Northland District Health Board (now Te Whatu Ora Te Tai Tokerau)

A Report by the Deputy Health and Disability Commissioner

(Case 20HDC00531)



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Executive summary

1. This report relates to Te Whatu Ora Te Tai Tokerau's management of a woman's postmenopausal bleeding between 2014 and 2019, and the management of her oncology care.

Findings

- The Deputy Commissioner considered that between 2014 and 2019 there were missed opportunities by multiple senior clinicians to consider the causes of the woman's symptoms critically, undertake appropriate imaging, and manage the post-menopausal bleeding appropriately. The Deputy Commissioner held Te Whatu Ora responsible for these omissions at an organisational level and found Te Whatu Ora in breach of Right 4(1) of the Code.
- 3. The Deputy Commissioner also found Te Whatu Ora in breach of Right 6(1)(b) of the Code as the woman was not provided with information that a reasonable consumer in her circumstances would expect to receive in relation to the options for treatment in 2015 and 2018, and that in 2018 and 2019 she was not provided with adequate information about the risks and benefits of removal of her uterus, ovaries and fallopian tubes. The Deputy Commissioner considered that the missed opportunities to provide this information was attributable to multiple clinicians and signified a failure at an organisational level, for which Te Whatu Ora Te Tai Tokerau held responsibility.
- In addition, the Deputy Commissioner considered that Te Whatu Ora had a responsibility to recognise that it could not provide patients with appointments with the same consultant and was concerned that the woman's care lacked overall coordination and clinical oversight, as clear systems and processes were not in place to ensure continuity of care.

Recommendations

- The Deputy Commissioner recommended that Te Whatu Ora Te Tai Tokerau provide a written apology to the woman's whānau for the breaches of the Code; develop a policy/pathway for unresolved post-menopausal bleeding (including when an ultrasound or CT scan should be performed, and when a case should be discussed at an MDM); and conduct an audit of patients who have re-presented to Te Whatu Ora Te Tai Tokerau over the past 12 months with symptoms of unresolved post-menopausal bleeding.
- The Deputy Commissioner recommended that Te Whatu Ora Te Tai Tokerau consider developing or reviewing systems and/or processes that identify and address the need for ongoing Takawaenga cultural support in the community post-patient/outpatient events. In addition, the Deputy Commissioner recommended that Te Whatu Ora Te Tai Tokerau provide updates on the Northern Regional project regarding access to imaging; the cultural audit tool developed by Te Poutokomanawa Continuous Quality Improvement Team, including any findings around discrimination and racism, cultural responsiveness and capacity of services, and the effectiveness of this tool in equity planning; and the Takaranga competency framework, including an explanation as to how the effectiveness of this framework is being measured.

7. The Deputy Commissioner also recommended that the woman's whānau be offered the opportunity to share their lived experiences, as well as the past and present impact it has had on their overall hauora (health) and their lives, as a legacy in her memory, and for this to be shared with Te Whatu Ora Te Tai Tokerau, Hei Āhuru Mowai, and Te Aho o Te Kahu.

Complaint and investigation

- 8. The Health and Disability Commissioner (HDC) received a complaint from Ms B about the services provided to her mother, Mrs A, by Northland District Health Board (NDHB) (now Te Whatu Ora Te Tai Tokerau). The following issue was identified for investigation:
 - Whether Northland District Health Board provided Mrs A with an appropriate standard of care from 2014 to 2020.
- 9. This report is the opinion of Deputy Commissioner Dr Vanessa Caldwell and is made in accordance with the power delegated to her by the Commissioner.
- 10. The parties directly involved in the investigation were:

Ms B	Complainant/consumer's daughter
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NDHB Provider

Dr C Consultant obstetrician and gynaecologist
Dr D Consultant obstetrician and gynaecologist
Dr E Consultant obstetrician and gynaecologist
Dr F Consultant obstetrician and gynaecologist

11. Also mentioned in this report:

Dr G Consultant obstetrician and gynaecologist

Dr H Oncologist

- Independent advice was obtained from a specialist gynaecologist/urogynaecologist, Dr Jacqueline Smalldridge (Appendix A), and an oncologist, Dr Orlaith Heron (Appendix B).
- E te whānau ka mihi aroha ki a koutou i tō tino mamae, tō pōuritanga o tō māmā ātaahua kua whetūrangitia. Kāore he kupu, he whakaaro hei whakaora te ngaro ka waenganui a

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¹ On 1 July 2022, the Pae Ora (Healthy Futures) Act 2022 came into force, which disestablished all district health boards. Their functions and liabilities were merged into Te Whatu Ora|Health New Zealand (now called Health New Zealand|Te Whatu Ora). All references to NDHB in this report now refer to Te Whatu Ora Te Tai Tokerau.

koutou. Nō reira ka tuku a mātou nei aroha, a mātou nei rangimārie ki a koutou katoa — Mauri Ora.²

14. At the outset, I offer my sincere condolences to Mrs A's whānau for their loss. I acknowledge that this matter continues to cause them significant distress, and I thank them for bringing their complaint to this Office.

Information gathered during investigation

Background

- This report relates to Te Whatu Ora Te Tai Tokerau's management of Mrs A's postmenopausal bleeding between 2014 and 2019, and the management of her oncology care. Mrs A (aged in her fifties at the time of events) developed an abdominal cancer (presumed ovarian) and, sadly, she passed away.
- In 1999, a pelvic ultrasound³ undertaken to investigate Mrs A's heavy (pre-menopausal) bleeding showed a large fibroid⁴ in her uterus. A further ultrasound was performed in 2006 after further issues with heavy menstrual bleeding, and this showed a large endometrial polyp ⁵ and multiple fibroids. Care was provided by Te Whatu Ora Te Tai Tokerau gynaecology service on these occasions. In August 2012, Mrs A had an abdominal ultrasound, which showed a normal gallbladder and common bile duct, and no gallstones.

First referral — July 2014

17. On 4 July 2014, Mrs A experienced post-menopausal vaginal bleeding and was referred for an outpatient appointment at Te Whatu Ora Te Tai Tokerau Gynaecology Department. The referral form documented that Mrs A's last cervical smear, undertaken a year previously, was normal and her blood tests indicated that she should be post-menopausal. Mrs A's iron studies showed that her ferritin and iron levels were slightly below the normal range for women.

^{8 21}µg/L. Mrs A's blood tests in January 2014 showed no evidence of iron deficiency or anaemia.



² Whānau, we acknowledge your deepest pain, the grief of the loss of your beautiful Mother who now adorns the night sky as a shining star amongst her ancestors. There are no words or thoughts to heal the loss that will be between you. So we send our love and our peace to you all — Mauri Ora.

³ A diagnostic examination that produces images that are used to assess organs and structures within the female pelvis. The examination allows quick visualisation of the female pelvic organs and structures, including the uterus, cervix, vagina, fallopian tubes and ovaries.

⁴ A non-cancerous growth.

⁵ An abnormal growth projecting from the inner lining of the uterus.

⁶ A test to check for abnormal changes in cells on the surface of the cervix.

⁷ Mrs A's Body Mass Index (BMI) was documented as 52.7 (BMI of over 30 is classified as obese).

- On 7 August 2014, Mrs A attended an appointment with Dr F, a consultant obstetrician and gynaecologist at Bay of Islands Hospital. Dr F carried out a speculum⁹ examination and removed a cervical polyp and took a pipelle sample ¹⁰ from the uterus lining. Dr F documented that further investigation, including hysteroscopy, ¹¹ would be required if there was abnormal histology or persistent bleeding, and that Mrs A was aware of this. Dr F stated that Mrs A was advised to monitor her bleeding very closely. Dr F did not document whether an abdominal and/or vaginal examination was performed, and did not refer Mrs A for a pelvic ultrasound, CT scan or other imaging.
- 19. The pathology results of the cervical polyp showed no evidence of malignancy. The pipelle pathology results ¹² showed normal histology (ie, no evidence of hyperplasia, ¹³ endometritis, ¹⁴ or malignancy).
- 20. Dr F wrote to Mrs A on 28 August 2014 and stated that the polyp removed from her cervix had no evidence of cancer and there was no sign of pre-cancer or cancer in the sample taken from her uterus lining. Dr F advised Mrs A to see her GP if she had recurrent bleeding and told her that recurrent post-menopausal bleeding can be a sign of cancer, and that further investigations would be important.

Second referral — January 2015

- On 22 January 2015, Mrs A's GP again referred her to NDHB Gynaecology Department as she was still experiencing post-menopausal vaginal bleeding. The referral stated that on examination Mrs A was not anaemic, and Mrs A's BMI was documented on the form as 47.5 on 2 September 2014.
- On 24 February 2015, Mrs A attended an appointment with Dr E, a consultant obstetrician and gynaecologist at Bay of Islands Hospital. Dr E documented that since her last appointment in 2014, Mrs A had experienced vaginal bleeding almost every day (sometimes heavy and sometimes spotting). Dr E referred Mrs A for a hysteroscopy and curettage. Dr E did not document whether an abdominal and/or vaginal examination was performed and did not refer Mrs A for a pelvic ultrasound, CT scan or other imaging.
- On 11 March 2015, Mrs A attended a peri-operative assessment for the hysteroscopy and curettage, and it was noted that her BMI was 52. A full blood count was obtained, and Mrs

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⁹ A tool used to widen the opening of the vagina during a pelvic examination.

 $^{^{10}}$ A small sample of tissue taken from the lining of the uterus using a thin, flexible, hollow tube.

¹¹ Examination of the inside of the womb (uterus) using a narrow telescope with a light and camera at the end.

¹² Dated 11 August 2014.

¹³ The enlargement of an organ or tissue caused by an increase in the reproduction rate of its cells, often as an initial stage in the development of cancer.

¹⁴ Inflammation or irritation of the lining of the uterus.

¹⁵ Passage of a narrow metal spoon-like instrument through the cervix to take a sample from the lining of the uterus.

A's mean cell haemoglobin (MCH) was slightly lower than the normal range. ¹⁶ Mrs A was assessed as fit for general or local anaesthesia.

