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PARKES January 2014

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Brain Tumour Alliance Australia Inc

2014-15 Pre-Budget Submission

- This submission by BTAA focuses attention on the public policy implications of the leading single cause of cancer related mortality in children and young to middle aged adults in Australia. It presents evidence on the special case for supporting brain tumour patients, their families and carers and community.
    - Brain tumours are the highest cause of cancer death for persons under 40.
    - Brain tumours kill more children than any other cancer, and are now equal with accidental drowning as the leading cause of childhood mortality from any cause.
    - Brain cancer incidence is also not known to be related to lifestyle factors, nor based on gender.

- The key recommendation is to provide funding to support increased access to specially trained, registered brain tumour care-coordinators to act as patient advocates, coordinating care for people with brain tumours, their families and carers.
    - The McGrath Foundation breast care nurses provides a model of service delivery that could be readily adapted for the 1,600 Australians diagnosed with malignant brain tumours each year.
        - These new positions could be structured to provide support for other rare cancer groups with poor prognosis, where appropriate.
        - These positions would recognise the special support needs of children with brain tumours.

- Additionally, we propose that the Commonwealth Government:

- Revisit the "National Health Priority Area Cancers set in the 1990s, to ensure cancer control priorities are commensurate with contemporary needs.
- Fund the AGOG Epi Study project for the years 2015 to 2020.
- Strengthen the capacity of the Cooperative Trials Group for Neuro-Oncology (COGNO) by at least doubling existing infrastructure and research grants.
- Establish grants for health professionals and students with a particular interest in brain tumours and other poor prognosis cancers to attend professional conferences or other educational events on neurooncology.

We therefore present to the government several funding opportunities. Ideally, BTAA would like to see each of these initiatives funded, with our key priority being brain tumour care coordinators.

However, given constrained revenues and expanding costs for governments, we accept that the choice to fund any of them will be determined by policy preferences. One or more of these initiatives may be especially consistent with broader health policy objectives of the government.

If successfully funded, and found to be useful, we ask that any of the above initiatives also be considered to be adapted to other cancer types, particularly those with poor outcomes. Similarly, we ask that the reciprocal hold true, and that brain tumours be considered among the first for quick adaptation of Commonwealth funded initiatives specific to other cancer types that are proving to be particularly effective.

The attached information provides background on the policy problem and policy response recommendations.

BTAA also supports any initiatives to establish centres of excellence of research and treatment for brain tumours, a much neglected disease.

BTAA particularly supports any initiatives in the area of paediatric brain tumours, which will be a key focus for BTAA in 2014.

Appendices include a summary of brain tumour facts and statistics (**Appendix 1**) and information about BTAA (**Appendix 2**).

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Summary of policy response recommendations

1. **That the Australia Government health priorities set in the 1990s be revisited, and that brain tumours be recognised as an Australian Government national health priority, in collaboration with the State and Territory Governments.**

   This initiative would focus public attention and health policy on the significant burden of brain tumours and other poor outcome cancers in Australia in terms of comparatively young average age at the time of incidence, and high numbers of annual person life years lost.

   By revisiting the prioritisation, there is potential for significant gain in terms of the quality of life of both patients and families, and their contribution to Australia.

2. **That the Australian Government provide funding of $2 million over four years ($500,000) commencing in 2014-5, for the creation of ten brain tumour care coordinators.**

   This funding be provided to treatment centres where there is interest and administrative support, and made available if required to ensure continuity of funding of the approximately 14 existing central nervous system (including brain) care coordinators (some part time).

   Brain tumours cause complex health issues and may require intervention from numerous specialities including neurosurgery, radiotherapy, medical oncology, neurology, and (too often) palliative care. Combined chemo-radiotherapy is now standard care for glioblastoma brain tumours and brings with it particular challenges and side-effects.

   BTAA envisages that Corporate Friends and individuals and fundraising would provide funding for an additional ten brain tumour care coordinators

   Moreover there is potential for such positions to support people living with other cancers such as pancreatic, unknown primary, lung and rarer cancers with poor outcomes.

