Health Quality & Safety
Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

Ngā Taero a Kupe

NGĀ WHEAKO PĀNGA KINO KI NGĀ WHĀNAU MĀORI I RŌ HŌHIPERA

WHĀNAU MĀORI EXPERIENCES OF IN-HOSPITAL ADVERSE EVENTS

2019

Ngā kaupapa | Contents

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Ngā mihi | Acknowledgements

This report was prepared by the Health Quality & Safety Commission | Kupu Taurangi Hauora o Aotearoa based on the information gathered during a research project of whānau Māori experiences of in-hospital adverse events.

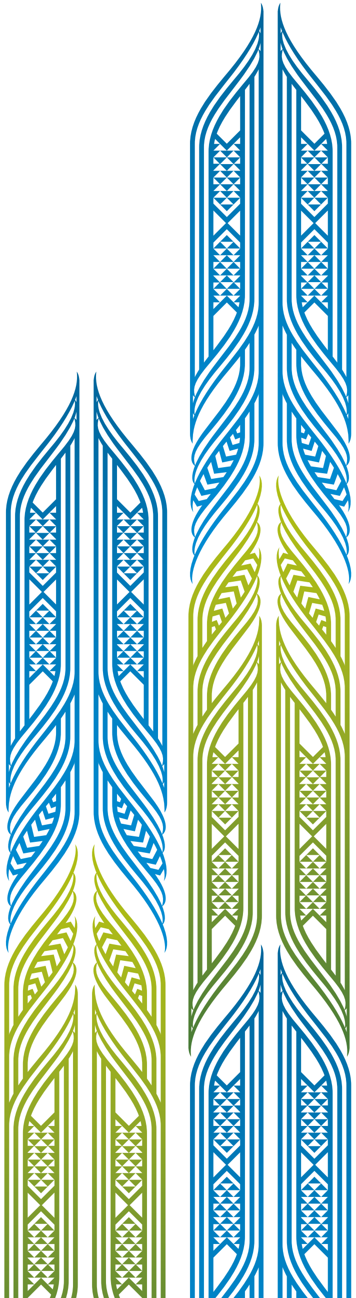
We would like to acknowledge all stakeholders who participated in this project.

A special mention must go out to all the whānau who courageously shared their stories with us. It was a privilege to meet each and every one of you, because without you, this project would not have been possible. We hope other whānau take comfort from your example and have the courage to tell their stories to contribute to improving systems for looking after Māori wellbeing.

We would also like to thank Ms Audrey Robin (Chief Executive Officer of Te Kupenga Hauora – Ahuriri) and Ms Teresa Olsen (Chief Executive Officer of Kōkiri Marae Keriana Olsen Trust) for their support in identifying and recruiting whānau Māori participants. We acknowledge the amazing role your organisations have in empowering, supporting and caring for our whānau – *ngā mihi nui ki a kōrua.*

Thank you to all the district health board clinical staff who shared their experiences of and perspectives on managing and reviewing in-hospital adverse events.

The report name, ***Ngā Taero a Kupe***, refers to the kareao (supplejacks), tataramoa (brambles), tūmata-kuru (spear grass) and ongaonga (nettles), which are called 'The Obstructions of Kupe'. These are physical and mental difficulties or blockages. They occur when cultural safety and cultural competency are not observed.



Tangohanga | Abstract

It is commonly known that Māori, who make up only 19.1 percent of the total population of Aotearoa New Zealand (Statistics New Zealand 2019), experience the poorest health outcomes across the population. To understand and support much-needed change to improve Māori health outcomes within the Aotearoa New Zealand health care system, the Health Quality & Safety Commission (the Commission) completed a research project that investigated whānau Māori experiences of in-hospital adverse events. This project primarily focused on whānau Māori views and experiences of an in-hospital adverse event and how that experience was managed. The Commission considered that understanding whānau Māori experiences of adverse events would enable directed and focused system improvements to occur.

Māori make up only

19.1%

of the population of Aotearoa, but experience the poorest health outcomes.

Objectives: This study sought to investigate and describe the experiences of whānau Māori who experienced a health care-related Severity Assessment Code 1 or 2 in-hospital adverse event.

Methods: The study was designed using a kaupapa Māori approach, which was applied throughout each phase of the project. A range of qualitative methods was applied to data collection and the analysis of all information collected from 17 whānau Māori and eight clinical staff from across the country.

Results: Whānau Māori had strong views about the way they were treated when accessing health care. For example, many whānau perceptions of the health care system was poor and as a result whānau were reluctant to access care unless absolutely necessary.

Conclusion: The need for change is critical to the quality of care that whānau Māori experience within the Aotearoa New Zealand health and disability system.

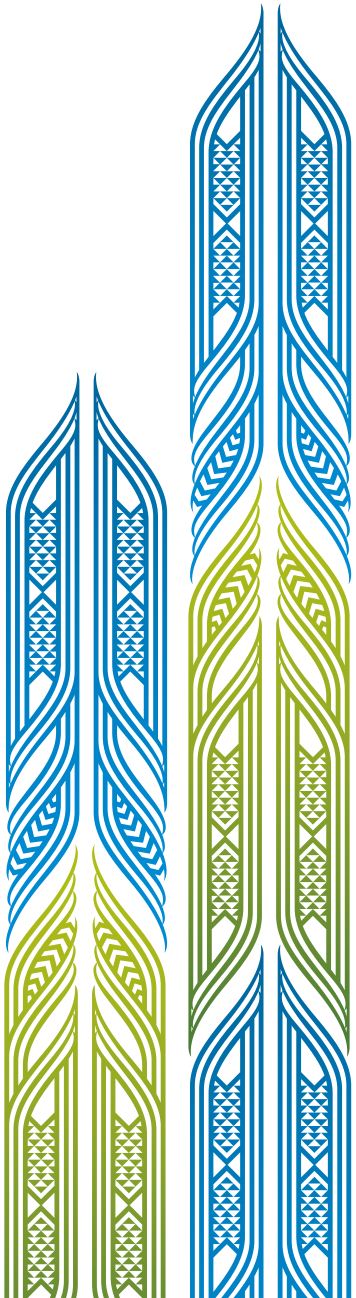
Kupu whakataki | Introduction

For most people who access health services, the care received goes according to plan and their health is restored. Hågensen et al (2018) state people enter health care services with the expectation that their care will be performed in a safe and beneficial manner. However, Mothibi et al (2015, p 660) claim, 'health care is a complex, fragmented, and discontinuous system that provides opportunities for systematic failure which can adversely affect patient safety'.

Court (2003, p 97) argues, 'we are unable to guarantee our patients that the care we provide will do no harm' and for an alarmingly high percentage of the population, their experience of health care services results in an unintended adverse event that causes significant preventable harm to them (see Merner et al 2019; Hågensen et al 2018; Mothibi et al 2015; de Vries et al 2008; and Court 2003).

Although patient safety in health care cannot be guaranteed, quality health care is a fundamental right of all health consumers across the globe. Providing quality health care should be considered an ultimate goal that each health care service provider aims to achieve.

> … [Q]uality health care is a fundamental right of all health consumers across the globe.



Adverse events

In-hospital adverse events are commonly described as undesirable and unintended experiences associated with the health care system, which cause unnecessary or preventable harm to consumers (Merner et al 2019). To note, de Vries et al (2008) say in-hospital adverse events 'kill' more people annually than breast cancer or AIDS.

> '… [I]n-hospital adverse events "kill" more people annually than breast cancer or AIDS.'
>
> **de Vries et al (2008)**

In-hospital adverse events are therefore, a significant problem facing contemporary health care (Harrison et al 2015) and, despite a range of collective efforts to improve patient safety, preventable health care-associated harm (particularly in hospitals) remains a significant issue for both clinicians and consumers alike (Lamont and Waring 2015).

Harrison et al (2015, p 424) suggest quality and safety initiatives are routine for improving the efficiency and effectiveness of health care. Hågensen et al (2018) argue patient safety activities and research on adverse events have, to date, followed a system-based and biomedical perspective.

However, Harrison et al (2015) say to improve health care quality and safety, greater emphasis on patient experiences of adverse events was not only required, but critical to any improvements to a system. Similarly, Robert (2013) claims that, for many years, health care policy frameworks describe patient experience as a core component of health care quality and should sit alongside clinical effectiveness and patient safety.

Currently, there exists a plethora of national and international research that examines patient experiences of in-hospital adverse events. Much of the research is aimed at investigating system failures, reducing hospital admissions and learning from patient adverse outcomes associated with the health care system. However, at present the voices and experiences of carers in patient safety research are limited, and research directed at investigating carers in hospitals often focuses on the carer's general role in supporting the patient rather than their safety-specific role (Robert 2013).

Examining patient experiences of in-hospital adverse events offers a unique opportunity to gain end-user perspectives into what works well, what does not work and where necessary system improvements may be needed.

Regardless of all good intentions to treat patients safely, many patients experience in-hospital adverse events associated with their health care (Sahlstrom et al 2018) and in Aotearoa New Zealand this is particularly evident for whānau Māori. While limited, research that specifically investigates whānau Māori experiences of in-hospital adverse events identified that 14 percent of Māori admissions during 1998 to 13 hospitals across the country were associated with an adverse event, compared with 11 percent of non-Māori admissions (Davis et al 2006).

Davis et al (2006, p 1922) continue to say:

> ‘Despite a predominantly publicly funded hospital system… hospital care received by Māori is marginally poorer than that received by New Zealand citizens of non-Māori/non-Pacific origin. Although no cause specific to Māori was evident, various policy and system issues can be and should be addressed.’

Thus, in 2019 the Health Quality & Safety Commission (the Commission) completed a research project that explored whānau Māori experiences of in-hospital adverse events. The Commission considered that understanding whānau Māori experiences of in-hospital adverse events would enable directed and focused system improvements to occur across the Aotearoa New Zealand health care system. The Commission also considered that, with good systems and interventions in place, the number of these events could be reduced and harm minimised.

This document presents a thematic analysis of a range of experiences from 17 whānau Māori from across Aotearoa New Zealand who experienced an adverse event while accessing the health and disability care system. Whānau were initially identified and selected to take part in this project through the Commission’s adverse events learning programme. However, due to unforeseen circumstances, the method of recruiting participants was altered (see the Research approach section for more details).

While it is anticipated this research will make a significant contribution to the growing body of knowledge of consumer experiences of in-hospital adverse events overall, it will be key to identifying what is missing in the identification and management of whānau Māori experiences within hospitals. Therefore, it is expected this research will provide insight into improving the quality of care that whānau Māori experience within the Aotearoa New Zealand health care system.

Commission reporting on national adverse events

Through its adverse events learning programme, the Commission has collated and reported on national Severity Assessment Code (SAC) 1 and 2 adverse events throughout the Aotearoa New Zealand health and disability sector for the past 10 years. The aim of the programme is to improve consumer safety by supporting organisations to report, review and learn from adverse events and near misses that occur in health and disability services across the country. The programme's annual report presents a snapshot of all episodes of individual harm within the health and disability sector that are reported to the Commission during a nominated period of time. The events reported are gathered from all district health boards (DHBs) and other health and disability service providers in Aotearoa New Zealand.

To support organisations with reporting, reviewing and learning from adverse events, the Commission created the adverse event policy framework (the policy), which was provided to each DHB and implemented in March 2012. The focus of the policy was updated and the current version was published in July 2017. In order to allow health and disability providers time to implement the new policy, they were given until July 2018 to implement it.

