HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Improper return of whare tangata after being sent for testing without consent

Introduction

1. This report discusses the care provided to Mx A by Health New Zealand | Te Whatu Ora (Health NZ) (the public hospital). The complaint concerns the improper return of Mx A's whare tangata[1] following a hysterectomy when Mx A had not consented to histological analysis of it.

Complaint

2. On 11 November 2024, this office received a complaint from Mx A about the improper return of their whare tangata. Mx A complained that despite having stated to hospital staff that they wanted their whare tangata returned whole (without testing) for cultural reasons and having filled out the 'Return of Tissue' form, their whare tangata was sent to the laboratory for testing. Mx A also raised concerns about how this error was communicated to them and the care they received from staff after the error was identified.

Scope of investigation

3. The following issues were investigated:

- *Whether Dr B provided Mx A with an appropriate standard of care for the period of 25 October to 31 October 2024.*
- *Whether Health New Zealand | Te Whatu Ora provided Mx A with an appropriate standard of care that took into account their cultural beliefs and preferences for the period of 25 October to 4 November 2024.*

Background

4. Mx A identifies as a Māori wahine in ao Māori (Māori worldview) and they/them in ao Pākehā (Western worldview). Mx A was raised by their whānau with the mauritanga[2] of their tūpuna.[3] As a whānau, ao Māori practices are the norm and a natural way of life for them.

5. On 25 October 2024, Mx A attended a preoperative appointment with Dr B at the public hospital to discuss Mx A's upcoming hysterectomy. Mx A stated that they were accompanied by a support person to ensure their wishes were communicated clearly. Mx A said that,

[1] Whare tangata literally translates to 'house' (whare) of people or humanity (ira tangata). It encompasses the sexual and reproductive functions of wāhine as one of many sources of strength and sacredness. Whare tangata has its own mana and is considered tapu (sacred). Whare tangata refers to the maternal body, including the uterus, cervix, fallopian tubes, ovaries, and vaginal canal.
[2] The life force or essence of a person, both dynamic and relational. It is constantly changing; it shapes one's spirit (wairua), balances the mind and body, and shapes how a person relates to self, others, and the wider environment and its ecosystem (e.g., maunga, hapū, iwi) (Durie 2001).
[3] Ancestors from whom one is descended.

during this appointment they requested that '[their] whare tangata be returned to [them] whole and intact after surgery, without any cutting or slicing'. Mx A stated that Dr B acknowledged this request and asked Mx A to fill in a Return of Tissue form and to remind the surgical staff of this request on the day of their surgery. It is important to note that Dr B disputes being told that Mx A would like their whare tangata returned whole without testing, but he does accept that he knew they wanted their tissue returned and that he advised that documentation would need to be completed. He agrees that he asked Mx A to remind the surgical team about this request.

6. Mx A understood that there was a possibility that their whare tangata might get cut during surgery because of the presence of a cyst and potential bowel lesions and requested that their whare tangata be returned as 'whole' or as 'untouched' as possible. Mx A stated:

> 'As a Māori woman, I whakapapa to Māori heritage, which holds the whare tangata as sacred. In my culture, this organ symbolizes our connection to ancestors, our land, and future generations. Returning it whole after surgery is a sign of respect for whenua, and it honours my cultural and spiritual beliefs. This request was not simply a preference; it was a matter of cultural and spiritual integrity.'

7. On 31 October 2024, the day of their surgery, Mx A arrived at 6.30am and filled out the patient information and admission forms. Before the surgery, Mx A also filled in a Return of Tissue form and verbally re-stated to the different staff involved in their care their request for their whare tangata to be returned whole. Mx A said that they were given reassurances from staff that their request would be respected.

8. Mx A's surgery was performed later that day without complications. After surgery, Mx A asked whether the surgeons had been able to remove their whare tangata intact and was told that it had been taken out whole.

9. On 1 November 2024, Mx A was told that they could pick up their whare tangata from the laboratory in two weeks, which they found confusing as they did not request any testing or cutting of their whare tangata. Mx A recalled that Dr C, one of the doctors present at this time, stated that she would contact the laboratory to confirm whether Mx A's whare tangata remained untouched. Later that day, Dr C informed Mx A that their whare tangata had not been altered and that no cutting or dying[4] had occurred.

