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Proposal for the Establishment of the Australian Brain Cancer Care Coordinator Framework

Senator Catryna Bilyk
PO Box 6100
Senate
Parliament House
Canberra ACT 2600

Dear Senator Bilyk

This letter serves as our formal proposal to establish the Australian Brain Cancer Care Coordinator (BCCC) framework, as discussed at Australian Parliament House on 20 November 2024 between yourself, Paul Metcalfe, Assistant Minister Ged Kearney and staff, and representatives of the Australian Brain Tumour Collaborative (ABTC).

On behalf of the Australian brain cancer community, the ABTC is seeking government funding to implement a national BCCC framework that will provide critical, much-needed support for Australian brain cancer patients and their families. For over a decade—the community has been requesting government funding for this critical initiative, dating back to 2011.

The exclusion of brain cancer from the Australian Cancer Nurse Navigator Program (ACNNP) has significantly impacted an already struggling community. Since the announcement of that program in November 2023, the ABTC has continuously engaged with government representatives, departments, and key stakeholders to rectify this omission.

Extensive qualitative and quantitative data highlight the devastating impacts of brain cancer—impacts that are disproportionate to those associated with many other cancers currently receiving substantial government funding. Government and departmental representatives involved in the implementation of the ACNNP have consistently acknowledged the unique, significant, and complex challenges of brain cancer. They have also noted that while brain cancer should ideally be funded through such programs, the current framework does not adequately address its complexities and a dedicated model for brain cancer is required.

Disappointingly, unlike many other cancers, the Australian brain cancer community has never received funding for survivorship supports. The ABTC and the broader Australian brain cancer community

remain resolute in our commitment to secure the necessary government funding to support these patients and their families.

On behalf of all current and past patients and families, we respectfully ask the government to commit to funding this initiative as a priority and provide the critical support our community urgently needs.

Yours sincerely,

Craig Cardinal

Chair Australian Brain Tumour Collaborative
Chair Brain Tumour Alliance Australia

About Us

In October 2021, the Chair and committee members from the Brain Tumour Alliance Australia met with Minister Greg Hunt and Shadow Minister Mark Butler. The objective was to understand how the brain cancer community could best inform government of the needs of brain cancer patients and families.

Shadow Minister Butler's advice was to be united in your voice to government and help enable them to confidently make decisions that best reflect the need of that community. Subsequently, the Australian Brain Tumour Collaborative (ABTC) was formed in December 2022.

The ABTC was established in December 2022 to nationally advocate for brain cancer patients, their families and their carers. The ABTC seeks changes in government policy and action to minimise the significant challenges faced by patients, their families and carers from date of diagnosis and throughout the survivorship journey.

The Collaborative's objectives are:

- Identify and promote **understanding of key gaps in services** and support for people impacted by brain tumours.
- Promote **integration, partnerships and information sharing** within the national brain tumour sector that better supports people impacted by brain tumours.
- Promote **patient-centred solutions to** challenges associated with the survivorship journey for people living with brain tumours, drawing on evidence-based research and lived experience.
- Individually and collectively advocate for **better access to service coordination and ongoing supports** for people with brain tumours, their families and carers.
- Continued **funding for research and clinical trials to** enable and accelerate better prevention, treatment and care.

The ABTC recognises and supports the individual objectives and achievements of all Australian brain tumour support providers and stakeholders, and seeks the enhancement of current critical initiatives, such as the Australian Brain Cancer Mission.

The Collaborative's nine founding member organisations are:

BRAIN TUMOUR ALLIANCE AUSTRALIA Inc.

Cure Brain Cancer Foundation

The Brain Cancer Group

peace of mind foundation

MARK HUGHES FOUNDATION

COGNO COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

the brain cancer centre MANY MINDS. ONE FOCUS. | Founded by Carrie's Beanies 4 Brain Cancer

PoCoG Psycho-oncology Co-operative Research Group

RCD The Robert Connor Dawes Foundation

1. Executive Summary

Brain cancer is one of Australia's most challenging and devastating diseases, affecting nearly 2,000 individuals annually across diverse age groups and tumour types. Despite its complexity—including varied clinical presentations, common rapid progression, and significant psychosocial impact—brain cancer has historically received limited research funding and insufficient support services. Our submission outlines the establishment of a National Brain Cancer Care Coordinator (BCCC) Model designed to:

- **Improve Patient Outcomes:** Deliver timely, seamless, and coordinated care across the entire brain cancer trajectory—from diagnosis through palliative care and bereavement support.
- **Enhance Quality of Life:** Reduce the frequency of emergency department (ED) presentations and hospital admissions through proactive care management.
- **Achieve Economic Efficiency:** Generate significant cost savings by reducing acute care utilisation and streamlining care delivery.
- **Promote Equitable Access:** Extend specialist care coordination into regional and rural communities, overcoming the current "postcode lottery."

