DRAFT FOR FIRST CONSULTATION

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

Contents

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. 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 in Appendix xx [available at second consultation], who provided written papers or informal advice to the group, without whom this guidance would have been incomplete.

4. 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, October 2004

Acknowledgements

5.These will follow in the final published document

Key recommendations

6.• Planning, commissioning and adequate funding for all aspects of care, across the whole healthcare system, should be coordinated at strategic level, 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 care as locally as possible.

7.• Commissioners should ensure, through cancer networks in partnership with services for children and young people, where appropriate that:
  - o there is a clear organisational structure for these services, including cancer network leads for children, teenagers and young adults with cancer.
  - o 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.
  - o principal treatment centres are able to provide a sustainable range of services, with defined minimum levels of staffing, as outlined in the guidance.
  - o 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.
  - o all sites delivering cancer therapy in this age group should be subject to peer review.
  - o all relevant national guidance is followed (see Appendix A).

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. 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 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 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 inclusion in a relevant clinical trial is not possible or appropriate, 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.

14. •The issues related to the registration of cancers in 15–24 year olds and the potential value of a separate register should be addressed urgently at a national level.

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 A).

19. The population, healthcare settings and services and key areas of clinical management are included in detail in the Scope (see appendix B [available at second consultation]). 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.

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

Challenges

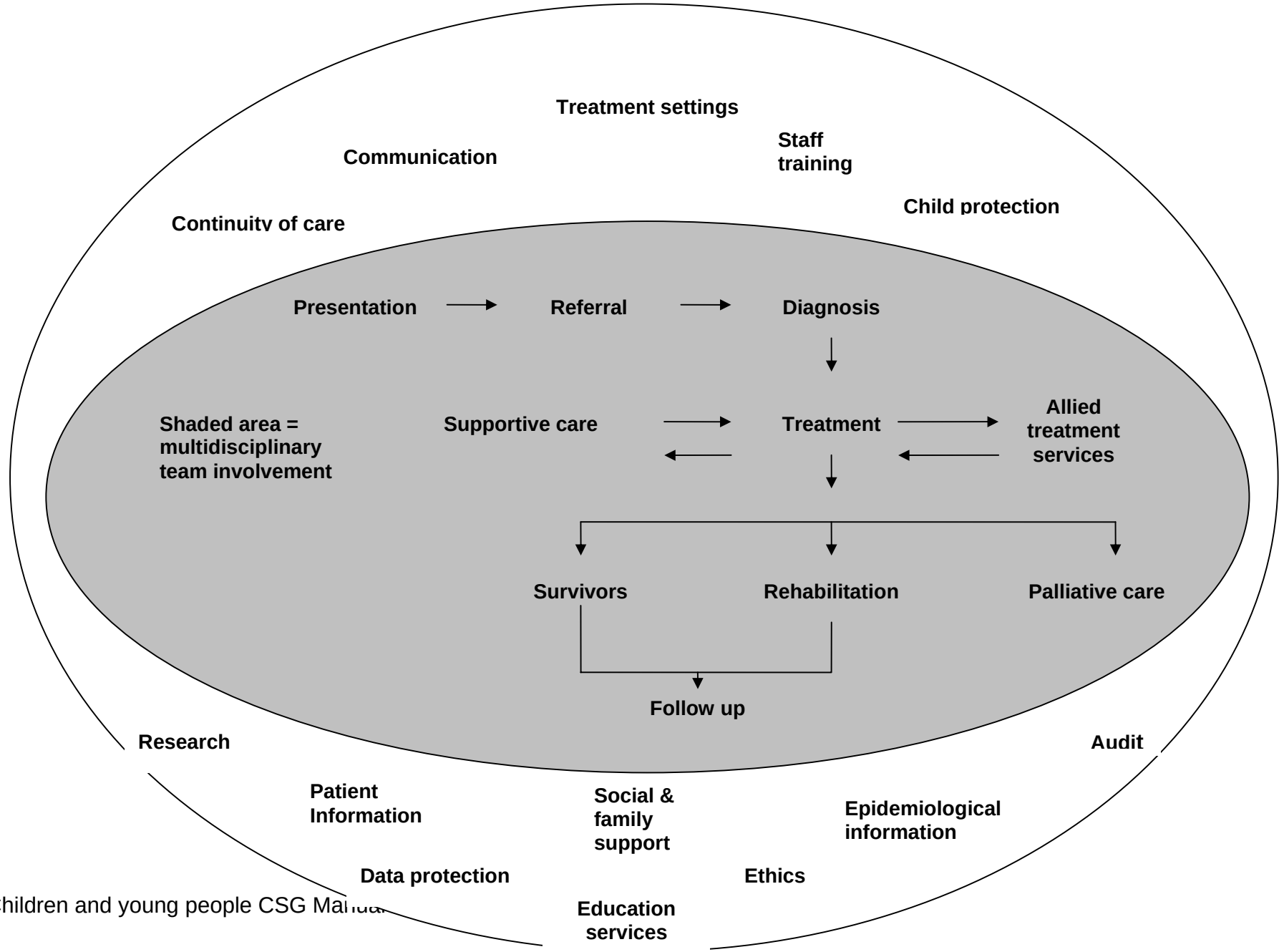
21. There were challenges in the development of this guidance. The potential material for inclusion was vast and the Group have tried to focus on those aspects of the service which are likely to have a significant impact on health outcomes.

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.

CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH CANCER



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.

Sources of evidence

27. A number of relevant existing guidelines and reviews were accessed (see Evidence document [available at second consultation]).

28. Searches of various databases were undertaken in response to specific questions formulated by the Group (methodology outlined in the Evidence document).

29. A nominated panel of experts was invited to contribute via the submission of formal position papers for consideration of the GDG (see appendix C [available at second consultation] and Evidence document).

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 and classification

32. Registration of cancer cases is voluntary. There are 9 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 (ONS) collates cancer registration data nationally for England, Wales and Scotland.

33. All registries systematically collect data from a number of sources to maximise completeness and accuracy. ONS data is coded using the International Classification of Diseases system (ICD) version 10. This is

based on a topographical description of tumour site, which is appropriate for the adult presentation of cancers. Cancers that develop in childhood are different from those in adult life. There is increased histological diversity and many tumours develop from embryonal tissue. The International Classification of Childhood Cancer (ICCC) provides an alternative classification to the ICD coding, based on histological characteristics. This system is used by the National Registry of Childhood Tumours (NRCT) in Oxford, which registers cases of childhood malignancy under the age of 15 years. This registry is estimated to have a completeness of dataset approaching 100%.

34. There is no national registry of cancer cases occurring between the ages of 15–24 comparable to the NRCT.

35. The existence of two coding systems causes difficulty in data collection and analysis; there is no nationally agreed conversion table between these systems. There is an added difficulty in the classification of cancers in adolescents and young adults for whom the prevalent cancers are different from those of children and adults.

Aetiology

36. 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 factors include genetic, infective, hormonal, radiation and socioeconomic causes.

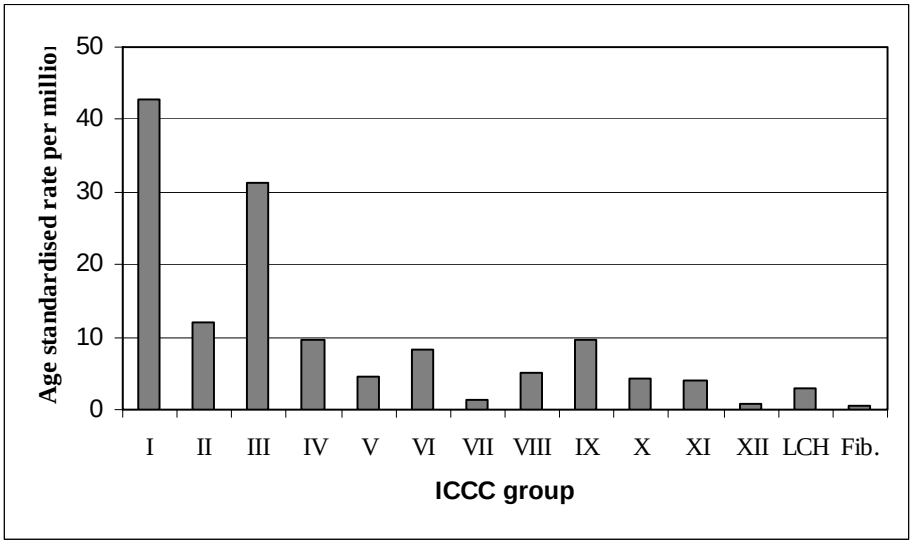
Incidence

37. Childhood (<15 years) cancers are rare, causing less than 1% of all cancers in industrialised countries. Data from 1981–1990 (Parkin et. al) suggest an age standardised annual incidence in England and Wales of 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.

38. 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 is hepatic tumour (1.3 per million).

