REVIEW



Progress, challenges and ways forward supporting cancer surveillance in Latin America

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Abstract

Population-based cancer registries (PBCRs) are the only means to provide reliable incidence and survival data as a basis for policy-making and resource allocations within cancer care. Yet, less than 3% and 10% of the respective populations of Central America and South America are covered by high-quality cancer registries. The Global Initiative for Cancer Registry Development provides support to improve this situation via the International Agency for Research on Cancer Regional Hub for Latin America. In this paper, we summarize activities (advocacy, technical assistance, training and research) over the last 5 years, their impact and current challenges, including the implementation of new PBCR in four countries in the region. Despite the favorable political support to cancer registration in many countries, the sustainability of cancer registration remains vulnerable. Renewed efforts are needed to improve data quality in Latin America while ensuring maximum visibility of the data collected by disseminating and promoting their use in cancer control.

Abbreviations: CCHD, Cooperation among Countries for Health Development; CI5, Cancer Incidence in Five Continents; GICR, Global Initiative for Cancer Registry Development; IAEA, International Atomic Energy Agency; IARC, International Agency for Research on Cancer; INC–INCAN, (*Instituto Nacional de Cancerología*) National Cancer Institute; INCART, (*Instituto Nacional de Cáncer Rosa Emilia Tavares*) National Cancer Institute; Rosa Emilia Tavares; INEN, (*Instituto Nacional de Enfermedades Neoplásicas*) National Tumor Institute; LA HUB, Regional Hub for Cancer Registry Development in Latin America; LMIC, Iow- and middle- income countries; MOH, Ministry of Health; NCD, non-communicable diseases; PAHO CO, Pan American Health Organization– Country Office; PAHO, Pan American Health Organization; PBCRs, population-based cancer registries; UICC, Union for International Cancer Control; WHO, World Health Organization.

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Latin America, neoplasms, population surveillance, public health

1 | INTRODUCTION

Global commitments to assist with the development of high-quality cancer incidence and mortality data have been included in the World Health Organization (WHO) Global Action Plan for the Prevention and Control of noncommunicable diseases (NCDs) 2013 to 2020,^{1,2} in the 2017 World Health Assembly cancer resolution and more recently in the WHO Cervical Cancer Elimination and Global Childhood Cancer Initiatives.^{3,4} Placing an onus on low- and middle- income countries (LMIC) to improve surveillance is challenging, where the availability of vital statistics and high quality health information lags behind higher income settings.^{5,6}

The only reliable means to obtain cancer incidence is through a population-based cancer registry (PBCR), an ongoing surveillance system collecting new cancer cases in a defined population.^{7,8} Whether of national or subnational coverage, PBCR need to ensure they provide complete and valid data following international standards.⁷ Assessing the quality of PBCR requires adherence to established procedures^{9,10}; at the global level this is periodically evaluated by the International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries via *Cancer Incidence in Five Continents*. In its last published volume, the population covered by high-quality PBCR showed enormous disparities across world regions: while 98% of the U.S. population were covered by high-quality PBCR, corresponding figures in Latin America, Asia, and Africa were 8%, 6%, and 2%, respectively.⁵

To support countries to increase the coverage and quality of cancer incidence information, multiple international partners launched the Global Initiative on Cancer Registry Development (GICR) in 2013.¹¹ This initiative is led by the IARC with targeted actions that are coordinated by six IARC Regional Hubs. Tailored support to a country/registry is initiated by site visits to assess all aspects of cancer registration in the local context. The recommendations provided after site visits are the basis for further guidance, facilitated by the establishment of official agreements between IARC and the program owners to reflect political will and the need for longer-term commitment. Training, a cornerstone activity in the GICR, is of particular relevance given the specialized knowledge and tasks required in a cancer registry, more so in LMIC where formal training programs in cancer registration are absent. Training is offered through various modalities. Among them, registration training courses target different levels and topics, together with mentoring to provide tailored support. In order to support a greater number of people, groups of regional trainers in specific topic areas have been assembled through the GICRNet.¹¹ They provide guidance to registries and are involved in the development of content and the delivery of courses in the region. Another important working area of GICR is related to cancer control through data dissemination and research.

