Implementation of a population-based cancer registry network in Mexico 2017-2020

Alejandro Mohar, MD, DSc,[1,2] Andrea Paredes, MD, MSc,[3] Hasan Brau-Figueroa, MD, MSc,[4] Alejandro Sánchez, MD, MSc,[5] Alejandra Palafox, MD,[6] Rebeca Rivera-Gómez, MD,[7] Kristal Pech, MD, MSc,[1] Mario Carranza-Matus, MD, MSc,[8] Oscar Arrieta, MD, MSc,[9] Andrea Inchaustegui, BS,[10] Elena Moreno, MD,[10] Marion Piñeros, MD, MSc.[11]

Abstract

The growing cancer burden particularly among less developed countries requires local data to plan and evaluate cancer control measures. This article describes the development of a population-based cancer registry network (PBCRN) in Mexico that took place between 2017 and 2020 and present related data. The PBCRN, led by the National Cancer Institute (Incan), included nine registries representing 11.3% of the Mexican population. Definitions, coding, and operative processes were based on international standards. All cities were visited to set up local structure; personnel were hired by Incan and trained in basic cancer registration in Merida. A specific software was developed. Regular virtual meetings took place for data verification and quality control. Data collection included institutions of the public and private health system. Personnel included 34 registrars, nine local leaders, and 12 staff members at the Incan. A total of 13 517 cases were recorded between 2017-2020, 64% percent of them were among females. Breast cancer was the more frequent

Resumen

En países en vías de desarrollo, la magnitud del cáncer requiere información local para planear y evaluar su control planes. Este artículo describe el desarrollo de la Red de Registros de Cáncer de Base Poblacional (RRCBP) en México, durante el periodo 2017-2020. La RRCBP, coordinada por el Instituto Nacional de Cancerología (Incan), incluyó nueve registros, cuya población representó 11.3% de la población en México. La definición, codificación y procesos operativos se realizaron con base en estándares internacionales. Se establecieron reuniones con los responsables de esta red para la verificación y control de calidad de la información obtenida. La recolección y registro de los casos nuevos de cáncer incluyó instituciones pertenecientes al sector público y privado. Se incluyeron 13 517 casos nuevos, 64% de los cuales correspondió al sexo femenino. El cáncer de mama fue la neoplasia más frecuente (23.3%), seguida por los órganos digestivos (18.4%) y cánceres del aparato genital en mujeres (13.5%). Cáncer pediátrico (0-14 años) y en adolescentes (15-19 años) representó 4.4% del

(1) Unidad de Epidemiología e Investigación Biomédica en Cáncer, Instituto Nacional de Cancerología. Mexico City, Mexico.
(2) Instituto de Investigaciones Biomédicas, Universidad Nacional Autónoma de México. Mexico City, Mexico.
(3) Coordinación del Registro Nacional de Cáncer, Instituto Nacional de Cancerología. Mexico City, Mexico.
(4) Hospital General de Hermosillo. Hermosillo, Sonora, Mexico.
(5) Dirección de Prospectiva Sectorial, Secretaría de Salud. Guadalajara, Jalisco, Mexico.
(6) Hospital La Joya. San Miguel Allende, Guanajuato, Mexico.
(7) US-Mexico-Border Health Commission, Tijuana Population-Based Cancer Registry BajaREG. Tijuana, Baja California, Mexico.
(8) Departamento de Registros en Salud, Secretaría de Salud. Guadalajara, Jalisco, México
(9) Dirección General, Instituto Nacional de Cancerología. Mexico City, Mexico.
(10) Registro de Cáncer de La Paz. La Paz, Baja California Sur, Mexico.
(11) Cancer Surveillance Branch, International Agency for Research on Cancer. Lyon, France

malignancy (23.3%), followed by digestive organs with (18.4%) and female genital cancers (13.5%). Childhood (0-14 years) and adolescents cancer represented 4.4% of the total new cancer cases. The network was suspended in 2020. The present effort lacked sustainability and data were only partial. However, the experience provides valuable insights to be considered for the renewed cancer registration efforts that are currently ongoing in Mexico.

Keywords: neoplasms; cancer registry; surveillance; Mexico

total de nuevos casos registrados. La operación del RRCBP fue suspendida en 2020. El esfuerzo aquí presentado careció de la sustentabilidad necesaria; los resultados son parciales. Sin embargo, esta experiencia aporta elementos valiosos para los recientes esfuerzos en la renovación del Registro de Cáncer en México.

