION • INTERVIEW WITH DR ANU AGRAWAL • PROGRESS ON THE UN HIGH LEVEL MEETING OUTCOMES • THE CHANGING ROLE OF PHARMACISTS • REVOLUTIONIZING ADOLESCENT AND YOUNG ADULT CANCER CARE • AIR QUALITY IN MONGOLIA • DEVELOPING PALLIATIVE CARE IN INDIA

global health dynamics



To access the electronic editions of this *AMR Control Supplement: The Challenge for the Cancer Community* please visit one of the following websites at:

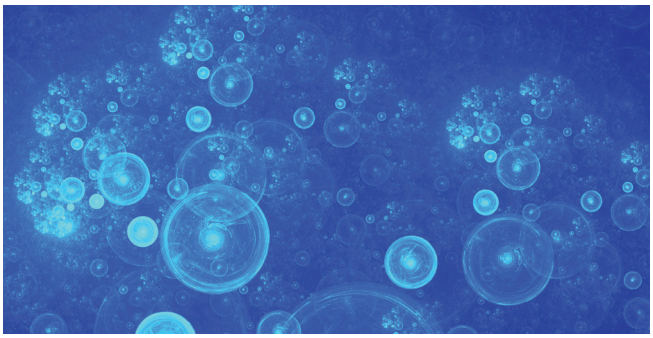
www.amrcontrol.info
www.cancercontrol.info
www.globalhealthdynamics.co.uk
www.uicc.org

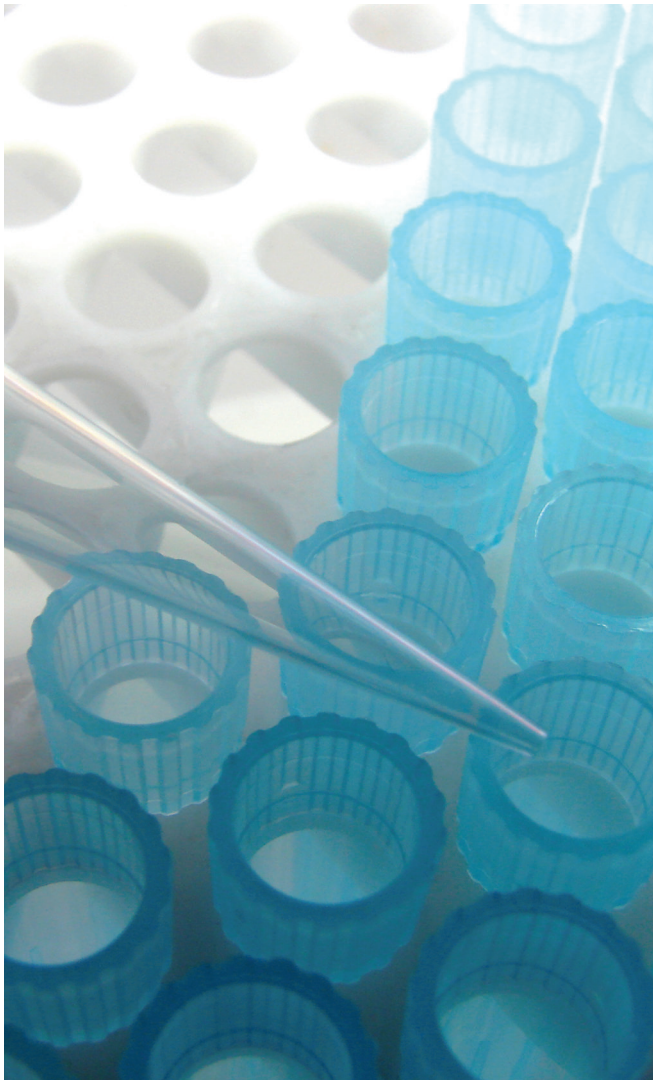
For further information contact:
Tim Probart, Global Health Dynamics
e: tprobart@globalhealthdynamics.co.uk

global health dynamics

CANCER CONTROL 2026

CANCER CARE IN EMERGING HEALTH SYSTEMS





global health dynamics

www.cancercontrol.info / www.globalhealthdynamics.co.uk

EDITOR-IN-CHIEF
PROFESSOR SIMON SUTCLIFFE, PRESIDENT, TWO WORLDS CANCER COLLABORATION

COMMISSIONING EDITOR
MARK LODGE, CHAIR, UK AND IRELAND GLOBAL CANCER NETWORK
For editorial enquires including submissions contact: mlodge@canet.org

PUBLISHER
TIM PROBART
Contact details: tprobart@globalhealthdynamics.co.uk

DESIGN
MARRIOTT GRAPHICS
www.smarriott.co.uk

COPY EDITOR
MADELINE PEARSON

CANCER CONTROL 2026
is published by Global Health Dynamics Limited

GLOBAL HEALTH DYNAMICS
20 QUAYSIDE, WOODBRIDGE,
SUFFOLK IP12 1BH, UK
P: +44 1394 446023
www.globalhealthdynamics.co.uk
cancercontrol@globalhealthdynamics.co.uk

ISBN 978-1-917290-04-3

FIRST PUBLISHED 2026

Contents

Contents

Editorial

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

From the mid-17th century, illness has been pursued from "big picture" to molecular detail – cell to genome to phenome, molecular structure to expression and metabolic target. Driven by molecular mechanism of action and imaging, therapeutic interventions now compliment surgical resection through radiation, radio-pharmaceuticals, cytotoxics, biologicals, and targeted drugs.

Over the past 75 years cancer control outcomes have improved continuously, accompanied by an evidence-informed, disease-based literature. *Cancer Control*, however, is more about the burden of cancer as seen at all resource levels; about the deployment of medical and social sciences to address cancer as perceived by peoples of different culture, education, geography, social circumstances, equity, and philosophy – looking back up the through the microscope from the tissue and cell to the "eyes, thoughts and actions" of the beholder. *Cancer Control* is about interdisciplinarity, inter-professional and inter-sectoral care – about what is being done, and how and why it works (or not) – about adapting and adjusting healthcare and cancer control plans within a country context and sharing ways to address differences in health outcomes between the higher- and lesser-resourced worlds.

We are entering a new world order, a global pandemic followed by changing understandings related to foreign aid, multilateralism, global security, "social good", and the pursuit of well-being. The CONSULT prompts re-thinking strategy, relationships, collaboration and partnerships within this new world order. The SURVEY invites perspectives from thought-leaders in diverse global regions, reflecting on the world "as it is now", the impact of change, and new partnerships and business practices to achieve population health goals. Dr Anu Agrawal, former Vice-President Global Support, American Cancer Society presents a "situational intelligence and perspective" on current cancer control practice in the INTERVIEW.

At a Global health policy level, Katy Cooper and colleagues address Navigating uncertainty: NCDs in a new era of global health.

Better global patient-centred care insights are provided in Beyond the dispensary, Part II: Listening to the voices of pharmacists working in resource-constrained settings by Ladha and colleagues, highlighting the skills and expertise of pharmacists as integral members of the inter-disciplinary healthcare team. Heykoop and colleagues draw attention to Revolutionizing a cancer care and support ecosystem in British Columbia unique to adolescents and young adults (AYAs), noting that cancer care systems often fail to meet unique life-stage needs, resulting in significant inequities in cancer care. Age-appropriate principles and practices are required to support and respond to the holistic needs of AYAs.

From the Asian region, Erdenekhuu Nansalmaa presents Cancer control in Mongolia: Air pollution and molecular insights into hepatocellular carcinoma. Whilst viral hepatitis remains a major etiological factor for one its most common cancers, molecular evidence suggests that environmental exposures, including air pollution, may play a significant role in carcinogenesis. Synthesizing epidemiological, environmental, and molecular evidence, recent genomic analyses of Mongolian HCC reveal distinct mutational signatures associated with environmental carcinogens, suggesting a broader environmental contribution to cancer risk beyond traditional factors.

In Achieving universal health coverage for palliative care: A case study of integration of palliative care into government primary healthcare from South-Central India, Gayatri Palat and colleagues report on a model of primary palliative care integrated into the government primary healthcare system for a large state population. Success involved partnerships between the local government health system, civil society, and tertiary health facilities; high quality staff training combined with ongoing clinical supervision; establishing referral pathways; and ensuring access to opioids and other essential medicines.

I hope you will enjoy the 2026 edition of *Cancer Control*. If you would like to contribute an article or respond to an article in this edition. Please contact us at info@globalhealthdynamics.co.uk ■

THE *CANCER CONTROL* CONSULTATION

Is there an appetite for a healthier, more just and equitable world?

"If international organizations seem ineffective, it is because their structure no longer reflects the current reality... The solution to the multilateralism crisis is not to abandon it, but to rebuild it on fairer and more inclusive foundations."
Luiz Inácio Lula da Silva, Brazilian President, *The Guardian*, 10 July 2026

"Today I will talk about a rupture in the world order, the end of a pleasant fiction and the beginning of a harsh reality … the Old Order is not coming back…we need to see "the world as it is", not "as we might wish it to be".
Mark Carney, Prime Minister of Canada, World Economic Forum, Davos, January 2026

Health is deeply interconnected with equity, social justice, clinical innovation, and environmental stewardship – a resource for living, equipping a resilient society through awareness, information, choice and opportunity. Health and well-being flourish with peace, security, social stability, resilience and sustainability. They are an expectation in high resource countries, but commonly about endurance, resilience against adversity, or suffering in low- and middle-income countries (LMICs). War, insurgency, forcible displacement, persecution, generalized violence and natural or man-made disasters currently impact more than 120 million people, the majority in LMICs facing protracted adversity, uncertain legal status, compromised food, shelter, healthcare, education, and social protection.

Geopolitical uncertainty, financial contraction, eroding multilateralism, rising nationalism, transactional politics, and the shifting world order have changed traditional concepts of development assistance and "foreign" aid. Global health governance, formerly rooted in the wealthy assisting the poor through financial aid (charity) needs re-vitalization to generate collaborative leadership, health system capacity-building, and technology development (molecular medicine, AI, population data with sovereignty, etc.) in concert with national investment and "ownership" of the population's health, well-being, and disease control. The true strength of a nation is the health, well-being and productivity of its people, yet public spending is decreasing for almost half of all LMICs. Debt repayment deprives poorer nations of funds to improve population health, limiting choices, and encouraging behaviours and lifestyles leading to poor health, loss of well-being, disability and premature death.

Overcoming inequalities of health outcomes resulting from limited access to available, affordable, good quality health services requires new legal and organizational frameworks to address health, illness control and well-being in the emerging context of the politics, economics, medicine and environment in the new world order – the greatest good for the greatest number through the best use of available resources.

Can an increasingly knowledgeable, longer-lived, technology-enriched and wealthy society generate "social good"? Could a new multilateralism harness the power of collaborative, co-invested relationships to:

- build trust and confidence through information rather than disinformation;
- replace external debt repayment in exchange for improved social determinants of health;
- replace repeated cycles of emergency and disaster relief leading to dependency, indignity and social unrest through building resilient infrastructure and sustainable development;
- align external financial support with improvements in population health, more complete universal health coverage, social protections and stronger, more resilient societies;
- forge open and inclusive collaborations based upon knowledge transfer and shared purpose rather than financial assistance/aid – collaboration rather than transactions?

Globally, the world is "cash-rich", but "social-good poor". Time is running out for indifference, inattention or complacency. Is there an appetite for a healthier, more just and equitable world? "Nostalgia is not a strategy" (Carney, 2026).

RESPONSES

HRH Princess Dina Mired *of the Hashemite Kingdom of Jordan, Past-President of the Union for International Cancer Control*

Absolutely. People everywhere want the same fundamentals: to live healthy lives, to protect their children, and to know that if illness strikes, they will receive the care they need. The appetite is there. The real question is whether our political and economic systems share it.

Nowhere is this disconnect clearer than in cancer. We are living through an extraordinary era of scientific progress, with immunotherapies, targeted treatments and personalized medicine transforming what is possible. Yet we have not even closed the old equity gap, and already a new one is opening.

Millions of people still lack access to basic diagnostics, surgery, radiotherapy, essential medicines and palliative care. Now we risk creating two worlds of cancer care: one benefiting from genomic testing, precision oncology, immunotherapy and the latest therapies, and another still waiting for the basics. What does scientific progress mean if your chances of benefiting from it still depends on where you were born or what you can afford?

We must ask whether our systems are truly designed around health. Governments operate within short political cycles, while prevention demands sustained investment over decades. Markets reward innovation, but not necessarily affordability, prevention or equitable access. The result is a fundamental mismatch between what our systems incentivise and what healthier societies actually need.

And then comes the more difficult question: is there a serious appetite not simply to aspire to healthier and more equitable societies, but to advocate and fight for them when it really matters?

Nowhere is that question more painfully tested than in the genocide in Gaza, where these contradictions reach their most unbearable extreme. What does "health equity" mean when hospitals and ambulances are targeted and attacked, healthcare workers are killed or detained, and cancer patients are left without diagnosis or treatment – or even the most basic right to die free from pain?

This is where our commitment to equity is truly tested. It is easy to advocate for health equity in declarations, conferences and strategies. It is far harder to defend it when doing so is uncomfortable, politically difficult or controversial. Yet surely that is precisely when our voices matter most.

For me, what has made this even more shocking and deeply disappointing has been the loud silence from much of the global cancer community. We are a community that speaks passionately about equity, universal health coverage and leaving no cancer patient behind. But these principles cannot apply only when they are easy or politically comfortable to defend. They must matter most when they are hardest to uphold.

If we cannot raise our voices for cancer patients when their very access to care is being destroyed, then we must ask ourselves what our commitment to equity truly means. And if the right to health disappears in war, can we truly call it a right?

So yes, the appetite for a healthier, more just and equitable world exists. We have unprecedented scientific knowledge, extraordinary innovation and resources that previous generations could scarcely have imagined.

What we lack is the collective courage to align our political and economic priorities with what people actually value: life, dignity and wellbeing – and to make health and equity non-negotiable, everywhere.

RESPONSES

David Reddy, *Director General, The International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)*

The future of health globally will be shaped by how effectively we can translate scientific progress into better health outcomes. This cannot be done by one institution or sector, but will be built through partnerships that strengthen health systems and ensure that innovation reaches the people who need it most.

Today, we have unprecedented tools to prevent, detect, treat, and even cure disease. In cancer alone, advances in vaccines, diagnostics, precision medicine, immuno-oncology, and cell and gene therapies are transforming outcomes, with more than 4,700 potential cancer medicines in development. Every €1 invested in cancer medicines is estimated to return €6.80 in societal and economic value. Similar breakthroughs are reshaping our response across non-communicable diseases, which today account for nearly three-quarters of global deaths and increasingly define the health and prosperity of nations.

Innovation can only fulfill the potential of science when people can access it. It also requires stronger health systems, sustainable financing, and effective collaboration across governments, industry, healthcare professionals, patients, and civil society.

Modern multilateralism should enable countries to build healthier societies through investment, knowledge sharing, and long-term partnerships. When innovation, access, and collective action work together, health becomes not only a development outcome, but an investment in societal resilience and economic growth.

RESPONSES

HE Dr Leslie Ramsammy, *Ambassador and Permanent Representative of the Cooperative Republic of Guyana to Switzerland*

Global solidarity-based multilateralism has been weakened by fragmentation, inefficiency, misaligned mandates, development assistance contraction and the emergence of transactional multilateralism, resulting in threats to decade-long gains and impeded progress towards a healthier, more just and equitable world.

A reimagined, fit-for-purpose multilateralism for a healthier, more just and equitable world, without transactional geopolitical limitations, respecting national and regional voices, and based on human rights, must facilitate global resources for strengthening and transforming health systems by building adequate national capacities for biosecurity, health emergency responses, reduced child and maternal mortality, comprehensive capacity for critical care and surgical interventions, access to technology, including digital and AI technologies, a fair supply chain, health human resource, and to combat other challenges so that every country has a life expectancy of at least 80 by 2050 (80 x 50).

The remodeled health architecture must adopt country-led approaches to respond to poly-crises, such as non-communicable diseases, achieve the SDGs and its successor and the WHO's cervical cancer goals, build Universal Health Coverage, implement the principles of the Lusaka Agenda, the Accra Reset and the Pandemic Agreement and transform vertical Global Health Initiatives such as GAVI, Global Fund, Pandemic Fund, UNITAID and Global Financing Facility to align with country-based integrated approaches.

RESPONSES

Dr Dingle Spence, *Clinical Oncology and Palliative Care Honorary Consultant, University of the West Indies, Kingston, Jamaica*

Cancer control is an increasing global problem, we know what needs to be done, but are we willing to implement what we already know, so that everyone can benefit?

The 2026 WHO Global Cancer report reminds us that the global cancer story is one of profound inequity, and that gap is widening between HICs and LMICs. A shift in educational approaches to understanding the spectrum of cancer care can help us close this gap.

The report calls for three shifts. Better capabilities, better protections, better value. We cannot address these without supporting better broad-based cancer education. Greater cancer literacy is mandatory for healthcare professionals and the public alike.

The demystification of cancer is a high priority. Policy implementation requires a wide spectrum of educated professionals to carry it out. Time to shift from a place where oncology education is siloed in specialism, is narrow and vertical in approach, to a wider, more horizontal-based approach, particularly in LMICs where cancer control needs to be focused more on prevention and early detection.

Can we view oncology education as a pyramid with a wide flat base, where all are included, tapering to a point where super specialization dwells? In a healthier, more just and equitable world oncology education for all must be prioritized.

RESPONSES

Dr Lorna Renner, *Associate Professor at the Department of Child Health, University of Ghana School of Medicine and Dentistry and the Head of the Paediatric Oncology Unit, Korle Bu Teaching Hospital, Accra, Ghana*

The 21st century is an age of design and calls for a healthier world, but there should also be a greater hunger, particularly in LMICs, for a more just and equitable world, not just an appetite. The maldistribution of healthcare, using childhood cancer from my standpoint, as a typical example, with 80% of cases occurring in LMICs, over 80% survival in HICs and less than 30% in LMICs paints a picture of the skewed distribution of the burden, resources, treatments and outcomes. This maldistribution which is evident not only from HICs to LMICs but also in-country, is the consequence of poor social policies and programmes, unfair economic arrangements, and lack of political will and champions.

The inequalities we see in health are linked to inequalities in society and reducing them is a matter of fairness and social justice. This is based on the ideology by Marmot and colleagues (2010) in England entitled "Fair society, healthy lives," commissioned by the United Kingdom's

Department of Health. Taking action to reduce these inequalities in health does not require a separate health agenda, but action across the whole of society, social determinants of health.

With current geopolitical disruptions, the priority is on increasing defence budgets and "traditional" donor funding to the health sector has dwindled – a misalignment of our desires and actions. The commitment of the UN agencies such as the WHO is evidence of an appetite for social justice. It may seem as though nothing is being done but there exist frameworks to get us there. Post the Millennium Development Goals (MDGs), lessons learned ushered us into Sustainable Development Goals (SDGs). The SDGs recognize that eradicating poverty and inequality, creating inclusive economic growth and preserving the planet are inextricably linked, not only to each other, but also to population health. Back to Childhood Cancer, the WHO launched the Global Initiative for Childhood Cancer in 2018 with its CUREALL framework, promoting domestic efforts and collaborative partnerships with health sovereignty in mind, to address health inequities.

We have the appetite to transform our world, exemplified by all the frameworks; however, what we need today is hunger for implementation, and better redesigning of our current efforts.

RESPONSES

Karen Canfell, *Lead, Cancer Elimination Collaboration, Sydney School of Public Health, The University of Sydney, Australia*

The global burden of cancer is enormous. In 2024, an estimated 20 million people were diagnosed with cancer, and the number of people dying from cancer approached 10 million. Underpinned by population health and ageing, and fuelled via the current inequitable access to evidence-based interventions at global and within-country levels, this burden is set to increase to 35 million diagnosed and 18 million dying from cancer by 2050 *(1)*.

The challenges in cancer control loom even more acutely in the context of the major shifts since 2025 in the global health funding landscape, and the consequent adjustments and re-prioritization processes that are now occurring.

The traditional development models, involving donor-funded and time-limited programmes, can only be the first part of the solution. The aim must continue to be that country- and community-led initiatives are embedded into health systems and that these are associated with enduring political commitment. Key to this must be the provision of high-quality, flexible technical assistance in cancer control policy and in the implementation of evidence-based strategies.

WHO's Cervical Cancer Elimination Initiative (CCEI) and the Global Breast Cancer Initiative (GBCI) are evidence-informed approaches to reducing the burden of cancer in women, especially in LMICs. These initiatives have enormous potential to provide a backbone for health systems strengthening, from primary care to oncology, and their momentum should be harnessed accordingly.

1. Data from IARC Global Cancer Observatory, 2024. https://www.who.int/news/item/01-02-2024-global-cancer-burden-growing--amidst-mounting-need-for-services

CANCER CONTROL SURVEY 2026

What changes to cancer care are being made in your country in response to the new, emerging global health care environment?

ARGENTINA

In response to the shifting global healthcare environment – which emphasizes fiscal sustainability, technological modernization, and precise resource allocation – Argentina has been undergoing radical structural and operational shifts in its cancer care framework. Driven heavily by the austerity and centralization policies of President Javier Milei's administration, the most critical changes to Argentina's oncological infrastructure include:

1. Administrative restructuring and defunding

- **Elimination of the National Cancer Institute (INC):** The government formally closed the standalone *Instituto Nacional del Cáncer*. Its duties have been absorbed directly into the Ministry of Health to eliminate what the administration cited as a "duplicity of tasks," logistics failures, and inefficient drug purchases. In our view this governmental decision is wrong, and will negatively influence cancer control for many years in the country.
- **Creation of ANES:** Argentina established the *Administración Nacional de Establecimientos de Salud* (ANES). This new unified entity now centrally manages five major national hospitals to streamline public health spending.
- **Budget reductions:** The national oncology budget faces drastic tightening. The specific federal programme designated for cancer research, prevention, and early detection (Programa 65) has seen billions of pesos stripped from its funding.

2. Digitalization and remote decentralization

- Telemedicine xxpansion: To navigate funding cuts and bridge geographic gaps, Argentina is leaning heavily on telemedicine to support rural continuity of care.
- Interoperable electronic health records: The country is actively rolling out interoperable electronic records. The goal is to track patient oncology data better and reduce the severe diagnostic delays that have historically plagued the decentralized provincial systems.

3. Restructured drug distribution and care access

- Suspension of DADSE support: The suspension and restructuring of the high-cost medication programme (DADSE) has deeply disrupted how uninsured or vulnerable patients acquire prohibitively expensive oncology drugs. This shift has forced a massive reliance on provincial-level distribution and non-governmental aid networks.
- Restriction on non-resident care: Under newly enacted regulations (such as Resolution 1066), public hospitals have ended free routine and non-emergency healthcare for non-resident foreigners. Non-residents must now pay out of pocket or use international health insurance for ongoing cancer treatments. Emergency life-saving interventions remain universally guaranteed.

4. Advanced clinical improvements

- Next-generation targeted therapeutics: Despite public sector restrictions, Argentina's private and some high coverage sectors continue adopting cutting-edge global medical standards. This includes implementing novel antibody-drug conjugates and advanced kinase inhibitors for high-risk breast cancers.

The lack of a national agency for high-cost medications (similarly to the NICE in the United Kingdom) is urgently needed for a better allocation of resources and to diminish patient inequities.

5. Cancer research

Cancer research in Argentina is currently at a historic and highly polarized turning point. On one hand, the country maintains top-tier human capital and scientific ingenuity that continues to achieve global milestones; on the other, it faces the most severe public funding crisis in decades, forcing a drastic shift toward private and transnational financing models.

- Austerity and budget cuts at CONICET: The National Scientific and Technical Research Council (CONICET), the historic engine of medical science in Argentina, is

experiencing an unprecedented budget paralysis under the current administration.

- The shift towards biotech startups and private capital: Faced with the collapse of state grants, leading Argentine scientists are rapidly turning to private venture capital and spin-off models to rescue decades of basic research and transition it into clinical phases.
- International alliances and global recognition: The global pharmaceutical and scientific community continues to recognize the high value of Argentina's remaining research infrastructure and its scientists' ingenuity.

While government officials defend these sweeping measures as necessary audits to curb public spending inefficiencies, the medical and scientific community agrees that basic oncological research is currently surviving solely due to the resilience of its professionals and external private funding.

Eduardo Cazap, MD, PhD, Founder and first President of the Latin American & Caribbean Society of Medical Oncology (SLACOM)

CANADA

Healthcare in Canada is a shared responsibility between the federal government and the provinces. Canadian organizations such as the Canadian Partnership Against Cancer focus primarily on domestic issues, including equity, cancer in Indigenous populations, the integration of care and the improvement of outcomes. Until recently, the Canadian focus in global health centred on advancing the health and rights of women and children. Recently, Canada has engaged in the G7 Cancer Alliance, which has primarily focused on research. Canadian organizations have a long history of global collaboration in clinical trials.

Professor Mary Gospodarowicz, Professor of Radiation Oncology at the University of Toronto and past Medical Director of the Princess Margaret Cancer Centre, Toronto, Ontario

COLUMBIA

Colombia enacted Resolution 1233, which adopts the Decennial Cancer Control Plan (2026–2035). This ten-year framework mandates a decentralized "territorial approach," shifting resources to address local needs and close urban-rural care gaps. It requires actionable interventions across prevention, early detection, treatment, and palliative care. Furthermore, the plan enforces stricter insurer accountability and establishes unified data tracking via the National Cancer Observatory to optimize patient outcomes nationwide. There is still a lot of work to implement it

Professor Gloria Ines Sanchez, MSc, MD, Faculty of Medicine, University of Antioquia, Medellin, Colombia

EASTERN MEDITERRANEAN REGION

The Eastern Mediterranean Region is working to build stronger, more connected, and fairer cancer care systems in the face of conflict, displacement, less aid, and rising non-communicable diseases. Key priorities include prevention, early detection, HPV vaccination, patient-centred care, strengthening digital health, and integrating cancer care into primary healthcare and universal coverage. There is also greater focus on maintaining cancer care during crises, building local skills, and closing gaps in access and outcomes.

Dr Ibtihal Fadhil, Founder and Chairperson of the Eastern Mediterranean NCD Alliance.

EGYPT

Public practice: Inclusion of more novel cancer therapeutic agents in the national reimbursement initiative specially the unified health insurance.

Private practice: More adoption of comprehensive genomic profiling with local and international panels and better adaption of precision oncology.

Professor Amr Shafik, Professor of Clinical Oncology, Ain Shams University, Cairo, Egypt

- 1. Continuation of national screening initiatives, particularly for breast, liver, and cervical cancers.
- 2. Further progress toward universal health coverage, including cancer care, in different parts of Egypt.
- 3. Establishing new cancer centres and strengthening existing ones.
- 4. The upcoming years will require greater coordination and collaboration among governments, universities, insurance providers, and private health services.
- 5. The ongoing challenge of refugees from neighbouring countries, which places an additional burden on the health system

Professor Ahmed Elzawaway, Professor at Suez Canal University and Chairman of Alsoliman Clinical and Radiation Oncology Centre and the Global Oncology University (GO-U)

GHANA

Ghana is gradually reshaping cancer care from a mainly hospital-based, late-treatment model toward prevention, earlier diagnosis, decentralized services and more comprehensive long-term care. Activities of Breast Care International within the communities are clear examples.

Digital tools, electronic records and telemedicine may also help with specialist consultations, pathology review, follow-up and professional training – particularly for facilities outside the main cities

Ghanaian institutions are increasingly participating in international cancer research, public-health programmes and clinical collaborations. The establishment of the Otumfuo Osei Tutu II Comprehensive Cancer Center of Excellence with Research and an AI Hub is very timely and demand driven for Ghana.

Our aim is to move toward prevention, early detection, decentralized and multidisciplinary care, stronger data systems, digital support, improved financial protection and better palliative care. The biggest challenge is turning these national goals into consistently available services across all regions

Beatrice Wiafe Addai, Chief Executive Offic, Peace and Love Hospitals, Ghana

HEALTHY CARIBBEAN COALITION

The Caribbean has not been immune to the rapidly changing global healthcare environment. Rising costs, inequities and workforce shortages are making access to cancer care – from essential treatment to cutting-edge therapies, particularly medicines – increasingly difficult and putting more and more people's lives at risk. PAHO and CARPHA are supporting equitable access to essential medicines, cervical cancer elimination and childhood cancer initiatives, while countries are expanding radiotherapy, oncology, and diagnostic capacity and CSOs like the Healthy Caribbean Coalition are advocating for meaningful engagement of people affected by NCDs in decision-making.

Current global efforts to shape a new, more equitable and people-centred global health architecture present an important window of opportunity for Caribbean countries and cancer societies to engage and ensure that lived realities help shape solutions that deliver change where it matters most.

Maisha Hutton, Executive Director, Healthy Caribbean Coalition

INTERNATIONAL AGENCY FOR RESEARCH ON CANCER (IARC)

From IARC's cancer prevention perspective, we observe many countries strengthening integrated cancer control approaches that connect prevention, early detection, diagnosis, treatment, and survivorship. Current priorities increasingly include equitable access to care, implementation of evidence-based screening programmes, digital health and AI-enabled solutions, workforce capacity, and data-driven decision-making through cancer registries. There is also growing emphasis on resilience, ensuring cancer services can be sustained despite financial, demographic, and global health pressures.

