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Guidance on Cancer Services

Improving Outcomes in Children and Young People with Cancer

The Manual

The paragraphs are numbered for the purposes of consultation. The final version will not contain numbered paragraphs.

NICE Stakeholder Consultation version

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Foreword

1. This guidance is the latest in the 'Improving Outcomes in Cancer' series and is the first to be produced by the National Collaborating Centre for Cancer (NCC-C). Developing this guidance gave particular challenges, not only because it was the first work of a new organisation and there was a very high standard to live up to, but also because of the special features of the topic. Whereas most of the previous guidance has dealt with a well defined tumour type, this guidance deals with the service provision for a group of cancer patients defined not by the characteristics of the tumour but by their age. This led very early on, when we were consulting on the draft scope for the guidance, to a problem of definition.
2. The original title of the guidance was 'Child and Adolescent Cancer', but it was soon clear that setting an arbitrary upper age limit was unacceptable. As a result the title and the scope have been changed to include children and young people with cancer. This is not just a cosmetic change, but reflects some important principles which we hope are clear in the guidance.
3. During the development of this guidance there have been changes in the structure of the NHS in England and its commissioning arrangements with the introduction from 1 April 2005 of Payment by Results. It is not yet clear what effect this will have on the way in which service guidance of this kind is implemented.
4. I should like to acknowledge the great commitment and hard work of the chair, Dr Cerilan Rogers, the lead clinician, Dr Meriel Jenney, and all the members of the guidance development group, who gave of their time willingly to this project, with the shared belief that this guidance provides an opportunity to improve the care of an especially vulnerable group of patients. We are all grateful to a number of other experts, acknowledged

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- in Appendix 6.4, who provided written papers or informal advice to the group, without whom this guidance would have been incomplete.
5. I hope that the guidance will provide an acceptable blueprint to the NHS in England and Wales and lead to significant and lasting changes to the care of children and young people with cancer, that improve not only the clinical outcomes, but also the experience of the patients and their families.

Dr Fergus Macbeth, February 2005

Key recommendations

6. • Planning, commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be coordinated, to ensure there is an appropriate balance of service provision and allocation of resources. The principle that underpins the guidance is that of age appropriate, safe and effective services as locally as possible, not local services as safely as possible.
7. • Commissioners should ensure, through cancer networks in partnership with services for children and young people, that:
 - there is a clear organisational structure for these services, including cancer network leads for children, teenagers and young adults with cancer.
 - all aspects of care for children and young people with cancer should be undertaken by appropriately trained staff.
 - principal treatment centres for each cancer type are identified for children and for young people, with associated referral pathways, including to centres outside the network of residence when necessary.
 - principal treatment centres are able to provide a sustainable range of services, with defined minimum levels of staffing, as outlined in the guidance.
 - shared care arrangements are established, which identify a lead clinician and have approved clinical protocols for treatment and care, minimum standards, and defined areas of responsibility with the principal treatment centres.
 - all sites delivering cancer therapy in this age group should be subject to peer review.
 - all relevant national guidance is followed (see Appendix 1).

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8. • Care should be delivered throughout the patient pathway by multidisciplinary teams (MDTs), including all relevant specialist staff. Membership and governance of these teams should be explicit and include clearly defined responsibility for clinical and managerial leadership.
9. • Appropriately skilled, professional key workers should be identified to support individual children and young people, and their families by:
 - coordinating their care across the whole system and at all stages of the patient pathway
 - providing information
 - assessing and meeting their needs for support.
10. • All care for children and young people under 19 years must be provided in age appropriate facilities [35, Appendix 1]. Young people of 19 and older should also have unhindered access to age appropriate facilities and support when needed. All children and young people must have access to tumour specific or treatment specific clinical expertise as required.
11. • Theatre and anaesthetic sessional time should be adequately resourced for all surgical procedures, including diagnostic and supportive procedures, in addition to other definitive tumour surgery. Anaesthetic sessional time should also be assured for radiotherapy and painful procedures. The paediatric surgeon with a commitment to oncology should have access to emergency theatre sessions during routine working hours.
12. • All children and young people with cancer should be offered entry to any clinical research trial for which they are eligible and adequate resources should be provided to support such trials.
13. • If there is no currently open relevant trial, children and young people with cancer should be treated according to agreed treatment and care protocols based on expert advice, and resources provided to monitor and evaluate outcomes.

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14. •The issues related to the registration of cancers in 15–24 year olds and the potential value of a dedicated register within the structures of the National Cancer Registries should be addressed urgently.
15. •The need for trained specialist staff across all disciplines, able to work with children and young people with cancer, should be included in workforce development plans by cancer networks, to ensure the provision of a sustainable service.
16. •Specific attention is required to address the shortage of allied health professional expertise in this area and the evaluation of the contribution of such services.

Background

Introduction

17. The purpose of this guidance is to provide recommendations on service provision for children and young people with malignant disease, based on the best available evidence. It is primarily for commissioners of services, but has equal relevance for service providers.
18. There are many other current national initiatives of relevance, not least national service frameworks (NSFs) and other “Improving Outcomes” guidance, and care has been taken not to duplicate this work. The guidance also assumes compliance with the relevant national guidelines on the administration/management of therapies (see Appendix 1) and any relevant legal frameworks.
19. The population, healthcare settings and services and key areas of clinical management are included in detail in the Scope (see Appendix 2). The guidance covers children from birth and young people in their late teens and early twenties, presenting with malignant disease, and the whole range of NHS services required to meet their needs. The guidance has not used a specific upper age limit in the recommendations, other than for the children’s NSF, recognising that any such limit would be arbitrary and that services should be appropriate for individual needs.

Principles

20. Certain principles were adopted by the Guidance Development Group (GDG) in considering their recommendations:
 - these should be evidence based
 - the aim is for safe and effective services as locally as possible, not local services as safely as possible
 - an integrated, whole systems approach to these services is essential

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- there needs to be a sustainable balance between centralisation and decentralisation.

Challenges

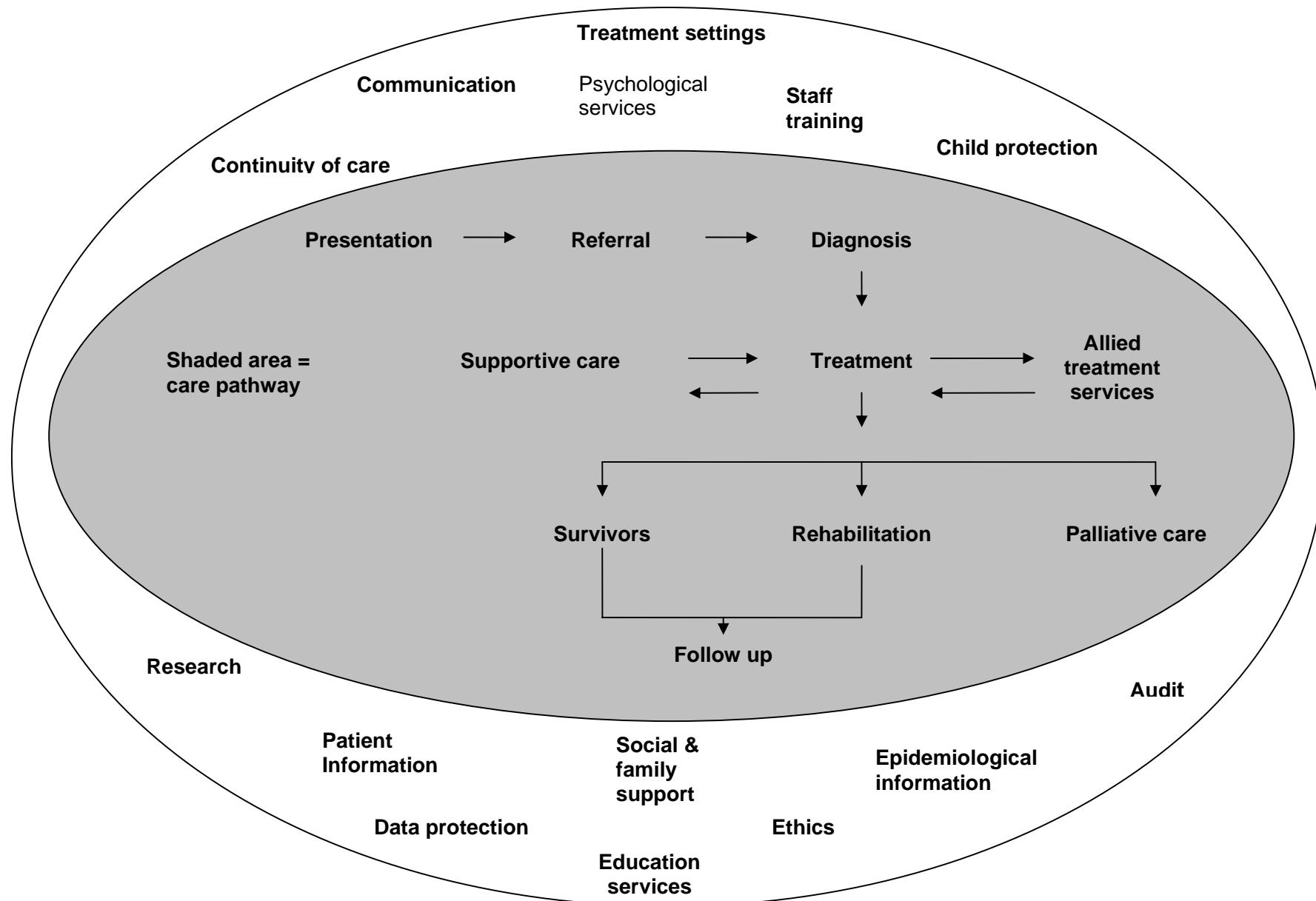
21. There were challenges in the development of this guidance. The potential material for inclusion was vast and the Group have tried to focus on those aspects of the service which are likely to have a significant impact on health outcomes.

Types of cancer

22. There are a wide range of conditions, which for convenience are grouped into three categories; solid tumours, haematological malignancies and central nervous system malignancies. A care pathway approach has been used (see figure A) to ensure inclusion of the main service issues. Some areas such as data protection, ethics and staff training are not specifically addressed in dedicated sections of the Guidance.

Figure A.

THE CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH CANCER AND ITS WIDER CONTEXT



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Definition of children and young people

23. There are various definitions of the boundary between childhood and adulthood used by society, some of which define a legal entitlement or access to services. Children are recognised as different because they are, both in terms of their needs and the disorders they experience. Their needs differ according to their developmental stage (emotional, social, psychological and physical) and the group covered by this guidance is therefore heterogeneous.
24. Indeed, across the age spectrum, children are as different from each other as they are from adults. The guidance is based around three main groups, children, teenagers and young adults, although the term "young people" is used throughout when it is unnecessary to differentiate between the latter two.

Age range

25. Very different issues arise depending on the age and maturity of the individuals whose needs are being addressed. Childhood and adolescence is a time of enormous change, physically, psychologically and socially, and this influences the different patterns of malignancy seen, their pathological behaviour, response to treatment and eventual outcomes. The truism that outcomes encompass more than improved health, in terms of survival, mortality and morbidity, is even more of a reality for children, whose outcomes need to include the ability to mature successfully into adulthood. The late effects of treatment are particularly relevant in this context.

Families

26. The dependence of children and young people on their families and the profound effect severe ill health and/or death of a child or young person has on other family members are additional important factors that significantly affect all service planning and delivery.

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Sources of evidence

27. A number of relevant existing guidelines and reviews were accessed (see the Evidence Review).
28. Searches of various databases were undertaken in response to specific questions formulated by the Group (methodology outlined in the Evidence Review).
29. A nominated panel of experts was invited to contribute via the submission of formal position papers for consideration of the GDG (see Appendix 6.4 and the Evidence Review).
30. Where there was no substantial evidence base for important key questions, consensus methods were used by the Group.

Epidemiology

31. The guidance development was supported by a needs assessment exercise, covering both England and Wales, undertaken by the National Public Health Service for Wales, some of which is included below. The full assessment is included in the Evidence document.

Registration

32. Registration of cancer cases is voluntary. There are nine population-based regional cancer registries in England. The Welsh Cancer Intelligence and Surveillance Unit has responsibility for cancer registrations on behalf of the Welsh Assembly Government. The National Cancer Intelligence Centre at the Office for National Statistics (NCIC-ONS) collates cancer registration data nationally for England, Wales and Scotland. All registries systematically collect data from a number of sources to maximise completeness and accuracy. Additionally, the National Registry of Childhood Tumours (NRCT) in Oxford registers cases of malignancy in children under the age of 15 years. There is no comparable dedicated national register of cancer cases occurring between the ages of 15-24.

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Classification

33. NCIC-ONS data are coded using the International Classification of Diseases system (ICD) version 10. This is based on a topographical description of tumour site and allows detailed coding of adult tumours. Cancers that develop in childhood are different from those in adult life. There is increased histological diversity and many tumours develop from embryonal tissue. ICD is less able to code these tumours accurately and so an alternative classification has been developed which is based on histological characteristics. This alternative system, The International Classification of Childhood Cancer (ICCC), is used by the NRCT.
34. The needs assessment conducted for this Guidance was required to use ICCC. The existence of the two coding systems caused delays in data collection. Data for the 0-14 year age group was received from NRCT and was coded in ICCC. To allow production of comparable analyses of incidence in the 15-24 year age groups, the ICD coded NCIC-ONS data had to be converted into ICCC. As there is no nationally agreed conversion table between these systems this process took time. ICCC coded prevalence, mortality and survival data were not available for the 15-24 year age group within the time available.

Aetiology

35. The identified risk factors for child and adolescent cancers account for only a minority of cases, so there is limited potential for preventive interventions. The identified risk factors for childhood cancer include genetic, infective, hormonal and radiation [1].

Incidence

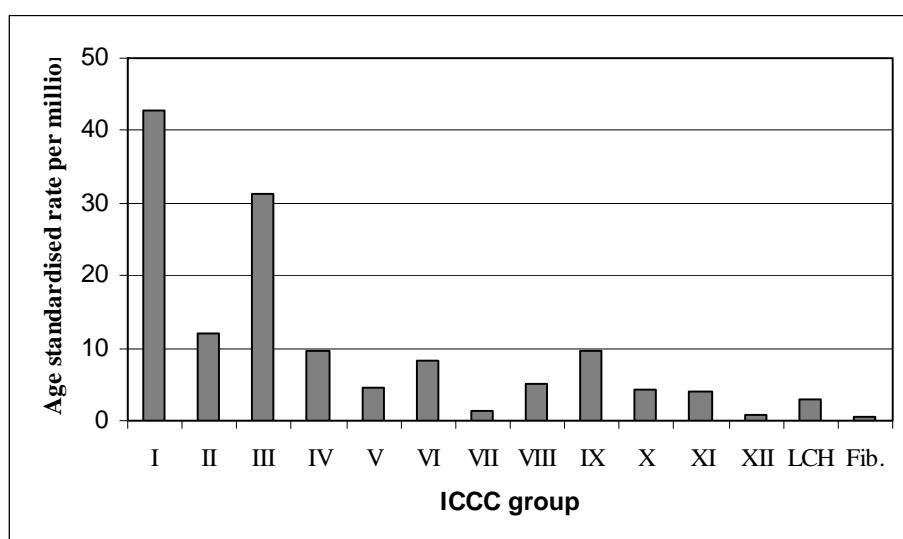
36. Cancers in children aged less than 15 years are rare, causing less than 1% of all cancers in industrialised countries [1]. Data from 1981–1990 [2] suggest an age-standardised annual incidence in England and Wales of

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122 per million children. The NRCT quotes a figure of 133.7 per million (for data between 1988 and 1997), but this includes a small number of non malignant diagnoses.

37. The most common diagnoses are leukaemia (42.9 per million), brain and spinal neoplasms (31.4 per million) and lymphoma (12.0 per million). The least common diagnosis in this age group are hepatic tumours (1.3 per million).

Figure B 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

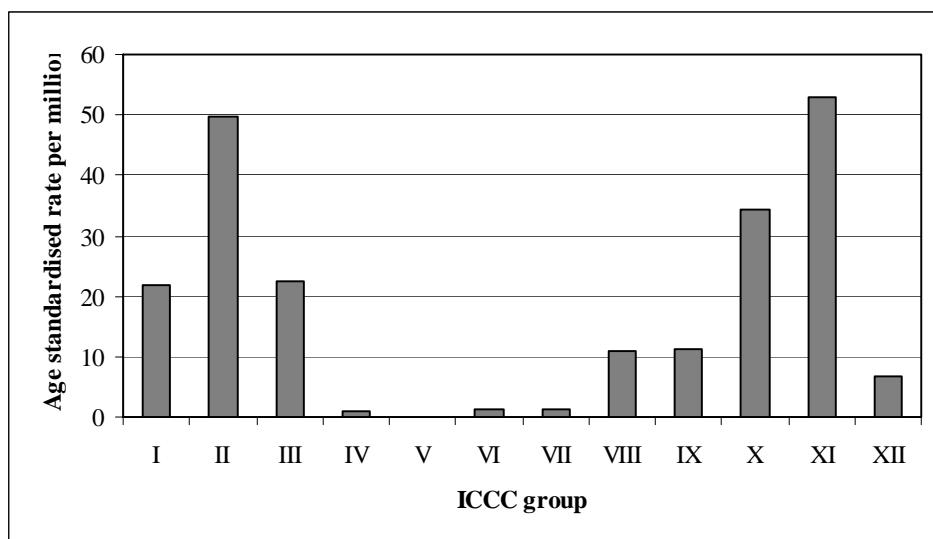
*International Classification of Childhood Cancers (ICCC) [3]

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. LCH – Langerhans cell histiocytosis; Fib. - fibromatosis

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38. In 15–24 year olds, ONS data from 1988–1997 give an overall age standardised rate of 213.9 per million. The most common diagnoses include carcinoma and epithelial neoplasms (53.1 per million) and lymphomas (49.7 per million). The least common diagnosis was retinoblastoma.

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



Source: - ONS

39. The Scotland and Newcastle Lymphoma Group (SNLG) database [4] provides additional information for 15–24 year olds diagnosed, between 1994–2002, inclusive. There were 282 cases of Hodgkin's lymphoma, 51% in males. The median age at diagnosis was 21 years. For non-Hodgkin's lymphoma there were 114 cases, 57% in males, median age at diagnosis 20 years. These data apply to the population of Scotland and the north of England.

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Trends

40. An increase in the incidence of childhood and adolescent cancers has been demonstrated for a wide range of diagnoses. A study examining trends in childhood malignancy in the North West of England (1954–1988) identified significant linear increases in acute lymphoblastic leukaemia and Hodgkin's disease [5]. Additional investigation identified a significant increase in chronic myeloid leukaemia. A related study found significant linear increases in juvenile astrocytoma in males, medulloblastoma and neuroblastoma in females and non skin epithelial tumours overall [6].
41. In 15–24 year olds, there have been significant increases in incidence from 1979 to 1997 across all diagnostic groups [7]. Significant increases occurred in the incidence of gonadal germ cell tumours, melanoma and carcinoma of the thyroid. Smaller increases occurred for lymphomas, central nervous system tumours, acute myeloblastic leukaemia and genitourinary tract carcinomas. Incidence rates calculated for this report show a rise in the incidence of carcinomas and epithelial neoplasms in the 20–24 year age group that has resulted in this group replacing lymphoma as the most common group overall (ONS).

Comparison of incidence with other countries

42. The Automated Childhood Cancer Information System (ACCIS) publishes comparative incidence data from European Cancer Registries. The five year (1993–1997) world standardised incidence rates of all childhood cancers in England and Wales of 133.7 cases per million children, is similar to rates in other European countries (Table 1). The incidence rates range from 127.3 per million in Ireland to 170.4 per million in Finland. Comparable data for adolescents and young adults are not available.

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Table 1 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: Automated Childhood Cancer Information System (ACCIS)

* Data collection 1994–1997

** Data collection 1988–1997

*** Data collection 1993–1995

**** Data collection 1993–1996

Variation of incidence with age

43. The incidence of malignancy varies with age, with a peak in the first five years of life [1] and lowest incidence in those aged 8–10 years [8]. Cancer is more common in adolescents (aged 15–19) than in children, with a reported incidence of 150–200 per million [8]. In young adults aged 20–24 years, the incidence is higher again at 226 per million [7].

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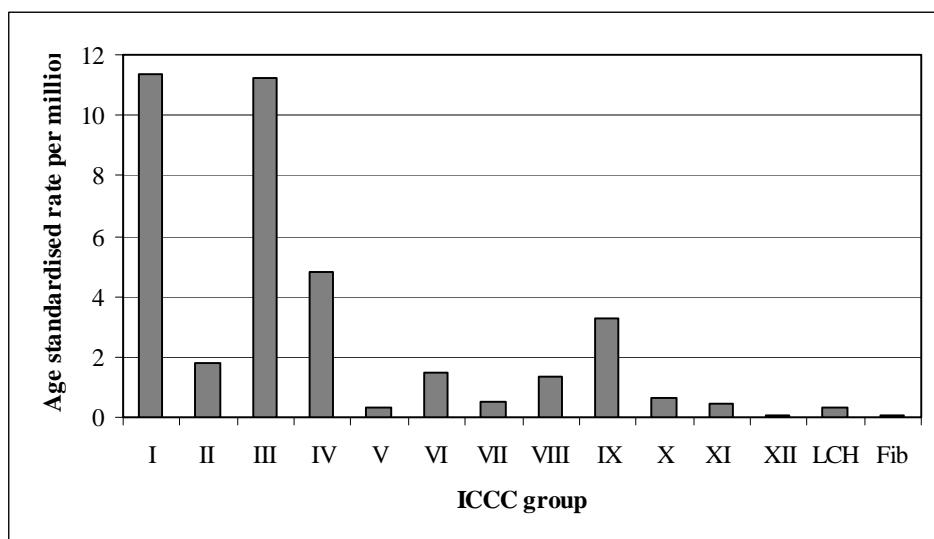
44. The type of malignancy also varies with age. Leukaemias and brain and spinal tumours are the most common malignancies of childhood [1, NRCT]. Epithelial neoplasms and lymphomas are the most common presentations in young adults and there is an increasing frequency of germ cell tumours and melanoma in this age group [7, ONS].
45. For most malignancies of childhood, the incidence is greater in boys than girls with an overall ratio of 1.2: 1 [2]. Malignancies more common in girls include malignant melanoma and cancers of the breast, thyroid and genitourinary tract [7].

Mortality

46. The highest mortality occurs in the diagnostic groups with highest incidence. Therefore in those aged 0–14 years, the leukaemias are the most common cause of death (30.7%). However, the relative frequencies in mortality between the ICCC groups is different from the relative frequencies in incidence because of variation in survival. For example, sympathetic nervous system tumours contribute 6.7% of new childhood cancer cases, but account for 12.3% of deaths due to poor survival. In contrast, retinoblastoma causes 3.2% of new cases but only 0.8% of deaths, suggesting favourable survival.

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Figure D Comparison of age-standardised mortality rates between the ICCC groups and non-malignant conditions in persons aged 0-14 years, per million population at risk, 1988-1997



Source: - NRCT

47. No ICCC coded mortality data are available for 15–24 year olds.

48. Using ICD-10 coded ONS data, the overall age-standardised mortality rate for 0–24 year olds is 41.4 per million (37.6 per million in the 0–14 year age groups (NRCT); higher in the older age group).

Survival

49. There have been remarkable improvements in the survival from most childhood malignancies over the past 30 years, with the overall survival in England and Wales for those diagnosed between 1993 and 1997 estimated to be 75% (Source: NRCT). The probability of survival varies with diagnosis. Lower survival is achieved, for example, in certain classes of brain and spinal tumours (43%), chronic myeloid leukaemia (44%) and neuroblastoma (55%), whilst 100% survival is reported for thyroid carcinoma.

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50. Improvement in survival has been attributed to advances in treatment and supportive care, centralising treatment to specialist centres and the inclusion of the majority of patients in national and international trials [1, 9], which has resulted in protocol-based management.
51. The paediatric section of the Eurocare 3 report [10] allows comparison of survival between 20 European countries in children aged less than 15 at the time of diagnosis. It reports the weighted five year survival for England and Wales for those diagnosed between 1990 and 1994 to be 71.1%. This is higher than the Eastern European countries where survival is reported to be between 63% and 66%, but lower than in Germany, Switzerland and the Nordic countries (except Denmark) where mean survival is 80%. The Automated Childhood Cancer Information System (ACCIS) also publishes comparative survival data from European registries for those aged 0–14, diagnosed between 1993 and 1997. This source quotes an overall survival of 73% for England and Wales, compared with 66% in Hungary and 81% in Iceland. This value for England and Wales value is not significantly different from other European countries, apart from Finland and Germany. The differences in survival reported by both sources may partly be due to differences in the registration and reporting of malignancies within population based registries. However, they may also reflect true differences in outcome.
52. National level survival data and comparative European survival data for 15–24 year olds have not been published.

Prevalence

53. The prevalence of disease is dependent upon the underlying incidence of disease and rates of survival. Increasing incidence of some diseases and overall improvements in survival are leading to an increasing population of children and young adults who have survived malignant disease.

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54. Among children aged 0–14 years, leukaemia is the most common diagnosis, 35.4% (age standardised rate 271.4 per million), brain and spinal neoplasm cases account for 20% (151.9 per million) and renal cases 8.5% (66.6 per million). These relative proportions show a difference from incidence data, reflecting the differing survival between disease groups.

