Health Service Commissioners Act 1993

Report by the Health Service Ombudsman for England of an investigation into a complaint made by Mr Nic Hart

6 December 2017

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Report by the Health Service Ombudsman for England on an investigation into a complaint made by

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Complaint about: Cambridgeshire and Peterborough NHS Foundation Trust
UEA Medical Centre
Norfolk and Norwich University Hospitals NHS Foundation Trust
Cambridge University Hospitals NHS Foundation Trust
North Norfolk Clinical Commissioning Group
NHS England

Introduction

1. Mr Hart complained to us[1] about the care and treatment provided for his 19 year old daughter Averil, who died on 15 December 2012 following a four year history of anorexia nervosa. He complained about the care provided by Cambridgeshire and Peterborough NHS Foundation Trust, UEA Medical Centre, Norfolk and Norwich University Hospitals NHS Foundation Trust, Cambridge University Hospitals NHS Foundation Trust and said that Averil died as a result of this. Mr Hart also complained to us about the response he received to his complaint about Averil's death from each organisation that cared for her, along with NHS England and the local clinical commissioning group. He also complained that the local clinical commissioning group failed to proactively supervise or quality control the community eating disorder service provided by Cambridge and Peterborough NHS Foundation Trust.

2. Four months before her death, Averil was discharged from inpatient care to outpatient services in Norfolk in line with her wish to begin an undergraduate course at the University of East Anglia. In the period following her discharge, Averil was seen by a GP and eating disorder service in the community. In the final days of her life she was admitted to two different hospital trusts.

[1] The complaint was submitted by Mr Hart on behalf of Averil's family.

3. We find that every organisation that provided care for Averil failed in some way. Cambridge and Peterborough NHS Foundation Trust and UEA Medical Centre missed opportunities that might have prevented her further deterioration from anorexia nervosa. Norfolk and Norwich University Hospitals NHS Foundation Trust missed opportunities to prevent her condition deteriorating further. This meant that she was in a severely weakened state and critically ill when she was transferred to Cambridge University Hospitals NHS Foundation Trust. Finally, we find that had Cambridge University Hospitals NHS Foundation Trust adequately assessed Averil's condition and provided treatment for her severely depleted glucose level she would not have died on 15 December 2012.

4. We also find that the response from the NHS was at points insensitive and defensive, and ultimately insufficiently open to support learning. This meant it has required huge effort and perseverance on the part of Averil's family to try and get answers to their questions. These failings understandably led to Mr Hart feeling profound frustration with the NHS organisations and exacerbated his and his family's deep distress resulting from Averil's avoidable death.

5. In this report we set out our findings in detail.

A brief background to anorexia nervosa[2]

6. Anorexia nervosa is a serious mental health condition. It is an eating disorder in which people keep their weight at unusually low levels by restricting the amount of food they eat, making themselves vomit, using laxatives, or exercising excessively. The exact causes of anorexia nervosa are unclear. It most commonly affects women, and on average the condition first develops at around the age of 16 to 17.

7. People with anorexia nervosa often go to great lengths to hide their behaviour from family and friends and do not seek help. Once in treatment, it can take several years to fully recover and relapses are common. Treatment usually consists of a combination of psychological therapy and individually tailored advice on eating and nutrition to help the person gain weight safely. This is mostly delivered in an outpatient setting, but inpatient treatment can be recommended for very ill patients. Around half of people with anorexia nervosa will continue to have some level of eating problem despite treatment and, sadly, anorexia nervosa is one of the leading causes of mental health-related deaths.

Local context

8. Averil's death from anorexia nervosa in 2012 followed that of another young woman in Norfolk four years earlier, in 2008. The Coroner's inquest into this earlier death found that inappropriate delays in acting on the initial referral to the mental health team and arranging an appointment with the mental health nurse reduced the likelihood of a recovery from the illness, prompting the Coroner to write to Norfolk and Waveney Mental

[2] Sources include http://www.nhs.uk/Conditions/Anorexia-nervosa/Pages/Introduction.aspx; http://b-eat.co.uk.

Health NHS Foundation Trust and NHS Norfolk under the provisions of the Coroners' Rules 1984[3]. This led to the setting up of the Norfolk Community Eating Disorders Service[4] (NCEDS).

The complaint

9. Mr Hart complains about the care provided for Averil by Cambridgeshire and Peterborough NHS Foundation Trust, UEA Medical Centre, Norfolk and Norwich University Hospitals NHS Foundation Trust, and Cambridge University Hospitals NHS Foundation Trust, following her discharge to outpatient services after an eleven month inpatient admission for treatment for her severe anorexia nervosa. Averil's family believe that failings in this care resulted in her death.

10. Mr Hart also complains about the failure of the organisations involved, along with North Norfolk Clinical Commissioning Group and NHS England, to respond appropriately and adequately to Averil's family's complaints regarding her death. He says that the process has been frustrating and unnecessarily painful.

11. Averil's family are seeking to clarify what went wrong with her care. They would like an apology for the mistakes made that led to her death and evidence that changes have been made for the benefit of other patients in the future.

12. The full complaint we received from Mr Hart, on behalf of Averil's family, is set out at Annex A of this report.

Our role[5] and approach

13. We have set out our role and approach to considering complaints, and the relevant standards for this case, in Annex B of the report.

Our investigation

14. We have considered Averil's clinical records and the papers relating to the local resolution of the complaint from each organisation investigated. We have also considered the evidence given to us by Mr Hart.

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[3] Rule 43(1) provides that '*where* –

a) a Coroner is holding an inquest into a person's death;

b) the evidence gives rise to a concern that circumstances creating a risk of other deaths will occur, or will continue to exist, in the future; and

c) in the Coroner's opinion, action should be taken to prevent the occurrence or continuation of such circumstances, or to eliminate or reduce the risk of death created by such circumstances, the Coroner may report the circumstances to a person who the Coroner believes may have power to take such action.'

[4] The Norfolk Community Eating Disorder Service (NCEDS) is part of Cambridge and Peterborough NHS Foundation Trust.

[5] Our role is formally set out in the *Health Service Commissioners Act 1993*.

15. We have met with Mr Hart on several occasions, and we have interviewed relevant members of NHS staff. Additional evidence obtained during the investigation from some of the organisations is in Annex C to this report.

16. We have taken advice from nine clinical advisers:

- A GP (the First GP Adviser)
- A GP (the Second GP Adviser)
- A consultant psychiatrist (the First Psychiatrist Adviser)
- A consultant psychiatrist (the Second Psychiatrist Adviser)
- A clinical psychologist (the First Psychologist Adviser)
- A consultant clinical psychologist (the Second Psychologist Adviser)
- A nurse (the First Nurse Adviser)
- A nurse (the Second Nurse Adviser)
- A consultant gastroenterologist[6] (the Gastroenterology Adviser)

17. In their role as advisers they are completely independent of the NHS. All the information which has been relevant to our findings is set out in this report.

Averil's care and treatment – key events

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)

18. Averil was admitted to ward S3 on the eating disorders unit at Addenbrooke's Hospital[7] (the Eating Disorders Unit) on 19 September 2011, aged 18[8], with a three year history of anorexia nervosa. Averil had agreed to be admitted, and reported feeling increasingly unwell, with weakness and chest and leg pain.

19. Averil's weight was recorded the morning after her admission as 30.4kg, giving her a very low body mass index (BMI[9]) of 11.2. Her immediate needs were assessed as:

- refeeding[10];
- managing her low heart rate and blood pressure;
- correcting a number of blood abnormalities;
- providing phosphate and potassium supplements; and
- daily blood monitoring.

[6] Gastroenterology is the branch of medicine focused on the digestive system and its disorders.
[7] Addenbrooke's Hospital is part of Cambridge University Hospitals NHS Foundation Trust. However, the Eating Disorder Unit, although based at Addenbrooke's, is part of Cambridge and Peterborough NHS Foundation Trust.
[8] During her period as an inpatient, Averil's family attended family days on the ward. Mr Hart has told us that during these, NCEDS staff referenced the case of the young woman who had died from anorexia nervosa a few years before (paragraph 8), saying that the service was much improved after this previous tragedy and that *"it could not happen again"*.
[9] Body mass index (BMI) is an index of body weight in relation to height that applies to adult men and women. The normal range is between 18.5 and 24.9kg/$m^{2.}$
[10] Refeeding is the process of giving nutrition to undernourished patients. It requires careful management to mitigate the risk of refeeding syndrome.

20. A month after her admission Averil's weight had increased and her BMI rose to 12.9, with indications that her overall condition was improving. This was followed however by some weight loss and plateauing of weight (neither weight loss nor weight gain).

21. Overall, from mid-October to mid-December 2011 Averil did not put on weight. At this time Averil reported using a technique to manipulate her weight – in this case '*water loading'* - which meant drinking copious amounts of water and not going to the toilet before weighing. On 20 December Averil's weight was 35.1kg and her BMI was 12.7.

22. In January 2012 Averil's meal plan was increased. By the end of January 2012 she weighed 36.8kg, with a BMI of 13.5. In February 2012 her meal plan was increased again. For the next three and a half months Averil slowly gained weight, and there were no further suggestions that she was falsifying her weight by water loading. In April 2012 she received an unconditional offer from the University of East Anglia to read English and Creative Writing. The records say that this offer excited Averil and motivated her to recover.

23. At Averil's Care Programme Approach[11] (CPA) review meeting in May 2012 it was agreed that her care would transfer to NCEDS in preparation for starting university, rather than to the local Suffolk Community Eating Disorder Service, followed by a second transfer to the Norfolk Community Eating Disorder Service (NCEDS). At her CPA review on 14 June 2012 Averil set herself a goal weight of 50kg by discharge on 1 August.

24. By mid-July 2012 Averil's weight was 44.5kg, (BMI of 16.3). At her CPA review on 12 July, Averil agreed that she would '*come back to the body image group and continue seeing* [the Eating Disorder Unit Psychologist] *in the interim*'. The Eating Disorder Unit Psychologist was the consultant clinical psychologist who had been providing therapy to Averil on the Eating Disorder Unit. She would continue to see Averil following her discharge, until Averil registered with a GP at the UEA Medical Centre (UEAMC) and was able to be seen by someone from NCEDS. Averil was discharged on 2 August 2012, weighing 45.2kg and (BMI of 16.6).

25. Averil's discharge summary noted that she was '*anxious about her discharge from ward S3*', but that there was '*no evidence of thought disorder or psychotic symptoms*'. The discharge summary explained the arrangements following her discharge. These included:

- a referral to NCEDS – her follow-up with the team was scheduled for when she started university in mid to late September, at which point a care coordinator would be appointed;
- that in the meantime, Averil would continue to work with the Eating Disorder Unit Psychologist; and
- that she would register with a GP at UEAMC as soon as she arrived.

[11] The Care Programme Approach (CPA) is a framework used to assess, plan, coordinate and review care needs. Patients should get a formal written care plan that outlines any risks – including details of what should happen in an emergency or crisis. This is managed by a CPA care coordinator.

26. The discharge summary also included the following instructions for UEAMC:

> '*Please check Averil's physical health every week (weight, BP* [blood pressure]*, heart rate and level of physical strength – Squat test*[12]*). This can be done by a nurse. Please monitor her bloods every 2 or 3 months, including U&Es*[13]*, bicarbonate*[14]*, LFTs*[15]*, bone profile*[16]*, muscle CK*[17]*, magnesium*[18] *and phosphate*.[19]'

From discharge to arrival at university

27. Averil met with the Eating Disorder Unit Psychologist on 9 and 30 August. At the second appointment the Eating Disorder Unit Psychologist documented *'weight stable 44kg'* and that Averil felt like she was *'stuck'*, on the one hand trying to *'push self'* while on the other, *'staying the same'*. Averil went on holiday abroad with her family, and cancelled an appointment booked with the Eating Disorder Unit Psychologist for 12 September. On 19 September Averil saw her GP in Suffolk, when her weight was recorded as 42.8kg, a drop of 2.4kg since her discharge from hospital.

28. On 20 September Averil saw the Eating Disorder Unit Psychologist and explained that she was going to university on Sunday 23 September and that she would register with a GP on the Monday and arrange to meet with a member of the university's Wellbeing Centre. Her weight was recorded as 42.6kg and the notes say that she was working at eating out more frequently.

29. On 21 September the Eating Disorder Unit Psychologist wrote to the NCEDS Consultant Clinical Psychologist (a consultant clinical psychologist at NCEDS) explaining that she had met Averil and discussed the plans for her care. The letter set out Averil's weight loss since discharge and explained that she had said she had lost some weight while on a family holiday, but was *'working hard to regain it'*. The Eating Disorder Unit Psychologist noted the need for Averil to do less exercise and be flexible in her routines. She also noted that she had explained to Averil that there would be a delay in allocating a therapist at NCEDS, and had committed to *'bridging the gap'* in the meantime, although *'given* [Averil's] *timetable* [they] *could only arrange telephone contact but* [this was]

[12] A test to measure muscle strength where the person is asked to squat and then stand up without using their hands.
[13] Urea and electrolytes - this blood test provides information about how the kidneys and other body systems are functioning.
[14] Bicarbonate levels provide a measure of the acid-base balance of the blood. This might be done if a doctor suspects that fluid is being retained or the patient is dehydrated.
[15] LFTs (liver function tests) – measurements of enzymes and other proteins in the blood which provide information about how the liver is functioning.
[16] A blood test which measures proteins; minerals and enzymes to assess bone turnover.
[17] Measurement of blood creatinine kinase, an enzyme. This blood test measures the amount of an enzyme called creatinine kinase (CK) in the blood. Levels of CK can rise after a heart attack, skeletal muscle injury, strenuous exercise, or drinking too much alcohol, and taking certain medicines or supplements.
[18] Measurement of the blood level of magnesium, which may be reduced in people who are malnourished.
[19] Measurement of blood phosphate which may be reduced in people who are malnourished (where their diet does not contain the right amount of nutrients to meet their body's demands).

better than nothing'. She asked NCEDS to add Averil to the list *'for the new starters'* as she felt that Averil needed to be *'picked up for CBT*[20] *as soon as possible'*.

30. On 27 September the Eating Disorder Unit Psychologist had a telephone conversation with Averil during which she said that she was *'doing well',* that her flatmates were *'nice'* and that she was trying to ignore *'the voice*[21]*'*. Averil confirmed that she had booked an appointment with a GP at UEAMC.

31. The Eating Disorder Unit Psychologist wrote to UEAMC on the same day and enclosed a copy of the King's College Guidelines *'A Guide to the medical risk assessment for eating disorders'* (2009)[22]. The Eating Disorder Unit Psychologist included a copy of Averil's discharge summary, which set out the requirements for monitoring (paragraph 26). She noted that she would be '*grateful for* [their] *medical monitoring of* [Averil] *who was recently discharged from hospital in Cambridge*', and that until Averil was *'picked up by the Norfolk Community Eating Disorder Service in Norwich,* [she] *would be her care coordinator*[23]*'*. She said that she wanted the '*safety net of* [the] *medical centre and hopefully a named GP for* [Averil]'. On the same day, the Eating Disorder Unit Psychologist telephoned UEAMC and explained the above, highlighting Averil's vulnerability and the fact that coming to university was *'potentially* [a] *dangerous time for her'*.

32. Averil's UEAMC records say '*first GP please bear the above in mind*'. On 2 October, following receipt of the King's College Guidelines and Averil's discharge summary, a further entry in Averil's UEAMC records reads '*please see recommendations in attached document about monitoring*'.

33. Averil submitted a new patient registration form to UEAMC on 29 September, in which she noted her weight was 42.2kg (BMI of 15.5). Her first appointment was on 5 October, and was a new patient health check with a healthcare assistant. Her weight (42kg), BMI (15.4) and blood pressure (103/67mmHg) were recorded.

34. On 4 October, the Eating Disorder Unit Psychologist had a further telephone call with Averil. She documented that Averil was setting *'goals for wellbeing',* that she was *'sitting down more'* and accepting unplanned food. The notes say that Averil's weight had gone down.

35. On 12 October Averil had an appointment with a GP at UEAMC. The GP recorded that Averil had an appointment arranged with NCEDS on 19 October, and that she was *'feeling well'* and *'settling into uni life well'*. Her weight was recorded (41kg) and a plan was set

[20] CBT (Cognitive Behavioural Therapy) is a type of psychological treatment that focuses on how thoughts, beliefs and attitudes affect the person's feelings and behaviour, and teaches coping skills for dealing with different problems.
[21] A feature of anorexia can often be the emergence of an internal 'anorexic voice' associated with eating disordered thoughts and feelings, which appears to offer a negative self-critical commentary on thoughts and actions.
[22] See Annex B, paragraphs B13 to B15.
[23] A care coordinator is the person responsible for assessing needs, developing a care plan and coordinating care to meet those needs. They should regularly review the care plan and monitor progress. Care coordinators can be social workers, community psychiatric nurses or occupational therapists.

out to *'check bloods, do forms next week'* and for Averil to see the same GP the following week after her appointment with NCEDS.

Start of treatment with NCEDS

36. During September, emails between the Eating Disorder Unit Psychologist and the NCEDS Consultant Clinical Psychologist show that NCEDS were recruiting staff and struggling to allocate a therapist to patients waiting to be seen. On 2 October, Averil was allocated to the NCEDS Care Coordinator (a trainee counselling psychologist[24]) at NCEDS. On 15 October the Eating Disorder Unit Psychologist spoke to the NCEDS Care Coordinator to provide background information about Averil and hand over her care.

37. Averil had her first session with the NCEDS Care Coordinator on 19 October. At this point, the NCEDS Care Coordinator became Averil's care coordinator. She documented that Averil was feeling *'nervous'* and *'anxious'* about treatment, and that her weight had fallen to 39.2kg (BMI 14.4). The notes say Averil was *'surprised'* and *'disappointed'* by her BMI because it was even lower than her previous weekly GP weigh-in. The NCEDS Care Coordinator noted that Averil attributed this additional loss of weight to '*starting university and post-inpatient experience'*. The notes also say that at this point Averil *'became tearful'* because she was *'afraid of the work involved in beating her* [eating disorder]*'*. They discussed what Averil had eaten the previous day and she admitted that she was *'not having her afternoon snack recently, nor a biscuit before bedtime'*. They also talked about Averil's *'compensating behaviour'* [over activity], the fact that she felt *'anxious when needing to sit still for any period'*, and that this was particularly difficult when attending lectures.

38. The NCEDS Care Coordinator advised Averil to continue with GP weekly monitoring, and recorded the following treatment goals:

- *'Normalise activity levels'*;
- lift mood (anxiety);
- longer term goal of not restricting food or calculating calorie intake; and
- *'Be more of the old me'* which Averil described as being *'funny, singing, engaging in physical activity for FUN ONLY'*.

39. The NCEDS Care Coordinator wrote that Averil said she was not binging or vomiting, nor was she using laxatives. They agreed that the next session would be on 26 October 2012 and Averil was given food diaries to complete daily.

40. Averil emailed the GP she had seen at UEAMC the next day with the following update:

[24] Although referred to correctly as *'trainee'*, The NCEDS Care Coordinator was in fact qualified but waiting for registration. She completed her final exam on 31 October 2012 and on 26 February 2013 the HCPC confirmed her registration as a qualified counselling psychologist.

'*Dear Dr* [],

My name is Averil Hart and I am a first year undergraduate at the University of East Anglia. I met with you in the afternoon of Friday 12th for our first appointment and planned to meet in weekly [sic] *for my weight to be monitored as part of my Eating Disorder support.*

Yesterday, Friday 19th, I attended my first appointment with the [Norfolk Eating Disorders Service] *who will be taking over my care whilst I'm at university and* [have] *arranged a weekly CBT session as well as weight monitoring. It was a very positive first visit and I feel that they will be able to offer me a lot of support and everything that I need to move forward and keep progressing well at University. I thought that you would like to be kept up to date as I was unable to make an appointment with you yesterday afternoon as a result – I have re-arranged this for the next available slot which is next week.*'

41. On 25 October Averil attended an appointment at UEAMC. A locum GP noted her weight (41kg), BMI (15.1), blood pressure (95/65mmHg) and heart rate (55bpm regular). The notes say that Averil experienced *'no problems with squat test'* and that she was *'struggling with work'* but was being supported by NCEDS and a mentor from the university. She said she was *'managing to eat regularly'* and was *'maintaining her weight'*. The locum GP confirmed with Averil that she had also started Cognitive Behavioural Therapy (CBT) the previous week which *'she found really helpful'*. The locum GP recorded *'Seeing* [N]*CEDS weekly now so review with GP in 2 weeks'*.

42. Averil had her second appointment with the NCEDS Care Coordinator on 26 October 2012. Averil shared her food diaries with her which showed that *'overall* […] *total food intake* [was] *not sufficient to effectively increase weight'*. The NCEDS Care Coordinator recorded that Averil's weight had increased by 0.4kg (39.6kg, BMI of 14.56). They explored the need for Averil to have an afternoon snack, particularly on days when lectures allowed this. They also talked about Averil's anxiety and her higher goals, which included getting her degree, not going back to hospital and getting her periods back.

43. The same day, the NCEDS Care Coordinator wrote to Averil and UEAMC setting out her care plan, and the treatment that NCEDS would be offering. It included many of the things which had been discussed in the previous two sessions (for example reintroducing afternoon and pre-bedtime snacks, managing anxiety and focusing on longer term goals such as graduating and staying out of hospital). It reaffirmed the importance of continued medical monitoring by UEAMC, but explained that *'these GP visits do not need to include taking your weight'* because this could be done at their weekly sessions to *'avoid the confusion of daily fluctuations in weight and between differing scales'*.

44. On 2 November Averil had her third appointment with NCEDS. The NCEDS Care Coordinator documented that Averil was suffering from a cold, but was not feeling ill enough to stay home. Averil explained that she had been to London and that this had impacted on her eating and her anxiety. The notes say that overall Averil reported keeping to the plan of afternoon snacks on four days, but admitted to compensating by increasing her activity. Her weight had gone down by 0.2kg, and it is documented that

Averil was *'realistic in prediction of weight before weighing and acceptance of weight fluctuations'*. The notes say that from the next session they would work on four weekly averages to *'chart weight trajectory'*. Aims for the week ahead were recorded as (1) increase afternoon snacks, and (2) to sit and relax for at least 30 minutes every evening.

45. On 8 November Averil attended a GP appointment at UEAMC. She again saw the locum GP. She was not weighed following the instruction from NCEDS. Her heart rate was documented (55bpm regular). A note was made to *'review in a month'*.

46. On 9 November Averil had her fourth session with the NCEDS Care Coordinator. The notes state that Averil said she felt the previous week had been *'positive'* and *'productive'*, and that she attributed this to *'enjoying some of her food and having enough energy to accomplish tasks'*. Her weight had gone down (38.6kg) and the notes say that Averil was *'visibly upset by this'*. They talked about using four week averages to discuss progress versus fluctuations, and *'revisited'* her food diaries. Averil admitted to eating five or six times a day, but mainly low calorie content foods which were *'insufficient to affect weight'*. They agreed a plan for additional snacks every day the following week. Averil admitted to having difficulty relaxing, which she attributed to poor planning and low self-compulsion. The notes of this appointment say that they discussed how Averil *'deserved to rest'* and *'put on healthy weight'* and how Averil selected giving the *'critical voice'* an *'unattractive accent'*.

47. On 16 November Averil had her fifth session with NCEDS. The weight chart shows that her weight was the same as the previous appointment – 38.6kg. Averil said that she had experienced some *'emotional distress'* and admitted that this had *'impacted on eating plan, with some afternoon snacks missed'*. She said that she had managed her 30 minutes rest on every day bar one when she was out *'happily socialising'*.

48. Averil also described *'heightened distress'* on a day when she had overslept by one hour. Although this did not cause her to miss any appointments or lectures, it did trigger *'criticism of self as a failure'*. This sparked broader concerns for her, including how she would cope at home over Christmas and *'being around family's scrutiny'*. She agreed with the NCEDS Care Coordinator that they would consider this in the remaining sessions before Christmas. The notes also say that Averil suggested ways of making her afternoon snack more substantial. The session ended with Averil talking about a *'tug of war'* in fighting against her eating disorder, and that she needed to use *'inner strength to actually win'*. They agreed that they needed to update her care plan and would do this at the next session.

49. On 23 November Averil attended her sixth session with the NCEDS Care Coordinator. The notes of this appointment say that she had experienced another *'up and down'* week, but that overall she had made *'progress in eating with more substantial snacks'* and having snacks every day, while *'developing strategies for overcoming indecisiveness/anxiety in selecting snacks each day'*. The notes also say that Averil's *'compensatory activity'* continued and her food intake had reduced over the weekend as she did not have the usual control over her routine. The notes record that Averil had lost a further 0.4kg, and now weighed 38.2kg, and that she was *'very disappointed when she saw'* this. During the meeting there was some discussion about why she had lost more

weight, and Averil *'admitted to doing more formal and informal activity than always revealed'*. They also discussed Averil's thoughts about activity, and how she realised that while doing more activity stopped her from gaining weight, it also made her feel exhausted, and this she said had a knock-on effect on her concentration at university. She said that she realised that the one day when she had rested she had felt much better and more alert.

50. The notes record that Averil *'made a commitment to give herself a break from swimming'* as this left her very tired. Averil's care plan was updated to include a goal about activity and regaining weight. It also included Averil's reflection about managing her eating disorder voice. She said that when her eating disorder first started she had *'far less in her life and therefore* [her eating disorder] *stopped her sense of loneliness'*. However, Averil was able to *'recognise that she had flatmates, …, supportive family, UEA course, all of which she loves'* and that these things offered her *'an alternative to addiction of anorexia'*. They also discussed that the NCEDS Care Coordinator would not be available for the session the following week, and Averil identified two actions: *'more ballsy snacks every day and increasing portion size of evening'*.

51. On 28 November Mr Hart and Averil's sister visited Averil at university. Mr Hart says that they were both shocked by her appearance (her last recorded weight five days earlier was 38.2kg), which seemed worse than when she had been admitted to hospital in September 2011. Mr Hart said that he was so concerned by Averil's appearance and slurred speech that he made an emergency call to the Eating Disorder Unit to convey his concern[25]. Mr Hart said he was reassured the following day when he received a telephone call telling him that action would be taken.

52. On 30 November, the NCEDS Lead Psychiatrist (a consultant psychiatrist and the lead clinician for NCEDS), sent an email to the NCEDS Care Coordinator and the NCEDS Specialty Doctor[26] which said:

> *'Averil's father visited her yesterday. He has not seen her in a month and was very concerned by her weight loss. He phoned the ward three times yesterday. I think she needs a medical review.* [The NCEDS Specialty Doctor]*, could you arrange to see her, please? With* [the NCEDS Care Coordinator] *if possible.'*

53. The records from NCEDS show that on 3 December, the NCEDS Care Coordinator called Averil to let her know that the NCEDS Specialty Doctor would be attending their appointment that Friday (7 December) for a *'medical review'*.

54. A further note on 5 December from the NCEDS Care Coordinator shows that she acknowledged the *'need to be on* [Averil's] *case to do things NOW! (danger of heading*

[25] In a subsequent email sent to the Eating Disorder Unit Lead Psychiatrist during local resolution, Mr Hart referred to this experience: *'I will never forget hearing your voice in the background when I called S3 to speak to you and I tried desperately to get help for Averil in those last days - you brushed my call aside and told the person answering the call…. "Tell him to call* [the NCEDS Lead Psychiatrist]"'.

[26] A specialty doctor is a career grade doctor, that is, one in a permanent non-training post but not a consultant.

back to S3[27])' and that they needed to *'stem this weight loss, use S3 weight chart to see reference points for her weight decline. Put to Averil weight loss since discharge (6kg)'*.

55. On 6 December Averil telephoned the NCEDS Care Coordinator in the evening and left a message to explain that she would not make their appointment the next day. The NCEDS Care Coordinator tried to contact Averil on 7 December, however, she did not answer her phone.

Admission and inpatient treatment at Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)

56. On the morning of 7 December, a cleaner working at the university found Averil collapsed in her room. The cleaner called an ambulance and Averil was taken to the emergency department at the Norfolk and Norwich University Hospital[28], arriving at approximately 11am. Shortly after her arrival, a nurse carried out observations and recorded the results, which included a low temperature (33.1°C), low blood pressure (87/61mmHg) and low blood glucose (2.1mmol/L). A note in her records said *'anorexic collapsed low blood sugar[29]'*. Averil was seen by a different nurse at about 12.15pm, when she described being unable to eat recently because it caused abdominal pains. Averil said she had felt weak and had rested her head back, but *'her friends felt she collapsed'*.

57. A doctor saw Averil at 12.40pm. The doctor documented that Averil had been experiencing abdominal pains for six or seven days before admission. The notes say that Averil was extremely underweight ('*cachectic* ++'[30]) and hypothermic[31]. The doctor wrote that there had been a deterioration of her anorexia and that she was hypoglycaemic and the plan was to give a *'slow'* intravenous infusion of Hartmanns solution[32]. The notes show some discussion with Averil, who was very concerned that this was '*a nutritional supplement'*, but the doctor explained that it was not. Shortly after this, at 1.25pm, Averil's blood glucose had fallen to 1.1mmol/L and the doctor explained the risk of coma if her low blood sugar was not corrected. Averil agreed to a dextrose intravenous infusion. Staff offered Averil warm blankets to help increase her body temperature. But the notes state that she refused these (at 1.30pm)[33].

58. Staff transferred Averil to the hospital's acute medical unit (AMU) where she was reviewed by a doctor at 2.55pm. During the review Averil reiterated her complaint of abdominal pain. The AMU doctor documented that Averil was severely underweight and that she wanted to move around the bed and '[walk] *all the time'*. Averil told the AMU

[27] The Eating Disorder Unit.
[28] Part of Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH).
[29] Hypoglycaemia refers to a blood glucose below normal levels, which may result in loss of consciousness and if severe or prolonged, death. When blood sugar drops below 3mmol/l, this is hypoglycaemia which can result in loss of consciousness and in severe cases, be fatal. A prolonged hypoglycaemic coma occurs after profound hypoglycaemia lasting more than five hours.
[30] Weakness and wasting of the body due to severe weight loss.
[31] Hypothermia refers to a body temperature below the normal range.
[32] Hartmann's solution is used for rehydration by replacing body fluids and mineral salts.
[33] In the later review carried out by the author of the MARSIPAN guidelines (paragraph 247), he commented on page 3 that *'some patients with anorexia nervosa encourage their body temperature to be low, so that they will shiver and hence use more energy'*.

doctor that she did not *'feel that her anorexia nervosa* [was] *bad at the moment'* and instead suggested that her weight loss was due to *'freshers flu'*.

59. The AMU doctor also documented a discussion with Mr Hart. It says that Mr Hart was concerned that Averil was frailer than when she had been admitted to the Eating Disorder Unit a year earlier, that she was not allowing him to visit her, and that her family were concerned that she had not been acting herself. Mr Hart was concerned that Averil would be discharged. The AMU doctor documented telling Mr Hart that Averil would not be discharged until she had been given fluids to improve her kidney function and it had been seen to have improved. The doctor also told Mr Hart that Averil had not given them consent to discuss her medical care with him, although she had allowed the AMU doctor to talk to him and *'to hear his side of the story and explain to him about respecting her confidentiality'*.

60. The AMU doctor documented that Averil had acute kidney injury[34], hypoglycaemia and elevated liver function tests *'? iatrogenic*[35] [secondary to] *paracetamol, aspirin'*, as Averil had mentioned taking these in the days before her admission. The AMU doctor also noted *'concerns'* about confidentiality (in particular sharing information with her parents) and that she appeared to have suffered a relapse with her anorexia, including *'critical BMI'*.

61. Averil was reviewed by a consultant in the AMU at 4pm. The plan documented was to:

- admit her;
- give her intravenous fluids;
- carry out an echocardiogram[36] to assess a heart murmur[37] that had been noted; and
- refer her to the gastroenterologists.

62. At 4.20pm, the AMU doctor noted that the NCEDS Lead Psychiatrist had telephoned to find out about Averil's condition. The notes of this conversation say that the NCEDS Lead Psychiatrist had called because Mr Hart had been in touch and was very concerned, and because Averil had been due to meet with someone from NCEDS that day. The ward doctor who answered the call noted that he was able to say '*very little*' on the phone, and gave no information about Averil's condition other than that she had low glucose and had been admitted to the AMU. The ward doctor confirmed that Averil would not be discharged over the weekend, and it was agreed that someone from NCEDS would visit Averil on Monday 10 December.

63. At 6.15pm Averil was reviewed by a gastroenterology registrar. She was noted to have been *'Feeling more unwell* [in the] *last few days'*, *'constipated'*, *'very tired/lethargic'*, with '[symptoms] *of dyspepsia/reflux'*[38] but *'no vomiting'*. It was

[34] Acute kidney injury refers to damage caused to the kidney, for example by dehydration or low blood volume.
[35] Iatrogenic refers to a response, usually unfavourable, to medical or surgical treatment.
[36] An ultrasound scan of the heart.
[37] Where the heartbeat has an extra, or unusual, sound caused by a disturbed blood flow through the heart.
[38] Dyspepsia is indigestion and reflux is the backward flow of food and gastric juice into the oesophagus.

recorded that Averil's weight had dropped since she had been at university and that she felt her *'strength* [was] *on a downward trend'*. The registrar noted that Averil had been *'unable to get up off the floor without using* [her] *hands'*, where she *'could 2* [days] *ago'*, and that she *'had to lift own legs onto bed'*. Her weight 31kg (31.4kg according to the MUST[39] assessment chart) and BMI of 11 were recorded. The notes document another discussion with Mr Hart, during which he explained that he felt *'excluded'* and the registrar explained that it was important to *'maintain Averil's trust* [and] *make her safe'*. The notes also say that the registrar had spoken to a gastroenterology consultant (the First Consultant) and that they had seen Averil. A management plan was agreed with Averil, which included:

- intravenous fluids;
- intravenous vitamins;
- tazocin (a combination of two antibiotics);
- monitoring her bloods;
- monitoring her paracetamol level;
- N-acetylcysteine (a medicine used for treating paracetamol overdose); and
- Averil keeping a food chart.

64. The notes say that Averil became more settled during the night and was told that she could *'ask for anything she want*[ed] *to eat'*, but had not asked for anything.

65. On 8 December at 9.20am a different gastroenterology consultant (the Second Consultant) saw Averil. They set out a management plan which included:

- continuing her intravenous fluids and vitamins;
- continuing her treatment for possible paracetamol overdose poisoning; and
- adding another intravenous antibiotic.

They also asked for blood tests to look for other possible causes of her abnormal liver function and for monitoring her INR[40]. The registrar went to see Averil in the afternoon, but she was not by her bed.

66. That evening a nurse noted that Averil had *'opened up'* a lot and that she had been feeling much more positive because she identified that she had *'many goals in life that she want*[ed] *to get better for'*. The nurse noted that Averil had told her she had really tried to *'fight her disorder'* and that she had managed to eat small amounts at every meal. The nurse also noted that Averil was *'compliant with all treatment'*. At 8.15pm the records show Averil had *'refused any foods',* had *'started to become agitated at the mention of food',* and *'explained that she* [was] *fine'*.

67. On 9 December 2012, the Second Consultant reviewed Averil at 9am and documented that her kidney function was *'slightly better'*, but that not all the N-acetylcysteine had been given. They noted Averil was not at her bedside, and so they came back at 9.30am

[39] MUST stands for Malnutrition Universal Screening Tool.
[40] INR (international normalised ratio) is a measure of how quickly the blood clots which can be affected by liver disease.

when she had returned. Notes were made about Averil's low platelet count[41], which was explained to her. Averil said she was feeling better.

68. Nurses monitored Averil during the day and documented on four occasions that they had bleeped the on-call gastroenterology doctor[42] because:

- she needed repeat blood tests;
- they were finding it difficult to get blood pressure readings;
- she was hypothermic; and
- her early warning score (MEWS) was elevated[43].

69. Each time nurses called the doctor they documented that the doctor would *'repeat bloods later this am'* or *'will come and review', or 'will come and review shortly'*. At about 4.20pm that afternoon a further note says that Averil was *'spending lots of time in the bathroom, asking to be disconnected from IV'* and *'therefore IV running behind time'*. At approximately 7.15pm, the notes say that Averil had fallen. The notes (which are hard to read) say she *'explained that she tripped'* and had suffered *'a small laceration on her eyebrow'*.

70. At 7.30pm the gastroenterology SHO[44] (the SHO) reviewed Averil. The notes indicate that the review focused on Averil's fall and not the concerns raised by nurses throughout the day. Averil was noted to have described falling because she was carrying her iPad and, while *'walking backwards',* one foot had slipped and she had fallen. Averil said she had not been lightheaded or having palpitations before the fall, and that she had immediately felt back to normal. She also said she had not been experiencing any headaches, unusual disturbances, nausea or vomiting.

71. A nurse documented at 8.10pm that she had told Averil they had tried to contact her mother and Averil had *'refused* [for the nurse] *to give any information about what happened to her'*. The nurse noted Mr Hart had telephoned to find out what was happening and Averil had said she *'did not want to let her father know about the fall'*. Averil told the nurse that she would call her parents and let them know. The nurse documented that she had advised Averil *'to stay in bed to avoid further falls'*, but that Averil was *'adamant she* [was] *alright'*. Averil told the nurse she was *'20 years old* [and] *an adult'*.

72. The NCEDS Specialty Doctor saw Averil on 10 December at about 12.30pm. Her very low weight (30.9kg), BMI (11.11) and low blood glucose (1.1mmol/l) were noted. The NCEDS Specialty Doctor wrote that Averil was *'Not yet fit to be discharged from medical ward, at least until finished N-acetylcysteine'*. She also documented a discussion with Averil, during which Averil said her *'A[*norexia*] N[*ervosa*]* [had] *never been so strong,* [she] *had tried really hard but things slipped without realising it'*. Averil told the NCEDS

[41] Blood platelets form part of the blood clotting mechanism.
[42] The calls to the on-call doctor were made at 9.55am, 11.00am, 12.20pm and 3.42pm.
[43] A modified early warning score (MEWS) is a guide used to quickly determine the degree of illness of a patient. It is based on a number of physiological readings (for example, systolic blood pressure, heart rate, respiratory rate, body temperature) and observations (for example, level of consciousness).
[44] SHO (senior house officer) was a junior grade doctor, usually one in training.

Specialty Doctor that she wanted to *'recover but it's v*[ery] *v*[ery] *hard'*. Averil said she did not *'think* [she was] *well enough to do on own or for mum to cope with'*, and that she did not *'realise* [she was] *so medically unwell'*. Averil thought she needed to start her eating disorder treatment from hospital (for example, at the Eating Disorder Unit where she had been an inpatient previously) and that she knew her father wanted her there as well. The NCEDS Specialty Doctor said that it was Averil's decision whether to now be admitted to S3 ward.

73. The NCEDS Specialty Doctor talked to Averil about sharing information with her parents, and Averil said she wanted to *'be treated as an adult and be independent'*. However, Averil could also *'see that* [her] *parents worried about her and* [was] *prepared for* [doctors] *to share info*[rmation] *about medical status with parents'*. The NCEDS Specialty Doctor spoke to the NCEDS Lead Psychiatrist who confirmed that admission to the Eating Disorder Unit would be appropriate as soon as Averil's medical treatment was completed and it was safe to move her. They also discussed that if Averil was going to remain in Norfolk and Norwich Hospital *'for any length of time'*, NCEDS would liaise with the gastroenterology team about feeding, for example nasogastric feeding[45].

74. Averil was also reviewed by a dietitian that afternoon. The dietician noted that Averil had been *'seen by NCEDS'* and was *'likely for transfer … to Addenbrooke's* [eating disorders] *unit … tomorrow'*. They noted that they had *'not undertaken a thorough dietary assessment … given that* [Averil would] *be receiving specialist care within 24 hours'*. The dietician briefly discussed the foods Averil was happy to eat (green vegetables, berries, soya milk, half a yoghurt), but concluded that it would be *'most appropriate at present to withhold implementing a nutritional plan and to await the care of an experienced dietitian'*. They noted that if Averil remained at the hospital longer than planned, they would *'liaise with the gastroenterology team to determine nutrition plan'*.

75. A nurse documented at approximately 5pm that Averil was moving frequently around the ward and her vitamin infusion was *'running behind'*. They noted that Averil had been encouraged to eat, but she was refusing. Averil had been weighed and her weight had fallen to 30.2kg. Shortly afterwards, Averil had a hepatology review[46]. The advice given was:

- to check the results of a hepatitis E test which had been done;
- continue N-acetylcysteine;
- carry out an ultrasound scan of the liver; and
- test Averil for Wilson's disease[47].

A medical review around the same time showed worsening liver function.

[45] Nasogastric feeding is a technique whereby a narrow plastic tube is placed through the nose, directly into the stomach. Once in place the tube can be used to give liquid food directly into the stomach to provide nutrition.
[46] This was a review by a doctor specialising in the treatment of liver illnesses.
[47] Wilson's disease is a rare genetic disorder in which copper builds up in the body.

