Malatest International

Discussion paper:

Ethical considerations in social research with children and young people

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1. Context

Including young people's's[1] voices in social research[2] informs our understanding of how to deliver services and develop policies to improve young people's wellbeing. However, despite the importance of hearing from young people, the New Zealand Human Rights Commission notes that children remain relatively invisible - their views are not routinely sought, and their rights are often not explicitly or adequately considered in policy and decision-making[3]. This highlights a real gap and demand for more research that meaningfully captures the voices of children and young people, and in doing so, better understands their needs.

Social researchers and evaluators working with children and young people (especially those aged under 16) have identified challenges in including them in social research. They describe:

- Conflicting legislation and a tension between inclusion and protection approaches
- Consent processes based on chronological age
- Inconsistent opinions about ethical considerations such as consent and assent
- Limited or no youth perspectives included in ethics reviews of research applications.

These challenges highlight some of the complexities of developing ethically robust social research with young people, whose unique contexts combined with a breadth of different types of research, mean the nature of ethical research must be considered for each project. There is no one size fits all approach that can be adopted. Applying the principles of ethical research to specific projects is better established for health research and the legislation is clearer than for social research.

In response to challenges identified by the sector, an initial workshop with experts in child and youth research and practice was convened by the Ministry of Social Development in early 2020. The aim of the workshop was to discuss how to apply the principles of ethically robust social research to research with young people. Additional interviews and a review of relevant literature was subsequently funded by Oranga Tamariki to inform their work with children and young people.

The aim of this paper is to summarise the views and perspectives from the workshops and interviews, to inform discussion about what researchers should consider when planning social research and evaluation with children and young people. It sits alongside

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[1] Young people will be used throughout to refer to children and young people under ages 16-18.

[2] In this discussion paper, the term 'research' refers to research and/or evaluation.

[3] Human Rights Commission. (2010). *Chapter 16 – Rights of children and young people.* Retrieved from: https://www.hrc.co.nz/files/7614/2388/0515/HRNZ_10_rights_of_children.pdf.

the literature, ethical guidance for research with children and young people[4], and other current work examining the ethics of inclusion of young people in social research[5,6].

2. Te Tiriti o Waitangi should be the backdrop informing all research in Aotearoa New Zealand.

Children and young people in Aotearoa have unique cultural and social contexts. As well as the research topics, young people's contexts, age and breadth of experiences influence what researchers need to consider to ensure their participation in research is ethically robust. All social research should be undertaken with a deep understanding of Aotearoa New Zealand's unique cultural contexts and recognition of Māori as tangata whenua.

Researchers must understand how their own worldviews influence their research, recognise their limits, seek to improve their understanding of different cultural contexts, and put in place ethical processes to ensure the inclusion of the breadth of cultural contexts.

Cultural and community consultation and co-design during the development and subsequent research stages helps to ensure the research has the right lens and culturally appropriate approaches to design, gaining consent, data collection, analysis, interpretation and reporting for different communities included in the research.

We emphasise the importance of leadership by Kaupapa Māori researchers and rangatahi Māori to inform the ethical principles for work with rangatahi Māori, including discussion about collective consent, rethinking what rights-based social research with children and young people looks like – particularly within a Te Tiriti framework that prioritises not just partnership, participation and protection, but also co-determination. Some of this research has already been completed or is underway.

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[4] Graham, A., Powell, M., Taylor, N., Anderson, D., & Fitzgerald, R. (2013). *Ethical research involving children.* Florence: UNICEF Office of Research – Innocenti

[5] https://voyce.org.nz/maori-participatory-rights-in-the-child-protection-system/

[6] Kia Tika, Kia Pono – Honouring truths – rangatahi centred work soon to be released by VOYCE – Whakarongo Mai https://voyce.org.nz/maori-participatory-rights-in-the-child-protection-system/

3. Moving towards a rights-based inclusion with protection approach

Young people in New Zealand have rights under the United Nations Convention on the Rights of the Child. Article 12 of the Convention emphasises that children capable of forming their own views have the right to express their views freely, and for their views to be given weight in accordance with their age and maturity.

Children's rights in New Zealand are also protected by:

- Te Tiriti o Waitangi.
- The United Nations Declaration on the Rights of Indigenous Peoples, which recognises tamariki and rangatahi Māori are tangata whenua.
- Convention on the Rights of Persons with Disabilities, which recognises the rights of children with disabilities to make decisions about their lives based on free and informed consent and to be active members in society.
- The Care of Children Act 2004 and the Evidence Act 2006, which aim to improve recognition and opportunities for children and young people to express their views and to be heard (particularly during court proceedings).

While young people's rights should provide the foundation for any research involving them, their rights to participate in research must be balanced with protection from any harms of participation. The balance between participation and protection was frequently raised in the workshop and interview discussions that informed this paper.

We heard it was common for agencies and ethics committees to 'protect' children by using a chronological age of 16 years as an indicator of a young person's competence to assess risks and provide informed consent to participate in research. They explained using this approach because it is an accepted standard, providing organisations with some protection from risk and providing guidance to inform decisions about young people's competence to assess the benefits and risks of participating in research.

Children younger than 16 are asked to 'assent' to participation to indicate they understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects. The age at which assent is consistently used as part of consent processes may vary by project.

Moving towards a rights-based inclusion with protection approach recognises that those younger than 16 can also be adequately protected from harm while providing self-consent to participate in research.

3.1. Capacity to consent

Ability to assess risks is not based on chronological age. Young people's capacity to consent is dependent on their developing cognitive development. The so called second stage of brain development starts with the rise in sexual and reproductive hormones which can be anytime between 8 and 16 years old (boys start later than girls) [7,8,9].

Cognitive development occurs in many ways including:

- Future thinking capacity and the development of the concept of time.
- The ability to think about thinking and the development of abstract conceptual thinking.
- Complexity of thinking with more connections coming live.

Informed consent depends on the ability to understand consequences, which involves future thinking, sometimes understanding concepts and complex ideas.

