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Original Paper

Childhood Cancer in Britain: The National Registry of Childhood Tumours and Incidence Rates 1978–1987

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The National Registry of Childhood Tumours contains population-based data on childhood cancers diagnosed throughout Great Britain from 1962 onwards. This paper describes the methodology of the Registry, presents incidence rates for 1978–1987 and describes other uses of the data. Total age-standardised annual incidence was 118.3 per million. The most frequent diagnostic groups were leukaemias (age-standardised rate 39.8), brain and spinal tumours (27.0), lymphomas (11.1), sympathetic nervous system tumours (8.3), kidney tumours (7.7) and soft-tissue sarcomas (7.5). Incidence rates were similar to those reported from other Western industrialised countries. The data are also used for a wide range of epidemiological and other studies. These include analyses of geographical variations in incidence, trends in survival, health of long-term survivors and their offspring and the genetics of childhood cancer. Information is frequently provided for clinicians and research workers, and series of specific types of cancer are compiled for further study. The Registry depends for the completeness and accuracy of its data on a wide range of organisations and individuals, and it is essential that this cooperation continues if the Registry is to be maintained.

Key words: childhood cancer, cancer registry, cancer incidence, epidemiological studies
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INTRODUCTION

THE CHILDHOOD CANCER Research Group (CCRG), U.K. was set up in 1975 following recommendations of a working party on childhood tumour registration of the Ministry of Health Standing Medical Advisory Committee Sub-Committee on Cancer. A primary objective was to create a register of childhood cancers, i.e. those occurring before the age of 15 years, with more information and better diagnostic data than were available in general cancer registries. The population-based National Registry of Childhood Tumours (NRCT) includes nearly all cases of childhood malignant disease occurring throughout England, Scotland and Wales from 1962 onwards, together with most children who died of cancer during 1953–61 and a series of long-term survivors who were also diagnosed before 1962. The NRCT is the largest childhood cancer registry in the world and now includes data on over 50,000 children. Detailed tables of incidence rates are published from time to time, the most recent covering the decade 1975–1984 [1]. The data have been used, and continue to be used, for a wide range of research both by members of the CCRG and by others. Many published reports of this research include a brief description of relevant aspects of the registry, but no detailed account of its operation has yet been published. The objectives of the present paper are to describe in detail the working methods of the NRCT, to present more up-to-date incidence rates, including estimates of incidence for some relatively recently defined diagnostic groups, and to describe briefly the other uses of the data.

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PATIENTS AND METHODS

Registration

Cancer registration in England and Wales is carried out by a network of population-based regional registries, and coverage has been national since 1962. Reporting to the regional registries is voluntary. Registration is coordinated nationally by the Office of Population Censuses and Surveys (OPCS), who maintain the national cancer registry. In Scotland, a similar system has been in operation since 1959, based on five regional registries, and coordinated nationally by the Information and Statistics Division (ISD) of the Scottish Health Service. Copies of all registrations from 1962 onwards relating to children aged under 15 years have been sent to the CCRG by OPCS, ISD and regional cancer registries.

The Manchester Children's Tumour Registry [2], the Northern Region Children's Malignant Disease Registry [3], the West Midlands Regional Children's Tumour Research Group [4] and the Yorkshire Children's Cancer Registry [5] all register childhood cancers on a regional basis and notify patients to the CCRG. Data have also been obtained from a 10-year population-based study of childhood cancer in south-western England [6].

The United Kingdom Children's Cancer Study Group (UKCCSG), which is the national organisation of paediatric oncologists and which coordinates clinical trials for all the major types of childhood cancer except leukaemia, maintains a register of children with malignant disease under the care of its members, and copies of all notifications are sent to the CCRG. Trials of treatment for leukaemia are coordinated by the Medical Research Council, and copies of notifications for all children in the trials are received from the Clinical Trial Service Unit, Oxford. Copies of death certificates for all deaths occurring before the age of 20 years with a neoplasm coded as the underlying cause are sent to the CCRG by OPCS (for England and Wales) and by the General Register Office (for Scotland).

