



Brain Tumour Alliance Australia Inc
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Committee Secretary
Select Committee into Funding for Research into Cancers with Low Survival Rates
Department of the Senate

Brain Tumour Alliance Australia (BTAA) represents the views of brain tumour patients, their families and carers across Australia. BTAA uses the term 'tumour' as it is all encompassing. A tumour can be malignant or non-malignant, but in the case of brain tumours all have debilitating impacts on patients.

BTAA provides a range of services to patients including free telephone support, information resources to newly diagnosed patients, and assists in the establishment of brain tumour support groups across Australia (see Attachment A for detail).

BTAA is making a submission to the Senate Inquiry because it considers the current research funding and health systems need a national strategic plan to increase the survivorship of rare cancer patients in Australia.

Whilst accepting that brain cancer is rare compared to more common and well known cancers, it is not acceptable in a highly developed country like Australia, that brain cancer which has the highest mean potential years of lost life is so poorly supported by our research and health systems.

Australia has made massive inroads in its awareness building, testing and treatment for some common cancers resulting in higher survivorship rates for patients. BTAA believes that a similar outcome can be achieved for patients with brain cancer by developing a national 10 year strategy to raise survivorship for rare cancers (including brain cancer) – a strategy that includes research, diagnosis, treatment, supportive care, and national awareness of rare cancers.

BTAA considers that intervention in the existing research funding system is the only way to increase survivorship for rare cancers.

Our submission addresses the Terms of Reference. Please contact BTAA on 1800 857 221 or email the Chair, Catherine Hindson at chair@btaa.org.au if you require further information.

Catherine Hindson

Chair, Brain Tumour Alliance Australia Inc

30 March 2017

Summary of BTAA Recommendations

a. Current NHMRC funding model

Rare cancers like brain cancer are: not well understood by the Australian community; have significantly lower survival rates than common cancers; and, have higher mean potential years of life lost to the economy. It is critical that Australia has a national 10 year strategy to increase survivorship for rare cancers, including brain cancer.

1. **BTAA recommends a national 10 year strategy to increase survivorship for rare cancers be developed, with a focus on research, diagnosis, treatment and care services.**
2. **BTAA recommends that rare cancers research be identified as a separate allocation of funding by the NHMRC.**
3. **BTAA recommends that the number, type and funding of rare cancer research projects be listed separately by NHMRC and Cancer Australia to inform patients, researchers and clinicians. This will also facilitate brain tumour research to be identified separately from other neurological research.**
4. **BTAA recommends that Government increase the pool of funding, expertise and access to clinical trials for rare cancer research in Australia by proactively linking our research to leading edge world research.**

b. Obstacles to running clinical trials

(i). Funding models that could better support much-needed clinical trials

Worldwide, clinical trials are identified by brain tumour patients as an opportunity to extend their survival time as survivorship for brain cancer patients has not improved over 30 years. Our relatively small population, our small number of brain tumour researchers, small number of brain cancer patients who can participate in trials, and the large overheads for clinicians and hospitals to participate in trials, means that Australian patients are rarely able to engage in brain cancer clinical trials.

5. **BTAA recommends that the NHMRC makes information on clinical trials (whether clinician or pharmaceutical company led) by stage of trial (open and recruiting) more accessible to brain tumour patients, possibly including having information being made available on Cancer Council websites.**
6. **BTAA recommends that an Australian Centre of excellent rare cancer research be identified across states and territories to facilitate larger patient numbers for clinical trials and to facilitate engagement with international rare cancer clinical trials.**
7. **BTAA recommends that federal, state and territory governments assist brain tumour patients and clinicians to participate in brain tumour clinical trials through subsidising travel and accommodation.**

8. **BTAA recommends funding for the provision of brain cancer care coordinators to assist patients in managing their treatments, including by alerting patients and clinicians to clinical trials.**

(II). Funding support for campaigns to raise awareness of the need for further research, including clinical trials

The Australian public is not aware of the debilitating impact of rare cancers (including brain tumours) on patients, families, carers and, their careers and life opportunities. Armed with statistics of survivorship and potential years of life lost, a national campaign will build support for increased research and support for future patients.

