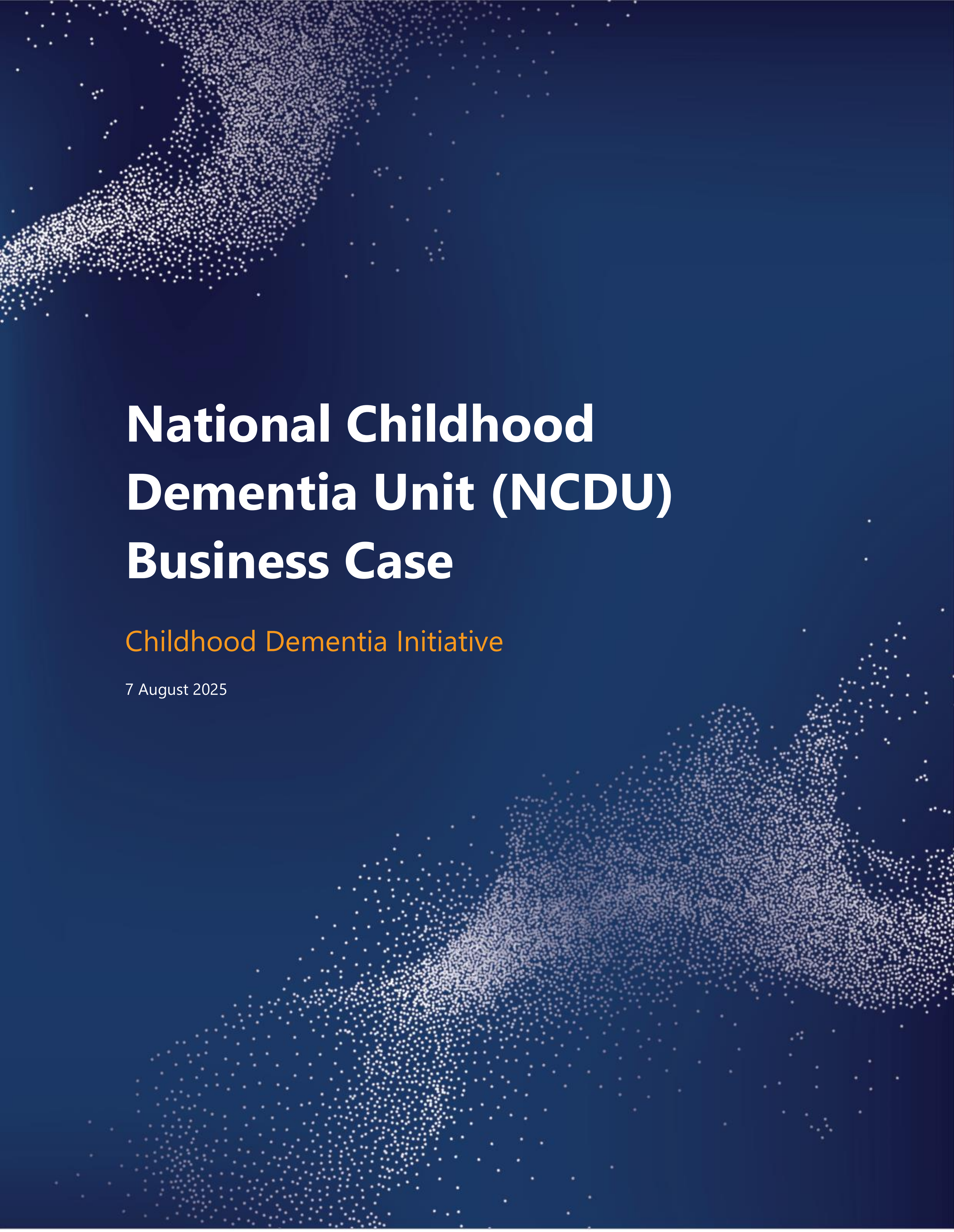

National Childhood Dementia Unit (NCDU) Business Case

Childhood Dementia Initiative

7 August 2025

Contents

1 Executive Summary

Childhood dementia affects 1 in every 2,900 births in Australia, yet children with dementia and their carers face fragmented care and limited access to therapies

Childhood dementia results from progressive brain damage and is caused by over 145 rare, progressive and life-limiting genetic conditions that affect approximately 1 in every 2,900 births in Australia. These conditions are inheritable, meaning some carers may have more than one affected child. Tragically, 50 per cent of children with dementia die before the age of 10, and 70 per cent before adulthood.

Symptoms typically include regression in communication and comprehension, sleep disturbances, mobility issues and behavioural challenges. These children require complex, non-linear care across health, disability, education, psychosocial and palliative services. Despite the severity and prevalence of childhood dementia, there has been little recognition or investment in this cohort, resulting in fragmented care and poor outcomes.

Childhood Dementia Initiative (CDI), founded in 2020, has led national efforts to raise awareness and improve care for children with dementia. CDI takes a world-first approach by considering all conditions that cause childhood dementia collectively, advocating for system-wide reform and policy change. Australia is now a global leader in recognising childhood dementia as a distinct cohort and effecting system change.

The childhood dementia cohort faces significant challenges accessing adequate, continuous and equitable care

Children with dementia and their carers face significant challenges navigating Australia's health system. Care is fragmented, reactive and inequitable. Children often undergo repeated assessments and experience significant delays in diagnosis that result in missed therapeutic windows. After diagnosis, carers are left to navigate disconnected systems without guidance, leading to gross inequities in care access. Many carers feel like they are managing care reactively and rely on emergency services for issues that could have been managed earlier.

Access to emerging therapies is also limited. Despite an increasing number of innovative gene therapies and N-of-1 trials being conducted internationally, Australia lacks the infrastructure, data visibility and clinical trial capacity to support innovation in childhood dementia treatment. Compared to childhood cancer, which causes a similar number of deaths each year, childhood dementia receives 4.6 times less funding per patient and has 43 times fewer clinical trials recruiting per patient in Australia. Fewer than 2 per cent of children with dementia have access to innovative treatments, compared to universal access for children with cancer. This has meant survivorship for childhood dementia has not significantly improved in the last two decades.

Awareness and expertise among health professionals is low. There is no guidance anywhere for childhood dementia care provision, and while some conditions might have guidelines others have nothing, and there is no nationally consistent or coordinated approach. Diagnostic delays are common. Children and carers often wait years for a diagnosis, attending dozens of appointments with different specialists. This diagnostic odyssey is inefficient and traumatising. Children are exposed to unnecessary procedures and medications due to misdiagnoses, while carers are left without support.

Carers, often mothers, bear the brunt of this burden. This can have knock on impacts to mental health and drives heightened levels of anxiety, grief and financial stress. They are often left to research treatments, coordinate care and educate providers independently, regularly repeating their child's story across settings in the absence of data and information sharing. Many carers leave the workforce entirely, contributing to gendered economic disparities. Children and carers in regional areas face additional barriers due to limited local expertise and resources.

The National Childhood Dementia Unit (NCDU) and this business case

This business case proposes the establishment of the National Childhood Dementia Unit (NCDU), a virtual centre of expertise to transform care, equity and outcomes for children with dementia and their carers.

In an increasingly complex care landscape and rapidly advancing research and therapies, the need for consistency and coordination has never been greater. The NCDU responds to this need by providing a nationally coordinated, virtual centre that embeds specialist expertise, standardises care and improves access to emerging therapies and data.

> The NCDU has two primary objectives:
>
> 1. Improve **survivorship and symptom management** for children with dementia through accelerated access to therapy and therapeutic development.
> 2. Provide **equitable access to timely, consistent and quality care and support** for children with dementia and their carers.

The four core components presented in this business case are:

1. **Model of Care:** A nationally standardised, evidence-based framework for diagnosis, treatment and support. It will cover the entire care pathway, including genetic counselling, clinical trials, end-of-life planning, and bereavement and beyond. The model will be hosted online and supported by tailored training resources. It will define roles and responsibilities across sectors and be embedded into services through education and promotional outreach to representatives from health services and jurisdictional bodies. **This will improve consistency, quality and equity of care for children with dementia, by addressing critical gaps in guidance for care providers.**
2. **National Reference Centre:** A virtual hub of expertise, guidance and support to build capacity among health professionals treating children with dementia. The centre will comprise multidisciplinary experts and host online regular forums to discuss complex cases and share best practices. It will also lead webinars, contribute to research and policy, and contribute to a digital platform for knowledge sharing. To ensure accessibility across Australia this reference centre will be delivered virtually. **This will improve access to care and support quality care provision by building childhood dementia knowledge and capability among health professionals.**
3. **Therapy Access Hub:** A centralised service to identify and facilitate access to innovative therapies and clinical trials. It will proactively connect clinicians, researchers, pharmaceutical companies and government. Activities include stakeholder engagement and networking, horizon scanning and creating reports with information of research opportunities or clinical trial options for clinicians treating children with dementia tailored to their patient. **This will increase access to emerging therapies and treatments that may represent the only chance of improving survivorship for children with dementia by improving clinical trial readiness, supporting planning and recruitment and reducing burden on clinicians and carers to identify appropriate trials.**
4. **Patient Data Solution:** A secure data platform to support data collection and information sharing, and inform research, policy and care improvements in childhood dementia. This user-friendly platform will enable self-nominating carers and/or their chosen delegates to input and share data on their child or children with dementia. With consent, this data can be shared directly with other stakeholders to support clinical trial recruitment, care planning and policy development. **This will reduce the burden of care shouldered by parents by supporting centralised and accessible information sharing and provide vital evidence for childhood dementia cases in Australia. This will support clinical trial planning and recruitment and contribute to childhood dementia research.**

This business case outlines the design of the NCDU, as well as estimated costs and benefits, and steps for implementation. CDI will be responsible for the set-up and implementation of the NCDU, overseeing funding, planning and recruitment. Ongoing governance structures and reporting lines will be determined at a later time, once the NCDU is operational and its scope and funding is finalised.

Cost analysis

The estimated total cost of the NCDU over five years is $12.64 million, including a “year zero” for implementation and four years of ongoing operation. Costs are broken down as follows:

National Childhood Dementia Unit (NCDU)	$12.64 million over 5 years	Model of Care	$3.70 million
		National Reference Centre	$3.16 million
		Therapy Access Hub	$2.88 million
		Patient Data Solution	$2.74 million

The primary cost driver is staffing, with 7 FTE proposed across the components. Roles include a Head of NCDU, Therapy Access Lead, Model of Care Manager, Information and Support Manager, Education and Communications Manager, Clinical Intelligence Analyst, Reference Centre Coordinator and Data Registry Manager.

Indicative benefits

The NCDU is expected to deliver wide-reaching benefits of $61.49 million over four years across six key areas:

1. **Improve Care for Patients:** By embedding consistent, evidence-based practices, the NCDU will enable earlier intervention, better symptom management and more proactive care planning. This will reduce variation in treatment and improve health outcomes.
2. **Improve Support for Carers:** Structured guidance on care options, centralised information and dedicated support roles will reduce anxiety and save time for carers. Estimated benefits include:
    - $35.35 million in reduced anxiety
    - $14.90 million in time savings achieved through standardised care
    - $0.36 million in time savings achieved through streamlined diagnosis
3. **Improve Equity of Service Access:** The NCDU will make specialist expertise and therapies available nationwide, reducing geographic and systemic disparities.
4. **Improve Understanding of Childhood Dementia:** Improved data collection, therapy access and sector capacity will accelerate learning and inform policy and clinical decision-making.
5. **Improve Efficiency of Health Services:** Coordinated service delivery will promote more cost-efficient and proactive care delivery. Estimated benefits include:
    - $3.30 million in reduced unplanned emergency department visits
    - $7.13 million in reduced unplanned hospitalisations
    - $0.44 million in time savings for health professionals achieved through streamlined diagnosis
6. **Improve Experience of Health Professionals:** Access to expert advice, training and collaborative networks will enhance provider confidence, reduce burnout and improve job satisfaction.

Implementation considerations

The NCDU will be implemented over a 16-month period, with phased activities aligned to each component. Early engagement with stakeholders, targeted awareness and education and robust governance will be critical to success. Risks include limited adoption, low awareness and cybersecurity breaches, all of which have proposed mitigation strategies.

Performance measures will track uptake, impact and satisfaction across stakeholders. These include service usage data, patient outcomes, and qualitative feedback from carers and providers.

Conclusion

The NCDU represents a transformative opportunity to improve care, equity and efficiency for children with dementia and their carers. By taking a nationally coordinated approach, it will reduce inconsistencies, expand access to services and therapies and position Australia as a global leader in childhood dementia innovation.

Over the long term this will contribute to an increased understanding and awareness of childhood dementia conditions, advancements in treatments that enable significant improvements in health outcomes, including potentially survivorship, and a health service system that delivers fair outcomes for children with dementia and their carers through an informed and capable workforce. The next steps include securing funding, finalising governance structures and engaging stakeholders to co-design and implement the unit.

2 Background and context

2.1 Childhood dementia in Australia

Childhood dementia results from progressive brain damage and is caused by over 145 rare, progressive and life-limiting genetic conditions. [1] Together, these conditions affect approximately 1 in every 2,900 births in Australia. [2] Because many of these disorders are inherited, up to one in five families may have more than one child impacted. [3] Tragically, every child diagnosed with childhood dementia faces a shortened life and there are currently no known cures. Half of these children will die before the age of 10, and 70 per cent will not reach adulthood. [4]

Despite the diversity of conditions, childhood dementia presents with common symptoms due to progressive neurocognitive decline. [5] These symptoms span multiple domains and typically include regression of comprehension and communication skills, sleep disturbances, mobility issues and behavioural challenges. This means children with dementia have high, non-linear care needs and need access to health, disability, community, psychosocial, education and palliative care services over the course of their journey. [6, 7]

There has historically been little recognition of and investment in childhood dementia, driven in part by the lack of visibility for this underserved cohort. Until recently, conditions that cause childhood dementia have been considered in isolation, resulting in fragmentation and high levels of unmet need in the Australian paediatric health system.[8] Unlike childhood cancer – which has a similar annual mortality rate (around 91 deaths per year) – childhood dementia has seen no significant improvement in survival rates. [9] In contrast, childhood cancer now has an >80 per cent survivorship rate. [10]

Childhood Dementia Initiative (CDI) has been instrumental in advocating for the recognition of childhood dementia in national policy and research since its founding in 2020. The organisation aims to improve accessibility and quality of care for children with dementia across Australia, collaborating with policymakers, sector stakeholders and condition-specific organisations where they exist.

CDI adopts a world-first approach to collectively consider all childhood dementia conditions to drive meaningful system and policy change. This is especially critical in giving visibility to children with the rarest disorders who may otherwise lack representation. Their efforts have helped elevate Australia to the global leader in recognising the childhood dementia cohort collectively to realise system-wide change.[11]

Outlined below is a non-exhaustive snapshot of childhood dementia advocacy and research in Australia in recent years.

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[1] Elvidge, K., Christodoulou, J. Farrar, M. *et al.* The collective burden of childhood dementia: a scoping review. *Brain.* 20 July 2023. https://doi.org/10.1093/brain/awad242

[2] Ibid.

[3] HealthConsult for Childhood Dementia Initiative. *Childhood Dementia Care and Support Landscape: Pathway Toward Report (Pathway Toward Report).* 29 October 2024.

[4] Childhood Dementia Initiative. *State of Childhood Dementia in Australia 2024.* 2024

[5] Djafar, J., Smith, N., Johnson, A. *et al.* Characterizing Common Phenotypes Across the Childhood Dementia Disorders: A Cross-sectional Study From Two Australian Centers. *Paediatric Neurology.* December 2023. https://doi.org/10.1016/j.pediatrneurol.2023.09.006

[6] Ibid.

[7] *Pathway Toward Report.*

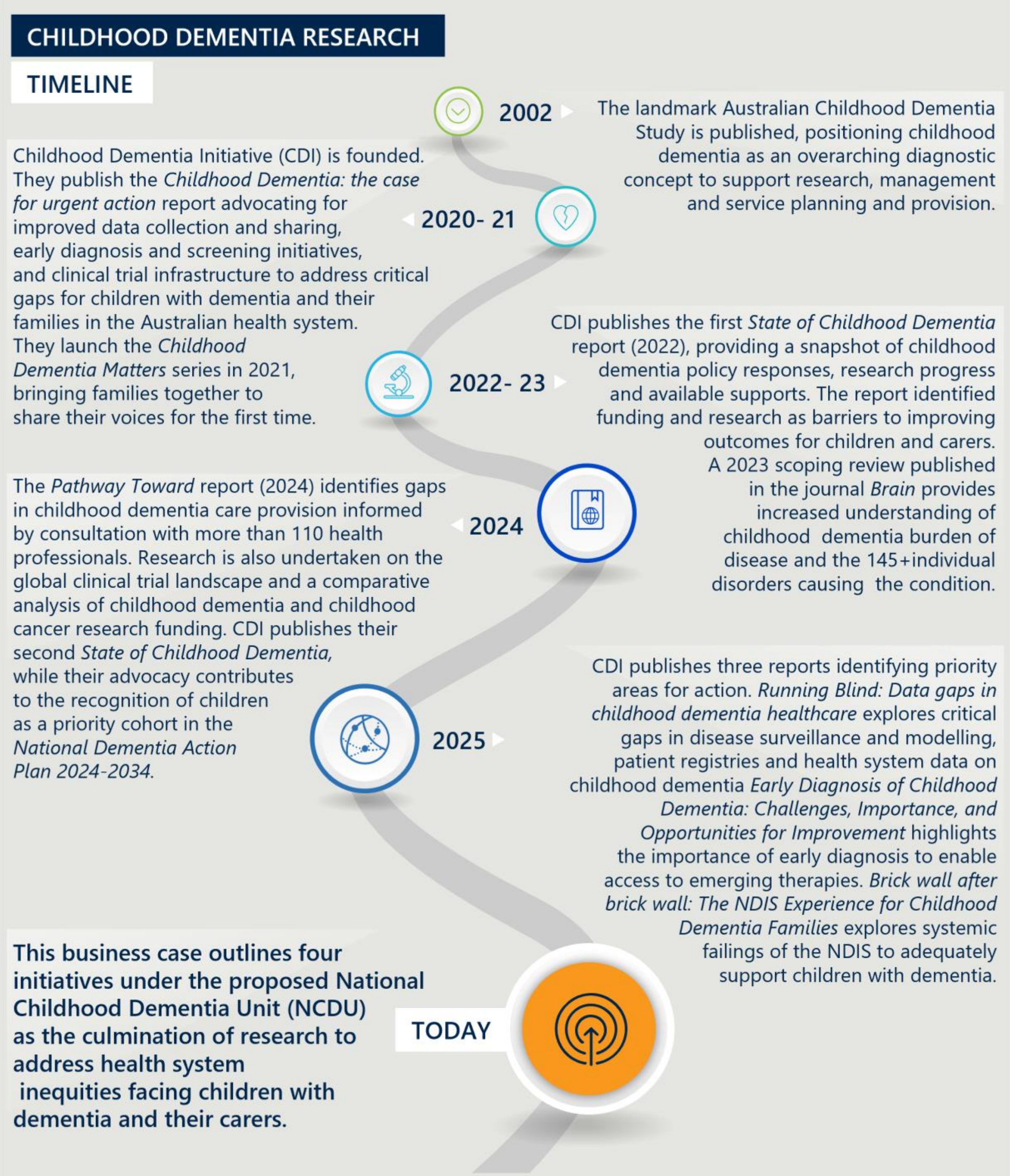
[8] *State of Childhood Dementia in Australia 2024.*

[9] *Pathway Toward Report*

[10] Childhood Dementia Initiative. *Australian Childhood Dementia Research Funding Report 2024 (Childhood Dementia Research Funding Report).* March 2024.

[11] *State of Childhood Dementia in Australia 2024.*

Figure 1 | Timeline of childhood dementia research and advocacy initiatives



CHILDHOOD DEMENTIA RESEARCH

TIMELINE

2002

The landmark Australian Childhood Dementia Study is published, positioning childhood dementia as an overarching diagnostic concept to support research, management and service planning and provision.

