



How to engage with consumers and whānau following an adverse event | Me pēhea e kōrero tahi ai me ngā kiritaki, ngā whānau whaimuri i tētahi mahi tūkinu

Engaging consumers and whānau in reviews of harm can help to make health care safer. Consumers and whānau can provide insights into their experiences of harm that can shed greater light on what happened and lead to a deeper analysis of underlying learning. This can encourage providers to think about alternative perspectives and provide insights into improvements and solutions to minimise the risk of further events. Consumer involvement can also help with healing and be restorative for the person involved.^{1,2}

Culturally responsive practice considers that each person has their own culture, values and beliefs that must be acknowledged and supported when harm has occurred. This supports the importance of wairuatanga – upholding values, belief systems and world views.

Consumers may also include whānau,³ especially where the affected consumer has died or is not able to take part in a review. When discussing harm with whānau, it is important to follow the Health Information Privacy Code 2020⁴ and local policies.

Te Tāhū Hauora Health Quality & Safety Commission has developed an eight-step guide to engaging with consumers and whānau following harm. In engaging with consumers and whānau, it is important to differentiate between consumers who are 'affected' by harm and 'independent consumers' who actively contribute to the review process.

¹ Health Quality & Safety Commission. 2015. *Engaging with consumers: a guide for district health boards*. Wellington: Health Quality & Safety Commission.

² Health Quality & Safety Commission. 2017. *Learning from adverse events 2016–17*. Wellington: Health Quality & Safety Commission.

³ Whānau is the family, extended family or family group of people who are important to a person who is receiving a service. Whānau includes a person's extended family, their partners, friends, guardians or other representatives chosen by the person. From: Te Tāhū Hauora Health Quality & Safety Commission. 2023. *Healing, learning and improving from harm: National adverse events policy 2023 | Te whakaora, te ako me te whakapai ake i te kino: Te kaupapa here ā-motu mō ngā mahi tūkinu 2023*. Wellington: Te Tāhū Hauora. URL: www.hqsc.govt.nz/resources/resource-library/national-adverse-event-policy-2023.

⁴ See the full code at: <https://privacy.org.nz/privacy-act-2020/codes-of-practice/hipc2020/>; and the Health Information Privacy Fact Sheet 1 at: <https://www.privacy.org.nz/privacy-act-2020/codes-of-practice/hipc2020/hipc-factsheet-1-overview/>

Step 1: Inform the affected consumer and whānau harm has occurred / Hīkoi 1: Whakamōhio atu i te kiritaki, i te whānau kua pāngia mai he tūkinu

Consumers and whānau have a right to know when something harmful or potentially harmful has happened to them. Open communication (also referred to as ‘open disclosure’) is a core principle of the Healing, learning and improving from harm: National adverse events policy 2023.⁵

The policy has the following criteria for open communication:

- Providers will work with consumers and whānau to understand the level of harm that has occurred.
- Consumers and whānau will be engaged in the review process with open communication that meets the guidelines set by the Health and Disability Commissioner and Te Tāhū Hauora.
- Providers will enable access to support and education for health care workers undertaking open communication.
- Open communication will be considered in situations where the system did not work as intended, even if no harm was experienced, eg, near misses.

According to the Health and Disability Commissioner’s Guidance on open disclosure policies,⁶ open communication following harm should:

- be timely (usually within 24 hours of the event occurring or the harm or error being recognised)
- be led by the provider with overall responsibility for the affected consumer’s care
- include acknowledgement of the harm, an explanation of what happened and what the next steps are
- include a sincere apology. This is the provider’s opportunity to say, ‘We are sorry this happened to you.’ It is not about allocating blame for the event’s occurrence but acknowledging the seriousness of an adverse event and the distress it causes.
- supply contact details and information about the local health and disability consumer advocate, as well as options for making a complaint.

Step 2: Explain the review process to the affected consumer and whānau / Hīkoi 2: Whakamārama atu i te tukanga arotake ki te kiritaki, ki te whānau

A key aspect of open communication is providing an explanation of what happened. However, this explanation is often not available until a review of the harm has taken place.

Early communication between the provider and the affected consumer and whānau should take place in a way that meets the individual cultural needs of the consumer and whānau throughout the process. Communications should include information about the review

⁵ Te Tāhū Hauora Health Quality & Safety Commission 2023, *op. cit.*

⁶ Health and Disability Commissioner. 2019. [Guidance on open disclosure policies](#). Wellington: Health and Disability Commissioner.

process, what will be involved, how long it will take, who will be the key contact for the consumer and whānau, and how the consumer and whānau can be involved in the review.