The IARC Regional Hub for Cancer Registry Development in Latin America (the LA Hub) was established in 2014, shortly after the "Oncology Commission of Cancer Control planning in Latin America" had issued recommendations to increase investment in cancer registration.¹² Building on well-established registries, and through the involvement of leadership from National Cancer Institutes, a coordinating center was initially established at the National Cancer Institute of Argentina in Buenos Aires. From the time of the Hub inception, support has been provided by the national cancer institutes of Brazil and Colombia and the National Cancer Registry of Uruguay. Relevant international regional stakeholders, among which is the Pan American Health Organization (PAHO), have been involved in the LA Hub Advisory Committee since 2015.¹³

The 20 Spanish and Portuguese speaking countries in Central, South America and the Caribbean that are supported by the LA Hub, have different levels of development in cancer registration; a baseline report illustrating this and highlighting different action items for improving cancer surveillance in the region has been previously published.¹³ We present here the current situation—5 years after establishment of the LA Hub—providing a brief overview, examining the main achievements, challenges, and factors that have influenced progress. Further steps to improve and accelerate change in cancer registration within Latin America are delineated.

2 | CANCER REGISTRATION IN LATIN AMERICA: CURRENT SITUATION

The cancer burden estimates for Central and South America account for 1.3 million new cancer cases and 670 000 deaths annually, with great variation in the estimated incidence between countries (Table 1). As illustrated in Table 1, the majority of countries in the IARC LA Hub have currently at least one PBCR, implying that almost one-guarter (23.3%) of the overall population in the region is covered with data providing for a PBCR. Nevertheless, when restricted to only high-quality PBCR (defined as included in the latest volume of the Cancer Incidence in Five Continents [CI5] publication) are considered, this percentage corresponds to only 2.4% of the population in Central America (including Spanish-speaking Caribbean countries) and 9.2% in South America (Table 1). The number of PBCR in the region increased from 76 to 84 in 2015 to 2019, mainly due to the establishment of a network of 10 sentinel registries in Mexico as well as newly established registries in El Salvador, Honduras, Dominican Republic and Paraguay, who previously did not have an operational PBCR.

Most of the countries with an established PBCR (excluding those with a recently established PBCR) have standard reports available either via the webpage of the corresponding Ministry of Health or national cancer institute. In most countries, the latest year of information available (as of 2020) is based on cancer data for 2016 (see Table 1). Nevertheless, timeliness varies between and within countries



TABLE 1	PBCR and population covered, b	country and subregion 2020,	IARC Regional Hub for Latin America

		Estimated new cancers (all sites but C44)	PBCR			Population by PBCR (9	covered %)	
Country and PBCR	Population UN 2017 (million)	Cases per year	All PBCR 2015	All PBCR 2020	High- quality PBCR ^b	All PBCR	High- quality PBCR ^b	Available cancer incidence report (printed; webpage or article) last year ^a
Central America—Caribbed	าท							
Belize	0.4	358	-	-	-	-	-	-
Costa Rica	4.9	12 957	1	1	1	100	100	2014
Cuba	11.5	45 534	1	1	-	100	-	2016
Dominican Republic	10.8	17 988	-	1	_	29.1	-	NA
El Salvador	6.4	10 326	-	1	-	28.4	-	NA
Guatemala	16.9	16 332	_	-	_	-	-	NA
Honduras	9.3	9942	-	1	-	13.0	-	NA
México	129.2	190 667	2	10	_	12.7	-	2016
Nicaragua	6.2	7956	-	-	_		-	
Panama	4.1	8244	1	1	_	100	-	2017
Puerto Rico	3.7	15504	1	1	1	100	100	2017
Subtotal Central America	203.2		6	17	2	22.1	2.4	
South America								
Argentina	44.3	129 047	16	16	5	41.0	18.6	2015 (Mendoza)
Bolivia	11.1	14 915	ni	ni	-			ni
Brasil	209.3	559 371	30	30	6	22.0	9.8	2017 (Barretos)
Colombia	49.1	101 893	6	6	4	25.0	9.1	2016 (Cali)
Chile	18.1	53 365	5	5	4	15.0	7.9	2012 (Valdivia)
Ecuador	16.6	28 058	6	6	5	45.9	41.4	2015 (Quito, Guayaquil)
Guyana	0.8	751	1	1	_	100		ni
Paraguay	6.8	11 244	-	1	_			
Peru	32.2	66 627	2	2	1	34.6	30.6	2014 (Arequipa)
Suriname	0.6	1042	1	1		100		ni
Uruguay	3.5	15 101	1	1	1	100	100	2012-216
Venezuela	32.0	61 979	ni	ni				ni
Subtotal South America	424.1		68	69	26	24.5	9.2	
Total	627.3		74	86	28	23.3	7.2	

Abbreviations: IARC, International Agency for Research on Cancer; ni, no information; PBCR, population-based cancer registry.

^aFor countries with more than one PBCR, the name of the registry with the most recent year of data in a report appears in brackets. ^bCI5 Vol XI for high-quality PBCR.