Palabras clave: neoplasias; registro de cáncer; vigilancia; México

The growing cancer burden represents a global public health problem, particularly in less resourced settings.[1] In Mexico, an estimated 195 000 new cancer cases and over 90 000 cancer deaths occur annually, with breast, prostate, colorectum, thyroid, cervix, lung, and stomach cancer being the most common malignancies.[1] Cancer represents the third cause of death in Mexico, after cardiovascular diseases and diabetes mellitus, and given the improvement in the life expectancy of the population and a high prevalence of risk factors, a 65% increase in new cancer cases is foreseen in the next two decades.[2] With a population of almost 130 million inhabitants and an enormous geographical and socioeconomic diversity there is a pressing need to have locally registered cancer data. So far, the sole cancer registry report is available for Merida.[3] Current incidence data available for Mexico have been estimated by the International Agency for Research on Cancer (IARC) from national mortality and mortality-to-incidence ratios derived from cancer registries in neighboring countries.[1]

Efforts to have accurate cancer data in Mexico started in 1930, with the implementation by the Ministry of Health of a national epidemiological surveillance program, that however emphasized infectious diseases.[4] From 1993 to 2003, a Histopathological Cancer Registry functioned with national coverage, registering all malignancies obtained from the pathology departments in all public and private institutions of the health sector.[5] Other two initiatives worthwhile to mention focused on pediatric cancer, namely the registry developed by the *Instituto Mexicano del Seguro Social* (IMSS) from 1996 to 2013 -covering 10 Mexican States-, and the 2013-2018 national initiative by the Ministry of Health covering population not covered by the social security, that represented around 40%.[6,7]

Additional efforts to obtain cancer data in Mexico was the local registry in the state of Jalisco, that started operations in 1975 being mainly histopathology based.[8] In 2016, the IMSS started the first population-based cancer registry (PBCR) in the city of Mérida in the state of Yucatán, with a catchment population of 908 536 inhabitants.[3] These initial programs and the pressing need to have valid and high-quality incidence and survival data together with an important funding received in 2017 were the background for the development of the Population-Based Cancer Registries Network (PBCRN-RedMex) in Mexico.[9] The National Cancer Control Plan (NCCP) proposed by the Ministry of Health in 2018,[10] included the PBCRN with the objective to develop population-based cancer registries in several cities throughout the country and obtain reliable cancer incidence data for Mexico.

Hereby, we aim to describe the implementation efforts and initial operation of the PBCRN, denoting its main strengths and limitations. In addition, we present preliminary results obtained between 2017 and 2020.

Materials and methods

Establishment of the PBCRN

In November 2016, a modification to the General Health Law approved the creation of a National Cancer Registry in Mexico, providing financial resources from 2017 onwards for its organization and implementation.[11] The *Instituto Nacional de Cancerología* (Incan) was the designated institution to coordinate this effort. Given the extension and population of Mexico, the National Cancer Registry was conceived as a subset of sentinel cancer registries forming the proposed PBCRN. Sentinel registries were proposed in cities located in each of the three major Mexican regions (North, Central and South), considering migration rates, population density, and the presence of adequate oncological services. Already existing registries like Jalisco and Tijuana were also included. A network coordinating center was established at the Incan, responsible of coordinating all necessary administrative and technical aspects for the implementation.

An agreement was signed between the Ministry of Health and Incan, ensuring access to public and private health institutions. However, apart from Merida located at an IMSS institution, which was not part of this network and only participated in training, there was no formal agreement to access cancer cases at the

IMSS institutions (covering around 55% of the Mexican population) nor institutions covering the Mexican Navy, military, and government personnel (covering 7% of the Mexican population). All financial resources for the operation of this network came from federal funding.[11]

Standard procedures

Based on IARC guidelines, a manual of procedures was elaborated by Incan, including the case definition, verification, data entry and quality control.[12] The use and implementation of the Manual aimed to ensure high operation standards and comparability of information; topography and morphology were coded using the International Classification for Diseases in Oncology (ICD-O) 3.1.[13] The pediatric malignancies were coded according to the International Classification of Childhood Cancer ICCC-3[14] and for hematological malignancies the Cancer Registry Project on Hematologic Malignancies (Haemacare) was used.[15] For staging purposes, the *Classification of Malignant Tumors* (TNM) was used, only for breast cancer and cervical cancer cases.[16] To begin data collection, the identification and updating of data sources by each PBCR was a key activity.