2020- 21

Childhood Dementia Initiative (CDI) is founded. They publish the *Childhood Dementia: the case for urgent action* report advocating for improved data collection and sharing, early diagnosis and screening initiatives, and clinical trial infrastructure to address critical gaps for children with dementia and their families in the Australian health system. They launch the *Childhood Dementia Matters* series in 2021, bringing families together to share their voices for the first time.

2022- 23

CDI publishes the first *State of Childhood Dementia* report (2022), providing a snapshot of childhood dementia policy responses, research progress and available supports. The report identified funding and research as barriers to improving outcomes for children and carers. A 2023 scoping review published in the journal *Brain* provides increased understanding of childhood dementia burden of disease and the 145+individual disorders causing the condition.

2024

The *Pathway Toward* report (2024) identifies gaps in childhood dementia care provision informed by consultation with more than 110 health professionals. Research is also undertaken on the global clinical trial landscape and a comparative analysis of childhood dementia and childhood cancer research funding. CDI publishes their second *State of Childhood Dementia,* while their advocacy contributes to the recognition of children as a priority cohort in the *National Dementia Action Plan 2024-2034.*

2025

CDI publishes three reports identifying priority areas for action. *Running Blind: Data gaps in childhood dementia healthcare* explores critical gaps in disease surveillance and modelling, patient registries and health system data on childhood dementia *Early Diagnosis of Childhood Dementia: Challenges, Importance, and Opportunities for Improvement* highlights the importance of early diagnosis to enable access to emerging therapies. *Brick wall after brick wall: The NDIS Experience for Childhood Dementia Families* explores systemic failings of the NDIS to adequately support children with dementia.

TODAY

This business case outlines four initiatives under the proposed National Childhood Dementia Unit (NCDU) as the culmination of research to address health system inequities facing children with dementia and their carers.

2.2 Developing this business case

To address the urgent and complex needs of children with dementia, CDI are proposing the establishment of a National Childhood Dementia Unit (NCDU). The NCDU is a virtual centre of expertise that would play a key role in advancing understanding and recognition of childhood dementia conditions, building capacity among health professionals and ensuring children with dementia have access to the care they need. The NCDU will include four key components, though it is expected initiatives will expand over time. These key components are:

1. Model of Care
2. National Reference Centre
3. Therapy Access Hub

4. Patient Data Solution.

CDI engaged Nous Group (Nous) to develop a business case for these four components. More than 50 stakeholders – including clinicians, researchers, policymakers, and carers – were consulted to shape the design of the NCDU. Their input informed a model that estimates both the costs and the potential benefits to children with dementia, their carers, and the broader health system.

This project adopted a four-stage approach to develop the business case, outlined in the figure below.

Figure 2 | Approach to the business case

STEP 01

Analysing challenges and opportunities

- Review of existing research to consolidate understanding of gaps in care provision.
- Consultation with representatives of comparable health initiatives.

STEP 02

Determining objectives and outcomes

- Defining NCDU component objectives and outcomes to address the challenges identified in the Discover phase.

STEP 03

Building component functions and features

- Development of NCDU solution design prototypes aligned to objectives defined in the previous phase.

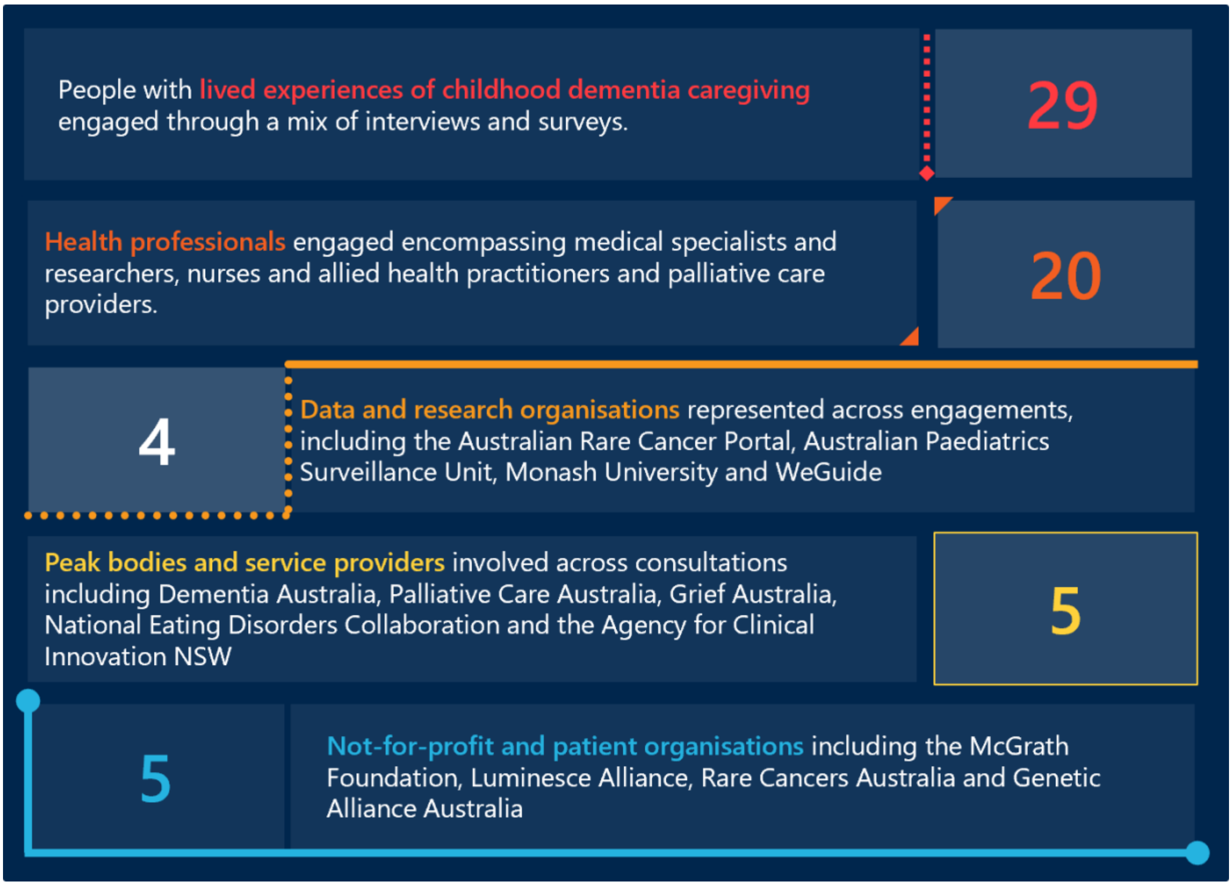
STEP 04

Developing the business case

- Testing and refining with feedback from stakeholders.
- Solution modelling and analysis.

A broad and diverse group of stakeholders contributed to the design of the NCDU, helping to build a strong evidence base for the business case. Their insights were gathered through more than 40 engagement sessions involving close to 50 participants, including:

Figure 3 | Project engagements



29 People with **lived experiences of childhood dementia caregiving** engaged through a mix of interviews and surveys.

20 **Health professionals** engaged encompassing medical specialists and researchers, nurses and allied health practitioners and palliative care providers.

4 **Data and research organisations** represented across engagements, including the Australian Rare Cancer Portal, Australian Paediatrics Surveillance Unit, Monash University and WeGuide

5 **Peak bodies and service providers** involved across consultations including Dementia Australia, Palliative Care Australia, Grief Australia, National Eating Disorders Collaboration and the Agency for Clinical Innovation NSW

5 **Not-for-profit and patient organisations** including the McGrath Foundation, Luminesce Alliance, Rare Cancers Australia and Genetic Alliance Australia

A full list of the stakeholders engaged can be found in Appendix A.

2.3 Limitations and exclusions

While all efforts have been made to ensure this document provides a considered analysis of potential impacts of the NCDU, it is important to note the following limitations:

- **The funding source for the NCDU is currently unknown** – this report aims to capture the general case for change, costs, benefits, and implementation considerations for the NCDU. These elements may require tailoring to match the criteria and needs of a funding source.
- **There is insufficient data for 'base case' analysis** – there is not enough data available to complete a thorough analysis of the health system utilisation and costs associated with childhood dementia. The NCDU cost estimates do not consider additional costs to the health system and other government funded services from patient interventions promoted by the NCDU.
- **There is insufficient data for a cost-benefit or cost-utility analysis** – benefits will not be evaluated against costs in a cost-benefit ratio or incremental cost-effectiveness ratio. This would understate the expected impact of the NCDU due to a lack of cohort data, lack of comparable interventions with available outcome data, and because many benefits from the NCDU are qualitative in nature.
- **The proposed timing of NCDU delivery is uncertain** – cost and benefit estimates report are presented in nominal terms assuming the NCDU implementation period starts in 2025.

Given the above, the analysis should be considered preliminary and indicative in nature and is likely to be subject to change depending on factors influencing the final NCDU design and implementation.

3 Case for change

3.1 Challenges and unmet needs

Children with dementia experience high levels of unmet need in the Australian health system. This has a significant impact not only on children but on their families as well. System responses to the complex care needs of children with dementia are hampered by several challenges.

Care for children with dementia is inconsistent, fragmented and inequitable

The current system of care for children with dementia is fragmented and reactive rather than proactive. Different sectors (health, disability, community, education) often operate in silos so children undergo unnecessary assessments. Additionally, without coordination, minor issues can escalate until a family is forced to seek help via emergency services, which is an inefficient (and costly) way to deliver care that could have been proactively handled earlier.

After receiving a diagnosis, carers must navigate disconnected health, disability, and education systems, often without guidance. This was described by several focus group attendees including one parent who said "There was nothing… I ended up getting on Google as we all do and found my support organisation… there's so many people who have the same experience" and another parent who said, "That was down to us… a lot of the time it does fall on the parent." This also leads to gross inequity of care as some families can access multiple services while others receive almost none. During these delays and gaps in care, children miss critical therapeutic windows and deteriorate without the support that might improve their quality of life.

Emerging or innovative therapies, which include gene and cell therapies and precision medicine, offer the only hope for improving survivorship in childhood dementia as there are currently no known cures. Treatments are extremely limited, often accessed too late for optimal outcomes and associated with complications and/or risks for children. For the few that are available in Australia, families face considerable barriers to access.

Despite an increasing number of innovative gene therapies and N-of-1 trials being conducted internationally, Australia lacks the infrastructure, data visibility and clinical trial capacity to support innovation in childhood dementia treatment. Without comprehensive clinical data there is no robust view of the childhood dementia cohort in Australia. This means it is very difficult to attract clinical trials, identifying eligible children for trials is challenging and realisation of the potential benefits of innovative therapies is hindered.

Limited clinical trial infrastructure in Australia (particularly outside major cities) and low awareness among time-constrained health professionals adds to the challenges families face. This leads to considerable disparities for children with dementia.

A 2024 report[12] comparing research funding for childhood dementia and childhood cancer found that:

- Childhood cancer received 4.6 times more funding per patient than childhood dementia.
- As of December 2023, globally there were 24-fold fewer clinical trials recruiting children with dementia than children with cancer in December of 2023. This disparity increased to a 43-fold difference in trials recruiting in Australia.
- During the period under analysis, survival for children after a cancer diagnosis was 87 per cent. By contrast, conditions that cause childhood dementia are terminal with no known cures.

Additionally, every child with cancer in Australia had an opportunity to participate in a clinical trial or innovative treatment at the time the report was published, while fewer than 2 per cent of children with dementia had those same opportunities.[13] This huge gap highlights how opportunities to access potentially

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[12] Childhood Dementia Initiative. *Australian Childhood Dementia Research Funding Report 2024.* March 2024.

[13] *Pathway Toward Report.*

disease modifying innovative therapies through clinical trials are very limited for children with dementia, significantly impacting chances of increasing survivorship.

There is limited expertise, awareness and understanding of childhood dementia in Australia

Awareness and understanding of childhood dementia in Australia are low and there is no standardised national guidance for care provision. This undermines quality and continuity of care for children with dementia and their carers. The National Dementia Action Plan identifies the absence of specialised services and care pathways for children with dementia as a major barrier to equitable access, making them a priority population for system reform.[14] There is also a lack of best-practice guidance for supporting the broader family unit and family members are often not referred to essential services such as psychological counselling, leaving them without the support they need.

Children with dementia and their carers experience poorer outcomes due to delayed access to services. For example, the average age of symptom onset is 2.5 years, but diagnosis typically occurs around age 4.[15] The average delay to diagnosis from symptom onset reported in international literature on childhood dementia is two years, though reported median diagnostic times for individual diseases have reached up to 16 years.[16] In a study conducted in New South Wales:

- 30 per cent of carers surveyed reported waiting more than five years for accurate confirmation of their child's disease.
- Half of them attended over 15 appointments with different health professionals over the diagnostic process.[17]

This creates inefficiencies in the health system in addition to subjecting carers to the anxiety of a "diagnostic odyssey".[18] This term describes the protracted journey of specialist visits, misdiagnoses and inconclusive tests children with dementia and their carers must take before the true cause is found.[19] During this time, children miss critical windows for early intervention and may be exposed to unnecessary procedures or potentially harmful medications due to misdiagnosis.[20]

Health professionals and service providers currently face a daunting challenge when working with children who have dementia as most have limited to no experience in these rare conditions. Many health professionals cite the limited and variable understanding of childhood dementia as the "primary challenge" in the care landscape for this cohort. Without standardised national guidance, they are reliant on local health service guidelines or models of care for the few conditions that have them. Health professionals acknowledge difficulties in care planning and medication management for these children due to their limited understanding of the conditions.

There is also an extremely limited understanding of who has childhood dementia in Australia, how diseases progress, how to best manage symptoms and what factors improve long-term health outcomes. Childhood dementia conditions are all rare or ultra-rare and knowledge is siloed with minimal data collection and sharing across Australia. Most of the data collected across state health systems is difficult to access, does not have appropriate classification to identify children with dementia and is inconsistently gathered across states and territories. The net effect is that knowledge about what works and what doesn't, or even about the natural progression of these diseases under current care, is severely limited.

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[14] Commonwealth Department of Health and Aged Care. *National Dementia Action Plan 2024-2034.* Last updated 5 February 2025.

[15] Elvidge, K., Christodoulou, J. Farrar, M. *et al.* The collective burden of childhood dementia: a scoping review. *Brain.* 20 July 2023. https://doi.org/10.1093/brain/awad242

[16] Childhood Dementia Initiative. *Early diagnosis of childhood dementia: challenges, importance and opportunities for improvement (Early diagnosis of childhood dementia).* 12 February 2025.

[17] Childhood Dementia Initiative. *Childhood Dementia: Family experiences of health systems in New South Wales.* March 2024.

[18] *Early diagnosis of childhood dementia.* 2025.

[19] Childhood Dementia Initiative. *Childhood Dementia: the case for urgent action.* 18 November 2020.

[20] *Early diagnosis of childhood dementia.* 2025.

The burden of childhood dementia care is immense for carers

The burden of care placed onto parents is immense. Parents shoulder the onus to 'project manage' their child's condition.[21] This involves independently identifying care and support services, organising and attending appointments and even educating health professionals about their child's disorder each time they transition to a new setting.[22] They often have to repeat the same information due to poor information-sharing between services. For example, a mother might have to recount her child's medical story to every specialist and chase up whether referrals have been sent or equipment orders processed. Carers spending valuable appointment time retelling their story is not only an inefficient use of health system resources but can be exhausting and retraumatising for parents.

In the absence of clear guidelines, parents and carers experience high anxiety and uncertainty about their child's care as they shoulder most of the work of researching and pursuing emerging therapies. Clinicians, especially general paediatricians or neurologists with busy practices, often do not have the time or specialised knowledge to stay abreast of the latest gene therapies, clinical trials, compassionate access programs or best strategies for symptom management and other interventions. This places an immense administrative and emotional burden on carers who often describe a fear of "missing something" that could help their child.

These experiences compound the psychological impacts of a childhood dementia diagnosis on parents. A 2025 study found:

- 100 per cent of carers surveyed reported pre-loss grief symptoms that imparted significant impairment.
- 70 per cent scored in the moderate to severe range for generalised anxiety.
- 60 per cent reported needing to access mental health resources to support them through their child's care journey.[23]

Much of this anxiety likely stems from the nature of the condition their child was diagnosed with and the resulting impact on their child's life. However, several parents emphasised the lack of early and ongoing mental health support they received as well as feeling overwhelmed and "spiralling" when they have no professional guidance between disparate specialist appointments.[24] One parent described it as: "You quit work, try and figure it all out yourself, while losing your mind because you're so exhausted and distressed, with no support".[25]

Carers also face significant financial burden to provide adequate care over multiple years for their child or children with dementia. For example:

- 84 per cent of carers reported spending over $1,000 out-of-pocket a year on medical costs, and nearly half spent more than $1,000 on non-medical related costs.
- 93 per cent of carers reported a change in work status since symptom onset.
- 41 per cent indicated they could not work at all due to caregiving duties.[26]

Because mothers are often the primary carers, this can contribute to gendered disparities in socio-economic outcomes.

The significant burden of care for childhood dementia worsens geographic and socioeconomic inequities. Families without local access to specialist expertise such as those in regional and rural areas face financial and logistical challenges to receive equitable care, including opportunities to participate in clinical trials. Often

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[21] Nous Group for Childhood Dementia Initiative. *'We don't fit': The lived experience of families affected by childhood dementia and their interactions with care and support services ('We don't fit' Report).* March 2023.

[22] *State of childhood dementia in Australia 2024.*

[23] Nevin, S. *Beyond the Diagnosis: An in-depth, Mixed-Methods Study investigating the Psychosocial, Financial and Psychological Struggles of Childhood Dementia on Caregivers and Families.* Interim Findings Summary. February 2025.

[24] Childhood Dementia Initiative. *Childhood Dementia Care Management*. Date unknown.

[25] Ibid.

[26] Nevin, S. *Beyond the Diagnosis: An in-depth, Mixed-Methods Study investigating the Psychosocial, Financial and Psychological Struggles of Childhood Dementia on Caregivers and Families.* Interim Findings Summary. February 2025.

families have had to travel long distances, or even relocate temporarily to capital cities, to access necessary specialist expertise for their child.

Some carers may also choose to enter the private health system to expedite access to care but this option is not available to all children with dementia. Placing the responsibility on parents to manage their child’s care also disproportionately impacts carers with lower English proficiency or health literacy who may struggle to navigate the complex web of the childhood dementia care and support landscape.

These unique experiences of childhood dementia care remain significantly under-researched. There is limited evidence on the psychological impacts, the experiences of siblings and the distinct challenges faced by carers from diverse backgrounds. This lack of insight highlights another health inequity for children with dementia, where other disease areas benefit from more extensive research and evidence.

4 National Childhood Dementia Unit (NCDU)

4.1 Overview of the NCDU

The NCDU will address critical gaps in childhood dementia care provision

A strategic national approach to childhood dementia is essential to tackle the longstanding issues of fragmented and inconsistent care, and the limited expertise among healthcare providers. The NCDU aims to address these challenges by establishing a centre of expertise for childhood dementia capability, knowledge and data. This initiative will embed expertise and ensure a unified approach to care and support for children with dementia.

The NCDU has two primary objectives:

1 Improve **survivorship and symptom management** for children with dementia through accelerated access to therapy and therapeutic development.

2 Provide **equitable access to timely, consistent and quality care and support** for children with dementia and their carers.

A national and collaborative approach will enable greater impact

In an increasingly complex landscape of rapidly advancing research and therapies, national consistency and coordination are more important than ever. A national centre of expertise, which is accessed virtually, will enable health professionals across Australia to seek clinical guidance and expertise as and when they need it, ultimately enabling all children with dementia to receive quality care regardless of the care setting or location.

Collaboration with key stakeholders in the health and care sectors will also be key to the enduring success of the NCDU. This includes partnerships and engagement with health professionals, state and territory health departments, patient organisations, service providers, researchers and industry.