9. **BTAA recommends a national rare cancer campaign across Australia linked to the major players including Cancer Australia, Cure Brain Cancer, the NHMRC and BTAA.**

c. Low survival rates for brain cancers and strategies to improve

Australian statistics on brain tumours are not representative as they do not include non-malignant tumours whose side effects are as devastating for families as malignant tumours. It is imperative that patients, clinicians and the Australian public can access representative statistics to identify trends and for researchers to conduct effective clinical trials. Data on brain tumours needs to be constantly up-to-date and readily available to patients and clinicians. Also, it should include information on Australian clinicians, hospitals/centres of treatment, and brain tumour nurse coordinators. An annual report on brain tumour cases – both benign and malignant – would ensure that the Australian government can measure improvements in survivorship.

10. **BTAA recommends that the National Cancer Registry record malignant and non-malignant brain tumours to assist ongoing research on brain cancer both in Australia and overseas.**
11. **BTAA recommends amalgamation and transparency of Australian brain tumour information on neurosurgeons and oncologists with a particular interest in CNS tumours so that patients can find relevant treatment centres and hospitals. This could potentially be undertaken by Cancer Australia using Medicare data.**
12. **BTAA recommends improved patient access to data on Brain Tumours. Remove any obstacles between states and territories to achieving a national brain cancer data set. Cancer Australia is working to improve cancer data sets but brain tumour/cancer data will be delayed with more common cancers with higher survivorship rates getting preference.**
13. **BTAA recommends specific brain cancer drugs and immunotherapies be fast tracked to the Australian PBS to enable equity of access for all patients desperate to increase their survival time.**

d. Other matters

The role of allied medical staff is often overlooked in treating rare cancer patients. Brain cancer patients (both malignant and non-malignant) require assistance in their journey following diagnosis. They require carers and assistance with all aspects of their ongoing treatments and life management. It is now time for the health system to identify and support these patients as they seek to live with dignity.

- 14. BTAA recommends improved training and provision of brain cancer care coordination nurses for patients. The positions could be funded through a new National Partnership Agreement with the States and Territories via COAG.**

BTAA Submission

a. NHMRC model

The NHMRC model of research funding is based on an assessment of the excellence of the research. This model is used by other research organisations around the world. However, the current model is not able to provide adequate funding to increase survival for brain cancer patients. This is because

- the number of brain cancer researchers in Australia is small
- the number of brain tumour clinicians is small
- the number of patients able to participate in trials is small
- the numbers of trials is small
- the range of trials available for patients at different stages of malignancy is very small
- the cost of trials is large for hospitals and clinicians
- fewer patients are able to trial longer survivor technologies

This means small numbers of brain cancer research projects (including clinical trials) are being funded in Australia. This applies to other rare cancers with poor prognosis including childhood cancers (Attachment B).

As noted by Cancer Research UK, despite some phenomenal progress, there are some forms of cancer where things have been much less encouraging, and where patients desperately need more options. Given this state of affairs, Cancer Research UK has set out to accelerate progress in four types of cancer (pancreatic, lung, oesophageal and brain) with the following characteristics:

- compared with other cancer types, there's a **smaller community of researchers** working on them
- as a result, they have **lower levels of research funding**
- **survival is generally poor**, and has barely changed for decades

Cancer Research UK states that '...it's in brain cancer research where scientists have come up against perhaps the most difficult set of challenges.' Cancer Research UK has identified the four key areas that need to be prioritised:

- how brain tumours are diagnosed and classified
- their fundamental biology
- how they develop and evolve
- and – most of all – working out how to turn this knowledge into new treatments

We in Australia - an advanced western country with a respected health system paid for by its citizens - expect action to be taken by our government to increase rare cancer survival.

Given the huge inroads that have been made by Australia increasing survivorship for several common cancers (through a combination of campaigns, early screening and detection, and

high technology treatments), it is time that focus was given to rare cancers with a poor prognosis. American research has shown that brain and other central nervous system cancers have the greatest mean years of potential life lost (YPLL) of all cancers – surely this is a significant reason for Australian governments to focus on how to increase survivorship.

It's often tempting to think that the way to accelerate progress in cancer research is simply to pump more cash into the system. But just throwing money at a problem rarely solves it. Instead, better results tend to spring from a carefully thought-through strategy, good leadership, and careful use of precious resources.

In the case of brain tumour research, we're working on all three, and Cancer Research UK has been working with some of the brightest minds in the field – both in the UK and abroad – to work out how to best support researchers to make a difference for patients with brain tumours (Cancer Research UK).

Given the Cancer Research UK views above and aware that governments, from time to time, intervene in the allocation of funding to direct it towards achieving specific goals, BTAA considers that a 10 year national strategy is urgently needed in Australia to increase survivorship for rare cancers with low prognosis.

