Te Whatu Ora|Health New Zealand Taranaki (formerly Taranaki District Health Board)

A Report by the

Deputy Health and Disability Commissioner

(Case 20HDC00772)

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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Executive summary

1. This report concerns the care provided to a woman by Te Whatu Ora Taranaki, in particular the management of Type 1 diabetes throughout the woman's pregnancy. The report highlights the importance of effective coordination of care, particularly when multiple services are involved in a consumer's care.

Findings

2. The Deputy Commissioner found that Te Whatu Ora Taranaki did not support the woman adequately in managing her diabetes throughout her pregnancy, and that this was underpinned by a failure by Te Whatu Ora Taranaki to have in place a coordinated antenatal diabetes service. The Deputy Commissioner also found that Te Whatu Ora failed to provide the woman with an appropriate standard of service in that she was not seen for an initial consultation in a timely manner due to an administrative error; a dietician review was not arranged in a timely manner owing to the referral not being marked as 'urgent' for the medical typists; a clinical nurse specialist review was not undertaken regularly, resulting in the woman being seen by the diabetes clinical nurse specialist on only four occasions throughout her pregnancy; and the care between the diabetes and antenatal services was not coordinated effectively.

3. The Deputy Commissioner found Te Whatu Ora in breach of Right 4(1) and Right 4(5) of the Code for failing to coordinate the woman's care effectively, resulting in her not receiving services of an appropriate standard throughout her pregnancy.

Recommendations

4. The Deputy Commissioner recommended that Te Whatu Ora Taranaki provide a written apology to the woman for the issues identified in the report. It was also recommended that Te Whatu Ora Taranaki provide evidence of an update on the progress of actions taken in response to the recommendations made in the internal review; provide evidence of the results of the documentation audit that was conducted, and the changes that have been implemented to address any concerns raised as a result of the audit; and provide evidence that it has used this case as an anonymised case study for the maternity/diabetes service multidisciplinary team, to highlight the importance of careful planning and management of women with diabetes during pregnancy.

Complaint and investigation

5. The Health and Disability Commissioner (HDC) received a complaint from Ms A about the services provided to her by Te Whatu Ora Taranaki (formerly known as Taranaki District Health Board (TDHB)[1]). The following issue was identified for investigation:

- *Whether Taranaki District Health Board provided Ms A with an appropriate standard of care in 2018.*

6. This report is the opinion of Deputy Commissioner Rose Wall and is made in accordance with the power delegated to her by the Commissioner.

7. The parties directly involved in the investigation were:

Ms A	Consumer/complainant
Te Whatu Ora|Health New Zealand Taranaki	Provider

8. Further information was received from a medical centre.

9. Endocrinologist Dr B is also mentioned in the report.

10. Independent advice was obtained from endocrinologist Dr Patrick Manning (Appendix A).

Information gathered during investigation

Introduction

11. In 2018, Ms A (aged in her twenties at the time of these events) became pregnant. Ms A has children and had had multiple pregnancies. She was diagnosed with type 1 diabetes in 2017, and she had a history of anxiety, asthma, and migraine with aura.[2]

12. This report concerns the care provided to Ms A by Te Whatu Ora Taranaki throughout her pregnancy.

Complaint

13. Ms A raised several concerns, including that staff at Taranaki Base Hospital did not acknowledge that her pregnancy was 'high risk', that on several occasions when she raised concerns, she felt that she was being perceived as 'over anxious', and that no investigations

[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. All references in this report to Taranaki District Health Board (TDHB) now refer to Te Whatu Ora Taranaki.
[2] A headache that occurs after or at the same time as sensory disturbances (aura), which can include flashes of light, blind spots, and other vision changes or tingling in the hand or face.

were undertaken in the final three weeks of her pregnancy, despite an escalation in a range of symptoms. Ms A told HDC:

> 'I came into TDHB [ED] and labour ward during my pregnancy with varying symptoms including one visit via emergency helicopter, but did not feel listened to. On at least ten occasions throughout the eight[h] month [of] pregnancy I experienced multiple varying symptoms and despite my condition of diabetes type one, was told that my pregnancy could be managed fine locally. I did question whether I should have been seen earlier in my pregnancy by the tertiary Hospital in [another district] and my GP has said that my pregnancy was a high risk pregnancy.'

14. Independent advice was obtained on the midwifery and obstetric care provided to Ms A during the course of her pregnancy, and no concerns were identified. Accordingly, this report will focus on the care provided to Ms A by Te Whatu Ora to assist her in managing her diabetes during her pregnancy.

GP consultation 8 Month1[3]

15. On 8 Month1, Ms A saw her general practitioner (GP) for a consultation about her pregnancy. Ms A's GP referred her to the antenatal clinic at Taranaki Base Hospital for obstetric care during her pregnancy and sent a copy of the record of this visit to the diabetes educator.[4]

First consultation with endocrinologist and diabetes clinical nurse specialist

16. On 28 Month1, at 9 weeks' gestation, Ms A was seen by a clinical nurse specialist at the Clinical Nurse Specialist Diabetes Clinic (the Diabetes Clinic). The diabetes nurse recorded that Ms A was taking 17 units of Lantus[5] daily and three units of Apidra[6] with meals for diabetes management. It was also documented that Ms A was managing her diabetes 'reasonably well' and that she was educated on the importance of this for the growth and development of her baby.

