

# Research Partnership Principles

Childhood Dementia Initiative (CDI) partners in research that:

- Addresses unmet needs of children with dementia and their families;
- Has the potential to benefit a wide range of childhood dementia conditions, for example through common disease mechanisms or platform technologies;
- Demonstrates that project outcomes will benefit those affected by childhood dementia broadly, not just in one geographical area; and
- Is collaborative, person-centred and carefully considers clinical implementation.

If childhood dementia is included in a research project as part of a wider cohort, for example intellectual disability, the progressive nature of childhood dementia and the medical complexities of these conditions must be considered and accommodated. Results specific to the childhood dementia cohort must be reported and negative results published or otherwise made public.

CDI can bring:

- Facilitation of collaborations with other industry, researchers and clinicians nationally and globally;
- The patient, family and caregiver perspective on research and its translation from bench to bedside;
- Access to our Childhood Dementia Advocates Program for consumer engagement via surveys or focus groups where appropriate; and
- Assistance with dissemination of research findings to a wide range of stakeholders.

## Letters of Support (LoS)

CDI will:

- Generally only provide LoS for research projects in which there has been ample opportunity to participate in co-design and provide input to the proposal;
- Request payment for consumer engagement in projects such as recruitment to and co-facilitation of advisory groups / focus groups. Families participating in such research must be reimbursed at rates recommended by Health Consumers NSW; and
- Consider providing in-kind support to researchers; however, our capacity to do this will depend on other commitments.

If you require a LoS, please provide the project title, application ID number and any other information you would like us to include.