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



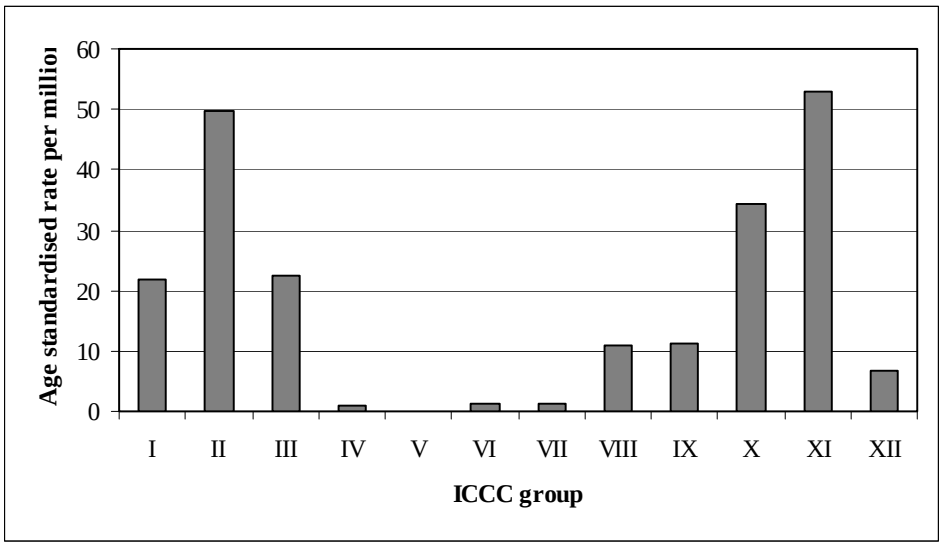
Source: - NRCT

39. In 15–24 year olds, ONS data from 1988–1997 gives 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, with only one case registration in the ten years under study.

1 International Classification of Childhood Cancers (ICCC) [4]

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

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



Source: - ONS

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

Trends

41. An increase in the incidence of childhood and adolescent cancers has been demonstrated across 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. 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.

42. In 15–24 year olds, there have been significant increases in incidence from 1979 to 1997 across all diagnostic groups. 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. A marked rise in the incidence of carcinomas and epithelial neoplasms in the 20–24 year age group has resulted in this group replacing lymphoma as the most common group overall.

Place

43. 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, selected, European countries, where the incidence ranges from 127.3 per million in Ireland to 170.4 per million in Finland. Comparable data for adolescents and young adults is not available.

Table 1

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

Source: ACCIS

* Data collection 1994–1997

** Data collection 1988–1997

*** Data collection 1993–1995

**** Data collection 1993–1996

Person

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

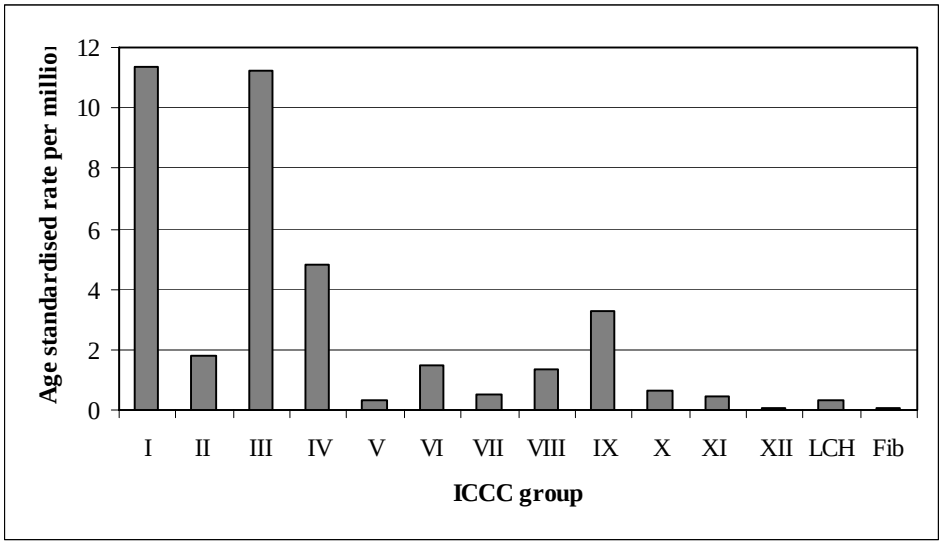
45. The type of malignancy also varies with age. Leukaemias and embryonal tumours are the most common malignancies of childhood. Epithelial neoplasms and lymphomas are the most common presentation in young adults and there is an increasing frequency of carcinomas, germ cell tumours and melanoma in this age group.

46. For most malignancies of childhood, the incidence is greater in boys than girls with and overall ratio of 1.2: 1. Those more common in girls include malignant melanoma and cancers of the breast, thyroid and genitourinary tract.

Mortality

47. The highest mortality figures occur in the diagnostic groups with highest incidence. In those aged 0–14 years, the leukaemias are the most common cause of death (30.7%). However, the relative frequencies of the ICCC groups alter from those seen in the incidence data due to more or less favourable 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.

Figure D Comparison of age standardised mortality rates within the ICCC groups and non-malignant conditions



Source: - NRCT

48. No ICCC coded mortality data is available for 15–24 year olds.

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

Survival

50. 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% (NRCT). Probability of survival varies with diagnosis.

51. 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, which has resulted in protocol-based management.

52. The paediatric section of the Eurocare 3 report 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 England and Wales value compares favourably with other European countries, falling within the 95% confidence intervals of all but 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.

53. Survival data for 15–24 year olds is not available at national level, nor is comparative European data for this age group.

Prevalence

54. 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.

55. 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 incident figures, reflecting the differing survival within disease groups.

Late effects

56. With increasing survival the physical, emotional and social sequelae, all of 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, such as impairment of endocrine function (for some including infertility), cardiac and neurological impairment and increased risk of developing a second cancer.

57. Four percent of cases develop a second primary malignancy, for which radiotherapy is a particular risk factor (Wallace *et al*., 2001 and Pui *et al.,* 2003). 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 (Wallace *et al*., 2001 and Pui *et al.,* 2003).

Key Points

58. 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.
59. Cancers in children and adolescents 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.
60. Overall survival is high (currently 75% in 0–14 year olds), although disease specific rates vary.
61. Improved survival is contributing to the increase in absolute numbers of patients who have or, have survived cancer, which has implications for service provision.
62. Improved survival is contributing to the increase in absolute numbers of prevalent cancer patients, which has implications for service provision.

Gatta G; Corazziari I; Magnani C et al. Childhood cancer survival in Europe *Annals Oncology* 2003; **14(s5)**; 119–127

Parkin, D.M. Kramarova, E. Draper, G.J. *et.al.* (Eds). *International Incidence of Childhood Cancer. II***;** 1998. IARC Scientific Publications, No. 144: Lyon

Pui, C-H. Cheng, C. Leung, W.et al.. Extended Follow-up of Long Term Survivors of Childhood Acute Lymphoblastic Leukaemia. *The New England Journal of Medicine*, 2003;. **349:** 640–9

Wallace, W.H.B. Blacklay, A. Eiser, C. et al. Developing strategies for long term follow up of survivors of childhood cancer, *British Medical Journal* 2001; **323**: 271–274

Current Services

63. 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

64. 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 8 Teenage Cancer Trust Units, which offer separate age appropriate facilities for young people.

65. Shared care centres are based in secondary care facilities and are affiliated to UKCCSG centres. The provision of services varies from initial diagnosis only to treatment of some haematological malignancies. Bone marrow transplantation services are changing, as a minimum number of procedures are now required to maintain clinical skills in a unit.

66. 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.

67. Results show that most centres have clinical oncology support, but only a minority have radiotherapy services delivered on site. Many centres undertake bone marrow transplantation, others refer cases, as necessary, to Bristol, Great Ormond Street, the Royal Marsden or Sheffield. Eight of the 18 responses recorded have access to paediatric neurosurgery services on site or within an eight-mile radius.

68. 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.

69. Centres refer patients out of region for specialist services such as bone or sarcoma surgery, retinoblastoma assessment, liver and thyroid services.

Supportive and palliative care

70. When asked to identify areas for improvement, centres suggested increased occupational therapy, psychology, psychiatry and social worker support, as particular service needs.

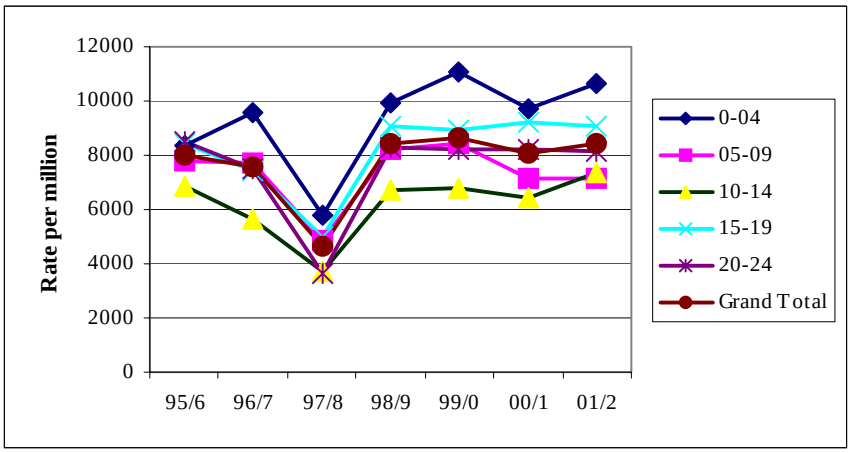
71. All centres have access to at least one children's hospice but 13 reported that their patients 'rarely' or 'never' used this or the adult hospice service. Seven of the 18 centres offer 24 hour home visit and telephone advice for those requiring palliative care. The levels of staffing in palliative care vary considerably between units, though the survey did not express staffing ratios in terms of new patients seen.

