# Complete Summary

## GUIDELINE TITLE

Improving outcomes in children and young people with cancer.

## BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Improving outcomes in children and young people with cancer. London (UK): National Institute for Health and Clinical Excellence (NICE); 2005 Aug. 194 p. [3 references]

## GUIDELINE STATUS

This is the current release of the guideline.

## COMPLETE SUMMARY CONTENT



## SCOPE

### DISEASE/CONDITION(S)

Malignant diseases, which for convenience are grouped into three categories:

- Solid tumours
- Haematological malignancies
- Central nervous system (CNS) malignancies

### GUIDELINE CATEGORY

Counseling
Diagnosis
Evaluation
Management
Treatment

## CLINICAL SPECIALTY

Critical Care
Dentistry
Family Practice
Internal Medicine
Medical Genetics
Nutrition
Oncology
Pediatrics
Psychiatry
Psychology
Radiation Oncology

## INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Clinical Laboratory Personnel
Dentists
Dietitians
Health Care Providers
Hospitals
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

## GUIDELINE OBJECTIVE(S)

- To provide recommendations on service provision for children and young people with malignant disease, based on the best available evidence
- 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

## TARGET POPULATION

- 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 the United Kingdom Children's Cancer Study Group [UKCCSG])
- Families of children and young people with cancer

Groups that are **not** covered include:

- Children and young people with benign tumours
- Children and young people with immune dysfunction or benign haematological conditions

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

## INTERVENTIONS AND PRACTICES CONSIDERED

### Diagnosis

1. Pathology (histopathological diagnosis)
2. Imaging (i.e., magnetic resonance imaging [MRI])

### Management/Treatment

1. Chemotherapy
2. Surgery
3. Neurosurgery
4. Radiotherapy
5. Supportive care
    - Management of febrile neutropenia
    - Provision of central venous access
    - Blood product support
    - Pain management
    - Management of nausea, vomiting and bowel disturbance
    - Nutrition support
    - Oral and dental care
6. Rehabilitation
7. Psychosocial care
8. Management of long-term sequelae
9. Palliative care
10. Bereavement support

### Service Organisation

1. Delivery of care by a multidisciplinary team (MDT)
2. Continuity of care
3. Provision of protocol-based care
4. Place of care (principal treatment centres, hospitals, other locations)
5. Cancer networks
6. Open communication with children, young people, and families
7. Workforce development
8. Other service considerations include:
    - Information requirements
    - Child protection
    - Education
    - Hospital facilities

## MAJOR OUTCOMES CONSIDERED

- Patient/parent/carer satisfaction
- Diagnostic accuracy
- Survival
- Morbidity

- Mortality
- Quality of life

## METHODOLOGY

### METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

#### Sources of Evidence

A number of relevant existing guidelines and reviews were accessed (see Appendix 1 of the original guideline document 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 guideline development group (GDG) (see Appendix 6.4 of the original guideline document 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.

### NUMBER OF SOURCE DOCUMENTS

Not stated

### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

#### Levels of Evidence

**1++** High quality meta-analyses, systematic review of randomised controlled trials (RCTs), or RCTs with a very low risk of bias

**1+** Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

**1-** Meta-analyses, systematic review of RCTs, or RCTs with a high risk of bias*

**2++** High quality systematic reviews of case-control or cohort studies. High quality case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal

**2+** Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal

**2-** Case-control or cohort studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal*

**3** Non-analytic studies (for example, case reports, case series)

**4** Expert opinion, formal consensus

*Studies with a level of evidence "-" should not be used as a basis for making a recommendation.

## METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

## DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

### Synthesising Evidence

There were very few randomised controlled trials (RCTs) relevant to the majority of the clinical questions. This is a widely acknowledged problem with health service research and every effort was made to maximise the retrieval of relevant high quality literature. Where available, evidence from good quality systematic reviews was appraised and included in the evidence tables; not all studies in the reviews were individually appraised.

Evidence for each topic was extracted into tables and summarised in the form of a considered judgement form (modified from the Scottish Intercollegiate Guidelines Network methodology). The tables recommended for use in the National Institute for Health and Clinical Excellence (NICE) methodology manual were modified to accept the type of studies identified for service guidance. The quality of evidence was graded using the NICE hierarchy of evidence and the quality checklists. Evidence was usually rejected if graded as poor quality, apart from where it had been cited in the expert position papers and/or was of Level 1 type and was highly relevant to the question.

