Scottish Parliament Region: Glasgow and Lothian

Case 200500603 & 200500688: Greater Glasgow and Clyde NHS Board[1] and Lothian NHS Board

Summary of Investigation

Category

Health: Assessment for Liver Transplant, Procedure for obtaining second opinion.

Overview

Mr A was referred to the Scottish Liver Transplant Unit (SLTU) in Edinburgh by his Consultant in Glasgow, for assessment for inclusion on the transplant list but was not considered suitable for inclusion. Mr A's uncle sought to challenge this decision and obtain a second opinion. This took several months and unfortunately Mr A died before a reassessment was possible. Mr C complained that Mr A had not received adequate care or proper assessment.

Specific complaint and conclusions

The complaints from Mr C which I have investigated are that:

(a) SLTU did not properly assess Mr A for transplant (*partially upheld)*;

(b) Gartnavel General Hospital, Glasgow failed to provide proper care for Mr A or arrange a timely review of his eligibility for transplant following his unsuccessful assessment *(partially upheld)*; and

(c) Greater Glasgow NHS Board failed to respond to his complaint in a timely manner *(upheld)*.

[1] On 1 April 2006 the National Health Service (Variation of the Areas of Greater Glasgow and Highland Health Boards) (Scotland) Order 2006 added the area of Argyll and Bute Council to the area for which Highland Health Board is constituted and all other areas covered by Argyll and Clyde Health Board to the area for which Greater Glasgow Health Board is constituted. The same Order made provision for the transfer of the liabilities of Argyll and Clyde Health Board to Greater Glasgow Health Board (now known as Greater Glasgow and Clyde Health Board) and Highland Health Board.

Redress and recommendations

(i) SLTU provide evidence of a common understanding amongst all staff of the SLTU guidance and its practical application with respect to family involvement;

(ii) SLTU revise their discharge procedures for patients not admitted to the transplant list to include information on the right to a second opinion and what such a process might entail and provide evidence of this change;

(iii) NHS Greater Glasgow ensure that the new process for obtaining an appropriate second opinion for patients negatively assessed for liver transplant is made known to the relevant clinical staff; and

(iv) NHS Greater Glasgow provide Mr C with a written apology for the acknowledged delay in responding to his complaint.

Main Investigation Report

Introduction

1. On 31 May 2005 the Ombudsman received a complaint from a man (referred to in this report as Mr C) that Greater Glasgow and Clyde NHS Board and Lothian NHS Board had failed in their care and treatment of his late nephew (referred to in this report as Mr A). In particular Mr C complained that Mr A had been turned down for a liver transplant by the Scottish Liver Transplant Unit (SLTU), based at the Royal Infirmary of Edinburgh. The principal events of this complaint occurred between August 2003 and Mr A's death in February 2004.

2. There was considerable correspondence with health professionals from both Health Boards about this matter between August and December 2003, all prior to Mr A's death. Mr C first raised these issues as a complaint with Greater Glasgow and Clyde NHS Board in January 2005. The Complaints Officer agreed to forward on Mr C's concerns about SLTU to Lothian NHS Board but unfortunately there was some confusion about this and SLTU were not properly notified of the complaint. In early May 2005 Mr C tried to chase matters up, but contacted this office as he had not received a response to his complaint from NHS Greater Glasgow. It was then agreed with all parties concerned that, to avoid further delays for Mr A's family, this office would accept the complaint and progress with the full co-operation of both Health Boards.

3. The complaints from Mr C which I have investigated are that:

(a) SLTU did not properly assess Mr A for transplant;

(b) Gartnavel General Hospital, Glasgow failed to provide proper care for Mr A or arrange a timely review of his eligibility for transplant following his unsuccessful assessment; and

(c) Greater Glasgow NHS Board failed to respond to his complaint in a timely manner.

4. Investigation of this complaint involved reviewing Mr A's relevant hospital records, obtaining the opinion of a medical adviser (referred to in this report as the Adviser), reading the documentation provided by Mr C and the numerous letters exchanged between Mr C, Mr A's Member of the Scottish Parliament (MSP 1) and medical professionals in a number of locations and making written enquiries of

both NHS Boards. Mr C, Lothian NHS Board and Greater Glasgow NHS Board have all had an opportunity to comment on the draft report. A summary of terms used is contained in Annex 1. A glossary of the medical terms is contained in Annex 2.

