

Partnering in research

Guidelines for engaging
children and young people
as consumer research
partners



**Healthy
Trajectories**

A Child and Youth Disability Research Hub

September 2024

Acknowledgement of Country

The Healthy Trajectories Child and Youth Disability Research Hub acknowledges the Traditional Owners of Country throughout Australia and recognises the continuing connection to the lands and waterways on which we live, learn and work. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders

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Document purpose

The purpose of this document, authored by [Healthy Trajectories](#), a child and youth disability research hub, is to establish guidelines and principles to support researchers to involve children and young people in research as partners and advisers. The core aim is to emphasise early engagement, inclusive participation, and effective communication tailored to their unique needs.

In this document you will find links to online resources, these are [blue and underlined](#).

Terminology note

The main focus throughout this document is "children", which refers to individuals under the age of 18, while "young people" defined as those aged 18 to 25 are also noted in the guidelines. Another term for the age group 13-17 is "adolescent",

It is crucial to adopt age-appropriate language, approaches, and considerations when engaging with these distinct demographic groups in research activities.¹

In this document we use the word "consumer". This word is used by the [National Health and Medical Research Council](#), to describe people who have a lived experience of a condition or who use health services, their families, service providers, and the public. We use consumer as some of the young people we partner with and their families find it an empowering word, but we know some people prefer to use other terms and it is important to respect this too.



Best practices for consumer involvement



Successful [consumer involvement](#) in child-onset disability research relies on a foundation of best practice principles and strategies that prioritise early engagement and inclusive participation through the [research process](#).² It is imperative for researchers to initiate consumer involvement at the research program or project's outset, from the beginning, to ensure diverse representation and alignment with community needs.

Effective communication with all consumer and community representatives using clear and accessible language, is crucial throughout the development and execution of a research project.³ Researchers should be mindful of potential challenges faced by consumer partners, understanding that they will have commitments beyond the study that impact their availability. Welcoming consumer partners into the research environment with respect and addressing power dynamics are important for fostering a collaborative atmosphere.⁴

To enhance consumer involvement, it is essential to [define roles clearly](#), provide adequate training and support, and involve consumers early on.

Neglecting these aspects can disengage consumer partners and diminish the perceived value of their contributions to the research.



Introducing the principles for research involving children

As research progresses, there is a growing emphasis on incorporating the viewpoints of children. While strides have been made in this area, there is still a need to enhance the involvement of individuals across different age groups.⁵ This enhancement may be influenced by a heightened awareness of ethical considerations when engaging with young participants and the importance of safeguarding their well-being by avoiding inappropriate inquiries.

While it is paramount to prioritise the protection of children, it is also essential to encourage active participation in research endeavours. The guide outlines key principles meant to assist researchers in effectively including children in research activities. These steps are structured to provide a comprehensive framework for elevating research capabilities, establishing ethical guidelines, and nurturing positive relationships.⁶

The principles are categorised to facilitate understanding and implementation by researchers, although there may be instances of overlap between certain steps. Furthermore, by adhering to these guidelines, researchers can ensure that the voices of children and young people are not only heard but also respected and integrated into the research process in a meaningful manner.⁷



Engaging with empathy and understanding

Image description: An icon showing a hand holding a heart



Empowering through child-centred approach

Image description: An icon showing a child in the middle of a circle



Communicating accessibly

Image description: An icon showing a speech bubble



Providing active support and accommodation

Image description: An icon showing a person asking a question to another person



Engaging creatively and dynamically

Image description: An icon showing someone having an idea, shown with a lightbulb



Integrating technology proactively

Image description: An icon showing a finger pressing a button to get information



Upholding ethical considerations

Image description: An icon showing a hand balancing a scale

The key principles

Engaging with empathy and understanding

Approach children with disabilities empathetically, striving to understand their unique needs, celebrate the diversity of children's experiences and identities within the research context. Create a culturally sensitive and inclusive space where all children feel valued, respected, and able to contribute meaningfully.⁸ Listen and show compassion towards their challenges and strengths. Commit to including young children in research, taking their evidence seriously, and understand their context and roles in research. Researchers should gain necessary skills to provide training on partnerships and build children's capability through involvement in the research process.



