

The investigation of a complaint by Mrs X
against
Betsi Cadwaladr University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201201954

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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. Mrs X's son, who this complaint is about is referred to as Mr X.

The Office of the Parliamentary and Health Service Ombudsman in England has investigated this complaint on my behalf as Public Services Ombudsman for Wales. The approach adopted is in line with my usual practice in circumstances where there might be a perception of a conflict of interest. This investigation has therefore been conducted entirely independently. In this report I refer to staff at the Health Service Ombudsman for England as 'my officers' for ease of reading.

Summary

This complaint is about the shortcomings in the care and treatment provided to Mr X at Glan Clwyd Hospital. In November 2000 Mr X had his first episode of bleeding from enlarged blood vessels in the gullet. This is a life-threatening complication of cirrhosis, a condition in which healthy liver tissue is gradually replaced with non-functioning scar tissue. The vessels were tied to prevent further bleeding. Several tests were carried out over the next few months. They showed clearly that Mr X had cirrhosis. Despite this, he was not informed of the diagnosis. Nor was he given necessary lifestyle advice. In September 2001 the hospital apparently made him an outpatient follow-up appointment, but Mr X was not told about this. This meant that Mr X was without any medical supervision for several years, with no information about his condition. As it happens, that probably made little difference to how his condition developed.

Mr X had further bleeding in August 2008. Again this was treated successfully, although for a while he was very unwell. This time Mr X received medication and some, but not all, of the necessary lifestyle advice. The Health Board also began investigating the cause of Mr X's cirrhosis, but stopped before finding it. Not until he requested, and received, a second opinion was Mr X told that he had been born with cirrhosis.

In 2010 Mr X returned to hospital several times in quick succession. He looked very unwell. Blood tests showed that his liver was failing. Despite this, the hospital sent him away, only finally admitting him three days after his appearance. By then Mr X was in liver failure and had a serious infection. Mr X rapidly deteriorated and he sadly died, aged 30, seven weeks later.

Had he been treated three days earlier, Mr X should have recovered from the infection and had a chance of receiving a liver transplant. This opportunity to survive and flourish was denied to him.

I upheld the complaints that were made to me. The Health Board subsequently agreed to my recommendations that it write to the family to acknowledge the failings and provide financial redress to Mr X's family; £5,000 in respect of the failings identified in Mr X's care and treatment plus a further £500 for the poor complaint handling. The Health Board also agreed to review the care pathway and its appointments system. The Consultant in charge of Mr X's care also agreed to consider the issues raised in the investigation and learn from these.

The complaint

1. Mrs X complained about the diagnosis and treatment of her son Mr X's liver condition between November 2000 and August 2010 by the Health Board. Mr X died in September 2010 after suffering liver failure. In particular, Mrs X complained that:

- despite diagnosing Mr X with cirrhosis in 2000, Glan Clwyd Hospital (the hospital) did not discuss this with Mr X or with anyone else in the family (paragraph 26)
- Mr X was not followed up after an episode of illness in 2000-01 (paragraph 85), and tests that should have been done were not
- the hospital, and the Second Consultant (Mr X's Consultant) in particular, failed to recognise the seriousness of Mr X's condition in summer 2010, which meant delays in referring him to a specialist liver unit.

2. Mrs X also complained that the Health Board did not handle her complaint properly. She said that there were long delays when she complained and that the Health Board staff that she met with (paragraph 79) seemed unprepared for the meeting and did not have her son's notes with them.

3. Mrs X's Advocate said that although Mrs X recognises that her son had a serious illness:

'it was manageable with correct and timely treatment and the outcome could have been much better. In Mrs X's view [her son] was failed by clinicians at Glan Clwyd Hospital and his untimely death was avoidable'.

4. As a result of the complaint, Mrs X said that she wanted changes to be made so that the mistakes are never repeated.

Investigation

5. My officers obtained comments and copies of relevant documents from Betsi Cadwaladr University Health Board and considered those in conjunction with the evidence provided by Mrs X.

6. In February 2013 my officer met members of Mr X's family: his mother, Mrs X; his sister, Ms X; and his partner, Ms W, to hear their account of what happened to Mr X.

7. Specialist advice was also obtained from one of my clinical advisers, Dr John Dawson, an experienced physician and gastroenterologist (the medical Adviser).

8. I have not included every detail investigated in this report but I am satisfied that nothing of significance has been overlooked.

9. Both Mrs X and the Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued.

Relevant legislation and standards

Good Medical Practice

10. The General Medical Council (GMC) is the organisation responsible for the professional regulation of doctors. It publishes Good Medical Practice, which contains general guidance on how doctors should approach their work. This represents standards that the GMC expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work.

11. A new edition of Good Medical Practice was published in 2013, but the version applying to the events complained about was published in 2006. That edition says that:

'Good clinical care must include:

- (a) adequately assessing the patient's conditions, taking account of the history (including the symptoms, and psychological and social factors), the patient's views, and where necessary examining the patient
- (b) providing or arranging advice, investigations or treatment where necessary
- (c) referring a patient to another practitioner, when this is in the patient's best interests'.

12. It goes on to say that 'In providing care you must:

- (a) recognise and work within the limits of your competence
- (b) prescribe drugs or treatment, including repeat prescriptions, only when you have adequate knowledge of the patient's health, and are satisfied that the drugs or treatment serve the patient's needs
- (c) provide effective treatments based on the best available evidence
- ...
- (e) respect the patient's right to seek a second opinion
- (f) keep clear, accurate and legible records, reporting the relevant clinical findings, the decisions made, the information given to patients, and any drugs prescribed or other investigation or treatment
- ...
- (i) consult and take advice from colleagues, when appropriate'.

13. Good Medical Practice also tells doctors that in order to 'communicate effectively [they] must share with patients, in a way they can understand, the information they want or need to know about their condition, its likely progression, and the treatment options available to them'.

Concerns, Complaints and Redress Arrangements

14. In 2010, when Mrs X first complained to the Health Board, the main guidance on complaint handling in Wales was Complaints in the NHS: A Guide to handling complaints in Wales (the Guide), published in April 2003. The Guide says that NHS organisations receiving a complaint should:

- 'Acknowledge the complaint within two working days and provide information on the process;
- 'Investigate thoroughly and fairly;
- 'Have a range of options to investigate and resolve complaints, including:
 - 'Inviting the complainant to meet with staff, practitioners and clinicians to discuss their concerns further;
 - 'Offering a second opinion on clinical issues;
 - 'Offering independent facilitation or mediation.
- 'Provide a full written reply within four weeks signed by the Chief Executive or senior partner or practitioner in the practice. Where this is not possible, to inform the complainant and complained against of the reason for the delay and when they can expect to receive a reply.'