Most children are notified from more than one source. Table 1 shows the numbers of cases diagnosed during 1978–1987, that were notified by each of the sources mentioned above. All but 305 (2.5%) were notified through a cancer registry. The mean number of notifications per child was 2.25. No prospective study of completeness of ascertainment has been carried out. Ascertainment is believed to be almost complete, however, and assuming independence of the various sources of notification, it has been estimated that 99% of incident cases of childhood leukaemias are included in the NRCT [7].

The histological diagnosis and date of diagnosis, together with initial treatment, follow-up and other clinical data, are verified and amended where appropriate using the records held by the hospitals at which the children were treated, by their general practitioners or by the organisers of clinical trials. In addition, the diagnoses for the great majority of children in the regional children's tumour registries [2–6] are centrally reviewed and their records have been checked against those of the NRCT. Approximately 5 years from diagnosis, identifying records of all survivors are sent for tracing and flagging in the National Health Service Central Registers (NHSCR) [8, 9]. The CCRG is then sent copies of any further cancer registrations and death certificates relating to any of the flagged patients. Together with notifications of embarkations from NHSCR, resulting in loss to follow-up, these data are used to calculate survival rates and as a source of ascertainment of second primary neoplasms. Among the 6669 children diagnosed during 1978–1987 for whom no notification of death has been received, only 190 (2.8%) have emigrated or could not be traced at NHSCR and are thus lost to follow-up. Birth records have been obtained for children in the Registry who were born during 1966 onwards and diagnosed before the end of 1986. Patients and their families are never approached for information.

Table 1. Sources of notification for children in the National Registry of Childhood Tumours diagnosed 1978–1987

Source	Number	%
Total	12399	100
Cancer registry*	12094	97.5
UKCCSG	8116	65.5
Leukaemia trials	2381	19.2
Death certificate	5249	42.3
All 4 sources	699	5.6
Any 3 sources	3958	31.9
Any 2 sources	5428	43.8
Any 1 source	2314	18.7

* Including regional childhood cancer registries.

Information on each child in the Registry is held in three places. A record card is stored in an alphabetical card index. All original paper documents are kept in a case folder. Identifying information and many other data in coded form are stored in a series of tables on a computerised database using the Oracle system. When a batch of notifications is received from any source, each case is checked against the card index and the database. Tumour topography and morphology are coded according to the International Classification of Diseases for Oncology (ICD-O) [10]. Congenital abnormalities and other chronic or familial diseases are coded according to the British Paediatric Association extension of ICD-9 [11]. Other data relating to the neoplasm and place of treatment are coded using code-lists developed at the CCRG. Addresses at diagnosis and death are postcoded using the computerised National Postcode Directory. Identifying information and coded data are then entered into a temporary database and, when the data have been validated internally and in relation to any data already held for the same children, the new data are added to the main database. Other geographical variables, namely 1981 census enumeration districts, grid references and health authority areas, are derived by computer from the postcodes. Codes for the county, district and census ward of each address are embedded in the enumeration district code.

The Registry follows standard cancer registry practice on confidentiality of records [12]. Requests from outside researchers for data, including identifying information on individual patients, are referred to an advisory group which was set up for this purpose.

Classification

Cancer incidence data for adults are generally tabulated according to the International Classification of Diseases, in which cancers other than leukaemias, lymphomas and melanomas are grouped by site of origin. Childhood cancers exhibit a great diversity of histological types as well as primary sites, but the common carcinomas among adults—those of lung, female breast, stomach, large bowel and prostate—are extremely rare in childhood. Consequently, it is more appropriate for childhood tumours to be classified according to their histology. In the standard classification scheme [13], the diagnostic groups are defined according to codes for morphology as well as topography in the first edition of ICD-O. The major groups are: leukaemias, lymphomas, brain and spinal tumours, sympathetic nervous system tumours, retinoblastoma, kidney tumours, liver tumours, bone tumours, soft-tissue sarcomas, gonadal and germ-cell tumours, epithelial tumours, other and unspecified malignant neoplasms. Since the ICD-O was published in 1976, further types of neoplasm have been recognised, including some that occur predominantly in children. Most of these additional types have codes in the second edition of ICD-O [14]. Work is in progress on a new version of the classification scheme, in which the groups will be defined according to codes in the second edition. For this paper, however, we have used the scheme based on first edition codes, but with a few modifications to admit newly recognised histological entities and to take into account