Source: Globocan 2108 for Cancer estimates.⁵¹

with some registries showing relevant delays in dissemination of their data (Table S1).

3 | TAILORED SUPPORT TO COUNTRIES **THROUGH GICR**

An overview of major GICR activities developed in the 2015 to 2019 period in the region is shown in Table 2. Activities are grouped by main areas of support, including those that were aimed at setting up the organizational structure through the signature of specific agreements with the Hub collaborating centers.

In order to better understand factors that have contributed to the development of new PBCRs in the period, we describe below the advances in cancer registration for five selected countries according to the baseline situation when the LA Hub was initiated (three countries with no PBCR and two countries with an interim development of cancer registration, but not high-quality PBCR). These five countries had two or more site visits and an agreement signed with IARC (Table 2). In Table 3, we summarize the diverse political, social and

	lain partners				(EA; INCAN Mexico; ana Farber; PAHO- CHD; INEN Peru			cuador: SOLCA; Dom sp: PAHO CO and ICART	rgentina INC; Chile: IOH and PAHO CO; olombia: INC and PAHO O		ruguay National Registry		anderbilt University; eru: MOH and INEN; lexico: INCAN; Colombia: ontificia Universidad veriana Bogota	CAN, (Instituto Nacional de les Neoplásicas) National
	2019 M		Uruguay		Dominican Republic; Ecuador; IA El Salvador; Guatemala; D Panama; Paraguay; Peru C	El Salvador		Dominican Republic, Basic Ec registration, National course Re IN	₹ΣŬŬ	Paraguay	Ū		Results-Merida PBCR V. (Mexico) ²⁰ Pt Gastric cancer trends Quito M (Ecuador) ²¹ Pc Access to data sources Ja (Colombia) ²²	srnational Atomic Energy Agency; IN EN Unstituto Nacional de Enfermedar
	2018		Brasil (INCA)		Mexico	Mexico		regional course	Ecuador, coding/staging Colombia, coding/staging	Honduras			Partnerships_NCl ¹⁹	try Development; IAEA, Inte itute Rosa Emilia Tavares: INI
	2017		Colombia (INC)		El Salvador (Pediatric); Guatemala (Pediatric); Peru (Lima, Arequipa); Guatemala; Paraguay; Mexico	Paraguay		Ecuador intermediate analysis, I	Colombia, coding	El Salvador	Essential TNM		Registration situation ¹³ Advancing registration in CA4 ¹⁷ Cancer in Peru ¹⁸	Slobal Initiative for Cancer Regis
	2016				Mexico (Merida); Honduras; El Salvador; Brazil (INCA); Guatemala	Panama			Argentina, reporting Chile, coding	Guatemala; Paraguay; Panama; El Salvador; Cuba			Cancer in Central and South America (supplement) ^{14,15} Cancer burden and patterns in LA ¹⁶	s for Health Development; GICR, (
r activities	2015	0	Argentina (INC); Uruguay		Mexico (Merida, Jalisco); El Salvador; Panama; Guatemala; Paraguay	Mexico (INCAN)		Panama data quality and analysis, regional course	5		CanReg5	research	ations	D, Cooperation among Countrie
GICR areas-majo		GICR Hub structur	Collaborative center agreements	Tailored support	Site visits	Country Agreements	Training	GICR training courses	Online transmissi of local courses	Mentorships	Webinars	Dissemination and	Joint GICR public	Abbreviations: CCH

GICR activities in the IARC Hub for Latin America, 2015 to 2019 TABLE 2 @uicc

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TABLE 3 Factors related to cancer registration advancement in a selected group of countries, 2015 to 2019

	No PBCR at base	Incipient PBCR			
Factors	El Salvador	Guatemala	Paraguay	Mexico	Panama
HDI 2015	Medium	Medium	Medium	High	High
Political will					
PBCR in cancer plan	х	х	х		
Influential leader in government	Х	-	х	Х	
MoH concern					
Country-led cancer burden analysis	Х	-	х	Х	Х
Participation of stakeholders in international CR meetings	Х	-	х	х	
Specific funding for the PBCR					
Government funds assigned	х	-	х	х	Х
Project (external funds)		Х			
Infrastructure					
Specific office assigned	х	-	х	х	Х
Team and personnel					
Dedicated personnel	х	-	х	х	Х
Epidemiologist in the team	х	Х	х	х	-
Mentorship for registrars		Х			
Mentorship for PBCR coordinator	х		х		Х

technical factors that may have been relevant to advance cancer registration.