   This initiative has a precedent in the Federal Government's current funding of McGrath Breast Care Nurses in the 2013-14 budget of $19.5 million over four years commencing in 2013-14. (see: '**World Leading Cancer Care — additional funding for McGrath Foundation Breast Care Nurse initiative — continuation and expansion'**

3. **That the Australian Government consider, as a matter of priority, funding the AGOG Epi Study project for the years 2015 to 2020.**

   BTAA proposed that the rate be equal to the current total annual funding, adjusted for inflation. These funds could be administered through the current major funder for the project, Cancer Australia.

4. **That the Australian Government further strengthen the capacity of the Cooperative Trials Group for Neuro-Oncology (COGNO).**

   BTAA proposes at least a doubling the current infrastructure and research grants from $300k and $200k pa to $600k and $400k pa.

   These funds could also be administered through Cancer Australia which, together with Cancer Institute NSW, is the majority funder of COGNO.

5. **That the Australian Government provide education grants to enable health professionals to attend conferences on neurooncology.**

   Establish grants for health professionals and students with a particular interest in brain tumours and other poor prognosis cancers to attend professional conferences on neurooncology. These could also be tiered as 'early' or 'later' career stage grants, with latter being greater in value.

Definition

Central nervous system (CNS) neoplasms are commonly referred to as brain tumours. Increasingly, to harmonise terminology with other cancer types, the term 'brain cancer' has been used in Australia to describe high grade (malignant) brain tumours. The central nervous system comprises the brain, the meninges, the spinal column and other areas. This submission uses the term brain tumour to include all CNS neoplasms unless otherwise specified.

The Problem

Brain tumours can affect a person at any age, and unlike many other cancers and diseases, there is no known cause or prevention. A few agents are known to increase the risk of a brain tumour, including ionising radiation, and the chemical vinyl chloride. More recently, genome wide sequencing has identified variations (allelism) in certain genes that are associated with an increased risk of developing a brain tumour. However, only a small minority of brain tumour incidences can be attributed to any proven or suggested causal factor; Like many complex diseases, brain tumour aetiology remains unclear, with contributions from genetic, environmental, and majority of case but the vast majority of brain tumour types. As per most cancer types, increasing age is one of the highest risk factors, however it is notable that the age-distribution of brain tumour incidence shows considerable incidences from birth onwards, albeit reaching peaks in the 60 years plus age cohort.

From a health public viewpoint, brain tumours are particularly challenging, causing both physical and neurocognitive damage along with personality changes in some instances. Brain tumours are the only cancer to affect both body and mind; they strike at the very essence of a person. Brain tumour patients face particular difficulties and have relatively very little support in the community and very limited support from cancer organisations including health consumer organisations. In Australia, unlike other survivors and their supporters for many of the other cancer types that also have high population health burdens, brain tumour survivors have had very limited success in obtaining philanthropic support for expanding upon government and privately funded health care services,.

In economic framework terms brain tumours present a special case for government intervention to address 'market failure: in particular there is 'information failure' in the sense that brain tumours can impair decision making and judgement and compound the challenge of obtaining best standard of care treatment. Another term for this is information asymmetry, which is common to most areas of health care, but is especially prevalent and problematic in less common conditions, where awareness is typically lower in the wider public and health professionals alike, with the exception of those who have specialised. Information asymmetry is defined as: '…when one party to a transaction has more or better information than the other party.'…'Information asymmetry can prevent consumers from making fully informed decisions.'

