Annex B

Brain & CNS cancers 2015

Epidemiology

1. The incidence of brain & CNS tumours in England was reported to be just under 4,000 in 2007.[1] This is expected to increase further with an aging population and also (possibly) because of increased access to imaging. The prevalence of brain & CNS cancer is not known but is likely to be growing faster than incidence as the people living with brain and CNS tumours (especially young people) is increasing. In addition, low grade lesions are not considered to be cancers even though these tumours are likely to eventually progress to a more malignant phenotype

2. Although brain tumours account for less than 2% of all primary tumours they are responsible for 7% of the years of life lost from cancer before the age of 70. If the burden of disease is considered in terms of the average years of life lost per patient, brain tumours are one of the most lethal cancers with over 20 years of life lost. The high rates of mortality make these rare cancers into the third leading cause of cancer-related death among economically active men between 15-54 years of age and the fourth leading cause of cancer-related death among economically active women between 15-34 years of age. The latest survival trends for patients with CNS malignancies have remained largely static reflecting the lack of therapeutic options for patients with these cancers.

3. It is also likely that the number of people with metastatic brain cancer will increase over the next 5 years especially as patients live longer after treatment for their primary cancers. For example, metastatic brain cancer is becoming more common in women with advanced breast cancer who have had their life extended by Herceptin. Therefore, greater resourcing and prioritisation of this growing problem will need to be established by 2015.

IOG implementation

4. The key priority for people with brain & CNS tumours is that the Improving Outcomes Guidance (IOG) is fully implemented across the country. An increase in workforce will be required to make this a reality.

Prevention

5. Radiation and genetic syndromes are possible causes of brain and CNS cancers as are some treatments for other primary cancers. It might be possible to reduce the risk of second cancers following treatment for primary brain or CNS cancer if DNA damaging primary treatments can be avoided. Some effect in reducing second cancer risk will occur with more sophisticated X-ray treatments, including image-guided radiotherapy (IGRT) and intensity modulated radiotherapy (IMRT). The biggest effect will be seen with the use of proton radiotherapy for children and younger adults requiring radiotherapy.

[1] Office for National Statistics, *Cancer Statistics registrations: Registrations of cancer diagnosed in 2007, England.* Series MB1 no.38. 2010, National Statistics: London. [C70-C72]

6. It is unlikely that there will be any conclusive evidence on the prevention of brain & CNS tumours by 2015 but information collected by the brain tumour registry should help build up a picture of where and why cases develop.

Screening

7. There will be no evidence to support the introduction of a national population based screening programme for brain & CNS cancers by 2015. Some brain & CNS tumours have genetic links but these are very rare and screening is unlikely to be feasible.

Raising Awareness/ Improving GP referral/Diagnostics

8. GPs have a difficult job to do as headaches in particular are very common and brain & CNS tumours are very rare – they often have no clear symptom patterns. Although there is NICE GP referral guidance it is unclear how helpful it has been to GPs – less than 1% of brain & CNS tumours are referred via the 2 week wait target. There may be roles for other healthcare professionals, particularly optometrists and A+E specialists, in identifying brain & CNS tumours and there may also be opportunities to learn from what is happening in other countries. The National Awareness and Early Diagnosis Initiative (NAEDI) should consider how best to raise awareness of the signs and symptoms of brain & CNS tumours amongst healthcare professionals and the public.

9. It was noted at the Royal College of General Practitioners conference *Sustainable primary care: growing healthy partnerships* (October 2010) that access to investigations would have facilitated the diagnosis in 20% of brain cancers, more than any other cancer.

10. The Royal College of Paediatrics and Child Health has recently published revised guidelines for the diagnosis of brain and spinal tumours in children and young people. There is an associated public awareness campaign planned for 2011/12 which will heighten awareness in the childhood population and their families. This is likely to create a demand for a similar response in the adult population so as to ensure timely access to diagnosis across the age spectrum.

11. It is likely that the recent expansion of scanning capacity in the NHS might enable GPs to lower the threshold for such tests. This might result in an increased diagnosis of low grade glioma which can be life threatening. However, increasing referrals for scans also gives a risk of identifying cysts and even early MS which a patient might find hard to come to terms with and may be difficult to manage.