Background to the medical issues of this complaint (provided by the Adviser)

5. Mr A was 43 years old at the time of his admission to SLTU in August 2003. He had a long history of alcohol abuse and suffered alcohol liver disease (ALD) with consequent ascites and other side-effects. He had been abstinent from alcohol since August 2002 but the liver damage was not reversible and by August 2003 he had end stage liver disease.

6. Liver transplantation is the only practical, successful way of treating end stage liver disease. In kidney transplants the diseased kidneys can be removed and the patient kept alive by dialysis until a donor becomes available but no such equivalent machine is available for liver diseases. As a consequence, if a liver transplantation fails there is no equivalent of the dialysis machine to fall back on. This means that livers can only be transplanted when the liver disease reaches a truly end stage. In some forms of liver disease, eg viral hepatitis or alcohol-induced disease, considerable recovery can occur when the injurious agent is removed (eg cessation of alcohol). It is, therefore, reasonable, particularly in alcoholic liver disease, to delay transplant until any recovery has occurred. Too early a referral is not appropriate. Unfortunately, it also happens not infrequently that a patient can be too ill for liver transplantation. Consequently, the window of opportunity for liver transplantation is often quite small.

7. The number of people in optimum transplant condition awaiting transplantation in the UK far exceeds the number of donor livers that become available. A nationally co-ordinated system decides who should receive an available donor liver based, not only on urgency of need, but also taking into consideration the most likely positive outcomes. The consequence of this sad fact is that there are many patients each year who die from liver disease without transplantation. Extremely difficult decisions have to be made in assessing the probability of successful long-term outcome in individual patients. The assessments for transplantation obviously include medical and technical data such

as anatomical details. However, more pragmatic issues also need to be addressed when considering the probability of long-term survival. These include:

- Evidence of treatment compliance, since careful control of life-long immunosuppressive drug treatment is essential.
- Probability of recurrence, such as return to hazardous alcohol use.
- The availability of social, emotional and medical support required over the waiting list period, the surgery, the episodes of rejection and the required life-style changes etc.

8. The Adviser told me that the only guidelines on assessment for liver transplantation are published by the British Society of Gastroenterology (in their journal *Gut*). These are largely based on national data on outcome and also on the experience of the individual centres. Minor details will vary from centre to centre and each centre will have its own more detailed guidance and protocols.

(a) SLTU did not properly assess Mr A for transplant.

9. Mr C complained that the assessment was carried out when Mr A was not physically well enough to participate constructively, that it relied on only one psychiatric view, that there was no minute of the assessment meeting, that Mr A was not given the necessary support following the negative decision and, in particular, Mr A's family were not asked to participate in any of the assessment process.

Mr C's Evidence

10. Mr C told me that Mr A had been unwell for three weeks prior to his assessment, suffering from a brain infection. Mr A's family believe that he was not fully recovered at the time of his assessment and this alongside the pain of the acute ascites, diminished his ability to concentrate and increased his irritability. Mr C said that Mr A could only recollect being visited once by a psychiatrist who woke him from a deep sleep and asked him if he wanted surgery – to which he replied 'yes'.

11. Mr C accepted that the decision of the Assessment Team to refuse Mr A a place on the transplant list was unanimous. He considered that this decision was substantially based on the opinion of a consultant psychiatrist (Consultant Psychiatrist 1) making the whole process overly biased to one opinion. Mr C felt

that there should be more than one psychiatric opinion sought and/or an appeal process as a matter of Human Rights. He also commented on the lack of any detailed record of the meeting.

12. Mr C told me that Mr A was given the news that he would not be added to the transplant list without any family member present to support him. Mr C told me that Mr A considered this as being given a 'death sentence' and was distraught when the family arrived. When the family did arrive there were no medical staff immediately available to discuss Mr A's options and it was only at Mr C's insistence that he spoke with a consultant physician (Consultant Physician 2). At this time he was told the decision was final and no appeal process or other options were mentioned.

