The investigation of a complaint
by Miss X
against Abertawe Bro Morgannwg University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201501032

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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 Miss X and her brother as Mr X.

Summary

Miss X said that her brother, Mr X, suffered from a congenital heart defect ("ACHD") and had surgically treated kyphoscoliosos (a condition in which the spinal column is convex both backward and sideways). She complained about the insufficient regularity of investigations, notably Echocardiagrams (a diagnostic test that uses ultrasound waves to make images of the heart chambers, valves and surrounding structures) ("ECHOs"), leading up to October 2011. She said that if ECHOs had been carried out every six months, treating clinicians might have detected a sub aortic membrane (a form of fixed sub aortic obstruction in which a fibrous membrane is located below the aortic valve) earlier than January 2012.

Miss X also complained that her brother could not be put on the waiting list for surgery until all tests and investigations had been completed and this took 11 months. She said that her brother was inappropriately prioritised for surgery; she said that he should have been prioritised due to his kyphscoliosis and the effect this had on his ability to expand his lungs. Miss X said that this would not have been an issue had the investigative tests been undertaken within a reasonable time. She said that the failure to undertake ECHOs far more frequently and to undertake investigative tests within a reasonable time meant that her brother did not receive surgery in time to save his life. Mr X was 57 years old when he passed away.

The Ombudsman concluded that there was no evidence to suggest that ECHO tests should have been undertaken more frequently. This was in light of the fact that the degree of obstruction caused by Mr X's sub aortic membrane (the narrowing of the left ventricle of the heart just below the aortic valve through which blood must pass) would have been unlikely to have been detected earlier than January 2012, which prompted the need for surgery. Given that there was no significant deterioration in Mr X's condition between October 2011 and December 2012, the Ombudsman found that the Health Board did not prioritise Mr X for surgery inappropriately. The Ombudsman upheld the complaint about the clinical advice given to Mr X during his wait for surgery. There was no evidence that Mr X was made aware of worrying symptoms. The Ombudsman upheld the complaint regarding Mr X's wait for treatment. Treatment should have been supplied within 26 weeks, but Mr X was not due to receive treatment until 50 weeks

had elapsed. Had Mr X received surgery more promptly, on the balance of probabilities, his death would have been avoided. The Ombudsman therefore took the view that Mr X's death was avoidable.

The Ombudsman made the following recommendations:

a) That the Health Board's Chief Executive personally apologises to Miss X for the failings identified in this report, most notably, Mr X's avoidable death.

b) That the Health Board concludes its "mirror" process to that conducted under the "Putting Things Right" ("PTR") in order to assess the level of compensation that it should offer to Mrs X in respect of the avoidable death of Mr X. The Health Board has confirmed that the file has already been shared with its legal department for this purpose and, with that in mind, it should conclude this process within **three months** of the date of issue of the report.

c) That the Health Board ensures that the British Heart Foundation leaflet entitled 'Heart Valve Disease' is given to every relevant patient at clinic and that the checklist is completed to reflect this, and that appropriate advice has been given. The Health Board should ensure that all Cardiology clinicians are aware of this requirement. Confirmation that all relevant clinicians are aware of the leaflet, have sufficient copies and are aware when it should be used, should be provided to his office within **two months** of the date of the report.

The Health Board agreed to implement the recommendations.

1 March 2016

The complaint

1. Miss X said that her brother, Mr X, suffered from a congenital heart defect ("ACHD") and had surgically treated kyphoscoliosos (a condition in which the spinal column is convex both backward and sideways). She complained about the insufficient regularity of investigations, notably Echocardiagrams (a diagnostic test that uses ultrasound waves to make images of the heart chambers, valves and surrounding structures) ("ECHOs"), leading up to October 2011. She said that if ECHOs had been carried out every six months, treating clinicians might have detected a sub aortic membrane (a form of fixed sub aortic obstruction in which a fibrous membrane is located below the aortic valve) earlier than January 2012.

2. Miss X also complained that her brother could not be put on the waiting list for surgery until all tests and investigations had been completed, and this took 11 months. She said that her brother was inappropriately prioritised for surgery; she said that he should have been prioritised due to his kyphscoliosis and the effect this had on his ability to expand his lungs. Miss X said that this would not have been an issue had the investigative tests been undertaken within a reasonable time. She said that the failure to undertake ECHOs far more frequently and to undertake investigative tests within a reasonable time meant that her brother did not receive surgery in time to save his life.

Investigation

3. I obtained comments and copies of relevant documents from Abertawe Bro Morgannwg University Health Board ("the Health Board") and considered those in conjunction with the evidence provided by Miss X. I also obtained advice from one of the Ombudsman's Professional Advisers ("the Adviser"). The Adviser, Dr Michael Norell, is a Consultant Cardiologist with over twenty years' experience. I have not included every detail investigated in this report, but I am satisfied that nothing of significance has been overlooked.

