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Commentary

COMMENTARY

Scaling Up the Surveillance of Childhood Cancer: A Global Roadmap

Marion Piñeros, MD, MSc,* Les Mery, MSc, Isabelle Soerjomataram, PhD, Freddie Bray, PhD, Eva Steliarova-Foucher, PhD

Section of Cancer Surveillance, International Agency for Research on Cancer, Lyon, France

*Correspondence to: Marion Piñeros, MD, MSc, Section of Cancer Surveillance, International Agency for Research on Cancer, 150 Cours Albert Thomas, 69008 Lyon, France (e-mail: pinerosm@iarc.fr).

Abstract

The World Health Organization recently launched the Global Initiative for Childhood Cancer aiming to substantially increase survival among children with cancer by 2030. The ultimate goal concerns particularly less developed countries where survival estimates are considerably lower than in high-income countries where children with cancer attain approximately 80% survival. Given the vast gap in high-quality data availability between more and less developed countries, measuring the success of the Global Initiative for Childhood Cancer will also require substantial support to childhood cancer registries to enable them to provide survival data at the population level. Based on our experience acquired at the International Agency for Research on Cancer in global cancer surveillance, we hereby review crucial aspects to consider in the development of childhood cancer registration and present our vision on how the Global Initiative for Cancer Registry Development can accelerate the measurement of the outcome of children with cancer.

Despite the dramatic increase in childhood cancer survival in high-income countries since the 1960s (1), where currently more than 80% of children survive 5 years after cancer diagnosis (2,3), this outcome goes largely unmonitored at the population level in many low- and middle-income countries (LMIC). Where overall childhood cancer survival has been reported (4–7), survival is much lower than in their higher-income counterparts and may be as low as 10% in some settings (8). There is, however, evidence that this gap can be reduced through measures that encompass improved awareness, earlier diagnosis, access to appropriate therapy, and provision of adequate supportive care (9–12). To address the described inequity, the World Health Organization launched the Global Initiative for Childhood Cancer (GICC) in 2018 (https://www.who.int/cancer/childhood-cancer/en). The initiative aims to support governments in building and sustaining high-quality national childhood cancer programs, with a global target of achieving at least 60% childhood cancer survival in the age group 0-19 years by 2030. To be successful, impact needs to be measured through reliable information systems. With survival as the outcome measure, the role of population-based cancer registries providing this indicator is central. While lack of comprehensive registry data has been identified as one of the barriers to generate national political priority for childhood cancer in LMIC, having credible indicators is a key determinant in achieving it (13). We describe next the specifics of childhood cancer surveillance, highlight differences compared with hospital-based information systems, and present a vision for advancing childhood cancer registration in LMIC, making use of the existing Global Initiative for Cancer Registration (GICR).

Acquiring Data to Measure the Progress

The cancer burden in the childhood population is measured by population-based cancer registries, which collect information on new cases (incidence) and on the proportion alive at a defined point in time following a cancer diagnosis (survival). The number of deaths (mortality) is usually provided by national or regional institutions mandated to gather vital statistics. The availability and quality of cancer registration and vital registration systems in a country are strongly related to its development level, with critical information on the burden of cancer largely absent in lower-resource settings (14,15). In such circumstances, it is particularly difficult to follow up cancer patients to generate robust statistics measuring survival or outcomes (16,17).

The International Agency for Research on Cancer (IARC) is mandated by the World Health Organization to compile, estimate, and disseminate comparable data and statistics on the cancer burden worldwide. These data are disseminated through the flagship periodic publications, *Cancer Incidence in Five*

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Continents (18) and *International Incidence in Childhood Cancer* (IICC) (19). These compilations are accompanied by targeted assistance to cancer registries by various means, including developing international standards for cancer registration, capacity building such as training registry personnel in registration practices and data analysis, assessing the quality of collected data, and promoting knowledge translation and dissemination of cancer data. To streamline these activities into a coherent and collaborative program together with international funding and technical partners, IARC launched the Global Initiative for Cancer Registry Development in 2012, with an overall aim to substantively increase the coverage and quality of population-based cancer registries (PBCRs) in LMIC (20).

Furthermore, IARC has hosted the Secretariat of the International Association of Cancer Registries since 1973. The International Association of Cancer Registries is the professional organization of more than 500 member registries established in 1966 to foster international standards and collaboration and advocate the global importance of cancer registration (21). In collaboration with its members, and in the framework of the GICR, IARCis in a critical position to contribute to the rapid development of childhood cancer registration and to measure the outcome of sustainable childhood cancer programs.

