An Assessment of Need for Child and Adolescent Cancer Services in England and Wales

A report to the National Collaborating Centre for Cancer

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Executive Summary

1. Purpose of report

1.1 The National Collaborating Centre for Cancer has been given the remit to produce service guidance for Child and Adolescent Cancer Services. The National Public Health Service for Wales was commissioned to conduct a health care needs assessment to inform the development of the guidance by providing a description of the burden of disease and current service provision for children and young people with cancer.

2. Definitions

2.1 Need is defined as the ability to benefit from health care. The guidance scoping document defined the terms of reference for the report to include 'children (from birth) and young people in their teens and early twenties (defined in this report as 0-24 years) presenting with malignant disease, including leukaemia and related conditions as defined by the International Classification of Childhood Cancer (ICCC). This classification incorporates the amendments used by United Kingdom Childhood Cancer Study Group (UKCCSG) and also 'benign tumours or conditions that require complex treatment pathways, potentially including chemotherapy and radiotherapy'.

3. Epidemiology of Child and Adolescent Cancer

3.1 The report describes the epidemiology of cancer in children and young people from the published literature. The description includes the recognised patterns of incidence associated with age and gender, as well as discussing risk factors, trends, survival and late effects of treatment.

4. Methods

4.1 The report aims to provide an analysis of the current burden of disease. Data were sought from nationally recognised sources to allow calculation of rates for incidence, prevalence, mortality and survival. The data presented cover the ten years from 1988 to 1997. The Director of the National Registry for Childhood Tumours advised the project team that this would provide a representative estimate of current rates. A discussion of the possible effects of population dynamics on the incidence of childhood cancer is included.

4.2 An analysis of hospital activity data between 1995/96 and 2001/02 has been undertaken in collaboration with the Department of Health and Information Products Team at Health Solutions Wales. The analysis includes England and Wales level data on numbers and rates of episodes, in-patient and day case bed days, patients and procedures, by year and age group. Rates of episodes, in-patient and day case bed days are calculated for strategic health authorities and Wales. Data on palliative care services are not included in hospital activity datasets. The absence of a national data collection system for palliative care means it has only been possible to report published estimates of service use.

4.3 A survey of UKCCSG and Teenage Cancer Trust (TCT) Centres providing care to children and young people with cancer in England and Wales was undertaken to obtain information on patient numbers, staffing levels and models of service provision.

5. Results

5.1 Incidence rates presented in this report are comparable to those previously reported for England and Wales. The age related pattern of incidence is also stable. However, survival is improving, so that the prevalence of cancer in the young population is increasing.

5.2 Overall levels of hospital activity suggest a small increasing trend over the last four years of better quality data, particularly for day case activity. Marked variation in rates between the strategic health authorities and Wales are shown. Further work is required to assess the influence of data quality on these findings. Data on bone marrow transplants were not robust enough for analysis.

5.3 All 17 UKCCSG Centres and eight TCT units responded to the survey. A wealth of information on current service provision is presented.

6. Conclusions

6.1 The combined effects of improved survival and the demographic effect of a declining birth rate mean that the absolute numbers of new and prevalent patients in the older age groups are likely to increase.

6.2 Health care needs assessment and service planning is enhanced by collation and analysis of data for the 0-14 age groups by the National Registry of Childhood Tumours (NRCT). It is hampered by the absence of a dedicated registry for the 15-24 age groups and the differences in the coding classification of cancers used between these age groups.

6.3 Hospital activity datasets are a valuable source of service data, but the pursuit of better quality clinical coding and recording of activity must continue. The absence of a system of national data collection for palliative care service activity is also a disadvantage for needs assessment, planning and evaluation of cancer services for children.

Contents

1. Introduction

1.1 The National Institute for Clinical Excellence (NICE) has received the remit from the Department of Health and the Welsh Assembly Government 'To prepare service guidance for the NHS in England and Wales for the cancers affecting children and adolescents'.[1] The National Collaborating Centre for Cancer (NCC-C) developed the scope for the guidance after a process of consultation with stakeholders. The scope for the guidance was approved by NICE and published in July 2003.[2] A Guidance Development Group (GDG) has been established to take the process of guidance production forward.

1.2 The National Public Health Service for Wales (NPHS) was commissioned by the NCC-C to carry out a health care needs assessment. A project team was established which included clinicians to advise on the content of the needs assessment, taking external advice from experts in the field when required.

1.3 The purpose of this report is to inform the development of the service guidance by providing a description of the burden of disease and current service provision for children and young people with cancer.

2. Definitions and scope of healthcare needs assessment

2.1 In the context of this report, 'need' is defined as the ability to benefit from health care.[3]

2.2 The terms of reference for the service guidance and the healthcare needs assessment, are set out in the guidance scoping document.[2] The guidance includes 'children (from birth) and young people in their late teens and early twenties presenting with malignant disease, including leukaemia and related conditions as defined by the International Classification of Childhood Cancer (ICCC).[4] This classification incorporates the amendments used by United Kingdom Childhood Cancer Study Group (UKCCSG) and also 'benign tumours or conditions that require complex treatment pathways, potentially including chemotherapy and radiotherapy'.

2.3 The guidance covers services offered in primary, secondary, tertiary and quaternary settings, including shared care and integration with the voluntary sector and other statutory services, and provides recommendations for diagnostic services, oncology treatment services, allied treatment services, palliative care, support services and follow up.

2.4 For the purpose of this needs assessment, the project team suggested that the age range should include children, adolescents and young adults aged from 0 to 24 completed years of life.

2.5 The guidance scoping document requires the use of the International Classification of Childhood Cancers (ICCC) incorporating the amendments used by UKCCSG.[4] ICCC is an update of the Birch-Marsden Classification, which takes into account the second edition of the International Classification of Diseases for Oncology (ICD–02) and the 10th revision of the International Classification of Diseases (ICD-10). It has twelve categories:

I. Leukaemia
II. Lymphoma and reticuloendothelial neoplasms
III. CNS and miscellaneous intracranial and intraspinal neoplasms
IV. Sympathetic nervous system tumours
V. Retinoblastoma
VI. Renal tumours
VII. Hepatic tumours
VIII. Malignant bone tumours
IX. Soft tissue sarcomas
X. Germ-cell, trophoblastic and other gonadal neoplasms
XI. Carcinomas and other malignant epithelial neoplasms
XII. Other and unspecified malignant neoplasms

2.6 To comply with the terms of the scoping document, and based on recommendations of clinicians in the project team, additional benign conditions were included. These were optic glioma, Langerhans cell histiocytosis, fibromatoses and some benign brain tumours, including craniopharyngioma.

3. The epidemiology of cancer in children and adolescents

The following account of the epidemiology of child and adolescent cancer has been compiled from published literature. It details variations in the incidence of disease by age and sex, as well as discussing risk factors, reported trends, survival and long term effects of treatment. In order to allow comparison with the new data presented in this report, data on rates of childhood cancer have been quoted only from UK studies.

3.1 Age

3.1.1 Childhood cancer (i.e. in children aged under 15 years) is relatively rare. It accounts for less than 1% of all cancers in industrialised countries.[5] Epidemiological studies have shown that the pattern of incidence up to the age of 15 years in England and Wales is comparable to the mainly white populations of industrialised countries in Europe and North America.[5] Data from 1981-1990 show a total age-standardised annual incidence of 122 per million children, with a cumulative risk of developing cancer of 1 in 564 below the age of 15 years. Overall, peak incidence occurs in the first five years of life.[5] The lowest incidence occurs in those aged 8-10 years.[6]

3.1.2 The most commonly presenting group of malignancies in children aged 0-14 years are the leukaemias, which account for around a third of all cases of cancer.[5] Within this group acute lymphoblastic leukaemia is the most common, with a peak incidence at age 2-3 years. The next most common group are brain and spinal tumours (20-25%), among which astrocytomas are the most common diagnosis. 10% of registrations are lymphomas, with non-Hodgkin lymphoma being more common than Hodgkin disease. The embryonal tumours of neuroblastoma, soft tissue sarcoma and Wilms' tumour each account for 6-7% of registered cases, with retinoblastoma accounting for around 3%. The peak incidence of neuroblastoma, retinoblastoma and hepatoblastoma occurs in the first year of life, but Wilms' tumour peaks at age 3 years. The remaining cases largely comprise bone sarcomas, germ-cell tumours and epithelial tumours (including nasopharyngeal carcinoma). The latter group are mainly malignant melanoma, skin carcinoma and thyroid carcinoma. It is of note that bone sarcomas and Hodgkin disease are uncommon before the age of two, but their incidence increases steeply thereafter.

3.1.3 Adolescence has been defined as the 'time of transition between childhood and adulthood'[7], but the age range this covers has been variously described as 15-19 years of age, 10-20 years and 13-23 years.[8]

3.1.4 Cancer is more common in adolescents aged 15-19 than in children, with a reported incidence of around 150-200 per million.[6] The profile of disease also differs from that seen at younger ages, representing a transitional pattern between that seen in children and 20-24 year olds.[9] The embryonal tumours (e.g. Wilms' tumour, neuroblastoma, retinoblastoma) are rare, with 90% of cases being accounted for by acute leukaemias, lymphomas, central nervous system tumours, bone and soft tissue sarcomas, germ cell and other gonadal

tumours, thyroid carcinoma and malignant melanoma.[6] Of these, only osteosarcoma reaches its peak incidence in this age range.

3.1.5 A study conducted in England found that incidence rates in young adults aged 20-24 between 1979 to 1997 were higher than rates observed in the 15-19 age group (226 per million persons aged 20-24 compared with 144 per million persons aged 15-19), and that the pattern of occurrence in the 20-24 age group more closely resembled that seen in adults.[9] The study showed that lymphomas were the most common in both age groups, but that leukaemia was only the fifth most common in 20-24 year olds, as opposed to being second in 15-19 year olds. Similarly, CNS tumours and bone tumours dropped in rank order, but carcinomas, germ cell tumours and melanoma became more frequent.

3.1.6 The solid tumours occurring in adolescence and early adulthood may be classified into three groups:[10]

1) 'Late' paediatric, such as Wilms' tumour, rhabdomyosarcoma and neuroblastoma
2) 'Age-specific' cancers such as bone tumours (with peak incidence at age 10-20 years) and testicular tumours (which are most common in men in their 20s).
3) 'Early onset' carcinomas. Of particular importance amongst these are malignant melanoma, thyroid carcinoma and nasopharyngeal carcinoma. Whilst the occurrence of carcinoma is more characteristic of the adult pattern, it should be noted that the types predominantly seen in this age group differ in that the dominant adult carcinomas of the lung, breast, cervix and gastrointestinal system remain rare.[9, 10]

3.2 Sex

3.2.1 Child and adolescent cancers are slightly more common overall in males than females. [5,9,10] Studies in the United Kingdom cite a male to female ratio of 1.2:1 in children aged 0-14.[11] However, certain malignancies are sex-specific. In boys, the risk of testicular germ cell tumours is greatest in early childhood, with lower rates seen thereafter until a substantive increase in incidence again after age 15 years.[5] For girls, ovarian germ cell tumours occur only rarely before the post pubertal rise in incidence, which occurs at an earlier age than in boys.[5] Germ cell tumours are markedly more common in males than females in the older age groups.[9] In contrast, malignant melanoma is more common in females in those aged over 15 years, as are carcinomas of the thyroid, breast and genito-urinary tract.[9] In fact, although rare in childhood, the female excess of thyroid carcinoma is still apparent in younger age groups.[11]

3.3 Risk factors

3.3.1 Relatively little is known about the causes of malignant disease in childhood and adolescence. There is evidence to support the influence of a range of risk factors, which are discussed in paragraphs 3.3.2 to 3.3.7. This list has been compiled by amalgamating information from a number of sources.[5,6,10,12] However, the factors identified only account for a minority of cases.[6] Much research has been carried out in an attempt to identify other causes. For example, the higher incidence of childhood cancer in the first few years of life suggests influences in the preconception time and during pregnancy. [5] Possible links with ionising radiation, smoking and exposure to certain drugs have been postulated, but have not been established. In the adolescent age groups, exposure to environmental carcinogens such as sunlight and tobacco may be risk factors. However, since it takes more than one or two decades for the effect of these to become manifest in most people[12] it is likely that even the so-called 'early onset' carcinomas have an inherited component.[10] The established risk factors are therefore as follows:

3.3.2 Genetic. Retinoblastoma is the clearest example of a genetically determined cancer, with the pattern of inheritance being a dominant autosomal gene with 90% penetrance. The aberrant gene is a tumour suppressor gene, with 90% of individuals who inherit the mutated form also having mutation in the corresponding normal gene. Wilms' tumour also appears to be genetically linked, but the relationship is complex. The risk of acute lymphoblastic leukaemia and acute non-lymphoblastic anaemia is about ten times higher in people with Down syndrome. This syndrome is also associated with an increased risk of germ cell tumours of the testis and brain. Other inherited conditions are also known to be linked to an increased risk of malignancy. These include neurofibromatosis (CNS tumours and soft tissue sarcomas), the familial cancer syndrome, xeroderma pigmentosa, hereditary dysplastic naevus syndrome and Turner's syndrome. Ewing's sarcoma is very rare in black and East Asian populations, suggesting a genetic link. Studies of siblings have shown an approximate doubling of risk of malignancy if one child is affected. Case reports have described twins with identical malignancies, but numbers in general are too small for risks to be calculated in this group. The one exception is childhood leukaemia where up to 25% of monozygous co-twins will also be affected. The risk of developing Hodgkin disease is seven times higher than the general population in adolescents and young adults with an affected sibling.

3.3.3 Infection. Certain viral infections are known to be causally linked to malignant disease. The links between the Epstein-Barr virus and Burkitt's lymphoma, and hepatitis B with liver carcinoma are well known. The hepatitis B example raises the possibility that mass immunisation may reduce the incidence of hepatocellular carcinoma in areas where this infection is endemic. More recently there has been a significant rise in the incidence of Kaposi sarcoma in African countries that has been attributed to the AIDS epidemic. Some studies have also postulated a link between exposure to an unidentified infectious agent or agents and childhood leukaemia[13], suggesting not that

leukaemia is an infectious disease, but rather that it is an unusual response to an infectious agent.

3.3.4 Hormonal. Exposure to diethylstilboestrol in pregnancy is known to cause clear cell adenocarcinoma of the vagina or cervix in the exposed female foetus in adolescence. Exposure to high levels of exogenous hormones in pregnancy has also been associated with an increased risk of testicular tumours in the male foetus. In contrast, and possibly acting through similar mechanisms, late puberty is thought to have a protective effect.

3.3.5 Radiation. Exposure to ionising radiation, especially if occurring antenatally, has been shown to increase cancer risk. The thyroid gland is particularly sensitive, evidenced by the increased incidence of thyroid carcinoma in Eastern Europe following the Chernobyl disaster. Also of note is that radiotherapy given to treat a primary cancer has been implicated in the genesis of second primary tumours. Non-ionising radiation has also been implicated as a risk factor. Ultra-violet radiation from the sun has a known causal link with malignant melanoma and other skin cancers, but links with exposure to electro-magnetic fields around power cables, and radon remain unproven.

3.3.6 Socioeconomic. No conclusive risk has been shown in relation to childhood cancer risk and parental occupation, but the incidence of childhood leukaemia appears to increase with increasing socio-economic status. Hodgkin disease is more common in adolescents of higher socio-economic status.

3.3.7 Other. A history of cryptorchidism or testicular trauma has been linked with the development of testicular tumours.

3.4 Trends in incidence

3.4.1 Notable trends have been described for Kaposi sarcoma and HIV in parts of Africa, and thyroid cancer secondary to the Chernobyl disaster. In England and Wales, the early childhood peak in mortality from acute lymphoblastic leukaemia began to emerge in the 1920s, but it is not clear whether this was due to changes in diagnostic practice rather than underlying risk.[5] A study examining trends in childhood malignancy in the North West of England between 1954-1988 identified significant linear increases in acute lymphoblastic leukaemia and Hodgkin disease for those aged 0-14 years, but not acute non-lymphoblastic anaemia and non-Hodgkin lymphoma.[14] Additional tests identified a significant increase in chronic myeloid leukaemia. A related study examining incidence of solid tumours in the same age group over the same time period found significant linear increases in juvenile astrocytoma in males, of medulloblastoma and neuroblastoma in females, and non-skin epithelial tumours overall.[15] Further analysis identified significant increases in gonadal germ cell tumours and skin cancers.

3.4.2 In adolescents and young people, an investigation of cancer registrations in those aged 15-24 between 1979 and 1997 in England reported a significant increase in incidence overall across all diagnostic groups.[9] The authors report significant increases in incidence of gonadal germ cell tumours (almost exclusively of the testis), melanoma and carcinoma of the thyroid. Smaller, but none the less significant, increases in incidence were also seen in lymphomas, CNS tumours, acute myeloblastic leukaemia (AML) and genito-urinary tract carcinomas. Rates of leukaemias overall, bone tumours and soft tissue sarcomas remained stable.

3.5 Survival

3.5.1 The past 30 years has seen remarkable improvements in survival for most childhood malignancies, with this effect being largely attributed to advances in treatment and supportive care and centralising treatment services into relatively few specialist centres.[5] There is also evidence that the inclusion of the majority of patients in national and international trials improves survival.[5,16]

3.5.2 Estimates published in 1994 showed a 65% five-year survival rate overall for childhood cancer.[17] A study in the North of England estimated a five-year survival rate for 0-14 year olds between 1988 and 1995 of 71%.[10] For haematological malignancies, the five-year survival rate was 77% and solid tumours 67%. For adolescents and young adults aged 15-24 years, five year survival was 73% overall, 72% for haematological malignancies and 75% for solid tumours. Particularly good outcomes in this age group were associated with Hodgkin disease (87% five year survival), testicular cancer (87%) and thyroid cancer and non-melanoma skin cancers (for which no deaths had been reported in the trial period).

3.6 Late effects of treatment

3.6.1 With improvements in treatment, there are increasing numbers of childhood cancer survivors in the population, estimated at an additional 850 per year in Britain.[18] However, treatment for childhood cancer has long term sequelae. Second primary malignancies occur in about 4% of survivors, and a history of radiotherapy is a particular risk factor.[18,19] The risk of second malignancy, which is known to exist up to 25 years after diagnosis, is estimated to be between four and six times the risk in the general population.[18,19] The risk varies considerably with the type of childhood cancer, for example being particularly high in survivors of heritable retinoblastoma, due to probable additional genetic influences.[5] In addition to second malignant disease, important late effects include growth, endocrine, fertility, orthopaedic, cardiac and neurological complications, along with educational, psychosocial and quality of life sequelae.[18] Many now argue that identification of these long-term sequelae of treatment should be life long and organised by specialist services.[18] However, the strategies for follow-up may differ depending on the original diagnosis, treatments received and likely risk of long term complications.[20]

4. Methods

4.1 Coding of Cancer in Children and Adolescents

4.1.1 Cancers developed by children are different from those developed by adults. In adults, the majority of cancers are carcinomas of specific sites, such as breast, lung, prostate, and are very rare in childhood. In contrast, the diseases seen in children show a great deal of histological diversity and might occur as primary tumours at many possible sites. Many of the childhood tumours develop from embryonal tissue, for example neuroblastoma and retinoblastoma, and are correspondingly rare in adults.[21]

4.1.2 Because of this difference in disease type a different coding system for childhood cancer is considered necessary. Adult cancers are coded using the International Classification of Disease (ICD), now in version 10, which is based on a topographical description of the site of the tumour.[22] However, childhood cancers are coded using the International Classification of Childhood Cancer (ICCC), a classification based on histological characteristics (see paragraph 2.5).[4]

4.1.3 A discrepancy in coding highlighted by some authors, and one for which there is no solution currently, is found in the classification of cancers in adolescents and young adults. [9,10] The prevalent cancers in the 15-24 age group are different from those of children and adults, and in some ways, represent a transition between the two. As the proportion of non-carcinoma tumours is still high, the site based ICD system is inappropriate.[23] However, certain embryonal tumours (including retinoblastoma and Wilms' tumour) are very rare in this age group, thus making groups IV, V, VI and VII of ICCC largely redundant.[9] Additionally, the subdivisions of ICCC do not fit the pattern of carcinomas seen in this age group effectively.[24] To attempt to overcome the difficulties, alternative classification systems have been suggested that are similar to ICCC and morphology based, but which allow a more accurate description of adolescent disease.[9,10] However, none are used routinely.

4.1.4 The scoping document required the use of the ICCC classification in this needs assessment, but the existence of the two different coding systems caused difficulty in collecting comparable data for the 0-14 and 15-24 age groups (see sections 4.2.2.1 to 4.2.2.4).

4.2 Data sources

4.2.1 Administrative sources of data

4.2.1.1 Registration of cancers in all age groups is voluntary, and is co-ordinated by a number of population based regional cancer registries.[25] In England, cancer registration data is collected in nine regional registries, which then submit a standard dataset to the Office for National Statistics (ONS) in London.[26] In Wales, the responsibility for cancer registration has been held by the Welsh Assembly Government since devolution, and is carried out on their

behalf by the Welsh Cancer Intelligence and Surveillance Unit (WCISU).[27] All registries systematically collect data from several sources, for example hospital activity data, death certificates and pathology records, to ensure the greatest possible accuracy and completeness. The National Cancer Intelligence Centre (NCIC) at ONS collates cancer registration data nationally for England, Wales and Scotland. All the registries code cancer registration data using ICD-10.

4.2.1.2 A specialist population based registry for childhood cancer, the National Registry of Childhood Tumours (NRCT) in Oxford, was established in 1975 under the auspices of the Childhood Cancer Research Group (CCRG).[25] The NRCT includes nearly all cases of childhood malignant disease (that is in children under the age of 15 years) diagnosed since 1962 in England, Wales and Scotland. It collects data from a number of sources, including specialist regional registries and UKCCSG members. It also collects data on certain benign tumours (e.g. benign brain tumours, Langerhans cell histiocytosis), but only if individuals are under the care of a UKCCSG Centre. It is estimated that the completeness of its dataset approaches 100%.[28] The NRCT codes registrations using ICCC.

4.2.1.3 Mortality data are derived from the statutory death registration process by the Office for National Statistics (ONS).

4.2.1.4 Details of hospital activity are routinely collected in England on the Hospital Episode Statistics (HES) database [29] and the Patient Episode Database for Wales (PEDW)[30] in Wales. Each record on HES and PEDW is a mandated Admitted Patient Care (APC) dataset of one Finished Consultant Episode (FCE or 'episode') of care during a hospital admission or day case[31]. Any one patient may have several episodes of care during one admission, particularly if their management is multi-disciplinary, involving the care of two or more consultants sequentially during the admission. Thus the number of episodes will exceed the number of hospital admissions, which in turn will exceed the number of individual patients, some of whom may have multiple admissions during a defined time period.

Data on out-patient activity are not included and neither, of particular interest in the current context, is palliative care. Clinicians describe that much work in paediatric oncology occurs in response to telephone requests for advice or a patient presenting to the ward. Despite being a significant part of the service provided to patients, no record of this activity will exist since admission is not necessarily the outcome of the consultation. Private hospitals are excluded from data collection, but data on private patients treated in NHS hospitals are included.

Trained clinical coders in each hospital enter details of each admission or day case onto the Patient Administration System (PAS), and monthly extracts are submitted centrally. These data items include administrative and demographic details such as NHS number, date of birth, sex, postcode, up to four diagnoses and up to six operations or procedures. Diseases are coded using ICD-10[22] and procedures are coded using the OPCS Classification of Operation and Procedures, Fourth Revision (OPCS-4)[32]. The recording of NHS number,

which enables analysis of data based on number of patients rather than episodes or admissions, was variable initially, but now has reached 90% for HES[33] and 93% for PEDW[34].

4.2.1.5 There is no systematically collected national administrative source of data on palliative care services in England and Wales.

4.2.2 Data available for the healthcare needs assessment

4.2.2.1 Incidence

4.2.2.1.1 For a definition of incidence please refer to the Glossary. The NRCT supplied numbers of new cases of cancer in children aged 0-14 years within the ICCC classification. Their data also included non-malignant conditions. Langerhans cell histiocytosis and fibromatosis were supplied as separate categories, but the other non-malignant tumours named in the guidance scope were included in the main ICCC classification. Non-malignant intracranial and intraspinal tumours were included in 'other specified central nervous system tumour' and 'unspecified central nervous system tumour' (ICCC group III), or 'central nervous system germ-cell tumour' (ICCC group X). Craniopharyngioma is included in 'other specified central nervous system tumour' and optic glioma is included under 'astrocytoma' (both ICCC group III).[28]

4.2.2.1.2 Discussions with the Director of the NRCT indicated that the last year for which data at the registry could confidently be assumed to be complete is 1997. In order to calculate rates with acceptable precision, ten years data from 1988 to 1997 were supplied. No other recent source of national data is available. Although the most recent data are six years old, it is unlikely that incidence rates will have changed substantively since 1997 to lose their value for current service planning.

4.2.2.1.3 Data were not readily available for the 15-24 age group. Some incidence data have been published, but not at the required England and Wales national level. [9,10] A request was therefore made to the NCIC in London for data from the same ten-year period (1988-1997). NCIC data are coded using ICD and the immediate problem encountered was translating to ICCC coding. Although some ICD codes translate easily into ICCC, for example the leukaemias and lymphomas, others do not, for example retinoblastoma and Wilms' tumour. [35] This is particularly problematic for sympathetic nervous system tumours (e.g. neuroblastoma) and soft tissue sarcomas (e.g. rhabdomyosarcoma, fibrosarcoma). [28] In ICD these would be coded as malignant tumours of a specific anatomical site, rather than by histology. Since information on incident cases collected at the registries includes histology, as a pilot exercise, NCIC were able to convert ICD coded incidence data to ICCC. Of the non-malignant conditions, benign brain tumours, craniopharyngioma and optic glioma were included. However, Langerhans cell histiocytosis and fibromatosis are not registrable by ONS, and so data on these conditions were not available.

4.2.2.2 Prevalence

4.2.2.2.1 For a definition of prevalence please refer to the Glossary. Discussion with clinicians highlighted the importance of including data on all children who had ever been diagnosed with cancer, irrespective of time since diagnosis, since even those cured of their primary disease remain at risk of late effects of treatment into their adult life. The NRCT supplied data on cancer prevalence, including non-malignant conditions, in children aged 0-14 years. NCIC were unable to provide prevalence data for the 15-24 years age group as these data are not routinely collated. No published prevalence estimates were available.

4.2.2.3 Mortality

4.2.2.3.1 The Project Team clinicians indicated that it would be preferable to present mortality estimates that include all deaths in children with cancer, irrespective of cause, since deaths not coded as caused by cancer may result from the effects of the disease or its treatment. The NRCT supplied data on mortality from cancer and non-malignant conditions in children aged 0-14 years.

4.2.2.3.2 For the 15-24 year age group, ONS mortality data were not routinely available data in ICCC format and we therefore used ONS data previously published in the Series DH2 (No's 15-24).[36] ONS mortality data only records the cause of death stated on the death certificate. Therefore, for these age groups, it is only possible to quote mortality data where cancer is recorded as the cause of death, rather than all deaths. Clearly, some cases will be missed, although the numbers are likely to be small. These data are coded by site only and no histology is available. It is therefore only possible to present mortality data in ICD for this age group.[36] From the non-malignant conditions, only non-malignant brain tumours have been included.

4.2.2.4 Survival

4.2.2.4.1 Survival refers to the proportion of children diagnosed with cancer between a defined time period still alive at the time of data collection. The NRCT supplied survival data for children aged 0-14 years, again including non-malignant conditions. Survival data for the 15-24 year age group were not available from NCIC.

4.2.2.5 Hospital activity

4.2.2.5.1 Dr. Brian Cottier, Head of Cancer Services Analysis for the Department of Health, supplied hospital activity data. The data source was a combined HES/PEDW database for England & Wales for the seven financial years between 1995/96 and 2001/02. This database was formed in collaboration with the Information Products team at Health Solutions Wales who provided the PEDW extract.

4.2.2.5.2 Five data extracts were supplied for numbers of: in-patient episodes, in-patient bed days, day case bed days, patients and procedures. Episodes with a valid episode start date and end date and a patient age between 0-24 with a diagnosis of cancer (ICD10 codes C or D0-48) were included. Bed days were calculated as the sum of length of stays. The extract of numbers of patients was based on the NHS number and a patient was counted once irrespective of whether he/she was admitted again that year or had been admitted in a previous year. Thus these data did not refer to new patients and are best considered as a point prevalence. Procedures were defined using OPCS-4 codes. Each extract included age in five year bands, financial year, ICD-10 diagnostic code, type of tumour derived from the ICD-10 code (malignant, in-situ, benign, uncertain), NHS trust, and strategic health authority of patient residence. Translation of ICD-10 into the ICCC classification was not considered sufficiently robust for these analyses.

4.2.2.5.3 The possibility of bias should be considered when interpreting the results of hospital activity analyses. Quality of clinical coding is known to vary widely between Trusts, particularly in regard to missing diagnostic codes and misclassification of activity using an incorrect code. Different hospitals may define the same event differently – for example coded as a day case in one hospital, as out-patient activity by another or not coded at all. Although variation in coding may be of smaller importance in the analysis of data aggregated at the national level, it may have a substantive influence on the interpretation of variation in activity among strategic health authorities or NHS Trusts. The 'provider effect' may partly explain differences in admission rates[37] due to supply side factors such as availability of hospital beds, admission policies and distance from hospital which all can influence whether a patient is admitted. Some of the provider effect may, in fact, be artefactual, related to the accuracy and completeness of coding.[37]

4.2.2.6 Palliative care

4.2.2.6.1 Palliative Care for children and young people with life-limiting conditions is defined as 'an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on quality of life for the child (or young person) and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement'.[38]

4.2.2.6.2 Palliative care expertise is an important part of the service offered to children and young people with cancer, with the skills being used from the time of diagnosis to manage the emotional, social and spiritual consequences to both the patient and his or her family. Although survival is improving, there will inevitably be those who die from their disease, and for whom palliative care becomes necessary. However, describing the epidemiological need for palliative care services is difficult. Palliative care services are not included in HES/PEDW, and no other data collection of service use operates at a national level. This is in part due to the fact that much of the service provision is non-NHS and funded by a range of independent charities. Therefore, there is very little data on palliative care services available for this needs assessment.

4.2.2.6.3 The Association for Children with Life-threatening or Terminal Conditions and their Families is a national organisation that aims to 'improve care and services for all children in the UK with life-threatening or terminal conditions and their families'.[39] The update of the report on children's palliative care services, published jointly with the Royal College of Paediatrics and Child Health,[40] gives data from which indirect estimates of need for services can be calculated. In this report, we will only assess the need for palliative care among those children with cancer

4.2.2.7 Population denominators

4.2.2.7.1 Denominator population data is routinely available from ONS. Mid-year population estimates by single year of age were taken for the years 1988 to 1997. These estimates were used to extract the total population at risk in each age group over the ten-year period.

4.2.2.7.2 Section 5.8 discusses the possible effects of changes in population size on disease incidence. The Government Actuary's Department (GAD) releases population projections, updated every two years.[41] To estimate population projections, assumptions are made on the population's long-term fertility, mortality and net migration. Previous population estimates based on the 1991 census (and last updated in 2001) were found to have both over-estimated the population of the United Kingdom by about one million and to have significantly over-estimated inward migration. Following publication of data from the 2001 census, interim corrected population projections were released ahead of the expected date and have been used in this report.

4.3 Analysis

4.3.1 Overview

4.3.1.1 Data in this report uses the ICCC classification where possible and are presented using the format and methodology described in the International Incidence of Childhood Cancer, Vol. II (1998).[11] Therefore, age group and sex specific, world standardised and cumulative rates are calculated, along with male/ female ratios and relative frequencies. 95% confidence intervals are calculated for the world-standardised rates, permitting direct comparison with world published data.

4.3.1.2 All rates are reported at the national England and Wales level. Rates are not calculated for smaller spatial levels, for example the 28 Strategic Health Authorities in England, since for many of the disease categories, the numbers of cases are small, and the corresponding confidence intervals wide. Such estimates would be insufficiently precise to allow meaningful interpretation and comparison.

4.3.1.3 The following five-year age groups are used: 0-4, 5-9, 10-14, 15-19, and 20-24. The project team decided not to further sub-divide the youngest age group into under 1 and 1-4 years, as it was considered unlikely to substantially alter the epidemiological interpretation. However, it is understood that the distinction is important clinically, since both treatment regime and prognosis often vary in those under 1 year of age at diagnosis.

4.3.2 Incidence, prevalence and mortality

4.3.2.1 The full analysis described in paragraph 4.3.1.1 was possible for incidence, prevalence and mortality for the NCRT data received for the 0-14 age groups. For the 15-24 age groups, the same analysis was repeated on incidence data received from NCIC. No prevalence data were available. Mortality data has been reproduced from published ONS data (see 4.2.2.3.2). These data were coded in ICD so that rates will not be directly comparable with the analysis conducted in the 0-14 age groups.

4.3.3 Survival

4.3.3.1 Survival estimates were received for each of the ICCC categories in the 0-14 year age group from NRCT. These have been reproduced in this report. Survival estimates for the older age groups are cited from the published literature.

4.3.4 Hospital activity

4.3.4.1 For each of the five extracts of activity made available (episodes, in-patient and day case bed days, numbers of patients and procedures), aggregate England & Wales data for all tumour types (malignant, benign, in-situ and uncertain) and malignant only were extracted from the pivot tables to cross-tabulate activity by age group and by year. It was not possible to identify the specific benign diagnoses (optic glioma, langerhans cell histiocytosis, fibromatosis and benign brain tumours) from these datasets. Crude rates per million population were calculated in this report. Since the data for 1997/98 considerably under-recorded activity in comparison to other years, the tables show data for 1998/99 to 2001/02. Trends in activity from 1995/96 to 2001/02 are shown in chart form.

4.3.4.2 Crude rates were calculated for episodes, in-patient and day case bed days, and numbers of patients at strategic health authority and all-Wales level to assess geographical variation in England & Wales. The only available population denominator available for the strategic health authorities was the 2001 census population, extracted from the neighbourhood statistics web site.[42]

4.3.4.3 Catchment populations for the 17 UKCCSG Treatment Centres and Scotland had previously been estimated based on patient flows from their electoral ward of residence to the hospital of admission. A ward and its total population aged 0-24 was defined as belonging in the catchment area of a Treatment Centre if more than 50% of the activity (defined by episodes) from that ward was carried out at that Centre. Catchment areas for England and Wales are included in this report (see 5.6.7).

4.3.4.4 Data on Bone Marrow Transplants (W34 – Graft of Bone Marrow) were extracted but the data were not analysed as they were clearly incomplete and of insufficient quality.

4.3.5 Palliative care

Clinicians have suggested that the need for palliative care services can be estimated by the annual mortality rate, since among cancer patients, death often occurs within a year once active treatment is no longer possible.[43] Using this as an indicator therefore, we have produced an estimate of need from the analysis already described. We have also quoted the estimates provided by the Association for Children with Life-threatening or Terminal Conditions and their Families as a comparison

5. Results

5.1 Overview

5.1.1 Summary tables of standard format are presented in the text for total population (males and females combined). These summary tables include age-specific rates for each of the twelve main diagnostic categories of ICCC, plus the non-malignant conditions of Langerhans cell histiocytosis and fibromatosis. The other non-malignant tumours named in the guidance scope were included by the NRCT in the main ICCC classification as described in 4.2.2.1.1.

5.1.2 Three summary rates are shown in the tables: crude rate; age-standardised rate and the cumulative rate. An explanation of the calculation of each of these rates is given in the Glossary. All rates presented are the average annual rate over the ten-year time period and are expressed per million population at risk.

5.1.3 More detailed data tables from which the summary tables are sourced are included as appendices. These tables include the raw data as well as detailed breakdowns by sex and ICCC sub-group.

5.1.4 In each sub-section, where possible, comparison is made with previously published England and Wales and current European data.

