

The investigation of a complaint
by Mrs X
against Aneurin Bevan Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201302660

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Introduction

This report is issued under section 16 of the Public Services Ombudsman (Wales) Act 2005.

In accordance with the provisions of the Act, the report has been anonymised so that, as far as possible, any details which might cause individuals to be identified have been amended or omitted. The report therefore refers to the complainant as Mrs X and her late father who is the focus of the complaint as Mr Y.

Summary

Mrs X complained about the length of time that her father (Mr Y) had to wait to be seen following a referral made by his GP in September 2012 for an endoscopy at the Royal Gwent Hospital. Mrs X highlighted that there had been a downgrading of the referral from urgent suspected cancer (USC) without her father having been seen and without any discussion with his GP. She was also concerned about the lack of clear ownership and responsibility for her father's care. Mrs X said that there was a lack of cohesion between the differing specialities involved which resulted in communication failures. Mrs X was of the view that her father's treatment and quality of life might have been improved if he had been seen in a more timely manner.

Mrs X also complained that the Health Board's subsequent investigation into her complaint failed to accept responsibility and acknowledge the harm that was caused by the delay in Mr Y receiving attention.

In investigating the complaint the Ombudsman took account of the view of one of her Clinical Advisers. The Ombudsman found there to be unacceptable delays in the care provided and said that no sense of urgency was shown to Mr Y's clinical condition. She said that there were shortcomings in the leadership and ownership of the care and treatment being provided to Mr Y.

The Ombudsman raised concern about inadequate communication with the GP and with Mr Y and his family.

The Ombudsman highlighted that the relevant Health Board policy did not comply with the NICE guidelines. The Ombudsman was also concerned about the waiting time for an urgent outpatient appointment. She said there had been an unnecessary delay in an endoscopy procedure being carried out. The primary site of cancer was identified following this.

The Ombudsman upheld the concerns raised by Mrs X about the clinical care. She noted that although a more timely response would not have changed the sad outcome, it might have avoided the unnecessary psychological suffering felt by Mr Y and his family. It was also possible that a tracheostomy procedure could have been avoided.

The Ombudsman also upheld Mrs X's complaint about the Health Board's subsequent complaint investigation.

The Ombudsman recommended that the Health Board:

- a. provide an apology to Mrs X for the significant shortcomings in her father's care and treatment.
- b. provide financial redress to Mrs X of £1500 for the distress caused to Mr Y and his family and £500 for the time and trouble incurred in making a complaint and for the shortcomings in the complaint response.
- c. review the endoscopy referral criteria for USC to ensure consistency with the relevant NICE guideline.
- d. ensure that the First Consultant Gastroenterologist considered the issues raised in this case.
- e. take action to ensure that the unacceptable delays for urgent outpatient appointments are addressed.
- f. review the process to ensure that abnormal results are acted upon urgently by a lead clinician or relevant cancer MDT.
- g. review how it communicates effectively and appropriately with patients and their families, particularly when more than one speciality is involved.
- h. comply with the "Putting Things Right" framework including a proper consideration of "qualifying liability" and seeking independent clinical advice in appropriate circumstances.

The complaint

1. Mrs X complained about the length of time that her father (Mr Y) had to wait to be seen following a referral made by his GP in September 2012 for an endoscopy at the Royal Gwent Hospital. Mrs X highlighted that there had been a downgrading of the referral from urgent suspected cancer (USC) without her father having been seen and without any discussion with his GP. She was also concerned about the lack of clear ownership and responsibility for her father's care. Mrs X said that there was a lack of cohesion between the differing specialities involved which resulted in communication failures. Mrs X was of the view that her father's treatment and quality of life might have been improved if he had been seen in a timelier manner.
2. Mrs X also complained that the Health Board's subsequent investigation into the complaint failed to accept responsibility and acknowledge the harm that was caused by the delay in Mr Y receiving attention.

Investigation

3. My Investigator obtained comments and copies of relevant documents from Aneurin Bevan Health Board and these have been considered in conjunction with the evidence provided by Mrs X. I have not included every detail investigated in this report but I am satisfied that nothing of significance has been over looked. As part of this investigation clinical advice was sought from one of my Professional Advisers, an experienced Consultant Physician, Dr Richard McGonigle.
4. Both Mrs X and Aneurin Bevan Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued.