Personnel, training and technical assistance

Incan hired 34 registrars and nine coordinators, mainly medical doctors to support local data collection. In collaboration with the Merida Cancer Registry the 34 registrars received a one-week basic registration training. An agreement with the IARC was signed to receive tailored support and assistance in the framework of the Global Initiative for Cancer Registry Development.[17]

This implied site visits, monthly virtual meetings with the Incan team, revision of the Manual of Procedures, and revision of the training program. The training was complemented by a three-month course for each one of the centers by the Coordination Center of the Incan; this course included codification, ICD-O data entry, information sources, and quality control; in addition, there were monthly regular virtual meetings for follow-up and a question-and-answer session with all the registrars and the coordinators of each center.

Confidentiality

The PBCR Network followed the international recommendations established by the IARC and the Mexican Government recommendations.[18,19]

Software and data storage

A specific software (RedCancerMX) was developed in the open data source software ASP.Net, allowing data entry, compilation, validation, control of accessed data and general analysis. The software included validation rules of IARC-Tools and ENCR-Data Quality.[20] Databases from each PBCR were exported in daily basis to a Microsoft cloud and stored in Azure.

Data analysis

For this report, the cancer cases registered during 2017-2020, were converted from ICD-O-3.1 to ICD-10 and analyzed using the SPSS Statistics version 24.0.*

Results

Implementation of the PBCR Network

The PBCRN included registries in eight Mexican cities and the state of Baja California Sur, covering in total 11.2% of the Mexican population. Table I presents information on the population covered by each registry, the year operations (data collection) initiated; incident cancer cases were registered from January 1, 2017. Figure 1 shows the geographical distribution of the PBCRN in Mexico, also including the Mérida cancer registry in it. Figure 2 describes the main processes and responsibilities of the RedMex. At Incan, nine persons were part of the coordination center, including three epidemiologists, three data programmers, two administrators and one medical oncologist.

Each one of the sentinel registries had a coordinator and two or three registrars responsible for case finding, abstraction, coding, and data entry. All cities were visited by the national coordinator between 2017 and 2018. Between 2017 and 2020 two training courses were held, one in Merida and the other at the Incan. In each of the registries data collection started with in average three months after the signature of the agreement. A total of 481 information sources were identified comprising all private and public health institutions pertaining to the Ministry of Health. For the current report, data were provided by those sources, as institutions pertaining to the IMSS were not included. A total of 13 517 new cancer cases were recorded between

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* IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.

Table I
POPULATION-BASED CANCER REGISTRIES OF THE MEXICAN NETWORK. 2017-2020

Registries*	Mexican population 2020‡	Year the registry was established	Initiation of data collection with network standards	Number of information sources	Number of new cases
Acapulco	779 566	2018	2018	105	621
Baja California Sur	798 447	2019	2019	6	410
Campeche	928 363	2018	2019	24	829
Guadalajara§	5 268 642	2018	2018	69	6 196
Hermosillo	936 263	2019	2019	111	1 239
León	1 721 215	2019	2019	14	1 334
Monterrey	1 142 994	2019	2020	27	416
Tijuana	1 922 523	2018	2018	24	1 550
Toluca	910 608	2018	2019	101	922
Total	14 408 621	-	-	481	13 517

* The PBCR of the city of Mérida participated only in the training of the registrars, not in the data collection of this network.
‡ Census 2020 *Instituto Nacional de Estadística y Geografía*, Mexico.
§ The PBCR of the city of Guadalajara includes the metropolitan area, which is integrated by 10 municipalities.

2017-2020, 64% among females. The female: male ratio was 2.1, a consistent finding across all registries with exception of Monterrey where it was 0.9. More than 85% of the new cancer cases were histologically confirmed, and 6.2% were obtained solely by death certificate.

The annual number and distribution of all cancer cases according to the major ICD-10 diagnostic groups is presented in table II. Breast cancer was overall the most frequent malignancy accounting for 23.3% of the cases, followed by digestive organs with 18.4%, cancer of female genital organs with 13.5% and male genital organs with 11.2%. The proportions have slight variations through the years comprising the study period. Among females, breast cancer (23.3%) and cervical cancer (13.2%) were the most common malignancies followed by ovary cancer (5.5%). Among males, prostate cancer (21.7%) was the most common malignancy, followed by colorectal (7.2%) and lung (5%) cancer cases (data not shown). In the year 2020 there was substantial decrease in the number of cases registered, due to the Covid-19 epidemic and the suspension of the activities of this network.