5.2 Incidence

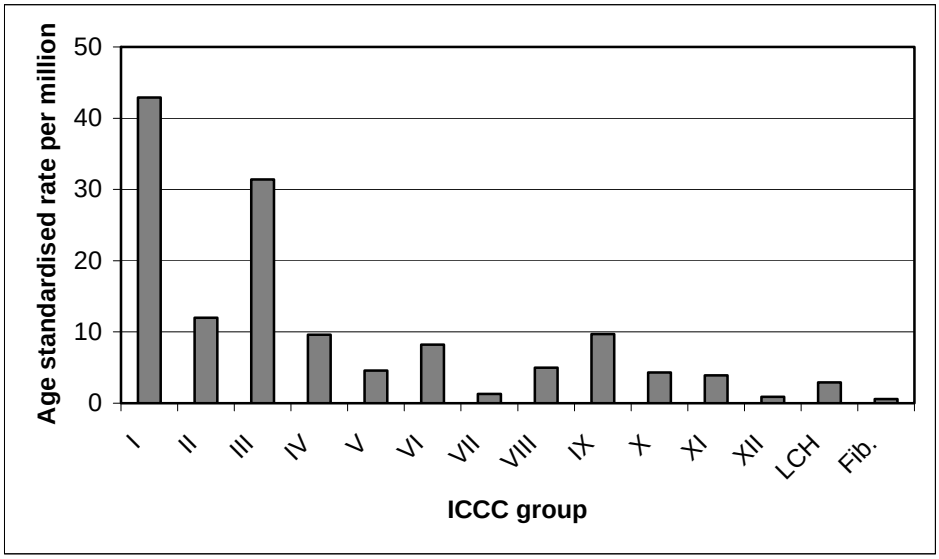
5.2.1 Table 1 shows incidence rates for England and Wales between 1988 and 1997 in children aged 0-14 years of age. The full source table is presented in **Appendix 1**. A comparison of the age-standardised rates of cancers between the twelve ICCC groups and non-malignant conditions is shown in Figure1.

Table 1: Incidence rates of cancer in children aged 0-14 years, per million population at risk, 1988 –1997

DIAGNOSTIC GROUP	Average annual incidence rates per million population at risk							M:F Ratio	Relative Frequency (%)
	0-4	5-9	10-14	Crude	ASR	ASR 95% CI	*Cum.*		
I Leukaemia	66.3	32.3	23.6	41.3	42.9	41.6 - 44.3	611	1.3	31.6
II Lymphoma	6.6	12.5	18.5	12.4	12.0	11.3 - 12.6	188	2.2	9.5
III Brain and Spinal Neoplasms	33.2	33.9	26.3	31.3	31.4	30.3 - 32.6	467	1.1	23.9
IV Sympathetic Nervous System Tumours	21.3	3.5	0.6	8.7	9.6	8.9 - 10.2	127	1.2	6.7
V Retinoblastoma	11.3	0.6	*0.1*	4.1	4.6	4.1 - 5.0	60	1.0	3.2
VI Renal Tumours	17.0	3.8	1.2	7.5	8.2	7.6 - 8.8	110	1.0	5.8
VII Hepatic Tumours	2.6	0.4	0.5	1.2	1.3	1.0 - 1.5	18	1.8	0.9
VIII Malignant Bone Tumours	0.7	4.1	11.6	5.3	5.0	4.6 - 5.4	82	1.0	4.1
IX Soft Tissue Sarcomas	12.4	7.9	8.2	9.6	9.7	9.1 - 10.4	143	1.3	7.3
X Germ Cell and Gonadal Neoplasms	5.5	2.1	5.0	4.2	4.3	3.8 - 4.7	63	0.8	3.2
XI Carcinomas and Epithelial Neoplasms	1.1	2.4	9.2	4.1	3.9	3.5 - 4.3	64	0.8	3.2
XII Other and Unspecified Neoplasms	1.2	0.6	0.7	0.9	0.9	0.7 - 1.1	13	0.6	0.7
ICCC TOTAL	179.4	104.1	105.6	130.6	133.7	131.4 - 136.0	1946	1.2	100
Langerhans Cell Histiocytosis	5.3	1.7	1.2	2.8	2.9	2.6 - 3.3	41	1.4	
Fibromatosis	1.0	0.3	*0.2*	0.5	0.6	0.4 - 0.7	8	1.6	
OVERALL TOTAL	185.7	106.1	107.0	133.8	137.2	134.8 - 139.5	1994	1.2	

Source: NRCT *Numbers in italics where rates based on fewer than ten cases*

Figure 1: Comparison of age-standardised incidence rates between the ICCC groups and non-malignant conditions in children aged 0-14 years, per million population at risk, 1988 – 1997



Source: NRCT

5.2.2 Among 0-14 year olds, the most common group of diagnoses is leukaemia (31.6%), with an age-standardised rate of 42.9 per million. The next most common is brain and spinal neoplasms (23.9%), followed by lymphomas (9.5%) and soft tissue sarcomas (7.3%). The least common diagnosis in this age group is hepatic tumours (0.9%). This pattern of incidence, with a male to female ratio of 1.2 to 1, is similar to that cited in previous studies.[11]

5.2.3 The age-standardised rate overall is 133.7 per million, which slightly exceeds that reported by Parkin *et.al*[11] for England and Wales of 122.1 per million in the ten years from 1981-1990. However, it is important to remember that the data received for this needs assessment include some non-malignant diagnoses, which will increase the overall incidence.

5.2.4 Table 2 shows age-standardised rates for selected European countries within the same time period as our results. As they are standardised to the same population, these rates are directly comparable to our data. Rates vary from a minimum of 127.3 per million in Ireland to 170.4 per million in Finland. The rate for England and Wales is towards the lower end of this range.

Table 2: Five-year world standardised incidence rates in 0-14 year olds, per million population at risk, for all tumours, 1993-1997, for selected European countries

Country	World Standardised Incidence Rate
Ireland*	127.3
Scotland	130.1
Germany	130.9
Hungary	132.4
England & Wales**	133.7
Netherlands***	138.9
Northern Ireland****	141.6
Spain***	143.7
Iceland	147.2
Norway	151.6
Denmark	158.1
Finland	170.4

Source: ACCIS[44]
* Data collection 1994-1997
** Data collection 1988-1997
*** Data collection 1993-1995
**** Data collection 1993-1996

5.2.5 Table 3 shows incidence rates for England and Wales between 1988 and 1997 in children aged 15-24 years of age. The full source table is presented in **Appendix 2**. A comparison of the age-standardised rates of cancers between the twelve ICCC groups is shown in Figure 2.

5.2.6 Among 15-24 year olds, the most common group of diagnoses are carcinomas and epithelial neoplasms (25.6%), with an annual age-standardised incidence rate of 53.1 per million. The next most common group is lymphomas (23.1%), followed by germ cell and gonadal neoplasms (16.5%), brain and spinal neoplasms (10.2%) and leukaemia (9.8%). The least common diagnosis in this age group is retinoblastoma. The male to female ratio remains at 1.2 to 1 in this age group. This pattern of incidence is broadly similar to that reported in 3.1.5, although the marked rise in the incidence of carcinomas and epithelial neoplasms in the 20-24 year age group has resulted in this group replacing lymphoma as the most common group in the overall figure.

5.2.7 The age-standardised incidence rate for all cancers in 15-24 year olds is 213.9 per million. This is higher than the rate for England between 1993 and 1997, reported by Birch *et.al.* (2002), of 197 per million.[9] Again, it must be remembered that data collected for this report include non-malignant diagnoses, which were excluded from the latter study.

Table 3: Incidence rates of cancer in persons aged 15-24 years, per million population at risk, 1988 – 1997

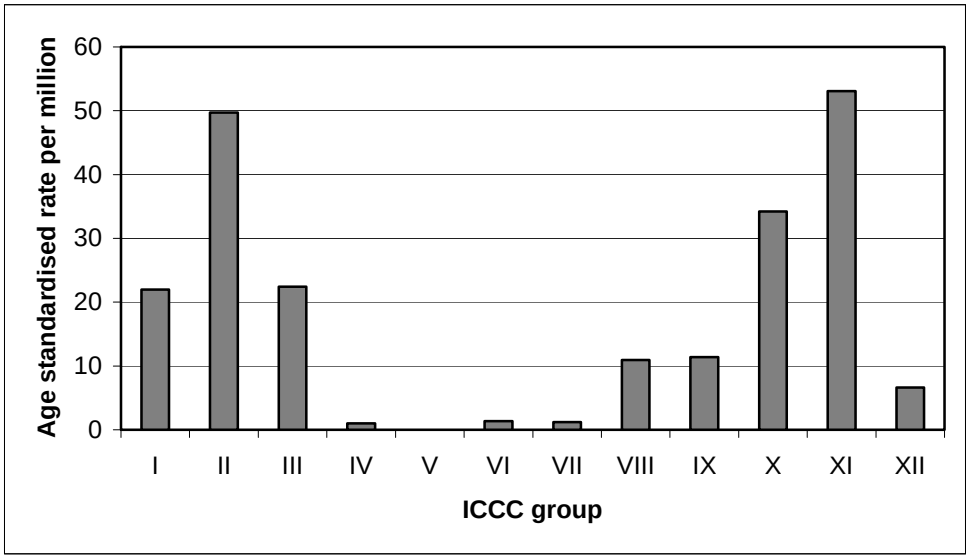
DIAGNOSTIC GROUP	Average annual incidence rates per million population at risk						M:F Ratio	Relative Frequency (%)
	15-19	20-24	Crude	ASR	ASR 95% CI	*Cum.*		
I Leukaemia	24.0	19.7	21.7	22.0	20.8 – 23.1	218	1.5	9.8
II Lymphoma	40.6	59.9	51.0	49.7	48.1 – 51.4	503	1.3	23.1
III Brain and Spinal Neoplasms	21.0	24.0	22.6	22.4	21.3 – 23.5	225	1.3	10.2
IV Sympathetic Nervous System Tumours	0.8	1.2	1.0	1.0	0.8 – 1.2	10	1.3	0.5
V Retinoblastoma	*0.0*	*0.0*	*0.0*	*0.0*	*0.0*	*0*	*0.0*	*0.0*
VI Renal Tumours	0.9	1.9	1.4	1.4	1.1 – 1.6	14	0.8	0.7
VII Hepatic Tumours	1.0	1.4	1.2	1.2	0.9 – 1.4	12	1.1	0.5
VIII Malignant Bone Tumours	13.8	7.7	10.5	10.9	10.1 – 11.7	108	1.7	4.8
IX Soft Tissue Sarcomas	10.3	12.5	11.5	11.4	10.6 – 12.2	114	1.1	5.2
X Germ Cell and Gonadal Neoplasms	18.6	51.8	36.4	34.2	32.8 – 35.5	352	3.9	16.5
XI Carcinomas and Epithelial Neoplasms	28.4	80.8	56.5	53.1	51.4 – 54.8	546	0.5	25.6
XII Other and Unspecified Neoplasms	5.0	8.4	6.8	6.6	6.0 – 7.2	67	0.7	3.1
ICCC TOTAL	164.5	269.4	220.7	213.9	210.4 – 217.3	2169	1.2	100

Source: ONS *Numbers in italics where rates based on fewer than ten cases*

5.2.8 No comparative European data were available for the 15-24 year age group.

5.2.9 Using the ONS data, we have estimated the overall crude annual prevalence rate for the whole time period for all age groups (0-24 years) as 168.9 per million. Calculations using the same data estimate the crude annual incidence rate for 0-14 year olds over the same time period to be 132.3 per million. This compares well with the equivalent crude annual rate calculated using the NRCT data of 133.8 per million, suggesting that case ascertainment in the two sources is similar. The crude incidence rate for 15-24 year olds is 220.7 per million, demonstrating the rise in incidence of cancer with age.

Figure 2: Comparison of age-standardised incidence rates between the ICCC groups in children aged 15-24 years, per million population at risk, 1988 – 1997



Source: ONS

5.3 Prevalence

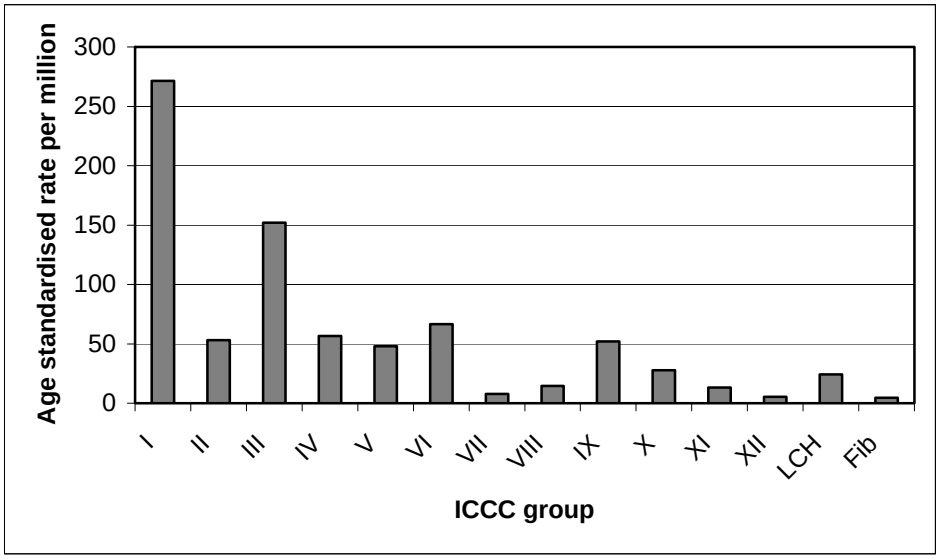
5.3.1 The data shown in table 4 are estimates of the point prevalence at the end of 1997 in children aged 0-14 years. The larger source table is shown in **Appendix 3**. Comparison of the age-standardised rates between the twelve ICCC groups and non-malignant conditions is shown in figure 3.

Table 4: Prevalence rates of cancer in children aged 0-14 years, per million population at risk, 1988 – 1997

DIAGNOSTIC GROUP	Point prevalence rates per million population at risk							M:F Ratio	Relative Frequency (%)
	0-4	5-9	10-14	Crude	ASR	ASR 95% CI	*Cum.*		
I Leukaemia	121.7	351.0	382.5	286.1	271.4	268.2 – 274.6	4276	1.2	35.4
II Lymphoma	9.5	51.1	113.2	57.7	53.0	51.6 – 54.4	869	2.5	7.1
III Brain and Spinal Neoplasms	56.7	178.4	249.4	161.7	151.9	149.5 – 154.3	2422	1.2	20.0
IV Sympathetic Nervous System Tumours	55.5	66.5	46.7	56.4	56.5	55.0 – 58.0	844	1.1	7.0
V Retinoblastoma	38.6	57.2	50.7	49.0	48.1	46.8 – 49.5	733	1.1	6.1
VI Renal Tumours	41.4	82.5	82.4	69.0	66.6	65.0 – 68.2	1031	1.1	8.5
VII Hepatic Tumours	8.6	7.0	7.4	7.6	7.7	7.2 – 8.3	115	1.7	0.9
VIII Malignant Bone Tumours	*0.9*	11.6	35.7	16.0	14.5	13.7 – 15.2	241	0.9	2.0
IX Soft Tissue Sarcomas	19.9	62.2	83.3	55.2	52.0	50.6 – 53.4	827	1.5	6.8
X Germ Cell and Gonadal Neoplasms	16.2	25.3	45.5	28.9	27.7	26.6 – 28.7	435	1.0	3.6
XI Carcinomas and Epithelial Neoplasms	*1.8*	7.6	35.1	14.7	13.3	12.6 – 14.0	222	0.8	1.8
XII Other and Unspecified Neoplasms	3.1	6.1	7.4	5.5	5.3	4.8 – 5.7	83	0.6	0.7
ICCC TOTAL	373.9	906.4	1139.3	808.0	767.9	762.5 – 773.3	12098	1.2	100
Langerhans Cell Histiocytosis	19.3	25.6	29.5	24.8	24.3	23.3 – 25.3	372	1.4	
Fibromatosis	4.0	5.5	4.6	4.7	4.7	4.2 – 5.1	71	1.8	
OVERALL TOTAL	397.2	937.5	1173.5	837.5	796.9	791.3 – 802.4	12541	1.2	

Source: NRCT *Numbers in italics where rates based on fewer than ten cases*

Figure 3: Comparison of age-standardised prevalence rates between the ICCC groups and non-malignant conditions in children aged 0-14 years, per million population at risk, 1988 – 1997



Source: NRCT

5.3.2 Prevalence is dependent upon both the underlying incidence of a disease and the survival associated with that disease. If two diseases occur at the same rate (i.e. have the same incidence) the condition for which there is the highest survival will have a greatest prevalence.

5.3.3 Table 4 shows the most prevalent diagnosis is leukaemia (35.4%), followed by brain and spinal neoplasms (20%), renal tumours (8.5%), lymphoma (7.1%) and sympathetic nervous system tumours (7%). Whilst broadly similar to the pattern seen in incidence, the relative proportions have changed, reflecting the differing survival within the disease groups.

5.3.4 It has not been possible to find comparative prevalence data for either England and Wales or Europe in this age group.

5.4 Mortality

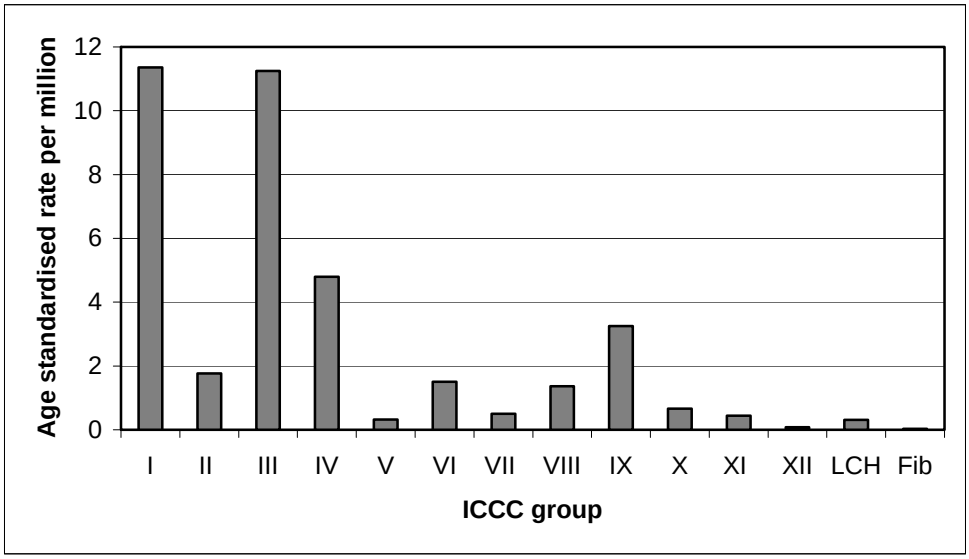
5.4.1 Mortality rates calculated using NRCT data are summarised in table 5. The more extensive source table can be found in **Appendix 4**. A comparison of mortality rates between the twelve ICCC groups and non-malignant conditions is shown in figure 4.

Table 5: Mortality rates for children aged 0-14 years, diagnosed with cancer, per million population at risk, 1988 – 1997

DIAGNOSTIC GROUP	Average annual mortality rates per million population at risk							M:F Ratio	Relative Frequency (%)
	0-4	5-9	10-14	Crude	ASR	ASR 95% CI	*Cum.*		
I Leukaemia	10.9	11.5	11.8	11.4	11.4	10.7 – 12.0	171	1.5	30.7
II Lymphoma	1.1	1.9	2.4	1.8	1.8	1.5 – 2.0	28	2.3	4.9
III Brain and Spinal Neoplasms	10.7	13.0	10.1	11.3	11.2	10.6 – 11.9	169	1.2	30.3
IV Sympathetic Nervous System Tumours	7.5	4.9	1.1	4.6	4.8	4.3 – 5.2	67	1.3	12.3
V Retinoblastoma	0.5	0.3	*0.1*	0.3	0.3	0.2 – 0.4	5	0.9	0.8
VI Renal Tumours	2.5	1.2	0.5	1.4	1.5	1.3 – 1.8	21	0.9	3.8
VII Hepatic Tumours	0.9	*0.2*	0.3	0.5	0.5	0.4 – 0.6	7	3.2	1.3
VIII Malignant Bone Tumours	*0.1*	0.6	3.9	1.5	1.4	1.1 – 1.6	23	1.0	4.0
IX Soft Tissue Sarcomas	3.7	3.1	2.8	3.2	3.2	2.9 – 3.6	48	1.0	8.7
X Germ Cell and Gonadal Neoplasms	0.9	0.4	0.6	0.6	0.7	0.5 – 0.8	10	0.6	1.7
XI Carcinomas and Epithelial Neoplasms	*0.2*	0.3	0.9	0.5	0.4	0.3 – 0.6	7	1.3	1.2
XII Other and Unspecified Neoplasms	*0.1*	*0.0*	*0.1*	*0.1*	0.1	0.0 – 0.1	1	0.3	0.2
ICCC TOTAL	39.1	37.5	34.7	37.1	37.3	36.1 – 38.5	556	1.3	100
Langerhans Cell Histiocytosis	0.8	*0.0*	*0.0*	0.3	0.3	0.2 – 0.4	4	1.3	
Fibromatosis	*0.1*	*0.0*	*0.0*	*0.0*	*0.0*	0.0 – 0.1	*0*	*0.5*	
OVERALL TOTAL	40.0	37.5	34.7	37.5	37.6	36.4 – 38.9	561	1.3	

Source: NRCT *Numbers in italics where rates based on fewer than ten cases*

Figure 4: Comparison of age-standardised mortality rates between the ICCC groups and non-malignant conditions in children aged 0-14 years, diagnosed with cancer, per million population at risk, 1988 – 1997



5.4.2 As expected, the highest mortality rates are found in those diagnostic groups that have the highest incidence. However, the relative frequencies of some of the diagnoses have changed, suggesting differing expectations of survival. For example, sympathetic nervous system tumours account for 6.7% of new childhood cancer cases diagnosed each year, but 12.3 % of deaths, suggesting relatively poor survival. In contrast, retinoblastoma accounts for 3.2% of new cases, but only 0.8% of deaths, suggesting favourable survival.

5.4.3 Mortality data for 15-24 year olds were only available from previously published ONS reports.[36] Since these data are coded using ICD, direct comparison with the results already presented for the 0-14 year old group will not be possible. To attempt to overcome this problem with comparability, a table of mortality rates for 0-24 year olds has been produced using the ICD coded ONS data. The table features the major subdivisions of ICD, along with specific diagnoses that have direct comparators in ICCC. Table 6 is an abbreviated version of this table, with the full version shown in **Appendix 5**.

5.4.4 Crude mortality rates calculated from ONS sources are smaller than those calculated using NRCT data, suggesting a slight under-estimation. For example, the crude mortality rate for 5-9 year olds in table 5 is 37.5 per million, whereas the same group in table 6 has a rate of 35.9. The effect is more marked in the 0-4 age group than either the 5-9 or 10-14 age groups.

5.4.5 Overall it can be seen that the highest death rates are seen in the malignant neoplasms of lymphatic and haematopoietic tissue (the lymphomas), with a relative frequency of 40.6% and an age-standardised rate of 16.8 per million. The next group is the malignant neoplasm of other and unspecified sites (relative frequency 29.5%), which includes a range of diagnoses including brain tumours, neoplasms of the eye and neoplasm of endocrine glands.

Lymphoid leukaemia is the next most common (17.6%), followed by malignant neoplasm of bone, connective tissue, skin and breast (16.5%). This pattern would fit with the known incidence of disease.

5.4.6 The overall age-standardised mortality rate for persons aged 0-24 is 41.4 per million. This is higher than the rate calculated for the 0-14 age group (37.6 per million), and would fit with the higher incidence of disease in the 15-24 year age group.

5.4.7 No source of comparative mortality rates for England and Wales or Europe was identified.

Table 6: Mortality rates for persons aged 0-24 years diagnosed with cancer, per million population at risk, 1988 – 1997

CAUSE OF DEATH	Average annual mortality rates per million population at risk								M/F Ratio	Relative Frequency (%)
	0-4	5-9	10-14	15-19	20-24	Crude	ASR	Cum		
Malignant neoplasm of lip, oral cavity and pharynx	0.2	0.4	0.5	0.8	0.8	0.5	0.5	14	1.1	1.3
Malignant neoplasm of digestive organs and peritoneum	1.4	0.4	0.9	2.0	3.8	1.8	1.6	42	1.3	4.1
Malignant neoplasm of respiratory and intrathoracic organs	0.3	0.2	0.2	0.5	1.2	0.5	0.4	12	1.6	1.1
Malignant neoplasm of bone, connective tissue, skin and breast	2.1	2.5	5.7	10.8	13.7	7.1	6.4	174	1.3	16.5
Malignant neoplasm of bone and articular cartilage	0.3	0.8	3.9	6.7	5.6	3.4	3.1	86	1.5	
Malignant neoplasm of connective and other soft tissue	1.8	1.6	1.6	3.4	4.3	2.6	2.4	63	1.2	
Malignant melanoma of skin	0.1	0.1	0.1	0.7	2.9	0.8	0.7	19	1.1	
Malignant neoplasm of female breast	0.0	0.0	0.0	0.0	0.7	0.2	0.1	3	-	
Malignant neoplasm of genitourinary organs	2.4	1.5	0.9	2.3	6.3	2.8	2.6	67	0.8	6.5
Malignant neoplasm of cervix uteri	0.0	0.0	0.0	0.0	1.4	0.3	0.2	7	-	
Malignant neoplasm of ovary and other uterine adnexa	0.0	0.1	0.2	0.8	1.2	0.5	0.4	11	-	
Malignant neoplasm of testis	0.0	0.0	0.1	0.8	2.3	0.7	0.6	16	-	
Malignant neoplasm of other and unspecified sites	15.9	16.9	10.4	9.0	10.9	12.7	13.0	316	1.3	29.5
Malignant neoplasm of eye	0.4	0.3	0.1	0.0	0.1	0.2	0.2	5	1.0	
Malignant neoplasm of brain	7.4	11.1	8.1	6.1	7.7	8.1	8.1	202	1.3	
Malignant neoplasm of other and unspecified parts of nervous system	0.4	0.3	0.5	0.4	0.4	0.4	0.4	10	2.5	
Malignant neoplasm of other and endocrine glands and related structures	7.1	4.8	1.2	1.0	0.8	3.0	3.3	74	1.2	
Malignant neoplasm of lymphatic and haematopoietic tissue	11.9	14.0	14.6	21.9	24.1	17.5	16.8	433	1.6	40.6
Non-Hodgkin lymphoma	1.3	1.8	2.1	3.8	5.4	2.9	2.7	72	2.3	6.8
Lymphosarcoma and reticulosarcoma	0.2	0.2	0.3	0.6	0.6	0.4	0.3	9	5.9	
Hodgkin disease	0.0	0.2	0.3	2.1	4.9	1.6	1.3	37	1.3	3.7
Other malignant neoplasm of lymphoid and histiocytic tissue	1.1	1.6	1.8	3.2	4.8	2.6	2.4	63	2.1	
All Leukaemias	17.1	18.3	17.9	23.9	21.4	19.8	19.5	494	1.6	
Lymphoid leukaemia	5.6	8.8	7.8	9.7	6.3	7.6	7.6	191	1.9	17.6
Myeloid leukaemia	4.0	2.7	3.7	5.5	6.9	4.6	4.4	114	1.2	10.8
Monocytic leukaemia	0.2	0.0	0.1	0.2	0.1	0.1	0.1	3	0.9	0.2
Other specified leukaemia	0.3	0.0	0.1	0.1	0.0	0.1	0.1	2	0.3	0.2
Leukaemia of unspecified cell type	0.6	0.6	0.5	0.4	0.6	0.5	0.5	13	1.7	1.2
Benign neoplasm of brain and other parts of nervous system	0.1	0.1	0.0	0.2	0.4	0.2	0.1	4	1.5	0.4
TOTALS	**34.4**	**35.9**	**33.2**	**47.5**	**61.3**	**43.0**	**41.4**	**1062**	**1.4**	**100.0**

Source: ONS[36]

5.5 Survival

5.5.1 Table 7 shows five-year percent actuarial survival figures for all ages and both sexes combined in the 0-14 age group. A more detailed table showing further breakdown by sex is included in **Appendix 6**. Because of improvements in survival, results are shown for only the last five years of the study period (1993-1997).[28]

Table 7: Childhood cancer in England and Wales: five-year percent survival of patients diagnosed 1993-97, age 0-14 years, males and females combined

DIAGNOSTIC GROUP	Total number of cases	Total Survival (%)
I LEUKAEMIA		
Acute Lymphoid Leukaemia	1645	81
Acute Non-Lymphocytic Leukaemia	322	55
Chronic Myeloid Leukaemia	50	44
Other specified leukaemia	4	-
Unspecified leukaemia	21	57
II LYMPHOMA		
Hodgkin disease	261	93
Non-Hodgkin Lymphoma + Burkitt's Lymphoma	339	77
Unspecified lymphoma	3	-
Miscellaneous reticulo-endothelial neoplasms	13	77
III BRAIN AND SPINAL NEOPLASM		
Ependymoma + Choroid Plexus tumours	174	67
Astrocytoma	706	79
Primitive neuroectodermal tumour	302	51
Other glioma	175	43
Other specified Central Nervous System Tumour	202	91
Unspecified Central Nervous System Tumour	77	66
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS		
Neuroblastoma	395	55
Other SNS	5	-
V RETINOBLASTOMA		
Retinoblastoma	215	96
VI RENAL TUMOURS		
Wilms' etc	369	83
Renal carcinoma	12	75
Other renal	3	-
VII HEPATIC TUMOURS		
Hepatoblastoma	55	75
Hepatic carcinoma	8	-
VIII MALIGNANT BONE TUMOURS		
Osteosarcoma	155	61
Chondrosarcoma	8	-
Ewing's sarcoma	89	63
Other specified bone tumour	6	-
Unspecified bone tumour	5	-

DIAGNOSTIC GROUP	Total number of cases	Total Survival (%)
IX SOFT TISSUE SARCOMAS		
Rhabdomyosarcoma	258	66
Fibrosarcoma	53	85
Kaposi's sarcoma	2	-
Other specified soft tissue sarcoma	142	63
Unspecified soft tissue sarcoma	38	39
X GERM CELL AND GONADAL NEOPLASMS		
Central Nervous System germ-cell	58	79
Other non-gonadal germ-cell	51	69
Gonadal germ-cell	104	97
Gonadal carcinoma	6	-
Other gonadal	0	-
XI CARCINOMAS AND EPITHELIAL NEOPLASMS		
Adrenocortical carcinoma	7	-
Thyroid carcinoma	26	100
Nasopharyngeal carcinoma	11	82
Melanoma	72	86
Skin carcinoma	23	96
Other carcinoma	69	81
XII OTHER AND UNSPECIFIED NEOPLASMS		
Other specified malignant	6	-
Other unspecified malignant	35	89
ADDITIONAL NON-MALIGNANT CONDITIONS		
Langerhans Cell Histiocytosis	156	94
Fibromatosis	35	91
TOTAL	**6771**	**75**

Source: NRCT Note: Survival not calculated where number of cases is less than 10

5.5.2 Thyroid carcinoma has the highest survival (100%). High survival is also seen in this age group for Hodgkin disease (93%), retinoblastoma (96%), gonadal germ cell tumours (97%) and skin carcinoma (96%). The 'other specified central nervous system tumour' group also has a high survival (91%), but included amongst these are non-malignant tumours. The non-malignant Langerhans cell histiocytosis and fibromatosis also have high survival (94% and 91% respectively). Disease types with poor survival include chronic myeloid leukaemia (44%), primitive neuroectodermal tumour (51%), glioma (43%) and neuroblastoma (55%). Again this pattern of survival is reported by other work.[5]

5.5.3 Table 7 shows the overall survival for childhood cancer is 75%.Inclusion of non-malignant diagnoses in the calculations may have slightly improved survival. However, overall survival is not significantly different from other European countries, apart from Finland and Germany (table 8).

Table 8: Five-year survival in 0-14 year olds for all cancers, 1993-1997, for selected European countries

Country	Survival (%)	95% confidence interval
Hungary	66	63 - 69
Netherlands**	69	66 - 72
Ireland*	70	63 - 77
Denmark	72	67 - 76
England & Wales**	73	71 - 74
Spain**	74	71 - 77
Norway	75	71 - 79
Scotland	77	73 - 80
Germany	78	77 - 79
Finland	80	77 - 83
Iceland	81	66 - 89

Source: ACCIS[44]
* Data collection 1994-1997
** Data collection 1993-1995

5.5.4 Survival data were not available at the England & Wales national level for the age groups 15-24. However, data have been published for this age group by the Northern Region Young Persons' Malignant Disease Registry.[10] For the time period 1988-1995, the five-year survival for all cancers for 15-24 year olds was 73% (95% CI 70-78%). For haematological malignancies in the same group it was 72% (95% CI 66-78%), and 75% for solid tumours (95% CI 70-79%).

5.6 Hospital Activity

5.6.1 Episode based analysis

Table 9 shows little variation in the episode rate between 1998/99 and 2001/02. Around 60,000 episodes for malignant disease occur each year, representing 3684 episodes per million children aged 0-24.

Table 9: Episodes by year: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
All activity	84,868	5,273	85,403	5,295	84,897	5,266	85,189	5,268	340,357	5,275
Malignant disease only	57,759	3,589	59,652	3,698	59,685	3,702	60,567	3,745	237,663	3,684

Table 10 shows the activity described in table 9 for malignant disease further disaggregated by age group. The highest episode rate is found in the youngest age groups.

Table 10: Episodes by year and age group: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
Age group	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
0-04	14,031	4,351	15,230	4,774	15,446	4,908	15,286	4,953	93,320	4,132
05-09	14,847	4,336	15,309	4,490	14,379	4,277	13,783	4,176	91,936	3,873
10-14	10,209	3,074	9,890	2,932	10,508	3,094	11,748	3,426	64,438	2,784
15-19	10,113	3,237	10,386	3,291	10,384	3,277	11,271	3,494	63,273	2,906
20-24	8,559	2,852	8,837	2,945	8,968	2,944	8,479	2,710	54,532	2,485
Grand Total	57,759	3,589	59,652	3,698	59,685	3,702	60,567	3,745	237,663	3,684

Figure 5 shows the trend in the episode rate for malignant disease from 1995/96 to 2001/02 by age group. Clearly the data quality is poor in 1997/98 showing a substantial under-recording of activity. The general trends in activity are increasing over the time period although this may reflect better data recording in more recent years.

Figure 5: Trends in the episode rate by year and age group, 1995/96 to 2001/02

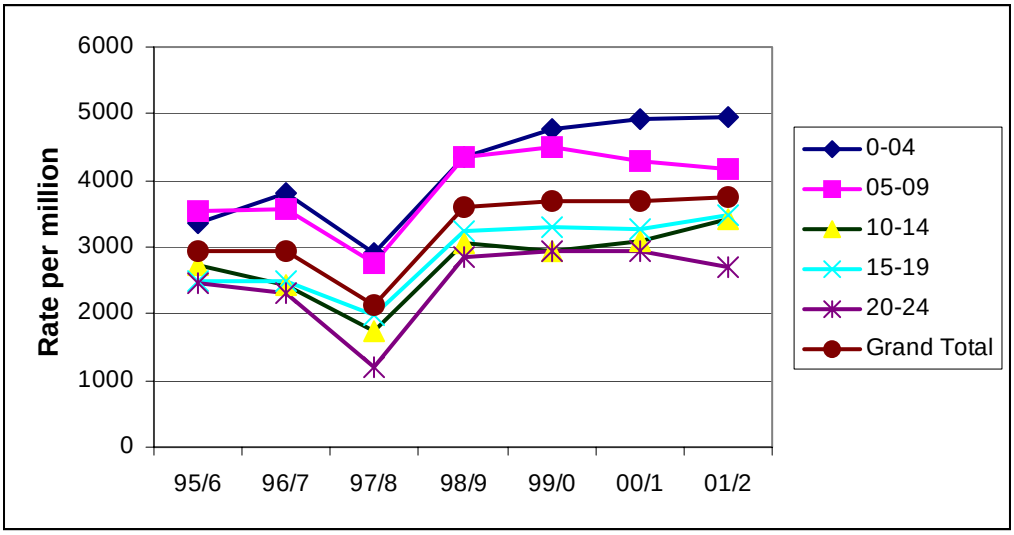


Table 11 shows the number of episodes by NHS Trust and year for 1995/96 to 2001/02 and table 12 by age group. The (arbitrary) criterion for inclusion in the tables was a total number of episodes greater than 2,500.

