SPSO Scottish Public Services Ombudsman

The Scottish Public Services Ombudsman Act 2002

Investigation Report

UNDER SECTION 15(1)(a)

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Scottish Parliament Region: South of Scotland

Case ref: 201602345, Ayrshire and Arran NHS Board
Sector: Health
Subject: Hospitals / Clinical treatment / Diagnosis

Summary

Mrs C complained about the care and treatment provided by the board to her late husband (Mr A). Mr A was diagnosed with pseudomyxoma peritonei (a very rare type of cancer that usually begins in the appendix) and the clinicians involved in his care decided to arrange for scans to be carried out every six months to monitor any development of the cancer. However, after two scans, further follow-up was not arranged. Mrs C complained that Mr A did not receive treatment for the pseudomyxoma peritonei until four years after the initial diagnosis, by which point it had progressed considerably.

During the investigation, we took independent medical advice on Mr A's care and treatment from two consultants in colorectal surgery, one of whom has extensive experience in the treatment of pseudomyxoma peritonei. We found that the delay in Mr A receiving treatment was largely due to a failure to review a scan that was carried out and make further appointments to monitor Mr A's condition. However, we also found that there was a failure of board staff to discuss Mr A's case at a multi-disciplinary meeting when he was first diagnosed, and to discuss Mr A's case with a specialist pseudomyxoma peritonei unit. We further found that there was a failure of the responsible consultant to communicate with Mr A and his GP regarding the diagnosis.

Mrs C also complained about the handling of her and Mr A's complaints. Mr A's first complaint to the board did not receive a response. When Mrs C later made a complaint, it did not receive a response for over a year, and Mrs C had to regularly contact the board for updates as they were not keeping her informed of progress. The final response that Mrs C received was a copy of an investigation that had been carried out into Mr A's care, and did not address all of the issues raised in the complaint, apologise to Mrs C and Mr A for failings identified, or give information as to remedial action taken or proposed. Additionally, details of how to contact the SPSO were not given to Mrs C. I considered the large number of failings in basic and fundamental complaints handling principles to be unreasonable.

Redress and recommendations

The Ombudsman recommends that the Board:	*Completion date*
(i) apologise to Mrs C for the failings identified in complaint (a) in relation to the delay in treatment for Mr A's pseudomyxoma peritonei;	24 May 2017
(ii) provide evidence that MDT meetings are being held to discuss this type of cancer in line with their standards;	24 May 2017
(iii) review their processes for ensuring that scan results are reviewed and followed up, and ensure that current processes are sufficient to avoid a repeat of the failings identified by this investigation;	21 June 2017
(iv) consider implementing a policy to discuss the treatment options for all cases of proven or suspected pseudomyxoma peritonei with a specialist unit;	21 June 2017
(v) draw the comments of Adviser 1 regarding communication of diagnoses to patients and GPs to the attention of the relevant consultant;	24 May 2017
(vi) apologise to Mrs C for the failings in complaints handling identified by this investigation;	24 May 2017
(vii) remind the relevant staff that formal complaints should be passed on to the complaints department; and	24 May 2017
(viii) review their handling of this complaint and identify areas for improvement.	24 May 2017

Who we are

The Scottish Public Services Ombudsman (SPSO) investigates complaints about organisations providing public services in Scotland. We are 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. We normally consider complaints only after they have been through the complaints procedure of the organisation concerned. Our 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 Mrs C. The terms used to describe other people in the report are explained as they arise and in Annex 1.

Introduction

1. Mrs C complained to my office about the care and treatment her late husband (Mr A) had received from Ayrshire and Arran NHS Board (the Board), and their subsequent handling of her complaint. The complaints from Mrs C I have investigated are that:

(a) the Board unreasonably delayed treatment for Mr A's pseudomyxoma peritonei (*upheld*); and

(b) the Board's handling of Mrs C and Mr A's complaint was unreasonable (*upheld*).

