

RESEARCH GOVERNANCE PROCEDURE

PURPOSE

Kids+ leads and partners on research projects that support young people with neurodevelopmental disabilities and their families to live the life they want to live and that will directly benefit their day-to-day life and the wider community. The purpose of this procedure is to set out how those involved in research activities at Kids+ will ensure research is conducted in a manner that is consistent with Kids+' vision, purpose, and values, and the principles, requirements, and standards of research are upheld.

SCOPE

This procedure applies to all personnel internal and external to Kids+ who conduct, or assist with the conduct of, research at Kids+ including:

- Researchers
- Students, interns, and trainees
- Kids+ staff
- Kids+ participants and their parents and carers
- Kids+ board members
- Volunteers
- Contractors, and consultants

DEFINITIONS

See below for definitions of key terms used in this procedure.¹

- **Kids+ participant:** a child or young person accessing Kids+ services (also referred to as NDIS participant or client).
- **Research:** The concept of research is broad and includes the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies, inventions and understandings. This could include synthesis and analysis of previous research to the extent that it is new and creative (National Health and Medical Research Council, 2018).
- **Researcher:** Person (or persons) who conducts, or assists with the conduct of, research (National Health and Medical Research Council, 2018).
- **Research lifecycle:** the process that a researcher undertakes when completing a research project or study, from inception to completion. It includes the steps of plan, acquire, process, analyse, preserve, share, results and reuse (National Library of Medicine, 2022).
- **Research governance:** processes used by organisations to ensure that they are accountable for the research conducted under their auspices. To be properly governed, research must be conducted according to established ethical principles, guidelines for responsible research conduct and relevant legislation and regulations (National Health and Medical Research Council, 2011).
- **Research project:** a discrete scientific endeavour to answer a research question or set of research questions with specified timeframes for completion (also referred to as research study) (Law Insider, 2022).

PROCEDURE

¹ All definitions taken from existing Kids+ policies and procedures, unless otherwise referenced.

Research governance requirements for all research activity undertaken at Kids+ are outlined below according to the research lifecycle stages:

1. Research project planning

- 1.1. Those seeking to undertake a research project at Kids+ (either to be led by Kids+ or that wishes to have Kids+ as a partner) are required to complete and submit a [Research Project Expression of Interest Form](#) to be approved prior to the commencement of the research project.
- 1.2. Before completing and submitting the Research Project Expression of Interest Form, those seeking to undertake a research project at Kids+ should contact the Kids+ Research Manager to discuss their proposed research project to determine if it has merit before proceeding.
- 1.3. Proposed research projects will be assessed against the following criteria:

Essential criteria	Description
1. The research uses a participatory or inclusive approach and as such, includes some involvement from Kids+ participants, family members and/or staff members as research team members or advisors	Participatory or inclusive research approaches can lead to: <ul style="list-style-type: none"> • Research being conducted that is relevant to community needs • More effective translation of research to deliver improved outcomes • Enhanced research processes • Empowerment of community members Kids+ only partners on research projects where Kids+ can inform and shape the research project across the research lifecycle.
2. The research is aligned with Kids+ vision, purpose, and values	Kids+ vision, purpose, and values guide what we do and how we work. As such, all aspects of the research project should align with: <ol style="list-style-type: none"> 1. Kids+ vision: A world with more possibilities; to be recognised nationally and internationally as a leading expert in service provision for children and young people with cerebral palsy, influencing community practices, attitudes, and expectations, here and abroad 2. Kids+ purpose: To provide families with guidance and support and to create opportunities for children and young people with cerebral palsy and similar neurodevelopmental conditions 3. Kids+ values: <ul style="list-style-type: none"> • Care: we care for each other and families we work with • Commitment: we are committed to professional excellence and in providing the best supports possible • Collaboration: we respect and value the insights and experiences of others and we willingly share ours and their expertise • Creativity: we are passionate about striving to do things differently and better • Celebration: we enjoy what we do and have fun doing it
3. The research addresses a strategic focus area of Kids+	<ol style="list-style-type: none"> 1. Participate: ensure that the lived experience and goals of young people with disabilities are at the forefront of service delivery and organisational design and thinking 2. Educate & Advocate: shape the development and delivery of disability services; publicly support the interests and empowerment of young people with disabilities 3. Innovate: encourage and embrace new ideas that improve and enhance participant outcomes and organisational competitiveness and effectiveness 4. Elevate: invest in organisational capacity building to enhance service delivery capability

