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How Should Low- and Middle-Income Countries Motivate Equity in Cancer Prevention and Control?

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Abstract

Cancer continues to be a prominent cause of morbidity and mortality in low- and middle-income countries (LMICs). Many LMICs, however, lack adequate data to better understand and respond to trends in cancer incidence. This article highlights crucial roles that government and public-private coalitions can play in cancer surveillance in LMICs. In particular, local and global investment in LMICs can build essential structures for cancer prevention and early detection, including public health surveillance systems and cancer control coalitions. Using examples from LMICs that show the promises and pitfalls of these approaches, this article argues that comprehensive cancer control can motivate health equity.

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Global Cancer Burden

Low- and middle-income countries (LMICs) bear a larger burden of cancer mortality than high-income countries (HICs),¹ with as many as 70% of cancer deaths occurring in LMICs.² Fewer resources to allocate to cancer,³ a rising rate of cancer incidence due to improvements in life expectancy from reduced infectious disease mortality,⁴ and exposure to other risk factors common in HICs, such as smoking tobacco, physical inactivity, and changes in dietary patterns, account for some of these trends and inequities.⁴

Effective cancer prevention and control require multilevel policy interventions to reduce cancer inequities, defined as disparities in multiple measures of cancer control, including cancer screening, incidence, morbidity, mortality.⁵

Using lessons from HICs and LMICs, we focus on 2 key levers in public health for improving cancer prevention and control and thereby reducing cancer inequities in LMICs: public health surveillance systems and cancer control coalitions.

Public Health Surveillance for Inequity

The World Health Organization (WHO) defines public health surveillance as "the continuous, systematic collection, analysis and interpretation of healthrelated data needed for the planning, implementation, and evaluation of public health practice."⁶ Toward this end, 3 types of cancer registries provide different levels of cancer-related data: population-based cancer registries (PBCR), hospital-based cancer registries, and pathology-based cancer registries.⁷ A PBCR collects all reportable cancer occurrences from multiple sources in a defined area and is best suited to capture population-level disease burden and inform approaches for cancer control.

An effective cancer registry supports a core set of functions related to data: collection, dissemination, analysis, and application.⁸ In the United States, the Surveillance, Epidemiology, and End Results (SEER) Program serves as a robust and well-coordinated system of local and national cancer registries containing data on cancer screening, incidence, treatment, and outcomes.⁹ The SEER registry is an example of a registry that helps streamline the dissemination, analysis, and application of data by making data readily available to researchers, providing statistical software for data analysis, and publishing reports for the public in order to increase awareness and understanding of cancer surveillance.

Cancer registries at the local and regional levels can provide particularly useful information for tailoring prevention and awareness strategies when local trends differ from national and regional trends. For example, a recent study using data for New York City (NYC) found racial and ethnic differences between NYC and national trends in the incidence of early adult-onset colorectal cancer.¹⁰ In another example, regional data from an Egyptian PBCR suggested that breast cancer incidence was higher among urban-dwelling women than women in rural areas, even when controlling for known risk factors.¹¹ Researchers and health officials are now considering environmental and other risk factors to understand these differences.

Although these examples at the local and national level illustrate the importance of accurate data collection as the foundation of effective <u>public</u> <u>health surveillance</u>, publicly available data suggest that current PBCRs cover

just 2% of Africa, 6% of Asia, and 8% of Central and South America.^{12,13} Lack of accurate population-level data and of systems to collect and organize it puts LMICs at a severe disadvantage when setting priorities for nascent cancer control initiatives.

What are the best ways for LMICs to build and run PBCRs? The International Agency for Research on Cancer (IARC) categorizes the core components necessary to build and run PBCRs into 2 domains: political/administrative and institutional/professional.⁷ The political/administrative domain includes local and national health department involvement and a cancer registry as part of a health information system for planning and managing services for cancer prevention and treatment. The institutional/professional domain includes key leaders needed to oversee a registry, cancer specialists, hospital directors within the geographic catchment area, and death registry departments.

Resource constraints cannot be overstated as a barrier to building PBCRs. For example, PBCRs incur not only fixed costs but also labor costs, as cancer registrars, who collect and process cancer data, play a crucial but often overlooked role in the organization and operation of cancer registries.⁸ In some LMICs, cancer is not defined as reportable per national legislation,¹⁴ making it even more difficult for stakeholders to make the case for government funding for registries. In contrast, all 50 US states now have programs that report incident cases of cancer to registries.⁹ The first study estimating resources used for total costs of cancer registries in select countries found that fixed and variable costs of maintaining registries were borne mostly by nongovernmental host institutions, such as local universities, and supported financially by multiple sectors.¹⁴ Governments can play a key role in encouraging development of registries through legislation, but it is often critical for governments in LMICs to develop partnerships with nongovernmental institutions to operate them.

A paucity of cost data for operating registries can limit how robustly stakeholders can support staff, labor, and technology resources. For the purposes of sustainability, LMICs and their global partners should estimate fixed and variable costs as early as possible, given the diversity of <u>public-private partnerships</u> (PPPs) for PBCRs found throughout LMICs. Although tools such as the IARC's Global Initiative for Cancer Registry Development support crucial capacity building across LMICs, ¹³ LMICs need further investment from and coordination with other stakeholders to expand PBCRs as a tool for identifying cancer disparities.

