Waikato District Health Board

Whanganui District Health Board

A Report by the

Health and Disability Commissioner

(Case 19HDC00239)

Health and Disability Commissioner

Te Toihau Hauora, Hauātanga

Contents

Executive summary

1. This case highlights the critical importance of clear and effective communication between clinicians and between district health boards (DHBs), and the devastating consequences if communication is poor. It also highlights the importance of implementing robust and effective screening systems for retinopathy of prematurity (ROP), especially at level two hospitals, which may be less familiar with the condition and its management.

2. A baby was born at 24 weeks' gestation in 2018 and had multiple complex health issues. He was particularly susceptible to developing ROP, a progressive eye condition that usually develops between 32 and 34 weeks' postmenstrual age (PMA), and that should be treated between 34 and 38 weeks' PMA. If ROP is identified and treated within these timeframes, there is a 90% chance that treatment will be successful. The baby developed ROP at 32 weeks' PMA, but he did not receive any further screening until he was 44 weeks' PMA.

Findings

3. The Commissioner considered that the system at Waikato DHB was not robust and, as a result, the need for ongoing ROP screening (including the expectation for a further screen of the baby's eyes at 34 weeks) was not communicated to Whanganui DHB. The Commissioner found that by failing to co-operate with Whanganui DHB adequately to ensure quality and continuity of services to the baby, Waikato DHB breached Right 4(5) of the Code.

4. The Commissioner also considered that a series of errors by Whanganui DHB indicated a system that lacked adequate safety-netting or clear protocols to ensure that babies do not fall through the cracks. The Commissioner regarded the errors as a serious departure from the expected standard of care, and found that by failing to treat the baby with reasonable care and skill, Whanganui DHB breached Right 4(1) of the Code.

Recommendations

5. The Commissioner recommended that Waikato DHB provide a written apology to the baby and his family for the deficiencies identified in this report; conduct an audit of its discharge letters for premature babies on transfer to another hospital; put in place a system to ensure that the staff member responsible for collating and printing a patient's discharge information is reliably and easily identified; ensure that the results of the ROP screenings are included in the clinical notes for premature babies; provide an update on staff education on its process of admission under a named Senior Medical Officer, and its guideline for generating electronic discharge letters; and consider whether it is appropriate to have a specific person responsible for ROP screening within NICU.

6. The Commissioner recommended that the consultant neonatal paediatrician responsible for the transfer of the baby's care from Waikato DHB to Whanganui DHB provide a written apology to the baby and his family for the deficiencies identified in this report.

Names have been removed (except Waikato DHB, Whanganui DHB, and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

7. In response to the Commissioner's recommendations in the provisional opinion, Whanganui DHB provided HDC with a formal apology to the family, and audits of the following: ROP screening for all at-risk babies who have received care from Whanganui DHB since these events; the effectiveness and timeliness of the Referral Centre in processing ROP referrals; and the adequacy of the triaging for ROP by the Ophthalmology Department.

Complaint and investigation

8. The Health and Disability Commissioner (HDC) received a complaint from Mr A about the services provided to his son, Baby A, at Waikato District Health Board and Whanganui District Health Board. The following issues were identified for investigation:

- *The appropriateness of the care provided to Baby A by Waikato District Health Board in respect of the handover of information about retinopathy of prematurity screening to Whanganui District Health Board.*
- *The appropriateness of the care provided to Baby A by Whanganui District Health Board in respect of retinopathy of prematurity screening.*

9. The parties directly involved in the investigation were:

Mr A	Complainant/consumer's father
Waikato District Health Board (DHB)	Provider
Whanganui DHB	Provider

10. Further information was received from:

Dr B	Neonatal paediatrician
Dr C	Clinical Director Paediatrics
Dr D	Paediatric Resident Medical Officer (RMO)
Dr E	Paediatrician
Dr F	Ophthalmologist
Ms G	Neonatal nurse practitioner
Dr H	Clinical Director Ophthalmology
Dr I	Clinical neonatologist

11. Also mentioned in this report

Dr J	Ophthalmologist
Registered Nurse (RN) K	Registered nurse

12. Independent expert advice was obtained from an ophthalmologist, Dr Shuan Dai (Appendix A), and a neonatal paediatrician, Dr Simon Rowley (Appendix B).

Information gathered during investigation

Background

13. On 17 Month1,[1] Baby A was born at Whanganui DHB at 24 weeks' gestation. He was the second of twins and weighed 675g.

14. On 18 Month1, Baby A and his twin were transferred to Waikato DHB owing to their extreme prematurity. The twin passed away a week later on 25 Month1. I extend my condolences to the family for the loss of their baby.

15. Baby A had a number of complications, including the following:

- Chronic lung disease requiring respiratory support
- High blood glucose concentrations requiring insulin treatment
- Low blood pressure requiring dopamine treatment
- Patent ductus arteriosus[2] requiring indomethacin treatment
- Anaemia requiring blood transfusions (10 in total)
- Urinary tract infection requiring antibiotics.

16. Given his low birthweight, his prematurity, and the complications outlined above, there was an increased risk that Baby A would develop retinopathy of prematurity.

Retinopathy of prematurity (ROP)

17. ROP is an abnormality in the growth of the blood vessels in the eye. The blood vessels that supply the retina grow from the centre of the retina to meet its periphery at full term. In premature babies this development can be interrupted. If left untreated, this can progress to retinal detachment and the loss of vision in the eye. ROP treatment is highly successful if diagnosis and treatment are provided in a timely manner, and over 90% of infants have a favourable outcome.

18. ROP affects premature babies with extremely low birthweight[3] and/or young gestational age.[4] Sixty-one percent of babies born at less than 28 weeks of gestational age, or less than 1000 grams, develop some degree of ROP.

19. Usually ROP develops between the postmenstrual age (PMA)[5] of 32 to 34 weeks, and treatment occurs between 34 to 38 weeks' PMA.

[1] Relevant months are referred to as Months 1–6 to protect privacy.
[2] Patent ductus arteriosus (PDA) is a persistent opening between the two major blood vessels leading from the heart.
[3] Less than 1500 grams.
[4] Less than 32 weeks.
[5] Postmenstrual age is the gestational age plus the chronological age.

20. ROP is classified into five stages. Stage 1 is very early and mild, and Stage 5 is the end stage. The aim of screening is to identify the babies with ROP, provide treatment, and prevent the progression of ROP.

Care at Waikato DHB

21. On 30 Month2, when Baby A was 30 weeks' PMA, Dr J, an ophthalmologist, performed the initial ROP assessment. Dr J documented, "Zone 1–2, Stage 0, hazy ++, see 2 weeks" in the Eye Book and in the clinical notes. The Eye Book is a brief handwritten summary that is kept at the NICU[6] reception area.

22. Dr B, a neonatal paediatrician, stated:[7]

> "All of this was as expected — the blood vessels were only partially developed on the inner lining of the eye (consistent with gestation), but there was no evidence on this date of any abnormalities of those blood vessels."

23. On 12 Month3, when Baby A was 32 weeks' PMA, Dr J reviewed Baby A and recorded, "Zone 1–2, Stage 1, vessels dilated mildly, R[ight]=L[eft], see 2 weeks" in the Eye Book. The assessment was documented by a nurse in the clinical notes as follows: "Eye check completed by Ophthalmologist." The results of the assessment were not documented in the clinical notes.

24. Dr B stated:

> "Again this is not unusual at this stage. There was some evidence of mild retinopathy, at a level usually seen in such premature infants. [Dr J] advocated continued screening at the usual intervals (2 weeks), and was not therefore concerned that the situation was deteriorating rapidly."

25. Before the next ophthalmology review could take place, Baby A was transferred to Whanganui DHB. Dr J was not informed of the transfer, and he told HDC that he had no further involvement in Baby A's care.

26. At the time of the transfer, Baby A was aged 33 weeks and 5 days' PMA. Baby A's next ophthalmology review was to take place on 26 Month3, when Baby A was aged 34 weeks' PMA.

Transfer from Waikato DHB

27. Dr B told HDC:

> "[Baby A's] journey through the Waikato NICU was an average one for a 24 week infant. He had had a number of complications throughout his admission, but not so many as to make his course particularly hard in comparison to other similar babies.

[6] Newborn Intensive Care Unit.
[7] In his statement to ACC dated 19 May 2019.

> There is always an imperative to move babies closer to their home when their clinical condition allows."

28. Dr B said that Baby A was transferred because he was well enough to be transferred to a level 2[8] NICU. Additionally, Waikato DHB was over-capacity, and after a discussion between Dr B and Dr E, a paediatrician at Whanganui DHB, Dr B felt reassured that Whanganui DHB had the capability for the transfer.

Verbal handover to Whanganui DHB

29. On 22 Month3, Dr B telephoned Dr E at Whanganui DHB to discuss Baby A's transfer. Dr B told HDC:

> "The purpose of the phone call is to establish that the receiving doctor is aware of the returning baby, and willing to accept the transfer. A similar phone conversation occurs at charge nurse level."

