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# The global challenge of cancer governance

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## Abstract

The global cancer statistics are stark, accounting for nearly 10 million deaths in 2020, around one in six of all deaths globally. The World Health Organization estimates that 70% of these cancer deaths occur in low- and middle-income countries and cancer will continue to rise as a proportion of deaths in these settings. We may usefully characterize cancer as a “social mess,” a set of interrelated problems and other messes including poverty and social determinants of health. One part of cancer’s “messiness” is the governance deficit around cancer burden and regional inequities. This policy paper assesses the field of global oncology governance and the interplay of legal instruments, soft law, national developments, donor activities, as well as partnerships, networks, and coalitions. Cancer governance is central to tackling cancer inequalities. Continuing to probe the complexities of cancer governance requires attention to market mechanisms, international agreements, soft power, political willpower, partnerships, collaborations and networks, and patient participation. Governance is inseparable from “paradigmatic” framings and cancer must be seen as a human rights issue.

## KEYWORDS

cancer governance, global health, LMIC

## Key points

- Cancer is a “social mess,” a set of interrelated problems and other messes including poverty and social determinants of health.
- Cancer governance is central to tackling cancer inequalities: legal instruments, soft law, donor activities, networks, and coalitions.

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- Governance is inseparable from “paradigmatic” framings and cancer must be framed as a human rights issue.

## INTRODUCTION

Global cancer statistics are stark, with nearly 10 million deaths in 2020, around one in six of all deaths globally. The World Health Organization (WHO) estimates that 70% of cancer deaths occur in low- and middle-income countries (LMICs) and cancer will continue to rise as a proportion of LMIC deaths as the result of aging and falling mortality attributable to other causes (Gelband et al., 2016). Cancer leads to immeasurable individual and community suffering. It is also a systemic evil—a barrier to health system-strengthening, sustainable development, and social justice (Daniels & Donilon, 2014; Knaul et al., 2021; Patterson, 2018). For the Global South, the pandemic further compounded the challenges of planning, financing, and implementing adequate cancer control measures (Mutebi, 2021). Cancer is Janus-faced, laying down intensely personal challenges but with solutions that are irrevocably global (research, financing, workforce). Grossi (2022) writes “Cancer is bigger than any one organization or country.” Governance is the heart of tackling the global cancer burden and reducing cancer inequalities, a global health, and social and economic challenges of our time.

## THE “MESSINESS” OF CANCER GOVERNANCE

Cancer is complex both as disease and health system challenge. There are over 600 types of cancer and cancer control activities (prevention, screening, diagnosis, surgery, curative therapies, and palliative care) range across the cancer continuum (WHO, 2020a). It is not straightforward to disentangle cancer from other noncommunicable or infectious diseases (NCDs) (Collins et al., 2019). Many cancer control activities (e.g., trade, transport, environment, education, and fiscal policy) fall outside the healthcare system and may not involve health professionals (Institute of Medicine, 2007). Prevailing assumptions that treating cancers in poor countries is just too difficult or that the disease is the result of individual responsibility help fuel the *5/80 cancer disequilibrium* whereby 5% of cancer spending takes place in LMICs, but those same countries account for 80% of disability-adjusted life years lost to cancer (Farmer et al., 2010). In discussing cancer, we may usefully characterize it as a “social mess” (Horn & Weber, 2007), a set of interrelated problems and other messes including poverty and social determinants of health.

One part of cancer’s “messiness” is the governance deficit around cancer burden and regional inequities (Sullivan, 2018). Cancer is a disease bedeviled by need for cross-border collective action but global interdependency, widely accepted for infectious diseases, remains less well understood for NCDs (Hatefi et al., 2018). Health governance involves multi-level actors—states, intergovernmental organizations, and nonstate actors—but where no centralized authority binds states to rules. Global cancer governance concerns formal *and* informal institutions, rules *and* processes that ensure cross-border action and cooperation (Fidler, 2010). Setting health priorities and allocating available resources are national decisions; however, in LMICs, these decisions are strongly influenced by the global health community, including public, private, and third sector interests, that provide advice, support, and funding (Institute of Medicine, 2007).