Investigation

2. In order to investigate Mrs C's complaint, my complaints reviewer examined all the information provided by both Mrs C and the Board, and obtained independent clinical advice from a colorectal surgeon (Adviser 1) and a consultant surgeon with expertise in pseudomyxoma peritonei (Adviser 2). In this case, I have decided to issue a public report on Mrs C's complaint because of the significant personal injustice suffered by Mr A and the significant failures identified by my investigation. I also had concerns about the Board's failures in complaints handling, specifically the length of time taken for the Board to respond to Mrs C's complaint and that they did not appear to have acknowledged the seriousness of what had happened in this case.

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

(a) The Board unreasonably delayed treatment for Mr A's pseudomyxoma peritonei

Background

4. On 14 October 2009, Mr A underwent surgery to repair a right inguinal hernia (a condition where an internal part of the body pushes through a weakness in the muscle or surrounding tissue wall in the right side of the groin area). During this surgery, a mucinous structure (a lump made up of or covered in mucus) was found, and sent to the pathology department for investigation. The pathology report of 15 October 2009 said that the appearances of the structure were those of pseudomyxoma peritonei (PMP) (a very rare type of cancer that usually begins in the appendix). Mr A was reviewed by the surgeon who had carried out his hernia repair, on 30 October 2009. The surgeon wrote to Mr A's GP stating that there was a suspicion of a diagnosis of PMP and it

was arranged that Mr A would be given a computerised tomography (CT) scan (a scan which uses x-rays and a computer to create detailed images of the inside of the body).

5. Mr A underwent a CT scan on 19 November 2009 and the report said that the fluid collections shown by the CT scan would fit in with a clinical diagnosis of PMP. The surgeon reviewed Mr A again on 12 March 2010 and reported that Mr A was not suffering from any symptoms.

6. Mr A had another CT scan on 12 July 2010 and the report of this concluded that the PMP had not progressed since the last scan. No further review of Mr A was arranged after this scan and it appeared that the surgeon did not have sight of the CT report at this point.

7. In February 2013, Mr A was referred for an ultrasound scan (a scan that uses sound waves to create images of organs and structures inside the body) by his GP as he had suffered some weight loss and haematuria (blood in the urine). The scan, carried out on 22 February 2013, revealed some abnormalities and, therefore, an urgent referral to the urology department was made by Mr A's GP. The urology department arranged for further scans to be carried out and it was noted that there was PMP in Mr A's abdomen with possible evidence of progression. Therefore, Mr A's care was taken over by the surgical team and later referred to a specialist in PMP in another health board. Mr A underwent radical surgery in November 2013 followed by chemotherapy, however, this was considered to be palliative, as opposed to curative, treatment. Sadly, Mr A passed away on 15 July 2015.

Concerns raised by Mrs C

8. Mrs C told us that Mr A's diagnosis of PMP was not communicated to him adequately after the diagnosis in 2009, and that he was under the impression he had cysts in his stomach. Mrs C said that she felt Mr A should have been offered treatment for his PMP much earlier than he was. She also raised concerns that Mr A had 'slipped through the net' and that was why he was not offered any follow up scans or treatment after the CT scan of July 2010.

The Board's response

9. In response to Mrs C's complaint, the Board arranged for a clinical review of the care Mr A had received to be carried out by an independent consultant surgeon. This review noted that PMP is a rare condition and that there are

limited national guidelines related to the management of it within the UK. The review stated that overall, the clinical management of Mr A's case was appropriate, though the clinician carrying out the review said that they would have considered discussing Mr A's care at a multi-disciplinary team (MDT) meeting. The review identified that the medical records did not show evidence that the diagnosis was communicated to Mr A. It also identified that after a CT scan was carried out in July 2010, it did not appear to have been reviewed by the referring clinician. This was concluded as results of past scans had been signed by the referring clinician, but this one had not. Additionally, the clinical review stated that there was no evidence of the CT report in Mr A's medical records, and the information could only be located electronically.

10. My complaints reviewer asked the Board to further clarify the learning actions they had taken as a result of this case. First, as the Board had acknowledged that there had been a failure to follow up a CT scan in 2010, my complaints reviewer asked the Board whether the system for reporting and reviewing scan results had been reviewed. The Board said that all medical imaging reports are now signed, dated and stamped before they are filed. The Board said that this process was not mandatory at the time of Mr A's scan in 2010.

