Counties Manukau District Health Board

A Report by the

Health and Disability Commissioner

(Case 16HDC01912)

Health and Disability Commissioner

Te Toihau Hauora, Hauātanga

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Executive summary

1. Miss A has had issues with her eyesight from early childhood. She was seen by the CMDHB ophthalmology service in December 2006 (at the age of five years) after a pre-school eye test. Glasses were ordered and she was advised to wear them at all times.

2. On 6 June 2012, Miss A was seen by her community optometrist, Ms C. On 12 June 2012, Miss A was formally referred by Ms C to the CMDHB ophthalmology service to assess the unexplained reduction in visual acuity of both eyes.

3. On 21 November 2012, Miss A was seen by consultant ophthalmologist, Dr D, in the CMDHB ophthalmology clinic for a first specialist appointment (FSA). CMDHB told HDC that Miss A was diagnosed with possible early Frust form keratoconus (progressive thinning of the cornea, which most commonly affects teenagers) as there was no obvious clinical evidence of keratoconus.[1] It was requested in Dr D's clinic letter that Miss A be seen again at the clinic in one year (approximately November 2013), or sooner if there were any problems.

4. The clinic letter was sent to the family general practitioner (GP), Dr E, but not copied to the referring optometrist, Ms C. The letter was also not copied to Miss A's family.

5. A follow-up ophthalmology clinic appointment for Miss A did not go ahead in November 2013. CMDHB told HDC that the delay in receiving the 12 month follow-up appointment was due to huge demand for the cornea service and a limited anterior segment and contact lens service at CMDHB.

6. CMDHB told HDC that during the period related to this case, the ophthalmology service used an electronic follow-up reporting system to capture overdue appointments. CMDHB said that most other clinics within the DHB were able to complete an electronic chart review to assess the urgency of booking follow-up appointments. CMDHB stated in ophthalmology, there were so many overdue follow-up appointments that all had the same clinical priority and it became extremely difficult to manage.

7. CMDHB also told HDC that there was no specific clinical acuity tool used at the time of Miss A's care to assist prioritisation.

8. On 3 November 2014 (a year after the cancelled November 2013 follow-up appointment), a letter was sent to Miss A's family outlining that an appointment has been made to see the ophthalmology team on 8 December 2014.

9. Miss A's family advised HDC that they did not receive this letter. Subsequently, Miss A did not attend the 8 December 2014 appointment. A standard DHB letter to the family was generated on 8 December 2014, outlining that the appointment had been missed and that "the specialist has reviewed your notes and would like you to make another appointment". The letter stated that if the DHB had not heard anything within 14 days, Miss A's care

[1] A conic protrusion of the cornea (front surface) of the eye, caused by thinning of the corneal stroma; usually it is bilateral, and can result in an irregular cornea, causing distorted vision.

might be discharged back to the family doctor. Miss A's family told HDC that they did not receive this letter and she was subsequently discharged from the ophthalmology service.

10. On 25 March 2015, an education service for children and young people who are blind, deafblind or have low vision (education service) sent a referral to CMDHB. On 14 August 2015, CMDHB issued a letter to Miss A's parents indicating that an appointment with the ophthalmology service has been made for 24 August 2015.

11. On 24 August 2015 (two years and nine months after the her first specialist appointment), Miss A attended the ophthalmology clinic with her grandmother and was reviewed by Dr D. Dr D's resulting clinic letter back to the education service concluded that "[Miss A] had bilateral keratoconus. The right eye is very severe and it is beyond treatment for crosslinking[2]".

Findings

12. CMDHB failed to arrange a timely follow-up appointment for Miss A in line with appropriate clinical time frames. CMDHB did not have an adequate prioritisation system for overdue follow-up specialist appointments. There were missed opportunities to identify and remedy the ongoing delay in Miss A being seen for specialist follow-up. CMDHB did not take sufficient account of potential clinical risks associated with heavy demand and a lack of capacity at the ophthalmology service, and did not take sufficient or adequate action to rectify the situation despite awareness of the issue. CMDHB did not provide services to Miss A with reasonable care and skill and, accordingly, breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights.[3]

Recommendations

13. It is recommended that CMDHB provide HDC with:

a) An independent evaluation of the systems in place to identify and prioritise overdue ophthalmology patients.

b) An update on progress of the work done alongside the Ministry to track and monitor progress toward zero ophthalmology patients waiting beyond clinically appropriate time frames.

c) A report on the investigation into the iPM system shortcomings identified by this matter.

14. It is recommended that CMDHB also provide a detailed update report on the steps taken that relate to the expert advisor's recommendations, those arising out of its own reviews, and its work alongside the Ministry of Health.

15. CMDHB has provided a formal written apology for forwarding to Miss A's family.

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[2] Also referred to as corneal collagen crosslinking — a procedure where the epithelium is removed from the surface of the cornea. Riboflavin drops are applied to the eye and the cornea is also exposed to UVA light.
[3] Right 4(1) states: "Every consumer has the right to have services provided with reasonable care and skill".

Complaint and investigation

16. The Commissioner received a complaint from Mr B about the care and services provided to his daughter, Miss A, by Counties Manukau District Health Board (CMDHB).

17. The following issue was identified for investigation:

Whether Counties Manukau District Health Board provided an appropriate standard of care to Miss A.

18. An investigation was commenced on 13 June 2017.[4] The parties directly referred to in this investigation report are:

Miss A	Consumer
Mr B	Complainant, consumer's father
Counties Manukau District Health Board	Provider

19. Information was also reviewed from:

Ms C	Community optometrist
Dr D	Consultant ophthalmologist, CMDHB
Dr E	General practitioner (GP)
Ministry of Health	

20. Independent expert advice was obtained from an ophthalmologist, Professor Charles McGhee (**Appendix A**).

Information gathered during investigation

Background

21. Miss A has had issues with her eyesight from early childhood. She was seen by the CMDHB ophthalmology service in December 2006 (at the age of five years) after a pre-school eye test. Glasses were ordered and she was advised to wear them at all times. In May 2007, Miss A's visual acuity was recorded as 6/9 in both eyes.[5]

Referral, 12 June 2012

22. On 6 June 2012, Miss A was seen by her community optometrist, Ms C. Miss A's visual acuity had dropped from a prior reading of 6/7.5 to 6/24 in the right eye, and from 6/7.5 to 6/18 in the left eye.

[4] The Ministry of Health was concurrently alerted to this case.

[5] Visual acuity reflects a comparison against normal vision. The first number is the distance in metres from the chart, to where the patient stands (6m), the second number is how well the patient can read when standing at 6m, compared with a normal person. Thus 6/9 means that a patient standing 6m away from the chart can read only as well as a normal person standing 9m away. Normal vision is 6/6 (previously, in feet, 20/20).The World Health Organization regards vision of 3/60 or worse (both eyes) as being "blindness".

23. On 12 June 2012, Miss A was formally referred by Ms C to the CMDHB ophthalmology service to assess the unexplained reduction in visual acuity of both eyes.

24. The process for managing referral documents requiring a first specialist assessment (FSA) is guided by the document *Referral and Appointment Centre Desk File, Referral Management and FSA scheduling process*.[6] On 20 June 2012, the referral was graded at CMDHB as a priority 3. The grading form stated that this meant that Miss A would be seen within three months; however, it was amended by hand to indicate that Miss A should be seen within two months.

25. On 13 July 2012, a pro forma letter was sent out by CMDHB, addressed to Miss A's parent/guardian, advising that she had been referred to the ophthalmology service with a priority grading of 3. The letter stated that the approximate wait time for an appointment was 16 weeks. The letter also stated: "Counties Manukau Health is required to see all patients referred for an appointment within five months of receiving their referral."

