Epidemiologic Reviews
Vol. 39, 2017
DOI: 10.1093/epirev/mxx003
Advance Access publication:
May 2, 2017

A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries

Marion Piñeros*, Ariana Znaor, Les Mery, and Freddie Bray

* Correspondence to Dr. Marion Piñeros, Cancer Surveillance Section, International Agency for Research on Cancer, 150 Cours Albert Thomas, 69372 Lyon Cedex 08, France (e-mail: pinerosm@iarc.fr).

Accepted for publication January 19, 2017.

The growing burden of cancer among several major noncommunicable diseases (NCDs) requires national implementation of tailored public health surveillance. For many emerging economies where emphasis has traditionally been placed on the surveillance of communicable diseases, it is critical to understand the specificities of NCD surveillance and, within it, of cancer surveillance. We propose a general framework for cancer surveillance that permits monitoring the core components of cancer control. We examine communalities in approaches to the surveillance of other major NCDs as well as communicable diseases, illustrating key differences in the function, coverage, and reporting in each system. Although risk factor surveys and vital statistics registration are the foundation of surveillance of NCDs, population-based cancer registries play a unique fundamental role specific to cancer surveillance, providing indicators of population-based incidence and survival. With an onus now placed on governments to collect these data as part of the monitoring of NCD targets, the integration of cancer registries into existing and future NCD surveillance strategies is a vital requirement in all countries worldwide. The Global Initiative for Cancer Registry Development, endorsed by the World Health Organization, provides a means to enhance cancer surveillance capacity in low- and middle-income countries.

neoplasms; noncommunicable diseases; registries; surveillance; world health

Abbreviations: HBCR, hospital-based cancer registry; IARC, International Association for Research on Cancer; NCD, noncommunicable disease; PBCR, population-based cancer registry; WHO, World Health Organization.

INTRODUCTION

In the last century, the scale and the profile of major diseases have profoundly changed worldwide. Rapid urbanization and advances in health care have been critical forces in decreasing mortality from communicable diseases (particularly in infancy and childhood). Their continuing displacement with noncommunicable diseases (NCDs) is part of an ongoing demographic transition linked to the conquest of infection (1) and social, economic, and health advances (2–4).

Currently, NCDs are the leading cause of death globally; in 2012, 38 million deaths from NCDs were estimated worldwide, with two-thirds of these (68%) occurring in low- and middle-income countries (4). The leading causes of NCD deaths in 2012 were cardiovascular diseases (46%), cancers (22%), and respiratory diseases (11%) (4). Cancer is, however, the leading cause of death in close to 50 high-income countries and ranks second in a further 40 countries undergoing major transition (5). Cancers of the lung, liver, stomach, colorectum, breast, and cervix are among the 10 leading causes of cancer deaths worldwide, illustrating an additional change in disease profile, with infection-related cancers still coexisting with lifestyle-related cancers (2, 3).

In September 2011, world leaders adopted a political declaration to combat the unprecedented rise of NCDs globally, committing to work toward strategies of prevention and management (6). To reach the overarching target set of a 25% reduction of premature mortality from all NCDs by 2025 (the so-called "25 by 25"), a broad spectrum of interventions—including prevention, early detection, treatment, and palliative care—is required for each of the major NCDs. Implementing an integrated approach to ensure the reduction of common risk factors shared by the major NCDs is an underlying principle of the evidence-based "best buys" proposed by the World Health Organization (WHO) (7).

Although most of the indicators included in the NCD Global Monitoring Framework through which countries

report on the control of NCDs relate to the surveillance of risk factor prevalence, disease surveillance remains a critical element to which countries and governments have committed. The ultimate indicator of progress in the NCD Global Monitoring Framework—an observed reduction in premature mortality by cause—can only be routinely observed where vital statistics systems exist and are of reasonable quality; yet, only 1 in 5 countries can presently report such data with high levels of completeness and coverage (8). Complementing mortality, incidence by type of cancer per 100,000 population, collected by population-based cancer registries (PBCRs), is included as one of the 25 core indicators of progress in the NCD Global Monitoring Framework; the necessary technical support in planning and developing PBCRs in low- and middle-income countries is being provided through the International Association for Research on Cancer (IARC)-led partnership, the Global Initiative for Cancer Registry Development (http://gicr.iarc.fr) (9, 10).

Changes in health and epidemiologic profiles of populations necessarily shape the mode and delivery of public health surveillance, irrespective of the fact that all such systems share data collection, analysis, and dissemination as core processes (11). Informing on the control of NCDs including cancer at the national level is challenging for many low- and middle-income countries, where public health surveillance has tended to prioritize reporting of communicable diseases and outbreaks over chronic conditions given the historic importance of communicable diseases in their health profiles. Moreover, the rather recent evolution of surveillance of chronic diseases (12) has placed an emphasis on risk factor surveillance rather than disease occurrence, thus requiring some clarity as to the role of PBCRs within NCD surveillance.

We therefore initially review and compare the perspectives and attributes of the surveillance of cancer versus communicable and noncommunicable diseases, proposing a comprehensive and complementary framework for cancer surveillance. We define a set of key global cancer surveillance measures that support the planning and evaluation of interventions across the cancer continuum and also outline the specific characteristics of PBCRs, elaborating on their unique role in cancer surveillance.

SURVEILLANCE OF COMMUNICABLE DISEASES, NCDS, AND CANCER

The WHO has advocated the strengthening of vital registration systems and cancer registries, integration of surveillance into national health systems, development of periodic risk factor surveillance, and the strengthening of technical and institutional surveillance capacities (13). Although surveillance is broadly defined as the "ongoing systematic collection, analysis, and interpretation of health data that are essential to the planning, implementation, and evaluation of public health practice" (14, p. 146), cancer (morbidity) surveillance is quite distinct from the more conventional and recognized concepts and implementation of communicable disease surveillance. Even compared with other major NCDs (comprising cardiovascular diseases, cancers, chronic respiratory disease, and diabetes that share several behavioral risk factors), a number of important distinctions with cancer surveillance are apparent; these are presented in Table 1.