10. Mx A told the Health and Disability Commissioner (HDC) that, over the weekend (2 and 3 November 2024), staff were unable to tell them specifically where their whare tangata was being held, although clinical notes record that it was in the laboratory. Mx A said that they were told they would get their whare tangata on Monday.

11. On 4 November 2024, Dr C told Mx A that the laboratory had cut into their whare tangata and dyed it on 1 November 2024, which contradicted the previous assurances given. Mx A said that the doctors apologised for this and said that 'they got their wires crossed'. Mx A was upset as they felt they could not have expressed their wishes more clearly and they felt

[4] Specimens are dyed during histology testing to make their structures more visible under a microscope. This process helps pathologists to identify any abnormalities and diagnose diseases.

lied to. For their whare tangata to be returned, Mx A had to sign a second Return of Tissue form, which stated that they understood the implications of their whare tangata not being tested and that consent was never given for testing.

12. At about 1.30pm, Mx A received their whare tangata from the mortuary and left the hospital.

13. Given the tapu nature of whare tangata and Mx A's explicit and numerous requests to have their whare tangata returned whole, this experience has caused immense distress for both Mx A and their whānau.

Information gathered

Response to complaint

14. In response to the HDC, Health NZ confirmed that Mx A saw Dr B on 25 October 2024 to discuss their hysterectomy and whether their ovaries would also be removed. This appointment was an opportunity for the potential risks and benefits of the surgery to be discussed and for Mx A to ask any questions.

15. Health NZ noted that the clinic letter for this appointment does not mention Mx A's request for their whare tangata to be returned whole, without testing and cutting, and no other documentation from this appointment references it either. As stated above, Dr B recalled that Mx A requested their whare tangata be returned during this appointment, but he does not recall Mx A requesting that no testing be performed or any discussion about the importance of their whare tangata being returned in one piece.

16. During the 25 October 2025 appointment, Mx A completed the 'Request for Treatment/Procedure(s)' form,[5] which Dr B co-signed on the day of the surgery. Health NZ said that the section of this form pertaining to the return of tissues was 'incorrectly' ticked 'yes' by Mx A. This section of the form states:

> 'I understand that tissue removed during the treatment/procedure(s) may be submitted for pathological examination, kept and referred to at a later date for clinical purposes, audit, teaching and for Ethics Committee approved research. I understand that the tissue may be returned to me if I wish (a Tissue Return Form (from the public hospital), or a Body Part Chain of Custody Form (from the public hospital) is required).'

17. Following this appointment, Mx A had a preoperative phone call with a registered nurse to check Mx A's current health status and provide information on other preoperative preparations and when to come in. The documentation from this phone call stated, 'tissue return please', which was also highlighted.

18. On 31 October, the day of their surgery, Mx A filled in a 'Human Tissue Return/Release' form and ticked the option[6] 'slides/blocks being returned to patient'. Mx A's preoperative

[5] This form outlines the consent for the treatment/procedure and the conditions associated with receiving that treatment/procedure.

[6] The options were 'slides/blocks being returned to patient', 'cremation and return of ashes (available for limbs only', 'temporary storage required', and 'delivery to a hospital outside of the […] Region'.

checklist shows that they had requested the return of their tissue and that the Tissue Return Form had been completed. However, Health NZ explained that the option 'Slides/blocks being returned to patient' that Mx A had selected meant that their whare tangata would be returned after testing. Health NZ advised that if Mx A had wanted their whare tangata returned without testing, they should have selected the option 'temporary storage required'. Health NZ apologised that its staff did not help Mx A to fill out this form or explain the different processes for the return of their whare tangata.

19. The public hospital's 'Human tissue, management and handling' policy notes that the different processes of tissue return should be explained to patients when they are offered the option of having their tissue returned. This includes the return of tissue after laboratory diagnostic processes or, if testing is not required, temporary storage of tissue until discharge or the opportunity for immediate possession of tissue.

20. The 'Human Tissue Return/Release' form also states that patients should be provided with a 'Human Tissue Information for Patients' brochure, and the pertinent sections should be discussed with the patient and their whānau. There is no evidence in the clinical record or in other information provided to the HDC that Mx A received this brochure or that the form was discussed with Mx A or their whānau.

