

The Australian Brain Cancer Landscape 2026

One year on: progress,
gaps and priorities



Brain Tumour
Alliance Australia

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Endorsement

The Australian Brain Cancer Landscape has been developed by Brain Tumour Alliance Australia (BTAA) with support from the Australian Brain Tumour Collaborative (ABTC).



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Abbreviation list

ABCM — Australian Brain Cancer Mission
ABCR — Australian Brain Cancer Registry
ABTC — Australian Brain Tumour Collaborative
ACNNP — Australian Cancer Nursing and Navigation Program
ACRP — Australian Cancer Research Program
AI — Artificial Intelligence
AIHW — Australian Institute of Health and Welfare
ANZCHOG — Australian and New Zealand Children's Haematology/Oncology Group
AT/RT — Atypical Teratoid/Rhabdoid Tumour
B3C — Bridging Barriers in Brain Cancer
BBB — Blood-Brain Barrier
BCCC — Brain Cancer Care Coordinator
BRAINS — Brain cancer Rehabilitation, Assessment, Intervention of survivor NeedS
BTAA — Brain Tumour Alliance Australia
BTF — Biomedical Translation Fund
CAYA — Childhood, Adolescent and Young Adult
CNS — Central Nervous System
COG — Children's Oncology Group
COGNO — Cooperative Trials Group for Neuro-Oncology
CSIRO — Commonwealth Scientific and Industrial Research Organisation
DIPG — Diffuse Intrinsic Pontine Glioma
DMG — Diffuse Midline Glioma
DNA — Deoxyribonucleic Acid
ETMR — Embryonal Tumour with Multilayered Rosettes
FET-PET — Fluoroethyl-L-Tyrosine Positron Emission Tomography
FTE — Full-Time Equivalent
GBM — Glioblastoma Multiforme
IDH — Isocitrate Dehydrogenase

IFPMA — International Federation of Pharmaceutical Manufacturers and Associations
MCRI — Murdoch Children's Research Institute
MHF — Mark Hughes Foundation
MIPS — Monash Institute of Pharmaceutical Sciences
MND — Motor Neurone Disease
MRFF — Medical Research Future Fund
MRI — Magnetic Resonance Imaging
NAS — National Advocacy Service
NATA — National Association of Testing Authorities, Australia
NCI — National Cancer Institute
NDC — Nanobody-Drug Conjugate
NDIS — National Disability Insurance Scheme
NHMRC — National Health and Medical Research Council
PBAC — Pharmaceutical Benefits Advisory Committee
PBS — Pharmaceutical Benefits Scheme
PGT — Precision-Guided Therapy
POMF — Peace of Mind Foundation
RCD — Robert Connor Dawes Foundation
RDTI — Research and Development Tax Incentive
RMH — Royal Melbourne Hospital
SHH — Sonic Hedgehog
SIOP — International Society of Paediatric Oncology
TGA — Therapeutic Goods Administration
TROG — Trans Tasman Radiation Oncology Group
US — United States
UTS — University of Technology Sydney
VCGS — Victorian Clinical Genetics Services
WEHI — Walter and Eliza Hall Institute
WHO — World Health Organization
WNT — WNT signalling pathway

All amounts in this document are expressed in Australian dollars unless otherwise indicated.

Foreword



Carrie Bickmore OAM

When my husband Greg was diagnosed with brain cancer, I assumed medicine would have answers. Instead, I learned how little had changed for brain cancer patients in decades. Greg died in 2010, when our son was just a little boy.

More than fifteen years later, too little has changed. Brain cancer still kills more children than any other disease in Australia, and more Australians under 40 than any other cancer. Survival rates have barely moved, and families are still being offered far too few options.

The only thing that will change that is research. Australia has world-class researchers ready to lead. My team at the Brain Cancer Centre are working in a collaborative way – creating discoveries that will one day save the lives of future brain cancer patients. They are doing that with researchers from other incredible centres around Australia – in Newcastle with the Mark Hughes Foundation and in Brisbane, Perth, Adelaide and Hobart. They are tirelessly at work on the problem and deserve more of our support.

Australians have shown how much they care. When I asked people to put on a beanie for brain cancer, they did in their hundreds of thousands, raising over \$30M for research they may never benefit from themselves. That philanthropy has been critical, funding new ideas, keeping talented researchers in their labs and opening clinical trials that give patients hope.

But philanthropy cannot do it alone. Fundraising is unpredictable, and research needs certainty measured in decades, not fundraising cycles. That is where government must continue to lead.

I am asking for long-term, dedicated funding for brain cancer research that matches the scale of the problem. The Government has already recommitted to the Australian Brain Cancer Mission – something that we are proud to be involved in. Let's work together to access the kind of capital that can be a paradigm shift in this space. Let's provide an incentive to Australia's most successful business people to support our Mission. Let's open up the commercial pathways and break down institutional barriers further incentivising collaboration and driving our researchers closer together. Let's invest in the data required to fully utilise the AI boom and its power to supercharge discoveries. Let's work together.

Grant cycles are important but have our researchers wasting precious time. This is the kind of investment that keeps our best researchers in Australia, builds the infrastructure they need, and gives every patient the chance to take part in a clinical trial. I want government to be a true partner, so every dollar raised at a bake sale or beanie day is multiplied, not left to carry the load.

Greg didn't have the options he deserved. With the right commitment now, the next generation of patients can.

Foreword



Dr Katie Nicoll

I lost my husband Richard earlier this year to the devastating impact of brain cancer. Having been by his side over the past three years as he underwent pioneering medical treatment and faced this devastating diagnosis, I saw his passion to make a difference, his commitment to lend whatever expertise and experience in medical research he could to the greater cause, and his commitment to being part of the growing voices asking urgently for investment, now, to change the outcomes for brain cancer patients.

Brain cancer remains one of the most complex and lethal forms of cancer, and one of the least understood. Despite advances we have seen in many other cancer types, brain cancer survival rates haven't improved in any meaningful way, for decades.

While research and treatment of brain cancer is complex and different to other cancer types, so too are supportive care requirements for brain cancer patients, and there is often such a narrow window to make a difference for patients and their families.

Richard was passionate about the need for investment in brain cancer in a way that appreciates the impact this cancer has on individuals and on families. He believed that specialised dedicated expert supportive care for those with brain cancer should be accessible to every patient around Australia.

Brain cancer requires a sustained coordinated national commitment.

The time to turbo-charge our commitment and investment in brain cancer research, and the time to step in and provide specialised compassionate support for those who may only have a short time left, is now.

An investment to change outcomes for brain cancer patients will be returned manyfold, and every delay is an opportunity lost, or another life gone too soon.

The time to pull out all stops is now.

Richard was a proud supporter of the work being done by BTAA and associated organisations, and their efforts to unite Australia's brain cancer research, clinical and patient support communities. The priorities of the community are ambitious but achievable. I have hope that together, with government, philanthropy, community and advocacy groups, we can make a real difference in the lives of all brain cancer patients.

Why the Landscape matters

A brain cancer diagnosis does not occur within a single part of the health system.

From the point of diagnosis, patients and families may simultaneously encounter complex clinical care, decisions about treatment and clinical trials, rehabilitation and symptom management, disability and income support, changes to work and family life, psychosocial care and, for some, palliative and end-of-life care.

The systems surrounding that person are often organised separately. The understanding of the challenges and solutions for brain cancer consumers must be a connected interrelated platform that supports patients and families from date of diagnosis to date of death.

The inaugural 2025 Australian Brain Cancer Landscape (Landscape) established a national baseline. For the first time, it brought together evidence about the burden of brain cancer, the existing Australian system and the priorities identified by the brain tumour community across three areas: Research & Trials, Clinical Care and Support Services (BTAA 2025).

The 2026 Landscape builds on that foundation. It asks what has changed over the past 12 months, where progress has occurred, what remains unresolved and what needs to happen next.

Brain cancer is rarely captured by a single announcement, treatment or funding decision. Change occurs across research investment, clinical practice, workforce capability, data, trial access, navigation, support services and policy. Viewed separately, these developments can appear fragmented. Viewed together, they show whether Australia is building a system capable of producing better outcomes and experiences for patients and families.

The Landscape is an annual reference and accountability document. Each edition provides a fixed point against which the next can be compared, creating a record of whether priorities have progressed, commitments have been delivered and previously identified gaps remain.

It is designed for people living with brain tumours and their families and carers; researchers and clinicians; nurses, allied health professionals and service providers; philanthropic and community organisations; governments and policy makers; and others working to improve outcomes for the brain tumour community.



**A single Landscape provides a snapshot.
An annual Landscape creates a record of progress.”**

The Landscape is organised around three pillars:



Research & Trials

This pillar considers Australia’s brain cancer research environment, including investment, coordination, research capability, clinical trials and access to emerging treatments.

It focuses on how research is translated into better outcomes for patients through collaboration between government, philanthropy, researchers, clinicians and consumers.



Clinical Care

This pillar considers how people experience diagnosis, treatment and ongoing disease management, including specialist and multidisciplinary care, nursing and care coordination, rehabilitation and workforce capability.

It focuses on whether high-quality, brain cancer-specific care is accessible and connected across the patient journey.



Support Services

This pillar considers the practical, psychological, social and financial support required by patients, carers and families beyond medical treatment.

It focuses on access to navigation, disability and income support, employment, aged care and other services that help people manage the broader impacts of brain cancer.

They are interdependent and inseparable

The 2026 Landscape deliberately treats research, clinical care and support services as three components of a single system rather than as competing priorities.

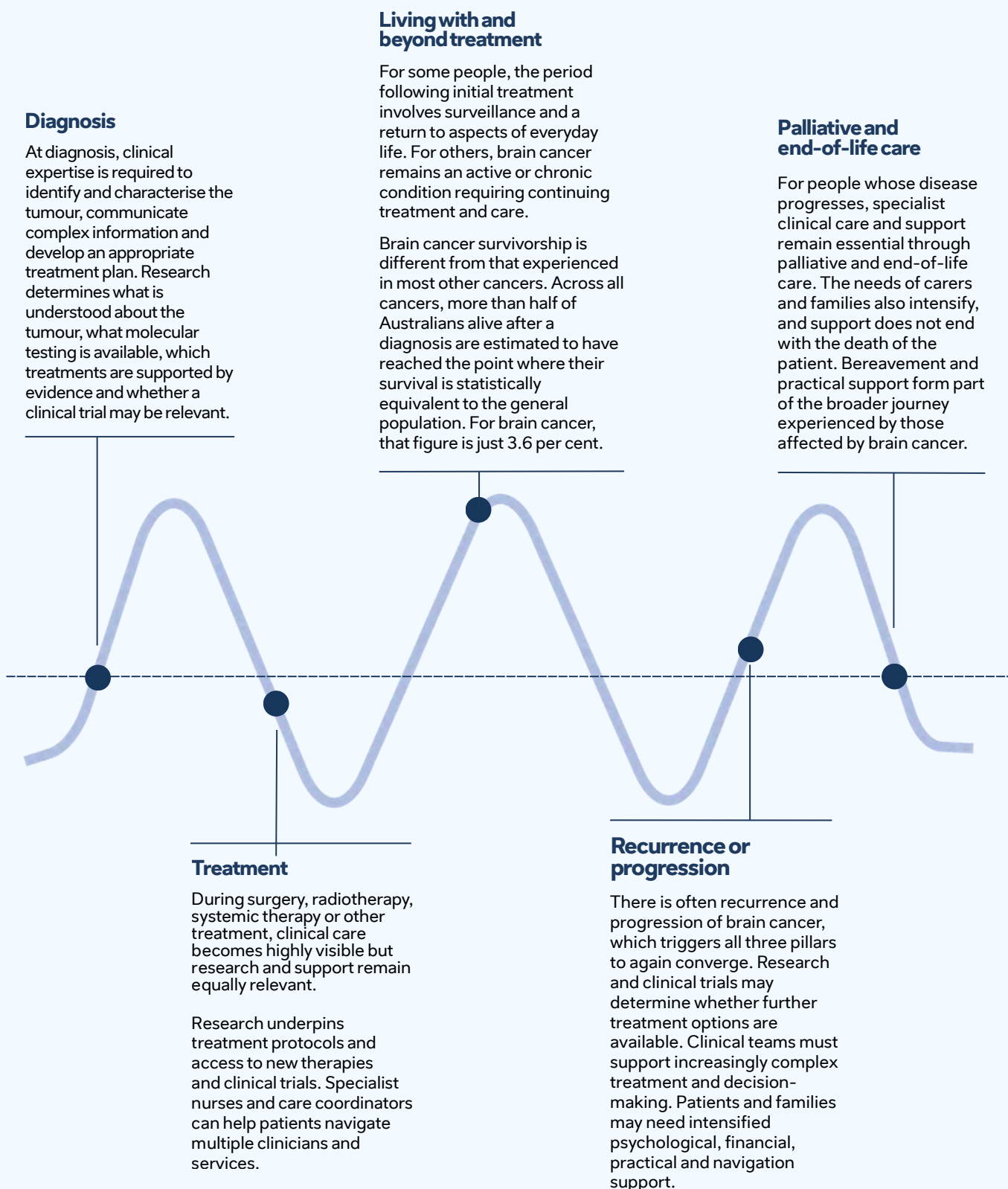
As the document notes, progress in one pillar that does not ultimately reach the person affected cannot be considered sufficient progress.

The pillars are separate for the purpose of understanding the system. They are inseparable in the experience of the person.

Following the patient journey

The interdependence of the three Pillars becomes clearest when the system is viewed through the experience of a person diagnosed with a brain tumour.

A brain tumour journey may extend over weeks, months, years or decades.



How to read this Landscape

The 2026 Landscape document has been structured to tell two stories at the same time:

- Where Australia stands today, and
- Where relevant, how that position has changed since the 2025 Landscape.

The opening sections establish the national context, summarise important developments over the previous 12 months and consider the issues that affect the system as a whole.

The Landscape then examines each of the three pillars in greater depth.

1 The problem we are trying to solve

Each pillar begins by defining the underlying system problem identified through the evidence and narrative of the 2025 Landscape.

This gives the reader the context needed to understand why action is required and why the priorities that follow were chosen.

This ensures that the annual Landscape does not begin with an advocacy ask in isolation. The ask is presented as a response to a clearly defined problem.

2 What we asked for in 2025

Each pillar then returns to the priorities identified in the previous Landscape.

This creates continuity between annual editions and allows a reader who has not read the 2025 Landscape to understand what the brain tumour community proposed as the response to the problem.

3 What happened in 2026

The report then examines developments over the previous 12 months. These may include new evidence, research investment, policy or funding decisions, service developments, clinical practice, collaborative initiatives or changes in the broader national environment.

4 What remains unresolved

This section identifies continuing gaps, inconsistencies, barriers to implementation and areas where evidence remains incomplete. It is deliberately intended to distinguish activity from outcome and progress from completion.

5 What happens next

Each pillar concludes by identifying the practical priorities arising from the evidence.

These provide the basis for continued sector collaboration and engagement with government over the following 12 months.

Cross-cutting themes

A brain cancer diagnosis presents challenges and issues that run through all three pillars and determine whether progress within any one of them ultimately reaches patients and families. The current Landscape identifies these as cross-cutting themes.

They should be read alongside each of the three pillars — Research & Trials, Clinical Care and Support Services — rather than as separate areas of activity. Each theme can influence progress across multiple pillars, highlighting the connections, dependencies and system-wide issues that need to be considered when assessing whether improvements translate into better experiences and outcomes for patients and families.

The 2026 Landscape focuses on four.



1. Equity and access

A person should be able to access appropriate diagnosis, treatment, research opportunities, specialist care and support regardless of where they live or their age, socioeconomic circumstances or tumour type.



2. Workforce and system capacity

Brain cancer care depends on highly specialised clinical and non-clinical workforces.



3. Survivorship and quality of life

Survival remains fundamental, but survival alone does not describe the impact of brain cancer.



4. Data and evidence in action

Better data changes what the brain tumour community can know, measure and ask of the system.

Scope and approach

The Landscape is intended to provide a national overview, not an exhaustive catalogue of every research project, clinical service, organisation or program operating in Australia.

It is not a clinical guideline and should not be used as a substitute for individual medical advice. It is also not intended to suggest that every question affecting brain cancer in Australia has already been answered.

Lived experience is included alongside research and system evidence because the consequences of brain cancer cannot be understood through clinical outcomes alone. Patients, families and carers encounter the connections, and the gaps, between research, health care, disability, social support and community services in ways that individual institutions may not.

This document is a description of the system and an argument for greater connection within it.

Research & Trials, Clinical Care and Support Services are not three separate ambitions.

Together, they form the infrastructure surrounding a person from diagnosis, through treatment and living with disease, and, where required, through palliative and end-of-life care and support for those left behind.

The purpose of the Landscape is ultimately straightforward:

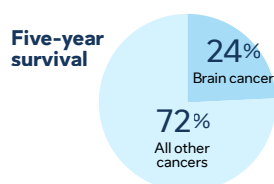
to understand the system, to identify where it can work better, and to measure whether the changes being pursued translate into better outcomes and experiences for people affected by brain cancer.

Executive Summary

2026 laid the foundations. 2027 is the year to build on them.

The Government's decision to include brain cancer as a dedicated mission within the new Australian Cancer Research Program (ACRP), with \$50 million over ten years, provides continuity for Australian brain cancer research and a platform for the next decade. Sustained advocacy by the brain cancer community helped ensure brain cancer retained that dedicated place. Alongside it, the evidence on what patients and families need has never been stronger.

Brain cancer remains one of Australia's least survivable cancers, and for almost everyone affected it is a disease lived with rather than moved beyond. Its consequences — cognitive and neurological change, loss of work and independence, and families who become carers overnight — run through the whole journey. This Landscape examines Research & Trials, Clinical Care and Support Services as one system, reports what changed against the 2025 asks, and sets out what must happen next.



3.6%

of people alive after a brain cancer diagnosis are "potentially cured", vs 52.3% for all other cancers

~8,700

of ~9,000 Australians living after a brain cancer diagnosis are living with the disease

\$8.7million

a year in economic value from the National Advocacy Service, mostly from carers staying in work

Sources: AIHW; Luo et al. 2026 (Lancet Regional Health – Western Pacific), 2025 estimates, ~8,700 derived; Mandala 2026 (commissioned by the Peace of Mind Foundation).

What moved

- **\$50 million** over ten years for a second brain cancer mission, and \$8.4 million in MRFF grants.
- **Voridasenib** listed on the PBS for IDH-mutant grade 2 glioma.
- **Research mapped:** a national scan led by the Mark Hughes Foundation Centre identified 164 current research projects, 71 with a paediatric focus.
- **Evidence matured:** BRAINS and new consensus work define what good coordination and supportive care must do.
- **Sector organised:** a research governance proposal and BTAA's new portfolio Board.
- **\$18.8 million** in MRFF funding established the Bridging Barriers in Brain Cancer Program.

Where the work continues

- **No co-designed research roadmap** or shared governance for the new investment.
- **No dedicated funding** for brain cancer care coordination.
- **Brain cancer is not among the 12** specialist services funded through national cancer navigation.
- **The National Advocacy Service (NAS)** still depends on philanthropy and is less secure than a year ago, as demand reaches ~1,000 people a year.

Scorecard: the 2025 asks, one year on

Of nine asks of government, **three were partly achieved, two are in progress and four were not achieved**. None were fully met. The sector's own commitments — building the Australian Brain Tumour Collaborative (ABTC) and establishing Brain Tumour Alliance Australia (BTAA) as the national peak body — are progressing. The pattern is consistent: national programs designed for all cancers are not reaching brain cancer's particular needs, and philanthropy is carrying much of the national infrastructure.

Executive Summary

Our 2026 asks

Ask 1

Co-design the Australian Brain Cancer Roadmap through a Joint Steering Committee, working across the Australian Cancer Research Program's (ACRP) for Childhood, Adolescent and Young Adult (CAYA) and Low Survival Cancers missions.

Ask 2

Build toward the scale required, leveraging the second mission against the \$200 million over ten years the sector identified.

Ask 3

Faster, fairer access to treatment: timely PBS pathways, more phase II/III trials, and an equitable compassionate-access pathway.

Ask 4

Fund a national Brain Cancer Care Coordination Framework (\$8.75 million, 23 coordinators), integrated with the Australian Cancer Nursing and Navigation Program (ACNNP) and McGrath Foundation.

Ask 5

Stabilise the National Advocacy Service (NAS): \$725,000 a year for three years, co-funded with philanthropy.

Ask 6

Bring brain cancer into national cancer navigation through the ACNNP Specialist Support Services stream.

Ask 7

Priority access to NDIS and aged care support, modelled on the Motor Neurone Disease (MND) priority pathway.

Ask 8

Measure what matters: outcome evaluation for coordination and support, and national expansion of the Australian Brain Cancer Registry (ABCR).

The case for change has been made. The work of 2027 is to act on it — so that every Australian affected by brain cancer can access the best available research, clinical care and support, wherever they live.

Cross-Cutting Themes

The 2026 Landscape identifies four cross-cutting themes:



Equity and access — whether people can access appropriate diagnosis, treatment, research opportunities, specialist care and support regardless of postcode, age, socioeconomic circumstances or tumour type.



Survivorship and quality of life — whether the system responds not only to survival, but to the neurological, cognitive, physical, psychological, social and financial consequences of brain cancer and its treatment.



Workforce and system capacity — whether Australia has the specialist people, capability, infrastructure and connected services required to deliver high-quality brain tumour research, care and support.



Data and evidence in action — whether Australia can identify variation and unmet need, measure outcomes and use evidence to improve research priorities, clinical practice, service design and policy.

These are not additional pillars. They are the conditions that determine whether the three pillars work together.

Australia will see an estimated 2,098 new brain cancer diagnoses in 2025, while 1,597 deaths were recorded in 2023. Five-year relative survival is approximately 24 percent compared with 72 percent across all cancers combined, and has improved only marginally in close to four decades. An estimated 9,034 Australians are living in 2025, having been diagnosed with brain cancer during the previous 30 years (Cancer Australia; Luo et al., 2026).

Against that background, these cross-cutting priorities are not peripheral issues. They are central to improving what patients and families experience.

Access should be determined by need, not circumstance

A person diagnosed with a brain tumour should be able to access appropriate diagnosis, treatment, clinical trials, specialist care and support regardless of where they live, their age, socioeconomic circumstances or tumour type.

Australia cannot yet say with confidence that this occurs consistently.

Variation begins with the disease itself. Brain tumours are biologically diverse, and different molecular subtypes can carry dramatically different prognoses and treatment options. Timely and complete molecular characterisation is therefore increasingly fundamental to accurate diagnosis, treatment selection and clinical trial eligibility. But not all variation is explained by biology.

Age is one of the clearest gradients in Australian brain cancer outcomes. Five-year relative survival is approximately 70 per cent for people diagnosed between the ages of 20 and 39, falling to 29 per cent for those aged 40 to 59, 8.9 per cent for those aged 60 to 79 and 1.8 per cent for people aged 80 and over (AIHW 2025). Tumour biology explains some of this difference, but treatment intensity and access to clinical trials may also vary with age.

Tumour type creates another significant gradient. **IDH-wild type glioblastoma accounts for approximately 64 percent of brain cancers diagnosed in Australia and has a five-year survival of around 6.3 per cent (Cancer Alliance Queensland 2025).** By comparison, IDH-mutant, 1p/19q-codeleted oligodendroglioma represents a much smaller proportion of cases and has substantially higher survival. Whilst survival is typically longer, this form of cancer often presents longer periods of significant burdens to patients, families and carers. This highlights the complexity of a system that requires different approaches to diagnosis, treatment and research.

IDH-wild type glioblastoma

64% 
of brain cancers
diagnosed in
Australia with a
5 year survival of 6.3%

Geography may create further inequity. Around seven million Australians live outside major cities. Broader Australian cancer evidence indicates that people living in rural and remote areas can experience poorer outcomes associated with later diagnosis, greater travel requirements, reduced access to specialist services, thinner allied health and psychosocial support and fewer opportunities to participate in clinical trials.

The evidence specific to brain cancer is less definitive. Some studies have not demonstrated the same regional survival gradient for primary brain cancer that is seen across cancers generally. This may reflect the fact that many brain tumour patients are referred to metropolitan neurosurgical centres, but it may also reflect limitations in the data currently available.

That uncertainty is itself important. Australia cannot yet measure geographic equity in brain cancer care with the precision required to determine where variation exists and why.

Why equity cuts across all three pillars



In **Research & Trials**, equity means access to molecular testing, research opportunities, clinical trials and emerging therapies.



In **Clinical Care**, it means access to specialist multidisciplinary expertise, treatment, rehabilitation and coordinated care regardless of where a person lives.



In **Support Services**, it means that practical, psychological, financial and navigation support is available based on need rather than postcode, service availability or a family's capacity to navigate complex systems themselves.

Improving equity therefore requires more than making individual services available. It requires understanding who is missing out, where variation occurs and what part of the system is producing it. Equity means that where a person lives or who they are should not determine whether they can access the best available research, care and support.

Living longer must also mean living as well as possible

Survival remains the most fundamental challenge in brain cancer.

But survival alone does not adequately describe either the burden of the disease or the outcomes that matter to patients and families.

Brain cancer survivorship is structurally different from survivorship in most other cancers. An estimated 9,034 Australians are alive in 2025 having been diagnosed with brain cancer during the previous 30 years. By 2050, this number is projected to reach 13,111 — an increase of approximately 45 per cent (Luo et al. 2026).

This growth is slower than for most other cancers, and poor survival is a major reason why. **The proportion of people with brain cancer whose survival has returned statistically to that of the general population is estimated at only 3.6 per cent in 2025, compared with 52.3 per cent across all cancers.** Translated into people, of approximately 9,000 Australians currently living after a brain cancer diagnosis, around 8,700 are living with disease that is not considered cured and may require initial treatment, surveillance or ongoing care.

Out of 9,000
diagnosed
8,700
are living with disease
not considered cured

Low prevalence should therefore not be interpreted as low need. For many people, brain cancer is an active or chronic condition rather than an illness that ends when initial treatment finishes.

The neurological consequences of the tumour and its treatment can also be profound. Cognitive impairment, fatigue, seizures, communication difficulties, personality and behavioural change, loss of mobility, inability to drive, loss of employment and reduced capacity for independent decision-making can emerge early and persist throughout the disease journey.

These are not always temporary treatment effects. In brain cancer, they may be consequences of the disease itself.

A national review of rehabilitation following brain tumour diagnosis found unmet needs across physical, cognitive, emotional and social domains. Importantly, these needs can persist and evolve over time and do not necessarily correspond neatly with tumour type or grade. While rehabilitation interventions can improve outcomes, that evidence has not consistently translated into routine practice or clinical guidelines (BRAINS Program 2026).

The impact also extends beyond the patient. Brain cancer can disrupt employment and household income, generate significant out-of-pocket costs and require family members to assume substantial caring responsibilities. All of which very often creates financial toxicity and hardships.

Carers can become responsible for transport, medication, appointments, behavioural management, personal care and decision-making while simultaneously managing work, children and household responsibilities. Their needs must therefore be considered, rather than solely as an extension of the patient's care.

Why survivorship cuts across all three pillars



In **Research & Trials**, outcomes such as cognition, function, independence, treatment toxicity, quality of life and carer impact should influence what Australia researches and how success is measured.



In **Clinical Care**, survivorship requires access to rehabilitation, neuropsychology, allied health, symptom management, palliative care and specialist coordination across the disease trajectory.