Late effects

55. With increasing survival the physical, emotional and social sequelae, which may impair the quality of life in the long term, become more important. Although many of those cured of cancer during childhood or young adulthood will return to good health, others will experience significant late sequelae. These sequelae can occur at any time during or following completion of therapy. They include problems such as impairment of endocrine function (for some including infertility, abnormal growth and development or bone mineral accretion), cardiac and neurological impairment, cognitive decline (e.g. following treatment for tumours of the CNS) and psychological effects and increased risk of developing a second cancer [11]. On average, four percent of childhood cancer survivors develop a second primary malignancy within 25 years of diagnosis [11], although for certain diagnoses this figure is higher [12]. Radiotherapy is a particular risk factor [11, 13]. The risk of second malignancy, which can occur many years after the primary diagnosis, is estimated to be between four to six times the risk in the general population [11, 13].

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Key points

56. Cancers in children and young people are rare with an annual rate of new cases of 133.7 per million in those aged 0–14 years and 213.9 per million in those aged 15–24 years.
57. Cancers in children and young people show a characteristic pattern of incidence that changes with increasing age. Leukaemia and brain and spinal neoplasms are the most common diagnoses in the 0–14 year age group. Carcinomas and epithelial neoplasms and lymphomas are the most common in the 15–24 year age group.
58. Overall survival is high (currently 75% in 0–14 year olds), although disease specific survival varies.
59. Improved survival is contributing to the increase in absolute numbers of survivors of childhood cancer, which has implications for service provision.
60. Issues of differential coding and data collection systems between those aged 0-14 and those aged 15-24 hampers the calculation of comparable rates and therefore definition of need in this population.

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Current services

61. Information on service availability is drawn from the results of a survey of United Kingdom Children's Cancer Study Group (UKCCSG) treatment centres and Teenage Cancer Trust (TCT) units.

Cancer treatment

62. In England and Wales, care of children with cancer is offered and coordinated at 17 centres registered by the UKCCSG. Some children's centres have dedicated adolescent beds and there are also eight Teenage Cancer Trust Units, which offer separate facilities for young people that are appropriate to their age.

63. Shared care centres are based in secondary care facilities and are affiliated to UKCCSG centres. The provision of services at shared care centres varies from initial diagnosis only to greater involvement in the delivery of care for children and young people with cancer. Bone marrow transplantation services are changing, as a minimum number of procedures are now recommended to maintain clinical skills in a unit.

64. All TCT units and UKCCSG centres responded to the survey of child and adolescent services. Eighteen responses are recorded as some units and centres responded under a single corporate heading. A follow up questionnaire (on allied health services) was sent to UKCCSG Centres only, to which 17 of the 18 centres replied.

65. Results show that most centres have clinical oncology support, but only a minority have radiotherapy services delivered on site. Many centres undertake allogeneic bone marrow transplantation, others refer cases, as necessary, to a Joint Accreditation Committee ISCT [International Society for Cellular Therapy] – EBMT [European Group for Blood and Marrow Transplantation {JACIE} accredited centre. Eight of the 18 responses

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recorded have access to paediatric neurosurgery services on site or within an eight mile radius.

66. Most centres offer a range of allied health services such as specialist pharmacy, physiotherapy, occupational therapy and pain management, though access to these services may be limited.
67. Centres refer patients out of region for specialised services such as bone or sarcoma surgery, retinoblastoma assessment, liver and thyroid services.

Supportive and palliative care

68. All centres have access to at least one children's hospice but 13 reported that their patients 'rarely' or 'never' used this or the adult hospice service. Seven of the 18 centres offer 24 hour home visit and telephone advice for those requiring palliative care. The levels of staffing in palliative care vary considerably between units, though the survey did not express staff numbers as a ratio to new patients seen.
69. When asked to identify areas for improvement, centres suggested increased occupational therapy, psychology, psychiatry and social worker support, as particular service needs

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Service use

70. Use of services is measured by routinely collected hospital activity data.

Between 1998/9 and 2001/2, there were an annual average of 3684 episodes per million children aged 0-24. Hospital episode rates decline with age, with highest rates in the 0-4 year age group (5.0 per thousand children aged 0 to 24 years, 2001-2002) and lowest in 20-24 year olds (2.7 per 1000).

71. There is a trend of increasing in-patient and day case activity (1995/6 to

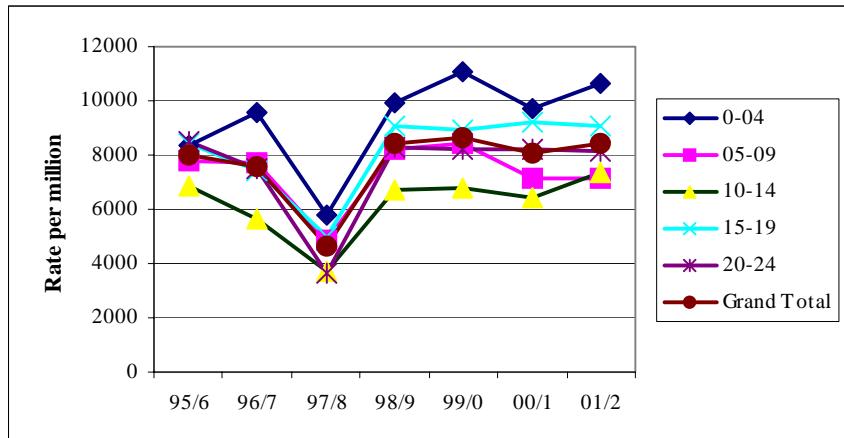
2001/02), which may, in part, reflect improved data collection. More intensive and complex treatments, greater use of clinical trial protocols, higher incidence of complications and improved survival all compound to increase activity levels. The data quality is poor in 1997/98 as a result of substantial under-recording of activity [14].

In-patient care

72. The highest in-patient episode rates are in the youngest age group (10.7 per 1000 children aged 0-4 years, 2001-02), reflecting the higher incidence of cancer in this group. Rates fall in 5-9 and 10-14 year olds but rise again from age 15 years (Figure E).

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



Data quality poor for 1997/8 – activity substantially under-recorded

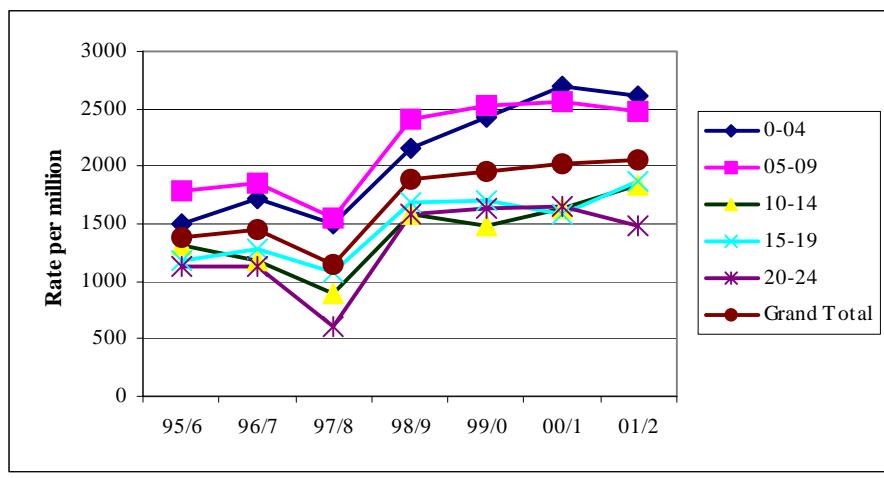
73. The mean number of in-patient bed days between 1995/6 and 2001/2 was 135,000 per annum for 0–24 year olds.

Day case care

74. Use of day case beds shows a small year on year increase, rising to a rate of 2.1 per 1000 children, aged 0–24 years in 2001/02. Figure F shows the variation in day case rates between age groups and the 0-4 and 5-9 age groups consistently have the highest rates.

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



Data quality poor for 1997/8 – activity substantially under-recorded

Procedures

75. The most commonly recorded procedures in childhood cancer patients are diagnostic and therapeutic spinal puncture for the management of leukaemia. Other common procedures include insertion of central venous lines, diagnostic bone marrow aspirate and administration of chemotherapy and immunotherapy. The administration of chemotherapy is the commonest procedure but is under recorded because of inaccuracy and quality of coding.
76. Measures of activity aggregated at strategic health authority level show wide variation in episode rates, in-patient and day case rates. This may be due to variations in clinical practice, but is more likely to result from variations in clinical coding and other data quality issues. Further work is required to explore these findings.

Palliative care

77. Most children with malignancy receive palliative care in the community, usually within the home. There are no routinely collected data that measure

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the use of palliative care services. The age-specific mortality rate has been taken as a proxy for need, though this will include many non-malignant conditions. One report estimates that the mortality due to malignancy for 13–24 year olds is 49.3 per million [15]. The wider definition of palliative care that includes conditions that may be ‘cured’ suggests that this would be a conservative figure of need for palliative care services.

Allied health services

78. These encompass the multidisciplinary care of the patient through active cancer therapy, rehabilitation and follow up. Many of these services are provided by allied health professionals (AHPs), who are particularly important in the delivery of supportive care, rehabilitation and palliative care. They also have a major contribution to make in the diagnostic phase and during acute care. The work of the AHP includes a sound grounding of the developmental aspects of childhood and adolescence and is considered a specialty area in itself.
79. AHPs encompass a wide range of disciplines, including diagnostic and therapeutic radiographers, physiotherapists, occupational therapists, dietitians and speech and language therapists. They support the individual’s biological, psychological and social wellbeing and health and can have a positive impact on the individual’s potential for recovery, as well as successful maturation to adulthood. They have strong links to non health services. Although not formally recognised as AHPs, other disciplines have an important role in these services, such as play specialists, activity coordinators and sonographers.

Non health services

80. Social care and education are essential in the management of children and young people with cancer and such services are provided by non health services from both the statutory and voluntary sectors.

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The care pathway

81. This chapter describes the service response, in terms of effective interventions, required to meet the needs of those within the remit of the guidance. A care pathway approach has been used (see figure A). It sets out the elements of care and support to be provided and includes which professionals should be involved in specific aspects of care, where it is felt necessary to define this. The organisation and coordination of care are covered in the chapter on service organisation.
82. Where possible, expected outcomes have been indicated. For this group, desirable outcomes include not only survival, but also normal development to adulthood, in so far as that is possible.
83. Recommendations about specific technologies or treatments have not been made unless they have a significant effect on service delivery or configuration.
84. Although cancer has been considered in the three main groups, solid tumours, haematological malignancies and central nervous system malignancies, many issues are generic. Where issues are specific to the particular type of tumour, this is indicated.

Presentation and referral

85. Cancer in children and young people is relatively rare. A GP will see, on average, a child under 15 with cancer every 20 years. There are a wide spectrum of malignancies in this group and a multiplicity of symptoms, many of which are common and non specific. Therefore the prompt diagnosis and referral of patients with suspected cancer from primary care may be very difficult and delay in appropriate referral is a key issue of concern for many patients and families. In addition it is well recognised that

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some deaths occur either before the diagnosis is made, or immediately around the time of diagnosis. These deaths are potentially avoidable.

86. The NICE clinical guidelines for general practitioners on *Referral for Suspected Cancer*,[60, Appendix 1] include a section on children's cancer. Implementation of these guidelines may help professionals in primary care identify the rare patients at greater risk of having a malignant diagnosis.
87. The recommendations are not presented here in detail, but two points are worth noting:
 - Parents know their child best. Parental insight and knowledge are important and persistent parental anxiety should be sufficient reason for investigation and/or referral.
 - It is particularly important to treat seriously those whose symptoms do not resolve as expected or who are seen repeatedly without a diagnosis being made.

A. Recommendations

88. Primary care trusts/local health boards should ensure appropriate training is provided for the implementation of the NICE clinical guidelines on *Referral for Suspected Cancer* [60, Appendix 1] as they apply to children and young people. This should include the new forms of primary care contact, such as NHS Direct, walk in centres, nurse practitioners and health visitors, and the use of relevant IT links.
89. Specific education for professionals in primary and secondary care in the recognition and referral of suspected CNS malignancy and other solid tumours in children and young people should be established.
90. Cancer networks should ensure that there are agreed local arrangements for referral of children and young people with suspected cancer from primary care to named clinicians or to specified clinics with adequate specialist time to see urgent referrals. This would be a secondary care

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paediatrician in the first instance, in keeping with the principles of shared care management. There should be robust guidelines as to how tertiary oncology services can be accessed by secondary care paediatricians.

These arrangements should be well publicised to all health professionals and should reflect the different types of cancer which may occur and age related needs. They should include the availability of telephone advice and named specialists.

91. Given the wide variety of symptoms and signs, initial referral may be to a wide variety of secondary care specialists, particularly for the older age group. Clear mechanisms should be in place for appropriate investigation and speedy referral on to the principal treatment centre (see the section on Place of care).

B. Anticipated benefits

92. Appropriate early referral may lead to a shorter time from first symptoms to diagnosis. This may improve clinical outcomes and will reduce the level of anxiety among parents and carers.

C. Evidence

93. A number of studies have described delays between symptom onset and referral. This period, which may be up to 3–6 months for brain tumours, comprises delays both by parents/carers and doctors. The evidence suggests that an increased awareness of childhood cancer as a possible diagnosis may help in reducing both sources of delay.

94. The early symptoms of central nervous system (CNS) malignancy mimic common and self limiting disorders of children and young people. The lag time from first symptom to diagnosis in these malignancies is the longest in any group of malignancies encountered in children and young people.

95. Delay in referral causes concern in parents and carers, particularly when they feel their special knowledge of the child has been disregarded. The

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results of the Teenage Cancer Trust (TCT) survey in 2004 suggest that there may be a particular problem with delayed referral of teenage patients.

96. Evidence that reducing delays improves clinical outcomes is hard to obtain, because shorter delays may indicate more aggressive disease and a poorer outcome. In children with bilateral retinoblastoma, there is some evidence of a higher rate of eye loss with longer delays.

D. Measurement¹

97. Structure

- clearly documented and well publicised local guidelines and protocols for initial referral of children and young people with suspected cancer.
- clearly documented and well publicised local guidelines and protocols for internal referral of children and young people with suspected cancer within secondary care from ENT or orthopaedics.
- training courses in primary care for implementation of the clinical guidelines

98. Process

- time from first GP consultation to referral
- time from referral to diagnosis
- patient pathways of those presenting to other specialities

99. Outcome

- clinical outcomes
- patient/parent/carer satisfaction

¹ The Measurement sections of the guidance are necessarily brief. Under the three headings 'Structure', 'Process' and 'Outcome' relevant topics are listed. These are directly related to the recommendations and suggest ways in which implementation of the guidance can be monitored. The topics may feed into any peer review process, may be subjects for regular or *ad hoc* clinical audit or be the subject of other forms of assessment such as patient surveys.

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E. Resource implications

100. There is likely to be resource implications in terms of specific education for health professionals, including postgraduate courses and CPD.
101. Additional funding may be required to support access to telephone advice where existing systems may not be in place.

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Diagnosis

102. Establishing an accurate diagnosis is essential for the management of cancer in children and young people. In almost all cases, a histopathologically or cytologically confirmed diagnosis from a needle or open surgical biopsy or bone marrow aspirate is required. Diagnosis also requires access to cytogenetics, molecular genetics and immunophenotyping. The process needs to be timely and efficient and requires a multidisciplinary approach.
103. There is a recognised shortage of most of the disciplines involved in diagnosis, not only paediatric pathologists, paediatric haematologists and paediatric radiologists, but also laboratory staff and scientists.

Pathology

104. Histopathological diagnosis of paediatric tumours can be difficult due to their relative rarity, the overlapping morphological phenotypes, the increasing use of small core biopsies for primary diagnosis and the different interpretation of pathological features in the context of paediatric as opposed to adult cases. Many tumours are unique to children and specialist knowledge is essential.
105. The requirements for the histopathological diagnosis of tumours in young people are very similar. There is clearly an overlap with tumours of the paediatric age group, but also the other tumours that are increasingly common in teenagers and young adults (such as lymphomas, bone tumours and germ cell tumours) all require very specific expertise for their correct diagnosis and assessment.
106. The report from the Royal College of Paediatrics and Child Health *The Future of Paediatric Pathology Services*,[77, Appendix 1] makes it clear that the specialty of paediatric pathology is currently in crisis with shortages across the country. It makes the following recommendations:

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107. Pathology and histopathology services for children should be provided in the long term only by paediatric pathologists and those with relevant specialist expertise. This is a matter of training, experience and governance.
108. Paediatric pathology should be concentrated at selected specialist paediatric surgical/ oncological and tertiary referral maternity sites. It should cover all post mortem examinations and all surgical and oncological work.
109. Paediatric pathology cannot be subsumed by general or other specialist pathologists without a further major reduction in both service and quality.
110. The action necessary to enable paediatric pathology to survive the present crisis and flourish requires recognition of its special nature by Government, Health Service Commissioners, the Medical Royal Colleges, and the Specialist Associations.'
111. Haematologists are responsible for the morphological diagnosis of leukaemia and for the reporting of bone marrow aspirates and trephine biopsies from patients with solid tumours. The spectrum of leukaemia in childhood is different from that in adults, and so diagnosis and the ongoing assessment of response to chemotherapy is best provided by a paediatric haematologist with specific expertise. Children are at greater risk of central nervous system involvement with leukaemia, which requires specialised input for the preparation and assessment of specimens.
112. Haematological malignancies in young people need access to the same laboratory expertise as in solid tumours, including cytogenetics and molecular genetics.

Imaging

113. Timely access to appropriately skilled diagnostic imaging, including nuclear medicine, is essential in evaluating children and young people with possible

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- or confirmed malignant disease. There are particular difficulties in imaging younger children and infants which mean that these procedures need to be carried out in centres with the appropriate expertise. A paediatric radiologist is required in paediatric oncology centres, trained in paediatric oncology imaging.
114. MR imaging is essential for the accurate diagnosis of CNS tumours and for many other solid tumours of childhood. However, there are difficulties with access in many centres in England and Wales. CT scanning is of value, but may be less sensitive for many tumours. Children and young adults with malignancy often require serial imaging for the assessment of disease response and recurrent CT scanning may expose them to significant amounts of radiation.
115. The role of positron emission tomography (PET) scanning in managing these patients is not yet well established and the recent Department of Health Report, *A Framework for the Development of Positron Emission Tomography Services in England* [36, Appendix 1], does not specifically refer to their needs, although it does make clear that it has a role in evaluating patients with malignant lymphoma, which constitute a significant proportion of patients in this age group. As it becomes more widely available, its specific indications within a paediatric setting will become clearer and its use is likely to increase.
116. For some patients, imaging-guided needle biopsy may be the most appropriate way of obtaining tissue for a diagnosis. Although this may prevent the need for an open surgical biopsy, it requires particular expertise not only for the procedure itself, but in the handling of the resulting tissue sample.

A. Recommendations

117. Specialist paediatric histopathologists should be involved with the pathological diagnosis of solid tumours in children.

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118. Specialist techniques, such as immunohistochemistry, cytogenetics, molecular genetics or spinal fluid cytology should be available in all departments dealing with paediatric tumour samples.
119. Facilities for tissue/cells/DNA storage, in accordance with appropriate consent and tissue use guidelines, should be available.
120. Paediatric haematologists should be involved in the laboratory and clinical management of children with leukaemia and haemopoietic stem cell transplantation (HSCT).
121. All laboratories dealing with paediatric leukaemias and solid tumours require appropriate quality assured laboratory facilities and support for diagnostic and assessment purposes and a number require facilities to store cells/DNA for future research taken with appropriate consent and within human tissue use guidelines.
122. In view of the current shortage of specialist paediatric pathologists and haematologists, there should be systems in place to facilitate urgent second opinion of pathological specimens by national and international experts, including lymphoma panel review as described in the NICE guidance on *Improving Outcomes in Haematological Cancer* [59, Appendix 1]
123. A surgical opinion from a specialist bone tumour centre should be sought for children and young people with suspected bone sarcomas. Pathological specimens, suspicious of sarcoma, should be urgently reviewed for definitive diagnosis by a paediatric or specialist sarcoma pathologist or a pathologist with a special interest in sarcoma.
124. A clear pathway for dealing with suspicious lumps and inconclusive scans should be developed and appropriate guidance prepared by each cancer network.

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125. Commissioners should address the recommendations of “*The Future of Paediatric Pathology Services*”[77, Appendix 1].
126. Flexible, workable systems should provide appropriate staff and facilities to allow all diagnostic procedures to be undertaken quickly within routine working hours, and there should be protected time for theatre access and adequate paediatric surgical, radiological and anaesthetic sessions.
127. The provision of MRI scanning should be sufficient to ensure that suspected cases of CNS, bone and soft tissue tumours and other malignancies can be investigated rapidly.

B. Anticipated benefits

128. Accurate and more rapid diagnosis will:
 - allow appropriate treatment
 - reduce treatment burden and disease impact
 - minimise stress to patients and their families.

C. Evidence

129. There is evidence from observational studies and UK guidelines to support the recommendation that diagnostic investigations should be performed in specialist paediatric oncology centres with adequate specialist staff and resources.
130. There is consistent, but limited, evidence on the importance of specialist pathological review in reducing diagnostic inaccuracy. Direct evidence for the effect of accurate diagnosis and staging on outcomes is lacking.
131. The role of the diagnostic multidisciplinary team is accepted as recommended practice in paediatric oncology. However, there is no direct evidence that such teams produce an improvement in outcomes.
132. The evidence for the optimum methods for the diagnosis of leukaemia is reviewed in the NICE guidance on *Improving Outcomes in Haematological*

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Cancers [59, Appendix 1]; this evidence confirms the requirement for specialist pathological review to improve diagnostic accuracy.

133. There is some evidence to confirm the role of PET in the diagnosis of malignant lymphoma; evidence for its role in other paediatric tumours is currently inconclusive, but research is ongoing.

D. Measurement

134. *Structure*

- adequate staff and resources to be provided to assure compliance with the waiting time requirements.
- provision of effective systems for communication between specialist pathologists, paediatric and other oncologists and the specialist diagnostic multidisciplinary teams.

135. *Process*

- time interval between first clinical appointment and diagnosis
- waiting times for biopsy and imaging
- proportion of invasive investigations taking place outside normal hours
- time taken for the production of pathology reports

136. *Outcome*

- patient satisfaction
- effect of diagnostic accuracy on patient outcomes

E. Resource implications

137. Protected time for anaesthetic and surgical diagnostic sessions is likely to require additional funding.
138. Resources should be available to ensure that diagnostic haematological and pathological cytogenetic services may be accessed directly.
139. The provision of CT and MRI scanners may have capital cost implications where access is limited.

Treatment

140. Treatment describes those therapeutic interventions used directly for the management of the malignant condition. The medical treatment of childhood and adolescent cancers comprises three main modalities; surgery, chemotherapy and radiotherapy. Other modalities are also used e.g. stem cell transplantation. The relative use of each modality depends on the underlying diagnosis and, to some extent, the age of the patient. For instance, radiotherapy is whenever possible avoided in children under three, because it results in greater long term effects.

Chemotherapy

141. Chemotherapy is the primary modality of treatment for haematological malignancies and also for many solid tumours, when it is usually used in combination with surgery, with or without radiotherapy. The use of chemotherapy in the treatment of central nervous system tumours has also increased over recent years. Regimens of varying intensity, employing different routes of administration and patterns of delivery, are used. Many are becoming increasingly complex and intensive and can be associated with significant immediate and late side effects and morbidity. The delivery of chemotherapy to children, particularly small children, is more complex with a greater potential for errors than in adults.
142. There are a number of reasons why there are particular risks of error in giving chemotherapy to children:
- All doses have to be carefully calculated and prepared and fluid volume has to be tailored to the size of the child. Standard or upper dose limits are less relevant in children and there is a wide range of dosage e.g. methotrexate.
 - Weight loss or gain can significantly alter the correct dosage, requiring close patient observation (this is also an issue for teenagers).

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- Many drugs are not licensed for use in children, in particular the very young. Many are not routinely prescribed and treatment protocols are often very complex.
 - Oral preparations may not be palatable or available to children and compliance may be difficult.
 - Tablets may not be available in sufficiently small sizes, requiring portions of the tablets to be given or necessitating metronomic prescribing.
143. Most children and young people receive treatment administered in hospital under the direct supervision of health professionals. Parts of some treatment regimens can be administered safely at home, either by children's community nurses, other health professionals or families. Some patients also receive prolonged outpatient based oral maintenance chemotherapy, during which the issue of compliance is important.
144. Some cancer centres have a dedicated computerised chemotherapy prescribing system. Other treatment sites rely on pre-printed paper based systems.
145. There are national strategies in England and Wales for the introduction of computerised prescribing and electronic transmission of prescriptions (ETP).

A. Recommendations

146. Chemotherapy should only be delivered by properly trained staff in an environment capable of providing the predicted level of support and should be appropriately resourced.
147. In order to deliver timely chemotherapy in accordance with the patient's treatment protocol and avoiding unnecessary delay, a treating unit should have adequate capacity with access to suitably equipped facilities for the preparation and administration of chemotherapy and a trained pharmacy support team.

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148. Paediatric and adult oncology units should be staffed with adequate numbers of appropriately trained staff to allow good communication and discussion on all aspects of treatment, its effects and possible toxicity.
149. Chemotherapy should only be prescribed and administered by clinical staff appropriately trained in the prescribing and administration of chemotherapy and the prevention/management of its side effects.
150. There should be written protocols, covering the administration of chemotherapy, agreed between the principal treatment centre and other treatment sites, which should clearly define responsibilities and organisational arrangements. There should be clear accountability for the prescription and delivery of chemotherapy included in these protocols and an agreed route for advice from the principal treatment centre in the event of chemotherapy related problems.
151. There must be compliance with current DOH guidelines on the safe prescribing, dispensing and administration of intravenous and intrathecal chemotherapy[32, Appendix 1].
152. All chemotherapy should be prepared and monitored by pharmacists trained to national standards; and there should be adequate provision of facilities for the aseptic reconstitution of cytotoxic agents. A designated pharmacist should be part of the multidisciplinary team (MDT) in all care settings.
153. Where chemotherapy can be safely administered in the home, by either appropriately trained community nursing teams or families, this should be developed, supported and adequately resourced.
154. New methods of monitoring and improving methods of compliance in patients should be explored and encouraged, including the concept of concordance.