Dr Véronique Chajès Programme Officer, Office of the Director, International Agency for Research on Cancer, Lyon, France

INDIA

India is transforming its cancer care ecosystem to be more affordable, technologically advanced, and geographically accessible. Several initiatives regarding cancer care are under way in India in response to the new, emerging global healthcare environment. These include import tax exemptions on essential cancer medications, advancing home-grown advanced cell therapies, and expanding cancer care facilities by upgrading existing hospitals as well as setting up new treatment units.

Dr Priya Ranganathan, Department of Anaesthesiology, Critical Care and Pain Tata Memorial Centre, Mumbai, India

India is responding to the changing global healthcare environment by strengthening cancer care through Health Technology Assessment, expanding Universal Health Coverage across states, and reducing customs duties on essential imported drugs and healthcare equipment. There is also greater focus on locally relevant research, healthcare infrastructure and a trained workforce. Hub-and-spoke models are bringing cancer care closer to patients, while the addition of HPV vaccination in the national immunization programme is strengthening efforts towards cervical cancer elimination.

Dr Bhawna Sirohi, Medical Director at Balco Medical Centre, Raipur, Chhattisgarh, India

KAZAKHSTAN

Kazakhstan is strengthening cancer care in response to a rapidly changing global health environment by prioritizing prevention, early detection and equitable access to modern treatment. National screening programmes are being

expanded, while molecular diagnostics, targeted therapies and immunotherapy are increasingly integrated into clinical practice. We are also strengthening regional cancer services, digital health and international collaboration. Our priority is to build a sustainable, patient-centred cancer system and reduce disparities in outcomes across the country.

Professor Dilyara Kaidarova, MD, PhD, Doctor of Medical Sciences, Academician of the National Academy of Sciences of the Republic of Kazakhstan under the President of the Republic of Kazakhstan, First Vice-Rector of Asfendiyarov Kazakh National Medical University, President of the Kazakhstan Cancer Society (KazCS), Almaty, Kazakhstan

LEBANON

Lebanon's cancer care in 2026 is being reshaped by war-related disruption, population displacement, and severe economic strain, requiring urgent national and international action. Medication shortages, damaged oncology infrastructure, and disrupted referral pathways have driven decentralization of services and expanded reliance on NGO support and global solidarity. Efforts now focus on strengthening emergency procurement, restoring diagnostic capacity, and coordinating care for displaced patients to preserve treatment continuity in an increasingly unstable regional environment.

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

MALAWI

Across low-resource settings like Malawi, where I provide services, cancer care is shifting as external funding tightens. Health ministries are strengthening the pathway by driving cancer control plans that connect fragmented services across screening, diagnosis, and treatment via remote monitoring. These enable continuous follow-up and reduced costs following early diagnosis, plus sustainable financing models. Digital tools that create connective infrastructure for the care pathway and integrate with national health systems are vital to this shift.

Dr Mercy Ofuya, Medical Statistician and Founder of CupArise

MALAYSIA

In Malaysia, cancer care is gradually shifting towards more person-centred models. Alongside expanding access to diagnosis and treatment, greater attention is being given to earlier diagnosis, patient navigation and financial toxicity. Public hospitals nonetheless need adequate resources to meet rising demand, supported by broader health-financing reform. Deliberate investment in the cancer workforce, sustainable partnerships with civil society and the private sector, real-world data, regional collaboration and global health diplomacy will be increasingly important in addressing resource constraints.

Professor Nirmala Bhoo Pathy, cancer epidemiologist and public health physician at University Malaya Medical Centre and Founder of Well with Cancer (WECAN)

NEPAL

Note: These responses were submitted before the recent flash flood and landslides.

Nepal is advancing cancer care through its National Cancer Control Strategy 2024–2030, shifting the focus from treatment alone to prevention, early detection, diagnosis, palliative care, and survivorship. Key initiatives include free treatments for children under 14, improving access to essential medicines for childhood cancers, implementing decentralized and shared-care models, expanding paediatric and regional oncology services, and promoting multidisciplinary approaches. Additionally, Nepal is exploring innovative therapies such as precision oncology, immunotherapy, and CAR-T therapy, while also focusing on cancer research, surveillance, workforce skills, and quality improvement efforts.

Dr Sudhir Raj Silwal, Consultant Radiation Oncologist, B&B Hospital, Lalitpur, Nepal

Nepal's dependence on imported cancer medicines has major vulnerabilities in its cancer-care system amid the changing global health environment. Recent geopolitical conflicts, particularly in the Middle East, together with global inflation and rising production and transportation costs, have disrupted the supply of essential anticancer medicines such as cisplatin and carboplatin. These shortages have directly jeopardized treatment continuity and optimal cancer outcomes. Currency devaluation and escalating international prices have also constrained the procurement of LINACs and CT simulators. These challenges highlight the urgent need for national policies focused on medicine security and long-term investment in cancer-care infrastructure and the workforce.

Dr Surendra Gauchan, Consultant Radiation Oncologist B P Koirala Memorial Cancer Hospital, Bharatpur, Chitwan, Nepal

PAKISTAN

For Pakistan I would say that the changes are: Increased awareness of cancer and its prevention amongst the general

public fostered by national media campaigns by the Shaukat Khanum Memorial Cancer Hospital and Research Center, with two fully functional state of the art cancer hospitals in Lahore and Peshawar and a third, larger facility in Karachi opening in December this year. This has stimulated other entities to plan similar cancer hospitals in other parts of the country to improve the availability of modern cancer care.

Professor Nausherwan Burki, Shaukat Khanum Memorial Cancer Hospital and Research Centre, Karachi, Pakistan

PHILIPPINES

I practice primarily in a public cancer centre, and I see the situation at first hand. We are expected to deliver care that increasingly reflects global standards while working within very real resource constraints. Advances in targeted therapies and immunotherapy for gynaecologic malignancies are remarkable; however, these breakthroughs remain largely inaccessible, often rendering timely treatment financially out of reach for many patients. Likewise, emerging surgical approaches, including robotic systems, have the potential to enhance precision, accelerate recovery, and improve quality of life. However, technological progress should be judged by whether it delivers demonstrable, meaningful gains in patient outcomes, and it should also be financially prudent for both the government and patients.

For the Philippines, the challenge, therefore, is not merely to embrace every emerging innovation, but to identify which advances and new therapies deliver genuine clinical value – advances that can be implemented equitably and sustained over time. Strengthening the nation's cancer preventive strategies and cancer infrastructure, expanding and supporting the workforce, reinforcing referral pathways, improving financing mechanisms, advancing research, and ensuring access to essential medicines are just as critical as adopting cutting-edge technologies. Ultimately, our objective should be to narrow the divide between what is feasible on a global scale and what is realistically within reach for Filipino patients. Every Filipino cancer patient deserves timely and complete treatment, regardless of where they live or what they can afford. No patient should have to wait for care that could save their life.

Dr Jimmy Billod, Medical Specialist Baguio General Hospital and Medical Center, Baguio City, Benguet, Philippines

SOUTH AFRICA

South Africa is responding to global health funding shifts by strengthening cancer control commitments, though implementation still lags targets. Emphasis has shifted toward earlier detection, with strengthened screening and diagnostic pathways underpinning a 2026–2030 Cervical Cancer Elimination Framework, HPV-DNA testing rollout, and single-dose vaccination. A first IAEA/WHO/IARC imPACT Review is informing a new National Cancer Control Plan, alongside decentralized oncology infrastructure, expanding digital health tools, and domestic financing amid persistent screening and treatment-delay gaps.

Elize Joubert, Chief Executive Officer, Cancer Association of South Africa (CANSA)

SOUTH SUDAN

South Sudan experienced protracted conflicts lasting decades resulting in the creation of "a cancer care desert zone"; no radiotherapy and stark deficiency in workforce and services across the continuum. In this post-conflict recovery phase, health professionals who returned home created the South Sudan Cancer Network and the Cancer Department at the Ministry of Health. International solidarity is urgently needed to collaborate in training the workforce, the development of NCCP and the cancer care delivery system.

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

SUDAN

In Sudan, cancer care is adapting to advances in global oncology while addressing conflict and severe resource limitations. Priorities include equitable access to essential medicines, stronger prevention and early diagnosis, clear referral pathways, reliable cancer registries, and improved patient support. Telemedicine, multidisciplinary collaboration, and decentralized services can maintain care for displaced populations. International partnerships, sustainable financing, workforce development, rebuilt infrastructure, and gradual access to precision medicine and modern radiotherapy are essential for resilience and equity.

Dr Nabeeha Karadawi, Consultant Medical Oncologist, Letterkenny University Hospital, Letterkenny, Ireland

UNITED KINGDOM

We all recognize the current challenges brought on by the diversion of governmental support for global health as exemplified by the action taken by the President of the United States and by recent governments in the United Kingdom. Clearly this has had a significant impact on cancer related programmes around the world.

We do still carry with us the lessons learned from the COVID pandemic which illustrated that we are a worldwide inter-related health network and that international collaboration is the path to overcoming the increasing health burden including diseases such as cancer.

From the UK perspective, the motivation remains undimmed. Within the National Health Service we are increasingly recognizing the benefit for our patients and our staff of engagement in cancer projects in collaboration with colleagues working in different health environments around the world. The commitment within the United Kingdom is illustrated by current activity and support for organizations such as the Kenya UK Health Alliance and the UK and Ireland Global Cancer Network.

Although some of the previously convention sources of funding have become more limited, we all know that there is more money in the world now than there has ever been before. We must now focus on exploring ways to reach alternative funding sources in order to maintain our momentum in the knowledge that the political thinking will change, bringing with it more governmental funding in the years ahead.

Professor Richard Cowan, MBBS, MRCP, FRCR, MD, Consultant in Clinical Oncology, The Christie NHS Foundation Trust, Manchester, United Kingdom

UNITED STATES OF AMERICA

For the first time, the 5-year relative survival rate for all cancers in the United States (diagnosed between 2015–2021) combined has reached 70%. Seven out of 10 people now survive from their cancer compared to less than 50% in the 1970s. On the other side, new changes have put a squeeze on funding for cancer research from governmental agencies. Financial toxicity continues to add to the burden of cancer patients. Ending on a bright note, daraxonrasib, benefits of GLP–1s' and new frontiers in artificial intelligence will hopefully continue the optimistically upward trajectory of cancer care and outcomes.

Professor Chandrakanth Are, MBBS, Surgical Oncologist University of Nebraska Medical Center (UNMC), Omaha, Nebraska, United States

Interview with Dr Anu Agrawal, former Vice President of Global Cancer Support at the American Cancer Society

Dr Anurag K Agrawal is a paediatric haematologist-oncologist and bone marrow transplant physician. He joined ACS in May 2024 to oversee the organization's global cancer support programmes which span the cancer continuum from cancer prevention to patient support and healthcare provider support.

He has a long history of global work. Most recently he was involved with the development of Southeast Asian Pediatric Hematology/Oncology (SEAPHO) in 2016, which is focused on strategic initiatives to improve paediatric cancer outcomes in Vietnam including initiating a two-year master's level training programme there since 2018 (ongoing). Prior to that, he was Medical Director of Paediatric Haematology/Oncology in Gaborone, Botswana as part of Texas Children's Cancer and Hematology Center from 2011–2012 and a Pediatric AIDS Corps Physician as part of Baylor International Pediatric AIDS Initiative from 2007-2008.

Anu has a Bachelor of Arts and Bachelor of Science degree from the University of Texas at Austin, USA and a Doctor of Medicine from Baylor College of Medicine.

The interview was on conducted on 22 April 2026. Dr Agrawal has susbsequently left the ACS and now works from Spain.

Cancer Control

Thank you very much for agreeing to this interview.

Anu Agrawal

My pleasure, thank you for inviting me.

Cancer Control

We think it's an important time to have this interview. You are the Vice President of Global Cancer Support at the American Cancer Society. First question: How did you get there?

Anu Agrawal

Many people come to me, as they surely do to many people in the global health space, to ask that question, "What is the path?" And there is no path. It's an unchartered path for a lot of the positions that we have, I think that we have to sometimes attribute the roles we are in to a little bit of luck, and timing. We all have attributes that compile… that allow us to get into these positions.

For me, it was really the juxtaposition of many things happening at the same time. I was mid-career as a paediatric oncologist, had spent several years working, largely in low- and middle-income countries in sub-Saharan Africa, as well as in Vietnam. So I was still doing that work, and had a very strong passion for that. But then our hospital was, going through a merger, which was very challenging for us. The general theme of the corporatization of healthcare in America, and the role of the physician is changing. So that led me to look for other opportunities, in many different industries, as well as in other institutions. I was fortunate to find this position was new as they were restructuring the global team at the American Cancer Society, and was fortunate to be selected.

Cancer Control

For those few people who might not know what the American Cancer Society is or does, could you tell us about the ACS?

Anu Agrawal

Sure. The American Cancer Society has been in existence for more than 100 years. It has three pillars. One is focused on discovery or research. It's the number one non-federal funder of cancer research in the United States. The second arm is the ACS CAN, or Cancer Action Network. This is the advocacy arm of the American Cancer Society and so very important; working from the grassroots, state to federal levels to influence policy that affects persons with cancer and family members or caregivers that might be affected by cancer.

And then the third arm, where our Global team sits, is within the patient support pillar where all of our activities are focused on supporting persons with cancer, and their family members. A lot of this is directed to patient resources in the United States, such as our over 30 Hope Lodges offering free accommodations; our Road to Recovery Program, which is ride assistance, and many other programmes, such as patient navigation. The Global Program has been in existence for multiple decades, with a similar idea of trying to support patients globally, similarly to what we do in the United States.

Cancer Control

In your present role what are the achievements of ACS that you are most proud of?

Anu Agrawal

When I was interviewing for the role, I was very impressed by the accomplishments of the team. For me, it's really been a matter of trying to grow that, and also to increase the dissemination of that. You know, sometimes you have people that are very altruistic, working in the space, and working quietly, doing amazing work, but not shouting it from the rooftops. I think that, in some of the discussions that we'll probably have about interconnectedness of the work that we do, that is one of my goals, to better showcase the work we're doing to both internally as well as external partners. We have a really amazing breadth and depth of work. We work with partners in over 70 countries, and I think a lot of people just don't know that. So, for me, that's really been the biggest thing that I've been trying to do; to showcase that amazing work that's already been happening.

Cancer Control

Liam Neeson, in one of his films, says he has "a special set of skills". I'm wondering whether there are the people who are really skilled at doing that quiet work and there are the people who are skilled at promoting and disseminating and going out, and that generally, you don't find them in the same person. Is that correct?

Anu Agrawal

That's true, yes. I think a lot of the skills that we have are innate. But then, of course, there's also the lifelong learning, and I think there's a lot of skills that we can acquire. I would say for myself, over my career moving from being a physician to being a physician leader, to being now a strategic leader you do take on new roles and responsibilities. I would not say I am naturally that type of person, but something that we really try to espouse within the leadership team is that is an important role that we play. Because as amazing as our work may be, if people don't know about it, and we can't get funding, etc, then it's not sustainable.

Cancer Control

We've talked previously about like the lack of interconnectedness – siloism, which is an ongoing problem. What are the other frustrations that you find?

Anu Agrawal

I was, very happy, and somewhat surprised when I started in this role as to how welcoming the community was of me as a new person, and the willingness to be collaborative. That has been a really amazing part of the work, and the opportunities for that are so large. But I think the frustration that I have, and I think many of us share, is that when we all go to meetings, where we have a great time, we meet, we convene, we collaborate, and we discuss opportunities. But then we all go back to our regular jobs, right? And a lot of those great opportunities to create more synergy and work closer together don't move from ideation to actualization. And I think that is really the biggest opportunity that we have.

I just went to a meeting last week of patient organizations; a really phenomenal meeting, very inspirational. But then at the end of the meeting, I was like, "Okay, well, what are the next steps to take this momentum forward and continue to work together when we have our regular jobs that take our time?" I think that's the biggest frustration for me. How do we actually move that discussion to realization, because there is already so much to do. I think that's part of the reason that everyone's so willing to collaborate. There's enough work for everybody.

Of course, there'll always be some competition for funding, which is understandable; Also, that point about having to have some notoriety in order to get funding, so there's always going to be that. You have to put your brand first. I think all those things can happen, but how do we actually start to work better together? I think it is happening slowly, but I think there is an opportunity to move that faster.

Cancer Control

Is it perhaps that, for many groups, we don't have enough people? I agree, we go to meetings, and during a chance conversation, one may suddenly realize, "This is an amazing opportunity! All the planets are aligned. We can do this now." But you actually need to go back and tell a gang of people "Right, we're going to do this." And that gang of people aren't there. We have so many opportunities but we can't realize them.

Anu Agrawal

No, that's true. The team jokes with me "You're going to this meeting, don't return with extra work for us!"

Cancer Control

You have also talked about making outcomes in low- and middle-income countries more achievable, and not to go chasing the perfect.

Anu Agrawal

Yes, I think it's the idea of chasing the shiny object, versus doing the things that are maybe less sexy, but will make the biggest difference for the least amount of money and with the highest

return on investment. So, I one hundred percent understand the desire to bring in innovative technologies and clinical trials, and that has to happen in parallel as the infrastructure improves. But the biggest opportunity is really to focus on prevention.

Forty percent of cancers are from modifiable behaviours and this is likely going to increase as countries become wealthier. There are still more than 1 billion tobacco users in the world, so, those are the opportunities that can make a huge difference without a lot of resources. Similarly, stage shifting for us is a key priority, as has happened in high-income countries. Most women now with breast cancer in the United States present with stage 1–2 disease where they're curable. Yes, there is the need for clinical trials and innovative therapies for patients, especially those that relapse or patients with certain underlying risk factors. But for the vast majority of patients, if you can get them to screening and early treatment, you can do that with relatively inexpensive, older drugs. And that, really, for us, is the other key. So that focus on the foundational principles – prevention, screening, early treatment – are really, for us, the opportunities, especially in our resource-limited environments, to make a huge difference in outcomes.

Cancer Control

Even within the wealthiest high-income country, there are pools, even large areas in some cases, of underserved populations, or difficult-to-reach populations. Does the ACS target those as well, as its global work?

Anu Agrawal

Yes, definitely, it's a key pillar for us, both domestically and globally. It's how we improve access for everybody, whether it's vulnerable populations or marginalized populations. There's many different ways to approach this and it can be done through all three pillars of the ACS. It can be done through research, it can be done through advocacy, and it can be done through direct-to-patient support.

We see that also engaging communities is a key aspect, especially when more and more you have to combat the negative messaging within social media and the misinformation, that is affecting vulnerable and marginalized populations. As much as you can, you engage the community, trusted members that can speak to that misinformation and guide the members of the community and provide them information in a trusted manner. I think that's really the key. And also patient navigation, is a key way to achieve that; in communities as well as at treatment facilities. I think that's really something that's been lacking: having somebody who looks like you, who has the same experience as you, that understands how you think and the way you speak, your language, I think those are really key ways to get back to the humanity of what we're trying to do and get people away from getting misinformation from their devices.

Cancer Control

I've often heard said that global work helps us do work at home. That getting to know other people's cultures – we're talking about immigrant populations now – going to the original host country, from whence they came, educates us and help us get a better understanding and appreciation of the situation at home. Would you agree? Or is that just us just saying that because it justifies Global Health?

Anu Agrawal

I agree. It's a two-way street that can be a win-win if we allow it to. I think for us here at the ACS, we have really tried to align the work and see the opportunities to learn bi-directionally. There's the phrase you've probably heard, "Think global, act local." That's exactly right. I think there's a lot of lessons that we can learn from the global work that can apply back to the local setting.

Previously there has been a lot of the "Let's take the learnings from the United States and apply them to the global setting", or we were working in silos separately. Now we're really focused on that exact point you made. It's "Well, if we have already made medical education materials for low- and middle-income countries, how can we use those potentially for immigrant or migrant populations in the United States who may need additional education?" I think that there's the opportunity to learn from lower resource environments and to apply it in higher resource environments, because there's resource limitations in all settings, and there's marginalized and vulnerable populations in all settings.

Cancer Control

Let's go back to what you were saying a few minutes ago. Health literacy is something that I think is going to increasingly become a buzzword. We've talked a lot about prevention and, we're always telling people what not to do and what not to do. Perhaps, we'd have an easier time of it if they understood this earlier, through school education, about how the body works, and what is good for it, and what's bad for it. There's no point turning up to somebody who's 35 and saying you should be doing more exercise. We seem to wait until the very last moment when we're on the point of crisis. If we're talking in terms of silos, education is often a silo quite distinct from Health, almost a separate planet, and it shouldn't be. They should be both interlinked.

Anu Agrawal

There's so many aspects to that that are important. You know, first and foremost, as a paediatrician our role is to start to

provide that education at a young age, and to prevent, for instance , people starting to smoke, and explaining why you should get the HPV vaccination, but it's very challenging when, first off, there's not enough physicians. Now, in the United States, you can use allied health professionals, physician assistants, nurse practitioners, nurses. community health workers, to start to fill those gaps. Here, you know, largely because the way the insurance system is, there's a propensity of specialists, but in primary care, there's not enough frontline workers. I think that's a problem globally, in low-resource settings, there are not enough frontline health workers and community health workers are asked to do so much with often no, or minimal remuneration. It's a very effective model that came out of HIV care, but how much can they be asked to do?

But you're right: the tenet of prevention has to start with education at a young age. I think the other factor that we're facing in the United States, and I think to an extent globally, but in America now, really it is a stark fact that 54% of adults read below the equivalent of a sixth grade level, and so you can imagine how that's going to impact on them.

Cancer Control
Sorry, what age group is that, just so that translates for non-US readers?

Anu Agrawal
It's about 11 or 12 years old.

Cancer Control
Okay

Anu Agrawal
So you have to consider how to provide education in a way that's understandable. We have a Learning and Development Manager now who's taught me a lot about adult learning, and how to deliver messages. Even Change Management Theory says that you have to deliver a message seven times in seven different ways in order to effect change. So imagine if you're the physician or the primary health worker: how are you going to achieve that?

There are a lot of challenges, but I think now, with technology I see so much opportunity for us to be able to deliver. At the same time, we've not really thought about how we can combat social messaging. I think that's something that the field really has to address because you can't respond to negative messaging with negative messaging. That's not the right approach. The problem is that the positive messaging just doesn't amplify the way negative messaging does. So that's really the big challenge.

Cancer Control
Do you think we're being outgunned on social media?
*

Anu Agrawal
Oh, a hundred percent. The algorithms… I'm sure you're aware of some of the landmark cases that have come through. It's great to see countries like Australia starting to ban social media for up to teenage years. I think they did it up to 16. And my hope is that we'll see more and more of that legislation. But I think, as we talked about before, so many of our challenges are based on, at the end of the day, corporate greed over health, which is multi-layered.

First and foremost, there's the insurance system, when a for-profit system should never exist when we're talking about healthcare. I think that's a challenge, and it's hard when you're profiting on another person's bad health. And then, of course, all the things that we're trying to prevent are really things that are developed through corporate greed, starting with tobacco which, after all these years is still developing new products. I started seeing these little pouches in the urinals in the bathroom, and I was like, "What are these?" And then I realized it's just another way to deliver nicotine.

Cancer Control
Exactly.

Anu Agrawal
So, we're faced with that challenge, and now with ultra-processed foods. There's probably some relation to seeing colorectal cancer, for instance, earlier now in younger populations. So I think that that, yes, we're by far outgunned, but… then again, I think there are a lot of opportunities, within the prevention space.

Cancer Control
It was very interesting to see at the UN high-level meeting on NCDs last September how the original draft of the Political Declaration had got watered down by industry pressure to take out criticism and remove warnings, reduce ambitions. We ended up with a "mild and watered" recipe, which was very disappointing. But it does indicate how powerful these forces are.

Anu Agrawal
Right, for certain. It highlights the challenge. As you said, we are outgunned, and we are definitely out-moneyed, by far. But we still have the moral compass, and I think that's the thing that's guiding all of us; that we are doing the right thing. We also see the end result. I think when you don't see the end result, you do not think about the consequences of your work. That's why

the patients' personal stories are so important. Those are the kind of stories that I think move people. None of the people that have contributed to that cancer are seeing that end point.

Cancer Control

You mentioned patient navigation. We've recently been talking to leaders from the Academy of Oncology Nurse and Patient Navigators, which has been interesting. Is patient navigation central to ACS's mission?

Anu Agrawal

The history of navigation really started with Harold Freeman, who was a physician in Harlem and also served as ACS president, and there was a strong linkage very early on with some of the studies he did showing the benefit in a low-resource population to access breast cancer screening and quality care. That work started, three or four decades ago, and has slowly grown, through all three ACS pillars, showing the evidence basis, largely in high-income settings and specifically the United States and Canada that supported advocacy for the passage of legislation in 2023 with reimbursement pathways through Centers for Medicare and Medicaid Services (CMS), and directly through our patient support activities, trying to help with capacity development and coalition building, both within the United States and globally through the National Navigation Roundtable in the United States, and the Global Alliance for Cancer Patient Navigation, which we formed last year to build awareness, consensus and sustainable implementation frameworks.

We talked recently with some of the Alliance Steering Committee members about our next steps in consensus-building. Patient navigation wouldn't need to exist in an ideal world if we had treatment where there was holistic care, and where we thought about all the needs of the patient and family as part of the workup, and provided them the resources to actually get through treatment, support their family, continue to gain an income. have appropriate survivorship care, palliation, etc. If you had all that you wouldn't need patient navigation.

Patient navigation is there because there are so many gaps in the way that care is provided. There's a lot to do, and if you're the physician, your training is focused on "Let's get the diagnosis, let's start the treatment, let's cure the patient…" But then, there's a lot of other factors that you don't get taught about; for example, the social determinants of health. You just take for granted that the patient's going to show up for their appointment. That they're going to figure it out, right?

I think this is changing now when we start to recognize that there's so much more that has to be accomplished for the patient and family to be able to get through treatment. Especially if we're thinking about marginalized, vulnerable populations, and also recognizing that treatment doesn't end when treatment ends, that the side effects continue, with ongoing follow-up, relapse, loss of job, etc. In paediatric patients, we know that if you had a paediatric cancer, your end-stage income and your career development is going to be affected. How do we provide support so you don't have lifelong effects, from your paediatric cancer treatment?

Patient navigation is really a process to try to identify those individualized barriers and to provide assistance or link to resources so that patients can have that holistic experience.

Cancer Control

This is like what we were saying at the beginning of this interview, about having different skill sets. You've got the clinical skill set, and then what we may call "the messy, everyday stuff". You're not going to find the same people to address both. Even if you did, they don't have the time. You can either be doing one thing or the other, but I wonder if this represents a maturing of the medical profession? The recognition that it's not enough to be a nurse or a doctor; patient care requires having all these other things as well, and that helps break down silos. Because you're saying "We've got to have other people in this, it's not just us."

*

Anu Agrawal

Right. And I think part of that also is seeing the stories as you go further in your career. Sometimes getting out of the ivory towers – same as for the politicians – getting down to the community level and seeing what the journey is for this patient by following in their footsteps and seeing all the things they had to do to even get to the appointment. When we get down to that granular level, where we can start to see all the other aspects and that's where patient advocacy organizations can help, and are getting more of a voice in, beyond just the ACS, to really be able to show that and tell that story. I do think with the Lancet Oncology's Commission on the Human Crisis in Cancer this is being highlighted. But we also recognize that resources are becoming more and more limited and care is getting more expensive. People are struggling more and more, and cancer incidence is going up. So, all these things are coming together at the same time.

And you're right, I think that anyone could provide patient navigation, but the physician is busy doing the diagnostic work-up and treatment, seeing a lot of patients, especially the adult oncologists. There can be clinical navigators, nurses, social workers, etc, or there can be non-clinical navigators, depending on the setting. It really just requires working out how do you develop a programme? How do you develop sustainability? How do you get reimbursement? How do you show the cost-benefit?

We've started to see the efficacy, but we still need more evidence to show the cost-benefit. These aren't extremely expensive resources, but you still have to pay, though not in all settings. In some low- and middle-income countries, it's volunteers, which is fine, but like community health workers, you would ideally like to pay people, provide them with a job, and with more respect as this is a paid position. So, I think there's still a lot to be figured out. But, to your point, in the ideal system these are things that would be provided for or thought of, and I think that's something that's happening slowly.

Again, I think technology is an opportunity to make that happen, too. Why shouldn't patients have a needs assessment at multiple time points during their treatment to say, "What are your needs? How are you doing with housing, finances, transportation?" Sometimes that gets done maybe once, or not at all, but now with technology, that's something that could happen relatively frequently, and we could then get the results back and really say "These are the key needs." We can't meet everybody's needs, but at least we can understand what the key needs are and try to address those.

Cancer Control

As a clinician dealing with childhood cancers, you will probably have had experiences of almost miraculous outcomes, against all odds, but also very tragic outcomes that have happened. Which, personally, weigh more heavily on you?