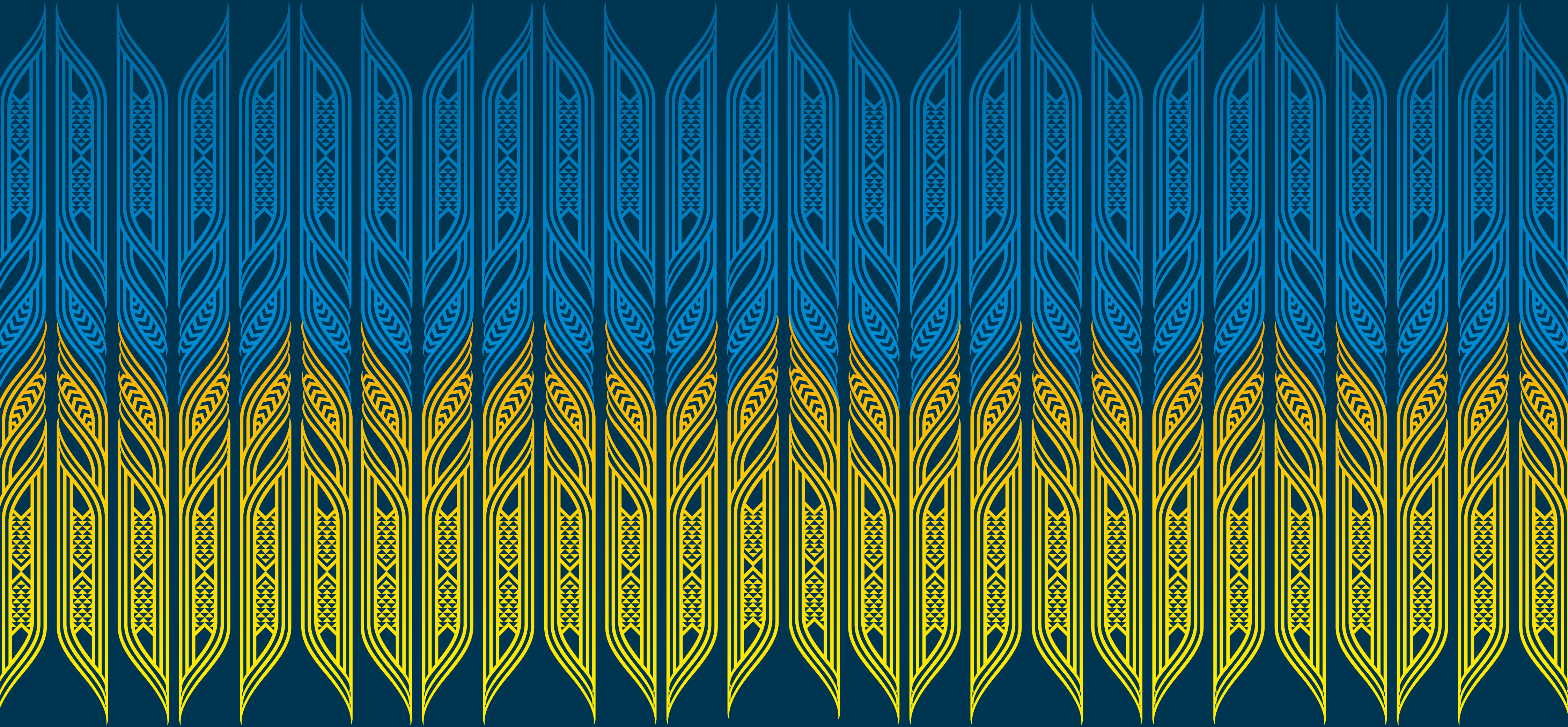
The Commission also developed and implemented a specific set of criteria in 2017 (see Appendix 1) to identify and rate the severity of adverse events. The SAC is a numerical rating that defines the severity of an adverse event and, as a consequence, the required level of reporting and investigation to be undertaken.

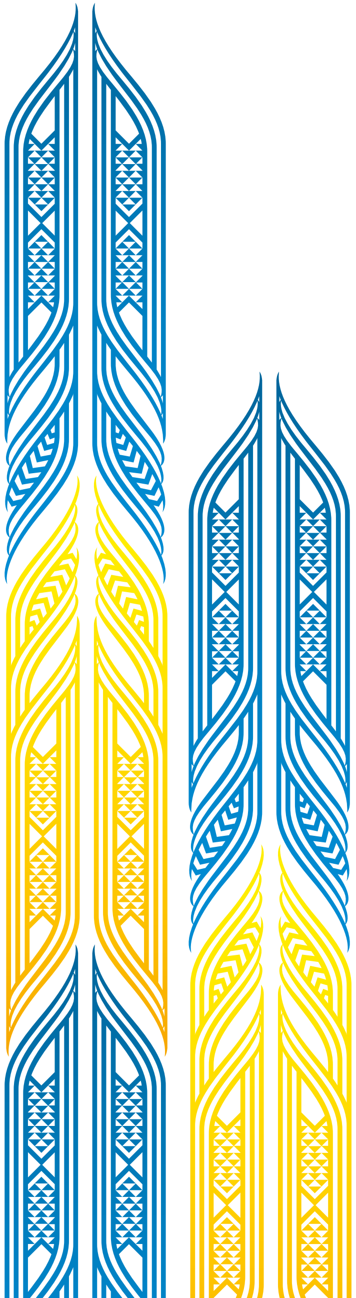
So that each health and disability service provider has a similar understanding of the requirements, the Commission holds education and training programmes to support implementation.

The policy and SAC rating tool were implemented to support and help the health and disability sector to identify, rate and report all adverse events to the Commission. In 2020 the Commission will look to review these documents so they remain current. In 2019, both were well established and embedded in the current operating health and disability care system.

When we consider that every reported SAC 1 and 2 adverse event represents a person who has experienced significant harm as a result of the current health care system, every avenue that explores how to reduce or minimise these events should be considered.

TE ARA | APPROACH





Arotake tuhituhinga | Literature review

Walton et al (2014) claim in-hospital adverse events are one of the top six health problems in the developed world, and when these events occur, the outcome for patients and their whānau can be devasting. Nevertheless, each event provides an opportunity to learn from what went wrong and make system changes to minimise the risk of future events.

To learn from adverse events, Court (2003, p 98) says,

> ‘It is not sufficient to determine the error that has precipitated an adverse outcome; we need to look behind that error to determine contributory factors in the work setting, and behind those to latent failures within the organisational culture.’

In addition, Martin et al (2017, p 1) state, ‘A pervasive theme of healthcare reform globally is greater candour about the imperfections of care quality, particularly for patients and family members when things go wrong.’

Patient experiences of adverse events provide a key source of information, and those experiences should be included when determining or understanding in-hospital adverse events.

Research that looks at the importance of learning from and including patient experiences as contributing factors to quality and safety improvement initiatives is becoming more prominent throughout the literature (Hågensen et al 2018; Mothibi et al 2015; de Vries et al 2008; Davis et al 2006; Court 2003). While patient safety is considered a priority for health care globally (Montague et al 2019), patient experiences of adverse events offer insight from an end-user perspective and should be included in improvements to quality and safety in the delivery of health care.

Patient safety is the term used to describe 'the collective efforts of health systems, services and practitioners to reduce the risk of unnecessary harm associated with health care to an acceptable minimum' (Merner 2019, p 1508).

Patient safety culture is defined as 'the product of individual and group beliefs, values, attitudes, perceptions, competencies, and patterns of behaviour that determine the organization's commitment to quality and patient safety' (Al Ma'mari et al 2019, p 230).

While there is a growing body of international knowledge of patient experiences of in-hospital adverse events, research that looks specifically at Indigenous experiences of in-hospital adverse events is limited. Moreover, within an Aotearoa New Zealand context, there is even less known about Māori experiences and their perceptions of adverse events within health.

Māori, who make up approximately 19.1 percent of the total population of Aotearoa New Zealand, experience significantly poorer health outcomes compared with non-Māori (Rumball-Smith et al 2013). The Commission's publication *A window on the quality of Aotearoa New Zealand's health care 2019 – a view on Māori health equity* (Window 2019) states, 'Despite 60 years of constant improvement, a stark difference in life expectancy exists between Māori and non-Māori' (Health Quality & Safety Commission 2019, p 9).

Rumball-Smith et al (2013) state that the differences in health outcomes between Māori and Pākehā are well documented and it is possible that differential treatment within the health system contributes to these health status inequalities.

Disparities in health status between different groups within a specific population are found worldwide. However, in Aotearoa New Zealand, ethnic inequalities between Māori and non-Māori/non-Pacific demonstrate the most consistent and compelling inequities in health (Ajwani et al 2003).

Similarly, Davis et al (2006, p 1924) claim, 'Māori experience poorer care than Pākehā in state-funded hospital care and Māori experience substantial disadvantages in health status compared to Pākehā.'

It is indeed fair to say that, within the current Aotearoa New Zealand health and disability system, significant change is required to address the disadvantages and significant inequities that exist, specifically for whānau Māori. Understanding the underlying issues associated with that disadvantage and existing inequities requires investigating Māori perspectives to recognise why these occur at such disproportionate levels. This opportunity is presented through analysing whānau Māori experiences of in-hospital adverse events.

When Aotearoa New Zealand health care improvements are aimed at improving quality and safety systems and Māori health outcomes, the role and inclusion of Māori cultural practices and concepts to the delivery of care should be considered. Cram et al (2003) said cultural practices or concepts that are imperative to Māori health and wellbeing have been undermined by dominant Pākehā views on health. However, culture plays a vital role in quality of care (Carlson et al 2019). Health and disability services have a responsibility to provide appropriate care (Carlson et al 2019) to whānau Māori. Support for clinicians to provide quality health care should always include ways to improve the care that whānau Māori receive in health.

Unconscious or implicit biases

Human biases can be so entrenched that people are unaware of their impact on their views, behaviours or interactions with others. Perry et al (2015, p 64) claim,

> ‘Awareness of personally-held biases are widely considered a critical step in reducing an individual’s prejudice and discrimination.’

Qian et al (2019, p 1440) refer to racial bias as,

> ‘… [A] tendency to react unfavourably to members of a racial group because of one’s group affiliation. Such bias is evidenced in derogatory attitudes or beliefs, negative affect, and hostile or discriminatory behaviour about a racial group. When left unchecked, racial bias can produce profound and far-reaching negative impacts at personal group or society levels.’

Curtis (2019, p 2) says, ‘Māori experience a high level of health care need, they experience less access to, and poorer care throughout… [H]ealth professionals and health care organisations are important contributors to racial and ethnic inequities in health care.’

There are some fundamental elements of Māori culture and behaviour that support providing a culturally appropriate health service. Many basic human behaviours should always be used when interacting or providing health care to patients, consumers and whānau Māori. These include (but are not limited to) dignity, respect, compassion, empathy and listening.

For example, Simões and Sapeta (2019, p 197) state,

> ‘It is known that positive results in health derive from factors such as valuation and respect; participation in decisions, positive self-esteem and the ability to exercise control over life itself, if the patient’s perception of dignity is a central element of care.’

However, the authors go on to say that dignity ‘is a complex concept, difficult to define, due to the lack of clarity regarding what it implies’.

There are many human characteristics that can impact on the emotions or perceptions that patients attach to health care. Dignity, respect and open communication are selected because they are everyday actions that are key to building trust, reciprocity or relationships in any situation. These characteristics were selected because, as behaviours or values, they are intertwined or overlap in meaning and will provide the backdrop of literature for this research project.

Dignity and respect

Hall and Mitchell (2016, p 2) argue that,

> ‘… [D]ignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.’

Andanda and Wathuta (2018, p 144) suggest that dignity is the sense of the ‘intrinsic value of human beings making it the ultimate rationale for human rights and the basis for the prohibition of discriminatory practices, degrading treatment and the instrumentalization of people.’

Moreover, Östlund et al (2019, p 2) say that dignity is a human right and is one of the highest priorities in health care. They define dignity as, ‘an entity consisting of body, soul, and spirit. Absolute dignity refers to values that are impossible to forsake e.g., human worth, freedom, responsibility, and serving one’s fellow humans.’

It is evident the definitions of dignity are complex and lack definitive clarity (Piper 2014) and while many may argue that the concept is empty and useless and can be replaced by ‘autonomy’ without loss of meaning (Piper 2014), it is a dimension of human behaviour, values or beliefs that is critical to allowing an ‘ill or frail person to live in accordance with their standards and values’ (Östlund et al 2019, p 2).

Open disclosure and clear communication

Piper (2014, p 197) states respect and dignity align closely to open and clear communication: ‘It is a way of keeping people informed which firstly aligns to concepts that facilitate consistency and effective communication during the delivery of care.’

Doctor–patient communication can be complicated, where some patients do not feel comfortable speaking up, as they believe their questions or involvement may seem like they are over-scrutinising their physician (Shoemaker and Smith 2019).

In contrast, Rajendran et al (2012, p 56) say that across health care, when patients speak up or ask questions, their ‘viewpoints are important for effective practitioner–patient communication; “understanding the patient’s perspective” and “sharing information” are acknowledged elements within the medical encounter’ and can facilitate beneficial health outcomes (Travaline et al 2005) for patients and consumers and, in this case, for whānau Māori.

Open and clear communication seems such a generic concept that it may be taken for granted that people fully understand the notion. Griffiths (2017) says that, although nurses receive training and learn how to communicate in the workplace, it is unlikely to be sufficient preparation for the more difficult conversations.

It is clear that human relationships or interacting with people requires consideration of some basic elements in one’s behaviour, such as open and clear communication, treating people with respect and maintaining their dignity. However, it is interesting that all the elements mentioned above – including consideration for cultural values – are intrinsic in a kaupapa Māori framework. Kaupapa Māori as an approach provides a pathway to interacting and building relationships across all groups of people. While it is an approach based on a Māori worldview, it encompasses the idea of challenging the dominant culture and cultural superiority (Bishop 1994). Barnes (2000) said kaupapa Māori involves a concept of the possibility of and desirability for change. When the components contained within kaupapa Māori can service the needs of all people, should this approach be considered as the key tenet to educate all health professionals when learning how to collaborate, interact and build relationships across all cultures?

Te kaupapa rangahau onāianei | The current research project

Purpose

The purpose of this research project was to gain qualitative information about the health and disability services during an adverse event for whānau Māori from across Aotearoa New Zealand. It was anticipated that the information collected would support the development of improved care for Māori during and after an adverse event.

Overall research question

The research aimed to investigate and examine one overall question: How do whānau Māori experience health care-related adverse events?

Aim

To investigate and describe the experiences of whānau Māori who experience a health care-related SAC 1 or 2 in-hospital adverse event.