Guidance

5. National Cancer Standards (June 2005)

The Standards state that patients who are referred by their GP as urgent with suspected cancer and confirmed as this by the Consultant or a designated member of the multi disciplinary team should begin definitive treatment within two months of receipt of referral at the hospital if diagnosed with cancer.

The “10 day wait” for initial assessment when referred urgently by a GP with suspected cancer (not a national reportable target) is a relevant contributor to performance against the two month target.

Patients who are not initially referred as urgent suspected cancer, but who are subsequently diagnosed with cancer should begin their definitive treatment within one month of diagnosis.

6. NICE Clinical Guideline 27 Referral guidelines for suspected cancer - Suspected upper GI cancer

1.4.2 dysphagia (unquantified), and unexplained dyspepsia¹ of recent onset in patients aged more than 55 years are both individual indicators for underlying cancer justifying urgent endoscopy.

The background events

7. In commenting on the draft report, the Health Board said that Mr Y had a very complex clinical background and had been attending numerous outpatient appointments. These included Cardiology, Vascular surgery and Radiology and the Chest clinic from July 2012.
8. The Health Board explained that an evaluation of Mr Y at the Chest clinic took place following the finding of a left pleural effusion and shadowing dating back to an admission at Aberystwyth in March 2011 when Mr Y had pneumonia and heart failure.

¹ Dyspepsia in unselected patients in primary care is defined broadly to include patients with recurrent epigastric pain, heart burn or acid regurgitation with or without bloating, nausea or vomiting.

9. **January 2012** By this time an abnormal chest x-ray² had been identified and a CT scan was recommended by the Radiology Department for Mr Y.³
10. **April** Mr Y underwent an endovascular repair of an abdominal aortic aneurysm following investigations for heart failure and impaired left ventricular function.
11. **15 May** A CT chest scan was undertaken. Further evaluation was recommended. The appearances of the scan at this time were reported to be unchanged from July 2011. The Radiology Department wrote to the Consultant Cardiologist following this.
12. In commenting on the draft report, the Health Board pointed out that the changes on Mr Y's X-ray in January and the CT thorax in May were unrelated to the metastases identified on the later CT scan of Mr Y's thorax (September). The Health Board added that the pleural changes did not alter on subsequent CT scans and were completely unrelated to Mr Y's subsequently diagnosed laryngeal cancer.
13. **31 May** The Consultant Vascular Surgeon wrote to the First Consultant Respiratory Physician for his view on how to proceed with the care. He referred to the result of the CT scan performed on 15 May. There was uncertainty about the nature of the lesion in the left lower zone of the lung which had been present since the previous CT had been undertaken.
14. **7 June** The Consultant Cardiologist⁴ also wrote to the First Consultant Respiratory Physician with the result of the CT scan. He noted that the CT had been arranged following an abnormal chest X-ray. He sought advice on the management of Mr Y's condition. A hand written note on this letter⁵ suggested that the First Consultant Respiratory Physician requested for Mr Y to attend the pleural clinic of the Second Consultant Respiratory Physician.

² An X-ray was undertaken on 6 January 2012, following a request via cardiology.

³ This was not undertaken until 15 May 2012. There was some reference to confusion over which consultant was involved.

⁴ Mr Y was noted to be under the Consultant Cardiologist's follow up.

⁵ Note was dated 20/6/12. A response was dated 21/6/12 and stated "Yes ok clinic of August/Sept if possible".

15. **8 June** The Health Board noted⁶ that the referral letter from the Consultant Vascular Surgeon was considered by the First Consultant Respiratory Physician and he requested an urgent outpatient appointment.

16. **24 July** Mr Y attended an outpatient appointment with the Second Consultant Respiratory Physician. The Second Consultant Respiratory Physician then wrote to the Consultant Cardiologist with the outcome of the consultation.⁷ A further CT scan (thorax), repeat chest x-ray and pleural ultrasound scan were arranged. A review in clinic was planned to take place in two months. At this point the Second Consultant Respiratory Physician also wrote to the appointments booking centre stating that Mr Y was quite distressed by the number of referral letters that he was receiving. The Second Consultant Respiratory Physician sought an explanation as to the reason Mr Y was receiving correspondence to attend the First Consultant Respiratory Physician's clinic as well as her own in September.