15. The Guide sets out that 'The Complaints Manager will ensure that the complaint is thoroughly and fairly investigated by:

- Identifying the staff concerned, any witnesses or supporting evidence (such as health records);
- Interviewing or obtaining statements from staff or other witnesses (including anyone who was present when the events complained of occurred, for example other patients or, with their permission, the complainant's visitors or relatives if they were present);
- Obtaining copies of health records or supporting evidence ...;
- Checking the evidence and identifying any gaps or contradictions;
- Obtaining clinical advice if necessary, including from nurses or therapists where indicated, and
- Identifying any procedures or policies in the organisation that are relevant to the event.'

16. If the complainant is not satisfied by that response, the Guide explains, they can ask for an independent review. Two independent people decide whether to set up a panel, take no further action, or refer the complaint back to the organisations for further work.

17. If a meeting is considered, the Guide explains, then:

'Where relevant, any health professional concerned should be consulted about whether a meeting would be useful. They should be informed well in advance of the meeting so that they can prepare answers or instruct an investigation to take place. A meeting with the complainant can be useful to answer some of the issues raised'.

The background events

Background

18. Mr X was born on 14 April 1980.

19. In 1992, after becoming poorly and losing weight, Mr X was referred by his GP to the hospital. Mr X had a low platelet count and was found to have an enlarged spleen. He was diagnosed with chronic idiopathic thrombocytopenic purpura: small red or purple spots under the skin caused by bleeding as a result of a low number of platelets in the blood. (Platelets are involved in blood clotting.)

20. Mr X's family said that they were told by the hospital that Mr X had an unusual clotting disorder, but that all they had to do was be careful if Mr X was bleeding as there could be problems with his blood clotting. They were told that he had an enlarged spleen, but the liver problem was never mentioned. They were told the spleen could be removed if it became a problem.

2000

21. Mr X had an appointment to see a Haematologist (blood specialist) on 12 April but did not attend.

22. On 14 November Mr X went to hospital, referred by his GP, after suffering chest pain and vomiting blood. He had a blood transfusion that evening. He stopped vomiting blood, although he passed black stools (implying internal bleeding).

23. The next day his stomach and oesophagus were examined using an endoscope (a flexible wire with a small camera attached). The bleeding was found to have been caused by oesophageal varices: dilated blood vessels in the oesophagus that are connected to the liver. Bleeding varices are commonly caused by cirrhosis. Cirrhosis is the condition in which healthy liver tissue is damaged and replaced by scar tissue that can prevent the liver from functioning. It can be caused by a number of different things, including excessive alcoholic drinking, infections, and congenital conditions (that people are born with), including some that are hereditary.

24. Mr X's varices were treated by banding (being tied off) to stop bleeding. While he was in hospital he also had an ultrasound scan of the liver, which showed an enlarged spleen.

25. On 17 November, Mr X was discharged. He was given a prescription for Propranolol, a beta blocker, to try to lower portal vein¹ blood pressure and reduce the likelihood of further variceal bleeding.

26. Mr X's family said that the nurses in the hospital assumed that Mr X was an alcoholic. The family said the hospital staff knew that he had cirrhosis but that they did not discuss this with Mr X or with anyone else in the family.

27. Attending a follow-up appointment in the gastroenterology clinic on 6 December, Mr X was reviewed by a junior doctor who planned to arrange for blood tests (including liver function tests), a follow-up endoscopy to check the oesophagus, a scan of the portal vein and then a liver biopsy².

28. The follow-up endoscopy was carried out on 19 December. Mr X had three varices banded and was asked to come back for a follow-up endoscopy the following year.

2001

29. Mr X had another endoscopy in clinic on 26 March. This was carried out by a Consultant Gastroenterologist ('the First Consultant'). The First Consultant found two oesophageal varices and applied bands to treat them. The endoscopy report says that Mr X should be reviewed in the gastroenterology clinic in 12 weeks' time.

30. On 3 April Mr X had an abdominal ultrasound scan. The report said that the appearance was of 'advanced cirrhosis' of unknown cause. It stated that the portal vein was not blocked, although there were some intermittent changes in the pattern of blood flow.

¹ The hepatic portal vein feeds the liver with nutrient-rich blood from the bowels. Cirrhosis can block blood flow through the liver which can lead to increased pressure in the portal vein, leading to varices: swellings in the blood vessels in the throat that can burst and bleed.

² A biopsy means taking a sample of tissue from the organ that is then tested in the laboratory.

31. A gastroenterology Registrar³ wrote to Mr X on 18 April asking him to have some blood tests done 'within the next week or two' either at the hospital or his GP surgery. On 14 May the Registrar wrote to Mr X's GP asking him to arrange to carry out blood tests.

32. Mr X saw the First Consultant on 5 June 2001. The First Consultant decided that a liver biopsy would be done if blood tests showed that his blood was clotting quickly enough to allow the procedure to be carried out safely. There is an unsigned letter on the Health Board's file from the First Consultant to Mr X dated 8 June asking him to have blood tests carried out either at the hospital or his GP surgery.

33. Mr X was given an appointment for 26 June which, according to the hospital's records, he cancelled. The records also say that he was given a further appointment with the First Consultant for 4 September 2001. However, the Health Board were unable to supply my officer with a copy of any letters sent to Mr X inviting him to attend this appointment. Mr X did not attend the appointment on 4 September.

34. There is no evidence of contact between Mr X and the Health Board until 2007, besides treatment for an unrelated hand injury in 2004.

2007

35. Mr X was seen by maxillofacial specialists for multiple teeth extractions. There is a letter from a Maxillofacial Specialist to Mr X's Dentist that stated:

'He explained to me that as a child he was under investigation for thrombocytopenia and neutropenia but since then he has had various operations and has not had any problems. I understand the last problem he had was oesophageal varices.'

³ A registrar is a doctor in the last few years of training before reaching consultant grade.