17. Later that day, Ms A was seen by an endocrinologist,[7] Dr B. Dr B sent a letter to the Diabetes Clinic advising that Ms A had experienced several hypoglycaemic episodes,[8] likely caused by missing meals, but that there was insufficient information to adjust her insulin dose at that stage. He queried the diagnosis of type 1 diabetes and questioned whether Ms A might have MODY[9] diabetes. A referral was made to the dietician service at TDHB for education on how to count carbohydrates. Dr B told HDC that he dictated the referral letter on 28 Month1, but

[3] Relevant months are referred to as Months 1–8 to protect privacy.
[4] A diabetes educator can be a registered nurse or other health professional who has specialist expertise in diabetes and working with people who have diabetes. A diabetes educator will help to educate patients on how to manage diabetes in day-to-day life.
[5] A long-acting insulin used in the management of type 1 and 2 diabetes; it is used once daily as an injection.
[6] A fast-acting insulin to control blood-sugar levels at mealtimes.
[7] A doctor who has specialist training in diagnosing and treating disorders of the endocrine system (the glands and organs that make hormones).
[8] Episodes of low sugar (glucose) in the blood. For many people, low blood sugar is a level below 70 milligrams per deciliter or 3.9 millimoles per litre (mmol/L).
[9] Maturity-onset diabetes of the young — a rare form of diabetes with a strong genetic link.

this was not typed until 16 Month2. Dr B said that the reason for the referral was to help control Ms A's blood-glucose levels (BGLs), but that he had initiated and intensified her glucose control treatment at her initial visits to address this. Dr B stated that he considered the delay in dietician input as 'acceptable and immaterial to the subsequent events'.

18. The plan was for the clinical nurse specialist to see Ms A to improve her blood-sugar control, and that Dr B would see Ms A again in three weeks' time.

19. Te Whatu Ora told HDC that the handheld device used by Dr B to dictate the referral letter on 28 Month1 was taken to the medical typists for download, but was not marked as urgent, so it went into the 'general queue' for typing. The letter to the Diabetes Clinic and the referral to the dietician were typed on 16 Month2, and the dietician service received the referral on 20 Month2. The referral was then prioritised by the service on 22 Month2 and given a priority rating of 'A' (urgent) with an aim for the patient to be seen within 28 days.

20. On 21 Month2, at 12 weeks' gestation, Ms A saw Dr B again. It was documented that Ms A had had a hypoglycaemic episode (with a BGL of 3.6mmol/L) at 3am that day, and Dr B advised her to reduce her Lantus medication from 17 to 16 units. She was diagnosed with latent autoimmune diabetes in adults[10] and Graves' disease, and the plan was for thyroid function tests on a monthly basis during (and for six months following) her pregnancy.

21. On 27 Month3, at 17 weeks' gestation, Ms A was seen by a dietician (about eight weeks after the referral was made).[11] It was documented that Ms A had gained 3kg during her pregnancy,[12] and that she had reduced her Lantus medication from 16 units to 8 units, which had helped her BGLs, and she had shown improved readings. The dietician gave advice about carbohydrate foods and how to assess carbohydrate intake. Ms A was advised to have regular snacks and include protein. The plan was to monitor Ms A's weight and provide nutritional supplement drinks as needed.

Second consultation with diabetes clinical nurse specialist

22. On 29 Month4, at 22 weeks' gestation, Ms A was seen again by the diabetes clinical nurse specialist, who documented that Ms A continued to have exercise-induced hypoglycaemic episodes. Ms A's BGLs[13] averaged around 6–7mmol/L, showing 'exceptional glycaemic control'. The HbA1c[14] result was 49mmol/mol.

Third consultation with diabetes clinical nurse specialist and second consultation with endocrinologist

23. On 26 Month5, at 26 weeks' gestation, Ms A was seen by the diabetes clinical nurse specialist after being transported to hospital via helicopter following a hypoglycaemic

[10] A type of diabetes that has characteristics of type 1 and type 2 diabetes.
[11] TDHB provided HDC with a timeline of the care provided to Ms A. The timeline states that Ms A was seen in the clinic on 17 Month3. However, the letter from the dietician was dated 27 Month3 and does not state that it had been dictated and typed on different dates.
[12] Her weight was documented as 57.95kg.
[13] BGLs are measured in mmol/L (millimoles per litre). Targets for self-monitoring of BGLs are 6–8mmol/L while fasting and before eating, and 6–10mmol/L for two hours after eating.
[14] A blood test that shows the average BGL over the last two to three months.

episode. Ms A's BGL was 9.3mmol/L. Her weight had reduced by 1kg (to 61.3kg), and she raised concerns that her baby had not been as active as previously. Ms A's very active lifestyle was noted as contributing to the difficulties controlling her blood-sugar levels. The documented management plan was to reduce the Lantus insulin, and for further follow-up by the clinical nurse specialist, and to try to organise Ms A's other antenatal appointments for the same day, because of her remote location.

24. On 29 Month5, at 26 +2 weeks' gestation, Ms A had an anatomy follow-up scan,[15] and the fetal growth parameters[16] were documented as normal.

25. On 18 Month6, at 29 weeks' gestation, Ms A was seen again by Dr B. Dr B documented that Ms A had experienced a major hypoglycaemic episode, 'despite us reducing her Lantus from 17 units down to 15'.[17] Dr B again noted that the unmeasurable factor in managing Ms A's BGLs was her exercise, and that after her major hypoglycaemic episode, her Lantus medication had been reduced to 12 units. However, he documented: '[Ms A] has now brought it back up to 14 but [she] is still having some [hypoglycaemic episodes] with minimal exercise.'

26. Dr B recorded that he reduced the Lantus medication to 13 units, but that Ms A could try taking an additional 2–3 units for breakfast and lunch. Dr B documented: 'As the pregnancy advances the heightened [i]nsulin sensitivity seen in the first trimester should go away and late in pregnancy [i]nsulin resistance develops.' Ms A's Graves' disease was in remission, and the plan was to see her in one month's time. A clinic letter was sent to the diabetes clinical nurse specialist.

Fourth consultation with diabetes clinical nurse specialist and third consultation with endocrinologist

27. On 30 Month6, at 30 weeks' gestation, Ms A attended the Diabetes Clinic, and her weight was recorded as 64kg (an increase of 2.7kg since 26 Month5). The clinical notes state that Ms A had been 'guestimating' the amount of insulin that she had been taking, and that this had caused a few hypoglycaemic events. The management plan was to increase the Lantus medication to 14 units and to follow up with the clinical nurse specialist after Ms A had seen the consultant obstetrician on 16 Month7. However, there is no evidence that Ms A was seen by the clinical nurse specialist on 16 Month7.