In 1999, Andrew Podger, as Secretary of the Federal Department of Health and Aged Care (now Department of Health), and Philip Hagan, also from the department, advised the Federal government that[1]:

> 'The problem for government is that — largely because of market failures (which are particularly severe when it comes to health):
> - growth in expenditure on care can be unsustainably high;
> - yet not all justified care is provided;
> - and care of doubtful value can end up being paid for.
>
> This has led recent reforms to attempt to transform the Australian health care system along the following lines.
>
> ***Shifting the focus from providers to consumers***
>
> Empowering the patient (or the patient's agent) with information to inform choice has the potential to further change the focus from producers to consumers of health care. Thus an obvious way to combat the problem of information asymmetry is for government to act as the source of authoritative health information and to successfully communicate it to target populations in cost-effective ways. There is mounting evidence that properly informed consumers can make rational choices about health care. And better-informed patients should not threaten the traditional decision-making role of providers. Rather, decisions should be made jointly — reflecting and encouraging a genuine partnership between doctor and patient.
> A prominent role for patients — amounting to a consumer democracy in health care — is perhaps the best guarantee that reforms to the system will be soundly based.'

The fundamental problem discussed in this fifteen year-old report remains a barrier to receiving effective healthcare today, and particularly so in the case of less common conditions with poor outcomes, such as brain tumours.

Official statistics show brain tumours (malignant and benign) are responsible for more than 1,600 deaths a year in Australia, and ranks 5th in terms of life years lost from disease. (See **Attachment 1**).

[1] 'Reforming the Australian Health Care System The Role of Government' Department of Health and Aged Care Occasional Papers: New Series No. 1

Given the high mortality rates of malignant brain tumours, brain tumours overall have a relative low survival rate compared with other cancers. Malignant brain tumours are the second highest cause of death for children aged one to 14 years, second only to accidental drowning.

Brain tumours cause complex health issues and may require intervention from numerous specialities including neurosurgery, radio therapy, medical oncology, neurology, and (too often) palliative care. Combined chemo-radiotherapy is now standard care for glioblastoma brain tumours and brings with it particular challenges and side-effects.

According to research conducted by Brain Tumour Alliance Australia (BTAA) Inc (background on BTAA at **Attachment 2**) in January 2011, there were only eleven brain tumour care coordinators, or system navigators. They include two working in the paediatric area and nine in the adult area, some on a part time basis. Furthermore, some of these coordinator positions are reliant on philanthropic or industry sources of funding from year to year. The situation in 2014 is little changed.

With more than 1,600 Australians of all ages each year diagnosed with a primary malignant CNS tumour — one of the most lethal cancer diagnoses - the vast majority of patients and families are currently missing out on much needed care coordinator. There is strong evidence for a greater focus on CNS tumours, led by the Australian Governments to improve diagnosis and treatment that will reduce mortality and morbidity and increase survival times.

Justification

BUILDING UPON THE NATIONAL HEALTH PRIORITY AREA CANCERS LIST

Currently, there are seven National Health Priority Area Cancers recognised at the State/Territory and Commonwealth level in Australia. These were chosen on the basis of discussions and an iterative selection process between levels of government, health professionals, and the public in the years immediately leading up to 1996.

In the words of the 'First report on National Health Priority Areas' 1996[2], these were described as:

> '...specific cancers which represent issues of major concern in all States and Territories, and where significant gains can be achieved through prevention and disease management.' ....'Seven cancers have been targeted in the 'Cancer control' priority area—lung cancer, skin cancer (melanoma and non-melanocytic skin cancer), colorectal cancer, prostate cancer in males and cancer of the cervix and breast in females. Non-melanocytic skin cancer is the most frequently occurring cancer in the population, but the least life threatening.'

It further describes the key performance indicators for the endeavour, and therefore the purpose of prioritisation, as follows:

> The National Health Priority Area of 'Cancer control' is represented by a cross-section of indicators reflecting the continuum of care, from illness prevention to

[2] Australian Institute of Health and Welfare. Commonwealth Department of Health and Family Services AIHW Cat. No. PHE 1.

treatment, support services and palliative care. Primary outcome indicators include cancer incidence, mortality, five-year survival rates and quality of life of cancer patients, their carers and families. Indicators reflecting intermediate outcomes include risk factor prevalence rates and patient satisfaction with cancer treatment. Process indicators include screening participation rates and establishment of hospital-based cancer registries.

