

**SCOTTISH
PUBLIC
SERVICES
OMBUDSMAN**



People Centred | Improvement Focused

The Scottish Public Services Ombudsman Act 2002

Investigation Report

UNDER SECTION 15(1)(a)

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Case ref: 202001373, Lanarkshire NHS Board

Sector: Health

Subject: Hospitals / Clinical treatment / diagnosis

Summary

C complained about the care and treatment provided to their spouse (A) during the period August 2018 to June 2019. A had been diagnosed with primary biliary cirrhosis (PBC, a disease that harms the liver's ability to function) in 2004 and was under the observation of gastroenterology (the branch of medicine focused on the digestive system and its disorders) for the condition. In June 2019 A was diagnosed with cholangiocarcinoma (a type of cancer that forms in the tubes connecting the liver with the gallbladder and small intestine). They died a short time later.

C complained that from 2018 onwards there were delays in diagnosing A's cancer and, that had A been diagnosed and received treatment earlier, this may have led to a different outcome. C also complained that the Board's communication with A was unreasonable, particularly that: A was not made aware cancer was a possibility; they were reassured that results were not sinister which minimised their concerns; and the results of the biopsy were not communicated with A.

The Board said that A did not show any signs of advanced liver disease. When an ultrasound scan showed abnormalities further investigations were carried out, however, a diagnosis could not be established until a liver biopsy was obtained and reviewed by specialists. The Board acknowledged a delay in the liver biopsy being taken, they apologised for this and assured C that they would take learning from the complaint.

The consultant involved in A's care acknowledged that it would have been better to have kept A informed and apologised for this. The Board explained that the results of the biopsy were sent to a different consultant in error and the report was not forwarded timeously. The Board apologised for the unacceptable delay in updating A with the results of the biopsy.

We sought independent advice from a consultant hepatologist (the Adviser). The Adviser told us that A's PBC was not well controlled and A developed signs of disease progression. A reasonable time to carry out investigations would have been 12 weeks, however, it took the Board 27 weeks to carry out the necessary investigations (not including the further delay in receiving the biopsy report). The Adviser noted that it appeared from the documentation that the possibility of cancer

was not communicated well enough. In conclusion, the Adviser said that it is possible A's quantity of life would have been better, and therefore, A could have lived longer if the diagnosis had been made earlier.

In light of the evidence we have seen and the advice received, we found that: the care and treatment provided by the Board before and leading up to the diagnosis was unreasonable; and the Board failed to reasonably communicate with A and they should have told A much earlier that the tests being carried out were for cancer. As such, we upheld C's complaints.

Redress and Recommendations

The Ombudsman's recommendations are set out below:

What we are asking the Board to do for C:

Complaint number	What we found	What the organisation should do	What we need to see
(a)	Under (a) we found the Board failed to: • provide reasonable care and treatment to A which led to a delay in the diagnosis of cancer; • identify that A was showing signs of advanced liver disease in 2017; • initiate further investigations (an ultrasound scan) at that time; and • failed to examine A in 2018 and ensure further investigations were carried out urgently. Under (b) we found the Board failed to communicate reasonably with A and A's GP.	Apologise to C for the failure to: - provide reasonable care and treatment to A - identify that A was showing signs of advanced liver disease - initiate and expedite further investigations, and - communicate with A reasonably. The apology should meet the standards set out in the SPSO guidelines on apology available at www.spsso.org.uk/information-leaflets	A copy or record of the apology. By: 22 July 2022

We are asking the Board to improve the way they do things:

Complaint number	What we found	Outcome needed	What we need to see
(a)	Under (a) we found that the Board did not identify that A was showing signs of advanced liver disease in 2017, and unreasonably failed to initiate further investigations (an ultrasound scan) at that time.	Patients showing signs of advanced liver disease should receive appropriate care and treatment that is in line with relevant guidance.	Evidence my findings have been shared with relevant staff in a supportive way for reflection and learning. Reflecting the passage of time, evidence that the Board now have appropriate guidance for staff which takes into account the relevant national guidance for treatment of advanced liver disease and that clinicians are aware of the guidance. If not, the evidence of the action taken to rectify this. By: 22 September 2022

Complaint number	What we found	Outcome needed	What we need to see
(a)	Under (a) we found that the Board failed to examine A in 2018 and ensure further investigations were carried out urgently.	Patients presenting with symptoms as in A's case should be examined and have further investigations carried out urgently. Cancer trackers should be utilised early in cases like this (where a lesion on the liver is a possible cancer) to avoid delays.	Evidence that my findings have been shared with relevant staff in a supportive way for feedback and reflection. Evidence that consideration has been given as to whether guidance is required for the management and reporting of liver biopsies. This should take into account relevant national guidance and the evidence should demonstrate that clinicians are aware of the guidance. Evidence that the Board have an adequate tracking system in place when cancer is suspected, to avoid delays like this happening again. By: 22 September 2022

