

**NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE**

**SCOPE**

**1 Guidance title**

Guidance on Cancer Services: Improving Outcomes in Child and Adolescent Cancer

**1.1 Short title**

Child and adolescent cancer

**2 Background**

- a) The National Institute for Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Cancer to develop service guidance on child and adolescent cancer for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and the Welsh Assembly Government (see Appendix). The guidance will provide recommendations for service provision that are based on the best available evidence.
- b) The Institute's service guidance will support the implementation of the National Cancer Plan. The service guidance, clinical guidelines and technology appraisals published by the Institute after the Cancer Plan was issued will have the effect of updating the plan.

**3 Clinical need for the guidance**

- a) Each year in the UK there are approximately 1500 new cases of cancer diagnosed in children under the age of 15, according to the United Kingdom Childhood Cancer Study Group (UKCCSG). The treatment for these children is often complex, with the frequent use of intensive

chemotherapeutic regimens (including high-dose therapy with autologous stem cell rescue), necessitating prolonged inpatient therapy for many. Children and their families commonly have to travel long distances to receive specialised care – although some areas have developed local shared-care centres, in other areas this has not been possible or suitable – 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 needs of adolescents with cancer have been increasingly recognised over recent years. Many adolescents do not feel comfortable within the paediatric setting, but they have unique needs that may not be addressed within adult services. It is generally believed that the ideal is to have a separate unit designated for the treatment of adolescents (and very young adults), and for these patients to have a choice about where they wish to receive their care. Many adolescent patients also have complex problems requiring intensive chemotherapy, and the prognosis for this group (compared with that for younger children) is often less good.
- c) An important part of the care of children with cancer is their follow up. 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 is needed as children mature. Overall survival rates for children are now approximately 70%. It has been estimated that approximately 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 and adolescents (below the age of 19 years) diagnosed with cancer, leukaemia and related conditions as defined by the International Classification of Childhood Cancer (incorporating the amendments used by UKCCSG).

### **4.1.2 Groups that will not be covered**

- a) Young adults aged 19 years and over.
- b) Children and adolescents with benign tumours.
- c) Children and adolescents with immune dysfunction or benign haematological conditions.
- d) Children and adolescents requiring bone marrow transplantation for other (non-malignant) reasons.

## **4.2 Healthcare setting and services**

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

- a) Primary care, including early diagnosis, care in the community of those receiving active treatment, follow up and palliative care.
- b) Secondary care.
- c) Tertiary care in specialist paediatric and adolescent oncology centres and their shared-care partner units.

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

### **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:
- GPs and other members of the primary care team
  - general paediatricians, haematologists and other specialists (for example, ENT surgeons and orthopaedic surgeons)
  - specialist paediatric oncologists and haematologists
  - pathology, including specialist diagnostic resources such as molecular genetics facilities and cytogenetics services
  - radiology.
- b.) Treatment services:
- surgery – general, neurosurgery, and specialist (including sarcoma, bone and retinoblastoma )
  - chemotherapy
  - bone marrow transplantation
  - radiotherapy
  - specialist and community-based palliative care.
- c.) Support services:
- psychology
  - social work
  - community liaison
  - practical support – including accommodation, travel, grants and benefits, domestic help, holidays and childcare
  - education
  - other multidisciplinary services – for example dietitians, physiotherapists and occupational therapists
  - palliative care and bereavement support.

d.) Follow up:

- need, frequency, location and by whom.
- specialist follow up for late effects of treatment (including growth, endocrine, fertility, cardiac and neurological effects).

#### **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 draft scope, which is subject to a 4-week period of consultation with stakeholders. After the consultation, the scope will be re-drafted and submitted to the Guidelines Review Panel and then to the Institute's Guidance Executive for approval. Once approved, it will be posted on the Institute's website.

##### **4.5.2 Guidance**

The development of the service guidance recommendations will begin in June 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*

## DRAFT FOR CONSULTATION

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

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## **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 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.”

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