Anu Agrawal

Yes, it's a great question. Paediatric oncology is such a special field and we've made such amazing gains in the last five decades as far as outcomes are concerned. I look at my contemporaries, and I don't know if I could have done it 30 or 40 years ago, when most children didn't survive. I was lucky to come into a space when 85% of children, at least in the US setting, were surviving. Of course, we have a long gap in low- and middle-income countries still, where only 15–20% of children survive.

I think I was falsely reassured by that higher statistic. You never know whether you are emotionally prepared. When you do your Fellowship, you focus on the deaths, you focus on the bad outcomes. It's a human thing. There are also the unlimited opportunities, clinical trials, and innovative therapies, so you're always wondering, "Did I miss something? Was there something else I could have tried for this patient?"

That gets better as you age in your career and develop more expertise. You doubt yourself less and you also recognize there's a lot of things that are out of your control. That this is going to happen this way, and there's nothing you can do to change that. But I would say for most of us, it's the tragedies that stick with you. The good outcomes are great. We all have those miraculous cases. I can think of many that I'm just so happy that child survived, and it was a miracle. But I think the sad cases definitely weigh on you. And there's that cumulative effect that we all face, and I think this is a really key point. How do we support the workforce, especially in environments where most of the children aren't surviving? I think that weighs very heavily.

Cancer Control

I don't know what the situation was in America, but the mental effect of dealing with COVID, in wards where previously you might have expected one or two deaths a week, but suddenly you're getting eight deaths a day… It may have scarred a generation of young NHS doctors and nurses. Those were very dark days. We've almost forgotten them now, but those were dark days, and hard choices needed to be made. Certainly, a lot of cancer appointments were cancelled, weren't they?

Anu Agrawal

For certain, and you have to have a level of desensitization to survive. But there's a very fine point where you become too desensitized, and we all hear about these situations. "The doctor was very brusque", "The doctor had no bedside manner". That person may have just tipped over into burnout, and then unable to communicate with patients, and even making mistakes. I think we have to look at how do we support our colleagues in these environments, working in incredibly challenging situations. There's a lot of opportunities to bring that community together, to support each other.

Cancer Control

And it's quite healthy that health professionals are looking to their own health as well, and those of their colleagues. We're becoming gentler and far more understanding with colleagues who have just reached the limit.

Anu Agrawal

And I think it's the same even with the patients. We're able to talk about comprehensive care, holistic care, supportive care, patient navigation. Because now we have better treatments, more and more patients are surviving, so we can start, for instance, to think about how do we actually reduce therapies to decrease side effects? In the past, it was just like, we have to focus on cure or palliation. Now, I think we're at a place where we can start to think about the whole patient and the whole provider as well.

Cancer Control

Do you feel that we've reached a "This is the best of times. This is the worst of times" moment, where we actually have so many exciting breakthroughs now, and a greater understanding of

cancer, and at the same time, the degraded public services and the financial environment in which we work have become harder and harder to navigate and harder to deal with, so that they become the enemy of promise? I can't think of a time when it's been so positive on the one side, and so negative on the other. It's odd, isn't it?

Anu Agrawal

Yes. In the United States, the opportunity to be cured is higher than ever, but the disproportionality that we see now between the resourced populations and the vulnerable and marginalized populations is worsening. And then we're faced also with increasing cancer incidence, largely in low- and middle-income countries, which also disproportionately share the burden of cancer death; 70% of cancer deaths are in these settings. And they are going to be disproportionately impacted as populations age, without the requisite infrastructure. So, I think, yes, that's exactly right. We have so many riches and made so much progress, but COVID also, I think, was a big reason that we started to really look at this more, with evidence, too, to show that there are many populations that are lagging. And there's not really a good explanation based on biology. It's all of these other things that are impacting their ability.

Cancer Control

COVID uncovered a lot. I don't think there was one health system in the world that came out shining from COVID, to be honest. It revealed flaws in every health system. Turning to the question of financing do you think sin taxes might be one of the fiscal measures that should be adopted to help fund healthcare services?

Anu Agrawal

I'm fully in support of sin taxes. I think, again, going back to the theme of prevention and screening, that preventing the cancer is the cheapest way. If you can prevent the cancer, you're going to save the most money. I think also recognizing that without a public health insurance system, whether it's universal or not, you're going to continue to have disproportionality between those that have more resources and those with less, and so you can use a sin tax to also fuel your public health insurance for cancer care. I think that is a clear, evidence-based opportunity.

And in many of these low-resource settings, we're still faced with a lack of chemotherapy drugs. These are not expensive drugs, as we talked about, especially if you are able to stage shift patients, treat them at stages 1 or 2. Most of these are old drugs that should be cheap and readily available. If the system was set up where you had a sin tax, and public health insurance, and you could appropriately forecast, as other blocs like the European Union and Latin America have been able to do, and work together with other countries to develop pooled procurement models, you can negotiate and drive down the prices significantly and actually provide the drugs.

So, I think all of those things in tandem could make for a better system. We are seeing significant infrastructure improvements, but without improving access to the treatments we have not really moved the needle. I think that was where HIV served as an amazing example. Once the drugs became available at a very low price, the care was able to be provided, and I think that example can be used better with chemotherapy and other anti-neoplastics. Most of these are generics, they could be made in a regional fashion, as long as you can ensure quality.

So, I do think this is an incredible opportunity for low- and middle-income countries to work better together, and this would become a key, key aspect, in addition to the prevention and screening.

Cancer Control

We're coming to the last quarter of the interview now and I'd just like to pick up on a couple of additional points. Given the opportunity what corrections would you like to make when you hear people in government talk about cancer, or other NCDs?

Anu Agrawal

I think first and foremost making it a clear national health priority. Cancer should be the number one national health priority. It will become, if it's not already, in most settings, the number one killer and so it should be viewed as such.

I think the other thing is that it also has to always be framed with hope. In many settings, in low- and middle-income countries, there's not that feeling of hope where you can receive treatment and be cured. And in many settings cancer is still stigmatized. People don't talk about cancer openly because of the stigma surrounding it, and the belief that you have cancer because of something you did. I think that is a huge problem. We even see this with, for instance, getting people to lung cancer screening. If you're a smoker, then you don't willingly go for your screening. So, I think we have to separate out that. Yes, of course, there are modifiable risk factors, but nobody's perfect. I'm not perfect, you know? We all do things that are imperfect, we're human. Shifting the blame away from the person or their situation is part of that destigmatization.

I think those are all ways that policymakers can also frame how we really tackle cancer. If you talk to the person with lived experience and the framing that they want, it's very different, too. They don't like the "War on Cancer", or perhaps "The Cancer Journey". It's "Well, I'm still living my life. I'm not on a journey, I'm not on a trip, I'm still doing normal things,". So,

involving persons with lived experience is very important.

And I think, again, the focus should be on the fundamentals: prevention; screening; getting people to treatment earlier; providing that front health workforce that can really start to provide education. We used to do public service announcements. I don't seem to see those anymore, but those are the types of things that can make a difference. And that's also partly on the healthcare professional. How do you frame the message as a positive message to say. "You should go for screenings so we can pick something up early when you can still be cured?"

There are other creative means, too. Do you make it part of a technological assessment? Where the patient gets assessed, and then it spits out, "These are the things you need to get done?" It makes it more of an objective statement. Yes, it's depersonalized a little bit, but also destigmatized. Like, everybody in your situation gets these tests.

Cancer Control

Two last questions. The first is unmet goals. Do you have any personal goals yet unmet that you would really like to achieve?

Anu Agrawal

Many, many unmet goals! I think that we have so much more to accomplish in this space.

I think, first and foremost for us, it is pivoting the way we work. Our team has spent many years on the ground working in low- and middle-income country settings. They have really done a lot of deep in-country work, but we're at a place now where the way we work is shifting very rapidly. Some of that also has come out of COVID and of course funding has really dried up. So, the way that we work has to change and pivot. There's also the opportunities with technology. How do we deliver support? How do we empower local organizations more in a sustainable manner?

Stripping all the funding, ripping off the Band-Aid was not the right solution. But, at the same time, we cannot continue in an environment where we create dependencies, where there's an expectation of "I'm going to continue to get funding, right?" Of course, there is the understanding that these are lower resource environments, but there are ways, like sin taxes, etc., by which you can start to create self-sustainability.

There is an opportunity for us, as we change how we work because of lower resources, to really think about how do we maximize the resources that are available? How do we support the local organizations, especially now that we've had two decades, really, of building upon an HIV infrastructure? And infrastructure is much better now than it was two decades ago. Being able to tackle cancer care is more achievable, whereas even a decade ago, it seemed very, very hard. Of course, there's still lots of challenges.

That, for us, is the largest change that we are trying to accomplish. We need to do a lot. There's a lot of places that need help. We have a lot of technical expertise and we have a lot of great resources. How do we start to deliver those more broadly? How do we use technology to provide accurate translations? How do we connect to the right partners?

I was thinking this morning, I found another organization yesterday that I hadn't heard of, and I was like, "Oh, that's a great organization that I would love to work with." There's an innumerable number of organizations. How do we create a system where we can better know who's doing what, where, and work in a more interconnected fashion? Even having a database of all the organizations that are in this space in each country, in each region just to proactively be able to say, "I'm thinking about this project. I work with these civil society organizations, (CSO) partners, in this country or region. Who else is there doing this work, or who has resources, or who can partner with us?"

Cancer Control

Everybody wants that. This is something that's really needed, because it's to do with a basic level of knowledge that has already been met in other sectors years ago. The financial sector, for example, take such things for granted. You have a spreadsheet and database of who's involved in mining, or whatever, providing full market knowledge. But with healthcare, we're 30 or 40 years behind, hampered by a chronic failure to invest and share information.

Anu Agrawal

This is where technology provides us the opportunity to create a more equitable playing field. I recognize that there is the danger of creating even more of a digital divide, but I see it as an incredible opportunity to use technology to very rapidly create these systems in an automated way that wasn't possible before. To take us to a place where, rather than me meeting you at a meeting in a random chance encounter, like you described, and us thinking "We can work together", that, in a much more proactive fashion, we get that information. And the voice, together, whether it's across cancer organizations, across disease states; that powerful voice that we have together. We've never really been able to activate that to the level that we need. So, for me, that is the largest untapped opportunity. My team sometimes laughs at me because they think it's too idealistic but for me, that's the legacy project.

Cancer Control

Well, there are countries who will willingly join you if we can get the money together. Because when people say, "That's

too idealistic!", you should say to them "Well, this level of community knowledge exists in stocks and shares, it exists in air travel. You can just press a button, and know who is doing what, where, and how, and you don't think anything about it, But in healthcare? What's our problem? Do you know?"

Anu Agrawal

It's been forced upon us now with the resource limitations. We need to think smarter and innovate around how we work in these settings, and how we work together. I think that it's going to push us in that direction. Technology is the other piece that fills the circle of actually being able to move that from Ideation to realization, as we talked about at the beginning, with the frustrations felt after being at a conference.

Cancer Control

But it's still all worthwhile, yes?

*

Anu Agrawal

No question. Yes, I think that if you are in a place where you're finding meaning in the work. It always comes down to the person at the end of that journey, whether you're able to provide some support and make their life different and better in some way, albeit small. We always try to think about those people that we're able to connect to services, and to highlight those stories. That always helps us continue to show the value and impact of our work and the meaning of it.

It's different, I think, in being in this type of role. As a physician, you get the direct gratification, you see the patient. You know, hopefully they get better. It's very different in a public health role where there's a significantly delayed gratification. But, yes, I agree, it's so important, the work that we're all doing together.

Cancer Control

Thank you so much for speaking to us. I think we can both agree we're in for the long haul.

Anu Agrawal

We are in for the long haul, for sure. I think there are innovative technologies that could prevent cancer, like a vaccine. And there's innovative technologies as to how we can eventually treat with a pill. But will those be equitable? Will those be available to everybody across the globe? I think in a capitalistic environment, the answer is "No", so there will always be lots to do. ■

Transcribed by Mark Lodge on 23 April 2026 using Zoom Pro Cloud transcription.

GLOBAL ISSUES

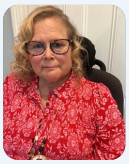
Navigating uncertainty: NCDs in a new era of global health

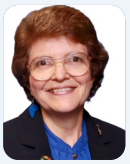
Katy Cooper, Chair, UK Working Group on NCDs; **Kendra Chow,** Senior Policy and Public Affairs Manager, World Cancer Research Fund International; **Stephen Connor,** Executive Director, Worldwide Hospice Palliative Care Alliance; **Helena Davies,** Palliative Care and NCD Advocate; **Julia Downing,** Chief Executive, International Children's Palliative Care Network; **Christine Hancock,** Founder and Director of C3 Collaborating for Health; **George Hayes,** Global Partnerships and Advocacy Manager, Cancer Research UK; **Katie Jakeman,** Policy Advisor, Age International and **Antonis A Kousoulis,** Director of Partnerships, United for Global Mental Health

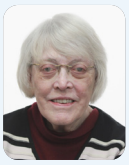

KATY COOPER


ENDRA CHOW


STEPHEN CONNOR


HELENA DAVIES


JULIA DOWNING


CHRISTINE HANCOCK


GEORGE HAYES


KATIE JAKEMAN


ANTONIS A KOUSOULIS

This article updates "The 2025 UN High-level Meeting on NCDs and mental health: The art of negotiation", published in Cancer Control 2025. It explains the challenges facing implementation of the Political Declaration that accompanied the High-level Meeting, within the context of a rapidly changing world as reflected in the ongoing discussions on reform of the structures and financing of global health. Positioning NCDs at the heart of this reform is a core challenge for all advocates of better cancer prevention and treatment.

Setting the scene

Cancer is one of the five main conditions that the World Health Organization (WHO) includes within its "NCDs" agenda, alongside cardiovascular disease, diabetes, chronic lung disease and mental health conditions. These commonly share five major risk factors: unhealthy diet, tobacco use, physical inactivity, alcohol use and air pollution.

The fourth UN High-level Meeting (HLM4) on Non-communicable Diseases (NCDs) and Mental Health, held in 2025, brought together governments to secure commitments, build political will, and attract increased funding *(1)*.

The article last year set out the process leading up to HLM4. The accompanying Political Declaration on NCDs and Mental Health (PD) *(2)* was negotiated amid fiscal pressures, geopolitical tensions and sustained commercial lobbying, which led to the weakening of commitments on prevention, risk-factor regulation, accountability and equity. Securing its approval was a significant achievement in an increasingly contested global health environment, and civil society played a vital role in ensuring that the final PD retained a meaningful baseline of ambition.

This article brings things up to date, discussing the challenges in making the PD a reality and the changes in wider global health that will have repercussions for NCDs including cancer.

Progressing the Political Declaration: Slow steps forward

The months immediately following HLM4 were critical. The PD was expected to be adopted by consensus in September 2025, but last-minute objections from the United States and Argentina meant it was referred to the UN General Assembly for a formal vote. In December, it was adopted with overwhelming Member State support, showing that objections were isolated and that broad global commitment to action on NCDs and mental health remains strong.

The PD is the first to address NCDs and mental health together and includes new global targets to be achieved by 2030: reducing tobacco use, improving hypertension control and expanding access to mental health care. However, it has also been criticised for leaving several areas of comprehensive NCD care weakly addressed or largely neglected. These gaps matter because effective prevention, treatment, care and long-term support require a broader health-system response than the PD fully reflects (see Box 1). The PD is not the ceiling for ambition. Instead, it is a foundation for integrated, equitable action throughout life.

Advocacy since HLM4 has continued to underline the importance of ensuring governments translate global commitments into equitable, inclusive national policy and financing. Momentum carried into the 79th World Health

Assembly (WHA) in May 2026. Obesity and mental health featured more prominently on Member State agendas, and prevention was discussed more frequently, though often at a conceptual rather than operational level. Health should be considered an investment and not a cost: that "health is wealth" was reflected in WHA's adoption of the Economics of Health for All strategy *(3)*.

Lessons can be drawn from this year's HIV High-Level Meeting, where community leadership, rights-based approaches and accountability took centre stage (4). Meaningful engagement of people living with and affected by HIV is central, as it has been for many decades. The NCD agenda should draw from this model: communities and civil society must be resourced not only as advocates, but as essential partners in service delivery and accountability.

Moving from commitments to investment to implementation to impact is now the question civil society must keep pressing – within health, and increasingly, beyond it.

Taking NCDs forward

Global NCD processes

A forthcoming crucial step is the Third International Dialogue on Sustainable Financing for NCDs and Mental Health, due to be held in Manila in February 2027 (postponed from September 2026 to allow the Philippine Government more time to prepare) *(17)*. For governments, this Dialogue is the "how" to the Political Declaration's "what": it has been described by the Philippine Government as the "structure" to deliver on the HLM, and the aim is for it to deliver a series of practical steps to ensure robust financing for addressing countries' NCD burdens. A "Manila Declaration" is proposed, which will be a recommitment to UHC, financial protection and equitable access to services. It also hopes to expand on the PD by including opportunities presented by the loss of patent-protection for multiple high-impact medicines (including GLP–1s). A regional compact on improving countries' access to health products and services is planned, along with a Sustainable Financing Toolkit, and a range of country commitments on implementation and reform.

But the continuing marginalization of civil society is a concern – and one can but hope that the postponement of the Dialogue is taken as an opportunity for better inclusion of civil society and people living with NCDs. The global NCD community continues to have a critical role to play in holding governments accountable for their commitments – but this remains challenging if non-governmental voices are largely excluded from these important policy processes.

Another important moment for NCDs will be the Third HLM on Universal Health Coverage in 2027 *(18)*. At a time of seismic shifts within global health, this is likely to be a heavily contested Political Declaration – but with the growing burden of NCDs globally, it is crucial that gaps in NCD care are closed, preventive measures are scaled up, and NCD services are properly integrated within primary healthcare. A UHC PD that sets the tone for governments' priorities into the 2030s cannot afford to neglect NCDs.

Box 1: What is missing? Persistent gaps in the NCD agenda

Several key areas remain insufficiently integrated within the Political Declaration and the NCD agenda more broadly.

- **Mental health** continues to face chronic underfunding and limited-service capacity *(5)*.
- **Oral health** is critical to overall health and well-being, but is often neglected and health systems are not able to provide the care needed. The impacts and costs of poor oral health are felt most acutely by those living in marginalized communities, but prevention is low-cost and effective *(6)*.
- The population of people living with **advanced HIV disease (AHD)***(7)* is ageing and living with varying degrees of impaired immune functioning *(8)*. HIV has long been associated with certain cancers, and there is now increasing multi-morbidity and overlap of chronic care needs between AHD and conditions such as diabetes, heart failure, dementia and chronic lung disease.
- **Rehabilitation** is essential for maintaining function and quality of life, and **palliative care** is critical for people living with advanced or life-limiting conditions. More than three-quarters of the global need for both is in low- and middle-income countries, where fewest services are available. An estimated 2.4 billion people could benefit from rehabilitation *(9)* and over 73 million patients could benefit annually from palliative care services *(10)*, including more than 10 million children *(11,12)*.
- The management and impact of **pain** is a major problem as 80% of countries have such overly restrictive limitations on the use of pain relief that it is unavailable *(13)*.
- **Meaningful engagement of people with lived experience** remains poor across the whole of NCDs and mental health *(14)*.
- **Commercial determinants of NCDs** remained a serious and under-addressed concern. Health-promoting (and NCD-preventing) fiscal and cost-effective "Best Buy" policies (for example, on sugar-sweetened beverage taxes) were diluted or removed entirely in the final PD *(15)*, and language such as to "encourage" or "consider" some key policies was used, rather than "commit". Health-harming industries lobbied and sought meetings with governments throughout the negotiation process, and the final version of the PD seems in places to favour protection of the profits of these industries over that of public health. This is not new. The previous three HLMs on NCDs policies on alcohol, tobacco and unhealthy foods had the lowest levels of implementation, and one-third of these policies was reversed *(16)*.

Changes in the structures and funding of global health

Beyond NCDs, the geopolitical shifts that have seen defence

Box 2: An Africa-led agenda

Two recent transformation efforts have had their genesis in Africa and are having a powerful influence on the direction of travel in global health. The Lusaka Agenda (2024) is the output of a series of consultations on ways to reshape the financing of global health *(21)*. It includes calls for the major global health institutions to strengthen their support for integrated primary care (going beyond their traditional silos) and for a transition towards domestic resourcing for health. The Accra Reset (2025) focuses on external development assistance more broadly (with health as a vital starting point), calling for a shift from the aid model to an investment model *(22)*.

Box 3: What can you do?

- **Stay informed and stay connected.** There are international networks that exist to keep implementation moving when the global picture stalls. In the UK and beyond, these include the NCD Alliance, the UK Working Group on NCDs, the UK-Ireland Global Cancer Network, HearCSO, and the Global Mental Health Action Network. Whatever your role – clinical, research, policy – use them: HearCSO's regular surveys and consultations, GMHAN's Advocacy Roadmap *(23)* and evidence such as the new WHO Global Status Report on Cancer *(24)*.
- **Build on existing lived experience expertise,** in which cancer and mental health both have strong traditions. The harder task is a collective one. NCDs are a disparate group of diseases, and advocacy that speaks with one voice does not assemble itself. We now have a strong guide: the WHO Framework for Meaningful Engagement *(14)*. Press for lived-experience representation on boards, task forces and government delegations, and remember that the power for securing a seat cannot rest with people traditionally excluded from decision-making.
- **Make your voice heard.** Locally, within your community, or through international campaigns such as World Mental Health Day, Universal Health Coverage , World Hospice and Palliative Care Day and the annual Global Week for Action on NCDs *(25)*.
- **Finally, integration is not only a policy demand.** Cancer, for example, rarely arrives alone; it comes with comorbidities, including other NCDs, and takes a toll on the mental health of patients and families. To the extent possible and appropriate, protect the factors that matter – movement, good nutrition, connection, not smoking or drinking alcohol – in the systems that we run and in our own lives. Those of us in the sector should lead by example. Every family is touched by NCDs. This is not someone else's agenda. It is everyone's business – and it starts, quietly, with us.

spending prioritized at the expense of development assistance have led to a steep decline in donor contributions. This is forcing a complete rethink of the funding and structures of the global health architecture (GHA) – namely, the roles of different health agencies, their governance structures and how they are financed. The current GHA was developed in an era in which infectious disease and childhood and maternal health were principal health concerns. The Sustainable Development Goals recognized in 2016 that this focus was too narrow (including an SDG target on NCDs), but the surrounding GHA has not yet adapted to changing epidemiology and demographics. NCDs should be at the heart of the GHA – but have, to date, been under represented.

Now, however, the world is being forced to do more with less. Providing assistance on only one disease at a time is not cost-effective and does not effectively benefit those most in need. Instead, integration must be at the heart of any reforms. This approach was strongly highlighted in the PD – although it fell short of its promise by setting a process target for mental health (access to care) and outcome targets for NCD risk factors, when the aim should be true integration of prevention and care across the lifecourse *(19)*.

There are several responses to the crisis running in parallel (see also Box 2). At the level of UN agencies, a WHO-coordinated Joint Task Force (comprising governments (including the UK), UN agencies and the major funders – but with no formal seat at the table for civil society) is developing a process for a new approach to global health *(20)*.

This is a crucial moment: how the cards fall will dictate how NCDs fit into funding and global structures for years to come. But many questions remain to be answered:

- Will reform be the needed root-and-branch changes, or merely tweaking of existing systems?
- Will power and decision-making be re-situated with national governments rather than with donors?
- Will health funding be rebalanced towards areas of greatest need – including, increasingly, NCDs and mental health?
- Crucially, how will the views and voices of civil society and people with lived experience be included, both within the ongoing processes and within the final, reformed architecture?
- Decisions should be made with input throughout from those whose lives depend on those decisions – among them, the millions of people living with and at risk of NCDs including cancer.

The future of NCD advocacy

The PD hands the NCD and cancer communities a real lever for advocacy. It also arrives in a fracturing world, with donor commitments cut, health systems at risk of backsliding and multilateralism itself being renegotiated. The Declaration is only as strong as the implementation behind it, and the political weather is against progress.

The honest response is neither despair nor toxic positivity.

Advocates should concentrate on what we have and get it implemented, including guarding against the pessimism that paralyses: aspiration and realism are not opposites here. And the real work will be in the accountability. The PD's targets are new, but the older ones are already being missed, and national targets matter as much as global ones. The next Financing Dialogue has produced commitments; the question is who returns to them in three years and asks what was delivered. That is a role that belongs to everyone in our field (see Box 3). ■

Kendra Chow is Senior Policy and Public Affairs Manager at World Cancer Research Fund International. She is a global health and public health policy specialist, whose research focuses on NCDs, commercial determinants of health, and health inequities. She is a registered dietitian with an MSc in Public Health (London School of Hygiene and Tropical Medicine).

Dr Stephen Connor is Executive Director of the UK-based Worldwide Hospice Palliative Care Alliance with over 500 organizational members in 122 countries, which is in official relations with WHO and in consultative status with the UN. He has worked in the hospice/palliative care movement since 1976 as a clinician, educator, and executive.

Katy Cooper has 20 years' experience in global NCD prevention, as assistant director for C3 Collaborating for Health and now as a freelance consultant specializing in advocacy/policy writing and strategy. Her clients include the WHO and she also chairs the UK Working Group on NCDs.

Dr Helena Davies is a lived-experience NCD and palliative-care advocate, until recently advocacy officer for the Worldwide Hospice Palliative Care Alliance. She has worked with the WHO in the field of lived experience. Before having to take ill-health retirement, she was a consultant paediatrician and medical educator.

Professor Julia Downing is an experienced palliative care nurse, advocate, educationalist and researcher. She is Chief Executive of the International Children's Palliative Care Network with members in >150 countries, which has an MoU with the WHO. She has appointments at universities in Africa, Serbia and the UK. She has worked within palliative care for 30+ years, working closely with governments around the world for palliative care development.

Christine Hancock is founder and director of C3 Collaborating for Health, working globally focused on prevention of the main risk factors. An experienced clinician and manager in the UK NHS, she led the Royal College of Nursing and then the International Council of Nurses. C3 has recently developed programmes in oral health in Africa and India.

George Hayes is Global Partnerships & Advocacy Manager at Cancer Research UK. He has well over a decade of experience in global health, in roles spanning advocacy and policy engagement, programme management and communications. George has an MA in Human Rights from University College London.

Katie Jakeman is a Policy Advisor at Age International, working on ageing, global health and humanitarian issues. She leads advocacy and research to ensure older people's voices are heard in international development and crisis response. Katie is committed to promoting inclusion, equity and dignity for people of all ages.

Dr Antonis A Kousoulis is the Director of Partnerships at United for Global Mental Health and leads the Global Mental Health Action Network, a community of over 10,000 advocates from 170 countries. He is a public health specialist with over 10 years' senior executive experience across the not-for-profit sector, government and academia.