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B. Anticipated benefits

155. Delivery of chemotherapy by adequately trained staff in an appropriate environment should reduce morbidity.
156. Adequate preparation facilities and treatment capacity will avoid unnecessary delay and maximise treatment benefit.
157. Development of chemotherapy services in the home, where this is appropriate, will lead to less disruption of family life and schooling.
158. Agreed protocols across cancer networks and within shared care arrangements, ensuring the safe administration of appropriate and timely treatment, should:
 - result in better clinical outcomes in terms of response, survival and symptom control
 - minimise complications and errors in the prescription and administration of chemotherapy
 - improve patient and family confidence.
 - improve quality of life
159. Reduction in risk may be achieved by:
 - computerised prescribing
 - patient held records
 - information for parents/carers and families
 - training and education for staff in all care settings in which chemotherapy is given
 - designated pharmacist as part of MDT.
160. High levels of compliance with all aspects of treatment should also result in better clinical outcomes.

C. Evidence

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161. There is good quality evidence that ETP reduces prescribing errors, although there are no papers specifically concerned with children with cancer.
162. Where chemotherapy is delivered in the community, there is insufficient evidence to determine whether nurses are superior to parents or carers in terms of delivery skills.
163. There is some evidence to suggest that compliance in these age groups with taking oral anticancer drugs is not good. Rates of non compliance in a review of six observational studies of children being treated for leukaemia and lymphoma ranged from 2% to 50%. Compliance appeared to be worse in teenagers and in those with a poorer understanding of their illness and greater levels of denial.
164. The evidence is inconsistent on whether ETP improves patient compliance with medication.
165. There was poor quality evidence that concluded that methods for monitoring compliance are not effective.

D. Measurement

166. Structure

- appropriate staff levels and training
- clearly documented and well publicised protocols

167. Process

- rates of refusal and failure to complete treatment – annual report
- compliance with chemotherapy protocols
- incident reporting of errors and near misses

168. Outcome

- survival
- morbidity

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- errors and near misses
- prescribing errors

E. Resource implications

169. There are likely to be substantial resource implications to ensure that sufficient numbers of appropriately trained staff, including clinicians, pharmacists and nurses, are in place for the safe and effective use of chemotherapy.
170. Dedicated funding should be made available for centres without existing electronic prescribing systems.

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Surgery

171. The majority of children with solid tumours require surgery, either a biopsy to establish a diagnosis or surgical resection before or after chemotherapy as part of the definitive treatment. Many patients need surgery for other reasons, such as establishing and maintaining central venous access or the insertion of a gastrostomy to aid nutrition.
172. Some patients present as emergencies or develop complications requiring urgent surgery. It is important that there is appropriate access to emergency operating theatre sessions. However, most surgical interventions, including diagnostic biopsies, are urgent, rather than emergency, procedures, but still require unhindered access to theatre sessions.
173. Anatomical site specialisation is well developed for many adult cancers and the treatment of cancers in the majority of older teenagers and young adults is appropriately undertaken by specialist surgeons within these teams. For younger children, the paediatric surgeon, who specialises in oncology surgery, is primarily responsible for the surgical aspects of care for many patients, and participates in the paediatric oncology MDT. In addition, some children require surgery from a variety of other surgical specialists, for example specialists in thoracic surgery, ophthalmology, gynaecology, orthopaedic surgery, paediatric cardiac surgery and head and neck surgery (which may be provided by a variety of surgical disciplines).
174. Following surgery, AHPs such as physiotherapists, occupational therapists, speech and language therapists and dietitians, can have a positive outcome on the return to functioning or development of new skills or adaptive behaviour. This is particularly true after limb amputation, head and neck surgery or neurological surgery, when there may be a need for intensive and prolonged rehabilitation.

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A. Recommendations

175. Surgery in children known to have, or suspected of having, a malignant tumour should only be carried out by surgeons appropriately trained either in paediatric oncological surgery or other appropriate surgical specialities, working in a centre with appropriate support from paediatric anaesthetists and intensive care facilities.
176. Referral systems should be in place, if necessary across cancer networks, to provide easy access to a variety of other surgical specialists.
177. Theatre and anaesthetic time should be adequately resourced for all surgical procedures, including diagnostic and supportive procedures, in addition to other definitive tumour surgery. The paediatric surgeon with a commitment to oncology should have access to emergency theatre sessions during routine working hours.
178. The surgical management of tumours in children and young adults should be in the context of the appropriate paediatric or specialist MDT, including preoperative discussion in all cases, except emergencies.
179. Surgery for retinoblastoma, bone tumours and certain liver tumours requires very specialist expertise that should only be provided in supraregional centres. Surgery for non-rhabdomyosarcoma soft tissue sarcomas, particularly in young people, should only be undertaken following review at a designated sarcoma MDT.
180. Children and young people with a rhabdomyosarcoma should be treated by the local paediatric MDT. If there are cases where the round cell tumour lump is unusual or poses particular problems, the paediatric surgeon should consult with the Sarcoma MDT.
181. Involvement of AHPs should be planned, where possible, before surgery.

B. Anticipated benefits

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182. Access to the appropriate level of specialisation will produce:
- Improved outcomes in terms of choice of procedure, reduced morbidity and cure
 - Improved long term function of survivors.

C. Evidence

183. The evidence was inconsistent on the effect of specialist surgery on patient outcomes. The paediatric oncology papers did not meet the inclusion criteria in one good quality systematic review and this was confirmed by a comprehensive literature review.
184. There are policy documents and guidance that conclude that there are improved outcomes with specialist surgeons.

D. Measurement

185. **Structure**
- provision of access to appropriate specialist surgical care
 - written protocols for referral to specialist surgery
 - provision of resources for adequate provision of theatre and anaesthetic time.

186. **Process**

- delays in theatre access, particularly for emergency procedures during regular working hours.
- provision and uptake of educational programmes.
- structure and function of MDT to be audited as part of peer review

187. **Outcome**

- studies on the effect on outcome of surgery performed by specialist paediatric surgeons
- patient and parent/carer satisfaction
- effects of delays in surgical diagnosis on patient outcome

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E. Resource implications

188. Protected time for anaesthetic and surgical treatment sessions, including emergency theatre sessions during working hours, is likely to have significant resource implications.

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Neurosurgery

189. Skilled neurosurgery is perhaps the most important determinant of outcome in many CNS malignancies. The presenting symptoms are such that referral is often correctly made directly to a neurosurgical centre. The initial management is often the relief of raised intracranial pressure, using a procedure that diverts the flow of cerebrospinal fluid in the brain. Subsequent therapy is dependent on the condition of the child, the likely diagnosis and is guided by the relevant national or international therapeutic protocols. Around 4500 neurosurgical procedures are performed each year in England and Wales on children under 15 years of age. Tumour work represents only 10% of this work load.
190. There are approximately 150 neurosurgeons in England and Wales and the hospitals in which they work are affiliated to UKCCSG centres to varying extents; some are located in the same hospitals or have regular links, while others are very separate. The number of children and young people operated on also varies, with some centres seeing very few each year, while 4 units perform over 400 and 13 units over 200 neurosurgical procedures each year. In the centres that perform neurosurgical operations on children and young people, the number of surgeons experienced in neuro-oncology varies, as does the degree of subspecialisation.
191. Certain anatomical locations, for example trans-sphenoidal or base of skull surgery, pose particular difficulties and a number of surgeons have 'super-specialised' in these rare and complex operations.

A. Recommendations

192. For all children and young people, there should be robust mechanisms to ensure that a neurosurgeon, neuroradiologist and oncologist are always available to discuss a given case before a major therapeutic decision is

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instituted, even if an actual MDT meeting is not possible due to the urgency of the case.

193. Definitive surgery should be carried out by a surgeon experienced in paediatric CNS tumour surgery, or when necessary by a surgeon (neurosurgeon, ENT, maxillofacial, spinal, trans-sphenoidal etc) with specialist skills for lesions in rare anatomical sites with the support of the paediatric team.
194. Treatment of raised intracranial pressure is an emergency and access to staff trained in CSF diversion procedures should be available at all times and provided in locations that are easily accessed.
195. Basic neurosurgical training should allow, when necessary, adult surgeons to institute life saving measures to enable paediatric patients to be stabilized before transfer to specialized paediatric units.
196. Children under 15 with CNS tumours should be managed in a centre with full paediatric support facilities, including 24 hour paediatric nursing and medical staff, paediatric anaesthetic staff, paediatric intensive care and readily available paediatric neurology, endocrinology, oncology, imaging and neuroradiology. There should be support for a paediatric neuro-oncology nurse specialist within each centre.
197. There should be at least two such neurosurgeons in the unit supported by their adult colleagues for on call purposes.

B Anticipated benefits

198. More accurate staging and careful selection of therapy by the MDT achieved by earlier referral and access to neuroimaging.
199. Careful audit of therapy with appropriate recognition of short and long term morbidity, so that therapeutic regimens can be adapted appropriately both to the individual and the disease process.

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200. Long term functional outcome assessment with neurology, endocrine, educational, neuropsychological and psychological appraisals and occupational therapy assessments to ensure the quality as well as the length of life is measured.

C Evidence

201. There are consensus guidelines and policy documents that recommend the requirements for a comprehensive paediatric neurosurgical service
202. There are observational studies that show that there are improved outcomes such as fewer complications, with specialist paediatric neurosurgeons

D Measurement

203. **Structure**
- evidence that MDTs are established in each principal treatment centre.
 - provision of adequate staff and resources to provide an adequate neurosurgical service including emergency procedures

204. **Process**

- measurement of neurosurgical training and experience in line with recommendations by the British Association of Paediatric Neurosurgeons and the Royal Colleges.
- delays in treatment

205. **Outcome**

- outcomes with specialist paediatric neurosurgical care
- patient satisfaction

E Resource implications

206. Increased resources may be required to ensure that there are sufficient specialist paediatric neurosurgeons, in terms of both employment and training.

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207. Similarly, additional resources may be required for the training and provision of paediatric oncology nurse specialists.
208. In some areas, there may be resource implications for the provision of 24 hour care for children under 15 with CNS tumours in line with the guidance.

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Radiotherapy

209. Radiotherapy is an important part of the management of many children and young people with cancer. Its main role is to improve locoregional tumour control and overall survival in solid tumours and tumours of the CNS, but it is also part of the curative treatment of some lymphomas and leukaemias and plays a key role in palliating localised symptoms in patients with advanced disease. Total body irradiation is also used for myeloablation prior to HSCT.
210. It is essential that the patient remains still for up to 25 minutes during treatment with radiotherapy, and so there are particular challenges treating infants and young children, who may need to be anaesthetised for their treatment. As curative radiotherapy commonly requires daily treatment for several weeks, appropriate anaesthetic skills and support need to be easily available. Play therapy is vital in helping young children through this process, and may prevent the need for anaesthesia.
211. Anatomical site specialisation among both clinical oncologists and therapy radiographers is increasingly recognised as important in the provision of high quality radiotherapy. Most cancer centres have identified one or more consultant clinical oncologists to take the lead in the management of paediatric tumours (specialisation by age and not anatomy), but there may not always be appropriately skilled cross cover arrangements.
212. Age-specific specialisation may be less appropriate for the management of many tumours in teenagers and young adults, where the radiotherapy may be best managed by the clinical oncologist with the appropriate tumour site specialisation and expertise. Nevertheless, age appropriate support should be available during the period of treatment and follow up.

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213. Therapy radiographers, with specific training in the management of children, are needed to provide safe and efficient care during radiotherapy through their specialist, detailed knowledge of the planning, delivery and anticipated side effects of radiotherapy and maintain continuity of care during the planning and treatment period for the child and family.

A. Recommendations

214. Radiotherapy for children and young people should be commissioned from centres that can demonstrate they comply with the requirements in Table 2.

215. There are some rare conditions for which radiotherapy is high risk or very complex or requires specialised equipment and which should be commissioned from agreed supraregional, national or international centres. They include:

- total body irradiation as part of the conditioning regimen for a haemopoietic progenitor transplant (should take place in a JACIE accredited centres)
- irradiation of infants with retinoblastoma
- biological targeted radioisotope treatments
- brachytherapy
- radiosurgery
- hypofractionated stereotactically guided radiotherapy.

216. Radiotherapy should start as soon as possible after a decision to use it has been made and within the time frame specified by the relevant treatment protocol and the Royal College of Radiologists' guidelines, unless the patient is too ill to tolerate planning or therapy. There is a minimum time required to start complex, radical radiotherapy, due to the logistics of the manufacture of customised immobilisation devices and the use of 3D conformal planning, but delays for other reasons should be minimised.

B. Anticipated benefits

217. Improved outcomes and reduced treatment-related morbidity.

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218. Improved compliance with treatment.

C. Evidence

219. There is no high quality evidence that provision of specialist radiotherapy facilities and support improve clinical outcomes in children and young people. However the recommendations are consistent with the generally agreed move to subspecialisation in clinical oncology outlined in the Calman Hine Report [23, Appendix 1] and in the publications of the Royal College of Radiologists and the Society and College of Radiographers. The resource requirements are also consistent with those outlined by the UKCCSG
220. National strategic documents and Royal College publications indicate that a move to subspecialisation in clinical oncology is required.
221. The resource requirements and the need for age appropriate facilities are documented in national guidance and guidance from the UKCCSG.
222. There is some evidence from the literature that delays in radiotherapy may affect tumour control in patients with sarcomas and high grade gliomas, but the impact of delays in therapy have not been assessed systematically and have not been analysed for most indications of radiotherapy in children, particularly for more recently established protocols using reduced dose radiotherapy. Therefore it is important to ensure that radiotherapy is delivered within the time frames specified in the relevant protocol, unless the patient's condition precludes this.

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Table 2

- Appropriate consultant subspecialisation in paediatric radiotherapy, including membership of the UKCCSG, and consultant cross cover arrangements
- Access to appropriate paediatric professional development
- Integration of the consultant clinical oncologists as core members of the paediatric oncology MDTs (and therapeutic radiographers where appropriate)
- Availability of clinical oncologists with declared subspecialisation in the tumour types common in young people
- A lead therapy radiographer with specific training and responsibility for treating children and young people
- Appropriate technical equipment, staff and facilities to provide high quality, megavoltage radiotherapy (including mould room, 3 dimensional computerised planning and treatment delivery systems)
- Access to paediatric anaesthetists, Operating Department Assistants (ODAs) and nurses with paediatric recovery training, with modern facilities (including full resuscitation) and recovery area on site
- Policies and procedures for the safe supervision of children receiving sedation or anaesthesia
- Support of a play specialist
- Age-appropriate support facilities and staff with appropriate training for this specialised field
- Clinical protocols agreed with principal treatment centre
- Compliance with nationally agreed quality assurance standards
- Compliance with nationally agreed waiting times

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D. Measurement

223. *Structure*

- provision of adequate resources and staff and site specialist consultant clinical oncologists to assure compliance with waiting time requirements.
- provision of cross cover arrangements.
- provision of anaesthetic services.
- provision of services such as play specialists to assist in the delivery of radiotherapy to young children.

224. *Process*

- compliance with nationally agreed quality assurance standards
- compliance with nationally agreed waiting times

225. *Outcome*

- evidence for the effect of delays in radiotherapy on outcome
- patient and parent/carer satisfaction with the delivery of radiotherapy

E. Resource implications

226. Increased resources may be required for the training of, and to ensure access to, paediatric radiotherapists and radiographers and clinical oncologists.

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Supportive care

227. Supportive care is the term for interventions used to support the patient through the anticancer treatment period. Outcomes in cancer are dependent not only on the safe and effective delivery of treatment, but also on the timely and effective management of the acute and longer term side effects. Improvements in supportive care have played a key role in increased survival.
228. The management of issues such as pain and fatigue is also important for children and young people with cancer. When input is provided at the right time, it can facilitate home discharge and benefit the health and wellbeing of parents/carers, as well as the patient.

Febrile neutropenia

229. Neutropenia is a frequent side effect of chemotherapy. The patient is vulnerable during this period to potentially life threatening infections. Febrile neutropenia is the term used when a child develops a fever when the neutrophil count is low, and is a significant, potentially avoidable cause of morbidity and mortality.
230. Episodes of febrile neutropenia (FNP) should be managed with caution and most patients are admitted for intravenous antibiotics. There may be some who do not need admission, but more research is needed before this subset can be clearly identified.

A. Recommendations

231. There should be a written protocol for the management of febrile neutropenia in all patients having chemotherapy. When care is shared across treatment sites, this protocol should be agreed between the principal treatment centre and other treatment sites and should include urgent transfer of sick patients when required. The protocol should be

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- available in all relevant clinical areas, including wards and accident and emergency departments.
232. The protocol should be informed by the development of national guidance for the management of febrile neutropenia in children and young people with cancer.
 233. Any treating unit should ensure it has sufficient capacity to allow admission to a bed with:
 - appropriate infection control facilities
 - staff, both medical and nursing, trained in the management of febrile neutropenia and its complications.
 234. Antibiotics, antifungals, growth factors and blood products, if required to support patients through episodes of chemotherapy-related neutropenia, should be adequately resourced.
 235. Patients and parents/carers should have education and written information on the importance of seeking appropriate medical attention in a timely fashion and how that care can be accessed.
 236. There should be an agreed route of referral in the event of a febrile neutropenic episode, with an open access policy to the unit that acts as the first point of contact and with no wait in an A&E department.
 237. National research is required for:
 - the development of robust methods of risk stratification in the management of febrile neutropenia.
 - the exploration of the safe introduction of shorter periods of inpatient admission and/or community based therapy for low risk episodes.
 - prevention of febrile neutropenia.
 - use of antivirals and antifungals.

B. Anticipated benefits

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238. Lower number of deaths and episodes of serious complications from neutropenic sepsis.
239. With appropriate risk stratification, a reduction in the number of patients with fever requiring admission to hospital.
 - Reduction in duration of hospital admission for some patients.

C. Evidence

240. There are no UK guidelines for the management of FNP.
241. The evidence from three randomised controlled trials on the outpatient treatment of febrile neutropenic episodes is inconsistent. There are two good quality guidelines (both from the USA) that conclude that some selected patients may be treated as outpatients.
242. There is one systematic review and one prospective cohort study that indicate that there are clinical features and laboratory measures that can be used to select children and adolescents for treatment in an outpatient setting but that further research is required. There are further observational studies to provide indications for selection criteria.

D. Measurement

243. **Structure**
 - development of national guidelines on FNP
 - development of risk-stratified protocols for the management of FNP
 - development of protocols for outpatient treatment of FNP
 - provision of adequate information on FNP to patient and parent/carers

244. **Process**
 - number of patients with FNP treated as inpatients/outpatients
 - compliance with protocols and guidelines
 - bed occupancy

245. **Outcome**

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- deaths from neutropenic sepsis
- number of patients with fever requiring admission to hospital
- patient and parent/carers views
- number of PICU admissions as a result of neutropenic sepsis

E. Resource implications

246. Management of febrile neutropenia in children and young people in line with the guidance may have resource implications.
247. Written information and training for patients and carers to ensure they seek appropriate attention in a timely fashion should be adequately resourced.

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Central venous access

248. Children and young adults requiring venous access for chemotherapy, radiotherapy and supportive treatment for cancer often need central venous access devices. This need is greater compared to older adults because:
- peripheral veins are more difficult to find and maintain in children than in adults.
 - the physical and emotional distress associated with peripheral venous access is an unacceptable burden for a child.
 - the treatment regimens are complex
249. However, central venous catheters (CVCs) are associated with significant morbidity and, sometimes, mortality. Therefore attention to detail in choice of device, method and timing of insertion, post insertion care, maintenance and removal is essential. CVCs may be inserted by a surgeon, radiologist, anaesthetist or nurse specialist, depending on the type of device required. Removal of CVCs is potentially hazardous.

A. Recommendations

250. CVCs should be inserted in an area designed for clean surgical procedures, usually an operating theatre with image intensifier or intraoperative ultrasound, or an interventional radiology suite. Sedation and local anaesthesia are required for young people. General anaesthesia is usually necessary for children and may be necessary for many in the older age group. Theatre sessions should be available. For most centres this will mean at least one weekly dedicated operating list, in larger centres more than one list per week will be required.
251. Removal of CVCs should only be done by trained personnel in an appropriate setting. Provision of sedation and anaesthesia as described above is usually necessary for these procedures too.

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252. There should be written guidance on the management of central venous access devices, including expert advice on type of vascular device, which is consistent across treatment settings. All healthcare professionals involved in caring for patients with these devices should be trained and assessed as competent. The inserting practitioner should be appropriately trained and experienced and should maintain that experience.
253. Where appropriate, patients and parents/carers should be given choice in the selection of type and siting of central line and provided with the information needed to inform that choice.

B. Anticipated benefits

254. Agreed standardisation of the care of central venous access devices within a clinical network or shared care arrangement will:
 - reduce the incidence of failed insertion and need for revision of CVC
 - reduce infection and other complication rates, including late effects due to vascular occlusion
 - reduce pain and distress for patients and parents/carers
 - improve continuity of care
 - reduce interruption of chemotherapy regimes
 - reduce hospitalisation
 - promote confidence in families in the clinical competence of the health professionals providing care.

C. Evidence

255. There is a large amount of observational evidence on the optimum method of central venous line insertion.
256. There is evidence to indicate that all staff involved in the management of central venous access devices should be trained and have their competency assessed.

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257. There is good evidence from randomised controlled trials that an image intensifier should be used at the time of insertion of all central venous access lines to avoid misplacement and the need for later revision.
258. There is some evidence to suggest the use of 2D ultrasound to guide the procedure rather than using the more traditional anatomical landmark technique but this advice applies mainly to adults and to percutaneous puncture of the internal jugular vein. There is no evidence to indicate that these devices help percutaneous puncture of the subclavian vein in children and the anatomical landmark technique is considered acceptable.

D. Measurement

259. *Structure*

- evidence of the presence of written guidance on the management of central venous access devices
- provision of adequate training for all healthcare professionals involved in the management of these devices.
- provision of suitable facilities and resources for insertion and removal
- provision of adequate information to patients and parents/carers
- provision of dedicated theatre time

260. *Process*

- staff attendance at training
- delays in access to theatre time

261. *Outcome*

- complication rates, particularly incidence of CVC associated infection

E. Resource implications

262. Procedures for the safe insertion and removal of central venous catheters should be adequately resourced.

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Blood product support

263. Children and young people with leukaemia, and most patients who receive chemotherapy for cancer, develop pancytopenia (anaemia, neutropenia and thrombocytopenia from bone marrow suppression) and will require support with red cell and platelet transfusion. Some may develop abnormal blood clotting needing correction with fresh frozen plasma, and others may require regular intravenous immunoglobulin during periods of immunosuppression.
264. Hospitals will have a transfusion committee, which will produce local guidelines and oversee appropriate and specific training of all staff involved in the management and use of blood products support and report adverse transfusion events to the Serious Hazards of Transfusion (SHOT) Scheme.

A. Recommendations

265. There should be a written protocol for the management of blood product support, agreed between the principal treatment centre and any other treatment sites and available in all relevant clinical areas.
266. There should be timely access to blood products at all times, including outside normal working hours.
267. Medical, nursing and laboratory staff at all treatment sites should be aware of the special transfusion needs of children, in particular the indications for the transfusion of CMV screened, irradiated and non-UK sourced, virus inactivated blood or blood products.

B. Anticipated benefits

268. The safe administration of blood and blood products with errors and complications minimised.

C. Evidence

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269. There is evidence from national surveillance reports of the incidence of errors in administration of blood products. Children, particularly those in the first year of life, are at particular risk of being transfused with a blood product of the wrong specification. The commonest errors in 2003–2004 were the failure to request irradiated blood appropriately and non-UK sourced plasma for children born after January 1996.
270. There are good quality guidelines on the administration of blood products to neonates and older children

D. Measurement

271. *Structure*

- production of local guidelines and protocols
- provision of appropriate training
- compliance with national ‘haemovigilance’ requirements

272. *Process*

- protocol and guideline compliance
- transfusion errors

273. *Outcome*

- morbidity and mortality of transfusion errors

E. Resource implications

274. Funding may be required to secure access to blood products, including access outside working hours.

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Pain management

275. Effective pain management is essential in many aspects of the management of children and young people with cancer. There are different types of pain which may be experienced by these patients, associated with the disease process, the acute side effects of treatment and progressive disease. In all cases assessment of pain is essential. The WHO guidelines for cancer pain relief and the use of the “analgesic ladder” are well established and help ensure systematic practice in pain control.
276. A particular issue in the treatment of children with leukaemia is a need for regular painful procedures such as lumbar puncture and bone marrow biopsy. Most children require general anaesthesia for these procedures.
277. Play and the use of techniques, such as distraction, or the use of cognitive behaviour therapies to enhance coping skills, can prepare children and young people for painful procedures. Play specialist and activity coordinators are able to facilitate nursing care and invasive medical procedures and their input may reduce the need for sedation and anaesthesia.

A. Recommendations

278. Multidisciplinary protocols should be in place to support the safe and effective use of analgesia and these should be available in all care settings.
279. Ready access to specialist multidisciplinary pain services is required, for advice and support in complex pain management.
280. All children requiring hospital care should have daily access to play specialists or, for older children and young people, activity coordinators, to assist in preparation for painful procedures. These members of staff should have access to formal psychology support in developing techniques such as relaxation and visualisation.