17. In commenting on the draft report, the Health Board said that the radiology tests arranged (following this July appointment) were planned for September, to follow up what at that time was believed to be a benign pleural abnormality.

18. **9 August** A Hospital appointment record shows that Mr Y did not attend an appointment with the First Consultant Respiratory Physician and noted that follow up with the Second Consultant Respiratory Physician was already arranged.

19. **14 August** A Hospital appointment record shows that Mr Y could not attend an appointment with the Second Consultant Respiratory Physician. It was noted that a further appointment was required.

20. **7 September** Mr Y was referred to the Royal Gwent Hospital following a consultation with his GP. He had symptoms of heartburn, indigestion and mild dysphagia. The GP referral to gastroenterology was forwarded as urgent suspected cancer (USC) via facsimile.

⁶ Health Board's complaint response timeline (3 July 2013).

⁷ Although the Second Consultant Respiratory Physician decided to follow up Mr Y, at this point she noted that the pleural thickening was likely to be after Mr Y's treated pneumonia and parapneumonic effusion possibly with a contribution from heart failure.

21. **10 September** The First Consultant Gastroenterologist triaged the GP referral. It was judged that the symptoms described within the referral letter did not qualify for the Health Board's criteria as USC. The First Consultant Gastroenterologist triaged the referral for an initial outpatient appointment on an urgent basis.⁸ This change in status was not communicated to the GP.

22. Mrs X commented that the clinicians had picked up a lesion in the left lower zone of Mr Y's lung in May and that along with Mr Y's physical symptoms (which resulted in him visiting the GP) should have rung alarm bells. She added that it was wrong to downgrade her father from USC.

23. Mrs X also added that a GP "glues" a person's healthcare together and said that the GP should have been advised. She also said that it was unacceptable to downgrade a person's referral without even seeing the patient. Mrs X said that the delay severely impacted on Mr Y's quality of life.

24. Mrs X also commented that 'urgent' should still mean that a person is seen promptly.

25. The Health Board also told my Investigator that the First Consultant Gastroenterologist triaged the referral for an urgent out-patient appointment rather than for direct access gastroscopy because the GP had referred to Mr Y's left ventricular failure and warfarin which could pose a risk for gastroscopy.⁹

26. In commenting on the draft report, the Health Board said that at the time of the GP referral a diagnosis of cancer had not been made. It said that at this point Mr Y was awaiting a planned follow-up CT scan (arranged by the Second Consultant Respiratory Physician in July). The Health Board said that this was to follow-up on what at the time was considered to be scar tissue as a reaction to the pneumonia that occurred in March 2011. The Health Board said that in addition to the GP referral, the First Consultant Gastroenterologist reviewed the results of the CT scan from May as well as the clinic letter from Mr Y's appointment with the Second Consultant Respiratory Physician in July.

⁸ The Health Board (complaint response 3 July 2013) stated that Mr Y was put on the out-patient waiting list as of 7 September.

⁹ This is an upper gastrointestinal endoscopy.

27. The Health Board told my Investigator that the symptoms mentioned in the referral letter were unlikely to be connected with Mr Y's eventual diagnosis.¹⁰

28. The Health Board in commenting on the draft report said that consultants can review GP referrals and decide how to manage them. It said a referral can be downgraded without a patient being seen. However the Health Board stated that it would have been its normal practice to communicate with a patient's GP and said that the communication fell below an appropriate standard in Mr Y's case.

29. **11 September** A Hospital appointment record shows that Mr Y did not attend a follow up appointment with the Second Consultant Respiratory Physician. The appointment record noted pleural clinic in 2-3 months. The Health Board also provided a copy of a confirmation letter which it said was sent to Mr Y on 6 July informing him of this appointment at 10.00 am. Mrs X said that this appointment letter was never received and said her father would never consciously not turn up to an appointment.

30. **27 September** A CT of Mr Y's thorax was performed (following the referral made by the Second Consultant Respiratory Physician on 24 July). Due to the findings (noted as almost certain metastases) a CT of Mr Y's abdomen and pelvis was recommended by the Radiology Department. It was not clear whether this result was immediately shared with the Second Consultant Respiratory Physician.