Key functions will span across care, knowledge sharing and research

The NCDU aims to improve care quality and support for children with dementia and their carers. Four core components of the unit will work together to standardise care, build expertise, improve access to therapies and enhance understanding of childhood dementia in Australia. These include:

1. **Model of Care:** A standardised model that outlines evidence-based care and support for childhood dementia conditions.
2. **National Reference Centre:** A virtual hub of expertise, guidance and support to build capacity among health professionals treating children with dementia.
3. **Therapy Access Hub:** A centralised service to identify and facilitate access to innovative therapies and clinical trials for children in Australia.
4. **Patient Data Solution:** A secure data platform to support data collection and sharing and inform research, policy and care improvements in childhood dementia.

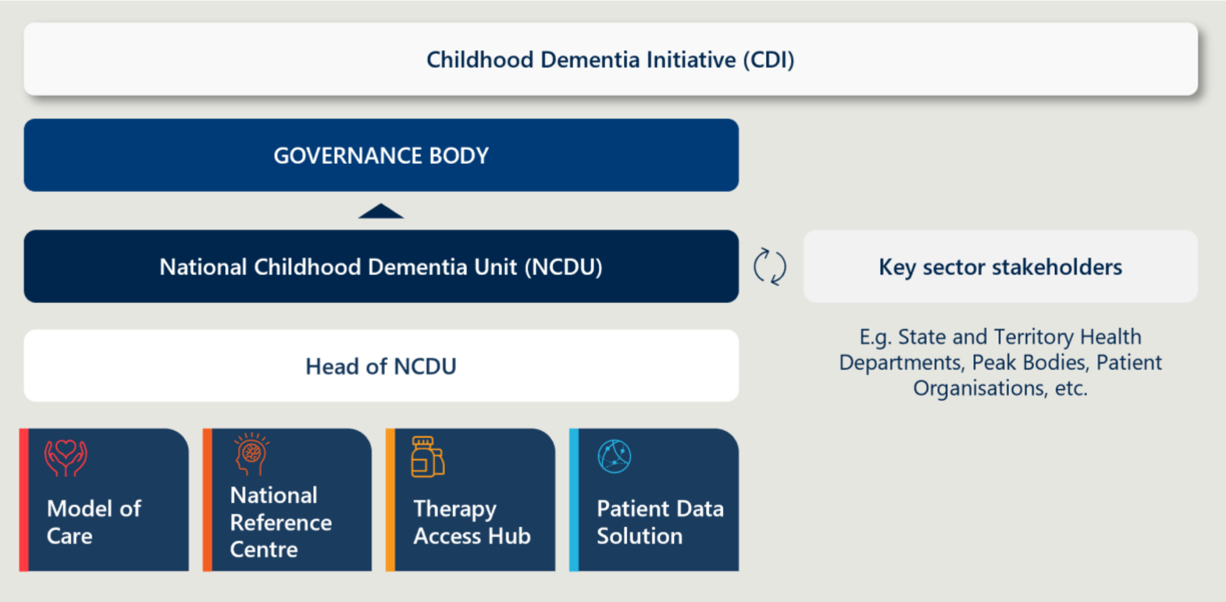
Strong leadership and robust governance will be critical to the NCDU’s operation

The NCDU will work closely with the wider health and support system and play a key role in connecting, enabling and guiding others. The NCDU will comprise a small team led by a Head of NCDU supported by specialist managers. Further detail on NCDU resourcing is outlined in Section 4.2.

CDI will be responsible for the set-up and implementation of the NCDU, overseeing funding, planning and recruitment. Ongoing governance structures and reporting lines will be determined at a later time, once the NCDU is operational and its scope and funding is finalised.

It will be important to emphasise principles of clinical safety, integrity and independence to establish the NCDU as a trusted organisation in the Australian health environment. The NCDU is expected to collaborate closely with key sector stakeholders to align initiatives and expand service reach.

Figure 4 | High level NCDU structure and governance



Childhood Dementia Initiative (CDI)

GOVERNANCE BODY

National Childhood Dementia Unit (NCDU)

Key sector stakeholders

E.g. State and Territory Health Departments, Peak Bodies, Patient Organisations, etc.

Head of NCDU

Model of Care

National Reference Centre

Therapy Access Hub

Patient Data Solution

4.2 Detailed design

The figure below outlines the four core components of the NCDU included in this business case. They are described in more detail in the following subsections.

Figure 5 | NCDU core components

MODEL OF CARE	A nationally standardised, evidence-based framework encompassing diagnosis, treatment, post-diagnostic support and timely connection to community and psychosocial services. It will cover the entire care pathway, including genetic counselling, clinical trials, end-of-life planning and bereavement and beyond. The model will be hosted online and supported by tailored training resources. It will define roles and responsibilities across sectors and be embedded into services through outreach and education.
NATIONAL REFERENCE CENTRE	A virtual hub of expertise, guidance and support to build capacity among health professionals treating children with dementia. The centre will be comprised of multidisciplinary experts and host regular forums to discuss complex cases and share best practices. It will also lead webinars, contribute to research and policy, and contribute to a digital platform for knowledge sharing.
THERAPY ACCESS HUB	A centralised service to identify and facilitate access to emerging therapies and clinical trials. It will proactively connect clinicians, researchers, pharmaceutical companies and government (including regulators) to support planning and recruitment and drive innovation in the sector. Activities include horizon scanning, personalised scoping reports for clinicians and stakeholder outreach.
PATIENT DATA SOLUTION	A secure, user-friendly platform for self-nominating carers and/or their chosen delegates to input and share data on their child or children with dementia. With consent, this data will support clinical trial recruitment, care planning and policy development. Features include dynamic consent, real-time access and capturing patient reported outcome measures (PROMs).

Note: It is expected other NCDU initiatives will continue to build over time.

4.2.1 MODEL OF CARE

The Model of Care for childhood dementia aims to transform how care is delivered by embedding evidence-based best practices that ensure consistent, high-quality and equitable support across all settings. With a focus on smooth care transitions, whole-of-family support, and integration of the latest research, the model offers guidance on care options to better outcomes and a lasting impact for children and carers navigating this complex condition.

Table 1 below outlines the objectives and details of a national Model of Care for childhood dementia.

Table 1 | Model of Care design

	Details
Objectives	1. Develop and embed nationally standardised best practice for diagnosis, treatment and support aligned to the latest research and evidence. 2. Enable consistent, integrated, timely and high-quality care across different settings. 3. Create seamless transitions between different levels of care (primary, secondary, tertiary) and across different providers, ensuring continuity and avoiding fragmentation. 4. Enable equitable access and quality care for patients regardless of demographics, location or other factors. 5. Enable planning and capacity building in care provision for children with dementia. 6. Promote increased coordination of health, disability, education and community supports.
Functions	The Model of Care will be evidence-based and will outline how care and support should be delivered across each stage of the disease. It will focus on commonalities across conditions that cause childhood dementia and define the roles, responsibilities and capabilities of health professionals across the care continuum. It will include direction to disease-specific guidelines where they are available. The scope of the Model of Care will include: • The entire childhood dementia care pathway, including post-diagnostic support, genetic counselling, referrals, service transition points, clinical trials, end of life planning, bereavement and beyond. • Cross-sector supports including health, psychosocial, education, disability and financial welfare. • Care and support for the full family unit, including parents and siblings. The Model of Care will be an interactive digital resource hosted online and delivered through a mobile application, ensuring it is easily accessible to anyone who is interested, including carers as well as health professionals or other support services. A digital resource allows the model to be updated regularly in line with emerging evidence and research into childhood dementia. The model will be supported by training and education resources that are available online and are tailored to specific audiences. The model will be embedded into services through targeted education and communications, as well as training activities. The Model of Care will be monitored and evaluated through service engagement, patient reported outcomes and semi-structured interviews with users.
Resources required	Several resources are required for the development, implementation and ongoing operation of a Model of Care. These include: Implementation • Project management personnel • Software Developer • Graphic Designer • Working group: lived experience representation; specialists (paediatric neurologist, metabolic physician, geneticist); paediatric nurse; speech therapist;

	occupational therapist or physiotherapist; psychologist or social worker; pharmacist. Ongoing • Model of Care Manager • Information and Support Manager • Education and Communications Manager
Dependencies	The success of the Model of Care will rely on: • Endorsement and collaboration with the health system, including state and territory health departments. • Alignment to and embedding within national policies and guidelines. • Sector participation in the ongoing national communication and education program to ensure widespread knowledge of childhood dementia and the Model of Care. • Support from dedicated childhood dementia information and support service.[27]

4.2.2 NATIONAL REFERENCE CENTRE

The National Reference Centre brings together multidisciplinary expertise to strengthen and unify childhood dementia care across Australia, ensuring high-quality, evidence-based support is accessible regardless of location or provider. Through shared learning, clinical advice and capacity building, it fosters a more consistent, holistic and equitable approach to care for children and their carers.

Table 2 below outlines the objectives and details of a National Reference Centre.

Table 2 | National Reference Centre design

	Details
Objectives	1. Improve care quality regardless of location across diagnosis, care planning and delivery, medication management, psychosocial support and transitions. 2. Bring together multidisciplinary expertise to support holistic healthcare provision at all stages. 3. Build capability of local providers and services through provision of expert clinical advice. 4. Sharing of evidence-based and best practice care to collectively improve the quality and consistency of childhood dementia care provision.
Functions	The National Reference Centre will be a virtual hub of expertise, guidance and support comprised of a multidisciplinary team of professionals who are experts in childhood dementia conditions. Experts will provide information, education and clinical advice to health professionals managing childhood dementia conditions. The Reference Centre will meet virtually on a regular basis (proposed monthly) to discuss and advise on clinical cases that have been referred to them. Topics may include: • diagnostic processes • application of tests • treatments

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[27] CDI is separately considering a dedicated information and support service, which would be a key enabler to the adoption of a Model of Care.

	• medicines • care planning. They will also play a broader role in building capacity and knowledge in childhood dementia. Activities may include: • supporting education activities and webinars • leading in Communities of Practice • developing and updating the Model of Care • contributing to research, policy and advocacy efforts. The National Reference Centre will be supported by a digital platform (website) to host information resources and facilitate knowledge sharing for healthcare professionals.
Resources required	The panel of multidisciplinary experts should include, but are not limited to: • Childhood dementia specialists (paediatric neurologist, metabolic specialist, geneticist). • Medical professionals (paediatrician, sleep physician). • Allied health professionals (nurse, pharmacist, speech therapist, physiotherapist, behaviour specialist). • Paediatric palliative care practitioners. • Lived experience representation. The Reference Centre will also require operational support and tools, including: • Coordinator support to manage referrals, schedule meetings/consultations and organise webinars/conferences. • Development of online content and coordinated marketing and outreach. • Virtual meeting technology and licensing (e.g. Microsoft Teams).
Dependencies	The success of the National Reference Centre will rely on: • Successful recruitment of multidisciplinary experts in childhood dementia. • Integration with jurisdictional health systems. • A strong model of care to support consistent, evidence-based advice. • Widespread awareness of the centre and its services.

4.2.3 THERAPY ACCESS HUB

The Therapy Access Hub is a central platform designed to accelerate access to innovative and emerging therapies for children with dementia in Australia. By connecting clinicians, researchers and industry, the Hub reduces barriers to clinical trials, streamlines access to information and fosters global collaboration. It offers families renewed hope for timely, equitable and world-leading treatment options.

Table 3 below outlines the objectives and details of the Therapy Access Hub (the Hub).

Table 3 | Therapy Access Hub design

	Details
Objectives	1. Remove systemic barriers to accessing innovative and emerging therapies in Australia. 2. Generate new knowledge about disease progression, treatment efficacy and optimal care approaches.

	3. Drive innovation in Australia's approach to emerging therapy research and clinical trials, improving capacity and agility. 4. Enhance local and international relationships with pharmaceutical companies, researchers, regulators and health professionals. 5. Reduce administrative burden for carers and health professionals researching and advocating for access to emerging or innovative therapies.
Functions	The Hub will drive efforts to identify and facilitate access to innovative therapies and clinical trials for children in Australia. It will act as a catalyst between clinicians, researchers, pharmaceutical companies and government, including regulators. Clinicians, researchers, industry and government will be able to turn to the Therapy Access Hub for support and information, and collectively drive change. Core activities will include: • Acting as a central point of contact for local/international researchers and pharmaceutical companies interested in running a clinical trial. • Maintain up-to-date understanding of childhood dementia patients in Australia, including their demographics, location and other data required for clinical trial participation.[28] • Horizon scanning to proactively identify emerging therapies and desirable trials. • "Concierge" support to assist clinicians to identify and access latest therapies/trials for their patients. This includes the development of personalised scoping reports to provide current information about relevant therapies/trials and support clinician decision-making. • Supporting advocacy related to Special Access Schemes, compassionate access and Health Technology Assessments (HTAs). • Proactive engagement and advocacy across an established network of local/international clinicians, researchers, pharmaceutical companies and government departments.
Resources required	Several resources are required for the ongoing operation of the Hub. These include: • Therapy Access Lead. • Clinical Intelligence Analyst. • Education and Communications Manager. • Digital horizon scanning tools (e.g. Text mining AI). • Travel (e.g. for conferences or on-site education on service).
Dependencies	The success of the Therapy Access Hub will rely on: • The patient data solution. • Childhood dementia information and support service. • Abundant relationships with key stakeholders, locally and internationally. • Robust governance and strict independence policies. • Awareness and regular engagement with treating clinicians.

4.2.4 PATIENT DATA SOLUTION

The Patient Data Solution empowers carers to actively contribute to a centralised, secure data platform that enhances communication, care coordination and clinical trial access for children with dementia. With real-

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[28] This will be enabled by the Patient Data Solution within the NCDU.

time data sharing, dynamic consent and actionable insights, it supports more personalised and efficient care, while informing policy, research and system-wide improvements.

Table 4 below outlines the objectives and details of a patient-led data solution.

Table 4 | Patient Data Solution design

	Details
Objectives	1. Establish a centralised source of data on all known and consenting/self-nominating childhood dementia cases in Australia. 2. Facilitate seamless information sharing between carers and healthcare professionals. 3. Drive evidence-based improvements in care and policy. 4. Enable accurate identification of children with dementia for clinical trial planning and recruitment.
Functions	The "patient-led" data solution will allow carers to input data relating to their child or children's condition and care. Users will be able to input data and upload relevant files through an easy-to-use digital interface, via web or mobile app. Data may include information about the child, their preferences for engagement, health history, diagnosis documents and referral letters. Users will benefit from having all relevant data stored centrally, and they will also have the option to directly share this information with health professionals, enabling better communication and coordination with care providers. Data will also be used to facilitate other NCDU activities such as clinical trial recruitment and updating the model of care. Key features of the data solution include: • Dynamic consent: Give consent to share information with health professionals and organisations, as needed. • Real-time access: Access data in real-time to support information sharing, decision making and care coordination. • Additional data capture: Ad-hoc questionnaires to capture data and feedback from users, e.g. PROMs, PREMs, service usage, etc. Through consent and analysis, insights from the data provided can be used to: • Identify patients eligible for clinical trials. • Attract clinical trials to Australia. • Drive improvements and efficiencies within health services.
Resources required	Several resources are required for the ongoing operation of the Patient Data Solution. These include: • 3rd-party managed digital data platform. • Data Registry Manager. • Information and Support Manager • Education and Communications Manager.
Dependencies	The success of the Patient Data Solution will rely on: • Ongoing participation and data updates from carers. • Comprehensive data management and quality assurance. • Robust data security and privacy. • Easy-to-use interface and user support. • Information and Support Manager to assist carers and conduct quality assurance processes as data is uploaded.

5 Cost analysis

This section details the implementation and ongoing costs of the NCDU, including a “year zero” for an implementation period and four years of ongoing operation. Costs for each component are assessed individually and are based on the agreed NCDU design and implementation plan. Cost estimates are informed by desktop research into similar initiatives, expert and stakeholder engagement and materials provided by CDI.

Some resources are shared across components which has been factored into the cost breakdown. Costs for evaluation are also apportioned across components, and represent fees required to engage third party evaluators to design an evaluation framework and collect data to measure outcomes (one year after implementation and every two years ongoing).

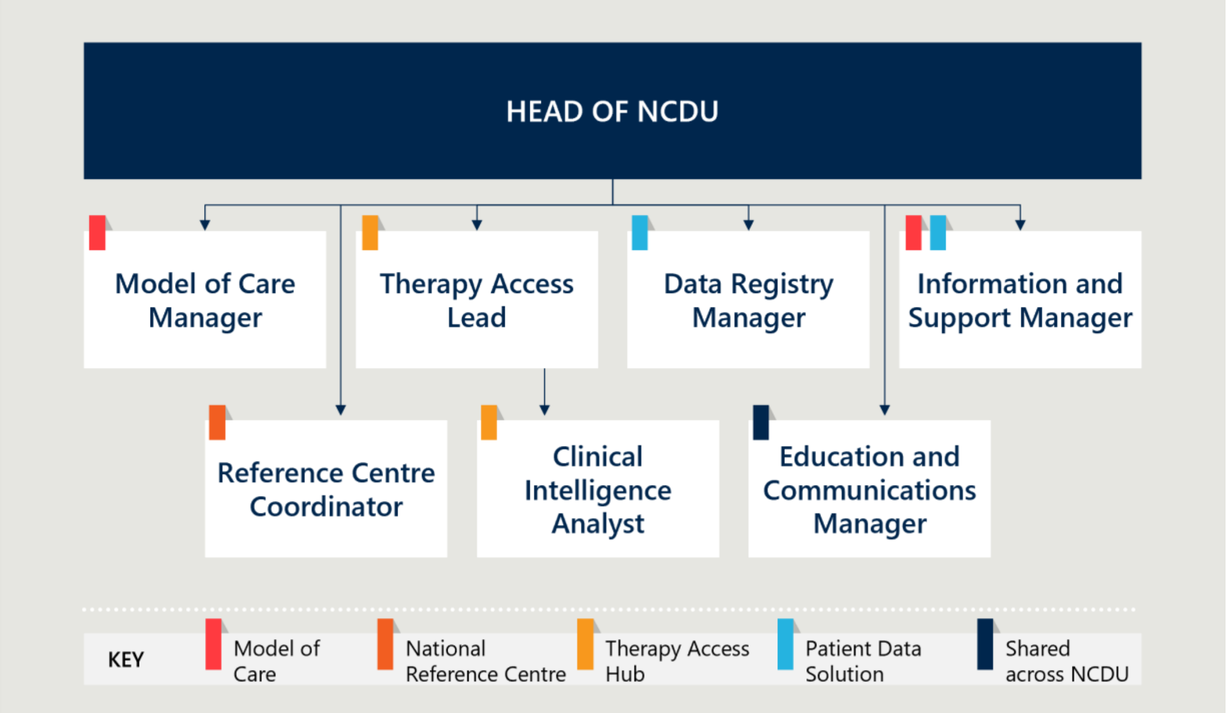
Table 5 shows the estimated cost of each NCDU component. All estimates are indicative and intended to guide further planning and refinement.

Table 5 | NCDU cost estimate ($m)

Component	Cost ($m)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Model of Care	1.16	0.47	0.77	0.50	0.81	3.70
Implementation	*0.79*	-	-	-	-	*0.79*
Ongoing costs	*0.37*	*0.47*	*0.77*	*0.50*	*0.81*	*2.91*
National Reference Centre	0.45	0.62	0.71	0.62	0.75	3.16
Implementation	*0.28*	-	-	-	-	*0.28*
Ongoing costs	*0.17*	*0.62*	*0.71*	*0.62*	*0.75*	*2.88*
Therapy Access Hub	0.45	0.57	0.69	0.60	0.73	3.04
Implementation	*0.16*	-	-	-	-	*0.16*
Ongoing costs	*0.29*	*0.57*	*0.69*	*0.60*	*0.73*	*2.88*
Patient Data Solution	0.65	0.46	0.56	0.48	0.59	2.74
Implementation	*0.39*	-	-	-	-	*0.39*
Ongoing costs	*0.26*	*0.46*	*0.56*	*0.48*	*0.59*	*2.35*
Total NCDU	**2.71**	**2.12**	**2.73**	**2.20**	**2.87**	**12.64**
Implementation	*1.63*	-	-	-	-	*1.63*
Ongoing costs	*1.09*	*2.12*	*2.73*	*2.20*	*2.87*	*11.02*

The estimated total cost of the NCDU over four years is **$12.64m**. The primary cost driver for each component is the ongoing staff (7 FTE) that make up the core NCDU team. The proposed organisational structure is shown in Figure 6.