current pathological opinion. These modifications are as follows: (1) Megakaryocytic leukaemia is transferred from Other and unspecified leukaemia to Acute non-lymphocytic leukaemia; (2) Langerhans cell histiocytosis (histiocytosis X) has been removed from Lymphomas as registration of this group of disorders is thought to be very incomplete and their status as neoplasms is controversial; (3) Primitive neuroectodermal tumour of all central nervous system sites is classified with Medulloblastoma; (4) Neuroectodermal tumour of bone is classified with Ewing's sarcoma; (5) Neuroectodermal tumour of other sites is classified with other sympathetic nervous system tumours; (6) Bone-metastasising renal tumour of childhood (clear-cell sarcoma of the kidney) and rhabdoid renal tumour are classified with Wilms' tumour; (7) Rhabdoid tumour of other sites is classified with Other and unspecified soft tissue sarcoma; (8) An extra category has been created for Skin carcinoma; (9) Pancreatoblastoma is classified with Other and unspecified malignant neoplasms.

Calculation of rates

Incidence rates have been calculated as annual rates per million population rather than per 100 000 as is usual for adult cancers. The denominators are annual mid-year estimates of the child population at ages 0, 1–4, 5–9 and 10–14 for 1978–1987. These were obtained from OPCS for England and Wales and from the Registrar-General for Scotland. In addition to the age-specific rates, two measures of overall incidence have been calculated. The first is an age-standardised annual rate based on the World Standard Population, which gives weights of 2.4, 9.6, 10 and 9, respectively, to the four age groups 0, 1–4, 5–9 and 10–14 [15]. The second is a cumulative rate, formed by summing the incidence rate at age 0, 4 times that at age 1–4, and 5 times those at age 5–9 and 10–14. This is an estimate of the risk of developing a cancer in the first 15 years of life and is equivalent to 15 times the age-standardised rate based on a uniform age distribution.

RESULTS

Incidence

Table 2 gives the numbers of registrations, estimated incidence and sex ratio of cumulative incidence rates during 1978–1987 for all the groups in the classification described above. Overall, there were 12 399 registered cases, an average of 1240 per year. The age-standardised incidence was 118.3 per million. The cumulative incidence to age 15 years was 1720 per million, giving a risk of 1 in 581 for the first 15 years of life. Boys were affected 1.2 times as frequently as girls. Overall, 91% of registrations were histologically verified. For two major diagnostic groups, however, histology was available for fewer than 80% of registrations. These were brain and spinal tumours (77% with histology), for which many cases were diagnosed on the basis of radiology, and retinoblastoma (79%), which is frequently diagnosed by examination under anaesthetic without biopsy.

The most common diagnostic group was the leukaemias, accounting for one third of all registrations. Within this group, 80% were acute lymphoblastic leukaemia (ALL). Immunophenotype was available for 2179 (67%) children with ALL. Of these, 1626 (75%) were common ALL, 343 (16%) were T-cell, 46 (2%) were B-cell and 164 (8%) were null ALL; pre-B ALL could not be reliably distinguished for most of the study period, and any cases so described have been included with common ALL. The relative frequency of these subtypes varied with age and sex: common ALL was the most frequent phenotype at all ages from 1 year upwards; below age 1 year null ALL accounted for 60% of typed cases; T-cell ALL accounted for 20% of typed cases among boys and 10% among girls, the highest relative frequency for this subgroup being 31% at age 10–14. Of the 96 children classified as having chronic myeloid leukaemia (CML), 45 (47%) were stated to have Philadelphia chromosome positive, adult CML, 32 (33%) had juvenile CML and no chromosomal information was available for the remaining 19 (20%). Median age at diagnosis was 10 years for adult CML and 2 years for juvenile CML.