Communicable diseases

Reporting cases of communicable diseases from health-care providers to health departments has been one of the earliest forms of surveillance. Its principal feature is the compulsory notification of a list of selected diseases at the national or subnational level, with the public health objective of interrupting and monitoring the distribution and potential spread of an epidemic (12). Inherent to communicable disease surveillance is the investigation of outbreaks; this component has been a major focus of global training programs directed to develop and improve surveillance capacity in low- and middle-income countries; the US Centers for Disease Control and Prevention–led Field Epidemiology Training Program and its predecessor, the Epidemic Intelligence Service, have been pivotal in strengthening communicable diseases surveillance on a global scale, evolving from the late-1970s (in the case of the Field Epidemiology Training Program) to be now established in more than 80 countries (15).

Although the list of diseases included in communicable disease surveillance has expanded over time, the 2 main reporting strategies are passive, either from health-care facilities and providers and/or via disease control programs for specific diseases, for example, acquired immunodeficiency virus (AIDS), human immunodeficiency virus (HIV) prevalence, tuberculosis (TB), and malaria (16). One of the most striking features of communicable diseases surveillance is rapidity in reporting. Timely reports, often on a weekly basis, support the core purpose of reducing or eliminating the risk of spread of disease (Table 1). Such reporting has a longstanding tradition in the *Mortality and Morbidity Weekly Report* (MMWR), published by the Centers for Disease Control and Prevention, that dates back to 1898 (17).

Noncommunicable diseases

The observed worldwide increase in cardiovascular diseases and the findings of the Framingham Heart Study (18) and the Seven Countries Study (19) provided a core foundation for the surveillance of common behavioral risk factors associated with major NCDs; here, representative surveys of the prevalence of risk factors are the common strategy for data collection (20). Measurement techniques have evolved, particularly over the past 2 decades, and comparable information is now available for many countries from international initiatives including the Global Tobacco Surveillance System and the WHO Stepwise Approach to Surveillance surveys (20, 21). The latter includes 8 major behavioral, physical, and biological risk factors and seeks to promote a stepwise and flexible approach to risk factor surveillance: In step 1, demographic and behavioral (tobacco use, alcohol consumption, dietary behaviors, physical activity, and history of NCD-related conditions) risk factors are collected through a survey; step 2 involves the collection of physical measurements of height and weight; and step 3 includes biochemical measurements (22).

Table 1. Commonalities and Differences in the Surveillance of Communicable Diseases, Other NCDs, and Cancer

Surveillance Aspects	Communicable Diseases	Other NCDs (CVD, Diabetes, and COPD)	Cancers
Core purpose	Interruption of transmission of disease	Estimate of burden/focus on prevalence	Estimate of burden/focus on risk (incidence)
Main system of classification	Based on causal agent	Based on organ and function	Based on organ and morphology
	ICD-10	ICD-10	ICD-10; ICD-O-3
Aim of follow-up of cases	Identification of carrier status	Identification of chronic complications/ vital status	Identification of spread and recurrence/ identification of multiple primaries/vital status
	Establishment of case fatality		
Target population	Nationwide including nonresidents	Regional and/or national (all residents in defined area)	Regional and/or national (all residents in defined area)
Reporting	Real time	Annual/*x*-year period	Annual/*x*-year period

Abbreviations: COPD, chronic obstructive pulmonary disease; CVD, cardiovascular disease; ICD-10, *International Classification of Diseases, Tenth Revision*; ICD-O-3, *International Classification of Diseases for Oncology, Third Edition*; NCD, noncommunicable disease.

Implementing the Stepwise Approach to Surveillance approach ensures countries have necessary data to monitor and report the majority of risk factors related to the corresponding global monitoring framework targets among adults. To date, the Stepwise Approach to Surveillance has been implemented in 122 countries, of which 112 have completed the 3 steps. Although 48 low- and middle-income countries in the WHO Africa region and 21 in the Americas (including the Caribbean) have conducted the Stepwise Approach to Surveillance survey to date, several highly populated countries, notably Brazil, Mexico, or the Russian Federation, have yet to do so (22). Both the Stepwise Approach to Surveillance and the Global Tobacco Surveillance System surveys have associated training programs that, with the support of WHO regional and country offices, have contributed to the training of health professionals in NCD risk factor surveillance globally (21).

The possibility of multiple visits to different health institutions during the patient pathway is a characteristic of chronic diseases that has implications on (morbidity) surveillance and is even shared with some infectious diseases such as the human immunodeficiency virus infection; for diabetes, available information on the prevalence of the disease (one of the global monitoring framework indicators) is provided from diabetes registries that combine information from multiple sources (e.g., treatment and biochemical measurements) (23–26) or based on survey-based estimations (27). Global report on the prevalence of diabetes has been compiled by the World Diabetes Foundation, the report now in its seventh edition (28). The focus of diabetes surveillance is evidently on prevalence, related quality of care (mainly in the primary health-care setting), and complications (24, 25). Despite the existing information on diabetes prevalence at a global level, there are also specific challenges in its surveillance, particularly related to disease definition, interlaboratory variations when based on biochemical measurements, and others that still need to be overcome. Another major obstacle to providing comparable global estimates of diabetes, as well as prevalence of other NCDs, is lack of uniform definitions and standards, which for cancer have been historically developed and safeguarded by the IARC and the International Association of Cancer Registries (29, 30).

Cancer

The major challenge to cancer surveillance is the heterogeneity of the disease, comprising greater than 100 entities, each characterized by out-of-control cell growth and classified by site of origin and type of cell initially affected. Therefore, detailed information on both the organ affected and the histological type is required to classify the nature and extent of disease, essential in planning treatment and evaluating outcomes. Classification systems have been developed, with the most widely used in surveillance being the *International Classification of Diseases for Oncology*, which contains more than 700 codes in its third edition (31). Advances in knowledge of tumor biology and underlying mechanisms of carcinogenesis are yielding further molecular and genetic subclassifications that add further challenges to the complexity of cancer and its classifications.