Figure 6 | Proposed NCDU Organisational Structure



The responsibilities and costs of each resource are as follows:

- **Head of NCDU**: responsibilities will include providing strategic direction, leading continuous improvement, managing people, holding accountability for program success, and chairing the monthly reference centre forums. This will be a single resource (1 FTE total) with an estimated base yearly salary of $190,000. This role is apportioned across all NCDU components.
- **Model of Care Manager**: responsibilities will include leading the development of the Model of Care, overseeing regular updates, embedding the model in the health system, and developing and conducting training sessions for health professionals. This will be one resource (1 FTE total) with an estimated base yearly salary of $130,000. This role is apportioned to the Model of Care.
- **Therapy Access Manager**: responsibilities will include building a network of local and global relationships, leading development of scoping reports and coordinating horizon scanning. This will be one resource (0.8 FTE total) with an estimated base yearly salary of $136,000. This role is apportioned to the Therapy Access Hub.
- **Data Registry Manager**: responsibilities will include managing data entry into the data solution, curating data, reporting and analytics, system planning, compliance, and managing access to data. This will be a single resource (0.8 FTE) with an estimated base yearly salary of $104,000. This role is apportioned to the Patient Data Solution.
- **Information and Support Manager**: responsibilities will include supporting carers with the Model of Care, supporting carers to use the Patient Data Solution and overseeing integration with the childhood dementia information and support service.[29] This will be one resource (1 FTE total) with an estimated base yearly salary of $150,000. This role is apportioned to the Model of Care and Patient Data solution.
- **Education and Communications Manager**: responsibilities will include managing communications, educational content creation, and promoting awareness and engagement with NCDU resources. This will be a single resource (1 FTE total) with an estimated base yearly salary of $125,000. This role is apportioned across all NCDU components.
- **Clinical Intelligence Analyst**: responsibilities will include managing requests to the Therapy Access Hub, compiling insights for tailored scoping reports and managing horizon scanning. This will be a single

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[29] Note that CDI is separately developing a proposal for a national childhood dementia information and support service. Costs and design considerations for this function are not included in this report.

resource (0.8 FTE total) with an estimated base yearly salary of $92,000 p.a. This role is apportioned to the Therapy Access Hub.

- **Reference Centre Coordinator**: responsibilities will include coordinating monthly reference centre forums, manage referrals to National Reference Centre, and providing administrative support. This will be a single resource (0.6 FTE) with an estimated base yearly salary of $57,000. This role is apportioned to the National Reference Centre.
- An on-cost rate of 40 per cent has been applied to all resources to reflect superannuation, other benefits, software licenses, professional development, professional memberships and other on-costs.[30]

The activity level breakdown of costs for each component is provided below in Sections 5.1– 5.4. Detailed assumptions and rationale underlying each cost item are outlined in Appendix B.

5.1 Model of Care

The estimated total cost for the Model of Care is **$3,702,000** for implementation and ongoing operation for four years. Implementation costs are estimated at **$793,000**, consisting of a facilitated co-design process, building an interactive PDF and app to share the Model of Care, compensation for expert stakeholders, resource onboarding costs, and evaluation design. The ongoing costs are estimated at **$2,909,000**, consisting of salaries and on-costs for ongoing resources, costs to update the Model of Care every two years, app maintenance costs, budget to attend events and conferences, and evaluation implementation. Table 6 below shows the detailed costing breakdown for the Model of Care.

Table 6 | Model of Care cost breakdown ($'000)

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Implementation costs	793	-	-	-	-	793
NCDU implementation project management	53	-	-	-	-	**53**
Model of Care design and project management	390	-	-	-	-	**390**
Multidisciplinary team consultation	94	-	-	-	-	**94**
Interactive PDF document development	14	-	-	-	-	**14**
Model of Care interactive app development	120	-	-	-	-	**120**
Resource onboarding (including recruitment and hardware costs)	54	-	-	-	-	**54**
Evaluation design	68	-	-	-	-	**68**
Ongoing costs	371	471	765	496	805	2,909
Resource costs	371	385	395	405	415	**1,970**
Model of Care Manager (1 FTE)	*182*	*187*	*191*	*196*	*201*	***958***
Information and Support Manager (0.5 FTE)	*105*	*108*	*110*	*113*	*116*	***552***
Head of NCDU (0.2 FTE)	*67*	*55*	*56*	*57*	*59*	***293***
Education and Communications Manager (0.2 FTE)	*18*	*36*	*37*	*38*	*39*	***167***
Model of Care maintenance and update	-	-	157	-	165	**323**

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[30] On-costs includes 30% mark-up for salaried employees to reflect employment benefits (as per IHACPA Pricing Framework for Australian Public Hospital Services), and an additional 10% mark-up for basic software requirements, WFH allowance, and other miscellaneous expenses required.

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
App maintenance costs	-	15	16	16	17	**64**
Events and conferences	-	37	38	39	40	**154**
Advertising and PR	-	24	24	25	26	**99**
People and administrative costs	-	10	11	11	11	**43**
Evaluation implementation	-	-	124	-	131	**255**
Total	**1,164**	**471**	**765**	**496**	**805**	**3,702**

Key parameters for the Model of Care costing include:

- A 12-month implementation phase will be led by the Model of Care Manager and supported by expert input.
- The Model of Care will cover all care domains, including health, community, and education.
- Multidisciplinary experts that are engaged during the Model of Care design process will be compensated at market rates.
- The Model of Care will be published as an interactive PDF and as a smartphone app developed during implementation. The PDF's availability online is dependent on the website (costed under the National Reference Centre).
- The Model of Care will require 1.9 FTE ongoing. Ongoing activities that are costed include:
  - Regular updates to the Model of Care to reflect latest evidence and care practices (initially 12 months post-launch, then every two years).
  - Training, resource development, and coordination of childhood dementia information and support service provision to embed the Model of Care into existing systems.
  - Coordinated marketing and outreach.

Detailed assumptions and rationale underlying the cost estimates can be found in Appendix B.

5.2 National Reference Centre

The estimated total cost for the National Reference Centre is **$3,160,000** for implementation and ongoing operation for four years. Implementation is expected to cost **$279,000**, consisting of resource onboarding costs, website development, and evaluation design. The ongoing cost is expected to be **$2,881,000**, consisting of salaries and on-costs for ongoing resources, content development, compensation for reference centre forum participants, content development, website maintenance, budget to attend events and conferences, and evaluation implementation. Table 7 below provides the costing breakdown for the National Reference Centre.

Table 7 | National Reference Centre cost breakdown ($'000)

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Implementation costs	279	-	-	-	-	**279**
NCDU implementation project management	53	-	-	-	-	**53**
Website build	60	-	-	-	-	**60**
Resource onboarding (including recruitment and hardware costs)	108	-	-	-	-	**108**

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Evaluation design	58	-	-	-	-	**58**
Ongoing costs	168	622	715	624	752	**2,881**
Resource costs	168	263	269	276	283	**1,260**
Head of NCDU (0.4 FTE)	*133*	*109*	*112*	*115*	*118*	***586***
Reference Centre Coordinator (0.6 FTE)	-	*82*	*84*	*86*	*88*	***340***
Education and Communications Manager (0.4 FTE)	*35*	*72*	*74*	*75*	*77*	***333***
Reference Centre forum panel (11 members on average)	-	202	208	213	218	**841**
Content Development	-	72	44	46	47	**209**
Website maintenance	-	8	9	9	9	**35**
Events and conferences	-	37	38	39	40	**154**
Advertising and PR	-	24	24	25	26	**99**
People and administrative costs	-	15	16	16	17	**64**
Evaluation implementation	-	-	106	-	112	**218**
Total	**447**	**622**	**715**	**624**	**752**	**3,160**

Key parameters for the National Reference Centre costing include:

- Monthly forums that will have a panel of childhood dementia specialists, medical professionals (paediatrician, sleep physician), allied health professionals (nurse, pharmacist, speech therapist, physiotherapist), paediatric palliative care practitioners, and lived experience representation.
- All monthly forum participants will be compensated at market rates.
- The National Reference Centre will require 1.4 FTE ongoing. Ongoing activities that are costed include:
  - Chairing of the monthly forum.
  - Triage and management of referrals to the National Reference Centre.
  - Development of online content to be shared on the website.
  - Coordinated marketing and outreach.

Detailed assumptions and rationale underlying the cost estimates can be found in Appendix B.

5.3 Therapy Access Hub

The estimated total cost for the Therapy Access Hub is **$3,043,000** for implementation and ongoing operation for four years. Implementation is expected to cost **$163,000**, consisting of resource onboarding costs, and evaluation design. The ongoing cost is expected to be **$2,880,000**, consisting of salaries and on-costs for ongoing resources, horizon scanning tools and database subscriptions, budget to attend events and conferences, and evaluation implementation. Table 8 shows the detailed costing breakdown for the Therapy Access Hub.

Table 8 | Therapy Access Hub cost breakdown ($'000)

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Implementation costs	163	-	-	-	-	163
NCDU implementation project management	53	-	-	-	-	**53**
Resource onboarding (including recruitment and hardware costs)	54	-	-	-	-	**54**
Evaluation design	56	-	-	-	-	**56**
Ongoing costs	286	573	690	604	727	2,880
Resource costs	211	418	428	439	451	**1,948**
Therapy Access Lead (0.8 FTE)	*95*	*195*	*200*	*205*	*211*	***907***
Clinical Intelligence Analyst (0.8 FTE)	*32*	*132*	*135*	*139*	*142*	***581***
Head of NCDU (0.2 FTE)	*67*	*55*	*56*	*57*	*59*	***293***
Education and Communications Manager (0.2 FTE)	*18*	*36*	*37*	*38*	*39*	***167***
Horizon scanning database subscriptions and tools	75	103	106	109	112	**504**
Events and conferences	-	19	19	20	20	**77**
Advertising and PR	-	24	24	25	26	**99**
People and administrative costs	-	10	11	11	11	**43**
Evaluation implementation	-	-	102	-	108	**210**
Total	**449**	**573**	**690**	**604**	**727**	**3,043**

Key parameters for the Therapy Access hub costing include:

- The hub will require minimal supporting digital infrastructure or capabilities beyond subscription horizon scanning tools and health research database subscriptions.
- The Therapy Access Hub will require 2 FTE ongoing. Ongoing activities that are costed include:
    - Building relationships and liaising between representatives of trial sites, clinicians, researchers, regulators and industry.
    - Providing tailored scoping reports for treating clinicians with childhood dementia patients.
    - Proactive horizon scanning for emerging innovative treatments, clinical trials and advancements in care practices.
    - Coordinated outreach to health professionals and representatives of trial sites.
    - Note: The Therapy Access Hub will connect trial organisers with existing resources and expertise, but will not provide intensive support conduct trials, including with ethics applications.

Detailed assumptions and rationale underlying the cost estimates can be found in Appendix B.

5.4 Patient Data Solution

The estimated total cost for the Patient Data Solution is **$2,739,000** for implementation and ongoing operation for four years. Implementation is expected to cost **$390,000**, consisting of a contractor from CDI to oversee the registry design, engagement of a software provider to build the solution, integration with the CDI

CRM platform, resource onboarding costs, and evaluation design. The ongoing cost is expected to be **$2,350,000**, consisting of salaries and on-costs for permanent resources, ongoing solution IT support and maintenance, cybersecurity insurance, budget to attend events and conferences, and evaluation implementation. Table 9 below shows the detailed costing breakdown for the Patient Data Solution.

Table 9 | Patient data solution cost breakdown ($'000)

Cost item	Cost ($'000)					
	Year 0	Year 1	Year 2	Year 3	Year 4	Total
Implementation costs	390	-	-	-	-	390
NCDU implementation project management	53	-	-	-	-	**53**
Patient data solution design and project management	105	-	-	-	-	**105**
Legal advice and assessment	38	-	-	-	-	**38**
Registry development	90	-	-	-	-	**90**
Registry software build	44	-	-	-	-	**44**
User testing and quality assurance	30	-	-	-	-	**30**
Integration with CDI Salesforce	16	-	-	-	-	**16**
Resource onboarding (including recruitment and hardware costs)	54	-	-	-	-	**54**
Evaluation design	50	-	-	-	-	**50**
Ongoing costs	262	457	560	481	590	2,350
Resource costs	262	347	356	365	375	**1,706**
Information and Support Manager (0.5 FTE)	*105*	*108*	*110*	*113*	*116*	***552***
Data Registry Manager (0.8 FTE)	*73*	*149*	*153*	*157*	*161*	***693***
Head of NCDU (0.2 FTE)	*67*	*55*	*56*	*57*	*59*	***293***
Education and Communications Manager (0.2 FTE)	*18*	*36*	*37*	*38*	*39*	***167***
Ongoing IT support and registry maintenance	-	54	56	58	59	**227**
Public Liability and Cybersecurity insurance	-	26	26	27	28	**107**
Advertising and PR	-	24	24	25	26	**99**
People and administrative costs	-	5	5	5	6	**21**
Evaluation implementation	-	-	92	-	97	**189**
Total	**652**	**457**	**560**	**481**	**590**	**2,739**

Key parameters for the Patient Data Solution costing include:

- A 6-month implementation phase will design the patient data solution and define the data requirements, including engagement of relevant experts to support the process.
- Carers and their delegates will be responsible for inputting data into the app and providing consent for data to be shared.
- The Patient Data Solution will require 1.7 FTE ongoing. Ongoing activities that are costed include:
    - Ongoing support for users and data quality assurance.

  - Coordinated outreach to carers of children with dementia.

Detailed assumptions and rationale underlying the cost estimates can be found in Appendix B.

5.5 Sensitivity analysis

The costs of each NCDU component are estimates only. They are likely to vary depending on the availability of key resources for each role, the external providers that are engaged for project management and developing the digital infrastructure, and the extent and type of expert consultation required. High and low estimates of NCDU costs have been developed and are provided in Table 10. They contain a variance of +/-15 per cent to reflect the level of uncertainty surrounding key inputs.

Table 10 | NCDU cost estimate range ($m)

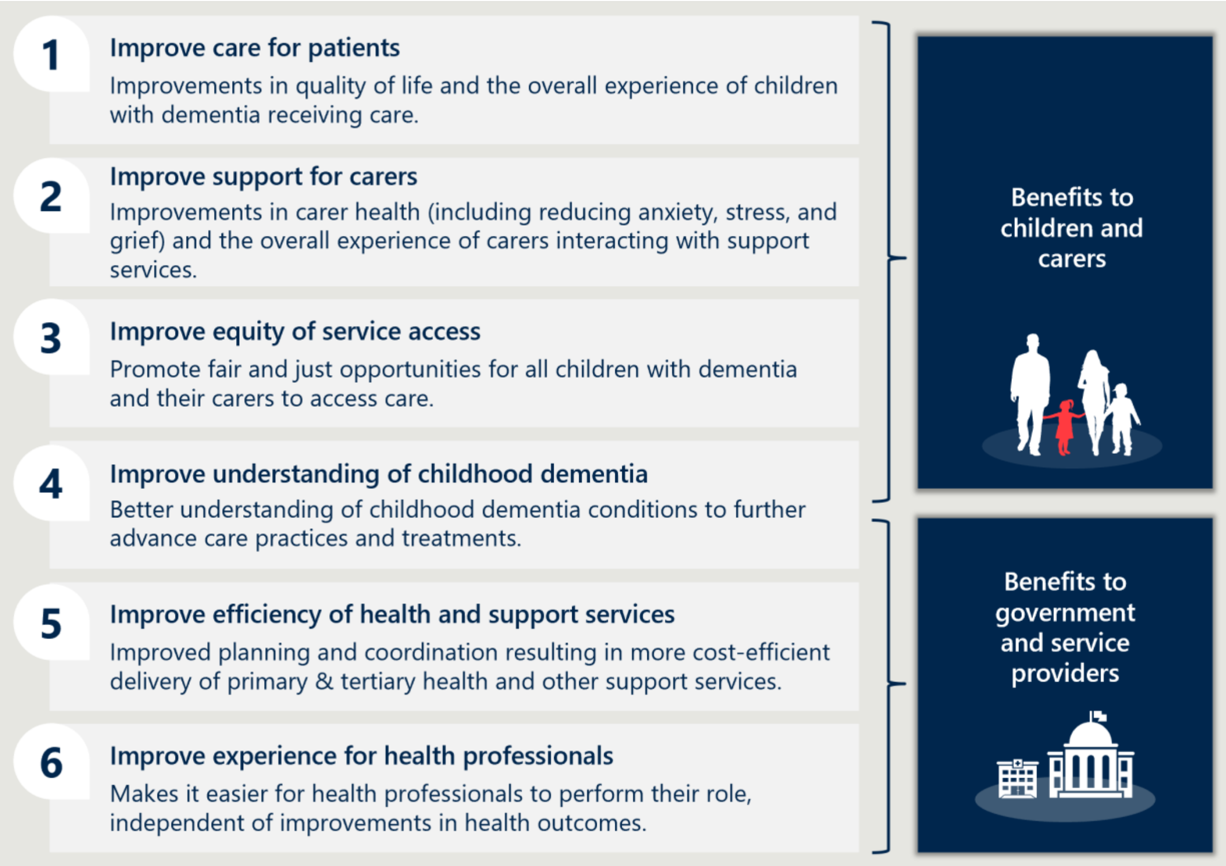
Component	Low estimate	Central estimate	High estimate
Model of Care	3.15	3.70	4.26
National Reference Centre	2.69	3.16	3.63
Therapy Access Hub	2.59	3.04	3.50
Patient Data Solution	2.33	2.74	3.15
Total NCDU	**10.75**	**12.64**	**14.54**

6 Benefits

The NCDU will improve care, equity and service efficiency

The NCDU will deliver wide-reaching benefits by improving the quality and accessibility of care for children with dementia and their carers. It will enhance patient care, reduce carer burden and promote equitable access to services across Australia. It will also strengthen the health system by reducing the burden on primary health care, deepening understanding of childhood dementia, and building health professional capacity by providing them with the tools and knowledge they need to deliver compassionate, effective and efficient care. The six major benefits of the NCDU are outlined in Figure 7.

Figure 7 | NCDU benefit categories



1 **Improve care for patients**
Improvements in quality of life and the overall experience of children with dementia receiving care.

2 **Improve support for carers**
Improvements in carer health (including reducing anxiety, stress, and grief) and the overall experience of carers interacting with support services.

3 **Improve equity of service access**
Promote fair and just opportunities for all children with dementia and their carers to access care.

4 **Improve understanding of childhood dementia**
Better understanding of childhood dementia conditions to further advance care practices and treatments.

5 **Improve efficiency of health and support services**
Improved planning and coordination resulting in more cost-efficient delivery of primary & tertiary health and other support services.

6 **Improve experience for health professionals**
Makes it easier for health professionals to perform their role, independent of improvements in health outcomes.

Benefits to children and carers

Benefits to government and service providers

The NCDU will deliver benefits to children, carers, government and service providers. However, certain components are expected to contribute more strongly than others to particular benefits, as outlined in Table 11 overleaf. Further detail about how each component will support these benefits is provided in Appendix C.

Table 11 | Benefit categories for each NCDU component

	Model of Care	National Reference Centre	Therapy Access Hub	Patient Data Solution
Benefit 1: Improve care for patients	✓	✓	✓	✓
Benefit 2: Improve support for carers	✓		✓	✓
Benefit 3: Improve equity of service access	✓	✓	✓	✓
Benefit 4: Improve understanding of childhood dementia		✓	✓	✓
Benefit 5: Improve efficiency of health services and support services	✓			
Benefit 6: Improve experience for service providers	✓	✓		

Benefits are outlined qualitatively and are supported by indicative estimates where possible

This analysis sought to explore the economic and social impacts of the NCDU. Due to data limitations, this report provides both a qualitative discussion of benefits and indicative estimates for those benefits where relevant information is available.

