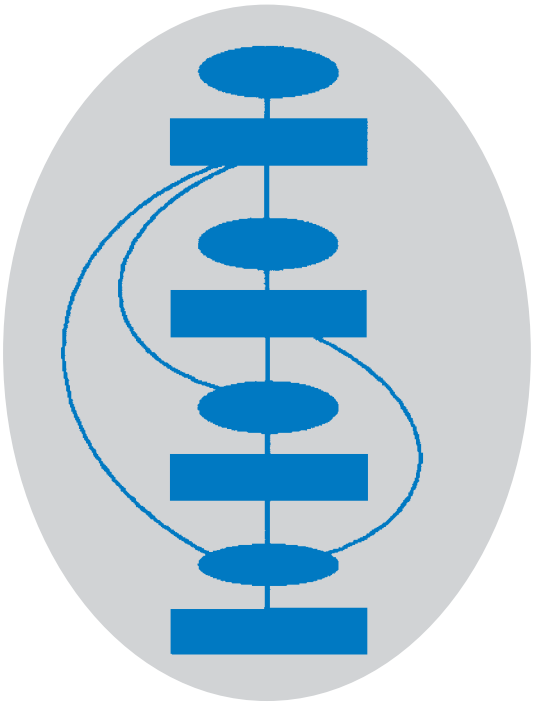
NHS

National Institute for Health and Clinical Excellence

Guidance on Cancer Services

# Improving Outcomes in Children and Young People with Cancer

## The Manual



August 2005

Developed by the National Collaborating Centre for Cancer

**Improving Outcomes in Children and Young People with Cancer**
Cancer service guidance supports the implementation of *The NHS Cancer Plan* for England,[1] and the NHS Plan for Wales *Improving Health in Wales.*[2] The service guidance programme was initiated in 1995 to follow on from the Calman–Hine Report, *A Policy Framework for Commissioning Cancer Services.*[3] The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.

**References**


1. Department of Health (2001) *The NHS Cancer Plan.* Available from: www.dh.gov.uk

2. National Assembly for Wales (2001) *Improving Health in Wales: A Plan for the NHS and its Partners.* Available from: www.wales.gov.uk/healthplanonline/health_plan/content/nhsplan-e.pdf

3. *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* (1995). Available from: www.dh.gov.uk



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# Contents

# Foreword



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.

The original title of the guidance was *Child and Adolescent Cancer*. When consulting on the draft scope 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 in their late teens and early twenties. This is not just a cosmetic change, but reflects some important principles that we hope are clear in the guidance.

During the development of this guidance there have been changes in the structure of the NHS in England and its commissioning arrangements, with the introduction from 1 April 2005 of Payment by Results. It is not yet clear what effect this will have on the way in which service guidance of this kind is implemented.

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 6.4, who provided written papers or informal advice to the group, and without whom this guidance would have been incomplete.

I would like to thank all the children and teenagers with cancer, and their siblings and parents, who contributed their valuable opinions to the research carried out by the National Children's Bureau and the Teenage Cancer Trust on our behalf. Without their commitment the guidance would have been incomplete.

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**

# Key recommendations



- Planning, commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be coordinated to ensure that there is an appropriate balance of service provision and allocation of resources. The principle that underpins the guidance is that of age-appropriate, safe and effective services as locally as possible, not local services as safely as possible.

- Commissioners should ensure, through cancer networks in partnership with services for children and young people, that:

  - there is a clear organisational structure for these services, including a cancer network lead for children with cancer and a cancer network lead for young people with cancer

  - all aspects of care for children and young people with cancer should be undertaken by appropriately trained staff

  - principal treatment centres for each cancer type are identified for children and for young people, with associated referral pathways, including to centres outside the network of residence when necessary

  - principal treatment centres are able to provide a sustainable range of services, with defined minimum levels of staffing, as outlined in the guidance

  - shared care arrangements are established, which identify a lead clinician and lead nurse and have approved clinical protocols for treatment and care, and defined areas of responsibility with the principal treatment centres

  - all sites delivering cancer therapy in this age group should be subject to peer review

  - all relevant national guidance is followed (see Appendix 1).

- 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.

- 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.
- All care for children and young people under 19 years old must be provided in age-appropriate facilities [35, Appendix 1]. Young people of 19 years and older should also have unhindered access to age-appropriate facilities and support when needed. All children and young people must have access to tumour-specific or treatment-specific clinical expertise as required.
- Theatre and anaesthetic sessional time should be adequately resourced for all surgical procedures, including diagnostic and supportive procedures, in addition to other definitive tumour surgery. Anaesthetic sessional time should also be assured for radiotherapy and painful procedures. The paediatric surgeon with a commitment to oncology should have access to emergency theatre sessions during routine working hours.
- 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. Participation in trials must be an informed choice.
- Children and young people with cancer who are not participating in a clinical trial should be treated according to agreed treatment and care protocols based on expert advice, and resources provided to monitor and evaluate outcomes.
- The issues related to the registration of cancers in 15–24-year-olds and the potential value of a dedicated register within the structures of the National Cancer Registries should be addressed urgently.
- 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.
- 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

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.

There are many other current national initiatives of relevance, not least national service frameworks (NSFs) and other *Improving Outcomes* guidance; care has been taken not to duplicate this work, but adherence to such guidance is expected. The guidance also assumes compliance with the relevant national guidelines on the administration/management of therapies (see Appendix 1) and any relevant legal frameworks.

The population, healthcare settings, and services and key areas of clinical management are included in detail in the Scope (see Appendix 2). The guidance covers children from birth and young people in their late teens and early twenties presenting with malignant disease, and the whole range of NHS services required to meet their needs. These needs are influenced by a complex interaction between the condition, stage in the care pathway and individual maturity. The guidance has not used a specific upper age limit in the recommendations, other than for the children's NSF, recognising that any such limit would be arbitrary and that services should be appropriate for individual needs.

### Principles

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

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 that are likely to have a significant impact on health outcomes.

### Types of cancer

There is a wide range of conditions, which for convenience are grouped into three categories: solid tumours, haematological malignancies and central nervous system (CNS) malignancies. A care pathway approach has been used (see Figure 1) to ensure inclusion of the main clinical issues affecting services.

### Service organisation

Many issues are not condition specific, but involve the way services are delivered and/or organised, and are dealt with in the section on service organisation. Some areas, such as data protection, child protection and staff training, are also addressed in the section on service organisation in the guidance.

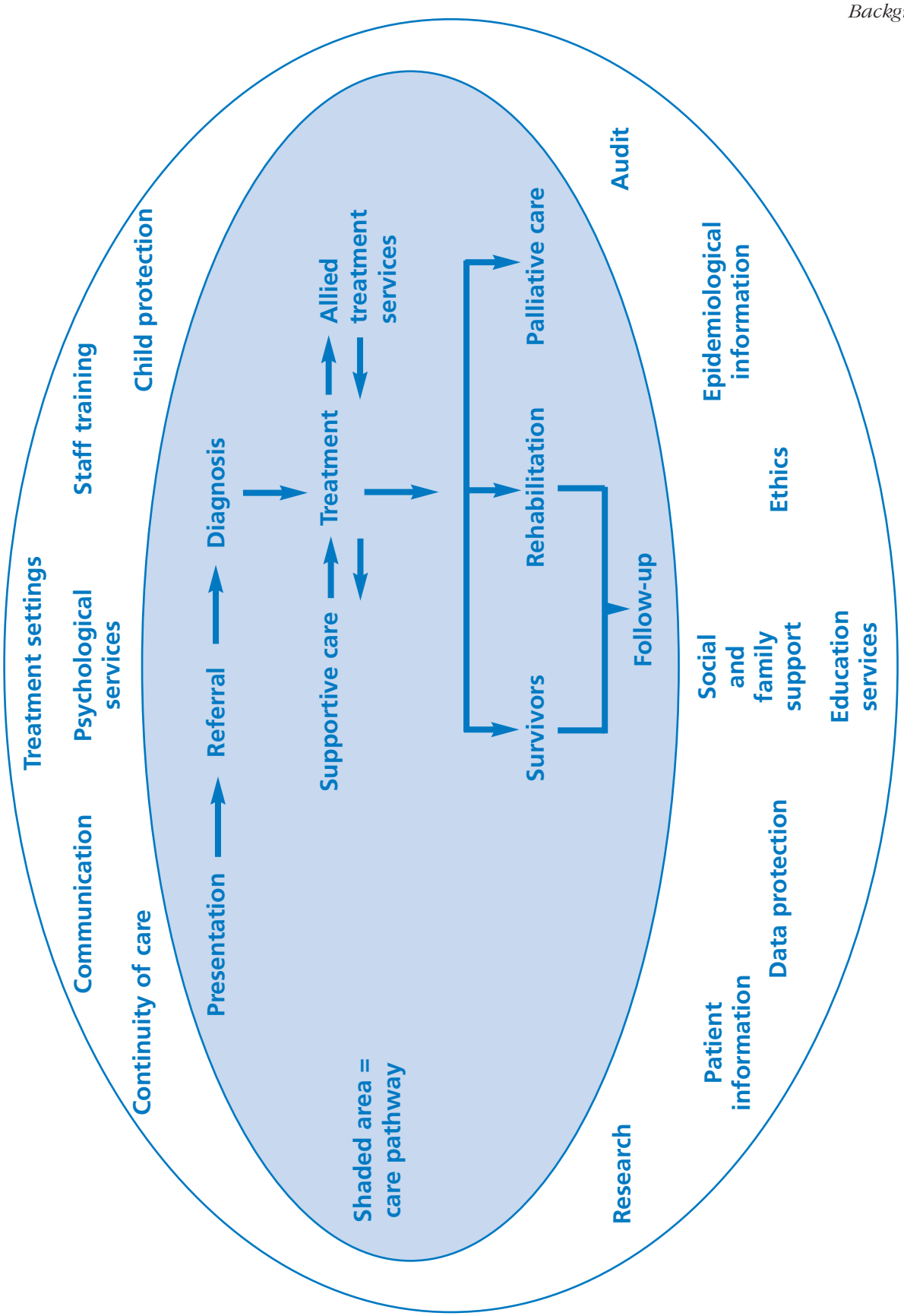



**Figure 1 The care pathway for children and young people with cancer and its wider context.**

### Definition of children and young people

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.

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 teenagers and young adults.

### Age range

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

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

A number of relevant existing guidelines and reviews were accessed (see Appendix 1 and the Evidence Review).

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

A nominated panel of experts was invited to contribute via the submission of formal position papers for consideration by the GDG (see Appendix 6.4 and the Evidence Review).

Specific work was commissioned to elicit the views of children and young people with cancer, and their siblings and parents, on current service provision. This study was performed by the National Children's Bureau (NCB) and is available in Appendix D of the Evidence Review.

In addition, the results of a survey of teenagers' views on the provision of cancer services, from a conference organised by the Teenage Cancer Trust (TCT) in 2004 (see Appendix E of the Evidence Review), were used to provide information on the specific requirements of this age group.

Where there was no substantial evidence-base for important key questions, consensus methods were used by the GDG.



# Epidemiology

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 this is included below. The full assessment is included in the Evidence Review.

## Registration

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

## Classification

NCIC-ONS data are coded using the International Classification of Diseases system (ICD) version 10. This is based on a topographical description of tumour site and allows detailed coding of adult tumours. Cancers that develop in childhood are different from those in adult life. There is increased histological diversity and many tumours develop from embryonal tissue. The ICD is less able to code these tumours accurately, so an alternative classification based on histological characteristics has been developed. This alternative system, the International Classification of Childhood Cancer (ICCC), is used by the NRCT.

The needs assessment conducted for this Guidance was required to use ICCC. The existence of the two coding systems caused delays in data collection. Data for the 0–14-year-old age group were received from NRCT and were coded in ICCC. To allow production of comparable analyses of incidence in the 15–24-year-old age groups, the ICD-coded

NCIC-ONS data had to be converted into ICCC. As there is no nationally agreed conversion table between these systems, this process took time. ICCC-coded prevalence, mortality and survival data were not available for the 15–24-year-old age group within the time available.

## Aetiology

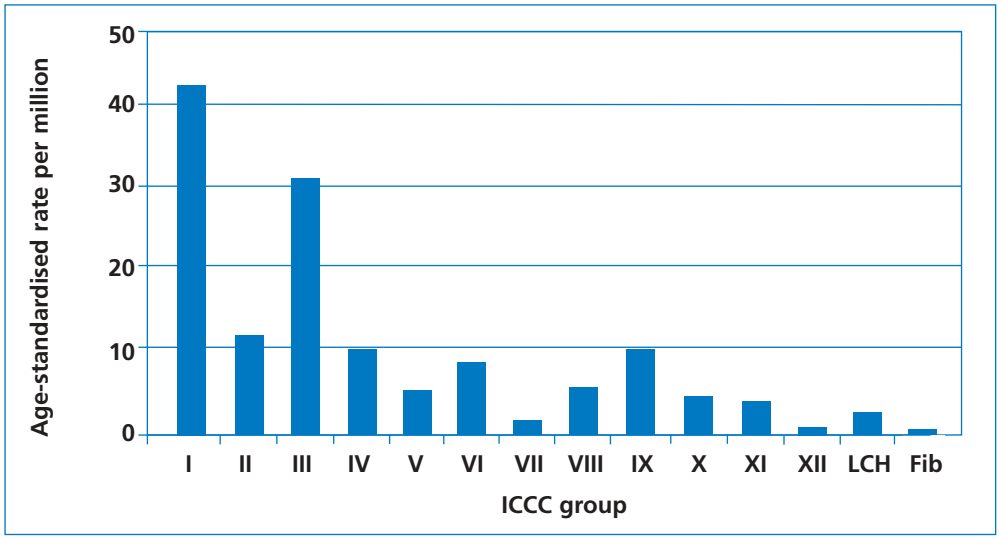
The identified risk factors for child and adolescent cancers account for only a minority of cases, so there is limited potential for preventive interventions. The identified risk factors for childhood cancer include genetics, infections, hormones and radiation.[1]

## Incidence

Cancers in children aged less than 15 years old are rare, causing less than 1% of all cancers in industrialised countries.[1] Data from 1981–1990[2] suggest an age-standardised annual incidence in England and Wales of 122 per million children. The NRCT gives a figure of 133.7 per million (for data between 1988 and 1997), but this includes a small number of non-malignant diagnoses.

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).

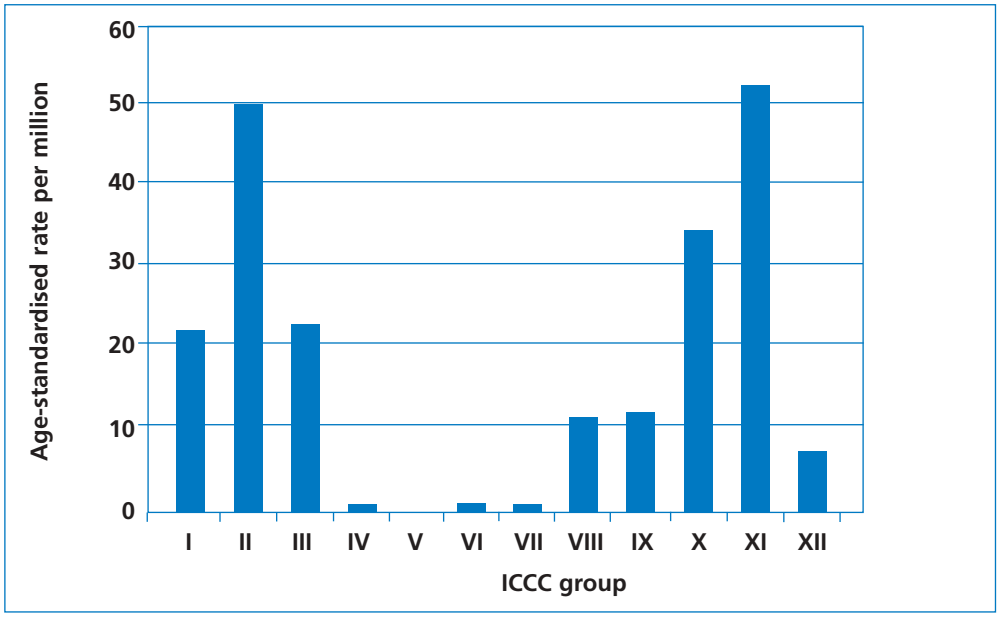
**Figure 2 Comparison of age-standardised incidence rates between the International Classification of Childhood Cancers (ICCC) groups and non-malignant conditions in children aged 0–14 years, per million population at risk (1988–1997).**




ICCC groups[3]
I. Leukaemia; II. Lymphoma and reticuloendothelial neoplasms; III. CNS and miscellaneous intracranial and intraspinal neoplasms; IV. Sympathetic nervous system tumours; V. Retinoblastoma; VI. Renal tumours; VII. Hepatic tumours;VIII. Malignant bone tumours; IX. Soft tissue sarcomas; X. Germ-cell, trophoblastic and other gonadal neoplasms; XI. Carcinomas and other malignant epithelial neoplasms; XII. Other and unspecified malignant neoplasms. LCH – Langerhans cell histiocytosis; Fib – fibromatosis.

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

**Figure 3 Comparison of age-standardised incidence rates between the International Classification of Childhood Cancers (ICCC) groups in persons aged 15–24 years old, per million population at risk (1988–1997).**




For details of ICCC groups, see Figure 2. Source: Office of National Statistics.

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

## Trends

An increase in the incidence of childhood and adolescent cancers has been demonstrated for a wide range of diagnoses. A study examining trends in childhood malignancy in the north-west of England (1954–1988) identified significant linear increases in acute lymphoblastic leukaemia and Hodgkin's disease.[5] Additional investigation identified a significant increase in chronic myeloid leukaemia. A related study found significant linear increases in juvenile astrocytoma in males, medulloblastoma and neuroblastoma in females, and non-skin epithelial tumours overall.[6]

In 15–24-year-olds, there have been significant increases in incidence from 1979 to 1997 across all diagnostic groups.[7] Significant increases occurred in the incidence of gonadal germ cell tumours, melanoma and carcinoma of the thyroid. Smaller increases occurred for lymphomas, CNS tumours, acute myeloblastic leukaemia and genitourinary tract carcinomas. Incidence rates calculated for this report show a rise in the incidence of carcinomas and epithelial neoplasms in the 20–24-year-age group that has resulted in this group replacing lymphoma as the most common group overall (ONS).

## Comparison of incidence with other countries

The Automated Childhood Cancer Information System (ACCIS) publishes comparative incidence data from European Cancer Registries. The 5-year (1993–1997) world-standardised incidence rate of all childhood cancers in England and Wales of 133.7 cases per million children is similar to rates in other European countries (Table 1). The incidence rates range from 127.3 per million in Ireland to 170.4 per million in Finland. Comparable data for adolescents and young adults are not available.