We are requesting a funding allocation of **$8.75 million** over three years. Our proposal is underpinned by robust evidence from clinical studies, retrospective cohort research, and comprehensive scoping reviews in neuro-oncology care coordination.

2. Introduction and Background

2.1 The Challenge of Brain Cancer

Brain cancer presents a unique and multifaceted challenge, significantly impacting patients, families, and healthcare systems. The complexities of the disease require a comprehensive approach to treatment and support.

Key Challenges:

Heterogeneity of Tumour Types

- There are over 100 distinct brain tumour types, requiring individualised approach to diagnosis and treatment.

Complex Clinical Course

- Patients can experience a range of severe physical symptoms along with:
    - Neurological impairments
    - Cognitive decline
    - Psychological distress
    - Disruptions to daily functioning

Low Survival Rates

- The five-year survival rate for brain cancer is only 23%.
- Patients can face rapid deterioration and or long-term significant disabilities and impairments after diagnosis.

Emotional and Social Burden

- A brain cancer diagnosis imposes a significant emotional toll, patients, families and carers. The diagnosis and progression of the disease often leads to social and financial toxicity.

2.2 The Urgent Need for Brain Cancer Support and Survivorship Funding

Brain cancer's devastating impact highlights the critical need for increased funding for research, support services, and survivorship programs.

Key Reasons for Urgent Investment:

High Mortality Rates

- Brain cancer is the leading cause of disease-related deaths in children.
- It is one of the leading causes of overall child deaths, following land transport accidents and perinatal conditions.
- More people under 40 die from brain cancer than from any other cancer.

Lack of Progress in Survival Rates

- Over the past 40 years, survival rates have increased by only 1.5%.
- Brain cancer remains one of the deadliest cancers, requiring urgent medical advancements.

Economic and Healthcare Burden

- One of the highest total cost disease burdens.
- The disease results in significant disabilities and impairments, creating long-term healthcare demands.
- The National Disability Insurance Scheme (NDIS) funding for brain cancer patients is 4-5 times higher than the standard disability support package.

Impact on Daily Life

- Most brain tumour patients lose the ability to drive or work shortly after diagnosis and the start of treatment.
- Patients face significant difficulties navigating the healthcare system due to the cognitive and physical impairments caused by the disease and its treatments.
- Brain cancer care requires highly complex allied health support, often involving multiple specialist services.

2.3 Cost Burden of Brain Cancer in Australia (Example – IDH-mutant glioma)

Brain cancer has an exceptionally high-cost burden on patients, families, and society. Extensive contemporary research, funded by Servier and conducted by Evohealth, specifically analysed the impact of IDH-mutant glioma, can be low- or high-grade brain cancer primarily affecting people aged 20-45 years. The findings demonstrate a devastating economic and social toll:

Burden on Patients & Families

- **Years of life lost (2024 estimates):**
    - 9,125 years of life lost, with an average of 22 years lost per person due to premature death.
    - 3,715 years of healthy life lost due to disability.
    - 12,840 total disability-adjusted life years (DALYs) lost annually.
- **Financial burden per household:** $53,460 per year, covering medical costs, lost income, and care expenses.

Economic Cost to Society

- **Total societal cost:** Estimated at $3.5 billion annually (or $1.1 million per person per year).
- **Productivity loss due to inability to work:**
    - Patients: $74.8 million per year in lost income.
    - Carers: $71.6 million per year due to reduced work capacity.

Policy Implications

These figures only reflect one specific type of brain cancer and do not account for the cost burden of other more common brain cancers, highlighting the urgent need for targeted and immediate government action.

2.4 Gaps in the Current System

Despite the seriousness of brain cancer:

- **Limited Specialist Roles:** Only 29 Brain Cancer Care Coordinators (BCCCs) (approximately 20.6 full-time equivalents) are available nationwide, predominantly in urban centres. This equates to approximately 1 BCCC every 69 patients.
- **Fragmented Service Delivery:** The absence of standardised roles and protocols forces patients and carers to navigate a complex, disjointed system.
- **Underinvestment:** Brain cancer receives less than five percent of overall Commonwealth cancer research funding.
- **Incomplete Continuity:** Existing care coordination models largely focus on acute treatment phases, neglecting comprehensive support through recurrence, palliative care, and bereavement.