The number of new cancer cases registered in children aged 0-14 years and adolescents (15-19 years) are presented in table III. In the 0-14 years group there were 416 cases, representing 3.1% of the total new cancer cases. In this age group, the most frequent malignancy were leukemias and other myeloproliferative diseases (48.6%), followed by malignant and benign tumors of the central nervous system (CNS) and miscellaneous intracranial and intraspinal neoplasms (11.1%), soft

tissues and extraosseous sarcomas 9.9%, lymphomas and reticuloendothelial tumors (6%). In the 15-19 years group there were a total of 182 cases; 41 (22.5%) corresponded to germ cell tumors, trophoblastic tumors, and neoplasms of gonads being the most frequent malignancies, followed by leukemia and myeloproliferative diseases (20.9%), and CNS tumors (11.5%).

Discussion

During 2017-2020 Mexico did an enormous effort to implement a network of nine subnational population-based cancer registries, covering 11.3% of the population, financed by the federal government and coordinated by the Incan. The 13 517 cases registered during the years of operation, despite being only partial information, follow an expected distribution of main cancers. With a strong financial support, the establishment of this network required the development of several agreements with local authorities, hiring and training the personnel, developing the software, and starting operations according to international standards.

The model selected in Mexico for cancer registration, based on a subset of sentinel cancer registries integrated in a network is appropriate for countries with large populations where it is difficult to achieve national coverage. Similar models have been established for example initially in the United States with the SEER (Surveillance, Epidemiology, and End Results) cancer registries, in India and the cancer registry network in Africa.[21-23] In Latin America and The Caribbean,

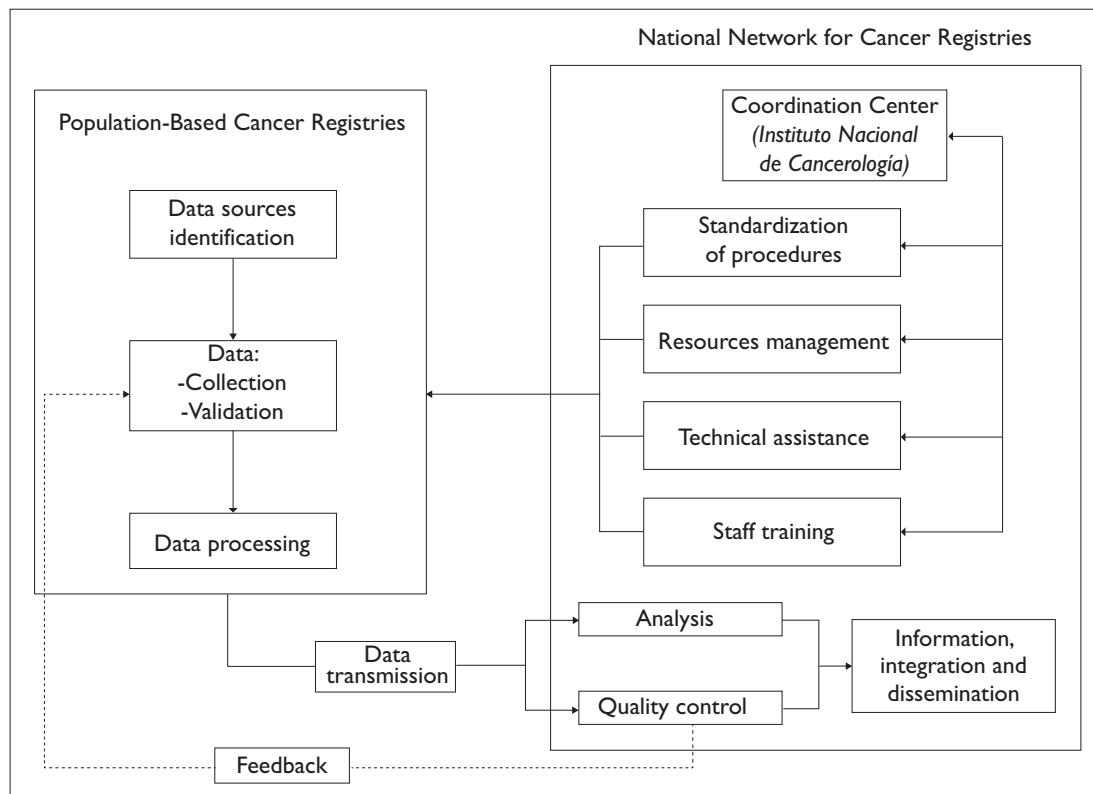**FIGURE 1. GEOGRAPHIC DISTRIBUTION OF THE POPULATION-BASED CANCER REGISTRY NETWORK IN MEXICO 2017-2020**