Although risk factor surveillance data are extremely useful in developing and appraising cancer control strategies, in estimating the potential to lower premature mortality by the 4 main NCDs by addressing 6 risk factors, a reduction of only 7% in premature deaths from cancer was projected by 2025 relative to 34% estimated for cardiovascular diseases (32). This can be predominantly attributed to the requirement of a greater duration of time needed to observe the effects of specific interventions for cancer, as well as of the diversity of major risk factors involved in cancer etiology. Despite the fact that hepatitis B virus vaccination and availability of human papillomavirus vaccines are considered as additional indicators in the WHO NCD Action Plan, only tobacco, alcohol, and obesity, among the common risk determinants considered for the NCD targets, are important causes of cancer, while for many cancers (e.g., prostate and pancreas), the major determinants are still to be identified (32, 33).

Specific approaches to the surveillance and control of cancer must then be adapted to the local scale, profile, and risk of disease in the population (34). PBCRs are integral to

measuring this burden and assessing the impact of specific interventions, as well as investigating etiological factors, the elimination or reduction of which could reduce the future cancer burden (35, 36). Cancer incidence information by histological subtype, facilitated through the *International Classification of Diseases for Oncology* (31), yields valuable information on the changing risks in populations, often related to underlying changes in the prevalence and distribution of known or putative risk factors. As an example, the observation of shifting distributions of the predominant histological subtypes of lung cancer during the last 3 decades worldwide, including a displacement of squamous cell carcinoma with adenocarcinoma as the most common subtype in several countries (37–39), permits an assessment of changes in risk following the introduction of filters in cigarette manufacturing, alongside changes in smoking prevalence (40). Equally, PBCRs are central in providing population-based estimates of cancer survival, in assessing the quality of tertiary prevention for specific types of cancer in a given region or country, as well as benchmarking survival differences between populations (36).

It is important to note the distinction between PBCRs and hospital-based cancer registries (HBCRs), given the popular misconception that the latter institutions are functional proxies of PBCRs for cancer surveillance. HBCRs are an integral part of hospital management, serving administrative purposes and auditing performance by recording and reporting the specific diagnosis and treatment of patients in relation to tumor characteristics and clinical outcome (9). Unlike PBCRs however, HBCRs cannot serve national cancer planning and evaluation purposes, as the sampling frame is not population based; HBCRs, by definition, rely on patient attendance at 1 or more hospitals, with the scale and profile of cancer determined by referral patterns and the facilities and expertise within these institutions. Given the intersection in source information, the common ambition to "upgrade" HBCRs to PBCRs in time may seem a reasonable one, but it has rarely been attempted or achieved in practice. In any case, such an evolution is somewhat contradictory in that both institutions play vital and complementary roles in supporting health care.

In stark contrast to communicable diseases, reporting by PBCR operates within an entirely different time frame in keeping with the long latency of the disease, the processes of quality control evaluation, and the requirement for multiple information sources on the same patient to ensure optimal completeness and validity. A recent report on 116 European PBCRs showed that the median time to completion of last year of incidence is in the range of 4–60 months, while the preparation of a printed report could take, on average, 7 months (41).

A FRAMEWORK FOR GLOBAL CANCER SURVEILLANCE

Cancer surveillance: components in a simplified framework

Although it is clear that there is a common approach in the surveillance of communicable diseases (compulsory notifications and rapid reporting) as well as for NCDs in general (assessment of risk factors and mortality surveillance), the complexity of cancer and the fact that *new cases* of cancer can be counted—unlike cases of most other major NCDs—have led to a unique and evolving surveillance strategy through PBCRs that has truly become a global and "gold standard" activity (9, 42).

How then can PBCRs and other cancer surveillance strategies be integrated into existing disease surveillance systems? Consistent with an extended view of cancer surveillance in planning and evaluation of cancer-control activities, representatives from various US institutes presented a national framework for cancer surveillance for the country in 2005 (43). Beyond the basic measures of disease occurrence, the US model proposed a set of core elements for cancer surveillance, including several permitting the assessment of inequities, outcomes, and quality of care (43). Despite the usefulness and comprehensiveness of this model, many of the proposed measures by necessity require linkages to other data sets, as in the case of quality of life to clinical trials or research databases, posing a difficulty in terms of applicability to many low- and middle-income countries at present. In addition, most aspects related to the quality of care are linked to treatment and management protocols that, if available, tend to be country specific, hindering comparability on a global scale.

In the development of a simplified surveillance cancer framework at a global level (Figure 1), the natural history of disease from inception through to resolution (cure or death) and its associated control measures (prevention, early detection, treatment, and end-of-life care) provide the general structure for surveillance as previously noted by Wingo et al. (43) in developing a US template. As such, 4 population subgroups important to surveillance and, thus, cancer control are defined: 1) healthy populations, 2) newly diagnosed populations, 3) populations living with cancer, and 4) populations that have died from cancer. The corresponding *core surveillance measures* for each population subgroup relevant to cancer measurement and associated probabilities of progression are as follows: 1) prevalence of risk factors (probability of exposure to develop the disease), 2) cancer incidence (magnitude and probability of disease occurrence), 3) cancer survival (probability of survival), and 4) cancer mortality (magnitude and probability of occurrence). Each core measure has a well-defined and clearly differentiated surveillance strategy of data collection: population surveys for the prevalence of risk factors; PBCRs for cancer incidence and survival; and vital statistics systems as the main strategy for mortality by cause of death (Figure 1). Anatomical extent of disease/stage constitutes an important measure permitting the differentiation of early to late cancer diagnosis and, thus, the probability of survival; in the proposed framework, it is assumed to be a variable collected by PBCRs from which core measures (incidence, survival) can be stratified. Cancer survival relies on adequate follow-up of vital status of cancer patients (Table 1) and requires longstanding PBCRs along with sufficient analytical capacity. Nevertheless, it is imperative for its sustainability that, after the implementation phase of generating quality-ensured incidence, they develop survival estimates, ideally stratified by collected stage.