Empowering through child-centred approach

Prioritise the child's well-being and agency in all research activities, ensuring their voices are heard and respected. Treat children as active participants and partners in research, clarify how their evidence will be used, and provide them with the option to participate. Consider confidentiality and safety. Include different groups of children and consider various aspects of identity and inclusion.⁹



Communicating accessibly

Use clear, age-appropriate language when communicating with children, ensuring information is actively accessible and easily understood. Adapt communication methods to meet the diverse needs of children with different disabilities. Build supportive, trustful, and professional relationships between parents, support staff and children, as well as among children and young people. Prioritise respect, listen to children's views, and ensure their safety. Create a safe and enjoyable environment for children to speak and share their opinions authentically.¹⁰



Providing active support and accommodation

Proactively provide necessary support and accommodations to facilitate the full participation of children with disabilities in research activities. This includes physical accommodations, assistive devices, and trained support staff when needed – cluster methods into interviews, discussions, visuals, narratives. Enable children to express their emotions, needs, and desires using various communication platforms.¹¹



Engaging creatively and dynamically

Introduce fun and interactive research methods that appeal to children's interests and preferences. Use creative tools such as storytelling and play-based activities to make the research process engaging and enjoyable. Consider the role of partners and carers in the research process and power dynamics. While parental guidance and support staff assistance are valuable, children should be allowed to form their own opinions and have their voices heard without influence.¹²



Integrating technology proactively

Use the power of technology to actively engage children in research. Use online tools, apps, and virtual platforms to actively facilitate communication, data collection, and collaboration. Ensure that these technologies are actively accessible and user-friendly for children with disabilities.¹³



Upholding ethical considerations

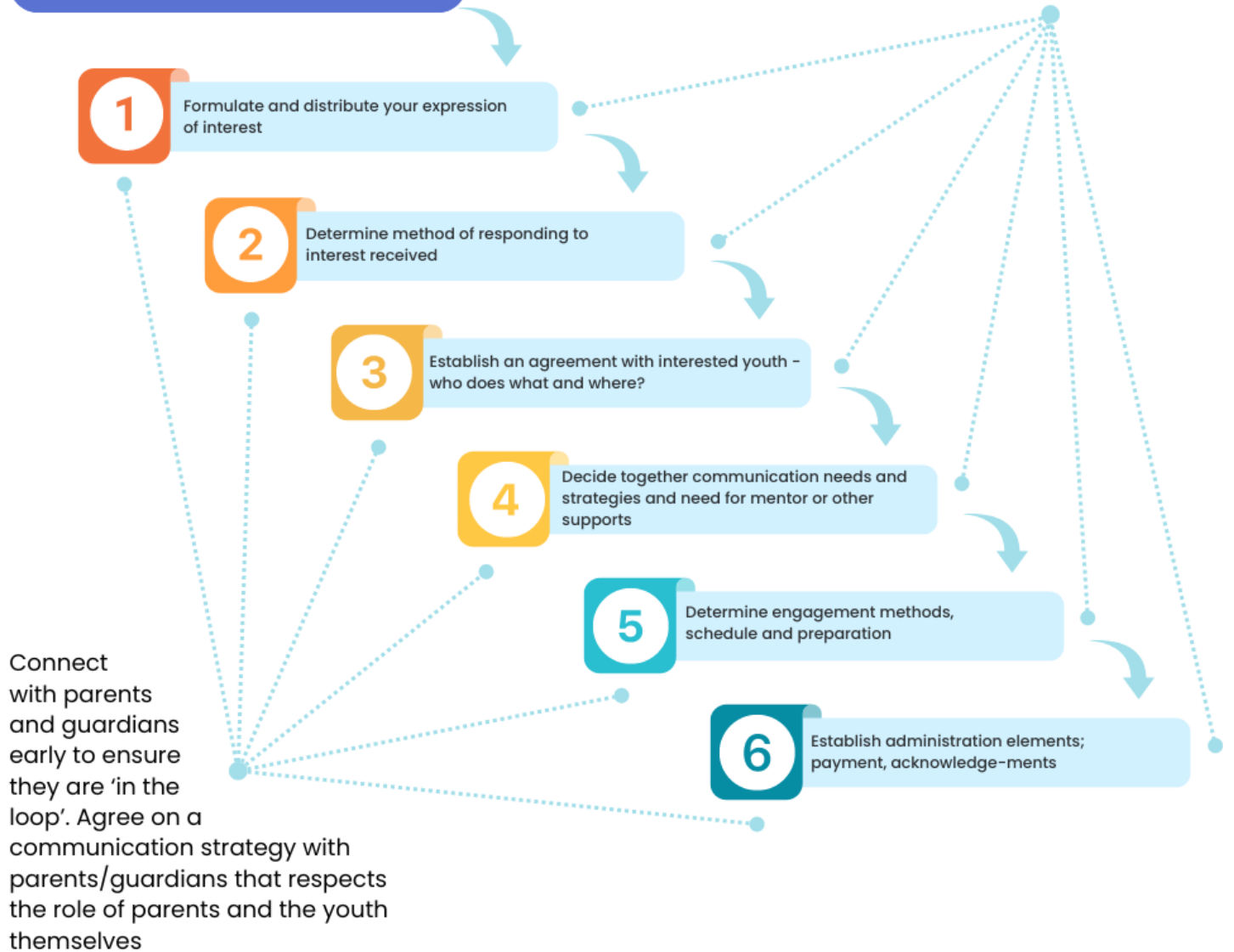
Actively adhere to ethical guidelines and standards when conducting research with children, especially those with disabilities. Obtain informed consent from guardians, prioritise confidentiality and privacy, and ensure that research practices do not cause distress to participants or partners.¹⁴