76. On the morning of 11 December 2012 Averil called the acute medical unit junior doctor because she had a pill stuck in her throat and felt unable to swallow. She also explained that she was finding it difficult to pass urine and was not passing any stool. The junior doctor observed that Averil was so weak that she was unable to lift her head from the bed, and unable to bend her knees actively without the assistance of her hands. The gastroenterology junior doctor was informed, and came to review Averil shortly after. He noted that she had '*critical body mass*' and '*worsening physiological function*'. He noted that she had only eaten half a yoghurt that morning, and a small amount of dry cornflakes, plus managing to eat one or two portions of salad or vegetables once a day. He documented that she needed to be transferred to Addenbrooke's Hospital.

77. Approximately one hour after this review, the NCEDS Lead Psychiatrist visited Averil. He documented that she had not been eating well over the weekend, had been standing and walking, and that overall she had deteriorated physiologically. The NCEDS Lead Psychiatrist noted that the MARSIPAN guidelines would apply to Averil[48], and that she required one-to-one nursing in order to manage her eating disorder behaviour. The notes say that Averil needed *'nasogastric tube* [NG] *feed as not managing with oral intake'* but that she was refusing NG feeding and would *'need MHA assessment[49]'*. The review said that Averil needed both medical and eating disorder specialist treatment, and *'would be safer treated in Addenbrooke's'*. The note says that ward S3 would hold a bed for her and would provide one-to-one care. The recommendation was for Averil to be transferred as soon as possible and that *'a MHA assessment can be arranged at Addenbrooke's'*. The note states:

> *'while she is currently an informal patient she does not have capacity to make decisions about her treatment, she is cognitive*[ly] *impaired and cannot weigh up information about her health and treatment'.*

78. The NCEDS Lead Psychiatrist's note concludes by saying that if a transfer could not be arranged immediately, one-to-one care would need to be provided to encourage Averil to *'sit down and eat'*. It said to contact the NCEDS Lead Psychiatrist as soon as the transfer had been arranged so that he could *'arrange a MHA assessment in Addenbrooke's'* and that Averil *'is happy to be transferred to Addenbrooke's*'.

Transfer to Addenbrooke's Hospital
(Cambridge University Hospitals NHS Foundation Trust - CUHT)

79. Averil arrived on ward N2 (gastroenterology ward) at Addenbrooke's Hospital at around 2.40pm on 11 December 2012. She was severely underweight and very weak. Observations were done at 3.30pm (temperature of 34.9°C, heart rate of 55 beats per

[48] *CR162: MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa* (2010) includes guidelines for the management of patients with severe anorexia nervosa. An updated second edition of the report was published in 2014.
[49] That is an assessment to establish whether treatment needed to be provided under the Mental Health Act if Averil did not agree to accept treatment.

minute, blood pressure of 95/55mmHg and respiratory rate of 13 breaths per minute. Her MEWS[50] was 4).

80. The NCEDS Lead Psychiatrist reviewed Averil with a consultant (the Consultant) and the dietician that evening between 7.30pm and 8pm. Mr Hart was also present during this review. The Consultant noted Averil was very weak and that she was unable to support her own bodyweight. She appeared severely emaciated but was alert and orientated. Observations showed that she was hypotensive[51], bradycardic[52] and hypothermic.

81. The notes record that in the days before her transfer, Averil had refused nasogastric feeding, but as she now seemed willing to accept this, it was not necessary to provide treatment under the Mental Health Act. The NCEDS Lead Psychiatrist told Averil that her *'medical risk'* was their highest concern, and that he *'would need to arrange a MHA assessment if she refused treatment'*. The Consultant documented his plan for Averil to have a number of blood tests (including electrolytes, creatinine, liver function tests, full blood count and coagulation) and to monitor her blood glucose level. The plan said that if Averil's blood glucose fell below 3mmol/l then she should be given oral glucose. The Consultant recorded that they should not start nasogastric feeding until the following day, and no intravenous fluids were to be given to her overnight. A healthcare assistant employed by CPFT was allocated to stay with Averil during the night. CPFT have told us the healthcare assistant's role was to manage any anorexic behaviours designed to sabotage treatment, not to provide any nursing or medical care, which remained the responsibility of the staff on N2 ward.

82. The junior doctor (the Junior Doctor) allocated to the medical ward for the night between 11 and 12 December 2012 saw Averil at approximately 10.20pm, at which point she noted that Averil was very weak, unable to lift her head, and severely underweight, but fully aware of her surroundings (Glasgow Coma Score of 15/15[53]). She asked a colleague to take a blood sample for the required blood tests and, seeing that Averil's blood glucose had not been tested since her arrival, asked a nurse to do a finger prick blood glucose test.

83. Attempts were made to obtain Averil's blood glucose level at 11.22pm and 11.33pm. The reading on each occasion was *'unrecordable'* (lower than 0.6mmols/l). The Junior Doctor therefore asked the nurses to give Averil oral glucose, and left to attend to another patient.

84. At around 1.10am on 12 December 2012 nursing staff recorded Averil's observations and her MEWS was 4. A nurse bleeped the Junior Doctor at 1.45am to explain that Averil had refused to take any oral glucose. They said that they did not yet have the laboratory blood test results. Shortly after this the Junior Doctor telephoned the Consultant at home.

[50] See footnote 43 for definition of MEWS. The CUHT MEWS pathway says that a score of 4 or more requires the shift charge (nurse in charge of the ward), critical care outreach team and the patient's medical team to be informed. It also requires observations and MEWS scores to be recorded hourly for at least four hours.
[51] Low blood pressure.
[52] A pulse rate of below 60 beats per minute.
[53] A structured scoring system used to assess and record a person's level of consciousness.

85. The Junior Doctor said that she gave the available results to the Consultant. This included specifically telling him that Averil had an unrecordable/low finger prick glucose level, that the laboratory blood sample was not yet available and that Averil had refused her oral glucose. The Junior Doctor recalled asking the Consultant whether they should force Averil to have this treatment, and that his response was if Averil's clinical status was stable, this was not necessary. The medical record says '[Consultant] *happy with current management no need for forced glucogel if patient is stable/asymptomatic regardless of glucose level'*.

86. During the local investigation, the Consultant said that it had been a *'bad line'* and he recalled this conversation differently. He remembered the Junior Doctor telling him that they *'could not get'* a finger prick glucose test done and that the blood sample from the laboratory was not yet available. He said that his advice to the Junior Doctor was that if Averil was alert and orientated at that stage, decisions about further management could wait until the laboratory results were available.

87. At about 2.40am[54] the Junior Doctor spoke to a biochemistry technician who told her that Averil's laboratory blood glucose result was 1.9mmols/l. The Junior Doctor asked the nursing staff to contact her if there was any change in Averil's condition. No further action was taken and no further blood glucose monitoring was done overnight.

88. At approximately 4.55am a retrospective nursing entry recorded that Averil's blood glucose had been as low as 0.6mmol/l on two occasions, and that Averil had refused oral glucose, other than a small amount on her finger. The note says that this nurse had again explained to Averil the need for oral glucose, but that she had refused, that the doctor was made aware of this, and that a '*nurse*[55]*'* was beside the bed all night.

89. Averil's MEWS had risen from 4 to 7 over about six hours. A score of 7 was significantly high and the Junior Doctor was called to review Averil. Despite this indication that Averil's condition was deteriorating, the Junior Doctor was told that there was no change in Averil's clinical picture and was reassured by what she heard[56].

90. The Junior Doctor did not review Averil before the morning handover started, and at 8.50am, she was reviewed by the Consultant. Averil was found barely breathing, and not rousable. The healthcare assistant was still sitting next to her bed. The records say that the cardiac arrest team was called at 8.54am.

91. The Consultant removed the warming blanket from Averil and gave her 200mls of 10% dextrose. The medical records say that cardiopulmonary resuscitation was not started due to Averil's frailty. A nasopharyngeal airway was inserted and oxygen given.

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[54] The blood sample was received by the laboratory at 11.42pm.

[55] This was the healthcare assistant allocated by CPFT to sit with Averil overnight to stop Averil displaying any behaviours designed to sabotage her treatment.

[56] In a statement the Junior Doctor provided for CUHT's Serious Incident investigation she said *'I explained to* [the staff nurse] *I was seeing a patient with 10 out of 10 chest pain but that if they thought it necessary I could come down immediately. The staff nurse told me she was not worried so I told her I would not worry either but that if she did start to worry I would come down straight away. She repeated that this was not necessary'*.

92. In the following hours Averil made some improvement physiologically (that is, her blood pressure started to improve and she began to breathe weakly), but she was noted to have disconjugate eye movement (her eyes were moving in opposite directions) which doctors thought suggested brain damage, with a number of possible causes, including hypoxia, hypotension, hypoglycaemia or a bleed in her brain.

93. Averil's condition continued to deteriorate and, after discussion with her family[57], she was placed on the Liverpool Care Pathway[58] on 13 December 2012. Averil died on 15 December 2012 at 11pm, aged 19, with her family by her side.

Our findings

94. We have set out our findings about each organisation in turn. In deciding whether there has been service failure, we refer to our Principles of Good Administration (paragraphs B5 to B7). In order to 'get it right' in their care of Averil, staff at each organisation should have taken account of the relevant standards and established good practice (as set out in Annex B and as described by our advisers in Annex D). In reaching our findings, we have thought about what should have happened and what did happen.

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)

Discharge from the Eating Disorder Unit and transition to NCEDS

95. Mr Hart believes that Averil was discharged too soon from the Eating Disorder Unit. While we can understand that concern given the events that unfolded following her discharge, we find that the decision to discharge Averil was appropriate. In reaching this decision we have taken into account our clinical advice, which says that: the decision to discharge Averil at that time was in line with established good practice given her BMI (although still in the anorexia range at 16.6) was considered low risk; her immediate risk at the time of discharge was low; she was willing to engage in outpatient care; and she wanted to be discharged to achieve her goal of going to university.

96. Having made a decision to discharge a patient, staff should make sure the relevant risk assessments have been done, and that appropriate discharge arrangements are in place. Averil had severe anorexia nervosa and had only made limited progress during her time on the Eating Disorder Unit, putting on some weight but not the amount they had aimed for. Our clinical advisers have told us that the period after discharge can be a vulnerable time for patients with some initial weight loss common. This means that close medical monitoring is required during this time. Additionally, as the First Psychiatrist Adviser has highlighted, Averil was not only making the move from the safe environment

[57] Mr Hart has shared his recollection of this discussion with the Consultant. He told us that the Consultant said that Averil was dying and that her family should not ask themselves 'why' as there would always be many questions that could not be answered, but instead try to put everything behind them. He said that the Consultant did not mention that Averil had been hypoglycaemic, and that Averil's family believe that he hid this fact from the family. Mr Hart said '*this was a cruel and devastating way for Averil's family to be treated - being lied to by the consultant as Averil lay in the next room dying.*'

[58] The Liverpool Care Pathway (LCP) was a pathway for patients in the final days or hours of life. It was designed to provide palliative care options for these patients, and to help doctors and nurses provide quality end-of-life care.

of the Eating Disorder Unit into the community, she was also leaving home and moving into a new environment where she would have to shop and prepare food for herself. This posed a risk to Averil of relapse and self-neglect, and there should have been a clear plan to mitigate this risk. This requirement was made more pressing by the knowledge that NCEDS, the service that was to take over care, was afflicted by recruitment problems that would impinge on the provision of clinical expertise and experience. Both NCEDS and the Eating Disorder Unit were managed by CPFT, and this situation must have been known when plans were being drawn up for Averil's discharge and transfer.

97. We have seen some evidence that staff were thinking about the risk of relapse Averil faced, particularly the Eating Disorder Unit Psychologist who took the lead in handing over Averil's care. She described Averil's changing situation and her resulting vulnerability to UEAMC when she was in touch with them about the need for physical monitoring, and she told NCEDS that Averil had lost weight since being discharged. We recognise therefore that staff on the Eating Disorder Unit were aware of the risks Averil faced at the time of her discharge. Her discharge summary notes that she was no longer at immediate risk, but this referred specifically to her physical health, and was correct at that time.

98. Having said that, after careful consideration, and discussion with our clinical advisers, we consider that the risk assessment carried out at the time of Averil's discharge (included in her discharge summary and CPA documents) was not robust or explicit enough and could have been improved. In particular, we consider that there should have been a detailed contingency plan to follow if Averil's condition deteriorated. This should have included specific BMIs or other parameters which would trigger particular action. The staffing problems at NCEDS added to the need for contingency plans.

99. A key decision was allowing Averil to transfer her care directly to NCEDS when she moved to Norfolk, rather than arranging an interim move to the local Suffolk eating disorder service and then to NCEDS. We know that this was first discussed in May 2012 and formally documented in her care plan on 14 June 2012.

100. Our advisers told us that it is important in this situation to tailor the service to the needs and wishes of the patient. It was important to keep Averil's trust and for her to be engaged and motivated in her care. Averil had said that she did not want to transfer her care between two different services. And for this reason the Eating Disorder Unit Psychologist agreed to provide interim support to Averil until she went to university and her care could be transferred directly to NCEDS. Her action in doing this was appropriate. However, our advisers also told us that, when staff became aware that this was what Averil wanted, it would have been established good practice for a care coordinator from NCEDS to attend her CPA meetings on the Eating Disorder Unit, either in person or by telephone. We know that this did not happen, and we have not seen any evidence that anyone tried to arrange this. As a result, not only was there no face-to-face contact with the care coordinator about to assume responsibility, there was no opportunity for Averil to meet the person she would need to form a therapeutic relationship with prior to her move to Norwich.

101. Given the risks Averil faced, as part of her discharge planning she should have been offered weekly appointments to be weighed during this interim period. In the event,

Averil saw the Eating Disorder Unit Psychologist face to face on three occasions and had a couple of further telephone contacts, but this was the extent of the professional input at a very vulnerable time. There was no contact with any professionals between appointments on 9 and 30 August. Averil then went on a family holiday and she also cancelled an appointment on 12 September. These events, which were outside CPFT's control also impacted on the lack of contact during this time.

102. Averil's final face to face appointment with the Eating Disorder Unit Psychologist was on 20 September, three days before she moved to university. There was then a delay of a month before Averil had her first appointment with the new care coordinator (the NCEDS Care Coordinator). We recognise that the Eating Disorder Unit Psychologist handed over the necessary physical monitoring to UEAMC whilst Averil was waiting to be allocated a care coordinator and this meant that she was weighed twice in Norfolk before she saw the NCEDS Care Coordinator on 5 and 12 October. We can see that the Eating Disorder Unit Psychologist communicated with the NCEDS Consultant Clinical Psychologist at NCEDS during this time emphasising the need for arrangements to be made for Averil's care as soon as possible. We also acknowledge that NCEDS understood this and did prioritise allocating a therapist to Averil. However, despite the efforts of the individuals involved, the fact remains that staff shortage at NCEDS meant that there was a gap in therapy and support being provided for Averil at a very vulnerable time, when she really needed it. In the two weeks before her first appointment with the NCEDS Care Coordinator Averil lost a further 2.8kg, meaning that she had lost a total of 6kg since discharge, a significant amount.

103. Overall, we consider that, having recognised the risk to Averil of self-neglect and relapse more should have been done by CPFT to plan for her discharge and avoid these gaps in her care in line with established good practice.

Care provided by NCEDS including the appointment of and care provided by the NCEDS Care Coordinator

The appointment of the NCEDS Care Coordinator

104. Mr Hart complains that it was inappropriate for the NCEDS Care Coordinator to be assigned to Averil as she had no experience in managing patients with anorexia nervosa, and separately that the NCEDS Care Coordinator failed to carry out the full extent of her duties as care coordinator and provided poor care and treatment to Averil.

105. There are two key questions to consider when looking at whether Averil was assigned an appropriate therapist and care coordinator. The first is whether or not the NCEDS Care Coordinator was appropriately qualified to take on these roles. The second is whether she was appropriately supervised and supported in carrying them out.

106. The NCEDS Care Coordinator had completed her training as a counselling psychologist and was qualified. It is also true, however, that she was new in both her role as a therapist and as a care coordinator, and lacked any direct experience of working with patients with anorexia nervosa. For this reason CPFT's own investigation report concluded that it was '*questionable*' whether it had been appropriate for her to be allocated as the sole eating disorder professional in face-to-face contact with Averil. In contrast, the

consultant psychiatrist commissioned by the CCG to undertake a review[59] of Averil's care said that it had been appropriate to place Averil with a new therapist, who was closely supervised by a senior and experienced member of NCEDS. Our clinical advisers share the view that assigning Averil's care to the NCEDS Care Coordinator was appropriate and in line with established practice. Taking all this into account, we conclude that assigning an inexperienced therapist was acceptable, provided that adequate supervision and support were provided.

107. The assignment of a care coordinator who lacked experience of the condition and was in her first post gives us significant concern. A care coordinator needs to know who to communicate with and how to mobilise others when care deviates from plan, and this is bound to be more difficult for a novice. We are aware that decisions about the allocation of patients to members of staff within an eating disorders service have to be taken on the basis of caseload and capacity. We know that NCEDS were experiencing problems with staff shortages at this time, exacerbated by recruitment problems. The First Psychiatrist Adviser told us that eating disorders is an extremely specialised, small field, and it is not uncommon to advertise jobs and have no applicants due to the shortage of professionals with experience in this area. Given that NCEDS needed to provide a care coordinator for Averil, and that delay would have meant a further gap in her care, we have concluded that this decision was not out of line with practice accepted elsewhere in these circumstances, subject to the provision of adequate supervision and support in this role. We do, however, believe that this is an unsatisfactory situation nationally.

108. We now consider whether the NCEDS Care Coordinator was adequately supervised in her two roles. Both the care coordinator and her supervisor told our advisers that there was a good level of regular supervision. On the basis of what they heard, our advisers said that overall the NCEDS Care Coordinator was closely supervised in line with established good practice and the HCPC standard of Conduct and Ethics about effective supervision (paragraphs B18), as well as the British Psychological Society principles and policy on supervision (paragraph B20). It was, however, impossible to confirm this on the basis of the records of supervision, which were scant, poorly kept and with irregular dates that did not amount to a consistent weekly pattern. Although the verbal accounts did suggest effective supervision, we retain a concern that this should have been demonstrated much more clearly in the records, particularly given the added responsibility of undertaking care coordination as well as therapy.

109. Turning next to the support provided, we have concluded that the NCEDS Care Coordinator (and therefore Averil) should have had the benefit of support from a multidisciplinary team earlier in the course of her treatment. As therapist, the NCEDS Care Coordinator was left as the sole point of contact with Averil. Established practice would be for a multidisciplinary team from the outset, with '*more pairs of eyes*' on Averil, increasing the chance that any problems or issues would have been spotted. It would also have offered the opportunity for other colleagues to have challenging conversations with Averil about the risks she was facing, readmission or the use of the Mental Health Act, whilst allowing the NCEDS Care Coordinator to maintain the therapeutic alliance she was building with her. There is no evidence such conversations

[59] A consultant psychiatrist was commissioned as an independent expert to provide a report about Averil's care by the CCG.

took place. We acknowledge that this was being planned for the medical review on 7 December, but it should have been done earlier. An earlier opportunity was therefore missed to either refer Averil for psychiatric review or a discussion at a multidisciplinary team meeting when the significance of her weight loss was noted. Our advisers told us that the NCEDS Care Coordinator should not have been working in isolation with Averil.

110. As Averil's care coordinator, the NCEDS Care Coordinator was expected to oversee the management of her care in accordance with Trust policy (paragraph B40). Although the NICE guidance does not specify there should be multidisciplinary working, our clinical advice tells us it would have been established good practice for Averil to have had a multidisciplinary review. In her role as care coordinator, it was even more important that the NCEDS Care Coordinator had access to a multidisciplinary team, the principal resource that she would have been coordinating within NCEDS itself. Although the NCEDS Care Coordinator also had to liaise with the GPs at UEAMC, as we consider elsewhere, it is difficult to see what else she was coordinating. The support provided to the NCEDS Care Coordinator in both her roles was inadequate.

The care and treatment provided by the NCEDS Care Coordinator

111. Mr Hart complains about the standard of care provided by the NCEDS Care Coordinator and specifically points to the opinion of the consultant psychiatrist commissioned by the CCG to undertake a review, that Averil lacked true insight into her condition. As we understand it, the key concerns Mr Hart has are focused on what he considers was the NCEDS Care Coordinator's inability to anticipate Averil's behaviours. In particular, the fact that Averil might have been falsifying her weight, and was exhibiting symptoms that the NCEDS Care Coordinator did not notice, and therefore failed to properly monitor Averil's progress – or lack of – when treating her.

112. This is a difficult point on which to reach a conclusion. Having discussed this with the advisers, it is clear that there was no compelling evidence at the time that Averil was artificially increasing her weight, although with hindsight Averil's personal diaries[60] suggests that she was. It is possible a more experienced therapist might have been more alert to this. We recognise that Averil's history (only one recorded incidence of weight falsification which she had admitted to), would have meant that this would not necessarily be considered a significantly increased risk, although clinicians should always be alert to the possibility. In addition, physical deterioration is not always easy to recognise at first in patients with anorexia due to their tendency to minimise physical symptoms and remain active, engaging and driven in the face of deteriorating physical health. Therefore whilst we find that having more professionals working with Averil would have been of benefit here, having taken into account the advice we have received, we find that the care provided by the NCEDS Care Coordinator was in accordance with established good practice.

113. We also note that, as Mr Hart has pointed out to us, the NCEDS Care Coordinator made a mistake in calculating the four weekly averages from the weights recorded (whether these were true weights or not). These were recorded as 39.2kg, 39.4kg, and

[60] Averil kept a personal diary recording her thoughts and feelings. Extracts of this diary have been shared with us by Mr Hart. This is different to any food diary she was asked to keep as part of her treatment.

38.7kg for weeks 4, 5 and 6 of the NCEDS Care Coordinator's sessions with Averil, when they should have been 39.2kg, 39.05kg, and 38.7kg. We note that the difference in value is small, but we can understand Mr Hart's view that this calculation error is significant. The impact of the error was that a trend of consistent weight loss, rather than some weight gain and then weight loss was not noted. The lack of support to the NCEDS Care Coordinator meant that there was no opportunity to pick up this error.

114. Turning to Mr Hart's complaint that the decision by the NCEDS Care Coordinator to stop UEAMC from weighing Averil was flawed, the NCEDS Care Coordinator told us at interview that this decision was made in a session with her supervisor. The advice we have been given is that this decision was appropriate. In terms of whether the NCEDS Care Coordinator should have picked up on other physical signs that Averil might have been deteriorating, the care plan was clear that the monitoring of her physical parameters was the responsibility of UEAMC. The decision did, however, place a premium on effective two-way communication between NCEDS and UEAMC to ensure that the plan was properly understood and implemented and that information about Averil's progress was shared, as we have considered elsewhere.

115. Mr Hart is also understandably concerned that the NCEDS Care Coordinator did not arrange cover when she went on leave following her sixth appointment with Averil. This meant there was a fortnight when Averil would have had no contact with NCEDS. As it happened events took over and Averil was admitted to NNUH before her next appointment could take place. Having considered the evidence and the advice we have received, we share Mr Hart's concern about this. Weekly weighing was part of the agreed care plan and was being carried out during the appointments with the NCEDS Care Coordinator; in her absence either cover should have been arranged, or if this was not available, the GP should have been asked to weigh Averil that week. Ensuring that such arrangements were in place clearly fell within the remit of the care coordinator.

Communication between NCEDS (the NCEDS Care Coordinator) and UEAMC

116. We turn now to Mr Hart's complaint about the communication between the NCEDS Care Coordinator and UEAMC. He says that the NCEDS Care Coordinator should have done more to ensure that UEAMC were doing the monitoring they had been asked to do. We understand why Mr Hart is so concerned that the NCEDS Care Coordinator did not contact UEAMC to check that the required monitoring was taking place. It is correct that, had the NCEDS Care Coordinator contacted UEAMC, this might have highlighted that the monitoring was not being done as set out in the care plan. However, our advisers have told us that the NCEDS Care Coordinator acted in accordance with the NICE guidance on eating disorders (paragraph B9) and HCPC standards for proper and effective communication (paragraph B18). That is, a telephone call would only be needed if there were concerns that the patient was not being honest about the medical monitoring. In Averil's case, there was no reason to suspect she was not being honest about the checks being done. Her reports and weight chart were broadly consistent, she had a history of engagement and compliance with monitoring and intervention, and her weight was going down and causing concern - in other words - this did not appear to have been concealed. We fully recognise that given the subsequent events and the entries in Averil's personal diaries that Mr Hart does not feel able to accept this. However, in the absence of any specific concerns that Averil was not being honest, it was appropriate, and in line with

guidance for the NCEDS Care Coordinator to trust that the appropriate monitoring was being done. Nevertheless, as it turned out, the UEAMC GPs did not continue the monitoring, and NCEDS remained unaware that this was the case. We would expect that in any arrangement where care is shared between two or more clinicians or units, steps would be taken to establish effective two-way communication. This did not happen.

The Eating Disorder Unit Lead Psychiatrist's refusal to take Mr Hart's emergency telephone call

117. Mr Hart visited Averil on 28 November 2012 and was so alarmed about her condition that he telephoned ward S3 (the Eating Disorder Unit). He has described hearing the Eating Disorder Unit Lead Psychiatrist in the background telling her colleague who had answered the call to ask Mr Hart to contact an alternative colleague (paragraph 62), and the impression this left on him. At interview we asked the Eating Disorder Unit Lead Psychiatrist about this and she told us that she directed the person who took the call to tell Mr Hart to call the NCEDS Lead Psychiatrist directly because she did not know anything about Averil's recent care and thought this would be better than trying to deal with the situation second-hand. While we can see that it might have been more helpful and sympathetic to have listened to Mr Hart's concerns and to have explained the need for a colleague to deal with his concerns, we can also see that as the Eating Disorder Unit Lead Psychiatrist had no clinical role at the NCEDS (other than covering when the NCEDS Lead Psychiatrist was on leave), she would not have had any up to date knowledge about what had been happening with Averil. And overall we do not find that the Eating Disorder Unit Lead Psychiatrist acted inappropriately.

Appointment of a healthcare assistant at Addenbrooke's Hospital

118. Mr Hart's final complaint about CPFT is about the last hours of Averil's life and the allocation of a healthcare assistant during her admission to Addenbrooke's Hospital. Specifically he has told us that the healthcare assistant, who was based in Averil's room, did nothing to help him (and his family) as they had to look after Averil. Rather, he describes the healthcare assistant reading a book as he had to carry Averil to and from the toilet.

119. We have tried to clarify what the role of the healthcare assistant was during this time. It seems reasonable for Mr Hart, and his family to have expected a healthcare assistant allocated to be with Averil, to provide them with help to care for her. CPFT have told us that the healthcare assistant was there primarily to prevent Averil displaying any behaviours designed to sabotage her treatment, for example, water loading, over activity, tampering with nasogastric tubes, rather than to provide any acute nursing care. However, it is clear that by this time Averil was so weak that she was unable to get out of bed, or even lift her head from her pillow, let alone carry out the sabotaging behaviours described. As such it is clear to us that the role allocated to this healthcare assistant was redundant. At the very least this should have been made clear to Mr Hart at the time and the healthcare assistant could, and should, have done more to assist Averil and her family regardless of the role specifically allocated, even if this had meant flagging up that due to the severity of her condition Averil no longer required the supervision that the healthcare assistant was there to provide.

Summary

120. Overall some of the care and treatment provided by CPFT was in line with established good practice and the relevant standards. On balance it was appropriate to discharge Averil so that she could go to university, and to have appointed the NCEDS Care Coordinator as her therapist and care coordinator. We also found that the NCEDS Care Coordinator appropriately asked UEAMC to monitor Averil's physical condition, but because effective two-way communication was not established, she did not know that UEAMC had not continued the monitoring requested. However, we found that not enough was done to adequately plan for Averil's discharge and this resulted in gaps in her care. Although verbal accounts suggested there was effective supervision of the NCEDS Care Coordinator, we were concerned that this was not demonstrated clearly in the records. Moreover, the NCEDS Care Coordinator was not adequately supported by a multidisciplinary team and was the sole clinician reviewing Averil. Finally, we found there was a lack of clarity about the role of the healthcare assistant when Averil was admitted to hospital. In these respects, CPFT actions fell so far short of established good practice and the applicable guidance, that it was service failure.

University of East Anglia Medical Centre (UEAMC)

The allocation of a named GP

121. Mr Hart complains that Averil was not allocated a named GP.

122. When planning for Averil's care to be transferred to UEAMC, the Eating Disorder Unit Psychologist asked for a named GP for Averil. The GP Advisers have explained to us that the role of a named GP is one of oversight, rather than personally seeing a patient at each appointment. It is not always the best plan for a patient to only see one GP because GPs often work part-time and may have other commitments, and a patient may then feel unable to see another GP. However, given that the Eating Disorder Unit Psychologist had asked for a named GP, we have concluded that a named GP should have been identified to provide oversight of Averil's care. If there was a reason this was not possible, then this should have been discussed with the Eating Disorder Unit Psychologist. For their part, UEAMC argues that they had an informal system in place where the first GP to see a patient would become the patient's lead GP, but this system was not documented and was not clear to the locum GP who subsequently saw Averil.

The monitoring provided by UEAMC

123. Mr Hart complained that UEAMC did not provide the care that they should have done in line with Averil's discharge summary.

124. UEAMC accepted Averil's care plan as recorded in her discharge summary when she registered as a patient. This set out clearly what monitoring was needed. This was communicated effectively to UEAMC, as evidenced in Averil's records, where it had been documented and made available to the GPs who subsequently saw her. The GPs at UEAMC should have kept to this plan. If they saw a need to change it, they should have clearly

communicated their rationale for this with Averil and others involved in her care, in accordance with *Good Medical Practice* (paragraph B25), which says that doctors must communicate effectively with colleagues within and outside the team. It says sharing information with other healthcare professionals is important for safe and effective patient care. This did not happen. Averil was seen by GPs at UEAMC on three occasions and also by a healthcare assistant. Whilst some limited monitoring did take place:

- at the four appointments she had at the UEAMC, her weight, blood pressure, heart rate and level of physical strength was only effectively recorded at one appointment;
- after 8 November 2012, a decision was taken to '*review in a month*' and no further appointments were made; and
- blood tests were not done at all.

125. UEAMC told us that the blood tests were not considered urgent as they had been asked to do them every two or three months. They said that they required '*co-operation from the patient for any care to be given*' and that it had been confirmed to them that the '*monitoring requested by previous* [eating disorder service] *in Cambridge was now being undertaken by* [NCEDS]'. They also told us that NCEDS had confirmed they were seeing Averil weekly and that the GPs could not force a patient to come to their practice, especially if '*both patient and the service confirm that care is being provided elsewhere*'.

126. What UEAMC told us is not supported by the evidence. It is correct that in their letter of 26 October, NCEDS adjusted the care plan by confirming that Averil's GP visits no longer needed to include weighing her; however there is nothing else in this letter to suggest that any other aspect of UEAMC's involvement should change. In fact, the letter emphasised the importance of her being regularly monitored by a GP. Our advisers could not see any good reason for the decision to extend the interval between Averil's appointments at UEAMC to monthly. Any decision to change Averil's care plan in such a significant way should have been a reasonable one based on all relevant considerations, and appropriately documented and communicated in accordance with *Good Medical Practice* (paragraph B25). The actions of UEAMC fell far short of these criteria.

King's College Guidelines

127. Mr Hart's next complaint about UEAMC is that they failed to follow the King's College guidelines.

128. The Eating Disorder Unit Psychologist sent a copy of the King's College Guidelines '*A Guide to the medical risk assessment for eating disorders*'(2009) to UEAMC on 27 September 2012, and said she would be grateful if they carried out the necessary medical monitoring of Averil. These guidelines set out the limitations of BMI as a marker of medical risk, and emphasise the need to carry out additional examinations of muscle strength, blood pressure, pulse rate, peripheral circulation and core temperature. Along with the information in Averil's discharge summary from ward S3, these provided the GPs at UEAMC with clear instructions about what medical monitoring should have entailed. Despite an entry in Averil's UEAMC records which reads, '*please see recommendations in attached document about monitoring*', it is clear from the evidence we have seen and the

advice we have received that these guidelines were not followed by the GPs who saw her, as they should have been.

Observation of Averil's physical symptoms

129. Finally, Mr Hart complained that the GPs failed to observe Averil's physical symptoms.

130. As we have noted above, the GPs at UEAMC who saw Averil did not carry out the appropriate examinations or tests that would have allowed them to effectively monitor Averil's medical condition. This meant that they did not put themselves in a position to observe the deterioration in her health that extracts from entries in Averil's diary throughout October and November 2012 point to. Averil recorded that she was experiencing swelling in her ankles, increasing difficulty walking upstairs, pain in her chest, fluid around her knees, a sore and bloated stomach, and swollen glands. The point of medical monitoring was to identify any signs that might suggest deterioration in Averil's physical health; information that could then have been shared with the team at NCEDS and allowed them to reconsider her care plan as necessary. The GPs at UEAMC who saw Averil failed to do this appropriately, and therefore missed the opportunity to appreciate the full picture of what was happening to Averil.

Summary

131. Overall, we find UEAMC carried out some limited monitoring of Averil's condition during the time she was a patient with them. However, this fell far short of the medical monitoring expected. Furthermore, the decision to stop seeing Averil weekly was not in accordance with her care plan and was not communicated to Averil's care coordinator. We find that the actions of the GPs at UEAMC at that time fell far short of what should have happened, and that this was service failure.

Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)

132. Mr Hart complains that following her admission to NNUH on 7 December, Averil received inappropriate care and treatment for a patient with anorexia nervosa, including that she was allowed to walk around the ward and feed herself from a trolley on the ward, resulting in over-reporting of how much she was eating. He also complains that she was not seen by a psychiatrist until 10 December 2012, three days after her admission.

133. It is clear to us that doctors at NNUH lost sight of the severity of Averil's underlying condition – anorexia nervosa – and the central role of this in her deteriorating condition. Our Gastroenterology Adviser said that Averil was seriously ill on admission and in urgent need of refeeding in accordance with the MARSIPAN guidelines (paragraph B12). This urgency was not reflected in the actions of the doctors, and their focus instead appears to have inexplicably been on whether her abnormal liver function had been caused by an overdose of paracetamol to treat cold and flu symptoms, along with checking for other unlikely diagnoses such as Wilson's disease. There is no evidence that anyone connected her medical condition (and her continued deterioration) to her severe anorexia nervosa until 10 December when she was reviewed by the NCEDS Specialty Doctor. This

recognition was key to Averil's treatment and was missing; without her anorexia nervosa being appropriately managed, she was unlikely to improve.

134. This is perhaps most starkly demonstrated by the AMU doctor's actions on the afternoon of 7 December. The AMU doctor documented Mr Hart's concerns about his daughter's frailty compared to a year earlier, his concerns that she had suffered a relapse of her anorexia nervosa, and her *'critical BMI'*. However, the AMU doctor would not discuss Averil's condition with the NCEDS Lead Psychiatrist when he telephoned to find out about Averil's condition. We appreciate that if the AMU doctor had concerns about the authenticity of the NCEDS Lead Psychiatrist's call they may have felt unable to disclose information immediately, but they should have offered to telephone him back to confirm his identity. Had they done so, the NCEDS Lead Psychiatrist could have provided Averil's doctors with advice about managing her nutrition and her eating disorder behaviours (a point the principal author of the MARSIPAN guidelines made in his review). As it was, the NCEDS Lead Psychiatrist was given minimal information about Averil's condition and on that basis made plans for the NCEDS team to see her after the weekend, on Monday 10 December.

135. A further example of this is the medical review by the SHO on the evening of 9 December after Averil had fallen on the ward. Nurses had bleeped the gastroenterology on-call doctor on four occasions throughout the day with concerns about Averil, yet it was more than nine hours after they were first alerted that the SHO went to see her[61]. When the SHO did see her, the focus was solely on the reasons Averil gave for her fall. The SHO did not consider the causes of Averil's persistently low blood pressure, low body temperature, and low blood sugar. Nor did they identify the lack of recording of Averil's nutritional needs or intake, despite her history of anorexia nervosa and having been in hospital for two days. They equally failed to consider the implications of Averil being disconnected from her intravenous infusion, in terms of the delay to her medication, nor did they ask why she was spending so much time in the bathroom and moving about (potentially sabotaging behaviours associated with her anorexia nervosa). This assessment was not in accordance with GMC guidance, *Good Medical Practice,* which says that an adequate assessment should take into account the patients history, including their symptoms and psychological factors (paragraph B23).

136. Most importantly, the consultant who assessed Averil on the evening of 7 December (the First Consultant), and their colleague who saw Averil the next day (the Second Consultant), should have been aware of the MARSIPAN guidelines and recognised that with a BMI of 11, Averil was a high risk patient. They should have understood the importance of consulting a medical expert in nutrition, avoiding refeeding syndrome, and avoiding underfeeding syndrome by frequently reassessing and increasing calories as soon as it was safe.

137. The Gastroenterology Adviser explained to us that the First Consultant had two options. They could have suggested immediate transfer of Averil to

[61] When we shared a draft copy of the report with the SHO, she told us she had seen Averil at 12 noon on 9 December 2012. She said she measured Averil's blood pressure and heart rate, and it was her handwriting on the observation chart. The SHO said she was unable to recall the reason she did not write an entry in the patient notes at the time, but speculated that she had been bleeped to attend to an emergency before she had a chance to do so.

Addenbrooke's Hospital, in accordance with NICE guidelines on eating disorders (paragraph B9). This was a setting that could provide the skilled implementation of refeeding with careful physical monitoring in combination with psychosocial interventions. Alternatively, they could have ensured a monitored, graded feeding regime was put in place for Averil with psychiatric support at Norfolk and Norwich Hospital. They did neither.

138. In the event, Averil did not see a dietician until 10 December, three days after her admission. By this point, given her impending transfer to Addenbrooke's Hospital, no advice was given. This was not in line with NICE guidance on nutritional support in adults (paragraph B28) which required NNUH to provide Averil with appropriate nutritional support.

139. From the clinical advice we have received and the evidence in Averil's medical records, it is clear that there was a general failure of Averil's doctors to recognise and address the primary cause of her admission – her anorexia nervosa. There was no holistic review of her condition until 10 December when the decision was taken to transfer her to Addenbrooke's Hospital. By that stage her weight had dropped further making her situation even more critical. During this period MARSIPAN guidelines were not followed, as Averil was allowed to leave her bed and move around, staff paid no attention to her calorie intake, and did not recognise that she may have been deliberately avoiding food. Averil did not see a psychiatrist until 10 December and, as we have noted, a doctor failed to take up the opportunity to speak to a consultant psychiatrist from NCEDS.

140. In fact, there appears to have been no focus at all on Averil's anorexia nervosa, despite it being clear from admission that this was her principal medical problem. Instead, the focus appears to have been mainly on why her liver function was abnormal, and whether this was caused by an overdose of cold and flu remedies. There is no evidence that anyone connected her medical condition (and her continued deterioration) to her anorexia nervosa until 10 December when she was reviewed by the NCEDS specialty doctor. And without Averil's anorexia nervosa being appropriately managed, she was unlikely to improve.

141. Mr Hart complains that his daughter did not receive appropriate care and treatment as a patient with anorexia nervosa. And this is what we find. We have seen no evidence of any attention being paid to Averil's calorie intake during her admission or, as the Gastroenterology Adviser has pointed out, any recognition that Averil might have been deliberately avoiding food. In short, we find that the Trust's doctors did not 'get it right' because they did not provide Averil with the treatment she needed for her anorexia nervosa, as *Good Medical Practice* (paragraph B23) says they should have done.

142. Mr Hart also complains that Averil did not see a psychiatrist until 10 December and again this is what we find. *Good Medical Practice* says that good clinical care must include referring a patient to another practitioner, when this is in the patient's best interests, but we found that Averil's doctors did not do this. In fact, on one occasion a doctor actually turned down the chance to speak to a consultant psychiatrist from the eating disorder service who might well have been able to help doctors manage Averil's anorexia nervosa.

Nursing care

143. The nursing care Averil received in NNUH followed the same pattern as the medical care: a failure to recognise the seriousness of her anorexia nervosa and take appropriate action to address her nutritional needs and sabotaging behaviours. We acknowledge that junior nurses on the ward may have had little experience of the behavioural issues associated with anorexia nervosa, but as our First Nurse Adviser has pointed out, a senior member of the team should have been able to guide colleagues on how to identify deterioration in a patient like Averil.

144. Looking specifically at where the actions of nursing staff were not in accordance with the NMC Code of Conduct (paragraph B27), we can see that mistakes were made in the completion of assessment documentation when Averil first arrived on the ward. Nurses correctly identified that Averil had anorexia nervosa and was known to NCEDS, that she had low blood pressure and was experiencing mild pain, yet subsequently ticked '*no issues identified*' under the headings '*Nutrition*', '*Cardiovascular*', and '*Pain*'.