4. Both Miss 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 Guidance

5. In March 2005, the First Minister and Minister for Health and Social Services announced that, by December 2009, no patient in Wales would wait more than 26 weeks from referral by a General Practitioner or other medical practitioner to treatment in hospital, including waiting times for any diagnostic tests or therapies required. The Referral to Treatment ("RTT") target, "begins at the receipt of a referral in secondary care and ends when treatment commences". The guiding principles of the target were set in policy through a range of Welsh Health Circulars.

6. 'Rules for Managing Referral to Treatment Waiting Times' ("the guidance") set out that,

> "The achievement of the 26 week target is the responsibility of Local Health Boards".

7. The cardiac RTT target was announced in 2005 and aims to achieve better clinical outcomes for patients with cardiac conditions, through early diagnosis and treatment. The guidance at paragraph 34 states that the target applies to all Welsh residents, whether treated in Wales or elsewhere. At paragraph 34 it confirms,

> "The target includes waits for all diagnostic procedures and all referrals to other consultants by the cardiologist, where that referral is relevant to the diagnosis and treatment of the patients within the scope of the target".

8. Paragraph 122 of the guidance confirms that,

> "Where a patient's RTT period takes place across more than one organisation, and the consultant responsible for the care of the patient does not change, the clock will continue when the patient is transferred between the organisations".

9. The current Welsh Government targets for NHS RTT waiting times are that:

- At least 95 per cent of patients waiting to start treatment must have waited less than 26 weeks from referral to treatment.
- 100 per cent of patients not treated within 26 weeks must be treated in 36 weeks.

The background events

10. On 19 September **2011**, Mr X's GP referred him to the Health Board. Mr X was then aged 56.

11. On 4 October, an ECHO was carried out.

12. On 31 October, the Consultant Cardiologist wrote to Mr X and said that the ECHO suggested that the narrowing of his aortic valve had progressed slightly. As a result, a transoesphageal echocardiogram ("TOE") (a test that uses ultrasound to produce moving, real-time images of the heart) was warranted and was due to be performed within the following three months.

13. On 12 January **2012**, the TOE was carried out.

14. On 5 March, Mr X attended the Consultant Cardiologist's clinic. In a letter dated 12 March to Mr X's GP, the Consultant Cardiologist said that she had given Mr X a six month follow up appointment. Also on 12 March, the Consultant Cardiologist wrote to Mr X to ask that he attended the Electrocardiogram ("ECG") (a painless test that records the heart's electrical activity) department for a scan at his earliest convenience.

15. On 4 April, the ECG was carried out.

16. On 16 April, the Consultant Cardiologist wrote to another Consultant Cardiologist in University Hospital of Wales Cardiff ("the Hospital") ("the second Consultant Cardiologist") to request that Mr X's case be presented at a case conference in Bristol.

17. On 29 May, the second Consultant Cardiologist presented Mr X’s case at the case conference in Bristol. In his letter to the Consultant Cardiologist on 30 May, he said that,

> “It was agreed [at the case conference] that the degree of sub aortic stenosis (the narrowing of the left ventricle of the heart just below the aortic valve through which blood must pass) and aortic regurgitation (a condition that occurs when the heart’s aortic valve does not close tightly) warranted intervention...it is likely that an aortic valve replacement (the aortic valve controls the flow of blood out of the heart’s left ventricle to the aorta) would be required. In view of Mr [X’s] age it was felt that a mechanical aortic valve replacement may be the best option.
>
> It was considered that further information in the form of formal lung function tests..are required. Also coronary angiogram or CT angiogram (this test uses a CT scanner to produce detailed images of both blood vessels and tissues ion various parts of the body)...I will await the lung function tests and the decision about CT angiography before instituting a formal referral to the surgical team”.

18. On 7 June, the Consultant Cardiologist requested a lung function test.

19. On 9 July, the lung function test was carried out.

20. On 16 July, the Consultant Cardiologist requested a CT angiogram.

21. On 4 September, the CT angiogram was carried out.

22. On 1 October, the Consultant Cardiologist requested a respiratory opinion.

23. On 9 October, the second Consultant Cardiologist wrote to the Consultant Cardiologist. He said that Mr X would need a further TOE prior to any planned surgery. Also on 9 October, the second Consultant Cardiologist requested an appointment for Mr X to have transthoracic (an ultrasound imaging scan of the heart using high frequency sound waves to see all four chambers of the heart, the valves and the sac around the heart) and TOE tests done at the Hospital.