26. On 29 October 2012, a further standard CMDHB letter was sent to Miss A's parents requesting that they contact the DHB to arrange a suitable appointment time. On 1 November 2012, the DHB issued a letter confirming a scheduled appointment date of 21 November 2012.

Clinic appointment, 21 November 2012

27. On 21 November 2012, Miss A was seen in the CMDHB ophthalmology clinic for the FSA. CMDHB told HDC that Miss A was diagnosed with possible early Frust form keratoconus (progressive thinning of the cornea, which most commonly affects teenagers) as there was no obvious clinical evidence of keratoconus.

28. The resulting clinic letter, written up on 26 November 2012 by the reviewing consultant ophthalmologist, Dr D, described Miss A having visual acuity of 6/7.5 in the right eye and 6/9.5 in the left eye. The clinic letter also stated:

> "[C]lear corneas. No clinical sign of keratoconus. However, on refraction, retinoscopy shows light appearance and topography confirmed the presence of slightly irregular astigmatism."

29. Miss A was given eye drops, advised not to rub her eyes, and advised to go back to her optician for refraction checking.[7]

Follow-up date

30. It was requested in Dr D's clinic letter that Miss A be seen again at the clinic in one year's time (meaning in approximately November 2013), or sooner if there were any problems.

Clinical guidelines

31. In relation to clinical guidelines adopted or referred to in determining clinically appropriate timeframes for follow-up review appointments in this case, CMDHB told HDC:

[6] Version 1.0. Issued October 2007.
[7] The act of determining the nature and degree of the refractive errors in the eye and correction by lenses.

> "The ophthalmologist has advised that there are no national or international guidelines for screening children with keratoconus. As [Miss A's] diagnosis was unclear in 2012, a one year follow-up was requested for ongoing monitoring and if any progression was noted, the follow-up appointments would be more frequent. Management of Keratoconus requires a joint care approach between the optometrist, ophthalmologist and the child's parents who can monitor the child and advise if they rub their eyes or detect their child's sight is deteriorating. The child therefore still attends their own optometrist appointments as well as ophthalmologist appointments."

Copies of clinic letter

32. The 21 November 2012 clinic letter was sent to the family GP, Dr E, but not copied to the referring optometrist, Ms C. The letter was also not copied to Miss A's family.

33. CMDHB stated:

> "The Patient Administration System, iPM, allows only the primary referrer, to be recorded. However if the primary referrer is not the patient's General Practitioner (GP), they will not receive electronic notifications about the referral status as these can only be sent to GPs at this point in time. A clinician who sees a patient in clinic should dictate a clinic letter to the optometrist referrer as well as the GP if they are different. For the 21 November 2012, the clinic letter was sent to the GP only and we acknowledge this oversight."

34. In relation to his awareness of the referral, Dr E told HDC:

> "In view of [Miss A] being referred to [Dr D] by the optician, we were confident that, in response to her referral, [Dr D] had sent the same letter to the optician and that either the optician, who has been following [Miss A] regularly, or the DHB would arrange the requested appointment for [Miss A]. It is a regular practice that the DHB books patients for follow-up and then recalls patients for review if that is requested by their doctors. Although this is not documented, in order to be sure, I remember advising her family to contact the DHB when the time comes and make sure that [Miss A] is seen by an ophthalmologist. I was aware this was a proactive and organised family that were watching [Miss A's] eyesight closely."

November 2013 follow-up

35. A follow-up ophthalmology clinic appointment for Miss A did not go ahead in November 2013. Mr B told HDC that he recalls telephoning the clinic when Miss A had not been recalled within the year. Mr B said that he was told "something along the lines of 'we are short staffed and cannot always make appointments as requested by the team'", which Mr B said he found unusual.

36. Dr E told HDC:

> "[Miss A's] family kept us informed during other consultations and when the follow-up did not happen, I was told they tried to arrange it themselves via the outpatient call centre. I recall contacting the Eye department myself asking if [Miss A] had been lost

> to follow-up. I did not know if [Miss A's] issue was still astigmatism but pointed out the planned follow-up had not occurred …"

37. Dr E also said that on checking the regional website (where family doctors can view their DHB patients' results) he could see that after the 22 November 2012 appointment, a follow-up appointment was planned in the DHB system. He could also see that on 22 November 2013, the time when the appointment should have occurred, there was a logged patient encounter but no notes or details.

38. CMDHB stated:

> "A one year follow up appointment was planned for 22 November 2013. At the time, [CMDHB] had only one Paediatric Orthoptist who had a large and increasing workload. (Orthoptists[8] are a scarce workforce and the DHB was carrying one vacancy which was taking considerable time to recruit to). We do know that the planned appointment on 22 November 2013 was cancelled but there is no reason entered on the system to indicate why. Reviewing the clinic availability in the booking system in November/December 2013 indicates that there were four half day sessions held for that period instead of eight half day sessions, due to the orthoptist vacancy."

Capacity issues

39. CMDHB told HDC that the delay in receiving the 12-month follow-up appointment was due to huge demand for the cornea service and a limited anterior segment (front of the eye) and contact lens service at CMDHB. The increasing demand on the follow-up cornea service also impacted on the number of patients requiring contact lenses.

40. In relation to specific capacity issues at CMDHB influencing delays in patients receiving their follow-up appointments around this time, CMDHB told HDC:

- The incidence of chronic disease associated with the ageing population has placed, and continues to place, significant demands on ophthalmology resources, with referrals to the service increasing year on year.
- In 2009, the service moved into a new purpose-built facility, which soon reached maximum capacity.
- In 2013, planning commenced to expand the facility further with a number of options being considered. The shortage of ophthalmologists became an important concurrent factor impacting upon the ability to expand services, and required a concentrated recruitment drive to run alongside the facility expansion planning.
- In the interim period, the ophthalmology department increased extra clinic capacity by adding weekend and evening clinics and an extra locum workforce to try to manage the challenges.

[8] Orthoptists are allied health professionals involved in the diagnosis and treatment of sight-related problems, such as those connected with abnormalities of eye movement and eye position.

Overdue specialist follow-up appointments

41. CMDHB told HDC that during the period related to this case, the ophthalmology service used an electronic follow-up reporting system[9] to capture overdue appointments. These appointments were flagged and reflected in an expired/overdue follow-up report — titled "Planned Appointments Process Report/Expired Planned Appointments" (PAPR).

42. The planned appointment process allocated a time frame for the next appointment (in this case a 12-month follow-up for Miss A) and had a priority assigned to each appointment. The priority indicated how long over the planned time frame the appointment could be booked. Miss A's priority was listed as "4" (weeks). A four-week priority meant that the appointment could be booked up to a month either side of the planned appointment time. Miss A's 22 November 2012 follow-up appointment expiry date is listed on the PAPR as 3 January 2014.

43. The process for managing outpatient follow-up waiting listings is provided for by CMDHB's "iPM Management — Managing Outpatient Planned Follow Up Waiting Lists (via Day Clinic View)" document. CMDHB told HDC that all patients who required a follow-up appointment had a comment added on file to inform staff booking the next follow-up appointment, to indicate the type of clinic or appointment required. However, CMDHB stated: "[A]s the numbers of follow-up appointments increased rapidly, [this] system no longer worked efficiently." CMDHB said that due to huge volumes of overdue follow-up appointments in the ophthalmology service (in the diabetes, glaucoma, cornea, and Avastin injection[10] clinics), the longest overdue follow-up appointments were booked as a priority.

44. The process for any patients who contacted the ophthalmology service directly asking for a more urgent appointment was that they were contacted by the ophthalmology nurse specialist and assessed over the telephone.[11] A more urgent appointment may or may not have been booked according to the outcome of that assessment. All clinics were fully booked as a result of the increasing numbers of urgent cases that needed to be seen.