145. The First Nurse Adviser told us that given the initial assessment of Averil, her clinical observations and medical history, her care plan should have included (in accordance with established good practice):

- hourly cardiovascular observations with clear triggers for escalation;
- discussions with Averil about her risk of falling and moving around;
- arrangements for the management of her nutrition;
- liaison with psychiatry; and
- consideration of the level of nursing care she might require.

146. Looking specifically at the question of nutrition, the First Nursing Adviser told us that as Averil was a very high risk patient, an action plan should have been drawn up with very clear goals. The action plan should have been reviewed daily with escalation to the medical team if goals were not being met. A food intake chart should have been completed after every meal and Averil's behaviour before and after meals should have been noted. Her oral intake should also have been recorded. As it was, nurses' assessment of Averil identified her history of anorexia nervosa and a MUST screening tool completed on 7 December placed her at *'Very High'* risk, but no action was taken other than to refer Averil to a dietitian. There was no action plan and no food chart, and the notes that were made about Averil's food intake did not give any indication of the type of food, or quantity she had eaten. Likewise, the fluid chart gave no indication of Averil's oral fluid intake. There was no evidence that nurses escalated any concerns about Averil's nutrition to the medical team as they should have done in accordance with the NMC Code of Conduct (paragraph B27).

147. There is also no evidence to suggest that nurses recognised Averil's constant moving around as a sabotaging behaviour designed to expend energy – a behaviour identified in the MARSIPAN guidelines. For example: there are entries in the medical notes where Averil was noted to be away from her bed; the AMU Doctor noted that Averil wanted to walk all the time; and the Registrar noted that Averil's strength was on a

'downward trend'. In the circumstances, the First Nurse Adviser told us nurses should have talked to Averil about the impact of her continual movement and escalated her behaviour to the nurse in charge if Averil would not agree to restrictions to her movement.

148. However, again there is no evidence that nurses took any action about this. There is no evidence that nurses talked to Averil about the effect of her exercising or tried to agree restrictions with her. If it had been clear that Averil would not accept any restrictions on her behaviour, the First Nurse Adviser told us that nurses should have considered one-to-one nursing of Averil to try and talk her out of moving around and reduce her risk of falling, and a referral to the psychiatric liaison team, so that consideration could be given to a Mental Health Act assessment.

149. Lastly, the First Nurse Adviser told us that although nurses took Averil's observations regularly, they should have been taken more often. She pointed to periods when there was no record of Averil's oxygen saturation readings and when Averil was hypotensive, her observations were not repeated for four to five hours. She also pointed to instances where Averil's oxygen saturations were noted to have been unobtainable (because of hypothermia) and told us that these readings should have been repeated after Averil's hands had been warmed, not left blank.

150. Averil's nurses did not *'get it right'*. We have seen no evidence that nurses recognised the seriousness of Averil's underlying condition. No attention was paid to Averil's nutrition or to her possible sabotaging behaviours, such as her continually moving about. There is nothing to indicate that nurses escalated any concerns about her eating and drinking or behaviour to the medical team or referred her to the psychiatric liaison team. We find that nurses did not provide care based on the best available evidence or best practice, as the NMC Code says they should have done. And they did not consult and take advice from colleagues when appropriate.

Summary

151. Overall, the care provided for Averil by NNUH was inadequate, and fell far short of the applicable standards and established good practice. There were serious failings during this admission, because staff did not recognise the significance of her underlying condition – anorexia nervosa. This meant they did not provide adequate care for their critically ill young patient. The NNUH's actions fell far short of what should have happened. This was service failure.

Cambridge University Hospitals NHS Foundation Trust (CUHT)

The care immediately following transfer

152. Mr Hart complains that there was a significant delay in any consultant seeing Averil when she was admitted to N2 ward at Addenbrooke's Hospital following her transfer from NNUH.

153. Averil was transferred to the gastroenterology ward (N2) at Addenbrooke's Hospital at approximately 2.40pm on 11 December 2012, but was not seen by a doctor until

approximately 7.30pm, when she was reviewed by the consultant gastroenterologist and the NCEDS Lead Psychiatrist from NCEDS. Given the seriousness of Averil's situation, it is inexplicable that she was not seen by a doctor for nearly five hours following her transfer. The Gastroenterology Adviser told us that when Averil arrived at Addenbrooke's Hospital, in accordance with the GMC guidance *Good Medical Practice* (paragraph B23), her clinical situation required immediate medical assessment, including blood tests (which should have included blood glucose). He said that there should have been a robust plan to monitor and treat her, and this should have been communicated in due course to the overnight medical and nursing teams. As it was, no blood tests were done during this period, there was no other clinical examination (other than basic observations), and therefore no decisions were made about her ongoing treatment or clinical risk. This fell far short of what should have been done according to *Good Medical Practice*.

Assessment of Averil's capacity to make decisions

154. Mr Hart also complains that there was a failure to assess Averil's capacity to make decisions about her care in line with the Mental Health Act.

155. The Gastroenterology Adviser explained that hypoglycaemia results in brain damage and death and requires urgent treatment. He said that once Averil's finger prick blood glucose was unrecordable (during the evening of 11 December), and she refused treatment, urgent action was necessary. It was not acceptable to consider only her apparent lucidity. This failure to act was not in accordance with *Good Medical Practice*, which says that doctors should adequately assess a patient, if necessary by examining them, and provide further investigations or treatment as necessary (paragraph B23). An immediate mental capacity assessment should have been arranged to establish whether Averil had capacity to make such decisions about her care. This should have included a discussion with Averil about the risks of not accepting treatment, and an assessment of whether she understood the consequences of doing so, in line with the MCA Code of Practice. Although the notes suggest that nurses did discuss with Averil the need to take oral glucose, there was no discussion with doctors, and certainly no evidence that Averil's capacity to make this decision was considered.

156. The Gastroenterology Adviser said that once the subsequent laboratory blood test had confirmed hypoglycaemia, treatment with glucose should again have been offered, and when Averil refused, it was even more critical to carry out an immediate capacity assessment. He told us that established good practice would have been for the junior doctor covering the ward to undertake the capacity assessment, if necessary with advice from a senior doctor. If Averil was judged not to have capacity, she should have been treated in her best interests. If it was found that she did have capacity, then a mental health assessment should have been sought, with a view to treating Averil under the Mental Health Act. Either way, Averil should have been provided with the appropriate treatment for her severe hypoglycaemia.

157. Averil was transferred to Addenbrooke's Hospital precisely so that her situation could be managed more appropriately. However, none of the critical steps were taken. This fell significantly below established good practice and the GMC's guidance, *Good Medical Practice*.

Averil's overall care and treatment

158. Mr Hart further complains that Averil's care and treatment was poor. He is particularly concerned that blood tests were ordered too late and advice about the monitoring of her glucose levels was unclear.

159. In addition to the critical failure to treat Averil's hypoglycaemia, we have seen that her overall care and treatment was poor from the moment she was transferred to ward N2. There was no assessment of her needs, as the Nurse Adviser says there should have been in line with established good practice and only one blood glucose entry at 11.30pm (0.6mmol/l). The first set of observations - which were done at 3.30pm - showed that Averil was very unwell and required prompt medical review – her MEWS was 4, which, in accordance with CUHT policy (paragraphs B41 to B43), meant that her situation needed to be escalated and observations carried out hourly. There is some evidence that Averil's abnormal observations were escalated to a doctor at this time, however as we have set out above, she was not seen by a doctor until 7.30pm that evening. The next observations were done at 6.30pm at which point her MEWS was still 4. The Nurse Adviser said that there is evidence that nurses escalated this information to a doctor, however in line with established good practice they should have continued to escalate this until Averil was seen by a doctor. If nurses were finding it difficult to obtain a medical review, the senior nurse on the ward should have escalated this to a more senior colleague until Averil was seen. This did not happen.

160. Following the measurement of Averil's blood glucose at 11.30pm, her physiological observations were not recorded again until 1.10am on 12 December. Her MEWS remained at 4, but again there is no evidence that any action was taken. This was yet another failing in Averil's care. No further observations were done until more than five hours later at 6.30am, which was not in line with CUHT policy. By this time, the Nurse Adviser said that Averil's temperature had dropped to 32°C, her blood pressure was around 65/45mmHg and her pulse was 45bpm. This meant that her MEWS was 7, significantly high. A note in Averil's records says that the nurse who took over from the night staff was *'awaiting a doctor to review patient'*, however there is no further evidence that suggests urgent action was taken. The Nurse Adviser said that any registered nurse should have recognised that Averil needed immediate medical intervention, yet this does not appear to have been sought or provided. Under CUHT policy, the nurse in charge, the critical care outreach team and Averil's medical team, should have been informed immediately. Again this did not happen.

161. At 7.45am Averil's MEWS score was still 7. Although the records show that the nurse in charge had been informed, there is no other evidence to suggest that the urgency of the situation was raised with medical staff or the critical care outreach team. *Good Medical Practice* required doctors looking after Averil to adequately assess her, if necessary by examining her, and to arrange further investigations or treatment as necessary. However, in her statement, the junior doctor who was contacted by the ward said that she was aware of Averil's MEWS of 7, but that *'the staff nurse told* [her] *she was not worried'* and therefore she should *'not worry either'*. This was clearly inadequate and not in line with *Good Medical Practice*. Averil required urgent medical attention. The

records also say that *'around 0845* [the consultant] *was on the ward and I informed him about* [Averil's MEWS]*'*.

162. It is clear that doctors did not follow CUHT policy, *Good Medical Practice* or established good practice when confronted with Averil's high MEWS. This was combined with the nursing staff's failure to follow CUHT policy or established good practice in carrying out regular observations and escalating concerns about a patient who was very seriously ill. These were basic, critical, failings in Averil's care.

The Consultant's communication with Averil's family

163. Last Mr Hart complains that the Consultant who was in charge of Averil's care told her family, at the time she was dying, that they should not question 'why', but rather try and put it behind them, as there would always be many questions that could not be answered .

164. The Trust told us that the Consultant refutes saying this to Averil's family. We cannot know exactly what was said. However, in line with *Good Medical Practice*, the Consultant should have ensured that what he said to Averil's family was sensitive and provided them with the information they needed (paragraph B24). Mr Hart clearly found the message he received unclear and unhelpful. Therefore the Consultant did not act in accordance with GMC guidance.

Summary

165. CUHT provided wholly inadequate care for Averil. There were multiple serious failings during her stay on ward N2 where staff did not provide appropriate acute care for their critically ill young patient. Most significantly, staff did not respond correctly to Averil's very low blood sugar level. CUHT's actions fell far short of what should have happened. This was service failure.

The impact of the failures we have identified in Averil's care and treatment

166. Mr Hart says that failings on the part of all the organisations involved in Averil's care resulted in her death.

167. Once we have decided whether there has been service failure and maladministration using our usual approach (as set out in paragraphs B2 to B4) we then go on to decide whether the injustice identified by the complainant (in this case, Averil's death) arose in consequence of that. In deciding this, we consider the evidence we have seen and the clinical advice we have received and make a decision on the balance of probabilities whether the injustice arose in consequence of the service failure.

168. We have found failures on the part of all the organisations involved in providing Averil with care – some more serious than others.

169. CPFT failed to adequately plan for Averil's discharge and the gaps that therefore resulted in her care; and CPFT failed to provide a multidisciplinary team to support the NCEDS Care Coordinator. UEAMC failed to provide the medical monitoring expected and

made a decision to stop seeing Averil weekly contrary to Averil's care plan. Each failure represented a missed opportunity to prevent Averil's further deterioration.

170. By the time of Averil's admissions to Norfolk and Norwich Hospital her condition had deteriorated significantly – such that she required urgent care. The failures in Averil's care up until this point contributed to the serious nature of her illness on admission to Norfolk and Norwich Hospital. At this time she urgently required care that addressed her dietary restriction and sabotaging behaviours. However, clinicians utterly failed to recognise this need. NNUH therefore missed opportunities to prevent her condition deteriorating further. This meant that she was in a severely weakened state and critically ill when she was transferred to Addenbrooke's Hospital (part of CUHT).

171. Finally, at CUHT we have identified that there were some basic, critical, failings in Averil's care. Had they assessed her condition and provided treatment for her severely depleted glucose level, on balance she would not have died on 15 December 2012.

The handling of Averil's family's complaint – key events

Complaint to Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)

172. On 19 December 2012 CPFT contacted Mr Hart to explain that they planned to do a Serious Untoward Incident Investigation (SUI) and asked for Averil's family's contributions. The family provided their contributions in March 2013[62].

173. On 1 February 2013 Mr Hart asked for copies of all Averil's clinical records held by CPFT.

174. On 14 February the Patient Information Team Leader at CPFT sent an email to the Eating Disorder Unit Lead Psychiatrist asking whether Averil's files had arrived. The Eating Disorder Unit Lead Psychiatrist responded explaining that she could not release the files as they included a lot of confidential information that Averil did not want shared with her family. She explained that she would ring Mr Hart that evening to find out what he was asking for, and which sections of the notes could be made available to him. A subsequent handwritten note on the hard copy of this email reads, *'copy parts of vol 4 only, for collection 25th Feb (*[Nic] *Hart)'*[63].

175. On 15 February the Eating Disorder Unit Lead Psychiatrist completed an internal form advising that volumes 1 to 3 of Averil's records did not need to be copied and that this had been discussed with Mr Hart.

176. On 20 February the Patient Information Team Leader wrote to the Eating Disorder Unit Lead Psychiatrist advising that volume 4 of the clinical notes had been copied and that he was waiting for confirmation that Averil's mother supported Mr Hart's application for the records. In this note, he asked the Eating Disorder Unit Lead Psychiatrist whether

[62] This was a detailed submission and included concerns about the care Averil received from other organisations, not just CPFT. CPFT shared this submission with CUHT and undertook to share with NNUH. The CCG also agreed with Mr Hart that it would ensure he received responses from all the relevant organisations.
[63] Collection of the records was subsequently postponed to 28 February 2013.

she required all of Averil's records. The Eating Disorder Unit Lead Psychiatrist responded that all four volumes should be sent over '*just in case there is something*'.

177. On 26 February Mr Hart provided CPFT with a letter signed by both himself and Averil's mother confirming that they were acting as executors for Averil, and that they would like to see her records.

178. On 28 February Mr Hart was given volume 4 of Averil's records – these records were about the care and treatment she received after her discharge from ward S3.

179. During this period Mr Hart met the team from CPFT who were undertaking the SUI investigation. In March the CPFT SUI team also met staff from CUHT. The purpose was to provide CUHT with details of Mr Hart's concerns to help inform their SUI investigation. CPFT agreed to send Mr Hart's submission to NNUH to help inform their investigations. CPFT and CUHT also agreed a date to meet with Mr Hart to discuss the SUI reports and any questions Mr Hart had. This was to be held in June, however the meeting did not go ahead. Mr Hart felt it was too soon to meet with staff.

180. On 13 May CPFT produced their SUI report which considered the period from Averil's discharge in August 2012 to her death on 15 December 2012. A copy of this report was shared with Mr Hart.

181. On 12 November Mr Hart asked for a meeting with CPFT's Chief Executive. His email was acknowledged on 19 November confirming that the Chief Executive would be happy to meet him. A meeting was subsequently arranged for 3 December in advance of which Mr Hart sent the Chief Executive a number of documents to consider.

182. On 4 December following their meeting, the Chief Executive wrote to Mr Hart. He explained that the Clinical Commissioning Group's (CCG) offer of an independent investigation would go ahead, but that CPFT wanted to provide Mr Hart with answers to all the questions he raised in his submission to the SUI review, as well as those which he had put to the CCG. The Chief Executive explained that he hoped this would resolve the need for a formal complaint and noted that the NCEDS team were keen to meet Mr Hart to discuss his concerns.

183. On 9 December Mr Hart emailed the Chief Executive (via his Executive Assistant). In this email Mr Hart repeated the concerns that Averil's family had about NCEDS, and their desire for an independent inquiry into Averil's care. The Chief Executive acknowledged Mr Hart's email the following day saying that they would answer his questions in January 2013.

184. On 13 December Mr Hart emailed one of CPFT's consultant psychiatrists noting that Averil's family would be scattering her ashes on 21 December. The NCEDS team responded on 20 December expressing their sympathy, assuring him that they would answer his questions and saying they were more than willing to meet with him.

185. On 30 December Mr Hart replied to the suggestion of a meeting, '*maybe this will be possible at some stage, but meeting those responsible for the lack of care that led to Averil's death will be incredibly hard for our family*'.

186. On 8 January 2014 Mr Hart submitted a formal complaint on behalf of Averil's family. Mr Hart explained that this was the first part of a major complaint, setting out 14 points on which he believed CPFT failed in relation to Averil's transitional care between hospital and the community.

187. On 17 January CPFT's Chief Executive wrote to Mr Hart with a response to his initial questions as agreed in his letter of 4 December. This response did not include answers to Mr Hart's complaint of 8 January. The responses provided were brief and the Chief Executive said in his covering letter that they were '*initial answers*' and that further detail would be better presented at a face-to-face meeting.

188. On 17 January Mr Hart acknowledged the letter from the Chief Executive. He wrote: '*I would like to reiterate we will not be having a meeting with any of the team responsible for Averil's death until an independent external inquiry has been completed to our satisfaction*'.

189. On 28 January CPFT's Chief Executive wrote to Mr Hart noting that Mr Hart no longer wished to meet the team, and saying that he felt it was important to make two points: 1) that CPFT had not provided Mr Hart with full answers because '*some of the answers are extremely sensitive and for this reason we would like to explain what happened face to face and feel that this is better done that way*', and 2) to place on record that the offer of a meeting remained open.

190. On 29 January Mr Hart thanked the Chief Executive for the preliminary work CPFT had done. He explained that, '*On completion of the external inquiry we will be in a position to decide whether as a family we would wish to meet with the team responsible for Averil's death*', and he added that Averil's family's '*recent receipt of correspondence from the Secretary of State for Health, Jeremy Hunt, regarding Averil's case, has provided us with assurance that Averil's case will be looked into as a matter of urgency and with the full rigour that is required*'.

191. On 30 January the Chief Executive responded to Mr Hart saying that CPFT fully understood how important it was for Averil's family to understand as much as possible of the circumstances surrounding her death, but that answers needed to be given face-to-face. The Chief Executive noted that an independent inquiry was not taking place; rather that the CCG had proposed to arrange an independently chaired investigation.

192. On 14 March Mr Hart contacted the Chief Executive to request clarification on when Averil had been seen by members of the NCEDS team, by whom, and for what reason.

193. On 17 March Mr Hart requested a meeting with the Chief Executive to '*bring us both up to date with developments and to run through "information" that is currently patchy in nature and will need further investigation*'.

194. On 24 March the Chief Executive replied to Mr Hart. He expressed concern that the multiple questions Mr Hart was sending to both CPFT and the CCG would cause confusion and repeated his offer to meet with Mr Hart and members of the NCEDS team. Mr Hart

replied on 26 March stating that he did want to meet with the Chief Executive, but that he did not feel able to meet with the team responsible for Averil's care.

195. On 27 March the Chief Executive emailed Mr Hart to confirm a meeting date. In this correspondence, the Chief Executive acknowledged that Mr Hart had said he was not ready to meet members of the NCEDS team, but he went on to say that he believed it would be helpful if the Service Manager attended, as they would be well placed to answer more detailed questions about Averil's care. Mr Hart replied the same day saying that the member of staff in question had been Service Manager of NCEDS at the time of Averil's death, and repeated that he was not able or willing to meet any of the team at that point in time.

196. On 28 March Mr Hart's email was acknowledged by the Chief Executive's Executive Assistant. The acknowledgement stated that the Chief Executive was aware of Mr Hart's concern about the Service Manager attending any meeting, but that she was not a clinician and therefore had no direct involvement with the treatment of patients.

197. On 1 April Mr Hart replied to the Chief Executive reiterating his wish to meet him without any members of the NCEDS team. Mr Hart also referred to questions he had submitted on 14 March and requested that they were answered under the Freedom of Information Act. The Chief Executive's Executive Assistant replied the same day noting his request to meet alone with the Chief Executive and offering him a slot directly before the meeting that was already scheduled.

198. On 9 April the Chief Executive wrote to Mr Hart and said that his recent questions would not fall under the requirements of the Freedom of Information Act. He stated again that CPFT were keen to provide a full response, but that due to the nature and possible implications of the answers, staff at the Trust felt a face-to-face meeting would be the best way of providing these. Mr Hart replied the same day asking whether the Trust were refusing to answer his questions and urging them to be more open and honest with the family. Mr Hart's email was acknowledged the following day by the Chief Executive's Executive Assistant.

199. On 11 April Mr Hart emailed the Chief Executive asking for an update on the progress of his 8 January complaint and for a response to his questions of 14 March about which staff from NCEDS saw Averil and when. The same day the Chief Executive wrote back to Mr Hart noting his concerns, assuring him that CPFT were '*certainly not involved in a "cover up"'* and saying that he looked forward to meeting him and hoped he was '*happy with our suggestion that* [the Service Manager] *attend'*.

200. On 22 April Mr Hart requested an update on the progress of his formal complaint. He repeated Averil's family's concern about a cover-up of the facts and asked that the information originally requested on 14 March be provided under the Chief Executive's Duty of Candour.

201. On 24 April Mr Hart met the Chief Executive. An internal email sent between CPFT staff explains that, '[the Service Manager] *was also present in the building, but Mr Hart declined her participating in the meeting between the parties*'.

202. On 9 May the Chief Executive wrote to Mr Hart enclosing a document setting out the dates of Averil's contact with CPFT staff, as well as a copy of the specification for NCEDS, which Mr Hart had also asked for. He apologised for not yet responding to Mr Hart's formal complaint of 8 January.

203. On 22 May CPFT sent Mr Hart a written response to his formal complaint of 8 January. Mr Hart emailed the Chief Executive that evening questioning the accuracy of the answers provided and telling him that he intended to launch a website highlighting Averil's case. The following day Mr Hart emailed the Chief Executive to ask why it had taken so long to provide him with a response to his complaint.

204. On 27 May the Chief Executive replied to Mr Hart. He said that the delay in responding was entirely his fault and offered his sincere apologies for this. He explained that he had not recognised it as a complaint separate to the other correspondence Mr Hart had sent. The Chief Executive said that the situation had been exacerbated by the fact that he had been dealing directly with Mr Hart (rather than through the complaints team) and that this had meant the complaint had not been registered in the usual way.

205. On 21 July Mr Hart wrote to the Chief Executive's Executive Assistant to update his contact details. At the same time he advised that he was '*finalising a range of questions concerning NCEDS supervision, NCEDS staff experience and other areas of concern in the coming weeks*'. The following day Mr Hart asked for a copy of the exact guidelines that were sent by a member of CPFT staff to UEAMC - these were sent to him later that day.

206. On 25 July Mr Hart asked for a digital copy of CPFT's SUI report (which he had previously received in hard copy). However, on 28 July CPFT explained that this was against their policy.

207. On 31 July Mr Hart requested a full set of Averil's clinical records. He also emailed eight questions about the decision to weigh Averil at NCEDS rather than UEAMC.

208. On 3 August the Medical Director acknowledged Mr Hart's email and advised him that his questions were being looked at and that the Chief Executive would respond.

209. On 4 August Mr Hart emailed the Medical Director explaining that he had also raised three questions with the CCG under the Freedom of Information Act about the cost of inpatient care on the Eating Disorder Unit, CPFT statistics for inpatients who subsequently relapsed, and CPFT policy for transitional care arrangements. He noted that the CCG had asked him to forward these to CPFT for a response. The same day the Medical Director emailed Mr Hart stating that she had begun to progress his request, but that she needed to ask him to do something '*horribly bureaucratic*' and send his request to the Trust Secretary.

210. On 7 August Mr Hart sent the Medical Director a detailed set of questions about Averil's care and treatment at NCEDS.

211. On 11 August, following a telephone conversation between Mr Hart and the Records and Information Governance Manager, the Medical Director contacted Mr Hart and explained that the Chief Executive was dealing with his recent questions, and that she

(the Medical Director) would be handling his request for Averil's records. In her correspondence she made reference to the fact that Mr Hart was upset on the telephone to her colleague, and asked whether he had spent any time thinking about his psychological health and well-being, and to contact her if she could help in any way.

212. In reply Mr Hart thanked the Medical Director for her concern. However, he noted that she had copied her email to him to the NCEDS team (who in his opinion were '*responsible for Averil's death*') when he had asked for confidentiality to be paramount.

213. On 12 August the Medical Director responded to Mr Hart saying '*I can absolutely assure you that there is no cover up in relation to your daughter's death. I am so sorry if my expression of concern for your health felt inappropriate*'. The same day Mr Hart responded and asked for the details of the person who would be reviewing and preparing Averil's records (following his request of 31 July) and a statement confirming that this individual had no connection with the NCEDS team or the clinicians at the Eating Disorder Unit, and no prior knowledge of Averil's case. He also asked the Medical Director how she was able to say that there was no cover-up.

214. On 13 August the Medical Director told Mr Hart that she could say this with confidence because Averil's death had been a '*terrible blow*' to the clinicians involved in her care, and because all the clinicians who have since reviewed Averil's care were given '*full unredacted copies of medical records*', with '*no form of pressure on either of these individuals to do anything other than freely form their own view of the care and treatment of your daughter*'. She repeated her apology that Mr Hart found her expression of concern for his health disingenuous.

215. On 13 August Mr Hart wrote back to the Medical Director. He said: '*The fact that Averil's death was a "blow to the clinicians involved" is a natural response when they realised that their lack of care was responsible for her death.*' He explained that he did not find her concern disingenuous, but that his meetings with others had shown that this was a commonly used tactic when faced with direct criticism or concerns about a cover-up.

216. On 29 August Mr Hart chased a response to his questions of 31 July. On 2 September the Medical Director replied saying that the Chief Executive was overseeing a single response to all the questions Mr Hart submitted during late July and early August, and that it should be with him soon.

217. On 4 September the Chief Executive wrote to Mr Hart. He stated that CPFT had cooperated openly with the independent review of Averil's care commissioned by the CCG, and that they are '*absolutely committed to learning the lessons from Averil's tragic death*'. He said that the volume and complexity of Mr Hart's further requests was disruptive to the work of a small team who needed to concentrate on the care of other seriously ill patients. The Chief Executive also expressed concern about the '*selected information*' Mr Hart was publishing on his website and said that this was likely to undermine the service and could put vulnerable service users at greater risk. The Chief Executive stated that, for these reasons, he did not believe it was appropriate to answer Mr Hart's questions in writing, and reiterated the proposal to meet with the team to discuss his ongoing concerns.

218. In reply (on 4 September) Mr Hart explained to the Chief Executive that it was never his intention to interfere with the provision of care to others, but that a lack of willingness on the part of CPFT to take responsibility for the tragic outcome had hampered the process. Mr Hart said that he would like to take up an offer of being involved with monitoring the implementation of changes put in place following Averil's death, but reiterated that Averil's family were not prepared to meet the NCEDS team until they had agreed an accurate chronology of Averil's care and until CPFT had recognised and admitted responsibility for their failings. On the same day, Mr Hart asked the Medical Director for a date when he would be able to collect Averil's medical records, noting that '*After more than seventeen months of waiting, these missing records are becoming of concern to myself and others*'.

219. On 5 September the Medical Director replied explaining the steps involved in preparing the records (including identifying the information Averil had not wanted to be shared). The Medical Director said that she anticipated the work would take a further month. Mr Hart replied the same day expressing concern about the time taken to respond to his request and asking the Medical Director to confirm who was undertaking the '*censorship of Averil's medical records*'.

220. The Medical Director responded that CPFT had a legal duty after the death of a patient not to release information which they might reasonably believe the patient would not have wanted released. The Medical Director set out the process being followed and said that she was aware Mr Hart felt the process had taken a long time. She added '*As I wrote to you previously some considerable part of that time period seems to have arisen as a result of a misunderstanding on the part of* [CPFT] *about what you had requested be released. I accept that this was an error on* [CPFT's] *part*'.

221. On 8 September Mr Hart emailed the Chief Executive to chase a request he had made a month earlier for the job description of the role of Head of Unit. The job description was sent to him on 15 September.

222. On 17 September Mr Hart emailed the Medical Director to say that CPFT had deliberately delayed releasing evidence to Averil's family. He asked her to confirm whether she had read the report commissioned by the CCG and the original remit of this. Mr Hart asked the Medical Director for a response to these questions on 24 September. She replied the same day to let him know that a copy of Averil's records was now ready and referred him to the Chief Executive about the other matters.

223. On the same day (24 September) CPFT sent Mr Hart copies of Averil's records. They explained that these were subject to certain redactions, made in line with the *Access to Health Records Act 1990* and that this included entries which were particularly sensitive and private, information about third parties, and documents generated by organisations other than CPFT. CPFT confirmed that information about the care given to Averil had not been redacted from the records. They apologised for the confusion in processing Mr Hart's initial request for records in 2013 and noted that they had misunderstood this at the time. They apologised for the distress this had caused Averil's family.

224. On 14 October Mr Hart was given copies of internal emails sent by CPFT staff about the investigation of his complaint in response to subject access requests[64] for this information. CPFT explained to Mr Hart that some emails or parts of emails had been redacted and set out the reasons for this.

225. On 23 October Mr Hart asked the Chief Executive for copies of the NCEDS annual report. He also asked for a seat at the next CPFT board meeting as a patient representative.

226. On 27 October the Chief Executive gave Mr Hart the date of the next board meeting and explained that members of the public were welcome to attend in the audience, but that its constitution did not include a patient representative. He reiterated that CPFT remained keen to meet with him. Mr Hart replied the same day asking for the contact details for the Chair of the forthcoming board meeting. The Chief Executive provided these details and a copy of the NCEDS annual report two days later. Mr Hart attended the board meeting on 5 November.

227. On 16 March and 26 May 2015 Mr Hart was given copies of further internal emails sent by CPFT staff about the investigation of his complaint, in response to his subject access request. CPFT explained to Mr Hart that some emails or parts of emails had been redacted and the reasons for this (for example, personal email and telephone numbers, information from third parties). They explained to Mr Hart that it had not been possible to search the Eating Disorder Unit Lead Psychiatrist's account for emails before 22 February 2013 because these had been deleted and deleted messages were only retained for 365 days.

228. On 6 August, following an investigation into CPFT's handling of Mr Hart's subject access requests, the Information Commissioner's Office wrote to CPFT with the conclusion of their investigation. They concluded that it appeared that CPFT had provided all the personal information that it held for Mr Hart, and that any information withheld was not shared on the grounds that it was deemed to be third party information or was no longer held by CPFT. The ICO commented that '*any information deleted has been done so in accordance with the Trust's own retention policy*'.

Complaint to University of East Anglia Medical Centre (UEAMC)

229. On 3 January 2013 Mr Hart contacted the University Medical Service (of which UEAMC is a part) to ask whether they had started a '*Critical Incident Inquiry*' following his daughter's death, and to tell them that he would like to have the opportunity to submit questions, and discuss any recommendations arising from it.

230. On 8 January the senior partner at UEAMC replied to Mr Hart's letter. She said that they were '*very saddened*' to learn of Averil's death and that there was a '*Significant Event Review*' meeting scheduled for 30 January, and that Mr Hart would be welcome to forward any questions or observations he had for discussion. She explained that UEAMC

[64] Under the *Data Protection Act 1998* (DPA) individuals have the right to get a copy of the information that is held about them. This is known as a subject access request.

had not had any contact with Averil in the month prior to her hospital admission and that, based on communication from both her and NCEDS, they had believed that Averil was receiving the care she required.

231. On 2 April Mr Hart asked for an update on the progress of their inquiry and for a copy of all Averil's medical records held by UEAMC. Mr Hart enclosed a copy of the letter the Eating Disorder Unit Psychologist had sent to UEAMC setting out the monitoring requirements and asked whether these health checks had been completed on a weekly basis as requested.

232. On 5 April UEAMC acknowledged receipt of Mr Hart's letter and on 11 April they sent him copies of Averil's medical records.

233. On 23 May UEAMC provided a response to Mr Hart's questions. They said that:

- Averil was seen on a number of occasions by GPs at UEAMC;
- they had received an email from Averil on 20 October 2012 which confirmed that she was receiving care from NCEDS, and that '*whilst it was recognised Averil had a significant medical problem that carried risk and vulnerability, the fact that her weight appeared to remain steady and that she reported feeling positive and confirmed that she was attending weekly monitoring, led the clinicians up until early November to believe that there were no immediate serious concerns*'; and
- UEAMC had carried out an internal review and '*steps have been taken to ensure that all colleagues are aware of the guidelines issued by King's College and of training and refresher courses*'.

234. On 24 May Mr Hart confirmed receipt of this letter and said he understood it was the result of prompting by the CCG to reply to his earlier letter after several weeks of delay. He asked for a list of the dates when Averil attended UEAMC, and full details of the health checks that were done and the results of any tests. Mr Hart also commented '*it is normal for* [anorexia nervosa] *sufferers to go to great lengths to hide weight losses and your suggestion that an email from a mentally sick patient was sufficient reason not to provide primary care is totally unbelievable*'. He concluded by saying, '*the tragic death of our daughter is a direct consequence of the lack of care provided by you and the University Medical Service*'.

235. On 31 May UEAMC responded to Mr Hart and apologised for '*some confusion about the correspondence*'. They said they had been under the impression that Mr Hart had been given the information he wanted when Averil's medical records were sent to him, which is why they had only recently written again. They said that these records included the details he had asked for about Averil's appointments, and enclosed a copy of the email she had sent to UEAMC. UEAMC added that they had received a letter from NCEDS dated 26 October 2012 which '*changed the management plan outlined in September and confirmed that* [Averil] *would be seen and weighed weekly at their service*'. In response to Mr Hart's concluding statement about Averil's death being due to their lack of care, the senior partner at UEAMC commented that it is '*very strongly made*' and noted that Mr Hart had not complained officially and that they were happy to meet if he asked for this.

236. On 10 June Mr Hart wrote to UEAMC. He said that the medical records he had received were '*far from clear*' and asked them to complete a table he had provided to show the dates of Averil's visits to UEAMC, the tests that were completed, and the results of these tests.

237. On 12 June Mr Hart sent a further letter to UEAMC asking them to complete another table to show when UEAMC had communicated with any of the other agencies involved in Averil's care. UEAMC replied on 14 June saying '*as stated in previous correspondence you already have Averil's complete medical record which should give you the answers that you require*'. They offered again to meet with Mr Hart.

238. On 21 June Mr Hart repeated his request for the information he had asked for, saying that once he had received this information, he would arrange a meeting with UEAMC.

239. On 26 June Mr Hart asked UEAMC to send a copy of Averil's medical records to the CCG. UEAMC confirmed to Mr Hart on 1 July that they had done this. On 4 July Mr Hart thanked UEAMC for sending the records to the CCG and asked them to forward a copy of the report of their significant event review into Averil's death.

240. On 15 July the CCG wrote to UEAMC enclosing a table they had completed, as requested by Mr Hart based on the information in Averil's records and asking them to comment. They asked UEAMC to send Mr Hart the information he had asked for about eating disorders training that doctors from UEAMC had attended and a copy of their internal review into Averil's death. Mr Hart also wrote to UEAMC on the same day repeating his requests for information.

241. On 26 July UEAMC replied to the CCG saying that they felt it would be more appropriate to meet Mr Hart in person because '*it is not productive to engage in protracted correspondence, nor reasonable to keep doing so*'. They advised the CCG that they had '*sent* [Mr Hart] *an information leaflet about* [their] *complaints procedure which include*[d] *information about the ombudsman service and on this issue we have received no response*'. They also enclosed copies of Averil's email of 20 October 2012 which they described as '*very positive in its tone*' and Mr Hart's letter of 26 May 2013, directing the CCG to the '*very strong statement*' in its conclusion.

242. On 12 August UEAMC sent a second letter to the CCG in which they said that it was important that the table the CCG had completed omitted Averil's email to them. They stated that '*whilst any university student with healthcare needs can be offered reasonable adjustments, they are autonomous individuals who must be offered patient choice. Averil did make contact and knew how to obtain support from the Medical Centre, the Dean of Students' Office and* [NCEDS]'. They noted that Averil's weight had remained steady during the time she had been under their care and that '*the fact that the suggestion that her blood tests should be done every 2-3 months rather than weekly or fortnightly, did indicate that the level of concern about sudden physical deterioration seemed low*'. They added that '*after we had been advised to stop weighing her we would have expected communication from* [NCEDS] *if there was alarm or concern about a*

deterioration in her weight or general wellbeing'. UEAMC listed the main action points identified following their significant event meeting as:

- '*Working in partnership across all the Services, particularly in terms of communication and safety netting*[65].
- *Highlighting the difficulties of respecting the duty of confidentiality whilst respecting patient's choice and autonomy.*'

243. On 30 January 2014, having invited Mr Hart to compile a list of his questions, the CCG forwarded these to UEAMC.

244. On 31 January UEAMC replied to this letter. They said Averil had registered with them on 26 September 2012 and they had received a telephone call from the Eating Disorder Unit Psychologist on 27 September, followed by a copy of Averil's discharge summary on 2 October. They said that this asked them to '*check her physical weight every week and to monitor bloods every 2-3 months*'. UEAMC explained that Averil had had an initial health check on 5 October and that she saw a GP on 12 October who noted a 1kg weight loss, but that Averil was well and settling in. UEAMC said Averil was next seen by a GP on 25 October. They said that at this appointment her weight, BMI, blood pressure, heart rate, and squat test were recorded, and '*it was noted that she was doing well and felt supported. She was eating regularly and maintaining weight. It was noted that she was seeing* [NCEDS] *weekly so an appointment was made for 2 weeks.*' UEAMC explained that they had received a copy of NCEDS' letter on 30 October telling them that Averil was being weighed there weekly so did not need to have this done at UEAMC. They said Averil had been seen again on 8 November as planned and refused to be weighed. Her heart rate was recorded and the doctor asked her to arrange an appointment for one month's time. UEAMC said that Averil was judged to be stable at this point, and that they understood there had been a deterioration in her health in the weeks following this appointment, but had not been made aware of this, '*so sadly were not given an opportunity to intervene*'. They confirmed that Averil had not had an ECG[66] done at UEAMC, that she had had a squat test on 25 October, and that the appointment to arrange blood tests had been cancelled by Averil. They said that, '*according to the King's guidelines, as the BMI was over 15 there was no indication to do them urgently*'.

Complaint to Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)

245. On 9 January 2014 Mr Hart complained to NNUH. He said that Averil's family felt a major contributory factor in her death was the lack of appropriate treatment and care that she received at NNUH, and that they had failed to follow appropriate guidelines for anorexia patients while she was in their care.

246. On 14 February NNUH responded, setting out Averil's care from her admission on 7 December 2012 until her transfer to Addenbrooke's Hospital. In their letter NNUH said that they believed that *'MARSIPAN guidance was met and every effort was made to liaise*

[65] Safety netting is important in high risk clinical situations. It requires effective systems and processes to make sure a patient is monitored and investigated, and that any deterioration in their condition is picked up.

[66] An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity.

promptly with the psychiatric team as the risks and challenges of treating a very sick young woman with anorexia nervosa were recognised by staff'. They concluded that the *'severity of* [Averil's] *liver failure was* […] *a significant contribution to her deterioration'*.

247. Mr Hart was understandably unhappy with this response and asked for an external review of Averil's care. The Trust arranged for this to be done by one of the authors of the MARSIPAN guidelines, and this report was completed in March. In April, the then Chief Executive of NNUH met Mr Hart and the author of the report. During this meeting NNUH agreed to commission an independent review to consider the care provided to Averil and the Trust's guidelines for the care of patients with acute anorexia. This review was to be carried out by the principal author of the MARSIPAN guidelines. He met Mr Hart, at Mr Hart's request in July. His review was completed in August and shared with Mr Hart in September. NNUH started to implement his recommendations in October.

Complaint to Cambridge University Hospitals NHS Foundation Trust (CUHT)

248. On 10 May 2013 CUHT completed a Serious Untoward Incident report (SUI), looking at the period from Averil's transfer to Addenbrooke's Hospital on 11 December 2012 until her death on 15 December. The SUI found there was a delay in Averil being seen by a doctor and that blood tests should have been done. The SUI report also found that there was a misunderstanding between the junior doctor and the consultant about the ongoing management of Averil's hypoglycaemia, and that there was inadequate escalation of the MEWS score at 6.30am and 7.45am on 12 December. However, the report also found that it was appropriate that the decision about NG feeding was deferred overnight. The report concluded that if Averil had been reviewed earlier, it was likely that more information would have been available and this would have helped inform the plan for her care overnight. But the report concluded that it was unclear whether this would have changed the outcome for Averil.