## Activating political will

The global prioritization of tackling cancer is relatively recent and explicitly acknowledged in the 1996 *The Global Burden of Disease* (Murray et al., 1996). The 2000 World Health Assembly subsequently endorsed “intersectoral action, appropriate legislation, health care reforms, and collaboration with nongovernmental organizations, industry and the private sector” to tackle NCDs (WHO, 2000). A cancer resolution at the 2005 World Health Assembly called on Member States to develop national cancer plans and reinforce programs, and identified the need for funding mechanisms and treatment options suited to developing countries (WHO, 2005). The Global Action Plan that followed contained interventions to address modifiable risk factors (tobacco, diet, inactivity, alcohol), and highlighted the WHO Framework Convention on Tobacco Control and strategies targeting unhealthy diet and alcohol harm (WHO, 2008).

Cancer was back on the “global menu” with the 2011 UN Political Declaration on Noncommunicable Diseases (Sullivan, 2012), only the second time specific health issues had been discussed at a UN General Assembly (the first being HIV). The meeting focused global attention on NCDs but fell short of providing targets, timelines, or new funding mechanisms (Patterson, 2018). WHO's 2013 Global Action Plan acknowledged the primary role and responsibility of Governments in addressing NCDs alongside international cooperation to underpin national efforts (WHO, 2013). To track progress, Member States adopted time-bound commitments to set national NCD targets, prepare national plans, reduce NCD risk factors, and strengthen health system responses. Progress in meeting these commitments has, however, been disappointing (WHO, 2020a).

A 2020 World Health Assembly resolution called for the elimination of cervical cancer and led to the first global health strategy for the *elimination* of a cancer as a public health problem (WHO, 2020a). A second major initiative seeks to level global inequalities in treating childhood cancers whereby only 20%–30% of children in LMICs survive, compared to more than 80% in high-income countries (WHO, 2020b). For both of these initiatives implementation funding gaps loom large. WHO regional frameworks for action, influencing health policies and formulating regional cancer responses for member states, include those for the Eastern Mediterranean and the African Region (WHO, 2020a). Global commitments to tackling the cancer burden span United Nations agencies including the UN Interagency Task Force on NCDs (and WHO's Global NCD Platform) (United Nations Inter-Agency Task Force on the Prevention and Control of Non-communicable Diseases, 2019). International trade agreements with potential impact on cancer control include the WTO Agreement on Trade-related Aspects of Intellectual Property Rights. This TRIPs Agreement allows a government to approve the production of a patented product or process without the consent of the patent holder in circumstances of national emergency. Such “compulsory licensing” may improve pharmaceutical availability (Farmer et al., 2010) and has widened access to oncology medicines in Thailand and India (Bognar et al., 2016).

The World Cancer Declaration launched under UICC leadership at the 2006 World Cancer Congress—later aligned with the Global Action Plan—is a consensus statement and sets targets for tackling the global cancer burden and inequalities. The Declaration called for cancer control to be integrated into the global health and development agenda and, alongside the NCD Alliance, significant UICC advocacy helped position NCDs in the 2030 Sustainable Development Goals (United Nations, 2018). Target 3.4 is to “reduce by one-third premature mortality from NCDs through prevention and treatment, and promote mental health and wellbeing.” This marked a watershed in global development in acknowledging NCDs, including cancer, as urgent health and development challenges. Reductions in cancer deaths will be essential in meeting such targets and cancer control a pillar of any strategy towards achieving Universal Health Coverage (Target 3.8).