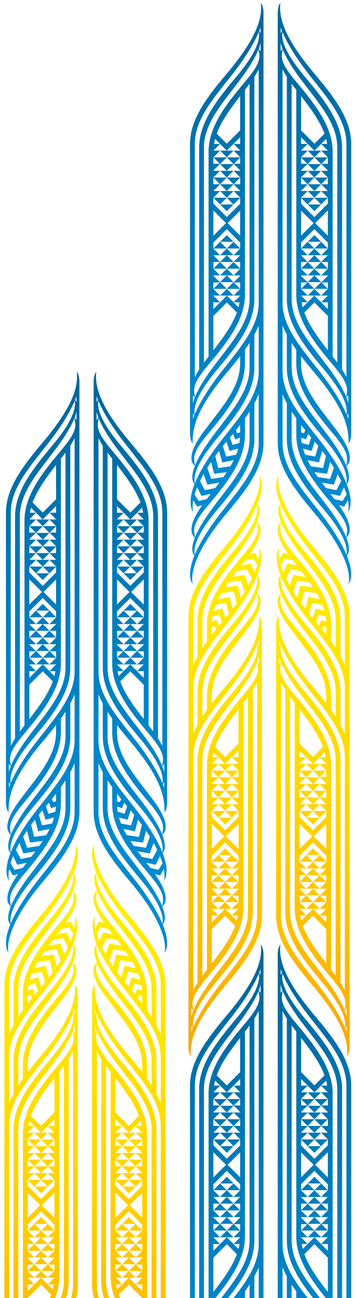
Objectives

› Collect qualitative data describing the whānau Māori perspective of how health service providers managed the event both during and after.

› Identify practices that would improve experiences.

› Describe current open communication practices.

› Develop guidance for providers on how to engage with whānau Māori following a health care-related adverse event.



Informed consent

Each participant was given an information sheet that provided details about the research project and a consent form to sign.

At the start of each interview, researchers spent approximately 10 minutes explaining the research and answering any questions before asking participants to sign the consent form. This was to ensure participants understood why the Commission was completing the study and what information would be included in the report, and to reassure them that their anonymity would always be maintained.

All signed consent forms were scanned into the research team's database and hard copies were filed in a secure location. Participants were informed that their consent forms would be held for up to seven years after the publication of the final report. After that timeframe the Commission would delete and destroy all copies.

Ethics

This project was classed as a low-risk observational study. It did not involve the delivery of health care to patients, the use of stored samples, secondary use of identifiable health information without consent, or vulnerable participants. The Health and Disability Ethics Committees exempt low-risk observational studies, so ethics approval was not needed for this study. However, an application was submitted to check this was the case. The Health and Disability Ethics Committees' response notes the study was low risk and sat outside of the requirements for gaining ethical approval.

Project processes

The research team:

- developed a project plan that outlined a staged approach to developing, implementing and successfully completing the research project
- developed review tools, including interview guides, information sheets and consent forms
- determined criteria for an adverse event that fell within a SAC 1 or 2 event
- targeted at least 20 whānau Māori who had experienced a recent (within 12 months) adverse event to participate in the project
- developed interview schedules and completed kanohi-ki-te-kanohi interviews with 17 whānau Māori
- recruited eight clinicians to follow up on what barriers may exist for quality engagement and review processes with whānau.

Ara rangahau | Research approach

Methodology

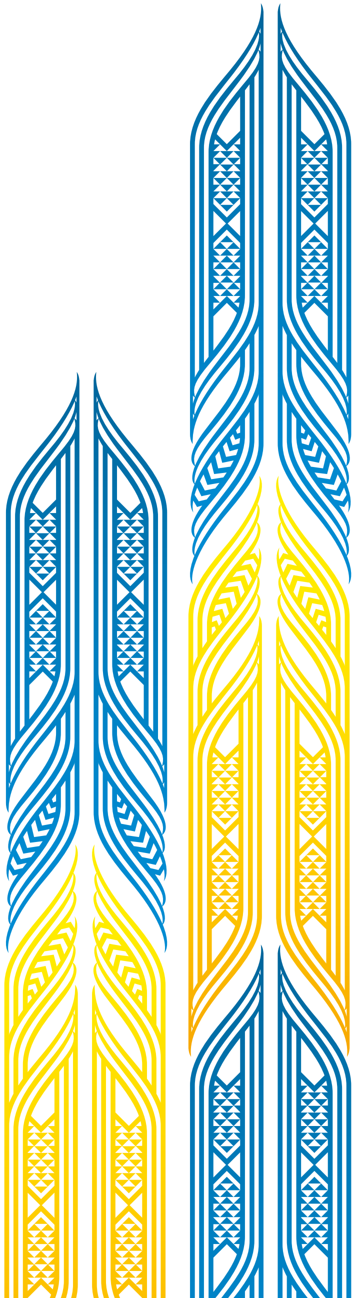
The emergence of kaupapa Māori research has encouraged new ways of thinking about research practices (Barnes 2000). Cram et al (2018) state that, while kaupapa Māori does not inform how to carry out a research project, the cultural and ethical values within kaupapa Māori facilitate good Māori research, and are well documented (see Smith 1992; Barnes 2017; and Cram et al 2018).

Smith (1992) describes kaupapa Māori as the philosophy and practice of being and acting Māori. It assumes the taken-for-granted social, political, historical, intellectual and cultural legitimacy of Māori people in that it is a position where Māori language, culture, knowledge and values are accepted in their own right. Further, kaupapa Māori presupposes positions that are committed to a critical analysis of the existing unequal power relations within our society (Cram et al 2018).

Kaupapa Māori research recognises Māori values, customs and protocols as core aspects of the research process. The current study employed a range of qualitative methods developed within a kaupapa Māori framework, which was applied to all elements of the research project.

Moreover, kaupapa Māori research focuses on Māori advancement, adopting a theoretical position and multi-methods approach born of the need to challenge colonising power, norms and assumptions so that Māori ways of knowing and operating are central (Smith 1999; Walker et al 2006). Barnes (2000) emphasises three defining principles of this approach:

- it is by Māori for Māori
- Māori worldviews are the normative frame
- research is for the benefit of Māori.



Method

The present study used a qualitative mixed method developed within a kaupapa Māori approach. A total of 20 Māori were initially targeted to participate in semi-structured interviews. A maximum of 21 whānau Māori agreed to participate in the study; however, of the 21 participants, four cases were (at the time of recruitment) going through the Aotearoa New Zealand coronial review process. Each interview completed was recorded for accuracy of information and transcribed verbatim.

During the development phase of the project the research team controlled for age, and all minors, children and/or young people under the age of 18 were removed from the selection process.

We experienced many challenges in recruiting whānau Māori to participate in the research. Details about the challenges we experienced are provided in the Whānau Māori recruitment process section below.

Semi-structured interview process

Interview schedules were developed for both whānau and clinicians (see Appendix 3). The interviews followed an open-ended format with the interviewer raising relevant topic areas and encouraging participants to talk rather than pursuing set questions. One of the roles as researchers working within a kaupapa Māori framework is to listen to and document Māori experiences and meanings (Cram et al 2018).

A range of topics were discussed during each interview and included:

- participants' understanding of in-hospital adverse events
- support provided by hospital staff
- shared decision processes during the care provided
- cultural awareness and/or consideration of cultural needs.

Each interview was transcribed verbatim, checked against the audiotape or video recording, and returned to participants for approval before inclusion in the database. Participants were given pseudonyms, and identifying markers were masked to preserve confidentiality.

Participating DHBs

The research team invited all 20 DHBs to take part in the study. Two declined at the start of the project. They claimed that after discussing the aim and/or objective of the study within their hospital clinical teams, they were concerned that asking whānau to recall and discuss the adverse event would retraumatise them. There were four hospitals that initially agreed to take part in the research but did not respond to subsequent requests for information.

Clinician participants

The research team also completed interviews and/or surveys with 10 clinicians from randomly selected DHBs to gauge levels of understanding and implementation of policies aimed at managing adverse event review processes. This process allowed the team to identify synergies (if any) between a system based on a clinical view and whānau perceptions surrounding the identification and management of adverse events.

Whānau Māori recruitment process

In the 2017/18 *Learning from adverse events* annual report, 621 in-hospital SAC 1 or 2 adverse events were reported to the Commission. Of those 621, a total of 63 indicated they were of Māori descent. This meant the research project had a total target population of 63 whānau Māori who had experienced a SAC 1 or 2 event. From the 63, the team selected and clustered 20 whānau based on locations (or hospitals) where three or more whānau had experienced a SAC 1 or 2 adverse event.

Initially, the team contacted the quality and risk managers (QRMs) of each of the identified DHBs and asked them to identify the whānau they had reported to the Commission during 2017/18 as experiencing a SAC 1 or 2 adverse event. The QRMs were asked to call the whānau and ask if a research team member could call and invite them to take part in the study. While initial contact with each QRM was positive and they agreed to support the Commission with whānau recruitment, the QRMs struggled to find whānau with the contact details provided during the hospital admission. Of the seven QRMs contacted, only one managed with the support of a local Māori provider to locate a person who agreed to take part in the study. Due to unforeseen circumstances, this whānau was unable to take part in the research. There were also a small number of whānau who declined to be involved.

Recruitment challenges

As the research team experienced a range of unexpected challenges throughout the whānau Māori recruitment process for the project, many discussions were held with the project's working group and other key stakeholders. This resulted in the research team changing the whānau recruitment approach to include Māori health and social service providers from across the country as well as a range of Te Puni Kōkiri regional offices. The research team also changed the research criteria to include adverse events that occurred within a 2–5-year period.

It was anticipated that, as Te Puni Kōkiri regional offices had key relationships with Whānau Ora collectives from around the country, they would be able to support the research team to identify whānau Māori who had experienced an in-hospital adverse event. Using this approach, the research team recruited 17 of the 21 whānau who agreed to take part in the study.

The information collected from the 17 whānau is presented below. A thematic analysis was completed, which identified and grouped similar responses under one major theme. This method also ensured whānau anonymity was maintained throughout the entire research process.

Whānau demographics

Table 1 shows the gender and age makeup of the 17 whānau Māori who participated in the semi-structured interviews. Whānau came from across the country and from four DHB catchments.

Table 1: Whānau gender and age range

Gender	Number
Male	3
Female	14

Age range (years)	Number
40–49	3
50–59	5
60–69	5
70–79+	4

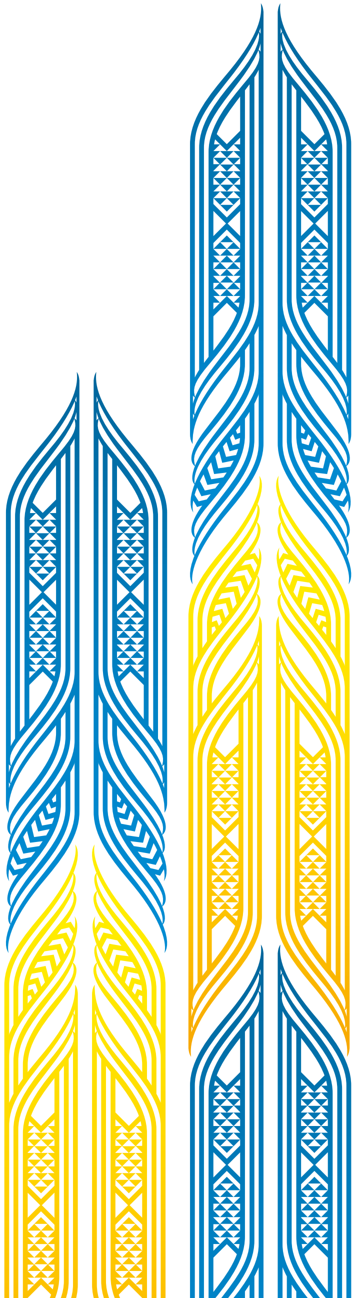
Iwi affiliation

Whānau participants identified a vast range of iwi affiliations. Identifying iwi connections was important to build the researcher–participant relationship; however, it was unnecessary to record for the purposes of the research.

