How the Tivaevae methodology can be used to guide ethical research when capturing Pacific youth voices

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Abstract

Introduction: Health research involving children and young people is essential to gain a better understanding of their unique perspectives, and health needs, particularly for Pacific populations in New Zealand, which are comparatively young. Research involving children and young people presents ethical challenges, as children and persons under 16 years of age are considered vulnerable and in need of protection. The capacity and appropriateness of children and young people providing individual consent or assent can be a contentious issue and for Pacific children and young people, individual consent may conflict with collectivist cultural values.

Methods A review of the Cook Islands' Tīvaevae research methodology was undertaken against the New Zealand health research ethical standards to assess its suitability for guiding consent processes involving Pacific youth.

Conclusion: This paper argues that the values of the Cook Islands' Tīvaevae methodology namely tu-inangaro (relationships) and akaari kite (a shared vision) can be used to reframe the consent process from an individual transaction to a collective dialogue to ease the tension in capturing informed consent for young Pacific people and children, thereby mitigating potential harm and fostering trust in research participation.

Keywords: Pacific research ethics, Pacific methodology, Tīvaevae methodology, Cook Islands

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Introduction

The ethics of conducting research with children and young people

It is widely accepted that children and young persons should be able to participate in research and that their views should be given due weight in accordance with the age and maturity of the child in matters affecting the child. This principle is articulated in Articles 12 and 24 of the Convention on the Rights of the Child (UN,1989), which affirms that children are entitled to special care and assistance. In New Zealand, ethical practice in health research is guided by the National Ethics Advisory Ethical (NEAC) standards. This paper argues that the Tīvaevae methodology can be used as a culturally responsive guide for ethical research involving Pacific youth, particularly in navigating consent within collectivist contexts.

In New Zealand consent for children and young people varies depending on age and capacity. For persons between the ages of 16-17 who are competent, that is, persons who are not intellectually impaired, or impaired as a result of a medical condition, unconscious or otherwise, and thus deemed unable to provide consent, may provide consent without a formal capacity assessment (NEAC, 2019). Under the Health and Disability Code of Rights, all health service consumers are presumed competent to make an informed choice and give informed consent with no specific age threshold (Health and Disability Commissioner, 2014). For research participants under 16 years of age, capacity should be assessed (National Ethics Advisory Committee, 2019), and the complexity and risk of the research may dictate what level of capacity is deemed suitable. Importantly, age should not be used as an arbitrary determinant of capacity, assessments should be individualised (see also Gillick competency). NEAC guidelines also stipulate research with children should only be conducted if comparable research with adults would not appropriately answer the research question, or if the question could be answered by older children, then older children should be used in preference to younger (NEAC, 2019).

Children and young people can provide their own consent to participate in research; however, for those under the age of 16, this depends on the context, risks, age and the child's assessed capacity (NEAC, 2019). In situations where a parent or legal guardian provides consent, children should be asked to provide dual consent or assent whenever possible. The right to withdraw from the research study remains with the child, except in cases where refusal would exclude them from research intended to provide potential therapeutic benefit, and no alternative therapy is available (NEAC, 2019). When assent is required, the parent or guardian provides consent for the child to participate in the research, and the child affirms their willingness to take part.

The Tīvaevae methodology

The Cook Islands' research methodology Tīvaevae was developed by Teremoana Maua Hodges for use in education research. It has since been used by many Cook Islands and non-Cook Islands' researchers to capture knowledge guided by Cook Islands' values. The underlying concepts or values that underpin the Tīvaevae methodology have been articulated by various authors. The most commonly cited are from Te Ava (2011) who articulated five key concepts of the methodology. The key concepts are taokotai – collaboration; tu akangateitei – respect; uriuri – reciprocity; tu inangaro – relationships; and akaari kite – a shared vision (Te Ava, 2011). A subsequent set of values were purposed by Maua Hodges (2018) and include aro'a (love); 'kauraro' respect; 'tā'aka'aka' to be humble; 'akamoe'au' to be peaceful and 'apaitu'anga to use peaceful ways to achieve your goal of mutual obligation. These values are grounded in Cook Islands' Māori understandings and while the Tīvaevae methodology is ethnic specific the values may resonate and align with wider Pacific values.

