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Registration of childhood cancer: Moving towards pan-European coverage?

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Abstract Cancer is relatively rare in childhood, but it contributes considerably to childhood mortality, years of life lost per person and late effects in survivors. Large populations need to be covered to set up meaningful studies of these rare conditions. Cancer registries ensure cancer surveillance, thus providing the basis for research as well as policy decisions. In this paper we examine coverage of childhood population by cancer registries in Europe and encourage national cancer registration.

Over 200 cancer registries in various stages of development were identified as collecting data on childhood cancer patients in Europe. They cover 52% of the childhood population in the World Health Organisation (WHO) European region and 83% in the European Union (EU). More than 80% of this coverage is ensured by nationwide data collection, which is ongoing in 29 European countries. Overall coverage of the childhood population could increase to around 98%, if the recently established cancer registries start producing results and others improve their quality and dissemination plans. Paediatric cancer registries are being established with increasing frequency even in the areas covered by general cancer registries, and they tend to be national.

Compared with regional registration, national cancer registries are more cost-effective, record larger number of cases, they can achieve higher completeness, less biased incidence and survival estimates and they are conditioned for national and international research. National registration of childhood cancer should be the rule in Europe, so that accurate regional,

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nation-wide and international statistics can provide solid baselines for research, clinical practice and public health policy. Governmental support and stakeholders' involvement are indispensable to guarantee optimal data quality and completeness.

1. Introduction

Childhood cancer is rare in absolute terms. The estimated incidence of cancer among children under 15 years of age in Europe for 2012 is 139 per million [1]. The estimated total number of cases of childhood cancer in Europe represents 0.5% of the cases at all ages. Five percent of all deaths in childhood (15% in ages 5–14 years) are due to cancer, the leading disease causing death in children beyond infancy [2]. Young age also means the potential proportion of life lost to cancer per case is greater than later in life. Five-year survival attains 80% or more [3] but survivors are subject to 8–11-times increased overall mortality [4–6], which remains at a 3-fold excess even 45 years after diagnosis [7], compared to the general population. Up to 90% of survivors suffer some late effect [8], including a 3–4-fold increased risk of subsequent malignancies [9,10] years after their first diagnosis. Childhood cancer is comprised of numerous tumour entities which are unusual in adults (e.g. embryonal tumours) or are expressed differently (e.g. leukaemia).

Among 63 cancer registries contributing to the Automated Childhood Cancer Information System (ACCIS), the annual number of registrations varied between 5 and 1736 with a mean of 123 and a median of 23 cases per registry [11]. The relatively low absolute numbers of childhood cancer in almost all cancer registries mean that long time periods are required to accumulate sufficient numbers of cases to discern the patterns of childhood cancer occurrence. It is not surprising that rising incidence rates in the childhood population of Europe over the period 1978–1997 were clearly revealed from the pooled pan-European data in the framework of ACCIS [11], while the data from the contributing cancer registries either did not show any increase (Spain-Catalonia [12]), documented increase for some cancer types only (Norway [13], Central Italy [14], Hungary [15], Netherlands [16]) or the increase pertained to a much longer time period (Sweden [17]). Only some, mostly large cancer registries of Germany [18], Great Britain [19] or Spain [20] were in accordance with the ACCIS findings. One way to increase the study size is to enlarge the population covered by cancer registration. This may be achieved by expanding the coverage of the regional cancer registries within countries and by reinforced data sharing internationally. The aim of this paper is to examine coverage of the childhood population and discuss the advantages of national coverage for childhood cancer registration in the countries of Europe.

2. Methods

2.1. Delineating Europe

Different sources were consulted to obtain the list of countries that belong to Europe (Table 1). We identified 59 countries and territories which are included in Europe according to at least one of the physiographic [21], the United Nations (UN) [22], or the World Health Organisation (WHO) definitions [23]. We also considered specifically the 28 countries of the European Union (EU-28), the European Free Trade Association (EFTA) and the candidate countries (CC) for joining the EU [24,25].

2.2. Data sources

Estimates of national population for 2010 for all ages and childhood (age 0–14 years) were obtained for most countries and territories from the UN estimates [26]. Other sources [27,28] were consulted when the UN estimates only provided grouped data for certain entities, as specified in Table 1.

All population-based cancer registries operating in the countries listed in Table 1 were identified on the following grounds: participation in peer-reviewed international studies, such as Cancer Incidence in Five Continents (CI5) [29,30], International Incidence of Childhood Cancer volume 2 (IICC-2) [31], EUROCARE [3,32], CONCORD [33], ACCIS [11] or a publication of the registry data in a peer-reviewed international journal. The following international activities were also recognised: European Cancer Observatory (ECO, [34, this issue]), membership in the International Association of Cancer Registries (IACR) [35], European Network of Cancer Registries (ENCR) [36] and NORDCAN$_3$ [37]. Lists of the relevant national network of cancer registries [38–43] were consulted, too. For some registries the only source of information about its existence was personal communication.

[3] The NORDCAN project presents the incidence, mortality, prevalence and survival statistics from 50 major cancers in the Nordic countries.

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