Additionally, the model includes *extended measures* for which surveillance at the population level usually requires

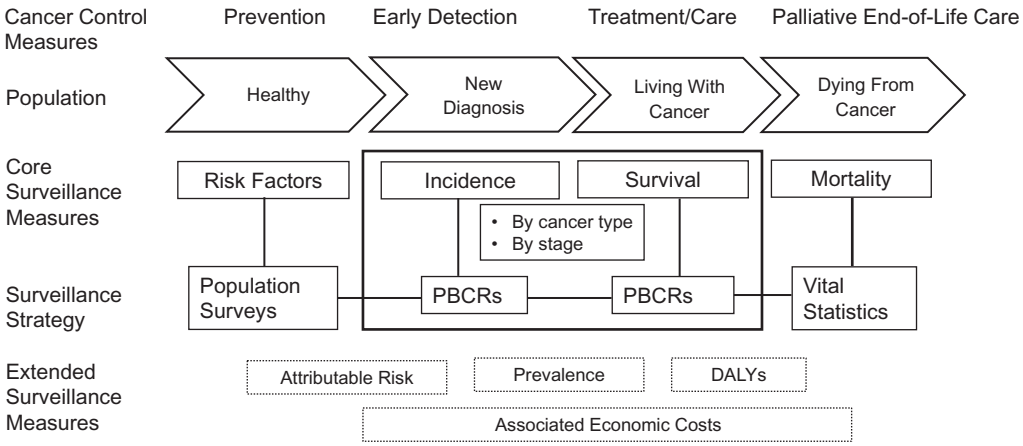

Figure 1. Measures and strategies for cancer surveillance at the population level. Adapted from Wingo et al. (43). DALY, disability-adjusted life-year; PBCR, population-based cancer registry.

further data and more advanced analytical capacity (Figure 1). Information on the attributable fraction of cancer may help to inform decision makers in developing preventative actions, while disability-adjusted life-years reflect premature loss of life as well as quality of life in surviving cancer (44, 45) and aid assessments of overall health and life expectancy. Different extended measures have been reported at the global level by subregions (46–48); linking these to the economics of cancer, for example, to lost productivity, provides valuable perspectives for decision makers seeking to ensure that resources are prioritized to cancer control.

In the described framework, cancer surveillance shares the twin strategies of risk factors and mortality with surveillance of other NCDs, the latter of which is, in turn, shared by all disease types. In adapting measures and strategies for the specific subpopulations of the newly diagnosed and those living with the disease, we can apply the framework to other major NCDs by accounting for the specificities of the disease in question (Table 1). Within the proposed framework, 3 of the core surveillance measures will facilitate the provision of most of the indicators established by the WHO global monitoring framework, namely, the reduction of premature mortality, the prevalence of specific risk factors, and cancer incidence rates by type.

Cancer incidence, mortality, and survival: attributes and availability

Descriptive studies identifying differences in cancer incidence across regions have been and continue to be crucial for the identification of risk factors (49). Cancer mortality data are vital measures of disease outcome and the former in assessing the effectiveness of cancer-screening programs, especially for those cancers for which a precursor lesion is not the target of the intervention (49). As mortality depends on both incidence and case fatality, it is a poor surrogate of incidence where prognosis is improving in the population as a result of improving care, novel treatments, and so on. Cancer incidence and survival used in combination illustrate the impact of cancer, providing information on the level of risk and the prognosis following diagnosis at the population level (50). As with incidence, survival estimates are susceptible to changes in diagnostic practices and disease classifications, as well as the impact of screening interventions where earlier detection of cases is not accompanied with a postponement of death, artificially inflating incidence and survival (51, 52). Many of the factors that affect incidence equally apply to mortality, given that both rely on the accuracy of the initial cancer diagnosis. These issues emphasize the need to ensure assessment of these indicators in combination, where possible. Indeed, there is growing consensus that such a combined description of incidence, mortality, and survival can confirm and clarify the underlying biological, epidemiologic, and clinical processes.

Over and above such concerns is the sustained lack of availability of recorded incidence and mortality data in most countries of the world. Mortality data ideally come from vital statistics systems, yet less than one-fifth of 178 countries ($n = 34$) presently report high-quality mortality data to the WHO (8). This unquestionably poses challenges for the measurement of the NCD Global Monitoring Framework overarching target of premature mortality reduction. Among major global initiatives currently implemented to improve mortality data are the World Bank- and WHO-led Global Civil Registration and Vital Statistics Scaling Up Investment Plan (53), the Bloomberg Data for Health Initiative (54), and the International Network of Health and Demographic Surveillance Systems working with sentinel sites in Africa and Asia (55). A compilation of methods and initiatives to obtain cause-of-death statistics is presented in a comprehensive manner by Jha (56).

The NCD Global Monitoring Framework recognizes the importance of the collection of *cancer incidence by type of cancer* as one of the 25 core indicators in monitoring national progress (6). Currently, only about one-third (36%) of all countries worldwide have PBCRs of high-quality incidence data as compiled by the IARC in the *Cancer*

Incidence in Five Continents series (57, 58). The coverage of high-quality cancer registration ranges from 100% in the Nordic countries to 7.5%, 5.7%, and 1.9% in Latin America, Asia, and Africa, respectively (57). Still there are registries covering 10%–20% of these continents, and the inequity is being addressed through a global partnership of key international organizations, entitled the Global Initiative for Cancer Registry Development (10). This initiative is helping low- and middle-income countries increase the availability, quality, and utilization of cancer data in national cancer-control plans and in capacity-building research. To provide a global snapshot, IARC provides estimates of cancer incidence, mortality, and prevalence through GLOBOCAN for 184 countries and 27 major cancer sites and by sex. A comprehensive overview and detailed methods are provided by Ferlay et al. (59) and are presented at the Global Cancer Observatory (http://gco.iarc.fr) (60).