4. The research addresses a research priority area identified by Kids+ participants, their families and/or staff members	The priorities of Kids+ participants, their families, and staff members shape our research agenda. Research priorities may change over time, and information regarding the current research priorities should be sought from the Kids+ Research Manager.
5. The research benefits Kids+ participants and/or their families in day-to-day life	Kids+ leads and partners on research projects that support Kids+ participants and their families to live the life they want to live and that will directly benefit their day-to-day life.
6. The research is of sound quality	Research should be of the highest ethical, scientific, and scholarly standards, contributing to the advancement of knowledge. It should be translated, when appropriate, into relevant policies and practice and provide impact beyond Kids+ that meets the needs of Kids+ participants, their families, the community, and other stakeholders.
7. The research has funding to pay the following people if applicable: <ul style="list-style-type: none"> • advisory group members, • consumer and community researchers, and/or • participants 	Kids+ is committed to adequately compensating Kids+ participants and their family members for their involvement as research advisory group members, consumer and community researchers or as participants of research.
8. The research includes strategies for knowledge translation	Kids+ supports research that improves Kids+ policy, practice, training, and the lives of Kids+ participants, their families, and the broader community. As such, Kids+ is interested in research that includes knowledge translation strategies so that research findings are more readily translated into policy and practice.
9. All personnel involved in the research have the appropriate qualifications and authorisations including: <ul style="list-style-type: none"> • Current Working with Children Check • Current criminal record check 	Kids+ support the protection of child safety and wellbeing as per the Child Safe Policy. Kids+ require all personnel internal and external to Kids+ who conduct, or assist with the conduct of, research at Kids+ to have and maintain all relevant checks for the duration of the research project.

1.4. The completed Research Project Expression of Interest Form will be initially assessed by the Kids+ Research Manager who will:

1.4.1. Reject Kids+ participation and contribution to the research project if it does not meet the essential criteria outlined in 1.3 above, OR

1.4.2. Refer the proposed research project to the Executive General Manager of Therapy Services and CEO for approval

1.5. In case of 1.4.2 above, the Executive General Manager of Therapy Services and CEO will:

1.5.1. Approve/reject Kids+ participation and contribution to the research project, OR

1.5.2. Refer to the proposed research project to the Kids+ Participant Advisory Group and Kids+ Parent and Carer Advisory Group who will make a recommendation to approve or reject to the Executive General Manager of Therapy Services and CEO

2. Research project authorisation

2.1. Research project partnerships will be governed by a Memorandum of Understanding (MOU), Research Agreement or Contract Agreement

2.1.1. Research projects conducted in partnership with Deakin University staff or students will be governed by the existing Deakin University and Kids Plus Foundation Research Framework Agreement. A Project Schedule is required to be completed for each research project conducted under this Research Framework Agreement.

- 2.2. Any disputes arising as part of the research project partnership will be governed by the agreed dispute resolution process in the MOU, Research Agreement or Contract
- 2.3. Prior to the commencement of a research project, all research projects must be ethically and scientifically reviewed through an appropriate pathway by a Human Research Ethics Committee (HREC), or other ethical review body
 - 2.3.1. Kids+ will provide a letter of support for any ethics application for projects that have been approved according to the process outlined in 1. above
 - 2.3.2. Kids+ must be provided with copy of the ethics application and approval prior to research project commencement
- 2.4. Prior to the commencement of a research project, all involved personnel must decide on the identification, ownership, storage, management, access to and disposal of research data and materials related to the research project
- 2.5. Prior to the commencement of a research project, the principal investigator must complete a budget identifying revenue sources and expense items and ensure the project is sufficiently funded

3. Research project monitoring

- 3.1. It is the responsibility of the principal investigator to be compliant with reporting to the HREC and informing Kids+ of any changes to ethics (e.g., amendments, withdrawal of ethical approval)
- 3.2. It is the responsibility of the Kids+ Research Manager to keep an up-to-date register of research projects being undertaken at Kids+

4. Research project closure

- 4.1. It is the responsibility of the principal investigator to ensure research project outcomes are reported to research participants and Kids+ in an appropriate format e.g., presentation at Kids+ team meeting, infographic

RELEVANT POLICIES, PROCEDURES AND GUIDELINES

Key policies, procedures and guidelines related to this policy:

- Research Governance Policy
- Consumer and Community Involvement in Research Guidelines
- Participant Payment Engagement Policy

LEGISLATION

Key legislation, standards, and statements relevant to this procedure:

- *Australian Code for the Responsible Conduct of Research*
- *National Statement on Ethical Conduct in Research Involving Humans*
- *National Statement on Consumer and Community Involvement in Health and Medical Research*
- *National Health and Medical Research Council Act 1992*
- *Privacy and Data Protection Act 2014 (Vic)*
- *Disability Services Act 2006 (Vic)*
- *Working with Children Act 2005 (Vic)*
- *Working with Children Regulations 2006 (Vic)*
- *Victorian Child Safe Standards*
- *Disability Worker Exclusion Scheme*
- *National Standards for Disability Services*
- *Freedom of Information Act 1982 (VIC)*

- *Australia's Disability Strategy 2021-2031*
- *NDIS Quality and Safeguarding Framework*

REFERENCES

Law Insider. (2022). *Dictionary*. <https://www.lawinsider.com/dictionary/research-project>

National Health and Medical Research Council. (2011). *Research Governance Handbook: Guidance for the national approach to single ethical review*. Canberra: Commonwealth of Australia Retrieved from <https://www.nhmrc.gov.au/sites/default/files/documents/reports/research-governance-handbook.pdf>

National Health and Medical Research Council. (2018). *Australian Code for Responsible Conduct of Research*. Canberra: Commonwealth of Australia Retrieved from <https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018>

National Library of Medicine. (2022). *Data Glossary*. <https://www.nlm.gov/guides/data-glossary/research-lifecycle#:~:text=Definition,project%20leading%20into%20the%20next>