**Scottish Parliament Region: Highlands and Islands**

**Case 201004742: Highland NHS Board**

**Summary of Investigation**

***Category***

Health: Hospital; Oncology; clinical treatment; diagnosis

***Overview***

The complainant (Mr C) raised a number of concerns against Highland NHS Board (the Board) that if a small mass found on his kidney in December 2005 had been regularly and appropriately checked, the delay to diagnose his renal cancer could have been prevented. Mr C also complained about the inadequate manner the Board dealt with his complaint about this.

***Specific complaints and conclusions***

The complaints which have been investigated are that the Board:

(a) delayed to diagnose Mr C's renal cancer (*upheld*); and

(b) failed to address his complaint appropriately (*upheld*).

***Redress and recommendations***

| The Ombudsman recommends that the Board: | *Completion date* |
|---|---|
| (i) ensure that measures are taken to feedback the learning from this event to all medical staff, to understand the importance of avoiding similar situations recurring; | 6 June 2012 |
| (ii) review how hospital teams ensure that the results of patient investigations received after discharge are read and acted upon; | 6 June 2012 |
| (iii) conduct a Significant Events Review of this case; | 6 June 2012 |
| (iv) review their Complaints Management Procedures to ensure compliance, with reference to sections 5, 6 and 7; and | 23 May 2012 |
| (v) apologise for the failures identified in the report. | 9 May 2012 |

The Board have accepted the recommendations and will act on them accordingly.

## Main Investigation Report

### Introduction

1. The complainant (Mr C) raised a complaint against Highland NHS Board (the Board) about a misdiagnosis which resulted in a prolonged delay to his receiving the correct treatment from the Board.

2. In December 2005 Mr C said he admitted himself to Raigmore Hospital (the Hospital) with severe chest pain. During his stay in the Hospital an ultrasound scan detected an 8 millimetre mass on the outside of his left kidney. This was diagnosed as a benign fatty tumour. Thereafter, Mr C received no further out-patient appointments to attend for further scans. The Hospital account about this differs.

3. In June 2009 when Mr C was again admitted to the Hospital, an ultrasound scan found a mass had grown and renal cell carcinoma (renal cancer) was diagnosed.

4. Mr C stated that if the 8-millimetre mass found on his kidney in 2005 had been regularly checked it would not have become the 4 to 5 centimetre cancerous tumour found in 2009 – that this could have been prevented. As a result of this delayed diagnosis, Mr C stated that he had to undergo a partial nephrectomy to remove the tumour and part of his left kidney. He stated that this was major chest surgery which left him with the known complication of chronic and debilitating pain on the left side of his chest that limits all daily mobility. Mr C stated he could not perform daily chores and required his family to look after him. With the assistance of a Citizens Advice Bureau (CAB), Mr C complained to the Board on 16 September 2010, however, he was unhappy with their response. He raised a complaint with the Ombudsman on 28 February 2011 seeking a full investigation into what had happened.

5. The complaints from Mr C which I have investigated are that the Board:

(a) delayed to diagnose Mr C's renal cancer; and

(b) failed to address his complaint appropriately.

### Investigation

6. In her investigation of this complaint, my complaints reviewer obtained and examined Mr C's clinical records relevant to this complaint (the Records) and the complaint correspondence from the Board. She sought advice from one of

my professional advisers (the Adviser). My complaints reviewer also identified relevant government legislation and reviewed the Board's complaint policies and procedures.

7. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mr C and the Board were given an opportunity to comment on a draft of this report.

**(a) The Board delayed to diagnose Mr C's renal cancer**

8. Mr C stated that in December 2005 he presented to the Hospital with severe pains in his chest. He said he was diagnosed with pericarditis (inflammation of tissue surrounding the heart), though his medical notes indicated acute pancreatitis (inflammation of the pancreas).

9. During his hospital stay, Mr C said an ultrasound scan detected an 8 millimetre mass on the outside of his left kidney. Mr C stated that the radiologist thought this was a benign fatty tumour and scheduled a repeat ultrasound scan to be undertaken three months later. The subsequent ultrasound scan showed the mass was still present.