The process

"We have a project idea, and would like to involve young people as consumer partners..."

Provide sufficient detail about the project, in accessible formats, for youth to make informed decisions and choice throughout.



There are ten elements to this set of guidelines, each are important.

1. Recruiting Methods
2. Engaging with Support Networks
3. Agreements and Parental Consent
4. Orientation
5. Awareness of Accessibility
6. Meetings and Accessible Preparation Materials
7. Offering Mentorship
8. Payment
9. Flexible Ways of Involvement
10. Evaluation Framework and Practices

Over the next few pages you will find details of each of the guidelines and specific advice for engaging young people.

1. Recruiting methods

The first point of contact with potential partners is through the process of recruiting them to your project via [an expression of interest](#) (EOI). Using various recruiting methods to reach potential consumer partners is key. Engage children through child-friendly platforms, schools, and youth organisations, with a focus on parental involvement and clear communication channels.

Young people: Target young people through social media platforms, educational institutions, and specialised youth groups, emphasising independent engagement and tailored messaging.

2. Engaging with support networks

Engaging with the support networks of child consumer partners, such as parents or guardians, and support staff is essential for successful research. Maintain open and honest communication with all involved to build trust and mutual respect. Understand the preferences of the child, caregivers, and support staff, involving them in decisions. Listen to and address concerns from all parties, prioritizing confidentiality, and privacy throughout the process to ensure information is secure.

Based on the preferences and needs of the child or young person, support staff can play an essential role in enabling the involvement of children and young people in research by aiding with their devices and other accommodations to ensure accessibility to information. Assistance in navigating technology, facilitating communication, and supporting the feedback process for the benefit of research activities.

3. Agreements and parental consent

Obtaining consent from parents or guardians for the involvement of minors as partners in the research is essential. Clear agreements with child consumer partners and parents outlining their roles, responsibilities, and expected contributions is necessary. This is usually done via an [online form](#) (Redcap or Qualtrics) after they have had a chance to discuss the project and have any questions answered.