As is occurring in the UK, through its 10 year cancer strategy, brain cancer survivorship could be improved through actions such as encouraging:

- Experienced cancer researchers from other fields to apply their expertise to brain tumours.
- Younger researchers, at the beginning of their careers, to specialise in brain tumour research.
- Experts in relevant fields outside cancer research – e.g. neuroimmunology (the brain's immune system) and developmental neurology (how the brain develops) – moving into cancer research.
- Large international collaborative brain tumours studies.
- More sharing of research data and expertise, to build an Australian and international network of brain tumour researchers.
- A better environment to run clinical studies, which will ultimately see more patients given the opportunity to take part in clinical research.
- Initiatives to reduce the number of brain cancers diagnosed at a late stage and greater support for GPs.

According to Cancer Australia, *'Australia's increasing expenditure on cancer highlights the importance of priority-driven investment in cancer control to guide the optimal use of available resources and enable the health system to be responsive to current and future challenges'*.

The Australian government provides funding for health and medical research, but every year many great research projects with the potential to lead to new and important discoveries go

unfunded. Recently, the Medical Research Future Fund (MRFF) was announced to fund this research.

Even when research is funded and the findings are promising there is often not enough funding to take the idea further. According to its promotion, the MRFF will mean more research will be developed into new drugs, devices and therapies that can benefit patients¹.

Hospitals and clinics engaged in research will provide more effective healthcare, have access to pioneering clinical trials that bring treatments to Australian patients earlier, and attract the best and brightest health professionals².

In light of the above, BTAA considers it is time for a national strategy to increase survivorship for rare cancer patients.

- 1. BTAA recommends that a national 10 year strategy to increase survivorship for rare cancers be developed, with a focus on research, diagnosis, treatment and care services.**

Further, in terms of funding the action identified through the 10 year strategy, Government can increase brain cancer survivorship by providing a 'ring fenced allocation of funding' for a specified period via the NHMRC to brain cancer research and research for all childhood cancers. Perhaps the MRFF could contribute to funding given '...more research will be developed into new drugs, devices and therapies that can benefit patients'.

- 2. BTAA recommends that rare cancer research (brain and other rare cancers) be identified as a separate allocation of funding within the NHMRC.**

One complaint from brain tumour patients is finding out information about brain tumour research. Trying to identify brain cancer and other rare cancer research using the NHMRC research grant database is virtually impossible. There are many projects, a lot of medical jargon, and its presentation is based on old technology. Like other national research organisations across the globe, NHMRC needs to update its data presentation to enable patients, clinicians, allied health professionals, and policy makers to find information quickly and accurately. Adopting a presentation like that of the website for Cancer Research UK would be a good starting point for the NHMRC.

Poor transparency means no one, including very concerned patients and their families, can identify what and how much is being funded each year. Without easy access to such data, it is not possible to accurately measure the trends in research.

- 3. BTAA recommends that the number, type and funding of rare cancer research projects be listed separately by NHMRC and Cancer Australia to inform patients, researchers and clinicians. This will also facilitate brain tumour research to be identified separately from other neurological research.**

¹ MRFF website

² MRFF website

Recognising the relatively small population of researchers and clinicians working on brain cancers and other rare cancers in Australia, we consider it imperative that Australia gets the best leverage from its research funding by collaboration with high quality international research projects. By combining forces, Australia gains access to and contributes to new techniques, technologies and developments, including clinical trials. It is noted that the conduct of clinical trials of new drugs is very expensive and generally takes place overseas or as dictated by pharmaceutical companies. International collaboration means access to higher research funding and to large technologically advanced projects that will benefit Australian patients.

4. BTAA recommends that Government increase the pool of funding, expertise and clinical trials for rare cancer research in Australia by proactively linking our research to leading edge world research.

Research funding bodies (such as the NHMRC, Cancer Australia, and Cure Brain Cancer) would need to have a role in identifying, supporting and collaborating in such research. In due course, the Medical Research Future Fund could contribute given it proposes to double medical research funding within 6 years.

The GBM Agile project is an example of a collaborative world project which has a far-reaching vision and is an opportunity to enhance the lives of future brain cancer patients, illustrating how international collaboration will increase brain cancer survivorship.

b. Obstacles to Clinical Trials

Clinical trials are fundamental to establishing whether new cancer treatments or new ways of using existing therapies, diagnostic tests, preventative or supportive interventions are effective and they generate the evidence for best-practice cancer care (Cancer Australia).

