

Central Nervous System (CNS) Tumours – developing a national tumour registry

NCIN Data Briefing

Background

Primary tumours of the Central Nervous System (both in and impinging on the brain and or spinal cord) are an important cause of morbidity and mortality in the UK population. Based on data from England between 2002 and 2007, and using the World Health Organisation (WHO) International Classification of Disease codes for malignant Central Nervous system (CNS) tumoursⁱ, the overall survival for adults with such tumours is about 40% at one year, and around 24% 5 years after diagnosis. Non-malignant CNS tumoursⁱⁱ in adults fare much better with nearly 90% survival at 5 years.

CNS tumours (both malignant and non-malignant) form the second most common group of cancers in people under 16 years old and account for 25% of all cancers in this age groupⁱⁱⁱ. The common tumour types differ from those seen in adults and survival is better for this age group with 80% alive at one year and 65% at five years. However, the impact of brain tumours on these young people can be particularly devastating with many years of life lost or years lived with disability^{iv}.

What we know

Compared to other more common malignant tumours we know relatively little about CNS tumours, despite their significant effect on the population through long-term disability and years of lives lost. This is for several reasons: Firstly, as a group they are relatively rare; figures for 2006 in the UK show that there were 4532 malignant and 3470 non-malignant tumours registered; less than 2% of all the malignant tumours registered that year^v. Secondly, they encompass a very large number of different histological types; the WHO's latest histological classification of brain tumours^{vi} identifies more than 130 different varieties and changes of this classification system over the last twenty years makes rigorous long-term studies difficult.

Data from the UK for the last 17 years shows that gliomas and meningiomas account for the majority of brain tumours with over 60 of the brain tumour types in the WHO classification having fewer than 10 cases diagnosed over the period. Finally, the brain and central nervous system is an anatomically difficult site to access and this makes tissue biopsy and surgery difficult and due to the presence of the blood-brain-barrier conventional chemotherapy is often less effective. Nevertheless, advances in radiology and molecular genetics are transforming diagnosis, new forms of radiotherapy and its combination with newer forms of chemotherapy are improving survival and the introduction of molecular targeted therapies are showing promise.

What we need to know

The rarity of so many of these tumours types means that if we are to understand this group of cancers, we need to collect accurate information on every case. Misclassifying or failing to recognise even one or two uncommon cancers has the potential to compromise the validity of the information held on these tumours.

KEY MESSAGE:

Augmented cancer registration for CNS tumours has the potential to transform our knowledge for this group of patients.

Accurate, detailed registration using the new WHO histological classification will allow us to correlate the tumour type with the clinical, pathological and molecular features and ultimately the response to treatment and outcomes.

The best data on brain tumours that we have in England currently comes from the UK cancer registries. We have analysed these data for CNS tumours diagnosed between 1990 and 2006. Our results show that while these data can be moderately informative for the very common brain tumours it is not sufficiently reliable to provide a core national registry. The National Cancer Intelligence Network (NCIN) CNS Site-Specific Clinical Reference Group, has concluded that the best interests of future patients would be served by improving existing and developing new data collection methods to underpin a new national brain tumour registry.

Defining a future national brain/CNS dataset

Under the auspices of the National Cancer Intelligence Network and in common with the other NCIN Site-Specific Clinical Reference Groups (SSCRGs), the brain and CNS SSCRG has defined an expanded dataset to capture key information on this tumour group. Although it will be several years before this dataset is widely available and can be reliably and consistently collected across the NHS, development of the dataset is important groundwork and will mandate data items that need to be collected on all patients diagnosed with these tumours. The new national brain tumour registry, being piloted in collaboration with the NCIN and the UK Association of Cancer Registries, will hold all the information in the new dataset.

New data flows from Neuroscience Treatment Centres

Work has started to collect data directly from the 28 neuroscience treatment centres in England; the majority of centres had submitted data by the end of 2010. Furthermore, around 30% of brain tumours are now diagnosed by radiology and traditional cancer registration data collection has not had access to this information. In partnership with Cancer Research UK and the National Early Diagnosis and Intervention Initiative we are developing national systems to harvest information from Radiology Information Systems to support the brain and CNS registry.

Patient groups and all the clinical expert groups treating brain tumours are committed to the development of the new national brain tumour registry. The registry will be a national resource underpinning clinical practice, quality and research on brain, CNS, skull-base and pituitary tumours and delivering direct patient benefit.

ⁱ Malignant brain tumours are those with an ICD code C70-72, and are essentially equivalent to the tumours that have WHO grades II-IV.

ⁱⁱ Non-malignant brain tumours are those with ICD10 D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5 and broadly correspond to WHO grade I tumours.

ⁱⁱⁱ CancerStats: Childhood Cancer - Great Britain and UK, Cancer Research UK, November 2010

^{iv} Burnet NG, Jefferies SJ, Benson RJ, Hunt DP, Treasure FP. [Years of life lost \(YLL\) from cancer is an important measure of population burden and should be considered when allocating research funds](#). Br J Cancer. 2005 Jan 31;92(2):241-5.

^v Office for National Statistics (www.statistics.gov.uk); and Cancer Research UK (www.cancerresearchuk.org)

^{vi} [WHO classification of Tumours of the Central Nervous System](#). Eds Louis, D.N 4th Edition IARC Lyon

The National Cancer Intelligence Network is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.