

Shared goals of care principles for health service providers



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Introduction

Shared goals of care are when the patient, their family and whānau, and clinicians explore the patient's values along with the care and treatment options available and agree the goal of care for the current admission if the patient deteriorates.

Health service providers need to take a systems-level approach to shared goals of care to ensure these discussions occur with patients and whānau and are in line with their Te Tiriti o Waitangi responsibilities. The shared goals of care principles described here will help to guide providers in doing this.

The principles outline what is required for providers to have shared goals of care discussions with adult patients and their whānau. They may also be applied to other patient groups, for example, children, upon further exploration of the experiences of those involved.

The three articles¹ of Te Tiriti o Waitangi and the Ritenga Māori declaration² have been embedded into the shared goals of care principles. They are:

- kāwanatanga – partnering and shared decision-making
- tino rangatiratanga – recognising Māori authority
- ōritetanga – equity
- wairuatanga – upholding values, belief systems and worldviews.

The principles have been developed through literature review, lived experience, expert opinion and testing with two district health boards (DHBs). They are primarily written for use by hospitals but may be applicable in other settings.

Why shared goals of care are important

When shared goals provide the basis for clinical treatment plans, there is less risk of a patient receiving unwanted or unwarranted treatments if their condition deteriorates.

Evidence shows that engaging patients and whānau results in better health and care outcomes.³ The patient and whānau are more likely to feel valued and involved in their treatment, and their experience in hospital is better.

Providing excellent clinical care underpins clinicians' values and drives their work ethic. Valuing shared goals of care discussions should become part of this care provision by all clinicians. For some, this may mean a change in practice. It can be difficult and confronting to have these discussions but the outcomes warrant having them. There are guides and training that can help with these discussions, for example, the Serious Illness Conversation Guide (<https://www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-clinicians/tools/serious-illness-conversations/>).

Clinicians who communicate effectively, through sharing information and listening to seek understanding, can draw out patients' values and preferences for care. This forms the basis for informed decisions about complex medical treatment options, should the patient's condition deteriorate.

When shared goals of care discussions should take place

Shared goals of care discussions should take place before episodes of acute deterioration so everyone can engage fully without the pressures of an evolving clinical crisis. Discussions should be documented with all adult patients, ideally within 24 hours of admission and be reviewed and documented during the admission if there are changes in the patient's condition. If patients have advance care plans and/or advance directives, these need to support the discussion.

The discussion may be straightforward and brief if the patient and whānau understand the clinical situation, and therefore may be appropriately discussed on admission or on a ward round. For others, the situation may be more complicated and involve several discussions before a decision can be made. Through listening, clinicians will be able to pick up subtle cues from patients and whānau that indicate more time may be needed for these discussions.

1 See Appendix A for more information on using the articles in place of the principles of Te Tiriti o Waitangi.

2 Sometimes also called the 'fourth article', the 'forgotten article' or the 'oral article'.

3 Health Quality & Safety Commission. 2020. *Tauākī Koranga | Statement of Intent 2020–24*. Wellington: Health Quality & Safety Commission. URL: www.hqsc.govt.nz/publications-and-resources/publication/4048.

The shared goals of care principles

1. Shared goals of care are when patients, whānau and clinicians, explore patients' values, the care and treatment options available and agree the goal of care for the current admission if the patient deteriorates.
2. Health service providers ensure that governance systems, organisational culture and structures encourage shared goals of care discussions through resourcing and by supporting patients, whānau and clinicians, to have these discussions.
3. Cultural safety is an essential component of shared goals of care discussions.
4. Patients, whānau and clinicians are supported before, during and after shared goals of care discussions.
5. Patients have those they want to have with them, including those who have decision-making responsibilities.
6. Shared goals of care discussions take place in appropriate environments to maintain patients' privacy and dignity.
7. Shared goals of care discussions are facilitated by the appropriate clinician/s and may include other members of multi-disciplinary teams involved in patients' care.
8. Shared goals of care discussions happen as early in the admission as possible and with the agreement of the patient. The patient, whānau or clinician can begin the discussion.
9. Shared goals of care discussions result in a shared understanding through engaging with patients and whānau, sharing clinicians' understanding and exploring patients' values and what is important to them.
10. Shared goals of care discussions and decisions are documented in a clearly identifiable and accessible clinical form, with information available to all clinicians caring for patients.

