Childhood Dementia Global Consensus

Project Brief

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Contents

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Background

The Childhood Dementia Initiative (CDI) is leading a global consensus project on childhood dementia definition and terminology. This strategic initiative will establish international agreement through a structured consensus methodology facilitated by 67health, a UK-based independent health consultancy. As outlined below, this project is a critical first step towards strengthened global advocacy and accelerated treatment development and improved clinical care and support.

About childhood dementia

A landmark burden of disease study published in 2023 identified over 145 rare genetic disorders that cause childhood dementia which is characterised by progressive neurocognitive decline with onset before the age of 18[1]. The study estimated that collectively, these conditions:

- Affect approximately 1 in 2,900 births
- Cause a similar number of deaths as childhood cancer in high income countries
- Have a median life expectancy of just 9 years
- Result in death before adulthood in 70% of cases

There are limited treatment options and very few clinical trials for children with dementia. For the treatments and trials that do exist, early diagnosis and treatment is essential, however diagnosis is typically delayed by 2+ years.[2]

Childhood dementia has profound psychological, social, and economic impacts on families, yet current care and support services are not meeting their complex needs.[3–6]

Childhood dementia, the story so far

The term "childhood dementia" first appeared in medical literature in 1945 when French physicians Girard, Kohler, and Thevenin published on "the main clinical aspects of childhood dementia."[7] Over the subsequent decades, researchers used various terminologies for similar conditions–"progressive childhood encephalopathy" in Scandinavian studies[8,9] (1992, 2007), "childhood dementia" in the Australian Childhood Dementia Study[10] (1993-1995), and "Progressive Intellectual and Neurological Deterioration" (PIND) in the UK's long-running study (1997-2024).[11]

Despite this historical precedent, these efforts remained disconnected, with no organisation or health system anywhere in the world adopting "childhood dementia" as an organising principle until the Childhood Dementia Initiative (CDI), founded in 2020, pioneered its use as a unifying framework for driving systemic change in policy, care, and research.[12,13]

CDI's approach has already begun to yield significant impacts in awareness, policy, research, clinical care, and family support, particularly in Australia:

- Publication on the collective burden of childhood dementia in the journal Brain (2023), which, coupled with significant media exposure over the past 5 years has brought international attention to the issue
- Children with dementia named as a priority population in Australia's National Dementia Action Plan (2024) and included in the World Health Organisation (WHO) endorsed National Dementia Education and Training Standards Framework (Dementia Training Australia)
- Australian Government investment of >$6 million into research, understanding the health care landscape and development of solutions for improved care and support
- First government research funding call specifically for childhood dementia (2022) as a result of CDI's advocacy, which resulted in new funding for 5 research projects ranging from biomarker discovery to gene therapies
- Dementia organisations supporting adults with dementia (including and Dementia Support Australia [14] and Dementia Australia) expanded services to include children with dementia
- Australian families strongly endorsed using the term 'childhood dementia', finding it most effective for communicating their child's condition.

As we launch this Global Consensus Project, we build on proven success. By establishing global consensus on definition and terminology, we will enable coordinated international efforts to develop life saving treatments and improve clinical care and support.

"I find [childhood dementia] a really easy way to explain what's going on with the boys. People understand dementia, it's a more common term, they get it, they've seen it in elderly people, they can translate that into younger kids."

- Parent of two boys with childhood dementia.

Why Consensus Matters

The Need for Global Consensus

To advance meaningful progress for children with dementia and their families, we must establish international agreement on:

1. Standardised definition of childhood dementia
2. Inclusion criteria for conditions that cause childhood dementia

Establishing this consensus will enable coordinated global efforts that unite data, research, clinical care, and advocacy initiatives. It will accelerate progress toward better outcomes for children and families affected by childhood dementia by providing a unified foundation for collaboration. This consensus also serves as the essential first step toward driving forward a collaborative global research agenda (see next steps below).

Fragmentation in Terminology and Classification

Currently, multiple terms are used globally to describe similar neurological conditions in children:

- “Childhood dementia”
- “Childhood Alzheimer’s”
- “Progressive intellectual and neurological deterioration (PIND)”
- “Progressive childhood encephalopathy”
- ”Neurodegenerative” or ”neuroregressive” disorders
- “Neuronopathic inborn errors of metabolism”

While most conditions that cause childhood dementia are neurodegenerative and all involve neuroregression, these broader terms, although widely used, lack the specificity needed to properly categorise conditions that share the distinctive challenges of progressive cognitive decline. The terms ”neurodegenerative” and ”neuroregressive” are particularly problematic as classification tools because:

- Neurodegenerative conditions can affect motor function without significant cognitive impact (e.g. Friedreich’s ataxia)
- Common developmental conditions like autism spectrum disorder may involve periods of transient neuroregression without progressive deterioration
- These terms don’t adequately capture the unique care requirements and treatment approaches needed for progressive cognitive disorders.