11. My complaints reviewer also asked the Board whether action had been taken to ensure that cases of PMP are discussed at local MDT meetings. The Board said that their colorectal cancer MDT has met weekly since 2001 and is a forum to discuss all patients with colorectal cancer. They said that since 2015 the standard has been to discuss 95 percent of new diagnoses of colorectal cancer prior to treatment.

12. Finally, my complaints reviewer asked the Board whether a care pathway had been established for patients for PMP. The Board said that all cases of PMP should be discussed at a weekly colorectal MDT meeting for treatment planning. They also said that a link had been in place with a specialist unit in England since 2007, for patients who require complex surgery and treatment to be referred for further assessment and treatment.

Medical advice

13. Adviser 1 explained that PMP is a rare, slowly progressive tumour within the abdominal cavity which can be fatal. Adviser 1 said that it usually arises

from the appendix and does not spread to other parts of the body outside of the abdominal cavity.

14. Adviser 1 said that PMP can be very difficult to diagnose. Once diagnosed, however, Adviser 1 said that there are four possible approaches to treatment. The first option is a 'watch and wait' approach, which is appropriate for the milder form of the disease when there is no evidence of perforation of the appendix tumour. The second option is debulking surgery, which removes as much of the disease as possible but means recurrence is inevitable. The third option is cytoreductive surgery and heated intra-peritoneal chemotherapy, which involves radical surgery to remove all of the visible disease and administering chemotherapy into the abdomen at the time of surgery. Finally, there is the option of chemotherapy to improve and control the disease subsequent to surgery.

15. Adviser 1 told my complaints reviewer that they considered Mr A's diagnosis of PMP to have been definitive in November 2009, when there was both radiological and histological information pointing towards a diagnosis of PMP. Adviser 1 said that at this point Mr A's case should have been discussed at an MDT meeting. Adviser 1 said that it was a reasonable decision to suggest that a further CT scan should be repeated in six months' time if a 'watch and wait' policy had been adopted, and that this policy was verified by the fact that the repeat CT scan in July 2010 did not show any progression of the disease. However, Adviser 1 said that it would have been appropriate for the consultant to ask for the case to be discussed in a national or regional centre where there was specialist interest in this disease. Adviser 1 said that had this happened it would have been likely that a specialist unit would have discussed the advantages and disadvantages of elective radical surgery versus a 'watch and wait' policy. Adviser 1 said that the decision to offer radical surgery would have depended on many factors including Mr A's overall health, but that Mr A should have been given the opportunity to have the details of his case discussed at a specialist centre and then to make an informed choice on the most appropriate treatment.

16. With regards to the CT scan of July 2010 which was not reviewed or followed up, Adviser 1 said that had this report been seen by the relevant consultant it is likely that Mr A would have been offered the choice of radical surgery or a continuation of the 'watch and wait' approach. Adviser 1 said that if Mr A's overall health was good, as it seemed to have been from the medical

records that Adviser 1 reviewed, Mr A most likely would have been offered surgery.

17. Adviser 1 said that, given no treatment for PMP was offered to Mr A until November 2013, they considered the Board to have unreasonably delayed treatment for Mr A by the order of three and a half to four years.

18. Adviser 1 also commented on the level of communication with Mr A about his diagnosis of PMP. Adviser 1 said that overall the communication was poor as Mr A was not aware of the potential ongoing problems related to the diagnosis of PMP. Adviser 1 said that if Mr A had a clear understanding of his diagnosis he may have been more proactive in following up a hospital appointment after the July 2010 CT scan. Adviser 1 further said that the communication from the Board to Mr A's GP was unhelpful as it did not confirm the diagnosis of PMP.

19. Adviser 1 said that as PMP is a rare disease which is slowly progressive, it is difficult to quantify the effect the delay in treatment had on Mr A's final outcome in any meaningful way. Adviser 1 suggested that my complaints reviewer requested advice from a consultant with specialist knowledge of PMP for their opinion on the case with regards to the potential adverse effects of a delayed diagnosis.