Shared goals of care principles - expanded

- 1. Shared goals of care are when patients, whānau and clinicians explore patients' values, the care and treatment options available and agree the goal of care for the current admission if the patient deteriorates.**

The shared decision-making process involves exploring the patient's values, developing a shared understanding of what is important to the patient and what care and treatment options are available before the goal of care is agreed and documented. This relies on whakawhanaungatanga (building connections/relationships) and transparency between patients, whānau and clinicians. This requires allowing space and time to make decisions on the goal of care.

The goal of care decision may be one of the following:

- A. curative and restorative with all appropriate life sustaining treatments
- B. curative and restorative
- C. quality of life
- D. comfort while dying.

The decision describes what will be offered if the patient deteriorates. Each patient will have unique factors to their condition(s) and situation. (See Appendix D for more information on the steps in the discussion.)

- 2. Health service providers ensure that governance systems, organisational culture and structures encourage shared goals of care discussions through resourcing and by supporting patients, whānau and clinicians to have these discussions.**

Taking a systems-level approach will help health service providers put in place governance, management support, and education and training programmes to promote and support shared goals of care. Clinical governance, which includes a focus on patient deterioration, should reflect te ao Māori concepts and include Te Tiriti partnerships.

3. Cultural safety is an essential component of shared goals of care discussions.

Clinicians need to be aware of their own cultural norms, any bias or power imbalance that they bring to discussions and consider the cultural needs of patients and whānau.

Clinicians have a responsibility to avoid imposing their own cultural values and practices, and should promote and reinforce best practice within their teams. All professional bodies have developed standards for cultural safety that guide professional practice. As an example, the Medical Council of New Zealand outlines the following to consider in practice:

- The effect of your own culture, history and attitudes.
- The ongoing development of your own cultural awareness and an understanding of how your social-cultural influences inform biases that impact your interactions with patients, whānau, and colleagues.
- Consciously not imposing your cultural values and practices on patients.
- Recognising that there is an inherent power imbalance in the doctor–patient relationship and ensuring that this is not exacerbated by overlaying your own cultural values and practices on patients.
- Challenging the cultural bias of individual colleagues or systemic bias within health care services, which may contribute to poor health outcomes for patients of different cultures.⁴

(See Appendix B for more information and examples.)

4. Patients, whānau and clinicians are supported before, during and after shared goals of care discussions.

The support provided to patients and whānau is essential and may include:

- information provided before and during the discussion
- karakia
- provision of an interpreter
- provision of a spiritual carer
- other members of the health care team
- Māori, Pacific and/or disability advisors.

Support extends to ensuring there is a clinician (or person the patient is most comfortable with) available after the discussion to help patients and whānau process the information and respond to follow-up questions as able. The patient decides which support people they wish to include in the discussion.

The support provided to clinicians is essential and may include:

- clinical communication skills training and education
- tools to aid understanding about implicit bias
- mentoring to aid reflective learning
- role-modelling by senior clinicians
- time to have the shared goals of care discussion(s).

4 Medical Council of New Zealand. 2019. *Statement on cultural safety*. Wellington: Medical Council of New Zealand. URL: <https://www.mcnz.org.nz/our-standards/current-standards/cultural-safety/>.

5. Patients have those they want to have with them, including those who have decision-making responsibilities.

When planning to discuss shared goals of care, a priority is to first seek who the patient wants to have with them.⁵ This may be members of their whānau or a support person. The health care provider will do all they reasonably can to ensure that the identified whānau and support people are included in these discussions. If the timing of the discussion is urgent due to the clinical situation, then providers should seek phone or virtual presence of whānau or support people.

The discussion should include the patient, even if the patient has limited capacity. To make sound decisions where the patient has no capacity, discussions must be held with people who have the legal right to make decisions on behalf of the patient.⁶ To support sound decision-making in these circumstances include whānau or support people with an interest in the welfare of the patient and who were not excluded by the patient.

Providers need to have a link with whānau to ensure the process used reflects what will suit the patient and whānau and to determine who will be the whānau lead. Patients and whānau should be given the opportunity to lead the discussion, or part of it, and say what support they need to do this.

6. Shared goals of care discussions take place in appropriate environments to maintain patients' privacy and dignity.

Shared goals of care discussions can be distressing, so private and quiet spaces are needed. Providers should plan to have the discussion around who will be involved, including the appropriate environment and space for privacy and to maintain dignity. It should not be possible for discussions to be overheard by other patients. The environment should be able to accommodate those participating and be free of unhelpful noise and distraction.⁷

7. Shared goals of care discussions are facilitated by the appropriate clinician/s and may include other members of multi-disciplinary teams involved in patients' care.