13. Mr C told me that Mr A had ceased taking alcohol in August 2002 and started to rebuild his life. The medical records make several references to this over many months and there is no indication that Mr A was taking alcohol after that date nor that those involved in his care doubted Mr A's cessation of alcohol. Mr C told me that, while his abstention was known to the doctors, the other positive changes Mr A had made were not and, as the family were not consulted, there was no opportunity to make these things known. Mr C referred to several statements made in correspondence by doctors involved with SLTU that Mr A had no social support and that his attitude still required to change before he could be considered for a transplant.

14. Mr C told me that both he and Mr A's mother had accompanied Mr A on admission and advised staff that they lived nearby and would be visiting regularly (as indeed they did). Mr C also told me that he and Mr A's mother had expected to be involved in discussions at some point in the assessment and were surprised that they were not approached by staff for this purpose. Mr C told me that he considered this omission was critical as it greatly disadvantaged Mr A. Mr C told me he believed that Consultant Psychiatrist 1 and others involved in Mr A's care falsely assumed that Mr A had little family support. Mr C also told me that Mr A had a wide circle of friends, many of whom he had known from schooldays, and who supported him through his illnesses.

15. Mr C acknowledged that Mr A might appear angry, rude or unco-operative to

medical staff, but in fact this belied his underlying confusion and fear. Mr A's family have commented that Mr A had an unconventional attitude and that this could too easily be misunderstood by those who did not take the time to get to know him. Mr A's family commented that there appeared to be a lack of sympathy and understanding from a number of health professionals who worked with Mr A. They noted that this had not been the case with staff at the NHS Hospital in England (NHS Hospital 1), where Mr A was a patient for several weeks prior to his death, or with his GP, who had known him for a considerable time.

16. Mr C told me that he considered Mr A's refusal to take his medication in SLTU to be an indication of his impaired condition at the time as Mr A was meticulous in taking his medication at home.

Evidence from the medical correspondence

17. In their response to MSP 1, dated 5 September 2003, Consultant Physician 2 and the surgeon responsible for Mr A during his assessment at SLTU (Consultant Surgeon 1) stated that Mr A's psychiatric assessment had lasted for around 90 minutes and that he had been considered to be awake and orientated throughout. They also advised that Consultant Psychiatrist 1 had reviewed all Mr A's medical notes from NHS Greater Glasgow and spoken with Mr A's GP (GP 1). The doctors advised that an important factor in the assessment process is the compliance of the patient with medical therapy as post-transplant patients are required to take immunosuppressive medication for life. The patient's history of compliance with medical treatment is considered to be the best measure of their future behaviour in this respect. The doctors noted that where a patient has alcoholic liver disease a more detailed assessment is undertaken to assess the likelihood of a patient returning to harmful drinking following transplant, and that there are a number of factors to be considered. These factors included reasons for abstinence (ill health or abstinent with medical advice when feeling well), polysubstance abuse and any substitute activity available (so that following transplant the patient is not subject to the same routine which previously included alcohol). Finally, the doctors noted that the question of what would happen if the patient did return to drinking was also considered - in particular, if a relapse occurred, would there be any possible intervention?

18. The letter also noted that Mr A had been advised of the decision by

Consultant Surgeon 1 and Consultant Physician 2, who had been responsible for the SLTU the week of Mr A's admission. They advised that the matter was discussed with Mr A in a single room and the discussion ended when Mr A indicated he would prefer to leave. Both doctors stated that they tried to approach Mr A in a sensitive and professional way while acknowledging the difficult decision that had been made.

19. In a second letter of 19 September 2003 to MSP 1, Consultant Physician 2 and Consultant Surgeon 1 stated that one of the concerns raised in the assessment was Mr A's failure to comply with his current treatment as he had failed to take his medication a number of times while in the unit. The doctors also referred to Mr A's problem as one of alcohol dependency, rather than misuse, and that Mr A had indicated the reason for his abstinence was his worsening physical condition rather than a change of lifestyle. The doctors noted that Mr A had returned to alcohol use in previous periods of physical recovery. They finally referred to Mr A's apparent lack of social support outside of his family as a cause for concern.

20. As a result of Mr A's negative assessment, GP 1 sought a further opinion of Mr A's motivation towards maintaining abstinence from a psychiatrist (Consultant Psychiatrist 2) based in Glasgow working with the addiction unit. Consultant Psychiatrist 2 wrote to GP 1 on 18 September 2003 indicating that in his opinion Mr A was motivated to continued abstinence.