31. In commenting on the draft report, the Health Board said that the hold-up in the subsequent CT of Mr Y's abdomen /pelvis (to look for the primary source of cancer) was a consequence of a delay in reviewing the scan result and arranging a clinic appointment. The Health Board said that it had cancelled one appointment although it was not clear on the reason for this having occurred. It said that there had been a few weeks delay in Mr Y being informed of the results of the September scan and the requesting of further investigations.

¹⁰ The Health Board said that Mr Y's symptoms rapidly changed during the autumn. It said that the symptoms described in the referral letter were lower oesophageal in nature, whereas the subsequent tests found laryngeal cancer with lung metastases.

32. The Health Board in commenting on the draft report said that it recognised that this was a shortcoming and wished to apologise for this.

33. **15 October** A note in the clinical records refers to a query cancellation on this date. There is reference to 23 October. A Hospital appointment record on 16 October also noted that Mr Y was to attend a 'rapid access' respiratory clinic but the appointment had been cancelled by the Hospital with follow up planned at a pleural clinic during October.

34. **19 October** Mr Y returned to see his GP with a family member. Mrs X said that her father's condition had deteriorated considerably. Mrs X said that the GP was very concerned that Mr Y had not been seen following his previous referral and added that the GP contacted the endoscopy unit during the consultation. The GP did not obtain a response and said that he would continue trying to make sure that Mr Y was seen urgently. The Health Board subsequently told my Investigator that it had no record of the GP making contact to expedite the referral.

35. **23 October** Mr Y was seen by the First Consultant Respiratory Physician. The clinical records show that this Consultant discussed the recent CT scan of 27 September with Mr Y and referred to "? met. cancer". Amongst other points the First Consultant Respiratory Physician noted that Mr Y required an endoscopy and he requested a CT of Mr Y's abdomen/pelvis. The First Consultant Respiratory Physician referred to the Second Consultant Gastroenterologist and provided an update on Mr Y's condition and noted that Mr Y was on the waiting list for an endoscopy.

36. Mrs X said that her father was informed by the First Consultant Respiratory Physician that secondary nodes had been identified on his lungs but that the primary malignancy could not be located without further tests.

37. Mrs X emphasised that at this point her father was informed that he had cancer but was still not seen by a gastroenterology consultant until 4 December.

38. The Health Board in its final complaint response¹¹ to Mrs X highlighted that the referral to the Second Consultant Gastroenterologist was made on

¹¹ Health Board complaint response of 3 July 2013.

this date. It stated that there was a six week gap from the First Consultant Gastroenterologist triaging the GP referral letter to the Second Consultant Gastroenterologist being involved in Mr Y's care and managing Mr Y as having a suspected cancer. It noted that Mr Y was already under the care of the respiratory team and being investigated for a suspected cancer.

39. **25 October** Mrs X e-mailed the Health Board's enquiry line asking how long a patient should expect to wait for an USC endoscopy referral. Mrs X said that she received no response to this.

40. **26 October** The Second Consultant Gastroenterologist discussed the findings in relation to Mr Y at a Multi-Disciplinary Gastrointestinal X-ray meeting. Following the discussion a diagnosis was made of metastatic pulmonary nodules. The CT of Mr Y's abdomen and pelvis was still awaited.

41. **30 October** The Second Consultant Gastroenterologist wrote back to the First Consultant Respiratory Physician explaining that the CT scan had been reviewed at the Multi-Disciplinary Gastrointestinal X-ray meeting and that the consensus was that Mr Y should have a CT scan of his abdomen and pelvis which was noted to have been arranged for later that week. The record shows that the Second Consultant Gastroenterologist had "...not arranged endoscopic investigation for the time being".

42. **31 October** Mr Y had a CT scan of his abdomen and pelvis. In commenting on the draft report the Health Board said that this scan was not a follow up, rather it was carried out as a non-invasive way of looking for the presumed primary tumour. The Health Board said that it wanted to carry out this scan before arranging an endoscopy. The Health Board noted that the referral for this scan was written on 23 October¹² and that the procedure was carried out within 7 days. The Health Board said that there was no delay in the CT scans being undertaken by radiology on receipt of a request. The scan showed no evidence of primary malignancy within the abdomen or pelvis. The Radiology Department suggested that an endoscopy should be performed in the presence of dysphagia. Mrs X said that the outcome of the CT scan was intended to be available within a week.

¹² The referral form (Radiological Imaging Request Form) shows that it was faxed on 23 October 2012.

