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: Glasgow

Case ref: 201402644, Greater Glasgow and Clyde NHS Board
Sector: Health
Subject: Hospitals; communication; staff attitude; dignity; confidentiality

Summary
Mr A was referred by his GP to the ear, nose and throat (ENT) clinic at his local hospital (in another NHS board area) in January 2014 with a swelling below his left ear. This was found to be cancerous and Mr A was referred to the board for surgery. The surgery, which resulted in extensive facial disfigurement, was carried out on 11 March 2014 and Mr A was discharged on 27 March 2014.

Mr A's daughter (Mrs C) complained to the board that they failed to explain the extent of Mr A's surgery and the possible impact on him. Mrs C also complained about delays following surgery in arranging onward referrals for Mr A to various specialists.

The board noted that the process for obtaining consent for complex procedures such as this takes place over multiple visits, with information being given by different medical professionals. This is to ensure that patients fully understand the information being given to them. They said that Mr A appeared to understand the proposed procedure. They also noted that Mr A was found to be competent and, therefore, able to give consent himself. They said that staff always try to involve patients' families with this process though there was no formal obligation to do so. They were sorry that Mr A's family felt they were not adequately involved.

I took independent medical advice from a consultant maxillofacial surgeon (doctor specialising in the treatment of diseases affecting the mouth, jaws, face and neck). My adviser said that, before such a major procedure, it is important that the patient has all the relevant information, and enough time to discuss it with family and friends, to make an informed decision. He confirmed that a family presence during discussions is not a legal necessity but said it would be recommended by most doctors. My adviser also explained that, although Mr A was diagnosed in another NHS board area, it was the board's responsibility to explain the procedure and get consent. He said that there was a lack of evidence in Mr A's medical notes to show that this was done as it should have been.

In addition, my adviser informed me that most patients who have been diagnosed with head and neck cancer will be seen by a head and neck cancer nurse specialist (CNS), who can help reinforce the issues that have been discussed.

I upheld Mrs C's complaint. It is crucial that patients are given enough information about planned procedures to allow them to make an informed decision. They should also be given enough time to make a decision. The advice I have received, which I fully accept, indicates that Mr A should have been seen earlier by the consultant who performed the surgery, preferably in an out-patient setting with his family and the CNS present. There is no evidence of any involvement by the CNS, or of relevant patient information literature having been provided. This may potentially have been provided by the CNS in Mr A's local NHS board area, but I can see no evidence of the board's CNS having taken action to confirm this. There need to be clearer lines of responsibility when a patient is being referred from one health board to another.

Regarding the complaint about the delays in referrals, my adviser noted that records showed that all the relevant referrals were made within a few weeks of Mr A being discharged from hospital. However, this was not done by the time of discharge. This appears to have been as a result of confusion as to which health board was responsible. I consider that the board ought to have taken steps to clarify this and ensure it was specified in the discharge plan, so I also upheld Mrs C's complaint about the support given to Mr A following his discharge.

Redress and recommendations

The Ombudsman recommends that the Board:	*Completion date*
(i) reflect on the failings highlighted in this report with a view to improving the process for obtaining informed consent and report back to me with their findings;	18 November 2015
(ii) take steps to ensure that there is more involvement of the CNS in similar future cases and that this involvement is clearly documented;	18 November 2015
(iii) apologise to Mr A and his family for the failings identified in the process for obtaining informed	23 September 2015

	consent;	
(iv)	review their process for treating patients referred by other health boards, and discharging them back into their care, in order to ensure that clear lines of responsibility exist; and	18 November 2015
(v)	apologise to Mr A and his family for the failings identified in the discharge process.	23 September 2015

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 and the aggrieved as Mr A. 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 the Ombudsman about Greater Glasgow and Clyde NHS Board (the Board)'s actions in relation to surgery her father (Mr A) received at the Southern General Hospital (the Hospital). The complaints from Mrs C I have investigated are that:

(a) the communication surrounding Mr A's surgical procedure in March 2014 was unreasonable (*upheld*); and

(b) the post-operative support following Mr A's surgical procedure in March 2014 was unreasonable (*upheld*).