45. CMDHB said that most other clinics within the DHB were able to complete a virtual (electronic) chart review to assess the urgency of booking follow-up appointments. CMDHB stated: "[H]owever in ophthalmology, there were so many overdue follow-up appointments that all had the same clinical priority, [and] it became extremely difficult to manage."

Acuity tool not in use

46. CMDHB told HDC that there was no specific clinical acuity tool used at the time of Miss A's care to assist prioritisation. It stated:

[9] Report OP10010D.
[10] Treatment that successfully reverses vision loss and prevents blindness in patients with age-related macular degeneration, a condition that previously had been untreatable.
[11] This process is outlined in a CMDHB flow chart, "Ophthalmology Overdue Planned Appointment", which governs the advice to give to patients who telephone regarding an overdue planned appointment.

> "The service prioritised overdue patients according to the length of time the patient had been waiting i.e. how overdue their appointment was and on their clinical priority as specified at the time of booking …"

47. CMDHB told HDC that the service managed the overdue appointments by identifying those patients who had waited the longest and were expected to be more at risk — these patients were seen at the extra clinics and as soon as practicable. Patients, or their health providers, who advised the service that they were concerned were reassessed, escalated, and given appointments sooner than they would have been if they had remained on the overdue list.

48. CMDHB told HDC that around this time the increase in the number of patients needing appointments in the ophthalmology service rose dramatically, and that use of an acuity tool "would not have assisted managing the overdue patients as [CMDHB] did not have enough physical facilities, technical equipment or staff resources to cope with the increase".

Support for appointment coordinator and ophthalmology registered nurse

49. In relation to support for its booking staff and nurses, CMDHB stated:

> "The appointment coordinators and the registered nurses received clinical oversight by consultants in the ophthalmology service. Any query or concern could be referred to the charge nurse manager and/or the consultants, who would review and provide advice to the appointment coordinators and registered nurses about whether a patient should be reprioritised."

50. CMDHB stated that clerical booking practices were overseen to ensure that patients with the highest priority were being booked first. Extra weekend and evening clinics were booked under supervision of the Charge Nurse and former Service Manager. The Service Manager met monthly with the ophthalmology team to monitor the situation and discuss further opportunities to manage the overdue follow-ups.

2014 appointment

51. CMDHB told HDC that on 3 November 2014 (a year after the cancelled November 2013 follow-up appointment) a letter was sent to Miss A's family outlining that an appointment had been made to see the ophthalmology team on 8 December 2014.

52. Miss A's family advised HDC that they did not receive this letter despite their address not having changed since the early 1990s. Miss A's family also told HDC that they received no telephone call or text alert regarding appointment confirmation. Subsequently, Miss A did not attend the 8 December 2014 appointment. Miss A's clinical notes at 4pm on 8 December 2014 state: "DNA [did not attend]: Phone no answer."

53. A standard DHB letter to the family was generated on 8 December 2014, outlining that the appointment had been missed and stating: "[T]he specialist has reviewed your notes and would like you to make another appointment." The letter also stated that if the DHB had not heard anything within 14 days, Miss A's care might be discharged back to the family doctor. At the time, a copy of such a letter was not routinely sent to GPs to alert them to this. Miss A's family told HDC that they did not receive the 8 December 2014 letter. Subsequently, Miss A was discharged from the ophthalmology service.

54. At this time, Miss A's follow-up appointment was 12 months overdue. CMDHB stated:

> "The level of clinical risk was considered low. Keratoconus is a progressive disease with speed of progression variable from case to case. The condition is primarily managed by community based optometrists who are qualified to refer back to secondary care if there is progression. At the time, a one year follow-up appointment was indicated with instructions given that if there were concerns to return to the community optometrist."

2015 referral

55. On 25 March 2015, the education service sent two forms to CMDHB. The first form requested information from CMDHB about Miss A in order "to determine eligibility for [their] services". It included an annotation stating "URGENT PLEASE!". The second was a referral form. The reason for the referral was documented as "vision concerns" and "ensure her educational opportunities are optimised".

56. CMDHB received this referral on 26 March 2015. A DHB "referral management" stamp dated 30 March 2015 noted that it was a second referral and a planned appointment date of 8 June 2015 was made. CMDHB told HDC that the forms were then sent for grading, and a comment was written in the grading section on 31 March 2015 stating: "[N]ot a referral, [a] request for information, info sent."

57. CMDHB stated that although an appointment was originally planned for 8 June 2015, this was later changed to 24 August 2015. CMDHB explained that the referral had not been written clearly, and therefore was not graded correctly. As a result, Miss A was not seen more urgently.

58. On 14 August 2015, CMDHB issued a letter to Miss A's parents indicating that an appointment with the ophthalmology service had been made for 24 August 2015.

2015 appointment — severe keratoconus

59. On 24 August 2015 (two years and nine months after her previous specialist review) Miss A attended the ophthalmology clinic with her grandmother, and was reviewed by Dr D.

60. Miss A's visual acuity was recorded as 6/60 in the right eye and 6/30 in the left eye. On examination, the anterior segment of the eyeball showed bilateral papillary conjunctivitis[12] with bilateral advanced keratoconus, particularly in the right eye. A Pentacam test[13] confirmed the diagnosis.

61. Dr D's resulting clinic letter back to the education service (copied to GP Dr E and to the patient, but not to the community optometrist) concluded: "[Miss A] has bilateral keratoconus. The right eye is very severe and it is beyond treatment for crosslinking.[14]"

[12] A type of allergic conjunctivitis. A foreign body causes prolonged mechanical irritation, which results in a reaction in the eye.
[13] A type of comprehensive eye scanner.
[14] Also referred to as corneal collagen crosslinking — a procedure where the epithelium is removed from the surface of the cornea. Riboflavin drops are applied to the eye and the cornea is also exposed to UVA light.

62. The treatment plan was for Miss A to have left corneal cross-linking surgery, to use Patanol[15] drops twice a day in both eyes, and for there to be a discussion about the use of contact lenses to improve her vision. Dr D booked Miss A into the contact lens clinic.

Ensuing correspondence

63. On 24 August 2015, CMDHB wrote to Miss A's family advising that an appointment had been made for 30 September 2015 regarding contact lenses.

64. On 2 September 2015, the DHB wrote to Miss A's family and to Dr E advising that as a result of specialist assessment, Miss A required surgery. The letter stated: "[T]he time frame for treatment will be dependent on the clinical priority but will not be longer than [four] months."

Surgery priority

65. On 3 September 2015, Dr E received the following electronic RSD[16] message from the DHB:

> "Electronic RSD 3/09/2015
> Usual Practitioner: [Dr E]
> [Miss A]
> Address Not Supplied
> DATE REFERRAL RECEIVED: 26-Mar-2015
> SPECIALTY REFERRED TO: Ophthalmology
> WAITING LIST PRIORITY: P1 — Urgent
> EXPECTED WAITING TIME: Is Unknown
> Organisation: [CMDHB]
> Referral Modification
> Referral on waiting list"

66. CMDHB stated that Dr E was erroneously notified that Miss A's "waiting list priority" was "P1 — Urgent". This was not the correct priority classification, and was a default setting within the iPM system. CMDHB said that the correct priority classification was the Clinical Priority Assessment Criteria (CPAC). Miss A received a CPAC score of 90, for surgery to be undertaken within four months.

67. On 30 September 2015, Miss A was seen at the contact lens clinic. On 9 October 2015, CMDHB wrote to the family advising that Miss A's surgery had been booked for the morning of 20 October 2015, and provided a fact sheet about what she needed to bring on the day.