2008

36. On 2 February Mr X was seen by a Consultant Haematologist (the Haematologist) at the request of the maxillofacial specialists. The Haematologist noted that Mr X had always had low platelets and said an ultrasound scan had been requested. The Haematologist also noted that the planned liver biopsy did not seem to have happened. (The Haematologist recommended that the oral surgeons split the dental work over two appointments because of Mr X's bleeding risk).
37. The ultrasound on 25 March showed cirrhosis. On 2 April the Haematologist wrote to the First Consultant explaining the ultrasound finding and asking him to review Mr X. On 14 April 2008 the Haematologist saw Mr X in outpatients' clinic. He wrote to Mr X's GP explaining the ultrasound result. He also advised Mr X to reduce his weekend alcohol consumption (which was apparently half a bottle of vodka).
38. The Haematologist's letter is stamped as received by the gastroenterology department and someone has handwritten 'routine app't 16/4/08' on the letter. However, there is no record of this appointment being made on the hospital's list of Mr X's appointments.
39. On the evening of 1 August, Mr X's family said that Mr X went to the hospital's Emergency Department after vomiting a lot of blood. He was observed and sent home with no treatment. (The notes from 4 August stated that he 'self-discharged'.)
40. On 4 August Mr X went to hospital suffering from oesophageal bleeding. He was said to have drunk '1 litre vodka over the weekend'. He had had an episode of rectal bleeding. The following day he had three units of blood transfused. His varices were banded over the course of a few endoscopy procedures that were difficult owing to the amount of bleeding and Mr X's lack of tolerance for the procedure.
41. Mr X's family said that he was admitted to the Intensive Care unit and that at one point they were told that he might not survive. During this hospital admission, they said that the Second Consultant asked them whether they knew that Mr X had liver disease. This was the first time they had heard this diagnosis, and the first time they realised how serious Mr X's condition was.

42. On 7 August Mr X was seen by the North Wales Drug and Alcohol Agency. Mr X reported drinking:

'up to 1 litre vodka over the weekend. Patient does not feel his drinking is the only cause for his admission but admits that his drinking is over the recommended limit and possibly needs addressing for the sake of his health. Motivational session carried out ... follow up support offered but declined. Contact numbers and info given'.

43. Mr X was discharged on 8 August. He returned to hospital two days later 'in agony' with a swollen testicle. He was treated with drugs, including an antibiotic called Ciprofloxacin, and discharged the same day.

44. The GP referred him back to the Second Consultant on 21 August because he had been increasingly jaundiced. The GP asked the Second Consultant to review Mr X 'as soon as possible'.

45. Mr X saw the Second Consultant on 4 September. The Second Consultant attributed Mr X's recent jaundice to either a viral illness or to the Ciprofloxacin. He said he had prescribed Propranolol. The Second Consultant wrote to Mr X's GP that:

'Looking through his notes, I think [Mr X] has had cirrhosis since childhood. Looking through the scans and the bloods he had when he was under the paediatric team, he had all the features of hepatic fibrosis with portal hypertension then. I have discussed all my views with [Mr X] ... At the moment he is avoiding alcohol, although this is not the cause of his problems'.

46. The Second Consultant carried out a follow-up examination of Mr X's oesophagus with an endoscope in outpatients' clinic on 20 October. He did not find any new varices. He noted that Mr X had had problems with Propranolol and had stopped taking it. He arranged another appointment for reviewing Mr X's blood test results.

47. On 4 November, at a meeting of urologists (specialists in treating the male reproductive system), the ultrasound scan of Mr X's testicle was discussed. They had found some possible abnormalities and arranged for a follow-up ultrasound examination.

48. Mr X saw a gastroenterology Registrar on 26 November. The Registrar wrote to Mr X's GP, saying that blood tests had not indicated a possible cause for Mr X's liver problems. The Registrar wrote:

'I have explained to [Mr X] that we do not know the cause for this cirrhosis and the next step could be liver biopsy which may or may not provide us with the answers. I will discuss this with [the Second Consultant] and if any further investigation is needed we will keep you updated. I have given him a further follow up appointment in six months' time'.

49. On 15 December Mr X wrote to the Second Consultant asking for further testing or a second opinion because he was unhappy that there were no plans to investigate the cause of his liver disease.

2009

50. On 8 January the Second Consultant arranged a second opinion consultation for Mr X with a Consultant Hepatologist (liver specialist). Mr X, attending with Ms W, was seen on 12 March. The Hepatologist diagnosed 'Cirrhosis due to probable congenital hepatic fibrosis'. Ms W said that the Consultant told her that Mr X should go to hospital if he developed jaundice or confusion.

51. Mr X's family said that they discussed the possibility of transferring to another doctor but in the end Mr X decided to stick with the Second Consultant, who already knew him.

52. Mr X was seen by the Urologist again on 2 July. They planned to review him again in a year.

53. On 6 July Mrs X e-mailed the Second Consultant's Secretary to ask her to arrange a review appointment. Mr X was seen on 30 July. The Second Consultant arranged for another endoscopy, to check for any new varices, and an ultrasound scan to check that he had not developed liver cancer. Mr X had both in September, and both were reported as being normal.

2010

54. After a week in Tenerife with his family, Mr X returned to Wales and then began feeling unwell. He had swellings owing to fluid retention (fluid build-up in the body, a common effect of end-stage liver disease).⁴ His GP prescribed a diuretic (a drug that increases urine production). Ms W said that Mr X also developed a swollen testicle and was prescribed antibiotics by the out-of-hours GP service.

55. Mr X had his annual check-up with the Second Consultant on 2 August. The appointment had been brought forward at the request of Mr X's GP because, for the last few months, the GP said, Mr X had had 'worsening ascites, bilateral leg oedema and scrotal swelling'.⁵ Blood tests carried out on that day showed bilirubin of 380⁶ and albumin of 32 (grams per litre, compared to a normal result of 35 to 50). The results also included creatinine of 85 (within the normal range of 62 to 106) and urea of 5.7 (within the normal range of 2.5 to 7.8).⁷

56. The Second Consultant saw 'no evidence of ascites' when he reviewed Mr X. However, he quadrupled Mr X's diuretic dose and said he had arranged for Mr X to have an endoscopy and an ultrasound scan.

57. Ms W said that when she accompanied Mr X to this appointment, she told the Second Consultant that Mr X was not eating. The Second Consultant told her it was probably just a virus and that Mr X should eat less salt. He encouraged Ms W to make Mr X eat. Ms W said that she asked the Second Consultant what worrying signs they should be looking out for. The Second Consultant said he did not want to tell them, because they would be looking too closely for the signs and there were years to go before that would be necessary. The Second Consultant said he would expect Mr X's condition to be stable for 20 or 30 years.

⁴ Liver damage can prevent the liver from manufacturing albumin, a protein that helps keep fluid in the parts of the body where it should be. Fluid can then accumulate in other parts of the body.

⁵ Ascites is fluid accumulation in the abdomen. Oedema is swelling owing to retained fluid (and bilateral in this context means that the swelling is in both legs).

⁶ Bilirubin is a yellow waste product from the blood that is processed by the liver. An increased level of bilirubin in the body indicates a problem with liver function. Bilirubin retained in the body is responsible for the appearance of jaundice. It is measured in micromoles per litre. A result of less than 17 is normal. Jaundice will usually be visible in a patient who has a bilirubin level greater than 40.

⁷ Creatinine and urea are both waste products that are processed by the kidneys. Both are measured in micromoles per litre of blood (a measure of the number of molecules in the blood). Increased levels of these waste products indicate that the kidneys are not functioning properly.