References

1. WHO. HLM4: On the road to 2025 and beyond. Geneva, updated regularly https://www.who.int/teams/noncommunicable-diseases/on-the-road-to-2025
2. WHO. Political declaration of the fourth high-level meeting of the General Assembly on the prevention and control of noncommunicable diseases and the promotion of mental health and well-being. Geneva, 2025 https://www.who.int/publications/m/item/political-declaration-of-the-fourth-high-level-meeting-of-the-general-assembly-on-the-prevention-and-control-of-noncommunicable-diseases-and-the-promotion-of-mental-health-and-well-being
3. WHO. Draft Strategy on the Economics of Health for All (WHA A79/5 Add.1) 2025 https://apps.who.int/gb/ebwha/pdf_files/WHA79/A79_5Add1-en.pdf
4. UNAIDS. The 2026 UN Political Declaration on HIV/AIDS: Accelerating progress towards ending AIDS as a public health threat. 29 June 2026. https://www.unaids.org/en/resources/presscentre/featurestories/2026/june/20260629_HLM_PD
5. United for Global Mental Health. No Health without Mental Health. A Mental Health Summary of the Political Declaration of the UN High-Level Meeting on Noncommunicable Diseases and Mental Health. 2025 https://unitedgmh.org/app/uploads/2025/09/No-Health-Without-Mental-Health-2025.pdf
6. WHO. Draft Global Oral Health Action Plan (2023–2030). Geneva, 2023 https://cdn.who.int/media/docs/default-source/ncds/mnd/oral-health/eb152-draft-global-oral-health-action-plan-2023-2030-en.pdf
7. Rangaraj A, Connor S, Harding R, et al. Advanced HIV disease and health related suffering - exploring the unmet need of palliative care. *Lancet HIV* 2023;10(2):e126–33 https://doi.org/10.1016/S2352-3018(22)00295-8
8. Justice A, Althoff K, et al. The Lancet HIV Commission on ageing and HIV: a global perspective. *The Lancet HIV Commissions* 2026; 13:8e569–e610 https://doi.org/10.1016/S2352-3018(26)00058-5
9. WHO. Rehabilitation. Geneva, 2024 https://www.who.int/news-room/fact-sheets/detail/rehabilitation
10. Knaul F, Bhadelia A, Kwete XJ, et al. The evolution of serious health-related suffering from 1990 to 2021: an update to the Lancet Commission on Global Access to Palliative Care and Pain Relief. *The Lancet Global Health* 2025;13:e422–36 https://doi.org/10.1016/S2214-109X(24)00476-5
11. Downing J, Knaul FM, Kwete XJ et al. The global need for paediatric palliative care: the evolution of serious health-related suffering in children aged 0–19 years from 1990 to 2023. *Lancet Child Adolesc Health* 2026;10(3):167–78 https://doi.org/10.1016/S2352-4642(25)00338-4
12. International Children's Palliative Care Network, Close the gap: palliative care for children everywhere, 2026 https://icpcn.org/close-the-gap/
13. Rosa B, Knaul FM, Touchton M, et al. Towards opioid access without excess. *Lancet Public Health.* 2025;10(5): e422–7 https://doi.org/10.1016/S2468-2667(25)00035-0
14. WHO, *WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions.* Geneva, 2023. https://www.who.int/publications/i/item/9789240073074
15. NCD Alliance. Political Declaration of the High-Level Meeting on NCDs and Mental Health: NCDA Priority Asks – Rev. 3, 2025 https://ncdalliance.org/sites/default/files/2025-08/ncda_rev.3_priority_comments_final.pdf
16. Akselrod S, Collins TE, Berlina D, Collins A, Allen LN. The impact of UN high-level meetings on non-communicable disease funding and policy implementation. *BMJ Global Health.* 2023;8:e012186 https://doi.org/10.1136/bmjgh-2023-012186
17. WHO. Third International Dialogue on Sustainable Financing for NCDs and Mental Health, 2026. https://www.who.int/news-room/events/detail/2027/02/16/default-calendar/third-international-dialogue-on-sustainable-financing-for-ncds-and-mental-health
18. UHC2030. UN High-Level Meeting on Universal Health Coverage 2027. https://www.uhc2030.org/advocacy/un-high-level-meetings/un-high-level-meeting-on-universal-health-coverage-2027/
19. Vinko M, Collins T, Kousoulis A. A path to true integration: making global mental health commitments a national reality. *Slovenian Journal of Public Health.* 2025;64(4):178–80 https://doi.org/10.2478/sjph-2025-0023
20. WHO. Reforming the global health architecture, 2026. https://www.who.int/about/governance/global-health-architecture
21. UN Foundation. Lusaka Agenda explained. 2024. https://unfoundation.org/what-we-do/issues/global-health/global-health-resource-center-2/lusaka-agenda-explained/
22. Accra Reset. 2025 https://accrareset.org/
23. Global Mental Health Action Network. https://gmhan.org/2026-roadmap
24. WHO and International Agency for Research on Cancer. *Global Status Report on Cancer 2026: The Future We Choose Together. 2026*, Geneva. https://iris.who.int/handle/10665/386576.
25. NCD Alliance. Global Week for Action on NCDs. https://ncdalliance.org/about/our-work/global-week-for-action-on-ncds

Commonwealth needs Commonhealth: A personal view

Mark Lodge, Commissioning Editor, *Cancer Control 2026* and member, Lancet Oncology Commission on Cancer in the Commonwealth

In a few months time the Commonwealth's Heads of Government (CHOGM) will meet in St John's, the capital of Antigua and Barbuda (CHOGM 2026, 1–4 November 2026). As a voluntary association of 56 independent national governments representing a total population of 2.7 billion people, the Commonwealth already carries a disproportionate share of the global burden of cervical cancer *(1)*. In February 2023, with the support of the then Commonwealth Secretary General Baroness Patricia Scotland KC, a *Lancet Oncology* (LO) Commission on Cancer in the Commonwealth was launched as a working collaboration between Lancet Oncology and the Commonwealth Secretariat, with the remit to explore how Commonwealth member states could respond individually and collectively to the challenge posed by cancers.

Over the past three years the LO Commission has engaged closely with the Commonwealth Secretariat and with Commonwealth countries, including holding interviews with senior officials of the Secretariat and with focal persons for health. A two-day meeting hosted by the Commonwealth Secretariat at Marlborough House in London facilitated the participation of civil society and Commonwealth professional associations and included a roundtable discussion with leadership and members of the Commonwealth Advisory Committee on Health (CACH). Commission members participated in the Commonwealth Ministers of Health Meetings in Geneva, Switzerland, in 2024 and 2025 and the Commission's preliminary findings were trailed at the inaugural Commonwealth Health Coordination Forum in Geneva on 16 May 2026.

The Commission's work includes a new analysis of the costs of scaling interventions, incorporating estimated health and economic benefits and projected returns on investment. It addresses the need for raising levels of health literacy and quantifies the direct and spillover effects of cancer control investments in adjacent economic sectors and the induced effects on Gross Value Added to Commonwealth economies. The LO Commission is now ready to report but informed sources suggest that it will struggle to gain a hearing in front of the Commonwealth Heads of Government when they meet in November. Why should this be?

Part of the reason is the new Commonwealth Strategic Plan 2025–2030 *(2)* that Commonwealth governments hurriedly endorsed in September 2025. The new Strategic Plan, which carries a Foreword by the Commonwealth's new Secretary General, the Honourable Shirley Botchwey, focuses on three policy pillars: building democratic, economic, and environmental resiliencies. Plans for a fourth policy pillar of social resilience (i.e. strengthening health and education, Commonwealth Core Value 11 declared in the Commonwealth Charter of 2013 *(3)* see Panel 1) has been ditched and the dedicated support team within the Commonwealth

Panel 1: The Commonwealth's Core Principles and Values

1. Democracy
2. Human Rights
3. International Peace and Security
4. Tolerance, Respect and Understanding
5. Freedom of Expression
6. Separation of Powers
7. Rule of Law
8. Good Governance
9. Sustainable Development
10. Protecting the Environment
11. Access to Health, Education, Food and Shelter
12. Gender Equality
13. Importance of Young People in the Commonwealth
14. Recognition of the Needs of Small Island States
15. Recognition of the Needs of Vulnerable States
16. The role of Civil Society

Source: The Commonwealth Charter 2013
https://thecommonwealth.org/charter

Secretariat reduced. Instead, the Plan promises "a new focus on partnerships with international organizations and Commonwealth-accredited organizations, to help address the needs of member countries in areas like education and health" *(2)*. In lay terms, this means that life-saving collective action on health and education by Commonwealth governments is off the table.

It is fair to say that the Commonwealth's new recipe for resilience has caused dismay and puzzlement in equal measure. How can democracy be safeguarded without first having an educated electorate? Have not the COVID-19 pandemic, the resurgence of Ebola, the rising cost of treating NCDs and the global shortage of trained health workforces shown the power of ill health to disrupt national economies? Allegedly, the three new policy pillars will be underpinned by Commonwealth Core Value 12 (gender equality), 13 (youth empowerment) and 14 (support for small and vulnerable states) *(3)*. Along with the limited time originally allowed for consultation, it is this arbitrary cherry picking from the basket of Commonwealth Core Values that has caused concern among the wider Commonwealth family. As David Jones, Chair of the Independent Forum of Commonwealth Organizations, warns "The failure to recognise the centrality of social policy to the achievement of the three pillars leaves the impression, perhaps inadvertently, that the Commonwealth is not really interested in the daily lives of its peoples."*(4)*.

This echoes the anxiety expressed elsewhere in this edition of Cancer Control by HRH Princess Dina Mired as to whether there isn't a fundamental mismatch between what governing structures (in this example, the Commonwealth governments) like to incentivise and what a healthy society needs? "People everywhere want the same fundamentals: to live healthy lives, to protect their children, and to know that if illness strikes, they will receive the care they need. The appetite is there. The real question is whether our political and economic systems share it…." *(5)*.

The Commonwealth's swerve is in line many (but not all) liberal democracies in pursuit of prosperity and economic growth. Clearly the job of government in the 21st century is not enviable. Unstable global economic conditions caused by volatile foreign, (i.e. non-Commonwealth) presidents, mounting sovereign debt, geopolitical inequity, and worsening climatic conditions have had an understandably chilling effect on conventional mindsets intent on maintaining the status quo. Building resilience in democracy, the economy and how we deal with extreme climate change are all laudable objectives but most cancer deaths in Commonwealth countries are due to a failure of equity rather than medical failure.

Good health and an educated population are not luxuries; they are necessary factors for economic growth. Pandering to market forces and following a path that leads to brushing off human suffering and aspirations as inconsequential compared with profit and greatness does little to address persistent inequities. Access to health and education are not only human rights declared generations ago by the United Nations (6); they are the day-to-day concerns of citizens in all countries, who are less interested in parliamentary procedure and advantage and more interested in their family's future. Cancer is one of the four or five conditions grouped under the label "non-communicable diseases" (NCDs) that impose substantial economic and social costs, reducing productivity, increasing health expenditure, and constraining economic growth *(7)*. Elected leaders striving for sustainable economic growth cannot afford to ignore these realities.

HM King Charles III, who is the Head of the Commonwealth, recently quoted Shakespeare's play The Tempest "What's past is prologue" *(8,9)*, to which one should add George Santayana's warning "Those who cannot remember the past are condemned to repeat it" *(10)*. Article V of the 1978 Ala Ata Declaration states that Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures *(11)*. Through its Good Offices and its convening power the Commonwealth has a unique role to play in helping its members do their duty.

To quote Tancredi Falconeri "If we want things to stay as are, things will have to change" *(12)*. Health and education need to be visible as valued cross cutting issues that cut across the three pillars of the Commonwealth's new Strategic Plan, with their oversight demonstrably being the business of the Offices of the Heads of Government and of a properly funded Commonwealth Secretariat. CHOGM 2026 is the reset that provides the Commonwealth leaders with the opportunity to reaffirm all the fundamentals of the 2013 Commonwealth Charter. They can do this by extending an invitation to the authors of the Lancet Oncology Commission on Cancer in the Commonwealth to present their important findings to the Heads of Government in St John's. A reset that starts with the passive suppression of significant expert evidence does not bode well. ■

Mark Lodge is a consultant systematic reviewer specializing in cancer and the immediate past Chair of the UK & Ireland Global Cancer Network (2024-2026). He has provided technical advice to the NHS, European Investment Bank and the Commonwealth Secretariat and was the International Network for Cancer Treatment and Research's UK Executive Director 2008- 2024. He is the Commissioning Editor for the annual Cancer Control published by Global Health Dynamics, a member of the Lancet Oncology Commission on Cancer in the Commonwealth, and between 2019-2023 was the creator and Convenor of London Global Cancer Week.

References

1. *Cervical Cancer Elimination Across the Commonwealth A Compendium of Country Case Studies.* Publ Commonwealth Secretariat 2026 https://comsec-web-static.s3.eu-west-1.amazonaws.com/s3fs-public/2025-09/commonwealth-secretariat_strategic-plan-2025-2030-full-text.pdf2. The Commonwealth Strategic Plan 2025-2030 publ. The Commonwealth Secretariat 2026
3. The Comm onwealth Charter 2013 publ. The Commonwealth Secretariat https://thecommonwealth.org/charter
4. Jones D. Opinion: The Commonwealth Strategic Plan 2025–2030. Facing the challenge of an unstable world. *The Round Table: The Commonwealth Journal of International; Affairs and Policy Studies 2026* (August), pp 777-782 https://www.commonwealthroundtable.co.uk/commonwealth/opinion-the-commonwealth-strategic-plan-2025-2030-facing-the-challenge-of-an-unstable-world/
5. HRH Princess Dina Mired. Response to the Consultation, *Cancer Control 2026*
6. Universal Declaration of Human Rights U.N. General Assembly Resolution 217 A(III) 10 December 1948, https://www.un.org/en/about-us/universal-declaration-of-human-rights
7. The Health and Economic Benefits of Tackling Non-Communicable Diseases Report OECD Health Policy Studies April 2026 https://www.oecd.org/en/publications/the-health-and-economic-benefits-of-tackling-non-communicable-diseases_e20cbbc3-en.html
8 "King says 'what is past is prologue' after Bayeux tour with Macron and Burnham". The National, 3 Sept. 2026 https://www.thenational.scot/news/national/26517381.king-says-what-past-prologue-bayeux-tour-macron-burnham/
9. Shakespeare W. *The Tempest*, Act 2 Scene 1
10. Santayana G. *The Life of Reason*, 1905
11. Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978 https://www.globalfamilydoctor.com/site/DefaultSite/filesystem/documents/starfield/declaration_almaata.pdf
12. Di Lampedusa, Giuseppe Tomasi. *The Leopard* (Il Gattopardo, 1958.

CANCER CARE

35 Beyond the dispensary: Listening to the voices of pharmacists working in resource-constrained settings

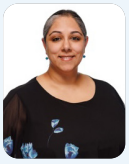
Fatima Ladha, Clinical Educator and Pharmacist, Fraser Health Authority; Clinical Instructor, University of British Columbia, Faculty of Pharmaceutical Sciences and Director, Two Worlds Cancer Collaboration; **Anthony Lau,** Clinical Pharmacy Specialist – Neurosciences, Royal Columbian Hospital, Canada and Clinical Assistant Professor – Faculty of Pharmaceutical Sciences, University of British Columbia, Canada; **Saroja Gangaiah,** Senior Pharmacist and Co-ordinator, Department of Palliative Medicine, Kidwai Memorial Institute of Oncology, Karnataka, India; **Fazle-noor Biswas,** Chief Pharmacist and Coordinator, Cancer Services and Research Centre, Dhaka, Bangladesh and **Azza Abel-Aty,** Chief Pharmaceutical Specialist, KACCH/Al-Sabah Hospital, Kuwait

40 Revolutionizing a cancer care and support ecosystem in British Columbia unique to adolescents and young adults

Cheryl A Heykoop, Associate Professor and Research Lead of Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada; **Alice O'Grady,** Professor, School of Performance and Cultural Industries, University of Leeds, United Kingdom; **Tiffany T Hill,** PhD Candidate, OISE, University of Toronto, Ontario, Canada and Associate Faculty and Senior Researcher, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada; **Jennifer Wolfe,** Program Coordinator, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada and **Kat Dornian,** Research Assistant, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada.

Beyond the dispensary: Listening to the voices of pharmacists working in resource-constrained settings

Fatima Ladha, Clinical Educator and Pharmacist, Fraser Health Authority; Clinical Instructor, University of British Columbia, Faculty of Pharmaceutical Sciences and Director, Two Worlds Cancer Collaboration; **Anthony Lau,** Clinical Pharmacy Specialist – Neurosciences, Royal Columbian Hospital, Canada and Clinical Assistant Professor – Faculty of Pharmaceutical Sciences, University of British Columbia, Canada; **Saroja Gangaiah,** Senior Pharmacist and Co-ordinator, Department of Palliative Medicine, Kidwai Memorial Institute of Oncology, Karnataka, India; **Fazle-noor Biswas,** Chief Pharmacist and Coordinator, Cancer Services and Research Centre, Dhaka, Bangladesh and **Azza Abel-Aty,** Chief Pharmaceutical Specialist, KACCH/Al-Sabah Hospital, Kuwait


FATIMA LADHA


ANTHONY LAU


SAROJA GANGAIAH


FAZLE-NOOR BISWAS


ABEL-ATY

In our previous "Beyond the dispensary" article in Cancer Control 2025, we reflected on what we had learned from working alongside pharmacists in resource-constrained settings. One lesson stayed with us. Meaningful global partnerships begin with humility, curiosity, and a willingness to learn rather than teach. If we truly believe that, then we also need to know when to step back and let others tell their own stories. This commentary is our attempt to do that.

We invited three pharmacy leaders from different parts of the world to share their experiences. Fazle-noor Biswas is the Coordinator and Chief Pharmacist at the Cancer Services and Research Center in Dhaka, Bangladesh. Azza Ahmed Abdel-Aty is the Senior Pharmaceutics Specialist at the Pediatric Palliative Care Hospice BACH/Sabah Main Pharmacy in Kuwait City, Kuwait. Saroja Gangaiah is the Senior Pharmacist at the Department of Palliative Medicine at Kidwai Memorial Institute of Oncology in Bengaluru, India.

Although they work in different healthcare systems, many of the same ideas came up throughout our conversations. Their stories remind us that the best global partnerships begin by listening before offering solutions.

Theme one: Expanding the pharmacist's professional identity

One message came through right away. None of our colleagues described themselves as pharmacists whose work begins and ends with dispensing medicines. Instead, they spoke about being medication experts, educators, clinical partners, and advocates for their patients. Their work includes optimizing complex medication regimens, counselling patients and families, managing symptoms, improving medication safety, and contributing to multidisciplinary care. They also described growing responsibilities in antimicrobial stewardship, deprescribing, and reducing inappropriate polypharmacy.

Despite everything they contribute, many still feel that people do not fully understand what pharmacists do.

Fazle-noor described this frustration well: "When people assume pharmacists 'just dispense medications,' it feels almost surreal because it erases about 90% of what pharmacists do, especially in a complex health system like Bangladesh. That assumption does not match my experience at all, and honestly, it does not match the reality of modern pharmacy anywhere in the world."

Saroja described a similar reality: "Indian pharmacists often work at the intersection of patient care, medicine access and system management. We do clinically meaningful work inside a system that still demands intense dispensing and logistics performance."

Azza described her role in practical terms: "My role is to help patients as much as I can by finding medications or suitable alternatives and explaining those options to physicians,

especially when newer treatments may not yet be familiar."

Although they work in different settings, they all described a profession that is steadily becoming more involved in direct patient care. Public and professional perceptions have been slower to change.

One thing we kept noticing was that none of them talked about expanding pharmacy practice simply for the benefit of the profession. The conversation always came back to patients. Better symptom control. Safer medication use. Helping families understand treatment. Reducing suffering. Recognition was important, but only because it helped them care for patients better.

At the same time, they were realistic about the challenges that remain.

As Fazle-noor explained: "Pharmacists are in a good position to assist Bangladesh in addressing its growing problems, which include poly-pharmacy, non-communicable diseases, and antibiotic resistance. However, their impact is restricted by systemic obstacles such as poor policy recognition, a lack of clinical positions, and insufficient training pathways."

Theme two: Pharmacy practice has tremendous opportunities for growth

Although each pharmacist described different challenges, they all pointed to the same underlying issue. Healthcare systems have not always kept pace with what pharmacists are trained to do.

Fazle-noor described how these challenges affect pharmacy practice in Bangladesh: "In Bangladesh, community pharmacies are managed by non-pharmacists. This set-up commonly results in inconsistent medication counselling to patients and their families, and there might be irrational dispensing. The cultural norm further devalues pharmacists' expertise, with medication decisions dominated by doctors and families frequently dependent upon informal advice from drug shops. Ultimately, it has created a feedback loop of mistrust by the public and the perception of our profession as a business rather than a clinical service."

Saroja described a similar challenge from a different healthcare system: "The infrastructure and healthcare culture do not always utilize pharmacists as full members of the clinical team. In many cases, the problem is not what pharmacists cannot do, but what the system does not yet allow or support us to do."

That sentence stayed with us. It shifts the focus from individual pharmacists to the systems they work in. Even with these barriers, the conversations never felt discouraging. Instead, each pharmacist spoke about the moments that continue to give them hope.

For Fazle-noor: "Hope comes from patients' resilience and colleagues' determination for safe medication usage despite systemic challenges."

For Saroja: "I find hope in the moments when medicines are used well, suffering is reduced, families feel supported, and local teams create meaningful solutions despite limited resources. I am encouraged by the fact that pharmacy practice in India is evolving towards a more clinical, visible, and patient-focused role."

Those comments are impactful. They remind us that meaningful change often happens one patient, one family, and one healthcare team at a time.

Theme three: Finding solutions in resource-constrained settings

Working with limited resources is simply part of everyday practice. It requires flexibility, creativity, and constant problem solving. They described finding practical ways to adapt evidence-based practice to the realities of their healthcare systems.

Community-based care, volunteer-supported programmes, and other locally developed models were described as strengths. Rather than seeing limited resources as barriers, our colleagues described them as opportunities to think differently and adapt care to local needs.

Saroja shared one example from India. Some of the most meaningful innovations in palliative care have come from community-based services, multidisciplinary home visits, and volunteer-supported care. These models are built around patients, families, and communities rather than expecting patients to navigate the healthcare system on their own.

Reading these stories made us rethink one of our own assumptions. We often think of innovation as new technology or bigger budgets. Our colleagues reminded us that it can also come from necessity. These conversations reminded us that meaningful innovation is already happening every day in resource-constrained settings.

Theme four: Access to medicines and relief from suffering

No matter where the conversation starts, it eventually came back to one issue: access to medicines. Medications, such as morphine, that should be routinely and universally available and are recognized as such by the WHO (World Health Organization. The selection and use of essential medicines, 2025: WHO Model List of Essential Medicines, 24th list. Geneva: World Health Organization; 2025. Report No.: B09474. Available from: https://iris.who.int/handle/10665/381503) remain difficult or impossible to access because of regulatory barriers, supply challenges, affordability, and stigma.

Fazle-noor described how these barriers affect patient

care every day: "My ability to deliver high-quality care is directly impacted by our system's ability to access necessary medications."

He continued, "Strict regulations, limited prescribers, and administrative barriers delay or block access to essential medicines like morphine, leaving patients in avoidable pain. Even when opioids are available, financial pressures lead families to stretch doses, choose less effective options, or travel long distances, adding emotional and economic stress. Stigma from patients, families, and even healthcare providers further restricts appropriate use, as fears of addiction, judgment, or regulatory consequences discourage timely prescribing and dose adjustments."

Listening to these stories reminded us that access to medicines is never simply about supply. It is about whether patients can live with comfort, dignity, and relief from suffering.

This is where pharmacists become advocates, educators, and navigators who help patients receive the care they need. They help patients and families overcome barriers and work with healthcare teams to provide the safest and most compassionate care possible.

Theme five: Education and advocacy around opioid use

Our conversations naturally led to another important topic – education.

All three pharmacists described stigma as one of the greatest barriers to effective pain management. Often, patients and families are afraid of opioids. Sometimes healthcare professionals are too. Misunderstandings about addiction, dependence, and appropriate opioid use continue to influence treatment decisions.

So, how have they addressed this challenge? They all began by listening.

Education is not simply about giving patients more information. It is about understanding their concerns, building trust, and helping them make informed decisions that reflect their goals and values.

Fazle-noor described these conversations as an opportunity to translate clinical evidence into language that patients and families can understand.

"I emphasize that in palliative care, the goal is comfort and function, not sedation, and that addiction is extremely rare when opioids are used correctly for serious illness."

Azza shared a similar approach in her own practice.

"Many patients and families are worried about addiction when opioids are prescribed. My role is to explain the benefits and risks, discuss possible side effects, and help them understand how these medicines can improve quality of life.

Saroja captured the importance of those conversations in a single sentence: "Trust matters as much as pharmacology in whether pain relief is accepted."

Clinical knowledge is essential. So are empathy, communication, and trust. Without trust, even the best treatments may never be accepted. These conversations also reminded us that opioid stewardship looks different depending on where you practice. In many high-income countries, stewardship has largely focused on reducing inappropriate opioid use in response to the opioid overdose crisis. In many low- and middle-income countries, however, the greater challenge remains access. Patients continue to experience unnecessary suffering because essential opioid medicines are unavailable or inaccessible.

When asked what global support should look like, Fazle-noor said: "It would start with international policies that prioritize balanced opioid regulation, helping countries modernize outdated laws so that fear of misuse no longer outweighs the obligation to relieve suffering. It would also include global investment in local production and supply chains to make opioids affordable and consistently available, rather than relying on expensive imports or fragmented procurement. Equally important is addressing stigma through worldwide education campaigns for clinicians, policymakers, and communities, so opioids are understood as essential medicines, not symbols of addiction or moral failure. Finally, true support would strengthen the workforce by training pharmacists, nurses, and physicians in safe opioid use, symptom management, and compassionate communication. In essence, global support would mean aligning policy, supply, education, and funding so that no patient suffers simply because of where they live."

Theme six: Learning from one another

Our conversations eventually turned to partnership. We asked each pharmacist what makes an international collaboration feel respectful and helpful. We also asked what approaches have not worked well, whether they had experienced partnerships that unintentionally created dependency, and what real co-learning looks like.

They are built through curiosity, shared leadership, and recognizing that local expertise is just as valuable as international experience. They do not begin with assumptions or ready-made solutions.

Fazle-noor described this particularly well: "I feel valued when partners come in with curiosity and ask how things work in Bangladesh, what our constraints look like on the ground, and what innovations we've already created. It matters when they listen first instead of assuming their model will automatically fit here. I do not want someone to hand me ready-made solutions. I want to shape something together that works for Bangladeshi

patients, the country's health system, and our culture."

Saroja echoed this: "It feels helpful when it leads to practical change and better access to training rather than recommendations that do not fit my setting."

Each pharmacist emphasized that meaningful partnerships include shared authorship, visibility, and leadership.

As one contributor reflected: "Sharing credit fairly in authorship, visibility, and leadership feels like a true partnership rather than extraction."

Another reflected that meaningful collaboration happens when international colleagues are willing to learn from local realities, adapt their ideas, and acknowledge what they do not know. When this happens, both sides benefit, but local capacity grows stronger.

Not every partnership had been positive. Across the conversations, several examples were shared where well-intentioned international initiatives depended heavily on external funding, expertise, or leadership without fully developing local ownership. When outside support ended, programmes often struggled to continue.

Fazle-noor reflected on one of these experiences: "Partnerships could be more effective had they prioritized early investment in community capacity-building, including local volunteers' training, strengthening family- and neighbourhood-level networks, and establishing governance structures that were genuinely rooted in the community. A gradual transition of responsibility and mechanisms for local resource generation would have shifted the model from externally supported to locally owned."

So, it starts when local leadership is built into the work from the beginning. When we asked what real co-learning looks like, all three pharmacists returned to the same principle concept: it is built on equality.

Fazle-noor summarized it this way: "Each side brings forms of knowledge the other simply cannot access. Local teams understand culture, patient behaviour, resource constraints, and system realities, while international colleagues bring global evidence, frameworks, and comparative experience from other health systems."

Co-learning combines global evidence with local knowledge to develop solutions that fit the communities being served. Sometimes the most valuable thing we can bring to a partnership is a willingness to listen.

Theme seven: Where pharmacists are clinical leaders and partners in care

As our conversations came to a close, we asked each pharmacist about their hopes for the future.

They want pharmacists to play a greater role in direct patient care. They hope to see pharmacists more involved in research, education, policy development, and leadership. They want stronger integration within interdisciplinary healthcare teams and greater involvement in medication-related decision making.

Their vision was never about professional recognition alone. It was about improving care for patients. Instead, they reflected a shared belief that patients benefit when pharmacists can contribute fully as medication experts.

They reminded us that progress cannot simply be imported from elsewhere. It must be built within each healthcare system by the people who understand it best.

Despite the challenges they described, every conversation ended with hope. Hope for patients. Hope for the profession. Hope that pharmacy will continue to grow as healthcare systems recognize the value pharmacists bring to patient care.

Looking ahead

When we finished these conversations, we found ourselves thinking less about what we could teach and more about what we still must learn.

Our pharmacist colleagues are not waiting for someone else to improve pharmacy practice in their countries. They are already leading change within their own healthcare systems through patient care, education, advocacy, and innovation.

Last year, we wrote that meaningful global partnerships begin with listening.

We set out to create space for our colleagues to share their experiences in their own words. We hope this commentary has done that. If there is one message, we hope readers take away, it is recognizing that the future of global pharmacy will not be shaped by one healthcare system teaching another. It will be shaped by pharmacists around the world learning from one another, listening to one another, and working together as equal partners. ■

Dr Fatima Ladha, BSc, BSc (Pharm), PharmD, R Phis a clinical pharmacist specializing in medical education. She earned her Bachelor of Pharmacy at the University of British Columbia (UBC), Canada, in 2008, completed the UBC Community Pharmacy Practice Residency Program in 2012, and holds a Doctor of Pharmacy from the University of Toronto, Canada. She is a clinical instructor with the Faculty of Pharmaceutical Sciences at UBC and contributes to the Fellowship in Pediatric Palliative Medicine for South and Southeast Asia offered through the Hyderabad Center for Palliative Care. Dr Ladha has 20 years' clinical experience in oncology, pain and symptom management, and palliative care. She is a director with the Two Worlds Cancer Collaboration.

Anthony Lau, BSc(Pharm), ACPR, PharmD, BCPS is a Clinical Pharmacy Specialist in Neurosciences at the Royal Columbian

Hospital, Canada and a Clinical Assistant Professor in the Faculty of Pharmaceutical Sciences at the University of British Columbia, Canada, and a Board Certified Pharmacotherapy Specialist (BCPS). He has previously served as a Clinical Pharmacy Specialist in Emergency Medicine at Vancouver General Hospital, Canada, for five years. His clinical practice and research interests include neurosciences, emergency medicine, critical care pharmacotherapy, pharmacokinetics, palliative care, and cancer care.

Fazle-noor Biswas is a clinical pharmacist and palliative care professionals with over 14 years of experience in onco-palliative pharmacy and service development in Bangladesh. He holds postgraduate degrees in pharmacy and public health, as well as a fellowship in palliative care from India. Currently, he serves as Chief Pharmacist and Coordinator at the Cancer Services and Research Centre and was elected as Director, of the International Association for Hospice and Palliative Care (IAHPC). His prior roles include leadership positions in various palliative care projects and corporate hospitals. He has received extensive international training, numerous scholarships, and has a strong publication record in related fields.