21. Mx A's completed 'Patient Information' form lists their iwi, that they are Māori, and that they would like a visit from Whānau Care services. Mx A's 'Patient Admission to Discharge Plan' (dated 31 October 2024) similarly states that Mx A's priority for their hospital admission was 'respect[ing] [their] cultural needs'.

22. After Mx A's surgery, Dr B completed a laboratory request form, with a 'Return to Patient' sticker and ticked the box for histology. That is, the form anticipated histological testing and analysis of the whare tangata. This form was sent to the laboratory with Mx A's whare tangata.

23. During the morning ward round on 1 November 2024, Mx A was told that they would get a 'letter in [a] month with [the test] results'. Mx A's clinical records document: '[Mx A] wants tissues returned. Doesn't want tested. Understands implications of this.' A plan was made for the Senior House Officer, Dr C, to call the laboratory to convey this.

24. A nursing note from 8.20pm confirms that the pathology laboratory was contacted to explain Mx A's wishes.

25. On 2 November 2024, a nursing note from 11.15am outlines contact with the laboratory to identify where the tissue was and the process for return. It was agreed on this day that Mx A would remain an inpatient until their whare tangata could be returned, which was expected to be Monday 4 November 2024.

26. At 8.29am on 4 November 2024, Dr C documented several calls she had with the laboratory to arrange return of the whare tangata. The records show that initially Dr C was told that Mx A's whare tangata had not been processed and explicitly that Mx A's whare tangata had not been cut or dyed. However, in a subsequent conversation, it was disclosed that prior to

Dr C's call on 1 November, cutting and dying of the whare tangata had occurred in line with the initial processing procedure in the laboratory.

27. Following this, Dr C explained to Mx A what had happened and apologised that Mx A had been told on Friday that their whare tangata had not been cut or dyed, as it appears that the laboratory had already done so at that point. Dr C documented that she 'explained that it appears that the forms [Mx A] signed [were] just for tissue return & this usually happens after testing'.

28. Dr C noted that Mx A was visibly upset, and she told Mx A that she would give them the details of the person to whom Mx A could speak to ensure that this would be investigated.

29. In an email to Dr C, the usual process where testing of tissue is not required was explained, and in particular that there needed to be written acknowledgement from the patient and clinician that there would be no report of testing issued.

30. In its response to the HDC, the public hospital acknowledged that the existing policies are written such that, by default, tissue is returned after testing. The public hospital identified that these policies need to be amended to highlight that patients may request their tissue be returned without testing.

31. In a statement to the HDC, Dr B acknowledged the hurt Mx A experienced and apologised for the breach of tikanga (take)[7] that occurred in these events. Dr B offered to participate in tikanga to help restore ea[8] if Mx A felt that this was appropriate. He also acknowledged:

> 'Tikanga has not been respected, and while my opinion is this has occurred through miscommunication rather than neglect, nonetheless it has occurred. Utu must occur for ea [to be] restored.'

32. A copy of the apology provided by Dr B has been provided to Mx A.

33. In response to these events, Dr B also changed his practice so that when a patient requests the return of their tissue, he will ask whether they consent to testing of their tissue and documents their wishes on the consent form.

34. The public hospital informed the HDC that it is completing an internal review of this error and, upon completion, it intends to present the learnings from the error to the Women's Health Service education meeting. The public hospital said that it also offered to meet with Mx A, and, while Mx A has declined to meet at this stage, the offer remains open.

Response to provisional decision

35. All parties were given the opportunity to comment on my provisional decision. Health NZ accepted my provisional decision and proposed recommendations.

[7] 'Take' in te reo Māori refers to an issue with or breach of tikanga.

[8] A state of balance or a settled state, usually achieved through the process of utu (the actions taken to achieve ea).

36. Mx A reiterated the impact these events have had on them.

37. Dr B acknowledged the significance of these events and the distress caused for Mx A. He reiterated that he did not believe there was direct communication with him that Mx A wanted their whare tangata returned whole or without histological testing. He also commented that, when patients have special requests such as this (which is rare), he would document the request and undertake the consent process at the time. Dr B explained that the absence of documentation relating to histological testing is indicative that this conversation did not take place.