With regard to cancer survival indicators, comparative data at the global level have been made available by 2 major initiatives: the global comparison of population-based cancer survival (CONCORD) program (61, 62) and the IARC-led cancer survival in Africa, Asia, the Caribbean, and Central America (SurvCan) program (63, 64), both now in their third iteration.

POPULATION-BASED CANCER REGISTRIES: MAKING THEM WORK

Although there is broad consensus that population-based cancer data are essential for setting priorities and evaluating progress in cancer control, and numerous examples have illustrated their value (36, 65), implementation and sustainable development require that governments invest in operational national cancer-control plans that embed such cancer data as a critical asset that informs planning, monitoring, and evaluation purposes. Although currently many countries in Africa, Asia, and Latin America have developed national cancer or cancer-specific control plans (66), a careful revision of their data and information needs is highly warranted. Given the longstanding traditional surveillance of communicable disease, it is not uncommon that personnel in ministries of health are not familiar with the specificities of cancer incidence surveillance and PBCRs; the same may be true of other public health professionals and epidemiologists specializing in other disease domains.

To comply with the international commitment of reporting cancer incidence by type, a common misconception by central governments grounded in the mechanisms of communicable disease surveillance is the equating of nationwide mandatory cancer reporting as a central principle of PBCRs. In the absence of adhering to the necessary methodological requirements of PBCRs that will be briefly described below, such initiatives have proven to provide an erroneous assessment of cancer incidence burden (67) and subsequently cancer-control priorities.

The specific requirements for PBCRs have been set out several times (9, 68); Figure 2 provides a general scheme that summarizes the major elements of cancer registration in 3 broad areas: in context and operation, in the key definitions and methods of registration, and in quality indicators and their evaluation. A cancer registry's operation will depend on the medical services (diagnostic, therapeutic, and palliative) available for cancer patients, the size and geographic

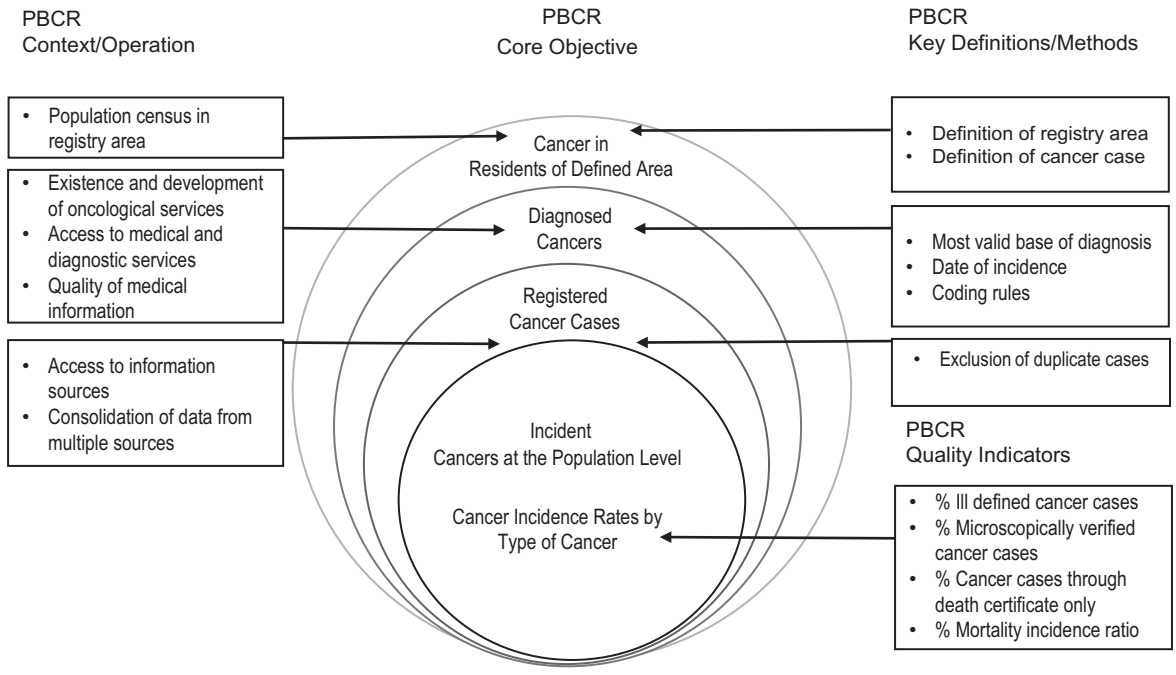

Figure 2. Key elements of population-based cancer registries for cancer incidence surveillance. PBCR, population-based cancer registry.

spread of the population, and the (material and financial) resources available. There must also be a system for reporting clinical and pathological data, and reliable population data need to be available. In checking the quality of information collected, there is a standard set of quality indicators, including the percentage of cases with a morphological verified diagnosis, the percentage of cases registered by death certificate only, and the mortality:incidence ratio; these are linked to the completeness, validity, comparability, and timeliness of the data and, thus, should be presented when informing cancer incidence (69, 70). In order for cancer incidence to be as close as possible to the true (unknown) magnitude in the population, the reporting and assessment of each of these aspects in the 3 areas are essential (69, 70).