20 October 2015 — day surgery

68. On 20 October 2015, Miss A underwent left eye corneal collagen cross-linking[17] day surgery. She was discharged home with drops and painkillers the same day. The discharge summary was sent to Dr E. Miss A was seen again for ophthalmology service follow-up

[15] Patanol eye drops are used to treat seasonal, allergic conjunctivitis — inflammation of the eye due to pollens that cause an allergic response, resulting in watery, itchy and/or red eyes.
[16] Referral, Status and Discharge electronic messaging (such as that used via MedTech).
[17] Treatment used to strengthen the cornea in people with keratoconus.

clinics on 21 October, 23 October, 12 November, 18 November, 2 December, and 16 December 2015 (for a left eye contact lens fitting, which corrected her vision to 6/7.5).

2016 review

69. On 21 November 2016, Miss A was reviewed at the ophthalmology service by a locum consultant ophthalmologist.

70. Miss A reported being happy with the vision provided by her left eye contact lens. Visual acuity was recorded as 1/60 uncorrected in the right eye and 6/9 in the left eye with the lens. A further Pentacam test revealed marked progression in the right eye, but the right cornea was too thin for safe collagen cross-linking. Miss A was prescribed further Patanol ophthalmic eye drops. A follow-up appointment was requested for 12 months' time. The resulting clinic letter was addressed to GP Dr E and copied to Miss A's family.

Serious Sentinel Event (SSE) Case Review Report

71. CMDHB told HDC that there was no internal review or investigation undertaken in relation to Miss A's case. The DHB said that it became aware of the concerns only on receipt of the complaint forwarded by HDC.

72. CMDHB said that it had become aware of similar issues in the ophthalmology service prior to this case, and had already conducted an internal investigation (Serious and Sentinel Event (SSE) review) of its services regarding the delay in an appointment of another patient.

73. CMDHB said that "as the concern about [Miss A's] care related to the same issue, her case was integrated into the SSE report …".[18] The SSE event was notified to the Ministry of Health as an ACC Treatment Injury Event Notification.

Further information — CMDHB

74. CMDHB acknowledged that any loss of vision in a child is devastating for the child and for everyone involved in the child's care. CMDHB stated that it has tried hard to meet the demands of the service, which sees 50,000 patients in a year.

DHB risk register

75. Included in its responses to HDC, CMDHB stated that "Ophthalmology services have been in crisis at Counties Manukau (and nationally across all DHBs) since 2009". Issues and concerns within the CMDHB ophthalmology service have been recorded on the DHB Risk Register from November 2009 onward.

76. CMDHB provided HDC with a copy of the register as it related to the ophthalmology service, and, in particular, "Risk Register File #160 — Inability to meet Ophthalmology Clinic demand". In summary, the register lists approximately monthly entries, from November 2009 onward, outlining various concerns about the service's ability to meet clinic demand owing to the volume of patients exceeding capacity. The register also outlines the steps taken to attempt to address staff recruitment issues, and has embedded in

[18] The report concerned a patient whose initial referral to the Eye Service for an FSA was graded as P2 — to be seen within four weeks — but patients were routinely not being seen for three months. The patient endured permanent deterioration in eyesight. That report does not feature any specific details concerning Miss A's case.

it three specific progress reports (requested by the Board) to the Advisory Committee dated March 2011, January 2013, and March 2014.

Progress reports

March 2011

77. The March 2011 progress report stated that the volume of patients referred to the ophthalmology service was the highest for any service within CMDHB outpatient services — 15,869 for 2009/10 and 11,053 for 2010/11 (at the relevant year to date), which was 15.3% of all referrals logged. Other key issues reported were:

- An increase in several ophthalmology conditions with ageing, such as glaucoma.
- The high incidence of diabetes having a direct impact on the volume of patients being managed by the ophthalmology service.
- Many patients had chronic conditions and once seen were to be monitored for life.
- New screening programmes for newborns, and the "B4 school check" (the universal programme offered to all families with children turning 4 years of age) had increased the number of referrals for paediatric ophthalmology.
- A steady increase in referral volumes year on year.
- Over 1,600 patients were overdue their follow-up appointment time frames.

78. In March 2012, there were 2,347 overdue follow-up appointments reported. By December 2012 the volume of overdue follow-ups had increased to 3,205.

January 2013

79. The January 2013 progress report outlined that the volume of patients referred to the ophthalmology service was 15,869 for 2009/10, 17,804 for 2010/11, and 19,036 for 2011/12, which was 18% of all referrals logged. Other updated key issues included:

- The high incidence of diabetes, with approximately 40,000 diabetics in the CMDHB catchment.
- Many patients having chronic conditions.
- Avastin had become standard treatment. The procedure used to be managed with monthly injections through theatre, but then became an outpatient procedure.
- A further steady increase in referral volumes.
- The emphasis on seeing First Specialist Assessments within six months had been extremely difficult for the ophthalmology service. There has been a need for additional clinics and outsourcing of FSAs to the private sector. To achieve the five-month target required greater outsourcing as the growth in follow-up demand continued to grow and needed to be managed to avoid clinical adverse incidents.
- Over 3,800 patients were overdue their follow-up appointment time frames.

80. The report also outlined the efforts made to address these issues in the areas of recruitment of suitable staff, improvements in facilities, service re-design and alternative workforces, and improved equipment. The report stated:

> "For the 2012/13 year a business case was prepared for additional FTE to manage the growth in Ophthalmology. This included the following:
>
> - 0.8 FTE Paediatric Ophthalmologist
> - 0.5 FTE Ophthalmic technician
> - 0.5 FTE Optometrist
> - 0.7 FTE Nurse Coordinator for ORL, Ophthalmology and Urology.
>
> Only the nurse coordinator position was approved.
>
> Application for Ministry of Health project funding for the transfer of clinics to Mangere was not approved as [it] was not related to FSA but follow-up and this was not covered by the criteria.
>
> …
>
> [O]ver the past year we have struggled to manage the demand. Many of the staff have worked additional sessions with 16 non-clinical/administration sessions converted to clinics and 20 Saturdays worked during 2012 for approximately 2,200 appointments."

81. The report also noted: "In Ophthalmology there is clinical risk which may affect vision and if not identified in a timely way may result in loss of vision which may be irreversible."

82. In June 2013, overdue follow-up appointments numbered 3,118, and the following month numbered 3,041. In October 2013, the number was 2,862, and in December 2013 it was 2,933. By February 2014, the number was 3,239.

March 2014

83. The March 2014 report updated the key issues:

> "Ophthalmology referrals made up 16% of all Counties Manukau referrals logged.
>
> 15,869 — 2009/10
> 17,804 — 2010/11
> 20,023 — 2011/12
> 19,039 — 2012/13 — (the first time in seven years where referrals levelled off)"

84. The 2014 report updated the efforts made to address these issues in the areas of recruitment of suitable staff, improvements in facilities, service re-design and alternative workforces, and improved equipment.

More recent steps taken to address issues

85. CMDHB told HDC that the ophthalmology service has been faced with significant demand growth, and while the service has been successful in managing cataract demand (the most common cause of loss of vision), it has struggled to meet ongoing demand growth for other progressive eye conditions that also can result in irreversible blindness if not treated effectively.

86. By the end of 2016, the ophthalmology service had secured the recruitment of two new ophthalmologists, and had begun a building project to create new physical clinical capacity. One new ophthalmologist started in December 2016, and another in August 2017. A further ophthalmologist returned from leave in August 2017.

87. During 2016, CMDHB allocated financial support for the establishment of a new fully equipped ophthalmology suite supplementary to the site. The new outpatient suite has been operational since June 2017, adding three extra clinic rooms, three extra diagnostic rooms, and a new laser room to the service operation.

