Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

A Decision by the Deputy Health and Disability Commissioner

(Case 23HDC00401)

Introduction

1. This report is the opinion of Dr Vanessa Caldwell, Deputy Health and Disability Commissioner, and is made in accordance with the power delegated to her by the Commissioner.

2. The report discusses the care provided to Mrs A by Health New Zealand Te Whatu Ora (Health NZ) between 19 April 2019 and 10 November 2022 (inclusive).

3. On 16 February 2023 this Office received a complaint from Mr B about the care provided to his mother, Mrs A, by Health NZ.

4. Mr B advised that since 2017 Mrs A had been undergoing surveillance liver ultrasound scans every six months as she was susceptible to liver cancer. For reasons unknown at the time of submitting the complaint to this Office, these scans stopped in 2019. On 10 November 2022 whilst presenting to a Health NZ Emergency Department (ED), Mrs A had a computerised tomography[1] (CT) scan and was diagnosed with liver cancer.

5. Sadly, Mrs A passed away.

6. The following issue was identified for investigation:

   - *Whether Health New Zealand Te Whatu Ora provided Mrs A with an appropriate standard of care between 13 April 2019 and 10 November 2022 (inclusive).*

7. The parties directly involved in the investigation were:

Mr B	Complainant/Mrs A's son
Mrs A	Consumer (deceased post complaint)
Health New Zealand Te Whatu Ora	Group provider — subject of complaint

8. Further information was received from Mrs A's GP.

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[1] A computerised tomography (CT) scan combines a series of X-ray images taken from different angles around the body and uses computer processing to create cross-sectional images (slices) of the bones, blood vessels, and soft tissues inside the body. CT scan images provide more detailed information than plain X-rays.

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Background

9. Mrs A was known to be at high risk for liver cancer as she was diagnosed with primary biliary cholangitis (PBC)[2] in 2011 when a liver biopsy indicated cholestatic hepatitis.[3]

10. A gastroenterologist first met with Mrs A in 2014.

11. On 24 May 2017, the gastroenterologist requested six-monthly surveillance liver ultrasound scans for Mrs A to assess ascites[4] around her liver, with follow-up gastroenterology outpatient appointments afterwards.

12. On 23 November 2018, the gastroenterologist referred Mrs A for magnetic resonance imaging (MRI)[5] of her liver as the most recent surveillance ultrasound had demonstrated an increase in hyperechoic regions.[6]

13. The MRI concluded that there was no evidence of a mass lesion, with probable mild portal hypertension,[7] which was consistent with Mrs A's known cholestatic hepatitis. A follow-up MRI in 12 months' time was suggested.

14. The surveillance ultrasound scans ceased, with the last being done on 12 April 2019.

15. Between 2019 and 2022 Mrs A attended Health NZ for other health issues, including an admission to the ED for acute coronary syndrome. There was no concern about her liver during this time.

16. In November 2022 Mrs A attended the ED with a referral from her GP, as she was experiencing nausea, fatigue, reduced appetite, and right upper quadrant back pain. A CT scan identified advanced liver cancer, and Mrs A received palliative care until her death.

Information gathered

Provider response to Mr B's complaint

17. The gastroenterologist responded on behalf of Health NZ by summarising the adverse event review (AER)[8] that Health NZ had undertaken, which determined that the reason for the delay in Mrs A's cancer diagnosis was 'multifactorial', as explained below. A copy of the full AER has since been received, supporting the gastroenterologist's response.

[2] Primary biliary cholangitis is liver disease that damages the bile ducts. Early treatment may help prevent liver failure.
[3] Cholestatic hepatitis is any form of liver disease that causes inflammation of the liver and a problem with bile transport.
[4] A build-up of fluid in the abdomen.
[5] A scan used to create detailed images of organs and tissues inside the body.
[6] Increased density of sound waves compared to surrounding structures, which may indicate a concern.
[7] Elevated pressure within a system of veins called the portal venous system. The portal vein is a major vein that leads to the liver. The most common cause of portal hypertension is cirrhosis (scarring) of the liver.
[8] Adverse events are events that generally have resulted in harm to a patient. Te Whatu Ora districts are required to report such events to the Health Quality & Safety Commission.