Surveillance of Cancer in Children

Within the general cancer surveillance framework that calls on data on risk factors, incidence, survival, and mortality (22), the surveillance of childhood cancer has specific aspects to consider, as highlighted next.

Given the current knowledge of preventable risk factors for childhood cancer, there are limited grounds for the population-based surveillance of risk factors and precancerous conditions in children. Rather, emphasis is placed on the provision of high-quality information on incidence, survival, late effects, and quality of life of survivors. Cancer control in children is informed by detailed information on the disease, treatment, and quality of care, and thus, the collection of information on diagnosis, treatment, and long-term follow-up of a growing population of survivors has become an integral part of childhood cancer surveillance (23,24).

Childhood cancers represent a small proportion of cancers, approximately 1%-2% of all cancers (10,25), with the proportion varying according to the age distribution of the population. In countries with low Human Development Index, where populations are younger, children represent a larger proportion of cancer patients compared with countries with very high Human Development Index and older populations (0.4% vs 5%, respectively) (Figure 1). Furthermore, morphological types of cancers occurring in childhood vary considerably in comparison with those among adults (1). Whereas the *International Classification of Diseases and Causes of Death* (ICD) (26) is well adapted to describe the distribution of primary sites of the tumors in adults, which are mostly carcinomas, the ICD groups correspond less well to the most common cancer types in childhood, such as hematological malignancies, sarcomas, and embryonal tumors (Figure 2). To ensure appropriate reporting of statistics by meaningful categories, the specific classification systems of childhood cancers have been proposed since the 1950s (27–30). The third edition of the *International Classification of Childhood Cancer* was revised in 2017 (31).

Similarly, criteria for staging cancers vary by type of cancer, and as such, the TNM classification system (33) used mainly for

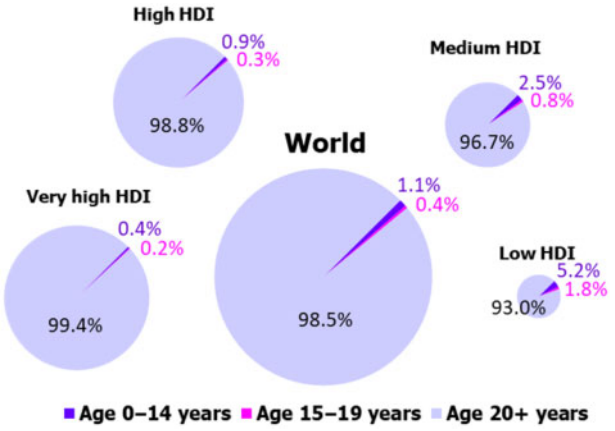

Figure 1. Distribution of the estimated numbers of new cancer cases by age group in settings categorized by Human Development Index (HDI), 2018. The area of the circles is proportionate to the total number of cancer cases (32).

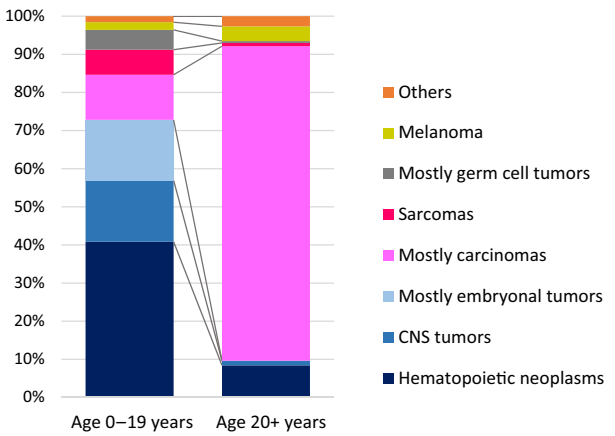

Figure 2. Composition of cancer types occurring in children and adults, circa 2008–2012. Based on 5 431 905 cases recorded in Australia, Belarus, Costa Rica, Brazil (Goiania), India (Chennai), Israel, Republic of Korea, United Kingdom (England), United States (SEER 18), Turkey (Izmir), Uganda (Kyadondo), and Zimbabwe (Harare, African) during the contributory period to *Cancer Incidence in Five Continent*, volume XI (circa 2008–2012) (18). CNS = central nervous system.

common carcinomas is not applicable for a majority of pediatric cancers. This gap has been recently addressed in the Toronto pediatric staging guidelines via a 2-tier staging system for 18 major childhood cancers (34). So far, this system has been successfully applied for solid and hematological malignancies in Australia (35,36).

The small number of cancer cases observed in childhood populations requires an increased attention to data quality, because small errors may have a large impact on the generated data. For example, where 4 cases are reported for a specific category, 1 additional case represents a 25% increase in incidence. Incomplete dates of birth, diagnosis, and death may result in a misclassification of age or even an exclusion of cases and, thus, produce a biased estimate of incidence or survival.