Investigation

2. In order to investigate Mrs C's complaint, my complaints reviewer considered all the information received from Mrs C and the Board. Independent advice was obtained from a consultant maxillofacial / head and neck surgeon (the Adviser). In this case, we have decided to issue a public report on Mrs C's complaint due to the significant personal injustice suffered by Mr A and in light of systemic issues relating to the processes followed by health boards when obtaining consent from patients.

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.

Background

4. Mr A was referred by his GP to the ear, nose and throat (ENT) clinic at his local hospital (in another NHS board area) on 9 January 2014 with a swelling below his left ear. This was subsequently found to be cancerous and Mr A was referred to the Board for surgery. The surgery, which was extensive, was carried out on 11 March 2014 and Mr A was discharged on 27 March 2014. Mr A was 76 years old at the time.

5. Mrs C complained that the Board failed to adequately explain the extent of the surgery and the impact it would have on Mr A. She also complained of delays in referring Mr A to relevant other specialists, such as community dentistry, following the surgery.

(a) The communication surrounding Mr A's surgical procedure in March 2014 was unreasonable

6. In her complaint to the Board, Mrs C indicated that Mr A's surgical procedure had been a complete surprise to him and was completely different to what was described before surgery. She advised that, as a result of the surgery, he had lost one of his ears (and hearing) and also the sight in the only eye he previously had sight in. She said he was also unable to eat any food that was not liquid. In particular, Mrs C complained that the explanation said to have been given by the consultant who carried out the surgery (Consultant 1) the night before surgery, with no family members present, was 'inadequate, inappropriate and unethically late'.

7. Mrs C said that Mr A had understood the surgery to involve some skin being taken from his arm to re-create where the cancer was being removed from, along with a procedure called a neck dissection (surgical removal of lymph nodes from the neck). She said Mr A voiced this understanding at the pre-surgery consultation and the consultant (Consultant 2) seemed to agree with this description of the planned procedure.

8. When Mrs C and her mother visited Mr A the day after the surgery, Mrs C explained that he was in intensive care with a flap of approximately 20 centimetres by 10 centimetres where his ear, cheek and part of his neck had been completely removed; stitches in his only eye that had sight; stitches in and above his lip; a tracheotomy (tube inserted in an opening in the windpipe to assist with breathing); and a large 15 inch scar in his thigh. She said none of this was communicated to them and she considered that they were misled regarding the procedure. She said, despite the family's belief that Mr A's cancer was situated where it was presenting itself externally, they subsequently learned that it had been quite extensive and had travelled to his ear, jaw and cheek.

9. The procedure carried out included a comprehensive neck dissection (surgical removal of all the lymph nodes in the neck between the jaw and the collarbones), pinnectomy (surgical removal of the external ear) and a total parotidectomy (surgical removal of the parotid gland – a salivary gland on the side of the face below the ear). An anterolateral thigh flap (soft tissue from Mr A's thigh) was used to reconstruct the surgical defect and a nerve graft (transplantation of a healthy nerve to replace a damaged nerve) was also carried out to reconstruct Mr A's facial nerve.

10. Mrs C said Consultant 1 subsequently indicated that he had explained the planned surgical procedure to Mr A the evening before his surgery. She questioned whether this was the case, noting that Mr A had remained unclear after the surgery as to what exactly had been done. She noted that Mr A had already been in hospital for 48 hours by this stage and said this late communication, if it took place, was completely inappropriate. She suggested that best practice would presumably permit a period of time between communication of surgery and the operation itself so that any concerns, decisions or questions can be considered.