- Dr E performed a hysteroscopy, curettage and polypectomy¹⁷ on 15 April 2015 at Whangārei Hospital. During the procedure, a vaginal examination was carried out. A large submucosal fibroid polyp¹⁸ (with a large broad base) and an endometrial polyp¹⁹ were identified. The endometrial polyp was removed, but the submucosal fibroid polyp was not removed because of its large broad base. Dr E documented that Mrs A's endometrium was 'otherwise normal'. Samples of the uterus were taken by curettage.
- The discharge summary documented that if Mrs A felt unwell or had severe stomach pain or large amounts of bleeding, she should seek medical advice as soon as possible.
- The pathology results ²⁰ of the removed endometrial polyp were benign, ²¹ as was the pathology of the uterine curettings, although there were small fragments of tissue possibly from an endocervical polyp, ²² and inactive endometrial epithelium ²³ (a normal finding in postmenopausal women).
- On 9 July 2015, Mrs A attended an appointment with Dr D, a consultant obstetrician and gynaecologist at Kaitaia Hospital, for review following her hysteroscopy and polypectomy. In response to the provisional opinion, Te Whatu Ora stated that Mrs A reported only occasional vaginal spotting after her first hysteroscopy and polypectomy.
- On 10 July 2015, Dr D wrote to Mrs A's GP stating that it was reassuring that there was no evidence of malignant process. ²⁴ Dr D noted that the plan was for Mrs A to have an appointment in 12 months' time, and, if she was still experiencing persistent bleeding, a further hysteroscopy would be considered, including resection of the submucosal fibroid polyp. Dr D documented that Mrs A knew that if the bleeding became worse, she could bring forward her appointment.
- In October 2015, a full blood count showed that Mrs A's MCH was still outside the normal range at 25.0pg.



¹⁶ A low MCH value typically indicates the presence of iron deficiency anaemia. Mrs A's result was 25, and the normal range is 27–33.

¹⁷ Procedure to remove polyps.

¹⁸ A fibroid that develops in the muscle layer beneath the womb's inner lining and grows into the cavity of the womb.

¹⁹ Endometrial polyps are overgrowths of endometrial glands that typically protrude into the uterine cavity.

²⁰ Dated 20 April 2015.

²¹ No evidence of cancer.

²² An endocervical polyp is the type of polyp that most commonly occurs in premenopausal women. Typically, they arise from the cervical glands in the endocervix.

²³ A response of the endometrium to the decrease in hormone levels after menopause, within which cancerous changes may develop.

²⁴ Cancerous changes in the cells.

2016-2017

- In June 2016, Mrs A's MCH had risen slightly to 26.00pg but her ferritin levels remained the same. On 21 July 2016, Mrs A cancelled an outpatient appointment and reported that she had no bleeding, and Dr D discharged her back to the care of her GP. On 25 July 2016, Mrs A's GP documented that her parietal cell antibodies²⁵ were positive and that these are associated with pernicious anaemia and patients with autoimmune endocrine disease.
- By April 2017, Mrs A's MCH level had increased to within the normal range.

Third referral — January 2018

- On 15 January 2018, Mrs A's GP referred her to NDHB Gynaecology Department because of post-menopausal bleeding and her history of an endometrial polyp. The referral noted: '[U]rgent high suspicion of cancer.' The GP documented that Mrs A's BMI was 48.4. Mrs A's MCH levels were within the normal range in January 2018. In response to the provisional opinion, Te Whatu Ora stated that it was at this appointment that Mrs A reported spotting to her GP for the first time in six months, which is what prompted re-referral.
- On 18 January 2018, Mrs A attended an appointment with Dr D and the senior house officer to Dr D,²⁶ at Kaitaia Hospital. Mrs A reported that she was experiencing 'ongoing spotting' approximately three times a year, and that her last episode of vaginal bleeding had lasted for a day. A smear test was performed (following a request from Mrs A) and a pipelle sample was taken. It is documented that Mrs A was reluctant but agreed to have a pelvic examination and a pipelle sample at this appointment. It is also recorded that the abdominal examination was limited because of Mrs A's obesity, and that a repeat hysteroscopy and curettage was discussed with Mrs A, but she was reluctant to go ahead with this.
- Dr D documented that his plan was to review the results of the smear and pipelle and review Mrs A in three months' time. Dr D did not refer Mrs A for a pelvic ultrasound.
- The pipelle pathology results showed no evidence of endometritis, hyperplasia or malignancy, and the features were in keeping with an endometrial polyp. The smear test results showed cells from within the uterus²⁷ and no signs of cancer, pre-cancer, or other significant abnormalities.²⁸
- On 16 February 2018, Dr D wrote to Mrs A and informed her that the tissue from her uterus was normal but that the smear test showed cells from within the uterus that were not normal after menopause.



²⁵ Ninety percent of people with pernicious anaemia test positive for antiparietal cell antibodies.

²⁶ The senior house officer signed the letter to Mrs A's GP, but NDHB did not confirm who saw Mrs A on 18 January 2018.

²⁷ The smear results stated that endometrial cells were present and that the presence of these cells in women over 40 can be a normal finding or seen in association with HRT or neoplasia (uncontrolled abnormal growth of cells or tissue in the body).

²⁸ The specimen was negative for intraepithelial lesion or malignancy.

Follow-up appointment — May 2018

Mrs A attended the planned follow-up appointment with Dr D on 10 May 2018 and reported some vaginal bleeding. In a letter to Mrs A's GP about the appointment, Dr D stated:

'[W]e have concluded that, rather than moving to a hysteroscopy to see if she does have a polyp again, it would be perfectly reasonable to simply see her in twelve months' time.'

- 38. Dr D documented that if Mrs A continued to spot during the year, the plan was to repeat the pipelle to ensure that she had not developed endometrial cancer. Dr D documented that Mrs A 'seemed very happy with that as a plan rather than anything more definitive'.
- 39. Dr D did not document whether an abdominal and/or vaginal examination was performed and did not refer Mrs A for a pelvic ultrasound, CT scan or other imaging.

Fourth referral — August 2018

- Three months later, on 24 August 2018, Mrs A's GP referred her to NDHB Gynaecology Department and requested a review with pipelle, as Mrs A was experiencing continued vaginal bleeding ('blood is fresh and more than spotting') three to four days out of seven. Mrs A's BMI was noted as 50.3.
- Mrs A attended an appointment with Dr C on 27 September 2018. After the appointment, Dr C wrote to Mrs A's GP noting that with Mrs A's agreement, as she had been experiencing repeated episodes of much heavier bleeding, she had been put on the waiting list for an urgent hysteroscopy.
- Dr C did not document whether an abdominal and/or vaginal examination was performed and did not refer Mrs A for a pelvic ultrasound, CT scan or other imaging.
- On 5 October 2018, Dr E and a senior house officer carried out Mrs A's hysteroscopy and curettage. A large polyp that filled the majority of the womb cavity and 'looked like a fibroid' was identified. Owing to the size of the polyp, Dr E and the senior house officer were unable to remove it but obtained samples from the lining of Mrs A's womb for testing. A gynaecology outpatient appointment was scheduled for two months' time to review her symptoms.
- The pathology report ²⁹ noted features indicative of endometrial polyps with inactive appearing endometrium, and no evidence of endometritis, hyperplasia or malignancy was seen.
- On 19 October 2018, on behalf of Dr E, a consultant obstetrician and gynaecologist wrote to Mrs A and informed her that the tissue removed from her uterus showed a benign polyp with no evidence of pre-cancerous change. The obstetrician and gynaecologist stated that there was a large fibroid polyp inside her uterus, and that the removal of the smaller one

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²⁹ Dated 11 October 2018.

might not have an effect on her bleeding. The obstetrician and gynaecologist did not inform Mrs A of the option of hysterectomy and bilateral salpingo-oophorectomy.³⁰

Follow-up appointment — November 2018

- On 27 November 2018, Mrs A attended the planned follow-up appointment and was seen by Dr F. Dr F documented that Mrs A was shown photographs of the polyp or fibroid in her womb, and that the diagnosis was reviewed with Mrs A. Dr F noted that Mrs A was told about the importance of monitoring for any further vaginal bleeding, and that they 'briefly discussed hysterectomy as well if [Mrs A did] have further bleeding'.
- 47. Mrs A was discharged from NDHB Gynaecology Department with advice to contact her GP if she experienced a recurrence of vaginal bleeding.

Fifth referral — 2019

- On 18 Month1,³¹ Mrs A's GP again referred Mrs A to NDHB Gynaecology Department. The referral letter states that this was the first time she had presented to the GP since July 2018, and that she continued to experience vaginal bleeding.
- Mrs A attended an appointment on 1 Month2 with Dr G, a consultant obstetrician and gynaecologist, who documented Mrs A's history of bleeding every day. Dr G noted that the plan was to remove the polyp by MyoSure.³² Mrs A was placed on the waiting list for hysteroscopy pending suitable equipment for hysteroscopic resection of the fibroid.

Months 3-4

- 50. On 30 Month3, routine blood tests showed borderline anaemia (haemoglobin 112g/L), normal red cell parameters and ferritin levels, but low serum iron. On 2 Month4, iron supplementation was prescribed with a plan to repeat Mrs A's bloods in three weeks' time.
- On 24 Month4, Mrs A attended a further appointment with Dr G, who documented Mrs A's history of continuing post-menopausal bleeding and a haemoglobin of 106g/L (the normal haemoglobin for a woman ranges from 115 to 160g/L). Dr G documented a plan for Mrs A to undergo iron replacement and noted that Mrs A was on the waiting list for surgery to remove the fibroid. Dr G recorded that Mrs A was aware that the operation might not stop the bleeding, and might not remove all the fibroid, and that she might need interventional radiology. Dr G noted: '[Mrs A] is aware that hysterectomy is unsafe and she does not want a hysterectomy.' Dr G also documented: '[O]bviously with [Mrs A's] weight all possible interventions are difficult and have side effects.'

³² A minimally invasive procedure to remove uterine tissue, including fibroids and polyps, using a camera inserted inside the uterus, and a wand to cut and remove the tissue.



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³⁰ Removal of the uterus, ovaries and fallopian tubes.

³¹ Relevant months are referred to as Months 1–7 to protect privacy.

In response to the provisional opinion, Te Whatu Ora told HDC that Mrs A was commenced on Provera (hormone treatment) and booked for a further hysteroscopy and MyoSure resection of the fibroid.

Month5

- On 19 Month5, Mrs A attended the Emergency Department (ED) as she was due to receive an iron infusion in preparation for the elective surgery to remove the fibroid scheduled for the following week. During her presentation to ED, Mrs A reported a history of increasing sharp pain in her stomach, which was radiating to her upper back, and on examination it was noted that she had a fever.
- Mrs A underwent an abdominal ultrasound scan, which was unremarkable. A computerised tomography (CT) scan³³ was also performed, which showed a large pelvic mass that was highly suspicious of an ovarian neoplasm.³⁴
- On 21 Month5, Mrs A underwent a magnetic resonance imaging (MRI) scan³⁵ at Whangārei Hospital, which confirmed probable stage four cancer with raised tumour markers.