Service Use

72. Use of services is measured by routinely collected hospital activity data. This method reflects episodes of care, not individual patient data. Hospitals where the numbers of episodes did not exceed 2,500 per annum are not included in this analysis.

73. There is a trend of increasing activity (1995/6 to 2001/02), which may, in part, reflect improved data collection. More intensive treatments and improved survival also increase activity levels. The data quality is poor in 1997/98 showing a substantial under-recording of activity (Cottier, B, personal communication).

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

74. Rates of hospital activity are inversely proportional to 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).

In patient care

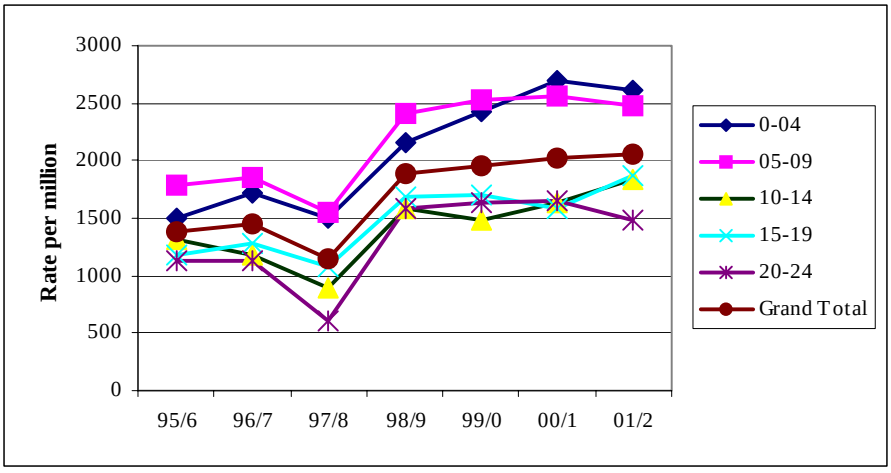
75. Inpatient episodes also show highest rates in the youngest age group (10.7 per 1000 children aged 0–4 years, 2001–02), reflecting the higher incidence of cancer in this group. Rates fall in 5–8 and 10–14 year olds but rise again from age 15 years (9.0 per 1000 children aged 15–19 years, 2001–02).

76. The total number of in patient bed days is stable at a mean of 135,000 per annum for 0–24 year olds (1995–2002).

Day case

77. 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. Rates show small fluctuations between age groups, though the 0–4 year group again shows highest overall service use (2.6 case bed days per 1000 children aged 0–4 in 2001/2).

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

78. The most commonly performed 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. Because of the well known inaccuracies of coding, the commonest procedure, the administration of chemotherapy does not get adequately recorded.

79. Measures of activity by strategic health authority show wide variations in episode rates, inpatient and day case rates and patients seen. 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 results.

Palliative care

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

81. 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.

82. AHPs encompass a wide range of disciplines, including diagnostic and therapeutic radiographers, sonographers, physiotherapists, occupational therapists, play therapists, activity coordinators, dieticians 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.

Non health services

83. Social care and education are important 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.

The Care Pathway

84. 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.

85. 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.

86. Recommendations about specific technologies or treatments have not been made unless they have a significant effect on service delivery or configuration.

87. 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

88. 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 deaths occur either before the diagnosis is made, or at the time of consideration of the diagnosis. These deaths are potentially avoidable.

89. The NICE clinical guidelines for general practitioners on *Referral for Suspected Cancer*, 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.

90. 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

91. Primary care trusts/local health boards should ensure appropriate training is provided for the implementation of the guidelines on *Referral for Suspected Canc*er 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.

92. 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.

93. 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 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.

94. Given the wide variety of symptoms and signs, initial referral may be to a wide variety of secondary care specialists. Clear mechanisms should be in place for appropriate investigation and speedy cross referral.

B. Anticipated benefits

95. 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.

96. Telephone access will avoid inherent delays in postal or fax referral systems.

C. Evidence

97. 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 and doctors. The evidence suggests that an increased awareness of childhood cancer as a possible diagnosis may help in reducing both sources of delay.

98. 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.

99. Delay in referral causes concern in parents, particularly when they feel their special knowledge of the child has been disregarded. The results of the Teenage Cancer Trust (TCT) survey in 2004 suggest that there may be a particular problem with delayed referral of teenage patients.

100. 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. Measurement

101. The following aspects of care should be subject to regular audit.

102. **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

103. **Process**

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

104. **Outcome**

- improved clinical outcomes
- patient/parent/carer satisfaction

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Diagnosis

105. 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. The process needs to be timely and efficient and requires a multidisciplinary approach.

Pathology

106. 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.

107. 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 the teenagers and young adults (such as lymphomas, bone tumours and germ cell tumours) all require very specific expertise for their correct diagnosis and assessment.

108. The report from the Royal College of Paediatrics and Child Health *The Future of Paediatric Pathology Services*, makes it clear that the specialty of paediatric pathology is currently in crisis with shortages across the country. It makes the following recommendations:

109. • 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.

110. • 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.
111. • paediatric pathology cannot be subsumed by general or other specialist pathologists without a further major reduction in both service and quality.
112. • 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.'

113. There is also a recognised shortage of paediatric haematologists.

Haematology

114. Haematologists are responsible for the morphological diagnosis of leukaemia. 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. Diagnosis also requires access to cytogenetics, molecular genetics and immunophenotyping. Children are at greater risk of central nervous system involvement with leukaemia, which requires specialised input for the preparation and assessment of specimens.

115. Haematological malignancies in young people need access to the same laboratory expertise.

Imaging

116. Timely access to appropriately skilled diagnostic imaging is essential in evaluating children and young people with possible 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.

117. MRI 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 exposed them to significant amounts of radiation.

118. 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,* 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 use is likely to increase.

119. 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

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

121. Specialist techniques, such as immunohistochemistry, cytogenetics or molecular genetics, should be available in all departments dealing with paediatric tumour biopsies.

122. Facilities for tissue storage, according to appropriate consent and tissue use guidelines, should be available.

123. Paediatric haematologists should be involved in the laboratory and clinical management of children with leukaemia.

124. All laboratories dealing with paediatric leukaemias require appropriate 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.

125. 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 *Improving Outcomes in Haematological Cancer*.

126. 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 by a paediatric or specialist sarcoma pathologist.

127. A clear pathway for dealing with suspicious lumps and inconclusive scans should be developed and appropriate guidance prepared by each cancer network.

128. Commissioners should address the recommendations of "*The Future of Paediatric Pathology Services".*

129. 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.

130. The provision of MRI scanning should be sufficient to ensure that suspected cases of CNS and other malignancies can be investigated rapidly.

B. Anticipated benefits

131. Accurate and more rapid diagnosis will:

- allow appropriate treatment
- reduce treatment burden and disease impact
- minimise stress to patients and their families.

C. Evidence

132. 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.

133. 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.

134. 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.

135. The evidence for the optimum methods for the diagnosis of leukaemia is reviewed in the NICE guidance on *Improving Outcomes in Haematological Cancers;* this evidence confirms the requirement for specialist pathological review to improve diagnostic accuracy.

136. 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 inconclusive.

D. Measurement

137. **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 oncologists and the specialist diagnostic multidisciplinary teams.

138. **Process**

- Audit of time interval between first clinical appointment and diagnosis
- Audit of waiting times for biopsy and imaging
- Proportion of invasive investigations taking place outside normal hours

139. **Outcome**

- Patient satisfaction surveys
- Effect of diagnostic accuracy on patient outcomes

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

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 modalities; surgery, chemotherapy and radiotherapy. 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.

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 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. Standard or upper dose limits are less relevant in children.
- Weight loss or gain can significantly alter the correct dosage, requiring close patient observation.

- Many drugs are not licensed for use in children, in particular the very young. Many are not routinely prescribed.
- Oral preparations may not be palatable 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 adults 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. There are national strategies in England and Wales for the introduction of computerised prescribing and electronic transmission of prescriptions (ETP). Some UKCCSG centres have a dedicated computerised chemotherapy prescribing system.

A. Recommendations

145. 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.

146. 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 suitably equipped facilities for the preparation and administration of chemotherapy.

147. 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.

148. Chemotherapy should only be prescribed and administered by medical and nursing appropriately trained in the prescribing and administration of chemotherapy and the prevention/management of its side effects.

149. 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.

150. There must be compliance with current DOH guidelines on the prescribing, dispensing and administration of intravenous and intrathecal chemotherapy.

151. All chemotherapy should be prepared 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.

152. Where chemotherapy can be safely administered in the home, by either community nursing teams or families, this should be developed, supported and adequately resourced.

153. New methods of monitoring and improving methods of compliance in patients should be explored and encouraged, including the concept of concordance.

B. Anticipated benefits

154. Delivery of chemotherapy by adequately trained staff in an appropriate environment should reduce morbidity.

155. Adequate treatment capacity will avoid unnecessary delay and maximise treatment benefit.

156. Development of chemotherapy services in the home, where this is appropriate, will lead to less disruption of family life and schooling.