The Board's response

11. The Board noted that Mr A was found to be competent and able to understand and that he had, therefore, given consent for the procedure himself. They said that the process for obtaining consent for such complex procedures takes place over several visits and encounters, with information being given by a number of different surgeons and professionals. They noted that patients often find it difficult to assimilate large amounts of information all in one sitting and that, in Mr A's case, the surgery was explained to him on multiple occasions.

12. The Board noted that details of the procedure were explained to Mr A by Consultant 1, and one of his colleagues, towards the end of the afternoon on the day before surgery. They stated that, as part of the consent process, Consultant 1 asked Mr A about his understanding of the procedure and was satisfied that it was fully understood. They said Consultant 1 considered that the consent process had been more than adequate and they categorically refuted the suggestion that Mr A was not fully informed of the procedure. They reiterated that the consent process took place over several weeks and multiple visits and that Mr A appeared to understand and be able to recount the proposed procedure on numerous occasions.

13. The Board noted that a number of particular operative details are often decided upon after a significant amount of computerised planning and preparation, primarily relating to the form of reconstruction rather than the extent of the surgical resection (removal of the cancer). They said this was the case with Mr A, however, they maintained that he fully understood the extent of the surgery and what lay ahead.

14. The Board said that at no time did the medical team exclude Mr A's family from the discussion. They said medical staff always endeavour to involve patients' families with the consent process but noted that there was no formal obligation to do so. They expressed regret that Mr A's family felt they were not adequately involved in the discussion but observed that Mr A had not communicated any wish for more information to be given to his family.

15. The Board provided details of the procedure carried out and sought to explain Mrs C's observations from when she visited Mr A after surgery. In particular, they noted that his eye had been stitched closed temporarily to ensure that no damage to the cornea occurred in the post-operative period. They confirmed that Mr A's thigh was the donor site for the flap used for reconstruction and said he was informed pre-operatively that there would be scarring at the donor site.

Medical advice

16. Although Mr A was diagnosed in another NHS board area, he was referred to the Board for surgery. As such, the Adviser explained that it was the Board's responsibility to ensure that all appropriate counselling and consent matters had been adequately dealt with. He said that, before such an extensive procedure, it is important that the patient has been given all the relevant information to make an informed decision. He noted that these issues are discussed in the General Medical Council's guidance on 'Consent: patients and doctors making decisions together' and the Scottish Government's 'A Good Practice Guide on Consent for Health Professionals in NHS Scotland'. These guidelines stress the importance of giving enough information about the planned procedure and potential complications, as well as giving enough time for consideration and discussion with family and friends.

17. The Adviser said that, in Mr A's case, the documented evidence in relation to explaining the planned procedure and gaining consent is poor. Although Mrs C mentions in her complaint that they saw Consultant 2 and discussed the procedure at the pre-assessment clinic on 5 March 2014, the Adviser could not find any entries or clinical letters relating to this consultation.

18. My complaints reviewer contacted the Board to query this and they asked Consultant 2 about it. He explained that his role at the pre-assessment clinic was that of 'consultant surgeon liaison with the entire team at the clinic' and that, when he saw Mr A and Mrs C, his role was a facilitatory one. He said

there was no documentary record of his consultation as he had no direct role in Mr A's management at that time.

19. The Adviser noted that a clerking sheet was filled in when Mr A was subsequently admitted on 9 March 2014 but it made no mention of the planned procedure. He observed that the next entry in the medical notes is from the ward round on the morning of 10 March 2014, which includes:

'quick chat with [Consultant 2] about procedure
- likely hearing loss
- possible facial nerve damage'

As these are the only two possible complications documented, as of the morning before planned surgery, the Adviser considered that Consultant 2 still did not appear aware at that point as to what the operating team were exactly planning to do.