In **Support Services**, people may need help navigating employment, income, disability, transport, housing, family responsibilities and the psychological consequences of diagnosis and treatment.

A national response to brain cancer must therefore ask not only whether people live longer. It must also ask how they live, what function and independence they retain, and what support surrounds them and their families.

For brain cancer, better outcomes must mean more than living longer. They must also mean living as well and as independently as possible.

For most cancers, “survivorship” describes life after cancer. For brain cancer it largely describes life with cancer. National projections show that while the share of all people with a past cancer diagnosis who are potentially cured will rise to 56 per cent by 2050, the brain cancer figure is projected to reach only 8.2 per cent (Luo et al. 2026). The gap persists across the full range of modelling assumptions. Even the most optimistic estimate for brain cancer (19 per cent in 2025) sits well below the lowest estimate for cancers overall (46 per cent).

In practical terms, almost every person diagnosed with brain cancer will carry survivorship needs for the rest of their life: neurological, cognitive, functional, psychological and financial. So will their families. These needs are not a phase that follows treatment. They run alongside it.

Only 3.6 per cent of Australians living after a brain cancer diagnosis are estimated to be “potentially cured”, compared with 52.3 per cent across all cancers combined – a proportion around 14 times higher. In practical terms, **fewer than 4 in every 100 people living after a brain cancer diagnosis are estimated to have reached the point where their survival is statistically equivalent to the general population** (Luo et al. 2026).

By 2050, the proportion of **people living after a brain cancer diagnosis who are estimated to be potentially cured is projected to increase to only 8.2 per cent**, compared with 56.1 per cent across all cancers. Of the projected 13,111 Australians living after a brain cancer diagnosis in 2050, around 12,000 would therefore still be living with the disease rather than beyond it (Luo et al. 2026).

The contrast with more common cancers is particularly stark. In 2025, the **potentially cured share** was estimated at 73 per cent for prostate cancer, 70 per cent for breast cancer, 67 per cent for melanoma and 82 per cent for testicular cancer, compared with **just 3.6 per cent for brain cancer** (Luo et al. 2026).

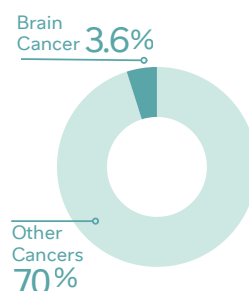
Around **1 in 6 Australians living after a brain cancer diagnosis were diagnosed within the previous 12 months**. This represents 17 per cent of the brain cancer population—1,562 of 9,034 people—compared with 9 per cent across all cancers, or 145,887 of 1,666,020 people. This difference **reflects the comparatively small proportion of people with brain cancer who survive long enough to become long-term survivors** (Luo et al. 2026).

The number of Australians **living after a brain cancer diagnosis is projected to increase by 45 per cent between 2025 and 2050**, compared with 57 per cent across all cancers. Of the 24 cancer types examined, 17 are projected to grow faster than brain cancer. This slower growth is not a sign of lower need; persistently poor survival is a major reason why fewer people accumulate as long-term survivors (Luo et al. 2026).

Fewer than
4 in 100

Fewer than

by 2050



Diagnosed

this past year

 45%
Predicted
growth in
2025

Brain cancer compared with all cancers and the three most prevalent cancer types

Measure	Brain	All cancers	Breast	Prostate	Melanoma
People alive after a diagnosis in previous 30 years (2025)	9,034	1,666,020	298,109	309,663	249,892
Potentially cured ("living beyond cancer"), 2025	3.60%	52.30%	69.50%	73.30%	66.80%
95% uncertainty interval, 2025	0.0–19.0%	46.2–58.0%	67.4–71.5%	70.6–76.1%	61.5–72.6%
Potentially cured, 2050 (projected)	8.20%	56.10%	72.50%	75.90%	69.80%
Share diagnosed in the previous 12 months (2025)	17%	9%	7%	7%	7%
Share diagnosed in the previous 5 years (2025)	45%	34%	31%	33%	30%
Projected growth in 30-year prevalence, 2025–2050	45%	57%	63%	52%	33%

Source: Luo et al. 2026, Table 1 and Fig. 4. Shares diagnosed in the previous 12 months and 5 years are derived by dividing 1-year and 5-year prevalence by 30-year prevalence. Percentages rounded. "Potentially cured" is a statistical, population-level measure: time since diagnosis has passed the point at which survival matches the general population. It does not mean an individual is free of disease.

The authors of Australia's first long-term cancer prevalence projections note that far less is known about people living with cancer than those living beyond it, and that people living with advanced disease have significant unmet needs (Luo et al. 2026).

Brain cancer is the clearest example of this gap. Survivorship models built around surveillance after curative treatment do not fit a population where more than 95 per cent are still living with the disease. Brain cancer needs models of care built for continuing, changing and often increasing need, and sustained specialist care coordination is central to that.

The right expertise must be available when and where it is needed

Brain cancer depends on a relatively small and highly specialised workforce.

Across the patient journey, people may require expertise from neurosurgery, neuropathology, neuro-oncology, medical oncology, radiation oncology, specialist nursing, neuropsychology, rehabilitation, allied health, palliative care, psychosocial services, dedicated support and navigation services and community support.

Research similarly depends on specialised scientists, clinician-researchers, clinical trial staff, data specialists and supporting infrastructure.

The challenge is therefore not simply whether Australia has skilled people. It is whether that capability is sufficient, sustainably funded, connected across services and accessible to patients regardless of location.

Care coordination illustrates the problem clearly. Recent Mark Hughes Foundation funded research found that the introduction of a dedicated brain cancer care coordinator was associated with fewer emergency presentations and admissions, a 24 per cent reduction in aggregate length of stay and potential savings to a single health service exceeding \$500,000 (Mark Hughes Foundation Centre for Brain Cancer Research 2026a).

A 2026 Australian and Aotearoa New Zealand study also brought together experts and stakeholders, including consumers, to reach consensus on what optimal care coordination for people with primary brain tumours should include and on quality indicators that could be used to assess it (Jeon et al. 2026).

Together, these developments strengthen the evidence that specialist coordination is not simply an additional service. It is part of the infrastructure required to deliver complex brain cancer care effectively.

The broader workforce challenge extends much further. Brain cancer expertise is highly specialised and often concentrated in major centres. Thin workforces can result in delay, variation and dependence on individual clinicians or locally funded positions. This creates vulnerability.

When specialist positions are not embedded within sustainable models, the departure of one experienced clinician, nurse, coordinator, researcher or navigator can mean the loss of expertise, referral pathways, institutional knowledge and patient continuity that may have taken years to develop.

Importantly, specialist capability does not necessarily need to be physically concentrated in large metropolitan hospitals.

The Mark Hughes Foundation funded research found that an Australian regional cancer service using an outsourced subspecialised neuro-oncology model achieved clinical quality and survival outcomes comparable with a high-volume metropolitan centre (Mark Hughes Foundation Centre for Brain Cancer Research, 2026b).

This suggests that expertise can be distributed when service models are deliberately designed to connect people and capability.

Why workforce cuts across all three pillars



In **Research & Trials**, capability depends on retaining researchers and clinician-researchers, supporting trial networks and maintaining the infrastructure required for discovery, translation and clinical research.



In **Clinical Care**, it requires sustainable access to specialist clinicians, nurses, care coordinators, rehabilitation and allied health expertise.



In **Support Services**, it requires specialist navigators, advocates, counsellors and others who understand the particular challenges created by brain tumours and can connect families with appropriate systems and services.

The objective is not simply to increase workforce numbers. It is to create a system in which expertise is sustainable, connected and able to reach the person who needs it.

Capacity is not simply having expertise somewhere in the system. It is ensuring the right expertise can reach the patient when it is needed.

From describing the problem to measuring and changing it

For much of the past three decades, Australian brain cancer advocacy has relied on a powerful but relatively blunt measure: survival remains poor and has improved only marginally.

What Australia has historically been less able to determine is where care varies, why it varies, who is affected and whether particular interventions improve outcomes. That is beginning to change.

A major development has been the **establishment of the ABCR, led by Brain Cancer Australia in partnership with Cancer Alliance Queensland and CSIRO's Australian e-Health Research Centre**. The ABCR is Australia's first national clinical quality registry dedicated to brain cancer and is designed to bring together population-wide information on diagnosis, treatment and outcomes (Brain Cancer Australia 2026; Cancer Alliance Queensland 2025).

Brain Cancer Australia has played a central role in developing this national infrastructure. It convened the original registry working group in 2019 and subsequently led work to develop a set of brain cancer Clinical Quality Indicators that provide the framework against which care can be measured. The indicators are intended not simply to describe what happens to patients, but to identify variation in care and help define whether people are receiving treatment consistent with best practice.

In October 2025, Brain Cancer Australia launched the ABCR's first **Clinical Quality Indicators and Statistical Report**, covering the period 2014–2023 and using population-wide Queensland data. Other states and territories are being progressively incorporated during 2026 and 2027, with Brain Cancer Australia aiming for the registry to capture data from up to 90 per cent of Australian brain cancer patients.

The registry is designed to support both public reporting and confidential, benchmarked feedback to hospitals and clinicians. This creates the potential to move beyond national survival averages and begin identifying variation in the actual care people receive — including whether patients are accessing appropriate surgery, multidisciplinary care, molecular testing, radiotherapy, rehabilitation and other components of optimal brain cancer care.

The significance of this work is that **data can become a mechanism for improving care, rather than simply describing poor outcomes**. Where variation is identified, clinicians and health services can better understand gaps, compare practice against agreed indicators and target quality improvement.

Other national developments add to this capability. The **National Cancer Data Framework**, launched by Cancer Australia in November 2025, establishes a nationally consistent direction for collecting, managing and using cancer data. It is intended to improve benchmarking, identify disparities and support data-driven improvements in patient care and research, while embedding principles of Indigenous Data Sovereignty (Cancer Australia 2025).

The Australian Institute of Health and Welfare is also expanding the geographic detail available in national cancer reporting. Cancer incidence by Statistical Area 3 was introduced in 2026, with survival reporting by Statistical Area 3 and incidence and survival by Primary Health Network and Local Government Area planned for 2027 (AIHW 2026).

Together, these developments should progressively make questions about geographic, clinical and population equity more measurable.

The challenge, however, is not simply to collect more data. Data must be used to change care.

Why data cuts across all three pillars



In **Research & Trials**, data can identify knowledge gaps, inform national priorities, support trial design and help evaluate whether investment is translating into meaningful outcomes for patients.



In **Clinical Care**, data can identify variation in treatment, access, service delivery and outcomes and provide clinicians and health services with the evidence required to improve quality and reduce unwarranted variation.



In **Support Services**, better data can help identify where patients and carers experience unmet need, whether services are reaching people equitably and where additional support capacity is required.

The development of the ABCR is therefore more than a data project. Led by Brain Cancer Australia, it creates national infrastructure capable of showing where brain cancer care is working, where it is falling short and where change is required.

What these priorities mean for the Landscape

- The four cross-cutting themes should be read alongside every pillar that follows.
- They provide a set of questions against which progress across the system can be tested. A research breakthrough that cannot be accessed by the people who might benefit is an equity and access issue.
- A successful treatment that extends life but leaves significant cognitive, functional or psychological needs unaddressed is also a survivorship and quality-of-life issue.
- A model of research, care or support that depends on a small number of individuals and cannot be sustainably staffed is a workforce and system capacity issue.
- And a system that cannot identify variation, measure unmet need or demonstrate whether interventions improve outcomes has a data and evidence problem.
- Equity, quality of life, workforce capacity and evidence determine whether those three parts function as one system.

Pillar One

Research & Trials



From research investment to patient impact

Research and clinical trials are fundamental to changing the trajectory of brain cancer. They generate the knowledge, treatments and innovations needed to improve survival, reduce treatment burden and preserve quality of life.

Australia has built important brain cancer research capability over the past decade. The Australian Brain Cancer Mission (ABCM) created a major increase in investment and helped strengthen research networks, clinical trial capability, infrastructure and collaboration (Cancer Australia 2026).

The 2025 Landscape recognised those achievements, but it also made clear that the central problem had not been solved: survival remained poor, treatment options remained limited and significant gaps persisted across the research continuum.

The question for 2026 is therefore not simply whether research activity has increased. It is whether Australia is building a **coordinated, sustainable research system capable of translating investment into better outcomes for patients.**

The problem we are trying to solve

Brain cancer remains one of the most difficult cancers to treat. Its biological complexity, diversity of tumour types, high rates of recurrence and limited treatment options mean that transformative progress depends on sustained research across the full continuum — from understanding the fundamental biology of disease through to translation, clinical trials, survivorship and supportive care.

The 2025 Landscape identified a fundamental mismatch between the burden of brain cancer and the investment and research infrastructure available to address it.

Historically, brain cancer research funding had lagged behind several more common cancers despite persistently poor survival and a high burden of premature mortality.

The ABCM began to address that gap. It built important foundations, strengthened networks and increased research and clinical trial capacity.

However, the independent review of the ABCM identified continuing weaknesses (Centre for International Economics 2023):

- foundational biology and discovery research remained comparatively underfunded
- some tumour groups were under-supported
- workforce pressures persisted
- collaboration with clinicians and industry needed to deepen
- consumer engagement was inconsistent
- competitive funding models did not always support the high-risk, high-reward research required for transformative change.

Clinical trials present a related challenge. For many people with brain cancer, particularly where standard treatment options are limited, trials may provide access to emerging therapies. Yet access is not consistent.

The 2025 Landscape identified clinical trial access as an important part of the broader research problem, alongside the need to strengthen the pipeline of future treatments.

The problem is therefore broader than funding alone.

Australia needs a research system in which **investment, priority-setting, scientific capability, translation, clinical trials, consumer involvement and patient** access work together.



What we asked for in 2025

The 2025 Landscape proposed a coordinated national response rather than a series of isolated research investments.

The brain cancer community asked the Australian Government to invest **\$200 million over 10 years** in a renewed national approach to brain cancer research, built around three connected elements (BTAA 2025)

Renew national strategic investment

Build on the foundations established through the ABCM with sustained investment of sufficient scale and duration to support meaningful scientific and clinical progress.

Develop an Australian Brain Cancer Roadmap

Establish a coordinated national roadmap spanning:

- foundational and discovery science
- translational research
- clinical trials
- survivorship
- supportive care.

The purpose was to provide an agreed set of priorities around which government, researchers, clinicians, philanthropy and the brain cancer community could align.

Strengthen research-enabling capability

Invest in the people and infrastructure required to turn research funding into outcomes — including workforce, data systems, biobanking, clinical trial networks and collaborative research capability.

The 2025 proposition was not simply “fund more research.” It was sustain investment, coordinate priorities and strengthen the system required to translate research into patient benefit.

**\$200
million
over 10 years**



**Renew national
strategic
investment**



**Australian Brain
Cancer Roadmap**



**Strengthen research
enabling capability**

What happened in Research & Trials in 2026

During 2026, the national brain cancer research environment began to transition.

As the ABCM approaches the end of its ten-year term, new national cancer research arrangements are emerging and brain cancer remains part of the national research agenda.

At the same time, the Australian brain tumour community has moved from advocating for a general renewal of the ABCM to developing a more detailed proposition for how future brain cancer research priorities could be set. This represents an important evolution of the 2025 ask.

A central development has been the proposal for a Joint Steering Committee to co-design an Australian Brain Cancer Roadmap, bringing together government, researchers, clinicians, consumers and philanthropic partners to establish national priorities across the research continuum (Australian Brain Tumour Collaborative 2026a).



**Joint Steering Committee
to co-design an Australian
Brain Cancer Roadmap**

In 2026, \$18.8 million in MRFF funding established the Bridging Barriers in Brain Cancer Program, accelerating research to develop new therapies capable of crossing the blood-brain barrier.

The issue is no longer only how much Australia invests in brain cancer research, but also how that investment is prioritised, coordinated and governed and partnered with philanthropic.

The remainder of this pillar examines the developments of the past year in more detail, including changes in national research arrangements, the proposed governance and roadmap model, Australia's research capability and areas of scientific focus, and the evolving clinical trials and treatment-access environment.

What remains unresolved



A coordinated Australian Brain Cancer Roadmap is not yet in place

Australia has strong researchers, institutions, clinical trial groups and philanthropic organisations, but there is still no single national framework setting out the priorities that is fully co-designed with the brain cancer community, which would guide brain cancer research investment over the coming decade.



The future scale and sustainability of investment remains critical

Brain cancer research requires long-term investment. Capability developed through one funding cycle can be difficult to retain if researchers, infrastructure and collaborative networks do not have sufficient certainty to plan beyond individual grant rounds.



The research pipeline remains uneven

Foundational and discovery science remain essential because genuinely new treatments depend on a deeper understanding of brain cancer biology. Translational capability is then required to move discoveries toward clinical testing, while strong trial infrastructure is needed to bring those treatments to patients.



Clinical trial access remains an important measure of success

Research impact should ultimately be judged by whether discoveries reach people.

The availability of a clinical trial does not necessarily mean that an Australian patient can access it. Geography, tumour type, eligibility, trial activation and health-system capacity can all influence whether an opportunity exists in practice.



Consumer participation needs to be embedded, not episodic

The 2025 Landscape called for more systematic involvement of patients and carers in research priority-setting.

That remains important because research outcomes valued by patients extend beyond survival alone. Cognitive function, independence, treatment toxicity, quality of life, survivorship and the impact on carers and families should also shape what Australia chooses to investigate.

What needs to happen next

The next stage is to move from individual investments and programs toward a coordinated national research system.

The goal is not simply to increase the volume of brain cancer research. It is to build a system capable of converting research investment into research impact and research impact into better outcomes for people affected by brain cancer.

The specific Research and Trials priorities for the year ahead are set out in Summary, Next Steps and 2026 Asks:

Ask 1

Co-design the Australian Brain Cancer Roadmap through a Joint Steering Committee, working across the ACRP's partner missions.

Ask 2

Build toward the scale the challenge requires.

Ask 3

Faster, fairer access to new treatments, including a compassionate-access pathway.

The Australian Brain Cancer Research environment



Professor Mike Fay
Foundation MHF Chair in Brain Cancer and Centre Director, Mark Hughes Foundation Centre for Brain Cancer Research.

Picture: Jonathan Carroll Newcastle Herald.

In early 2026, the Mark Hughes Foundation Centre for Brain Cancer Research (MHF Centre) commenced an environmental scan of the Australian brain cancer research environment, with a view to gaining a deep understanding of current (and recent) research (Mark Hughes Foundation Centre for Brain Cancer Research 2026c).

Driven by the desire to see a more strategically coordinated and collaborative effort across the country to push for the patient outcomes that remain stubbornly elusive, the scan sought to:

- discover who is doing what and where
- identify institutional strengths and high-value infrastructure assets
- uncover opportunities for collaboration
- reveal gaps in research

The scope of the scan was limited to current or recent (past 5 years) research and research outputs. Information was gathered via desktop research and through direct engagement with research institutions and researchers. The scan focused on lab-based research.

The results of the scan, while comprehensive, are limited by the institutional response rate, as well as the variability of data provided. It is also important to note that this is a dynamic research environment, with new projects commencing all the time.

Data capture

A literature extraction (using Scopus) identified 777 brain cancer related publications since 2021 with a first and/or last author affiliated with an Australian institution (Mark Hughes Foundation Centre for Brain Cancer Research 2026c).

Desktop research and follow-up direct engagement with research institutes verified 164 unique projects. Of these, 71 projects were reported to have a paediatric patient focus.

A wide range of information was sought for each project – including researchers involved, patient focus, research stage, tumour type, tumour grade, research models, and funding information.

Research breakdown

Research activity is spread across the country, with concentrations in NSW, SA, VIC and WA – which together account for 91.9% of all projects (Mark Hughes Foundation Centre for Brain Cancer Research 2026c).

The concentration is also institutional. The top four administering institutions account for 63.5% of records. The largest portfolios are at Adelaide University, WEHI/The Brain Cancer Centre, the University of Newcastle and The Kids Research Institute Australia / University of Western Australia.

NSW, SA, VIC and WA together account for 91.9% of all projects

State/Territory	Projects
NSW	65
SA	37
VIC	29
WA	20
QLD	5
TAS	3
ACT	3
National	2

Phase of research

Projects indicate a predominantly upstream-to-translational pipeline. Discovery research dominates adult/comprehensive focus research, which means the field is still investing heavily in understanding tumour biology, mechanisms, targets, and new approaches.

Translational work is also substantial – particularly with paediatric focused research projects – which suggests a healthy pipeline from lab insights toward application.

Research Stage	Comprehensive/adult focused research projects	Paediatric patient focused research projects
Discovery	37	32
Discovery and Translational	33	6
Translational/Pre-clinical	22	34
Clinical Trials	4	4

Tumour type and grade

Projects are dominated by glioma-family and other aggressive brain tumours. With 46 projects, glioblastoma is the dominant adult tumour focus, suggesting national alignment around its persistent lack of effective therapies and major unmet need. In paediatric brain cancer research, there is a strong focus on DIPG/DMG (40 projects) and medulloblastoma (20). The field is also overwhelmingly focused on high-grade disease, with high grade tumours being the focus of 126 projects. This reflects clinical urgency and the funding attractiveness of high-need diseases where survival gains could be most meaningful.

Research themes

Reflecting the upstream to translational pipeline, a thematic scan of the current and recent research projects finds a strong emphasis on therapeutic development, molecular profiling and translational tools.

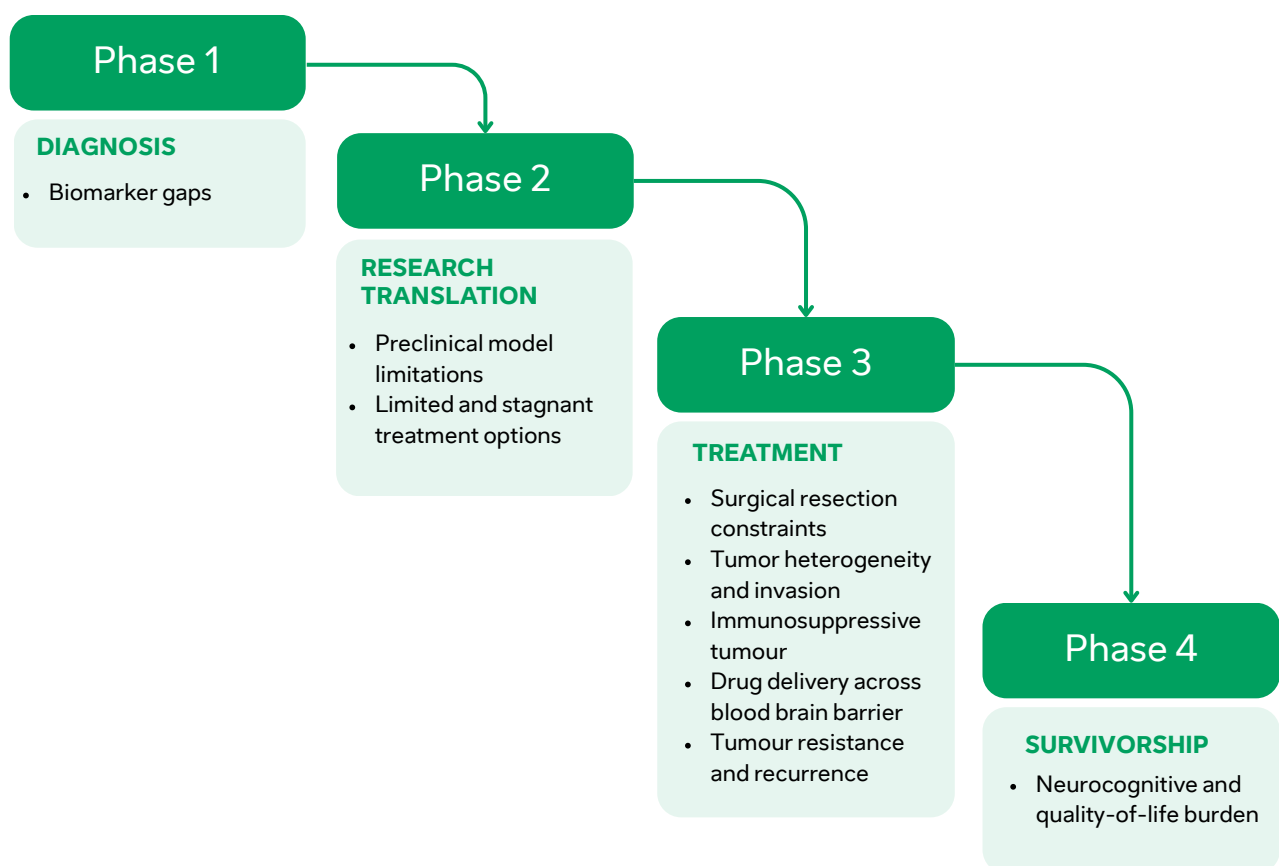
In concentration order, the themes of current research are:

- Therapeutics and drug development
- Models, organoids and patient-derived xenografts
- Molecular biology, genomics and single-cell approaches
- Immunotherapy or tumour immunology
- Clinical trials or treatment optimisation
- Biomarkers, diagnostics and liquid biopsy
- AI, computational or data-science approaches
- Survivorship, quality of life and supportive care (noting that this category has not been explored in detail for the purposes of this scan).

Current research activity has also been reviewed in the context of the challenges identified in the literature. Each is an active field of research with some clear institutional leaders:

- **Biomarker gaps** - University of Newcastle leading with extensive work on MRI-based biomarkers, molecular signatures, and liquid biopsy approaches.
- **Preclinical model limitations** - Adelaide University and University of Newcastle are both heavily investing in developing and utilising diverse preclinical models including Drosophila, iPSC-derived systems, patient-derived tumouroids, and various animal models.
- **Tumour heterogeneity and invasion** - University of Newcastle dominates this space with extensive work on spatial mapping, single-cell analysis, and understanding intracranial dissemination patterns in glioblastoma.
- **Immunosuppressive tumour microenvironment** - University of Newcastle and Adelaide University have substantial programs investigating immune checkpoint inhibitors, CAR-T cell therapies, and strategies to overcome the immunosuppressive nature of the brain tumour microenvironment.

- **Drug delivery across the blood brain barrier** – The WEHI/Brain Cancer Centre’s Lessene-led Blood-Brain Barrier Program is a lead initiative in this space. Macquarie University is focused on innovative approaches including brain-targeted artificial viral vectors and nanoparticle delivery systems while Adelaide University focuses on convection-enhanced delivery and blood-brain barrier penetration strategies.
- **Treatment resistance and recurrence** - University of Newcastle is extensively researching chemoresistance mechanisms, recurrent disease monitoring through liquid biopsy, and strategies to prevent or treat recurrent glioblastoma.



Gaps and opportunities

Deep exploration and interrogation of the research scan findings will help the research community identify gaps and opportunities.

Collaboration and cooperation is key

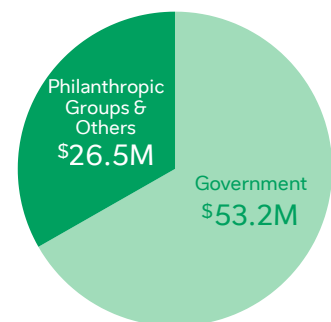
A more strategically coordinated approach with increased collaboration across the field of brain cancer research in Australia is critical. Despite best efforts under the Australian Brain Cancer Mission, patient outcomes remain stubbornly elusive and the research community is increasingly motivated to change this.