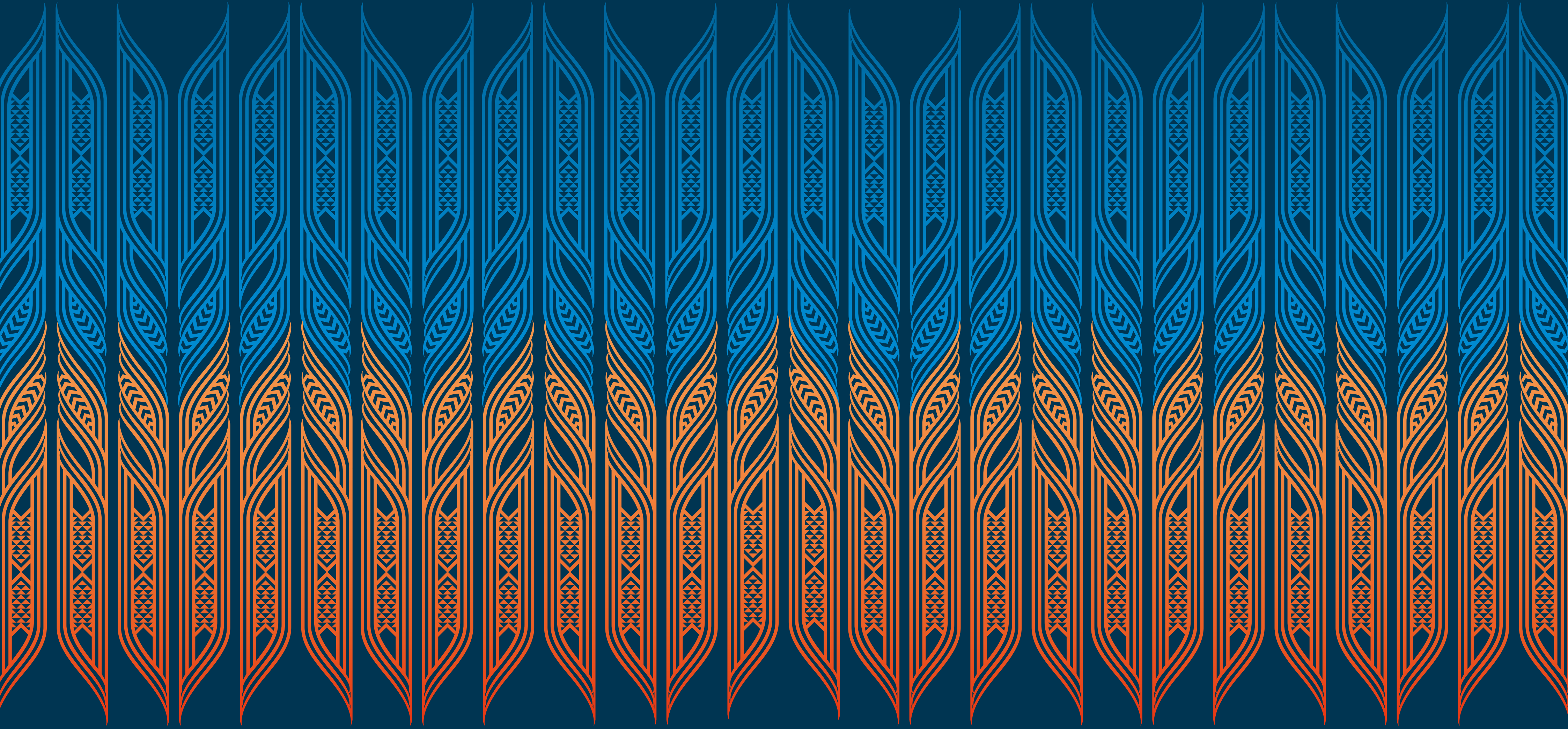
Clinician participants

Clinicians from a range of hospitals were invited to take part in the project. To ensure responses were gathered from several regions across the country, we targeted hospitals from both urban and rural locations and, where possible, a range of clinicians (for example, doctors, nurses and quality improvement leads). All participating clinicians had many years of experience working in the health sector, ranging from six years to more than 25 years of service.

The next section presents the findings of the research. The findings for each group of participants are grouped under major themes specific to that group. We have included comments from individuals to highlight and strengthen each theme. It was also anticipated that these comments could help staff identify and manage in-hospital adverse events.



NGĀ KITENGA | FINDINGS



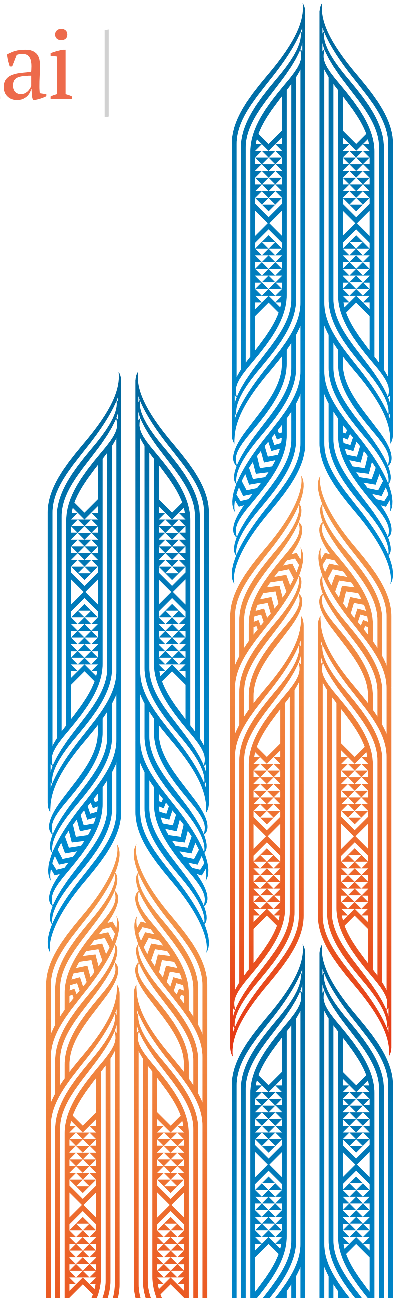
Ngā kitenga a ngā whānau whakauru mai | Whānau participant findings

Describing an in-hospital adverse event

While whānau were not asked to provide specific detail about their adverse event experience, they were asked to describe what they believed an in-hospital adverse event was. This question yielded a range of interesting comments, many of which highlight that whānau had mixed views. Whānau described in detail their adverse event information. Many had an emotional recount of their experience of the event.

To note, all whānau self-reported as experiencing an in-hospital adverse event for this project. When the research team applied the Commission's SAC rating tool events to the reported events, some events aligned to the SAC 1 or 2 domain of the criteria (causing death or significant harm) and others fell within the SAC 3 or 4 domain (causing minimal to no harm). In general, whānau levels of understanding what a SAC 1 or 2 adverse event was were the same. One participant described it as, 'when something goes really wrong when in hospital and with the healthcare you receive'.

Many whānau explained poor behaviour or not being listened to when voicing a concern as adverse events. However, as the conversations unfolded, many whānau had indeed experienced significant harm, a prolonged stay in hospital or an injury as a result of an adverse event.



In total, five major themes and two sub-themes were identified from the comments collected from a selected group of whānau Māori. These themes were:

1. **Communication issues** – whānau were not updated or informed about what was going on with their care.
   a. **Am I being heard?** – a sub-theme of communication issues; whānau believed that, when voicing concerns, these were unheard.
2. **Perceived lack of care** – whānau considered the care they received was inadequate.
3. **Lack of general respect** – whānau views were strong about a general lack of respect, including a real lack of empathy.
4. **Cultural safety and culturally appropriate services** – culture was not included or considered at any point of their care.
   a. **Unconscious bias** – another sub-theme that is included because whānau believed being Māori impacted on the care received.
5. **Whānau views to improve the system** – this is a major theme that adds value and insight into elements of change that may improve the safety and quality of care provided to whānau.

Whānau perceptions of each theme are discussed below.

Communication issues

For the majority of whānau who participated in the study, there was a belief that a lack of communication was a real issue. All 17 whānau were asked to describe their experience during their admission into hospital. Whānau said the admission process was 'stock standard', where they [the hospital staff] asked a range of general questions prior to the whānau being medically assessed and then admitted to hospital.

Participants were then asked if, during the admission process, they were given the option of having a support person or an advocate to support them during their initial admission stage. Most whānau said no, they were not offered that support, and many said they could not remember if an advocate or support person visited at any stage during their care.

There were also a number of whānau who said they entered the hospital via an ambulance and their admission was faster than when they were assessed through the accident and emergency department. Many (9 of the 17) described the ambulance staff's behaviour, manner or treatment towards them as much kinder or gentler than that of the hospital staff. One person said,

> 'The paramedics… were awesome, although she did not like going with them… but she went willingly. They treated her with gentleness and patiently and gave her time to ask questions. They were very respectful… I suppose in terms of comfort they were very good.' (W5)

Another person said that once they entered the hospital there was a real lack of communication and they were unclear as to what was going on: 'We were not too sure what was going on and what the delays were when we were to see the doctor.' (W5)

Whānau considered hospitals sometimes were understaffed, and doctors and nurses could be overworked as a result. Five people said the 'wait time' to see the doctor (after admission) was long, and one said, 'not one person kept us informed of what was going on'. (W4)

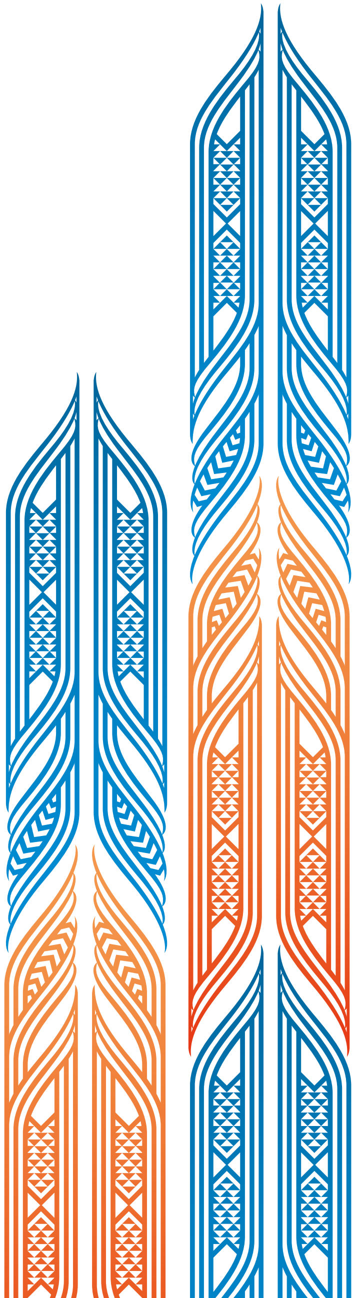
Informing people of all outcomes of their health and wellbeing situation is key to keeping them involved. Not undertaking this simple act could be considered as a missed opportunity to build and maintain a key relationship with people. The whānau in this study reported a real sense of a lack of clear communication.

Am I being heard?

The lack of communication was not restricted to just the admission process. For some whānau this extended throughout the duration of their stay in the hospital. Interestingly, whānau-perceived communication issues included an inability to voice their opinions or concerns about their health and wellbeing. For the vast majority of whānau, they believed they were not listened to when questions were asked about their care, including explaining levels of pain and discomfort.

There were six people who said they 'complained' to medical staff about their pain levels and claimed they were made to feel like their opinions or concerns were unimportant. One person said,

> 'I was treated like I was dumb. I was treated like I didn't have a voice or an opinion. I was not listened to… I was treated like I was a hypochondriac. I was treated like, you're not really sick you are just fat, you're over-exaggerating.' (W2)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Another person gave an example of not being listened to and said no one listened when they complained.

> 'I was constantly told there was nothing wrong with me and the pain I was feeling was a part of the process. I complained about the pain… they kept telling me, I had stretched muscles… I was fine and there was nothing wrong with me… all I needed to do was walk up and down the corridor.' (W3)

For some whānau, not being listened to while in hospital was an everyday occurrence, even when explicit instructions were given and were added to the file of the patient. One person, who was the advocate and 'spokesperson' for the welfare of her father, said,

> 'I said to the staff and I made them put it on his file that they were not to tell my father anything significant or give him any information about his diagnosis without me being there or tell me first. I did this because I had experienced how he misinterpreted information in the past.' (W1)

This person continued to say that most of the hospital staff believed they knew what was best for their whānau member.

> 'We [my whānau and I] all knew that he was going to pass away, and we accepted that, but we believed that it may have been better he passes in the comfort of his own home surrounded by his whānau, not alone in the hospital.' (W1)

Perceived lack of care

The idea of providing whānau with inadequate health care that causes significant harm or impacts on a person's wellbeing is rarely discussed in open forums and very seldom included in research. However, for most of the whānau in this study, their perceptions of lack of care are based on a tangible experience, and they feel that the lack of care resulted in a negative outcome.

Many whānau associated experiences of adverse events with a perceived lack of care they received. Whānau who believed their care was inadequate provided in-depth explanations of their experiences. One person said,

> '… [T]he hospital staff could not tell us if she had eaten during the day… we could see they were not changing her regularly… she had been left in a soiled nappy for over an hour.' (W5)

This person goes on to say that 'the care received was so inadequate in terms of hygiene, in terms of physical wellbeing or spiritual wellbeing' (W5).

Throughout the findings there were different levels of 'perceived lack of care'. For example, one participant said he went in and out of hospital multiple times with the same problem and pain. He said he had four operations to investigate the problem and it was never properly fixed. Shortly after his last operation, where they inserted a tube into his lower abdomen, he said the doctors and nurses constantly told him he had to leave because they needed the bed for people who were actually sick. Although he explained to the doctors that he was still in pain, a few hours later, he said he was escorted out of the hospital, by security staff, with the tube still in place.

At the time the interview was conducted, this participant began to sweat and claimed he was in excruciating pain. We paused the interview so he could take pain relief and recompose himself, and when the pain subsided the interview was completed.

Another person said there were many incidences where the lack of care that their whānau member received was terrible:

> 'He would talk about how the staff had left him in the shower on a number of occasions and for long periods time… he said they would say they needed to go and do/get something… come back about half an hour later and he would be freezing cold.' (W1)

This person went on to say,

> 'They [hospital staff] were supposed to assist him to the bathroom because he was partially immobile, but they didn't, they had other priorities… he fainted in the bathroom a few times. On one occasion when he fainted, they did CPR on him, I said you know he has an ICD inserted so you would just need to do the breathing? They told me yes but at the time the team that was on did not know that. From that he ended up with bruised ribs and pain in his chest.' (W1)

One woman said for many years she suffered from a sore wrist that would swell often. She said, 'At times it was so bad that I had wear a sling for months at a time' (W12). She had an operation to release some of the pressure and regain some mobility in her hand. She said that her doctor smelled like alcohol and slurred when he spoke. While she did not think any of that at the time, after a few months her wrist never healed properly, and to this day, she cannot move it properly. She goes back to the doctor often to relieve some of the pain she has.