Table 11: Number of episodes by NHS Trust and year, 1995/96 to 2001/02

NHS Trust	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01	2001/02	Grand Total
Central Manchester & Manchester Children's Hospitals	4,048	4,163	3,714	4,463	4,818	5,162	5,965	32,333
The Royal Marsden Hospital NHS Trust	4,229	2,816	2,983	4,413	4,538	4,769	4,469	28,217
Southampton University Hospitals NHS Trust	2,836	2,567	2,412	2,735	2,488	2,304	2,792	18,134
United Bristol Healthcare NHS Trust	3,843	3,497	2,275	3,425	2,272	1,481	1,136	17,929
Leeds Teaching Hospitals NHS Trust	1,234	1,815	1,505	2,715	2,951	3,360	3,226	16,806
The Newcastle Upon Tyne Hospitals NHS Trust	1,670	1,545	1,473	2,736	2,568	2,560	3,087	15,639
Great Ormond Street Hospital For Children	2,406	2,620	1,127	2,173	2,304	2,660	2,320	15,610
Christie Hospital NHS Trust	2,315	1,862	1,558	2,829	2,371	1,314	1,960	14,209
Barts & The London NHS Trust	1,932	2,041	1,628	2,025	1,781	1,772	1,634	12,813
Birmingham Children's Hospital NHS Trust	1,758	1,590	1,091	1,680	1,897	1,395	1,768	11,179
University College London Hospitals NHS Trust	1,123	1,040	1,108	1,704	1,933	1,901	2,033	10,842
Royal Liverpool Childrens NHS Trust	1,177	1,306	1,087	1,574	1,543	1,583	2,294	10,564
Queen's Medical Centre, Nottingham Univ Hospital	681	1,106	777	1,446	2,113	2,229	1,501	9,853
Oxford Radcliffe Hospital NHS Trust	1,382	1,408	261	1,685	1,414	1,386	1,443	8,979
Addenbrooke's NHS Trust	1,013	1,040	666	1,228	1,384	1,566	1,884	8,781
Sheffield Children's NHS Trust		933	146	1,741	1,729	2,007	1,998	8,554
Cardiff & Vale NHS Trust	1,053	1,186	1,057	1,027	1,358	1,352	1,298	8,331
University Hospitals Of Leicester NHS Trust	888	1,092	709	1,137	1,631	1,181	1,353	7,991
Gloucestershire Hospitals NHS Trust	443	538	417	939	867	857	633	4,694
Hammersmith Hospitals NHS Trust	425	475	309	532	457	373	377	2,948
North Staffordshire Hospital NHS Trust	305	220	217	443	596	553	475	2,809
Royal Devon & Exeter Healthcare NHS Trust	382	459	315	278	457	397	473	2,761

Table 12: Number of episodes by NHS Trust and age group, 1995/96 to 2001/02

NHS Trust	0-04	05-09	10-14	15-19	20-24	Grand Total
Central Manchester & Manchester Children's Hospitals	11,934	11,000	6,365	2,412	622	32,333
The Royal Marsden Hospital NHS Trust	7,597	8,454	5,372	4,128	2,666	28,217
Southampton University Hospitals NHS Trust	4,886	5,819	4,156	2,401	872	18,134
United Bristol Healthcare NHS Trust	4,357	4,946	4,103	2,823	1,700	17,929
Leeds Teaching Hospitals NHS Trust	4,593	4,912	2,809	2,770	1,722	16,806
The Newcastle Upon Tyne Hospitals NHS Trust	3,922	4,200	2,904	2,878	1,735	15,639
Great Ormond Street Hospital For Children	7,399	5,829	2,204	170	8	15,610
Christie Hospital NHS Trust	1,070	1,266	2,185	5,373	4,315	14,209
Barts & The London NHS Trust	5,650	2,758	1,856	1,365	1,184	12,813
Birmingham Children's Hospital NHS Trust	4,213	3,629	2,665	670	2	11,179
University College London Hospitals NHS Trust	393	1,030	2,856	4,584	1,979	10,842
Royal Liverpool Childrens NHS Trust	3,099	3,281	2,846	1,255	83	10,564
Queen's Medical Centre, Nottingham Univ Hospital	2,966	3,650	2,026	948	263	9,853
Oxford Radcliffe Hospital NHS Trust	2,315	2,514	1,347	1,377	1,426	8,979
Addenbrooke's NHS Trust	2,726	2,070	1,514	1,211	1,260	8,781
Sheffield Children's NHS Trust	3,128	2,661	2,116	649		8,554
Cardiff & Vale NHS Trust	2,478	2,297	1,428	1,335	793	8,331
University Hospitals Of Leicester NHS Trust	1,662	1,217	1,453	1,775	1,884	7,991
Gloucestershire Hospitals NHS Trust	1,085	1,391	844	824	550	4,694
Hammersmith Hospitals NHS Trust	42	290	338	885	1,393	2,948
North Staffordshire Hospital NHS Trust	616	464	655	772	302	2,809
Royal Devon & Exeter Healthcare NHS Trust	536	581	251	328	1,065	2,761

5.6.2 In-patient bed days analysis

Bed days are a measure of resource utilisation. Table 13 shows little variation in the in-patient bed days rate between 1998/99 and 2001/02.

Table 13: In-patient bed days by year: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
All activity	157,909	9,811	162,707	10,087	151,976	9,427	157,238	9,724	629,830	9,762
Malignant disease Only	135,698	8,431	139,878	8,672	130,549	8,098	136,411	8,436	542,536	8,409

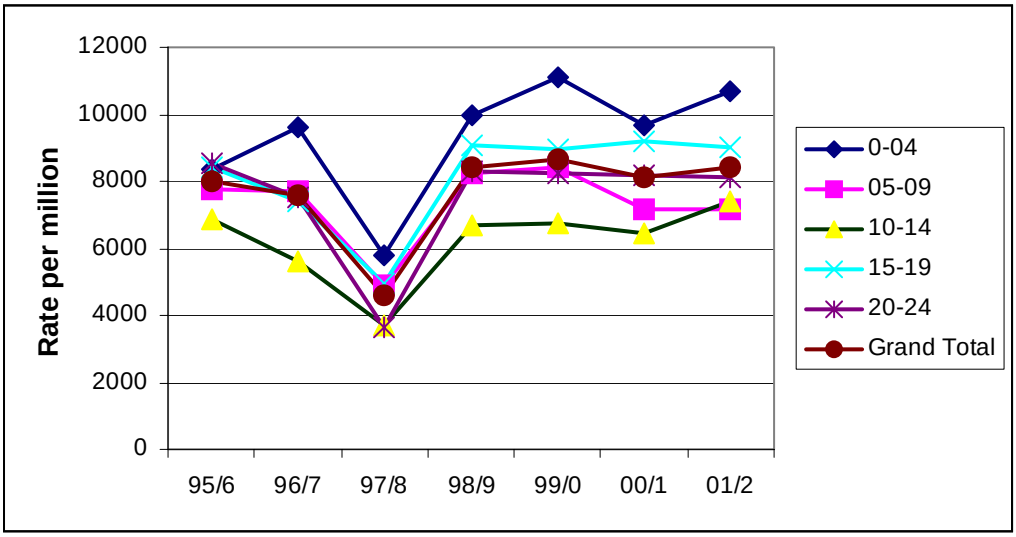
Table 14 shows the activity described in table 13 for malignant disease further disaggregated by age group. The highest in-patient bed days rate is found in the youngest age groups.

Table 14: In-patient bed days by year and age group: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
Age group	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
0-04	32,064	9,944	35,384	11,091	30,527	9,700	32,916	10,666	209,789	9,289
05-09	28,124	8,213	28,766	8,437	24,041	7,152	23,614	7,154	173,848	7,325
10-14	22,305	6,716	22,797	6,759	21,822	6,425	25,330	7,386	144,167	6,229
15-19	28,266	9,048	28,227	8,943	29,218	9,220	29,151	9,038	177,740	8,163
20-24	24,939	8,309	24,704	8,232	24,941	8,187	25,400	8,117	164,844	7,511
Grand Total	135,698	8,431	139,878	8,672	130,549	8,098	136,411	8,436	542,536	8,409

Figure 6 shows the trend in the in-patient bed days rate from 1995/96 to 2001/02 by age group. Clearly the data quality is poor in 1997/98 showing a substantial under-recording of activity. The general trends in activity are increasing over the time period although this may reflect better data recording in more recent years. The last four years of data suggest a stable trend in in-patient bed days with some small year-on-year fluctuations.

Figure 6: Trends in the in-patient bed days rate by year and age group, 1995/96 to 2001/02



As a measure of resource use, figure 7 shows the trend in numbers of in-patient bed days. The numbers of bed days is stable at a mean of 135,500 per annum and a peak in 1999/00 of 140,000.

Figure 7: Trends in the numbers of in-patient bed days by year and age group, 1995/96 to 2001/02

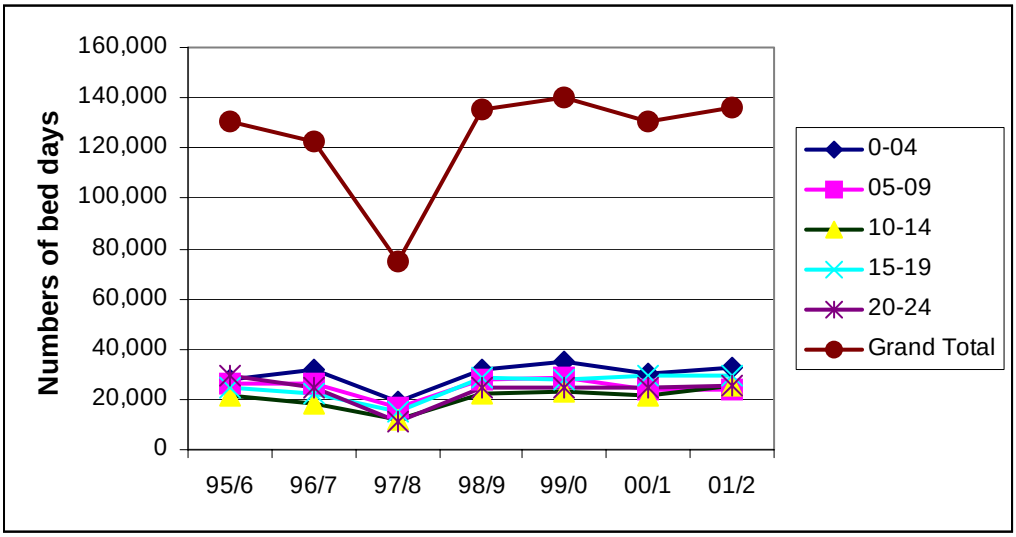


Table 15 shows the number of in-patient bed days by NHS Trust and year for 1995/96 to 2001/02 and table 16 by age group. The (arbitrary) criterion for inclusion in the tables was a total number of episodes greater than 8,000.

Table 15: Number of in-patient bed days by NHS Trust and year, 1995/96 to 2001/02

NHS Trust	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01	2001/02	Grand Total
Leeds Teaching Hospitals NHS Trust	4,481	5,861	4,182	8,577	8,958	9,181	8,902	50,142
Central Manchester & Manchester Children's Hospitals	7,268	6,702	5,364	7,636	7,957	7,002	8,153	50,082
University College London Hospitals NHS Trust	5,517	5,640	4,159	7,751	8,599	6,822	7,525	46,013
Great Ormond Street Hospital For Children	6,739	7,304	2,656	6,767	7,384	7,313	7,281	45,444
The Newcastle Upon Tyne Hospitals NHS Trust	5,950	4,871	3,767	7,060	7,413	6,378	8,691	44,130
The Royal Marsden Hospital NHS Trust	6,785	5,720	4,032	6,276	6,774	6,151	6,697	42,435
Birmingham Children's Hospital NHS Trust	6,341	6,477	4,610	6,566	6,443	5,093	5,276	40,806
United Bristol Healthcare NHS Trust	6,235	5,433	3,111	5,905	5,606	5,615	4,848	36,753
Barts & The London NHS Trust	5,796	5,300	4,308	4,437	4,514	4,432	4,248	33,035
Cardiff & Vale NHS Trust	4,649	3,575	3,036	3,592	4,858	3,895	3,530	27,135
Southampton University Hospitals NHS Trust	4,237	3,915	2,968	3,897	3,724	3,198	3,578	25,517
Addenbrooke's NHS Trust	3,484	3,088	1,491	3,547	3,901	3,513	4,551	23,575
Royal Liverpool Childrens NHS Trust	3,087	3,332	2,553	3,552	3,450	3,031	3,829	22,834
Christie Hospital NHS Trust	3,901	3,794	1,822	2,744	2,617	2,601	3,351	20,830
Queen's Medical Centre, Nottingham Univ Hospital	2,481	3,314	1,640	3,356	3,557	3,600	2,539	20,487
Oxford Radcliffe Hospital NHS Trust	3,314	3,042	469	3,600	2,658	2,246	2,495	17,824
University Hospitals Of Leicester NHS Trust	2,165	2,585	1,354	2,403	3,112	2,218	2,572	16,409
Sheffield Children's NHS Trust		2,386	211	3,201	2,752	3,228	3,320	15,098
Hammersmith Hospitals NHS Trust	2,104	2,175	994	1,562	1,671	1,562	1,611	11,679
Royal Free Hampstead NHS Trust	1,751	1,036	592	1,021	2,139	1,762	1,890	10,191
University Hospital Birmingham NHS Trust	1,614	1,265	347	995	1,591	2,443	1,797	10,052
St George's Healthcare NHS Trust	1,195	1,296	676	1,289	1,714	1,120	1,330	8,620

Table 16: Number of in-patient bed days by NHS Trust and age group, 1995/96 to 2001/02

NHS Trust	0-04	05-09	10-14	15-19	20-24	Grand Total
Leeds Teaching Hospitals NHS Trust	13,320	11,675	8,110	9,247	7,790	50,142
Central Manchester & Manchester Children's Hospitals	19,661	13,425	9,079	4,757	3,160	50,082
University College London Hospitals NHS Trust	2,788	3,236	10,362	18,674	10,953	46,013
Great Ormond Street Hospital For Children	24,123	14,103	6,542	676	0	45,444
The Newcastle Upon Tyne Hospitals NHS Trust	12,796	10,244	7,546	8,066	5,478	44,130
The Royal Marsden Hospital NHS Trust	8,928	8,719	7,307	9,023	8,458	42,435
Birmingham Children's Hospital NHS Trust	15,694	12,448	10,203	2,461	0	40,806
United Bristol Healthcare NHS Trust	9,777	10,134	7,380	6,611	2,851	36,753
Barts & The London NHS Trust	9,616	6,465	5,934	5,345	5,675	33,035
Cardiff & Vale NHS Trust	8,764	5,955	4,441	5,214	2,761	27,135
Southampton University Hospitals NHS Trust	7,157	5,564	4,811	4,334	3,651	25,517
Addenbrooke's NHS Trust	7,457	4,469	4,171	3,693	3,785	23,575
Royal Liverpool Childrens NHS Trust	6,992	5,919	6,677	3,201	45	22,834
Christie Hospital NHS Trust	577	683	1,664	8,985	8,921	20,830
Queen's Medical Centre, Nottingham Univ Hospital	6,674	6,325	4,495	2,143	850	20,487
Oxford Radcliffe Hospital NHS Trust	4,278	4,477	2,799	3,378	2,892	17,824
University Hospitals Of Leicester NHS Trust	3,623	2,405	2,982	4,158	3,241	16,409
Sheffield Children's NHS Trust	5,391	4,439	4,066	1,202		15,098
Hammersmith Hospitals NHS Trust	32	618	1,254	3,591	6,184	11,679
Royal Free Hampstead NHS Trust	544	1,999	2,178	2,480	2,990	10,191
University Hospital Birmingham NHS Trust			140	3,906	6,006	10,052
St George's Healthcare NHS Trust	2,144	2,591	1,671	1,005	1,209	8,620

5.6.3 Day case bed days analysis

Table 17 shows a small year-on-year increase in the day case bed days rate between 1998/99 and 2001/02.

Table 17: Day case bed days by year: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
All activity	50,159	3,116	50,071	3,104	50,837	3,153	50,953	3,151	202,020	3131
Malignant disease only	30,479	1,894	31,639	1,962	32,727	2,030	33,279	2,058	128,124	1986

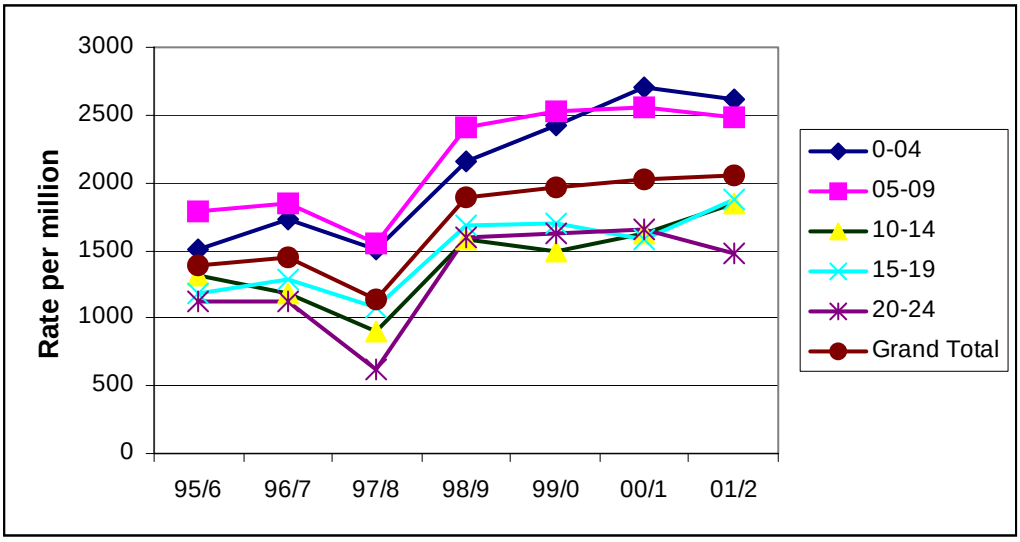
Table 18 shows the activity described in table 17 for malignant disease further disaggregated by age group. The highest day case bed days rate is found in the youngest age groups.

Table 18: Day case bed days by year and age group: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
Age group	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
0-04	6,934	2,150	7,741	2,426	8,502	2,701	8,080	2,618	46,938	2,078
05-09	8,266	2,414	8,595	2,521	8,608	2,561	8,195	2,483	51,378	2,165
10-14	5,239	1,577	5,030	1,491	5,527	1,627	6,312	1,841	32,965	1,424
15-19	5,268	1,686	5,374	1,703	5,033	1,588	6,060	1,879	32,485	1,492
20-24	4,772	1,590	4,899	1,633	5,057	1,660	4,632	1,480	28,772	1,311
Grand Total	30,479	1,894	31,639	1,962	32,727	2,030	33,279	2,058	192,538	1,701

Figure 8 shows the trend in the day case bed days rate from 1995/96 to 2001/02 by age group. Clearly the data quality is poor in 1997/98 showing a substantial under-recording of activity. The general trends in activity are increasing over the time period although this may reflect better data recording in more recent years. The last four years of data suggest a slowly increasing trend in the day case bed days rate with some small year-on-year fluctuations between age groups.

Figure 8: Trends in the day case bed days rate by year and age group, 1995/96 to 2001/02



As a measure of resource use, figure 9 shows the trend in numbers of day case bed days. The numbers of bed days increased to a peak in 1999/00 of 33,279.

Figure 9: Trends in the numbers of day case bed days by year and age group, 1995/96 to 2001/02

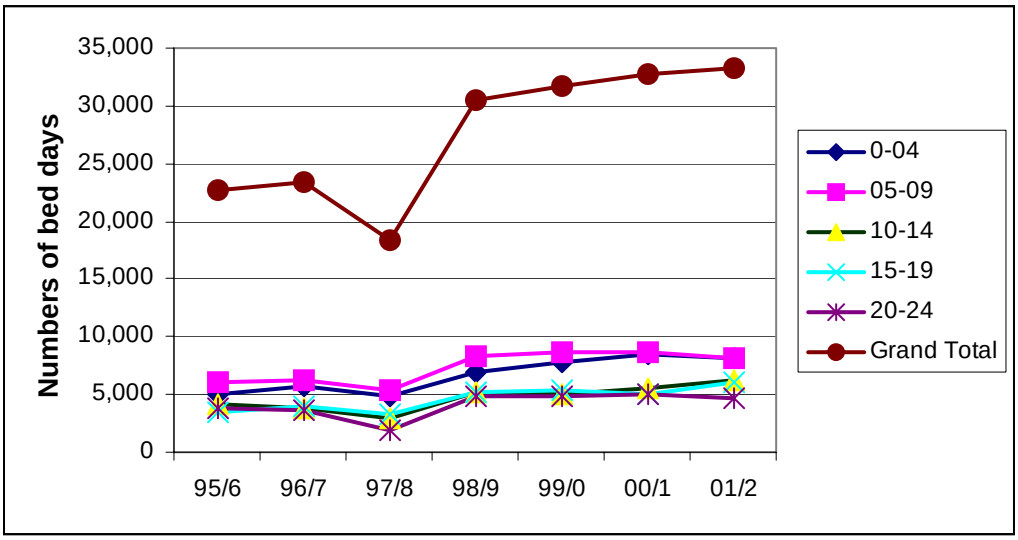


Table 19 shows the number of day case bed days by NHS Trust and year for 1995/96 to 2001/02 and table 20 by age group. The (arbitrary) criterion for inclusion in the tables was a total number of episodes greater than 1,200.

Table 19: Number of day case bed days by NHS Trust and year, 1995/96 to 2001/02

NHS Trust	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01	2001/02	Grand Total
Central Manchester & Manchester Children's Hospitals	2,831	2,984	2,736	3,156	3,449	3,783	4,262	23,201
The Royal Marsden Hospital NHS Trust	3,232	2,095	2,161	3,424	3,671	3,867	3,624	22,074
Southampton University Hospitals NHS Trust	1,965	1,840	1,859	1,987	1,783	1,671	2,098	13,203
United Bristol Healthcare NHS Trust	2,755	2,379	1,683	2,466	1,040	399	216	10,938
Christie Hospital NHS Trust	1,525	1,243	1,152	2,199	1,867	691	1,369	10,046
Great Ormond Street Hospital For Children	1,167	1,433	738	1,197	1,339	1,630	1,381	8,885
Leeds Teaching Hospitals NHS Trust	488	879	671	1,235	1,376	1,650	1,513	7,812
The Newcastle Upon Tyne Hospitals NHS Trust	516	547	670	1,550	1,290	1,380	1,603	7,556
Barts & The London NHS Trust	666	733	596	914	972	1,133	1,011	6,025
Queen's Medical Centre, Nottingham Univ Hospital	205	503	403	738	1,252	1,523	979	5,603
Sheffield Children's NHS Trust		332	77	1,029	1,141	1,286	1,252	5,117
Oxford Radcliffe Hospital NHS Trust	646	749	152	995	810	802	781	4,935
Royal Liverpool Childrens NHS Trust	498	580	427	711	675	811	1,223	4,925
University Hospitals Of Leicester NHS Trust	152	356	422	615	1,085	774	811	4,215
Addenbrooke's NHS Trust	425	445	249	538	586	808	1,023	4,074
University College London Hospitals NHS Trust	254	424	446	490	510	528	722	3,374
Cardiff & Vale NHS Trust	382	495	451	377	484	548	557	3,294
Gloucestershire Hospitals NHS Trust	181	248	192	531	535	644	501	2,832
Birmingham Children's Hospital NHS Trust	15	20	52	90	549	631	951	2,308
Hammersmith Hospitals NHS Trust	216	281	184	272	250	204	205	1,612
Nottingham City Hospital NHS Trust	168	172	2	224	161	215	290	1,232
North Staffordshire Hospital NHS Trust	116	117	48	128	279	270	246	1,204

Table 20: Number of day case bed days by NHS Trust and age group, 1995/96 to 2001/02

NHS Trust	0-04	05-09	10-14	15-19	20-24	Grand Total
Central Manchester & Manchester Children's Hospitals	8,194	8,309	4,493	1,776	429	23,201
The Royal Marsden Hospital NHS Trust	6,143	7,090	4,414	2,934	1,493	22,074
Southampton University Hospitals NHS Trust	3,521	4,580	3,117	1,693	292	13,203
United Bristol Healthcare NHS Trust	2,195	3,053	2,732	1,718	1,240	10,938
Christie Hospital NHS Trust	908	1,065	1,679	3,665	2,729	10,046
Great Ormond Street Hospital For Children	3,839	3,663	1,300	76	7	8,885
Leeds Teaching Hospitals NHS Trust	2,200	2,642	1,300	1,061	609	7,812
The Newcastle Upon Tyne Hospitals NHS Trust	1,820	2,266	1,480	1,298	692	7,556
Barts & The London NHS Trust	3,102	1,305	563	535	520	6,025
Queen's Medical Centre, Nottingham Univ Hospital	1,579	2,239	1,127	505	153	5,603
Sheffield Children's NHS Trust	1,886	1,648	1,221	362		5,117
Oxford Radcliffe Hospital NHS Trust	1,222	1,431	650	710	922	4,935
Royal Liverpool Childrens NHS Trust	1,334	1,745	1,266	512	68	4,925
University Hospitals Of Leicester NHS Trust	873	490	735	932	1,185	4,215
Addenbrooke's NHS Trust	1,194	1,075	614	519	672	4,074
University College London Hospitals NHS Trust	63	272	899	1,522	618	3,374
Cardiff & Vale NHS Trust	717	980	613	525	459	3,294
Gloucestershire Hospitals NHS Trust	650	915	455	517	295	2,832
Birmingham Children's Hospital NHS Trust	1,001	694	499	114		2,308
Hammersmith Hospitals NHS Trust	19	174	167	492	760	1,612
Nottingham City Hospital NHS Trust	2		36	467	727	1,232
North Staffordshire Hospital NHS Trust	266	142	258	387	151	1,204

5.6.4 Patient based analysis

Table 21 shows a steady increase in the annual numbers of patients recorded on HES/PEDW. This may represent a genuine increase in patient incidence, a higher frequency of treatment in successive years, or merely a year-on-year improvement in the recording of the NHS number on the datasets.

Table 21: Patients admitted or day case by year: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
All activity	23,962	1,489	24,206	1,501	24,966	1,549	25,288	1,564	98,422	1526
Malignant disease Only	4,837	301	4,987	309	5,370	333	5,517	341	20,711	321

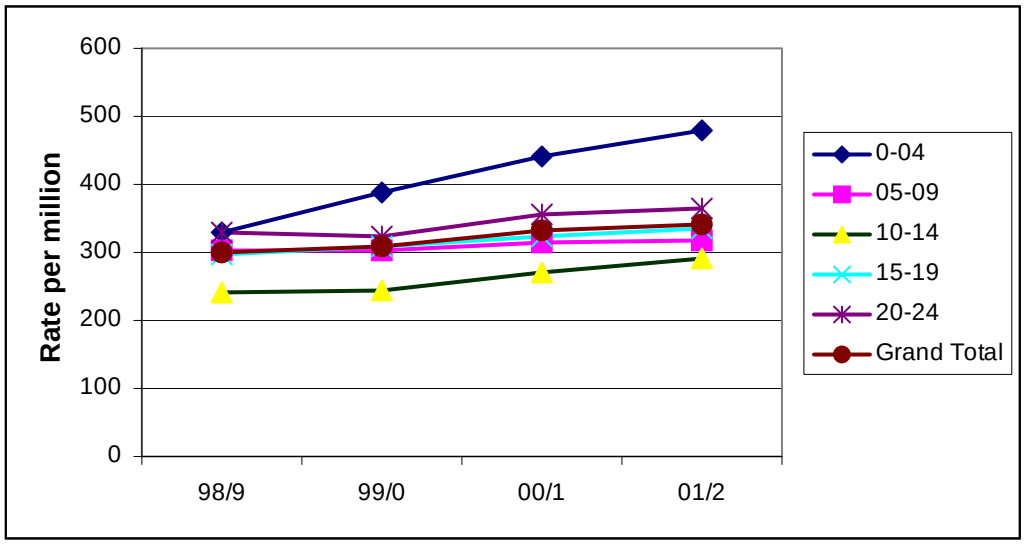
Table 22 shows the activity described in table 21 for malignant disease further disaggregated by age group. The highest rate of admitted patients is in the youngest age group and the general pattern is the same as shown in the incidence data in tables 2 and 3 (section 5.2).

Table 22: Patients admitted or day case by year and age group: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
Age group	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
0-04	1,066	331	1,234	387	1,389	441	1,481	480	5,170	409
05-09	974	302	963	302	989	314	982	318	3,908	290
10-14	779	242	777	244	855	272	898	291	3,309	245
15-19	958	297	984	308	1,014	322	1,034	335	3,990	315
20-24	1,060	329	1,029	323	1,123	357	1,122	364	4,334	356
Grand Total	4,837	301	4,987	309	5,370	333	5,517	341	20,711	321

Figure 10 shows the trends in the annual rates from table 22. Increasing trends, particularly in the 0 to 4 age group, are seen but these may reflect better recording of data or an increase in the number of admissions per individual patient in successive years, rather than a true rise in the incidence of new cases.

Figure 10: Trends in the annual rate of patients admitted by age group, 1998/99 to 2001/02



5.6.5 Analysis of the ten most commonly performed procedures

Table 23 shows the numbers and rate of the ten most commonly coded procedures in children aged 0 to 24 years with malignant disease. Table 24 gives a description for each OPCS-4 code.

A54, the commonest procedure, and A55 are particularly required in the management of the leukaemias. The majority of the L91 activity is for central venous catheters and W36 for diagnostic bone marrow aspirates. X35 includes chemotherapy and a small amount of immunotherapy. The majority of the sub-cutaneous and intra-muscular injection categories is also for chemotherapy. The majority of the injection of therapeutic substance category is for gamma globulin. The data suggest an increasing trend in the numbers and rate of the ten commonest procedures.

Table 23: The ten most commonly performed procedures by year: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
OPCS-4 code	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**
A54	4,661	290	5,855	363	5,888	365	5,776	357	31,082	482
A55	3,459	215	3,427	212	3,807	236	3,548	219	22,831	354
L91	3,357	209	3,554	220	3,685	229	3,528	218	21,397	332
W36	3,136	195	3,435	213	3,325	206	3,419	211	21,149	328
X 35	16,509	256	14,974	232	15,280	237	15,462	240	62,225	241
X 33	5,450	84	5,490	85	4,718	73	5,381	83	21,039	82
X29	1,416	22	2,886	45	3,416	53	4,300	67	12,018	47
C86	404	25	407	25	444	28	372	23	2,688	42
X36	2,380	37	2,476	38	2,548	39	2,930	45	10,334	40
T87	276	17	326	20	347	22	315	19	2,015	31
Totals	27,457	426	27,536	427	28,055	435	30,095	466	113,143	438

Table 24: OPCS-4 codes and description of the ten most commonly performed procedures

OPCS-4 code	Description
A54	Therapeutic spinal puncture total
A55	Diagnostic spinal puncture total
L91	Other vein related operations total
W36	Diagnostic puncture of bone total
X 35	Other intravenous injection total
X 33	Other blood transfusion total
X29	Continuous infusion of therapeutic substance total
C86	Other operations on eye total
X36	Blood withdrawal total
T87	Excision or biopsy of lymph node total

Table 25 shows data on all procedures performed on children with malignant disease by age group, and less evidence of an increasing trend compared to the ten most common procedures.

Table 25: Procedures by year and age group: number and rate per million children aged 0 to 24 years, 1998/99 – 2001/02

	1998-1999		1999-2000		2000-2001		2001-2002		Grand total	
Age group	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
0-04	5,389	1,671	6,125	1,920	6,193	1,968	5,922	1,919	36,299	1,607
05-09	5,665	1,654	6,296	1,846	6,029	1,793	5,656	1,714	36,070	1,520
10-14	3,400	1,024	3,741	1,109	4,158	1,224	4,425	1,290	23,094	998
15-19	2,673	856	2,741	868	2,977	939	3,076	954	17,148	788
20-24	2,407	802	2,384	794	2,570	844	2,411	770	15,461	704
Grand Total	19,534	1,214	21,287	1,320	21,927	1,360	21,490	1,329	84,238	1,306

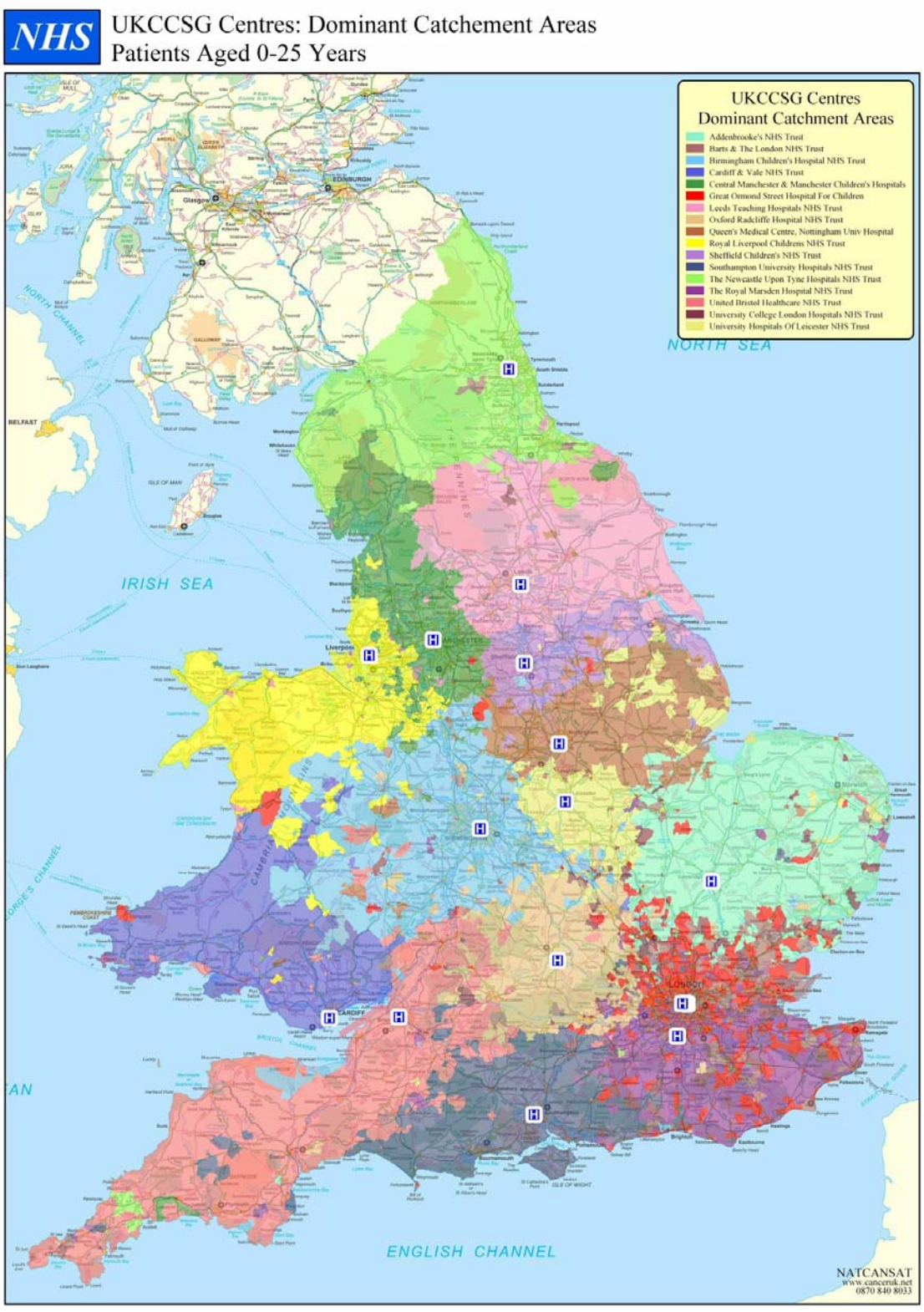
5.6.6 Variation in activity by Strategic Health Authority

Table 26 shows variation in rates of activity by Strategic Health Authority. The data show a two and a half-fold variation in episode rates, a one and a half-fold variation in in-patient bed days, a six and a half-fold variation in day case bed days, and nearly a two fold variation in the numbers of patients admitted. These variations may result from variations in clinical practice throughout the NHS in England and Wales, but it is perhaps more likely that the variation results from differences in clinical coding and the other problems of data quality. The rates in the table are not age-standardised and some of the variation might be explained by differences in the age structure of the SHA populations, but it is unlikely that this would account for the observed variation. Clearly further work is required to explore the reasons behind these quite marked variations in activity.