The scan confirmed that various collaborative relationships exist in the research community at an institutional and project level. The scan also found a number of different registries, clinical data resources and research enabling platforms currently being developed, either collaboratively or for shared benefit across the research community. These shared infrastructure platforms will help to minimise unnecessary or duplicate investment and will save the research and patient community valuable time.

The research community is also represented by a range of member organisations and consortia with a variety of remits. The way the research community comes together is important. There is an opportunity to ensure the purpose of each representative group is distinctive to avoid duplication or overlap. There is also an opportunity to consider whether there are any aspects of brain cancer research that should have representation at a 'community' level that currently do not.

The role of philanthropy

Philanthropic foundations continue to make a very important contribution to brain cancer research in Australia. Based on the funding information provided in the scan (i.e. not all projects), **current and research funding totalled approximately \$80 million – of which the Government funded around 66.5% (\$53.2M), and philanthropic groups, charities or other sources accounted for around \$26.5 M).**



As philanthropic funding is very often personally driven, it is often tied to a particular type of brain cancer. This is very significant as it can often mean philanthropic funding is directed to focused pieces of research that would not be considered as suitable for large scale funding, which is usually provided by Government. This broadens the scope of the research effort and has been able to provide the start that researchers need to get their ideas off the ground. The WEHI/Brain Cancer Centre's Lessene-led Blood Brain Barrier Program is a good example. With the help of a philanthropic grant, the program was able to get established and has just been awarded an NHMRC grant of \$18.8M.

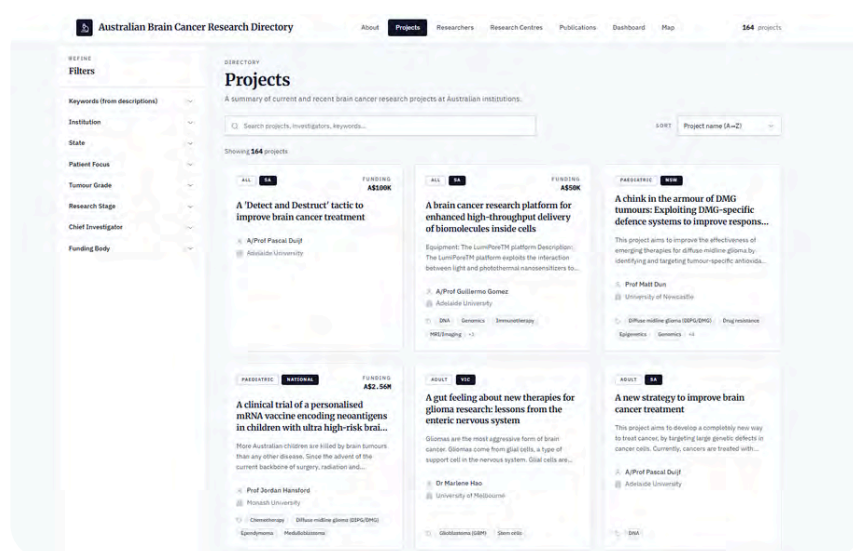
The two funding streams are highly complementary and critical - with philanthropic funding allowing research breadth, while Government funding provides depth.

Philanthropic support is also a critical element of the brain cancer research ecosystem. Fundraising helps to raise awareness of the disease and of the need to increase funding to push for patient outcomes. Philanthropic support is a particularly important component of the paediatric brain cancer research environment.

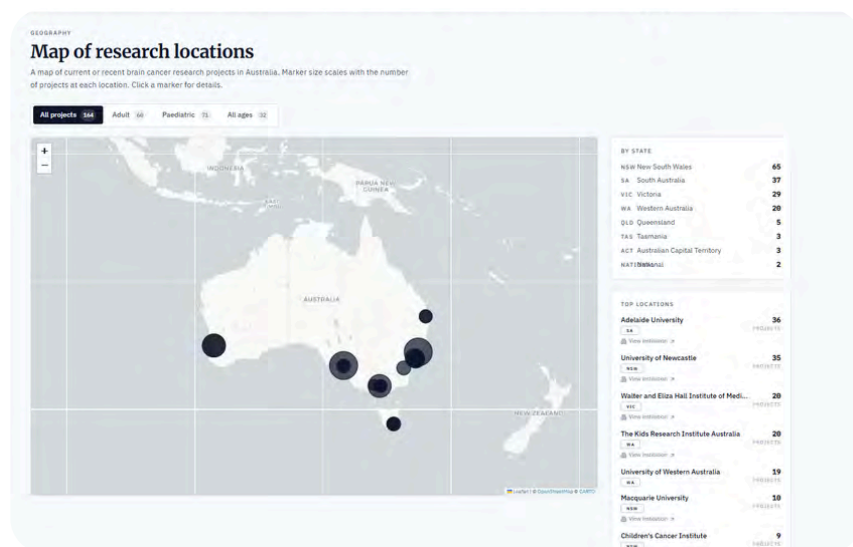
Mapping brain cancer research

The **Mark Hughes Foundation Centre for Brain Cancer Research** has developed the scan findings into an online Australian Brain Cancer Research Directory. The platform will provide user-friendly access to detailed information about current projects, research centres (their strengths, infrastructure, streams/labs etc) and individual researchers (their projects, leadership roles and publications).

The Directory includes a live dashboard which can provide key metrics and a map which illustrates the geographical distribution and concentration of the research effort. The platform presents a game-changing opportunity for the brain cancer research sector to provide and access up-to-date information about research activities, to inform collaboration, minimise duplication and identify gaps.



The Australian Brain Cancer Research Directory includes a dynamic dashboard



A map shows the distribution of current and recent brain cancer research projects across Australia

Research in Focus:

Blood Brain Barrier



Professor Guillaume Lessene
Chief Investigator – Blood Brain Barrier
The Brain Cancer Centre



Driving change and giving hope when hope feels hard to reach

What does it take to bring lifesaving treatments and care to patients facing a serious and devastatingly impactful disease? And if, despite extensive research and effort by brilliant minds, the advances in therapy over decades are minimal and the standard of care for the most common and aggressive subtypes of the disease offer limited survival benefit, what then? What is needed to drive meaningful progress and offer hope to patients, their loved ones and their care teams?

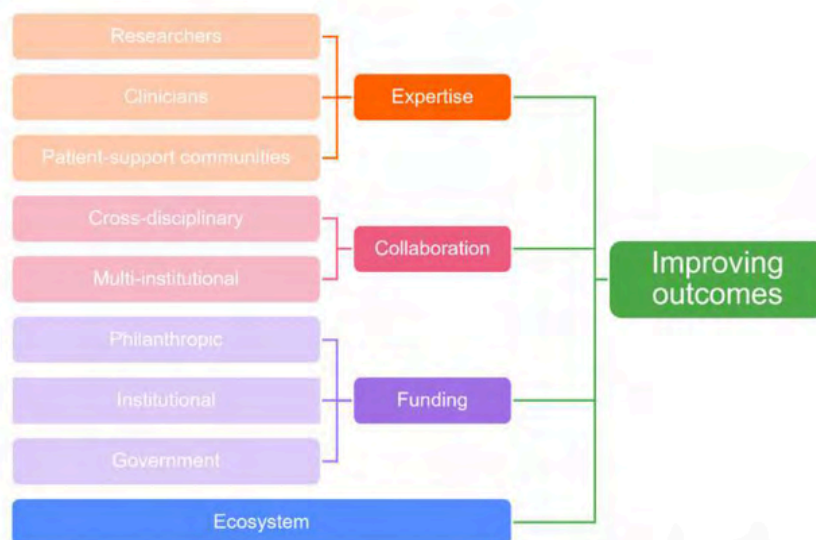


Figure 1 What it takes to drive new therapies and improve outcomes for patients

The Bridging Barriers in Brain Cancer (B3C) Program is a model for what it takes -

researchers, clinicians and patient-support communities who each have deep expertise and extensive relationships, coming together in true multidisciplinary and cross-institutional collaboration, fuelled by targeted philanthropic, institutional and government funding provided at key times to preserve momentum and knowledge, all supported by a collaborative and focused ecosystem (Figure 1).

Urgent need for new treatments for poor survival brain cancer

Brain tumours are the leading cause of cancer-related mortality in Australians aged under 40, with only 23% of patients surviving more than five years. Patients experience significant neurological and cognitive impairments that severely diminish their quality of life, and face significant socioeconomic impacts that lead to the highest total lifetime cohort cost of any cancer in adolescent or young adults (Canteen Australia 2017). These stark realities underscore the urgency for effective treatment.

Targeted therapies have been transformative in many fields of oncology but have been ineffective for brain cancer. This disparity is largely due to the **blood-brain barrier (BBB)**, a highly selective physiological barrier that shields the brain from toxic substances. Although crucial for maintaining brain health, it also impedes the delivery of many drugs, **limiting the ability of these drugs to reach brain tumours at efficacious concentrations**. Other major obstacles include poor tissue penetration and drug specificity. These challenges are underscored by the fact that, despite an increasing number of new drugs in development, the success rate remains low, with **no new drugs for the treatment of high-grade gliomas approved in 20 years**.

The Bridging Barriers in Brain Cancer (B3C) program is committed to changing this therapeutic landscape with a vision to transform brain cancer treatment by delivering potent drugs across the blood-brain barrier to significantly improve patients' lives.

Expertise & collaboration – tackling the blood-brain barrier problem

The genesis

In mid-2021, researchers and clinicians from across WEHI, the Brain Cancer Centre, Peter MacCallum Cancer Centre (Peter Mac), the Monash Institute of Pharmaceutical Sciences (MIPS) and the University of Queensland came together in collaboration under the Blood Brain Barrier Theme, funded by the Brain Cancer Center. The Blood Brain Barrier Theme aimed to tackle the bottlenecks to effective brain cancer therapeutics – lack of drug specificity and lack of drug penetration.

This multidisciplinary collaboration spanned fundamental science including synthetic chemistry, cancer biology, protein engineering, as well as the biology and physiology of the blood brain barrier. With a united vision and alignment from discovery to the clinic, the team overcame the potential barriers of geographical and institutional separation to function as a strong and close-knit team, ready **to tackle the technical barriers to success**.

The technical barriers – delivery of drugs to the brain and tumour

Gliomas present a significant therapeutic challenge. As well as being complex diseases, characterised by the alterations of multiple cellular pathways, gliomas are shielded by the blood-brain barrier from 98% of small molecule drugs and nearly all large biologics. For this reason, **targeted therapies have not shown success in gliomas as they have for other solid cancers**.

Drugs that could make a difference do not reach brain tumours at levels sufficient to elicit a therapeutic response.

Despite its name, the blood-brain barrier is not entirely impermeable; it has its own transport systems to deliver key nutrients to the brain. Cells in the blood-brain barrier contain specialised “docking stations” that recognise nutrient-carrying proteins (“transporters”) and actively draw them into the brain. (Figure 2A)

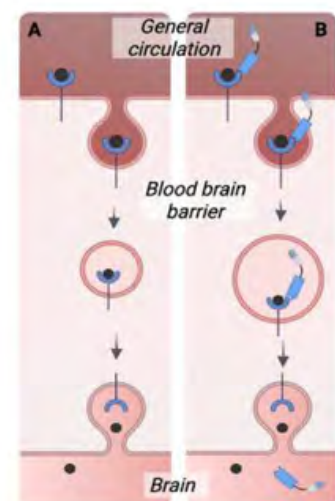


Figure 2 Receptor-mediated transport of natural nutrients (A), leveraged to bring therapies into the brain (B)

Leveraging these mechanisms offers real opportunities for more effective treatments in brain cancer.

Indeed, in examples that provide exciting proof-of-concept for this mechanism, therapies for neurological diseases such as Hunter syndrome have shown that drugs can be shuttled across the blood-brain barrier using ‘**Trojan horse**’ approaches, in which drug payloads are attached to antibodies (the “transporters”) targeting naturally expressed receptor proteins (the specialised “docking stations”). (Figure 2B)

This approach is not yet available for brain cancer; the **Bridging Barriers in Brain Cancer Program is focused on breaching that divide** by combining potent small molecule drugs targeting glioblastoma (GBM) in adults and diffuse midline glioma (DMG) in children with nanobodies (the “transporters”) that can carry drug payloads across the blood-brain barrier – this combination of drugs and nanobodies are termed nanobody-drug conjugates (NDCs).

Nanobody-drug conjugates – a promising solution

NDCs are an emerging class of biologics that combine the targeting power of antibodies with the small size and high tissue penetration of nanobodies. A tenth of the size of conventional antibodies, **nanobodies targeting relevant receptors at the blood-brain barrier can cross this physiological barrier.**

Their small size is predicted to allow for deeper penetration into solid tumours and higher tumour uptake. Nanobodies are inherently stable and soluble, highly advantageous features for maintaining structural integrity during manufacture and long-term storage. They are also less immunogenic and easier to engineer and manufacture than antibodies.

These properties make them ideal carriers for anti-cancer drug payloads (Figure 3). The modularity of nanobodies allows for ease of linking to different drugs of interest with precise loading, allowing for accurate dose regimens to be established, a feature that is still poorly controlled with antibody-drug conjugates.



Figure 3 Nanobody-drug conjugate (NDC) basic design

The Blood Brain Barrier Theme – a powerful collaboration

However, outsmarting the blood-brain barrier is a challenge no single laboratory or research team can solve. The blood-brain barrier remains one of the least understood and under-researched biological structures in the human body. Furthermore, NDCs are an emerging class of biologics, and a successful translation from concept to therapy requires breakthrough ideas and national collaboration of deep expertise across a broad knowledge base:

- **Deep target biology insights:** rigorously selected targeted therapies in which the team have deep experience, and which have poor brain penetration and known ‘on target’ adverse effects – perfect candidates for targeted delivery via NDCs.
- **Deep knowledge in the biology and physiology of the blood-brain barrier:** this expertise ensures the team can assess brain penetration of these new therapies with the most appropriate assays.
- **Established platform capabilities:** engineering NDCs to elicit the best possible transport cross the blood-brain barrier and payload release, which requires leveraging broad expertise and access to both new and established cutting edge in vitro and in vivo preclinical models for GBM and DMG.
- **Clinical promise:** the generation of data showing a proof-of-concept to kill GBM-derived neurospheres with minimal toxicity to non-cancerous cells.

With the right funding and support, the founders and collaborators of the Blood Brain Barrier Theme knew they could address long-standing gaps in drug development, by delivering a tailored and extensive pipeline for brain penetrance and NDC efficacy – offering the potential to **significantly improve patients' outcomes, including enhanced survival, reduced side effects, and better quality of life.**

Funding & ecosystem – critical to progress

Research, especially the deeply collaborative research undertaken in the Blood Brain Barrier Theme and now the Bridging Barriers in Brain Cancer Program, doesn't happen in a vacuum. Institutional, ecosystem, philanthropic and government support is critical to support and progress the work being undertaken.

Program initiation – seed funding and the strength of philanthropy and institutional support

The Brain Cancer Centre, founded by Carrie's Beanies 4 Brain Cancer Foundation and established in partnership with WEHI with support from the Victorian Government, provided \$1.88m over four years in seed funding to the collaboration under the Blood Brain Barrier Theme. This funding was instrumental in establishing and progressing the pioneering research program and was critical to:

- Build the team of researchers and clinicians with the deep technical expertise required to successfully tackle the problem;
- Initiate the program of work;
- Establish the pipeline of payloads, linkers and nanobodies;
- Develop the platform capabilities to an early-stage – appropriate assays and in vitro and in vivo preclinical models for GBM and DMG;
- Generate preliminary data; and
- Build confidence that this approach could deliver an efficacious glioma treatment.

However, by mid-2025 the collaboration had reached a funding and efficiency crossroad.

Program acceleration – investment by government to advance health and medical outcomes

In mid-2026, the collaboration under the Blood Brain Barrier Theme was awarded \$18.8m in funding from the Australian Government's Medical Research Future Fund's (MRFF) Frontier Health and Medical Research program. This MRFF funding is complemented by further support from WEHI and Carrie's Beanies 4 Brain Cancer Foundation.

This significant funding over five years has established the **Bridging Barriers in Brain Cancer (B3C) Program**, building on the work established under the Blood Brain Barrier Theme, and has underpinned a significant acceleration of activities. Crucially, the funding arrived at a critical juncture, sustaining momentum and ensuring continuity of expertise and knowledge on the program. The founding collaborative partner organisations - WEHI, the Brain Cancer Centre, Peter MacCallum Cancer Centre (Peter Mac), the Monash Institute of Pharmaceutical Sciences (MIPS) and the University of Queensland - all renewed their commitment and involvement in the program, and have been joined by Royal Melbourne Hospital (RMH) and University Technology Sydney (UTS) as official partner organisations.

The funding has enabled the expansion of the key expert teams in areas such as payload and linker chemistry, nanobody engineering, blood-brain barrier penetration and biopharmaceutical properties, and in vivo/in vitro brain cancer biology. It also funds the addition of critical expertise to the program in bioinformatics and in vivo imaging, and cements the place of clinicians, consumers and health economics at the heart of the program, ensuring alignment from discovery to the clinic. Such consumer focus with expert clinical guidance will ensure the NDC candidates reflect treatment preferences of patients with lived experience and their carers, and the outcomes are actionable by clinicians treating patients with brain cancer.

Over the next five years, the Bridging Barriers in Brain Cancer Program will:

- Develop an optimised preclinical candidate NDC (lead candidate) ready to enter the later stages of drug development and clinical trials;
- Expand the platform to a second payload with evidence of in vitro efficacy and sufficient brain exposure (follow-on candidate proof of concept); and
- Lay the foundation for preclinical development and initiate the discovery of predictive biomarkers for patient stratification (selection/treatment response predictors) and companion diagnostics.

Longer term, the investment paves the way for the Bridging Barriers in Brain Cancer Program's "moonshot" – a goal over the next 10 years to successfully translate into clinical application an NDC to treat poor survival gliomas and other brain cancers, and to establish a national platform to develop the next generation of brain-penetrating drugs.

Bridging Barriers in Brain Cancer Program – A case study

The Bridging Barriers in Brain Cancer Program's initiation pathway, achievements to date, and future ambitions are a study in what is enabled and accelerated when the expertise and experience embodied by researchers, clinicians and patient support communities are connected by multidisciplinary and cross-institutional collaboration and supported by a foundation of philanthropic, institutional and governmental funding, all brought together in a supportive and connected ecosystem.



Peter's story

Our journey began with Pete's initial tonic-clonic seizure in 1988, after returning from his job driving a Fuel Tanker. That moment marked the beginning of 38 years in which brain cancer remained part of Pete's life and the life of our family.

Pete fought brain cancer for 38 years. During that time he endured five surgeries, radiation once and chemotherapy twice. He underwent MRI's every 3-6 months for 38 years, only moving to yearly scans for 2 years. Each recurrence meant facing the possibility of more treatment and another disruption to the life he was trying to live. What was not available to Pete was any other options for treatment. After 38 years he had no other options. Nothing. By the end of his life Pete was on 5 different medications one being added on top of the other to help control his seizures.

Despite the lack of options, Pete's approach was remarkably direct. When a recurrence occurred, he was the one who would say, in effect, 'just get it out.' He did not complain about what he had to endure. He kept going and faced each new challenge as it came. He would always say he would do it again if and when the tumor recurred.

The result of the surgery and the multitude of medications for his epilepsy also took away things that mattered deeply to him. One of the greatest losses was his ability to drive trucks. He had been made redundant from three jobs he loved when he could no longer drive because of seizures. After his first two surgeries, 2 years was the waiting time before he could drive trucks again. After the third surgery, he was told he would have to wait ten years. That was an impossible amount of time for him, and giving up driving broke his heart.



Our family lived with it too

Although Pete was the person with the cancer, the illness affected our whole family. Our 3 children and 5 grandchildren have no memory of Pete without brain cancer.

The family therefore did not simply experience 38 years of medical treatment. They experienced 38 years of living around an illness that could return, change plans and place limits on what Pete could do.

There was the practical side: surgeries, recovery, treatment, seizures, mood changing medications, personality changes, extreme fatigue and driving restrictions and each worsening following each recurrence. There was also the emotional side — knowing that the disease was still there, wondering what the next recurrence would bring, and repeatedly having to face the possibility of losing someone who was central to the family.

The family also had to watch Pete lose abilities and independence. His frustration when he could no longer do things he had once been able to do was difficult to witness. Until the 3rd occurrence in 2015 he could fix almost anything. Later, losing those skills was frustrating for him and sad for those around him.

A life that continued alongside the illness

It is important that Pete's story is not reduced to cancer. For much of those 38 years, there was also a life being lived.

Pete loved music. Jazz and many other kinds of music were a constant presence in our house, often played and sung loudly. He loved tinkering in the garage, working on clocks, lawnmowers, chainsaws, cars, boats and bikes. He converted a school bus to a motorhome, which we travelled Australia in. He spent hours working alongside friends, his brothers and later with his sons.

Motorbikes were another constant. There were dirt bikes, road bikes and even a sidecar. We always had boats and spent countless hours waterskiing. His passions were shared and enjoyed by his family.

There were Friday night dinners and movies, trips to the coast, overseas holidays, visits to lighthouses, coffees that could last for hours, catch-ups with friends, watching the children participate in sport, watching his children grow up, get married and have children of their own.

These ordinary things mattered. They were the pieces of a family life that continued despite the illness.

After Pete's 3rd surgery in 2015 I found myself needing support, after never being offered much from the hospital system. I googled support groups for brain Cancer families and found Brain Tumour Alliance Australia (BTAA). Susan Pitt rang me and from there Pete and I attended monthly support group meetings. I eventually joined the BTAA committee, became the treasurer and still hold that position on the new Board.

In early 2023 I was fortunate enough to sit next to Fiona Hassman from Peace of Mind Foundation (POMF) at a lunch at a BTAA forum.

While we discussed our husbands brain tumour journeys, Fiona suggested that it would be a good idea to get in contact with POMF and the National Advocacy Service (NAS) and get their assistance to apply for the NDIS for Pete before he turned 65. 65 being significant as you can't apply for NDIS when you reach that age. From then it's the aged care system.

I made contact with POMF and received the most amazing assistance from their advocate, Mary Sutton, from the NAS. Within a few weeks Pete had been approved for a package offering support for his care. At the time Pete was struggling with a few deficits and what he needed at the time was minimal, compared to what was to come.

After his 4th craniotomy on 13 January this year and his 5th craniotomy on 16 January after a brain bleed, Pete's circumstances changed dramatically.

He was left with very significant physical, cognitive and communication difficulties. He was unable to do almost anything for himself. His left side was completely immobile and his right side was extremely weak. Things that most of us take for granted — moving, reaching, communicating and looking after basic needs like feeding himself — were no longer things he could manage independently. He was also almost completely non-verbal. Every now and then he would say something, sometimes strange, or inappropriate, but also quirky comments which made us think he was still here. For a man who had always had a cheeky sense of humour and plenty to say, losing the ability to communicate was another heartbreaking part of what the illness had taken from him. He could not even communicate whether he was in pain or how much pain he was in. At times he would comment they just do it anyway, when he wasn't able to respond to requests to provide care. This is not a criticism but the reality for a proud capable man who could no longer speak for himself.

After a few months it became clear that things were not going to improve significantly for him. The allied services in the hospital withdrew care (telling me that he was not a priority) and there was no way he would be able to get to rehab, his future was a nursing home. It was put to me that bluntly and with him able to hear it all.

It took 3 months for a social worker to reach out to me at the hospital, but when he did it was the beginning of a new trajectory for Pete's future. I had said that a nursing home wasn't what we wanted for Pete. It was then that we started looking at a change of circumstances to Pete's NDIS plan. Once the social worker started working on this idea the option of a supported living accommodation became a possibility. It took a few months to get sorted but once we had the change of circumstances approved, on Mary Sutton's lead we were able to get Pete transported to Qld and a new supported living accommodation near our family living in Brisbane. My plan was, and is, to move from Canberra to join them all.

Pete seemed happy with this new arrangement, he was communicating a bit better and was enjoying his time with our kids and grandchildren.

Without the POMF helping us get NDIS for Pete in 2023 he would probably still be in Canberra hospital waiting for a nursing home willing to take on someone who needed such extensive care.

For the family, the eight months from Pete's initial surgery in January to 30 August, when he passed away, were confronting in ways that are difficult to put into words. We had known Pete as independent, practical and capable. To see him become completely dependent on others was devastating.

We had to adjust to a very different way of being with him.

Sometimes communication was as simple as a look, a familiar expression or a small indication that he understood someone was there. We learned to value those moments because they became so important.

The eight months also brought an enormous amount of uncertainty and emotional exhaustion for the family. There was the practical reality of caring for someone who could no longer care for himself, but there was also the grief of losing pieces of Pete before we actually lost him. We were watching someone we loved become increasingly limited by the disease, while still recognising the Pete we knew underneath it all.

Those final eight months were not simply the end of Pete's life. They were months of caring, adapting, visiting, hoping and trying to make sure he was comfortable and knew he was loved.

The cost was not only to Pete and our family, but to the broader community — 207 days in hospital at a minimum of \$3,000 per day, together with substantial NDIS support. And that was only the final stage of his illness. How different might things have been if more treatments were available?

And that brings me to another matter - Voluntary assisted dying. Pete did not want to live in the condition he was left in after his final surgery. No one wants to lose their dignity and choices. He clearly said to me prior to the 13 January that if he was in a vegetative state and not able to do anything for himself he did not want to live. There needs to be a way for people to make their wishes known, that their family can make that decision for them. Before they go into surgery, for example, sign a declaration stating their wish for their family to request VAD on their behalf.

Sadly, the move to Qld ended with Pete passing away exactly 38 years to the day from the initial seizure in 1988. We miss him every day but are relieved he now has his dignity back.



Research in Focus:

Australian Paediatric Brain Cancer Research and Impact Overview



Dr Kim Wark
Head of Research
Robert Connor Dawes Foundation

Brain and other central nervous system (CNS) tumours remain the leading cause of childhood cancer deaths. They are the second most common childhood cancers, after leukemia (AIHW (2017)).

This document summarises the main tumour types, current Australian statistics and the state of paediatric brain cancer research in Australia: how it is funded, where the funding gaps lie, what research is being prioritised, the state of the research workforce, and questions about the long-term sustainability of the field.

Executive summary

- There are over 100 types of paediatric brain tumours with different biology, responses to treatment and outcomes.
- Paediatric brain tumours are distinct from adult brain tumours, requiring dedicated biological research.
- Clinical Trials play a critical role in improving outcomes for children with brain tumours and permit access to cutting edge therapies not otherwise available in Australia.
- Philanthropy plays an essential role in the research funding ecosystem.
- The Australian Brain Cancer Mission (ABCM) and the ZERO Childhood Cancer Program have built strong foundations to accelerate research.
- Collaborative, innovative and equitable funding models between governments, philanthropy and other funding partners are critical to fully realise previous investments and change the odds for kids with brain cancer.

Robert Connor Dawes Foundation

- RCD Foundation is the largest Australian charity solely dedicated to funding and advocating for paediatric brain cancer research.
- Represents 70,000 members & donors of brain community (including 319 affected children- our brain stars)
- Invested over \$12M in research and leveraged a further \$12.5M through partnerships with like-minded charities, governments, institutes and universities.

Achievements:

- Aim Brain project validated, translated and accredited DNA methylation profiling of brain tumours as a diagnostic test for Australian children with brain cancer.
- mRNA brain cancer vaccine project has built expert capability and informs aspects of the PaedNEO-VAX clinical trial.
- Current initiative -National Paediatric Brain Cancer Data Linkage Platform- automates patient data workflows and linkage.