3.1 | Countries with no PBCR at baseline

Among factors that triggered the interest and decision of establishing a PBCR in El Salvador were the assistance of high-level Central American decision makers to the 2014 International Conference on Bioinformatics, a scientific conference that included a cancer registration workshop.¹⁷ This conference, as well as an external expert site visit that had taken place in 2014 had the close involvement and support of the vice minister of Health. In 2016, the National Cancer Control Plan of El Salvador and its subsequent implementation plan²³ considered the need for a PBCR. The different GICR site visits to El Salvador contributed to the definition of the registration area (Department of San Salvador) and to the appointment of a cancer registry coordinator, who benefited from a two-week training mentorship at the Cancer Registry of Uruguay. In 2019, a GICR Partner Country agreement was signed between IARC and the Ministry of Health (MoH). The registry's office at the MoH was equipped following funding from an international NGO, two cancer registrar's positions were secured in late 2019 and data collection started in 2020.

In Guatemala, financial support of the U.S. National Cancer Institute facilitated a 3-year pilot project to implement a PBCR in Guatemala City starting in late 2014. The project was managed by the Guatemalan Cancer League, the major cancer care provider in the city that also operates the sole hospital-based cancer registry in the country. The LA Hub supported a 3-week mentorship stay at the Mendoza Cancer Registry in Argentina for two cancer registrars, and followed up closely through annual site visits and recommendations (Table 2). Nevertheless, despite GICR and PAHO country office advocacy efforts with the MoH and the Cancer League, funds to continue and reorganize cancer registry activities could not be secured. The high turnover of health ministers (seven since 2014)²⁴ and limited funding prioritized for cancer surveillance in Guatemala, are seen as the main contributing factors. In 2020, the Ministry of Health started renewed efforts to include cancer registration as part of epidemiologic disease surveillance.

The first GICR site visit to Paraguay took place in 2015 and was followed in 2016 by a 2-week mentorship stay of the registry coordinator at the National Cancer Registry of Uruguay, one of the collaborating centers. The same year a scientific meeting (focusing on cancer registration and epidemiology) was organized between the German Insurance Fund and the MoH with the presence of national and international relevant stakeholders. An initial agreement was signed in 2017; shortly after the commencing data collection was interrupted due to changes in the MoH. During this time the MoH of Paraguay completed a Cancer Mortality Atlas²⁵ and a GICR partner country agreement with the MoH has now been signed; a new registry coordinator has been appointed and data collection for the Asunción Cancer Registry started.

3.2 | Countries with incipient PBCR at baseline

Mexico, the largest country in Central America, has had several failed attempts at establishing a national cancer registry.²⁶ Following a GICR site visit in 2015, an agreement was signed between IARC and the

National Cancer Institute in Mexico (INCAN), to support and improve cancer registration in the two incipient PBCRs (Merida and Jalisco). In 2017, under decided INCAN leadership, the Mexican Senate approved a law to establish registration in Mexico. This was subsequently followed in 2018 by an allocation of funds for the development of a network of 10 subnational PBCRs. A new agreement was signed to support the development of this network.

Panama, with longstanding registration efforts, has a national PBCR that underwent an important reorganization since 2012.²⁷ In 2015, Panama hosted a GICR course, which was followed by a site visit 1 year later and the signature of an agreement. This was oriented mainly to support improvement of data quality and coverage given that registration operations coincided greatly with definitions of a— previously existing—pathology-based registry. Challenges lie in the high turnover of staff at reporting institutions who hold important responsibilities. Reports are regularly uploaded to the MoH webpage; nevertheless adjustments to follow international standards²⁷ are still required.

4 | PROGRESS IN TRAINING AND RESEARCH

Training courses developed by GICR in the region have been fewer than initially planned but have nevertheless benefitted close to 400 participants. The regional experts that are part of the GICRNet²⁸ were trained in specific topics by IARC/GICR, and have actively engaged as faculty in courses, performed site visits and provided online consultations. Mentorships, mainly supported through one of the collaborating centers, have facilitated on-site training, a highly valued resource to build skills especially in the absence of formal training programs.^{29,30} In turn, remote online transmission of locally organized cancer registration courses has led to additional opportunities to expand participation, especially on the topic of cancer coding (Table 2). However, this modality encountered some challenges given competing tasks for which attendants are usually not relieved, together with courses not being specifically designed for virtual learning, limiting as such an active interaction of remotely connected participants.