38. Dr B believed that Mx A had told other staff that they wanted their whare tangata returned without histological testing but that these requests were not communicated to him.

Decision: Dr B – breach

39. I acknowledge that there is conflicting evidence about what was discussed and understood at the preoperative consultation on 25 October 2024. Specifically, Mx A's evidence is that they expressly stated they wanted their whare tangata returned whole without cutting, whereas Dr B does not agree that this was communicated and that, had it been, he would have clearly documented such a request. It is not disputed that Mx A requested their whare tangata to be returned and that Dr B advised them that a form would need to be completed and they should remind surgical staff of this request on the day of the procedure.

40. I note the clear evidence that, after the 25 October consultation, Mx A made or attempted to make multiple efforts to have their whare tangata returned and was very explicit on 1 November (the day after the operation) that they wanted their whare tangata returned intact without testing when they became aware it had been sent to the laboratory. I have little doubt that this was Mx A's intended position from the outset – a perspective entirely consistent with their deeply held cultural beliefs and needs.

41. Regrettably, it appears that Dr B, however well intentioned, proceeded on an assumption that tissue return would occur after testing.

42. Right 6(1) of the Code of Health and Disability Services Consumers' Rights (the Code) states that every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive.

43. In the circumstances, I am of the view that, noting Mx A's request for tissue return, they were entitled to be told what would happen to the tissue when taken and the options for having it returned.

44. Although I acknowledge that there was opportunity for other staff to explain the 'Human Tissue Return/Release' form to Mx A on the morning of 31 October 2024, I consider that, in the given situation, the responsibility for ensuring that information relating to the removal, testing, and return of tissue is conveyed to the patient appropriately lies with the clinician performing the procedure (and in this case Dr B completed the laboratory request form for testing). I am mindful that Mx A's request might be considered outside the norm; however, I note that the HDC has received multiple complaints in recent years reflecting consumers'

concerns about a lack of information regarding what happens to tissue when it is tested and concerns about compromised return or a failure to return.

45. I acknowledge Dr B's submission that he was not advised of Mx A's wishes by the nursing and anaesthetic teams who reviewed the health questionnaires Mx A had completed preoperatively. Nevertheless, Dr B was aware of Mx A's request for tissue return, and in my view that should have prompted a conversation with them about what would happen to their tissue. There were several opportunities for him to have done so. Had this conversation occurred, Mx A would have been able to make their position clear, allowing for further discussion about the risks associated with non-testing, and it is likely this would have prevented the 'errors' that occurred on the various forms. My position in this respect is largely consistent with the public hospital's 'Human tissue, management and handling' policy, which envisages that the different options for return, with or without testing, are explained to the patient.

46. Right 7(1) outlines that services may only be provided to a consumer if they make an informed choice and give informed consent. Although Mx A gave informed consent to undergo a hysterectomy, they did not give consent for their whare tangata to undergo histological testing. I wish to emphasise that these are two separate consents, and a consumer's request for their tissue to be returned does not imply that they consent to the histological testing of that tissue. This is reinforced by right 7(10), which states that no body part may be stored, preserved, or used otherwise than with the informed consent of the consumer.

47. For the reasons described above, I conclude that Dr B breached rights 6(1) and 7(1) of the Code.

48. I acknowledge that Dr B has expressed his deep sadness for what occurred for Mx A, and he has unhesitatingly apologised for the upset and distress this caused. As a result of this event, he has changed his practice to ensure that patients requesting return of tissue are engaged on the limits and extent of testing they will agree to and, in relation to Māori consumers, he further emphasises what will happen to tissue to ensure that tikanga is respected.

Adverse comment — documentation

49. I am also mildly critical that on 25 October 2024 Dr B did not document that Mx A had requested the return of their whare tangata.

50. It is my expectation that any discussions had about the return of tissue, regardless of whether the patient wants their tissue to be returned or consents to laboratory testing, would be documented.

51. For the avoidance of doubt, noting Dr B's position that he was not aware of Mx A's request for return of their whare tangata intact without testing, this criticism does not extend to his failure to document those matters.

52. I acknowledge that, since these events, Dr B has changed his practice to explicitly discuss whether consumers want their tissue to be returned and, if so, whether they consent to further testing.

