Capital and Coast District Health Board

A Report by the

Health and Disability Commissioner

(Case 13HDC01012)

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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Executive summary

1. Between 14 June 2011 and 1 February 2012, Mrs A was diagnosed with four urinary tract infections. On three occasions Mrs A consulted with the general practitioners at a medical centre (Medical Centre 1) (14 June 2011, 19 December 2011 and 1 February 2012). On one occasion (31 December 2011) Mrs A was seen at a different clinic, Medical Centre 2.

2. Blood tests in April showed a reduction in Mrs A's renal function. Between April and June 2012, Medical Centre 1 arranged further investigations, including a blood test, mid-stream urine tests (which showed white and red blood cells but no bacterial growth (no infection)), and testing for an atypical organism (which was not detected).

3. On 28 June 2012, Mrs A was reviewed by general practitioner Dr E at Medical Centre 1. Mrs A did not report any further dysuria (painful urination), but she had experienced three episodes of haematuria (blood in the urine) the previous week. Dr E referred Mrs A to a urologist at the public hospital (Capital and Coast District Health Board). Dr E sent a further urgent letter to the urology department on 1 July 2012, when Mrs A's urine cytology returned positive for malignant cells.

4. On 10 July 2012, Mrs A had a CT scan of her abdomen and pelvis. The scan showed a large right-sided renal carcinoma with associated lymphadenopathy.[1] Mrs A's CT scan result was discussed at a multidisciplinary team meeting on 18 July 2012. Urologist Dr G stated that the plan following this meeting was "to proceed to palliative nephroureterectomy [the surgical removal of a kidney and its ureter] and regional lymph node dissection if staging interventions did not show further widespread metastatic disease".

5. On 15 August 2012, Mrs A and her daughter-in-law, Ms B, attended an appointment with senior urology registrar Dr I. Dr I advised Dr E that she had booked Mrs A on the urgent list for the surgical removal of her kidney. Ms B understood from this consultation that her mother-in-law's diseased kidney would be removed and that everything would be fine. She said that they did not discuss any postoperative treatment with Dr I, but were advised that they would do so after the operation.

6. Mrs A's surgery was incorrectly entered into the booking system as semi-urgent instead of urgent. From the date of Mrs A's consultation with Dr I and her referral for surgery, it was 78 days before Mrs A underwent surgery.

7. Mrs A's CT scan of her chest completed on 2 August 2012 was reviewed by the urology team three days prior to her surgery. Mrs A had a chest X-ray eight days before surgery but did not have a further CT scan.

8. On 1 November 2012, Mrs A had surgery, but not all of the cancer was surgically resectable. On 7 December 2012, Mrs A had a CT scan, and the results showed

[1] Renal carcinoma is cancer of the kidney. Lymphadenopathy refers to lymph nodes that are abnormal in size, number or consistency, and is often used as a synonym for swollen or enlarged lymph nodes.

evidence of disease progression and masses in her mediastinum.[2] Mrs A underwent radiotherapy and chemotherapy. Her chemotherapy was discontinued and, sadly, she died.

Findings

9. Medical Centre 1 appropriately managed and investigated Mrs A's urinary symptoms.

10. Capital and Coast District Health Board (CCDHB) did not provide Mrs A with services with reasonable care and skill and breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code) by failing to carry out Mrs A's surgery within a clinically appropriate timeframe, and for the failure of its staff to discuss and consider Mrs A's chest CT scan report adequately prior to 29 October 2012.[3]

11. Adverse comment is made about CCDHB for the explanation given to Mrs A about her condition. Adverse comment is also made about Dr G for not performing a further staging CT chest scan prior to Mrs A's surgery.

12. Other comment is made about Medical Centre 2.

Complaint and investigation

13. The Commissioner received a complaint from Mr A about the services provided by Capital and Coast District Health Board to his wife, Mrs A. An investigation was commenced on 16 May 2014. The following issue was identified for investigation:

The appropriateness of the care provided by Capital & Coast District Health Board to Mrs A from July 2012 to December 2012.

14. The parties directly involved in the investigation were:

Mr A	Complainant
Capital and Coast District Health Board	Provider
Medical Centre 1	Provider
Medical Centre 2	Provider

15. Information was also reviewed from Ms B, Mrs A's daughter-in-law, general practitioner Dr C, and urologist Dr G.

Also mentioned in this report:

Dr D	General practitioner

[2] The mediastinum is the cavity that separates the lungs from the rest of the chest. It contains the heart, oesophagus, trachea, thymus, and aorta.

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

Dr E	General practitioner
Dr F	Urologist
Dr H	Radiologist
Dr I	Senior urology registrar
Dr J	General practitioner
Dr K	Senior urology registrar
Dr M	Medical oncologist

16. Independent expert advice was obtained from general practitioner Dr David Maplesden (**Appendix A**) and urologist Dr Patrick Bary (**Appendix B**).

Information gathered during investigation

Background

17. Mrs A (aged 68 years at the time of these events) had been a patient at Medical Centre 1 since 24 February 2010. It has completed two cycles of the CORNERSTONE Accreditation Programme.[4]

18. Following a number of urinary tract infections (UTIs), Mrs A was diagnosed with renal squamous cell carcinoma in June 2012.[5] She underwent treatment at the public hospital but, sadly, she subsequently died.

19. Mrs A's husband, Mr A, was concerned about the delay in his wife's diagnosis by Medical Centre 1, and the delay in CCDHB performing a nephrectomy.[6]

UTI June 2011

20. Between 24 February 2010 and 14 June 2011, there are no urinary symptoms documented in Mrs A's medical records. On 14 June 2011, general practitioner (GP) Dr C recorded in Mrs A's medical records: "Has been getting symptoms of frequency, w/dipstick demonstrates wbc [white blood cells] and blood, discussed renal function … BP 110/72."[7] Dr C prescribed trimethoprim to treat the UTI, and Accuretic for her blood pressure.[8] Dr C reviewed Mrs A on 5 September 2011. Mrs A did not complain of persisting urinary symptoms, but she told Dr C that since stopping her diuretic, she no longer had to pass urine at night.

[4] CORNERSTONE is an accreditation programme specifically designed by the Royal New Zealand College of General Practitioners for general practices in New Zealand. Once accredited, practices move into an annual maintenance programme. The annual programme is based on a four-year cycle.
[5] Cancer of the kidney.
[6] A nephrectomy is the surgical removal of a kidney.
[7] Normal blood pressure is 120/80mmHg.
[8] Trimethoprim is a common antibiotic that eliminates bacteria that cause urinary tract infections. Accuretic is medication used to lower blood pressure.

UTI December 2011

21. On 19 December 2011, Mrs A was seen by GP Dr D at Medical Centre 1, presenting with symptoms of a UTI. A mid-stream urine test (MSU) result confirmed a UTI, and Mrs A was notified on 20 December 2011. Dr D recorded in Mrs A's medical records: "Aware has UTI and is now feeling better. Going away Boxing Day for 1/52. Will do post-[treatment] sample once returned."

Consultation at Medical Centre 2

22. On 31 December 2011, Mrs A was seen at another clinic, (Medical Centre 2). An MSU was ordered, and she was treated for a further UTI. This consultation was reported to Medical Centre 1 on 1 January 2012. The results of the MSU taken on 31 December 2011 were reported on 9 January 2012 and showed no bacterial growth. Medical Centre 2 told HDC that it thinks the delay in reporting was because the laboratory was closed over the holiday period. Medical Centre 2 told HDC that the test results were sent to Medical Centre 1. However, Medical Centre 1 stated that it did not receive the test results, and it does not have a copy of them in Mrs A's medical record.

Consultation for cough

23. On 9 January 2012, Mrs A had a consultation with Dr C complaining of a chronic cough. A chest X-ray was ordered and she was prescribed antibiotics. A nursing note entry on 11 January 2012 records: "[N]otified [chest X-Ray] clear, [review] 2/52 if still coughing, still coughing but much better already, will [review] if any residual."

UTI February 2012

24. On 1 February 2012, Mrs A was reviewed by Dr D with further symptoms of a UTI. Dr D recorded that she had had a recent history of recurrent infections (her third episode in two months). Dr D ordered an MSU. Dr D recorded: "Discussed possible use of Ovestin cream and USS [ultrasound scan of kidneys] if ongoing problems."[9] The laboratory test results confirmed a UTI. Mrs A was prescribed antibiotics and advised to provide a further post-treatment sample. The repeat sample was done on 13 February 2012 and showed a persistent UTI.

25. On 15 February 2012, a nurse telephoned Mrs A and recorded that she still had mild to moderate symptoms of her UTI but was feeling otherwise well. As Mrs A was still symptomatic, nitrofurantoin[10] was prescribed on 16 February 2012 by GP Dr E, as Dr D was not working that day. A nursing note recorded on 20 February 2012 states: "[H]as collected prescription and feel[s] better."