Initial efforts in the LA Hub to promote collaborative cancer research have been led by IARC and focused on better documenting the cancer registration situation in the region.^{13,17} Together with some local experts, a complete series on cancer burden and patterns in Latin America,^{14,15} followed by an overview article¹⁶ was produced. The value of partnerships in strengthening the activities was highlighted by GICR partners¹⁹ Similarly, a comprehensive review of the cancer burden in Peru¹⁸ as well as the process and results of the Merida Cancer registry in Mexico,²⁰ were published in a collaborative manner. The formal involvement of Academia (Pontificia Universidad Javeriana, Bogotá) in the Hub advisory committee has yielded further benefits. Students from both Masters and Doctoral programs in Public Health and Clinical Epidemiology, working in close relation with cancer registries personnel, have yielded successful presentations at

congresses^{21,22,31} scientific publications³²⁻³⁴ and longer term collaborations (Table 2).

5 | ASSETS, CHALLENGES AND WAYS FORWARD IN SUPPORTING CANCER REGISTRATION

The GICR activities have undoubtedly contributed to a better understanding and interest in cancer registration among many stakeholders in the region, particularly in those countries where cancer registration was nonexisting or recent. Factors that influenced advances in cancer registration include the involvement of an influential leader in the government, local concern regarding the cancer burden (reflected in local cancer situation analyses), the participation of high-level stakeholders in international scientific meetings, and the assignment of specific funds (See Table 3). Some of these factors, specifically the leadership from individual mobilizers and the perceived severity of a given problem are factors that have been found to be determinant in contributing to the success of global health initiatives.³⁵

5.1 | Sustaining long-term cancer registration

Even if clear commitments have been made by local authorities, there have been previous instances where progress was hampered by frequent or subsequent changes in leadership that have led to inadequate funding and interruptions in registries' operation, a finding that has been also acknowledged in other regions.³⁰

As governmental funding for cancer registry activities is subject to annual planning and approval of the respective budget lines, sustainability remains a concern if surveillance is not within a clearly established operational program. Countries have used different approaches to increase funding. For example, Panama dedicates part of the tobacco taxes revenues to support the registry, similar to other countries such as Guam.³⁶ The link with the Academia has been an option in Colombia to sustain and co-finance registries while developing research.³⁷ This link represents a unique opportunity for both registries and students to further increase use and visibility of the cancer registry data and can certainly be facilitated by the GICR. This may also have positive effects in improving timeliness and visibility, an aspect in which most established PBCR in the region, particularly in South America, need to do significant efforts to improve. However, whatever option is envisioned to improve funding, visibility and sustainability of registries, the primary responsibility of population-based surveillance as a key element for cancer control rests with governments. Even where the registry may be partially financed by other parties, the provision and subsequent use of data by the health sector needs to be ensured locally and nationally.

The strong increases foreseen in cancer burden for the next years in the region and the growing interest in cancer data do not seem nevertheless be accompanied by the required long-term planning vision and an understanding of the specificity of cancer surveillance.⁸ The wide-spread aspiration to have national PBCRs among many stakeholders in the region needs to be carefully balanced vis a vis the feasibility of achieving and sustaining national coverage without affecting quality.

5.2 | Advancing IT solutions

The relatively recent advances in interoperability and information technology that are underway in many local health systems and institutions in the region may have contributed to the expanded vision that "automated" and obligatory cancer reporting systems could replace the active processes used by cancer registries.³⁸ Yet, the complexity of cancer surveillance and the implications of standard methods to achieve completeness, comparability and validity of incidence information^{7,8} need to be considered. In two countries in the region, nation-wide mandatory cancer notification programs that were set up mainly for administrative purposes have shown to significantly underestimate the cancer burden.^{18,39}

Conversely, many PBCRs need to incorporate developments in information technology into their operations more comprehensively than is currently the case. The expanding use of electronic medical records as information sources implies adapting and introducing new ways of operation as well as the need for stronger IT support. Furthermore, collaboration among different cancer information systems in a given country is a prerequisite. For example, joint efforts between a childhood cancer surveillance system and the PBCR in Cali has demonstrated a notable improvement in the quality and completeness of data.⁴⁰ Though communication and collaboration between different (health and cancer) information systems in a given country should be improved, privacy regulations can pose serious barriers to a more optimized collaboration between players in this important field in public health as shown in the region,³³ and similarly in Europe.⁴¹

5.3 | Regional support to registration

Support through regional cooperation mechanisms, such as UNASUR in South America and The Council of Health Ministers of Central America and Dominican Republic (COMISCA in Spanish) in Central America, were proposed in the first years of the LA Hub but unfortunately did not yield concrete results. Since the inception of the Hub, PAHO has provided critical support for training and site visits from both its regional, sub regional offices and the different country offices. More recently, PAHO support has been channeled through a specific "Cooperation among Countries for Health development" (CCHD)⁴² project, aiming to share expertise and build capacity between countries. To further expand support beyond this project, the technical cooperation agreements which are regularly signed between ministries of health and the PAHO country offices, should explicitly include resources for cancer surveillance.