21. GP 1 wrote to the consultant at SLTU (Consultant Gastroenterologist 1) on 23 September 2003 referring to the views of Consultant Psychiatrist 2. The letter was passed to another consultant psychiatrist (Consultant Psychiatrist 3) who undertook a review of Mr A's records and discussed the matter directly with Consultant Psychiatrist 1 and Consultant Psychiatrist 2. He responded to GP 1 on 29 September 2003. Consultant Psychiatrist 3 stated that Consultant Psychiatrist 2 was not incorrect, but that following their discussion of the criteria used to assess patients for possible liver transplant, Consultant Psychiatrist 2 had been able to reassess his view of Mr A and he now agreed with the conclusion originally reached by Consultant Psychiatrist 1. Consultant Psychiatrist 3 also stated that Consultant Psychiatrist 1 had in fact consulted with him prior to giving his views to the Assessment Team meeting. He noted that there had been a

possible omission by Consultant Psychiatrist 1 in not seeking collateral information from a family member. However, he felt Mr A had given a very full history and there was no need to fill the gaps. He concluded that family accounts are often less useful because opinions are, understandably, heavily influenced by what is at stake. He commented that it was his practice to speak with the family.

22. Consultant Psychiatrist 3 also referred to the number of negative factors in Mr A's assessment, including his ongoing use of cannabis and an unequivocal intention to continue this use. This was regarded as a contraindication by the transplant Assessment Team because of its strong association with relapse drinking and non-compliance. He made reference to research supporting his view of the need for rigorous assessment of ALD patients. He finally set out a number of options for Mr A, including an independent opinion from an alcohol expert and providing correcting information if it was considered there were factual errors in the original assessment. In either event the assessment would be reconsidered.

23. In response to the draft of this report the Board provided further details concerning the involvement of Mr A's family. The Board stated that they are assiduous in involving the family in assessments and that it is quite common for relatives to be with their family member during most of the final day. In this case the transplant co-ordinator clearly remembered that Mr A was reluctant to give details for a next-of-kin and made it clear that he was not keen for his family to be involved in a major way during his assessment. The Board acknowledged that there is no record of this in the file. The Board also stated that it was Mr A's wish to discuss the outcome of the assessment although he had no family member present and that it was Mr A who terminated the meeting by leaving the room.

24. The Board have also told me that it had not been their practice to record which family members are involved in discussions or that the patient has declined to have family members involved. They acknowledged that this had caused problems. The Board advised me that they have already changed their paperwork to specify the relatives with whom discussions took place, or if no family members were present. As a result of this complaint they are further amending the paperwork to include a specific reference to the reasons why family were not involved where this is the case.

25. The Board made an additional comment on informing patients of the right to a second opinion. The Board told me that this issue has been the subject of discussions among the UK transplant units with specific reference to alcoholic liver disease. As a consequence, the SLTU have agreed that the patient will be informed of the right to have their notes reviewed by another transplant team in the first instance, with a view to a further assessment by the team, if it considers this is warranted. The Board have advised me that this information will now be included in their own literature. I have passed on information regarding this change to NHS Greater Glasgow to ensure the relevant staff there are aware of this revised process.

The Adviser's evidence

26. The Adviser told me that he is not aware of any aspect of medicine outside of mental health legislation where there is a formal appeal process. However, the Adviser also stated that it is not uncommon for a second opinion to be sought and that this was appropriate in Mr A's circumstances.

27. The Adviser reviewed Mr A's psychiatric assessment and social assessment and told me that the assessment was criterion based and the evidence for Consultant Psychiatrist 1's opinion was clearly stated in a report to Consultant Gastroenterologist 1. He also considered that the 29 September 2003 letter from Consultant Psychiatrist 3 to GP 1 expanded on the explanation in an objective and dispassionate way. He concluded that Mr A's assessment was consistent with the principles published by the British Society of Gastroenterology (see paragraph 8).

28. The Adviser told me that Mr A was assessed by very experienced hepatologists and there is no documented evidence that he was confused at the time of their assessment. He considered that the decision to decline liver transplantation was based on the opinion of a psychiatrist who was experienced in the field of transplantation medicine and this was appropriate and consistent with common practice.