Types of Paediatric Brain Cancer

Paediatric brain cancer is not a single disease but a complex collection of different tumours, each with its own biology, responses to treatment and prognosis.

Moreover, it is now understood that paediatric brain cancers are distinct from adult brain cancers due to difference in their cells of origin, developmental context and unique genetic and epigenetic drivers.

For example, many paediatric brain tumours develop from mutations that arise in specific stem and progenitor cells during defined developmental windows (Cassim et al. 2025; Sun et al. 2023). As a result, effective treatments for children with brain tumours are unlikely to emerge as a byproduct of adult brain cancer research, but rather from specifically understanding paediatric tumour biology.

Traditionally, paediatric brain tumours were classified based on their anatomical location, cell/tissue type, histological appearance, tumour clinical behaviour, age of patient, tumour grade (1 = lower to 4 = higher) and increasingly with molecular/ genetic characteristics. The advent of new technologies defining the latter, has been revolutionary in informing and changing World Health Organisation (WHO) classification guidelines.

Moreover, many tumour categories have been further dissected into multiple molecular genetic subtypes with distinct clinical features and survival outcomes (Louis et al. 2021). For example, there are four main molecular subgroups of medulloblastomas, the most common malignant brain tumour, which have now been divided into thirteen distinct subtypes (Gottardo 2023; Cavalli et al. 2017).

Similarly, ependymoma, another common childhood brain tumour, consists of six to ten molecular and anatomical subtypes (Kresbach et al. 2022; Louis et al. 2020; Ellison D et al. 2020).

In total, there are now over 100 histologically distinct childhood brain tumour subtypes (Moore K et al. 2020; Waite K et al. 2020), which is a major reason that treatment cannot be standardised the way it can for more uniform cancers (i.e. ones that are more uniform in their biology, molecular genetic features, responses to therapy and prognosis).

In addition to sequencing the genetic code of a patient's brain tumour, an advanced molecular test called DNA methylation profiling of the brain tumour has proven to be an accurate diagnostic test to determine the tumour type. This test has been validated in Australia and NATA-accredited for use in the Victorian Clinical Genetics Services (VCGS) at the Murdoch Children's Research Institute (MCRI), Melbourne (White et al. 2023; ANZCHOG 2022).

For paediatric brain tumours, this test is an essential part of diagnosis and can change both the diagnosis and the treatment plan in up to 30% of cases (VCGS 2023). This has become a standard of care test, and proven to be a game changer, placing Australia alongside Canada, United States, United Kingdom and some European countries (Ontario Health 2025).

Furthermore, it has been adopted into the 5th Edition of the WHO diagnostic criteria for CNS tumours (Louis et al. 2021).

This detailed information is essential for clinicians facilitating more accurate diagnosis and to select appropriate treatment plans. It also enables researchers to understand the biology of each tumour and develop more effective therapies.

Nevertheless, for the public, paediatric brain tumours are often described at a much higher level.

Cancer Australia (2026) groups them into the following categories:

Gliomas and astrocytomas, arising from glial support cells, range from slow-growing, low-grade tumours such as juvenile pilocytic astrocytoma through to fast-growing, high-grade tumours such as glioblastoma and anaplastic astrocytoma (Cancer Australia 2026). A particularly aggressive subtype, diffuse midline glioma (which includes diffuse intrinsic pontine glioma, or DIPG), typically arises in the brainstem and carries the poorest prognosis of any brain tumour with almost all children succumbing by 2 years post diagnosis (NCI 2025; Hoffman et al. 2018).

Medulloblastomas arises in the cerebellum and is now understood to comprise four molecularly distinct subgroups (WNT, Sonic Hedgehog/SHH, Group 3 and Group 4), which behave differently and respond differently to treatment (Louis et al. 2021; Taylor et al. 2011).

Ependymomas develop from cells lining the brain's ventricles or the spinal cord and are classified by location as supratentorial, posterior fossa, or spinal (Louis et al. 2021).

Optic pathway gliomas arise in or near the optic nerve and visual pathways, and **rarer tumour types** include atypical teratoid/rhabdoid tumours (AT/RT), embryonal tumour with multilayered rosettes (ETMR), pineoblastomas, CNS embryonal tumours not otherwise specified, CNS germ cell tumours and craniopharyngioma (Cancer Australia 2026).



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Paediatric Brain Tumour Statistics in Australia

Approximately 110 (AIHW 2017) to 200 (Youlden et al. 2020) Australian children aged 0-14 years old are newly diagnosed each year with a paediatric brain tumour, which accounts for 15% of all childhood cancer diagnoses (Cancer Australia 2025; AIHW 2022a; AIHW 2017).

This translates to an age-standardised incidence rate of about 2.3 per 100,000 children (AIHW 2022a). This aligns with European rate (2.2 per 100,000 children) and is slightly below the average rate for high income earning countries (2.6 per 100,000 children (Roach et al. 2026; Wang 2025)).

In 2024, malignant brain tumours alone accounted for more than 9% of deaths in children aged 1-14 years old (AIHW 2022b).

Paediatric brain cancer's disproportionate impact is most clearly reflected in mortality data. The Australian Institute of Health and Welfare (AIHW) identifies it as the leading cause of cancer death in Australian children under the age of 10 years (AIHW 2017).

In 2020, 33 children under the age of 14 years died from paediatric brain cancer (Cancer Australia 2025a; AIHW 2022b). It is estimated that between 30-40 Australian children die from brain cancer per year, accounting for well over a third of childhood cancer deaths each year (Cancer Australia 2024; AIHW 2022b).

Whilst the five-year survival rate across all childhood cancers in Australia increased from 73% in 1983-1994 to 87% by 2007-2018 (Youlden et al. 2023), outcomes for paediatric brain cancers remain dismal, well below averages of other tumour types (AIHW 2026; Cancer Australia 2025b; Youlden et al. 2023; Youlden et al. 2021).

Moreover, survival rates significantly vary across brain tumour categories and even molecular subtypes. For example, the overall medulloblastoma 5-year survival rate is ~ 65-70% , but for children diagnosed with subgroup 3 with a MYC gene amplification or metastases at diagnosis, the 5-year survival is only 20-50% (Guild et al. 2026; Girardi et al. 2023).

In comparison, children with DIPG face a 5-year survival of ~ 2%, making it the most lethal childhood cancer (Hoffman 2018). These statistics illustrate the complexity and importance of considering brain tumour type and not quoting averages.

**Malignant
Brain
Tumours** **9%**
of deaths in children
(1-14yrs)

15% of all childhood
cancers are diagnosed as
paediatric brain tumour

30-40
Australian children
die from brain
cancer per year

Medulloblastoma
5-year survival rate
65-70%

Paediatric Brain Cancer Research Funding landscape

Australian paediatric brain cancer research is funded through a mix of federal government investment, state government program funding, hospital foundations, research institutions, universities, and most notably charities and philanthropy.

Importantly, there is no single, stable funding stream which is the main challenge given that it is complex, and we know that it will not be solved by a single therapy, nor one laboratory or institute, but instead requires collaboration across multiple teams, disciplines and borders over a sustained period of time.

Currently, there aren't any published data regarding paediatric brain cancer research funding. This is problematic given that paediatric and adult brain tumours are fundamentally different sets of diseases.

That aside, brain cancer remains underfunded relative to other cancer types. Brain and CNS research for all ages received 5% of all cancer research funding in 2003–2005 (\$1.5M) and 7% between 2018–2020 (\$54.1M) (Cancer Australia 2023).

These statistics and strong advocacy contributed to the formation of the ABCM, a joint Australian Government and philanthropic initiative administered through Cancer Australia and the Medical Research Future Fund (MRFF). The ABCM has been structured as a 10-year, \$126.4 million program which was announced in 2017.

It comprises \$50 million in direct federal government funding plus \$76.4 million in matched philanthropic and partner commitments (Cancer Australia 2026).

In 2024, the Australian Government announced a further \$20 million over seven years through the MRFF's Emerging Priorities and Consumer-Driven Research initiative, targeted specifically at clinical trials and new treatments for childhood brain cancers (Australian Government Department of Health 2025; 2024).

Through this initiative, the Australian and New Zealand Children's Haematology /Oncology Group (ANZCHOG) was awarded \$14 million to lead the Consortium for Australian Children's Trials in Brain Cancer (CoACT-Brain Cancer), a major investment to build a national clinical trial alliance that accelerates breakthroughs in childhood brain cancer treatment and improves patient survival and quality of life (ANZCHOG 2025).

A welcomed announcement by the Federal government in mid-2026 sees a further commitment of \$50 million across 10 years for a second ABCM with a view to once again, successfully leverage investments with philanthropy.

This offers continuity and the opportunity to learn from, build on and exploit the foundations and achievements from the first Mission. However, it is critical that philanthropy, government and other funding partners work collaboratively to co-design and deliver funding via an equitable and robust governance framework using innovative funding models to achieve the greatest impact for patients and the broader community.

Additional government funds could potentially be accessed via the Low Survival Cancers Mission (\$150M) and the CAYA Cancer Mission (\$50M) over the next ten years. Missions also announced under MRFF Australian Cancer Research Program (ACRP) totalling \$300M (Australian Government DHDA 2026a; 2026b).

Over the last few decades charities have, and continued to play an essential role, funding early- and mid-career researcher fellowships, basic laboratory and translational research and clinical trial infrastructure. In particular, they have supported workforce capacity, seeded early stage, basic research to maintain a pipeline of innovation, compared to competitive government grants via MRFF which have been largely focused on translational research (CIE 2023).



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Paediatric Brain Cancer Research focus areas

Basic research

Due to the dismal survival rates of many paediatric brain tumours relative to other childhood cancers, the majority of funding has focused on discovering and developing new therapies. Current research priorities are heavily weighted toward the tumour types with the greatest unmet need such as Diffuse Midline Gliomas (DMG) including Diffuse Intrinsic Pontine Gliomas (DIPG) and other high-grade tumours, treatment-resistant gliomas and toward precision and immunotherapy approaches. Molecular and genetic information, from brain tumours analysed through the Zero Childhood Program (funded by the federal government (\$192.4M) and contributions from the Minderoo Foundation (\$17.2M) and other philanthropic organisations) is providing excellent data for basic research; however, this must be made more readily available and embedded in basic research across Australia. Basic science is fundamental to understanding how these individual tumour types arise, why some are resistant or become refractory to certain treatments over time, and how we can utilise this biological knowledge to target different brain tumours. This is the beginning of the translational pipeline and without investment here the pipeline eventually dries up. Whilst considered slow and higher risk, this research, often funded by philanthropic seed grants or small projects, generate the necessary data for larger pre-clinical and translational NHMRC research grants.

Clinical trials

Discoveries and promising results must be tested and turned into treatments through well designed clinical trials.

Since the ABCM's launch, Australian paediatric oncology researchers, coordinated largely through ANZCHOG have opened or expanded eleven paediatric brain cancer clinical trials, including SJ-ELiOT, COZMOS, INFORM2 NivEnt, VICTORY and TarGeT (Hansford et al. 2024; ANZCHOG 2024).

These trials build on international partnerships with institutions in Canada, Germany and the United States and existing ties to the Children's Oncology Group (COG) as well as the International Society of Paediatric Oncology (SIOP).

Some of these trials (e.g. INFORM2 and TarGeT) reflect a broader shift both in Australia and globally towards molecularly informed trials which match treatment to a patient's tumour molecular subtype rather than its location and histological information alone (Hanz et al. 2020).

The first clinical trial within the ZERO Childhood Cancer Program (PRISM) recommended treatments in 73% of high-risk CNS cases based on sequencing results (Lau et al. 2024). In this study, 43% of patients with a recommendation received it, at their oncologist's discretion. Although the survival curves showed a survival advantage for patients treated with a precision guided therapy (PGT), the outcome remains dismal for these high-risk patients with a survival at 2 years of less than 10%, whether or not patients were treated with a PGT (Lau et al. 2024).

ZERO2, the subsequent trial, as well as other prospective studies, should assist in determining a more accurate place for molecular profiling in the management of children with brain tumours. This highlights the importance of supporting multiple research approaches which complement precision medicine. For example, focusing on how a person's genetic background can affect their ability to respond to medicines, known as pharmacogenetics and therapeutic drug monitoring.

Survivorship/late effects research

Survivorship and palliative care research for children with brain tumours in comparison, has received less funding. This is in part due to the statistics for Australian paediatric brain cancer but also strong advocacy for more therapies.

Nevertheless, in the last ten years there has been a subtle shift towards investing more in survivorship research and redefining surviving into thriving. The government has invested \$9.9M (19.8% of their Mission contribution) into brain cancer survivorship research via the ABCM MRFF grants (DoHA 2020). Of the three projects funded through the ABCM's two Brain Cancer Survivorship grant opportunities administered through the MRFF (2019 and 2020), only one—the Engage Brain project—focused specifically on childhood brain cancer survivors.

Survivorship and quality of life research was highlighted in the ABCM review (CIE 2023). In addition, the Children's Cancer Colab (CCCColab) has identified this as an area of unmet need (CCCColab 2026a) and has commissioned a national landscape and economic assessment to map services across Australia, quantify the lifetime burden of survivorship, and identify care gaps, which is due for completion in December 2026 (CCCColab 2026b). Moreover, CCCColab has established its Survivorship and Living Well Impact Program (CCCColab 2026c). However, it is not clear yet, what amount of funding will go into research to inform the policy reforms, national frameworks and digital solutions that they propose.

Charities such as [The Kids' Cancer Project](#), [Children's Hospital Foundation](#), Queensland and the [Children Cancer Foundation](#) invest in survivorship and supportive care research in the paediatric space, whilst [Canteen](#) covers the adolescent and young adult populations as well.

More broadly, the Cancer Councils in Victoria, New South Wales and Tasmania also fund research grants into survivorship and quality of life research for adolescence and young adults. These investments help improve quality of life and understand late effects, while also informing safer, more personalised treatments that reduce unnecessary treatment and long-term impacts (TKCP 2025).

Research infrastructure

Research infrastructure underpins and enables research excellence. These key resources face two main challenges - funding and sustainability. Consequently, many platforms such as biobanking, registries, and data sharing, are often duplicated across Australia.

In some instances, this is required due to very practical aspects (e.g. ethics and governance considerations, access to patients, concentration of expertise, accompanying infrastructure enhancing the data or geographical challenges) and other areas are just a result of the funding landscape. Likewise, infrastructure is one aspect in which some economies of scale can be achieved across adult and paediatric brain cancer.

Leadership and collaboration between government and philanthropic funders could potentially reduce unnecessary duplication, gain efficiencies, leverage investments and provide resources which are both sustainable, and arguably better quality.

Secure, sustained clinical trial infrastructure is also a critical component for Australia to remain competitive in paediatric brain cancer research, as well as allowing access for our children to participate in national and international trials.

ANZCHOG has previously been funded via Cancer Australia and to a lesser degree philanthropy on a trial-by-trial basis. Whilst some core operational funding is included in the well-received CoACT grant (ANZCHOG 2025), a longer-term strategy between a funding circle, including philanthropy and government would provide sustained ongoing funding allowing ANZCHOG to confidently commit to international trial opportunities as they arise, increasing Australia's capacity and number of Australian children with brain cancer trial options.

Workforce

The Australian paediatric brain cancer research workforce is relatively small. Growing and maintaining a critical mass of these researchers who remain in the field, and country is crucial. Senior research leaders have identified workforce capacity and succession planning as a major issue. This is due to the nature of funding in the sector, lack of secure career pathways and generational bottlenecks. NHMRC grants provide some support for project related positions which are time-dependent. Conversely, philanthropy (The Kids Cancer Project, Cure Brain Cancer Foundation and Children's Cancer CoLab) offers some open, competitive PhD scholarships, as well as early and mid-career fellowships. Whilst this develops the next-generation to a certain degree, career pathways become limited thereafter, in the later-stage career as well. Academic roles are highly competitive, with few positions available forcing many young trainees overseas. Some solutions have been suggested such as philanthropy supporting government grant near misses, or co-funding grant rounds to allow more projects to be supported and separately, government directly funding career grants.

Similarly, the clinical research workforce experiences the same issues, with ~ 67% of research associates and nurses funded from external, non-operational sources such as philanthropy and time-limited grants, rather than from hospitals' core operating budgets (Trahair 2026; Hansford et al. 2024). Short term contracts translate to recruitment and retention issues with experienced staff opting for more secure roles in pharmaceutical and biotech industries (Hansford et al. 2024). Other countries, like Canada, United Kingdom, Netherlands, Singapore and Nordic countries have successfully integrated research, education and clinical practice into the healthcare system. In this context, clinical trials should not be considered 'research' in the paediatric oncology workforce, especially given that trials are part of standard of care in children's cancer overall. Adoption of core staffing is desperately needed to sustain growth of clinical trial access in Australia.

These solutions and other innovations to change the workforce present an opportunity for funders, government and institutions to strategically unite and formulate a robust framework to build and maintain the Australian paediatric brain cancer research workforce.

Summary

Australia has made a substantial, coordinated investment in brain cancer research over the past decade through the ABCM and its philanthropic partners, considerably expanding clinical trial access and international collaboration. However, it's built on a funding model that leans heavily on philanthropy and short-term grants rather than longer term, secure funding, producing a sustained research workforce. Addressing that structural instability, rather than simply adding further time-limited funding rounds, is the key challenge for the sustainability of paediatric brain cancer research in Australia. This can only be achieved by funders across the sector working collaboratively together to codesign more permanent and sustainable solutions.

Gideon's Story

Gideon was quite reserved and shy with new people. He would take everything in and often needed time before he felt comfortable enough to show people who he really was. Once he did, you met this gorgeous, funny little boy with a quirky sense of humour and a wonderfully different way of looking at the world.

He loved music, drawing and writing stories, and he had an incredible memory. He also developed a very serious obsession with Cookie Monster and all things cookie-related. Most of all, family was incredibly important to Gideon. He was so proud of his little sister Naava and his brother Isaac. He loved birthdays, Jewish holidays and spending time with his grandparents and cousins. Those are the things I want people to know about him first. He was our beautiful boy long before brain cancer became part of his story.

When everything changed

Gideon was eight when he was diagnosed with an aggressive brain tumour, a glioblastoma. The lead-up to his diagnosis was frighteningly brief. He had vomited, complained of a headache and then developed a facial droop over the weekend. I remember sitting in emergency and somehow knowing that the news was going to be bad. I could almost see our lives changing forever in front of me.

Our perfect family life was perfect no more

Gideon underwent surgery to remove as much of the tumour as possible, but the surgery left him with weakness and we knew there was a high risk the tumour would grow again. Very quickly, we were plunged into the world of cancer treatment — surgery, radiotherapy and targeted chemotherapy.

After surgery, his next hurdle was 25 sessions of radiotherapy over five weeks. We spent a lot of time preparing him because lying completely still on a table with a mask secured over your face is daunting for anyone, let alone a child.

We used play therapy and music therapy, and we created a playlist for him. Leigh, Gideon's Dad, and I took him to hospital every day, often with another family member. Sometimes Leigh would bring his guitar and entertain everyone in the waiting room.

Somehow, Gideon found humour even there.

He took Cookie Monster and his soft toy duck, Duckie, to appointments and developed an ongoing story about the two of them getting married every day on the radiotherapy table. He also created his own rather inappropriate version of Advance Australia Fair, which he insisted on singing before radiotherapy and medical appointments. Toilet humour became a significant feature of our lives.



The hospital staff adored his little songs and jokes.

| Very little seemed to faze him.

Surgery left Gideon with left hemiplegia. He lost the use of his left hand and walked with a limp. Radiotherapy caused him to lose his hair, but he wasn't self-conscious about it at all. He used to joke with me that at least his hair would grow back and his Dad's wouldn't.

For a few precious months, newer medications gave us some stability. Gideon was able to return to school for three hours each morning, and his cheeky smile and quirky sense of humour charmed the aides who helped him.

It was during this time that we really discovered how extraordinary his memory was. He could remember every movie he had seen at the cinema since he was five and who he went with. Give him a date from 2016, 2017 or 2018 and he could often tell us what day of the week it was and what we were doing.



Losing Gideon

In December, we learned that the tumour had spread significantly. Gideon gradually became weaker. He became dependent on a wheelchair, then slowly lost his ability to swallow and eat, and later his ability to speak and communicate. That loss of communication was incredibly frustrating for Gideon and heartbreaking for us.

In his final 10 days, he could no longer communicate, move or open his eyes. But we kept doing the things that had always mattered to us. We went for walks together. We listened to music. We read stories. We surrounded him with family.

Almost 12 months after his diagnosis, Gideon died.

Throughout his treatment we were fortunate to be well supported by both the oncology and palliative care teams. The palliative care team took the time to really know Gideon and our family. Very Special Kids was also a wonderful support for our other children, and we still value our connection with their sibling days. Gideon is still part of everything we do and remains at the centre of our family.

Eighteen months after he died, we welcomed another little boy, Rafael. Today, Gideon's two brothers and sister are all incredibly proud of him.

We speak about Gideon every day. We talk about the things he liked and disliked. We look at his photos, play with his toys, read his books and celebrate his birthday.

**Gideon is still part of everything we do
Gideon remains at the centre of our family.**

Our family has also tried to create a legacy for Gideon that can help improve outcomes for other children diagnosed with brain tumours.

A few months after Gideon died in 2019, we created Team Gideon for Connor's Run as part of the RCD foundation. Over the years, our team has raised more than \$750,000. We have helped fund a PhD student researching paediatric brain tumours and have plans to support a paediatric brain cancer platform. Each May our school celebrates Go Grey and holds a bake sale, and each September more than 40 people come together as part of Team Gideon for Connor's Run.

My own experience has also made me passionate about research and family advocacy. I am a legacy ambassador for the Robert Connor Dawes Foundation, a co-investigator on three Medical Research Future Fund projects and a member of the ANZCHOG CoACT committee. In those roles I can bring together my experience as Gideon's mum with my training as a doctor and researcher to contribute a family and consumer perspective to cancer research.

What I want to change

Progress in paediatric brain cancer remains far too slow.

I want research and clinical care to improve to the point where children can live with brain cancer and still have a good quality of life, rather than dying within 12 months, as Gideon did. I want Gideon's legacy to help improve children's survival and quality of life.

As bereaved parents, we have also learnt what it means to experience opposing emotions at the same time — happiness and sadness, joy and heartache. At every family event Gideon is both present and absent. As our family grows and life continues, his absence is still there, front and centre in our minds.

One thing we have always asked of our friends and family is to talk about Gideon. People sometimes worry that mentioning him might upset us. But they cannot remind us that Gideon died — we never stop thinking about him. We want to hear his name. We want to hear the stories people remember.

And we will always be happy to laugh, cry and remember our beautiful boy.



“I want Gideon’s legacy to improve children’s survival and quality of life.”

Research in Focus: Trials and Access



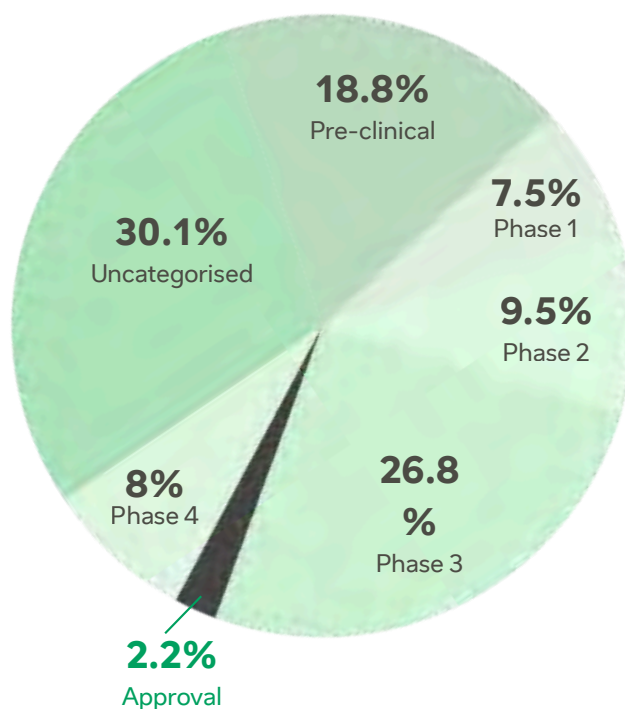
Oliver Jarrett
BTAA Board Director



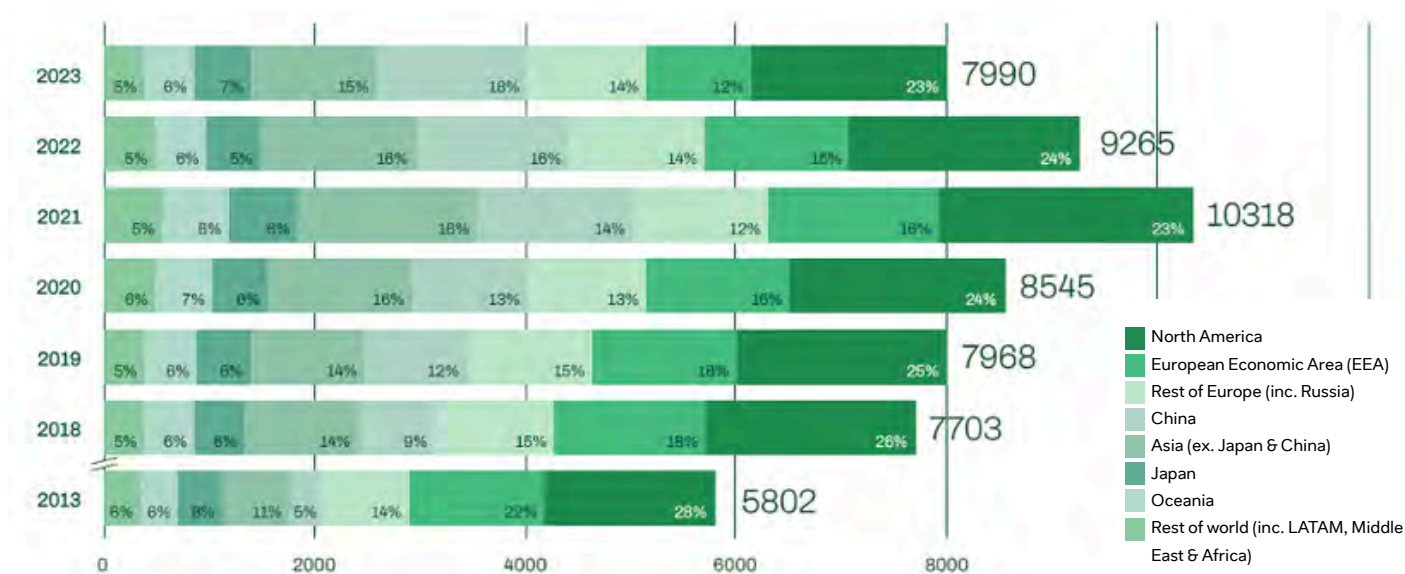
Professor Divya Mehta
BTAA Board Director

Global Pharma Industry Initiatives Supporting Clinical Research – An Overview¹

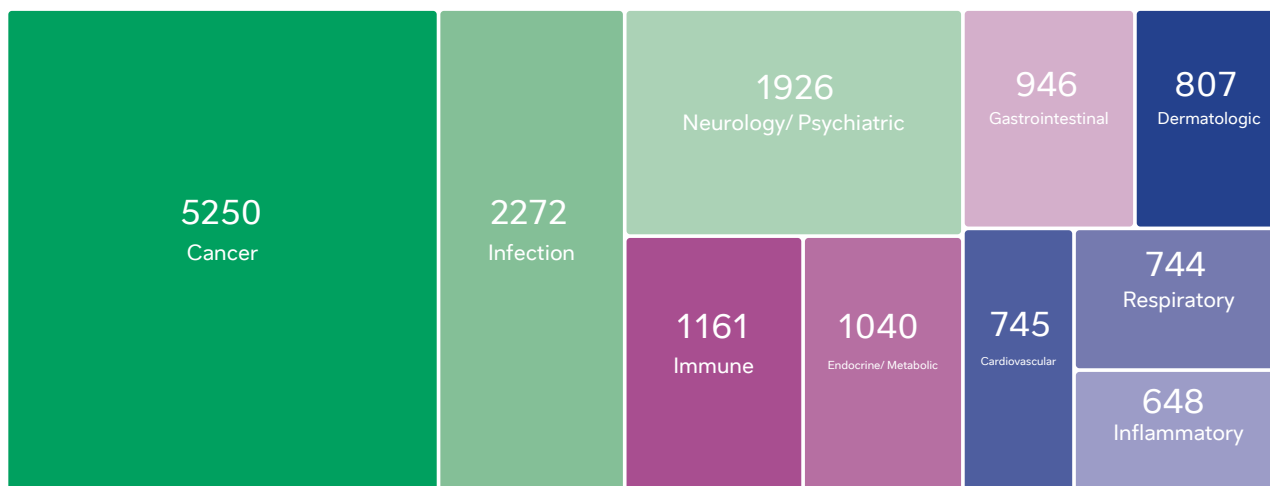
Pharmaceutical companies are the largest contributor to the innovation of new treatments from a financial and number perspective. The pharmaceutical industry contributes approximately 30% of their revenue back into R&D, more than any other industry¹. In 2026 it is estimated that the top 50 pharma companies will invest US\$250B into R&D activities. Accounting for failures, it is calculated that it costs USD\$2.6B to bring a new treatment to market (IFPMA 2024).