28. On 9 Month7, at 32 +1 weeks' gestation, a growth scan indicated that the estimated fetal weight (EFW) was in the normal range[18] and the abdominal circumference had increased and was above the 98th percentile, and abnormal umbilical artery Dopplers[19] were noted. A

[15] During the course of Ms A's pregnancy, eight formal ultrasounds were performed.
[16] Growth parameters include biparietal diameter, head circumference, abdominal circumference, mid-thigh circumference, and femoral diaphysis length.
[17] This differs from the record made by the dietician during the appointment on 27 Month3, which states that Ms A had reduced her Lantus medication from 16 units to 8 units.
[18] The EFW was 2292 grams and in the 77th percentile.
[19] An umbilical arterial Doppler measures the blood flow within the vessels of the umbilical cord to assess fetal wellbeing in the third trimester of pregnancy.

further growth scan was performed on 22 Month7 at 34 weeks' gestation, which showed increased growth of the abdominal circumference, and abnormal umbilical artery Dopplers. A plan was made for induction of labour at 37 weeks' gestation.

29. On 10 Month7, Ms A was admitted to the maternity ward with severe back pain. No cause for the back pain was identified, but it was documented that her BGLs were variable[20] and that she continued to smoke. Ms A was discharged on 12 Month7.

30. On 23 Month7, Dr B reviewed Ms A at 34 weeks' gestation. It was recorded that over the previous two weeks Ms A's average BGL was 9.0mmol/L, but that her results were 'a scatter shot of data[21]'. Dr B documented that insulin resistance (which is common in the final stages of pregnancy) was setting in, and so he changed the daily insulin to 7 units at breakfast and 7 units at dinner to achieve a fasting glucose[22] of between 6–8mmol/L. Ms A was advised to reduce her exercise and eat similar amounts of carbohydrates with each meal. The plan was for review by either the diabetes clinical nurse specialist or Dr B the following week.

31. On 29 Month7, a further growth scan showed that the Doppler indices[23] were normal but a small 3mm pericardial effusion[24] had developed, and so a referral was made to the Maternal Fetal Medicine (MFM) Unit at another DHB. The MFM consultant advised that it was appropriate for Ms A to deliver her baby at Taranaki Base Hospital, and that she did not need to be seen by the MFM Unit. It was documented that Ms A was due to be induced on 13 Month8.

32. On 30 Month7, at 35 weeks' gestation, Ms A was seen again by Dr B, who documented that Ms A had titrated[25] her Lantus medication up from 14 units to 18 units, and that she had managed to eliminate her exercise. (In response to the provisional opinion, Ms A told HDC that the 'exercise' referred to was related to where she lived.) Dr B documented:

> 'All told [Ms A's] average [blood glucose level] in the last two weeks has been a glucose of 7.9 correlating to an expected A1c of 49mmol. This is excellent performance. It is the best that can be safely achieved, especially with her changing patterns of exercise, eating and increasing insulin resistance with late pregnancy.'

33. Dr B recorded that Ms A's baby did not appear large from the ultrasounds. The plan was to reduce the Lantus medication from 18 units to 17 units, and that he would review Ms A again in one week's time.

[20] BGL results were 9.7mmol, 4.1mmol, 7.7mmol and 11.4mmol.
[21] Measured through the FreeStyle Libre system, which measures glucose levels through a small sensor applied to the back of the upper arm to provide real-time glucose readings for up to 10 days, both day and night.
[22] The amount of glucose in the blood after an overnight fast.
[23] Measurements used to examine the blood flow.
[24] The build-up of too much fluid around the heart.
[25] Started at a specific dose and either slowly raised or slowly lowered to achieve the target dose.

34. A further growth scan at 36 weeks' gestation (5 Month8) showed that the abdominal circumference was above the 98th percentile, and it was noted that the baby was well above the 90th percentile on the customised growth chart used in the clinic.

35. On 7 Month8, at 36+2 weeks' gestation, Ms A saw Dr B again. In a clinic letter[26] to the clinical nurse specialist, he noted that Ms A had had a few more hypoglycaemic events at breakfast and dinner, and that her average BGL was down to 6.9mmol/L, representing a decreased A1c of 43mmol. Dr B noted that Ms A's baby was large, that there had been a finding of a small pericardial effusion, and that an induction was planned in 10 days' time. A plan was made to review Ms A again the following week. There was a delay in typing the letter, and it was circulated on 20 Month8 (sadly, after the subsequent death of Ms A's baby).

Subsequent events

36. On 8 Month8, at 36+3 weeks' gestation, Ms A was visiting someone on the labour ward at Taranaki Base Hospital. At 8.30am Ms A reported increased swelling in her feet. Her blood pressure was taken and was normal. At 1pm, Ms A returned to the maternity ward and reported to staff that she felt that something was wrong with her baby. A midwife was unable to hear the fetal heartbeat, and the obstetrics team was informed. The obstetrics team attended at 2.40pm and confirmed that, sadly, Ms A's baby had died. Ms A returned to the ward the following day for the induction process, and she delivered her son on 10 Month8.

Further information

Ms A

37. Ms A wrote a letter to TDHB dated 10 October 2018, raising several concerns about the care she received throughout her pregnancy.

Te Whatu Ora Taranaki

38. Te Whatu Ora accepted that there was a delay between the referral being sent by Ms A's GP on 8 Month1, and the referral reaching the antenatal clinic service on 20 Month2. Te Whatu Ora advised that this was due to an 'administration error'.

39. Te Whatu Ora told HDC that it engaged an external reviewer to conduct a Maternity Review of the care provided to Ms A, and a copy of the Maternity Review report was sent to the whānau in 2020. The Maternity Review identified the following key issues relating to the management of diabetes in pregnancy:

1. There were significant delays in Ms A seeing key people early on in the pregnancy.
2. There was a lack of service co-ordination, and 'Taranaki DHB is the only DHB out of 16 surveyed that **does not** [emphasis in original] have some form of combined Obstetric/Endocrine antenatal diabetes clinic running'.