2.5 Disparities in Funding Compared to Other Cancers

- **Breast cancer:** ~20,000 diagnoses per year, ~3,200 deaths per year, and consistently receives high levels of funding for survivorship.
- **Prostate cancer:** ~24,000 diagnoses per year, ~3,400 deaths per year, and receives substantial survivorship funding.
- **Brain cancer:** Has only ~8-10% of the diagnoses of breast and prostate cancer, yet accounts for ~45% of their total deaths—and has **never received dedicated survivorship funding that provide critical care coordination supports**.

3. Proposal Overview

3.1 Objectives

The National BCCC Model is designed to:

- **Improve Clinical Outcomes:** Reduce unnecessary ED visits and hospital admissions.
- **Ensure Continuity of Care:** Provide integrated, multidisciplinary support throughout the entire brain cancer journey.
- **Empower Patients and Carers:** Offer individualised education, resource navigation, and emotional support.
- **Enhance Healthcare Efficiency:** Streamline care processes to generate significant cost savings.
- **Address Geographic Inequities:** Extend specialist care coordination into under-resourced regional and rural areas.

3.2 Model Structure and Implementation Strategy

- **Dedicated Role:**
  - BCCCs will be experienced clinicians (nurses, social workers, neuropsychologists, or occupational therapists) with specialised training in neuro-oncology care coordination.
  - Each patient will be assigned a dedicated BCCC who serves as their single point of contact throughout the care continuum.
- **Integrated Multidisciplinary Approach:**
  - Regular communication among neurosurgeons, oncologists, palliative care specialists, allied health professionals, and primary care providers.
- **Geographic Coverage:**
  - Establish central hubs in major cities with satellite centres in regional areas.
- **Alignment with National Strategies:**
  - The proposed model complements the Australian Cancer Plan and fills gaps identified in existing initiatives such as the ACNNP.
- **Phased Implementation:**
  - A pilot phase will precede a gradual, nationwide rollout.

4. Research and Literature Review

4.1 Evidence on Cancer Care Coordination in Oncology

Research in oncology demonstrates that:

- **Enhanced Access and Adherence:** Dedicated care coordinators improve treatment access, reduce delays, and enhance follow-up adherence.
- **Improved Patient Experience:** Patients report reduced anxiety and increased confidence when supported by a dedicated coordinator.
- **Cost Efficiency:** Coordinated care models lower healthcare costs through reduced ED visits and shorter hospital stays.
- **Multidisciplinary Integration:** Care coordinators facilitate communication among specialist teams, leading to more cohesive care delivery.

4.2 Findings from the Hunter New England Study

A retrospective cohort study conducted in the Hunter New England Local Health District (HNELHD) revealed:

- **Comparable Survival Rates:** Median overall survival was 12.0 months (pre-BCCC) versus 11.16 months (post-BCCC).
- **Reduced Acute Care Utilisation:**
  - ED presentations per patient decreased from 4.4 to 3.1.
  - A 24% reduction in the aggregate length of hospital stay.
- **Economic Impact:**
  - Estimated annual healthcare savings of over $167,000.
  - After coordinator costs, net annual savings of approximately $4,410 were achieved.

4.3 Insights from the Jeon et al. Scoping Review

The scoping review “Identifying components of care coordination for primary brain tumour: a scoping review” by Jeon et al. highlights:

- **Predominance of Nurse-Led Models:** Most current care coordination models are nurse-led and situated in tertiary centres.
- **Core Components:** Essential elements include system navigation, regular psychosocial assessments, tailored information provision, and timely referrals.
- **Continuity Gaps:** There is a need for models that span the entire disease trajectory, particularly during recurrence, palliative care, and bereavement.
- **Facilitators and Barriers:** Successful coordination requires dedicated staff, standardised protocols, and robust documentation systems, while resource limitations and fragmented care remain significant challenges.