In contrast to the surveillance of NCD common risk factors, where nationally representative surveys are developed periodically, or to the surveillance of infectious diseases where mandatory notification is established at the national level, this is not a requirement for the surveillance of cancer incidence. Indeed, most of the requirements for cancer planning and monitoring can be achieved through registration of a representative subset of the national population, using one or a series of regional PBCRs. The benefits of increasing population coverage toward national PBCRs for cancer-control purposes are not straightforward; feasibility and long-term sustainability need to be carefully evaluated. In Brazil, Colombia, Turkey, and China, registration has advanced via the development of a few strategically situated regional PBCRs, from which reliable estimates are being obtained at subnational geopolitical divisions (71–74). Following this approach, Nigeria has developed a plan to establish several PBCRs and is expected to soon have subnational estimates; the combined data of 3 of these PBCRs have already been used to inform national estimates in GLOBOCAN (75).

Despite a growing awareness of the centrality of robust data from PBCRs in support of cancer control initiatives, there remain a number of challenges to ensuring their implementation and sustained development in low- and middle-income countries, reflecting limited human and financial resources. Success requires political will, clinical commitment, and the professional responsibility of the registry director, with adequate financing and numbers of dedicated staff key to ensure the sustainability of the enterprise to inform national cancer control plans (38, 75–80). The multipartner Global Initiative for Cancer Registry Development (http://gicr.iarc.fr/) provides assistance to countries in social and economic transition seeking to expand and improve registries as a core element of cancer and NCD surveillance at the population level. The Global Initiative for Cancer Registry Development model is founded on developing centers of regional assistance, alongside country-led surveillance plans, with IARC regional hubs for Africa, Asia, Latin America, the Caribbean, and Oceania implemented and operational in collaboration with designated local investigators and institutions. The vision of the Global Initiative for Cancer Registry Development is to save lives through cancer data by directly contributing to the development of in-country capacity for cancer surveillance, with the hubs providing targeted support, training, research capacity building, and advocacy as a means to ensure the sustainable expansion of high-quality PBCRs in low- and middle-income countries (10).

CONCLUSIONS

Given the diverse but changing profiles of the disease burden worldwide, public health actions and disease control measures are required across the spectrum of major communicable and noncommunicable diseases. Although there is increasing evidence of epidemiologic and therapeutic interrelationships between, for example, cancer, diabetes, and heart disease, inherent differences in surveillance obligate that disease-specific systems coexist to generate the necessary high-quality indicators to inform health planning. As with other major NCDs, cancer surveillance evidently shares risk factor and mortality as core measures of monitoring and evaluation, yet cancer permits the counting of new cases (incidence) and, by extension, the follow-up of the vital status of cancer cases to determine average survival at the population level. A conceptual framework has been set out that seeks to facilitate the understanding of the specificities of cancer surveillance within broad disease domains and, thus, narrow resource-related gaps in the national availability of surveillance data for disease control. The proposed *core surveillance measures* facilitate the provision of most of the indicators established by the WHO global monitoring framework for the control of noncommunicable diseases. Through the Global Initiative for Cancer Registry Development partnership, efforts are underway to ensure that PBCRs are sustainably developed according to their requirements and integrated, where feasible, into NCD planning. Cancer registries remain a unique and effective means to inform and evaluate national cancer control policies and to instigate local capacity for cancer research.

ACKNOWLEDGMENTS

Author affiliations: Cancer Surveillance Section, International Agency for Research on Cancer, Lyon, France (Marion Piñeros, Ariana Znaor, Les Mery, Freddie Bray).

Conflict of interest: none declared.

REFERENCES

1. Caldwell JC. Population health in transition. *Bull World Health Organ*. 2001;79(2):159–160.
2. McKeown RE. The epidemiologic transition: changing patterns of mortality and population dynamics. *Am J Lifestyle Med*. 2009;3(1 suppl):19S–26S.
3. Santosa A, Wall S, Fottrell E, et al. The development and experience of epidemiological transition theory over four decades: a systematic review. *Glob Health Action*. 2014;7:23574.
4. World Health Organization. Global Health Observatory (GHO) data: NCD mortality and morbidity. http://www.who.int/gho/ncd/mortality_morbidity/en/. Updated 2016. Accessed May 2, 2016.