30. Dr B said that he verbally handed over Baby A's care to Dr E, but he did not discuss Baby A's ROP status or the timing for the follow-up ROP examination. Dr B said that at the time of transfer, Baby A's ROP status was not a front-of-mind issue, and the main focus was on maintaining a stable respiratory status and ensuring ongoing growth.

31. Dr B also said that Whanganui DHB was an "unusual transfer hospital" for Waikato DHB staff as it was outside the region. Dr B stated that he is very familiar with the services available at Waikato DHB's "usual transfer" hospitals, and that for these hospitals he has "full confidence" that the receiving specialist understands the ROP requirements for preterm babies. Dr B said that as a result, it was not his routine practice to inform a receiving specialist of the ROP requirements, believing that they would consider the need for this to be obvious, and noting that the discharge letter would also contain the appropriate detail. However, in this case, the discharge letter did not contain the appropriate detail — that is, it did not identify Baby A's ROP status.

Written handover to Whanganui DHB

32. Ms G is a neonatal nurse practitioner at Waikato NICU. Ms G said that the usual procedure, once the verbal handover from the neonatologist at Waikato DHB to the neonatologist at the receiving hospital has occurred, is to update the discharge letter and arrange transport to the receiving hospital.

33. Ms G said that at the time of Baby A's transfer, there was no standardised template for a discharge letter. She stated that a discharge letter is commenced soon after a baby is born, and that information is updated continuously by medical staff during the admission. Ms G told HDC that the letters can be long and complex owing to the duration of the admission, and that they cover events that take place over several months. The discharge letter

[8] Level 2 NICU units generally care for babies aged 32 to 40 weeks and babies who have been transferred from Level 3 units.

includes the baby's delivery information, neonatal problems, progress, procedures and investigations, discharge medication, and follow-up plan.

34. Ms G stated that on the day of transfer, the discharge letter is printed out by the medical staff member who is available at the time. She said that sometimes the person who prints the discharge letter is logged in under another practitioner's name, so the person completing or checking the discharge letter may not necessarily be the same person whose name appears on it. Ms G said that the discharge letter is not checked by a consultant or senior medical officer before printing.

35. In respect of Baby A's discharge, Ms G said that although her name is on the discharge letter, it was not necessarily completed by her.

36. Baby A's discharge letter recorded information about Baby A's admission, including a Neonatal Problems list of 10 neonatal problems. The discharge letter did not mention Baby A's ophthalmological status or ROP screening requirements.

37. Dr B said that usually the ROP details are included in the discharge letter, but in this case they were not. He stated:

> "For very preterm infants where the ROP status is pertinent, it has been our standard to include a reference to it in the discharge letter as an extra comment or paragraph. I regret to observe that in [Baby A's] case, this did not occur."

38. Ms G said that when a baby is discharged, she also includes a printout of recent blood results and the Australian & New Zealand Neonatal Network (ANZNN) datasheet.

39. Ms G said that Baby A's ophthalmology status was included in the ANZNN datasheet. The ANZNN datasheet documents the following: "ROP (gr) 0." This suggests that there were no abnormal findings as a result of an ROP assessment. As outlined above, on 12 Month3, Baby A had Stage 1 ROP.

40. On 23 Month3, Baby A, then aged 33 weeks and four days' PMA, was transferred to Whanganui DHB.

Admission to Whanganui DHB

41. On 23 Month3, Baby A was admitted to Whanganui DHB. Dr E, the receiving paediatrician, told HDC that Baby A was stable and well.

42. Dr E received the transfer documentation for Baby A, and told HDC that the requirement for ROP follow-up assessment, and the timing for the assessment, was not included. He said that there was no indication from the documentation that ROP was required urgently.

43. Dr E wrote a management plan for Baby A that focused on continuing the medication and treatments that were already in place, and arranging routine follow-up assessments. Dr E

told HDC that he was aware of the guidelines for the management of ROP, and as part of the management plan, he documented: "ROP and head [ultrasound scan] follow-up."

44. Dr E did not arrange an ROP assessment, although he continued to see Baby A regularly until 27 Month4. Dr E told HDC:

> "Over the coming days [Baby A] made good progress and the thought of ROP screening referral had slipped my mind. I realise now that I failed to write a referral form."

Care at Whanganui DHB

45. At Whanganui DHB, Baby A was reviewed daily by a consultant paediatrician accompanied by an RMO.[9]

46. Mr A, Baby A's father, stated to HDC that the nurse at Waikato DHB who managed the transfer to Whanganui DHB told him to "make sure they test his eyes". Mr A said that as a result, he mentioned it numerous times to doctors and nurses at Whanganui DHB.

47. On 7 Month4, RN K documented in the clinical notes: "Father asking if [Baby A] needs any further eye tests."

48. Whanganui DHB told HDC that RN K recalled that the conversation took place at the end of her night shift, but she was not able to recall the conversation itself or whether she handed over the information to the next shift.

49. An ROP assessment was not arranged or undertaken.

Discharge from Whanganui DHB and ROP referral

50. On 31 Month4, Baby A was discharged home. He was then aged 39 weeks and two days' PMA. Whanganui DHB said that Baby A was fully fit for discharge, and that he was feeding independently, gaining weight, and maintaining his temperature, and had been rooming with family for the previous few days.

51. On 31 Month4, prior to discharge, Baby A was reviewed by a paediatrician, Dr C. Dr C recognised that ROP screening had not been undertaken, and he asked Dr D[10] to arrange it within one to two weeks, as an outpatient.

52. Dr D completed a standard "request for outpatient appointment form" (the referral). The referral stated:

> "Please review in [Outpatients Department] for screening for Retinopathy of Prematurity.
>
> Current corrected gestational age 39 weeks (31 [Month4]).

[9] Resident Medical Officer (a junior doctor).
[10] A paediatric RMO.

> Born at 24 + 2 weeks. [Transferred] to Waikato DHB and had initial ROP screen there.
>
> [Discharged] from Whanganui DHB today. Would appreciate final ROP screen in 1–2 weeks."

53. Dr D told HDC that because there was no information in the Waikato DHB discharge letter about Baby A's initial ROP screenings at Waikato DHB, she was not able to include that information in the referral. She said that there was no checkbox on the standard referral form to indicate whether a referral was routine or urgent. However, Dr D noted on the referral form that the screening should be performed within one to two weeks, and provided her contact details.

54. On 31 Month4, the referral was faxed to the Referral Centre at Whanganui DHB, and Baby A was discharged home.

Triage of referral

55. On 7 Month5, ophthalmologist Dr F triaged the referral. Baby A was then aged 40 weeks' PMA.

56. Dr F said that the referral was sent to him on 7 Month5 because all referrals received during the week are triaged together on a Monday morning.[11]

57. Dr F marked the referral as having insufficient information, and returned the referral to the Referral Centre to send back to the primary referrer, the Paediatric Department. Dr F stated that the reasons for marking the referral as having "insufficient information" included:

- The referral did not appear to be urgent. ROP screening would have been requested before discharge if it had been urgent.
- The referral stated "last ROP screen".[12] Dr F said that he assumed that in the presence of ROP, paediatric staff would not be seeking a final ROP screen. He stated that in the absence of ROP, screening can be terminated at 39 weeks. He said that he assumed that previous ROP screens were normal if the Paediatric Team were suggesting a final screen at 41 to 42 weeks.[13]
- The Paediatric Team wanted Baby A to be seen in one to two weeks, so there was sufficient time for the referral letter to be returned, for the additional information to be provided and for the appointment to be made.
- Details of previous ROP screens are essential to continued ROP screening.

58. Whanganui DHB told HDC that the referral was rejected because it did not contain the earlier ROP screening results.

[11] Referrals are triaged once a week. 31 Month4 was a Monday, and 7 Month5 was the following Monday.
[12] The referral stated "final ROP screen".
[13] Baby A was 40 weeks of age on 7 Month5.

59. Dr I[14] conducted a case review of these events for Whanganui DHB. She stated:

> "The information on the referral letter is adequate in my opinion in that it states clearly the need for review (retinopathy of prematurity), birth gestation and current gestation."

Referral Centre

60. The referral was returned to the Referral Centre with the expectation that it would be returned to the Paediatric Department for further information.

61. On 8 Month5, the referral was sent to Baby A's parents, and to Baby A's GP advising that the referral had been declined and requesting further information.

62. On 23 Month5, the GP sent the referral back to the Referral Centre with instructions to forward it to the Paediatric Department at Whanganui DHB. The Referral Centre received this letter on 25 Month5.

63. Baby A was then aged 42 weeks' PMA.

64. Dr D told HDC that she did not receive a telephone call to discuss the referral or to request further information until 28 Month5. She stated:

> "On being informed that the referral form had been returned I went directly to the Ophthalmology Outpatients Department and discussed the case with [Dr F]. He accepted the referral and advised me to send a new referral form to the Outpatients Referral Centre, from which a ROP screening appointment was made."

65. On 28 Month5, Dr D completed another referral, which stated: "As discussed with [Dr F], for review in 1–2 weeks for ROP screen … Would appreciate review. Currently 43 weeks [PMA]."