The number of clinical trials for rare cancer patients (including brain cancer) in Australia is too small. Patients looking for clinical trials contact BTAA and it directs them to the websites at Cancer Australia (Australia's 13 National Cancer Cooperative Trials Groups) and the NHMRC. Patients say there are no trials available for them - yet for brain cancer patients access to trials can potentially increase their survivorship.

Organisers of international trials report that Australia does not offer the number of patients required to participate in their trials – having small patient numbers means that recruitment is slow.

Another problem brought to the attention of BTAA relates to ease of access to trial information for brain tumour patients. Information needs to be easily located, up to date and searchable on both grade and other limitations, so that patients and clinicians can identify whether there are opportunities for engagement.

5. BTAA recommends that the NHMRC/Cancer Australia make information on clinical trials (whether clinician or pharmaceutical company led) by stage of trial (open and recruiting) more accessible so patients can easily identify trials from the time of diagnosis.

BTAA notes that new APs are appearing to assist access to clinical trials – for example, the Haematology Clinical Research Network (HRCN NSW/ACT) developed ClinTrial Refer as a mobile application to facilitate clinician and patient access to current recruitment for trials, and improve trial participation by increasing referrals.³ Such technologies will revolutionise knowledge about and access to clinical trials.

(i) Funding models that could better support much-needed clinical trials

BTAA has recommended a 10 year national rare cancer strategy and recommended engaging with international brain cancer research, including clinical trials.

Because so few people are affected by rare cancers such as brain cancer, a real obstacle is finding enough patients to take part in clinical trials testing new treatments. The size of a trial matters because a large trial with many patients should give much clearer, more reliable evidence than several small ones with fewer participants. Researchers will be more certain that the patterns seen in trial results are real and not just down to chance. But the scarcity of patients with rare cancers makes it hard to work out the best ways to tackle these diseases.

Two new models for clinical trials are worth examining.

- (1) A new collaboration of clinical trials is developing treatments for rare cancers - the International Rare Cancers Initiative (IRCI).

The IRCI's main aim is to design clinical trials involving patients across several countries that will reveal the most effective treatments for rare cancers. By bringing together researchers in the UK, the USA and the rest of Europe, the initiative provides scientists with access to many more patients. And more trial participants means better science, more helpful results, and – ultimately – increased survival from these diseases.

- (2) The UK also has 18 Experimental Cancer Medicine Centres (ECMC) where the researchers are world leading scientists and clinicians who drive the discovery, development and testing of new treatments to combat cancer. The ECMC Network is funded by Cancer Research UK and the health departments of England, Wales, Scotland and Northern Ireland with the overall aim to deliver real benefits for patients.

As part of a national 10 year strategy for rare cancers, Australia could consider actions to build clinical trial infrastructure in Australia. For example, a Rare Cancer Centre of Excellence linked to all health institutions doing research and clinical trials across Australia and engaging with overseas trials.

Such a Centre would be a magnet for new research students and for those training in cancer allied health treatments and support. Data sharing would be part of the ethos of the centre.

³ <http://www.health.nsw.gov.au/innovation/2013awards/Documents/clin-trial-refer-mobile-app-web-12.pdf>

Such a Centre would be ideally suited to engagement with new molecular responses to brain cancer emerging in the AGILE trial.

- 6. BTAA recommends that an Australian Centre of excellent rare cancer research be identified across states and territories to facilitate larger numbers for clinical trials and to engage with international rare cancer clinical trials.**

To facilitate patient access to clinical trials, BTAA considers government support is needed to assist patients to travel and be accommodated.

- 7. BTAA recommends that federal, state and territory governments assist brain tumour patients and clinicians to participate in brain tumour clinical trials through subsidising travel and accommodation.**

Further, BTAA has identified the importance of educating those who assist patients in their brain tumour/cancer journey – brain tumour care coordinators.

- 8. BTAA recommends funding for the provision of brain cancer care coordinators to assist patients in managing their treatments, including by alerting patients and clinicians to clinical trials.**

(ii) funding support for campaigns designed to raise awareness of the need for further research, including clinical trials

While volunteer organisations like BTAA and similar rare cancer support bodies can build knowledge of rare cancers, the small number of patients and their deficits and carer needs means the focus is on supporting them to cope with physical, mental, career and financial concerns.

The reality for tumours with a poor prognosis is that there is not a large survivor cohort able to conduct effective awareness campaigns.

BTAA works to raise awareness through support of International Brain Tumour Awareness Week and of Brain Cancer Action Week.

Organisations like Cure Brain Cancer Foundation and some other organisations associated with particular clinical centres struggle to raise funds and awareness of the needs for research.