6.1 Overall benefits

The indicative value of benefits that could be achieved by NCDU over the next four years is **$61.49m**, as shown in Table 12.

- The estimated value of benefits from improving support to carers is **$50.62m** over four years. This is driven by a reduction in anxiety in carers, time savings to carers from standardising ongoing care, and streamlining diagnosis pathways.
- The estimated value of benefits from improving efficiency for service providers is **$10.87m** over four years. This is driven by a reduction in unplanned emergency department (ED) presentations, a reduction in unplanned hospitalisations, and time savings to health professionals from streamlining diagnosis pathways.

Detailed methodology, rationale and assumptions for the quantified measures in Table 12 are detailed in Appendix D.1. All benefit values in this report are adjusted for inflation with no discount rate applied.[31]

The quantified benefits in Table 12 does not exhaustively capture all benefits from the NCDU. Appendix D.2 outlines the quantitative measures that are predicted to be impacted by the NCDU but were not included in this report due to a lack of data.

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[31] Measures 1, 4, and 5 use an inflation rate of 2.8% (reflecting 10-year-average of CPI increases) and Measures 2, 3, and 6 use an inflation rate of 2.55% (reflecting 10-year-average of wage price increases)

Table 12 | Estimated benefits of NCDU ($m)

Benefit category / quantitative measure	Year 1	Year 2	Year 3	Year 4	Total
Benefit 2: Improve support for carers	12.15	12.48	12.82	13.17	50.62
Measure 1: Reduction in anxiety for carers	8.48	8.71	8.96	9.21	35.35
Measure 2: Time savings to carers from standardising ongoing care	3.58	3.68	3.77	3.87	14.90
Measure 3: Time savings for carers from streamlining diagnosis pathways	0.09	0.09	0.09	0.09	0.36
Benefit 5: Improve efficiency for providers	2.61	2.68	2.75	2.83	10.87
Measure 4: Reduction in unplanned ED visits	0.79	0.81	0.84	0.86	3.30
Measure 5: Reduction in unplanned hospitalisations	1.71	1.76	1.81	1.86	7.13
Measure 6: Time savings to health professionals	0.11	0.11	0.11	0.11	0.44
Total estimated NCDU benefit	**14.75**	**15.16**	**15.57**	**16.00**	**61.49**

6.2 Benefit 1: Improve care for patients

The NCDU will transform care for approximately 1,600 children with dementia across Australia by embedding consistent, evidence-based practices across the health system.[32] Children with childhood dementia and their carers currently face fragmented pathways, delayed diagnoses, and missed therapeutic windows. By establishing clear care standards and access to expertise, the NCDU will enable earlier intervention, better symptom management, improved access to innovative therapies and more proactive care planning. This will reduce unnecessary variation in treatment and ensure that all children receive high-quality care regardless of where they live or which provider they see.

6.3 Benefit 2: Improve support for carers

Carers often shoulder the burden of coordinating care, researching treatments, and navigating disconnected services, all while managing the emotional toll of their child’s condition. The NCDU will ease this burden by providing structured care and support service guidance, centralised information, and access to psychosocial supports. This will help carers to feel more confident and less isolated. These improvements are expected to reduce anxiety, improve mental health, and save time for carers, allowing them to focus more on their child or children and wellbeing.

Indicative value:

- **Reduction in anxiety for carers**: It is estimated that the NCDU could reduce anxiety in 313 carers each year, resulting in an estimated benefit of **$35.35m** over four years.[33] This could be achieved through the NCDU reducing uncertainty around care options and treatment stages, increased access to psychosocial supports, and enabling greater certainty that their child is getting the best care possible.
- **Time savings to carers from standardising ongoing care**: It is estimated that the NCDU could save 92,352 hours of carer time organising ongoing care, resulting in a benefit of **$14.90m** over four years.[34] This could be achieved through the NCDU reducing the time requirements for carers in managing

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[32] Only includes children with untreatable childhood dementia conditions. Prevalence of childhood dementia conditions is estimated based on incidence and life expectancy of individual conditions. Detailed assumptions and methodology are shown in Appendix D.

[33] Assumes 63% of the increased number of carers that experience severe, moderate, and mild anxiety compared to the general population will experience a reduction in anxiety. Detailed rationale, limitations, and sensitivity analysis are shown in Appendix D.

[34] Assumes an average 7.4-hour reduction in the number of hours spent by carers facilitating care each week in the year following their child’s diagnosis. Detailed rationale and limitations are shown in Appendix D. This measure only includes time savings to carers after their child has been diagnosed.

ongoing care and researching emerging treatments and clinical trials in the year following their child's diagnosis.

- **Time savings for carers from streamlining diagnosis pathways**: It is estimated that the NCDU could save 2,257 hours of carer time seeking a diagnosis for their child each year, resulting in a benefit of **$0.36m** over four years.[35] This could be achieved through the NCDU enabling access to expertise that enables health professionals to make earlier diagnoses and timely referrals to relevant services.

6.4 Benefit 3: Improve equity of service access

Access to care and support for childhood dementia is currently inequitable, with disparities between regions and socioeconomic groups among others. The NCDU will address this by making specialist expertise, clinical guidance and emerging therapies more available nationwide. Whether a family lives in a metropolitan centre or a remote community, they will be able to access the same high-quality resources and support. This will reduce geographic and systemic inequities, ensuring that care is based on need rather than location or personal networks.

6.5 Benefit 4: Improve understanding of childhood dementia

Childhood dementia remains poorly understood due to the rarity and diversity of the underlying conditions – over 145 distinct genetic disorders are known to cause it, each with different trajectories and care needs. Despite this complexity, Australia currently lacks a centralised system for collecting and analysing data on childhood dementia. The NCDU will accelerate understanding by improving data collection, facilitating access to therapies and building knowledge and capacity across the sector. By connecting researchers, clinicians and carers, the initiative will generate new knowledge about disease progression, treatment efficacy and optimal care approaches. This will help shape future policy, improve clinical decision-making, and ultimately lead to better outcomes for children.

6.6 Benefit 5: Improve efficiency of health and support services

The current system is reactive and fragmented – leading to wasted resources and preventable crises. The NCDU will promote increased coordination of health, disability, education and community supports. This will improve communication between providers and enable earlier intervention. As a result, children with dementia will experience fewer unplanned hospital visits, and providers will be able to deliver care more efficiently. These improvements are expected to increase the cost-efficiency of health services and reduce pressure on emergency services.

Indicative value:

- **Reduction in unplanned ED visits**: It is estimated that the NCDU could reduce unplanned ED visits by 751 each year, resulting in a benefit of **$3.30m** over four years.[36] This could be achieved through the NCDU enabling better management of symptoms and proactive care planning for children.
- **Reduction in unplanned hospitalisations**: It is estimated that the NCDU could reduce unplanned hospitalisations by 258 each year, resulting in a benefit of **$7.13m** over four years.[37] This could be achieved through the NCDU enabling better management of symptoms and proactive care planning for children.
- **Time savings to health professionals**: It is estimated that the NCDU could save 410 hours of health professional each year, resulting in a benefit of **$0.44m** over four years.[38] This could be achieved through

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[35] Assumes an average 30% reduction in the number of pre-diagnosis medical appointments with health professionals. Detailed rationale and limitations are shown in Appendix D. Note this measure only includes time savings to carers before their child has been diagnosed.

[36] Assumes a 30% reduction in unplanned ED visits. Detailed rationale, limitations, and sensitivity analysis are shown in Appendix D.

[37] Assumes a 15% reduction in unplanned hospitalisations. Detailed rationale, limitations, and sensitivity analysis are shown in Appendix D.

[38] Assumes an average 30% reduction in the number of pre-diagnosis medical appointments. Detailed rationale and limitations are shown in Appendix D.

the NCDU enabling access to expertise that enables health professionals to make earlier diagnoses and timely referrals to relevant services.

6.7 Benefit 6: Improve experience of service providers

Many health professionals feel underprepared to support children with dementia due to limited training, expertise and experience. The NCDU will enhance their confidence and effectiveness by offering access to a standardised framework of care, expert advice, education resources and collaborative networks. Health professionals will be better equipped to make informed decisions, manage complex cases and deliver compassionate care. This support will improve job satisfaction, reduce burnout and foster a more capable and resilient workforce.

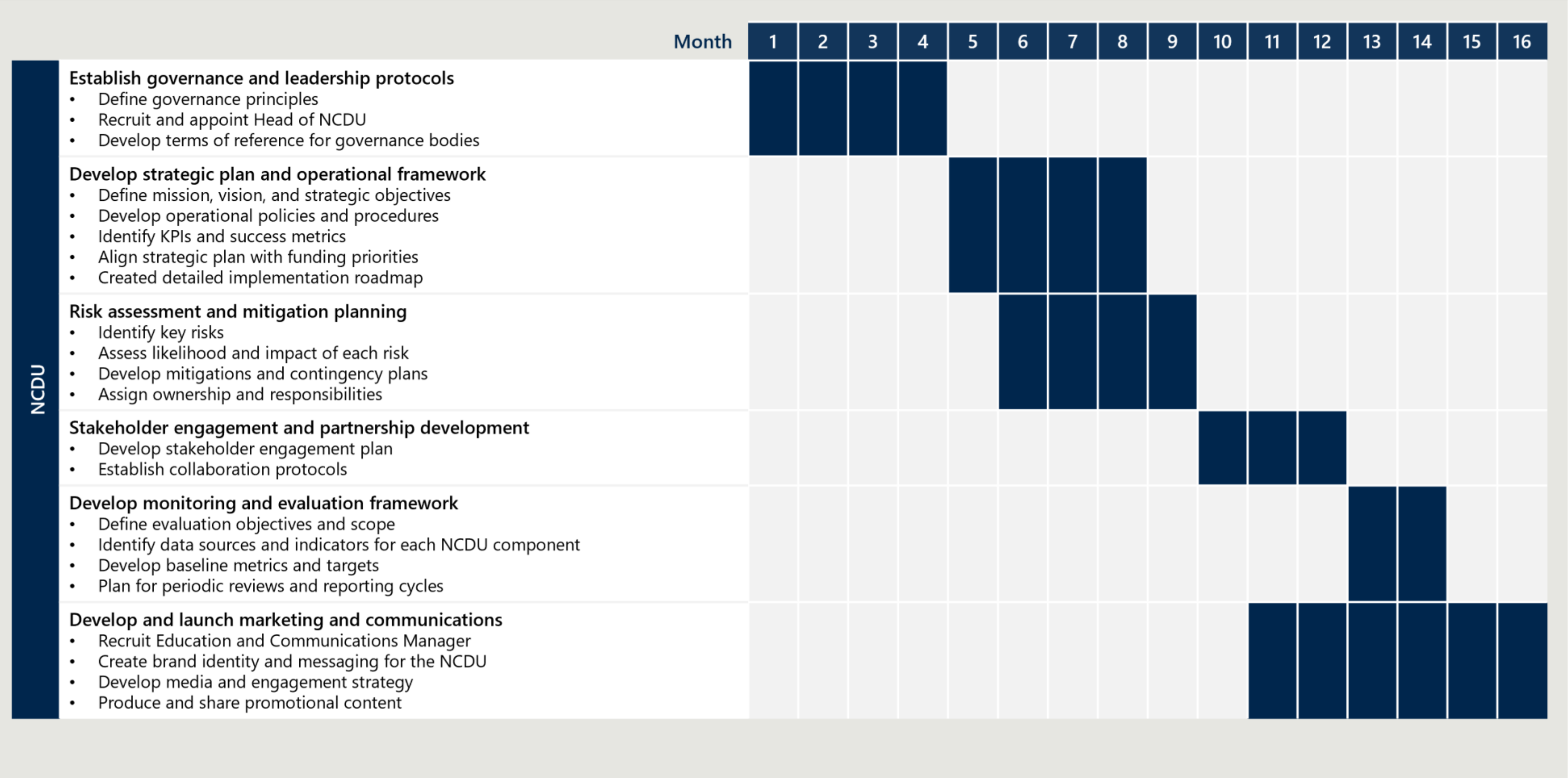
7 Implementation plan

This section outlines the key implementation considerations for launching the NCDU, including the implementation timeline, provisional resource planning, key risks and mitigations, and provisional performance measures.

7.1 Implementation timeline

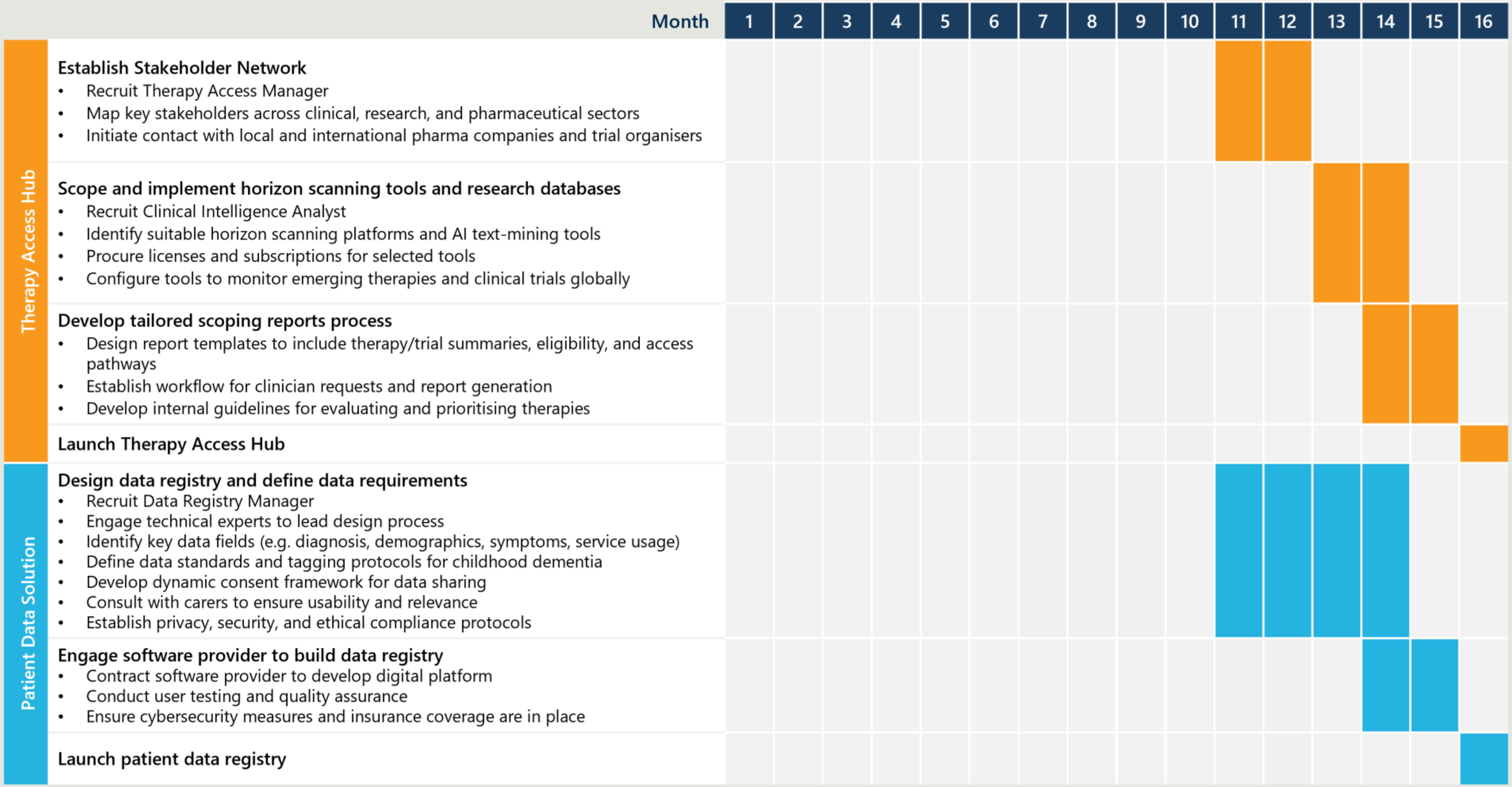
Figure 8 overleaf shows the timeline and phasing of activities that are likely to be required to implement the four NCDU components: Model of Care, National Reference Centre, Therapy Access hub, and Patient Data Solution. Implementation activities and design considerations are staged over 16 months and informed by the detailed design in Section 4.

Figure 8 | NCDU Implementation Plan



	Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
NCDU	**Establish governance and leadership protocols** • Define governance principles • Recruit and appoint Head of NCDU • Develop terms of reference for governance bodies	■	■	■	■												
	Develop strategic plan and operational framework • Define mission, vision, and strategic objectives • Develop operational policies and procedures • Identify KPIs and success metrics • Align strategic plan with funding priorities • Created detailed implementation roadmap					■	■	■	■								
	Risk assessment and mitigation planning • Identify key risks • Assess likelihood and impact of each risk • Develop mitigations and contingency plans • Assign ownership and responsibilities						■	■	■	■							
	Stakeholder engagement and partnership development • Develop stakeholder engagement plan • Establish collaboration protocols										■	■	■				
	Develop monitoring and evaluation framework • Define evaluation objectives and scope • Identify data sources and indicators for each NCDU component • Develop baseline metrics and targets • Plan for periodic reviews and reporting cycles													■	■		
	Develop and launch marketing and communications • Recruit Education and Communications Manager • Create brand identity and messaging for the NCDU • Develop media and engagement strategy • Produce and share promotional content											■	■	■	■	■	■

	Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Model of Care	**Initial scoping of Model of Care requirements** • Recruit Model of Care Manager and Information and Support Manager • Review existing care pathways and guidelines • Identify gaps in current service delivery and care coordination • Conduct stakeholder consultations • Map common symptoms and care needs across conditions • Define scope of care domains • Document key challenges and unmet needs to address					🟥	🟥	🟥	🟥								
	Design Model of Care requirements • Engage and procure consultants for design and project management • Form a multidisciplinary working group including clinical experts, allied health professionals, and lived experience representatives • Develop evidence-based clinical and support guidelines for each stage of care • Define roles and responsibilities of providers across the care journey • Outline referral processes and integration points across health, education, disability, and psychosocial services • Align guidelines with national policies, standards, and latest research • Obtain endorsement from relevant health authorities and peak bodies									🟥	🟥	🟥	🟥	🟥	🟥		
	Develop sharing platforms • Engage designer to develop interactive PDF • Engage app developer and develop app															🟥	🟥
	Develop plan to embed model in service system • Identify priority service settings for initial rollout • Develop outreach strategy to engage health services and professionals • Coordinate with state and territory health departments for integration • Define role of Family Support Coordinator in supporting implementation • Align embedding activities with national guidelines and accreditation standards																🟥
	Launch Model of Care																🟥
National Reference Centre	**Develop National Reference Centre website** • Engage web development team to build secure, user-friendly platform • Integrate referral management tools • Develop content in collaboration with clinical experts and lived experience reps											🟧	🟧	🟧			
	Engage and enrol forum panel members • Recruit Reference Centre Coordinator • Develop role descriptions and expectations for forum participation • Recruit panel members • Confirm availability and secure commitment • Provide onboarding materials • Establish referral and case review protocols											🟧	🟧	🟧	🟧	🟧	
	Launch National Reference Centre																🟧

