

Tōku Reo, Tōku Whakāetanga, Tōku Mana – My Voice, My Informed Consent

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A thesis submitted to Auckland University of Technology in fulfilment
of the requirements for the degree of
Master of Philosophy

2019

Faculty of Health and Environmental Studies

AUT University

Abstract

Based on a balanced and fair understanding of what is involved throughout the research process, informed consent acts as an agreement for participants to be fully informed about a research study before deciding to participate. This kaupapa Māori research explored the perspectives and understandings of seven rangatahi aged between 13 and 17 years from a secondary school in Tamaki Makaurau about the informed consent process in research studies. The aim was to understand how the informed consent process is interpreted by rangatahi and the factors that contribute to their decision to participate in research. A focus group was carried out with the rangatahi to elicit their views on the kaupapa and create healthy kōrero amongst peers. This research sits within a kaupapa Māori paradigm and uses cultural values to underpin every aspect of the research; thus, ensuring a safe research for rangatahi and making certain their voices are heard. This research demonstrates the importance of carrying out research with rangatahi that provides information which uses youth-friendly terminology and is conducted in a mana-enhancing way. The thesis demonstrates that rangatahi are very much autonomous and make decisions in their everyday lives. Therefore, it is important for researchers to acknowledge young people's decision-making skills and provide a process that allows them to be fully informed and reduce barriers put in place that jeopardises their autonomy. Several recommendations were identified by rangatahi to improve the informed consent process carried out with young people. These recommendations will help rangatahi gain a better understanding of why they choose to consent or not-consent to participate in research, and increase the rigour of research because rangatahi become more comfortable and familiar with the research aims. Overall, this research has been gifted with useful messages for researchers to create an informed consent process that would be more beneficial for both rangatahi and researchers in the coming times.

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Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgments), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed: _____

Date: _____ 26/03/2019 _____

Acknowledgments

Ko Mookau ki runga,
Ko Tāmaki ki raro
Ko Mangatoatoa ki waenganui.
Pare Hauraki, Pare Waikato
Te Kaokaoroa-o-Paatetere.
Waikato Taniwharau
He Piko he Taniwha He Piko he Taniwha.

First, I would like to acknowledge the seven rangatahi participants who gave up their time to contribute towards the kaupapa of the research. The kōrero that you have all shared in order to support the understandings of the informed consent process have been invaluable.

E tipu, e rea, mō ngā rā o tōu ao; ko tō ringa ki ngā rākau a te Pākehā hei ara mō tō tinana, ko tō ngākau ki ngā taonga a ō tūpuna Māori hei tikitiki mō tō māhuna; ko tō wairua ki tō atua, nāna nei ngā mea katoa.

Grow up and thrive for the days destined to you, your hand to the tools of the Pākehā to provide physical sustenance, your heart to the treasures of your Māori ancestors as a diadem for your brow, your soul to your God, to whom all things belong.

Ngata (n.d., cited in Brougham, Reed & Kāretu, 2012, p. 89)

A huge mihi to Kathryn Moore and Neil McEnteer for their continued care and going above and beyond to support my research. From giving up your time, bringing kai in for hui, and genuinely taking an interest in every aspect of the research.

I would like to acknowledge my supervisors from Taupua Waiora, Dr Alayne Mikahere-Hall and Professor Denise Wilson for their continued guidance throughout my master's journey. Your knowledge and wisdom do not go un-noticed and I will cherish the valuable lessons that have been learned throughout the process. Also, a big thank you to Dr Shoba Nayar for the amazing mahi you put into proofreading my thesis.

To my colleagues on the Harmonised project, I thank you all for providing your continued support and wisdom throughout my journey – ngā mihi kia koutou.

To my whānau and best friends, who may not completely understand my research but always support me. Thank you all for uplifting me in various ways. My Tureia / Martin whānau who provided a space for me to work, kōrero, and be productive. My nana for guiding me through the kaupapa and contributing your mātauranga Māori, thank you!

My mum Judy, siblings Tui and Kelly, nieces and nephew Waimarie, Poppy, and Noah. Thank you for giving me the strength and perseverance to get through and for putting up with my journey. Each of you has provided your individual support for me. My fiancé Iakopo, I applaud you for being by my side no matter what and providing positive encouragement when times were overwhelming. Thank you for everything that you all do.

Lastly, I would like to acknowledge a significant man in my life who gave me strength, guidance, and wisdom for 24 short years of my life. You continue to shine down and look over me throughout every phase.

This thesis is dedicated with love to my late father,

Sidney Anthony Barbarich

Forever my guardian angel.

Glossary

Māori kupu come with a greater depth and meaning. However, for the purposes of reading this thesis with ease, a list of short translations has been provided to support understanding.

Aroha ki te tangata: Respect for people

Aroha: Compassion

AUTEC: Auckland University of Technology Ethics Committee

Axiology: The nature of ethics

ERIC: Ethical research involving children

Haerenga: Journey

Hapū: Subtribe

He kanohi kitea: A face that is known or seen

Hui: Meeting

Iwi: Tribe

Kai: Food

Kaitiaki / Kaitiakitanga: Guardians or advocates

Kanohi ki te kanohi: Face to face

Karakia: Prayer

Karanga: Ceremonial call

Kaua e takahia te mana o te tangata: Do not trample on the dignity of people

Kaupapa Māori: Māori approach

Kaupapa: Topic or reason or purpose

Kawa: Customs

Kia māhaki: Be humble

Kia tupato: Be cautious

Koha: Gift

Kōrero: Stories

Kupu: Word

Māhaki: Respectful conduct

Mahi: Work

Mai te timata me te whakamutunga: From start to finish

Mamae: Hurt

Mana tangata: Autonomous individuals

Mana: Spiritual power

Manaaki ki te (ngā) tangata: Looking after people

Manaaki: To support

Mātauranga Māori: Traditional knowledge

Mātauranga: Wisdom, knowledge, and skills.

Mihimihi: Speech of greeting

Pākehā: non-Māori

Pōwhiri: Welcoming ceremony

Ranga: Raised up

Rangahau Māori: Māori research

Rangatahi: Young person / youth

Rangatira: Chiefly

Takahia te mana: Trampling on the dignity

Taiohi: Youth

Taitamariki: Youth

Tāmakimakaurau: Auckland

Tamariki: Children (0-18 years)

Tangata Māori: Māori people as a collective

Tangata whenua: Local people

Taonga: Treasure

Te Ao Māori: Māori world view

Te Tiriti o Waitangi:The Treaty of Waitangi

Teina: Younger

Tika: To be correct

Tikanga Māori: Māori protocols and practices

Tikanga: Customs

Titiro, whakarongo...kōrero: Look, listen... then speak

Tuakana: Elder

Tuarā: Backbone

Tūpuna: Ancestors

Tūrangawaewae: Standing place

Tūturu: True

UNCRC: United Nations Convention on the Rights of
the Child

Wāhanga: Chapter

Whaikōrero: Formal speech

Whakamā: Embarrassment

Whakapapa: Genealogy

Whakatauākī: Proverb (original author known)

Whakataukī: Proverb (original author unknown)

Whakawhanaungatanga/Whānaungatanga: Establishing connections

Whānau: Family

Wāhanga Tuatahi: Introduction

Ka pū te ruha, ka hao te rangatahi

As an old net withers, another is remade

Williams (1971)

Rangatahi is a common term used within Aotearoa for young people, youth, or adolescents. The meaning behind the kupu (words), however, is much more significant and comes from the well-known whakataukī (proverb) that begins the journey of this thesis: Ka pū te ruha, ka hao te rangatahi - As an old net withers another is remade. This whakataukī does not directly imply the idea of replacing an object when it is worn out. More so, it speaks to the kaupapa (topic) of weaving mātauranga (knowledge) from the older, retiring generations into younger generations. Thus, ensuring the tikanga (customs) and mātauranga of te ao Māori (Māori world view) continues to be passed on, preventing the loss of traditions and customs.

The pursuit of knowledge in the research environment inevitably leads to conversations and discussions concerning ethics and various ethical considerations. Capturing the principles and moral codes of indigenous peoples is an endeavour that is lacking; in particular, the voices of our rangatahi are seldom heard. *Tōku Reo, Tōku Whakāetanga, Toku Mana – My voice my informed consent* makes a start to investigating rangatahi thoughts, views, and opinions as they relate to the ethical informed consent process. Western determined consent processes have become widely accepted and rarely challenged in the research environment (Tuhiwai Smith, 2012). Thus, standardised consent processes are pre-set with little consideration for the tikanga (cultural customs) of indigenous Māori of Aotearoa New Zealand. Appropriately, kaupapa Māori (Māori approach) underpins the cultural lens from which to explore the unheard voices of rangatahi (Rameka, 2015; Tuhiwai Smith, 1999; Ware, 2009).

Ka pū te ruha, ka hao te rangatahi, is about weaving the mātauranga from our tūpuna (ancestors) to ensure that the relevance it has had throughout the generations remains integral to indigenous research. Likewise, rangatahi have a responsibility to contribute to what we know and what we seek to know about the future. The validity of whānau (family), hapū (subtribe), and iwi (tribe) are central to kaupapa Māori where rangatahi voices are exemplified. *Tōku Reo, Tōku Whakāetanga, Toki Mana* seeks to hear and acknowledge the too often concealed voices of rangatahi Māori in the research environment.

Ma te rangatahi pea o tēnei rā, e whatu he kanoi kōrero
Perhaps the youth of today will weave a strand of history
Ngata and Ngata (1993)

Introduction

Rangatahi Māori (referred to as rangatahi), as with many other groups within Aotearoa, belong to a number of distinctive groups within society. For contemporary rangatahi, these groups are complex and multifaceted. For instance, Māori and rangatahi (youth) are two groups that are important to identify within the thesis. Ware (2009) concurred with this viewpoint and acknowledged rangatahi as being members of distinct groups—Māori and youth—whilst acknowledging that they may fit into other groups as well. Being rangatahi Māori also involves being part of wider whānau, hapū and iwi context(s). It is important for researchers to remain mindful of and understand where rangatahi fit in each of these diverse groups.

In addition to their cultural identity, rangatahi also fit within the broader youth arena as they share similar life experiences and traits with other young people in Aotearoa. For rangatahi, finding their position within the youth category is another important aspect in which they must ground themselves to ensure they remain supported and aware of this ever-expanding social group. Action for Children and Youth Aotearoa Incorporation (2007, p. 15) confirmed rangatahi exist within a society of extensive relationships, and they have the right to know about, contribute positively to, and benefit from those

relationships. Rangatahi participation in research and the importance of establishing relationships highlight the necessity of understanding where they fit in society and how these can impact or support participation within research.

The aims of this thesis are to (1) acknowledge and understand through a kaupapa Māori way, rangatahi perspectives about the ethical process of informed consent within a research study, and (2) examine the reasons behind their decisions for participating in a research study. The study was undertaken in a manner that upheld the mana (spiritual power) of the rangatahi as individuals whilst valuing and recognising them as the owners of their knowledge. This approach created a space for the collective and individual thoughts and ideas of the rangatahi regarding the research kaupapa. Ultimately the cultural insights gathered from rangatahi will provide an informed consent process that is specifically tailored for our rangatahi in Aotearoa.

Mātauranga is about handing down cultural knowledge previously learnt, and for it to occur within a research context we must identify how the informed consent process has been carried out over time and where it is today. Exploring previously unheard voices of rangatahi attempts to ensure mātauranga is carried down through the generations in a way that directly links to the rangatahi generation of today. Existing mātauranga provides a platform for further research to be carried out and gives an opportunity for rangatahi to share their thoughts and insights into a kaupapa that directly affects them. It also provides an opportunity to influence best practice for researchers and practitioners when they conduct studies with rangatahi in the future.

From a search of the literature, I could find no studies or ethical standards aimed directly at rangatahi. However, there are a number of guidelines that target ethical research with children aged birth to 18 years old; these include United Nations Convention on the Rights of Children (UNCRC) (United Nations,

1989), Ethical Research Involving Children (ERIC) (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013) and Te Ara Tika (Hudson, Milne, Reynolds, Russell, & Smith, 2010), which is a holistic kaupapa Māori ethical framework that guides working with Māori of all ages.

Research Objectives

In this thesis, I asked the question:

“What are rangatahi perspectives of the informed consent process as a research participant?”

The overall objectives of the research were to:

- Guide this process to make it beneficial for rangatahi Māori.
- Understand rangatahi choices in participation within a research study.
- Work collaboratively with rangatahi to ensure their voices are heard within an ethics context.
- Tailor a plan to support the informed consent process specifically with rangatahi.

I have chosen to research the ethical processes that are inclusive of the informed consent process for many reasons. Firstly, it has been an important topic for me as an emerging researcher. Knowing and understanding how the informed consent process is carried out within research in Aotearoa is important to investigate as it sheds light onto a practice that is regularly carried out. More specifically, understanding how this process is undertaken with research amongst our rangatahi is increasingly important to determine if this process is appropriate and meaningful for the targeted group. Secondly, working collaboratively with rangatahi will elicit their views of how an informed consent process could be more applicable and tailored to their group that is ultimately beneficial for participants and research teams. Bridging the ethics process gap when working with rangatahi is advantageous for creating and supporting a process by which rangatahi are fully informed and more involved in the ethical process; thus, creating better engagement with rangatahi in research. Overall, ensuring our

rangatahi feel more supported and understood in any form of research is the ultimate goal whilst balancing the perceptions of balance and bias.

Background

Informed consent processes

Informed consent is a process that is carried out to ensure participants are fully aware of every aspect of the study, along with understanding their rights and obligations. Collins (2006) explained that the informed consent processes in western research seeks written consent from individual participants. However, in te ao Māori it is important to acknowledge the extensive oral traditions that are transmitted through the generations and understand how Western processes need to fit within a kaupapa Māori context. Collins added that within research she carried out with Māori, written consent would be related to a contractual agreement which would prevent community members from participating. Collins identified that verbal consent was a preferred means to ensure that potential participants understood clearly what their participation involved. With people who have strong oral traditions, verbal consent is strongly valued (Collins, 2006).

Informed consent continues to be a process that has been carried out in similar ways for many years. Graham et al. (2013) claimed ethical research involving children requires consent from individual participants that needs to be elicited in a way that is understood and relevant to their age range. Yet, there are a range of mixed messages in society given to whānau regarding consent (Age of Consent, 2018; Kiwi Families, 2018) and I wondered what these mixed messages do for rangatahi during the research consent process. While researchers rely on parents to gatekeep rangatahi participation in research, this compromises rangatahi autonomy in decision making. Therefore, this thesis gives rangatahi a voice on the topic of the informed consent process with the aim to contribute to the way that research is conducted with them. Through a process of listening to rangatahi, their

recommendations of the informed consent process are documented in a way that is culturally appropriate for rangatahi.

Contexts of Consent in Aotearoa

Within Aotearoa, there are various contexts where rangatahi are legally able to provide consent. These include, but are not limited to, giving consent for sexual activities. The Age of Consent (2018) stated that in New Zealand, a person aged 16 years or older is considered old enough to legally participate in sexual activities. The Kiwi Families (2018) legislation stated rangatahi (and other young people) can provide consent in the following situations:

- Get married at 16 years old (with parental consent);
- Babysit young children at 14 years old;
- Obtain a learner's drivers licence at 16 years; and
- Leave home at 16 years old.

These various activities highlight the inconsistent messages within Aotearoa as to the age when it is appropriate and not appropriate for young people to give consent. They also highlight the range of mixed messages that can generate confusion amongst whānau and rangatahi in Aotearoa as to when rangatahi can make independent decisions in their own right. For Māori whānau, this causes more confusion as there are significant cultural variables and differences. For instance, from a young age Māori are always looking after people (Edwards, McCreanor, & Moewaka-Barnes, 2007).

Metge (1995) explained in traditional Māori whānau structures there are clear relationships between the generations and an understanding of how these link with one another to define everyone's roles. This leads us to the context of tuakana (elder) – teina (younger). Edwards et al. (2007) discussed how amongst sibling's relationships are intended to support the welfare of the whānau as a collective. For instance, tuakana often take on the responsibility and roles of leadership, protection, and advice;

whereas the teina are required to serve and provide. Consent in te ao Māori is not solely focused on age; rather, it is associated with an individual's position within the whānau. While it is important to understand consent in a Western paradigm, consent also needs to be comprehended within the context of the Māori culture and whānau. Particularly as the Children's Commissioner (2018) stated that young people have the right to have their voice heard and the right for what is best for them.

Sociology of Childhood

Since the development of theory around the sociology of childhood in the 1990s, research involving children has progressed immensely resulting in a well-informed practice about ascertaining young people's perceptions through research (Bühler-Niederberger, 2010). Alanen (2010) stated that the sociology of childhood has been largely derived from the commitment of researchers toward improving children's position and value within society, enhancing children's rights, and providing young people the chance to express themselves within society.

Sociology of childhood supports the need for understanding the unique culture of tamariki (children) and young people, and how the world appears to them. Equally, within the broader Māori and Indigenous literature there is a need to reclaim our cultural understandings to understand rangatahi within the contexts of whānau (Tipene-Clarke, 2005; Ware, 2009). Therefore, a qualitative design was chosen for my research to establish a foundation for understanding rangatahi perspectives of informed consent in a way that supported their ability to express their opinions. Graham, Powell, and Taylor (2014) stated that developments with the way children are viewed have generated a stronger emphasis on listening their views, thus gaining a better understanding of their experiences. Tipene-Clarke (2005) took this further, discussing the need to empower rangatahi by providing opportunities so they can participate in decisions that will affect their lives. Therefore, understanding how to work and effectively communicate with rangatahi is vital to supporting their development. Gaining this

knowledge can create and strengthen what is known about embracing and accessing rangatahi views through research.

Research with Māori Rangatahi

In order to understand the term rangatahi, for use within this piece of writing, it is important to unpack this term and explore it within a pre-colonised context while also acknowledging its use within today's westernised settings. Because a range of terms and understandings of what constitutes rangatahi exist, it is imperative to identify what is meant by rangatahi including other terms such as taitamariki (youth) and taiohi (youth). These differences exist outside of Western conceptions of adolescents and youth and highlight the importance of articulating Māori understandings of rangatahi.

In taking a deeper look at the traditional meaning of rangatahi, I begin by discussing relevant terms:

- Ranga – Ryan (1997) defined ranga as being raised up from the ground, performing the rite over the child and weaving. Oxford University Press (2018) explained rite as a religious or other solemn ceremony or act. Performing the rites over a child is a significant aspect defining ranga and how this term directly links to rangatahi. Rangatahi are the younger generation that has tikanga passed down to them through various cultural rituals and the weaving of mātauranga (Māori knowledge).
- Rangatira – is a “chiefly, noble or esteemed person that is either male or female” (Ryan, 1997, p. 211). Rangatira provides a pathway of learning from the older to the younger generations, instilling kaupapa and tikanga Māori to the younger people.
- Rangahau – is to seek, research, or carry on (Ryan, 1997). Rangahau ties up the understanding of the previous words because it weaves through the notion of how knowledge is sought and carried on from one generation to another.

All these terms are deemed important to understand because, in te ao Māori, rangatahi are included within the context of whānau, hapū, and iwi. It also involves explaining exactly how the term rangatahi is woven into a Māori approach to promote an overall understanding of the direct links.

Rangatahi, Taiohi and Taitamariki are interchangeable terms used to describe young people or youth and is a dialect or regional kupu used. I have decided to use the term rangatahi within my research as this kupu is commonly used in my own iwi that I whakapapa to and is also regularly used within my whānau.

Identifying and understanding the various 'ranga' in a te ao Māori framework, forms the basis for comprehending the traditional use of the term rangatahi and how it is applied within this piece of writing. The term rangatahi is often used in a westernised context and differences in what it means have deviated from traditional understandings in response to colonisation. In Western frameworks, rangatahi or youth fall under the young person stage. Rather than a fixed age range, similar to the common understanding about who constitutes youth, the age range for rangatahi varies within different contexts despite similarities remaining. In the Youth Development Strategy Aotearoa (YDSA), both the Ministry of Youth Development – Te Manatū Whakahiato Taiohi (2018) and Ministry of Youth Affairs (2002) identified that youth are those persons falling in the age range of 12 to 24 years inclusive. This concurred with Te Puni Kōkiri (2012), who noted in their statistics that rangatahi are young Māori aged 15 to 24 years of age. On the other hand, in Western frameworks such as the UNCRC (United Nations, 1989) and ERIC (Graham et al., 2013), young people are often referred to as child/ren, who are human beings under the age of 18 years old.

To avoid any misunderstandings, for the purpose of this thesis, rangatahi are participants aged 13 to 18 years of age, or those in Years 9 to 13 in secondary schools. The reason for identifying the rangatahi age range was to capture a diverse range of views in a secondary school setting. This age range allowed

for a unique student's view, from the junior (year 9 and 10) through to the senior (year 11 to 13) years, to be heard.

Rangatahi Māori are an integral indigenous social group within Aotearoa. Eruera and Ruwhiu (2015, p. 1) explained that indigenous children are central to the development of wellbeing strategies for their families, communities, and people. When undertaking research with rangatahi Māori, other studies also included this target group such as Edwards et al. (2007), Ware (2009), and Crengle, Clark, Robinson, Bullen, Dyson, Denny et al. (2013). However, literature on the research ethics and informed consent process does not appear to be covered well. In fact, very little literature focuses solely on rangatahi as a population. The Children's Commissioner (2018) stated that striving to be child-centred helps to make decisions that are in the best interests of the child. In carrying out research with rangatahi, it is important to ensure their rights as an indigenous (and a) young person be upheld and respected to avoid further harm. The Human Rights Commission (2019) stated through The Treaty of Waitangi and United Nations Declaration on the Rights on Indigenous Peoples, that indigenous have the right to equality, non-discrimination, participation in decision-making, and are entitled to self-determination. Action for Children and Youth Aotearoa Incorporated (2007) stated that when working with rangatahi it is crucial to ensure their rights are upheld and they feel empowered as a valued and unique individual, along with being an integral member of the whānau, hapū, iwi, and overall society of Aotearoa.