Decision: Health NZ – breach

Consent for testing of whare tangata – breach

53. I consider that the public hospital's processes for obtaining informed consent for tissue return were structured in a way that did not enable Mx A to provide informed consent about the return of their whare tangata, including whether Mx A consented to histological testing. As such, Health NZ breached Right 7(10) of the Code, which states that no body part removed in the course of healthcare may be used, including for laboratory testing and examination, otherwise than with the informed consent of the consumer.

54. The 'Request for Treatment/Procedure(s)' form contains the following wording:

> 'I understand that tissue removed during the treatment/procedure(s) may be submitted for pathological examination, kept and referred to at a later date for clinical purposes, audit and teaching and for Ethics Committee approved research. I understand that the tissue may be returned to me if I wish (a Tissue Return Form (public hospital specific form) or a Body Part Chain of Custody Form (public hospital specific form)) is required.'

55. This section is reflective of a bundled model of consent, where the consent for the return of a patient's tissue is bundled with the consent for laboratory examination and other additional consents.[9] Therefore, even if a patient ticks 'yes' in relation to this statement, indicating their agreeance, it would be difficult for clinicians and laboratory staff to deduce whether the patient agrees with this statement in whole or in part. In my opinion, these consents could be, and should have been, 'unbundled' into separate consents to better enable patients to give informed consent.

56. As there was no way for Mx A to indicate whether they consented to each of the statements listed in that paragraph, I do not consider that by ticking 'yes' in relation to this paragraph, Mx A gave informed consent for their whare tangata to be tested. It appears that Mx A ticked 'yes' to indicate that they understood that their whare tangata could be returned to them by filling in a 'Human Tissue Return/Release' form.

57. Similarly, the options[10] for tissue return stated in the 'Human Tissue Return/Release' form are not written in a manner that would facilitate patient understanding. While I appreciate that this form is meant to be accompanied by a brochure and discussed with a member of staff, the form should still clearly outline the different options for tissue return. The use of plain language is particularly important should a situation like this occur, where the form is completed by the patient without the accompanying brochure or discussion with staff.

58. While those in the health sector may easily understand that the phrase 'slides/blocks being returned to patient' infers that tissue will be returned following testing, I consider that a reasonable consumer may not understand that their tissue is to be tested or the manner by which this occurs (slicing and dying). Similarly, I consider that a reasonable consumer may

[9] As well as the storage and re-use of their tissue for future purposes — eg, future unspecified research, teaching, audit, etc.

[10] The options were 'slides/blocks being returned to patient', 'cremation and return of ashes (available for limbs only', 'temporary storage required', and 'delivery to a hospital outside of the […] Region'.

not understand that 'temporary storage required' means that their tissue is to be held temporarily until their discharge and is not to be sent to the laboratory for testing.

59. In all the circumstances as outlined in this section, I consider that Health NZ did not provide Mx A with an opportunity to express clearly whether they consented to the testing of their whare tangata. The testing of Mx A's whare tangata without their explicit consent represents a breach of Right 7(10) of the Code.

Provision of culturally appropriate care – breach

60. Right 1(3) of the Code explicitly states that services should take into account the 'needs, values, and beliefs of Māori'.

61. In ao Māori, whare tangata has its own mana and is considered tapu (sacred). The revered significance of the whare tangata is because it is the transitional space between te ao mārama and te pō (life and death), the space where procreation occurs and new life is sourced. For Māori, the whare tangata is the connection to whakapapa and the continuation of genealogy for whānau, hapū, and iwi and whenua (land) and has a vital role in sustaining life and culture.

62. Mx A told the HDC that they requested that their whare tangata be returned whole, without any cuts, for cultural reasons. As Mx A stated:

> 'Returning it whole after surgery is a sign of respect for whenua, and it honours my cultural and spiritual beliefs. This request was not simply a preference, it was a matter of cultural and spiritual integrity.'

63. As well as expressing this request both verbally and through consent forms, Mx A listed that they are Māori, named their iwi, and expressed that their priority for their hospital admission was 'respect[ing] [their] cultural needs'. Given that Mx A was undergoing a hysterectomy, the disclosure of this information should have signalled to staff that additional care and consideration was needed to uphold the mana of both Mx A and their whare tangata.