Gynecology Multidisciplinary meeting — Auckland DHB

- NDHB told HDC that when a probable cancer case is identified, it is referred to the regional gynaecology multidisciplinary meeting (MDM) at another DHB (DHB2). NDHB stated that DHB2's MDM meets on Wednesday mornings, and an MRI is required before a case will be discussed. Therefore, as Mrs A's MRI took place on 21 Month5, the first MDM after this was on 27 Month5.
- At DHB2's MDM, Mrs A was diagnosed with a stage four right ovarian mass with peritoneal disease ³⁶ /omental disease, ³⁷ a cardiophrenic lymph node tumour, ³⁸ and endometrial thickening. DHB2 recommended that Mrs A undergo endometrial sampling and biopsy and a chest CT scan, and then re-present to DHB2's MDM.

Biopsy attempt one and two

Mrs A's first biopsy was scheduled for 29 Month5 but was rescheduled by the Radiology Department. NDHB told HDC that the rescheduling took place because interventional radiologists are available in Whangārei Hospital only on certain days.

³⁸ Lymph nodes that are frequently visible on CT imaging of patients with advanced ovarian cancer.



³³ A series of X-rays taken from different angles around the body to give detailed images of the organs and other structures in the body.

³⁴ Cancer that forms in tissues of the ovary.

³⁵ A scan that produces detailed three-dimensional images of the inside of the body. It can be used to diagnose and plan treatment of tumours.

³⁶ Cancer that has spread to the lining surfaces of the abdominal cavity.

³⁷ Cancer that has spread to the fold of tissue that connects or supports the abdominal structures.

- Four days later, on 2 Month6, an ultrasound-guided biopsy 39 was attempted, but 59. unfortunately, the lesion could not be seen, and therefore a CT-guided biopsy 40 was scheduled for the next day, 3 Month6.
- The second attempt to take a biopsy, on 3 Month6 (a CT-guided biopsy), was unsuccessful 60. because Mrs A experienced severe back pain and was unable to stay in the required position long enough for the procedure to be completed. The Radiology Department requested that Mrs A receive a loading dose of analgesia before the next attempted biopsy. This was scheduled for 10 Month6. NDHB did not provide HDC with an explanation of why the third attempt at biopsy was scheduled seven days later.

Care between 3 and 8 Month6

Dr H, an NDHB oncologist, told HDC that in this period Mrs A was generally unwell, and her 61. Eastern Cooperative Oncology Group (ECOG) performance status was three, 41 she had developed significant oedema⁴² in her waist, and she had low albumin⁴³ and anaemia. Dr H stated that Mrs A received care from the palliative care team, Te Poutokomanawa Māori Health Services, 44 and the medical team.

Oncology assessment — 9 Month6

- On 9 Month6, Mrs A was reviewed by Dr H with her whānau present. The review took place 62. 48 hours after Mrs A had been referred to Oncology informally by the Gynaecology team. Dr H told HDC that he explained that the CT scan showed that Mrs A had cancer, but there was uncertainty about the type of cancer it was (endometrial or ovarian) and, if it was ovarian cancer, whether it was low- or high-grade cancer.
- 63. Dr H said that he told Mrs A and her whānau that the cancer was not curable, and that even with chemotherapy, Mrs A's prognosis would be measured in a short number of months or possibly a short number of years. Dr H told HDC that he said that he would tentatively schedule chemotherapy for three days after the biopsy (13 Month6)⁴⁵ as he had hoped that he would have received Mrs A's provisional biopsy results.
- Dr H stated that he told Mrs A that if she had a high-grade serous cancer then chemotherapy 64. was the appropriate treatment, and that despite her current performance status, given her young age he was keen to treat her with a dose of chemotherapy (platinum based) in hospital. Dr H said that if Mrs A had a good response, it could be escalated to another type

³⁹ The use of ultrasound to guide a needle to the area of concern and take a sample of tissue for examination under a microscope.

⁴⁰ The use of CT scanning to guide a needle to the area of concern to obtain a tissue sample for examination under a microscope.

⁴¹ Capable of only limited self-care; confined to bed or a chair more than 50% of waking hours.

⁴² Fluid retention.

⁴³ A protein in blood plasma. Low albumin levels may be the result of kidney disease, liver disease, inflammation or infections.

⁴⁴ Te Poutokomanawa (Māori Health Directorate) is comprised of four units, including the Takawaenga service.

⁴⁵ Dr H told HDC that four days is not a delay by the Oncology service.

of chemotherapy (carboplatin or paclitaxel). Dr H stated that if the histology demonstrated a low-grade tumour then hormone therapy might be more appropriate.

Third biopsy attempt

- On 10 Month6, a second CT-guided biopsy was attempted with intravenous sedation, but Mrs A experienced severe back pain and became anxious and asked for the procedure to stop. It was explained to Mrs A that she would require a general anaesthetic to complete a CT-guided biopsy.
- Dr H recalls that whilst Mrs A was undergoing the biopsy attempt, he went to the Radiology Department, and he and the radiologist spoke to Mrs A and her daughter, and jointly they decided to abandon the attempts at performing a biopsy.
- of. Ms B told HDC that she believes the failure to provide her mother with a general anaesthetic at this guided biopsy may have been a contributing factor to the delay in the commencement of her mother's treatment.

Chemotherapy decision

- Dr H documented that on 11 Month6 he spoke with Mrs A and expressed his concern that waiting for further attempts to perform a biopsy could result in a decline in her situation. Dr H stated that he informed Mrs A that her chemotherapy could proceed without a biopsy, but he could not advise her on the likelihood of the treatment's benefits.
- Or H told HDC that he discussed the risks of chemotherapy with Mrs A, including that her condition was borderline and that there was a real risk that treatment could potentially lead to further decline in her health and potentially prove terminal. Dr H stated that he also discussed his concern about her short-term prognosis, but that even with treatment there was a significant chance that her cancer would not respond and that she could die from her cancer. Dr H stated that Mrs A decided that she wished to proceed with treatment, and therefore he planned for her chemotherapy to begin on 13 Month6. Dr H requested a blood transfusion before starting the chemotherapy.

Bowel obstruction

- On 12 Month6, Mrs A developed a bowel obstruction.⁴⁶ On 13 Month6, Dr H reviewed Mrs A and informed her that she could not receive chemotherapy whilst she had a bowel obstruction because there was an unacceptably high chance of death if treatment commenced.
- obstruction was cleared. Ms B also stated that Dr H raised the possibility of Mrs A receiving a bowel bypass operation to allow the chemotherapy to occur, but none of the staff were prepared to undertake the operation because of her BMI. Dr H told HDC that the Gynaecology team considered that surgery was not an option for Mrs A.



⁴⁶ A blockage of the bowel.

The palliative care service and the Gynaecology Department decided to arrange for Mrs A to be transferred to hospice, and this took place on 13 Month6.

13 Month 6 to 6 Month 7

- 73. Ms B told HDC that her mother's bowel obstruction cleared on 13 Month6, and her bowel continued to work until 4 Month7, but during this period no attempt was made to commence chemotherapy.
- Dr H told HDC that his understanding was that Mrs A planned to be discharged from palliative care on 19 Month6 because she wished to be at home with her family. Dr H stated that he supported the decision for Mrs A to return home at this point, as he did not think that Mrs A was well enough for treatment. Dr H told HDC that he intended to offer Mrs A's family hope that if she was making improvement with her strength, they could reconsider the prospect of chemotherapy, and that this would be revisited.
- Mrs A's ECOG on 20 Month6 was 3–4, and the district nurse's notes document that Mrs A had continued significant oedema with secondary serous ooze that required dressings, and dressings were also required for her abdominal wound.
- Ms B stated that on 23 Month6 she spoke to Dr H and informed him that Mrs A's bowel had been unobstructed since leaving hospital, and she wanted to discuss the commencement of chemotherapy treatment. Ms B stated that Dr H said that it would be best for Mrs A to enjoy time with her family. Ms B told HDC that this was a 22-day delay in Mrs A receiving treatment.
- On 6 Month7, Dr H documented that he was due to see Mrs A to assess whether she was well enough to commence chemotherapy. Dr H recorded that Mrs A's family had contacted him and told him that Mrs A had been re-admitted to hospice. Dr H documented that Mrs A and her family had decided that they did not wish Mrs A to have chemotherapy, and they wished to focus on comfort cares. Dr H recorded that he had discharged Mrs A from the Medical Oncology service but was happy to be involved in discussions around her care.

Subsequent events

78. Sadly, on 9 Month7, Mrs A passed away.

Further information

Te Whatu Ora Te Tai Tokerau

79. Dr C, a consultant obstetrician and gynaecologist and clinical director at NDHB, told HDC that between 2014 and 2018 NDHB had severely limited resources, particularly in relation to access to pelvic ultrasounds, and clinicians were encouraged to refer patients for hysteroscopy to investigate the cause of post-menopausal bleeding. Dr C stated that the department was reminded repeatedly that ultrasound scanning in NDHB was a relatively scarce resource.

80. Dr C stated that there were also staffing issues, which meant that it was difficult for patients to see the same doctor at each appointment.

Ms B

Ms B told HDC that she is concerned that the lack of screening may be the result of where Mrs A lived. Ms B stated that over a five-year period, Mrs A did not receive any referrals for further testing, which was unacceptable. Ms B said that she is of the view that her mother may have been more successful in receiving a referral if she had lived somewhere other than Northland. Ms B is also concerned that the poor outcome for her mother may have been because of being Māori. Ms B told HDC that she noted that the female uterine cancer registration rate and mortality rate by site is significantly higher for Māori than non-Māori.

Dr C

- Dr C told HDC that symptoms and signs of ovarian cancer are typically insidious, and often women have advanced disease before diagnosis. Dr C stated that Mrs A did not report any symptoms suggesting ovarian cancer before her acute admission in Month5. He said that there had been no reason to consider investigation for pelvic mass before that time, and even when she presented acutely, the diagnosis was unexpected. Dr C stated that ovarian cancer did not usually present with vaginal bleeding, so there was no indication to look for it. Dr C further explained that not all abdominal masses arise from the ovaries, and ovarian tumours vary in type.
- Dr C accepted the opinion of HDC's independent advisor, Dr Smalldridge (discussed further below) that a hysterectomy could have been offered to Mrs A at some stage because of recurrent post-menopausal bleeding. However, Dr C made the following points:
 - The main purpose of investigating post-menopausal bleeding is to diagnose or exclude endometrial cancer. Dr C stated that ultrasound scanning is used primarily to demonstrate a thin endometrium to avoid hysteroscopy. He said that in Mrs A's case, ultrasound imaging was of very limited value because of her body shape and size. This led to the decision to go straight to hysteroscopy, which allows direct imaging of the inside of the uterus, removal of polyps, and biopsy.
 - On repeated occasions, direct uterine biopsy showed no endometrial cancer or hyperplasia (a usual precursor for cancer) but did show an alternative benign explanation for the bleeding (polyps).
 - If the Gynaecology Department had felt that hysterectomy was an appropriate option, this would have been undertaken, but the gynaecologists who saw Mrs A did not think it was indicated when benign explanations for the post-menopausal bleeding were repeatedly found on hysteroscopy.