The experiences mentioned above were not experienced by all whānau. One woman said,

> 'If I am honest, they were very good and very nice, and if I think back, I cannot remember if I had any issues with the care I received. Although mostly I think it might have been because I am a good patient.' (W16)

However, as she continued to talk, she said,

> 'I had a hip replacement… the doctors and nurse began to panic, because it got infected and I ended up staying in hospital for an extra two weeks. I was in so much pain… and I never complained, but then I didn't know that I could complain about that.' (W16)

General lack of respect

All whānau participants believed the care they received lacked a general respect and that staff made comments or broad assumptions about their background.

For some whānau their dignity was not considered and there was no opportunity to maintain privacy, nor was it offered. For one woman, her stay in hospital was fraught with multiple issues, including having to share a room with seven men. She said, 'I thought it was odd that I was the only woman in the cubical; but I did not want to complain, although, I was too unwell to complain as well' (W15).

She was moved to a female room/ward only after her husband complained to the nurses. He said that, while they were not happy about moving her, they did, '[a]lthough the fact that I had to ask to move her [when she was so unwell] was odd and just bemusing' (W15).

For another participant, his admission began as 'a normal procedural process' (W11). He said he was handed a form to complete and ushered to a seat in the waiting room. Just before he sat down the nurse on duty asked: 'What are your expectations of us? You know we cannot help and there is nothing we can do' (W11).

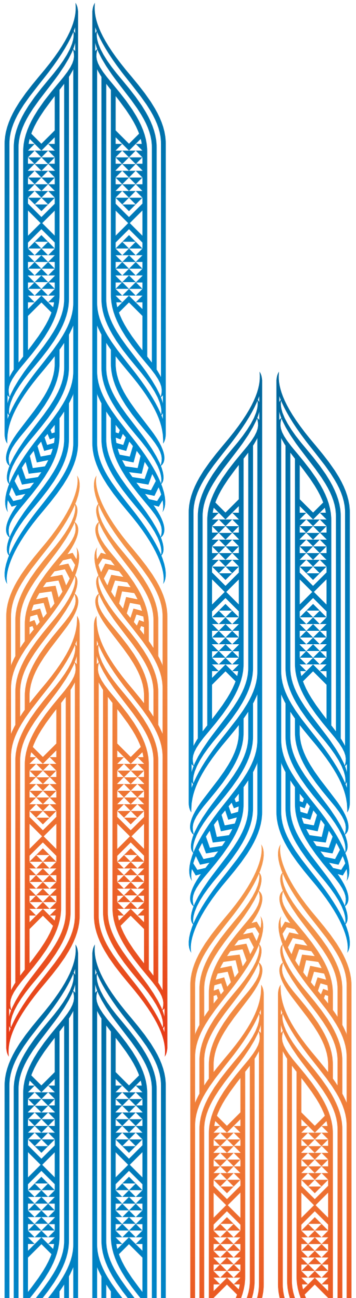
For this person the lack of empathy without consultation was unexpected and overwhelming. 'It took me a couple of minutes to collect my thoughts to say well the expectation is that you will help me with my pain, and she goes well you know we cannot help you with that.' (W11)

Generally, people enter into the health care system because they are unwell and require support to restore their health. However, for this person to be asked his expectations of the hospital demonstrated a lack of 'tact' and a general lack of empathy.

Cultural safety and culturally appropriate service

Participants were asked to describe levels of cultural safety while in hospital and if the care they received was culturally appropriate. All but one person who took part in the study said culture does not seem to be an element that is considered important when accessing health care services. Similarly, when the question about culture was posed, participants gave similar responses. All whānau said that, in the care they received, it was evident their culture was not considered.

One person said that once a person goes into the hospital it becomes a process of 'paint by numbers' where the communication with whānau is nil. For many people, being admitted into hospital is a frightening experience, where they feel vulnerable. Advocating for yourself in an uncomfortable situation is difficult even when you are well. Being in a position of vulnerability can be exacerbated when you are unwell and advocating for yourself can be a difficult situation to manage.



One person said,

> 'It would have been really helpful [for staff] to have known my whānau member was Māori and was an elderly kuia. It would have been really helpful to have had someone meet her… who could talk te reo so that she knew what was going on… and who could take care of kawa and tikanga… to do karakia to settle her would have helped and made a big difference for her.' (W8)

While this person said the whānau could have assisted with these rituals and did at times, the service offered by the hospital to meet cultural needs was not a part of the care provided.

For many, Māori culture is a key component to their wellbeing and one whānau explained how staff interacting and delivering care to whānau was a very important factor in their care. It was interesting that Taurangamoana is one of the only hospitals across the country that has successfully created and implemented a kaupapa Māori ward. This means that Māori cultural concepts are at the forefront of how hospital staff interact and care for whānau. On admission to this hospital, whānau are asked if they would like to be admitted into the ward.

One whānau member compared their experiences of being in the Taurangamoana kaupapa Māori ward and another hospital. The most interesting part of this person's kōrero was when she said, 'the kaupapa ward had a number of non-Māori who elected to be admitted into it' (W14). When she asked the other patients why they said yes to being admitted into this ward, they said, 'because every morning staff here take the time to say hello and talk to you… they treat you with respect, dignity and basic human kindness… not many others do that' (W14).

Unconscious biases

Unconscious bias is a contentious, 'touchy' subject or theme in this case because it takes the position that people make assumptions or judgements about another person based on race. For participants in this study, they believed clinicians' assumptions negatively impacted on their wellbeing. All the participants claimed that, because they were Māori, they were treated a little differently to other people, and some described 'poor' behaviour when accessing publicly funded health care services. A few whānau claimed they knew and understood racial biases because they had experienced them most of their lives.

Some participants said they were treated so poorly that staff's behaviour bordered on discrimination. One woman said she could hear nurses mocking and laughing at her because she was Māori. They assumed she had limited education and lived in poverty, which was not the case. She said, 'it was bizarre… it was horrible… so I left still in pain' (W2).

Another person said she spent many hours arguing with hospital staff and doctors about other options that would extend and improve the quality of life for her whānau member. She said not all interventions were presented to them at the time of admission and, when she asked, they were told there was nothing they could do because although they could do an operation, her whānau member may not survive it. However, when offered an option of choosing between having an alternative intervention with the risk of dying or do nothing and die, the whānau chose to take the risk and have the operation. As a result, their whānau member lived another decade. This person said,

> 'In that 10 years he got to know lots of moko… so if we had not had that argument, he would have died… and so, I wondered how many other whānau are told the same thing that there was nothing they could do… you should just go home.' (W8)

Others believed they were not given appropriate care because assumptions were based on the way they looked, with no investigation into why pain was present. One person said, 'she was told she was fat and needed to walk around because the pain she was experiencing was a part of the process' (W4).

They went on to say, 'you get the impression that because I'm black I get spoken to this way… so I'll save myself the agony… and I'll fix it myself' (W4).

Assumptions purely based on appearance can be harmful and negatively impact on the way whānau interact with clinicians. One woman said her whānau member, who was elderly, was a very articulate woman, and although she was not deaf, she was treated like she was. She said, 'they yelled not to be angry, but they treated her like an old Māori woman that was deaf… they were condescending in the way they dealt with her' (W9).

This woman said they [the doctors and nurses] would look at her rather than look at the whānau member in terms of wanting to know answers to questions asked.

Whānau views to improve system

All whānau were asked to consider what improvements would help hospitals to provide better-quality health care to them or their whānau members.

Similar to the unconscious bias theme, one person said,

> 'If I could change people's assumptions, I would change that so they [hospital staff] would not base their perceptions on how others look… if there are training programmes that could help people identify and consider negative assumptions or perceptions of others who are not them… before they interact with whānau would help.' (W5)

She went on to say,

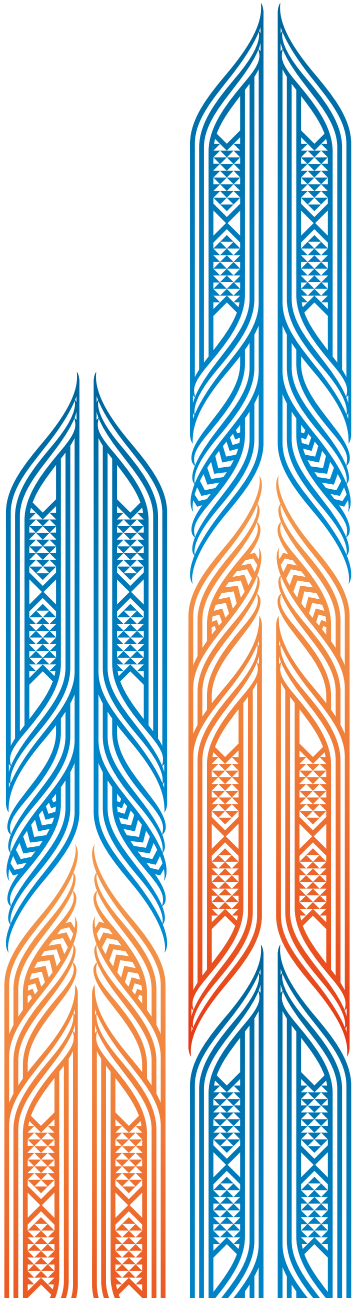
> 'I don't know how to change racism or change institutionalised racism… how do you change systemic racism because I did not [once] feel like I was a valued member of society… who deserves to be well.' (W5)

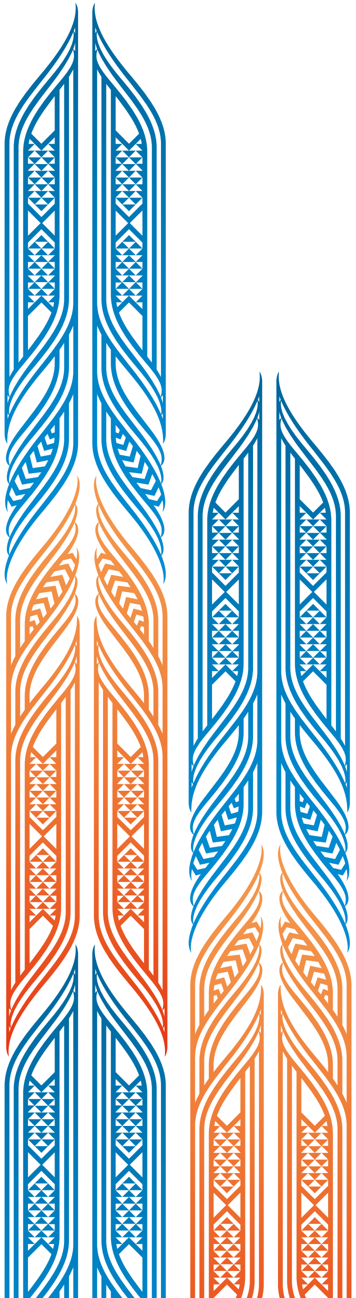
Another person said the current cultural practice training programmes were not good enough as the application of cultural safety and competence is not appropriately applied for whānau, '… and I think this one is a biggy' (W4).

One whānau member explained that, for older Māori, providing advocacy would help them understand the processes involved with admission and make them feel more comfortable. She said,

> 'When I've been in hospital, I feel vulnerable, I am not my best advocate when I am unwell… it feels… that the nursing students have a cultural component missing and they have a lack of understanding of how to work with Māori… especially older Māori.' (W5)

Lastly, it would have helped the research team access whānau reported to the Commission during 2017/18 who experienced an in-hospital adverse event if each DHB had created and maintained strong relationships with their community Māori health and social service providers. This process would ensure a pathway to access whānau is considered and remains constant, and that contact details are valid. As this was not the case (for all but one DHB), the DHBs could not help the Commission find whānau who reported as having a SAC 1 or 2 in-hospital adverse event during 2017/18.





Ngā kitenga haumanu | Clinician findings

The clinician interviews/surveys were to gauge their experience and understanding of in-hospital adverse events and to identify or determine the processes involved with reporting and managing the event.

Unlike whānau, clinicians were given the option of either completing a survey questionnaire or undertaking a telephone interview with a research team member. This was to ensure the research did not cause any disruptions to their workloads.

Of the eight clinicians that participated, two completed telephone interviews and the remaining six completed the survey questionnaire. All surveys were sent electronically and stored in the Commission's secure database. A copy of the survey questionnaire is attached (see Appendix 2). A thematic analysis was undertaken on all responses gathered and the findings are presented below.

Describing adverse events

In line with the initial question that whānau were asked, clinicians were asked to explain their involvement with a SAC1 or 2 adverse event (as a reviewer or provider of care). This question was used to set the scene and ensure these participants had experience with managing and/or reviewing in-hospital adverse events.

All eight said yes, they had some involvement with an in-hospital adverse event. Clinicians were then asked to discuss the type of adverse event they were involved with.

Of the eight participants, seven gave a brief overview of the event and explained which SAC criteria the event met. The remaining person said they did not want to discuss details of specific events because their community was small and people could be recognised and/or identified. One person's response centred on engagement with te ao Māori, but they were not Māori.