Blood tests and investigations April–June 2012

26. On 3 April 2012, Mrs A telephoned for a repeat prescription of her usual medication[11] and was advised that she needed a repeat blood test and blood pressure check. A

[9] Ovestin cream is a hormone replacement therapy which contains the female hormone oestriol (an oestrogen). Oestrogen deficiency can lead to recurrent UTIs.
[10] Nitrofurantoin is an antibiotic specifically used to treat UTIs.
[11] Cilazapril, aspirin, omeprazole and atorvastatin.

nursing note on 11 April 2012 records: "[W]ell at present." Mrs A's blood test results from 11 April showed a reduction in her renal function, and she was advised to repeat the blood test with an MSU in six weeks' time. An MSU was done on 31 May 2012, which showed white and red blood cells but no bacterial growth (no infection). The sample was repeated with the same results. Further tests were conducted to consider whether the sterile pyuria[12] was due to an atypical organism.[13] No atypical organism was detected.

27. On 28 June 2012, Mrs A was reviewed by Dr E. Mrs A did not report any further dysuria,[14] but she had experienced three episodes of haematuria[15] the previous week. Dr E referred Mrs A to a urologist at the public hospital. Dr E sent a further urgent letter to the urology department on 1 July 2012, when Mrs A's urine cytology returned positive for malignant cells. Dr D (at Dr E's request) met with Mrs A the following day to discuss the result and management plan. Dr D recorded that she told Mrs A that malignant cells were present in her recent urine test, and that she had been referred to the Urology Department for urgent investigation.

Referral to Urology Department, July 2012

28. On 10 July 2012, Mrs A had a CT scan of her abdomen and pelvis.[16] The scan showed a large right-sided renal carcinoma with associated lymphadenopathy.[17]

29. On 18 July 2012, urologist Dr F reviewed Mrs A, arranged further investigations, including a CT scan of her chest and a bone scan, and booked her a clinic appointment with urologist Dr G for August. The result of Mrs A's CT scan of her abdomen and pelvis was discussed at a multidisciplinary team meeting later that day. Dr G stated that the plan following this meeting was "to proceed to palliative nephroureterectomy and regional lymph node dissection if staging interventions did not show further metastatic disease".[18]

30. The CT scan of Mrs A's chest was completed on 2 August 2012. It was reviewed and electronically approved by radiologist Dr H. She queried a mediastinal mass[19] and reported:

> "Within the mediastinum there is evidence of a hiatus hernia[20] and there is a small lobular density adjacent to the oesophagus … On balance I think this is likely to

[12] Sterile pyuria is the presence of elevated numbers of white cells in urine that appears sterile.
[13] An organism not commonly associated with pyuria in New Zealand, eg, tuberculosis.
[14] Dysuria is painful or difficult urination.
[15] Haematuria is the presence of blood in the urine.
[16] CT scans are X-ray tests that produce cross-sectional images of the body using X-rays and a computer. CT scans are also referred to as computerised axial tomography.
[17] Renal carcinoma is cancer of the kidney. Lymphadenopathy refers to lymph nodes that are abnormal in size, number or consistency, and is often used as a synonym for swollen or enlarged lymph nodes.
[18] Nephroureterectomy is the surgical removal of a kidney and its ureter (the duct by which the urine passes from the kidney to the bladder). Regional lymph node dissection is the removal of some of the lymph nodes.
[19] A mediastinal mass is a mass found in the cavity that separates the lungs from the rest of the chest. Mediastinal masses are caused by a variety of cysts and tumours.
[20] Protrusion in the upper part of the stomach into the thorax.

> be a slight protuberance of the hiatus hernia rather than a node. If this would make a significant difference to the planning of surgery, I will be very happy to recall the patient to … further clarify this. Within the lungs, there is a single tiny nodule … This is non specific, but can be monitored at subsequent scans. This measures just under 3mm."

31. Dr G stated that the scan did not show definite metastatic disease, and that a 3mm lung nodule is a non-specific finding.

32. Dr H stated that she has no recollection of having had any conversation about the CT chest report, and noted that there is no documentation of any discussions or meetings about the report.

Urology appointment, 15 August 2012

33. On 15 August 2012, Mrs A and her daughter-in-law, Ms B, attended an appointment with senior urology registrar Dr I. Dr G was not present as he was on unexpected leave. Ms B told HDC that they spent only about five minutes with Dr I. She understood from this consultation that her mother-in-law's diseased kidney would be removed. Ms B stated: "We both thought that by removing the kidney everything would be fine." She said that they did not discuss any postoperative treatment with Dr I, but were advised that they would do so after the operation.

34. In a letter to Dr E, Dr I stated that Mrs A's CT chest and bone scan did not show any obvious evidence of metastatic disease. She wrote: "I explained to [Mrs A] today that the treatment is a radical nephrectomy plus sampling the para-aortic lymph nodes. We have gone through what is involved in surgery today. I have booked her on the urgent list for this procedure …"

35. It was not documented in Mrs A's medical record or in Dr I's letter to Dr E as to whether or not the procedure was intended to be palliative in nature. Dr I was asked to provide a statement to HDC, but CCDHB advised that Dr I "has no memory of [Mrs A] specifically. She was very sorry to hear that she had died and wishes to have her condolences conveyed to [Mr A] and family."

36. In response to my provisional opinion, Dr I stated:

> "I accept [Mrs A] and her daughter-in-law left that clinic appointment with the impression that 'everything would be fine'. However, reviewing my clinical notes it is clear my impression was of a serious disease requiring urgent treatment … It is also true that further treatment (e.g chemotherapy, radiotherapy) would be dependent on the surgical outcome and pathology report. I cannot recall the consultation that took place that day, however I am certain that given the information recorded in my notes I would not have minimised the seriousness of the disease or falsely reassured the patient."

37. Dr G was not present at the consultation, but told HDC that in "the context of the known abdominal lymph node metastases, and intention of a palliative procedure, [he] agree[d] with the surgical plan put in place by [Dr I]".

38. CCDHB stated:

> "Certainly, by way of general comment it is not uncommon that a patient has exploratory surgery with the view to removing local regional disease which up until that procedure was thought to be the case with [Mrs A] … This is not unusual with carcinoma surgery for a cancer which is thought to be resectable pre-operatively and is found actually at surgery not to be operable. Whether the terminology of palliative is appropriate in this case, as stated above, it would be recognised implicitly that this was probably not a curable cancer right from the outset."

Delay in receiving surgery date

39. On 11 September 2012, Dr E sent a letter to Dr G noting that Mrs A had not yet received a date for her surgery.

40. On 19 September 2012, Mrs A received a letter from the booking clerk[21] at the Urology Department stating that surgery was expected to be provided within the next six months. Following that letter, the nurses at Medical Centre 1 attempted to contact the Urology Department to get more information about the operation date.

41. On 28 September 2012, Dr J from Medical Centre 1 contacted Dr G directly, who advised that Mrs A would receive a date for surgery within the next week.

42. CCDHB explained that Mrs A's surgery was incorrectly entered into the booking system as semi-urgent instead of urgent. CCDHB is unable to explain why there was a delay from 15 August 2012 until 19 September 2012 for Mrs A's planned surgery to be entered into the booking system.

43. CCDHB acknowledged that it did not complete Mrs A's surgery within a clinically appropriate timeframe. It said further: "It is difficult to know however whether [Dr G] would have been able to complete [Mrs A's] surgery sooner had the expected process been followed, due to the urgent priority of other patients also requiring surgery."

Events prior to surgery

44. Mrs A's surgery was scheduled for 1 November 2012. CCDHB (on behalf of Dr G) told HDC: "It is unclear why the opportunity to personally see [Mrs A] in clinic after her staging imaging and prior to the planned surgery was not arranged as this is [Dr G's] usual practice."

45. In response to my provisional opinion, Dr G said that he regrets that "the urology department did not arrange a formal re-consultation with [Mrs A] and her family in clinic in the days prior to her surgery, which would have allowed for appropriate documentation of the decisions made and confirmation of [Mrs A's] understanding and expectations of the surgery".

[21] The letter is signed off by "Nurse Coordinator"; however, CCDHB stated that it did not have a Nurse Coordinator at that time, and the letter was signed off by the booking clerk.

46. In response to my provisional opinion, CCDHB and Dr G advised that they had additional clinical records not previously provided to HDC. Dr G told HDC: "The additional information now known is that an X-ray of Mrs A's chest was taken on 24 October 2012, eight days before her surgery. The request indicated that the X-ray was to assess lung fields and exclude additional lung pathology."

47. The X-ray report findings were: "No prior chest films, although … there has been a recent CT. Heart is not enlarged. The presence of a rounded mass behind the heart is consistent with the known hiatus hernia. Lungs and pleural space are clear."