Saroja Gangaiah is a senior pharmacist and palliative care health professional with over 27 years of experience in palliative care. She holds a Diploma in Pharmacy with Foundation and Advanced Palliative care Courses. She is currently serving as Senior Pharmacist and Course Coordinator and Faculty at the Department of Palliative Medicine, KMIO. She has received international training, bursary awards, and an Award for Excellence for Leadership from the Cancer Aid Society. She has published articles and is involved in research activities. She has been Co-director for the Palliative Care Pharmacy Course since 2021. Her prior roles include leadership positions as a Working Committee member for Palliative Care Policy, Govt of Karnataka; Advisory Panelist for Palliative Care Network and EC member council.

Azza A. Abdel-Aty, BPharm, is a Chief Pharmaceutical Specialist at KAACH/Al-Sabah Hospital, Kuwait, with over 28 years of pharmacy experience, including 12 years dedicated to palliative and paediatric palliative care. She holds a Diploma in Hospital Management from Nottingham International University, completed independently in 2019. She completed the Harvard Medical School Program in Palliative Care Education and Practice and is an EPEC Paediatrics Train-the-Trainer. Her achievements include completing the Arabic translation of the St Jude communication in- palliative care materials. Her abstract, "Pharmacists and Compliance: Can Counselling Improve Adherence?", was accepted for presentation at the Maruzza Congress.

Revolutionizing a cancer care and support ecosystem in British Columbia unique to adolescents and young adults

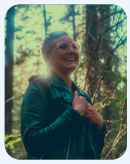
Cheryl A Heykoop, Associate Professor and Research Lead of Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada; **Alice O'Grady,** Professor, School of Performance and Cultural Industries, University of Leeds, United Kingdom; **Tiffany T Hill,** PhD Candidate, OISE, University of Toronto, Ontario, Canada and Associate Faculty and Senior Researcher, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada; **Jennifer Wolfe,** Program Coordinator, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada and **Kat Dornian,** Research Assistant, Anew, Faculty of Interdisciplinary Studies, Royal Roads University, British Columbia, Canada


CHERYL A HEYKOOP


ALICE O'GRADY


TIFFANY T HILL


JENNIFER WOLFE


KAT DORNIAN

Globally, the incidence of cancer in adolescents and young adults (AYAs) is rising significantly and cancer care systems often fail to meet their unique life-stage needs. For many AYAs, dying from or surviving cancer is influenced by their intersecting social identities alongside health system factors, resulting in significant inequities in AYA cancer care. Further, AYAs want to contribute to improvements in their care, yet have few opportunities to do so. In this article, we argue that to develop AYA-focused programmes there are important guiding principles for consideration to revolutionize AYA cancer care and support and respond to the holistic needs of AYAs.

Globally, over 1.3 million adolescents and young adults (AYAs), between the ages of 15 to 39 are diagnosed with cancer each year *(1–3)*, and the incidence of cancer in AYAs is on the rise *(1,4–6)*. AYAs have distinct medical and psychosocial needs that differ from children and older adults *(1,4–8)*; yet, cancer care systems often have limited capacity to respond *(5)*. This gap widens in lesser-resourced countries and is further amplified by an AYA's intersectionality (e.g., race, age, sex, gender, culture, socio-economics, geography, family) and access to healthcare *(2,9–11)*.

In this article, we, a group of participatory, arts-based researchers and people with lived experience with cancer as AYAs, share important guiding principles to help revolutionize AYA cancer care and support ("AYA care") and respond to the holistic needs of AYAs. We begin with an orientation to the distinct realities of AYAs globally. We then briefly share about our work to transform AYA care, before advocating for the adoption of guiding principles to shape and inform AYA care globally in research and praxis.

Adolescent and young adult cancer care and support

By definition, AYAs are classified as anyone diagnosed with cancer between the ages of 15 to 39 *(6)*. AYAs with cancer face unique clinical and life stage challenges compared to children and older adults (1,4–8). A cancer diagnosis thrusts AYAs into a medical environment misaligned with their life stage and coincides with major life transitions such as entrance to post-secondary education or employment, independent living, marriage and partnerships, parenthood, or caring for ageing relatives *(1,4–8)*. Further, it brings added anxieties and psychosocial impacts *(12,13)* including fear of early death *(12,13)*, infertility *(14)*, social and financial disruptions *(15,16)*, social isolation *(7,12,16,17)*, and fear for the future *(12,16–19)*.

Despite the distinct needs and realities of AYAs, cancer care and support for AYAs is often inconsistent and fails to respond to their needs *(1,4–8)*. Further, the annual diagnoses of cancer in AYAs are markedly rising *(20,21)*. AYA cancers are poorly understood *(5)*, pathways to diagnosis are generally prolonged meaning AYAs frequently present with advanced disease *(1,4–7)*, and AYAs continue to have limited access to clinical trials *(22)*. Although most AYAs are expected to survive, AYA survivorship outcomes have not seen similar improvements compared to other populations *(23)*, and in survivorship, AYAs often face physical and psychosocial challenges impacting quality of life and healthcare systems *(5,7)*. There is urgency for AYA-specific care that responds to the unique needs of AYAs

and supports them to survive and flourish.

Globally, there is an increased interest in AYA care *(6,24–26)*. For example, the American Society of Clinical Oncology recommends comprehensive and coordinated care and support for AYAs alongside specialized training for clinicians working with AYAs *(24,25)* and, in several higher resourced countries (e.g., United Kingdom, Australia), AYA care is standard practice *(25,26)*.

Despite global movements to advance AYA care, significant inequities remain *(1,2)*. In lesser-resourced countries, AYA cancers are more likely to be advanced and fatal *(2)*, and specialized AYA care is often non-existent *(2)*. These inequities are amplified by an AYA's intersectionality and access to healthcare. There is an urgent need to address global health disparities and improve cancer care for AYAs who consistently "have been under-recognized, under-diagnosed, and under-served" *(2)*.

Lastly, evidence suggests AYAs want to play an active role in contributing to change and have tangible recommendations to facilitate improvements *(27–29)*. Yet, AYAs rarely have opportunities to share their insights and this lack of engagement is further pronounced in non-curative contexts *(27)*.

"AYA cancers are poorly understood, and AYAs face unique challenges navigating cancer in their lives. More needs to be done to understand and address cancer for AYAs. I've lost too many friends and want to be part of the change." – AYA with cancer

To address the issues identified above and revolutionize AYA care, a new approach is required. We call for an approach that places AYAs at the heart of the process, which draws on their unique and diverse experiences, provides them opportunities to exercise their agency to shape and influence practice, and draws on the power of creativity and partnerships to facilitate change.

Our commitment to create change in AYA care

Over the last five years, we have been working together with AYAs and knowledge users (healthcare providers, decision makers, researchers, community organizations, funders, supporters) in British Columbia, Canada, to better understand the cancer care and support experiences, needs, priorities, and capacities of AYAs and knowledge users; build awareness, understanding, and support amongst knowledge users; and co-design comprehensive AYA care in research and programming.

Through engagements with AYAs and knowledge users, we have intentionally used arts-based and creative practices to generate knowledge, build understanding, and create conditions for change. For example, we used drawing, poetry, and video with AYAs to support them in sharing their experiences and perspectives about cancer care and support *(30–32)*, and worked with AYAs to co-design immersive theatre experiences for healthcare providers, decision makers, and other knowledge users to get a felt sense of what it means to navigate cancer as an AYA *(33)*. This work informed and shaped collaborations with AYAs and knowledge users to co-design initiatives and resources to improve AYA care, including the establishment of an AYA counselling pilot, AYA-specific resources, and an oncofertility programme that includes resources for both AYAs and healthcare providers, a care pathway, and a prompt in the electronic medical record *(34–36)*. We are now witnessing strengthened collaborations amongst AYAs and interdisciplinary knowledge users and building momentum to revolutionize and reimagine AYA care.

As we seek to apply our learning more broadly, we believe it is vital to draw on interdisciplinary research and expertise in innovative, creative, holistic, and inclusive ways to respond to the unique experiences, needs, priorities, and capacities of AYAs, and nurture their health and wellbeing across contexts. We highlight the following principles for consideration.

Guiding principles for revolutionizing AYA cancer care and support

Value the wisdom of AYAs and knowledge users. Research indicates AYAs have a clear understanding of how their cancer experiences can be improved and want to play an active role in doing so *(28,37)*. Yet, historically, AYAs have had little opportunity to share their insights with cancer care systems and contribute to transformative change *(29)*. Of the AYA programmes developed in Canada, AYAs had have limited engagement in programme co-design *(29)*. Yet, literature from patient-oriented research and knowledge translation (KT) demonstrates that relevant patient and stakeholder engagement can improve research quality, healthcare practice, KT efforts, informed health decision-making, and patient reported outcomes *(29,38–46)*. Further, engagement of AYAs with an uncertain future can develop new skills and insights, build networks, promote self-confidence, and contributes to legacy building *(27)*. To create meaningful change in AYA care, it is essential that AYAs and knowledge users are meaningfully engaged as partners and collaborators to co-design, implement, monitor, and evaluate initiatives and programmes. This includes being at the heart of arts-based approaches that challenge conventional paradigms of health research.

Address inequities and enhances representation. Within research and healthcare practice generally, and in AYA-focused cancer care and support specifically, there remains a limited focus on understanding and improving care for AYAs with diverse intersectional identities *(47–50)*. Evidence suggests that AYAs with certain facets of identity are particularly

underrepresented and underserved in research and practice, i.e., younger AYAs *(4)*, AYAs who live rurally and remotely *(51,52)*, AYAs who identify as 2SLGBTQIA+ *(53,54)*, AYAs who identify as Indigenous *(55,56)*, racialized AYAs *(30,31,56)*, and AYAs with advanced cancer *(57,58)*. Further, as Kimberlé Crenshaw explains in her theory of intersectionality, the overlapping, intersecting nature of identities (e.g., age, sex, gender, race, class, geography, disability) and how they intersect and reflect social structures of oppression and privilege amplify inequities *(59–61)*. In addition, healthcare systems and practices have a longstanding history of being discriminatory, oppressive, and in some cases harmful to individuals with diverse intersectional identities

In our work, we intentionally work with AYAs who have been historically and systematically excluded, marginalized, and underserved because of their identities *(30,31,47–51,53–61)* to better understand their lived experiences; interrogate health systems and practices; and co-design programmes, initiatives, and systems that better respond to the needs and realities of AYAs with diverse intersectional identities. For example, we engaged racialized AYAs to use arts and creative processes to explore their experiences with cancer care and support and identify solutions to improve their care *(30,31)*, and we are working with AYAs living in rural and remote communities to explore how to better respond to their distinct needs in both research and practice. In all our research efforts, we work intentionally to engage AYAs with diverse experiences and intersectional identities, and we strive to ensure that members of our research teams are from communities who are historically excluded or underrepresented in research and practice. As we approach research and programming, we must commit to meaningfully engage AYAs with diverse intersectional identities to understand their experiences, needs, priorities, and capacities; interrogate the systems that provide care and support; and co-design equitable solutions. We must recognize the crucial importance of building a care system where AYAs with diverse intersectional identities see their identities are valued and represented in the people, services, cultures, practices, and systems.

Extend along the continuum of cancer care. In theory, cancer care and support extends along the continuum of cancer including prevention and screening, diagnosis, treatment, post-treatment care and survivorship, and end-of-life care. Yet, AYA programming and research tends to focus on active treatment phases, with limited focus on the other phases of care and on the continuity of care across phases *(62)*. There is a need to provide cancer care and support to AYAs across the continuum of cancer.

Span across geographies and organizations. The AYA care landscape is vast and diverse and involves many organizations and players. Simultaneously, AYA care often straddles both pediatric and adult care. Amidst this landscape, there is often limited integration and coordination across organizations (including community organizations) while healthcare systems are under pressure and strain. Further, pilot projects and specialized services (e.g., fertility services) tend to focus on AYAs in urban settings *(52)*; however, digital health innovations offer opportunities to expand access to care. As we develop AYA programmes globally, it is critical that we focus on partnerships to overcome borders (e.g., geographical and organizational) to reach all AYAs.

Include a focus on creative health. Cancer care and support efforts, and healthcare efforts more generally, often focus on medical interventions and treating disease rather than adopting a more holistic conceptualization aligned with the World Health Organization *(63)*. Adopting the orientation of creative health currently popularized in the United Kingdom shows promise, where creative health refers to creative approaches and activities that benefit health and wellbeing alongside more medicalized approaches *(64–66)*. This includes prescribing arts and creativity through social prescribing; exploring the role of the arts and creativity in the provision of care; considering the role and function of arts and creativity in research and professional development; and leveraging creative partnerships and community collaborations to improve health and wellbeing *(64–66)*. Broadening our perspectives to include a focus on creative health opens possibilities for innovation in AYA care and supporting the health and wellbeing of AYAs.

Apply creative approaches. Aligned with a creative health orientation, we argue for creative, arts-based approaches in health research, KT, and clinical practice. Arts-based and creative approaches use any form of art or creativity to collect, interpret, and/or share new knowledge *(67,68)*, and they can support meaningful participation by valuing the perspectives and insights of participants, provide opportunities for participants to exercise their agency and contribute in ways that feel meaningful and important to them, share perspectives that may be new or overlooked, and move beyond power imbalances that may exist *(67–71)*. In the context of health research, arts-based research practices are considered emancipatory or even radical in that they seek to amplify perspectives that are typically silenced or repressed *(69)*, can challenge injustices and inequities *(72)*, and challenge dominant research paradigms *(67)*. Through our work using arts-based and creative approaches with AYAs and knowledge users, we witnessed the capacity of arts and creativity to disrupt power imbalances and create changes in AYA care. There are unique opportunities to leverage creative approaches to envision a novel and revolutionary approach to AYA care that does not yet exist and to inspire interdisciplinary actors and cancer

care systems to respond to the unique experiences, needs, priorities, and capacities of AYAs.

Leverage medical knowledge and expertise alongside qualitative research. Research indicates that some cancers in AYAs are biologically distinct; however, research on AYA cancer remains sparse. For example, in Canada, only 0.4% of all cancer research focuses on AYA cancer *(73)* and AYAs often have limited access to clinical trials *(22)*. Further, clinician and patient reported outcomes suggest that AYAs can present with unique symptoms and respond to treatment differently compared to the average adult or paediatric patients *(1,5,6,74)*. There is an urgent need to leverage the specialized knowledge and expertise of genomic research, clinical trials, population-based studies, and biomedical research to explore and extend how to best tailor and target cancer care and support for AYAs while simultaneously engaging in qualitative, participatory research studies to understand the lived and living experiences of AYAs and identify patient-centred priorities and solutions for AYA care.

Leverage digital health innovations. Advances in technology – and digital health specifically – are rapidly transforming possibilities for cancer care and support *(75,76)*, and AYA's technical savviness and comfort position AYAs to access, develop, and leverage technology innovations along the cancer care continuum *(77,78)*. Opportunities for digital health innovations in oncology are vast and have the potential to improve patient experience and safety; facilitate patient engagement and empowerment; enhance patient interactions with clinicians and peers; streamline diagnoses and ongoing monitoring; improve clinical workflows, documentation and resource allocations; provide decision support for AYAs and clinicians; improve clinical trial access and monitoring; and enhance equitable clinical and supportive care, particularly for underserved AYAs and those who live in rural and remote locations *(75–79)*. Further, digital health and technology innovations offer creative ways to engage in research, improve cancer care, and facilitate KT *(80)*. It is important to explore and leverage technology and digital health innovations to revolutionize AYA care, while also recognizing the associated challenges and ethical considerations around privacy, equitable access, and responsible data *(77)*.

Adopt an ethic of care. As we seek to revolutionize AYA care, we recognize we have a responsibility to care for the wellbeing of AYAs in research and practice, and commit to applying an ethic of care to our work *(81,82)*. Based on our previous research projects, adopting an ethic of care means building AYA specific counselling support (or other culturally relevant supports) into all research budgets, ensuring participants have the means to access the supports they need throughout the research process; providing food in all group gatherings (e.g., grocery or food delivery cards for virtual gatherings, catered meals for in-person gatherings that meet participants' dietary and cultural food needs); providing compensation to AYAs for their time and expertise *(83)*; offering both virtual and in-person research opportunities to support more equitable access; ensuring venues are accessible; providing a secure internet connection; not scheduling events during cultural days and times of significance; building in time and space for prayer; offering child and family care; and ensuring participants do not incur out-of-pocket expenses. Adopting an ethic of care also involves providing opportunities to AYAs to showcase or extend existing capacities and develop new capacities. For example, we seek to leverage and build the existing knowledge, skills, and capacities of AYAs to create change (e.g., catering, graphic recording, professional communications, and counselling) and we are committed to hiring AYAs with the required project skills to effectively support projects. As leaders, researchers, and practitioners, we must commit to building knowledge, skills, and capacities of knowledge users and AYAs to develop the next generation of researchers able to address complex challenges in innovative, interdisciplinary, and novel ways and improve AYA care. As we seek to revolutionize AYA care, a commitment to adopting an ethic of care remains at the forefront.

Conclusion

In summary, as awareness about AYA cancer care and support grows and incidence of AYA cancer rises, we have a distinct opportunity to reimagine AYA care. These principles provide a strategic framework that can be responsive to local contexts and set a new agenda for global change in AYA cancer care and support in research and praxis. ■

Cheryl Heykoop, DSocSci, is a Michael Smith Health Research BC Scholar and an associate professor in the Faculty of Interdisciplinary Studies at Royal Roads University. She leads Anew, a research collaborative focused on reshaping cancer care with adolescents and young adults (AYAs) and care providers in British Columbia and Canada. Heykoop has 20 years of experience leading patient-oriented, participatory action research projects. Heykoop was diagnosed with cancer as a young adult and continues to be a fierce advocate for change in AYA cancer care and support.

Alice O'Grady, PhD, is a professor of applied performance at the University of Leeds, United Kingdom. She is a member of the Creative Arts and Health Research Laboratory which explores inclusive arts-based and digital methodological innovation in healthcare and is leading the establishment of a creative health strategy in West Yorkshire. O'Grady's expertise in applied theatre lies in exploring performance as a means of facilitating social

agency, engagement, and expression. Her research explores participation across a range of health contexts and investigates how participatory practices are mobilized as embodied tools for engaging with and problematizing processes of research, resistance and representation.

Tiffany T Hill, MA, is a queer of colour interdisciplinary researcher, educator, and artist from the Pilipino diaspora. She is associate faculty in the Faculty of Interdisciplinary Studies at Royal Roads University. Her work builds and convenes critical knowledge about health and wellness, with particular attention to grief, social and racial justice, and systems change. Hill's research brings together critical grief studies, participatory action research, visual and arts-based methods, and indigenous feminist ethics to explore lived experiences of grief and possibilities for more just and responsive systems of care.

Jennifer Wolfe, BA, is research program coordinator for the Anew Research Collaborative supporting all projects to move forward in an effective and timely manner and contributing communications expertise. She holds a degree in communications and worked extensively with BC Cancer's Primary Care Program developing and delivering education to improve cancer care at the community level throughout BC/Yukon.

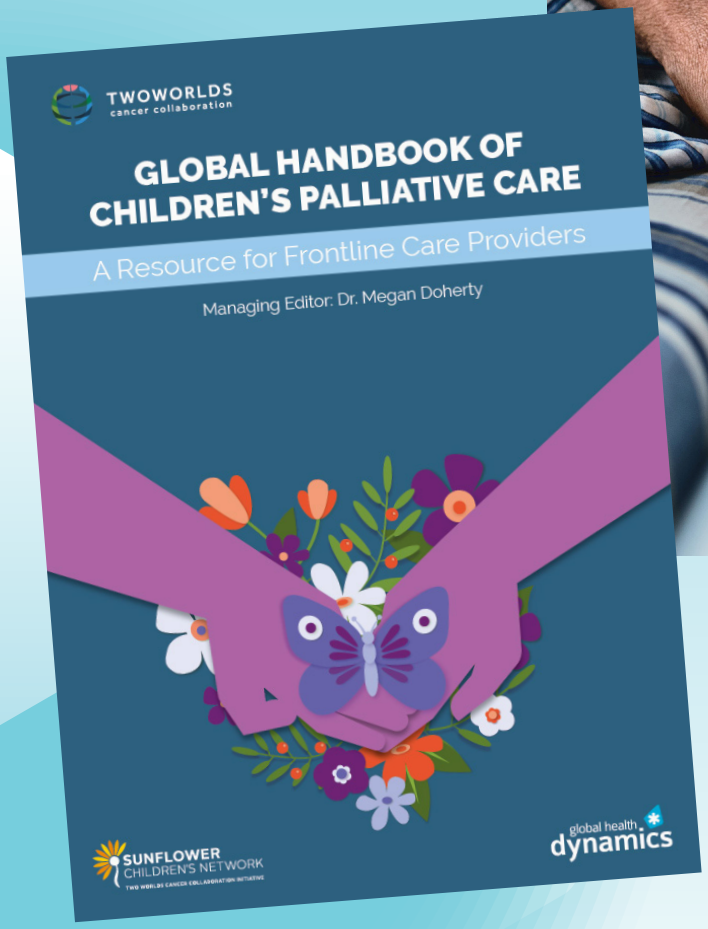
Kat Dornian, MSc, is a research assistant at Anew. They have led community-engaged, educational projects in museums, universities, and local communities to increase involvement in sustainability, science, and engineering among groups that have been historically excluded from formalized participation in those fields. For their master's programme in engineering, they investigated the role of mentorship for diverse students in engineering outreach programmes. Now, as a young adult living with cancer, they bring their design, communication, and facilitation expertise to support change in AYA cancer care and support.

References

1. Coccia PF. Overview of adolescent and young adult oncology. *Journal of Oncology Practice* 2019;15(5):235–7
2. Li W, Liang H, Wang W, et al. Global cancer statistics for adolescents and young adults: population-based study. *Journal of Hematology & Oncology* 2024;17(1):99
3. Miller KD, Fidler-Benaoudia M, Keegan TH, et al. Cancer statistics for adolescents and young adults, 2020. *CA: A Cancer Journal for Clinicians* 2020;70(6):443–59
4. McInally W, Gray-Brunton C, Chouliara Z, et al. Experiences of living with cancer of adolescents and young adults and their families: a narrative review and synthesis. *Enfermería Clínica* (English Edition) 2021;31(4):234–46
5. Berkman AM, Mittal N, Roth ME. Adolescent and young adult cancers: unmet needs and closing the gaps. *Current Opinion in Pediatrics* 2023;35(1):84–90
6. Chisholm J, Hough R, Soanes L, editors. *A practical approach to the care of adolescents and young adults with cancer*. Cham: Springer International Publishing, 2018
7. Young Adult Cancer Canada. YAC prime report [Internet]. St. John's: Young Adult Cancer Canada 2023 [cited 2026 Aug 13]. Available from: https://youngadultcancer.ca/wp-content/uploads/2023/04/YAC-Prime-Report.pdf
8. Barr RD, Ferrari A, Ries L, et al. Cancer in adolescents and young adults: A narrative review of the current status and a view of the future. *JAMA Pediatrics* 2016;170(5):495–501
9. Gupta S, Harper A, Ruan Y, et al. International trends in the incidence of cancer among adolescents and young adults. *JNCI: Journal of the National Cancer Institute* 2020;112(11):1105–17
10. Wen YF, Chen MX, Yin G, et al. The global, regional, and national burden of cancer among adolescents and young adults in 204 countries and territories, 1990–2019: a population-based study. *Journal of Hematology & Oncology* 2021;14(1):89
11. Alvarez EM, Force LM, Xu R, et al. The global burden of adolescent and young adult cancer in 2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Oncology* 2022;23(1):27–52
12. Korenblum C, Taylor RM, Fern LA, et al. Factors affecting psychosocial distress in adolescents and young adults with cancer: BRIGHTLIGHT cross-sectional and longitudinal cohort study results. *Cancers* 2025;17(7):1196
13. Smrke A, Leung B, Srikanthan A, et al. Distinct features of psychosocial distress of adolescents and young adults with cancer compared to adults at diagnosis: patient-reported domains of concern. *Journal of Adolescent and Young Adult Oncology* 2020;9(4):540–5
14. Daniel LC, Sabiston CM, Pitock M, et al. Fertility preservation in young adults: prevalence, correlates, and relationship with post-traumatic growth. *Journal of Adolescent and Young Adult Oncology* 2021;10(4):389–96
15. Mahon KN, Garland SN, Eaton G, et al. The financial impact of cancer on Canadian young adults. Journal of Cancer Survivorships: Research and Practice 2023;17: 174–86
16. Jones JM, Fitch M, Bongard J, et al. The needs and experiences of post-treatment adolescent and young adult cancer survivors. *Journal of Clinical Medicine* 2020;9(5):5
17. De R, Sutradhar R, Kurdyak P, et al. Incidence and predictors of mental health outcomes among survivors of adolescent and young adult cancer: a population-based study using the IMPACT cohort. *Journal of Clinical Oncology* 2021;39(9):1010–9
18. Schulte FSM, Chalifour K, Eaton G, et al. Quality of life among survivors of adolescent and young adult cancer in Canada: a young adults with cancer in their prime (YACPRIME) study. *Cancer* 2021;127(8):1325–33
19. Lane BE, Garland SN, Chalifour K, et al. Prevalence and factors associated with fear of recurrence in a mixed sample of young adults with cancer. *Journal of Cancer Survivorship* 2019;13(6):842–51
20. Ledford H. Why are so many young people getting cancer? What the data say. *Nature* 2024;627(8003):258–6
21. Hamilton AC, Coleman HG. Shifting tides: the rising tide of early-onset cancers demands attention. *BMJ Oncology* 2023;2(1): e000106
22. de Rojas T, Neven A, Terada M, et al. Access to clinical trials for adolescents and young adults with cancer: a meta-research analysis. *JNCI Cancer Spectrum* 2019;3(4): pkz057
23. Trama A, Bernasconi, A, McCabe MG, et al. Is the cancer survival improvement in European and American adolescent and young adults still lagging behind that in children? *Pediatric Blood & Cancer* 2019;66(1): e27407
24. Shaw PH, Castellino SM, Guerrettaz R, et al. Adolescent and young adult oncology in the United States in 2025: finding its place in the oncology world part 2 of 2. *Journal of Pediatric Hematology/Oncology* 2025;47(7):327–34
25. Osborn M, Johnson R, Thompson K, et al. Models of care for adolescent and young adult cancer programs. *Pediatric Blood & Cancer* 2019;66(12): e27991
26. Ferrari A, Stark D, Peccatori FA, et al. Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). *ESMO Open* 2021;6(2):100096
27. Burgers VWG, Dickhout A, Harthoorn NCGL, et al. Involving adolescents and young adults (AYA) with an uncertain or poor cancer prognosis as research partners. *Acta Oncologica* 2023;62(8):961–8
28. Hawkins J. What adolescents and young adults want health professionals to know. In: Chisholm J, Hough R, Soanes L, editors. *A Practical Approach to the Care of Adolescents and Young Adults with Cancer*. Cham: Springer International Publishing, 2018. 211–38
29. Oveisi N, Cheng V, Taylor D, et al. Meaningful patient engagement in adolescent and young adult (AYA) cancer research: a framework for qualitative studies. *Current Oncology* 2024;31(4):1689–700
30. Hill TT, Cooper IR, Gill PK, et al. Learnings from racialized adolescents and young adults with lived experiences of cancer: "It's okay to critique the system that claims to save us." *Current Oncology* 2024;31(2):1091–101
31. Hill TT, Cooper IR, et al. Imagining futures amidst the uncertainty of living: a critical participatory action research project with adolescents and young adults with lived experiences with cancer. *Journal of Critical Race Inquiry* 2024;11(2):40–61
32. O'Grady A, Heykoop CA, Weigler W. The PAR3TY Project: Revealing unique cancer experiences and insights of teenagers and young adults through patient engagement, participation, and performance. *Current Oncology* 2024;31(10):5896–907
33. Heykoop CA, Hill TT, O'Grady A, et al. From empathy to action: Exploring the impact of immersive theatre experience on audience members to improve adolescent and