There was a total of three major themes, and while two themes were the same as those identified for whānau, the other was role-specific and related to levels of training targeted at the review process of an adverse event. The three major themes for clinicians were:

1. open and clear communication/disclosure
2. preparedness to review events
3. culturally appropriate review process.

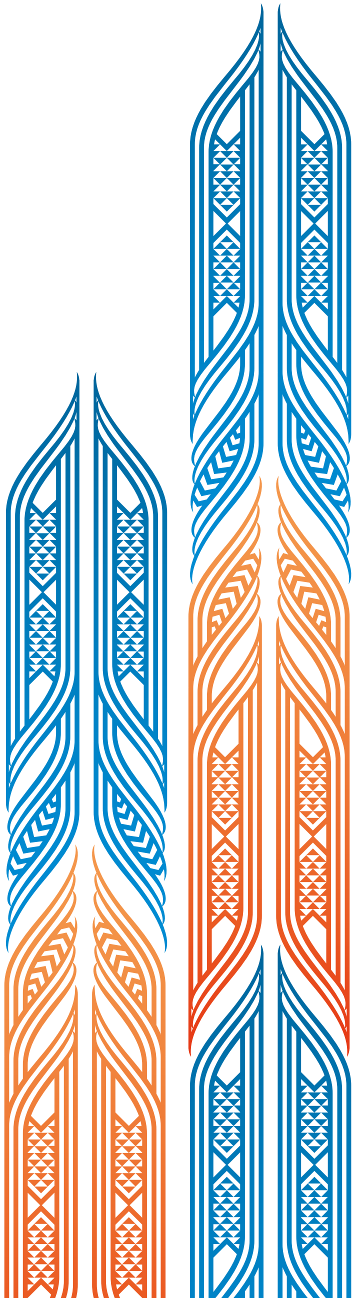
Open disclosure and clear communication

Most clinicians said that open communication/open disclosure occurred for consumers and/or their representatives when an adverse event occurred, or when a serious complaint had been received, regardless of whether the patient had suffered harm while receiving care. One person said, ‘consumers are entitled to open communication/open disclosure under right six of the Code of Health and Disability Services Consumers’ Rights.’

All eight clinicians stated that open and clear communication was provided during the entire process of reviewing and managing adverse events. Each person gave a detailed account of the processes that were undertaken, with many of them talking about the documentation process and ensuring they presented factual and complete information.

To demonstrate opportunities where open communication was clearly used, participants described a whānau hui process to inform the whānau an event had occurred, then explained who would be present at the hui. There were four participants who also said during the whole process the Māori support team (attached to the hospital) was involved.

Participants said that during and after an adverse event whānau were given an opportunity to ask any questions of the clinical staff involved and/or senior staff.



Preparedness to review events

Clinicians' views of preparedness to review adverse events centred on lack of education and training programmes. To manage and review events, clinical staff undertake a range of training and educational programmes, and many talked about specific programmes that were offered. Five participants discussed possible training programmes that would include specific information aimed at improving the management and review of adverse events. One person said this inclusion 'may also ensure optimal coverage and understanding within trained staff'.

Another person said,

> 'Training on doing SMART recommendations in reviews should be provided – then, they make more meaningful, less judgemental, actions. This means people will start to believe that the reviews are system focused rather than that just being lip service.'

However, many of the participants said they had limited opportunities to take part in educational programmes aimed at managing review processes when adverse events take place, and some reported they had not received any training. One person said they had no training apart from many years as a clinician. Another person said, 'senior and junior doctors are not well supported in processes that follow an adverse event... I think this training is needed at medical school'.

Culturally appropriate care

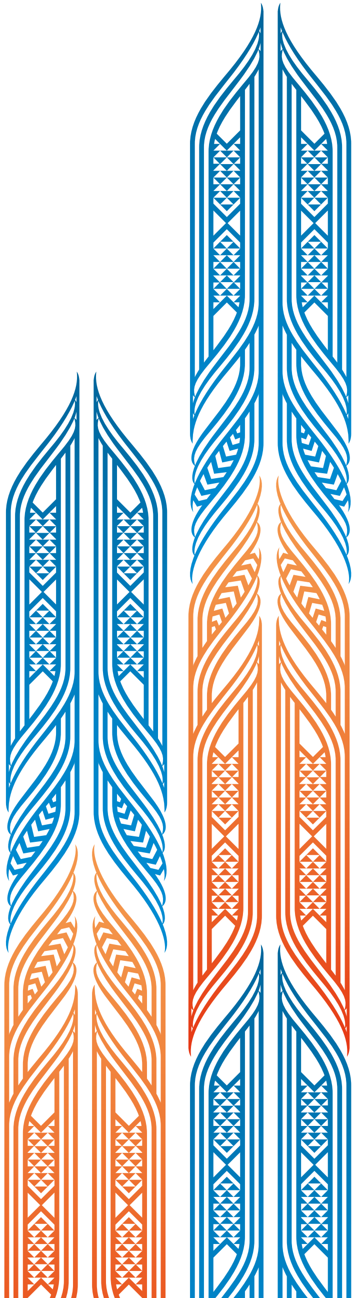
Many of the participants said that, although they had received tikanga Māori training as part of their induction to the hospital, this needed to be ongoing. One person said that learning te reo in a non-health care setting is very helpful.

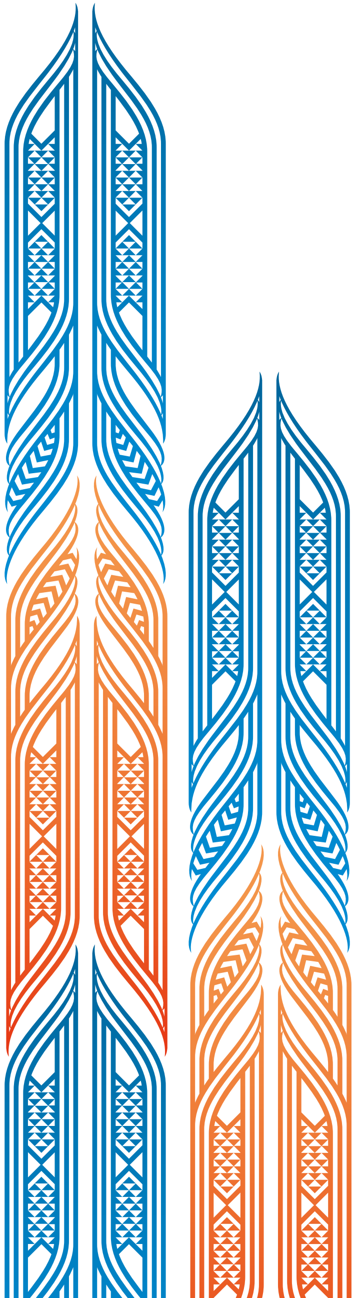
Another person said they had completed a number of cultural competency papers as part of their formal education and had attended DHB-based workshops on the subject. This person went on to say, 'I also have frequent informal discussion with peers and colleagues… which is always helpful'.

One person said that,

> 'All new and existing staff have participated in our cultural training programme run by the Māori Health Service… whānau centred care is one of our key guiding principles throughout the hospital.'

In contrast, one staff member said their cultural training had been very minimal but they had made attempts to attend some departmental registered medical officer teaching sessions on this topic. This person went on to say that the training sessions had been quite theoretical – that is, they had a strong Treaty, equity or language focus, but less practical advice.





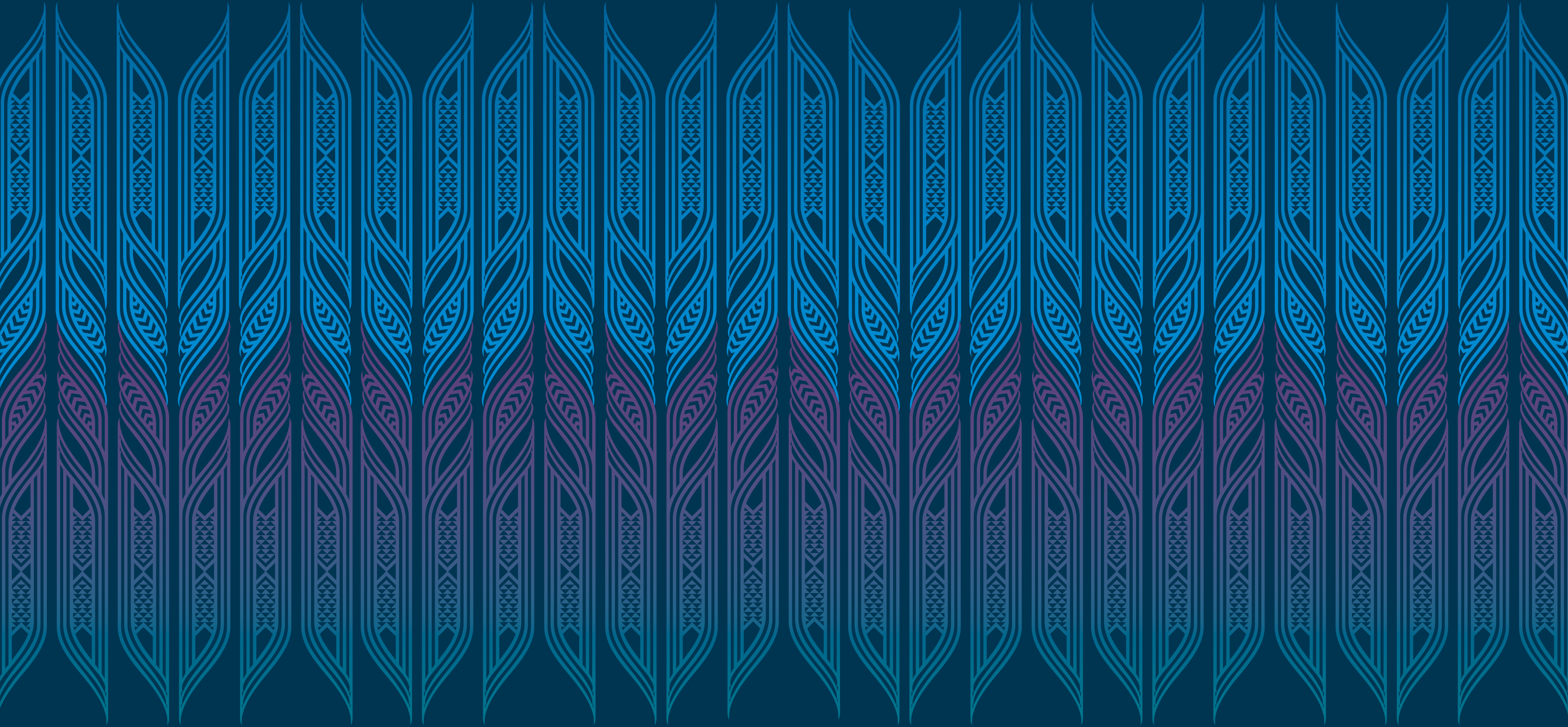
Improvements

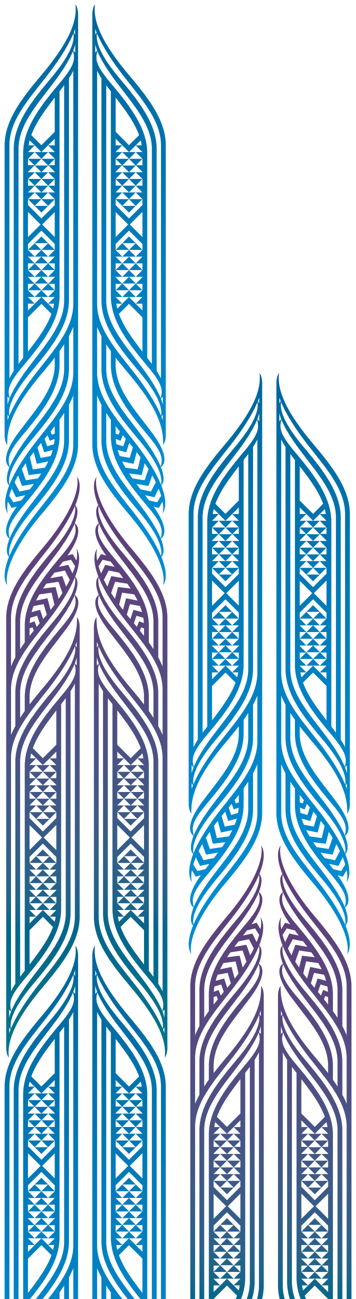
Clinicians were asked to discuss what they thought would help improve the management and review process of adverse events. One person said that, when reporting on a SAC 1 or 2 events, it would be helpful to have feedback because currently this process is minimal: 'We often rely on corridor conversations or chasing emails to find out where things are up to.'

Like whānau, clinicians believed that implementing a follow-up process when adverse events occurred would keep them updated and informed about the outcomes of the review.

Similarly, clinicians also consider that regular communication to whānau (usually waiting for an update of outcomes) requires improvement. One person said, 'we could do with more staff supporting quality activities, and we have limited resources'.

TĀTARI ME TE WHAKAKAPI | ANALYSIS AND CONCLUSION





Tātari me te kōrerorero | Analysis and discussion

Although the information presented in this document offers insight into whānau Māori experiences of adverse events, we must advise caution when generalising the results or findings of this research, as they are relevant to the 17 people who participated in it. However, while their explanations are specific to their experiences and may differ from other populations or other whānau, for these people their views and comments reflect valid experiences they believe caused significant harm.

