

CONSUMER AND COMMUNITY INVOLVEMENT IN RESEARCH GUIDELINES

PURPOSE

In 2022 Kids+ released a three-year Research Strategy outlining Kids+' commitment to strengthening consumer and community involvement in research. Kids+ believes that the meaningful involvement of Kids+ participants, parents, carers, and staff members will enhance and strengthen the quality of our research and its translation. Kids+ is committed to involving Kids+ participants, parents, carers, and staff members in all aspects of its research activities, including, but not limited to:

- Helping to decide research priorities
- Contributing to the preparation of research grant applications and proposals to investors
- Contributing to the design and conduct of research projects, tools, and resources
- Linking researchers with consumers and community
- Contributing to and reviewing research reports and papers
- Presenting at conferences, seminars, and other forums
- Participating in the preparation of newsletters, media statements and social media
- Promoting research to funders, sponsors, and philanthropists

The purpose of these guidelines is to guide the involvement of Kids+ participants, parents, carers, and staff members in the research activities of Kids+.

SCOPE

These guidelines apply 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 these guidelines.¹

- **Advisors:** Kids+ participants, their parents and carers, or Kids+ staff who advise researchers on their research projects.
- **Consumer and community researcher:** Kids+ participants, their parents or carers, or staff who have been trained to work with researchers to conduct all or part of a research project. Consumer and community researchers are equal partners in the research project. They might be involved in developing the methodology of the project, interviewing other Kids+ participants, parents or carers, co-facilitating focus groups or analysing results of interviews or questionnaires (Consumer and Community Involvement Program, 2020).

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

- **Kids+ Parent and Carer Advisory Group:** group of at least three and up to five parents or carers of current or former Kids+ participants. It aims to provide insights and recommendations to the Kids+ team on ways in which Kids+ can best support participants across Kids+ programs, including but not limited to research activities.
- **Kids+ Participant Advisory Group:** group of at least two and up to five current or former Kids+ participants. It aims to provide insights and recommendations to the Kids+ team on the ways in which Kids+ can best support participants across Kids+ programs, including but not limited to research activities.
- **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 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).

LEVELS OF INVOLVEMENT

There are many ways Kids+ participants, parents, carers, and staff members can be involved in research at Kids+. The levels of involvement range from low levels of involvement such as being informed about research activities, to high levels of involvement such as participant led research (see Figure 1).

Kids+ will promote high levels of participant, parent, carer, and staff member involvement across all research projects at Kids+.

At the least, all research projects at Kids+ will involve participant, parent, carer, and/or staff members at the level of “Advise” as advisors.

At the level of “Equal partners” we will involve consumer and community researchers as equal partners in the research project. A consumer and community researcher is a Kids+ participant, parent or carer, or staff member who has been trained to work with researchers to conduct all or part of a research project. They might be involved in developing the methodology of the project, interviewing other Kids+ participants, parents or carers, co-facilitating focus groups or analysing results of interviews or questionnaires (Consumer and Community Involvement Program, 2020).

For every research project, the level of involvement sought needs to be specified and agreed to by the Kids+ participant, parent, carer, and/or staff member prior to commencement.