National Cancer Institutes have leading roles in cancer control and surveillance across the region and have played an important role in supporting the LA Hub for cancer registration. However important challenges remain. For example, Brazil has 30 well-established PBCRs that receive guidance from the National Cancer Institute,⁴³ with staff and financial support mainly provided by local governments; yet, only a few registries were included in the last two volumes of Cancer Incidence in Five Continents.^{5,44}

The different training modalities including mentorship stays are critical to build cancer surveillance capacity,^{45,46} requiring efforts of all involved parties to plan regularly and allocate sufficient budget. While some registries have incorporated training in annual plans, it is a component requiring strengthening at the regional level, taking advantage of common Spanish language across most countries. Related is the lack of young staff entering long-term positions in the registries, with increasing concerns in registries in the region that experienced staff are retiring over the next decade without successors in place.

5.4 | Supporting the dissemination and use of information

The dissemination of standard registry reports is an aspect that demands efforts to improve the visibility and timeliness of registry operations. While there has not been an exhaustive literature search related to research and production of PBCR, scientific writing has clear limitations. Much of the regional scientific literature regarding public health is in Spanish⁴⁷ that gradually has been gaining more visibility⁴⁸: a recent example with open access articles from Colombia and Quito constitute encouraging possibilities for data dissemination and visibility.^{20,32,49} The use of a country approach (as in the Peru article¹⁸) or cancer focused approaches involving several countries (as a more recent gallbladder cancer article)⁵⁰ have been encouraged by GICR and are meant as models to inspire local teams in producing collaborative research. This necessarily demands a local leader and wider interaction with the academic sector than, with a few exceptions, is currently the case. A clear limitation to augmenting use of the data beyond the production of a standard registry report, is the limited number of well-trained epidemiologists in many countries in the region, with few devoted to chronic diseases.

6 | CONCLUSIONS

Following the establishment of the IARC LA Hub for cancer registration, important advances have been made across the Latin American region. Nevertheless, much remains to be done to close gaps and support cancer surveillance. Interest in generating local cancer incidence data needs to translate into planning, allocating resources and developing concrete activities. PBCRs are a distinct surveillance strategy and program owners play a fundamental role in providing oversight and support to cancer surveillance. At a regional level, existing high-quality PBCRs are a valuable resource for training and supporting less developed registries. In addition, partners like PAHO and others have proved fundamental to support countries in their efforts. Finally, while the GICR has a pivotal role in coordinating global and regional efforts, robust and sustainable results from registries require the longterm commitment and planning of all local stakeholders.

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CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

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REFERENCES

- Nugent R, Bertram MY, Jan S, et al. Investing in non-communicable disease prevention and management to advance the sustainable development goals. *Lancet (London, England)*. 2018;391(10134):2029-2035.
- World Health Organization. Draft Comprehensive Global Monitoring Framework and Targets for the Prevention and Control of NCDs. Vol 2013. Geneva: WHO; 2013.
- World Health Organization. Global Initiative for Childhood Cancer. https://www.who.int/cancer/childhood-cancer/en/2018.Accessed October 03, 2020.
- World Health Organization. Global Strategy towards Eliminating Cervical Cancer as a Public Healh Problem (draft). Geneva: WHO; 2019. [Updated December 2019] Accessed October 03, 2020 https://www. who.int/docs/default-source/documents/cervical-cancer-eliminationdraft-strategy.pdf.
- Bray, F; Mery, L; Piñeros, M; Znaor, A; Zanetti, R; Ferlay, J. (editors). Cancer Incidence in Five Continents. Vol. XI Lyon, IARC; 2017. https:// ci5.iarc.fr/Default.aspx. Accessed 1 October, 2020.
- Mahapatra P, Shibuya K, Lopez AD, et al. Civil registration systems and vital statistics: successes and missed opportunities. *Lancet* (*London*, *England*). 2007;370(9599):1653-1663.
- Bray F, Znaor A, Cueva P, et al. Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings. Lyon: International Agency for Research on Cancer; 2014.
- Piñeros M, Znaor A, Mery L, Bray F. A global cancer surveillance framework within noncommunicable disease surveillance: making the case for population-based cancer registries. *Epidemiol Rev.* 2017;39 (1):161-169.

9. Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. *Eur J Cancer*. 2009;45(5):747-755.