References continued

young adult cancer care and support. *Cancer Control* 2026;33:10732748261456810
34. Smrke A, Marr K, Heykoop C. New resources, improved fertility care for adolescents and young adults navigating cancer. *Journal of Family Practice Oncology* 2025;45(Fall):3–4
35. Heykoop C, Smrke A, Wolfe J, et al. Reshaping adolescent and young adult cancer care and support through participatory engagement. *International Journal of Qualitative Methods* 2025;24:16094069251378343
36. Heykoop C, Smrke A, Marr K. Towards an AYA cancer care and support program for BC/Yukon. Journal of Family Practice Oncology 2026;46(Spring):20–1. https://www.bccancer.bc.ca/family-oncology-network-site/Documents/2026%20Spring%20FPONjournal%20FINAL.pdf
37. Janssen SHM, Vlooswijk C, Manten-Horst E, et al. Learning from long-term adolescent and young adult (AYA) cancer survivors regarding their age-specific care needs to improve current AYA care programs. *Cancer Medicine* 2023;12(12):13712–31
38. Government of Canada Canadian Institutes of Health Research [Internet]. Strategy for patient-oriented research - patient engagement framework, 2014 [cited 2026 Aug 13]. Available from: https://cihr-irsc.gc.ca/e/48413.html
39. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. BMC Health Services Research 2014;14(1):89
40. Manafo E, Petermann L, Mason-Lai P, et al. Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Research Policy and Systems* 2018;16(1):5
41. Sunderji N, Nicholas Angl E, Polaha J, et al. Why and how to use patient-oriented research to promote translational research. *Families, Systems, & Health* 2019;37(1):1–9
42. Husson O, Reeve BB, Darlington AS, et al. Next step for global adolescent and young adult oncology: A core patient-centered outcome set. *JNCI: Journal of the National Cancer Institute* 2022;114(4):496–502
43. Straus S, Tetroe J, Graham I, editors. *Knowledge translation in health care: moving from evidence to practice*, 2nd edition. BMJ Books, 2013
44. Chhatre S, Gallo JJ, Wittink M, et al. Patient-centred outcomes research: perspectives of patient stakeholders. *JRSM Open* 2017;8(11):2054270417738511
45. Frank L, Forsythe L, Ellis L, et al. Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. *Quality of Life Research* 2015;24(5):1033–41
46. Sharma AE, Grumbach K. Engaging patients in primary care practice transformation: theory, evidence and practice. *Family Practice* 2017;34(3):262–7
47. Horrill TC, Browne AJ, Stajduhar KI. Equity-oriented healthcare: what it is and why we need it in oncology. *Current Oncology* 2022;29(1):1
48. Lambert L, Horrill TC, McKenzie MR, et al. Health and healthcare equity in the cancer care sector in Canada: results of a rapid scoping review. *Journal of Clinical Oncology* 2022;40(16):e18536
49. Hammond C. Against a singular message of distinctness: challenging dominant representations of adolescents and young adults in oncology. *Journal of Adolescent and Young Adult Oncology* 2017;6(1):45–9
50. Gallegos D, Durham J, Rutter C, et al. Working towards the active participation of underrepresented populations in research: a scoping review and thematic synthesis. *Health & Social Care in the Community* 2023;2023(1):1312525
51. Frosch ZAK. Where have we been with rural-urban cancer care disparities and where are we headed? *JAMA Network Open* 2022;5(5):e2212255
52. Hess E, Anandan A, Osman F, et al. Disparities in treatment satisfaction and supportive care receipt for young adult oncology patients on the basis of residential location. *JCO Oncology Practice* 2022;18(9):e1542–52
53. Ussher JM, Kimberley A, Rosalie P, et al. Disrupted identities, invisibility and precarious support: a mixed methods study of LGBTQI adolescents and young adults with. *BMC Public Health* 2023;23(1):1837
54. Taylor PL, Lyver B, Kennedy M, et al. Inclusive care for sexual and gender diverse patients with cancer. Beyond words: the use of graphic medicine to convey the preliminary findings of a patients needs assessment. Poster presented at: Preaching to the Choir Conference: Canadian Psychological Association, 2023 Jun 21–23; Toronto, Canada
55. Horrill TC, Linton J, Lavoie JG, et al. Access to cancer care among Indigenous peoples in Canada: a scoping review. *Social Science & Medicine* 2019;238:112495
56. Taparra K, Kekumano K, Benavente R, et al. Racial disparities in cancer stage at diagnosis and survival for adolescents and young adults. *JAMA Network Open* 2024;7(8):e2430975
57. Drake EK, Weeks LE, van Manen M, et al. The delivery of palliative and end-of-life care to adolescents and young adults living with cancer: a scoping review. *Journal of Adolescent and Young Adult Oncology* 2023;12(5):611–24
58. Abdelaal M, Avery J, Chow R, et al. Palliative care for adolescents and young adults with advanced illness: a scoping review. *Palliative Medicine* 2023;37(1):88–107
59. Crenshaw K. Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review* 1990; 43:1241
60. Bowleg L. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *American Journal of Public Health* 2012;102(7):1267–73
61. Young R, Ayiasi RM, Shung-King M, et al. Health systems of oppression: applying intersectionality in health systems to expose hidden inequities. *Health Policy Plan* 2020;35(9):1228–30
62. James Lind Alliance [Internet]. James Lind Alliance priority setting partnership — adolescent and young adult cancer (Canada) top 10 priorities, 2024 [cited 2026 Aug 11]. Available from: https://www.jla.nihr.ac.uk/priority-setting-partnerships/adolescent-and-young-adult-cancer-canada
63. Schramme T. Health as complete well-being: the WHO definition and beyond. *Public Health Ethics* 2023;16(3):210–8
64. National Centre for Creative Health [Internet]. Oxford: National Centre for Creative Health. Why [cited 2026 Aug 11]. Available from: https://ncch.org.uk/why
65. The All-Party Parliamentary Group on Arts, Health and Wellbeing, & the National Centre for Creative Health. Creative health review: how policy can embrace creative health [Internet]. Oxford: National Centre for Creative Health, 2023. Available from: https://ncch.org.uk/creative-health-review
66. Jenkins C, Lambert K, Mackintosh W. An introduction to creative health. *InnovAiT* 2025;18(3):135–9
67. Hinsliff-Smith K, McGarry J, Ali P, editors. Arts based health care research: a multidisciplinary perspective. *Cham: Springer International Publishing*, 2022
68. Barone T, Eisner EW. Arts based research. *Thousand Oaks: Sage*, 2012
69. Bird J. Arts-based research as a radical methodology within healthcare. In: Hinsliff-Smith K, Julie McGarry, Parveen Ali, editors. Arts based health care research: a multidisciplinary perspective. *Cham: Springer Nature*, 2022. 1–14
70. Cox R, Heykoop C, Fletcher S, et al. Creative action research. *Educational Action Research* 2021;29(4):569–87
71. Matarasso F. *A Restless Art: how participation won, and why it matters*. London: Calouste Gulbenkian Foundation, 2019
72. Capous-Desyllas M, Morgaine K, editors. Creating social change through creativity: anti-oppressive arts-based research methodologies. *Cham:Palgrave MacMillan*, 2018
73. Rogers P, Buckland T, Digout C, et al. *Person-centred perspective indicators in Canada: adolescents and young adults with cancer* [Internet]. Toronto: Canadian Partnership Against Cancer, 2017 [cited 2026 Aug 13]. Available from: https://s22457.pcdn.co/wp-content/uploads/2019/10/Adolescents-and-Young-Adults-with-Cancer-Reference-Report-EN.pdf
74. Link C, Qi S, Thompson S, DeIure A, et al. Understanding the symptoms and concerns of adolescents and young adults with cancer in Alberta: a comparative cohort study using patient-reported outcomes. *Journal of Adolescent and Young Adult Oncology* 2023;12(2):199–206
75. Borkar S, Chakole S, Prasad R, et al. Revolutionizing oncology: a comprehensive review of digital health applications. *Cureus* 2024;16(4):e59203
76. Parikh RB, Basen-Enquist KM, Bradley C, et al. Digital health applications in oncology: an opportunity to seize. *JNCI: Journal of the National Cancer Institute* 2022;114(10):1338–9
77. Puthenpura V, Marks AM. Clinical application of digital technologies in adolescent and young adult oncology supportive care. *Journal of Adolescent and Young Adult Oncology* 2021;10(2):127–30
78. Zhang A, Zebrack B, Acquati C, et al. Technology-assisted psychosocial interventions for childhood, adolescent, and young adult cancer survivors: a systematic review and meta-analysis. *Journal of Adolescent and Young Adult Oncology* 2022;11(1):6–16
79. Steineck A, Lau N, Fladeboe KM, et al. Seeking virtual support: digital technology use in adolescent and young adults with advanced cancer. *Pediatric Blood & Cancer* 2022;69(11):e29938
80. Dodlek N, Kassianos A, Avraamides M, et al. 1898P Efficacy of virtual reality-based interventions in cancer-related symptom management in AYA's: a systematic review. *Annals of Oncology* 2024;35(2):S1108
81. Tronto JC. An ethic of care. *Generations: Journal of the American Society on Aging* 1998;22(3):15–20
82. Brannelly T. An ethics of care research manifesto. *International Journal of Care and Caring* 2018;2(3):367–78
83. Canadian Institutes of Health Research [Internet]. Patient partner compensation guidelines, 2022 [cited 2026 Aug 11]. Available from: https://cihr-irsc.gc.ca/e/53261.html



A NEW SERIES OF HANDBOOKS ON GLOBAL PALLIATIVE CARE

For further information visit:
https://www.globalhealthdynamics.co.uk/ghpc
OR
https://twoworldscancer.ca/resources

global health dynamics

REGIONAL FOCUS

Cancer control in Mongolia: Air pollution and molecular insights from hepatocellular carcinoma

Erdenekhuu Nansalmaa, MD, PhD,MPH

ERDENEKHUU NANSALMAA

Despite its beautiful landscapes and warm-hearted people, Mongolia unfortunately has one of the highest cancer mortality rates in the world, with hepatocellular carcinoma (HCC) being a major contributor. While viral hepatitis remains a major etiological factor, emerging molecular evidence suggests that environmental exposures, including air pollution, may also play a significant role in carcinogenesis. Recent genomic analyses of Mongolian HCC reveal distinct mutational signatures associated with environmental carcinogens, suggesting a broader environmental contribution to cancer risk beyond traditional factors. This article synthesizes epidemiological, environmental, and molecular evidence to examine the intersection between air pollution and cancer in Mongolia, with particular emphasis on urban exposure in Ulaanbaatar. It further discusses structural challenges in cancer control and identifies opportunities for integrating air quality interventions into national prevention strategies. Addressing environmental determinants represents a critical opportunity to reduce the cancer burden in Mongolia.

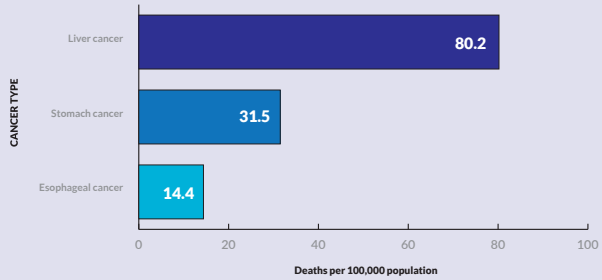
Cancer control in Mongolia presents a uniquely complex challenge shaped by infectious, behavioral, and environmental determinants. The country reports exceptionally high incidence and mortality rates for liver and stomach cancer, largely attributed to chronic infections with hepatitis B virus (HBV), hepatitis C virus (HCV), and Helicobacter pylori, together with high rates of alcohol consumption and tobacco use. However, this traditional explanation is increasingly insufficient.

Epidemiological pattern of cancer in Mongolia

Cancer distribution patterns in Mongolia show a persistently high burden of liver and stomach cancers in both men and women, with substantially higher proportions observed among males. As of 2025, liver cancer remains the leading malignancy in both sexes, accounting for 29.2% of cancers in males and 24.7% in females, followed by stomach cancer (22.9% vs.10.5%) and colorectal cancer (5.7% vs. 4.9%). Notably, among women, the incidence of cervical cancer (13.9%) and breast cancer (10%) has risen considerably, positioning these malignancies among the five most common cancers affecting Mongolian women *(1)*.

In men, lung cancer ranks as the third most common cancer, whereas among women lung cancer incidence (10.4% in males vs. 2.8% in females) does not appear within the top ten cancers. Pancreatic cancer, which had historically been common in both sexes, has shown a gradual decline over recent years, while colorectal cancer incidence continues to rise steadily. Overall,

Table 1: **Mortality rates by specific cancer site**



61.9% of all cancers in Mongolia are considered preventable and associated with environmental or external risk factors, and approximately 71% are potentially detectable through early screening and diagnosis *(1)*.

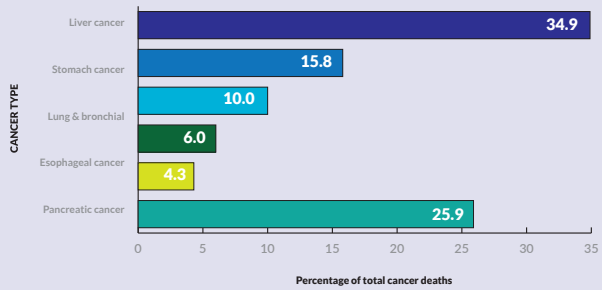
Mongolia continues to rank among the highest in the world for liver cancer (96.1/100,000), stomach cancer (35.5/100,000), and esophageal cancer (15.7/100,000) (Table 1). Although Mongolia ranks 45th globally in cancer incidence, with 235.8 newly diagnosed cases per 100,000 population, it ranks first worldwide in cancer mortality, with 181.5 deaths per 100,000 population *(2)*.

In 2025, mortality is still particularly high for liver cancer (80.2/100,000), stomach cancer (31.5/100,000), and esophageal cancer (14.4/100,000). Approximately 65–70% of cancer cases continue to be diagnosed at advanced stages, although this proportion has gradually declined in recent years, reaching 59.7% in 2025, which is notable achievement.

The leading causes of cancer-related mortality are liver cancer (34.9%), stomach cancer (15.8%), lung and bronchial cancer (10%), esophageal cancer (6%), and pancreatic cancer (4.3%), which these five cancers together account for 74.1% of all cancer deaths (Table 2).

Liver and stomach cancers alone account for 51.7% of total cancer mortality. Mortality patterns are similar between men and women for these two cancers, with liver cancer accounting for 34.4% of male cancer deaths and 35.5% of female cancer deaths, while stomach cancer accounts for 19% and 8.3%, respectively *(1)*.

Table 2: **Leading causes of cancer mortality in Mongolia**



Unique pattern of cancer risk

According to the Global Burden of Disease study 2019, Mongolia had the world's highest age-standardized DALYs for liver cancer (2,558.1) in 2019. Alcohol-attributable DALYs (786.6) were 29 times higher than the global average (26.1), and liver cancer due to hepatitis C (752.6) and B (763.2) were 21.5 (35.0) and 10.9 (69.1) times higher, respectively. In 2019, liver cancer incidence due to alcohol consumption was 3.1 times higher for males than females, and hepatitis B was 2.7 times higher for males than females. However, the incidence of hepatitis C and NASH were slightly higher for females *(3)*. Deaths from liver cancer accounted for 9.51% (2,365) of total deaths in Mongolia in 2019, with a continuously increasing trend in the fraction of death compared to 1990, which was 11 times higher than the global average (0.86%), particularly in females with a 319.6% (95% UI 234.9–435.7) increase observed during the study period. Liver cancer due to hepatitis B, C, and alcohol each shared about one-third of liver cancer deaths.

Recent advances in cancer genomics, particularly the work of Josep M Llovet and colleagues, have revealed that hepatocellular carcinoma (HCC) in Mongolian patients exhibits distinct molecular characteristics associated with environmental exposures. These findings suggest that environmental carcinogens, including those found in polluted air, may play a previously underappreciated role in cancer development.

The study on Hepatocellular Carcinoma in *Mongolia Delineates Unique Molecular Traits and a Mutational Signature Associated with Environmental Agents* provides one of the most compelling pieces of evidence connecting environmental exposure to cancer in Mongolia. Key findings were 1) identification of unique mutational signatures in Mongolian HCC tumours; 2) evidence of DNA damage patterns consistent with environmental carcinogens which is coal combustion; 3) high tumour mutational burden compared to other populations due to combined risk factors; and 4) distinct genomic alterations not fully explained by viral hepatitis alone. These results indicated that Mongolian patients are exposed to additional carcinogenic factors beyond infections, likely environmental in origin *(4)*.

At the same time, Ulaanbaatar experiences some of the highest levels of air pollution globally, particularly during winter time. This convergence of extreme environmental exposure and high cancer burden creates a compelling case for integrating environmental health into cancer control strategies. Given Mongolia's severe air pollution, it is biologically plausible that inhaled pollutants contribute to systemic carcinogenesis, including liver cancer. When we see in molecular level, the implications extend to other cancers, since airborne toxins enter circulation via the lungs, and triggers systemic inflammation which further promotes tumorigenesis throughout body, and similar mutational processes may occur in lung, bladder, and other tissues. Therefore, long lasting air pollution in Mongolia is considered a multi-organ carcinogenic exposure and would be counted one of biggest challenges in Mongolian public health. Therefore, Mongolians are exposed with a multi-hit model of carcinogenesis, where environmental pollutants amplify existing risks, unfortunately.

Air pollution and distinct mutational signatures in Mongolian HCC

Over the past three decades, Mongolia has experienced a steady increase in both the incidence and mortality of liver cancer. During the same period, rapid population growth, urbanization, extensive coal combustion for heating, and industrial expansion have substantially increased air pollution, particularly in urban areas. As a result, air pollution levels in Ulaanbaatar, the capital city of Mongolia, frequently rank among the highest in the world during the winter months. Despite growing concerns regarding its health impacts, insufficient air quality management and delayed mitigation measures have contributed to the continued deterioration of air quality across the country.

Rapid urbanization has transformed Ulaanbaatar into a densely populated metropolitan area where infrastructure development has struggled to keep pace with population

Figure 1: **Air quality scene of Ulaanbaatar ger area** *(iToim.mn.2019)*

growth. Approximately half of Mongolia's population resides in the capital city, with a large proportion living in ger districts that rely heavily on coal-based heating systems. During the winter season, emissions from household coal combustion, coal-fired power plants, and motor vehicles combine with temperature inversions that trap pollutants near the ground, resulting in extremely hazardous air quality (Figure 1).

Therefore, over the past three decades, Ulaanbaatar has become one of the most severely polluted cities in the world. During winter, concentrations of fine particulate matter (PM2.5) have frequently exceeded the World Health Organization (WHO) guideline levels by more than 20-fold, with daily average concentrations often reaching 550–650 μg m^3 during the coldest periods *(5)*.

Air pollution in Mongolia is characterized not only by its high concentration but also by its complex composition. Major pollutants include polycyclic aromatic hydrocarbons (PAHs), heavy metals such as arsenic and cadmium, volatile organic compounds (VOCs), and ultrafine particulate matter. Many of these substances are classified as Group 1 carcinogens by the International Agency for Research on Cancer (IARC) (6). Consequently, the prolonged exposure of Ulaanbaatar residents to these pollutants may have contributed substantially to the country's current cancer burden and elevated cancer risk.

The human impact of cancer is evident throughout Mongolia, where the disease continues to impose a substantial burden on patients, families, and the healthcare system. Medical and public health professionals recognize that cancer is a multifactorial disease influenced by numerous genetic, behavioural, environmental, and social determinants. However, I was surprised when some officials questioned my public comments regarding the potential relationship between air pollution and cancer risk. While scientific debate is essential, dismissing the possibility of such a relationship overlooks a growing body of evidence linking long-term exposure to air pollution with increased cancer incidence and mortality.

One of the most compelling studies demonstrating the carcinogenic effects of air pollution was published in 2022. Study of "Hepatocellular Carcinoma in Mongolia Delineates Unique Molecular Traits and a Mutational Signature Associated with Environmental Agents" provided some of the strongest molecular evidence linking air pollution exposure to Mongolian liver cancer development.

This study identified four mutational signatures in Mongolian hepatocellular carcinoma (HCC), including a novel signature, SBS Mongolia, which was detected in 25% of cases and was strongly associated with exposure to dimethyl sulfate (DMS), a probable carcinogen linked to coal combustion *(4)*.

Nevertheless, skepticism regarding these findings persists despite the increasing strength of scientific evidence. Although all residents of Ulaanbaatar are affected by severe air pollution,

the most vulnerable populations are those living in ger districts and young children. Residents of ger districts experience the highest levels of chronic exposure due to household coal combustion, poorer neighborhood air quality, and limited access to cleaner energy sources. These conditions contribute to a greater cumulative risk of developing pollution-related diseases, including various types of cancer.

Children are particularly vulnerable to air pollution, as exposure during critical stages of development can impair lung growth, compromise immune function, and adversely affect long-term health outcomes. Early-life exposure is of particular concern because of its potential to increase disease risk throughout the lifespan. Supporting this concern, Guo et al. (2019) reported that each 10 μg/m^3 increase in long-term PM2.5 exposure was associated with a 22% increase in cancer mortality risk *(7)*. Given that PM2.5 concentrations in Ulaanbaatar have frequently exceeded this level by 20–30-fold over many years, the potential implications for future cancer burden and population health are substantial.

The findings from the study of "Hepatocellular Carcinoma in Mongolia Delineates Unique Molecular Traits and a Mutational Signature Associated with Environmental Agents" challenge the traditional view that liver cancer in Mongolia is driven primarily by viral hepatitis. Instead, it requires us to incorporating environmental risk into cancer control programmes, expanding prevention strategies beyond infection control and specifically, recognizing air pollution as a major carcinogenic exposure. Accordingly, reducing air pollution and strengthening population-based prevention strategies were identified as key priorities during the development of Mongolia's National Cancer Control Plan following the IAEA 2024 imPACT Review Mission.

Policy implications and future directions

So, it is well known that reducing air pollution should be one major opportunity for cancer prevention in Mongolia, as environmental exposures can be addressed through effective policies and infrastructure improvements. Key strategies could include reducing coal dependence through cleaner energy sources, improving housing and heating systems, expanding sustainable transportation, and strengthening urban planning. International partnerships can support these efforts through technical and financial assistance. Further research, including long-term exposure studies and integration of environmental data into cancer registries, is needed to strengthen the evidence base for policymaking. Beyond its health impacts, air pollution also creates substantial economic costs, making investments in clean air both a public health and economic priority.

The persistence of severe air pollution reflects longstanding challenges in environmental governance, policy implementation, and institutional continuity. Frequent administrative turnover and inconsistent prioritization of public health objectives have hindered the development of sustainable long-term solutions. Although the need to reduce air pollution and strengthen cancer prevention is widely recognized, implementation remains challenging without stable governance structures, institutional capacity, and sustained political commitment. So, it is unfortunate that Mongolian HCC has identified with as unique molecular traits with a high mutational burden that has affected by complex of factors and its novel mutational signature associated with genotoxic environmental factor, coal combustion, which had been present in this country for last three decades.

We have many bitter lessons. In the "Mongolia Sustainable Development Vision 2030," adopted by the State Great Khural in 2016, Mongolia committed to reducing cancer mortality from 128 deaths per 100,000 population to 105 during Phase I (2016–2020), 90 during Phase II (2021–2025), and 80 during Phase III (2026–2030) *(8)*. The reality, however, has moved in the opposite direction. Rather than falling to the targeted level of 90 deaths per 100,000 population by 2025, cancer mortality has risen dramatically to 176.2 deaths per 100,000 population *(1)*. This stark discrepancy reflects not merely a failure to achieve national health targets, but a broader failure of governance and health policy implementation.

Without meaningful reforms, the situation is likely to worsen. Persistent political interference in the health sector, unstable governance, limited institutional capacity, and the continued neglect of public health priorities have collectively undermined efforts to reduce the burden of cancer. Unless policymakers recognize public health as a national development priority and commit to evidence-based decision-making, the gap between policy aspirations and health outcomes will continue to widen.

At last, Mongolia represents a unique case where molecular oncology, environmental health, and public policy intersect. The genomic evidence from HCC studies provides that air pollution is not merely a background risk, it is a central driver of disease that must be addressed within non-communicable disease planning and cancer control frameworks. In otherwise, long-term exposure to severe air pollution will not only continue to deteriorate population health but may also contribute to cumulative genetic and epigenetic damage, increasing the burden of cancer and other chronic diseases in future generations. ■

References

1. Annual statistics of Cancer. Division of cancer registration. *National Cancer Center of Mongolia.* 2025
2. Cancer Factsheets/Mortality,2022. *Cancer today*. DataViz. IARC, WHO. https://gco.iarc.who.int/today/en/dataviz. Retrieved May 16, 2026.
3. Batsaikhan O, Chimed-Ochir O, Kubo T, Jigjidsuren C, Delgermaa V, Purevdagva A, Sarankhuu A, Nansalmaa E, Tsegmed U, Davgasuren B, Purev O, Mokdad AH, Weaver ND, Erkhembayar R, Murray CJL and Naghavi M (2024) The burden of liver cancer in Mongolia from 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. Front. *Oncol*. 14:1381173. doi: 10.3389/fonc.2024.1381173
4. Torrens L, Puigvehí M, Torres-Martín M, et al. Hepatocellular carcinoma in Mongolia delineates unique molecular traits and a mutational signature associated with environmental agents. *Clin Cancer Res*. 2022;28(20):4509–4520.
5. Soyol-Erdene, T.O., Ganbat, G., Baldorj, B. (2021). Urban Air Quality Studies in Mongolia: Pollution Characteristics and Future Research Needs. *Aerosol Air Qual. Res.* 21, 210163. https://doi.org/10.4209/aaqr.210163
6. "List of Classifications, Agents classified by the IARC Monographs, Volumes 1–124". IARC Monographs on the Evaluation of Risk to Humans. *IARC*. July 7, 2019. Retrieved May 18, 2026.
7. Guo, Yuming & Teixeira, João Paulo & Ryti, Niilo. (2019). Ambient Particulate Air Pollution and Daily Mortality in 652 Cities. *New England Journal of Medicine*. 381. 10.1056/NEJMoa1817364.
8. State Great Khural of Mongolia. Resolution No. 19: Mongolia Sustainable Development Vision 2030 [Internet]. Ulaanbaatar: State Great Khural of Mongolia; 2016 Feb 5 [cited 2026 Jun 9]. Available from: https://legalinfo.mn/mn/detail?lawId=207105&showType=1

Achieving universal health coverage for Palliative Care: A Case Study of integration of palliative care into Government primary healthcare from South-Central, India

Gayatri Palat, MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad, India; **Gillian Fyles,** Two Worlds Cancer Collaboration Foundation; **Sri JN Jagannath,** Pain Relief and Palliative Care Society, Hyderabad, India; **Vineela Rapelli,** Pain Relief and Palliative Care Society, Hyderabad, India; **Priya Kumari,** Pain Relief and Palliative Care Society, Hyderabad, India; **Swarup Immaraju,** Pain Relief and Palliative Care Society, Hyderabad, India; **Simon Sutcliffe,** Two Worlds Cancer Collaboration Foundation; **Stuart Brown,** Two Worlds Cancer Collaboration Foundation and **Megan Doherty,** Two Worlds Cancer Collaboration Foundation; University of Ottawa, Ottawa, Ontario, Canada and Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada


GAYATRI PALAT


GILLIAN FYLES


SRI JN JAGANNATH


VINEELA RAPELLI


PRIYA KUMARI


SIMON SUTCLIFFE


STUART BROWN


MEGAN DOHERTY

Background: Integrating palliative care into primary care is essential to achieving universal health coverage; however, there is limited evidence of models of primary palliative care in resource-limited settings. The existing literature describes small-scale programmes, most often funded by civil society organizations; and there is limited evidence describing the integration of palliative care into government primary health care systems, critical to reaching the entire population.

Setting: The state government primary healthcare system in the state of Telangana, in South-Central India (state population – 39.6 million).

Objectives: To describe the context, process, challenges, opportunities, and outcomes of a large-scale state-wide model integrating palliative care into government primary healthcare to achieve universal coverage.

Methods: This is a descriptive case study describing the implementation of a primary palliative care model.

Results: Thirty-three district palliative care centres were established within the government primary care system, at each of the district hospitals in the state. Each palliative care centre provided home-based care, as well as outpatient and inpatient palliative care (10 bed ward). Each district centre was staffed by a dedicated team of nurses, a physician, a physiotherapist, and support staff. Staff received palliative care training through a 4-week residential course delivered by an established palliative care organization, which participated in the initiative as a knowledge partner. The training included theoretical and clinical components and was followed by ongoing mentoring and clinical supervision. A statewide referral network was also established to support bi-directional referrals between district centres and tertiary health facilities. The programme cared for 29,000 patients in the first five years, and opioids availability increased at all 33 district hospitals.

Conclusion: It is possible to implement a model of primary palliative care which is integrated into the government primary healthcare system and covers a large population. The critical components of the model which enabled success included partnerships between the local government health system, civil society, and tertiary health facilities; high-quality staff training combined with ongoing clinical supervision; establishing referral pathways; and ensuring access to opioids and other essential medicines.

Significance of the results: This is the first study to describe a large-scale primary palliative care model in an low- and middle-income country (LMIC). The study is particularly important as it is the first to demonstrate a model integration into the government-funded primary health care system, ensuring population-level palliative care coverage. The study identifies the context and processes which support health system integration of palliative care and suggests a model which can be implemented more broadly in primary health care systems globally.

Keywords: Low- and middle-income countries, end-of-life care, palliative care, implementation study, primary healthcare, universal health coverage

Palliative care is an approach to address the needs of people with serious illnesses, focusing on improving quality of life by preventing and relieving physical, emotional, social, and spiritual suffering for patients and their families and caregivers. Globally, every year more than 70 million people, include 25 million in the last year of life, require palliative care *(1)*. Despite the substantial need, fewer than 12% of those needing palliative care can access it. Currently, most palliative care is being provided in high-income countries, while 80% of the need for palliative care is in low-and middle-income countries (LMICs), leading to huge burden of preventable serious health-related suffering *(1,2)*. The World Health Organization (WHO) has identified palliative care as an essential component of universal health coverage (UHC), which is best achieved through primary healthcare *(3)*.