The Ladder of Participation

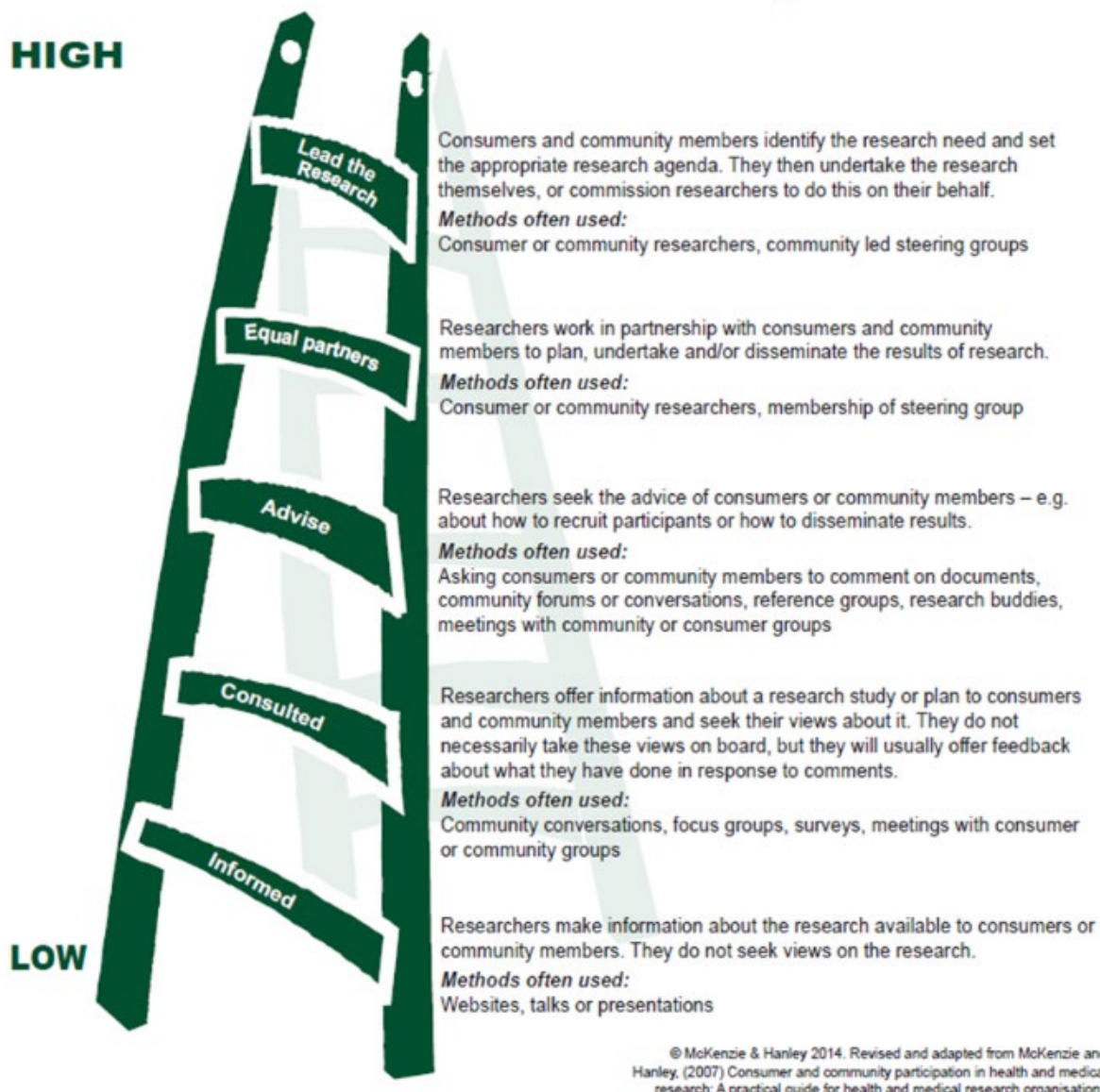


Figure 1. The Ladder Of Participation from McKenzie A., & Haines, H. (2014) Consumer and Community Participation Fact Sheets Series (2nd Edition). The University of Western Australia School of Population Health, and Telethon Kids Institute.

GUIDING PRINCIPLES AND VALUES

Kids+ participant, parent, carer, and staff member involvement in research will be guided by the following principles and values developed by Ayesha Siddiqua and Francine Buchanan as part of McMaster University's Family Engagement in Research Program:

A QUICK REFERENCE GUIDE: AUTHENTIC PARTNERSHIP IN RESEARCH

I	M	P	A	C	T
INCLUSIVITY	MUTUAL RESPECT	PARTNERSHIP	ACCOUNTABILITY	CO-LEARNING	TRANSPARENCY
P R I N C I P L E S & V A L U E S					
Integrate diverse partner perspectives and be reflexive of their contributions. Be inclusive of both people and their ideas	Acknowledge and value each other's expertise and experiential knowledge. Show respect by ensuring engagement is not burdensome (I.e. excessive time commitments or expenses)	Value the contributions of all stakeholder partners. Work together from the beginning to identify problems, gaps, set priorities for research and work together to produce and implement solutions	Maintain a safe environment that promotes honest interactions, cultural competence, training, and education. Team members should be accountable to one another for all decisions and actions	Support and flexibility should be provided to partners to ensure that they can contribute fully to discussions and decisions. Provide a supportive environment to ask questions and be willing to learn from each others' experiences	Information should be shared readily with all research partners and decision making should be inclusive. Be committed to open and honest communication with one another

BEST PRACTICES FOR INVOLVEMENT ACROSS THE RESEARCH PROJECT LIFECYCLE

Kids+ participant, parent, carer, and staff member involvement in research will be guided by the following best practices at each stage of the research lifecycle developed by Ayesha Siddiqua and Francine Buchanan as part of McMaster University's Family Engagement in Research Program:

BEST PRACTICES



RECRUITMENT

The lead researcher, also known as the Principal Investigator, is responsible for planning who to recruit to be involved in their research project. For example, if the project is about staff members only, it may be appropriate to only involve staff members. If the project is about a particular Kids+ program, it may be appropriate to involve Kids+ participants, parents, carers, and staff members who have experience with that program.