Given the large improvements in these indicators for many cancer types over the intervening years, for example with a commendable 14.2% improvement in mean 5-year relative survival rates for patients diagnosed in the years 2006 to 2010 versus those in 1988 to 1993[3], there may well be large discrepancies between the results of applying the prioritisation framework in 1996 and the results of applying the very same framework today. The question of whether a prioritisation framework of 18 years ago remains the best one for today – given the large developments in public health policy methodology in this time – is an additional, worthwhile question. Either way, what was a priority then may be less of a priority now, and vice versa.

From anecdotal experience, there is an 'accountability gap' in cancer control. State/Territory and Federal government agencies privately advise BTAA that far more needs to be done to address the continued poor patient outcomes in certain cancer types. However they report being constrained by the organisational charters to follow Government priorities, and those of the National Health Priority Area Cancers in particular.

On the other hand, parliamentarians report also being very concerned about the poor outcome cancers, but then state that the matter is out of their hands, as funding is limited, and that parliaments and Ministers have delegated cancer control functions to the relevant experts and heads of cancer control agencies. Therein lies the 'accountability gap'.

Non-government cancer control agencies have greater flexibility, but also report that – being funded by the public – they receive comparatively large donations to undertake research and provide support services for prevalent cancer types with relatively high survival, and few for the poor outcome cancers. In other words, popular support does not provide a means of rational resource allocation for reducing cancer burdens at the population level. An expected outcome, and the very reason for the existence of governments to impartially allocate resources based on the greater good.

Updating the priority cancers list through a contemporary prioritisation process is essentially a cost-neutral exercise for governments, but one with the almost guaranteed benefit of providing greater output (*e.g.*, improved survival rates) from an unchanged input (funding, intellectual effort, *etc*). It is an ideal policy for times of serious fiscal constraint.

Revisiting the prioritisation process at the Federal level would end the 'cancer blame game', and would also ventilate tensions that have been rising between patient advocates from different cancer types, who for years have been arguing without the benefit of a structured, rational framework. It would therefore improve health literacy in the population, engage consumers, and better ensure that cancer control priorities are commensurate with contemporary needs.

BRAIN TUMOUR CARE COORDINATORS

[3] Table 3.2. Page17 AIHW 2012. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer series no. 69. Cat. no. CAN 65. Canberra: AIHW.

BTAA conducted research on the needs for brain tumour care coordinators through a survey conducted in December 2010 – January 2011.

The 131 responses across all States and Territories provides strong evidence that health care professionals and consumers value the services of the small number of existing brain tumour care coordinators currently working in the Australian health system.

Patients and health professionals report that, where patients have had access to brain tumour care coordinators, it is evident that the outcomes are better.

Such care coordinators help patients and their carers navigate the complex health care system and enable more efficient access to choices available.

Workforce shortages for health care professionals are particularly acute for the various health professionals dealing with the particular challenges of brain tumour patients.

In private conversations, specialist health care professionals, including neurosurgeons, oncologists, and radiation oncologists advised BTAA that brain tumour care coordinators improve their efficiency and effectiveness by relieving their workload. They reported being able to see more patients, better focus the patient's attention on the most important points such as treatment options and upcoming milestones, and were able to better collaborate with specialist and allied health colleagues in providing cohesive, multidisciplinary care.

The consensus opinion of specialists at the forefront of cancer control efforts whether clinical, laboratory, or policy appears to be that the best hope for substantially improving survival rates in conditions with poor outcomes, such as brain tumours, are necessarily going to require the use of more than one modality (treatment approach), and therefore require multidisciplinary care. Indeed, the most successful advance in improving overall survival for patients with the highest grade (most malignant) of brain tumour has been concomitant (at the same time) radiotherapy and chemotherapy shortly after neurosurgery. This protocol was first reported by the neurooncologist Roger Stupp and colleagues in 2002, and the most recent analysis from their work in 2009[4] is that it provided an additional benefit of approximately 8% in 5-year overall survival for patients operated over the period 2000 to 2002 and followed thereafter. *I.e.,* per 100 diagnosed, a further eight survived beyond five years in addition to the number of survivors in the control arm.