In India, an ageing population and growing burden of non-communicable diseases is leading to a growing need for palliative care. For cancer alone, there are an estimated 916,000 deaths each year *(4)*. Many more patients with chronic heart, lung, and kidney diseases, HIV/AIDS, dementia, and other life-limiting conditions also need palliative care; however, palliative care reaches only 4% of patients needing it across India *(5)*. Moreover, palliative care services are not well distributed, with services concentrated at tertiary hospitals in urban areas, while 64% of the population lives in rural areas. Expanding access in rural areas is particularly important for palliative care, since patients with serious illnesses cannot easily travel beyond their local community and they spend most of their time at home *(6)*.

Primary palliative care, which is provided by non-specialists in primary care settings, is an important intervention which can meet the needs of patients and their families. For patients and their families, this model of care improves health, by treating physical symptoms and psychosocial distress, and it reduces direct and indirect healthcare costs for patients *(7,8)*. Primary palliative care offers additional benefits for health systems by improving the cost-effectiveness and sustainability of services *(9,10)*.

A limited number of primary palliative care models have been described in LMICs, and these models have described small-scale programmes at one or several health facilities, usually with funding from civil society organizations *(7)*. There have been very few studies describing primary palliative care models which adopt a public health approach, seeking to ensure palliative care coverage for the population of an entire country or region. One example of population-level coverage is found in the southern Indian state of Kerala, where home-based palliative care is provided by health professionals and trained volunteers, funded by donations from the local communities. Kerala's unusually high literacy rates, long-standing decentralized governance, strong public health infrastructure, and distinctive political economy differ markedly from most Indian states and the expansion and scaling-up of the Kerala model will require adaption and contextualization. Further studies are needed to understand models of primary palliative care which can be integrated into the government primary healthcare systems and which can be scaled-up to cover the entire population *(11)*.

The purpose of this study is to describe the context, process, challenges, opportunities, and outcomes of a large scale, state-wide initiative integrating palliative care into government primary healthcare in the state of Telangana to provide coverage for the entire population. The study explores the adaption and performance of a novel model of primary palliative care, seeking to identify key insights that can be applied to government primary healthcare systems to provide palliative care coverage at a population-level.

India's economic, political, and social context

India is a lower-middle income country and government spending on healthcare is US$ 37 per capita, or 3.3% of GDP, compared to the global average of 10.4% *(6)*. India has a multi-payer universal healthcare model, which includes publicly insured services as well as government-regulated private insurance and out-of-pocket spending. Government healthcare in Telangana includes basic primary, secondary and tertiary care services for all state residents, and the system is largely free for users. However, due to long wait times and low quality care, higher income groups typically seek private care, and as a result out-of-pocket health spending makes up 49.8% of total health spending (6).

Organizational context

The Telangana primary palliative care programme was implemented by the state government in partnership with Pain Relief and Palliative Care Society (PRPCS), is a local civil society organization with 15 years' experience providing palliative care in Hyderabad, the capital of Telangana. PRPCS provides large home-based palliative care and runs a community-based hospice facility (12). In the Telangana primary palliative care programme, PRPCS was designated by the government as a "knowledge partner", providing training to programme clinical staff as well as ongoing mentorship and clinical support. Additional knowledge support was provided by Two Worlds Cancer Collaboration a Canadian charitable foundation with a long-standing partnership with PRPCS, which provided financial support for training clinical staff and service delivery. The annual patient care volumes for PRPCS are shown in Table 1.

Methods

This study employed a descriptive case study methodology,

Table 1: **Summary of annual palliative care services in 2024**

Pain relief and palliative care society

Type of visit	Children	Adults
Consultation (new patient)	180	1224
Hospice admissions	367	1039
Home-care visits	3738	12093

with findings reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. The Consolidated Framework for Implementation Research (CFIR) guided the development of the research questions and the analytic approach.

Qualitative data were collected through semi-structured interviews with key stakeholders involved in the implementation process to explore the innovation, its context, and implementation processes, as well as perceived challenges and opportunities. Additional qualitative data sources included non-participant observations and document review to identify and triangulate key elements of the implementation process. Quantitative data were extracted from relevant programmatic databases to support reporting on programme outcomes.

Data analysis followed the review and recommendations of Ebneyamini et al. and involved iterative processes of data display, conclusion drawing, verification, and explanation building. Members of the research team synthesized and organized case study features – including context, process, challenges, opportunities, and outcomes – using CFIR constructs, with the aim of generating findings relevant to future research in this field.

Member checking was conducted by sharing analyzed findings with participants in written form. Participants who engaged in member checking were invited to join the research team to enhance global representation and contextual interpretation. All feedback received through this process was systematically reviewed and considered for inclusion in the final presentation of results.

Results

Developing and refining the Telangana primary palliative care model

In 2007, the first District Palliative Care Centre (DPCC) was created by PRPCS in partnership with the Department of Health and Family Welfare in Rangareddy, a rural district close to Hyderabad. A needs assessment was first conducted via household survey, identifying the characteristics and needs of local people with serious illnesses. The DPCC started by providing home-based care and then expanded to an outpatient clinic and an inpatient unit, located at the local government primary health centre. Programme staff eventually included nurses, support staff, a physician, and a van driver. A morphine licence was obtained, allowing opioids to be administered and dispensed.

Developing the Rangareddy DPCC helped develop and refine a contextualized model for providing palliative care at the primary care level in Telangana. In 2017, the government created eight DPCCs in other districts, eventually opened DPCCs in all 33 districts over the next two years. PRPCS collaborated with the government throughout this expansion, training DPCC staff and providing ongoing mentorship and support to address implementation challenges, with a particular focus on supporting opioid access.

PRPCS provided practical guidance about infrastructure, recruitment and training of staff and supported government health planners as they developed a shared understanding of how palliative care could be integrated into primary care.

Characteristics of the Telangana primary palliative care model

Core components of the DPCC

Each DPCC consists of an inpatient ward, an outpatient clinic, and a home-care service. The DPCC is physically located within the local district government hospital. Each DPCC provides core palliative care services, including treatment of pain and other common physical symptoms (e.g., nausea, dyspnea) and psychosocial and spiritual support for patients and families. Each DPCC also included clinics for lymphoedema, wound and stoma care, and cancer survivorship.

Physical space and supplies

Each DPCC inpatient wards has 10 beds and provides a bed for one family member to stay overnight, encouraging family presence. A kitchen was available where caregivers could prepare food, as well as an office and training space for staff. Food, essential medicines, basic medical supplies, all visits (outpatient or home), and admissions were provided free of charge. Each DPCC had a van stocked for home-care, and staff could dispense essential medicines and supplies during home visits.

Essential medicines and opioid access

DPCCs were required to obtain a morphine licence and have opioids available on site, thus avoiding the need for patients to travel to urban centres for medicines. Initially, opioid licensing was a significant challenge because each district drug inspector had an individual interpretation of the licensing process. To speed up licensing, PRPCS worked with the state drug controller to develop a common checklist and process,

Table 2: Essential elements of the checklist for obtaining opioid approval at DPCC, based on the Narcotic Drugs and Psychotropic Substances Act

Pharmacy: Establish and document pharmacy processes for maintaining accurate records of opioid procurement, safe storage, and dispensing.
Physician: Documentation of physician training through 1-month certificate course from PRPCS and MNJIO.
Prescribing: Develop appropriate prescribing documentation and ensure safe storage on ward.
Following submission of proper documentation, the district drug inspector conducts a site visit, prepares a report, and, providing all the elements are satisfactory, approval will be granted.

thereby standardizing the process for all districts (Table 2).

Health workforce and training

The DPCC dedicated staff team included full-time clinical and support staff of five nurses (inpatient [3], home-care [1], relief coverage [1]), three support stuff, a physiotherapist, a physician, and a driver. All staff were government employees.

Clinical palliative care training

All clinical staff completed the Basic Certificate in Palliative Care, a 1-month residential course, delivered by PRPCS. This standardized national course is delivered at palliative care centres across India, includes clinical training in the management of common physical, psychosocial, and emotional problems. The training emphasizes multidisciplinary care and the integration of palliative care into serious illness management. Training was delivered in Hyderabad with clinical exposure to home and facility-based palliative care, as well as classroom teaching and learner assessments.

Mentorship and clinical supervision

To provide additional support, PRPSC palliative care physicians and nurses provided DPCC staff with regular support through daily checks, virtual case conferences, and monthly site visits. Virtual case conferences consisted of monthly online teaching and case discussion sessions *(13)*. Daily checks were done by phone call or instant messaging with the DPCC team, reviewing admissions and clinical concerns. These three supports were continued until the end of 2021, when PRPCS staff determined that DPCC were functioning independently, and ongoing clinical support was transitioned to the referral network (see section below).

Community empowerment and awareness

Raising awareness about palliative care within the local communities was an important component of the programme, and awareness sessions (3 hours) were conducted in all districts. The sessions targeted government health administrators, primary care health workers (nurses and doctors), accredited social health activists (ASHAs), and auxiliary nurse midwives (ANMs).

Table 3: Training and awareness activities linked to DPCC (2019–2024)

Training: Certificate in Palliative Care (1-month residential course)

Type of health worker	N
Nurses	195
Doctors	42
Physiotherapists	35
Total	**272**

Awareness Sessions (3 hours)

Type of health worker	N
Accredited social health activists (ASHA) Workers	8,500
Mid-level health providers	2,450
Auxiliary nurse midwives (ANMs)	900
Primary healthcare physicians	750
Total	**12,600**

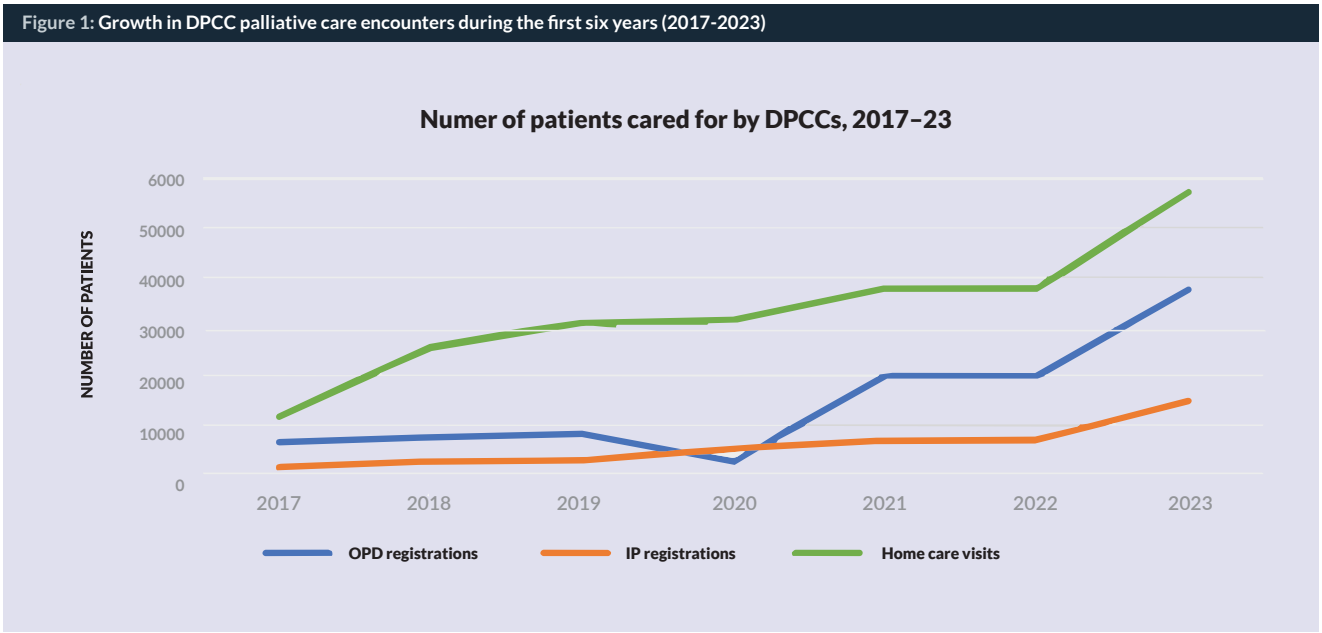
ASHAs and ANMs are community health workers providing the first point of contact for health and social care in rural areas. The awareness sessions focused on how to identify and refer people with a serious illness and how palliative care could help. Table 3 shows the number of health and social care workers who participated in training and awareness activities.

The DPCC programme was positively received in the local communities and strong government awareness about palliative care developed beyond the department of health, as government administrative staff frequently moved to other parts of the government, and in this way, awareness spread throughout the government.

Policies and administrative structure

Within the Department of Health and Family Welfare, a palliative care team was established. The team consisted of a state programme officer and three deputy programme officers who oversaw administration of the DPCCs. Working with district programme officers, this team supervised staffing, funding, medicines, equipment, data collection, evaluation and reporting. Standard monthly reporting templates were developed for DPCCs, and reporting audits were regularly conducted. The government set performance targets of 25–30 admissions and 200 home care visits per month for each DPCC.

Figure 1: **Growth in DPCC palliative care encounters during the first six years (2017-2023)**



A palliative care referral network

A referral network connecting the government cancer and children's hospitals in Hyderabad and the DPCCs was established. This network provided DPCC clinicians with rapid access to the palliative care specialists in Hyderabad for clinical questions and to clarify shared care plans. Gradually, other hospitals in Hyderabad began to use this network to referring patients to DPCCs.

Patients who had come to Hyderabad for care were referred to the local DPCC at the time of discharge or when they were returning home. The local DPCC team would then conduct a home visit to make the patient aware of the local DPCC services emphasizing that the DPCC was their primary point of contact. The DPCC and Hyderabad palliative care teams conducted monthly joint case review meetings to review and coordinate care. For patients coming home from Hyderabad with advanced progressive illness the teams coordinated end-of-life care, with the Hyderabad palliative care team developing an end-of-life care plan which was then reviewed with the DPCC team by phone. Following an initial home visit by the DPCC team, an update was sent back to the referring team in Hyderabad and the DPCC clarified the care plan as needed.

An additional element of the referral network was from community health workers (e.g., ANM, ASHA) who were encouraged to refer patients who they felt could benefit from palliative care.

Performance of the intervention

At the end of the study timeframe, the centres were well established and confident in providing core palliative care services. Morphine was available in all districts, ensuring access in all areas of the state. There were 330 palliative care inpatient beds at the primary care level, with 1,500 admissions per month and more than 300 home-based care visits occurring daily. Between 2017 and 2024, there were more than 330,000 palliative care clinical encounters in DPCCs, with a steady increase in the number of patients seen (Figure 1).

Discussion

The case study describes the development and implementation of a state-wide primary palliative care programme, a model for integration of palliative care within the existing government health and social care system to achieve population-level coverage, in this case for almost 40 million people. The "Telangana model" demonstrates that primary palliative care can be provided alongside active disease treatment, using a combination of in-patient outpatient, and home-based care. A skilled and trained health workforce is an essential component of the programme, with a team of full-time primary care providers in each district in the state providing palliative care. Health policies including morphine licensing and a statewide referral network to facilitate transitions between tertiary hospitals, district health facilities, and patients' homes improves care coordination. The Telangana model shows that it is possible to support patients needing palliative care in rural areas, including supporting end-of-life care closer to home, reducing reliance on tertiary health facilities and palliative care specialists.

Globally, the development of primary palliative care remains limited, with few successful large-scale initiatives having been described in the literature. Successful primary palliative care health service integration should consider key elements from the WHO health system building blocks, which include health workforce education and training, essential medicine

availability, health policies, empowering communities, and service delivery *(14)*. These building blocks have been organized into the WHO conceptual model of palliative care development (Figure 2). This model, which was developed through a structured, evidence-based consultative process with global experts and pilot testing in diverse country contexts, provides an outline of the core health systems considerations for primary palliative care service delivery models *(15)*.

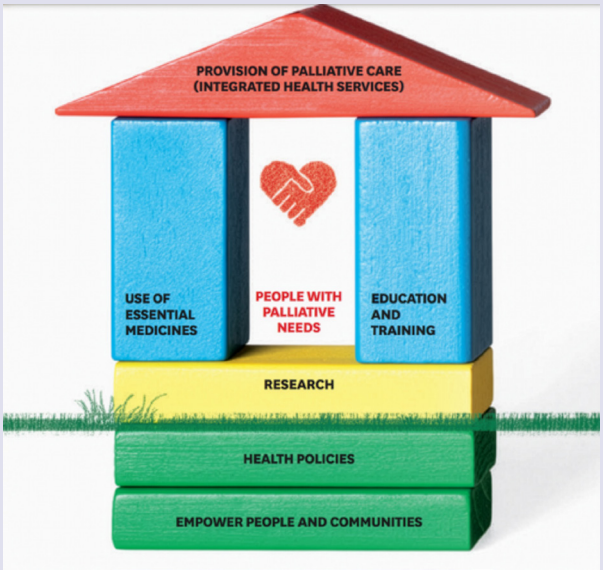
Provision of palliative care (integrated health services)

The development of the Telangana model of primary palliative care began with development and refining of the pilot DPCC in Rangareddy in 2007. The pilot phase was critical for the future success and scaling up of the model because the pilot phase allowed government and civil society partners to test and refine components of this new model in a real-world setting. By monitoring the programme and its impacts, the team was able to identify core palliative care interventions which could be provided within the local primary care model, ensuring that the supports were practical, culturally appropriate and meeting local needs and priorities. An important action in this phase was to conduct a household needs assessment survey to develop an in-depth understanding of the types of illnesses which were present in the local population and characterize their palliative care needs. Over time, clinical services were adapted to better meet local needs, with expansion from exclusively home-based care to include an outpatient clinic and eventually an inpatient palliative care unit. This reflects previous experiences from Malawi, where patients and caregivers preferred to receive palliative care either at home and from local health posts or clinics *(16)*. The pilot phase also allowed government and civil society to collaborate closely and build trust, through co-design of the project and joint problem-solving. These early actions created a strong foundation for the larger partnership during scaling up of the model.

Education and training

Clinical staff in the Telangana model were provided with high-quality palliative care training along with ongoing mentorship and sustained clinical supervision, which were key elements which leading to the programme's success. The initial training of DPCC staff used a standardized national course, thereby ensuring that all clinical staff had baseline competency with core palliative care skills. PRPCS's support as a knowledge partner was particularly important in ensuring that the training was not only clinical-relevant and context specific, while also providing health workers with hands-on experience to build clinical competence. The quality of training was particularly important for primary palliative care service expansion, since

Figure 21: Conceptual model of palliative care development



palliative care was not incorporated into undergraduate medical training for doctors in India until 2019. In 2021, palliative care was added to undergraduate nursing training, with a 20-hour mandatory module. The training delivered through the Telangana model also recognized that beyond one-time training, health workers require ongoing mentorship and clinical supervision to support practice change to deliver palliative care *(17)*. The model incorporated longitudinal support via monthly online teaching and case discussions, by connecting clinicians with expert faculty from their initial training. Connecting clinicians with familiar faculty from PRPCS further enhanced the support, helping participants to feel more comfortable posing clinical questions and sharing insights from their experiences. Daily checks via phone or messaging provided a low-cost, efficient solution to further support DPCC clinicians, providing ongoing connecting to faculty for clinical support. Further efforts to increasing health workforce capacity include regular certified training courses and standardized management protocols and guidelines, which could further support DPCC teams to provide optimal palliative care.

Health policies

Expanding palliative care within primary care to provide population-level covered for almost 40 million people was feasible only by addressing critical aspects of health policy and system, to ensure that the resources and activities of the health system were aligned with the initiative. Creation of a statewide referral network was essential for ensuring good coordination of care and reducing the need for patients to travel to Hyderabad for care. This reflects a key element from the Kerala model, which recognizes that people with a serious

illness spend most of their time at home, and that the local community should be the primary location of care. Addressing inconsistency in opioid licensing requirements was critical to ensuring essential medicine access in Telangana, which reflects the global palliative care literature which consistently identifies access to controlled medicines, particularly morphine, as indispensable to effective palliative care *(5,18)*.

Conclusions

The Telangana Model of DPCC represents one of the first initiatives describing the scaling up of primary palliative care services within government primary care, through collaboration between state government and civil society. Successful primary palliative care initiatives which achieve population coverage require a health systems approach, which incorporates the WHO conceptual model of palliative care development. These initiatives should consider service delivery models which include home- and facility-based care which is practical, culturally appropriate and addresses local needs and priorities. Additional considerations include providing ongoing clinical support from local experts beyond initial palliative care training, as well as considering solutions to address the need for referral networks and access to opioids.

Ethics Declaration: *This research was conducted in accordance with the World Medical Association Declaration of Helsinki. The study design and data analysis are based on publicly available information. The study does not involve direct interaction with human subjects or access to confidential information.*

Author contributions: *Conception and Design: GP, JNJ, VR, PK, SI, SB Collection and assembly of data: GP, VR, MD*
Data analysis and interpretation: GP, VR, MD, SB
Drafting of the article or revising it for intellectual content: all authors
Final approval of manuscript: *all authors*
Accountable for all aspects of the work: all authors

Acknowledgments: *The authors would like to acknowledge the support of Two Worlds Cancer Collaboration Foundation and Pain Relief and Palliative Care Society for their support with the implementation of palliative care programmes.*
Funding: *No funding was obtained for this study.*
Competing interests: *All authors have no conflicts to declare.*
Availability of data and materials: *Available upon request.*

Other Author's Emails:
Gayatri Palat, gpalat@gmail.com
Gillian Fyles, mfyles@shaw.ca
JN Jagannath jagannath52@yahoo.com
Vineela Rapelli vineela.rapelli@gmail.com
Priya Kumari drpriyarcc@gmail.com
Swarup Immaraju immaraju.swarup@gmail.com
Simon Sutcliffe cci-cancercontrol@shaw.ca
Stuart Brown stuart.brown@twoworldscancer.ca
Camara Van Breemen camaravanb@gmail.com

Dr Megan Doherty is a specialist in children's palliative care and the Director of the Sunflower Children's Network, a children's palliative care initiative of Two Worlds Cancer Collaboration. She has been involved in the development of clinical programmes and training to support the implementation of palliative care in a wide variety of settings globally. She is also a palliative care consultant with the World Health Organization. She is passionate about providing palliative care knowledge and skills to healthcare professionals and developing tools and guidelines to support greater implementation of palliative care within primary care and universal health coverage.

JN Jagannath (Jagannath Jayanthi Narasimham) is the President of the Pain Relief and Palliative Care Society (PRPCS). He is a retired Additional General Manager from the Indian Railway Traffic Service (IRTS) who has dedicated his post-retirement life to managing the NGO's healthcare and fundraising initiatives. He manages a multi-disciplinary staff of over 48 medical professionals (including doctors, nurses, and social workers) who treat terminally ill patients. He oversees operations for a 45-bed hospice facility (Kumudini Devi Hospice) alongside a network of 12 mobile homecare teams.

Dr Simon B Sutcliffe is a clinical oncologist (retired) and President of Two Worlds Cancer Collaboration (TWCC), a volunteer-based, non-profit, non-governmental society, engaged in global cancer control through collaboration and partnership particularly in South and Southeast Asia. A medical and radiation oncologist specializing in lymphomas and haematological malignancies, he has served as President and CEO of Princess Margaret Hospital, Toronto, Canada and the BC Cancer Agency (British Columbia, Canada), and been actively engaged in population-based cancer control planning and global health and cancer control initiatives between lesser and higher-resourced nations.

Dr Gillian Fyles is a retired palliative care physician in Canada, a Director Emeritus of the Two Worlds Cancer Collaboration Foundation and a Clinical Associate Professor in the Department of Family Practice at the University of British Columbia. She was the Medical Leader of the Pain and Symptom Management/Palliative Care Program at the BC Cancer Agency's Sindi Ahluwalia Hawkins Centre for the Southern Interior in Kelowna for almost 20 years.

References

1. Knaul FM, Arreola-Ornelas H, Kwete XJ, et al. The evolution of serious health-related suffering from 1990 to 2021: an update to The Lancet Commission on global access to palliative care and pain relief. *The Lancet Global Health.* 2025;13(3):e422-e436. doi:10.1016/S2214-109X(24)00476-5
2. Connor S. Global Atlas of Palliative Care 2nd Edition. *Worldwide Hospice Palliative Care Alliance;* 2020.
3. World Health Organization. WHA67.19 - Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course. *WHA Resolution; Sixty-seventh World Health Assembly,* 2014 (Arabic version). Published online 2017. Accessed September 30, 2017. http://apps.who.int/medicinedocs/en/d/Js21454ar/
4. Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, Piñeros M, Znaor A, Soerjomataram I, Bray F. *Global Cancer Observatory: Cancer Today.* Accessed December 23, 2024. https://gco.iarc.who.int/today/
5. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet.* 2018;391(10128):1391-1454. doi:10.1016/S0140-6736(17)32513-8
6. World Bank. World Bank Open Data. World Bank Open Data. Accessed December 23, 2024. https://data.worldbank.org/
7. Peeler A, Afolabi O, Adcock M, et al. Primary palliative care in low- and middle-income countries: A systematic review and thematic synthesis of the evidence for models and outcomes. *Palliat Med.* 2024;38(8):776-789. doi:10.1177/02692163241248324
8. Reid EA, Kovalerchik O, Jubanyik K, Brown S, Hersey D, Grant L. Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review. *BMJ Supportive & Palliative Care.* 2019;9(2):120-129.
9. World Health Organization. *Integrating Palliative Care and Symptom Relief into Primary Health Care: A WHO Guide for Planners, Implementers and Managers.* World Health Organization; 2018. Accessed October 11, 2024. https://iris.who.int/handle/10665/274559
10. Gupta M, Ankita K, Joshy LE, et al. Community-based palliative care needs and barriers to access among cancer patients in rural north India: a Participatory action research. *BMC Palliative Care.* 2024;23:1-17. doi:10.1186/s12904-024-01572-7
11. Kumar SK. Kerala, India: A Regional Community-Based Palliative Care Model. *Journal of Pain and Symptom Management.* 2007;33(5):623-627. doi:10.1016/j.jpainsymman.2007.02.005
12. Ishak Tayoob M, Rayala S, Doherty M, et al. Palliative Care for Newborns in India: Patterns of Care in a Neonatal Palliative Care Program at a Tertiary Government Children's Hospital. *Health-Serv-Insights.* 2024;17:11786329231222858. doi:10.1177/11786329231222858
13. Doherty M, Modanloo S, Evans E, et al. Exploring Health Professionals' Experiences With a Virtual Learning and Mentoring Program (Project ECHO) on Pediatric Palliative Care in South Asia. *Global Pediatric Health.* 2021;8:2333794X211043061. doi:10.1177/2333794X211043061
14. Manyazewal T. Using the World Health Organization health system building blocks through survey of healthcare professionals to determine the performance of public healthcare facilities. *Arch Public Health.* 2017;75(1):50. doi:10.1186/s13690-017-0221-9
15. Assessing the development of palliative care worldwide: a set of actionable indicators. Accessed September 19, 2022. https://www.who.int/publications-detail-redirect/9789240033351
16. Herce ME, Elmore SN, Kalanga N, et al. Assessing and Responding to Palliative Care Needs in Rural Sub-Saharan Africa: Results from a Model Intervention and Situation Analysis in Malawi. *PLOS ONE.* 2014;9(10):e110457. doi:10.1371/journal.pone.0110457
17. O'Mahony S, Baron A, Ansari A, et al. Expanding the Interdisciplinary Palliative Medicine Workforce: A Longitudinal Education and Mentoring Program for Practicing Clinicians. *Journal of Pain and Symptom Management.* 2020;60(3):602-612. doi:10.1016/j.jpainsymman.2020.03.036
18. Rosa WE, Knaul FM, Touchton M, et al. Towards opioid access without excess. *The Lancet Public Health.* 2025;10(5):e422-e427. doi:10.1016/S2468-2667(25)00035-0

CANCER CARE AND TECHNOLOGY

Tim Murphy, Principal Consultant, Tim Murphy Consulting, Edmonton, Albert, Canada and **Ewan Affleck,** Senior Medical Advisor - Health Informatics, College of Physicians and Surgeons of Alberta, Edmonton, Alberta, Canada

The leapfrog opportunity: Relational health data governance as the key to improving cancer control in under-resourced nations

Tim Murphy, Principal Consultant,Tim Murphy Consulting, Edmonton, Albert, Canada and **Ewan Affleck,** Senior Medical Advisor - Health Informatics, College of Physicians and Surgeons of Alberta, Edmonton, Alberta, Canada


TIM MURPHY


EWAN AFFLECK

Comprehensive cancer control is impossible without knowing who develops cancer, who dies from it, and who is being left behind. Yet only about 15% of the world's population, and roughly 1% of Africa's population, is covered by population-based cancer registries. Drawing cautionary lessons from wealthy health systems that have built data fragmentation of their own making, this article argues that relational data governance is the foundation on which all functional digital health services including cancer control stand. Digital health is recognized as a sociotechnical discipline, yet historically nations like Canada have focused on technical considerations while neglecting the human relationships that are foundational to high-functioning health data systems. The result is an expensive and complex health data mess that has broken public trust. A young or underserviced health data environment can leapfrog high-resource ecosystems by first investing in relational data governance that will pay long-term dividends in the form of a broad suite of solutions including high-function cancer registries that support healthier populations. This will enhance public trust allowing a country at any resource level to bypass the accumulated complexity of well-resourced nations and build in a few years what others have not achieved in decades.