Gillick competency[10] relates the stage of cognitive development with the nature of the decision. Thus, a simple decision which is all about me and all about now – for example answering straight forward questions or saying yes to starting the contraceptive pill can be made at an early stage of cognitive development. Questions about abstract concepts involving complexity and forecasting the future or consent to for example gender transition or acquiring a tattoo, require a much higher stage of development or the involvement of a trusted adult who can assist understanding[11].

Decisions about participation and protection are therefore influenced by the type, complexity and sensitivity of the research. For example, evidence indicates that children as young as nine years old can understand the implications of research participation[12] and it may be appropriate to include their self-consent to participating in a survey which asks about their views on a simple topic. Providing informed consent to participate in research that involves complicated issues or decisions requires young people to be competent to assess the risks of participation.

The view that researchers should assume competence and only move to screening for competence to consent if there is specific evidence that suggests that a young person

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[7] Goddings, A-L et al. (2014). The influence of puberty on subcortical brain development. NeuroImage 88 242–251.

[8] Giedd, J.N. et al. (2006). Puberty-related influences on brain development Molecular and Cellular Endocrinology 254–255 154–162.

[9] Herting M & Sowell E. (2017). Puberty and structural brain development Front Neuroendocrinol. Jan; 44: 122–137. Published online Dec 19. doi: 10.1016/j.yfrne.2016.12.003.

[10] McLean, K. (2000). Children and Competence to Consent: Gillick Guiding Medical Treatment in New Zealand. VUWLawRw 31; 31 Victoria University of Wellington Law Review 551.

[11] Information provided by Dame Sue Bagshaw.

[12] Santelli, J., Haerizadh, S., & McGovern, T. (2017). Inclusion with protection: Obtaining informed consent when conducting research with adolescents. *Innocenti Research Brief.* Retrieved from: https://www.unicef-irc.org/publications/877-inclusion-with-protection-obtaining-informed-consent-when-conducting-research-with.html.

may not be competent is backed by literature[13] [14], the United Nations Convention on the Rights of the Child and the Code of Rights[15].

3.2. Informing parents/caregivers

Although young people's consent is prioritised in an inclusion with protection approach, considering how to inform parents/caregivers and whether their assent or consent is needed is also part of planning social research. Deciding the role of parent/caregiver consent or assent depends on the risk of harm, the nature of the research and the population of children/young people being asked to take part in the research. A requirement for parental consent may be harmful for children or young people who have challenging relationships with their parents/caregivers. In these instances, researchers could consult with ethics advisors and any services connected to the child or young person to work out the best way to represent their best interests. This may involve asking them to identify a trusted adult who can help them provide informed consent.

If parental consent is included, a framework for joint decision-making will help to ensure parental consent does not override young people's wishes to participate. This could also include phased consent processes and opportunities for young people to ask questions in private. Deciding how to phase the process could be a focus of discussion with children and young people and parents/caregivers during consultation and co-design.

4. Ensuring consent to participate in research is voluntary and fully informed is the researcher's responsibility

An inclusion with protection approach requires the research team to ensure processes are in place to obtain fully informed consent and to manage any potential risks of participation.

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[13] Harcourt, D., & Sargeant, J. (2011). The challenges of conducting ethical research with children. *Education Inquiry, 2*(3), 421-436. doi: 10.3402/edui.v2i3.21992.

[14] Hein, I. M., De Vries, M. C., Troost, P. W., Meynen, G., Van Goudoever, J. B., & Lindauer, R. J. L. (2015). Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research. *BMC Medical Ethics, 16*(1), 76-81. doi: 10.1186/s12910-015-0067-z.

[15] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996. Retrieved from: https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/.

Young people's ability to evaluate the consequences of participation is strengthened by the researchers and other trusted adults (including whānau) providing information. For example, by using developmentally appropriate information tools, ensuring young people have access to their choice of a trusted adult they can talk with about participation, offering different modes to provide consent and providing other necessary supports.

Researchers must:

- Be upfront, honest, and transparent with young people about the purpose of the research, what information they will collect and what will happen with the information they provide.
- Be confident before proceeding that the young person understands the research process, potential risks, and consents to participation.
- Check throughout the research that the young person wants to continue participating. In a longitudinal study for example, this means confirming consent at each engagement and for each type of information being collected.

There is no one 'proper' way to obtain consent. Researchers need to be flexible and responsive to the needs of the child or young person. However, we have summarised some overarching principles we found in the literature review and heard in interviews.

Building strong relationships with children and young people and their communities: Cultures may have differing expectations about who can provide consent for young people to participate in research. Building rapport and relationships with children, young people, parents, whānau and communities may include involving representatives of communities and young people in planning and co-design and developing appropriate communication strategies to raise awareness and understanding of the research.

For qualitative research involving smaller samples and longitudinal studies, including a young person's wider 'village' or collective in consent processes is particularly important. In longitudinal studies, ongoing relationships are critical to maintaining sample retention and making the findings useful for children, young people and their whānau.

Relationship-building with young people is especially important when they may be asked to express sensitive or private views. However, while relationships help to mitigate power dynamics, care must be taken not to increase pressure to consent. Children and young people are often expected to comply (especially in school settings) and may feel coerced to give consent to taking part in the research. Additionally, young people may feel pressured to consent by their peers. For in-person data collection, building in informal time prior to data collection activities provides a space for young people to leave if they want or to tell the researcher they do not want to participate.

Adapting consent processes to the participants' levels of ability and understanding: Consent processes are often designed for adults and then replicated in research with young people with little consideration about whether this is appropriate. Pressure from agency legal and privacy teams can result in information sheets and consent forms that are not age appropriate. Information materials can take creative forms to meet developmental needs (e.g., animations, illustrations/graphics, etc.). Use of Easy Read[16] is recommended for young people with cognitive disability and may also be effective for young children. Researchers can cover other essential information verbally, through websites or embedded videos. Information sheets and consent forms should be trialled first with young people to check their usability.

If the young person needs to consent to multiple aspects of a research project, the consent form should break these down and use tick boxes so that the researcher knows which aspects of the process the young person is comfortable with, and what they do not consent to or need more information about. If recording consent on an information sheet, it is good practice to provide a copy to the young person for their reference.