10. Mr C said that his consultant urologist at that time (Consultant 1) stated that Mr C was subsequently sent a letter for an out-patient appointment and a request for a further ultrasound scan. Mr C said he did not receive either of these communications (see paragraph 2).

11. Mr C stated that on 30 June 2009 he was admitted to the Hospital with diarrhoea and vomiting. During an examination a chest scan was performed and the previously detected lump had grown from 8 millimetres to 40 millimetres by 50 millimetres. Following a computed tomography (CT) scan, this was diagnosed as a small cell carcinoma (see paragraphs 1 to 4).

12. In a letter from Consultant 1 to Mr C's GP (the GP) dated 13 July 2009 Consultant 1 stated:

> 'clearly what we were seeing back then was likely to be a very early renal cell carcinoma and I suspect we would have performed an indeterminate CT scan by today's standard, but at that stage took the word of the Ultrasonologist that this was an AML [angiomyolipoma].'

13. Mr C said that during a clinic appointment prior to partial nephrectomy surgery to remove the tumour and part of his left kidney, the consultant dealing with the kidney cancer (Consultant 2) told him that an ultrasound scan was the wrong test to be performed on a tumour and a CT scan should have been performed to identify the nature of the mass. Mr C said that Consultant 2 indicated that the ultrasound scan would not effectively show the make-up of the tumour, so another scan should have been done. Mr C stated that receiving the information that his previous test was incorrect angered him (see paragraph 9).

14. Mr C stated he previously worked full-time as a manager. Following his operation and when the complication of chronic pain set in, he became unable to work. He stated he was in pain 24 hours a day. This resulted in his inability to move about and, according to Mr C, 'it is like being under house arrest'. He said he has to rely on his family to care for him, for daily chores and financial support.

15. Mr C independently reviewed his medical records and noted Consultant 1 had stated in a letter to his GP that 'There has been a little mix up over the follow up on this chap'. Mr C stated that this indicated not that he failed to attend the Hospital appointments, but that medical staff had failed to notify him of these appointments. Mr C also stated that aspects of this letter were contradictory with what was said in the Board's letter to him about the need for follow-ups (see complaint b, paragraphs 53 to 56).

16. Mr C also stated that he could only find one letter in his medical records. This was dated 15 January 2007 and asked him to contact the urology department if he wished further follow-up. Mr C said he did not receive this letter either. He stated he was also unable to find any letter requesting the ultrasound scan (see paragraph 10).

17. I note from the Board's response to Mr C, dated 24 November 2010, that it stated that an investigating officer had reviewed his complaint and Consultant 1 (who looked after Mr C) had provided the background information. The Board then gave an account of Mr C's hospital admissions in December 2005 and June 2009. The Board stated that between those dates Consultant 1 had written to Mr C's GP on 7 July 2006 stating: that the mass had not changed over the past 6 months; that he had requested an x-ray for Mr C; and that he had requested a further urology appointment for him.

18. Thereafter the Board stated:

'you did not attend the appointment for 12 September 2006, so [Consultant 1] wrote to your GP informing him of this and that another ultrasound had been requested. You did not attend for the ultrasound and [Consultant 1] wrote to you again on 9 January 2007 asking you to contact the Urology Department if you wished to have further follow up. There were no contacts from you so it was assumed you did not wish any further appointments.'

19. The Board also stated that Consultant 1 was sure that, had he the opportunity to review Mr C, he would have considered deploying a CT scan, 'However [Consultant 1] was deprived of the opportunity as you failed to attend his clinic.' This letter also stated it was clearly documented that Mr C failed to attend his clinic and ultrasound appointments and that Consultant 1 'is at a loss to think what more could have been done to contact you'.

20. The Adviser noted from the Records that Mr C was admitted to the Hospital twice in 2005 as an emergency. On the first occasion, the diagnosis was of pericarditis and, on the second, pancreatitis. He stated that there was no suggestion, nor any evidence, that the specific management of these problems was at fault, and it should be stressed that the subject of this complaint – the finding of a renal mass – was a finding entirely coincidental and unrelated to these problems.