66. Dr F saw Baby A on 4 Month6. He was then aged 44 weeks and 2 days' PMA. Dr F found Stage 5 ROP with total retinal detachment in the right eye, and Stage three to four ROP in the left eye with partial detachment. This meant that Baby A had a complete loss of vision in his right eye, and either a profound loss of vision or a complete loss of vision in his left eye.

Subsequent events

67. On 4 Month6, Baby A was transferred by air ambulance to a main centre hospital, where he was assessed and returned home the next day. On 10 Month6, Baby A was transferred to another hospital by air ambulance for surgery to repair the partially detached retina in his left eye.[15] The right eye was inoperable.

[14] An independent clinical neonatologist.
[15] Surgery took place on 11 Month6.

Other comment by Waikato DHB

68. Following these events, Waikato DHB undertook an incident review. The review found that its discharge letter did not refer to Baby A's ophthalmological status, or advise that follow-up ROP screening had been recommended for 26 Month3. The review also noted that this was "an oversight, as this information is usually included".

Other comment by Whanganui DHB

69. Whanganui DHB told HDC that transfer letters from a level 3 hospital typically include a checklist of follow-up requirements. It stated: "Level 2 units typically depend on these checklists to ensure that no follow-up items are missed."

70. Whanganui DHB noted that in this case the transfer letter did have a checklist of follow-up requirements, but it did not mention ROP screening. Whanganui DHB stated: "We accept that Whanganui DHB should have recognised that the transfer documentation was incomplete."

71. Whanganui DHB also stated:

> "The Consensus Statement[16] does not contain a failsafe mechanism to pick up babies in level 2 units at smaller DHBs who have not had their need for ROP screening communicated to the level 2 unit by the neonatologist at the level 3 unit. We believe that this lack of direct guidance in the Consensus Statement to level 2 units regarding detection of vulnerable infants, who have not had their ROP follow up requirements communicated, is a systemic error in the Consensus Statement which needs to be corrected."

Responses to provisional opinion

72. Mr A, Waikato DHB, and Whanganui DHB were given the opportunity to respond to relevant sections of the provisional opinion.

73. Mr A stated: "We approve the information as correct."

74. Waikato DHB agreed with the provisional report and proposed courses of action, and did not wish to make any further comment. Waikato DHB stated: "[Dr B] ha[s] been provided with the opportunity to comment on the relevant parts of the provisional report, and has no further comments to make."

75. Whanganui DHB stated:

> "[W]e accept that Whanganui DHB is in breach of the Code and agree with the findings of the report. However, we believe that Waikato DHB were equally culpable for failing to inform us of the requirement for and timing of follow up retinal examination as per the Newborn Clinical Network Consensus statement for screening for Retinopathy of Prematurity. Therefore, we are prepared to accept joint

[16] The Consensus Statement is summarised in the next section of this report.

> responsibility with Waikato DHB but feel this matter is not an egregious one so does not warrant referral to the Director of Proceedings. The issue that occurred was systematic failure not unique to the Whanganui DHB and once it was brought to our attention we put a safety net in place to prevent recurrence."

76. Whanganui DHB also stated: "We agree with the recommendations made and have undertaken the required audits." Whanganui DHB told HDC that both clinicians mentioned in the provisional opinion (Dr E and Dr F) received a copy and were given the opportunity to comment on the opinion.

77. Dr F stated:

> "I am very disheartened and feel sorry from the bottom of my heart about the outcome of this incident and lifelong disability for [Baby A]. This incident has been a learning experience for my life. In retrospect, I agree that the referral should not have been marked as 'insufficient information'. Sending the referral back to the 'primary referrer' had the potential of delaying examination."

78. Dr F explained that he has modified his practice and he no longer marks referrals as "insufficient information" and, if further information is required, he contacts the primary referrer, particularly where time could be a critical factor.

Relevant standards

Consensus Statement for Screening for Retinopathy of Prematurity[17] (the Consensus Statement)

79. The Consensus Statement is the foundation document for ROP screening in New Zealand. It, or an adaptation of it, is adopted as policy by DHBs in New Zealand. Both Whanganui DHB and Waikato DHB accept that the Consensus Statement outlines the accepted standard of care for ROP screening.

80. The purpose of the Consensus Statement is to:

> "Establish ROP screening criteria and ensure consistency at all DHBs which is important due to the movement of babies from level 3 to level 2 units prior to the time that development of ROP signs may occur."

81. The criteria for screening include: "ROP screening should be arranged for all infants born with a gestation age at birth of less than 30 weeks or birthweight less than 1250 grams."

[17] Prepared by Nicola Austin and Shuan Dai on behalf of the Newborn Clinical Network Clinical Reference Group and the Paediatric Ophthalmology Interest Group 30 June 2015. Reviewed on 1 July 2017.

82. For babies born at a gestational age of less than 26 weeks, the first ROP screening examination should occur at 30–31 weeks' PMA.

83. In respect of the termination of ROP screening, the Consensus Statement provides: "Examinations should not stop prior to 36 weeks. Expect to go to PMA 38/39 weeks for infants (< 28 weeks)."

84. The Consensus Statement also outlines how ROP screening should be organised at DHBs, and who is responsible for aspects of the screening. The Consensus Statement states:

> "An effective ROP screening service requires each NICU to have a unit specific screening protocol with clear defined responsibilities for each of the medical personnel involved.
>
> It is suggested that each NICU should have a ROP nurse coordinator, or neonatal associate clinical nurse manager (ACNM) responsible for ROP screening.
>
> A record system must be established to automatically trigger and schedule the initial ROP examination for those infants at risk. One method to ensure infants are examined on time is to enter their details into a ROP book or electronic dataset, at the time of admission to the NICU, and book the date of their first examination at that time. This will occur electronically when the Neonatal Clinical Information System[18] is available throughout NZ.
>
> …
>
> For babies transferred from a level 3 to a level 2 unit it is the responsibility of the transferring NICU neonatologist to inform the neonatologist/paediatrician in the receiving DHB the requirement and timing of initial or follow-up ROP examination."

Consideration of issues

85. Baby A was born at 24 weeks' gestation. He weighed 675g and he had multiple complex health issues. This combination of factors made him particularly susceptible to developing ROP, a progressive eye condition that usually develops between 32 and 34 weeks' PMA, and that should be treated between 34 and 38 weeks' PMA. If ROP is identified and treated within these timeframes, there is a 90% chance that treatment will be successful.

[18] The Neonatal Clinical Information System is a digital health initiative that is being developed by the Ministry of Health as part of its digital health portfolio. It is a shared electronic health information system covering primary and secondary care.

86. The development of ROP was a known risk for Baby A. Despite this, a number of administrative errors and communication failures meant that Baby A was not screened in the critical period between 34 and 39 weeks' PMA.

87. As outlined by my expert neonatal paediatric advisor, Dr Simon Rowley:

> "The care of an extremely preterm infant involves a journey starting before birth, and includes consultation by the neonatologist with obstetricians and parents, passage through the NICU which is often fraught with crises, transfer to a hospital closer to home (usually a Special Care Baby Unit (SCBU)), discharge to the community with their homecare services, and long term follow up to monitor and audit outcome through to school age at least. Depending upon circumstances some of these steps may be curtailed, but the principle is the same."

88. As Dr Rowley notes, if discharge planning and systemic follow-up is not completed adequately, then much of the hard work along the premature baby's journey through NICU, to help that child achieve its full potential, risks being in vain. Good communication at all stages of discharge planning is essential to a successful outcome.

89. The systems at Waikato DHB and Whanganui DHB did not ensure that appropriate and timely ROP screening was undertaken. There were a number of occasions during Baby A's admission at both Waikato DHB and Whanganui DHB when the failure to arrange follow-up ROP screening could have been rectified. Baby A developed ROP at 32 weeks' PMA, but he did not receive any further screening until he was 44 weeks' PMA. Baby A now has a lifelong disability, which could have been prevented. This case highlights the critical importance of clear and effective communication between clinicians and between DHBs, and the devastating consequences if communication is poor. It also highlights the importance of implementing robust and effective screening systems for ROP, especially at level two hospitals, which may be less familiar with the condition and its management.

Opinion: Waikato DHB — breach

Ophthalmology care

90. Baby A was screened for ROP at 30 weeks' PMA and no abnormalities were detected. He was screened again at 32 weeks' PMA and Stage 1 ROP was detected. The finding of Stage 1 ROP was recorded in the Eye Book that was held at NICU reception, but was not recorded in the clinical notes. A plan was made for ophthalmological review again at 34 weeks' PMA. However, at 33 weeks and four days' PMA, Baby A was transferred to Whanganui DHB.

91. My expert ophthalmology advisor, Dr Shuan Dai, advised that the ophthalmological care provided to Baby A by Waikato DHB was appropriate, and I accept this advice.

Handover of care

92. On 23 Month3, Baby A was transferred to Whanganui DHB. A discharge letter was generated to assist with the handover of Baby A's care.