FIGURE 2. OPERATIONAL ORGANIZATION OF THE POPULATION-BASED CANCER REGISTRY NETWORK IN MEXICO 2017-2020

Table II

Annual number and distribution of new cancer cases by major sites, both sexes. Mexico, 2017-2020

Year	2017-2020	2017	2018	2019	2020
Cancer site (ICD-10)	N (%)	N (%)	N (%)	N (%)	N (%)
Lip, oral cavity, and pharynx (C00-14)	262 (1.9)	61 (1.7)	99 (2.0)	82(2.2)	20 (1.4)
Digestive organs (C15-26)	2 492 (18.4)	595 (16.5)	899 (18.6)	688 (18.8)	310 (22.3)
Respiratory organs (C30-39)	648 (4.8)	195 (5.4)	224 (4.6)	148 (4.0)	81 (5.8)
Bone, cartilage, melanoma (C40-43)	827 (6.1)	267 (7.4)	286 (5.9)	190 (5.2)	84 (6.0)
Breast (C50)	3 154 (23.3)	903 (25.0)	1 088 (22.5)	877 (23.9)	286 (20.6)
Female genital (C51-58)	1 828 (13.5)	492 (13.6)	689 (14.2)	495 (13.5)	152 (10.9)
Male genital (C60-63)	1 519 (11.2)	407 (11.3)	547 (11.3)	425 (11.6)	140 (10.1)
Urinary organs (C64-68)	596 (4.4)	165 (4.6)	195 (4.0)	160 (4.4)	76 (5.5)
Eye, brain, thyroid, etc. (C69-75)	350 (2.6)	93 (2.6)	126 (2.6)	89 (2.4)	42 (3.0)
Haematopoietic (C81-96)	419 (3.1)	101 (2.8)	150 (3.1)	134 (3.7)	34 (2.4)
Other and unspecified	1 422 (10.5)	335 (9.3)	541 (11.2)	381 (10.4)	165 (11.9)
All cancers	13 517 (100)	3 614 (100)	4 844 (100)	3 669 (100)	1 390 (100)

ICD-10: International Classification of Diseases, 10th edition.
Four-year (2017-2020) cancer frequencies collected from network Population-Based Cancer Registry.

Table III

Number and distribution of new cancer cases among children and adolescent by age groups. Mexico, 2017-2020

	Age group (years)		Total
Cancer site ICCC3	0-14	15-19	Total N (%)
	N (%)	N (%)	
Leukemias, myeloproliferative diseases and myelodysplastic diseases	202 (48.6)	38 (20.9)	240 (40.1)
Lymphomas and reticuloendothelial neoplasms	25 (6.0)	9 (4.9)	34 (5.7)
CNS and miscellaneous intracranial and intraspinal neoplasms	46(11.1)	21 (11.5)	67 (11.2)
Retinoblastoma	7 (1.7)	1 (0.5)	8 (1.3)
Kidney tumors	15 (3.6)	1 (0.5)	16 (2.7)
Hepatic tumors	15 (3.6)	2 (1.1)	17 (2.8)
Malignant bone tumors	13 (3.1)	17 (9.3)	30 (5.0)
Soft tissue and other extraosseous sarcomas	41 (9.9)	19 (10.4)	60 (10.0)
Germ cell tumors, trophoblastic tumors, and neoplasm of gonads	18 (4.3)	41 (22.5)	59 (9.9)
Other malignant epithelial neoplasms and malignant melanomas	4 (1.0)	1 (0.5)	5 (0.8)
Other and unspecified malignant neoplasms	30 (7.2)	32 (17.6)	62 (10.4)
All cancers	416 (100)	182 (100)	598 (100)

ICCC-3: International Classification of Childhood Cancer third edition.
Four-year (2017-2020) cancer cases collected from network Population-Based Cancer Registry.

the bigger populated countries like Argentina, Brazil, Chile, and Colombia also have subnational registries.[24] But contrary to the Mexican network, registries are not entirely financed and coordinated by a single institution, which certainly facilitates standards of operation, training, and quality control.