You cannot control what you cannot count

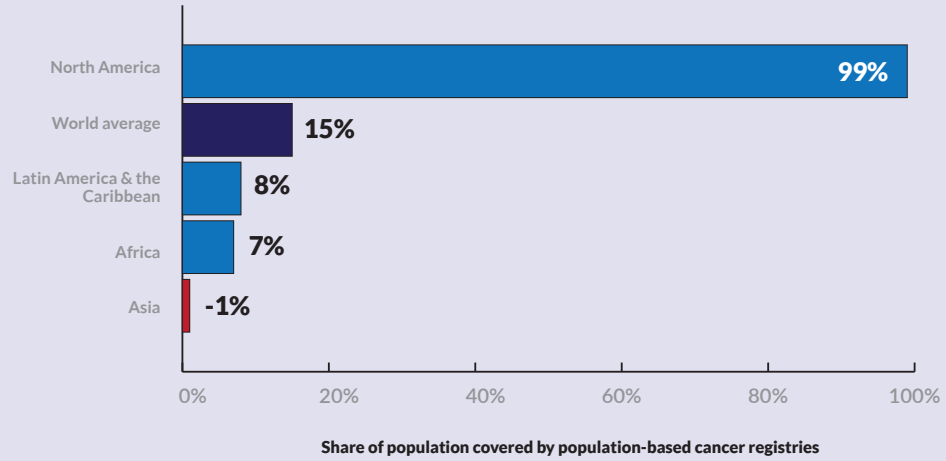
Ask a minister of health what cancer control requires and the response is quick: vaccinations, tobacco control, screening programmes, timely diagnosis, modern treatment, palliative care, and, increasingly, artificial intelligence. All these factors serve as the upper floors of a cancer-control building according to our analogy. For these floors to function beneath them must be a foundation that rarely gets mentioned in political speeches: population-based data that identifies who develops cancer, what exposures and activities put people at risk, who dies from it, and who is being left behind.

The World Health Organization's definition of cancer control is explicit on this point: comprehensive service aims to reduce the incidence and mortality of cancer to enhance the quality of life of those affected, through an integrated approach spanning prevention, early detection, treatment, rehabilitation and palliation *(1)*. The definition is population-based for a reason: incidence and mortality are population measures. A cancer control programme cannot reduce what it cannot measure. Gathering population-level data is crucial and will guide informed action.

Unfortunately, the global cancer data foundation is deficient. Only around 15% of the world's population is covered by population-based cancer registries: coverage approaches 100% in North America but falls to roughly 8% in Latin America and the Caribbean, 7% in Asia and 1% in Africa *(2, 3)* (see Figure 1). The map of cancer data is, almost exactly, an inverted map of cancer need with around 70% of cancer deaths now occurring in low- and middle-income countries *(4)*. Further the inversion is set to deepen; WHO projects that annual cancer cases will rise from an estimated 20.6 million today to nearly 35 million by 2050, with growth concentrated in lower-income countries, where survival is lowest and, as in Africa, registry coverage is thinnest *(5)*. In other words, the burden is growing most rapidly precisely where it is measured the least.

This paper makes three principal arguments. First, population-level data is not a luxury to be acquired after cancer treatment services are built. Health data is the lifeblood of all health programmes and services and is integral to any health system that learns. For cancer control to excel across the full scope of service, access to quality health data is essential; it is the foundation on which every other investment stands or falls.

Table 1: The map of cancer data is an inverted map of cancer need



Source: IARC Global Initiative for Cancer Registry Development (GICR); Omonisi et al., JCO Global Oncology 2020. Draft for redrawing to journal style.

Second, wealth does not necessarily buy that foundation; most high-income nations have spent decades and billions building technology-rich institution-centric information "islands" resulting in a self-imposed data complexity that has become an intractable barrier to essential population-based insight. Third, and most hopeful, countries that have not yet built health data systems are not necessarily behind. Unencumbered by the impediment of fragmented health information technology and by employing a set of principles based on lessons learned, they can build in a matter of years, something that many of the well-resourced countries have failed to achieve in decades.

The costs of an invisible burden

In every health system, budget lines follow numbers, and cancer burdens often exist only as anecdotes: the surgeon's impression, the crowded ward, and the family's grief. These cannot compete with the treasury of diseases that are represented in hard data and statistics. Political invisibility is the first and most expensive consequence of missing population data. This is especially true in the age of artificial intelligence (AI) whose success depends on vast quantities of high-quality data.

The second cost is poor planning. Without knowing which cancer a population has, screening programmes can be poorly targeted, drug procurement mismatched to caseloads, radiotherapy capacity guessed, and palliative care, the intervention most needed where patients present late, not planned at all because late-stage disease is never quantified. Without baseline data, programmes cannot demonstrate that they are working, budget cycles are founded on anecdote, and over time the case for investment grows weaker rather than stronger.

Ultimately, transparent population data creates accountability. A registry gives suffering a denominator. Once the burden of disease is counted, it can no longer be dismissed as anecdote. Someone in power must answer for the number and the question of what will be done about it follows on its own. The absence of data does not make the burden disappear. It silently transfers the cost onto patients, families, communities, and nations and it hands decision-making to whomever holds the data, whether a foreign donor, an industry, or often to no one at all.

A cautionary tale from well-resourced countries

It would be natural to assume that the remedy to this circumstance is money. We suggest that limited financial resources are not necessarily a constraint, and Canada offers some hard lessons in this regard. Canada has universal healthcare coverage, world-class cancer and discovery science, a robust clinical trials apparatus, among the highest per-capita healthcare spending in the world and has invested billions of dollars in health information technology solutions which date back decades. Yet, in 2026 Canada is host to an entrenched health data problem of its own making; a convoluted ecosystem of fragmented health data technologies across ten provincial and three territorial jurisdictions and thousands of institutions that do not, and often cannot, exchange digital data with one another.

Data fragmentation causes widespread harm, both clinical and financial. Picture a frail elderly cancer patient who requires transfer between three care settings in a single week, with each clinician working from an independent and partial clinical record. This is not an uncommon scenario in Canada, where adverse drug events account for up to 7% of acute care hospital admissions, and at least 58% of these are preventable,

driven in part by incomplete medication information *(6)*. A recent economic analysis for the Canadian Institute for Health Information estimated that connecting and properly using Canada's health data could unlock more than CA$ 9.4 billion in value annually *(7)*.

How did a wealthy country arrive at this state? Not through lack of technology: Canada bought plenty of it. The failure was one of sequence: technology first, governance and policy later. Institutions and jurisdictions procured health information technology systems to optimize their internal workflow, with no thought given to data interoperability with the other services with whom they share patients, or even recognition that interoperability was necessary for effective care. Incumbent IT vendors followed suit and profitably sold incompatibility. Over decades a service-centric or custodial model of data governance took root, in which institutions hold data and protect it, from each other, from researchers, and functionally from the patients the system is meant to serve. A recent Canadian report highlighted the root problem; no one oversees the strategic design and use of health data in Canada *(8)*. When no one is accountable for the data foundation, the system on the floors above breaks and no one fixes it. Deploying more technology on top of a weak data foundation makes matters worse.

The lesson is not that rich countries have problems too, but that the failure to effectively leverage health data for public good is self-inflicted and unnecessary. It is the result of the blind deployment of costly technology as a solution to what is, in essence, a problem of human relationships. Digital health technologies do not magically interoperate harmoniously if the people deploying them do not establish a clear model of cooperation.

The Canadian experience reflects an avoidable failure of health data governance and literacy, not financial or technology constraint. Countries now building their data foundations are advised to study the Canadian situation, and health data failures in other developed nations, the way engineers study bridge collapses: the lessons are abundant and can easily inform a path to coherent health data optimization.

Mindset, skillset, toolset – in that order

What led Canada, despite a wealth of financial and knowledge resources, to doggedly pursue the deployment of fragmented digital health systems without recognizing the folly of the strategy? It has been observed that Canada's focus on deploying health information technology has historically not been accompanied by any substantive effort to modernize supporting governance or policy. A recent paper suggests that the Canadian techno-centric digital health focus arose from significant gaps in health data literacy among clinicians, policymakers, and the public. The authors conclude that "without a shared level of literacy across the public, healthcare providers, decision-makers, and researchers, even advanced systems may result in fragmented care, poor decisions, wasted resources, and reduced public trust" (9). This finding suggests that Canada has lacked the literacy, or skillset, to fully understand that investing solely in technology, or toolsets, was not a recipe for success.

Evidence supports this conclusion. Stanford's Digital Economy Lab found in a study of successful enterprise AI deployments, that every dollar of technology investment requires up to ten dollars of "invisible work" – process redesign, policy development, training and change management – before any gain materializes from the technology deployment *(10)*. This is born out in a 2026 study in Africa that found that investment in human factors including policy and practice, training, active stakeholder participation in system design, and integration of digital tools into clinical workflows, are core determinants of successful health information technology projects *(11)*.

Ultimately the techno-centric focus of Canadian digital health initiatives highlights the longstanding "love affair" we have had with the value of technology and our belief in its ability to solve health sector deficits relative to the depreciation of the role human relationships have in health data function. The American Medical Informatics Association has long described health informatics as a sociotechnical domain. In Canada's rush to adopt information technology, we neglected to consider that the matrix of human relationships, and the policy and governance that frames them, need to work harmoniously with the technology we adopt. This highlights the need to shift our mindset away from a singular focus on technology and include consideration of the human interoperability needed to support digital health solutions. Without this shift in our mindset, acquiring the skillset needed to be data literate will continue to be challenging, and the toolsets we adopt will continue to fail.

The leapfrog opportunity

When Africa lacked comprehensive copper telephone networks it did not attempt to catch up by installing landlines; it advanced straight to mobile network technology, and in doing so overtook traditional market structures in telephone access and innovation *(12,13)*. The same leap is available in health data system development. A jurisdiction without legacy analogue hospital systems has no vendor lock-in to escape, nor decades of incompatible records to reconcile, or entrenched custodians set on complying with antiquated, privacy-focused legislation. Starting from scratch is usually framed as a deficit. We believe it is an advantage and one that well-resourced countries would pay dearly to recover.

Leap-frogging does not mean launching a national electronic health record megaproject. Rather, it should begin modestly and purposely consider the full scope of both human and technical factors needed for a small data project to succeed. In this manner, opportunities to learn will be afforded as the scope of the initiative grows.

Consider a population-based cancer registry as a first, affordable, high-leverage data investment. It would be a registry limited to one defined population, a minimum data set, and standard classifications (ICD-11). Consider adopting free, purpose-built software (IARC's CanReg5) and technical support through the Global Initiative for Cancer Registry Development and its regional hubs *(14)*. The growth of registries across sub-Saharan Africa under the African Cancer Registry Network demonstrates that this is feasible in low-resource settings *(15)*. Pause and reflect on what the properties of the data in this registry will need to have to serve the needs of impacted cancer patients. The data will need to follow them across services in their care journey and serve secondary purposes like research and innovation. To do so the data will need to be expressed in a standard language and traverse different data platforms. This will help dictate the partners who will need to collaborate to bring this registry to life and suggest a supportive policy suite, technology standards, and an inclusive and cooperative governance model.

Inevitably errors will be made; building a harmonized health data network is a demanding endeavour. But ultimately this is a sociotechnical effort; success is founded on the ability to forge cooperative relationships around the use of networked technology. The lessons learned from an initial small-scale project such as this can inform an approach to relational governance that is the foundation of much larger optimized health data system function.

Data governance as foundational sociotechnical architecture

Health data systems that work are distinguished from the fragmented majority less by their hardware or budgets than by how they are governed. In our experience, it is the human architecture that frames accountability for data. In our early report, Interoperability Saves Lives, we argued that most failures of health data are not technical but relational, arising from how institutions and providers relate to one another around a shared resource *(16)*. Data governance is the discipline that orders those relationships.

We describe data architecture as sociotechnical deliberately. A registry is never only a database; it is an agreement among people: clinicians, registrars, patients, communities and the state, to responsibly and safely collect, steward and use information about a population, employing technology but held together by trust. A jurisdiction that gets the agreement right can carry a population a long way on modest technology, while one that gets it wrong, as Canada did, will struggle to buy its way out.

Good governance begins with a single act: establish a data stewardship model. Operationally, this is a person or an organization with the authority and the accountability to foster data quality, access and use. From that centre of accountability other design commitments follow, and each is a facet of governance rather than a rival to it. Interoperability, the ability of data to be transmitted and mean the same thing wherever it goes, is as much a human agreement as a technical standard, since a shared minimum data set and a common coding language matter only when the people holding the data have agreed to share and work together. Data integrity, built from quality metrics and data provenance recorded from day one, is what makes the data worth trusting. Data security, kept proportionate to real risk rather than imported wholesale from a wealthy country's compliance apparatus, protects that trust with simple, enforced controls: role-based access, audit logs and encrypted storage. Confidentiality is the promise that makes a population willing to be counted, and it must serve patients rather than institutions. The failed Canadian custodial experiment shows how easily the language of privacy can be conscripted to defend the status quo. Lastly, data sovereignty recognizes that individuals, communities and nations retain rights over their own health information; where registries touch Indigenous and other rights-bearing communities, internationally recognized frameworks such as the CARE Principles for Indigenous Data Governance and the First Nations principles of OCAP® *(17,18)* turn data sharing from that of extraction into partnership, with terms, consent and benefits flowing both ways.

Held together by governance, interoperability and confidentiality do two things that money alone cannot buy. First, they build trust, and a trusted system is one in which people are willing participants in the use of their own health information. Second, they make leap-frogging achievable in practice. They are the reason a jurisdiction, starting today, can build in a few years what the well-resourced country failed to achieve in decades. Cooperative relational data governance is the foundation on which first class data systems are built, not the other way around.

Conclusion

Just as past generations built roads, railways and electrical grids as their public infrastructure, we are building data highways. In order for the data highway to function safely and effectively, it must be managed much like a road system that connects cities towns and countries with a common set of standards (which

side of the road one drives on, what the different colour of lights mean, speed limits, etc.) integrated technology (roads arriving at the edge of a city or a border connect with each other), and clear accountability for who ensures the infrastructure is maintained and functions. Unfortunately, Canada has failed to set agreed upon "rules of the road" for our data highway. There are no common standards for data content and exchange, data from different services and regions do not connect, and it is unclear who is accountable for system oversight. At heart this is a governance failure; it is very challenging for a complex system to function safely and effectively if no one is in charge.

Understood this way, data governance is far more than bureaucratic overhead imposed on a cancer registry: it is what makes the registry functional enough to be useful, trustworthy enough that a population consents to be counted, and it is what lets a young system sidestep the accumulated complexity of older ones. The experience of well-resourced countries teaches that a data governance foundation is very costly and difficult to build after the fact: it must be prioritized, and established deliberately and collectively, from the start.

This relational health data governance foundation is within reach of every nation and jurisdiction at every resource level, because the essential elements of good data governance: interoperability, sovereignty, integrity, security and confidentiality, are crafted from human relationships rather than purchasing power. A young or underserviced health data environment can leapfrog high resource ecosystems by first investing in relational data governance that will pay long-term dividends in the form of a broad suite of solutions including high-function cancer registries that support healthier populations. ■

Tim Murphy, MHA, MBA, is a health innovation executive with more than 30 years of leadership experience in health research, innovation, and system transformation. He is principal consultant at Tim Murphy Consulting, an independent practice supporting health research and innovation initiatives across Canada. Previously, as Vice President of Health at Alberta Innovates, he led programmes that modernized care delivery through data, technology, and patient-centred approaches. Tim holds a Master of Health Administration and an MBA and is a Chartered Professional Accountant. In 2023, he was named Digital Health Canada's Digital Health Executive of the Year. His work is guided by a single purpose: transforming health systems to improve lives.

Dr Ewan Affleck has worked and lived in northern Canada since 1992. He is currently serving as the Senior Medical Advisor – Health Informatics, College of Physicians & Surgeons of Alberta, Strategic Advisor – Clinical and Informatics at the Canadian Institute for Health Information and helped found Networked Health a pan-Canadian collective focused on optimizing health data design and use. He is the past Chief Medical Information Officer of the Northwest Territories, has served on many national health systems expert groups including as Co-Chair of the national Virtual Care Task Force, and a member of the Expert Working Group of the pan-Canadian Health Data Strategy. He was the Executive Producer and co-writer of The Unforgotten (2021), an award-winning film about inequities in health service for Indigenous people living in Canada. In 2013, he was appointed to the Order of Canada for his contribution to northern health care.

References

1. World Health Organization, *National Cancer Control Programmes: Policies and managerial guidelines*, 2nd ed. (Geneva: World Health Organization, 2002).
2. International Agency for Research on Cancer, "Global Initiative for Cancer Registry Development," accessed July 2026, https://gicr.iarc.who.int.
3. Omonisi AE, Liu B, Parkin DM. "Population-based cancer registration in sub-Saharan Africa: its role in research and cancer control", *JCO Global Oncology*, 6 (2020):1721-28.
4. World Health Organization. "WHO: Cancer: key facts," accessed July 2026, https://www.who.int/news-room/fact-sheets/detail/cancer.
5. World Health Organization. "WHO: Global cancer burden growing, amidst mounting need for services," accessed July 2026, https://www.who.int/news/item/01-02-2024-global-cancer-burden-growing--amidst-mounting-need-for-services.
6. Tamblyn R, et al. "Using novel Canadian resources to improve medication reconciliation at discharge: study protocol for a randomized controlled trial." *Trials* (2012): 13:150.
7. Mullie T, Chuck A, Razak F. "A health economic analysis of the potential in transforming Canada's health data systems." *Healthcare Quarterly* 28(2) (2025): 37-45.
8. Affleck E, Tam S, Bucci S, Lindeman C, Hunter R, Mita R, McPhail B, Spithoff S, Murphy T, Krempien J, Kitchen A, MacQueen A, Millar C, Sham C, Krecsy S, Fraser S, Joshi R, Schamper A, Lucyk A. "Data Disarray," (Alberta Virtual Care, 2024), accessed July 2026, https://www.networkedhealth.org/works/data-disarray.
9. Lindeman C, Affleck E, Rees G, et al. "Health Data Literacy in Canada: The Missing Metric in a Data-Rich Era," *Sage Journals, Healthcare Management Forum* (2026) https://journals.sagepub.com/doi/10.1177/08404704261447696.
10. Brynjolfsson E, et al. *The Enterprise AI Playbook: Lessons from 51 Successful Developments.* (Stanford Digital Economy Lab, April 2026).
11. "Nexus between policy and practice in institutionalization of clinical information systems and knowledge management in developing health systems: Context of tertiary hospitals in Malawi." PLOS *Digit Health.* 2026 Feb 17;5(2), accessed July 2026, https://pmc.ncbi.nlm.nih.gov/articles/PMC12912559/.
12. "Many countries are "leapfrogging" landlines and going straight to mobile phones." Our World in Data, April 2026, accessed July 2026, https://ourworldindata.org/data-insights/many-countries-are-leapfrogging-landlines-and-going-straight-to-mobile-phones.
13. "With "Leapfrog" Technologies, Africa Aims to Skip the Present and Go Straight to the Future," *IEEE Spectrum* April 2019, Accessed July 2026, https://spectrum.ieee.org/with-leapfrog-technologies-africa-aims-to-skip-the-present-and-go-straight-to-the-future.
14. International Agency for Research on Cancer.
15. Omonisi. Population-based cancer registration.
16. Affleck, E., Murphy, T., Williamson, T., Price, R., Wolfaardt, U., Price, T., Layton, A., Hamilton, B., Dean, S., Frazer, C., Chapman, A., Shute, R., West., Denman, M., Golonka, R., & Lindeman, C. "Interoperability Saves Lives." (Networked Health, 2024), accessed July 2026, https://www.networkedhealth.org/
17. Carroll SR, Garba I, Figueroa-Rodríguez OL, et al. "The CARE Principles for Indigenous Data Governance," *Data Science Journal* 19(1):43, (2020).
18. The First Nations Principles of OCAP®. First Nations Information Governance Centre, accessed July 2026, https://fnigc.ca/ocap-training.

REFERENCE

68 **Partner organizations**

Partner organizations

Global Health Dynamics and Cancer Control.info work with several organizations to develop their publications and we are grateful for their assistance and insights.

Two Worlds Cancer Collaboration (TWCC)

TWCC's vision is resilient healthcare enabling every person with cancer and other life-limiting illnesses to access compassionate care and live with dignity, hope and the highest quality of life.

Collaborating with partners in India and South Asia, TWCC advances compassionate care for adults and children with life-limiting illness, including cancer, through strategy, leadership and governance; in -person and virtual education, training, skills development, and mentorship, and accessible, affordable services.

TWCC is a volunteer-based, philanthropically-funded non -profit society and charity registered in BC and Canada. Its assets are knowledge, experience, and willingness to help.

Contact: PO Box 30006, North Vancouver, BC, Canada V7H 2Y8 info@twoworldscancer.ca

UK and Ireland Global Cancer Network (UKIGCN)

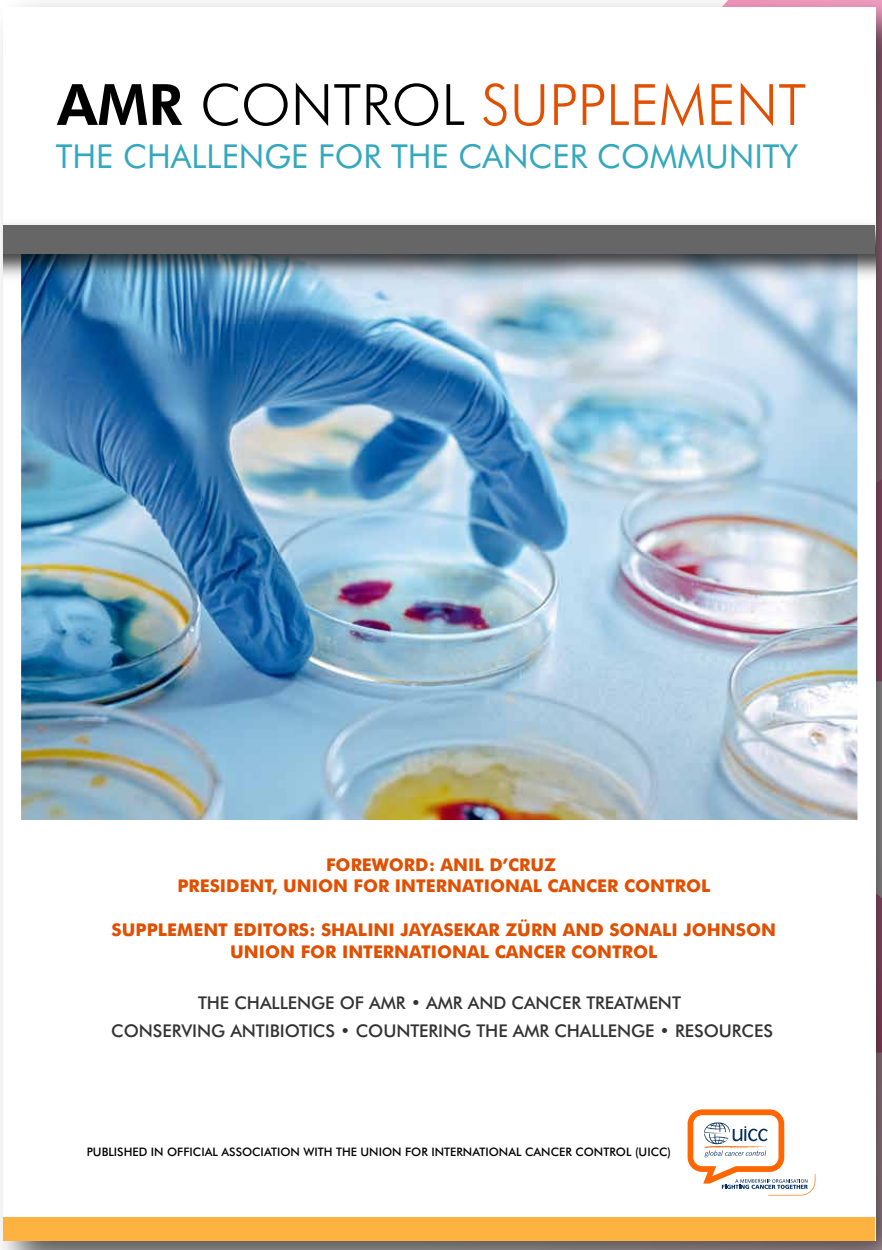
The Network is the independent, not-for-profit network of individuals and institutions based in United Kingdom and Ireland committed to working in partnership with colleagues in low- and middle-income countries (LMICs).

The mission of the UKIGCN is to bring together the talent, resources and enthusiasm of these individuals and organizations in a strategic and collaborative body in ways that improve the outcome and experience of populations affected by cancer in LMICs.

The principal objectives of the UKIGCN are:

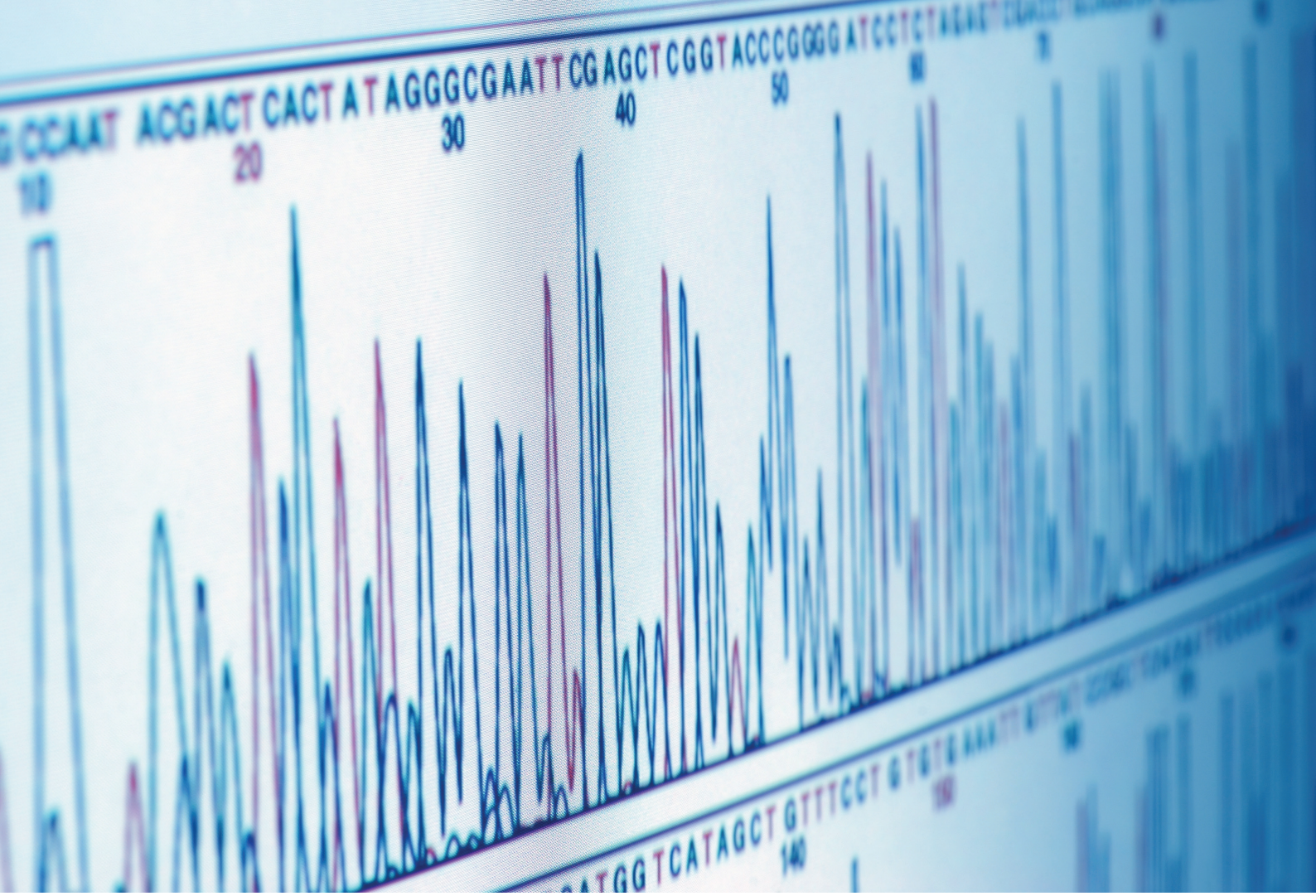
- To serve as a liaison point for a UK and Ireland cadre of Active Members and Supporters committed to working collaboratively with LMIC partners in cancer care.
- To raise awareness by engaging with UK and Ireland professionals, policymakers and the public about the worsening cancer burden in LMIC and how, through working in partnership with LMIC colleagues, together we can have a significant positive impact.
- To act as a catalyst for new UK and Ireland/ LMIC partnerships that contribute to sustainable improvements in cancer prevention, diagnosis, treatment and research that benefit populations in poorer resourced settings.

Contact: info@ukgcn.org



Visit **amrcontrol.info**
to see work on antimicrobial resistance for the cancer community

global health dynamics



global health dynamics

ISBN 978-1-917290-04-3