Table 26: Variation in activity by Strategic Health Authority: rates per million children aged 0 to 24 years, 1995/96 - 2001/02

SHA of residence	Episodes	IP	DC	Patients
Avon, Gloucestershire & Wiltshire HA	32.2	63.9	18.1	1.4
Bedfordshire & Hertfordshire HA	17.3	57.2	6.9	1.1
Birmingham & The Black Country HA	13.7	51.0	5.1	0.9
Cheshire & Merseyside HA	20.6	58.5	10.0	1.4
County Durham & Tees Valley HA	22.5	69.8	11.5	1.5
Coventry, Warwickshire, Herefordshire & Worcestershire HA	14.9	61.0	4.1	1.1
Cumbria & Lancashire HA	28.7	59.6	18.9	1.2
Dorset & Somerset HA	23.1	54.4	12.4	1.4
Essex HA	21.2	65.5	8.1	1.5
Greater Manchester HA	37.5	69.2	26.5	1.3
Hampshire & Isle Of Wight HA	32.8	57.3	22.2	1.8
Kent & Medway HA	21.0	61.3	10.4	1.4
Leicestershire, Northamptonshire & Rutland HA	23.8	64.2	11.6	1.4
Norfolk, Suffolk & Cambridgeshire HA	19.5	51.6	9.2	1.2
North & East Yorkshire and Northern Lincolnshire HA	18.1	59.4	8.5	1.4
North Central London HA	19.6	75.3	8.8	1.1
North East London HA	18.0	67.4	7.4	1.3
North West London HA	21.0	64.3	11.2	1.1
Northumberland, Tyne & Wear HA	20.1	63.0	9.5	1.3
Shropshire & Staffordshire HA	17.4	57.6	6.2	1.1
South East London HA	20.7	63.3	10.7	1.2
South West London HA	25.1	52.7	16.6	1.4
South West Peninsula HA	25.2	70.1	10.9	1.3
South Yorkshire HA	19.6	49.6	11.1	1.3
Surrey & Sussex HA	26.9	68.1	15.9	1.6
Thames Valley HA	17.9	45.6	8.8	1.1
Trent HA	21.8	56.2	12.5	1.2
West Yorkshire HA	18.6	61.1	9.0	1.3
Wales	18.5	65.6	8.1	1.0

5.6.7 Dominant catchment areas



Source: Department of Health

5.7 Palliative Care

5.7.1 Using the mortality rate as a proxy, the mortality data available for this report suggest a need for palliative care services at a rate of 37.5 per million children with cancer aged 0-14 years.

5.7.2 The most recent joint report of the Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health quotes a mortality rate for children with life limiting conditions aged 0-19 years of 1.5-1.9 per 10,000 (or 150-190 per million).[40] Of these, it is suggested that 40% will die from cancer (or 60-76 per million). They also cite a prevalence of severely ill children with life limiting conditions in need of palliative care of at least 12 per 10,000 children, aged 0-19 years (or 1200 per million). However, it is not stated what proportion of these would be cancer patients.

5.7.3 A further report exploring palliative care services for those aged 13-24 estimates the annual mortality rate for young people in this age range with life-limiting conditions is slightly over 1.7 per 10,000.[45] Of these, twenty nine percent are due to neoplasms (49.3 per million).

5.8 Population projections

5.8.1 When considering the future burden of disease, two factors should be considered. The first, which has been discussed earlier, are the trends in incidence and survival for the diseases in question. The second is the structure or demographic profile of the population. Since different age groups have distinctive patterns of cancer incidence, a change in population numbers in any of the age groups should cause a corresponding increase or decrease in the incidence of types of cancer occurring. Changes in the incidence of childhood cancer are related to population dynamics. Table 27 shows projected populations for England and Wales by age group.

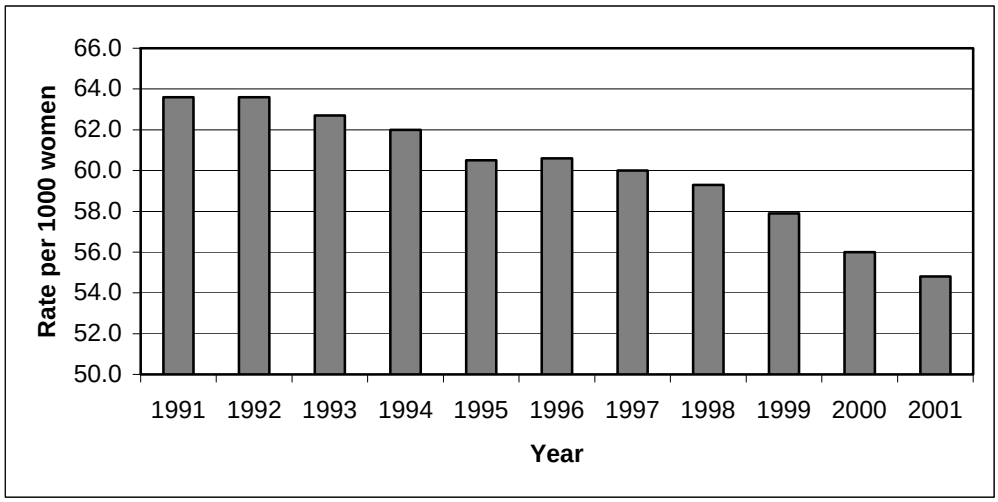
Table 27: England and Wales population projections by age group

Age Group	2001			2006			2011		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4	1,580	1,506	3,086	1,541	1,468	3,009	1,564	1,490	3,055
5-9	1,691	1,609	3,301	1,588	1,517	3,105	1,549	1,480	3,029
10-14	1,757	1,673	3,429	1,703	1,623	3,326	1,600	1,532	3,131
15-19	1,650	1,576	3,225	1,786	1,706	3,492	1,732	1,657	3,390
20-24	1,558	1,571	3,129	1,658	1,674	3,332	1,792	1,807	3,598

All data are quoted in thousands
Source: Government Actuary's Department, accessed at http://www.gad.gov.uk

5.8.2 The most marked trend is the falling birth rate, resulting in a progressive reduction in the population of 0-4, 5-9 and 10-14 year olds. This trend is further illustrated in figure 11. This shows the falling fertility rate since 1991, defined as the number of live births occurring within a year divided by the mid-year female population aged 15-44 years.[46] The rate is conventionally expressed as rate per 1000.

Figure 11: Age-specific fertility rate 1991-2001

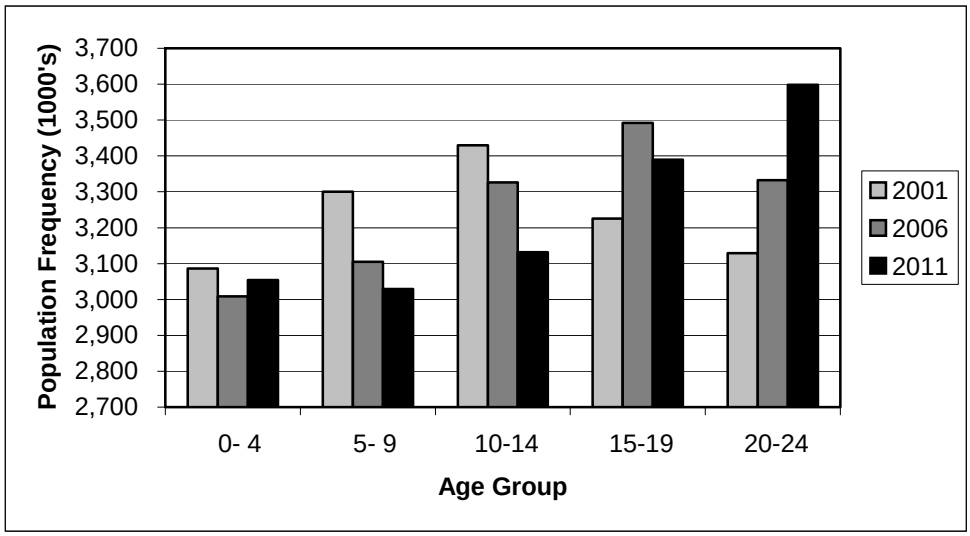


Source: ONS accessed at www.statistics.gov.uk

5.8.3 The data from table 27 are shown in figure 12. As the comparatively larger cohorts of children from the early 1990's move through the age groups, the age profile of the young population changes. There are more individuals in the younger age groups in 2001 whereas, by 2011, there are projected to be more individuals in the 20-24 age group. Therefore it would be expected that by 2011 the absolute number of the most prevalent conditions in this age group (e.g. testicular cancer) would increase. Correspondingly, the absolute numbers of cancers more characteristic of the younger age groups (e.g. embryonal tumours) would decrease. This assumes that incidence rates do not change.

5.8.4. The expected numbers of cases for the different sub-groups of cancer could be calculated by applying current incidence rates to the projected population estimates. This would allow estimates to be made of future service need. However, it would be important to interpret these calculations carefully. Firstly, these estimates based only on projected populations would show how the pattern of cancer incidence might be expected to alter with time, due to the changing age profile of the young population. They would not allow an extrapolation to the effect on clinical workload. Secondly, the identification of a falling birth rate cannot be interpreted that clinical workload is likely to reduce. The expansion of effective treatment methods and the proven value of the treatment of relapse suggest that clinical workload is likely to increase. In view of the uncertain value of projecting cancer incidence, these calculations are not shown in this report.

Figure 12: Population projections for England & Wales by five-year age group



Source: Government Actuary's Department, accessed at http://www.gad.gov.uk

6. Service Provision

6.1 Introduction

This section of the needs assessment describes the current service response to the burden of disease described by the epidemiology in Section 5. This account of child and adolescent cancer services across England and Wales is based on the results of a survey of UKCCSG Treatment Centres and Teenage Cancer Trust (TCT) Units.

6.2 The current service provision model

6.2.1 UKCCSG Centres

In England and Wales, care of children with cancer is offered and co-ordinated at the following 17 Centres, all of which are registered by the UKCCSG:

- The Children's Hospital, BIRMINGHAM
- Royal Hospital for Sick Children, BRISTOL
- Addenbrooke's Hospital, CAMBRIDGE
- Llandough Hospital, CARDIFF
- St. James University Hospital, LEEDS
- Leicester Royal Infirmary, LEICESTER
- Alder Hey Children's Hospital, LIVERPOOL
- Barts and the London Trust, LONDON
- Hospital for Sick Children, Great Ormond Street, LONDON
- The Middlesex Hospital, LONDON
- Royal Manchester Children's Hospital, MANCHESTER
- Royal Victoria Infirmary, NEWCASTLE-UPON-TYNE
- Queen's Medical Centre, NOTTINGHAM
- John Radcliffe Hospital, OXFORD
- Sheffield Children's Hospital, SHEFFIELD
- Southampton Children's Hospital, SOUTHAMPTON
- Royal Marsden Hospital, SUTTON

6.2.2 Teenage Cancer Trust (TCT) Units

In addition it is recognised that the needs of young people with cancer are different from those of younger children. Neither paediatric nor adult services are ideally suited to offer treatment to this group. Therefore the TCT is leading developments to offer age appropriate facilities. Currently there are seven TCT Units in England, with a further one due to open soon (*):

- Queen Elizabeth Hospital, BIRMINGHAM.
- Christie Hospital, MANCHESTER.
- St. James's Hospital, LEEDS.
- Alder Hey, LIVERPOOL.*
- Middlesex Hospital, LONDON.
- University College Hospital, LONDON.
- Royal Victoria Infirmary, NEWCASTLE-UPON-TYNE.
- Weston Park Hospital, SHEFFIELD.

All are built alongside existing NHS facilities. However, it is important to highlight that individuals in the older age groups may be treated in adult facilities.

6.2.3 Shared Care Centres (SCC's)

SCC's are based at secondary care level and are all affiliated to one of the UKCCSG Centres. The use of SCC's across England and Wales is variable, as is the service they offer. Some SCC's will treat haematological malignancies under the guidance of the tertiary centre, with the latter only being attended for initial diagnosis. Other SCC's will offer a more limited service.

6.2.4 Bone Marrow Transplantation (BMT)

The BMT service is currently changing. Centres offering the treatment are now required to carry out a minimum number of BMT's each year to maintain clinical skills. All BMT's are registered with the JACIE registry. This is one of a network of European BMT Registries, and is administered in Bristol.

6.2.5 Primary care

Primary care services are not formally involved in treatment, but will have a role in initial diagnosis and the provision of palliative care.

6.3 Survey of Treatment Centres

6.3.1. Background and methodology

6.3.1.1 A survey was conducted with the aim of producing a current and accurate description of the structure of child and adolescent cancer services within England and Wales. To ensure that the results would be useful and meaningful in a service context, the survey was compiled with the collaboration of clinicians and a TCT representative. With their guidance, the questionnaire also collected information on some of the significant issues that the panel considers face the service. Most questions were closed, but a series of open questions were included to allow respondents to highlight the strengths and weaknesses of their service. No pilot was conducted.

6.3.1.2 The survey questionnaire (**Appendix 7**) was sent out to all TCT Units on September 18, 2003, and to all UKCCSG Centres within England and Wales on September 25, 2003, with a deadline for return of the questionnaires set for October 7, 2003. A 100% response rate was achieved. Between March and June 2004 each Centre was sent a copy of this chapter and asked to validate the information and comment on the interpretation of the findings that specifically related to them. The validated results are presented in this report.

6.3.2 Results

6.3.2.1. Location

In total 18 replies were received from the 17 UKCCSG Centres and eight TCT units (the responses from Alder Hey include data from the Alder Hey TCT). Some of the other Centres also reported from a TCT they were associated with under a single corporate heading and one NHS Trust reported on the TCT only that it managed. The responses do not currently include information from the TCT at Weston Park Hospital in Sheffield.

6.3.2.2. New patient registrations and in-patient beds

6.3.2.2.1 Table 28 summarises the number of new patients reported annually by each Centre.

Table 28: New patient registrations and in-patient beds

Centre	New patients				Number of in-patient beds	Adolescent beds		Local TCT Unit (Yes/No)
	Number (annual)	Proportion aged 0-14 years (%)	Proportion aged 15+ years (%)	Maximum age (years)		Number	Oncology only (Yes/No)	
1	60-70	79	21	18	8	Not specified	No	No
2	172	95	5	<16*	14	4	Yes	Yes
3	90-100	85	15	18	10+2*	0	-	No
4	138	95	5	16	20	0	-	No
5	60	95	5	<16	14	0****	-	Yes
6	110	95	5	16	17**	0	-	No
7	108	89	11	20	11***	6	Yes	Yes*****
8	70-80	88	12	17	15	5	Yes	No
9	110-120	90	10	16-18	14	4	No	No
10	75-80	88	12	17	10	2	Yes	No
11	122	85	15	23	23	6	Yes	Yes*****
12	70-75	87	13	17	12**	Not specified	No	No
13	102§	90	10	17	19	4	Yes	Yes
14	145^	93	7	18	15	0	Yes	Yes
15	150	67	33	23	15	Not specified	Yes	Yes
16	106	-	-	<16*	9	0	-	No
17	75-90	47	53	20	14	14	Yes	Yes*****
18	100	30	70	24	13	13	Yes	Yes*****

* Reported as 15 years and 364 days
** Beds shared with general paediatrics but not necessarily ringfenced for oncology e.g. Centre #3
*** Divided between 2 sites (8 at first, 3 at second)
**** Cubicles used when possible
***** Located within unit and account for the adolescent beds featured in previous columns
§ 25 leukaemia, 77 solid tumours (of which, 25 brain)
^ UK residents

6.3.2.2.2 The Centres were asked to estimate this as an average number over the last five years. However, the estimate was to exclude those with non-malignant haematological conditions, those referred from overseas and those referred for a second opinion. In the table, the relative proportion in terms of age group of these new cases, either 0-14 years or 15+ years, is given as a percentage. The maximum age of new patients admitted by each Centre is also given. This data is presented alongside the number of designated in-patient oncology beds available within each unit. Some Centres gave details of the number of day case beds, but these are not included. Additionally, details are provided of the number of beds intended for use by adolescents and whether their use is dedicated for oncology. The presence or absence of a local TCT unit is also indicated. Additional comments made by the units are shown as subscripts where appropriate.

6.3.2.2.3 It can be seen that the range of the numbers of new patients seen extends from 60 to 172. Of these, the greater proportion of patients for most units are aged 0-14 years (range 67% to 95%, one Centre is a TCT only). However, the maximum age accepted varies from 16 to 24. The number of in-patient beds ranges from 8 to 23. Eight Centres (nine units) have dedicated adolescent beds (minimum 2, maximum 13). The age range for admission to an adolescent bed extended from as young as age 11 in one Centre up to age 23 in another. Six Centres have no dedicated adolescent beds and 3 did not give details. TCT units were accessible at 9 Centres.

6.3.2.3 Radiotherapy

Centres were asked whether their paediatric radiotherapy was delivered on site and how many clinical oncologists with a paediatric interest support the Centre. Five Centres have radiotherapy services on site, with patients having to travel within the locality to reach the service provider in the remaining 12. The details of this and the clinical oncology support are summarised in table 29.

Table 29: Radiotherapy services

Centre	Are radiotherapy services delivered on site? (Yes/No)**	Number of Clinical Oncologists
1	No	2*
2	No	1
3	No	1
4	No	4 Oncologists/ 3 Haematologists
5	No	2
6	Yes	1
7	Yes	2
8	No	1
9	Yes	2
10	No	1.7
11	No	1
12	No	1
13	No	2
14	Yes	1
15	No	1
16	No	1
17	Yes	1(+1 starting late 2004)
18	Yes	1

*part-time ** in some Centres (e.g. #3) radiotherapy is delivered at a different site but within the same trust

6.3.2.4 Bone Marrow Transplantation (BMT)

Centres were asked whether they carried out BMT or referred elsewhere. The place of referral was ascertained if the latter applied. Fourteen of the Centres performed BMT on site. When required, referrals were sent to Birmingham, Bristol, Great Ormond Street, the Royal Marsden or Sheffield. A detailed description of the results by Centre is given in table 30.

Table 30: Bone Marrow Transplantation

Centre	Where BMT service accessed
1	Bristol (occasionally), Great Ormond Street, The Royal Marsden
2	All on site
3	All on site
4	All on site
5	All on site
6	The Royal Marsden or Bristol
7	All on site
8	Autologous stem cell on site; otherwise Bristol
9	All on site
10	Bristol (if live in West) or London (if live in East)
11	All on site
12	Some on site; otherwise Sheffield
13	All on site
14	All on site
15	All on site
16	Birmingham, Bristol, Great Ormond Street
17	All on site
18	All on site

6.3.2.5 Paediatric neurosurgery

In this question we asked whether paediatric neurosurgery was available on site and if not, how far patients needed to travel if the service was provided elsewhere. There also followed a question about the availability of specialist paediatric neurosurgeons. Eight Centres had paediatric neurosurgery on site. For the remaining nine, paediatric neurosurgery services were provided at hospitals that were up to 20 miles away from the main site. Three Centres, however, did not have access to at least one specialist paediatric neurosurgeon. The detailed results are shown in table 31.

6.3.2.6 Specialist bone / sarcoma surgery

Centres were asked where they sent their patients requiring specialist bone or sarcoma surgery. Fifteen Centres referred exclusively to a single Centre for specialist bone surgery (12 to Birmingham and the remainder to the Royal National Orthopaedic Hospital in Stanmore). The other two Centres would use either of the two available Centres. Factors that influence this choice were not ascertained. Specialist sarcoma surgery was usually carried out on site although information from one Centre was incomplete and three Centres also referred patients elsewhere including St George's and UCLH.

Table 31: Paediatric neurosurgery service provision

Centre	Paediatric neurosurgery on site? (Yes/No)	If no, how far away is the service from the main site	Do you have specialist paediatric neurosurgeon(s)? (Yes/No)	If yes, how many?
1	No	1 mile	Yes	2
2	Yes	-	Yes	3
3	No	2-4 miles	No	-
4	Yes	-	Yes	3
5	Yes	-	Yes	2
6	Yes	-	Yes	2*
7	Yes	-	Yes	3
8	No	7 miles	Yes	2
9	No	6 miles	Yes	2*
10	Yes	-	Yes	1
11	No	2 miles	Yes	2
12	Yes	-	Yes	2
13	No	4 miles	Yes	2
14	No	5 miles	Yes	3
15	Yes	-	No	6*
16	No	20 miles	No	-
17	No	1 mile	Yes	3(+1 starting late 2004)
18	No	8 miles	Yes	4**

* Surgeons not exclusively paediatric ** Surgeons shared with other Centres

6.3.2.7 Retinoblastoma assessment

Centres were asked where patients with retinoblastoma were sent for specialist ophthalmic assessment and/or treatment. From the responses received, Birmingham and Barts and The London were identified as the two Centres providing this service. Seven Centres referred exclusively to Birmingham, six exclusively to Barts and The London, and the remaining four to either of the two.

6.3.2.8 Other specialist services

Centres were asked if they sent their patients out of region for any other specialist service. Five of the Centres reported that they did. Three referred for specialist liver services (one to Birmingham, two to Kings). One referred to Sheffield and London for specialist thyroid services. The latter also described a need to refer for specialist liver services, but thought that Birmingham no longer offered this. One referred to Great Ormond Street for immunological diseases. One Centre highlighted the additional availability of services for paediatric infectious disease, virology, gastroenterology, neurology, respiratory medicine and prosthetic limb fitting. Another Centre noted the availability of an isolation facility for radioactive treatment. One Centre reported that fertility preservation was not available on site.

6.3.2.9 Allied health services

6.3.2.9.1 Centres were asked to report how much designated support they had from allied health professionals and where they perceived additional support was needed (see **Appendix 8**). A total of 16 Centres provided information and a summary of the responses is shown in table 32.

Table 32: Allied health services

Centre		Physiotherapy	Occupational therapy	Psychology	Speech therapy	Dietetics	Play therapy	Adolescent support workers	*Diagnostic* paediatric radiographers	*Therapeutic* paediatric radiographers	Data managers	Research nurses
1	# wte and grade	1				0.5	1 spec	0	0	0	1	0
	# designated sessions per week		2	Trainee 0.5 sessions / wk	1 session / mo		1 session / mo					
2	# wte and grade											
	# designated sessions per week											
3	# wte and grade	0.4, gde 1	n/k	3.5, 1 gde B, 2.5 gde A	1.5, spec and snr gde	0.65, snr 1	2.3	0	3, 2 snr 1, 1 spr 3	1, snr 2	1, gde 4 CRA	0
	# designated sessions per week					5	IP 10, DC 3, OPD/RT as required		30		10	
4	# wte and grade	0.4, 0.2 spr 3, 0.2 snr 2	1, clin spec 3	0.9, 0.5 gde A, 0.4 gde B[1]	3.2	1.2	5, 1 snr 1, 4 play spec	0	30 between both categories		1.5, 0.5 A&C 5, 1 A&C 4	1, gde G
	# designated sessions per week	0	0	9+4[2]	0	0	0		0		0	
5	# wte and grade	0.5 snr 1	0	0	0	0	3.1	0	13.9, 7.8 snr 2, 5.1 snr 1, 1spr	0	2.1	
	# designated sessions per week		0	0	0	0		0	0	0	0	
6	# wte and grade	0.25	0	0.1	0	0.5	2, gde C	0	0	0.1	1	0.5, gde G
	# designated sessions per week	0[3]		0		5	20			1	10	5

[1] Proportions refer to allocated time of 2 full-time posts, gde A haemo-oncology, gde B neuro-oncology
[2] One post = 5 sessions, other post = 4 sessions + 4 sessions assistant
[3] Access as required (2.5 sessions per week)

Centre		Physiotherapy	Occupational therapy	Psychology	Speech therapy	Dietetics	Play therapy	Adolescent support workers	Diagnostic paediatric radiographers	Therapeutic paediatric radiographers	Data managers	Research nurses
7	# wte and grade	0.6	0	5.72[4]	0	1.1	2	0	General 0.52, 0.04 sup 1, 0.08 snr 1, 0.4 snr 2; Nuclear 0.34, 0.16 MTO4, 0.16 MTO3, 0.02 B17 scientist; MRI / CT 0.8, 0.2 sup 3, 0.6 snr 1; U/S 0.25		2.4, 1 A&C 7, 1.4 A&C 4	1.6, 1 gde G, 0.6 gde F
	# designated sessions per week	Referral on request	Referral on request				10					
8	# wte and grade	Shared with generic IP	0 IP, access to community	Very limited access for local patients	0 IP, access to community	0.5	3.6	0	[5]	Provided by another trusts	1	1, F gde
	# designated sessions per week						36			2	10	10
9	# wte and grade	No designated sessions, referral as required	0	No designated sessions, referral as required	Limited mainly for children living in community	1	1	0	No designated sessions, referral as required	No designated sessions, referral as required	1.2	0.5
	# designated sessions per week											
10	# wte and grade			0.3		0.4	2				0.8 gde 3	0.5 gde F
	# designated sessions per week	Access as required	Access as required		Access as required							
11	# wte and grade	2, 1 snr 1, 1 snr 2	0	0.7[6]	0	1.3, 0.8 snr 1, 0.5 snr 1	4, 2 gde B, 2 gde C	1 gde C	Access as required	Access as required	2, 1 A&C 3, 1 A&C 4	3.4, 2 gde F, 1.4 gde G
	# designated sessions per week	10		7							20	

[4] 4.29 for BMT / Oncology and 1.43 for Retinoblastoma
[5] # sessions not known, average 36.8 procedures per week
[6] 0.5 child psychology, 0.2 neuro-psychology

Centre		Physiotherapy	Occupational therapy	Psychology	Speech therapy	Dietetics	Play therapy	Adolescent support workers	Diagnostic paediatric radiographers	Therapeutic paediatric radiographers	Data managers	Research nurses
12	# wte and grade	Access as required	Access as required	Access as required	Access as required	0.8	1.4, 1 gde B, 0.4 gde C	0.6	Access as required	Access as required		
	# designated sessions per week											
13	# wte and grade	0	0	0.2	0	0.4	2	0	0	0	1.8	1
	# designated sessions per week			2		4	20				18	10
14	# wte and grade	0.4	Access to adult service	1.5	Local services as required		2.8, 1.8 gde C, 1 gde D	0	0	0	2	2
	# designated sessions per week	4				5 sessions available as required						
15	# wte and grade	1.5	0	0.5	0	0.5	1	0	0	0	1.5	1.5
	# designated sessions per week	15		2.5			10				10	
16	# wte and grade	1 snr 1	1 snr 2	n/k		1 snr 2	1 level 3	0				0
	# designated sessions per week										7.5 hrs per week	
17	# wte and grade			1		2	4	1				
	# designated sessions per week	Access as required	As required, shared with Middx TCT		Access as required							

6.3.2.9.2 More than half the Centres had access to physiotherapy. Only two Centres had designated paediatric OT services, although several others had limited access to shared, community or adult services. Ten Centres had access to psychology services; five of these Centres had access to psychiatric services as did two other Centres. Two Centres had access to speech therapy, another Centre limited access to children living locally and two others used community services. Most Centres had dietetic services (14/16) and play therapy (15/16). Only three Centres provided support workers for the adolescent age group. Six Centres had no designated paediatric radiographer (diagnostic or therapeutic) although two reported access as required. Nearly all Centres (14/16) had data managers and ten had research nurses.

6.3.2.9.3 Occupational therapy and psychology services were identified most frequently by Centres as gaps in the service and priorities based on need. Most of the other services were identified by organisations as under-supported but these gaps were spread fairly evenly between Centres suggesting local pressures. Notably only three Centres identified adolescent support services as a gap and/or priority for investment.

6.3.2.10 Staffing

Centres were asked to give details of medical and nursing staff numbers in terms of whole time equivalents (WTE). It is recognised that absolute numbers of staff will partly be a function of the size of the unit. Therefore, to allow comparison between Centres, summary measures (rounded to the nearest whole number) have been calculated, together with summary descriptive statistics where appropriate. For medical staff, the number of new patients per staff member (NNP) was calculated by dividing the annual number of new patients seen by the number of medical staff. For in-patient nursing staff, the number per bed (NPB) has been calculated by dividing the number of nurses by the total number of in-patient beds. NPB has only been calculated for nursing grades D to H. Grades D to H represent part of the hierarchy of qualified nurses, with H grade being the most senior. Those at grades B and C are likely to be employed as play specialists and activity co-ordinators. Grade A staff are housekeepers/ nursing assistants. For out patient nursing staff, number per new patients (NNP) is again calculated.

6.3.2.10.1 Nurse staffing

6.3.2.10.1.1 All Centres were asked if they had a lead nurse for their service and the title and grade of that post. The results are summarised in table 33.

6.3.2.10.1.2 Details of In-Patient and Day Care/ Out-Patient nurse staffing levels were sought. As these results are comprehensive, they are shown in tables 34 and 35 respectively. Additionally, data about other nursing posts, such as research nurses, were collected and are presented in table 36. Details were requested about the establishment at each grade (or the number for which funding had been approved) and the number actually in post. Additionally, the funding source for the post was requested. The majority of in-patient and out-patient nursing posts were funded by the NHS. Play staff were more likely to have their posts funded by charities, as were research nurses.

Table 33: Lead Nurse

Centre	Lead Nurse?	Grade	Title
1	Yes	G	Ward Sister
2	Yes	H	Lead Cancer Nurse/ Advanced Nurse Practitioner
3	Yes	H	Ward Manager
4	Yes	I	Modern Matron
5	Yes	Not specified	Senior Sister/ Ward manager
6	Yes	H	Senior Clinical Nurse
7	Yes	H	Senior Clinical Nurse
8	Yes	I	Senior Nurse/ Service Manager
9	Yes (2)	Not specified	Senior Nurse/ Matron Haematology/ Oncology services Senior Nurse/ Matron BMT services
10	Yes	H	Lead Nurse Paediatric Oncology
11	No	H	No lead nurse, 4 H grades each responsible for different areas
12	No	-	-
13	Yes	H	Oncology Unit Manager
14	Yes	I	Senior Sister
15	Yes	H	Lead Nurse Cancer
16	No	-	-
17	Yes	G/H*	Ward Sister
18	Yes	G	Ward Manager

* new appointment at grade G with opportunity for promotion to H

6.3.2.10.2 Medical staffing

6.3.2.10.2.1 Results are shown in table 37. There were differences in the way the survey forms were completed by different Centres, mostly affecting enumeration of paediatric surgeons and anaesthetists. Some appear to have given WTE figures for those staff dedicated to oncology services, whilst others have counted all those available within the hospital that might be involved in the management of patients. We have reproduced the figures given by each Centre.

6.3.2.10.2.2 Details of the areas covered by associate specialists and staff grades were requested. Where associate specialists were employed (four units), the areas they covered included paediatric oncology, late effects, renal, urology, haematology, dermatology, BMT, covering registrar absence and being Medical Director. The staff grades (four units) were more likely to be employed to cover daytime activities including out-patients and day care and to provide services such as out-patient chemotherapy, lumbar puncture, intrathecal chemotherapy and bone marrow aspiration.

6.3.2.10.2.3 We did not specifically ask about Clinical Fellows. However, Centres 7, 9 and 11 volunteered that they are employed within their units. Their roles ranged from covering registrar leave to supporting BMT and paediatric haematology and oncology services. Centre 14 also distinguished between their research and specialist registrars (two of each).