In the Mexican experience described, the Incan also assumed most of the quality control, the analysis and dissemination of data. This is certainly valid in the framework of data being used for a National Cancer Control plan but should not preclude local teams from analyzing and disseminating their own information, providing also feed-back to local decision makers. This is particularly important in a big country with different geographic and social contexts and federated implementation of cancer control actions. However, given the relatively short time of operation of the network, the efforts focused on the implementation and data quality

by the central team. Developing skills in descriptive cancer epidemiology and data analysis for local teams may require additional training efforts.

The strong political support received by Incan alongside with the allocation of important governmental funds, facilitated the setting up and organization of structures both at national and local levels, hiring and training of personnel as well as starting operations in a relatively short period compared to other new registries in low middle income countries, as has been also the case of the Merida registry.[3,9]

Directed support provided through the Global Initiative for Cancer Registry Development (GICR),[17] also contributed to accelerate some of the processes ensuring that international standards for cancer surveillance were included since the beginning.[17] Unfortunately, in 2020, given budgetary restrictions, the activities of the Mexican PBCRN were suspended, proving once again that sustaining registration efforts is one of the key challenges faced by PBCR in less resourced settings.[22,24-26]

The very preliminary results obtained during the years of operation, indicate that breast cancer, followed by cancers of the digestive organs, female genital malignancies, and male genital cancers were the most common malignancies. These findings, even in the absence of important information sources like those pertaining to IMSS, are consistent with the Globocan 2020 estimates for Mexico,[27] with the results observed in other countries of Latin America and the Caribbean[23] and with the recently published results by the Merida PBCR in Mexico.[3] The male: female ratio of 1:2.5 encountered in the preliminary results, is higher than has observed in some LAC countries, and deserves attention.[23]

Cancer in children and adolescents in this series represented 3.1% and 1.5% of the total number of cases, respectively, which for children is coherent with observed in other Mexican and LAC populations.[28,29] Leukemias, central nervous system malignancies, kidney tumors, and cancer of the bone were the more common childhood cancer. The contribution of leukemias in children was 48.6%, a finding that is consistent with the high frequency of this diseases in other children population with cancer in Mexico.[3,30]

The low frequency of cancer in adolescents when compared to other studies, could be associated with underreporting and low coverage of this population.[3,29]

There are several and important limitations in our study. The major limitation is the absence of completeness with a crucial sector of the population missing (the population covered by the IMSS which represents almost 50% of the population). This not only reflects the highly fragmented health system in the country but also the difficulty of data sharing among institutions, which is

encountered also in other settings.[31] In addition, another limitation is the short time frame to obtain and maintain valid data, a fact that is reflected amongst others in the lower number of new cases reported for 2020.

However, the different implementation efforts and the lessons learnt are of great value for the ongoing initiative of the Mexican Ministry of Health to reactivate in 2023 several of the previously established PBCR and the network as such. Cancer surveillance and thus, sustained support to PBCRs and the network, is a key component of the National Cancer Control Plan in Mexico to enable local population-based data on cancer incidence and survival to guide detailed planning and evaluation across the cancer control spectrum.

So far, there seems to be commitment to set an agreement with the different health sectors, including the IMSS; without this, the conditions to succeed cancer registration with the required standards are not set in the Mexican context. To achieve the objectives of the PBCRN, it is essential that policy makers, officials of the Ministry of Health and the IMSS and others includes well as directors of oncological cancer centers and pathology laboratories, have a good understanding on the importance of population-based cancer registries and commit to make it successful.

Additional efforts should be made to develop further and improve hospital-based cancer registries in the country that can in turn contribute to assure the quality, timing and exhaustiveness required in the PBCRN.

Conclusions

Cancer control based on local data should be a hallmark and a national public health priority. The effort in the development of this network, is a good basis for the continuation of cancer registry in Mexico as has been announced by the Ministry of Health of Mexico. It will also strengthen the so far weak cancer surveillance system that will provide the basis to plan for better screening and diagnostic services, assess the results of prevention programs, and better planning of human and financial resources. With the current federal legislation for cancer registration in Mexico, and the existing evidence for cancer control interventions, the opportunity to develop the network is set. It is about time that Mexico has reliable and valid data on the incidence rates, distribution, and mortality rates of cancer, that is currently the third cause of death in a country of more than 130 million inhabitants.

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