Ideally, discussions should take place within the context of an established clinical relationship. Where this is not feasible, the discussion can be facilitated by an appropriate clinician as per local policy, for example, registered medical officer, senior medical officer or nurse practitioner.

It may be helpful to involve other disciplines, such as social workers, spiritual carers and nursing staff.

Clinicians should check who patients would like to have present and, where possible, link with whānau to ensure the process used reflects what suits patients and whānau.

5 This includes when a supported decision-making process is needed to assist disabled persons to have control and choice in their lives. URL: www.aucklanddisabilitylaw.org.nz/supported-decision-making-home. This may be outlined in their health passport. URL: www.hdc.org.nz/disability/my-health-passport.

6 See Right 7(2), 7(3) and 7(4) of the Code of Health and Disability Services Consumers' Rights 1996. URL: www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights.

7 See Right 5(2): Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively. Code of Health and Disability Services Consumers' Rights 1996. www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights.

8. Shared goals of care discussions happen as early in the admission as possible and with the agreement of the patient. The patient, whānau or clinician can begin the discussion.

For acute patients, the shared goals of care discussion should happen as soon as possible within 24 hours of admission, ideally once the following has been determined:

- likelihood of deterioration
- future treatment options
- recommended treatment option(s) to discuss and document with the patient and whānau.

However, for rapidly deteriorating patients, the discussion may need to start before this information is available.

For elective patients, particularly those at high risk of deterioration after surgery, the discussion should ideally take place before the patient is admitted to hospital.

9. Shared goals of care discussions result in a shared understanding through engaging with the patient and whānau, sharing the clinician's understanding and exploring the patient's values and what is important to them.

Before beginning a discussion, clinicians should review the clinical record and talk to other clinical team members to see if wishes have been previously documented or verbalised.

Coming to a shared understanding starts by engaging with the patient and their whānau to get an understanding of their current condition and what may lie ahead, and how much information they want to know.

There is then an opportunity for the clinician to share their understanding of the patient's current condition and what may lie ahead.

Finally, the clinician explores the patient's values and what is important to them to understand their priorities, hopes, worries, what helps in tough times and what they would be willing to go through for more time.

Te ao Māori models and Pacific models of practice can be used to improve these discussions and ensure they are culturally safe and appropriate. Te Whare Tapa Whā⁸ describes a holistic approach to wellbeing using four cornerstones of health: taha tinana (physical health), taha wairua (spiritual health), taha whānau (family health) and taha hinengaro (mental health). All four cornerstones are important. (See Appendix C for more information.)

10. Shared goals of care discussions and decisions are documented in a clearly identifiable and accessible clinical form, with information available to all clinicians caring for patients.

Decisions about shared goals of care should be clearly documented in a clinical form (this could be electronic or paper) so the information is standardised and easy to access. All staff, including after hours and during a medical emergency, should know where to find this information. Ideally the form will contain:

- reference to any current advance care plan or advance directive documents
- details of those involved in the discussion
- the patient's values, preferences, wishes and goals
- decision on the treatment options
- the goal of care (A-D).

When a shared goals of care form has been completed, this information should be routinely referenced during each clinical handover. Consider how the patient and whānau will have access to the agreed decision for the goal of care.

Providers should have a process for the form to be available for subsequent admissions as background information for the next shared goals of care discussion.

8 See: www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-waha; based on: Durie MH. 1985. A Māori perspective of health. *Social Science Medicine* 20(5): 483–6.

Appendix A: Te Tiriti o Waitangi

The Health Quality & Safety Commission encourages the health and disability sector to 'develop active Te Tiriti partnerships with tangata whenua as part of its improvement efforts, so that improvement benefits Māori and helps to achieve health equity'.⁹

We've developed these shared goals of care principles so that when a health service provider aligns their work with the shared goals of care principles, they are also aligning with the articles of Te Tiriti o Waitangi and the Ritenga Māori declaration. When a health service provider aligns its work with the shared goals of care principles, it is also aligning with the articles of Te Tiriti o Waitangi and the Ritenga Māori declaration:

Kāwanatanga – partnering and shared decision-making

Informed and shaped equally by tangata whenua and tangata Te Tiriti worldviews and perspectives.

Tino rangatiratanga – recognising Māori authority

Recognising the importance of tangata whenua authority and autonomy. Supporting tangata whenua-led processes, actions and decision-making through shared power and resources.