Table 34: Nurse staffing (In-Patient)

Centre	H grade			G grade			F grade			E grade			D grade			C grade		B grade		A grade	
	Est.	No.	NPB	Est.	No.	NPB	Est.	No.	NPB	Est.	No.	NPB	Est.	No.	NPB	Est.	No.	Est.	No.	Est.	No.
1	-	-	-	1.0	1.0	0.13	3.8	3.8	0.48	8.45	7.45	0.93	3.0	2.0	0.25	-	-	0.8	0.8	0.5	0.5
2	0	0	-	3.3	2.4	0.17	13.1	13.1	0.94	15.1	13.1	0.94	8.28	6.48	0.46	0	0	3.6	3.6	6.26	6.26
3	1.0	1.0	0.08	1.0	1.0	0.08	4.0	5.0	0.42	10.0	8.0	0.67	5.0	4.0	0.33	0	0	1.0	0	0	0
4	-	-	-	2.0	2.0	0.1	13	12.13	0.61	19.0	13.0	0.43	9.0	12.0	0.6	1.0	0	2.0	3.0	3.0	3.0
5	1.0	1.0	0.07	1.0	1.0	0.07	3.92	3.92	0.28	13.55	13.23	0.95	7.49	7.49	0.54	0	0	2.01	2.01	1.67	0
6	1.0	1.0	0.06	1.0	1.0	0.06	5	3.5	0.21	13.2	10.6	0.62	7.88	9.6	0.56	-	-	-	-	-	-
7	1.0	0.6	0.05	1.0	1.0	0.09	6.74	7.1	0.65	11.64	11.41	1.03	8.18	6.19	0.56	-	-	0	0	2.0	2.0
8	0	0	-	2.0	2.0	0.13	7.37	7.13	0.48	16.62	11.6	0.77	4.0	6.0	0.4	0	0	0	0	4.52	2.86
9*	-	1.0	0.07	-	1.0	0.07	-	3.0	0.21	-	7.39	0.53	-	4.52	0.32	-	-	-	-	-	-
10	-	-	-	1.0	1.0	0.1	4.7	2.5	0.25	9.31	8.6	0.86	5.46	3.2	0.32	-	-	0.53	0.53	1.49	1.49
11	1.0	1.0	0.04	2.2	2.0	0.09	4.0	4.12	0.18	27.0	26.0	1.13	4.95	5.74	0.25	1.0*	2.0	1.0*	1.0	3.36	2.97
12	-	-	-	1.5	-	0.13	3.4	-	0.28	7.62	-	0.64	7.8	-	0.65	-	-	-	-	1.0	-
13	1.0	1.0	0.05	1.0	1.0	0.05	6.56	6.48	0.34	13.27	10.9	0.57	10.74	8.75	0.46	1.0	1.0	0	0	2.22	2.0
14	0	0	-	1.0	1.0	0.07	6.0	6.0	0.4	15.32	15.12	1.0	2.0	0.5	0.03	0	0	0	0	1	1
15	0	0	-	1.0	1.0	0.07	4.0	3.1	0.21	15.72	13.07	0.87	2.0	2.0	0.13	0	1.0	0	0	3.58	3.19
16	0	0	-	0	1.0	0.11	4.5	5.0	0.55	9.43	11.0	1.2	1.0	1.0	0.1	0	0	0.53	1.0	3.6	4.0
17	3.0	3.0	0.2	4.0	2.0	0.14	14.0	7.0	0.5	17.0	16.0	1.14	12.0	8.0	0.57	0	0	0	0	0	0
18	1.0	1.0	0.08	1.0	1.0	0.08	4.4	4.4	0.34	6.7	6.7	0.52	2.0	1.0	0.08	-	-	-	-	2.0	1.8

Est. = Establishment
No. = Number in post
NPB = Number per bed
* playworkers and activities co-ordinators (not nurses)

Table 35: Nurse staffing (Day care/out-patient)

Centre	H grade			G grade			F grade			E grade			D grade			C grade		B grade		A grade	
	Est.	No.	NNP	Est.	No.	NNP	Est.	No.	NNP	Est.	No.	NNP	Est.	No.	NNP	Est.	No.	Est.	No.	Est.	No.
1	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
2	0	0	-	0.85	0.85	202	1.7	1.7	101	6.68	5.68	30	0.85	0	-	0	0	0	0	1.7	1.7
3	0	0	-	1.0	1.0	100	1.0	1.0	100	0	0	-	0	0	-	0	0	0	0	0	0
4	1.0	0.8	173	-	-	-	6.0	4.1	34	4.0	4.23	33	0	1.8	77	-	-	2.0	2.0	-	-
5	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**	**
6	1.0	1.0	110	0	0	-	1.2	1.2	92	4.6	4.6	24	-	-	-	-	-	-	-	-	-
7	-	-	-	1.0	1.0	108	0.6	0.6	180	3.4	3.4	32	-	-	-	-	-	1.0	1.0	1.0	1.0
8	-	-	-	0.8	0.8	100	2.2	2.2	36	3.0	3.0	27	2.0	2.0	40	-	-	-	-	1.0	0.8
9	-	-	-	-	1.0	120	-	1.0	120	-	4.6	26	-	1.0	120	-	-	-	-	-	-
10	1.0	1.0	80	-	-	-	1.0	1.0	80	2.13	1.6	50	1.0	0.73	110	1.0	1.0	1.0	1.0	-	-
11	1.0	1.0	122	-	-	-	2.0	2.0	61	3.8	2.7	32	1.6	1.6	76	1.0	1.0	1.0	0	0.8	0.8
12	-	-	-	0.5	-	150	2.4	-	31	2.0	-	38	-	-	-	-	-	0.4	-	-	-
13	0	0	-	0	0	-	1.0	1.0	102	3.0	2.8	27	0	0	-	0.67	0.67	0.32	0.32	2.0	2.0
14	0	0	-	1.0	1.0	145	1.6	1.6	120	4.5	4.5	32	0	0	-	0	0	0	0	1.0	1.0
15	0	0	-	0.93	0.93	161	0.8	0.8	187	3.11	2.71	55	0.8	0.75	200	0	0	0	0	0.47	0.47
16	-	-	-	1.0	1.0	106	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
17	0	0	-	1.0	0	-	2.0	1.0	75	-	-	-	-	-	-	-	-	-	-	-	
18	-	-	-	-	-	-	1.5***	1.5***	67	-	-	-	-	-	-	-	-	-			

Est. = Establishment
No. = Number in post
NNP = Number of New Patients (annually) per staff

* = No dedicated day care unit. Shared with general paediatrics.
** = No separate establishment. Staffed by ward staff (0.8 F grade and 1.33 E grade). Included in in-patient figures
*** = Included in in-patient staffing numbers for Centre 18

Table 36: Other nursing posts

Centre	Nurse Specialists/ Practitioners		Outreach/Liason Team		Research Nurses		Education Posts		Other		
	No.	Grade	No.	Grade	No.	Grade	No.	Grade	Title	No.	Grade
1	-	-	3.0	1G,2H	-	-	0.5	F	-	-	-
2	3.0	2H, 1F	5.0	H	1.6	1G, 0.6F	1.4	0.8G, 0.6F	IV Therapy/ Chemotherapy Team Retinoblastoma Liaison	3.0 2.0	F G
3	1.0	H	1.0	H	-	-	1.0	G	BMT Specialist Nurse Retinoblastoma Specialist Nurse	1.0* 1.0	H H
4	3.0	2G,1H	**	**	1.0	G	1.8	G	PhD Nursing Fellow	1.0	I
5	0.2	G	2.0	H	1.0	G	0	-	-	-	-
6	-	-	3.0	G	0.5	G	1.0	F	-	-	-
7	1.0	G	7.0	G	2.0	G	1.0	F	-	-	-
8	0.6[§]	G	5.0	H	1.0	F	0.8	G	Chemotherapy nurse	1.0	Not specified
9	1.0	H	2.0	1H, 1G	1.0	H	0.6	G	BMT Co-ordinator	1.8	Not specified
10	1.0	G	2.0	1H, 1G	1.0	F***	-	-	-	-	-
11	4.4	1.8H, 1.8G, 0.8E	4.0	1H, 3G	3.4	1.4G, 2F	-	-	-	-	-
12	-	-	2.0	1F, 1G	0.4	F	0.8	G	-	-	-
13	1.6	H	4.5	G,H ¶	1.0	G	-	-	Nurse Consultant	1.0	-
14	1.4	G	3.0	1H,1G,1F	3.0	1G,2F	-	-	Shared Care Co-ordinator BMT Nurse	1.0 0.5	G F
15	0	0	3.8	H	1.4	H	-	-	-	-	-
16	0	0	2.0	G	0	0	0	0	-	-	-
17	4.0	2H,2G	1.0	H	1.5	G/H	3.0	-	CNS (haematology adolescent, central venous catheter care, paediatric/adolescent palliative care, stem cell transplantation)	4.0	G
18	-	-	1.0	H	1.0	G	-	-	-	-	-

No. = Number in post; ¶ Number not specified; * Currently vacant ** Outreach and palliative care are one team; *** Post vacant [§] Chemotherapy nurse

Table 37: Medical staffing (whole time equivalents)

Centre	Paediatric oncologists		Paediatric Haematologists		Paediatric Surgeons			Paediatric Anaesthetists		Associate Specialists		Staff Grades		Specialist Registrars		SHOs	
	No.	NNP	No.	NNP	No.	NNP	Specialties	No.	NNP	No.	NNP	No.	NNP	No.	NNP	No.	NNP
1	1.7	41	1.0	70	4	18	O,W,ENT	6	12	0	-	1	70	1	70	1	70
2	4.4	39	4	43	8	22	Th,G,H,O,U,C	?	-	1	172	0	-	5	34	5	34
3	3.6	28	0.8	125	3.7	27	N,O,GE,U,P, W,ENT,S,C,T	7	14	0	-	0	-	3	33	4	25
4	3.1	45	2.4	58	67.8	2	G,T,P,CT,Ne, R	39.34	4	4.19	33	2	69	4	35	3	46
5	2.4	25	1.8	33	2	30	Not specified	10	6	0	-	0	-	2	30	2	30
6	2.9	38	1	110	3	37	N,O,U,GE	6	18	0	-	1.5	73	2	55	1	110
7	4	27	2	54	5	22	S,H*,Op,CT	10	11	0	-	0	-	2	54	1	108
8	2.2	36	Vacant	-	4	20	O,G,Ne	5	16	0	-	1	80	2.2	36	3	27
9	3	40	1.5	80	1	120	G,Sa,N,Op	0.4	300	1	120	0.4	300	2	60	1	120
10	1.7	47	1	80	5	16	O	6	13	1	80	0	-	1	80	1	80
11	2.5	49	2	61	2	61	G,O	0.3	407	0	-	1	122	4	31	4	31
12	1	75	0.5	150	11	7	G,Ne,Op,ENT	6	13	0	-	1	75	1	75	1	75
13	2	51	1	102	0.6	170	O	18	6	1	102	0	-	1.8	57	1.5	68
14	3.5^	41^	1	145	2	72	G, O	5	29	0	-	1	145	4	36	2	72
15	3	50	3	50	0	-	-	0	-	1	150	1	150	3	50	3	50
16	1.2	88	Vacant	-	3	35	Not specified	5	21	2	53	Not specified	-	1	106	2	53
17	2	38	0	-	1	75	Op, U	0	-	0	-	0	-	1	75	5	15
18	0.7	143	0**	-	0**	-	-	0**	-	0	-	1	100	0	-	1	100
Range (x,y), Mean, Standard deviation	(0.7,4.4), 2.52, 1.07	(17,143), 48.6, 29	(0,4), 1.43, 1.07	(33,150), 82.9, 37.7	(0,11), 3.15, 2.97 note a	(2,175), 55.9, 57.8		(0,18), 5.65, 4.74 note b	(4,407), 62.1, 125.4	(0,4.19), 0.61, 1.07	(33,172), 105, 51.2	(0,2), 0.64, 0.63	(69,300), 118.4, 70.9	(0,5), 2.24, 1.34	(27,106), 51.1, 21.9	(1,5), 2.14, 1.26	(17,120), 62, 32.4

Key: NNP, Number of New Patients (annually) per staff; * Adult surgeon; ** Not available at this site; ^ UK residents; Surgical speciality abbreviations – O Oncology, P Plastic surgery, W Wilms' Tumour surgery, CT Cardiothoracic, ENT Ear, Nose and Throat, Ne Neurosurgery, Th Thoracic, R Renal, G General, Op Orthopaedics, H Hepatobiliary, S Solid tumours, U Urology, GE Gastroenterology, C Cleft, T Trauma and orthopaedic, N Neonatal/foetal, Sa Sarcoma surgery
Note a, extreme value (67.8) excluded; note b, extreme value (39.34) excluded

6.3.2.11 Palliative care

6.3.2.11.1 The Centres were asked about various aspects of their palliative care service for cancer patients. Initially, the number of deaths occurring in 2002 was ascertained, along with the place of death. Table 38 summarises the results. A separate question asked for average deaths over the last five years. However, this information was not always given and when it was, varied in the way it was presented. The results are therefore not included in this report.

6.3.2.11.2 Staffing levels, specifically the presence of a paediatric oncology outreach nurse(s) (POON), were sought. The results by Centre are given in Table 39. Again all staff numbers are in WTE's. Information about the funding of posts was not always given. However, in the majority of Centres (15), most or all of the nursing posts were NHS funded. Three had at least one WTE nurse funded by a charity. Social workers present were largely funded by the Sargent Cancer Fund (eight out of nine Centres). Psychologists were as likely to be NHS funded as funded from other sources (three out of six Centres)

6.3.2.11.3 All Centres have access to at least one children's hospice, with a range of one to three. However, when asked to grade the frequency of use of a paediatric hospice for in-patient, day care or hospice at home, 13 Centres said their patients 'rarely' or 'never' used these services. One unit reported that in-patient and hospice at home was 'sometimes' used, and one unit reported the same frequency of use for in-patient and day care services. Fourteen Centres reported that their patients 'rarely' or 'never' use adult hospice services. The one TCT unit reported that day care and hospice at home services were 'sometimes' used from an adult hospice.

6.3.2.11.4 Seven of the Centres offered 24 hour home visit and telephone advice for those requiring palliative care, although two cite low staff numbers as a cause of strain upon this service. Five provide telephone advice only, with the reasons for this being either or both of large geographical area and low staff numbers. Three Centres reported good local paediatric community support allowing provision of home visits. One Centre gave no reasons and one did not answer the question.

6.3.2.11.5 When asked what changes or additions would allow the provision of a comprehensive 24 hour palliative care service, 11 respondents (10 Centres) identified an increase in number of POON's, 10 respondents clinical psychology time, nine respondents increased social work time, eight respondents a bereavement support worker, 13 respondents more children's community nurses and five respondents a palliative care consultant. One expressed a need for a play therapist in the community.

Table 38: Place of death of patients dying in 2002

Centre	Total deaths	Age 0-14		Age 15-24		Home		Hospice		UKCCSG Centre		District General Hospital		Intensive Care Unit		Other	
		No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
1	18	12	67	6	33	14	78	1	5.5	1	5.5	1	5.5	1	5.5	0	-
2	39	31	79.5	8	20.5	20	51.3	1	2.6	2	5.1	0	-	8	20.5	8*	20.5
3	15	10	67	5	33	6	40	2	13.3	6	40	1	6.7	0	-	0	-
4	33	33	100	0	-	20	60.6	2	6.1	2	6.1	1	3	8	24.2	0	-
5	15	14	93	1	7	5	33	0	-	4	26.7	0	-	5	33	1	6.7
6	24	19	79.2	5	20.8	17	70.8	1	4.2	4	16.7	1	4.2	1	4.2	0	-
7	24	19	79.2	5	20.8	13	54.2	0	-	5	20.8	0	-	6	25	0	-
8	13	10	76.9	3	23.1	7	53.8	1	7.7	2	15.4	5	15.4	1	7.7	0	-
9	32	24	75	8	25	18	56.3	0	-	6	18.8	3	9.4	2	6.3	3	9.4
10	19	14	73.7	5	26.3	14	73.7	0	-	1	5.3	1	5.3	3	15.8	0	-
11	28	28	75.7	0	-	13	46.4	2	7.1	2	7.1	0	-	11	39.3	0	-
12	20	12	60	8	40	9	45	2	10	7	35	0	-	2	10	0	-
13	26	19	73	7	27	13	50	3	11.5	2	7.7	1	3.8	7	27	0	-
14	35	30	86	5	14	21	60	2	5.7	5	14	0	-	6	17	1	3
15	26	20	77	6	23	9	35	4	15.4	5	19.2	0	-	5	19.2	3	11.5
16	8	4	50	4	50	7	87.5	0	-	0	-	0	-	0	-	1	12.5
17	15	2	13	13	87	9	60	1	6.7	3	20	1	6.7	1	6.7	0	-
18	19	4	21.1	15	78.9	7	36.8	1	5.3	7	36.8	1	5.3	2	10.5	1	5.3

* = No details available on place of death

Table 39: Palliative care staffing

Centre	Macmillan Nurse		CLIC Nurse		Other Nurses		Social Worker	Clinical Psychologist	Paediatric Palliative Care Consultant	Adult Palliative Care Consultant
	No.	Grade	No.	Grade	No.	Grade				
1	0	-	2.0	H	1.0	G	1.0	0.1	0	Ad Hoc access
2	5.0	H	0	-	0	-	2.5	0.572	0	0
3	2.0	H	0	-	1.0	Not specified	2.0	0	0	Ad Hoc access
4	0	-	0	-	4.0	1H,2G,1F	0.5	Access available	1.7	0
5	*	*	*	*	*	*	-	-	-	-
6	0	-	1.5	G	1.5	G	0.5	0.1	0	1.0
7	4.0	G	0	-	0	-	4.25	0	0	0
8**	0	-	1.0	H	4.0	H	2.0	0	1.2	0
9	0	-	2.0	1H,1G	0	-	1.8	0	0	0
10	2.0	1H,1G	0	-	0	-	1.0	0	0	0
11	3.8	Not specified	0	-	0	-	4.1	0	0	0
12	1.0	G	0	-	0	-	0	0	0	0
13	5.0	Not specified	1.5	Not specified	1.0	Not specified	2.5	0.2	0.8	0
14	0	-	0	-	3.0	1F,1G,1H	3.0	1.5	0	1+Ad Hoc access
15	3.8	H	1.0	H	0	-	0	0	0	0
16	2.0	G	0	-	0	-	0.5	0	0	0
17	1.0	G	1.0	G	0	-	2.0	0.6	1.0	2.0
18***	0	-	0	-	0	-	2.0	0	0	0

* Palliative care provided by outreach nurses. No additional staff.
** Full time play specialist in team
*** No information given

6.3.2.12 Shared care

6.3.2.12.1 For the purposes of the survey, the following Birmingham Children's Hospital NHS Trust definitions of the levels of service offered by SCC's have been used:[47]

Level 1	Initiate treatment for acute lymphoblastic leukaemia. In-patient and out-patient care for children and young people with cancer following initiation of treatment by UKCCSG Centre. Treatment of febrile neutropenia.
Level 2	In-patient and out-patient care for children and young people with cancer following initiation of treatment by UKCCSG Centre. Treatment of febrile neutropenia.
Level 3	Out-patient care for children and young people with cancer following initiation of treatment by UKCCSG Centre. Treatment of febrile neutropenia.
Level 4	Treatment of febrile neutropenia.

6.3.2.12.2 Respondents were asked to enumerate the number of SCC's attached to their Centre and classify them using the Birmingham definitions as a guide. Respondents were also asked how many of the SCC's were associate members of the UKCCSG. The results are shown in Table 40.

Table 40: Shared care centre utilisation

Centre	Number of SCC's	Number at level 1	Number at level 2	Number at level 3	Number at level 4	Number that are associate members of UKCCSG
1	8	0	0	6	2	2
2	6	3	1	1	1	6
3	7	0	6	1	0	1
4	22	0	22	0	0	Not specified
5	0	-	-	-	-	-
6	14	0	0	14	0	3
7	0	-	-	-	-	-
8	1	0	0	1	0	1
9	9	2	6	0	1	9
10	10	0	0	10	0	4
11	7	0	0	1	3	1
12	0	-	2	-	-	-
13	6	0	0	0	6	0
14	29	1	1	25	2	2
15	0	-	-	-	-	-
16	2	0	0	0	2	0
17	50	Not specified	Not specified	Not specified	Not specified	Not specified
18	0	-	-	-	-	-

6.3.2.13 Family support

All Centres offer residential facilities for parents, but four gave no details of these. Most offer beds next to the patient's bed or on the ward. Parent rooms are often available within the hospital, but these are usually not exclusive to oncology. Six have parent accommodation in a separate facility (one of which is off site). One Centre offers family accommodation that is funded by CLIC. Other sources of funding include Ronald McDonald and Rhys Daniels.

6.3.2.14 Additional services

6.3.2.14.1 In a series of three open questions, Centres were asked about areas that added value to the service they offer, whether non-NHS organisations were involved in offering these or any other services and finally to identify what was lacking from the service they provide. A summary of the responses to these three questions is given in the next four paragraphs.

6.3.2.14.2 Most of the responses highlighted the important role of support groups. Many different types of support group were identified across the 17 Centres, but essentially all fall into one of three distinct groups: for patients, for their parents and for siblings. Bereavement groups also featured regularly. Several Centres reported regular trips, including holidays and activity weekends, for patients and particularly siblings and even friends, as a beneficial feature. Five Centres reported the provision of alternative therapies such as massage and aromatherapy for parents, and one cited the availability of 'Home from Home' accommodation within the hospital grounds for families. Only one Centre cited a clinical service in this section, which was a nurse led line insertion service for those over 10 years of age. Three Centres hold an annual memorial service.

6.3.2.14.3 Funding for the activities detailed in paragraph 6.3.2.14.2 were largely provided by charitable organisations. Many local charities were named but those mentioned as contributors by several Centres were Sargent and CLIC.

6.3.2.14.4 When identifying features lacking from service provision there were several recurring issues. The one mentioned most commonly (10 Centres) was the lack of adequate psychology and psychiatric support and occupational therapy. Similarly, five Centres mentioned the need for greater availability of social workers although one Centre (#7) had 4 wte social workers plus a part-time manager and a part-time administrator. Nurse staffing was also an issue, with seven Centres identifying a need for more ward nurses, four for research nurses and data managers, two for POON's, and one each for a late effects nurse, a bereavement nurse, a palliative care nurse and general community paediatric nurses. 24-hour community support was mentioned by one. Among other staff, individual Centres identified the need for a paediatric palliative care consultant, a paediatric oncologist, a staff grade doctor and out of hours theatre recovery staff. Four Centres highlighted the need for increased clerical support. In relation to allied health services, individual Centres also mentioned the need for increased pharmacy time, electronic prescribing, speech therapy, increased physiotherapy provision and

neuro-rehabilitation services. However, the need for staff type varied significantly between Centres, for example, one Centre (#7) had 7.8 wte dedicated pharmacy support including a specialist pharmacist, a technician and 3.5 wte pharmacists grade D to G.

6.3.2.14.5 Funding was raised as a specific issue by five Centres, particularly in relation to staff training. Availability of counselling services for both families and staff was raised, as well as a long-term bereavement service. The final significant issue for many Centres concerned facilities. Provision of a dedicated oncology ward and increasing the numbers of beds was highlighted, as was the provision of teenage facilities and general improvement of the ward environment. Accommodation for out-patient treatment was mentioned by two Centres and parent accommodation by another two.

6.3.2.15 Comments

Space was left at the end of the questionnaire for respondents to make any additional comments about their service. Many of the same issues were discussed here as in the previous section. However, in addition the issue of patients needing to be managed on outlying wards due to low bed numbers was raised, as was the competition for beds with other specialties within a hospital and consequent difficulty in accepting admissions. The problem of services being offered across several sites was also highlighted. Funding was again discussed in relation to SCC facilities, data managers and psychology support. Finally, the difficulty of filling posts even when funding has been agreed (specifically in relation to 24 hour POON and social workers in the Centres that responded) was mentioned.

7. Conclusions

7.1 Childhood cancer and cancers of young people show a characteristic pattern, and current incidence rates shown in this report are similar to those published from previous studies. Survival is improving which results in an increased prevalence of the diseases in the population. The falling birth rate will result in a change in population demographic profile, with increasing numbers in the older age groups projected to 2011. Since the incidence rate of cancer is higher in the 15-24 age group (214 per million) than the 0-14 age group (134 per million), increased survival and the changing demography are likely to result in increased absolute numbers of incident and prevalent cancer patients aged 15-24 years. These data and trends suggest an increased need for services, both in the short and longer term.

7.2 Valid, reliable and complete data collection is vital for needs assessment, service planning and evaluation. Cancers in all age groups are registered by the network of cancer registries. However, the NRCT additionally and comprehensively registers cancer in children under the age of 15 years, and publishes incidence, mortality, survival and prevalence data for this age group. There is no equivalent dedicated register for the 15-24 year age group.

7.3 The lack of a national data collection system for young people aged 15-24 hampers needs assessment and service planning in these age groups. No prevalence or survival data were available from ONS and mortality data had to be taken from published ONS reports, which reported deaths from cancer rather than deaths in children with cancer (as per the NRCT analysis). The NRCT uses the ICCC classification but the cancer registries, ONS and hospital activity datasets use ICD-10. No nationally agreed translation table exists to convert between ICD and ICCC, which hampers direct comparison between datasets. However, as a pilot exercise, ONS converted incidence data collated from the cancer registries to ICCC for comparison with the NRCT analysis for 0-14 age groups. Coding of cancers in the 15-24 age groups is complicated since neither ICD nor ICCC is a good classification for the cancers that present in this age group. This is likely to present continuing difficulties for needs assessment, particularly in view of the likely trends of increased numbers of new and prevalent patients in the older age groups.

7.5 Hospital activity datasets are improving in quality, and their use in describing and monitoring service activity is recognised. Data presented in this report have shown variation in activity across England and Wales, by age group, year, strategic health authority and NHS Trust. Interpretation is always hampered by consideration of data quality, but the data give a feel for the volume of activity being undertaken in England and Wales.

7.6 The absence of a system of national data collection for palliative care service activity is also a disadvantage for needs assessment, planning and evaluation of cancer services for children.

7.7 The analysis of service provision suggests wide variation in service activity but many common themes in terms of service delivery.

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9. Glossary

(Unless otherwise specified, the following definitions have been compiled with reference to Last's Dictionary of Epidemiology[46])

Actuarial survival rate - An actuarial rate is a theoretical measure of the risk of an event occurring at a point in time. Actuarial survival rate is a measure of the probability (or risk) of remaining alive at a specific point in time.

Age-specific rate - This is the rate of a particular disease for a specific age group. It is calculated by dividing the number of cases occurring within a defined time and age group by the population at risk in that age group. Due to the relatively small numbers of cases of childhood and adolescent cancer, such rates are conventionally multiplied by one million to produce rates per million person-years.

Age-standardised rate (ASR) – Age standardisation is a method for adjusting rates to allow for differences in the age structure of the underlying population. For example, if you have a population with a very large number of children aged 0-4 years of age, you would expect to have more cases of retinoblastoma than a population that had very few children in this age group. Therefore, a high rate of disease in the first population might be wholly explained by its different age structure rather than an underlying difference in the risk of retinoblastoma. This potential bias is overcome by age standardisation. Several methods exist, but in this needs assessment, the direct method of standardisation to the world population has been applied. To calculate the ASR for those aged 0-14 years, each of the age- specific rates is applied to the world standard population using the formula below. This produces a rate of disease (per million person-years) that can be compared with any other rate, which has been similarly adjusted. Thus comparison of rates is possible between different countries or regions without bias from differing population age structures.

$$ASR_{(0\text{-}14)} = [(r_1 x 12)+(r_2 x 10)+(r_3 x 9)]/31$$

Where: r_1 = Age-specific rate for ages 0-4
r_2 = Age-specific rate for ages 5-9
r_3 = Age-specific rate for ages 10-14
(Source: Parkin *et.al.*[11])

Confidence interval – This is a computed interval that indicates how likely it is that the true, but unknown, population value of a variable (in this report, a rate or percentage survival) lies within that interval. All confidence intervals in this report are 95% confidence intervals. This means that there is a 95% probability that the true population value lies within the interval quoted.

Crude rate – This is calculated by dividing the total number of cases by the total population at risk. It is expressed per million person-years.

Cryptorchidism – Undescended testis.

Cumulative rate – The cumulative rate is the sum over each year of age of the age-specific incidence rates. It is equivalent to an age-standardised rate where each age-specific rate is given the same weight. It is an approximation to the cumulative risk for an individual developing the specific cancer before age 14 or age 24, depending on the table in question.

Five-year survival rate – This is the proportion of a defined group that survive five years from diagnosis. In this needs assessment, survival data are given as percentages.

Incidence rate – the rate at which new events occur within a given population during a defined time. For example, the leukaemia incidence rate for 0-14 is the number of new diagnoses of leukaemia in the population of 0-14 year olds in one year. It is calculated using the formula below, being conventionally expressed per million population at risk.

$$\text{Incidence rate} = \frac{\text{Number of new events in specified period}}{\text{Population at risk in this period}} \times 1{,}000{,}000$$

Mortality rate –In this needs assessment the crude mortality rate is calculated using the following formula:

$$\text{Mortality rate} = \frac{\text{Number of deaths in specified period}}{\text{Population at risk in this period}} \times 1{,}000{,}000$$

Point prevalence rate – A point prevalence is the number of persons with a specified disease at a certain point in time. A point prevalence rate is this figure divided by the population at risk of having the disease at that point in time.

World Standard Population – the world standard population for those aged 0-24 years is summarised in the table below.

Age Group	**World Standard Population**
0-4	12,000
5-9	10,000
10-14	9,000
15-19	9,000
20-24	8,000
Total	48,000

Source: Accessed at http://www-dep.iarc.fr/dataava/ewstdpop.htm

Appendices

Appendix 1: NRCT Incidence data for the 0-14 age group

INCIDENT CASES 1988-1997

	NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION							
	0-4	5-9	10-14	All	*M/F*	Overall	Group	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	2227	1059	731	**4017**	1.3	31.6%	100.0%	66.3	32.3	23.6	41.3	**42.9**	41.6	44.3	611
Acute lymphoid leukaemia (ALL)	1840	881	504	**3225**	1.3	25.4%	80.3%	54.8	26.8	16.3	33.1	**34.6**	33.4	35.8	490
Acute non-lymphocytic leukaemia (ANLL)	304	147	178	**629**	1.2	4.9%	15.7%	9.1	4.5	5.7	6.5	**6.6**	6.1	7.1	96
Chronic myeloid leukaemia (CML)	50	19	28	**97**	1.9	0.8%	2.4%	1.5	0.6	0.9	1.0	**1.0**	0.8	1.2	15
Other specified leukaemia	5	2	6	**13**	0.6	0.1%	0.3%	0.1	0.1	0.2	0.1	**0.1**	0.1	0.2	2
Unspecified leukaemia	28	10	15	**53**	1.3	0.4%	1.3%	0.8	0.3	0.5	0.5	**0.6**	0.4	0.7	8
II LYMPHOMAS	223	410	572	**1205**	2.2	9.5%	100.0%	6.6	12.5	18.5	12.4	**12.0**	11.3	12.6	188
Hodgkins disease	32	143	305	**480**	2.0	3.8%	39.8%	1.0	4.4	9.9	4.9	**4.6**	4.2	5.0	76
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	181	257	253	**691**	2.3	5.4%	57.3%	5.4	7.8	8.2	7.1	**7.0**	6.5	7.5	107
Unspecified lymphoma	4	3	3	**10**	9.0	0.1%	0.8%	0.1	0.1	0.1	0.1	**0.1**	0.0	0.2	2
Miscellaneous reticulo-endothelial neoplasm	6	7	11	**24**	5.0	0.2%	2.0%	0.2	0.2	0.4	0.2	**0.2**	0.1	0.3	4
III BRAIN AND SPINAL NEOPLASMS	1116	1112	815	**3043**	1.1	23.9%	100.0%	33.2	33.9	26.3	31.3	**31.4**	30.3	32.6	467
Ependymoma and Choroid Plexus	172	73	56	**301**	1.3	2.4%	9.9%	5.1	2.2	1.8	3.1	**3.2**	2.9	3.6	46
Astrocytoma	458	468	361	**1287**	1.0	10.1%	42.3%	13.6	14.3	11.7	13.2	**13.3**	12.5	14.0	198
Primitive neuroectodermal tumour (PNET)	239	238	115	**592**	1.6	4.7%	19.5%	7.1	7.2	3.7	6.1	**6.2**	5.7	6.7	90
Other glioma	105	163	103	**371**	1.0	2.9%	12.2%	3.1	5.0	3.3	3.8	**3.8**	3.4	4.2	57
Other specified central nervous system (CNS) tumour	75	120	129	**324**	1.3	2.5%	10.6%	2.2	3.7	4.2	3.3	**3.3**	2.9	3.6	50
Unspecified central nervous system (CNS) tumour	67	50	51	**168**	1.0	1.3%	5.5%	2.0	1.5	1.6	1.7	**1.7**	1.5	2.0	26
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	715	116	20	**851**	1.2	6.7%	100.0%	21.3	3.5	0.6	8.7	**9.6**	8.9	10.2	127
Neuroblastoma	709	111	18	**838**	1.2	6.6%	98.5%	21.1	3.4	0.6	8.6	**9.4**	8.8	10.1	125
Other sympathetic nervous system (SNS) tumour	6	5	2	**13**	0.9	0.1%	1.5%	0.2	0.2	0.1	0.1	**0.1**	0.1	0.2	2
V RETINOBLASTOMA	381	19	2	**402**	1.0	3.2%	100.0%	11.3	0.6	0.1	4.1	**4.6**	4.1	5.0	60
VI RENAL TUMOURS	572	124	37	**733**	1.0	5.8%	100.0%	17.0	3.8	1.2	7.5	**8.2**	7.6	8.8	110
Wilms' tumour etc.	569	120	23	**712**	1.0	5.6%	97.1%	16.9	3.7	0.7	7.3	**8.0**	7.4	8.5	107
Renal carcinoma	1	3	14	**18**	1.3	0.1%	2.5%	0.0	0.1	0.5	0.2	**0.2**	0.1	0.3	3
Other renal	2	1	0	**3**	*	0.0%	0.4%	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
VII HEPATIC TUMOURS	86	14	16	**116**	1.8	0.9%	100.0%	2.6	0.4	0.5	1.2	**1.3**	1.0	1.5	18
Hepatoblastoma	82	5	6	**93**	1.8	0.7%	80.2%	2.4	0.2	0.2	1.0	**1.1**	0.8	1.3	14
Hepatic carcinoma	4	9	10	**23**	1.9	0.2%	19.8%	0.1	0.3	0.3	0.2	**0.2**	0.1	0.3	4

INCIDENT CASES 1988-1997
Continued

	NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION							
	0-4	**5-9**	**10-14**	**All**	***M/F***	**Overall**	**Group**	**0-4**	**5-9**	**10-14**	**Crude**	**ASR**	***LCL***	***UCL***	***Cum.***
VIII MALIGNANT BONE TUMOURS	25	135	360	**520**	1.0	4.1%	100.0%	0.7	4.1	11.6	5.3	**5.0**	4.6	5.4	82
Osteosarcoma	4	81	207	**292**	1.0	2.3%	56.2%	0.1	2.5	6.7	3.0	**2.8**	2.5	3.1	46
Chondrosarcoma	1	2	9	**12**	2.0	0.1%	2.3%	0.0	0.1	0.3	0.1	**0.1**	0.1	0.2	2
Ewing's sarcoma	17	48	127	**192**	1.2	1.5%	36.9%	0.5	1.5	4.1	2.0	**1.9**	1.6	2.1	30
Other specified bone tumour	1	1	11	**13**	0.4	0.1%	2.5%	0.0	0.0	0.4	0.1	**0.1**	0.1	0.2	2
Unspecified bone tumour	2	3	6	**11**	0.6	0.1%	2.1%	0.1	0.1	0.2	0.1	**0.1**	0.0	0.2	2
IX SOFT TISSUE SARCOMAS	418	259	253	**930**	1.3	7.3%	100.0%	12.4	7.9	8.2	9.6	**9.7**	9.1	10.4	143
Rhabdomyosarcoma	287	154	74	**515**	1.5	4.1%	55.4%	8.5	4.7	2.4	5.3	**5.5**	5.0	6.0	78
Fibrosarcoma etc.	30	25	47	**102**	0.9	0.8%	11.0%	0.9	0.8	1.5	1.0	**1.0**	0.8	1.2	16
Karposi's sarcoma	0	3	1	**4**	1.0	0.0%	0.4%	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	1
Other specified soft tissue sarcoma	80	61	105	**246**	1.0	1.9%	26.5%	2.4	1.9	3.4	2.5	**2.5**	2.2	2.8	38
Unspecified soft tissue sarcoma	21	16	26	**63**	1.4	0.5%	6.8%	0.6	0.5	0.8	0.6	**0.6**	0.5	0.8	10
X GERM CELL AND GONADAL NEOPLASMS	186	68	154	**408**	0.8	3.2%	100.0%	5.5	2.1	5.0	4.2	**4.3**	3.8	4.7	63
Intracranial and intraspinal (CNS) germ cell	27	35	59	**121**	1.2	1.0%	29.7%	0.8	1.1	1.9	1.2	**1.2**	1.0	1.4	19
Other non-gonadal germ cell	86	4	6	**96**	0.3	0.8%	23.5%	2.6	0.1	0.2	1.0	**1.1**	0.9	1.3	14
Gonadal germ cell	71	26	79	**176**	1.0	1.4%	43.1%	2.1	0.8	2.6	1.8	**1.8**	1.5	2.1	27
Gonadal carcinoma	0	3	10	**13**	0.2	0.1%	3.2%	0.0	0.1	0.3	0.1	**0.1**	0.1	0.2	2
Other gonadal	2	0	0	**2**	1.0	0.0%	0.5%	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	38	80	286	**404**	0.8	3.2%	100.0%	1.1	2.4	9.2	4.1	**3.9**	3.5	4.3	64
Adrenocortical carcinoma	5	4	5	**14**	0.2	0.1%	3.5%	0.1	0.1	0.2	0.1	**0.1**	0.1	0.2	2
Thyroid carcinoma	2	9	38	**49**	0.5	0.4%	12.1%	0.1	0.3	1.2	0.5	**0.5**	0.3	0.6	8
Nasopharyngeal carcinoma	0	3	20	**23**	2.3	0.2%	5.7%	0.0	0.1	0.6	0.2	**0.2**	0.1	0.3	4
Melanoma	24	34	78	**136**	0.7	1.1%	33.7%	0.7	1.0	2.5	1.4	**1.3**	1.1	1.6	21
Skin carcinoma	4	12	40	**56**	0.9	0.4%	13.9%	0.1	0.4	1.3	0.6	**0.5**	0.4	0.7	9
Other carcinoma	3	18	105	**126**	1.0	1.0%	31.2%	0.1	0.5	3.4	1.3	**1.2**	1.0	1.4	20
XII OTHER AND UNSPECIFIED NEOPLASMS	39	21	23	**83**	0.6	0.7%	100.0%	1.2	0.6	0.7	0.9	**0.9**	0.7	1.1	13
Other specified malignant	6	4	3	**13**	0.4	0.1%	15.7%	0.2	0.1	0.1	0.1	**0.1**	0.1	0.2	2
Other unspecified malignant	33	17	20	**70**	0.6	0.6%	84.3%	1.0	0.5	0.6	0.7	**0.7**	0.6	0.9	11
MALIGNANT TOTAL	6026	3417	3269	**12712**	1.2	100.0%		179.4	104.1	105.6	130.6	**133.7**	131.4	136.0	1946
NON-MALIGNANT CONDITIONS	212	66	42	**320**	1.4		100.0%	6.3	2.0	1.4	3.3	**3.5**	3.1	3.9	48
Langerhans Cell Histiocytosis	177	56	36	**269**	1.4		84.1%	5.3	1.7	1.2	2.8	**2.9**	2.6	3.3	41
Fibromatosis	35	10	6	**51**	1.6		15.9%	1.0	0.3	0.2	0.5	**0.6**	0.4	0.7	8
OVERALL TOTAL	6238	3483	3311	**13032**	1.2			185.7	106.1	107.0	133.8	**137.2**	134.8	139.5	1994