5. Bray F, Soerjomataram I. The changing global burden of cancer: transitions in human development and implications for cancer prevention and control. In: Gelband H, Jha P, Sankaranarayanan R, et al, eds. *Cancer: Disease Control Priorities*. Washington, DC: International Bank for Reconstruction and Development, The World Bank; 2015: 23–45.
6. World Health Organization. *Draft Comprehensive Global Monitoring Framework and Targets for the Prevention and Control of NCDs*. Geneva, Switzerland: World Health Organization; 2013.
7. World Health Organization. World economic forum: from burden to "best buys": reducing the economic impact of non-communicable diseases in low- and middle-income countries. http://www.who.int/nmh/publications/best_buys_summary.pdf?ua=1. Published 2011. Accessed February 9, 2016.
8. World Health Organization. *Global Status Report on Noncommunicable Diseases 2014*. Geneva, Switzerland: World Health Organization; 2014.
9. Bray F, Znaor A, Cueva P, et al. *Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings*. Lyon, France: International Agency for Research on Cancer; 2014.
10. International Agency for Research on Cancer. Global initiative for cancer registry development. http://gicr.iarc.fr/fr/. Published 2015. Accessed April 29, 2015.
11. Teutsch SM. Considerations in planning a surveillance system. In: Lee LM, Teutsch SM, Thacker SB, et al, eds. *Principles and Practice of Public Health Surveillance*. 3rd ed. New York, NY: Oxford University Press, Inc; 2010.
12. Thacker SB. Historical development. In: Lee LM, Teutsch SM, Thacker SB, et al, eds. *Principles and Practice of Public Health Surveillance*. 3rd ed. New York, NY: Oxford University Press, Inc; 2010.
13. World Health Organization. Global action plan for the prevention and control of noncommunicable diseases 2013–2020. http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf?ua=1. Published 2013. Accessed February 9, 2016.
14. Remington PL, Nelson DE. Communicating public health surveillance information for action. In: Lee LM, Teutsch SM, Thacker SB, et al, eds. *Principles and Practice of Public Health Surveillance*. 3rd ed. New York, NY: Oxford University Press, Inc; 2010.
15. Centers for Disease Control and Prevention. Field Epidemiology Training Program (FETP). http://www.cdc.gov/globalhealth/healthprotection/fetp/. Published 2016. Accessed May 31, 2016.
16. St. Louis ME, Walke H, Perry H, et al. Surveillance in low-resource settings. In: Lee LM, Teutsch SM, Thacker SB, et al, eds. *Principles and Practice of Public Health Surveillance*. 3rd ed. New York, NY: Oxford University Press, Inc; 2010.
17. Shaw FE, Goodman RA, Lindegren ML, et al. A history of MMWR. *MMWR Suppl*. 2011;60(4):7–14.
18. Mendis S. The contribution of the Framingham Heart Study to the prevention of cardiovascular disease: a global perspective. *Prog Cardiovasc Dis*. 2010;53(1):10–14.
19. Keys A. Coronary heart disease in seven countries. 1970. *Nutrition*. 1997;13(3):250–252.
20. Armstrong T, Bonita R. Capacity building for an integrated noncommunicable disease risk factor surveillance system in developing countries. *Ethn Dis*. 2003;13(2 suppl 2): S13–S18.
21. Warren CW, Lee J, Lea V, et al. Evolution of the Global Tobacco Surveillance System (GTSS) 1998–2008. *Glob Health Promot*. 2009;16(2 suppl):4–37.
22. Riley L, Guthold R, Cowan M, et al. The World Health Organization STEPwise approach to noncommunicable disease risk-factor surveillance: methods, challenges, and opportunities. *Am J Public Health*. 2016;106(1):74–78.
23. Ballotari P, Chiatamone RS, Vicentini M, et al. Building a population-based diabetes register: an Italian experience. *Diabetes Res Clin Pract*. 2014;103(1):79–87.
24. Borg S, Palaszewski B, Gerdtham UG, et al. Patient-reported outcome measures and risk factors in a quality registry: a basis for more patient-centered diabetes care in Sweden. *Int J Environ Res Public Health*. 2014;11(12):12223–12246.
25. Hallgren Elfgren IM, Grodzinsky E, Törnvall E. Swedish Diabetes Register, a tool for quality development in primary health care. *Prim Health Care Res Dev*. 2013;14(3):250–257.
26. Jo EC, Drury PL. Development of a virtual diabetes register using information technology in New Zealand. *Healthc Inform Res*. 2015;21(1):49–55.
27. Centers for Disease Control and Prevention. National diabetes statistics report 2014. http://www.cdc.gov/diabetes/data/statistics/2014statisticsreport.html. Updated 2015. Accessed February 10, 2016.
28. International Diabetes Federation. *IDF Diabetes Atlas*. 7th ed. Brussels, Belgium: International Diabetes Federation; 2015.
29. Taylor R, Zimmet P, Naseri T, et al. Erroneous inflation of diabetes prevalence: are there global implications? *J Diabetes*. 2016;8(6):766–769.
30. Zimmet P, Alberti KG, Magliano DJ, et al. Diabetes mellitus statistics on prevalence and mortality: facts and fallacies. *Nat Rev Endocrinol*. 2016;12(10):616–622.
31. Fritz A, Percy C, Jack A, et al. *International Classification of Diseases for Oncology (ICD-O)*. 3rd ed, 1st rev ed. Geneva, Switzerland: World Health Organization; 2013.
32. Wild CP, Bray F, Forman D, et al. Cancer in the 25 × 25 non-communicable disease targets. *Lancet*. 2014;384(9953): 1502–1503.
33. Wild CP, Bucher JR, de Jong BW, et al. Translational cancer research: balancing prevention and treatment to combat cancer globally. *J Natl Cancer Inst*. 2015;107(1):353.
34. Vineis P, Wild CP. Global cancer patterns: causes and prevention. *Lancet*. 2014;383(9916):549–557.
35. Glaser SL, Clarke CA, Gomez SL, et al. Cancer surveillance research: a vital subdiscipline of cancer epidemiology. *Cancer Causes Control*. 2005;16(9):1009–1019.
36. Parkin DM. The role of cancer registries in cancer control. *Int J Clin Oncol*. 2008;13(2):102–111.
37. Devesa SS, Bray F, Vizcaino AP, et al. International lung cancer trends by histologic type: male:female differences diminishing and adenocarcinoma rates rising. *Int J Cancer*. 2005;117(2):294–299.
38. Lortet-Tieulent J, Soerjomataram I, Ferlay J, et al. International trends in lung cancer incidence by histological subtype: adenocarcinoma stabilizing in men but still increasing in women. *Lung Cancer*. 2014;84(1):13–22.
39. Pesch B, Kendzia B, Gustavsson P, et al. Cigarette smoking and lung cancer—relative risk estimates for the major histological types from a pooled analysis of case-control studies. *Int J Cancer*. 2012;131(5):1210–1219.
40. Sun S, Schiller JH, Gazdar AF. Lung cancer in never smokers—a different disease. *Nat Rev Cancer*. 2007;7(10):778–790.
41. Zanetti R, Schmidtmann I, Sacchetto L, et al. Completeness and timeliness: cancer registries could/should improve their performance. *Eur J Cancer*. 2015;51(9):1091–1098.