58. Mr X returned to hospital the following day, 3 August, in pain and with difficulty in breathing. He was jaundiced, according to his family. Blood tests done that day reported a bilirubin of 395 along with albumin of 30. His prothrombin time was 29.7 seconds compared to a normal range of 12.3 to 16.3.⁸ His creatinine was 82 and urea was 6.2: both within normal range. The Doctor admitting Mr X wrote that he was 'very jaundiced' and had oedema but no ascites. Later, on the ward round, another Doctor reviewed him and wrote that he had ascites and:

'Decompensated liver disease.'⁹

'Known ... cirrhosis – under regular [review by the Second Consultant]

'Recent holiday (Tenerife) [with] family – drinking [alcohol] daily

'[reduced] appetite ... [sodium] rich diet'.

59. Mr X was discharged the following day. Blood test results from that day include creatinine of 86 and urea of 7.2: both within normal range, though higher than the previous day's results. He was asked to attend a follow-up appointment in three weeks' time. Ms W told my officer that although Mr X was normally skinny, the fluid retention had given him a huge belly and his legs and feet were so swollen that he struggled to put his trousers and shoes on. Later that day, she rang the ward for advice. The Nurse that Ms W spoke to wrote that:

'[Mr X]'s partner called ... concerned about [his increase] in abdo[minal] fluid and leg cramps. I ... spoke to [the Second Consultant] who advised to continue with [increased] dose of diuretics and try bitter lemon for cramps. If in pain + any worse to attend A+E'.

⁸ Prothrombin time is a measurement of how long it takes the blood to clot. This is relevant to liver function because the liver produces some of the substances that help blood to clot. So a longer prothrombin time indicates that the liver might not be functioning properly.

⁹ Decompensated liver disease means that the disease has reached a stage where the liver is no longer able to compensate for the damage it has received, and is therefore no longer functioning properly.

60. Mr X went to the Emergency Department at about 9.30pm and was admitted to hospital again in the early hours of 5 August. He had lower abdominal pain, feeling unwell with shivering and decreased urine output. By this time, Mr X's family said that he had 'the face of an old man'. He was found to have severely swollen hands and feet.

61. An ultrasound scan carried out that day found extensive liver damage from cirrhosis, and changes in Mr X's liver since his last scan. There were a number of abnormal areas that were reported as being possibly abscesses or liver cancer.

62. Mr X's albumin level had dropped to 6, while his urea and creatinine levels had both increased above their normal ranges, to 8.6 and 154 respectively. The same day, a sample of fluid was taken from Mr X's abdomen which showed that his ascites were infected with bacteria.

63. It was not until 6 August that a locum Registrar wrote in the notes that Mr X had decompensated liver disease. Her impression was that he also had hepatorenal failure.¹⁰ On 7 August the locum Registrar spoke to liver transplant specialists in a specialist liver unit in England (the liver unit) about transferring Mr X there for assessment of his suitability for liver transplant. She arranged for Mr X to be transferred to a specialist unit as soon as a bed was available. This was the first time Mr X's family had heard that he had liver or kidney failure. They said that the locum Registrar asked them, 'has no-one told you?'

64. Mr X was transferred to the liver unit the following day.

65. Mr X's family said that the doctors at the liver unit seemed annoyed at how ill Mr X had been allowed to become before being transferred. They said he should have been there a year earlier.

66. In the liver unit the specialists tried to improve Mr X's liver function, but his condition deteriorated. He was put on the waiting list for a liver transplant on 13 August. His jaundice continued to get worse over the next couple of weeks. In late August he developed pneumonia, which was treated with antibiotics. His condition got much worse and by mid-September he was struggling to get in and out of bed.

¹⁰ Hepatorenal failure means that the kidneys are not functioning properly as a result of the failing liver.

67. But then Mr X's condition deteriorated even further. The doctors at the liver unit arranged for him to receive dialysis to give him the best chance of being well enough for a transplant but his family were told he was so ill that he would have needed a liver from a beating heart donor. They did not realise at the time that this was never likely to happen. Mr X was never at the top of the transplant list, and was suspended from it on three occasions over the eight weeks he was in the liver unit when his condition deteriorated.

68. By 23 September Mr X had worsening encephalopathy (brain disorder caused by toxins that would normally be removed by the liver). Mr X's family told us that he was unable to think properly, which was very distressing for Mr X because he was highly intelligent. Mr X was deemed to be too unwell for transplant and was removed from the list.

69. Mr X sadly died on 24 September. His family pointed out that his death had been horrific.

Mrs X's complaint to the Health Board

70. Mrs X complained to the Health Board on 7 December 2010. She asked thirteen questions about her son's care going back to 1992. The Health Board acknowledged her letter in writing the following day.

71. The Health Board obtained comments from a Consultant in paediatrics who had not been involved in Mr X's care (because the Consultant who saw him as a child had since retired), and from the Second Consultant. These comments were submitted by the doctors to the complaints department on 24 December and 16 December respectively.

72. On 20 January 2011 the Health Board wrote to Mrs X to apologise for not providing a response 'within the 20 day standard', which was 'due to staff absences'.

73. The Health Board responded to Mrs X's complaint on 27 January, addressing her thirteen questions. In summary, those questions, and the Health Board's answers, were:

1. Why was Mr X not fully investigated for liver disease in 1992?
 - Because 'there were no indications during the period that he was under paediatric care that the problem related to his liver'. The Health Board noted that even if liver disease had been diagnosed, that would 'not have opened up any new options for treatment at that stage'.
2. Why was there no specialist involvement in his care following the oesophageal bleed?
 - Mr X did not attend his follow-up appointments after the bleed, for blood tests. In the absence of further contact from Mr X or his GP, no further appointments were made.
3. Hospital staff described Mr X as an alcoholic: on what basis? And were such statements recorded in the notes?
 - The Health Board said they had reviewed the records and spoken to two ward sisters but had been unable to determine 'where or by whom these comments were made'.
4. Why was Mr X not advised not to drink alcohol?
 - Patients with non-alcohol-related cirrhosis are not routinely asked to stop drinking, only informed about 'sensible safe levels of alcohol consumption'.
5. What was the treatment plan after congenital hepatic fibrosis was diagnosed? Was referral to a specialist liver unit considered?
 - Mr X was monitored with regular blood tests and ultrasound scans. He was stable when assessed in March and August 2009 and there was therefore no need for a transplant assessment referral.