[26] Copies were also sent to the LMC, GP, and obstetrician at Taranaki Base Hospital.

Responses to provisional opinion

40. Ms A was given the opportunity to comment on the 'information gathered' section of the provisional report and her comments have been incorporated into this report where relevant. In addition, I note that Ms A told HDC that she gets 'very high levels of anxiety as a result of [the events]' and that she has engaged in counselling, which unfortunately has not been helpful.

41. Te Whatu Ora Taranaki was given the opportunity to comment on the provisional opinion, including the proposed findings and recommendations. Te Whatu Ora Taranaki advised that it accepted the proposed findings and recommendations. In addition, it said:

> 'On behalf of Te Whatu Ora — Taranaki I wish to reiterate our deep sympathy to [Ms A] for the very sad loss of her treasured son, [Baby A]. We want to assure [Ms A] that we have taken the matters raised in her complaint very seriously and that we are committed to continuing to improve the services that we provide.'

Opinion: Te Whatu Ora|Health New Zealand Taranaki — breach

Introduction

42. In 2018, Ms A (aged in her twenties at the time of these events) was pregnant. Ms A had been diagnosed with type 1 diabetes in 2017, and she had a history of Graves' disease, anxiety, asthma, and migraine with aura.

43. Throughout her pregnancy, Ms A was under the care of Te Whatu Ora Taranaki, having been referred by her GP. Ms A received midwifery, obstetrics, and endocrinology input throughout this time. As part of my assessment of this complaint, I obtained independent advice from an internal medicine specialist, Dr Patrick Manning.

44. I note the following comments from Dr Manning:

> 'It is important to clearly define whether the inadequacies noted above of the care of [Ms A's] diabetes had a material impact on the outcome of her pregnancy. It is hard to get an accurate handle of the adequacy of glycaemic control as there are no self-monitoring of blood glucose … records in the medical record to determine whether pre- and post-prandial targets were met. The best that can be said is that based on the CGM description and HbA1c levels that glycaemic control may have been reasonable. On the other hand, the increased abdominal circumference of the fetus may be suggestive of suboptimal glycaemic control. Whether [Ms A's] induction of labour should have been earlier was an obstetric decision and was not based on her diabetes management. Therefore, I do not believe that there is sufficient information to indicate that the care of [Ms A's] diabetes during her pregnancy had a direct impact on the outcome of her pregnancy.'

45. At the outset, it is important to state that it is not my role to determine what caused the death of Ms A's baby. Further, even if causation could be established, it would not be determinative of my criticism, as it is not the role of this Office to determine whether clinical decision-making has caused certain health outcomes. My role is to determine whether the care provided to Ms A was reasonable in the circumstances and consistent with the accepted standard of care.

46. As part of my assessment of this complaint, I also obtained midwifery advice and obstetrics advice. My advisors did not identify any concerns with the midwifery and obstetrics care provided to Ms A. Accordingly, the focus of my opinion on the care Ms A received will be limited to the Te Whatu Ora endocrinology service's management of Ms A's diabetes during her pregnancy.

Antenatal diabetes MDT

47. Dr Manning advised that initially, a patient with type 1 diabetes who is pregnant should be seen by an antenatal diabetes multidisciplinary team (MDT). Dr Manning said that this would consist of input from a diabetes midwife, an obstetrician, an endocrinologist, a diabetes clinical nurse specialist, and a dietitian.

48. Te Whatu Ora advised that at the time of these events, it did not have an antenatal diabetes MDT, which meant that the obstetrics team and diabetes team were providing care from separate clinics. The Maternity Review undertaken by TDHB also identified that TDHB was the only district health board of 16 surveyed that did not have an MDT in place at the time of these events.

49. Dr Manning advised that the antenatal and diabetes services being provided as two distinct services, rather than a coordinated single MDT and unified clinic, would be considered 'sub-standard'. He stated:

> '[A]n integrated service allows for effective coordination and communication which is vital for the multidisciplinary care that underpins the delivery of antenatal diabetes services. It would be unusual to provide such care as distinct and separate services and would not meet the expected standard of care for managing women with diabetes in pregnancy.'

50. Dr Manning advised that the failure to have in place an antenatal diabetes MDT would be considered an '[a]t least moderate, bordering on severe' departure from accepted standards.

51. I accept Dr Manning's advice in this regard and am very critical that Te Whatu Ora did not have in place an antenatal diabetes MDT to manage diabetes in pregnancy appropriately and ensure continuity of care, particularly given the significant risks associated with diabetes and pregnancy. I am also concerned that TDHB was the only DHB of 16 surveyed that did not have an antenatal diabetes MDT in place. I acknowledge that since these events, Te Whatu Ora has established an antenatal diabetes MDT.

Initial diabetes consultation

52. Ms A was first seen by the diabetes service at 9 weeks' gestation, approximately three weeks after the referral was made by her GP.

53. Dr Manning advised that for patients with type 1 diabetes, the aim of an initial assessment should be to ensure that the patient is educated regarding the implications of pregnancy and diabetes and has satisfactory glycaemic[27] control; to adjust or discontinue medications if appropriate; to commence folic acid; and to assess the status of any diabetes-related complications and comorbidities that could have a bearing on pregnancy outcomes. Dr Manning considers that a patient with type 1 diabetes should be seen 'without delay', which usually should occur within one to two weeks. In Ms A's case, this did not occur.

54. Te Whatu Ora told HDC that the delay in Ms A being seen by the diabetes service was due to an administrative error.

55. Dr Manning advised that the delay in Ms A being seen by the diabetes service constituted a mild to moderate departure from accepted standards. He stated:

> 'It would have been preferable for [Ms A] to be seen earlier, especially as she had not been seen in the preconception period. This would have allowed for those aspects of care preferably performed preconception to have been attended to.'