21. The Adviser noted that on 11 December 2005 Mr C had an ultrasound scan of his abdomen. On 12 December 2005, a full report of this scan described a '2cm diameter mixed echogenic lesion - a CT scan is recommended for further evaluation'. The Adviser noted that when Mr C's final discharge summary was prepared on 22 December 2005 and typed on 29 December 2005, the letter made no mention of the renal finding and recommendation that a CT scan be undertaken. The Adviser said at this stage, Mr C's GP would, therefore, not be aware of the finding of the renal mass and it was unclear if Mr C knew. The Adviser also stated it is unclear if the team involved in Mr C's in patient care had appreciated the result of the scan.

22. The Adviser stated that on 10 February 2006 Mr C attended the Hospital for a repeat ultrasound scan. The Adviser stated there was no specific mention

made of the previous recommendation of a CT scan. A further follow-up ultrasound was suggested for three months time.

23. The Adviser could find no communication with Mr C or his GP regarding the finding of the renal mass at this point. He stated the possibility that the radiologist undertaking the scan may have mentioned it to Mr C at the time the scan was done. There was no record of this.

24. The Adviser noted Mr C was seen at a follow-up clinic in May 2006 and it was recorded there was a mass in the kidney. There was still no reference to the previous radiology recommendation regarding CT scanning after the first scan (see paragraph 20).

25. The Adviser noted that an appropriate referral to a urologist was then made, some six months after the initial finding of the mass, and on the basis of clinical information that was all available at least three months previously. Also, the letter to the GP, the letter to the urologist and the handwritten note did not indicate what information was given to Mr C regarding the finding in the kidney or the need for a follow-up ultrasound or urology opinion. The Adviser stated it was possible, therefore, that Mr C was not told at all that a referral would be made to the urologist and to expect an appointment in the post.

26. A further ultrasound scan was undertaken on 14 June 2006, which the Adviser presumed was the result of the clinic attendance in May 2006. This suggested a repeat scan in six months but did not say how it had been arranged.

27. On 7 July 2006 Consultant 1 (having had the scan forwarded to him) wrote to Mr C's GP, stating that the scan appearances had not changed over the past six months and that he had requested a further scan for six months time. This would mean that the next scan should have taken place in January 2007.

28. The Adviser stated that at this point it was unclear, given the fact that Mr C had not yet been seen in the urology clinic, if Consultant 1 had had the opportunity to review the notes or knew that a radiologist had initially recommended that a CT scan be undertaken.

29. The Adviser noted that on 12 September 2006 Consultant 1 wrote a letter to the GP which appeared to have originated from a clinic. The Adviser

assumed Mr C had not attended on that day (this fitted in with the plan for a four month review from the referral in May 2006). The Adviser noted in this letter that Consultant 1 stated Mr C need not be seen at the clinic as long as he attended for regular ultrasounds. The letter also stated 'a little mix-up in the follow up of this patient' however the Adviser was unclear precisely what this statement referred to. The Adviser also noted reference was made to 'the lesion has been incidentally detected again during investigations for pancreatitis'. In the Adviser's view this suggested possible confusion regarding the length of time that the lesion had actually been present.

30. The Adviser stated there was no record of any separate communications with Mr C: which informed him he did not attend; explaining the reason for follow-up, or encouraging him to attend at future ultrasound scan appointments. He stated, 'Again, there is no evidence to demonstrate that [Mr C] at any time had been told of the purpose of the follow up scans'.

31. The Adviser noted an unsigned form dated 5 January 2007 from an x-ray appointments officer (with no patient identification reference), addressed to Consultant 1 which highlighted a standardised statement, 'unfortunately the patient has not made any contact with this department'. In my review of this document I consider it ambiguous and unclear. It leaves me with several unanswered questions over the reason for the message it attempted to convey.

32. On 9 January 2007 Consultant 1 wrote to Mr C (copy to his GP). This letter stated that Mr C had been due to attend for an ultrasound scan 'towards the end of last year' and that if he wished further follow-up he should contact the Urology Department.