Above shows how the pharma industry invested its R&D capital in 2022. (Source PhRMA 2024, image from IFPMS1)



The graph above shows the number of global commercial clinical trial starts by region and year 2013-2023. (Source: EFPIA 2024, image from IFPMA)



The figure at left shows the number of new treatments in development by therapy in 2024. (Source: Cortellis Intelligence database, image from IFPMA)

Australian Government Initiatives Supporting Clinical Research – An Overview

The Australian government has implemented several initiatives to enhance the clinical trial environment and attract foreign investment (Ormandy 2024).

Key initiatives include:



#1. Health Research for a Future Made in Australia

The Medical Research Future Fund (MRFF) is a \$25.4 billion long-term investment supporting Australian health and medical research. The MRFF aims to transform health and medical research and innovation to improve lives, build the economy and contribute to health system sustainability (Australian Government Department of Health and Aged Care 2026a).



#2. National One Stop Shop for Clinical Trials

This initiative, boosted by government funding of \$18.8 million, will streamline clinical trial processes by harmonising regulations across Australia. The platform will make it easier for patients, researchers, and industry stakeholders to find, conduct, and participate in clinical trials.



#3. Clinical Trials Activity Initiative

A \$750 million initiative over a decade (2024-2034) to support clinical trial activity, particularly in rare diseases, rare cancers, and unmet needs. It also aims to attract investigator-led international trials to Australia (Australian Government Department of Health and Aged Care 2026b).



#4. R&D Tax Incentive (RDTI)

The RDTI helps companies offset the costs of eligible research and development, offering both refundable and non-refundable tax offsets depending on the company's turnover and R&D expenditure.



#5. mRNA Clinical Trial Enabling Infrastructure Grant

Providing \$5 million to organisations to support clinical trials of mRNA-based vaccines and therapeutics. As of 2026 there are 3 mRNA vaccine manufacturing facilities in Australia (Sanofi in Brisbane, Moderna in Melbourne and BioCina in Adelaide).



#6. Biomedical Translation Fund (BTF)

This fund offers venture capital to help biomedical discoveries transition into tangible products, services, and outcomes, ensuring Australia remains competitive in the global health research landscape.

While the Australian government has provided several initiatives to support Australian R&D and contributes disproportionately to many other developed countries, the amount of spending required to improve treatments for brain cancer impactfully needs to be much greater. The level of spending required can never be expected to be borne by any one or group of governments and the global pharma industry needs to be where Australia collaborates to improve treatment outcomes. In particular, attracting phase II and III studies into Australia is the best way for Australians to gain access to the latest clinical developments, years before they are registered and reimbursed in Australia.

Summary of Recommended Priorities and Focus

When considering opportunities to improve clinical research, trials and access, four principles can help identify where effort and investment may have the greatest impact:

- Magnitude of potential patient benefit
- Probability of patient benefit
- Time to patient impact
- Ability to influence the outcome.

Discovery science remains essential to the long-term future of brain cancer treatment. However, the pathway from laboratory discovery to routine clinical care is lengthy, costly and associated with high rates of attrition. **Over the next 3–10 years, some of the greatest opportunities to improve outcomes are likely to come from accelerating patient access to promising treatments, strengthening participation in clinical trials, and supporting the equitable adoption of innovations already progressing through the development pipeline.**

This does not reduce the importance of discovery research. Rather, it highlights the need for a balanced approach, continuing to invest in future breakthroughs while also addressing the barriers that can delay or prevent existing scientific progress from reaching patients.

Priority 1

PBS Reimbursement and Funding Decisions

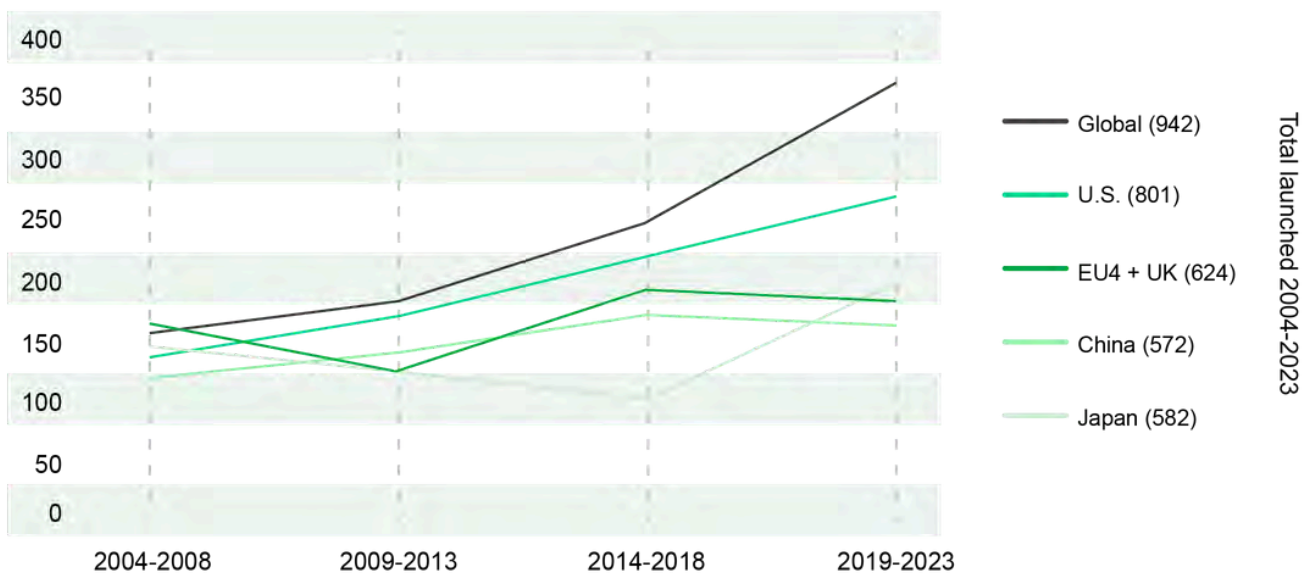
Reimbursement Advocacy: VERY HIGH ★★★★★

System Shaping: HIGH ★★★★★

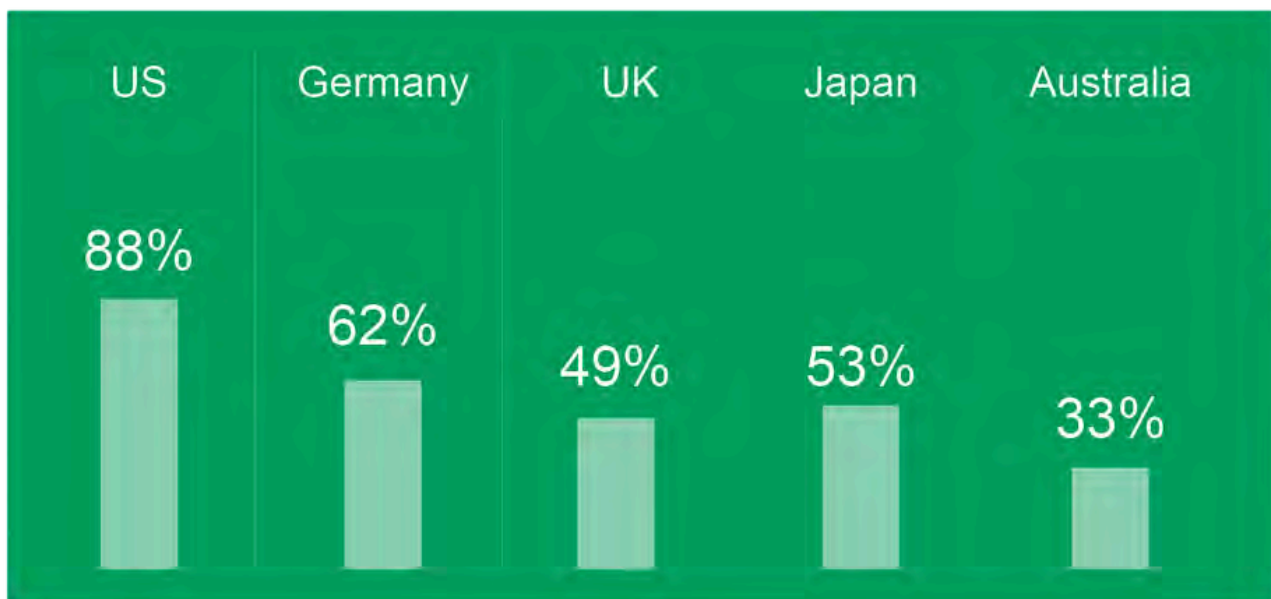
Securing timely and equitable PBS reimbursement for new brain tumour therapies represents the area of greatest potential impact for Australian patients. A treatment provides limited population benefit if it is approved by the TGA but remains financially inaccessible.

While securing PBS reimbursement is critical and should be an acute focus to advocating for funding, it's not an everyday priority for a specific treatment. Between acute phases of advocacy support the Australian brain cancer community will continue to advocate for efficient reimbursement pathways, equitable consideration of rare and high-burden diseases, incorporation of patient experience into reimbursement decisions, and funding models that appropriately recognise the unmet need associated with brain cancer. A fast and efficient process that secures a fair and reasonable price enhances Australia's attractiveness for clinical trial investment and willingness of companies to provide supported compassionate use programs (CUPs) and patient support programs (PSPs).

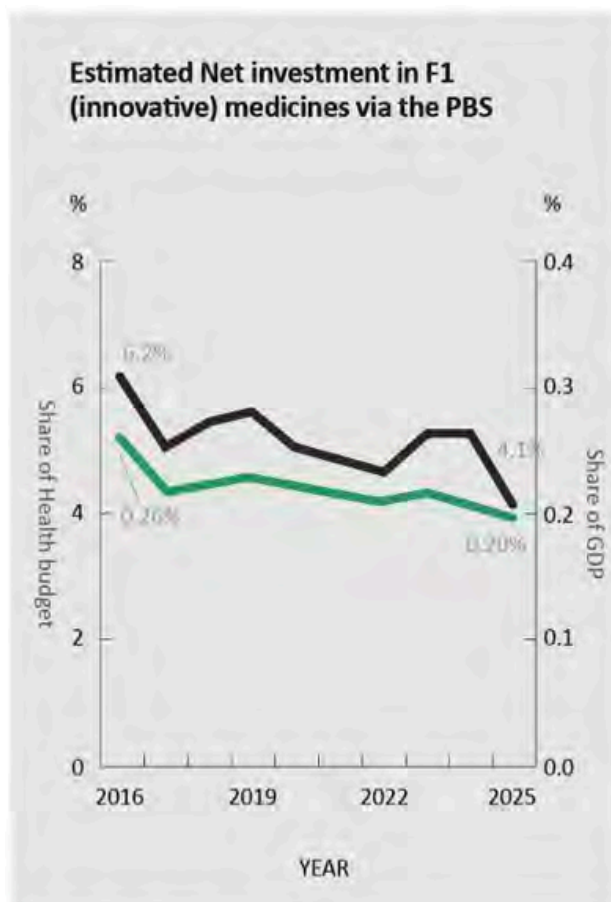
The Pharmaceutical Benefits Advisory Committee (PBAC) is experiencing an ever-increasing number of submissions, with an ever-smaller magnitude of clinical gain in the submission. Due to the ever-smaller magnitude of clinical gain, the PBAC requests additional data. Adding to the problem is that most trials are designed against the existing standard of care in the US and/or Europe. For a variety of reasons (including lack of funding for the European standard of care in Australia), the trial comparators are not appropriate for the Australian market. This is compounding to resource constraints at the PBAC and increasingly longer times to treatment reimbursement.



The image above shows the number of new active substances launched globally and in selected countries 2004-2023 (IQVIA 2024; IFPMA 2024).

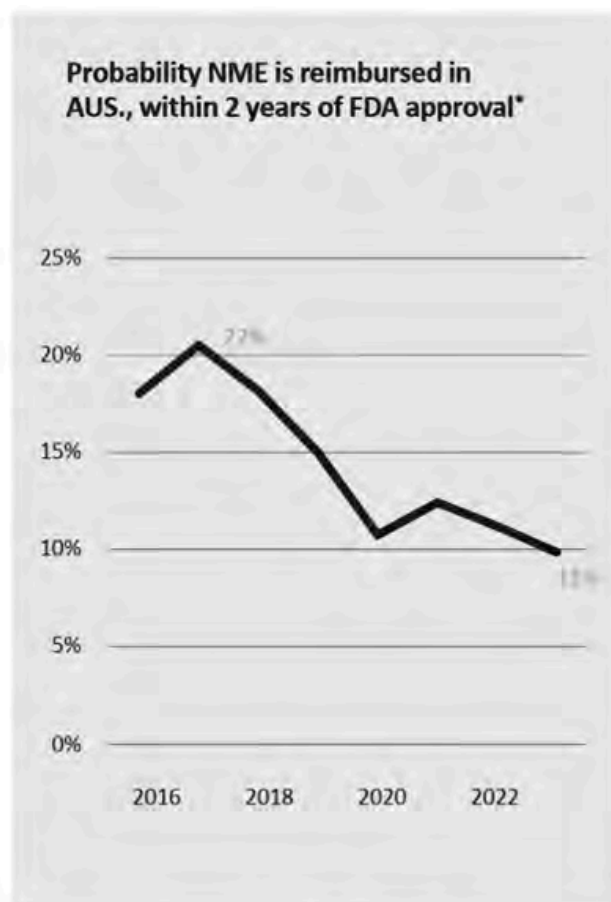


The image above shows the share of new cancer medicines reimbursed by public insurance within the last 10 years (Medicines Australia 2026).



Source: MA analysis of PBS Expenditure report

■ Share of GDP
■ Share of Health Budget



* 2 year moving average; NME is New Molecular Entity;
Source: MA Analysis of PhRMA database

The image above shows the share of the Australian health budget and Australian GDP that is spent on innovative medicines over time and the probability of securing reimbursement within 2 years (Medicines Australia 2026).

The trend in Australia for cancer patients is concerning. The Australian brain cancer community can play a strong role in advocating for improvements in these trends.

The recent successful approval of Voranigo (vorasidenib from Servier) has been a great success for patients with a grade 2 astrocytoma or oligodendroglioma with an IDH1 or IDH2 mutation. This successful reimbursement represents a great collaboration between the PBAC and Servier and should be strongly commended, especially given the aforementioned challenges but more still needs to be done in this space to ensure fast access to future treatments.

Priority **2**

Pre-Reimbursement Access / Compassionate Access Programs

VERY HIGH ★★★★★

Pre-reimbursement access programs, compassionate access programs and patient support programs can provide access to promising therapies months or years before PBS reimbursement is achieved. These programs have the potential to deliver immediate patient benefit and should be a major focus of engagement with pharmaceutical companies, clinicians and government stakeholders. Advocacy can play an important role in collaboratively defining standards for brain cancer, identifying opportunities, raising awareness, supporting equitable access and facilitating discussions with pharma companies. It is not acceptable to BTAA that families need to sell their house and deplete life savings to give their loved ones a fighting chance while waiting for bureaucratic process to proceed for a treatment that is known to be safe and efficacious.

Priority **3**

Phase II & III Clinical Trials

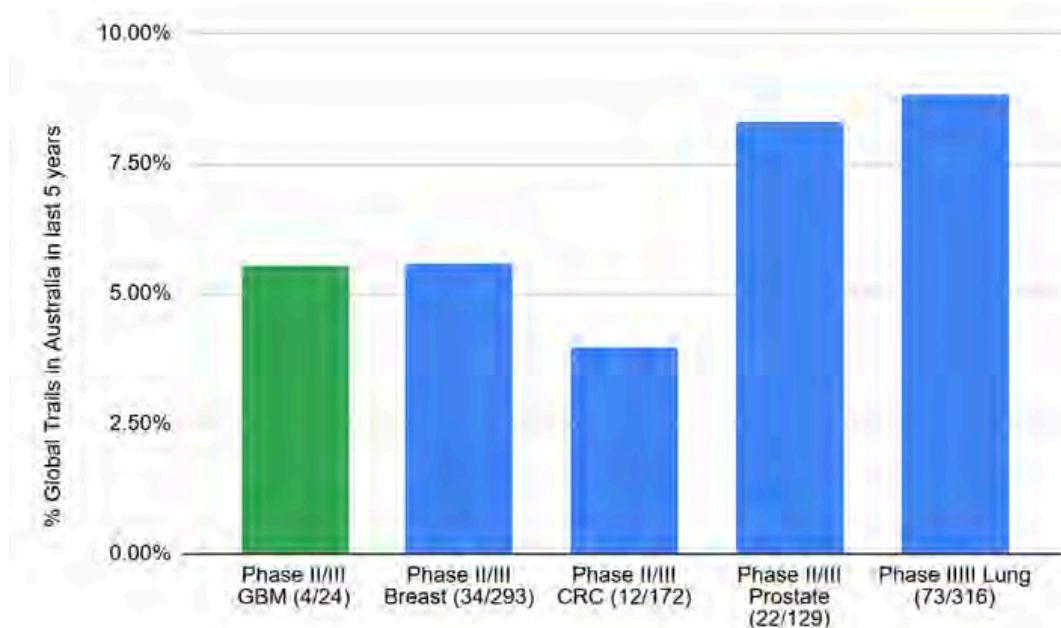
HIGH ★★★★★

Phase II & III clinical trials provide Australian patients with access to emerging therapies years before routine availability and are often the fastest mechanism for increasing treatment options. Because phase II data is often used in TGA and PBS submissions for rare diseases, phase II studies should be considered with equal importance as phase III studies. Securing timely and equitable PBS reimbursement for new brain tumour therapies represents the area of greatest potential impact for Australian patients. A treatment provides limited population benefit if it is approved by the TGA but remains financially inaccessible.

Between acute phases of advocacy support the Australian brain cancer community will continue to advocate for efficient reimbursement pathways, equitable consideration of rare and high-burden diseases, incorporation of patient experience into reimbursement decisions, and funding models that appropriately recognise the unmet need associated with brain cancer. A fast and efficient process that secures a fair and reasonable price enhances Australia's attractiveness for clinical trial investment and willingness of companies to provide supported compassionate use programs (CUPs) and patient support programs (PSPs).



The map above shows the global distribution of recruiting or starting interventional phase II and III studies for glioblastoma reported on clinicaltrials.gov on 29/09/2026 (ClinicalTrials.gov 2026).



The graph above shows that compared to other cancers, the rate of Australia's inclusion in clinical trials compares well. However, the absolute number is very low and the community can work to collaborate to improve Australia's participation globally.

The Australian brain cancer community should support initiatives that improve the number of phase II & III clinical trials in Australia, improve trial awareness, strengthen referral pathways, encourage rapid recruitment and position Australia as an attractive destination for global neuro-oncology studies. Collaboration with clinical trial networks, international sponsors and patient advocacy organisations should be a strategic priority.

Priority 4**Phase IV Studies and Real-World Evidence**

MEDIUM ★★☆☆

Real-world evidence and post-registration studies increasingly influence reimbursement decisions, label expansions and future treatment access. The community should support efforts to improve data collection, patient registries, outcomes monitoring and evidence generation that demonstrate the value of innovative therapies in Australian clinical practice. As an example, BioGrid has huge, untapped potential to support better outcomes for patients with rare brain tumours by enhancing cross-country data collaboration.

Priority 5**Discovery and Translational Research**

MEDIUM ★★☆☆

Discovery research underpins all future advances in diagnosis, imaging and treatment, and the community should continue advocating for equitable investment in brain cancer research relative to disease burden. But given the long timelines and high attrition rates associated with discovery science, focus should be on advocacy, awareness and support for translation pathways rather than direct strategic emphasis. Investment should be particularly directed toward research capable of progressing into clinical development and patient benefit.

Priority 6**TGA Registration Processes**

MEDIUM ★★☆☆

Timely regulatory approval is an important enabler of patient access, but the community's ability to directly influence regulatory decision-making is relatively limited. Advocacy should focus on maintaining efficient pathways for innovative therapies and ensuring Australia remains an attractive market for companies seeking regulatory approval.

Priority 7**Phase I Clinical Trials**

LOW ★☆☆☆

Phase I trials are important for the overall research ecosystem but generally involve small patient numbers and are primarily focused on safety rather than efficacy. There should be broader support for initiatives that strengthen Australia's translational research capability but should assign lower strategic priority to directly increasing participation in Phase I studies and more to studies that support treatments that have already been shown to demonstrate acceptable safety.

Area	Probability of Success	Time to Patient Impact	BTAA Influence	Priority	Frequency / Intensity
Discovery Research	0.01% -0.02%	10-20+ years	Moderate	Medium	Ongoing
Phase 1	7-10%	8-15 years	Low	Low	Low
Phase 2	15-20%	5-10 years (2-5 years for orphan)	Moderate	High	High
Phase 3	55-58%	2-5 years	Moderate	High	High
Pre-Registration Compassionate Use	>50%	Months	High	Very High	As needed (when new treatments are available)
TGA Registration	?	6-24 month	Moderate	Medium	Ongoing
Pre-Reimbursement Access	>50%	Months	High	Very High	As needed (when new treatments are available)
PBS Reimbursement	50-55%	Immediate - 3 years	High	Very High	High (for system improvement to support phase 2 & 3 trial attractiveness)
Phase 4 / Real World Evidence	~>50%	2-5 years	Moderate	Medium	Medium

Getting existing treatments to patients faster is the priority for the next 3-10 years. Securing timely and equitable PBS reimbursement comes first, followed by pre-reimbursement and compassionate access, which can reach patients months or years sooner. Bringing more Phase II and III trials to Australia gives patients access to emerging therapies before they are registered, and real-world evidence helps secure funding for those that follow. Discovery research, TGA registration and Phase I trials remain important to the wider ecosystem, so BTAA will keep supporting and monitoring them. The goal is a balanced approach that continues to invest in future breakthroughs while making sure today's scientific progress reaches patients without delay.



Coby's story

If I tell you only about Coby's brain cancer, I will have missed the most important part of his story.

Coby is my son. He is a gorgeous, funny, loved and loving 16-year-old who has spent most of his life in Dodges Ferry, one of the seaside towns outside Hobart. He has an older brother, Flynn, and both boys have grown up loving the ocean, bodyboarding and camping by the beach in summer. Coby is fairly academic. He wanted to become a paediatric psychologist, to travel, to fall in love and, one day, to become a dad.

Mostly, though, what makes Coby happy is being with his friends. He has this huge group of incredible friends who have surrounded him and helped him continue to be a teenager through something no teenager should ever have to face.

I think that matters, because cancer can so quickly become the whole story. Coby is not his tumour. He is not a diagnosis, a scan or a treatment plan. He is our son, Flynn's brother, a friend, a young man with plans for a life he should still have ahead of him.

For almost a year before Coby was diagnosed, we knew something was wrong. His symptoms kept growing — gastrointestinal problems, heart-rate and blood-pressure changes, headaches, nausea, fatigue, tremors and spasms, and eventually facial drooping. He saw multiple specialists and underwent many tests, but it was not until an MRI was finally arranged in June 2025 that we learned the truth. Coby had a Diffuse Midline Glioma.

There is a before and an after with a diagnosis like this. The river of your life is flowing along and suddenly it meets a cliff.

The first week of July was devastating. Coby became critically ill and needed emergency surgery to relieve hydrocephalus, followed by a biopsy. When he woke from that biopsy, he could barely move, swallow or speak. Then came radiation. Through an extraordinary effort by the Royal Hobart Hospital team and Peter Mac, Coby was able to have his treatment in Hobart, close to the people he loved. On the first day of radiation, he had to be lifted onto the treatment bed. On the last day, he walked in. I will never forget that. Slowly, Coby started coming back to us.

Since then, he has endured more surgery, recovery and targeted treatment through the Zero Childhood Cancer program and the Optimise trial. For a time, his tumour reduced, and we were unbelievably excited. The treatment was brutal, but Coby kept going. He worked to eat and drink, to regain his strength, to see his friends and to keep living his life. We learned about precision oncology, clinical trials, targeted therapies and toxicity levels — a whole language I never imagined I would need to understand in order to try to keep my child alive.

And we learned about hope.

Hope is a muscle, not blind optimism. It is simply the belief that other futures are possible. For us, it has been about hoping for a better tomorrow, for more tomorrows. As a parent walking a terminally ill teenager through the awful choices – between the brutality of the experience of no treatment, and the brutality of treatment, (and the reality that we are lucky to have treatments) – hope is found in the spaces and cracks. Hope is stepping stones of extending life in the hope that one day a cure might be found, and they might be there to try it. And when someone shows you a stepping stone, you cannot simply turn away from it. When it is your child, even a chance of less than one per cent is still not zero.

In January, we learned about the PaedNeoVax trial, involving a personalised mRNA cancer vaccine. For Coby, other promising treatments were unlikely to match his tumour. This one felt different. It felt like his shot. So we waited.

Easter passed. Then June. Then July. And while we waited, Coby's tumour began growing again.

At the end of July, we discovered that another family was crowdfunding access to the same vaccine for their child. I still struggle to describe what that did to us. For months, we had believed that our only option was to wait for the trial to open. Had another pathway existed all along?

Would Coby die while we were patiently waiting, oblivious to another pathway?

Those questions are almost unbearable as a parent, because when every treatment is optional, every decision begins to feel as though it rests on your shoulders. Do we try another treatment? Do we wait? How much of the life Coby is living now should we risk for the possibility of more life later? What if we make the wrong decision? What if we do not push hard enough? What if our child dies while we are still trying to work out how to get through the system?

That is the reality behind words like “access” and “compassionate treatment”. To other people they may sound like policy language. To us, they are the extent to which our son gets a say in his life, and his death.