56. I accept Dr Manning's advice and am concerned that given the risks associated with Ms A's pregnancy (in light of her type 1 diabetes) and the importance of ensuring that Ms A's diabetes was managed closely from the outset, she was not seen by the service within the recommended time frame. I acknowledge Te Whatu Ora's comments that an administrative error occurred and that it has taken steps to minimise such an event occurring in the future (see 'changes made' section below).

Referral to dietician

57. On 28 Month1, Ms A was seen by endocrinologist Dr B. Dr B sent a clinic letter to the Diabetes Clinical Nurse Specialist service advising that Ms A had experienced several hypoglycaemic episodes, likely caused by missing meals, but that there was insufficient information to adjust her insulin dose. A referral was made to the dietician service for education on how to count carbohydrates.

58. Dr B told HDC that he dictated a referral letter to the dieticians on 28 Month1, but this was not typed until 16 Month2, when it was received and prioritised by the dieticians on the same day. Dr B said that the reason for the referral was to help control Ms A's BGLs, but that he had initiated and intensified her glucose control treatment at her initial visits to address this. Dr B stated that he considered the delay in dietician input as 'acceptable and immaterial to the subsequent events'.

59. Te Whatu Ora told HDC that the handheld device used by Dr B to dictate the referral letter on 28 Month1 was taken to the medical typists for download, but was not marked as urgent,

[27] Level of glucose in the blood.

so it went into the 'general queue' for typing. The letter and referral were typed on 16 Month2, and the referral was received by the dietician service on 20 Month2. The referral was then prioritised by the service on 22 Month2 and given a priority rating of 'A' (urgent) with an aim for the patient to be seen within 28 days. Ms A was seen by a dietician on 27 Month3 at 17 weeks' gestation (approximately eight weeks after the referral was made).

60. My independent advisor, Dr Manning, advised that assessment by a dietician for a patient with type 1 diabetes should take place as soon as practically possible in the early stages of pregnancy. He stated:

> 'The 2-month delay resulting in the patient being seen at 17 weeks gestation would be viewed as a significant departure from accepted practice. However, I do not believe that it had a significant role to play in the adverse pregnancy outcome experienced in this case.'

61. I accept Dr Manning's advice. I also acknowledge his comment that it is unlikely that the delay in Ms A being seen by a dietician played a significant role in the adverse pregnancy outcome. However, I note that it is not the role of this Office to determine or be influenced by outcome, and therefore I remain critical that there was a two-month delay in Ms A being seen by a dietician to aid in the management of her diabetes during her pregnancy, and that this appears to have been due to the dictation having been placed in the 'general queue' and subsequently not being typed by the medical typists for approximately two weeks.

Contact with diabetes clinical nurse specialist

62. Ms A was assessed by the diabetes clinical nurse specialist on four occasions throughout her pregnancy.

63. Dr Manning advised that this is 'less than optimal', and that during pregnancy there should be at least weekly contact with a clinical nurse specialist, by telephone or by an in-person visit. Dr Manning said that in the initial stages of pregnancy, insulin sensitivity increases, and insulin dosages often need to be reduced to avoid hypoglycaemic episodes. However, later in pregnancy the dosages need to be escalated, as insulin resistance becomes more problematic. Dr Manning advised:

> 'For this reason, patients need to be in regular contact with, at least, the Diabetes [clinical nurse specialist] on a weekly basis (if not more often) and is usually seen by the MDT every 1–3 weeks depending on any issues that are arising.'

64. Te Whatu Ora acknowledged that the frequency of visits to Ms A was not optimal. Te Whatu Ora told HDC:

> 'The Diabetes [clinical nurse specialists] follow up one to two weekly dependent on [the] clinical need of the patient, this maybe face to face, text, phone call or email thus ensuring there is some form of Interaction and contact occurring on a fortnightly basis. They do not use a specific timeline for frequency of contact, this is based on their clinical judgement.'

65. Dr Manning advised that he is concerned about the frequency of interaction between the diabetes clinical nurse specialist and Ms A. He stated:

> 'If this is reflective of the usual standard of care, I would have significant reservations about the level of care delivered to women with diabetes who are pregnant. This could either indicate diabetes nursing staff shortages or a lack of awareness of the level of nursing input that is required for the management of diabetes in pregnancy.'

66. Dr Manning advised that the lack of contact with Ms A by the clinical nurse specialist was a severe departure from the accepted standard of care. Given Ms A's risk factors as a patient with type 1 diabetes, I accept Dr Manning's advice and am critical of this significant oversight.

Conclusion

67. Te Whatu Ora|Health New Zealand is responsible for providing services and care to an appropriate standard. This includes the coordination of services when multiple clinical specialties are involved in the provision of care.

68. As discussed above, Ms A had several existing conditions at the time of her pregnancy, including type 1 diabetes. However, the care provided by Te Whatu Ora to Ms A did not support Ms A adequately in managing her diabetes throughout her pregnancy. This was underpinned by the failure by Te Whatu Ora to have in place a coordinated antenatal diabetes service. I consider that Te Whatu Ora also failed to provide Ms A with an appropriate standard of service in the following ways:

- Ms A was not seen for an initial consultation in a timely manner due to an administrative error;
- A dietician review was not arranged in a timely manner owing to the referral not being marked as 'urgent' for the medical typists;
- A clinical nurse specialist review was not undertaken regularly, resulting in Ms A being seen by the diabetes clinical nurse specialist on only four occasions throughout her pregnancy; and
- Care between the diabetes and antenatal services was not coordinated effectively.

69. Dr Manning advised HDC:

> 'The coordination between the diabetes team and the obstetric team appears to be fragmented. It is unclear from the health record as to whether the two teams undertake a combined clinic. A combined multidisciplinary clinic is essential for coordination and communication between the two specialties. It is also optimal from the patient's perspective as it means being seen by all of the important team members on one occasion rather than having multiple visits. If the two specialties are not providing a combined clinic then this would be viewed as suboptimal care.'

70. Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code) stipulates that every consumer has the right to have services provided with reasonable care and skill. Right 4(5) of the Code states that every consumer has the right to co-operation among providers to ensure quality and continuity of services. At the time of these events, Te Whatu Ora did not have in place an established antenatal diabetes MDT, which resulted in a clear disconnect between the two specialties and did not enable effective coordination of clinical care (as outlined above).

71. I consider that the failings in this case indicate systems issues at Te Whatu Ora. In my view, the failure to coordinate Ms A's care effectively resulted in her not receiving services of an appropriate standard throughout her pregnancy. Accordingly, I consider that Te Whatu Ora breached Right 4(1) and Right 4(5) of the Code.

Changes made

72. Te Whatu Ora Taranaki told HDC that following these events, it sought an external review of the care provided to Ms A. Te Whatu Ora said that it has made the following changes as a result of this complaint:

- GP referrals are now sent to a central 'Best Practice' electronic system, which transfers Antenatal Clinic referrals directly to the 'Antenatal Clinic Generic' email address, which is accessed by key staff on a Monday to Friday basis.
- The Dietitian Department has commenced recruitment for two full-time dietitians who focus solely on diabetes. One will be required to attend the MDTs.
- Two further staffing resources have been employed specifically to support Māori patients with the diabetes service (Kaitautoko).
- It updated its 'Secondary Care Midwifery/Obstetrician Antenatal Clinic Guidelines' to support the triage and prioritisation of referrals by the specialist obstetrics team.
- It employed a Complex Care Midwife.
- A multidisciplinary team clinic has been set up to coordinate the care of women with diabetes during pregnancy. The team includes a consultant obstetrician, a consultant endocrinologist, a diabetes nurse specialist, and an antenatal clinic coordinator.
- Diabetes MDT meetings are held fortnightly, with the 'Diabetes in Pregnancy Management' guidelines being progressed as part of the MDT meetings with medical leadership.
- Complex Care meetings have resumed and are held monthly for the discussion and planning of care for women with high-risk and complex pregnancies.
- A clinical documentation audit was undertaken.

Recommendations

73. In light of the above changes already made, I recommend that Te Whatu Ora Taranaki provide a written apology to Ms A for the issues identified in this report. The apology is to be provided to HDC within three weeks of the date of this report, for forwarding to Ms A and her whānau.

74. Te Whatu Ora Taranaki is to provide evidence of the following, within three months of the date of this report:

a) An update on the progress of actions taken in response to the recommendations made in the internal review.

b) Results of the documentation audit that was conducted, and the changes that have been implemented to address any concerns raised as a result of the audit.

c) Having used this case as an anonymised case study for the maternity/diabetes service multidisciplinary team, to highlight the importance of careful planning and management of women with diabetes during pregnancy.

Follow-up actions

75. A copy of this report with details identifying the parties removed, except Te Whatu Ora Taranaki, Taranaki Base Hospital and the independent advisor on this case, will be sent to Te Whatu Ora|Health New Zealand, Te Tāhū Hauora|Health Quality & Safety Commission, Diabetes New Zealand, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Te Kāreti o ngā Kaiwhakawhānau ki Aotearoa|New Zealand College of Midwives, and Te Tatau o te Whare Kahu|Midwifery Council of New Zealand, 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 internal medicine specialist Dr Patrick Manning:

'2 November 2021

…

Dear Commissioner,

Re: Complaint: Taranaki District Health Board 20HDC00772

Thank you for asking me to provide expert advice to the Commissioner regarding the complaint referenced above. Specifically, you have asked me to address the following questions:

Whether the care provided to [Ms A] by the diabetes clinic (TDHB) was reasonable in the circumstances and why. In particular you have asked me to comment on:

a) Was the delay to be seen by the dietitian following the referral by the endocrinologist acceptable?

b) The management of [Ms A's] diabetes during her pregnancy.

c) The co-ordination between the Endocrinology Service and the Antenatal Service.

d) Any other matters that warrant comment.

For each question, you have asked me to advise:

a) What is the standard of care/accepted practice?

b) If there has been a departure from the standard of care or accepted practice, how significant a departure do you consider this to be?

c) How would it be viewed by your peers?

d) Recommendations for improvement that may help to prevent a similar occurrence in future.

<u>Background</u>

[Ms A] was diagnosed with diabetes [in 2017]. Laboratory results indicated that she had Latent Autoimmune Diabetes of Adulthood (LADA) and she was appropriately treated with insulin. [Ms A] had a strong family history of diabetes …

On the 3rd of [Month1] [Ms A] had a pelvic ultrasound indicating that she was 5 weeks and 3 days pregnant.

[Ms A] was referred by her GP on 8th [Month1] to the obstetric team for care during her pregnancy because she had Type 1 diabetes. The referral was also copied to the

Diabetes Service. Her other comorbidities included migraine with aura, asthma, anxiety and current smoker. …

[Ms A] was then seen by the CNS Diabetes on 28 [Month1] at 9 weeks gestation. She was being treated with Lantus 17U per day and Apidra 3U tds. Her HBA1c at this time was 55mmol/mol. She had no complications of diabetes. She was taking folic acid 0.8mg and iodine 150mcg. It is commented that the patient was managing her diabetes reasonably well.

On this date she was also assessed by [Dr B] (endocrinologist). His letter indicates that the patient had had several hypoglycaemic episodes and that there was not enough blood glucose monitoring data on which to adjust her insulin doses. He wondered about the validity of the diagnosis of Type 1 diabetes and mooted the possibility of her having MODY 3. She was referred to a dietitian for education to learn carbohydrate counting and was to work with her Diabetes CNS to improve her glycaemic control. He planned to see her again in several weeks.

She was next seen by [Dr B] on 21st [Month2] at 12 weeks gestation. It was noted that the patient had had a nocturnal hypoglycaemic episode and so her Lantus dose was reduced by 1 unit. He felt that the diagnosis was LADA based on her GAD antibody titre. He also diagnosed her with euthyroid Graves Disease based on positive TSH receptor antibodies and suggested that she have her thyroid function tests checked on a monthly basis throughout her pregnancy.