Further, understanding the various societal contexts that rangatahi are immersed in is important. The Ministry of Youth Affairs (2002) indicated there are no set boundaries when it comes to the progression from children to young people and into adulthood. All these stages are dependent on a person's culture or cultural identification, their own personality and choices, along with their social and financial circumstances. Drewery and Bird (2004) explained that in Aotearoa, growing up was when you got a job and moved out; however, this is changing in society and the process is being

prolonged as young people live at home with family for longer and continue onto further education. There is tremendous diversity for rangatahi around their individual characters and backgrounds. The Ministry of Youth Affairs (2002) explained that individual characteristics for young people such as gender, ethnicity, socio-economic status, rural or urban location, and family structure have significant effects on the development process, life experience, and outcomes. These characteristics all contribute to the fact that youth development approaches require careful consideration (Ministry of Youth Affairs, 2002).

Operational Definitions

Some words or terms used within this thesis have meaning within the context of rangatahi Māori. In this section I present the operational definition for terms used in this thesis.

Whakatauākī / Whakataukī

Whakatauākī and whakataukī are Māori proverbs that are used in this thesis to begin and close off each chapter. Proverbs are commonly used within te ao Māori and can act as guidelines and be interpreted in a variety of ways. The proverbs used within the thesis are chosen specifically to fit each chapter's theme and the meaning embedded in the chapter—they help to tell the story of its contents. I acknowledge both whakatauākī and whakataukī because although they both refer to proverbs there are differences (Ako Māori, 2018). Whakatauākī is when the author or person who first wrote the proverb is known; whereas whakataukī is when the author or person who first said it is unknown.

Definition of Whānau

Whānau is often translated simply to family. However, in a Māori context whānau consists of grandparents, parents, siblings, aunties, uncles, cousins, family friends, both blood and non-blood relatives—an extended family network. Cram and Kennedy (2010) stated that whānau is about

relationships that extend beyond the walls of a house. Within this thesis, the use of whānau includes kaupapa whānau who Cram and Pitama (1998) discussed as being people who are not whānau through whakapapa. This means whānau can be, and are also, non-whakapapa (genealogy) people. That is, not blood relatives.

Organisation of this Thesis

The structure of this thesis is presented in a way that tells the readers a story or journey of the research. It is important to describe how this research has come about; identifying and critiquing the literature carried out previously, exploring the chosen processes for each aspect, and finally encapsulating the mātauranga gained from my research and how this could guide future research with rangatahi.

The introduction chapter (**Wāhanga Tuatahi**) outlines the overall study and provides the context for this kaupapa Māori research. The research questions and objectives are introduced at this point along with a list of relevant definitions to support the understanding of some terms used.

In **Wāhanga Tuarua**, research surrounding the kaupapa of this thesis is explored. The literature review canvases various research and mahi (work) that has been conducted with rangatahi or young people. Key themes in the literature in relation to the ethical research process are presented. These include informed consent, kaupapa Māori research ethics, as well as the contentious issue of assent versus consent. The literature on ethical research with rangatahi or young people is highlighted within a mainstream westernised context as well as an indigenous context.

Within the Research Design and Methodology chapter (**Wāhanga Tuatoru**) there is a significant emphasis on outlining the theoretical framework underpinning the research design. Thus chapter

provides a foundation for the use of qualitative research design and kaupapa Māori Methodology. Methods used for participant selection and recruitment criteria, data collection methods employed, data analysis are also discussed followed by ethical considerations, rigour and reflexivity.

Upon completion of data collection and analysis, **Wāhanga Tuawha** presents the findings from the focus groups and overall from the study. These results were analysed and grouped into themes using a thematic analysis method. The findings derived from the study are identified through themes and subthemes. These include varying understandings of consent and withdrawal from research is awkward.

Wāhanga Rima offers a discussion of the study findings and situates these within the literature. This chapter also provides an understanding of successful aspects of this research, the limitations of the study, along with recommendations for future studies and best practice guidelines to promote and support informed consent within ethical research that involves rangatahi.

Finally, the conclusion chapter (**Wāhanga Ono**) weaves together and summarises the main findings of the research. This chapter also summaries recommendations that were identified in the previous chapter and how these recommendations will have implications for practices and future research carried out around this kaupapa.

Hāpaitia te ara tika pūmau ai te rangatiratanga mō ngā uri whakatipu

Foster the pathway of knowledge to strength, independence and growth for the future generation

(Cited in Phase, 2016, p. 6)

Wāhanga Tuarua: Literature Review

Whiriwhiria ngā taonga tuku iho, e arahina koe i tō mahi

To select unsurpassed treasures of the past,

To respond appropriately to circumstances of today.

(Kingi, cited in Kingi, Sokratov, & O'Brien, 2013, p. 3)

Introduction

Informed consent with rangatahi is an emerging concept that requires both a kaupapa Māori informed approach and one that directly targets the proposed age group. In this chapter, I will present a review of the literature related to rangatahi perspectives of the informed consent process as a research participant. In presenting this review, I will firstly discuss the search strategy; the inclusion and exclusion criteria used to select the literature; the literature that exists on this topic, including key themes derived from previous research and literature; gaps identified in the literature; and lastly, the rationale for the research question. Most literature refers to rangatahi or young people as child or children. Therefore, rangatahi or young people include all individuals under the age of 18 years. Article One of the UNCRC defined "a child as a human being below the age of eighteen years unless, under the law applicable to the child, the majority is attained earlier" (United Nations, 1989).

Search Criteria

The search criteria used to identify and locate appropriate literature relevant to the kaupapa is an important aspect to ensure one can achieve a broad understanding of what previous mahi exists. The search strategy involved three phases; the first being thorough searches of various databases such as Google Scholar, EBSCOhost, Psych info/ Ovid and SAGE journals. Then, to locate kaupapa Māori publications, I searched networks and journals that publish Māori writing, research and literature, which included AlterNative, MAI Journal, MAI Review, He Kupenga Kōrero, and the Ngā Pae o te Māramatanga website. Lastly, literature was discussed with colleagues and supervisors to identify

other sources or authors whose mahi could contribute to the understanding of the kaupapa around informed consent with rangatahi, kaupapa Māori ethics, and other indigenous works that discuss ethical research internationally.

The inclusion and exclusion criteria for this search were imperative in identifying the literature that would be suitable to review for this chosen research. I used the inclusion and exclusion criteria outlined in Table 2.1 (p. 16). Literature excluded from this review included any that had an adult focus, included non-Māori or non-indigenous people, were not inclusive of young people, and that which did not emphasise a focus on ethical research or informed consent. The process for selection of literature involved an initial review and populating a PRISMA (2009) flowchart (Figure 2.1, p. 17). This process involved reviewing titles of each piece of writing to assess their eligibility for the review. From the articles deemed applicable, I scanned through each abstract to identify those that related to the kaupapa of the research. Finally, the articles deemed appropriate were read in full and key areas were used within the literature review. Excluded literature are identified in Table 2.2 (p. 16), along with the reasons for exclusion.

Based on the search I conducted, the results were limited, producing few articles able to be reviewed relating to this kaupapa. This was not unexpected as this research kaupapa is somewhat new and does not cover a specific area of rangatahi, rather it targets children aged 18 years and under as mentioned earlier. The literature selected (Table 2.3, p. 17) relates to published indigenous mahi and the sociology of childhood studies related to ethics and informed consent.

Table 2.1. Inclusion and Exclusion Criteria

Inclusion	Exclusion
Whānau	Had an adult focus
Rangatahi (13-17 years old)	Focused on-Māori or non-indigenous
Youth-focused	Not inclusive of young people
Informed consent	Did not emphasise a focus on ethical research or informed consent
Kaupapa Māori	
Indigenous	
Ethics and ethical research	

Table 2.2. Excluded Literature

Author	Title	Reason for exclusion
Walker, Eketone, & Gibbs (2006)	An exploration of kaupapa Maori research, its principles, processes and applications	Kaupapa Māori article but did not highlight ethics and informed consent
Flory & Emanuel (2004)	Interventions to improve research participants' understanding of informed consent for research	Was not applicable as it did not meet the inclusion criteria, did not focus on Māori or indigenous
Dyall, Bridgman, Bidois, Gurney, Hawira, Tangitu, & Huata (1999)	Māori outcomes: Expectations of mental health services	Did not meet the inclusion criteria for this study
Henry & Pene (2001)	Kaupapa Maori: Locating Indigenous ontology, epistemology and methodology in the academy	Discussed kaupapa Māori; however, did not meet the inclusion criteria for this study
O'Carroll (2013)	An analysis of how rangatahi Māori use social networking sites	Focused on rangatahi but did not meet the inclusion criteria for this study

Literature search strategy PRISMA 2009 Flow Diagram

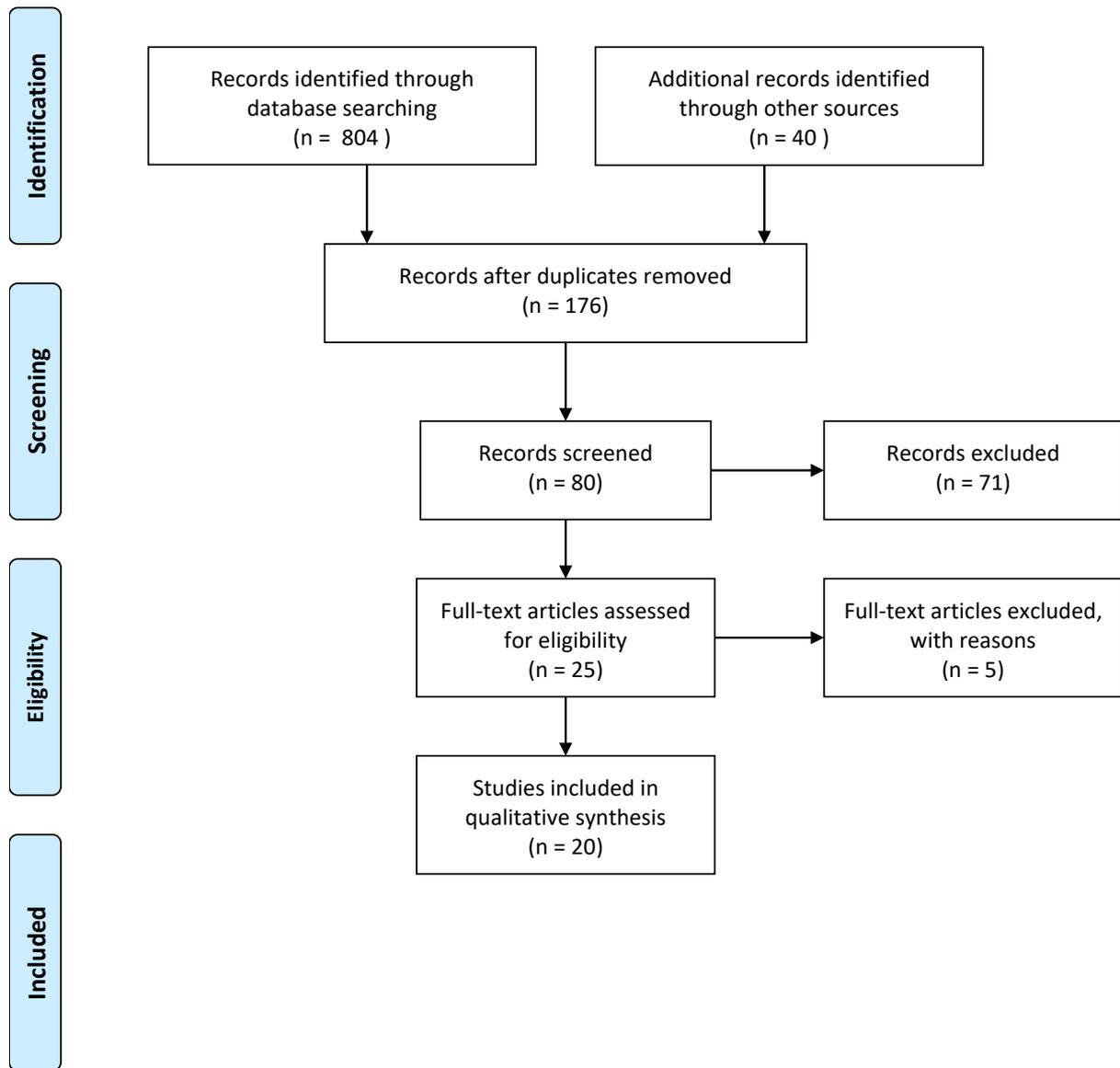


Figure 2.1. The literature search selection process

Source: Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group (2009).

Table 2.3. Summary of Literature

Author (Date)	Key Finding	Focus
Gallagher, Haywood, Jones, & Milne (2010)	<ul style="list-style-type: none"> • Four main features of informed consent 	<ul style="list-style-type: none"> • Informed consent
Graham, Powell, Taylor, Anderson, & Fitzgerald (2013)	<ul style="list-style-type: none"> • Consent is an agreement • Uses ERIC framework • Consent reflects underlying ethical considerations • Working in collaboration with young people • Focus on conducting and planning ethical research 	<ul style="list-style-type: none"> • Informed consent
Hudson, Milne, Reynolds, Russell, & Smith (2010)	<ul style="list-style-type: none"> • Mana tangata (autonomous individual) • Right to be informed of risk to participants mana • Collective and individual consent • Uses Te Ara Tika framework • Addresses Māori ethical issues in research • Encourages voices to be heard • Cultural safety 	<ul style="list-style-type: none"> • Informed consent • Kaupapa Māori research ethics
Harvey (2002)	<ul style="list-style-type: none"> • Contribution of ideas • Collective agreement • Research whānau • Confidentiality • Informed consent process aligns with University guidelines 	<ul style="list-style-type: none"> • Informed consent
McClintock, Tauroa, & Mellsop (2013)	<ul style="list-style-type: none"> • Traditional pōwhiri (welcoming ceremony) process • Engagement and participation 	<ul style="list-style-type: none"> • Informed consent
Parsons, Sherwood, & Abbott (2016)	<ul style="list-style-type: none"> • Argue for co-creation of research • Transparency • Sharing creative solutions 	<ul style="list-style-type: none"> • Informed consent
The Office of the Children's Commissioner, Paediatric Society New Zealand & Ko Aotearoa (2013)	<ul style="list-style-type: none"> • Collaborative approach • Promoting human rights 	<ul style="list-style-type: none"> • Informed consent
Tuhiwai Smith (1999)	<ul style="list-style-type: none"> • Western research legitimised colonial practise • Do not trample on the mana 	<ul style="list-style-type: none"> • Kaupapa Māori research ethics
Rameka (2015)	<ul style="list-style-type: none"> • Colonialism silenced minority indigenous voices • Causing no harm 	<ul style="list-style-type: none"> • Kaupapa Māori research ethics
Tuhiwai Smith (2012)	<ul style="list-style-type: none"> • Important to develop research that is ethical and culturally based 	<ul style="list-style-type: none"> • Kaupapa Māori

	<ul style="list-style-type: none"> Western research has been disadvantageous and harming 	research ethics
Cram (2017)	<ul style="list-style-type: none"> Community-up research processes Values underpinning tikanga Ensuring ethics procedures are applied Guidance for researcher's engagement with communities Axiology (nature of ethics) Strengthening relationships Understanding contexts rangatahi sit within 	<ul style="list-style-type: none"> Kaupapa Māori research ethics Ethics research involving young people
Te Puni Kōkiri (1994)	<ul style="list-style-type: none"> Values and ethical behaviours 	<ul style="list-style-type: none"> Kaupapa Māori research ethics
Cram (1993)	<ul style="list-style-type: none"> Gain knowledge in a safe and engaging manner Upholding interests and mana of groups Researchers are not building their own status Knowledge gained is powerful 	<ul style="list-style-type: none"> Kaupapa Māori research ethics
Graham, Powell, & Taylor (2015)	<ul style="list-style-type: none"> Highlights systems and procedures put in place 	<ul style="list-style-type: none"> Ethical research involving young people
Horgan (2017)	<ul style="list-style-type: none"> Recognising power Context of valuing rangatahi perspectives 	<ul style="list-style-type: none"> Ethical research involving young people
Uprichard (2008)	<ul style="list-style-type: none"> Importance of sharing experiences 	<ul style="list-style-type: none"> Ethical research involving young people
Dickinson, Wrapson, & Water (2014)	<ul style="list-style-type: none"> Giving voice to children Empowering young people 	<ul style="list-style-type: none"> Ethical research involving young people
Erai, Pitama, & Allen (2007)	<ul style="list-style-type: none"> Recognising specific needs of rangatahi 	<ul style="list-style-type: none"> Ethical research involving young people
Santelli, Haerizadeh, & McGovern (2017)	<ul style="list-style-type: none"> Adolescents tend to be excluded Protection and inclusion 	<ul style="list-style-type: none"> Assent versus consent
Alderson and Morrow (2011)	<ul style="list-style-type: none"> Assent can be misleading Consent is preferable over assent 	<ul style="list-style-type: none"> Assent versus consent

Key Themes Derived from the Literature

Several themes emerged from the 20 pieces of literature selected as applicable to the research kaupapa (Table 2.3). The themes identified within the literature are informed consent, Kaupapa Māori ethics, ethical research involving rangatahi/young people and, lastly, the issues of assent versus consent. The following review contributes to the knowledge and understanding of the informed consent processes and how these will inform research with rangatahi.

Informed Consent

Informed consent for children and young people has four main features (Gallagher, Haywood, Jones, & Milne, 2010). It:

1. involves a written or verbal agreement;
2. requires participants to be informed and understand the research before consent can be given;
3. should be given freely without coercion; and
4. should be renegotiable to allow children the ability to withdraw at any stage of the research process.

Graham et al. (2013) explained informed consent as an agreement that explicitly requires research participants to be informed about and understand the research they are potentially partaking in. This universal term for informed consent is consistent in most of the literature reviewed. Graham et al. further added that research involving children should obtain consent from all children participating in the research and researchers should ensure they (the children) are aware of what their potential involvement will be.

Using the ERIC framework, Graham et al. (2013, p. 23) explained that best practise for consent needs to be based on a balanced and fair understanding of what is involved throughout and after the research process. This balanced and fair approach creates a basis for best practice in ethical research that involves children and young people. These features are essential for ensuring informed consent is obtained in an ethically appropriate manner and respecting young people as being the owners of their own knowledge. Graham et al. went on to say that consent is the cornerstone of research processes and reflects important underlying ethical considerations. These considerations include demonstrating a respect for the individual participant's dignity and acknowledging the individual's capability and right to make decisions about matters affecting him or her. From a kaupapa Māori perspective, Hudson et al. (2010) added that mana tangata (autonomous individuals) refers to the individual's choice to participate in research and their right to be appropriately informed of the risks to the mana of individuals or the collective. This occurs whilst appreciating oral consent in some Māori settings as an integral aspect that demonstrates cultural respect for the mana of Māori participants. Kaupapa Māori approaches to informed consent and the process for obtaining consent in research settings, such as providing clear information about the requirements for informed consent, favour both individual and collective consent, and identifying risks for individuals/collectives (Hudson et al., 2010). Similarities exist between what these authors (Graham et al., 2013; Hudson et al., 2010) are saying about informed consent, such as consent being given voluntarily without coercion.

Harvey (2002) carried out a study with five Māori rangatahi aged 15-17 years in Rotorua to gain their perspectives on leisure. Although this study did not technically focus on gaining informed consent perspectives from participants, it did discuss ways in which informed consent was gained as they endeavoured to work in collaboration with the rangatahi. Harvey stated that within the research they carried out, they discussed traditional informed consent to ensure that rangatahi were aware of the research and had the opportunity to create a research whānau and how the agreement would be achieved. "The research whānau agreement went beyond the usual boundaries of a focus group

because it provided the participants with the opportunity to contribute ideas in their own words on what they wanted to happen within the focus group discussion” (Harvey, p. 77). Unfortunately, while Harvey’s research discussed informed consent and a form being completed by each individual rangatahi, there was no further information provided about what this process comprised. Within the study, the informed consent process consisted of a form that was developed in accordance to the university ethics guidelines, with assurance given to participants that confidentiality was a key aspect of ensuring their safety (Harvey).

McClintock et al. (2013) discussed their mahi in child and adolescent mental health services for indigenous populations and gaining rangatahi perspectives. In their research, McClintock et al. discussed how their approach aligned with the traditional pōwhiri (welcoming ceremony) process that involved engagement and participation, and particularly through various components such as mihimihi (speech of greeting), karanga (ceremonial call), whaikōrero (formal speech) and koha (gift). The informed consent process was more significant. The traditional pōwhiri process assisted the consent process as the engagement between researchers and rangatahi by creating respectful relationships, shared commitment, and reciprocity between caregivers and child and adolescent mental health services. This, in turn, created a deeper understanding of the research kaupapa and a comfortable environment for the participants. Furthermore, Parsons et al. (2016) argued for the need for research information that is co-created with young people.

Working in collaboration with young people regarding the development of informed consent practices is increasingly important to ensure there is a clearer plan to guarantee all participants have a stronger understanding of their involvement within any research. Graham et al. (2013) also supported the notion of transparency between rangatahi or young people and the researchers regarding informed consent. Graham et al. addressed the fact that ethical research requires participants to be well informed about planned research activities, expectations of participants and researchers, and the

methodologies that will be used. Therefore, information given to children must be appropriate to their age, competency, and the evolving capacities of each child (Graham et al., 2013). Promoting research that is true and valid to rangatahi, is achieved by ensuring they have been given all available and relevant information so that they are well-informed about the research and can, therefore, provide fully informed consent.

The literature that discusses informed consent shows clear patterns held by academics and researchers when seeking it from rangatahi or young people (Gallagher et al., 2010; Graham et al., 2013; Harvey, 2002). This includes processes to ensure the information, objectives, and what is required from the rangatahi or young people are clear from the beginning (Graham et al., 2013). Participants should also know of their right to withdraw from the research at any time if they are uncomfortable participating (Graham et al., 2013; McClintock et al., 2013). The Office of the Children's Commissioner, Paediatric Society New Zealand, and Ko Awatea (2013) further explained that in health research, a best practice approach involves collaborative partnership between health care providers and children, young people, and their whānau. These are key aspects identified throughout the literature amongst researchers to ensure that young people feel valued (Graham et al., 2013; McClintock et al., 2013; The Office of the Children's Commissioner et al., 2013). Thus, promoting human rights and power sharing occurs by encouraging participants' rights and the acknowledgement of their expertise about their own experiences; thereby, generating an ethically correct research process.