29. The Adviser did consider that it would be common practice to take into account the family's view of the problem for the purpose of corroboration of the patient's statements. It would also be good practice, with the express permission of the patient, to discuss the outcome of the investigations and assessment. He

expressed concern that this appeared not to have occurred in Mr A's case in a way that was satisfactory for the family.

30. He noted that there were a number of occasions when Mr A was recorded in the clinical notes as non-compliant with treatment.

31. The Adviser noted that Mr A was not offered counselling after being declined liver transplantation but said that in fact few NHS institutions have available trained counsellors. He concluded that it was not possible to say from the records to what extent Mr A's own attitude and behaviour may have contributed to the degree of emotional support given.

Other Evidence

32. The SLTU Patients' Handbook provides information for patients undergoing assessment. This document stated that the purpose of the assessment is to (amongst other things):

- 'Provide you and your family with the information you need about transplant
- Find out how you and your family feel about your liver disease and the possibility of a transplant'

(a) Conclusion

33. Based on the medical advice I have received and my review of the correspondence, I conclude that Mr A was fit for assessment during his stay at SLTU. I also conclude that a single psychiatric review is in line with reasonable practice and that there is sufficient recording of the overall assessment process.

34. Mr A's assessment was based on his account of his family and personal circumstances. The concern expressed by Consultant Psychiatrist 1 was not about a lack of immediate family support. Mr A commented in his social work assessment that he did not have any social network outside of his family and, in his psychiatric assessment, that he continued to associate with polydrug users. In assessing suitability for transplant consideration is given not just to the physical and emotional support that is available to the potential donee at the time of transplant and recovery but also to the longer term likelihood of leading a lifestyle

compatible with good overall mental and physical health. In denying Mr A a transplant the SLTU were not suggesting that Mr A did not have a supportive family but were concluding that his future lifestyle after a transplant would continue to involve exposure to a considerable number of risk factors. I acknowledge Mr C's concern that the assessment of Mr A was factually flawed and suggested a lack of family support. I have not seen any factual inaccuracies, although some statements are based solely on the SLTU statement of Mr A's account without any attempt being made to check these and with no evidence of Mr A's apparent wish not to involve his family. I conclude that there was no clinical failing in the assessment of Mr A.

35. I am concerned that the assessment of Mr A did not include discussions with his family. The SLTU handbook indicates that this would happen and Consultant Psychiatrist 3 and the Adviser have also indicated it is the usual practice. I cannot say whether or not such discussions would have altered the outcome for Mr A. Due to a lack of appropriate evidence in the medical record I cannot comment on the Board's statement that Mr A did not want his family involved. Consequently, while I cannot conclude whether there was a failure in the assessment process, I consider that such discussions would have assisted the family in understanding the process and criteria for assessment and reduced their anxiety about the quality of information on which the assessment was made. I have an additional concern that this possible failure contributed to a delay in Mr A obtaining a second opinion which I refer to in complaint (b).

36. I conclude that, while the overall decision was clinically appropriate, there was a failure to follow the expected process which caused undue distress for Mr A's family. To this extent I partially uphold this complaint.

(a Recommendation

37. In light of this conclusion the Ombudsman recommends that the SLTU provide this office with evidence of a common understanding amongst staff of the SLTU guidance with respect to family involvement and of its revised paperwork.

(b) Gartnavel General Hospital failed to provide proper care for Mr A or arrange a timely review of his eligibility for transplant following his unsuccessful assessment.

38. Mr C complained that NHS Greater Glasgow, and the consultant responsible for Mr A's treatment at NHS Greater Glasgow (Consultant Physician 1) in particular, did not act promptly to secure Mr A a second opinion. Mr C considered that this delay meant Mr A's physical condition had deteriorated too far by the time he was admitted to NHS Hospital 1 and he was never able to participate in the further assessment and died while awaiting this further assessment. Mr C also complained that NHS Greater Glasgow did not do enough to stabilise or improve Mr A's condition while he was awaiting referral but frequently discharged him from hospital when he was not fit for discharge.

Mr C's evidence

39. Mr C told me that GP 1 had approached Consultant Physician 1 in early November 2003 and offered to make a direct approach to NHS Hospital 1, but was told by Consultant Physician 1 that he 'washed his hands of the business'.