How the Tīvaevae methodology can be used to guide ethical research with Pacific children and young persons

In research involving Pacific children and young people, cultural context is central to ethical practice. Culture shapes a child or young person's understanding of autonomy and collective decision making, language and communication style, and trust in healthcare systems. All of which influence a young person's understanding of research and willingness to participate. The Tīvaevae methodology provides values that can support ethical decision making; this article focuses on the use of tu-inangaro, (relationships) and akaari kite, (a shared vision) to navigate engagement and the consenting process.

Consent for research participants is a dynamic, iterative process that requires ongoing negotiation (NEAC, 2019). The Tivaevae methodology sets out a process of creating a shared vision through reciprocity and enables understanding of what has value, to an individual and the collective (Te Ava & Page, 2018). As a guiding metaphor, the process of making a tīvaevae, often involves a tu'anga (expert) who leads the creation, alongside collective contributions, one person may draft and cut the pattern and as a group the pattern is tacked and embroidered. At each stage the group inspects the creation and a shared vision is created (Rongokea, 1992). Although time-consuming, the process is intentionally communal, reflecting the collective nature of the creation of a tīvaevae.

Relationships are key to the methodology, not only in developing trust with participants but in the creation of knowledge. It is through relational understanding that we understand what we claim to know. This understanding is developed through our relationships, our connections. By recognising our relational knowledge, gained through our connections through our shared ancestry, the wider community, and the environment, we develop shared understanding and knowledge (Henry, 2024). Recognising relational knowledge foregrounds collective meaning-making and supports ethical engagement that honours individual and community perspectives.

The concepts of shared vision and reciprocity align closely with Te Ara Tika research ethics framework and Māori data sovereignty principles. Te Ara Tika emphasises tika (what is right), manakitanga, (cultural and social responsibilities), whakapapa, (relationships), and Mana, (justice and equity) (Hudson et al., 2010). Consistent with the Tīvaevae methodology the collection and interpretation of data should uphold the dignity of the community and the individual, and research should be designed to ensure the collective and individual benefit (Hudson et al., 2010).

The Tīvaevae methodology in holding as key concepts tu-inangaro, relationships, and akaari kite, a shared vision, highlights the relationships between people and stories. The stories are shared with the objective of connecting the stories and developing a shared narrative. This is where Western ethical principles intersect and sometimes conflict with the collectivist values embedded in the Tīvaevae methodology. When it is understood that knowledge is collective, and relational then individual consent may seem at odds with the application of the methodology.

Within health research, the right of fully informed individual consent is one of the principal rights of research participants (NEAC, 2019). While individual consent is necessary to protect research participants from unknowingly taking part in research without their knowledge. The use of individual informed consent as a protection against research harms has been questioned in relation to communities from collective cultures (West-McGruer, 2020). Similarly, indigenous researchers have questioned the privileging of the autonomous individual over collective decision making and the risk of removing collective knowledge with only individual consent (Tauri, 2018; West-McGruer, 2020).

Young persons from collectivist cultures may experience tension when asked to assert individual autonomy over the family or community authority. Enacting agency through individual choice requires young people to navigate their existing social structures and available resources (Munford & Sanders, 2015). These dynamics may complicate assessments of assent or individual consent. This is where the concepts from the Tīvaevae methodology, tu-inangaro (relationships) and akaari kite (a shared vision) become important in the dynamic consenting process. They underscore the importance of engaging with Pacific families and community especially in research involving children or young persons. Requesting individual consent without relational engagement can risk disrupting family or community cohesion and could lead to disapproval. Given that children and young persons are recognised as a vulnerable population (NEAC, 2019), protecting their place within their community should be balanced between the agency of the young person and the potential benefit of the research for the individual and the community.