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18. The gastroenterologist explained that Mrs A had her last outpatient appointment with him on 13 February 2019. This was a follow-up from an in-patient admission for chest pain and constipation, not as a follow-up to a surveillance ultrasound. At this appointment, Mrs A no longer had these symptoms, but was concerned about a 'funny feeling in her head and bilateral leg oedema[9]'. This was determined to be due to low albumin,[10] which was likely related to her cholestatic hepatitis and can contribute to leg oedema.

19. At this appointment, Mrs A was advised that the MRI from 23 November 2018 had shown a nodular liver without cancer, and that a further MRI was likely to be required in 12 months' time.

20. The gastroenterologist advised in his clinic letter from 13 February 2019:

> 'Further follow up ultrasounds for the liver are already booked [12.04.2019], this will assess ascites around the liver. Follow up with me should be in 6 months, earlier if needed.'

21. After the appointment on 13 February 2019, Mrs A attended the hospital for other reasons, including acute coronary disease. The AER advised that during these presentations there was no concern about her liver.

22. The gastroenterologist noted in his response that despite seeing other specialists during this time, they did not consider whether Mrs A was due for liver follow-up or request additional scans.

23. Mrs A had the last surveillance liver ultrasound scan on 12 April 2019. The scan report noted a nodular liver surface with coarsened echotexture[11] in keeping with cirrhosis. No focal mass lesion or ascites were identified. The report summary stated: 'Liver morphology consistent with cirrhosis. No liver mass disease or haemodynamic[12] evidence of portal hypertension.'

24. Also in April 2019, the Radiology Department changed to a new system for electronic referrals. The new system does not accept repeat or recurring requests, including recurring requests for follow-up liver surveillance ultrasound scans, meaning that future scans required a new referral for each scan.

25. Health NZ advised in the AER that through this change of system it identified the importance of single, rather than recurring, requests for radiology examinations and procedures. Health NZ explained that surveillance referrals can cause there to be an assumption that there has been no change in the patient's presentation between scans, or radiology does not receive appropriate updates about a patient's current status, which comes with a clinical risk. Repeat referrals were also considered to impact on scheduling,

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[9] Swelling caused by too much fluid trapped in the body's tissues.
[10] A low level of the protein albumin, which can indicate a disorder of the liver or kidneys.
[11] The normally smooth surface of the liver has been lost.
[12] Study of the blood flow.

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as for those with significant changes, appointments were not being cancelled or scheduled appropriately for the consumer's current presentation.

26. The AER noted that in April 2019 an email was sent from the Radiology Manager to clinical staff detailing the introduction of the new electronic referral system and advising that repeat referrals on the same referral form were not supported by the system, and clinicians were asked to create a new referral for each examination.

27. An email discussion between the Radiology Manager, Chief Medical Officer, and Clinical Directors also took place to consider how best to manage these changes with surveillance programmes. It was suggested and agreed upon by the Radiology service that the clinical nurse specialist managing the surveillance programme would have delegated authority to order surveillance requests, on behalf of a medical specialist.

28. No further requests for a follow-up liver ultrasound scan were received by the Radiology Department for Mrs A.

29. The AER also identified that the planned follow-up appointment six months after Mrs A's 2019 appointment with the gastroenterologist was not scheduled. The AER stated:

> '[T]he review team found that staff in the Outpatient Appointment Office did not follow the process for booking follow-up appointments for [Mrs A] which resulted in her not receiving a follow-up appointment.'

30. The AER noted:

> 'The [AER] investigation has highlighted the importance of safety netting when transitioning to new systems and processes to ensure that provision of care is seamless.'

31. A routine follow-up appointment was later made for Mrs A to see the gastroenterologist on 10 March 2021, but this was deferred to 8 April 2021. This appointment was cancelled by Mrs A as she had been unable to attend, and no further appointments were made.