6. What prognosis was Mr X given?
 - The prognosis in congenital fibrosis is uncertain. The Second Consultant 'has seen patients in their 40s and 50s with the same diagnosis and remaining perfectly stable'.
7. This was a question about the GP's actions, which the Health Board said they could not answer.
8. Why did the Second Consultant fail to diagnose liver failure in July 2010 when Mr X 'clearly had all the symptoms'?
 - The leg swelling was attributed to Mr X's recent failure to watch his salt intake when on holiday (leading to fluid build-up). His GP was treating him with a diuretic. The Second Consultant was planning a repeat endoscopy and further review.
9. Why did the Second Consultant not refer Mr X for transplant before he developed total liver failure?
10. Why did the Second Consultant discharge Mr X from hospital [on 4 August] after only a night 'when he was so clearly jaundiced and unwell'?
 - Mr X's deterioration 'was very rapid and very atypical'. Later test pointed to infected ascites: it is 'well recognised that infection or bleeding can cause sudden severe deterioration of an otherwise stable liver'. Mr X was discharged on 4 August because he 'looked and felt better from the previous day'. He was told to come straight back if he felt worse – which is what he did on 5 August. The Second Consultant wanted to treat the infection, once diagnosed, before considering transfer as 'the liver centre do not usually take patients for transplant where there is an ongoing infection' because of the need for post-operative immunosuppressants.¹¹

¹¹ People who received organ transplants usually need to take drugs to suppress their immune system, in order to prevent it attacking (rejecting) the transplanted organ. Because their immune system is suppressed they will be less able to fight infection.

11. Mrs X requested, and was given, the name of the junior Doctor (a Registrar) who arranged for Mr X's transfer to the liver unit.
12. After the assessment at the liver unit why was no bed found for Mr X back in the Welsh hospital?¹²
 - The Second Consultant did not recall being contacted about a return transfer, but the Health Board's Clinical Nurse Manager apologised for the delay and for 'the distress this must have caused'.
13. Mrs X asked the hospital and the Second Consultant to 'justify why mistakes were made in the last 2 years of [Mr X's] life'.
 - The Health Board said that the Second Consultant did not accept that mistakes were made and maintained that Mr X's deterioration was 'very rapid and out of character'.

Independent review

74. Mrs X complained to the NHS Wales Independent Complaints Secretariat about the Health Board.

75. The lay reviewer and lay adviser took clinical advice from a gastroenterologist and a haematologist. The gastroenterology advice, which was structured around the same thirteen questions Mrs X had asked in her original complaint, said that:

- It was not entirely clear why Mr X was lost to follow-up after treatment for varices and 'it is possible that more direct attempts to keep him under follow-up could have been made'.
- There was no mention of Mr X drinking heavily or being an alcoholic in the clinical notes. In fact the notes in August 2008 (paragraph 45) said both that alcohol was not the cause of Mr X's condition and that he had been avoiding it.

¹² This appears to be based on a misunderstanding. Mrs X and the Health Board both believed that Mr X would have been transferred from the liver unit back to Wales after being assessed, in fact the decision to keep him in the liver unit was made by doctors in the liver unit, based on Mr X's worsening condition.

- The Health Board's response to the question of whether Mr X was given advice about alcohol intake was reasonable.
- Regarding the complaints about the delayed diagnosis, early discharge, and timing of the liver unit referral, more detailed explanations might be useful. The advice says that 'the clinical judgement made by [the Second Consultant] is backed up by the medical records'.

76. The haematology advice was critical of the care Mr X received as a child. It also said that in some respects the Health Board's response to Mrs X's complaint had been 'inadequate, incorrect and misleading'.

77. On 3 January 2012 the lay reviewer wrote to Mrs X to say the complaint was being referred back to the Health Board for her to receive 'greater clarification on a number of issues relating to the care and treatment your son received and the course of events that took place' and also for the Health Board to respond to some issues Mrs X had raised which had not yet been put to them. The lay reviewer suggested the Health Board offer to meet Mrs X in person.

78. The issues requiring greater clarification included:

- explanations of the natural history of liver disease
- evidence showing that Mr X was not labelled as an alcoholic
- clarification about the appointments Mr X missed
- an explanation of why liver disease was not diagnosed between 1995 and 2001
- information about tests done when Mr X was a child.

Meeting

79. On 5 April 2012, Mrs X and her husband, along with Ms X, Ms W, and their Advocate, met the Second Consultant and the Health Board's Clinical Nurse Manager and Patient Experience Facilitator.

80. The minutes of the meeting record that the Second Consultant said again how surprised he was by Mr X's rapid deterioration. He said that patients often 'become very unstable and can improve very quickly with treatment'. He said that Mr X was transferred to the liver unit 'as soon as it was apparent his liver was failing'. He also explained that he regularly spoke to Mr X about his condition. The Clinical Nurse Manager explained that changes had been made to reduce patients' non-attendance, including offering a greater choice of dates and times, as well as more letters being sent and GPs being informed of their patient's non-attendance.

81. Mrs X said during the investigation that the Health Board representatives did not have copies of her son's notes with them at the meeting.

82. The minutes of the meeting record Mrs X asking which appointments the Health Board thought had been missed by Mr X and which of them had been cancelled by the Health Board. The solution was for the Patient Experience Facilitator to provide this information after the meeting, along with a copy of Mr X's medical notes.

83. After the meeting, the Health Board added that the Second Consultant had spoken to a Hepatologist at the liver unit who apparently 'agreed that [Mr X's] deterioration was too rapid to predict and did not criticise [the Second Consultant's] management from 2008'. There was further e-mail correspondence between Mrs X, her Advocate and the Health Board after this, before Mrs X brought her complaint to my office.

Mr X's family's evidence

84. Mr X's family said that, in retrospect, Mr X had classic symptoms of liver disease. He had yellow-tinged skin and a poor appetite – he tended to eat little more than chicken and bananas. He never had much energy – he would never join his sister for a run when she offered, for example – but they did not realise that that was because he was ill.

85. Mr X's family said that Mr X was not followed up after the episode in 2000. The hospital has said that Mr X did not attend appointments, but Mrs X said her son did not receive appointments, and that his post was always sent to her home even when he was living elsewhere. Mrs X said that at one of the meetings she had with hospital staff, they told her that their appointments system had failed in the past. Mrs X added that her son's GP had not received copies of the hospital's letters either.

86. Mrs X said that she accompanied her son to his early appointments with the Second Consultant. She asked the Second Consultant what the next stage would be, whether she could be a living donor, and whether he could be added to the transplant list. The Second Consultant replied that it would be years before things reached that stage.

87. Mr X's family said that Mr X was advised not to binge drink (for example, if drinking with friends who had five pints each, he should only have a couple), but he was never told not to drink at all. No-one ever explained to Mr X how bad liver disease was, or what to expect from it.

88. In retrospect, Mr X's family said that when he was admitted to hospital in August (paragraph 60) it seemed to be common knowledge among hospital staff that Mr X was in liver failure. But no-one told either Mr X or anyone in his family.