48. CCDHB told HDC that it audited its electronic health record and found that senior urology registrar Dr K reviewed the X-ray report on 28 October 2012 on behalf of the urology team. CCDHB said that the report would have been available at the urology team meeting on 29 October 2012 (three days prior to Mrs A's surgery). Mrs A's CT scan of her chest completed on 2 August 2012 was accessed by Dr F and also reviewed by the urology team at this meeting.

49. CCDHB (on behalf of Dr G) told HDC that Dr G does not recall, and there is no evidence to suggest, that he reviewed the CT scan or Dr H's report prior to the urology team meeting on 29 October 2012. CCDHB stated that the purpose of such a meeting is to confirm that the right operation is being planned for the right patient. CCDHB said that such meetings are not documented, but if there were any changes in the operative plans then this would be documented in the individual patient records.

50. In response to my provisional opinion, Dr G stated:

> "The discussions at this planning meeting … are not formally recorded in writing and there is no specific mechanism or facility for this … It is intended as an additional safeguard.
>
> In this case, while notes of the 29 October 2012 meeting do not exist, I am confident that both the CT scan and the X-ray of a few days prior would have been discussed. The fact that the X-ray was requested to exclude additional lung pathology shows that in my view the report of the 2 August 2012 CT scan was considered and responded to."

51. Mrs A did not have a further CT scan prior to surgery. CCDHB stated:

> "We have considered whether repeating scans closer to the time of surgery would have made a difference to the management of [Mrs A's] case. Given the speed of the tumour growth, it is likely that a repeat scan would have shown changes but this is only noted because the speed of the tumour can be estimated now in retrospect."

52. CCDHB also stated that, "[i]n hindsight, it is agreed that a repeat staging chest CT was indicated in [Mrs A's] case". CCDHB said further that it was Dr G's responsibility as lead clinician to decide whether a repeat CT was needed.

53. In response to my provisional opinion, Dr G's legal advisor submitted that "there was no expectation or clinical need for repeat staging imaging to be a CT as opposed to an X-ray in this case … [Dr G] has consulted senior colleagues and there is no consensus that a clinical situation like [Mrs A's] required a CT as opposed to an X-ray." Dr G stated that on "reinspection of the abdominal CT scan, it fairly accurately reflected the disease that we encountered [during the surgery]".

Surgery performed, 1 November 2012

54. On 1 November 2012, surgery was performed. Written consent for the procedure was taken by Dr K.[22] CCDHB told HDC that it is unsure whether the "probable palliative nature" of this procedure was discussed at this point.

55. The operation record states that Mrs A's surgery was for the management of her right renal tumour "likely transitional cell carcinoma with squamous differentiation affecting the collecting system". The operation record reports that the surgery was "prolonged and difficult" and "successful in the intent of performing a nephrectomy". However, Mrs A had "significant residual lymph node metastases around the great vessels which despite some effort was not surgically resectable".

56. Dr G said that there was no expectation of a cure from the nephrectomy surgery. He stated:

> "The regional lymph node metastases were recognised on pre-operative imaging, and that the disease at presentation was therefore incurable. However, there was potential advantage in a palliative nephrectomy … Our hope too was that the regional lymph node disease would be resectable simultaneous with the nephrectomy, and that her survival, in addition to her quality of life, might be improved."

57. Dr G recorded the postoperative instructions as being a referral to oncology to consider systemic chemotherapy.

Palliative care

58. Mrs A was seen by medical oncologist Dr M on 29 November 2012. Dr M recorded: "I have discussed with [Mrs A] that the disease is not resectable and therefore not curable." He provisionally booked her in for chemotherapy.

59. On 7 December 2012, Mrs A had a CT scan, and the results showed evidence of disease progression and masses in her mediastinum.[23] Mrs A's medical record states that she received palliative radiotherapy between 10 and 14 December 2012. On 18 January 2013, Mrs A commenced chemotherapy. However, following a restaging CT scan, which showed progressive disease within her abdomen, chemotherapy was discontinued.

[22] Dr K has not held a New Zealand practising certificate since May 2013. HDC has been unable to contact Dr K.

[23] The mediastinum is the cavity that separates the lungs from the rest of the chest. It contains the heart, oesophagus, trachea, thymus, and aorta.

60. Mrs A subsequently died in hospice care.

Other comment

61. CCDHB has made enquiries with other district health boards about the possibility of transferring patients out of the region for nephrectomies.

Changes made

62. CCDHB advised that it has made the following changes to its service as a result of Mrs A's case:

a) It has introduced a surgical booking form that requires the surgeon to document the required timeframe for urgent cases and to discuss very urgent cases directly with the booking clerk. It has also implemented a tracking and audit system that will enable it to check compliance with these changes and identify when treatment dates are not being achieved.
b) It has mapped the booking clerk processes within the Urology Department.
c) Mrs A's case was discussed at the combined multidisciplinary meeting on 23 October 2013.
d) It has progressed its recruitment strategy to appoint another urology consultant.
e) It has employed a nurse coordinator to assist the Urology Department in case coordination, monitoring the status of patients on the urology booking list, and further reviewing and refining the booking system and processes.

63. Dr G stated that arrangements have been made to achieve re-consultation for patients coming forward for complex surgery, where the pre-operative management has been with team members other than the operating surgeon.

Apology

64. CCDHB stated: "We would however appreciate the Commissioner passing on our sincere apology for the delay in [Mrs A's] surgery and for the uncertainty and distress this has caused."

Response to my provisional opinion

65. A response to the "information gathered" section was received from Mr A.

66. Responses to my provisional opinion were received from CCDHB, Dr G, and Medical Centre 1. Where appropriate, the responses have been incorporated into the "information gathered" section above (or included in the section that follows).

67. In response to my provisional opinion, CCDHB considers that it has a team approach to planning and delivering patient care. It stated:

> "The Urology Service has a team approach to planning surgery and there was a significant contribution to [Mrs A's] pre-assessment and surgical planning by four team members, [Drs F, G (lead consultant), I and K]. This joint management approach and decision-making continued through the pre-operative team meeting, [Mrs A's] surgery and her post-operative course in hospital."

68. CCDHB also accepts that the delay in providing surgery to Mrs A was not of a standard it expected to provide patients. CCDHB "remain[s] saddened by [Mrs A's] death knowing the planning of her surgery was not within the required timeframe".

Opinion: Medical Centre 1 — Other comment

69. My expert clinical advisor, Dr David Maplesden, noted the rarity of Mrs A's condition and the tendency to late diagnosis owing to the "subtle and non specific way it can present leading to an overall very poor prognosis". He also noted the frequency of UTI as a presentation in primary care.

70. On 14 June 2011, Mrs A attended a consultation with Dr C at Medical Centre 1 and was diagnosed and treated for a UTI. On 19 December 2011, Mrs A was seen by Dr D at Medical Centre 1, presenting with symptoms of a UTI. On 31 December 2011, Mrs A was seen at a different clinic, Medical Centre 2, presenting with further UTI symptoms. On 1 February 2012, Mrs A was reviewed by Dr D at Medical Centre 1 with further symptoms of a UTI. In summary, Mrs A was diagnosed with four UTIs within a nine-month period. The diagnoses were made by three different doctors at two separate practices.

71. Dr Maplesden stated:

> "[Mrs A] saw several providers in the year prior to her diagnosis but I do not feel this significantly affected her continuity of care. Each provider recounted the previous history and accurately documented the frequency and nature of [Mrs A's] symptoms and relevant results."

72. Dr Maplesden advised that each episode of infection was treated appropriately. He stated that following the fourth infection (1 February 2012), which was noted by Dr D to be persistent, Dr D documented an intention to investigate further with ultrasound should the current infection not settle with a change in antibiotics, or if there was further recurrence. Dr Maplesden noted that the symptoms settled, there was no recurrence, and Mrs A remained otherwise well over this period.

73. Mrs A's blood test results from 11 April 2012 showed a further reduction in her renal function, and Mrs A was advised to repeat the blood test with an MSU in six weeks' time. The results of an MSU (done on 31 May 2012) showed white and red blood cells but no bacterial growth (no infection). The sample was repeated with the same results. Further tests were conducted to consider whether an atypical organism was causing the sterile pyuria.

74. On 28 June 2012, Mrs A was reviewed by Dr E. Mrs A did not report any further dysuria, but she had experienced three episodes of haematuria in the previous week. Dr E referred Mrs A to a urologist. Dr E sent a further urgent letter on 1 July 2012, when Mrs A's urine cytology returned positive for malignant cells. Dr Maplesden

advised that "when [Mrs A] was found to have pyuria and haematuria in the absence of infection appropriate further initial testing was performed". He also advised that an appropriate referral was made within four weeks, which was reasonable as further investigations were being performed during this period and Mrs A remained well.

75. Dr Maplesden concluded that the clinical management of Mrs A by her providers at Medical Centre 1 was consistent with expected standards. I accept Dr Maplesden's advice. In my view, Medical Centre 1 appropriately managed and investigated Mrs A's urinary symptoms.