Although mortality is an essential indicator of cancer burden, it is less frequently used to measure cancer burden in children, for several reasons. First, some essential cancer types cannot be extracted from the official statistics on causes of death [coded to ICD (26); https://www.who.int/healthinfo/mortality_data/en]. For example, germ cell tumors cannot be identified in data coded to the site-based ICD-10, because this

morphology type can originate in many different organs of the body. A second barrier is the absence of vital statistics in many LMIC and its quality and precision in the countries where causes of death are recorded (37). Finally, the mortality rates describe the status in the age range limited to the first 15 or 20 years of life, although there is an increased risk of death among childhood cancer survivors, which extends beyond the arbitrary age range limits of childhood or adolescence.

Can Pediatric Hospital-Based Cancer Registries Produce Population-Based Data?

The small number of childhood cancer cases and their distinct features have led to a centralization of treatment in a reduced number of highly specialized referral facilities (38). Such a concentration of resources coupled with standardized treatment and social support have contributed to a substantial improvement of the outcomes in high-income countries (39,40). Furthermore, many centralized facilities have developed hospital-based cancer registries (HBCRs) or information systems measuring the outcomes linked to specific treatment protocols (many within clinical trials), with some particularly successful developments in LMIC (11,41). As such, pediatric HBCRs may accrue a substantial number of childhood cancer cases, especially because most of these patients are treated in a small number of specialized childhood cancer care facilities. This has led to a widely held belief that a pediatric HBCR—or the sum of several of them—can per se provide population-based data on childhood cancer incidence or survival.

The overarching aims, data sources, and methods of case ascertainment differ between the PBCRs and the HBCRs (38). Data from HBCRs complement population-based data collection but cannot be used as a surrogate of the population-based data (42) relevant for planning, monitoring, and evaluating cancer control plans. Although the input from pediatric and general HBCRs can be essential for ensuring completeness of the PBCRs (43,44), equally important is the mutual collaboration of childhood and all-ages general PBCRs, which improves data completeness and quality on both sides (44–48).

As an example, in the childhood cancer registry of Argentina, HBCRs of specialized pediatric treatment facilities and pediatric oncologists centralized their data nationally. The constituted database is regularly complemented with data from the national mortality register and from a number of subnational general (all-ages) PBCRs, the latter covering approximately 30% of the childhood population in the country and ascertaining new cases from additional data sources. Using this collaborative framework, the 2013 national pediatric cancer registry ascertained 91% of the expected number of cases (49).

If a well-developed pediatric HBCR exists in a specific region of the country, it could provide a good basis for setting up a subnational pediatric PBCR, which wouldincorporate the relevant registration standards and additional sources of information. Although specific pediatric PBCRs sometimes fail to ascertain cases from outpatient treatment facilities, especially in older children and adolescents, general PBCRs may miss certain cancers that are treated in specialized facilities such as retinoblastoma or may not be registering nonmalignant CNS tumors (if they are not included in the registry's case definition) (44,46–48).

Death certificates are a key data source for PBCRs. Although the proportion of cases identified from death certificates is usually relatively low among children in comparison with older ages, in the populations where the registry can access death certificates, they are an important data source for production of reliable and comparable incidence statistics in children as well.

Given the relatively low annual number of cases and the dynamic interactions with the pediatric oncology community, childhood PBCRs are often able to collect additional data items. Collecting information on selected predisposing conditions, stage at diagnosis, prognostic markers and risk groups, presence of comorbidities, treatment protocols, and adherence to therapy increases the value of the registry, because it provides valuable evidence on determinants of incidence and outcome including survival (50–52).

Strategies to Improve Population-Based Childhood Cancer Registration

Current Situation

In the most recent childhood cancer international comparative study (53), the majority of datasets were provided by general PBCRs, whereas 19 pediatric cancer registries provided population-based data. Nevertheless, as illustrated in Figure 3, because of the specific contribution by the pediatric cancer registry, the coverage of the childhood population (aged 0–14 years) doubled for Africa and increased by 1% in Asia, by more than 6% in Latin America, and by 20% in Europe compared with the covered population of adolescents (aged 15–19 years), which was ensured almost entirely by the general (all-ages) cancer registries (54). These figures clearly depict the importance of the contribution of pediatric PBCRs to the description of childhood cancer burden, as well as the inequities in data availability and the challenge constituted by the need of measuring achievements of any childhood cancer control program.