Responses to provisional opinion

Mrs A's whānau

Mrs A's whānau were given the opportunity to respond to the 'information gathered' section of the provisional report. A hui ā-whānau to discuss the provisional report also took

place on 22 June 2023. The whānau did not wish to make any comments regarding the provisional report but did highlight during the hui ā-whānau that Mrs A's condition would not have been detected if she had not consulted a private gynaecologist.

Te Whatu Ora Te Tai Tokerau

- Te Whatu Ora Te Tai Tokerau was given the opportunity to respond to the provisional report. Te Whatu Ora's response has been incorporated into this report where relevant.
- Te Whatu Ora expressed its sincere condolences to Mrs A's family and stated that its aim is to provide excellent care always, along with respectful and effective communication, and apologised that it did not meet the whānau's reasonable expectations in this regard.
- Te Whatu Ora accepted that there continues to be inequity of access to health care and of health outcomes for Māori compared to non-Māori, which is present across New Zealand, and stated that it continues to strive to recognise and address inequity across all its services.
- Te Whatu Ora stated that the purpose of investigating post-menopausal bleeding is to diagnose or exclude cervical or uterine cancer. It said that usually the steps in investigation are:
 - Clinical examination, including a bimanual vaginal examination;
 - Transvaginal ultrasound to assess the endometrial thickness and to exclude a uterine mass (as CT scanning is considered inferior to ultrasound for this examination); and
 - Hysteroscopy.
- 89. Te Whatu Ora stated that an examination and pipelle biopsy occurred at Mrs A's first specialist appointments in 2014 and 2018, and as Mrs A was booked for a hysteroscopy under general anaesthesia in February 2015, it was felt unnecessary to perform a transvaginal ultrasound. Te Whatu Ora said that the hysteroscopy confirmed that Mrs A had several uterine polyps, which could well have explained her post-menopausal bleeding, and therefore the course of investigation was appropriate and in line with good practice.
- Te Whatu Ora stated that Mrs A's recurrent presentations with post-menopausal bleeding should have triggered re-evaluation and consideration of treatment options, including a hysterectomy and/or hormonal therapy, and it is unclear from the clinical records whether these options were considered and offered to Mrs A earlier in her treatment pathway.

Opinion: Te Whatu Ora

Introduction

- At the outset, I offer my sincere condolences to Mrs A's whānau for their loss. I acknowledge that this matter continues to cause them significant distress, and I thank them for bringing their complaint to this Office.
- Te Whatu Ora is responsible for the operation of the clinical services it provides and carries responsibility for service failures. Te Whatu Ora had a duty to ensure that the services Mrs A received were provided with reasonable care and skill.
- My role is to assess whether, with the information available to Mrs A's healthcare providers at the time of events, those providers acted appropriately and in accordance with an acceptable standard of care. When retrospectively assessing the care provided, I have endeavoured to make that assessment free from hindsight bias, notwithstanding the tragic outcome. I acknowledge that an earlier diagnosis may not have been made, and that an earlier diagnosis may not have influenced the ultimate outcome.
- In considering whether Te Whatu Ora Te Tai Tokerau provided services to Mrs A with reasonable care and skill, I have considered independent advice provided to this Office by a specialist gynaecologist/urogynaecologist, Dr Jacqueline Smalldridge, and an oncologist, Dr Orlaith Heron.

Gynaecology investigations and treatment 2014-2019

Cause of post-menopausal bleeding

- From August 2014 to Month4 2019, Mrs A's GP referred her to Te Whatu Ora Te Tai Tokerau's Gynaecology Department on five occasions with symptoms of post-menopausal vaginal bleeding.
- In response to the provisional opinion, Te Whatu Ora stated that the purpose of investigating post-menopausal bleeding is to diagnose or exclude cervical or uterine cancer. It stated that usually the steps in investigation are a clinical examination, transvaginal ultrasound, and hysteroscopy.
- Te Whatu Ora also stated that Mrs A underwent an examination and pipelle biopsy at her specialist appointments in 2014 and 2018, and a hysteroscopy in 2015, which confirmed that she had several uterine polyps that could explain her post-menopausal bleeding. Te Whatu Ora said that the intermediary step of a transvaginal ultrasound was unnecessary given the hysteroscopy, and the investigations were appropriate and in line with good practice.
- 98. Dr Smalldridge advised that, in her opinion, the outpatient records during this period suggest that the clinicians were excluding only endometrial cancer as a cause for Mrs A's post-menopausal bleeding, and when this was done, they were not thinking about other causes despite her frequent re-referrals by the GP. Dr Smalldridge noted that ovarian cancer

is 'notoriously difficult to diagnose and is often very insidious but the symptom of [post-menopausal bleeding] can be associated with it and was not considered according to the records'.

I acknowledge that ovarian cancer is difficult to diagnose, and that Mrs A's cancer may not have been detected earlier had other treatment or investigations been provided during this period. I also acknowledge that Mrs A's post-menopausal bleeding may not have been attributable to her later diagnosis, and I do not attempt to make any findings in this regard. However, I am concerned about a lack of critical thinking at key points by the clinicians involved in Mrs A's care.

Management of post-menopausal bleeding 2015–2019

- option to treat post-menopausal bleeding in 2015 and 2018.

 Dr Smalldridge advised that further consideration should have been given to offering Mrs A surgery (a total abdominal hysterectomy and bilateral salpingo-oophorectomy 47) as an option to treat post-menopausal bleeding in 2015 and 2018.
- By April 2015, Mrs A had had two GP referrals and two years of post-menopausal bleeding, and polyps had been identified. In July 2015, following a hysteroscopy that concluded 'no detectable cancer', the plan was for Mrs A to be reviewed in a year's time, and, if the bleeding persisted, for a further hysteroscopy to be considered.
- Dr Smalldridge stated that in light of the findings from the first hysteroscopy in April 2015, there was a missed opportunity to offer Mrs A the removal of her uterus, ovaries and fallopian tubes as a treatment option. Dr Smalldridge said that no other plan to manage Mrs A's post-menopausal bleeding was mentioned in the clinical records.
- Three years later, in January 2018, Mrs A was still experiencing post-menopausal bleeding, a smear test showed cells from within the uterus that were not normal after menopause, and a pipelle sample noted features in keeping with an endometrial polyp. No plan was made to treat Mrs A's post-menopausal bleeding, and she was not informed of the treatment option of the removal of her uterus, ovaries and fallopian tubes.
- In October 2018, tissue removed from Mrs A's uterus showed a benign polyp with no evidence of pre-cancerous change. Dr Smalldridge stated that the findings at hysteroscopy (in October 2018) of a large polyp/fibroid causing the bleeding were not dealt with, so it was likely that Mrs A would continue to bleed. Dr Smalldridge advised that if there is persistent post-menopausal bleeding despite normal histology, then the accepted practice is to perform surgery to remove the uterus, ovaries and fallopian tubes because of the risk of underlying malignancy.
- In response to the provisional opinion, Te Whatu Ora accepted that recurrent presentations with post-menopausal bleeding should have triggered re-evaluation and consideration of treatment options including a hysterectomy and/or hormonal therapy, and it is unclear from

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⁴⁷ Removal of the uterus, ovaries and fallopian tubes.

the clinical records whether these options were considered and offered to Mrs A earlier in her treatment pathway.

There is no documented evidence that Mrs A was provided with information about the 106. option of having her uterus, ovaries and fallopian tubes removed in 2015 or in January 2018, and it is noted as having been only 'briefly discussed' in November 2018. In Month4 2019, it was recorded that Mrs A understood that a hysterectomy would be 'unsafe'. Dr Smalldridge advised that had Mrs A been provided with the appropriate information and then chosen not to proceed, 'then this should have been documented in detail as this would have meant that she understood the consequences of no treatment'.

107. Dr Smalldridge highlighted that this would have been difficult surgery, but there were DHBs that could plan and manage the risks, and 'most gynaecologists would have a low threshold for performing a hysterectomy and bilateral salpingo-oophorectomy in recurrent [postmenopausal bleeding] even in the face of potential complications from high BMI'. Dr Smalldridge advised:

> 'In most DHBs, there are senior Gynaecologists who would take on difficult hysterectomies or pelvic surgery in patients with raised BMIs. The patient would be discussed at the M&M⁴⁸ meeting first. There would be a consensus from the attendees that this was the correct and necessary approach. They would arrange a meeting with the patient and their family members (+/- cultural support) to discuss the risks and likely outcomes of the surgery and the consequences of not having the surgery. They would liaise with the anaesthetic department and book the patient on a list at the main hospital and have scheduled for post op[erative] care a high dependency unit bed or ICU bed if appropriate. They would plan to operate with a colleague to add expertise with the difficult surgery. If this was not possible to do then it would be appropriate for the patient be referred to a DHB that does perform difficult surgeries on patients with high BMI. The reality is that all DHBs encounter patients with high BMI and need to develop the necessary expertise.'

In response to the provisional opinion, Te Whatu Ora noted that Mrs A did not develop 108. endometrial or uterine cancer related to failure to offer treatment earlier. However, it acknowledged that Mrs A was at higher risk of developing endometrial or uterine cancer due to her history of recurrent post-menopausal bleeding, high BMI, and a large submucosal polyp. Te Whatu Ora apologised that more treatment options and further investigations were not made available to Mrs A over this timeframe.

Mrs A was experiencing symptoms that spanned five years, and despite multiple referrals 109. to Te Whatu Ora and many investigations, no plan was put in place to address her symptoms, and surgery was not offered as a viable treatment option in 2015 or 2018. Dr Smalldridge advised that this was a severe departure from accepted practice.

⁴⁸ Multidisciplinary mortality and morbidity.



I accept this advice. I am critical of the failure by multiple clinicians to manage Mrs A's postmenopausal bleeding appropriately, and for not providing adequate information about the available treatment options (even if this was not with them) and the associated risks and benefits.