40. Mr C told me that he then contacted the psychiatrist at NHS Hospital 1 and was advised that they were aware of Mr A's case, but had lost his paperwork, and that in any event they could not accept a referral from a GP. Mr C said he then contacted the LTU at NHS Hospital 1 and was advised that no formal referral had been received and that this would have to be sent by an NHS Greater Glasgow consultant.

41. Mr C said that Consultant Physician 1 never seemed to be concerned about Mr A and admitted to him that he did not know what to do.

42. Mr C told me that the family had arranged a private appointment for Mr A with a Consultant Hepatologist on 13 November 2003. At this appointment Mr C told me that Mr A was advised that he should be seen by the LTU at NHS Hospital 1 but should stay in hospital until such time as a transplant was arranged. Mr C said Mr A was in fact discharged and readmitted to Gartnavel Hospital on several occasions.

43. Mr C told me that on 8 December 2003 he was informed by Consultant

Physician 1 that arrangements were in hand to admit Mr A to NHS Hospital 1 'possibly within a week'. Mr A received a letter from NHS Hospital 1 on 17 December 2003 confirming his referral but with no specific timescale for admission. On 8 January 2004 Mr C called NHS Hospital 1 to check what was happening and was advised that Mr A would be admitted on 11 January 2004.

Evidence from the medical correspondence

44. In his letter of 24 September Consultant Gastroenterologist 1 suggested to GP 1 that if he wished to pursue Mr A's case for transplant then the next step would be to arrange a further psychiatric opinion and offered to arrange a review by Consultant Psychiatrist 3. On 1 October 2003, GP 1 accepted this offer. In fact by this time Consultant Psychiatrist 3 had already become involved because of the correspondence with MSP 1 and had written to GP 1 on 29 September 2003 with his review of the position. Consultant Psychiatrist 3 set out the possible options, including a further psychiatric opinion from an alcohol expert. GP 1 wrote to Consultant Psychiatrist 3 on 15 October 2003 suggesting a name. Consultant Psychiatrist 3 accepted this suggestion in a letter dated 30 October 2003 and suggested GP 1 make the arrangements (although he also offered to do so).

45. On 16 October 2003 Consultant Physician 1 wrote to GP 1 with a review of Mr A (following a hospital admission). In this letter he noted that the family were pursuing a further psychiatric opinion with SLTU and raised the question of whether a review by another Transplant Unit might be preferable. Mr C discussed this by telephone with Consultant Physician 1 on 24 October 2003 and it was agreed Consultant Physician 1 would approach a psychiatrist from the LTU in NHS Hospital 1.

46. In a letter to Mr C dated 7 November 2003, Consultant Physician 1 wrote that he had made contact but had had no direct response from the psychiatrist. He passed on the details to Mr C and suggested he might contact the psychiatrist directly to arrange a review.

47. On 8 November 2003 (prior to receipt of the letter referred to in the previous paragraph), Mr C wrote to Consultant Physician 1 informing him that a private appointment had been arranged for Mr A with a Consultant Hepatologist in London

on 13 November 2003. The letter also repeated the request for Consultant Physician 1 to arrange a review from the psychiatrist at the LTU in NHS Hospital 1.

48. On 13 November 2003 (after receipt of the letter referred to in the previous paragraph), Consultant Physician 1 wrote to GP 1 expressing concern that they were acting at cross purposes as Mr A was being reviewed in London while he had been trying to arrange the review at NHS Hospital 1. Consultant Physician 1 indicated he would step back from any further arrangements.

49. On 19 November 2003, the London Consultant Hepatologist wrote to Consultant Physician 1 with a summary of his views and offering a possible further review in London if the psychiatric review from NHS Hospital 1 was unfavourable.

50. On 10 December 2003, Consultant Physician 1 wrote to NHS Hospital 1 with a copy of the Discharge Summary from SLTU. The letter stated that NHS Hospital 1 had indicated that a psychiatric review could not be given without a full review and requested such a review. The letter also indicated that Mr A's condition was 'frail' and he may not be able to travel.