Complaint number	What we found	Outcome needed	What we need to see
(b)	Under (b) we found that the Board's communication with A, particularly around the reasons for surveillance investigations and that cancer was a possibility, was unreasonable.	Patients should receive clear explanations for any investigations proposed or carried out and should be provided with appropriate information about their condition, including where cancer is a possibility. Where discussions have taken place, this should be documented.	Evidence my findings have been shared with relevant staff in a supportive way for feedback and reflection. Evidence the Board have reminded relevant staff that patients should be informed about the reasons for screening scans in good time. By: 22 September 2022
(b)	Under (b) we found that A's GP should have been written to about pain relief and arranging palliative care rather than copied in to correspondence regarding this.	GPs should be contacted directly about care to be organised by the GP practice.	Evidence that my findings have been shared with relevant staff in a supportive way for feedback and reflection, and a note of any actions or changes as a result. By 22 August 2022

We are asking the Board to provide evidence of action they have already taken:

Complaint number	What we found	What the organisation should do	What we need to see
(a)	Under (a) we found that there was an unreasonable delay in the liver biopsy results being made available to Consultant 1.	Clinicians should receive biopsy results within an appropriate timescale.	Evidence of the discussions already held with radiology staff to highlight the importance of forwarding results to the referring clinician immediately, and a note of any actions or changes as a result. By: 22 July 2022

Feedback

Points to note

We are sharing this with the Board in the spirit of reflective learning to drive service improvement.

The Adviser considered A's PBC was not well controlled with fluctuating alkaline phosphatase. A developed signs of potential disease progression (spider naevi), an additional risk factor for liver cirrhosis (diabetes) and had weight loss. The Adviser highlighted that, in their view, the management of A's condition earlier in the disease could have been better if A had been followed up by a consultant with liver interest (and liver nurses as part of a liver team).

The Adviser also highlighted that it is good practice to copy all communication (i.e. clinic letters to other specialists, GPs etc.) to the patient for improved patient communication. The Board may wish to note this and refer to the 'please write to me' guidance on writing out-patient letters.

We encourage the Board to consider this feedback carefully to inform whether changes are required to the way in which they manage similar patients in the future.

Who we are

The Scottish Public Services Ombudsman (SPSO) investigates complaints about organisations providing public services in Scotland. The Ombudsman is the final stage for handling complaints about the National Health Service, councils, housing associations, prisons, the Scottish Government and its agencies and departments, the Scottish Parliamentary Corporate Body, water and sewerage providers, colleges and universities and most Scottish public authorities. The SPSO normally considers complaints only after they have been through the complaints procedure of the organisation concerned. SPSO's service is independent, impartial and free. We aim not only to provide justice for the individual, but also to share the learning from our work in order to improve the delivery of public services in Scotland.

The role of the SPSO is set out in the Scottish Public Services Ombudsman Act 2002, and this report is published in terms of section 15(1) of the Act. The Act says that, generally, reports of investigations should not name or identify individuals, so in the report the complainant is referred to as C. The terms used to describe other people in the report are explained as they arise and in Annex 1.

Introduction

1. The complainant (C) complained to my office about the care and treatment provided to their spouse (A) during the period August 2018 to June 2019. A had been diagnosed with primary biliary cirrhosis (PBC) in 2004 and was under the observation of gastroenterology for the condition. In June 2019, A was diagnosed with cholangiocarcinoma (a type of cancer that forms in the tubes connecting the liver with the gallbladder and small intestine). They died a short time later. C complained that from 2018 onwards there were delays in diagnosing A's cancer and, that had A been diagnosed and received treatment earlier, this may have led to a different outcome.

2. The complaint from C I have investigated is that:

(a) The care and treatment provided to A by the Board between August 2018 and June 2019 was unreasonable (*upheld*); and

(b) The Board's communication with A between August 2018 and June 2019 was unreasonable (*upheld*).

Investigation

3. In order to investigate C's complaint, I and my complaints reviewer requested and considered information and documentation, including A's relevant medical records, from the Board. I also took independent advice from a consultant hepatologist and gastroenterologist (the Adviser).

4. I appreciate that at the time of reporting, the NHS is under considerable pressure due to the impact of COVID-19. Like others, I recognise, appreciate and respect the huge contribution everyone in the NHS (and public services) has made, and continues to make. However, much as I recognise this, I also recognise that patient safety, personal redress, and learning from complaints are as relevant as ever and it is important that collectively we do not miss opportunities to learn for the future.