We believe the specialists are genuine in their advice that brain tumour care coordinators improve the quality of care for patients, and better enable them to conduct clinical trials. We believe the many patients and caregivers reporting having very positive experiences with these positions, and being more confident when seeking health care services, are also telling the truth. We cannot provide 'evidence' in the form of a randomised control trial comparing patient outcomes *with-versus-without* a brain tumour care coordinator. We suggest that such research is unnecessary. Research on the effectiveness of the position has been undertaken in Australia, most recently in the Cancer Australia CanNET trials. An excerpt from recommendations in the final National Evaluation Report[5] is shown below:

[4] Stupp et al, 2009. Lancet Oncology. 10(5):459 to 466.
[5] CanNET National Support and Evaluation Service. Final National Evaluation Report. Miller. 2009

> *'Some of the CanNET networks piloted or further developed new and innovative roles for cancer care in their local jurisdictions and were able to demonstrate that roles such as cancer care coordinators, MDT [multi disciplinary team] coordinators and MDT administrators make the introduction and maintenance of quality MDTs less of a burden for clinicians.'*

In at least one case (the Canberra trial site), the effectiveness of the position was considered sufficient for the State/Territory government to agree to provide ongoing funding on a permanent basis, albeit as one of several other cancer types seen by this health professional.

The existing body of research, while by no means extensive, is uniformly positive in regards to the value provided by brain tumour care coordinators. We ask that these data indeed be considered sufficient evidence of the position's effectiveness to justify Commonwealth government expenditure on existing positions without guaranteed funding, and on new placements in geographic areas currently without access, particularly for public patients in regional and remote areas, as they have the greatest likelihood of receiving uncoordinated, sub-standard care.

For the leading cause of cancer related death in people under 40 in Australia, the brain tumour care coordinator position is the answer to the problem of information asymmetry discussed by Health Secretary Andrew Podger:

> '*There is mounting evidence that properly informed consumers can make rational choices about health care. And better-informed patients should not threaten the traditional decision-making role of providers. Rather, decisions should be made jointly — reflecting and encouraging a genuine partnership between doctor and patient.*'

The above outlined why brain tumours remain a serious problem for public health in Australia, and briefly discussed some of the approaches that have improved, albeit slightly, the outcomes for patients with high grade (malignant) brain tumours. Globally, the key efforts of health professionals with particular interests in improving survival rates for people with high grade (malignant) brain tumours is directed towards developing new therapies in a pre-clinical setting, and/or then undertaking randomised clinical trials to critically analyse evidence of improvement over existing treatments.

EPIDEMIOLOGICAL STUDY ON CAUSES

Recently, a research project, the Genomics and Clinical Outcomes of Glioma (AGOG) Epi Study, is undertaking a large-scale, Australian-wide epidemiological analysis of causal factors for brain tumours. The target sample size is 800 people with a brain tumour ('cases'), and 800 people without a brain tumour ('controls').

Funding for the research is being provided by Cancer Australia, among other funders, and these agencies should be commended for contributing to world-class research on the causes of brain tumours. It is the understanding of BTAA that funding for this project is only guaranteed until 2015, and even so will only last until then on a severely constrained expenditure. The complexity posed by the presence of over a 120 different types of brain tumours (see **Attachment 1**); Large number of genes, other DNA sequences, physical traits, lifestyle and environmental factors associated with brain tumour incidence, are considered to

be the major reasons for the lack of progress in this research field. However, the work is important as an understanding of the causal factors has been shown to facilitate improvements in rational medicine design and treatment options in other cancer types, with the HER2 gene mutation and Herceptin for breast cancer being a prime example.