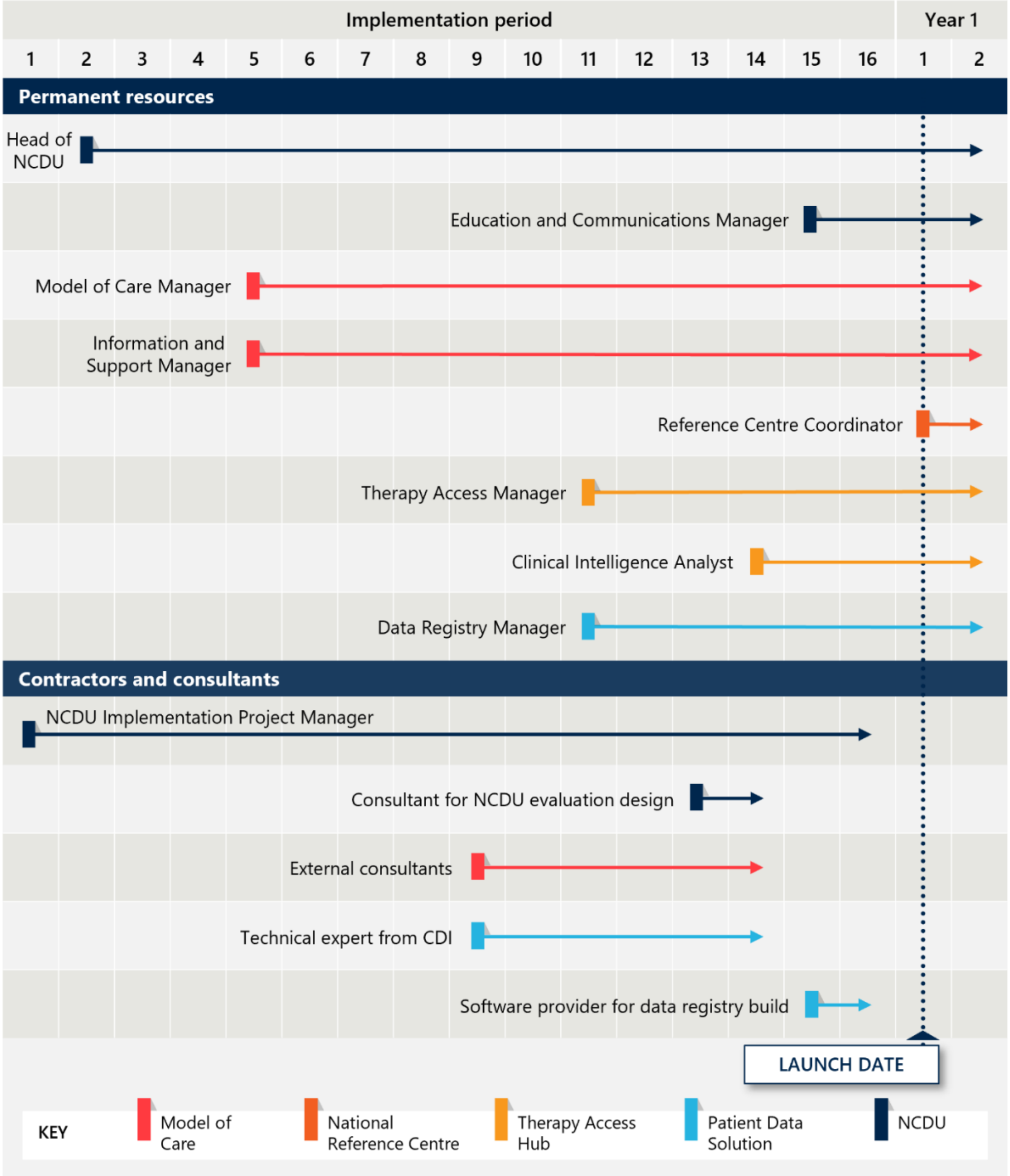


	Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Therapy Access Hub	**Establish Stakeholder Network** • Recruit Therapy Access Manager • Map key stakeholders across clinical, research, and pharmaceutical sectors • Initiate contact with local and international pharma companies and trial organisers											🟧	🟧				
	Scope and implement horizon scanning tools and research databases • Recruit Clinical Intelligence Analyst • Identify suitable horizon scanning platforms and AI text-mining tools • Procure licenses and subscriptions for selected tools • Configure tools to monitor emerging therapies and clinical trials globally													🟧	🟧		
	Develop tailored scoping reports process • Design report templates to include therapy/trial summaries, eligibility, and access pathways • Establish workflow for clinician requests and report generation • Develop internal guidelines for evaluating and prioritising therapies														🟧	🟧	
	Launch Therapy Access Hub																🟧
Patient Data Solution	**Design data registry and define data requirements** • Recruit Data Registry Manager • Engage technical experts to lead design process • Identify key data fields (e.g. diagnosis, demographics, symptoms, service usage) • Define data standards and tagging protocols for childhood dementia • Develop dynamic consent framework for data sharing • Consult with carers to ensure usability and relevance • Establish privacy, security, and ethical compliance protocols											🟦	🟦	🟦	🟦		
	Engage software provider to build data registry • Contract software provider to develop digital platform • Conduct user testing and quality assurance • Ensure cybersecurity measures and insurance coverage are in place														🟦	🟦	
	Launch patient data registry																🟦

7.2 Provisional resource planning

The provisional resource planning for the NCDU is outlined in Figure 9. The Head of NCDU should be onboarded first to establish the NCDU, 16 months before the launch date. The Model of Care Manager should be onboarded 12 months before the launch date to lead the 12-month Model of Care development process. The remaining permanent resources should be onboarded within 6 months of the launch date. External consultants and technical experts from CDI may be engaged in earlier phases to support the design of the NCDU evaluation framework, Model of Care and Patient Data Solution.

Figure 9 | NCDU provisional resource plan



The roles and responsibilities of each resource during the implementation period are as follows:

- **Head of NCDU**: support establishment of governance and leadership protocols, lead development of strategic plan and operation framework, lead risk assessment and mitigation planning, engage stakeholders and partners, and support with implementation of NCDU components.
- **Education and Communications Manager**: create a brand identity for the NCDU, develop a media and engagement strategy, and produce and share promotional content.
- **Model of Care Manager**: scope initial Model of Care requirements, support Model of Care design, develop plan to embed the model in the service system, and manage engagement with consultants, designers and app developers.
- **Information and Support Manager**: support development of the Model of Care and Patient Data Solution and oversee integration with the childhood dementia information and support service.
- **Therapy Access Manager**: establish stakeholder network, scope and implement horizon scanning tools and databases, and develop tailored scoping report processes.
- **Clinical Intelligence Analyst**: support implementation of horizon scanning tools and development of tailored scoping reports process.
- **Data Registry Manager**: support design of the Patient Data Solution and engage software provider to build the data registry digital infrastructure.
- **NCDU Implementation Project Manager**: project manage NCDU implementation, lead the establishment of governance and leadership protocols, resolve issues and recruit key personnel.
- **External Consultants for Model of Care/Eval design**: project manage Model of Care design process, lead stakeholder engagement, and develop the monitoring and evaluation framework.
- **Technical expert from CDI**: project manage design of the Patient Data Solution and defining of data requirements.
- **Software provider**: build the data registry digital infrastructure.

7.3 Risk assessment and mitigation plans

The preliminary risk register for the NCDU in Table 13 outlines key risks across governance, clinical engagement, technology, funding, and stakeholder participation. Each risk is paired with a mitigation strategy to support successful implementation and long-term sustainability. This register provides a foundational framework for proactive risk management and continuous improvement throughout the NCDU rollout.

Table 13 | Preliminary NCDU risk register

Risk	Likelihood	Impact	Mitigation
Limited adoption of the Model of Care across services	Medium	High	Aligning the Model of Care with national guidelines and actively engaging state and territory health departments early in the implementation process to ensure it is fit for purpose.
Limited use of National Reference Centre and Therapy Access Hub from health professionals	Medium	High	Prioritising early and ongoing engagement with clinicians through co-design processes and securing endorsement from peak clinical bodies to build credibility and trust.
Low engagement with Therapy Access Hub due to perceived bias or influence	Medium	High	Maintain strict independence through suitable governance, quality assurance and compliance controls.

Risk	Likelihood	Impact	Mitigation
Lack of awareness or visibility of NCDU among target audiences	Medium	High	A targeted marketing and communications campaign to raise awareness among clinicians and carers leveraging stakeholder networks and digital platforms.
Difficulties or delay in finding suitable candidates for key roles	Medium	Medium	Recruitment planning has been scheduled to begin early in the project timeline.
Low uptake of Patient Data Solution by carers	Medium	High	Designing the registry with a strong focus on user experience. Support carers through onboarding assistance and clear communication of the platform's value and benefits.
Implementation or ongoing activities exceed funding amount	Low	High	Budgets will be monitored carefully throughout program implementation and delivery.
Cybersecurity breach or data privacy incident in Patient Data Solution	Low	High	The NCDU will engage a software provider to build a medical clinical-quality registry that has the same standard of protection as Electronic Medical Records.

7.4 Provisional performance measures

The provisional performance framework for the NCDU in Table 14 overleaf shows clear measures of success across its core components, including care quality, clinical capability, therapy access, data collection, and stakeholder engagement. Data to measure each KPI could be collected using a combination of family surveys, health professional surveys, patient data registry data, and internal performance tracking. This framework will support continuous improvement and accountability throughout the NCDU's implementation and operation.

Table 14 | Provisional NCDU performance measures

Component	KPIs
Overall	• Reduction in carer anxiety (via GAD-7 results) • Time savings reported by carers • Time savings reported by health professionals • Reduction in unplanned ED visits • Reduction in unplanned hospitalisations.
Model of Care	• Number of services adopting the Model of Care • Number of health professionals trained in the Model of Care • Carer-reported confidence in organising care.
National Reference Centre	• Number of cases referred to the Reference Centre • Clinician-reported confidence in managing childhood dementia.
Therapy Access Hub	• Number of tailored scoping reports delivered • Number of clinical trials facilitated or supported • % increase in trial participation among eligible children.
Patient Data Solution	• Number of carers registered in the data platform • % of complete data entries • Compliance with data privacy and security standards.
Marketing and awareness	• Website traffic • Resource downloads • Social media engagement.

8 Conclusion

The NCDU represents a strategic investment to address the longstanding gaps in care, support and research for children living with dementia in Australia. The total funding required to establish and operate the NCDU over five years is estimated at $12.64 million. This includes implementation and ongoing costs for four core components: the Model of Care, National Reference Centre, Therapy Access Hub and Patient Data Solution.

The NCDU is expected to deliver wide-reaching benefits, with an estimated benefit of $61.49 million over four years. These benefits include improved care quality and consistency for patients, reduced anxiety and time burden for carers, enhanced equity of access to services and therapies, better understanding of childhood dementia through data and research and increased efficiency across the health system. The initiative will also support service providers with expert guidance and training, improving their confidence and capacity to deliver compassionate care.

Following this business case, efforts for the NCDU should focus on securing funding, finalising governance arrangements and initiating a phased implementation plan. This will involve recruiting key personnel, engaging stakeholders across health and community sectors and co-designing service components with carers and clinicians. Early and ongoing engagement will be critical to ensure the NCDU is fit-for-purpose and widely adopted. Performance measures and risk mitigation strategies have been outlined to support successful delivery. With strong leadership and collaboration, the NCDU has the potential to transform the landscape of childhood dementia care in Australia and address critical inequities in care for the children living with these conditions.

Appendix A Stakeholder engagement

A.1 Consultations and focus groups

	Organisation	Name	Role	Date
1	Perth Children's Hospital	Maina Cava	Paediatrician and paediatric neurologist	31-Mar
2	University of Melbourne	Samantha Loi	Associator Professor and Registry manager	1-Apr
3	Sydney Children's Hospital Network	Paula Bray	Network Director of Research	9-Apr
4	McGrath Foundation	Kerry Patford	Chief Nurse	15-Apr
5	Prader-Willi	Kathlene Jones	CEO and Founder	21-Apr
6	Canteen	Peter Orchard	CEO	22-Apr
7	National Eating Disorders Collaboration	Hilary Smith	Health Promotion Lead	24-Apr
8	Monash Registries	Susannah Ahern	Co-Divisional Director	28-Apr
9	Women's and Children's Health Network, South Australia	Nick Smith	Consultant Neurologist	12-May
10	ARC Portal	Damien Kee	Medical Oncologist	19-May
11	ARC Portal	Allison Bourne	Project Officer	19-May
12	Cocoon Baby	Esa Fleming	Community Nurse	29-May
13	Sanctuary Continence Nursing	Sharon Baillie	Clinical Nurse Consultant	29-May
14	Health QLD	Rebekah Monk	Nurse	29-May
15	Rare Cancers Australia	Cathy Slattery	Head of Patient Programs	29-May
16	Young Maggies	Catherine Olsson	Founder	2-Jun
17	Murdoch Children's Research Institute	Lottie Morison	Speech pathologist	2-Jun
18	Sydney Children's Hospital Network	Michelle Lorentzos	Clinical Trials Lead	2-Jun
19	Perth Children's Hospital	Karen Twyford	Registered Music Therapist	3-Jun
20	Perth Children's Hospital	Jodie Mazzucchelli	Senior Occupational Therapist	3-Jun
21	Independent support worker	Josefina Cremaschi	Paediatric speech therapist and support worker	3-Jun
22	Sydney Children's Hospital Network	Gloria Tzannes	Head speech pathologist	3-Jun
23	Axia support	Jessica Krushelnisky	Behaviour support practitioner	3-Jun
24	Paediatric Palliative Care	Alyson Gundry	Allied Health Clinical Lead	4-Jun
25	Wesley Mission Queensland	Elham Day	Head of Family Support	4-Jun
26	Paediatric Palliative Care	Anthony Herbert	Nursing Director	4-Jun

	Organisation	Name	Role	Date
27	Child and Adolescent Health Service	Suzanne Kearney	Clinical Lead WA Hospice Project	4-Jun
28	Star Bloom	Jehan Suleiman	Paediatric Neurologist	4-Jun
29	The Sydney Children’s Hospitals Network	Lauren Bradbury	Clinical trials nurse - Kids Neuro Trials	4-Jun
30	Sydney Quantum Academy	Rebecca Halligan	Chief Operating Officer	4-Jun
31	Palliative Care Australia	Josh Fear	National Policy Director	5-Jun
32	Agency for Clinical Innovation	Tracey Szanto	Manager, Disability	5-Jun
33	Grief Australia	Bianca Lavorgna	Manager Clinical Practice and Education	5-Jun
34	Palliative Care Australia	Annette Vickery	Paediatric Projects Manager	5-Jun
35	Agency for Clinical Innovation NSW Health	Rachael Havrlant	Transition Care Network Manager	10-Jun
36	Very Special Kids	Belinda Munn	Physiotherapist	10-Jun
37	UNSW Sydney	Professor Michelle Farrar	Paediatric Neurologist	17-Jun
38	Sydney Children's Hospital	Alex Johnson	Paediatric Neurologist, Geneticist	17-Jun
39	Australian Neimann Pick C Disease Foundation	Deanna Carpino	General Manager	17-Jun
40	Genetic Alliance	Emma Bonser	Chief Executive Officer	17-Jun
41	Sydney Children’s Hospital Network	Carolyn Ellaway	Clinical and Metabolic Geneticist	20-Jun
42	Genetic Alliance	Nicky Conway	Co-Founder and Director	26-Jun
43		Felicity Taylor	Family	30-Jun
44	Queensland Children’s Hospital	Dr Ross Drake	Paediatric Palliative Care	1-Jul
45		Nicole Jamieson	Family	3-Jul
46		Renee Staska	Family	4-Jul
47		Pip Johnston	Family	4-Jul
48		Emad Aziz	Family	8-Jul

A.2 Carer survey results and analysis

Nous distributed a survey to carers of children with a diagnosis of a childhood dementia condition, and those bereaved in the past 2 –3 years. We received 23 responses that were used to understand and quantify the benefits of the NCDU. The responses and analysis that were used in this document are shown below and overleaf. Where average results from survey questions have been used for benefit modelling assumptions in Appendix D.1, values are assigned to each answer and a weighted average is calculated using these values.

Q1: Thinking back to when your child/first child was diagnosed, how much time did you spend in a typical week doing research about the care your child might need?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
1-3 hours	0%	0	1.5	0.0
4-6 hours	17%	4	5	1.0
7-9 hours	13%	3	8	1.1
10-12 hours	17%	4	11	2.1
13+ hours	43%	10	13	6.2
Unsure	9%	2	Excluded	Excluded
Total responses (exc. Unsure)		**21**		**10.4**

Q2: Do you think having access to a clear, easy-to-use reference document that outlined the care your child should receive, and the different health professionals your child should see, would have been beneficial for you?

Answer	Responses (%)	Responses (count)
Yes	90%	19
No	5%	1
Unsure	5%	1

Q3: How much time do you think this reference document would have saved you in a typical week?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
0-3 hours	13%	3	1.5	0.2
4-6 hours	35%	8	5	2.0
7-9 hours	9%	2	8	0.8
10-12 hours	9%	2	11	1.1
13+ hours	22%	5	13	3.3
Unsure	13%	3	Excluded	Excluded
Total responses (exc. Unsure)		**20**		**7.4**

Q4: To what extent would having access to this reference document reduce any anxiety you may feel surrounding the care your child/children receives?

Answer	Responses (%)	Responses (count)
No reduction in anxiety	0%	0
Small reduction in anxiety	26%	6
Moderate reduction in anxiety	17%	4
Large reduction in anxiety	35%	8
Very large reduction in anxiety	22%	5
Total responses (exc. Unsure)		**23**

Q5: How beneficial would a dedicated care coordinator that helped organise care for your child and provided wider support for the family be to you?

Answer	Responses (%)	Responses (count)
Not beneficial	0%	0
Slightly beneficial	0%	0
Moderately beneficial	5%	1
Highly beneficial	14%	3
Very highly beneficial	81%	17
Total responses (exc. Unsure)		**21**

Q6: How beneficial would a service that provides information about emerging treatments and clinical trials that may be suitable for your child/children be to you?

Answer	Responses (%)	Responses (count)
Not beneficial	0%	0
Slightly beneficial	10%	2
Moderately beneficial	10%	2
Highly beneficial	14%	3
Very highly beneficial	62%	13
Unsure	5%	1
Total responses (exc. Unsure)		**20**

Q7: To what extent would having access to this service reduce any anxiety you may feel surrounding the care your child/children receives?

Answer	Responses (%)	Responses (count)
No reduction in anxiety	0%	0
Small reduction in anxiety	13%	3
Moderate reduction in anxiety	17%	4
Large reduction in anxiety	39%	9
Very large reduction in anxiety	30%	7
Total responses (exc. Unsure)		**23**

Q8: Approximately how many appointments with health care professionals did you attend in seeking a diagnosis for your child?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
1-3 appointments	9%	2	2	0.2
4-6 appointments	13%	3	5	0.7
7-9 appointments	9%	2	8	0.7
10-12 appointments	17%	4	11	2.0
13-15 appointments	9%	2	14	1.3
16+ appointments	39%	9	16	6.5
Unsure	4%	1	Excluded	Excluded
Total responses (exc. Unsure)		**22**		**11.4**

Q9: How much time do you spend on a typical appointment with a medical professional, including attending, travelling, preparing for, and following up?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
1-2 hours on average	0%	0	1.5	0.0
2-3 hours on average	22%	5	2.5	0.5
4-5 hours on average	35%	8	4.5	1.6
6-7 hours on average	9%	2	6.5	0.6
8+ hours on average	35%	8	8	2.8
Total responses		**23**		**5.5**

Q10: Approximately how many unplanned visits to the emergency department did your child/children have in the last 24 months?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
0	9%	2	0	0.0
1-2	30%	7	1.5	0.5
3-4	35%	8	3.5	1.2
5-6	22%	5	5.5	1.2
7+	4%	1	7	0.3
Total responses		**23**		**3.17**

Q11: Approximately how many of these unplanned emergency department visits resulted in a hospital admission over the last 24 months?

Answer	Responses (%)	Responses (count)	Assigned value	Weighted average
0	30%	7	0	0
1-2	26%	6	1.5	9
3-4	35%	8	3.5	28
5-6	4%	1	5.5	5.5
7+	4%	1	7	7
Total responses		**23**		**2.15**

Q12: Is there anything else you would like to share about your responses?

Answer
The long term nature of my children's condition exacerbates the impacts.
Our diagnosis was MANY years ago. I don't remember exact details
Can't use ED in Launceston not even for her epilepsy Always left sitting in emergency no eegs on ward not correct specialists or equipment hey we do not Ben hav air conditioning in summer
When your kids are the only two in the country with their life limiting conditions the opportunity to be part of a bigger network of support is enormously beneficial to the children with the diagnosis, their immediate family and their extended family.
Thanks
Some questions are a bit narrow: it would work to have someone whom knew my child's condition BUT grouping together with other conditions could actually be detrimental if the significant differences aren't recognised.
I would also love for health care providers to be more aware of the condition that cause childhood dementia, know the signs and act quickly to give them the best outcomes possible. My child was misdiagnosed three times - as early as nine weeks old - and when we finally received the new diagnosis, he was deemed too old for most treatments and trials. It is my hope to bring wider awareness of childhood dementia so that a major misdiagnosis never happens to another child.