The poor prognosis of those diagnosed with brain tumours, and the burden of the disease on the patient and their carers and the diversity of their age, sex and deficits arising from the disease and the treatment means there are not large groups of activists, unlike breast and prostate cancer. It is hard to raise funds from a group of patients and carers who are physically, emotionally and financially reduced.

Reducing the cost of brain cancer to the community (as it costs more per patient than any other cancer) will bring economic benefits. Workforce participation for both people living with brain cancer and their carers, will increase through increased survival and reduced

harm. The highest cost of cancer care per patient will be reduced and there will be the positive impact of increased medical tourism, especially from Asia.⁴

BTAA considers that the national strategy to increase rare cancer survival should include a campaign to increase national awareness of the need to provide support for those living with brain tumours.

9. **BTAA recommends a national rare cancer campaign across Australia linked to the major players Cancer Australia, Cure Brain Cancer, Brain Tumour Alliance Australia, Peace of Mind Foundation and the NHMRC.**

c. Factors affecting low survival rates

Terminology and statistics

BTAA uses the term 'brain tumour' to refer to all central nervous system tumours including brain tumours, tumours of the meninges and spinal column. BTAA represents people with both malignant tumours – or brain cancers (grades 2,3,4) - and so-called benign or non-malignant tumours (grade 1).

Unlike the United States of America⁵, the Australian health system does not register brain tumours unless they are malignant. This means we are not aware of how many people are suffering from deficits from brain tumours and consequently their needs for ongoing physical, emotional and financial support.

Australian data understates the number of brain tumours and the burden of disease. Whilst a benign brain tumour may not be fatal it may lead to severe neurocognitive deficits and in some cases, require institutionalisation of young persons in aged care facilities.

England and Canada have recently commenced collecting data on all brain tumours – malignant and benign. Until now, the Brain Tumour Foundation of Canada has not systematically recorded incidence rates for all primary brain tumours, traditionally omitting non-malignant brain tumours. It estimates that two-thirds of all non-malignant brain tumours are not reported in cancer registries and yet they can be just as devastating as malignant ones. Data resources from a Canadian Brain Tumour Registry with readily available case information would help researchers expedite their studies regarding incidence and survival patterns, factors that may cause or prevent brain tumours, equal access to care, and quality of life.⁶

BTAA considers that official Australian statistics should include both malignant and non-malignant primary brain tumours of the brain and central nervous system.

While official survival data is not available in Australia for people with non-malignant tumours, it is expected it would be in line with the US which reports five-year relative survival after diagnosis with a non-malignant brain/other CNS tumour is 90.4%. Summary

⁴ Cure Brain Cancer Foundation. Priorities submission to MRFF in response to 'Consultation in the development of Australian Medical Research and Innovation Strategy and related priorities'.

⁵ The American CBRTUS collects information on both malignant and benign tumours.

⁶ Brain Tumour Foundation of Canada website

statistics on brain tumours including incidence, mortality and other indicators are at Attachment B.

10. BTAA recommends that the National Cancer Registry record malignant and non-malignant brain tumours to assist ongoing research on brain cancer in Australia and overseas.

Brain tumour patients are diverse

There are over 120 different types of primary central nervous system tumours, mainly brain tumours. The needs of brain tumour/cancer patients and their families and carers are diverse, depending on the type of tumour, grade of tumour and location of the tumour.

Whilst more common in older persons they affect people of all ages. There are around 35 children a year aged 0 – 14 years who die from malignant brain tumours. Parents of a child with a diagnosis of Glioblastoma Multiforme (GBM) or Diffuse Intrinsic Pontine Gliomas (DIPGs) face a disease that is 100 per cent fatal. Parents of children with medullablastoma have some hope but know that if their child survives it will be with significant deficits. There are other rare cancers that are just as devastating.

Adults and children with malignant brain tumours have a disease that has no known cause, no early screening process, is usually 100 per cent fatal, and aggressive and debilitating treatments prolong life, but offer no cure at this time. The combination of rarity, complexity and lack of effective treatment creates huge obstacles to the provision of holistic care and in many cases significant medical, psychological and social needs remain unmet⁷.

A common tumour in adults and older persons is a meningioma – usually a low grade tumour – that has a good prognosis in terms of survival but can cause lifelong disability, as well as physical and psychological distress.