157. 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.

158. Reduction in risk may be achieved by:

- computerised prescribing
- patient held records
- information for parents and families
- training and education for staff in all care settings in which chemotherapy is given.

159. High levels of compliance with all aspects of treatment should also result in better clinical outcomes.

C. Evidence

160. There is good quality evidence that ETP reduces prescribing errors, although there are no papers specifically concerned with children with cancer.

161. Where chemotherapy is delivered in the community, there is insufficient evidence to determine whether nurses are superior to parents in terms of delivery skills.

162. 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.

163. The evidence is inconsistent on whether ETP improves patient compliance with medication.

164. There was poor quality evidence that concluded that methods for monitoring compliance are not effective.

D. Measurement

Audit of the following aspects is required.

165. **Structure**

- Appropriate staff levels and training
- Clearly documented and well publicised protocols

166. **Process**

- Rates of refusal and failure to complete treatment – annual report
- Compliance with chemotherapy protocols
- Incident reporting

167. **Outcome**

- Survival
- Reduction in morbidity

- Reduction in prescribing errors

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Surgery

168. The majority of children with solid tumours require surgery, either an open surgical 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.

169. 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.

170. 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 has specialised 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, head and neck surgery, orthopaedic surgery and paediatric cardiac surgery.

171. Following surgery, AHPs such as physiotherapists, occupational therapists, speech and language therapists and dieticians, 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.

A. Recommendations

172. 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.

173. Referral systems should be in place, if necessary across cancer networks, to provide easy access to a variety of other surgical specialists.

174. 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.

175. The surgical management of tumours in children and young adults should be in the context of the appropriate paediatric or specialist MDT.

176. Surgery for retinoblastoma, sarcomas and certain liver tumours requires very specialist expertise that should only be provided in supraregional centres.

177. If a local paediatric surgeon cannot excise the lump with wide margins or the lump is unusual, the patient should be dealt with by a specialist sarcoma surgeon; all deep limb sarcomas should be referred to a specialist soft tissue sarcoma surgeon and excised with wide margins.

178. Involvement of AHPs should be planned, where possible, before surgery.

B. Anticipated benefits

179. 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

180. 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.

181. There are policy documents and guidance that conclude that there are improved outcomes with specialist surgeons.

D. Measurement

182. **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.

183. **Process**

- Audit of 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

184. **Outcome**

- Studies on the effect on outcome of surgery performed by specialist paediatric surgeons
- Patient and carer satisfaction surveys

- Effects of delays in surgical diagnosis on patient outcome

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Neurosurgery

185. 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.

186. 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.

187. 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

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

189. 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 etc) with specialist skills for lesions in rare anatomical sites with the support of the paediatric team.

190. 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.

191. 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.

192. Younger children 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.

193. There should be at least two such neurosurgeons in the unit supported by their adult colleagues for on call purposes.

B Anticipated benefits

194. Earlier clinical diagnosis and referral to the MDT through the instigation of a process of education.

195. More accurate staging and careful selection of therapy by the MDT achieved by earlier referral and access to neuroimaging.

196. 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.

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

C Evidence

198. There are consensus guidelines and policy documents that recommend the requirements for a comprehensive paediatric neurosurgical service

199. There are observational studies that show that there are improved outcomes such as fewer complications, with specialist paediatric neurosurgeons

D Measurement

200. **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

201. **Process**

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

202. **Outcome**

- Measurement of improved outcomes with specialist paediatric neurosurgical care
- Patient satisfaction surveys

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Radiotherapy

203. 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.

204. It is essential that the patient remains still for several 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.

205. 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.

206. 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.

207. 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

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

209. 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 or national centres. They include:

- total body irradiation as part of the conditioning regimen for a haemopoietic progenitor transplant (should take place in a Joint Accreditation Committee ISCT [International Society for Cellular Therapy] – EBMT [European Group for Blood and Marrow Transplantation] {JACIE} accredited centres)
- irradiation of infants with retinoblastoma
- biological targeted radioisotope treatments
- brachytherapy
- radiosurgery
- hypofractionated stereotactically guided retreatment.

210. Radiotherapy should start as soon as possible after a decision to use it has been made. There is a minimum time required to start complex, radical radiotherapy due to the manufacture of customised immobilisation devices and the use of 3D conformal planning, but delays for other logistic reasons should be minimised.

B. Anticipated benefits

211. Improved outcomes and reduced treatment-related morbidity.

212. Improved compliance with treatment.

C. Evidence

213. 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 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

214. National strategic documents and Royal College publications indicate that a move to subspecialisation in clinical oncology is required.

215. The resource requirements and the need for age appropriate facilities are documented in national guidance and guidance from the UKCCSG.

216. There is some evidence from the literature that delays in radiotherapy may affect tumour control in patients with sarcomas and high grade gliomas but do not appear to affect overall or event free survival in patients with medulloblastoma.

Table 2

- Appropriate consultant subspecialisation in paediatric radiotherapy, including membership of the UKCCSG, and cross cover arrangements
- Access to appropriate paediatric professional development
- Integration of the consultant clinical oncologists as core members of the paediatric oncology MDT
- 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 therapist
- 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

D. Measurement

217. **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 therapists to assist in the delivery of radiotherapy to young children.

218. **Process**

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

219. **Outcome**

- Evidence for the effect of delays in radiotherapy on outcome
- Surveys of patients and carer satisfaction with the delivery of radiotherapy

Supportive care

220. 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.

221. 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 carers, as well as the patient.

Febrile neutropenia

222. Neutropenia (low white blood cell count) 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.

223. 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

224. 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. The protocol should be available in all relevant clinical areas, including wards and accident and emergency departments.

225. The protocol should be informed by the development of national guidance for the management of febrile neutropenia in children and young people with cancer.

226. 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.

227. Antifungals, growth factors and blood products, required to support patients through episodes of chemotherapy-related neutropenia should be adequately resourced.

228. Patients and 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.

229. 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.

230. 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 below risk episodes.

B. Anticipated benefits

231. Lower number of deaths and episodes of serious complications from neutropenic sepsis.

232. With appropriate risk stratification, a reduction in the number of patients with fever requiring admission to hospital.

C. Evidence

233. There are no UK guidelines for the management of FNP.

234. The evidence from three randomised controlled trials on the outpatient treatment of febrile neutropenic episodes is inconsistent. There are two good quality guidelines (US) that conclude that some selected patients may be treated as outpatients.

235. 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

236. **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 carers

237. **Process**

- Number of patients with FNP treated as inpatients/outpatients
- Compliance with protocols and guidelines

238. **Outcome**

- Audit of deaths from neutropenic sepsis
- Audit of number of patients with fever requiring admission to hospital
- Audit of patient and carers views

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Central venous access

239. Children and young adults requiring venous access for chemotherapy and other 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

240. However, central venous catheters (CVCs) are associated with significant morbidity and, sometimes, mortality. Therefore attention to detail in choice of device, method 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

241. CVCs should be inserted in a clean, purpose designed area, usually an operating theatre with image intensifier or intraoperative ultrasound, or an interventional radiology suite. General anaesthesia is usually necessary for children and 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.

242. Removal of CVCs should only be done by trained personnel in an appropriate setting (and under general anaesthetic, for children).

243. 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.

244. Where appropriate, patients and carers should be given choice in the selection of central line and provided with the information needed to inform that choice.

B. Anticipated benefits

245. 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 complication rates, including late effects due to vascular occlusion
- reduce pain and distress for patients and 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

246. There is a large amount of observational evidence on the optimum method of central venous line insertion.

247. 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.

248. 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.

249. 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

250. **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
- Provision of adequate information to patients and carers
- Provision of dedicated theatre time

251. **Process**

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

252. **Outcome**

- Audit of complication rates

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Blood product support

253. 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.

254. Most 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.

A. Recommendations

255. 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.

256. There should be timely access to blood products at all times, including outside normal working hours.

257. Medical, nursing and laboratory staff 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

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

C. Evidence

259. 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.

260. There are good quality guidelines on the administration of blood products to neonates and older children

D. Measurement

261. **Structure**

- Production of local guidelines and protocols
- Provision of appropriate training
- Compliance with national ‘haemovigilance’ requirements

262. **Process**

- Audit of protocol and guideline compliance
- Audit of transfusion errors

263. **Outcome**

- Survey of effects of transfusion errors on morbidity and mortality

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Pain management

264. 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.

265. 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.

266. 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 therapists 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

267. Multidisciplinary protocols should be in place to support the safe and effective use of analgesia and these should be available in all care settings.

268. Ready access to specialist multidisciplinary paediatric pain services is required, for advice and support in complex pain management.

269. 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.

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

B. Anticipated benefits

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

C. Evidence

272. 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.

273. Standards for Hospital Services for Children and Young People, published in the National Service Framework for Children, 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

274. **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

275. **Process**

- Audit of delays in providing adequate pain relief

276. **Outcome**

- Audits of pain control
- Patient and carer satisfaction with pain relief

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Management of nausea and vomiting

277. Nausea and vomiting are among the most distressing side effects of cytotoxic chemotherapy, and vary with the emetogenic potential of the drugs and individual susceptibility. Advances in the management of nausea and vomiting have occurred with the use of improved drugs and evidence based multidisciplinary protocols.