88. CMDHB has provided many additional clinics in the evenings and on Saturdays, as standard practice, using locum and current staff to cope with the overdue appointments. Additional fixed-term employees have been employed to maximise all options for increasing capacity at the current clinic site.

89. Optometrists can now apply to CMDHB for access to a system where they are able to view the electronic[19] records of their patients, including clinic letters. However, access has been available only in the last two years.

90. CMDHB advised that its other strategies include the following:

- Custom clinics — customised clinics have been used to meet specific needs during any given week, addressing areas of high demand.
- Risk communication — all patients and general practitioners receive a notice attached to their clinic letters highlighting access issues, and are advised to contact CMDHB if there is any future delay in receiving a follow-up appointment.
- Recruitment — the ophthalmologist recruitment process has been ongoing for the past five years, with difficulty in securing new consultants until December 2016, when two contracts (as above) were secured.
- Extra clinic room — a new clinic room was created in January 2017 to provide increased capacity to see patients.
- New workforce added — implementation of clinical nurse specialist (CNS) led clinics has resulted in the senior nursing workforce managing procedures such as Avastin injections. The recruitment of a second CNS has assisted with this group of patients.
- Extra nursing and technician FTE approval — in January 2017 an increase in nursing and technician staffing levels was approved and recruitment has been finalised.
- New triaging system — a triaging system implemented by ophthalmologists for the glaucoma waiting list has resulted in a clearer understanding of which patients are waiting and at what clinical priority.
- Clinical training centre planned — a clinical training centre project is underway with the intention of establishing a clinical training partnership with the University of Auckland School of Ophthalmology and School of Optometry. Optometry

[19] Clinical applications portal that enables staff to access patient summary information in multiple clinical applications without the need to log on to each application separately.

students undergoing undergraduate study will be involved in clinics at CMDHB, seeing CMDHB patients under the supervision of the university optometrists.

- Advanced practice optometrists employed — two optometrists with advanced practice in glaucoma have been recruited.
- Additional funding — in June 2017 CMDHB received funding from the Ministry of Health's additional funding for eye health services initiative for a PASCAL laser, and a fixed-term period of funding for an ophthalmic technician will enable an increased focus on treatment for diabetic retinopathy.
- Monthly reporting on overdue follow-ups — CMDHB is reporting to the Ministry of Health on a monthly basis about the reduction in expired follow-up appointments in relation to the project.
- Project governance board — CMDHB has established a project governance board to guide the reduction of overdue follow-ups — project members include clinicians (both secondary and primary care), managers, analysts, patient advocates, and consumer representatives.

Triaging system introduction — 2016

91. In June 2016, a "traffic light" classification system for managing overdue patient appointments was set up at CMDHB. The system was initiated by a senior medical officer.

92. The system was established because of the increasing demand for ophthalmology services and the resource constraints faced, which affected CMDHB's ability to see this group of patients. The ophthalmology service enhanced the tracking of overdue follow-up appointments in early 2017, enabled by improved production planning and data. This helped to inform the business case to the Ministry of Health for a share of funding to DHBs.

93. The system classified glaucoma patients as either red (highest priority), green (lower priority), or orange (those between red and green) using visual field criteria and DDLS (disc damage likelihood scale)[20] criteria. The system advises that patients can always be re-classified or modified by clinical judgement.

94. The classification is linked to permitted flexibility in booking glaucoma patient appointments as follows:

Red patients
Bookings requested for 3 months' time or less must be given appointments within 1 week of request.
Bookings requested for 4, 6 or 9 months' time: an appointment must be given within 4 weeks of request.

Orange patients

[20] The Disc Damage Likelihood Scale (DDLS) is based on the appearance of the neuroretinal rim of the optic disc corrected for disc diameter. The eight stages, extending from no damage to far advanced damage, are based on the width of the neuroretinal rim or the circumferential extent of absence of neuroretinal rim.

Bookings requested for 3 months' time or less: appointment must be given within 2 weeks of request.
Bookings requested for 4, 6 or 9 months' time: appointment must be given within 6 weeks of request.

Green patients
Should be fitted in as soon as possible after an appointment request, after RED and ORANGE patients have been booked.

95. The traffic light system was implemented for overdue glaucoma patients. However, some senior medical officers have implemented the traffic light system in other sub-specialties, and it is intended to be implemented for other sub-specialties in the near future.

2018 update

96. CMDHB has provided a written apology to Miss A's family, and is willing to meet with the family should they wish to do so.

97. CMDHB also provided the following update to HDC:

- Approximately 60% of optometrists are now referring patients electronically to the ophthalmology service, and there is a programme underway to ensure that 100% of optometry referrals are electronic by October 2018.
- Brief treatment and re-referral guidelines now accompany letters to the GP and optometrists.
- CMDHB is working with RANZCO[21] to introduce an acuity tool for the prioritisation of follow-up appointments. This should be in place in the second half of 2018.
- A referral of a child with keratoconus is usually seen for a first specialist assessment within a month. The orthoptist and optometrists who do the paediatric triaging are aware that this condition is a semi-urgent priority. Optometrists and GPs are also being educated on the importance of sending detailed clinical referrals to the service.
- Since last year, a keratoconus progression clinic has been run on a two-weekly rotation. These clinics are run by very experienced optometrists, under supervision of the corneal specialist. Follow-up with these children occurs every three to six months to avoid missing any progression of the disease. If there is any documented case of progression of keratoconus the child is booked for corneal collagen crosslinking straight away.
- An immediate strategy to deal with current demand is to establish new clinical processes such as virtual clinics. The ophthalmology service is currently recruiting to enable this change in process.

Further information — Ministry of Health

98. The Ministry of Health is working with DHBs that have a backlog of ophthalmology patients, and is discussing the plans each has in place to address the issue.

[21] The Royal Australian and New Zealand College of Ophthalmologists.

99. In December 2016, the Ministry wrote to all DHBs reinforcing its support for improving capacity and managing demand. The support will include further funding to assist DHBs to develop, implement, or improve eye health care models. (DHB service improvements may include improved capacity and demand planning, improved referral management, consistent prioritisation, and alternative workforce options.)

100. The Ministry advised HDC that this would assist DHB teams to develop, implement, or improve care models to best support their local district's eye health. In addition, the Ministry will also lead key national improvements in service planning and patient flow.

101. The funding provided is intended to support immediate DHB activities to address existing backlogs and minimise clinical risk to patients, establish sustainable improvements to planning and delivery of services, and enable reporting of the success of local initiatives.

102. In June 2017, the Ministry advised HDC that in addition to service improvement work underway, such as increasing the number of clinic rooms, advanced training for clinicians, employing additional ophthalmology workforce and the purchase of equipment, CMDHB contracted with the Ministry to reduce the number of overdue follow-ups.

103. The initiative required CMDHB to provide the Ministry with:

- Monthly data on the number of patients waiting for follow-up appointments;
- Milestone reporting of progress and achievements; and
- A final report on the results achieved.

104. The Ministry, with the New Zealand branch of RANZCO, formed a multidisciplinary service improvement expert advisory group. Senior leaders from RANZCO and DHB management have ongoing monthly teleconferences with the Ministry to discuss issues facing ophthalmology services.

Responses to provisional opinion

105. Miss A's father, Mr B was provided with an opportunity to respond to the "information gathered" section of the provisional decision. Mr B advised that he was happy with this section of the report.

106. CMDHB was provided with an opportunity to comment on the provisional opinion. CMDHB advised that it "unreservedly accepts" the findings and "accepts and takes on board" the recommendations. CMDHB noted that whilst there has been positive progress, the issues facing CMDHB in the provision of its ophthalmology services as still very real and concerning. CMDHB noted the "limited prospects of securing substantial additional funding in an austere fiscal environment, growing numbers requiring its services, and staffing remaining ongoing problems".