Given the diversity of tumour types, ages and impacts on patients, BTAA seeks to provide information resources to newly diagnosed persons, their carers and families. BTAA imports an American information booklet for adults and a Canadian one for families with children with brain tumours. We are now in the process of developing a resource for culturally and linguistically diverse (CALD) communities through funding from Cancer Australia. Also, BTAA organises or supports patient information forums to enable people to meet others living with brain tumours.

The Special Case for CNS Tumours

American research indicates that malignant brain and other CNS tumours have the greatest mean years of potential life lost (YPLL), thereby reflecting their short survival time past diagnosis. These findings will hopefully motivate more research into mitigating the impact of these debilitating tumours.⁸ To date, routine screening for brain tumours is not currently available. However, an earlier diagnosis may result in a better prognosis and longer survival,

⁷ Commission Expert Group on rare diseases (2016) Recommendations to support the incorporation of rare diseases into social services and policies.

⁸ Chaturia Rouse, Haley Gittlemann, Quinn T. Ostrom, Carol Kruchk, and Jill S. Barnholtz-Sloan. *Years of potential life lost and CNS tumors relative to other cancers in adults in the United States, 2010*. *Neuro-Oncology* 18(1), 70-77, 2016.

thus helping to reduce total years of potential life lost and the consequent impact on the economy.

The UK Headsmart campaign aims to increase awareness of the symptoms of brain tumours in the community to assist with earlier diagnosis.

Early diagnosis – particularly of paediatric tumours – leads to a better outcome in terms of both survival and neurological functioning.

BTAA knows of only a handful of long term survivors of the most malignant brain tumours – longer than 10 years - and none who live without side effects of the treatment and the disease.

The psychological impact of the disease and treatment is considerable. The burden on the caregiver is also considerable and considered to be higher than for the patient.

Epilepsy is a major cause of distress and poor quality of life in patients with brain tumors. It impacts on ability to drive, work and enjoy social interactions.⁹

The reality for most patients is that malignant brain tumours are eventually fatal and survival rates have not improved in the last 30 years¹⁰. Some therapies have shown promise in trials, and some have increased progression free survival, but the trial has failed as the therapy did not improve overall survival.

The evidence is that those who have access to multidisciplinary teams, including neurosurgeons with a particular interest in brain tumours (able to do maximum resections) and access to good medical and radiation oncology services do better.

For tumours that are in different locations or in so-called eloquent areas and/or are highly aggressive then the patient's quality of life and length of survival depends on the skills of the neurosurgeon.

Aggressive resection by the neurosurgeon, in one or more craniotomies, leads to a better outcome.

Anecdotal experience is that there are around ten neurosurgeons across Australia who are capable of providing the level of resection needed in the more difficult neurosurgeries, whilst balancing the risks associated with such resections.

Some of the specialist brain tumour neurosurgeons operate only in the private system where they can get the equipment and medical team and theatre time they require. They face such high insurance levels that most patients cannot afford their services, even if they have private medical care. Some operate in the public system alone and provide excellent surgical expertise within the support of multidisciplinary teams. Some operate in both systems.

⁹ Grant R. (2016) How bad are your seizures and did the treatment help? Neuro-Oncology Vol 19 Issue 1 Jan 2017 p.5

¹⁰ Cancer Research UK website

However, patients do not have transparency in terms of who these neurosurgeons are, what techniques they employ, and the costs of treatment. And there is a significant gap in terms of the type of neurosurgery, the extent of resection, the quality of the pathology report provided which guides subsequent treatment. and the type of rehabilitation offered to patients across Australia. This situation is far from equitable.

11. BTAA recommends amalgamation and transparency of Australian brain tumour information on neurosurgeons and oncologists with a particular interest in CNS tumours so that patients can find treatment centres and hospitals with a particular interest in brain tumours. This could potentially be undertaken by Cancer Australia using Medicare data.

12. BTAA recommends improved patient access to national data on Brain Tumours. Remove any obstacles between states and territories to achieving a national brain cancer/tumour data set. We understand that Cancer Australia is working to improve cancer data sets but it is likely that brain tumour/cancer data will be delayed with more common cancers with higher survivorship rates getting preference.

Finally, noting that there are limited treatments available for brain tumour patients, it is imperative that they can get access to the cancer drugs that will assist them. This means that action is needed to fast track them through the Australian PBS.

13. BTAA recommends specific brain cancer drugs and immunotherapies be fast tracked to the Australian PBS to enable equity of access for all patients desperate to increase their survival time.

d. Other relevant matters

We want a health system that will better manage people, from diagnosis through treatment and rehabilitation, in multi-disciplinary teams. We want a system that can give patients and their families hope.