43. **12 November** Mrs X rang the First Consultant Respiratory Physician's office. Mrs X was informed that the First Consultant Respiratory Physician was on leave and would not be back until the following week. Mrs X said that her father's physical and mental state and the anguish that he was suffering was unacceptable. Arrangements were subsequently made for the Second Consultant Respiratory Physician to review the scan and she then telephoned the family.

44. **13 November** The Second Consultant Respiratory Physician wrote to the Second Consultant Gastroenterologist confirming the result of the CT scan and requesting that Mr Y be seen in clinic or for endoscopy. The letter refers to dysphagia remaining a problem.

45. The Health Board subsequently told my Investigator that the Second Consultant Gastroenterologist believed that he picked up the letter from the respiratory team during week commencing 19 November and that the procedure was scheduled for two weeks after that.

46. **22 November** The Health Board records show that Mr Y was on the outpatient waiting list. An e-mail stated that no appointment had been booked and there was a query to the Second Consultant Gastroenterologist about whether Mr Y should be booked for an outpatient appointment or be referred directly for an endoscopy.

47. **28 November** The Second Consultant Gastroenterologist made a referral for a gastroscopy procedure. The referral was marked as 'USC' and Mr Y was placed on a waiting list for a gastroscopy with instructions for the Second Consultant Gastroenterologist to undertake the procedure.

48. **29 November** Mr Y saw the GP with a family member. Mrs X said that the GP was very alarmed and wanted Mr Y admitted to hospital immediately due to his deterioration. Mr Y was not keen on this taking place at that point. Mrs X said that her father thought he would not be returning home if he went into hospital.

49. Mrs X said that the GP contacted the Hospital and eventually found out that Mr Y's appointment was scheduled for 4 December. Mrs X said that this was the first time that the family had heard about this appointment.¹³

50. **4 December** A gastroscopy was carried out on Mr Y. Mrs X said that at this point they were informed that the original GP referral had been downgraded to 'urgent'. The procedure unfortunately showed a tumour in the tonsillar or pharyngeal region, and a rapidly enlarging swelling to the left side of Mr Y's neck. The Second Consultant Gastroenterologist discussed the findings with the ENT Team.

51. **5 December** Mr Y was admitted to the Royal Gwent Hospital¹⁴ following an outpatient appointment with the Consultant Head and Neck Surgeon. By 14 December the pathology findings were discussed with Mr Y and his family. Mr Y received palliative care following this and sadly Mr Y passed away on 11 March 2013.

52. Mrs X said that while the diagnosis may not have been different, the treatment and quality of life for her father might have been, had he been seen in a timely manner as intended by his GP. Mrs X emphasised the psychological damage caused and said that her father was immediately admitted when he was finally seen and required an emergency tracheostomy. Mrs X suggested that her father may not have needed a tracheostomy had it not been left so long. She added that "there were enough warning signs in the timeline for him to have been seen much earlier than he was seen". Mrs X said that her father's quality of life in the terminal phase could have been made considerably more comfortable and she said that perhaps he could have remained at home.

53. The Health Board subsequently told my Investigator that Mr Y's circumstances were not straight forward. In commenting on the draft report, the Health Board also said that Mr Y never at any stage raised concern with his throat or complained of ear, nose or throat symptoms. It explained that

¹³ The Health Board provided a copy of a letter dated 28 November 2012 sent to Mr Y explaining the arrangements for the endoscopy on 4 December.

¹⁴ For a pan endoscopy and biopsy (7/12/12).

Mr Y was referred by cardiology to the chest clinic and by the GP to the Health Board with what appeared to be two unrelated problems. The Health Board said that neither of the referrals met the USC criteria.¹⁵

54. The Health Board added that generally the wait for an urgent outpatient appointment was approximately four months. The Health Board said that this service had been subject to external review by the Royal College of Physicians and that changes were underway to allow for more gastroenterology outpatient clinics and endoscopy procedures.

Complaint handling

55. **19 November 2012** Mrs X complained to the Health Board about the lack of management and communication in respect of her father's care. Mrs X said that she submitted this letter of complaint in an attempt to get her father seen. She raised concern that the referral from Mr Y's GP had not been appropriately actioned. Mrs X explained that her father was unable to swallow properly, unable to sleep and eat and had lost weight. She said that her father was hoarse when he spoke and said his throat was badly burned. Mrs X said that her father had been treated with a complete lack of compassion or awareness of his needs. Mrs X said that the various specialities had failed to communicate with each other and with her father as the patient. Mrs X also highlighted that it was doubtful that the national cancer guidelines had been met.