12. By 2015:
    a. an assessment needs to have taken place to see if GP referral guidelines are effective and, if not, what other mechanisms might help GPs to make appropriate referrals for suspected cancers eg. a risk stratification tool to help GPs and patients make decisions;
    b. the role of optometrists and lessons from other countries should have been considered as potential ways to improve referral;
    c. a pilot to consider how best to manage unresolved headaches should take place and learning shared;

d. GPs should have received advice about appropriate referrals for scanning the head and be acting on it. There should be effective IT networks across hospitals so that scans suggestive of a brain or CNS tumour are promptly sent to and assessed by the nearest specialist neuroscience team;
e. all patients presenting with a seizure, transient ischaemic attack (TIA) or stroke should have at least a CT, preferably an MRI, on admission.

13. Over the next five years it is likely that more advanced imaging and molecular diagnostic techniques will become available. For example, it is expected that by 2015 there will be evidence to support increased use of PET in: the assessment of the grade of brain tumours; assessment of response to treatment; and assessment of treatment side-effects versus new tumour growth.

14. Advanced imaging includes PET and MRI techniques which necessitate the use of a 3T magnet. These imaging techniques are not commonly available in neuroscience units in the UK, which means that patients can be denied access to full evaluation of their tumour prior to treatment. This may limit the number of treatment options and the ability to monitor response to treatment. All neuroscience units which treat brain tumours should have ready access to high field magnets, preferably on site, by 2015. There should also be sufficient spare capacity on the routine imaging list to allow emergency patients to be scanned in a timely manner prior to surgery.

15. It will be vital that neuroscience centres are staffed by specialist neuroradiologists and neuropathologists and medical physicists as set out in the IOG if such techniques are to be introduced. These staff groups are in short supply and this can lead to delays in diagnosis. Therefore, investment and support for training and development of these staff groups should be a key focus to provide rapid diagnosis and enable patients to access early entry to treatment pathways. Specialisation in neuropathology should become a recognised training component of the Royal College of Pathologists.

16. Despite these expected advancements a biopsy will still be the key diagnostic tool for the foreseeable future.

<u>Treatment</u>

17. All brain & CNS tumour patients should have access to a specialist MDT.

18. It is expected that there will be more combination therapy over the next 5 years including surgery with chemo-radiation. New developments in treatment are therefore likely to be an addition to, rather than replacement for, other treatments.

19. If brain & CNS cancers are picked up earlier it will be important to have access to new treatments that have been developed. There is concern that NICE's current technology appraisal methodology does not work fairly for patients with rare cancers. For example, where cancer drugs treat small patient groups it can be hard to demonstrate cost effectiveness using the existing QALYs. In particular, NICE does not take sufficiently into account quality of life and socio-economic issues including the impact on a family. Drug evaluation might

benefit from the use of Average Years of Life Lost, which could be calculated in collaboration with the lead CNS tumour registry. The Cancer Drugs Fund and the introduction of value-based pricing may have improved access to drugs for brain & CNS cancers by 2015.

20. By 2015, there will be an increased ability to use validated prognostic and predictive genetic and molecular testing to target patient treatment. Ensuring that these tests are available should be a national priority.

21. Modern radiotherapy treatments are likely to become more common over the next 5 years such as highly conformal radiotherapy and hyperfractionated radiotherapy. Without access to these new treatments many hospitals will not be able to take part in new trials as they will not be able to meet the trial protocols. Proton therapy is also expected to have an increasing role to play in the treatment of brain tumours especially for children and access to this treatment needs to be equitable across the country.

22. By 2015:
    a. NICE needs to have reconsidered its appraisal methodology to ensure that it is not unfairly disadvantaging brain & CNS cancer patients;
    b. all patients must have appropriate access to NICE-approved technologies;
    c. the 31 day waiting times target needs to be met for all treatments not just the first definitive treatment. This will help patients requiring radiotherapy following brain surgery;
    d. patients with benign tumours also need to receive treatment quickly. For example, a patient with a benign brain tumour could go blind if they wait too long for treatment;
    e. patients in England need to have equitable access to proton therapy as evidence to support its use develops. A national mechanism is already in place for referrals abroad for proton therapy, under the auspices of the National Commissioning Group for Highly Specialised Services. Increasing referrals are likely and more resource may be required to run this mechanism in an efficient and timely manner.