**Table 1 Five-year world-standardised incidence rates in 0–14-year-olds per million population at risk for all tumours for selected European countries (1993–1997).**

| Country | World-standardised incidence rate |
|---|---|
| Ireland[a] | 127.3 |
| Scotland | 130.1 |
| Germany | 130.9 |
| Hungary | 132.4 |
| England and Wales[b] | 133.7 |
| The Netherlands[c] | 138.9 |
| Northern Ireland[d] | 141.6 |
| Spain[c] | 143.7 |
| Iceland | 147.2 |
| Norway | 151.6 |
| Denmark | 158.1 |
| Finland | 170.4 |

Source: Automated Childhood Cancer Information System
[a] Data collection 1994–1997
[b] Data collection 1988–1997
[c] Data collection 1993–1995
[d] Data collection 1993–1996

## Variation of incidence with age

The incidence of malignancy varies with age, with a peak in the first 5 years of life[1] and lowest incidence in those aged 8–10 years.[8] Cancer is more common in adolescents (aged 15–19 years) than in children, with a reported incidence of 150–200 per million.[8] In young adults aged 20–24 years, the incidence is higher again at 226 per million.[7]

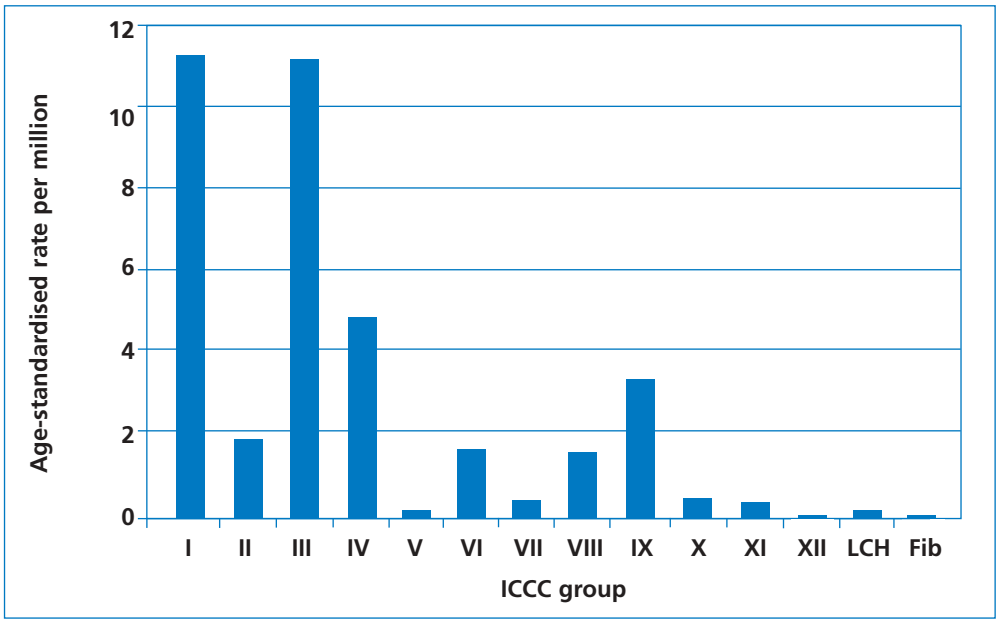
The type of malignancy also varies with age. Leukaemias, and brain and spinal tumours, are the most common malignancies of childhood[1] (NRCT). Epithelial neoplasms and lymphomas are the most common presentations in young adults and there is an increasing frequency of germ cell tumours and melanoma in this age group[7] (ONS).

For most malignancies of childhood, the incidence is greater in boys than girls with an overall ratio of 1.2:1.0.[2] Malignancies more common in girls include malignant melanoma and cancers of the breast, thyroid and genitourinary tract.[7]

## Mortality

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

**Figure 4 Comparison of age-standardised mortality rates between the International Classification of Childhood Cancers (ICCC) groups and non-malignant conditions in persons aged 0–14 years, per million population at risk (1988–1997).**




For details of the ICCC groups, see Figure 2. Source: National Registry of Childhood Tumours.

There are no ICCC-coded mortality data available for 15–24-year-olds.

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

## Survival

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

Improvement in survival rates has been attributed to advances in treatment and supportive care, centralising treatment to specialist centres and the inclusion of the majority of patients in national and international trials,[1,9] which has resulted in protocol-based management.

The paediatric section of the Eurocare 3 report[10] allows comparison of survival rates between 20 European countries in children aged less than 15 years at the time of diagnosis. It reports the weighted 5-year survival rate in England and Wales for those diagnosed between 1990 and 1994 to be 71.1%. This is higher than the Eastern European countries where the survival rate is reported to be between 63% and 66%, but lower than in Germany, Switzerland and the Nordic countries (except Denmark) where mean survival rate is 80%. ACCIS also publishes comparative survival data from European registries for those aged 0–14 years diagnosed between 1993 and 1997. This source quotes an overall survival rate of 73% for England and Wales, compared with 66% in Hungary and 81% in Iceland. This value for England and Wales is not significantly different from that in other European countries, apart from Finland and Germany. The differences in survival rates 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.

National-level survival data and comparative European survival data for 15–24-year-olds have not been published.

## Prevalence

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

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

## Late effects

With increasing survival, the physical, emotional and social sequelae, which may impair the quality of life in the long term, become more important. Although many of those cured of cancer during childhood or young adulthood will return to good health, others will experience significant late sequelae. These sequelae can occur at any time during or following completion of therapy. They include problems such as impairment of endocrine function (for some including infertility, abnormal growth and development or bone mineral accretion), cardiac and neurological impairment, cognitive decline (for example, following treatment for tumours of the CNS) and psychological effects

and increased risk of developing a second cancer.[11] On average, 4% of childhood cancer survivors develop a second primary malignancy within 25 years of diagnosis,[11] although for certain diagnoses this figure is higher.[12] Radiotherapy is a particular risk factor.[11,13] The risk of second malignancy, which can occur many years after the primary diagnosis, is estimated to be between four and six times the risk in the general population.[11,13]



## Key points

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.

Cancers in children and young people show a characteristic pattern of incidence that changes with increasing age. Leukaemia, and brain and spinal neoplasms, are the most common diagnoses in the 0–14-year-old age group. Carcinomas and epithelial neoplasms and lymphomas are the most common in the 15–24-year-old age group.

Overall survival rate is high (currently 75% in 0–14-year-olds), although disease-specific survival rates vary.

Improved survival rates are contributing to the increase in absolute numbers of survivors of childhood cancer, which has implications for service provision.

Although cancers in children and young people are rare, death from all causes is rare in these age groups, so cancer remains a very important cause of death in children and young people.

Issues of differential coding and data collection systems between those aged 0–14 years and those aged 15–24 years hampers the calculation of comparable rates and therefore definition of need in this population. For the purpose of producing comparative epidemiological analyses, synchronising the two coding systems would be ideal.

# Current services

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

## Cancer treatment

In England and Wales, care of children with cancer is offered and coordinated at 17 centres registered by the UKCCSG (see Appendix 3.1). Some children's centres have dedicated adolescent beds and there are also eight TCT units (see Appendix 3.2), which offer separate facilities for young people that are appropriate to their age.

Shared care centres are based in secondary care facilities and are affiliated to UKCCSG centres. The provision of services at shared care centres varies from initial diagnosis only to greater involvement in the delivery of care for children and young people with cancer.

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.

The results show that most centres have clinical oncology support, but only a minority have radiotherapy services delivered on site. Bone marrow transplantation services are changing, as a minimum number of procedures are now recommended to maintain clinical skills in a unit. Many centres undertake allogeneic bone marrow transplantation; others refer cases, as necessary, to a Joint Accreditation Committee International Society for Cellular Therapy–European Group for Blood and Marrow Transplantation (JACIE)-accredited centre. Eight of the 18 responses recorded access to paediatric neurosurgery services on site or within an 8-mile radius.

Most centres offer a range of allied health services such as specialist pharmacy, physiotherapy, occupational therapy and pain management, although access to these services may be limited.

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

### Supportive and palliative care

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

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

## Service use

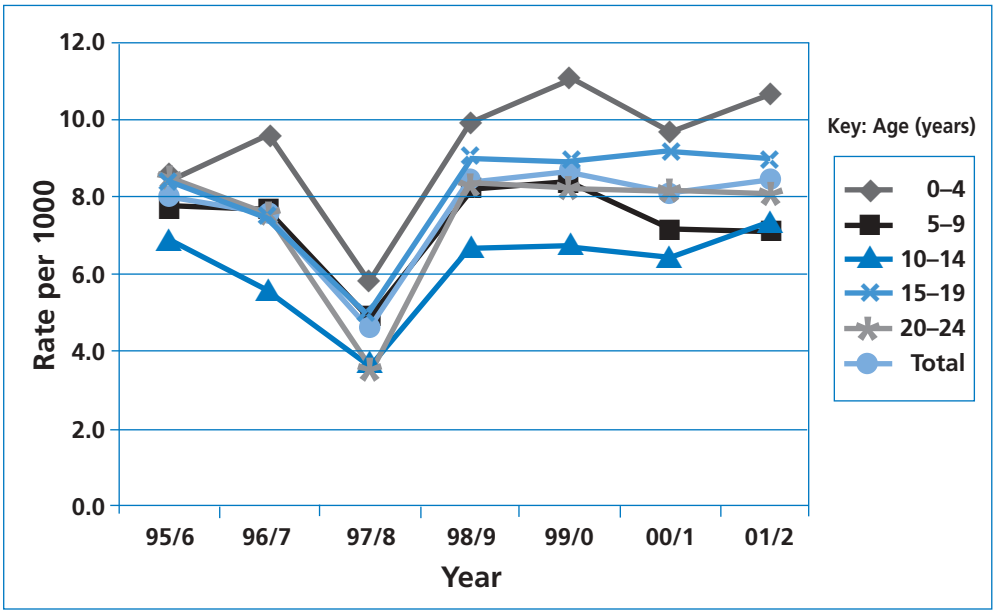
Use of services is measured by routinely collected hospital activity data. Between 1998/9 and 2001/2, there were an annual average of 3.7 total episodes per 1000 children and young people aged 0–24 years. Hospital episode rates decline with age, with the highest rates in the 0–4-year-old age group (5.0 per thousand children aged 0–4 years, 2001–2002) and lowest in 20–24-year-olds (2.7 per 1000).

There is a trend of increasing overall activity (1995/6 to 2001/2), which may, in part, reflect improved data collection. More intensive and complex treatments, greater use of clinical trial protocols, higher incidence of complications and improved survival rates all compound to increase activity levels. The data quality is poor in 1997/8 as a result of substantial under-recording of activity (B Cottier: personal communication 2004). Inpatient and day case activity are described below.

### Inpatient care

The highest inpatient bed-days rates are in the youngest age group (10.7 per 1000 children aged 0–4 years, 2001/2), reflecting the higher incidence of cancer in this group. Rates fall in 5–9- and 10–14-year-olds, but rise again from age 15 years (Figure 5). Overall, there is little trend in inpatient bed-days rates, except for a possible upward trend in the 0–4-year-olds. The mean number of inpatient bed-days between 1998/9 and 2001/2 was 82,000 per annum in 0–14-year-olds, 28,700 per annum in 15–19-year-olds and 25,000 per annum in 20–24-year-olds.

**Figure 5 Trends in the inpatient bed-days rate by year and age group, 1995/6 to 2001/2.**

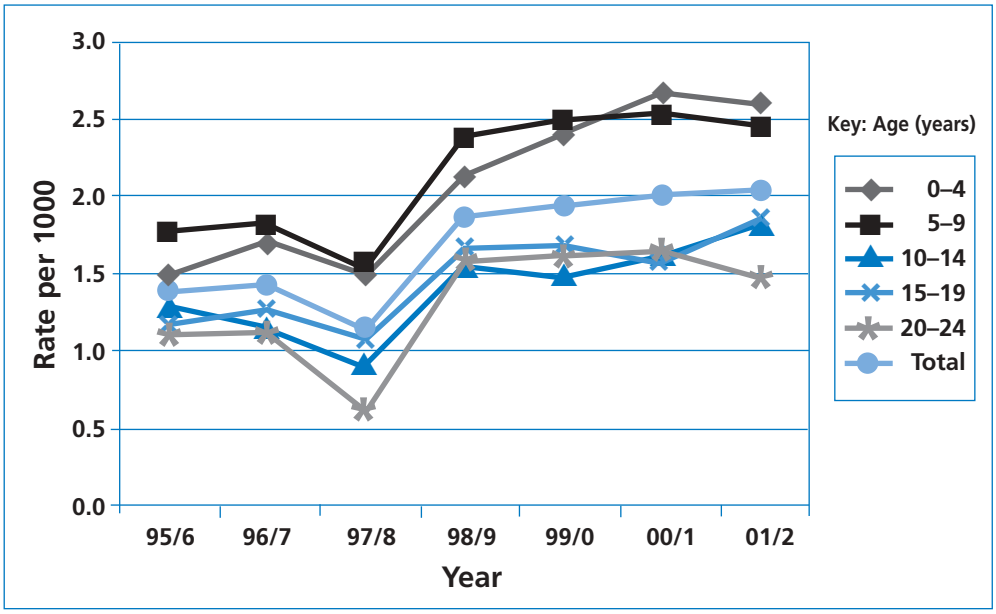



Data quality for 1997/8 was poor: activity was substantially under-recorded.

## Day case care

Use of day case beds rose considerably between 1995/6 and 2001/2 to a rate of 2.1 per 1000 children and young people aged 0–24 years in 2001/2. Figure 6 shows the variation in day case rates between age groups and the 0–4- and 5–9-year-old age groups consistently have the highest rates. The mean number of day case bed-days between 1998/9 and 2001/2 was 21,800 per annum in the 0–14-year-olds, 5500 per annum in the 15–19-year-olds and 4800 per annum in the 20–24-year-olds.

**Figure 6. Trends in the day case bed-days rate by year and age group, 1995/6 to 2001/2.**




Data quality for 1997/8 was poor: activity was substantially under-recorded.

## Procedures

The most commonly recorded procedures in childhood cancer patients are diagnostic and therapeutic spinal puncture for the management of leukaemia. Other common procedures include insertion of central venous lines, diagnostic bone marrow aspirate, and administration of chemotherapy and immunotherapy. The administration of chemotherapy is the commonest procedure, but is under-recorded because of inaccuracy and quality of coding.

Measures of activity aggregated at strategic health authority level show wide variation in episode rates, inpatient and day case rates. This may be due to variations in clinical practice, but is more likely to result from variations in clinical coding and other data quality issues. Further work is required to explore these findings.

## Palliative care

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. Using age-specific mortality from cancer as a proxy for need, 37.5 per million children aged 0–14 years would be estimated to require palliative care services. In the older age group, a report published in 2001 estimated an annual mortality rate for young people aged 13–24 years with life-limiting conditions to be slightly over 1.7 per 10,000.[14] Twenty-nine percent of these are due to neoplasms: equivalent to a rate of 49.5 per million in this age group.

## Allied health services

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 AHPs includes a sound grounding in the developmental aspects of childhood and adolescence and is considered to be an area of speciality in itself.

AHPs encompass a wide range of disciplines, including diagnostic and therapeutic radiographers, physiotherapists, occupational therapists, dietitians, and speech and language therapists. They support the individual's biological, psychological and social wellbeing and health, and can have a positive impact on the individual's potential for recovery, as well as successful maturation to adulthood. They have strong links to non-health services. Although not formally recognised as AHPs, other disciplines, such as play specialists, activity coordinators, sonographers and clinical pharmacists, have an important role in these services.

### Non-health services

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

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# The care pathway





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 1). 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.

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.

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

Although cancer has been considered in the three main groups, solid tumours, haematological malignancies and CNS malignancies, many issues are generic. Where issues are specific to the particular type of tumour, this is indicated.

# Presentation and referral

Cancer in children and young people is relatively rare. A general practitioner (GP) will see, on average, a child under 15 years old with cancer every 20 years. There is 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 some deaths occur either before the diagnosis is made or immediately around the time of diagnosis. Some of these deaths are potentially avoidable.

The NICE clinical guideline for GPs on *Referral Guidelines for Suspected Cancer* [60, Appendix 1] includes a section on children's cancer. Implementation of the recommendations in this guideline may help professionals in primary care to identify the rare patients at greater risk of having a malignant diagnosis.

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

Primary care trusts/local health boards should that ensure appropriate training is provided for the implementation of the recommendations in the NICE clinical guideline on *Referral Guidelines for Suspected Cancer* [60, Appendix 1] as they apply to children and young people. This provision 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.

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.

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. For children, in many cases this will be to a secondary care paediatrician in the first instance, but referral to another specialist or specialist centre may be appropriate and should be specified in the local arrangements. 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 that may occur and age-related needs. They should include the availability of telephone advice and named specialists.

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

## B. Anticipated benefits

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

## C. Evidence

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

The early symptoms of 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.

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

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*

### 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 ear, nose and throat (ENT) or orthopaedics
- training courses in primary care for implementation of the clinical guidelines

### Process

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

### Outcome

- clinical outcomes
- patient/parent/carer satisfaction

# E. Resource implications

The resource implications will primarily be in terms of specific education for health professionals, including postgraduate courses and continuing professional development (CPD). The estimated annual costs associated with training and education for CPD of the core staff for each principal treatment centre that treats children is considered in the resource implications in the section on workforce development.

Further calculations will be required at a network or local level to calculate the costs relating CPD for those staff employed at shared care centres.

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

Additional funding will be required to support access to telephone advice if no existing system is in place. The recommended staffing levels to provide a safe and sustainable service for children and young people are discussed in the resource implications in the section on place of care. This section considers staffing for all aspects of the guidance.

# Diagnosis



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, open surgical biopsy or bone marrow aspirate is required. Diagnosis also requires access to cytogenetics, molecular genetics and immunophenotyping. The process needs to be timely and efficient and requires a multidisciplinary approach.

In some instances, particularly in young people, collaboration with pathologists expert in particular tissues or systems will be necessary.

There is a recognised shortage of most of the disciplines involved in diagnosis, not only paediatric pathologists, paediatric haematologists and paediatric radiologists, but also laboratory staff and scientists.

## Pathology

Histopathological diagnosis of paediatric tumours can be difficult because of 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.

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 the other tumours that are increasingly common in teenagers and young adults (such as lymphomas, bone tumours and germ cell tumours) all require very specific expertise for their correct diagnosis and assessment.

The report from the Royal College of Paediatrics and Child Health *The Future of Paediatric Pathology Services* [78, Appendix 1] makes it clear that the speciality of paediatric pathology has severe shortages across the country. It makes the following recommendations:

- 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.

- 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.

- Paediatric pathology cannot be subsumed by general or other specialist pathologists without a further major reduction in both service and quality.

- 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.

Haematologists are responsible for the morphological diagnosis of leukaemia and for the reporting of bone marrow aspirates and trephine biopsies from patients with solid tumours. The spectrum of leukaemia in childhood is different from that in adults, so diagnosis and the ongoing assessment of response to chemotherapy are best provided by a paediatric haematologist with specific expertise. Children are at greater risk of CNS involvement with leukaemia, which requires specialised input for the preparation and assessment of specimens.

Young people with haematological malignancies need access to the same laboratory expertise as for solid tumours, including cytogenetics and molecular genetics.

## Imaging

Timely access to appropriately skilled diagnostic imaging, including nuclear medicine, is essential in evaluating children and young people with possible or confirmed malignant disease. Imaging in younger children and infants creates particular difficulties that mean that these procedures need to be carried out in centres with the appropriate expertise. A paediatric radiologist, trained in paediatric oncology imaging, is required in paediatric oncology centres.

Magnetic resonance imaging (MRI) 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. Computed tomography (CT) scanning is of value, but may be less sensitive for many tumours. Children and

young adults with malignancy often require serial imaging for the assessment of disease response and recurrent CT scanning may expose them to significant amounts of radiation.

The role of positron emission tomography (PET) scanning in managing these patients is not yet well established; the recent Department of Health (DH) Report, *A Framework for the Development of Positron Emission Tomography Services in England* [36, Appendix 1], does not specifically refer to their needs, although it does make clear that PET has a role in evaluating patients with malignant lymphoma, which constitute a significant proportion of patients in this age group. As it becomes more widely available, its specific indications within a paediatric setting will become clearer and its use is likely to increase.

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 also in the handling of the resulting tissue sample.

## A. Recommendations

Specialist paediatric histopathologists should be involved with the pathological diagnosis of solid tumours in children. Access to expertise in specific tumour site pathology should be available for the diagnosis of tumours in young people.

Specialist techniques such as immunohistochemistry, cytogenetics, molecular genetics or spinal fluid cytology should be available in all departments dealing with tumour samples.

Facilities for tissue/cells/DNA storage, in accordance with appropriate consent and tissue use guidelines, should be available.

Paediatric haematologists should be involved in the laboratory and clinical management of children with leukaemia and those undergoing haemopoietic stem cell transplantation (HSCT).

All laboratories dealing with leukaemias and solid tumours require appropriate quality-assured laboratory facilities and support for diagnostic and assessment purposes, and a number require facilities to store cells and DNA, taken with appropriate consent and within guidelines for the use of human tissue, for future research.

There should be systems in place to enable second opinions on pathological specimens to be obtained urgently from national and

international experts, including the lymphoma panel review as described in the NICE guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1]. This is particularly important while there is a current shortage of specialist paediatric pathologists and haematologists.

All children and young people with suspected bone sarcoma should be referred to a specialist bone sarcoma multidisciplinary team (MDT) with access to age-appropriate facilities.