Opinion: introductory comment

107. I am very aware of the resourcing pressures and associated demographic factors affecting long-term ophthalmology treatment in New Zealand, and that some DHB catchments have challenging population characteristics.

108. In relation to this demand, my expert advisor, Professor Charles McGhee, commented:

> "Unfortunately the demand for eye services has increased almost exponentially across New Zealand for glaucoma, age related macular degeneration (Avastin) and to a lesser extent cataract over the last decade. Undoubtedly this has impacted adversely on the provision of eye services in CMDHB and most other DHBs in New Zealand. However, this demand should not result in abrogation of services to other patients who may have preventable vision loss, from unmonitored waiting times for FSA and follow-up appointments."

109. I agree. As I said in a recent case,[22] I consider that the Ministry of Health has a role, with DHBs, to recognise the effect of the introduction of such new technologies and associated pressures on the system, and plan accordingly. However, the existence of systemic pressures does not remove provider accountability in addressing such issues. A key improvement that all DHBs and the Ministry of Health must make, now and in the future, is to assess, plan, adapt, and respond effectively to the foreseeable effects that new technologies and population change will have on systems and demand.

Opinion: Counties Manukau District Health Board — breach

110. As I have emphasised in previous cases, district health boards (DHBs) are responsible for the operation of the clinical services they provide, and are responsible for any service failures.[23] It is incumbent on all DHBs to support their staff with systems that guide good decision-making and promote a culture of safety.[24] In addition, it is the responsibility of DHBs to prioritise patients appropriately and in a timely manner, and provide patients with good information, particularly when waiting for resource-constrained specialist services.

111. Miss A did not receive follow-up specialist eye care in line with the appropriate clinical time frames requested by her clinicians.

112. Professor McGhee advised:

> "Undoubtedly [Miss A's] case highlights significantly greater visual loss in a progressive disease affecting children/young adults that probably could have been treated at a much earlier stage had her review appointment occurred in the planned 12 month period."

[22] Opinion 16HDC01010 (12 March 2018).
[23] Opinion 14HDC01187 (30 June 2016).
[24] See also Opinion 09HDC02089 (4 July 2012).

113. I will not revisit a detailed clinical chronology here, but I make the following comments on the key issues of this investigation.

Time frame for follow-up appointment post FSA

114. Professor McGhee advised that although he is unaware of any agreed national or international guidelines in relation to these circumstances (either in 2012 or more recently), in his view it was entirely reasonable in this case for a follow-up appointment to be scheduled initially for between 6 and 12 months post FSA. He said:

> "I believe the initial clinical assessment and 12 month review appointment was appropriate. The major failing here was the enormous delay in the follow-up review appointment — despite requests by GP — and only initiated by a new referral from [the education service]."

115. Following Miss A's first specialist assessment on 21 November 2012, Miss A should have had a follow-up ophthalmology review appointment 12 months later in November 2013 (as requested by Dr D). Although there is evidence that a follow-up appointment was planned for 22 November 2013, it did not go ahead, despite contact made with the DHB by Mr B and Dr E about the issue. I am very critical of this delay.

Demands on the ophthalmology service

116. Professor McGhee advised:

> "I note that CMDHB indicate that their Ophthalmology service had been 'in crisis' since 2009. Therefore, one would have expected by 2012, if not earlier, a systematic review and scoring system for all delayed follow-ups would have been fully established. This does not appear to be the case."

117. The responses supplied by Mr B, Dr E, and CMDHB indicate that the delay that occurred was attributed to the many capacity issues created by the huge demand for the CMDHB ophthalmology service (as described above), in this case its cornea service. However, I am very concerned that CMDHB management had been on notice since 2009 that there was, while subject to some fluctuation, a clear and ongoing inability to meet ophthalmology clinic demand due to volumes of referrals exceeding capacity. The potential risk of this was concisely pointed out in the 2013 progress report: "[T]here is clinical risk which may affect vision and if not identified in a timely way may result in loss of vision which may be irreversible."

Prioritisation systems and management of overdue follow-up

118. CMDHB told HDC that during the period related to this case, the ophthalmology service used an electronic reporting system to capture overdue appointments. These appointments were flagged in an overdue follow-up report. The process allocated a timeframe for the next appointment and had a priority assigned to each appointment. A four-week priority meant that the appointment could be booked up to a month either side of the planned appointment time. (Miss A's 22 November 2012 follow-up appointment expiry date was listed as 3 January 2014.)

119. CMDHB told HDC that due to huge volumes of overdue follow-up appointments the longest overdue follow-up appointments were booked as a priority. Patients were booked according to who had been waiting the longest. The process for any patients who contacted the service directly asking for urgency was that they were telephoned by an ophthalmology nurse specialist and assessed verbally. However, I note that a more urgent appointment was not necessarily booked according to the outcome of that assessment.

Acuity tool not in use

120. CMDHB told HDC: "[T]here were so many overdue follow-up appointments that all had the same clinical priority, [and] it became extremely difficult to manage." CMDHB also advised that there was no specific clinical acuity tool used at the time of Miss A's care. CMDHB said that the increase in the number of patients needing appointments rose dramatically, and that the use of an acuity tool would not have assisted in managing the overdue patients, as the service did not have enough space or resources to cope.

2016 classification system

121. In June 2016 a "traffic light" classification system for managing overdue patient appointments was set up at CMDHB. The system was initiated by a senior medical officer. The system classified patients as either red (highest priority), green (lower priority), or orange (those between red and green) using clinical criteria. The traffic light system was implemented for overdue glaucoma patients. (However, some medical officers used the traffic light system in other sub-specialties, and it was intended to be implemented for other sub-specialties.)

122. Professor McGhee is of the view that in addition to a "traffic light" prioritisation system for glaucoma, a similar system should have been implemented across the board at CMDHB — including the corneal service.

Conclusion

123. Professor McGhee concluded in relation to the DHB process:

> "The DHB processes and systems in place at the time of these events, specifically in relation to prioritising and booking overdue follow-up appointments and identification of higher-risk patients, appears completely inadequate and below the standard of expected care. A 20 month delay of a planned 12 month review in a child with ocular allergy, eye rubbing, suspected keratoconus and mild intellectual disability is simply unacceptable and certainly contributed to more advanced disease than could be treated (halted) by collagen cross-linking, and thus significant loss of visual acuity."

124. I am mindful of the more recent reviews and actions taken by CMDHB to attempt to address the deficiencies identified, particularly since 2016. However, I am concerned that at the time of Miss A's care, despite CMDHB managers being on notice of concerns about clinical risk inherent in some follow-up delays, these delays became the "norm", and a prioritisation approach was adopted that primarily considered the length of time an appointment had been overdue, without sufficient consideration of associated acuity issues or higher patient risk factors. The overall system in place for management of delayed follow-up appointments was not adequate and put patients at risk. At all times, and

particularly when a system is under pressure, appropriate patient prioritisation must be the central focus.

Discharge back to GP, December 2014

125. It is relevant to note that owing to the nature of the CMDHB Patient Administration System at the time, the resulting 21 November 2012 clinic letter was sent to the family GP, Dr E, but was not able to be copied to the original referring community optometrist. This continuity deficiency was suboptimal.

126. Although it is acknowledged that a follow-up specialist appointment was eventually scheduled, 12 months overdue, for 8 December 2014, this did not go ahead either, as the family did not receive correspondence or telephone or text alert from CMDHB regarding the appointment. Care was then transferred by CMDHB back to Miss A's GP. It is concerning that the correspondence was not received, and that Miss A lost continuity in her care as a result.