93. The discharge letter is a summary of the information documented in the clinical notes. If information has not been documented in the clinical notes, then it will not automatically be included in the discharge letter, and must be added manually. In this case, critical information about Baby A's ROP status was not documented in his clinical notes (notably the second screening assessment) and was, therefore, not automatically included in the discharge letter. Further, it was not added manually when the discharge letter was generated. Accordingly, the discharge letter did not document that ROP screening had been initiated,[19] nor did it record the results of the second, more concerning screening assessment that had taken place. The system also did not reliably identify who had prepared the discharge letter and who took final responsibility for its content, owing to the practice of staff members completing and printing the summary while logged in as someone else.

94. Dr Dai advised:

> "Waikato DHB neonatal service should have clearly documented, and conveyed to the receiving NICU at Whanganui DHB that [Baby A] needs ongoing ROP screening given his higher risk of developing sight threatening ROP, especially when the screening ophthalmologist recommended a follow up screening at two week interval. This was clearly in departure from the standard of care proposed by the New Zealand National ROP screening and treatment guideline. There needs to be a revision of current standard clinical discharge letter to include ROP examination recommendations as an essential part of such document when infants are transferred to another NICU."

95. My expert neonatal paediatric advisor, Dr Simon Rowley, made the following observation about the system for documenting ROP screenings:

> "[I]t is generally accepted that the eye examinations done on NICU for infants less than 30 weeks gestation at birth and starting at six weeks of age are a procedure that needs documenting both in the notes and in the problem list — the same way as an ultrasound examination for intra-ventricular hemorrhage might be, or a special [X-ray]. It should therefore immediately be transferred on the problem list to any letters generated for transfer or discharge."

96. Dr Rowley concluded: "[T]here was an inadequate system for reminding people reading [Baby A's] file that ROP screening was needed to continue."

97. I agree. Baby A's Stage 1 ROP was not documented in his clinical notes or in the discharge letter. It appears that the only place that Baby A's Stage 1 ROP result was recorded was in the Eye Book, which was held at the NICU reception desk. While this system may be

[19] Although Baby A's ophthalmology status from his initial assessment was recorded in the ANZNN datasheet.

adequate when the ongoing ophthalmological care is to be provided at Waikato DHB, it is not adequate in cases where the baby is to be transferred to another hospital or DHB that will not have access to the Eye Book. It appears that there was no system for the ROP screening results to be added to Baby A's problem list in his clinical notes, and therefore they were not automatically included when the discharge letter was generated. This omission contributed to the failure to provide appropriate information at handover.

Conclusion

98. When a baby is at risk of developing ROP, and care is to be transferred to another provider or hospital, it is especially important that robust systems are in place to ensure that all relevant information is captured by the discharging hospital and shared with the receiving hospital. The guidelines in the Consensus Statement were developed for this purpose.

99. As identified, the system at Waikato DHB was not robust and, as a result, the need for ongoing ROP screening (including the expectation for a further screen of Baby A's eyes at 34 weeks' PMA) was not communicated to Whanganui DHB. Accordingly, Waikato DHB failed to co-operate with Whanganui DHB adequately to ensure quality and continuity of services to Baby A, and breached Right 4(5) of the Code.[20]

Opinion: Dr B — adverse comment

100. Dr B was the clinician responsible for the transfer of Baby A's care from Waikato DHB to Whanganui DHB. The Consensus Statement requires the transferring clinician to communicate the requirement for, and the timing of, the initial or follow-up ROP examinations, to the receiving clinician. Dr B telephoned Dr E at Whanganui DHB to hand over Baby A's care, but neither he, nor any other clinician at Waikato DHB involved in the discharge, communicated to clinicians at Whanganui DHB the results of the ROP assessments already undertaken, and the requirement for Baby A to undergo ongoing ROP screening and when that screening should take place.

101. In explanation for why this did not occur, Dr B stated that Whanganui was an unusual transfer hospital for Waikato clinicians. In relation to the transfer of babies to hospitals in the Waikato/Bay of Plenty region, Dr B stated that he has full confidence that the local specialists in those hospitals understand the needs of pre-term infants, including ROP follow-up. Accordingly, it was not his routine practice to inform those specialists of ROP requirements, although in Baby A's case he expected that the discharge letter would contain the appropriate detail.

102. The obligations on the transferring paediatrican are clearly outlined in the Consensus Statement. I am critical that Dr B did not advise Whanganui DHB that Baby A had Stage 1

[20] Right 4(5) of the Code of Health and Disability Services Consumers' Rights (the Code) states: "Every consumer has the right to co-operation among providers to ensure quality and continuity of services."

ROP and that ongoing screening was required within a few days of transfer. The fact that Dr B did not routinely relay this information to receiving hospitals does not mitigate the requirement for him to do so.

Opinion: Whanganui DHB — breach

Care from 23 Month3 to 31 Month4

103. On 23 Month3, Baby A was admitted to Whanganui DHB. Dr E recognised and documented that follow-up ROP screening was indicated, but it was not arranged. The care provided by Dr E is outlined in more detail later in this report.

104. Baby A received care at Whanganui DHB from 23 Month3 until he was discharged on 31 Month4. These five weeks were the critical period for the detection and treatment of ROP. During that time, Baby A was seen by multiple clinical staff, including paediatric consultants, RMOs, and nurses. However, the fact that he needed ROP screening was either not recognised by staff or not actioned.

105. During the admission, Baby A's father raised the issue of further eye tests with nursing staff, and this was noted in the clinical records by RN K. However, RN K was not able to recall the conversation itself or whether she handed over the information to the next shift.

106. In Dr Rowley's view, Dr E and staff at Whanganui DHB were "remiss in not following through with the initial observation that further ROP screening was needed until the point of discharge".

107. As noted by Dr Dai, at the time of Baby A's admission to Whanganui DHB he was aged nearly 34 weeks' PMA, which "is considered to be the peak time for severe ROP to develop in infants at risk". Dr Dai advised that as a result of the missed screening, Baby A "lost the opportunity for ROP treatment that has a success rate of approximate 90%". Dr Dai stated:

> "This 5–6-week delay in arranging for ROP screening for [Baby A] was a serious error. The lack of a system, or protocol in conducting ROP screening in a given institution usually is the cause of such failure and this clearly needs to be addressed to prevent a similar event from occurring in the future."

108. I accept this advice and conclude that this was a serious systems failure. I am critical that the risk of Baby A developing ROP was not considered by clinical staff (or, if it was, not acted upon), and that ROP screening was not arranged for Baby A during his five-week admission at Whanganui DHB. I agree with my experts that this indicates that the system was inadequate, and lacked appropriate safety-netting and protocols to protect babies like Baby A and ensure that they did not fall through the cracks.

Referral to ophthalmology

109. On 31 Month4, Baby A was reviewed by Dr C, who recognised that ROP screening had not been undertaken and asked Dr D to arrange this within one to two weeks, as an outpatient. Given that by this date Baby A was aged 39 weeks and 2 days' PMA, and had not had any ROP screening during his five weeks at Whanganui DHB, in my opinion the referral request did not convey sufficient urgency. Requesting a "final ROP in 1–2 weeks" suggests that there was some flexibility in the timing for the screening. There was not. As clearly indicated in the Consensus Statement, screening should not stop before 36 weeks and is expected to continue to 38–39 weeks' PMA.

Triage of referral

110. Dr F triaged the referral on 8 Month5. He did not accept the referral, and he returned it to the Referral Centre to be sent back to the Paediatric Department. The care provided by Dr F is outlined in more detail later in this report.

Return of the first referral and progress of the second referral

111. On 8 Month5, instead of sending the referral back to the Paediatric Department, the Referral Centre mistakenly sent it to Baby A's GP. The GP realised the error and returned it to the Referral Centre on 23 Month5.

112. Whanganui DHB has not offered a reason for this error, and it is not clear whether this is a one-off error or symptomatic of poor administrative processes at the Referral Centre. In any event, the administrative error resulted in a delay in notifying the Paediatric Department that the screening had not been arranged.

113. The referral was returned to the Paediatric Department on 23 Month5, but an ophthalmology appointment was not secured until ten days later, on 4 Month6. Baby A was then aged 44 weeks and 2 days' PMA, and was outside the parameters for the effective treatment of ROP.

114. I am critical that the ROP referral was misdirected by the Referral Centre to Baby A's GP, instead of being sent to the Paediatric Department, and that when the error was discovered, an immediate appointment was not arranged.

Conclusion

115. Whanganui DHB recognised the need for ROP screening at admission, and documented the family's query about the need for eye tests for Baby A. However, through a series of medical and administrative errors by multiple staff, Whanganui DHB failed to screen Baby A for ROP at the critical 34-week PMA mark, or at any other time throughout his five-week admission. Whanganui DHB did not refer Baby A for screening until the point of discharge from hospital, and even then there was no sense of urgency. Once the referral to the Ophthalmology Department was eventually arranged, it was inappropriately rejected and then misdirected by the Referral Centre. As a result, Baby A was not screened for ROP until he was 44 weeks' PMA — 10 weeks after he was transferred to Whanganui DHB's care. Tragically, by that time it was too late for successful treatment.