Pathological specimens, suspected of being sarcoma, should be urgently reviewed for definitive diagnosis by a paediatric or specialist sarcoma pathologist or a pathologist with a special interest in sarcoma.

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

Commissioners should address the recommendations of *The Future of Paediatric Pathology Services* [78, Appendix 1].

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.

The provision of MRI scanning should be sufficient to ensure that suspected cases of CNS, bone and soft tissue tumours and other malignancies can be investigated rapidly.

## B. Anticipated benefits

Accurate and more rapid diagnosis will:

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

## C. Evidence

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.

There is consistent, but limited, evidence on the importance of specialist pathological review in reducing diagnostic inaccuracy. There is little direct evidence for the effect of accurate diagnosis and staging on outcomes.

The role of the diagnostic MDT is accepted as recommended practice in paediatric oncology. However, there is no direct evidence that such teams produce an improvement in outcomes.

The evidence for the optimum methods for the diagnosis of leukaemia is reviewed in the NICE guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1]; this evidence confirms the requirement for specialist pathological review to improve diagnostic accuracy.

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

## D. Measurement

### Structure

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

### Process

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

### Outcome

- patient satisfaction
- effect of diagnostic accuracy on patient outcomes

## E. Resource implications

Protected time for anaesthetic and surgical diagnostic sessions is likely to require additional funding. The guidance recommends that each principal treatment centre has available a minimum of 0.7 full-time equivalent (FTE) anaesthetists dedicated to children, costing approximately £67,000 per year. This provision would need to be met by two or more individuals. The costs relating to this recommendation are considered in full in the resource implications in the section on place of care.

Resources will be required to ensure that diagnostic haematological and pathological cytogenetic services can be accessed directly. The DH is currently modernising pathology services, and the workforce issues are being considered by The Cancer Workforce Initiative. It will take some time for these improvements to have an impact on current shortages. The guidance recommends minimum staffing levels for all staff employed at principal treatment centres, including paediatric pathologists and haematologists, to ensure that the service provided is safe and sustainable. Minimum staffing levels are considered in the resource implications in the section on place of care. The recommendation is for each centre for children with cancer to have available 0.5 FTE pathologist dedicated to children with cancer, comprising two or more individuals to cover holiday and sickness. Employment costs and salary plus on-costs would be about £48,000. It may be that in some principal treatment centres, an increase in pathology time may be required. In view of national shortages any additional staff may not be appointed immediately.

The provision of CT and MRI scanners will have capital, operational and staffing cost implications where access is limited. This will need to be considered by local commissioners. Costs relating to this aspect of the guidance have not been considered further as they are currently under review by the DH.

Additional costs will be incurred in some centres where the recommended staffing levels described in the resource implications in the section on place of care are not met. For instance, the suggested minimum staffing level for paediatric radiologists is 0.6 FTE with an approximate cost of £57,100 per centre.

# Treatment

Treatment describes those therapeutic interventions used directly for the management of the malignant condition. The medical treatment of childhood and adolescent cancers comprises three main modalities: surgery, chemotherapy and radiotherapy. Other modalities are also used, for example, stem cell transplantation. The relative use of each modality depends on the underlying diagnosis and, to some extent, the age of the patient. For instance, radiotherapy is whenever possible avoided in children under 3 years old, because it results in greater long-term effects.

## Chemotherapy

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 CNS 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.

There are a number of reasons why there are particular risks of error in giving chemotherapy to children:

- All doses have to be carefully calculated and prepared and fluid volume has to be tailored to the size of the child. Standard or upper dose limits are less relevant in children and there is a wide range of dosage, for example, methotrexate.

- Weight loss or gain can significantly alter the correct dosage, requiring close patient observation (this is also an issue for teenagers).

- Many drugs are not licensed for use in children, in particular the very young. Many are not routinely prescribed and treatment protocols are often very complex.

- Oral preparations may not be palatable or available to children and compliance may be difficult.

- Tablets may not be available in sufficiently small sizes, requiring portions of the tablets to be given or necessitating metronomic prescribing.

Most children and young people receive treatment administered in hospital under the direct supervision of health professionals. Parts of some treatment regimens can be administered safely at home, either by children's community nurses or by other health professionals or families. Some patients also receive prolonged outpatient-based oral maintenance chemotherapy, during which the issue of compliance is important.

Some cancer centres have a dedicated computerised chemotherapy-prescribing system. Other treatment sites rely on pre-printed paper-based systems.

There are national strategies in England and Wales for the introduction of computerised prescribing and electronic transmission of prescriptions (ETP).

## A. Recommendations

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

Chemotherapy should only be delivered in an environment capable of providing the predicted level of support required and should be appropriately resourced.

In order to deliver timely chemotherapy, in accordance with the patient's treatment protocol and avoiding unnecessary delay, a treating unit should have adequate capacity, with access to suitably equipped facilities for the preparation and administration of chemotherapy and a trained pharmacy support team.

All oncology units treating children and young people should be staffed with adequate numbers of appropriately trained staff to allow good communication and discussion on all aspects of treatment, and its effects and possible toxicity.

There should be written protocols covering the administration of chemotherapy agreed between the principal treatment centre and other treatment sites, and this should clearly define responsibilities and organisational arrangements. Clear accountability for the prescription and delivery of chemotherapy should be included in these protocols, with an agreed route for advice from the principal treatment centre in the event of chemotherapy-related problems.

There must be full compliance with current DH guidelines on the safe prescribing, dispensing and administration of intrathecal chemotherapy [32, Appendix 1].

All chemotherapy should be prepared by pharmacy technicians and monitored by pharmacists trained to national standards, and there should be adequate provision of facilities for the aseptic reconstitution of cytotoxic agents. A designated pharmacist should be part of the MDT in all care settings.

Where safe administration of chemotherapy in the home is possible, either by appropriately trained community nursing teams or families, this should be developed, supported and adequately resourced.

New methods of monitoring and improving methods of compliance in patients should be explored and encouraged, including the concept of concordance, which embraces partnership between patients and doctors in managing medicines.

Funding should be made available for provision and maintenance of EPS for chemotherapy.

## B. Anticipated benefits

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

Adequate preparation facilities and treatment capacity will avoid unnecessary delay and maximise treatment benefit.

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

Agreed protocols across cancer networks and within shared care arrangements, ensuring the safe administration of appropriate and timely treatment, should:

- result in better clinical outcomes in terms of response, survival and symptom control
- minimise complications and errors in the prescription and administration of chemotherapy
- improve patient and family confidence
- improve quality of life.

Reduction in risk may be achieved by:

- computerised prescribing
- patient-held records

- information for parents/carers and families
- training and education for staff in all care settings in which chemotherapy is given
- having a designated pharmacist as part of MDT.

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

## C. Evidence



There is good-quality evidence that electronic prescribing (e-prescribing) reduces prescribing errors, although there are no papers specifically concerned with children with cancer.

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

There is some evidence to suggest that compliance with taking oral anti-cancer drugs is not good in these age groups. 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.

The evidence on whether e-prescribing improves patient compliance with medication is inconsistent.

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

## D. Measurement

### Structure

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

### Process

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

### Outcome

- survival
- morbidity
- errors and near misses
- prescribing errors

## E. Resource implications

There will be resource implications for those principal treatment centres that do not currently meet the staffing levels recommended in this guidance to ensure a safe and sustainable service for the delivery of chemotherapy (see resource implications in section on place of care).

National initiatives currently in progress aim for all hospitals providing chemotherapy to have an e-prescribing system in place by 2006. The cost estimates for e-prescribing systems are between £0.15 and £0.25 million per centre. Further details are included in the Evidence Review. The costs are included for reference. It is not clear whether this expenditure is part of the cost implications of the guidance or should be considered as a cost relating to the national strategy for the whole of the NHS. As with other areas of the guidance it is suggested that cost considerations be taken at a local level.

### Surgery

The majority of children with solid tumours require surgery: either a biopsy to establish a diagnosis or surgical resection before or after chemotherapy as part of the definitive treatment. Many patients need surgery for other reasons, such as establishing and maintaining central venous access or the insertion of a gastrostomy tube to aid nutrition.

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.

Anatomical site specialisation is well developed for many adult cancers and specialist surgeons within these teams appropriately undertake the treatment of cancers in the majority of older teenagers and young adults. For younger children, the paediatric surgeon who specialises in oncology surgery is primarily responsible for the surgical aspects of care for many patients and participates in the paediatric oncology MDT. In addition, some children require surgery from a variety of other surgical specialists, for example specialists in thoracic surgery, ophthalmology, gynaecology, orthopaedic surgery, paediatric cardiac surgery, and head and neck surgery (which may be provided by a variety of surgical disciplines).

Following surgery, AHPs such as physiotherapists, occupational therapists, speech and language therapists, and dietitians can have a positive outcome on the return to functioning, 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

Diagnostic biopsy or definitive 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.

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

Theatre and anaesthetic sessional time should be adequately resourced for all surgical procedures, including diagnostic and supportive procedures, as well as other definitive tumour surgery. The paediatric surgeon with a commitment to oncology should have access to emergency theatre sessions during routine working hours.

The surgical management of tumours in children and young people should be discussed by the appropriate paediatric or specialist MDT, including preoperative discussion, in all cases except emergencies.

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

Surgery for non-rhabdomyosarcoma soft tissue sarcomas in teenagers and young adults should only be undertaken by a surgeon with appropriate expertise, and in age-appropriate facilities, after review at a designated sarcoma MDT.

Where possible, involvement of AHPs should be planned before surgery.

## B. Anticipated benefits

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

The evidence on the effect of specialist surgery on patient outcomes was inconsistent. 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.

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

## D. Measurement

### 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

### Process

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

### Outcome

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

## E. Resource implications

Protected time for anaesthetic and surgical treatment sessions, including emergency theatre sessions during working hours, is likely to have significant resource implications. The costs relating to minimum staffing levels for consultants and other staff are considered in the resource implications in the section on place of care.

### Neurosurgery

Skilled neurosurgery is perhaps the most important determinant of outcome in many CNS malignancies in children and young people. 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 (CSF) in the brain. Subsequent therapy is dependent on the condition of the child and the likely diagnosis, and is guided by the relevant national or international therapeutic protocols. About 4500 neurosurgical procedures are performed each year in England and Wales on children under 15 years old. Tumour work represents only 10% of this workload.

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 completely separate. The number of children and young people operated on also varies, with some centres seeing very few each year, while 4 units perform more than

400 and 13 units more than 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.

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



For all children and young people, there should be robust mechanisms to ensure that a neurosurgeon, neuroradiologist and oncologist are always available to discuss a given case before a major therapeutic decision is instituted, even if an actual MDT meeting is not possible due to the urgency of the case – the decision should be formally reviewed at the next MDT meeting.

Definitive surgery should be carried out by a surgeon experienced in paediatric CNS tumour surgery, or when necessary by a surgeon (for example, neurosurgeon, ENT, maxillofacial, spinal or trans-sphenoidal surgeons) with specialist skills for lesions in rare anatomical sites with the support of the paediatric team.

The definition of specialist expertise in paediatric CNS tumour surgery should be considered urgently.

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.

Basic neurosurgical training should allow, when necessary, adult surgeons to institute life-saving measures to enable paediatric patients to be stabilised before transfer to specialised paediatric units.

Children under 15 years old 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. Each centre should have a paediatric neuro-oncology nurse specialist.

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

## B. Anticipated benefits

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

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.

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

## C. Evidence

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

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

## D. Measurement

### 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

### Process

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

### Outcome

- outcomes with specialist paediatric neurosurgical care
- patient satisfaction

## E. Resource implications

Increased resources for salaries and training will be required to ensure that there are enough specialist paediatric neurosurgeons. Similarly, additional resources will be required for the training and provision of paediatric neuro-oncology nurse specialists. Staffing issues are included in the resource implications in the section on place of care and training issues are considered in the resource implications in the section on workforce development.

In some centres there may be resource implications for the provision of 24-hour care for children under 15 years old with CNS tumours in line with the guidance. This service is vulnerable to staff shortages and the implications for staffing are considered in the resource implications in the section on place of care.

Similarly, additional resources may be required for the training and provision of paediatric neuro-oncology nurse specialists. Further cost implications and details of minimum staffing recommendations are in the resource implications in the section on place of care.

### Radiotherapy

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 rate in patients with solid tumours and tumours of the CNS, but it is also part of the curative treatment of some lymphomas and leukaemias and plays a key role in palliating localised symptoms in patients with advanced disease. Total body irradiation is also used for myeloablation prior to HSCT.

It is essential that the patient remains still, sometimes for up to 25 minutes, during treatment with radiotherapy. Thus, there are particular challenges in 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.

Anatomical-site specialisation among both clinical oncologists and therapeutic 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.

Age-specific specialisation may be less appropriate for the management of many tumours in teenagers and young adults, for whom 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.

Therapeutic 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. They also enable maintenance of continuity of care during the planning and treatment period for the child and family.

## A. Recommendations

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

For some rare conditions radiotherapy is high risk, very complex or requires specialised equipment, and it should be commissioned from agreed supraregional, national or international centres. Such radiotherapy includes:

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

Radiotherapy should start as soon as possible after a decision to use it has been made and within the time frame specified by the relevant treatment protocol and the Royal College of Radiologists' guidelines, unless the patient is too ill to tolerate planning or therapy. There is an unavoidable period of delay before complex, radical radiotherapy can be started because of the logistics of the manufacture of customised immobilisation devices and the use of three-dimensional conformal planning, but delays for other reasons should be minimised.

## B. Anticipated benefits

Improved outcomes and reduced treatment-related morbidity.

Improved compliance with treatment.

## C. Evidence

There is no high-quality evidence that provision of specialist radiotherapy facilities and support improve clinical outcomes in children and young people. However, the recommendations are consistent with the generally agreed move to subspecialisation in clinical oncology outlined in the Calman–Hine Report [23, Appendix 1] and in the publications of the Royal College of Radiologists and the Society and College of Radiographers. The resource requirements are also consistent with those outlined by the UKCCSG.

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

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

There is some evidence from the literature that delays in radiotherapy may affect tumour control in patients with sarcomas and high-grade gliomas, but the impact of delays in therapy have not been assessed systematically and have not been analysed for most indications of radiotherapy in children, particularly for more recently established protocols using reduced-dose radiotherapy. Therefore, it is important to ensure that radiotherapy is delivered within the time frames specified in the relevant protocol, unless the patient's condition precludes this.

**Table 2 Core components of radiotherapy centres treating children and young people with cancer.**

- More than one consultant clinical oncologist with appropriate subspecialisation in paediatric radiotherapy, including membership of the UKCCSG, and programmed activities for paediatric radiotherapy specified in the job plan, to enable consultant cross-cover arrangements
- Integration of the consultant clinical oncologists as core members of the paediatric oncology multidisciplinary teams (and therapeutic radiographers where appropriate)
- Availability of clinical oncologists with declared subspecialisation in the tumour-types common in young people
- A lead therapeutic 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, three-dimensional computerised planning and treatment delivery systems)
- Access to paediatric anaesthetists, operating department assistants (ODAs) and nurses with paediatric recovery training, with modern facilities (including full resuscitation) and recovery area on site
- Policies and procedures for the safe supervision of children receiving sedation or anaesthesia
- Support of a play specialist
- Age-appropriate support facilities and staff with appropriate training for this specialised field
- Clinical protocols agreed with principal treatment centre
- Compliance with nationally agreed quality assurance standards
- Compliance with nationally agreed waiting times
- Participation in clinical trials

## D. Measurement

### Structure

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

### Process

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

### Outcome

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

## E. Resource implications

Increased resources will be required at some centres for the training of, and to ensure access to, paediatric radiographers and clinical oncologists. The suggested minimum staffing level for consultant oncologists with expertise in paediatric radiotherapy is 0.7 FTE with an approximate cost of £66,700 per centre. It is further recommended that these consultant posts are staffed by at least two individuals.

# Supportive care

Supportive care is the term for interventions used to support the patient through the anti-cancer 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.

The management of issues such as pain and fatigue is also important for children and young people with cancer. When input is provided at the right time, it can facilitate home discharge and benefit the health and wellbeing of parents/carers, as well as the patient.

### Febrile neutropenia

Neutropenia is a frequent side effect of chemotherapy. The patient is vulnerable during this period to potentially life-threatening infections. Febrile neutropenia (FNP) 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.

Episodes of FNP in children and young people 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

There should be a written protocol for the management of FNP in all patients having chemotherapy. When care is shared across treatment sites, this protocol should be agreed between the principal treatment centre and other treatment sites and should include provision for the urgent transfer of sick patients when required. The protocol should be available in all relevant clinical areas, including wards and accident and emergency (A&E) departments.

The protocol should be informed by guidance for the management of FNP in children and young people with cancer; it should be developed nationally.

Any unit providing chemotherapy should ensure it has sufficient capacity to allow admission of a child/young person to a bed with:

- appropriate infection-control facilities as recommended in the NICE guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1]

- staff, both medical and nursing, trained in the management of FNP and its complications
- levels of staffing reflecting the requirements set out in *Defining Staffing Levels for Children's and Young People's Services* [72, Appendix 1].

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

Patients receiving chemotherapy and parents/carers should have education, including written information, on the importance of seeking appropriate medical attention in a timely fashion and how that care can be accessed.

There should be an agreed route of referral in the event of a FNP 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.

National research is required for:

- the development of robust methods of risk stratification in the management of FNP
- the exploration of the safe introduction of shorter periods of inpatient admission and/or community-based therapy for low-risk episodes
- the prevention of FNP
- the use of antivirals and antifungals.

## B. Anticipated benefits

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

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

Reduction in duration of hospital admission for some patients.

## C. Evidence

There are no UK guidelines for the management of FNP.

The evidence from three randomised controlled trials (RCTs) on the outpatient treatment of FNP episodes is inconsistent. There are two good-quality guidelines (both from the USA) that conclude that some selected patients may be treated as outpatients.

There is one systematic review and one prospective cohort study that indicate that there are clinical features and laboratory measurements 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

### Structure

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

### Process

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

### Outcome

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

# E. Resource implications

Management of FNP in children and young people in line with the guidance may have resource implications. This has not been specifically costed, but is not thought to be great.

### Central venous access

Children and young adults requiring venous access for chemotherapy, radiotherapy and supportive treatment for cancer often need central venous access devices. This need is greater compared with 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.

However, central venous catheters (CVCs) are associated with significant morbidity and, sometimes, mortality. Therefore, attention to detail in the choice of device, method and timing of insertion, post-insertion care, maintenance and removal is essential. CVCs may be inserted by a surgeon, radiologist, anaesthetist or nurse specialist depending on the type of device required. Removal of CVCs is potentially hazardous.

# A. Recommendations

Insertion of CVCs should be done in an area designed for clean surgical procedures, usually an operating theatre with image-intensifier or intra-operative ultrasound, or an interventional radiology suite. Sedation and local anaesthesia are required for young people. General anaesthesia is usually necessary for children and may be necessary for many in the older age group. An appropriate number of theatre sessions should be available. For most centres this will mean at least one dedicated operating list per week; in larger centres more than one list per week will be required.

Removal of CVCs should only be done by trained personnel in an appropriate setting. Provision of sedation and anaesthesia, similar to that described above for insertion of CVCs, is usually necessary.

There should be written guidance on the management of central venous access devices, including expert advice on the type of vascular device, which is consistent across treatment settings. All healthcare professionals involved in accessing these devices in patients should be trained and assessed as competent. The inserting practitioner should be appropriately trained and experienced and should maintain that experience.

Where appropriate, patients and parents/carers should be involved in choosing the type and siting of central line and provided with the information needed to inform that choice.



## B. Anticipated benefits

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 CVCs
- reduce infection and other complication rates, including late effects due to vascular occlusion
- reduce pain and distress for patients and parents/carers
- improve continuity of care
- reduce interruption of chemotherapy regimes
- reduce hospitalisation
- promote confidence in families in the clinical competence of the health professionals providing care.

## C. Evidence

There is a great deal of observational evidence on the optimum method of central venous line insertion.

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.

There is good evidence from RCTs 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.