The Kids+ Research Coordinator will support the recruitment of Kids+ participants, parents, carers, or staff members to be involved in the research project.

Kids+ participants, parents, carers, or staff members can be invited to be involved in a research project in several ways, including, but not limited to:

- Email
- Social media posts
- Flyers distributed across the Kids+ centre
- Presentations at staff meetings
- Kids+ participants, parents and/or carers being told about the opportunity by a therapist prior to or at the end of a therapy session
- Kids+ participants, parents and/or carers being told about the opportunity at a Kids+ Participant Advisory Group meeting or a Kids+ Parent and Carer Advisory Group meeting

The Principal Investigator is responsible for creating any recruitment materials that the Kids+ Research Coordinator will disseminate.

Kids+ participants, parents, carers, and staff members will make a commitment to the length of the research project.

SUPPORT

The Principal Investigator is responsible for:

- Planning clear timelines, roles and responsibilities, and pathways of communication together with the Kids+ participants, parents, carers, and staff members involved in the research project
- Ensuring the Kids+ participants, parents, carers, and staff members are provided with required reasonable adjustments to enable their involvement in the research project
- Providing opportunities for the involved Kids+ participants, parents, carers or staff members to discuss any concerns about their role in their preferred manner

If required, Kids+ participants, parents, carers, and staff members may be provided with additional training to undertake their role in discussion with the Principal Investigator and the Kids+ Research Coordinator.

Additional training may include completion of the [Consumer and Community Involvement in Health Research online training](#) module developed by Consumer and Community Involvement Program or the online [Family Engagement in Research Course](#) developed by CanChild, McMaster University and Kids Brain Health Network.

RECOGNITION OF CONSUMER AND COMMUNITY INVOLVEMENT

1. Payment

Kids+ participants and parents and carers refer to the Kids+ Participant Payment Engagement Policy.

Kids+ staff members may be involved in Kids+ research projects during paid work hours. The amount of time available for work on Kids+ research projects is to be negotiated with their team leader/manager and the research project Principal Investigator. The amount of time agreed upon will vary dependent on the size and scope of the research project and the level of involvement of the staff member.

2. Authorship

Kids+ participants, parents and carers, and staff will be acknowledged for their involvement in publications (e.g., journal articles, presentations, reports) in line with the recommendations of the International Committee of Medical Journal Editors.

Kids+ participants, parents and carers, and staff will be named an author on the publication if they meet the following criteria:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Kids+ participants, parents and carers, and staff who do not meet all four criteria outlined above will be acknowledged by name in the publication if they provide permission to be acknowledged.

EVALUATING INVOLVEMENT

Involvement of Kids+ participants, parents and carers, and staff members in research activities may be evaluated in several ways including, but not limited to:

- Check-ins at the end of each research project meeting that give people the opportunity to provide feedback on what worked well and what did not work well.
- Annual individual check-ins with the Principal Investigator of the research project
- At the end of a research project, involvement of Kids+ participants, parents and carers, and staff members may be formally evaluated using measures such as the Patient Engagement In Research Scale – PEIRS-22 or the Public and Patient Engagement Evaluation Tool (PPEET).

EXIT

When a Kids+ participants', parents', carers', or staff members' involvement in a research project comes to an end, the Principal Investigator is responsible for:

- Undertaking an exit interview
- Arranging a letter of acknowledgement for their involvement

RELEVANT POLICIES, PROCEDURES AND TERMS OF REFERENCE

Key policies and procedures related to these guidelines:

- Research Governance Policy
- Research Governance Procedure
- Participant Payment Engagement Policy

- Kids+ Parent and Carer Advisory Group Terms of Reference
- Kids+ Participant Advisory Group Terms of Reference

RESOURCES

McKenzie, A. & Haines, H (2014) [Consumer and Community Participation Fact Sheet Series](#). The University of Western Australia School of Population Health and Telethon Kids Institute

Australian Clinical Trials Alliance (2023) [Consumer Involvement & Engagement Toolkit](#)

REFERENCES

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