116. In my view, this outcome could have been prevented if adequate mechanisms had been in place for ROP screening at Whanganui DHB. The series of errors indicate a system that lacked adequate safety-netting or clear protocols to ensure that babies like Baby A did not fall through the cracks. I regard these errors as a serious departure from the expected standard of care. Accordingly, I am satisfied that Whanganui DHB failed to provide Baby A services with reasonable care and skill, and therefore breached Right 4(1) of the Code.[21]

Opinion: Dr E — adverse comment

117. As outlined above, on 23 Month3, Baby A was admitted to Whanganui DHB. Dr E recognised that ROP screening was indicated, and documented that follow-up ROP screening was required. Dr E told HDC that he forgot to make a referral for follow-up ROP screening and, as a result, a referral was not made.

118. My expert, Dr Rowley, confirmed that every paediatrician working in a level 2 neonatal unit should be aware that extreme prematurity is a high risk factor for a number of developmental problems, including visual problems secondary to retinopathy, and there is an expectation that they will pick up the screening of transferred babies. The referral should have happened in the first few days of Baby A's admission.

119. Dr Dai advised:

> "The paediatrician at Whanganui DHB should have referred [Baby A] to ophthalmology for ongoing ROP screening as soon as they took over [Baby A's] care from Waikato DHB when [Baby A] was barely at 34 weeks of PMA which is considered to be the peak time for severe ROP to develop in infants at risk ([Baby A] was clearly one of these infants)."

120. Dr Rowley advised that the failure to communicate the need for ROP follow-up was a moderate departure from the accepted standard of care.

121. I share my experts' concern. Dr E recognised the importance of ROP screening for Baby A. The failure by Dr E to make a referral for follow-up ROP screening was a significant oversight with catastrophic consequences for Baby A. I am critical that Dr E did not make the referral.

[21] Right 4(1) of the Code states: "Every consumer has the right to have services provided with reasonable care and skill."

Opinion: Dr F — adverse comment

122. The referral was not triaged by Dr F until a week after it was made,[22] when Baby A was aged 40 weeks' PMA. Dr F said that the referral did not appear to be urgent because Baby A was being discharged, the referral was for a final screen (after the critical 39-week PMA mark), and there were no details about an earlier screen. As a result, Dr F marked the referral as having "insufficient information" and instructed that it be returned to the primary referrer.

123. Dr I conducted a case review for Whanganui DHB and determined that the information in the referral letter was adequate.

124. Dr Dai advised:

> "The referral letter to the ophthalmologist was brief but given that they had not received important information from the Waikato DHB team about previous screening results it contained enough information to indicate a degree of risk. I believe in this situation the triage team were deficient in sending back the referral knowing that this would lead to further delays in [Baby A] being seen."

125. At 40 weeks' PMA Baby A was already at the outer limits of the opportunity for successful treatment, and timeliness was therefore critical. When the referral reached Dr F, it was not accepted. I accept my expert's advice that there was sufficient information for the referral to be accepted, and I am critical that it was not. I also note Dr Rowley's comment that instead of sending the referral back, a telephone call to the referring provider asking for more information may well have avoided any subsequent delay.

126. In response to my provisional decision, Dr F expressed: "I am very disheartened and feel sorry from the bottom on my heart about the outcome of this incident and lifelong disability for [Baby A]. This incident has been a learning experience for my life." He agreed that in retrospect the referral should not have been marked as "insufficient information", and that sending the referral back to the primary referrer had the potential to delay the examination. Dr F has modified his practice so that he no longer marks referrals as "insufficient information", and if further information is required, particularly where time could be a critical factor, he contacts the primary referrer.

[22] Referrals are triaged once a week. 31 Month4 was a Monday, and 7 Month5 was the following Monday.

Changes implemented

Waikato DHB

127. Waikato DHB stated that a NICU Discharge Letter Guideline has been developed for generating an electronic discharge letter.[23] The NICU Discharge Letter Guideline refers specifically to infants under 1500g or less than 30 weeks' gestation, and requires: "ROP check — results, dates and follow-up recommendation."

128. Waikato DHB stated that babies are admitted to NICU under the generic neonatal team, but in future, all babies will be admitted under a named Senior Medical Officer (SMO). It said that this will ensure that a named SMO is responsible for checking all results, letters, and documentation for the baby. Waikato DHB stated that it will hold education sessions on the use of an electronic tool to support this new process.

Whanganui DHB

129. Whanganui DHB stated that the following changes have been made:

- A review of the ROP procedure has been completed.
- The Clinical Nurse Manager will co-ordinate ROP screening in paediatric services.
- A medical referral checklist has been developed for each baby on admission.
- A referral for ROP screening requires a written referral to the Ophthalmology Department and a specialist-to-specialist telephone conversation.
- ROP cases are audited to ensure that all follow-up is completed.
- Kōrero Mai[24] has been launched in the paediatric area.

Other comment

130. Dr Rowley stated:

> "I am aware that Waikato DHB have amended their discharge documentation recommendations to include ROP in the discharge material, that Whanganui DHB have also built in steps to ensure that ROP screening is completed, and that the Ophthalmology Department in Whanganui DHB is instituting safety checks to ensure that ROP screening is given more weight in triaging so that this unfortunate outcome for [Baby A] does not happen again."

[23] This template was implemented on 8 Month6.
[24] Kōrero Mai is a Health Quality & Safety Commission programme aimed at improving communication with the patient, family, and whānau.

131. I am also aware that the Ministry of Health is developing the Neonatal Clinical Information System, which is a shared electronic health information system. I am hopeful that this will help to ensure that critical information is shared between health providers when caring for vulnerable premature infants like Baby A. I intend to raise this matter with the Director-General of Health and ask for an update on the progress of the system.

132. The Newborn Clinical Network will be provided with a copy of this report so that it can consider whether the Consensus Statement provides suitable guidance to level 2 units for ROP screening.

Recommendations

133. I recommend that within three months of the date of this report, Waikato DHB:

a) Conduct an audit of its discharge letters for premature babies on transfer to another hospital over the last six months, to ensure that ROP details were included, and report the findings of the audit to HDC;

b) Put in place a system to ensure that the staff member responsible for collating and printing a patient's discharge information is reliably and easily identified;

c) Ensure that the results of the ROP screenings are included in the clinical notes for premature babies;

d) Provide an update on the electronic tool mentioned earlier in this report,[25] and explain how it is supporting improved documentation in discharge letters; and

e) Consider whether it is appropriate to have a specific person responsible for ROP screening within NICU (as suggested in the Consensus Statement), and report the findings to HDC.

134. I also recommend that Waikato DHB provide a written apology to Baby A and his family for the deficiencies identified in this report. The apology should be provided to HDC within three weeks of the date of this report, for forwarding to Baby A and his family.

135. I recommend that Dr B provide a written apology to Baby A and his family for the deficiencies identified in this report. The apology should be provided to HDC within three weeks of the date of this report, for forwarding to Baby A and his family.

136. I recommend that Dr E provide a written apology to Baby A and his family for the deficiencies identified in this report. The apology should be provided to HDC within three weeks of the date of this report, for forwarding to Baby A and his family.

[25] In the "Changes implemented" section.

137. I recommend that Dr F provide a written apology to Baby A and his family for the deficiencies identified in this report. The apology should be provided to HDC within three weeks of the date of this report, for forwarding to Baby A and his family.

138. In response to the provisional decision, Whanganui DHB provided HDC with a formal apology to the family for forwarding, as well as audits of:

- ROP screening for all at-risk babies who have received care from Whanganui DHB since these events;
- The effectiveness and timeliness of the Referral Centre in processing ROP referrals; and
- The adequacy of the triaging for ROP by the Ophthalmology Department.

Follow-up actions

139. Whanganui DHB will be referred to the Director of Proceedings in accordance with section 45(2)(f) of the Health and Disability Commissioner Act 1994 for the purpose of deciding whether any proceedings should be taken. In making this referral I have had regard to the seriousness of the breach, the particular vulnerabilities of Baby A where the risks to him should have been known and there was a clear expectation of care, and the public interest in holding providers to account.

140. A copy of this report with details identifying the parties removed, except the names of Waikato DHB, Whanganui DHB, and the experts who advised on this case, will be sent to the Royal Australasian College of Physicians, the Technical Advisory Service, the Royal Australian and New Zealand College of Ophthalmologists, the Health Quality & Safety Commission, and the Director-General of Health, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

141. A copy of this report with details identifying the parties removed, except the names of Waikato DHB, Whanganui DHB, and the experts who advised on this case, will be sent to the Newborn Clinical Network, to consider whether the Consensus Statement provides suitable guidance to level 2 units for ROP screening.

142. I will be writing to the Director-General of Health to bring to his attention the issues highlighted in this report about Waikato DHB and Whanganui DHB's screening for ROP, and to ask for an update on the progress of the Neonatal Clinical Information System.

Addendum

143. The Director decided to institute a proceeding in the Human Rights Review Tribunal.

Appendix A: Independent advice to the Commissioner

The following expert advice was obtained from Dr Shuan Dai, an ophthalmologist:

"1st December 2019

…

RE: Complaint of Waikato DHB, Whanganui DHB

Your reference: C19HDC00239

My name is Shuan Huai Dai, I am a fully qualified Medical Practitioner, Vocationally registered with the New Zealand Medical Council in the branch of Ophthalmology (NZ Medical Council 22582) and the Australia Health Practitioner Registration Authority (AHPRA MED0002190278).