Being responsive to children and young people's needs: Written consent or electronic confirmation of consent is the default position required by most ethics committees. However, verbal consent should also be accepted for in-person research, particularly for the very young, those who are not literate and those who prefer to provide verbal consent. Researchers should plan ahead for situations where written consent will not be obtained and have protocols to verify that a proper process was followed and that voluntary consent was given.

Formalising informed consent and assent as well as informed dissent processes: Empowering young people to understand they can agree or disagree to participate. For in-person research, it is important for researchers to be mindful of body language and to understand ways to help young people learn to say no. They should reiterate the option to say no at multiple points throughout any study or interview, and check young people are still comfortable with participating.

Withdrawing information: Researchers should clarify the extent information can be withdrawn. The type of methodology affects the degree to which information can be withdrawn. For example, it is not possible to withdraw consent for an anonymous online survey once the answers have been submitted, as the answers cannot be linked to an individual. It is important to communicate to the young person what this 'point of no return' is, when they will not be able to change their mind.

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[16] https://www.odi.govt.nz/guidance-and-resources/a-guide-to-making-easy-read-information/

5. Privacy and confidentiality

Researchers must be committed to respecting children and young people's privacy and ensuring their information remains confidential. The NEAC guidelines and standards in health research provide a solid ethical foundation for considering how to protect privacy and confidentiality for research participants.

There are some additional considerations for children and young people:

- **Avoiding potential identification of individuals by certain characteristics or experiences in recruitment.** Eligibility criteria and recruitment approaches may be identifying for a particular subset of young people, especially if participants are recruited in a school, community or care and protection setting. Researchers must develop recruitment strategies that protect the privacy of young people.
- **Thinking about where and how information is collected from young people so their participation remains confidential**. In some projects, young people may not want their parents/caregivers or peers (especially at school) to know about their participation and whether they have consented to take part. Researchers must balance approaches to engaging with communities to build awareness of studies with strategies to protect the confidentiality of participants. The appropriate balance will depend on the topic, participant profiles and number of participants.
- **Considering how to provide privacy for young people if this is not the usual social or cultural practice.** For example, parents may want to be present during interviews but young people must consent (or children assent) to their participation. Researcher attributes (like gender and age, police checks and backgrounds) and presence of a support person will affect how comfortable parents will be in leaving their child with the researcher.
- **Managing parental desires to access information about their children.** Parents may want to know more about their child's thoughts and behaviours and may feel entitled to the data. However, researchers are obliged to protect their young participants' confidentiality even from their parents and to be clear about this in participant recruitment. This could be managed by developing general summaries of research for all young people, parents/caregivers and communities.
- **Thinking about what to do if a child or young person does not want to be anonymous.** Some young people may want their real names used to indicate their ownership and participation in the project and may not understand why pseudonyms are important. Discuss the long-term risks of using their real names and how these could be managed.

- **Where photographic data is collected.** Consider blurring faces to maintain confidentiality (but also bear in mind how this impacts young people's voices).

6. Identifying and managing risks to enhance safety in social research with children and young people

Risk should be considered in terms of the vulnerability of children and young people and the sensitivity of the research topic. For example, young people in care have experienced trauma and may be more likely to be triggered by questions about families and whānau than their peers who do not have care experience. Gender minority children and young people may not be publicly "out" to anyone in their lives, and recruitment and data collection processes could risk identifying them.

Defining when a child or young person is at risk may be more complex than in research with adults. While some criteria are clear (e.g., the young person is planning suicide or harm to others or discloses experiencing abuse), others are less clear (e.g., the young person (aged just under 16) discloses having sex, using marijuana, or shoplifting).

Data collection methods can also impact risk and the degree to which immediate supports can be provided (anonymous online surveys limit follow-up of young people who provided concerning responses, while interviews allow researchers to immediately connect young people with support if needed).

There is no single safety method that should be utilised. Appropriate safety strategies will vary depending on the topic, the type of research being conducted and the characteristics of the child or young person.

Guidance from the literature and interviews suggest the following strategies:

Establish clear protocols to minimise harm and distress and to designate what should be done if safety concerns are raised. This could include developing clear protocols to provide young people with follow-up support, discussing what actions to take should they raise a safety concern, and having protocols to protect young people during the research process (e.g., police vetting of researchers). If there is a safety risk, researchers should discuss with a qualified expert whether reporting a disclosure puts the young person at greater risk, and whether the behaviour being disclosed indicates serious harm. The research team must have access to an appropriately qualified expert whose input has been arranged in advance. Input from young people about safety thresholds is very helpful as part of this process.

Provide training for researchers on how to assess risk and manage distress of young people. This should include knowledge of how to refer to follow-up support. Clear boundaries between research and counselling/support should be maintained, but researchers must be trained about how to respond to issues that arise during the research.

Provide explicit communication about confidentiality (and its limits) during the consent process. If research is confidential, and young people have been assured they will remain anonymous, then the young people involved must know and understand the limitations to this and what actions would be taken (and with whom) if the researcher has to breach confidentiality.

Have clear protocols to manage requests for support: A young person participating in research might also ask for additional help or support. For example, they need access to a social service, or the researcher identifies the need for them to see a health professional. Although not explicit safety risks, the researcher must have processes in place to respond. However, responding by providing additional support may change a study from an observational study. This can impact a longitudinal study and researchers must plan for any potential impacts on the study design. A research design such as an action-research approach that builds interventions and their outcomes into the study design may be valuable in a longitudinal study with young people who may be likely to identify a need for support.

Providing appropriate support for young people during and after research participation: Opportunities to support young people during and after research include:

- The option of a support person(s) being present during research. The appropriate support person must be the young person's choice and could be a peer, family or community member, youth worker, or teacher.
- Including options to access support in data collection methods (e.g., providing contact details for organisations; in an online anonymous survey, having a button at the top of the screen to link young people to support if they need it or a write-in box).
- If a young person becomes distressed during research, researchers should ask if they have current supports in place, and if they do not, if there is something or someone they know of that could help. Researchers cannot assume that a child or young person who becomes distressed during research, knows who to access and what works for them. Researchers need to be prepared with options on who could help to facilitate a link to support.