24. On 13 November, the respiratory opinion was provided.

25. On 22 November, there was a conference discussion regarding Mr X's case at the ACHD unit at the Hospital. It was considered that an operation to inspect the left ventricular outflow tract (a portion of the heart through which blood passes in order to enter the great arteries) should be offered.

26. On 7 December, the second TOE was carried out.

27. On 22 January **2013**, there was a case conference at Bristol. Mr X was placed on the surgical list. A pre-assessment appointment prior to surgery was booked for 2 April 2013.

28. On 31 January, the second Consultant Cardiologist wrote to a colleague in Bristol, ("the third Consultant Cardiologist"), to thank him for agreeing to meet Mr X in clinic to discuss the proposed surgery. This was for inspection of the left ventricular outflow tract, resection of the sub aortic stenosis and valve replacement.

29. On 26 March at 1.50pm, Mr X was admitted to Princess of Wales Hospital Bridgend with shortness of breath and pain in his left arm. He had been feeling unwell for around three days and had been burping, short of breath and tired.

30. On 27 March, sometime before 9.00am, Mr X suffered a sudden haemodynamic deterioration (a deterioration in the blood circulation). A cardiac arrest call was made, but resuscitation was unsuccessful. Mr X died at 9.10am.

31. On 27 May, Miss X complained about Mr X's treatment to the Health Board. On 29 May, the Health Board acknowledged Miss X's complaint.

32. On 9 July, the Health Board responded to Miss X's complaint.

33. On 26 July, the Health Board's Cardiology Specialist Manager prepared an investigation report. On 9 August, this was sent to Miss X.

34. On 23 August, the Clinical Governance Manager contacted the Consultant Cardiologist to arrange a meeting with the complainant.

35. On 7 October, a meeting took place. Present were Miss X and her sister, the Consultant Cardiologist and the Clinical Governance Manager. Also present was Miss X's niece.

36. On 14 February **2014**, the notes of the meeting held on 7 October 2013 were sent to Miss X.

37. On 16 April, Miss X contacted the Clinical Governance Manager and said that she was disappointed with the notes of the meeting. She included comments that she felt were missing in the notes. The Clinical Governance Manager said that she would review the notes and discuss the matter further with the Consultant Cardiologist.

38. On 1 July, the Clinical Governance Manager provided an amended version of the notes of the meeting with the Consultant Cardiologist's input.

39. On 16 October, and as a result of a query from Miss X, the Consultant Cardiologist offered to meet with her. On 27 October, Miss X agreed to attend a meeting with the Consultant Cardiologist.

40. On 18 November, the Clinical Governance Support Officer asked Miss X if she could meet with the Consultant Cardiologist on 15 January **2015**. That meeting took place on 15 January.

Miss X's evidence

41. Miss X said that, when her brother was referred to Neath Port Talbot Hospital in 2006, he was told that he would need ECHOs every six months. Miss X noted that the Health Board's investigative report showed that Mr X had received two ECHOs two years after the previous ECHOs. Miss X said that she did not understand why these services could not be made available after normal clinic hours to relieve the pressure on services. Miss X said that she would have been prepared to pay for her brother to have these tests privately; however, she was told that this was not possible.

42. Miss X said that she was upset that the Health Board's investigative reports appeared to be blaming her brother for not making medical staff aware that his condition was deteriorating. She said that her brother had learnt to cope with the difficulties that his health conditions placed upon him from a young age and was not inclined to complain. She said that had the Consultant Cardiologist, in March 2012, made them aware of concerning symptoms to be aware of, particularly the more unusual symptoms, she would have been more alert and would have sought medical attention before she did. Miss X said that it would also have provided her with an opportunity to contact the Consultant Cardiologist a few months before her brother's death to discuss her concerns about his health. Instead, she felt that they had to rely on the clinician, to whom they spoke following the TOE carried out on 7 December, to notify the Consultant Cardiologist of her concerns, which he failed to do. She said that,

> "My failure to ensure that [the Consultant Cardiologist] was aware of my concerns will be on my conscience for the rest of my life and I would, therefore, suggest that patients should now be given this important information in writing".

The Health Board's evidence

43. The Health Board's response to the complaint on 9 July 2013 said that Mr X had been under review at the Cardiology department of Neath Port Talbot Hospital since 2006 and ECHOs had taken place in 2006, 2007, 2009 and 2011. The 2011 ECHO detected a sub aortic membrane which, although never visualised in previous tests, had probably been present since birth. It said that technological advancements in addition to development in the skills of technicians were probably the reasons why the membrane had not been detected previously. The Consultant Cardiologist then referred Mr X for a TOE to further assess his condition. Following receipt of the results, Mr X was referred to the second Consultant Cardiologist with a view to him being considered for congenital cardiac surgery in Bristol.