Young people: Establish direct agreements with young adult consumers, outlining responsibilities, expected contributions, and ensuring informed consent throughout their engagement.

4. Orientation

Ensuring a detailed orientation is necessary for effectively engaging with support networks in research. This orientation is specifically crafted for children, their parents, support staff, by the research team to get an idea of the project, and its objectives before making any commitments. The primary goal of this orientation is to [define the roles](#) of each member as a consumer partner while also facilitating an opportunity for everyone to meet, interact, inquire, and familiarise themselves with one another.

Customising the orientation to fit different age groups and using appropriate language guarantees that all involved understand their roles and contributions to the research team or project before onboarding. This tailored approach allows a collaborative and co-designed environment, leaving everyone feeling well-informed, engaged, and able to make the decision.

Young people: Tailor orientations to suit the needs and preferences of young adults, emphasising the value of their contributions, responsibilities, and active engagement in the research process.

5. Awareness of accessibility

Knowledge and preparation are needed to ensure the accessibility of meetings, online via [Zoom](#) or in person. While some things should be routine, for example always enhancing online accessibility by ensuring that captions are turned on in online meetings, other tools may or may not be required. For example, using interactive collaboration tools (e.g., [Mural](#) or other virtual whiteboards), providing interpreting services as needed and other measures to ensure inclusivity for all consumer partners is crucial.

Young people: Focus on providing accessible online platforms, accommodating varying schedules and preferences, and ensuring inclusive communication methods for young adult participants in research activities.

6. Meetings and accessible preparation materials

Scheduling regular meetings with young children to discuss the research progress, upcoming tasks, and gather their input is important. For children still in educational settings offer early evening meetings. Providing preparation materials for each meeting to help them understand the topics to be discussed is essential. The goal should be 'no surprises' – who will be in attendance, what will be asked or discussed, any decisions to be made, should be clearly outlined prior to the meeting, in time for children to prepare their thoughts and responses.

Young people: Arrange flexible meeting schedules for young adults and provide detailed preparation materials tailored to their comprehension level and preferences.

6.1 Plain language

Writing plainly is essential. It ensures that research projects are accessible to those beyond the research community. Plain language writing does not mean simplifying your research; rather, it's about presenting it in a straightforward and clear manner. To write effectively in plain language, aim for clarity, brevity, and simplicity, avoiding unnecessary complexity.

Here are some **tips** to help you write in plain language:

- Imagine explaining your research to a family member or a friend.
- Use straightforward and familiar language.
- Avoid technical terms and jargon.
- Define any specialised terms you do use.
- Keep your sentences short and easy to follow.
- Do not use acronyms or abbreviations, but if you need to, explain them so they are understood.

6.2 Easy to read

In addition to plain language, creating [easy-to-read](#) materials are likely to be required. Easy-to-read information ensures that everyone can understand it, regardless of their background. Easy-to-read content combines images with short phrases explaining the content. Here, the use of images is key!

6.3 Using images: descriptions vs alternative text

Alt text and image descriptions are text-based descriptions of visual details in an image written primarily for people who are visually impaired (inclusive of blind/low vision). If an image fails to load on a website, alt text will be displayed in its place, and alt text is also used for search engine optimization.

Image descriptions are like alt text descriptions that are used by screen readers to recognize images, though there are a few key differences between alt text and image descriptions.

7. Offering mentorship

Offering mentorship and guidance to children throughout the research process is also important. This may be in the form of assigning them a mentor or allocating a designated team member who can provide regular support, answer questions, and help them navigate their roles effectively. A mentor usually supports a child before (to prepare) and after (to de-brief)

8. Payment

Compensating child or young adult consumer partners for their contributions through a [gift pay](#) account. Every team should follow clear guidelines on payment rates to ensure fairness and transparency. Other forms of reimbursement are available depending on individual preferences, such as payment via direct invoice.