56. **17 December 2012** The Health Board's Assistant Directorate Manager for Gastroenterology investigated the complaint supported by the Second Consultant Gastroenterologist. The Health Board's response explained what had happened with the GP referral and apologised that the change in referral status had not been communicated to Mr Y's GP. It said that it was making improvements to the relevant processes. The Health Board added that the service aimed to see all urgent referrals within six to eight weeks and an apology was given for the fact that Mr Y had not been seen by gastroenterology before he visited his GP again.

¹⁵ The Health Board referred to the National Cancer Standard target for patients diagnosed by the non USC route i.e. 31 days from the diagnostic investigations to commencing treatment. The Health Board said that sadly in Mr Y's case the only treatment that could be offered was a palliative tracheostomy.

57. The Health Board also apologised that the results of Mr Y's CT scan of his abdomen and pelvis were not returned to Mr Y until Mrs X made contact with the Health Board.

58. The Health Board accepted that there had been failures in communication.

59. **3 July 2013** The Health Board responded to Mrs X's complaint following it being referred via my Office on the basis that the earlier responses had not complied fully with the 'Putting Things Right' framework. Mrs X had also written again (30 April 2013) to the Health Board further explaining her concerns.

60. In this final response the Health Board:

- explained that the original referral letter from the GP was appropriately triaged based on the clinical information provided.
- stated that Mr Y received appropriate care and treatment. A timeline was included which showed the clinical events which had taken place.
- provided an apology for the distress it had caused to Mrs X in sending appointment letters following Mr Y's death. It explained how systems were being changed to prevent this from happening in future.
- provided an apology that Mr Y's GP had not been advised of the outcome of the triage of the GP referral. It also explained that new processes had since been put in place.
- provided an apology for the lack of response to an e-mail sent by Mrs X on 25 October 2012. It explained that unfortunately a computer problem meant that the message had got lost in transit.

61. The Health Board accepted that there were shortcomings but did not find any breach of duty in care and noted that there was "no qualifying liability" owed in this case.

62. Mrs X remained dissatisfied with the response. She said that the Health Board's investigation into the complaint failed to accept responsibility and acknowledge the harm that was caused by the delay in Mr Y receiving

attention. She added that there were several important omissions in the Health Board's account which showed that it was completely unaware of the anguish and trauma that had been caused.

Professional advice

Consultant Physician Adviser 'The Medical Adviser'

63. The Medical Adviser noted that at the outset there was a delay in following up on an abnormal X-ray in January 2012. He pointed out that the CT scan was not undertaken until 15 May and even then was initiated by the Radiology Department.

64. The Medical Adviser also highlighted that an urgent outpatient appointment for what might have been a possible cancer should not take six weeks¹⁶ to take place.

65. The Medical Adviser said that following the outpatient appointment on 24 July it was not unreasonable for the next appointment to be some weeks later because cancer was not suspected at that time. The Medical Adviser noted that the Second Consultant Respiratory Physician considered the radiological findings might be related to a previous episode of pneumonia in 2011. The Medical Adviser said this was reasonable as it was unclear whether the initial left lower zone consolidation was related to cancer. The Medical Adviser was therefore not critical of the fact that the tests including a further CT of the thorax were not arranged sooner.

66. The Medical Adviser commented on the GP referral of 7 September. He noted that the GP referral letter was brief but was of the view that the First Consultant Gastroenterologist's decision was not reasonable. The Medical Adviser said that there was no evidence of how the decision had been reached and of what information had been taken account of at the time of the 'downgrading'. The Medical Adviser said that although there was no cancer diagnosis at that point that there should have been a suspicion of cancer and said that this should have been considered.

¹⁶ An urgent outpatient appointment was requested on 8 June and took 6 weeks to take place (i.e. 24 July).

67. The Medical Adviser explained that the triage was not appropriate for two reasons. Firstly, he said that the First Consultant Gastroenterologist would have known that there was up to a four months delay for an urgent outpatient appointment. The Medical Adviser emphasised that this length of wait was unacceptable. Secondly, the Medical Adviser said that the recent onset heart burn and dysphagia are sufficient criteria for urgent endoscopy under NICE guidelines. He said that the Health Board's own criteria¹⁷ relating to dysphagia were too strict¹⁸ and not consistent with the NICE guidelines.