I am a Fellow of the Royal Australian and New Zealand College of Ophthalmologists, Member of the American Academy of Ophthalmology and Member of the American Association of Paediatric Ophthalmology and Strabismus. I am an executive member of the scientific committee of the Royal Australian and New Zealand College of Ophthalmologists. I serve as the current president of Australia & New Zealand Strabismus Society. I am the current Director of Ophthalmology at Queensland Children's Hospital Brisbane Australia and Associate Professor, School of Medicine, University of Queensland.

I have a special interest and clinical expertise in Retinopathy of prematurity (ROP) which is a vascular proliferative retinal disease affecting infants born prematurely. I was the lead ophthalmologist in ROP screening and treatment in Auckland, New Zealand for the last 12 years prior to moving to Brisbane later in 2018. I had been involved in the development of the New Zealand National ROP screening guideline which was endorsed by the Newborn Network and the Fetus and Newborn Special Interest Group of the Paediatric Society of New Zealand in 2015, and in the same year the guideline was published in the *Journal of Paediatrics & Child Health*, the official journal of the Royal Australia & New Zealand College of Paediatrics. I am the current clinical lead in Queensland State ROP Screening Services and the only committee member representing Australia & New Zealand in the international ROP consortium for reclassification of ROP.

I have multiple scientific publications in the area of ROP care and have given numerous invited lectures on the topic of ROP management in New Zealand, Australia and internationally.

When preparing this report, I understand that my overriding duty is to HDC. I have read HDC's Guidelines for Independent Advisors and agree to be bound by it.

In preparation of this report I have had access to the following:

1. Letter of complaint dated 7 February 2019
2. Response received from Whanganui DHB dated 30 July 2019
3. Response received from Waikato DHB dated 23 August 2019
4. Report prepared by [Dr F], Whanganui DHB, for ACC dated 26 April 2019
5. Report prepared by [Dr B], Waikato DHB, for ACC dated 19 May 2019
6. Waikato DHB's clinical records for the period 17 [Month1] until 23 [Month3]
7. Whanganui DHB's clinical records for the period 23 [Month3] until 12 [Month6] reviewing past and present ROP screening guidelines and relevant literatures.

BACKGROUND HISTORY

[Baby A] was born, as one of the twins, on 17th [Month1] with a gestational age of 24 weeks, and a birthweight of 675 grams and [Baby A] was transferred to Waikato DHB Neonatal Unit for ongoing care on the 18th [Month1] due to his extreme prematurity. While he was in Waikato DHB [Baby A] had numerous other complications including

- Chronic lung disease requiring prolonged respiratory support
- High blood glucose concentrations requiring insulin treatment
- Low blood pressure requiring dopamine treatment
- Patent ductus arteriosus requiring indomethacin treatment
- Anaemia requiring blood transfusions (10 in total)
- Urinary tract infection requiring antibiotics.

In addition to his extreme low birth weight and gestational age the above complications put [Baby A] at increased risk of developing retinopathy of prematurity (ROP). Rightfully he underwent regular ROP screening to detect sight threatening ROP with first such screening occurring on the 29th of [Month2] when [Baby A] was 30 weeks of post menstrual age (PMA) and again on the 12th of [Month3] when [Baby A] was at 32 weeks PMA. The screening ophthalmologist clearly documented then the stage of ROP as 'Zone 1–2, Stage 1, vessels dilated mildly' and made a correct recommendation to review [Baby A] in '2 weeks time' based on his examination on the 12th of [Month3]. The recommended date for repeat examination of [Baby A's] eye would have been on the 26th [Month3]; by then [Baby A] had been transferred to Whanganui DHB for ongoing care (23rd [Month3]).

[Baby A] was only referred by Paediatrician colleagues to Ophthalmology Dept. at Whanganui for ROP retinal examination when [Baby A] was at PMA 39 weeks, and he wasn't reviewed by the local ophthalmologist until 44 weeks of PMA when he was found to have 'stage 4 ROP in the right eye; stage 5 ROP with total detached retina in his left eye'. Further treatment in [a main centre] was unsuccessful due to advanced ROP which was not treatable.

Specific replies & comments to your questions are listed below:

Please review the enclosed documentation and advise whether you consider the ophthalmology care provided to [Baby A] by Waikato DHB and Whanganui DHB were reasonable in the circumstances, and why.
I found the ophthalmology care provided to [Baby A] at Waikato DHB was appropriate and in keeping with the New Zealand and international guidelines for ROP screening. The ophthalmologist conducted the ROP screening in a timely manner while [Baby A] was cared in Waikato DHB. As to the ophthalmology care at Whanganui DHB it was clearly far too late when [Baby A] was first referred to the local ophthalmologist at PMA 39 weeks. [Baby A] would have already developed advanced ROP well before then.

For Waikato DHB
1. Whether the ROP screening provided to [Baby A] by clinicians at Waikato DHB was met or departed from the expected standard of care/accepted practice, and why.
The ROP screening at Waikato DHB was in keeping with national and internal guidelines and standards. ([Baby A] was screened at 30 weeks PMA and again at 32 weeks PMA with mild ROP requiring ongoing screening which was clearly documented by the screening ophthalmologist.)

2. Whether Waikato DHB should have communicated the need for ROP screening to Whanganui DHB when [Baby A] was transferred on 23 [Month3].
Waikato DHB neonatal service should have clearly documented, and conveyed to the receiving NICU at Whanganui DHB that [Baby A] needed ongoing ROP screening given his higher risk of developing sight threatening ROP, especially when the screening ophthalmologist recommended a follow up screening at 2 week interval. This was clearly in departure from the standard of care proposed by the New Zealand National ROP screening & treatment guideline[1]. There needs to be a revision of the current standard clinical discharge letter to include ROP examination recommendations as an essential part of such document when infants are transferred to another NICU.

3. Any other matters involving the care provided to [Baby A] by Waikato DHB that you consider amount to a departure from accepted standards.
Waikato DHB should have followed the New Zealand National ROP screening and treatment guideline which was endorsed by the Newborn Network and the Fetus and Newborn Special Interest Group of the Paediatric Society of New Zealand. As a level 3 neonatal intensive care unit, Waikato DHB NICU was a member of this national group. The New Zealand ROP screening guideline document clearly specified that 'It is the responsibility of the discharging NICU neonatologist to inform the neonatologist in the receiving NICU regarding the requirement and timing of initial or follow-up ROP examination for transferred babies.' The Waikato neonatal service's practice in [Baby A's] case clearly breached this standard.

Whanganui DHB

1. Whether the ROP screening provided to [Baby A] by clinicians at Whanganui DHB met or departed from the expected standard of care/accepted practice, and why.

The ROP screening examination conducted when [Baby A] was 44 weeks PMA, at Whanganui DHB showed bilateral advanced ROP (stage 4 in the right eye and stage 5 in [Baby A's] left eye). The ophthalmologist's examination itself was obviously accurate in establishing the correct diagnosis of advanced ROP and hence prompt referral was made to colleagues in [other centres] for surgical treatment for [Baby A]. Unfortunately, it was far too late for any treatment to be effective then. The paediatrician at Whanganui DHB should have referred [Baby A] to ophthalmology for ongoing ROP screening as soon as they took over [Baby A's] care from Waikato DHB when [Baby A] was barely at 34 weeks of PMA which is considered to be the peak time for severe ROP to develop in infants at risk ([Baby A] was clearly one of these infants). The delayed referral of [Baby A] (when [Baby A] was 39 weeks PMA & ready to be discharged home from Whanganui Paediatric service) to the ophthalmologist for ROP screening demonstrated the lack of sufficient understanding among concerned paediatricians of the significant risks of ROP developing in premature infants. This delay undoubtedly led to the loss of opportunity for timely diagnosis and treatment of [Baby A's] ROP, which sadly resulted in a very poor visual outcome for [Baby A]. This practice failed to reach the minimal standard of ROP care one would expect to have in a neonatal unit which was accredited to provide neonatal care.

2. Any other matters involving the care provided to [Baby A] by Whanganui DHB that you consider amount to a departure from accepted standards.

There appears to be a system failure in Whanganui DHB as far as ROP screening is concerned. This is evidenced in the statement made by [the] CEO of Whanganui DHB, 'ROP screening was considered on admission however referral not completed until discharge on 31 [Month4]'. This 5–6-week delay in arranging for ROP screening for [Baby A] was a serious error. The lack of a system, or protocol in conducting ROP screening in a given institution usually is the cause of such failure and this clearly needs to be addressed to prevent a similar event from occurring in the future.

Commentary

Retinopathy of Prematurity (ROP) is a proliferative retinal vascular disease affecting premature infants with extreme lower birth weight (< 1500grams) and/or young gestational age (<32weeks). About one third of infants born under 32 weeks of age develop some degree of ROP. The incidence is higher (61%) in those born less than 28 weeks of gestational age, or less than 1000 grams. ROP treatment is highly successful (over 90% have a favourable outcome) if diagnosis and treatment is provided in a timely fashion.