Kaupapa Māori Research Ethics

Kaupapa Māori research ethics is an integral theme to emerge from the literature search and explains the development of frameworks to ensure Māori are protected within all areas of research that are conducted. Kaupapa Māori research ethics are inclusive of the various avenues of research from ethics committees through to the way in which the processes of research involving Māori are developed.

The need for appropriate kaupapa Māori ethics has been a significant aspect of kaupapa Māori research as Māori reclaim the research environment. This creates an ever-increasing reality of the importance to ensure appropriate research ethics aligned with the needs of culturally safe practice when working with Māori in the research environment. Tuhiwai Smith (1999) explained that Western research and theory has legitimated colonial practices, both in Aotearoa and elsewhere. Rameka (2015) further added that colonialism has effectively silenced minority voices of indigenous peoples through research processes and, instead, emphasised the voice of the powerful coloniser. These experiences have shown the importance of kaupapa Māori ethics to manaaki (support) ethical issues that may arise.

Kaupapa Māori research ethics has been developed to help address Māori ethical issues in research and around decision making of emerging research by ethics committees. Hudson et al. (2010) stated that Te Ara Tika draws on foundations of tikanga Māori (Māori protocols and practices) and is deemed useful for researchers, ethical committee members, and those who are involved in consultation or provide advice around Māori ethical issues from a wide-ranging perspective. Tuhiwai Smith (2012) explained how the importance of developing appropriate culturally-based ethical research in response to research that has predominantly been Westernised has had a disadvantageous or harming effect on participants or researchers. Hudson et al. stated that, over the years, Māori have contributed to the critiques of research practice on them and have advocated for the inclusion of tikanga Māori to be a formal aspect of ethical decision-making processes. From the literature reviewed for this thesis, thus far, a need for a framework that empowers Māori and encourages their voices to be heard through research as experts of their own lives and cultural practices is evident (Hudson et al., 2010; Rameka, 2015; Tuhiwai Smith, 1999). This key message of having a framework that addresses Māori ethical issues is consistent across the various literature explored and further supports the inclination of having a framework addressing Māori ethical issues (Hudson et al., 2010). This in turn will support rangatahi voices to be heard through a research paradigm.

Values underpinning tikanga are deemed a major backbone to ensure kaupapa Māori research aligns directly with the views held by those being researched and the researchers. Tuhiwai Smith (2012) and Cram (2017) identified kaupapa Māori values that guide appropriate and safe practices around kaupapa Māori research (Table 2.4, p. 25). These values are relevant to my research as they are a guiding tool for working with Māori, while also promoting safe engagement through the entire research process.

Table 2.4. Community-Up Process

Kaupapa Māori Values	Explanation
Aroha ki te tangata	A respect for people that within research is about allowing people to define the research context (e.g., where and when to meet)
He kanohi kitea	Being a face that is seen and known to those who are participating in research
Titiro, whakarongo...kōrero	Look, listen and then, later, speak. Researchers need to take time to understand people’s day-to-day realities, priorities and aspirations
Manaaki ki te tangata	Looking after people. This is about sharing, hosting and being generous with time, expertise, relationships, etc.
Kia tupato	Be cautious. Researchers need to be politically astute, culturally safe, and reflexive practitioners
Kaua e takahia te mana o te tangata	Do not trample on the mana (dignity) of people. People are often the experts on their own lives, including their challenges, needs and aspirations
Kia māhaki	Be humble. Researchers should find ways of sharing their knowledge while remaining humble

Source. Tuhiwai Smith (2012) and Cram (2017)

Cram (2017) summarised these values and explained the community-up research practices as guidance for researchers engaging with communities and participants to both design and deliver

Māori health research. Te Puni Kōkiri (1994) explained ethics as being about values and ethical behaviours that reflect values held by people. For Māori, ethics is about tikanga, as it is grounded in our values, beliefs, and the way we view the world. This supports the notion and significance of research ethics targeting Māori to ensure tikanga is upheld in all areas of research. Hudson et al. (2010) claimed articulating ethical dimensions of tikanga as they relate to particular research proposals is necessary to ensure support is available for Māori members of ethics committees; thus, allowing them to fulfil their responsibilities of being a kaitiaki (guardians and advocates). In their guidelines entitled Te Ara Tika, Hudson et al. (2010) refer to four tikanga based principles: 1) whakapapa (relationships), 2) tika (research design), 3) manaakitanga (cultural and social responsibility), and 4) mana (justice and equity). These principles provide an avenue to ensure all research carried out with Māori is both ethically safe and links ethical issues to the rights, roles, and responsibilities affirmed by Te Tiriti o Waitangi (the Māori version of the Treaty of Waitangi). Tikanga based principles exist to help assess the risks, benefits, outcomes, rights, roles, and responsibilities that researchers must acknowledge and abide by in order to have research ethically approved (Hudson et al. 2010). Therefore, following the guidance in this framework creates safe research that works to prevent harm for Māori as a whānau, hapū, and Iwi. “The main principles within Te Ara Tika, draw on tikanga Māori and its philosophical base of mātauranga Māori (traditional knowledge), and also integrate understandings from Te Tiriti o Waitangi, indigenous values and Western ethical principles” (Hudson et al., 2010, p. 3).

Tikanga and kaitiakitanga are terms used coherently within the Māori tikanga and literature as they are deemed integral to ensuring the kaupapa and safety of research mahi are carried out, and that it is inclusive and mana enhancing for Māori. Knowledge is created in a way that views, the information, and stories gained in a context empowers the participants and values their participation. Such an approach also ensures the research does not jeopardise the participants in their daily lives and creates

a sense of guardianship. This is inclusive of ethics committees ensuring their power and responsibility does not result in inadequate and harmful research with Māori, in general (Hudson et al., 2010).

Gaining knowledge in a safe and engaging manner has been a key aspect across the literature as well as ensuring that the research is strengths-based (Cram, 1993; Tuhiwai Smith, 2012). Cram (1993) stated the main purpose of knowledge for Māori is to ensure upholding the interests and mana of the group and that it serves the community. Unlike some forms of mainstream research, Māori research and knowledge are about the advancement of Māori in general. Cram (1993) further explained that Māori researchers are not building up their own status; their concern is about improving outcomes for their iwi and the overall Māori population.

Knowledge is a powerful tool that helps further develop a kaupapa that can be additionally advanced and understood to guide future mahi. Cram (2017) and Tuhiwai Smith (2012) explained that gaining knowledge prevents issues such as takahia te mana o te tangata (trampling on the dignity of the people) whether it be through the ethics committees, researchers, or participants. Researchers' processes need to realise the aim of improving outcomes for Māori overall. This requires an increased awareness and understanding of the kaupapa and focuses on the collective people, rather than the individual researcher or group of researchers (Hudson et al., 2010). Mahuika (2008) additionally stated that kaupapa Māori research seeks to challenge frequently accepted aspects of research in order to honour Māori ways of knowing and being.

From the review of literature around kaupapa Māori research ethics Cram (2017), Tuhiwai Smith (2012), Hudson et al. (2010), and Rameka (2015) similarly explained processes such as valuing tikanga, upholding the mana and, most importantly, ensuring ethics procedures are applied across the board

so that no further harm is caused to Māori. These processes also result in knowledge that supports progress of the informed consent processes and rangatahi.

Ethical Research Involving Rangatahi/Young People

Ethical research involving rangatahi is increasingly prevalent in Aotearoa. Graham et al. (2015) explained the importance of involving children in the research setting, and has highlighted systems and procedures put in place to govern how ethical issues in research are addressed. This in return creates a significant amount of information about ethical research and the informed consent process in relation to mainstream research. However, due to the absence of research in kaupapa Māori or indigenous settings, the research practices are generally applicable for young people but are not necessarily culturally appropriate practice when working with Māori rangatahi.

Graham et al. (2013) explained that ERIC is a project focusing on planning and conducting ethical research with children and young people in different geographical, social, cultural, and methodological contexts. Graham et al. contended that cultural considerations, such as strong obedience of children to adults, play a significant part when carrying out research with young people as they can impact children's autonomy and their willingness to participate in research. This is an explicitly clear aspect in the ERIC framework and is supported by Hudson et al. (2010) who explained that going beyond cultural safety, māhaki (respectful conduct) needs to acknowledge the spiritual integrity and Māori philosophy to ensure safe application of protocols. From a kaupapa Māori viewpoint and te ao Māori context, cultural considerations are inclusively identified as an integral part of ensuring ethical research is carried out. Cram (2017), who examined axiology (the nature of ethics), discussed the importance of ethical obligations for Māori within research as primarily being about the maintenance and strengthening of relationships with participants, researchers, and the community. This aspect is further ensured through cultural processes.

Children and young people's rights to participate in research affecting them are a hugely contentious area in ensuring the research remains safe and ethical. Graham et al. (2013) acknowledged that children's rights to participate in decisions affecting them are a basic human right. The United Nations (1989) stated in Article 12 of the UNCRC that any child who can form their own views has the right to express these freely in all matters that affect the child.

In recognising the power and context of valuing rangatahi perspectives, and capturing their views in a format that generates creative and engaging results, it is important to understand childhood studies in the context of ethical research with rangatahi and young people. Horgan (2017) stated that childhood studies present childhood as being a structural construction category of society, thus placing a major emphasis on the children's here and now status. This is an incredibly powerful and empowering statement as the idea of rangatahi being identified and acknowledged as human beings. The statement also supports the ideology that rangatahi are currently living their experiences and are in a realm where their expertise is vital for improving their quality of life and supporting aspects that require more support or resources. Therefore, to further promote ethical research with rangatahi, it is pivotal to acknowledge them not as research participants but as the experts of their lives and teaching the researchers in a context that is applicable to their youthful ways. Horgan (2017) and Uprichard (2008) both added that childhood studies argue for children to share their experiences as well as emphasising their rights to decide the nature and extent of their participation within research. Dickinson et al. (2014) concurred that giving 'voice' to children empowers them to contribute toward processes and systems that affect their health and wellbeing. In order to achieve ethical research with rangatahi, it is increasingly evident just how important the need to understand the contexts and lives of rangatahi are, by recognising the importance of the social contexts and structures rangatahi are encapsulated within.

From my review of the literature on ethical research involving rangatahi and young people, it appears that frameworks specifically targeting the age group identified are primarily based on Westernised thinking, ethics and values (Graham et al., 2013; Graham et al., 2015). The lack of frameworks tailored to young Māori people is a significant gap in the literature needing to be addressed to support future research carried out with indigenous rangatahi. Attending to this gap in the literature, will ensure rangatahi are accepted and their rights as young people to be research participants, and as indigenous experts about their wellbeing, is an important aspect that has been conscientiously discussed (Graham et al., 2013; Hudson et al., 2010). Erai, Pitama, and Allen (2007) stated,

In recognising that youth are the key population to influence, it is essential that the specific needs of youth are recognised, in particular, indigenous youth, and consideration given to young Māori within the context of their whānau, hapū, and iwi, if long-term changes are to be achieved. (p. 19)

Understanding the contexts rangatahi sit within, more so within their whānau, hapū and iwi, plays a considerable part within ethical research; especially for the indigenous rangatahi as it is important to remain mindful about indigenous and cultural considerations throughout the entire research process. Thus, remaining ethically and culturally appropriate for all participants will, in return, promote a piece of work that is culturally safe, ethical, and valid (Cram, 2017; Tuhiwai Smith, 2012).

The Issue of Assent versus Consent

Assent versus consent is a contentious issue when working on a research study with rangatahi or young people in general. Assent is explained as being a child's agreement to participate in research, recognising both emerging decisional capacity in children and that many children may not be fully capable of providing informed consent (Santelli et al., 2017). Consent involves but is not limited to a written or verbal agreement and is obtained if participants are informed about and have an understanding of the research (Graham et al., 2013). A key concept that may be more fitting from a kaupapa Māori perspective is collective consent. Collins (2006) identified a form of collective consent

through their research by seeking a verbal agreement from the wider marae community as opposed to individuals which in turn reduced the individualistic “contractual” agreement. This concept also lessened any offense that would generally come from individual consent and the notion of a written contract.

Santelli et al. (2017) stated that adolescents tend to be excluded from research studies because there is a significant amount of confusion over whether they should be regarded as adults or children and, therefore, who has the rights and ability to give consent for them to participate within research. This poses a sense of risk, because a significant portion of the population becomes disadvantaged from the non-inclusion within any form of research. Santelli et al. further highlighted that uncertainty about what constitutes proper ethical balance between protection from, and inclusion in, research has ultimately resulted in adolescents being excluded.

The United Nations (1989) in Article Five of the UNCRC stated

...parties shall respect the responsibilities, rights, and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child. The term ‘evolving capacities of the child’ acknowledges the ideology that young people are continuously evolving in their perceptions of the world and developing their own personal views and expressions.

Therefore, it is important to recognise that although the UNCRC is inclusive of children 18 years and under, many have the capacity to provide informed consent regarding their participation. Graham et al. (2013) added that whilst general guidance has been given in ethical guidelines, researchers are encouraged to consider each study case-by-case, while also remembering to consider the children’s age, local context and capacity to understand. Alderson (2001, p. 139) also stated that respect for children’s participation recognises them as subjects rather than objects of research, who ‘speak’ and report valid views and experiences. The international charter, ERIC (Graham et al., 2013), continues

to support the notion of consent and explains that children's consent must always be sought alongside parental consent and any other requirements that are necessary for the research to proceed ethically.

Assent has mixed reviews throughout the literature. According to Graham et al. (2013), assent is neither universally recognised nor supported, attracting criticism that it is an agreement with minors who have no legal rights to consent. Assent is a term most commonly used in the medical and health field, frequently used in North American and in international biomedical guidelines (Graham et al., 2013).

Parsons et al. (2016) also found that assent versus consent was a contentious issue, and some of their participants argued assent is inappropriate because it would assume the participant understood what they were agreeing to. This stance is supported by Alderson and Morrow (2011) who suggested assent can mislead and cover up children's refusal to consent. Cocks (2006) contended that assent cannot be enough to ensure ethical integrity. Within a kaupapa Māori research framework, Cram and Kennedy (2010), drawing on the work of Morrow (2009), maintained that assent should only be used to gain participation from rangatahi under 16 years of age. Even so, researchers need to seek out their assent or permission as well as a caregiver's consent.

I found these contradicting viewpoints create a significant amount of confusion regarding consent and assent. In saying this, Alderson and Morrow (2004, 2011) made a strong argument that the term consent is preferable over assent for three very significant reasons:

- Assent is not needed when children are legally able to consent.
- Questions are raised if a partly informed decision is made by children assenting who do not necessarily understand all the issues that are required for consent.
- Assent can be used to mislead and not fully acknowledge the child's refusal of consent towards the research.

The issue of assent as it continues is an adult dilemma of a parent determining a young person's readiness to give consent. There are existing gaps for Māori and Indigenous rangatahi and there are few (Māori) research studies to draw upon. Assent versus consent remains as a culturally contested research dilemma that will require on-going investigation to ensure rangatahi Māori stand to benefit from the outcomes of ethically based research.

A key point that has derived from my review of the literature is that it is evident the use of the terms assent and consent are to be based on individual pieces of research. This indicates there is no general rule of thumb when it comes to informed consent in research with people under the age of 18 years. However, with the appropriate information, children or rangatahi can make informed decisions to guide their participation within a research study. This is further supported by Graham et al. (2015) who stated children can make informed decisions when they receive adequate information.

Gaps in the Literature

From the completion of the review of the literature, it has become increasingly apparent gaps have emerged within the literature. This research will attempt to contribute to reducing these gaps by placing rangatahi views of an effective informed consent process at the forefront through utilising kaupapa Māori methods. One clear section that appears to be missing from the literature was a Māori approach to informed consent with rangatahi. However, there is a growing body of literature that contains culturally appropriate information for working with Māori rangatahi (McClintock et al., 2013; Parsons et al., 2016; Harvey, 2002). This area would benefit from the expansion of further research and can be viewed as ground-breaking for the development of culturally appropriate methods for informed consent with rangatahi.

Gaining informed consent is continuously deemed as a multifaceted process and Parsons et al. (2016) added that gaining informed consent is complex because it is difficult to determine the participant's level of understanding beforehand. This is a key area that is briefly mentioned by one author (Parsons et al.), however, a considerable gap in the literature exists. This concept is key to understanding exactly how to approach informed consent with rangatahi and young people in order to ensure there is a collective understanding of what the researchers are asking of the rangatahi participants and how much they comprehend. This follows on from the literature related to the consent and assent debate. Nevertheless, there is still a significant amount of confusion regarding assent and consent.

Rationale

This thesis aims to address the varying gaps that have been identified within the literature in order to guide future research being carried out with, not on, rangatahi aged 13-17 years old in Aotearoa. By creating an indigenous approach towards understanding rangatahi views around informed consent, the aim is to ensure the processes carried out are of sound knowledge based on the voices of the rangatahi. This research is required because there is still a lot of contention around the informed consent and assent process with rangatahi as they fall into the gap of young adults. To gain a more comprehensive understanding of the process and elicit the views of informed consent from the rangatahi themselves, crucial and ground-breaking research is necessary. Through working collaboratively with rangatahi, this research will be able to inform other researchers and academics in the field of ethics involving rangatahi. Therefore, in order to progress, it is paramount that the research is carried out ethically, culturally, and in a way in which rangatahi are empowered to direct change through their own lived experiences.

Naku te rourou nau te rourou ka ora ai te Iwi

With your basket and my basket, the people will live

(cited in Woodward Māori (2017))

Wāhanga Tuatoru: Research Design and Methodology

Ko te ahurei o te tamaiti arahia o tatou mahi

Let the uniqueness of the child guide our work.

(Literacy NZ, 2012)

Introduction

Kaupapa Māori theory underpinned the research informing this thesis to ensure a holistic approach was undertaken when working with rangatahi. Rangatahi make up a significant proportion of both the Māori and youth population in Aotearoa. According to Statistics New Zealand (2013), rangatahi make up a third of all young people under the age of 15 years. Therefore, the importance of ensuring their voices are heard was key to informing decisions that will impact rangatahi. Privileging the Māori rangatahi voice was crucial to ensure they are heard and acknowledged in a way that remained tūturu (true) to the tikanga of te ao Māori. It was important to acknowledge that an increasing number of rangatahi are able to have daily conversations in te reo Māori (Ware & Walsh-Tapiata, 2010) and allow the methodology chosen to support every aspect in order to capture their diverse views. For instance, having the option of basic te reo Māori words written on the information rangatahi are provided with and the opportunity for the information to be translated if needed.

This research design and methodology chapter provides a foundation for the use of qualitative research design and kaupapa Māori Methodology. Methods used for participant selection and recruitment criteria, data collection methods employed, data analysis are also discussed followed by ethical considerations, rigour and reflexivity.

Research Design

“Qualitative research approaches have the potential to respond to epistemic challenges

and crises, to unravel and weave, to fold in and unmask the layers of the social life and depth of human experience.” (Tuhiwai-Smith, 2005, p. 103)

Qualitative research is largely expressive and has an extensive emphasis on processes, meanings, and understandings that are gained through a varying use of tools (Mooney, 2012; Tuhiwai Smith, 2005). Qualitative research enables a process where different perspectives can be shared through various social interactions and activities that help result in a shared understanding of a kaupapa. Mooney (2012) explained that qualitative research complements the position of sharing different perspectives through social interaction because it seeks to understand how individuals make sense of social settings. This is a vital aspect of qualitative research and ensuring it is carried out in a kaupapa Māori way, staying true to tikanga will be beneficial. Mooney added that when working with rangatahi it is crucial to build a rapport as this reduces barriers to communication and encourages further discussion. Through a qualitative approach, the use of kōrero is an integral part of establishing rapport through whanaungatanga (kinship) where connections are identified as well as karakia (prayer) and stories. Thus, qualitative research is strongly based around the inclusiveness and connectedness of the human experience in a context that does not pre-empt the perceptions held by a participant.

It is increasingly evident that active participation from rangatahi is necessary within the research process, to understand the social world of the children and young people, as explained by Barron (2000) who stated listening to voices of young people makes them feel more valued and more of a contributing member within society. In saying that, to overcome interpretations that can be deemed as adult-centred, it is vital to employ a methodology which allows rangatahi to speak and be appreciated for their own perceptions. This, in return, will provide an avenue that supports healthy discussions about the kaupapa amongst rangatahi in an environment which respects their views. In carrying out research with rangatahi, a consideration of the overall methodology to be employed in the study is critical to ensure the research empowers rangatahi voices.

Methodology

Kaupapa Māori Research

This research adopts a qualitative Kaupapa Māori methodology that will be woven through the entire processes mai te timata me te whakamutunga (from start to finish). Kaupapa Māori is the overarching methodology that guided, and was instilled in, every aspect to ensure the safety of the rangatahi, their taonga (treasure) of kōrero (stories) as well as the researcher. Tuhiwai Smith (2006) has observed that kaupapa Māori research methodology provides the opportunity for the expression of marginalised and often silenced voices. It attempts to re-present the experience of marginalisation in genuine and authentic ways.

Cram (2017) further explained that Kaupapa Māori research has been carried out through various disciplines since the 1980s. It promotes a structural analysis of Māori health disparities that is a response to the colonisation that occurred in Aotearoa New Zealand, which saw many Māori marginalised in their own lands. Therefore, Kaupapa Māori has predominantly been identified as the Māori way, which ultimately reduces deficits and provides a strengths-based approach where Māori lead the way. Cram discussed how Kaupapa Māori health research moves away from the discourse of victim blaming and personal deficits, to understanding the lives of Māori and systematic determinants of health and wellbeing in a strengths-based manner. Kaupapa Māori continuously involves critically thinking, including developing a critique of Pākehā (non-Māori) constructions and definitions of Māori affirming the importance of Māori self-definitions and self-evaluations (Cram, 2018b). Therefore by carrying out Kaupapa Māori research, one is encouraged and honoured to ensure the study continually remains for Māori, by Māori, and with Māori.

