

RESEARCH GOVERNANCE POLICY

PURPOSE

Kids+ are committed to supporting young people with neurodevelopmental disabilities and their families to live the life they want to live through excellence in research. Kids+ aim to undertake research that will directly benefit the day-to-day life of young people with neurodevelopmental disabilities and their families at Kids+ and the wider community. To ensure research is conducted in a manner that is consistent with Kids+' vision, purpose, and values, this policy describes the principles, requirements, and standards of research at Kids+.

SCOPE

This policy 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

RESPONSIBILITIES

1. All personnel internal and external to Kids+ who conduct, or assist with the conduct of, research at Kids+ have responsibility for meeting the requirements of this Policy. Details of specific research governance responsibilities and roles in reviewing, approving, managing, and monitoring research are provided in the relevant Policies, Procedures and Guidelines outlined in this document.
2. It is the responsibility of all personnel internal and external to Kids+ who conduct, or assist with the conduct of, research at Kids+ to familiarise themselves with this Policy and associated Policies, Procedures and Guidelines outlined in this document. If personnel do not fully understand what is required of them it is their responsibility to seek further clarification, support and/or training.
3. Any incident, action or behaviour that does not comply with this policy and associated procedures may be considered a breach of policy and/or a breach of the law.
4. It is the responsibility of all Kids+ personnel to report any breaches. A breach may result in disciplinary action for involved Kids+ personnel which, depending on the severity, may range from a written warning to termination of employment.
5. Additionally, all Kids+ personnel are required to report breaches of the law, therefore it may also result in action being taken by an external agency such as the Police.

DEFINITIONS

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

- **Kids+ participant:** a child or young person accessing Kids+ services (also referred to as NDIS participant or client).

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

- **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).

POLICY STATEMENTS

1. Kids+ leads and partners on research projects that are consistent with Kids+' vision, purpose, and values, and advance Kids+ strategic focus areas and research priorities.

Kids+ only partners on research projects where Kids+ can inform and shape the research project across the research lifecycle.

Kids+ contribution to research partnerships can include providing all or some of the following:

- Industry expertise
 - Research expertise
 - Access to sites, study participants, staff knowledge and/or data
 - Financial support
 - In-kind support
2. Kids+ may, from time to time, assist in the recruitment of Kids+ participants, parents and carers, or Kids+ staff for research projects they are not involved in as a partner on a case-by-case basis.

Assistance in the recruitment of Kids+ participants, parents and carers, or Kids+ staff can include all or some of the following:

- Emailing Kids+ participants, parents, carers and/or staff about the research project
- Sharing information about the research project on Kids+ social media
- Kids+ staff sharing information with Kids+ participants, parents, and carers about the research project.

Kids+ assistance in recruitment does not indicate endorsement of the research project.

3. **Kids+ is committed to the following principles:**

- 3.1. **Research integrity:** Research will be conducted with the highest levels of research integrity, enabling people to have trust and confidence in the research and its results. All those engaged in research must abide by all relevant guidelines and legislative and regulatory requirements.

- 3.2. Research 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.
- 3.3. Ethics review:** Human research must be ethically and scientifically reviewed through an appropriate pathway by a Human Research Ethics Committee (HREC), or other ethical review body, to ensure the research is:
- 3.3.1.** ethically sound according to the principles of merit, integrity, justice, beneficence, and respect as specified in the NHMRC National Statement
 - 3.3.2.** scientifically sound, designed using methods appropriate for achieving the aims of the research proposal and based on a thorough study of current and historical literature. All research will be compliant with any ethics review required of that research.
- 3.4. Quality collaboration:** Those undertaking research activities will work to ensure effective and transparent collaboration among internal and external stakeholders including national and international partners. This includes creating clear, mutually beneficial and effective partnership arrangements.
- 3.5. Participant partnerships:** Those undertaking research activities should partner with Kids+ participants and their families at all stages of research lifecycle to enhance and strengthen the quality of our research and its translation.
- 3.6. Integrated knowledge translation:** Those conducting research will partner with knowledge users at all stages of the research process to ensure our research has impact. Knowledge users may be Kids+ participants, their families, Kids+ staff, health and other service providers, and/or the broader community who identify a problem and have the authority to implement our research recommendations.
- 3.7. Research Participant engagement and protection:** Those undertaking research involving humans will have a participant centred approach that involves meaningful engagement with respect for and protection of participants' rights.
- 3.8. Accountability and transparency:** Those conducting research will take responsibility and be accountable for their behaviour and actions. All research activity will be open to review and all findings and data will be made publicly available where possible.
- 3.9. Qualified personnel:** All those conducting research should be appropriately qualified and experienced and conduct their research with due regard to the safety of themselves, their colleagues and collaborators and any participants in their research.
- 3.10. Risk management:** Those conducting research and Kids+ are to manage the risks associated with research projects. This includes financial, legal, insurance and reputational risks to protect researchers, participants, Kids+ and research partners.
- 3.11. Monitoring and review:** Research processes at Kids+ will be monitored and areas of risk for those conducting research or Kids+ reviewed as part of Kids+' Governance responsibility.
- 3.12. Relevance:** Research should offer the prospect, either directly or through the generation of preliminary results, of benefit to the day-to-day life of Kids+ participants and/or their families.
- 3.13. Sustainability:** Research activities are managed in a sustainable manner to support and promote research, maintain, and develop a skilled research workforce, provide the best possible research infrastructure and foster future investment in research.

RELEVANT POLICIES, PROCEDURES AND GUIDELINES

Key policies, procedures and guidelines related to this policy:

- Research Governance Procedure

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

LEGISLATION

Key legislation, standards and statements relevant to this policy:

- *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

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