249. On 9 January 2014 Mr Hart made a formal complaint to CUHT. He complained about:

- '*failure of Addenbrooke's to ensure an appropriate assessment of Averil's mental capacity as per MARSIPAN guidelines, with no use of the* [Mental Health Act] *to ensure Averil's safety*';
- '*failure to instigate safety procedures to ensure that Averil's blood glucose levels were maintained at a safe level, resulting in a major seizure with catastrophic results*';
- '*failure to ensure commencement of treatment for a patient in a critical condition in a timely way*';
- '*failure to ensure implementation of the basic risk assessment for Averil, leading to the neglect of a high risk, vulnerable patient overnight and preventable death of a young person*';
- '*failure to assign appropriate staff to a patient in a critical condition (with knowledge of Averil's condition and capable of dealing with a condition which after several days with no nutrition, glucose levels would be critical)*'; and
- '*failure to keep Averil's family fully informed of the situation.*'

Mr Hart said that he believed *'the lack of care by Addenbrooke's (particularly the maintenance of Averil's blood chemistry) was instrumental in the rapid deterioration of Averil's health* […] *and this was a major contributory factor in her death'*.

250. On 5 February CUHT responded to Mr Hart explaining the outcome of the SUI and that they had identified learning from this. They said that they believed the questions Mr Hart had asked were answered in the SUI report and enclosed a copy.

251. On 4 September Mr Hart replied saying that whilst he appreciated that CUHT had made efforts to understand what went wrong in Averil's case, her family believed further work was needed. He set out his outstanding concerns which were:

- that the report did not discuss safety procedures for maintaining blood glucose levels and carrying out routine tests;
- that the report did not directly address the use of the Mental Health Act, especially in the context of anorexia nervosa; and
- that the report suggested there should be a clear pathway for managing patients with anorexia nervosa, but failed to outline what steps had been taken and why they are sufficient.

252. Mr Hart requested an external review and referred to the fact that another organisation[67] he had complained about had agreed to this and that he had been particularly impressed with their response when he raised similar concerns with them. CUHT agreed to carry out an external review[68]. However this has not been done[69].

Complaint to the Clinical Commissioning Group (CCG)

253. On 17 May 2013 following a number of questions raised by Mr Hart, the CCG met with him. At this meeting the Chief Officer agreed a number of actions. These included that the CCG would chase CPFT for the completion of the SUI report and follow up UEAMC's lack of response to Mr Hart's letter.

254. On 21 May the CCG sent Mr Hart the final SUI reports from CPFT and CUHT, along with CPFT's action plan. The CCG confirmed that their Head of Clinical Quality and Safety would be reviewing the reports to determine if all aspects had been fully considered.

255. In June Mr Hart wrote to the CCG to inform them that following their meeting and receipt of the CPFT SUI report, the family were in the process of compiling a list of further questions. Mr Hart asked for the CCG's help to ensure their questions were fully and truthfully answered. He also asked for specific information from the CCG which he

[67] This was NNUH.
[68] Mr Hart told us that this agreement only came about following pressure from a variety of sources. He cites these as; *'A) Persistent phone calls to the CE's office and PALS, B) Involvement of the Patients Association and Katherine Murphy's personal intervention, C) A web site for Averil that highlighted the lack of care that Averil received, D) The implication that Averil's family would take legal action if no external review took place, E) The news that the case was being referred to the PHSO'*.
[69] This was not done because they were not able to agree an expert to carry out the review with Mr Hart.

said was needed in order for the family to raise the relevant questions about CPFT's SUI report.

256. On 25 June the CCG wrote to CPFT. In this letter the Head of Corporate Affairs explained that the CCG was asked to '*take the lead role in reviewing the Root Cause Analysis Reports arising and ensuring that recommendations were carried out*.' She also explained that her personal role was to act as a liaison officer between the family and agencies involved, including NHS Trusts. She asked that CPFT address a number of questions the family had raised, which she set out.

257. In July the CPFT Patient Safety Lead responded to the CCG. She explained that they were keen to meet Mr Hart to discuss the SUI report and any further questions he had. She explained that CPFT had offered Mr Hart a joint meeting with themselves and CUHT on 17 June; however, Mr Hart had felt that this was too soon. The CPFT Patient Safety Lead asked whether the CCG would help set up a meeting with Mr Hart, CPFT and CUHT so that they could respond to Mr Hart's questions.

258. The CCG met with Mr Hart again in July and following this meeting provided Mr Hart with a table of correspondence between UEAMC and 'other agencies'. A copy of this table was sent to UEAMC with a request for some further information.

259. On 17 September the CCG contacted CPFT as they had not yet received CPFTs response to the issues that Mr Hart had raised (as set out in the June letter). The CCG informed CPFT that Mr Hart had told them that *'he will soon now open formal complaints into his late daughter's care if there is no movement and we should have every expectation that his complaints will be escalated to the Health Ombudsman'*. The Head of Corporate Affairs at the CCG said that she was aware that CPFT was keen to meet Mr Hart, but she explained that Mr Hart was clear that *'he did not wish to meet with providers'* until he had the full picture of what had happened and why.

260. CPFT responded by explaining that Mr Hart had at times been emailing several times a day with many questions to the point that staff could not turn these around before another set of questions came in. A meeting had therefore been suggested as a way to try to pull all the threads together.

261. On 27 September the Head of Corporate Affairs at the CCG wrote to Mr Hart. She confirmed that a further meeting would be held between Mr Hart, the Chief Officer and the Head of Quality and Safety in October. She also said that the CCG had written to CPFT to express the CCG's concern about the lack of response from CPFT in relation to the issues raised in June.

262. Following the meeting with the CCG, Mr Hart wrote to them to ask for a copy of the minutes from the meeting and for contact details of the Chief Executive of CPFT so he could arrange a meeting with him. He also asked the CCG to arrange an independent external inquiry into the failures at NCEDS and UEAMC.

263. On 24 October the Chief Officer of the CCG wrote to Mr Hart setting out the issues that had been discussed at their recent meeting. The Chief Officer explained that he did not think an external enquiry would be appropriate. He said that this was because the

investigations arising from Averil's death had identified gaps in service and action plans had been produced to address these. And the CCG was monitoring the delivery of the action plans, in relation to services which they commissioned. The Chief Officer agreed that there had been unhelpful delays in responding to a number of Mr Hart's enquiries to date and said he regretted that as a result Mr Hart had lost confidence in the services. However, the Chief Officer asked that CPFT was given the opportunity to respond to all his outstanding questions, either in writing or in a meeting.

264. In an email reply to the Head of Corporate Affairs Mr Hart said he felt that the minutes of the meeting did not represent an accurate picture of what was said. He requested a further meeting with the CCG. The Chief Officer responded that he saw little value in a further meeting with CCG staff at that time.

265. Mr Hart remained unhappy with the responses from the CCG and wrote again to the Chief Officer setting out his concerns that the CCG did not have '*the drive and determination to find the truth and root causes behind* [his] *daughter's death*'.

266. The Chief Officer responded on 26 November. In his letter he said that he had been reflecting on how best to ensure that Mr Hart got all the information he required as soon as practicable. He explained that he had therefore contacted UEAMC and the Chief Executives of the other organisations involved in Averil's care and asked for their personal commitment to respond fully and openly to Mr Hart's questions. He asked Mr Hart to provide a list of all the questions he wanted answered. The Chief Officer said the CCG would take responsibility for ensuring that responses were received within the timescales that were to be agreed. The Chief Officer said that once they had received satisfactory responses, Mr Hart and his family would be invited to a meeting with the CCG and as many of the providers Mr Hart would like to meet with to discuss the responses. The CCG proposed to ask the local Healthwatch[70] to provide an independent person to chair the meeting. In addition the CCG told Mr Hart that they would be asking the Royal College of Psychiatrists to recommend the services of an independent consultant psychiatrist with relevant specialist interest to look at the care Averil received.

267. They asked Mr Hart to contact them by 16 December with any further questions he had, and to confirm whether he agreed with their proposed plan.

268. On 2 December Mr Hart responded saying that Averil's family were considering the CCG's proposal. He asked them to provide the questions they had asked NCEDS about Averil's death (excluding the questions which the family had asked).

269. On 10 December the CCG wrote to Mr Hart and explained that their contact with NCEDS was primarily about the management of the current contract. The letter also explained that the CCG did not accept that details of the CCG's performance management of NCEDS would have an impact on the family's outstanding questions about Averil's actual care. On the same day the CCG contacted the Royal College of Psychiatrists and asked them to recommend a suitable professional to review Averil's care.

[70] The health and social care reforms of 2012 created a Healthwatch in every local authority area across England and Healthwatch England, a national body. The network works to share information, expertise and learning in order to improve health and social care services.

270. On 17 December the Royal College of Psychiatrists told the CCG that their request was in hand, but they needed further information to ensure that they did not approach anybody that had a conflict of interest.

271. On 2 January 2014 the CCG told Mr Hart that they had not asked any specific questions about Averil's care given that their '*prime function* [was] *the management of the contract since 1 April* [2013] *and testing assurances that gaps identified in the Root Cause Analysis*[71] *into Averil's death* [had] *been bridged*'.

272. On 7 January the CCG provided the Royal College of Psychiatrists with a list of staff employed by the local eating disorder service. This included the Eating Disorder Unit Lead Psychiatrist, the NCEDS Lead Psychiatrist, the NCEDS Specialty Doctor, and the NCEDS Consultant Clinical Psychologist. The NCEDS Care Coordinator was also mentioned.

273. On 17 January the list of staff was sent to the Royal College of Psychiatrist's Eating Disorders Executive Committee. They told us that the consultant psychiatrist commissioned by the CCG to undertake a review (the Consultant Psychiatrist) was the only clinician who responded to their request. The CCG updated Mr Hart, telling him that a cohort of independent consultant psychiatrists had been invited to contact them in response to their request for someone to carry out an expert review into the quality of Averil's care. This letter also said that the CCG understood Mr Hart had provided a comprehensive list of questions concerning Averil's care to CPFT, which CPFT were addressing, and that CPFT would arrange a meeting with relevant staff once Mr Hart had had the opportunity to consider the response. The CCG said it would ensure that responses from the other providers involved were also provided. The CCG asked that Mr Hart inform them if he had already contacted the other providers direct to avoid confusion. The CCG also explained that they felt that the proposal for the meeting to be independently chaired by Healthwatch '*appeared to be no longer relevant although* [Mr Hart might] *wish to consider this further*.'

274. On 28 January the CCG wrote to CPFT to request Averil's records.

275. On 30 January the CCG sent a brief case history to the Consultant Psychiatrist to ensure that she still felt able to carry out the review. They described the proposed remit of the review as to provide a '*professional opinion about the overall robustness of the management of* [Averil's] *condition*'. The CCG added that they would also value an independent professional view of matters raised by Averil's father. The CCG included a number of questions as part of the terms of reference. Also on 30 January, the CCG wrote to UEAMC, the CUHT and NNUH with the questions Mr Hart had raised in his letter (to CPFT), but that CPFT were unable to answer. The CCG explained that the intention going forward was to obtain the answers to Mr Hart's questions and then arrange a meeting with Mr Hart and the providers to discuss the responses and any further questions the family might have. The CCG asked for responses by 21 February.

[71] The CCG reviewed both the SUI reports from CPFT and from CUHT to determine whether '*all aspects of the case have been fully and appropriately considered*.'

276. On 11 February the CCG wrote to Mr Hart to confirm that they had secured an independent consultant psychiatrist to carry out the review, and had requested the relevant records needed to facilitate this work. The CCG also confirmed that it had written to all the providers other than CPFT and asked them to address his outstanding concerns. The CCG also explained that it was looking for an independent physician to provide an opinion on the care provided by CUHT and NNUH. The letter explained that once it had received all the responses, it would convene the meeting it had previously outlined. The CCG said that in relation to Mr Hart's comment that he did not wish to meet with providers in the circumstances other than under the auspices of an external inquiry, it did not have the powers either to call for or to establish such an inquiry.

277. On 10 March Mr Hart met with the CCG. He has provided us with notes of the meeting which included the following:

> '[The CCG's Chief Executive] *stated that* [the CCG] *had enlisted the help of a psychiatrist from the* […] *area to look at the paperwork, case notes and answers provided by NCEDS and the other service providers involved.* [The CCG] *were also looking for an external physician to look at the same records.* [Mr Hart] *pointed out that the answers so far provided by NCEDS and UEA medical centre were superficial NHS policy statements in many cases and provided little clue as to the real course of events in Averil's tragedy.* [Mr Hart] *felt that in the majority of cases the answers had been phrased to mislead the reader and divert from the fundamental causes of Averil's death.*
>
> [Mr Hart] *strongly felt that the process was therefore fundamentally flawed. Any inquiry should be external and be able to look at exactly what went wrong, raise new questions about the course of events, interview those concerned in Averil's care and provide a detailed timeline of what went wrong, when it went wrong and what should be done to ensure no repetition of this tragedy.*
>
> [Mr Hart] *suggested that the Hart family should have an opportunity to meet and discuss the facts of Averil's case with anyone taking part in an investigation into Averil's death prior to their work. This was agreed by* [the Chief Executive]'

278. On 11 March the CCG wrote to Mr Hart. They confirmed that they would keep him informed about his request to meet the two experts who were providing an independent opinion (the CCG had also agreed to commission a physician's view) and about the subsequent meeting that the CCG was convening chaired by Healthwatch. They also included their understanding of the information that had been shared with Mr Hart. This included the following:

> *'Concerning other parties' failure to respond to questions raised, I confirmed that I had sent copies to you* [Mr Hart] *of responses by the UEA Medical Practice and the Norfolk and Norwich Hospital – also further enclosed here. I note that Addenbrooke's responded to you directly to say that they believed the issues raised had been addressed in the Serious Incident Report. Concerning CPFT's responses, my recollection yesterday was that they had responded to a number of questions to say that some matters would be best addressed during one to one discussion and that I would now secure those answers given your express wish not*

to meet with the team responsible for Averil's care at the present time. However, having reviewed the file this morning… I find that they did in fact answer every question. If you would now like full clarification in writing of these 'partial answers' do please let me know.'

279. In relation to a meeting between Mr Hart and the independent experts, the Chief Executive wrote:

'I will keep you informed concerning your request to meet with the two parties from whom the CCG is seeking an independent expert opinion into Averil's care; and concerning the subsequent meeting to be convened by the CCG chaired by HealthWatch.'

280. On 15 March Mr Hart contacted the CCG saying that he would like to meet with the Consultant Psychiatrist during the week beginning 17 March. On 19 March the CCG told Mr Hart that she had declined his request to meet.

281. On 3 April Mr Hart was sent a revised document setting out the scope of the review the Consultant Psychiatrist had been commissioned to undertake by the CCG. At the Consultant Psychiatrist's request, the scope had been amended to read, '*quality of the clinical management of* [Averil's] *case*'.

282. On 7 April the CCG told Mr Hart that work carried out by the Consultant Psychiatrist would be conducted '*wholly offline*', so as to avoid the risk of compromising its independence. They said they were not going to influence the matter further.

283. On 22 April Mr Hart emailed the CCG, saying that they had promised he could meet the Consultant Psychiatrist and that he was seeking to discuss with her the complete history of what had happened. He explained he was '*seeking a full and proper inquiry with questions and remit provided externally*', which allowed '*interviews of those concerned where applicable*'. Mr Hart asked that the CCG '*stand by* [their] *initial promise*' and allow him to meet with the Consultant Psychiatrist as soon as possible.

284. On 25 April the CCG's Chief Executive emailed the Consultant Psychiatrist to ask her if she would reconsider her decision not to meet with Mr Hart. The CCG also wrote to the Consultant Psychiatrist to confirm formally that they were '*seeking an independent professional opinion concerning the overall quality of the clinical management*' by CPFT and UEAMC. The letter enclosed the records obtained by the CCG and explained that they would like her to consider a number of matters raised by Mr Hart.

285. On 2 May the Consultant Psychiatrist contacted the CCG to discuss their request that she reconsider meeting with Mr Hart. The CCG subsequently emailed Mr Hart to offer a meeting with her. Their email explained that in '*the interests of balance, the CCG will also invite key members of the psychiatric team who cared for Averil to speak to* [the Consultant Psychiatrist] *too, if they wish'*.

286. On 12 May Mr Hart replied to the CCG saying that he was '*somewhat surprised at the sudden change in stance*', and that '[w]*ider questions are now being asked as to what*

has happened to change the CCG's stance'. He said that he had been advised that any meetings should only take place once a proper external inquiry had been established.

287. On 19 May the CCG wrote to Mr Hart and explained that the initial reluctance for a meeting was due to concerns it might compromise the independence of her opinion, and that the change in position was as a result of further input from Mr Hart. The CCG explained that the Consultant Psychiatrist would not be running an inquiry, but doing a review of Averil's care and reiterated the offer to meet with her.

288. Mr Hart responded on the same day explaining that he would speak to the Patients Association and other interested parties about the review. He asked a series of questions about: whether the Consultant Psychiatrist had *'worked with or been involved with – in a professional capacity or socially'* any members of the NCEDS team in the previous ten years; whether the Consultant Psychiatrist was aware that '*the 'inquiry' as it currently stands, is against the RCPsych MARSIPAN guidelines in cases where there had been a serious incident or death*'; and whether the Consultant Psychiatrist was aware that the family were looking for a properly convened external inquiry.

289. On 27 May the CCG replied to Mr Hart saying that they refuted the claim that they were attempting to close the file on Averil. They explained that the Royal College of Psychiatrists had been provided with the names of individuals who had been involved in Averil's care so as to avoid a conflict of interest. They reiterated that they were not conducting an inquiry or an investigation, explaining that they do not *'have the powers to either call for or conduct the former'* and that *'the investigation into Averil's care was undertaken by providers following her death'*. The CCG said that it was conducting a review of Averil's care across all the providers involved because *'we believe that we have a duty to you and to the wider community to ensure that any shortcomings identified in Averil's care are identified, individual organisations held to account and any necessary action take to reduce the changes of any future repetition.'*

290. There was further correspondence between Mr Hart and the CCG from 25 to 27 June. Mr Hart explained that Averil's family were not happy with the review, and asked that it be halted immediately. He asked the CCG to *'establish a proper inquiry with the family and Patients Association at its centre'*.

291. The decision was made that the Consultant Psychiatrist should continue her review, despite Mr Hart's request, and she produced a first version of her report on 13 July. In her report she referred to the MARSIPAN guidelines 2014 – an update to the MARSIPAN guidelines published in 2010. These were still in draft form and included a case study of Averil's story. This is set out below:

> *'In early 2013,* [the principal author of the MARSIPAN guidelines] *was approached by the parents of A, a 19 year old young woman who tragically died in hospital. The story represents a cautionary tale for all those involved in commissioning and delivering care for patients with severe Anorexia Nervosa. The account has been anonymised, as it may be subject to further enquiry, and summarised from the parents' full account.*

A had suffered from Anorexia for around three years, but after completing her 'A' levels, her health deteriorated quickly and she was admitted to Acute Hospital 1 as an inpatient. She regained her health and she transferred her studies to a University nearer home. Shortly after discharge from Acute Hospital 1, she began her studies there at a healthy BMI.

On discharge from Acute Hospital 1 she was referred to the University medical centre and the local community eating disorders service (CEDS).

There was a 3½ week gap before she was seen by the CEDS. She was then seen by them, but physical monitoring was sporadic and she deteriorated rapidly. A few days after one of her appointments at the CEDS, the cleaner at the university raised the alarm because A looked so ill, but no action was taken by the university. Two days later she was found unconscious and was taken to hospital by ambulance to Acute Hospital 2. Between her referral to the CEDS and her admission to hospital, her weight fell from 44.2 to under 30kg. In hospital she was allowed to get up, fall over, and was expected to feed herself from a trolley. No specialist eating disorders staff visited for 3 days. The local hospital recognised that her treatment was not adequate and she was transferred back to Acute Hospital 1. There she became hypoglycaemic but that was not corrected in time, and she went into a coma and died. She was 19.

A's care failed at almost every point that she was in contact with services: transition from hospital to primary care, uptake by community care, monitoring in the community, care by the university, local hospital care and care in the hospital in which she died.

A's father: "A died from a curable illness and in my opinion as a direct result of the negligence of the NHS and individuals working within a number of NHS organisations".

A's mother: "I haven't yet found the words to describe how much I miss A – her conversation, the cuddles, the future we won't have. I have tried to keep my emotion and experience as a carer out of A's story – this is more about service delivery and lessons that should be learned".'

292. The Consultant Psychiatrist expressed her view that *'the inclusion of* [Averil's] *case history, as summarised by her father, as an appendix to the revised MARSIPAN guidelines 2014, is unfortunate and inappropriate'.* She said that despite the fact that the principal author of the MARSIPAN guidelines *'did not have all the facts of the case at his disposal'* he had concluded '*that A's care failed at nearly every point and allowed an allegation that individual staff have been 'negligent' to appear in a nationally distributed guideline'.* The Consultant Psychiatrist said that this guideline would be *'read by workers in the field and commissioners who may well be able to identify the case, without allowing staff any opportunity to comment'.* On sight of this report, members of CPFT's eating disorder service emailed the Chief Executive's Executive Assistant to say that they shared the Consultant Psychiatrist's concerns.

293. On 15 August CPFT sent the principal author of the MARSIPAN guidelines an anonymised version of the CCG's commissioned report, with permission from the CCG. (NNUH[72] had also sent the principal author of the MARSIPAN guidelines a copy of the CCG's commissioned report at the end of July). The note with this report highlighted that CPFT was concerned that a recent independent investigation into a serious incident in their service commissioned by the CCG had brought to light the fact that there might be a problem with the appendix to the MARSIPAN guidance. The note went on to say that the appendix in the MARSIPAN guidance appeared to take at face value the narrative of a bereaved relative in relation to their service rather than the facts identified through investigation. The following day, the principal author of the MARSIPAN guidelines responded to CPFT to confirm that he had removed the case study from the draft guidelines.

294. On 18 August the principal author of the MARSIPAN guidelines spoke to the Consultant Psychiatrist saying that in quoting the case study in her report she had compromised its anonymity. He said that the MARSIPAN guidelines 2014 were still in draft form and should not be quoted from and confirmed that he had removed the case study. On 23 August he wrote to the CCG to ask that reference to the MARSIPAN guidelines 2014 be removed from the report the CCG had commissioned. The CCG agreed to this.

295. On 18 September the final draft of the report commissioned by the CCG was released to Mr Hart. On page 5 of her report, the Consultant Psychiatrist listed her *'declarations of interest'* which included when and where she had trained and worked (which overlapped with the Eating Disorder Unit Lead Psychiatrist), and that she knew both the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist professionally. The report considered the care provided to Averil at CPFT and UEAMC. The report noted the findings of CPFT's SUI and did not comment further on these issues. The Consultant Psychiatrist found that it was appropriate to place Averil with the NCEDS Care Coordinator, who was closely supervised. However, she said there should not have been a gap of one month between Averil's last appointment with the Eating Disorder Unit Psychologist, and her first appointment with the NCEDS Care Coordinator. She considered that Averil should have been reviewed by a psychiatrist at NCEDS whilst she was waiting for a therapist to be allocated. Overall the review found that the clinical management of Averil when she was under the care of NCEDS was satisfactory. The Consultant Psychiatrist also found that the clinical quality of the management of Averil by UEAMC was satisfactory as she considered that they did what was asked of them.

Complaint to NHS England (NHSE)

296. On 2 December 2013 Mr Hart complained to NHSE's East Anglia Area Team about the following issues:

- that UEAMC had contravened NHS guidelines on disclosure, by failing '*on numerous occasions to provide the information*' Mr Hart had requested from them. Mr Hart

[72] An internal email from the Chief Executive of NNUH asked for permission from the CCG to release the report to the principle author of the MARSIPAN guidelines, who was at this time carrying out a review of the care provided for Averil by NNUH (paragraph 247) – permission was granted shortly after.

complained that as a result of this, they had '*caused the process to become particularly protracted and painful for Averil's family*';
- that there was a '[c]*atologue of failures, negligence and neglect by UEAMC*'. Mr Hart said that UEAMC was asked to carry out a number of checks on Averil, including weekly basic health checks, bi-monthly blood tests, and a regular ECG (in line with guidelines), but that her records '*indicate that only one out of every five of the requested basic health checks were carried out, and none of the requested blood checks were carried out by the UEAMC*';
- that there was a failure to communicate with outside agencies. Mr Hart said that UEAMC '*failed to undertake any meaningful communication with other services to co-ordinate Averil's health care*'; and
- that there was a failure by UEAMC to respond to Mr Hart in an open and honest manner.

Mr Hart also set out his views about several other failures by UEAMC.

297. On 2 December the Complaints Manager from the East Anglia Area Team (the Complaints Manager) sent Mr Hart an email explaining that she had received his complaint, offering her condolences and asking for his address. Mr Hart responded the same day, reiterating his concern that after *'ten months of dealing with* [NCEDS] *and the primary care team at UEAMC we (Averil's family) have very little faith left in the NHS actually getting to the true facts behind the negligence and neglect that Averil suffered'*.

298. On 6 December Mr Hart sent the Complaints Manager a further email in which he explained that he wanted to arrange a meeting with the individuals investigating his complaint about UEAMC. Mr Hart explained that this was a very serious complaint, that in his view UEAMC were responsible for the tragic outcome, and that he wanted to have confidence in the process and individuals undertaking the investigation.

299. On 10 December Mr Hart sent a further follow-up email asking the Complaints Manager to arrange the meeting *'in the next few days'*.

300. On 13 December the Complaints Manager emailed Mr Hart explaining that she had been *'gathering information about what* [had] *happened in respect of your complaint'* and that she planned to write to him to explain *'what* [would] *happen next in accordance with legislative guidance around investigating* [his] *complaint'*.

301. On 16 December the Complaints Manager wrote to Mr Hart outlining the key issues that she believed Mr Hart wanted to be investigated:

- that Averil attended the University of East Anglia in September 2012 and died within 10 weeks;
- that she had been discharged from Addenbrooke's Hospital in September 2011 suffering from anorexia nervosa;
- that the university was notified by Addenbrooke's Hospital that Averil was at "high risk of relapse" and that weekly check-ups were needed to be established to monitor her; and

- that no monitoring was established by UEAMC and that Averil's care was neglected.

302. In this letter the Complaints Manager asked Mr Hart to *'confirm that these are indeed your primary concerns'*. She also said that this was a summary and that *'your original complaint will be used for the investigation; please feel free to amend any points'*. The letter asked for Mr Hart's consent to approach UEAMC for Averil's records, and explained that the Complaints Manager's role would be to *'request the university to undertake an investigation into the concerns you have raised and support this with documentation and best practice guidance on the decisions made'*. Shortly after receiving this letter Mr Hart spoke with the Complaints Manager to express his dissatisfaction with the way she had summarised his complaint and his lack of faith in her ability to investigate his serious concerns. Mr Hart said that he had emailed NHSE to ask for his complaint to be allocated to someone with more experience and more authority, and that he had received an automatic reply acknowledging his request.

303. On 10 January 2014 the Complaints Manager contacted Mr Hart asking for his consent to approach UEAMC, explaining that without it she would not be able to request the relevant records. She asked Mr Hart who he wanted to meet at UEAMC.

304. On the same day Mr Hart replied to the Complaints Manager to explain that he was extremely disappointed by the service he had received from her department, and had therefore asked NHSE for his complaint to be investigated by an alternative complaints authority. The Complaints Manager responded reiterating that, until she had his consent, she was unable to proceed, and that Mr Hart should let her know if he wished to close his complaint.

305. Following this three emails were exchanged in which Mr Hart repeated to the Complaints Manager that he was *'seeking a more competent investigation'* and therefore had asked NHSE for a change in investigation authority. When asked by the Complaints Manager whether he had received an acknowledgment to his request, Mr Hart confirmed that he had, but when asked the details of who the case had been allocated to Mr Hart explained that he was at that time abroad and unable to provide those details. Mr Hart suggested that the Complaints Manager pass the files back to her line manager and said that he would be in touch when he returned.

306. On 25 February the Complaints Manager wrote to Mr Hart explaining that she had not received the signed consent form and that if he did not get in touch with her within 10 working days, she would assume his concerns had been addressed or were being managed by another Area Team and close his case.

307. In April 2014 the East Anglia Area Team closed Mr Hart's complaint having received no further correspondence from him. Mr Hart was not notified of this.

Our findings

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)

CPFT's response to Mr Hart's complaints

308. Mr Hart has made a number of complaints about how CPFT dealt with him and his complaint. Firstly, he complains that CPFT failed to respond to his complaints openly and honestly. He says that CPFT failed to acknowledge mistakes and did not apologise for Averil's death.

309. From our review of the evidence, we can see that CPFT at least started the process genuinely trying to engage with Mr Hart. They completed their SUI in a timely fashion, and openly shared the mistakes this had highlighted in their report. This was in line with the Principles of Good Complaint Handling (paragraph B7). That said, we can see that the relationship quickly deteriorated and we can understand why CPFT's actions increasingly gave rise to the perception that they were being defensive and were not willing to be open with Averil's family. We can understand why their answers on occasion led to Mr Hart's concern that they were replying to his specific questions with general policy statements, rather than providing real answers that would help him understand what happened to his daughter.

310. In particular, we noted that throughout their correspondence with Mr Hart, CPFT continued to propose he attend a meeting with NCEDS staff against his express wishes. We can appreciate that given the volume, scope, and sensitivity of Mr Hart's questions, CPFT felt it would be better to discuss these in a face-to-face environment. At the time there were several investigative processes that ran concurrently or overlapped. These included the SUI and Averil's family's response, Mr Hart's formal complaint of January 2014, the CCG report, and follow-up questions and requests for information from Mr Hart to both CPFT and the CCG. We can also understand CPFT's concern that answering questions '*out of context and without background*' would not help Mr Hart understand what happened with Averil's care.

311. However, although Mr Hart initially thought that a meeting might be possible, he later made it very clear that he wanted an external inquiry to be completed first. When a meeting was again proposed, Mr Hart explicitly said he did not want a meeting with NCEDS staff as he was not yet ready to face the team who had provided care to Averil. Despite this, CPFT continued to suggest someone from the NCEDS team attend a meeting. This was not in accordance with the Principles of Good Complaint Handling (paragraph B7). It was neither sensitive nor customer focused. The Principles of Good Complaint Handling say that organisations should respond flexibly to the circumstances of the case. CPFT should therefore have worked with Mr Hart to find a way forward, to provide full answers to his questions, without him having to attend a meeting that he would clearly find very distressing. CPFT told Mr Hart how sorry they were to hear about Averil's death and offered their '*deepest condolences*' to her family. Given Mr Hart's belief that their actions (or inactions) led to Averil's death, we can understand why he would be seeking an apology for her death from them. While we recognise that CPFT did not believe they were responsible for Averil's death, the Principles of Good Complaint Handling says that organisations should acknowledge mistakes and apologise where appropriate. CPFT have

subsequently identified and acknowledged that failings occurred in the care Averil received, but they have failed to apologise for those failings.

Mr Hart's request for Averil's records

312. Mr Hart complains that, having requested copies of all Averil's records in February 2013, what he subsequently received from CPFT was an incomplete set. He told us that following the publication of the report commissioned by the CCG (in September 2013), Averil's family *'became aware of relevant information that did not appear in'* their copy of the records, and the fact that *'a significant volume of evidence from Averil's time in S3 ward…was unavailable'* to them.

313. It is clear that the only records released to Mr Hart in February 2013 were the records about Averil's care after her discharge from the Eating Disorder Unit. The Eating Disorder Unit Lead Psychiatrist told us that she had met Mr Hart in early 2013 before his request for records, and that he had been very concerned about the care Averil had received in the community and wanted a multi-agency review of this. The Eating Disorder Unit Lead Psychiatrist said that Mr Hart did not express any concern about the care Averil had received while on the Eating Disorder Unit. She said that she had called Mr Hart following his request for records because of the volume involved, and that her understanding from their conversation was that a release of Averil's records from after her discharge would meet his needs.

314. The evidence we have seen supports that this was the Eating Disorder Unit Lead Psychiatrist's understanding. The note on the internal document sent to CPFT's record department asking for the records (dated 15 February 2013) clearly says *'see notes for relevant parts of vol 4 to be provided'* and *'do not need to* [photocopy] *any of vol 1, 2 or 3'*. It was also confirmed in internal emails which explained that only volume four was copied, although the Eating Disorder Unit Lead Psychiatrist asked for all four volumes to be sent to her in advance of her meeting with Mr Hart to share the records, *'in case'*. This meeting took place on 28 February 2013.

315. Mr Hart did not raise any concern about the records until 31 July 2014, at which time he requested all Averil's remaining records. CPFT provided him with these – subject to certain redactions - on 24 September 2014. They apologised for the misunderstanding that had arisen following his request in February 2013. It is clear however, from what the Eating Disorder Unit Lead Psychiatrist has told us, and from the internal email from the Medical Director Mr Hart has highlighted to us, that there are different views about whether or not there was a misunderstanding.

316. We were not privy to the conversation that took place between the Eating Disorder Unit Lead Psychiatrist and Mr Hart, but it is of course always possible for two parties to leave the same conversation with two different ideas about what has been agreed. We fully acknowledge Mr Hart's belief that CPFT intentionally withheld records, however we have reached a decision that on the balance of probabilities CPFT acted in line with what they believed Averil's family wanted. We also note that when Mr Hart later asked for the additional records, CPFT provided these appropriately, and in a timely way.

Response to Mr Hart's complaint of 8 January 2014

317. Mr Hart complains that there was a delay in responding to his complaint of 8 January 2014.

318. Our Principles of Good Complaint Handling (paragraph B7) state that public organisations should deal with complaints promptly, avoiding unnecessary delay. As they have acknowledged and apologised for the delay, CPFT clearly did not meet this standard in relation to their response to Mr Hart's complaint of 8 January 2014. Due to apparent confusion about the complaint on the part of CPFT's Chief Executive, it took over five months for their response to reach him. While we recognise that the volume of complaints correspondence in this case was significant and the motivations behind circumventing some of their normal complaints process (allowing Mr Hart to deal directly with the Chief Executive's office), this nonetheless appears to have caused a delay which was not customer focused, and could and should have been avoided.

Actions of CPFT in relation to a case summary in draft MARSIPAN guidelines

319. Mr Hart is also concerned that a summary of Averil's case that had been included in draft updated MARSIPAN guidelines was later removed. The principal author of the MARSIPAN guidelines explained to us it was not removed entirely, but trimmed down to a section about Averil's inpatient care in December 2012 and heavily anonymised. The summary in its original form was based on the family's account of events which reflects the evidence we have seen about Averil's clinical care. Given their motivation to ensure what happened to Averil drives improvements for other patients, it is understandable that they wanted the learning from her story to be shared widely, particularly amongst professionals who rely on the guidelines.

320. The principal author of the MARSIPAN guidelines told us that the decision to remove the summary was his, taken because he recognised that the account as written was no longer accurate and could have jeopardised the authority of the guidelines.
Mr Hart told us that after the Consultant Psychiatrist raised her objections to the summary being included, the principal author of the MARSIPAN guidelines asked Mr Hart and Averil's mother to meet with him. Mr Hart said that during this meeting, the principal author of the MARSIPAN guidelines told them that he had come under '*extreme pressure*' from a variety of sources to remove the summary of Averil's case before the guidelines were published. Mr Hart said that the principal author of the MARSIPAN guidelines also told him he would lose funding for the MARSIPAN guidelines and a Master's Degree course he was running if he refused to do so.

321. Mr Hart's account clearly differs from what the principal author of the MARSIPAN guidelines told us. However, we have considered the actions specifically of CPFT. While we recognise the very real concern this issue has caused Averil's family, we can understand why CPFT objected to the inclusion of the summary as it stood on the basis of the concerns they shared with the Consultant Psychiatrist. The summary had been included without all the facts of the case being available to the author at the time. Furthermore, staff involved had not been given the opportunity to comment on the allegations made. These were allegations that were largely unsupported by the findings of the Consultant Psychiatrist, who had been commissioned by the CCG to review Averil's

care, and whose draft report had been shared with CPFT staff. Having considered all of the evidence we have concluded that the actions of CPFT in sharing the objections with the principal author of the MARSIPAN guidelines were in line with the Principles of Good Complaint Handling (paragraph B7) by acting fairly to staff as well as Mr Hart.

Trust emails

322. Mr Hart has complained that the Eating Disorder Unit Lead Psychiatrist intentionally deleted email history relating to Averil's case. He has provided us with an internal email which she sent to CPFT's Medical Director advising that she had deleted emails prior to 22 February 2013. We understand his concern about this, and appreciate entirely why this has contributed to his view that CPFT have not acted openly in response to his complaint.

323. All relevant email correspondence should have been available for the investigation. However, the Information Commissioner's Office concluded that emails were deleted in line with CPFT policy.

324. Having said that, we do consider that deleting these emails was ill-considered. Given the circumstances – a young person had died and the potential for further, ongoing investigations – it is our view that all professionals involved should have sought to preserve any material that would have helped them to understand as much as possible about what had happened and answer any questions that arose from those looking at the case. Deleting emails under these circumstances destroys material valuable for learning and improvement as well as responding to complaints, and is likely to generate understandable suspicion of cover up. It was inappropriate.

325. Mr Hart has also complained that internal emails suggest that CPFT were trying to protect themselves from reputational damage.

326. We have considered the emails Mr Hart has pointed us to, as well as all those CPFT have provided. We understand why the redacted versions of emails that Mr Hart directed us to, could appear suspicious. However, we have looked at the unredacted versions of these emails, and this has reassured us that there is no cause for concern. This is because we have seen that the information discussed that was not released to Averil's parents was withheld on appropriate grounds: that it was considered sensitive material that Averil would not have wanted shared, or that it was third party material. We have not seen anything to suggest that CPFT were trying to protect themselves by not releasing evidence that would have caused them reputational damage. Furthermore, having seen the internal emails sent during the local investigation of Mr Hart's complaint, whilst at times it is clear that staff felt challenged by the volume or frequency of requests for information, there is nothing to suggest they were not genuine in their attempts to comply with these.

327. Mr Hart has highlighted in particular an email sent by CPFT's Medical Director to some of her colleagues to tell them about our involvement. Mr Hart was concerned about her phrase that she had '*concocted a plan*', and an instruction to staff to ensure that they had provided all relevant information and the mention of a planning meeting at which Trust solicitors would be present in advance of investigators from PHSO interviewing staff.

328. Considering first the request to staff to provide any other relevant information they might have because '*this is probably the last moment that* [CPFT] *can produce new documents*'. We can appreciate Mr Hart's concern about this, because we can see how it might have been read as suspicious, particularly when taken together with the belief that CPFT had deliberately withheld records from Averil's family, deleted emails and were more concerned with their reputation than learning. We also take the view that in this difficult context the choice of the word '*concocted*' has unhelpful connotations. However, on balance we consider that staff were acting in accordance with the Principles of Good Handling (paragraph B7) in that they were seeking to ensure that they were open and accountable and had provided us with all the relevant information.

329. The second point is more difficult. We recognise that an Ombudsman investigation can be very stressful for staff and understand the need for organisations to offer support through the process, particularly when faced with interviews. For this reason we do not consider that a meeting with this aim is in itself problematic. However, if that preparation goes further, and for example staff are being briefed about what they should say, rather than supporting them to be as open and accountable, then it would not be reasonable. We have thought very carefully about whether the evidence suggests that this was what happened. Certainly we can see the tone of this email and mention of solicitors does not point to a spirit of openness. However, we have not seen any evidence that this meeting resulted in '*model interview answers*' or anything along these lines. The '*responses*' referred to in the email appear to relate to the questions we had put to CPFT at that early stage in our investigation, rather than interview questions we later asked, and there is no evidence to suggest that CPFT staff were overly defensive or unwilling to engage with us at interview. On this basis, we consider that CPFT were acting in accordance with the Principles of Good Complaint Handling, they were acting fairly towards staff by supporting them during the process.

The suggestion to Mr Hart that he needed therapy

330. Mr Hart has complained that CPFT repeatedly suggested at meetings with him that he needed therapy. We were not privy to the discussions in these meetings and CPFT have told us that they do not believe they offered or suggested that Mr Hart required therapy. However, we have seen evidence in CPFT's correspondence with Mr Hart that they enquired about his well-being and whether he needed any support to deal with the loss of his daughter. We accept that it is a difficult balance for an organisation to strike in these circumstances between offering support and saying something that could be perceived as intrusive or unhelpful, or designed to distract from the questions that are being asked. For some bereaved families offers of support can prove a lifeline. For others, this will not feel welcome or appropriate, particularly if coming from the organisation they consider has failed their loved one. It is clear that for Mr Hart his priority from the outset was to establish the facts about Averil's care, and we can understand why he was unhappy about this suggestion, particularly in the context of a growing impression that CPFT were being defensive and obstructive. However, overall, we consider CPFT were trying to be sensitive to Mr Hart's needs and therefore their actions were in accordance the Principles of Good Complaint Handling (paragraph B7).

Summary

331. This was a challenging complaint for CPFT to respond to, in terms of its scope, complexity and the very serious nature of what had happened and the resulting emotion involved. We acknowledge the efforts made to engage with Mr Hart and the steps taken to try to resolve the complaint. However, we also understand entirely why Mr Hart increasingly got the impression that CPFT were being overly defensive and why he considered the answers they did provide were incomplete. In particular, we find that they repeatedly failed to provide Mr Hart with full written answers to his questions, and their response to his formal complaint was significantly delayed. We find that CPFT's handling of the complaint was so poor that this was maladministration.