9. Flexible ways of involvement

Offering flexible ways of involvement is key to both maintaining engagement and also to respect the interests and capacity of individual consumers. Varied communication channels can be used to accommodate the preferences and needs of consumer partners. Flexibility considerations relate to (i) amount of time the child or young person wants to contribute; (ii) methods of communication, including using email, telephone, one-on-one check-ins with the consumer engagement lead or research project lead; and (iii) level of involvement – to be informed or consulted, to be an advisor or partner.

10. Evaluation framework and practices

When conducting research involving children and young people, it is crucial to establish a strong evaluation framework and ensure the effectiveness and integrity of the research. Evaluation serves as a fundamental tool to assess the impact, outcomes, and overall success of the research. Here are some key guidelines for establishing an evaluation framework:

- **Stakeholder involvement:** Include input from young people, parents, and other stakeholders in the evaluation process.
- **Data collection:** Gather data through surveys, interviews, and observations.
- **Monitoring and feedback:** Continuously monitor progress and gather feedback for improvements.
- **Ethics:** Ensure ethical considerations and protections are prioritised.



What our research partners say

Quotes from consumers about their involvement in Healthy Trajectories...

"I was as inspired to find my spark and discover potential avenues of study within the disability advocacy sector." RS

"I am also honoured to be a part of an advisory team that values each other and their experiences no matter how similar or different they are." NK

"The meeting are coordinated and facilitated well and I can ask questions, it is a safe and always welcoming space - I feel well supported." CH

"Being involved in research helps me lead the trail for others and improve the lives of people like me with the things that matter." IR



In conclusion, let's remember the key points of these guidelines as we work together in our research partnerships. Through early involvement, inclusivity, and respectful collaboration, we empower young consumers and their families to play an active role in the research that matters to them.

Together, we can create a welcoming environment where every voice is heard and valued. With clear communication, thoughtful support, and a commitment to accessibility, we can build a stronger research community that leads to meaningful results.

As we embark on this journey together, let's stay dedicated to respecting and honouring the experiences of those we serve. When we do this, we enhance the quality of our research and help pave the way for better futures for all children, adolescents, and young people. Let's embrace this mission with open hearts, knowing that together we can make a real difference through nurturing positive change.

Glossary

Consumer: this word is used by the National Health and Medical Research Council, to describe people who have a lived experience of a condition or who use health services, their families, service providers and the public. We use consumer as an empowering word as it has an important role and drives choice.

Expression of Interest: A process where an open call is made to invite people (consumers, community members, other researchers) to tell us they are interested to collaborate and partner with us in research. Open expressions of interest are preferred, so that everyone has an equal opportunity to take part.

Involvement in research is where consumers and community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy, and practice. Meaningful consumer involvement needs to be present at all stages of the research cycle.

Participation is authentic and meaningful. It requires both attending (either a physical or virtual situation) and being involved while attending a life situation or activity.

Payment: an overarching term applied to all forms of monetary or in-kind support that is provided to participants in research including remuneration, compensation, reimbursement.

Recruitment: is the process of researchers identifying eligible people for a given study and seeking informed consent from them for their voluntarily participation in that research study.

Research cycle: is a series of stages that helps us work through the process of researching information and drawing conclusions.

More information and terms can be found online in our [Glossary](#) document.

References

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4. [Victorian Auditor-General's Office \(VAGO\). \(2020\). Involving Children and Young People in Research: Report on Youth Engagement.](#)
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Reading list

- Australian Human Rights Commission. (2021). [Children's rights as human rights.](#)
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Resources

The following link to *Healthy Trajectories* resources available online

- [Consumer involvement strategy](#)
- [Easy to read material](#)
- [Expression of interest checklist](#)
- [Involvement through the research cycle](#)
- [Role description for consumer research partners](#)
- [Terms of reference for consumer councils](#)
- [Wellbeing resources](#)

The following link to external resources available online

Consumer safety resources

- [Child safe standards](#)
- [Blue Knot](#)
- [Mental Health First Aid](#)

Further reading

- [IAP2 Spectrum of Public Participation](#)
- [WH&Y: Guidebook: Youth Engagement in Health Research](#)



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