There is some evidence to suggest the use of two-dimensional 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

### Structure

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

### Process

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

### Outcome

- complication rates, particularly incidence of CVC-associated infection

## E. Resource implications

Costs of dedicated theatre time to ensure procedures for safe insertion and removal of CVCs for children were not available from Trusts; this will have cost implications for some principal treatment centres. The National Tariff does not include costs for CVC insertion as a separate procedure: more usually it is included as part of other procedures.

## Blood product support

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 blood 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.

Hospitals will have a transfusion committee, which will produce local guidelines and oversee appropriate and specific training of all staff involved in the management and use of blood products support and report adverse transfusion events to the Serious Hazards of Transfusion (SHOT) Scheme.

# A. Recommendations

There should be a written protocol for the management of blood product support. It should be agreed between the principal treatment centre and any other treatment sites and be available in all relevant clinical areas.

Medical and nursing staff should have timely access to blood products at all times, including outside normal working hours.

Medical, nursing and laboratory staff at all treatment sites should be aware of the special transfusion needs of children, in particular the indications for the transfusion of cytomegalovirus (CMV)-screened, irradiated, virus-inactivated blood or blood products.

# B. Anticipated benefits

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

# C. Evidence

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 the use of non-UK-sourced plasma for children born after January 1996.

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

## D. Measurement

### Structure

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

### Process

- protocol and guideline compliance
- transfusion errors

### Outcome

- morbidity and mortality of transfusion errors

## E. Resource implications

The recommendations on blood product support are not expected to have significant resource implications.

### Pain management

Effective pain management is essential in many aspects of the management of children and young people with cancer. There are different types of pain that 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 World Health Organization (WHO) guidelines for cancer pain relief and the use of the 'analgesic ladder' are well established and help to ensure systematic practice in pain control.

A particular issue in the treatment of children with leukaemia is a need for regular procedures that are painful, such as lumbar puncture and bone marrow biopsy. Most children require general anaesthesia for these procedures.

Play, 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 specialists 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

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

Ready access to specialist multidisciplinary pain services should be available for advice and support in complex pain management.

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.

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

## B. Anticipated benefits

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

## C. Evidence

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

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

## D. Measurement

### 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

### Process

- delays in providing adequate pain relief

### Outcome

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

## E. Resource implications

The only aspect of these recommendations that is likely to have significant cost implications is the provision of appropriate numbers of play therapists, activity coordinators and child psychologists, and addressing their training and education needs (see resource implications in the sections on workforce development and on place of care).

### Management of nausea, vomiting and bowel disturbance

Nausea, vomiting and change in bowel habits are among the most distressing side effects of cytotoxic chemotherapy. Nausea and vomiting vary with the emetogenic potential of the drugs and individual susceptibility. Diarrhoea is a side effect of many drugs and also occurs as a result of immunosuppression. Constipation is also a common symptom. Advances in the management of these symptoms have occurred with the more effective use of improved drugs and evidence-based multidisciplinary protocols.

There are other causes of nausea and vomiting, which require assessment and appropriate management, for example, radiotherapy and symptoms within the palliative phase.

Non-pharmacological approaches to the management of nausea and vomiting are also available. Children and young people can be helped in the management of anticipatory nausea and vomiting through play and the use of techniques such as distraction, or the use of cognitive behaviour therapies such as relaxation and guided imagery to enhance coping skills. Many patients undergoing active chemotherapy and suffering from severe diarrhoea require inpatient management.

## A. Recommendations



There should be written protocols for the management of chemotherapy- and radiotherapy-induced nausea and vomiting and bowel disturbance. If care is shared across treatment sites, these protocols should be agreed between the principal treatment centre and other treatment sites. The protocol should also be available in all relevant clinical areas.

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

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

## B. Anticipated benefits

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

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

## C. Evidence

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

## D. Measurement

**Structure**

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

**Process**

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

## E. Resource implications

The only aspect of these recommendations that is likely to have significant cost implications is access to occupational therapists and psychologists (see resource implications in sections on the workforce development and on place of care).



### Nutrition

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.

There are different modalities for delivering nutritional support, all of which require access to appropriate personnel and facilities.

## A. Recommendations

Nutritional support, enteral or parenteral, should be designed to provide adequate protein, energy, vitamins and minerals for all children and young people, taking into account their age, condition and treatment, and should be adequately resourced across treatment settings, including home-based enteral feeding.

Training in the field of general paediatrics should be provided for dietitians before working in oncology with children.

Training, recruitment and retention of specialist dietitians should be funded.

Staff of relevant disciplines should adhere to agreed national professional guidelines on nutritional support.

## B. Anticipated benefits

Adequate and effective nutrition will speed recovery, reduce the chance of prolonged nutritional problems and improve general wellbeing.

Children with cancer will have their nutritional needs met by dietetic involvement.

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

## C. Evidence

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

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

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

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

## D. Measurement

### Structure

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

### Process

- numbers of trained dietitians working in this service area

### Outcome

- nutritional status of patients

# E. Resource implications

The only aspect of these recommendations that is likely to have significant cost implications is employment and training of dietitians (see resource implications in the sections on workforce development and on place of care). There should be a minimum of 1 FTE dietitian at each paediatric principal treatment centre and at least 0.8 FTE dietitian in centres where young people are treated. The employment costs of these core staff members are expected to be about £57,000 per annum. This is considered in full in the resource implications in the section on place of care.

## Oral and dental care

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.

There is variation in oral care practice between centres with regard to preventative therapies and dental check-ups. National evidence-based guidelines for oral care for children and young people being treated for cancer is being developed. Children are often referred back to their general dental practitioner (GDP) after completion of their cancer treatment.

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.

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.

National evidence-based guidelines for oral and dental care are being developed and will inform care in this area.

## A. Recommendations

There should be special provision of emergency dental treatment for children and young people who have teeth with poor prognosis before the start of chemotherapy.

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

A named dental professional, identified by the principal treatment centre, should coordinate care throughout the care pathway, including transition to adult care.

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

There should be support for young adults who no longer qualify for free NHS dental care in general practice, but have dentition at risk because of treatment.

## B. Anticipated benefits

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

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

## C. Evidence

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

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

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

## D. Measurement

### 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

### Process

- compliance with treatment protocols
- access for patients who require dental follow-up post treatment

### Outcome

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

## E. Resource implications

Funding will be needed in some areas to ensure that each principal treatment centre has the recommended dental services, including an emergency service and a named dental professional available to coordinate care. This has not been formally costed.

# Rehabilitation

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. An important part of rehabilitation is the active role played by the patient and their families/carers. The requirements for rehabilitation fluctuate and can be urgent.

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.

*The National Service Framework for Children, Young People and Maternity Services* [35, Appendix 1] and the *Children Act 2004* [102, Appendix 1] recommend the use of the Common Assessment Framework for multi-agency assessment and support of children and young people.

The WHO model, the *International Classification of Functioning, Disability and Health* [113, Appendix 1], is suitable for considering the strengths and needs of children and young people with cancer, across all professional disciplines. The need for early referral to specialist care (for example, endocrine) for high-risk patients is also important.

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. Multi-agency liaison is important to avoid such delays.

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 neuro-rehabilitation 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 (including neuropsychology) are all disciplines that contribute, although this list is not exhaustive.

## A. Recommendations

There should be clear, agreed routes of referral for rehabilitation, including self-referral, throughout the patient pathway. These routes should be agreed across cancer and children's networks. Rehabilitation should extend into the community setting, where the involvement of community paediatricians may be beneficial.

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

An appropriate key worker should be assigned to each patient during rehabilitation.

Cancer networks should liaise with other NHS Trusts, primary care trusts/local health boards and other agencies to establish robust rehabilitation equipment strategies and strategies for psychosocial support and for communication with education services.

Training courses should be established to meet the CPD needs of AHPs working in oncology services for children and young people across all service settings.

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.

Additional investment is needed to support both clinical and health services research into the rehabilitation of these patients and this should be coordinated nationally.

Adequate funding for rehabilitation equipment should be provided.

## B. Anticipated benefits

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, for example, respiratory infection
- restore function, for example, following amputation or surgery
- promote normal developmental progression in the younger patients

- minimise the effects of neurological sequelae following CNS treatments
- maximise skill development and adaptive behaviour following treatment for CNS conditions.

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.

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

Children, young people and their parents/carers would receive a higher standard of care and support with a work force that is up to date, experienced and able to respond with sufficient availability of staffing resources.

## C. Evidence

The evidence available in this area is generally of poor quality. Evidence from other areas of paediatric rehabilitation cannot always be extrapolated due to the nature of the conditions concerned.

The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1] provides comprehensive evidence for effective rehabilitation services for adults with cancer and some of the recommendations can be extended to address children and young people with cancer.

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.

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

## Structure

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

## Process

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

## Outcome

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

## E. Resource implications

Minimum staffing levels for AHPs, play therapists, speech therapy, social workers and clinical psychologists to support all aspects of the guidance are considered in the resource implications in the section on place of care. It will be for local commissioners to decide if additional staff will be required in each principal treatment centre. Costs relating to the CPD needs of AHPs are considered in the resource implications in the section on workforce development. Rehabilitation occurs in different settings and costs will be incurred across these. There may be resource implications to ensure adequate provision of rehabilitation equipment, but it has not been possible to cost this.

# Psychosocial care

Psychosocial care comprises the psychological and social supportive care for a child or young person and his/her family during active cancer therapy, long-term follow-up and palliative care, as well as for families after bereavement, and includes respite care.

The diagnosis of cancer in a child or young person often throws a family into crisis. The patient faces the challenge of the disease, its symptoms and the side effects of treatment. Many children and young people experience significant problems with body image, relationships with peers and potential partners, difficulties with schooling and other education, or with employment. The family experiences the shock and grief of a child faced with a life-threatening illness and they too will have significant psychosocial needs.

There are also many practical issues for families to face during the treatment, such as difficulties with work, increased costs due to travel (including hospital parking), living away from home, increased family stress, caring for other siblings, anxiety and depression in other members of the family. Access to information on these issues (for example, Hospital Travel Costs Scheme and other transport concessions) is important.

The provision of appropriate psychosocial support to children, young people and their families is complex and multidimensional. Multi-agency patterns of support are required. The provision of support from social care professionals has relied heavily on voluntary sector funding.

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

Psychological services have an important role to play at all stages along the patient pathway, including after completion of treatment and into adult life.

Young people may require occupational advice. An occupational therapist, often in conjunction with other services outside of health, such as social workers, careers organisations and educational establishments, can support individuals to maximise their physical, emotional, cognitive, social and functional potential.

2

# A. Recommendations

All children and young people with cancer and their families, in particular siblings, should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed.

There should be access to expert psychological support with clear routes of referral in principal treatment centres and other treatment settings. This should include identified psychologists or other members of psychological services with expertise in the care of children and young people with cancer. It is important that use is made of existing services and that access to these is facilitated.

A structured psychosocial assessment at significant points throughout the care pathway should be provided, including:

- at diagnosis
- during treatment
- at end of treatment
- during long-term follow-up
- at relapse
- during palliative care
- at bereavement.

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

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

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

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

Commissioners should consider the needs of children and young people with cancer when developing psychological support services. All families of children diagnosed with cancer should be offered benefits advice by a benefits/welfare rights specialist at the time of diagnosis, as recommended by the NICE Guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1].

## B. Anticipated benefits

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

Access to a social worker and/or benefits/welfare rights specialist would ensure equity of access to benefits and external community support.

## C. Evidence

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

There are good-quality UK guidelines, surveys and consensus to indicate the various constituents of a good psychosocial service and illustrate the importance of clear medical treatment plans and referral routes.

The published NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1] provides recommendations for psychosocial service provision for all cancer patients. The guidance also recommends that cancer networks have a pivotal role to play in service provision for children and young people with cancer.

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

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

## D. Measurement

### Structure

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

### Process

- delays in provision of psychological services

### Outcome

- outcomes with psychological input
- patient and parent/carer satisfaction

## E. Resource implications

The provision of social care professionals' services has relied heavily on voluntary sector funding, largely through Sargent Cancer Care professionals at £2 million per annum. Additional funding for expert psychological and neuropsychological support will be necessary where the existing provision is inadequate (see resource implications in the section on place of care).

# Long-term sequelae

More than 1200 survivors of childhood cancer become eligible for long-term follow-up each year in the UK and the number of patients needing this service will steadily rise with improvement in survival rates.

The risk of sequelae is dependent on the treatment received, the age of the patient at diagnosis, the gender, and the time since completion of therapy. The late effects of therapy are well recognised and involve most organ systems. Of particular importance is the effect on fertility, with approximately 15% of patients having a high risk of early and irreversible gonadal failure. Cardiac, endocrinological, psychological, neuropsychological and neurological late-effects are also common. Some patients will have a second malignancy.

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. A significant number 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.

Groups anticipated to develop significant adverse effects include those with CNS tumours and those who have received high-dose chemotherapy or body/chest/cranial/pelvic radiotherapy, particularly if they are very young.

Most patients enter long-term follow-up at 5 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 specialist with an understanding of the patient's previous disease and therapy.

Thus coordination and communication across MDTs are very important.

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

Each principal treatment centre should have at least one clinician with expertise in the management of the late sequelae of treatment for children and young people with cancer.

Some patients have complex long-term problems, so their care should be provided by an MDT of doctors, nurses and AHPs. The MDT should usually include an oncologist, endocrinologist, a specialist nurse and other medical specialists as appropriate (see Table 5).

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.

Clear lines of communication should be established with appropriate specialities such as endocrinology, gynaecology and reproductive medicine.

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

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

Care plans should be devised for each survivor, in partnership with the patient/carer, as they enter long-term follow-up in accordance with national guidelines. A summary of treatment received and complications experienced should be available to the patient and healthcare professional. This should include details of the total doses of chemotherapy, details of radiotherapy and surgery, and information on existing or anticipated late effects.

The potential risk of infertility should be considered by the treating oncologist, and there should be fertility advice by appropriately trained personnel for all patients and/or their families at the time of diagnosis and referral to an Assisted Reproduction Treatment Unit as appropriate. There should be access to semen storage for peripubertal and postpubertal boys. The issue of egg storage is currently being researched. Further advice is necessary as children mature and patients should have access to appropriate endocrine and fertility services in accordance with the NICE Clinical Guideline *Fertility: Assessment and Treatment for People with Fertility Problems* [62, Appendix 1].

There should be early and prompt diagnosis and treatment of any therapy-induced sex steroid deficiency.

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

Training and clinical facilities are required to increase the number of clinical staff available to allow the management of late sequelae.

## B. Anticipated benefits

Early identification and appropriate assessment and treatment of problems with growth, development, sexual and reproductive health are important in preventing later morbidity.

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.

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

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.

Evidence of the morbidity that occurs in these patients has been recently published in the Scottish Intercollegiate Guidelines Network (SIGN) Guidelines and the position paper for this Service Guidance. A recent large retrospective cohort study, The Childhood Cancer Survivor Study (see the Evidence Review) of 20,346 childhood cancer survivors has determined the prevalence of many of the late effects in these survivors. A similar population-based study is underway in the UK, based on approximately 14,000 survivors: this will further determine the extent of the healthcare needs of this patient group.

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

## D. Measurement

### Structure

- evidence of care plans for all patients
- 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 at the appropriate time
- good communication networks

### Process

- appropriate follow-up of patients at risk of late effects

### Outcome

- treatment outcomes such as morbidity and mortality

## E. Resource implications

Fully staffed MDTs, including doctors with specific expertise, nurses and AHPs, need to be resourced for the follow-up and management of long-term sequelae in patients.

Resources may be necessary to identify and support appropriate key workers.

# Palliative care

Palliative care involves care of the patient from the time when therapy is no longer given with curative intent. It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. Its core elements are given in Table 3. Many of these core elements are equally applicable throughout the care pathway.

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.

Childhood death is a rare experience for many healthcare professionals, particularly in primary care. Access to specialist paediatric palliative care expertise from the oncology team, often from the paediatric oncology outreach nurse specialist (POONS), for end-of-life care is essential. Those professionals providing palliative care to children with cancer are expected to be part of a wider paediatric palliative care network. Community children's nursing services provide much of the care for those dying at home, but provision is variable across the country. GPs need to be kept fully informed and many play an active role during this phase of care. Where hospices exist, they also provide an important resource and an alternative choice in place of care.

There are very few dedicated services for teenagers and young people. In many centres POONS undertake/coordinate the palliative care of young people into their twenties. Some children's community nursing services do not accept referrals for patients over 16 years old. Adult Macmillan nursing services do not generally have experience in caring for this age group. There is at present very limited hospice provision for young people.

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, including provision of specialist equipment
- Expert symptom management, including radiotherapy and chemotherapy
- Access to 24-hour specialist advice and expertise
- Emotional, spiritual and practical support for all family members
- Respite care, with medical and nursing input, when required

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.

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.

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

# A. Recommendations

To ensure there is equitable access to palliative care, which encompasses the core elements in Table 3, there should be a paediatric palliative care network that has:

- a comprehensive community children's nursing infrastructure
- MDTs
- 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 a palliative care nurse or medical consultant (one per principal treatment centre)
- appropriate links with voluntary services and other statutory children's services, including local children's clinical networks
- appropriate medication and specialist equipment should be available. Sensitivity should be shown to a family's needs and wishes with regard to the introduction and later removal of equipment.

Teenagers and young adults with palliative care needs require special provision, again encompassing the core elements in Table 3, which will often entail the development of partnerships between children's and adults' services. These patients require individual packages of care that:

- recognise teenagers and young adults as a distinct group with special needs
- give full involvement in all aspects of decision-making
- are provided by multidisciplinary, multi-agency 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.

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

There should be sufficient numbers of medical and nursing specialists, the majority of whom are POONS, to provide 24-hour advice and support to families and to local health and social care professionals when patients are receiving palliative care.

Hospice and respite services for teenagers and young adult patients, whose needs are very different from those of younger children, should be developed.

Children's hospices represent an important potential resource for children with cancer and their families. Information on local hospice provision should be given to families in a timely and considered fashion, so that they can decide whether these services will help to meet their care and support needs.

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

Support from a member of the psychological services should be available in all areas and there should be clear lines of referral.

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

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 undertaken for young people. This should lead in turn to national guidelines in paediatric and young people's palliative care.

In view of the lack of high-quality evidence on services for palliative care for children and young people with cancer, further research in this area should be encouraged.

## B. Anticipated benefits

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

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

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

Appropriate services will be available to:

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

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

## C. Evidence

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.

The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1] provides good-quality evidence for the requirements of a palliative care service for adults.

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 POONS.

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

### Structure

- written policies to inform referral for palliative care
- availability of appropriate and adequately staffed palliative care services in hospitals and the community, particularly in the home setting

- availability of 24-hour telephone support and effective information services
- availability of respite services

### Process

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

### Outcome

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

## E. Resource implications

Resources may be required to ensure that palliative care key workers, such as POONS, can provide coordinated and integrated care and 24-hour advice and support to families and to local health and social care professionals. These services rely on having adequate staffing levels as detailed in the resource implications in the section on place of care.

Although relatively few children and young people with cancer are cared for by hospices, either children's or adults', there may well be costs associated with this service. It was not possible to give reliable estimates of these costs.

Provision of a comprehensive community children's nursing infrastructure and further research on services for palliative care for children and young people with cancer will have cost implications, but it has not been possible to formally cost these.

# Bereavement

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 death. Death usually occurs at home, following a period of palliative and terminal care, but may also occur in hospital. Less commonly, death may occur during treatment, either in hospital or at home. Bereavement support frequently begins during terminal care. Wherever death occurs, families need unhindered access to a senior member of staff, preferably one experienced in bereavement advice.

Following the Redfern Report in 2001 [103, Appendix 1], many Trusts have a bereavement coordinator who takes the lead or supports nursing staff in this role. At home, families are usually supported around the time of death by their POONS or children's community nursing team. Support may also be provided by an oncology social worker.

Specific issues to be considered following death, particularly when it occurs in hospital, include:

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

Many families are able and wish to take the lead in the arrangements after their child's death. Appropriate information and support should be available to assist them in this process if needed, with an awareness of the family's spiritual and cultural practices.

Access to spiritual care at this point is often of particular value. However, it is important to recognise that access to such support may be of relevance to many families throughout the care pathway. Support from a psychological services professional at this time may also be of value not only for children, young people and their families, but also for professionals.