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- 10. Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods part II. Completeness. *Eur J Cancer*. 2009;45 (5):756-764.
- Mery L, Bray F. Population-based cancer registries: a gateway to improved surveillance of non-communicable diseases. *Ecancermedicalscience*. 2020; 14:ed95.
- Goss PE, Lee BL, Badovinac-Crnjevic T, et al. Planning cancer control in Latin America and the Caribbean. *Lancet Oncol.* 2013;14(5): 391-436.
- Piñeros M, Abriata M, Mery L, Bray F. Cancer registration for cancer control in Latin America: a status and progress report. *Pan Am J Public Health.* 2017;41(e2):1-8.
- 14. Sierra MS, Forman D. Cancer in central and South America: methodology. *Cancer Epidemiol*. 2016;44(suppl 1):S11-s22.
- 15. Sierra MS, Soerjomataram I, Antoni S, et al. Cancer patterns and trends in Central and South America. *Cancer Epidemiol*. 2016;44(suppl 1):s23-s42.
- Bray F, Pineros M. Cancer patterns, trends and projections in Latin America and the Caribbean: a global context. *Salud Publica de Mexico*. 2016;58(2):104-117.
- Pineros M, Frech S, Frazier L, et al. Advancing reliable data for cancer control in the Central America four region. J Global Oncol. 2018;4: 1-11.
- Piñeros M, Ramos W, Antoni S, et al. Cancer patterns, trends, and transitions in Peru: a regional perspective. *Lancet Oncol.* 2017;18(10): e573-e586.
- Frech S, Muha CA, Stevens LM, et al. Perspectives on strengthening cancer research and control in Latin America through partnerships and diplomacy: experience of the National Cancer Institute's Center for Global Health. *Journal of Global Oncology*. 2018;4:1-11.
- Leal YA, Reynoso-Noveron N, Aguilar-Castillejos LF, Meneses-Garcia A, Mohar A, Pineros M. Implementation of the populationbased cancer registry in the city of Merida, Mexico: process and early results. *Salud Publica de Mexico*. 2020;62(1):96-104.
- Tarupi W, De Vries E, Cueva P, Yepez J, editors. Stagnation in Decreasing Gastric Cancer Incidence and Mortality in Quito: Time Trend Analysis, 1985-2013; International Association of Cancer Registries– Conference 2018, Arequipa, Peru. Lyon: IACR; 2018. http://www. iacr2018.org/pdf/abstract-book.pdf.
- 22. Gil F, Uribe C, de Vries E, eds. El Impacto Sobre la Supervivencia Relativa al Emplear Tablas de Vida a Diferentes Niveles Poblacionales. Congreso Internacional 85 años INC. Bogotá, Colombia: Instituto Nacional de Cancerología Colombia; 2019.
- Ministry of Health El Salvador, Ministerio de Salud de EL Salvador. Plan de implementación de la Política Nacional para la prevención y control del cáncer; 2017. http://asp.salud.gob.sv/regulacion/pdf/ planes/plan_de_implementacion_politica_de_cancer.pdf.
- Ministros de Salud Pública y Asistencia Social en la historia; 2020. https://wikiguate.com.gt/ministerio-de-salud-publica-y-asistenciasocial/.
- Paraguay, Ministerio de Salud Publica y Bienestar Social, Dirección de Vigilancia de Enfermedades no Transmisibles. Atlas de mortalidad por Cáncer en el Paraguay; 2017. http://portal.mspbs.gov.py/dvent/wpcontent/uploads/2018/02/AtlasMortalidad_2017.pdf.
- Mohar-Betancourt A, Reynoso-Noverón N, Armas-Texta D, Gutiérrez-Delgado C, Torres-Domínguez JA. Cancer trends in Mexico: essential data for the creation and follow-up of public policies. *J Global Oncol.* 2017;3(6):740-748.
- Panama Ministerio de Salud. Registro Nacional del Cáncer de Panamá. http://minsa.b- cdn.net/sites/default/files/general/2017_registro_ nacional_del_cancer_de_panama_.pdf.