Kaupapa Māori informs research in a manner that is culturally appropriate, acknowledging the mana and tikanga of tūpuna, rangatahi, whānau, hapū and iwi. It also provides a safe forum for perspectives and experiences to be acknowledged. Graham Smith (1997) has written expansively about Kaupapa Māori and has summarised Kaupapa Māori research to be:

- Associated with being Māori
- Philosophy and principles linked to Māori
- Highlighting validity and legitimacy of being Māori
- Highlighting Māori language and culture and
- Focusing on struggles for autonomy over cultural wellbeing

Kaupapa Māori research requires the engagement and consistent involvement of Māori to ensure the regaining of power within the research structure. Cram (2018b) discussed the importance of having Māori participation (as with other indigenous peoples throughout the world), in the entire research process as being vital to reignite the confidence of whānau, hapū, and iwi in research. Using Kaupapa Māori approaches seek to improve health and wellbeing of Māori whānau and sets out to make a positive difference for Māori while continuing to be an active aspect in building the research capacity of Māori (Pihama, Cram, & Walker, 2002; Tuhiwai Smith, 1999). Through this crucial intervention, research with Māori has allowed for healing to begin and Māori obtaining control and power over their wellness. Wilson (2017, p.6) discussed the importance of working safely with vulnerable populations, as they are subjected to forms of social marginalisation which contribute to persistent inequities in their social and health outcomes, as well as differences in their use and access to necessary services. It is essential for researchers to ensure their research is guided strongly by tikanga as opposed to western methods when working with vulnerable and Māori populations. Wilson explained the researcher's decisions and processes utilised can further increase the risk of vulnerability and marginalisation, therefore, the need to remain mindful is important.

Kaupapa Māori is guided by principles that act as the tuarā (backbone) of the research, which continue to take precedence and provide guidance for researchers; thus ensuring their research stays true and pure to whānau, hapū, iwi, and the research team. Cram (2009) and Tuhiwai Smith (1999) have applied

kaupapa Māori approaches over a number of years and have noted seven principles that can guide effective Kaupapa Māori research.

The values, identified below have been articulated by Cram (2009) and Tuhiwai Smith (1999); however, the definitions are my interpretation of how these kaupapa Māori research values are used for this research study (Table 3.1, p. 40). These values were used to structure the methodology outlined as they were a great guide for ensuring I remained culturally appropriate and did not cause harm, thus holding myself accountable through the whole process. These values were also used to inform the interpretation of findings, by acknowledging the data collected and prioritising the voices of rangatahi from the focus group. The values supported the various subthemes that were identified by keeping me grounded and solely focused on filtering the data to ensure the mana of rangatahi are at the forefront.

The values have recently been identified as “community-up” research practices. This new title is in recognition of these values being sound research practices all researchers working with Māori should follow. This, in turn, allows communities being researched, the ability to guide how they want to be treated in research projects.

Table 3.1. Community-Up Research Values

Value	Meaning
Aroha ki te tangata	A respect for people that within research is about allowing people to define the research context (e.g., where and when to meet)
He kanohi kitea	Being a face that is seen and known to those who are participating in research
Titiro, whakarongo...kōrero	Look, listen and then, later, speak
Manaaki ki te tangata	Looking after people
Kia tupato	Be cautious
Kaua e takahia te mana o te tangata	Do not trample on the mana of people
Kia māhaki	Be humble

Source: (Cram, 2009; Tuhiwai Smith, 1999). Table was adapted to identify how each value is used within this thesis.

Cultural values guided the research when I was out in the community and were an effective guideline to ensure the research remained Kaupapa Māori through every aspect. Cram (2009) outlined the following cultural values that guided and ensured the research remained Kaupapa Māori. The definitions provided have been tailored for this specific research with rangatahi to show exactly how these values apply directly to all participants, researchers, and communities involved. **Aroha ki te tangata** – Having respect for the rangatahi and their whānau, I allowed them to define the research context. Maintaining respect for the stories shared and research data collected. **He kanohi kitea** – Ensuring I was seen and known to the participants by engaging with participants through whakawhanaungatanga and hui. I will be familiar to the communities to ensure trust and communication is developed through kōrero with the school community, board of trustees, and other stakeholders. **Titiro, whakarongo...kōrero** – Look, listen and then, later, speak. I took the time through the process to understand the complexities of the day to day realities and priorities of rangatahi. This

allowed questions asked to be relevant. ***Manaaki ki te Tangata*** – looking after people. I ensured time, relationships, and expertise of rangatahi were appreciated. ***Kia tūpato*** – be cautious. I remained culturally safe and reflexive throughout the entire research process by collaborating with whānau, hapū, and iwi members. This helped guide the research processes and me as the researcher within the kaupapa Māori setting. ***Kaua e takahia te mana o te tangata*** – I must not trample on the dignity of the people throughout the research. Rangatahi are experts in their lives and lived experiences. They hold the knowledge of their stories, aspirations, and dynamics. I ensured I actively sought opportunities for collaboration on research reports and agendas. ***Kia māhaki*** – be humble. I ensured knowledge was shared in an appropriate way for the rangatahi. The act of sharing between the researcher and rangatahi ultimately led to a shared understanding of the kaupapa resulting in a more trustworthy research.

Kaupapa Māori will also help guide the interpretation of findings by ensuring appropriate methods of sharing are acknowledged and the use of data are treated in a culturally safe manner. In this way I was able to encapsulate the taonga of kōrero from the participants and help to reduce health disparities for tangata Māori (Māori people as a whole). Cram (2017) explained that the future direction for Kaupapa Māori health research is challenging disparities and seeking to fully represent Māori realities and aspirations. With the various principles and values guiding this research, every aspect of the process will acknowledge and address the importance of decolonisation and empowering rangatahi as the owners and experts of their knowledge and skills (Tuhiwai Smith, 1999).

Participant Recruitment

I had built previous relationships with the selected school through my roles in academia and in the health sector. This prior relationship provided an avenue to a low decile secondary school in Auckland that has one-third Māori students on the current role and continues to be involved in a variety of research conducted throughout the country.

The principal or school liaison of the selected school was initially asked to promote the research study within the school using the advertising poster created (Appendix A). This helped to ensure a sense of self-selection for the rangatahi and identify those who would genuinely be interested in the research. The next step was to identify 7-15 students with a diverse range of ages and gender that would fit the outlined criteria. The principal or school liaison's knowledge of their school community was enough to achieve this goal without any form of bias or conflict of interest being a factor.

Expressions of interest were obtained through general information in the weekly newsletter, at assembly, and through discussion boards at the secondary school. All avenues of discussion forums such as daily notices, school email, and assembly notices were considered to ensure the target audiences were reached. This was because the busy schedules of rangatahi can impact and limit many notices reaching them when they are only advertised in one specific area. Recruitment was carried out through a hui (meeting) with interested rangatahi attending a lunchtime information session to discuss the research and ask questions before deciding to participate. Holding a hui kanohi ki te kanohi (face to face) ensures the researcher becomes a familiar person to the potential participants. The hui also created a form of whakawhānaungatanga and began to reduce any form of whakamā (embarrassment) the rangatahi may be feeling. Information was provided at this point via the rangatahi information sheets, along with the rangatahi assent and consent forms. Further discussions with the rangatahi in attendance happened at the hui to ensure the rangatahi went away to think about their participation whilst being fully informed through a context that they would understand. Next, information sheets and consent forms were sent home, with the rangatahi, for their whānau to review and send back. There was also an opportunity for a whānau hui to answer any queries they had and provide an avenue to further understand the research process; however, this offer was not taken up by any whānau members.

Participant Criteria

This study aimed to recruit between 7 to 15 rangatahi. Ministry of Youth Affairs (2002) defined young people as the younger generation or youth. For this research, rangatahi were aged between 13 and 17 years (inclusive) and attending a secondary school in Aotearoa New Zealand. To qualify for inclusion within the study, participants had to meet the following criteria:

- Be 13 to 17 years old (inclusive). This will ensure the study remains rangatahi focused and encapsulates the views of their age group.
- Self-identify as being of Māori descent. This aspect safeguards the research approach and remains Kaupapa Māori and ensures participants were Māori.
- Have previously been involved as a participant in a research study. This was to ensure participants could draw on their previous experiences of the informed consent process and elaborate on what works well or does not work well.

The exclusion criteria for participants within this study were as follows:

- Those who do not have the ability to give voluntary informed consent.

It is important to acknowledge that with an initial aim to have 7-15 rangatahi participate within the research, only seven were successfully recruited within the timeframe appointed. A number of factors contributed to low recruitment of participants, which included busy school scheduling, wrapping up the school term, preparing for mock examinations, and rangatahi under 16 years of age not being able to return whānau consent forms.

Principal and Board of Trustees Consent

Once ethics approval was granted from AUTEK, I contacted the deputy principal, who became the school liaison or key contact. Discussions ensued about obtaining access into the school for research purposes and further details about what the research entailed were provided. Following, I visited with

the deputy principal in person to continue our discussion kanohi ki te kanohi. This kanohi ki te kanohi approach allowed for further rapport to be made between me as the researcher and the school. Kanohi kit e kanohi ultimately created a sense of trust about the study and reduced the notion of a stranger coming into the school community. It also acknowledged the fact that the school principals know their school better than anyone. Therefore, it was important for me to build that trust and avoid tramping on the dignity of the community (i.e. kauhā e takahia te mana).

At the hui, the Deputy Principal was provided with a Principal Information Sheet (Appendix B) as well as the corresponding consent form (Appendix C). The Deputy Principal was also provided with the information sheets and consent forms that the whānau and rangatahi were given. The Principal's consent form was more of an access form to allow the research to be conducted within the school setting and support for the recruitment of rangatahi through various notice forums within the school. I discussed the criteria for participants with the school liaison to ensure she was up to date with every aspect of the research recruitment, allowing for a process that was well informed and robust. Although this study had minimal risks, it was important that if any disclosures arose a process was adopted to ensure the rangatahi were safe. The plan to ensure the safety of the rangatahi included the general referral pathways for the school – the first point of contact is the school liaison who would then contact the health centre team where a nurse, guidance counsellor, and social worker are employed full time. This process did not need to be implemented during the focus groups.

Whānau Consent

The whānau consent process carried out in this research involved the opportunity for the whānau of rangatahi, who had self-identified, to attend a hui with the researcher kanohi ki te kanohi. This opportunity was made available to ensure whānau were able to gain a stronger understanding of the research aims, the recruitment criteria, what the data will contribute to and be used for. In carrying out a Kaupapa Māori research, it was important to ensure whānau had the opportunity to better

understand the research and contribute as this further promoted the awareness of rangatahi being a part of an Iwi, hapū, and whānau.

Initially, all rangatahi were sent home with a whānau/caregiver/guardian information sheet (Appendix D) and a whānau/caregiver/guardian consent form (Appendix E). Along with these forms, the rangatahi information sheet, consent form, assent form (for rangatahi under the age of 16) and the research group contact details were provided. All forms were sent home to the whānau with the rangatahi after the first recruitment hui, to be signed and sent back to school for collection along with the invitation to identify interest in attending a whānau hui. The whānau were free to contact me or the research supervisors if they had questions or required further information regarding the research. AUTEK details were also provided should whānau have any ethical concerns. These processes ensured the researcher supported the whānau and rangatahi, manaaki ngā tangata by allowing various avenues for further discussion. No whānau indicated interest in attending a whānau hui and no feedback was provided from whānau directly about not attending the hui made available. There was one signed consent form was returned from a rangatahi under 16 years old. There were no whānau who declined their rangatahi participation within the research.

Rangatahi Consent/Assent

It was important for the rangatahi to understand what they were consenting to and the criteria for the research. At the start of all interactions with the rangatahi, whether it was the hui or focus groups, I would start off by introducing myself, who I am through my whakapapa, current role, and the reason for the study. This was an important to ensure the rangatahi became familiar with me and the research remained culturally safe in a Kaupapa Māori way. Cram (2009) and Tuhiwai Smith (1999) supported this notion through their value of he kanohi kitea, being a face that is seen and known.

The rangatahi were given an information sheet (Appendix F), consent form (Appendix G) and rangatahi assent form (Appendix H) for the participants who were under the age of 16 years old. I felt strongly that the rangatahi should have a full understanding of the study before eliciting their consent. This also ensured I did not takahia te mana of the rangatahi, and continuously highlighted the fact that they had the ultimate choice to participate or not in the research. Cram (2009) and Tuhiwai Smith (1999) explained that a researcher should not trample on the dignity of the participants, acknowledging they are often the experts on their own lives including their challenges, needs, and aspirations. Therefore, rangatahi were informed that their school and some of their whānau had consented to the study being carried out; however, regardless, it was still their decision to consent.

Before discussions began, the rangatahi were given the opportunity to opt out of the study without any adverse effects to them or the school. I was very aware it could be difficult for rangatahi to tell an adult they did not want to participate as well as factoring in the issue of peer pressure. However, a Kaupapa Māori research philosophy seeks to empower the rangatahi by supporting their decisions and building their self-confidence – Aroha ki te tangata (Cram, 2009; Tuhiwai Smith, 1999). Rangatahi were informed that they did not have to answer all the questions asked within the focus group if they did not wish and that there was simply no right or wrong answer; hence the reason for the study. This continued to ensure that I, as the researcher, remained cautious and did not trample on the dignity of the rangatahi—Kia tupato, Kāua e takahia te mana o te tangata (Cram, 2009; Tuhiwai Smith, 1999).

Method

Ethical Approval

This study was reviewed and approved by the Auckland University of Technology Ethics Committee (AUTEC) on the 06 July 2018. Ethics application: 18/51 Tōku Reo, Tōku Whakāetanga, Tōku Mana: My voice, my informed consent (Appendix I)

Use of Focus Groups

In carrying out any form of research with rangatahi it is extremely important to do so in a manner that allows the participants to become actively involved in telling their stories in ways that empower them and continue to ensure their mana is upheld. It was evident that focus groups would be used as the primary means of data collection for this research as it would create healthy discussions amongst the rangatahi around the kaupapa.

Finch and Lewis (2003) concurred that "... focus groups are now well established as a method used within the fields of social research and are an extremely valuable research approach ..." (p. 170). Focus groups allow for discussion to be held around a kaupapa to establish views held by participants. O'Carroll (2013) explained that focus groups are utilised to capture co-constructed dialogue from participants regarding their experiences, attitudes, and understanding of a topic. The main reason for focus groups being chosen as the qualitative method in this research was to draw upon the valuable experiences and thoughts rangatahi can input towards the kaupapa of the research. Webster, Walsh-Tapiata, Warren, and Kiriona (2007) identified that the use of qualitative research methods, such as focus group interviews, enables the exploration of young people's experiences and stories. The interactions carried out within these focus groups are crucial features because the interface amongst participants significantly portrays their own views of the world.

When facilitated well, participation in focus groups can be a positive experience for rangatahi. Skilled facilitation of focus groups allows researchers to step back from leadership, effectively enabling rangatahi to take charge of the process. In doing so, rangatahi are provided with a safe space to communicate their true views on a topic. Cram (2018a) further explained that the researcher can step further into the background in larger group interactions by using tools that encourage participants to engage more directly with one another and taking turns to share a story about a topic.

Walker et al. (2006) explained that specific types of qualitative research, such as focus groups, fit well with the Māori way of doing. Focus groups are used regularly when carrying out Kaupapa Māori research as they provide a forum where participants are valued for their input and continue to maintain a dominant position within the study. Focus groups provide the rangatahi with an opportunity to be valued and respected as the experts whilst also having the chance to work in collaboration with the researchers. There were several indicative questions used within the focus groups to prompt feedback from rangatahi (Appendix J). It was important to ensure that rangatahi had full control over where the conversations led, with minimal input from me (researcher and focus group facilitator). The process allowed rangatahi to answer the questions openly and honestly, whilst giving them the opportunity to generate additional kōrero.

As with any methods of data collection, focus groups do come with limitations. One key limitation that can impact significantly on the data collected is that the researcher has less control over the data that is attained. In comparison to quantitative research and individual one to one interviewing, researchers using focus groups as a tool need to take into consideration the ability for participants to chat with each other and remain aware that the researcher has minimal control over the interactions. However, using tikanga, Webster et al. (2007) explained that Māori processes such as mihimihi, karakia and whakawhānaungatanga are natural cultural processes that occur and help to remove the barriers of the unknown between rangatahi participants and the researcher. Webster et al. discussed how tikanga processes allow rangatahi to make whakapapa links with others in the group. Therefore, carrying out a kaupapa Māori qualitative research using focus groups, meant acknowledging the limitations and ensuring the mana of the rangatahi participants was held in high standard. It is also important for the success of the focus group and data collection, that participants have experience specific to the context of the topic being researched.

Data Collection

This research collected data from rangatahi through one focus group (60 minutes, during the school lunch break) that consisted of seven rangatahi at a secondary school in Tāmaki Makaurau (Auckland). The optimal size of a focus group is five to eight participants; larger groups can be difficult to manage and result in some participants not feeling comfortable to participate (Krueger & Casey, 2002). The intentions and aims of the focus group were to have an open and safe discussion with the rangatahi participants around their perceptions of informed consent and the processes they felt would best work for them as young, Māori participants on research studies. Data were collected by voice recording the focus group and having open and safe discussions in an environment familiar to them—the focus group were held in a meeting room at the school.

From the data that were collected, I personally transcribed the recordings and collated the information given. I also checked the recordings against the transcripts to ensure their accuracy and confirm that all identifying information was removed for confidentiality reasons. Any identifying factors were removed and replaced with placeholders (such as [city] and [organisation], for example). Ultimately, the data helped create indicators for a guideline for current and future researchers around best practice for ethics and the informed consent process when working with rangatahi participants in research studies.

Data Analysis

The data that were collected within the research were analysed using thematic analysis. Braun and Clarke (2006) explained that thematic analysis is a method for identifying, analysing, and reporting patterns of themes within data whilst potentially interpreting various aspects of the research topic. Thematic analysis was chosen as the preferred process as this would allow key themes and subthemes from the focus group to be identified and understood in the context of the rangatahi views rather than adult interpretations. Braun and Clarke further explained that “keyness” of a theme is not necessarily

dependent on quantifiable measures but in terms of whether it captures something important in relation to the overall research question.

Discussions were transcribed soon after the focus group was held, and the accuracy of the transcripts was confirmed by reviewing the written transcriptions while listening to the recording. This process allowed for common themes to be identified and ensured each rangatahi response is captured accurately. A copy of the transcript was made available to the rangatahi to confirm or alter what had been discussed and provide verification. None of them chose to do this.

Kaupapa Māori helped guide the data analysis and findings by strengthening the korero through a Māori world view and weaving the various mātauranga shared, thus allowing the rangatahi perspectives to be highlighted significantly. As the researcher, I brought my particular philosophical stance to the research which focuses predominately on experiences and tikanga to steer the data interpretation. However, I was also adamant that data was in fact the current views of the participants and not my own interpretation that would impact the mana of the rangatahi.

Themes within data can be identified in two different ways: inductive or theoretical. Braun and Clarke (2006) explained that an inductive approach is where themes are directly linked to the data and theoretical approaches are analytic-driven. All themes and sub-themes were generated from the data rather than pre-conceived from the researcher, allowing an inductive approach to be utilised. This ensured rangatahi voices drove the findings and that I was able to continually keep the rangatahi views at the forefront. Broad themes were identified and reinforced by the rangatahi participants through multiple references during the discussion.

Codes were assigned to participants' transcripts and subsequent quotes to ensure confidentiality was upheld while ensuring rangatahi responses could be tracked respectively. These were assigned through the rangatahi self-identified iwi affiliation, gender, and age. Iwi affiliation was depicted by the first letter or letters in the iwi names. Waikato-Tainui = WT, Ngāpuhi = NP. Gender was represented by Kōtiro = Girl, Tama = Boy. Lastly, age of the rangatahi is represented by their identified age as a number. As an example, a 15-year-old female rangatahi quote from Waikato-Tainui would be represented as WTK15. Relevant quotes were also noted from this structure, so they could be easily retrieved.

Ethical Considerations

Ethical considerations were paramount for this research, thus ensuring the safety of both the participants, in this case, the rangatahi and their whānau, as well as myself. Hudson et al. (2010) stated that ethics is about values and ethical behaviour reflects values held by people at large. For Māori, ethics is also about tikanga, because it reflects our values, beliefs, and the way we view the world.

Te Ara Tika: Guideline for Māori Research Ethics (Hudson et al., 2010) identified four tikanga based principles deemed to be primary ethical principles in relation to research ethics. The principles are Whakapapa, Tika, Manaakitanga, and Mana. These principles identify expectations required by researchers to ensure their research is of an ethical standard, especially working within an indigenous framework. Graham et al. (2013), within the ERIC framework, outlined similar principles around ethical considerations when working with children such as respect, benefit, and justice.

Whakapapa involves kaitiaki, engagement, and consultation (Hudson et al., 2010) where researchers must ensure they clarify and continuously consult with their local community around the kaupapa of the study, thus avoiding harm caused to the participants and their whānau but ensuring their mahi is carried out in a respectful manner. Graham et al. (2013) added that it is important to consider, as

widely as possible, any potential harms and/or benefits for child participants, their families, or wider community groups. Building relationship with the school, whānau and, most importantly, the rangatahi, as participants, occurred by consulting at every aspect of the study and maintaining engagement with everyone involved. Hudson et al. (2010) stated that whakapapa refers to the quality of relationships and the structural processes established to support these relationships within the study.

Tika represents the relationships with Māori and reflects the responsibilities, roles, rights of researchers and Māori communities, along with the relation to Treaty principles of partnership, participation, and protection (Hudson et al., 2010). To maintain tika within this research, it remained a priority to ensure participants were well informed of their consent process and rights within the study to allow for a solidified informed process and that they understand their value within the study. Informed consent was managed through the research by thoroughly going through the information sheets with the rangatahi, having questions asked and answering them at both the first hui and focus group. A round robin of rangatahi discussing their interpretation of what they were signing up to allowed them to have a better understanding of their decision to provide informed consent.

Manaakitanga is a concept that ensures the dignity of both researchers and participants is upheld throughout the study. Hudson et al. (2010) noted that manaakitanga means a traditional sense with a central focus on certifying the mana of both parties are upheld in the context of cultural and social responsibility. Identifying the process of privacy and confidentiality for the rangatahi, as participants within the study, and negotiating this level by factoring in, although minimal, the potential effects disclosures may have, ensured rangatahi continued to be in a key position to guide safety procedures and safety pathways within their school if the circumstances should arise. Confidentiality was managed through the whole process of the research by continuously reinforcing the fact that names would not be shared to anyone beyond the research team (student and supervisors). All transcripts

and references to kōrero gained would only identify rangatahi participants by their acronyms. Their participation within the study was not made “public” within the school or community. It was the rangatahi choice to identify their participation within the research, outside of the focus groups and hui.