# A. Recommendations

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

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 receive informed and sensitive support in decision-making.

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

Services should be tailored and responsive to the needs of individual families, including spiritual and cultural needs.

Support and supervision should be available for all staff involved in the death of a child or young person.

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

# B. Anticipated benefits

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

A clearly identified source of support will be available at a particularly vulnerable time.

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

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

## C. Evidence

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

## D. Measurement

### Structure

- provision of readily accessible bereavement services

### Process

- bereavement services provided

### Outcome

- effect of bereavement advice on quality of life of parents/carers and siblings
- parent/carer satisfaction

## E. Resource implications

Additional funding may be required to ensure that all families that have experienced the death of a child or young person have access to specialist bereavement support. The recommendations on specialist bereavement support are not expected to have significant resource implications.

# Service organisation



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.

Services need to be commissioned across all levels of care and seen as a whole system across community and hospital settings. Successful outcomes are dependent on both effective cancer services and effective services for children and young people. The position of these services with regard to commissioning frameworks is variable and unclear.

Equitable access to services is a key issue. Many services have evolved over time and within geographical and other constraints, such as the availability of expertise and level of funding. These constraints remain real, but efforts must be made to minimise the variations in access. The overriding principle for the provision of services must be 'safe and effective services as locally as possible, not local services as safely as possible'.

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.

A balance has to be struck between 'care' needs, addressed by the care environment, and 'disease' needs, addressed by specialised clinical treatment. This requires an individualised approach to treatment that takes account of service provision, particularly for older patients.

## A. Recommendations

Planning, commissioning and funding for all aspects of care, across the whole healthcare system, should be coordinated to ensure there is an appropriate balance of service provision and allocation of resources.

The commissioning arrangements for services for children and young people with cancer need further clarification to ensure the above recommendation can be met. These need to ensure that commissioning arrangements for children are brought together with those for cancer.

# Delivery of care

## Multidisciplinary teams

A complex range of services is required for children and young people with cancer, involving many disciplines and professional groups, and crossing organisational and institutional boundaries. Modern cancer care has come to be defined by its delivery through teams of professionals working together, known as MDTs. These teams have been described in adult cancer care principally with regard to those involved in the diagnosis, staging and (medical) treatment planning for the individual patient. A broader definition of these teams is now emerging, in line with good practice in cancer services for children and young people, where the MDT has long been recognised as including all those involved in care and support of the individual child and family throughout the care pathway.

The team's composition at any one point in a patient's journey will vary and should reflect the patient's needs at that time, both disease- and age-related, as well as the expertise and skills of particular team members. Tables 4–6 show the essential members of the MDT in relation to particular needs. Other healthcare professionals may be involved in some or all of these meetings. The constitution and organisation of teams and meetings should also reflect the specific clinical activity/profile of individual treatment settings. The MDT will also need access to other expertise, for example, a microbiologist.

However, there is a need for a separate MDT for late effects, as there is a wider range of professionals involved over a prolonged time period.

**Table 4 Suggested core attendance of multidisciplinary team (MDT) members at principal treatment centres during the care pathway.**

| |
|---|
| **Diagnosis**[a] |
| Oncologist/haematologist |
| Radiologist |
| Surgeon/neurosurgeon |
| Pathologist/cytogeneticist |
| Clinical oncologist |
| **Treatment**[a] |
| Treating oncologist |
| Key worker[b] |
| Paediatric haematologist |
| Specialist nurses |
| Nurses from inpatient and day care units |
| Specialist pharmacist |
| Dietitian and other appropriate allied health professionals |
| Paediatric oncology or other speciality outreach nurse/key worker[b] |
| **Psychosocial support** |
| Treating oncologist and haematologist |
| Key worker[b] |
| Play specialist; activity coordinator/youth worker |
| Psychological services professional |
| Specialist outreach nurse |
| Appropriate allied health professionals |
| Teacher |
| Social worker |
| Nurses from inpatient and day care units |
| **Palliative care** |
| Lead clinician |
| Key worker[b] |
| Palliative care specialist/oncologist/haematologist |
| Social worker |
| Specialist outreach nurse |
| Specialist pharmacist |
| Psychological services professional |
| Appropriate allied health professional |
| [a] Medical staff represent tumour-specific or paediatric expertise |
| [b] See section on continuity of care (key worker may come from any of the disciplines involved in the MDT) |

**Table 5 Suggested core attendance of multidisciplinary team (MDT) members responsible for the care of patients following completion of treatment.**

| **Late effects MDT** |
|---|
| Lead clinician (oncologist with expertise in late effects) |
| Key worker[a] |
| Specialist nurse |
| Endocrinologist |
| Appropriate allied health professional |
| Psychological services professional |

[a] See section on continuity of care (key worker may come from any of the disciplines involved in the MDT)

**Table 6 Suggested core membership of multidisciplinary teams (MDT) at other treatment sites.**

| |
|---|
| Lead paediatrician/oncologist/haematologist |
| Key worker[a] |
| Designated nurse |
| Pharmacist |
| Ward nurse/community nurse |
| Allied health professionals |
| Social worker |

[a] See section on continuity of care (key worker may come from any of the disciplines involved in the MDT)

## A. Recommendations

Care should be delivered throughout the care pathway by MDTs, including all relevant staff (see Tables 4–6). Decisions should be recorded and disseminated to all relevant health professionals. Where care involves more than one treatment setting or specialist team, the remit and membership of the MDTs should reflect the arrangements for shared care.

There are several tumour types whose management and treatment planning should be undertaken by either a specialist tumour-specific MDT or through liaison with other subspecialists. These include:

- tumours of the CNS
- bone sarcoma
- soft tissue sarcomas (particularly in young people)
- retinoblastoma
- lymphomas (for specialist pathological review)
- malignant thyroid tumours.



All hospitals with shared care arrangements (see section on place of care) should have an MDT that facilitates the interface between that centre and both primary care and the principal treatment centre.

Membership of MDTs should be explicit and include clearly defined responsibility for clinical and managerial leadership. MDTs should have adequate administrative support to organise team meetings and provide secretarial support.

There should be clear, two-way communication between the MDT at the principal treatment centre and MDTs in any other treatment setting with designated individuals responsible for ensuring continuity.

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 be held weekly.

Centres providing care for teenagers and young adults should ensure that the skills and experience represented in the MDT are appropriate to their age-related needs. Members should be familiar with the communication issues specific to working with teenagers and young adults and their families and appropriate training and support should be available.

## B. Anticipated benefits

MDTs ensure that each patient is considered from a range of viewpoints and expertise.

MDTs promote shared learning between professionals.

MDTs offer a greater probability of timely, appropriate treatment and better continuity of care.

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.

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



## C. Evidence

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.

The advantages of a multidisciplinary shared care programme for young people have been demonstrated in a RCT performed in Denmark.

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

## D. Measurement

### 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

### Process

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

### Outcome

- outcomes with multidisciplinary care of patients with certain tumour types



## E. Resource implications

The recommended minimum staffing levels to provide a safe and sustainable service for children and young people with cancer (see resource implications in the section on place of care) include provision for MDT meetings. Local commissioners will need to consider the opportunity costs of any increase in existing MDT meetings and some centres will need to employ additional staff as a consequence. In addition, consideration would need to be given to whether existing meetings are held within normal working hours. This has not always been the case in the past.

The guidance recommends that each principal treatment centre has an MDT coordinator. It is probable that not all teams currently have coordinators or adequate administrative support. It is anticipated that each coordinator would be contracted to facilitate all MDTs for children and young people with cancer based at the centre. Based on a full time post, Clerical and Administrative Grade 4–5, the salary plus on-costs would be approximately £21,500 per annum. Local commissioners would need to investigate whether the principal treatment centre has a coordinator currently in post.

Additional video-conferencing equipment may be required in some principal treatment centres and hospitals with shared care arrangements to facilitate MDT working. The cost of a video-conferencing system with high-quality image transfer capability would be about £15,000 (£18,000 inclusive of VAT and delivery) per centre (comprising a mobile video-conferencing unit, two plasma screens [for added functionality] and a visual presenter [Document Camera] for high-magnification requirements, installation, software and 3-year maintenance contract).

## Continuity of care

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.

Patients may require long-term follow-up care at all ages, 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.

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.



Such complexity of need demands a coordinated approach to service provision and in other services, a key worker approach has been effective in ensuring such coordination. The role of a key worker is set out in Table 7. This role is expected to be carried out in partnership with other members of the team, for example, ward nurses, social workers and teachers.

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 from the key worker identified for long-term follow-up. There are times along the patient pathway when the identity of the key worker may change for a particular episode of care, such as at the time of a bone marrow transplant.

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 POONS. For teenagers and young adults, the role of the outreach nurse specialist is less well developed and other clinical nurse specialists have taken on elements of the role of key worker.

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.

Nurses in shared care units, in other treatment sites or in the community may also take on the role of key worker for individual patients.

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.

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.

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.



**Table 7 The role of the key worker.**

- Provide practical and emotional support to the child/young person and family
- Coordinate the provision of information and ensure that it is timely, tailored to the age of the child or young person and the needs of the family, and understood
- Ensure the provision of a written care/treatment plan and an initial needs assessment of the child or young person and family to inform the care plan
- Liaise with health and social care agencies and professionals in the community, including the primary care team
- Liaise with educational institutions and support reintegration for the child or young person wherever possible
- Ensure that the child, young person and family acquire new skills as needed, for example, 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, for example, during radiotherapy
- Coordinate palliative and terminal care to provide specialist advice and support to families and healthcare professionals, with cross-cover to provide a 24-hour service, if required. The key worker may provide direct clinical care and expertise at this time if appropriate.

## A. Recommendations

A key worker should be identified for each child or young person and their family to coordinate services and assess their support needs. There should be clear routes of communication between different care/treatment settings.

Each child or young person and their family should have a written care/treatment plan that draws together the provision of all components of care; where appropriate, voluntary agencies should be recognised as integral to the care plan.

The written care/treatment plan should include the individual arrangements for transition from paediatric to adult services and should be informed by protocols/guidelines drawn up by the respective services.

## B. Anticipated benefits

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.

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

There is a paucity of evidence to indicate the requirements for service provision to achieve a well-coordinated transition or continuity of care for children and young people with cancer. One review of the evidence concluded that further research was required to determine continuity of care for young people.

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.

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

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

# D. Measurement

### Structure

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

### Process

- care/treatment plans
- planned transition outcomes

### Outcome

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

# E. Resource implications

The staffing levels for principal treatment centres, as considered in the resource implications in the section on place of care, include an estimate for key workers. The actual cost of employing key workers will vary according to the professional undertaking, the role and the caseload. Further work to assess the cost impact will need to be conducted at the local level. This analysis does not consider the economic implications of key workers at the shared care centres because the situation for funding is far more complex.

### Protocol-based care

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.

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 exception to this is for 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.

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

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 or the patient decides not to participate.

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

Standardised, evidence-based treatment, as set out in specified protocols based on expert advice, should result in:

- improved survival rates
- reduction in the intensity of therapy for some patients
- lower morbidity

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

## C. Evidence

The dramatic improvement in survival rates for children and young people with 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.

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.

The evidence is inconsistent in determining whether it is a true protocol effect or an effect of treatment setting that is important in all tumours of children and young people.

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.

There are now recommended treatment protocols for more than 80% of CNS malignancies in children: these cover how the diagnosis is made, the timing of surgery, the measurement of disease extent and the therapeutic strategy.

## D. Measurement

### 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

### Process

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

### Outcome

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

## E. Resource implications

It is not possible to determine the cost implications of protocol-based care in this guidance, as these are dependent on clinical guidelines and may result in an increase or decrease in costs.

# Place of care

Throughout the care pathway, the various components of care will be delivered at a number of locations, ranging from the community to tertiary centres and, for some, highly specialised quaternary centres.

The major elements of treatment, particularly management planning by an 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, 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 some chemotherapy, may be undertaken closer to home.



At present, patients over 16 years old are treated within a paediatric oncology service, in adult cancer services, or in specialist teenage or young adult services attached to either paediatric or adult units. Very few paediatric services offer shared care for children over 16 years old.

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.

There is little clinical nurse specialist support for young people with cancer.

The guidance sets out below the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made, regarding provision of care, throughout this guidance.

## Principal treatment centres

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.

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.

Principal treatment centres for children are largely represented by UKCCSG centres, which have developed in response to need and availability of expertise. However, there is wide variation in workload and in the facilities offered. Facilities and levels of consultant and nursing staff are partly determined by other work issues, such as whether bone marrow transplants are undertaken in the centre and the number of new patients with cancer treated at the centre each year.

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; adequate cross-cover arrangements are required.

Teams caring for young people need to be experienced in and responsive to the specific social, psychological, and educational needs of teenagers and young adults with cancer and their families, in addition to their expertise in the treatment of the cancer itself. Such services may be delivered most effectively within dedicated units that include specific inpatient facilities for teenagers and young adults. They should be developed in sympathy with established local cancer provision and operate through partnerships between paediatric and adult oncology services.

Although the management of many cancers (for example, carcinomas, germ cell tumours) in young adults may be less complex and largely outpatient-based, they still require services that are responsive to their care needs.

Pressures on consultant workload have arisen from various sources including:

- the reduction in junior doctors' hours
- compliance with the *European Union Working Time Directive* [39, Appendix 1]
- compliance with the *European Union Directive on Good Clinical Practice in Clinical Trials* [38, Appendix 1]
- increased intensity of treatment initially and at relapse.

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

There are also pressures leading to increased nursing workloads including:

- greater intensity and complexity of treatment
- need to deliver in-house training
- poor retention rate of senior staff.

## Hospitals with shared care arrangements

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, depending on age and the nature of condition.

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

**Table 8 Core components of shared care arrangements.**

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

## Other locations of care

Elements of specialist care may take place in a range of other locations, for example special surgical facilities or radiotherapy units, and care may be given in the community, usually at home or in hospices, and during the palliative stage.

Children's community nursing services are not comprehensive across the UK and a significant number of children and young people are cared for in the community by general district nurses, who may not be able to undertake certain interventions needed by the child and family. Both general children's community nurses and district nurses may need support, information and training in taking on new skills. The POONS or other outreach and liaison teams generally provide this from the principal treatment centre.

Wherever care is given, it is essential that the GP and primary care team are kept informed on a child or young person's care and treatment plan.

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

The definitive investigation of children and young people with a suspected diagnosis of cancer should only take place in principal treatment centres, which should have the appropriate staff and resources to meet the waiting time requirements of the *NHS Cancer Plan* [27, Appendix 1] and the *Wales National Cancer Standards* [21, Appendix 1].

The care of each child and young person with cancer should be directed from an identified principal treatment centre by a dedicated MDT 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.

Principal treatment centres should be able to provide a sustainable range of services, as described above, with defined minimum levels of staffing, as outlined in Tables 9 and 10 and in the documents *Defining Staffing Levels for Children's and Young People's Services* [72, Appendix 1] and the NICE Guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1].

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

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

**Personnel**[a]

- Designated lead clinician
- Paediatric oncologists
- Paediatric haematologists

} Minimum of five consultant staff, at least two of each discipline

- At least two clinical oncologists with expertise in paediatric radiotherapy
- Paediatric surgeon with expertise in specialist oncology[b]
- Adequate training and middle-grade cover

Other specialist services necessary on site:

- Paediatric anaesthetics[b]
- Paediatric radiology[b]
- Paediatric pathology[b]
- Designated paediatric oncology pharmacist
- Designated lead psychological and psychiatric services

Nursing establishment[c]

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

Core allied health professionals:

- Dietitians
- Physiotherapists
- Occupational therapists
- Play specialists

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

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, nuclear medicine, other specialised surgical services)
- Dental services
- Pain management teams
- Palliative care team

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

[b] With adequate cross-cover arrangements

[c] See *Defining the Staffing Levels for Children's and Young People's Services* [72, Appendix 1] and the NICE guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1]

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

**Personnel**[a]

- Designated lead clinician
- Lead haematologist
- Other consultant staff with expertise in the care of malignancies seen in this age group
- Adequate training and middle-grade cover[e]

Other specialised services necessary on site as required for site-specific expertise:

- Radiology[b]
- Pathology[b]
- Designated oncology pharmacist
- Psychological and psychiatric services

Adequate nursing establishment[c]

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

Core allied health professionals:

- Dietitians
- Physiotherapists
- Occupational therapists
- Activity coordinator

Designated social workers

Research support:

- Research nurse
- Data managers

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

| *There should be immediate access to:* |
|---|
| • Intensive care[d] |
| • Neurosurgical services |
| • Other tertiary services |
| • Dental services |
| • Pain management teams |
| • Palliative care team |

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

[b] With adequate cross-cover arrangements

[c] See *Defining the Staffing Levels for Children's and Young People's Services* [72, Appendix 1] and the NICE guidance on *Improving Outcomes in Haematological Cancers* [59, Appendix 1]

[d] Where intensive care facilities are not on site, a retrieval service should be in place

[e] 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.



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

There should be designated principal treatment centres for teenagers and young adults.

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

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

All care for children and young people under 19 years old must be provided in age-appropriate facilities [35, Appendix 1]. Young people of 19 years and older should also have unhindered access to age-appropriate facilities and support when needed.

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.

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.



Clinical nurse specialist posts, to address the care and support needs of young people with cancer, should be developed and appropriate training provided.

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

There are a number of intensive treatment protocols that should only be delivered within a principal treatment centre; those that 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.

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

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

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.

Currently, different models of shared care in the UK reflect various factors, especially local geography and distribution of facilities; however, all shared care arrangements should involve the provision of an agreed level of coordinated care with the principal treatment centre and there should be a responsible MDT within that treatment setting (see Table 8).

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.

Shared care arrangements should be reflected in consultant job plans; there should be adequate time for training and CPD for all members of the clinical team.

There should be a comprehensive children's community nursing infrastructure to support the care of children with cancer.

Adequate resources are required not only for principal treatment centres, but also for all settings that are participating in the delivery of care, particularly those with shared care arrangements.



## B. Anticipated benefits

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

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

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.

Identified leads will improve communication between treatment settings.

## C. Evidence

Research evaluating current models of specialist provision for children's cancer is very limited. Survival has been used as the principal endpoint in several studies, but no clear correlation between hospital type and 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 endpoints that are too narrow to reflect all the advantages or disadvantages of a particular treatment centre.

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 Framework for Children, Young People and Maternity Services* [35 and 112, Appendix 1] in both England and Wales recommend age-appropriate facilities. Further research to define the needs of young adults is required: they have both a changing spectrum of cancers and a broader range of social, educational and vocational profiles that may be less easily encompassed by single-care models.

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

Evidence on prevalence of shared care in the 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 may at first 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.

There is no evidence to indicate that protocol compliance is greater when treatment is performed in a principal treatment centre compared with a shared care centre.

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

## D. Measurements

### Structure

- documented arrangements to ensure that treatment for children and young people with cancer is performed in designated specialist centres

- provision of dedicated age-appropriate facilities

### Process

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

### Outcome

- accurate data for the tumour-specific differences for different outcomes when treatment is received in inappropriate settings
- patient and parent/carer satisfaction with treatment facilities
- delays to start of planned chemotherapy
- delays to diagnostic and definitive surgery
- delays to start of radiotherapy

## E. Resource implications

Additional costs are likely to be incurred in shared care arrangements with regard to nominated leads.

Where service delivery costs are incurred in a shared care arrangement, the balance of resource will need to reflect the place of delivery of care.

#### Principal treatment centres

In assessing the economic implications of the guidance, minimum staffing levels at principal treatment centres to provide a safe and sustainable service and the consequent costs have been estimated.

The employment costs of the medical, nursing and other staff caring for children and young people with cancer at a principal treatment centre with 15 beds and treating about 80 new patients per year is approximately £2.47 million per year (±25%, range £1.85 million to £3.0 million). The estimated annual cost per bed at each centre treating children at the proposed staffing level is about £165,000

(±25%, range £124,000 to £206,000). The estimated annual cost per child with cancer, to provide a safe and sustainable service at the proposed level of staffing, is about £31,000 (±25%, range £23,000 to £38,700).

