

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 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*.

The guidance will also refer to other NICE service guidance documents currently under development, including *Referral guidelines for suspected cancer*, *Supportive and palliative care for people with cancer*, *Improving outcomes in child and adolescent cancer*, *Improving outcomes in head and neck cancers* and *Improving outcomes in haemato-oncology*. 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 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 over 40 years of age. In 2001 around 3300 adults died from brain and other CNS tumours (Cancer Research UK).
- b) Although relatively uncommon tumours, at around 2% of all registered cancers, the treatment of brain and CNS tumours is complex requiring the input of many different health care professionals. A proportion of patients are significantly disabled both physically and mentally by their illness and the consequences of treatment, and this adds considerably to the overall burden of care for both family and health professionals.

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.

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- b) Adults with pituitary tumours.
- c) Adults with brain metastases from tumours at other primary sites in whom complex neurological or neurosurgical intervention is required.

4.1.2 Groups that will not be covered

- a) Children and adolescents with brain and CNS tumours.
- b) Adults and children with tumours of the cranial and peripheral nerves (for example, optic glioma and auditory neuroma).
- c) Adults and children with other space occupying brain lesions (for example, arteriovenous malformation).

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

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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.

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 – radiotherapy, chemotherapy and immunotherapy
 - specialist centres providing stereotactic radiosurgery.
- c) Follow up.
- d) Rehabilitation and supportive care of patients with physical and neuropsychological 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) Information resources for patients, carers and family members.
- 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 upon practice and outcomes for adults with brain and CNS tumours.

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 Guideline 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 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). 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 (previously 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.”

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