## Setting priorities and investing wisely

Global commitment to tackling cancer and meeting goals and targets must be translated into national actions that reflect domestic circumstances: epidemiology, finance, and infrastructure. The “global” cancer burden is unique *national* burdens, risks, and solutions (Wild, 2019). The 2005 World Health Assembly called on all countries to develop National Cancer Control Plans (NCCPs) for situation analyses, to understand risk factors, document cancer control activities and resources, and assess political and socioeconomic context. NCCPs have the potential to improve country cancer outcomes at the population level however many countries lack high quality and operational plans (Oar et al., 2019). For example, research suggests half of NCCPs do not outline referral pathways from primary care for patients with potential cancer-related symptoms (Nicholson et al., 2018).

Cancer registries providing population-based data are central to implementing NCCPs. However, population-based registry coverage in the Global South remains patchy and, alongside resource constraints, in some LMIC countries cancer is not a reportable disease within national legislation (Patterson, 2018). The 2017 World Health Assembly Cancer Resolution reaffirmed global commitments to addressing cancer and reiterated calls for adequately resourced national cancer control plans and for improvements in disease registries (WHO, 2017). With only 35% of countries having a high-quality PBCR in 2019 (WHO, 2020a) it is urgent that national systems— supported by international collaboration— prioritize financing, infrastructure, and human resourcing of effective registries. The International Agency for Research on Cancer champion the collection of quality cancer data and with WHO have developed guidelines for establishing cancer registries, as well as the Global Initiative for Cancer Registry Development utilizing regional hubs, for example, the African Cancer Registry Network (Mery & Bray, 2020). The International Atomic Energy Agency supports radiotherapy within its human health portfolio and acknowledges that equipment and training must be embedded in a wider context of cancer control strengthening. IAEA organizations have supported more than 90 governments via *imPACT* review missions and through WHO cancer initiatives in cervical, childhood, and breast cancers.

## Donor dissonance

Longstanding criticism is levelled at bilateral, multilateral, and philanthropic donor failure to spend enough on cancer control in LMICs compared with other diseases and the absence of cancer from the donor-driven global health agenda (Bollyky et al., 2017; Farmer et al., 2010). Bilateral (government and development agencies), multilateral (UN and Development Banks), and philanthropic (private, NGO) organizations allocate about 2% of budgets for NCDs (WHO, 2020a), a miniscule amount in comparison to funding for HIV and other infectious diseases. There is a lack of bilateral enthusiasm for funding NCD control, either directly or through organizations that resemble Gavi, the Vaccine Alliance. There is a lack of funding to support essential pillars of national cancer action such as national registries (Sullivan, 2018). Despite the absence of dedicated budget or programs to address cancers, bilateral aid agencies could prioritize cancer control within their national-level discussions and fund specific projects that align with NCCPs (Institute of Medicine, 2007). While smaller-scale initiatives do exist some argue that the international response has struggled without US leadership (National Academies of Sciences, Engineering, and Medicine, 2017).

Despite growing global recognition of the importance of NCDs few analysts anticipate major global funds being allocated toward national cancer prevention any time soon (Gelband et al., 2016). The available resources focus on prevention and screening



programs because of their cost-effectiveness with a corresponding neglect of diagnosis and treatment. Access to cancer treatments is not working for most of the global population with emphasis skewed toward prohibitively expensive cancer drugs, and with surgical (Sullivan et al., 2015) and radiotherapy (Gospodarowicz, 2021) interventions overlooked for LMICs. The 19th WHO Model Lists of Essential Medicines was updated in 2015 with 16 cancer drugs—including three high-cost medicines—added (Chivukula & Tisocki, 2018), and four further cancer medicines added to the 23rd list in 2021. However, there is insufficient access and need for international collaborations (i.e., global governance *innovations*) to allow LMICs access to affordable “essential” medications (Cuomo & Mackey, 2018; Fundytus et al., 2021). To date, relatively little use is made of TRIPS compulsory licensing, and we have not sufficiently interrogated how governments may better exercise actual and latent power under this agreement (Ooms & Hanefeld, 2019).