89. Mrs X said that her son 'endured great pain and suffering in his last three months'. He had a promising career and planned to marry Ms W.

The Health Board's evidence

The First Consultant's comments

90. The First Consultant said that, when he was Mr X's Consultant, there was no confirmed diagnosis because of Mr X's non-attendance at follow-up. Mr X's non-attendance also prevented him from completing the investigations that were required.

The Second Consultant's comments

91. The Second Consultant said that he was desperately disappointed that his 'care was found to be deficient'. He accepted the comments made by the medical Adviser (see below).

Professional advice

92. The medical Adviser said that Mr X's condition should have been fully investigated either during or soon after his admission in November 2000. These investigations would probably have included extensive blood tests, a CT scan¹³ and a liver biopsy. He should have had a follow-up endoscopy, with additional banding carried out to ensure eradication of the varices.

93. The medical Adviser said that Mr X should have been advised about beta blockers to reduce portal pressure to reduce the risk of further variceal bleeding. He should have been told about his diagnosis and its prognosis. He should have been advised about the features of a sensible lifestyle, including drinking only in moderation. He should have been offered vaccination for hepatitis A and pneumococcus,¹⁴ and given general advice as to when to seek medical help. A follow-up endoscopy should have been done (which it was, on 19 December – paragraph 28).

94. Whatever the reason that he did not have blood tests carried out as requested in June 2001 (paragraph 32), the medical Adviser said, the Health Board should have taken steps to ensure that Mr X was followed up, and/or advised Mr X's GP about a suitable management plan.

¹³ A CT scan is a series of X-rays that are compiled by a computer into a 3D image of the inside of the body.

¹⁴ Hepatitis A is a virus that attacks the liver. Pneumococcus is a type of bacterium that can cause pneumonia and meningitis, among other infections.

95. The medical Adviser said that consultant gastroenterologists are aware of the significance and risks of bleeding oesophageal varices, which is part of their training and documented in standard texts.¹⁵ Failure to investigate and manage appropriately contravened Good Medical Practice (paragraph 11).

96. There is no specific treatment for the liver disease Mr X had, the medical Adviser said, so he did not miss out on that. He added that the failure to follow up Mr X probably had no impact on the progress of his liver disease or the eventual outcome.

97. The medical Adviser said that the Haematologist who saw Mr X in 2008 correctly concluded that he had undiagnosed chronic liver disease and did the right thing by referring him for a gastroenterological opinion.

98. The Haematologist advised Mr X to reduce his alcohol intake (paragraph 37). The medical Adviser said that this was reasonable in the context of a history of high alcohol intake and evidence of liver disease. The medical Adviser would not expect patients with congenital cirrhosis to be told to avoid alcohol altogether, but to drink only moderately.

99. Given that Mr X had stable cirrhosis, the medical Adviser said, it was reasonable for the Second Consultant to see him on an annual basis.

100. During his admission in August 2008, the medical Adviser said, Mr X should have had further investigations either performed or arranged as an outpatient. At this stage those investigations would have included, as a minimum, an ultrasound. There should have been a clear management plan to include consideration of a beta blocker to reduce portal pressure and thus to reduce the risk of further variceal bleeding. He should have been given specific advice (as in paragraph 93).

101. The medical Adviser said that when the Second Consultant saw Mr X in clinic (paragraph 45), he correctly concluded that the diagnosis was chronic liver disease from childhood, probably due to hepatic fibrosis. He said there is evidence from the notes that this was appropriately discussed with Mr X. However, he added, other than a further ultrasound no further, direct tests to confirm this diagnosis were performed. Mr X had already been admitted

¹⁵ The medical Adviser gave as an example Sleisenger and Fordtran's Gastrointestinal and Liver Disease, edited by Mark Feldman, Lawrence S Freidman and Lawrence J Brandt, published by Saunders (currently in its ninth edition).

twice with life threatening variceal haemorrhage (which carries a 30% mortality risk) and he should either have been fully investigated locally or referred for a formal opinion from a Hepatologist.

102. The medical Adviser was asked to comment on whether an alternative medication should have been offered to Mr X when he was unable to tolerate Propranolol. The medical Adviser said that although beta blockers are usually prescribed to patients with oesophageal varices after a variceal bleed, they are frequently not tolerated and there is no suitable recognised oral alternative.

103. By 2 August 2010, the medical Adviser said, it was clear that Mr X was decompensating. There was clinical evidence of oedema. The medical Adviser said that Mr X must clearly have been jaundiced since the blood taken on that day showed a bilirubin of 380. The medical Adviser said that one of the fundamental roles of a gastroenterologist is recognising and managing a patient with jaundice. The Second Consultant should have admitted Mr X to hospital immediately.

104. There is no record that these significantly abnormal blood test results were seen during Mr X's readmission to hospital the following day, the medical Adviser said. His blood test results (paragraph 58) were suggestive of severe liver disease.

105. The medical Adviser said that urgent investigations should have been carried out. Mr X should not have been discharged the following day.

106. The medical Adviser said that the failure of both outpatient and inpatient assessment, and discharge, meant that the care provided to Mr X fell well below the standard of Good Medical Practice: provision of good clinical care (paragraph 11).

107. The medical Adviser said that the presence of bacteria in the ascites sample taken on 5 August (paragraph 62) suggested that he had developed spontaneous bacterial peritonitis, and that this was later confirmed by tests. He said that spontaneous bacterial peritonitis is a common cause of deterioration in patients with cirrhosis. The medical Adviser said that the ascites sample should have been carried out no later than 3 August and, when the cloudy fluid was seen, antibiotics should have been started for the presumed diagnosis of spontaneous bacterial peritonitis.

108. The medical Adviser said that blood test results show that Mr X was beginning to develop hepatorenal failure by 5 August. He said that the Second Consultant failed to promptly recognise and treat Mr X's overwhelming infection. This was a failure to meet the standards of Good Medical Practice (paragraph 11).

109. The medical Adviser said that patients with decompensated liver disease with ascites who do not receive a liver transplant have only a 50% chance of surviving two years. However, he said, if Mr X had been admitted on 2 August, and his spontaneous bacterial peritonitis treated, then he should have recovered sufficiently to be considered for a transplant after recovery. As a rule of thumb, patients are referred for transplant when their condition is such that they are likely to die within six months without transplant. Mr X would probably have been in that condition, or close to it, had he stabilised after treatment in 2010.

110. The medical Adviser said that, because there are so many variables involved, it is impossible to say whether Mr X would have received a transplant. Mr X could, for example, have gone on to suffer a fatal episode of sepsis or oesophageal bleeding at any time, and the availability of appropriate livers is unpredictable. Nor is it possible to say whether a transplant would have been successful even had Mr X survived to receive one.