44. The Health Board said that,

> "Patients with congenital heart lesions such as [Mr X's] are generally operated on in specialist centres by congenital cardiac surgeons. Wales does not have a funded adult congenital heart disease service

> and so most cases are referred to our linked congenital surgical centre in Bristol. [Mr X's] case highlights the need for such a service in Wales, and fortunately the Welsh Health Specialised Services Committee ("WHSSC") ha[s] recently commenced plans to develop one".

45. The Health Board went on to outline the steps that were taken to progress Mr X's case to surgery, including the tests and investigations carried out. The Health Board said that following a repeat TOE and respiratory opinion, Mr X's case was again discussed at a case conference in Bristol. Mr X was accepted for surgery and placed on the waiting list on 22 January 2013. The Health Board said that once a patient is accepted for surgery, "the routine wait for surgery in Bristol is around four months".

46. The Health Board outlined the timeframe for tests and investigations. It said that, "a patient is only placed on the waiting list when all necessary investigations ...have been completed. These investigations unfortunately take time, often with three month waits for specific tests. The waits become cumulative when tests are required sequentially, as is what happened in [Mr X's] case, meaning that this period of time was eleven months. This is the average cumulative waiting time for the[se] investigations. Such waiting times are heavily influenced by capacity and demand issues within the service. Diligent efforts are continuously made by the Health Board to resolve these issues and so reduce these waiting times; however we fully accept that as yet they have not decreased sufficiently".

47. In terms of the urgency with which Mr X's case was managed, the Health Board said that it had been appropriately prioritised. It said that the Consultant Cardiologist had assessed Mr X in March 2012 and he had then only suffered a slight deterioration in his exercise capacity over five years. The Consultant Cardiologist felt that much of the deterioration could be attributed to Mr X's kyphoscoliosis and the corresponding restriction in lung capacity and his BMI (body mass index; a person's weight divided by their height).

48. The Health Board said that Miss X was "right to assume that [Mr X] should have been advised of symptoms to be alert to whilst waiting for surgery". It said that the Consultant Cardiologist "routinely" mentions this to patients in clinic.

49. On 27 August 2015, the Health Board responded to my office's letter of 1 June which advised that the complaint would be investigated. It said that, since Mr X's death, WHSSC had recognised the need to expand the ACHD service. It said that, "this will hopefully enable us to treat patients in a more timely manner and closer to their homes". It added that,

> "A Phase One investment of £400,000 has been made available in 2015 in order to take the service forward. A full time ACHD Consultant has been appointed at Cardiff who will lead this service and each Health Board across Wales has nominated a local ACHD Cardiologist and ACHD cardiac physiologist...Monthly ACHD clinics have been introduced within each Health Board".

50. The Health Board confirmed that ACHD cases were being presented to case conferences in Bristol on a weekly basis, rather than a six weekly basis as they were at the time of Mr X's care. It said that it now has the facilities to perform CT angiograms and TOEs within the Health Board, although patients with complex ACHD may still be referred to UHW for tests and investigations. In UHW, the wait for tests as at August 2015 was up to eight weeks for TOEs, six weeks for CT angiograms and urgent CT angiograms could be performed within twenty four hours. The Health Board said that it did not have "direct responsibility" for the waiting times for the investigations at UHW. It added that there was "no indication of significant deterioration in [Mr X's] clinical condition" that would have required prioritisation.

51. The Health Board said that, equally, there was no clinical need for ECHOs to be carried out on a more frequent, or six monthly, basis. It noted that Miss X had suggested that if they had been carried out more frequently, the sub aortic membrane would have been detected earlier. It said that the membrane had only been detected in 2011 as a result of technological advances and the increased skills and training of technicians.

52. The Health Board noted that Mr X had been referred by his GP for diagnostic testing in 2009. He then had an appointment with another Consultant Cardiologist ("the fourth Consultant Cardiologist") and was referred for an ECHO. The fourth Consultant Cardiologist made a diagnosis of aortic valve stenosis and suggested that Mr X should be considered for surgery if there was significant deterioration in his condition, or he developed any symptoms. The Health Board said that whilst Mr X was asymptomatic at

that time, he should have been given a follow up appointment six months after his clinic appointment with the fourth Consultant Cardiologist. It, however, acknowledged that this was not done and that Mr X did not receive a further ECHO until 2011, when his GP re-referred him.

53. The Health Board noted Miss X's concern about the way in which her complaint had been handled. It said that whilst the original response was issued in a timely manner, there were a number of delays and omissions regarding the later meetings and investigation report for which it apologised. It offered Miss X £250 in recognition of these failings. (Miss X felt that the offer was "unnecessary" and declined it).