In an attempt to educate brain care coordination nurses, BTAA provides financial support to brain cancer nurses/care coordinators and other brain tumour allied health professionals to attend national and international educational events such as COGNO.

BTAA supports calls by patients for better access to brain cancer care coordinators as they play a critical role linking patients with treatments and with clinical trials, as well as assisting them to navigate the medical system following diagnosis.

Enabling equity of access to specialist brain cancer care/nurse coordinators, particularly for those with a poor prognosis, would make a significant difference in terms of accessing treatments and would not be significant in terms of budgetary resources. Yet most Australian states and territories only have **general cancer care coordinator nurses** who are not aware of the specific needs of brain tumour patients.

Specialised cancer care coordinator nurses create efficiencies in the system by freeing up other specialists and can assist with recruitment to clinical trials. As suggested previously, while there have private and private/public models to provide specialist nurses for cancers such as breast, prostate and some others, we are calling for equitable access for all Australian cancer patients with a poor prognosis.

The Australian Government needs to provide funding to enable patients to have access to brain cancer care coordinator nurses to enhance their survival. The National Partnerships Agreement between the Commonwealth/States and Territories via COAG could be a vehicle to tie such funding to the provision of brain cancer care coordinator nurses.

14. BTAA recommends improved training and provision of brain cancer care coordination nurses for patients. The positions could be funded through a new National Partnership Agreement with the States and Territories via COAG.

Brain Tumour Alliance Australia Inc

Brain Tumour Alliance Australia Inc (BTAA) is the national volunteer organisation that gives a voice to those living with brain tumours from the consumer (patient, family and carer) perspective.

BTAA focuses on all brain tumours (neoplasms) of the central nervous system (CNS), which include the meninges, brain and spine.

BTAA was established in 2008 as the peak consumer organisation representing the interests of people diagnosed with brain tumours. Our committee of volunteers includes persons living with brain tumours and persons caring for people living with the diagnosis of a brain tumour.

Our key focus is on immediate support for the patient and carer in terms of access to information and advice to enable treatment decisions to be made. BTAA seeks to get in touch with all newly diagnosed patients and their families and provide information to assist them in the early days of diagnosis and treatment. We have a national subscriber data base of over 2,000 persons, including those with a brain tumour, their family and carers, health professionals, and researchers with a particular interest in brain tumours. We seek to provide all newly diagnosed brain tumour with relevant resource information including an American Brain Tumour handbook.

We circulate e-news and newsletters to all BTAA subscribers throughout the year. And we have an informative website www.btaa.org.au that provides access to resources, brain tumour updates, e-news and a mechanism to stay in touch with patients and help them to access support.

Importantly, we provide a 24 hour seven day a week Freecall number **1800 857 221** to enable a patient or carer to speak to someone who understands the brain tumour journey. Through it we link people to their nearest support services. This service provides additional support beyond that from the medical and allied health professionals. And, importantly, it provides that service at a time that suits the caller.

BTAA's website provides advice to patients seeking clinical trials – see <http://www.btaa.org.au/page/16/clinical-trials-in-australia>. It provides a range of trial sites:

- [Australian Cancer Trials Website](#) or the [ANZ Clinical Trials Register](#).
- The Cancer Council Victoria trial search facility [here](#).
- The [Australian Clinical trials](#) website contains links to other websites which have listings of clinical trials and is searchable by disease or keyword.
- US website <http://clinicaltrials.gov/ct2/search/advanced> and enter the words "brain tumours" and "Australia" (no quotation marks) in the relevant search boxes.

- [This is a link](#) to the (Australian) Cooperative Trials Group for Neuro-Oncology (COGNO).

BTAA works collaboratively with other related organisations to provide a consumer voice across a range of cancer and brain tumour specific organisations including:

- the NSW Neuro Oncology Group
- the Cure Brain Cancer Foundation
- Rare Cancers
- Cancer Voices NSW
- the Mark Hughes Foundation
- the Cancer Councils
- the Cure Starts Now,
- International Brain Tumour Alliance, and
- other organisations with a particular interest in brain cancer support and/or research.

Brain Tumour Statistics

This data excludes so-called 'benign' brain tumour data as it is not collected by the Australian cancer registries. It also does not include secondary brain tumours (metastases) arising from primary cancers elsewhere in the body.