Appendix B NCDU costing methodology and assumptions

Tables 15 - 19 detail the common methodology, rationale, assumptions used for costing the NCDU.

Table 15 | Common costing assumptions

Cost item / parameter	Methodology, data sources and rationale	Assumption
General escalation rate	• The average rise in the Australian Bureau of Statistics (ABS) Consumer Price Index from March 2015 to March 2025 is used to represent inflationary cost increases over time. • The general escalation rate is applied to all non-resource costs starting from Year 1.	General escalation rate: **2.80%**
Resource escalation rate	• The average rise in the Australian Bureau of Statistics (ABS) Wage Price Index from March 2015 to March 2025 is used to represent wage and salary cost increases over time. • The resource escalation rate is applied to all resource costs starting from Year 1.	Resource escalation rate: **2.55%**
Resource on-costs	• The upper end of the IHACPA Pricing Framework for Australian Public Hospital Services range of 25-30% for on-costs for full-time health professionals has been used to reflect superannuation, leave entitlements, and other employee benefits. • An additional 10% has been included to reflect costs for basic software licenses (i.e. Microsoft Office, Adobe), professional memberships, and professional development. • The on-cost rate mark-up is applied to all fixed salary resources in the NCDU.	On-cost markup: **40%**
NCDU implementation project management	• NCDU will engage a contractor to project manage NCDU implementation, lead the establishment of governance and leadership protocols, resolve issues and recruit key personnel. • Contractor base salary will be $160,000. • Onboarding costs and on-cost mark-ups are added on top. • Costs are attributed evenly across NCDU components.	Contractor base cost: **$240,000**
Resource on-boarding costs	• Includes $5,000 for hardware for each salaried resource.	On-boarding cost per resource: **$27,000**

Cost item / parameter	Methodology, data sources and rationale	Assumption
	• Includes $21,000 recruitment cost for each salaried resource to reflect costs associated with job description development, job advertising, and pre-employment checks. This is in line with the Majer Recruitment estimate for average recruitment costs.[39] • Includes $1,000 per resource for financial management (inc. payroll setup, AP/AR integration, financial controls setup, onboarding compliance) • Costs are allocated across NCDU components in line with resource allocations.	
Events and conferences	• The Head of NCDU, Model of Care Manager, Information and Support Manager, Education and Communications Manager, and Therapy Access Lead will attend events and conferences. • Average event cost covers registration, travel/transport, accommodation, and meals. • Costs are allocated across NCDU components in line with resource allocations.	Number of events and conferences per resource each year: **9** Cost per event: **$2,000**
PR and Advertising	• PR and advertising costs include PR agency fees, Search Engine Marketing (SEM) and other online advertising, Search Engine Optimisation (SEO), and collateral design, print, and distribution. • Costs are allocated evenly across NCDU components.	Yearly costs for: • PR agency fees: **$10,000** • SEM and online advertising: **$10,000** • SEO research and content plan budget: **$7,500** • SEO: **$45,000** • Collateral design, print, and distribution: **$20,000**
People and administrative costs	• People and administrative costs represent costs associated with travel, yearly on-site meetings, replacement costs and other employee engagement expenses.	Yearly cost per resource: **$5,000**
Evaluation design	• Evaluation design costs are allocated across NCDU components proportionate to the overall costs of each component.	Per cent of overall cost: **2%**
Evaluation implementation	• Evaluation implementation be timed in line with updates to the Model of Care. • Evaluation implementation costs are allocated across NCDU components proportionate to the overall costs of each component.	Per cent of overall cost: **3.5%**

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[39] Majer Recruitment. 7 Australian recruitment statistics that will change the way you hire. April 2021. https://www.majerrecruitment.com.au/australian-recruitment-statistics/

Table 16 | Model of Care costing assumptions

<table>
<tr><th>Cost item / parameter</th><th>Methodology and rationale</th><th>Assumption</th></tr>
<tr><td>Model of Care design and project management (consultant engagement)</td><td>Consultancy fee represents team including a ‘Principal’ resource (12+ years of experience), a ‘Senior Manager’ resource (7-10 years of experience) and a ‘Junior Consultant’ resource (1-3 years of experience).
Consultants will be engaged for six months (26 weeks) in total.</td><td>Resourcing:
Principal: 0.1 FTE
Senior Manager: 0.4 FTE
Junior consultant: 1 FTE
Day rates:
Principal: $4,000
Senior Manager: $3,000
Junior consultant: $1,400</td></tr>
<tr><td>Multidisciplinary team consultation</td><td>Workshops will run for half a day each and involve medical specialists (including pediatric neurologists, metabolic physicians, and geneticists), allied health workers (including speech therapists, occupational therapists, physiotherapists, and psychologists), pediatric nurses, social workers, and lived experience participants.
Meetings will be virtual and no additional teleconferencing software licenses will be required.
Participants will be compensated with casual hourly rates in line with their market rates:
Medical specialist – determined with reference to rates for comparable positions available on the Western Health website.[40]
Allied health – determined with reference to the Pay Guide - Health Professionals and Support Services Award [MA000027].
Nurses and social worker – determined with reference to the award rates on the AMA Queensland website.[41]
Lived experience – determined with reference to Level 3–5 of Health Professionals Award.
The total hourly cost for workshops is calculated as per the below workings:
<table>
<tr><th>Participant type</th><th>Average attendees per workshop</th><th>Hourly market rate</th><th>Total hourly cost</th></tr>
<tr><td>Medical Specialist</td><td>5</td><td>$250</td><td>$1,750</td></tr>
</table></td><td>Number of workshops: 8
Workshop length: 4 hours
Hourly cost: $2,940</td></tr>
</table>

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[40] Western Health. Salary rates by employment group. Accessed July 2025. https://www.westernhealth.org.au/Careers/Pages/Salary-Rate.aspx

[41] Australian Medical Association Queensland. Change of award rates and superannuation rate 2025. June 2025. https://www.ama.com.au/qld/workplacerelations/changeofawardrates2025

Allied Health	3	$105	$441
Nurses / Social Workers	4	$85	$476
Lived Experience	3	$65	$273
Total	**15**	-	**$2,940**

Cost item / parameter	Methodology and rationale	Assumption
Interactive PDF document development	• Estimated to require 15 days of freelance senior graphic designer time. • Senior designer hourly rate informed by CDI estimate.	Senior designer hourly rate: **$120**
Model of Care interactive app development	• App development represents costs to develop an app with basic features including registration, a resource directory, user login security and access to the data registry. It does not include more costs to develop advanced features including external integrations, AI powered features, and live chats. • Cost estimate was determined with reference to the Tech Go estimated cost range ($35,000 to $120,000) for developing an app with basic features.	App development cost: **$120,000**
Model of Care maintenance and update	• MOC will be reviewed and updated after 1 year, and every 2 years after that as per NSW MOC Development Framework guidance. • Maintenance and update costs are calculated as a percentage of the cost of the initial development (including design time) for each refresh.	Cost per update: **30%** of initial development costs
App maintenance costs	• Includes costs for licensing and hosting, bug fixes, updates, OS compatibility, data protection and privacy updates.	Yearly costs: • Licensing and hosting: **$3,000** • Bug fixes, updates, and OS compatibility: **$10,000** • Data protection and privacy updates: **$2,000**

Table 17 | National Reference Centre costing assumptions

<table>
<tr><th>Item</th><th>Methodology and rationale</th><th>Assumption</th></tr>
<tr><td>Website build</td><td>Website build reflects the costs for building a website or a website extension that primarily serves as a resource directory without built-in referral channels or external integrations.
Cost estimate was determined with reference to the WP Creative estimated cost range ($30,000 - $150,000+) for a basic custom website design.[42]</td><td>Website build cost: $60,000</td></tr>
<tr><td>Reference Centre forum participants</td><td>The Reference Centre forum will meet for half a day per month. Forums will involve medical specialists (including pediatric neurologists, metabolic physicians, and geneticists), allied health workers (including speech therapists, occupational therapists, physiotherapists, and psychologists), pediatric nurses, social workers, and lived experience participants.
One meeting per year will be held in person with $1,000 per person included to cover travel for 20 participants.
Other meetings will be virtual and no additional teleconferencing software licenses will be required.
Participants will be compensated with casual hourly rates that represent their market rate for their time to prepare for and attend meetings.
The total hourly cost is calculated as per the workings below:
<table>
<tr><th>Participant type</th><th>Average attendees per workshop</th><th>Hourly market rate</th><th>Total hourly cost</th></tr>
<tr><td>Medical Specialist</td><td>5</td><td>$250</td><td>$1,750</td></tr>
<tr><td>Allied health</td><td>2</td><td>$105</td><td>$294</td></tr>
<tr><td>Nurses / Social Workers</td><td>2</td><td>$85</td><td>$238</td></tr>
<tr><td>Lived Experience</td><td>2</td><td>$65</td><td>$182</td></tr>
<tr><td>Total</td><td>11</td><td>-</td><td>$2,464</td></tr>
</table></td><td>Number of forums: 12 per year
Forum length: 4 hours
Prep time: 30 mins for each hour of meeting time
Face-to-face meeting cost: $20,000 per year
Hourly cost: $2,464</td></tr>
<tr><td>Content Development</td><td>Educational videos will be an average of 30 minutes long and will be ‘talking head’ style which are appropriate for lectures and expert talks.</td><td>Number of educational videos:
Year 1: 20 videos</td></tr>
</table>

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[42] WP Creative. How much does a website cost in Australia? [Pricing Guide 2025]. *WP Creative*. 2025. https://wpcreative.com.au/how-much-does-a-website-cost-in-australia/

Item	Methodology and rationale	Assumption
	• Production cost per video was determined with reference to Blue Carrot's cost guide of $100 per minute for 'talking head' style videos. • Video production costs include 2 hours of medical professional time per video, compensated at $250 per hour.	• Year 2 onwards: **12** per year Video production cost: $**3,500** per video
Website maintenance	• Website maintenance reflects costs required for domain name rights, web hosting, ongoing maintenance, and stock image and asset licensing.	Yearly costs: • Domain name rights: $**50** • Web hosting: $**1,200** • Ongoing maintenance: $**6,000** • Stock image and asset licensing: $**1,000**

Table 18 | Therapy Access Hub costing assumptions

Item	Methodology and rationale	Assumption
Horizon scanning database subscriptions and tools	• Horizon scanning database subscriptions reflect subscription costs for resources such as Biointelect Horizon Scanning Reports and IQVIA. • Horizon scanning tools reflect implementation and licensing costs for AI tools such as IBM Micromedex / Merative, Clarivate Cortellis and GlobalData Pharma Intelligence Center. • Implementation will include setting up horizon scanning tools and tailoring dashboards, alerts, and analytics to NCDU specifications.	Implementation cost: **$75,000** Ongoing yearly costs • Horizon scanning database subscriptions: $**50,000** • Horizon scanning tools: $**50,000**

Table 19 | Patient Data Solution costing assumptions

Item	Methodology and rationale	Assumption
Patient data solution design and project management	• NCDU will engage a contractor to project manage data registry development, conduct research, and define requirements over a period of six months. • Contractor base salary will be $160,000. • Onboarding costs and on-cost mark-ups are added on top.	Contractor base cost: **$75,000**

Item	Methodology and rationale	Assumption
Legal advice and assessment	- Legal advice will be required to develop guidelines for Patient Data Solution.	Legal time: **75** hours Cost: $**500** per hour
Registry software build	- Registry software build reflects software development costs for Patient Data Solution. - Costs are determined with reference to cost estimates provided by WeGuide with a contingency added on top.	Build cost: $**44,000**
User testing and quality assurance	- Basic user testing and quality assurance testing will be required for the Patient Data Solution - Cost estimates are determined with reference to Tech Brains estimated cost range ($15,000 - $50,000) for user testing and quality assurance.[43]	User testing and quality assurance cost: $**30,000**
Integration with CDI Salesforce	- Integration with CDI Salesforce reflects the cost of integrating Patient Data Solution with the Salesforce CRM platform. - Costs are determined with reference to cost estimates provided by WeGuide.	Integration cost: $**16,000**
Ongoing IT support and registry maintenance	- Ongoing IT support and registry maintenance reflects ongoing maintenance and IT support costs associated with the Patient Data Solution. - Costs are determined with reference to cost estimates provided by WeGuide.	Yearly cost: $**53,000**
Public Liability and Cybersecurity insurance	- Public liability and cybersecurity insurance reflects costs for insurance cover for incident response, notification costs, data restoration, business interruption, cyber extortion, crisis management, and third-party liability.	Yearly cost: $**25,000**

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[43] Jones, S. A complete guide to healthcare app development cost in 2025. Tech Brains Blog. November 2024. https://www.technbrains.com/blog/healthcare-app-development-cost/

Appendix C NCDU benefit logic

Model of Care

Benefit	Logic and evidence
Improve patient care, access and equity by embedding evidence-based care practices.	Embedding evidence-based care practices through a structured Model of Care is a proven method for integrating clinical pathways and standardised processes into healthcare systems.[44] This approach is critical for minimising unwarranted variation in service delivery, which has been identified by Eide et al. (2023) as a key strategy for enhancing patient outcomes and ensuring equitable access to care.[45]
Improve support for carers by providing structured guidance on care options that incorporate psychosocial support.	The Model of Care will substantially reduce the coordination burden on carers by clearly outlining the roles, responsibilities and referral pathways for health professionals at each stage of care. This clarity helps ensure that care coordination does not default to parents, and the availability of structured, evidence-based pathways via an intuitive digital app will support carers in anticipating disease progression and care needs. Incorporating psychosocial support into these pathways has been shown to significantly improve carers' quality of life and reduce symptoms of depression and anxiety.[46]
Improve efficiency and experience of support services and through structured planning and coordination of health and community services.	Research by Duan-Porter et al. (2021) demonstrates that coordination interventions using systematic strategies to address fragmentation and promote continuity of care can lead to reductions in hospitalisations and emergency department visits.[47] The Model of Care supports this by enhancing family understanding of available care options, streamlining referrals between providers, and facilitating timely, proactive symptom management.

National Reference Centre

Benefit	Logic and evidence
Improve care for patients by enabling greater access to timely care due to streamlined diagnosis pathways.	The National Reference Centre will significantly reduce diagnostic delays by providing clinicians with direct access to expert multidisciplinary input early in the diagnostic process. Rather than navigating prolonged referral pathways, paediatricians, neurologists, and geneticists can consult the Centre's expert panel to expedite decision-making. Baynam et al. (2024) highlight that expert panels and virtual reference centres enhance diagnostic precision and reduce time to diagnosis for rare diseases, thereby alleviating pressure on carers and the broader healthcare system.[48]

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[44] Lavelle, J., Schast, A., & Keren, R. *Standardizing care processes and improving quality using pathways and continuous quality improvement*. 2015. https://doi.org/10.1007/s40746-015-0026-4

[45] Eide, H.P., Barach, P., Søreide, E., Thoresen, C., & Tjomsland, O. *Managing unwarranted variation in hospital care – findings from a regional audit in Norway. Res Health Serv Reg*. 2023. https://doi.org/10.1007/s43999-023-00033-7

[46] Lee, J.Z.J., Chen, H.C., Lee, J.X., & Klainin-Yobas, P. *Effects of psychosocial interventions on psychological outcomes among caregivers of advanced cancer patients: a systematic review and meta-analysis*. 2021. https://doi.org/10.1007/s00520-021-06102-2

[47] Duan-Porter, W., Ullman, K., Majeski, B., Miake-Lye, I., Diem, S., & Wilt, T.J. *Care coordination models and tools—systematic review and key informant interviews*. 2022. https://doi.org/10.1007/s11606-021-07158-w

[48] Baynam, G., Baker, S., Steward, C., Summar, M., Halley, M., & Pariser, A. *Increasing diversity, equity, inclusion, and accessibility in rare disease clinical trials*. 2024. https://doi.org/10.1007/s40290-024-00529-8

Improve equity of service access and understanding of childhood dementia by uplifting standards of knowledge and care.	By offering virtual access to specialist expertise, the National Reference Centre ensures that clinicians across Australia - regardless of location - can deliver consistent, high-quality care for children with dementia. [49] This model is expected to reduce geographic disparities in outcomes, aligning with Chandrakar's (2024) findings that virtual reference centres improve access to specialised care in underserved regions. [50] Over time, engagement with the Centre will also build local capability, as health professionals gain confidence and competence through regular interaction with experts. [51]
Improve experience for service providers by providing them with expertise and capability uplift.	The National Reference Centre will serve as a trusted source of knowledge and support for health professionals, enhancing their ability to deliver informed, high-quality care. Through webinars, training sessions, and case discussions, the Centre will facilitate ongoing knowledge transfer and professional development. Feedback from consulted providers indicates that access to expert guidance improves clinical confidence, enhances job satisfaction, and may help mitigate burnout.

Therapy Access Hub

Benefit	Logic and evidence
Improve support for carers and health professionals by developing personalised reports on emerging therapies and trials	The Therapy Access Hub will ease the burden on carers, who often spend extensive time searching for clinical trials, by equipping health professionals with tailored "concierge" support to identify emerging therapies for each child. This proactive approach not only saves time but also helps reduce anxiety for carers by assuring them that all viable treatment options have been explored.
Improve equity of access for emerging treatments and clinical trials.	By serving as a national connector and facilitator, the Therapy Access Hub ensures that access to innovative therapies and trials is driven by clinical need and eligibility rather than location or personal networks. Adachi et al. (2023) emphasise that national coordination and strategic promotion of emerging treatments are essential to overcoming disparities in access and ensuring equitable care. [52]
Improved patient care and understanding of childhood dementia by facilitating more clinical trials and synthesising insights.	The Therapy Access Hub will play a pivotal role in advancing research by coordinating clinical trial opportunities and synthesising insights across the sector. Acting as a broker between clinicians, researchers, and industry, the Hub will help attract and facilitate innovative trials in Australia, an essential step toward improving outcomes for children with rare conditions. [53]

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[49] Doarn, C.R. Advancing Telehealth to Improve Access to Health in Rural America. In: Doarn, C.R. (eds) *Telemedicine, Telehealth and Telepresence*. November 2020. https://doi.org/10.1007/978-3-030-56917-4_11

[50] Chandrakar, M. *Telehealth and digital tools enhancing healthcare access in rural systems*. 2024. https://doi.org/10.1186/s12982-024-00271-1

[51] *Health Services and Outcomes Research Methodology*. https://link.springer.com/journal/10742

[52] Adachi, T., El-Hattab, A.W., Jain, R., et al. *Enhancing equitable access to rare disease diagnosis and treatment around the world: a review of evidence, policies, and challenges*. 2023. https://doi.org/10.3390/ijerph20064732

[53] Nabbout, R., & Hilgers, R.D. *Innovative methodologies for rare diseases clinical trials*. 2024. https://doi.org/10.1186/s13023-024-03189-8

Patient Data Solution

Benefit	Logic and evidence
Identification of eligible children for emerging therapies and clinical trials	The Patient Data Solution will accelerate research into childhood dementia by enabling the identification of suitable participants for clinical trials. Clinicians consulted during development noted that pharmaceutical companies often require access to patient registry data to justify investment in trial sites. Establishing such a registry in Australia is expected to increase the availability of local clinical trials for children with dementia.
Improved support for carers by streamlining data collection and sharing between service providers	By creating a centralised, integrated record accessible to authorised providers, the Patient Data Solution will reduce the need for carers to repeatedly provide the same information across services. Carers can securely share data as needed, enabling providers to make faster, more informed decisions. Research by Karam et al. (2021) shows that streamlined data sharing improves continuity, accessibility, and safety of care for patients with complex needs. [54]
Improve understanding of childhood dementia and improving health outcomes.	The Patient Data Solution will support the NCDU in tracking health outcomes over time, enabling comparisons of treatment effectiveness and informing evidence-based care. A systematic review of health outcome measurement found that data registries significantly improve patient outcomes by supporting continuous learning and quality improvement in healthcare delivery. [55]

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[54] Karam, M., Chouinard, M.-C., Poitras, M.-E., et al. *Nursing care coordination for patients with complex needs in primary healthcare: a scoping review*. March 2021. https://doi.org/10.5334/ijic.5518

[55] Kampstra, N.A., Zipfel, N., van der Nat, P.B., et al. *Health outcomes measurement and organizational readiness support quality improvement: a systematic review*. December 2018. https://doi.org/10.1186/s12913-018-3828-9

Appendix D Benefit modelling methodology and assumptions

D.1 Detailed assumptions

Tables 20 - 26 detail the methodology, rationale, and assumptions for the common parameters used to quantify the benefits of the NCDU.