5. Components and Operational Elements of the Proposed Model

5.1 Key Activities and Role Functions

The proposed model will integrate:

- **Single Point of Contact:** Each patient will have a dedicated BCCC responsible for coordinating all aspects of their care.
- **Healthcare System Navigation:** BCCCs will assist with scheduling, referrals, and ensuring seamless transitions between care settings.
- **Psychosocial Assessment and Screening:** Regular assessments using standardised tools will help monitor patient distress and unmet needs.
- **Information and Education:** Tailored education will be provided regarding diagnosis, treatment options, and available support services.
- **Referral and Coordination Management:** Timely referrals to allied health services, palliative care, and community resources will be coordinated.
- **Multidisciplinary Coordination:** BCCCs will participate in regular MDT meetings to update and refine care plans.
- **Continuity Across the Disease Trajectory:** The model will provide support from diagnosis through acute treatment, recurrence management, palliative care, and bereavement.

5.2 Facilitators and Barriers to Effective Care Coordination

Facilitators:

- A dedicated, well-trained workforce with strong communication and interpersonal skills.
- Standardised protocols and checklists to guide coordination activities.
- Regular MDT meetings and integrated electronic medical records (EMRs) that facilitate seamless information sharing.

Barriers:

- Funding instability and staffing shortages, particularly in regional and rural areas.
- Fragmented care delivery and inconsistent documentation practices.
- Limited training resources and a lack of standardised outcome measures.

6. Economic Analysis and Health Service Impact

6.1 Reduction in Health Service Resource Utilisation

Effective care coordination is expected to lead to:

- **Fewer ED Presentations:** Proactive symptom management reduces crisis-driven emergency visits.

- **Shorter Hospital Admissions:** Streamlined coordination facilitates timely discharges.
- **Prevention of Service Duplication:** Improved integration minimises unnecessary tests and repeated consultations.

6.2 Cost Savings and Cost-Offset Analysis

- **Direct Economic Benefits:**
    - Savings of approximately $1,200 per patient in ED costs and $5,500 per inpatient admission.
- **Aggregated Annual Savings:**
    - An estimated reduction of over $167,000 in healthcare expenditures across the patient population.
- **Net Savings:**
    - After accounting for coordinator salaries and related expenses, the model is projected to yield net annual savings of approximately $4,410 (based on study estimates).
- **Long-Term Efficiency:**
    - Reduced acute care utilisation and improved continuity of care are expected to yield additional downstream savings.

7. Implementation Plan and National Strategic Framework

7.1 Pilot Phase Details

- **Site Selection:** Select a mix of metropolitan and regional pilot sites to evaluate the model's effectiveness across diverse settings.
- **Data Collection and Monitoring:** Utilise integrated EMRs and REDCap for real-time data capture.
- **Stakeholder Engagement:** Involve patients, carers, healthcare providers, and local health authorities in pilot design and evaluation.
- **Key Performance Indicators (KPIs):** Track metrics such as ED visits, hospital admissions, patient satisfaction, and cost savings.

7.2 Recruitment, Onboarding, and Training of BCCCs

Recruitment
Our goal is to build a robust workforce over three years with a target of 23 BCCCs by Year 3, using the full personnel budget. We plan as follows:

- **Year 1 – 30% of Final Target:**
    - **Target:** Recruit 7 BCCCs (approximately 30% of 23).
    - **Annual Cost:** 7 × $150,000 = **$1,050,000**.
- **Year 2 – 70% of Final Target:**
    - **Target:** Expand to a total of 16 BCCCs.
    - **Annual Cost:**
        - Continuing 7 from Year 1: 7 × $150,000 = $1,050,000
        - New recruits: 9 × $150,000 = $1,350,000
        - **Total for Year 2:** $1,050,000 + $1,350,000 = **$2,400,000**.
- **Year 3 – 100% of Final Target:**
    - **Target:** Expand to a total of 23 BCCCs.

- **Annual Cost:**
  - Continuing 16 from Year 2: 16 × $150,000 = $2,400,000
  - New recruits: 7 × $150,000 = **$1,050,000**
  - **Total for Year 3:** $2,400,000 + $1,050,000 = **$3,450,000**.