A principal treatment centre for young people with cancer with minimum staffing levels for a unit with 8 beds caring for a minimum of 60 new patients per year would cost an estimated £1.0 million per year (±25%, range £0.8 million to £1.2 million). The annual employment costs per bed are estimated to be £124,700 (±25%, range £93,500 to £156,000). For young people, the annual cost per new patient is estimated to be £16,600 (±25%, range £12,500 to £20,800).

Some of the estimated cost implications detailed include staff such as play specialists and some palliative care nurses, who are often funded by charities. The guidance recommends that all core staff are funded through NHS resources. This could represent an additional NHS expenditure for children with cancer of about £0.24 million per principal treatment centre per year for outreach nurses and play specialists alone. Some sessional time has been funded through charities; this should also be considered by commissioners.

Any additional staff requirement as a result of the guidance would need to be considered by commissioners at a principal treatment centre level. The data collected from finance directors would indicate that the mean cost of staffing is about £18,500 (SD £7468) per new patient per year. The total cost of providing a safe and sustainable service is estimated to be £31,000 per patient per year. This suggests a possible shortfall in investment in staff per new patient. Using both the standard deviation from the finance directors' survey and the sensitivity analysis from the staffing levels to produce a safe and sustainable service, there is a resulting range of –£0.22 million (representing a saving) to £2.21 million (representing a shortfall). However, as the range demonstrates, the level of uncertainty around this estimate is high. It should be acknowledged that some additional staffing requirement might not require new staff: some NHS staff might be redeployed or re-designated. It will be for local commissioners to estimate any shortfall in staffing and thereby any additional staffing costs.

**Place of care: age-appropriate facilities**

The guidance does not anticipate any increase in the provision of age-appropriate facilities for children. However, there may be a need for an increase in the number of facilities for young people. Currently there are eight such units (TCT units).

The estimated cost of planning, building and equipping each new unit for young people would require an expenditure of about £1.0 million, with a range of £0.75 million to £1.25 million. This estimate would provide accommodation for both inpatients and day cases.

Staffing one new unit for young people would entail recurring annual costs of £1.0 million (±25%, range £0.75 million to £1.25 million) per unit, based on the estimates for staffing to provide a safe and sustainable service for a unit with 8 beds treating 60 patients a year. This estimate includes nursing, activity coordinators and some medical support. Not all the staff would be new: many might be redeployed from existing adult or paediatric wards.

Some of the costs outlined above could be offset against income generated for the units treating young people from other service providers who were not able to offer age-appropriate facilities in their localities. There would be potential cost savings in other areas of cancer services where young people have been previously treated, such as adult or paediatric wards. It has not been possible, however, to quantify these savings.

# Cancer networks

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

## A. Recommendations

Cancer networks should, in discussion with the commissioners of cancer services for children and young people, 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 a network lead for children and a network lead for young people with cancer, recognising that given the difficulty with boundaries, these leads will need to work collaboratively.

- appropriate principal treatment centres for each cancer type are identified for children and for young people with associated referral pathways, including pathways 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.

Cancer networks should work in partnership with other services for children and young people, both statutory and voluntary.

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

Where catchment areas for a particular principal treatment centre or shared care arrangement cut across the boundaries of a number of networks, the cancer networks should work with the commissioners to ensure that all aspects of care are recognised and resourced. The host network for the principal treatment centre would be expected to lead on this process on behalf of other networks.

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

## B. Anticipated benefits

The provision of well coordinated care.

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

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

The setting up of cancer networks was recommended in the Calman–Hine Report [23, Appendix 1].

Cancer networks are the organisational model for cancer services to implement the *NHS Cancer Plan* [27, Appendix 1] and *Improving Health in Wales: A Plan for the NHS with its Partners* [111, Appendix 1].

## D. Measurement

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

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

## E. Resource implications

We have not formally costed for these recommendations; however, better coordination of care and appropriate targeting of resources may lead to cost savings.

# Communication with children, young people and families

Open communication between professionals, children/young adults and their families is a prerequisite for success. It is essential that the patients and their families understand their cancer, their treatment and any choices that they may have. Many patients and families are able to contribute to the management of their condition.

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: 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

All healthcare professionals caring for children and young people with cancer should have training in age-appropriate communication skills. They should be trained to communicate sensitively and effectively and allowed sufficient time to do so. Psychology services can play a key role in supporting this aspect of care.

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

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

Patients, families and carers should have access to information that 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.

Where patients and families wish and are able to contribute to the management of their condition, this should be supported and appropriate training provided.

Information should be age- and culture-appropriate (including language), and accessible and available in an appropriate format; there should be specific age-appropriate information for very young children.

A core set of accredited information materials for children and young people with cancer should be encouraged and supported.

The quantity of information and the time and rate at which it is given should be based on an individual's needs. Contact details for providers of information and advice should be made available, so that their services can be accessed readily.

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

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

Online information resources should be made available to families in principal treatment centres. Advice should be provided on which websites are authoritative and useful.

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

## B. Anticipated benefits

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.

Accredited information materials 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

The TCT conference survey found that 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'.

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.

There is considerable evidence that there are problems with communication and information-giving (both inter-professional and between patients/parents/carers).

There is good-quality evidence (RCTs and systematic reviews) that training courses to improve communication are effective.

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

There is expert opinion, consensus and evidence, reviewed in the NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* [61, Appendix 1], to suggest the information requirements of patients with cancer. Children and young people with cancer have specific information needs for which there is little good-quality evidence to indicate the optimum service requirements.

The evidence from the Macmillan Cancer Relief directory of information materials indicates that there are few good-quality information materials that have been produced specifically for children. Online and published information materials need to be evaluated carefully.

# D. Measurement

### Structure

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

### Process

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

### Outcome

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

# E. Resource implications

We have not formally costed for these recommendations; however, support for staff training in communication and the development of appropriate patient information are not expected to have significant resource implications.

# Research

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.

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, RCTs cannot be undertaken successfully and the potential for improvements in survival rates is lost.

There are also rare tumours of childhood where it is not possible to conduct RCTs, even on an international basis, but where well-coordinated single-arm studies, compared with historical controls, have resulted in improvements in survival.

Recruitment to clinical trials is lower in the older age group compared with children up to the age of 15 years, 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. The establishment of the National Cancer Research Institute's (NCRI's) Teenagers and Young Adults Clinical Studies Development Group may start to address this issue and is welcomed.

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.

The need for research in this area is wider than treatment intervention and includes biological studies, translational research, supportive care, psychological issues and models of service delivery.

# A. Recommendations

All innovative treatments should be part of a clinical trial.

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, and that this must be an informed choice.

The development of clinical trials that include teenagers and young adults should be encouraged.

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

Where clinical trials are undertaken, there must be compliance with the relevant legal and regulatory frameworks with adequate resource provided for research nurses, clinical trials coordinators and data managers. Adequate resource should also be provided for laboratory staff and facilities.

There should be clearly defined routes for national and local funding for the support of clinical trials and other research, as outlined above, for children and young people.

# B. Anticipated benefits

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

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

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

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.

A recent review has challenged this finding and has stated that there are 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'.

Recent case series suggest that, in certain diagnostic groups such as acute lymphoblastic leukaemia, the outcome for patients in the age group covered by this guidance is better when treated on paediatric rather than adult protocols. The converse, however, may also be true for other diagnostic groups.

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 a data manager.

There is expert opinion that there is 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 is very variable.

# D. Measurement

## 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

## Process

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

## Outcome

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

# E. Resource implications

The resource implications of the research recommendation have not been formally costed, but there is likely to be increased costs for the research funding agencies.

# Workforce development

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.

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

- paediatric radiologists and diagnostic radiologists
- paediatric pathologists
- laboratory staff and scientists
- AHPs
- paediatric haematologists
- nurses
- clinical psychologists and other members of the psychological team
- clinical oncologists and therapy radiographers
- specialist hospital pharmacists.

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

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 FNP
- pain management

- rehabilitation approaches
- blood product support
- communication skills.

This list is by no means exhaustive.

## A. Recommendations

Strategic Health Authority (SHA) workforce development directorates in England should address the training and education needs of staff working with children and young people with cancer. The relevant national bodies should advise on what training is required for all staff groups.

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.

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.

Specific attention is required to address the shortage of AHP expertise in this area and the need to develop robust evaluation of the contribution of such services.

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

## B. Anticipated benefits

Equitable access to services

## C. Evidence

There are currently no specific training opportunities within the UK for AHP working in paediatric or adolescent oncology rehabilitation.

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

## D. Resource implications for staff training

A cost estimate for CPD has been calculated on the basis of a mean cost per module of £754 for key nursing, AHP and scientific staff. The CPD for doctors was estimated to be £3000 per year (further details are included in the Evidence Review). The costs relating to staff time while training has been included in the section detailing the costs of employing additional staff.

The estimated annual costs associated with training and education for CPD of the core staff for each principal treatment centre that treats children would be about £75,200 (±25%, range £56,400 to £94,000). The estimated cost of CPD for a unit for young people would be about £31,500 (±25%, range £23,600 to £39,400). This assumes a basic professional skill level as a baseline.

Additional calculations would be required at a cancer network level or local level to calculate the costs relating to CPD for those staff employed at shared care centres and providing community support, and indeed any specific training that might be required in the principal treatment centre.

# Other service considerations

## Information requirements

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.

Services have to comply with the Data Protection Act and the Freedom of Information Act; good records management with appropriate IT support is essential (hardware and software).

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

### A. Recommendations

Experts should be commissioned at a national level to consider the issues related to the registration of cancers in 15–24-year-olds, including the potential value of a dedicated register.

National IT strategies in England and Wales should consider the needs of the services for children and young people with cancer when introducing new IT systems.

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

### A. Recommendations

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

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

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

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

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

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.

All children will suffer disruption of their normal education and their specific needs should be addressed.

Some children may have special education needs as a result of physical or other disability, which require additional education support and/or specialist input. Assessment and input from educational psychologists is essential but provision of this resource is variable across the country.

## A. Recommendations

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 importance of preserving access to education throughout the care pathway and should promote effective interagency working to address this for all age groups.

### Hospital facilities

## A. Recommendations

Hospital facilities must meet requirements for good infection control.

Hospital catering services must be responsive to the particular needs of sick children. These may arise from clinical, cultural or personal needs.

Because children and young people with cancer often have prolonged inpatient stays, suitable accommodation for parents and carers should be provided.

Age-appropriate facilities for young people should include an environment shared by peers and access to designated social and educational facilities.

## Hospital parking

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 1

# Guidelines/guidance and key strategic* documents: children and young people with cancer†



| Guideline title | Source |
|---|---|
| 1. Guidelines for Pediatric Cancer Centers | American Academy of Pediatrics, 2004 |
| 2. Voices for Change. Current Perception of Services for Children with Palliative Care Needs and their Families | Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003 |
| 3. Guidelines for the Management of Unscheduled Interruption or Prolongation of a Radical Course of Radiotherapy | Board of the Faculty of Clinical Oncology, The Royal College of Radiologists London, 1996 |
| 4. Extending the Working Day for Delivery of Radiotherapy | Board of the Faculty of Clinical Oncology, The Royal College of Radiologists London, 1997 |
| 5. Equipment, Workload and Staffing for Radiotherapy in the UK 1992–1997 | Board of the Faculty of Clinical Oncology, The Royal College of Radiologists London, 1998 |
| 6. The Guidelines for the Surgical Management of Endocrine Disease | British Association of Endocrine Surgeons, 2003 |

* Bold typeface indicates strategic documents

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

| Guideline title | Source |
|---|---|
| 7. A Guide for Purchasers and Providers of Paediatric Surgical Services | British Association of Paediatric Surgeons and The Royal College of Surgeons Edinburgh, 1995 |
| 8. The British Association of Paediatric Surgeons. A Guide for Purchasers and Providers of Paediatric Surgical Services | British Association of Paediatric Surgeons, 1995 |
| 9. Response to the Kennedy Report "Learning from Bristol" | British Association of Paediatric Surgeons, 2001 |
| 10. Paediatric Surgery: Standards of Care | British Association of Paediatric Surgeons, 2002 |
| 11. Reconfiguration in Paediatric Surgery | British Association of Paediatric Surgeons, 2003 |
| 12. BCSH Guidelines on the Insertion and Management of Central Venous Lines | British Committee for Standards in Haematology, 1997 |
| 13. Transfusion Guidelines for Neonates and Older Children | British Committee for Standards in Haematology, 2004 |
| 14. Guidelines on the Diagnosis and Management of Chronic Lymphocytic Leukaemia | British Committee for Standards in Haematology, 2004 |
| 15. Transfusion Guidelines for Neonates and Older Children | British Committee for Standards in Haematology |
| 16. Guidelines on the Diagnosis and Management of Chronic Lymphocytic Leukaemia | British Committee for Standards in Haematology |
| 17. A Strategy for Fertility Services for Survivors of Childhood Cancer. A Report of a Multidisciplinary Working Group Convened by the British Fertility Society | British Fertility Society, 2003 |

| Guideline title | Source |
|---|---|
| 18. Hepatology and Nutrition: A Guide for Purchasers of Paediatric Gastroenterology | British Society for Paediatric Gastroenterology, 2003 |
| 19. Guidelines for MRI in Paediatric Brain Tumours | British Society of Paediatric Radiology, 1999 |
| 20. A Survey of Radiotherapy Services in England and Wales 1999 | Cancer Services Co-ordinating Group (Wales) |
| 21. Wales National Cancer Standards | Cancer Services Co-ordinating Group (Wales) and Welsh Assembly Government, 2005 |
| 22. National Service Framework Assessments: No. 1 – NHS Cancer Care in England and Wales | Commission for Health Improvement/Audit Commission, 2001 |
| **23. A Policy Framework for Commissioning Cancer Services. A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales** | **Department of Health; Welsh Office, 1995** |
| **24. Paediatric Intensive Care "A Framework for the Future". National Coordinating Group on Paediatric Intensive Care Report to the Chief Executive of the NHS Executive** | **Department of Health, 1997** |
| 25. A Survey of Radiotherapy Services in England 1999 | Department of Health, 2000 |
| 26. Meeting the Challenge: A Strategy for the Allied Health Professions | Department of Health, 2000 |
| **27. The NHS Cancer Plan** | **Department of Health, 2000** |
| **28. The Removal, Retention and Use of Human Organs and Tissue from Post-Mortem Examination** | **Department of Health, Chief Medical Officer, 2001** |

| Guideline title | Source |
|---|---|
| **29. Delivering 21st Century IT Support for the NHS. National Strategic Programme** | **Department of Health, 2002** |
| 30. Implementing a Scheme for General Practitioners with Special Interests | Department of Health, 2002 |
| **31. Strengthening Accountability Involving Patients and the Public. Policy Guidance Section 11 of the Health and Social Care Act 2001** | **Department of Health, 2003** |
| **32. Updated National Guidance on the Safe Administration of Intrathecal Chemotherapy** | **Department of Health, 2003** |
| **33. Getting the Right Start: National Service Framework for Children, Young People and Maternity Services. Part 1: Standards for Hospital Services** | **Department of Health, 2003** |
| 34. Patient and Public Involvement in Health: The Evidence for Policy Implementation | Department of Health, 2004 |
| **35. National Service Framework for Children, Young People and Maternity Services** | **Department of Health, 2004** |
| 36. A Framework for the Development of Positron Emission Tomography Services in England. Consultation Document | Department of Health, 2004 |
| **37. Manual of Cancer Services, 2004** | **Department of Health, 2004** |

| Guideline title | Source |
|---|---|
| 38. European Union Directive on Good Clinical Practice in Clinical Trials | Directive of the European Parliament and of the Council on the Approximation of the Laws, Regulations and Administrative Provisions of the Member States Relating to Implementation of Good Clinical Practice in the Conduct of Clinical Trials on Medicinal Products for Human Use (The Clinical Trials Directive 2001/20/EC) |
| **39. European Working Time Directive** | **European Union Council Directive No 93/104/EC of 23 November 1993 Concerning Certain Aspects of the Organisation of Working Time** |
| **40. Code of Practice, 6th Edition** | **Human Fertilisation and Embryology Authority, 2003** |
| 41. Childhood Cancer – Guidelines for Standards of Treatment & Care | International Society for Paediatric Oncology (SIOP), 2003 |
| 42. Recommendations for the Organisation of a Paediatric Cancer Unit | SIOP, 1993 |
| 43. Aims and Recommendations for Psychosocial Care | SIOP, 1993 |
| 44. Guidelines for Care of Long-Term Survivors | SIOP, 1996 |
| 45. Guidelines for the Communication of the Diagnosis | SIOP, 1997 |
| 46. Guidelines for a Therapeutic Alliance Between Families and Staff | SIOP,1998 |

| Guideline title | Source |
|---|---|
| 47. Guidelines for Assistance to Siblings of Children with Cancer | SIOP, 1999 |
| 48. Guidelines for Assistance to Terminally Ill Children with Cancer | SIOP, 1999 |
| 49. Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer | SIOP, 2000 |
| 50. Refusal, Non-Compliance, and Abandonment of Treatment in Children and Adolescents with Cancer | SIOP, 2002 |
| 51. Valid Informed Consent and Participative Decision Making in Children with Cancer and their Parents | SIOP, 2003 |
| 52. Too Serious a Thing – The Carlile Review – The Review of Safeguards for Children and Young People Treated and Cared for by the NHS in Wales. | National Assembly for Wales, 2002 |
| 53. A Survey of Radiotherapy Services in England and Wales, 2001 | National Cancer Services Analysis Team |
| 54. NCCN Pediatric Neuroblastoma Practice Guidelines | National Comprehensive Cancer Network, 1996 |
| 55. NCCN Pediatric Acute Lymphoblastic Leukemia Practice Guidelines | National Comprehensive Cancer Network, 1997 |
| 56. Who Operates Where – WOW II | National Confidential Enquiry into Perioperative Deaths, 2003 |

| Guideline title | Source |
|---|---|
| 57. Palliative Care for Children | National Council for Hospice and Specialist Palliative Care Services, Association for Children with Life-Threatening or Terminal Conditions and their Families, and Association of Children's Hospices, 2001 |
| 58. Guidance on the Use of Human Growth Hormone (Somatropin) in Children with Growth Failure | National Institute for Clinical Excellence, 2002 |
| 59. Guidance on Cancer Services. Improving Outcomes in Haematological Cancers | National Institute for Clinical Excellence, 2003 |
| 60. Referral Guidelines for Suspected Cancer | National Institute for Health and Clinical Excellence, 2005 |
| 61. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. | National Institute for Clinical Excellence, 2004 |
| 62. Fertility: Assessment and Treatment for People with Fertility Problems | National Institute for Clinical Excellence, 2004 |
| 63. Facilities for Cancer Care Centres: Design and Briefing Guidance | NHS Estates, 2001 |
| 64. Nurse Specialists, Nurse Consultants, Nurse Leads. The Development of New Roles to Improve Cancer and Palliative Care. An Advisory Report | NHS Executive, 2001 |
| 65. Radiology: A National Framework for Service Improvement | NHS Modernisation Agency, 2003 |
| 66. Radiotherapy Toolkit | NHS Modernisation Agency, 2003 |

| Guideline title | Source |
|---|---|
| 67. Chemotherapy Toolkit | NHS Modernisation Agency, 2003 |
| 68. Cancer Services Collaborative Improvement Partnership. Improving Communication in Cancer Care | NHS Modernisation Agency, 2004 |
| 69. The Management of Pain in Patients with Cancer | NHS Quality Improvement Scotland, 2004 |
| 70. Guidance on the Provision of Paediatric Anaesthetic Services | Royal College of Anaesthetists, 2001 |
| 71. Children's Nursing Workforce, July 2002 | Royal College Nursing, 2002 |
| 72. Defining Staffing Levels for Children's and Young People's Services | Royal College Nursing, 2003 |
| 73. Services for Children and Young People: Preparing Nurses for Future Roles | Royal College Nursing, 2004 |
| 74. Guidelines for the Ethical Conduct of Medical Research Involving Children | Royal College of Paediatrics and Child Health: Ethics Advisory Committee, 2000 |
| 75. Guidelines for Good Practice. Recognition and Assessment of Acute Pain In Children | Royal College of Paediatrics and Child Health, 2001 |
| 76. Standards for Development of Clinical Guidelines in Paediatrics and Child Health | Royal College of Paediatrics and Child Health, 2001 |
| 77. Old Problems, New Solutions. 21st Century Children's Healthcare | Royal College of Paediatrics and Child Health, 2003 |
| 78. The Future of Paediatric Pathology Services | Royal College of Paediatrics and Child Health, 2002 |
| 79. Providing a Service for Children. Workforce Census, 2001 | Royal College of Paediatrics and Child Health, 2003 |