She was seen on 27th [Month3] at approximately 17 weeks gestation by the dietitian and given education concerning carbohydrate counting. It was reported that the patient had stopped her short acting insulin and halved her basal insulin to prevent hypoglycaemic episodes. She had gained 3kg in weight during this pregnancy. Her current weight was 57.9kg. She was advised about having regular snacks. It was determined that her glycaemic control was satisfactory based on pre and post prandial blood glucose levels.

29th [Month5] Ultrasound: no abnormalities identified at 26 weeks and 2 days gestation.

She was next seen on the 18th [Month6] by [Dr B] at 29 weeks gestation. Because of hypoglycaemic episodes he reduced her Lantus dose from 14 to 13 U per day. He noted that she may need to add in short acting insulin with breakfast and lunch. He commented that her Graves' Disease remained in remission.

Ultrasound scan 9th [Month7] at approximately 32 weeks gestation indicated that the fetal abdominal circumference (AC) circumference was >98th percentile. Abnormal umbilical artery dopplers noted.

Repeat ultrasound 22nd [Month7]: AC >98th percentile and abnormal umbilical artery dopplers. Planned for induction of labour at 37 weeks gestation.

She was next seen on the 23rd of [Month7] by [Dr B] at approximately 34 weeks gestation. By this time she was using a Freestyle Libre Continuous Glucose Monitor and her 2 week average glucose was 9mmol/L but that her levels were scatter shot. He changed her to a twice daily Lantus regimen in the hope that it may smooth out her glucose profiles.

Ultrasound scan 29th [Month7] indicated dopplers normal but a 3mm pericardial effusion identified.

She was seen a week later (35 weeks gestation) and because of on-going issues with low blood glucose levels at night the dose of Lantus was reduced by 1 unit. CGM average glucose was 7.9mmol/L and this was regarded as demonstrating an excellent result. He felt that the baby's growth was normal based on ultrasound results.

Ultrasound 5th [Month8] indicating pericardial effusion present (6mm) and AC >98th percentile.

Her next visit with [Dr B] was on 7th [Month8] at 36 weeks gestation and her average blood glucose level was 6.9mmol/L. On this occasion it was determined that the baby was large and he was aware that the baby had a small pericardial effusion. He was also aware that a planned induction of labour was planned for 10 days' time.

The following day she was admitted at 36+ weeks with an intrauterine death.

The medical records contain only a few records of interactions with a diabetes CNS. The timeline (sequence of events) records that CNS visits occurred on 4 occasions:

28th [Month1] — 9 weeks gestation

29th [Month4] — 22 weeks gestation

26th [Month5] — 26 weeks gestation

30th [Month6] — 30 weeks gestation

There may have been other interactions that are not recorded in the medical file.

Opinion

a) Was the delay to be seen by the dietitian following the referral by the endocrinologist acceptable?

i. What is the standard of care/accepted practice?

Referral to a dietitian to ensure that a patient with Type 1 diabetes has appropriate education on carbohydrate counting and nutritional approaches should ideally take place prior to conception. However, when pregnancy is unplanned, the dietitian assessment should take place as soon as practically possible in the early stages of pregnancy.

ii. If there has been a departure from the standard of care or accepted practice, how significant a departure do you consider this to be?

The 2-month delay resulting in the patient being seen at 17 weeks gestation would be viewed as a significant departure from accepted practice. However, I do not believe that it had a significant role to play in the adverse pregnancy outcome experienced in this case.

iii. How would it be viewed by your peers?

I believe that in a multidisciplinary antenatal diabetes team this delay would be deemed unacceptable.

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

A dietitian is an integral member of the multidisciplinary team caring for women with diabetes in pregnancy. The dietitian should therefore be readily available to see a patient at short notice — within 1–2 weeks. If such a team does not exist presently then establishing such a team is a high priority for this DHB.

b) The management of [Ms A's] diabetes during her pregnancy.

i. What is the standard of care/accepted practice?

For a patient with Type 1 diabetes the accepted standard of care would be for the patient to initially be seen by the antenatal diabetes multidisciplinary team (MDT) prior to pregnancy. This team would consist of a diabetes midwife; obstetrician; endocrinologist; Diabetes CNS and dietitian. The aim of this assessment is to ensure that the patient is educated regarding the implications of diabetes and pregnancy; has satisfactory glycaemic control; adjust or discontinue medications if appropriate; commence folic acid; and assess status of any diabetes related complications and co-morbidities that could have a bearing on pregnancy outcomes. Suboptimal glycaemic control at conception is associated with an increased risk of fetal anomalies and miscarriage.

Following conception, a patient with Type 1 diabetes should be seen by the MDT without delay, usually within 1–2 weeks. In the initial stages of pregnancy insulin sensitivity increases and insulin dosages often need to be reduced to avoid hypoglycaemic episodes. Later in pregnancy insulin resistance becomes more problematic and insulin dosages need to be escalated. For this reason, patients need to be in regular contact with, at least, the Diabetes CNS on a weekly basis (if not more often) and is usually seen by the MDT every 1–3 weeks depending on any issues that are arising. Close coordination between the diabetes and obstetric members of the MDT is essential so that relevant clinical information and plans are known by all members of the team. This is particularly important later in the pregnancy when the results of growth scans become an important indicator of fetal health and metabolic control so that plans can be made for delivery.

ii. If there has been a departure from the standard of care or accepted practice, how significant a departure do you consider this to be?