Table 20 | Common benefit modelling assumptions

Parameter	Methodology and rationale	Assumption value
Number of children with Childhood Dementia	• **Definition:** The total number of children with a childhood dementia diagnosis in Australia that will benefit from the NCDU. This assumption is used in measures 1, 4, and 5 to measure the overall impact across all children with dementia in Australia. • **Methodology and data source:** The number of children is calculated with prevalence-based modelling using incidence and life expectancy of untreatable conditions in the *Collective Burden of Childhood Dementia supplementary material*[56] and ABS's Count of Registered Births from 1940 - 2023.[57] • **Rationale:** Prevalence based modelling is used to estimate the prevalence of childhood dementia as there are no available datasets that records children with dementia in Australia. Only untreatable conditions are included in this analysis as children with treatable conditions are likely to have lower care needs and benefit less from the NCDU. • **Data quality and limitations:** 76 Childhood Dementia conditions have been excluded from this analysis due to a lack of reliable incidence and life expectancy data on these conditions. While these are expected to be the rarer conditions, the cohort size used in this report likely slightly underestimates the number of children with dementia in Australia.	**1,601** children with Childhood Dementia
New cases of Childhood Dementia per year	• **Definition:** The total number of new diagnosed cases of childhood dementia in Australia each year. This assumption is used in measures 2, 3 and 6 to measure the overall impact across all newly diagnosed children with dementia in Australia. • **Methodology and data source:** The number of new cases is calculated using the incidence treatable and untreatable conditions in the *Collective Burden of Childhood Dementia supplementary material*[58] and the ABS's Count of Registered Births in 2023.[59]	**240** new cases per year

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[56] Kenyon, C.C., Vasan, A., Fiks, A.G., et al. *Inequities in time spent coordinating care for children and youth with special health care needs*. March 2023. https://doi.org/10.1016/j.acap.2023.03.002

[57] Australian Bureau of Statistics. October 2024. https://www.abs.gov.au/statistics/people/population/births-australia/latest-release

[58] Elvidge, K., Christodoulou, J. Farrar, M. et al. *The collective burden of childhood dementia: a scoping review*. Brain. July 2023. https://doi.org/10.1093/brain/awad242

[59] Australian Bureau of Statistics. October 2024. https://www.abs.gov.au/statistics/people/population/births-australia/latest-release

Parameter	Methodology and rationale	Assumption value
	• **Rationale:** Both treatable and untreatable conditions are included in this analysis as all children with treatable conditions are expected to benefit from streamlined diagnosis pathways. • **Data quality and limitations:** 76 Childhood Dementia conditions have been excluded from this analysis due to a lack of reliable incidence and life expectancy data on these conditions. While these are expected to be the rarer conditions, the cohort size used in this report likely slightly underestimates the number of new cases of childhood dementia in Australia.	

Table 21 | Measure 1: Reduction in anxiety for carers assumptions

Parameter	Methodology and rationale	Assumption value
Number of affected carers	• **Definition**: The number of primary carers of children with a childhood dementia diagnosis in Australia that will benefit from the NCDU. • **Data source and methodology:** Assumption of one primary carer per child is best practice for service planning in line with guidance and definitions from ABS and AIHW. • **Rationale**: In instances where children have multiple carers, it is assumed that anxiety is caused by the burden of caretaking and any improvements because of the NCDU is shared (i.e. in the instance of two caretakers, any improvements in anxiety of each will be half as significant compared to instances with one caretaker.).	**1 carer** per child with childhood dementia condition
Increased number of carers with anxiety (compared to general population)	• **Definition**: the increase in the proportion of carers who experience different severity levels of anxiety compared to the average population. • **Data source and methodology:** Calculated assuming that the proportion of carers is 8%, 6%, and 17% higher than the general Australian population. This is in line with UNSW report findings of the percentage of carers scoring in the 'mild', 'moderate' and 'severe' range of the GAD-7 test (36%, 17%, and 26% respectively) compared to the general Australian population (28%, 11%, and 9% respectively).[60]	Increased number of carers with anxiety: • Mild anxiety: **128** • Moderate anxiety: **96** • Severe anxiety: **272**
Proportion of carers with anxiety reductions	• **Definition**: the percentage reduction in the increased rate of anxiety in carers that could be caused by the NCDU. • **Data source and methodology**: Calculated assuming a 63% reduction in the increased number of carers with anxiety (compared to general population). This reduction is in line with the proportion of carers who predict a 'large' or 'very large' reduction from having access to a Model of Care document (57%) and the Therapy Access Hub (69%) in Q4 and Q7 of the Carer survey (see Appendix A.2).	Number of carers with: • Reduced anxiety from mild to minimum: **81** • Reduced anxiety from moderate to mild: **61**

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[60] Nevin, *Beyond the Diagnosis: An in-depth, Mixed-Methods Study investigating the Psychosocial, Financial and Psychological Struggles of Childhood Dementia on Caregivers and Families.*

<table>
<tr><th>Parameter</th><th>Methodology and rationale</th><th>Assumption value</th></tr>
<tr><td></td><td>

Rationale: This reflects the impact that the NCDU is anticipated to have in terms of alleviating the pressure on carers to "project manage" care for their child and reduce uncertainty over whether their child is receiving the best care and emerging treatments they possibly can.
Data quality and limitations: due to limited availability of reliable reference points, this assumption has been made under some uncertainty. The sensitivity analysis below outlines how the estimated benefit of Measure 1 is influenced by changes in this assumption:
<table>
<tr><th>Decreased number of carers with anxiety</th><th>Measure 1 yearly benefit ($m)</th></tr>
<tr><td>40% reduction</td><td>5.38</td></tr>
<tr><td>50% reduction</td><td>6.73</td></tr>
<tr><td>**63% reduction**</td><td>**8.48**</td></tr>
<tr><td>70% reduction</td><td>9.42</td></tr>
<tr><td>80% reduction</td><td>10.76</td></tr>
</table>

</td><td>

Reduced anxiety from severe to moderate: **171**

</td></tr>
<tr><td>Economic value of decreased anxiety</td><td>

Definition: Carer quality of life is adjusted according to the decline in utility weight that corresponds with GAD-7 scores for mild, moderate, and severe anxiety.
Data source and methodology: The economic value of decreased anxiety is determined by mapping utility weights to GAD-7 score range. The benefit in Quality-Adjusted Life Year (QALY) terms is calculated from the difference between utility weights of different levels of anxiety.

Utility weights are mapped to GAD-7 scores according to correlation analysis performed by Franklin & Hernández Alava (2023). Detailed utility weight mapping methodology is outlined below:

<table>
<tr><th>Level of anxiety</th><th>GAD-7 Score</th><th>Mapped utility weight</th><th>Rationale for utility weight mapping</th></tr>
<tr><td>Minimal</td><td>0-4</td><td>0.93</td><td>Franklin & Hernández Alava (2023) found that a GAD score of 0 corresponds with a predicted utility weight of 0.93-0.95. The lower end of this range is assumed to be the predicted utility value of GAD-7 scores in the minimal (0-4) range.</td></tr>
</table>

</td><td>
QALY benefit per carer with:

Reduced anxiety from mild to minimum: **0.05**
Reduced anxiety from moderate to mild: **0.08**
Reduced anxiety from severe to moderate: **0.15**

Economic value of QALY: **$245,000**
</td></tr>
</table>

<table>
<tr><th>Parameter</th><th>Methodology and rationale</th><th>Assumption value</th></tr>
<tr><td></td><td>
<table>
<tr><td>Mild</td><td>5-9</td><td>0.88</td><td rowspan="2">Although there are no published utility weights for moderate (10–14) and mild (5–9) GAD-7 scores, they are assumed to fall between the weights for scores of 0 (0.93–0.95) and 21 (0.55), based on Franklin & Hernández Alava (2023). A logarithmic distribution of utility weights across GAD-7 scores is used to reflect the disproportionately greater impact of severe anxiety on quality of life. This aligns with AIHW's Burden of Disease Study utility weights for anxiety disorders.</td></tr>
<tr><td>Moderate</td><td>10-14</td><td>0.80</td></tr>
<tr><td>Severe</td><td>15-21</td><td>0.65</td><td>Franklin & Hernández Alava (2023) found that a GAD score of 21 corresponds with a predicted utility weight of 0.55-0.60. The predicted utility value is assumed to be 0.65 for the severe range (scores of 15-21) reflecting that GAD-7 scores in the lower end of the severe range will likely correspond with slightly higher utility weights.</td></tr>
</table>
Utility weights are converted into economic values using the Commonwealth Office of Impact estimate for a Value of Statistical Life Year.
Rationale: Utility weights are used to quantify health impacts as per guidance from the Medical Services Advisory Council.
</td><td></td></tr>
</table>

Table 22 | Measure 2: Time savings to carers from standardising ongoing care assumptions

Parameter	Methodology and rationale	Assumption value
Carer time spent coordinating care	• **Definition**: average weekly time commitment for carers to coordinate ongoing care and treatments for their child in the first year after receiving a diagnosis. Tasks include scheduling appointments, communicating with multiple providers, managing insurance and referrals, researching innovative therapies, liaising with clinical organisers and educational services. • **Data source:** This assumption draws from the weighted average of responses to Q1 in the carer survey (Appendix A.2) • **Rationale and data limitations**: In absence of data on the childhood dementia cohort, children with complex SHCN are used as a proxy as a cohort with similar care needs. This assumption does not account for cohort differences and differences between care systems in the USA and Australia.	**10.4 hours** per week
Time reduction spent coordinating care due to NCDU	• **Definition**: estimated reduction of time required from carers to coordinate ongoing care and treatments for their child resulting from having access to the Model of Care and Therapy Access Hub.	**7.4** hours saved per week

Parameter	Methodology and rationale	Assumption value
	- **Data source:** This assumption draws from the weighted average of responses to Q3 in the carer survey (Appendix A.2) - **Rationale**: Assumption reflects a relatively small reduction in caretaker hours required to coordinate care due to being able to access a clear, easy-to-use reference document that outlined care options for children. This is anticipated to save time communicating with providers, managing referrals, and coordinating therapies and educational services	
Value of carer time savings	- **Definition**: Time savings for carers are valued in terms of the opportunity cost of lost personal time. - **Data source and methodology:** Commonwealth Office of Impact Analysis recommended a leisure time value of $32 per hour in Feb 2019. This has been indexed to March 2025 using the Wage Price Index. - **Rationale**: Valuing time savings as leisure time appropriately measures the benefits to increase personal time, personal wellbeing, and other hidden costs of caregiving without assuming time savings for carers will directly translate to increased employment, earnings, or other economic benefits.	**$38.81** per hour

Table 23 | Measure 3: Time savings for carers from streamlining diagnosis pathways assumptions

Parameter	Methodology and rationale	Assumption value
Average number of appointments required for a diagnosis	- **Definition**: The average number of medical appointments that children and carers attend before receiving a diagnosis for a childhood dementia condition. - **Data source:** This assumption draws from the weighted average of responses to Q8 in the carer survey (Appendix A.2)	**11.4** appointments
Hours required from carers per appointment	- **Definition**: Average time requirement for carers to prepare for, attend, travel to, and follow-up medical appointments. - **Data source:** This assumption draws from the weighted average of responses to Q5 in the carer survey (Appendix A.2)	**5.5** hours
Cases referred to National Reference Centre	- **Definition**: The percentage of childhood dementia cases (from Table 21) that are referred to and the National Reference Centre. - **Rationale**: Assumption reflects that not all cases will be referred to the National Reference Centre due to variability in referral practices, awareness, and system integration.	**50%** referral rate
Reduction in pre-diagnosis appointments	- **Definition:** The percentage reduction in the average number of appointments required for a diagnosis resulting from the National Reference Centre. - **Rationale:** Assumption reflects a moderate reduction in the number of appointments resulting from medical practitioners being able to make earlier diagnosis and streamlined referrals resulting from improved access to expertise as part of the National Reference Centre.	**30%** reduction

Parameter	Methodology and rationale	Assumption value
Value of carer time savings	• See Table 22 for definition, methodology, data source and rationale.	**$38.81** per hour

Table 24 | Measure 4: Reduction in unplanned ED visits assumptions

Parameter	Methodology and rationale	Assumption value
Unplanned Emergency Department (ED) visits	• **Definition**: Refers to a patient presenting to the emergency department without a scheduled appointment, typically due to sudden or unexpected health issues. • **Data source:** This assumption draws from the weighted average of responses to **Q10** in the carer survey (Appendix A.2). The weighted average has been halved to derive a yearly average.	**1.59** unplanned ED visits a year per child

Reduction in unplanned ED visits	• **Definition**: The percentage reduction in unplanned ED visits resulting from the NCDU.
	• **Data source and methodology:** This assumption is made with reference to:
	  • Simon et al. (2014) reports on average 30% reduction in ED visits because of coordinated care for Children with Medical Complexity.
	  • Kuo et al. (2011) reports on average 25-40% reduction in ED visits because of effective care coordination for Children with Medical Complexity.
	• **Rationale and data limitations**:
	  • In absence of childhood dementia cohort data, Children with Medical Complexity are used as a proxy as a cohort with similar care needs. This assumption does not account for any cohort differences or differences between care systems in the USA and Australia.
	  • Effective coordination in Simon et al. (2014) and Kuo et al. (2011) is used as a proxy for the impact of the NCDU, however this is unlikely to be a perfect representation of the impact of the NCDU.
	  • Due to limited availability of reliable reference points, this assumption has been made under some uncertainty. The sensitivity analysis below outlines how estimated benefit of Measure 4 is influenced by changes in this assumption:
		30% reduction

Reduction in ED visits	Measure 4 yearly benefit
10% reduction	0.26
20% reduction	0.53

Parameter	Methodology and rationale	Assumption value
	30% reduction **0.79** 40% reduction 1.06 50% reduction 1.32	
Cost per ED visit	• **Definition**: The average cost of each unplanned visit to the ED. • **Data source and methodology:** This assumption was made with reference to the national average cost of ED presentation as per the IHACPA National Hospital Cost Data Collection, 2022-2023. • **Rationale and data limitations**: The national average cost of an ED visit has been used due to a lack of available data specific to children with dementia.	**$1,040** per ED visit

Table 25 | Measure 5: Reduction in unplanned hospitalisations assumptions

Parameter	Methodology and rationale	Assumption value
Unplanned hospitalisations	• **Definition**: An unplanned hospitalization occurs when a patient is admitted to hospital urgently or unexpectedly, rather than through a scheduled or elective process • **Data source:** This assumption draws from the weighted average of responses to **Q11** in the carer survey (Appendix A.2). The weighted average has been halved to derive a yearly average. • **Rationale and data limitations**: In absence of data on the childhood dementia cohort, Children with Medical Complexity are used as a proxy as a cohort with similar care needs. This assumption does not account for cohort differences and differences between care systems in the USA and Australia.	**1.08** unplanned hospitalisations a year per child
Reduction in unplanned hospitalisations	• **Definition**: The percentage reduction in unplanned hospitalisations visits resulting from the NCDU. • **Rationale:** This assumption is assumed to be half the magnitude of the change to unplanned ED visits (See Table 24) as cases requiring hospitalisations are more likely to have more significant underlying health issues that will not be averted by NCDU interventions. • **Data limitations**: • Due to limited availability of reliable reference points, this assumption has been made under some uncertainty. The sensitivity analysis below outlines how estimated benefit of Measure 4 is influenced by changes in this assumption:	**15%** reduction

<table>
<tr><th>Parameter</th><th>Methodology and rationale</th><th>Assumption value</th></tr>
<tr><td></td><td><table>
<tr><th>Reduction in hospitalisations</th><th>Measure 5 yearly benefit</th></tr>
<tr><td>10% reduction</td><td>0.57</td></tr>
<tr><td>20% reduction</td><td>1.14</td></tr>
<tr><td>30% reduction</td><td>1.71</td></tr>
<tr><td>40% reduction</td><td>2.28</td></tr>
<tr><td>50% reduction</td><td>2.85</td></tr>
</table></td><td></td></tr>
<tr><td>Cost per hospitalisation</td><td>• Definition: The average cost of each unplanned hospital visit.
• Data source and methodology: This assumption was made with reference to the national average cost of acute admission as per the IHACPA National Hospital Cost Data Collection, 2022-2023.
• Rationale and data limitations: The national average cost of acute admission has been used due to a lack of available data specific to children with dementia.</td><td>$6,619 per hospitalisation</td></tr>
</table>

Table 26 | Measure 6: Time savings to health professionals assumptions

Parameter	Methodology and rationale	Assumption value
Average number of appointments required for a diagnosis	• See Table 23 for definition, data source, and methodology.	**11.4** appointments
Cases referred to National Reference Centre	• See Table 23 for definition and rationale.	**50%** referral rate
Reduction in pre-diagnosis appointments	• See Table 23 for definition and rationale.	**30%** reduction

Parameter	Methodology and rationale	Assumption value
Hours required from health professional per appointment	- **Data source and methodology:** Assumes 45 minutes per appointment and 15 minutes of preparation and note-taking time.	**1 hour** per appointment
Value of health professional time savings	- **Definition**: Time savings for health professionals are valued in terms of consultation cost. - **Data source and methodology:** This assumption was estimated with reference to the cost of a consultation with a pediatrician as per Medicare Benefits Schedule item 132: Initial attendance by a consultant physician. - **Rationale**: The consultation cost is used to value time savings, as this best reflects the benefit to the health system of each reduced appointments.	**$258.80** per hour

D.2 Excluded quantitative measures

The quantitative measures in Table 27 have not been included in the benefit analysis due to the unavailability of baseline data and outcomes from comparable initiatives. We have explored each benefit category qualitatively but have not been able to gather necessary modelling inputs to quantify them.

Table 27 | Quantitative measures excluded from benefit analysis

Benefit Category	Possible quantitative measures	Rationale for exclusion in quantitative analysis
Improved care for patients	Improved child quality of life	• No cohort data or appropriate proxy for measuring changes in health condition due to implementing a Model of Care, National Reference Centre or Patient Data Solution • In-direct causal relationship between the NCDU and the benefit.
Improved support for carers	Reduction in prevalence of other health conditions (including depression, grief, etc.)	• No data on current prevalence of depressive disorders in carers. • This measure may over-lap and double-count benefits with reduced anxiety disorders.
	Reduction in carer time taken to research innovative treatments	• No data on or appropriate proxy for current time requirements for researching innovative treatment
Reduced costs to government	Reduction in clinician time taken to research appropriate care options	• No data on or appropriate proxy for current time requirements for clinicians to research appropriate care options for children with dementia. • The causal relationship between the NCDU and benefit measure is relatively in-direct.
	Reduction in clinician time taken to facilitate clinical trials	• No data on or appropriate proxy for current time requirements to facilitate clinical trials.
	Reduction in Health / NDIS service utilisation	• No appropriate proxy for measuring changes in service efficiency from implementing a Model of Care, National Reference Centre or Patient Data Solution • The causal relationship between the NCDU and benefit measure is relatively in-direct.
Other	Economic benefits from increased carer productivity	• Carer time savings is more appropriately valued as ‘time savings to carers’ rather than increased productivity to the economy as per health economics evaluation best practice. Doing both would be double counting. • The causal relationship between the NCDU and benefit measure is relatively in-direct.

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