Mortality, Incidence and Risk

- There were **1,391 deaths** due to malignant neoplasm of brain (ICD-10 C71) in 2015.
Source: ABS, 3303.0 – Causes of Death, Australia, 2015, dated 29 September 2016.
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02015?OpenDocument>
- There were **1,636 new cases** of brain cancer diagnosed in Australia in 2013.
Source: AIHW 2017. Australian Cancer Incidence and Mortality (ACIM) books: Brain cancer. Canberra: AIHW <http://www.aihw.gov.au/acim-books>.
- **Brain cancer was the leading cause of disease death among children aged 1–14 in 2011–13** (94 deaths; 6.5 per cent of all deaths; 0.8 deaths per 100,000 population) and the third leading cause of death from all causes – after land transport accidents (202; 14 per cent; 1.7 per 100,000) and certain conditions originating in the perinatal period and congenital conditions (128; 8.9 per cent; 1.1 per 100,000).
Source: AIHW, Leading causes of death, <http://www.aihw.gov.au/deaths/leading-causes-of-death/>.
- **Brain cancer was the 2nd leading cause of cancer death among young people aged 15–24 in 2011–13** (55 deaths; 1.5 per cent of deaths; 0.6 deaths per 100,000 population) – after leukaemia (59; 1.7 per cent; 0.6 per 100,000).
Source: AIHW, Leading causes of death, <http://www.aihw.gov.au/deaths/leading-causes-of-death/>.
- **Brain cancer was the 3rd leading cause of cancer death among adults aged 25–44 in 2011–13** (335 deaths; 2.2 per cent of deaths; 1.7 deaths per 100,000 population) – after breast cancer (459; 3.0 per cent; 2.4 per 100,000) and colorectal cancer (353; 2.3 per cent; 1.8 per 100,000).
Source: AIHW, Leading causes of death, <http://www.aihw.gov.au/deaths/leading-causes-of-death/>.
Source: AIHW 2012. Cancer incidence projections: Australia, 2011 to 2020. Cancer Series no. 66. Cat. No. CAN 62. Canberra: AIHW.
<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421440>
- Brain cancer accounted for 2.8% of cancer deaths for all ages in Australia in 2007. However, **it was the most common cause of cancer death for 15-29 year olds from 2003 to 2007, accounting for 14.2% of all cancer deaths in this age group.**
Source: AIHW 2011a. Cancer in adolescents and young adults: an analysis of incidence, mortality and survival in Australia. Can. Canberra: AIHW.

Hospitalisations

- In 2013–14 there were 5,758 hospitalisations due to primary brain cancer, with the average length of stay being 9.9 days.
Source: AIHW National Hospital Morbidity Database, *Principal diagnosis data cubes*, viewed 7 October 2015, <http://www.aihw.gov.au/hospitals-data/principal-diagnosis-data-cubes/>.
- Primary brain cancer accounted for 3.5% of all palliative care hospitalisations in 2012–13, the 7th highest among all the cancers.
Source: AIHW 2014. *Cancer in Australia: an overview 2014. Cancer series no. 90. Cat. no. CAN 88. Canberra: AIHW.*

Relative survival

- In 2007–11, people with primary brain cancer had a 22% chance of surviving for at least 5 years relative to the general population. Five-year survival was slightly higher for females (23%) than for males (21%).
Source: AIHW 2014. *Cancer in Australia: an overview 2014. Cancer series no. 90. Cat. no. CAN 88. Canberra: AIHW.*

Prevalence

- At the end of 2009, there were an estimated 6,206 living Australians who had been diagnosed with primary brain cancer sometime in the previous 28 years (when national records began). This included 2,756 people who had been diagnosed in the past 5 years.
Source: AIHW 2014. *Cancer in Australia: an overview 2014. Cancer series no. 90. Cat. no. CAN 88. Canberra: AIHW.*

Projections

- Projections for brain cancer in Australia, based on an extrapolation of the trends in incidence from 1982 to 2007, indicates that rates are expected to increase for males aged 65-84, and aged 85 and over. Based on expected changes to the population structure and estimated age-standardised rates, an estimated 1,230 new cases will be diagnosed in men in 2020. Age-standardised rates of brain cancer in women are highly erratic, but it is expected that an estimated 825 cases of brain cancer will be diagnosed in women in Australia in 2020.

Expenditure

- AIHW data on the estimated cost of brain cancer is in the report *Health system expenditure on cancer and other neoplasms in Australia, 2008-09*, <http://www.aihw.gov.au/publication-detail/?id=60129545611>.

Some of the above data was provided to BTAA by the Australian Institute of Health and Welfare on a fee for service basis in 2015. You are free to reproduce it but please acknowledge the AIHW/ABS source and BTAA.