Such incongruity, whereby allocation decisions fail to follow evidence of NCD needs and treatment options results in bumpy and stunted cancer control pathways for the Global South. Weak donor support for NCDs/cancer is explained in part by the limited progress in framing cancer control as an urgent global priority.

## Twinning, partnerships, networks, and coalitions

Legal instruments, soft-laws, member-state commitments, and donor activities are markers on the landscape of global cancer governance. There are also less institutionalized relationships that draw together and mobilize diverse stakeholders to shape policy and service responses. These typically link healthcare interests in high- and low-income countries (local providers, professional groups and associations, research institutions, international organizations, Third Sector bodies, advocacy groups, national governments). Activities are multi-level (local, national, regional), multi-modal (advocacy, technical support, digital mentoring, site visits), and multi-nodal (decentered leadership, devolved decision-making) and increasingly promote equitable relationships and a “collaborative ethos of global oncology” (Mutebi, 2021) that counters paternalistic models of collaboration.

*Twinning*—long-term pairings of established cancer centers with new or existing centers (Institute of Medicine, 2007)—is a well-established cancer collaboration, including World Child Cancer since 2007 to support countries to develop local solutions rather than importing them wholesale (Hopkins et al., 2013). Pairings may involve South-South support, for example, the Uganda Cancer Institute was facilitated to support stakeholders in Swaziland in setting up and operating a cancer unit in Mbabane Government Hospital (Kiyange et al., 2018). Instances of *partnerships* include an initiative first convened by a national sponsor organization, US National Cancer Institute, subsequently continued under the leadership of a volunteer-led expert, the Africa Cancer ECHO Steering Committee spanning six countries (Nakaganda et al., 2021). Enduring partnerships that last beyond the grant cycle is a key benchmark when assessing meaningful collaboration.

The language of collaboration is increasingly one of *networks*, with decentered relationships independent of governments and major institutions. National exemplars include the UK Global Cancer Network (Stanway et al., 2021) (“not-for-profit network of UK-based individuals and institutions working in partnership with colleagues in LMICs”) and the emerging Canadian global cancer control network (Rodin et al., 2021). Elsewhere, the City Cancer Challenge (C/Can) innovation has been to operate at the city level to improve access to quality cancer care (Adams et al., 2017). C/Can brings together city-wide commitment and public-private collaborations in low-resource settings (including a strong patient voice), focusing on the policy environment and cancer control plan, encompassing core cancer services including improving diagnostic capacity.





Tackling the cancer burden has produced national and global *coalitions*— language previously associated with political and military urgency—harnessed for addressing cancer. These include patient-focused organizations organized around specific cancers (lung, kidney, ovarian), and as a response to the pandemic, the Global Cancer Coalition Network, collectively representing over 750 cancer patient advocacy and support organizations (Global Cancer Coalitions Network, 2020). Similarly, UICC as a global cancer organization representing all cancer types has formal relations with WHO, and connects leaders and advocates to influence policy.

Alongside specific objectives—advocacy, training, or technical support— most network initiatives have sustainability and shared decision making as key goals. Interestingly, research on global health networks identifies effective networks as where their members develop a persuasive *framing* of the issue, including problem definition, and agreement on solutions. Moreover, effective coalitions reach beyond traditional health constituencies and engage the politics and power relations, rather than focussed solely on technical aspects (Shiffman et al., 2016).

Cancer collaborations include private institutions taking the lead in twinning, and those initiatives address specific cancers (e.g., childhood cancer), or provide resources for capacity-building, training, medicines, technology, and capital investments (Blanchard et al., 2021). The Global Coalition for Cancer Diagnostics is a public–private initiative developing collaborations across diagnostic organizations, civil society, local innovators, and advanced start-ups to support locally-led cancer care initiatives in LMICs. Collaborations are essential to ensure technology uptake: adoption, implementation, and finance. Private finance for cancer control in low-income settings may support necessary investments (WHO, 2020a) although if predominantly aimed at new precision cancer medicines it risks exacerbating treatment imbalances, including prevention (Gospodarowicz, 2021; Wild, 2019).