20. The complaint from Mrs C indicated that Mr A first saw Consultant 1 at about 18:00 on the night of 10 March 2014. The Adviser said the procedure described on the consent form was that which was carried out. He noted that Mr A's local NHS board indicated that they only discussed brief details of the planned surgery with him as the definitive treatment would be carried out by the Board. He said that this, coupled with the only documented interaction between Mr A and Consultant 2 being a 'quick chat' on the ward round on 10 March 2014, means the first evidence of Mr A being given the definitive surgical treatment plan was only the night before the planned surgery.

21. The Adviser accepted what the Board said about the potential difficulty for patients assimilating large amounts of information given in one sitting. However, he advised that the information given must be consistent and reinforce and add to the previous information given. In this case, he noted that the information varied from 'may be able to save some of the ear' (Mr A's local NHS board) to Consultant 2 noting 'possible damage to facial nerve' and 'likely hearing loss'. He reiterated that the operating surgeon is ultimately responsible for gaining adequate and informed consent and it should not be assumed that others have already provided this information.

22. The Adviser felt that, given the magnitude of the surgery planned, Consultant 1, as the lead operating surgeon, should have met Mr A and his family in an out-patient setting to discuss the operation in detail and its potential

consequences in terms of significant facial disfigurement, hearing loss and other related issues. He said that, in major cases such as this, a further appointment is also sometimes useful to ensure all the pertinent points have been understood. Then the final discussion the day before, or morning of, surgery simply reiterates the previous discussions and finally the consent process is complete and the form can be signed. He did not consider that the consent process was satisfactorily completed in this case.

23. In addition, the Adviser informed me that most patients who have been diagnosed with a head and neck cancer will be seen by a head and neck cancer nurse specialist (CNS), who plays a very important role within the head and neck multi-disciplinary team. He said that the CNS should also have been present had a prior out-patient discussion took place between Consultant 1 and Mr A and his family. He noted that the CNS can help reinforce the issues that have been discussed and also give valuable feedback to the rest of the team if there are any concerns. He said that the CNS will occasionally sense that the full extent of the procedure has not been fully understood by the patient and/or family and will suggest to the surgeon or oncologist that a further visit to discuss the details would be appropriate.

24. The Adviser noted that, while the pre-assessment clinic documentation was ticked to indicate that Mr A was seen by the CNS, the relevant CNS section of that documentation is blank. My complaints reviewer contacted the Board to ask whether any other records made by the CNS were available and they responded advising that no separate records were held.

25. I was referred by the Adviser to the Scottish Intercollegiate Guidelines Network (SIGN)'s document 'Diagnosis and management of head and neck cancer – A national clinical guideline' (2006). Chapter 16 of this is entitled 'Information for discussion with patients and carers' and the introduction to this chapter states:

> 'This section of the guideline is to help patients, who have been diagnosed with head and neck cancer, and their carers understand all the stages of their care. It will focus on diagnosis, investigation, treatment and follow up for head and neck cancer. It can only give a broad view as each patient's cancer and treatment will be different. Detailed verbal, written and visual information regarding specific cancers and their treatment should be readily available to patients from the specialist cancer team at all stages of their care.'

The Adviser suggested that it would have been useful for Mr A to have received a MacMillan general information booklet on head and neck cancers, as well as a more specific booklet relating to his particular cancer. He said he could not see any evidence of any patient information booklets having been given by the CNS or of any pre-surgery meetings between Mr A and the CNS. He noted that Mr A was seen previously by the CNS in his local NHS board area but said that clear arrangements should be in place regarding who is responsible for issuing appropriate patient information literature.

26. With regards to Mrs C's concerns that Mr A's family were not involved in discussions, and the Board's view that he was competent to consent to the procedure himself, the Adviser agreed that there was nothing to suggest Mr A did not have capacity to sign the consent form. He confirmed that a family presence during discussions is not a legal necessity but said it is very desirable and would be recommended by most clinicians. While Mr A had family present at the pre-assessment clinic, where a discussion with Consultant 2 was said to have taken place but was not documented, the Adviser reiterated that there seemed to have been ongoing uncertainty about the planned procedure at that point. He, therefore, maintained that the first evident discussion about the planned procedure took place the day before surgery when the consent form was signed. He could not see any documentation in which the planned procedure was discussed with Mr A in the presence of his family.