68. The Medical Adviser was also of the view that Mr Y's medical fitness should not have affected any downgrading of referral. He said that Mr Y's GP could have been contacted, or his clinical records could have been reviewed to confirm his medical fitness. The Medical Adviser highlighted that Mr Y had recently had a successful aortic stent without complications and was medically fit for the endoscopy. He did however note that it was not unreasonable that a clinician would want to review Mr Y before an endoscopy procedure. The Medical Adviser also said that any reclassification of referral should have been communicated to Mr Y's GP.

69. The Medical Adviser was of the view that once the CT scan of Mr Y's thorax was available on 27 September that this should have prompted an urgent response. The Medical Adviser said that it was not satisfactory that the appointment with the First Consultant Respiratory Physician took place on 23 October, more than three weeks after the scan result was available. The Medical Adviser commented that it was however appropriate for the First Consultant Respiratory Physician to refer to Gastroenterology on 23 October when Mr Y was eventually seen. The Medical Adviser commented that "this was an inappropriate and unnecessary delay". He said that this reflected the lack of urgency in Mr Y's case. He said that disseminated pulmonary metastases had been identified and urgency was required in investigating and managing the patient.

70. The Medical Adviser noted that the CT of Mr Y's abdomen and pelvis did not take place until 31 October.

¹⁷ The Health Board's criteria - Urgent Suspected Cancer Outpatient Endoscopy Referral Criteria.

¹⁸ The Medical Adviser noted that the Health Board's criteria do not mention dyspepsia of recent onset. The Medical Adviser added that in his view the Health Board criterion "Persistent progressive dysphagia: unable to manage solids" would reflect advanced oesophageal or gastric disease which if related to cancer might even prove inoperable due to advanced disease causing such severe symptoms.

71. The Medical Adviser added that it was not appropriate that the results of this CT scan were not relayed to Mr Y and his GP as soon as possible. He commented that this potentially delayed further investigations. He said that it should not have been the responsibility of Mrs X to chase her father's investigation results. The Medical Adviser said that action on the results of the CT scan should not have been affected by a consultant's holiday absence.

72. The Medical Adviser concluded that there was a worrying lack of urgency and a failure to expedite investigations when cancer was suspected.

73. The Medical Adviser said that the care and treatment provided for Mr Y was not within reasonable standards. He was of the view that the primary site for Mr Y's cancer should have been identified sooner. The Medical Adviser drew particular attention to the repeated delays for the gastroscopy procedure, pointing out that three different clinicians¹⁹ had requested this. He said that Mr Y's symptoms of dysphagia and recent onset heartburn/indigestion ought to have led to an urgent endoscopy leading to the diagnosis. He said that an endoscopy would have identified the laryngeal cancer.

74. The Medical Adviser said that although the communication between clinicians was generally appropriate, he was of the view that individual clinicians did not accept responsibility for following Mr Y's patient pathway. The Medical Adviser said that individual consultants did not appear to accept responsibility for ensuring X-rays and CT scans were reviewed.

75. The Medical Adviser also said that communication with Mr Y and his family was inadequate.

76. The Medical Adviser said that the sad outcome was not affected by the delays in Mr Y's investigations but he noted the distress that the significant shortcomings had caused to Mr Y and his family. Although he could not be certain, the Medical Adviser was of the view that had the primary cancer been identified sooner that it might have been possible to have avoided a tracheostomy.

¹⁹ The GP, the First Consultant Respiratory Physician, the Second Consultant Respiratory Physician.

77. The Medical Adviser was of the view that the Health Board's complaint responses were inadequate in that they failed to identify that the care provided to Mr Y had been unsatisfactory. He said that it was also a shortcoming that the Health Board had failed to recognise that its own guidance did not comply with the relevant NICE guideline.

78. In considering the comments made by the Health Board at the draft stage of the report, the Medical Adviser said that in his view there was no justification for any further delay in undertaking an endoscopy when Mr Y's primary symptom was dysphagia.