CLINICAL TRIALS OF TREATMENTS

In Australia, the key group undertaking the majority of clinical trials in brain tumours is the Cooperative Trials Group for Neuro-Oncology (COGNO), established in 2007. Its intended purpose was to develop a central mechanism enabling a coordinated, structured approach to the management of large scale multi-centred neuro-oncology trials. Its focus is the conduct of investigator-initiated and collaborative group trials addressing important clinical questions in patients with brain tumours.

It is a member of the Cooperative Clinical Trials Groups of the Clinical Oncological Society of Australia (COSA), is funded by Cancer Australia and the Cancer Institute NSW, and is located at the National Health and Medical Research Council (NHMRC) Clinical Trials Centre (CTC), with the latter also coordinating the clinical trials activity within COGNO.

As the access for Australian's with brain tumours remains poor, particularly in regional areas, the Commonwealth should consider doubling the current annual funding for the Cooperative Trials Group for Neuro-Oncology (COGNO) infrastructure. BTAA understands the current infrastructure funding is approximately $300k a year and proposes an increase to $600k a year.

In addition BTAA calls for increased funding through the NHMRC project grants for brain tumour specific research. There is currently only one brain tumour grant in progress. Funding an increase from $200K pa to $400K pa would allow an additional trial or broader participation in an existing trial.

These funds could also be administered through Cancer Australia. BTAA understands the COGNO existing Commonwealth funding is as follows:

> Cancer Australia Infrastructure grants - $1,379,859, July 13 – June 16
>
> NHMRC Project Grant: CATNON: $396,175, Jan 12 - Dec 14 Cancer Australia/Cancer Council grant – CATNON - Phase III trial of Concurrent and Adjuvant Temozolomide chemotherapy in non-1p/19q non deleted anaplastic glioma

SHARING NEW DEVELOPMENTS THROUGH EDUCATIONAL GRANTS

Lastly, like neurooncology itself, clinical trials in brain tumours are challenging to conduct, their results are challenging to interpret, and often positive trial results take time to filter down through the wider medical community, including cancer specialists.

Health professionals have advised us that is very useful to be present at the time and location that clinical trial results are announced and discussed by the lead clinicians of the trials themselves, as occurred in 2004 when Stupp and his colleagues reported their interim Phase

II results at the 2004 New Orleans meeting of the American Society of Clinical Oncology (ASCO). In the words of co-author Prof Martin van den Bent at the time: "This is the first trial that has been clearly positive in brain cancer in 30 years. This is a great day."

Conferences help share that excitement in an area of medicine where it is in such short supply; Build collaborative networks of the type required to conduct multidisciplinary clinical trials; help to attract, retain, and develop emerging neurooncology professionals with the requisite skill sets and resources to conduct and interpret these trials. We therefore propose that the Commonwealth government establish grants for health professionals and students with a particular interest in brain tumours to attend professional conferences on neurooncology. These could also be tiered as 'early' or 'later' career stage grants, with latter being greater in value.

The grants could be administered by Cancer Australia and be capped at $170k per annum for brain tumour and other poor prognosis cancer health professionals and students. This would provide an estimated 34 grants of $5k each to support attendees with registration, travel and accommodation. Additional funds may need to be allocated to administer the grants.

They would be an effective way to reward excellence in leadership of clinical practice, as well as building capacity in the health workforce for those providing services to groups known to have worse treatment outcomes. These could be people diagnosed with cancers known to result in poor health outcomes, and of these people, particularly those living in rural, regional and remote areas, and/or those from culturally and linguistically diverse backgrounds.

Attachment 1: Brain Tumour Facts and Statistics

Brain tumour symptoms vary

- Brain tumours may have a variety of symptoms, as different parts of the brain control different functions and symptoms can vary depending on the tumour's location. Symptoms may include some of the following:
    - headaches (strong enough to wake you up in the morning);
    - seizures in a person who does not have a history of seizures;
    - cognitive or personality changes;
    - eye weakness, nausea or vomiting, speech disturbances; or
    - memory loss.