5. I have decided to issue a public report on C's complaint. This reflects my concern about the failings identified in A's care and treatment; the significant personal injustice caused by the failings identified and the potential for wider learning from the complaint.

6. This report includes the information that is required for me to explain the reasons for my decision on this case. Please note, I have not included every detail of the information considered. My complaints reviewer and I have reviewed all of the

information provided during the course of the investigation. C and the Board were given an opportunity to comment on a draft of this report.

7. Although the focus of the investigation of the Board's actions is on the period August 2018 to June 2019, it was found during the investigation that events predating this time, particularly from 2017 onwards, were directly relevant. Given this I have reviewed events dating back to 2017 in this report.

Background and key events

8. I have set out below the background and key events that relate to both (a) and (b) above.

9. Before 2011 A was diagnosed with PBC. In 2016 it was noted that A's PBC was asymptomatic (showing or producing no symptoms) with no liver disease. In 2017 it was noted that spider naevi (swollen spider-like blood vessels on the skin) was present and that there should be yearly monitoring.

10. On 23 August 2018, A was seen in clinic by nurses. It was noted that A had lost weight (it was also noted that they were overweight and had developed diabetes). An ultrasound (a procedure that uses high-frequency sound waves to create an image of part of the inside of the body) scan was requested for surveillance.

11. In September 2018 the ultrasound scan was carried out. The scan reported the liver to be coarse and heterogeneous (looking very different from one area to the next). It also reported there was a large shadow on the liver.

12. On 9 October 2018 a triple phase computerised tomography (CT) scan was carried out and reported a large area (of the liver) as irregular. An additional small lesion and a pancreatic cyst were also reported.

13. On 5 February 2019 a magnetic resonance imaging (MRI) scan was carried out and reported possible thrombosis (local coagulation or clotting of the blood in a part of the circulatory system); not typical for a tumour. Discussion with liver specialist colleagues in the Scottish Liver Transplantation Unit (SLTU) was advised. The specialists recommended that a biopsy (a procedure that involves taking a small sample of body tissue so it can be examined under a microscope) be taken as they were uncertain if A had cancer.

14. The biopsy was carried out in April 2019. This was reported in April 2019; however, the report was given to the consultant who carried out the biopsy (Consultant 2) rather than the consultant managing A's care (Consultant 1).

Consultant 1 was not aware of the biopsy report until June 2019. The report detailed a diagnosis of cholangiocarcinoma

15. On 17 June 2019, Consultant 1 received a copy of the biopsy report and arranged to speak with A on 20 June 2019 to communicate the results.

16. On 24 July 2019, Consultant 1 wrote to the SLTU with a copy to the GP which mentioned that the GP would involve palliative care for pain control.

17. On 25 July 2019, A was examined at a clinic review and was asked to contact the consultant to arrange admission for an ascitic drain (a procedure to remove excess fluid from the abdomen) if the ascites (a condition where fluid collects in spaces in the abdomen) got worse.

18. On 27 July 2019, A was admitted for the drain which improved their comfort.

19. A died on 23 August 2019.

(a) The care and treatment provided to A by the Board between August 2018 and June 2019 was unreasonable.

Concerns raised by C

20. The following paragraphs set out the concerns C raised.

21. During the period 23 August 2018 to 26 June 2019 the consultant in charge of A's care for PBC (Consultant 1) did not see or examine A.

22. After the ultrasound was carried out, a CT scan was recommended. Consultant 1 wrote to A to say there was a small shadow on their liver caused by fatty changes.

23. In relation to the findings of the CT scan, Consultant 1 sent a letter to A telling them that the shadow on their liver was not usually sinister. C also said that when Consultant 1 spoke with A by telephone they said the radiologist (who carried out the scans) was being too cautious.

24. On 20 June 2019 during an appointment with Consultant 1, A was told that they had cancer, 11 weeks after the biopsy was taken.

25. C complained that Consultant 1 did not offer any help with pain management or arrange/give information about additional help, such as Macmillan nursing, during the 20 June 2019 appointment.

26. A complained of pain to Consultant 1 and that their abdomen was badly swollen. Consultant 1 spoke about possibly inserting a drain to relieve the pressure from A's stomach; however, C said this procedure was not carried out. A was later admitted to hospital by their GP, at which point six litres of fluid was drained from A's abdomen.

27. C said daily ward rounds during A's admission to hospital were a snapshot in time and may not have been truly reflective of A's experience. There were times outwith ward rounds where C sought out help from nurses to ask for medication to manage A's pain.

28. In their response to C's complaint, Consultant 1 said A was not showing signs of advanced disease before further investigations (i.e. the ultrasound in 2018) showed abnormalities; however, C believes A was showing signs of advanced disease and if Consultant 1 had examined A, they would have been aware of that.