| Guideline title | Source |
|---|---|
| 80. Specialist Health Services for Children and Young People. A Guide for Primary Care Organisations | Royal College of Paediatrics and Child Health, 2003 |
| 81. Commissioning Tertiary and Specialised Services for Children and Young People | Royal College of Paediatrics and Child Health, 2004 |
| 82. Medicines for Children | Royal College of Paediatrics and Child Health, 2004 |
| 83. Pituitary Tumours. Recommendations for Service Provision and Guidelines for Management of Patients. | Royal College of Physicians, 1997 |
| 84. Cancer Units: Improving Quality in Cancer Care. The Provision of Non-Surgical Specialist Cancer Services in District General Hospitals. | Royal College of Physicians, 2000 |
| 85. Guidelines for the Management of Thyroid Cancer in Adults | Royal College of Physicians and The British Thyroid Association, 2002 |
| 86. Guidelines for External Beam Radiotherapy | Royal College of Radiologists' Clinical Oncology Information Network, 1999 |
| 87. Safe Sedation, Analgesia and Anaesthesia within the Radiology Department | Royal College of Radiologists, 2003 |
| 88. Clinical Radiology and the Patients of General Practitioners | Royal College of Radiologists and Royal College of General Practitioners, 2004 |
| 89. 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 |

| Guideline title | Source |
|---|---|
| 90. Clinical Guidelines. The Oral Management of Oncology Patients Requiring Radiotherapy: Chemotherapy: Bone Marrow Transplantation | Royal College of Surgeons of England, 1999 |
| 91. Children's Surgery – A First Class Service | Royal College of Surgeons of England, 2000 |
| 92. Better Blood Transfusion: RCPCH Policy Document | Royal Liverpool Children's NHS Trust, 1999 |
| 93. Control of Pain in Patients with Cancer. A National Clinical Guideline | Scottish Intercollegiate Guidelines Network, 2000 |
| 94. Long Term Follow Up of Survivors of Childhood Cancer. A National Clinical Guideline | Scottish Intercollegiate Guidelines Network, 2004 |
| 95. Safe Sedation of Children Undergoing Diagnostic and Therapeutic Procedures. A National Clinical Guideline | Scottish Intercollegiate Guidelines Network, 2004 |
| **96. 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** |
| 97. 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 |
| 98. Overview of the National Workforce Competence Framework for Children's Services | Skills for Health, 2004 |
| 99. Safe Paediatric Neurosurgery | Society of British Neurological Surgeons, 1998 |
| 100. Safe Paediatric Neurosurgery | Society of British Neurological Surgeons, 2001 |

| Guideline title | Source |
|---|---|
| **101. Department of Health *Children Act 1989 – Guidance and Regulations*** | **Stationery Office, 1991** |
| **102. Department of Health *Children Act 2004*** | **Stationery Office, 2004** |
| **103. The Report of the Royal Liverpool Children's Inquiry** | **Stationery Office, 2001** |
| 104. The Resources and Requirements of a UKCCSG Treatment Centre | United Kingdom Children's Cancer Study Group (UKCCSG), 2004 |
| 105. Shared Care | UKCCSG, 2004 |
| 106. UKCCSG Centre Coordinator Responsibilities | UKCCSG, 2004 |
| 107. Criteria for Centres Undertaking Phase I and II Studies | UKCCSG, 2004 |
| 108. UKCCSG Centre Data Managers – Role and Responsibilities | UKCCSG, 2004 |
| 109. UKCCSG Guide to GCP (Good Clinical Practice and the EU Directive on Clinical trials 2001/20/EC) | UKCCSG, 2004 |
| 110. 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 |
| 111. Improving Health in Wales. A Plan for the NHS with its Partners | Welsh Assembly Government, 2001 |

| Guideline title | Source |
|---|---|
| **112. National Service Framework for Children, Young People and Maternity Services in Wales. Consultation Document** | **Welsh Assembly Government, 2004** |
| 113. International Classification of Functioning, Disability and Health | World Health Organization, 2001 |

# Appendix 2

# Scope of the guidance National Institute for Clinical Excellence

A2

## Scope

## 1 Guidance title

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

**Short title**

Child and adolescent cancer

## 2 Background

a) The National Institute for Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Cancer to develop service guidance on child and adolescent cancer for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and the Welsh Assembly Government (see Appendix). The guidance will provide recommendations for service provision that are based on the best available evidence.

b) The Institute's service guidance will support the implementation of the National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The guidance will support current national initiatives outlined in the *NHS Cancer Plan*, the Calman–Hine report, the Cameron report, the *Manual of Cancer Service Standards for England* and the *All Wales Minimum Standards for Cancer Services*. Cross-reference will be made to these and other documents as appropriate.

# 3 Clinical need for the guidance

a) Each year in the UK there are approximately 1500 new cases of cancer diagnosed in children under the age of 15 years, according to the United Kingdom Childhood Cancer Study Group (UKCCSG). The diagnosis and treatment of childhood cancers is often complex. The frequent use of intensive chemotherapeutic regimens (including high-dose therapy with autologous stem cell rescue) may involve prolonged inpatient care. Children and their families commonly have to travel long distances to receive specialised care – although some areas have developed local shared-care centres, in other areas this has not been possible or appropriate – and the impact on family life during therapy can be significant. The role of community support staff and social care for these families should not be underestimated.

b) The distinct needs of young people with cancer have been increasingly recognised over recent years. Many young people do not feel comfortable within the paediatric setting, but they have unique needs that may not be addressed within adult services. Many also have complex problems requiring intensive chemotherapy, and the prognosis for this group (compared with that for younger children) is often less good. Assessment of the service configuration that will best meet the needs of these patients is one of the objectives of this guidance.

c) An important part of the care of children and young people with cancer is their rehabilitation, follow-up and transition into adult services. Many will be very young at completion of therapy and follow-up is essential to ensure a normal healthy development into adulthood. Advice regarding fertility and other lifestyle issues (including psychological support and the social impact of their cancer) is needed as children mature. Overall survival rate for children is now approximately 70%. It has been estimated that 1 in 1000 young adults is a cancer survivor.

# 4 The guidance

a) The guidance development process is described in detail in three booklets that are available from the NICE website (see Section 5, Further information). *The Guideline Development Process – Information for Stakeholders* describes how organisations can become involved.

b) This document is the scope. It defines exactly what this piece of service guidance will (and will not) examine and what the developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see Appendix).

c) The areas that will be addressed by the guideline are described in the following sections.

## 4.1 Population

### 4.1.1 Groups that will be covered

a) Children (from birth) and young people in their late teens and early twenties presenting with malignant disease, including leukaemia and related conditions as defined by the International Classification of Childhood Cancer (ICCC) (incorporating the amendments used by UKCCSG).

b) Benign tumours or conditions that require complex treatment pathways, potentially including chemotherapy and radiotherapy.

### 4.1.2 Groups that will not be covered

a) Children and young people with benign tumours.

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

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

## 4.2 Healthcare setting and services

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

a) Primary care (general practitioners and associated staff) and community-based care (for example, home care, day care). The guidance will address the management, in primary care, of early diagnosis, active treatment, rehabilitation, follow-up and palliative care.

b) Shared care centres.

c) Secondary care.

d) Tertiary care in specialist paediatric and adolescent oncology centres and their shared care partner units.

e) Quaternary care in specialist regional or national units for selected diagnoses (for example, retinoblastoma, bone tumour surgery).

f) Integration with the voluntary sector.

g) Integration with other statutory services.

## 4.3 Key areas of clinical management

The guidance will include recommendations for the following areas.

a) Diagnostic services (excluding referral guidelines), including the roles of:

- general practitioners and other members of the primary care team
- specialist paediatric oncologists and haematologists
- adult clinical and medical oncologists and haematologists
- paediatric and adult histopathologists
- specialist diagnostic resources such as molecular genetics facilities, cytogenetics services and immunophenotyping
- diagnostic radiology
- general paediatricians, haematologists and other specialists to whom these patients will present.

b) Oncology treatment services

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

c) Allied treatment services

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

d) Palliative care

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

e) Support services

- community liaison
- play therapy
- youth support

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

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

f) Follow-up

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

g) Other issues

- research and clinical trials
- data management
- ethical issues

## 4.4 Audit support within the guidance

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

## 4.5 Status

### 4.5.1 Scope

This is the final version of the scope.

### 4.5.2 Guidance

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

# 5 Further information

Information on the guidance development process is provided in:

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

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

## Appendix: Referral from the Department of Health and Welsh Assembly Government

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

"To prepare service guidance for the NHS in England and Wales for the cancers affecting children and adolescents. This would form part of the *Improving Cancer Outcomes* series and NICE will be expected, as in previous topics in the series, to involve DH [Department of Health] and NAW [National Assembly for Wales] closely in the development of the guidance. In particular, DH and NAW should be alerted at an early stage to any issues in the developing guidance which are likely to lead to significant changes in the current service provision."

Appendix 3

# United Kingdom Children's Cancer Study Group Centres and Teenage Cancer Trust Units in England and Wales



**3.1 List of United Kingdom Children's Cancer Study Group (UKCCSG) Centres in England and Wales**

**3.2 List of Teenage Cancer Trust Units in England and Wales**

Appendix 3.1

# List of United Kingdom Children's Cancer Study Group (UKCCSG) Centres in England and Wales



1. The Children's Hospital, Birmingham
2. Addenbrooke's Hospital, Cambridge
3. Leicester Royal Infirmary, Leicester
4. Great Ormond Street Hospital for Children, London
5. Royal Manchester Children's Hospital, Manchester
6. Queen's Medical Centre, Nottingham
7. Southampton General Hospital, Southampton
8. The Middlesex Hospital, London
9. Royal Hospital for Sick Children, Bristol
10. University Hospital of Wales, Cardiff
11. St James's University Hospital, Leeds
12. Alder Hey Children's Hospital, Liverpool
13. Barts & The London Trust, London
14. Royal Victoria Infirmary, Newcastle-upon-Tyne
15. Sheffield Children's Hospital, Sheffield
16. Royal Marsden Hospital, Sutton
17. John Radcliffe Hospital, Oxford

A3

## Appendix 3.2

# List of Teenage Cancer Trust Units in England and Wales

1. The Middlesex Hospital, London
2. The Christie Hospital, Manchester
3. St James's Hospital, Leeds
4. Royal Victoria Infirmary, Newcastle upon Tyne
5. University College Hospital, London
6. Queen Elizabeth Hospital, Birmingham
7. Alderhey Children's Hospital, Liverpool
8. Weston Park Hospital, Sheffield

# Economic implications of the guidance

## Executive summary

A detailed costing exercise was conducted in order to estimate, where possible, the cost implications of implementing the key recommendations of the *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer* in England and Wales. The analysis focuses on those aspects of the key recommendations that are likely to be of greatest consequence in terms of cost.



It is acknowledged that there is considerable uncertainty around the estimates presented and that there will be variation among cancer networks. Sensitivity analyses were conducted to account for uncertainty in the estimated costs. Further assessments will be needed at cancer network level and/or NHS trust level to determine the exact cost implications. Work is currently being carried out in the NHS in England, in connection with 'Payment by Results', to develop a better understanding of costs of treatment and care, and this may help these assessments in the future.

It should be noted that whilst one of the key recommendations of the guidance manual is that "*commissioning and funding for all aspects of care for children and young people with cancer, across the whole healthcare system, should be coordinated, to ensure there is an appropriate balance of service provision and allocation of resources*", the cost implications addressed in this document focus on the costs incurred at principal treatment centres.

There will also be significant cost implications for those services, often located within local hospitals, that offer shared care facilities. The costs of increasing the support available to families closer to home, for example by the recommended continuing development of children's community nursing teams, has not been addressed. It is also possible that there are potential cost savings resulting from changes introduced by the guidance. These have not been estimated in this analysis.

# Staffing at principal treatment centres

For the purposes of determining the economic implications of the Manual, staffing levels to provide a safe and sustainable service for a minimum activity level at principal treatment centres have been estimated by the guidance development group (GDG) members. This estimate includes provision for any staffing implications of the Manual, such as attending multidisciplinary team (MDT) meetings and key worker provision. The staffing levels for nurses per patient bed were estimated using both Royal College of Nursing (RCN) recommendations and recommendations from the NICE guidance on *Improving Outcomes in Haematological Cancers* (NICE, 2004). NHS staff salary pay scales were used to calculate the current staffing cost 2004/5.

The costs discussed below are intended as a benchmark for commissioners. They will be indicative of a minimum investment in staffing levels at principal treatment centres. This minimum level is intended to enable centres to provide a safe and sustainable service for children and young people; bed numbers and activity are considered. It is recognised that there will be a requirement for increased staffing in centres where children and young people with complex needs are treated, in centres that offer specialist services and at centres treating more than 80 patients per year. However, the staffing levels presented will allow commissioners to compare the staffing levels that exist currently in their centres with the minimum recommended (bed numbers may also vary depending on levels of shared care undertaken).

The employment costs of the medical, nursing and other staff caring for children with cancer at a principal treatment centre with 15 beds and treating about 80 new patients per year is approximately £2.47 million per year (±25%, range £1.85 million to £3.0 million). The estimated annual cost per bed at each centre treating children, at the proposed staffing level is about £165,000 (±25%, range £124,000 to £206,000). The estimated annual cost per child with cancer, to provide a safe and sustainable service at the proposed level of staffing, is about £31,000 (±25%, range £23,000 to £38,700).

The cost calculations used for young people **do not include all the** clinical staff that would be involved with the patients' care, primarily because tumours would be site-specific rather than age-specific. Ancillary, catering or administration workforces are not included in either estimate. These factors would need to be considered by commissioners.

A principal treatment centre for young people with cancer with minimum staffing levels for a unit with 8 beds caring for a minimum of 60 patients per year would cost an estimated £1.0 million per year (±25%, range £0.75 million to £1.25 million). The annual employment

cost per bed is estimated to be £124,700 (±25%, range £93,500 to £156,000). For young people, the annual cost per new patient is estimated to be £16,600 (±25%, range £12,500 to £20,800).

In many cases core staff at principal treatment centres and some shared care centres have been funded through charitable sources. The minimum staffing levels described above should be considered by commissioners as core requirements for NHS funding. This could represent an additional NHS expenditure for children with cancer of about £0.24 million per principal treatment centre per year for outreach nurses and play specialists alone. Some sessional time has been funded through charities; this should also be considered by commissioners.

Any additional staff requirement as a result of the recommendations in the Manual would need to be considered by commissioners at a principal treatment centre level. Finance directors were asked to provide information regarding the level of investment in staffing children and/or young people with cancer for the financial year 2002/3. Using both the standard deviation from the finance directors' survey and the sensitivity analysis from the staffing levels to produce a safe and sustainable service, there is a resulting range of –£0.22 million (representing a saving) to £2.21 million (representing a shortfall) in a centre treating a mean of 80 new patients per year. This wide range could result from a difference in reporting methods by the finance directors and requires further investigation at a local level. It could also result from:

- differing levels of staffing required for treating children and young people with complex needs
- differing levels of shared care activity between centres
- some non-consultant grade doctors being funded from other sources, such as training budgets
- research staff being funded directly through research monies.

It should be acknowledged that any additional staff requirement might not require new staff: some NHS staff might be redeployed or re-designated.

It was apparent from the needs assessment conducted to inform the development of the Manual that some centres had limited access to physiotherapists, speech and language therapists, occupational therapists, play specialists or clinical psychologists. It was also stated that 24-hour on-call systems had been withdrawn in some centres because of nursing staff shortages. In view of current NHS national staff shortages any required recruitment may not be immediate.

The full staffing requirement and other associated services for a shared care centre are complex to cost, and the data provided were incomplete. It has therefore not been possible to estimate the cost of providing shared care.

## Multidisciplinary teams

The members of the MDTs based at principal treatment centres and shared care centres are outlined in the Manual. The attendance at MDT meetings for children and young people with cancer will vary according to need and whether the meeting is diagnostic, treatment, psychosocial or palliative.

It is anticipated that there will currently be approximately 25 core MDTs based at the principal treatment centres in England and Wales, comprising 17 UKCCSG centres plus 8 existing, or shortly to open, Teenage Cancer Trust (TCT) units. Where new units for young people are developed, the number of MDTs will rise. In addition, there will be MDTs at non-principal treatment centres with shared care arrangements.

Members of MDTs for children and young people will generally be employed by the principal treatment centres or shared care centres. Local commissioners will need to consider the opportunity costs of any increase in existing MDT meetings and some centres may need to employ additional staff as a consequence. In addition, consideration would need to be given to whether existing meetings are held within normal working hours. This has not always been the case in the past. The Manual recommends that each principal treatment centre has an MDT coordinator. It is probable that not all teams currently have coordinators or adequate administrative support. It is anticipated that each coordinator would facilitate all MDTs for children and young people with cancer based at the principal treatment centre. It is assumed that this post would be full time, Clerical and Administrative Grade 4–5. The salary plus on-costs would be about £21,500 per full time post per annum. Local commissioners would need to investigate whether the principal treatment centre has an existing coordinator in post.

Additional video-conferencing equipment may be required in some principal treatment centre and hospitals with shared care arrangements to facilitate MDT working. Teleconferencing offers the advantages that travel time is reduced, allowing for more efficient use of scarce specialist staff. This would mainly affect the shared care teams.

The cost of a video-conferencing system with high-quality image transfer capability would be about £15,000 (£18,000 inclusive of VAT and delivery) per centre: this would comprise a mobile

video-conferencing unit, two plasma screens (for added functionality) and a visual presenter (Document Camera) for high magnification requirements, and installation, software and a 3-year maintenance contract.

## Training and educational needs

The training and educational needs of the core staff to be employed in the principal treatment centre to provide a safe and sustainable service have been estimated. The estimations for courses are based on existing course costs and with reference to the Royal Colleges. The costs of time have not been taken into account because continuing professional development (CPD) is incorporated into current NHS contracts. It may be that some Trusts will incur opportunity costs, in particular locum costs. This will need to be considered at both a principal treatment centre and a more local level.

The estimated annual costs associated with training and education for CPD of the core staff for each principal treatment centre that treats children would be about £75,200 (±25%, range £56,400 to £94,000). The estimated annual cost of CPD for a young people's unit would be about £31,500 (±25%, range £23,600 to £39,400). This assumes a basic professional skill level as a baseline.

Additional calculations would be required at a cancer network or local level to calculate the costs relating to CPD for those staff employed at shared care centres and providing community support, and indeed any specific training that might be required in the principal treatment centre.

## Place of care

The estimated cost of planning, building and equipping one new unit for young people, with accommodation for both inpatients and day cases would require an expenditure of about £1.0 million (range £0.75 million to £1.25 million).

Staffing one additional unit for young people would entail recurring annual costs of £1.0 million (±25%, range £0.75 million to £1.25 million) per unit, based on the estimates for staffing to provide a safe and sustainable service for a unit with 8 beds treating 60 patients a year. This estimate includes nursing, activity coordinators and some medical support. Not all of the staff would be new: many might be redeployed from existing adult or paediatric wards. The estimate assumes that additional medical staff would be shared with other age groups.

Since these facilities are yet to be commissioned, the additional funding and staffing requirements will be incurred over a number of years in line with commissioning decisions.

## Financial support for the NHS from charitable sources

Members of the GDG considered it important to assess the extent to which charities support NHS services for children and young people with cancer. Therefore, although this is not an economic implication of the key recommendations in the Manual, it has been included for completeness.

The financial contribution to research and the care and support of children and young people with cancer from charitable sources is estimated to be between £32.9 million and £48.8 million per annum. This comprises between £19.3 million and £32 million raised from charitable sources that specifically support children and young people with cancer, with a further £13.5 million to £16.6 million contributed to children and young people as a result of fund-raising by cancer charities focusing on people with cancer. It was not possible to estimate the charitable contribution to hospice services for children and young people with cancer. It is often the case that staff working in specialist centres and in the community are funded by charities. These include paediatric oncology outreach nurse specialists (POONS), who are often funded by charities, including CLIC Sargent and Macmillan Cancer Relief. These charitable sources of funding currently form an essential aspect of the service provision for children and young people with cancer for both staffing and equipment.