UEA Medical Centre (UEAMC)

332. Mr Hart complains that UEAMC has been defensive and failed to respond to his complaints.

333. Looking at what UEAMC told Mr Hart in response to his questions, we can see that they provided him with a limited account of their involvement in Averil's care. However, this was not a full and complete explanation based on all the available evidence. Additionally, some of the information they provided did not present a genuine reflection of what had happened. An example of this is in their letter to Mr Hart of 31 May 2013, in which UEAMC stated that NCEDS' letter of 26 October 2012 had '*changed* [Averil's] *management plan*'. Whilst it is true to say that there had been a change, that change did not remove UEAMC's duty to continue to monitor Averil's physical health as they seem to imply.

334. Similarly, what UEAMC told the CCG during the local resolution process about the monitoring they had been asked to carry out was not a full or accurate representation. Averil's weight was only one of several parameters the original discharge summary asked them to monitor, and they provided no explanation as to why they did not carry out the rest of the monitoring in line with Averil's care plan. A thorough and detailed review of the evidence by UEAMC should have highlighted the same failings that Averil's family and our investigation identified. UEAMC missed the opportunity to be open and accountable and failed to provide evidence-based explanations and reasons for their decisions in line with our Principles of Good Complaint Handling (paragraph B7). As a result of this, they failed to put matters right.

335. One of the questions Mr Hart repeatedly put to UEAMC without success was a request for details of the care they had given his daughter. It is clear that underlying this request was his concern that Averil's care had not been in line with the care plan set out in her discharge summary. Although we accept that the strength of Mr Hart's assertion, that Averil's death was a direct consequence of the lack of care provided by UEAMC, must have been upsetting for staff to read, they should nevertheless have provided an account of their actions and answered his concerns in accordance with the Principles of Good Complaint Handling (paragraph B7). It was completely unreasonable to tell him - as a lay

person and a bereaved parent - to find the information he was looking for himself in his daughter's records. It was also insensitive to repeatedly insist that he attend a meeting with them when he was not ready to do so. UEAMC told the CCG that it was not productive or reasonable to engage in '*protracted correspondence*' with Mr Hart. However, it seems to us that their failure to provide the information Mr Hart asked for contributed to this.

336. Mr Hart has also complained about the brevity and tone of UEAMC's response to us. Whilst we acknowledge that the intended audience for this was not Averil's family, organisations complained about should engage openly in our process and show that they have considered a complaint carefully and fully in line with the Principles of Good Complaint Handling (paragraph B7). UEAMC's actions were not in accordance with these principles. Again we have concerns about the accuracy of some of their statements, such as, '*it was confirmed to us that the monitoring requested by* [… S3] *in Cambridge was now being undertaken by* [NCEDS] *in Norfolk and they confirmed to us that they were seeing her weekly*'. Furthermore, we can entirely appreciate why some of the language used was distressing to Mr Hart, particularly the reference to '*anorexics*'.

337. Finally, while we understand Mr Hart is concerned about UEAMC providing us with one corporate response to our initial enquiries, we do not share his view that this was unreasonable provided all involved parties were able to contribute to this. However, given the opportunity to comment and the serious nature of the complaint, we consider that the GP who took the key decision to change the frequency of Averil's monitoring at UEAMC should have ensured she had access to the consultation notes to enable her to review these, reflect, and comment appropriately. We have seen no good reason why this could not have happened and no evidence that at this first opportunity, the GP treated the complaint with the consideration it warranted.

Summary

338. UEAMC's investigation of Mr Hart's complaint was not good enough. It did not uncover the serious failings in Averil's care and so did not provide the answers Mr Hart sought. UEAMC's complaint handling fell so far short of the Principles of Good Complaint Handling that it was maladministration.

Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)

339. Mr Hart complains that NNUH's response to the complaint from Averil's family was inappropriate, and that the NNUH did not provide a copy of the family's complaint to the principal author of the MARSIPAN guidelines who was commissioned to carry out an independent review of her care at NNUH.

340. Mr Hart complained to NNUH on behalf of Averil's family on 9 January 2014. He complained that *'a major contributory factor in Averil's death was the lack of appropriate treatment and care that she received whilst at the Norfolk and Norwich Hospital'*. Mr Hart listed several areas of concern and asked for a full external

investigation, remedial action to overhaul the standard of care provided for high risk patients, disciplinary action where relevant, and an apology to Averil's family and friends.

341. NNUH's response, dated 14 February 2014, set out their view that the care provided for Averil was compliant with MARSIPAN guidelines and that the *'risks and challenges of treating a very sick young woman with anorexia nervosa were recognised by staff'*. On the basis of the significant failures in medical and nursing care we have identified in our investigation, we cannot see how a thorough review of the same evidence in accordance with the Principles of Good Complaint Handling (paragraph B7) could have led NNUH to reach this conclusion. In this response, NNUH failed to identify any of the learning points they should have done and, so they did not even begin to help Mr Hart and his family understand what should have happened to Averil during this admission. It follows that they could not have expected this to resolve Mr Hart's complaint.

342. Thanks to Mr Hart's persistence in establishing what had happened to Averil, NNUH agreed to do further work and commissioned two independent reviews. This was in accordance with the Principles of Complaint Handling (paragraph B7) which says that organisations should ensure that the complaint is reviewed by someone not involved in the events which led to the complaint. These reviews highlighted several important failures in Averil's care and learning points for NNUH.

343. We recognise that this, albeit belated, engagement from NNUH was a positive step to be open and accountable and attempt to resolve Mr Hart's complaint in line with the Principles of Good Complaint Handling, and these efforts have been acknowledged by Mr Hart. However, Mr Hart should not have had to drive this process – the Trust should have done a thorough investigation in response to his complaint given the serious issues it raised. Neither should it have been left to Averil's family to provide background papers to the reviewer.

Summary

344. The NNUH's first investigation of Mr Hart's complaint did not identify the serious failings in her care and it was only due to Mr Hart's persistence that a second investigation occurred. It follows that the NNUH's complaint handling fell so far below Principles of Good Complaint handling that it was maladministration.

Cambridge University Hospitals NHS Foundation Trust (CUHT)

345. Mr Hart complains that CUHT did not respond to Averil's family's complaint in a way that was appropriate to the seriousness of the event and the complaint, and that they did not recognise the failings in Averil's care.

346. We have found a number of failings in the care CUHT provided for Averil, and that had these not occurred, Averil would not have died on 15 December 2012. Comparing our very serious findings to those of CUHT, we can see that they failed to identify most of the failings in her care, and that where they did identify failings, they did not consider the impact of these on Averil. Their investigation was not thorough as it should have been,

and was therefore not in line with the Principles of Good Complaint Handling (paragraph B7).

347. An example of this is that CUHT's investigation found that the decision not to start nasogastric feeding during the evening of 11 December 2012 was appropriate. However, there was no consideration, as there should have been, of whether the decision to start nasogastric feeding would have been taken sooner if Averil had been seen by the consultants earlier in the day. Equally, their report acknowledged the length of time it took for Averil to be seen by a consultant on admission, stating that the reason for this was '*unclear*', yet it did not go on to consider the impact of this. CUHT's investigation did not go far enough in exploring the failures in nursing and medical care during the night of 11/12 December and did not therefore recognise that had they not happened, Averil would not have died on 15 December. While there may have been a misunderstanding between the on-call junior doctor and the consultant at home about how to manage Averil's glucose levels – as their conflicting accounts suggest - the fact is that her glucose level was dangerously low and whatever the discussion between the two doctors, the failure to put this right was a fundamental error. Furthermore, there was a clear instruction in Averil's medical records about what should be done if her blood glucose level fell below 3mmol/l. Similarly, while the report acknowledged that there was inadequate escalation of Averil's MEWS during the early hours of 12 December, there was no consideration of the fact that Averil's MEWS was over 4 from the moment she arrived at Addenbrooke's Hospital, and that the actions set out in CUHT's own policy (paragraphs B41 to B43) were clearly not followed.

348. There was absolutely no consideration of Averil's capacity to make decisions about her care in the CUHT report. There was no consideration of whether the junior doctor should have asked a senior colleague for advice when she became aware that Averil was refusing life-saving glucose supplements. This was despite advice from the consultant psychiatrist clearly documented in the medical record about what to do if she refused treatment. Finally, the report failed to explore the impact of failings on Averil. It mentioned a reference to Averil having only a 20% probability of survival at the point of transfer, but the basis for this estimate is not explained nor explored. The fact remains that, even without concluding that Averil's death was avoidable, CUHT were in a position to conclude that several opportunities were missed throughout her admission to provide Averil with the life-saving treatment she required.

349. Although CUHT tried to be open and accountable in accordance with the Principles of Good Complaint Handling (paragraph B7) by promptly sending Mr Hart a copy of their investigation report, the lack of a robust and thorough assessment of the evidence meant that Averil's family did not receive a full explanation of what went wrong. This was not in accordance with the Principles of Good Complaint Handling. It was also unreasonable and insensitive to refuse to answer Mr Hart's subsequent specific complaints, instead advising him that his questions had already been addressed in their report. Mr Hart complained about serious issues (the death of his 19 year old daughter), and he should have received an open, honest and evidence-based response to his complaint in line with the Principles of Good Complaint Handling.

Summary

350. The standard of CUHT's investigation of Mr Hart's complaint fell a long way short of what Averil's family should have had. It did not identify the serious failings in her care and therefore did not put CUHT in a position to acknowledge the impact on Averil; that is, that if the failings had not happened, she would not have died on 15 December 2012. Furthermore, they did not respond appropriately or sensitively to Mr Hart's follow-up complaints. It follows that CUHT's complaint handling was so far below the applicable standards that it was maladministration.

North Norfolk Clinical Commissioning Group (the CCG)

The supervision of the provision of services by NCEDS

351. Mr Hart complains that there was a failure to proactively supervise or quality control the provision of services by NCEDS. He told us that that despite paying CPFT approximately £850,000 each year to provide the eating disorder service, it was revealed at a meeting with Averil's family on 17 May 2013 that the CCG does not proactively supervise or quality control the provision of services by NCEDS. Mr Hart said that the CCG's view was that in the absence of a complaint, '*all must be well*'[73]. Mr Hart says that this attitude was inappropriate and did not promote high quality services.

352. In order to get it right, the CCG should have carried out its functions in line with recognised quality standards, established good practice or both. The Department of Health's *Guide to the Healthcare System in England* (paragraphs B34 and B35) and the NHS Commissioning Board's *The functions of the CCG* help explain the function of the CCG (paragraphs B36 and B37).

353. The former of these explains that the boards of organisations providing NHS care have the primary responsibility to ensure that the care they provide is safe and of high quality, and that beyond this, the Care Quality Commission is responsible in their role as regulator for assessing and making judgments as to the level of safety and quality of care provided. If failings in quality are identified at a service provided by a Foundation Trust (of which CPFT who commission NCEDS is one), then Monitor could intervene to resolve these, in line with their duty to protect and promote patients' interests by ensuring that health care services are provided effectively, efficiently and economically.

354. The role of the CCG is described as '*accountability for the way that the majority of local NHS services are planned and paid for,* […] *supported by NHS England*'. The guidance adds that CCGs hold providers of NHS services to account through their contract with them and are accountable to NHS England for how well they meet their population's needs. The NHS Commissioning Board's document also states that, amongst other things, the CCG must exercise its functions with a view to securing continuous improvement in

[73] In letters to us dated 14 July 2016 and 28 June 2017 the CCG refuted that this statement had been made. It said the Chief Officer at the time *'was present at the meeting held on 17 March 2013 with Mr Hart and whilst there* [were] *no minutes of the meeting, the comment above* [was] *not one which either* [he]*, or the senior colleague who accompanied* [him] *would have ever made.'*

the quality of services provided for individuals for or in connection with the prevention, diagnosis or treatment of illness.

355. The CCG told us that at the time of Averil's treatment the contract that CPFT had with their predecessor, NHS Norfolk Primary Care Trust,[74] required it to provide monthly reports setting out activity, performance and quality data, which were considered at quarterly contract performance meetings. They also held quarterly clinical quality review meetings at which the quality of service provision was tested. These arrangements are still in place and measures for monitoring quality include the consideration of:

- complaints;
- serious incidents;
- quality incident reports;
- patient experience and outcome reports; and
- action plans arising.

356. The CCG also told us that:

> *'This committee provides a structure by which to review the safety and quality of both the CCG's commissioned services and its own processes. It is accountable to the governing body for the identification and management of clinical risk and the provision of assurance that robust action is being taken to maintain high quality, safe services. The Committee's outputs influence commissioning plans and monitor the CCG's effectiveness to deliver continuous improvement within commissioned pathways by drawing on trends, themes and learning from adverse quality and safety incidents.'*

357. Overall, we have seen evidence which demonstrated that the CCG had put in place a process to manage and monitor their contract for services provided by NCEDS as they should have done.

The independent physician's review of Averil's care

358. Mr Hart also complains that the CCG failed to provide an independent physician's review of Averil's care which they had promised him they would.

359. After Mr Hart brought his complaint to us (in August 2014) events continued to develop and in February 2015 he was given the independent physician's review of Averil's care commissioned by the CCG. It is clear that this took much longer to complete than anticipated, and indeed we can see from the information the CCG has given us that at the time of Mr Hart's complaint to us they had still not managed to secure an independent expert. In a response to Mr Hart of 24 September 2014, the CCG described the '*great*

[74] A primary care trust (PCT) was part of the NHS in England from 2001 to 2013. PCTs were largely administrative bodies, responsible for commissioning primary, community and secondary health services from providers. They were replaced by clinical commissioning groups (CCGs), such as North Norfolk Clinical Commissioning Group (NNCCG), on 1 April 2013. And as NNCCG was not established until April 2013, it told us it would not have been responsible for the CPFT/NCEDS contract at the time Averil was being seen by NCEDS.

difficulty' they were experiencing in doing so, and said that '*the failure thus far is not for want of trying*'.

360. Having reviewed the correspondence between the CCG and external parties they contacted in their efforts to secure an expert, we can see that this statement is an accurate reflection of the work that was happening behind the scenes. We do not consider that the delay was a result of a lack of effort on the part of the CCG to make progress. That said, we can absolutely understand Mr Hart's frustration at the length of time this took, and his reasons for bringing the complaint to us. The CCG did acknowledge his frustration at several points, however most of the updates given to Mr Hart were in response to him chasing for information, rather than the CCG proactively contacting him. This was not customer focused, and in line with the Principles of Good Complaint Handling the CCG should have been more open about the work they were doing in order to explain the delay.

The professional connections between the Consultant Psychiatrist commissioned by the CCG to undertake a review (the Consultant Psychiatrist) and the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist

361. Mr Hart complained that there was also a failure to take account of Averil's family's concerns that the Consultant Psychiatrist had significant professional connections with the Eating Disorder Lead Psychiatrist and the NCEDS Lead Psychiatrist, and that the Eating Disorder Lead Psychiatrist had an interest in a positive report as CPFT were tendering for the NCEDS contract in October 2014.

362. At the outset of her report for the CCG, the Consultant Psychiatrist declared that she knew the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist professionally, and explained that consultant psychiatrists working in the field of eating disorders tend to know most of their colleagues across the country. She confirmed that she did not know about Averil's case from any of the clinicians involved and had no involvement herself in Averil's care. She stated that she did not meet with any of the clinicians involved during the completion of her report, although they, and eventually Mr Hart, were given the opportunity to talk with her.

363. There are no directly applicable standards when considering how the CCG should have managed this. However, NHS England's guidance published in March 2013, *'Managing conflicts of interest: guidance for clinical commissioning groups'*, has some relevant principles (paragraphs B38 and B39). This document explains that conflicts *'can arise from personal or professional relationships with others, e.g. where the role or interest of a family member, friend or acquaintance may influence an individual's judgement or actions or could be perceived to do so'*.

364. It is clear that in this case there was, and continues to be, a perception on the part of Averil's family that the professional relationships between the Consultant Psychiatrist and the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist influenced her judgement and therefore her report about Averil's care. The Consultant Psychiatrist was adamant in her rejection of this when we interviewed her, and emphasised again the points she had made in the report about the collaborative nature of the work of consultant psychiatrists in the field of eating disorders. The Eating Disorder Unit Lead

Psychiatrist also told us at interview that their relationship was '*purely professional*', that she had had no idea who was doing the review for the CCG until she saw it, and that she and the Consultant Psychiatrist did not discuss it.

365. The question for us then, is whether this perceived potential conflict of interest was appropriately managed, or whether on identifying this, there was more the CCG could and should have done. We consider that the Consultant Psychiatrist acted appropriately in being transparent about her connections to the Eating Disorder Lead Psychiatrist and the NCEDS Lead Psychiatrist and setting these out in her report. We also believe that it would have been difficult for the CCG to have found an NHS professional with the necessary experience, who would be perceived as more independent, to comment on Averil's care. This is because there is a relatively small group of professionals with the relevant experience, the collaborative nature of the field as described by the Consultant Psychiatrist, and the fact that no other psychiatrists put themselves forward when approached by the Royal College. Nevertheless, we believe that it is incumbent on those commissioning investigations to make every effort to ensure an appropriate degree of independence, either by going further afield or by appointing two investigators as a check. Given the seriousness of the incident, the CCG could have done more.

366. We also consider that, in line with the Principles of Good Complaint Handling the CCG should have been more open with Mr Hart about this in their communications with him. They should have shared this information and explained why they still thought the Consultant Psychiatrist was an appropriate choice. This would have given Mr Hart the opportunity to share his views and might have avoided the situation which developed when he was chasing the CCG for information about the Consultant Psychiatrist's connections and was concerned about the Eating Disorder Lead Psychiatrist's interests in the report.

The remit of the Consultant Psychiatrist

367. Mr Hart complains that the CCG failed to include Averil's family's concerns in the remit of the Consultant Psychiatrist's review, and as a result their key concerns were not addressed in her report. He also complains that the CCG initially refused their request to meet with the Consultant Psychiatrist.

368. Looking at the questions the Consultant Psychiatrist was asked to consider by the CCG, it is clear that these were based on what they thought the primary concerns of Averil's family were. These were modified in negotiation with the Consultant Psychiatrist to eliminate any potential bias or assumptions in the wording. In November 2013, when the CCG was in the process of finding an expert, they invited Mr Hart to provide them with any further questions he had. We consider that it was reasonable for the CCG to draft the remit for the review and recognise that Mr Hart was given an opportunity to comment on this in April 2014. In seeking to ensure that they had understood Mr Hart's concerns in this way, the CCG acted in accordance with the Principles of Good Complaint Handling. However, we also understand that he did not take this opportunity because by this point the concerns of Averil's family had grown to the extent that they had lost faith in the review process.

369. It seems this lack of faith was in no small part down to how Mr Hart's request to meet with the Consultant Psychiatrist was handled by the CCG. We can see why this was such a poor experience for Averil's family and contributed to their sense of being excluded from the process. We understand the CCG's predicament when the Consultant Psychiatrist initially said she did not want to meet Mr Hart. However, before her involvement, the CCG had told Mr Hart that Averil's family would be able to meet with the reviewer. Given this, the CCG should have told the Consultant Psychiatrist at a much earlier stage that a meeting was a condition of taking on the review, in accordance with generally recognised practice. Any concerns about this could then have been resolved between the Consultant Psychiatrist and the CCG, without creating uncertainty for Mr Hart. As it was, by the time a meeting was finally agreed as a result of continued pressure from Mr Hart, he had lost faith in the review process. Having agreed with Mr Hart that a meeting would be part of the process, the CCG were not being customer focused when they failed to meet this commitment.

The Consultant Psychiatrist's report

370. Mr Hart complains that the CCG's report was contradictory in parts, and did not adequately address a number of key issues.

371. We note Mr Hart's significant concerns about the content and conclusions of the CCG's report. As the CCG is the subject of our investigation, not the Consultant Psychiatrist, the question we have considered is whether the CCG did what they should have done in relation to this. In order to ensure it met the relevant standard (the Principles of Good Complaint Handling, paragraph B7), the CCG should have ensured that the decision was appropriate, proportionate and fair. The question, therefore, is whilst recognising that this was an independent opinion (and therefore to intervene or seek to influence its content would not have been appropriate) were they right to be satisfied that the report they had commissioned had considered the issues set out in the remit for the investigation, and reached appropriate, evidence based conclusions.

372. The report commissioned by the CCG failed to identify significant flaws in Averil's care, in particular the failings in monitoring by UEAMC. The CCG should have identified these shortcomings in the report they commissioned. They did not. Given the seriousness of the issue raised, the CCG should not have relied upon the advice of a clinical psychologist and should have sought appropriate advice from a GP. In not seeking appropriate advice, the CCG did not put themselves in a position to identify the failings that we have found. This meant the response to Mr Hart's complaint was inadequate, and all the necessary learning was not identified. The CCG's actions were not in line with the Principles of Good Complaint Handling.

The letter from the CCG to Mr Hart following their meeting on 10 March 2014

373. Mr Hart complains that he met with the CCG on 10 March 2014 but received a letter from them the following day which did not reflect the content of this meeting. He says that the CCG's letter contained only broad themes and NHS policy on the topics discussed. He says that the specific promises made by the CCG, which Averil's family noted, were not included.

374. We have considered the notes of the meeting of 10 March 2014 provided by Mr Hart (paragraph 277), the letter sent by the CCG on 11 March, including what the Chief Executive said about the meeting between Mr Hart and independent experts (paragraphs 278 and 279). We can see that the CCG's reference to Mr Hart's '*request*' to meet with the independent experts would have seemed a watered down version of something he had understood to have been settled and agreed, and why this would have felt like a setback and reduced his confidence in the process. We were not privy to the conversation that took place, so it is not possible for us to know exactly what was said or agreed. However, we can see no reason why Mr Hart would have made inaccurate notes. It was therefore a shortcoming on the part of the CCG that they did not accurately reflect this in their letter.

Summary

375. The CCG had a process in place to monitor and manage the quality of the eating disorder service it commissioned. It made significant efforts to resolve Mr Hart's complaint about its service. In particular, it offered to arrange a meeting with all the organisations involved in Averil's care to discuss the organisations responses and Mr Hart's outstanding concerns, and to appoint an independent person to Chair this meeting. It also engaged external reviewers to help resolve his complaint. Unfortunately Mr Hart's confidence in the CCG was undermined when initially they did not keep their promise that he could meet the reviewer. The CCG also failed to put themselves in to a position to identify the failings in the care that Averil received by UEAMC by not taking appropriate advice. This was not in accordance with the Principles of Good Administration. Given the seriousness of the issues raised, we consider that taken overall the CCG's actions were so poor that they amounted to maladministration.

NHS England (NHSE)

NHS England's interpretation of Mr Hart's complaint

376. Mr Hart complains that NHSE failed to identify the substance of his complaint, wrongly interpreting it and reducing it to four bullet points in their acknowledgement letter.

377. Mr Hart sent NHSE a detailed complaint letter, which set out exactly what his concerns were and why he was complaining to them. In line with our Principles of Good Complaint Handling, NHSE should have demonstrated in their acknowledgement of Mr Hart's complaint, that they had understood the issues and the outcome he was seeking. The acknowledgement NHSE sent Mr Hart was appropriate insofar as it explained the process NHSE would follow, asked for his views and confirmed that his original complaint would be used for the investigation. NHSE also appropriately invited him to amend any points he felt did not represent his concerns accurately.

378. However, the acknowledgment showed that NHSE fundamentally misunderstood Mr Hart's complaint. It reduced it to four bullet points, three of which were merely statements of fact, plus a final point which was a very broad summary of his overall concerns. In addition, these points contained inaccuracies such as the date of Averil's discharge from the Eating Disorder Unit. Compounding the disappointment Mr Hart told us

he felt when he saw how poorly his complaint had been summarised, the letter went on to say that the next steps would involve asking the university to carry out an investigation. This was despite the fact that the complaint was clearly about the care provided by a GP practice.

379. Mr Hart's complaint was a serious one and his letter of complaint was comprehensive. The least Mr Hart should have received in line with the Principles of Good Complaint Handling (paragraph B7) was an accurate summary of something which, we have no doubt, took him time and effort to put together. Instead, the summary was simply not good enough. The fact that Mr Hart had an opportunity to address these deficiencies does not mitigate this initial failure.

Action following the transfer of Mr Hart's complaint from the NHS East Anglia Area Team.

380. Mr Hart also complains that there was a failure to act on his complaint once it had been transferred from the NHS East Anglia Area Team to be handled elsewhere in NHSE.

381. The situation in relation to this aspect of Mr Hart's complaint is less clear. There is no question that following Mr Hart's request to have the case reallocated nothing was done by NHSE, and his complaint closed in April 2014. We asked the East Anglia Area Team, the Customer Contact Centre and NHSE central office what had happened, but no one was able to tell us what the reference Mr Hart had quoted to us (045/001-002) meant, or which part of NHSE it came from.

382. From Mr Hart's perspective, we appreciate that he made a request for his complaint to be reallocated, believed he had received an acknowledgment to that effect, and communicated this understanding to the Complaints Manager at the East Anglia Area Team. However, we have found no evidence that the Complaints Manager received any internal communication about this, and there is no record of any other complaint or request by Mr Hart. In addition, NHSE point to the fact that the Complaints Manager at the East Anglia Area Team wrote to Mr Hart in February 2014 to ask for his consent and to explain that his complaint would be closed if they did not receive this. We understand that Mr Hart may have chosen to disregard that letter as it came from the same person who authored the acknowledgment to his complaint. However, we can also understand that in the absence of a response or consent from Mr Hart to proceed, NHSE felt it had no option but to close his complaint.

383. Overall, it is evident that no effort was made by the Complaints Manager to ascertain whether Mr Hart's complaint had actually been reallocated. In fact, although Mr Hart confirmed that he had received an acknowledgment, the Complaints Manager would have been aware by the time she sent him the letter in February 2014 that his case had not in fact been reallocated to anyone. She would have been able to alert Mr Hart to this, or make her own enquiries, but instead chose not to take any further action. This effectively meant leaving Mr Hart with the erroneous impression that someone would be looking at his complaint, when in fact in April the complaint was closed. Given the seriousness of Mr Hart's complaint, and the obvious misunderstanding that had occurred, this was poor complaint handling.

Summary

384. NHS England's actions in response to Mr Hart's complaint were inadequate. They failed to demonstrate that they understood the very serious issues he complained about and due to a misunderstanding they closed his complaint without investigating it. NHS England's approach was not customer focused. It was so poor that it was maladministration.

Injustice

385. Mr Hart told us that Averil's family's motivation for pursuing this complaint is twofold: to find out what happened, and to make sure that changes are made to stop the same situation happening to someone else. Prior to bringing his complaint to us, Mr Hart had been in correspondence with the six different NHS organisations for more than a year and a half. The responses that Mr Hart and the rest of Averil's family received, however, were often inadequate and at times insensitive.

386. Amongst the six organisations we have investigated there were some examples of good complaints handling practice, which has been acknowledged by Mr Hart, and which it is important for us to recognise. This included the CCGs attempts to engage with Mr Hart and the second investigation by NNUH. However, what our consideration of the evidence has also shown us is that at other times during local complaint handling, Mr Hart faced decisions and actions on the part of the organisations which were insensitive and overly defensive. Examples of this include:

- CPFT's repeated insistence that attending a meeting with staff was the only way in which Mr Hart was going to receive full answers to his questions;
- UEAMC's refusal to answer Mr Hart's questions, instead directing him to Averil's records to find the answers for himself;
- NNUH's poor first review;
- CUHT's failure to respond appropriately to Mr Hart's follow-up questions;
- the CCG's failure to seek appropriate advice about the care Averil received from UEAMC; and
- NHS England's failure to correctly identify Mr Hart's concerns.

387. The responses to Mr Hart's complaints would have been frustrating for Mr Hart and his family, and he should not have had to expend so much energy and emotion, trying to find out what had happened to Averil and to be reassured that the organisations concerned had identified what went wrong and taken action to prevent it happening again. We cannot begin to imagine the frustration and distress this has caused for Mr Hart and his family, following the devastating death of his daughter. We have found that this was the impact of the maladministration we identified.

Our recommendations

Personal recommendations

388. Sadly we cannot remedy the injustice to Averil, but we can ask the organisations involved to take action that might go some way to remedying the injustice to her family. Mr Hart told us that his family wanted to know what went wrong with Averil's care. We are conscious that our investigation has taken much longer than it should and has been difficult and unnecessarily stressful for Averil's family. We apologise for that unreservedly. Mr Hart also told us that he wanted an apology for mistakes made by the NHS and evidence that changes have been made for the benefit of other patients in the future.

389. In line with our Principles for Remedy, we are making three personal recommendations to each of the organisations where we found that service failure and/or maladministration led to injustice to Averil and/or her family.

An apology

390. The Principles for Remedy say that public organisations should be customer focused by apologising for and explaining poor service. With that in mind, we recommend that CPFT, UEAMC, NNUH and CUHT write to Mr Hart to acknowledge the service failure we identified in the care they provided for Averil and the maladministration in the way they handled Mr Hart's complaint.

391. We also recommend that the CCG and NHS England write to Mr Hart to acknowledge the maladministration we identified in their complaint handling.

392. We further recommend that each of the organisations – CPFT, UEAMC, NNUH, CUHT, the CCG and NHS England apologise to Mr Hart and his family for the injustice that they suffered (as set out above) as a result of the failings we found.

393. The Trusts and NHS England should send these letters to Mr Hart within one month of this report. They should also send a copy of their letter to us.

Compensation

394. The Principles for Remedy say that public organisations should put things right by, if possible, returning the complainant to the position they would have been in if the poor service had not occurred. If that is not possible, public organisations should consider compensating the complainant appropriately.

395. No recommendation we could make will lessen the agony and distress for Averil's family in knowing that had she received the care she should have done the chances of her further deterioration would have been reduced and ultimately she would not have died on 15 December 2012. However, we recommend a payment from each of the organisations by way of tangible acknowledgement of the added distress her family have suffered.

396. Our standard approach where we make a finding of avoidable death is to recommend compensation of £10,000 to £15,000. These amounts, which have stood since 2010, are intended to be comparable to what the NHS Litigation Authority (now NHS Resolutions) would pay in the event of a claim for clinical negligence resulting in an avoidable death, which in turn takes account of the level of compensation payable under the provisions of the *Fatal Accidents Act 1976*. Where the case is particularly tragic, for example where the deceased was unusually vulnerable, we have tended to recommend larger sums. Here, we decided that £20,000 was an appropriate starting point for consideration. In this case we also found the failures of some organisations involved in Averil's care were more serious than others. We therefore decided that each organisation should be asked to pay compensation proportionate to the impact of their failings on Averil's family.

397. Specifically we recommend that:

- CUHT pay Mr Hart £15,000
- NNUH pay Mr Hart £3,000
- CPFT pay Mr Hart £3,000
- UEAMC pay Mr Hart £1,000

398. The organisations should do this within one month of the date of this report, and write to us to confirm the compensation has been paid.

Learning lessons

399. The Principles for Remedy also say that public organisations should seek continuous improvement by using the lessons learned from complaints to ensure that poor service is not repeated.

400. Mr Hart told us he wanted to see evidence that changes had been made for the benefit of other patients in the future. All these organisations, the CCG and NHS England, have told us that they have taken action to ensure that lessons are learned from what happened, so that the same failings will not happen in the future. We therefore recommend that each organisation writes to Mr Hart to explain what they have done and what they plan to do and to ask him how he would like to be reassured that changes have been made to prevent the same failings happening in the future.

401. The organisations should do this within three months of the date of this report.

Rob Behrens

Rob Behrens CBE
Ombudsman and Chair

6 December 2017

Annex A

Mr Hart's complaint in full

A1. On behalf of Averil's family, Mr Hart complains about the following aspects of her care and treatment:

Cambridgeshire and Peterborough NHS Foundation Trust

- that Averil was discharged too early from S3 ward, a full risk assessment was not done when she was discharged, and there was a failure to update and communicate the risk assessment that was done to other organisations;
- that it was inappropriate for the NCEDS Care Coordinator to be assigned to Averil as she had no experience in managing patients with anorexia nervosa;
- that the NCEDS Care Coordinator failed to carry out the full extent of her duties as care coordinator and provided poor care and treatment to Averil;
- that there was a lack of communication between NCEDS and UEAMC;
- that the Eating Disorder Unit Lead Psychiatrist refused to take Mr Hart's emergency call to S3 ward; and
- that following Averil's transfer to Addenbrooke's Hospital on 11 December 2012, it was inappropriate to appoint a healthcare assistant to look after her overnight.

University of East Anglia Medical Centre

- that Averil was not provided with a named GP;
- that the care provided was not in line with instructions in Averil's discharge summary;
- that there was a failure to follow King's College Guidelines; and
- that there was a failure by GPs to observe Averil's physical symptoms.

Norfolk and Norwich University Hospitals NHS Foundation Trust

- that Averil was not seen by a psychiatrist until 10 December 2012; and
- that she received inappropriate care and treatment for a patient with anorexia nervosa, including that she was allowed to walk around the ward and feed herself from a trolley on the ward, resulting in over-reporting of how much she was eating.

Cambridge University Hospitals NHS Foundation Trust

- that there was a significant delay in any consultant seeing Averil when she was admitted to N2 ward at Addenbrooke's Hospital following her transfer;
- that there was a failure to assess Averil's capacity to make decisions about her care in line with the Mental Health Act;
- that Averil's care and treatment was poor, including the issue of feeding and monitoring glucose levels; and
- that the Consultant told Averil's family when she was dying that they should not ask 'why'.

Mr Hart also complains about how each of the organisations below handled his complaints about the care Averil received:

Cambridgeshire and Peterborough NHS Foundation Trust

- that there was a failure to respond openly and honestly, to acknowledge mistakes, and apologise for Averil's death;
- that there was a failure to comply appropriately with Mr Hart's request for Averil's records;
- that there was a delay in the response to Mr Hart's complaint of 8 January 2014;
- that CPFT put the principal author of the MARSIPAN guidelines under '*undue pressure*' to remove a summary of Averil's case from the draft MARSIPAN guidelines;
- that the Eating Disorder Unit Lead Psychiatrist intentionally deleted email history relating to Averil's case;
- that internal emails suggest CPFT were trying to protect themselves from reputational damage; and
- that CPFT made continual suggestions at meetings with Mr Hart that he needed therapy.

University of East Anglia Medical Centre

- that UEAMC have been defensive and failed to respond to numerous communications.

Norfolk and Norwich University Hospitals NHS Foundation Trust

- that NNUH's response to Averil's family's complaint was inappropriate, and that they did not provide a copy of the complaint to the principal author of the MARSIPAN guidelines.

Cambridge University Hospitals NHS Foundation Trust

- that there was a failure to respond to Averil's family's complaint in a way that was appropriate to the seriousness of the event and the complaint, and that CUHT provided no recognition of the failings in Averil's care.

North Norfolk Clinical Commissioning Group

- that despite paying CPFT approximately £850,000 each year the CCG did not proactively supervise or quality control the provision of services by NCEDS;
- that there was a failure to provide a promised independent physician's review of Averil's care;
- that there was a failure to take account of Averil's family's concerns that the Consultant Psychiatrist commissioned by the CCG to undertake a review had significant professional connections to the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist, and that the Eating Disorder Unit Lead

Psychiatrist had an interest in a positive report as CPFT was tendering for the NCEDS contract in October 2014;
- that there was a failure to include Averil's family's views in the remit of the CCG's review, and initially, a refusal to their request to meet with the Consultant Psychiatrist commissioned by the CCG to undertake a review;
- that the report commissioned by the CCG was contradictory in parts, and did not adequately address a number of key issues; and
- that a letter of 11 March 2014 did not reflect the content of a meeting between Mr Hart and the CCG on 10 March 2014.

NHS England

- that NHSE failed to identify the substance of Mr Hart's complaint, wrongly interpreting it and reducing it to four bullet points in their acknowledgement letter; and
- that there was a failure to act on Mr Hart's complaint once it had been transferred from the NHS East Anglia Area Team to be handled elsewhere in the organisation.

Our role and approach

Our jurisdiction and approach

B1. Our role is to consider complaints about the NHS in England. We start by considering whether there is evidence that there has been maladministration by an NHS organisation, a failure in a service it provided or a failure to provide a service it was empowered to provide. If so, we consider whether that led to an injustice or hardship.

How we consider complaints

B2. When considering a complaint we begin by comparing what happened with what should have happened. We consider the general principles of good administration that we think all organisations should follow. We also consider the relevant law and policies that the organisation should have followed at the time.

B3. If the organisation's actions, or lack of them, were not in line with what they should have been doing, we decide whether that was serious enough to be maladministration or service failure.

B4. We then consider whether that maladministration or service failure has led to an injustice or hardship that has not been put right. If we find an injustice that has not been put right, we will recommend action. Our recommendations might include asking the organisations to apologise or to pay for any financial loss, inconvenience or worry caused. We might also recommend that the organisation takes action to stop the same mistakes happening again.

Relevant standards in this case

Our principles

B5. Our Principles of Good Administration, Principles of Good Complaint Handling and Principles for Remedy[75] are broad statements of what public organisations should do to deliver good administration, provide good customer service and respond properly when things go wrong.

B6. One of the Principles of Good Administration particularly relevant to this complaint is:

[75] You can find more detail about our Principles at www.ombudsman.org.uk/__data/assets/pdf_file/0013/1039/0188-Principles-of-Good-Administration-bookletweb.pdf; www.ombudsman.org.uk/__data/assets/pdf_file/0005/1040/0188-Principles-of-Good-Complaint-Handling-bookletweb.pdf; and www.ombudsman.org.uk/__data/assets/pdf_file/0009/1035/0188-Principles-for-Remedy-bookletweb.pdf.

- *'Getting it right'* – which means that public organisations must act in accordance with recognised quality standards, established good practice or both, for example about clinical care; and that decision making should take account of all relevant considerations and balance the evidence appropriately.

B7. A number of the Principles of Good Complaint Handling are particularly relevant to this complaint:

- '*Being customer focused*' – which means, amongst other things, that public organisations should treat complainants sensitively. It means public organisations should respond flexibly to the circumstances of the case and consider how they may need to adjust their normal approach to handling a complaint in the particular circumstances. It also means keeping complainants regularly informed about progress and the reasons for any delays.

- '*Being open and accountable*' – which means, amongst other things, that public organisations should give clear, evidence-based explanations, and reasons for their decisions. When things have gone wrong, they should explain fully and say what they will do to put matters right as quickly as possible.

- '*Acting fairly and proportionately*' – which means, amongst other things, that public organisations should ensure that complaints are investigated thoroughly and fairly to establish the facts of the case; that complaints are reviewed by someone not involved in the events leading to the complaint; and that they act fairly towards staff complained about as well as towards complainants.

Eating Disorder guidelines

The National Institute for Health and Clinical Excellence (NICE)

B8. The National Institute for Health and Clinical Excellence (NICE) has produced guidance on the management of eating disorders in the over 8's (CG9). The full guideline *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders* is published by the National Collaborating Centre for Mental Health (2004).

B9. This includes:

> *'2 Eating Disorders*
>
> *2.7 Treatment and management of eating disorders in the NHS*
>
> *2.7.4 Primary-secondary care interface*
>
> *It is particularly important for effective management that communication is good and that areas of responsibility are clear. Sometimes, for example a patient may be receiving psychological therapy from a secondary care service, but responsibility for physical monitoring may remain with primary care.*

2.7.5 Physical health care

In any treatment plan, it must be clear who is taking responsibility for physical assessment and how any risk identified is to be managed. This often involves effective communication between primary and secondary care services

2.9 Engagement, consent and therapeutic alliance

Whilst a forceful approach may result in a degree of weight gain in anorexia nervosa, clinicians are increasingly drawing attention to the importance of engagement and positive motivation if short-term gains are to be maintained in the long-term, whatever the treatment setting.

4 Summary of recommendations

4.2 Care across all conditions

4.2.1 Assessment and coordination of care

4.2.1.1 Assessment of people with eating disorders should be comprehensive and include physical, psychological and social needs, and a comprehensive assessment of risk to self.

4.2.1.2 The level of risk to the patient's mental and physical health should be monitored as treatment progresses because it may change – for example following weight change or at times of transition between services in cases of anorexia nervosa.

4.2.1.4 Where management is shared between primary and secondary care, there should be clear agreement amongst individual health care professionals on the responsibility for monitoring patients with eating disorders. This agreement should be in writing (where appropriate using the care programme approach) and should be shared with the patient and, where appropriate, his or her family and carers.

4.4 Anorexia nervosa

4.4.2 Psychological interventions for anorexia nervosa

4.4.2.1 Therapies to be considered for the psychological treatment of anorexia nervosa include cognitive analytic therapy (CAT), cognitive behaviour therapy (CBT), interpersonal therapy (IPT), focal psychodynamic therapy and family interventions focused explicitly on eating disorders.

4.4.2.3 The aims of psychological treatment should be to reduce risk, encourage weight gain, healthy eating, and reduce other symptoms related to an eating disorder, and to facilitate psychological and physical recovery.

4.4.2.4 Most people with anorexia nervosa should be managed on an outpatient basis with psychological treatment (with physical monitoring) provided by a health

care professional competent to give it and to assess the physical risk of people with eating disorders.