Histological subtype was specified for 556 (95%) of the children with Hodgkin's disease. Nodular sclerosis was the commonest subtype, accounting for 40% of boys and 61% of girls with known subtype. Lymphocyte predominance occurred in 25% of boys and 8% of girls, and mixed cellularity in 27% each of boys and girls. Lymphocyte depleted histology accounted for only 4% of cases among either sex. Numbers of cases of each subtype increased with age, but nodular sclerosis was particularly frequent at age 10–14 (55%), whereas mixed cellularity accounted for 53% of cases of known subtype at age 1–4. Immunophenotype was only specified for 50% of children with non-Hodgkin lymphoma (NHL), and so no conclusions could be drawn.

Brain and spinal tumours accounted for 23% of all registrations. Of the 321 children classified as having ependymoma, 57 (18%) had choroid plexus papilloma; this diagnosis was most common among infants aged under a year, with the 21 cases accounting for over 60% of ependymoma at this age and giving an annual incidence of 3.0 per million. Astrocytoma was the most common type of central nervous system tumour, with 1087 cases accounting for 37% of the total; of these, 553 (51%) were specified as juvenile astrocytomas, including optic nerve glioma, and 164 (15%) as adult astrocytomas. Adult type tumours were relatively more common among older children but even at age 10–14, 94/121 (78%) of astrocytomas of specified type were juvenile. The great majority (561/622, 90%) of primitive neuroectodermal tumours were medulloblastoma, the remainder being tumours of non-cerebellar sites. The 423 other gliomas included 48 oligodendrogliomas; histology was only available for 102 of the remaining 375 cases. The 446 other and unspecified CNS tumours included 146 craniopharyngiomas, 55 pinealomas and a further 15 unspecified pineal tumours, 36 meningiomas, 36 non-malignant germ-cell tumours, 18 gangliogliomas, and 6 pituitary adenomas: the remaining 134 were tumours of unspecified type, all but 17 without histology.

The great majority of sympathetic nervous system tumours are neuroblastoma. Of the remainder, 20/28 (71%) were peripheral neuroectodermal tumours, including Askin's tumour and olfactory neuroblastoma.

Of the 332 children with retinoblastoma, 192 (58%) had unilateral and 129 (39%) bilateral tumours; laterality was unrecorded for the other 11 children. A family history of retinoblastoma was recorded in 54 cases, although some familial aggregations may have been missed and this percentage should be regarded as a minimum estimate (16%).

Over 90% of renal tumours were Wilms' tumour etc. Within this group, 21/698 (3%) were bone-metastasising renal tumours of childhood (clear cell sarcoma of kidney) and 16 (2%) were rhabdoid renal tumours.

Hepatoblastoma was the most common liver tumour, with 92% of cases occurring below age 5 years; above this age, hepatocellular carcinoma was more common. In addition to

Table 2. Registrations and annual incidence rates per million for childhood cancer in England, Scotland and Wales, 1978–1987