6.1. Children and young people with care experience

Children and young people with care experience present additional considerations in terms of best practice in ethically sound research. Their experiences mean they will likely have been exposed to risk and trauma that affect their parental/whānau attachments and social relationships with others.

Important considerations for this group include:

- **Ensuring a trauma lens guides the research:** Young people in care have a common trauma as well as potential exposure to a range of other traumas that increase the risk of them being retraumatised by questions in the research. However, trauma and vulnerability should not exclude participation in research (in line with the NEAC guidelines). Their research participation should be prioritised and facilitated in safe and supportive ways, while ensuring that they do not feel obliged to take part.
- **Thinking about how to engage with them:** Young people in care often experience diminished trust that may influence their decisions about taking part in research. For example, they may not want to participate because they feel they are constantly being assessed, they do not trust how the findings will be used and/or they are concerned about confidentiality and how services may respond to what they say. Researchers should invest substantial time and effort in building trusting relationships, and to ensuring these children and young people feel valued, respected and listened to, before moving onto any data collection. This could include ensuring consent processes address their level of need, mitigating power dynamics and including trusted adults they can consult with independently about the research.
- **Navigating young people's mobility and instability:** Young people in care are typically transient and often experience multiple placements. They can experience uncertainty about the type of home situation they are able to return to and may not be used to a sense of security and stability. This can have implications for engaging with them consistently, as well as gaining parental/caregiver consent, as this may change multiple times over the course of their childhood and adolescence.
- **Ensuring voluntary consent:** There may be cases where the State has consented for the young person's participation in research or a service. However, the researchers are still obliged to ensure the young person has given voluntary and informed consent or assent.
- **The over-representation of tamariki and rangatahi Māori in Oranga Tamariki care:** In Aotearoa New Zealand, statistics show that tamariki and rangatahi Māori are disproportionately taken into State care. This has implications for engagement, consultation and funding.
    - Iwi oversight, engagement and consultation should be at the forefront of any work involving tamariki and rangatahi Māori.
    - Adequate funding should be allocated – if the research were to terminate abruptly and unexpectedly due to inconsistencies or uncertainty of sustainable funding, this could lead to harm experienced by young people in care. These young people may feel their voices and

experiences are not being valued and this could lead to greater disconnection with institutions.

6.2. Gender minority young people

Gender minority young people includes transgender, gender-diverse and gender non-conforming youth (such as people who identify as non-binary, agender and genderqueer) and people with Indigenous genders (such as takatāpui, whakawahine, fa'afafine, fakaleitī).

There are no Aotearoa New Zealand statistics about the proportion of gender minority young people who live in care but in the United Kingdom and the United States gender minority young people disproportionately live in care environments compared to their cis-gender peers. These high rates have been partially attributed to some gender minority children and young people entering care due to family rejection of their gender.

Important considerations for this highly vulnerable population group include:

- **Privacy and confidentiality:** Some gender minority young people might not have disclosed their gender or only recently disclosed it. Gender minority young people must have the autonomy to share their gender identity on their own terms. Risks of being 'outed' before they choose to disclose their gender can be harmful for them. Researchers should consider where the research will be conducted, the amount of privacy the young person receives during data collection and providing options to have someone they are comfortable with in the room.
- **Safety:** Gender minority young people may be more likely to disclose and discuss their gender in a safe space. After the survey it would be important to guide them to resources to discuss their gender further if they want to. This could include national community organisations such as OUTLine, RainbowYOUTH and Gender Minorities Aotearoa or regional support organisations such as QTopia in Christchurch.

Following best practice guidelines on collecting gender data and research with gender minority youth is vital to maintain the cultural safety of the gender minority young people taking part in the research. Guidelines based on formal consultation with young people aged 18 and over in the Rainbow community and informal discussions with younger age groups include:

- Following statistical standards and best practice guidelines by Statistics New Zealand.
- Consulting or co-designing the data collection with gender minority young people.

- Considering how language can be used to create an inclusive environment or inadvertently hurt gender minority young people - avoiding gendered language (e.g. thanks guys), asking for their pronouns and researchers sharing their own, and asking for their preferred name can be key to building whanaungatanga and trust with gender minority young people.
- Using gender minority interviewers where possible or alternatively, at a minimum, using interviewers that have experience with gender minority youth and receive relevant training.

7. Consultation with children, young people, and communities helps ensure research is relevant and ethical

Embedding obligations for meaningful consultation with children and young people or including them in genuine co-design is best practice in research design. Involving children and young people in all aspects of social research design was frequently mentioned in interviews as a way to ensure that research is appropriate and relevant.

7.1. Co-design and consultation

Co-design and consultation with young people are valuable because the processes provide:

- Unique perspectives that can inform engagement, review, research design and implementation.
- Peer perspectives about the benefits and risks of participation and how to manage potential risks.
- Deeper understandings of how to facilitate trust and good relationships with young people, which enhances the quality of the data that can be collected.
- Knowledge of the best mediums and technologies to engage with young people to gather their views and how they prefer to provide their information.
- Assistance in directing the researchers into spaces they may not have previously considered.

The extent and ways young people are involved in research design will vary depending on the research topic and the ages of intended participants. Even at a very young age, children can inform the design of data collection tools and processes.

Effective consultation includes:

- Recognising and empowering children and young people as co-researchers and the experts of their own experience.
- Providing opportunities to review processes and findings of the project with children and young people at the end of the project to discuss how their input impacted the process and how the information they provided will influence policies and programmes.

7.2. Engagement with whānau and wider communities

Children and young people are part of their whānau and communities. Building relationships and consulting with the communities in which young people live is important in building awareness of research, in considering the needs of the community and how to plan, interpret and understand research in the context of communities. Engaging with communities and whānau is a fundamental part of any research with Māori and Pacific young people, and young people from other collective communities.

Adults in whakapapa and kaupapa whānau can both prevent and facilitate young people’s participation. Adults can play a key role in motivating them to participate and in explaining what participating means. Inability for researchers to build effective relationships may result in ‘gatekeeping’ and can prevent or limit young people’s participation in research.