<u>Supportive & Palliative Care</u>

23. Length of stay in hospital is estimated to be longer for patients recovering from brain & CNS cancers than any other cancer. Part of this length is contributed to by problems getting access to post treatment rehabilitation and also access to equipment and support that might be needed on discharge. This is particularly important for young people for whom discharge to a nursing home would be inappropriate and also for families and carers who need help and support to care for their loved ones. Care needed is not just medical.

24. The CNS has a key role to play in the experience of both the patient and their family/carers. They are a key source of support throughout the care pathway and are particularly important in ensuring a seamless transition between different aspects of the pathway, e.g. neurosurgery to oncology services. However, their role is at risk due to financial restrictions in employing Trusts. Commissioners should be made aware that a neuro-oncology service requires CNSs and that the funding for these posts should be explicit in the costing of the service. The value

of the CNS role can be measured in terms of improved patient and carer experience and should be audited as such.

25. By 2015 it is vital that:
    a. health and social care are working together to ensure that patients are not staying in hospital longer than they need to and that families and carers are receiving an appropriate level of support;
    b. the vital role that the CNS plays is recognised by commissioners;
    c. all newly diagnosed brain & CNS tumour patients are provided with an appropriate, clear and helpful information prescription, including information on support groups;
    d. physical and cognitive rehabilitation services will have been improved, reducing unnecessary delays in discharge.

Follow up

26. For brain and CNS tumours there are two main types of follow up:
    a. cancer follow up (including looking for recurrence) – this is best done from the specialist centre with the GP informed so that they can take a guided role as required;
    b. rehabilitation follow-up (including late effects of treatment) – this could be done closer to home via shared care mechanisms with specialist input as required.

27. As well as follow-up with specialist neuro-oncologists, follow-up must include endocrine and ophthalmology services. Endocrine services in particular may be required for the patient's lifetime.

28. Both types of follow-up need to be tailored to a patient's individual needs. In both models there are key roles for:
    a. patient support groups;
    b. psychiatric and psychological support;
    c. social worker support;
    d. Cancer Nurse Specialists (CNSs);
    e. GPs.

29. The cohort of adult survivors of childhood brain & CNS tumours with high survival rates (e.g. low-grade glioma) is growing every year. This constitutes a major burden of patients who will require long-term neuroscience and rehabilitation follow-up. Particular care needs to be given to patients who need to transition from paediatric to adult services. The involvement of TYA (Teenagers and Young Adults) units may help in this. Typically, more consultant time is required for transitioning patients than for adult patients, which will need to be made available.

30. By 2015 there needs to be clarity about management of long and short term follow-up for patients.

Data collection

31. A National Brain Tumour Registry has been set up under the umbrella of the National Cancer Intelligence Network (NCIN). This should help improve the

collection of accurate information about brain & CNS cancer incidence and outcomes.

32. By 2015 the key audits identified in the IOG need to be embedded to ensure that services are IOG complaint and patients are benefitting. Patient reported outcome measures (PROMs) should be an integral part of these audits.

33. The National Cancer Data Set for Brain should begin to gather data on metastatic brain disease beginning with referral pattern to CNS MDTs and overall survival data.

Research

34. Primary and secondary CNS malignancy should become a key focus of neuroscience and cancer research.

35. As patients with brain tumours cannot drive, they can find it difficult to travel distances to major clinical trial centres. Appropriate support, e.g. subsidised travel, will need to be provided to facilitate greater participation in trials.

36. Storing tissues for research (tumour banking) is becoming increasing difficult and action needs to be taken on a national basis to resolve this. Tissue should be collected from every patient together with a blood sample. The material should be sent to designated research centres for appropriate analysis and research. Care should be taken to ensure that smaller units or units without an academic infrastructure are encouraged to participate. A hub and spoke model may be developed allowing wider participation.

Commissioning

37. Due to the rarity of brain & CNS tumours, there is a strong argument for specialist national commissioning of services for these cancer types.

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