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281. There should be adequate provision of general anaesthesia for patients undergoing regular painful procedures (e.g. bone marrow and lumbar puncture).

B. Anticipated benefits

282. Effective pain management should result in improved compliance with procedures and improved quality of life.

C. Evidence

283. There is a systematic review of evidence and guidelines that suggest the type of services that are effective in providing adequate pain relief to children and young people with cancer.

284. Standards for Hospital Services for Children and Young People, published in the National Service Framework for Children [35, Appendix 1] , indicate how important the management of pain (or its poor management) is to children in hospital, and give clear guidance as to the importance which should be placed on this aspect of care.

D. Measurement

285. **Structure**

- evidence that specialist and age appropriate pain relief services are available when required
- provision of adequate training for staff in pain relief techniques
- written protocols for pain relief procedures

286. **Process**

- delays in providing adequate pain relief

287. **Outcome**

- pain control
- patient and parent/carer satisfaction with pain relief

E. Resource implications

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288. Funding is necessary to support appropriate numbers of play specialists, activity coordinators and child psychologists, and to address their training and education needs.

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Management of nausea, vomiting and bowel disturbance

289. Nausea, vomiting and change in bowel habits are among the most distressing side effects of cytotoxic chemotherapy. Nausea and vomiting vary with the emetogenic potential of the drugs and individual susceptibility. Diarrhoea is a side effect of many drugs and also occurs as a result of immunosuppression. Constipation is also a common symptom. Advances in the management of these symptoms have occurred with the use of improved drugs and evidence based multidisciplinary protocols.
290. There are other causes of nausea and vomiting, which require assessment and appropriate management e.g. radiotherapy and symptoms within the palliative phase.
291. Non pharmacological approaches to the management of nausea and vomiting are also available. Children and young people can be helped in the management of anticipatory nausea and vomiting through play and the use of techniques such as distraction, or the use of cognitive behaviour therapies such as relaxation, guided imagery to enhance coping skills. Many patients undergoing active chemotherapy with severe diarrhoea require inpatient management.

A. Recommendations

292. There should be a written protocol for the management of chemotherapy and radiotherapy induced nausea and vomiting. If care is shared across treatment sites, this protocol should be agreed between the principal treatment centre and other treatment site. The protocol should also be available in all relevant clinical areas.
293. The antiemetic drugs specified in the protocol should be readily available across all treatment sites.

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294. There should be timely access to occupational and psychological or behavioural therapies for patients with anticipatory nausea and vomiting.

B. Anticipated benefits

295. Better control of nausea and vomiting through a systematic approach to management.
296. Consistency across care settings will enhance parental/patient/carer confidence in shared care.

C. Evidence

297. There is evidence that the use of clear guidelines can help in the management of these side effects of treatment.

D. Measurement

298. *Structure*

- written protocol in use with evidence of multidisciplinary input and regular review.

299. *Process*

- compliance with and effectiveness of protocol
- evidence of staff training in this aspect of treatment

E. Resource implications

300. The provision of antiemetic drugs needs to be adequately resourced.
301. The recommendation that there should be timely access to occupational and psychological or behavioural therapies might require additional psychologists to be employed with consequent resource implications.

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Nutrition

302. Children differ metabolically from adults and continued growth and development is desired throughout treatment. Nutritional support in childhood cancer is an important part of supportive care and as treatment has become more intensive this has become even more essential. Nutritional depletion, secondary to prolonged anorexia, nausea, vomiting, mucositis and significant infectious complications, can be severe. Other common side effects such as taste abnormalities, dry mouth, constipation, renal impairment and food aversion also affect nutritional intake.
303. There are different modalities for delivering nutritional support. Total parenteral nutrition requires access to appropriate personnel and facilities.

A. Recommendations

304. Nutritional support, enteral or parenteral, should be designed to provide adequate protein, calories, vitamins and minerals for all children and young people, taking into account their age, condition and treatment.
305. Training in the general field of paediatrics should be provided for dietitians, before working in oncology with children and young people.
306. Training, recruitment and retention of specialist dietitians should be funded.
307. Staff of relevant disciplines should adhere to agreed national professional guidelines on nutritional support.

B. Anticipated benefits

308. Adequate and effective nutrition will speed recovery, reduce the chance of prolonged nutritional problems and improve general wellbeing.
309. Children with cancer will have their nutritional needs met with dietetic involvement.

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310. Additional investment will allow dietetic services to adequately meet the nutritional needs of this group of vulnerable young people.

C. Evidence

311. There is evidence from observational studies to indicate that the response to chemotherapy is influenced by nutritional status.

312. There is evidence from case series that the metabolism of chemotherapeutic agents is affected in malnourished patients

313. Some case series have demonstrated higher infection rates in malnourished patients.

314. There is some poor quality evidence to indicate poorer outcomes in children with cancer who are malnourished at the time of diagnosis

D. Measurement

315. **Structure**

- provision of protocols detailing measures to ensure adequate nutritional support
- provision of specialist dietetic advice/training/interventions
- provision of information on nutritional requirements to patients and parents/carers

316. **Process**

- numbers of trained dietitians working in this service area

317. **Outcome**

- nutritional status of patients

E. Resource implications

318. The main costs will be for the recruitment and training of dietitians.

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Oral and dental care

319. Cancer treatment results in acute oral cavity problems, such as mucositis and infection, as well as affecting developing teeth with an increased incidence of structural dental anomalies.
320. There is variation in oral care practice between centres with regard to preventative therapies and dental check ups. National evidence base guidelines for oral care for children and young people being treated for cancer is being developed. Children are often referred back to their general dental practitioner (GDP) after completion of their cancer treatment.
321. The provision of dental services to children, undergoing treatment for childhood cancer, is fairly well developed; most paediatric oncology centres have established links with paediatric dentistry teams. However on discharge, many of these patients are lost to dental care follow up.
322. The group most at risk from failure of dental services are young adults, especially those who have received radiotherapy to the mandible and maxilla or total body irradiation, followed by bone marrow transplantation. Many such young adults with extreme dental needs, foreshortened roots and some with devastated dentition, are outside the age range to qualify for 'free' NHS treatment and find the cost of the treatment prohibitive. Access to NHS funded primary dental providers is also difficult.
323. National evidence based guidelines for oral and dental care are being developed and will inform care in this area.

A. Recommendations

324. There should be special provision of emergency dental treatment for teeth with poor prognosis before the start of chemotherapy.

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325. Information on the effects of cancer treatment on the mouth should be provided to all patients and their parents/carers.
326. A named dental professional, identified by the principal treatment centre, should coordinate care.
327. There should be clear protocols and referral routes for follow up.
328. There should be clear guidance for young adults who no longer qualify for free NHS dental care in general practice and who find the costs of appropriate therapy unaffordable.

B. Anticipated benefits

329. Preventing dental disease for this group will minimise detrimental effects on their general health.
330. The effects of treatment for their malignancy on development of dentition and function of oral tissues will be addressed.

C. Evidence

331. There are some consensus guidelines produced by the Royal Colleges on dental care for children receiving cancer treatment.
332. There are surveys on the variation in practice of oral and dental care between the paediatric oncology centres in the UK.
333. There is a lack of good evidence on the effective treatments for oral infections and oral mucositis.

D. Measurement

334. **Structure**
 - evidence that there are effective dental screening and treatment protocols available before and during treatment.
 - evidence that there are written protocols for treatment of oral infections.
 - evidence of follow up protocols with clear referral routes

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335. ***Process***

- compliance with treatment protocols
- patients who are attending a GDP for dental follow up post treatment

336. ***Outcome***

- incidence of cases of oral infection and oral mucositis during treatment
- dental problems in long term survivors of cancer.

E. **Resource implications**

337. Additional funding may be required to ensure that there is emergency dental treatment for children and young people whose teeth have a poor prognosis before the start of chemotherapy
338. It may be that funding will need to be found to ensure that each principal treatment centre has a named dentist available.

Rehabilitation

339. Rehabilitation comprises the interventions used to improve overall physical, emotional, social and educational outcomes during and after cancer therapy. It uses a combination of approaches and interventions by a variety of different professional groups at different stages in the patient's pathway. The requirements for rehabilitation fluctuate and can be urgent.
340. Staff need a sound understanding of normal and abnormal human development, as well as an understanding of the nature and role of play in functioning and maturation into adulthood.
341. The World Health Organisation model, the International Classification of Functioning [111. Appendix 1], is suitable for considering the strengths and needs of children and young people with cancer, across all professional disciplines. The need for early referral to specialist care (e.g. endocrine) for high risk patients is also important.
342. Rehabilitation equipment can be an important part of therapy. Assessment by a suitably experienced and qualified professional is essential. Environments may need to be adapted to allow installation of equipment. Delays are often experienced in the provision of such support, which can adversely affect the quality and speed of rehabilitation. Multiagency liaison is important to avoid such delays.
343. Survivors of CNS malignancy are among the neediest of all cancer survivors, because of the effects of the tumour and multimodality therapy, all of which affect neurological, psychological, endocrine and academic function and become more evident with increasing age. Skilled neurorehabilitation often makes the difference between a child who grows into an independent adult and one who needs complex care packages. Speech and language therapy, physiotherapy, occupational therapy,

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neurology, endocrinology and psychology (including neuropsychology) are all disciplines that contribute, although this list is not exhaustive.

A. Recommendations

344. There should be clear, agreed routes of referral for rehabilitation, including self referral, throughout the patient pathway and agreed across cancer networks. Involvement of community paediatricians, where appropriate, may be beneficial.
345. All children and young people with CNS malignancy should have access to a neurorehabilitation service, even years after treatment.
346. Cancer networks should liaise with other NHS Trusts, primary care trusts/local health boards and other agencies to establish robust equipment strategies and strategies for psychosocial support and for communication with education services.
347. Training courses should be established to meet the continuing professional development (CPD) needs of allied health professionals (AHPs) working in oncology services for children and young people across all service settings.
348. Support is required to allow staff to access training opportunities, as these are unlikely to be provided locally, due to the small numbers of professionals involved. Appropriate cover should also be provided.
349. Additional investment is needed to support research in this area and this should be coordinated nationally.

B. Anticipated benefits

350. Timely provision of an appropriate rehabilitation service would improve outcomes, not encompassed by survival, through its impact on self esteem and participation in daily life, productive occupations and improved quality of life. It may help to:
 - prevent secondary conditions e.g. respiratory infection

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- restore function e.g. following amputation or surgery
 - promote normal developmental progression in the younger patients
 - minimise the effects of neurological sequelae following CNS treatments
 - maximise skill development and adaptive behaviour following treatment for CNS conditions.
351. Equipment can promote a child or young person's functioning where skills are being developed, returning after loss or being compensated for. The risk of injury or accident can be reduced when equipment is used with suitable manual handling procedures. Appropriate equipment can hasten home discharge.
352. Investment in staffing capacity would ensure the provision of an effective and equitable rehabilitation service.
353. Children, young people and their parents/carers would receive a higher standard of care and support with a work force that is up to date and experienced and able to respond with sufficient availability of staffing resources.
- C. Evidence**
354. The evidence available in this area is of generally poor quality. Evidence from other areas of paediatric rehabilitation cannot always be extrapolated due to the nature of the conditions concerned.
355. The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1] provides comprehensive evidence for effective rehabilitation services for adults with cancer and some of the recommendations can be extended to address children and young people with cancer.
356. There is some evidence from good quality guidelines for children and young people with head injury that propose effective rehabilitation services and these models can be applied to patients with CNS tumours.

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357. There is some evidence from observational and expert opinion that timing of rehabilitation is important and that there is also a need for the adequate provision of a range of adequately trained AHPs.

D. Measurement

358. *Structure*

- documented referral policies to guide referral for rehabilitation.
- availability of adequately staffed rehabilitation teams to support children and young people and their families in hospital and the community
- availability of specialised neurorehabilitation services
- availability of psychology services/counselling support
- appropriate facilities for rehabilitation
- availability of AHPs to provide rehabilitation services in the patient's home.

359. *Process*

- referral pathways
- involvement of rehabilitation teams in the care of children and young people with cancer
- time to provision of rehabilitation care

360. *Outcome*

- patient satisfaction with rehabilitation services
- effect of rehabilitation on patient outcomes such as improvement in functioning, educational attendance and attainment and quality of life measures

E. Resource implications

361. Substantial investment is required to address AHP workforce and capacity issues to provide access to an equitable service, meeting the CPD needs of AHPs.

Psychosocial care

362. Psychosocial care comprises the psychological and social supportive care for a child or young person and his/her family during active cancer therapy, long term follow up and palliative care, as well as for families after bereavement, and includes respite care.
363. The diagnosis of cancer in a child or young person often throws a family into crisis. The patient faces the challenge of the disease, its symptoms and the side effects of treatment. Many children and young people experience significant problems with body image, relationships with peers and potential partners, difficulties with schooling and other education, or with employment. The family experiences the shock and grief of a child faced with a life threatening illness and they too will have significant psychosocial needs.
364. There are also many practical issues for families to face during the treatment, such as difficulties with work, increased costs due to travel (including hospital parking), living away from home, increased family stress, caring for other siblings, anxiety and depression in other members of the family. Access to information on these issues e.g. Hospital Travel Costs Scheme and other transport concessions is important.
365. The provision of appropriate psychosocial support to children, young people and their families is complex and multidimensional. Multiagency patterns of support are required. The provision of support from social care professionals has relied heavily on voluntary sector funding.
366. Psychosocial support needs are highly individual and will change as individuals and families move through the different stages of the patient pathway.

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367. Psychological services have an important role to play at all stages along the patient pathway, including after completion of treatment and into adult life.
368. Young people may require occupational advice. An occupational therapist, often in conjunction with other services outside of health, such as careers organisations and educational establishments, can support individuals to maximise their physical, emotional, cognitive, social and functional potential.

A. Recommendations

369. All children or young people with cancer and their families, in particular siblings, should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed.
370. There should be access to expert psychological support with clear routes of referral in principal treatment centres and other treatment settings. This should include identified psychologists or other member of psychological services with expertise in the care of children and young people with cancer. It is important that use is made of existing services and that access to these is facilitated.
371. A structured psychosocial assessment at significant points throughout the care pathway is required, including:
 - at diagnosis
 - during treatment
 - end of treatment
 - at relapse
 - palliative care
 - bereavement.
372. The assessment should include family information needs and coping skills, as well as practical support issues, and address the social context of the

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patient and family, including needs relating to education and employment. The needs of siblings should be addressed.

373. Access to neuropsychological services for cognitive assessment should be provided, for all patients, particularly those with CNS tumours, and also to guide schooling and career decisions.
374. The role of other members of the MDT in providing psychological and emotional support to patients, families and carers should be acknowledged and appropriate training and support provided.
375. Sibling and family support groups have proved a valuable resource in a number of treatment centres and should be encouraged across all settings. Peer support networks for patients should also be encouraged.
376. Cancer networks should consider the needs of this group of patients when developing psychological support services.
377. All families of children diagnosed with cancer should be offered benefits advice by a benefits / welfare rights specialist at the point of diagnosis, as recommended by the NICE Guidance on *Improving Outcomes in Palliative and Supportive Care in Adults with Cancer* [61, Appendix 1].

B. Anticipated benefits

378. An agreed minimum level of service defined in psychosocial care would support equitable access to services.
379. Access to a social worker and/or benefits/welfare rights specialist would ensure equity of access to benefits and external community support.

C. Evidence

380. Two systematic reviews have found that the evidence for the best model of psychosocial service provision is poor.

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381. There are good quality UK guidelines, surveys and consensus to indicate the various constituents of a good psychosocial service and illustrate the importance of clear medical treatment plans and referral routes.
382. The published NICE guidance on *Improving Outcomes in Palliative and Supportive Care in Adults with Cancer* [61, Appendix 1] provides recommendations for psychosocial service provision for all cancer patients. The guidance also recommends that cancer networks have a pivotal role to play in service provision for children and young people with cancer.
383. There is evidence to support the particular psychosocial needs of patients with CNS tumours
384. Both professionals and parents and carers have identified a significant lack in formal psychological input and psychology services and support, which represents a significant area of unmet need.

D. Measurement

385. **Structure**
 - policies for referral to psychosocial care
 - access to specialist psychologists or other members of psychological services with paediatric experience
 - availability of neuropsychology services for patients, particularly those with brain and CNS tumours

386. **Process**
 - delays in provision of psychological services

387. **Outcome**
 - outcomes with psychological input
 - patient and parent/carer satisfaction

E. Resource implications

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388. The provision of social care professionals' services has relied heavily on voluntary sector funding, largely through Sargent Cancer Care professionals at £2m annually.
389. Additional funding for expert psychological support will be necessary, where there is existing inadequate provision.

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Long-term sequelae

390. Over 1200 survivors of childhood cancer become eligible for long term follow up each year in the UK and the number of patients needing this service will steadily rise with improvement in survival rates.
391. The risk of sequelae is dependent on the treatment received, the age of the patient at diagnosis, the gender and the time since completion of therapy. The late effects of therapy are well recognised and involve most organ systems. Of particular importance is the effect on fertility with approximately 15% having a high risk of early and irreversible gonadal failure. Cardiac, endocrinological, psychological, neuropsychological and neurological late effects are also common. Some patients will have a second malignancy.
392. Some patients have little or no morbidity and only need to be able to contact the treatment centre or follow up clinic to receive relevant new information, emotional support or help with insurance and employment issues. Others need multidisciplinary hospital-based care including psychological expertise. There cannot be a follow up plan to fit all and the pattern of follow up (where, by whom and how often) will change over time.
393. Groups anticipated to develop significant adverse effects include those with CNS tumours, those who have received high dose chemotherapy, total body/cranial/pelvic radiotherapy, particularly if they are very young.
394. Most patients enter long term follow up at five years after finishing active treatment, but this depends on age at the time of therapy and the anticipated late effects. A particular challenge is the wide range of services needed, as referral needs to be to specialists with an understanding of the patient's previous disease and therapy.
395. All this means that coordination and communication across multi disciplinary teams are very important.

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396. Because patients experiencing late effects are likely to present first to a GP and not to those involved in their original treatment, continued communication with primary care is important.

A. Recommendations

397. Each principal treatment centre should have at least one clinician with expertise in the management of the late sequelae of treatment for children and young people with cancer.
398. Some patients have complex long term problems and so their care should be provided by a multidisciplinary team of doctors, nurses and AHPs usually including an oncologist, endocrinologist, a specialist nurse and other medical specialists as appropriate.
399. There should be robust and appropriate surveillance of survivors, which will be intensive for those with significant anticipated adverse late effects of therapy and minimal for others who are likely to remain well.
400. Clear lines of communication should be established with appropriate specialities e.g. endocrinologist, gynaecologist, reproductive medicine specialists.
401. Where possible patients should be reviewed by an MDT with good communication between paediatric and adult services and age appropriate transitional services.
402. An appropriate key worker should be assigned to each patient on long term follow up.
403. Care plans should be devised for each survivor as they enter long term follow up in accordance with national guidelines. A summary of treatment received and complications experienced should be available to the patient and healthcare professional. This should include details of the total doses

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of chemotherapy, details of radiotherapy and surgery, as well as information on existing or anticipated late effects.

404. The potential risk of infertility should be considered by the treating oncologist and there should be fertility advice by appropriately trained personnel for all patients and/or their families at the time of diagnosis and referral to an Assisted Reproduction Treatment Unit as appropriate. There should be access to semen storage for peripubertal and postpubertal boys. The issue of egg storage is currently experimental. Further advice is necessary as children mature and patients should have access to appropriate endocrine and fertility services in accordance with the NICE Clinical Guideline on *Fertility: Assessment and Treatment for People with Fertility Problems*.
405. There should be early and prompt diagnosis and treatment of any therapy-induced sex steroid deficiency
406. The risk of late effects should be discussed with the patient and parents/carers at the time of diagnosis and start of treatment and they should be given written information, copied to the GP.
407. Training and clinical facilities are required to increase the number of clinical staff available to deliver this service.

B. Anticipated benefits

408. Early identification and appropriate assessment and treatment of problems with growth, development, sexual and reproductive health are important in preventing later morbidity.
409. A key worker will provide immediate access for patients into the healthcare system with appropriate advice, support and facilitation of further follow up as required.

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410. The treatment summary provides written evidence of the patient's previous therapy and any significant complications encountered. This is of value not only for those providing follow up, but also for other health professionals whom the patient may consult. For instance previous exposure to radiotherapy or anthracyclines may lead to complications during pregnancy.

C. Evidence

411. A considerable body of work exists on the long-term impact of treatment, although this consists largely of retrospective, cross sectional studies. There is little evidence of how such information is, or could be, used systematically to plan follow up of the steadily increasing number of survivors. Between 50 and 90% of adult survivors of childhood cancer, have at least one moderate to severe adverse health outcome.
412. Evidence of the morbidity that occurs in these patients has been recently published in the SIGN Guidelines and the position paper for this Service Guidance. A recent large retrospective cohort study, The Childhood Cancer Survivor Study (see the Evidence Review), of 20,346 childhood cancer survivors has determined the prevalence of many of the late effects in these survivors. A similar population based study is underway in the UK, based on approximately 14,000 survivors, which will further determine the extent of the healthcare needs of this patient group.
413. The variability of follow up provided by different centres in the United Kingdom has also been highlighted in the literature.

D. Measurement

414. **Structure**
- evidence of timely produced care plans
 - availability of adequate MDTs with a designated key worker
 - availability of clinicians with expertise in the management of late effects at every principal treatment centre

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- referral to appropriate specialists
- good communication networks

415. ***Process***

- appropriate follow up of patients at risk of late effects

416. ***Outcome***

- treatment outcomes such as morbidity and mortality

E. Resource implications

417. Fully staffed MDTs, including clinicians with specific expertise, nurses and AHPs need to be resourced for the follow up and management of the long-term sequelae of patients.
418. Resources will be necessary to appoint and support appropriate key workers.

Palliative care

419. Palliative care involves care of the patient from the time when therapy is no longer given with curative intent. It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. Its core elements are given in Table 3. Many of these care elements are equally applicable throughout the care pathway.
420. Cancer remains a significant single cause of death for children and young people. When cure is no longer possible, care should be tailored to the choices of the patient and family and take into account variations in local service provision. Flexibility should be the hallmark of care for these patients.
421. Distinctions between general and specialist palliative care are less valid for paediatric services than for adult services. Childhood death is a rare experience for many healthcare professionals, particularly in primary care, and so access to specialist paediatric palliative care expertise from the oncology team, often from the paediatric oncology outreach nurse specialist (POONS), for end of life care is essential. However, all general practitioners need to be kept fully informed and many play an active role during this phase of care. Community children's nursing services provide much of the care for those dying at home, but provision is variable across the country.
422. Palliative care may also appropriately involve active treatment with chemotherapy, including Phase I and II research studies, surgery or radiotherapy. Many families may also explore complementary therapies at this stage.

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Table 3. Core elements of palliative care

- Timely and open communication and information
- Choices/options in all aspects of care, including complementary therapies
- Death in the place of choice
- Coordination of services at home, where this is the chosen place of care, including provision of specialist equipment
- Expert symptom management, including radiotherapy and chemotherapy
- Access to 24 hour specialist advice and expertise
- Emotional and practical support for all family members
- Respite care, with medical and nursing input, when required

423. Most children and young people choose to die at home. For some, particularly those with brain tumours, the palliative phase of their illness can be protracted and they may require complex symptom management during this time. It is important that appropriate medication and specialist equipment is always easily available. Sensitivity should be shown to a family's needs and wishes with regard to the introduction and later removal of equipment.
424. Where palliative care includes primary and secondary care teams, it is essential to communicate care plans and end of life decisions in a timely fashion so as to provide clear direction and optimise clinical care. The role of a key worker is crucial in ensuring the coordination of care between all settings.
425. Children's hospices represent an important potential resource for children with cancer and families require information on their services at the beginning of this phase of care.

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426. Dietetics, occupational therapy, play therapy and physiotherapy are an integral part of paediatric palliative care. Professionals from psychological services can also play a role in helping to support both children, young people and their families, as well as being a resource to professionals.

A. Recommendations

427. To ensure there is equitable access to palliative care, there should be a paediatric palliative care network which has:
- a sound community children's nursing infrastructure
 - multidisciplinary teams
 - coordination and continuity of care through a system of named key workers
 - skilled medical support from general paediatricians with an interest and some training in paediatric palliative care (one per NHS Trust) and from tertiary specialists, either palliative care nurse or medical consultant (one per principal treatment centre).
 - appropriate links with voluntary services.
428. Teenagers and young adults with palliative care needs require special provision, which will often entail the development of partnerships between children and adult services. These patients require individual packages of care, which:
- recognise teenagers and young adults as a distinct group with special needs
 - give full involvement in all aspects of decision making
 - provided by multidisciplinary, multiagency services
 - provide coordinated joint working or transitional care with adult services where appropriate
 - address specific staff training needs regarding both palliative care and the management of young people

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429. Palliative care for children and young people should be actively addressed within the palliative care group of each cancer network.
430. There should be sufficient numbers of POONS to provide 24 hour advice and support to families and to local health and social care professionals, when patients are receiving palliative care.
431. There is a need for the development of hospice and respite services for teenagers and young adult patients, whose needs are very different to those of younger children.
432. There should be timely and equitable access to dietetics, occupational therapy, play therapy and physiotherapy services in the community.
433. Clinical psychology support should be available in all areas with clear lines of referral within the cancer network.
434. A recognised training pathway for clinical staff wishing to develop specialist skills and knowledge in paediatric palliative care should be developed.
435. The work of the POONS group on palliative care pathways in paediatric oncology should be further developed and national research is needed to develop the evidence base for pain and symptom management; such development work also needs to be performed for young people . This should in turn lead to national guidelines in paediatric and young people's palliative care.
436. In view of the lack of high quality evidence on services for palliative care for children and young people with cancer, further research in this area would be welcome.