Opinion: Medical Centre 2 — Other comment

76. Mrs A presented to Medical Centre 2 on 31 December 2011 with symptoms of a UTI. An MSU was ordered and the results were received on 9 January 2012. Medical Centre 1 did not receive a copy of the results, and it does not have a copy of them on Mrs A's medical record. However, Medical Centre 2 stated that the results were provided to Medical Centre 1. It would be expected and appropriate for the results to have been forwarded on. However, due to the conflicting accounts, I am unable to make a finding as to whether or not Medical Centre 2 provided a copy of Mrs A's test results to Medical Centre 1.

Opinion: Capital and Coast District Health Board

Services of an appropriate standard — Breach

77. Under Right 4 of the Code, Mrs A had the right to services of an appropriate standard. I have concerns about the services provided by CCDHB to Mrs A, as discussed below.

Delay in receiving surgery

78. After seeing Mrs A on 15 August 2012, senior urology registrar Dr I wrote to Dr E and stated: "I explained to [Mrs A] today that the treatment is a radical nephrectomy plus sampling the para-aortic lymph nodes … I have booked her on the urgent list for this procedure …"

79. On 11 September 2012, Dr E from Medical Centre 1 sent a letter to Dr G noting that Mrs A had not yet received a date for her surgery. On 19 September 2012, Mrs A received a letter from the booking clerk at the Urology Department stating that surgery was expected to be provided within the next six months. Following this letter, the nurses at Medical Centre 1 attempted to contact the Urology Department to get more information about the operation date.

80. On 28 September 2012, Dr J from Medical Centre 1 directly contacted Dr G, who advised that Mrs A would receive a date for surgery within the next week. CCDHB explained that Mrs A's surgery was incorrectly entered into the booking system as semi-urgent instead of urgent.

81. From the date of Mrs A's consultation with Dr I and her referral for surgery, it was 78 days before Mrs A underwent surgery. CCDHB is unable to explain why there was such a delay for Mrs A's planned surgery to be entered into the booking system (15 August 2012 to 19 September 2012).

82. CCDHB has acknowledged that it did not complete Mrs A's surgery within a clinically appropriate timeframe. It said further: "It is difficult to know however whether [Dr G] would have been able to complete [Mrs A's] surgery sooner had the expected process been followed, due to the urgent priority of other patients also requiring surgery."

83. Mr expert advisor urologist, Dr Patrick Bary, stated: "[T]he delay between referral and nephrectomy is, in principle, a severe departure from expected standard of care. Having stated that I do not know of any unit in any DHB that has not had this unfortunate experience."

84. I accept Dr Bary's advice. Mrs A's surgery should have been entered into the booking system on 15 August 2012, but was not entered until 19 September 2012. It was also incorrectly entered as semi-urgent instead of urgent. In my view, this is totally unacceptable. CCDHB needs to ensure that it has a rigorous process in place to guarantee the accuracy of its booking system, and have sufficient checks and balances in place to ensure that all bookings in its system are carefully entered and monitored. I acknowledge the improvements made by CCDHB to its booking system following this incident.

Consideration given to CT scan

85. The CT scan of Mrs A's chest was completed on 2 August 2012. It was reviewed and electronically approved by radiologist Dr H, who queried a mediastinal mass and offered to undertake additional scanning to delineate this if it were felt appropriate.

86. The CT scan was ordered by Dr C and reviewed by Dr I prior to her consultation with Mrs A on 15 August 2012. CCDHB (on behalf of Dr G) told HDC that Dr G does not recall, and there is no evidence to suggest, that he reviewed the CT scan or Dr H's report prior to the urology team meeting on 29 October 2012 (three days prior to Mrs A's surgery). None of these clinicians appear to have discussed Dr H's findings with each other prior to 29 October 2012. Dr H stated that she does not recall having any conversation about the CT chest report, and noted that there is no documentation of any discussions or meetings about the report.

87. Dr G stated that the scan did not show definite metastatic disease, and that a 3mm lung nodule is a non-specific finding. Dr Bary advised:

> "The presence of metastatic disease in the chest is of great importance and any management decisions about and with [Mrs A] would need to include greater

> definition and acknowledgement of their presence. I accept [Dr G's] view that their presence may not preclude an operation but I do not see any evidence to see that a plan was initiated taking these into account. In particular I do not see evidence that a discussion about them was had with [Mrs and Mr A]. This may well have altered their decisions notwithstanding the symptoms and signs the local disease was causing. In summary my concern is that [Dr H's] report does not appear to have registered appropriately."

88. I accept Dr Bary's advice and consider that Dr H's report was not given the due consideration required in light of the non-conclusive nature of her report and the query about a mediastinal mass. There is no record that Dr H's report was discussed amongst, or considered by, the clinicians involved in Mrs A's care (other than Dr I's consideration) when deciding on her management plan prior to the team meeting on 29 October 2012. If it had, it may have altered the management of Mrs A.

Conclusion

89. In my view, CCDHB did not provide Mrs A services with reasonable care and skill by failing to carry out Mrs A's surgery within a clinically appropriate timeframe, and for the failure of its staff to discuss or consider Mrs A's chest CT scan report adequately. For these reasons, I find that CCDHB breached Right 4(1) of the Code.

Information — Adverse comment

90. On 15 August 2012, Mrs A and her daughter-in-law, Ms B, attended an appointment with senior urology registrar Dr I. Ms B told HDC that they spent only about five minutes with Dr I. Ms B understood from this consultation that her mother-in-law's diseased kidney would be removed. Ms B stated: "We both thought that by removing the kidney everything would be fine." She said that they did not discuss any postoperative treatment with Dr I, but were told that they would do so after the operation.

91. In response to my provisional opinion, Dr I stated:

> "I accept [Mrs A] and her daughter-in-law left that clinic appointment with the impression that 'everything would be fine'. However, reviewing my clinical notes it is clear my impression was of a serious disease requiring urgent treatment … It is also true that further treatment (e.g chemotherapy, radiotherapy) would be dependent on the surgical outcome and pathology report. I cannot recall the consultation that took place that day, however I am certain that given the information recorded in my notes I would not have minimised the seriousness of the disease or falsely reassured the patient."

92. In a letter to Dr E dated 15 August 2012, Dr I stated that Mrs A's staging CT chest and bone scan did not show any obvious evidence of metastatic disease. Dr I further recorded that she explained the treatment to Mrs A and what was involved in the surgery. Dr Bary advised:

> "The wording of [Dr I's] letter of 15 August 2012 shows that her view was that the operation would not clear all of the disease and therefore no attempt would be

> made for the operation to be curative in itself but there is no evidence of discussion with [Mrs A] of the possibility of further treatment such as chemotherapy or radiotherapy."

93. Dr G was not at the consultation on 15 August 2012, as he was on unexpected leave. In addition, Dr G did not review Mrs A personally prior to her surgery. However, he told HDC that in "the context of the known abdominal lymph node metastases, and intention of a palliative procedure, [he] agree[d] with the surgical plan put in place by [Dr I]". CCDHB told HDC that it is unsure whether the palliative nature of this procedure was discussed at Mrs A's consultation with Dr I. It was not documented in Mrs A's medical record or in Dr I's letter to Dr E.

94. CCDHB also stated:

> "Certainly, by way of general comment it is not uncommon that a patient has exploratory surgery with the view to removing local regional disease which up until that procedure was thought to be the case with [Mrs A] … This is not unusual with carcinoma surgery for a cancer which is thought to be resectable pre-operatively and is found actually at surgery not to be operable. Whether the terminology of palliative is appropriate in this case, as stated above, it would be recognised implicitly that this was probably not a curable cancer right from the outset."

95. It is apparent that the clinicians recognised from the outset that Mrs A's cancer was unlikely to be curable. However, it is not clear from the contemporaneous records whether Mrs A's surgery was intended to be palliative or not, in particular, Dr I did not refer to the procedure as being palliative in her reporting letter to Dr E. In addition, Dr G subsequently told HDC that the procedure was palliative in nature, and, in correspondence with HDC, CCDHB referred to the purpose of the procedure as being both palliative and exploratory. Irrespective of whether the procedure was intended to be palliative in nature or otherwise, it was important that Mrs A receive a careful and accurate explanation of the purpose of her surgery and her likely prognosis, prior to the surgery being undertaken.

96. I am unable to make a finding as to exactly what Mrs A understood about the purpose of her surgery prior to it being undertaken. However, I consider it unsatisfactory that, given such a serious diagnosis, it appears that Mrs A and her daughter-in-law were left with an impression that following surgery, Mrs A would be fine. In my view, while clinicians should endeavour to deliver difficult news to patients in an empathetic manner, it is essential that clinicians ensure that patients are aware of the seriousness of their diagnosis and the purpose of any proposed treatment. This ensures that patients can carefully weigh up the benefits of any planned treatment surgery with any negative aspects such as side effects.