Community engagement could include:

- Consulting locally and/or planning with the target communities, iwi and hapū when planning the research and developing protocols to ensure there is respect for whānau and communities in the design and implementation of the research.
- Partnering with trusted organisations or adults in the young person’s life to help young people to understand the implications (benefits and risks) of taking part so they can make a truly informed decision.

Exceptions to involving family, whānau and communities in a young person’s research involvement. In some circumstances, it may not be practical or safe to involve family or whānau, such as in situations where a young person experiences harm, discrimination or disconnection from their whānau. Researchers should think critically about whether parent/caregiver involvement is appropriate and talk with the young person about other options, including having another trusted adult (like a youth provider) involved.

8. Research planning includes considering the demographic and professional profiles of the research team as they may influence responses

Young people may share information differently with researchers with different demographic and/or professional characteristics or with different connections and mana in the community where research is taking place. The attributes of the research team can reduce or compound power dynamics between them and the young person. Options to mitigate power dynamics include peer researchers with older age groups and giving participants the choice of the researcher who interviews them (based on culture, gender, age and language options).

While all researchers have obligations to consider participant safety, researchers with professional qualifications such as social workers may experience additional conflicts in obligations between reporting and responding to perceived safety risks and their promise of confidentiality to young people. Young people may not confide in a person in a professional role they have just met, as they may be concerned the professional will take what they have said out of context and breach their confidentiality.

Obligations for different professional groups need to be clearly explained to participants.

Statutory agencies should consider their role in the research process and whether it is appropriate for them to be closely involved in research design, fieldwork, analysis and reporting. It may be inappropriate for entities with statutory roles to conduct research on/with people under their mandate for whom they make important, life-changing decisions, as there is an inherent power imbalance (e.g., Oranga Tamariki social workers/staff conducting research with young people in care). However, a clear separation between an internal research team and service delivery teams may mitigate any potential risks. Agency research teams must be transparent to participants about their degree of separation from the agency.

An additional consideration is the important role of agency or NGO provider staff in introducing ‘independent researchers’ to research participants. As long as any risks of coercion are managed, agency and provider staff know the young person and are often a trusted person who can explain the research process.

9. Some additional considerations for longitudinal research designs

- **The importance of building and maintaining long-term relationships with whānau.** This is the most important element for a successful longitudinal study and is especially critical for vulnerable communities who may have had their trust broken. Strong long-term relationships, particularly with a young person's whānau, mitigate attrition. Whānau can help researchers engage with young people especially as they age into adolescence and may be less interested in participation. Continuity of fieldworkers can enhance relationships with young people and whānau, as they have built trust over a long period of time.
- **Ensuring the right level and frequency of contact:** It is important to engage with children and young people (and their whānau/communities) to maintain relationships over time while ensuring minimal disruption to their lives (not over-contacting).
- **The transition from gathering information about children from their parents,** to asking children directly about themselves.
- **The age at which it is appropriate to start seeking informed consent from young people.** Promoting autonomy and decision-making is part of child development, so research suggests it is practical to start involving children as young as possible in decisions about whether they want to participate in research.
- **Changes in parenting and caregivers.** In longitudinal studies, researchers should ensure they have processes to determine and respond to changes in the primary caregiver over time.
- **Re-consenting at each study wave.** Consent processes should be enacted at each new wave of the longitudinal study, and for each type of data being collected (e.g., surveys, interviews, observations, biological data, linking to other data like the integrated data infrastructure (IDI)).
- **Young people's understandings of a longitudinal study.** It is important to be clear about the potential benefits of participation balanced against the time they would be asked to put into the study, how they could be involved, the consistency of engagement they could expect from the researchers and when they would hear back about findings. Communicating the benefits may include ensuring there is summary reporting that is interesting to young participants. Koha for young participants acknowledges the time they contribute to participation.
- **Adapting information and consent.** Information materials should change over time as a participant's capacity evolves, and consent should be obtained at each stage of the study.

10. Including young people’s perspectives in ethics review processes

Limited or no youth perspectives included in ethics reviews of research applications was identified as a challenge for social researchers. It is important that ethics committees that make decisions on research involving young people have the skills and experience and understand the importance of conducting research in the relevant area.

Options include:

- Developing strategies to include young people in ethics review processes. It is important that youth advisory groups are tailored for a project and have the relevant type of lived experience. For example, young people attending university may not reflect the lived experiences and realities of different groups of young people (e.g., young people in care, gender/ethnic minority young people, etc.). There is also a risk of young people on advisory committees becoming less engaged with the groups they represent, suggesting the need to consider the appropriate length of representation and to ensuring diverse representation.
- Requiring evidence of peer participation and community consultation in research design to provide information to assist ethics committees to assess the balance of inclusion and protection.
- Building the expertise of ethics committee members about social research with young people. For example, requiring members to have completed training on young people’s rights and how to consider their best interests.
- Co-opting people with appropriate knowledge as advisors to ethics committees to review social research with young people.
- Tailored ethics committees for specific projects: ensuring ethics committees for research with young people are tailored so they are specific to the topic and context of different projects – to achieve this, a network of youth practitioners, academics and other experts could be established, who hold the knowledge, expertise and connections within their communities. This resource could then be used to create bespoke ethics panels that take rights-based approaches and advocate for young people.

11. Next steps

There is no easy answer to the challenges social researchers reported as part of our discussions. While there are some recommendations in the literature and from experienced experts, the range of issues to be considered for each research project and young people’s different contexts mean there is no ‘one size’ fits all response.

There is general consensus amongst researchers of the need for a move towards an inclusion with protection approach. However, many ethics committees and agencies use a chronological age of 16 years as a safe guideline for when self-consent is appropriate. A chronological age cut-off limits participation of some groups of young people.

Appropriate safeguards and risk management are essential to move towards an inclusion and protection approach. There is the need for wide discussion to build a more consistent view of appropriate safeguards and risk management strategies. This paper aims to inform that discussion.