Consultant Physician 1's evidence

51. In response to my enquiries Consultant Physician 1 commented that he was aware of the family's concerns regarding the SLTU assessment and had suggested seeking the opinion of a specialist unit elsewhere. He had tried to contact the psychiatrist there but as he was not having any success, had suggested to Mr C that he might make the approach directly. Consultant Physician 1 stated that he had not been aware of the arrangements being made to have Mr A reviewed in London and withdrew from organising the referral to NHS Hospital 1 to avoid the situation becoming overly complicated. He did not regard this as 'washing his hands' of the matter and stated that patients in his care are often seen by other doctors at the same time and he does not consider this to be a problem. Consultant Physician 1 said that he felt that the best person to co-ordinate matters at the time was GP 1. He denied being unconcerned but stood by his view that everything possible had been done for Mr A, leaving him with no other course of action to suggest.

52. Consultant Physician 1 commented that Mr A's physical condition was such

that it was exceptionally difficult to balance between removing fluid with diuretics and causing an increase in swelling. Fluid may leak from the site of the abdominal tap used to drain the fluids but this is not in itself a reason for readmission.

53. Consultant Physician 1 also referred to the difficulties experienced by staff dealing with Mr A, who was noted to be resistant to co-operating with staff on a number of occasions in the medical and nursing records. This included an unwillingness to wash and move from his bed when nursing staff wanted to change the sheets.

54. In response to a further enquiry Consultant Physician 1 told me that he does not normally note an overall plan in the case sheet of any patient but follows the advice from the SLTU in terms of referral for consideration for transplant. He noted that it had been suggested to Mr A that he might be referred to a psychiatrist for assistance with abstinence but Mr A had indicated that he did not wish to pursue this.

55. In response to the draft of this report the Board advised me that they have a policy for obtaining a routine second opinion but that they generally regard the opinion of a supra-regional unit like the SLTU as final. Consultant Physician 1 would expect the Transplant Unit to have appropriate lines of referral.

The Adviser's evidence

56. The Adviser told me that the recorded clinical information is somewhat basic at times but generally provides a reasonably comprehensive account of Mr A's illness. The notes do not fall below a standard to be expected.

57. The Adviser noted that day-to-day management is duly recorded but there is no clear statement of the overall management plan with respect to longer term aims, eg in respect of assistance with abstinence or referral for transplantation. There is also no recorded evidence of any discussions with Mr A or his family. The Adviser told me that there is evidence within the record that Mr A was a challenging patient who was at times non-compliant with treatment and behaviourally disturbing.

58. The Adviser commented that Mr C's perception that Consultant Physician 1

was unconcerned at the severity of Mr A's condition is not borne out by the standards of effort and care indicated by the clinical record. The Adviser found no evidence that Mr A's treatment fell below a standard to be expected.

59. The Adviser commented that Consultant Physician 1 was arranging an appropriate further review in response to the family's distress when the situation became confused for him by other referrals elsewhere.

Other Evidence

60. The General Medical Council Guidance *'Good Medical Practice'* states (amongst other things) that the duties of a doctor include 'referring the patient to another practitioner, when indicated'.

61. The NHS Scotland publication *'The NHS and You*', published in June 2005, states 'You can ask for a second opinion at any time during your care'.

(b) Conclusion

62. It appears from the extensive correspondence contained in the medical records that there was a lack of clarity about the way ahead for Mr A following his negative assessment by SLTU as there was no agreed route for further referral. There was no clear understanding of the way ahead either between the many doctors involved in caring for, and reviewing, Mr A's care and Mr A's family. There was a clear willingness to obtain further review and referral on the part of all the medical personnel. Unfortunately on some occasions the attempts to be helpful only served to confuse matters and left Mr A's family struggling to try and clarify matters. The lack of a known route for a referral for a second opinion did lead to delays in the referral being made. It is not possible to say whether or not these delays were significant for Mr A or whether a further referral would have led to an alternative decision.

63. Mr A's condition, without transplant, was terminal and deteriorating. There were few, if any, options open to medical staff. Mr A was often noted to be uncooperative with staff who consequently struggled to provide appropriate nursing care.

64. The care and treatment Mr A received from NHS Greater Glasgow was

appropriate. However there was no clear plan for Mr A following negative assessment by SLTU and this led to a delay in the referral for a second opinion. I, therefore, to this extent, partially uphold this complaint.

65. This conclusion and that reached in complaint (a) both highlight the particular problem that arises in liver transplantation where the original opinion in effect denies life saving treatment to a patient, with inevitable fatal consequences. When the time taken to obtain a second opinion is so critical it is essential both that a patient is proactively made aware of this entitlement and that the mechanism for obtaining such an opinion is clearly known and understood by all parties.