64. The sacredness of Mx A's whare tangata was harmed by the way it was managed and regarded. At times, the location of Mx A's whare tangata was unknown to staff or was not communicated to Mx A. The systems implemented at the time did not facilitate compliance with Mx A's expressed choice for their whare tangata to be returned without histological testing.

65. On 1 November 2024, Mx A explicitly stated that they did not want their tissue tested and thereafter followed efforts to contact the laboratory. However, there were multiple missed opportunities for this 'error' to be corrected between 1 November 2024 and 4 November 2024.

66. In her efforts to locate and return Mx A's whare tangata, Dr C was given inconsistent information from the laboratory about Mx A's whare tangata, which increased the distress in this experience. I note that the reason why Dr C was given inconsistent information from the laboratory was unable to be resolved.

67. On 2 November 2024, staff first became aware that a process needed to be completed before Mx A's whare tangata could be returned and that a pathologist needed to approve its release. However, this was communicated to Mx A and actioned only on 4 November 2024.

68. Although I acknowledge the serious implications of tissue being returned without testing, only Mx A had the mana to decide whether their whare tangata was to be returned. As Mx A's whare tangata had already been cut and dyed without their consent, the requirement to provide a second consent form to receive their whare tangata from the laboratory significantly enhanced their distress.

69. As the whare tangata carries deep and significant meaning for Māori, clinicians working with whare tangata have a responsibility to protect it and its sacredness. However, this was not reflected in the care provided to Mx A or how their whare tangata was handled. As such, I consider that Health NZ breached Right 1(3) by failing to provide Mx A with culturally appropriate care.

70. In this context, I note there appears to be a lack of training provided to public hospital staff, particularly those working in the Women's Health Service, on how to provide culturally safe care. I understand that staff at the public hospital attend a session on 'Te Tiriti o Waitangi & Equity' as part of their induction. In addition to this, the Women's Health Service has had a two-part presentation about how history has shaped Māori health outcomes, and another presentation about tikanga in hapūtanga (pregnancy). However, it appears that staff have not received any training on the tapu nature of whare tangata and why extra care needs to be taken when retrieving and returning this part of the tinana (body). For staff to be able to provide culturally safe care to whānau Māori, they need to receive adequate and ongoing training in this area. I address this issue below.

Recommendations

71. I acknowledge that some changes have been made as a result of Mx A's experience. However, although such changes (including those made by Dr B) are positive, they are not sufficient to prevent similar events occurring in future. I am also aware of another complaint to the HDC concerning the improper return of a consumer's whare tangata in another Health NZ district and other complaints to the HDC that reflect a lack of information provided to consumers about histological testing in the context of requests for tissue return.

72. I am aware that Health NZ is in the process of developing a national informed consent policy, and I intend to engage in this process to strengthen the ability to obtain appropriate informed consent for the return of tissue.

73. As such, I recommend that Health NZ:

a) Provide a written apology to Mx A for its breaches of the Code; such apology is to be provided within three weeks of the date of this report, for forwarding to Mx A;

b) Consider the issues raised in this opinion and how they could be reflected in the proposed national informed consent policy, including ao Māori perspectives on tissue return;

c) In the meantime, amend the 'Request for Treatment/Procedure(s)' form to create separate consent requests for the return of tissue, testing of tissue, re-use of tissue (and histology results) for teaching, and the re-use of tissue (and histology results) for research purposes;

d) Amend the wording of the options for tissue return listed in the 'Human Tissue Return/Release' form. This should include explicit options about the return of tissue after laboratory testing and the return of tissue without laboratory testing;

e) Review and update the 'Human tissue, management and handling' policy to reflect the sacredness of whare tangata for Māori. This should include clear information about the preoperative, operative, and postoperative processes and the management of whare tangata throughout each process;

f) Provide staff in the Women's Health Service with further education about the significance of whare tangata and how to translate this knowledge into practice, including service delivery expectations.

74. For recommendations (b) – (f) above, Health NZ is to report back on and provide evidence of the implementation of those recommendations within three months of the date of this report.

Follow-up actions

75. This report will be provided to Mx A, Health NZ, and Dr B.

76. A copy of this report with details identifying the parties removed, except Health NZ, will be placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Morag McDowell
Health and Disability Commissioner