Pharma companies provided access initiatives for 57% of essential cancer medicines on the EML in 2017 (Cuomo & Mackey, 2018). However, evidence is limited on the implementation and impacts of such Patient Assistance Schemes' clinical and cost-effectiveness from a patient and healthcare system perspectives (Felder et al., 2011). Beyond access to medicines and the pharmaceutical sector, understanding the impact of all private sector initiatives will improve accountability of providers to patients. Private global health programs must evidence impact and sustainability, and also acknowledge the potential for redundancy and unnecessary competition. Of a reported 129 private-sector cancer-care initiatives, 19 operate in Kenya, with the majority of these initiatives supporting capacity-building activities (Doshi et al., 2020).

## Straightening things out?

There need remains for effective coordination (resolutions, statements, commitments, and initiatives), including WHO and regional offices, the World Bank, and regional development banks, as well as bilateral donors. Some suggest improved coordination necessitates a UN program and call for IARC to be a specialized UN agency within the UNDG (Cuomo & Mackey, 2018). Such an agency would undertake negotiations with national governments, Third sector partnerships and networks, and sponsorships with private organizations. Pooled procurement would also be a major new responsibility and allow greater LMIC access to cancer medications. For others, the way forward lies in innovative coalitions, such as an NCD Cooperative, an international public–private partnership organization beyond health that advocates, negotiates, and innovates incentives and financing (Nishtar, 2017). There is a clear lack of innovative financing instruments in global health for NCDs



(Atun et al., 2017). Scanning the “global menu” it remains to be seen whether there is appetite for a global fund for cancer similar to AIDS, TB, or malaria (Cortes et al., 2020).

Irrespective of whether coordination is refreshed or radically refashioned it is crucial to avoid centralization and compliance that stifle fresh thinking (Farmer et al., 2010). Emerging understandings of governance point to leadership being multi-level with key roles for national research funding bodies, nongovernmental agencies, states, and levels of civil society (WHO, 2020a). It is incumbent upon those shaping resource allocation and service interventions to make patients central to decision-making, amplifying voices of the Global South within any “ethos of global oncology.”

It is increasingly clear cancer matters globally. Governance matters for cancer control for reasons of responsiveness, responsibility, transparency, and accountability. Governance is fundamental to furthering the goal of participation, necessitating a role for civil society in agenda setting and mobilizing resources (WHO, 2020a). The international community has been slow to acknowledge and meaningfully include civil society organizations in the political response to NCDs (Dain, 2019). Many countries lack strong patient advocacy, although cancer advocacy organizations in high-income countries are now beginning to mentor those in LMICs. The Cancer Advocates programme developed by UICCC supports civil society in LMIC settings to strengthen their advocacy capacity for improved cancer control.

Global governance is messy. Continuing to probe the complexities of cancer governance involves market mechanisms, international agreements, soft power, political willpower, partnerships, collaborations and networks, and patient participation. Governance is coordination, cooperation and funding mechanisms, and engages compliance, innovation and effectiveness. Governance is inseparable from the “paradigmatic” framings that are brought to bear. The framing of problems has implications for proposed solutions. Regrettably, cancer remains some distance from being framed as a human rights issue (Boyle et al., 2019; Farmer et al., 2010). Evolving cancer governance, however messy, will be much easier to live with when framed by fundamental human rights: the optimal treatment, at the appropriate time, every time.

## AUTHOR CONTRIBUTIONS

Neil Lunt is the sole author and conceived, researched, and prepared the manuscript.

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## CONFLICT OF INTEREST STATEMENT

The author declares no conflict of interest.

## ETHICS STATEMENT

The article does not report primary data or raise issues related to informed consent and confidentiality. It did not require formal ethics committee review.

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