Pelvic ultrasounds and CT scans

- In the relevant period, Mrs A had three hysteroscopies to investigate her symptoms further, but she was not referred for a pelvic ultrasound.
- Dr Smalldridge advised that a pelvic ultrasound should be performed to look at the endometrial thickness, which should be less than 4mm in a postmenopausal woman, and to visualise the ovaries. Dr Smalldridge stated that if the endometrial thickness is thicker than 4mm, a sample is then obtained by pipelle or hysteroscopy dilation and curettage. Dr Smalldridge advised that a hysteroscopy also visualises the cavity and is useful if the ultrasound is difficult because of a raised BMI.
- Dr C told HDC that ultrasound scanning is used primarily to demonstrate a thin endometrium to avoid hysteroscopy. He stated that in Mrs A's case, ultrasound imaging was of very limited value because of her body shape and size. This led to the decision to go straight to hysteroscopy, which allows direct imaging of the inside of the uterus, removal of polyps, and biopsy. Dr C also told HDC that between 2014 and 2018, Te Whatu Ora Te Tai Tokerau had severely limited resources, particularly in relation to access to pelvic ultrasounds, and clinicians were encouraged to refer patients for hysteroscopy to obtain diagnosis for the cause of post-menopausal bleeding.
- In response to the provisional opinion, Te Whatu Ora told HDC that the Radiology Department does not recollect any specific limitations in access to ultrasounds during this period. Te Whatu Ora stated that although there may have been some general discussion around demand management, the intent is to always leave capacity for urgent cases, and post-menopausal bleeding, as a cancer symptom, is not an area in which it would seek to put limitations.
- 115. While Dr Smalldridge agreed that pelvic ultrasound examinations are often incomplete or hard to interpret because of a high BMI, she stated that further imaging (such as CT scans) can be undertaken if the ovaries are not visualised adequately on an ultrasound.
- Dr Smalldridge noted that a CT scan was performed only when Mrs A presented to the general surgeons with abdominal pain, and this was when the large ovarian mass was detected. Dr Smalldridge advised that this was a severe departure from the standard of care/accepted practice, and noted that opportunities to perform further imaging, which may have resulted in an earlier diagnosis, were missed.
- 117. I acknowledge the possible resource constraints faced by staff at Te Whatu Ora Te Tai Tokerau in relation to access to pelvic ultrasounds. Dr Smalldridge also acknowledged these constraints and advised that Te Whatu Ora Te Tai Tokerau had departed from the standard

of care severely, as it had failed to provide basic resources in the form of access to ultrasound for patients.

I accept this advice. I consider that Mrs A should have had further imaging between 2014 and 2018 to visualise her ovaries. I accept that Te Whatu Ora Te Tai Tokerau had limited resources in relation to access to pelvic ultrasounds. However, the option of referring Mrs A to a different region for a pelvic ultrasound scan does not appear to have been considered, and the failure to perform an ultrasound or CT scan meant that Mrs A's ovaries were not visualised after 1999.

Conclusion

- In summary, I consider that between 2014 and 2019 there were missed opportunities by multiple senior clinicians to:
 - Consider the causes of Mrs A's symptoms critically;
 - Manage Mrs A's post-menopausal bleeding appropriately; and
 - Undertake appropriate imaging by way of pelvic ultrasounds and/or CT scans.
- 120. I consider that Te Whatu Ora holds responsibility for these omissions at an organisational level. Accordingly, I find that Te Whatu Ora breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code).⁴⁹
- I also consider that Mrs A was not provided with information that a reasonable consumer in her circumstances would expect to receive in relation to the options for treatment in 2015 and January 2018, and I consider that in November 2018 and Month4 2019 she was not provided with adequate information about the risks and benefits of removal of her uterus, ovaries and fallopian tubes. The missed opportunities to provide this information are attributable to multiple clinicians, and signify a failure at an organisational level, for which Te Whatu Ora Te Tai Tokerau is responsible. Accordingly, I find that Te Whatu Ora Te Tai Tokerau breached Right 6(1)(b) of the Code. 50

Continuity of care — adverse comment

During this period, Mrs A attended nine appointments, at three different hospitals, and she saw five different consultants. On two occasions, clinicians who had not seen Mrs A personally were involved in her care. First, on 10 July 2015, Dr D wrote to Mrs A's GP stating that it was reassuring that there was no evidence of malignant process (he had had no prior involvement in Mrs A's care). Secondly, on 19 October 2018, an obstetrician and gynaecologist wrote to Mrs A on behalf of Dr E, and informed Mrs A that her tissue sample

⁵⁰ Right 6(1)(b) states: 'Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including an explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option.'



 $^{^{}m 49}$ Right 4(1) states: 'Every consumer has the right to have services provided with reasonable care and skill.'

was benign. Dr C told HDC that there were staffing issues, which meant that it was difficult for patients to see the same doctor at each appointment.

- In response to the provisional opinion, Te Whatu Ora accepted that developing an on-going relationship with a specialist provides the best continuity of care for patients presenting recurrently with the same condition, and it is likely that if Mrs A had lived in Whangārei, she would have seen the same specialist; however, this is not achievable in rural clinics, where providing timely access to a particular surgeon is more difficult as the frequency of clinics is less. In addition, Mrs A was also seen at Bay of Islands Hospital and sometimes at Kaitaia Hospital, and specialists attending rural clinics will change over time.
- In its response to the provisional opinion, Te Whatu Ora further stated that on each occasion on which Mrs A was re-referred to the gynaecology service, a potential cancer diagnosis was considered, dictating a short timeframe for first specialist appointments, and, while meeting this timeframe is prioritised, the constraints of the system make continuity harder to achieve. Te Whatu Ora said that one consequence of the change in clinicians would have been to reduce the risks of confirmation bias.
- Dr Smalldridge stated that it did not seem that Mrs A was 'owned' by any particular specialist who was taking overall responsibility for her care. Dr Smalldridge said that each visit seemed to be looked at in isolation as an individual episode of care rather than a continuum. I accept this advice and am concerned that Mrs A's care lacked overall coordination and clinical oversight.
- Previously, this Office has stated⁵¹ that a DHB's systems would be expected to operate in such a way that a patient who has attended numerous times with the same issue would be afforded continuity of services (for example, by having a dedicated team or lead clinician assigned to oversee, monitor, and plan the patient's care). I acknowledge that Mrs A's care spanned a five-year period, and that seeing the same clinician over such a long period of time may not have been possible. I also note Te Whatu Ora's statement that a change in clinicians would have reduced the risks of confirmation bias.
- 127. Although I appreciate the difficulties facing rural clinics, I am of the opinion that Te Whatu Ora had a responsibility to recognise that it could not provide patients with appointments with the same consultant, and it needed an effective system in place to ensure overall clinical oversight and continuity of care.

Oncology treatment — no breach

On 19 Month5, a CT scan showed a large pelvic mass that was suspected to be cancerous, and Mrs A was admitted to Whangārei Hospital. Three days later, she had an MRI, and on 27 Month5 her case was discussed at the next DHB2 MDM. On 2, 3 and 10 Month6, attempts were made to take biopsies for histology to identify the type of cancer, but unfortunately all three biopsy attempts were unsuccessful.

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⁵¹ 19HDC00256, available at www.hdc.org.nz.

- Dr H decided to see Mrs A on 9 Month6 without histology results. On 11 month6, Dr H expressed his concern to Mrs A that waiting for further attempts to perform a biopsy could result in a decline in her situation, and they decided together that she would start chemotherapy on 13 Month6 (five days after his initial discussion with her). Unfortunately, on 12 Month6 Mrs A developed a bowel obstruction, and Dr H decided that there was an unacceptable chance of death if chemotherapy commenced whilst she had the obstruction.
- On 13 Month6, Mrs A was transferred to hospice. On 6 Month7, Dr H reassessed Mrs A's condition and decided that she was too unwell to commence chemotherapy, and he discharged her from the Oncology service.
- 131. My independent clinical advisor, oncologist Dr Heron, advised that an oncology appointment 15 working days from admission (which occurred in this case) is prompt. He also explained that histology (for example, from a biopsy) dictates the treatment plan and is important for prognosis. Dr Heron advised that oncologists rarely see patients without histology, and he also would have waited for Mrs A's biopsy results so he could have a full discussion with Mrs A and her family.
- Dr Heron stated that after the three failed biopsy attempts, Mrs A's only remaining option was biopsy under general anaesthetic. He explained that this type of biopsy is logistically challenging, especially in regional hospitals, as it can take up to a week to organise, and it requires theatre space and the presence of an interventional radiologist and an anaesthetist. Dr Heron noted that some of these services are not available daily. He advised that Mrs A's health was deteriorating, she was a high anaesthetic risk, and she was already very borderline for chemotherapy. Dr Heron advised that Mrs A's health would not have withstood the wait for histology from a rescheduled biopsy, and that a further wait would have definitively rendered her unsuitable for chemotherapy. Dr Heron said that he agreed with the Gynaecology team and Dr H's decision not to organise a biopsy under general anaesthesia as, in his view, the risk outweighed any potential benefit.
- Dr Heron explained that Mrs A had either a primary ovarian or endometrial malignancy. Both cancers have several different variants, and some are sensitive to chemotherapy and others are quite resistant. Dr Heron stated that ovarian cancer has a higher response rate and better long-term prognosis than endometrial cancer in general, and surgery can be considered if there is a good response in the ovarian cancer setting.
- Dr Heron advised that given Mrs A's unwellness (ECOG 3) and degree of symptoms, only a highly chemosensitive cancer would respond in a timely enough fashion to turn around her clinical situation. Dr Heron stated that this information is important to help to weigh up potential benefit of chemotherapy versus its toxicity.
- Dr Heron also agreed with Dr H's decision not to commence chemotherapy on 13 Month6, as active bowel obstruction is a contraindication to chemotherapy. Dr Heron advised that he also would not have started chemotherapy after Mrs A was transferred to hospice. He explained that despite Mrs A's bowel obstruction appearing to settle, she was too unwell. He said that Mrs A was experiencing cellulitis, was sleeping during the day, and her mobility

was decreasing. He stated that the benefit of the doubt for treatment was given because of Mrs A's age and the possibility that this was a high-grade serous ovarian cancer. Dr Heron advised that unfortunately, the short window of opportunity for chemotherapy was lost when the bowel obstruction occurred.

- I accept this advice. I have examined the timeline from Mrs A's admission to hospital to when Mrs A first saw Dr H on 9 Month6 and have carefully considered Dr H's decisions regarding chemotherapy. I appreciate that during this difficult period, any wait is very stressful. Oncology involvement ordinarily occurs once histology has been obtained, and Dr H became involved in Mrs A's care before histology was obtained. I therefore consider that the commencement of oncology involvement was reasonable.
- 137. I also consider that Dr H's decisions regarding not commencing chemotherapy were appropriate. On 12 Month6, Dr H and Mrs A decided that she would undergo chemotherapy treatment. However, it was unsafe to commence chemotherapy on 13 Month6 because of her bowel obstruction, and afterwards Mrs A's health was not considered stable enough for her to receive chemotherapy.