Diagnostic group	Number of cases					Rates						
	Age					Age						
	0	1–4	5–9	10–14	Total	0	1–4	5–9	10–14	Age-standardised	Cumulative	Sex ratio M/F
All cancers	1068	4346	3263	3722	12399	153.6	161.1	92.8	91.7	118.3	1720	1.20
Leukaemia	210	1837	1105	878	4030	30.2	68.1	31.4	21.6	39.8	568	1.19
Acute lymphoblastic	113	1580	935	603	3231	16.3	58.6	26.6	14.9	32.3	458	1.23
Acute non-lymphocytic	66	196	145	228	635	9.5	7.3	4.1	5.6	5.9	87	1.00
Chronic myeloid	8	43	16	29	96	1.2	1.6	0.5	0.7	0.9	13	1.58
Other and unspecified	23	18	9	18	68	3.3	0.7	0.3	0.4	0.7	9	0.79
Lymphomas	21	181	404	716	1322	3.0	6.7	11.5	17.6	11.1	176	2.34
Hodgkin's disease	0	38	150	396	584	—	1.4	4.3	9.8	4.6	76	2.20
Non-Hodgkin, incl. Burkitt's and unspecified	15	136	250	303	704	2.2	5.0	7.1	7.5	6.2	94	2.53
Other reticuloendothelial	6	7	4	17	34	0.9	0.3	0.1	0.4	0.3	5	1.53
Brain and spinal	190	833	955	921	2899	27.3	30.9	27.2	22.7	27.0	400	1.18
Ependymoma	34	133	70	84	321	4.9	4.9	2.0	2.1	3.1	45	1.16
Astrocytoma	45	298	364	380	1087	6.5	11.0	10.3	9.4	10.0	149	0.98
Medulloblastoma/PNET	44	207	233	138	622	6.3	7.7	6.6	3.4	6.0	87	1.67
Other glioma	22	97	167	137	423	3.2	3.6	4.7	3.4	3.9	58	1.04
Other and unspecified	45	98	121	182	446	6.5	3.6	3.4	4.5	4.0	61	1.32
Sympathetic	225	413	96	31	765	32.4	15.3	2.7	0.8	8.3	111	1.07
Neuroblastoma	223	403	94	17	737	32.1	14.9	2.7	0.4	8.1	107	1.07
Other and unspecified	2	10	2	14	28	0.3	0.4	0.1	0.3	0.3	4	0.95
Retinoblastoma	152	163	16	1	332	21.9	6.0	0.5	0.0	3.7	48	1.04
Kidney	91	448	143	30	712	13.1	16.6	4.1	0.7	7.7	104	0.98
Wilms' tumour etc.	90	447	142	19	698	12.9	16.6	4.0	0.5	7.6	102	0.97
Carcinoma	1	1	1	11	14	0.1	0.0	0.0	0.3	0.1	2	1.71
Liver	34	37	13	19	103	4.9	1.4	0.4	0.5	1.1	15	1.13
Hepatoblastoma	33	37	3	3	76	4.7	1.4	0.1	0.1	0.8	11	1.17
Carcinoma	1	0	10	16	27	0.1	—	0.3	0.4	0.2	4	1.02
Bone	0	27	167	445	639	—	1.0	4.7	11.0	5.0	83	0.88
Osteosarcoma	0	6	61	235	322	—	0.2	1.7	6.3	2.5	41	0.83
Chondrosarcoma	0	1	4	11	16	—	0.0	0.1	0.3	0.1	2	0.95
Ewing's sarcoma	0	16	95	170	281	—	0.6	2.7	4.2	2.3	37	0.93
Other and unspecified	0	4	7	9	20	—	0.1	0.2	0.2	0.2	3	1.26
Soft-tissue sarcoma	83	241	215	255	794	11.9	8.9	6.1	6.3	7.5	110	1.20
Rhabdomyosarcoma	48	191	161	135	535	6.9	7.1	4.6	3.3	5.2	75	1.26
Fibrosarcoma etc.	21	16	25	46	108	3.0	0.6	0.7	1.1	1.0	15	0.95
Other and unspecified	14	34	29	74	151	2.0	1.3	0.8	1.8	1.3	20	1.19
Germ-cell and gonadal	48	128	50	159	385	6.9	4.7	1.4	3.9	3.6	53	0.92
Non-gonadal germ-cell	25	50	25	59	159	3.6	1.9	0.7	1.5	1.5	22	0.89
Gonadal germ-cell	23	77	22	85	207	3.3	2.9	0.6	2.1	1.9	28	1.07
Gonadal carcinoma	0	1	2	9	12	—	0.0	0.1	0.2	0.1	2	0.19
Other and unspecified gonadal	0	0	1	6	7	—	—	0.0	0.1	0.1	1	0.14
Epithelial	6	25	91	248	370	0.9	0.9	2.6	6.1	3.0	48	0.82
Adrenal cortical carcinoma	3	9	7	6	25	0.4	0.3	0.2	0.1	0.2	4	0.24
Thyroid carcinoma	0	0	11	51	62	—	—	0.3	1.3	0.5	8	0.42
Nasopharynx carcinoma	0	1	8	32	41	—	0.0	0.2	0.8	0.3	5	2.29
Melanoma	3	13	32	58	106	0.4	0.5	0.9	1.4	0.9	14	0.86
Skin carcinoma	0	0	12	50	62	—	—	0.3	1.2	0.5	8	0.84
Other carcinoma	0	2	21	51	74	—	0.1	0.6	1.3	0.6	10	1.03
Other and unspecified	4	7	9	18	38	0.6	0.3	0.3	0.4	0.3	5	1.45

these two diagnostic groups, there were 18 cases of sarcoma of the liver which are included with soft-tissue sarcomas in the classification scheme. Malignant germ-cell tumours of the liver have also occasionally been registered but there were none during the study period.