33. As noted above, the Adviser stated there was still no evidence that Mr C was aware of the reason for follow-up. His GP had been previously informed of the recommendation for follow-up in earlier letters, however, may have had no contact with Mr C.

34. The Adviser stated that at that point in time Mr C had apparently failed to attend one out-patient appointment and one ultrasound appointment, neither of which he may have known the purpose of. However, within the past eight months the Adviser noted that Mr C had attended one other out-patient appointment made for him and two out-patient ultrasound scans.

35. The Adviser noted that on 1 July 2009 Mr C presented at the Hospital with further abdominal pain and another ultrasound was done. The ultrasound report noted a 40 millimetre by 48 millimetre echoic soft tissue mass arising from the lower pole of the left kidney, which was subsequently found to be a carcinoma of the kidney. This was the same area of the kidney where the original lesion had been seen (see paragraph 20).

36. The Adviser stated that subsequent letters in the Records acknowledge that the lesion seen in the scans of 2005 and 2006 was likely to be very early renal cell carcinoma. In Consultant 1's letter dated 13 July 2009 to the GP, he stated that Mr C had defaulted from follow-up and 'I suspect we would have performed an indeterminate CT scan by today's standard but at that stage took the word of the Ultransonologist that this was an AML' (see paragraph 12).

37. The Adviser said that the investigation of a renal mass had evolved in recent years. He stated that the findings on ultrasound of a mass which is wholly or partly solid would now result in a CT scan being performed as a matter of routine, unless the patient was too unwell to permit investigation. Before CT scans were widely available, repeat ultrasounds would be undertaken to assess whether the mass was growing in size – were it to do so, the suspicion that it was malignant would increase.

38. The Adviser noted Mr C had three ultrasounds over an eight month period in 2005-6 (on 11 December 2005, 10 February 2006 and 14 June 2006), each of which demonstrated a solid mass which did not change in size over that time. Two scans suggested AML as the likeliest diagnosis, but suggested follow-up by repeat scan (see paragraphs 20 and 25). The other scan, the first, did not make a firm diagnosis but recommended CT scanning (see paragraph 19). According to the Adviser, this suggested a possible difference of approach amongst radiologists in this unit at this time (from 11 December 2005 to 14 June 2006) but, furthermore, that CT scanning was easily available and this diagnostic approach was understood within the department.

39. The Adviser said it was relatively reassuring that before the medical team formed the view that Mr C did not wish follow-up, the follow-up they proposed was frequent and should continue in the long term.

40. The Adviser stated that Consultant 1 may have had the clinical practice at that time to follow such abnormalities by ultrasound scan and not undertake

CT scanning unless other clinical information suggested it necessary. However, in the Adviser's opinion, such judgements are best made in conjunction with the radiologists reporting the scans, and ideally with the knowledge and understanding of the patient. In this case there was no evidence that there was such shared decision making and no evidence that Consultant 1 was aware that at least one radiologist had recommended CT scanning (see paragraph 19).

41. The Adviser has also not seen evidence that any member of the surgical team initially responsible for the care of Mr C in December 2005 was aware of the radiology report that recommended CT scanning. He stated if they were aware, it was surprising that no comment was made at the time. He also considered it noteworthy that in May 2006, on the basis of no extra clinical information (other than the fact that a repeat scan had shown no change in the lesion), a decision was made by the same team to refer Mr C to an urologist. This suggested to the Adviser that had the renal ultrasound findings been appreciated or more carefully considered in December 2005, a similar referral – and perhaps also a CT scan - would have taken place at that time. The Adviser stated it should be noted that the issue of how hospital teams ensure that results of investigations received after discharge of a patient are read and acted upon, is the subject of scrutiny in the Scottish NHS at this time.

42. In the Adviser's view, had the clinical teams involved in this case noted the recommendation that a CT scan be undertaken but then, after review of the ultrasound appearances or discussion with radiology (and ideally Mr C) made a judgement that a CT scan was not indicated at that point and documented this, then this would have, in his opinion, been entirely acceptable. However, there was no evidence the Adviser has seen that any such review or discussion took place, and no evidence that any clinician directly involved in Mr C's care appreciated the recommendation of the radiologist in December 2005 that a CT scan should be undertaken (see paragraph 20).