278. Non pharmacological approaches to the management of this symptom 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.

A. Recommendations

279. There should be a written protocol for the management of chemotherapy 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.

280. The antiemetic drugs specified in the protocol should be readily available across all treatment sites.

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

B. Anticipated benefits

282. Better control of nausea and vomiting through a systematic approach to management.

283. Consistency across care settings will enhance parental/patient confidence in shared care.

C. Evidence

284. There is evidence that the use of clear guidelines can help in the management of this side effect of treatment.

D. Measurement

285. **Structure**

- Availability of appropriate staffing
- Written protocol in use with evidence of multidisciplinary input and regular review.

286. **Process**

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

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Nutrition

287. 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.

288. But there is a shortage of trained registered dieticians leading to problems with recruitment and retention, as well as the ability to respond to the needs of the client group.

A. Recommendations

289. Nutritional support should be designed to provide adequate protein and calories for all children and young people, taking into account their age, condition and treatment.

290. Training in the general field of paediatrics should be obligatory for dieticians, before working in oncology for children and young people.

291. Training, recruitment and retention of specialist dieticians should be funded.

292. Staff should adhere to agreed national professional guidelines on nutritional support.

B. Anticipated benefits

293. Adequate and effective nutrition will speed recovery and reduce the chance of prolonged nutritional problems.

294. Children with cancer will have their metabolic needs met with dietetic involvement.

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

C. Evidence

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

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

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

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

D. Measurement

300. **Structure**

- Provision of protocols detailing measures to ensure adequate nutritional support
- Provision of adequately trained registered dieticians and other support staff
- Provision of information on nutritional requirements to patients and carers

301. **Process**

- Audit of the numbers of trained dieticians

302. **Outcome**

- Surveys of the incidence of malnutrition in children and young people

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Oral and dental care

303. 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.

304. There is variation in oral care practice between the centres with regard to preventative therapies and dental check ups. A need for national evidence base guidelines for oral care for children being treated for cancer is acknowledged. Children are often referred back to their general dental practitioner (GDP) after completion of their cancer treatment.

305. 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.

306. 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.

A. Recommendations

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

308. National and local evidence based guidelines for oral and dental care should be developed.

309. Information on the effects of cancer treatment on the mouth should be provided to all patients and their parents.

310. A named dental professional, identified by the principal treatment centre, should coordinate care.

311. There should be clear protocols and referral routes for follow up.

312. 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

313. Preventing dental disease for this group will minimise detrimental effects on their general health.

314. The effects of treatment for their malignancy on development of dentition and function of oral tissues will be addressed.

C. Evidence

315. There are some consensus guidelines produced by the Royal Colleges on dental care for children receiving cancer treatment.

316. There are surveys on the variation in practice of oral and dental care between the paediatric oncology centres in the UK.

317. There is a lack of good evidence on the effective treatments for oral infections and oral mucositis.

D. Measurement

318. **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

319. **Process**

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

320. **Outcome**

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

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Rehabilitation

321. 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.

322. 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.

323. The World Health Organisation model, the International Classification of Functioning, is suitable for considering the strengths and needs of children and young people with cancer, across all professional disciplines.

324. 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.

325. 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, neurology, endocrinology and psychology are all disciplines that contribute.

A. Recommendations

326. There should be clear, agreed routes of referral for rehabilitation, including self referral, throughout the patient pathway and agreed across cancer networks.

327. All children and young people with CNS malignancy should have access to a neurorehabilitation service, even years after treatment.

328. 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.

329. Training courses should be established to meet the continuing professional development (CPD) needs of Allied Health Professionals (AHPs) working in paediatric and adolescent oncology. 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.

330. Additional investment is needed to support research in this area and this should be coordinated nationally.

B. Anticipated benefits

331. 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
- restore function e.g. following amputation or surgery

- maximise skill development and adaptive behaviour following treatment for CNS conditions.

332. 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.

333. Investment in staffing capacity would ensure the provision of an effective and equitable rehabilitation service.

334. Children, young people and their 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

335. 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.

336. The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* 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.

337. 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.

338. 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

339. **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 specialist neurorehabilitation services
- Availability of psychology services
- Appropriate facilities for rehabilitation
- Availability of 'age appropriate' oncology outreach nurses to provide rehabilitation services in the patient's home.

340. **Process**

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

341. **Outcome**

- Surveys of patient satisfaction with rehabilitation services
- Audit of the effect of rehabilitation on patient outcomes such as improvement in functioning, quality of life measures.

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Psychosocial care

342. 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.

343. The diagnosis of cancer in a child or young person inevitably throws a family into crisis. The child faces the burden 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, 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.

344. 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.

345. 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.

346. Psychosocial support needs are highly individual and will change as individuals and families move through the different stages of the patient pathway.

347. Psychological services have an important role to play at all stages along the patient pathway.

348. Young people may require occupational advice. This is often the primary role of an occupational therapist, in conjunction with other services outside of health, such as careers organisations and educational establishments.

A. Recommendations

349. All families with a child or young person with cancer should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed.

350. 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 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.

351. A structured psychosocial assessment at significant points throughout the care pathway is required, namely:

- at diagnosis
- during treatment
- end of treatment
- palliative care
- bereavement.

352. The assessment should include family information needs and coping skills, as well as practical support issues, and address the social context of the patient and family, including needs relating to education and employment. The needs of siblings should be addressed.

353. Access to neuropsychological services for cognitive assessment should be provided particularly for patients with CNS tumours, and also to guide schooling and career decisions.

354. The role of other members of the MDT in providing psychological support to patients, families and carers should be acknowledged and appropriate training and support provided.

355. Sibling and family support groups have proved a valuable resource in a number of treatment centres and should be encouraged. Peer support networks for patients should also be encouraged.

356. Cancer networks should consider the needs of this group of patients when developing psychological support services.

357. To ensure equity of access to benefits and external community support, all families with a child or young person with cancer should be offered the advice and support of a social worker to ensure the need for wider family support is addressed.

B. Anticipated benefits

358. An agreed minimum level of service defined in psychosocial care would support equitable access to services.

359. Access to a social worker would ensure equity of access to benefits and external community support.

C. Evidence

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

361. 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 treatment plans and referral routes.

362. The published NICE guidance on *Improving Outcomes in Palliative and Supportive Care in Adults with Cancer* 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.

363. There is evidence to support the particular psychosocial needs of patients with CNS tumours

364. Both professionals and parents have identified a significant lack in formal psychological input and psychology services and support, which represents a significant area of unmet need.

D. Measurement

365. **Structure**

- Policies for referral to psychosocial care
- Access to specialist psychologists with paediatric experience
- Availability of neuropsychology services for patients, particularly those with brain and CNS tumours

366. **Process**

- Audit of delays in provision of psychological services

367. **Outcome**

- Audit of improved outcomes with psychological input
- Patient and carer satisfaction surveys

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Long term sequelae

368. Over 1200 survivors of childhood 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.

369. 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 include endocrinological, renal, gynaecological and neurological sequelae. Of particular importance is the effect on fertility with approximately 15% having a high risk of early and irreversible gonadal failure.

370. 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, as therapy changes.

371. 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 therapy.

372. All this means that coordination and communication across multi disciplinary teams are very important.

373. 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

374. Each principal treatment centre should have at least one clinician with expertise in the management of the late sequelae of treatment for childhood cancer.

375. 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.

376. 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.

377. Clear lines of communication should be established with appropriate specialists (e.g. endocrinologist, gynaecologist, fertility specialist).

378. Where possible patients should be reviewed by a MDT with good communication between paediatric and adult services and age appropriate transitional services.

379. An appropriate key worker should be assigned to each patient on long term follow up.

380. Care plans should be devised for each survivor as they enter long term follow up. 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 of chemotherapy, details of radiotherapy and surgery, as well as information on existing or anticipated late effects.

381. The potential risk of infertility should be considered by the treating oncologist and there should be fertility counselling by appropriately trained personnel for all patients and/or their families at the time of diagnosis.

There should be access to semen storage for peripubertal boys. Further counselling is necessary as children mature and patients should have access to appropriate endocrine and fertility services.

382. The risk of late effects should be discussed with the patient and carers at the time of diagnosis and start of treatment and they should be given written information, copied to the GP.

383. Training and clinical facilities are required to increase the number of clinical staff available to deliver this service.

B. Anticipated benefits

384. Early identification and appropriate assessment and treatment of problems with growth and fertility are important in preventing later morbidity.

385. 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.

386. 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

387. 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.

388. 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, 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.

389. The variability of follow up provided by different centres in the United Kingdom has also been highlighted in the literature.

D. Measurement

390. **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
- Referral to appropriate specialists
- Good communication networks

391. **Process**

- Appropriate follow up of patients at risk of late effects

392. **Outcome**

- Audit of treatment outcomes

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Palliative care

393. 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.

394. 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.

395. 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 (POON), for end of life care is essential. However, general practitioners should be kept fully informed.

396. 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.

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
- Expert symptom management
- 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

397. 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 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.

398. 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 and POONs are best placed to act as key workers.

399. 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.

400. Dietetics, occupational therapy, play therapy and physiotherapy are an integral part of paediatric palliative care. Clinical psychologists 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

401. 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 region).