As mentioned above, due to complications and challenges recruiting whānau participants, the method of recruitment was modified and whānau were accessed through alternative avenues (for example, Te Puni Kōkiri regional offices and several Māori health and social service providers from across the country).

Through these avenues, all identified whānau participants who experienced an in-hospital adverse event were self-reports. While some whānau experiences happened during 2017/18, our ability to control this was limited, and for at least two whānau their experience occurred five years prior to 2017/18.

Describing an adverse event

At the start of each interview, whānau were asked to explain their views of an adverse event. This question was included to gauge understandings and knowledge around what an in-hospital adverse event was. While whānau knowledge about SAC 1 and 2 adverse events lacked specific detail outlined in the criteria of the SAC rating and triage tool for adverse events, comments demonstrated whānau had a good general understanding of what in-hospital adverse events entailed.

Overall, their descriptions of an adverse event varied across the group and were broad. Their understandings ranged from causing significant harm to behavioural issues or the way whānau were treated while in hospital.

However, when the criteria set out in the SAC rating and triage tool for adverse events was applied to each event, all whānau self-reports of an adverse event corresponded to at least one SAC example outlined in the SAC criteria, with many examples falling within either the SAC 1 or 2 domains.

Many whānau had experienced an event that resulted in death or permanent severe loss of function (SAC 1) or an event that resulted in permanent major or temporary severe loss of function (SAC 2). However, for most of these whānau it was not the result or end outcome of the event that they considered important to discuss – the most important thing was the way in which they or their whānau member was treated during a time of significant vulnerability.

Communication issues

Communication or lack thereof was identified as a major concern for whānau in this study. This was a similar theme outlined in the 2014/15 *Learning from adverse events* annual report, which highlighted that 'communication failure was the most common theme identified in an analysis of clinical deterioration relating to serious adverse events' (Health Quality & Safety Commission 2015).

Describing the need to ensure clear and open communication is at the forefront of care, Court (2003, p 100) states,

> '... [A]n unexpected outcome happens during the course of care, it precipitates a feeling of extreme vulnerability in a patient. It is a time that patients are most dependent on the professional relationship. In this circumstance patients will experience a human compulsion to strive to understand the reasons for this outcome. Hence, they will expect an open and honest discussion following an adverse event. An empathic acknowledgement of that adverse outcome is the first step. Allowing the patient to determine the extent of information provision is the second.'

Whānau defined communication issues as being uninformed or not being kept up to date with any outcomes or decisions about care. Clear communication can be considered the most fundamental or basic act that allows people to inform others of outcomes or processes that may not be otherwise clear.

Although clinicians' perceptions of open communication were very clear and demonstrate considerable thought has been given to this question, they were directed at managing and reviewing the processes involved when an adverse event occurs and not at the care provided.

While there are similarities between whānau views and clinician views of what open communication should include, such as being open, truthful and responsive, whānau emphasised that open and clear communication should be a process that is considered for the duration of their hospital stay.

Raphael-Grimm and Zuccarini (2015) said positive interactions are the essence of happiness, where people can share moments of connectedness and gain a sense of affirmation or belonging. When clinicians and staff offer small gestures of direction, this simple act can be considered as extending an opportunity to support and provide comfort to consumers. For many participants in this study the lack of communication made them feel more vulnerable and dissatisfied with the service.

An unintended outcome of the study was that whānau compared hospital staff behaviours and levels of communication with those of ambulance staff in terms of the way they were treated throughout their health care experience. Many whānau felt that factors such as personnel issues and overworked staff may have contributed to the lack of clear communication. Unfortunately this study was unable to identify whether differences existed between ambulance staff and hospital staff behaviours, however, it would be an interesting question for future research.

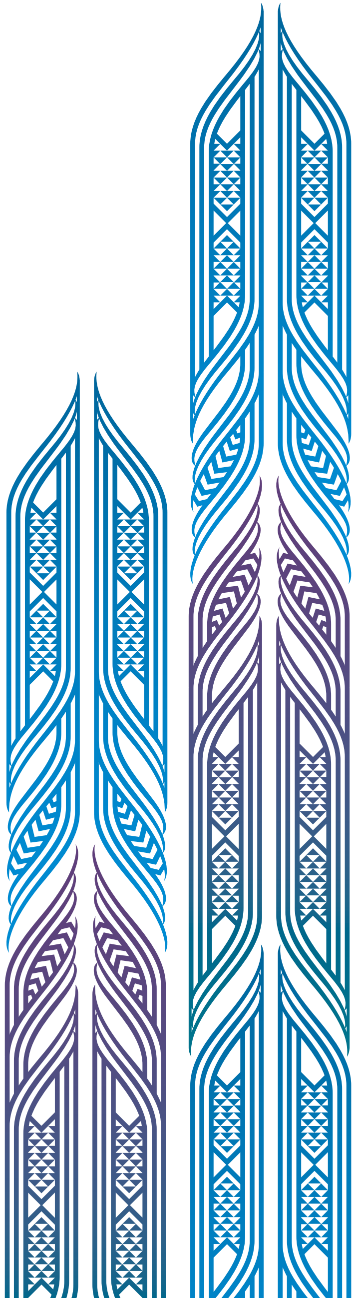
‘Am I being heard?’ and lack of respect

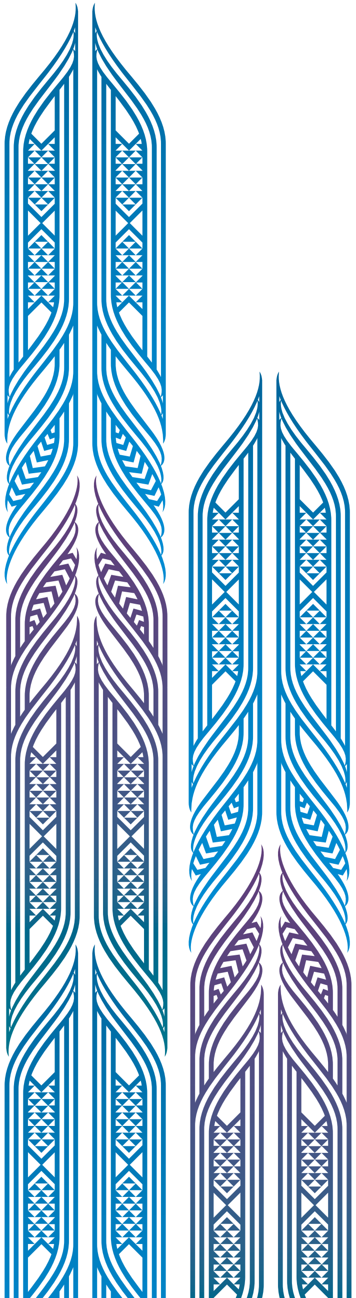
Communication issues were intertwined with other concerns such as behaviour, the way people were treated or a genuine lack of empathy being displayed. Raphael-Grimm and Zuccarini (2015, p 1) said: ‘Often worried, embarrassed, and sometimes in fear of death, people navigating the health system are especially sensitive to the manner in which they are treated.’ For many whānau in this study, the most memorable moments from their experiences of being in hospital are of how they were treated before, during and after the adverse event.

Many people may consider that voicing concerns is a mundane act in any everyday situation. However, during a time when people are unwell and feel most vulnerable, this can be a daunting and challenging situation to be in. Similarly, advocating for oneself when unwell is also a difficult situation that many people experience while in hospital.

Most whānau felt that, when they voiced their concerns, they went unheard or unnoticed. For example, when whānau complained about their pain levels, they were made to feel like they did not have a voice and that they were not telling the truth, and they were treated without respect and dignity. Chadwick (2012, p 188) claimed, ‘dignity and respect are fundamental elements of interpersonal interaction and which, as human beings, are part of our intrinsic basic human rights’.

Similarly, Gallagher (2004, p 1) argued that, ‘dignity can be considered both subjectively, taking into account individual differences and idiosyncrasies, and objectively, as the foundation of human rights’, and Magri (2019, p 332) claimed: ‘Respect inspires a specific attitude towards others which is not informed by benevolence or care but rather by the recognition of dignity.’ For the people in this study, these basic human rights or values were not afforded to them and, as a result, the poor behaviour is what they associate with an in-hospital adverse event.





Perceived lack of care

Of all the themes presented in this document, 'perceived lack of care' is the most compelling and distressing finding, because these whānau considered that the care they received was poor and inadequate.

While 'perceived lack of care' is a contentious topic that relates directly to the delivery of care, it suggests that, for whānau Māori, the Aotearoa New Zealand health care system is failing. Based on the views of 16 of the 17 whānau who participated in the research, the care provided was well below average and requires immediate action to rectify. This subject opens the door for further research to identify why this occurs and what actions are required to address it.

To understand the concept of poor or inadequate care, Shanahan (2019) explained care is understood as the delivery or receipt of clinical and interpersonal attention. She continues to say the consequences of poor care can be global in nature and include neglect and abuse, which can be hidden, unintentional and unrecognised.

Clinicians were not asked to discuss their views about dignity and respect or whether they listened to whānau complaints. However, their comments demonstrated that they believed whānau were treated with dignity and respect and were given every opportunity to voice concerns and ask questions during the review process of an adverse event. This is in stark contrast to what whānau believed. Whānau reported they were not listened to and not treated with dignity and respect.

Preparedness to review events

Clinicians spoke about their preparedness to review adverse events. While some reported educational opportunities they had participated in, others reported they had not undertaken any or had completed educational programmes long ago. Clinician participants claimed that private training providers delivered a large number of courses that focused on investigating incidents and most of these courses were aimed at health and safety events.

If we are to improve whānau Māori experiences of the health system during the process of an in-hospital adverse event, then staff need to have greater access to educational programmes.

Culture

Hospital staff including or considering culture in the delivery of care was not an element that was readily seen or experienced by participants. However, for many Māori, culture is not a separate element that is considered in isolation (Barnes et al 2017). For many, culture is key where wellness is determined (Valentine et al 2017). When cultural competency, cultural safety and delivering a culturally appropriate service to Māori is part of the core curriculum of new clinical staff, training programmes that deliver elements of culture need to be changed or improved. This may involve teaching practical applications of cultural safety and/or in-depth follow-up training sessions for clinical staff.

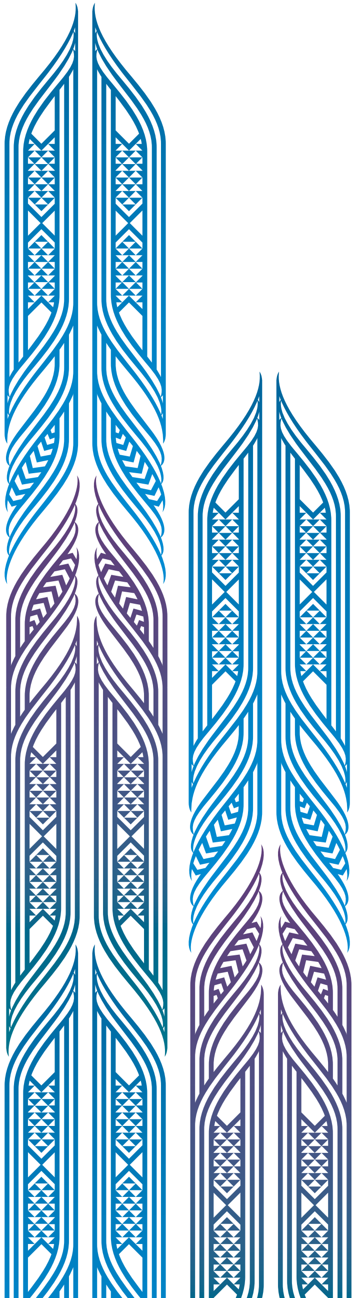
Unconscious bias featured as a sub-theme of culture. Whānau claimed unconscious bias also affected the care they received. Marcelin et al (2019, p 563) explain that, ‘overt discrimination in medicine based on gender, race, ethnicity, or other factors have become less conspicuous. Nevertheless, unconscious bias still influences all human interactions’.

Perry et al (2015, p 66) claim that, ‘making people aware of inconsistencies between their core value of equality and racially biased attitudes produced less prejudice and lower levels of discrimination immediately and for several weeks after the intervention’.

For these whānau Māori, overt biases, racism and discrimination were experienced and associated with adverse events. Significant change that provides an opportunity for clinicians to understand the impact their biases have for whānau is needed. Training that acknowledges and supports them to understand the outcomes associated with personal unconscious biases is not only necessary but required to improve health outcomes for whānau Māori.

When all participating clinicians described accessing support from the Māori health unit within their organisation, it is evident that clinicians considered providing a culturally appropriate service important in their practice. Effort to include cultural practices are always considered.

When asked what training they had received, participants gave a wide spectrum of answers that ranged from no or minimal, to a few completing formal papers as part of their education. However, in order to ensure knowledge and skill levels are high and clinicians have a good understanding of why whānau Māori consider culture important to wellbeing, the level of cultural education needs to improve and follow-up sessions be provided more frequently. This would contribute towards consistency in providing a culturally appropriate level of care.



Whakakapi | Conclusion

In conclusion, the findings and analysis of whānau Māori experiences of in-hospital adverse events presented some interesting insights into a service that is supposedly safe and of high quality for every New Zealander. However, for the majority of the whānau in this study, their perceptions and experiences indicate this was not the case.