The Board's response

29. The contents of the Board's response to C are known to all parties so I will not repeat them in detail. I have summarised the key points of their response:

- i. Hepatocellular carcinoma (liver cancer) is a complication in advanced PBC but A did not show any clinical signs of advanced disease. Consultant 1 checked A's alpha-fetoprotein level (the amount of this protein in the blood, if it is elevated it can be an indicator of damage to the liver or liver cancer) and found it to be normal.
- ii. When the ultrasound showed abnormalities, further investigations were carried out; however, a diagnosis could not be established until the liver biopsy was obtained and reviewed by specialists in the SLTU.
- iii. The biopsy report was sent to Consultant 2 in error. Consultant 2 did not forward the report to Consultant 1 until 17 June 2019. The Board said that, the reason this happened was because Consultant 2 put their own name as the referring clinician (rather than Consultant 1's name). Consultant 1 wrote to Consultant 2 to make them aware of the issue. Consultant 2 is no longer employed by the Board. This meant the Board were unable to speak with them further about this incident. Instead, the Board would ensure that the importance of putting the referring clinician's name on the form was discussed with radiology staff, and in the event that a result was sent back to them in error, to immediately forward this onto the referring clinician.

- iv. C raised a concern that the MRI scan taken in February 2019 demonstrated multiple likely intrahepatic metastases (spread of cancer in the liver). The Board said, at the time of the scan it was reported as not typical for metastases and noted to discuss with colleagues in the SLTU. In light of this, the case was discussed at a multi-disciplinary team meeting, which recommended a biopsy as they were not certain that A had cancer.
- v. In conclusion the Board said that cholangiocarcinomas are difficult to diagnose and it is not uncommon for multiple investigations (scans, tests, and procedures) to be undertaken before a definitive diagnosis is reached.
- vi. The Board apologised for the delay in the liver biopsy being actioned and assured C that they would take learning from this.

Relevant references

30. European Association for the Study of the Liver (EASL), European Association for the Study of Diabetes (EASD) and European Association for the Study of Obesity (EASO) clinical practice recommendations for the management of non-alcoholic fatty liver disease: evaluation of their application in people with Type 2 diabetes. *Diabet Med.* 2018 Mar;35(3):368-375¹.

Medical advice

31. The Adviser was asked to comment on the reasonableness of the general care and treatment provided to A. Their comments can be summarised as follows:

- i. The treating doctors could have been suspicious of liver cirrhosis (a chronic disease of the liver that occurs in patients with advanced liver disease) earlier. In 2017 A was noted to have spider naevi which can be a sign of cirrhosis/chronic liver disease. In September 2018 an ultrasound was requested as cancer surveillance (tests carried out to identify if cancer is or is not present). The result of this scan was that the liver looked coarse and heterogeneous which, in conjunction with the spider naevi found in 2017, suggests that A was already cirrhotic at that time. The Adviser noted that there was no mention of presumed cirrhosis in the notes recorded at the time of these investigations.
- ii. Given the large change in the liver noted in the ultrasound carried out in 2018 this should have triggered further investigations as urgent with the suspicion of

¹ [European Association for the Study of the Liver \(EASL\), European Association for the Study of Diabetes \(EASD\) and European Association for the Study of Obesity \(EASO\) clinical practice recommendations for the management of non-alcoholic fatty liver disease: evaluation of their application in people with Type 2 diabetes - PubMed \(nih.gov\)](#)

cancer. Cancer should also have been mentioned to A at an earlier stage (i.e. in 2018 when the ultrasound was requested for surveillance).

- iii. The sequence of tests carried out by the Board (ultrasound scan, CT scan, MRI liver, targeted biopsy) was correct, but the timing of 27 weeks from the initial scan in September 2018 to performing the biopsy in April 2019 (and longer to obtain the biopsy report) was far longer than it should have been.
- iv. Therefore, the general care and treatment provided to A by the Board was unreasonable.

32. The Adviser was also asked to comment on whether or not they considered the Board's position, that A was not showing signs of advanced PBC, to be reasonable or unreasonable. Their comments can be summarised as follows:

- i. The intent of annual reviews (for A's condition) would be to detect progression of liver disease and surveillance for liver cancer in cirrhotic patients. The additional reason for this would be to determine the patient's response to treatment. In A's case, the blood results indicate that A did not respond particularly well to treatment; however, there is no discussion in the notes on this point.
- ii. A was seen at a face-to-face appointment in August 2017, when the spider naevi were seen. As mentioned above, these can be signs of advanced liver disease and should have triggered further examination including an ultrasound of A's liver and abdomen at that time.
- iii. A was next seen face-to-face by nurses at an appointment in August 2018. They were weighed and found to have lost weight. A had developed diabetes and was overweight which gave them two additional risk factors for advanced liver disease. There was no comment recorded in the medical notes that would indicate Consultant 1 carried out a physical examination; however, the ultrasound for surveillance was requested. A physical examination carried out by Consultant 1 at this time would have helped to determine the severity of the liver disease in 2018, which was then likely more advanced than in 2017 (when Consultant 1 last examined A). This was particularly important because of the weight loss and diabetes which are significant risk factors for development of cirrhosis.
- iv. In light of the above, the Board's view that A did not show any signs of chronic liver disease was wrong.