4.4.2.11 Following inpatient weight restoration people with anorexia should be offered outpatient psychological treatment that focuses both on eating behaviour and attitudes to weight and shape, and wider psychological issues with regular monitoring of both physical and psychological risk.

4.4.2.12 The length of outpatient treatment on physical monitoring following inpatient weight restoration should be typically at least 12 months.

4.4.4 Physical management of anorexia nervosa

Anorexia nervosa carries considerable risk of serious physical morbidity. Awareness of the risk, careful monitoring and, where appropriate, close liaison with an experienced physician are important in the management of the physical complications of anorexia nervosa.

4.4.5 Service interventions for anorexia nervosa

4.4.5.3 Inpatient treatment should be considered for people with anorexia nervosa whose disorder is associated with high or moderate physical risk.

4.4.5.5 Inpatient treatment or day patient treatment should be considered for people with anorexia nervosa whose disorder has not improved with appropriate outpatient treatment, or for whom there is a significant risk of suicide or severe self-harm.

6 Treatment and management of anorexia nervosa

6.2 Psychological interventions

6.2.2 Current practice

Health care professionals involved in the treatment of anorexia nervosa should take time to build an empathic, supportive, and collaborative relationship with patients

Outpatient psychological treatments in first episodes and later episodes

6.2.9.6 For patients with anorexia nervosa, if during outpatient psychological treatment there is significant deterioration, or the completion of an adequate course of outpatient psychological treatment does not lead to any significant improvement, more intensive forms of treatment (for example, a move from individual therapy to combined individual and family work, day care or inpatient care) should be considered.

6.2.3.3 Evidence statements

Such treatment [admission to hospital] *may have lasting effects although weight loss is common after discharge. There is no unequivocal evidence that inpatient treatment confers long-term advantage except as a short-term life-saving intervention in patients at high risk.*

There is insufficient evidence to determine any advantage for inpatient care over outpatient psychological treatments.

6.4 Management of physical aspects

6.4.2 Current practice

In the UK, patients at low weight are frequently managed in an outpatient setting in specialist eating disorder services. In these instances there is a higher threshold for inpatient treatment with admission often not occurring until the patient's BMI falls below 13kg/m2.'

MARSIPAN guidelines

B10. The Royal College of Psychiatrists, together with the Royal College of Physicians, has produced specific guidance for anorexia nervosa - *MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa CR162* (October 2010).

B11. These guidelines (updated in October 2014) provide advice and recommendations on how to manage patients with anorexia nervosa who are admitted to general medical units. The guidelines provide advice on physical assessment, advice to primary care teams on when to admit, advice on the required members of the inpatient medical team and advice on the medical, nutritional and psychiatric management of patients with severe anorexia nervosa in medical units, including the appropriate use of mental health legislation. The guidelines also set out the advice for commissioners on required services for this group of patients.

B12. The guidelines contain a number of key recommendations for services. The more relevant ones in relation to our investigation are:

- medical and psychiatric ward staff need to be aware that adult patients with anorexia nervosa being admitted to a medical ward are often at high risk;
- physical risk assessment in these patients should include body mass index (BMI), physical examination, including muscle power, blood tests and electrocardiography (ECG);
- most adults with severe anorexia nervosa should be treated on specialist eating disorder units (SEDUs);
- criteria for medical admission are the need for treatment (such as intravenous infusion) not available on a psychiatric ward, or the unavailability of a suitable SEDU bed;
- the inpatient medical team should be supported by a senior psychiatrist, preferably an eating disorders psychiatrist. If an eating disorders psychiatrist is unavailable, support should come from a liaison or adult general psychiatrist;
- the key tasks of the inpatient team are to:

- safely refeed the patient;
- avoid refeeding syndrome caused by too rapid refeeding;
- avoid underfeeding syndrome caused by too cautious rates of re-feeding;
- manage, with the help of psychiatric staff, the behavioural problems common in patients with anorexia nervosa, such as sabotaging nutrition;
- occasionally to treat patients under compulsion (using section 3 of the Mental Health Act) with the support of psychiatric staff;
- manage family concerns; and
- arrange transfer to a SEDU without delay, as soon as the patient can be managed safely there.

King's College Guidelines

B13. These guidelines set out various parameters for doctors to consider when assessing the risk to a patient with an eating disorder. It explains that '[p]*eople with eating disorders, in particular those with anorexia nervosa, are at high risk in terms of their own health and safety*'.

B14. In relation to medical risk, the guide explains that '[s]*creening for risk with an examination of muscle strength, blood pressure, pulse rate, peripheral circulation and core temperature is essential'*.

B15. The guidelines can be found in full at:

http://www.kcl.ac.uk/ioppn/depts/pm/research/eatingdisorders/resources/GUIDETOMEDICALRISKASSESSMENT.pdf

Guidance for acutely ill patients

B16. NICE has also produced guidelines covering how patients in hospital should be monitored to identify those whose health may become suddenly worse and the care they should receive: *NICE guidance 50: Acutely ill patients in hospital: Recognition of and response to acute illness in adults in hospital (July 2007)*

B17. The guidance states:

'Graded response strategy

No specific service configuration can be recommended as a preferred response strategy for individuals identified as having a deteriorating clinical condition.

1.10 A graded response strategy for patients identified as being at risk of clinical deterioration should be agreed and delivered locally. It should consist of the following three levels.

- *Low-score group:*
    - *Increased frequency of observations and the nurse in charge alerted.*

- *Medium-score group:*

    - *Urgent call to team with primary medical responsibility for the patient.*
    - *Simultaneous call to personnel with core competencies for acute illness. These competencies can be delivered by a variety of models at a local level, such as a critical care outreach team, a hospital-at-night team or a specialist trainee in an acute medical or surgical specialty.*

- *High-score group:*

    - *Emergency call to team with critical care competencies and diagnostic skills. The team should include a medical practitioner skilled in the assessment of the critically ill patient, who possesses advanced airway management and resuscitation skills.*
    - *There should be an immediate response.'*

Professional guidance

B18. The Health and Care Professions Council (HCPC – previously the Health Professionals Council) is the regulator responsible for practitioner psychologists. They have produced standards for conduct, performance and ethics (2008). This guidance includes:

> *'6 You must act within the limits of your knowledge, skills and experience and, if necessary, refer the matter to another practitioner.*
>
> *7 You must communicate properly and effectively with service users and other practitioners.*
>
> *8 You must effectively supervise tasks that you have asked other people to carry out.'*

B19. The HCPC also produced standards for proficiency for psychologists (2009). These standards set out safe and effective practice in the profession. They set out what a student must know, understand and be able to do by the time they have completed their training, so that they are able to register with the HCPC. They include:

> *'1a Professional autonomy and accountability. This includes being able to practice within the legal and ethical principles of their profession.*
>
> *1b Professional relationships. This includes being able to contribute effectively to work undertaken as part of a multidisciplinary team.*
>
> *2a Identification and assessment of health and social needs*
>
> *2b Formulation and delivery of plans and strategies for meeting health and social needs. This includes being able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy or other actions safely and skilfully. It also*

includes being able to formulate specific and appropriate management plans including the setting of timescales.

2c Critical evaluation of the impact of, or response to, the registrant's actions. This includes being able to monitor and review the ongoing effectiveness of planned activity and modify it accordingly

3a Knowledge, understanding and skills. This includes knowing and understanding the key concepts of the bodies of knowledge which are relevant to their profession-specific practice.'

B20. The British Psychological Society (BPS) promotes excellence and ethical practice in the science, education and practical applications of psychology. It has produced generic professional practice guidelines (2008). These guidelines include that supervision should:

'Have a frequency that is proportionate to the amount and nature of the work, although a minimum of 1.5 hours per month is considered appropriate for a psychologist regularly engaged in psychotherapeutic or counselling work, increasing proportionally with extent of caseload.'

B21. The BPS also produces a Code of Ethics and Conduct (2009). The code is aimed at all psychologists and focuses on the quality of decision making allowing sufficient flexibility for a variety of approaches and methods, but providing ethical standards which apply to all. The code is based on four ethical principles. These are:

- respect;
- competence;
- responsibility; and
- integrity.

The General Medical Council

B22. The General Medical Council (the GMC – the organisation responsible for regulating doctors) publishes *Good Medical Practice*, which sets out the basic duties and responsibilities required from doctors in providing, among other things, good clinical care. *Good Medical Practice* published in November 2006 is relevant to this complaint.

B23. It said that good clinical care must include:

a) *'adequately assessing the patient's conditions, taking account of their history (including the symptoms, and psychological and social factors), the patient's views, and where necessary examining the patient;*
b) *providing or arranging advice, investigations or treatment where necessary;*
c) *referring a patient to another practitioner, when this is in the patient's best interests'*

B24. *Good Medical Practice* also said to communicate effectively doctors must:

'be considerate to relatives, carers, partners and others close to the patient, and be sensitive and responsive in providing information and support, including after a patient has died. …'

B25. About *'Sharing information with colleagues'* and *'Working with colleagues'* it said:

'Sharing information with other healthcare professionals is important for safe and effective patient care'

and that doctors must:

'communicate effectively with colleagues within and outside the team'

'make sure that [their] *patients and colleagues understand* [their] *role and responsibilities in the team, and who is responsible for each aspect of patient care'*

The Nursing and Midwifery Council

B26. The Nursing and Midwifery Council (NMC – the organisation responsible for regulating nurses and midwifes) publishes *The Code: Standards of conduct performance and ethics for nurse and midwives* (2008), which sets out the expected standards of good practice and behaviour that all registered nurses and midwives must uphold in their daily practice.

B27. The NMC Code published in 2008 is relevant to this complaint and it said that nurses must:

- *'consult and take advice from colleagues when appropriate';*
- *'make a referral to another practitioner when it is in the best interests of someone in their care';* and
- *'keep clear and accurate records of the discussions had, the assessments made, the treatment and medicines given and how effective these have been.'*

Other guidance

B28. The NICE guidance CG32 (2006) *Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition*, includes the following:

'Nutrition support should be considered in people who are malnourished, as defined by any of the following:

- *a body mass index (BMI) of less than 18.5 kg/m^2*
- *unintentional weight loss greater than 10% within the last 3–6 months*
- *a BMI of less than 20 kg/m^2 and unintentional weight loss greater than 5% within the last 3–6 months.*

Healthcare professionals should ensure that all people who need nutrition support receive coordinated care from a multidisciplinary team.'

Mental Capacity Act Code of Practice

B29. The *Mental Capacity Act 2005*[76] allows doctors to make decisions in connection with the care and treatment of an individual, as long as:

a) before making the decision the doctor has taken reasonable steps to establish whether the patient lacks capacity in relation to the matter in question, and;
b) when making the decision, the doctor reasonably believes that the patient lacks capacity in relation to the matter and that it will be in the patient's best interests for the decision to be made.

B30. The MCA Code of Practice says that a person's capacity refers specifically to their capacity to make a particular decision at the time it needs to be made. A patient is presumed to have capacity unless it is established that capacity is lacking. In order to assess someone's capacity to make a decision for themselves, the MCA Code of Practice sets out a two-stage test:

First:

> *'Does the person have an impairment of the mind of brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.)'*

Second:

> *'If so, does the impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made.'*

B31. In answering these two questions, the MCA Code of Practice sets out the key considerations for a reaching a view on a patient's capacity:

i. *Does the person have a general understanding of what decision they need to make and why they need to make it?;*
ii. *Does the person have a general understanding of the likely consequences of making, or not making, this decision?;*
iii. *Is the person able to understanding, retain, use and weigh up the information relevant to this decision?;*
iv. *Can the person communicate their decision (by talking, using sign language, or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?*

B32. In explaining these tests, and specifically relevant to our investigation, the MCA Code of Practice explains point (iii) above. It says that in order to have capacity to make a particular decision, the person must have the ability to weigh up information and use it to arrive at a decision. It explains that sometimes an impairment or disturbance leads to a

[76] Sections 5(1)(a) and 5(1)(b).

person making a specific decision without understanding or using the information they have been given. For example:

> *'a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore.'*

B33. The Royal Marsden Hospital *Manual of clinical nursing procedures* (2008) is a manual of basic clinical procedures frequently used by trusts to inform their internal policies. The manual describes the principles of assessment stating:

1. *'Patient assessment is patient focused, being governed by the notion of an individual's actual, potential and perceived needs.*
2. *It provides baseline information on which to plan the interventions and outcomes of care to be achieved.*
3. *It facilitates evaluations of care given … influencing a patients outcome …*
4. *It is a dynamic process that starts when problems of symptoms develop, which continues throughout the care process, accommodating continual changes in the patient's condition and circumstances …'*

Department of Health's Guide to the Healthcare System in England

B34. This guidance explains the role of the CCG.

B35. The guidance can be found in full at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/194002/9421-2900878-TSO-NHS_Guide_to_Healthcare_WEB.PDF

NHS Commissioning Board's *The functions of the CCG*

B36. This guidance paper sets out the range of core clinical commissioning group (CCG) functions as set out in legislation.

B37. The guidance can be found in full at:

https://www.england.nhs.uk/wp-content/uploads/2013/03/a-functions-ccgs.pdf

NHS England's *Managing Conflicts of Interest: guidance for CCGs*

B38. This guidance sets out how CCG's should manage conflicts of interest.

B39. The guidance can be found in full at:

https://www.england.nhs.uk/commissioning/pc-co-comms/coi/

Local guidance

CPFT policy

B40. The CPFT care planning policy (2012) includes the following:

> ***'6.5 Care Coordinators for service users supported under CPA***
>
> *Care Coordinators have the key responsibility for overseeing the management of care and allocation of resources for service users supported through CPA and should have the authority to coordinate delivery of the care plan. Where there is more than one provider involved, the Care Coordinator will be the professional best placed to coordinate care - this may not always be a member of Trust staff. The Care Coordinator is not necessarily the person that delivers the majority of care. There will be times when this is appropriate but there will be other times when therapeutic input may be provided by others, particularly where more specialist intervention is required.'*

CUHT policy

B41. At the time of the events complained about, CUHT had a policy on *'Completing the adult generic observation chart'*. The purpose of the policy was to ensure a consistent way of documenting physiological parameters, and also to ensure that:

> *'The patient's physiological parameters* [were] *interpreted and appropriate referrals and interventions* [were] *undertaken when these* [fell] *outside the normal parameters.*

B42. This policy set out a *'Modified early warning score (MEWS) algorithm'* designed to specify the actions to be taken according to the MEWS score.

B43. Relevant to this complaint, CUHT's algorithm specified that when the MEWS score was 4 or more, staff should *'inform shift charge, critical care outreach* [and] *patient's medical team'*. It said that staff should record observations and MEWS at least hourly every four hours. It said these same actions should continue to be taken until the MEWS score was 3 or below.

Established good practice

B44. We ask our advisers to provide advice supported by reference to recognisable professional standards or guidance relevant at the time of the events complained about. Those standards have been set out above. However where no such standards or guidance exist we ask our advisers to refer to 'established good practice'. This is what was recognised as evidence-based practice at the time of the events complained about.

Annex C

Information obtained during the course of our investigation

Internal CPFT emails Mr Hart has raised as a concern

C1. Following his request for copies of internal emails, Mr Hart identified a number of these which he is concerned suggest that CPFT have acted to protect themselves from damage to their reputation.

C2. The first two emails of this bundle (subject '*A Hart files*') have been redacted before sharing with Mr Hart. Part of what is redacted in each is the name of someone who had requested that some notes were withheld from Averil's parents. As part of our investigation we have had access to the unredacted versions of internal CPFT emails relating to this case. Comparing the two sets, we can see that the name redacted in the first email is Averil's (referring to records she did not wish to be shared with her parents). In the second email, the name is of a member of CPFT staff, and cross-referencing this with the other records we have, the '*small bundle*' of notes referred to appears to relate to a few documents which are grouped together under a cover sheet which says '*Entries of a sensitive nature, which would be deducted from* [the NCEDS Care Coordinator] *supervision notes, should the records be disclosed to family*'. There are three items listed, with the reason for redaction recorded next to it. This reads '*sensitive information*' for the first document, and '*other patient's information*' for the other two.

Problems experienced by the CCG in sourcing a physician to review Averil's care

C3. The CCG also promised Mr Hart they would commission a physician to review Averil's care. The CCG explained to us during our investigation that they had found it very difficult to find a suitable expert to provide the advice.

C4. They said that they initially approached the GMC and BUPA for help in securing an independent opinion from a gastroenterologist, but to no avail. They approached a doctor in a letter dated 24 February 2014 (the details had been obtained from the BUPA website), and subsequently approached the *'Medical Workforce Unit'* at the Royal College of Physicians. A list of possible physicians was provided and four physicians were contacted on 30 April 2014. Only one responded to explain that they might be able to do the work, but only if additional time was provided. On 9 May, the CCG agreed to extend the deadline but heard nothing further from the physician. The CCG approached the Head of Clinical Transformation at another CCG on 26 June, however after a preliminary review of the papers he also confirmed that he was unable to provide the advice required, and provided the contact details of another physician. On 4 August, following receipt of the records from CUHT, the CCG approached the physician suggested by the Head of Clinical Transformation, but his focus was primary care and therefore he was unable to undertake the work. The CCG also approached the British Society of Gastroenterologists and the NHS Litigation Authority (NHSLA), who referred them to one of their law firms.

C5. On 22 August, two further physicians were approached, but neither felt able to undertake the review, and on 27 August, the CCG approached NHS England, again without any success. On 1 September, the CCG received the contact details of physicians used by a law firm suggested by the NHSLA; two of these physicians were approached on 17 September, and two days later an expert was appointed.

C6. Once the expert was commissioned to provide his report, a draft was shared with CUHT on 21 November for comments. A substantive response was received from CUHT in January, and subsequently that response and the report was shared with Mr Hart on 25 February 2015.

Information provided to us by UEAMC

C7. In his complaint to us, Mr Hart refers to the nature of UEAMC's response to questions we asked them during the initial stages of our investigation. This was a letter dated 22 January 2015 which included the following points:

- They always advise patients to try to stick to one doctor, but students sometimes find this difficult to fit with their timetable. At Averil's first appointment with a GP they had discussed seeing her weekly, but she failed to turn up for her second appointment and in her email had said that NCEDS '*had provided her with a mentor, she was happy and doing well and she was going to see them weekly instead of us for monitoring and weighing and would not be coming to us weekly anymore. We cannot force patients to attend or to comply with monitoring – only encourage.*'

- Averil's blood tests had not been considered urgent as they only needed to be done 2-3 monthly, and that '*it was confirmed to us that the monitoring requested by previous* [eating disorder services] *in Cambridge was now being undertaken by* [NCEDS] *in Norfolk and they confirmed to us that they were seeing her weekly. We cannot force a patient to come to our practice or have reason to if both patient and the service confirm that care is being provided elsewhere*'.

- They could not see any evidence in the records that suggested BMI was a focus (the suggestion being that they did not follow guidance which says that this is not a sufficient marker of progress).

- Averil's weight had been consistent on the first two occasions she was weighed at UEAMC. On the third visit she refused, and her last appointment with them was on 8 November, before it is believed that her weight dropped significantly.

C8. UEAMC's letter to us also included the following comment from the locum GP who saw Averil at her second and third appointments there:

> '*I haven't got copies of my consultations so can't remember exactly what was included. I do remember her providing excuses to refuse monitoring as anorexics often do. I have attended Eating Disorder workshops and meetings to improve my knowledge of management. However, anorexia has the highest mortality of any mental health illness and is a very complex and difficult thing to manage, particularly in severe cases which need specialist care.*'

C9. We received further correspondence from UEAMC after we shared our second piece of GP advice with them. In an email to us of 28 September 2015, UEAMC said that '*the practice accepts that there was a service failure*'. They provided us with the following statement from the locum GP:

> '*I have now re-read both of the Medical Adviser's reports, as well as* [Averil's] *records, and looked at my previous response and feel that on reflection and after discussion, with the benefit of hindsight, I certainly agree that there was a service failure, in which I was involved.*
>
> *I do regret my part in the service failure and accept that there were areas in my management of* [Averil] *that could have been done differently and better, such areas were documenting weekly review, noting that a blood test was required, complying with the King's College guideline more thoroughly and informing* [NCEDS/UEAMC] *doctor of ongoing problems.*
>
> *I have really thought about my management of* [Averil] *and accept the criticisms of the Medical Adviser.*
>
> *I am very sad about the death of such a*[n] *intelligent young woman and this has lead me to learn and explore more about eating disorders in order to prevent the same service failure happening again.*
>
> *I now have more knowledge about eating disorders, their management and who and when to contact for help.*
>
> *I have established protocols at my current practice so that patients are reviewed at agreed intervals, by a named doctor, and that we have clear details of what examination and investigations need to be carried out and their frequency* [] *and recalls set up to alert the practice and myself to missed appointments.*
>
> *This process of reflection and review has taught me valuable lessons.*'

C10. After we shared a draft copy of this report with UEAMC we received further comments from them. About Mr Hart's complaint that Averil had not been allocated a named GP, UEAMC said that the practice had a shared patient list, where patients would

generally see whichever GP was available. But UEAMC said that for high risk patients, like Averil, the practice system at the time was for the first GP who saw the patient to become their lead GP. UEAMC said the lead GP would then be the person to whom other GPs and practice staff would refer if issues arose concerning that patient. UEAMC acknowledged that they had not been able to locate a written protocol for this, but they said it was how the practice did things at the time.

C11. To further explain its systems for establishing a patient's lead GP, UEAMC said that if a doctor saw a patient who needed follow up for a complex health condition, like an eating disorder, then the expectation would be that the patient would continue to see that same GP (or in some cases two GPs) in order to build a relationship and lead the patient's care. And who this GP is would then be clear in the consultation notes. But, UEAMC said that Averil was not registered with the practice long enough for this relationship to develop.

C12. In Averil's case, UEAMC said the GP who saw her on 12 October 2012 became her lead GP, in keeping with the practice's systems at that time. They said that, as stated in the notes, this GP intended to see Averil again the following week, but Averil changed the appointment and re-booked an appointment with another GP (a locum GP) on 25 October. UEAMC said the locum GP then changed the frequency of Averil's reviews without talking to her lead GP. And UEAMC acknowledged that this meant that the systems the practice had in place did not work in Averil's case.

C13. With its correspondence UEAMC sent us a copy of a document headed 'Patient of Concern Record', updated on 24 October 2012, as evidence that the first GP to see Averil had become her lead GP. The document listed the first GP to see Averil as her *'Main D*[octo]*r'*. UEAMC explained that high risk patients were added to the 'Patient of Concern Record' and their case briefly discussed at the next practice meeting attended by all the doctors and a nurse representative. UEAMC said the aim was to ensure that if a patient on the 'Patient of Concern Record' came into the practice everyone would be aware of them and know that they were a high risk patient. UEAMC said locum GPs were also welcome to attend these meetings.

C14. Following this correspondence, we visited UEAMC to see for ourselves the practice's systems and the electronic copies of the 'Patient of Concern Records' (as the paper copy we had been sent had had information removed to maintain the confidentiality of other patients).

NHSE

C15. During our investigation we spoke to the Complaints Manager from NHS East Anglia Area Team who originally handled Mr Hart's complaint. She confirmed that she was not approached by anyone within NHSE and was not aware that Mr Hart's complaint had been reallocated. We also spoke to the Customer Contact Centre and NHSE Central Office to find out whether Mr Hart's complaint was reallocated, and whether they knew where the reference number Mr Hart had quoted to us originated from. They confirmed that the complaint was not reallocated, and did not recognise the reference number.

Annex D

Advice from the Clinical Advisers

UEAMC

The First GP Adviser

D1. The First GP Adviser said that, fundamentally, the GPs should have done what they had committed to doing, in line with their duties to their patient and national standards which are explained below. This means that when they were first contacted by the Eating Disorder Unit Psychologist with the specific monitoring requirements, they should have either:

a) explained that they would be unable to undertake the monitoring asked of them; or
b) agreed to carry out the plan, and then kept to it.

D2. The First GP Adviser said that the GPs were entitled to vary the plan if they felt it was necessary – but in such cases it would be established good practice to make the variation clear, and to communicate it to anyone else involved in the care of the patient. In this case, if the GPs decided that weekly monitoring was no longer required and monthly monitoring would be sufficient; they should have clearly communicated this to NCEDS, including their reasons why. This would have been in line with NICE CG9 (paragraph B9).

D3. Overall the First GP Adviser said that from the first consultation, the GPs took on board what the Eating Disorder Unit Psychologist told them, and clearly recorded the plan, the conversation and the discharge summary in Averil's records. On the whole the First GP Adviser said that they undertook most of the monitoring up to and including the 25 October 2012 as they had been asked to do, even though only one appointment fully met all the monitoring requirements of Averil's discharge plan.

D4. The First GP Adviser said that, although not ideal, it would be difficult to be critical of the GPs for not recording all the requested parameters as there were only three consultations (not including the 8 November) and they checked three out of four of the minimum requirements as per NICE guidance, which states check BMI, pulse and blood pressure (BP) as a minimum. As they checked the BP during two consultations the machine would have also checked the pulse, it simply is not recorded. It was only in one consultation that the BP and pulse was not checked (12 October). Additionally there is documented evidence that Averil stated she was doing well and engaging. The observations which were carried out were all within the accepted range as set out in the King's College Guidelines. In the absence of any alarm bells, there was nothing additional for them to do.

D5. The only abnormal reading was Averil's diastolic blood pressure measured on 25 October. The King's College guidance (paragraphs B13 to B15) provided to UEAMC states that a diastolic BP less than 70 should cause '*concern*'. A low BP can be an indicator of dehydration or circulation problems. The guidance is not clear what next steps should be taken. However at the very least the BP reading should have been recognised as an abnormal parameter with a need to either discuss with the specialist service or monitor

closely. This would provide further reason to question the decision to increase the monitoring interval by the GP at the next consultation on 8 November.

D6. The First GP Adviser said that UEAMC then received a very clear letter from NCEDS on 26 October which stated that NCEDS would monitor Averil's weight, but that the GPs should continue the regular medical monitoring given her low BMI. At this stage, UEAMC had direct contact from NCEDS. They had the contact details of Averil's psychologist and care coordinator, and they had specific confirmation that regular medical monitoring was still required. The First GP Adviser said that at this point, UEAMC had another opportunity either to do what was being asked of them, or explain why they could not. Instead, the GPs decided to vary the plan they had been following until then and to review Averil in a month. The First GP Adviser said that although there were no 'alarm bells' that she needed any immediate intervention from the GP, her weight was decreasing, so it was difficult to understand why they decided that a monthly review was now appropriate. This was clearly not in line with the discharge summary or the plan that they had agreed to follow.

D7. In summary, the First GP Adviser said that having agreed to undertake the monitoring in September, and with confirmation of this agreement and the plan in the letter from NCEDS in October, there was no reason why UEAMC could not follow the plan. The First GP Adviser said that if they were unable to continue such intensive monitoring, this should have been discussed with NCEDS and a clear explanation should have been given that they could no longer provide this service. This seems especially important given that in September it was highlighted how important this monitoring was and how vulnerable Averil was in relation to her previous inpatient treatment. The GPs did provide a reasonable level of monitoring until and including the 25 October consultation but failed to recognise a decline in physical markers and were perhaps falsely reassured by her engagement with NCEDS.

D8. The First GP Adviser did note, however, that there should have been a clearer understanding about what to do with the results of the monitoring, and at what point they should contact the NCEDS service. Apart from the letter in October, there was no further contact from NCEDS and no clear arrangement for how the GPs should communicate abnormal results. The First GP Adviser said that in general, having a specialist service involved in a patient's care does blur the lines of responsibility for GPs and it is therefore especially important to ensure that there is clarity. However, this does not absolve UEAMC's fundamental requirement to do what was asked of them, or explain why they could not.

Named GP

D9. In relation to the issue of a named GP, the First GP Adviser said that this was not about an obligation for one GP to see the patient exclusively, but rather it was more about one GP having overall oversight of the patient's care. The First GP Adviser said that Averil was not a patient at UEAMC long enough to build up a relationship with a particular GP, although she did see the same GP on two occasions. However, the record keeping was clear and therefore each GP was aware of Averil's needs.

BMI

D10. The First GP Adviser said that there is evidence that the GPs were not just focusing on Averil's BMI, but that they attempted to consider her overall well-being, including her psychological well-being as well as her physical well-being. Up to 25 October there were no concerning signs from a medical perspective, and the evidence the GPs had was that Averil was engaging with university life and treatment from NCEDS.

Failure to reflect on Averil's physical symptoms and falsifying weight

D11. The First GP Adviser said that there was not enough in her physical symptoms to trigger any particular action at that stage. However, Averil's condition did justify maintaining the plan as it had been agreed. The First GP Adviser said that in practice, there was not much that the GPs could have done about the possibility that Averil was falsifying her weight – this would not have been within their expertise. The First GP Adviser said, however, that it was most surprising that given her weight was dropping, albeit slowly, that they decided to review Averil in a month.

Impact

D12. The First GP Adviser said that if the GPs had continued to monitor Averil, they may have identified medical signs that she was deteriorating. This might have prompted them to contact NCEDS, or particularly in the two weeks when Averil appears to have lost a lot of weight, it may also have prompted them to refer her to hospital sooner. The fact that UEAMC decided to review Averil in a month was effectively a missed opportunity to keep a close eye on Averil's condition, although it is very difficult to say with certainty what the impact of that would have been.

The Second GP Adviser

D13. The Second GP Adviser made the following comments about the actions of GPs at UEAMC with regards to Averil's care:

- 27 September 2012: Following the call from the Eating Disorder Unit Psychologist, a clear, sufficiently detailed, and well-documented note was entered into Averil's records, describing a care plan, and drawing attention to the written guidance that should be followed. The entry records that Averil had had a prolonged admission for her eating disorder, and was at risk of relapse. It was written that UEAMC was to be a '*safety net*', and that there will '*hopefully* [be] *a named GP*', although it is not clear what was agreed on this point (the Second GP Adviser added here that it is not always the best plan for a patient to see only one GP because GPs often work part-time and have outside commitments, and then a patient may not feel they can see another GP). There was a lack of a plan for what to do if Averil did not attend and who was responsible for checking on this. However, it did not make a difference in this case because she attended until she was advised on 8 November that she should attend a review in a month's time.

- 29 September 2012: Averil's weight and some general information such as alcohol intake were recorded (information taken from a new patient form that Averil completed when she registered with UEAMC). This was normal procedure and in accordance with established good practice; nothing else should have been recorded within this context.

- 2 October 2012: A note was entered in Averil's records highlighting the monitoring requirement information. This was established good practice as it indicated the document was important.

- 5 October 2012: A healthcare assistant who completed a New Patient Medical for Averil entered a weight, BMI, and blood pressure reading into the records. This was standard procedure and in line with established good practice.

- 12 October 2012: Averil's first appointment with a GP at UEAMC; her weight had fallen by 1kg in a week. This put her in the '*concern*' category in the guidance UEAMC was given, which indicated the need for urgent referral and appropriate medical intervention. It also states that the risk should have been shared with Averil's carer. No other parameters were recorded at this appointment, but a pulse, lying and standing blood pressure, and strength test should have been done and documented in line with the care plan, and particularly in light of the weight loss. The Eating Disorder Unit Psychologist should have been informed, and this may have been a missed opportunity to contact the Eating Disorder Unit Psychologist and intensify the support Averil was receiving.

- 25 October 2012: A different GP saw Averil and recorded her blood pressure, pulse and squat (strength) test. Her lying and standing blood pressure were not checked as per the guidance, and despite a decrease in her BMI and blood pressure readings (the diastolic reading was at a level which again put her in the '*concern*' category), it was decided that Averil could be seen in two weeks, rather than one. There is a mention that Averil was seeing NCEDS weekly at this point, but this was for cognitive behavioural therapy and weighing, not medical monitoring, so she should have been seen again at UEAMC the following week.

- 8 November 2012: Averil was seen again by the same GP as on 25 October, who noted that Averil was being seen weekly by NCEDS and weighed by them. The GP recorded a pulse rate, but no squat test or blood pressure reading. She did not document Averil's weight as had been advised in a letter from NCEDS that made it clear medical monitoring was still required by UEAMC (at this point Averil's weight had fallen further to 39.2kg). In view of this, the GP should have taken advice from the NCEDS Care Coordinator on whether blood tests or further actions needed to be taken. Averil should have had another appointment made for the following week; instead the GP decided she could be seen in a month's time. The GP should have also asked Averil to have the blood tests done that the Eating Disorder Unit Psychologist had recommended at the start of UEAMC's involvement.

Impact

D14. The Second GP Adviser told us that it is impossible to say for certain whether GPs at UEAMC would have picked up that Averil was becoming more unwell had they continued to monitor her as per the care plan. However, she said that the lack of monitoring that followed the appointment on 8 November was a lost opportunity to act, and that given Averil's weight fell to 31kg by the time of her admission to hospital, it is likely that a GP would have noted and responded to a 10kg weight loss in an already underweight patient.

Other comments

D15. The Second GP Adviser said that she was surprised that NCEDS had not checked that medical monitoring was happening given Averil's falling BMI, or convey her weights to UEAMC given they had advised they did not need to do this.

D16. The Second GP Adviser commented that UEAMC appear to have put in place an excellent care plan for patients with eating disorders in future, which should make it clear what is required and gives responsibility for chasing patients who do not attend to a named person.

D17. The Second GP Adviser added that the response from the second GP to our preliminary concerns was not reasonable, because although Averil declined to be weighed during her appointment on 8 November, the second GP should have tried to continue with other physical checks, and find out her weight from NCEDS. The Second GP Adviser said that the second GP indicates that Averil should have seen her usual GP for her weekly checks, but that there is nothing in the records to suggest that this was discussed or who it was. The Second GP Adviser said that it is a concern that the second GP has said she would not[77] have changed anything about the care she provided, as it suggests she does not accept responsibility for suggesting a review in a month rather than a week in a patient who was losing weight and who UEAMC had agreed to monitor weekly.

The First Psychiatrist Adviser

D18. We took psychiatrist advice from a specialist who works in an eating disorders service in order to understand the impact of UEAMC's failings on Averil. The First Psychiatrist Adviser told us the following:

- During the period between 25 October and 23 November 2012, Averil lost an average of 0.7kg per week, a rate of weight loss that is a cause for concern. Weekly weight monitoring and physical observations would have shown a gradual but consistent reduction in weight, likely to have been associated with deterioration in physical observations (reduced blood pressure and heart rate, increased difficulties with squat test).

[77] The second GP subsequently reflected further and agreed that there were things she could have done better (see paragraph C9).

- This would have at least been an indication for close medical monitoring and repeating blood tests, and would have reliably demonstrated Averil's true physical health status (whereas weight or BMI alone is not a reliable marker of medical risk in patients with anorexia nervosa because it is open to manipulation and falsification).

- Between 23 November and 7 December 2012, given the extent of Averil's weight loss, there would definitely have been a deterioration in all her physical health parameters, including blood tests. Had this been identified, the rapid deterioration in Averil's health is likely to have prompted urgent referral to inpatient care.

CPFT

The First Psychiatrist Adviser

Discharge and handover

D19. The First Psychiatrist Adviser noted that Averil suffered from severe anorexia nervosa and that her illness was characterised by severe dietary restriction and over activity. Her BMI was 11.2 when she first presented to the mental health service and she was urgently admitted informally[78] to the Specialist Eating Disorder Unit for treatment. During 11 months of intensive inpatient care, her weight restoration was slow and hampered by over activity (1.4kg per month compared to the expected restoration of 0.7-1kg per week). The First Psychiatrist Adviser said that there appeared to be a recurring pattern of weight loss when Averil was on leave from the Unit. There was a history of weight manipulation by water loading (referred to once). Averil did not appear to fully appreciate how her ongoing behaviour (over activity) affected her ability to restore weight.

D20. The First Psychiatrist Adviser said the decision to discharge Averil in August 2012 appeared to have been made by Averil due to her desire to attend the University of East Anglia in September. And she told us that there was no information in the notes to suggest that the medical team opposed this decision. The First Psychiatrist Adviser said that this was reasonable, given the length of time that Averil still had to restore to a healthier weight before starting university. Having a goal to work towards may have proven to have been an important motivator for recovery. Sadly this was not the case.

D21. The First Psychiatrist said by May 2012 discharge plans were being discussed and preparations were being made for Averil to start university in September. Averil set herself a weight target of 50kg (BMI 18.5) prior to discharge in August. This meant that Averil would have had to restore 1kg per week, which she had never managed to achieve before during her admission.

D22. The First Psychiatrist Adviser said Averil's weight was 5kg below target on discharge (45.2kg, BMI 16.6). At the time of discharge Averil was an informal patient who had capacity. She planned to continue restoring weight in the community (which the First

[78] Meaning she was admitted as a voluntary patient, and did not have to be admitted against her wishes under the *Mental Health Act 1983*.

Psychiatric Adviser said was a somewhat unrealistic expectation given her weight restoration history and circumstances) and agreed to regular medical monitoring. As such, the First Psychiatrist Adviser said it was highly unlikely, at the time of her discharge from ward S3, that Averil would have met the criteria for detention and treatment in hospital under the Mental Health Act.

D23. The First Psychiatrist Adviser told us that there were several factors that increased Averil's risk of relapse/deterioration after discharge:

- Chronicity and severity of Averil's illness:

  There was a 3 year history of untreated illness with accelerated weight loss in the 3 months prior to admission. Admission BMI of 11.2 indicates severe emaciation and risk to life. CPA review dated 31 July 2012 stated *'A's weight loss may be sudden – may become frail and prone to falls'*. She had not recovered from anorexia and remained underweight on discharge.

- Slow rate of weight restoration despite receiving intensive inpatient treatment:

  Over activity appeared to be the main contributing factor and this remained a problem on discharge;

- Averil's inability to restore weight whilst on home leave;

- Averil being *'unable to recognise when she is deteriorating'* (5 August 2012 – record);

- Averil's move to independent living for the first time in her life, after spending 11 months in a protected and supportive environment.

D24. The First Psychiatrist Adviser added that these risk factors were somewhat mitigated by Averil's agreement to engage with NCEDS and to attend regular medical monitoring after discharge. Her BMI was over 14 and therefore not considered to be in the high risk category. She had also seemingly engaged in relapse prevention work in the months prior to discharge. With this in mind, at the time of Averil's discharge, the First Psychiatrist Adviser told us she would not have considered there to have been a significant risk to Averil's physical health or of self-neglect. However, she would have considered Averil as being at significant risk of relapse in her new environment, and someone requiring close medical monitoring and risk management.

D25. The First Psychiatrist Adviser said the Eating Disorder Unit Psychologist offered to remain in contact with Averil following her discharge as Averil did not want to be seen by the Suffolk Eating Disorders Community Team prior to her move to Norfolk (a period of 7 weeks). According to the notes, the Eating Disorder Unit Psychologist had contact with Averil on 9 and 30 August, and 20 September. This meant that Averil was not having regular weekly physical health and weight monitoring during this time.

D26. The First Psychiatrist Adviser said in transferring Averil's care to NCEDS, the Eating Disorder Unit Psychologist wrote to and had telephone contact with UEAMC, NCEDS and the University Wellbeing Team. She highlighted the following:

- risk of over activity;
- weight loss in the three weeks post discharge;
- risk of vulnerability to relapse given her current major life changes; and
- information/guidance on medical monitoring.

D27. The First Psychiatrist Adviser noted that the discharge summary from ward S3 stated Averil's admission BMI as 12.5, which was significantly different to her actual BMI of 11.2.

D28. The First Psychiatrist Adviser said the Eating Disorder Unit Psychologist's letter to NCEDS dated 21 September 2012 stated that her discharge weight was 44.2kg (BMI 16.2), instead of her actual discharge weight of 45.2kg (BMI 16.6). She said while these seem like small discrepancies, they may have impacted on future risk assessments for example rate of weight loss from discharge and severity of illness.

D29. The First Psychiatrist Adviser explained that the Eating Disorder Unit Psychologist clearly attempted to transfer Averil's care as comprehensively as possible. However, her efforts were not supported by a formalised CPA transfer process. The fact that Averil appeared to be reluctant to engage with the local Suffolk Community Eating Disorders Service prior to her transfer to Norfolk may have also complicated the process.

D30. For a patient in Averil's position, the First Psychiatrist Adviser said established good practice would have been for ongoing weekly contact with NCEDS for therapy (if appropriate) and weight monitoring, as well as regular weekly medical monitoring as advised by King's College guidelines. Weight loss after discharge is common. She said it would be established good practice to continue weekly physical monitoring until there is evidence that the patient is managing to maintain their weight. If the patient's weight is monitored by the Eating Disorders Service, it would be their responsibility to alert the GP if they lost weight.

D31. The First Psychiatrist Adviser noted that Averil was last seen in Suffolk by the Eating Disorder Unit Psychologist on 20 September 2012. This meant that there was a delay of one month before she attended her first appointment with the NCEDS Care Coordinator on 19 October 2012. She said Averil had no contact with eating disorder services for one month after leaving Suffolk and her weight was not being monitored. At her first appointment with the NCEDS Care Coordinator, Averil had already lost 6kg in eleven weeks since her discharge (over 0.5kg per week, which the First Psychiatrist Adviser said would be a cause for concern).