Opinion: Dr G — Adverse comment

97. Mrs A's chest CT scan completed on 2 August 2012 was reviewed by the urology team three days prior to her surgery. Mrs A did not have a further chest CT scan prior to her surgery on 1 November 2012. However, a chest X-ray was taken on 24 October 2012, eight days prior to her surgery.

98. CCDHB stated: "In hindsight, it is agreed that a repeat staging chest CT was indicated in Mrs A's case." CCDHB said further that it was Dr G's responsibility, as lead clinician, to decide whether a repeat CT was needed.

99. In response to my provisional opinion, Dr G submitted that "there was no expectation or clinical need for repeat staging imaging to be a CT as opposed to an X-ray".

100. Dr Bary advised:

> "With respect to the preoperative chest xray, I maintain my view that, given that the tumour was high grade and that there was significant delay between the CT scan and the operation, an up to date CT of the abdomen and chest may well have altered [Mrs A's] management and may have allowed further information to be given to [Mrs A] and her family, thereby giving them the opportunity to make informed decisions. A chest xray gives a far less accurate view of the chest than does a CT and in my view is not accurate enough, given [Mrs A's] situation. I note also that the chest xray request form did not make any mention of the nature of the renal disease; nor did it mention the chest changes seen on the previous CT."

101. I am concerned that Dr G did not request a further CT scan prior to surgery. In my view, given the delay between the scan on 2 August and the surgery on 1 November, a further CT scan may have provided both Dr G and Mrs A with further information about the status of her condition, which may have influenced the clinicians' management plan and Mrs A's decision about the management of her condition.

Recommendations

102. I recommend that CCDHB:

a) Provide a written apology to Mrs A's family. The apology is to be sent to HDC within three weeks of the date of this report, for forwarding to Mrs A's family.

b) Report to HDC on the effectiveness of the new surgical booking form implemented since this complaint, within three months of the date of this report.

c) Report to HDC on the effectiveness of the tracking and audit system implemented since this complaint, within three months of the date of this report.

d) Provide HDC with an update on the progress of its recruitment strategy, within three months of the date of this report.

e) Provide HDC with an update on the effectiveness of the appointment of the nurse coordinator to the Urology Department, within three months of the date of this report.

f) Continue to access and encourage staff use of the advance care planning material, and report back to HDC within three months of the date of this report.

Follow-up action

103. A copy of this report with details identifying the parties removed, except Capital and Coast District Health Board and the experts who advised on this case, will be placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Appendix A — Independent expert advice to the Commissioner

The following expert advice was obtained from general practitioner Dr David Maplesden on 13 November 2013:

"1. Thank you for providing this file for advice. I have reviewed the available information: complaint from [Mr A], husband of [Mrs A] (dec); response from [Dr C] (GP); response from [Dr E] (GP); response from Capital & Coast DHB (CCDHB); [Medical Centre 1] GP notes; [the public hospital's] clinical notes.

2. Complaint from [Mr A]

(i) [Mrs A] [died from] renal squamous cell carcinoma (RSCC) diagnosed in June 2012. The diagnosis was made by a GP at [Medical Centre 1] [Mrs A] had seen for the first time. Prior to this she had seen [Dr C] for recurrent urinary tract infections (UTIs) from at least mid-2011. [Mr A] feels these infections were treated without consideration as to the underlying cause, and without appropriate and timely investigation that might have led to earlier diagnosis of his wife's cancer.

(ii) [Mr A] complains that there were delays in [Mrs A] having her nephrectomy performed — surgery performed on 1 November 2012 when [Mrs A] had been told it would be undertaken before mid-August 2012.

(iii) Following the nephrectomy [Mrs A] could not swallow and lost significant weight over the next five weeks. Eventually a CT scan was performed which showed two large mediastinal masses putting pressure on the oesophagus and left main bronchus. A CT scan performed in August 2012 had shown an ill-defined abnormality in a similar area. [Mr A] is concerned that, under the circumstances, his wife's ability to swallow was not investigated earlier. He feels earlier detection of the masses may have resulted in earlier commencement of adjunctive therapy before his wife had become so debilitated, and may have improved her short-term prognosis.

(iv) [Mr A] met with the surgeon who performed his wife's nephrectomy, [Dr G]. [Dr G] implied that imaging or reporting prior to surgery (*July scan*) had been suboptimal so that the discovery of *the cancerous mass he found behind the stomach* was unexpected.

(v) Primary care management of [Mrs A] will be addressed in the first part of this report before I proceed to comments regarding her secondary care management.

3. [Medical Centre 1] notes review (notes from 24 February 2010 to current)

(i) First consultation at [Medical Centre 1] was 26 February 2010 for repeat of usual medications (simvastatin, omeprazole, Accuretic). Routine blood tests were ordered (results not on file). Flu vaccine was given on 20 April 2010 and repeat prescription (request per telephone) of usual medications supplied on 31 May 2010. On 27 August 2010 review was undertaken by [Dr C] — persisting reflux

symptoms noted and dose of omeprazole increased. Follow-up blood tests ordered 30 November 2010 with nurse contact recorded 17 December 2010 advising [Mrs A] to attend for her next prescription (rather than telephone) as tests had shown some renal impairment (**copy of results to be obtained**). At no stage in 2010 was a complaint of urinary symptoms documented.

(ii) [Mrs A] saw [Dr C] on 1 March 2011 for repeat medications. *Looking to fine tune renal conservation, discussed options ... maybe lower bp a bit more ...* Simvastatin dose was increased and aspirin commenced. On 27 May 2011 repeat prescriptions were requested per telephone (and provided) and [Mrs A] advised she needed a blood pressure check (112/70 30 May 2011) and blood test check.

(iii) Review with [Dr C] 14 June 2011 is the first documentation of urinary symptoms: *Has been getting symptoms of frequency, u/dipstick demonstrates wbc and blood, discussed renal function ... BP 110/72 ...* presumed UTI was treated with trimethoprim and Accuretic changed to Accupril. Further blood tests were ordered with [Mrs A] advised of the results on 5 August 2011 with nurse recording comment *is feeling better.* On 17 August 2011 the practice nurse requested [Mrs A] see [Dr C] when her next repeat was due.

(iv) Review with [Dr C] 5 September 2011 — notes [Mrs A] no longer had to get up at night to pass urine since cessation of her diuretic. BP 160/86 and dose of Accupril increased. No complaint of persisting urinary symptoms.

(v) 19 December 2011 ([Dr D]) — *Symptoms of UTI ... nil fevers, back pain or renal angle tenderness ... urine dipstick — lots of leucocytes, blood. Imp: UTI. Plan: MSU, abs* [trimethoprim prescribed] *and ural sachets ...* Urine culture confirmed infection with E coli and [Mrs A] was notified 20 December 2011 — *Aware has UTI and is now feeling better. Going away Boxing Day for 1/52. Will do post-tx sample once returned.*

(vi) On 1 January 2012 [Mrs A] attended another medical centre ([Medical Centre 2]) with urinary symptoms and was treated for a UTI (not clear if MSU was done on this occasion). On 9 January 2012 she attended [Dr C] complaining of four months of chronic cough (no mention of urinary symptoms). Chest was clear. Consideration was given to this being a medication side effect and her ACEI changed from Accupril to cilazapril. Chest X-ray was ordered and antibiotics prescribed. Nurse notes 11 January 2012 include *notified cxr clear, rev 2/52 if still coughing, still coughing but much better already, will rev if any residual.*

(vii) [Dr D] reviewed [Mrs A] on 1 February 2012: *Further symptoms of UTI ...* recent history of recurrent infections noted *… unclear what has set this off. Menopause 17yrs ago. Today — freq of urination, afebrile, achy back, nil renal angle tenderness. Urine dipstick large blood, leuco. Imp: UTI (3rd episode in 2 months). Plan: MSU to lab, triprim and ural. Discussed possible use of Ovestin cream and USS* [ultrasound scan of the kidneys] *if ongoing problems.* Urine culture showed E coli and [Mrs A] was advised of this, and to repeat a sample post therapy. The repeat sample (13 February 2012) showed persistent E coli infection

and [Mrs A] was treated with Nitrofurantoin as she was still symptomatic (nurse call 15 February 2012 — *still having mild/mod symptoms of UTI — feels otherwise well in self.* Nurse call 20 February 2012 — *has collected* [prescription] *and feel better.*

(viii) On 3 April 2012 [Mrs A] telephoned for a repeat of her usual medications and was advised she needed a repeat blood test and BP check (nurse check 11 April 2012 — *bp 148/80 ... well at present*). Blood test results 11 April 2012 showed further reduction in renal function and [Mrs A] was advised to repeat the bloods with a urine test in six weeks. MSU on 31 May 2012 showed leucocytes and blood cells but no bacterial growth (ie no infection to explain these previously noted findings). The sample was repeated (same results) and further tests done for atypical organisms given the sterile pyuria.