Ōritetanga – equity

Undertaking specific actions to ensure equitable outcomes for tangata whenua and recognising that these actions can also support equitable outcomes for other groups.

Wairuatanga – upholding values, belief systems and worldviews

Prioritising tangata whenua worldviews, values and belief systems.

As a framework, we have used the articles rather than using the principles (partnership, protection and participation) derived from the articles. This is in line with the Wai 2575 Health Services and Outcomes Kaupapa Inquiry stage one report (www.waitangitribunal.govt.nz/inquiries/kaupapa-inquiries/health-services-and-outcomes-inquiry).

⁹ Health Quality & Safety Commission 2020, *op. cit.*

Appendix B: Cultural safety and examples from nursing and medical councils

Cultural safety is core to clinical practice and leadership. The importance of cultural safety is becoming more recognised across clinical specialties, particularly the recognition that it is more than cultural competency. Hospital systems need to support clinicians' culturally safe practice.

The Nursing Council of New Zealand defines cultural safety as:

The effective nursing practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability.

The nurse delivering the nursing service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and well being of an individual.¹⁰

The Medical Council of New Zealand¹¹ defines cultural safety as:

The need for doctors to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery.

The commitment by individual doctors to acknowledge and address any of their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided.

The awareness that cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities.¹²

Clinicians and organisations are encouraged to review the cultural safety information from the councils and their specialities.

In addition, the Health Quality & Safety Commission has developed education modules on understanding bias in health care (www.hqsc.govt.nz/our-programmes/patient-safety-week/publications-and-resources/publication/3866).

10 Nursing Council of New Zealand. 2011. *Guidelines for Cultural Safety, the Treaty of Waitangi and Māori Health in Nursing Education and Practice*. Wellington: Nursing Council of New Zealand. URL: https://www.nursingcouncil.org.nz/Public/Nursing/Standards_and_guidelines/NCNZ/nursing-section/Standards_and_guidelines_for_nurses.aspx.

11 Medical Council of New Zealand 2019, *op. cit.*

12 Curtis E, Jones R, Tipene-Leach D, et al. 2019. Why cultural safety rather than cultural competency is required to achieve health equity. *International Journal for Equity in Health* 18: 174.

Appendix C: How Te Whare Tapa Whā can be used for shared goals of care approaches

Health care providers can use a range of te ao Māori models and practices for their shared goals of care approaches. Ultimately the model and practices to use should be directed by Māori and agreed in partnership with Māori when establishing and sustaining shared goals of care approaches.

Te Whare Tapa Whā,¹³ developed by Sir Mason Durie, describes a holistic approach to wellbeing using four cornerstones of health: taha tinana (physical health), taha wairua (spiritual health), taha whānau (family health) and taha hinengaro (mental health). All four cornerstones are important. A person (or collective) may become 'unbalanced' if one of these cornerstones is missing or damaged.

*Te Ara Whakapiri: Principles and guidance for the last days of life*¹⁴ outlines what can be expected as adult New Zealanders come to the end of their life. This guidance sets out the components of care within the framework of Te Whare Tapa Whā. The baseline assessment summary table below provides a useful link with shared goals of care discussions.

Te taha tinana: <i>Physical health</i>	Te taha hinengaro: <i>Mental health</i>
1.1 Recognition the person is dying or is approaching the last days of life	1.5 Assessment of the person's preferences for care
1.2 Identification of the lead health practitioner	Te taha whānau: <i>Extended family health</i>
1.3 Assessment of physical needs	1.6 Identification of communication barriers
1.4 Review of current management and initiation of prescribing of anticipatory medication	1.8 The family/whānau's awareness of the person's changing condition
1.7 The person's awareness of their changing condition	1.9 Discussion of cultural needs
1.11 Provision of food and fluids	1.15 Provision of information to the family/whānau about support and facilities
1.12 Availability of equipment to support the person's care needs	Te taha wairua: <i>Spiritual health</i>
1.13 Consideration of cardiac devices	1.10 Provision of opportunity for the person and family/whānau to discuss what is important to them
1.14 Advice to relevant agencies of the person's deterioration	

13 See: www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha; based on: Durie MH. 1985. A Māori perspective of health. *Social Science Medicine* 20(5): 483–6.

14 Ministry of Health. 2017. *Te Ara Whakapiri: Principles and guidance for the last days of life*. (2nd edition). Wellington: Ministry of Health.