54. In conclusion, the Health Board offered its sympathies to Miss X. It said that it would,

> "Like to reassure her that the Health Board is committed to ensuring that appropriate and timely treatment is provided to its ACHD patients within the limitation of its available resources. We are working in partnership with WHSSC and the other Health Boards to provide a clearer pathway for referral and investigations for ACHD patients. While this may not help in Miss [X's] case [the Health Board] would like to advise her that the service has taken significant steps forward from the provision that was in place at the time of her brother's sad death".

Professional advice

55. In relation to the frequency with which ECHOs should have been carried out in Mr X's case, the Adviser said that they are not necessarily carried out every six months in ACHD patients. He said that the interval between the tests would vary depending on the specific nature of the patient's condition and the rate of progression which was apparent. In Mr X's case, the Adviser noted that he was seen on a regular basis from 1968 to 1989. In 2007 he was reviewed again and followed up until October 2011**,** when the Consultant Cardiologist suspected a sub aortic membrane which was confirmed in 2012. A referral was then made to the second Consultant Cardiologist. The Adviser concluded that ECHOs and clinical reviews, "took place at irregular but acceptable intervals".

56. In relation to the detection of the sub aortic membrane, the Adviser noted that this occurred after the ECHO of 4 October 2011 and that this was the cause of the obstruction to the blood flow, rather than the aortic valve itself. He said that, "previous ECHO scans had not picked up this aspect for technical reasons and not because this development had been a recent one. Therefore more frequent scans would not have revealed this at an earlier stage". The Adviser added that,

> "Even if this abnormality had been appreciated earlier it would have been the degree of obstruction (measured as a pressure drop across the membrane) that would have prompted the need for intervention rather than simply the presence of a membrane itself".

The Adviser therefore concluded that,

> "Earlier scans would not have detected a membrane sooner. Even if they did it would not have significantly altered the course of events".

57. In respect of the second TOE, the Adviser commented on whether this would have been necessary if the images from the previous study had been available. He said that it was not done because of a failure to see the results of the first TOE. The Adviser said that,

> "The initial TOE...revealed the membrane but not the "walled off" ventricular septal defect ("VSD"; a hole in the wall that separates the right and left ventricles of the heart). This was only seen on a CT scan in September 2012 and it was for this reason that [the second Consultant Cardiologist] requested a further TOE...that was undertaken on 7 December".

The Adviser concluded that the TOE in December 2012 would still have been required, given the results of the CT scan.

58. The Adviser said that it was usual for all test results to be available before a patient would be accepted for surgery. He noted that Mr X's anatomy was not completely clear until December 2012, following the second TOE. This would have been an important factor in planning surgery. The Adviser noted that following the case conference discussion, the referral for surgery was made in January 2013 with the benefit of all the necessary information.

59. The Adviser described the length of time Mr X spent waiting for and undergoing tests as “unfortunate [but] not unreasonable”. He noted that Mr X required two TOEs, CT scanning, lung function tests and a respiratory opinion, as well as obtaining details relating to previous skeletal surgery and whether or not metallic devices had been used (as this was relevant to MRI scanning). This data then needed to be collated before being considered at a case conference in Bristol in November 2012.

60. In relation to the method by which Mr X was prioritised for surgery, the Adviser said that,

> “I could find no evidence by which surgery was prioritised in terms of clinical urgency..no mention of clinical priority is evident”.

The Adviser, however, noted that at the time of the case conference in November, Mr X was noted to be breathless with moderate exertion and able to walk his dog on a daily basis. Symptoms such as chest pain, which might have prompted clinical urgency, were not present. He confirmed that, in the absence of symptoms and given the chronic nature of the condition, there was no clinical urgency. Whilst there was a progression of Mr X’s condition between 2007 and 2011, this was not, “at a particularly rapid rate”.

61. The Adviser said that there was also no evidence of deterioration in Mr X’s condition whilst he waited for surgery, particularly between October 2011 and December 2012. The Adviser noted that when Mr X attended the respiratory physician in November 2012, he was described as having “only mild breathlessness”.

62. In respect of Mr X’s kyphoscoliosis, the Adviser said that it might have impacted upon the feasibility of surgery as well as his anaesthetic and operative risk. It would, however, not have impacted upon his prioritisation for surgery.

63. Taking his comments above into account, the Adviser confirmed that the Health Board’s view that there was no clinical urgency for Mr X’s surgery was reasonable.

64. In relation to the advice that should have been given to Mr X while awaiting surgery, the Adviser was clear that, “he should have been advised to be aware of certain symptoms but was not”. The Adviser said that the common symptoms in cases of left ventricular outflow obstruction, such as Mr X’s, are chest pain, breathlessness and loss of consciousness, particularly with exertion. The Adviser said that Mr X should have been advised to be aware of undue breathlessness (given that he had longstanding breathlessness related to his lung function), chest pain or loss of consciousness. The Adviser confirmed that,

> “There is no evidence that he had been so advised and presented to hospital in March 2013 having been ‘unwell with intermittent breathlessness’ for three days and having noted chest pain for one day”.