The consumer and whānau should be updated regularly about the progress of the review and given the opportunity to both share their story as part of the review and tell the review team what their needs are from a review.

Providers should make affected consumers and whānau aware that contributing to the review is voluntary and they have a choice about how much they want to be involved. Not all consumers and whānau who have been involved in harm will want to share their story or give feedback on the draft review report, however they must be given the opportunity.

Step 3: Listen to the story of the affected consumer and whānau | Hīkoi 3: Whakarongo ki te kōrero a te kiritaki, a te whānau

Consumers and whānau who have experienced harm should be supported to work in partnership with health care workers, to define how they want to be involved, to share their experiences in a way that is meaningful for them and suggest improvements that address their needs.

All consumers and whānau who have been affected by an adverse event should be given the opportunity to tell their story of the event. Providers should start reviews by talking with the affected consumer and whānau and listening to and documenting their story of what happened. This should include how the consumer and whānau feel about what happened, what they think may have contributed to the event, how the event has affected them and what they feel might reduce the risk of the event happening again. The consumer and whānau should be reassured that their information will be kept confidential. At this time, it is important to ascertain what support the consumer and whānau will require, offer that support and provide a person (and deputy) who the consumer and whānau can contact when they need to.

Step 4: Be open to consumer and whānau perspectives in review of the event | Hīkoi 4: Me ngākau māhaki ki ngā whakaaro o te kiritaki o te whānau i te wā arotake

The story of the consumer and whānau should be given equal consideration with the perspectives of health care workers in the analysis of harm.

One way of strengthening the consumer and whānau voice in the review process is by inviting an independent consumer to be a part of the review team or during the sense-making process in a learning review. This person is not generally an employee of the provider organisation and will not have been affected by the harm under review. They can provide a consumer perspective on understanding what happened and what actions for improvement might arise from the review.

Providers should aim for diversity and inclusion when engaging independent consumers to be part of review teams. This means involving people who reflect the lived experiences and characteristics of the population using the health service (eg, age groups, cultural backgrounds, socioeconomic status and education levels). This also means considering and addressing the barriers that prevent diverse groups from taking part, particularly those involving people from a different culture.

Examples of ways to increase consumer involvement in the adverse review process include:

- having an independent consumer on the review team who is from the same cultural group as the affected consumer, taking into consideration their willingness to take part in the learning review process.
- having a range of cultural advisors available to contribute to the review when required.

If the consumer and whānau have been under mental health and addiction services, then there may already be consumers and family advisors within the organisation employed specifically for supporting consumers and whānau.

Step 5: Check the draft report with the affected consumer and whānau | Hīkoi 5: Me titiro tahi me te kiritaki, me te whānau ki te pūrongo tauira

Providers should give the affected consumer and whānau the opportunity to review the draft report, including the learning opportunities and recommended actions for improvement, so they can provide feedback on it.

The feedback from the affected consumer and whānau should be given serious consideration. While not all feedback will result in a change to the report, all feedback must be considered, and an explanation provided where feedback does not result in a change to the report.

Step 6: Communicate all review findings to the affected consumer and whānau | Hīkoi 6: Me kōrero katoa ngā kitenga o te arotakenga ki te kiritaki, ki te whānau

The affected consumer and whānau should be given a copy of the final review report in a way that meets their needs and the provider's obligations to open communication. In line with the principles of honest and full communication, providers should produce one final review report for all, including providers and consumers and whānau.

Step 7: Commit to acting | Hīkoi 7: Me ū kia whakatikaina

The provider should commit to implementing any recommended actions for improvement from reviews. They should also monitor and follow up improvements to ensure they are sustainable and effectively implemented without unintended consequences.

Step 8: Follow up with the affected consumer and whānau on actions taken | Hīkoi 8: Me kōrero ki te kiritaki me te whānau mō ngā mahi hei whakatika

The affected consumer and whānau involved should be updated on actions taken following the review.

Organisational governance plays a critical role in this final stage of consumer engagement in review and learning. Governance bodies are responsible for implementing and following up actions for improvement and keeping consumers and whānau updated on implementation progress. It is important to ask consumers what they would like in terms of ongoing update on progress.

Published in June 2023 by Te Tāhū Hauora Health Quality & Safety Commission, PO Box 25496, Wellington 6146, New Zealand.