Cultural considerations — other comment

- 138. I note that Takawaenga⁵² support was offered when Mrs A was transferred to hospice for palliative care. However, I consider that Takawaenga support could have been offered to Mrs A at a much earlier stage.
- Early Takawaenga engagement with whānau to support Mrs A may have given her an opportunity to exercise her mana motuhake (self-determination) in her treatment options and care. I consider that Takawaenga engagement also may have assisted Mrs A during the biopsy interventions, in that she may have benefited from her taha wairua (spiritual and emotional wellbeing) being taken into consideration.
- 140. In its response to the provisional opinion, Te Whatu Ora stated:

'Takawaenga are specifically allocated to specific wards to ensure that there is continuity and an opportunity to identify and engage with whānau who are admitted and offer tautoko and support ... Where necessary Takawaenga will assist the whānau to navigate through the hospital services including connecting whānau with allied health staff (Social workers/OT) as required for the duration of their stay and in preparation for discharge. This follow up has also been provided for transfer of whānau between hospitals in Te Tai Tokerau.'



⁵² The Takawaenga cultural support service is a unit within Te Poutokomanawa that provides a liaison between Māori patients, whānau and inpatient wards to achieve the best outcome for Māori patients and their whānau.

- Te Whatu Ora noted Takawaenga's involvement during Mrs A's hospital admission of 19 Month5 to 13 Month6,⁵³ and stated that its contact with Mrs A and her whānau was appropriate.
- 142. Clinical records show that initially Takawaenga support was declined by Mrs A on admission to NDHB, but that on 28 Month5, during a social worker visit, Takawaenga services were required to assist with Ms B staying overnight in the hospital. On 4 Month6, a staff member from Te Poutokomanawa visited Mrs A and advised her to request a referral to Māori Health Services. Takawaenga services were contacted on 9 Month6 by the social worker and further visits from Takawaenga are documented on 10 and 12 Month6.
- Although I acknowledge that Takawaenga did engage when notified, I remain of the view that Takawaenga support should have been offered to Mrs A proactively throughout her care. In particular, I refer to the advice of Dr Smalldridge in paragraph 107, in which she highlighted a prime opportunity for cultural support through a meeting with the patient and their whānau '(+/- cultural support)' following an M&M, to discuss the risks and likely outcomes of the surgery and the consequences of not having the surgery.
- In my view, offering support at the start and end of care is not a culturally responsive or appropriate approach, especially given Mrs A's long-standing engagement with the healthcare system. I therefore take this opportunity to remind Te Whatu Ora of the importance and need for the service to be culturally appropriate⁵⁴ (as obligated by the Ngā Paerewa Health and Disability Services Standards⁵⁵), and to be mindful of the timing of offering support and presenting the service throughout a patient's journey.
- 145. Furthermore, I note that Takawaenga services transition between inpatient wards and are provided in preparation for discharge. Mrs A was transferred to hospice on 13 Month6 and therefore Takawaenga support ceased, possibly when she needed support the most. Given that Takawaenga services centre around continuity of care, I will recommend that Te Whatu Ora give consideration to the continuity of cultural care and tautoko in outpatient settings.

⁵⁵ Outcome 2.3.1 of the Ngā Paerewa Health and Disability Services Standards (NZS 8134:2021) states that '[s]ervice providers shall ensure there are sufficient health care and support workers on duty at all times to provide culturally and clinically safe services'.



⁵³ In particular: 19, 28 Month5, 4, 10, 11, 12, and 13 Month6.

⁵⁴ The Ngā Paerewa Health and Disability Services Standards (NZS 8134:2021) define cultural safety as '[a] principle that requires service providers and health care and support workers to examine themselves and the potential impact of their own culture in their interactions with people using a service. To practise cultural safety, service providers and health care and support workers acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures, and characteristics that may affect the quality of service provided.'

Changes made since events

- In response to the provisional opinion, Te Whatu Ora Te Tai Tokerau told HDC that since 2020, a specific clinic for post-menopausal bleeding has been established in Whangārei for women across Northland, which offers a streamlined assessment process whereby they receive an ultrasound, examination, and pipelle (if indicated) and are booked for a hysteroscopy (if indicated), all during the first specialist appointment.
- 147. Te Whatu Ora Te Tai Tokerau stated that women who are unable to travel to Whangārei are seen in a peripheral clinic where a pipelle can be done but where the likelihood of getting an ultrasound is much less. Te Whatu Ora Te Tai Tokerau is supporting a streamlined approach by purchase of a dedicated ultrasound machine for the Gynaecology Clinic and purchase of additional hysteroscopes to enable outpatient procedures.
- Te Whatu Ora Te Tai Tokerau reviewed the Te Whatu Ora Counties Manukau District guidelines for management of post-menopausal bleeding and noted that the revised post-menopausal bleeding clinic in Whangārei is consistent with this pathway, although it offers the services in a 'one-stop visit' to accommodate the rurality of the Northland population. Te Whatu Ora Te Tai Tokerau said that it will ensure that its pathway is also consistent with the pending national guidelines on post-menopausal bleeding.
- Te Whatu Ora Te Tai Tokerau recognised that there are ongoing resource issues for access to medical imaging and stated that this has been the subject of a Northern Regional project in which considerable progress has been made and continues to be made. Te Whatu Ora Te Tai Tokerau said that the wait-time data is reported monthly to the regional director, with emphasis on ensuring equity of access for Māori patients.
- In its commitment to growing Te Poutokomanawa, Te Whatu Ora Te Tai Tokerau has secured an additional ten full-time employees (FTE), whose roles have a specific focus on equity and will support the organisation to develop an increased capacity to deliver culturally safe care. The roles include:
 - A Kaiarai Kaupapa Māori (Cultural Specialist Educator);
 - A Kaiwhakahaere Māori (Māori Health Advisor);
 - A Kaitirotiro Oranga (Health Equity Analyst);
 - Two further FTE in Workforce Capacity and Capability; and
 - Five further FTE Takawaenga roles.
- Te Whatu Ora Te Tai Tokerau has established an in-house (Te Poutokomanawa) Continuous Quality Improvement Team, who will work closely with the Quality Improvement Directorate to develop and implement an organisation-wide cultural audit tool⁵⁶ to focus



⁵⁶ Ngā Paerewa, the revised Health and Disability Service Standards (effective 22/02/22), will provide the framework for the cultural audit tool.

directly on discrimination and racism; review cultural responsiveness, capability, and capacity of services; and allow services and departments to be proactive in their approach to equity planning to improve outcomes.

- Te Whatu Ora Te Tai Tokerau told HDC that the development of the 'Honouring the Treaty' and 'Engaging with Māori' training programmes, which are mandatory for all staff, has increased understanding and ensures that staff are mindful of cultural constructs that impact on barriers faced by Māori when accessing the health system. Te Whatu Ora Te Tai Tokerau stated that the need for a further full-time trainer/educator to provide cultural training to all departments has been identified.
- Te Whatu Ora Te Tai Tokerau told HDC that a pilot is being trialled to introduce a Kaupapa Māori Framework Takarangi Competency Framework, for all staff, which will enable Te Whatu Ora Te Tai Tokerau to improve the use of te reo Māori and understanding of tikanga Māori, and the recognition and application of staff knowledge in te ao Māori.

Recommendations

- 154. I recommend that Te Whatu Ora Te Tai Tokerau:
 - Provide a written apology to Mrs A's whānau for the breaches of the Code identified in this report and provide details of the changes it has made to ensure that the issues outlined in this report do not happen to another patient in the future, within one month of the date of this report.
 - b) Develop a policy/pathway for unresolved post-menopausal bleeding, including when an ultrasound or CT scan should be performed, and when a case should be discussed at an MDM. Evidence that this has been done is to be sent to HDC within six months of the date of this report.
 - c) Conduct an audit of patients who have re-presented to Te Whatu Ora Te Tai Tokerau over the past 12 months with symptoms of unresolved post-menopausal bleeding. The audit is to report the percentage of patients who have had ultrasounds and/or CT scans (if the ultrasound could not view the ovaries and whether the case was discussed at an MDM). The outcome of the audit, as well as any further changes that have been made as a result, are to be provided to HDC within six months of the date of this report.
 - d) Provide an update on the Northern Regional project regarding access to medical imaging, including any work completed and/or planned, which has or will address:
 - Access to imaging in the Gynaecology Department;
 - Barriers to accessing appropriate investigations (ie, diagnostic imaging), such as a patient's BMI;
 - Equitable access to imaging for Māori patients; and

• Communication to the Obstetrics & Gynaecology Department around demand management for imaging, and how it will ensure that this messaging does not cause hesitation around using diagnostic imaging when it is clinically indicated.

Please provide a timeline for completion of any work that is still in the planning stage and explain how the effectiveness of relevant changes are being measured. This is to be provided to HDC within six months of the date of this report.

- e) Consider developing or reviewing systems and/or processes that identify and address the need of ongoing Takawaenga cultural support in the community post-inpatient/outpatient events. I recommend that Te Whatu Ora Te Tai Tokerau report back to HDC on this consideration within six months of the date of this report, including an explanation of any cultural support currently offered in the community and collaboration with external agencies (ie, contracted Kaupapa Māori services), and whether this forms part of the changes implemented in Māori support services.
- f) Provide an update on the cultural audit tool developed by Te Poutokomanawa Continuous Quality Improvement Team, including any findings around discrimination and racism, cultural responsiveness and capacity of services, and the effectiveness of this tool in equity planning. This is to be provided to HDC within six months of the date of this report.
- g) Provide an update on the Takarangi competency framework, including an explanation as to how the effectiveness of this framework is being measured. This is to be provided to HDC within six months of the date of this report.
- I also recommend that Mrs A's whānau be offered the opportunity to share their lived experiences, as well as the past and present impact it has had on their overall hauora (health) and their lives, as a legacy in Mrs A's memory to be shared with Te Whatu Ora Te Tai Tokerau and Hei Āhuru Mowai.

Follow-up actions

A copy of this report with details identifying the parties removed, except Te Whatu Ora Te Tai Tokerau (previously known as Northland DHB), Whangārei Hospital, Bay of Islands Hospital, Kaitaia Hospital, and the advisors on this case, will be sent to the Hei Āhuru Mowai | Māori Cancer Leadership Aotearoa, and Te Aho o Te Kahu | Cancer Control Agency, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Appendix A: Independent clinical advice to Commissioner

The following independent advice was obtained from Dr Jacqueline Smalldridge, a specialist gynaecologist/urogynaecologist, dated 26 March 2021:

'My name is Dr Jacqueline Smalldridge MBBS, FRCOG, FRANZCOG. I am a practising general and urogynaecologist. I practised at CMDHB for 22 years until 2015. I am now in private practice. I am familiar with the management of postmenopausal bleeding.