111. Once Mr X had been admitted to hospital on 5 August, the medical Adviser said, he was promptly and appropriately investigated, appropriately treated, and early contact made with the liver unit to which he was transferred. This management was reasonable. The medical Adviser said that there were no indications at any time earlier in Mr X's care that he required a liver transplant.

112. The medical Adviser said that the deterioration in Mr X's condition in summer 2010 might have been due to the natural history of his underlying cirrhosis rather than being triggered by anything external, although it was possible that drinking more than usual on holiday could have contributed to it. His rapid deterioration during the first week in August was due to sepsis and the spontaneous bacterial peritonitis.

Analysis and conclusions

Medical care of Mr X

113. To get it right, once they had discovered and treated Mr X's oesophageal varices in November 2000, the First Consultant and his team should have taken account of established good practice. Established good medical practice includes 'providing or arranging advice, investigations or treatment where necessary' (paragraph 11).

114. The medical Adviser said that the necessary treatment would have included follow-up variceal banding and beta blocker prescription. The necessary investigations in this case were blood tests, a CT scan and a liver biopsy. The necessary advice, once Mr X's cirrhosis was discovered, would have included information about his condition and what to expect from it, along with lifestyle advice (such as about alcohol consumption) and advice about available immunisations.

115. Mr X was given the necessary treatment: he had follow-up endoscopy on 19 December (paragraph 28), and he was prescribed beta blockers (paragraph 25). A series of investigations were started, that would have culminated in a liver biopsy, but they were not completed. That was because Mr X was to have blood tests. The First Consultant apparently asked Mr X to have these carried out in June 2001 (paragraph 32) but he did not.

116. Mrs X said that her son did not miss appointments but that he simply did not receive them. She said that the GP was not told about the appointments either and Mrs X said that there were other problems with the hospital's appointment system. Unfortunately it is not possible for me to reach a definitive judgement on whether the letter written to Mr X in June was actually sent to him.

117. There was another chance for Mr X to attend hospital on 4 September 2001. However, it seems that the Health Board did not ask him to attend (paragraph 33). The Health Board then apparently discharged him back to the care of his GP. There was no evidence that the GP was informed of this arrangement. That was a serious shortcoming.

118. In 2001 the doctors – the First Consultant and the gastroenterology Registrar - knew that Mr X had, or very probably had, cirrhosis. He had had bleeding varices, which are associated with cirrhosis, and an ultrasound scan had showed the appearance of advanced cirrhosis (paragraph 30). They were arranging investigations to determine the cause of that cirrhosis, but there does not seem to have been any doubt about the diagnosis. Yet they did not tell Mr X what he had or give him the necessary advice (as described in paragraph 114). Mr X's family said that Mr X did not know he had cirrhosis, and the Maxillofacial Specialist's letter (paragraph 35) confirms that. Mr X was not given the information he needed to know about his condition and its likely progression. Communication with Mr X therefore fell below the standards of Good Medical Practice (paragraph 11).

119. Having been lost to follow-up, Mr X was not seen again (apart from in the Emergency Department) until 2008 when he was seen by the Haematologist, who rightly referred Mr X back to gastroenterology. Unfortunately, despite receiving this letter and apparently planning to make an appointment for Mr X for 16 April, the gastroenterology department failed to offer Mr X another appointment. That was a serious shortcoming.

120. Later that year Mr X returned to hospital with oesophageal bleeding. His varices were treated, as was the later episode of testicular swelling. At a follow-up outpatients' appointment, the Second Consultant told Mr X of his diagnosis and discussed this with him (paragraph 45). He prescribed Propranolol, and arranged for blood tests to help find the cause of Mr X's cirrhosis. The Second Consultant also discussed alcohol consumption with Mr X. It is not clear from the Second Consultant's notes precisely what information he gave to Mr X, but the understanding that his family had (paragraph 87) implies that Mr X was told he should restrict his drinking to moderate levels. That is consistent with what the medical Adviser said should have happened (paragraph 98). The Second Consultant also began the process of investigating the cause of Mr X's cirrhosis by arranging blood tests. This was all in line with what should have happened (paragraph 114).

121. However, there is no evidence that the Second Consultant discussed with or offered Mr X immunisations against Hepatitis A and pneumococcus. And after blood tests did not demonstrate the cause of Mr X's cirrhosis, no further tests were carried out, despite the Registrar's intention to discuss arranging a liver biopsy with the Second Consultant (paragraph 48). It was

important to find the cause of Mr X's cirrhosis in order to treat this. A CT scan and/or a liver biopsy should have been carried out. They were not. As the necessary advice was not given to Mr X, and not all the necessary investigations were carried out, Mr X's care fell below the standard of Good Medical Practice.

122. The lack of definitive diagnosis prompted Mr X to request a second opinion. In arranging this for Mr X, the Second Consultant was respecting his right to a second opinion and therefore was acting in line with Good Medical Practice (paragraph 12). This led to Mr X finally being given a diagnosis (paragraph 50). His annual check-up later that year with the Second Consultant seems to have been unremarkable.

123. It was not until the following year that Mr X's condition began to deteriorate. When it did, it was vital that he be treated as soon as possible. It is clear from the GP's notes (paragraph 55), and from what Ms W noted (paragraph 59), that Mr X had significant fluid retention in the form of oedema and ascites. His GP was worried enough to have his appointment with the Second Consultant brought forward. His bilirubin level was such that he must have had noticeable jaundice (paragraph 104).

124. Given all of this, it is difficult to understand why the Second Consultant was so confident that Mr X's condition was not problematic and would continue not to be for many years (paragraph 57). In fact, the medical Adviser says, it should have been clear from the clinical signs and the blood test results that his liver was no longer functioning properly (paragraph 103). This needed investigating urgently to find the cause of Mr X's sudden deterioration. But the Second Consultant did not adequately assess Mr X's condition.

125. Mr X returned to hospital the following day and a doctor described him as having decompensated liver disease (paragraph 58). That is, they knew he was in liver failure. Yet the Second Consultant discharged him the following day. There was another opportunity to bring Mr X back into hospital for investigations when Ms W rang the ward (paragraph 59), but the Second Consultant did not act on that either.

126. Mr X should have been investigated on 2 August. But these additional opportunities over the next two days to start investigating and treating his infection were also missed, compounding the original error. The Second Consultant did not adequately assess Mr X's condition, taking account of his history, and he did not provide the necessary investigations or treatment.

127. The care that Mr X was given over the ten years before his death fell significantly below the standard of Good Medical Practice on a number of occasions (paragraphs 118, 119 and 121), most seriously between 2 and 4 August 2010 (paragraph 126). The care on these occasions fell so far below the standard that there was service failure.