INCIDENT CASES 1988-1997	FEMALE											
	NUMBER OF CASES				RATES PER MILLION							
	F 0-4	F 5-9	F 10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	993	454	307	**1754**	60.5	28.3	20.3	36.9	**38.4**	36.6	40.3	546
Acute lymphoid leukaemia (ALL)	817	377	207	**1401**	49.8	23.5	13.7	29.4	**30.8**	29.2	32.4	435
Acute non-lymphocytic leukaemia (ANLL)	142	64	82	**288**	8.7	4.0	5.4	6.1	**6.2**	5.5	6.9	90
Chronic myeloid leukaemia (CML)	17	5	12	**34**	1.0	0.3	0.8	0.7	**0.7**	0.5	1.0	11
Other specified leukaemia	5	1	2	**8**	0.3	0.1	0.1	0.2	**0.2**	0.1	0.3	2
Unspecified leukaemia	12	7	4	**23**	0.7	0.4	0.3	0.5	**0.5**	0.3	0.7	7
II LYMPHOMAS	67	110	194	**371**	4.1	6.9	12.8	7.8	**7.5**	6.7	8.3	119
Hodgkins disease	5	40	114	**159**	0.3	2.5	7.5	3.3	**3.1**	2.6	3.6	52
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	60	67	80	**207**	3.7	4.2	5.3	4.3	**4.3**	3.7	4.9	66
Unspecified lymphoma	0	1	0	**1**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	0
Miscellaneous reticulo-endothelial neoplasm	2	2	0	**4**	0.1	0.1	0.0	0.1	**0.1**	0.0	0.2	1
III BRAIN AND SPINAL NEOPLASMS	527	511	384	**1422**	32.1	31.8	25.4	29.9	**30.1**	28.5	31.6	447
Ependymoma and Choroid Plexus	64	31	34	**129**	3.9	1.9	2.2	2.7	**2.8**	2.3	3.3	40
Astrocytoma	232	235	185	**652**	14.1	14.6	12.2	13.7	**13.7**	12.7	14.8	205
Primitive neuroectodermal tumour (PNET)	105	93	31	**229**	6.4	5.8	2.0	4.8	**4.9**	4.3	5.6	71
Other glioma	55	75	57	**187**	3.4	4.7	3.8	3.9	**3.9**	3.3	4.5	59
Other specified central nervous system (CNS) tumour	38	49	56	**143**	2.3	3.1	3.7	3.0	**3.0**	2.5	3.4	45
Unspecified central nervous system (CNS) tumour	33	28	21	**82**	2.0	1.7	1.4	1.7	**1.7**	1.4	2.1	26
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	327	51	9	**387**	19.9	3.2	0.6	8.1	**8.9**	8.0	9.8	119
Neuroblastoma	322	49	9	**380**	19.6	3.1	0.6	8.0	**8.8**	7.9	9.6	116
Other sympathetic nervous system (SNS) tumour	5	2	0	**7**	0.3	0.1	0.0	0.1	**0.2**	0.0	0.3	2
V RETINOBLASTOMA	189	8	0	**197**	11.5	0.5	0.0	4.1	**4.6**	4.0	5.3	60
VI RENAL TUMOURS	279	62	22	**363**	17.0	3.9	1.5	7.6	**8.3**	7.4	9.1	112
Wilms' tumour etc.	279	61	15	**355**	17.0	3.8	1.0	7.5	**8.1**	7.3	8.9	109
Renal carcinoma	0	1	7	**8**	0.0	0.1	0.5	0.2	**0.2**	0.0	0.3	3
Other renal	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
VII HEPATIC TUMOURS	30	6	5	**41**	1.8	0.4	0.3	0.9	**0.9**	0.6	1.2	13
Hepatoblastoma	30	2	1	**33**	1.8	0.1	0.1	0.7	**0.8**	0.5	1.0	10
Hepatic carcinoma	0	4	4	**8**	0.0	0.2	0.3	0.2	**0.2**	0.0	0.3	3

INCIDENT CASES 1988-1997 *Continued*	FEMALE											
	NUMBER OF CASES				RATES PER MILLION							
	F 0-4	F 5-9	F 10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	15	64	177	**256**	0.9	4.0	11.7	5.4	**5.0**	4.4	5.7	83
Osteosarcoma	2	43	102	**147**	0.1	2.7	6.7	3.1	**2.9**	2.4	3.3	48
Chondrosarcoma	1	1	2	**4**	0.1	0.1	0.1	0.1	**0.1**	0.0	0.2	1
Ewing's sarcoma	10	17	62	**89**	0.6	1.1	4.1	1.9	**1.8**	1.4	2.1	29
Other specified bone tumour	1	1	7	**9**	0.1	0.1	0.5	0.2	**0.2**	0.1	0.3	3
Unspecified bone tumour	1	2	4	**7**	0.1	0.1	0.3	0.1	**0.1**	0.0	0.2	2
IX SOFT TISSUE SARCOMAS	176	117	118	**411**	10.7	7.3	7.8	8.6	**8.8**	7.9	9.6	129
Rhabdomyosarcoma	109	63	35	**207**	6.6	3.9	2.3	4.3	**4.5**	3.9	5.1	64
Fibrosarcoma etc.	14	12	27	**53**	0.9	0.7	1.8	1.1	**1.1**	0.8	1.4	17
Karposi's sarcoma	0	2	0	**2**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	1
Other specified soft tissue sarcoma	42	31	50	**123**	2.6	1.9	3.3	2.6	**2.6**	2.1	3.0	39
Unspecified soft tissue sarcoma	11	9	6	**26**	0.7	0.6	0.4	0.5	**0.6**	0.3	0.8	8
X GERM CELL AND GONADAL NEOPLASMS	91	45	94	**230**	5.5	2.8	6.2	4.8	**4.9**	4.2	5.5	73
Intracranial and intraspinal (CNS) germ cell	18	15	22	**55**	1.1	0.9	1.5	1.2	**1.1**	0.8	1.5	17
Other non-gonadal germ cell	67	3	5	**75**	4.1	0.2	0.3	1.6	**1.7**	1.3	2.1	23
Gonadal germ cell	5	25	58	**88**	0.3	1.6	3.8	1.8	**1.7**	1.4	2.1	28
Gonadal carcinoma	0	2	9	**11**	0.0	0.1	0.6	0.2	**0.2**	0.1	0.3	4
Other gonadal	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	26	40	156	**222**	1.6	2.5	10.3	4.7	**4.4**	3.8	5.0	72
Adrenocortical carcinoma	3	4	5	**12**	0.2	0.2	0.3	0.3	**0.2**	0.1	0.4	4
Thyroid carcinoma	1	3	28	**32**	0.1	0.2	1.8	0.7	**0.6**	0.4	0.8	10
Nasopharyngeal carcinoma	0	0	7	**7**	0.0	0.0	0.5	0.1	**0.1**	0.0	0.2	2
Melanoma	18	17	43	**78**	1.1	1.1	2.8	1.6	**1.6**	1.2	1.9	25
Skin carcinoma	3	7	20	**30**	0.2	0.4	1.3	0.6	**0.6**	0.4	0.8	10
Other carcinoma	1	9	53	**63**	0.1	0.6	3.5	1.3	**1.2**	0.9	1.5	21
XII OTHER AND UNSPECIFIED NEOPLASMS	28	8	16	**52**	1.7	0.5	1.1	1.1	**1.1**	0.8	1.4	16
Other specified malignant	5	2	2	**9**	0.3	0.1	0.1	0.2	**0.2**	0.1	0.3	3
Other unspecified malignant	23	6	14	**43**	1.4	0.4	0.9	0.9	**0.9**	0.7	1.2	14
MALIGNANT TOTAL	2748	1476	1482	**5706**	167.5	92.0	97.9	119.9	**122.9**	119.7	126.1	1787
NON-MALIGNANT CONDITIONS	88	28	15	**131**	5.4	1.7	1.0	2.8	**2.9**	2.4	3.4	40
Langerhans Cell Histiocytosis	79	22	10	**111**	4.8	1.4	0.7	2.3	**2.5**	2.0	3.0	34
Fibromatosis	9	6	5	**20**	0.5	0.4	0.3	0.4	**0.4**	0.2	0.6	6
OVERALL TOTAL	2836	1504	1497	**5837**	172.9	93.7	98.9	122.7	**125.9**	122.6	129.1	1827

INCIDENT CASES 1988-1997	MALE											
	NUMBER CASES				RATES PER MILLION							
	M 0-4	M 5-9	M 10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	1234	605	424	**2263**	71.8	36.0	26.8	45.5	**47.2**	45.3	49.2	673
Acute lymphoid leukaemia (ALL)	1023	504	297	**1824**	59.5	30.0	18.8	36.6	**38.2**	36.4	39.9	542
Acute non-lymphocytic leukaemia (ANLL)	162	83	96	**341**	9.4	4.9	6.1	6.8	**7.0**	6.3	7.8	102
Chronic myeloid leukaemia (CML)	33	14	16	**63**	1.9	0.8	1.0	1.3	**1.3**	1.0	1.6	19
Other specified leukaemia	0	1	4	**5**	0.0	0.1	0.3	0.1	**0.1**	0.0	0.2	2
Unspecified leukaemia	16	3	11	**30**	0.9	0.2	0.7	0.6	**0.6**	0.4	0.8	9
II LYMPHOMAS	156	300	378	**834**	9.1	17.9	23.9	16.8	**16.2**	15.1	17.3	254
Hodgkins disease	27	103	191	**321**	1.6	6.1	12.1	6.4	**6.1**	5.4	6.8	99
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	121	190	173	**484**	7.0	11.3	10.9	9.7	**9.6**	8.7	10.4	146
Unspecified lymphoma	4	2	3	**9**	0.2	0.1	0.2	0.2	**0.2**	0.1	0.3	3
Miscellaneous reticulo-endothelial neoplasm	4	5	11	**20**	0.2	0.3	0.7	0.4	**0.4**	0.2	0.6	6
III BRAIN AND SPINAL NEOPLASMS	589	601	431	**1621**	34.3	35.8	27.2	32.6	**32.7**	31.1	34.3	487
Ependymoma and Choroid Plexus	108	42	22	**172**	6.3	2.5	1.4	3.5	**3.6**	3.1	4.2	51
Astrocytoma	226	233	176	**635**	13.2	13.9	11.1	12.8	**12.8**	11.8	13.8	191
Primitive neuroectodermal tumour (PNET)	134	145	84	**363**	7.8	8.6	5.3	7.3	**7.3**	6.6	8.1	109
Other glioma	50	88	46	**184**	2.9	5.2	2.9	3.7	**3.7**	3.1	4.2	55
Other specified central nervous system (CNS) tumour	37	71	73	**181**	2.2	4.2	4.6	3.6	**3.5**	3.0	4.1	55
Unspecified central nervous system (CNS) tumour	34	22	30	**86**	2.0	1.3	1.9	1.7	**1.7**	1.4	2.1	26
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	388	65	11	**464**	22.6	3.9	0.7	9.3	**10.2**	9.3	11.1	136
Neuroblastoma	387	62	9	**458**	22.5	3.7	0.6	9.2	**10.1**	9.2	11.0	134
Other sympathetic nervous system (SNS) tumour	1	3	2	**6**	0.1	0.2	0.1	0.1	**0.1**	0.0	0.2	2
V RETINOBLASTOMA	192	11	2	**205**	11.2	0.7	0.1	4.1	**4.6**	3.9	5.2	60
VI RENAL TUMOURS	293	62	15	**370**	17.1	3.7	0.9	7.4	**8.1**	7.2	8.9	108
Wilms' tumour etc.	290	59	8	**357**	16.9	3.5	0.5	7.2	**7.8**	7.0	8.6	105
Renal carcinoma	1	2	7	**10**	0.1	0.1	0.4	0.2	**0.2**	0.1	0.3	3
Other renal	2	1	0	**3**	0.1	0.1	0.0	0.1	**0.1**	0.0	0.1	1
VII HEPATIC TUMOURS	56	8	11	**75**	3.3	0.5	0.7	1.5	**1.6**	1.3	2.0	22
Hepatoblastoma	52	3	5	**60**	3.0	0.2	0.3	1.2	**1.3**	1.0	1.7	18
Hepatic carcinoma	4	5	6	**15**	0.2	0.3	0.4	0.3	**0.3**	0.1	0.4	5

INCIDENT CASES 1988-1997 *Continued*	MALE											
	NUMBER CASES				RATES PER MILLION							
	M 0-4	M 5-9	M 10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	10	71	183	**264**	0.6	4.2	11.6	5.3	**4.9**	4.4	5.5	82
Osteosarcoma	2	38	105	**145**	0.1	2.3	6.6	2.9	**2.7**	2.3	3.1	45
Chondrosarcoma	0	1	7	**8**	0.0	0.1	0.4	0.2	**0.1**	0.0	0.3	3
Ewing's sarcoma	7	31	65	**103**	0.4	1.8	4.1	2.1	**1.9**	1.6	2.3	32
Other specified bone tumour	0	0	4	**4**	0.0	0.0	0.3	0.1	**0.1**	0.0	0.1	1
Unspecified bone tumour	1	1	2	**4**	0.1	0.1	0.1	0.1	**0.1**	0.0	0.2	1
IX SOFT TISSUE SARCOMAS	242	142	135	**519**	14.1	8.5	8.5	10.4	**10.7**	9.7	11.6	155
Rhabdomyosarcoma	178	91	39	**308**	10.4	5.4	2.5	6.2	**6.5**	5.7	7.2	91
Fibrosarcoma etc.	16	13	20	**49**	0.9	0.8	1.3	1.0	**1.0**	0.7	1.3	15
Karposi's sarcoma	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
Other specified soft tissue sarcoma	38	30	55	**123**	2.2	1.8	3.5	2.5	**2.4**	2.0	2.9	37
Unspecified soft tissue sarcoma	10	7	20	**37**	0.6	0.4	1.3	0.7	**0.7**	0.5	1.0	11
X GERM CELL AND GONADAL NEOPLASMS	95	23	60	**178**	5.5	1.4	3.8	3.6	**3.7**	3.1	4.2	53
Intracranial and intraspinal (CNS) germ cell	9	20	37	**66**	0.5	1.2	2.3	1.3	**1.3**	1.0	1.6	20
Other non-gonadal germ cell	19	1	1	**21**	1.1	0.1	0.1	0.4	**0.5**	0.3	0.7	6
Gonadal germ cell	66	1	21	**88**	3.8	0.1	1.3	1.8	**1.9**	1.5	2.3	26
Gonadal carcinoma	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
Other gonadal	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	12	40	130	**182**	0.7	2.4	8.2	3.7	**3.4**	2.9	3.9	56
Adrenocortical carcinoma	2	0	0	**2**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	1
Thyroid carcinoma	1	6	10	**17**	0.1	0.4	0.6	0.3	**0.3**	0.2	0.5	5
Nasopharyngeal carcinoma	0	3	13	**16**	0.0	0.2	0.8	0.3	**0.3**	0.2	0.4	5
Melanoma	6	17	35	**58**	0.3	1.0	2.2	1.2	**1.1**	0.8	1.4	18
Skin carcinoma	1	5	20	**26**	0.1	0.3	1.3	0.5	**0.5**	0.3	0.7	8
Other carcinoma	2	9	52	**63**	0.1	0.5	3.3	1.3	**1.2**	0.9	1.5	20
XII OTHER AND UNSPECIFIED NEOPLASMS	11	13	7	**31**	0.6	0.8	0.4	0.6	**0.6**	0.4	0.8	9
Other specified malignant	1	2	1	**4**	0.1	0.1	0.1	0.1	**0.1**	0.0	0.2	1
Other unspecified malignant	10	11	6	**27**	0.6	0.7	0.4	0.5	**0.5**	0.3	0.8	8
MALIGNANT TOTAL	3278	1941	1787	**7006**	190.8	115.7	113.0	140.7	**144.0**	140.6	147.3	2097
NON-MALIGNANT CONDITIONS	124	38	27	**189**	7.2	2.3	1.7	3.8	**4.0**	3.4	4.6	56
Langerhans Cell Histiocytosis	98	34	26	**158**	5.7	2.0	1.6	3.2	**3.3**	2.8	3.9	47
Fibromatosis	26	4	1	**31**	1.5	0.2	0.1	0.6	**0.7**	0.4	0.9	9
OVERALL TOTAL	3402	1979	1814	**7195**	198.0	117.9	114.7	144.5	**148.0**	144.5	151.4	2153

Appendix 2: NCIC Incidence data for the 15-24 age group

INCIDENCE (1988-1997) 15-24 years

	NUMBER OF CASES				RELATIVE FREQUENCY (%)		RATES PER MILLION						
	15-19	20-24	All	M/F	Overall	Group	15-19	20-24	Crude	ASR	LCL	UCL	Cum.
I LEUKAEMIA	768	726	1494	1.5	9.8%	100.0%	24.0	19.7	21.7	22.0	20.8	23.1	218
Acute Lymphoid Leukaemia (ALL)	428	247	675	2.2	4.4%	45.2%	13.4	6.7	9.8	10.2	9.5	11.0	100
Acute non-lymphocytic leukaemia (ANLL)	248	338	586	1.2	3.9%	39.2%	7.8	9.2	8.5	8.4	7.7	9.1	85
Chronic myeloid leukaemia (CML)	50	89	139	1.6	0.9%	9.3%	1.6	2.4	2.0	2.0	1.6	2.3	20
Other specified leukaemia	16	21	37	0.8	0.2%	2.5%	0.5	0.6	0.5	0.5	0.4	0.7	5
Unspecified leukaemia	26	31	57	0.7	0.4%	3.8%	0.8	0.8	0.8	0.8	0.6	1.0	8
II LYMPHOMAS	1300	2213	3513	1.3	23.1%	100.0%	40.6	59.9	51.0	49.7	48.1	51.4	503
Hodgkins disease	868	1564	2432	1.0	16.0%	69.2%	27.1	42.4	35.3	34.3	32.9	35.7	347
Non-hodgkin lymphoma (NHL) and Burkitt's lymphoma	397	596	993	2.1	6.5%	28.3%	12.4	16.1	14.4	14.2	13.3	15.1	143
Unspecified lymphoma	27	33	60	1.1	0.4%	1.7%	0.8	0.9	0.9	0.9	0.6	1.1	9
Miscellaneous lymphoreticular neoplasms	8	20	28	1.5	0.2%	0.8%	0.3	0.5	0.4	0.4	0.2	0.5	4
III BRAIN AND SPINAL NEOPLASMS	671	887	1558	1.3	10.2%	100.0%	21.0	24.0	22.6	22.4	21.3	23.5	225
Ependymoma	48	61	109	1.1	0.7%	7.0%	1.5	1.7	1.6	1.6	1.3	1.9	16
Astrocytoma	289	378	667	1.3	4.4%	42.8%	9.0	10.2	9.7	9.6	8.9	10.3	96
Primitive neuroectodermal tumours (PNET)	53	65	118	1.8	0.8%	7.6%	1.7	1.8	1.7	1.7	1.4	2.0	17
Other gliomas	88	142	230	1.5	1.5%	14.8%	2.8	3.8	3.3	3.3	2.8	3.7	33
Miscellaneous intracranial & intraspinal (CNS) neoplasms	114	153	267	0.9	1.8%	17.1%	3.6	4.1	3.9	3.8	3.4	4.3	39
Unspecified intracranial & intraspinal (CNS) neoplasms	70	83	153	1.6	1.0%	9.8%	2.2	2.2	2.2	2.2	1.9	2.6	22
9060-9102 Benign Brain	9	5	14	0.8	0.1%	0.9%	0.3	0.1	0.2	0.2	0.1	0.3	2
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	24	46	70	1.3	0.5%	100.0%	0.8	1.2	1.0	1.0	0.8	1.2	10
Neuroblastoma and ganglioneuroblastoma	15	13	28	1.0	0.2%	40.0%	0.5	0.4	0.4	0.4	0.3	0.6	4
Other sympathetic nervous system (SNS) tumours	9	33	42	1.5	0.3%	60.0%	0.3	0.9	0.6	0.6	0.4	0.7	6
V RETINOBLASTOMA	0	1	1	0.0	0.0%	100.0%	0.0	0.0	0.0	0.0	0.0	0.0	0
VI RENAL TUMOURS	29	70	99	0.8	0.7%	100.0%	0.9	1.9	1.4	1.4	1.1	1.6	14
Wilms tumour, rhabdoid and clear cell sarcoma	12	2	14	1.3	0.1%	14.1%	0.4	0.1	0.2	0.2	0.1	0.3	2
Renal carcinoma	14	59	73	0.7	0.5%	73.7%	0.4	1.6	1.1	1.0	0.8	1.2	10
Unspecified malignant renal tumors	3	9	12	0.7	0.1%	12.1%	0.1	0.2	0.2	0.2	0.1	0.3	2
VII HEPATIC TUMOURS	32	51	83	1.1	0.5%	100.0%	1.0	1.4	1.2	1.2	0.9	1.4	12
Hepatoblastoma	3	2	5	1.5	0.0%	6.0%	0.1	0.1	0.1	0.1	0.0	0.1	1
Hepatic carcimona	29	45	74	1.1	0.5%	89.2%	0.9	1.2	1.1	1.1	0.8	1.3	11
Unspecified malignant hepatic tumors	0	4	4	1.0	0.0%	4.8%	0.0	0.1	0.1	0.1	0.0	0.1	1

INCIDENCE (1988-1997) 15-24 years

	NUMBER OF CASES				RELATIVE FREQENCY (%)		RATES PER MILLION						
	15-19	20-24	All	M/F	Overall	Group	15-19	20-24	Crude	ASR	LCL	UCL	Cum.
VIII MALIGNANT BONE TUMOURS	442	284	726	1.7	4.8%	100.0%	13.8	7.7	10.5	10.9	10.1	11.7	108
Osteosarcoma	251	128	379	1.7	2.5%	52.2%	7.8	3.5	5.5	5.8	5.2	6.4	57
Chrodosarcoma	20	30	50	1.6	0.3%	6.9%	0.6	0.8	0.7	0.7	0.5	0.9	7
Ewing sarcoma	129	84	213	1.9	1.4%	29.3%	4.0	2.3	3.1	3.2	2.8	3.6	32
Other specified malignant bone tumours	12	15	27	1.1	0.2%	3.7%	0.4	0.4	0.4	0.4	0.2	0.5	4
Unspecified malignant bone tumours	30	27	57	1.1	0.4%	7.9%	0.9	0.7	0.8	0.8	0.6	1.1	8
IX SOFT TISSUE SARCOMAS	331	462	793	1.1	5.2%	100.0%	10.3	12.5	11.5	11.4	10.6	12.2	114
Rhabdomyosarcoma and embryonal sarcoma	103	51	154	1.9	1.0%	19.4%	3.2	1.4	2.2	2.4	2.0	2.7	23
Fibrosarcoma, neurofibrosarcoma and other fibromatous neoplasms	74	143	217	1.1	1.4%	27.4%	2.3	3.9	3.1	3.0	2.6	3.5	31
Kaposi sarcoma	1	37	38	3.2	0.2%	4.8%	0.0	1.0	0.6	0.5	0.3	0.6	5
Other specified soft-tissue sarcomas	108	162	270	0.7	1.8%	34.0%	3.4	4.4	3.9	3.9	3.4	4.3	39
Unspecified soft-tissue sarcomas	45	69	114	1.4	0.7%	14.4%	1.4	1.9	1.7	1.6	1.3	1.9	16
X GERM CELL AND GONADAL NEOPLASMS	594	1911	2505	3.9	16.5%	100.0%	18.6	51.8	36.4	34.2	32.8	35.5	352
Intracranial and intraspinal (CNS) germ-cell tumors	39	26	65	5.5	0.4%	2.6%	1.2	0.7	0.9	1.0	0.7	1.2	10
Other and unspecified non-gonadal germ-cell tumors	26	52	78	1.8	0.5%	3.1%	0.8	1.4	1.1	1.1	0.8	1.3	11
Gonadal germ-cell tumors	427	1445	1872	10.5	12.3%	74.7%	13.3	39.1	27.2	25.5	24.3	26.6	262
Gonadol carcinomas	62	245	307	0.1	2.0%	12.3%	1.9	6.6	4.5	4.1	3.7	4.6	43
Other and unspecified malignant gonadol tumours	40	143	183	3.7	1.2%	7.3%	1.3	3.9	2.7	2.5	2.1	2.8	26
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	910	2984	3894	0.5	25.6%	100.0%	28.4	80.8	56.5	53.1	51.4	54.8	546
Adrenocortical carcinoma	3	3	6	0.2	0.0%	0.2%	0.1	0.1	0.1	0.1	0.0	0.2	1
Thyroid carcinoma	136	345	481	0.2	3.2%	12.4%	4.3	9.3	7.0	6.6	6.0	7.2	68
Nasopharyngeal carcinoma	39	34	73	2.5	0.5%	1.9%	1.2	0.9	1.1	1.1	0.8	1.3	11
Malignant melanoma	337	1053	1390	0.5	9.1%	35.7%	10.5	28.5	20.2	19.0	18.0	20.0	195
Skin carcinoma	173	436	609	0.8	4.0%	15.6%	5.4	11.8	8.8	8.4	7.7	9.1	86
Other and unspecified carcinomas	222	1113	1335	0.4	8.8%	34.3%	6.9	30.1	19.4	17.9	16.9	18.8	185
XII OTHER AND UNSPECIFIED NEOPLASMS	161	310	471	0.7	3.1%	100.0%	5.0	8.4	6.8	6.6	6.0	7.2	67
Other specified malignant tumours	9	13	22	0.2	0.1%	4.7%	0.3	0.4	0.3	0.3	0.2	0.4	3
Other unspecified malignant tumors	152	297	449	0.7	3.0%	95.3%	4.8	8.0	6.5	6.3	5.7	6.9	64
TOTAL	5262	9945	15207	1.2	1		164.5	269.37	220.69	213.9	210.4	217	2169

INCIDENCE (1988-1997) 15-24 years	MALE									
	NUMBER OF CASES			RATES PER MILLION						
	15-19	20-24	All	15-19	20-24	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	467	437	904	28.7	23.6	26.0	26.3	25.4	27.2	262
Acute Lymphoid Leukaemia (ALL)	287	175	462	17.6	9.4	13.3	13.8	13.1	14.4	135
Acute non-lymphocytic leukaemia (ANLL)	133	183	316	8.2	9.9	9.1	9.0	8.5	9.5	90
Chronic myeloid leukaemia (CML)	29	57	86	1.8	3.1	2.5	2.4	2.1	2.6	24
Other specified leukaemia	4	12	16	0.2	0.6	0.5	0.4	0.3	0.5	4
Unspecified leukaemia	14	10	24	0.9	0.5	0.7	0.7	0.6	0.9	7
II LYMPHOMAS	736	1228	1964	45.2	66.3	56.5	55.2	53.9	56.4	558
Hodgkins disease	438	805	1243	26.9	43.5	35.7	34.7	33.7	35.7	352
Non-hodgkin lymphoma (NHL) and Burkitt's lymphoma	277	395	672	17.0	21.3	19.3	19.1	18.3	19.8	192
Unspecified lymphoma	17	15	32	1.0	0.8	0.9	0.9	0.8	1.1	9
Miscellaneous lymphoreticular neoplasms	4	13	17	0.2	0.7	0.5	0.5	0.3	0.6	5
III BRAIN AND SPINAL NEOPLASMS	367	510	877	22.6	27.5	25.2	24.9	24.1	25.7	250
Ependymoma	22	35	57	1.4	1.9	1.6	1.6	1.4	1.8	16
Astrocytoma	163	220	383	10.0	11.9	11.0	10.9	10.3	11.4	109
Primitive neuroectodermal tumours (PNET)	34	42	76	2.1	2.3	2.2	2.2	1.9	2.4	22
Other gliomas	52	86	138	3.2	4.6	4.0	3.9	3.5	4.2	39
Miscellaneous intracranial & intraspinal (CNS) neoplasms	54	70	124	3.3	3.8	3.6	3.5	3.2	3.9	35
Unspecified intracranial & intraspinal (CNS) neoplasms	40	53	93	2.5	2.9	2.7	2.6	2.4	2.9	27
9060-9102 Benign Brain	2	4	6	0.1	0.2	0.2	0.2	0.1	0.2	2
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	16	23	39	1.0	1.2	1.1	1.1	0.9	1.3	11
Neuroblastoma and ganglioneuroblastoma	10	4	14	0.6	0.2	0.4	0.4	0.3	0.5	4
Other sympathetic nervous system (SNS) tumours	6	19	25	0.4	1.0	0.7	0.7	0.5	0.8	7
V RETINOBLASTOMA	0	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0
VI RENAL TUMOURS	12	31	43	0.7	1.7	1.2	1.2	1.0	1.4	12
Wilms tumour, rhabdoid and clear cell sarcoma	7	1	8	0.4	0.1	0.2	0.3	0.2	0.3	2
Renal carcinoma	3	27	30	0.2	1.5	0.9	0.8	0.6	0.9	8
Unspecified malignant renal tumors	2	3	5	0.1	0.2	0.1	0.1	0.1	0.2	1
VII HEPATIC TUMOURS	14	29	43	0.9	1.6	1.2	1.2	1.0	1.4	12
Hepatoblastoma	2	1	3	0.1	0.1	0.1	0.1	0.0	0.1	1
Hepatic carcimona	12	26	38	0.7	1.4	1.1	1.1	0.9	1.2	11
Unspecified malignant hepatic tumors	0	2	2	0.0	0.1	0.1	0.1	0.0	0.1	1

INCIDENCE (1988-1997) 15-24 years	MALE									
	NUMBER OF CASES			RATES PER MILLION						
	15-19	*20-24*	*All*	*15-19*	*20-24*	*Crude*	*ASR*	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	272	183	455	16.7	9.9	13.1	13.5	12.9	14.1	133
Osteosarcoma	157	83	240	9.7	4.5	6.9	7.2	6.8	7.7	71
Chrodosarcoma	11	20	31	0.7	1.1	0.9	0.9	0.7	1.0	9
Ewing sarcoma	80	60	140	4.9	3.2	4.0	4.1	3.8	4.5	41
Other specified malignant bone tumours	6	8	14	0.4	0.4	0.4	0.4	0.3	0.5	4
Unspecified malignant bone tumours	18	12	30	1.1	0.6	0.9	0.9	0.7	1.1	9
IX SOFT TISSUE SARCOMAS	185	237	422	11.4	12.8	12.1	12.0	11.5	12.6	121
Rhabdomyosarcoma and embryonal sarcoma	71	29	100	4.4	1.6	2.9	3.0	2.7	3.4	30
Fibrosarcoma, neurofibrosarcoma and other fibromatous neoplasms	35	77	112	2.2	4.2	3.2	3.1	2.8	3.4	32
Kaposi sarcoma	1	28	29	0.1	1.5	0.8	0.7	0.6	0.9	8
Other specified soft-tissue sarcomas	48	66	114	3.0	3.6	3.3	3.2	2.9	3.5	33
Unspecified soft-tissue sarcomas	30	37	67	1.8	2.0	1.9	1.9	1.7	2.2	19
X GERM CELL AND GONADAL NEOPLASMS	425	1573	1998	26.1	84.9	57.4	53.8	52.6	55.0	555
Intracranial and intraspinal (CNS) germ-cell tumors	32	23	55	2.0	1.2	1.6	1.6	1.4	1.8	16
Other and unspecified non-gonadal germ-cell tumors	16	34	50	1.0	1.8	1.4	1.4	1.2	1.6	14
Gonadal germ-cell tumors	345	1364	1709	21.2	73.6	49.1	45.9	44.8	47.0	474
Gonadol carcinomas	7	33	40	0.4	1.8	1.1	1.1	0.9	1.2	11
Other and unspecified malignant gonadol tumours	25	119	144	1.5	6.4	4.1	3.8	3.5	4.2	40
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	369	897	1266	22.7	48.4	36.4	34.8	33.8	35.8	356
Adrenocortical carcinoma	0	1	1	0.0	0.1	0.0	0.0	0.0	0.1	0
Thyroid carcinoma	26	70	96	1.6	3.8	2.8	2.6	2.4	2.9	27
Nasopharyngeal carcinoma	30	22	52	1.8	1.2	1.5	1.5	1.3	1.7	15
Malignant melanoma	135	345	480	8.3	18.6	13.8	13.2	12.6	13.8	135
Skin carcinoma	78	189	267	4.8	10.2	7.7	7.3	6.9	7.8	75
Other and unspecified carcinomas	100	270	370	6.1	14.6	10.6	10.1	9.6	10.6	104
XII OTHER AND UNSPECIFIED NEOPLASMS	69	118	187	4.2	6.4	5.4	5.2	4.9	5.6	53
Other specified malignant tumours	1	2	3	0.1	0.1	0.1	0.1	0.0	0.1	1
Other unspecified malignant tumors	68	116	184	4.2	6.3	5.3	5.2	4.8	5.5	52
TOTAL	2932	5266	8198	180.3	284.3	235.64	229.2	226.7	231.73	2323