Importantly, terms such as “Progressive intellectual and neurological deterioration” and “Progressive childhood encephalopathy” are not accessible to the general public and fail to communicate effectively with families, communities, and non-specialist healthcare providers. The term ”childhood dementia” immediately conveys the severity and nature of these conditions to lay audiences–much like ”childhood cancer” does–creating instant understanding and emotional connection. Furthermore, aligning with terminology used in adult dementia enables knowledge transfer between fields and creates opportunities for increased awareness, policy inclusion and shared research, resources, and treatment approaches across the lifespan.

Currently, inconsistent terminology and classification reinforces fragmentation and creates substantial barriers across multiple domains:

- **Policy and advocacy:** Fragments efforts to raise awareness and secure support for affected families
- **Epidemiology:** Prevents accurate assessment of disease burden and comparison across regions
- **Research:** Hampers development of unified protocols and collaborative approaches
- **Clinical care and support:** Impedes the creation of standardised diagnosis and care pathways and treatment guidelines
- **Funding:** Reduces visibility for targeted research investment

“Our speech therapist said, “When you started talking about the kids having dementia, it really got me thinking about the techniques that I use with my dementia patients and I tried something different.” They have changed their clinical practice as a result of engaging ‘dementia’ techniques and we cannot believe the improved connection and communication that we have seen.”

- Parent of two children with dementia.

Global Consensus Development

Methodology

The project will follow "Delphi methodology" and is estimated to take 12 months in total. This is a proven method of driving consensus on a specific topic through a series of questionnaires and feedback rounds.

Phase 1: Project Setup

- Literature review and environmental scan
- Stakeholder mapping and recruitment
- Global Childhood Dementia Steering Group formation and initial alignment meeting

Phase 2: Delphi Study

- Round 1: Open-ended questions to generate comprehensive list of elements for the definition
- Round 2: Structured rating of elements identified in Round 1
- Round 3: Final consensus on definition components
- Virtual meeting(s) to address any outstanding issues

Phase 3: Publication and Dissemination

- Development of manuscript for submission to high-impact journal
- Creation of supporting materials (slides, infographics)
- Dissemination planning

Expert Engagement

The following have been confirmed as members of the Global Childhood Dementia Steering Group:

- Professor Justin Baker, palliative care paediatrician (Stanford, USA)
- Professor Michelle Farrar, paediatric neurologist (Sydney, Australia)
- Professor Simon A. Jones, consultant in paediatric inherited metabolic diseases (Manchester, UK)
- Kris Kusidlo, community representative, Sanfilippo Initiative (Germany), International Sanfilippo Syndrome Alliance (ISSA) (Frankfurt, Germany)
- Toni Mathieson, community representative, NPUK, LSD Collaborative, Trustee INPDA and INPDR (Newcastle Upon Tyne, UK)
- Associate Professor, Colin Reilly, psychologist (Gothenburg, Sweden)
- Associate Professor Kourtney Santucci, paediatrician (Colorado, USA)
- Dr Nicholas J.C. Smith, paediatric neurologist (Adelaide, Australia)

- Professor Jo M. Wilmshurst, paediatric neurologist (Cape Town, South Africa)
- Professor Sameer Zuberi, paediatric neurologist (Glasgow, UK)
- Professor Peter Schofield (non-executive chair), University of NSW, Sydney.

The consensus project will engage a diverse group of experts spanning all 6 WHO regions of the world including:

- **Families and patient organisations**: Families impacted by childhood dementia and groups representing and supporting these families
- **Clinical specialists**: With experience treating children with conditions that cause dementia, including paediatric neurologists, metabolic medicine specialists, geneticists, neuropsychiatrists, palliative care specialists, allied health professionals, and adult dementia specialists
- **Researchers**: Neuroscientists and other researchers focused on fields relevant to childhood dementia, including basic science, clinical research, epidemiology and health economics
- **Pharmaceutical and biotechnology companies**: With interests in diagnostics, drug development, clinical trials, gene therapy, precision medicine, biomarkers or other innovative approaches to childhood dementia
- **Professional bodies and health organisations**: With an interest in improving the landscape of care and research for children with dementia, including medical colleges, nursing associations, allied health professional bodies, and healthcare quality improvement organisations
- **Governments and policy makers**: Including health ministers, department officials, and policy advisors working at local, national, and international levels
- **Research funders**: Including government research agencies, private foundations, philanthropic organisations, industry partners, and international funding bodies committed to advancing childhood dementia research and care.