(ix) [Mrs A] saw [Dr E] for review on 28 June 2012. The recent history and results to date were recounted. There had been no further dysuria but *last week has 3 episodes of haematuria over course of 1/7, initially red urine x 2 then small clot following morning, has appeared clear since then, no pain assscd, otherwise well ... Abdo soft, non tender, no palp masses ... Plan: refer urology, Urine cytology, rpt meds, rpt bloods/urine Aug, see prn.* A urology referral was made with a further urgent letter sent 1 July 2012 when urine cytology returned positive for malignant cells (results and management plan conveyed face-to-face by [Dr D] on 2 July 2012.

(x) On 10 July 2012 [Mrs A] had CT of the abdomen and pelvis which showed a large right sided renal carcinoma with associated lymphadenopathy. Further investigations were ordered by the urologists and she was booked for a clinic appointment with surgeon [Dr G] early August 2012.

(xi) GP management after this time was largely supportive with respect to the malignancy. On 1 September 2012 [Dr E] sent a letter to [Dr G] noting [Mrs A] had not yet received a date for her surgery and on 19 December 2012 [Mrs A] received a letter *stating surgery was expected to be provided within the next 6 months.* [Medical Centre 1] practice nurses attempted to contact urology clinic to get more certainty regarding the operation date and on 28 September 2012 [Dr J] from [Medical Centre 1] contacted [Dr G] directly who advised [Mrs A] would receive a date for surgery within the next week. Surgery was eventually performed on 1 November 2012.

4. Relevant New Zealand guidelines on suspected cancer in primary care[1] make the following recommendations with respect to suspicion for renal or bladder cancer:

[1] NZGG/MoH. Suspected cancer in primary care: Guidelines for investigation, referral and reducing ethnic disparities. 2009. New Zealand Guidelines Group, Wellington. ISBN (Print): 978-1-877509-12-4

(i) *A person of any age presenting with painless macroscopic* [visible to the naked eye] *haematuria should be referred urgently to a specialist. In a younger person, cancer is unlikely to be the cause of the bleeding.* See section 4(iv).

(ii) *A person aged 40 years and older presenting with recurrent or persistent urinary tract infection associated with haematuria should be referred urgently to a specialist.* [Mrs A] may have fallen into this category perhaps from January 2012 (although she was seen by a different provider for each of the first three UTIs, with the third infection treated at another medical centre). At the time of her fourth infection in 12 months in February 2012 (which was also a persistent infection) [Dr D] had considered ordering an ultrasound if there were ongoing problems. [Mrs A] had no further symptoms suggestive of UTI after her second lot of antibiotics in February 2012 and she did not attend [Dr D] again prior to her diagnosis. The recommendation contained in this section of the guidelines does not define or quantify 'persistent or recurrent' UTI (but see section 5(i)) and must be considered in the context of UTI frequency in the general population (see section 5) and other local recommendations regarding haematuria (see section 6).

(iii) *A person with an abdominal mass identified clinically or on imaging that is thought to arise from the urinary tract should be referred urgently to a specialist.* [Mrs A] did not have an abdominal mass detected on palpation when she was examined by [Dr E] on 28 June 2012.

(iv) *A person presenting with symptoms suggestive of a urinary infection who also presents with macroscopic haematuria should be referred urgently to a specialist if investigation does not confirm infection.* [Mrs A] fell into this category from 28 June 2012 although she had persistent microscopic haematuria in the absence of infection from 31 May 2012 (see below). Further tests were taken at that time to exclude atypical infections and when these proved negative [Mrs A] was referred for specialist review, urgent priority requested when the results of urine cytology were positive for malignancy.

(v) *Good practice point: A person with persistent microscopic haematuria, with no obvious cause (eg, menstruation) may have non-cancerous renal pathology and should be assessed for renal disease, including tests for proteinuria, estimated glomerular filtration rate (eGFR) and serum creatinine. Further action should be based upon clinical assessment.* [Mrs A] was having her renal function monitored as it was impaired. The most likely cause for this was renovascular disease secondary to her hypertension and hypercholesterolaemia and these risk factors were being treated appropriately and monitored. Impaired renal function would not raise suspicion of a unilateral renal malignancy in the absence of other suspicious symptoms and [Mrs A] had no symptoms suggestive of renal calculi or obstructive uropathy.

5. Urinary tract infections are common. Studies in the US have shown that approximately 50% of all women will have a urinary tract infection in their

lifetime, of these 25% will have recurrent infections[2]. Each year approximately 5% of women present to their GP with frequency and dysuria. With respect to management of patients with recurrent UTIs, a comprehensive and current medical literature review[3] includes the following points:

(i) *Recurrent urinary tract infection (UTI) refers to ≥2 infections in six months or ≥3 infections in one year. Most recurrences are thought to represent reinfection rather than relapse, although occasionally a persistent focus can produce relapsing infection … In a Finnish study of women ages 17 to 82 who had E. coli cystitis, 44 percent had a recurrence within one year … Among postmenopausal women, mechanical, and/or physiological factors that affect bladder emptying are associated with recurrent UTI.* In February 2012 [Dr D] considered a physiological cause for [Mrs A's] recurrent infections (atrophic urethritis) and planned to trial topical oestrogen cream and investigate with ultrasound had her symptoms recurred or persisted.

(ii) *Excretory urography and cystoscopy have been shown to uncover few abnormalities to influence subsequent management of UTI in women with recurrent UTIs. Thus, urologic evaluation of women with recurrent cystitis generally results in unnecessary expense and potential toxicity. However, further evaluation of the urinary tract is recommended if suspicion arises with any of the recurrences about complicating factors, such as structural or functional abnormalities of the genitourinary tract.* The presence of blood test results suggesting renal impairment might have lowered the threshold for further investigation such as ultrasound — more to assess kidney size and exclude obstructive uropathy rather than because malignancy was suspected. However, it was equally reasonable to monitor renal function (as was done) in the first instance to determine rate of progression, and to treat renovascular risk factors, and minimise any drug related nephrotoxicity, as was done.

6. A recent BPAC article[4] contained recommendations on investigation of patients presenting with haematuria — either visible (macroscopic) or non-visible (microscopic):

(i) *A urine dipstick positive for haematuria or proteinuria is a relatively common occurrence in primary care. For many patients there may be a benign or transient explanation for their results, e.g. urinary tract infection, however, persistent positive results require further investigation. Management is determined by the presence of associated symptoms, risk factors for malignancy and additional investigations to identify an urological or nephrological cause.* In [Mrs A's] case her microscopic haematuria was quite reasonably attributed to her symptomatic and culture-confirmed UTIs until it became evident at the end of May 2012 that

[2] Mehnert-Kay SA. Diagnosis and management of uncomplicated urinary tract infections. Am Fam Phys. 2005; 72:451–6

[3] Hooton T et Gupta K. Recurrent urinary tract infection in women. Uptodate. Last updated March 2013. www.uptodate.com

[4] BPAC. Interpreting urine dipstick tests in adults: a reference guide for primary care. Best Tests. June 2013

haematuria was persisting in the absence of infection, raising the likelihood of an alternative cause.

(ii) *Transient, non-visible haematuria is common and, depending on the studied population, may be reported in as many as 39% of people. It is associated with a mixture of urological and glomerular causes. Persistent, non-visible haematuria is defined as urine positive on two out of three consecutive dipsticks, e.g. over a one to two week period. It is estimated to occur in 2.5–4.3% of adults seen in primary care.*

(iii) *Haematuria can be symptomatic or asymptomatic. Relevant lower urinary tract symptoms include dysuria, frequency, urgency and hesitancy … A clinical history and examination may indicate a possible source of bleeding. As urinary tract infection (UTI) is a common cause of haematuria, this should first be considered and excluded. Non-visible haematuria is often transient so persistence should be confirmed by the presence of two out of three positive dipstick tests, seven days apart … Clinical suspicion of significant urological disease should be raised in people with haematuria with the following risk factors:*

- *History of recurrent visible haematuria*
- *Age over 40 years*
- *Current smoker or recent history of smoking*
- *History of recurrent urinary tract infection (UTI) or other urological disorders*
- *Occupational exposure to chemicals or dyes*
- *Previous pelvic irradiation*
- *History of excessive analgesic use*
- *Treatment with cyclophosphamide*

[Mrs A's] known risk factors were her age, her recurrent infection history (by definition, from early 2013) and her macroscopic haematuria (from June 2012). As discussed above, she was assessed for UTI on each occasion she presented with suspicious symptoms and infection was confirmed on each occasion. It was not until she was noted to have asymptomatic haematuria (and pyuria) at the end of May 2012 that suspicion for a non-infective cause for her symptoms was raised.