402. 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

403. Palliative care for children and young people should be actively addressed within the palliative care group of each cancer network.

404. 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.

405. 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.

406. There should be timely and equitable access to dietetics, occupational therapy, play therapy and physiotherapy services in the community.

407. Clinical psychology support should be available in all areas with clear lines of referral within the cancer network.

408. A recognised training pathway for medical and nursing staff wishing to develop specialist skills and knowledge in paediatric palliative care should be developed.

409. 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.

B. Anticipated benefits

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

411. Each family will have the support of an experienced and knowledgeable key worker who will coordinate and lead during palliative and terminal care.

412. Specialist support will be available over the 24 hour period.

413. Appropriate medication will be available to:

- enable a rapid response to symptom management
- to prevent escalation of pain and symptoms
- minimise readmission to hospital.

414. Appropriate personnel and equipment will be available to support death at home.

C. Evidence

415. 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.

416. The guidelines that exist are not evidence based and are generally of poor quality. The NICE guidance on *Improving Supportive and Palliative care in Adults with Cancer* provides good quality evidence for the requirements of a palliative care service for adults.

417. 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.

418. Expert opinion and consensus indicate the central role of the cancer networks in ensuring that there are clear referral routes and that the needs of children and young people are addressed by the palliative care groups within the networks.

D. Measurement

419. **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 telephone support and effective information services

420. **Process**

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

421. **Outcome**

- Audit of symptom control
- Surveys of patient and carer satisfaction with palliative care

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Bereavement services

422. 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 also occurs during treatment in hospital. 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 counselling.

423. Following the Redfern Report in 2001, 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.

424. Specific issues to be considered following death include:

- acute grief reactions from family members
- post mortem, consent and tissue retention (including sperm donation)
- coordination of care in the bereavement suite and transfer home.
- registration of the child's death.

425. With appropriate information and support, many families are able and wish to take the lead in the arrangements after their child's death.

A. Recommendations

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

427. 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.

428. 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.

429. Services should be tailored to the needs of individual families.

430. Staff support/supervision should be available for all those involved in the death of a child.

431. Bereavement counselling needs to be part of communication skills training.

B. Anticipated benefits

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

433. Clearly identified source of support will be available at particularly vulnerable time.

434. The facilitation of grieving should help prevent the detrimental consequences of bereavement.

435. Identified support to healthcare professionals who engage in this work should help minimise staff distress.

C. Evidence

436. There is evidence from good quality surveys to illustrate the variation in provision of bereavement care within the UKCCSG centres.

437. There is evidence from guidelines to indicate the need for bereavement services to be flexible and accessible when required.

438. There is evidence from provisional studies on guidelines and the development of standards for bereavement care to indicate service requirements.

D. Measurement

439. **Structure**

- Provision of readily accessible bereavement services

440. **Process**

- Audit of bereavement services provided at principal treatment centres

441. **Outcome**

- Surveys on the effect of bereavement counselling on quality of life of parents and siblings
- Carer satisfaction surveys

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Service organisation

442. 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.

443. 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 so called “postcode lottery”. 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”.

444. Services need to be commissioned across all levels of care and seen as a whole system across community and hospital settings.

445. 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.

446. 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.

Delivery of care

Multidisciplinary teams

447. A complex range of services is required for children and young people with cancer, involving many disciplines and different organisations. Modern cancer care has come to be defined by its delivery through teams of professionals working together, known as multidisciplinary teams (MDTs). At its most basic, such a team includes those directly involved in the diagnosis, staging and medical treatment planning for each individual patient. In practice, such teams are often larger and more complex, with varying membership, depending on their place within the care pathway and specific function.

448. Suggested core members of MDTs are given in Tables 4 and 5. Multidisciplinary management has to reflect both 'care' and 'disease' needs and a range of meetings and team configurations often exist.

Table 4 Suggested core membership of MDTs at principal treatment centres

Diagnostic MDT*
• Oncologist/haematologist • Radiologist • Surgeon/neurosurgeon • Pathologist/cytogeneticist • Clinical oncologist

Treatment MDT*

- Treating oncologist
- Paediatric haematologist
- Specialist nurses
- Ward based nurse
- Day care nurse
- Specialist outreach nurse/key worker**
- Specialist pharmacist
- Dietician and other appropriate allied health professionals
- Paediatric oncology or other speciality outreach nurse/key worker**

Psychosocial support MDT

- Treating oncologist and haematologist
- Play therapy; activity coordinator/youth worker
- Psychologist or other member of psychological service
- Specialist outreach nurse/key worker**
- Appropriate allied health professionals
- Teacher
- Social worker
- Nurses from in-patient and day care units

Late effects MDT

- Lead clinician (expertise in late effects)
- Key worker**
- Specialist nurse
- Endocrinologist
- Appropriate AHP

Palliative care MDT

- Lead clinician
- Palliative care specialist/oncologist/haematologist
- Social worker
- Key worker**

** Medical staff represent tumour specific or paediatric expertise*

*** See section on continuity of care*

Table 5 Suggested core membership of MDT at other treatment sites

- Lead paediatrician/oncologist/haematologist
- Key worker**
- Specialist nurse
- Pharmacist
- Ward nurse
- Allied health professionals

*** See section on continuity of care*

449. There are several tumour types which need consideration by either a specialist 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
    - Bone sarcoma
    - Lymphomas (for specialist pathological review)

A. Recommendations

450. 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, the remit and membership of the MDT should reflect the arrangements for shared care.

451. All non principal treatment centres (see 'Place of care', page 111) participating in shared care should have an MDT that facilitates the interface between them and both primary care and the principal treatment centre.

452. Membership of MDTs should be explicit and include clearly defined responsibility for clinical and managerial leadership.

453. 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.

454. 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.

455. 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

456. MDTs ensure that each patient is considered from a range of viewpoints and expertise. MDTs promote shared learning between professionals.

457. They offer a greater probability of timely, appropriate treatment and better continuity of care and enable services to lose the “referral” culture.

458. 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.

459. Regular patient centred meetings, joint assessments and shared recording systems will enable teams to provide more comprehensive services.

C. Evidence

460. 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.

461. The advantages of a multidisciplinary shared care programme for young people have been demonstrated in a randomised controlled trial performed in Denmark.

462. There are national guidelines/guidance that provide information on the frequency and composition of MDTs

D. Measurement

463. **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.

464. **Process**

- Audit of protocols for referral to specialist MDTs
- Staff attendance at the MDT meetings
- Evidence that all patients are discussed at an appropriate MDT

465. **Outcome**

- Patients with certain tumour types have improved outcomes with multidisciplinary care

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Continuity of care

466. 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,

467. 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.

468. 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.

469. 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 6.

470. 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 also 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.

471. In most instances, a specialist nurse can most effectively undertake the key worker role, and in many principal treatment centres, and for the younger

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

472. 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 6 The role of the key worker

- Provide practical and emotional support to the child/young person and family at the time of diagnosis
- Coordinate the provision of information and ensure that it is timely, tailored to the age of the child and the needs of the family, and understood
- Ensure the provision of a written care/treatment plan and undertake 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, and provide training, education and support when needed
- Liaise with educational institutions to ensure that the child's educational needs are addressed and supported and that reintegration is promoted 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
- 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

473. 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.

474. 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.

475. 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

476. A key worker should be identified for each child or young person and their family to coordinate services and assess their support needs.

477. There is a need for identified nurse specialists to address the care and support needs of teenagers and young adults.

478. There should be clear routes communication between different care/treatment settings.

479. 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.

480. 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

481. 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.

482. 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

483. There is a paucity of evidence to indicate the requirements for service provision to achieve a well co-ordinated 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.

484. 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

485. There is observational evidence on the essential role of a key worker in the continuity of care.

486. Results from patient surveys show that the key worker model is supported by families of children and young people with cancer.

D. Measurement

487. **Structure**

- Documented local protocols for the continued care and follow up of patients
- Written care/treatment plans
- Provision of adequate numbers of key workers to coordinate care
- Good communication networks
- Provision of patient held records

488. **Process**

- Audit of care/treatment plans
- Audit of planned transition outcomes

489. **Outcome**

- Surveys of patient and carer satisfaction with the continuity of care.

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Protocol based care

490. 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.

491. 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.

492. 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

493. 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.

494. 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

495. 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

496. A better understanding of tumour biology and response to treatment will be derived from collaborative care.

C. Evidence

497. 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.

498. 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.

499. 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

500. 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.

501. 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

502. **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

503. **Process**

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

504. **Outcome**

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

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Place of care

505. 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.

506. 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.

507. 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.

508. 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.

Principal treatment centres

509. 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.

510. 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.

511. 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 malignancies treated at the centre each year.

512. 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.

513. Teams caring for young people need to be experienced in and responsive to the specific social, psychological, and educational needs of teenagers 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. They should be developed in sympathy with established local cancer provision and operate through partnerships between paediatric and adult oncology services.

514. 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.

515. The pressures of consultant workload have arisen from the following:

- the reduction in junior doctors' hours
- compliance with the European Union Working Time directive
- compliance with the European Union GCP in Clinical Trails directive
- increased intensity of treatment initially and at relapse.

516. There therefore needs to be adequate core consultant staff in each principal treatment centre

Local hospitals

517. 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 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.