Case example

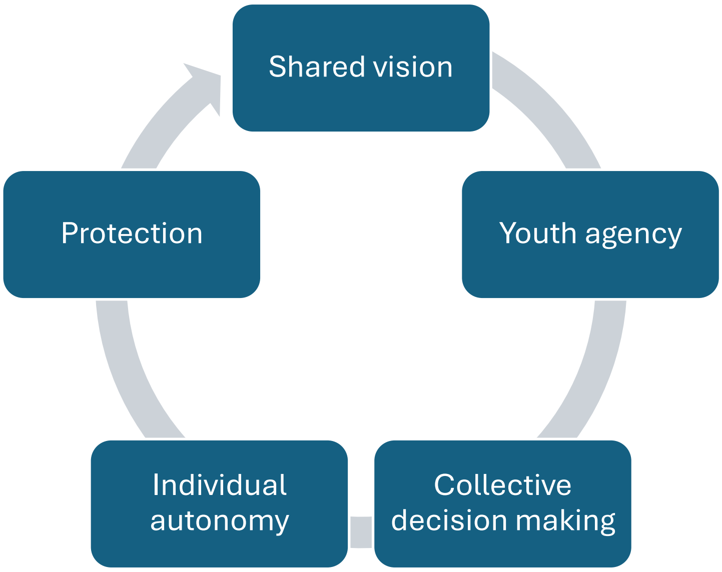

Diagram 1: process of applying the value of akaari kite (shared vision)

This case illustrates how applying the principles of the Tīvaevae methodology, in particularly akaari kite (shared vision) and uriuri (respect) can reconcile tensions between Western research ethics and community expectations. In a study of youth sexuality in the Cook Islands (age 15-24), conflict arose between an ethics committee, the researcher and the wishes of the local community. The ethics committee wanted parental consent, for the young persons included in the study. The researcher believed this requirement could discourage young people from participating in the study or expose them to potential risk by forcing them to disclose to their parents their intention to take part in a study on sexuality. The community wanted to know the views of young persons and reached out to a researcher to undertake the work (Puati, 2017).

Applying the values from the Tīvaevae methodology a shared vision and respect can help guide the consent process. This begins with establishing a shared vision through community consultation and developing an understanding of the sociocultural context in which the young person lives. Such an approach facilitates an assessment of the risks and benefits to the young person, thereby supporting the attainment of fully informed consent. This enables the young person to exercise agency and provide individual consent, while also engaging with and honouring the collective aspirations of the community. In this case, the young persons were permitted to provide individual consent without parental consent, and their data was deidentified to protect the young person’s position within the family and community. This process balances safeguarding the young person, honouring collective values, and ensuring informed consent at the individual level.

While this case example is brief and does not fully describe the layers of complexity in protecting young person's participating in research it demonstrates how meaningful engagement with families and community can align with recognition of children and young person's agency and collective responsibilities through a consent/assent process that honours relational decision making while balancing agency.

Conclusion

In conclusion, obtaining consent from a young Pacific person or child to participate in a research study using Western ethical principles presents several challenges, particularly in balancing individual autonomy with family or community authority. The key issues revolve around differences in how risks, and benefits are understood and prioritized in Western versus collectivist cultures. To counter these potential harms, the Tīvaevae methodology provides a meaningful and culturally responsive approach. The Tīvaevae methodology emphasizes relationality, shared vision, reciprocity and respect, and can be used as a guide for addressing the needs and values of participant. By applying the Tīvaevae methodology, researchers can mitigate the risks of cultural harm, foster mutual respect, and create research environments where the interests of both individuals and their broader communities are considered, in turn promoting ethical integrity and cultural sensitivity in research involving young Pacific people.

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