32. In 2020, Health NZ established a liver cirrhosis database and nurse-led liver cirrhosis clinic for people with a diagnoses of hepatitis B or C. Additional people who required surveillance could be added by their clinicians if considered appropriate. This service was not yet running when Mrs A was expected to have her ultrasound scan in 2019.

33. Health NZ suggested in its response that the GP not requesting a follow-up scan was a factor in the delay in diagnosis for Mrs A. However, there does not appear to be any record of advice to GPs or primary carers that the practice had changed and repeat referrals could not be accepted.

34. In his initial response to the complaint, the gastroenterologist advised that the Gastroenterology Department in Health NZ was under-resourced compared to tertiary centres. He cited a New Zealand Society of Gastroenterology study, which found that in

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smaller centres, 'there are substantial numbers of patients nationwide already on unacceptably long waiting lists for gastroenterology follow-up'. The gastroenterologist said that this issue was raised with Health NZ on multiple occasions, although he is unable to ascertain with certainty whether this may have affected Mrs A's care.

Response to provisional opinion

35. Mr B was given an opportunity to respond to the introduction, background, and information gathered sections of the provisional opinion. Mr B acknowledged receipt of this information and provided no comment.

36. Health NZ was given an opportunity to respond to the provisional opinion. Health NZ acknowledged and accepted the breach of Right 4(2) of the Code of Health and Disability Services Consumers' Rights (the Code). Health NZ provided an apology for Mr B as recommended in the provisional opinion.

Changes made since events

37. Health NZ has been forthcoming with the outcome from the AER undertaken to identify the reasons for the delay in Mrs A's liver cancer diagnosis, which it considered multifactorial. Included in the AER were the following recommendations intended to be implemented by Health NZ:

a) Consider updating clinic letters to include a request for GPs to organise a liver ultrasound scan if the patient has not received a scan appointment within 12 months, as a safety measure.

b) Complete a triangulated audit of the liver cirrhosis surveillance programme to ensure that no other surveillance patients have been missed since the electronic system changeover.

c) Apologise to Mrs A and her whānau for the distress caused by the delay in her cancer diagnosis.

d) Update the follow-up appointment process for the outpatients appointment office, provide staff training, and monitor compliance with the process.

e) Review the liver cirrhosis surveillance programme database to ensure that it meets best practice.

   - Establish whether a database can be set up in the Patient Information Care System (PICS) to create a virtual database.
   - Establish whether the use of a local clinical surveillance database for liver cirrhosis meets best practice guidelines.
   - Communicate with secondary and primary care providers to capture people with liver cirrhosis who are new to the district and meet the criteria to be placed on a surveillance programme.

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38. In response to the provisional opinion, Health NZ advised that the specialist who runs the liver cirrhosis clinic checks clinic letters for inclusion of the GP in all correspondence and has full oversight of the liver cirrhosis patient database. This includes ensuring that all diagnosed liver cirrhosis patients are followed up with six-monthly ultrasound scans and blood tests.

39. Health NZ also advised that two fully functioning Endoscopy Suites have since been opened.

Opinion: Health New Zealand Te Whatu Ora — breach

40. First, I was saddened to hear of Mrs A's passing and offer my sincere condolences to Mrs A's son and wider family. I also wish to acknowledge the impact the delayed diagnosis had on Mrs A and her family.

41. I appreciate that Health NZ undertook an AER once it became aware of the delay in Mrs A's cancer diagnosis. I commend the team at Health NZ who took the time to meet with Mrs A to provide an apology for the delays and discuss the AER process. I understand that Health NZ also offered to meet with Mr B to discuss the outcome of the AER.

42. A serious systems incident occurred, which resulted in a significant delay in cancer diagnosis for Mrs A. Whilst ultimately earlier detection may not have resulted in a different outcome for Mrs A, it would likely have allowed her time to accept the diagnosis and spend more time as she would have wanted.