127. Given that at the 2012 appointment Miss A appeared to have no definitive clinical disease of the cornea (at that stage it was suspected), Professor McGhee advised that it could be considered that discharge back to the GP for further management was not unreasonable, but that the reasonableness of such a course of action presumes that the patient was still under the care of the referring optometrist and that the GP and optometrist were aware of treatment options, if keratoconus became manifest. Professor McGhee advised:

> "An associated failing which might have resulted in earlier re-referral and urgent reassessment was lack of clear communication between the CMDHB Ophthalmology service, the general practitioner and the referring optometrist."

128. As described earlier, this case highlighted that the system for communication and feedback of relevant clinical information to referring optometrists and GPs by the DHB was deficient, and I am critical of this.

Action following referral the education service, March 2015

129. A follow-up appointment went ahead on 24 August 2015, after the referral from the education service, marked urgent, which had been received five months earlier on 24 March 2015. At the 24 August 2015 appointment (two years and nine months after her previous specialist review), Miss A was reviewed by Dr D, who confirmed bilateral keratoconus. The right eye was considered to be very severe and beyond treatment for cross-linking.

130. Professor McGhee was of the view:

> "I would have expected a reasonably rapid review priority. Especially since the window for cross-linking treatment in children can be relatively short. I believe most practitioners would have prioritised a review with several weeks not five months later (24 August 2015)."

131. I acknowledge that there was some confusion at the DHB as to the clarity and purpose of the referral from the education service. However, the reason for referral did state "vision concerns" and to "ensure her educational opportunities are optimised". The DHB "referral

management" stamp dated 30 March 2015 also noted that it was a second referral, and a planned appointment date of 8 June 2015 was made.

132. I am critical that the relevant specialist review did not occur earlier that 24 August 2015 in these particular clinical circumstances. I note that once Miss A was seen at this review, her left eye cross-linking surgery was then carried out within two months, on 20 October 2015, which was a reasonable time frame post-review.

133. I also note that on 3 September 2015, Dr E was erroneously notified that Miss A's "waiting list priority" was "P1 — Urgent". This was not the correct priority classification and was a default setting within the iPM system. CMDHB said that the correct priority classification was the Clinical Priority Assessment Criteria (CPAC). Miss A received a CPAC score of 90 for her surgery, initiating surgery within four months.

Conclusion

134. Professor McGhee advised: "Unfortunately the care provided in this case clearly falls below the standard expected from a major eye service in New Zealand/Aotearoa."

135. CMDHB failed to arrange a timely follow-up appointment for Miss A in line with appropriate clinical time frames. CMDHB did not have an adequate prioritisation system for overdue follow-up specialist appointments. There were missed opportunities to identify and remedy the ongoing delay in Miss A being seen for specialist follow-up. CMDHB did not take sufficient account of potential clinical risks associated with heavy demand and a lack of capacity at the ophthalmology service, and did not take sufficient or adequate action to rectify the situation despite awareness of the issue. In my view, CMDHB did not provide services to Miss A with reasonable care and skill and, accordingly, breached Right 4(1) of the Code.

Recommendations

136. I recommend that within three months of the date of this report, CMDHB provide HDC with:

a) An independent evaluation of the systems in place to identify and prioritise overdue ophthalmology patients.

b) An update on progress of the work done alongside the Ministry to track and monitor progress toward zero ophthalmology patients waiting beyond clinically appropriate time frames.

c) A report on the investigation into the iPM system shortcomings identified by this matter.

137. I recommend that within three months of the date of this report, CMDHB also provide a detailed update report on the steps taken that relate to the expert advisor's

recommendations, those arising out of its own reviews, and its work alongside the Ministry of Health, with specific reference to the following:

a) The new outpatient suite operational since June 2017.

b) Additional clinics in the evenings and on Saturdays, and use of additional fixed-term employees.

c) Community optometrists' access to *CareConnect* and the ability to view the electronic records of their patients, including clinic letters.

d) Other strategies CMDHB has indicated it has adopted, including: custom clinics, risk communication to patients and GPs, recruitment progress, extra clinic room space, new workforce additions, extra nursing and technician FTE, a clinical training centre project, employment of advanced practice optometrists, monthly reporting to the Ministry of Health on overdue follow-ups, and a project governance board.

e) The brief treatment and re-referral guidelines that now accompany letters to GPs/referring optometrists following a FSA.

f) The application of the "traffic light", or similar prioritisation scheme, to delayed follow-up appointments across all arms of the ophthalmology service, including the corneal service.

g) The regular circulation of waiting time information to GPs, optometrists, and ophthalmology colleagues such that re-prioritisation of patients can be made where necessary.

h) Development of a structured, collegial, inter-professional approach to shared care.

i) Consideration of virtual clinics by non-medical staff where imaging techniques allow.

j) Consideration of the development of a regional ophthalmology plan between CMDHB, ADHB and WDHB, including regional appointment of SMOs in ophthalmology with duties at more than one site.

k) Establishment of the appropriate support and clinical space required for ophthalmic services, and consideration of whether all services should be supplied at all sites.

138. CMDHB has provided a formal written apology to Miss A's family. The apology will be forwarded to Miss A's family within three weeks of the date of this report.

Follow-up actions

139. Counties Manukau 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.

140. A copy of the final report with details identifying the parties removed, except Counties Manukau DHB and the expert advisor in this case, will be sent to the Director-General of Health (Ministry of Health), HealthCERT (Ministry of Health), HQSC, the Royal Australian and New Zealand College of Ophthalmologists (RANZCO), the National CMO Group, and Central TAS, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Addendum

141. The Director of Proceedings filed proceedings by consent against Counties Manukau DHB in the Human Rights Review Tribunal. The Tribunal issued a declaration that CMDHB breached Right 4(1) of the Code by failing to provide services to Miss A with reasonable care and skill.

Appendix A: Independent advice to the Commissioner

The following expert advice was obtained from a consultant ophthalmologist, Professor Charles McGhee.

> "Thank you for asking my advice in regard to the above complaint. I have studied the extensive documentation provided and considered the key questions you have posed. Hopefully I have addressed all of the key matters in my answers below.
>
> **History**
>
> In essence [Miss A], was referred to the Ophthalmology Services at Manukau DHB in **14th July 2012** by her optometrist [Ms C] in relation to a reduction in vision that was noted by the optometrist when the patient was assessed having broken her spectacles. Visual acuity was noted to be **moderately reduced from 6/7.5 each eye, to 6/18 right and 6/15 left**.* No refraction was noted but the eyes were reported normal to examination 'no abnormalities were noted at all' and no diagnosis was suggested by the optometrist (in relation to this referral it is noteworthy that 11 years of age was beyond the amblyogenic risk age). (* *I note that these are the visual acuities stated in [Ms C's] referral letter of 14 July 2012 — however, oddly in reply to the HDC enquiry, [Ms C's] letter of 21/12/2016 re-states the vision as a line poorer in each eye, dropping from 6/7.5 each eye to 6/24 right and 6/18 left*.)
>
> I presume an entirely appropriate, non-urgent, review was coordinated by CMDHB (referral grading by CMDHB suggests 'within 2 months' at 20/06/12) and [Miss A] was subsequently reviewed by the service on **21st November 2012**.
>
> At that FSA, [Dr D] (SMO Cornea/Paediatrics) noted that vision could actually be corrected to near 'normal' in both eyes 6/7.5 right and 6/9.5 left and the patient had astigmatism, allergic eye disease and the possibility of **subtle or subclinical ('forme fruste') keratoconus** was noted.
>
> Therefore it was planned that [Miss A] continue under the care of her optometrist and that a **follow-up review occur 12 months** later in CMDHB ophthalmology. I note only the GP (Dr E) was copied into the letter related to this FSA letter (26/11/2012) *but not the referring optometrist* ([Ms C]).
>
> Unfortunately the 12 month appointment **(Nov./Dec. 2013)** did not occur and eventually [Miss A] was reviewed some time later on **24th August 2015** — more than 2.5 years after the initial review and 20 months later than the planned follow-up clinic (Nov. 2013)! (I note that during this delayed follow-up the patient's GP [Dr E] attempted a re-referral because of her reduced vision on 29 March 2015 but the referral was rejected by CMDHB stating 'assessment not required'.)
>
> Regrettably by this point [Miss A] had developed **moderately advanced keratoconus** and significant reduction in vision (6/60 unaided right and 6/30 unaided left). Subsequently, in October 2015, she underwent collagen cross-linking to halt disease progression in the left eye but unfortunately by this point the keratoconus in the right eye was too advanced to undergo CXL treatment.