128. The failings in Mr X's care in 2001 and 2008 meant that he was left for many years without proper knowledge of his condition, how to manage it or what to expect from it. It must have been frustrating to know that there was something wrong but not be told what it was. By 2008, Mr X was dissatisfied enough to request a second opinion and to consider asking for his care to be permanently transferred to another doctor.

129. However, through chance, these delays did not make much difference to what happened later. There was no specific treatment for congenital liver disease (paragraph 96), only for related conditions such as portal vein hypertension and oesophageal varices – and these are conditions that Mr X was treated for. He did not miss out on anything that would have been likely to extend his life.

130. Mr X's rapid deterioration in summer 2010 should have led to hospitalisation and urgent investigations beginning on 2 August. That would have led to a diagnosis of spontaneous bacterial peritonitis, and (more importantly) treatment with antibiotics, three days earlier. At that point treatment would have been started before Mr X's kidneys began to fail. That should have allowed Mr X to recover fully from the acute episode of infection.

131. Had he recovered from this episode, Mr X should have been considered for transplant. There is no guarantee that he would have received a transplant or that, if he had, it would have been successful, but this certainly would have given him a greater chance of survival in the long-term. I cannot say that Mr X definitely would have survived, whether or not he had received

a transplant before his condition deteriorated again. But he stood some chance of surviving for many years to come, perhaps ultimately in considerably better health than he had been previously, if investigated and treated from 2 August 2010.

132. As it was, this chance to survive and flourish was denied to Mr X. That is the injustice he suffered as a result of the failings in his care in August 2010. I **uphold** the complaint about the shortcomings in diagnosis and treatment of Mr X's medical condition.

Complaint handling by the Health Board

133. In order to get it right when dealing with Mrs X's complaint, the Health Board should have acted in accordance with their statutory powers and duties and any other rules governing the services they provide: in this case, the Guide (paragraphs 14 to 17).

134. The Health Board's response should have been sent to Mrs X within four weeks; that is, taking bank holidays into account, by 7 January 2011. If the Health Board was not going to manage that, it should have informed Mrs X of the reasons for the delay and let her know when she could expect a response. This was done but not until 20 January, almost two weeks after the end of the deadline. In that respect, the handling of the complaint fell short of the standards set out in the Guide.

135. In order to investigate Mrs X's complaint thoroughly and fairly, the Health Board should have carried out the actions listed at paragraph 15. The Health Board evidently did identify some of the people concerned - the Second Consultant, and the Paediatric Consultant, obtained copies of the necessary health records, and got statements from the staff involved (or, in the case of the Paediatric Consultant, one of his successors). For reasons that are not clear, however, they did not involve the First Consultant in the investigation.

136. It is not clear what evidence-checking was carried out, or whether any relevant policies and procedures were identified. But the Health Board's response is factually consistent with the evidence on which it is based, including Mr X's clinical notes and the Consultants' submissions. My officers did not identify any relevant policies or procedures during the investigation that should have been included in the Health Board's response.

137. My major concern about the Health Board's response to Mrs X's complaint is that they did not identify the failings in Mr X's care (see paragraph 126). Although the complaint process was followed by the Health Board, the outcome of that was a response that did not identify the delays in recognising and treating Mr X's serious condition between 2 August and 5 August 2010.

138. No independent clinical advice was sought by the Health Board during their investigation. That meant that serious errors in care were less likely to be identified. The Guide says that health boards should obtain clinical advice 'if necessary'. In this case the Health Board should have seriously considered doing so. The complaint was a very serious one, since Mrs X was alleging that mistakes in her son's care led to his death. Taking advice about the care of Mr X (when he was an adult), from a doctor who was not involved in that care, would have been a sensible step to take. Thorough and independent clinical advice should have identified the same failings in Mr X's care that this investigation has found, given the availability of objective evidence demonstrating the seriousness of Mr X's condition on 2 August 2010 (paragraph 123). It is unfortunate that the independent review did not identify these failings.

139. After the independent review the Health Board was asked to carry out further work, including arranging a meeting. This was carried out. At this point the care of Mr X – at least when he was an adult – had been vindicated by the independent review (paragraph 75). It is understandable therefore that the Health Board were not prompted by the independent review to re-evaluate that part of the complaint. Instead the Health Board attempted to resolve the complaint by answering Mr X's family's questions at the meeting, as requested by the lay reviewer.

140. Mrs X has said that the Health Board staff seemed unprepared for the meeting and did not have Mr X's notes with them. Mrs X's recollection, along with the fact that the Health Board was unable to clarify the reasons for Mr X's missed appointments at the meeting, suggests that they did not have Mr X's notes with them, or at least that they did not have a comprehensive set of his notes. However, the minutes describe detailed answers to many of the questions that Mrs X and her family asked. That shows that the attendees must have prepared for the meeting, particularly if they had to

work from memory. Also, after the meeting, the Health Board filled in any remaining gaps. So, while I can understand Mrs X's complaint that the meeting attendees were under-prepared, taken as a whole I consider that the Health Board made sufficient efforts to answer the remaining points after the independent review.

141. The overriding concern I have about the handling of Mrs X's complaint is that the Health Board did not identify the serious errors made in Mr X's care. The process was generally carried out properly and in line with the Guide. However, objective consideration should have identified the errors in that care. The Health Board did not identify those errors. Therefore their investigation was not thorough. There was maladministration.

142. That maladministration meant that Mrs X and her family had to pursue further avenues in order to get a thorough investigation. They were left without proper answers for over two years longer than necessary. This was after their initial complaint had been delayed for several weeks during which time they were left without any information about when to expect a response (paragraph 134). As a result of these shortcomings I **uphold** this element of the complaint.

Recommendations

143. I recommend that within one month:

144. The Health Board writes to acknowledge and accept responsibility for, the failings identified in this report and the injustice arising from them. However, in line with Mrs X's wishes the Health Board should **not** apologise for those failings in the letter.

145. The Health Board provides financial redress of £5,000 to Mrs X for the distress caused by the failings identified, and to acknowledge the uncertainty she lives with over whether her son would have lived but for the failings identified. The Health Board should also provide a further £500 to Mrs X in recognition of the shortcomings in complaint handling.

146. The Second Consultant considers the issues raised in this case and the learning points that arise. Personnel matters are not within my jurisdiction, but, for example, the Second Consultant could complete a piece of reflective writing with regard to the learning points from this case and discuss this with his appraiser. The completed appraisal documentation might identify learning and development objectives which arise and how they could be met.

147. I recommend that within four months:

148. In order to ensure that these failings do not reoccur the Health Board should review its appointments system and process, and gastroenterology care pathways. Safeguards should be put in place to prevent patients being lost to follow-up or left without information about their diagnosis and prognosis.

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

Peter Tyndall
Public Services Ombudsman for Wales

3 October 2013



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