B. Anticipated benefits

437. Every child, young person and their family will have choice in the place of death.

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438. Each family will have the support of an experienced and knowledgeable key worker who will coordinate and lead during palliative and terminal care.
439. Specialist support will be available over the 24 hour period.
440. Appropriate services will be available to:
 - enable a rapid response to symptom management
 - to prevent escalation of pain and symptoms
 - minimise readmission to hospital.
441. Appropriate personnel and equipment will be available to support death at home.

C. Evidence

442. There is lack of high quality evidence on the best model of service provision for palliative care for children and young people with cancer. The authors of one good quality systematic review comment on the poor quality of studies and emphasise that the effectiveness of the palliative care team, working as unit, is difficult to measure. There is evidence from expert opinion that standardised outcome measures would be valuable for practice and research.
443. The NICE guidance on *Improving Supportive and Palliative care in Adults with Cancer* [61, Appendix 1] provides good quality evidence for the requirements of a palliative care service for adults.
444. The evidence from good quality surveys of current palliative care provision is used to make recommendations for service components to provide adequate palliative care. There is a particular requirement for adequate provision of trained paediatric oncology outreach nurses.
445. Expert opinion and consensus indicate the central role of the cancer networks in ensuring that there are clear referral routes and that the needs

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of children and young people are addressed by the palliative care groups within the networks.

D. Measurement

446. *Structure*

- written policies to inform referral for palliative care
- availability of appropriate and adequately staffed palliative care services in hospitals and the community, particularly in the home setting.
- availability of 24 hour telephone support and effective information services
- availability of respite services

447. *Process*

- proportion of patients referred for palliative care
- home visits made by the palliative care team
- time to provision of specialist palliative interventions

448. *Outcome*

- improved symptom control
- patient and parent/carer satisfaction with palliative care

E. Resource implications

449. The cost of supporting palliative care key workers, such as POONS, must be met to ensure coordinated and integrated care.
450. Funds to provide 24-hour advice and support by palliative care key workers to families and local health and social care professionals, will be necessary.
451. Funding for children's hospices is predominantly supported through charitable sources.

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Bereavement services

452. Although the family of a child or young person with cancer may experience a sense of bereavement from the time of diagnosis, this section deals only with bereavement after the death. Death usually occurs at home, following a period of palliative and terminal care, but may also occur in hospital. Less commonly, death may occur during treatment, either in hospital or at home. Bereavement support frequently begins during terminal care. Wherever death occurs, families need unhindered access to a senior member of staff, preferably one experienced in bereavement advice.
453. Following the Redfern Report in 2001[101, Appendix 1], many trusts have a bereavement coordinator who takes the lead or supports nursing staff in this role. At home, families are usually supported around the time of death by their paediatric oncology outreach nurse or children's community nursing team. Support may also be provided by an oncology social worker.
454. Specific issues to be considered following death include:
- acute grief reactions from family members and ongoing needs
 - post mortem, consent and tissue retention (including sperm storage)
 - coordination of care in the bereavement suite and transfer home.
 - registration of the child's death.
455. Many families are able and wish to take the lead in the arrangements after their child's death. Appropriate information and support should be available to assist them in this process if needed.
456. Access to spiritual care at this point is often of particular value. However it is important to recognize that access to such support may be of relevance throughout the care pathway to many families.

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457. Support from a psychological services professional at this time may also be of value not only for children, young people and their families, but also professionals.

A. Recommendations

458. Cancer networks should ensure that all families, who have experienced the death of a child or young person have access to specialist bereavement support. The specific needs of siblings should be recognised. This should be a collaborative provision/development including children's and young people's hospices and other agencies.

459. All families should have the support of an identified key worker at the time of death of a child or young person, whether in hospital or at home. The key worker should be experienced in bereavement support to enable families to have informed and sensitive decision making.

460. Each treatment centre should provide ongoing support to bereaved families after death, whether in hospital or home for an appropriate period. This should include the provision of clear information about the experience of bereavement and how to access other support.

461. Services should be tailored and responsive to the needs of individual families.

462. Staff support/supervision should be available for all those involved in the death of a child or young person.

463. Provision of bereavement support should be an integral part of communication skills training.

B. Anticipated benefits

464. Families will have equal access to a flexible and responsive model of care and support.

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465. Clearly identified source of support will be available at particularly vulnerable time.
466. The facilitation of grieving should help prevent the detrimental consequences of bereavement.
467. Identified support to healthcare professionals who engage in this work should help minimise staff distress.

C. Evidence

468. There is evidence from good quality surveys to illustrate the variation in provision of bereavement care within the UKCCSG centres.
469. There is evidence from guidelines to indicate the need for bereavement services to be flexible and accessible when required.
470. There is evidence from provisional studies on guidelines and the development of standards for bereavement care to indicate service requirements.

D. Measurement

471. **Structure**
 - provision of readily accessible bereavement services
472. **Process**
 - bereavement services provided
473. **Outcome**
 - effect of bereavement advice on quality of life of parents/carers and siblings
 - parent/carer satisfaction

E. Resource implications

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474. Additional funding will be needed to ensure that all families, who have experienced the death of a child or young person, have access to specialist bereavement support.

Service organisation

475. This section covers the organisation of services and issues that affect service delivery, and contribute to successful outcomes. The differences between services for children and those for young people are discussed.
476. Services need to be commissioned across all levels of care and seen as a whole system across community and hospital settings. The position of these services with regard to commissioning frameworks is variable and unclear.
477. Equitable access to services is a key issue. Many services have evolved over time and within geographical and other constraints, such as the availability of expertise and level of funding. These constraints remain real, but efforts must be made to minimise the variations in access. The overriding principle for the provision of services must be “safe and effective services as locally as possible, not local services as safely as possible”.
478. Services have to recognise and be responsive to individuals' often complex needs and take into account their level of independence, maturity and features of the disease (type of cancer, stage, new presentation or recurrence, potential late treatment sequelae). An additional factor is the common and understandable regression of behaviour in older age groups, at times of crisis.
479. A balance has to be struck between “care” needs, addressed by the care environment, and “disease” needs, addressed by medical treatment. Nevertheless needs are defined by an individualised approach to treatment and care is required that takes account of local service provision, particularly for the older patients.

A. Recommendations

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480. Planning, commissioning and funding for all aspects of care, across the whole healthcare system, should be coordinated, to ensure there is an appropriate balance of service provision and allocation of resources.
481. The commissioning arrangements for services for children and young people with cancer need further clarification to ensure the above recommendation can be met.

Delivery of care

Multidisciplinary teams

482. A complex range of services is required for children and young people with cancer, involving many disciplines and professional groups, and crossing organisational and institutional boundaries. Modern cancer care has come to be defined by its delivery through teams of professionals working together, known as multidisciplinary teams (MDTs). These teams have been described in adult cancer care principally with regard to those involved in the diagnosis, staging and (medical) treatment planning for the individual patient. A broader definition of these teams is now emerging, in line with good practice in cancer services for children and young people, where the MDT has long been recognised as including all those involved in care and support of the individual child and family throughout the care pathway.
483. It is not necessary for each member of the MDT to attend all meetings. The team's composition at any one point in a patient's journey will vary and should reflect the patient's needs, both disease and age related, at that time as well as the expertise and skills of particular team members. Tables 4-6 below give the essential members of the MDT in relation to particular needs. Other health care professionals may be involved in some or all of these meetings. The constitution and organisation of teams and meetings should also reflect the specific clinical activity/profile of individual treatment settings. The MDT will also need access to other expertise e.g. microbiologist.
484. However, there is a case to consider for a separate MDT for late effects, as there is a wider range of professionals involved over a prolonged time period.

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Table 4 Suggested core attendance of MDT members at principal treatment centres during the care pathway

Diagnosis *
<ul style="list-style-type: none"> • Oncologist/haematologist • Radiologist • Surgeon/neurosurgeon • Pathologist/cytogeneticist • Clinical oncologist
Treatment *
<ul style="list-style-type: none"> • Treating oncologist • Key worker** • Paediatric haematologist • Specialist nurses • Ward based nurse • Day care nurse • Specialist outreach nurse • Specialist pharmacist • Dietitian and other appropriate allied health professionals • Paediatric oncology or other speciality outreach nurse/key worker**
Psychosocial support
<ul style="list-style-type: none"> • Treating oncologist and haematologist • Key worker** • Play specialist; activity coordinator/youth worker • Psychological services professional • Specialist outreach nurse • Appropriate allied health professionals • Teacher • Social worker • Nurses from in-patient and day care units

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Palliative care

- Lead clinician
- Key worker**
- Palliative care specialist/oncologist/haematologist
- Social worker
- Specialist outreach nurse
- Specialist pharmacist
- Psychological services professional
- Specialist outreach nurse
- Appropriate allied health professional

Table 5 Suggested core attendance of MDT members responsible for the care of patients following completion of treatment

Late effects MDT

- Lead clinician (oncologist with expertise in late effects)
- Key worker**
- Specialist nurse
- Endocrinologist
- Appropriate allied health professional
- Psychological services professional

* Medical staff represent tumour specific or paediatric expertise

** See section on continuity of care (Key worker may come from any of the disciplines involved in the MDT).

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Table 6 Suggested core membership of MDT at other treatment sites

- | |
|---|
| <ul style="list-style-type: none">• Lead paediatrician/oncologist/haematologist• Key worker**• Specialist nurse• Pharmacist• Ward nurse/community nurse• Allied health professionals• Social worker |
|---|

*** See section on continuity of care. (Key worker may come from any of the disciplines involved in the MDT.)*

485. There are several tumour types whose management and treatment planning need consideration by either a specialist tumour specific MDT or through liaison with other sub-specialists. These include:

- Tumours of the CNS
- Bone sarcoma
- Some soft tissue sarcomas (particularly in young people)
- Retinoblastoma
- Lymphomas (for specialist pathological review)
- Malignant thyroid tumours

A. Recommendations

486. Care should be delivered throughout the patient pathway by MDTs, including all relevant staff. Decisions should be recorded and disseminated to all relevant health professionals. Where care involves more than one treatment setting or specialist team, the remit and membership of the MDTs should reflect the arrangements for shared care.

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487. All non principal treatment centres (see section on ‘Place of care’) participating in shared care should have an MDT that facilitates the interface between that centre and both primary care and the principal treatment centre.
488. Membership of MDTs should be explicit and include clearly defined responsibility for clinical and managerial leadership.
489. There should be clear, two way communication between the MDT at the principal treatment centre and MDTs at any other treatment setting with designated individuals responsible for ensuring continuity.
490. MDT membership and responsibilities require dedicated time and should be recognised in job plans. The frequency and purpose of MDT meetings should be explicitly stated and monitored, but most should meet weekly.
491. Centres providing care for teenagers should ensure that the skills and experience represented in the MDT are appropriate to the age related needs. Members should be familiar with the communication issues specific to working with teenagers and their families and appropriate training and support should be available.

B. Anticipated benefits

492. MDTs ensure that each patient is considered from a range of viewpoints and expertise. MDTs promote shared learning between professionals.
493. They offer a greater probability of timely, appropriate treatment and better continuity of care and enable services to lose the “referral” culture.
494. Regular discussion in the context of an MDT is more likely to lead to improved clinical policies, more effective delivery of care and multidisciplinary participation in audit and research.
495. Regular patient centred meetings, joint assessments and shared recording systems will enable teams to provide more comprehensive services.

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C. Evidence

496. There is no high quality evidence demonstrating that MDTs improve outcomes in children and young people with cancer. Extrapolating from observational studies on multidisciplinary management of paediatric and adolescent cancers, there is some evidence suggesting that there may be improved outcomes in patients with osteosarcoma, hepatic tumours and medulloblastoma.
497. The advantages of a multidisciplinary shared care programme for young people have been demonstrated in a randomised controlled trial performed in Denmark.
498. There are national guidelines/guidance that provide information on the frequency and composition of MDTs

D. Measurement

499. *Structure*

- evidence that MDTs are established in each principal treatment centre and shared care centres
- effective communication methods between the MDTs based in the principal treatment centres and the shared care teams
- adequate provision of specialist staff for every MDT
- provision of staff with age appropriate experience.

500. *Process*

- protocols for referral to specialist MDTs
- staff attendance at the MDT meetings
- evidence that all patients are discussed at an appropriate MDT

501. *Outcome*

- outcomes with multidisciplinary care of patients with certain tumour types

E. Resource implications

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502. Some centres will need to employ additional staff to provide administrative support and to coordinate MDT meetings. Other staffing issues include a national shortage of MDT members, including paediatric radiologists and radiographers, paediatric pathologists and AHPs.
503. Resources will be required to enable members of the MDTs to attend meetings.

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Continuity of care

504. Care may need to be sustained over many years, often across organisational and professional boundaries. Continuity of care is important in the treatment and follow up of the original disorder, its sequelae or relapse, as well as in the provision of palliative care,
505. Patients may require long term follow up care at all ages and so the transition from paediatric to adolescent healthcare and on into adult medical care must be addressed. Parallels can be drawn with other conditions, although the needs of this group are unique and highly variable, often involving a number of MDTs.
506. There is a need to ensure integration and coordination of care within and between primary, secondary and tertiary care settings, between the statutory and voluntary sector, and across health, social care and education.
507. Such complexity of need demands a coordinated approach to service provision and in other services, a key worker approach has been effective in ensuring such coordination. The role of a key worker is set out in Table 7. This role is expected to be carried out in partnership with other members of the team e.g. ward nurses, social workers, teachers.
508. Key workers may change over the period of treatment and follow up. The key worker identified during active treatment and early follow up is likely to be different to the key worker identified for long term follow up. There are times along the patient pathway when the identity of the key worker may change for a particular episode of care, such as at the time of a bone marrow transplant.
509. In most instances, a specialist nurse can most effectively undertake the key worker role, and in many principal treatment centres, and for the younger

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age range, this role is likely to be undertaken by a POONS. For teenagers and young adults, the role of the outreach nurse specialist is less well developed and other clinical nurse specialists have taken on elements of the role of key worker.

510. The workload involved with the increased age range of patients and the complexity of care needs mean that POONS are not currently able to fulfil the role of the key worker at all stages of the patient journey. This will require additional resources for outreach teams.

Table 7 The role of the key worker

- | |
|--|
| <ul style="list-style-type: none">• Provide practical and emotional support to the child/young person and family.• Coordinate the provision of information and ensure that it is timely, tailored to the age of the child or young person and the needs of the family, and understood• Ensure the provision of a written care/treatment plan and an initial needs assessment of the child or young person and family to inform the care plan• Liaise with health and social care agencies and professionals in the community, including the primary care team.• Liaise with educational institutions and support reintegration for the child or young person wherever possible.• Ensure that the child, young person and family acquire new skills as needed, e.g. care and management of nasogastric tubes or gastrostomies, care of central lines.• Case manage the care needs of the child or young person and family as they move between care settings along the patient pathway e.g. during radiotherapy.• Coordinate palliative and terminal care to provide specialist advice and support to families and healthcare professionals, with cross cover to provide a 24 hour service, if required. The key worker may provide direct clinical care and expertise at this time if appropriate |
|--|

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511. There are different models of a more disease-specific specialist nurse, such as leukaemia nurse specialist, orthopaedic oncology nurse specialist and neuro-oncology nurse specialist in some principal treatment centres, who might take on the role of key worker for a defined patient population.
512. Sometimes, such as in long term follow up, the key worker role may be undertaken by other staff, including a primary care team member, paediatric oncologist or other specialist who may have to monitor the most likely late effects.
513. Good communication between professionals across all sectors is important for the appropriate management and continuity of care and is facilitated by effective MDT arrangements, the use of written care/treatment plans and patient held records.

A. Recommendations

514. A key worker should be identified for each child or young person and their family to coordinate services and assess their support needs.
515. There should be clear routes of communication between different care/treatment settings.
516. Each child or young person and their family should have a written care/treatment plan, which draws together the provision of all components of care; where appropriate, voluntary agencies should be recognised as integral to the care plan.
517. The written care/treatment plan should include the individual arrangements for transition and should be informed by protocols/guidelines drawn up by the respective services.

B. Anticipated benefits

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518. A written care plan will allow the family to receive adequate information about planned treatment and will minimise errors in treatment planning. It will also identify contact personnel for the patients and their families during treatment.
519. A key worker will provide additional support for the family and point of contact with the principal treatment centre for support/clarification through issues arising during the patient's treatment.

C. Evidence

520. There is a paucity of evidence to indicate the requirements for service provision to achieve a well coordinated transition or continuity of care for children and young people with cancer. One review of the evidence concluded that further research was required to determine continuity of care for young people.
521. There are consensus and expert opinions that emphasise the need for good communication between all agencies concerned with care and the existence of written care/treatment plans that should be informed by local guidelines/protocols
522. There is observational evidence on the essential role of a key worker in the continuity of care.
523. Results from patient surveys show that the key worker model is supported by families of children and young people with cancer.

D. Measurement

524. **Structure**
 - documented local protocols for the continued care and follow up of patients including identification of key workers for individual patients
 - written care/treatment plans
 - provision of adequate numbers of key workers to coordinate care
 - good communication networks

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- provision of patient held records

525. ***Process***

- care/treatment plans
- planned transition outcomes

526. ***Outcome***

- patient and parent/carer satisfaction with the continuity of care.

E. Resource implications

527. The cost of employing key workers to support individual children, young people, and their families, must be met.

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Protocol based care

528. Much of the first line medical treatment of childhood cancer in the UK over the last 25 years has been through clinical trials, leading to the development of national, and more recently international, collaborative protocols. This is to be welcomed, as most of the individual conditions are rare and collaboration is needed to best use available expertise and to develop further studies and audit.
529. In contrast, the treatment of cancer in older teenagers and young adults is less consistent and there is a need for greater collaboration between adult and paediatric clinicians working within the same tumour field. The protocol chosen for therapy often depends on where patients receive treatment and the protocol, paediatric or adult, in use within the unit at that time. The exceptions to this are those tumours, such as osteosarcoma and Ewing's sarcoma, where the tumour type is well recognised across all age ranges and the appropriate protocol is available to all.
530. The pattern of cancers in older teenagers and young adults is different from both the paediatric and adult groups and systematic, protocol-based care, backed by research and audit, is important to further understanding of the biology of these tumours and their response to therapy.

A. Recommendations

531. Treatment and care for children and young people with cancer should be based on agreed treatment protocols, if inclusion in a relevant clinical trial is not possible.
532. The choice of paediatric or adult protocol for the treatment and care of teenagers and young adults should be based on clear evidence of the best outcomes.

B. Anticipated benefits

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533. Standardised, evidence based treatment, as set out in specified protocols based on expert advice, should result in:
 - improved survival
 - reduction in the intensity of therapy for some patients
 - lower morbidity
534. A better understanding of tumour biology and response to treatment will be derived from collaborative care.

C. Evidence

535. The dramatic improvement in survival for some cancers, particularly for those aged 1–15 years, is believed to be, at least in part, related to early collaborative working and the development of randomised trials.
536. There is some good quality evidence (systematic review, prospective cohort study and case series) to support the positive effect of protocol-based care on outcomes; one review of studies did not find a protocol effect, but the studies were not assessed for quality.
537. The evidence is inconsistent to determine in all tumours of children and young people whether it is a true protocol effect, or the treatment setting that is important
538. There is some evidence (see also section on Research) to indicate that for some cancers, young people who are treated on paediatric protocols have improved outcomes compared with those receiving treatment according to adult protocols.
539. There are now recommended treatment protocols for over 80% of CNS malignancies in children, which cover how the diagnosis is made, the timing of surgery, the measurement of disease extent and the therapeutic strategy.

D. Measurement

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540. ***Structure***

- availability of adequate support/resources to enable equitable access for children and young people to be treated on a defined protocol within a clinical trial.
- demonstration of greater collaboration between adult and paediatric oncologists

541. ***Process***

- unmet need in children and young people with cancer for protocol based care.
- protocol compliance by both patients and clinical specialists

542. ***Outcome***

- evidence of the effect of treatment according to defined clinical protocols, on outcomes.

E. **Resource implications**

543. An increase in protocol based care is likely to result in cost savings as a result of the anticipated improvement in outcomes.

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Place of care

544. Throughout the care pathway, the various components of care will be delivered at a number of locations, ranging from the community to tertiary and, for some, highly specialised quaternary centres.
545. The major elements of treatment, particularly management planning by a MDT, usually takes place at a specialist cancer centre, most often, for children, one of the 17 UKCCSG centres in England and Wales. Patients frequently live some distance away, and so it is a widely established practice for the paediatric oncology centre to work in conjunction with local secondary paediatric services, usually known as shared care centres. Thus some episodes of care, for example management of infective episodes or delivery of simple chemotherapy, may be undertaken closer to home.
546. Patients over 16 years may be treated within a paediatric oncology service, in adult cancer services, or in specialist teenage or young adult services attached either to paediatric or to adult units. Very few paediatric services offer shared care for children over 16 years.
547. There are relatively few services specifically designed for teenagers with cancer and, in general, there is a lack of coordination and infrastructure of services for patients in this older age group.
548. There is a need for identified clinical nurse specialists to address the care and support needs of teenagers and young adults.
549. The Guidance sets out below the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to

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address the recommendations made, regarding provision of care, throughout this guidance.

Principal treatment centres

550. The principal treatment centre provides expertise and experience in the management of an individual patient's particular type of cancer, which includes the provision of multidisciplinary care, the coordination of an individual's care with other appropriate locations and access to clinical trials and research. Such centres will have defined clinical governance structures and clear policies for transition to age appropriate environments and specialist teams.
551. Access to such facilities should be with the least inconvenience to patients and families, but the rarity of cancer in these age groups means that treatment may involve considerable travel for families, often beyond a closer, but less appropriate, cancer facility. This is generally well accepted by patients and families, but does impose additional burdens on them.
552. Principal treatment centres for children are largely represented by UKCCSG centres, which have developed in response to need and availability of expertise. However, there is wide variation in workload and in the facilities offered. Facilities and levels of consultant and nursing staff are partly determined by other work issues, such as whether bone marrow transplants are undertaken in the centre and the number of new patients with cancer treated at the centre each year.
553. Principal treatment centres need 24 hour specialist medical and nursing staff cover and also expertise in a wide range of cancers. Specialisation in paediatric cancers is generally not site specific as it is in adults, because of the relatively small number of patients, but specialisation does occur for CNS tumours, haematological malignancies and solid tumours and adequate cross cover arrangements are required.

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554. Teams caring for young people need to be experienced in and responsive to the specific social, psychological, and educational needs of teenagers and young adults with cancer and their families, in addition to their expertise in the treatment of the cancer itself. Such services may be delivered most effectively within dedicated units which include specific inpatient facilities for teenagers and young adults. They should be developed in sympathy with established local cancer provision and operate through partnerships between paediatric and adult oncology services.
555. Although the management of many cancers (e.g. carcinomas, germ cell tumours) in young adults may be less complex and largely outpatient based, they still require services that are responsive to their needs.
556. Pressures on consultant workload have arisen from various sources including:
 - the reduction in junior doctors' hours
 - compliance with the European Union Working Time directive [39, Appendix 1]
 - compliance with the European Union GCP in Clinical Trials directive [38, Appendix 1]
 - increased intensity of treatment initially and at relapse.
557. There therefore needs to be adequate core consultant staff in each principal treatment centre
558. There are also pressures leading to increased nursing workloads including:
 - Greater intensity and complexity of treatment
 - Need to deliver in-house training
 - Poor retention rate of senior staff

Local hospitals

559. For most patients it will be appropriate and necessary for some elements of care to be provided by their local hospital, rather than their principal

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treatment centre, in a “shared care” arrangement. The local hospital may or may not provide specialist cancer services and the responsible team may be from paediatric or adult services, depending on age and the nature of condition.

560. Currently different models of shared care exist in the UK reflecting various factors, especially local geography and distribution of facilities; however all shared care arrangements should involve the provision of an agreed level of coordinated care with the principal treatment centre and there should be a responsible MDT within that treatment setting (see Table 8).
561. Shared care arrangements are seen frequently in the paediatric setting, but are less well established for the care of teenagers and young adults.

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Table 8 Key features for shared care

- Coordinated care supported by appropriate structures and process
- A named consultant in the principal treatment centre, with overall clinical responsibility for care, and a named consultant who takes responsibility at the local level
- An identified nursing lead at the non principal treatment site
- An identified pharmacist lead at the non principal treatment site
- Robust two way systems of communication
- Age appropriate environment
- Written guidelines to support the level of care agreed
- Education and training programmes for staff in all settings
- Arrangements for unexpected admissions
- Identified contacts for families
- Identified funding

Other locations of care

562. Elements of specialist care may take place in a range of other locations, for example special surgical facilities or radiotherapy units, and care may be given in the community, usually at home or in hospices, and during the palliative stage.
563. Children's community nursing services are not comprehensive across the UK and a significant number of children and young people are cared for in the community by general district nurses, who may not be able to undertake certain interventions needed by the child and family. Both general children's community nurses and district nurses may need support, information and training in taking on new skills. The POONS or other outreach and liaison teams generally provide this from the principal treatment centre.

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564. Wherever care is given, it is essential that the GP and primary care team are kept informed as to a child or young person's care and treatment plan.
565. The primary care givers will often be the family and those healthcare professionals who can support the family at home. Where children's community nursing teams do not exist, other members of the primary healthcare team, such as district nurses, will need to take on aspects of care. These need support, and in some cases training, from specialist services.