Lastly, mana, as the final principle within the framework, addresses issues of power and authority around the identification of rights, roles, and responsibilities regarding the risks, benefits, and outcomes of the project (Hudson et al. 2010). Graham et al. (2013) concurred with the notion of ensuring the dignity and safety of participants are upheld by employing strategies to minimise distress for children participating. I ensured rangatahi were acknowledged and appreciated for the time they gave up in order to participate in the research study by providing them with kai (food) and a koha of a gift voucher each.

Mana was further upheld through acknowledging the mātauranga obtained through the study and sharing these new learnings back to the iwi, hapū, school community, whānau, and rangatahi. The dissemination of findings from the research project is a key aspect of ensuring mana is maintained right until the end of the study through consulting with relevant communities to create an adequate dissemination plan. Graham et al. (2013) included the need to take measures to ensure that harm is not caused to children, families or communities in the dissemination of the research findings. Data, consent forms, and voice recordings were stored in a secured drive on an AUT server that was password protected. Only I was able to access this information, a point reiterated at every hui with the rangatahi. All hard copy documents were stored in a sealed envelope inside a locked cupboard on the AUT south campus.

Many similarities were identified through Te Ara Tika and the ERIC document regarding ethical considerations. Overall, the importance of ethical considerations within any research, but more specifically Kaupapa Māori research, needs to ensure the safety of participants and the researcher in a culturally safe manner whilst upholding the mana throughout.

Rigour

Rigour is paramount in any research to ensure the trustworthiness of the study. Rolfe (2006) stated that rigour is achieved if another trained researcher could analyse the same data in the same way and come to essentially the same conclusions. It is extremely important that within qualitative research rigour is upheld in a manner that will support future researchers to carry out the same process in a way that is trustworthy. Rigour was achieved using a Kaupapa Māori framework from Te Ara Tika (Hudson et al., 2010) to ensure Kaupapa Māori standards guided the process. This was done through the following headings:

Mana – Justice & Equity

Data gained remains under the ownership of rangatahi and it is important to ensure the dissemination process is conducted in a culturally safe manner. Hudson et al. (2010) highlighted the need to acknowledge the guardianship responsibilities in relation to the protection and dissemination of information from the research project. Therefore, to achieve rigour through the dissemination phase, as the researcher I was continuously aware that the taonga of the rangatahi views received would be presented in forums that improve the development of rangatahi.

Tika – Research Design

Within the research design, rigour was achieved by ensuring every aspect and consultation on the design of the research was carried out by Māori, with Māori, and for Māori. Hudson et al. (2010) added

the use of a kaupapa Māori framework to develop research that is designed by, conducted by, made up of, and benefits Māori.

Manaakitanga – Cultural and Social Responsibility

It is extremely important to ensure rigour within the study, not only because I was working with a young population, but, due to the research being Kaupapa Māori, it was imperative to remain tika and culturally safe throughout. Cram (1997) explained that researchers are not building up their own status; they are indeed fighting for the improvement of their iwi and for Māori people in general. Within this study, rigour was obtained by ensuring the questions asked would allow rangatahi to reflect directly on their experiences within previous research studies and draw on what they believed would create a better practice for future informed consent processes. This was confirmed by the rangatahi when they all discussed the importance to enhance the mana of themselves and their peers, while acknowledging their happiness at being listened to about matters and aspects that apply to them.

Whakapapa - Relationships

I ensured rangatahi had the opportunity to review all the transcripts from the focus groups. All focus groups were recorded and transcribed by myself, which allowed for a deeper understanding of the data and themes derived. Transcripts were checked and given back to the rangatahi to re-confirm that what was discussed in the focus groups was correct; for example, “This is what you've told me, have I got it right?” This process was pivotal to the outcomes of the research to ensure that the information provided by the rangatahi were in fact their actual views, and not necessarily my own interpretation. In ensuring I achieved rigour of the research by providing the opportunity for the rangatahi participants to review the transcripts further entrenched tikanga and avoided any mamae (hurt).

Reflexivity

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions (Malterud, 2001, pp. 483-484).

Reflexivity is a key element within research that ultimately relates to the level of impact the researcher intentionally or unintentionally employs. Jootun, McGhee, and Marland (2009) discussed reflexivity as one of the pillars of critical qualitative research that relates to the degree of influence the researcher exerts, either intentionally or unintentionally, on the findings. It was important for me, as the researcher, to ensure I did not influence the findings but continued to *manaaki ki ngā tangata* (looking after the rangatahi) and *kia tūupato* (remaining cautious) (Cram, 2009). I remained cautious of my position within the research study and reflected on the findings in a manner that would not influence the themes and subthemes identified. Primeau (2003) states that reflexivity increases the research quality because of its capacity to strengthen our understanding of how researcher positions impact the varying stages of research. It is extremely important to stay mindful through the process of this research and acknowledge the position held within the study through a Kaupapa Māori viewpoint of *kia māhaki* (Cram, 2009); remaining humble about the findings of the data. This references the idea that publications and dissemination of the data acknowledges the rangatahi and school community from which data were collected.

Insider research is a key component when discussing reflexivity as it promotes and generates a greater connection to all avenues of data collection. I was able to *whakapapa* to the *kawa* (customs) of the school, as their *marae* takes lead from the Waikato–Tainui *tikanga* and the fact that I, too, am a Māori descendant created a form of *whakawhanaungatanga* between the participants and the researcher. Being an insider researcher placed an onus on me, the primary researcher, to remain *tika* about what I was doing and the impact the research had on the rangatahi. Tuhiwai Smith (1999) acknowledged an

insider researcher as those researchers who are connected at a close whakapapa level with those with whom they are doing the research.

Assumptions I brought to the research was the understanding of giving consent towards research and the idea that rangatahi would have prior knowledge of an informed consent process. During data collection, these assumptions were managed by seeking clarification of the rangatahi understandings regarding the mentioned terms and re-asking the questions to ensure they were rangatahi driven. I managed my insider status by ensuring my role as facilitator remained professional, building a rapport with the participants through cultural connections and ensuring they felt comfortable to be present in the focus groups. This was done by reassuring the rangatahi that they were in control of the focus group and their ideas, and respect was to be upheld by all members in the room (participants and facilitator).

Summary

This chapter has provided insight into the use of a Kaupapa Māori research methodology using a qualitative research design. It is increasingly important to privilege the kōrero of rangatahi Māori and ensure tikanga is upheld even more so in a kaupapa Māori research. The participant's criteria were outlined explicitly to detail the inclusion and exclusion information for potential participants; thereby ensuring all participants involved in the research were able to draw on previous experiences of informed consent processes. Along with ensuring there were rangatahi with a variety of age and year levels within the focus group to allow for a broad range of age groups to be represented.

Data were analysed using a thematic analysis method allowing key themes and subthemes to be directly derived from the data gained through the focus group. The inductive approach allowed rangatahi views to determine the themes and ruled out any potential for pre-determined themes held by the researcher. The Community-Up research values and principles were adopted within this study to ensure culturally safe and ethical research was maintained through every aspect. These principles

and values also ensured the research remained robust, trustworthy, and reflexive. From the approach taken throughout this research study, rangatahi were provided with a safe environment that was familiar to them where they could discuss and relay their views of ethics and the informed consent process.

Titiro whakamuri; hoki whakamua

We are the future, the past and the present.

(Cited in Ritchie, Duhn, Rau, & Craw, 2010, p. 45)

Wāhanga Tuawha: Findings

He taonga rongonui te aroha ki te tangata

Goodwill towards others is a precious treasure

Kingi Potatau Te Wherowhero (cited in Woodward, 2018)

Introduction

This chapter presents the findings from a focus group held with seven rangatahi aged between 13 and 17 years of age at a secondary school in Tāmaki Makaurau. The rangatahi were asked a series of prompt questions about the informed consent process to generate discussions about their perceptions of the kaupapa. The subsequent themes have been generated from the data provided by the focus group. The rangatahi discussions have provided multiple pages of information regarding the informed consent process and what they believe is an effective strategy.

The process undertaken to generate the themes and subthemes was to first analyse the transcripts multiple times to ensure I had a clear and strong understanding of the responses rangatahi gave. An inductive approach was used to guarantee the themes emerged directly from the data, rather than having pre-determined themes. Analysing the data, two overall themes and five sub-themes emerged (Figure 4.1, p. 60):

1. *Varying understandings of consent. Sub-themes: permission versus consent, making informed decisions and enabling the process*
2. *Difficult decisions about not participating in research. Sub-themes: feelings deter withdrawal and restating the right to withdrawal.*

These themes are discussed in this chapter and are supported by selected quotes from the rangatahi to ensure their voices are consistently privileged. Each theme is represented and discussed, including

the subthemes. The subthemes interconnect with the overarching theme as they shed light on the various interpretations the participants had on consent and how these all work together to show a mixed understanding.

Table 4.1. Themes and Sub-themes

THEME: VARYING UNDERSTANDINGS OF CONSENT	THEME: DIFFICULT DECISIONS ABOUT NOT PARTICIPATING IN RESEARCH
Sub-Themes	Sub-Themes
Permission versus consent	Feelings deter withdrawal
Making informed decisions	Restating the right to withdrawal
Enabling the process	
- Researcher role is important or enabling the process is important	

Varying Understandings of Consent

A consistent theme was the varying understandings rangatahi had about consent. Rangatahi had their own interpretations about consent, the terminology they used, and views they held. Consent and assent underpin the kaupapa of this research study. When asked about their understanding of the term consent, two of the seven rangatahi did not understand the term at any level, three were able to discuss their own views of the term consent, while the last two remained unsure and opted to hear conversations from their peers.

“Nah, I don’t know what consent means, aye – just being honest.” NGT16

“Yeah, like having our permission for something.” NGK16

Overall there were mixed responses and understandings from these rangatahi regarding the use of the term consent; however, a common word used was permission. The following subthemes of

permission versus consent, making informed decisions, and enabling the process were identified within the data that further elaborate on this theme.

Permission versus Consent

“Permission” was the term rangatahi preferred to use. This seemed to be a better fit for the rangatahi than the term consent, as they were more confident and comfortable talking about permission over consent. The discussion helped the other rangatahi who did not really know what was meant by consent to gain an interpretation of the meaning. This was a strong aspect that needs to be acknowledged as often the rangatahi have preference for words with which they are more familiar. It is important to recognise that the use of permission is used regularly throughout this chapter.

“Consent to me means permission.” TTT16

“Yeah, permission.” NGT17

“That [consent] means you’re giving them your permission.” WHT13

The rangatahi who did not understand what was meant by the term consent requested an explanation to help them clarify their understandings. Explanations were provided by other members of the focus group who were happy to put into context their views of consent. Peers providing an explanation in a rangatahi friendly context resulted in a definition that was applicable to their age range.

“...yeah, like having our permission for something. And it can come in many forms like a survey or like a contract.” NGK16

Upon gaining a better understanding of consent, in a way that the rangatahi could affiliate with, it was clear that there is a stronger need to use terminology familiar to them. From this key finding, further discussions were had amongst the rangatahi who did not understand consent. This was then followed up by the idea of not being able to give informed consent if you did not have a clear understanding of what consent meant. It was very striking and an important area to pursue, as further commented on

by a participant who simply referred to the fact that you cannot give something if you do not really understand what it is that you are giving.

“You can’t give it if you don’t know what it means.” NGT16

For rangatahi, consent is a process of giving permission by which one can understand the information so that they can provide their agreement towards a kaupapa.

“That means you’re giving them your permission to do what they want and what you want with them.” WHT13

In aligning the rangatahi views of consent, discussion about not giving consent revealed some unique insights into what this term meant to them. The general response regarding what rangatahi knew about non-consent most commonly included, but was not limited to, non-consent being the opposite of consent.

“Not giving permission. It’s like the opposite.” TTT16

Other understandings showed that non-consent was about being able to freely participate or not participate within a research study. This included a common phrase raised by two rangatahi about freedom of choice and the ability to decide what they would want to be a part of.

“It’s like freely doing it within your own choice.” NGK16

“Yeah, just doing it like... free willing.” NGT16

Although there were various understandings held by rangatahi around non-consent, the common consensus was that not consenting to research meant the rangatahi were able to remain in control over their decisions.

Making Informed Decisions

Making informed decisions involves rangatahi being empowered and informed throughout the research process and provided with the opportunity to participate freely. Relinquishing of power was important to explore and rangatahi were asked for their opinions of under 16-year olds requiring an assent form along with a whānau consent form. This included exploring the role rangatahi believed whānau consent played. As most participants were over the age of 16 years, they were given a whānau/parent/caregiver consent form to be signed if they desired. However, as it was not a requirement the rangatahi voiced they would not do this. Most participants agreed that a consent form from rangatahi themselves was valid enough. However, there were circumstances where rangatahi voiced wanting to have whānau input, such as potentially harmful situations, circumstances related to sexual health, and medical procedures or visits.

“Maybe [research that is] highly sexual or something. It could need like a bit more parental consent.”

NGT16

“... or harmful ...” TTT16

Rangatahi had mixed views about the use of assent forms.

“We can do it [providing consent] ourselves.” NGT16

“... like if you wanted to join so bad but then your mum or dad didn’t want you to join then you’ll feel like disappointed that you’re too young to sign it by yourself.” WHT13

Another situation where rangatahi saw the use of an assent form and signed whānau consent was needed was dependent on an individual’s capability to provide informed consent. In such situations, rangatahi believed the use of assent forms would be required on a case by case basis dependent on potential risks or harm that could occur.

Participants strongly objected to the idea of rangatahi under 16 years old, requiring assent forms signed by whānau. Collectively rangatahi viewed these extra forms as prohibiting their participation in research directly applicable to them. The assent process was also seen to silence the voices of

rangatahi who might otherwise have strong opinions on a particular topic. Rangatahi believed the assent process and their non-participation in research ultimately impacts on the overall outcome of the research.

“I wouldn’t be worried about it, just put it out of the way because something if it is something, I have to approach my mum and dad about, tell them about what it is and get them to sign it as a young’un I’d just chuck it in the bin outside class.” NGT16

The “hassle” of having forms signed by whānau hindered the rangatahi participation within research – despite considerable interest in the kaupapa as it is viewed in a way that generates more work for them. Thus, resulting in the disposal of forms and not giving the research a second thought.

Rangatahi talked candidly about the various reasons behind their independent choices to consent toward a research study and what would prevent them from participating. The following korero offers insight into the complex influences rangatahi are faced with when making decisions.

“Yeah, and like another example when you tell someone they can like mock you for it. If they don’t understand your culture so they just make a joke out of it... and they’ll make you feel like you don’t want to do it because they don’t want you, coz like when you want to follow someone. Yeah when you’re just being a follower.” TTT16

“... [they] take advantage of you.” NGT16

“or just laugh at you.” WHT13

“Just like no one like, no one in my family takes it seriously anymore. And like they just look past it especially because like all my family is old and like not really worried about it at the time.”NGT16

An empowering aspect for rangatahi was their ability to kōrero with friends and whānau prior to consenting to research. Kōrero amongst peers, whānau, and other support people was an essential process for the rangatahi. It allowed them to confirm their participation within research and access the help of others to come to a decision.

Talking to siblings and educating them around the consent process or what is required from them for research purposes was important for one participant. It helped him to ensure his siblings would be fully informed and understood the study in a way that applies to them.

“... just help them understand it [the research] more before they give permission.” NGT17

For the rangatahi, talking with friends who had the same interests also helped with their decisions to participate as it allowed them to have discussions prior to the research being undertaken.

“Yeah, just decide by myself, [and] just talk to mates that are interested in the same thing.” TTT16

“[It is helpful talking with others], especially with people you trust.” TTT16

Peer pressure can play a major part in rangatahi decision making, therefore it was important to talk with someone they trust. This reduced the chances of rangatahi being mocked, criticised, not being taken seriously, being called a follower or shamed for partaking in an area that interests them.

Consultation with whānau and having them present at a research information hui was not an option for most of the participants. Rangatahi spoke openly about complex whānau situations – meaning a research hui would not be a priority and the simple fact that rangatahi would prefer to keep school based mahi at school. Only one rangatahi said they have had experience of a whānau member (mother) attend a whānau hui, which she did not find helpful because she just supported what the rangatahi wanted and did not provide further advice.

“... not really because it went on her [whānau member] supporting my choice of why I wanted to do it [participate in research], and her just being there getting the extra support and like umm agreeing with what I wanted to do.” NGK16

On the other hand, rangatahi added if whānau consent was required for extracurricular activities then the rangatahi views changed and they strongly encouraged whānau attendance and signing forms.

“... for sports, I'll do like anything [to encourage whanau], aye.” NGT16

Rangatahi expressed events where they would want their whānau to attend a hui and these included anything related to their sexual health or medical conditions (general or specialised). These activities were deemed by rangatahi as being something “big”.

The reasons for rangatahi not involving their whānau differed significantly (Table 4.2) and included the fact that according to the rangatahi participants, the whānau would not care about the research or they would not understand. Other reasons included the “unnecessary” effort required from the rangatahi to try and explain their choice to participate in research and what it would entail. Therefore, the significance of whānau involvement was seen to be minimal and not an important factor for the rangatahi.

Table 4.2. Inclusion and Exclusion of Whānau

Inclusion	Exclusion
Mothers would care	Would not care about the research
Ask questions to determine any risks	Would not understand
	Unnecessary effort for rangatahi
	Rangatahi having to explain their choices to consent

Most rangatahi have not had any whānau input throughout their participation within research. The discussion led to questions of wondering if whānau would care. Four rangatahi instantly said their whānau usually did not care, and they just simply would not understand. Although two rangatahi stated their parents (usually mothers) would care and ask some probing questions to determine any risks or implications that could arise for their children.

“... mine will, but they’ll probably ask like how it will impact on my [decision], on what I want to do.”

NGK16

“My mum would ask, ‘What’s the research about?’, and everything.” TRK17

“... to be honest my family wouldn’t even care.” NGT16

“... [my whānau would be] just be like, ‘Oh yeah, that’s good.’” NGT16

The flipside to consultation with whānau was making sole decisions. Several rangatahi indicated that consultation was not for them as they preferred to make their own individual decisions. It is important to highlight that even though it seemed like a common practice for the rangatahi to consult with others, there were also aspects that would prevent rangatahi from talking with their peers and parents.

Making an informed consent decision to participate in a study has a bearing on the rigour, validity and trustworthiness of the study. Therefore, it was extremely important for rangatahi that they were able to make an informed decision through verbal and written information. This next section presents the rangatahi views and understandings of the information that was provided to them, along with how it contributed toward them being able to make an informed decision. It included what they received from promotion of the research within their school, the discussions they had with teachers or school liaisons people who worked collaboratively with the researcher, and finally the actual research information sheets and consent forms.

Rangatahi talked about the helpfulness of information sheets and consent forms, and whether these were a guiding tool in their decisions to consent in research studies. The majority of the rangatahi said the information they were provided with helped considerably, although they only read a portion of the information sheets, not all of it. Thus, the likelihood to consider all aspects the information contained within an information sheet was low.

“... part of it, like first two paragraphs, I’m being honest.” NGT16

To be effective, rangatahi claimed it was important to get the information across without lengthy paragraphs. Rangatahi generally agreed that having shortened versions of the information sheet would capture their attention and inform them better. However, two participants identified that information did not help, and they generally chose to participate in research as an independent choice that required no further discussion about the research.

Aspects of the research information provided helps support rangatahi understanding and decision-making to consent. Knowing the research was kaupapa Māori and targeted at rangatahi facilitated their decisions to consent to participate in research. Most rangatahi based their decision to consent on wanting to learn more about a culture they identified with but were not strongly involved with. My research provided an opportunity for them to become more involved in research aimed at rangatahi and included tikanga Māori.

“I think for me, it’s just like not knowing when something like, like, something like Māori, [being] familiar with my Māori side. Oh, I’m familiar with it a little bit, but not as much as I want to be.”

NGT16

The familiarisation with their culture was a strong deciding factor for rangatahi to participate in research as they commonly made reference to lost connections and missing pieces to the puzzle about knowing their culture.

“... just want to learn more about the Māori culture.” NTT17

“... the missing piece of the puzzle.” WHT13

Enabling the Process

The *enabling process* is the subtheme that describes rangatahi views about how research can promote a process of enablement for them. All the rangatahi expressed a desire to be provided with opportunities to consent or non-consent to participate in research, regardless of their ages. The implications of having to provide a signed parental consent form along with a rangatahi assent form negatively affected rangatahi participation. When asked if they would have had to provide a signed parental/whānau consent form would they participate, half the rangatahi indicated they would not have participated in the focus group for a number of reasons outlined below. Rangatahi also expressed their feelings towards getting a whānau signed consent form as being a restrictive process which does not create an enabling environment or process for them; rather acts as more of a restriction.

“Like if you wanted to join so bad, but then your mum or dad didn’t want you to join then you’ll feel like disappointed that you’re too young to sign it by yourself.” WHT13

Having to provide an assent form created more work for the rangatahi on top of an already busy schedule. Requiring rangatahi to obtain whānau consent placed pressure on them and had adverse effects on their participation in research they were interested in or passionate about. This potentially affected the outcome of the research because the ages and experiences of participants would not be necessarily diverse, skewing and limiting the information captured.

“... worrying about it [the signed consent form from whānau] that it’s not going to be done.” TTT16

“We want to like... actually want to learn about these types of things. And come into it like we want to attend these types of stuff.” NGT16

“I wouldn’t be like just not worried about it [participating]... I have to go and approach my mum and dad about [the research] and tell them about what it is and get them to sign it.” NGT16

Another strong view often raised by the rangatahi, in supporting all ages in high schools being able to consent, was the notion of being involved in research that relates to Māori. Rangatahi agreed cultural research was highly desirable because it promoted a connection back to their culture.

“Yeah, coz its good. Coz its cultural stuff. It’s your lost ... connection” - TTT16

Filling the void and reconnecting the rangatahi back to tikanga aspects of their heritage proved to be a deeply spiritual part of rangatahi decisions to consent and another crucial aspect for enabling rangatahi.