43. In its response and AER, Health NZ determined the reasons for the delay in diagnosis to be multifactorial.

44. I consider that the most significant factor in the delay of Mrs A's cancer diagnosis was the change of radiology referral systems without appropriate safety-nets in place to pick up those patients who were pre-scheduled for appointments, including surveillance scans, and would require new referral for these to continue.

45. A system change requires a certain amount of forethought about the risks posed and how to mitigate them. I am particularly concerned that when it was determined that surveillance ultrasound scans would require a new referral, there appears to have been no consideration as to how this might pose a risk to patients requiring new referrals for repeat scans to be generated, and how to mitigate this.

46. I accept Health NZ's reasons for no longer accepting the same referral for multiple surveillance scans. However, I am critical that there were no checks to determine those already on surveillance schedules and how those would be continued to be scheduled as required. In the context of a stretched resource in Gastroenterology, I consider that it was not the sole responsibility of the referrer (in this case, the gastroenterologist) to make new referrals for all patients under surveillance. A system with safety-netting (eg, a message to GPs about the change) should have been in place to support them to do this.

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47. In addition, in the AER and response, Health NZ considered that the GP's failure to pick up that surveillance scans were not being carried out (despite not being the referrer) was one of the reasons for the delay in Mrs A's cancer diagnosis.

48. Whilst a GP is routinely responsible for primary care-led recall tests, there is no evidence that the GP was requested to undertake a monitoring role in this situation. Further, there is no evidence that the GP was made aware of the system change. On this matter, I disagree that the GP had a responsibility to act as a safety net to ensure follow-up testing was completed and do not consider this to be a factor in this case.

49. Likewise, it does not hold that other specialists (not liver related) should have picked up that Mrs A's surveillance ultrasound scans were not occurring six monthly as expected, as indicated by Health NZ.

50. While I accept that there was email communication to staff about the change, I consider that this was not sufficient to explain who had responsibility to generate the new referrals, particularly in light of the suggestion that the clinical nurse specialist could have delegated authority to order surveillance requests on behalf of a medical specialist.

51. It is also concerning that Mrs A's six-monthly follow-up outpatient appointment with the gastroenterologist was not booked in 2019 due to a process error in the Outpatients Appointment Office. This was a missed opportunity to identify that Mrs A was overdue for her surveillance scan, and the recommended MRI follow-up could also have been actioned.

52. Under Right 4(2) of the Code, Health New Zealand Te Whatu Ora had a duty to ensure that the services provided to Mrs A complied with legal, professional, ethical, and other relevant standards.

53. The Health and Disability Services Standards 2008 (HDS Standards)[13] are designed to establish safe and reasonable levels of services for consumers, and to reduce the risk to consumers from those services. In my view, this includes ensuring that appropriate processes and robust safety-netting is in place when making systemic changes. I specifically highlight standard 3.3.4, which relates to services being coordinated in a manner that promotes continuity in service delivery and promotes a team approach where appropriate. Health New Zealand Te Whatu Ora did not meet these standards in its provision of services to Mrs A.

54. Health NZ's system was deficient in that it failed to continue Mrs A's surveillance liver ultrasound scans after April 2019, and it failed to book an outpatient appointment with the gastroenterologist in a timely manner. Mrs A did not receive services that promoted a continuation in service delivery. Therefore, I find that Health NZ Te Whatu Ora to provide services to Mrs A that complied with the HDS Standards, and it breached Right 4(2) of the Code.

[13] NZS 8134.0:2008 and NZS 8134.1:2008.

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Recommendations

55. I recommend that the Health New Zealand Te Whatu Ora district specific to this case:

a) Provide evidence that the recommendations set out in its AER have been implemented, and report on any further changes that occurred following the implementation of those recommendations, within three months of the date of this report.

b) Establish a process to ensure that when implementing a new system/programme, appropriate safety-netting is in place to ensure that the changes do not result in patients being missed. This can be included in an already established process or prepared as a new process. A copy should be sent to HDC within three months of the date of this report.

Follow-up actions

56. A copy of this report with details identifying the parties removed, except Health New Zealand Te Whatu Ora, will be sent to Te Aho o Te Kahu|the Cancer Control Agency and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.