A. Recommendations

566. The definitive investigation of children and young people with a suspected diagnosis of cancer should only take place in principal treatment centres, which should have the appropriate staff and resources to meet the waiting time requirements of the NHS Cancer Plan [27, Appendix 1] and the Welsh Cancer Standards [21, Appendix 1].
567. The care of each child and young person with cancer should be directed from an identified principal treatment centre with a dedicated multidisciplinary team with expertise in the cancer related issues of this age group and their families. Written guidelines for referral, admission, communication at discharge and follow up should be in place.
568. Principal treatment centres should be able to provide a sustainable range of services, with defined minimum levels of staffing, as outlined in Tables 9 and 10.
569. The principal treatment centre should have the capacity to accept referrals and admit patients in a timely fashion.

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Table 9 Core components of a principal treatment centre (children)

<p><i>Personnel*</i></p> <ul style="list-style-type: none">• Designated lead clinician• Paediatric oncologists• Paediatric haematologists<ul style="list-style-type: none">(minimum of 5 consultant staff, at least 2 of each discipline above)• At least 2 Clinical oncologists with expertise in paediatric radiotherapy• Paediatric surgeon with expertise in specialist oncology**• Adequate junior and middle grade cover <p>Other specialist services necessary on site:</p> <ul style="list-style-type: none">• Paediatric anaesthetics• Paediatric radiology• Paediatric pathology• Designated paediatric oncology pharmacist• Designated lead psychological and psychiatric services <p>Nursing establishment**</p> <ul style="list-style-type: none">• Identified lead nurse• Specialist trained nurses for ward and day care• Paediatric oncology outreach nurses <p>Core allied health professionals:</p> <ul style="list-style-type: none">• Dietitians• Physiotherapists• Occupational therapists• Play specialists <p>Designated social workers</p> <p>Research support:</p> <ul style="list-style-type: none">• Research nurse• Data managers <p><i>There should be immediate access to:</i></p> <ul style="list-style-type: none">• Paediatric intensive care• Paediatric neurosurgical services

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- Other tertiary paediatric services (cardiology, renal, endocrinology, other specialised surgical services)
- Dental services
- Pain management teams

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Table 10 Core components of a principal treatment centre (young people)

<p><i>Personnel*</i></p> <ul style="list-style-type: none">• Designated lead clinician• Other consultant staff with expertise in the care of malignancies seen in this age group• Adequate junior and middle grade cover+ <p>Other specialised services necessary on site as required for site specific expertise:</p> <ul style="list-style-type: none">• Radiology• Pathology• Designated oncology pharmacist• Psychological and psychiatric services <p>Adequate nursing establishment**</p> <ul style="list-style-type: none">• Identified lead nurse• Specialist trained nurses for ward and day care• Key worker/ outreach nurses <p>Core allied health professionals:</p> <ul style="list-style-type: none">• Dietitians• Physiotherapists• Occupational therapists• Activity coordinator <p>Designated social workers</p> <p>Research support:</p> <ul style="list-style-type: none">• Research nurse• Data managers <p><i>There should be immediate access to:</i></p> <ul style="list-style-type: none">• Intensive care• Neurosurgical services• Other tertiary services• Dental services
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- Pain management teams

** Where numbers are given this represents a minimum requirement of wte staff; in many settings the requirement will be higher dependent on patient activity/ intensity of treatment/types of referral to centre etc. There must be expertise with cross cover for haematological, CNS and other solid malignancies. NB: For consultant staff, the numbers need adjustment where services are provided by academic staff (fewer service sessions available).*

*** With adequate cross cover arrangements*

+This may be a particular issue where the facility for young people is ‘stand alone’. There should be clear lines of responsibility from paediatric, haematology and/or clinical oncology teams, appropriate to local needs

570. The principal treatment centre for children with cancer should be a UKCCSG centre, unless the requirement for specific expertise demands otherwise.
571. Whatever the age of the patient they should have access to:
 - expertise in the management of the malignant condition
 - age appropriate facilities
 - appropriate MDTs .
572. In each care setting, care should:
 - be delivered by appropriately trained, experienced staff
 - be responsive to tumour type and stage
 - reflect the age related needs of patients and families
 - include explicit arrangements for unexpected admissions.
573. Partnerships between age appropriate facilities, such as teenage wards/units, and tumour specific services, which may be primarily located within an adult setting, are required. This group would benefit from the development of clear “signposts” to the most appropriate care pathways based on need.

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574. There should be clear and rapid communication between each care agency and location.
575. There are a number of intensive treatment protocols which should only be delivered within a principal treatment centre; those which predictably produce profound and prolonged neutropenia and carry a significant risk of requiring intensive support. These patients should have access to other tertiary specialities and in particular direct access to intensive care facilities.
576. Some rarer malignancies require specialised services, which should be provided in a limited number of centres. These include retinoblastoma, bone tumours, some sarcomas and liver tumours.
577. Allogeneic bone marrow transplantation should only be undertaken by accredited JACIE centres.
578. All Trusts undertaking elements of cancer care (whether primary, secondary or tertiary) for children and young people with cancer should identify clinical leadership with overall responsibility for the delivery of the service this should include the development of age and disease appropriate services, with responsibility for the maintenance of policies and governance structures.
579. Where there are shared care arrangements, there should be identified individuals with responsibility for clear, two way communication between these sites allowing treatment decisions to be clearly cascaded and any issues raised by other treatment sites addressed.
580. Shared care arrangements should be reflected in consultant job plans; there should be adequate time for training and CPD for all members of the multidisciplinary team.
581. Adequate resources are required not only for principal treatment centres, but also for all settings which are participating in the delivery of care.

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B. Anticipated benefits

- 582. Improvement in survival for patients treated by MDTs with expertise in treating their cancer
- 583. Improvements in supportive care and psychosocial support for the patients and their families
- 584. The delivery of some aspects of care closer to the patient and family home; reduced travel costs to families; reduced impact on family life; increased confidence of patients/families in local services.
- 585. Identified leads will improve communication between treatment settings.

C. Evidence

- 586. Research evaluating current models of specialist provision for children's cancer is very limited. Survival has been used as the principal end point in several studies, but no clear correlation between hospital type or size has emerged. Many available studies are particularly limited by being old, focusing on specific techniques such as bone marrow transplantation, but especially by using end points which are too narrow to reflect all the advantages or disadvantages of a particular treatment centre.
- 587. Justification for separate facilities for children with cancer may not require endorsement through further research. Similar levels of support for separate and specific provision for teenagers and young adults do not yet exist, although the National Service Frameworks for Children's Services [35, Appendix 1] in both England and Wales recommend age appropriate facilities. Further research to define needs of young adults is required as they have both a changing spectrum of cancers and a broader range of social educational and vocational profiles which may be less easily encompassed by single care models.
- 588. Designated units for teenagers and young adults, which exist in England, have been well received by young people and their families.

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589. Evidence on prevalence of shared care in UK shows variation in practice. Evidence on efficacy of shared care in different settings shows that where shared care is ad hoc or unstructured, outcomes may be worse, but where shared care is well coordinated, outcomes may be as good or better. Patients at first may have reservations but generally evaluate schemes positively. Shared care can reduce costs to both health service and the patient, but this depends on the model used.
590. There was no evidence to indicate that protocol compliance was greater when treatment is performed in a principal treatment centre compared with a shared care centre.
591. Evidence from families reflects very different experiences of shared care, and highlights the importance of communication and collaborative care across care settings.

D. Measurements

592. ***Structure***

- documented arrangements to ensure that treatment for children and young people with cancer is performed in designated specialist centre.
- provision of dedicated age appropriate facilities

593. ***Process***

- number of patients managed annually by the principal treatment centres and shared care centres
- use of locally agreed clinical protocols
- placing patients with febrile neutropenia on wards other than the specialist oncology wards
- inability to accept new referrals

594. ***Outcome***

- accurate data for the tumour specific differences for different outcomes when treatment is received in inappropriate settings.

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- patient and parent/carer satisfaction with treatment facilities
- delays to start of planned chemotherapy
- delays to diagnostic and definitive surgery
- delays to start of radiotherapy

E. Resource implications

595. The provision of age appropriate facilities may have cost implications in some areas.

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Cancer networks

596. Services for children and young people with cancer require the development of specific and formal networks to ensure delivery of care. Many of the established cancer networks have not yet engaged with these services, but now have a key role in developing appropriate services for children and young people with cancer, whether or not the network actually contains a UKCCSG centre.

A. Recommendations

597. Cancer networks should, in discussion with the commissioners, ensure that children and young people have access to all elements of the appropriate cancer services. They should ensure that:
- an identifiable organisational structure exists for cancer services for children and young people. This should include network leads for children, teenagers and young adults with cancer.
 - appropriate principal treatment centres for each cancer type are identified for children and for young people with associated referral pathways, including to centres outside the network of residence when necessary.
 - an identified cancer network hosts each principal treatment centre
 - shared care arrangements are established and clarified, with written, agreed protocols across the network for all age groups.
 - if care is shared, the non principal treatment centre identifies a lead clinician, adopts the network protocols, and agrees areas of responsibility.
598. All principal treatment centres for both children and young people should be members of an identified cancer network.
599. Where catchment areas for a particular principal treatment centre or shared care arrangement cut across the boundaries of a number of networks, the

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cancer networks should work with the commissioners of cancer services for children and young people to ensure that all aspects of care are recognised and resourced. The host network for the principal treatment centre would be expected to lead on this process on behalf of other networks.

600. Commissioners should ensure that these services are actively taken forward proactively by cancer networks.
601. Cancer networks should work in partnership with other services for children and young people.

B. Anticipated benefits

602. The provision of well coordinated care.
603. Targeting of resources where they are most required to serve the needs of their local population.
604. The needs of children and young people with cancer to be recognised in the continuing development of cancer services at both local and national level.

C. Evidence

605. The setting up of cancer networks was recommended in the Calman Hine Report [23, Appendix 1].
606. Cancer networks are the organisational model for cancer services to implement the NHS Cancer Plan [27, Appendix 1] and Improving Health in Wales; A Plan for the NHS with its partners [109, Appendix 1].

D. Measurement

607. Compliance with any relevant standards for cancer networks described in Topic 1a of the Manual of Cancer Services 2004 [37, Appendix 1] and in the Welsh Cancer Standards [21, Appendix 1]. It is recognised that not all standards are applicable.

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608. Further standards will be developed to address the recommendations in this guidance and these will be essential for peer review of these services.

E. Resource implications

609. It is probable that increased involvement of cancer networks in service provision for children and young people with cancer as recommended by the guidance will have cost implications, possibly resulting in cost savings.

Communication with children, young people and families

610. Open communication between professionals, children/young adults and their families is a prerequisite for success. It is essential the patients and their families understand their cancer, their treatment and any choices that they may have. Many patients and families are able to contribute to the management of their condition.
611. Information can be provided in different ways, including verbal, written and audiovisual. Different age groups will have different needs, as will parents, families and carers, and ensuring information is provided in an accessible way is a challenge. There are many specialist organisations that can assist services to provide appropriate information for different, often disadvantaged, groups.

A. Recommendations

612. All healthcare professionals caring for children and young people with cancer should have appropriate training in developing communication skills. They should be trained to communicate sensitively and effectively and allowed sufficient time to do so. Psychology services can play a key role in supporting this aspect of care.
613. Facilities used for the imparting of important information, especially at the time of diagnosis should be private and comfortable. Patients and parents/carers should be involved in treatment decisions at all stages of their treatment and care.
614. Patients, families and carers should have access to a written care/treatment plan and the use of patient held records should be encouraged.
615. Patients, families and carers should have access to information which promotes informed choice. They should have the opportunity to ask

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questions and discuss treatment options and be given ready access to further information and support.

616. Where patients and families wish and are able to contribute to the management of their condition, this should be supported and appropriate training provided.
617. Information should be age and culture appropriate (including language), accessible and available in an appropriate format; there should be specific age appropriate information for very young children. The development of a national template should be supported.
618. The timing, quantity and rate at which information is given should be based on an individual's needs. Contact details should be provided, so that information or advice can be accessed readily.
619. Play specialists and activity coordinators should be key members of the multidisciplinary team as they can help to promote effective communication.
620. The information needs of siblings should be considered and appropriate, relevant information provided. Members of the extended family, such as grandparents, who also provide support need access to information.
621. On line information resources should be made available to families in principal treatment centres. Advice should be provided on authoritative and useful websites.
622. There should be regular consultation with representatives of patient and parent/carer groups in the continuing development of services for children, young people and families.

B. Anticipated benefits

623. Good communication with patients and their families and between professionals will:

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- promote better clinical care by ensuring safe and effective treatment
 - provide better support to patients and families
 - reduce stress for patients and families
 - reduce the risk of errors
 - promote compliance
 - improve clinical outcomes.
624. A national template for written material would provide opportunities to reduce duplication and cost, while promoting consistency and high quality. This would build on the work undertaken by the Coalition for Cancer Information in England, which is supporting the development of high quality information for adults with cancer. This information should be available in a range of languages to meet service users' needs.
- C. Evidence**
625. There is evidence from the Teenage Cancer Trust conference survey that 45% of participants felt that information was not designed for their own age group and 37% felt that they were only involved in making decisions about their treatment 'some of the time' or 'not much of the time'.
626. The National Children's Bureau survey demonstrated that even very young children are capable of expressing quite complex feelings and emotions when staff skilled in such communication provides the opportunity.
627. Considerable evidence exists that problems with communication and information giving (both inter-professional and between patients/parents/carers) exist.
628. There is good quality evidence (randomised controlled trial and systematic reviews) that training courses to improve communication are effective.
629. There is national guidance recommending the use of patient held records.

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630. There is expert opinion, consensus and evidence reviewed in the NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1] to suggest the information requirements of patients with cancer. Children and young people with cancer have specific information needs for which there is little good quality evidence to indicate the optimum service requirements.
631. The evidence from the Macmillan Cancer Relief directory of information materials indicates that there are few good quality information materials that have been produced specifically for children. Online and published information materials need to be evaluated carefully.

D. Measurement

632. Structure

- provision of training in communication skills for clinical and other staff involved in patient care.
- availability of appropriate information in a range of formats for children and young people and their families of all ethnic groups.
- provision of private rooms for communicating bad news.
- provision of adequate resources to facilitate effective inter-professional communication, particularly between secondary and primary care.

633. Process

- assessment of whether patients' and their parents'/carers' information and communication needs are being fulfilled.
- proportion of staff involved in patient care who have received formal communication training.

634. Outcome

- patients' views on how information was communicated to them.
- problems with inter-professional communication.

E. Resource implications

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635. Funds will be required to support staff training in effective communication. The development of appropriate patient information resources should be supported with adequate funding.

Research

636. The inclusion of children in clinical trials has been an important factor, among others, that has led to the improved survival rates in childhood cancers over the past 25 years.
637. The low incidence of cancer in children (approximately 1500 newly diagnosed cases per year in the UK aged <15 years) and young people increases the importance of national and international trials. To ensure that children are treated appropriately in trials, it is vital that the maximum number of eligible patients participate, as this allows the consideration of identified prognostic factors, such as age, stage of disease and certain biological characteristics. Without high levels of participation, randomised clinical trials cannot be undertaken successfully and the potential for improvements in survival are lost.
638. There are also rare tumours of childhood where it is not possible to conduct randomised clinical trials, even on an international basis, but where well coordinated single arm studies, compared to historical controls, have resulted in improvements in survival.
639. Recruitment to clinical trials is lower in the older age group, compared with children up to the age of 15, and also varies according to the principal place of treatment; fewer are enrolled from adult settings than from paediatric settings. This is true even for tumours where the same protocol is used for treatment, such as osteosarcoma and Ewing's sarcoma.
640. Changes in the ethical and regulatory requirements have increased the administration necessary to underpin clinical trials considerably. The diversity of diagnoses means that any principal treatment centre would expect to conduct at least 20 clinical trials at any time, including not only phase III trials, but pharmacokinetic and supportive care, and in some centres phase I and II, trials.

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A. Recommendations

641. All innovative treatments should be part of a clinical trial.
642. Principal treatment centres should ensure that all eligible children and young people are offered the opportunity to be treated within relevant specific clinical trials, where these are available.
643. The development of clinical trials, which include teenagers and young adults, should be encouraged.
644. Local research and development arrangements should facilitate the introduction of nationally approved clinical trials.
645. Where clinical trials are undertaken, there must be compliance with the relevant legal and regulatory frameworks with adequate resource provided for research nurses, clinical trials coordinators and data managers.
646. There should be clearly defined routes for national and local funding for the support of clinical trials for children and young people.

B. Anticipated benefits

647. A greater number of children and young people will have access to clinical trials.
648. Teenagers and young adults will have access to treatment in an appropriate clinical trial or on an agreed treatment protocol.
649. Further improvements in outcome, including:
 - treatment reductions and decrease in morbidity for patients with good risk disease
 - improved survival for those with poor risk disease.

C. Evidence

650. There is considerable evidence from both prospective and retrospective cohort studies to indicate that the survival of children and young people

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with malignancy treated on clinical trials is significantly higher than patients not on a trial. In some studies, the effect was only seen among certain subgroups defined by calendar period of diagnosis or clinical features at presentation but no study found a worse outcome for trial compared with non-trial patients.

651. A recent review has challenged this finding and has stated that there is insufficient data to conclude that enrolment into clinical trials leads to improved outcomes. The report states that studies involving children with cancer or patients with haematological malignancies were disproportionately represented among those indicating a benefit for inclusion in clinical trials. The authors of the review however, concluded that there should be strong support for clinical trials for ‘their unquestioned role in improving options and outcome in patients with cancer’.
652. Recent case series suggest that, in certain diagnostic groups, such as acute lymphoblastic leukaemia, the outcome for patients in this age group is better when treated on paediatric rather than adult protocols. The converse however may also be true for other diagnostic groups.
653. A recent UKCCSG review has concluded that in order to ensure that trials are conducted in the required manner, there are two distinct, but complementary, roles required within participating principal treatment centres, a clinical trials coordinator and data manager.
654. There is expert opinion that problems with funding has led to inequity in the funding received by UKCCSG centres compared with that received by the adult sector. This situation is even more complex for teenagers and young adults, where the number of designated principal treatment centres is small and access to clinical trials within their treatment centres they require is very variable.

D. Measurement

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655. ***Structure***

- documented evidence that local research and development arrangements are supporting the introduction of national clinical trials
- provision of resources to enable the participation of the principal treatment centres in clinical trials.
- adequate provision of research nurses and other staff to facilitate clinical trials and research.
- definition of funding arrangements for research for all principal treatment centres

656. ***Process***

- demonstration of adherence to the requirements of the EU Directive of Good Clinical Practice [38, Appendix 1]
- surveys of numbers of children and young people who are entered into available clinical trials

657. ***Outcome***

- outcomes of children and young people involved in clinical trials and research protocols

E. **Resource implications**

658. The economic implications of the research as suggested by the guidance will have resource consequences for the research funding agencies.

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Workforce development

659. Services can only be sustained and developed if there are adequate numbers of appropriately trained staff. Providing care for children and young people with cancer and their families is emotionally demanding and staff need help and support in dealing with such issues.
660. There are particular issues around the recruitment and retention of the following:
- paediatric radiologists and diagnostic radiologists
 - paediatric pathologists
 - laboratory staff and scientists
 - allied health professionals
 - paediatric haematologists
 - nurses
 - clinical psychologists and other members of the psychological team
 - clinical oncologists and therapy radiographers
 - specialist hospital pharmacists
661. The importance of appropriate training has been alluded to throughout this Guidance. Sufficient time should be available to ensure this in all treatment settings.
662. Examples of specific areas for staff training and education that have been identified are:
- recognition of symptoms and appropriate investigation and referral (primary care)
 - the prescription and administration of chemotherapy
 - management of central venous access devices
 - management of febrile neutropenia
 - pain management
 - rehabilitation approaches

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- blood product support
 - communication skills.
663. This list is by no means exhaustive.
- A. Recommendations**
664. SHA Workforce development directorates in England should address the training and education needs of staff working with children and young people with cancer. The appropriate training required for all staff groups should be addressed by the relevant national bodies.
665. All staff should be trained and competent to undertake specific tasks and address the specific care needs of patients and families. They should also undertake relevant CPD to maintain their competence and stay abreast of scientific and technological advances.
666. The need for trained specialist staff across all disciplines, able to work with children and young people with cancer, should be included in workforce development plans by cancer networks, to ensure the provision of a sustainable service.
667. Specific attention is required to address the shortage of allied health professional expertise in this area and the need to develop robust evaluation of the contribution of such services.
668. There should be access for nurses and other healthcare professionals to appropriate post-qualifying specialist education in the care of children and young people with cancer.
- B. Anticipated benefits**
669. Equitable access to services
- C. Evidence**

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670. There are currently no specific training opportunities within the UK for allied health professionals working in paediatric or adolescent oncology rehabilitation.
671. Workforce vacancy rates for allied health professionals continue to be significantly high, compared to other staff groups. The provision of services across the UK is variable.

D. Resource implications

672. Continuing professional development is necessary and should be resourced adequately to ensure that all staff maintain a high standard of training.

Other service considerations

Information requirements

673. Good data collection and information analysis are vital for service planning, audit and epidemiology. The needs assessment for the guidance has highlighted the need for better sources of data and the limitations in current data will hamper future needs assessment, service planning and evaluation if not addressed. Data management capacity is limited in the service at the moment, which has consequences for service provision and the ability to sustain research activities.
674. Services have to comply with the Data Protection Act and the Freedom of Information Act and good records management with appropriate IT support is essential (hardware and software).
675. There is an ongoing problem with accurate coding of hospital activity which has led to clear inaccuracies in recent reports.

A. Recommendations

676. Experts should be commissioned at a national level to consider the issues related to the registration of cancers in 15–24 year olds, including whether a separate register should be established.
677. National IT strategies in England and Wales should consider the needs of these services when introducing new IT systems.
678. The coding of common procedures in the management of children and young people with cancer should be reviewed and made consistent across England and Wales

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Child protection

679. All services for children and young people must demonstrate robust child protection arrangements, regardless of the setting in which care is delivered.
680. All staff having contact with children should have mandatory child protection awareness training.
681. All staff whose work brings them into contact with children should be Criminal Records Bureau checked.
682. Children, young people and parents/carers should be made aware of how to make a complaint and have access to independent advocacy if required.
683. All staff having access to children should be trained to a full understanding of children's rights and an appropriate level of awareness of the needs of children; they should be required to respect and apply these rights.

Education

684. Education services must be provided across the age range. These are not NHS services, but they have an important impact on the quality of survival. Commissioners should be aware of the issues and pursue them through the appropriate fora.
685. Community education is often available, but the necessary information and communication with schools is underdeveloped, so that teachers and pupils are unable to respond appropriately. Arrangements for emergency special needs support in schools may also not be established, so the necessary support may not be available.
686. Some children may have special education needs as a result of disability, which require additional education support and/or specialist input. Assessment and input from educational psychologists is essential but provision of this resource is variable across the country.

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Hospital facilities

687. Hospital facilities must meet requirements for good infection control.
688. Hospital catering services must be responsive to the particular needs of sick children. These may arise from clinical, cultural or personal needs.
689. Prolonged inpatient stays make the provision of suitable accommodation for parents and carers an essential component of these services.

Hospital parking

690. Accessible affordable parking is of particular importance for this group of patients who often have to travel significant distances to access specialist care, and for whom repeated hospital appointments and prolonged hospital admissions are common.