Cancer Control Coalitions

In addition to cancer registries, cancer control coalitions offer a potentially wide-reaching opportunity for informing population-level cancer prevention activities, which include raising awareness about cancer, supporting PBCRs, and generating multisector approaches for outreach to populations. Cancer control coalitions often bring together individuals from health departments, academic institutions, community-based organizations, advocacy groups, and health care systems in order to set agendas for increasing awareness and for prevention, early detection, and access to care.

In the United States, Centers for Disease Control and Prevention (CDC) funding and strategic planning advanced the growth of these coalitions in the late 1990s through the development of cancer control programming.¹⁵ In San Francisco, a broad, community-based cancer coalition—San Francisco Cancer Coalition—was launched in 2016 to address 5 of the most common cancers according to PBCR data, and the coalition prides itself on raising awareness of the physical and social environments and other social determinants of health that impact cancer outcomes and health equity.¹⁶ Indeed, the emergence of coalitions has tracked with steady gains in cancer prevention and control. For example, the NYC Citywide Colorectal Cancer Control Coalition, convened by the NYC Department of Health and Mental Hygiene, set clear goals to increase screening colonoscopy rates and eliminate racial and ethnic screening disparities in the early 2000s.¹⁷ Engaging diverse partners in the coalition, it focused on public awareness and physician education, easing the referral process for colonoscopies, promoting colonoscopy quality, supporting patient navigation in screening, and promoting public health messaging in communities known to have low screening rates. By 2013, gaps reflecting racial and ethnic inequities had closed and the colonoscopy screening rate had risen from 42% to 69% in NYC.¹⁷

Although fewer in number compared with high-income countries, examples of coalition building exist in LMICs. In one case, better defined as a PPP, the Rwandan Ministry of Health worked closely with a pharmaceutical company, medical device company, the American Society of Clinical Pathology, and the CDC, among others, to devise a comprehensive plan for cervical cancer prevention, screening, and treatment.¹⁸ The plan included a national human papillomavirus (HPV) vaccination campaign, expanded cervical HPV infection screening and treatment, and pathology education.¹⁸ Often noted as an example of a highly successful PPP because of its population health results,¹⁹ this unique constellation of partners helped create roadmaps for PPPs in other LMIC settings.

Despite the potential for success that coalitions and PPPs hold, many challenges must be addressed throughout the lifespan of a coalition or PPP in order to achieve or sustain improvements. Partnership members' funding and organizational priorities can change or even conflict with a coalition's or PPP's mission and framework. And power differentials among stakeholders in the coalition or PPP can stall progress on stated shared goals. In LMICs, in particular, one risk is that coalitions or PPPs will draw resources away from an already fragile health infrastructure—for example, by diverting local health worker labor from essential core health care functions to report writing for funders.¹⁹

The participation of corporations and other private sector or nongovernmental organization members can present additional conflicts of interest within a coalition or PPP. Corporate participation can give companies unfair market advantages or negatively impact governmental and public health priorities, and, in some cases, products of a particular corporation (eg, tobacco and food industry corporate partners) can be at odds with or thwart public health goals.²⁰ For example, one foundation's holdings in a corporation presented potential conflicts of interest on multiple levels,¹⁹ at least in part because some products, such as soda, promote obesity,²¹ which is a risk factor for certain cancers.²²

Given this context, how might LMICs chart an ethical way forward? One way is for governments and public health agencies to follow a coalition governance framework that enforces evidence-based public health priority setting to keep policy design at arm's length from private sector partners and evaluate effects on health and the health care system of potential partners' products in order to mitigate risk and vet the appropriateness of potential partners.²³ As a result of careful consideration, some potential partners might be excluded from coalitions and others might be given clearly defined participatory guardrails.

Successful cancer coalitions also foster accountability and shared decision making among coalition members, diversified funding, and flexible structure and prioritize evidence-based work plans.^{24,25} Engaging a convening entity, such as an academic institution or health department; revising goals based on emerging data; reviewing local assets and challenges; and periodically re-evaluating stakeholder representation can further strengthen coalitions.¹⁷ Effective communication, both within a coalition and between a coalition and its audiences, requires understanding the media landscape, crafting messages

that resonate with intended recipients, and purposeful coordination among coalition stakeholders and external partners.²⁶ Lessons learned from places such as NYC, San Francisco, and Rwanda provide guideposts for HICs and LMICs trying to reduce cancer inequities.

Conclusion

Public health surveillance systems and cancer control coalitions are necessary but not sufficient for ending cancer inequities between HICs and LMICs, and, in the case of coalitions, how a coalition's membership and governance are structured affect progress toward achieving equity in cancer prevention and control. Of course, ending cancer inequity requires more policy interventions than we have discussed, including those aimed at (1) collecting populationbased behavioral risk and environmental data and establishing cancer screening registries, (2) maintaining an adequate health care workforce,²⁷ (3) providing health education concerning prevention and early detection, (4) increasing access to preventive services, (5) controlling tobacco use, and (6) establishing programs to address the social determinants of health. In addition, advancing knowledge about and solutions to cancer inequity is a process that is most effective when it is bidirectional—that is, with relevant experiences in LMICs informing policies in HICs and vice versa. In the end, the degree to which we improve cancer outcomes in LMICs and eradicate global inequities in cancer control is dependent in part upon the degree to which people and societies make a commitment to focus on cancer surveillance in I MICs.

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