(a) Decision

27. It is crucial that patients are given sufficient information about planned procedures in order to allow them to make an informed decision. They should also be given sufficient time to make a decision. The Board indicate that the surgery was explained to Mr A on a number of occasions. However, the first documented discussion that makes reference to the actual procedure that was carried out did not take place until the day before surgery, without Mr A's family present. Mrs C is clear that Mr A and his family did not comprehend the extent of the surgery and there is no evidence of a comprehensive explanation having been provided to them sufficiently in advance of the operation. This is particularly concerning given the scale of the surgery carried out and the significant impact it inevitably had on Mr A and his family. The advice I have received, which I fully accept, indicates that Mr A should have been seen earlier by Consultant 1, preferably in an out-patient setting with his family and the CNS present. There is no evidence of any involvement by the CNS and no record of

relevant patient information literature having been provided. While I am conscious that this could potentially have been provided by the CNS in Mr A's local NHS board area, I can see no evidence of the Board's CNS having taken action to confirm this, or indeed any action at all. There needs to be clearer lines of responsibility when a patient is being referred from one health board to another (which I will touch upon further under complaint (b)). In all circumstances, I uphold this complaint.

(a) Recommendations

28. I recommend that the Board:	*Completion date*
(i) reflect on the failings highlighted in this report with a view to improving the process for obtaining informed consent and report back to me with their findings;	18 November 2015
(ii) take steps to ensure that there is more involvement of the CNS in similar future cases and that this involvement is clearly documented; and	18 November 2015
(iii) apologise to Mr A and his family for the failings identified in the process for obtaining informed consent.	23 September 2015

(b) The post-operative support following Mr A's surgical procedure in March 2014 was unreasonable

29. Mrs C complained to the Board about delays in arranging relevant onward referrals following surgery. For instance, she advised that Mr A's dentures no longer fitted him as a result of the surgery and he required a referral to community dentistry. She noted that she had to chase this referral up despite it being required urgently due to Mr A being able to eat only pureed food, thus impacting on his recovery from surgery and preparation for radiotherapy.

30. Mrs C said they were advised that Mr A's local NHS board would be organising this dental referral, along with referrals to ophthalmology (specialism dealing with the diagnosis and treatment of eye conditions) and audiology (specialism dealing with the diagnosis and treatment of hearing and balance problems). She noted that none of these referrals were made until Mr A returned to Consultant 1's clinic and he chased them up.

31. Mrs C expressed concern that Mr A's discharge from the Hospital was process driven and not patient driven. She indicated that staff had said it would

be better and easier for them to move Mr A to his local NHS board before discharge.

The Board's response

32. The Board explained that it was normal practice for patients from Mr A's local NHS board area, who have had complex surgery, to be discharged back to their local hospital prior to discharge home. They said this is to allow local teams in the community to be engaged more effectively. They said this was originally the plan for Mr A, however, as his family raised concerns about discharge back to his local hospital, this plan was modified at relatively short notice and he was kept at the Hospital a little bit longer than had been planned. He was, therefore, discharged directly home.

33. The Board said this change of plan may have led to some minor confusion with regard to onward referral to additional specialities but that all of these issues had been resolved by the time of discharge.

Medical advice

34. The Adviser noted that a number of additional appointments were to be arranged in the days leading up to Mr A's discharge from the Hospital on 27 March 2014. He confirmed that these included audiology, community dentistry, ophthalmology and dermatology (specialism dealing with the diagnosis and treatment of skin disorders). He noted that the discharge summary stated that ophthalmology and dermatology reviews were to be arranged and Mr A was to be seen by a community dentist in his local NHS board area.