65. In conclusion, the Adviser said that, “there was no evidence of clinical urgency in this case”. He noted that, whilst it was around a year from the assessment by the Consultant Cardiologist in March 2012 until Mr X’s sad death, a number of tests and investigations were required during this time. He noted that,

> “Even if those tests had been more rapidly undertaken, it is unlikely that Mr [X] would have undergone corrective surgery before his death on 27 March 2013. However, had he done so then on the balance of probabilities his death would have been avoided”.

66. Shortly before the issue of a draft of this report, the Health Board received a copy of the independent advice it sought from a consultant cardiologist on the complaint. That advice was shared with the complainant under a “mirror” procedure to the Welsh Government’s health complaints procedure entitled “Putting Things Right” (“PTR”). That advice supported the conclusions proposed in this report, that Mr X’s death was avoidable. I would encourage the Health Board to reflect upon its own reaction to that advice.

Miss X’s comments on the draft report

67. In relation to the need for tests to be undertaken prior to surgery, Miss X said that,

> “I did, of course, understand that these tests were necessary in order to determine what would need to be done during surgery but, because of the prolonged waiting times for tests, felt that those patients needing tests were disadvantaged compared to those who didn’t need any tests. For this reason, I suggested that those needing tests should either have been put on the waiting list, with an indication that they wouldn’t be ready for surgery until tests had been completed, or put on a separate list and, when tests had been completed slotted into the waiting list as near as possible to where they might have been if they hadn’t needed any tests. Had [Mr X] not needed any tests, he could have had surgery in September/October 2012; if he hadn’t needed the second TOE, he could have had surgery in February/March 2013. The waiting times for tests prevented [Mr X] having surgery in time to save his life”.

68. Miss X went on to say that,

> “[The Consultant Cardiologist] and the Health Board acknowledged that these waiting times were unacceptable and a serious risk factor for those awaiting surgery. At the meeting on 7 October 2013, [the Consultant Cardiologist] told us that she was not aware that any of her patients, apart from [Mr X], had died whilst waiting for surgery but said that there had been quite a few near misses. These near misses, not [Mr X’s] death, should have been the catalyst for doing everything possible to highlight and minimise risk”.

69. Finally, Miss X thanked my office for investigating her complaint. She said that,

> “Although it’s extremely upsetting to know that mistakes were made and opportunities to prevent [Mr X’s] death missed, it’s better than always wondering whether this was the case, if things could have turned out differently for [him] and whether or not we’ve been told the truth. Hopefully, in time, this will help us to come to terms with [Mr X’s] death”.

The Health Board's comments on the draft report

70. The Health Board said that it had met with the Consultant Cardiologist and the Clinical Director. It said that it fully accepted the findings and recommendations made in the draft report.

71. The Health Board said that there had been,

> "significant improvement in communication with ACHD patients since the employment of two full time specialist nurses in 2015 who attend the majority of ACHD clinics. ACHD patients are also referred to these nurses for further assessment, where necessary. The Health Board said that ACHD patients are also given a dedicated telephone number which they can use to access the nurses for advice and information".

72. In relation to the proposed recommendation of the production of a leaflet for ACHD patients, the Clinical Director referenced a booklet already produced by the British Heart Foundation, a copy of which was supplied, entitled 'Heart Valve Disease'. This booklet provided advice specifically for patients with heart valve disease and (on page seven) contained information on symptoms patients should be aware of.

73. The Health Board confirmed that this booklet was not available at clinic at the time of Mr X's assessment. The Clinical Director confirmed that, "in view of the array of problems that could be encountered by patients with heart valve problems...it would be difficult to produce a leaflet specifically for ACHD patients, advising them of every symptom to be aware of for every condition". The Health Board, however, considered that the British Heart Foundation's booklet would be helpful in advising patients of symptoms to be aware of. Utilising this information, in conjunction with the input of the specialist nurses, would provide appropriate direction and information for patients, the Health Board considered.

74. The Health Board added, on the suggestion of the Consultant Cardiologist, that a standard checklist could be introduced into patient records so that it could be confirmed that information leaflets had been supplied, and advice given with regard to symptoms.

75. Finally, the Health Board's Chief Executive said that he,

> "Would like to take this opportunity to again offer my sincere condolences to [Miss X] and apologise for the delay in providing cardiac treatment to her brother, and for the findings in the Ombudsman report that this delay contributed to his death which was ultimately avoidable".