## METHODS USED TO FORMULATE THE RECOMMENDATIONS

Informal Consensus

## DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

### Drafting Recommendations

The Guideline Development Group (GDG) members were allocated specific topic areas and asked to review the evidence tables pertaining to the topic and draft recommendations for the service guidance. At the 10th GDG meeting of the 12 during the development phase, the GDG members participated in an event that involved external facilitation. This resulted in a list of three types of recommendations that were classified as essential, desirable, and potential. The resulting recommendations were then examined by the Chair and Clinical Lead prior to writing the first draft of the guidance.

### Agreeing Recommendations

Once an early draft of the guidance was produced, the GDG members were asked to review the draft document and consider whether:

a. there appeared to be any major gaps in the synthesised evidence
b. the recommendations were justified from the evidence presented and whether they were sufficiently practical and precise so that health service commissioners and the relevant front line health care professionals could implement them

During the development of this guidance no formal consensus methods were used. Consensus was achieved by informal means during GDG meetings and correspondence outside the meetings.

The absence of high quality evidence for the majority of the clinical questions/topic areas made the grading of the recommendations impractical.

### Writing of the Guidance

The first formal draft version of the guidance was coordinated by the Chair and Clinical Lead of the GDG in accordance with the decisions of the GDG.

## RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

## COST ANALYSIS

### 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 National Health Service (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.

For further details of the economic implications of the guidance, see Appendix 4 of the original guideline document.

## METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

## DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The guideline was validated through two consultations.

1. The first draft of the guideline (The full guideline, National Institute for Clinical Excellence (NICE) guideline and Quick Reference Guide) were consulted with Stakeholders and comments were considered by the Guideline Development Group (GDG)
2. The final consultation draft of the Full guideline, the NICE guideline, and the Information for the Public were submitted to stakeholders for final comments.

The final draft was submitted to the Guideline Review Panel for review prior to publication.

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

Please refer to the original guideline document for discussions on epidemiology, current services, and service use.

#### The Care Pathway

#### Presentation and Referral

Primary care trusts/local health boards should ensure that appropriate training is provided for the implementation of the recommendations in the National Institute for Health and Clinical Excellence (NICE) clinical guideline on *Referral Guidelines for Suspected Cancer* as they apply to children and young people. This provision should include the new forms of primary care contact, such as National Health Service (NHS) Direct, walk-in centres, nurse practitioners and health visitors, and the use of relevant information technology (IT) links.

Specific education for professionals in primary and secondary care in the recognition and referral of suspected central nervous system (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 below on place of care).

#### Diagnosis

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* [see reference #59 Appendix 1 of the original guideline document]. 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* [see reference #78 in Appendix 1 of the original guideline document].

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 magnetic resonance image (MRI) scanning should be sufficient to ensure that suspected cases of CNS, bone and soft tissue tumours, and other malignancies can be investigated rapidly.

**Treatment**

*Chemotherapy*

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 Department of Health (DH) guidelines on the safe prescribing, dispensing, and administration of intrathecal chemotherapy [see reference #32 in Appendix 1 of the original guideline document].

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.

*Surgery*

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 specialties, 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 allied health professionals (AHPs) should be planned before surgery.

*Neurosurgery*

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, ear, nose, and throat [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 cerebrospinal fluid (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.

*Radiotherapy*

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

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 Joint Accreditation Committee ISCT-EBMT [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 customized immobilisation devices and the use of three-dimensional conformal planning, but delays for other reasons should be minimised.

**Supportive Care**

*Febrile Neutropenia*

There should be a written protocol for the management of febrile neutropenia (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* [see reference #59 in Appendix 1 of the original guideline document]

- 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* [see reference #72 in Appendix 1 of the original guideline document]

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 an 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

*Central Venous Access*

Insertion of central venous catheters (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.

*Blood Product Support*

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.

*Pain Management*

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).

*Management of Nausea, Vomiting, and Bowel Disturbance*

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.

*Nutrition*

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.

*Oral and Dental Care*

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.

**Rehabilitation**

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 continuing professional development (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.

**Psychosocial Care**

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* [see reference #61 in Appendix 1 of the original guideline document].

**Long-term Sequelae**

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 of the original guideline document).

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 specialties 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 post-pubertal 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* [see reference #62 in Appendix 1 of the original guideline document].

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.

**Palliative Care**

To ensure there is equitable access to palliative care, which encompasses the core elements in Table 3 of the original guideline document, 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 of the original guideline document, 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 paediatric oncology outreach nurse specialist (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.

**Bereavement**

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.

## Service Organisation

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*

Care should be delivered throughout the care pathway by MDTs, including all relevant staff (see Tables 4-6 of the original guideline document). 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 sub-specialists. 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.