# How this guidance manual was produced

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



The first stage in the development of the guidance was the production of a scope (Appendix 2), which defined in detail the patient population, the healthcare settings, and services and key areas of clinical management that the guidance should cover. This was then subject to a 4-week consultation with registered stakeholders in line with NICE methodology. Following this, a multidisciplinary GDG was formed comprising clinicians representing the main stakeholder organisations and representatives from relevant patient organisations and charities (Appendix 6.1). The GDG was convened by the NCC-C and chaired by Dr Cerilan Rogers in close association with the Clinical Lead, Dr Meriel Jenney. All GDG members made and updated any declarations of interest. The Group met monthly during development of the guidance and NCC-C staff provided methodological support and leadership for the development.

During the development phase of the guidance the GDG identified areas where there was a requirement for expert input on particular specialist topic areas. These topics were addressed by the production of a position paper by a recognised expert who had been identified via the relevant registered stakeholder organisation. All relevant expert positions papers are presented in Appendices F to L of the Evidence Review.

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

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

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



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

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

All the evidence reviews used to inform the manual are summarised in the document *Improving Outcomes in Children and Young People with Cancer: The Research Evidence* and this includes details of all the studies appraised. This document is available on CD-ROM, a copy of which is included on the inside cover of the manual.

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

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

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

Appendix 6

# People and organisations involved in production of the guidance

Appendix 6.1

# Members of the Guidance Development Group (GDG)

**GDG Chair**

| | |
|---|---|
| Dr Cerilan Rogers | Director, National Public Health Service for Wales |

**GDG Lead Clinician**

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

**Group Members**

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

| | |
|---|---|
| Dr Anthony Michalski | Consultant Paediatric Oncologist, Great Ormond Street, London |
| Professor Adrian Newland | Professor of Haematology, North East Thames Cancer Network |
| Dr Frank Saran | Consultant Clinical Oncologist, The Royal Marsden NHS Foundation Trust |
| Mr Richard Spicer | Consultant Paediatric Surgeon, Bristol Children's Hospital |
| Mrs Janet Vickers | Macmillan Paediatric Oncology Outreach Nurse Specialist, Alder Hey Hospital, Liverpool |
| Dr Jeremy Whelan | Consultant Medical Oncologist, University College London Hospitals NHS Trust |
| Dr Andrew Winrow | Consultant Paediatrician, Kingston Hospital |

Appendix 6.2

# Organisations invited to comment on guidance development

Action for Sick Children

Addenbrooke's NHS Trust

Afiya Trust, The

Anglesey Local Health Board

Association for Children with Life-Threatening or Terminal Conditions

Association of Breastfeeding Mothers

Association of Children's Hospices

Association of Clinical Biochemists, The

Association of Hospice and Specialist Palliative Care Social Workers

Association of Professional Music Therapists

Association of Surgeons of Great Britain and Ireland

Association of the British Pharmaceuticals Industry (ABPI)

Aventis Pharma

Bard Limited

Barts and the London NHS Trust – London

Bath and North East Somerset PCT

Bayer PLC

Bedfordshire & Hertfordshire NHS Strategic Health Authority

Bexley Care Trust NHS

Birmingham Heartlands & Solihull NHS Trust

Blackburn with Darwen PCT

Brain and Spine Foundation

British and Irish Orthoptic Society

British Association for Counselling and Psychotherapy

British Association for Parenteral & Enteral Nutrition (BAPEN)

British Association of Art Therapists

British Association of Dermatologists, The

British Association of Head and Neck Oncologists

British Association of Oral and Maxillofacial Surgeons

British Association of Paediatric Surgeons



British Association of Plastic Surgeons

British Dietetic Association

British Fertility Society

British Infertility Counselling Association

British Liver Trust

British National Formulary (BNF)

British Nuclear Medicine Society

British Oncology Pharmacy Association

British Orthopaedic Association

British Paediatric Neurology Association

British Paediatric Pathology Association

British Paediatric Psychiatry & Psychology Group

British Psychological Society, The

British Psychosocial Oncology Society

British Society for Haematology

British Society for Paediatric Endocrinology and Diabetes (BSPED)

British Society of Paediatric Radiology

British Thyroid Association

Cancer and Leukaemia in Childhood (UK)

Cancer Black Care

Cancer Research UK

Cancer Services Collaborative 'Improvement Partnership' (CSCIP)

Cancer Services Co-ordinating Group

Cancer Voices

CancerBACUP

CEMACH

Cephalon UK Ltd

Changing Faces

Chartered Society of Physiotherapy

Children's and Adolescent Cancer Partnership (CACP)

Christian Lewis Trust – Cancer Care for Children

Chugai Pharma UK Ltd

Clatterbridge Centre for Oncology NHS Trust

College of Occupational Therapists

Community Psychiatric Nurses' Association

ConvaTec

Department for Education and Skills

Department of Health

Eisai Limited

Eli Lilly and Company Ltd

Faculty of Dental Surgery

Faculty of Public Health

General Medical Council

Gloucestershire Hospitals NHS Trust

Gorlin Syndrome Group

Great Ormond Street Hospital for Children NHS Trust

Healthcare Commission

Help Adolescents with Cancer

Help the Hospices

Hertfordshire Partnership NHS Trust



Institute of Physics and Engineering in Medicine

Joint Committee on Palliative Medicine

King's College Hospital NHS Trust

Leeds Teaching Hospitals NHS Trust

Let's Face It

Leukaemia Research Fund

Lymphoma Association

Macmillan Cancer Relief

Medicines and Healthcare Products Regulatory Agency (MHRA)

Merck Pharmaceuticals

Move4Health

National Alliance of Childhood Cancer Parent Organisations

National Cancer Alliance

National Cancer Network Clinical Directors Group

National Cancer Research Institute (NCRI) Clinical Studies Group and National Cancer Research Network (NCRN)

National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)

National Council for Palliative Care

National Patient Safety Agency

National Public Health Service – Wales

National Youth Advocacy Service

Neonatal & Paediatric Pharmacists Group (NPPG)

NHS Modernisation Agency, The

NHS Quality Improvement Scotland

Novartis Consumer Health (Novartis Medical Nutrition)

Novartis Pharmaceuticals UK Ltd

Ortho Biotech

Pfizer Limited

Plymouth Hospitals NHS Trust

Princess Alexandra Hospital NHS Trust

Queen Mary's NHS Trust

Richmond & Twickenham PCT

Rotherham Primary Care Trust

Royal College of Anaesthetists

Royal College of General Practitioners

Royal College of General Practitioners Wales

Royal College of Nursing (RCN)

Royal College of Ophthalmologists

Royal College of Ophthalmologists – 2nd Contact (Child and Adolescent Cancer)

Royal College of Paediatrics and Child Health

Royal College of Pathologists

Royal College of Physicians of London

Royal College of Psychiatrists

Royal College of Radiologists

Royal College of Speech and Language Therapists

Royal College of Surgeons of England

Royal College Patient Liaison Groups

Royal Liverpool Children's NHS Trust

Royal National Orthopaedic Hospital NHS Trust

Samantha Dickson Research Trust, The

Sargent Cancer Care for Children

Scottish Intercollegiate Guidelines Network (SIGN)

Serono Pharmaceuticals Ltd

Sheffield Children's NHS Trust

Social Care Institute for Excellence (SCIE)

Society and College of Radiographers

Society for Endocrinology

Society of British Neurological Surgeons

South & Central Huddersfield PCTs

Specialist Child and Adolescent Mental Health Service

Tameside and Glossop Acute Services NHS Trust

Taunton and Somerset NHS Trust

Teenage Cancer Trust, The

Teenager Cancer Trust Multidisciplinary Forum

Thames Valley Strategic Health Authority

The Association for Family Therapy

The Leukaemia Society UK

The Medway NHS Trust

The Royal Society of Medicine

The Royal West Sussex Trust

UK Association of Cancer Registries

UK Brain Tumour Society

UK Childhood Leukaemia Working Party

UK Children's Cancer Study Group

UK Pain Society

University College London Hospitals NHS Trust

Welsh Assembly Government (formerly National Assembly for Wales)

Wessex Cancer Trust

Wyre Forest Primary Care Trust

Young Minds

# Appendix 6.3

# Researchers carrying out literature reviews and complementary work

| | |
|---|---|
| **Overall Co-ordinators** | |
| Dr Fergus Macbeth | National Collaborating Centre for Cancer, Cardiff |
| Dr Andrew Champion | National Collaborating Centre for Cancer, Cardiff |
| **Project Managers** | |
| Dr Andrew Morton | National Collaborating Centre for Cancer, Cardiff |
| Angela Bennett | National Collaborating Centre for Cancer, Cardiff |
| **Senior Researcher** | |
| Dr Mary Webb | National Collaborating Centre for Cancer, Cardiff |
| **Information Specialists** | |
| Stephanie Arnold | National Collaborating Centre for Cancer, Cardiff |
| Karen Field | National Collaborating Centre for Cancer, Cardiff |
| **Health Economists** | |
| Dr Dyfrig Hughes | Director, Centre for the Economics of Health, Institute of Medical and Social Care Research, University of Wales, Bangor |
| Dr Rhiannon Tudor Edwards | Director, Centre for the Economics of Health, Institute of Medical and Social Care Research, University of Wales, Bangor |

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| Pat Linck | Research Officer, Centre for the Economics of Health, Institute of Medical and Social Care Research, University of Wales, Bangor |
| Bronwyn Tunnage | Research Fellow, Centre for the Economics of Health, Institute of Medical and Social Care Research, University of Wales, Bangor |

**Needs Assessment**

| | |
|---|---|
| Dr Siân Griffiths | Specialist Registrar, National Public Health Service for Wales |
| Dr David Fone | Clinical Senior Lecturer/ Honorary Consultant, National Public Health Service for Wales |
| Dr Quentin Sandifer | Director of Health Improvement, Kent and Medway Strategic Health Authority |

## Appendix 6.4

# Expert advisors to the Guidance Development Group

| | |
|---|---|
| Dr Deborah Christie | Consultant Clinical Psychologist, University College London and Middlesex Hospitals, London |
| Professor Monty Duggal | Consultant in Paediatric Dentistry, University of Leeds |
| Dr Richard Hain | Senior Lecturer in Paediatric Palliative Medicine, University Hospital of Wales, Cardiff |
| Miss Tasneem Khalid | Principal Pharmacist, Haematology/Oncology Services, Royal Manchester Children's Hospital |
| Mr James Leggate | Consultant Neurosurgeon, Salford Royal Hospitals |
| Dr Kieran McHugh | Consultant Paediatric Radiologist, Great Ormond Street Hospital, London |
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# Appendix 6.5

# Reports‡ commissioned to assist with guidance development

| Organisation | Report title |
|---|---|
| Teenage Cancer Trust | Analysis of Teenage Cancer Patient Questionnaire Responses<br><br>Author: Teenage Cancer Trust Conference, 2004 |
| National Children's Bureau | Consultation with Children with Cancer, Their Siblings and Parents<br><br>Authors: Jessica Datta, Claire Lanyon, Lucy Read, Emma Sawyer, Janine Shaw, Ben Street |
| Children's and Adolescent Cancer Partnership (CACP) | Results of Questionnaire Distributed to Paediatric Oncology and Teenage Cancer Treatment Centres in the United Kingdom in November 2003 |

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

Appendix 6.6

# Members of the Guideline Review Panel

**Chair**

John Hyslop

**Members**

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# Appendix 7

# Glossary of terms

**Allied health professional (AHP)**
One of the following group of healthcare workers: physiotherapists, occupational therapists, art therapists, chiropodists/podiatrists, dietitians, drama therapists, music therapists, orthoptists, paramedics, prosthetists/orthotists, radiographers, speech and language therapists.

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

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

**Antiemetic**
A drug that prevents or reduces nausea and vomiting.

**Antifungal**
A drug that treats infections caused by fungi.

**Aseptic**
Free from infection or septic material, sterile.

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

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

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

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

**Cancer Networks**
The organisational model for cancer services to implement the NHS Cancer Plan, bringing together health service commissioners and providers, the voluntary sector and local authorities. There are currently 34 Cancer Networks in England covering a population of between 600,000 and 3 million (two-thirds serve a population of between 1 million and 2 million people).

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

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

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

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



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

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

**Clinical oncology**
The specialist treatment of cancer patients, particularly through the use of radiotherapy, but which may also use chemotherapy.

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

**Computed tomography**
An X-ray imaging technique.

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

**Cytogenetics**
The study of chromosomes and chromosomal abnormalities.

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

**Diagnostic imaging**
Visualising body structures to help identify a disease or condition, by using X-ray, ultrasound, radioisotopes or magnetic resonance.

**Diagnostic radiographer**
Diagnostic radiographers are responsible for providing safe and accurate imaging examinations.

**Dietitian**
A specialist in the study of nutrition.

**Embryonal tissue**
Tissues formed during the development of an embryo.



**Emetogenic**
Induces vomiting.

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

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

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

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

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

**Febrile**
Feverish.

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

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

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

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

**Gonadal failure**
Failure of the gamete-producing gland: an ovary, testis or ovotestis.

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



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

**Haematology**
The branch of medicine concerned with the study and treatment of disorders of the blood and blood-forming tissues.

**Haemopoietic progenitor transplant**
Taking stem cells (which can develop into new bone marrow cells) obtained from a sample of blood, bone marrow or umbilical cord blood, and injecting them into a patient.

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

**Hepatic**
Referring to the liver.

**Heterogenous**
Derived from a different source or species.

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

**Histopathology**
The study of microscopic changes in diseased tissues.

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

**Hypofractionated stereotactically guided retreatment**
Radiotherapy given with a few large doses aimed very precisely, from a large number of different angles.

**Immunoglobulin**
A protein that acts as an antibody.

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



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

**Immunosuppression**
Suppression of the immune system.

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

**Intracranial pressure**
Pressure that occurs within the cranium (skull).

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

**Intrathecal**
Into the fluid around the spine.

**Intravenous**
Into a vein.

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

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

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

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

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

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



**Lumbar puncture**
A procedure in which a needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give anti-cancer drugs intrathecally.

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

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

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

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

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

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

**Metronomic prescribing**
Giving anti-cancer drugs in small, regularly repeated doses, rather than as large single doses.

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

**Morbidity**
Either: (1) the state of being diseased; or (2) the morbidity rate, which reflects the number of cases of disease per unit of population in any specific region, age group, disease or other classification, usually expressed as cases per 1000, 10,000 or 100,000.



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

**Mortality**
Either: (1) the condition of being subject to death; or (2) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000.

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

**Needle biopsy**
The removal of tissue or fluid through a needle for examination under a microscope

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

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

**Neuroimaging**
Production of images of the brain by non-invasive techniques, for example, computed tomography, magnetic resonance imaging or positron emission tomography.

**Neurological**
Having to do with the nervous system.

**Neuro-oncology**
The branch of medical science dealing with tumours of the nervous system.

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

**Neuroradiologist**
A doctor trained in radiology specialising in creating and interpreting pictures of the nervous system.

**Neuroradiology**
The branch of radiology that deals with the nervous system.



**Neurorehabilitation**
Rehabilitation that concentrates on improving physical and cognitive or understanding impairment resulting from damage to the nervous system.

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

**Neurosurgery**
Surgery on any part of the nervous system.

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

**Neutropenic episode**
A period of time when there is neutropenia.

**Neutropenic sepsis**
Life-threatening infection made more severe by the reduced neutrophil count.

**Neutrophils**
A specific sub-type of granulocyte.

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

**Occupational therapist**
A specialist who is concerned with a person's ability to participate in meaningful occupations and the impact of their environment on this; they will work with a person to design a programme of intervention based on the individual's unique lifestyle, environment and preferences.



**Oncologist**
A doctor who specialises in treating cancer.

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

**Oral**
Having to do with the mouth.

**Oral mucositis**
Inflammation of the mucous membranes in the mouth (sore mouth).

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

**Paediatric oncologist**
An oncologist who specialises in the treatment of children.

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

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

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

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

**Pathological behaviour**
The natural history of a disease.

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

**Percutaneous puncture**
A puncture in the skin made in order to perform a procedure through the skin, such as a biopsy; aspiration of fluid from a space below the skin using a needle, catheter and syringe; or installation of a fluid in a cavity or space by similar means.

**Peripubertal**
Around the time of puberty.

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

**Phenotypes**
A group of organisms that resemble each other in appearance.

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

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

**Positron emission tomography**
A highly specialised imaging technique using radioisotopes that is used to produce a computerised image of metabolic activity of body tissues.

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

**Prognostic factor**
Patient or disease characteristics, for example, age or comorbidity, which influence the course of the disease under study.

**Protocol**
An agreed policy that defines appropriate action.

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

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



**Psychosocial**
Concerned with psychological influence on social behaviour.

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

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

**Radiologist**
A doctor who specialises in creating and interpreting pictures of areas inside the body. An interventional radiologist specialises in the use of imaging techniques to assist treatment, for example, the insertion of intravenous catheters.

**Radiosurgery**
A radiation therapy technique that delivers radiation directly to the tumour while sparing the healthy tissue.

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

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

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

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

**Sequelae**
A secondary consequence or result.

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

**Sonographer**
A specialist in the use of ultrasound.

**Speech and language therapist**
A specialist trained in the assessment and management of communication and swallowing difficulties.

**Spinal puncture**
See lumbar puncture.

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

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

**Therapeutic radiographer**
Therapeutic radiographers are responsible for providing radiotherapy treatment.

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

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

**Trans-sphenoidal**
Performed through the sphenoid bone, part of the base of the skull below the brain.

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

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

**WHO analgesic ladder**
Guidelines issued by the World Health Organization that describe a method of prescribing increasing strength standardised pain killers for patients with increasing pain.

# Abbreviations

| | |
|---|---|
| **ACCIS** | Automated Childhood Cancer Information System |
| **AHP** | allied health professional |
| **CMV** | cytomegalovirus |
| **CNS** | central nervous system |
| **CPD** | continuing professional development |
| **CSF** | cerebrospinal fluid |
| **CT** | computed tomography |
| **CVC** | central venous catheter |
| **DNA** | deoxyribonucleic acid |
| **DH** | Department of Health |
| **EBMT** | European Group for Blood and Marrow Transplantation |
| **ENT** | ear, nose and throat |
| **ETP** | electronic transmission of prescriptions |
| **FNP** | febrile neutropenia |
| **FTE** | full-time equivalent |
| **GCP** | good clinical practice |
| **GDG** | Guidance Development Group |
| **GDP** | general dental practitioner |
| **HSCT** | haemopoietic stem cell transplantation |
| **ICCC** | International Classification of Childhood Cancer |
| **ICD** | International Classification of Diseases |
| **ISCT** | International Society for Cellular Therapy |
| **JACIE** | Joint Accreditation Committee ISCT–EBMT |
| **MDT** | multidisciplinary team |
| **MRI** | magnetic resonance imaging |
| **NCB** | National Children's Bureau |
| **NCC-C** | National Collaborating Centre for Cancer |

| | |
|---|---|
| **NCIC-ONS** | National Cancer Intelligence Centre at the Office for National Statistics |
| **NCRI** | National Cancer Research Institute |
| **NRCT** | National Registry of Childhood Tumours |
| **NSF** | National Service Framework |
| **ODA** | operating department assistant |
| **ONS** | Office for National Statistics |
| **PET** | positron emission tomography |
| **PICU** | paediatric intensive care unit |
| **POONS** | paediatric oncology outreach nurse specialist |
| **RNA** | ribonucleic acid |
| **RCT** | randomised controlled trial |
| **SHA** | strategic health authority |
| **SHOT** | serious hazards of transfusion |
| **SIGN** | Scottish Intercollegiate Guidelines Network |
| **SNLG** | Scotland and Newcastle Lymphoma Group |
| **TCT** | Teenage Cancer Trust |
| **UKCCSG** | United Kingdom Children's Cancer Study Group |
| **WHO** | World Health Organization |

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