They mean knowing there may be a treatment that could make a difference to Coby and still not knowing whether we can reach it in time. They mean researching, emailing doctors, writing to politicians, making calls and trying to understand systems and processes while caring for our child. They mean wondering whether we should be spending precious hours beside Coby or using those hours trying to find a pathway to treatment.

And then there is the money.

No family living through this should also have to ask whether their child's chance depends on how much money they can raise, how many people they know or how effectively they can advocate while experiencing the worst days of their lives. If we manage to find a pathway for Coby, what happens to the family that does not know whom to call? What happens to the parents who cannot run a fundraiser, navigate the health system or write to decision-makers? What happens to their child?

That is why what began as a fight for Coby has become something bigger.

We want a clear, ethical and equitable pathway for children who may benefit from emerging treatments when a clinical trial is not open, when timing excludes them or when the cost makes access impossible. There needs to be financial support, clinical capacity and help for families to navigate these decisions. A treatment existing somewhere is not enough if the child who needs it cannot reach it before their disease progresses.

All the while, Coby's tumour continues to grow.

That is the part that is so difficult to reconcile. Science is moving. Researchers are doing extraordinary things. New treatments are emerging. There is genuine reason for hope. But Coby does not have the luxury of waiting for every process to catch up.

We are caught between before and after — desperate to be out of this nightmare and, at exactly the same time, desperate never to leave it, because leaving it means a future in which Coby may no longer be here. So we live now.

We are grateful for every day and terrified of losing them. We care for Coby's body, but also his heart and his mind. We try to protect the parts of his life that still belong to him — his friends, his independence, his laughter, the ocean, the ordinary moments that cancer has not taken.

Hope for us is not pretending everything will be okay. Hope is getting up in the morning and doing what needs to be done. It is medication and appointments and scans. It is another email, another question, another phone call. It is friends showing up. It is researchers continuing to search for answers. And sometimes it is simply sitting beside my son and remembering that before all of this, and underneath all of this, I am his mum.

Before Coby became sick, I thought I would have the rest of my lifetime to teach him about the beauty of the world. I thought I would teach him that underneath everything, it is all love. I never imagined that he would be the one teaching me.

My son has a level 4 brain tumour. We know what we have been told about his future. But my son is still here.

Coby is 16 years old. He loves his brother, his friends and the ocean. He wanted to become a paediatric psychologist. He wanted to travel. He wanted to fall in love. He wanted to become a dad. I want a future with him in it.

And while he is here, we will keep fighting for every opportunity that might give him more time, more life and more ordinary days with the people he loves.

**For Coby, time is not
a policy discussion.**

**It is his life.
And every
day matters.**





Professor Eng-Siew Koh

The person behind the research

Professor Eng-Siew Koh

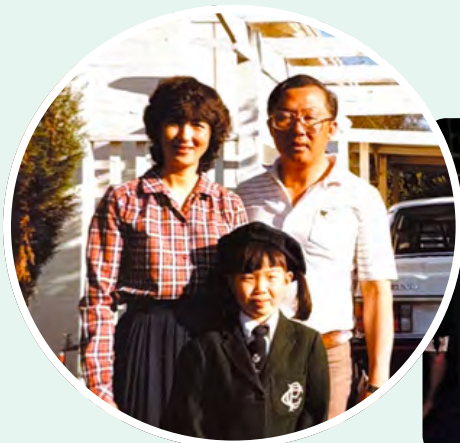
I was born in Adelaide to parents of Malaysian-Chinese heritage, who came to Australia in the 1960s for their secondary education. My father became an architect and my mother worked as a teacher and small business owner. I have a wonderful sister who also works in the medical field. Their collective values shaped me deeply — particularly the importance of hard work, community and service.

At school, mathematics was my favourite subject. I considered studying either Medicine or Commerce and Law before entering university and choosing medicine. I remain incredibly grateful that I did. The opportunity to work in healthcare and contribute to the lives of patients and families has been a real privilege.

My early medical training exposed me to research, Radiation Oncology and paediatrics, whilst I was also drawn to the fields of psychiatry and psycho-oncology. Oncology ultimately brought many of those interests together — clinical medicine, imaging, technical expertise and the deeply human experience of living with serious illness.

I was fortunate to have wonderful mentors during my Radiation Oncology training at Westmead and Nepean Hospitals in New South Wales, followed by a three-year fellowship at the Princess Margaret and Sick Kids Hospitals, University of Toronto, Canada, focused on brain tumour care and research in adults and children. I also trained in haematology and cancer survivorship research — both of which I have carried forward to develop throughout my career since.

The opportunity to work in healthcare and contribute to the lives of patients and families has been a real privilege.



Returning to Liverpool Hospital in South West Sydney gave me the opportunity to work within a diverse community and a supportive, flourishing clinical and research environment.

The collective ‘why’

What has stayed with me most throughout my career is the courage and generosity of patients and families.

Choosing to participate in research or a clinical trial during one of the most difficult periods of a person’s life is an extraordinary contribution. It reflects a willingness not only to seek better options for themselves, but to contribute to a future in which outcomes may be better for those who come after them.

Patients and carers continually remind me why this work matters. They have taught me about courage in the face of enormous adversity, about persistence and sacrificial care and about the importance of persevering against a difficult collective adversary that is brain cancer - even when progress can feel slow.

Brain cancer research and delivering impactful clinical trials to all those affected is certainly a marathon, not a sprint.

Across the neuro-oncology community, I have been privileged to work alongside clinicians, researchers, triallists and consumer advocates who provide continued expertise, perspective, motivation and support — and who always bring us back to our shared purpose.

That collective “why” sits at the centre of my work.



National collaboration remains an absolute imperative as we deal with brain cancer, a rare cancer, and seek to leverage individual strengths for transformational collective impact.

Research through collaboration

Some of the work I am most proud of demonstrates what can be achieved when that collective purpose becomes action.

The COGNO-led MAGMA trial in adults with glioblastoma recruited 337 participants across 28 sites despite the challenges of the pandemic, making it the largest glioblastoma trial undertaken in Australia and New Zealand to date.

LUMOS2, a precision oncology trial for adults with recurrent IDH-mutant glioma, uses surgery and tumour molecular profiling to help assign participants to novel drug interventions. Securing funding to deliver the trial across both Australia and Canada has been particularly impactful and a full-circle moment given my fellowship years in Toronto.

The TROG 18.06 FET-PET in Glioblastoma (FIG) trial is examining the role of FET-PET imaging in radiotherapy planning and the management of pseudoprogression. It is the largest study of its kind internationally, with over 315 participants from 11 Australian centres, and if the trial is positive there is the longer-term hope that patients can access FET-PET as part of their routine care.

These trials are not individual achievements. They are the product of scientific leadership, multidisciplinary collaboration and a community willing to work across institutions and borders.



National collaboration remains an absolute imperative as we deal with brain cancer, a rare cancer, and seek to leverage individual strengths for transformational collective impact.”



Building a national neuro-oncology community

Serving as Chair of COGNO for the past six years has been one of the great honours of my professional life so far.

Together with an extraordinary leadership team and national network, we have strengthened COGNO's structure, achieved not-for-profit medical charity status, broadened national and international partnerships and continue to develop a diverse and innovative trial portfolio spanning early phase I to large phase III studies in glioblastoma, IDH-mutant glioma and rare CNS cancers, alongside key supportive care and translational science research.

National collaboration is particularly important in brain cancer because it is a rare and complex disease. We need to take breakthroughs in discovery science and accelerate them into well-designed clinical trials that as many patients as possible can access.

We need to take breakthroughs in discovery science and accelerate them into well-designed clinical trials that as many patients as possible can access.

Key to this is that patients and carers must also be recognised as experts and research partners, with an important contribution to make.

Looking forward

I remain driven by the belief and conviction that a transformational breakthrough in our understanding and therefore treatment of brain cancer will come. We have brilliant minds working toward the same goal!

Science and technology are moving rapidly. The development of IDH inhibitors is one example of how scientific understanding can translate into new treatment options and major international phase III trials in a relatively short period of time, with Australia playing an important role.

The opportunity now is to continue to bring those individual experts and their strengths together — researchers, clinicians, patients, carers and advocates — and turn them into transformational collective impact.

National collaboration is particularly important in brain cancer because it is a rare and complex disease. We need to take breakthroughs in discovery science and accelerate them into well-designed clinical trials that as many patients as possible can access.

Pillar Two

Clinical Care



From fragmented care to coordinated, brain tumour-specific care

Clinical care determines whether advances in research and treatment become meaningful outcomes for patients.

Brain tumours can create rapidly changing neurological, cognitive and functional needs, while requiring care across multiple clinical specialties and support services. This complexity can make it particularly difficult for patients and families to coordinate care and navigate the health system without specialist support.

This creates a distinct clinical challenge: **the people who must navigate one of the most complex cancer pathways may also be losing some of the capacities required to navigate it.**

For families and carers, the same diagnosis can abruptly bring responsibility for appointments, medications, transport, treatment decisions, behavioural change, household management and communication with multiple health professionals.

The central clinical care question is therefore not only whether Australia has high-quality specialist services.

It is whether those services are **connected around the person from diagnosis through treatment, survivorship or living with disease, recurrence, palliative care and end of life.**

The problem we are trying to solve

Complex needs are being managed through a fragmented system

The 2025 Landscape identified a longstanding gap in Australian brain cancer care: access to specialist care coordination remained limited, geographically uneven and dependent on local health services, philanthropy and individual positions rather than a nationally consistent model (BTAA 2025).

Drawing on the ABTC's 2024 report Navigating the Unknown: A Call for Nationwide Brain Cancer Care Coordination, the 2025 Landscape identified 29 Brain Cancer Care Coordinators nationally, equivalent to 20.6 full-time positions — about one full-time coordinator for every 100 new diagnoses each year — with most located in major metropolitan centres. It also documented the sector's concern that existing national cancer nursing arrangements did not provide a dedicated brain tumour-specific coordination model.

**~100
new patients
per
coordinator**

20.6 full-time brain cancer care coordinators for about 2,100 new diagnoses a year. Most coordinators are in major metropolitan centres. By comparison, one specialist neuro-oncology nurse practitioner profiled in this Landscape supports 130–140 newly diagnosed patients a year. There are approximately 9,000 Australians living with brain cancer with around 8,700 patients requiring some form of observation, treatment or support placing an incredible demand on the small cohort of dedicated clinical care coordinators and nurse navigators.

Derived: Navigating the Unknown (29 coordinators, 20.6 FTE) and Cancer Australia 2025 incidence

The need for coordination is driven by the complexity of the disease itself. Research undertaken through the **Psycho-Oncology Co-operative Research Group (PoCoG)** and the **Brain cancer Rehabilitation, Assessment, Interventions for Survivorship Needs (BRAINS) Program** has progressively demonstrated that people affected by brain tumours experience significant and changing needs across physical, cognitive, psychological, informational and practical domains.

A prospective study of people with high-grade glioma identified four distinct trajectories of distress. Some people experienced persistently low distress, but others moved from low to high distress, from high to lower distress, or remained highly distressed. Unmet supportive care needs changed alongside those distress patterns.

This matters because need cannot reliably be predicted once, at diagnosis. It **must be identified repeatedly across the disease trajectory**. Research examining existing Australian supportive care also found that although some services were available, psychosocial care, specialist allied health and primary care were not routinely integrated into the care of people with high-grade glioma and their carers.

Health professionals interviewed about psychosocial support described difficulty fitting people with brain tumours into existing care pathways, particularly over the longer term. They identified the benefits of continuity, interdisciplinary connections and care coordination, while noting that access could vary considerably across the illness trajectory. The problem, therefore, is not simply a shortage of services. It is a coordination problem, an access problem and a continuity problem.

Australia has many of the individual components of good brain tumour care. What remains inconsistent is the mechanism that connects those components around the patient and family.

What we asked for in 2025

The 2025 Landscape proposed a direct response to this problem.

The brain tumour community called for **\$8.75 million to implement a national Brain Cancer Care Coordinator framework**, including 23 specialised coordinators (BTAA 2025).

The proposal had three connected elements.

1 A national framework for coordinated care

Establish a nationally consistent BCCC model providing support across the full disease trajectory — from diagnosis and treatment through survivorship, recurrence, palliative care and end of life.



2 Specialist coordination embedded within multidisciplinary care

Embed dedicated brain cancer coordinators within multidisciplinary teams across metropolitan, regional and rural settings so that coordination becomes part of the clinical pathway rather than an optional additional service.



3 Data-driven deployment and outcomes

Use evidence generated through the BRAINS Program and other national data to identify areas of greatest unmet need and measure whether care coordination improves patient, carer and health-system outcomes.



The 2025 proposal envisaged more than additional nursing positions.

It described a national model of care in which specialist coordinators would undertake needs assessment, screening, navigation, information provision, referral, carer support and monitoring of outcomes while connecting clinical teams with rehabilitation, primary care and community services.

The associated pre-budget proposal carried the same principle: specialist brain cancer coordination should be treated as part of the infrastructure of high-quality care rather than left dependent on local or philanthropic funding arrangements.

The question for 2026 is therefore:

Are Australians now closer to consistent access to specialist brain tumour care coordination and do we know more clearly what that care should look like?

What happened in Clinical Care in 2026

The evidence has moved from identifying the need to defining the response

One of the most important developments in clinical care has been the maturation of the evidence generated through the BRAINS Program and related Australian research.

The BRAINS Program was established through the Australian Brain Cancer Mission with \$4.97 million in Medical Research Future Fund (MRFF) investment (Australian Government Department of Health and Ageing 2020).

Led through PoCoG and involving multiple Cancer Cooperative Trials Groups, universities, clinicians, researchers and community organisations, the program was designed to improve understanding of the frequency and severity of symptoms and needs experienced by people affected by brain cancer and their caregivers, and then use that evidence to develop care that is responsive, timely and proportionate to need.

BRAINS has organised its work around five themes. Together, they provide an important evidence base for what a national brain cancer clinical care model needs to do.

Theme 1: Implementing needs assessment

The problem

Needs change over time: a single assessment misses people who need help later.

What BRAINS found

Distress and unmet needs vary across the disease course. A brief nine-item screening tool identified most patients with unmet needs.

What comes next

Routine, repeated screening linked to referral pathways; the BRAINS ADAPT Portal is being developed to support this.

Theme 2: Models of survivorship and supportive care

The problem

Transitions between surgery, oncology, surveillance, rehabilitation and palliative care create gaps — worse when cognition declines.

What BRAINS found

Continuity and connection are valued most. An Australian and Aotearoa New Zealand Delphi consensus has defined care coordination and its quality indicators.

What comes next

Translate the consensus into a national coordinator model with agreed role scope, competencies, referral pathways and outcome measures.

Theme 3: Better information

The problem

Information arrives when the tumour may be affecting memory, attention and communication.

What BRAINS found

Many resources are not designed for cognitive challenges; the ICONIC study is examining how communication can be adapted.

What comes next

Information that is timely, adapted, repeated, available to carers and linked to a person who can interpret it.

Theme 4: Caring for caregivers

The problem

Family members take on care and decision-making almost immediately, often unprepared.

What BRAINS found

The Care-IS nurse-led trial (188 carers) improved preparedness but not distress; carers' own needs often go unrecognised.

What comes next

Carer needs assessment, education, psychological support and referral built into routine care, including bereavement.

Theme 5: Rehabilitation and supportive care

The problem

Enduring cognitive, behavioural and functional impairment; rehabilitation not integrated into pathways.

What BRAINS found

Low referral to some allied health; only five interventions found for personality and behavioural change. Programs include LaTCH, Tele-MAST and RESTORE.

What comes next

Clearer pathways into routine practice, with coordination connecting referral and follow up.

From BRAINS evidence to clinical implementation

Taken together, the five BRAINS themes tell a consistent story.

People affected by brain tumours need:

- needs identified repeatedly
- care coordinated continuously
- information adapted to their capacity and circumstances
- carers recognised and supported
- rehabilitation and supportive interventions connected to routine clinical care.

The importance of BRAINS is therefore not simply that it has produced a body of research.

It has progressively defined the functions that an effective brain tumour care system needs to perform.

The implementation question is now how those functions can be delivered consistently across Australia.

Navigating the Unknown: defining the need for a dedicated coordinator

The ABTC's 2024 report *Navigating the Unknown: A Call for Nationwide Brain Cancer Care Coordination* brought these issues together around the role of the Brain Cancer Care Coordinator (Australian Brain Tumour Collaborative 2024).

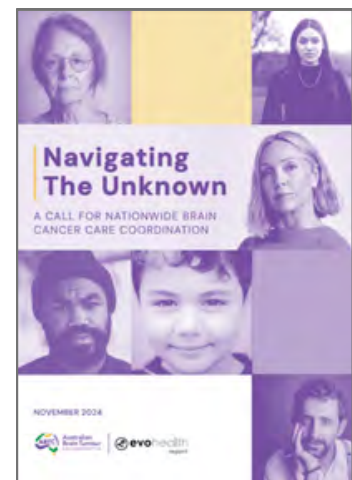
The report examined the complexity of brain cancer, the need for brain cancer-specific coordination, the effect coordinators can have on patient and carer experience and the potential impact on health-system utilisation. Its final section set out a roadmap toward more consistent national brain cancer care.

Its central argument was that the neurological, cognitive, functional and psychosocial consequences of brain tumours create coordination requirements that are different from those experienced by many other cancer populations.

The coordinator is therefore not simply an appointment scheduler.

The role connects the patient with the multidisciplinary clinical team; monitors changing needs; helps interpret information; coordinates investigations and appointments; facilitates referrals to rehabilitation, psychology, allied health, primary care and palliative care; supports carers; and provides continuity as the patient's circumstances change.

That proposition is now reinforced by the BRAINS evidence and the newer consensus framework on optimal brain tumour care coordination.



The national policy context

The policy environment in which the 2025 clinical care ask was made has continued to develop.

Australian Cancer Nursing and Navigation Program (ACNNP)

The ACNNP represents a substantial national investment in cancer nursing and navigation (Australian Government Department of Health 2026; McGrath Foundation 2026). The Australian Government states that \$406 million has been committed since November 2023. The program comprises Cancer Navigation Services, Cancer Care Nursing Services and Specialist Support Services and is intended to provide access across all cancer types and locations.

For people without access to a disease-specific service, Cancer Council Australia's navigation service and McGrath Cancer Care Nurses provide routes into support.

The Specialist Support Service stream also funds 12 non-government organisations to provide disease-specific or specialist support. Rare Cancers Australia is one of those organisations.

The remaining question is whether the national system provides the dedicated neuro-oncology clinical coordination required by the particular complexity of brain tumours.

The McGrath Model of Care and the need for a dedicated brain cancer framework

The expansion of the McGrath Cancer Care Nurse model through the ACNNP represents an important investment in cancer nursing across Australia. It creates opportunities for greater consistency, stronger referral pathways and improved access to nursing support for people affected by cancer.

For the brain cancer community, however, an all-cancer nursing model does not remove the need for a dedicated brain cancer clinical care framework.

Brain cancer presents clinical and survivorship challenges that are substantially different from those experienced across many other cancers. Patients may experience rapidly changing neurological symptoms, cognitive and behavioural impairment, seizures, communication difficulties, functional decline and loss of decision-making or self-advocacy capacity. Their care can require coordination across neurosurgery, neuro-oncology, radiation oncology, rehabilitation, neuropsychology, allied health, psychosocial services and palliative care, often simultaneously and across different health services.

The Navigating the Unknown report found that Brain Cancer Care Coordinators require specialist clinical and communication capability to manage these complex and changing needs and to provide continuity across the disease trajectory. It also identified significant gaps in access to dedicated brain cancer coordination nationally.

The issue is therefore not whether brain cancer patients can access a general cancer nurse. The issue is whether they can access **brain cancer-specific clinical coordination with the expertise, continuity and multidisciplinary integration their disease requires.**

There are clear benefits in aligning with the McGrath Model of Care and the broader ACNNP. Referral pathways, workforce development, shared resources and national service infrastructure could all strengthen the experience of people affected by brain cancer. But alignment should not mean that the distinct need for specialist brain cancer clinical care is absorbed into an all-cancer model.

The brain tumour community's position remains that Australia requires a **nationally defined, dedicated Brain Cancer Care Coordination Framework and Network.** That framework should operate as an integrated part of the broader cancer system, while retaining brain cancer-specific clinical standards, competencies, workforce development and governance.

Whether or not dedicated Commonwealth funding is immediately available, establishing and maintaining that framework is essential. It defines what appropriate brain cancer care should look like, provides a basis for working constructively with the McGrath Foundation and other national services, and ensures that the unique clinical needs of people with brain cancer are not lost within a broader all-cancer model.

General cancer nursing and specialist brain cancer coordination should complement one another. They should not be treated as interchangeable.

Note: Unlike many other cancers, Australia has never received funding for dedicated brain cancer clinical care and supports and remains an issue affecting the experience of brain cancer patients and families.



What remains unresolved

Australia now has substantially more evidence about what good brain tumour care coordination should look like. What it does not yet have is consistent implementation.



Specialist brain cancer coordination remains uneven

Access continues to depend on where a patient is treated and whether a dedicated position exists locally. National cancer navigation services have expanded, but access to a service and access to a dedicated brain tumour clinician embedded within the neuro-oncology pathway are not the same thing.



Needs are identified more clearly than they are routinely acted upon

BRAINS has demonstrated that needs change over time and has developed practical approaches to screening and stepped care.

Routine, repeated brain tumour-specific needs assessment is not yet embedded consistently across Australian services.



Rehabilitation and psychosocial care remain inconsistently integrated

Evidence exists for the importance of rehabilitation, psychological care and specialist allied health, but referral and access remain variable.

The gap between evidence and routine practice remains substantial.



Carers continue to carry significant hidden clinical workload

Families routinely assume care coordination, symptom monitoring, transport, medication and decision-making responsibilities.

Research increasingly defines their needs and identifies interventions that can improve preparedness, but structured carer assessment and support are not yet a consistent part of the clinical pathway.



Handoffs remain vulnerable

The need for coordination does not disappear when active treatment ends. Transitions into surveillance, recurrence, rehabilitation, palliative care and bereavement are precisely the points at which continuity becomes most important.

A model that funds coordination only around treatment risks reproducing the fragmentation it was intended to solve.



National standards now need national implementation

The evidence base has progressed considerably. BRAINS has defined needs. Navigating the Unknown documented the coordination gap.

Australian health-system evidence has demonstrated measurable benefits from dedicated coordination. And the new consensus work has defined the components and indicators of optimal care coordination.

The unresolved issue is increasingly implementation at scale.

What needs to happen next

The sector is seeking a nationally consistent Brain Cancer Care Coordination Framework, aligned with the ACNNP and integrated with existing national, state and community services.

The framework would build on the **2025 proposal for \$8.75 million and 23 specialised brain cancer care coordinator positions**, while incorporating the stronger evidence and national infrastructure now available.

\$8.75 million & 23 specialised brain cancer coordinator positions



The framework should define a nationally consistent brain tumour-specific role; support people across the whole disease trajectory, from diagnosis to bereavement; embed routine needs assessment and stepped care; place coordinators within neuro-oncology multidisciplinary teams; provide equitable regional and remote access; recognise and support carers; build a supported national workforce; and measure the outcomes that matter to patients, carers and the health system.

This is Ask 4 in Summary, Next Steps and 2026 Asks.

The brain tumour community's 2026 proposition is therefore not to build a parallel cancer navigation system.

It is to ensure that the national system recognises and consistently provides the additional brain tumour-specific clinical coordination required by this uniquely complex disease.



Marina Kastelan, Neuro-Oncology Nurse Practitioner, The Brain Cancer Group

For Marina Kastelan, the value of neuro-oncology nursing can be captured in something deceptively simple: when a patient or carer calls, they should not have to start their story again.

After more than 30 years in nursing, including experience in the United Kingdom health system, oncology and intensive care, Marina moved into specialist neuro-oncology in 2008. She later completed a Master of Nursing as a Nurse Practitioner and today works with The Brain Cancer Group, providing specialist clinical care, coordination, education and support to patients and families across the brain tumour journey.

Unlike episodic care, neuro-oncology nursing allows Marina to build relationships with people over time — meeting their families, understanding what matters to them, and remaining a familiar point of contact as circumstances change.



**They need to be known,
heard and supported.”**

That continuity matters because a brain tumour diagnosis rarely affects only one part of a person's life.

No two brain tumour journeys are the same. Marina supports people from diagnosis through treatment and surveillance, recurrence and, when needed, palliative care.

Her work combines advanced clinical practice with care coordination and practical navigation. It can include helping patients and families understand complex information, assessing and managing symptoms, prescribing where appropriate, arranging referrals to allied health and psychology, and working closely with neurosurgeons, medical oncologists, radiation oncologists and the wider multidisciplinary team. But one of the most important functions is simply being the person who already knows the patient.

For families juggling multiple specialists, appointments and life-changing decisions, having one consistent clinician who understands their history can remove some of the burden of repeatedly explaining what has happened and what they need. That need for continuity is particularly pronounced in brain tumour care.

Brain tumours can affect cognition, memory, communication, behaviour, mobility, personality and independence, as well as physical health. Those changes can transform family relationships almost overnight.

A partner may become a carer. They may suddenly take responsibility for driving, medication management, appointments and decision-making while also maintaining employment, caring for children and managing a household.

For Marina, that is what makes specialist neuro-oncology knowledge so important.

A nurse who understands the neurological, cognitive and behavioural consequences of brain tumours can recognise changing needs earlier, connect patients and families to appropriate services and bridge gaps between different parts of the health system before people are left to navigate those gaps alone.

130–140 newly diagnosed brain cancer patients are supported by Marina each year, alongside their families, through specialist neuro-oncology nursing and care coordination. Marina's experience has also shown her that navigators themselves need navigation, connection and support. She helped establish a Neuro-oncology Nurses Network because specialist nurses and care coordinators were often working in relative isolation, supported locally by medical and allied health teams but without strong links to peers doing the same highly specialised work elsewhere.

The network created a way to share knowledge, resources and experiences — including the difficult periods that come with working in an area where loss and complexity are common.

Marina believes taking that approach nationally could strengthen professional support, improve referral pathways, spread successful models of care and create greater consistency between metropolitan, regional and rural services.

Through The Brain Cancer Group's Collaborative Care Project, she is already helping provide specialist support, resources and knowledge-sharing to Brain Cancer Care Coordinators across New South Wales, with the aim of strengthening capability and consistency of care.

What Australia needs next

For Marina, the goal is not to build a new system that duplicates what already exists. It is to connect and strengthen the specialist expertise Australia already has. That means investment in specialist neuro-oncology nursing positions, but also investment in the people filling them: workforce development, education, professional support, shared resources, clear referral pathways, service standards and better data about unmet need.

Without sustainable funding and support, experienced nurses can move into other positions. When they leave, the loss is not simply a vacancy — it is a loss of specialist capability, relationships and continuity for patients and families.

There is also a need to better demonstrate what neuro-oncology-specific care coordinators actually do and the value they create across the patient journey.

For Marina, the endpoint is straightforward: regardless of where someone lives, a person diagnosed with a brain tumour — and the family supporting them — should be able to access specialist navigation and coordinated care.

Brain tumours can affect almost every aspect of a person's life. That complexity demands more than a series of appointments.

It requires specialist clinicians who can see the whole person, understand the disease, connect the different parts of the system and remain alongside patients and carers as their needs change.

As Marina puts it, patients and carers should be able to call a neuro-oncology care coordinator without having to repeatedly retell their story to someone new.