(iv) *Investigating visible haematuria: If UTI or other obvious causes have been excluded, imaging of the urinary tract is indicated. Assessment by an Urologist and cystoscopy will also be required in the majority of cases, although in young people (age less than 40 years with no risk factors for urothelial malignancy) cancer is unlikely to be the cause. If investigations are normal, i.e. do not suggest a urological cause, a nephrology opinion is required to exclude a medical renal cause, with urgency dependent on the continuing level of haematuria.*

(v) *Investigating non-visible haematuria with urinary tract symptoms: Non-visible haematuria is regarded as significant once transient causes, e.g. urinary tract infection (UTI) or exercise, or benign causes, e.g. menstruation, have been excluded. Urinary tract imaging is indicated for all patients of any age with*

recurrent, symptomatic, non-visible haematuria … Urological assessment and cystoscopy is also required for patients aged over 40 years, or for patients with risk factors for urothelial malignancy … Baseline assessment of blood pressure and renal function with testing of creatinine (eGFR), ACR/PCR and urine microscopy for urinary casts and dysmorphic red cells are also recommended to identify patients with a renal medical cause for non-visible haematuria. See preceding discussion on infection being confirmed as the most likely cause of [Mrs A's] presumed transient, but recurrent, microscopic haematuria.

7. A review article on RSCC[5] includes the following points:

(i) *Squamous cell carcinoma of the renal pelvis and ureter is a rare malignancy, having an incidence of 6% to 15% (of all urothelial tumors). Few cases of primary squamous cell carcinoma of kidney have been reported in the world literature.*

(ii) *The insidious onset of symptom and lack of any pathognomonic sign, leads to delay in the diagnosis and subsequent treatment, resulting in grave prognosis for these patients … Because of non-specific signs and symptoms, most of the patients present with advanced disease (stage pT3 and pT4) … SCC is frequently associated with calculus disease and hydronephrosis. Solid mass, hydronephrosis and calcifications are common but nonspecific radiological findings, which may explain why diagnosis is not frequently established before the histopathological examination of the resected surgical specimen … Early metastatic spread is common and the prognosis is poor with few patients surviving longer than 5 years.*

(iv) *Chronic irritation of urothelium is presumed to be a cause of squamous metaplasia with subsequent malignant progression to SCC … The common causes of chronic irritation in decreasing order are long duration of renal calculus disease, previous history of renal calculus surgery, chronic analgesic abuse or radiotherapy … The strongest association has been reported with renal calculus disease … Unfortunately, our current knowledge of squamous cell carcinoma is based on few case reports … the disease is found equally in both the sexes. The mean age of presentation is 56 years with no predilection for side (laterality) … Pain and hematuria are the most common presenting symptoms. Pain is due to pelviureteric junction obstruction and/or local extension … Hematuria may be due to primary tumor mass or calculus disease. The patients may present for the first time with anorexia, weight loss and/or lethargy, particularly in advanced cases … The diagnosis is usually confirmed by histopathological examination of the surgical specimen. Late onset pain, solid mass with or without hydronephrosis and rarity of the tumor are possible culprits behind late diagnosis of this entity.*

(iii) *Nephrectomy with ureterectomy is the treatment of choice in these patients. Even in the face of metastatic disease, nephrectomy should be performed to establish the histological diagnosis, for local control of symptoms such as pain,*

[5] Singh V, Sinha RJ, Sankhwar SN, Mehrotra B, Ahmed N, et al. (2010) Squamous Cell Carcinoma of the Kidney — Rarity Redefined: Case Series with Review of Literature. J Cancer Sci Ther 2: 087-090. doi:10.4172/1948- 5956.1000029

hematuria and elimination of source of infection particularly if associated with renal calculi.

(iv) *There is lack of evidence regarding survival benefit with chemo-radiation following surgery but it is still advocated by some with the hope of increasing survival. Overall prognosis is dismal.*

(v) These references emphasise the rarity of [Mrs A's] condition and the tendency to late detection and poor prognosis. I could not identify that she had any particular risk factors for the disease. Her sole presenting symptoms were apparently (in hindsight) recurrent UTI associated with haematuria — microscopic until June 2012 when it became macroscopic. She had no palpable mass and remained generally well at the time of diagnosis, with no reference to complaints of unexplained weight loss, anorexia, unexplained abdominal pain or lethargy.

8. Concluding comments on GP management of [Mrs A]

(i) **Comments below are subject to my review of [Mrs A's] blood and urine test results for the period 1 January 2011 to 1 August 2012. These will need to be obtained from the [Medical Centre 1]. Could they please also supply chest X-ray result from January 2012, and any notes received from [Medical Centre 2] in January 2012.**

(ii) [Mrs A] saw several providers in the year prior to her diagnosis but I do not feel this significantly affected her continuity of care. Each provider recounted the previous history and accurately documented the frequency and nature of [Mrs A's] symptoms and relevant results.

(iii) [Mrs A] presented initially with a very common problem in primary care — that of recurrent urinary tract infections. Each episode was appropriately investigated and infection confirmed. Each episode of infection was treated appropriately. Following the fourth infection (the third being treated at another medical centre) which was noted to be persistent, [Dr D] documented an intention to investigate further with ultrasound should the current infection not settle with a change in antibiotics, or if there was further recurrence. The symptoms settled and there was no recurrence. It is important to note [Mrs A] remained otherwise well over this period.

(iv) Earlier, [Mrs A's] chronic cough was promptly and appropriately investigated by [Dr C] by way of clinical examination and chest X-ray. The chest X-ray showed no signs of metastatic disease or other significant pathology and subsequent sequential CT scans did not show evidence of pulmonary metastatic disease although a benign nodule was found. Cough is a common side effect of the ACEI medication [Mrs A] was taking and can develop at any time during treatment. There was apparently a response to [Dr C] altering the type of ACEI [Mrs A] was taking.

(v) When [Mrs A] was found to have pyuria and haematuria in the absence of infection appropriate further initial testing was performed to exclude atypical

infections, and the microscopic examination repeated to exclude transient haematuria. Appropriate referral was made within four weeks of initial detection of the non-infection related haematuria which was reasonable noting further investigations were being performed over this period and [Mrs A] remained well. The referral was expedited when further testing confirmed the presence of malignant cells in the urine.

(vi) I note the rarity of [Mrs A's] condition and tendency to late diagnosis because of the subtle and non-specific way it can present leading to an overall very poor prognosis. I note also the frequency of UTI as a presentation in primary care.

(vii) I conclude that the management of [Mrs A] by her providers at [Medical Centre 1] was consistent with expected standards. However, I recommend the doctors use this case as an opportunity to refresh their knowledge of current guidelines in the investigation and management of recurrent UTI and haematuria."

Further expert clinical advice was obtained on 26 May 2014:

"1. Thank you for requesting review of additional information supplied on this case. My original advice was provided on 13 November 2012 and any additional comments made here should be read in conjunction with that advice. I have reviewed results of blood and urine tests performed on [Mrs A] during 2011 and 2012 together with a chest X-ray result from 10 January 2012 (normal). I have also reviewed notes from a consultation [Mrs A] had at [Medical Centre 2] (31 December 2011, consultation reported to [Medical Centre 1] 1 January 2012) in which she presented with symptoms and dipstick urinalysis findings suggestive of urinary tract infection, and received appropriate treatment for this. I requested a copy of urine results from the [Medical Centre 2] consultation noting a MSU had been requested at that time. The only result was dated 9 January 2012 which would have been following completion of the course of antibiotics prescribed. This showed no growth of bacteria, but persistent pyuria and microscopic haematuria. It does not appear a copy of this result was forwarded to [Medical Centre 1] (and this is acknowledged in the clinical notes) which might represent a missed opportunity for triggering further investigation in early 2012, although I note two urine samples taken by [Medical Centre 1] in February 2012 were consistent with infection and an intention was documented to investigate further should [Mrs A] have ongoing symptoms (which she did not until June 2012). I would expect casual providers to either 'copy in' a patient's usual GP when requesting tests, or to provide the usual GP with copies of any potentially abnormal results requiring follow-up once such results have been received. The failure to do so on this case, when the result might also have been consistent with the clinical scenario of recent use of antibiotics for UTI, was perhaps a mild departure from expected practice, but [Medical Centre 2] should have a robust process in place for handling of test results requested on casual patients.

2. There is one factor that requires further clarification by [Medical Centre 1]: on file are blood and urine results dated 31 May 2012, additional urine results dated 7

> and 18 June 2012 and faecal occult blood results dated 18 June 2012, all ordered by [Dr J]. However, I can find no record in the clinical notes regarding the circumstances surrounding ordering of these tests or how the results were to be followed up. While there was no obvious significant delay in management at this time, a documented structured management plan should have been in effect given the absence of an 'innocent' cause for [Mrs A's] sterile pyuria and her history of recurrent UTI. It appears active investigation and management was not resumed until [Mrs A] returned with gross haematuria on 28 June 2012. This could represent a mild departure from expected standards of clinical documentation and possibly of management (if there was no intention to further follow-up the persisting sterile pyuria) but any delay at this point was minimal and did not affect [Mrs A's] prognosis or eventual management."