Participants expressed their desire to be more connected to and involved in Māori research and support researchers of the same culture. Whilst there was a slight reference towards the research topic impacting on rangatahi choices to consent, what resonated more with rangatahi was the importance of supporting the success of Māori.

“So yeah, when I hear like the research is coming, like the research is just to help out your fellow Māori do what they’re trying to do in their life.” NGT16

Bringing the rangatahi together in a platform where their tikanga and culture are identified and valued throughout the entire process created a sense of unity for them. This is important for connecting everyone and remediating their lost connections.

“It could also be more on the supporting hand, like how you’re Māori and we’re Māori and like bringing it all together.” NGK16

Supporting the development and success of fellow Māori proved to be influential in the rangatahi decisions to consent to research. This was because it provided them with the ability to be a poignant voice within an area that would benefit their people. It also provided rangatahi with a sense of

achievement. They felt they were helping a kaupapa that meant all Māori were climbing a ladder toward success and reducing previously-held stigmas.

“Yeah, how we can develop more to success, looking in the future.” (NGT16)

“We’re climbing up the ladder.” WHT13

The enabling process is crucial for achieving research that uplifts and seeks to understand and promote the views of rangatahi as we conduct research with them through their stage of life. Research that allows space and opportunity for the voices of rangatahi to be gathered and presented is regarded as enabling. It is, therefore, crucial to understand how important the researcher role is for rangatahi in supporting the enabling process.

The researcher, being a known face, is especially important for engaging with rangatahi. Rangatahi felt very passionate about the researcher being a face that was known and indicated that this strongly influenced their feedback during the interviews and focus groups. Meeting with the researcher prior to consenting toward research was a crucial step for rangatahi. This first step helped to ‘break the ice’ between the researcher or research team and rangatahi and provided an avenue for developing comfort and trust. It also helped rangatahi to know who they were going to talk to by creating a connection with the researcher early. Rangatahi all agreed this helped them with their choices to participate in research.

“Yup, because that’ll umm like take the first step when being confident and when giving answers.”

NGK16

“So, because we met you two or more weeks ago, we were like we’re familiar with you and what you’re doing, so it’ll increase what we say and how we say it.” NGK16

“... and we can trust them.” WHT13

“Yeah, it’s like the icebreaker.” TTT16

Prior engagement with the researcher further supported rangatahi sense of confidence when responding to questions during data collection. This process conveyed to rangatahi that their kōrero was valued and that they could influence future outcomes for their peers.

Establishing a relationship with the researcher also contributed to rangatahi abilities to withdraw at any point of the research.

“Actually, I reckon like in this research it’s like it’s like comfortable like. I’d be comfortable leaving because you gave us like that um that warning, like yeah, you can leave if you want to leave during any of this process.” NGT16

Rangatahi indicated being comfortable with a researcher, with whom they had a prior connection, decreased the likelihood of feeling pressured to stay in a study if they experienced discomfort. This sense of a collective obligation, similar to conformity, where rangatahi did not want to let the researcher down was stronger when rangatahi did not know the researcher and felt uncomfortable withdrawing. They indicated that as a consequence, their responses and interactions within a study were adversely affected as they would not partake in discussions or provide minimal input.

“Yeah, it can kind of differ with how well you know the researcher or what the study is about. So that depends on how you or like see the outcome of it and if you want to be a part of it, the outcome or... just leave.” NGK16

The use of accurate information about the research, becoming a trusted person prior to the research data being collected, and ensuring the rangatahi are able to connect with the researcher were all integral aspects identified for creating a more comfortable research experience for rangatahi and improving the responses around the kaupapa of the research study.

The theme of *varying understandings of consent* along with the identified subthemes provides insights and understanding of the rangatahi participating in this research about their mindsets around consent and how it can impact their decisions to partake in research. A key finding within the sub-theme *enabling the process* is the need for information provided to rangatahi to be short and concise, whilst containing the most relevant points. This will optimise the likelihood of rangatahi reading the information provided, and helps to further inform their decision of being a research participant. It is important to acknowledge specific language (for instance, permission) rangatahi prefer to use rather than the word consent. Using familiar terminology gives rangatahi a sense of empowerment and connection with a research kaupapa. This section also highlighted rangatahi views around consulting with friends and whānau, and how this could be approached.

Difficult decisions about not participating in research

Difficult decisions about not participating in research was identified by the rangatahi and highlighted how much this can impact on their participation within research as well as their responses within the kōrero. Withdrawal from research was uncomfortable for rangatahi, even if they wanted to leave. Having to deal with the awkwardness they felt about the thought of leaving affected their decisions and, at times, influenced their participation in answering questions asked by researchers. *Difficult decisions about not participating in research* comprises the following subthemes:

- Feelings deter withdrawal
- Restating the right to withdrawal.

Feelings deter withdrawal

Feelings deter withdrawal influences rangatahi comfort levels and subsequent decisions to stay in a study or withdraw, dependent upon their confidence levels. Nevertheless, rangatahi *feeling committed to the kaupapa* was mixed, ranging from some feeling committed to the research even if they were not comfortable with what the research entailed to those who were not. These feelings of

being committed, no matter what, prevented some rangatahi from withdrawing from research. On the other hand, others commented on their ability to feel sufficiently confident to withdraw from research. All rangatahi agreed if they decided to leave a study they would do so at the beginning, rather than at some other point in the research. This prevented any awkwardness and allowed them to feel confident in their decision.

“I don’t think I have like left in between a study it’ll most probably be in the beginning or just stay throughout.” NGK16

Leaving at the beginning of research or not showing up at all was the better option put forward by the rangatahi, because it meant they did not have to feel like they were letting the researcher down. The notion of feeling committed to the research despite not wanting to participate is an issue for most of the rangatahi.

“... yeah, hard. I feel uncomfortable because you’ve already like gave them your commitment and like told them that you’re going to be there. Even though I’ve done it like heaps of times it is still like ... yeah... it’s still like it’s not good ...” NGT16

Feeling comfortable during the entire study, helped affirm for rangatahi that they were in control.

Restating the right to withdrawal

Restating the right to withdrawal was an important area for rangatahi who were passionate about individual choice and not feeling forced into consenting to a research study. Two rangatahi discussed they have felt pressured or coerced into participating in research in the past. They felt they had no choice, felt uncomfortable participating, and felt bad about saying no. The coercion to participate and the pressure placed on them caused a significant amount of stress.

“They [organisation] kept on asking me to join [the research], and when I kept on saying no, they umm really wanted me to join since I was the only Māori at my school”. WHT13

“... I don’t know like... like, I just can’t say no, I just have to say yes.” TRK17

Rangatahi were very comfortable and open discussing their experiences of pressure. They experienced mixed feelings and emotions around the notion of being pressured into research, especially because they were Māori. Consequently, they had an inability to say no or felt they were placed in situations where they could not say no.

The remaining five rangatahi did not feel any pressure at all to participate in research. If they experienced pressure to participate in the past, they would feel empowered to hold their ground and do what felt right for them. These rangatahi identified that their participation was voluntary and at their own discretion, without prejudice. One rangatahi was very confident, acknowledging his current school was supportive of their decisions to partake in research and did not place pressure on them.

“I felt like in this school here we don’t feel pressured at all. Don’t, don’t have like that weight on our shoulders like other schools or other people might put on you.” NGT16

There was a clear agreement amongst the group that their school participated in a variety of government based and academic based research. Most rangatahi agreed that the school encouraged rangatahi to have a fair understanding of the research, made information available to make informed decisions based on their own judgments. This was also evident through the entire recruitment process from engagement with the school through to the data collection with rangatahi.

Conclusion

In this chapter I have presented the findings from focus groups discussions with seven rangatahi aged 13 to 17 years at a secondary school in Tāmaki Makaurau. The following themes emerged from the focus group, all of which were discussed in-depth along with each of the subthemes that were encapsulated within each broader theme:

1. *Varying understandings of consent* and its sub-themes *permission versus consent* and *not giving consent*
2. *Difficult decisions about not participating in research* and its sub-themes *feelings deter withdrawal* and *restating the right to withdrawal*.

Thematic analysis enabled not undermining or downplaying what rangatahi shared and prioritised their input for the research kaupapa. Understanding rangatahi views of consent and identifying the term they preferred to use, other than consent, was an important finding. Rangatahi can have stronger understanding and exert their autonomy by ensuring they have information in amounts and forms they can use, optimising their participation in research. The findings highlight the importance of the researcher in promoting empowerment and autonomy of rangatahi, and reinforce why the rangatahi believe the researcher plays a significant part in their participation in, and contribution to, a study.

Poipoia te kakano kia puāwai

Without foresight or vision, the people will be lost

(Cited in Massey University, 2018)

Wāhanga Tuarima: Discussion

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly: if you bow your head, let it be to a lofty mountain

(cited in Woodward Māori, 2018)

Introduction

One of the most powerful findings that shone through the research conducted with the seven rangatahi at a secondary school was they had individual voices that needed to be acknowledged. Having the opportunity to reflect on their own experiences and discuss these with their peers allowed the rangatahi to be more comfortable and confident to consent for their participation in the focus group.

The rangatahi in this study were very aware of their ability to provide accurate judgements about a situation or kaupapa, and had the confidence to convey their own understandings and viewpoints. Regardless of age, rangatahi in this study believed they were able to provide informed consent about their participation in a research study. The use of a focus group and an array of indicative questions allowed for full participation and discussion from group members. A focus group enabled the rangatahi to take control, draw on their previous experiences and what was important to them, rather than being directed by the researcher. Cram (2018a) explained that in focus groups the researcher is able to take a step back and use tools that encourage the participants to engage with one another directly as they draw on their experiences.

Rangatahi in the study tended to shift their mindset between acknowledging their own experiences and views, to thinking about what the implications could be for their fellow peers. All of which was important to capture and is of interest as it allows for their perceptions and experience of the informed consent process to be valued.

This chapter discusses key findings from the focus group, while ensuring the rangatahi voices are at the forefront and acknowledges them as the experts in their lives. This discussion will refer to the literature in developing a deeper understanding of the informed consent process for rangatahi aged 13-17 years in Aotearoa, and how this process can be tailored to strengthen the consent process.

In this chapter, I will discuss key findings that emerged from this study with reference to the existing literature, including Kaupapa Māori research ethics, consent and assent, informed consent, and ethical research involving children and young people. The findings will be positioned within previous research, showing insights into how the views of rangatahi could transform the kaupapa of informed consent and ethical research within this population.

Assent and Consent within a Kaupapa Māori Research Involving Rangatahi

The issues of obtaining assent or consent from rangatahi have proven to be a very mixed process. Literature (Cram & Kennedy, 2010; Graham et al., 2013; Hudson et al., 2010) regarding assent and consent shows conflicting opinions and ideas. Thus, to understand rangatahi views on the assent and consent processes, it was important to ask them directly. I knew that the direct approach and kōrero with rangatahi would prove more beneficial as I was able to get a better grasp on the context of their views and how these can be applied toward the overall recommendations.

Santelli et al. (2017) explained there is still significant contention around young people's ability to give consent which tends to exclude them from research. This is currently a significant issue that is faced with research involving rangatahi (Graham et al., 2013; Santelli et al., 2017). Within this study, assent forms used as a requirement from the ethics committee actually excluded a large proportion of our rangatahi and silenced their voices. Assent forms and the requirement for parental consent, for some rangatahi, was talked about significantly within the focus group as rangatahi had strong feelings about having an equal approach and the need for more voices to be heard from various ages. It was clear

when discussing the assent and consent debate that there was only one junior student and the rest were senior students. Not only do the assent criteria cause exclusion, it also creates more harm to our rangatahi as their voices are not being heard because significant barriers are in place. The United Nations (1989) discussed in Article Five of the UNCRC, the importance of understanding the evolving capacities of children and the development of their own personal views and expressions. Lansdown (2005) stated all children are capable of expressing a view whether it be through emotions, drawing painting or signing, and are entitled to express their views and to have them taken into account, thus exercising their evolving capacities.

This idea of respecting the evolving capacities of rangatahi is important to understand as it provides a basis for understanding their abilities and what rangatahi might be comfortable or willing to consent to on their own accord. This minimises any coercion from peers, the school, research community, and wider whānau as the rangatahi have the power to consult with whomever they feel confident to talk with. Rangatahi all spoke about their ability to provide their own consent towards research as they feel with the right information, that is clear and succinct, the age barrier should not affect them. They consent in relation to many other life activities and rangatahi indicated that it is important they be given the opportunity to consent to research that both aims to help rangatahi, and in instances their non-indigenous peers, and supports a strong connection to their culture and development.

Graham et al. (2013) explained that while there are ethical research guidelines outlining criteria to be met, there is a strong viewpoint that each research should be considered individually. Nevertheless, they highlight the importance that the researcher should indeed consider strongly a child or young person's age, capacity to understand the expectations and rights of participating in research. Taking this into account, rangatahi agree research with young people requiring assent forms should be a case by case basis. However, they strongly believed that a significant number of their peers had the ability and knowledge to provide individual consent. Researchers need to ensure they are providing

rangatahi with information that is right for them, effectively explain the appropriate information in a way this is brief yet effectively covers key points and is age appropriate. An example that was provided from the rangatahi was to have information that is no longer than two paragraphs and uses terms that they know, such as permission rather than consent. Alderson (2001) also touched on the notion of young people's rights to provide their own consent and the urgency to recognise participants as subjects and not objects of research. This is further supported from the rangatahi as they were very much aware of their strengths and weaknesses in being able to consent toward a research or, in fact, partake in activities or events within their daily lives. Therefore, it is important not to restrict them but provide further support to empower their knowledge and what they are capable of doing.

Graham et al. (2013) stressed the importance of obtaining consent from children and young people alongside their parents to ensure a research proceeds ethically. This idea was opposed strongly from the rangatahi unless the research involves a high level of risk or is focused on their health, as mentioned earlier, because such an action can jeopardise rangatahi participation with the research. Creating extra work and placing unnecessary pressure on the rangatahi results in the research information being put in the rubbish, as this is seen as more work than it is worth. Rangatahi spoke openly about when they would want to have strong involvement from their wider whānau, and this is included within the findings as well as discussion chapters. Rangatahi were very clear in stating that consent from whānau is not always needed; however, touched on the idea of whānau knowing about the research through information being given out. Cram and Kennedy (2010) furthered the notion of assent being used to gain participation for rangatahi under 16 years, along with the importance of gaining the caregiver's consent, which is again strongly disagreed upon from the rangatahi perspective. There is some degree of confusion as within schools the senior students (Years 11-13) are in fact given the freedom to consent to various events in school such as leadership roles and sporting events, whereas the junior students (Years 9-10) are not. This aspect shows an imbalance in capabilities where the school is concerned, which tends to create a sense of similar thinking across

the board, further highlighting the importance of understanding the rangatahi views and having their voices in a platform where they are likely to be all heard equally. Again, rangatahi stressed that there is a space for whānau to be informed about research, although the need for their consent was not seen to be required, especially in indigenous research studies.

The term assent derives from the North American and international biomedical guidelines as outlined by Graham et al. (2013). This is an interesting point, as rangatahi clearly mentioned the need for whānau consent processes when there are medical related issues, or if they are at risk or in harm. All rangatahi agreed on this point when it was raised as they described feelings of not being confident or understanding the medical jargon that is used. In these situations, rangatahi felt their whānau needed to be a part of the process and advocate for them to avoid any mistreatment or adversity. However, the voices of our rangatahi and what is written in literature indicates more information needs to be provided around the assent and consent argument, both to provide consistency and to ensure there are clear guidelines that allow for a smoother process. There is a need for more Aotearoa, preferably indigenous, based literature to further support tikanga processes around informed consent and highlight the effects assent can have on the overall research as societies change along with world views.

On reflection, the aspects of assent and consent, and the role it plays within an indigenous research, is still very much a work-in-progress. However, we now know that from the rangatahi who participated within this research, it is extremely the important to hear their voices and ensure the research team or ethics committees do not place significant barriers in their way. This not only creates more harm, which Kaupapa Māori researchers pride themselves on avoiding but also silences the voices of such a significant and vulnerable population within our society. We also know that with the right information and making a connection with our rangatahi helps to reduce any harm and proves that we truly value and respect their input towards the kaupapa. The use of assent and consent both have their individual

barriers; however, when assent is resulting in our rangatahi not being able to participate in a research that is particularly important to them, this is when the potential for harm can occur. The aim of using consent is to empower our rangatahi and ensure they are equipped to provide their fully informed consent or non-consent towards a research on their own accord and without any coercion or biases. In saying this, greater consistency is needed along with the ethics committees revising the somewhat intrusive barriers caused by assent. Although being aware that consent is a complex topic to approach with rangatahi under 16 years, and determining their abilities or comprehension, the continuance of assent in lower risk research entrenches the need to build rapport with rangatahi prior to data being collected. Thus, promoting the use of consent over assent.

Informed Consent

Informed Consent Processes

It is important to note that many of the informed consent processes discussed in the literature, such as how consent is obtained and the way in which researchers carried out their informed consent process, are not discussed in-depth (Gallagher et al., 2010; Harvey, 2002). It was, therefore, difficult to gauge what or how the informed consent process was undertaken and if the chosen consent method was beneficial or applicable to the rangatahi understanding their rights and expectations regarding participation in research. However, a key highlight by Harvey (2002) has been the acknowledgment that the informed consent process typically consists of forms that are in accordance with university ethics guidelines. Using pre-determined templates and populating these forms to ensure they are in line with the ethics committee requirements negatively affected the full understanding and comprehension of information for the rangatahi. Rangatahi spoke clearly within the focus group about the use of information sheets and consent forms. In this study the information sheets and consent forms were also created from the ethics guidelines outlined. Rangatahi commented that these tended to be too long and far too wordy, and openly discussed that they

tended to only read a portion of the information sheets, at the most two paragraphs. Despite being able to articulate what was incorporated within, lengthy information sheets discouraged them from reading them fully. Thus, lengthy information sheets can jeopardise rangatahi decision making in multiple ways, such as them not being fully informed prior to discussions or interviews being held, being at risk of consenting to research that they are not entirely comfortable with, and lastly, impeding their contributions and responses to questions being asked. Therefore, rangatahi suggested having information sheets that are tailored to their needs in a shortened form that highlights key points.

McClintock et al. (2013) identified traditional pōwhiri processes of engagement as an important process for informed consent, which enabled their informed consent process to be a well informed and unified method. Rangatahi in McClintock et al.'s study spoke candidly about traditional pōwhiri processes as it allowed them to get to know the researcher better before carrying out data collection, and helped to fill the missing link to their culture. They continued to converse about how this process helped with the data collection as they were comfortable, which resulted in rangatahi being more willing to share. In contrast, rangatahi in this study identified that a poorly executed informed consent process influenced their comfort with participating in the research, and consequently, the quality of their contribution. Parsons et al. (2016) and Graham et al. (2013) both commented on the importance of co-creation of research information and ensuring the appropriateness of the research information that considers aspects such as age, competency and evolving capacities of children and young people.

The informed consent process for *Tōku Reo, Tōku Mana, Tōku Whakāetanga* involved me attending a lunchtime hui at the selected secondary school where the research was discussed in a relaxed kanohi ki te kanohi meeting over kai. This allowed the rangatahi to be in a space that was a tūrangawaewae for them and enhance their mana as the tangata whenua of their school community. Following from this hui, rangatahi were given the opportunity to take the information and consent forms home to their whānau to read and sign if they were under 16 years of age. Then, a date was set for me to return

and continue with the research and data collection. At that point, rangatahi had their signed consent forms completed and handed back into the school, which meant focus group organisation could be carried out. This process proved to be extremely beneficial for the research as it allowed the rangatahi who were genuinely interested in the kaupapa to have autonomy, which promoted self-selection and meant they were comfortable with what the research entailed without any form of coercion. Ensuring the rights of rangatahi as participants in a research study is integral for generating research that is mana enhancing. It also means that through tikanga Māori practices, informed consent becomes a forum where rangatahi can be well informed about the entire research, and they can influence the data collection process to better meet their needs. Thus, ensuring research has their voices at the forefront.

A key finding, albeit a concerning one, from my study, was a sense from rangatahi of having been coerced in previous research. Gallagher et al. (2010) reinforced that consent must be obtained willingly and without coercion. Therefore, hearing from rangatahi that they felt like they could not say no was disheartening and showed how coercion can affect participants, thus causing harm. Powell, Fitzgerald, Taylor, and Graham (2012) claimed that within a school context, participants can feel coerced and the culture of schools is conformity and compliance with adult/authority requests which tend to be compulsory. Alderson and Morrow (2011) stated it is extremely important to avoid coercion, especially when this can result in participants being multiply disadvantaged. Within my research it was pivotal to ensure rangatahi who self-identified and met the criteria were able to take their time to decide on participation without any form of coercion. Thus, ensuring their autonomy was valued.

Overall the informed consent processes that are discussed within literature (Graham et al., 2013; McClintock et al., 2013; Parsons et al., 2016) offer similarities and differences such as engagement processes when conducting research with rangatahi. The need to be fully informed in a manner that

is appropriate to the rangatahi and in terms that they are familiar with is increasingly evident from rangatahi within the focus group and in literature (Graham et al., 2013). As are other aspects, such as co-creation of information with rangatahi and the use of tikanga Māori protocols that further promote connection to culture (Collins, 2006; McClintock et al., 2013). Some variations that were identified from the rangatahi, which are not discussed in a Western protocol, were the importance of knowing your researcher before any data are collected. Being a face that is known is a vital within Kaupapa Māori research and a pivotal way to ensure that positive and ethical engagement with rangatahi is undertaken (Cram, 2017; Tuhiwai Smith, 2012). Ensuring rapport is built between the two parties (that is, rangatahi and researchers), promotes a stronger foundation for the informed consent process and rangatahi input.

Understanding Rangatahi Views of Consent

From the discussions held with rangatahi, it was important to use terminology that they would understand, rather than those pre-determined by adults. Regarding consent, rangatahi opted to use 'permission' which is a more commonly known term amongst this group. Permission for the rangatahi allowed them to provide a deeper understanding of their views around being a research participant and what this meant for them, as the term consent proved to be an uncomfortable or unfamiliar term. Gallagher et al. (2010) explained that consent is a process that is given voluntarily, involving an explicit act of a written or verbal agreement and must be renegotiable to allow participants the ability to withdraw at any time. Similarly, the rangatahi in the focus group understood the idea that consent is where permission is given either in writing or verbally and meant they are happy to participate in a research.