Appendix D: Three steps for clinicians in the shared goals of care discussion

1. Prepare

Gather information, including the patient's capacity, privacy needs, wishes for support people they would like to have present and any cultural needs. Review the patient information to gain an understanding of their potential medical trajectory. Nursing and allied health staff can play a part in this stage of preparing for the discussion. There needs to be agreement from the patient to go ahead with the discussion. Plan having the discussion around who will be involved, including the appropriate environment and space for privacy and to maintain dignity.

2. Discuss

- Explore the patient's (and whānau's, as appropriate) current understanding of their condition and what may lie ahead, and find out how much information they would like to know.
- Share with the patient information about the clinical team's understanding of their current condition and what may lie ahead.
- Explore the patient's values and what is important to them, including their priorities, hopes, worries, what helps in tough times and what they would be willing to go through for more time.
- Summarise and check for shared understanding.

3. Recommend and close

Explain your recommendation in plain language, outlining which treatments are more likely to cause benefit than harm. Then reach a decision with the patient and whānau for the goal of care for the admission. This decision and plan should be documented clearly on the shared goals of care form. Any other follow-up actions should also be documented in the clinical record.

Appendix E: Glossary of definitions

Advance care plan	<p>A document that includes what is meaningful to a person, such as people and pets, their values and the ways they would like those caring for them to look after their spiritual and emotional needs. It also tells their loved ones and medical staff about the treatment and care they want if they are no longer able to communicate.</p> <p>It can also cover what sort of funeral they would like, whether they want to donate their organs, whether they want to be buried or cremated, where their important papers are and whether they have in place an enduring power of attorney or advance directive.¹⁵</p>
Advance directive (sometimes called a 'living will')	<p>A written or oral directive:</p> <ul style="list-style-type: none"> by which a person makes a choice about a possible future health care procedure that is intended to be effective only when they are not competent.¹⁶
Cultural safety	Refer to Appendix B.
Enduring power of attorney ¹⁷ (EPA) for personal care and welfare	<p>A legal document that a person uses to authorise someone else (called an 'attorney') to make decisions on their behalf about personal care and welfare if they become mentally incapable. The attorney is often a whānau member or trusted friend.</p> <p>The EPA starts once the person has been declared mentally incapable. A relevant health practitioner or Family Court must decide that the person is not capable of making a decision about their care or welfare. The attorney must follow any conditions or restrictions set out in the person's EPA when making decisions. The overriding consideration is to promote and protect the person's welfare and best interests.</p> <p>As far as practicable, when acting under the EPA, the attorney must seek advice from the person and anyone the person has named in the EPA to be consulted.¹⁸</p> <p>There are some things an EPA cannot do, including refusing consent to standard medical treatment that might save the person's life or prevent serious damage to the person.</p> <p>See also the Community Law Manual online at www.communitylaw.org.nz/legal-information.</p>
Health service providers	<p>Organisations and individuals who provide health services within Aotearoa New Zealand.</p> <p>The main audience for this document is hospital health service providers.</p>
Whānau ¹⁹	<p>Can include the direct family group, the extended family group, the primary unit of support and, sometimes, friends with no kinship ties to other members.</p> <p>It is a concept that supports inclusive relationships between people. Whanaungatanga is an active expression of whānau, conveying connection and a sense of belonging through close relationships with each other. 'Whānau' is not limited to the nuclear family unit, or to the common understanding of the term 'family'; it extends to others that a person develops a close family-like friendship or reciprocal relationship with.</p> <p>It is up to the person and those closest to them to communicate who is in their whānau. It is important that health staff never assume who is in or is outside of the person's whānau.</p>

15 As defined in the advance care planning section of the Health Quality & Safety Commission website: <https://www.hqsc.govt.nz/our-programmes/advance-care-planning/information-for-consumers/faq/>.

16 Health and Disability Commissioner. 1996. Code of Health and Disability Services Consumers' Rights. Wellington: Health and Disability Commissioner. URL: www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights.

17 Enduring power of attorney information found at: www.govt.nz/browse/family-and-whanau/enduring-power-of-attorney/enduring-power-of-attorney-epa-for-personal-care-and-welfare/#an-epa-for-personal-care-and-welfare.

18 Ministry of Social Development. nd. *Standard explanation of effects and implications of enduring power of attorney in relation to personal care and welfare*. Wellington: Ministry of Social Development. URL: <http://superseniors.msdc.govt.nz/documents/epa-documents/standard-explanation-epa-personal-care-and-welfare.pdf>.

19 Health Quality & Safety Commission 2020, *op. cit.*