20. My complaints reviewer, therefore, went on to obtain advice from Adviser 2. Adviser 2 explained that there is still ongoing uncertainty as to the outcomes of surgery and debate as to how to monitor and treat PMP. Adviser 2 said that it was difficult to determine whether or not the three and a half to four year delay in treatment (identified by Adviser 1) had a negative effect on Mr A's eventual outcome as treatment for PMP is not always successful. However, Adviser 2 did say that the earlier the treatment, the more likely it is to have a curative effect.

21. Adviser 2 said that there is no Scottish guidance that determines the care pathway for patients with PMP and, therefore, they found it difficult to criticise the Board for not asking a specialist centre to discuss Mr A's case. However, Adviser 2 said that one of the specialist centres in England has advised on and treated the majority of Scottish cases of PMP and in their opinion a patient with suspected or confirmed PMP should be discussed with an experienced

specialist unit as, whilst not the official pathway, this is regular and good practice.

(a) Decision

22. The advice I have received from Adviser 1, which I accept, is that the Board unreasonably delayed treatment for Mr A's PMP. In my investigation of this case I found that the delay in treatment was largely due to a failure to review a CT scan that was carried out in July 2010 and make further appointments to monitor Mr A's condition. I have not seen evidence that the surgeon responsible for Mr A's care reviewed the results of this scan and the Board have acknowledged that this appears to be the case. However, I do not consider the Board to have addressed this aspect of the complaint in sufficient detail and that there does not appear to have been any significant action taken as a result of this failing. Whilst the Board have stated that now all results must be signed, dated and stamped before being filed, I do not consider this to effectively address the issue which arose in Mr A's case. The clinical review of Mr A's case stated that the results did not appear to have been seen by the referring clinician, and they could only be located electronically. Therefore, this suggests that the results of the CT scan were neither reviewed nor filed, and, therefore, the Board's process of ensuring results are signed before being filed does not address the issue which arose here, which was that the scan was apparently not seen by the referring clinician. Consequently, I consider that it is possible that this situation could arise again.

23. I note Adviser 1's comments that Mr A's case should have been discussed at an MDT meeting when the diagnosis of PMP was first made in 2009. The Board have commented that weekly colorectal cancer MDT meetings are carried out and that this has been the case since 2001, but did not offer an explanation as to why Mr A's case was not discussed at an MDT meeting. I note, however, that they now have a standard of discussing 95 percent of new diagnoses and consider that this will reduce the likelihood of a case such as Mr A's not being discussed in the future.

24. Both Adviser 1 and Adviser 2 commented that it would have been good practice for Mr A's care to have been discussed with a specialist PMP unit when the diagnosis was made, to determine whether surgery could have been offered. I recognise that this was not a required action for the Board to take in terms of any national or local protocol. However, I note that the Board have a link with a specialist unit, which has been in place since 2007. The Board said

that this link is to transfer patients who require complex surgery, and I realise that at the time of his diagnosis Mr A did not necessarily need surgery. While Adviser 1 said that it was reasonable to take a 'watch and wait' approach at this point, they considered that it would have been appropriate to refer Mr A to a national specialist centre to consider the possibility of radical surgery. Due to the failure to arrange a follow up appointment in 2010, the first point at which treatment should have been offered may have been missed, and treatment was not offered until 2013. Additionally, when treatment was offered in 2013, Mr A was still not referred to the specialist unit in England with whom the Board have links, but rather to a smaller unit in Scotland.

25. I am concerned that the review carried out by the Board identified that there was a lack of communication about the diagnosis to Mr A but that they have taken no action as a result of this finding. Adviser 1 considered it possible that, had Mr A been clear as to the diagnosis of PMP and the significance of this diagnosis, he may have been more proactive in following up the CT scan of July 2010. Additionally, I note that the confirmed diagnosis of PMP was never communicated to Mr A's GP and consider this a failing on the part of the Board, as it may have been that had Mr A's GP been aware of the diagnosis they would have been more alert to new symptoms or changes in Mr A's condition.

