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Editorial Comment

EUROCARE

Cancer registries have a long history of collaboration [1,2]. Studies of possible causes, incidence, geographical and ethnic distribution, and occupational and other exposures are vital for healthcare planning, for public health initiatives to prevent the disease, and to support biological research. The best information is derived from population-based registries, that is those that collect accurate diagnostic information on all cases resident within a defined geographical area where the population denominators are known. If few patients are lost to follow-up, then mortality and survival data can also be calculated, allowing the impact of new treatments to be assessed among the total population.

It is ironic, therefore, that, even while the European Union-funded EUROCARE studies are still being analysed, the future of cancer registries could be jeopardised by the European Directive of 1995. This concerns the protection of individuals with regard to processing identifiable personal data, and has been interpreted in some countries as requiring the patient's consent. However, cancer registries should be exempted from this requirement, as specified in article 8. Many believe that it is impossible to obtain informed consent from every patient (or parent) and unnecessary, especially when only anonymised data are used as in EUROCARE [3].

The EUROCARE database included 4 million cancer cases from 65 cancer registries in 20 European countries. The main results of its analyses, EUROCARE I (1978–1985) and II (1985–1989) showed that for adults survival trends over time increased everywhere. When highly effective treatment was available, as for testicular cancer and Hodgkin's Disease, intercountry differences were small. But when prognosis depends on stage at diagnosis, such as colorectal and breast cancer, large differences between countries were found. The worst results were from Eastern Europe [4].

For the paediatric analyses, the EUROCARE II database was supplemented by data from the national paediatric cancer registries in the UK and former West Germany (together contributing 69% of all paediatric patients), the Italian Piedmont registry and the national Dutch leukaemia registry. Volume 37, Number 6 of the *European Journal of Cancer* was devoted to 16 papers on survival rates in children (aged 0–14 years) and one on cancer mortality for children and adolescents (15–19 years) which used the World Health Organization's (WHO's) database for 1955–1995. The analyses were carried out by multidisciplinary teams which included cancer epidemiologists, biostatisticians and paediatric oncologists.

Survival data for 45 000 children from 17 countries and 34 established population-based cancer registries were obtained, that is for approximately 45% of all cases of childhood cancer occurring in Europe during 1978–1992 (most of the former Soviet Union was excluded). However, weaknesses were detected; for example, there was evidence of under-ascertainment of some cancers, particularly central nervous system (CNS) tumours, thyroid cancers and malignant melanoma, probably because not all were referred to paediatric oncologists, on whom the registration is particularly reliant in countries such as Germany. For 10 countries, the cancer registries covered the whole population. For seven, data came from regional registries covering 3.9–17.5% of their populations, for which they were assumed to be representative [5]. The proportions of patients lost to follow-up or with follow-up shorter than 5 years varied markedly from country to country and could have influenced some of the survival differences observed. However, only 1.7% of the European cases overall were lost to follow-up, with 10.3% having a follow-up of less than 5 years.

An important aspect of the study was that tumours were classified according to the International Classification of Childhood Cancer, based on both morphology and topography, rather than on the WHO International Classification of Disease (ICD) codes, which do not allow the identification of some tumours such as neuroblastoma. Microscopic confirmation of diagnosis was achieved in 98.1% of cases [5].

The analyses showed that in European children there was a small increase in incidence for all cancer types over the period of 1978–1989. Overall survival increased markedly, particularly for leukaemias, lymphomas and embryonal tumours. A regression analysis of incidence, mortality and survival rates over the whole database strongly indicated that these improvements were real and not due to changes in diagnostic procedures [6]. In Western Europe, mortality fell from the mid-1960s

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onwards, and there was an estimated total number of 4500 avoided deaths per year. In Eastern Europe, the declines started around the mid-1970s or the late 1980s and were approximately 30%, reflecting a more recent adoption of effective treatments [7]. EUROCARE III, on 23 139 European children diagnosed in 1990–1994 confirmed that large survival differences persist (45% in Estonia, 90% in Iceland) being generally low in Eastern Europe and best in the Nordic countries [8].

For adolescents (aged 15–19 years) mortality in Western Europe fell by nearly 50% from the 1960s, but in Eastern Europe by only 20% in boys and 25% in girls, and only over the last decade. This age group may be disadvantaged by a lack of centralised specialist care and access to national trials, which have been shown to be so important in paediatric cancer [9]. Another analysis, of the EUROCARE III database, of 15 101 patients from 56 adult cancer registries diagnosed in 1990–1994, showed that adolescents (15–19 years) also had significantly poorer survival than young adults (20–24 years) for all malignancies combined [10].

EUROCARE and Surveillance, Epidemiology and End Results (SEER) data on survival in European and American children diagnosed with cancer during 1985–1989 have shown that, unlike the survival of adults, the survival of children with cancer is very similar in Western Europe and the United States of America (USA) [11].

Among many other important findings of EUROCARE II were that survival improvement for CNS tumours was more modest than for other cancers, with marked country to country variability. This was attributed to delays in introducing modern imaging, centralised multidisciplinary care and clinical trials, and sub-optimal resection of brain tumours. For acute lymphoblastic leukaemia, the ability to deliver effective protocols safely was the over-riding factor, while for acute non-lymphoblastic leukaemia, it was entry into national trials and treatment in teaching hospitals. Encouragingly, modifications since the 1970s to chemotherapy for Hodgkin's disease, to reduce late effects, did not affect the falling mortality. However, it is disappointing that while survival rates increased substantially for osteosarcoma until about 1985, and for rhabdomyosarcoma until about 1989, they have improved little since [8].

For neuroblastoma, the risk of death fell by 37% between 1978–1981 and 1990–1992. However, survival rates were higher in France, Germany and Italy than in England, Wales and Scotland and had a positive correlation with the incidence rates. Indeed, for all European countries, there was a linear relationship between incidence and survival, confirming the work of the Study for the Evaluation of Neuroblastoma Screening in Europe (SENSE) group, who suggested that both are related to the frequency of diagnosing asymptomatic tumours in infants, which have a good prognosis and may regress spontaneously. The diagnosis of these asymptomatic cases may reflect healthcare surveillance systems and the use of ultrasound scans [12].

The EUROCARE studies involve a remarkable international collaboration which is providing invaluable information to oncologists, scientists, healthcare planners and politicians. It is clear that there is scope for further improvements in outcomes, particularly in Eastern Europe, and these studies give helpful indications as to how they might be achieved. EUROCARE needs to continue to monitor not only survival, patient access to agreed protocols and reasons for poorer outcomes, but also to examine the prevalence of survivors and their treatment-related side-effects, which are being addressed by the EUROPREVAL project [4]. Unfortunately, these endeavours are threatened because their funding from the EC is not being renewed beyond the end of 2003. It would be a tragedy if data protection legislation were to impede these efforts, or if the full potential of the investment in the EUROCARE project were not realised through difficulties over funding.

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