Review of case

GP referral number 1 - 4/7/14 Post menopausal bleeding (PMB)

7/8/14 Outpatient visit. [Mrs A] was [in her fifties]. She had a past history of 2 previous outpatient appointments in 1999 and 2006 when she was noted to have heavy menstrual bleeding (HMB) and was known to have a fibroid uterus and endometrial polyps. She was noted to be 2 years post menopause with a BMI of 52. She was found to have polyps and a pipelle biopsy was taken that showed normal histology. There was no pelvic ultrasound report in the clinical records.

GP referral number 2-23/1/15 still having postmenopausal bleeding 21/2/2015 outpatient visit. It was noted that she still had PMB and her BMI was 53. She was booked for hysteroscopy D&C under Local anaesthetic. There was no record of a pelvic ultrasound having been performed.

11/3/15 Anaesthetic review by [triage nurse]. Noted BMI 52, Previous laparotomy and appendicectomy in the past. Raised BP on medication. The impression was that the patient was fit for GA or regional anaesthesia.

15/4/15 Operation hysteroscopy D&C under local anaesthetic. There was a large polypoid mass and submucosal polyp noted. The pathology was benign. 9/7/2015 Post op visit. Spotting still but a plan made for review in a year. "BMI of 50 which is a bit of a problem" noted.

21/7/15 Outpatient appointment was scheduled but cancelled because patient was okay with no bleeding reported.

GP referral number 3 - 24/8/18 postmenopausal bleeding.

19/1/2018 Outpatients clinic. BMI 52 noted and having postmenopausal bleeding again. Hysteroscopy suggested but the patient was reluctant to go ahead. A Smear was taken.

15/2/2018 The smear had been taken with endometrial cells on the smear. This can indicate endometrial pathology.

10/5/2018 Outpatients clinic with more postmenopausal spotting. The plan was made to follow up yearly.

GP referral number 4 — 24/8/18 PMB

27/9/18 Outpatients clinic. Heavy PMB and booked for repeat hysteroscopy. No record of a pelvic ultrasound being performed.

5/10/18 Hysteroscopy D&C LA "Large polyp in uterine cavity too big to remove but some endometrial samples taken". Benign pathology reported. 3/12/18 Outpatient clinic. No further bleeding. "We briefly discussed hysterectomy as well if she does have ongoing bleeding."

GP referral number 5 — 18 [Month1] 2019 Further PMB

4 [Month5] Outpatients clinic. PMB and anaemia noted. Myosure procedure discussed to remove the polyp hysteroscopically. "[Mrs A] has again reiterated that she is aware hysterectomy is unsafe and she does not want a hysterectomy."

GP referral number 6-7 [Month5] — To private gynaecologist in [another region]. For an opinion and advice. "Family immensely worried."

Acute Admission 19 [Month5] Patient unwell with abdominal pain, fevers ? cholecystitis. BMI 55. CT scan showed large pelvic mass 20x15x20cm, peritoneal disease. Confirmed on MRI as probable stage 4 ovarian cancer with raised tumour markers.

27 [Month5] Gynaecological oncology multidisciplinary meeting DHB2 Likely stage 4 ovarian cancer, thickened endometrium. For biopsy. 3 [Month6] — attempted biopsy performed by radiologist. Palliative care team and medical oncologist involved. Multidisciplinary discussions with family.

- 13 [Month6] Admitted to the Hospice
- 8 [Month7] Returned home
- 9 [Month7] [Mrs A] passed away.

The reasonableness of the care provided to [Mrs A] during each of her presentations to Whangārei Hospital Gynaecology Services.

What was the standard of care/accepted practice, was it appropriate for the management and follow up of PMB? Was further imaging required and the appropriateness of referral back to the GP?

The standard of care/accepted practice for investigation of PMB is to take a history to find out if there are any causes such as taking hormone replacement therapy, or anti-coagulants. A gynaecological history would be taken to see if there were any preexisting conditions ([Mrs A] had had known fibroids). A smear history would be taken. The patient would be examined abdominally and vaginally and any causes from the lower genital tract would be excluded.

A pelvic ultrasound would be performed to look at the endometrial thickness that should be less than 4mm in a postmenopausal woman and to visualize the ovaries. A sample is then obtained of the endometrium if it is thicker than 4 mm. This can be done by pipelle or hysteroscopy D&C. A hysteroscopy also visualises the cavity and is useful if the ultrasound is difficult because of raised BMI.

If there is persistent PMB despite normal histology then the accepted practice would be to perform a hysterectomy, and bilateral salpingo-oophorectomy because of the risk of underlying malignancy.

This decision was not taken in this instance. [Mrs A's] case is complex. She was known premenopausally to have problems with heavy menstrual bleeding fibroids and polyps. She was also noted to have a raised BMI.

She saw 6 different senior medical officers (SMOs) over the years 2014–2019. It did not seem that she was 'owned' by any particular Specialist who was taking overall responsibility for her care. Each visit seemed to be looked at in isolation as an individual episode of care rather than a continuum. She was repeatedly given blood and iron infusions because of anaemia. This and the repeated referrals from the GP should have raised "red flags".

The advice given for further investigations with regard to hysteroscopy D&Cs were appropriate in that samples of the endometrium were taken that excluded endometrial cancer. But the findings at hysteroscopy of a large polyp/fibroid causing the bleeding were not dealt with so it was likely that she would continue to bleed. Hysteroscopy is a diagnostic procedure but when something is identified that may be causing the bleeding then a plan is made to deal with it. It seemed that they were falsely reassured by the findings of normal pathology despite a grossly enlarged uterus with a polypoid mass and was referred back to the GP without the problem being resolved.

There are difficulties physically examining a patient with a raised BMI because it is not possible to palpate pelvic masses. Similarly pelvic ultrasound examinations are often incomplete or hard to interpret because of this. There were ultrasound reports in the notes from 1999 and 2006. The ovaries were reported as normal on the 1999 ultrasound but not visualised in 2006. It is unclear as to whether formal pelvic ultrasounds were performed after this. There are no reports in the clinical records. If the ovaries are not adequately visualised on a transvaginal ultrasound then further imaging is then undertaken to check them. Further imaging with a CT scan was only performed when she presented to the General surgeons with abdominal pain and this was when the large ovarian mass was detected.

The outpatient records suggest that the SMOs were only excluding endometrial cancer as a cause for [Mrs A's] PMB and when this was done then they were not thinking about other causes despite her frequent re-referrals by the GP. Ovarian cancer is notoriously difficult to diagnose and is often very insidious but the symptom of PMB can be associated with it and was not considered according to the records.

It is not clear from the clinical records what kind of discussions were had with the patient concerning the risk of hysterectomy surgery since there was no clearly documented anaesthetic opinion from a specialist anaesthetist concerning her actual risks. She was given an ECOG score of 1 (Restricted in strenuous physical activity but ambulatory and able to carry out work of a light/sedentary nature). She had Hypertension on medication and took a Statin. Her BMI was elevated but that is in itself not necessarily a contraindication to surgery.

There was no documentation about discussions with the patient as to explore her feelings about hysterectomy. Was she reluctant because she was told she might die from the surgery or because she had cultural beliefs about it? There is no evidence of any family meetings to discuss this further. Were family members present at any of the consultations between 2014–2019? There is no documentation. There was no evidence of any cultural support services offered to her by the DHB.

There was no documentation as to whether her case had been discussed at a Multidisciplinary Mortality and morbidity (M&M) meeting where complex obstetric and gynaecology cases would be discussed. This is an opportunity to relook at the patient's history, examination findings and pathology reports and to get opinions from colleagues. There was no evidence of any discussion with the radiologists about better ways to image [Mrs A's] pelvis. At the conclusion of these meetings there is a plan of action that is minuted.

In most DHBs, there are senior Gynaecologists who would take on difficult hysterectomies or pelvic surgery in patients with raised BMIs. The patient would be discussed at the M&M meeting first. There would be a consensus from the attendees that this was the correct and necessary approach. They would arrange a meeting with the patient and their family members (+/- cultural support) to discuss the risks and likely outcomes of the surgery and the consequences of not having the surgery. They would liaise with the anaesthetic department and book the patient on a list at the main hospital and have scheduled for post op care a high dependency unit bed or ICU bed if appropriate. They would plan to operate with a colleague to add expertise with the difficult surgery. If this was not possible to do then it would be appropriate for the patient be referred to a DHB that does perform difficult surgeries on patients with high BMI. The reality is that all DHBs encounter patients with high BMI and need to develop the necessary expertise.

In summary

There has been a severe departure from the standard of care/accepted practice in this case. There were opportunities that were missed to have performed further imaging that may have made the diagnosis earlier. Most gynaecologists would have a low threshold for performing a hysterectomy and bilateral salpingo-oophorectomy in recurrent PMB even in the face of potential complications from high BMI. There is no evidence that specific risks were discussed with the patient or even that they had been canvassed from the anaesthetic department in a formal way. There is no evidence that

there was any in depth discussion with the patient and family concerning this. [Mrs A] was obviously an intelligent woman ... and would have been able to understand the pros and cons of surgery. If she had then chosen not to proceed then this should have been documented in detail as this would have meant that she understood the consequences of no treatment.'

The following further advice was received from Dr Smalldridge:

'13 June 2022

Complaint: Northland DHB

Ref: 20HDC00531

Thank you for your correspondence dated 3/6/22 and the documents provided. I have no new conflicts of interest to disclose.

In answer to your specific questions about [Mrs A's] management in Outpatients between 2014–2018, I would like to preface them by commenting that I understand from [Dr C's] (Clinical Director) comments that NDHB was having severely limited resources, particularly access to pelvic ultrasound. In view of this, I understand that the clinicians were encouraged to refer patients for hysteroscopy for a more definitive diagnosis of the cause of the post menopausal bleeding. I also understand that it is difficult for a patient to see the same doctor at each appointment because of staffing issues and I am very sympathetic to these remarks. At that time they appeared to be working in a very constrained and resource poor environment. I note that he agrees that a hysterectomy and bilateral salpingo-oophorectomy should have been performed for her recurrent post menopausal bleeding long before she was diagnosed in 2019 with ovarian cancer.

Therefore with regard to —

The outpatient appointment on 4 July 2014 with [Dr F]
The outpatient appointment on 24 February 2015 by [Dr E]
The follow-up appointment on 10 May 2018 by [Dr D]
The outpatient appointment on 27 September 2018 by [Dr C]

It is usual to record that abdominal and vaginal examination was performed and what the findings were in the clinical records. If an examination was not performed, it is usually recorded as such. If it is not recorded, then the assumption is that it has not been performed.

Therefore, if the clinicians were instructed to rely more on hysteroscopic findings, then this is potentially acceptable in the circumstances they find themselves in. The doctors themselves would probably agree that it is a departure from accepted practice and so would their peers.