26. I note Adviser 2's comments that it is not possible to state definitively that Mr A would have either been suitable for treatment at an earlier point, or that earlier treatment would have resulted in a different outcome for Mr A. However, Adviser 2 did say that earlier treatment is more likely to have a curative effect. I consider the issues identified in this investigation to have resulted in a missed opportunity for Mr A to have his case discussed by specialists. Additionally, the delay of three and a half to four years (as identified by Adviser 1) in offering treatment to Mr A resulted in a reduced potential for treatment to be curative, and I consider this to be a significant personal injustice to Mr A.

27. Given the above, I uphold this complaint. I, therefore, make the following recommendations to the Board.

(a) Recommendations

28. I recommend that the Board:	*Completion date*
(i) apologise to Mrs C for the failings identified in complaint (a) in relation to the delay in treatment for	24 May 2017

	Mr A's PMP;	
(ii)	provide evidence that MDT meetings are being held to discuss this type of cancer in line with their standards;	24 May 2017
(iii)	review their processes for ensuring that scan results are reviewed and followed up, and ensure that current processes are sufficient to avoid a repeat of the failings identified by this investigation;	21 June 2017
(iiii)	consider implementing a policy to discuss the treatment options for all cases of proven or suspected PMP with a specialist unit; and	21 June 2017
(iv)	draw the comments of Adviser 1 regarding communication of diagnoses to patients and GPs to the attention of the relevant consultant.	24 May 2017

(b) The Board's handling of Mrs C and Mr A's complaint was unreasonable

Background

29. In July 2013 Mr A complained in writing directly to one of the Board's consultants about his care and treatment. Mrs C provided me with a copy of this complaint; however, it was not in the complaints documentation provided by the Board. On review of the clinical records my complaints reviewer identified a copy of this complaint in amongst medical records and it did not appear that this complaint was responded to, either by the consultant it was addressed to or the Board's complaints team.

30. Mrs C and Mr A's GP Practice made a joint complaint to the Board on 6 May 2014. This was addressed to a different consultant to Mr A's complaint of the previous year and was passed to the Board's complaints department. The complaints department wrote to Mrs C on 16 June 2014 to acknowledge the complaint, and requested that Mr A signed a consent form. The complaints department wrote again to Mrs C on 30 June 2014 to acknowledge receipt of the signed consent form.

31. The Board wrote to Mrs C on 16 September 2014 to advise her that it had been decided that an independent clinical review of Mr A's case was to be carried out. The Board apologised for the time taken to reach this decision.

32. On 12 November 2014, Mr A's GP wrote to the Board on Mrs C's behalf to enquire as to the progress of the complaint. The Board contacted Mrs C to explain that a clinical review was to be carried out in the next few weeks, and wrote to Mr A's GP saying the same on 26 November 2014.

33. The Board wrote to Mrs C again on 26 January 2015 as she had been inquiring as to the status of the complaint. They said that the case was under clinical review and that an update would be provided to her on conclusion.

34. On 1 May 2015 the Board wrote to Mrs C to explain that the clinical review had now been completed by an independent consultant surgeon. They offered Mrs C a meeting with Board staff to discuss the findings of the review. It was unclear if this offer was responded to by Mrs C, but the clinical review was sent to Mrs C by the Board on 21 May 2015. The Board sent a covering letter apologising for the delays Mrs C had experienced in relation to her complaint. This letter did not detail that Mrs C could take her complaint to the SPSO if she was dissatisfied with this response.

The Board's response to SPSO enquiries

35. My complaints reviewer asked the Board whether the complaints department had ever received or responded to Mr A's original complaint of July 2013. The Board said that the complaint should not have been filed in Mr A's medical records and that they had no record of it having been passed to the complaints team from the consultant that it was addressed to. The Board confirmed that consultants should be aware that all complaints should be passed to the complaints department and could not offer an explanation as to why this did not happen with Mr A's complaint of July 2013.

36. My complaints reviewer also asked the Board whether they would normally enclose details of how to contact the SPSO in their final response letters. The Board confirmed that a leaflet which has details of the SPSO is normally sent with final response letters, but said that it did not appear that this happened in this case. The Board said that this was likely to be due to the fact the complaint had been handled slightly differently as it was subject to a clinical review.