Further expert clinical advice was obtained on 23 June 2014:

> "The following comments should be read in conjunction with the additional clinical advice provided on 26 May 2014. I have reviewed the additional information obtained from [Medical Centre 1] GP [Dr J] in relation to blood, urine and faeces tests ordered in June 2012. [Dr J] has provided a satisfactory explanation regarding the clinical rationale for ordering of the tests (the faeces tests being ordered in error) and she has provided documentary evidence of actions taken on receipt of the results. I conclude that the clinical management of [Mrs A] in relation to this testing was consistent with expected standards, and that the documentation associated with the testing (comments recorded on the patient results) was consistent with common and accepted practice."

Appendix B — Independent expert advice to the Commissioner

The following expert advice was obtained from urologist Dr Patrick Bary on 13 December 2013:

"I have been asked to comment on:

1. The timeliness and appropriateness of [Mrs A's] preoperative staging.

I am happy that the investigations following the referral were done in a timely fashion and were appropriated. However the report by [Dr H] on the CT chest dated 2 August 2012 raised a question about a mediastinal mass and offered to do more to delineate this if it were felt appropriate. Whether this CT was discussed or not and the possible mass discounted is not stated in any of the notes as far as I can see. It would appear in hindsight that this was a nodal mass so its presence may well have altered the decision to undertake a nephrectomy.

With respect to the delay before surgery was undertaken there appears to be some confusion. The letter written by [Dr I] on 15 August 2012 stated that the operation was to be booked on the urgent list. I don't know exactly what that means [at CCDHB] but it would certainly be best, if an operation were deemed appropriate, to do it within a few weeks at the most in these circumstances.

A letter to [Mrs A] from the Nurse Coordinator, written on 19 September 2012, stated that the last assessment date was 15 September but I can see no record of this. This letter stated that the waiting time would be up to six months.

The wait from the consultation with [Dr I] to the operation on 1 November 2012 was 107 days. Given that the clinical picture was that of either a high grade transitional cell carcinoma with squamous change or a squamous cell carcinoma of the upper urinary tract and given that there appeared to be metastatic disease at least locally, if an operation were deemed appropriate this appears to be a long delay. It would appear also that, since the question of mediastinal disease was raised in the chest CT report, a more up to date CT would most likely have influenced the decision to undertake the operation.

2. The delay between investigation and treatment; the CCDHB's response; remedial measures.

I have given my views about the delays in the above paragraphs. There would certainly appear to be clerical errors and it would appear every attempt has been made to remedy these. There is no mention of whether the urology department undertakes regular waiting time reviews in order to try to find people such as [Mrs A] whose priority may have been missed. If this does not occur it would be well worth considering.

[Comments removed for privacy reasons] [I]f the operation is deemed urgent and there is no opportunity for a particular surgeon to undertake laparoscopically, it could well be done as an open operation which is perfectly acceptable practice. I cannot see any note suggesting this as an alternative action.

3. Postoperative course; earlier imaging.

The clinical notes make particular mention of [Mrs A's] postoperative nausea and mention ([Dr I], 3 November 2012) of the fact that, during the operation there was considerable dissection in the area of the duodenum (see operation note also). It is well known that dissection in this area can cause slowing of gut motility and associated nausea. This was monitored (according to the notes) and appeared to settle as [Mrs A] began to pass flatus. Nursing notes and medical notes on the day of discharge describe a sore throat and some difficulty swallowing but that this was helped 'by chewing food longer than normal' (Espina, 5 November, 2012). I therefore feel that the problem was noted and appropriately managed according to the documentation.

A letter dated 15 November 2012 notifies receipt of a referral to Oncology and [Mrs A] was seen by [Dr M] on 29 November 2012. A CT scan done on 7 December showed further advancement of the disease. I feel that the timelines for referral and imaging were appropriate.

My conclusions are:

1. The lack of further clarifying imaging following the report of the CT by [Dr H] is of concern. If there was discussion with [Dr H] and a mutual decision was made that the possible mass was of no concern I would accept that to be a reasonable action. If however the concern in the report was not addressed I would regard that as moderate departure from expected standards of care.

2. The lack of an up to date CT scan given the elapsed time prior to surgery may well be of significance. There is no mention in the clinical notes prior to the operation to suggest exactly what was the reason for undertaking the nephrectomy. There was no evidence of any significant renal symptoms in the notes prior to the operation but a note by [Dr M] in November 2012 mentions back pain that was resolved by the operation. If it was felt that the operation was potentially curative then an up to date CT would have been important. If however it was to alleviate symptoms, the extent of metastatic disease would not have altered management. I cannot glean from the notes exactly what it was thought would be gained so further comment is not possible.

3. The delay between referral and nephrectomy is, in principle, a severe departure from expected standard of care. Having stated that I do not know of any unit in any DHB that has not had this unfortunate experience. Perhaps regular priority reviews and more clinician intervention in waiting time allocation would be of benefit.

4. I do not feel there was any significant lapse in [Mrs A's] postoperative management.

PATRICK BARY"

Further expert urology advice was obtained from Dr Patrick Bary on 21 July 2014:

"My advice is with respect to the questions you raise in your recent communication and is based on the correspondence and notes you have provided.

1. [Dr H's] radiology report. There does not appear to be any record of a radiology or MDT meeting at which [Dr H's] views about [Mrs A's] CT chest have been aired and discussed. The presence of metastatic disease in the chest is of great importance and any management decisions about and with [Mrs A] would need to include greater definition and acknowledgement of their presence. I accept [Dr G] view that their presence may not preclude an operation but I do not see any evidence to see that a plan was initiated taking these into account. In particular I do not see evidence that a discussion about them was had with [Mrs and Mr A]. This may well have altered their decisions notwithstanding the symptoms and signs the local disease was causing. In summary my concern is that [Dr H's] report does not appear to have registered appropriately. The responsibility for this lies with the clinicians. I would regard that as a moderate departure from expected standards of care.

2. The question of whether the nephrectomy was intended to be palliative treatment. The wording of [Dr I's] letter of 15 August 2012 shows that her view was that the operation would not clear all of the disease and therefore no attempt would be made for the operation to be curative in itself but there is no evidence of discussion with [Mrs A] of the possibility of further treatment such as chemotherapy or radiotherapy. I can not comment on how much [Mrs A] may have understood about her overall situation.

   Given that the last CT scan was dated 2 August 2012 and that a question was raised about whether there was evidence of metastatic disease in the chest at that time, I feel an up to date CT would have been helpful not only to the surgeon but also to [Mrs A].

3. I suspect there was human error involved with respect to the waiting list classification. [Dr I] stated in her letter [Mrs A's] operation was booked as an urgent operation but the form shows the booking to be semiurgent. Perhaps it would be helpful to have weekly or fortnightly reviews of the people on the urgent list in order to minimise the chance of delay. I can make no comment on the consent process as this is basically a verbal interaction but the letter to the GP should state that the expectations, likely outcomes and possible complications of the operation have been discussed.

4. I apologise that my calculation was wrong. The time from seeing [Dr F] to the operation was 107 days; the time from when [Dr I] placed [Mrs A] on the urgent waiting list was 78 days (15 August to 1 November).

5. The procedural changes proposed by CCDHB seem appropriate. I feel it is important that the clinicians have a system in place that allows time for interdepartmental discussion to occur. Is there a dedicated radiology meeting in which patients' radiology can be discussed and decisions made on whether further investigations are needed? If the only time is during a MDT, is there sufficient time? Do they have a dedicated uroradiologist?

6. [Comments removed for privacy reasons]

In response to my provisional decision, new information was provided by Capital and Coast District Health Board, and further expert urology advice was obtained from Dr Patrick Bary on 1 June 2015:

"1. As far as the original CT scan is concerned, I note that there was a lack of documentation about whether it was discussed and by whom and, in particular, what decisions about further care were made based on any discussion. I understand that it may have been likely that discussion and decisions did happen but if there is no documented evidence there can be no definite conclusion about that.

2. With respect to the preoperative chest xray, I maintain my view that, given that the tumour was high grade and that there was significant delay between the CT scan and the operation, an up to date CT of abdomen and chest may well have altered [Mrs A's] management and may have allowed further information to be given to [Mrs A] and her family, thereby giving them the opportunity to make informed decisions. A chest xray gives a far less accurate view of the chest than does a CT and in my view is not accurate enough, given [Mrs A's] situation. I note also that the chest xray request form did not make any mention of the nature of the renal disease; nor did it mention the chest changes seen on the previous CT.

3. I would also comment that, although [Dr I] states that she did not paint an unreasonably optimistic picture to [Mrs A], again there is no documented evidence to state in any detail that which she actually said.

4. [Comments removed for privacy reasons] Nephrectomy is a core urological operation and should not need to be delayed should an individual surgeon not be available.

5. Along with that it appears that the fundamental problems arose through a possible lack of communication and consequent understanding of the state and stage of [Mrs A's] cancer and a lack of documentation to support the assertions made in the explanatory response from the parties involved."