There has been a severe departure from the standard of care from the DHB. The DHB had failed to provide basic resources in the form of access to ultrasound for the patients

and enough staff for the doctors to be able to do their job competently and provide continuity of care.

With regard to —

The outpatient appointment on 18 January 2018 by [Dr D]:

Findings of endometrial cells on her smear is a soft marker for endometrial pathology. This would raise a "red flag" and would prompt further investigation with an endometrial sample (pipelle or hysteroscopy) and an ultrasound scan. This would be particularly important since she had recurrent postmenopausal bleeding. This did not happen after the appointment on 18 January 2018. It was reported that a hysteroscopy had been suggested but the patient was reluctant to go ahead. She eventually had her second hysteroscopy on 11 October 2018, 10 months later.

The findings from the first hysteroscopy on 15th April 2015 were abnormal (but benign pathology) and at that stage she had had 2 referrals from the GP and 2 years of postmenopausal bleeding. There was a missed opportunity to perform a total abdominal hysterectomy and bilateral salpingo-oophorectomy at that point. There was no other plan mentioned in the clinical records of how else to manage her bleeding. This was a severe departure from standard accepted practice.

The findings of the hysteroscopy on 11th October 2018 was that of a large polypoid mass in the uterus. By then, she had been referred 4 times by the GP for postmenopausal bleeding. The biopsies were taken from the normal tissue around it and so this was not really a representative sample. Benign histology in the face of a recurrent problem also requires surgery. Surgery is not just for endometrial or ovarian pelvic cancer. [Mrs A] was experiencing severe symptoms requiring blood and iron infusions. This was a severe departure from standard accepted practice.

I do not agree with the statement in the summary reply on page 20 that the purpose of assessment is to exclude cancer. I believe the purpose of assessment is to provide care for the patient and prevent serious harm. If there is serious morbidity, then surgery should be discussed and planned in a multidisciplinary setting.

As I suggested in my previous report dated 26th March 2022 on page 4, there were at least 2 opportunities in 2015 and 2018 for a decision to be made for her to consider having a total abdominal hysterectomy and bilateral salpingo-oophorectomy for her recurrent postmenopausal bleeding. This would have potentially avoided the ovarian cancer or at least diagnosed it earlier.

With regard to the comment about the multidisciplinary meeting, I think there has been a misunderstanding. The referral to the Gynaecology oncology MDM in [DHB2] was done appropriately and delayed because of a lack of imaging. Her case should have been discussed at the local DHB MDM anytime from 2015–2018 where difficult cases are discussed and management plans made.

I cannot comment on points 3, 4, 5, 6, 7, 8, 9, 10, 11, and 12 specifically. I am not familiar with oncology processes and procedures. It seemed that the clinicians were understaffed and under resourced to be able to provide the service in a timely manner.'

Appendix B: Independent clinical advice to Commissioner

The following independent advice was obtained from an oncologist, Dr Orlaith Heron:

'I was requested to comment on the five questions below. These questions also largely cover concerns raised by [Mrs A's] daughter [Ms B] numbered 2 and 4. Thank you for providing the relevant documentation for consideration.

Whether I would expect any further action in relation to the failed biopsy on 9 [Month6]?

No, I would not expect any further action in relation to this failed biopsy. This was essentially the third attempt at omental biopsy; on 03 [Month6] an ultrasound approach was deemed unsuitable and CT-guided biopsy arranged for that day. [Mrs A] experienced discomfort despite repositioning and the use of sponges for back support. Again biopsy on 09 [Month6], with the use of analgesia, was abandoned due to pain and discomfort. The only remaining option was biopsy under general anaesthetic. These are logistically challenging, even more so in regional hospitals, as an Interventional Radiologist, Anaesthetist and theatre space need to be available. Some of these services are not available daily and biopsy under GA can take >1 week to organise. [Mrs A's] health was deteriorating, she was a high anaesthetic risk and was already very borderline for chemotherapy. Her health would not withstand the wait for histology from a rescheduled biopsy. A further wait would have definitively rendered her unsuitable for systemic treatment (chemotherapy). I concur with the decision made by the Gynaecology team and [Dr H] not to proceed organising a biopsy under GA as I believe risk outweighed any potential benefit. I expect the opinion of my peers would align. As [Dr H] suggested, if [Mrs A's] health were to improve this could be revisited in future.

The appropriateness of Dr H's decision not to commence chemotherapy

a) Chemotherapy was not commenced immediately.

Like [Dr H], when he briefly saw [Mrs A] on the ward 03 [Month6], I would have opted to wait for a biopsy result to have a full discussion with [Mrs A] and her family. I believe my peers would agree; medical oncologists rarely see people without histology. Histology dictates the treatment plan and is important for prognostication. From [Dr H's] new patient letter, the Gynaecology MDM radiology report and treatment plan, [Mrs A] had either a primary ovarian or endometrial malignancy. There are several different variants of both cancers, some are sensitive to chemotherapy and others are quite resistant. Ovarian cancer has a higher response rate and better long-term prognosis than endometrial cancer in general and, as alluded to in [Dr H's] new patient letter, surgery can be considered if there was a good response in the ovarian cancer setting. Given [Mrs A's] unwellness (ECOG 3) and degree of symptoms, only a highly chemosensitive cancer would respond in a timely enough fashion to turn her clinical situation around. This information is important to help weigh up potential benefit of chemotherapy versus its toxicity.

- b) I agree with [Dr H's] decision not to commence chemotherapy on 13 [Month6]. Active bowel obstruction is a contraindication to chemotherapy.
- c) I would not have started chemotherapy after [Mrs A] was transferred to Hospice. Despite bowel obstruction appearing to settle, she was too unwell. The hospice notes ([CMO's] letter [date]) document cellulitis, sleeping during the day and decreasing mobility. [Mrs A] was very unwell as an inpatient. Benefit of the doubt for treatment was given because of her age and the possibility that this was a high grade serous ovarian cancer ([Dr H's] new patient letter). [Dr H] documented in the written ward notes and the addendum to his new patient letter starting 11 [Month6], that he believed there was a short window of opportunity to give chemotherapy. Unfortunately, that opportunity was lost when bowel obstruction occurred. I am confident my peers would agree.

Whether there are any delays in [Mrs A's] cancer pathway from the time of diagnosis (19 [Month5]) to when she was assessed by [Dr H] on 9 [Month6]?

I acknowledge and empathise that to a person with cancer and their family, any wait is agonisingly long. [Mrs A] had a Medical Oncology appointment 3 weeks, 15 working days, after presentation with symptoms. This is prompt and she was seen without histology.

[Mrs A] had imaging suggesting an advanced gynaecological malignancy on 19 [Month5]. This imaging was discussed at Gynaecology MDM on 27 [Month5]. Biopsy was originally scheduled for 29 [Month5]. I cannot ascertain from documentation if the biopsy was requested directly after imaging (20 [Month5]) or after MDM discussion. If it was the latter, perhaps there was a few days' delay to requesting a biopsy. As a Medical Oncologist who treats gynaecological cancers and is an MDM attendee, biopsy seems the logical next step and from the clinical details I would not expect up front surgery to have been recommended. However, this is likely an overly harsh criticism as I suspect that many if not most general gynaecologists would bring imaging to an MDM first. Gynaecology MDM is weekly and run from [DHB2]. The case was presented at the next available meeting. Although a biopsy did not occur during this time, an MRI did so there were additional investigations happening.

If biopsy was requested prior to MDM, there was up to a 10 working day delay to the deferred biopsy date of 03 [Month6]. I believe all clinicians would consider this suboptimal for an urgent inpatient biopsy but unfortunately it is sometimes a reality of our current overburdened system. As mentioned by [the CMO], an interventional radiologist is not available daily in Whangārei. Re-biopsy was scheduled for 10 [Month6], one week or 5 working days later. Once again, I would wish for a sooner date but 5 days is not excessive when there is not a daily interventional list.

There was a delay in definitive diagnosis due to failed biopsy attempts. Due to the location and burden of disease, [Mrs A] experienced discomfort and was unable to remain in the desired position for sufficient time despite attempts to increase comfort

by the radiology staff. This occasionally happens and is not predictable. It is infrequent that general anaesthetic is required for biopsy and I would not have requested one at the outset. Nor would my peers. If biopsy on 3 [Month6] was successful, the diagnosis would have been timely. Unfortunately, it was the burden of disease causing symptoms for [Mrs A] which impeded biopsy attempts resulting in a delay in definitive diagnosis.

During this time, the inpatient Palliative Care team, Te Poutokomanawa Māori Health and a dietician were involved to optimise [Mrs A's] well-being and manage symptoms.

Whether I would have expected any further action from [Dr H]?

No, I would not have expected any further action from [Dr H] after visiting [Mrs A] as an inpatient 13 [Month6]. From his timeline of events, he explained why chemotherapy was no longer possible. The written medical notes from 13 [Month6] are concordant. At the time of discharge, it is reasonable to assume that [Mrs A's] care was passing over to the Hospice team and follow-up with Medical Oncology was not required or appropriate given her prognosis and ongoing obstruction. Neither I nor my peers would have made a routine follow-up appointment if we believed one was in the last days/weeks of life. [Dr H] had discussed that with an obstruction, prognosis may be measurable in days (documented in written ward notes 13 [Month6]). He did leave his mobile number in the notes and documented that he was happy to be involved in discussions.

Any other matters in relation to the oncological care provided to [Mrs A] that I consider warrant comment

- We need to acknowledge that Northland Cancer and Blood Service is an outpatient service. The Medical Oncology team do not have an inpatient ward. This means that [Dr H] visiting [Mrs A] and her family twice on the ward was in addition to his scheduled duties.
- There is no documentation of [Dr H's] phone call with [Mrs A's] daughter in late [Month6]. This phone call was during his annual leave and was unexpected. He did follow it up by scheduling an appointment on his return to work. It is best for conversations like these to be documented but I appreciate [Dr H's] circumstances. Collegiality, patient care and family distress were prioritised by both taking the call from Hospice and contacting the family while on leave.
- [Dr H] raised the possibility of reconsidering chemotherapy if bowels started functioning again (ward notes 13 [Month6]). He has stated, in letter to Health and Disability Commissioner, to his knowledge he was not contacted by the Hospice team whilst [Mrs A] was an inpatient.
- I and my peers would be comfortable with the Hospice team explaining deterioration to a point of not being well enough for chemotherapy. This is within their scope of practice and expertise. The documented notes support that [Mrs A] was deteriorating despite bowels beginning to function and was not well enough for

systemic treatment. The Palliative Care specialists communicated this with [Mrs A] and her family.

Recommendations for improvement that may help prevent a similar occurrence in future

No.

Is Mise le Meas,

Dr Orlaith Heron'