The care of [Ms A] departs from the standards outlined above in several ways:

1. She was not seen and assessed prior to pregnancy. However, this is not uncommon since pregnancy is often unplanned. It is unclear from the information provided as to whether [Ms A's] pregnancy was planned or not. It is also unclear as to whether she had previously been educated as to the importance of preconception planning.
2. Once pregnant [Ms A] was first seen by the diabetes team at 9 weeks gestation. It would have been preferable for her to have been seen earlier, especially as she had not been seen in the preconception period. This would have allowed for those aspects of care preferably performed preconception to have been attended to. From the time of referral by her GP there was approximately a 3-week gap before she was seen. There was thus an opportunity to see [Ms A] earlier. One change to her management that could have been attended to by an earlier assessment would have been to increase her folic acid dose to that generally used in pregnancy complicated by diabetes.
3. From what can be gleaned from the health record the patient was assessed by the Diabetes CNS on 4 occasions during her pregnancy. If this is an accurate picture of the situation then this is less than optimal. Usually, a woman with Type 1 diabetes would have at least weekly contact (by telephone or in person visit) with a Diabetes CNS during pregnancy. There may be multiple other interactions that are recorded elsewhere than the provided health record and this would be important to know. However, no report has been submitted by the Diabetes Clinical Nurse Specialist caring for [Ms A] during her pregnancy.
4. The coordination between the diabetes team and the obstetric team appears to be fragmented. It is unclear from the health record as to whether the two teams undertake a combined clinic. A combined multidisciplinary clinic is essential for coordination and communication between the two specialties. It is also optimal from the patient's perspective as it means being seen by all of the important team members on one occasion rather than having multiple visits. If the two specialties are not providing a combined clinic then this would be viewed as suboptimal care.

iii. How would it be viewed by your peers?

I believe that the two main aspects of care that would be deemed to be sub-standard in the delivery of care to [Ms A] (if confirmed by further investigation) by my peers would be:

1. [Ms A] only being contacted on 4 occasions by a Diabetes CNS during her pregnancy.
2. The antenatal diabetes service being provided as two distinct services rather than a coordinated single MDT and unified clinic.

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

An adequately resourced multidisciplinary antenatal diabetes team as outlined above should be formed as a high priority. Local guidelines based on the national standards set out by the NZ Ministry of Health and the Australasian Diabetes in Pregnancy guidelines should be developed. An audit system should be in place to review outcomes and make recommendations on a regular basis.

c) The co-ordination between the Endocrinology Service and the Antenatal Service.

There is no formal description of the exact format of the diabetes in pregnancy service at the time of [Ms A's] pregnancy but from what I can glean from the record it would appear that it is not an integrated service with combined clinics and review meetings. As alluded to above an integrated service allows for effective coordination and communication which is vital for the multidisciplinary care that underpins the delivery of antenatal diabetes services. It would be unusual to provide such care as distinct and separate services and would not meet the expected standards of care for managing women with diabetes in pregnancy.

d) Any other matters that warrant comment.

My main concern, if the hospital record is a correct reflection of the interaction between the diabetes service and women who are pregnant with diabetes, is the inadequate frequency of interaction between the Diabetes CNS and the patient. If this is reflective of the usual standard of care, I would have significant reservations about the level of care delivered to women with diabetes who are pregnant. This could either indicate diabetes nursing staff shortages or a lack of awareness of the level of nursing input that is required for the management of diabetes in pregnancy.

It is important to clearly define whether the inadequacies noted above of the care of [Ms A's] diabetes had a material impact on the outcome of her pregnancy. It is hard to get an accurate handle of the adequacy of glycaemic control as there are no self-monitoring of blood glucose (SMBG) records in the medical record to determine whether pre- and post-prandial targets were met. The best that can be said is that based on the CGM description and HbA 1 c levels that glycaemic control may have been reasonable. On the other hand, the increased abdominal circumference of the fetus may be suggestive of suboptimal glycaemic control. Whether [Ms A's] induction of labour should have been earlier was an obstetric decision and was not based on her diabetes management. Therefore, I do not believe that there is sufficient information to indicate that the care of [Ms A's] diabetes during her pregnancy had a direct impact on the outcome of her pregnancy.

If further information is required, please do not hesitate to contact me.

Yours sincerely,

Professor Patrick Manning
Consultant Endocrinologist'

The following further advice was obtained from Dr Manning on 16 August 2022, in response to specific questions asked by HDC:

'***Can you please respond to the following questions:***

1. Throughout your report, you have identified that antenatal diabetes services being provided as two distinct services rather than a coordinated single MDT and unified clinic, would be considered "substandard". The DHB have since confirmed that at the time of these events, there was no MDT for the management of diabetes in pregnancy.

Can you please advise whether this failure constitutes a mild, moderate or severe departure from accepted standards.

At least moderate, bordering on severe. As the Maternity Review document mentions — they were the only DHB of 16 surveyed that did not have an MDT in place.

2. With regards to [Ms A] being contacted on only four occasions by a Diabetes CNS throughout her pregnancy, you considered that this would be viewed as substandard.

a) If [Ms A] was only seen on four occasions by the CNS (as is documented), would this be considered a mild, moderate or severe departure from accepted standards?

Severe — the standard for a high risk pregnancy such as this would be at a minimum of fortnightly contact and perhaps more often if required which would equate to closer to 20 visits throughout the pregnancy.

b) If [Ms A] was seen on more than four occasions, but this was just not adequately documented, would this be considered a mild, moderate or severe departure from accepted standards?

The gap between 4 and 20 is large. So, unless there are many visits/interactions that are purported to have occurred that were not documented, the departure is severe.

3. Based on the response received from Taranaki DHB and the SAE report, whether you have any further comment to make or whether any of the information causes you to change or amend any of your previous advice.

I am pleased that an MDT is now in place. I would recommend that an endocrinologist is a member of the MDT and attends the weekly meetings as was also advised in the Maternity Review report.

4. In relation to [Ms A] being first seen by the diabetes service at 9 weeks' gestation (approximately three weeks after the referral was made by her GP) you advised that a patient with Type 1 diabetes should be seen "without delay" usually within one to two weeks. You stated: "It would have been preferable for [Ms A] to be seen earlier, especially as she had not been seen in the preconception period. This would have allowed for those aspects of care preferably performed preconception to have been attended to". TDHB advised in its response that this delay was due to an administration error.

Can you please advise whether this failure constitutes a departure from accepted standards. And if so, do you consider it to be a mild, moderate or severe departure from accepted standards.

Yes — this is a departure from accepted standards and the 1–2 week delay would be mild–moderate."