33. The Adviser provided the following comments in relation to the delay in receiving the biopsy result:

- i. It appears it was a genuine error that the histopathology report (results of the biopsy) went to the wrong consultant (i.e. the consultant who took the sample rather than the consultant managing A's care).
- ii. The action taken by the Board to highlight this to the radiologists was reasonable. However, the Board should ensure that there is a cancer tracker involved early in cases like A's. Had it been in place in A's case, it would have chased/sped up the scans and ensured that the report went to the right person or the multi-disciplinary team for discussion.
- iii. The action taken by the Board to rectify this error was reasonable but incomplete with regards to collaboration of different clinicians for the management and reporting of liver biopsies. The Adviser highlighted that newer guidelines on liver biopsy were issued during 2020². These guidelines make recommendations about facilitating collaborative working for the management and reporting of liver biopsies.

34. The Adviser was asked whether or not they considered the care and treatment provided to A after they were diagnosed with cancer was reasonable or unreasonable. The Adviser's comments can be summarised as follows:

- i. From the notes it appeared that necessary steps were taken by the consultant to control A's pain, including the involvement of district and Macmillan nurses. The consultant asked in a letter that A contact them if they experienced worsening ascites.
- ii. It is possible that A's pain was not perfectly controlled; however, there were entries in the notes taken during ward rounds to say that A was not in pain.
- iii. On the basis of the medical records, it appears that the Board's management of A's cancer was reasonable after they were diagnosed.

35. Overall, the Adviser concluded that:

- i. A's PBC was not well controlled with fluctuating alkaline phosphate (an enzyme found in the blood – high levels of this enzyme can indicate liver disease). A developed signs of potential disease progression (spider naevi), an additional risk factor for liver cirrhosis (diabetes) and had weight loss. The management of A's PBC would have been better if A had been followed up by a consultant with liver interest (and liver nurses as part of a liver team).

² [Guidelines on the use of liver biopsy in clinical practice from the British Society of Gastroenterology, the Royal College of Radiologists and the Royal College of Pathology - The British Society of Gastroenterology \(bsg.org.uk\)](https://www.bsg.org.uk/guidelines-on-the-use-of-liver-biopsy-in-clinical-practice-from-the-british-society-of-gastroenterology-the-royal-college-of-radiologists-and-the-royal-college-of-pathology)

- ii. A more reasonable time for the investigations to be completed would have been:
- Ultrasound reviewed by consultant – 1 week
 - Triple phase CT Scan carried out – 2 weeks
 - Results reported and reviewed by consultant – 2 weeks (at this stage the cancer tracker should have been used)
 - MRI scan carried out – 2 weeks
 - Results reported and reviewed by consultant – 1 week
 - Review by SLTU – 2 weeks
 - Biopsy arranged and carried out – 2 weeks
- iii. This is a total time of 12 weeks which would have been more than four months earlier than in this case.
- iv. Had the investigations been carried out within this time, it could have made a significant difference in A's management (including pain management) and it is entirely possible that A's quantity of life would have been better.
- v. In commenting on the proposed report, the Board told us that many people with hepato-pancreato-biliary (HPB) cancer cannot be offered curative treatments following multi-disciplinary discussion. We asked the Adviser to consider these comments and whether or not they would impact their advice. The Adviser said that in the liver there are different types of cancer with the cholangiocarcinoma (the cancer A had) being one for which there is typically no cure. However, sometimes there is treatment which can prolong life, and therefore, it is possible that A could have lived longer if the diagnosis had been made earlier (i.e. quantity of life could have been better).
- vi. The Board also commented that they have a number of cancer trackers in place which they considered worked effectively. In this case A was not known to the tracking team due to the route of referral and being followed up with the clinical team for PBC. They also provided information in relation to current regional project work they are involved in to improve cancer care for HPB patients and also internal work being carried out by the Board to support the identification and diagnosis for patients with suspicious liver lesions. The Board's comments were considered by the Adviser who confirmed that the comments did not alter their advice.

(a) Decision

36. I have carefully considered the advice I received, which I accept. The Adviser told me that whilst the Board's management of A's condition after they were diagnosed with cancer was reasonable, the care and treatment provided by the Board before and leading up to the diagnosis was unreasonable.