The GICR was launched to build sustainable capacity in cancer registration, supporting local ownership of data and expertise (https://gicr.iarc.fr). It uses a global, regional, and country approach that is in accordance with general guidelines established in the field of technical cooperation (55,56). Through the activities summarized next and in Table 1, the GICR constitutes a valuable resource and a clear opportunity for improving childhood cancer registration, thus complementing and supporting GICC.

Site Visits and Tailored Support

In line with a general technical assistance implementation model (55), site visits ensure an external assessment of the cancer registration situation in a given context, providing regional or international expertise and recommendations based on international standards tailored to a specific context and local mode of operation. Given the specificities of pediatric cancer outlined earlier, GICR site visits may provide a specific assessment of childhood cancer registration and key aspects of its quality.

The program of a site visit includes an inventory of, and visits to, childhood cancer treatment institutions, meetings with key stakeholders, a review of the existing information systems (including pediatric HBCRs if existent), and involvement of all potential collaborating parties. It also implies facilitating a dialogue between the pediatric oncology professionals and the PBCR team to develop best adapted strategies and to foster better use and understanding of data. As the GICR works in close collaboration with government representatives, the needs and principles of sustainable pediatric cancer registration and adequate monitoring of outcomes to fulfill the GICC target can be

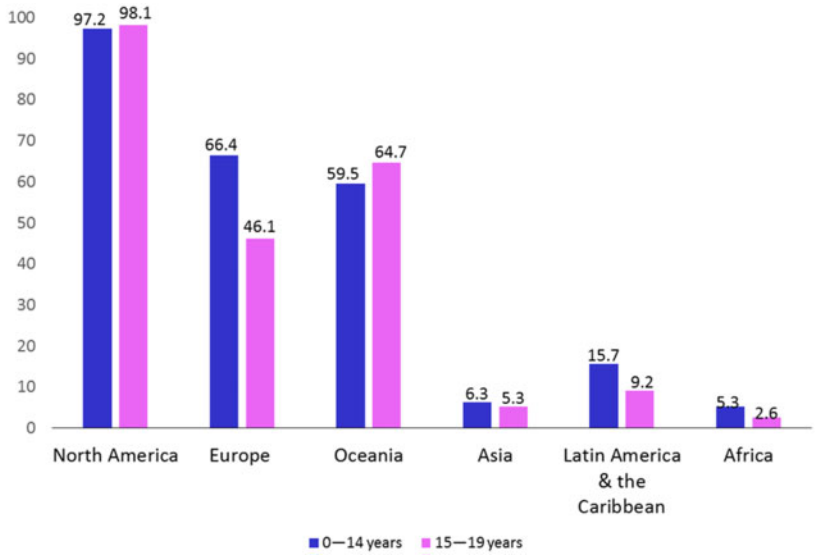

Figure 3. Percentage of population covered by registries contributing to IICC-3 in 2010, by continent (53).

Table 1. GICR areas of work and outcomes to advancing childhood cancer registration[a]

GICR area of work	Outcomes
Site visits and tailored support	Assessment of childhood cancer registration in the local context
Expert appraisal and guided support	Structured recommendations (to MoH, to PBCR, to HBCR) following findings, according to registration standards and tailored to the context
	Action plan for adoption of recommendations
	Collaborative agreements to formalize commitments, follow-up, and support
Training and knowledge transfer	Trained registry personnel
Building competencies and skills through combination of approaches and methods	Trained regional trainers
	Standardized presentations and materials to improve childhood cancer registration
Cancer control and research	Childhood cancer data disseminated according to standards
Promoting surveillance goals Understanding childhood cancer burden and patterns	Childhood cancer burden assessment leading to decisions
	Promotion and development of collaborative childhood cancer research projects
Networking and collaboration	Interaction among established regional and local networks linking pediatric oncologists and registry personnel
Facilitating collaboration among partners and stakeholders	Collaborative projects

[a]GICR = Global Initiative for Cancer Registration HBCR = hospital-based cancer registries; MoH = Ministry of Health; PBCR = population-based cancer registries.

discussed with the decision makers. In this regard, the importance of patient follow-up, reliable vital statistics, availability of mortality records, and data sharing warrant particular attention. Based on a situation analysis, GICR recommendations will provide a tailored road map for childhood cancer registration development, improvement, and reporting. Additional support and follow-up is provided where local commitment is demonstrated and supported through specific agreements that increase engagements and commitments from involved parties.