D32. The First Psychiatrist Adviser said Averil's weight loss had accelerated in the two weeks prior to her first meeting with the NCEDS Care Coordinator. She had lost 2.8kg in 3 weeks, but the NCEDS Care Coordinator would not have appreciated this unless she was aware of the GP's recorded weights (5 October – 42kg, and 19 October, 39.2kg).

D33. The First Psychiatrist Adviser said that the NCEDS Care Coordinator appeared to recognise the risk to physical health and reaffirmed the importance of weekly health checks with the GP (26 October 2012). Over the next 6 weeks, however, from the NCEDS Care Coordinator's weight records, Averil's weight remained relatively stable. She lost 1kg over 6 weeks which would not have been considered high risk to physical health and an indication for urgent medical review. However, Averil's diary entry on 22 November implies that she was manipulating her weight, *'she wanted to realistically know how much she weighed'*. The First Psychiatrist Adviser said that one could only assume Averil was water loading or using another mechanism to falsify her weight.

D34. The First Psychiatrist Adviser said that a therapist with experience in eating disorders may have been better able to recognise physical deterioration in a patient, regardless of recorded weight, and may have given more consideration to the possibility of weight manipulation. However, she added that physical deterioration is not always easy to recognise in patients with anorexia due to the patient's tendency to minimise physical symptoms and remain active, engaging and drive in the face of deteriorating physical health. Averil's family were clearly able to recognise a significant deterioration in her health, without knowing her BMI or physical observations.

D35. The First Psychiatrist Adviser explained that she did not know whether the initial weight loss of 6kg from discharge was discussed at supervision session or recognised as significant. For a patient with this history of rapid weight loss since discharge, she said that a referral for psychiatric review would have been appropriate, primarily to agree a risk management plan. This plan would have been likely to include regular review by the psychiatrist.

D36. The First Psychiatrist Adviser said the role of the consultant psychiatrist in an eating disorders service could be variable, but primarily they would be involved in providing clinical leadership to multidisciplinary teams and taking a lead in risk management. She added that she would expect a consultant psychiatrist to review complex cases, especially those presenting with significant psychiatric or physical comorbidity. They would also review patients who are not making progress in therapy or whose mental or physical health is deteriorating.

D37. The First Psychiatrist Adviser said regular physical examination may have demonstrated declining physical health, for example loss of muscle strength and deteriorating physical observations (blood pressure and pulse), but Averil's weight remained stable and there seemed to be less clinical indication to repeat bloods and physical examinations. She added that the frequency of repeating investigations was a clinical judgement and depended on the previous results and the patient's presentation.

D38. In summary, the First Psychiatrist Adviser said the care that Averil received from NCEDS appeared to be in line with NICE guidance (paragraphs B8 and B9); Averil was receiving weekly psychological therapy and having her weight monitored. However, she was not advised to attend regular medical reviews, or referred for a psychiatric review as her weight appeared stable.

Inpatient admission to NNUH

D39. The First Psychiatrist Adviser said that once NCEDS was informed of Averil's admission to NNUH, established good practice would have been for the NCEDS team and the treating physicians to liaise and formulate a treatment plan in line with MARSIPAN guidelines, by the next day. This care would include:

- bed rest with one-to-one observations;
- urgent dietetic advice and meal plan formulated and revised 12 hourly;
- monitoring food intake by accurate recording;
- monitoring for refeeding and underfeeding syndrome; and
- behavioural management plan to avoid treatment sabotaging behaviours.

D40. The First Psychiatrist Adviser told us that there were several factors that contributed to the failure to follow MARSIPAN guidelines when planning Averil's care on admission to NNUH. Firstly, when NCEDS did attempt to contact the medical ward, there did not appear to be adequate information sharing, by both parties, including Averil's admission weight. Averil had had no contact with either the NCEDS Lead Psychiatrist or the NCEDS Specialty Doctor since discharge from ward S3 and her notes would indicate that she was last weighed two weeks previously and her weight had been relatively stable for six weeks prior to this. The First Psychiatrist Adviser added that it did not appear that either the treating medical team or the NCEDS psychiatrist recognised that Averil's weight had fallen by 6.8kg in two weeks, putting her in the very high medical risk category at the time of admission. The First Psychiatrist Adviser explained that even if the history was unknown, a patient presenting with BMI of 11.2, no matter what the cause, would be regarded as a high risk patient requiring urgent nutrition. Having not been recognised as a MARSIPAN patient on admission, and knowing that Averil would not be discharged from hospital over the weekend, she said it was understandable that the psychiatrist had decided to review Averil on the ward after the weekend. Had it not been the weekend, there would have been an opportunity for the consultant psychiatrist to review Averil the next day.

D41. The First Psychiatrist Adviser said that there was also a lack of a pre-existing agreement/protocols for managing severely ill patients with anorexia nervosa in a medical setting, in line with MARSIPAN guidelines.

D42. The First Psychiatrist Adviser said medical attention was diverted to managing Averil's abnormal liver tests (thought to be related to an accidental paracetamol overdose) and later Averil's fall.

D43. The First Psychiatrist Adviser told us that all Averil's signs, symptoms and abnormal blood results could be attributed to severe malnutrition. Her intake was not being monitored nor was a refeeding plan put in place until the day after Averil was transferred to Addenbrooke's Hospital. She said Averil lost a further 1.2kg during this time.

D44. The First Psychiatrist Adviser explained that failure to recognise Averil's medical risk and treat her in line with MARSIPAN guidelines led to a critical deterioration in her health. Averil was not fed and her overactivity was not managed.

Healthcare assistant

D45. The First Psychiatrist Adviser said the purpose of having one-to-one observation in this context was to support feeding and to manage the patient's treatment sabotaging behaviours (for example, over activity, water loading, purging, tampering with nasogastric tubes). However, by the time Averil was admitted to Addenbrooke's Hospital, she was bedbound; hence there was little need for a trained mental health nurse or one with eating disorders expertise to be allocated to '*special'* Averil overnight. She said it was unclear what the role of the healthcare assistant was, so it was difficult to comment on the appropriateness of her allocation. The First Psychiatrist Adviser added that if the healthcare assistant was not responsible for monitoring Averil's physical observations, it was possible that she did not recognise Averil's deteriorating physical health, as she could have merely appeared to be sleeping.

Subsequent advice

D46. We considered the advice we had received from the First Psychiatrist Adviser and we asked some further questions to clarify our understanding of some aspects of her advice, particularly the issues of risk assessment and the allocation of Averil's case to the NCEDS Care Coordinator.

D47. The First Psychiatrist Adviser told us that Averil's immediate risk at the time of her discharge from inpatient care was low/not significant, because although she was still underweight there was no physical harm, and she appeared keen to engage with services. Her medium term risk, however, was significant. This risk was of self-neglect and relapse.

D48. The First Psychiatrist Adviser said Averil had severe anorexia nervosa and transitions are a time of significant risk for patients. She said Averil was not only moving from full time care into the community, but also leaving home and moving into a new environment where she would have to shop and prepare food for herself.

D49. Regarding the delay in transferring to a new care coordinator at NCEDS, the First Psychiatrist Adviser said it would have been smoother had Averil transferred to the local community eating disorder service in Suffolk and then onto NCEDS when she moved to university. Given that Averil was still underweight on discharge, and the risks posed by transition and the fact that a lot of patients lose weight initially on discharge, close medical monitoring was important. She said it should at least have been part of her discharge plan that she had regular formal contact for monitoring of her weight (this did not necessarily have to be an eating disorders professional, a GP would have been able to do this).

D50. As it was, the First Psychiatrist Adviser said Averil lost 6kg between discharge and first presenting to the NCEDS Care Coordinator, and this is a significant amount. Given the extent of this loss, she should have been referred for psychiatric review at the point of starting with NCEDS. A psychiatrist would have arranged to review Averil and could have offered the NCEDS Care Coordinator more support. However, she said it is difficult to know how much meaningful difference this would have made as alarm bells would have still calmed down as Averil's sessions with the NCEDS Care Coordinator progressed. This is because, on the face of it, Averil was attending appointments, her weight loss was

stabilising, and she did not have any comorbidity that would have increased the risk she faced (for example: self-harm[79], suicidality, depression).

D51. The First Psychiatrist Adviser said it would also have been established good practice, once Averil's wish to transfer straight to NCEDS was known (rather than via the Suffolk outpatients service), for a care coordinator from NCEDS to attend her CPA reviews on the inpatient ward (via telephone link if necessary due to the distance or other logistical difficulties).

D52. The First Psychiatrist Adviser said the risk assessments documented in Averil's files around the time of her discharge from inpatient care were deficient and not robust or explicit enough. She said Averil's discharge summary and discharge CPA documents do not mention the words 'relapse' or 'self-neglect', and there should have been discussion about both the current risk she faced and the medium term risk. However, the First Psychiatrist Adviser said there was evidence that some of this was in the thinking of professionals involved, particularly the Eating Disorder Unit Psychologist at the time of Averil's transition between services. The Eating Disorder Unit Psychologist relayed some of this to others she was handing Averil's care over to (for example UEAMC), and she also noted the first 3kg of Averil's 6kg weight loss and communicated this to NCEDS.

D53. The First Psychiatrist Adviser said decisions about the allocation of patients to members of staff within an eating disorders service are taken on the basis of caseload and capacity. What comes into play if you have a relatively inexperienced person working with patients is the support and supervision they have around them. Eating disorders make up a tiny proportion of mental health patients. It is an extremely specialised, small field, and it is not uncommon to advertise for jobs and have no applicants due to the shortage of people with experience in that area.

D54. The First Psychiatrist Adviser said it was a priority to allocate Averil to a care coordinator sooner rather than later, and the records show that the care provided by the NCEDS Care Coordinator during her appointments with Averil was in line with established good practice, although she could possibly have been more assertive with Averil about the amount of exercise she was doing. Whilst the NCEDS Care Coordinator lacked experience, it is clear that she had the knowledge required.

D55. The First Psychiatrist Adviser said had the NCEDS Care Coordinator been sufficiently worried about Averil's weight, the NCEDS Care Coordinator should have arranged for her to be weighed whilst she was on annual leave. However, the recorded weights would not have given rise to this level of concern.

D56. The First Psychiatrist Adviser said it would have been established good practice to involve a dietician or occupational therapist (for food management) in Averil's care, however, it was early days in her treatment, and the records show that the NCEDS Care Coordinator was providing appropriate advice and suggestions regarding meal plans.

[79] Self-harm in this context refers specifically to acts such as cutting or deliberately overdosing.

D57. The First Psychiatrist Adviser said this was a complex case, and unfortunately aspects of what happened will remain unknown. It is probable that Averil was falsifying her weight during the time she was under the care of NCEDS (although we do not know to what degree, and it is possible that she did experience the sudden, drastic drop the recorded weights indicate). If Averil had been falsifying her weight, this should probably have been observed by the NCEDS Care Coordinator. However, she said it is the case that even an experienced therapist may not have spotted this because they would not have known Averil as an individual and there was only one documented episode of her falsifying her weight previously (meaning there would not be a high degree of suspicion of this).

The Second Psychiatrist Adviser

D58. The Second Psychiatrist Adviser noted that Averil was admitted informally to ward S3 at Addenbrooke's Hospital on 19 September 2011. At this point, she was 18 years old and her weight was 30.4kg, a BMI of 11.2. She noted that despite some weight gain in the initial period of her admission to a BMI of 12.9, with some stabilisation of her overall condition, there seemed to have been stagnation in her progress, with the explanation of possibly increased exercising up until January 2012. According to the notes, there was also one reference of Averil falsifying her weight by drinking increased amounts of water before being weighed, '*water-loading*'.

D59. The Second Psychiatrist Adviser said from January 2012 up until her discharge in August 2012, Averil managed to increase her weight to 45.2kg, a BMI of 16.6, which although still in the anorexic range was considered relatively low risk. Although Averil's discharge weight was significantly under her target weight of 50-52kg, a BMI of 18.4, she explained that it was not uncommon for patients, after an initial post-discharge drop, to achieve further weight gain later on with outpatient support, as their motivational levels might increase by building on having *'a bigger life'*, for example starting university.

D60. The Second Psychiatrist Adviser told us that there were no guidelines about length of admission to specialist eating disorder services. She said that a recent multicentre study with 14 participating UK specialist centres (Goddard et al 2013[80]) showed that the majority of patients were discharged when their BMI remained within the anorexia nervosa diagnostic weight range (less than 17.5) and two thirds of the sample remained within the clinical range for general and specific psychopathology. The study also showed that there is a wide range in the length of stay (28 to 991 days, median 153), but with little difference in discharge outcomes.

D61. The Second Psychiatrist Adviser explained that according to NICE guidelines for eating disorders (paragraphs B8 and B9), a stepped care approach to treatment is generally recommended, with inpatient care reserved for those with high risk and poor psychosocial resources. In addition, a risk of institutionalisation is well known, especially in young people.

[80] *A multi-centre cohort study of short term outcomes of hospital treatment for anorexia nervosa in the UK* Goddard et al. BMC Psychiatry 2013, 13:287 http://www.biomedcentral.com/1471-244X/13/287

D62. The Second Psychiatrist Adviser added that in clinical practice, an average length of stay would be three to six months, and in adult services it was common practice to discharge a patient with a BMI of 16, which is considered low risk, into day or outpatient treatment, where further weight gain can be achieved.

D63. Therefore, the Second Psychiatrist Adviser said that the decision to discharge Averil on 2 August 2012 after more than ten months of inpatient treatment and a weight gain of 14kg was clinically sound, in particular in view of her wanting to start studying at the University of East Anglia (UEA) in the autumn term, as well as a planned family holiday before. In her discharge summary it was mentioned that Averil was *'anxious about her discharge from Ward S3'*, which the Second Psychiatrist Adviser said was an appropriate emotion after a long inpatient stay comes to an end and a new start is in sight. She said that there was no indication that a longer stay would have changed Averil being anxious about being discharged.

Handover to NCEDS

D64. The Second Psychiatrist Adviser said that when transferring between services, there should ideally be a handover CPA meeting, however in clinical practice this was not always possible in similar cases to Averil's, for example when a patient was in the process of moving and had not yet registered with the new GP.

D65. The Second Psychiatrist Adviser told us that the handover from CPFT to NCEDS was consistent with established good practice. She said the referral to NCEDS was made timely, and the Eating Disorder Unit Psychologist, agreed to provide continuity of care between home and her move to Norwich. She liaised effectively via telephone and letters with NCEDS as well as UEAMC. She clearly communicated areas of concern, for example, Averil's loss of weight since discharge. She sent the King's College guidelines on medical risk to UEAMC and highlighted Averil's vulnerability in times of transition and followed Averil up via telephone until she was seen by NCEDS.

D66. From Averil's arrival in Norwich on 23 September 2012, the Second Psychiatrist Adviser noted that it took 3½ weeks for Averil to be allocated to her care coordinator (the NCEDS Care Coordinator), who was also her therapist. She said that this delay seemed to have been due to staffing problems. The Second Psychiatrist Adviser said that, given Averil's known weight loss since discharge, and a general vulnerability during times of transition, it would have been established good practice for a psychiatrist from NCEDS to review Averil prior to that.

D67. However, the Second Psychiatrist Adviser added that it was established good practice in such cases, for GP practice staff to monitor the physical health of patients on a weekly basis until the specialist eating disorders service takes over. And Averil was seen on 5 and 12 October at her GP practice, before she started seeing the NCEDS Care Coordinator from 19 October.

Allocation of the NCEDS Care Coordinator

D68. The Second Psychiatrist Adviser told us that the NCEDS Care Coordinator had in fact completed her training as a counselling psychologist and completed her final exam on

31 October 2012, and was only waiting for professional registration. The NCEDS Care Coordinator also had some previous clinical experience with a patient with eating disorders while in training. Therefore, the Second Psychiatrist Adviser considered that the allocation of the NCEDS Care Coordinator as Averil's therapist was acceptable. She said the team were working on the presumption of a BMI of between 15 and 16 at the time of allocation, which was considered to be relatively low risk.

The care provided by NCEDS

D69. The Second Psychiatrist Adviser noted that the NCEDS Care Coordinator had regular supervision meetings with the NCEDS Consultant Clinical Psychologist, where Averil's case was discussed and where her weight loss was discussed and thought about. A medical review was only arranged after concern was raised by Averil's father. However, she said there was no indication up to that point that an urgent review was needed, as the rate of Averil's weight loss appeared to have slowed down while in therapy with NCEDS, compared to immediately after her discharge.

D70. The Second Psychiatrist Adviser explained that the purpose of a medical review was often to show the patient in a more concrete way, that the team was seriously concerned and that other treatment options were being considered, for example, an inpatient admission. This could help increase the patient's motivation for weight gain in outpatient therapy. She said in Averil's case, her therapy with the NCEDS Care Coordinator was in the initial engagement/settling in phase and from the content of the sessions it looked hopeful for further weight gain up until Averil's last session with the NCEDS Care Coordinator on 23 November 2012. The Second Psychiatrist Adviser said that from the supervision notes and the statements, it looked likely that a medical review with a discussion of inpatient admission would have been considered if there had been further weight loss in any of the sessions after 23 November.

D71. The Second Psychiatrist Adviser added that if a medical review had taken place earlier, she did not think an inpatient admission would have been considered at this point, as there was reasonable evidence to suggest that Averil would have been able to make use of the outpatient therapy. For example, Averil seemed to have developed a good therapeutic alliance with the NCEDS Care Coordinator and her rate of weight loss appeared to have slowed down as compared to post discharge from ward S3. Furthermore, Averil seemed very motivated to continue her studies. The Second Psychiatrist Adviser said a possible outcome from a medical review could have been to liaise with the GP about more frequent blood tests in light of Averil's weight loss and having missed her previous blood test. She said that it was, however, unclear whether a blood test at this point would have shown any significant abnormalities, as Averil's dramatic weight loss from a BMI of 11 (7kg in 14 days) appeared to have happened after her last appointment with the NCEDS Care Coordinator. The Second Psychiatrist Adviser said that it was impossible to say whether this weight loss was genuine or not, or perhaps due to Averil falsifying her weight. She said the clinical team at the time did not have any reason to suspect falsification. And even if there had been some falsification, it was impossible to say whether any blood tests would have shown this.

D72. However, the Second Psychiatrist Adviser said that it would have been established good practice to discuss a patient like Averil in a clinical team meeting with psychiatrists present, given she had lost weight consistently since her discharge from the inpatient unit – down to a BMI of between 14 and 15. The Second Psychiatrist Adviser was unsure whether such a meeting took place and if so, whether Averil's case was considered[81]. A discussion with a psychiatrist might have prompted an earlier medical review and/or a request to the GP to increase the frequency of blood tests to weekly.

D73. The Second Psychiatrist Adviser further explained that the recommendation in the ward S3 discharge summary for blood tests every two to three months was based on Averil's physical state and progress at the time. In light of Averil's consistent weight loss following discharge, it would have been established good practice for NCEDS to have reviewed the frequency of blood tests with recommendations to the GP.

D74. The Second Psychiatrist Adviser said blood results (for example, low sodium) might have revealed some ways of falsifying weight (for example, if Averil was drinking copious amounts of water before weighing) or might have shown a general tendency of physical deterioration, for example, neutropaenia[82] or increased LFTs. She said abnormal results would have increased Averil's risk to higher than only assessing her BMI and observations. However, the Second Psychiatrist Adviser said that she could not say whether more frequent blood tests would have indicated a higher risk in Averil's case.

D75. The Second Psychiatrist Adviser told us the decision that weights would be monitored weekly at NCEDS and not at the GP surgery was in keeping with established good practice, as weighing usually forms part of the therapy and different weighing scales indeed can show different results. She said this can be unnecessarily upsetting for patients.

D76. However, given Averil's continuous weight loss, the Second Psychiatrist Adviser said that it would have been established good practice to arrange for at least physical monitoring cover while the NCEDS Care Coordinator was on leave – either by another member of NCEDS or by the GP.

D77. The Second Psychiatrist Adviser said that despite the above identified failings in practice, it was however impossible to say whether they directly contributed to Averil's death. She said with the available clinical findings at the time, it would have been difficult to predict Averil's dramatic weight loss of nearly 7kg in 14 days from her last appointment with the NCEDS Care Coordinator to her collapse and emergency admission. She said such a drastic weight loss, from a BMI of 14 to a BMI of 11 in 14 days, seems impossible at first sight, even to the experienced eyes of an eating disorders consultant psychiatrist. She said it might be that Averil was falsifying her weight before, meaning her BMI might have been much lower already when she was being seen by the NCEDS Care Coordinator.

[81] When we interviewed the NCEDS Care Coordinator, she confirmed that Averil's case was never discussed at these meetings, as they were designed to discuss high risk cases – Averil's case was not assessed as being high risk at the time.

[82] Neutropaenia is an abnormally low level of neutrophils. Neutrophils are a common type of white blood cell important to fighting off infections – particularly those caused by bacteria.

D78. But the Second Psychiatrist Adviser added that given Averil's observed high rate of weight loss while an inpatient at NNUH (about 0.4kg per day), this extremely high rate could well have been a genuine loss of weight in her particular case. She said it is questionable whether another, more experienced therapist would have picked up the possibility of weight falsification in Averil's case, as there was only one episode of falsifying weight by water loading in her history while an inpatient. She said if Averil had falsified her weight, this would have occurred very early on in the therapy, when the focus was on engagement and developing a therapeutic relationship based on trust. This would probably have made it difficult for any therapist to develop or pursue suspicions about falsification of weight.

Communication between NCEDS and UEAMC

D79. The Second Psychiatrist Adviser said that she could not find any particular failures in communication between UEAMC and NCEDS. A therapy initiation letter was sent to UEAMC by the NCEDS Care Coordinator and instructions were given for Averil to be weighed at NCEDS only. This was established good practice and the expectation would be to communicate with the GP practice after medical reviews, advice on changes of monitoring regimes and at discharge from primary care. GPs who monitor bloods would be expected to communicate any concerns to the relevant eating disorders service, in this case NCEDS. However, in Averil's case, there were no results available, as Averil had cancelled her appointment to do this. As the GP practice was working under the presumption that Averil's weight was around a BMI of 15, this was not seen as an urgent matter.

Averil's admission to NNUH

D80. The Second Psychiatrist Adviser said that the records show that NCEDS called the ward at NNUH shortly after Averil's admission on 7 December. However, the only information given was that Averil had been admitted to NNUH with low glucose. Shortly after this, the NCEDS Lead Psychiatrist called the ward as well, but was not given any information about Averil's clinical state. Given that the latest information the NCEDS Lead Psychiatrist had about Averil was that her BMI had been around 14, it would have been within established good practice for the NCEDS Lead Psychiatrist not to have seen Averil as an emergency that day. The Second Psychiatrist Adviser added that it was, however, very unfortunate that the NCEDS Lead Psychiatrist was not given the full information about Averil's clinical state. This was a missed opportunity for an early discussion about management of a patient with life-threatening anorexia nervosa according to MARSIPAN guidelines. The Second Psychiatrist Adviser said the NCEDS Lead Psychiatrist did not necessarily need to see Averil on the Friday, but it would have been established good practice for the NCEDS Lead Psychiatrist to have had a full telephone discussion about her physical state and provide psychiatrist/eating disorders specialist advice to NNUH staff at that time. Unfortunately though, NCEDS was not made aware of Averil's drastically increased risk. Once they saw Averil on 10 December, they offered assistance and co-working according to MARSIPAN guidelines.

The role of the healthcare assistant

D81. The Second Psychiatrist Adviser said it was her understanding that the healthcare assistant was appointed to observe Averil's mental state (and not her physical state) – for example, preventing Averil from trying to get up, and to provide encouragement if she needed treatment.

The First Psychologist Adviser

The decision to discharge in summer 2012

D82. The First Psychologist Adviser explained that the notes record that on 7 June 2012 Averil initiated a plan, in collaboration with the team at her CPA Care Plan Review, for discharge on 1 August. This was linked to a plan of Averil's to attempt to regain weight, from that point forward, at a rate of approximately 1kg per week to get to a weight of approximately 50kg, BMI circa 18.5; a rate that she had not previously achieved during her admission. It was also linked to an overall *'life plan'* that Averil felt positive about, including attending university in September.

D83. The First Psychologist Adviser told us that it was relevant to note that Averil had been on the ward for nearly nine months by that point, and her weight regain trajectory, after a plateau between early in the admission and December 2011, had been fairly steady since then at or just under half a kilogram a week on average. He told us that this length of stay was on the longer side of average, but not unusual. And this was a rate of weight gain that was below ideal targets (0.5kg per week +), but was very common and no small achievement given Averil's anorexia, her ambivalence and her reported responses to direct challenge. However, he said Averil's weight in mid-June had plateaued again for about a month.

D84. The First Psychologist Adviser explained that for patients with anorexia regaining weight can be hard at different times, for varying reasons. Patients with a BMI fluctuating between 15 and 16 often struggle with continuing to gain weight. He said that it is physically hard to continue to eat more calories, past the point of feeling full, for a long time. He said that often the meal plan has to be increased just to keep regaining weight at the same rate. As you cannot advise more than three meals and three snacks, only portion size and energy density can be increased. The first makes you feel full and the second means eating fear foods[83]. The First Psychologist Adviser said this problem is compounded because you do not want to restrict physical activity or leave too much because patient's need for psychosocial recovery is to return to normal activities. He said every decision is a balance of pros and cons. At this point in an admission, the First Psychologist Adviser said patients are often 'feeling fat', and comparing themselves negatively to newly admitted emaciated patients. In

[83] Eating disorder patients often have a fear that certain types or amounts of food will lead to an instant or discernible weight gain. These 'fear foods' may include any high-calorie items or groups of food such as fats, "junk food" or meat.

addition, he said they can feel relatively well by this point, physically and cognitively, which makes it harder for them to keep in mind that they continue to be underweight and that they still need to put on more weight.

D85. The First Psychologist Adviser said by June Averil's BMI was approximately 15.6 and thus in the relatively safe range from the point of view of acute risk, as reflected in the physical risk assessments. Averil's goal was agreed with the multidisciplinary team at the CPA meeting on 14 June.

D86. The First Psychologist Adviser said that in responding to Averil's plan, the ward S3 team should have considered the evidence base. However, there was an extremely limited evidence base for inpatient treatment of anorexia nervosa.

D87. The First Psychologist Adviser highlighted that the NICE guidelines say that there is no unequivocal evidence that inpatient treatment offers long-term advantages [paragraph B9, *'6.2.3.3 Evidence statements'*]:

> *'Such treatment* [i.e. admission to hospital] *may have lasting effects although weight loss is common after discharge. There is no unequivocal evidence that inpatient treatment confers long-term advantage except as a short-term life-saving intervention in patients at high risk.'*

And:

> *'There is insufficient evidence to determine any advantage for inpatient care over outpatient psychological treatments.'*

D88. Therefore, the First Psychology Adviser said that there was no significant clinical evidence to extend Averil's admission and such decisions are based on clinical judgment.

D89. The First Psychologist Adviser said at the point of Averil's request, the ward S3 team would have had to consider the risks and benefits of available options to them, having regard to duties to balance risk and benefit in a reasoned decision (HCPC standards of proficiency 1a.1, 1a.5, 1a.6 and 2b.4 and British Psychological Society (BPS) principle 3.3 and 3.2 regarding best interests, maintaining safety and duty of care), as well as ethical principles of informed consent respecting right of self-determination (BPS principle 1).

D90. The First Psychologist Adviser said views on inpatient anorexia treatment in general vary considerably. He said the trend in England over recent years has been towards seeing inpatient treatment as something to be minimised and only used when absolutely necessary. For instance, he said the NICE guidelines state [paragraph B9, *'Psychological interventions for anorexia nervosa 4.4.2.4'*]:

> *'Most adults with anorexia nervosa should be managed on an outpatient basis with psychological treatment provided by a service that is competent in giving that treatment and assessing the physical risk of people with eating disorders.'*

D91. The First Psychologist Adviser said many areas have commissioned community and outpatient eating disorder services specifically to reduce bed use by averting and shortening admissions. He said when considering whether inpatient treatment is 'necessary', this can be divided into immediate lifesaving medical necessity (which did not apply to Averil in June 2012, as noted above) and necessary for effective treatment. He said in relation to the latter, Averil had not had any failed attempts at outpatient treatment (she had not had any significant outpatient treatment); therefore a trial of outpatient treatment would be suitable to her situation as at June 2012.

D92. The First Psychologist Adviser said Averil's clinical presentation had a mixture of positive and negative prognostic indicators.

Positive:

- She was young and it was a first admission. She was not bingeing or purging.
- The progress in terms of eating, weight and managing physical activity that she had already made on the ward.

Negative:

- Slow rate of weight regain.
- Partial insight into necessary behaviours (intake and physical activity) to realise stated weight goals.
- Intense core cognitive psychopathology ('Anorexic Voice'). Severe body image distortion.
- A reported approximately three year history untreated prior to August 2011.
- Eating disorder linked to perfectionist and obsessive compulsive traits.
- Ambivalent motivation (for example, still joking that she 'ought' to be more afraid of weight regain than she was).
- She showed routine and compensatory compulsive exercise and a difficulty sitting still. Amongst the compensatory behaviours to prevent weight gain, physical activity can be especially hard for a patient to regulate or for a ward to contain. Whilst purging can be managed to some extent via observation at critical times (for example, after meals), restricting access to laxatives and supervising or restricting access to bathrooms, physical activity is something patients can do in many ways and at almost any time and cannot be easily restricted.

D93. The First Psychologist Adviser said the major advantage of inpatient treatment is the intensity of work on weight and eating and the range of related issues. In published reports, unsurprisingly, the rate of weight regain in the short term tends to be greater in inpatient units. However, he said major disadvantages of inpatient treatment include:

- Disconnection from other aspects of life (for example, studying) that provide motivation for recovery and alternative sources of self-esteem than weight control. Overvaluation of eating, weight and shape and control of those things is the 'core psychopathology' of eating disorders and marginalisation of other sources of identity and self-esteem is considered one of the key maintaining factors in eating disorders (Fairburn 2008[84] is a key text describing this).

- Remaining in a setting where eating and weight are a major focus amongst staff and peers, where toxic comparisons can be made. Making biased and selective comparisons with other people's bodies is considered a maintaining factor for body image problems and eating disorders (Fairburn 2008).

- The risk of conflict and confrontation with staff over eating disorder which can 'engender resistance', that is, lead a patient to defend his or her eating disorder to a greater extent, can damage engagement specifically and inter-relationships more generally and can undermine patient self-esteem. Problematic communication cycles are considered an important factor in eating disorders (for example, the Maudsley Model for Individual Treatment of Anorexia, MANTRA, is a key model of anorexia and its treatment).

- A patient's eating disorder continues to be externally regulated (by the ward and its staff). This does not automatically lead to a sense of internal responsibility for managing eating disorder. At best it is postponing an inevitable need for a patient to try to retake their own control over eating and weight. At worst it can be an active obstacle to that internal change, creating an unhealthy dependence on external responsibility for eating sufficiently.

D94. The First Psychologist Adviser said reading the clinical notes revealed at least some signs of all of the above indicators against inpatient treatment applying in Averil's case. He said in addition Averil's weight regain had stalled. And other options to return to weight gain, apart from engaging in her own 'life plan' were risky. He said ward S3 might have had to resort to aspects of restriction that risked escalating conflict between the ward and Averil and/or risked her motivation and psychosocial recovery (for example, severe restriction of leave, non-collaborative meal plan decisions).

D95. The First Psychologist Adviser said the NICE guidelines refer to the pros and cons of compulsory admission for anorexia and say:

> *'The potential benefits of compulsory admission have been identified as weight gain (Ramsay et al., 1999), saving life (Honig & Bentovim, 1996), opportunities for further treatment and avoiding significant harm (Honig*

[84] *Cognitive Behaviour Therapy and Eating Disorders, Christopher G Fairburn, 2008*

& Bentovim, 1996), improvement in mood and concentration and reduction in symptoms (Maloney & Farrell, 1980), and less starvation induced cognitive impairment (MacDonald, 2002).

The potential risks are: obstacles to the development of a therapeutic relationship (Orback & Rathner, 1998; Lancely & Travers, 1993), negative physical and psychological effects (Dresser & Buisaubin, 1986), negative countertransference...., damage to self-esteem, escalation of resistance (Rathner, 1998; Fichter, 1995).'

D96. The First Psychologist Adviser said these considerations would also have been relevant to a longer informal admission.

D97. Nevertheless, the First Psychologist Adviser said in the case of a voluntary patient's first admission, such as Averil's, established good practice would still be to encourage continuing treatment until a healthy BMI is reached and the patient has spent a period maintaining that weight, including while on leave. He said there is some tentative evidence that this reduces risk of readmission. The *Guidelines for the nutritional management of anorexia nervosa* (Royal College of Psychiatrists, 2005), say under the heading *Target weight* (page 18): *'There is limited research evidence that discharge at a low weight is associated with a poorer outcome and a higher readmission rate (Baran et al, 1995; Howard et al, 1999)'.*

D98. However, the First Psychologist Adviser said the overriding factor was Averil's stated intent to leaving the ward to go to university. And the CPA care plan of 31 July 2012 says the discharge was part of Averil's 'Total Life Plan'. He said a strong attempt to challenge her intention was unlikely to succeed and might have been counterproductive. An attempt to compel a longer stay under the Mental Health Act would not realistically have been considered for Averil. The NICE guidelines [paragraph B9, *'2.9 Engagement, consent and therapeutic alliance'*] say:

'Whilst a forceful approach may result in a degree of weight gain in anorexia nervosa, clinicians are increasingly drawing attention to the importance of engagement and positive motivation if short-term gains are to be maintained in the long-term, whatever the treatment setting (Ward et al, 1996)'

D99. The First Psychologist Adviser said the ward team would have anticipated the possibility of needing to acquiesce in Averil taking her discharge against medical advice at an even lower BMI than she had achieved by June or by the time of her discharge, discharging herself at an earlier date, or remaining on the ward but ceasing or reversing her weight regain and recovery efforts, which, though not 100% consistent, were positive and substantial.

D100. Therefore, on balance, the First Psychologist Adviser said the ward team should have considered it positive that Averil collaborated with a plan for discharge on 1 August and with a renewed commitment to weight gain including a target weight and behavioural plans to achieve this. He said [a specialty doctor in

eating disorders'] update to the Individual Patient Placement Agreement (IPPA) Appendix on 26 June reflects this.

D101. In summary, the First Psychologist Adviser said Averil's discharge at this point in her progress would be in keeping with established good practice. It would be within standards for best interests and safety. Although it is an advantage when they do, patients, particularly during a first admission, very often do not reach healthy weight during their inpatient stays and many patients are discharged at lower weights as a result of the overall risk benefit of further inpatient treatment vs community treatment. Averil's progress and weight at discharge would have been seen as relatively positive given her overall presentation.

D102. For the purposes of comparison, the First Psychologist Adviser said the average BMI at discharge of patients [at another unit he was aware of] was approximately 17 in 2006 and 16 in 2011. He said surveying actual discharge weights reported in the literature, higher discharge weights tend to be reported only for patients that have themselves chosen to stay that long (for example, opting for rehabilitation), and Averil's discharge weight is more typical of patients deciding to leave a ward early or 'dropping out'.

The choice of discharge date

D103. The First Psychologist Adviser said a secondary consideration would have been the exact timing (that is, a month or more before actually starting university). This decision too would have had its 'pros' and 'cons'. It is usually considered positive for somebody to have some time coping at home before attempting to cope at university. There was a desire to facilitate normal family contact and a holiday. He said inpatient units generally try to facilitate as much normal activity and positive family contact as possible, including facilitating important things like Christmas or family holidays wherever safe (and including in more risky situations than applied to Averil in the summer of 2012). The decision to incorporate some time at home before going to university into the timing of discharge was in keeping with established good practice and the relevant ethical and proficiency standards.

Keeping to the plan in the light of Averil's anxiety and failure to reach a health weight range

Anxiety

D104. The First Psychologist Adviser said Averil's expressions of anxiety indicate an appropriate level of awareness of the challenges to be faced and are typical for patients making a discharge decision from an eating disorder ward. Averil's expressions of anxiety would not have signalled that it was a poor decision or the wrong time. Averil also made positive statements about discharge and discharge plans (for example, *'need to go for it'*), reflecting fluctuations in ambivalence and confidence that are typical of anorexia nervosa. The First Psychologist

Adviser said the care plan elements indicates a good degree of awareness of the range of risk and protective factors and methods for addressing those, including specific relapse prevention work with Averil's peer worker from 19 June at least until 28 July, and preparations for support at university.

Weight

D105. The First Psychologist Adviser said Averil appeared to have perfectionist traits, which as well as driving eating disorder can also shape the way that a patient with anorexia nervosa approaches recovery, including targets chosen. Averil appeared to favour concrete and ambitious plans. It is common for patients suddenly to set themselves demanding recovery targets when coping with the oscillations in their feelings of conflict about eating disorder and recovery and fluctuations in feeling ready, willing or able to change. Patients bring their traits of striving to achieve and to please others to both sides of their dilemmas.

D106. The First Psychologist Adviser said patients with anorexia overestimate how much weight they will gain. They fear weight gain suddenly being extreme (many stones and kilos) and running out of control, hence, unless they more completely face their fears, they make small changes resulting in slow weight regain. The same biases apply when setting recovery targets. Gaining weight is seen as something highly likely to happen, and so they under-estimate how hard it will be deliberately to gain weight and over-estimate what can be achieved.

D107. The First Psychologist Adviser said that at the time Averil made her plan, the ward team should have recognised the optimism in the plan, but remained open-minded to the actual outcome. The ward team should have been open-minded to the possibility of Averil achieving her target weight by the date she had set, although it seemed unlikely, but also the probability of her not doing so. When agreeing to the plan they should have, as noted above, been aware of having little legal or practical means of safely and effectively forcing change and been keen to collaborate to see how far they could help Averil before discharge.

D108. The First Psychologist Adviser said the typical approach is to work with the patient's goals, agree in collaboration specific behavioural plans to achieve them. And as and when patients 'under-shoot', reflect this back to them (to gradually increase insight and build a more accurate perception of the connection between eating and weight) and reflect on the reasons for falling short and problem solve those. He said this process is evident throughout Averil's admission including from June to August. For instance, he said [a specialty doctor in eating disorders'] IPPA update of 26 June indicates an improvement to Averil's progress linked to a plan she owned - the CPA care plan dated 7 June indicated Averil was *'pleased with* [the] *new plan'* - and an intention to gain *'as much as possible'* over the 4 to 5 weeks.

D109. The First Psychologist Adviser said that between June and August, as is typical of anorexia nervosa and consistent with her admission as a whole, Averil achieved some behavioural changes and not others from time to time as her

ambivalence and coping capacity fluctuated. Notably, Averil was managing some more herself, for example, doing puzzles to limit physical activity and standing and walking. He said the overall relative proportion of successful vs unsuccessful behaviour change for Averil was on the positive side of typical for cases like hers. He said it is not uncommon for patients to cease weight regain or to lose weight in the time period between a discharge date being set and the actual date arriving, whereas Averil started to gain again at her previous rate. Averil's progress in terms of weight and self-management between June and August, despite falling short of her own over-optimistic stated intentions, would have been seen as a relatively positive return to her prior rate of weight regain. And also as a positive indication that she was more able than before to eat when on leave and own more change and necessary recovery steps linked to her life plan, as the regain continued with greater independent management of eating on Averil's part.

D110. The First Psychologist Adviser said that, as noted above, collaborating with Averil in her plans is likely to have achieved an overall outcome in terms of motivation, behaviour change, ownership and independence of management of eating and weight, self-esteem and weight, that was better than the likely outcome if the ward had not collaborated with Averil's discharge plan and its timing. Furthermore, Averil was working within a 'plan' and losing or letting go of that 'plan' would have had unpredictable consequences.

D111. In summary, the First Psychologist Adviser said that sticking to the original date was consistent with established good practice and with ethical and proficiency standards.

Risk assessment

D112. Between 27 March and 3 April 2012, the First Psychologist Adviser said Averil's risk, as recorded in the CPA and Management Ward round reviews, changed from *'moderate'* to *'no immediate risk'*, as her BMI recovered from 14.7 to 15.1. And that remained the risk assessment up to the 31 July 2012 CPA (ward round).

D113. The First Psychologist Adviser said psychological risks of not recognising eating disorder behaviours were noted continually in the same place (CPA weekly management rounds and CPA reviews). He said the current risk assessment was placed in context by the CPA Part 2 Discharge Summary dated 3 August 2012, which included recorded medical observations (blood tests), DEXA scan[85] and ECG, and the weight chart covering the period from admission to discharge. He said the section on treatment refers to the need for "*quite a high meal plan"* and the discharge plan specifies frequency of physical health checks which will be the responsibility of the GP.

[85] A DEXA scan is a special type of X-ray that measures bone mineral density (BMD).