INCIDENCE (1988-1997) 15-24 years	FEMALE									
	NUMBER OF CASES			RATES PER MILLION						
	15-19	*20-24*	*All*	*15-19*	*20-24*	*Crude*	*ASR*	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	301	289	590	19.1	15.7	17.3	17.5	16.8	18.2	174
Acute Lymphoid Leukaemia (ALL)	141	72	213	9.0	3.9	6.2	6.6	6.2	7.0	64
Acute non-lymphocytic leukaemia (ANLL)	115	155	270	7.3	8.4	7.9	7.8	7.4	8.3	79
Chronic myeloid leukaemia (CML)	21	32	53	1.3	1.7	1.6	1.5	1.3	1.7	15
Other specified leukaemia	12	9	21	0.8	0.5	0.6	0.6	0.5	0.8	6
Unspecified leukaemia	12	21	33	0.8	1.1	1.0	0.9	0.8	1.1	10
II LYMPHOMAS	564	985	1549	35.9	53.5	45.4	44.2	43.1	45.3	447
Hodgkins disease	430	759	1189	27.4	41.3	34.9	33.9	32.9	34.9	343
Non-hodgkin lymphoma (NHL) and Burkitt's lymphoma	120	201	321	7.6	10.9	9.4	9.2	8.7	9.7	93
Unspecified lymphoma	10	18	28	0.6	1.0	0.8	0.8	0.6	0.9	8
Miscellaneous lymphoreticular neoplasms	4	7	11	0.3	0.4	0.3	0.3	0.2	0.4	3
III BRAIN AND SPINAL NEOPLASMS	304	377	681	19.3	20.5	20.0	19.9	19.1	20.6	199
Ependymoma	26	26	52	1.7	1.4	1.5	1.5	1.3	1.7	15
Astrocytoma	126	158	284	8.0	8.6	8.3	8.3	7.8	8.8	83
Primitive neuroectodermal tumours (PNET)	19	23	42	1.2	1.3	1.2	1.2	1.0	1.4	12
Other gliomas	36	56	92	2.3	3.0	2.7	2.6	2.4	2.9	27
Miscellaneous intracranial & intraspinal (CNS) neoplasms	60	83	143	3.8	4.5	4.2	4.1	3.8	4.5	42
Unspecified intracranial & intraspinal (CNS) neoplasms	30	30	60	1.9	1.6	1.8	1.8	1.6	2.0	18
9060-9102 Benign Brain	7	1	8	0.4	0.1	0.2	0.3	0.2	0.4	2
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	8	23	31	0.5	1.3	0.9	0.9	0.7	1.0	9
Neuroblastoma and ganglioneuroblastoma	5	9	14	0.3	0.5	0.4	0.4	0.3	0.5	4
Other sympathetic nervous system (SNS) tumours	3	14	17	0.2	0.8	0.5	0.5	0.4	0.6	5
V RETINOBLASTOMA	0	1	1	0.0	0.1	0.0	0.0	0.0	0.1	0
VI RENAL TUMOURS	17	39	56	1.1	2.1	1.6	1.6	1.4	1.8	16
Wilms tumour, rhabdoid and clear cell sarcoma	5	1	6	0.3	0.1	0.2	0.2	0.1	0.3	2
Renal carcinoma	11	32	43	0.7	1.7	1.3	1.2	1.0	1.4	12
Unspecified malignant renal tumors	1	6	7	0.1	0.3	0.2	0.2	0.1	0.3	2
VII HEPATIC TUMOURS	18	22	40	1.1	1.2	1.2	1.2	1.0	1.3	12
Hepatoblastoma	1	1	2	0.1	0.1	0.1	0.1	0.0	0.1	1
Hepatic carcimona	17	19	36	1.1	1.0	1.1	1.1	0.9	1.2	11
Unspecified malignant hepatic tumors	0	2	2	0.0	0.1	0.1	0.1	0.0	0.1	1

INCIDENCE (1988-1997) 15-24 years	FEMALE									
	NUMBER OF CASES			RATES PER MILLION						
	15-19	*20-24*	*All*	*15-19*	*20-24*	*Crude*	*ASR*	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	170	101	271	10.8	5.5	7.9	8.3	7.8	8.8	82
Osteosarcoma	94	45	139	6.0	2.4	4.1	4.3	4.0	4.7	42
Chrodosarcoma	9	10	19	0.6	0.5	0.6	0.6	0.4	0.7	6
Ewing sarcoma	49	24	73	3.1	1.3	2.1	2.3	2.0	2.5	22
Other specified malignant bone tumours	6	7	13	0.4	0.4	0.4	0.4	0.3	0.5	4
Unspecified malignant bone tumours	12	15	27	0.8	0.8	0.8	0.8	0.6	0.9	8
IX SOFT TISSUE SARCOMAS	146	225	371	9.3	12.2	10.9	10.7	10.1	11.2	108
Rhabdomyosarcoma and embryonal sarcoma	32	22	54	2.0	1.2	1.6	1.6	1.4	1.9	16
Fibrosarcoma, neurofibrosarcoma and other fibromatous neoplasms	39	66	105	2.5	3.6	3.1	3.0	2.7	3.3	30
Kaposi sarcoma	0	9	9	0.0	0.5	0.3	0.2	0.2	0.3	2
Other specified soft-tissue sarcomas	60	96	156	3.8	5.2	4.6	4.5	4.1	4.8	45
Unspecified soft-tissue sarcomas	15	32	47	1.0	1.7	1.4	1.3	1.1	1.5	13
X GERM CELL AND GONADAL NEOPLASMS	169	338	507	10.7	18.4	14.9	14.3	13.7	15.0	146
Intracranial and intraspinal (CNS) germ-cell tumors	7	3	10	0.4	0.2	0.3	0.3	0.2	0.4	3
Other and unspecified non-gonadal germ-cell tumors	10	18	28	0.6	1.0	0.8	0.8	0.6	0.9	8
Gonadal germ-cell tumors	82	81	163	5.2	4.4	4.8	4.8	4.5	5.2	48
Gonadol carcinomas	55	212	267	3.5	11.5	7.8	7.3	6.8	7.7	75
Other and unspecified malignant gonadol tumours	15	24	39	1.0	1.3	1.1	1.1	0.9	1.3	11
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	541	2087	2628	34.4	113.5	77.0	71.6	70.2	73.0	739
Adrenocortical carcinoma	3	2	5	0.2	0.1	0.1	0.2	0.1	0.2	1
Thyroid carcinoma	110	275	385	7.0	14.9	11.3	10.7	10.2	11.3	110
Nasopharyngeal carcinoma	9	12	21	0.6	0.7	0.6	0.6	0.5	0.7	6
Malignant melanoma	202	708	910	12.8	38.5	26.7	24.9	24.1	25.7	257
Skin carcinoma	95	247	342	6.0	13.4	10.0	9.5	9.0	10.0	97
Other and unspecified carcinomas	122	843	965	7.8	45.8	28.3	25.7	24.9	26.5	268
XII OTHER AND UNSPECIFIED NEOPLASMS	92	192	284	5.9	10.4	8.3	8.0	7.5	8.5	81
Other specified malignant tumours	8	11	19	0.5	0.6	0.6	0.6	0.4	0.7	6
Other unspecified malignant tumors	84	181	265	5.3	9.8	7.8	7.5	7.0	7.9	76
TOTAL	2330	4679	7009	148.2	254.4	205.4	198.2	195.8	200.5	2013

Appendix 3: NCIC Prevalence data for the 0-14 age group

PREVALENCE - PATIENTS ALIVE END 1997**																
	TOTAL NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION								
	0-4 born 93-7	5-9 born 88-92	10-14 born 83-7	All	*M/F*	Overall	Group	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	397	1208	1244	**2849**	1.2	35.4%	100.0%	121.7	351.0	382.5	286.1	**271.4**	268.2	274.6	4276
Acute lymphoid leukaemia (ALL)	323	1066	1100	**2489**	1.2	30.9%	87.4%	99.0	309.7	338.3	250.0	**236.4**	233.4	239.4	3735
Acute non-lymphocytic leukaemia (ANLL)	57	118	119	**294**	1.2	3.7%	10.3%	17.5	34.3	36.6	29.5	**28.4**	27.4	29.5	442
Chronic myeloid leukaemia (CML)	11	16	16	**43**	2.1	0.5%	1.5%	3.4	4.6	4.9	4.3	**4.2**	3.8	4.6	65
Other specified leukaemia	1	2	2	**5**	0.3	0.1%	0.2%	0.3	0.6	0.6	0.5	**0.5**	0.3	0.6	8
Unspecified leukaemia	5	6	7	**18**	1.0	0.2%	0.6%	1.5	1.7	2.2	1.8	**1.8**	1.5	2.0	27
II LYMPHOMAS	31	176	368	**575**	2.5	7.1%	100.0%	9.5	51.1	113.2	57.7	**53.0**	51.6	54.4	869
Hodgkins disease	4	49	157	**210**	2.2	2.6%	36.5%	1.2	14.2	48.3	21.1	**19.1**	18.2	19.9	319
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	27	121	199	**347**	2.6	4.3%	60.3%	8.3	35.2	61.2	34.9	**32.3**	31.2	33.4	523
Unspecified lymphoma	0	1	5	**6**	2.0	0.1%	1.0%	0.0	0.3	1.5	0.6	**0.5**	0.4	0.7	9
Miscellaneous reticulo-endothelial neoplasm	0	5	7	**12**	3.0	0.1%	2.1%	0.0	1.5	2.2	1.2	**1.1**	0.9	1.3	18
III BRAIN AND SPINAL NEOPLASMS	185	614	811	**1610**	1.2	20.0%	100.0%	56.7	178.4	249.4	161.7	**151.9**	149.5	154.3	2422
Ependymoma and Choroid Plexus	46	64	63	**173**	1.3	2.2%	10.7%	14.1	18.6	19.4	17.4	**17.1**	16.3	17.9	260
Astrocytoma	81	310	400	**791**	1.0	9.8%	49.1%	24.8	90.1	123.0	79.4	**74.4**	72.7	76.0	1189
Primitive neuroectodermal tumour (PNET)	21	96	131	**248**	1.7	3.1%	15.4%	6.4	27.9	40.3	24.9	**23.2**	22.3	24.1	373
Other glioma	12	48	77	**137**	1.3	1.7%	8.5%	3.7	13.9	23.7	13.8	**12.8**	12.1	13.5	207
Other specified central nervous system (CNS) tumour	20	70	110	**200**	1.2	2.5%	12.4%	6.1	20.3	33.8	20.1	**18.8**	17.9	19.6	301
Unspecified central nervous system (CNS) tumour	5	26	30	**61**	0.7	0.8%	3.8%	1.5	7.6	9.2	6.1	**5.7**	5.2	6.2	92
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	181	229	152	**562**	1.1	7.0%	100.0%	55.5	66.5	46.7	56.4	**56.5**	55.0	58.0	844
Neuroblastoma	181	223	149	**553**	1.2	6.9%	98.4%	55.5	64.8	45.8	55.5	**55.7**	54.2	57.2	830
Other sympathetic nervous system (SNS) tumour	0	6	3	**9**	0.5	0.1%	1.6%	0.0	1.7	0.9	0.9	**0.8**	0.7	1.0	13
V RETINOBLASTOMA	126	197	165	**488**	1.1	6.1%	100.0%	38.6	57.2	50.7	49.0	**48.1**	46.8	49.5	733
VI RENAL TUMOURS	135	284	268	**687**	1.1	8.5%	100.0%	41.4	82.5	82.4	69.0	**66.6**	65.0	68.2	1031
Wilms' tumour etc.	134	282	263	**679**	1.1	8.4%	98.8%	41.1	81.9	80.9	68.2	**65.8**	64.2	67.4	1019
Renal carcinoma	0	1	5	**6**	2.0	0.1%	0.9%	0.0	0.3	1.5	0.6	**0.5**	0.4	0.7	9
Other renal	1	1	0	**2**	*	0.0%	0.3%	0.3	0.3	0.0	0.2	**0.2**	0.1	0.3	3
VII HEPATIC TUMOURS	28	24	24	**76**	1.7	0.9%	100.0%	8.6	7.0	7.4	7.6	**7.7**	7.2	8.3	115
Hepatoblastoma	28	23	20	**71**	1.8	0.9%	93.4%	8.6	6.7	6.2	7.1	**7.3**	6.7	7.8	107
Hepatic carcinoma	0	1	4	**5**	0.7	0.1%	6.6%	0.0	0.3	1.2	0.5	**0.5**	0.3	0.6	8

PREVALENCE - PATIENTS ALIVE END 1997**

	TOTAL NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION							
	0-4 born 93-7	5-9 born 88-92	10-14 born 83-7	All	*M/F*	Overall	Group	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	3	40	116	**159**	0.9	2.0%	100.0%	0.9	11.6	35.7	16.0	**14.5**	13.7	15.2	241
Osteosarcoma	0	17	71	**88**	0.9	1.1%	55.3%	0.0	4.9	21.8	8.8	**7.9**	7.4	8.5	134
Chondrosarcoma	0	1	4	**5**	1.5	0.1%	3.1%	0.0	0.3	1.2	0.5	**0.5**	0.3	0.6	8
Ewing's sarcoma	1	18	39	**58**	1.0	0.7%	36.5%	0.3	5.2	12.0	5.8	**5.3**	4.8	5.7	88
Other specified bone tumour	1	1	1	**3**	0.0	0.0%	1.9%	0.3	0.3	0.3	0.3	**0.3**	0.2	0.4	5
Unspecified bone tumour	1	3	1	**5**	0.7	0.1%	3.1%	0.3	0.9	0.3	0.5	**0.5**	0.4	0.6	7
IX SOFT TISSUE SARCOMAS	65	214	271	**550**	1.5	6.8%	100.0%	19.9	62.2	83.3	55.2	**52.0**	50.6	53.4	827
Rhabdomyosarcoma	44	152	153	**349**	1.7	4.3%	63.5%	13.5	44.2	47.0	35.1	**33.1**	32.0	34.2	523
Fibrosarcoma etc.	10	13	40	**63**	1.4	0.8%	11.5%	3.1	3.8	12.3	6.3	**6.0**	5.5	6.5	96
Karposi's sarcoma	0	0	2	**2**	1.0	0.0%	0.4%	0.0	0.0	0.6	0.2	**0.2**	0.1	0.3	3
Other specified soft tissue sarcoma	10	38	62	**110**	1.0	1.4%	20.0%	3.1	11.0	19.1	11.0	**10.3**	9.7	10.9	166
Unspecified soft tissue sarcoma	1	11	14	**26**	0.9	0.3%	4.7%	0.3	3.2	4.3	2.6	**2.4**	2.1	2.7	39
X GERM CELL AND GONADAL NEOPLASMS	53	87	148	**288**	1.0	3.6%	100.0%	16.2	25.3	45.5	28.9	**27.7**	26.6	28.7	435
Intracranial and intraspinal (CNS) germ cell	3	17	32	**52**	0.9	0.6%	18.1%	0.9	4.9	9.8	5.2	**4.8**	4.4	5.2	78
Other non-gonadal germ cell	25	30	33	**88**	0.3	1.1%	30.6%	7.7	8.7	10.1	8.8	**8.7**	8.1	9.3	133
Gonadal germ cell	25	39	81	**145**	2.2	1.8%	50.3%	7.7	11.3	24.9	14.6	**13.9**	13.1	14.6	220
Gonadal carcinoma	0	0	1	**1**	0.0	0.0%	0.3%	0.0	0.0	0.3	0.1	**0.1**	0.0	0.1	2
Other gonadal	0	1	1	**2**	1.0	0.0%	0.7%	0.0	0.3	0.3	0.2	**0.2**	0.1	0.3	3
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	6	26	114	**146**	0.8	1.8%	100.0%	1.8	7.6	35.1	14.7	**13.3**	12.6	14.0	222
Adrenocortical carcinoma	2	2	4	**8**	1.0	0.1%	5.5%	0.6	0.6	1.2	0.8	**0.8**	0.6	1.0	12
Thyroid carcinoma	0	3	15	**18**	0.5	0.2%	12.3%	0.0	0.9	4.6	1.8	**1.6**	1.4	1.9	27
Nasopharyngeal carcinoma	0	0	6	**6**	2.0	0.1%	4.1%	0.0	0.0	1.8	0.6	**0.5**	0.4	0.7	9
Melanoma	2	14	44	**60**	0.7	0.7%	41.1%	0.6	4.1	13.5	6.0	**5.5**	5.0	5.9	91
Skin carcinoma	1	3	15	**19**	0.9	0.2%	13.0%	0.3	0.9	4.6	1.9	**1.7**	1.5	2.0	29
Other carcinoma	1	4	30	**35**	1.2	0.4%	24.0%	0.3	1.2	9.2	3.5	**3.2**	2.8	3.5	53
XII OTHER AND UNSPECIFIED NEOPLASMS	10	21	24	**55**	0.6	0.7%	100.0%	3.1	6.1	7.4	5.5	**5.3**	4.8	5.7	83
Other specified malignant	0	5	4	**9**	0.8	0.1%	16.4%	0.0	1.5	1.2	0.9	**0.8**	0.7	1.0	13
Other unspecified malignant	10	16	20	**46**	0.6	0.6%	83.6%	3.1	4.6	6.2	4.6	**4.5**	4.1	4.9	69
MALIGNANT TOTAL	1220	3120	3705	**8045**	1.2	100.0%		373.9	906.4	1139.3	808.0	**767.9**	**762.5**	**773.3**	12098
NON-MALIGNANT CONDITIONS	76	107	111	**294**	1.5		100.0%	23.3	31.1	34.1	29.5	**29.0**	27.9	30.0	443
Langerhans Cell Histiocytosis	63	88	96	**247**	1.4		84.0%	19.3	25.6	29.5	24.8	**24.3**	23.3	25.3	372
Fibromatosis	13	19	15	**47**	1.8		16.0%	4.0	5.5	4.6	4.7	**4.7**	4.2	5.1	71
OVERALL TOTAL	1296	3227	3816	**8339**	1.2			397.2	937.5	1173.5	837.5	**796.9**	**791.3**	**802.4**	12541

PREVALENCE - PATIENTS ALIVE END 1997** **FEMALE**

	NUMBER OF CASES				RATES PER MILLION							
	0-4	5-9	10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
	born 93-7	born 88-92	born 83-7									
I LEUKAEMIA	179	551	550	**1280**	112.6	327.5	346.0	263.3	**249.7**	245.3	254.1	3931
Acute lymphoid leukaemia (ALL)	140	478	501	**1119**	88.1	284.2	315.2	230.2	**217.3**	213.2	221.4	3437
Acute non-lymphocytic leukaemia (ANLL)	27	66	41	**134**	17.0	39.2	25.8	27.6	**26.7**	25.3	28.2	410
Chronic myeloid leukaemia (CML)	6	3	5	**14**	3.8	1.8	3.1	2.9	**2.9**	2.5	3.4	44
Other specified leukaemia	1	2	1	**4**	0.6	1.2	0.6	0.8	**0.8**	0.6	1.1	12
Unspecified leukaemia	5	2	2	**9**	3.1	1.2	1.3	1.9	**2.0**	1.6	2.4	28
II LYMPHOMAS	11	53	102	**166**	6.9	31.5	64.2	34.1	**31.5**	29.9	33.0	513
Hodgkins disease	0	15	50	**65**	0.0	8.9	31.5	13.4	**12.0**	11.1	13.0	202
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	11	37	48	**96**	6.9	22.0	30.2	19.7	**18.5**	17.3	19.7	296
Unspecified lymphoma	0	0	2	**2**	0.0	0.0	1.3	0.4	**0.4**	0.2	0.5	6
Miscellaneous reticulo-endothelial neoplasm	0	1	2	**3**	0.0	0.6	1.3	0.6	**0.6**	0.4	0.8	9
III BRAIN AND SPINAL NEOPLASMS	79	285	383	**747**	49.7	169.4	240.9	153.7	**143.8**	140.5	147.2	2300
Ependymoma and Choroid Plexus	19	29	26	**74**	12.0	17.2	16.4	15.2	**14.9**	13.8	16.0	228
Astrocytoma	38	159	200	**397**	23.9	94.5	125.8	81.7	**76.3**	73.8	78.7	1221
Primitive neuroectodermal tumour (PNET)	7	31	54	**92**	4.4	18.4	34.0	18.9	**17.5**	16.4	18.7	284
Other glioma	3	21	36	**60**	1.9	12.5	22.6	12.3	**11.3**	10.4	12.3	185
Other specified central nervous system (CNS) tumour	10	32	47	**89**	6.3	19.0	29.6	18.3	**17.2**	16.0	18.3	274
Unspecified central nervous system (CNS) tumour	2	13	20	**35**	1.3	7.7	12.6	7.2	**6.6**	5.9	7.3	108
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	90	107	65	**262**	56.6	63.6	40.9	53.9	**54.3**	52.2	56.4	806
Neuroblastoma	90	104	62	**256**	56.6	61.8	39.0	52.7	**53.2**	51.1	55.3	787
Other sympathetic nervous system (SNS) tumour	0	3	3	**6**	0.0	1.8	1.9	1.2	**1.1**	0.8	1.4	18
V RETINOBLASTOMA	62	95	71	**228**	39.0	56.5	44.7	46.9	**46.3**	44.4	48.2	701
VI RENAL TUMOURS	61	139	129	**329**	38.4	82.6	81.2	67.7	**65.1**	62.8	67.3	1011
Wilms' tumour etc.	61	139	127	**327**	38.4	82.6	79.9	67.3	**64.7**	62.4	67.0	1005
Renal carcinoma	0	0	2	**2**	0.0	0.0	1.3	0.4	**0.4**	0.2	0.5	6
Other renal	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
VII HEPATIC TUMOURS	12	8	8	**28**	7.6	4.8	5.0	5.8	**5.9**	5.2	6.6	87
Hepatoblastoma	12	8	5	**25**	7.6	4.8	3.1	5.1	**5.4**	4.7	6.0	77
Hepatic carcinoma	0	0	3	**3**	0.0	0.0	1.9	0.6	**0.5**	0.3	0.7	9

PREVALENCE - PATIENTS ALIVE END 1997** **FEMALE**

Continued

	NUMBER OF CASES				RATES PER MILLION							
	0-4	**5-9**	**10-14**	**All**	**0-4**	**5-9**	**10-14**	**Crude**	**ASR**	***LCL***	***UCL***	***Cum.***
	born 93-7	**born**	**born**									
VIII MALIGNANT BONE TUMOURS	2	23	58	**83**	1.3	13.7	36.5	17.1	**15.5**	14.4	16.6	257
Osteosarcoma	0	9	37	**46**	0.0	5.4	23.3	9.5	**8.5**	7.7	9.3	143
Chondrosarcoma	0	1	1	**2**	0.0	0.6	0.6	0.4	**0.4**	0.2	0.5	6
Ewing's sarcoma	1	10	18	**29**	0.6	5.9	11.3	6.0	**5.4**	4.8	6.1	89
Other specified bone tumour	1	1	1	**3**	0.6	0.6	0.6	0.6	**0.6**	0.4	0.8	9
Unspecified bone tumour	0	2	1	**3**	0.0	1.2	0.6	0.6	**0.6**	0.4	0.8	9
IX SOFT TISSUE SARCOMAS	34	68	122	**224**	21.4	40.4	76.7	46.1	**43.6**	41.8	45.4	693
Rhabdomyosarcoma	22	42	64	**128**	13.8	25.0	40.3	26.3	**25.1**	23.7	26.5	395
Fibrosarcoma etc.	3	6	17	**26**	1.9	3.6	10.7	5.3	**5.0**	4.4	5.6	81
Karposi's sarcoma	0	0	1	**1**	0.0	0.0	0.6	0.2	**0.2**	0.1	0.3	3
Other specified soft tissue sarcoma	9	14	32	**55**	5.7	8.3	20.1	11.3	**10.7**	9.8	11.6	171
Unspecified soft tissue sarcoma	0	6	8	**14**	0.0	3.6	5.0	2.9	**2.6**	2.2	3.1	43
X GERM CELL AND GONADAL NEOPLASMS	23	41	80	**144**	14.5	24.4	50.3	29.6	**28.1**	26.6	29.6	446
Intracranial and intraspinal (CNS) germ cell	2	9	16	**27**	1.3	5.4	10.1	5.6	**5.1**	4.5	5.8	83
Other non-gonadal germ cell	20	24	25	**69**	12.6	14.3	15.7	14.2	**14.0**	13.0	15.1	213
Gonadal germ cell	1	8	37	**46**	0.6	4.8	23.3	9.5	**8.5**	7.7	9.3	143
Gonadal carcinoma	0	0	1	**1**	0.0	0.0	0.6	0.2	**0.2**	0.1	0.3	3
Other gonadal	0	0	1	**1**	0.0	0.0	0.6	0.2	**0.2**	0.1	0.3	3
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	3	20	56	**79**	1.9	11.9	35.2	16.3	**14.8**	13.7	15.9	245
Adrenocortical carcinoma	0	2	2	**4**	0.0	1.2	1.3	0.8	**0.7**	0.5	1.0	12
Thyroid carcinoma	0	2	10	**12**	0.0	1.2	6.3	2.5	**2.2**	1.8	2.6	37
Nasopharyngeal carcinoma	0	0	2	**2**	0.0	0.0	1.3	0.4	**0.4**	0.2	0.5	6
Melanoma	2	11	22	**35**	1.3	6.5	13.8	7.2	**6.6**	5.9	7.3	108
Skin carcinoma	1	2	7	**10**	0.6	1.2	4.4	2.1	**1.9**	1.5	2.3	31
Other carcinoma	0	3	13	**16**	0.0	1.8	8.2	3.3	**2.9**	2.5	3.4	50
XII OTHER AND UNSPECIFIED NEOPLASMS	8	12	14	**34**	5.0	7.1	8.8	7.0	**6.8**	6.1	7.5	105
Other specified malignant	0	3	2	**5**	0.0	1.8	1.3	1.0	**0.9**	0.7	1.2	15
Other unspecified malignant	8	9	12	**29**	5.0	5.4	7.5	6.0	**5.9**	5.2	6.6	90
MALIGNANT TOTAL	564	1402	1638	**3604**	354.9	833.4	1030.4	741.4	**705.4**	697.9	712.8	11094
NON-MALIGNANT CONDITIONS	30	46	44	**120**	18.9	27.3	27.7	24.7	**24.2**	22.8	25.6	370
Langerhans Cell Histiocytosis	28	40	35	**103**	17.6	23.8	22.0	21.2	**20.9**	19.6	22.2	317
Fibromatosis	2	6	9	**17**	1.3	3.6	5.7	3.5	**3.3**	2.8	3.8	52
OVERALL TOTAL	594	1448	1682	**3724**	373.7	860.8	1058.1	766.1	**729.5**	722.0	737.1	11463

* = No female cases, therefore ratio calculation not possible (n/0=infinity)

** 1997 population estimates used as denominator for calculation of rates

PREVALENCE - PATIENTS ALIVE END 1997**	MALE											
	NUMBER OF CASES				RATES PER MILLION							
	0-4	5-9	10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
	born 93-7	born 88-92	born 83-7									
I LEUKAEMIA	218	657	694	**1569**	130.3	373.3	417.5	307.9	**292.1**	287.4	296.7	4605
Acute lymphoid leukaemia (ALL)	183	588	599	**1370**	109.3	334.1	360.3	268.8	**254.7**	250.4	259.1	4019
Acute non-lymphocytic leukaemia (ANLL)	30	52	78	**160**	17.9	29.5	46.9	31.4	**30.1**	28.6	31.6	472
Chronic myeloid leukaemia (CML)	5	13	11	**29**	3.0	7.4	6.6	5.7	**5.5**	4.8	6.1	85
Other specified leukaemia	0	0	1	**1**	0.0	0.0	0.6	0.2	**0.2**	0.1	0.3	3
Unspecified leukaemia	0	4	5	**9**	0.0	2.3	3.0	1.8	**1.6**	1.3	1.9	26
II LYMPHOMAS	20	123	266	**409**	11.9	69.9	160.0	80.3	**73.6**	71.3	75.9	1209
Hodgkins disease	4	34	107	**145**	2.4	19.3	64.4	28.5	**25.8**	24.5	27.2	430
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	16	84	151	**251**	9.6	47.7	90.8	49.3	**45.5**	43.6	47.3	741
Unspecified lymphoma	0	1	3	**4**	0.0	0.6	1.8	0.8	**0.7**	0.5	0.9	12
Miscellaneous reticulo-endothelial neoplasm	0	4	5	**9**	0.0	2.3	3.0	1.8	**1.6**	1.3	1.9	26
III BRAIN AND SPINAL NEOPLASMS	106	329	428	**863**	63.3	187.0	257.5	169.4	**159.6**	156.1	163.0	2539
Ependymoma and Choroid Plexus	27	35	37	**99**	16.1	19.9	22.3	19.4	**19.1**	17.9	20.3	291
Astrocytoma	43	151	200	**394**	25.7	85.8	120.3	77.3	**72.6**	70.2	74.9	1159
Primitive neuroectodermal tumour (PNET)	14	65	77	**156**	8.4	36.9	46.3	30.6	**28.6**	27.1	30.1	458
Other glioma	9	27	41	**77**	5.4	15.3	24.7	15.1	**14.2**	13.2	15.2	227
Other specified central nervous system (CNS) tumour	10	38	63	**111**	6.0	21.6	37.9	21.8	**20.3**	19.1	21.5	327
Unspecified central nervous system (CNS) tumour	3	13	10	**26**	1.8	7.4	6.0	5.1	**4.8**	4.2	5.4	76
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	91	122	87	**300**	54.4	69.3	52.3	58.9	**58.6**	56.5	60.7	880
Neuroblastoma	91	119	87	**297**	54.4	67.6	52.3	58.3	**58.1**	55.9	60.2	872
Other sympathetic nervous system (SNS) tumour	0	3	0	**3**	0.0	1.7	0.0	0.6	**0.5**	0.3	0.8	9
V RETINOBLASTOMA	64	102	94	**260**	38.2	58.0	56.5	51.0	**49.9**	48.0	51.9	764
VI RENAL TUMOURS	74	145	139	**358**	44.2	82.4	83.6	70.3	**68.0**	65.7	70.2	1051
Wilms' tumour etc.	73	143	136	**352**	43.6	81.3	81.8	69.1	**66.8**	64.6	69.1	1033
Renal carcinoma	0	1	3	**4**	0.0	0.6	1.8	0.8	**0.7**	0.5	0.9	12
Other renal	1	1	0	**2**	0.6	0.6	0.0	0.4	**0.4**	0.2	0.6	6
VII HEPATIC TUMOURS	16	16	16	**48**	9.6	9.1	9.6	9.4	**9.4**	8.6	10.3	141
Hepatoblastoma	16	15	15	**46**	9.6	8.5	9.0	9.0	**9.1**	8.2	9.9	136
Hepatic carcinoma	0	1	1	**2**	0.0	0.6	0.6	0.4	**0.4**	0.2	0.5	6

Appendix 4: NRCT Mortality data for the 0-14 age group

MORTALITY 1988-1997	NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION							
	0-4	5-9	10-14	All	*M/F*	Overall	Group	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	366	378	365	**1109**	1.5	30.7%	100.0%	10.9	11.5	11.8	11.4	**11.4**	10.7	12.0	171
Acute lymphoid leukaemia (ALL)	190	293	243	**726**	1.7	20.1%	65.5%	5.7	8.9	7.8	7.5	**7.3**	6.8	7.9	112
Acute non-lymphocytic leukaemia (ANLL)	134	66	91	**291**	1.1	8.0%	26.2%	4.0	2.0	2.9	3.0	**3.0**	2.7	3.4	45
Chronic myeloid leukaemia (CML)	25	11	22	**58**	1.5	1.6%	5.2%	0.7	0.3	0.7	0.6	**0.6**	0.4	0.8	9
Other specified leukaemia	2	0	2	**4**	0.3	0.1%	0.4%	0.1	0.0	0.1	0.0	**0.0**	0.0	0.1	1
Unspecified leukaemia	15	8	7	**30**	1.5	0.8%	2.7%	0.4	0.2	0.2	0.3	**0.3**	0.2	0.4	5
II LYMPHOMAS	38	64	75	**177**	2.3	4.9%	100.0%	1.1	1.9	2.4	1.8	**1.8**	1.5	2.0	28
Hodgkins disease	0	5	11	**16**	2.2	0.4%	9.0%	0.0	0.2	0.4	0.2	**0.2**	0.1	0.2	3
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	36	57	61	**154**	2.3	4.3%	87.0%	1.1	1.7	2.0	1.6	**1.5**	1.3	1.8	24
Unspecified lymphoma	2	0	0	**2**	*	0.1%	1.1%	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
Miscellaneous reticulo-endothelial neoplasm	0	2	3	**5**	1.5	0.1%	2.8%	0.0	0.1	0.1	0.1	**0.0**	0.0	0.1	1
III BRAIN AND SPINAL NEOPLASMS	358	427	312	**1097**	1.2	30.3%	100.0%	10.7	13.0	10.1	11.3	**11.2**	10.6	11.9	169
Ependymoma and Choroid Plexus	60	34	28	**122**	1.8	3.4%	11.1%	1.8	1.0	0.9	1.3	**1.3**	1.1	1.5	19
Astrocytoma	69	134	112	**315**	1.1	8.7%	28.7%	2.1	4.1	3.6	3.2	**3.2**	2.8	3.5	49
Primitive neuroectodermal tumour (PNET)	138	109	78	**325**	1.4	9.0%	29.6%	4.1	3.3	2.5	3.3	**3.4**	3.0	3.8	50
Other glioma	40	119	64	**223**	0.9	6.2%	20.3%	1.2	3.6	2.1	2.3	**2.2**	1.9	2.5	34
Other specified central nervous system (CNS) tumour	13	12	18	**43**	0.8	1.2%	3.9%	0.4	0.4	0.6	0.4	**0.4**	0.3	0.6	7
Unspecified central nervous system (CNS) tumour	38	19	12	**69**	1.0	1.9%	6.3%	1.1	0.6	0.4	0.7	**0.7**	0.6	0.9	10
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	252	161	33	**446**	1.3	12.3%	100.0%	7.5	4.9	1.1	4.6	**4.8**	4.3	5.2	67
Neuroblastoma	251	160	32	**443**	1.3	12.2%	99.3%	7.5	4.9	1.0	4.5	**4.8**	4.3	5.2	67
Other sympathetic nervous system (SNS) tumour	1	1	1	**3**	0.5	0.1%	0.7%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.1	0
V RETINOBLASTOMA	16	11	3	**30**	0.9	0.8%	100.0%	0.5	0.3	0.1	0.3	**0.3**	0.2	0.4	5
VI RENAL TUMOURS	84	38	17	**139**	0.9	3.8%	100.0%	2.5	1.2	0.5	1.4	**1.5**	1.3	1.8	21
Wilms' tumour etc.	83	38	13	**134**	0.9	3.7%	96.4%	2.5	1.2	0.4	1.4	**1.5**	1.2	1.7	20
Renal carcinoma	0	0	4	**4**	0.3	0.1%	2.9%	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	1
Other renal	1	0	0	**1**	*	0.0%	0.7%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0

MORTALITY 1988-1997

Continued

	NUMBER OF CASES					RELATIVE FREQUENCY (%)		RATES PER MILLION							
	0-4	**5-9**	**10-14**	**All**	***M/F***	**Overall**	**Group**	**0-4**	**5-9**	**10-14**	**Crude**	**ASR**	***LCL***	***UCL***	***Cum.***
VIII MALIGNANT BONE TUMOURS	3	21	120	**144**	1.0	4.0%	100.0%	0.1	0.6	3.9	1.5	**1.4**	1.1	1.6	23
Osteosarcoma	1	14	71	**86**	1.0	2.4%	59.7%	0.0	0.4	2.3	0.9	**0.8**	0.6	1.0	14
Chondrosarcoma	0	0	3	**3**	2.0	0.1%	2.1%	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Ewing's sarcoma	2	7	45	**54**	1.0	1.5%	37.5%	0.1	0.2	1.5	0.6	**0.5**	0.4	0.7	9
Other specified bone tumour	0	0	1	**1**	0.0	0.0%	0.7%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Unspecified bone tumour	0	0	0	**0**	*	0.0%	0.0%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
IX SOFT TISSUE SARCOMAS	125	101	87	**313**	1.0	8.7%	100.0%	3.7	3.1	2.8	3.2	**3.2**	2.9	3.6	48
Rhabdomyosarcoma	71	69	46	**186**	1.0	5.1%	59.4%	2.1	2.1	1.5	1.9	**1.9**	1.6	2.2	29
Fibrosarcoma etc.	8	5	6	**19**	0.6	0.5%	6.1%	0.2	0.2	0.2	0.2	**0.2**	0.1	0.3	3
Karposi's sarcoma	0	2	0	**2**	1.0	0.1%	0.6%	0.0	0.1	0.0	0.0	**0.0**	0.0	0.0	0
Other specified soft tissue sarcoma	34	20	26	**80**	0.9	2.2%	25.6%	1.0	0.6	0.8	0.8	**0.8**	0.6	1.0	12
Unspecified soft tissue sarcoma	12	5	9	**26**	1.4	0.7%	8.3%	0.4	0.2	0.3	0.3	**0.3**	0.2	0.4	4
X GERM CELL AND GONADAL NEOPLASMS	31	13	19	**63**	0.6	1.7%	100.0%	0.9	0.4	0.6	0.6	**0.7**	0.5	0.8	10
Intracranial and intraspinal (CNS) germ cell	14	6	12	**32**	0.9	0.9%	50.8%	0.4	0.2	0.4	0.3	**0.3**	0.2	0.4	5
Other non-gonadal germ cell	17	4	1	**22**	0.5	0.6%	34.9%	0.5	0.1	0.0	0.2	**0.2**	0.1	0.3	3
Gonadal germ cell	0	0	5	**5**	0.3	0.1%	7.9%	0.0	0.0	0.2	0.1	**0.0**	0.0	0.1	1
Gonadal carcinoma	0	1	1	**2**	0.0	0.1%	3.2%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Other gonadal	0	2	0	**2**	0.0	0.1%	3.2%	0.0	0.1	0.0	0.0	**0.0**	0.0	0.0	0
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	6	10	29	**45**	1.3	1.2%	100.0%	0.2	0.3	0.9	0.5	**0.4**	0.3	0.6	7
Adrenocortical carcinoma	0	2	4	**6**	0.0	0.2%	13.3%	0.0	0.1	0.1	0.1	**0.1**	0.0	0.1	1
Thyroid carcinoma	0	0	0	**0**	*	0.0%	0.0%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Nasopharyngeal carcinoma	0	2	4	**6**	2.0	0.2%	13.3%	0.0	0.1	0.1	0.1	**0.1**	0.0	0.1	1
Melanoma	5	4	5	**14**	1.0	0.4%	31.1%	0.1	0.1	0.2	0.1	**0.1**	0.1	0.2	2
Skin carcinoma	0	0	0	**0**	*	0.0%	0.0%	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Other carcinoma	1	2	16	**19**	2.8	0.5%	42.2%	0.0	0.1	0.5	0.2	**0.2**	0.1	0.3	3
XII OTHER AND UNSPECIFIED NEOPLASMS	4	1	3	**8**	0.3	0.2%	100.0%	0.1	0.0	0.1	0.1	**0.1**	0.0	0.1	1
Other specified malignant	1	1	2	**4**	0.3	0.1%	50.0%	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	1
Other unspecified malignant	3	0	1	**4**	0.3	0.1%	50.0%	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	1
MALIGNANT TOTAL	1313	1231	1073	**3617**	1.3	100.0%		39.1	37.5	34.7	37.1	**37.3**	36.1	38.5	556
NON-MALIGNANT CONDITIONS	29	0	1	**30**	1.1		100.0%	0.9	0.0	0.0	0.3	**0.3**	0.2	0.5	4
Langerhans Cell Histiocytosis	26	0	1	**27**	1.3		90.0%	0.8	0.0	0.0	0.3	**0.3**	0.2	0.4	4
Fibromatosis	3	0	0	**3**	0.5		10.0%	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
OVERALL TOTAL	1342	1231	1074	**3647**	1.3			40.0	37.5	34.7	37.5	**37.6**	36.4	38.9	561