The Health Board's further comments

79. Following its consideration of the draft report the Health Board stated that improvements in arrangements had already taken place. It noted for example that the Health Board has:

- a policy in place in respect of reviewing the results of radiological reports
- improved communication with GPs specifically regarding downgrading of USC referrals
- introduced e-referrals which provide an electronic communication pathway between the Health Board and primary care.

80. The Health Board said that the action taken will mitigate any further such incidents occurring in relation to communication with GPs.

81. The Health Board also said that it recognised the pressures on the gastroenterology outpatient waiting times. It said that the concerns were being investigated by two committees – a National Implementation Group and a Health Board group which is reviewing endoscopy in line with the NICE guidance. The Health Board also noted that endoscopy sessions had been lost and that consideration was being given to how greater access could be achieved for patients.

Analysis and conclusions

82. Having carefully considered all the evidence I fully agree with the Medical Adviser's findings and conclusions. It is clear that there were unacceptable delays with no sense of urgency being shown to Mr Y's clinical condition. There was also an overall lack of leadership and ownership of the care and treatment being provided to Mr Y. The shortcomings included:

- A lack of clarity about who was following up on the X-ray undertaken in January 2012 and a consequent delay in organising the CT scan in May 2012
- A delay in offering an urgent outpatient appointment
- Confusion over appointment bookings
- An unsatisfactory response to a GP USC referral
- A delay in providing a consultant appointment following the concerning CT scan of 27 September and therefore a delay in Mr Y receiving follow up (including the CT scan (31 October)) once the secondary cancer had been identified
- A delay in undertaking an endoscopy procedure
- A failure to review scan results in a timely manner and appropriately communicate the result of these.

83. The fact that the Health Board's policy did not comply with the NICE guidelines underpinned some of the shortcomings and led to an unnecessary delay in identifying the primary cancer.

84. I am of the view that each of the concerns raised by Mrs X about the clinical care were significant and I **uphold** all aspects of the complaint. In stating this, I do however accept the Health Board's comments that lung cancer was not suspected by the Health Board throughout the whole of the identified timeline for Mr Y. Certainly at the point of Mr Y's review by the Second Consultant Respiratory Physician (July) it was clear that she did not believe this to be the case.

85. I recognise that a more timely response would not have changed the sad outcome, but it is very unsatisfactory that at a time of great need for Mr Y and his family that they were let down by the service. I am of the view that at the very least this caused unnecessary psychological suffering for them. It is also a possibility that a tracheostomy might have been avoided.

86. I turn next to the Health Board's management of Mrs X's complaint. I was concerned that the Health Board failed at the outset to comply appropriately with the "Putting Things Right" framework.²⁰ Subsequently the Health Board also failed to find fault and identify the significant shortcomings. In my view it would have been appropriate for the Health Board to have considered seeking totally independent and impartial clinical advice in this case. There was no evidence that this had been considered.

87. I **uphold** fully Mrs X's complaint about the Health Board's complaint investigation. The Health Board failed to adequately identify and acknowledge the unnecessary distress that was caused to Mr Y and his family.

Recommendations

88. That the Health Board within one month:

- Provides an apology to Mrs X for the significant shortcomings in her father's care and treatment.
- Provides financial redress to Mrs X of £1500 for the distress caused to Mr Y and his family and £500 for the time and trouble incurred in making a complaint and for the shortcomings in the complaint response.

89. That the Health Board within three months:

- Reviews the endoscopy referral criteria for USC to ensure consistency with the relevant NICE guideline.
- Takes action to ensure that the unacceptable delays for urgent outpatient appointments are addressed.
- Ensures that the First Consultant Gastroenterologist considers the issues raised in this case and any learning points that arise. Personnel matters are not within my jurisdiction but, for example, this Consultant might discuss at his next appraisal whether any learning and development objectives should be agreed and how they could be met.


²⁰ The NHS (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011.

- Reviews the process to ensure that abnormal results are acted upon urgently by a lead clinician or relevant cancer MDT.
- Reviews how it communicates effectively and appropriately with patients and their families, particularly when more than one speciality is involved.
- Complies with the "Putting Things Right" framework including a proper consideration of "qualifying liability" and seeking independent clinical advice in appropriate circumstances.

90. I am pleased to note that in commenting on the draft of this report the Health Board has agreed to implement these recommendations.

Prof Margaret Griffiths
Acting Ombudsman

8 July 2014



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