518. 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 7).

519. Shared care arrangements are seen frequently in the paediatric setting, but are less well established for the care of teenagers and young adults.

Table 7 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
- 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

520. 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 and at the palliative stage.

521. 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 POON or other outreach and liaison teams generally provide this from the principal treatment centre

522. 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.

523. 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

524. The 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 and the Welsh Cancer Standards.

525. 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.

526. Principal treatment centres should be able to provide a sustainable range of services, with defined minimum levels of staffing, as outlined in Tables 8 and 9.

527. The principal treatment centre should have the capacity to accept referrals and admit patients in a timely fashion.

Table 8 Core components of a principal treatment centre (paediatrics)

*Personnel**

- Designated lead clinician
- Paediatric oncologists
- Paediatric haematologists

  (minimum of 5 consultant staff, at least 2 of each discipline above)
- 2 Clinical oncologists with expertise in paediatric radiotherapy
- Paediatric surgeon with expertise in specialist oncology**
- Adequate junior and middle grade cover

Other specialist services necessary on site:

- Paediatric anaesthetics
- Paediatric radiology
- Paediatric pathology
- Designated pharmacist
- Psychological and psychiatric services

Nursing establishment**

- Identified lead nurse
- Specialist trained nurses for ward and day care
- Paediatric oncology outreach nurses

Core Allied Health Professionals:

- Dietician
- Physiotherapist
- Occupational therapists
- Play specialists

Designated social workers

Research support:

- Research nurse
- Data managers

There should be immediate access to:

- Paediatric intensive care
- Paediatric neurosurgical services

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

Table 9 Core components of a principal treatment centre (young people)

*Personnel**

- Designated lead clinician
- Other consultant staff with expertise in the care of malignancies seen in this age group
- Adequate junior and middle grade cover+

Other specialist services necessary on site as required for site specific expertise:

- Radiology
- Pathology
- Designated pharmacist
- Psychological and psychiatric services

Adequate nursing establishment**

- Identified lead nurse
- Specialist trained nurses for ward and day care
- Key worker/ outreach nurses

Core Allied Health Professionals:

- Dietician
- Physiotherapist
- Occupational therapists
- Activity coordinator

Designated social workers

Research support:

- Research nurse
- Data managers

There should be immediate access to:

- Intensive care
- Neurosurgical services
- Other tertiary services
- Dental services

- Pain management teams

** Where numbers are given this represents a minimum requirement; 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*

*** 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

528. The principal treatment centre for children with cancer should be a UKCCSG centre, unless the requirement for specific expertise demands otherwise.

529. Whatever the age of the patient they should have access to:

- expertise in the management of the malignant condition
- age appropriate facilities
- appropriate MDTs .

530. 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.

531. 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.

532. There should be clear and rapid communication between each care agency and location.

533. 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.

534. Some rarer malignancies require specialist services, which should be provided in a limited number of centres. These include retinoblastoma, bone tumours, some sarcomas and liver tumours.

535. Allogeneic bone marrow transplantation should only be undertaken by accredited JACIE centres.

536. 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.

537. 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.

538. 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.

539. Adequate resources are required not only for principal treatment centres, but also for all settings which are participating in the delivery of care.

B. Anticipated benefits

540. Improvement in survival for patients treated by MDTs with expertise in treating their cancer

541. Improvements in supportive care and psychosocial support for the patients and their families

542. 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.

C. Evidence

543. 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.

544. 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 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.

545. Designated units for teenagers and young adults, which exist in England, have been well received by young people and their families.

546. 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.

547. 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.

548. Evidence from families reflects very different experiences of shared care, and highlights the importance of communication and collaborative care across care settings.

D. Measurements

549. **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

550. **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
- Audit of inability to accept new referrals

551. **Outcome**

- Accurate data for the tumour specific differences for different outcomes when treatment is received in inappropriate settings.
- Surveys of patent and 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

[Resource implications will be available in the second consultation version of this document.]

Cancer networks

552. 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 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

553. 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.

554. Where catchment areas for a particular treatment centre or shared care arrangement cut across the boundaries of a number of networks, the 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.

555. All principal treatment centres for both children and young people should be members of an identified cancer network.

556. Commissioners should ensure that these services are taken forward proactively by cancer networks.

B. Anticipated benefits

557. The provision of well coordinated care.

558. Targeting of resources where they are most required to serve the needs of their local population.

559. 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

560. The setting up of cancer networks was recommended in the Calman Hine Report.

561. Cancer networks are the organisational model for cancer services to implement the NHS Cancer Plan and Improving Health in Wales; A Plan for the NHS with its partners

D. Measurement

562. Compliance with the standards for cancer networks described in Topic 1a of the Manual of Cancer Services 2004 and in the Welsh Cancer Standards.

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Communication with children, young people and families

563. Open communication between professionals, children/young adults and 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.

564. 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

565. 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.

566. Facilities used for the imparting of important information, especially at the time of diagnosis should be private and comfortable. Patients and carers should be involved in treatment decisions at all stages of their treatment and care.

567. Patients, families and carers should have access to a written care/treatment plan and the use of patient held records should be encouraged.

568. Patients, families and carers should have access to information which promotes informed choice. They should have the opportunity to ask questions and discuss treatment options and be given ready access to further information and support.

569. 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.

570. 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.

571. Play specialists and activity coordinators should be key members of the multidisciplinary team as they can help to promote effective communication.

572. The information needs of siblings should be considered and appropriate, relevant information provided. Members of the extended family, such as grandparents, who provide support also need access to information.

573. On line information resources should be made available to families in principal treatment centres. Advice should be provided on authoritative and useful websites.

574. There should be regular consultation with representatives of patient and parent groups in the continuing development of services for children, young people and families.

B. Anticipated benefits

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

- 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.

576. 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

577. 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'.

578. 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.

579. Considerable evidence exists that problems with communication and information giving (both inter-professional and between patients/carers) exist.

580. There is good quality evidence (randomised controlled trial and systematic reviews) that training courses to improve communication are effective.

581. There is national guidance recommending the use of patient held records.

582. There is expert opinion, consensus and evidence reviewed in the NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* 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.

583. The evidence from the Information Directory produced by the Macmillan Cancer Fund indicates that some online information resources are of poor quality and if such facilities are to be provided in principal treatment centres need careful evaluation.

D. Measurement

584. **Structure**

- Provision of training in communication skills for clinical and other staff involved in patient care.
- Availability of appropriate information 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.

585. **Process**

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

586. **Outcome**

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

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Research

587. 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.

588. 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.

589. 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.

590. 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.

591. 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.

A. Recommendations

592. All innovative treatments should be part of a clinical trial.

593. 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.

594. The development of clinical trials, which include teenagers and young adults, should be encouraged.

595. Local research and development arrangements should facilitate the introduction of nationally approved clinical trials.

596. Where clinical trials are undertaken, there must be compliance with the EU Directive of Good Clinical Practice with adequate resource provided for research nurses, clinical trials coordinators and data managers.

597. There should be clearly defined routes for funding for the support of clinical trials for children and young people.

B. Anticipated benefits

598. A greater number of children and young people will have access to clinical trials.

599. Teenagers and young adults will have access to treatment in an appropriate clinical trial or on an agreed treatment protocol.

600. 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

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

602. 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'.

603. 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.

604. 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.

605. 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

606. **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

607. **Process**

- Demonstration of adherence to the requirements of the EU Directive of Good Clinical Practice.
- Surveys of numbers of children and young people who are entered into available clinical trials

608. **Outcome**

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

E. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Workforce development

609. 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.

610. There are particular issues around the recruitment and retention of the following:

- paediatric radiologists and therapeutic radiographers
- paediatric pathologists
- allied health professionals
- paediatric haematologists
- nurses
- clinical psychologists
- clinical oncologists

611. The importance of appropriate training has been alluded to throughout this Guidance. Sufficient time should be available to ensure this in all treatment settings.

612. 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

- blood product support
- communication skills.

613. This list is by no means exhaustive.

A. Recommendations

614. Workforce development confederations should address the training and education needs of staff working with children and young people with cancer.

615. 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.

616. 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.

617. 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.

618. There should be access for nurses and other healthcare professionals to appropriate post-basic specialist education in the care of children and young people with cancer.

B. Anticipated benefits

619. Equitable access to services

C. Evidence

620. There are currently no specific training opportunities within the UK for allied health professionals working in paediatric or adolescent oncology rehabilitation.

621. Workforce vacancy rates continue to be significantly high, compared to other staff groups. The provision of services across the UK is variable.

D. Resource implications

[Resource implications will be available in the second consultation version of this document.]

Other service considerations

Information requirements

622. 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.

623. 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).

624. There is an ongoing problem with accurate coding of hospital activity which has led to clear inaccuracies in recent reports.

A. Recommendations

625. 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.

626. National IT strategies in England and Wales should consider the needs of these services when introducing new IT systems.

627. 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

Child protection

628. All services for children and young people must demonstrate robust child protection arrangements, regardless of the setting in which care is delivered.

629. All staff having contact with children should have mandatory child protection awareness training.

630. All staff whose work brings them into contact with children should be Criminal Records Bureau checked.

631. Children and young people should be made aware of how to make a complaint and have access to independent advocacy if required.

632. 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

633. 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.

634. 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.