*Continuity of Care*

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.

*Protocol-based Care*

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.

**Place of Care**

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* (see reference #27 in Appendix 1 of the original guideline document) and the *Wales National Cancer Standards* (see reference #21 in Appendix 1 of the original guideline document).

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 of the original guideline document and in the documents *Defining Staffing Levels for Children's and Young People's Services* [see reference #72 in Appendix 1 of the original guideline document] and the NICE Guidance on *Improving Outcomes in Haematological Cancers* [see reference #59 in Appendix 1 of the original guideline document].

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

The principal treatment centre for children with cancer should be a United Kingdom Children's Cancer Study Group (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 [see reference #35 in Appendix 1 of the original guideline document]. 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 of the original guideline document).

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.

**Cancer Networks**

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.

**Communication with Children, Young People, and Families**

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.

**Research**

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 trial 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.

**Workforce Development**

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.

## Other Service Considerations

*Information Requirements*

Experts should be commissioned at a national level to consider the issues related to the registration of cancers in 15- to 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*

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*

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*

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.

### CLINICAL ALGORITHM(S)

None provided

## EVIDENCE SUPPORTING THE RECOMMENDATIONS

### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting each section of the care pathway is specifically stated in the technical companion titled *Improving outcomes in children and young people with cancer*. *The evidence review*. NICE clinical guideline. 2005 Aug. 467 p. Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

### POTENTIAL BENEFITS

In general, the guidance may lead to significant and lasting changes in 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.

Refer to the original guideline document for anticipated benefits upon implementation of guidelines under the following topics:

- Presentation and Referral
- Diagnosis
- Treatment: Chemotherapy
- Treatment: Surgery
- Treatment: Neurosurgery
- Treatment: Radiotherapy
- Supportive Care: Febrile Neutropenia
- Supportive Care: Central Venous Access
- Supportive Care: Blood Product Support
- Supportive Care: Pain Management
- Supportive Care: Management of Nausea, Vomiting and Bowel Disturbance
- Supportive Care: Nutrition
- Supportive Care: Oral and Dental Care
- Rehabilitation
- Psychosocial Care
- Long-term Sequelae
- Palliative Care
- Bereavement
- Delivery of Care: Multidisciplinary Teams

- Delivery of Care: Continuity of Care
- Delivery of Care: Protocol-based Care
- Place of Care
- Cancer Networks
- Communication with Children, Young People and Families
- Research
- Workforce Development

### POTENTIAL HARMS

Not stated

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

The Measurement sections of the guidance list "structures," "processes," and "outcomes" directly related to the recommendations and suggest ways in which implementation of guidance can be measured. 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. Resource implications are also provided for each section of "The Care Pathway."

### IMPLEMENTATION TOOLS

Audit Criteria/Indicators
Foreign Language Translations
Patient Resources
Quick Reference Guides/Physician Guides

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

End of Life Care
Living with Illness

### IOM DOMAIN

Effectiveness
Patient-centeredness
Timeliness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Improving outcomes in children and young people with cancer. London (UK): National Institute for Health and Clinical Excellence (NICE); 2005 Aug. 194 p. [3 references]

## ADAPTATION

Not applicable: The guideline was not adapted from another source.

## DATE RELEASED

2005 Aug

## GUIDELINE DEVELOPER(S)

National Collaborating Centre for Cancer - National Government Agency [Non-U.S.]

## SOURCE(S) OF FUNDING

National Institute for Health and Clinical Excellence (NICE)

## GUIDELINE COMMITTEE

Guideline Development Group (GDG)

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All guideline development group (GDG) members made and updated any declarations of interest.

## GUIDELINE STATUS

This is the current release of the guideline.

## GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) format from the National Institute for Health and Clinical Excellence (NICE) Web site.

## AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Improving outcomes in children and young people with cancer. Analysis of the potential economic impact of the guidance. NICE clinical guideline. 2005 Aug. 91 p. Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.
- Improving outcomes in children and young people with cancer. An assessment of need for cancer services for children and young people in England and Wales. NICE clinical guideline. 2005 Aug. 114 p. Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.
- Improving outcomes in children and young people with cancer. The evidence review. NICE clinical guideline. 2005 Aug. 467 p. Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.

## PATIENT RESOURCES

The following is available:

- Healthcare services for children and young people with cancer. Understanding NICE guidance – information for the public. 2005 Aug. 4 p. Available in English and Welsh in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.



## NGC STATUS

This summary was completed by ECRI on December 6, 2005. The information was verified by the guideline developer on September 19, 2006.

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Date Modified: 11/3/2008