MORTALITY 1988-1997	FEMALE											
	NUMBER OF CASES				RATES PER MILLION							
	0-4	5-9	10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
I LEUKAEMIA	170	132	144	**446**	10.4	8.2	9.5	9.4	**9.4**	8.5	10.3	141
Acute lymphoid leukaemia (ALL)	94	91	86	**271**	5.7	5.7	5.7	5.7	**5.7**	5.0	6.4	85
Acute non-lymphocytic leukaemia (ANLL)	63	30	44	**137**	3.8	1.9	2.9	2.9	**2.9**	2.4	3.4	43
Chronic myeloid leukaemia (CML)	6	6	11	**23**	0.4	0.4	0.7	0.5	**0.5**	0.3	0.7	7
Other specified leukaemia	2	0	1	**3**	0.1	0.0	0.1	0.1	**0.1**	0.0	0.1	1
Unspecified leukaemia	5	5	2	**12**	0.3	0.3	0.1	0.3	**0.3**	0.1	0.4	4
II LYMPHOMAS	12	18	24	**54**	0.7	1.1	1.6	1.1	**1.1**	0.8	1.4	17
Hodgkins disease	0	1	4	**5**	0.0	0.1	0.3	0.1	**0.1**	0.0	0.2	2
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	12	16	19	**47**	0.7	1.0	1.3	1.0	**1.0**	0.7	1.2	15
Unspecified lymphoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Miscellaneous reticulo-endothelial neoplasm	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
III BRAIN AND SPINAL NEOPLASMS	159	210	136	**505**	9.7	13.1	9.0	10.6	**10.6**	9.7	11.5	159
Ependymoma and Choroid Plexus	18	13	12	**43**	1.1	0.8	0.8	0.9	**0.9**	0.6	1.2	14
Astrocytoma	31	68	52	**151**	1.9	4.2	3.4	3.2	**3.1**	2.6	3.6	48
Primitive neuroectodermal tumour (PNET)	66	42	25	**133**	4.0	2.6	1.7	2.8	**2.9**	2.4	3.4	41
Other glioma	20	65	35	**120**	1.2	4.1	2.3	2.5	**2.4**	2.0	2.9	38
Other specified central nervous system (CNS) tumour	7	10	7	**24**	0.4	0.6	0.5	0.5	**0.5**	0.3	0.7	8
Unspecified central nervous system (CNS) tumour	17	12	5	**34**	1.0	0.7	0.3	0.7	**0.7**	0.5	1.0	11
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	111	69	14	**194**	6.8	4.3	0.9	4.1	**4.3**	3.7	4.9	60
Neuroblastoma	111	68	13	**192**	6.8	4.2	0.9	4.0	**4.2**	3.6	4.8	59
Other sympathetic nervous system (SNS) tumour	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
V RETINOBLASTOMA	11	3	2	**16**	0.7	0.2	0.1	0.3	**0.4**	0.2	0.5	5
VI RENAL TUMOURS	44	20	10	**74**	2.7	1.2	0.7	1.6	**1.6**	1.3	2.0	23
Wilms' tumour etc.	44	20	7	**71**	2.7	1.2	0.5	1.5	**1.6**	1.2	1.9	22
Renal carcinoma	0	0	3	**3**	0.0	0.0	0.2	0.1	**0.1**	0.0	0.1	1
Other renal	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
VII HEPATIC TUMOURS	8	1	2	**11**	0.5	0.1	0.1	0.2	**0.2**	0.1	0.4	3
Hepatoblastoma	8	0	1	**9**	0.5	0.0	0.1	0.2	**0.2**	0.1	0.3	3
Hepatic carcinoma	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1

MORTALITY 1988-1997 *Continued*	FEMALE											
	NUMBER OF CASES				RATES PER MILLION							
	0-4	5-9	10-	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	2	10	59	**71**	0.1	0.6	3.9	1.5	**1.4**	1.1	1.7	23
Osteosarcoma	0	8	34	**42**	0.0	0.5	2.2	0.9	**0.8**	0.6	1.1	14
Chondrosarcoma	0	0	1	**1**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Ewing's sarcoma	2	2	23	**27**	0.1	0.1	1.5	0.6	**0.5**	0.3	0.7	9
Other specified bone tumour	0	0	1	**1**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Unspecified bone tumour	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
IX SOFT TISSUE SARCOMAS	68	48	43	**159**	4.1	3.0	2.8	3.3	**3.4**	2.9	3.9	50
Rhabdomyosarcoma	33	34	25	**92**	2.0	2.1	1.7	1.9	**1.9**	1.5	2.3	29
Fibrosarcoma etc.	7	2	3	**12**	0.4	0.1	0.2	0.3	**0.3**	0.1	0.4	4
Karposi's sarcoma	0	1	0	**1**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	0
Other specified soft tissue sarcoma	22	8	13	**43**	1.3	0.5	0.9	0.9	**0.9**	0.7	1.2	13
Unspecified soft tissue sarcoma	6	3	2	**11**	0.4	0.2	0.1	0.2	**0.2**	0.1	0.4	3
X GERM CELL AND GONADAL NEOPLASMS	19	11	10	**40**	1.2	0.7	0.7	0.8	**0.9**	0.6	1.1	13
Intracranial and intraspinal (CNS) germ cell	8	5	4	**17**	0.5	0.3	0.3	0.4	**0.4**	0.2	0.5	5
Other non-gonadal germ cell	11	3	1	**15**	0.7	0.2	0.1	0.3	**0.3**	0.2	0.5	5
Gonadal germ cell	0	0	4	**4**	0.0	0.0	0.3	0.1	**0.1**	0.0	0.2	1
Gonadal carcinoma	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
Other gonadal	0	2	0	**2**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	1
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	4	4	12	**20**	0.2	0.2	0.8	0.4	**0.4**	0.2	0.6	6
Adrenocortical carcinoma	0	2	4	**6**	0.0	0.1	0.3	0.1	**0.1**	0.0	0.2	2
Thyroid carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Nasopharyngeal carcinoma	0	1	1	**2**	0.0	0.1	0.1	0.0	**0.0**	0.0	0.1	1
Melanoma	3	1	3	**7**	0.2	0.1	0.2	0.1	**0.1**	0.0	0.3	2
Skin carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Other carcinoma	1	0	4	**5**	0.1	0.0	0.3	0.1	**0.1**	0.0	0.2	2
XII OTHER AND UNSPECIFIED NEOPLASMS	3	0	3	**6**	0.2	0.0	0.2	0.1	**0.1**	0.0	0.2	2
Other specified malignant	1	0	2	**3**	0.1	0.0	0.1	0.1	**0.1**	0.0	0.1	1
Other unspecified malignant	2	0	1	**3**	0.1	0.0	0.1	0.1	**0.1**	0.0	0.1	1
MALIGNANT TOTAL	611	526	459	**1596**	37.2	32.8	30.3	33.5	**33.8**	32.1	35.5	502
NON-MALIGNANT CONDITIONS	14	0	0	**14**	0.9	0.0	0.0	0.3	**0.3**	0.2	0.5	4
Langerhans Cell Histiocytosis	12	0	0	**12**	0.7	0.0	0.0	0.3	**0.3**	0.1	0.4	4
Fibromatosis	2	0	0	**2**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	1
OVERALL TOTAL	625	526	459	**1610**	38.1	32.8	30.3	33.8	**34.1**	32.5	35.8	506

MORTALITY 1988-1997	MALE											
	NUMBER OF CASES				RATES PER MILLION							
	0-4	**5-9**	**10-14**	**All**	**0-4**	**5-9**	**10-14**	**Crude**	**ASR**	***LCL***	***UCL***	***Cum.***
I LEUKAEMIA	196	246	221	**663**	11.4	14.7	14.0	13.3	**13.2**	12.2	14.2	200
Acute lymphoid leukaemia (ALL)	96	202	157	**455**	5.6	12.0	9.9	9.1	**8.9**	8.1	9.7	138
Acute non-lymphocytic leukaemia (ANLL)	71	36	47	**154**	4.1	2.1	3.0	3.1	**3.2**	2.7	3.7	46
Chronic myeloid leukaemia (CML)	19	5	11	**35**	1.1	0.3	0.7	0.7	**0.7**	0.5	1.0	10
Other specified leukaemia	0	0	1	**1**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Unspecified leukaemia	10	3	5	**18**	0.6	0.2	0.3	0.4	**0.4**	0.2	0.5	5
II LYMPHOMAS	26	46	51	**123**	1.5	2.7	3.2	2.5	**2.4**	2.0	2.8	37
Hodgkins disease	0	4	7	**11**	0.0	0.2	0.4	0.2	**0.2**	0.1	0.3	3
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	24	41	42	**107**	1.4	2.4	2.7	2.1	**2.1**	1.7	2.5	32
Unspecified lymphoma	2	0	0	**2**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	1
Miscellaneous reticulo-endothelial neoplasm	0	1	2	**3**	0.0	0.1	0.1	0.1	**0.1**	0.0	0.1	1
III BRAIN AND SPINAL NEOPLASMS	199	217	176	**592**	11.6	12.9	11.1	11.9	**11.9**	10.9	12.8	178
Ependymoma and Choroid Plexus	42	21	16	**79**	2.4	1.3	1.0	1.6	**1.6**	1.3	2.0	24
Astrocytoma	38	66	60	**164**	2.2	3.9	3.8	3.3	**3.2**	2.7	3.7	50
Primitive neuroectodermal tumour (PNET)	72	67	53	**192**	4.2	4.0	3.4	3.9	**3.9**	3.3	4.4	58
Other glioma	20	54	29	**103**	1.2	3.2	1.8	2.1	**2.0**	1.6	2.4	31
Other specified central nervous system (CNS) tumour	6	2	11	**19**	0.3	0.1	0.7	0.4	**0.4**	0.2	0.5	6
Unspecified central nervous system (CNS) tumour	21	7	7	**35**	1.2	0.4	0.4	0.7	**0.7**	0.5	1.0	10
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS	141	92	19	**252**	8.2	5.5	1.2	5.1	**5.3**	4.6	5.9	74
Neuroblastoma	140	92	19	**251**	8.1	5.5	1.2	5.0	**5.3**	4.6	5.9	74
Other sympathetic nervous system (SNS) tumour	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
V RETINOBLASTOMA	5	8	1	**14**	0.3	0.5	0.1	0.3	**0.3**	0.1	0.4	4
VI RENAL TUMOURS	40	18	7	**65**	2.3	1.1	0.4	1.3	**1.4**	1.0	1.7	19
Wilms' tumour etc.	39	18	6	**63**	2.3	1.1	0.4	1.3	**1.3**	1.0	1.7	19
Renal carcinoma	0	0	1	**1**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Other renal	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
VII HEPATIC TUMOURS	22	5	8	**35**	1.3	0.3	0.5	0.7	**0.7**	0.5	1.0	10
Hepatoblastoma	20	1	2	**23**	1.2	0.1	0.1	0.5	**0.5**	0.3	0.7	7
Hepatic carcinoma	2	4	6	**12**	0.1	0.2	0.4	0.2	**0.2**	0.1	0.4	4

MORTALITY 1988-1997 *Continued*	MALE											
	NUMBER OF CASES				RATES PER MILLION							
	0-4	5-9	10-14	All	0-4	5-9	10-14	Crude	ASR	*LCL*	*UCL*	*Cum.*
VIII MALIGNANT BONE TUMOURS	1	11	61	**73**	0.1	0.7	3.9	1.5	**1.4**	1.0	1.7	23
Osteosarcoma	1	6	37	**44**	0.1	0.4	2.3	0.9	**0.8**	0.6	1.1	14
Chondrosarcoma	0	0	2	**2**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	1
Ewing's sarcoma	0	5	22	**27**	0.0	0.3	1.4	0.5	**0.5**	0.3	0.7	8
Other specified bone tumour	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Unspecified bone tumour	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
IX SOFT TISSUE SARCOMAS	57	53	44	**154**	3.3	3.2	2.8	3.1	**3.1**	2.6	3.6	46
Rhabdomyosarcoma	38	35	21	**94**	2.2	2.1	1.3	1.9	**1.9**	1.5	2.3	28
Fibrosarcoma etc.	1	3	3	**7**	0.1	0.2	0.2	0.1	**0.1**	0.0	0.2	2
Karposi's sarcoma	0	1	0	**1**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	0
Other specified soft tissue sarcoma	12	12	13	**37**	0.7	0.7	0.8	0.7	**0.7**	0.5	1.0	11
Unspecified soft tissue sarcoma	6	2	7	**15**	0.3	0.1	0.4	0.3	**0.3**	0.1	0.5	5
X GERM CELL AND GONADAL NEOPLASMS	12	2	9	**23**	0.7	0.1	0.6	0.5	**0.5**	0.3	0.7	7
Intracranial and intraspinal (CNS) germ cell	6	1	8	**15**	0.3	0.1	0.5	0.3	**0.3**	0.1	0.5	5
Other non-gonadal germ cell	6	1	0	**7**	0.3	0.1	0.0	0.1	**0.2**	0.0	0.3	2
Gonadal germ cell	0	0	1	**1**	0.0	0.0	0.1	0.0	**0.0**	0.0	0.1	0
Gonadal carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Other gonadal	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
XI CARCINOMAS AND EPITHELIAL NEOPLASMS	2	6	17	**25**	0.1	0.4	1.1	0.5	**0.5**	0.3	0.7	8
Adrenocortical carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Thyroid carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Nasopharyngeal carcinoma	0	1	3	**4**	0.0	0.1	0.2	0.1	**0.1**	0.0	0.1	1
Melanoma	2	3	2	**7**	0.1	0.2	0.1	0.1	**0.1**	0.0	0.2	2
Skin carcinoma	0	0	0	**0**	0.0	0.0	0.0	0.0	**0.0**	0.0	0.0	0
Other carcinoma	0	2	12	**14**	0.0	0.1	0.8	0.3	**0.3**	0.1	0.4	4
XII OTHER AND UNSPECIFIED NEOPLASMS	1	1	0	**2**	0.1	0.1	0.0	0.0	**0.0**	0.0	0.1	1
Other specified malignant	0	1	0	**1**	0.0	0.1	0.0	0.0	**0.0**	0.0	0.1	0
Other unspecified malignant	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
MALIGNANT TOTAL	702	705	614	**2021**	40.9	42.0	38.8	40.6	**40.6**	38.9	42.4	608
NON-MALIGNANT CONDITIONS	15	0	1	**16**	0.9	0.0	0.1	0.3	**0.4**	0.2	0.5	5
Langerhans Cell Histiocytosis	14	0	1	**15**	0.8	0.0	0.1	0.3	**0.3**	0.2	0.5	4
Fibromatosis	1	0	0	**1**	0.1	0.0	0.0	0.0	**0.0**	0.0	0.1	0
OVERALL TOTAL	717	705	615	**2037**	41.7	42.0	38.9	40.9	**41.0**	39.2	42.8	613

Appendix 5: ONS Mortality data for the 0-24 age group

MORTALITY BY ICD CODE (AGE 0-24 years) 1988-1997

		NUMBER OF CASES							RELATIVE FREQUENCY (%)	RATES PER MILLION							
ICD	**CAUSE OF DEATH**	**0-4**	**5-9**	**10-14**	**15-19**	**20-24**	**All**	**M/F**	**Overall**	**0-4**	**5-9**	**10-14**	**15-19**	**20-24**	**Crude**	**ASR**	***Cum***
140-149	**Malignant neoplasm of lip, oral cavity and pharynx**	7	12	15	26	31	91	1.1	1.3	0.2	0.4	0.5	0.8	0.8	0.5	0.5	14
150-159	**Malignant neoplasm of digestive organs and peritoneum**	46	13	27	65	140	291	1.3	4.1	1.4	0.4	0.9	2.0	3.8	1.8	1.6	42
160-165	**Malignant neoplasm of respiratory and intrathoracic organs**	11	6	6	16	43	82	1.6	1.1	0.3	0.2	0.2	0.5	1.2	0.5	0.4	12
170-175	**Malignant neoplasm of bone, connective tissue, skin and breast**	71	82	175	346	506	1180	1.3	16.5	2.1	2.5	5.7	10.8	13.7	7.1	6.4	174
170	Malignant neoplasm of bone and articular cartilage	9	26	120	213	205	573	1.5		0.3	0.8	3.9	6.7	5.6	3.4	3.1	86
171	Malignant neoplasm of connective and other soft tissue	60	52	50	109	159	430	1.2		1.8	1.6	1.6	3.4	4.3	2.6	2.4	63
172	Malignant melanoma of skin	2	3	4	22	106	137	1.1		0.1	0.1	0.1	0.7	2.9	0.8	0.7	19
174	Malignant neoplasm of female breast	0	0	0	0	25	25	-		0	0	0	0	0.7	0.2	0.1	3
179-189	**Malignant neoplasm of genitourinary organs**	82	49	29	72	232	464	0.8	6.5	2.4	1.5	0.9	2.3	6.3	2.8	2.6	67
180	Malignant neoplasm of cervix uteri	1	0	0	0	51	52	-		0.0	0.0	0.0	0.0	1.4	0.3	0.2	7
183	Malignant neoplasm of ovary and other uterine adnexa	1	2	5	27	43	78	-		0.0	0.1	0.2	0.8	1.2	0.5	0.4	11
186	Malignant neoplasm of testis	1	0	3	26	86	116	-		0.0	0.0	0.1	0.8	2.3	0.7	0.6	16
190-199	**Malignant neoplasm of other and unspecified sites**	534	556	323	289	404	2106	1.3	29.5	15.9	16.9	10.4	9.0	10.9	12.7	13.0	316
190	Malignant neoplasm of eye	15	11	2	1	3	32	1.0		0.4	0.3	0.1	0.0	0.1	0.2	0.2	5
191	Malignant neoplasm of brain	247	365	251	196	286	1345	1.3		7.4	11.1	8.1	6.1	7.7	8.1	8.1	202
192	Malignant neoplasm of other and unspecified parts of nervous system	12	11	15	12	16	66	2.5		0.4	0.3	0.5	0.4	0.4	0.4	0.4	10
194	Malignant neoplasm of other and endocrine glands and related structures	240	156	37	31	30	494	1.2		7.1	4.8	1.2	1.0	0.8	3.0	3.3	74
200-208	**Malignant neoplasm of lymphatic and haematopoietic tissue**	401	460	453	699	891	2904	1.6	40.6	11.9	14.0	14.6	21.9	24.1	17.5	16.8	433
200,202	**Non-Hodgkin's lymphoma**	42	60	65	122	199	488	2.3	6.8	1.3	1.8	2.1	3.8	5.4	2.9	2.7	72
200	Lymphosarcoma and reticulosarcoma	6	6	8	19	23	62	5.9		0.2	0.2	0.3	0.6	0.6	0.4	0.3	9
201	Hodgkin's disease	0	5	10	67	181	263	1.3	3.7	0.0	0.2	0.3	2.1	4.9	1.6	1.3	37
202	Other malignant neoplasm of lymphoid and histiocytic tissue	36	54	57	103	176	426	2.1		1.1	1.6	1.8	3.2	4.8	2.6	2.4	63
204-208	**All Leukaemias**	575	602	555	766	791	3289	1.6		17.1	18.3	17.9	23.9	21.4	19.8	19.5	494
204	Lymphoid leukaemia	187	288	243	309	232	1259	1.9	17.6	5.6	8.8	7.8	9.7	6.3	7.6	7.6	191
205	Myeloid leukaemia	136	87	115	177	254	769	1.2	10.8	4.0	2.7	3.7	5.5	6.9	4.6	4.4	114
206	Monocytic leukaemia	6	1	3	5	2	17	0.9	0.2	0.2	0.0	0.1	0.2	0.1	0.1	0.1	3
207	Other specified leukaemia	11	0	2	3	0	16	0.3	0.2	0.3	0.0	0.1	0.1	0.0	0.1	0.1	2
208	Leukaemia of unspecified cell type	20	19	15	14	21	89	1.7	1.2	0.6	0.6	0.5	0.4	0.6	0.5	0.5	13
225	Benign neoplasm of brain and other parts of nervous system	4	2	0	5	16	27	1.5	0.4	0.1	0.1	0.0	0.2	0.4	0.2	0.1	4
TOTALS		**1156**	**1180**	**1028**	**1518**	**2263**	**7145**	**1.4**	**100.0**	**34.4**	**35.9**	**33.2**	**47.5**	**61.3**	**43.0**	**41.4**	**1062**

Appendix 6: NRCT Survival data for the 0-14 age group

Childhood cancer in England and Wales – 5-year % survival of patients diagnosed 1993-97
Note: results not given where N(cases)<10

	MALE n (cases)	Survival (%)	FEMALE n (cases)	Survival (%)	TOTAL n (cases)	Survival (%)
I LEUKAEMIA						
Acute lymphoid leukaemia (ALL)	919	80	726	81	1645	81
Acute non-lymphocytic leukaemia (ANLL)	174	53	148	58	322	55
Chronic myeloid leukaemia (CML)	33	39	17	53	50	44
Other specified leukaemia	1		3		4	
Unspecified leukaemia	11	45	10	70	21	57
II LYMPHOMAS						
Hodgkins disease	173	94	88	93	261	93
Non-Hodgkin lymphoma (NHL) and Burkitt's lymphoma	249	80	90	70	339	77
Unspecified lymphoma	3		0		3	
Miscellaneous reticulo-endothelial neoplasm	12	75	1		13	77
III BRAIN AND SPINAL NEOPLASMS						
Ependymoma and Choroid Plexus	99	60	75	76	174	67
Astrocytoma	346	79	360	80	706	79
Primitive neuroectodermal tumour (PNET)	182	55	120	46	302	51
Other glioma	87	46	88	40	175	43
Other specified central nervous system (CNS) tumour	115	93	87	87	202	91
Unspecified central nervous system (CNS) tumour	37	65	40	68	77	66
IV SYMPATHETIC NERVOUS SYSTEM TUMOURS						
Neuroblastoma	220	52	175	60	395	55
Other sympathetic nervous system (SNS) tumour	3		2		5	
V RETINOBLASTOMA	**109**	**96**	**106**	**95**	**215**	**96**
VI RENAL TUMOURS						
Wilms' tumour etc.	193	83	176	83	369	83
Renal carcinoma	6		6		12	75
Other renal	3		0		3	
VII HEPATIC TUMOURS						
Hepatoblastoma	38	68	17	88	55	75
Hepatic carcinoma	3		5		8	

Childhood cancer in England and Wales – 5-year % survival of patients diagnosed 1993-97
Note: results not given where N(cases)<10
Continued

	MALE n (cases)	Survival (%)	FEMALE n (cases)	Survival (%)	TOTAL n (cases)	Survival (%)
VIII MALIGNANT BONE TUMOURS						
Osteosarcoma	72	56	83	65	155	61
Chondrosarcoma	6		2		8	
Ewing's sarcoma	43	63	46	63	89	63
Other specified bone tumour	2		4		6	
Unspecified bone tumour	2		3		5	
IX SOFT TISSUE SARCOMAS						
Rhabdomyosarcoma	162	69	96	60	258	66
Fibrosarcoma etc.	28	86	25	84	53	85
Karposi's sarcoma	1		1		2	
Other specified soft tissue sarcoma	69	59	73	67	142	63
Unspecified soft tissue sarcoma	21	43	17	35	38	39
X GERM CELL AND GONADAL NEOPLASMS						
Intracranial and intraspinal (CNS) germ cell	30	87	28	71	58	79
Other non-gonadal germ cell	12	67	39	69	51	69
Gonadal germ cell	44	98	60	97	104	97
Gonadal carcinoma	0		6		6	
Other gonadal	0		0		0	
XI CARCINOMAS AND EPITHELIAL NEOPLASMS						
Adrenocortical carcinoma	2		5		7	
Thyroid carcinoma	8		18	100	26	100
Nasopharyngeal carcinoma	8		3		11	82
Melanoma	34	76	38	95	72	86
Skin carcinoma	10	100	13	92	23	96
Other carcinoma	35	71	34	91	69	81
XII OTHER AND UNSPECIFIED NEOPLASMS						
Other specified malignant	2		4		6	
Other unspecified malignant	11	100	24		35	89
NON-MALIGNANT CONDITIONS						
Langerhans Cell Histiocytosis	90	96	66	91	156	94
Fibromatosis	19	100	16	81	35	91
TOTAL	3727	74	3044	75	6771	75

Appendix 7: Survey of UKCCSG Centres and TCT Units

Child and adolescent cancer services needs assessment

The following survey will be sent to all UKCCSG Centres and TCT Units. It forms part of the needs assessment being conducted on behalf of NICE. Its aim is to provide a descriptive account of current service provision, covering aspects of the service for which current information is not available. All results will be anonymised.

The questionnaire has been developed in consultation with clinicians and service users. It is designed with the hope that the information required to answer the questions will be readily obtainable. We therefore ask for completed forms to be returned by 26th September, 2003.

We have included a comments page at the end of the document. If you feel you wish to elaborate on answers, but no space is given in the questionnaire, feel free to write your points here. Please reference the question(s) to which any additional points relate.

The questionnaire is subdivided into the following subheadings:

NAME OF UKCCSG / TCT CENTRE……

Location of Unit (tick)	Children's Hospital	
	University Hospital	
	Cancer Treatment Centre	
	General Hospital	
	Other (please specify)	

Size of population served (approximately)…….

Service structure

1. How many designated oncology beds do you have available in your unit?

……..

2. How many beds intended for use by teenagers/ young people do you have?

……..

Are any of these dedicated for oncology (or are they used by other services)?

If so, how many? …….

3. Do you have a TCT unit in your area? Yes/ No

If so, how many beds does it have?……...

Specialist service provision

1. Where is paediatric radiotherapy delivered?

……..

2. How many clinical oncologists with paediatric interest support your Centre?

……..

3. Where do you send your patients for Bone Marrow Transplantion? (tick)

On site

Other Unit (please specify)…….

4. Is your paediatric neurosurgery unit on site? Yes/ No

If no, where are patients sent……..

and approximately how far is this from your Centre…….

5. Do you have a specialist paediatric neurosurgeon(s) ? Yes/ No

If so, how many?……..

6. Where do you send your patients requiring specialist bone/ sarcoma surgery?

……..

7. Where are your patients with Retinoblastoma sent for specialist ophthalmic assessment/ treatment?

……..

8. Do you send any other patients out of region for specialist services?

……..

Patient Activity

(For the question 1, please estimate numbers based on average admissions over the last 5 years. Please exclude from the estimate patients with non-malignant haematological conditions, those referred from overseas and those who are referred for a second opinion.)

1. How many <u>new</u> patients do you see in a year?…….

Of these, how many are aged 0-14 years?……..

How many are aged 15+ years?…….

2. What is the maximum age of new patients seen?……

Allied Services (a follow-up questionnaire was sent out in March 2004 to collect further information, see Appendix 8 – the results presented in this report include data from this and the follow-up questionnaires)

Do you have access to the following services? (tick if yes)	Specialist pharmacy	
	Occupational Therapy	
	Physiotherapy	
	Rehabilitation	
	Pain management	
	Psychology	
	Nutrition	
	Oral Health	
	Specialist Endocrinology Services	
	Fertility counselling	
	Fertility preservation	
	Other (please specify)	

Staffing

In the following section about staffing, please estimate personnel numbers in Whole Time Equivalents (WTE) if possible.

1. How many of the following medical staff are employed within your unit?

a. Paediatric Oncologists……

b. Paediatric Haematologists……..

c. Paediatric Surgeons……

Please specify the surgical specialities of the above……..
……..
……..
……
……..

d. Paediatric anaesthetists……..

e. Associate Specialists…….

Please specify the designated areas covered by your Associate Specialists……
……
……
……
……

f. Staff Grades……

Please specify the designated areas covered by your Staff Grades…….
……
……
……
……

g. Specialist Registrars……..

h. SHO's……..

2. Please complete the following section in relation to nurse staffing

Is there a designated Lead Nurse post for your service? Yes/No
If yes, what is the Title & Grade of that post?……

In-Patient Nurse staffing

Grade	Establishment	No in post	Funding source	Comments
H				
G				
F				
E				
D				
C				
B				
A				
Play staff or equivalent				

Day/Care Out-Patient staffing

Grade	Establishment	No in post	Funding source	Comments
H				
G				
F				
E				
D				
C				
B				
A				
Play staff or other				

Please Give All Other Nursing Posts which support your service:
Nurse Specialists/Nurse practitioners **(Please identify by Job Title)**
Title: Grade: No in Post: Funded by:

Outreach/Liaison Team
Numbers in Post: Grade: Funded By:

Research Nurses
Numbers in Post: Grade: Funded By:

Education Posts
Numbers in Post: Grade: Funded By:

Other Posts (by Title/Function; Grade; & No in post

Palliative Care

1. Place of Death. Please estimate the number and place of death for all deaths within your unit in 2002.

Age	Home	Hospice	UKCCSG Ward	DGH Ward	ICU	Other
0-14yrs						
15-24yrs						
Total						

2. Please estimate the number of all palliative deaths for your Centre, averaged over the last 5 years (January 1997 – December 2002).

(It may be difficult to obtain the data to complete this table. Whilst the information would be useful, please only complete it if it can be done easily).

Age group	Average number of deaths
0 – 14 years	
15– 24 years	
Overall Average	

3. <u>Service provision</u>
Does your Centre have a paediatric oncology outreach nurse(s) (POON) with a specific remit for supportive and palliative care?

Yes/ No

If yes complete the table below.

Personnel	**Total WTE & grades**	**NHS funded WTE**	**Other funded WTE (specify)**	**24 hour telephone support**	**24 hour home visits**
Macmillan Nurse					
CLIC nurse					
Other nurses					
Social Worker					
Clinical psychologist					
Palliative care Consultant (Paed)					
Palliative care consultant (adult)					
Other (specify)					

4. Do you have a children's hospice within the area served by your Centre?

Yes……. No……. If yes, how many……..

5. Do your patients use hospice facilities?

Paediatric Hospice	Inpatient	Day care	Hospice at home
Frequently			
Sometimes			
Rarely			
Never			

Adult Hospice	Inpatient	Day care	Hospice at home
Frequently			
Sometimes			
Rarely			
Never			

6. Bereavement Support. What service is provided following the death of a child? (tick all that apply)

	POON	**Social worker**	**Consultant**	**Ward Nurse**	**Bereavement co-ordinator**	**Other (specify)**
Immediate contact						
Attend funeral						
Send flowers						
Letter contact						
Follow-up appointment						
Professional de-brief						
Bereavement planning meeting						
Home visits						
Contact for a set period						
Open ended contact						
Bereaved Parent Groups						
Sibling groups						

7. If your POON team does not provide 24hour on-call telephone and home support for palliative care, please state reasons why.

……
……
……

8. What other changes / additions would you need to provide a comprehensive 24 hour palliative care service from you Centre.

Increased number of POONS	
Clinical psychology time	
Increased social work time	
Bereavement support worker	
Children's community nurses	
Palliative care consultant	
Other (specify)	

Shared Care

The following description of the levels of shared care units is taken from the Standards document issued by Birmingham Children's Hospital NHS Trust.

Level 1 Initiate treatment for acute lymphoblastic leukaemia.
In-patient and out-patient care for children and young people with cancer following initiation of treatment by UKCCSG centre.
Treatment of febrile neutropenia.

Level 2 In-patient and out-patient care for children and young people with cancer following initiation of treatment by UKCCSG centre.
Treatment of febrile neutropenia.

Level 3 Out-patient care for children and young people with cancer following initiation of treatment by UKCCSG centre.
Treatment of febrile neutropenia.

Level 4 Treatment of febrile neutropenia.

Please answer the questions in this section using this as an approximate guide if possible.

1. How many shared care centres (SCC's) are attached to your Centre?

……..

2. Of these, how many work at:

Level 1……
Level 2……
Level 3……
Level 4……

3. How many of your SCC's are associate members of the UKCCSG?

……..

Family Support

1. Do you have residential facilities for relatives? Yes/ No

How many parent beds are available?……..

Additional services

1. Can you identify areas of the service you provide that add value?
(e.g relaxation, sibling groups etc.)

……
……
……
……
……
……

2. Are other non-NHS organisations involved in providing these or other services? Please specify.

……
……
……
……
……
……

3. What would you identify as being lacking from your service provision?

……
……
……
……

Comments

Thank you for your time and contribution

Appendix 8: Supplementary survey of UKCCSG Centres and TCT Units examining Allied Health Services

1. How much designated support to you have at your from Allied Health Professionals?

Please describe number of whole time equivalents, or other access as available:

	Number of WTE and grade	Number of designated sessions per week	Access as required (informal sessions) per week
Physiotherapy:			
Occupational Therapy:			
Psychology:			
Speech Therapy:			
Dietetics:			
Play Therapy:			
Adolescent Support Workers:			
Diagnostic **Paediatric Radiographers:**			
Therapeutic **Paediatric Radiographers:**			
Research Nurses			
Data Managers			

Please indicate below where, in your opinion, your service is under-supported (if possible please prioritise where you perceive particular needs).

2. Regarding psychological/psychiatric services. Please clarify whether you have support from:

a) Psychiatric Services ……YES/NO

If YES please specify the average number of sessions/ week ……

b) Psychological Services ……YES/NO

If YES please specify the average number of sessions/ week ……

3. What is the age of patients that you would routinely admit to your adolescent ward/unit? ……

Please send all your responses to the NCC-C by **Friday 7th May** at the following address:

National Collaborating Centre for Cancer
2nd Floor, Front Suite, Park House
Greyfriars Road
Cardiff
CF10 3AF

or preferably by e-mail to andrew.champion@nccc.wales.nhs.uk