42. Parkin DM. The evolution of the population-based cancer registry. *Nat Rev Cancer*. 2006;6(8):603–612.
43. Wingo PA, Howe HL, Thun MJ, et al. A national framework for cancer surveillance in the United States. *Cancer Causes Control*. 2005;16(2):151–170.
44. Poole C. A history of the population attributable fraction and related measures. *Ann Epidemiol*. 2015;25(3):147–154.
45. Soerjomataram I, Lortet-Tieulent J, Ferlay J, et al. Estimating and validating disability-adjusted life years at the global level: a methodological framework for cancer. *BMC Med Res Methodol*. 2012;12:125.
46. Arnold M, Pandeya N, Byrnes G, et al. Global burden of cancer attributable to high body-mass index in 2012: a population-based study. *Lancet Oncol*. 2015;16(1):36–46.
47. de Martel C, Ferlay J, Franceschi S, et al. Global burden of cancers attributable to infections in 2008: a review and synthetic analysis. *Lancet Oncol*. 2012;13(6):607–615.
48. Soerjomataram I, Lortet-Tieulent J, Parkin DM, et al. Global burden of cancer in 2008: a systematic analysis of disability-adjusted life-years in 12 world regions. *Lancet*. 2012;380(9856):1840–1850.
49. Boyle P. Relative value of incidence and mortality data in cancer research. *Recent Results Cancer Res*. 1989;114:41–63.
50. Ellis L, Woods LM, Esteve J, et al. Cancer incidence, survival and mortality: explaining the concepts. *Int J Cancer*. 2014; 135(8):1774–1782.
51. Berrino F, Micheli A, Sant M, et al. Interpreting survival differences and trends. *Tumori*. 1997;83(1):9–16.
52. Dickman PW, Adami HO. Interpreting trends in cancer patient survival. *J Intern Med*. 2006;260(2):103–117.
53. World Bank, World Health Organization. *Global Civil Registration and Vital Statistics: Scaling Up Investment Plan 2015–2024*. Washington, DC: World Bank Group; 2014.
54. Bloomberg MR, Bishop J. Understanding death, extending life. *Lancet*. 2015;386(10003):e18–e19.
55. Streatfield PK, Khan WA, Bhuiya A, et al. Cause-specific mortality in Africa and Asia: evidence from INDEPTH health and demographic surveillance system sites. *Glob Health Action*. 2014;7:25362.
56. Jha P. Reliable direct measurement of causes of death in low- and middle-income countries. *BMC Med*. 2014;12:19.
57. Forman D, Bray F, Brewster D, et al. *Cancer Incidence in Five Continents*. Vol X. Lyon, France: International Agency for Research on Cancer; 2014.
58. World Health Organization, International Agency for Research on Cancer. WHO cancer mortality database. http://www-dep.iarc.fr/WHOdb/WHOdb.htm. Accessed May 11, 2014.
59. Ferlay J, Soerjomataram I, Dikshit R, et al. Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer*. 2015;136(5): E359–E386.
60. International Agency for Research on Cancer. Global cancer observatory. http://gco.iarc.fr/. Published 2016. Accessed May 30, 2016.
61. Allemani C, Weir HK, Carreira H, et al. Global surveillance of cancer survival 1995–2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). *Lancet*. 2015;385(9972): 977–1010.
62. Coleman MP, Quaresma M, Berrino F, et al. Cancer survival in five continents: a worldwide population-based study (CONCORD). *Lancet Oncol*. 2008;9(8):730–756.
63. Sankaranarayanan R, Swaminathan R, Brenner H, et al. Cancer survival in Africa, Asia, and Central America: a population-based study. *Lancet Oncol*. 2010;11(2):165–173.
64. Sankaranarayanan R. Cancer survival in Africa, Asia, the Caribbean and Central America. Introduction. *IARC Sci Publ*. 2011;(162):1–5.
65. Armstrong BK. The role of the cancer registry in cancer control. *Cancer Causes Control*. 1992;3(6):569–579.
66. International Cancer Control Partnership. National plans. http://www.iccp-portal.org/map. Published 2016. Accessed June 14, 2016.
67. de Vries E, Pardo C, Henriquez G, et al. Discrepancies in the handling of cancer data in Colombia [in Spanish]. *Rev Colomb Cancerol*. 2016;20(1):45–47.
68. Jensen OM, Parkin DM, Maclennan R, et al, eds. *Cancer Registration: Principles and Methods*. Lyon, France: International Agency for Research on Cancer; 1995.
69. 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.
70. 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.
71. Chen W, Zheng R, Zeng H, et al. Annual report on status of cancer in China, 2011. *Chin J Cancer Res*. 2015;27(1):2–12.
72. Eser S, Yakut C, Özdemir R, et al. Cancer incidence rates in Turkey in 2006: a detailed registry based estimation. *Asian Pac J Cancer Prev*. 2010;11(6):1731–1739.
73. Ministerio da Saude, Instituto Nacional de Câncer José Alencar Gomes da Silva. *Cancer Incidence in Brazil* [in Portuguese]. Rio de Janeiro, Brazil: Instituto Nacional de Câncer José Alencar Gomes da Silva; 2015.
74. Pardo Ramos C, Cendales Duarte R. *Estimated Incidence and Mortality From Cancer in Colombia 2002–2006*. 2nd ed [in Spanish]. Bogotá, Colombia: National Institute of Cancerology; 2010.
75. Jedy-Agba EE, Oga EA, Odutola M, et al. Developing national cancer registration in developing countries—case study of the Nigerian national system of cancer registries. *Front Public Health*. 2015;3:186.
76. Hadji M, Nahvijou A, Seddighi Z, et al. Challenges to promoting population-based cancer registration in Iran: a workshop report. *Asian Pac J Cancer Prev*. 2013;14(10): 6189–6193.
77. O'Brien KS, Soliman AS, Awuah B, et al. Establishing effective registration systems in resource-limited settings: cancer registration in Kumasi, Ghana. *J Registry Manag*. 2013;40(2):70–77.
78. 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.
79. Piñeros M, Pardo C, Gamboa O, et al. *Atlas of Cancer Mortality in Colombia*. 3rd ed [in Spanish]. Bogotá, Colombia: Instituto Geográfico Agustín Codazzi; 2010.
80. Singh E, Ruff P, Babb C, et al. Establishment of a cancer surveillance programme: the South African experience. *Lancet Oncol*. 2015;16(8):e414–e421.