They should be known. They should be heard. And they should be supported.

Pillar Three

Support Services



Supporting the person beyond the treatment

Brain cancer does not stop at the doors of the hospital

Brain cancer patients may receive excellent treatment but are still very likely to lose their driving licence, employment, income, independence or ability to manage their own affairs.

A family member may become a carer almost overnight and will likely need to reduce work. Patients and families may suddenly need to understand the NDIS, Centrelink, aged care, insurance, employment rights, accommodation, palliative care and community services — often while also coping with cognitive change, physical disability, psychological distress and profound uncertainty.

These consequences are not peripheral to the brain cancer experience. Around 90 per cent of people with glioblastoma experience cognitive deficits affecting memory, attention, reasoning and language (Ghadmi et al. 2025).

Almost three in four people with brain cancer experience psychological distress (Randazzo 2016). People with high-grade glioma and their carers face median out-of-pocket costs of \$535 a month (Newton et al. 2024), and carers of people with just one subtype, IDH-mutant glioma, provided an estimated 1.8 million hours of unpaid care in 2024 (Evohealth 2025).

Among people supported by the National Advocacy Service, NDIS disability support packages are typically four to five times the national average (POMF NAS client data).

The capacity to self-advocate is often diminished at precisely the point at which people must engage with the NDIS, Centrelink, aged care and insurance. These consequences determine whether a person can remain safely at home, whether a carer can stay in work, and whether a family can access the supports that make treatment and daily living possible.



9 in 10

people with glioblastoma
experience cognitive deficits

Memory, attention, reasoning and language can all be affected — the very capacities needed to navigate the NDIS, Centrelink and aged care.

Ghadmi et al. 2025, as cited in Mandala 2026

1.8 million hours



of unpaid care provided by carers of
Australians with IDH-mutant glioma
in 2024.

That figure covers one subtype only.
Across all brain cancers, the unpaid
caring load is greater still.

Evohealth 2025, as cited in Mandala 2026



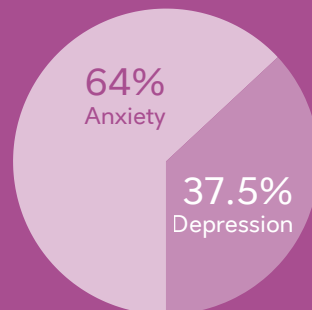
\$535
a month

median out-of-pocket
costs for people with
high-grade glioma and
their carers.

Costs arrive at the same
time as income often falls,
when a patient stops work
and a family member
reduces hours to care.

Newton et al. 2024, as cited in
Mandala 2026

Almost **2 in 3** carers of people with brain cancer experience
anxiety — and more than **1 in 3** experience depression



64 per cent and **37.5 per cent** respectively. Carers
are service users in their
own right.

Chen et al. 2025 (systematic review and
meta-analysis), as cited in Mandala 2026



4–5× the national average:

typical NDIS support packages for people
with brain cancer supported by NAS.

The size of these packages reflects the level of disability
brain cancer causes: cognitive and physical impairment
that often calls for high levels of directed support to keep
people safe at home (POMF NAS client database 2026).

For this reason, dedicated and focused support services
for patients are not an optional addition to clinical care.
They are part of the infrastructure surrounding a person
from diagnosis through treatment, living with disease,
recurrence, palliative and end-of-life care, and
bereavement (BTAA 2025).

Does Australia have a sustainable and equitable system that helps people affected by brain cancer navigate the practical, financial, psychosocial and social consequences of the disease?

The problem we are trying to solve

Diagnosis is often sudden. Needs can escalate quickly. At precisely the point at which people are required to make complex decisions and engage with multiple government and community systems, a brain tumour may be affecting cognition, communication, memory, behaviour, mobility and decision-making capacity.

Families frequently become the default navigators.

They are expected to locate services, understand eligibility requirements, collect clinical evidence, complete applications, appeal decisions and coordinate support while simultaneously managing treatment, caring responsibilities, employment and grief.

The 2025 Landscape identified three connected problems: high unmet support need, the complexity of navigating multiple systems after diagnosis, and fragmented and inequitable access to assistance — particularly for people outside major metropolitan centres.

The issue is therefore not simply whether programs such as the NDIS, Centrelink, My Aged Care, palliative care or community support exist.

It is whether a person affected by brain cancer can successfully access and navigate them when they need them.

General cancer navigation services can help connect people with information and services, but brain cancer creates additional complexity. The ACNNP now provides general navigation, cancer care nursing and specialist support services nationally. Brain cancer, however, is not separately listed among its disease-specific Specialist Support Services.

| That distinction matters.

A person may need help identifying a service. They may also need specialist advocacy to demonstrate disability, gather evidence, challenge an unsuccessful application, coordinate with clinicians and continue the process when cognitive or functional impairment makes self-advocacy increasingly difficult.

How do we make specialist brain tumour support and systems navigation available consistently, nationally and sustainably rather than depending on geography, philanthropy or a family's own capacity to navigate crisis?

What we asked for in 2025

The 2025 Landscape identified the National Advocacy Service (NAS) as an existing national response to this problem (BTAA 2025; Peace of Mind Foundation 2025).

Delivered by the Peace of Mind Foundation (POMF), NAS provides specialist, non-clinical support and navigation for people affected by brain cancer and other brain tumours.

The 2025 Landscape called on the Australian Government to:

- Sustain and scale the National Advocacy Service
- Provide secure funding so that an established national service could continue operating and expand its capacity.
- Invest in specialist workforce capacity

The 2025 proposal sought \$1.175 million in dedicated annual funding, supporting eight full-time equivalent positions to provide tailored navigation, advocacy and psychosocial support with national reach.

Formalise NAS within the national cancer system

Recognise NAS as a national brain cancer support service and strengthen referral pathways from hospitals, multidisciplinary teams, Brain Cancer Care Coordinators and national cancer navigation services.

Measure outcomes, not simply activity

Use NAS service data to understand unmet need and evaluate outcomes such as access to services, distress, quality of life, reach and health-system impact.

The 2025 Landscape therefore did not argue for the creation of another disconnected service.

It proposed sustaining and integrating an existing specialist model that helps patients and families access services already funded across health, disability, aged care and social support systems.

The question for 2026 is:

Has specialist brain cancer navigation and advocacy moved from philanthropic uncertainty toward sustainable national infrastructure?



Sustain and scale
National Advocacy
Service (NAS)



**Secure
funding**
for expansion



Invest
in specialist
workforce
capacity



**Formalise
NAS**
within the national brain
cancer support service



**Measure
outcomes**

The answer is:

**demand and evidence
have strengthened,
but funding certainty
has not.**

What happened in Support Services in 2026

Demand continued to grow

The strongest evidence of need is the extent to which patients, families, clinicians and services continue to use NAS.

Since forming in late 2021, NAS had provided direct person to person support and advocacy to **3,332 people since inception and responded to 11,708 support requests** across advocacy, counselling, financial assistance, support groups, retreats and navigation programs.

In 2025, 922 people accessed the service. During the first eight months of 2026, 681 people had already received support, while average monthly caseload increased from 77 to 85.

Importantly, much of this demand comes through the health system itself.

Clinicians and community services refer people to NAS because many of the problems families bring to them cannot be resolved through clinical treatment.

That demonstrates an important point:

NAS does not sit outside the clinical system. It fills gaps around it.

Specialist navigation has become an established part of the brain cancer ecosystem

NAS provides practical assistance across systems that are often difficult to navigate even without the neurological and cognitive effects of a brain tumour.

Its work includes advocacy and navigation through the NDIS, Centrelink and My Aged Care; helping families prepare applications and supporting evidence; connecting people with local and community services; providing psychosocial and peer support; and supporting people through recurrence and bereavement.

The service therefore occupies a different but complementary position to clinical care coordination.

A Brain Cancer Care Coordinator helps connect the clinical pathway.

NAS helps connect the person and family with the systems surrounding that pathway.

Those functions should increasingly operate as one connected journey.

Who does what around a person with brain cancer

Role	Where they work	Main focus	What sits outside their role
Brain Cancer Care Coordinator	Hospital / treating team	Coordinating treatment, appointments, results and clinical referrals	Applications and appeals to NDIS, Centrelink and aged care; support at home
Hospital social worker	Hospital	Practical and emotional support while the person is receiving care	Sustained support after discharge and between clinical contacts
National Advocacy Service	National, remote and outreach	Navigating NDIS, Centrelink, My Aged Care and grants: evidence, applications, reviews	Clinical coordination; in-person support at home
Community Brain Cancer Navigator	In the community and at home	Care planning, emotional support, appointments, carer burden, bereavement	Clinical treatment decisions

Source: Mandala 2026; Landscape analysis.

National cancer navigation investment has expanded

The broader policy environment has also changed.

Since November 2023, the Australian Government has committed \$406 million to establish and deliver the ACNNP. The program includes Cancer Navigation Services, Cancer Care Nursing Services and Specialist Support Services, and is intended to improve access to high-quality, culturally safe care across all cancer types and Australian locations (Australian Government Department of Health, Disability and Ageing 2026).

This is important progress. It also demonstrates that the principle underpinning the brain cancer community's ask — that people need help navigating a fragmented cancer system — is already accepted nationally.

The Australian Cancer Plan makes the same point. Action 2.2.1 calls for integrated, multi-channel and multidisciplinary navigation models that ensure consumers receive the right support at the right time across the cancer continuum (Cancer Australia 2023).

The question is therefore increasingly not whether navigation should be funded, but how national navigation infrastructure connects with the specialist expertise required by conditions such as brain cancer.

NAS is generating evidence as well as delivering support

Another development is the growing value of NAS as a source of evidence.

Traditional cancer datasets largely capture diagnosis, treatment and clinical outcomes.

They do not necessarily capture what happens when someone loses their licence, cannot work, cannot secure an NDIS package, needs home modifications, is rejected for financial assistance or has a partner leave employment to become a full-time carer.

NAS encounters those issues directly.

Its service data therefore provides a view of disability, system barriers and unmet support need that is difficult to obtain from clinical datasets alone.

This creates an opportunity for support-service data to inform policy and service design rather than simply recording how many people received assistance.

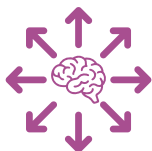
What remains unresolved



National demand still does not have national funding

The central problem identified in 2025 remains. NAS is delivering a national service, but it does not have a secure long-term Commonwealth funding base.

That means service capacity remains linked to fundraising cycles and individual philanthropic commitments rather than the level of demonstrated patient and family need. A national service should not become less available simply because one funding agreement ends.



Navigation remains fragmented across systems

Australia is making significant investment in cancer navigation, but the needs of people affected by brain cancer often extend well beyond the cancer system itself.

Patients and families may need to navigate the NDIS, Centrelink, aged care, employment, insurance, housing, legal services, financial assistance, palliative care and community support — each with different eligibility criteria, processes and evidence requirements.

The challenge is therefore not simply access to navigation, but continuity between clinical care coordination, cancer navigation and specialist systems advocacy.

Families should not be expected to understand which organisation, service or government program is responsible before they can receive the help they need.

Brain cancer-specific support is not yet consistently embedded within Australia's national navigation infrastructure.



Support remains too dependent on whether families know where to look



The outcomes of support are not yet measured consistently

Support services commonly report activity:

- how many people were seen
- how many calls were answered
- how many referrals were made

Those measures matter, but they do not establish whether people's lives improved.

A mature national support model should be able to measure outcomes such as:

- successful access to entitlements
- reduced distress
- improved quality of life
- reduced administrative burden on carers
- continued workforce participation
- equitable access across geography and population groups
- potential reductions in avoidable health-system use

This aligns with the Australian Cancer Plan's emphasis on ongoing monitoring and evaluation of navigation models.



The specialist workforce remains vulnerable

Brain tumour advocacy and navigation requires expertise. Staff develop detailed knowledge of disability systems, cancer services, evidence requirements, referral pathways and the particular functional and cognitive effects of brain tumours.



Specialist navigation is funded for others, but not yet for brain cancer

The Australian Government already recognises that people with complex conditions may need specialist support to navigate the systems designed to assist them. The National Dementia Support Program provides nationally funded information, education, post-diagnostic support and connection to services for people living with dementia, their families and carers (Australian Government Department of Health, Disability and Ageing 2026). The National Dementia Action Plan 2024–2034 recognises that people living with dementia may need to navigate health, aged care and disability systems, and that cognitive impairment can make processing complex information and making decisions increasingly difficult (Australian Government Department of Health and Aged Care 2024).

Brain cancer shares the features that justify that investment: progressive cognitive and neurological impairment, rapidly changing needs, and carers who become the default navigators. Yet no brain cancer-specific service is funded within the national navigation program, and the one national specialist service that exists depends on philanthropy. The principle has been accepted. It has not yet been applied to brain cancer.

	Dementia	Brain cancer
Progressive cognitive and neurological impairment affects capacity to self-navigate	Yes	Yes
Needs change across the disease trajectory, including end of life	Yes	Yes
Carers take on navigation and decision-making	Yes	Yes
Dedicated Commonwealth-funded, condition-specific support program	Yes — National Dementia Support Program, funded on an ongoing basis	No
Included in the ACNNP Specialist Support Services stream	Not applicable	Not among the 12 funded organisations
Existing national specialist service	Funded by government	NAS — philanthropically funded

0/12

specialist support organisations funded through the ACNNP are brain cancer-specific

The Specialist Support Services stream of the ACNNP funds 12 non-government organisations to provide disease-specific support. None is dedicated to brain cancer.
Department of Health, Disability and Ageing

What needs to happen next

The next stage should build on what already exists rather than create another parallel system. The priorities for Support Services are:

Fund NAS on a multi-year basis. Commit \$725,000 a year for three years, **co-funded with philanthropy**, to stabilise specialist staff and meet growing demand.

Bring brain cancer into national navigation. Include brain cancer in the ACNNP Specialist Support Services stream, or fund an equivalent brain cancer-specific capability, with formal referral pathways between Brain Cancer Care Coordinators, national cancer navigation services and NAS. Recognise carers as service users. Support pathways should cover carers and families from diagnosis through recurrence, palliative care and bereavement.

Measure outcomes, not activity. Fund an evaluation framework so that Australia has its first outcome data on brain cancer support, and use NAS data alongside clinical and registry evidence. Deliver the Australian Cancer Plan. Action 2.2.1 commits to integrated navigation across the cancer continuum. Brain cancer is the test of whether that commitment reaches the people who need it most.

These priorities are carried into Asks 5 to 8 in Summary, Next Steps and 2026 Asks.

Clinical care treats the disease. Specialist support helps the person and family live with everything the disease changes. A national brain cancer system needs both.

Case study:

National Advocacy Service in action



The Australian Government is investing substantially in exactly the kind of service brain cancer families need. It is simply not investing in it for them.

Case study: the National Advocacy Service

What NAS does

NAS fills a critical gap between the clinical health system and broader social support systems. It provides practical, brain cancer-specific assistance that mainstream services are often not equipped to deliver, including:

- specialist navigation and advocacy across the NDIS, Centrelink, My Aged Care and other financial and disability systems
- preparing and submitting applications, gathering clinical evidence and coordinating with health professionals
- connecting patients, carers and families with local services, community supports, grants and other assistance
- help by phone, online and through outreach, including for people living in regional and remote communities
- psychosocial support, peer connection and lived-experience pathways, including during recurrence and bereavement
- data and lived-experience evidence that informs national policy, service design and advocacy

NAS does not duplicate existing Commonwealth or clinical services. It helps people access them. Clinicians and hospitals can refer patients and families to a trusted specialist service, allowing health teams to focus on treatment while NAS addresses the practical and systemic issues surrounding a diagnosis.

Who NAS supports

NAS supports patients, carers, parents, partners, children, families and loved ones affected by brain cancer and other brain tumours. The need is particularly acute because brain tumours can affect cognition, memory, communication and independence. Mandala reports that 90% of people with glioblastoma experience cognitive deficits, while 74% of brain cancer patients experience psychological distress. Reported depression and anxiety among caregivers are 37.5% and 64% respectively (Mandala 2026).

The service supports people across the disease pathway and across Australia. Over 3,200 families have been supported since NAS began in 2021, with referrals from more than 450 hospitals and allied health services, and more than 1,100 clinicians relying on NAS for their patients. Around 75% of referrals are received from clinicians, demonstrating that NAS has become part of the national brain cancer care ecosystem.

Why NAS matters to the Australian health system

NAS addresses the significant non-clinical needs associated with brain cancer and brain tumour diagnoses. Through specialist navigation, advocacy and coordination, it helps consumers access health, disability, aged care, financial and community supports, reducing barriers to care and improving continuity across multiple service systems. By helping patients and families navigate complex pathways, NAS enables healthcare professionals to focus on clinical care while consumers receive practical support to make informed decisions and access timely assistance.

The service also contributes to health system efficiency by identifying unmet needs early, connecting people with appropriate services, reducing duplication and supporting coordinated care across sectors. Because brain tumours can affect cognition, communication, physical function and the ability to self-advocate, NAS is important to equitable access, particularly for people living in regional, rural and underserved communities.

Growing demand and national reach

As at 7 September 2026, NAS had supported 3,332 people since inception and responded to 11,708 support requests across advocacy, counselling, financial grants, retreats, support groups and navigation programs.

In 2025, 922 people accessed the service. In the first eight months of 2026, 681 people had already been supported, with the average monthly caseload increasing from 77 to 85, approximately 10% growth (Peace of Mind Foundation 2026).

As at September 2026

NAS supported **3,332**
people

Responded to **11,708**
support requests across:

**Advocacy, Counselling, Financial grants,
Retreats Support groups & Navigation programs**

In 2025

922 people accessed
the service

To August 2026

681 people were
already supported

10% average case
increase

Measure	Since inception (2021)	2025	2026 (to 7 Sep)
People supported	3,332	922	681
Support requests responded to	11,708	3,984	2,257
Average new people supported per month	—	77	85
Referred by health or community organisations	2,344		
Self-referred	981		

Source: POMF NAS service data supplied 7 September 2026. Active caseload of 350+ people at any one time; approximately 1 in 12 people supported is under 25.

About 1,000 people a year are now supported by NAS **922 people in 2025, and 681 in the first eight months of 2026** — on track for around 1,000 this year. 3,332 people have been supported since 2021.

POMF NAS service data to 7 September 2026; 2026 annual figure is a projection

NAS Support
1,000
approx. people
per year
3,332 since 2021

7 in 10 people come to NAS through a health or community service **2,344 of 3,325 referrals since inception came from hospitals, clinicians and community organisations.** NAS does not sit outside the health system; it fills the gaps around it.

POMF NAS service data to 7 September 2026

 **7/10**
from health or
community services

1 in 12 people supported by NAS is under 25. Brain cancer affects children, adolescents and young adults, and their parents and siblings, as well as older Australians.

POMF NAS service data

1 in 12 
Under 25

Helping families access existing supports

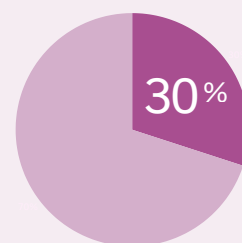
For many families, the barrier is not that assistance does not exist. It is reaching it. On average, 80 per cent of applications to the NDIS meet access requirements. For people with brain cancer, the figure is around 30 per cent, despite a disease that commonly causes profound cognitive and physical disability. For applications supported by NAS, it is 97 per cent (Mandala 2026).

Charmane's experience shows what sits behind the 30 per cent. Diagnosed with glioblastoma and given 12 to 14 months to live, she was refused NDIS support repeatedly, and her case went to the Administrative Review Tribunal. She was granted a package 51 weeks into her prognosis. With specialist advocates beside her she won. Many families do not have that support, or the capacity to keep fighting.

Each year, NAS provides specialist triage and application support to around 733 families, and connects 326 with NDIS assistance averaging around \$253,000 (Mandala 2026).

97% of NDIS applications supported by NAS meet access requirements. **For brain cancer applications generally, the figure is around 30 per cent.**

Mandala 2026 ("Access Met" decisions; sources NDIS 2025; Building the Bridge 2025)



Having to spend the last year of my life constantly proving that I was dying, proving that I deserved support and proving that I needed help was one of the cruellest experiences I've ever endured."

— Charmane, living with glioblastoma, Tasmania, Voices from Support

Patient and family experience	Reported outcome
Better understanding of available services and supports	96%
Reduced stress or anxiety when navigating financial support	93%
Accessed supports that may not have been accessed independently	92%
Improved support managing caregiver burdens	92%
Better understanding of NDIS, Centrelink and My Aged Care	93%

Source: Peace of Mind Foundation (2026) Patient Experience Survey, as reported in Mandala 2026. Results show respondents who agreed or strongly agreed.

Impact on patients, carers, families and the community

NAS support can change what is possible for a family. It can help a patient access equipment, income support or disability funding; help a carer remain connected to work; reduce the time and stress spent dealing with government systems; and give families a trusted person who understands the specific consequences of brain cancer.

Independent economic analysis commissioned by the Peace of Mind Foundation estimates that NAS generates approximately \$8.7 million in economic value each year, around \$23,500 for every participant supported (Mandala 2026). Most of that value (\$7.5 million) comes from carers and family members being able to maintain or return to work once financial and practical supports are in place. The remaining \$1.2 million reflects lower government administration costs, because well-prepared applications are processed more efficiently.

Across the Foundation's full model, which includes NAS, the Community Brain Cancer Navigator program and counselling, Mandala estimates at least \$12 million in annual economic value, or \$8.40 for every dollar invested. If the model reached every newly diagnosed brain cancer patient in Australia, Mandala estimates it could generate around \$85 million in net economic value each year.

Component	Value per year	Basis
National Advocacy Service	\$8.7M	\$7.5M workforce participation + \$1.2M avoided government administration; ~\$23,500 per participant
Community Brain Cancer Navigator	\$3.2M	\$1.9M carer time saved + \$1.1M avoided healthcare use + \$0.2M direct financial relief; ~\$36,500 per family
Events and paid counselling	\$0.1M	~\$600 per participant
Peace of Mind Foundation total	\$12.0M	\$8.40 in economic value per \$1 invested (8.4 : 1)
Modelled: 50% of new brain cancer patients	\$37M net	Mandala projection
Modelled: all new brain cancer patients	\$85M net	Mandala projection

\$8.7 million in economic value generated by NAS each year
\$7.5 million (86%) comes from carers and families maintaining or returning to work
\$1.2 million (14%) from avoided government administration costs. That is about
\$23,500 for every participant supported, not NAS alone

\$8.40 for every \$1 in economic value across the Peace of Mind Foundation model
NAS, the Community Brain Cancer Navigator program and counselling together generate
at least \$12 million a year. Scaled to every newly diagnosed patient, Mandala estimates
\$85 million in net economic value annually.

Mandala 2026 — whole-of-POMF figures, not NAS alone

The case for sustained national investment

NAS has demonstrated a clear national need, measurable patient and family benefits, and economic value for government and the broader community. Yet the service does not have secure, long-term Commonwealth funding. Cure Brain Cancer Foundation funding ended on 30 June 2026. Peace of Mind Foundation has secured philanthropic commitments and continues to seek co-funding, but these arrangements do not provide the stable base required for a national service.

The previous NAS pre-budget submission did not result in an allocated Commonwealth funding commitment. Since NAS inception until 30 June 2025 Cure Brain Cancer Foundation, was the sole the funding partner and remain a primary funding partner. Other philanthropic funding partners include Hospice Foundation Geelong, Rewilding Minds and Telix Pharmaceutical. Whilst this provides funding for some NAS operations and resourcing but is insufficient to meet the demand of the NAS. These philanthropic partnerships demonstrate strong sector support, but do not provide the stable base required for a national service.

Without a sustained funding pathway, workforce capacity is at risk at the same time as demand is increasing. One specialist position ended in August 2026 and a second is under notice. Further reductions would limit the number of new referrals NAS can accept, increase wait times and reduce timely access to specialist advocacy.

A national brain cancer response must address more than tumour treatment. It must also help people navigate the practical, financial, emotional and social consequences of the disease. NAS provides a proven way to do that. Sustained government investment would protect what is already working, extend its reach and make the journey easier for the next patient and family.

Peace of Mind Foundation is seeking Australian Government investment of \$725,000 per year for three years to stabilise NAS, retain specialist staff and expand capacity. This investment would complement, rather than replace, philanthropic support. It would provide a practical foundation for a scalable national service that works alongside clinicians, hospitals, Brain Cancer Care Coordinators, social workers, disability and aged-care systems, palliative care and broader cancer navigation programs (Peace of Mind Foundation 2026).

This is aligned with the Head to the Hill 2026 call for sustained government funding for brain cancer support services. National investment in NAS would ensure that support is available based on need, not postcode, philanthropic cycles or whether a family has the capacity to navigate complex systems alone.

Meet the team



Fiona Hassmann

**Manager – National
Advocacy Service
Head of Programs &
Services**



Tera Jespersen

**NAS Client
Support Specialist**



Helen Kington

**NAS Client
Support Specialist**



Mel Davies

**NAS Client
Support Specialist**



Jess Schluter

**NAS Client
Support Specialist**



Mary Sutton

**NAS Client
Support Specialist**



Wendy Gulash

**NAS Client
Support Specialist**



Charmane's Story



For much of her working life, Charmane Hardy dedicated her career to supporting some of the most vulnerable members of the community.

She began with Burnie City Council as a Youth Worker in the JPET Program, delivering programs and life skills training to young people under 25 who were experiencing significant challenges, including homelessness, school refusal, substance dependence, and involvement with the criminal justice system.

Following the conclusion of the program, Charmane joined Devonport City Council, where she continued her commitment to community support and progressively advanced into leadership roles, ultimately managing a broad portfolio of community programs and services.

Throughout her career, she was known for her ability to help people navigate complex systems, access vital support services, and improve their quality of life. As Community Development and Volunteer Coordinator, her role required exceptional leadership, organisational skills and community engagement.

Beyond her professional achievements, Charmane was a devoted mother, grandmother, volunteer and carer who always put the needs of others before her own. She later stepped away from her career to care for her husband during his illness, remaining dedicated to her family until his passing.

On 27 June 2025, Charmane's life changed without warning. While driving across the Devonport Bridge, she suddenly became disoriented and unable to navigate familiar surroundings. Later that day, after suffering multiple seizures at home, she was transported to hospital and ultimately airlifted to the Royal Hobart Hospital, where scans revealed a large brain tumour.

Following urgent brain surgery, Charmane was diagnosed with Grade 4 Glioblastoma (GBM), the most aggressive and incurable form of brain cancer. Despite undergoing surgery, radiotherapy and chemotherapy, there is no cure for Glioblastoma. Following surgery, Charmane's treating specialists advised that her life expectancy was likely to be between 12 and 14 months.

The diagnosis had an immediate and profound impact on every aspect of her life.

Once highly independent and actively engaged in her community, Charmane experienced significant cognitive impairment, reduced executive functioning, memory difficulties, fatigue, seizures, vision changes, impaired judgement and a progressive loss of independence. Her treating team advised that it was no longer safe for her to live alone, requiring family, friends and community members to coordinate extensive support while she underwent treatment.

Recognising her substantial disability and support needs, an application for the National Disability Insurance Scheme (NDIS) was lodged in July 2025. Despite medical evidence confirming a diagnosis of Glioblastoma and the significant functional impacts arising from the disease, the application was initially rejected.

The first decision incorrectly determined that Charmane did not meet the age eligibility criteria. Following review, this was overturned; however, the application was then declined on the basis that the NDIS could not establish medical permanency.