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Appendix 1

GUIDELINES/GUIDANCE AND KEY STRATEGIC^{*} DOCUMENTS CHILD AND ADOLESCENT CANCER²

GUIDELINE TITLE	SOURCE
1. Guidelines for Pediatric Cancer Centers	American Academy of Pediatrics 2004
2. Voices for change. Current perception of services for children with palliative care needs and their families	Association for Children with Life Threatening or Terminal Conditions and their Families 2003
3. Guidelines for the management of unscheduled interruption or prolongation of a radical course of radiotherapy	Board of the Faculty of Clinical Oncology The Royal College of Radiologists London 1996
4. Extending the Working Day for Delivery of Radiotherapy	Board of the Faculty of Clinical Oncology The Royal College of Radiologists London 1997
5. Equipment, Workload and Staffing for Radiotherapy in the UK 1992–1997	Board of the Faculty of Clinical Oncology The Royal College of Radiologists London 1998
6. The Guidelines for the Surgical Management of Endocrine Disease	British Association of Endocrine Surgeons 2003
7. A Guide for Purchasers and Providers of Paediatric Surgical Services.	British Association of Paediatric Surgeons and The Royal College of Surgeons Edinburgh 1995
8. The British Association of Paediatric Surgeons. A Guide for Purchasers and Providers of Paediatric Surgical Services	British Association of Paediatric Surgeons 1995
9. Response to the Kennedy Report "Learning from Bristol"	British Association of Paediatric Surgeons 2001
10. Paediatric surgery : Standards of Care	British Association of Paediatric Surgeons 2002
11. Reconfiguration in Paediatric Surgery	British Association of Paediatric Surgeons 2003
12. BCSH Guidelines on the insertion and management of central venous lines	British Committee for Standards in Haematology 1997
13. Transfusion guidelines for neonates and older children	British Committee for Standards in Haematology 2004
14. Guidelines on the diagnosis and management of chronic lymphocytic leukaemia.	British Committee for Standards in Haematology 2004

^{*} Bold = strategic documents

² Further guidelines/strategic documents are referred to in the Evidence Review

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15. Transfusion guidelines for neonates and older children	British Committee for Standards in Haematology.
16. Guidelines on the diagnosis and management of chronic lymphocytic leukaemia...	British Committee for Standards in Haematology.
17. A strategy for fertility services for survivors of childhood cancer. A Report of a Multidisciplinary Working Group convened by the British Fertility Society	British Fertility Society 2003
18. Hepatology and Nutrition A Guide for Purchasers of Paediatric Gastroenterology,	British Society for Paediatric Gastroenterology 2003.
19. Guidelines for MRI in Paediatric Brain Tumours.	British Society of Paediatric Radiology 1999
20. A Survey of Radiotherapy Services in England and Wales 1999	Cancer Services Co-ordinating Group (Wales)
21. All Wales Cancer Standards (draft for consultation)	Cancer Services Co-ordinating Group, Wales, 2004
22. National Service Framework Assessments: No.1 – NHS Cancer Care in England and Wales	Commission for Health Improvement/Audit Commission 2001
23. A Policy Framework for Commissioning Cancer Services. A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales	Department of Health; Welsh Office 1995
24. Paediatric Intensive Care “A Framework for the Future”. National Coordinating group on Paediatric Intensive Care Report to the Chief Executive of the NHS Executive	Department of Health 1997
25. A Survey of Radiotherapy Services in England 1999	Department of Health 2000
26. Meeting the Challenge: A Strategy for the Allied Health Professions	Department of Health 2000
27. The NHS Cancer Plan	Department of Health 2000
28. The Removal, retention and use of Human Organs and Tissue from Post-mortem Examination	Department of Health, Chief Medical Officer 2001
29. Delivering 21st Century IT Support for the NHS. National Strategic Programme	Department of Health 2002
30. Implementing a Scheme for General Practitioners with Special Interests	Department of Health 2002
31. Strengthening Accountability Involving Patients and the Public. Policy Guidance Section 11 of the Health and Social Care Act 2001	Department of Health 2003

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32. Updated national guidance on the safe administration of intrathecal chemotherapy	Department of Health 2003
33. Getting the right start: National Service Framework for Children, Young People and Maternity Services. Part 1: Standards for hospital services.	Department of Health. 2003
34. Patient and Public Involvement in Health : The Evidence for Policy Implementation	Department of Health 2004
35. National Service Framework for Children, Young People and Maternity Services	Department of Health 2004
36. A Framework for the Development of Positron Emission Tomography (PET) Services in England. Consultation Document.	Department of Health 2004
37. Manual of Cancer Services 2004	Department of Health 2004
38. EU Directive on Good Clinical Practice in clinical trials	Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States relating to implementation of Good Clinical Practice in the conduct of clinical trials on medicinal products for human use. (The Clinical Trials Directive 2001/20/EC)
39. European Working Time Directive	European Union Council Directive No 93/104/EC of 23 November 1993 concerning certain aspects of the organisation of working time
40. Code of Practice 6th Edition	Human Fertilisation and Embryology Authority 2003
41. Childhood Cancer – Guidelines for Standards of Treatment & Care	International Society for Paediatric Oncology (SIOP) 2003
42. Recommendations for the organisation of a paediatric cancer unit	SIOP 1993
43. Aims and recommendations for psychosocial care	SIOP 1993
44. Guidelines for Care of Long-Term Survivors	SIOP 1996
45. Guidelines for the communication of the diagnosis	SIOP 1997
46. Guidelines for a Therapeutic Alliance between Families and Staff:	SIOP 1998
47. Guidelines for Assistance to Siblings of Children with Cancer	SIOP 1999

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48. Guidelines for assistance to terminally ill children with cancer	SIOP 1999
49. Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer	SIOP 2000
50. Refusal, Non-Compliance, and Abandonment of Treatment in Children and Adolescents with Cancer	SIOP 2002
51. Valid Informed Consent and Participative Decision Making in Children with Cancer and their parents	SIOP 2003
52. Too Serious a Thing – The Carlile Review – The Review of Safeguards for Children and Young People Treated and Cared for by the NHS in Wales.	National Assembly for Wales 2002
53. A Survey of Radiotherapy Services in England and Wales 2001	National Cancer Services Analysis Team
54. NCCN pediatric neuroblastoma practice guidelines.	National Comprehensive Cancer Network. 1996
55. NCCN pediatric acute lymphoblastic leukemia practice guidelines.	National Comprehensive Cancer Network. 1997
56. Who operates where – WOW II	National Confidential Enquiry into Perioperative Deaths 2003
57. Palliative care for children.	National Council for Hospice and Specialist Palliative Care Services, Association for Children with Life Threatening or Terminal Conditions and their Families, and Association of Children's Hospices 2001
58. Guidance on the use of human growth hormone (somatropin) in children with growth failure.	National Institute for Clinical Excellence 2002
59. Guidance on Cancer Services. Improving Outcomes in Haematological Cancers	National Institute for Clinical Excellence 2003
60. Referral guidelines for suspected cancer (draft for consultation)	National Institute for Clinical Excellence 2004
61. Guidance on Cancer Services. Improving Outcomes in Supportive and Palliative Care for Adults with Cancer.	National Institute for Clinical Excellence 2004
62. Fertility:assessment and treatment for people with fertility problems	National Institute for Clinical Excellence 2004
63. Facilities for cancer care centres: design and	NHS Estates 2001.

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briefing guidance.	
64. Nurse Specialists, Nurse Consultants, Nurse Leads. The development of new roles to improve cancer and palliative care. An advisory report	NHS Executive 2001
65. Radiology: A National Framework for Service Improvement	NHS Modernisation Agency 2003
66. Radiotherapy Toolkit	NHS Modernisation Agency 2003
67. Chemotherapy Toolkit	NHS Modernisation Agency 2003
68. Cancer Services Collaborative Improvement Partnership. Improving Communication in Cancer Care	NHS Modernisation Agency 2004
69. The Management of Pain in Patients with Cancer	NHS Quality Improvement Scotland 2004
70. Guidance on the provision of paediatric anaesthetic services	Royal College of Anaesthetists 2001
71. Children's Nursing Workforce July 2002	Royal College of Nursing 2002
72. Services for children and young people: preparing nurses for future roles	Royal College of Nursing 2004
73. Guidelines for the ethical conduct of medical research involving children	Royal College of Paediatrics and Child Health : Ethics Advisory Committee 2000
74. Guidelines for Good Practice. Recognition and Assessment of Acute Pain in Children	Royal College of Paediatrics and Child Health 2001
75. Standards for development of clinical guidelines in paediatrics and child health,	Royal College of Paediatrics and Child Health, 2001.
76. Old problems, new solutions. 21 st Century children's healthcare	Royal College of Paediatrics and Child Health, 2002.
77. The Future of Paediatric Pathology Services	Royal College of Paediatrics and Child Health, 2002.
78. Providing a Service for Children. Workforce Census 2001	Royal College of Paediatrics and Child Health 2003
79. Specialist health services for children and young people. A guide for primary care organisations	Royal College of Paediatrics and Child Health. 2003.
80. Commissioning Tertiary and Specialised Services for Children and Young People	Royal College of Paediatrics and Child Health 2004
81. Medicines for Children	Royal College of Paediatrics and Child Health 2004
82. Pituitary tumours. Recommendations for service provision and guidelines for management of patients.	Royal College of Physicians 1997
83. Cancer units: improving quality in cancer care. The provision of non-surgical specialist cancer services in district general hospitals.	Royal College of Physicians. 2000

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84. Guidelines for the management of thyroid cancer in adults	Royal College of Physicians & the British Thyroid Association 2002
85. Guidelines for External Beam Radiotherapy	Royal College of Radiologists' Clinical Oncology Information Network 1999
86. Safe Sedation, Analgesia and Anaesthesia within the Radiology Department	Royal College of Radiologists 2003
87. Clinical Radiology and the Patients of General Practitioners	Royal College of Radiologists and Royal College of General Practitioners 2004
88. A multidisciplinary survey of radiotherapy services in the UK at 04.06.2002	Royal College of Radiologists, The Society of Radiographers; The Institute of Physics and Engineering in Medicine 2003
89. Clinical Guidelines. The oral management of oncology patients requiring radiotherapy: chemotherapy: bone marrow transplantation	Royal College of Surgeons of England 1999
90. Children's Surgery – A First Class Service	Royal College of Surgeons of England 2000
91. Better Blood Transfusion RCPCH Policy Document	Royal Liverpool Children's NHS Trust 1999
92. Control of Pain in Patients with Cancer. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2000
93. Long term follow up of survivors of childhood cancer. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2004
94. Safe Sedation of Children Undergoing Diagnostic and Therapeutic Procedures. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2004
95. The report of the Public Inquiry into children's heart surgery at Bristol Royal Infirmary 1984–1995 Learning from Bristol	Secretary of State for Health 2001
96. The Victoria Climbié Inquiry. Report of an Inquiry by Lord Laming	Secretary of State for Health and the Secretary of State for the Home Department 2003
97. Overview of the National Workforce Competence Framework for Children's Services	Skills for Health 2004
98. Safe Paediatric Neurosurgery	Society of British Neurological Surgeons 1998
99. Safe Paediatric Neurosurgery	Society of British Neurological Surgeons 2001
100. Department of Health <i>Children Act 1989 – Guidance and Regulations</i>	Stationery Office 1991
101. The Report of the Royal Liverpool Children's Inquiry	Stationery Office 2001

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102. The Resources and Requirements of a UKCCSG Treatment Centre	United Kingdom Children's Cancer Study Group (UKCCSG) 2004
103. Shared care	UKCCSG 2004
104. UKCCSG Centre Coordinator Responsibilities	UKCCSG 2004
105. Criteria for Centres Undertaking Phase I and II Studies	UKCCSG 2004
106. UKCCSG Centre Data Managers – Role and Responsibilities	UKCCSG 2004
107. UKCCSG Guide to GCP (Good Clinical Practice and the EU Directive on Clinical trials 2001/20/EC)	UKCCSG 2004
108. Guidance for Services for Children and Young People with Brain and Spinal Tumours	United Kingdom Children's Cancer Study Group (UKCCSG)/Royal College of Paediatrics and Child Health, 1997
109. Improving Health in Wales. A plan for the NHS with its partners	Welsh Assembly Government 2001
110. National Service Framework for Children, Young People and Maternity Services in Wales. Consultation Document	Welsh Assembly Government 2004
111. International Classification of Functioning, Disability and Health	World Health Organisation 2001

Appendix 2

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

SCOPE

1 Guidance title

Guidance on cancer services: improving outcomes in child and adolescent cancer

1. *Short title*

Child and adolescent cancer

2 Background

- a) The National Institute for Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Cancer to develop service guidance on child and adolescent cancer for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and the Welsh Assembly Government (see Appendix). The guidance will provide recommendations for service provision that are based on the best available evidence.
- b) The Institute's service guidance will support the implementation of the National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The guidance will support current national initiatives outlined in the *NHS Cancer Plan*, the Calman-Hine report, the Cameron report, the *Manual of Cancer Service Standards for England* and the *All Wales Minimum Standards for Cancer Services*. Cross reference will be made to these and other documents as appropriate.

3 Clinical need for the guidance

- a) Each year in the UK there are approximately 1500 new cases of cancer diagnosed in children under the age of 15, according to the United Kingdom Childhood Cancer Study Group (UKCCSG). The diagnosis and treatment of childhood cancers is often complex. The frequent use of intensive chemotherapeutic regimens (including high-dose therapy with autologous stem cell rescue), may involve prolonged inpatient care for many. Children and their families commonly have to travel long distances to receive specialised care – although some areas have developed local shared-care centres, in other areas this has not been possible or appropriate – and the impact on family life during therapy can be significant. The role of community support staff and social care for these families should not be underestimated.
- b) The distinct needs of young people with cancer have been increasingly recognised over recent years. Many young people do not feel comfortable within the paediatric setting, but they have unique needs that may not be addressed within adult services. Many also have complex problems requiring intensive chemotherapy, and the prognosis for this group (compared with that for younger children), is often less good. Assessment of the service configuration which will best meet the needs of these patients is one of the objectives of this guidance.
- c) An important part of the care of children and young people with cancer is their rehabilitation, follow up and transition into adult services. Many will be very young at completion of therapy and follow up is essential to ensure a normal healthy development into adulthood. Advice regarding fertility and other lifestyle issues (including psychological support and the social impact of their cancer) is needed as children mature. Overall survival rates for children are now approximately 70%. It has been estimated that 1 in 1000 young adults is a cancer survivor.

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4 The guidance

- a) The guidance development process is described in detail in three booklets that are available from the NICE website (see Section 5, Further information). *The Guideline Development Process – Information for Stakeholders* describes how organisations can become involved.
- b) This document is the scope. It defines exactly what this piece of service guidance will (and will not) examine and what the developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see Appendix).
- c) The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

- a) 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 (incorporating the amendments used by UKCCSG).
- b) Benign tumours or conditions that require complex treatment pathways, potentially including chemotherapy and radiotherapy.

4.1.2 Groups that will not be covered

- a) Children and young people with benign tumours.
- b) Children and young people with immune dysfunction or benign haematological conditions.

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- c) Children and young people requiring bone marrow transplantation for other (non-malignant) reasons.

4.2 *Healthcare setting and services*

The guidance will cover the following NHS services in England and Wales.

- a) Primary care (general practitioners and associated staff) and community-based care (for example, home care, day care). The guidance will address the management, in primary care, of early diagnosis, active treatment, rehabilitation, follow up and palliative care.
- b) Shared care centres.
- c) Secondary care.
- d) Tertiary care in specialist paediatric and adolescent oncology centres and their shared-care partner units.
- e) Quaternary care in specialist regional or national units for selected diagnoses (for example, retinoblastoma, bone tumour surgery)
- f) Integration with the voluntary sector.
- g) Integration with other statutory services.

4.3 *Key areas of clinical management*

The guidance will include recommendations for the following areas.

- a) Diagnostic services (excluding referral guidelines), including the roles of:
 - general practitioners and other members of the primary care team
 - specialist paediatric oncologists and haematologists
 - adult clinical and medical oncologists and haematologists
 - paediatric and adult histopathologists

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- specialist diagnostic resources such as molecular genetics facilities, cytogenetics services and immunophenotyping
- diagnostic radiology
- general paediatricians, haematologists and other specialists to whom these patients will present.

b) Oncology treatment services

- surgery – general, neurosurgery and specialist (including sarcoma, bone and retinoblastoma)
- chemotherapy, including the management of acute side effects
- radiotherapy
- bone marrow transplantation
- anaesthetics
- paediatric intensive care
- specialist paediatric oncology nursing
- pharmacy

c) Allied treatment services

- psychology
- nutrition
- pain management
- oral healthcare
- rehabilitation
- specialist endocrinology services and treatment
- fertility

d) Palliative care

- specialist palliative care – both hospital- and home-based, and the interface with other providers

e) Support services

- community liaison

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- play therapy
- youth support

The guidance will not make recommendations for services provided by non-NHS providers, but will look at the interface with the following services or sectors:

- voluntary sector
- hospices
- social services (including social work)
- practical support
- the education sector
- support for families, carers and siblings (including bereavement support)

f) Follow up

- need, frequency, type, location and by whom
- the process of transition from paediatric to adult services
- specialist follow up for late effects of treatment (including growth, endocrine, fertility, orthopaedic, cardiac and neurological effects)
- emotional, psychological and social support

g) Other issues

- research and clinical trials
- data management
- ethical issues

4.4 *Audit support within the guidance*

The guidance will include key criteria for audit, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, particularly its impact upon practice and outcomes for children and adolescents with cancer.

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4.5 Status

4.5.1 Scope

This is the final version of the scope.

4.5.2 Guidance

The development of the service guidance recommendations begins in July 2003.

5 Further information

Information on the guidance development process is provided in:

- *The Guideline Development Process – Information for the Public and the NHS*
- *The Guideline Development Process – Information for Stakeholders*
- *The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups*

These booklets are available as PDF files from the NICE website (www.nice.org.uk). Information on the progress of the guideline will also be available from the website.

Appendix – Referral from the Department of Health and Welsh Assembly Government

The Department of Health and Welsh Assembly Government asked the Institute:

“To prepare service guidance for the NHS in England and Wales for the cancers affecting children and adolescents. This would form part of the *Improving cancer*

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outcomes series and NICE will be expected, as in previous topics in the series, to involve DH and NAW [National Assembly for Wales] closely in the development of the guidance. In particular, DH and NAW should be alerted at an early stage to any issues in the developing guidance which are likely to lead to significant changes in the current service provision."

Appendix 3

List of United Kingdom Children's Cancer Centres in England and Wales

1. The Children's Hospital, BIRMINGHAM
2. Addenbrooke's Hospital, CAMBRIDGE
3. Leicester Royal Infirmary, LEICESTER
4. Great Ormond Street Hospital for Children, LONDON
5. Royal Manchester Children's Hospital, MANCHESTER
6. Queen's Medical Centre, NOTTINGHAM
7. Southampton General Hospital, SOUTHAMPTON
8. The Middlesex Hospital, LONDON
9. Royal Hospital for Sick Children, BRISTOL
10. Llandough Hospital, CARDIFF
11. St. James University Hospital, LEEDS
12. Alder Hey Children's Hospital, LIVERPOOL
13. Barts & The London Trust, LONDON
14. Royal Victoria Infirmary, NEWCASTLE-UPON-TYNE
15. Sheffield Children's Hospital, SHEFFIELD
16. Royal Marsden Hospital, SUTTON
17. John Radcliffe Hospital, OXFORD

Appendix 4

Economic implications of the guidance

Executive summary

A detailed costing exercise was conducted in order to estimate the cost implications of implementing the key recommendations of the “Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer” in England and Wales. The potential costs for inclusion was vast, the economic analysis focuses on those aspects of the key recommendations which are likely to have significant costs implications. It is acknowledged that there is an element of uncertainty around the estimates presented and that there will be variation between cancer networks. Further assessments will be needed at cancer network level and/or NHS Trust level to determine exact cost implications.

The major impacts on costs fall into the following broad areas, Table 1.

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Table 1: Cost Summary (All costs in £million per year)

	Mid Point	Range ($\pm 25\%$)	
Additional staffing at principal treatment centres			
Low scenario*	6.4	4.8	8.0
Moderate scenario**	14.5	10.9	18.2
Multi-disciplinary teams			
Low scenario	2.0	1.6	2.6
Moderate scenario	3.0	2.3	3.9
Training and Education			
CPD for additional staff	0.2	0.1	0.3
Key worker			
	3.3	2.5	4.1
Place of Care			
10 additional units for young people	7.5	5.6	9.3
Total Low Scenario*	19.4	14.6	24.2
Total Moderate Scenario**	28.5	21.4	35.7

* Low scenario – considers the cost of employing at least one whole time equivalent (WTE) key professional at each principal treatment centre: and weekly MDTs meeting of 1 hour duration

** Moderate scenario – considers the cost of employing at least 2 WTE key professionals at each principal treatment centre: and weekly MDTs meeting of 1 hour duration

Staffing at principal treatment centres

Two scenarios have been used to estimate the costs required for additional staffing at the 17 principal treatment centres and 8 Teenage Cancer Trust (TCT) units in England and Wales. The mid point estimate for the low scenario is £6.4 million with a range of between £4.8million and £8 million. This would ensure a

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minimum staffing level of at least 1 whole time equivalent (WTE) of each key professional at each centre. The moderate scenario mid point estimate is £14.5 million with a range of between £10.9 million and £18.2 million. This would enable each centre to have at least 2 WTEs. The key professionals include paediatric clinical oncologists, clinical psychologists, paediatric oncology outreach nurses (POONS) and play specialists among others.

Multidisciplinary Teams (MDT)^{*}

It has been estimated that the annual costs in England and Wales for MDTs as outlined in the guidance would be between £1.6 million and £2.6 million for 1 hour meetings once a week or between £2.3 million and £3.9 million for 2 hourly meetings, again weekly. The costs will vary across cancer networks in line with existing MDT configurations and staffing levels.

Training and educational needs

The estimated costs associated with the training and education of the additional staff detailed above would be between £146,000 and £257,500 in England and Wales. This calculation assumes a basic professional skill level as a baseline.

Key worker

The cost of employing new staff as designated key workers in England and Wales, based on a nursing salary plus on-costs, would be in the order of £3.3 million, with a range of £2.5 million and £4.1 million. This calculation is based on one key worker per 30 patients at principal treatment centres.

Place of care

The estimated cost of planning, building and equipping 10 additional units dedicated for young people with accommodation for both in-patients and day cases would require expenditure of between £5.6 million and £9.3 million.

^{*} It should be noted that for some members of the MDT, in particular the key worker, extra funding may not be required as this post may already exist but under a different name.

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Staffing each additional unit would entail recurring annual costs of between £0.6 million and £0.75 million per TCT unit, based on information from 2 NHS Trust managers.

Financial support for the NHS from charitable sources

Members of the GDG considered it important to assess the degree of support that charities gave to NHS services for children and young people with cancer. Therefore, although this is not an economic implication of the guidance it has been included here.

The financial contribution to services for children and young people with cancer from charitable sources is estimated to be between £35 million and £62million per annum. This comprises estimations that between £19.3 million and £32million is raised from charitable sources annually to specifically support children and adolescents with cancer, a further £13.5million to £26.5 million is contributed to children and young people as a result of fund raising by cancer charities focusing on people with cancer; a further £2.2 million to £3.6million supports hospice services. It is often the case that staff working in specialist centres and in the community are funded by charities, such as Children's Leukaemia in Childhood (CLIC) or paediatric oncology outreach nurses (POONs) often funded by Macmillan Cancer Relief. This charitable source of funding forms an essential aspect of the service provision for children and young people with cancer for both staffing and equipment.

Appendix 5

How this guidance manual was produced

This service guidance is intended to guide health organisations (strategic health authorities, primary care trusts, local health boards, cancer networks and trusts), their managers and lead clinicians in improving the effectiveness and efficiency of services for children and young people with cancer. The information and recommendations in the manual are based on reviews of the best available evidence on diagnosis, treatment and service delivery. This evidence is retrieved by information specialists and assessed by researchers within the National Collaborating Centre for Cancer (NCC-C) and the recommendations are the product of extensive discussion with the Guidance Development Group (GDG). A brief overview of the development process to produce the guidance is provided below.

The first stage in the development of the guidance was the production of a scope (Appendix 2) which defined in detail the patient population, the healthcare settings and services and key areas of clinical management that the guidance should cover. This was then subject to a four week consultation with registered stakeholders in line with NICE methodology. Following this a multidisciplinary GDG was formed comprising clinicians representing the main stakeholder organisations and representatives from relevant patient organisations and charities (Appendix 6.1). The GDG was convened by the NCC-C and Chaired by Dr Cerilan Rogers in close association with the Clinical Lead, Dr Meriel Jenney. All GDG members made and updated any declarations of interest. The Group met on a monthly basis during development of the guidance and NCC-C staff provided methodological support and leadership for the development.

During the development phase of the guidance the GDG identified areas where there was a requirement for expert input on particular specialist topic areas. These topics were addressed by the production of a position paper by a

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recognised expert who had been identified via the relevant registered stakeholder organisation. All relevant expert positions papers are presented in Appendices F-L of the Evidence Review.

The identification and retrieval of evidence to support the recommendations in the guidance manual is described in detail in the Evidence Review. Briefly, there were three stages to this process:

- Clinical question development. Members of the GDG were asked to submit clinical questions to the NCC-C on issues covered by the project scope.
- Literature searching. All clinical questions were prioritised and were subject to either a systematic or 'high level' search.
- Critical appraisal. Finally all full papers relevant to each clinical question were appraised using the methodology described in the *NICE Guideline Development Methods* manual.

It should be noted that most of the published research on cancer topics focuses on clinical evaluations of treatment; little direct research has been carried out on the organisation and delivery of services.

In order to elicit the views of children and young people on current cancer service provision a piece of research was commissioned by the NCC-C. The National Children's Bureau (NCB) performed this study, the full results of which are given in Appendix D of the Evidence Review.

Finally the results of a survey of teenagers (14-23) views on the provision of cancer services from a conference organised by the Teenage Cancer Trust in 2004 were also used to provide information on the specific requirements of this age group. (see Appendix E of the Evidence Review).

All the evidence reviews used to inform the manual are summarised in the document *Improving Outcomes in Children and Young People with Cancer: The Research Evidence* and includes details of all the studies appraised. This

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document is available on CD-ROM, a copy of which is included on the inside cover of the manual.

Additional complementary research, designed to quantify the potential cost of major changes in services, was carried out by the Centre for the Economics of Health, Institute of Medical and Social Care Research (IMSCAR) at the University of Bangor. This work involves literature searching, interviews with clinicians and managers, and analyses of costs.

The writing of the guidance manual was coordinated by the Chair and Clinical Lead of the GDG in accordance with all members of the GDG, assisted by Dr Fergus Macbeth and Dr Mary Webb at the NCC-C.

The production of this guidance was funded by the National Institute for Clinical Excellence (NICE), and has been subject to the full NICE consultation process.