The New Zealand ROP guidelines recommended ROP screening for all infants born less than 31 weeks, or birthweight less than 1250 grams. Most ROP develops between 32 to 34 postmenstrual ages (PMA). Onset of ROP is rare before 31 weeks of PMA and treatment requiring ROP occurs between 34–38 weeks of postmenstrual age with a

median age of 36 weeks PMA. The first ROP examination should commence in all infants with risk at 4–6 weeks postnatal age and subsequent examinations be done at least every two weeks until retinal vascularisation has progressed to Zone 3.

Infants' transfer between different hospitals is common and to ensure the ROP screening process is completed, the guidelines specified, 'It is the responsibility of the discharging NICU neonatologist to inform the neonatologist in the receiving NICU regarding the requirement and timing of initial or follow-up ROP examination for transferred babies'; 'It is the responsibility of the neonatologist to ensure that infants who are eligible for screening are scheduled on time for initial and follow-up ROP eye examinations'.

Assessment of [Baby A's] Care

[Baby A] was clearly considered to have a high risk of development of ROP given his lower birthweight (620grams) and smaller gestational age (24 weeks). This risk had been recognised by both the neonatologist and ophthalmologist involved at Waikato DHB, hence the initiation of the first ROP screening examination and subsequent reviewing examination which occurred on the 28th of [Month2] ([Baby A] was at 30 weeks PMA) and 12th of [Month3] ([Baby A] was at 32 weeks PMA). The examining ophthalmologist's recommendation for a follow-up eye examination 2 weeks later, when [Baby A] would be 34 weeks of PMA, clearly highlighted his concern of the ongoing risk of [Baby A] developing significant ROP. Obviously, [Baby A's] risk for developing ROP and requiring treatment existed well beyond 34 weeks PMA and this risk would only diminish when the retinal vascularisation reached Zone 3 which often is around 40 weeks of PMA.

In the discharge letter from Waikato DHB, there was an identifiable failure in the communications between the Waikato DHB neonatal team and those in the Whanganui DHB in that no recommendation was made to indicate the ongoing need of eye examination for [Baby A]. There was also a clear failure in recognising the ongoing risk of ROP by paediatricians at Whanganui DHB. These unfortunately resulted in [Baby A's] eye examination for significant ROP being missed and he lost the opportunity for ROP treatment that has a success rate of approximate 90%.

OPINION

It is my opinion that [Baby A] would have retained useful eyesight had his eye examination been undertaken in a timely fashion according to the recommendation from the New Zealand & international guideline for ROP screening & treatment. The failure to adhere to the national ROP screening guideline by the paediatric service in Whanganui DHB resulted in [Baby A's] visual loss which was entirely preventable.

Dr Shuan Dai MBBS, MSc, FRANZCO
Director of Ophthalmology
Associate Professor, School of Clinical Medicine, University of Queensland

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Addendum

I should have specified these points.

For Waikato DHB it is a moderate event.

For Whanganui DHB it is a severe event.

Regards

Shuan"

The following further advice was received from Dr Dai on 30 April 2020:

"I have studied all documents from Whanganui and Waikato DHBs. My views remain unchanged in this case and I hope all involved learnt the lesson and make appropriate changes in their system so future incidents can be prevented."

Appendix B: Independent advice to the Commissioner

The following expert advice was received from neonatal paediatrician Dr Simon Rowley:

"7 August 2020

…

Re: Reference 19HDC00239

My full name is Robert Simon Hearn Rowley. I am a Registered Medical Practitioner and Specialist Neonatal Paediatrician. My qualifications are MB ChB. FRACP. I am a Neonatal Paediatrician working at Children's Health, Auckland City Hospital which includes clinical management of level 3 and level 2 infants in NICU. I have also practised as a General Paediatrician in private practice here in Auckland for over 30 years. I am also the Chair of the Northern Region Paediatric Vocational Training Committee.

I have had access to the following documents:

1. Letter of complaint dated 7 February 2019
2. Response received from Whanganui DHB dated 30 July 2019
3. Response received from Waikato DHB dated 23 August 2019 and appendices
4. Report prepared by [Dr F], Whanganui DHB, for ACC dated 26 April 2019
5. Report prepared by [Dr B], Waikato DHB, for ACC dated 19 May 2019
6. Referrals and discharge letter extracted from Whanganui DHB clinical notes (full clinical records also attached)
7. Waikato DHB's clinical records for the period 17 [Month1] until 23 [Month3]
8. Whanganui DHB's clinical records for the period 23 [Month3] until 12 [Month6]
9. Waikato DHB's response dated 7 April 2020 and appendices
10. Whanganui DHB's response dated 17 March 2020

Salient points

[Baby A] is a male infant, the second of twins born on 17 [Month1] at 24 weeks gestation following spontaneous onset of preterm labour. Antenatal steroids had only been given shortly before delivery. The Wellington Hospital NICU team were onsite and available to help stabilize the babies. Unfortunately his twin died from overwhelming sepsis at a week of age. Birth weight was 675G. Apgar scores (an indication of the need for resuscitation with 10 as the score requiring no resuscitation and 0 as showing no signs of life) scores were 6 at one and 9 at 5 minutes with immediate intubation, administration of curosurf and institution of assisted ventilation. Umbilical lines were inserted prior to transfer to Waikato DHB by the Wellington Hospital NICU transport team. Once in Waikato DHB [Baby A] was started on intravenous nutrition, then oral feeds were introduced. His neonatal course until the time of transfer was complicated by chronic lung disease requiring steroids to

facilitate extubation as well as diuretics, episodes of sepsis or suspected sepsis requiring antibiotics and brief periods of re-ventilation. He also had hyperglycaemia treated with insulin, anaemia for which he received 10 blood transfusions, indomethacin treatment for a patent ductus arteriosus, and initial hypotension requiring inotropic support.

These events were much as expected for an infant born so prematurely and of such low birth weight, and serve to remind us of how vulnerable they are, and the need to follow them up once discharged. Of particular note is that the risk of developing retinopathy of prematurity (ROP) is directly related to the degree of prematurity. Other risk factors for ROP include the degree of unwellness of the baby, chronic lung disease and inadvertent over-oxygenation. At the time of discharge [Baby A] had ROP screening started but not completed (guidelines suggest start screening from 30 weeks gestation and continuing until the retinal vasculature has completed its development to the edge of the retina).

The second review a fortnight after his first eye check indicated dilated retinal vasculature and so recommendation was for ophthalmologic review in 1–2 weeks. However in the interim the baby was able to be transferred to Whanganui DHB for the remainder of his level 2 hospital stay. At this stage he was 33.4 weeks gestation.

[Baby A] spent approximately five weeks in the SCBU before being discharged home. Although the admitting doctor ([Dr E]) correctly noted the need for further ophthalmology assessment, nothing was initiated until the day of discharge when a letter of referral was sent to the local ophthalmology team by [Dr D]. The Ophthalmologist [Dr F] then rejected the referral on triage and sent it back requesting further information. The letter was misdirected leading to further delays so that [Baby A] was not seen until 44 weeks corrected age. By this time it was too late and he had suffered a retinal detachment in one eye and significant damage to the other eye which required emergency corrective surgery.

Nowhere in the transfer letter from Waikato DHB to Whanganui DHB, or in the problem list handover to the receiving Whanganui DHB team was ROP screening mentioned — either the slightly concerning finding of retinal vessel dilatation or the need for continuing surveillance. There is a discharge sheet from Waikato DHB which has a space ‘Check Eye Book — follow-up still required? Yes/No’ but this was not filled in. This preparation for discharge four page check list is like a number of such tick box check lists and is easy to overlook a component e.g. the eye check. The neonatal problem sheet also has spaces on the second page labeled ‘Eyes’ for comment but this was also not filled in despite other health issues such as renal scan being mentioned.

Although the admitting doctor in Whanganui noted the need for ROP screening nothing was initiated during the Whanganui stay and he was referred as an outpatient on discharge home two weeks later. It is not clear why this did not take place following admission but by the time of discharge five weeks later the baby was

definitely referred. This failure to acknowledge prior demonstration of ROP and need for follow-up is also an oversight. Every paediatrician working in a level 2 neonatal unit should be aware of the fact that extreme prematurity is a high risk factor for a number of developmental problems — cerebral palsy, cognitive delays, hydrocephalus, behavioral and attentional problems, hearing problems and visual problems secondary to retinopathy. This is an important part of their practice and one would expect them to have a checklist for monitoring these important sensory outcomes. This is usually generated automatically in the discharge process.

This referral was rejected on triage due to inadequate information. I don't accept that a blanket rejection asking for more information was acceptable at triage. The triaging Ophthalmologist would have been aware of the high risk nature of the baby's extremely premature gestation and have been aware that retinopathy may still have occurred in the interim. In fact in his statement [Dr F] outlines very clearly the high risk nature of VLBW and extreme gestation with respect to retinopathy, but ignores his own advice. His very informative letter outlines all the reasons why ROP should be taken seriously until its conclusion. Those of us working for many years in the health system are very familiar with the slowness of mail referrals and usually insist on phone consultation if we wish to avoid delays in a patient being seen. The next referral letter was sent to the GP meaning further delay in it arriving at the correct place.