37. It is the Board's position that A did not show any signs of advanced liver disease. However, the evidence I have seen and the advice I have received indicates that there were signs that A's liver disease had advanced. These signs were apparent as early as 2017 when an ultrasound should have been arranged but particularly so by August 2018 when A had developed additional risk factors in conjunction with the spider naevi identified the previous year. I am critical that an ultrasound was not carried out in 2017. In addition, by September 2018 the ultrasound that was carried out showed that there had been significant changes in the liver.

38. The consultation and tests carried out in 2018 should have alerted the Board to the possibility of liver cirrhosis earlier (particularly when considered along with the examination carried out in 2017), and should have triggered further urgent investigations with the suspicion of cancer. There is no evidence a physical examination was carried out by Consultant 1 in 2018. This would have helped to determine the severity of the liver disease. When scans and tests were carried out, the timing of these was significantly longer than they should have been.

39. Of particular concern to me is that A was not tracked as part of a cancer tracker. While I note the Board's position when commenting on a draft of this report, including that they have a number of cancer trackers in place, it remains the case that A should have been tracked as part of a cancer tracker system and was not. Had they been this should have ensured A received a diagnosis within a shorter, more reasonable timeframe. While I welcome the work the Board is now doing in this regard they need to ensure as a matter of urgency that there is an adequate system in place to prevent this happening again. It is of vital importance that the Board have an adequate tracking system in place where cancer is suspected to ensure patients presenting like A, receive the required tests and results in the appropriate timescale.

40. In light of the above, I consider the Board failed to ensure that A was provided with a reasonable standard of medical care and treatment in the management of their PBC and the subsequent cancer surveillance investigations. I uphold this complaint.

41. It will be very difficult for C to read that earlier diagnosis may have made a difference in A's management (including pain management) and that it is possible that A's quantity of life would have been better. They have my utmost sympathy.

42. I have made a number of recommendations to address the issues identified and these are set out at the end of this report. The Board have accepted the recommendations and will act on them accordingly. My complaints reviewer and I will follow up on these recommendations. I expect evidence to demonstrate that appropriate action has been taken before I can confirm that the recommendations have been met.

(b) The Board's communication with A between August 2018 and June 2019 was unreasonable.

Concerns raised by C

43. During the investigations (i.e. ultrasound, CT and MRI scans), Consultant 1 did not make A or C aware that cancer was a possibility.

44. After the radiologist recommended an MRI scan, Consultant 1 sent a letter to A telling them that the changes in A's liver found on the CT scan were not usually sinister and when they spoke with A by telephone they said the radiologist was being too cautious. C said this minimised their concerns.

45. Consultant 1 did not communicate the results of the biopsy, which was performed in April 2019, with A. In June 2019 during an appointment with Consultant 1, A was told they had cancer, 11 weeks after the biopsy was taken.

The Board's response

46. The contents of the Board's response to C are known to all parties so I will not repeat them in detail. I have summarised the key points of their response:

- i. Consultant 1 apologised that C felt that they provided A and C with false reassurance during A's investigations. They have reflected on this. The MRI report indicated that A had a lesion on their liver that was not typical of a tumour. The report recommended that Consultant 1 discuss A's case with the SLTU. Consultant 1 felt that it was better to wait until they had a response from the SLTU before they wrote to A with an update. On reflection, Consultant 1 acknowledged that it would have been better to have kept A informed and apologised that this did not happen.

- ii. Consultant 1 said when a patient is undergoing a biopsy, they would usually meet with the patient prior to the procedure to obtain consent and explain the procedure. However, due to staffing issues, A's biopsy was performed in a different hospital, therefore, Consultant 1 did not have the opportunity to do this. The Board apologised that there was a missed opportunity for staff to update A at the time of that procedure.
- iii. The biopsy report was sent in error to Consultant 2 who carried out the biopsy. This consultant did not forward the report to Consultant 1 until 17 June 2019. The Board apologised for this unacceptable delay in updating A with the results of the biopsy.

Relevant guidance

47. Academy of Medical Royal Colleges, 'Please write to me. Writing outpatient clinic letters to patients. Guidance'³.

Advice

48. The Adviser was asked to comment on the reasonableness of the Board's general communication with A. Their comments can be summarised as follows:

- i. The consultant did not give sufficient weight to the fact that A had PBC that was not very well controlled over years, had diabetes as an additional risk factor, and was very likely cirrhotic at the time of the first ultrasound. The ultrasound was requested as surveillance as the consultant was aware that A had lost a significant amount of weight. It is standard that surveillance is for cancer even if many patients do not have cancer. Therefore, this should have been considered and mentioned to A when the surveillance started and for every scan.
- ii. There is minimal documentation in the notes of what was communicated about this; however, it appears that the possibility of cancer was not communicated well enough, and therefore, the communication was unreasonable. It would have been good practice to consider copying A into their letters to other clinicians, particularly given that guidance on writing out-patient clinic letters was issued in September 2018 (listed in the guidance section above).
- iii. Consultant 1 wrote a letter to the SLTU in which they mentioned pain relief and palliative care to be organised by the GP. There was no indication in the records that Consultant 1 wrote to the GP separately. Given the importance of this, a direct letter should have been written to them because a GP might not fully read

³ [Please, write to me. Writing outpatient clinic letters to patients. Guidance - Academy of Medical Royal Colleges \(aomrc.org.uk\)](https://www.aomrc.org.uk/please-write-to-me-writing-outpatient-clinic-letters-to-patients-guidance)

and act on a letter into which they were just copied. As noted above, it is good practice to copy all communication to the patient, which was not done. Had this been done it would have improved the communication.

(b) Decision

49. I have carefully considered the advice I received, which I accept. The Adviser told me that the Board should have informed A that the surveillance scans were to check for cancer. The possibility of cancer was not communicated well enough.

50. Whilst the consultant did write to the SLTU and explained that pain relief and palliative care would be organised by the GP, there was no evidence that they wrote separately to the GP about this. Given the letter to SLTU referred to pain relief and palliative care that would normally be organised by a GP, I consider A's GP should also have been contacted directly about this. I consider not doing so was unreasonable. The Board also did not copy A into their letters to other clinicians, which would have been good practice.

51. I recognise C was unhappy with the length of time taken to communicate the results of the biopsy. In light of this, I have given careful consideration to what happened here. I recognise that there was a failure on the part of the Board as they did not list the correct consultant on the biopsy request and failed to forward the results to Consultant 1 which created a delay (as addressed in complaint (a)). However, I also recognise that once Consultant 1 had been forwarded the biopsy report and was aware of the results on 17 June 2019, they arranged to communicate the results to A on 20 June 2019. The time taken from the point Consultant 1 knew the results to communicating the results was three days, which I consider was reasonable.

52. I recognise that the Board have already acknowledged their communication with A about the cancer diagnosis could have been better. However, the Board should also have taken steps to ensure A knew why scans were being performed, what the outcome of these scans were, and the implication of the results.

53. In light of the above, having accepted the advice I received, it is my view that the Board failed to reasonably communicate with A. My investigation has highlighted that there were communication failures in this case irrespective of whether or not the care and treatment was reasonable or unreasonable. The Board should have told A much earlier (i.e. in 2018) that the tests being carried out were for cancer surveillance and that it was a possibility that A may have cancer.

54. I uphold this complaint.

55. I have made recommendations to address the issues identified and this is set out at the end of this report. The Board have accepted the recommendations and will act on them accordingly. My complaints reviewer and I will follow up on these recommendations. I expect evidence that appropriate action has been taken before I can confirm that the recommendation has been met.

Recommendations

Learning from complaints

The Ombudsman expects all organisations to learn from complaints and the findings from this report should be shared throughout the organisation. The learning should be shared with those responsible for the operational delivery of the service as well as the relevant internal and external decision-makers who make up the governance arrangements for the organisation, for example elected members, audit or quality assurance committee or clinical governance team.

What we are asking the Board to do for C:

Complaint number	What we found	What the organisation should do	What we need to see
(a)	Under (a) we found the Board failed to: • provide reasonable care and treatment to A which led to a delay in the diagnosis of cancer; • identify that A was showing signs of advanced liver disease in 2017; • initiate further investigations (an ultrasound scan) at that	Apologise to C for the failure to: i. provide reasonable care and treatment to A ii. identify that A was showing signs of advanced liver disease iii. initiate and expedite further investigations, and iv. communicate with A reasonably. The apology should meet the standards set out in the SPSO guidelines on	A copy or record of the apology. By: 22 July 2022

Complaint number	What we found	What the organisation should do	What we need to see
	time; and failed to examine A in 2018 and ensure further investigations were carried out urgently. Under (b) we found the Board failed to communicate reasonably with A and A's GP.	apology available at www.spsso.org.uk/information-leaflets.	