(b) Recommendation

66. In light of this conclusion the Ombudsman recommends that NHS Greater Glasgow ensure that the new process for obtaining an appropriate second opinion established by SLTU for patients negatively assessed for liver transplant, is made known to the relevant clinical staff.

(c) Greater Glasgow NHS Board failed to respond to Mr C's complaint in a timely manner.

67. Mr C complained that he had raised the issues of his complaint with NHS Greater Glasgow in a report dated 29 September 2004 when he requested a copy of Mr A's medical records. He met with complaint staff in January 2005 to formally lodge a complaint but heard nothing more until he chased matters up in May 2005.

68. I contacted the complaints officer responsible for Mr C's complaint at NHS Greater Glasgow (Complaints Officer 1) in June 2005 who acknowledged that she had not contacted Mr C after the relevant elements of his complaint had been forwarded to NHS Lothian. She apologised that this had happened and asked me to convey her apology to Mr C.

69. The NHS Complaints Procedure expects that a complainant will receive an acknowledgement of their complaint within three working days and a full response (or, if not, an explanation why not) within 20 working days.

(c) Conclusion

70. There was a failure to provide a response or explanation within 20 working

days. I, therefore, uphold this aspect of the complaint. I note, however, that once the failure was recognised, the complaints staff readily acknowledged the error and apologised. I do not consider there was any failure in this case, but rather that it reflects the inherent complexity of complaints that cross more than one NHS organisation.

(c) Recommendation

71. The Ombudsman welcomes the actions of complaints staff in personally acknowledging and apologising for the delay. In light of this conclusion the Ombudsman recommends that the Board provide Mr C with a written apology for the acknowledged delay in responding to his complaint.

72. In summary, I have concluded that the recognised national shortage of donor organs necessitates a very stringent protocol for assessment of patients for liver transplant. The evidence shows that Mr A's assessment was clinically appropriate. However, I concluded that the lack of family involvement was not properly recorded and contributed to the delay which prevented Mr A obtaining a second opinion. I have also concluded that NHS Greater Glasgow provided appropriate treatment but failed to provide timely planning for Mr A following his negative assessment by SLTU. I also concluded that NHS Greater Glasgow failed to deal with Mr C's complaint in accordance with the NHS Complaints Procedure. In the light of these findings, the Ombudsman recommends that NHS Greater Glasgow apologise to Mr C for their failure and that NHS Greater Glasgow and NHS Lothian make a number of specific procedural changes (as outlined in the Redress and Recommendation section of this report).

73. Greater Glasgow and Clyde NHS and NHS Lothian have accepted the recommendations and will act on them accordingly.

26 September 2006

Annex 1

Explanation of abbreviations used

Mr C	The complainant (Mr A's uncle)
Mr A	The aggrieved
SLTU	Scottish Liver Transplant Unit, based in the Royal Infirmary of Edinburgh
The Adviser	The medical adviser
MSP 1	Mr A's Member of the Scottish Parliament
ALD	Alcohol liver disease
Consultant Psychiatrist 1	The psychiatrist who assessed Mr A at SLTU
Consultant Physician 2	The physician responsible for Mr A during his assessment at SLTU
NHS Hospital 1	The NHS hospital in England where Mr A was referred for a second opinion
Consultant Surgeon 1	The surgeon responsible for Mr A during his assessment at SLTU
Consultant Psychiatrist 2	The psychiatrist in Greater Glasgow NHS who reviewed Mr A after his negative assessment by SLTU
Consultant Gastroenterologist 1	The doctor at SLTU who corresponded with GP 1 following Mr A's negative

	assessment at SLTU
Consultant Psychiatrist 3	The psychiatrist who reviewed the decision of Consultant Psychiatrist 1 at SLTU
Consultant Physician 1	The physician responsible for Mr A's treatment at NHS Greater Glasgow
Complaints Officer 1	The complaints officer responsible for Mr C's complaint at NHS Greater Glasgow

Annex 2

Glossary of terms

Ascites	Accumulation of fluid in the abdomen.
(End Stage) Liver failure	When the damage to the liver reaches the stage when the liver can no longer maintain its normal functions, the liver begins to “fail”. Ultimately this is terminal.
Spironolactone	A diuretic.