43. On balance, therefore, the Adviser considered that this represented care below a standard which could reasonably be expected in a hospital of this sort at that time.

44. The Adviser summarised Mr C's follow-up pathway at the Hospital as follows:

- from the Records it seems likely that Mr C was sent a single appointment for the urology clinic and did not attend;

- it was less clear if the ultrasound appointment in December 2006/ January 2007 was actually sent and Mr C did not attend, or whether he was asked and failed to arrange a scan date;
- Mr C did not appear to have been provided with any direct information regarding the justification for and importance of follow-up; and
- the GP was not made sufficiently aware of the importance of follow-up.

45. The Adviser said that based on his review of the records, it was not possible to determine if appointments were actually sent or received. However, he considered the evidence supported the view that Mr C was not sufficiently well informed about the reason that follow-up was being requested, in order to make a sensible decision about whether or not to attend. Mr C had never met a urologist, may not have been told he was being referred to a urologist and it was not clear whether the radiologist, the clinician who saw him in the Out Patient Department in May 2006, or his GP (who was given little information himself) ever explained the renal findings and their potential implication to Mr C.

46. Given the potential (and ultimately actual) seriousness of the renal problem, the Adviser stated he did not feel that all that could have been done to attempt to ensure that follow-up occurred did actually occur.

*(a) Conclusion*

47. Mr C complained that the diagnosis of his renal cancer was delayed. As a result of this, and complicated by the major and more severe surgery he had to undergo, his health and quality of life has been severely affected. He can no longer work; has to live with parental support and is in constant and acute pain.

48. My investigation has established several systemic failures which occurred from December 2005, that:

- there is no evidence of shared decision making (such as of case reviews or discussions);
- there is nothing documented to indicate whether Consultant 1 was aware or not of the radiologist's critical recommendation for a CT scan;
- there is nothing documented to indicate whether any member of the surgical team was aware or not of the radiology report that recommended CT scanning;
- Mr C's GP was not made sufficiently aware of the importance of follow-up regarding Mr C's condition or presented symptoms;

- there is no evidence that Mr C was sufficiently informed of the reason for follow-up to empower him to reach a decision about his condition/prognosis; and
- there is no evidence that any of the medical staff in the Urology Department explained the potential significance or justification for follow-up to Mr C.

49. I have carefully considered all the evidence outlined above and the issues and active knowledge presented in the Records. Taking all these factors into account, I uphold this complaint.

*(a) Recommendations*

| 50. I recommend that the Board: | *Completion date* |
|---|---|
| (i) ensure that measures are taken to feedback the learning from this event to all medical staff, to understand the importance of avoiding similar situations recurring; | 6 June 2012 |
| (ii) review how hospital teams ensure that the results of patient investigations received after discharge are read and acted on; and | 6 June 2012 |
| (iii) conduct a Significant Event Review on this case. | 6 June 2012 |

**(b) The Board failed to address his complaint appropriately**

51. Mr C said he was assisted through the Board's complaint's procedure by a Citizens Advice Bureau (CAB). He stated that the subsequent complaint response he received from the Board was 'lacklustre'. In his view the points raised within the response did not match the actual medical notes he obtained. Mr C also said the Board did not find fault in their procedures which had left his health and quality of life severely affected (see complaint a).

52. I have seen Mr C's complaint letter dated 16 September 2010 to the Board, in which he stated that:

- he was advised regular ultrasound scans would take place but this never happened;
- in his medical notes was a copy of a missed appointment letter which he never received; and
- he was never given appointments to monitor the 8 millimetre mass found in 2005.

53. Mr C also raised several issues and questions, for example, he asked why he was given ultrasound scans and not CT scans, which he was told could have detected the cancer sooner and this was something confirmed to him by a consultant (see paragraph 13).