We are asking the Board to improve the way they do things:

Complaint number	What we found	Outcome needed	What we need to see
(a)	Under (a) we found that the Board did not identify that A was showing signs of advanced liver disease in 2017, and unreasonably failed to initiate further investigations (an ultrasound scan) at that time.	Patients showing signs of advanced liver disease should receive appropriate care and treatment that is in line with relevant guidance.	Evidence my findings have been shared with relevant staff in a supportive way for reflection and learning. Reflecting the passage of time, evidence that the Board now have appropriate guidance for staff which takes into account the relevant national guidance for treatment of advanced liver disease and that clinicians are aware of the guidance. If not, the evidence of the action taken to rectify this. By: 22 September 2022

Complaint number	What we found	Outcome needed	What we need to see
(a)	Under (a) we found that the Board failed to examine A in 2018 and ensure further investigations were carried out urgently.	Patients presenting with symptoms as in A's case should be examined and have further investigations carried out urgently. Cancer trackers should be utilised early in cases like this (where a lesion on the liver is a possible cancer) to avoid delays.	Evidence that my findings have been shared with relevant staff in a supportive way for feedback and reflection. Evidence that consideration has been given as to whether guidance is required for the management and reporting of liver biopsies. This should take into account relevant national guidance and the evidence should demonstrate that clinicians are aware of the guidance. Evidence that the Board have an adequate tracking system in place when cancer is suspected, to avoid delays like this happening again. By: 22 September 2022

Complaint number	What we found	Outcome needed	What we need to see
(b)	Under (b) we found that the Board's communication with A, particularly around the reasons for surveillance investigations and that cancer was a possibility, was unreasonable.	Patients should receive clear explanations for any investigations proposed or carried out and should be provided with appropriate information about their condition, including where cancer is a possibility. Where discussions have taken place, this should be documented.	Evidence my findings have been shared with relevant staff in a supportive way for feedback and reflection. Evidence the Board have reminded relevant staff that patients should be informed about the reasons for screening scans in good time. By: 22 September 2022
(b)	Under (b) we found that A's GP should have been written to about pain relief and arranging palliative care rather than copied in to correspondence regarding this.	GPs should be contacted directly about care to be organised by the GP practice.	Evidence that my findings have been shared with relevant staff in a supportive way for feedback and reflection, and a note of any actions or changes as a result. By 22 August 2022

We are asking the Board to provide evidence of action they have already taken:

Complaint number	What we found	What the organisation should do	What we need to see
(a)	Under (a) we found that there was an unreasonable delay in the liver biopsy results being made available to Consultant 1.	Clinicians should receive biopsy results within an appropriate timescale.	Evidence of the discussions already held with radiology staff to highlight the importance of forwarding results to the referring clinician immediately, and a note of any actions or changes as a result. By: 22 July 2022

Feedback

Points to note

I am sharing this with the Board in the spirit of reflective learning to drive service improvement.

The Adviser considered A's PBC was not well controlled with fluctuating alkaline phosphatase. A developed signs of potential disease progression (spider naevi), an additional risk factor for liver cirrhosis (diabetes) and had weight loss. The Adviser highlighted that, in their view, the management of A's condition earlier in the disease could have been better if A had been followed up by a consultant with liver interest (and liver nurses as part of a liver team).

The Adviser also highlighted that it is good practice to copy all communication (i.e. clinic letters to other specialists, GPs etc.) to the patient for improved patient communication. The Board may wish to note this and refer to the 'please write to me' guidance on writing out-patient letters.

I encourage the Board to consider this feedback carefully to inform whether changes are required to the way in which they manage similar patients in the future.

Terms used in the report

Annex 1

A	the aggrieved
C	the complainant
the Board	Lanarkshire NHS Board
the Adviser	a Consultant Hepatologist and Gastroenterologist who provided independent advice on this case
cholangiocarcinoma	a type of cancer that forms in the tubes connecting the liver with the gallbladder and small intestine
Consultant 1	the consultant in care of A's care and treatment for their liver condition
Consultant 2	the consultant in a different hospital who carried out the liver biopsy and to whom the biopsy report was sent
CT	computerised tomography scan, a scan that uses x-rays and a computer to create detailed images of the inside of the body
gastroenterology	the branch of medicine focused on the digestive system and its disorders
GP	General Practitioner
MRI	magnetic resonance imaging scan
PBC	primary biliary cirrhosis, a disease that harms the liver's ability to function
spider naevi	swollen spider-like blood vessels on the skin
SLTU	Scottish Liver and Transplant Unit

ultrasound scan

a procedure that uses high-frequency sound waves to create an image of part of the inside of the body

List of legislation and policies considered

Annex 2

Academy of Medical Royal Colleges, 'Please write to me. Writing outpatient clinic letters to patience. Guidance'

European Association for the Study of the Liver (EASL), European Association for the Study of Diabetes (EASD) and European Association for the Study of Obesity (EASO) clinical practice recommendations for the management of non-alcoholic fatty liver disease: evaluation of their application in people with Type 2 diabetes. Diabet Med. 2018 Mar;35(3):368-375.

Guidelines on the use of liver biopsy in clinical practice from the British Society of Gastroenterology, the Royal College of Radiologists and the Royal College of Pathology - The British Society of Gastroenterology