These views held by the rangatahi concur with the literature regarding the meaning of consent. Rangatahi, however, use terms that are age appropriate and commonly used. Hudson et al. (2010) identified the use of verbal consent as being a significant aspect in some Māori settings and the

importance of addressing this factor as a tikanga practice that validated the mana of rangatahi, and Māori as a collective. The understanding that in te ao Māori verbal consent is a common practice was something preferred by rangatahi. In fact, from their understanding, consent can be verbal. This came across as a norm for rangatahi, which was enlightening as it acknowledges the oral traditions of traditions passed from our tūpuna. Collins (2006) posited that people with extensive oral traditions tend to value verbal consent.

Furthermore, Graham et al. (2013) explained consent as being a pillar of research processes that acknowledge ethical considerations and help to promote the dignity of participants. Hudson et al. (2010) agreed with this ideology from a Kaupapa Māori perspective about mana tangata and the autonomous individual. Rangatahi indicated that research participation can be affected by the consent process and they wanted more opportunities to make their own decisions. It is important to understand that added layers, such as the assent process, made participating in a research study problematic for some rangatahi. Assent restricts participation of rangatahi as they become reliant on parental consent, which in turn inhibits rangatahi autonomy. Gibson and Twycross (2007) further added that the use of parental consent for children under 16 years contradicts moves towards upholding children's rights to be involved in decisions. However, ensuring rangatahi are able to make informed decisions promotes their empowerment as individuals who are capable of making informed decisions when provided with the right information.

Ethical Research Involving Rangatahi/Young People

The literature around ethical research involving rangatahi/young people proved to be scarce, and those that were identified are based around a mainstream approach that included children under 18 years old. This notable gap in the literature, along with social marginalisation and social and health inequities that rangatahi experience, is an area that needs further research. This research contributes to forming a beginning understanding of informed consent with rangatahi; however, it is clear that

more needs to be done. Beginning to fill an extensive gap in literature has shown some benefits as the rangatahi were able to begin the foundation of change for their peers and ethical research. Graham et al. (2013) explained that ethical research involving children assists researchers and the wider research community to carry out ethical research in varying contexts. It is important to acknowledge as young people and children are very much involved in multiple contexts; therefore, researchers need to be mindful of this aspect in order to understand where young people are at in their life stages.

United Nations (1989) added that it is of vital importance to ensure a child who can share their own views, be given the right to share their views freely with matters that affect them. This is very much supported by the rangatahi views given within the focus group. The rangatahi felt that not receiving the opportunity or having the right to participate in a research that would potentially affect them, poses a huge disadvantage for rangatahi overall. This research helps to combat these potential disadvantages against rangatahi by ensuring their views are captured in various ways. In order to promote rangatahi voices within the focus group, I used a variety of tools that included:

- questions being asked and answered;
- paper and pen were made available for the rangatahi to write notes and any replies they were not comfortable expressing to the group; and
- round robins.

Such tools ensured everyone was able to have an equal say in a way that was comfortable for them. Rangatahi enjoyed this and expressed it was a valuable way for them to get their views across; and they had a strong sense that their contributions were truly appreciated and would in fact help guide the future informed consent processes. Also central in implementing the rights of rangatahi within research is the social construction formed by rangatahi. Horgan (2017) discussed the notion of children's social construction and the importance of understanding their current status that includes

a strong emphasis on acknowledging rangatahi and their commitments within society, whānau, hapū, and iwi. Understanding and respecting rangatahi in the roles they play within their own social communities is vital. They have first-hand and current knowledge of what applies to them and what would be beneficial for their development. Rangatahi provided a wealth of knowledge toward the kaupapa of the research and helped the researcher to be mindful and understand of where the positioning of their views came from. Through being mindful of the complex situations for rangatahi and what they are involved in socially, although this is a relatively multifaceted factor, proved to be significant.

The literature surrounding ethical research involving rangatahi has shown significant gaps and the need to ensure that consent processes are tailored specifically for indigenous rangatahi. This is strongly supported by the rangatahi themselves as the need to have their voices recorded for their people shows a sense of empowerment. As the literature exploring informed consent is almost non-existent, it is important to understand the effects this has on rangatahi Māori. The need to ensure we, as researchers and community workers, are aware of these gaps and work collaboratively to fill this obvious opening. Horgan (2017) and Uprichard (2008) argued for the need to ensure children can share their experiences and emphasised the importance of their rights to participation. The current study will contribute towards reducing the evidence gaps, whilst remaining ethical with the hope of creating informed research from indigenous rangatahi.

In Kaupapa Māori and mainstream literature, there is a strong recognition of ensuring the research remains ethical by promoting the fact that rangatahi are the experts. These views complement each other significantly, alongside the urge to ensure their views are captured directly without misinterpretation from the adults. Erai et al. (2007) supported this statement acknowledging that the specific needs of young people should be recognised with a strong emphasis on the indigenous youth.

Rangatahi strongly agreed and feel that it is important to understand their needs and how important it is for their diverse contexts to be incorporated within a research setting.

Ethical research with rangatahi goes far beyond ethics applications. Practising culturally responsive research and being aware of the multiple worlds rangatahi are involved in is crucial. It is important for researchers to understand this as it will allow for a more comprehensive understanding of rangatahi lives and how these aspects contribute to the kōrero they provide. As outlined, literature around the ethical research involving rangatahi is minimal; however, the findings of the current study have provided the first step towards addressing the gap. This discussion attempts to touch on what is needed, and clearly shows the desire for further studies to be conducted in order to strengthen the processes carried out with our rangatahi in Aotearoa.

Kaupapa Māori Research Ethics

Kaupapa Māori research ethics played an integral part throughout the entirety of this research, as these were able to support the engagement between the researcher and participants, the data collection, and post-focus group processes. Ethics further ensured all rangatahi participants were protected in every aspect throughout the research. Tuhiwai Smith (1999) and Rameka (2015) both stated that Western research and theory have legitimised colonial practices, which have in fact silenced minority voices through research. Allowing the rangatahi to have their voices heard is very important as it creates a sense of empowerment and allows them to be directly involved in research that may inform a process of change for issues that affect them.

Community Up Process

The community-up process which is underpinned by values (such as, aroha ki te tangata, he kanohi kitea, titiro, whakarongo...kōrero, manaaki ki te tangata, kia tupato, kaula e takahia te mana o te tangata and kia māhaki) played a major role within this study as these values provide effective ways

to engage with communities that are culturally and ethically tika (Cram, 2017; Tuhiwai Smith, 2012). Tuhiwai Smith (2012) and Cram (2017) both explained the community-up process as a means of ensuring best practice for engagement within Māori health research settings. Te Puni Kōkiri (1994) further stated that ethics are about values and ethical behaviours that reflect views held by people. The values described in the community-up process (Cram, 2009; Tuhiwai Smith, 1999) helped ensure the entire research was effectively carried out in a way that respected the rangatahi as participants, the school community and the wider research team. The guidelines effectively supported the nature of the research and further reinforced how important it is to have these types of values as they allow the researcher and participants to generate research that is more personal and relevant to the rangatahi.

Tikanga

A strong sense of tikanga is another significant value that contributes to ethical research in an indigenous setting. Hudson et al. (2010) explained that tikanga is a vital dimension to be upheld in all areas of research as it helps to ensure the responsibilities of researcher and ethics committees are maintained. For researchers, tikanga encourages connection building between researcher and participants through whanaungatanga, knowledge promotion, and reduction of harm. For ethics committees, tikanga educates committee members about the kaitiaki role they play in supporting researchers (Hudson et al., 2010). Incorporating tikanga proved to be highly advantageous in the research planning and collection phase as rangatahi felt this was an important aspect that influenced their participation in the study. The majority of the rangatahi agreed that the tikanga principles and Kaupapa Māori research attracted them because it meant they had a chance to support the progress of their people and allowed them to learn more about various cultural protocols.

Mana Tangata

Mana tangata, another consistent theme throughout Māori and Western literature reinforces the ideas of providing participants with the opportunities to take control or have the freedom to direct aspects of the research. Hudson et al. (2010) explained that mana tangata supports the individual's choices to partake in any aspect of the research. This was also discussed by Harvey (2002) where mana tangata is upheld by providing the participants with the opportunity to contribute ideas about what they would like to happen through the data collection phase. Walker et al. (2006) added autonomy is a key standpoint in Kaupapa Māori research. These aspects were further entrenched in the data collection phase as it was vital to provide the rangatahi room to control how the focus groups ran. Mana tangata was beneficial for and supported by the rangatahi as they had the indicative questions to help begin conversations but were not restricted or limited in their replies. Being able to their express their views at their current stage of life was very important for the rangatahi. Participants were able to speak freely about their views and future expectations of informed consent processes within research and draw on their current reality of being a rangatahi in Aotearoa. These aspects proved to be positive throughout the research and showed how confident they were to take the lead in the focus groups, thus promoting mana tangata. Cram (2017) touched on strengthening relationships with Māori in research as a strong ethical obligation allowing for a more solid and grounded research. This is a key area of discussion amongst any research carried out, more so with Māori and rangatahi as we look deeper into these connections. The strengthening of relationships with rangatahi in the research meant their contributions towards the focus group and overall research came from a place of manaaki and aroha.

Mātauranga

Kaupapa Māori ethics strongly encourages mātauranga through the entirety of the framework and supports the idea of gaining, seeking, and providing knowledge. Hudson et al. (2010) discussed Te Ara Tika as a framework that bases aspects of the principles around mātauranga Māori and the notion of

traditional knowledge. The knowledge gained through this research has been extremely generous and valuable for the development of informed consent processes with rangatahi. The newfound knowledge gained throughout the process of working with the rangatahi participants, showed how important it is to reciprocate the process and share knowledge back to them in a mana enhancing way that ensured a sense of manaakitanga and māhaki. The process of sharing mātauranga between rangatahi (as participants) and the researcher created a sense of empowerment for rangatahi as this group of young people had contributed to developing mātauranga regarding informed consent processes for young people. Dennehy, Cronin, and Arensman (2019) also found within their research that young people valued the opportunity to be involved in a space that discussed a topic of interest and relevance to young people. Knowing that they were not being taken for granted and their abilities to contribute toward the kaupapa enabled mātauranga from the rangatahi to flow out.

Mātauranga is a powerful tool and is used to uphold the views of participants or communities. Cram (1993) expanded on mātauranga as being an avenue that enhances the mana of Māori whilst serving the community overall. Rangatahi strongly advocated this when they discussed the importance of Māori succeeding and how their views could promote change for their peers in a positive way. This acknowledges the importance of furthering the knowledge of those who have contributed to a kaupapa. Mātauranga further addressed the importance of knowledge sharing from participants to researcher and vice versa which works towards creating a practice of reciprocation and empowerment.

Māori research ethics aim to create a safe research environment and minimise harm for Māori. They also provide a useful support domain for researchers and ethics committees; however, minimal understanding held by members of ethics committees can cause a disadvantage and takahia te mana of the researcher, participants involved, and ngā tangata Māori. On the other hand, these same ethics protocols contributed significantly towards engagement between the researcher and participant.

They allowed the rangatahi to have their voices put forward on a platform to contribute directly to processes that affect them, thus improving and reinforcing what works well for their societal group.

Advantages and Limitations of the Study

It is important to acknowledge the advantages and limitations of this study as it promotes growth and identifies further work to be conducted. It is very clear that from the literature review that studies eliciting rangatahi views of the informed consent process are minimal. Although there were some studies that promote “best practice” around consent with children (aged 18 years and younger), it was clear that very few spoke directly with the rangatahi to engage with their views (Harvey, 2002; Ware, 2009) The use of methodologies in those studies tended to minimise the true perceptions of rangatahi and, therefore, might restrict how rangatahi would actually respond to the questions. These can also place a stronger adult perception on the study rather than what is truly elicited from rangatahi.

The rangatahi that participated in this study thoroughly enjoyed the experience of being in a focus group and contributing their views toward a kaupapa that is frequently experienced by the fellow peers. The view of being seen as experts on the informed consent process proved to be an empowering tool for the participants and they were appreciative of their voices actually being heard. Through allowing the rangatahi the ability to respond to the various indicative questions in ways they preferred such as kōrero, writing notes on post-it notes and the round robin process, a full and thorough understanding of their perceptions of both consent and the informed consent process was gained. Within this research, the age range targeted was 13-17 years old, with the aim to have a range of varying secondary school year levels. However, due to the requirement set out from the ethics committee and needing to have both assent forms for under 16-year olds and the consent forms for those over 16 years of age, only one assent form was received from rangatahi and their whānau. This

meant the voices from our rangatahi came from the senior end of the school and an equal approach was not able to be had.

There is the possibility, based on what the participants said, that some of them may not fully understand what they consented to. However, when I met with them over kai, we discussed what the study was about and why we were doing this. In saying this, the use of focus groups where there were seven rangatahi present, can prove a difficult setting to fully gauge how their responses may be skewed to conform to the rest of the group. This is another reason why the responses were able to be oral or written. Like all group interactions, there are always going to be members of the group who conform to others' opinions or have people who are more responsive than others which can result in data being lost. Acocella (2012) explained the importance of having participants in a group where hierarchical positions, education, and cultural levels are not too distant as this can jeopardise the level of participation among those who feel a sense of shame or intimidation. It is important to highlight this concept because it plays a part in the outcomes of the data and is a timely reminder to ensure focus groups remain manageable where each member gets time to vocalise their perspectives.

This is a small study and caution is needed when using the findings beyond the participant group. However, what the study does do is provide valuable insights into rangatahi Māori views of informed consent. This is worth further in-depth research. In some respect, it was evident that rangatahi were finding it difficult to draw on experiences of the informed consent processes they had previously been involved in, as their participation solely involved either signing a piece of paper or, if electronic, clicking a button. This resulted in consent being a minor procedure in their eyes, and something they did not necessarily understand as being an informed consent process, which impeded their ability to discuss their previous experiences. Instead, they were focused on the kaupapa of the research they were involved in at the time.

Conclusion

This chapter has broken down four key themes derived from the literature review and identified subsequent sub-themes that were applicable in order to provide an overall understanding of the entire process. At times, there was a lot of overlapping information that needed to be heard in their unique and often straightforward manner, with the hopes of educating researchers and academics of the processes rangatahi want; for rangatahi, by rangatahi. Discussions had within this chapter include understanding rangatahi views of the informed consent, and how informed consent processes are utilised through literature and within my study. Kaupapa Māori research ethics and ethical research with rangatahi is highlighted strongly to place more insight on informed consent processes with rangatahi. Lastly this chapter highlights the advantages and limitations of the study.

The overall process of this research has been an interesting roller coaster with various obstacles endured throughout the course. However, the need is evident to have more rangatahi voices represented within studies, helping guide future areas of research that may affect them. It is also important to acknowledge the strength it takes for our rangatahi to open up honestly about their expectations for future protocols and how research should be conducted with them.

Whāia te mātauranga hei oranga mō koutou

Seek knowledge for the sake of your wellbeing

(cited in Inspiring Communities, 2018)

Wāhanga Tuaono: Conclusion

Ma Te huruhuru, Ka rere Te manu

Me Whakahoki mai te Mana ki te

Whānau, Hapū, Iwi

Adorn the bird with feathers so it can fly

(cited in Whānau Tahī, 2019)

Introduction

Informed consent has similar meanings across the literature, and these are similarly expressed amongst rangatahi. In a broad context, informed consent is viewed as an agreement that requires participants to be well informed and understand the research study in which they may be taking part (Graham et al., 2013). This research study has presented the rangatahi views on informed consent and the ethical process which is undertaken in research studies. This was of particular interest as the views held by rangatahi in a secondary school in Tamaki Makaurau began the process of ensuring informed consent with this age group are tailored to support them. In concluding this chapter, revisiting the research question and the importance of understanding rangatahi views towards the informed consent process through a Kaupapa Māori research method will be discussed, along with key findings within the thesis, recommendations for future research studies, and concluding comments.

Revisiting the Research

In my research I set out to understand the rangatahi perspectives on the informed consent process through a Kaupapa Māori framework. By working with rangatahi in a secondary school setting, I hoped to gain an array of perspectives from participants amongst all year groups. However, upon carrying out my research I was quickly met with barriers that would impact on the ability to carry out kōrero with rangatahi from all year levels. The timeframe given within the school setting to undertake the

research and the time taken to get ethics approval meant the original target of 7-15 rangatahi and a good mix of year levels was compromised. In the data collection timeframe rangatahi were embarking on extracurricular activities and preparing for exam leave, which impacted on their availability to participate. Also, the need for rangatahi under 16 years old to return a signed consent form from their whānau meant the return rate was significantly low. With only one rangatahi supplying a signed consent form this meant there were minimal perspectives captured from rangatahi who transition to high school and into senior status.

Revisiting the Research Questions

It is important to revisit the research questions identified at the beginning of the study, to ensure the consistency of the research as well as staying true to the haerenga (journey) that was embarked on.

This research has examined the question:

“What are rangatahi perspectives of the informed consent process as a research participant?”

This question was supported with the overall objectives of the research as:

- Guide this process to make it beneficial for rangatahi Māori.
- Understand rangatahi choices in participation within a research study.
- Collaboratively work with rangatahi to ensure their voices are heard within an ethics context.
- Tailor a plan to support the informed consent process specifically with rangatahi.

In my research I covered a range of questions and had a lot of kōrero with rangatahi to attain their perspectives on the informed consent process. I feel I achieved what I set out to accomplish with the research; however, there is still a lot of mahi that needs to be carried out and further research to be undertaken. This will allow for follow-on from my current research with the aim to complement and

add to the current findings to create a succinct plan that will support best practice protocols for an effective, informed consent process for rangatahi in Aotearoa.

Key Points in the Thesis

Qualitative research uses an array of tools that place emphasis on understanding processes. Using Kaupapa Māori research and a qualitative approach allowed rangatahi to share their views in a culturally safe way that enhanced their mana and empowered their position within the research. Research with rangatahi has been highlighted increasingly throughout the study and the term rangatahi has been unpacked thoroughly to provide the readers with a deeper understanding of what it means. The term rangatahi is used within this thesis as Māori young people aged 13-17 years of age.

Consent in Aotearoa is a complex kaupapa as there are various ages at which young people can consent for activities; however, in research, young people under 16 years must provide a consent form from their families. This aspect has been discussed widely throughout the thesis including perspectives rangatahi have around the kaupapa.

Ensuring rangatahi views were captured through an uplifting process allowed the kōrero elicited to provide a forum for beginning positive change amongst ethical research with young people. Cram (2017) highlighted how Kaupapa Māori encourages the move from a discourse in health research that places Māori in more harm and attempts to understand the lived realities of Māori along with the various determinants that impact them; thus, moving toward a strengths-based approach that increases the overall wellbeing of Māori. Kaupapa Māori research values, defined by Cram (2009) and Tuhiwai Smith (1999), have been used to support engagement with rangatahi and school communities throughout the entire research. This ensured the research was culturally safe and enhanced mana tangata, reduced harm for participants, held myself as the researcher accountable and created research that is tūturu to the kaupapa. Rangatahi consent and assent (for participants under 16 years

old) was sought from the participants within the research. Assent was a requirement set out by the ethics committee, which also required a signed whānau consent form.

Data were analysed using an inductive approach to thematic analysis which ensured all themes identified came directly from the data collected. All recordings were transcribed by me to allow a stronger grasp and understanding of the data collected. Having a deeper understanding of the data and the themes privileged the voices of rangatahi.

Findings have been displayed under two broad themes with associated subthemes. Each theme has been identified, described and supported by quotes direct from rangatahi participants. The following themes were identified and discussed:

1. *Varying understandings of consent. Sub-themes: permission versus consent, making informed decisions and enabling the process*
2. *Difficult decisions about not participating in research and its sub-themes feelings deter withdrawal and restating the right to withdrawal.*

Overall, from the research conducted with the rangatahi, one of the key points highlighted has been the need for rangatahi to have their own individual voice and be acknowledged in a forum that addresses issues directly affecting them.

Māori Ethics Frameworks

Māori ethical frameworks are a tool that supports the engagement of the ethics process for ethics committees and researchers, thus ensuring the roles of kaitiakitanga are sustained. Hudson et al. (2010) stated that Te Ara Tika is based on four principles that support culturally safe and ethical

research to reduce any harm toward participants, communities, and the researcher. Whilst frameworks, such as Te Ara Tika, are valuable assets to have, these tools need to be strengthened across indigenous communities and mainstream ethics committees, thus providing a consistent approach toward Kaupapa Māori research that is carried out through mainstream institutions. An example of an inconsistency was the whānau information sheets and consent forms originally submitted. The response received from the ethics committee, regarding the whānau forms, was to add parent or caregiver to the title. This experience proved to be contentious as the use of whānau is an inclusive term and recognises that other members of a whānau may have important caregiving roles with rangatahi (for instance, aunts or grandparents). Walker (2019) explained whānau is often simply translated to mean 'family.' However, whānau is a multigenerational extended family network (contrasted with nuclear family constructions) that is inclusive of physical, emotional, and spiritual dimensions and is based whakapapa (Metge, 1995). Walker added that whānau can be multi-layered, flexible, and dynamic. Whānau is based on a Māori and a tribal worldview. Acknowledging that rangatahi are a part of a whānau, hapū, and iwi is important to understand as this is a significant area that requires attention because of the role it plays in the rangatahi lives. Excluding the term whānau—which is a widely understood term amongst the people—can have a substantial effect on researcher and tikanga values.

Another area for improvement includes the ability to ensure the kaitiaki position held within the ethics committees is consistent. Hudson et al. (2010) stated that ensuring tikanga is upheld in ethical processes provides a support system for Māori members of ethics committees to fulfil their duties as an advocator/kaitiaki. However, when this is not always apparent, it results in detrimental effects for the researchers who are working tirelessly for the betterment of Māori. The ethics process for this research was comprehensive and resulted in three responses back and forth to the committee, totalling five months from first application to approval. Cram (1993) claimed that Māori researchers have a strong desire to advocate for their people rather than building their own status. Advocating for

Māori was highly relevant for this research and was further supported by the rangatahi within the focus group where success and empowerment of Māori was important.