Expected Outcomes and Impact

Immediate Deliverables

- **Peer-reviewed publication** establishing internationally accepted definition of childhood dementia
- **Supporting resources** for researchers, clinicians, and advocacy groups including presentations, posters and infographics to enable dissemination of the findings
- **Global Network of engaged experts** committed to advancing childhood dementia policy, diagnosis, research and care
- **Framework for data collection** to support future research such as epidemiological studies, patient registries & natural history studies, health economic analyses and health service planning.

Long-term Impact

Establishing consensus on childhood dementia will create a foundation for:

- **Strengthened global advocacy** with unified messaging and approach
- **Accelerated research progress** through standardised approaches and shared language
- **Coordinated and collaborative international research** to improve childhood dementia diagnosis, research and care

Next steps

The Consensus Project will create the shared language and conceptual framework necessary for coordinated international action. It will also engage key stakeholders–clinicians, researchers, and patient advocates–building collaborative relationships and unified vision to take the next steps.

The Childhood Dementia Initiative will harness the momentum gained from the Consensus Project to drive the development of a ***Global Blueprint for Childhood Dementia Research***. This strategic framework will mirror the WHO's blueprint for adult-onset dementia and align with the goals of the "Intersectoral global action plan on epilepsy and other neurological disorders", the "World Health Assembly Resolution on Rare Diseases" and other relevant global health policies.

The Global Blueprint for Childhood Dementia Research will identify common research objectives and methodologies and highlight inequalities in funding, policy inclusion and care resources. It will create opportunities to accelerate research progress, create clear pathways and galvanise collaborative task forces to deliver life-changing treatments and care.

For more information about childhood dementia and CDI's global work, please visit www.childhooddementia.org/globalagenda or email hello@childhooddementia.org.

About Childhood Dementia Initiative

The Childhood Dementia Initiative is a leading not-for-profit organisation dedicated to transforming the landscape for children with dementia and their families. CDI is uniquely positioned to lead this consensus project:

- **Established leadership:** Founded in 2020, CDI is the world's first organisation focused exclusively on addressing childhood dementia as a collective group of conditions
- **Strong track record:** CDI has published pioneering research on the collective burden and impact of childhood dementia, including papers in high-impact journals such as Brain
- **Existing networks:** CDI has established relationships with leading childhood dementia experts globally
- **Independence:** As a dedicated organisation focused on the whole childhood dementia field rather than specific conditions, CDI can facilitate unbiased consensus development
- **Patient-centered approach:** CDI's work is led by patient voice and validated by expert insight and evidence, ensuring that outcomes reflect both lived experience and clinical expertise
- **Proven impact:** CDI's work has already influenced policy changes (see page 1), and has attracted >AUD$3 million investment from the Australian Government to improve care and support for Australian families—a significant endorsement that demonstrates CDI's capacity to deliver measurable outcomes and validates the rigor of our approach.

About 67health

67health, a specialist health communications and public affairs consultancy based in London, brings critical expertise to this project:

- **Independence:** As an external facilitator, 67health provides impartiality in the consensus process
- **Proven consensus methodology expertise**: Successfully conducted a consensus study with the Niemann-Pick disease community, published in Orphanet Journal of Rare Diseases
- **Deep rare disease experience**: Extensive work with the International Niemann-Pick Disease Alliance and International Gaucher Alliance (both of these conditions cause childhood dementia)
- **Healthcare communications excellence:** Recognised industry leader as "Small Consultancy of the Year" winner (2023) and highly commended (2024) at the Communiqué Awards
- **Stakeholder management capabilities**: Expertise in mapping and engaging diverse stakeholders from patient communities to clinicians globally
- **Structured impact measurement**: 67health's IMPACT framework tracks success metrics throughout the project and measures long-term influence
- **Publication expertise:** Partnership with Synthesis Health for developing high-impact peer-reviewed publications

Their comprehensive approach—combining empathy, problem-solving, and a talent for reaching the heart of complex healthcare issues—makes them ideally positioned to deliver this critical global consensus project.

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