35. There is an entry in the notes from 24 March 2014 which says Mr A had been seen by ophthalmology and that Mrs C had requested an in-patient dermatology review. The Adviser said that, at the time of discharge, he could not see a referral to community dental services and he was unsure whether this is done by letter, telephone or whether the intention was that the team at Mr A's local NHS board would arrange this.

36. There is also an entry from 2 April 2014 indicating that Consultant 1 contacted Mrs C to inform her that all the outstanding out-patient tests would be referred to their local NHS board and carried out in their catchment area. The next documentation relating to these appointments appears to be a letter of 14 April 2014 from Consultant 1 to the consultants at the other health board

asking them to arrange appointments with occupational therapy, ophthalmology, audiology and the community dental services.

37. The Adviser concluded that all relevant appointments that may have been needed in Mr A's case were requested. However, he said they do not appear to have been requested until 14 April 2014 and had not, therefore, been requested at the time of discharge on 27 March 2014. He considered that discharge arrangements need to be clearer. He said it should be made clear on the discharge documentation if the plan is for another board to make the necessary arrangements and that this should be passed to the team within the other board, either through the multi-disciplinary team, a direct letter to the clinician or through the CNS teams.

(b) Decision

38. While all relevant referrals appear to have been made within a few weeks of Mr A being discharged, they were not made by the time of discharge. This appears to have been as a result of some confusion as to which health board was responsible for arranging the referrals. I consider that the Board ought to have taken steps to clarify this and ensure it was specified in the discharge plan. This will obviously have been an anxious time for Mr A and his family, coming to terms with the impact of major surgery, and uncertainty over follow-up appointments would not have been helpful. As already noted above, clearer lines of responsibility need to exist between health boards for such cases. I uphold this complaint.

(b) Recommendations

39. I recommend that the Board:	*Completion date*
(i) review their process for treating patients referred by other health boards, and discharging them back into their care, in order to ensure that clear lines of responsibility exist; and	18 November 2015
(ii) apologise to Mr A and his family for the failings identified in the discharge process.	23 September 2015

40. 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 dates 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
the Board	Greater Glasgow and Clyde NHS Board
Mr A	the aggrieved
the Hospital	Southern General Hospital (now South Glasgow University Hospital)
the Adviser	consultant maxillofacial / head and neck surgeon
GP	general practitioner
ENT	ear, nose and throat
Consultant 1	consultant oral and maxillofacial / head and neck surgeon (who carried out Mr A's surgery)
Consultant 2	consultant oral and maxillofacial / head and neck surgeon
CNS	head and neck cancer nurse specialist
SIGN	Scottish Intercollegiate Guidelines Network

Annex 2

Glossary of terms

anterolateral thigh flap	soft tissue from the thigh area commonly used in reconstructive surgery
audiology	specialism dealing with the diagnosis and treatment of hearing and balance problems
comprehensive neck dissection	surgical removal of all the lymph nodes in the neck between the jaw and the collarbones
cornea	the clear outer layer at the front of the eyeball
dermatology	specialism dealing with the diagnosis and treatment of skin disorders
maxillofacial	specialism dealing with the diagnosis and treatment of diseases affecting the jaws and face
nerve graft	transplantation of a healthy nerve to replace a damaged nerve
ophthalmology	specialism dealing with the diagnosis and treatment of eye conditions
parotidectomy	surgical removal of the parotid gland
parotid gland	a salivary gland on the side of the face below the ear
pinnectomy	surgical removal of the external ear
radiotherapy	a treatment to destroy cancer cells with radiation

tracheotomy	surgical procedure to open the windpipe to assist with breathing

Annex 3

List of legislation and policies considered

Consent: patients and doctors making decisions together (General Medical Council, June 2008)

A Good Practice Guide on Consent for Health Professionals in NHS Scotland (Scottish Executive Health Department, June 2006)

Diagnosis and management of head and neck cancer – A national clinical guideline (Scottish Intercollegiate Guidelines Network, October 2006).