20

- International Agency for Research on Cancer, Global Initiative for Cancer Registry Development. *Training Via the GICRNet*. Lyon: IARC; 2018. https://gicr.iarc.fr/building-capacity/training-via-gicrnet/
- Motsuku L, Chokunonga E, Sengayi M, Singh E, Khoali L, Borok M. Strengthening African population-based cancer registration through regional mentorship: UICC fellowship experience at Zimbabwe National Cancer Registry. *Journal of Global Oncology*. 2018;4(Supp 2):65s-s.
- Znaor A, Eser S, Anton-Culver H, et al. Cancer surveillance in northern Africa, and central and western Asia: challenges and strategies in support of developing cancer registries. *Lancet Oncol.* 2018;19(2): e85-e92.
- Tarupi W, Guarnizo C, de Vries E, editors. Educational inequalities in gastric cancer incidence and mortality, Quito 1996-2013. International Association of Cancer Registries, Annual Conference; Arequipa, Peru.
- Corral Cordero F, Cueva Ayala P, Yépez Maldonado J, Tarupi Montenegro W. Trends in cancer incidence and mortality over three decades in Quito–Ecuador. *Colomb Med.* 2018;49:35-41.
- Gil F, de Vries E, Wiesner C. Importancia del acceso de los registros de cáncer de base poblacional a las estadísticas vitales: barreras identificadas en Colombia. *Revista Colombiana de Cancerologia*. 2019; 23(2):56–61.
- Tarupi W, de Vries E, Cueva P, Yepez J. Stagnation in decreasing gastric cancer incidence and mortality in Quito: time trend analysis, 1985-2013. J Cancer Epidemiol. 2019;2019:1504894.
- Shiffman J, Schmitz HP, Berlan D, et al. The emergence and effectiveness of global health networks: findings and future research. *Health Policy Plan.* 2016;31(suppl 1):i110-i123.
- David AM, Haddock RL, Bordallo R, Dirige JT, Mery L. The use of tobacco tax revenues to fund the Guam Cancer Registry: a double win for cancer control. J Cancer Policy. 2017;12:34-35.
- Pardo C, Bravo LE, Uribe C, et al. Comprehensive assessment of population-based cancer registries: an experience in Colombia. *J Registry Manag.* 2014;41(3):128-134.
- Gomes AL, Turbay T, Venturella P, Cecagno L, Johnson G, Caleffi M. Cancer diagnosis and treatment: the need for compulsory registration. J Global Oncol. 2018;4(suppl 2):153s-s.
- de Vries E, Pardo C, Wiesner C. Active versus passive cancer registry methods make the difference: case report from Colombia. J Global Oncol. 2018;4:1-3.
- Ramirez O, Aristizabal P, Zaidi A, Ribeiro RC, Bravo LE. Implementing a childhood cancer outcomes surveillance system within a population-based cancer registry. J Global Oncol. 2018;4:1-11.
- Andersen MR, Storm HH. Cancer registration, public health and the reform of the European data protection framework: abandoning or

improving European public health research? *Eur J Cancer*. 2015;51(9): 1028-1038.

- Pan American Health Organization, World Health Organization CE. Coperation for Health Development in The Americas—Policy Document; 2013; 06022019. http://iris.paho.org/xmlui/bitstream/handle/ 123456789/4404/CD52_11eng.pdf?sequence=1&isAllowed=y.
- 43. Brasil MdS, Cancer INd. Vigilancia de Cancer. https://www.inca.gov. br/numeros-de-cancer/vigilancia-de-cancer
- 44. Forman D, Bray F, Brewster D, et al. *Cancer Incidence in Five Continents*. Vol X. Lyon, Lyon: IARC; 2014 2014.
- Lengerich EJ, Siedlecki JC, Brownson R, et al. Mentorship and competencies for applied chronic disease epidemiology. J Public Health Manage Pract. 2003;9(4):275-283.
- Spadaro AJ, Grunbaum JA, Dawkins NU, et al. Training and technical assistance to enhance capacity building between prevention research centers and their partners. *Prev Chronic Dis.* 2011; 8(3):A65.
- 47. Williams JR, Bórquez A, Basáñez MG. Hispanic Latin America, Spain and the Spanish-speaking Caribbean: a rich source of reference material for public health, epidemiology and tropical medicine. *Emerg Themes Epidemiol.* 2008;5:17.
- Zacca-Gonzalez G, Chinchilla-Rodriguez Z, Vargas-Quesada B, de Moya-Anegon F. Bibliometric analysis of regional Latin America's scientific output in public health through SCImago Journal & Country Rank. BMC Public Health. 2014;14:632.
- Bravo LE, Munoz N. Epidemiology of cancer in Colombia. Colombia Med. 2018;49(1):9-12.
- Miranda-Filho A, Pineros M, Ferreccio C, et al. Gallbladder and extrahepatic bile duct cancers in the Americas: incidence and mortality patterns and trends. *Int J Cancer*. 2020;147:978-989.
- Global Cancer Observatory. *Cancer Today*. Lyon: [Internet. International Agency for Research on Cancer; 2018. Accessed 1 October, 2020.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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