54. The Adviser's view was sought on the medical aspects of the Board's complaint response of 24 November 2010 to Mr C. The Adviser said that in this letter:

(i) it did not state that a CT scan had been recommended after the first ultrasound scan;

(ii) it made reference to a 'further' urology appointment when in fact Mr C had not been seen in urology at this time nor had he missed any urology appointments;

(iii) in describing the contents of Consultant 1's letter dated 12 September 2006 to the GP, it did not include Consultant 1's statement that the urology clinic review was not actually necessary, provided further ultrasound scans had taken place; and

(iv) in a subsequent paragraph it stated Consultant 1 would have 'considered alternative investigation by CT scan. However he was deprived of the opportunity as [Mr C] failed to attend his clinic'.

55. The Adviser said this statement is 'at odds' with (iii), which had indicated Consultant 1 did not feel he needed to see Mr C in the clinic and also, within this response, no mention had been made that a radiologist had actually recommended CT scanning.

56. The Adviser stated that for the reasons outlined in paragraph 54, the Board's response to Mr C was incomplete and inaccurate.

57. I consider that, given the seriousness the substance of the complaint warranted, there was a lack of detail and explanation the complaint response should have reflected. For example, in his complaint letter of 16 September 2010, Mr C requested why ultrasound scans were preferred and not CT scans, which he was told could have detected the cancer sooner. Within the Board's response dated 24 November 2010 this issue had not been addressed (see paragraph 54).

58. I also consider that, both in tone and content, the Board's response was inadequate. It reflected a position whereby the Board had viewed/judged the events from 2005 onwards as Mr C's responsibility and his alone. Furthermore, it appeared that the response had included only sections of Consultant 1's letter dated 12 September 2006 to Mr C's GP that as outlined in paragraph 54, presented an ambiguous and misleading account of events to Mr C (see also complaint a, paragraph 15).

*(b) Conclusion*

59. Mr C is dissatisfied with the Board's response to his complaint. I consider the response failed to demonstrate an appropriate level of understanding which the serious issues at the heart of this complaint merited and given the evidence available in the Records. I also consider that the Board presented misleading, imprecise and insufficient information to Mr C and also failed to give direct answers to the questions he posed. Furthermore, I am critical that the outcome of the Board's investigation into his complaint appeared to determine that Mr C had sole responsibility for the events that followed December 2005 (see also complaint a). For all these reasons I uphold this complaint.

*(b) Recommendation*

| 60. I recommend that the Board: | *Completion date* |
|---|---|
| (i) review their Complaints Management Procedures to ensure compliance, with reference to sections 5, 6 and 7. | 23 May 2012 |

*General Recommendation*

| 61. I recommend that the Board: | *Completion date* |
|---|---|
| (i) apologise for the failures identified in the report. | 9 May 2012 |

62. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that the Board notify him when the recommendations have been implemented.

**Annex 1**

**Explanation of abbreviations used**

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|---|---|
| Mr C | The complainant |
| The Board | Highland NHS Board |
| The Hospital | Raigmore Hospital |
| CAB | Citizens Advice Bureau |
| The Records | Mr C's clinical records |
| The Adviser | A specialist adviser to the Ombudsman |
| Consultant 1 | Mr C's consultant urologist |
| CT scan | Computed Tomography scan |
| The GP | The GP at Mr C's local practice |
| The Ultrasonologist | Ultrasound scanning specialist |
| AML | Angiomyolipoma |
| Consultant 2 | The consultant dealing with Mr C's kidney cancer |

**Annex 2**

## Glossary of terms

| | |
|---|---|
| Acute pancreatitis/ pancreatitis | Inflammation of the pancreas |
| Angiomyolipoma | Most common benign tumour of the kidney |
| Benign fatty tumour | These are known as lipomas and most frequently occur in soft tissue |
| Echogenic lesion | A tumour detected by ultrasound |
| Nephrectomy | The surgical removal of a kidney |
| Pericarditis | Inflammation of tissue surrounding the heart |
| Renal cell carcinoma<br>Small cell carcinoma | Renal cancer |
| Ultrasound scan | Diagnostic imaging technique of internal body structures |
| Urology | Medical and surgical study of the urinary tract |