Analysis and conclusions

Frequency of ECHO tests

76. Miss X felt that Mr X should have received ECHOs every six months. Had he done so, the sub aortic membrane would have been detected earlier and treatment would have followed more rapidly. I note that the Adviser has, however, said that patients with ACHD should not necessarily receive ECHOs every six months and that the frequency of testing is largely dependent on the nature of the condition and its progression. In Mr X's case, there had been slight deterioration in his condition in his exercise capacity in the five years preceding March 2012. I do not, therefore, take the view that the progression of Mr X's condition in 2011 was such that it would have warranted more frequent, six monthly, ECHOs being carried out.

77. Even if more frequent ECHOs had been carried out, it seems unlikely that the sub aortic membrane would have been detected earlier than January 2012. The Health Board has said, and the Adviser agrees, that technological advances and an increase in the skill of technicians were likely to have accounted for the detection of the membrane. Furthermore, the Adviser was clear that the presence of the membrane alone would not have been sufficient to have warranted intervention. Earlier detection would not necessarily, sadly, have altered the course of events. Whilst I note Miss X's concerns, I **do not**, therefore**, uphold** this complaint.

Prioritisation for surgery

78. Miss X has said that Mr X could not be placed on the waiting list for surgery until all relevant tests and investigations had been carried out. Miss X has said that, given that this took 11 months, Mr X did not receive

surgery in time to save his life. She has also said that she would have been prepared to have paid privately for tests to have been carried out, which would have speeded up the process.

79. It would not have been usual or appropriate for Mr X to have been placed on the waiting list prior to the conclusion of all relevant tests and investigations, given that the treatment to be provided might have changed as a result. The Adviser has confirmed that the tests and investigations carried out in Mr X's case were necessary and appropriate. He said that it was reasonable that Mr X was not placed on the waiting list for surgery until after the second TOE, given that the first TOE was not clear enough. Whilst Miss X's view that Mr X could or should have been placed on the list while the tests were being carried out, thus saving time, is understandable, I cannot agree that this would be reasonable or appropriate. I do, however, agree with Miss X that, had there been 'near misses' in terms of patients awaiting surgery, this should have prompted the Health Board to have ensured that it was taking every possibly action to minimise the risk of harm to ACHD patients.

80. In relation to Mr X's prioritisation for surgery, I note Miss X's view that her brother's kyphoscoliosis should have meant that he received priority, given its effect on his lung function. Again, whilst Miss X's view is understandable, I cannot see that there was any clinical indication for Mr X to be prioritised. Whilst Mr X's condition was chronic, there is little evidence that it was significantly worsening. I note that the Adviser has said there was no deterioration between October 2011 and December 2012. The general progression over the preceding few years was also not at "a particularly rapid rate". Also, symptoms which would or should have prompted rapid action, such as chest pain, were not being experienced by Mr X. Mr X's kyphoscoliosis would also not have had an impact upon his prioritisation for surgery although it would have impacted upon the surgical risk that Mr X posed. Accordingly, I cannot agree that the Health Board inappropriately prioritised Mr X. I **do not uphold** this complaint.

Clinical advice given during the wait for surgery

81. Miss X has said that she and Mr X should have been made aware of concerning symptoms to look out for, but they were not. She has said that, had she been made aware, she would have sought medical help before she did. The Health Board has said that the Consultant Cardiologist routinely advises patients of the symptoms to be aware of.

82. The Adviser has been very clear that Miss and Mr X should have been made aware of concerning symptoms. I agree that there is no evidence in Mr X's medical records that they were so advised and that they should have been. I do not doubt Miss X's statement that she would have sought treatment in the few days leading to her brother's death before she did, had she been aware, or that she would have discussed her concerns with the Consultant Cardiologist.

83. This is a matter that has caused Miss X concern. I agree that patients should be given information regarding concerning symptoms and when to seek medical assistance when awaiting treatment. I also agree that the Health Board should give written information to patients, in addition to recording in the patient's records that the information has been given. Having carefully considered the matter, the information leaflet supplied by the Health Board and produced by the British Heart Foundation is sufficient, in my view, to raise awareness of worrying symptoms in patients with heart valve disease. I also note, and welcome, the Health Board's introduction of specialist nurses and a dedicated telephone number for ACHD patients. The checklist seems to me, in addition, to be a useful tool for clinicians to be able to demonstrate that appropriate advice has been given with regard to symptoms. It is surely fundamental that ACHD patients awaiting treatment are fully aware of what symptoms would be concerning and when to seek help. I **uphold** Miss X's complaint in this regard and make a recommendation accordingly.