The Board's Complaints Procedure

37. The Board's complaint policy and procedure states that where it is not possible to respond within 20 working days, the complainant will be provided with an explanation as to why there is a delay and, where possible, a revised

timetable. It states that once the investigation process has been completed and has fully investigated all the issues raised, a report of the investigation will be issued. It states that the report will include:

- the results of the investigation;
- a reply to all the points the complaint made;
- an apology where things have gone wrong;
- information as to any remedial action taken or proposed as a consequence of the complaint;
- an offer of the opportunity to talk to a member of staff about the report; and
- details as to how the complainant can contact the SPSO if they are not satisfied with the outcome of the investigation.

(b) Decision

38. The Board failed to acknowledge or reply to Mr A's original complaint of July 2013. This appears to be due to the consultant to whom it was addressed failing to pass the complaint on to the complaints department and instead filing it in Mr A's medical records.

39. When Mrs C and Mr A's GP made a joint complaint to the Board on 6 May 2014, the Board failed to provide a response in 20 working days and I consider that they did not reasonably provide Mrs C with an explanation for this, or a revised timetable. I note that after the Board acknowledged receipt of the signed consent form on 30 June 2014, they did not contact Mrs C to update her again until 16 September 2014, 55 working days later, and 95 working days after the complaint was initially made.

40. I note that after this point, when it was decided that a clinical review would be carried out, Mrs C was only updated as to the status of her complaint when she, or Mr A's GP, contacted the Board. I do not consider it reasonable that Mrs C had to continually contact the Board in order to find out the status of her complaint.

41. I do not consider it reasonable that once the clinical review of Mr A's care was complete the Board sent a copy of this to Mrs C as the final complaints response. I do not consider that the clinical review addressed all of the issues raised in the complaint, apologised to Mrs C and Mr A for the failings identified, or gave information as to remedial action taken or proposed.

42. Whilst the covering letter for the clinical review sent to Mrs C apologised for the delays in responding to the complaint and offered a meeting with the medical director, I do not consider this to have been a sufficient response to the detailed complaint made and the delay of over a year in the response being issued. I also note that the response did not give details of how Mrs C could contact the SPSO if she was dissatisfied with the response.

43. Overall, I do not consider the Board to have reasonably or appropriately handled Mrs C and Mr A's complaint. I am disappointed in the number of failings in the Board's handling of this complaint, and that several of these failings are errors in basic and fundamental complaints handling principles. Therefore, I uphold this aspect of Mrs C's complaint.

(b) Recommendations

44.	I recommend that the Board:	*Completion date*
(i)	apologise to Mrs C for the failings in complaints handling identified by this investigation;	24 May 2017
(ii)	remind the relevant staff that formal complaints should be passed on to the complaints department; and	24 May 2017
(iii)	review their handling of this complaint and identify areas for improvement.	24 May 2017

45. The Board have accepted the recommendations and will act on them accordingly. We will follow-up on these recommendations. The Board are asked to inform us of the steps that have been taken to implement these recommendations by the date specified. We will expect evidence (including supporting documentation) that appropriate action has been taken before we can confirm that the recommendations have been implemented.

Annex 1

Explanation of abbreviations used

Mrs C	the complainant
Mr A	the aggrieved
the Board	Ayrshire and Arran NHS Board
Adviser 1	colorectal surgeon
Adviser 2	consultant surgeon with expertise in pseudomyxoma peritonei
PMP	pseudomyxoma peritonei
CT	computerised tomography
MDT	multi-disciplinary team

Annex 2

Glossary of terms

computerised tomography (CT) scan	a scan which uses x-rays and a computer to create detailed images of the inside of the body
cytoreductive surgery	surgery that removes as much of a tumour as possible
haematuria	blood in the urine
heated intra-peritoneal chemotherapy	chemotherapy heated to 42 degrees centigrade and administered straight into the abdominal cavity
mucinous structure	a lump made up of or covered in mucus
pseudomyxoma peritonei	a very rare type of cancer that usually begins in the appendix
right inguinal hernia	a condition where an internal part of the body pushes through a weakness in the muscle or surrounding tissue wall in the right side of the groin area
ultrasound scan	a scan that uses sound waves to create images of organs and structures inside the body