Categories of brain tumours – primary malignant, primary benign and secondary

- Central nervous system tumours are tumours that arise in the brain, spine or meninges.
    - Primary brain tumours are further grouped into "benign" and "malignant" tumours.
        - A malignant brain tumour is life threatening, invasive and usually rapid growing.
        - A benign tumour consists of very slow growing cells, usually has distinct borders, and rarely spreads.
            - Treatment and/or surgery is often effective, however, if a benign tumour is located in a vital area of the brain, it can be considered life threatening.
        - Primary brain tumours rarely spread outside the brain and spinal cord.
    - Metastatic (or secondary) brain tumours arise when cancer cells which begin growing elsewhere in the body (i.e. lung, breast or other areas) then travel to the brain.
        - All metastatic brain tumours are malignant since they begin as cancer elsewhere in the body.
    - There are over 120 different types of brain tumours alone, of which some 40 are classified as malignant.[6]
    - The location and grade of the tumour, the treatments undertaken and a range of other factors influence the impact on the patient, their abilities and prognosis.
    - The term 'brain cancer' is used by some including the statisticians and the term 'brain tumour' by others. Brain tumours may spread within the central nervous system but rarely outside.
    - BTAA uses the term 'brain tumour' to refer to all tumours of the central nervous system.

Causes unknown

6 World Health Organization (Furnari et al. 2007). The most common primary intrinsic brain tumors are the gliomas for adults and medulloblastomas for children. http://braintumor.org/patients-family-friends/about-brain-tumors/tumor-types/

- The causes of brain tumours are unknown; they are not preventable by any known lifestyle changes; early detection is not possible.
    - There are no screening tests for brain tumours.
- It is possible that each type of brain tumour has different causal factors, and its degree of severity or malignancy (the grade of tumour), its location within the brain, the size of surrounding tissue mass affected by the tumour, whether it is diffuse or defined, are considered when classifying , treating or researching brain tumours.

Treatment and support

- Cause complex health issues and may require intervention from numerous specialities.
- A range of tests may be performed to diagnose brain tumours, including neurological examination by a doctor, a CT-scan, MRI and biopsy.
    - Better treatment leads to longer life expectancy and better neurological outcomes.
    - Critical shortages in health professionals best able to manage health of brain tumour patients.
    - Brain tumours (and treatment side effects) may impair decision making, mood and judgement.
    -

Summary statistics

- Brain tumour research funding is low compared to the burden of the disease – along with lung cancer and mesothelioma, bladder cancer, pancreatic cancer, lymphoma and cancers of unknown primary site.[7]
- There are an estimated 5,600 living Australians who have been diagnosed with primary brain tumours sometime in the previous 26 years (when national records began).[8]
    - This includes 2,444 people diagnosed in the past 5 years.[9]
- Statistics for the period 2006–2010 show people with primary malignant brain tumours had a 22% chance of surviving for at least 5 years compared to the general population.[10] Five year survival was:
    - slightly higher for females (24%) than for males (20%).[11]
    - highest for those aged 0–39 at diagnosis (59%) and dropped steeply with age thereafter. [12]
    - less than 5% for those aged 70–79 at diagnosis. [13]
- There were more than 1,600[14] new cases of primary malignant brain tumours in Australia in 2010, including around 90 in children[15]. In addition it is estimated that, annually, there are more than 2,000 new cases of so-called benign brain tumours that may cause disability or (rarely) death.[16]

7 Cancer research in Australia: An overview of cancer research projects and research programs in Australia, 2003 to 2005, Cancer Australia, pg2

8 AIHW 2012. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer series no. 69. Cat. no. CAN 65. Canberra: AIHW, pp. 43–44.

9 AIHW 2012. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer series no. 69. Cat. no. CAN 65. Canberra: AIHW, pp. 43–44.