Thereafter CMDHB (clinic letter for 16/12/2015) notes a visual acuity of 6/7.5 in the left eye with a contact lens (no note of vision in right eye being managed with a semi-scleral contact lens by her own optometrist).

Latest CMDHB ophthalmology review, 21/11/2016 (locum consultant ophthalmologist]), suggested unaided vision of 1/60 right eye, 'pinholing' to 6/60 (likely best spectacle correction) and 6/9 left eye with contact lens. Although the right eye may be improved further by contact lens wear, on the basis of notes available to me, I believe it can be assumed that the patient has lost significant visual acuity in the right eye that might only be remedied by a corneal transplant, if possible, in due course. The risk of corneal graft failure in such advanced disease in a child is high.

Comments in relation to specific questions:

1. I am unaware of any widely agreed national, or international, guidelines in 2012 (or more recently) in relation to clinically appropriate follow-up time-frames after an FSA in cases of suspected keratoconus (in children or adults). However, the agreed time-lines in relation to confirmed progression of established keratoconus to the point that requires corneal cross-linking treatment are usually over 6 to 12 months. Increasingly those in the field think 3–6 months may be more appropriate in children but there is no consensus at the present time.
2. In the specific clinical circumstances of an 11 year old with suspected keratoconus — but no convincing clinical evidence thereof other than non-specific corneal topography appearances — I believe an entirely reasonable standard of care would have been a follow-up appointment between 6 and 12 months post FSA.
3. The DHB processes and systems in place at the time of these events, specifically in relation to prioritizing and booking overdue follow-up appointments and identification of higher-risk patients, appears completely inadequate and below the standard of expected care. A 20 month delay of a planned 12 month review in a child with ocular allergy, eye rubbing, suspected keratoconus and mild intellectual disability is simply unacceptable and certainly contributed to more advanced disease than could be treated (halted) by collagen cross-linking, and thus significant loss of visual acuity.
4. I note that CMDHB indicate that their Ophthalmology service had been 'in crisis' since 2009. Therefore, one would have expected by 2012, if not earlier, a systematic review and scoring system for all delayed follow-ups would have been fully established. This does not appear to be the case.
5. Bearing in mind that [Miss A] may have missed a review appointment in December 8th 2014, but that at the earlier FSA in 2012 she appeared to have no clear-cut clinical disease of the cornea (i.e. only suspected keratoconus) it could be considered that discharge back to the GP for further management was not unreasonable.

   However, the reasonableness of this 'discharge' course of action presumes that a) the patient was still under the care of the referring Optometrist and that b) the GP and Optometrist were aware of treatment options, if keratoconus became manifest, such as corneal collagen cross-linking.

In contrast, it could equally be reasoned that a) there was suspicion of keratoconus b) keratoconus can progress relatively quickly in children especially if they eye-rub and c) keratoconus appears to be more severe in Pasifika and Maori in New Zealand.

6. Following the 'urgent please' referral on 24th March 2015, to **determine eligibility for the education service** I would have expected a reasonably rapid review priority. Especially since the window for cross-linking treatment in children can be relatively short. I believe most practitioners would have prioritized a review within several weeks not five months later (24 August 2015).

7. I note that following review on 24 August 2015 the cross-linking surgery was carried out on 20th October 2015, some 2 months later. I believe this is a reasonable time-frame for non-urgent eye surgery.

8. Undoubtedly [Miss A's] case highlights significantly greater visual loss in a progressive disease affecting children/young adults that probably could have been treated at a much earlier stage had her review appointment occurred in the planned 12 month period.

   I further believe this should have merited a **Serious Sentinel Event Review**, both in relation to the harm caused to the individual and also in the context this is a relatively common disease, often diagnosed in more advanced stages, in the younger population in CMDHB catchment area.

9. […] [A] 'traffic light' prioritisation system for glaucoma a similar system should have been implemented across the board at CMDHB —including the corneal service.

10. Unfortunately the demand for eye services has increased almost exponentially across New Zealand for glaucoma, age related macular degeneration (Avastin) and to a lesser extent cataract over the last decade. Undoubtedly this has impacted adversely on the provision of eye services in CMDHB and most other DHBs in New Zealand. However, this demand should not result in abrogation of services to other patients who may have preventable vision loss, from unmonitored waiting times for FSA and follow-up appointments.

    Obviously each health board has dealt with these issues as best they can via improved efficiency, staffing and alternative provision of care as highlighted by CMDHB responses to this complaint.

11. CMDHB appear to have taken a number of reasonable steps to deal with heavy demand on ophthalmology services but I believe these have largely been hampered by chronic lack of space, often incomplete medical staffing and lack of an agreed regional plan for appropriate provision of services.

12. Unfortunately the care provided in this case clearly falls below the standard expected from a major eye service in New Zealand/Aotearoa.

13. I believe the initial clinical assessment and 12 month review appointment was appropriate. The major failing here was the enormous delay in the follow-up review appointment — despite requests by GP — and only initiated by a new referral from the education service. An associated failing which might have

resulted in earlier re-referral and urgent reassessment was lack of clear communication between the CMDHB Ophthalmology service, the general practitioner and the referring optometrist.

14. **Recommendations**

A. The patient and her family should receive a fuller explanation of the events, avoidable outcomes and a sincere apology from CMDHB for significant loss of vision related to delays in review.

B. Letters from ophthalmology service should routinely be copied to Optometry referrers with patient's permission (allowing exceptions for matters of patient confidentiality in respect to certain illnesses).

C. Where possible, brief treatment and re-referral guidelines should accompany letters to GP/Optometry following FSA (e.g. progression and treatment of keratoconus).

D. A 'traffic light' or similar prioritization scheme should be applied to delayed follow-up appointments in CMDHB such that cases such as this are avoided in the future.

E. Genuine waiting times should be regularly circulated to GPs, Optometrists and Ophthalmology colleagues such that re-prioritization of patients, or alternative management plans can be made where necessary.

F. A structured, collegial, inter-professional approach to shared care should be developed by corneal (and other) services at CMDHB — e.g. many keratoconus cases could be followed up by appropriately skilled, or upskilled, optometrists. However, this would require changes to funding streams and additional funding for a service 'in crisis'.

G. Virtual clinics by non-medical staff might be considered where imaging techniques allow — e.g. computerised tomography in corneal disease.

H. A regional ophthalmology plan should be developed between CMDHB, ADHB and WDHB to supply appropriate staff and appropriate services for the greater Auckland Metropolitan region to balance inequality of access.

I. Appropriate support and clinical space required for ophthalmic services should be established and perhaps not all services should be supplied at all sites (though often this is necessary to attract subspecialists e.g. Cornea).

J. Consideration should be given to regional appointment of SMOs in ophthalmology with duties at more than 1 site (CMDHB, ADHB, WDHB) to even out stated difficulties of recruitment at CMDHB.

Yours sincerely

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