

## SCOPE

### 1 Guidance title

Guidance on cancer services: Improving outcomes for people with tumours of the brain and central nervous system (CNS).

#### 1.1 Short title

Brain and CNS tumours

### 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 tumours of the brain and central nervous system for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and 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*.
- c) The guidance will also refer to other NICE service guidance documents, including *Improving outcomes in haemato-oncology (published October 2003)*, *Referral guidelines for suspected cancer*, *Supportive and palliative care for people with cancer*, *Improving outcomes in child and adolescent cancer* and *Improving outcomes in head and neck cancers (all currently under development)* . Cross reference will be made to these and other documents as appropriate.

### **3 Clinical need for the guidance**

- a) There were approximately 4000 new cases of primary brain and other CNS tumours in adults registered in the UK during 1999 (Cancer Research UK). These cancers can occur at any age but are more common in adults older than 40 years of age. In 2001, around 3300 adults died from brain and other CNS tumours (Cancer Research UK). These figures are now widely thought to be an underestimate and this issue needs investigation as part of the Guidance development.
- b) Brain and CNS tumours are relatively uncommon, at around 2% of all registered cancers, but their treatment is complex. It requires the input of many different healthcare professionals. A proportion of patients are significantly disabled physically, cognitively and psychologically by their illness and the consequences of treatment. This adds considerably to the overall burden of care provided by both healthcare professionals and the family.

### **4 The guidance**

- a) The guideline development process is described in detail in three booklets that are available from the NICE website (see '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 guidance are described in the following sections.

## **4.1 Population**

### **4.1.1 Groups that will be covered**

- a) Adults with tumours of the brain (including primary CNS lymphomas and teratomas), meninges and other sites in the central nervous system.
- b) Adults with cranial nerve tumours and primary base-of-skull tumours.
- c) Adults with pituitary tumours.
- d) Adults with brain metastases from tumours at other primary sites, in whom complex neurological or neurosurgical intervention is required.
- e) Adults with syndromes where there is a recognised increased lifelong risk of CNS tumour formation.
- f) Adults with nerve-root tumours compressing the spinal cord.

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

- a) Children and adolescents with brain and CNS tumours, whose care will be covered by the guidance on *Child and adolescent cancer* that is under development.
- b) Adults and children with tumours of peripheral nerves.
- c) Adults and children with other space-occupying brain lesions (for example, arteriovenous malformation).
- d) Adults and children with spinal cord compression due to metastatic disease.

## **4.2 Healthcare setting and services**

- a) Primary care, including diagnosis, treatment and follow up.
- b) Secondary care, including the role of cancer networks and multidisciplinary teams.
- c) Tertiary care in cancer centres and neurosurgical units.
- d) Specialist rehabilitation centres.

- e) Quaternary care in specialist centres for particular indications (for example, stereotactic radiosurgery).

### **4.3 Key areas of clinical management**

The following key areas of clinical management will be included, because they have direct implications for service delivery.

- a) Services for diagnosis and staging (excluding those being addressed as part of the updated referral guidelines), including:
- primary care
  - acute services in secondary care
  - neurology departments
  - neurosurgical departments
  - pathology departments
  - diagnostic radiology departments
  - psychiatric services
  - endocrinology departments.

In addition, the guidance will address the important issue of data collection and registration of brain and CNS tumours.

- b) Treatment services, to include treatment in the following settings:
- neurology departments
  - neurosurgical departments
  - cancer centres
  - cancer units
  - endocrinology departments
  - specialist centres providing stereotactic radiosurgery.
- c) Follow up.
- d) Rehabilitation and supportive care of patients with physical and neuropsychological/neuropsychiatric disability.

- e) Specific elements of supportive and palliative care that meet the particular needs of patients with brain and CNS tumours, and of their families and carers.
- f) Communication and information resources for patients, carers, family members and healthcare professionals
- g) Health service research and clinical trials on service delivery.

#### **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 on practice and outcomes for adults with brain and CNS tumours.

#### **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 will begin in January 2004.

### **5 Further information**

Information on the guideline 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](http://www.nice.org.uk)). Information of 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 formally known as the National Assembly for Wales, NAW) asked the Institute:

“To prepare service guidance for the NHS in England and Wales for tumours of the brain and central nervous system. This would form part of the *Improving cancer outcomes* series with NICE expected, as previously, to involve DH and NAW 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.”