Importantly, the NDIS accepted that Charmane met the disability impairment criteria. The dispute centred solely on whether sufficient evidence had been provided to demonstrate that her condition was permanent, despite Glioblastoma being universally recognised as incurable, progressive and ultimately fatal. Multiple reviews produced the same outcome and the matter proceeded to the Administrative Review Tribunal, where it remained unresolved almost twelve months later.

“
**Despite having a terminal diagnosis,
I was knocked back over and over again.
Eventually my case ended up before the
Administrative Review Tribunal.**

For most participants, administrative delays are frustrating. For someone living with a terminal brain cancer and a limited life expectancy, those delays carry far greater consequences.

As Charmane's condition progressed, her daughters were forced to significantly reduce their employment commitments, with one ultimately ceasing work entirely to provide full-time care. The family absorbed substantial emotional, financial and practical burdens while navigating a complex appeals process. Rather than focusing on making memories together during what could be the final months of Charmane's life, they found themselves repeatedly required to prove the permanence of a disease for which there is no cure.

Charmane describes the NDIS process as more distressing than her cancer treatment itself. "Having to spend the last year of my life constantly proving that I was dying, proving that I deserved support and proving that I needed help was one of the cruellest experiences I've ever endured. It was exhausting. It was confusing. It was degrading."

In June 2026, almost twelve months after her original application, Charmane connected with the Peace of Mind Foundation. Through specialist NDIS advocacy support, it became apparent that while extensive medical evidence had been provided, no clinician had explicitly documented permanency in the precise manner required by the NDIS.

A concise supporting statement was prepared and endorsed by her treating clinician, clearly outlining that Glioblastoma is permanent, progressive and incurable, and that treatment is directed solely towards disease control, symptom management and quality of life rather than recovery.

Following submission of this evidence, NDIS access was approved and a funded support package was established within seven weeks.

For Charmane, the outcome raised an unavoidable question: why did it require almost a year of appeals, reviews, tribunal proceedings and family hardship to achieve an outcome that was ultimately granted on the basis of information already known to all parties?

Today, Charmane's tumour has recurred and treatment options have been exhausted. There are no further surgical, radiation or chemotherapy interventions available. Her medical team has commenced high-dose steroid therapy to manage symptoms and preserve quality of life.

What is particularly difficult for Charmane and her family is the stark reality that the time spent fighting for NDIS support closely mirrors the prognosis she was given following surgery. She was told she may have only 12 to 14 months to live.

It took the same amount of time for her access to disability support to be resolved.

Like many Australians living with Glioblastoma, Charmane's focus is now on maximising the precious time she has left with her children and grandchildren rather than continuing battles with complex administrative systems.

Charmane's experience highlights a critical gap within the current disability access pathway for people living with terminal brain cancers. Where life expectancy may be measured in months rather than years, prolonged periods of time in eligibility disputes can consume a substantial proportion of a person's remaining life, delaying access to supports that reduce carer burden, preserve dignity and improve quality of life.

As part of the Head to the Hill 2026 campaign, Charmane is asking Federal Parliamentarians to consider not only the human impact of delayed access to disability supports, but also the gaps that exist within the broader brain cancer support pathway.

Her experience demonstrates the need for:

1. Improved understanding of Glioblastoma and other incurable brain tumours within NDIS decision-making processes.
2. Reduced administrative burden on patients and families already facing life-limiting diagnoses.
3. Greater recognition of the impacts experienced by informal carers who are often forced to leave employment to provide full-time support.
4. Sustainable government investment in specialist brain cancer advocacy, navigation and support services.
5. Formal recognition and integration of specialist patient navigation services within the brain cancer care pathway.

Charmane's experience also highlights a significant gap in the current health and disability systems.

Despite the complex medical, psychosocial, financial and practical challenges faced by people diagnosed with brain cancer, specialist navigation and advocacy support is not routinely embedded within patient care. As a result, many patients and families are left to independently navigate complex health, disability and government systems at a time when they are least equipped to do so.



Many patients and families are left to independently navigate complex health, disability and government systems at a time when they are least equipped to do so.

The Peace of Mind Foundation currently receives no government funding and is not embedded within the Australian Cancer Nursing and Navigation Program (ACNNP) model. Consequently, referrals are largely dependent on chance discovery, clinician awareness, or patients finding the service themselves.

Had Charmane been connected to specialist advocacy support at the time of diagnosis, her NDIS access challenges would have been identified and resolved much earlier, reducing unnecessary distress and enabling her family to focus on care, treatment and quality time together. Instead, almost twelve months were lost navigating appeals, reviews and tribunal proceedings.

Her hope is that every Australian diagnosed with a brain tumour is automatically connected with specialist navigation, advocacy and support services from the point of diagnosis.

No patient facing a life-limiting brain cancer should be expected to find their own way through complex systems while simultaneously coping with treatment, disability, uncertainty and declining health.

Charmane's story is not simply about one person's struggle. It reflects the experience of many Australians living with brain cancer who spend precious time fighting systems rather than focusing on treatment, family and quality of life.

Her hope is that future patients will receive timely access to specialist support from diagnosis, ensuring their remaining time is spent living, not navigating bureaucracy.

“

No person who is dying should have to spend their precious time fighting for basic dignity.



The year in summary

The year in summary 2026 was a year in which the evidence moved further than the funding.

The Government's decision to include brain cancer as a dedicated mission within the new ACRP, with \$50 million over ten years, provides continuity for Australian brain cancer research and a platform for the next decade. Sustained advocacy by the brain cancer community — through the 2025 Landscape, Head to the Hill event and direct engagement with government — helped ensure brain cancer retained that dedicated place. Alongside it, the evidence on what patients and families need has never been stronger. The opportunity now is to bring investment, evidence and the sector together.

Brain cancer remains one of the least survivable cancers in Australia. Five-year relative survival is around 24 per cent, compared with 72 per cent across all cancers, and it has barely moved in three decades. New national projections show that just 3.6 per cent of Australians alive after a brain cancer diagnosis are estimated to have reached the point where their survival matches the general population, compared with more than half of all people with a past cancer diagnosis. Of about 9,000 Australians living after a brain cancer diagnosis, around 8,700 are living with the disease rather than beyond it.

Against that background, there has been real progress since the 2025 Landscape. The Australian Government also awarded \$8.4 million in MRFF grants through the ABCM. Vorasidenib was listed on the PBS for people with IDH-mutant grade 2 astrocytoma and oligodendroglioma. The BRAINS Program and new consensus work have defined, in far greater detail, what good brain cancer care coordination and supportive care must do. The ABCR published its first Clinical Quality Indicators report. And demand for specialist support continued to grow, with the NAS now supporting around 1,000 people a year.

But the central problems identified in 2025 remain largely unresolved. There is still no co-designed national research roadmap or shared governance for the new investment. There is still no dedicated funding for brain cancer care coordination, and brain cancer is not among the specialist services funded through the national cancer navigation program. The one national specialist support service for brain cancer still depends on philanthropy, and its funding has become less secure, not more.

The pattern is consistent across all three pillars. National programs designed for all cancers are not reaching the particular needs of brain cancer — the cognitive and neurological consequences, the long and changing journey, and the families who become carers and navigators overnight. Philanthropy and the sector are carrying much of the national infrastructure. The case for change has been made; what remains is to act on it.

Scorecard: the 2025 asks, one year on

Status as at 30 September 2026. Statuses rate progress against each ask as stated in the 2025 Landscape.

2025 ask	What happened in 2026	Status	Assessment
Pillar One — Research and Trials			
Renew national strategic investment: \$200 million over 10 years	\$50 million over 10 years committed to a second brain cancer mission within the \$300 million ACRP; \$8.4 million in MRFF grants awarded through the ABCM (July 2026).	Partly achieved	Continuity is secured and welcome, at a quarter of the level the sector identified. Leverage with philanthropy will be essential.
Develop a co-designed Australian Brain Cancer Roadmap	The ABTC submitted a Joint Governance Partnership proposal to government in March 2026, centred on a Joint Steering Committee to co-design the roadmap. Discussions with government are continuing.	In progress	No roadmap or shared governance is yet in place for the new investment. Priorities risk being set without the people who live with the disease.
Strengthen research-enabling capability: workforce, data, biobanking, trial networks	National clinical trial initiatives continue across all diseases. A sector-led environmental scan mapped 164 current Australian brain cancer research projects. No brain cancer-specific capability investment was announced.	Not achieved	Capability built through the first mission remains dependent on short-term grants and philanthropy.
Pillar Two — Clinical Care			
Fund a national Brain Cancer Care Coordinator framework: \$8.75 million, 23 coordinators	No dedicated funding. The all-cancer ACNNP continued to expand, but does not include brain cancer-specific clinical coordination.	Not achieved	Access to a specialist coordinator still depends on where a patient is treated.
Embed specialist coordination in multidisciplinary care, across the whole disease trajectory	BRAINS evidence and new consensus work defined the functions and indicators of optimal coordination.	Partly achieved	Progress is sector-led and evidence-led. National implementation has not begun.
Data-driven deployment and outcome measurement	BRAINS ADAPT portal in development; the Australian Brain Cancer Registry published its first quality indicators (Queensland data, October 2025).	In progress	The data infrastructure is emerging; it is not yet linked to how coordination is funded or deployed.

2025 ask	What happened in 2026	Status	Assessment
Pillar Three — Support Services			
Sustain and scale the National Advocacy Service: \$1.175 million a year, 8 FTE	The pre-budget submission was not funded. Cure Brain Cancer Foundation funding ended on 30 June 2026. Specialist positions have been lost or put at risk while demand grew to around 1,000 people a year.	Not achieved	The service is more needed and less secure than a year ago.
Formalise NAS within the national cancer system	Brain cancer is not among the 12 organisations funded through the ACNNP Specialist Support Services stream.	Not achieved	The principle of specialist navigation is accepted nationally; it has not been applied to brain cancer.
Measure outcomes, not simply activity	Independent economic evaluation (Mandala, commissioned by the Peace of Mind Foundation) estimated \$8.7 million in annual value from NAS; a patient experience survey was completed. A national evaluation framework is not funded.	Partly achieved	The sector has generated the evidence itself. It now needs a funded framework.
Enablers — the sector's own commitments			
Build the Australian Brain Tumour Collaborative	Brought its member organisations together behind the research governance proposal.	Progressing	The ABTC is now producing joint positions and co-design, not only discussion.
Establish BTAA as the national peak advocacy body	BTAA moved from a volunteer committee to a portfolio-based Board in 2026, adding professional and sector expertise while keeping lived experience at its core.	Progressing	Governance is in place; sustainable operational capacity is the next step.

What 2026 has taught us

- **Evidence is no longer the main constraint.** Australia now knows in considerable detail what brain cancer patients and families need, and what good coordination and support look like. The gap is implementation and funding.
- **All-cancer programs are not reaching brain cancer.** National investment in navigation, nursing and research has grown, but brain cancer's particular needs — cognitive impairment, rapid change, long journeys, carer burden — are consistently falling between those programs.
- **Philanthropy is carrying national infrastructure.** Specialist support, much of the research workforce and sector coordination depend on philanthropic and time-limited funding. That is not a stable base for a national response.
- **A coordinated sector is a stronger partner.** The ABTC and a strengthened BTAA give government one considered position and a ready implementation partner.

Our 2026 asks

The asks below consolidate the priorities set out in each pillar. They are directed to the Australian Government and are intended to inform the 2027–28 Budget and the year of engagement ahead.



Research and Trials

ASK 1 Co-design the Roadmap through a Joint Steering Committee

Establish a Joint Steering Committee of government, researchers, clinicians, people with lived experience and philanthropic partners to co-design an Australian Brain Cancer Research and Trials Roadmap, guiding the \$50 million second brain cancer mission across discovery, translation, clinical trials, survivorship and supportive care. The Roadmap should also work collaboratively across the partner missions of the Australian Cancer Research Program — the Childhood, Adolescent and Young Adult Cancer Mission and the Low Survival Cancers Mission — both of which are directly relevant to brain cancer. Brain cancer researchers should have access to those missions, with coordinated priorities, shared infrastructure and no duplication, so that the combined investment delivers the greatest benefit.

Minister for Health; Department of Health, Disability and Ageing; MRFF

ASK 2 Build toward the scale the challenge requires

Use the second mission to leverage philanthropic and industry co-investment, and commit to reviewing the adequacy of investment against the \$200 million over ten years the sector identified in 2025, with sustained support for research workforce, data, biobanking and trial networks.

Department of Health, Disability and Ageing; MRFF

ASK 3 Faster, fairer access to new treatments

Support timely PBS pathways for brain cancer therapies, attract more phase II and III trials to Australia, and create a clear, equitable compassionate-access pathway — including a discretionary funding mechanism — for children and adults when trials are not yet open or costs are out of reach.

Minister for Health; PBAC; TGA; Department of Health, Disability and Ageing



Clinical Care

ASK 4 Fund a national Brain Cancer Care Coordination Framework

Build on the 2025 proposal for \$8.75 million and 23 specialist coordinators to establish a nationally consistent framework, integrated with the ACNNP and McGrath Cancer Care Nurses, and co-designed with the brain cancer community through a national clinical care pathway.

Department of Health, Disability and Ageing; Cancer Australia



Support Services

ASK 5 Stabilise the National Advocacy Service

Commit \$725,000 a year for three years, co-funded with philanthropy, to retain specialist staff and meet growing national demand.

Department of Health, Disability and Ageing

ASK 6 Bring brain cancer into national cancer navigation

Include brain cancer in the ACNNP Specialist Support Services stream, or fund an equivalent brain cancer-specific capability, with formal referral pathways between Brain Cancer Care Coordinators, national navigation services and NAS.

Department of Health, Disability and Ageing

ASK 7 Priority access to disability and aged care support, modelled on MND

Building on existing priority arrangements, establish a brain cancer priority pathway modelled on the NDIS priority pathway for motor neurone disease: assessment by staff with brain cancer expertise, fast access decisions, and packages that are adjusted quickly as needs change. People with brain cancer who are 65 or over should receive the same urgent priority for Support at Home that was extended to people with MND in June 2026. As the NDIS moves toward functional assessment, the pathway should be protected under the new arrangements, so that no one spends their remaining time proving they are dying.

National Disability Insurance Agency; Department of Health, Disability and Ageing

Across the system

ASK 8 Measure what matters

Fund outcome evaluation for brain cancer coordination and support services, and support national expansion of the ABCR, so that future Landscapes can report outcomes, not only activity. Department of Health, Disability and Ageing; Cancer Australia; states and territories

What the sector will do

The brain cancer community asks nothing of government that it is not prepared to contribute to itself. Over the next twelve months:

- **The Australian Brain Tumour Collaborative** will continue to bring its members to one position on research priorities.
- **Brain Tumour Alliance Australia** will complete its transition to a portfolio-based peak advocacy body, carry the asks above into sustained engagement with government, and continue to put lived experience at the centre of national advocacy.
- **Member organisations** will continue to fund and deliver research, trials, clinical care and supports, and to share data — including NAS service data — so that unmet need can be measured rather than assumed.

Next steps

When	What
Next 3 months	Launch the 2026 Landscape with members, parliamentarians and government. Lodge 2027–28 pre-budget submissions aligned to Asks 1–8. Continue research governance discussions with government.
Next 6 months	Agree an outcome evaluation framework for NAS and care coordination.
Next 12 months	Report progress against every ask in the 2027 Landscape, using the same scorecard, so that each year’s edition shows what has changed and what has not.

A final word

Research & Trials, Clinical Care and Support Services are not three separate ambitions. For the person diagnosed and the family beside them, they are one journey. The progress of 2026 shows what is possible when government, researchers, clinicians, philanthropy and the community act together. The work of 2027 is to make that the rule rather than the exception — so that every Australian affected by brain cancer can access the best available research, care and support, wherever they live.

About Brain Tumour Alliance Australia

Building a sustainable peak body

For most of its history, BTAA operated through a volunteer committee, with many members bringing direct lived experience as patients, carers and family members.

That model sustained BTAA for many years and built much of what exists today — including national advocacy, patient forums, information and education resources, Head to the Hill and the establishment of the ABTC.

As BTAA's national advocacy role has grown, so too has the need for a governance model capable of supporting sustained engagement across government, research, clinical care, patient support, partnerships and organisational development.

A significant transformation in 2026

In 2026, BTAA commenced its transition from a committee structure to a portfolio-based Board.

Continuity was central to that change. Existing committee members transitioned to become directors of BTAA, retaining the lived experience, organisational knowledge and relationships built over many years.

At the same time, additional Board members were recruited to bring complementary expertise and capability in areas important to BTAA's future as a national peak advocacy organisation.

The result is a Board that combines lived experience and organisational history with specialist professional and sector expertise.

The portfolio model provides a clearer structure through which directors can contribute to defined areas of BTAA's strategy while retaining collective responsibility as a Board.

A portfolio-based Board

BTAA's Board is organised around strategic portfolios aligned to the breadth of its national role.

Advocacy and Government Relations

Strategy, Risk and Governance

Clinical Care and Support Pathways

Research, Clinical Trials and Partnerships

Fundraising, Marketing and Communications

Governance and accountability

The portfolio structure enables directors to focus their expertise on particular areas of strategy and activity, while formal decision-making and accountability remain with the full Board.

The transition is part of a broader effort to build the organisational capacity required for continuous national advocacy — including sustainable funding, executive capability and stronger systems to support BTAA's work over the long term.

BTAA's foundations, however, remain unchanged: it continues to be lived-experience led, national in scope and focused on the needs of people affected by all brain tumours.

Executive Team



Craig Cardinal
CHAIR



Philip Dunn
VICE CHAIR



Pat Wynn
TREASURER



Billy Williams
PUBLIC OFFICER

Portfolio Board

Advocacy and Government Relations



Mainul Haque
OAM
DIRECTOR



Damian Ogden
DIRECTOR

Strategy, Risk & Governance



Emma Pitfield
DIRECTOR



Professor
Darrell Evans
DIRECTOR

Portfolio Board

Fundraising, Marketing & Communications



Sally Cane
DIRECTOR



Pam Hubner
DIRECTOR



Jaimee Eaton
DIRECTOR



Billy Williams
DIRECTOR

Clinical Care & Support Pathways



Gerry Tye
DIRECTOR



Brett Levin
DIRECTOR



Craig Steele
DIRECTOR

Research, Clinical Trials & Partnerships



Professor
Divya Mehta
DIRECTOR



Oliver Jarrett
DIRECTOR

Executive Officer



Amanda Redford

Advocacy in action

Advocacy is central to BTAA's role as the national consumer organisation for the brain tumour community. Alongside representing community priorities in policy discussions, BTAA creates opportunities for people with lived experience to speak directly to decision-makers and build the confidence and capability to advocate for change.

Head to the Hill

BTAA's flagship advocacy initiative, Head to the Hill, brings patients, carers, bereaved families, clinicians, researchers and sector organisations together with parliamentarians and their advisers at Australian Parliament House.

The initiative was shaped through BTAA's lived-experience leadership, with Diane Dunn, BTAA Committee Member, playing a foundational role in its creation and development. At its heart was a simple idea: people affected by brain tumours should have a direct voice in the decisions that shape research, treatment, care and support.

The inaugural Head to the Hill was held on the lawns of Parliament House in November 2023, with around 80 people attending. In 2026, more than 350 people are expected to attend, with the event moving into the Great Hall.

Head to the Hill began with a simple idea: lived experience should reach the people who can change the system.

The shoe installation has become one of the most powerful symbols of Head to the Hill. Each pair represents a person affected by a brain tumour — someone living with disease, a survivor, a child, parent, partner or someone who has died. Many are accompanied by personal stories, allowing parliamentarians to see the people and families behind the statistics.

From its beginnings as a symbolic display, the installation has grown to almost 300 story-linked pairs of shoes. Running shoes, work boots, school shoes, slippers and much-loved personal footwear create a visible reminder that every diagnosis represents a life, a family and a community.



Advocate Program

In 2026, BTAA took the next step with the introduction of the Brain Tumour Advocate Program. More than 70 advocates have joined the program, creating a growing national network of people with lived experience who are supported to engage with decision-makers confidently and effectively.

The program provides a structured pathway to learn, prepare, engage and continue, supported by five dedicated Advocacy Guides, briefing materials, shared key messages, MP letter and email templates, talking points, one-to-one preparation and peer connection.

Advocacy is intentionally flexible. People may meet their local MP or Senator, write a letter, share their story, participate in media or social media, attend Head to the Hill, or advocate in another way that feels right for them.

Importantly, the program is not designed to end when people leave Parliament House. BTAA is building capability for year-round advocacy — supporting advocates to maintain relationships with their representatives, follow up after meetings, participate in future policy consultations and continue raising issues affecting the brain tumour community.

For parliamentarians, Head to the Hill provides something a conventional policy briefing cannot. The Australian Brain Cancer Landscape provides the evidence, data and national policy priorities. Head to the Hill introduces parliamentarians to the people represented by that evidence. Lived experience does not replace evidence — it gives the evidence context.

In 2026, advocates are connecting their individual experiences to shared national priorities across Research & Clinical Trials, Clinical Care and Support Services, creating a stronger and more consistent national voice. The longer-term legacy of Head to the Hill is therefore greater than one event.

BTAA is building a connected national network of informed lived-experience advocates who can continue bringing the brain tumour community's voice into decision-making throughout the year.



National Leadership and Collaboration

One sector. Shared priorities. Collective action.

The Australian Brain Tumour Collaborative (ABTC) was established in 2022 to create a national mechanism for organisations across the brain tumour community to work together on issues that no single organisation can solve alone.

Australia has strong organisations working across research, clinical trials, clinical care, patient and family support, advocacy and philanthropy. Historically, much of that work has developed within individual organisations and areas of expertise.

The Collaborative brings those perspectives together.

Its purpose is not to replace the work of its members, but to help them identify shared national priorities, develop collective positions and coordinate action across the brain tumour landscape.

The principle underpinning the Collaborative is straightforward:

No single organisation, however capable, can alone deliver the systemic change required to improve outcomes for people affected by brain tumours.

In 2026, the Collaborative strengthened its governance by consolidating its original Memorandum of Understanding, Governance Framework and Terms of Reference into a single National Compact and Governance Framework.

This reflects the evolution of the ABTC from an emerging partnership into a more established mechanism for national sector collaboration.

A cross-section of the whole brain tumour system

The strength of the ABTC lies in the breadth of perspectives around the table. Its membership spans:

- consumer advocacy
- patient and family support
- philanthropic research funding
- clinical research
- clinical trials
- specialist clinical leadership

Together, these perspectives reach across the full brain tumour continuum — from research discovery and clinical trials through diagnosis, treatment, survivorship, palliative care and family support.

This enables the Collaborative to see connections, gaps and hand-offs that may not be visible from within a single part of the system.

A research organisation sees the research environment.

A clinical group sees the care pathway.

A support organisation sees the family experience.

The Collaborative brings those perspectives together to understand the system as a whole.

A shared vision

The Collaborative's vision is a connected, coordinated and compassionate national brain tumour system in which Australians can access evidence-based care, support and research opportunities regardless of where they live.

That vision reflects an important principle: excellence in brain tumour research, clinical care and support should not be determined by postcode, age, tumour type or socioeconomic circumstance.

The ABTC therefore exists not simply to bring organisations together, but to create the conditions for more coordinated national action.

How the Collaborative works

The ABTC is a collaborative partnership, not a separate service organisation or corporate entity.

Member organisations remain autonomous. They retain their own identity, governance, mandate, programs and supporters.

The Collaborative provides the structure through which those organisations can work together where their interests and priorities intersect.

The model is deliberately designed to enable collective action without requiring organisations to give up their independence.

The ABTC seeks consensus wherever possible. Where consensus cannot be reached, each member organisation has one vote and decisions require 75 per cent support of members present.

Membership is open to national not-for-profit organisations and peak bodies working across the brain tumour landscape. Other stakeholders — including clinicians, researchers, universities, hospitals and other organisations — can contribute through consultations, advisory groups and collaborative initiatives.

The Collaborative and BTAA

The roles of the ABTC and BTAA are complementary.

The Collaborative coordinates. It creates the mechanism through which autonomous organisations can discuss evidence, identify common priorities and develop shared positions.

BTAA represents and advocates. It carries those priorities into sustained engagement with government and the broader health system and maintains continuity between consultations, funding decisions and policy cycles.

A strong Collaborative requires a peak advocacy body capable of carrying agreed priorities forward.

A credible peak body, in turn, is strengthened by a sector that has already done the work of building consensus.

Why collaboration matters

A coordinated sector creates value beyond the organisations involved.

For government, it provides a clearer counterpart for policy development and implementation.



One considered position

Where organisations have already worked through different perspectives and reached agreement, government receives a clearer proposition rather than multiple overlapping or competing requests.



Better-informed advice

Positions developed through the Collaborative can be tested across research, clinical trials, clinical care, support and consumer perspectives before they are advanced nationally.

This means advice is informed by the people and organisations likely to be affected by — or required to implement — the resulting decisions.



A stronger implementation partner

National initiatives are more likely to succeed when the organisations and people required to support their delivery have been involved in their development.

The Collaborative provides a mechanism through which new ideas can be discussed, tested, socialised and refined across the sector.



Reduced fragmentation

A coordinated sector reduces duplication and makes it easier to identify where organisations can work together rather than separately.

The current ABTC model was designed specifically to create that kind of national coordination.

Collaboration in action

The value of the Collaborative is increasingly visible in the work being undertaken across the three pillars of this Landscape.

In Research & Trials, the ABTC has moved beyond identifying fragmentation as a problem and has developed a formal proposition for shared national research governance.

In March 2026, the Collaborative submitted a proposal for a Joint Governance Partnership with the Australian Government, centred on a Joint Steering Committee that would co-design a national brain cancer research and trials roadmap. Importantly, the proposal focuses on priority-setting and governance rather than fund-holding, preserving government authority over funding decisions and peer review.

In Clinical Care, the Collaborative is also being used as a mechanism for sector-led co-design. Within the community-designed navigation initiative described in Pillar Two, the ABTC convenes member organisations, ensures broad representation and endorses the delivery options that emerge, while clinicians and consumers participate directly through project governance.

These examples illustrate the role the Collaborative is intended to play: bringing the sector together before solutions are finalised, so national initiatives are shaped by the people and organisations that understand the problem from different parts of the system.

What the collaborative is - and what it is not

- ☐ The ABTC is not a new service provider.
- ☐ It does not replace its members, compete with their programs or seek to centralise their work.
- ☐ It does not hold government research funding on behalf of the sector or make individual grant decisions.
- ☒ Its role is to create a trusted structure for coordination, consensus, co-design and collective action.
- ☒ Member organisations remain independent.
- ☒ The value lies in what becomes possible when those organisations choose to act together.
- ☐ Collaboration is not the outcome. It is the mechanism that makes coordinated national action possible.

Meet the Collaborative

The Australian Brain Tumour Collaborative brings together organisations contributing across research, clinical trials, clinical care, advocacy, philanthropy and patient and family support.

Together, its members form a cross-section of the Australian brain tumour landscape from laboratory research and clinical trials through specialist clinical practice to the experience of patients and families navigating life after diagnosis.



Robyn Strong
Chief Executive Officer



Ginta Orchard
Executive Officer



Craig Cardinal
Chair



Rebecca Mallett
Founder



Professor Hui Gan
Chair



Dr Kim Wark
Head of Research



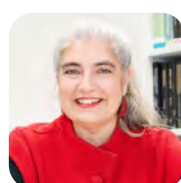
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