Hospital facilities

635. Hospital facilities must meet requirements for good infection control.

636. Hospital catering services must be responsive to the particular needs of sick children.

637. Prolonged inpatient stays make the provision of suitable accommodation for parents and carers an essential component of these services.

Hospital Parking

638. 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.

Appendix A

GUIDELINES/GUIDANCE AND KEY STRATEGIC[1] DOCUMENTS CHILD AND ADOLESCENT CANCER

GUIDELINE TITLE	SOURCE
Guidelines for Pediatric Cancer Centers	American Academy of Pediatrics 2004
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
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
Extending the Working Day for Delivery of Radiotherapy	Board of the Faculty of Clinical Oncology The Royal College of Radiologists London1997
Equipment, Workload and Staffing for Radiotherapy in the UK 1992–1997	Board of the Faculty of Clinical Oncology The Royal College of Radiologists London1998
A Guide for Purchasers and Providers of Paediatric Surgical Services.	British Association of Paediatric Surgeons and The Royal College of Surgeons Edinburgh 1995
The British Association of Paediatric Surgeons. A Guide for Purchasers and Providers of Paediatric Surgical Services	British Association of Paediatric Surgeons 1995
Response to the Kennedy Report " Learning from Bristol"	British Association of Paediatric Surgeons 2001
Paediatric surgery : Standards of Care	British Association of Paediatric Surgeons 2002
Reconfiguration in Paediatric Surgery	British Association of Paediatric Surgeons 2003
BCSH Guidelines on the insertion and management of central venous lines	British Committee for Standards in Haematology 1997
Transfusion guidelines for neonates and older children	British Committee for Standards in Haematology 2004
Guidelines on the diagnosis and management of chronic lymphocytic leukaemia.	British Committee for Standards in Haematology 2004
Transfusion guidelines for neonates and older children	British Committee for Standards in Haematology.
Guidelines on the diagnosis and management of chronic lymphocytic leukaemia…	British Committee for Standards in Haematology.
Hepatology and Nutrition A Guide for Purchasers	British Society for Paediatric

of Paediatric Gastroenterology,	Gastroenterology 2003.
Guidelines for MRI in Paediatric Brain Tumours.	British Society of Paediatric Radiology 1999
A Survey of Radiotherapy Services in England and Wales 1999	Cancer Services Co-ordinating Group (Wales)
All Wales Cancer Standards (draft for consultation)	Cancer Services Co-ordinating Group, Wales, 2004
National Service Framework Assessments: No.1 – NHS Cancer Care in England and Wales	Commission for Health Improvement/Audit Commission 2001
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**
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**
A Survey of Radiotherapy Services in England 1999	Department of Health 2000
Meeting the Challenge: A Strategy for the Allied Health Professions	Department of Health 2000
The NHS Cancer Plan	**Department of Health 2000**
The Removal, retention and use of Human Organs and Tissue from Post-mortem Examination	**Department of Health, Chief Medical Officer 2001**
Delivering 21st Century IT Support for the NHS. National Strategic Programme	**Department of Health 2002**
Implementing a Scheme for General Practitioners with Special Interests	Department of Health 2002
Strengthening Accountability Involving Patients and the Public. Policy Guidance Section 11 of the Health and Social Care Act 2001	**Department of Health 2003**
Updated national guidance on the safe administration of intrathecal chemotherapy	**Department of Health 2003**
Getting the right start: National Service Framework for Children, Young People and Maternity Services. Part 1: Standards for hospital services.	**Department of Health. 2003**
Patient and Public Involvement in Health : The Evidence for Policy Implementation	Department of Health 2004
National Service Framework for Children, Young People and Maternity Services	**Department of Health 2004**
Manual for Cancer Services 2004	**Department of Health 2004**
EU Directive on Good Clinical Practice in clinical	Directive of the European Parliament

trials	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)
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**
Childhood Cancer – Guidelines for Standards of Treatment & Care	International Society for Paediatric Oncology (SIOP) 2003
Recommendations for the organisation of a paediatric cancer unit	SIOP 1993
Aims and recommendations for psychosocial care	SIOP 1993
Guidelines for Care of Long-Term Survivors	SIOP 1996
Guidelines for the communication of the diagnosis	SIOP 1997
Guidelines for a Therapeutic Alliance between Families and Staff:	SIOP 1998
Guidelines for Assistance to Siblings of Children with Cancer	SIOP 1999
Guidelines for assistance to terminally ill children with cancer	SIOP 1999
Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer	SIOP 2000
Refusal, Non-Compliance, and Abandonment of Treatment in Children and Adolescents with Cancer	SIOP 2002
Valid Informed Consent and Participative Decision Making in Children with Cancer and their parents	SIOP 2003
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
A Survey of Radiotherapy Services in England and Wales 2001	National Cancer Services Analysis Team
NCCN pediatric neuroblastoma practice	National Comprehensive Cancer

guidelines.	Network. 1996
NCCN pediatric acute lymphoblastic leukemia practice guidelines.	National Comprehensive Cancer Network. 1997
Who operates where – WOW II	National Confidential Enquiry into Perioperative Deaths 2003
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
Referral guidelines for suspected cancer (draft for consultation)	National Institute for Clinical Excellence, 2004
Facilities for cancer care centres: design and briefing guidance.	NHS Estates, 2001.
Nurse Specialists, Nurse Consultants, Nurse Leads. The development of new roles to improve cancer and palliative care. An advisory report	NHS Executive 2001
Radiology: A National Framework for Service Improvement	NHS Modernisation Agency 2003
Radiotherapy Toolkit	NHS Modernisation Agency 2003
Chemotherapy Toolkit	NHS Modernisation Agency 2003
Cancer Services Collaborative Improvement Partnership. Improving Communication in Cancer Care	NHS Modernisation Agency 2004
The Management of Pain in Patients with Cancer	NHS Quality Improvement Scotland 2004
Guidance on the provision of paediatric anaesthetic services	Royal College of Anaesthetists 2001
Children's Nursing Workforce July 2002	Royal College Nursing 2002
Services for children and young people: preparing nurses for future roles	Royal College Nursing 2004
Guidelines for the ethical conduct of medical research involving children	Royal College of Paediatrics and Child Health : Ethics Advisory Committee 2000
Guidelines for Good Practice. Recognition and Assessment of Acute Pain in Children	Royal College of Paediatrics and Child Health 2001
Standards for development of clinical guidelines in paediatrics and child health,	Royal College of Paediatrics and Child Health, 2001.
Old problems, new solutions. 21st Century children's healthcare	Royal College of Paediatrics and Child Health, 2002.
Providing a Service for Children. Workforce	Royal College of Paediatrics and Child

Census 2001	Health 2003
Specialist health services for children and young people. A guide for primary care organisations	Royal College of Paediatrics and Child Health. 2003.
Commissioning Tertiary and Specialised Services for Children and Young People	Royal College of Paediatrics and Child Health 2004
Medicines for Children	Royal College of Paediatrics and Child Health 2004
Cancer units: improving quality in cancer care. The provision of non-surgical specialist cancer services in district general hospitals.	Royal College of Physicians. 2000
Guidelines for External Beam Radiotherapy	Royal College of Radiologists' Clinical Oncology Information Network 1999
Safe Sedation, Analgesia and Anaesthesia within the Radiology Department	Royal College of Radiologists 2003
Clinical Radiology and the Patients of General Practitioners	Royal College of Radiologists and Royal College of General Practitioners 2004
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
Clinical Guidelines. The oral management of oncology patients requiring radiotherapy: chemotherapy: bone marrow transplantation	Royal College of Surgeons of England 1999
Children's Surgery – A First Class Service	Royal College of Surgeons of England 2000
Better Blood Transfusion RCPCH Policy Document	Royal Liverpool Children's NHS Trust 1999
Control of Pain in Patients with Cancer. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2000
Long term follow up of survivors of childhood cancer. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2004
Safe Sedation of Children Undergoing Diagnostic and Therapeutic Procedures. A National Clinical Guideline	Scottish Intercollegiate Guidelines Network 2004
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**
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
Overview of the National Workforce Competence Framework for Children's Services	Skills for Health 2004
Safe Paediatric Neurosurgery	Society of British Neurological Surgeons 1998

Safe Paediatric Neurosurgery	Society of British Neurological Surgeons 2001
Department of Health *Children Act 1989 – Guidance and Regulations*	**Stationery Office 1991**
Royal Liverpool Children's Inquiry	**Stationery Office 2001**
The Resources and Requirements of a UKCCSG Treatment Centre	United Kingdom Children's Cancer Study Group (UKCCSG) 2004
Shared care	UKCCSG 2004
UKCCSG Centre Coordinator Responsibilities	UKCCSG 2004
Criteria for Centres Undertaking Phase I and II Studies	UKCCSG 2004
UKCCSG Centre Data Managers – Role and Responsibilities	UKCCSG 2004
UKCCSG Guide to GCP (Good Clinical Practice and the EU Directive on Clinical trials 2001/20/EC)	UKCCSG 2004
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
Improving Health in Wales. A plan for the NHS with its partners	Welsh Assembly Government 2001
National Service Framework for Children, Young People and Maternity Services in Wales. Consultation Document	**Welsh Assembly Government 2004**

[1] Bold = strategic documents