Cumulative Personnel Costs Over 3 Years:

- **Year 1:** $1,050,000
- **Year 2:** $2,400,000
- **Year 3:** $3,450,000
- **Total:** $1,050,000 + $2,400,000 + $3,450,000 = **$6,900,000**

7.3 National Strategic Initiatives

To ensure a comprehensive and sustainable model, we will implement the following strategic steps:

1. **Establish a National Working Group:**
   - Form a multidisciplinary panel including experts in neuro-oncology, patient advocacy, government, and healthcare administration to guide the initiative.
2. **Co-design a National Model of Brain Cancer Care Coordination:**
   - Develop tumour and age-appropriate pathways.
   - Integrate with the ACNNP.
   - Ensure public, private, and care integration.
   - Achieve regional access equity.
   - Establish robust data collection and sharing systems.
   - Incorporate psychosocial and peer supports for BCCCs.
   - Develop comprehensive education and training programmes.
3. **Site Mapping and Capacity Assessment:**
   - Evaluate potential sites for integration, outreach capability, access to specialised services, and flexibility in service delivery.
4. **Define and Standardise Workforce Competencies:**
   - Establish core competencies and expertise for BCCCs.
   - Ensure early involvement and continuity of care.
   - Develop clear career pathways to attract and retain talent.
5. **Develop a Governance and Implementation Plan:**
   - Set up program governance and standards.
   - Secure sustainable funding and administrative support.
   - Establish robust monitoring and evaluation mechanisms.

7.4 National Rollout Strategy

- **Phased Expansion:** Following a successful pilot, we will gradually scale the model nationwide.
- **Policy Integration:** Ensure alignment with the Australian Cancer Plan and other national health initiatives.
- **Sustainability Measures:** Develop long-term strategies for funding, training, and workforce retention.

- **Communication and Reporting:** Provide regular updates and progress reports to all stakeholders.
- **External Evaluation:** Engage independent evaluators to assess the model's effectiveness and impact.

8. Budget and Funding Requirements

The total funding request is **$8,750,000** over three years. Below is the summary breakdown:

Category	3-year Total	Annual Breakdown	Notes
Personnel Costs for BCCC	$6,900,000	Year 1 = $1,050,000 – 7 x BCCC **(7 total)**	Funds the recruitment onboarding, and progressively expanding workforce – targeting 23 BCCC's by year 3
		Year 2 = $,2,400,000 /+ 9 x BCCC **(16 total)**	
		Year 3 = $3,450,000/+ 7 x BCCC **(23 total)**	
Project & Operational Costs	$1,850,000	Approximately $616,667 per year	Covers recruitment and onboarding, training and professional development, IT/Infrastructure, Project Management, governance and national strategic initiatives.
Total Funding	**$8,750,000**	Approximately $2,916,667 per year	Establishment of national BCCC Framework

9. Monitoring, Evaluation, and Quality Assurance

To ensure the success and sustainability of the National BCCC Model, we propose:

- **Key Performance Indicators (KPIs):**
  - Reduction in ED presentations and hospital admissions.
  - Improvement in patient and carer satisfaction scores.
  - Measurable cost savings and resource efficiencies.
- **Regular Reporting:**
  - Quarterly and annual progress reports to be submitted to all stakeholders.
- **Independent Evaluation:**
  - Engage external evaluators to assess the model's impact, efficiency, and sustainability, with findings disseminated through peer-reviewed publications and policy briefs.
- **Continuous Quality Improvement:**
  - Regular feedback sessions with BCCCs, patients, carers, and care teams.

- Ongoing adjustments to training, protocols, and care pathways based on evaluation outcomes.

10. Conclusion and Call to Action

Brain cancer remains one of the most challenging diagnoses in Australia, with profound impacts on patients, families, and the healthcare system. While care coordination may not directly extend survival, its substantial benefits in reducing acute care utilisation, improving quality of life, and achieving significant cost savings are undeniable. The compelling evidence from the Hunter New England study and the comprehensive insights from the Jeon et al. scoping review provide a robust rationale for establishing a National Brain Cancer Care Coordinator Model.

We urge the Commonwealth Government to invest in this transformative initiative. With your support, every Australian with brain cancer patient will receive coordinated, high-quality, and compassionate care throughout their disease journey—regardless of geographic location. This investment will not only transform individual lives but also contribute to a more efficient, equitable, and sustainable healthcare system.

Thank you for your time and consideration. We welcome the opportunity to discuss this proposal further and provide any additional information required.

11. Supporting Documents (attached)

- *Navigating the Unknown – A call for nationwide Brain Cancer Care Coordination*
- *The impact of brain cancer care coordinators on healthcare utilisation and outcomes in patients with glioblastoma*
- *Invisible Brain Cancers – Living with the social and economic impact of IDH-mutant glioma (embargoed Confidential copy awaiting publication – controlled hardcopy version only)*
- *Identifying components of care coordination for primary brain tumour: a scoping review*