Appendix 6

People and organisations involved in production of the guidance

- 6.1 Members of the Guidance Development Group**
- 6.2 Organisations invited to comment on guidance development**
- 6.3 Researchers carrying out literature reviews and complementary work**
- 6.4 Expert advisors to the Guidance Development Group**
- 6.5 Reports commissioned to assist with guidance development**
- 6.6 Members of the Guideline Review Panel**

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Appendix 6.1

Members of the Guidance Development Group (GDG)

GDG Chair

Dr Cerilan Rogers Director, National Public Health Service for Wales

GDG Lead Clinician

Dr Meriel Jenney Consultant Paediatric Oncologist, Cardiff and Vale NHS Trust

Group Members

Dr Helen Cox	General Practitioner in Loughborough, and Hospital Practitioner in Paediatric Oncology, Leicester Royal Infirmary.
Mr Simon Davies	Chief Executive Officer, Teenage Cancer Trust
Mr Chris Gibbs	Chairman, National Alliance of Childhood Cancer Parent Organisations (NACCPO)
Dr Brenda Gibson	Consultant Paediatric Haematologist, Royal Hospital for Sick Children, Glasgow
Dr Siân Griffiths	Specialist Registrar in Public Health, National Public Health Service
Mrs Alison Hill	Clinical Specialist Occupational Therapist, Countess of Chester NHS Trust
Miss Rachel Hollis	Senior Sister, Paediatric & Adolescent Oncology & Haematology, St James's University Hospital

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Mrs Margaret Johnson	Patient/Carer Representative, Macmillan Cancer Voices
Ms Pat Linck	Research Officer, Centre for the Economics of Health
Dr Antony Michalski	Consultant Paediatric Oncologist, Great Ormond Street, London
Professor Adrian Newland	Professor of Haematology, North East Thames Cancer Network
Dr Frank Saran	Consultant Clinical Oncologist, The Royal Marsden Hospital
Mr Richard Spicer	Consultant, Bristol Children's Hospital
Mrs Janet Vickers	Macmillan Paediatric Oncology Outreach Nurse Specialist, Alder Hey Hospital, Liverpool
Dr Jeremy Whelan	Consultant Medical Oncologist, University College London Hospitals NHS Trust
Dr Andrew Winrow	Consultant Paediatrician, Kingston Hospital

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Appendix 6.2

Organisations invited to comment on guidance development

Action for Sick Children
Addenbrookes NHS Trust
Afiya Trust, The
Anglesey Local Health Board
Association for Children with Life Threatening or Terminal Conditions
Association of Breastfeeding Mothers
Association of Children's Hospices
Association of Clinical Biochemists, The
Association of Hospice and Specialist Palliative Care Social Workers
Association of Professional Music Therapists
Association of Surgeons of Great Britain and Ireland
Association of the British Pharmaceuticals Industry,(ABPI)
Aventis Pharma
Bard Limited
Barts and the London NHS Trust - London
Bath and North East Somerset PCT
Bayer PLC
Bedfordshire & Hertfordshire NHS Strategic Health Authority
Bexley Care Trust NHS
Birmingham Heartlands & Solihull NHS Trust
Blackburn With Darwen PCT
Brain and Spine Foundation
British and Irish Orthoptic Society
British Association for Counselling and Psychotherapy
British Association for Parenteral & Enteral Nutrition (BAPEN)
British Association of Art Therapists

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British Association of Dermatologists, The
British Association of Head and Neck Oncologists
British Association of Oral and Maxillofacial Surgeons
British Association of Paediatric Surgeons
British Association of Plastic Surgeons
British Dietetic Association
British Fertility Society
British Infertility Counselling Association
British Liver Trust
British National Formulary (BNF)
British Nuclear Medicine Society
British Oncology Pharmacy Association
British Orthopaedic Association
British Paediatric Neurology Association
British Paediatric Pathology Association
British Paediatric Psychiatry & Psychology Group
British Psychological Society, The
British Psychosocial Oncology Society
British Society for Haematology
British Society for Paediatric Endocrinology and Diabetes (BSPED)
British Society of Paediatric Radiology
British Thyroid Association
Cancer and Leukaemia in Childhood (UK)
Cancer Black Care
Cancer Research UK
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)
Cancer Services Co-ordinating Group
Cancer Voices
CancerBACUP
CEMACH
Cephalon UK Ltd

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Changing Faces
Chartered Society of Physiotherapy
Children's and Adolescent Cancer Partnership (CACP)
Christian Lewis Trust - Cancer Care for Children
Chugai Pharma UK Ltd
Clatterbridge Centre for Oncology NHS Trust
College of Occupational Therapists
Community Psychiatric Nurses' Association
Convatec
Department for Education and Skills
Department of Health
Eisai Limited
Eli Lilly and Company Ltd
Faculty of Dental Surgery
Faculty of Public Health
General Medical Council
Gloucestershire Hospitals NHS Trust
Gorlin Syndrome Group
Great Ormond Street Hospital for Children NHS Trust
Healthcare Commission
Help Adolescents with Cancer
Help the Hospices
Hertfordshire Partnership NHS Trust
Institute of Physics and Engineering in Medicine
Joint Committee on Palliative Medicine
King's College Hospital NHS Trust
Leeds Teaching Hospitals NHS Trust
Let's Face It
Leukaemia Research Fund
Lymphoma Association
Macmillan Cancer Relief

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Medicines and Healthcare Products Regulatory Agency (MHRA)
Merck Pharmaceuticals
Move4Health
National Alliance of Childhood Cancer Parent Organisations
National Cancer Alliance
National Cancer Network Clinical Directors Group
National Cancer Research Institute (NCRI) Clinical Studies Group and National Cancer Research Network NCRN
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)
National Council for Hospice and Specialist Palliative Care Services
National Patient Safety Agency
National Public Health Service - Wales
National Youth Advocacy Service
Neonatal & Paediatric Pharmacists Group (NPPG)
NHS Modernisation Agency, The
NHS Quality Improvement Scotland
Novartis Consumer Health (Novartis Medical Nutrition)
Novartis Pharmaceuticals UK Ltd
Ortho Biotech
Pfizer Limited
Plymouth Hospitals NHS Trust
Princess Alexandra Hospital NHS Trust
Queen Mary's NHS Trust
Richmond & Twickenham PCT
Rotherham Primary Care Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners Wales
Royal College of Nursing (RCN)
Royal College of Ophthalmologists

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Royal College of Ophthalmologists - 2nd Contact (Child & Adolescent Cancer)
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians of London
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Speech and Language Therapists
Royal College of Surgeons of England
Royal College Patient Liasion Groups
Royal Liverpool Children's NHS Trust
Royal National Orthopaedic Hospital NHS Trust
Samantha Dickson Research Trust, The
Sargent Cancer Care for Children
Scottish Intercollegiate Guidelines Network (SIGN)
Serono Pharmaceuticals Ltd
Sheffield Children's NHS Trust
Social Care Institute for Excellence (SCIE)
Society and College of Radiographers
Society for Endocrinology
Society of British Neurological Surgeons
South & Central Huddersfield PCTs
Specialist Child and Adolescent Mental Health Service
Tameside and Glossop Acute Services NHS Trust
Taunton and Somerset NHS Trust
Teenage Cancer Trust, The
Teenager Cancer Trust Multidisciplinary Forum
Thames Valley Strategic Health Authority
The Association for Family Therapy
The Leukaemia Society UK
The Medway NHS Trust
The Royal Society of Medicine

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The Royal West Sussex Trust
UK Association of Cancer Registries
UK Brain Tumour Society
UK Childhood Leukaemia Working Party
UK Children's Cancer Study Group
UK Pain Society
University College London Hospital NHS Trust
Welsh Assembly Government (formerly National Assembly for Wales)
Wessex Cancer Trust
Wyre Forest Primary Care Trust
Young Minds

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Appendix 6.3

Researchers carrying out literature reviews and complementary work

Overall co-ordinators

Dr Fergus Macbeth Dr Andrew Champion Dr Andrew Morton Angela Bennett	National Collaborating Centre for Cancer, Cardiff
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Senior Researcher

Dr Mary Webb National Collaborating Centre for Cancer, Cardiff

Information specialist

Stephanie Powell National Collaborating Centre for Cancer, Cardiff

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Health Economists

Dr Dyfrig Hughes Director, Centre for the Economics of Health,
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Dr Rhiannon Tudor Edwards Director, Centre for the Economics of Health,
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Pat Linck Research Officer, Centre for the Economics of
Health, Institute of Medical and Social Care
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Bronwyn Tunnage

Research Fellow, Centre for the Economics of
Health, Institute of Medical and Social Care
Research, University of Wales, Bangor

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Appendix 6.4

Expert advisors to the Guidance Development Group

Dr Deborah Christie	Consultant Clinical Psychologist, UCL and Middlesex Hospitals, London
Professor Monty Duggal	Consultant in Paediatric Dentistry, University of Leeds
Dr Richard Hain	Senior Lecturer in Paediatric Palliative Medicine, University Hospital of Wales, Cardiff
Miss Tasneem Khalid	Principal Pharmacist, Haematology/Oncology Services, Royal Manchester Children's Hospital
Mr James Leggate	Consultant Neurosurgeon, Salford Royal Hospitals
Dr Kieran McHugh	Consultant Paediatric Radiologist, Great Ormond Street Hospital, London
Denise McLellan	Director of Performance and Governance, Heart of Birmingham Teaching Primary Care Trust
Geraldine Mynors	Head of Projects, Royal Pharmaceutical Society, GB
Dr Neil Sebire	Consultant Paediatric Anaesthetist, Birmingham Children's Hospital

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Dr Helen Spoudeas	Consultant in Paediatric Neuro Endocrinology, University College London Hospitals & Great Ormond Street
Dr Monica Stokes	Consultant Paediatric Anaesthetist, Birmingham Children's Hospital
Geoff Thaxter	Director of Services, CLIC/Sargent Cancer Care for Children
Dr Paul Veys	Director of BMT, Great Ormond Street Hospital, London
Dr W Hamish Wallace	Consultant Paediatric Oncologist, Royal Hospital for Sick Children, Edinburgh
Evelyn Ward	Paediatric Oncology Dietitian, St James' University Hospital, Leeds

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Appendix 6.5

Reports* commissioned to assist with guidance development

Organisation	Report Title
Teenage Cancer Trust	<p>Analysis of Teenage Cancer Patient Questionnaire Responses</p> <p>Author: Teenage Cancer Trust Conference 2004</p>
National Children's Bureau	<p>Consultation with children with cancer, their siblings and parents</p> <p>Authors: Jessica Datta, Claire Lanyon, Lucy Read, Emma Sawyer, Janine Shaw, Ben Street</p>
Children's and Adolescent Cancer Partnership (CACP)	<p><i>Results of questionnaire distributed to Paediatric Oncology and Teenage Cancer treatment centres in the United Kingdom in November 2003</i></p>

* These reports will be available in the Evidence Review that accompanies this Service Guidance

Appendix 6.6

Members of the Guideline Review Panel

Chair

John Hyslop

Members

Mark Emberton

Graham Archard

Steven Karp

Jane Cowl

Appendix 7

Glossary of terms

Allied health professional (AHP)

One of the following group of health care workers: physiotherapists, occupational therapists, art therapists, chiropodists/podiatrists, dietitians, drama therapists, music therapists, orthoptists, paramedics, prosthetists/orthotists, radiographers, speech & language therapists.

Anatomical site specialisation

The way in which doctors specialise in the care of patients with tumours in different parts of the body.

Anthracycline

One of a particular group of antibiotic anti-cancer drugs.

Antiemetic

A drug that prevents or reduces nausea and vomiting.

Anti fungal

A drug that treats infections caused by fungi.

Aseptic

Freedom from infection or septic material, sterile.

Biopsy

Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Bone marrow

The soft inner part of the bone. Bone marrow produces the stem cells which develop into the three different types of blood cells: red blood cells, white blood cells and platelets.

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Bone marrow transplantation (BMT)

A procedure to replace bone marrow that has been destroyed by high dose therapy. There are two types of transplant – allogeneic where healthy bone marrow is taken from a donor who has a similar tissue type to the patient, and autologous, where the patient's own bone marrow is used.

Brachytherapy

Radiotherapy delivered by a temporary or permanent implant of radioactive material into a tissue or organ.

Cancer Networks

The organisational model for cancer services to implement the NHS Cancer Plan, bringing together health service commissioners and providers, the voluntary sector and local authorities. There are currently 34 Cancer Networks in England covering between 600,000 and 3 million population, (two-thirds serve a population of between one and two million people).

Carcinoma

Cancer of the epithelial tissue that covers all the body organs and lines all the body cavities. Most cancers are carcinomas.

Central nervous system (CNS)

The portion of the nervous system comprising the brain and spinal cord.

Central venous catheter/central line

A long thin plastic tube which is inserted through the skin into a vein in the arm or neck through which blood tests can be taken and intravenous chemotherapy and blood transfusions can be given. Once in place it can remain in the vein for many months.

Cerebrospinal fluid

The fluid that flows around the brain and the spinal cord.

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Chemotherapy

The use of drugs that kill cancer cells, or prevent or slow their growth.

Clinical oncologist

A doctor who specialises in the treatment of cancer patients, particularly through the use of radiotherapy, but may also use chemotherapy.

Clinical oncology

The specialist treatment of cancer patients, particularly through the use of radiotherapy, but may also be through the use of chemotherapy.

Cohort studies

Research studies in which groups of patients with a particular condition or specific characteristic are compared with matched groups who do not have it.

Computed tomography (CT)

An x-ray imaging technique.

Concordance

A new way of defining the process of successful prescribing and taking medicines, based on a partnership between doctors and patients (see www.medicines-partnership.org).

Cytogenetics

The study of chromosomes and chromosomal abnormalities.

Cytotoxic

Toxic to cells. This term is used to describe drugs which kill cancer cells or slow their growth.

Diagnostic imaging

Visualising body structures to help identify a disease or condition, by using x-ray, ultrasound, radio-isotopes or magnetic resonance.

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Dietitian

A specialist in the study of nutrition.

Embryonal tissue

Tissues formed during the development of an embryo.

Emetogenic

Induces vomiting.

Endocrine

Having to do with glandular tissues that secrete hormones directly into the bloodstream.

Endocrinologist

A doctor who specialises in treating diseases of the endocrine system.

Epidemiology

The study of populations in order to determine the frequency and distribution of disease and measure risks.

Epithelial cancers

Cancers originating in epithelial tissue. This is a membrane-like tissue that lines internal and external surfaces of the body including organs, vessels and other small cavities. See also 'Carcinoma'.

Ewing's sarcoma

A type of bone cancer that usually forms in the middle (shaft) of large bones. It occurs most frequently in children and young adults.

Febrile

Feverish.

Gastrostomy

The surgical creation of an opening through the abdominal wall into the stomach in order to insert a tube through which liquid food can be given.

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Genitourinary tract

The system of organs concerned with the production and excretion of urine and with reproduction.

Germ cells

The reproductive cells of the body. In men, the testicular cell that divides to produce the immature sperm cells; in women the ovarian cell that divides to form the egg.

Glioma

A cancer of the brain that begins in glial cells (cells that surround and support nerve cells).

Gonadal failure

Failure of the gamete-producing gland; an ovary, testis, or ovotestis.

Growth factor

A substance made by the body that functions to regulate cell division and cell survival.

Haematologist

A doctor who specialises in disorders of the blood and blood-forming tissues.

Haematology

A branch of medicine concerned with the study and treatment of disorders of the blood and blood-forming tissues.

Haemopoietic progenitor transplant

[Definition to come.]

Haemovigilance

Monitoring the blood count of patients in case the cell counts drop very low.

Hepatic

Referring to the liver.

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Heterogenous

Derived from a different source or species.

Histology

An examination of the cellular characteristics of a tissue.

Histopathologist

A person who specialises in the diagnosis of disease through study of the microscopic structure of tissue.

Histopathology

The study of microscopic changes in diseased tissues.

Hodgkin's lymphoma

A type of cancer in which the cells of the lymph tissue are produced in excess and result in the progressive, painless enlargement of lymph nodes, the spleen and general lymph tissue. A particular abnormal cell, known as the Reed–Sternberg cell is found in Hodgkin's lymphoma.

Hypofractionated stereotactically guided retreatment

Radiotherapy given with a few large doses aimed very precisely, from a large number of different angles.

Immunoglobulin

A protein that acts as an antibody.

Immunohistochemistry

A technique that uses antibodies to show up specific proteins in tissues seen down a microscope.

Immunophenotype

Pattern of specific proteins (antigens) present on the surface membrane of blood cells.

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Immunosuppression

Suppression of the immune system.

Immunotherapy

Treatment by stimulating or restoring the body's own immune system.

Intracranial pressure

Pressure that occurs within the cranium (skull).

Intraoperative ultrasound

A diagnostic technique that uses a portable ultrasound device to scan the body during surgery. The method enables surgeons to locate and identify tumours or other structures that may not be detected by computed tomography or other techniques.

Intrathecal

Into the fluid around the spine.

Intravenous (IV)

Into a vein.

Irradiation

The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumours.

Juvenile astrocytoma

A primary tumour of the brain with particular microscopic features, that occurs especially in children and young adults.

Late effect

A side-effect of radiotherapy or chemotherapy that occurs some months or years after treatment.

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Leukaemia

Cancer of the blood forming system in the bone marrow, usually characterised by the production of abnormal white blood cells which may be present in the bone marrow and blood.

Locoregional

Limited to a localised area, as contrasted to systemic or metastatic, such the spread of pathological change beyond the site of origin but only into the nearby region.

Lymphoma

Cancer of the lymphatic system. There are two main types of lymphoma – Hodgkin's disease and non-Hodgkin's lymphoma.

Lumbar puncture

A procedure in which a needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give anticancer drugs intrathecally.

Magnetic resonance imaging (MRI)

A non-invasive method of imaging which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).

Malignant

Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body.

Medical oncology

The specialist treatment of cancer patients through the use of chemotherapy, and for some tumours immunotherapy.

Medulloblastoma

A malignant brain tumour that begins in the lower part of the brain and that can spread to the spine or to other parts of the body.

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Melanoma

A form of skin cancer that arises in melanocytes, the cells that produce pigment.

Meta-analysis

The statistical analysis of the results of a collection of individual research studies in order to add the findings together.

Metronomic prescribing

Giving anticancer drugs in small, regularly repeated doses, rather than as large single doses.

Molecular genetics

The branch of genetics that focuses on the chemical structure and the functions, replication and mutations of the molecules involved in the transmission of genetic information, namely DNA and RNA.

Morbidity

A diseased condition or state.

Morphological

Pertaining to morphology which is the science of the forms and structures of organisms.

Mortality

Either a) the condition of being subject to death or b) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000.

Nasogastric tube

A tube that is passed through the nose and into the stomach.

Needle biopsy

The removal of tissue or fluid with a needle for examination for cancer cells under a microscope.

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Neoplasm

An abnormal mass of tissue that results from excessive cell division.

Neuroblastoma

Cancer that arises in immature nerve cells and affects mostly infants and children.

Neuroimaging

Production of images of the brain by non-invasive techniques e.g. computed tomography, magnetic resonance imaging, and positron emission tomography.

Neurological

Having to do with the nervous system.

Neuro-oncology

The branch of medical science dealing with tumours of the nervous system.

Neuropsychology

A discipline combining neurology and psychology to study the relationship between the functioning of the brain and cognitive processes or behaviour, using psychological testing and assessment to assay central nervous system function and diagnose specific behavioural or cognitive deficits or disorders.

Neuroradiologist

A doctor trained in radiology who specialises in creating and interpreting pictures of the nervous system.

Neuroradiology

The branch of radiology that deals with the nervous system.

Neurorehabilitation

Rehabilitation that concentrates on improving physical and mental disability resulting from damage to the nervous system.

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Neurosurgeon

A doctor who specialises in surgery on the brain, spine, and other parts of the nervous system.

Neurosurgery

Surgery on any part of the nervous system.

Neutropenia

A condition in which the number of granulocytes (neutrophils) in the blood is below normal.

Neutropenic episode

A period of time when there is neutropenia.

Neutropenic sepsis

Life-threatening infection made more severe by the reduced neutrophils.

Neutrophils

A specific sub-type of granulocyte.

Non-Hodgkin's lymphoma (NHL)

Any cancer of the lymphatic system other than Hodgkin's lymphoma. There are two main groups – high grade which are aggressive and fast growing and low grade which are slow growing (also known as indolent lymphomas). High grade lymphomas include: diffuse large B cell lymphoma (DLBCL), peripheral T-cell lymphoma, Burkitt's lymphoma, mantle cell lymphoma and AIDS-related lymphoma. Low grade or indolent lymphomas include: follicular lymphomas, Waldenstrom's lymphoma and marginal zone lymphomas. Extra-nodal lymphomas are those that develop outside lymph nodes such as those affecting the skin or intestine.

Oncologist

A doctor who specialises in treating cancer.

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Oncology

The study of the biology and physical and chemical features of cancers. Also the study of the causes and treatment of cancers.

Oral

Having to do with the mouth.

Oral mucositis

Inflammation of the mucous membranes in the mouth (sore mouth).

Osteosarcoma

A cancer of the bone that usually affects the large bones of the arm or leg. It occurs most commonly in young people and affects more males than females.

Paediatric oncologist

An oncologist who specialises in the treatment of children.

Paediatrician

A physician who specialises in the development and care of infants and children and in the treatment of their diseases.

Palliative

Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it.

Palliative care

Active, holistic care of patients with advanced, progressive illness which may no longer be curable. The aim is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable in earlier stages of the cancer journey in association with other treatments.

Pancytopenia

A marked reduction in the number of red blood cells, white blood cells and platelets.

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Pathological behaviour

The natural history of a disease.

Pathologist

A person who specialises in the diagnosis of disease through study of the microscopic structure of cells and tissues.

Percutaneous puncture

A puncture in the skin caused by performing a procedure through the skin, such as a biopsy; aspiration of fluid from a space below the skin using a needle, catheter, and syringe; or installation of a fluid in a cavity or space by similar means.

Peripubertal

Around the time of puberty.

Pharmacokinetics

The process by which a drug is absorbed, distributed, metabolised and eliminated by the body.

Phenotypes

A group of organisms that resemble each other in appearance.

Physiotherapist

A specialist trained using exercise and physical activities to condition muscles and improve level of activity.

Play specialist

A trained mental health professional who facilitates play so that the child can systematically address and resolve his/her own problems.

Positron emission tomography (PET)

A highly specialised imaging technique using radio-isotopes that is used to produce a computerised image of metabolic activity of body tissues.

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Prognosis

A prediction of the likely outcome or course of a disease; the chance of recovery or recurrence.

Prognostic factor

Patient or disease characteristics, e.g. age or co-morbidity, which influence the course of the disease under study.

Protocol

An agreed policy which defines appropriate action.

Psychological

Adjective of psychology; which is the scientific study of behaviour and its related mental processes. Psychology is concerned with such matters as memory, rational and irrational thought, intelligence, learning, personality, perceptions and emotions and their relationship to behaviour.

Psychologist

A specialist who can talk with patients and their families about emotional and personal matters, and can help them make decisions.

Psychosocial

Concerned with psychological influence on social behaviour.

Radiographer

A person who assists the radiologist in imaging (diagnostic radiographer) or the radiotherapist in treatment (therapeutic radiographer).

Radioisotope treatment

A type of internal radiotherapy. A radioisotope liquid is given either by mouth or as an injection into a vein. As the radioisotope material breaks down it releases radiation within the body.

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Radiologist

A doctor who specialises in creating and interpreting pictures of areas inside the body. An interventional radiologist specialises in the use of imaging techniques to assist treatment e.g. the insertion of intravenous catheters.

Radiosurgery

A radiation therapy technique that delivers radiation directly to the tumor while sparing the healthy tissue.

Radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells and treat tumours.

Randomised controlled trial (RCT)

A type of experiment which is used to compare the effectiveness of different treatments. The crucial feature of this form of trial is that patients are assigned at random to groups which receive the interventions being assessed or control treatments. RCTs offer the most reliable (i.e. least biased) form of evidence of effectiveness.

Retinoblastoma

An eye cancer that most often occurs in infants and young children.

Sarcoma

A cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

Sequelae

Secondary consequences or results.

Solid tumour

An abnormal mass of tissue that usually does not contain cysts or liquid areas. Different types of solid tumours are named for the type of cells that form them.

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Sonographer

A specialist in the use of ultrasound.

Spinal puncture

See lumbar puncture.

Supportive care

Care that helps the patient and their family and carers to cope with cancer and its treatment throughout the cancer journey, and in the case of the family and carers, into bereavement. It aims to help the patient maximise the benefits of treatment and provide the best possible quality of life.

Sympathetic nervous system

One of the two divisions of the vertebrate autonomic nervous system.

Thrombocytopenia

A decrease in the number of platelets in the blood that may result in easy bruising and excessive bleeding from wounds or bleeding in mucous membranes and other tissues.

Toxicity

Refers to the undesirable and harmful side effects of a drug.

Trans-sphenoidal

Performed through the sphenoid bone, part of the base of the skull below the brain.

Tumour

A mass of excess tissue that results from abnormal cell division. Tumours perform no useful body function.

Vascular occlusion

Blockage of a major artery or vein, usually by a clot.

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WHO analgesic ladder

Guidelines issued by the World Health Organisation that describe a method of prescribing increasing strength standardised pain killers for patients with increasing pain.

Appendix 8

Abbreviations

ACCIS	Automated Childhood Cancer Information System
AHP	allied health professionals
CMV	cytomegalovirus
CNS	central nervous system
CPD	continuing professional development
CSF	cerebrospinal fluid
CT	computed tomography
CVC	central venous catheters
DNA	deoxyribonucleic acid
EBMT	European Group for Blood and Marrow Transplantation
ENT	ear, nose and throat
ETP	electronic transmission of prescriptions
FNP	febrile neutropenia
GCP	good clinical practice
GDG	Guideline Development Group
GDP	General Dental Practitioner
HSCT	haemopoietic stem cell transplantation
ICCC	International Classification of Childhood Cancer
ICD	International Classification of Diseases
ISCT	International Society for Cellular Therapy
JACIE	Joint Accreditation Committee ISCT - EBMT
MDT	multidisciplinary team
MRI	magnetic resonance imaging
NCC-C	National Collaborating Centre for Cancer
NCIC-ONS	The National Cancer Intelligence Centre at the Office for National Statistics
NRCT	National Registry of Childhood Tumours

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NSF	national service framework
ODA	operating department assistant
ONS	Office for National Statistics
PET	positron emission tomography
PICU	paediatric intensive care unit
POONS	paediatric oncology outreach nurse specialist
SHA	strategic health authority
SHOT	serious hazards of transfusion
SIGN	Scottish Intercollegiate Guidelines Network
SNLG	Scotland and Newcastle Lymphoma Group
TCT	Teenage Cancer Trust
UKCCSG	United Kingdom Children's Cancer Study Group
WHO	World Health Organisation