10 Ibid

11 Ibid

12 Ibid

13 Ibid

14 AIHW & AACR 2012. Cancer in Australia: an overview 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW, pp. 81, 105

15 AIHW 2012. ACIM book for brain cancer. AIHW: Canberra. http://www.aihw.gov.au/acim-books

16 Based on ratio for primary brain tumours in the USA according to CBTRUS www.cbtrus.org/factsheet/factsheet.html

- There were 1,247 deaths from primary brain tumours (both malignant and benign) registered in 2010.[17]
    - Primary brain tumours were the second highest cause of death for children aged 1 – 14 years from all causes – after drowning/immersion; and the highest cause of cancer death for this age group (an average of 31 deaths per year over the period 2008 to-2010).[18]
    - Primary brain tumours were the highest cause of cancer death in **persons** aged less than 40 (an average of 111 deaths per year over the period 2006 to 2010).[19]
        - Leading cause of cancer death in **males** aged less than 45 (an average of 93 deaths per year over the period 2006 to2010).[20]
        - Leading cause of cancer death in **females** aged less than 35 (an average of 32 deaths per year over the period 2006 to 2010).[21]
- Largest lifetime financial costs faced by households of any cancer type, at $149,000 per person, and the highest lifetime economic cost of any cancer type, at 1.89 million dollars per person.[22]
- In 2008–09 there were 5,037 hospitalisations, with an average length of stay of 11.9 days — a longer average length of stay than for any other cancer type.[23]
- Primary brain cancer accounted for 2.3% of all palliative care hospitalisations in 2009–2010, the 7th highest of the cancers.[24]

Last updated March 2013

(New statistics are available but at a charge to BTAA and AIHW advice was that they are little changed.)

More data is available in BTAA's submission to a previous budget process here http://www.btaa.org.au/btaabudgetsubmissionv6a.pdf

17 AIHW & AACR 2012.

18 ABS, Table 1.3 Underlying cause of death, Selected causes by age at death, numbers and rates, Australia, 2008-2010.

19 AIHW, unpublished data, National Mortality Database. Compiled from S&T Registrars of Births, Deaths and Marriages, the National Coronial Information System, and the ABS.

20 Ibid.

21 Ibid.

22 Cost of Cancer in NSW. 2005, Cancer Council NSW, prepared by Access Economics, 2006

23 AIHW 2010. Cancer in Australia 2010: an overview. Cancer series no. 60. Cat. no. CAN 56. Canberra: AIHW, pp. 168–171.

24 AIHW & AACR 2012. pp. 81, 105

Attachment 2: About Brain Tumour Alliance Australia (BTAA) Inc

- BTAA is the only national patient and caregiver organisation in Australia. BTAA is a not for profit organisation established in 2008 by a group of brain tumour patients and current and former care givers.
- BTAA is concerned about all brain tumours (neoplasms) of the central nervous system (CNS), which includes the meninges, brain and spine.
- Whilst welcoming the advice and input of health care professionals, BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. BTAA is incorporated in the Australian Capital Territory.
- BTAA coordinates and liaise between organisations, groups and service providers with an interest in central nervous system (including brain) malignant (cancer) and benign tumour care and support.

BTAA seeks to:

- provide peer-support to people living with a brain tumour, and to their caregivers, family and friends;
- financially assist the professional development of health care professionals with a particular interest in brain tumours;
- guide improvements to brain tumour research, treatment and care;
- ensure health consumer's treatments are based on the best available evidence;
- make recommendations to government about brain tumour policy and priorities; and
- guide government and health professionals in brain tumour policy and programs.

Other:

- BTAA has a subscriber data base of over 1,600 persons – persons with a brain tumour, their family and carers and health professionals and academics with a particular interest in brain tumours.
- BTAA is operated by a committee of volunteers.
- BTAA is a voting member of the Consumers Health Forum of Australia. More information about BTAA is available at www.btaa.org.au.
- BTAA is incorporated in the ACT.
- ABN 97 733 801 179