Recommendations

The following recommendations have been derived from the findings within the research and are grouped according to who they are aimed at. Rangatahi contributed significantly towards the following recommendations and were given the opportunity to have additional input as required.

Ethics committees:

- It is important for the researcher to reaffirm and explain to rangatahi that they can provide consent or non-consent and decide to withdraw from any research, throughout the research process.
- Strategies are put in place to ensure rangatahi feel comfortable in all aspects of the research, so they can withdraw or participate freely with answering questions
- Information sheets should be kept concise and focused, tailored to rangatahi age group to address their attention span. Information that is more than two paragraphs can impact on what rangatahi retain and determines if they read fully what is provided.
- A karakia to start and finish each engagement helps set a precedent for rangatahi and brings participants and researcher together as one.

Researchers:

- The use of multiple focus groups for with rangatahi promotes obtaining more points of view that are inclusive of focus groups with non-Māori and a range of year levels.
- Researchers should meet with their participants in a relaxed setting prior to any data collection to promote rangatahi to becoming comfortable with the researcher.

- Provide kai for the participants to connects everyone.
- Making connections (whakawhanaungatanga) between the researcher and rangatahi is vital for the rangatahi to have a positive research experience.
- Explain the consent process in a manner that is easy for rangatahi to comprehend, whilst avoiding research jargon that tends to cause confusion or are easily misinterpreted by rangatahi.

Concluding Comments

Rangatahi fit into several societal groups in Aotearoa and figure out the position they hold in these varying dynamics on a regular basis as they become individuals within their social and whānau roles. This thesis set out to (1) acknowledge and understand through a Kaupapa Māori lens, the perspectives held by rangatahi around the ethical process of informed consent within a research study; and (2) examine the reasons behind their decisions for participating in a research study. The research was conducted in a way that upheld the mana of rangatahi as an individual and valuing their expertise as the knowledge holders of their lived realities. The approach taken throughout the research has created a space for rangatahi to share their thoughts on a kaupapa regarding the informed consent process. The insights that have been provided from the rangatahi have helped to inform the informed consent process and provided recommendations that will improve the process for future research carried out with rangatahi. There is much more work to be done on creating an effective framework for the informed consent process with indigenous young people; however, this research contributes toward understanding rangatahi perceptions.

Mehemea kaa moemoeaa ahau, Ko ahau anake, Kaa moemoeaa taatou, Kaa taea e taatou...

If I dream, I dream alone. If we dream together, together we shall achieve.

(Herangi, cited in Waikato-Tainui, 2018)

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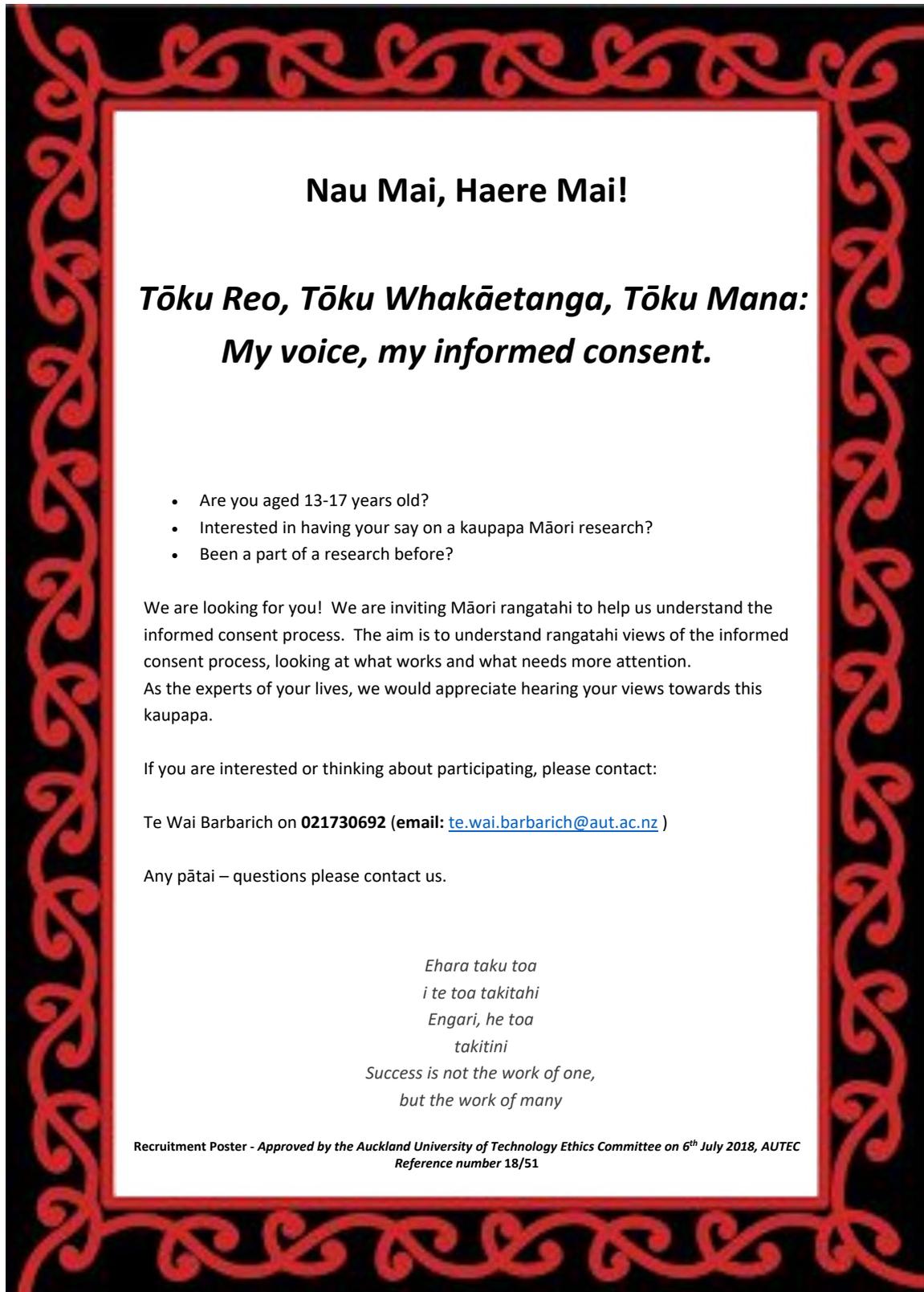
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Appendices

Appendix A: Recruitment Poster



Nau Mai, Haere Mai!

***Tōku Reo, Tōku Whakāetanga, Tōku Mana:
My voice, my informed consent.***

- Are you aged 13-17 years old?
- Interested in having your say on a kaupapa Māori research?
- Been a part of a research before?

We are looking for you! We are inviting Māori rangatahi to help us understand the informed consent process. The aim is to understand rangatahi views of the informed consent process, looking at what works and what needs more attention. As the experts of your lives, we would appreciate hearing your views towards this kaupapa.

If you are interested or thinking about participating, please contact:

Te Wai Barbarich on **021730692** (email: te.wai.barbarich@aut.ac.nz)

Any pātai – questions please contact us.

*Ehara taku toa
i te toa takitahi
Engari, he toa
takitini
Success is not the work of one,
but the work of many*

Recruitment Poster - Approved by the Auckland University of Technology Ethics Committee on 6th July 2018, AUTEK
Reference number 18/51

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Tēnā Koe,

Ko Waikato-Tainui te Iwi

Ko Ngāti Mahtu rāua ko Ngāti Paoa ngā Hapū

Ko Tainui te Waka

Ko Taupiri te Maunga

Ko Taniwha te Marae

Ko Te Wai Barbarich ahau

We are inviting rangatahi to help us understand their views of the informed consent process from a Māori lens, when participating in a research study. Thank you for showing an interest in the research. Please read this information sheet carefully before deciding to participate.

What is the purpose of this research?

Rangatahi from your school will be given the opportunity to share their experiences of previously being research participants and the informed consent process. This research will also contribute to a Master of Philosophy qualification.

How was I identified and why am I being invited to participate in this research?

Rangatahi will be identified by the school principal / school liaison as a recommended participant for this study. They will have been invited to partake because they have experienced other research studies through the school setting. The rangatahi also have identified themselves as being of Māori descent.

What we are asking of the school?

Every school community is different and we acknowledge that you know your school better than anyone, so we will be asking you to assist us in the recruitment of rangatahi for these focus groups. The criteria for your selection will be that rangatahi are aged between 13 and 17 years of age, and in your opinion, will be able to participate effectively in the focus group discussions. We will also be asking you to release these pupils for 90 minutes focus group discussion. We will also be looking to you for guidance on how best to obtain consent from parent/caregivers

How do I agree to participate in this research?

Participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage the Board, School or Pupils. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then rangatahi will be offered the choice between having any data that is identifiable as belonging to them removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

The research will be a focus group of about 10 to 15 rangatahi at their secondary school. It will be a group discussion around informed consent and looking at this kaupapa through a Māori lens. There will be a set of 10 questions that will be asked to gain a better understanding of rangatahi thoughts regarding informed consent and the processes that are carried out.

How will my privacy be protected?

All information gathered from the surveys and focus groups will be treated as confidential. However, should the Research Team come to believe that rangatahi may not be safe, we will be ethically obliged to engage with an appropriate agency previously agreed upon by you to facilitate their safety. Should this happen, we will discuss this issue with you and the participants first. The discussions will be audio recorded. If at any time during the discussions, rangatahi want to leave they can or if they want the recorder turned off we can turn it off. The words on the tape will be typed out and will only be seen by the research team. After they have finished with the transcript, the recording will be destroyed. We may use what the rangatahi says in some of the reports we write but names will be kept private. The information participants provide will be kept confidential and will be stored in our secure database.

Results from the study will be presented to the research team and published more widely. When this is done, nothing personally about the participants or school will be published, only generalised information about the group will be used.

What are the costs of participating in this research?

There is no cost for the school or participants.

What opportunity do I have to consider this invitation?

We will offer two weeks for you to think about your participation.

What data or information will be collected?

The rangatahi discussions will be recorded and transcribed. The Research Team and the person who types the transcripts will have access to the information from the discussion groups. Results of this project may be published, but any data included will in no way be linked to the Board, the School or the rangatahi. The data collected will be securely stored. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

A summary of the research findings will be made available to the school upon completion of the study. Please indicate on the access form if you wish to receive a copy of these.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Alayne Mikahere-Hall (Ngāti Whatua, Te Rarawa, Tainui), alayne.hall@aut.ac.nz, 921 9999 ext. 7115

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the access Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Te Wai Barbarich, te.wai.barbarich@aut.ac.nz, 021730692

Project Supervisor Contact Details:

Dr Alayne Mikahere-Hall, alayne.hall@aut.ac.nz, (09) 921 9999 ext. 7115

Secondary Supervisor Contact Details:

Professor Denise Wilson (Ngāti Tahinga), dlwilson@aut.ac.nz , (09) 921 9999 ext. 7392

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly: if you bow your head, let it be to a lofty mountain

Appendix C: Principal Access Permission Form

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My voice, My Informed Consent.

Project Supervisor: Dr Alayne Mikahere-Hall

Researcher: Te Wai Barbarich

Name of School: _____

Name of Principal: _____

I have read the Information Sheet concerning this project and understand what it is about. I have also read a copy of the rangatahi and whānau information sheets and consent forms. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any phase.

I understand that:

- Our school and school pupils' participation in this project is entirely voluntary; I am free to withdraw our school's participation from the project at any time without any disadvantage to the Board, School or pupils from our school;
- That the participants will be selected by me, the Principal, on the basis that they are aged between 13 and 17 years and are in my opinion able to participate in the focus group discussion;
- I will invite the parents/legal guardians, if they are agreeable, to consent to their child's participation in this project. I will give them an information sheet and a consent form to sign. I will also be advising them that the Research Team is available to discuss the project further should they wish to;
- That the selected rangatahi from our school will take part in a focus group discussion and will be asked to talk about informed consent processes;
- I consent for the Research Team to notify an appropriate agency (agreed to prior to the start of the focus groups) should any child disclose personal experiences during or after the discussion of a nature that the Research Team believes may be harmful to them;
- That the rangatahi will not be interviewed without parental/legal guardians consent and the consent of the rangatahi;
- I understand that the Research Team and the person who typed the transcripts will have had access to the personal information of the rangatahi. We understand that the research data on the rangatahi [audio-tapes and transcript] will be retained in secure storage and personal data [names and consent forms] will be destroyed at the end of the study;
- That the results of the project may be published but the schools and rangatahi names will not be used in any reports;
- That I will have access to the Research Team should I need to discuss this project with her or discuss any issues that may arise from this project for the school, parents or children.
- I would like to receive a copy of the research findings upon completion.

I give consent for our school to take part in this project.

(Signature of Principal) (Date).....

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Tēnā Koe,

Ko Waikato-Tainui te Iwi

Ko Ngāti Mahtu rāua ko Ngāti Paoa ngā Hapū

Ko Tainui te Waka

Ko Taupiri te Maunga

Ko Taniwha te Marae

Ko Te Wai Barbarich ahau

We are inviting rangatahi to help us understand their views of the informed consent process from a Māori lens, when participating in a research study. Thank you for showing an interest in the research. Please read this information sheet carefully before deciding to participate.

What is the purpose of this research?

Rangatahi will be given the opportunity to share their experiences of previously being research participants and the informed consent process. This research will also contribute to my Master of Philosophy qualification.

How was I identified and why am I being invited to participate in this research?

The school principal or school liaison person has identified your rangatahi as a potential participant for this study. They have been invited to participate because they have been in other research studies through the school setting. The rangatahi also have identified themselves as being of Māori descent.

How do I agree for my rangatahi to participate in this research?

Participation in this research is voluntary (it is your and your rangatahi choice). Whether or not your rangatahi chooses to participate he or she will not be disadvantaged. Your rangatahi will also have to give their consent to participate and is able to withdraw from the study at any time.

What will happen in this research?

The research will be a focus group of about 5 rangatahi at their secondary school. It will be a group discussion around informed consent and looking at this kaupapa through a Māori lens. There will be about 10 questions that will be asked to gain a better understanding of rangatahi thoughts regarding informed consent and the processes that are carried out.

How will the privacy of my rangatahi be protected?

All information gathered will be treated as confidential. However, through discussions should the research team feel rangatahi may not be safe we are ethically obliged to engage with an appropriate agency to help make them safe. However, we will discuss this with you and the young person first.

The discussions will be audio recorded. If at any time during the discussions, your child wants to leave they can or if they want the recorder turned off we can turn it off. The words on the tape will be typed out and will only be seen by the research team. After they have finished with the transcript, the

recording will be destroyed. The information your child provides will be kept confidential and will be stored in our secure database.

Results from the study will be presented to the research team and published more widely. When this is done, nothing that is personally identifiable about you or your rangatahi will be published, only generalised information about the group will be used.

What are the costs of participating in this research?

There is no cost for the participants in the research.

What opportunity do I have to consider this invitation?

We will offer two weeks for you to think about your participation.

Will I receive feedback on the results of this research?

Rangatahi will be given a copy of the notes from the focus group to look over and check to make sure they are all ok.

A summary of the research findings will be made available to the school upon completion of the study. Please indicate on the consent form if you wish to receive a copy of these.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Alayne Mikahere-Hall, alayne.hall@aut.ac.nz , 921 9999 ext. 7115

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, ethics@aut.ac.nz , 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Te Wai Barbarich, te.wai.barbarich@aut.ac.nz, 021730692

Project Supervisor Contact Details:

Dr Alayne Mikahere-Hall, alayne.hall@aut.ac.nz, (09) 921 9999 ext. 7115

Secondary Supervisor Contact Details:

Professor Denise Wilson (Ngāti Tahinga), dlwilson@aut.ac.nz , (09) 921 9999 ext. 7392

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly: if you bow your head, let it be to a lofty mountain

Appendix E: Whānau Consent Form

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My voice, My Informed Consent.

Project Supervisor: Dr Alayne Mikahere-Hall

Researcher: Te Wai Barbarich

- I have read and understood the information provided about this research project in the Information Sheet dated 1st February 2018.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the focus group and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw my child from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw my child from the study then I will be offered the choice between having any data that is identifiable as belonging to my child removed or allowing it to continue to be used. However, once the findings have been produced, removal of our data may not be possible.
- I would like to receive a copy of the research findings upon completion.

- I agree to my child taking part in this research.

Child's name:

Parent/Guardian's signature:

Parent/Guardian's name:

Hapū:

Iwi:

Date:

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Tēnā Koe,

Ko Waikato-Tainui te Iwi

Ko Ngāti Mahtu rāua ko Ngāti Paoa ngā Hapū

Ko Tainui te Waka

Ko Taupiri te Maunga

Ko Taniwha te Marae

Ko Te Wai Barbarich ahau

We are inviting rangatahi to help us understand their views of the informed consent process from a Māori lens, when participating in a research study. Thank you for showing an interest in the research. Please read this information sheet carefully before deciding to participate.

What is the purpose of this research?

Rangatahi will be given the opportunity to share their experiences of previously being research participants and their understanding of the informed consent process. You have been identified by your principal / school liaison as a recommended participant for this study. You have been invited to partake because you have experienced other research studies through the school setting. You also have identified yourself as being of Māori descent. This research will also contribute to a Master of Philosophy qualification.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

The research will be a focus group of about 10-15 rangatahi at your school. It will be a group discussion around informed consent and looking at this kaupapa through a Māori lens. There will be a set of 10 questions that will be asked to gain a better understanding of your thoughts regarding informed consent and the processes that are carried out.

How will my privacy be protected?

We will keep everything you say private but if we think that you, or someone in your whānau are not safe, we might have to tell some other adults who can help make you safe. We will talk with you about this first. You can ask us any questions you like before you take part in the focus group.

The discussions will be audio recorded. If at any time during the discussions, you want to leave you can or if you want the recorder turned off we can turn it off. The words on the tape will be typed out and will only be seen by the research team. After they have finished with the transcript, the recording will be destroyed. The information you provide will be kept confidential and will be stored in our secure database.

There is no cost for the participants in the research and we will offer two weeks for you to think about your participation. You will also be given a copy of the notes from the focus group to look over and check to make sure they are all ok.

Results from the study will be presented to the research team and published more widely. When this is done, nothing about you personally will be published, only generalised information about the group will be used.

A copy of the research findings will be made available once the study is completed. You can choose to have a copy provided by indicating on the consent form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Alayne Mikahere-Hall (Ngāti Whatua, Te Rarawa, Tainui), alayne.hall@aut.ac.nz, [921 9999 ext. 7115](tel:9219999)

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Te Wai Barbarich, te.wai.barbarich@aut.ac.nz, 021730692

Project Supervisor Contact Details:

Dr Alayne Mikahere-Hall, alayne.hall@aut.ac.nz, [921 9999 ext. 7115](tel:9219999)

Secondary Supervisor Contact Details:

Professor Denise Wilson (Ngāti Tahinga), dlwilson@aut.ac.nz, [921 9999 ext. 7392](tel:9219999)

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly: if you bow your head, let it be to a lofty mountain

Appendix G: Rangatahi Consent Form

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Project Supervisor: Dr Alayne Mikahere-Hall

Researcher: Te Wai Barbarich

- I have read and understood the information provided about this research project in the Information Sheet dated 1st February 2018.
- I have had an opportunity to ask questions and to have them answered.
- I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- I understand that notes will be taken during the focus group and that it will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then, while it may not be possible to destroy all records of the focus group discussion of which I was part, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I would like to receive a copy of the research findings when the study is completed.
- I agree to take part in this research.

Hapū:

Iwi:

Date of Birth:

Contact Phone/Email:

Gender:

Rangatahi Signature:

Rangatahi Name:

Date:

Appendix H: Rangatahi Assent Form

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Project Supervisor: Dr Alayne Mikahere-Hall

Researcher: Te Wai Barbarich

- I have read and understood the sheet telling me what will happen in this study and why it is important.
- I have been able to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that I can stop being part of this study whenever I want and that it is perfectly ok for me to do this.
- If I stop being part of the study, I understand that then I will be offered the choice between having any information that that other people can know is about me removed or letting the researcher keep using it. I also understand that sometimes, if the results of the research have been written, some information about me may not be able to be removed.
- I would like to receive a copy of the research findings when the study is completed.
- I agree to take part in this research.

Hapū:

Iwi:

Date of Birth:

Contact Phone/Email:

Gender:

Rangatahi Signature:

Rangatahi Name:

Date:

Appendix I: Ethical Approval

6 July 2018

Alayne Mikahere-Hall
Faculty of Health and Environmental Sciences

Dear Alayne

Re Ethics Application: **18/51 Toku Reo, Toku Whakāetanga, Toku Mana: My voice, my informed consent**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 6 July 2021.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/research/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/research/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/research/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,



Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: Te Wai Barbarich; Denise Wilson

Tōku Reo, Tōku Whakāetanga, Tōku Mana: My Voice, My Informed Consent.

Tēnā koutou katoa, ngā mihi kia koutou i tēnei rā.

The consent process is an important part of research that is undertaken. This is a kaupapa Māori study and I'm interested to see what consent looks like for rangatahi Māori.

We will go over a few questions that will help me understand what your view of the consent process might look like from a rangatahi perspective, and how we can guide this process to make it beneficial for rangatahi Māori. We know in the past people have come to studies because of their friends or for a free kai. But today we are looking to go beyond this and find out more about what you think processes are like etc.

- Participation: for you, what does this mean?
- What do you know about consent?
- What do you know about non-consent?
- From previous studies you have been involved with, can you tell me what features influenced your decision to participate in the study?
- Were your whānau involved in the consent process at all?
 - If yes: Did you find this helpful?
 - If no: Why do you think this was?
- When you think about other studies that you've been a part of, what was the consent process like for you?
- Is it important for you to meet the researchers before you consent?
- Have you ever felt uncomfortable about withdrawing from a study?
- Did you ever feel like you had to complete your involvement in a study?
- How does the information given guide your decision to consent?
- Do you have any recommendations for other rangatahi who are thinking about participating in research?
- Is there anything you would do differently in the consent process?
- Can you tell me how did you find out about the study?
- Is there anything else you can think of that we have not yet covered?

Ngā mihi kia koutou katoa, kua mutu aku pātai inaianei. Thank you all very much, that is the end of my questions today. Thank you for your time and effort that has been put in today.