Knowledge Transfer and Capacity Building

Cancer registration is a precise area of work that follows well-documented standards (57,58). Building the necessary skills and competencies locally is a key area of work of the GICR. The training and knowledge transfer component of the GICR incorporates varied approaches and methods. The traditional teaching courses encompass basic, intermediate, and advanced cancer registration courses that are being more frequently developed at the regional level. To better support the GICC, these courses need to incorporate specific aspects of childhood cancer registration, which are often neglected given the low caseload of childhood cancer. Moreover, the GICR "train the trainers" approach, which builds a network of specialized regional trainers and develops locally adapted standardized material for PBCRs, has equal application in childhood cancer registration. Both general and pediatric PBCRs must gain or maintain skills in abstracting data on childhood cancer in coherence with international recommendations. An existing pool of qualified and internationally recognized experts will gain additional proficiency to be able to provide support in various aspects of childhood cancer registration within their reference region. Furthermore, mentorships designed to facilitate learning of personnel of less developed registries within high-quality PBCRs are an additional GICR strategy to accelerate capacity building and improve skills that can be easily dedicated to pediatric cancer. Finally, a directed GICR e-learning curriculum will address specific aspects of childhood cancer registration.

Cancer Control and Research

Data assembled by PBCRs not only are indispensable for cancer-control planning and evaluation but also constitute a valuable

resource for cancer research (59). Registry data have been used to studypossible cancer risk determinants of both primary and subsequent cancers. Large international studies have shown differences in disease occurrence between areas and ethnic groups, raising interest in targeted studies to address specific hypotheses. For example, data from cancer registries contributed to the study and understanding of the high incidence of Burkitt lymphoma in areas with endemic prevalence of malaria (60), the rise and decline of Kaposi sarcoma in countries affected by HIV infection (61,62), and the association of hepatic carcinomas in areas with high prevalence of HBV infection (Africa, Asia) (63–65).

Although the registry data do not provide direct evidence with respect to the causality of specific factors, the unbiased information that PBCRs provide forms a basis for further research on the probable causes or cancer-control interventions.

National and global estimates of childhood cancer incidence, mortality, and other indicators are useful comparators in evaluation of the burden of the disease (14,66), but they cannot substitute continuously recorded local surveillance data, and estimates are only as good as the data they are based on (67). Currently, any estimate of childhood cancer incidence in Africa is based on some 5% of the covered population (54) with only 14 countries being able to provide high-quality data for IICC-3 (53). This situation clearly illustrates difficult underlying situations and the need to continue supporting development of population-based cancer registration. Importantly, a recent dedicated report on childhood cancer in sub-Saharan Africa highlights the efforts and shows improvements in coverage with 16 population-based registries, members of the African Cancer Registry Network, achieving adequate coverage of their target population (68).

International collaboration is essential in studying rare diseases, such as cancer in childhood. An integral component of comparative studies is careful review of individual records as a means of data quality improvements. IARC has a long-standing experience in coordinating large studies as an independent international organization. Registries strive to achieve the data quality levels required by *Cancer Incidence in Five Continents* (18) and IICC (53) projects. The specific feedback registries receive on their data helps ensure continuously increasing quality and comparability of cancer registration.

Quality and comparability within international studies can only be ensured when data are analyzed centrally. The review process allows not only continuous realignment with international standards but also identification of potential errors that may not have been identified by individual registries. Data sharing and mechanism to ensure safety of the data are of utmost importance. International data-sharing policies have to be addressed, especially in light of the recent General Data Protection Regulation issued in the European Union (69,70) so that the interests of patients, their families, and populations are protected and respected, simultaneously.

Collaboration With Stakeholders and Networking

The development and improvement of childhood cancer registration information aimed through GICR demand collaboration and participation with many stakeholders, including pediatricians, registries, and civil society, among others. All of them have a crucial role in understanding the foundations as well as in supporting the data collection, analysis, and dissemination based on the statistics generated. Implementation of GICR activities through IARC Regional Hubs has permitted the establishment of networks and collaborations between regional and international partners that definitely favors working toward a common agenda of improving childhood cancer registration. An area that still remains to be explored further in GICR is the interaction with parents of the children with cancer and their supporting nongovernmental organizations, as they have contributed in many countries to an increased awareness, early diagnosis, to improved adherence to childhood cancer treatment (71,72) and to the development of specific information systems (44,73).

A strong support of the local stakeholders can only be obtained if the purpose and benefits of childhood cancer surveillance are well understood. With the pivotal role of GICR and contribution from all collaborating partners, increasing commitments for cancer registration as a fundamental pillar to plan and evaluate the GICC program are expected.

High-quality childhood cancer incidence and survival data at the population level are critical components for the recently launched GICC. Via the development of local capacity for cancer registration, the GICR provides a perfect platform and plan of support to the envisaged scale-up of childhood cancer control as well as prospects of benchmarking population-based childhood cancer incidence and survival.

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