Appendix 1: Working group participants and interviewees

The list below includes all those who participated in the Ministry of Social Development sponsored workshop and/or were interviewed as part of the Oranga Tamariki funded work. Not all participants necessarily agree with all views included in the guidance document. There are many others with expertise and not all were able to be included within the scope and timeframes of this work.

Youth advisors	Voyce: Whakarongo Mai youth advisory group
Sue Bagshaw	The Collaborative
Barbara Bradnock	Ministry of Health
Kelsey Brown	Office of the Children's Commissioner
Moira Clunie	Ara Taiohi
Glenn Colqhoun	Youth One Stop Shop
Tim Dare	University of Auckland
Peter Foaese	Office of the Children's Commissioner
Kirsten Forrest	Ministry of Health
Name withheld	University ethics advisor
Mark Henaghan	University of Auckland
Adele Hogan	Ministry of Social Development
Rob McHawk	Ministry of Health
Tracey McIntosh	University of Auckland
Kiri Milne	Oranga Tamariki
Susan Morton	Growing up in New Zealand – University of Auckland
Te Tatau Kitenga	SYPHANZ
Nicola Peart	University of Otago
Victoria Pond	Former manager of Rainbow Service for rangatahi
Kate Prickett	Roy McKenzie Centre for the Study of Families and Children
Ria Schroder	The Collaborative
Debra Small	Social Wellbeing Agency
Sarah Talboys	Oranga Tamariki
Jason Timmins	Education Review Office
Dan Tautolo	Auckland University of Technology
Nicki Taylor	University of Otago
Huia Tomlins-Jahnke	Massey University

Ian Town	Ministry of Health
Patrick Vakaoti	University of Otago
Gary Witte	University of Otago

Appendix 2: The NEAC guidelines

The National Ethics Advisory Committee (NEAC) guidelines define standards for health research In Aotearoa New Zealand[17].

The NEAC guidelines focus on standards relating to health and disability research; those relevant to social research include:

- Overarching ethical principles: Combining Te Ara Tika (Māori ethical principles) and bioethics principles.
- Research with Māori and Pacific peoples: Understanding how an equity lens must drive all research, the importance of health and disability research with Māori and cultural considerations for Māori and Pacific communities in research.
- Ethical management of vulnerability: Some populations may be vulnerable and researchers must consider whether the proposed research will create or exacerbate existing vulnerabilities.
- Informed consent: Based on understanding what participation involves and of the benefits and potential risks of participation.
- Research benefits and harms, ethical research development and design, and ethical implications of methodologies.
- Research conduct.
- Quality improvement.

The NEAC guidelines provide the foundation for social research ethics considerations. This guidance document expands and details specific points relating to social research with children and young people.

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[17] National Ethical Standards for Health and Disability Research and Quality Improvement (2020). Retrieved from: https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement.

Appendix 3: Bibliography

Arnott, L., Martinez-Lejarreta, L., Wall, K., Blaisdell, C., & Palaiologou, I. (2020). Reflecting on three creative approaches to informed consent with children under six. *British Educational Research Journal, 46*(4), 786-810. doi: 10.1002/berj.3619.

Auckland University of Technology. (n.d.). *Guidelines for research with children as participants.* Retrieved from: https://www.aut.ac.nz/research/researchethics/guidelines-and-procedures#12

AUT Pacific Health Research Centre. (n.d.). *Pacific Islands Families Study.* Retrieved from: https://phrc.aut.ac.nz/our-research/pacific-islands-families-study.

AUTEC. (n.d.). *When consent is not necessary.*

Bessell, S. (2011). Participation in decision-making in out-of-home care in Australia: What do young people say? *Children and Youth Services Review, 33*, 496-501.

British Medical Association. (2020). *Card 2: Assessing competence* (Children and young people tool kit). Retrieved from: https://www.bma.org.uk/advice-and-support/ethics/children-and-young-people/children-and-young-people-ethics-toolkit

Broome, M. E., Kodish, E., Geller, G., & Siminoff, L. A. (2003). Children in research: New perspectives and practices for informed consent. *IRB: Ethics & Human Research, 25*(5), S20-25. Retrieved from: https://jstor.org/stable/3564118.

Christian, B. J., Pearce, F. P., Roberson, A. J., Rothwell, E. (2010). It's a Small, Small, World: Data Collection Strategies for Research with Children and Adolescents. *Journal of Pediatric Nursing, 25*, 202-214.

Clark, T. C., Fleming, T., Bullen, P., Denny, S., Crengle, S., Dyson, B., Fortune, S., Lucassen, M., Peiris-John, R., Robinson, E., Rossen, F., Sheridan, J., Teevale, T., Utter, J. (2013). Youth'12 Overview: The health and wellbeing of New Zealand secondary school students in 2012. Auckland, New Zealand: The University of Auckland.

Cooper, G., Arago-Kemp, V., Wylie, C., & Hodgen, E. (2004). *Te rerenga ā te pīrere: A longitudinal study of kōhanga rep and kura kaupapa Māori students*. New Zealand Council for Educational Research. Retrieved from: https://www.nzcer.org.nz/system/files/12740.pdf.

Crivello, G., Morrow, V., & Wilson, E. (2015). *Young lives longitudinal qualitative research: A guide for researchers.* Retrieved from: www.younglives.org.uk.

David, M., Edwards, R., & Alldred, P. (2001). Children and school-based research: 'Informed consent' or 'educated consent'? *British Educational Research Journal, 27*(3), 347-365. Retrieved from: https://www.jstor.org/stable/1501900.

Devaney, C. & Rooney, C. (2018). *The Feasibility of Conducting A Longitudinal Study on Children in Care or Children Leaving Care Within the Irish Context*. Galway: UNESCO Child and Family Research Centre, National University of Ireland Galway.

Devaney, C. (2013). *Longitudinal study of children who leave care: Scoping study undertaken as part of the implementation of the National Strategy for Research and Data on children's lives, 2011-2016*. Galway, Ireland: Department of Children and Youth Affairs. Retrieved from:

http://www.childandfamilyresearch.ie/media/unescochildandfamilyresearchcentre/documentspdf/longitudinal-study-of-children-who-leave-care.pdf.