RTT times

84. I have set out above the Welsh Government's guidance on RTT times. I also include, as an appendix to this report, my timetable of Mr X's RTT. As noted earlier in this report, the RTT 'clock' must be stopped for tests and investigations. Even taking this into account, on the basis of my calculation,

there were 50 weeks between the original referral by Mr X's GP and the date of the pre assessment appointment for surgery in Bristol. Very sadly, Mr X died during the week prior to this appointment. It was, however, unlikely that Mr X would have received surgery until four months after he was placed on the waiting list, the Health Board has confirmed.

85. Given that Mr X should have received treatment within 26 weeks of the date of his referral, it is clearly completely unacceptable that he was not due to receive that treatment until well over a 50 week period had elapsed. The Adviser has said that, on the balance of probabilities, had Mr X received this surgery earlier, it would have saved his life. I can, therefore, take no other view than Mr X's death was avoidable. In light of this conclusion, it is in the public interest to publicise this report.

86. Whilst I welcome the steps taken by the Health Board to address the waiting times for patients with ACHD, it is now, very sadly, too late for Mr X to benefit from these improvements. There should have been a system in place whereby the Consultant Cardiologist, or a clinician from her department who knew the patient, could go directly to Bristol to discuss them. It is illogical that the Consultant Cardiologist had to write to the second Consultant Cardiologist who did not know Mr X, to ask him to present the case at Bristol, at a conference which took place some nine weeks later. It is a failing that Mr X had to wait eight weeks, taking into account the relevant test conducted in the meantime, for a clinic appointment with the Consultant Cardiologist. It is also a failing that the Consultant Cardiologist gave Mr X a routine follow up appointment for six months' time, when she did see him. Notwithstanding my comments above that Mr X was appropriately prioritised for surgery, there is an apparent lack of urgency of treatment for ACHD patients on the part of the Consultant Cardiologist but also within the Health Board as a whole. I **uphold** this complaint.

87. As I have upheld Miss X's complaint and consider that Mr X's death was avoidable, I feel it is appropriate to make a recommendation regarding redress. In doing so, I am mindful of the Health Board's positive response to this complaint and its acceptance of the failings I have found. The Health Board sought independent clinical advice on the complaint, as detailed at paragraph 66 of this report. It has fully accepted the conclusions of that advice, in addition to those reached in this report, with the benefit of my own clinical adviser. Furthermore, the Health Board has already implemented

improvements to the service provided to ACHD patients. With this in mind, I was confident that the Health Board would be able to objectively consider the level of redress that should be offered to Miss X under the “mirror” PTR process. I am, therefore, content to refer the matter back to the Health Board so that it may be considered and a figure reached and I commend the Health Board’s approach since I started my investigation.

Recommendations

88. I **recommend** that:

a) The Health Board’s Chief Executive personally apologises to Miss X for the failings identified in this report, most notably, Mr X’s avoidable death.

b) The Health Board concludes its “mirror” process to that conducted under the PTR in order to assess the level of compensation that it should offer to Mrs X in respect of the avoidable death of Mr X. The Health Board has confirmed that the file has already been shared with its legal department for this purpose and, with that in mind, it should conclude this process within **three months** of the date of issue of this report.

c) The Health Board ensures that the British Heart Foundation leaflet entitled ‘Heart Valve Disease’ is given to every relevant patient at clinic and that the checklist is completed to reflect this and that appropriate advice has been given. The Health Board should ensure that all Cardiology clinicians are aware of this requirement. Confirmation that all relevant clinicians are aware of the leaflet, have sufficient copies and are aware when it should be used, should be provided to my office within **two months** of the date of this report.

89. I am pleased to note that in commenting on the draft of this report the Abertawe Bro Morgannwg University Health Board has agreed to implement these recommendations.

Nick Bennett
Ombudsman

1 March 2015

Appendix

Mr X’s referral to treatment (“RTT”) times

Date	Date requested	Test, investigation or appointment	Number of weeks from referral
19.9.11		Referral from GP to Cardiology department	
4.10.11	19.9.11 ?	ECHO carried out	
12.1.12	31.10.11	TOE carried out	
5.3.12		Cardiac clinic appointment	8
4.4.12	12.3.12	ECG	1
29.5.12	4.4.12	Case conference in Bristol	9
9.7.12	7.6.12	Lung function test	1
4.9.12	16.7.12	CT angiogram	1
9.10.12		Letter to second Consultant Cardiologist	
22.11.12		Case conference in UHW	
7.12.12	9.10.12	TOE	5
22.1.13		Mr X on list for surgery after case conference	15
27.3.13		Mr X sadly dies	9
		NUMBER OF RTT WEEKS	**49**
2.4.13		Appointment for pre-assessment for surgery	10
		TOTAL NUMBER OF RTT WEEKS	**50**

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