A single phone call asking for more information may well have avoided all the subsequent delay with letters needing re-routing and the loss of a month between triaging and the baby being seen. I therefore feel that some of the responsibility for the delay in [Baby A] being seen must be shared by the Ophthalmology Service.

By the time the screening was done the baby was 44 weeks corrected age and there was an irreversible retinal detachment in one eye and retinal changes in the other eye needing urgent surgery to preserve some vision in that eye.

Discussion

Therefore there are three time points at which this baby fell through the cracks in terms of avoiding this complication. Although there is individual responsibility for the attending doctors to ensure that the eye checks are carried out it is also understandable that they made an assumption that the next person in attendance would also ensure the same. In this assumption is the knowledge that a practising level 2 neonatal paediatrician has the training and knowledge of the importance at risk and prevention of ROP.

These are essentially systems issues which need to be and have now been addressed.

Firstly it is generally accepted that the eye examinations done on NICU for infants less than 30 weeks gestation at birth and starting at six weeks of age are a procedure that needs documenting both in the notes and in the problem list — the same way as an

ultrasound examination for intra-ventricular hemorrhage might be, or a special XR. It should therefore immediately be transferred on the problem list to any letters generated for transfer or discharge. One might also have expected this to have occurred in the verbal handover. I see this as being a departure from accepted standards although I acknowledge [Dr B's] comment that he would have expected the receiving hospital to have followed this up as a part of routine care of the VLBW infant. Most level 3 NICUs would have had ophthalmology review for ROP as a routine on their problem sheet. At the verbal handover this should also have been mentioned. [Dr B] acknowledges in his report that this was an omission. Following a Unit Level Incident Review at Waikato DHB where the conclusions were that 'a simple omission with serious consequences had occurred' due to the ROP details not being included in the discharge letter, the discharge checklist now includes ROP details — checklist amended by … 09 [Month6] — *NICU Discharge Letter Guideline (CWS) 'Infants less than 1500gms or less than 30 weeks gestation (additional essential information); ROP Check — results, dates, and follow-up recommendation.'*

In addition while Whanganui DHB is capable of looking after VLBW infants for transfer back following intensive care, they only deal with limited numbers of these infants annually and might need reminding about what would be routine policy for a level 3 NICU but would be rarely encountered in their own practice.

On the other hand ROP is something that all level 2 consultant paediatricians are familiar with, and a certain expectation exists that they will pick up the screening on transferred babies. This referral should have happened in the first few days in Whanganui DHB rather than waiting until discharge five weeks later. [Dr B] refers to the fact that they seldom transfer babies to Whanganui DHB which is usually Wellington's referral area, but that he did satisfy himself in conversation with [Dr …] that they had level 2 capability and therefore knowledge about retinopathy of prematurity.

Similarly the triaging person in Whanganui DHB for ophthalmology appointments should know that ROP can be progressive and that early and ongoing assessments are important regardless of findings. If one is rejecting an inadequate referral letter to make a point about concise documentation in order to improve quality of communication, one should also consider the patient who is in the middle of such an interaction and put his/her needs first. The referral letter had enough information — gestation, current postmenstrual age and the fact that ROP screening was incomplete — in it to warrant immediate assessment.

The issue of referring the rejected referral back to the GP instead of the hospital doctor with a further delay (over one month) in the baby being seen is another avoidable situation which is being addressed I understand.

Summary and response to particular questions

The care of an extremely preterm infant involves a journey starting before birth, and includes consultation by the neonatologist with obstetricians and parents, passage through the NICU which is often fraught with crises, transfer to a hospital closer to home (usually a SCBU), discharge to the community with their homecare services, and long term follow up to monitor and audit outcome through to school age at least. Depending upon circumstances some of these steps may be curtailed, but the principle is the same. If discharge planning, including systematic follow-up, is not complete, then a lot of the hard work done by everyone along the way in order to achieve the end result — a child reaching his full potential — risks being in vain. Good communication particularly at the interface between these steps is the key to a successful outcome. In [Baby A's] case it seems that communication was based on assumptions by everyone that someone else would complete the tasks required. In the end his retinopathy screening fell through the gaps created by these assumptions. I therefore feel that no one person or DHB is entirely to blame for this sad outcome for [Baby A].

For Waikato DHB

The accepted practice for a handover for when ROP screening is required would be to both have it on a problem list and mention in the letter that it is still required.

The fact that no information was provided to the receiving hospital by [Dr B] and staff at Waikato DHB and that there was no reference to ROP screening in the letter or verbally, indicates inadequate handover. The lack of an adequate discharge letter guideline or template is noted. This issue has been addressed as mentioned in my discussion above. Although understandable assumptions were made about the expertise of the receiving hospital — Whanganui DHB, in my opinion this is an unacceptable standard of practice of moderate degree.

For Whanganui DHB

[Dr E] and staff at Whanganui DHB were also remiss in not following through with the initial observation that further ROP screening was needed until the point of discharge five weeks later. This is a departure from standard practice of moderate degree. The referral letter to the ophthalmologist was brief but given that they had not received important information from the Waikato DHB team about previous screening results it contained enough information to indicate a degree of risk. I believe in this situation the triage team were deficient in sending back the referral knowing that this would lead to further delays in [Baby A] being seen. They have already eloquently described just why the ROP examination is so important.

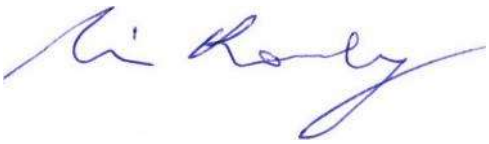
Summary

My opinion is that this omission of ROP screening completion is a major departure from recommended best practice. All the departments involved in [Baby A's] care

carry some responsibility. [Baby A] was unfortunately the victim of a number of systems and communication errors all of which contributed to his poor outcome. At each point in his management and transfer there were opportunities to recognize and correct omissions in ROP screening practice. Each team looking after [Baby A] made assumptions that the next person would have completed the processes. These assumptions were incorrect so that by the time [Baby A] was finally assessed at 44 weeks corrected gestation it was too late and he has been left with seriously impaired vision. All hospitals and departments mentioned have acknowledged their deficiencies, but unfortunately this is a small comfort for [Baby A] and his family.

I am aware that Waikato DHB have amended their discharge documentation recommendations to include ROP in the discharge material, that Whanganui DHB have also built in steps to ensure that ROP screening is completed, and that the Ophthalmology department in Whanganui DHB is instituting safety checks to ensure that ROP screening is given more weight in triaging so that this unfortunate outcome for [Baby A] does not happen again.

Yours sincerely,



Simon Rowley **MBChB,** FRACP
Consultant Paediatrician, Newborn Services
Chair, Paediatric Vocational Training Committee
Auckland and Northern Region"

The following further advice was received from Dr Rowley:

"21 August 2020

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Re: Reference 19HDC00239

You have received my report dated 7 August 2020 however you would like further expert advice following provision of further information including:

- Whether you consider that [Dr B] departed from the accepted standard of care in respect of the handover of information about ROP, and if so to what extent (mild, moderate or severe).
- Whether you consider that [Dr E] departed from the accepted standard of care in respect of ROP screening, and if so to what extent (mild, moderate or severe).

The following is my opinion regarding [Dr B] and [Dr E] individually.

[Dr B] works in a large level 3 NICU where responsibility for a number of daily activities is delegated to junior staff. This would include handover of patients and the discharge documentation on patients being transferred to other hospitals.

I have already alluded to the systems issues relating to having retinopathy of prematurity (ROP) and the fact that there was an inadequate system for reminding people reading [Baby A's] file that ROP screening needed to continue.

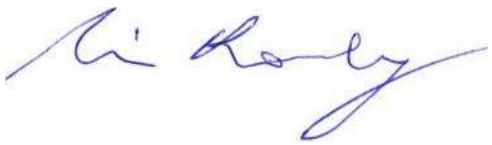
[Dr B] made an assumption about [Dr E] and his team receiving the information about [Baby A] specifically that he had been born at 24 weeks gestation — the assumption being that as a qualified paediatrician in a level 2 nursery [Dr E] would be able to complete the screening and follow-up according to international standards. This assumption was incorrect and I think to a certain extent mitigates the omission of the written and verbal handover about ROP status by junior staff. I regard this omission of care as being of mild degree.

[Dr E] correctly identified the need to follow-up on ROP screening on admission but failed then to follow through on this. The organisation of the Whanganui Paediatric rotations may have meant that he had no further involvement in [Baby A's] care — in which case a similar handover should have occurred to the other Whanganui paediatricians. Either way communication of the fact that [Baby A] needed ROP follow-up was inadequate. I regard this as a moderate omission of care.

The serious consequences of these omissions of care on the patient [Baby A] with the resultant poor visual outcome makes the combination of these errors much more severe but as I have pointed out the responsibility should be shared equally.

I hope this helps clarify my opinion.

Yours sincerely,



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