Dockett, S., Perry, B., & Kearney, E. (2013). Promoting children's informed assent in research participation. *International Journal of Qualitative Studies in Education, 26*(7), 808-828. doi: 10.1080/09518398.2012.666289.

Dworsky, A. (2014). Children as self-informants in longitudinal studies: Substantive findings and methodological issues. In G. B. Melton, Ben-Arieh, A., Cashmore, J., Goodman, G. S., & Worley, N. K. (Eds.), *The SAGE handbook of child research,* 391-431. SAGE Publications Ltd. doi: 10.4135/9781446294758.

Fergusson, D. (n.d.). *The Christchurch Health and Development study*. Retrieved from: https://www.parliament.nsw.gov.au/ladocs/inquiries/2280/The%20Development%20of%20Wellbeing%20in%20Children%20Part%202%20Fe.pdf.

Flanagan, P. (2012). Ethical review and reflexivity in research of children's sexuality. *Sex Education, 12*(5), 535-544. doi: 10.1080/14681811.2011.627731.

Flanagan, S. M., Greenfield, S., Coad, J., & Neilson, S. (2015). An exploration of the data collection methods utilised with children, teenagers and young people (CTYPs). *BMC Research Notes, 8*(1), 61-74. doi: 10.1186/s13104-015-1018-y.

Giedd, J.N. et al. (2006). Puberty-related influences on brain development Molecular and Cellular Endocrinology 254–255 154–162.

Goddings, A-L et al. (2014). The influence of puberty on subcortical brain development. NeuroImage 88 242–251.

Graham, A., Powell, M. A., & Taylor, N. (2015). Ethical research involving children: Putting the evidence into practice. *Family Matters,* 96, 23-28.

Graham, A., Powell, M., Taylor, N., Anderson, D., & Fitzgerald, R. (2013). *Ethical research involving children.* Florence: UNICEF Office of Research – Innocenti. (Chapter on Informed Consent).

Graham, A., Powell, M., Taylor, N., Anderson, D., & Fitzgerald, R. (2013). *Ethical research involving children.* Florence: UNICEF Office of Research – Innocenti. (Chapter on Privacy and confidentiality).

Graham, A., Powell, M., Taylor, N., Anderson, D., & Fitzgerald, R. (2013). *Ethical research involving children.* Florence: UNICEF Office of Research – Innocenti. (Chapter on Harms and benefits).

Gray, A. (2002). *Increasing the participation of children, young people, and young adults in decision making: A literature review.* Wellington, New Zealand: Ministry of Social Development. Retrieved from: https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/archive/2002-increasing-participation-children-young-adults-in-decision-making-literature-review.pdf.

Griffith, R. (2016). What is Gillick competence? *Human Vaccines & Immunotherapeutics, 12*(1), 244-247. doi: 10.1080/21645515.2015.1091548

Growing Up in New Zealand. (n.d.). *Your privacy and data.* Retrieved from: https://www.growingup.co.nz/your-privacy-and-data#3.

Harcourt, D., & Sargeant, J. (2011). The challenges of conducting ethical research with children. *Education Inquiry, 2*(3), 421-436. doi: 10.3402/edui.v2i3.21992.

Hasking, P. A., Lewis, S. P., Robinson, K., Heath, N. L., & Wilson, M. S. (2019). Conducting research on nonsuicidal self-injury in schools: Ethical considerations and recommendations. *School Psychology International, 40*(3), 217-234. doi: 10.1177/0143034319827056.

Health Research Council of New Zealand (n.d). *Research involving children guidelines*. Wellington, New Zealand: Health Research Council.

Hein, I. M., De Vries, M. C., Troost, P. W., Meynen, G., Van Goudoever, J. B., & Lindauer, R. J. L. (2015). Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research. *BMC Medical Ethics, 16*(1), 76-81. doi: 10.1186/s12910-015-0067-z.

Helgesson, G. (2005). Children, longitudinal studies, and informed consent. *Medicine, Health Care and Philosophy, 8*(3), 307-313. doi: 10.1007/s11019-005-0978-4.

Helweg-Larsen, K., Sundaram, V., Curtis, T., & Boving Larsen, H. (2003). The Danish youth survey 2002: Asking young people about sensitive issues. *International Journal of Circumpolar Health, 63 Suppl 2*(sup2), 147-152. doi: 10.3402/ijch.v63i0.17880.

Herting M & Sowell E. (2017). Puberty and structural brain development Front Neuroendocrinol. Jan; 44: 122–137. Published online Dec 19. doi: 10.1016/j.yfrne.2016.12.003.

Hiriscau, I. E., Stingelin-Giles, N., Stadler, C., Schmeck, K., Reiter-Theil, S. (2014). A right to confidentiality or a duty to disclose? Ethical guidance for conducting prevention research with children and adolescents. *European Child & Adolescent Psychiatry, 23*(6), 409-416. doi: 10.1007/s00787-014-0526-y.

Holland, S. (2009), Listening to Children in Care: A Review of Methodological and Theoretical Approaches to Understanding Looked after Children's Perspectives. *Children & Society, 23, pp.* 226-235, DOI: 10.1111/j.1099-0860.2008.00213.x

Human Rights Commission. (2010). *Chapter 16 – Rights of children and young people.* Retrieved from: https://www.hrc.co.nz/files/7614/2388/0515/HRNZ_10_rights_of_children.pdf.

Johnson, E. (2017). *Capturing the voices of looked-after children via computerised assisted self-interviewing technology: A longitudinal approach.* (Doctoral thesis, University College London, London, United Kingdom). Retrieved from: https://discovery.ucl.ac.uk/id/eprint/1573578/.

Kiili, J., & Moilanen, J. (2019). Participation as a methodological and ethical issue in child protection research. *Journal of Children's Services, 14*(3), 143-161. doi: 10.1108/JCS-02-2019-0009.

Kyegombe, N., Banks, L. M., Kelly, S., Kuper, H. & Devries, K. M. (2019). How to conduct good quality research on violence against children with disabilities: key ethical, measurement, and research principles. *BMC Public Health, 19.*

Lon, L. (2013, October). Children and research: Ethical issues. *Ethics Notes.* Wellington, New Zealand: Health Research Council of New Zealand.