Nearly all malignant bone tumours were osteosarcoma or Ewing's sarcoma. Osteosarcoma was overwhelmingly a tumour of the long bones of the leg (265/322, 82%), and a further 11% (36) of tumours were in the long bones of the arm. Ewing's sarcoma also showed a predilection for the leg bones, although less markedly so (112/281, 40%); the next most common site was the pelvis (65/281, 23%).

Rhabdomyosarcoma was the commonest soft tissue sarcoma. Embryonal rhabdomyosarcoma accounted for 52% of registrations and alveolar rhabdomyosarcoma for 15%, the remaining 33% being of other or unspecified subtype. Embryonal rhabdomyosarcoma predominated in all age groups, but there was a decrease with age in the proportion of embryonal tumours and a corresponding increase in the proportion of alveolar. Half (54) of the tumours classified as fibrosarcoma etc. were fibrosarcomas. The remainder were malignant fibrous histiocytoma (22, 20%), neurofibrosarcoma (22, 20%) and dermatofibrosarcoma protuberans (10, 9%). Of the 151 cases of other and unspecified soft-tissue sarcoma, 66 (44%) were unspecified, 23 (15%) were synovial sarcoma, 18 (12%) were angiosarcoma, haemangioendothelioma or haemangiopericytoma, 16 (11%) were liposarcoma, 11 (7%) were leiomyosarcoma and 17 (11%) were other rare, specified types; these last included only two cases of Kaposi's sarcoma.

Among children with malignant non-gonadal germ-cell tumours, the commonest primary sites were intracranial (87, 55%), pelvic including sacrococcygeal (43, 27%), abdominal (15, 9%) and intrathoracic (8, 5%). Malignant gonadal germ-cell tumours were the only diagnostic group for which the age distribution differed markedly between the sexes. Among boys, 93/110 (85%) of those affected were aged 0–4, whereas among girls 72/97 (74%) were aged 10–14.

The commonest sites for carcinoma were thyroid, nasopharynx and skin. The 74 carcinomas of miscellaneous other sites included 27 oral tumours; no other site within this category accounted for more than eight cases. Eleven (10%) of the cases of malignant melanoma were ocular.

Other uses of the data

In addition to the provision of national incidence rates as reported here, the Registry data are used for a wide range of other purposes. Geographical studies of incidence within Britain are facilitated by the postcoding of addresses. Analyses that have been published include a series of studies of geographical variations in the incidence of leukaemia and NHL throughout Britain [16], reports on cancer incidence in the vicinity of the Sellafield nuclear reprocessing plant [17] and around all nuclear installations [18], and investigations of Kinlen's hypothesis that childhood leukaemia is a rare response to a common infection and has a higher incidence when population mixing gives rise to impaired herd immunity [19, 20].

Using routinely received death certificates, flagging at NHSCR and information from hospitals, population-based survival rates are calculated and reported [21]. A series of studies has indicated that, for a range of diagnostic groups, survival rates are higher for children who were treated at specialist centres or entered in nationally organised clinical trials [22].

Studies of long-term survivors in the Registry have shown that most of those who survive at least 10 years can be regarded as cured [23]. These survivors have been included in systematic studies of the occurrence of second malignant neoplasms [24, 25], deaths from other causes [23] and reproductive history [26].

Registry data have been used to estimate the heritable fraction of all childhood cancers [27], to estimate the risk of occurrence of childhood cancer in the siblings and offspring of children with cancer [28–30] and to study in detail the genetic epidemiology of retinoblastoma [31].