While there were some inconsistencies between whānau Māori and clinicians' views of care provided, there are also synergies that indicate further research is required to improve the current system. Moreover, it is clear that clinicians would benefit from further education or training around managing or reviewing adverse events in general. The clinicians we surveyed considered further education was needed to improve their understanding and use of cultural practices when reviewing or managing adverse events.

This research provides learning opportunities that could lead to making long-lasting changes or improvements to the current health system. With courage, the acceptance and acknowledgement that change is absolutely required would not only contribute to addressing some of the inequities that Māori experience but also support the improvement of Māori health outcomes in the longer term. As Court (2003, p 100) said,

> 'Improving patient safety is a clinical, organisational, sector, and societal imperative. To make health care safer, we need to support professionals by moving from a blame culture to a reporting culture, in order to maximise the use of data to redesign systems.'

Reflections from the research team and author

The author notes a comment by Sir Mason Durie, in the conclusion of the Commission's Window 2019 (Health Quality & Safety Commission 2019, p 6):

> 'Good health for everyone demands a society that is fair and just, committed to equal opportunities as well as equal outcomes and ready to shift the focus which is needed.'

This comment resonated and was thought of often during the completion of this project. While it may be considered a romantic idea, in order for this to happen, some key and fundamental changes need to occur in the current Aotearoa New Zealand health system so we can start addressing the inequities that exist.

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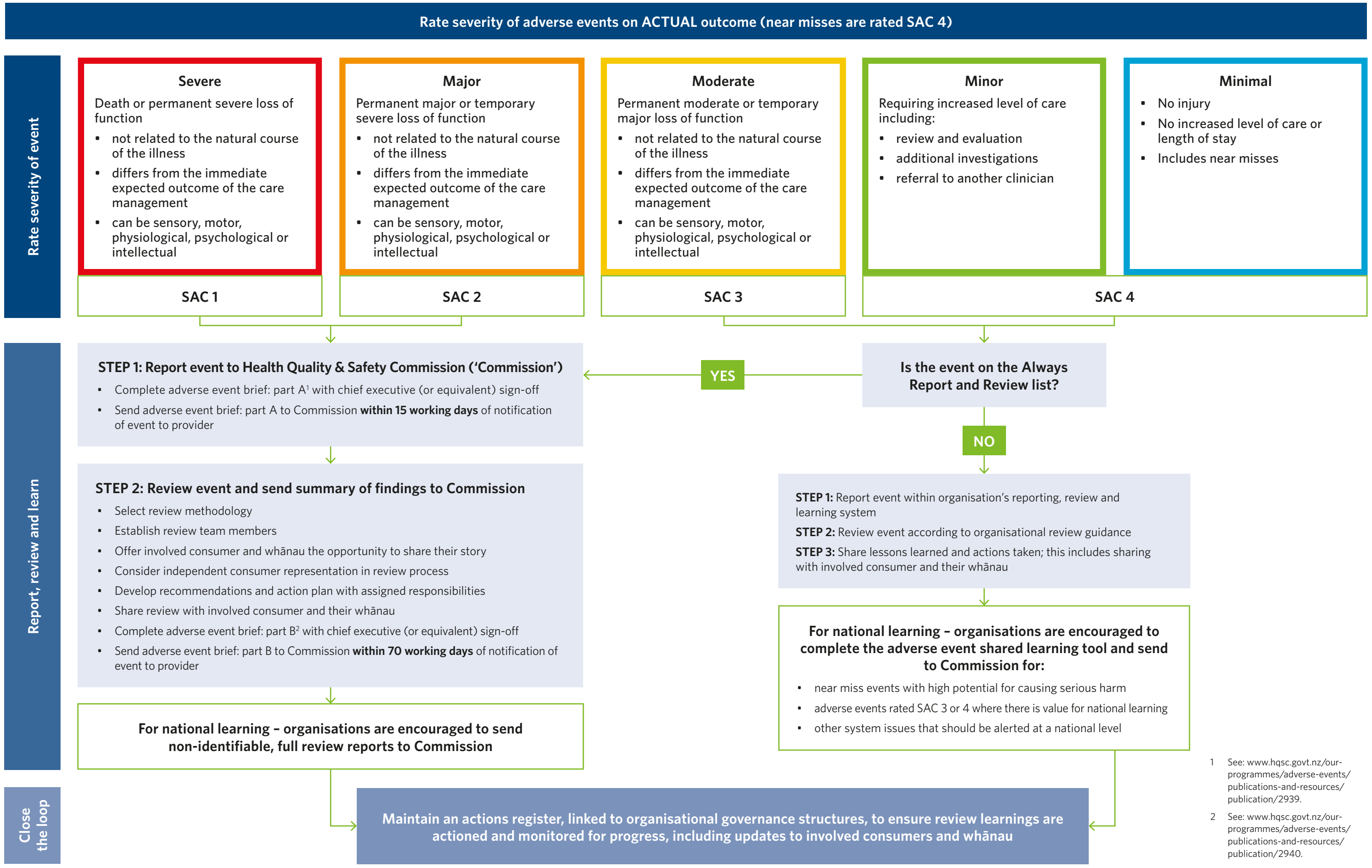
Āpitihanga 1 | Appendix 1

Severity Assessment Code (SAC) rating and triage tool for adverse event reporting

Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa



Rate severity of adverse events on ACTUAL outcome (near misses are rated SAC 4)

Rate severity of event

Severe
Death or permanent severe loss of function
- not related to the natural course of the illness
- differs from the immediate expected outcome of the care management
- can be sensory, motor, physiological, psychological or intellectual

SAC 1

Major
Permanent major or temporary severe loss of function
- not related to the natural course of the illness
- differs from the immediate expected outcome of the care management
- can be sensory, motor, physiological, psychological or intellectual

SAC 2

Moderate
Permanent moderate or temporary major loss of function
- not related to the natural course of the illness
- differs from the immediate expected outcome of the care management
- can be sensory, motor, physiological, psychological or intellectual

SAC 3

Minor
Requiring increased level of care including:
- review and evaluation
- additional investigations
- referral to another clinician

Minimal
- No injury
- No increased level of care or length of stay
- Includes near misses

SAC 4

Report, review and learn

STEP 1: Report event to Health Quality & Safety Commission (‘Commission’)
- Complete adverse event brief: part A[1] with chief executive (or equivalent) sign-off
- Send adverse event brief: part A to Commission **within 15 working days** of notification of event to provider

STEP 2: Review event and send summary of findings to Commission
- Select review methodology
- Establish review team members
- Offer involved consumer and whānau the opportunity to share their story
- Consider independent consumer representation in review process
- Develop recommendations and action plan with assigned responsibilities
- Share review with involved consumer and their whānau
- Complete adverse event brief: part B[2] with chief executive (or equivalent) sign-off
- Send adverse event brief: part B to Commission **within 70 working days** of notification of event to provider

For national learning – organisations are encouraged to send non-identifiable, full review reports to Commission

Is the event on the Always Report and Review list?

YES

NO

STEP 1: Report event within organisation’s reporting, review and learning system

STEP 2: Review event according to organisational review guidance

STEP 3: Share lessons learned and actions taken; this includes sharing with involved consumer and their whānau

For national learning – organisations are encouraged to complete the adverse event shared learning tool and send to Commission for:
- near miss events with high potential for causing serious harm
- adverse events rated SAC 3 or 4 where there is value for national learning
- other system issues that should be alerted at a national level

Close the loop

Maintain an actions register, linked to organisational governance structures, to ensure review learnings are actioned and monitored for progress, including updates to involved consumers and whānau

Published in June 2017 by the Health Quality & Safety Commission. Please send all related enquiries to: adverse.events@hqsc.govt.nz

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[1] See: www.hqsc.govt.nz/our-programmes/adverse-events/publications-and-resources/publication/2939.

[2] See: www.hqsc.govt.nz/our-programmes/adverse-events/publications-and-resources/publication/2940.

newzealand.govt.nz

Āpitihanga 2 | Appendix 2

Māori experiences of in-hospital adverse events questionnaire

Code ________________ Date ____________________

Background

For nine years the Commission has reported on national adverse events throughout the health sector. Adverse events are undesirable/unintended experiences that are associated with the health care system.

The Commission believes these events can be prevented with good systems in place, however, there is not a lot known about consumer experience of adverse events particularly for Māori. To better understand Māori experiences of adverse events the Commission is undertaking a review to investigate service effectiveness when a diverse event occurs and whether the support provided to whānau Māori is culturally appropriate.

We believe that in knowing and understanding your experiences there is an opportunity to change and improve the care that is provided to whānau like you/yourselves.

Please remember you **DO NOT** *have to discuss or answer any or all the questions asked of you.*

Questions

General

Gender ____

Age ____

Income ____

Iwi ____

Hospital/DHB ___________________________________

These next questions are before the event happened.

Do you have more than one illness that you take medication for? *Diabetes, heart disease, high blood pressure, gout…*

____

____

Can you please describe what happened when you were admitted to hospital? *How did they treat you or your whānau? Did the health professional tell you why you needed to be admitted?*

____

____

Leading up to the event can you please describe how the health care provider/s interacted with you (or your whānau) … *(how they spoke to you? did they listen to your questions and give you an answer? Did you understand the response the health care professional gave you? If not, did they explain their response further, so you could gain a better understanding?)*

____

____

Did the health care professional use open and clear communication? *Use language where you understood all that was said to you*

____

____

Were you or your whānau consulted and included in your health care decisions? If so, what did the health care professional say/do to include your whānau? What options were you given? You were included in all decisions about your care?

Before treatment were all possible risks (associated with the treatment) fully explained to you or whānau?

To the best of your ability did you follow their instructions? *Use chairs provided, take the medication they provided? Restrict movement?*

Can you please describe what mistake was made? *Medication error? Lab error? Fall? And what happened? What information was given to you after the mistake? Did anyone explain the information or was an explanation offered?*

These next few questions are about your experiences after the event.

Can you please describe what happened after the adverse event? *(What advice did they give you after the event? ie, where to go to for support, an apology, an explanation of what happened? How they spoke to you? Did they listen to your questions and give you an answer? Did you understand the response the health care professional gave you? If not, did they explain their response further, so you could gain a better understanding?)*

When dealing with the health care professional after the event how did you feel? *(Not listened to? They did not answer your questions? What advice did you receive? Were you informed about what support that is available to you? Or was support offered/provided to you after the event?)*

Do you think the care you received was culturally appropriate and met your needs? *Why?*

When you were discharged did you or your whānau receive clear instructions about what symptoms to watch for?

Did they tell you who to contact if you had questions about your treatment and the mistake/accident that occurred?

Did they arrange a follow-up doctors visit for you?

What is the one thing you would have liked done differently? *(Before and after the event?)*

Āpitihanga 3 | Appendix 3

Clinician questionnaire – adverse event process

Code ________________ Date ___________________

Background

You may be aware that the Health Quality & Commission reports on national adverse events from the hospital sector. An adverse event is an event which results in harm or has the potential to result in harm to a consumer of health care services.

The Commission believes reporting is only of value if it is accompanied by meaningful analysis that leads to system changes designed to prevent recurrence of these adverse events. The cultural viewpoint and practices of a consumer and their whānau should be considered in the open communication, reporting, review and learning process. There is not a lot known about consumer experience of adverse events particularly for Māori. To better understand Māori experiences of adverse events the Commission is undertaking a review to investigate service effectiveness when an adverse event occurs and whether the support provided to whānau Māori is culturally appropriate.

We believe that by knowing and understanding whānau Māori experiences during and after an adverse event there is an opportunity to change and improve the care that is provided to them.

Please call Glen Mitchell (021 933 475) or Te Raina Gunn (021 574 754) to organise a suitable time for us to complete an interview with you. Or if you prefer, you can complete the short questionnaire below. If you have any questions about the questionnaire or the review, please contact:

Te Raina Gunn
Email: teraina.gunn@hqsc.govt.nz
Mobile: (021) 574 754

Glen Mitchell
Email: glen.mitchell@hqsc.govt.nz
Mobile (021) 933 475

Please note you **DO NOT** *have to discuss or answer any or all the questions listed below.*

Questions

General

Name of hospital/DHB __________________________

What is your role? ______________________________

How long have you worked there? _______________

1. Have you ever been involved in a SAC 1 and/or SAC 2 adverse event (as a reviewer or provider of care)? If so, can you discuss the adverse event?

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2. Did you report the event? If so, can you discuss the process you used to report this event?

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3. If you were the reviewer or a member of a review team for an adverse event, can you describe the event and how it was managed?

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4. Can you describe the process used to review the event?

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5. Was the patient and/or their whānau informed of the event? If so, how were they informed and what information were they given?

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6. What do you understand by open communication/disclosure?

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7. Can you describe what open communication/disclosure processes were used during and after the adverse event?

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8. What training and/or education have you received to help you report and/or manage adverse events?

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9. Have you received any education in how to provide appropriate care to Māori? If so, can you describe how you ensure an appropriate service is provided?

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10. Reflecting on your experience what improvements would you suggest, supporting the adverse event management process in your DHB?

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11. Do you have any further comments you would like to add?

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Te Kāwanatanga o Aotearoa