Loveridge, J. (2010). *Involving children and young people in research in educational settings: Report to the Ministry of Education.* Wellington, New Zealand: Ministry of Education.

McLean, K. (2000). Children and Competence to Consent: Gillick Guiding Medical Treatment in New Zealand. VUWLawRw 31; 31 Victoria University of Wellington Law Review 551.

Ministry of Health (1998). *Consent in Child and Youth Health: Information for Practitioners*. Wellington, New Zealand.

Morrow, V. (2013). Practical ethics in social research with children and families in young lives: A longitudinal study of childhood poverty in Ethiopia, Andhra Pradesh (India), Peru and Vietnam. *Methodological Innovations Online, 8*(2), 21-35. doi: 10.4256/mio.2013.011.

Mumford, S. E. (1999). Children of the 90s: Ethical guidance for a longitudinal study. *Archives of Disease in Childhood – Fetal and Neonatal Edition, 81*(2), F146-F151. doi: 10.1136/fn.81.2.f146.

Munford, R., & Sanders, J. (2019). *The youth transitions study final report.* Retrieved from: http://www.youthsay.co.nz/massey/fms/Resilience/Documents/Youth%20Transitions%20Study%20Final%20Report.pdf.

New Zealand Association for Research in Education. (2010). *NZARE ethical guidelines 2010*. Retrieved from: https://www.nzare.org.nz/assets/Uploads/Policies-and-Practices-/NZAREEthicalGuidelines2010.pdf.

Office of the Children's Commissioner. (2015). *Engagement methods: Focus groups.* Retrieved from: https://www.occ.org.nz/listening2kids/how-you-engage/engagement-methods/focus-groups/.

Office of the Children's Commissioner. (2018). *Consent and ethics.* Retrieved from: https://www.occ.org.nz/assets/Uploads/OCC-Consentethics2.pdf.

Office of the Children's Commissioner. (2018). *Tips: Maximising participation of all children.* Retrieved from: https://www.occ.org.nz/assets/Uploads/542019MaximisingParticipation2.pdf.

Olson, K., Gulgoz, S. (2017). Early Findings From the TransYouth Project: Gender Development in Transgender Children. Child Development Perspectives, 12 (2), 93-97. https://doi.org/10.1111/cdep.12268

Parsons, S. (2015). The potential of digital technologies for transforming informed consent practices with children and young people in social research. *Social Inclusion, 3*(6), 56-68. doi: 10.17645/si.v3i6.400.

Peart, N., & Holloway, D. (n.d.). *Research involving children.* Retrieved from: https://www.hrc.govt.nz/sites/default/files/2019-06/Resource%20Library%20PDF%20-%20Research%20involving%20children.pdf

Phelan, S. K., & Kinsella, E. A. (2013). Picture this… safety, dignity, and voice – ethical research with children: Practical considerations for the reflexive researcher. *Qualitative Inquiry, 19*(2), 81-90. doi: 10.1177/1077800412462987.

Platt, L. (2016). *Method guide 5: Conducting qualitative and quantitative research with children of different ages.* Retrieved from: http://globalkidsonline.net/wp-content/uploads/2016/05/Guide-5-Research-with-children-of-different-ages-Platt.pdf.

Powell, M. A., Fitzgerald, R., Taylor, N. J., & Graham, A. (2012). *International literature review: Ethical issues in undertaking research with children and young people* (Literature review for the Childwatch International Research Network). Lismore: Southern Cross

University, Centre for Children and Young People/Dunedin: University of Otago, Centre for Research on Children and Families.

Powell, M. A., Graham, A., McArthur, M., Moore, T., Chalmers, J., & Taplin, S. (2019). Children's participation in research on sensitive topics: Addressing concerns of decision-makers. *Children's Geographies, 18*(3), 325-388. doi: 10.1080/14733285.2019.1639623.

Santelli, J., Haerizadh, S., & McGovern, T. (2017). Inclusion with protection: Obtaining informed consent when conducting research with adolescents. *Innocenti Research Brief.* Retrieved from: https://www.unicef-irc.org/publications/877-inclusion-with-protection-obtaining-informed-consent-when-conducting-research-with.html.

Shepherd, P. (2012). *Millennium cohort study: Ethical review and consent.* Retrieved from: https://cls.ucl.ac.uk/wp-content/uploads/2017/07/MCS-Ethical-review-and-consent-Shepherd-P-November-2012.pdf.

Taplin, S. (2005). *Methodological design issues in longitudinal studies of children and young people in out-of-home care: Literature review.* Retrieved from: https://www.facs.nsw.gov.au/__data/assets/pdf_file/0006/321729/oohc_methodology.pdf.

Turner (2009). From the Inside Out: Calling on States to Provide Medically Necessary Care to Transgender Youth in Foster Care. *Family Court Review, 47*(3), 552-569. https://doi.org/10.1111/j.1744-1617.2009.01273.x

Van Rooyen, A. (2016). *'Child competence' to participate in and consent to health treatment: A Foucauldian discourse analysis investigating the meaning of competence* (Master's thesis, Auckland University of Technology, Auckland, New Zealand). Retrieved from: https://openrepository.aut.ac.nz/handle/10292/10153

Van Rooyen, A., Water, T., Rasmussen, S., & Diesfeld, K. (2015). What makes a child a 'competent' child? *The New Zealand Medical Journal, 128*(1426), 88-95.

Veale J, Byrne J, Tan K, Guy S, Yee A, Nopera T & Bentham R (2019) *Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand.* Transgender Health Research Lab, University of Waikato

Walter, M., Lovett, R., Maher, B., Williamson, B., Prehn, J., Bodkin-Andrews, G., Lee, V. (2020). Indigenous data sovereignty in the era of big data and open data. *Australian Journal of Social Issues,* 1-14. doi: 10.1002/ajs4.141.

Wilson, B., Cooper, K., Kastanis, A.. (2014). Sexual and Gender Minority Youth in Foster Care: Assessing Disproportionality and Disparities in Los Angeles. *The Williams Institute.*