Computerised record linkage methods have been used in a study of cancer incidence among cohorts of children born or attending school in the vicinity of the Dounreay nuclear plant [32]. Similar methods are now being used to study cancer incidence among children whose parents are in the National Register of Radiation Workers [33], and for this study the birth records, including names of parents, play an essential part in matching between the two registers.

The Registry has also provided case ascertainment for two current aetiological studies. One of these is investigating the possible link between the administration of vitamin K for the prevention of haemorrhagic disease of the newborn and the subsequent occurrence of childhood cancer. The other is a wide-ranging study of possible antenatal and perinatal risk factors for which detailed histories have been obtained from maternity records.

The Registry has contributed to four international collaborative studies of childhood cancer. These are: International Incidence of Childhood Cancer [34] coordinated by the International Agency for Research on Cancer (IARC); the European Childhood Leukaemia/Lymphoma Incidence Study [35], also coordinated by IARC, which monitors incidence rates following the Chernobyl accident; a European study of clustering in childhood leukaemia; a study of the effectiveness of neuroblastoma screening in Europe.

The Registry enables clinicians who have encountered a case of any specific rare childhood cancer to contact others who have had similar patients. Several national series of rare cancers have been compiled from the Registry for retrospective clinical studies [36–39]. The national registry of childhood myelodysplasia is also being run in collaboration with the NRCT.

DISCUSSION

In general, the incidence rates reported here are similar to those found in other Western industrialised countries [34], including previously reported British data [1]. For a few diagnostic groups, the incidence rates in the study period are somewhat higher than those published previously; while this is likely to be due in part to improved diagnosis and case ascertainment, the trends in registration rates for ALL and neuroblastoma probably reflect a true underlying rise in incidence [40].

Basic information on the incidence of childhood cancer is required for planning health services. The detailed geographical information was originally collected to enable studies of incidence around nuclear installations to be carried out for the government Committee on Medical Aspects of Radiation in the Environment. The data can now be used for evaluating the importance of suspected 'clusters' of childhood cancer cases. When possible links of childhood cancer to other sources of environmental pollution are raised, the data are already available for these to be investigated.

Population-based studies of survival are required to assess the impact of modern methods of care on all patients diagnosed with

a particular disease; studies that only include those in clinical trials or selected hospital series are likely to be biased. The investigation of variations in survival with type of hospital and degree of standardisation of treatment are important for developing policy on the provision of services.

There are now over 10 000 adult survivors of childhood cancer in Britain [21], and this number is increasing by more than 500 per year. Most survivors are fit and well and can lead normal lives, but late effects can occur [41]. It is important that long-term follow-up studies be continued in order to identify late effects of treatment and to provide accurate estimates of the risks. Studies of the offspring of survivors provide valuable information for genetic counselling.

The Registry depends for the completeness and accuracy of its data on the co-operation of a wide range of organisations and individuals. Case ascertainment from general and specialist cancer registries, clinical trials and death certificates is essential. Much valuable information is provided by hospital clinicians, notably the members of the UKCCSG who now treat over 70% of children with cancer in Britain, and by family doctors. NHSCR provides an extremely accurate and cost-effective method of follow-up for studies of survival and second cancers [42].

It is vital that continuity of registration and co-operation in the provision of information are maintained during periods of change in the re-organisation of the National Health Service. One particular concern is the growing practice of destroying clinical records a relatively short time after patients have been treated, in many instances sooner than recommended in official guidelines [43]. A far greater threat to registration has been presented by the possible imposition of rules governing confidentiality, which if applied with the utmost rigour, would make cancer registration and much other epidemiological activity impossible [44]. One of the best ways of making a case for exemption from such disabling legislation is to demonstrate the wide range of uses which have been made of the data, while noting that there has never been a recorded instance of breach of privacy by a cancer registry in respect of a registered patient. The latest draft of the European directive on "protection of individuals with regard to the processing of personal data" takes into account epidemiologists' criticisms of earlier drafts, and there is now hope that a version will be enacted which will ensure the future of epidemiology throughout the European Community [45].

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