D114. The First Psychologist Adviser said the CPA care plan crisis plan lists several warning signs/relapse indicators, including Averil shutting herself away and becoming more active, difficult interpersonal relationships, overanalysing food and declining ability to make connections between emotions and physical reactions, along with a plan, to seek support from members of staff, family members and friends. He said crisis plans are to go to A&E in an emergency, the social services emergency duty team in the event of a severe social problem and the GP if a problem is urgent. Particular risks to be taken into account during a crisis were sudden weight loss and becoming frail and prone to falls.

D115. The First Psychologist Adviser said the Royal College of Psychiatrists Quality Network for Eating Disorders pilot standards (21.66) (2012) states: *'A post discharge and relapse prevention plan is included with CPA documentation'*. And he said the ward S3 team had done this.

D116. The First Psychologist Adviser said the risk assessment at the time of discharge appears to be in line with established good practice. It would have been a multidisciplinary responsibility.

D117. The First Psychologist Adviser said the crisis plan section of the CPA care plan notes the risk of 'sudden weight loss'. He said a weight loss of 19kg over the seven months prior to her first admission to ward S3 would be just under 0.7kg a week and therefore in the 'concern' not the 'alert' range, and a rate that Averil was not showing during her contact with the Eating Disorder Unit Psychologist or the NCEDS Care Coordinator. He said an IPPA document dated 15 September 2011 incorporates referral information to ward S3 and appears to indicate that Averil had weighed 34.1kg on 14 September 2011 at her GP. The First Psychologist Adviser said admission weight on 19 September 2011, at 2.30pm, appears to have been 32.3kg according to the physical assessment document. He said further context is provided by the CPA Assessment Part 1, which details the events leading up to Averil's admission, including: the dietetic assessment of eating pattern immediately prior to admission; having *'less than usual as she was coming into hospital for admission'*; and having 'loads of herbal tea'. Thus, he said there is evidence of a drop of about 1.8kg in five days associated with an increase in restriction and fluid intake in a short period when anticipating admission.

D118. The First Psychologist Adviser said there are QED[86] standards for discharge planning. Type 1 QED standards are considered essential such that failure to meet the standards would result in a significant threat to safety, rights or dignity and/or would breach the law. Type 2 represent standards that an accredited ward would be expected to meet and Type 3 represent standards that an

[86] The Quality Network for Eating Disorders (QED) is a collaboration between the Royal College of Psychiatrists, the British Psychological Society, the College of Occupational Therapists and the Royal College of Nursing. It works with services to assure and improve the quality of services treating people with eating disorders and their carers. Through a comprehensive process of review, it identifies and acknowledges high standards of organisation and patient care, and supports other services to achieve these.

excellent ward would meet. The First Psychologist Adviser said the following table indicates QED standards for discharge planning:

Standard	Type		Met?
21 .51	2	Discharge planning is considered within the first and every subsequent care plan review.	Yes.
21 .3	2	Managers and practitioners have agreed standards for discharge planning.	Not known - they seem structured.
21 .5	2	The patient is actively involved in developing their discharge plan.	Yes.
21 .52	2	Discharge planning includes relapse prevention and planning.	Yes.
21 .7	3	The patient and carer (if requested by the patient) are actively involved in who takes part in transfer/discharge planning.	Yes - mother attended CPA reviews.
21.53	2	At times of transition between services or service settings, there is evidence of risk assessment and management. Families and carers are involved in this process.	Yes.
21.54	3	Carers are involved in discharge planning.	Yes.
21 .9	2	The patient is given timely notification of transfer or discharge and this is documented in their notes. NB: the length of notice should be proportionate to the length of admission.	Yes - mid June to end July.

21 .11	1	The patient is given a copy of a written aftercare plan, agreed on discharge, which sets out: - the care and rehabilitation to be provided; - the name of their care coordinator (if they require further care); - the action to be taken should signs of relapse occur or if there is a crisis, or if the patient fails to attend treatment; - Specific action to take in the first week.	Not known if a copy was given to the patient. Discharge summary and care plan specified care to be provided; Care coordinator was tbc and the Eating Disorder Unit Psychologist identified in the interim; actions to be taken in the event of signs of relapse or crisis were specified and there were specific actions within the first week.
21.18	2	Written copies of discharge plans are sent out within seven days of discharge to the patient, carer(s) where relevant, social workers, community mental health nurses, GPs, other community, residential and day-care staff.	These were sent to NCEDS and initial GP within a week of discharge from the ward. They were forwarded to the Norfolk GP within a week of moving to Norfolk.
21 .33	2	The patient's allocated CMHT care coordinator/CPN meets with the patient prior to discharge.	The care coordinator was not a CPN in a CMHT and did not meet prior to discharge due to the move to Norfolk.
21.63	1	Unless a patient is transferred to another specialist mental health service, the service makes arrangements for follow up within seven days of discharge.	This occurred.
21 .65	2	Patients should have supported periods of home leave to develop independent eating, well in advance of discharge.	This occurred.

21.66	1	A post discharge and relapse prevention plan is included with the CPA documentation.	Yes.

D119. The First Psychologist Adviser said it should be noted that at the time of the case these standards were pilot and in any case they are voluntary. He said they are included here to illustrate standards of established good practice.

The care provided by NCEDS

Allocation of the NCEDS Care Coordinator

D120. The First Psychologist Adviser said Averil's case was of a severe and prolonged anorexia nervosa but not atypical of its kind, nor in the most complex or severe range in terms of physical or psychological comorbidities, or range of risks (that is, there was risk of harm from eating disorder, but suicide risk was not high and other risks, e.g. of harm to others, vulnerability to abuse, were not present). He said it was a case that a professional with the required practitioner psychologist training, which the NCEDS Care Coordinator had completed, could be expected to take on under close supervision. Practitioner psychologist qualification is post-graduate with several years' clinical practice. He said most courses incorporate some eating disorder training and general training and experience in risk assessment is at a high level for accredited courses. The NCEDS Care Coordinator had had some limited experience with eating disorder cases, although not yet anorexia. She would have needed specific guidance on appropriate monitoring (weight at NCEDS, other checks at GP), risk indicators and thresholds, and the importance of early behaviour change in therapy.

D121. The First Psychologist Adviser said the NCEDS Care Coordinator appears to have received that guidance. It was appropriate that recruitment included a focus on risk awareness. The NCEDS Consultant Clinical Psychologist reports[87] that the NCEDS Care Coordinator answered the risk assessment interview question well. It was appropriate that she was offered specific guidance on risk assessment and management on induction and close supervision when early in post. The NCEDS Care Coordinator describes[88] receiving guidance on her role in her induction, including regarding risk monitoring and achieving behaviour change within the first six sessions (that is, not to trade off urgent, important behaviour change to protect the therapy relationship) and this is consistent with the NCEDS Consultant Clinical Psychologist's description of her preparation of the NCEDS Care Coordinator for the case and similar cases. The NCEDS Care Coordinator indicates that at the time she received weekly supervision, which is established good practice for psychologists new to eating disorders. The use of a supervision log that includes weight and BMI for each patient suggests a good level of close monitoring of patients' progress in supervision in NCEDS, as does the presence of the audit form indicating standard practice of a review at session

[87] In a statement to us.
[88] In her statement and interview evidence.

six.

D122. The First Psychologist Adviser said, taking into account annual leave, the NCEDS Care Coordinator received supervision before session one, between session one and two, between session four and five, between sessions five and six and after session six. He said the level and scope of what is reportedly discussed in supervision in the witness statements is appropriate to the case, appropriate levels of concern and appropriate plans.

D123. In summary, the First Psychologist Adviser said he thought the NCEDS Care Coordinator was appropriately allocated Averil's case, and appropriately accepted it and was appropriately closely supervised in her management of it, consistent with established good practice. He said the NCEDS Care Coordinator and the NCEDS Consultant Clinical Psychologist acted consistently with HCPC standard of conduct and ethics 6 regarding acting within the limits of knowledge, skills and experience, and 8 effective supervision, as well as BPS principle 2.3 regarding practicing within the boundaries of competence and seeking supervision particularly in circumstances beginning to challenge professional expertise.

Care Planning at NCEDS October to December

D124. The First Psychologist Adviser said looking at Averil's BMI through this period (in the context of her trajectory of weight loss and the whole presentation), a trial of weekly outpatient CBT therapy coupled with the hoped motivating presence of the university course and in the context of continued monitoring of risk (weighing at NCEDS and other checks via primary care) was an appropriate plan. He said this was clearly documented in the start of therapy letter dated 26 October. And the NICE guidelines state:

> *'Assessment of people with eating disorders should be comprehensive and include physical, psychological and social needs and a comprehensive assessment of risk to self.'*

D125. The First Psychologist Adviser said the NCEDS Care Coordinator took over the very comprehensive ward S3 assessments, updated by the Eating Disorder Unit Psychologist's correspondence in late September and updated it with new information from 19 October onwards. He said the NCEDS Care Coordinator undertook a comprehensive assessment of current nutritional intake in the first session including ruling out bingeing and purging.

D126. The First Psychologist Adviser said the NCEDS Care Coordinator updated the CPA in draft in a document dated 22 November 2012. But it was unsigned as yet. The plan incorporated very specific plans for increases in dietary intake and decreases in physical activity, coupled with approaches to addressing associated anxiety and linked to the "higher goal" of university. He said the plan records that no carers' assessment had been requested or offered. The NCEDS Care Coordinator was aware of the carers' input at ward S3 and the prevailing requests for confidentiality. The NCEDS Care Coordinator's draft CPA care plan

highlighted relevant warning signs: Averil shutting herself away; increasing activity; and ignoring body signs to stop. It identified further weight loss as a contingency for a change of plan and included awareness of the particular risks in a crisis of sudden weight loss and falls from previous risk assessments. He said the plan was due to be reviewed on 1 March or sooner if there was any deterioration in health, a second, appropriate, contingency. He said this was a reasonable summary of the risks and these were reasonable contingencies.

D127. In summary, the First Psychologist Adviser said this was a reasonable draft care plan for Averil's presentation at that point in time and was in keeping with established good practice. He said it was an accurate risk assessment with salient warning signs and appropriate contingencies. And it was consistent with best interests and duty of care standards and standards for appropriate monitoring procedures for safety.

The Care Plan - Therapy

Choice of approach

D128. The First Psychologist Adviser said the NICE guidelines state, under the heading *Post hospitalisation psychological treatment* [4.4.2.11 and 4.4.2.12, paragraph B9] :

> *'Following inpatient weight restoration people with anorexia nervosa should be offered outpatient psychological treatment that focuses both on eating behaviour and attitudes to weight and shape, and wider psychosocial issues with regular monitoring of both physical and psychological risk'*

And:

> *'The length of outpatient treatment and physical monitoring following inpatient weight restoration should be typically at least 12 months'*

D129. Under the heading *Common elements of psychological treatment for anorexia* [4.4.2.1, paragraph B9] it says:

> *'Therapies to be considered for the psychological treatment of anorexia nervosa include cognitive analytic therapy (CAT), cognitive behaviour therapy (CBT), interpersonal therapy (IPT), focal psychodynamic therapy and family interventions focused explicitly on eating disorders.'*

D130. The First Psychologist Adviser said, as noted above, according to NICE guidelines at the time, the evidence base for anorexia nervosa did not support any one therapy over any other. He said the choice of CBT was appropriate from amongst the range of options and it includes active and early targeting of weight, nutrition and behaviour change. He said CBT for eating disorders, as trialled by researchers from [the Centre for Research on Eating Disorders at Oxford (CREDO)], should begin with twice weekly therapy. However, he said many expert centres do not follow that approach and once weekly is much more

common. The First Psychologist Adviser said the NICE guideline recommends one year of therapy. NCEDS offer was 40 sessions, which is slightly under that recommendation, but is in line with established good practice (sometimes less is offered). It is also close to one year once some breaks are taken into account, e.g. holidays, and may be one year, or more, if later sessions are tapered as is commonly done. In summary, the First Psychologist Adviser said the offer was in line with established good practice.

Implementation of approach

D131. The First Psychologist Adviser said the NICE guidelines say under the heading *Common elements of psychological treatment for anorexia nervosa* [4.4.2.3, paragraph B9]:

> *'the aims of psychological treatment should be to reduce risk, encourage weight gain, healthy eating, and reduce other symptoms related to an eating disorder, and to facilitate psychological and physical recovery.'*

D132. He said reviewing the content of the therapy sessions the NCEDS Care Coordinator appears to have performed well. She established weight monitoring and self-monitoring of eating and physical activity from an early stage. Her first session included goals to reduce activity, linked motivationally to longer term life goals, and sessions two onwards incorporated specific goals to increase dietary intake linked to motivation and methods for managing associated emotion like anxiety and work on issues like self-esteem. He said the NCEDS Care Coordinator 'problem solved' with Averil situations that impacted on emotion and, therefore, eating or activity. She followed up on behaviour change goals set, reviewed them with Averil and set new goals in response to the unfolding weight chart. He said the goals were increasing at a reasonable pace given Averil's limited progress and degree of underweight. In looking at intake, he said the NCEDS Care Coordinator appropriately considered as targets: frequency of meals and snacks; amounts or portion sizes; and energy density (what food group is chosen, e.g. low calorie options), as well as formal and informal physical activity. He said her first target was to reintroduce snacks. This was the correct first steps as a missed 'slot' for a meal or snack contributes no calories at all, therefore the priority is to introduce three meals and three snacks and to build from there.

D133. The First Psychologist Adviser said that the NICE guidelines say under the heading *Principles of psychological treatment* [6.2.2, paragraph B9]:

> *'Health care professionals involved in the treatment of anorexia nervosa should take time to build an empathic, supportive, and collaborative relationship with patients'*

D134. The First Psychologist Adviser said the notes reflect an attempt on the NCEDS Care Coordinator's part to balance the principles of collaboration and engagement with requirements to be realistic about eating and weight and required behaviour change. She appeared to do so in a manner that is consistent with established good practice, in terms of what she raises when and the tone in

which things are stated in writing and verbally according to the notes.

D135. The First Psychologist Adviser said there is always awareness that falsification is a possibility with any patient, even in the absence of a disclosure of it and that recall and reporting of eating and activity will not be completely reliable and is likely to be biased to over-reporting eating and under-reporting activity. Averil's history and presentation in combination would not have signalled a high likelihood of extreme levels of falsification to a degree that should have radically altered the risk assessment or the care plan. Averil eventually admitted to more activity than she had been reporting. Overall, subject to short term fluctuations on the weight chart, and expected biases to recall and the usual degree of under-reporting, Averil's weight chart and reported eating and activity were broadly consistent - it was apparent intake was not sufficient and that weight was going down, albeit not rapidly.

D136. The First Psychologist Adviser said the NCEDS Care Coordinator had sufficient training to offer that model of therapy, including to patients with serious eating disorders under close supervision, so it is consistent with standards for operating within the limits of knowledge, skills and experience and seeking supervision when indicated.

The Care Plan - Risk Management

Overall

D137. The First Psychologist Adviser said the plan for risk management included weekly weighing at NCEDS and primary care monitoring of other signs remained appropriate to Averil's clinical presentation up to the point where she was last seen in NCEDS. The Eating Disorder Unit Psychologist had ensured that UEAMC were aware of the discharge plan for monitoring and the guidance, and that NCEDS were aware of this. He said this was consistent with established good practice and proficiency standard 2b.4 regarding monitoring procedures and maintaining safety of service users.

The advice to cease weighing in primary care

D138. The First Psychologist Adviser said it is standard practice to limit weighing to once a week in one location as advised in the letter of 26 October. He said differences between scales in their calibration can lead to differences in apparent weights taken on different days over less than a week and can obscure true change when comparing a weight taken on one scale against a weight taken on another. He said that as outlined below, you can only usefully interpret the trend on the weight chart and not shorter term fluctuations. If the patient is weighed too frequently, it can increase eating disordered preoccupation. Furthermore, discrepancies between weights on different scales, subject to eating disorder misinterpretation, can themselves destabilise patients.

D139. The First Psychologist Adviser said given the choice between the GP practice or NCEDS weighing Averil, it would have been considered established good practice for weighing to be integrated into therapy because the therapist will work with eating

disordered misinterpretation of weights and use the information to improve insight, and motivationally to set targets for eating. He said weekly weighing was an appropriate level of monitoring at this stage in terms of absolute BMI and trajectory from the point of view of risk assessment and was the best balance of that need against the possible downsides of more frequent weighing and of weighing in two places.

D140. The First Psychologist Adviser said this approach is recommended by Dr Fairburn in his treatment manual *Cognitive Behaviour Therapy and Eating Disorders* (2008), a key text in the field that has been subjected to randomised controlled trials.

Progress over time

D141. The First Psychologist Adviser said HCPC proficiency standards 2b.4 and 2c.1 require monitoring for safety and to evaluate effectiveness.

D142. He said the NICE guidelines state [6.2.9.6, paragraph B9]:

> *'For patients with anorexia nervosa, if during outpatient psychological treatment there is significant deterioration, or the completion of an adequate course of outpatient psychological treatment does not lead to any significant improvement, more intensive forms of treatment (for example a move from individual therapy to combined individual and family work, day care or inpatient care) should be considered'.*

D143. And in relation to safety, he said the NICE guideline say [4.2.1.2 and 4.4.5.3, paragraph B9]:

> *'The level of risk to a patient's mental and physical health should be monitored as treatment progresses because it may change - for example following weight change or at times of transition between services in cases of anorexia nervosa.'*
>
> *'Inpatient treatment should be considered for people with anorexia nervosa whose disorder is associated with high or moderate physical risk.'*

D144. About *Current practice* he said the NICE guidelines say [6.4.2, paragraph B9]:

> *'In the UK, patients at low weight are frequently managed in an outpatient setting in specialist eating disorder services. In these instances, there is a higher threshold for inpatient treatment with admission often not occurring until the patient's BMI falls below 13 kg/m2.'*

D145. While he said physical factors associated with higher mortality cited in the same section of the NICE guidelines include:

> *'severity of weight loss, over-activity and vomiting, bulimia and purging...A BMI less than 13 kg/m2 is of prognostic significance as it indicates a greater risk of mortality...Data on malnourished females in famine indicate that with a BMI less than 11 kg/m2, risk of mortality increases sharply...Comorbid alcoholism has also been shown to be associated with increased mortality.'*

D146. The First Psychologist Adviser explained that in *A Guide to the Medical Risk Assessment for Eating Disorders* (IOP, Treasure, 2009) a BMI of less than 14 indicates 'Concern', a BMI of less than 12 indicates 'Alert'. While weight loss per week greater than 0.5kg equals 'Concern' and weight loss per week greater than 1.0kg equals 'Alert'.

D147. He said the MARSIPAN Guidelines (RCPsych, 2010), *Box 1 Risk Assessment in Anorexia Nervosa*, states for BMI *'medium risk 13-15'*, *'high risk <13'*.

D148. Also, in relation to effectiveness, the First Psychologist Adviser said that the NICE guidelines say [4.4.5.5, paragraph B9]:

> *'Inpatient treatment or day patient treatment should be considered for people with anorexia nervosa whose disorder has not improved with appropriate outpatient treatment.'*

D149. The First Psychologist Adviser said to understand the responses of the NCEDS Care Coordinator, and the Eating Disorder Unit Psychologist (see below), to Averil's progress over time, it is first necessary to understand how changes in numbers on a scale are interpreted. He said any single number on a scale is made up of a patient's weight and a variety of other things - for instance, clothing, the current contents of stomach, bladder and bowel, menstrual cycle (where applicable) and level of hydration. He said drinking a normal bottle of water (500ml) will weigh 0.5kg on the scale, but have no calories, therefore no effect on true weight.

D150. The First Psychologist Adviser said weight is always interpreted as a trend with a band. The typical band is a kilo up or down, a two kilo band (Fairburn 2008). He said thus professionals will tend to interpret the trend on the weight chart and not over-interpret any short-term variation that does not fall outside the 'band' or that does not endure over repeat weighing. The 'four weighings' referred to on Averil's weight chart in the notes reflects the NCEDS Care Coordinator's awareness of this common advice.

D151. The First Psychologist Adviser said at much lower weights on inpatient wards (for example, from <BMI 13 to the BMIs sometimes seen on inpatient units of <10) smaller and shorter term changes on the scale are given greater interpretation, first because of the more imminent risks, and second because true figures are more controllable (for example, weighing patients in underwear, ward control over standardised food and fluid intake and activity levels). Yet even then each weight is understood as a mixture of true weight change and unknown fluctuations.

D152. The First Psychologist Adviser said when the NCEDS Care Coordinator weighed Averil first on 19 October she would have seen that Averil had continued to lose weight since discharge from the ward. She would have seen that this was at a rate of approximately 0.8kg per week over previous four weeks (from the Eating Disorder Unit Psychologist's last weighing) or possibly, but not definitely, as it was a different scale and because of fluctuation bands, of about 1kg per week compared to weights taken on 5 and 12 October at Averil's GP. He said considering the rate of weight loss and imminent physical risk, the position would be 'concern', as per the Institute of Psychiatry (IoP) Risk Guidelines [paragraph D146] and established good practice in relation to Averil's

presentation as a whole. He said the most appropriate plan would have been to weigh again in a week's time, moving to 'alert' if the rate continued (however, it did not).

D153. The First Psychologist Adviser said from session one to session three, according to usual practice, the NCEDS Care Coordinator would not yet have 'over-interpreted' the increases or decreases of 0.2 or 0.4kg. He said the trend would have provisionally indicated either that Averil's weight was stabilising or the rate of weight loss had slowed. He said the possible imminent risk of continuing to lose more than 1kg or even 0.5kg per week (that is, risk related to rate of weight loss) was not yet evident. But he said this would have been tentative initial evidence, linked to Averil's engaged presentation and reports of some changes in physical activity and eating, that the therapy is starting to help and might prove helpful longer term.

D154. The First Psychologist Adviser said Averil's overall efforts by this time had clearly still been insufficient for her to regain weight (for various reasons it is much harder to eat for regain than to eat for stability). But he said a therapist would be reassured initially if Averil's BMI weight was starting to stabilise or even if weight loss was slowing. In the context of immediate relative safety this would be a platform a therapist would aim to build upon to achieve regain with the patient.

D155. The First Psychologist Adviser said session four would be the first point a therapist would interpret that weight was more likely to be dropping than stable or going up. The therapist at this point would not 'over-interpret' a single weight drop of 1kg, but would be concerned and very alert to what happened at the next weighing. He said when the weight was the same the following week (session five), this would have conveyed both positive and negative implications. He said, on the negative side, it increases the belief that the loss of 1kg was indeed a genuine loss of weight, not a hydration level based fluctuation. But on the positive side, it would have suggested that weight loss had not accelerated into the *'rapid weight loss'* described in the ward S3 risk assessment as a risk indicator or in the 'concern' or 'alert' ranges of the IOP risk guidelines.

D156. The First Psychologist Adviser said the weight at session six would have strengthened the confidence in both of those interpretations. The NCEDS Care Coordinator should have been clear that Averil's weight was not stabilising, but was dropping and the important issue would be the rate of loss in the context of the absolute BMI and other indicators. He said after session six, according to NCEDS protocols, the NCEDS Care Coordinator would have been undertaking her audit review. This is established good practice on NCEDS part.

D157. The First Psychologist Adviser said considering risk from rate of weight loss, from session one (39.2kg) to session six (38.2kg), the rate of weight loss was 0.17kg per week; conservatively, from session two (38.6kg) to session six it was 0.28kg per week. Therefore, he said rate of weight loss was not indicating imminent risk.

D158. The First Psychologist Adviser said he also did not think they could have been expected to have predicted the actual outcome. The difference between the last recorded weight at NCEDS and Averil's weight on admission to hospital is extremely rare. He said he had not seen it either as a degree of water loading or a speed of weight loss. Before her first ward S3 admission, Averil was recorded as losing weight at about 0.7kg a

week over several weeks and latterly possibly 1.8kg over five days. He said, whilst dramatic, that would not be seen as likely to convert into 7.2kg kilos over two weeks, since a 1.8kg drop over five days would incorporate short-term fluctuations, for example fluid (see below about 'fluctuation bands'). Also, he said there were not sufficient signs presented to indicate that sudden weight loss was about to happen in late November 2012.

D159. Nonetheless, the First Psychologist Adviser said the NCEDS Care Coordinator would also be aware that Averil's absolute BMI was, albeit not rapidly, going to be approaching the 'concern' area. He said considering other risk factors that complicate risk related to absolute BMI, on the risk side Averil had not spent a long time stable at low weights (which may be a safety factor in low BMIs), and she had a history of excessive and compulsive exercise and physical activity. But on the other hand, he said she did not show other indicators of substantially increased risks at relatively better BMI, such as alcohol abuse or purging. The main indicator for change to risk would have been change to weight and rate of weight loss.

D160. The First Psychologist Adviser said the CPA care plan dated 22 November 2012 had identified further weight loss as a contingency for a change of plan, which would have been a reasonable contingency plan at that point in time, consistent with established good practice. He said Averil was approaching the point that she needed to be reviewed for a change of plan. At this point the most commonly considered option for this presentation would possibly be a more intensive outpatient or community treatment. He said alternatively, given Averil's partial response to the CBT, it may have been continued for a further short period and reviewed again. The First Psychologist Adviser said at the time of the last contact it would be in keeping with established good practice to consider some continuation of outpatient treatment, perhaps increasingly directive about the behaviour changes required, to reverse the weight loss, avert readmission, and to stay at university; at the same time considering alternative options in case they proved necessary (for instance, there might be a specific meal plan and protocol for patients of BMI less than 13).

D161. The First Psychologist Adviser said the NCEDS Care Coordinator's rough note (in her supervision records) indicates, consistent with the NCEDS Consultant Clinical Psychologist's report[89] of supervision on 5 December, that the team was preparing to confront Averil with the severity of her predicament and the need for urgent behaviour change. Alongside that would have been continued monitoring of risk signs, and then if anything got worse or if Averil continued to lose weight, she would have been assessed for inpatient treatment, if necessary, compulsory treatment. He said they were clearly aware that if weight loss continued, Averil was at risk of requiring readmission to ward S3.

D162. The First Psychologist Adviser said organising a medical or multidisciplinary review within one to two weeks would have been established good practice at this time. It appears that Mr Hart's contact with ward S3 was relayed to NCEDS by 30 November 2012 prompting the NCEDS Specialty Doctor to arrange to join the NCEDS Care Coordinator at

[89] The NCEDS Consultant Clinical Psychologist described what was discussed in the supervision sessions in her statement to us.

the next appointment on 7 December for a medical review. The NCEDS Consultant Clinical Psychologist agreed in discussion with the NCEDS Care Coordinator that this was necessary.

D163. The First Psychologist Adviser said, given that NCEDS had taken over the responsibility for weekly weighing, it was not ideal that Averil was not seen and weighed at NCEDS between 23 November and 7 December, since the plan had been for weekly weighing. However, he said a two week gap at a BMI still just above 14 and a rate of weight loss of less than 0.3kg per week on average, falls within the range of established good practice. He said this is because of the relatively slow rate of weight loss and the apparent distance between Averil and imminent lethal risk, given that the very extreme weight loss she showed consequently was extremely rare and not predictable from other signs.

D164. When Averil failed to attend on 7 December, the First Psychologist Adviser said the level of alert would have risen considerably because she had previously engaged and withdrawal was a risk indicator and because the length of time not knowing her weight was going to become too long. He said the NCEDS Specialty Doctor and the NCEDS Care Coordinator would then have shared responsibility for the plan to offer another appointment five days later. This seemed reasonable from the information available at the time. Information that Averil was in hospital then took over.

D165. In summary, the First Psychologist Adviser said that at her last contacts with NCEDS outpatients, Averil was not at high risk and was approaching moderate risk and Averil had shown partial benefit (weight loss slowed and some behaviour changes occurred), but her weight was still dropping. He said the NCEDS Care Coordinator monitored changing risk and responded in a manner consistent with established good practice and HCPC standards and BPS principles [paragraphs B18 and B19].

D166. The First Psychologist Adviser said that once she received the information that Averil was in hospital, the NCEDS Care Coordinator's responsibility as care coordinator and psychological therapist would be to ensure liaison between dietitians and/or medics.

The transition from inpatient care to NCEDS

D167. The First Psychologist Adviser said at the CPA of 17 May it is first mooted that it might be best not to refer to Suffolk, but to refer directly to NCEDS. At the CPA (Ward Round) of 14 June the plan is noted '*to continue in Norfolk Team'*. The specialty doctor in eating disorders' correspondence in relation to the IPPA included an update for 26 June indicating that the plan was to bypass referral to Suffolk at the patient's request and for contact with the Eating Disorder Unit Psychologist to cover the interim. It appears that Averil wanted this plan and the team was in agreement.

D168. The First Psychologist Adviser said Suffolk community staff had been attending the CPA meetings for some time as is established good practice (in reality the attendance of community professionals when patients are inpatients can be patchy). To go from a community team, to a ward, and then back to the same team is a 'standard' situation. However, he said it is often necessary to individualise care plans when working in a

tertiary service[90] with young people, with family, education/work and general practice that can be subject to change and may be in different areas geographically. The situation of making a referral to a local community specialist eating disorder service, whilst also passing immediate medical monitoring to primary care and alerting student support services in order for a patient to attend university in a new location is not unusual. He said NCEDS did not begin attending care planning meetings or reviews. This is fairly common when there are significant geographical distances. However, he said witness statements report that in substitute there was regular contact by telephone and email between the Eating Disorder Unit Psychologist and the NCEDS Consultant Clinical Psychologist.

D169. Regarding inpatient follow-up, the First Psychologist Adviser said the overall frequency of contact and the respective roles of different professionals varies from service to service. There can be a variety of follow-up frequencies with nurses, unqualified liaison or support workers, dietitians, doctors, psychologists, occupational therapists etc. For comparison, he referred to a unit which offered returning to the ward for one day a week over four weeks and patients would typically meet whichever ward nurses were there at the time. At the more intense end is residential rehabilitation (from which a patient can attend college for example during the day) or a period at a day unit. But he said the former is only useful if the patient's work or study is near to it and the latter is not useful if someone is going to be studying or working.

D170. The First Psychologist Adviser pointed to a form that he could not identify nor date from the placing of a sticker and the way the photocopy had come out. But he said that it looked like a referral screening form and in the section for *'care coordinator'* he noted that it had the names of two Suffolk staff crossed out and the NCEDS Care Coordinator's name entered. He said it is not clear when the corrections were made. He said the discharge checklist dated 2 August 2012 says *'Community Care Coordinator Identified - Y*[es]*'*. While the CPA Care Plan dated 31 July 2012 still identified an individual from Suffolk as Care Coordinator. He said the CPA Part 2 Discharge Summary dated 3 August 2012 says *'referred to NCEDS'* and indicates follow-up by NCEDS when Averil starts university in mid/late September and her care coordinator to be assigned then. He said the Eating Disorder Unit Psychologist's role was specified as 'work', pending allocation of a care coordinator in mid-September from NCEDS. He said the CPA review schedule is signed, under the heading 'Care coordinator/Nurse' by the Eating Disorder Lead Psychiatrist on 31 July and another individual on 2 August and handing over the case as a whole to NCEDS. She identifies herself as 'care coordinator' in her letter to UEAMC GP dated 27 September, reflecting her 'de facto' role.

D171. The First Psychologist Adviser said although the recorded name of 'care coordinator' is inconsistent, the actual plan and responsibilities seem quite clear. The responsibility for medical monitoring was passed to Averil's Suffolk GP and thence to her Norwich GP, and the Eating Disorder Unit Psychologist takes responsibility for contributing to that with some sessions until 23 September, then ensuring the handover of medical monitoring from the local GP to the Norfolk GP. The responsibility for care planning remains with the Eating Disorder Unit Psychologist until Averil starts at NCEDS. The responsibility for therapy remains with the Eating Disorder Unit Psychologist until

[90] Tertiary services are services that provide highly specialised treatment.

Averil moves to Norfolk, and then there is a gap before a therapist is available to be allocated, within which time the Eating Disorder Unit Psychologist contributes some additional telephone calls.

D172. The First Psychologist Adviser said the frequency of the Eating Disorder Unit Psychologist's contact was not specified in the discharge plans. The Eating Disorder Unit Lead Psychiatrist indicates in her witness statement that she anticipated three contacts per week with Averil; the Eating Disorder Unit Psychologist plus two groups. It does not seem that the contact with the Eating Disorder Unit Psychologist was weekly nor is it clear whether it was intended to be. Averil it seems does not attend the groups, and the CPA indicates two group contacts in total were intended. The First Psychologist Adviser said as a multidisciplinary team responsibility this could have been clearer, but it is in keeping with established good practice not to identify exact frequency of contacts, since medical monitoring is primarily with the GP and arrangements between therapist and patient can be flexible to the patient's changing situation (for example, Averil went on holiday). He said for context, some patients voluntarily decline all contact in Averil's situation, so it is important to use existing engagement and motivation to facilitate as much contact as can be practically achieved. Allocation of follow up to a member of the multidisciplinary team with whom a patient is known to have a positive engagement, even if they are available less frequently, is common practice. He said the Eating Disorder Unit Psychologist was very well known to Averil and there is more than one reference to that being a positive engagement and those advantages need to be set against the frequency available: it increased the likelihood of Averil engaging (there is no use planning more frequent appointments that are not taken up) and of the contact helping (due to the existing therapeutic relationship).

D173. The First Psychologist Adviser referred to the NICE guidelines *'Continuity of care with an individual professional has been found to be valued'*.

General Follow-Up

D174. The First Psychologist Adviser said the Eating Disorder Unit Psychologist saw Averil within seven days on 9 August, according to the CPA care plan dated 31 July 2012 and established good practice. She saw Averil face-to-face twice in August (9 and 30) and once in September (20). Other sessions did not occur due to a cancellation and a family holiday. The Eating Disorder Unit Psychologist monitored weight and overall progress and encouraged maintenance and extension of progress using standard means of support and clinical management. He said, from the point of view of monitoring progress, this frequency of contact is within the range of established good practice and the outcome was that Averil's progress since discharge was known and handed over by the time she attended NCEDS.

D175. The First Psychologist Adviser said the Eating Disorder Unit Psychologist's follow-up did pick up Averil's weight loss. At the first follow-up there is not yet evidence of significant weight loss. Considering normal fluctuation bands of a kilo up or down, the weight of 44kg on 30 August is consistent with Averil's weight being broadly stable by that point. He said one tends to interpret the significance of each individual weight probabilistically, that is 44kg on 30 August would be interpreted as probably stable, not increasing, not dropping or if it is in reality dropping it is very slowly. And he said it

would not have been necessary to change the plan.

D176. The First Psychologist Adviser said the weight of 42.6kg on 20 September would be the first clear indication of a weight loss since discharge. The rate of weight loss between discharge (45.2kg at 2 August) and the Eating Disorder Unit Psychologist's final face-to-face contact (42.6kg at 20 September) was approximately 0.37kg per week. He said at this point it should have been clear that Averil was losing weight but not rapidly. This would have been considered a significant sign that Averil was not succeeding in raising weight as an outpatient, and may not be succeeding in maintaining either.

D177. However, the First Psychologist Adviser said neither the absolute weight nor the rate of weight loss at this point signaled imminent medical risk, nor were they at this point close to it (IOP Risk Guidelines). He said Averil's physical risk was by now still minimal.

D178. The First Psychologist Adviser said the main risk was around continued weight loss, for which a plan consistent with established good practice would be therapy plus connection to motivating life experiences (for example, university). He said the Eating Disorder Unit Psychologist was seeking to implement that as soon as it was possible via her correspondence with NCEDS on 21 September; the obstacle appeared to be the availability of NCEDS staff. Averil was reportedly already on the priority list and the consideration was whether to allocate her to an unqualified staff member in the meanwhile for the sake of it being a few days sooner (see below). It seems that Averil was being allocated to the first available suitable therapist according to clinical priority not waiting time from referral.

D179. To put the NCEDS delay into context, the First Psychologist Adviser said a survey by the eating disorder charity B-EAT in 2013 reported:

- 30% of people waited longer than 18 weeks to access outpatient treatment;
- 26% had a wait of longer than 6 months; and
- 8% had a wait longer than a year

D180. The First Psychologist Adviser said the Eating Disorder Unit Psychologist reports on 20 September reviewing Averil's care plan with respect to registering with GP in Norwich and with two members of the student support service at UEA. He said therefore her follow-up role assisted in ensuring Averil was engaged with and saw the necessary support services when she arrived at university.

D181. The First Psychologist Adviser said it would have remained important to continue to monitor weight and physical indicators as per the discharge plan, and the Eating Disorder Unit Psychologist arranged through her follow-up with Averil for the relevant information to be available as Averil transitioned from the Suffolk to Norwich GP. The Eating Disorder Unit Psychologist sent clear and complete information within three days of Averil's registering with her GP; a letter, the IOP guidelines and the ward S3 discharge summary. And she supplemented that with a telephone call to UEAMC regarding the dangers associated with starting university, Averil's vulnerability and the requirements for medical monitoring.

D182. The First Psychologist Adviser said Averil's GP noted that Averil weighed 42kg on 5 October, and 41kg on 12 October. Averil was then weighed by the NCEDS Care Coordinator on 19 October. Thus, he said despite the delay in allocation to NCEDS, ward S3 and the Eating Disorder Unit Psychologist had ensured that Averil was weighed weekly in this period according to the discharge plan and established good practice.

D183. In summary, the First Psychologist Adviser said the Eating Disorder Unit Psychologist's follow up was consistent with established good practice for a therapist and multidisciplinary team member given Averil's situation.

Therapy

D184. The First Psychologist Adviser said the NICE guidelines are not very specific about the timing, nature and frequency of therapy after an inpatient stay. There is an advantage from the point of view of therapy that weekly therapy continues seamlessly. However, this was not available in the community because Averil did not want to be referred to Suffolk and could not be compelled to; meanwhile she had not yet gone to Norfolk. Although the actual therapy arrangement, including the delay in starting NCEDS and the cover by the Eating Disorder Unit Psychologist, was not ideal, there does not seem to have been a better plan available consistent with Averil's stated wishes and return to university given staff availability.

D185. The First Psychologist Adviser said the Eating Disorder Unit Psychologist agreed to offer additional telephone calls until Averil started at NCEDS. To the extent that the calls provided an additional channel for receiving new information regarding progress and the implications of that for physical risk (monitoring), these calls were above established good practice. And the GP was responsible for medical monitoring which would have been a sufficient arrangement at her weight and weight trajectory. In so far as the telephone calls were bridging a therapy gap, they would have been considered a 'better than nothing' alternative to no contact in that time from any psychological therapist.

D186. The First Psychologist Adviser said the Eating Disorder Unit Psychologist undertook the duties of a therapist during follow-up and working towards an ending and handing over to colleagues, in line with established good practice and consistent with standards for effective intervention and communication.

Sharing information/making the transfer

D187. Averil was referred to NCEDS via letter on 30 July 2012. The First Psychologist Adviser said this referral letter included the circumstances of admission, diagnosis, weight progress, goal weight, psychological interventions and blood tests and bone health investigations. It enclosed the assessment letter, the CPA assessment and care plan and the draft discharge summary. *'Local eating disorder team'* were *'cc-ed'* to the 31 July 2012 CPA document. He said the referral correspondence is comprehensive.

D188. The First Psychologist Adviser said that, as noted above, both the Eating Disorder Unit Psychologist and the NCEDS Consultant Clinical Psychologist describe their email and telephone contact between July and September about Averil's case. He said the Eating Disorder Unit Psychologist supplemented the ward S3 discharge information and referral

letter with an email and clinical note to update NCEDS dated 21 September. This letter reported Averil's rate of weight loss and the contacts with university well-being staff, as well as confirming that the Eating Disorder Unit Psychologist was arranging physical monitoring via Averil's Norfolk GP. The First Psychologist Adviser said the handover as described is a reasonable summary of Averil's needs and presentation. It includes risk related information updated with the weight loss since discharge, and the Eating Disorder Unit Psychologist confirmed the implementation of the discharge care plan with respect to GP monitoring of safety indicators and transfer of that to Norwich primary care, plus support from UEA student support workers. It was copied to the Eating Disorder Unit Lead Psychiatrist and the NCEDS Lead Psychiatrist, so as responsible medics they would have been able to input if they had interpreted the situation differently to the Eating Disorder Unit Psychologist. The Eating Disorder Unit Psychologist requested CBT for Averil as soon as possible and arranged interim telephone calls.

D189. The First Psychologist Adviser said the Eating Disorder Unit Psychologist also says she had undocumented telephone contact with a support worker at the university which was part of ward S3's preparation for Averil to go to university. On 25 September, the NCEDS Consultant Clinical Psychologist alerted the Eating Disorder Unit Psychologist that allocation of a therapist was delayed. The NCEDS Consultant Clinical Psychologist says she suggested to the Eating Disorder Unit Psychologist an option of a session with an assistant psychologist (unqualified) prior to starting with a qualified therapist, which the Eating Disorder Unit Psychologist would *'bear in mind'*. He said this idea would have had pros and cons. The additional contact may have been of some value, but it would have been somebody unknown to Averil and unqualified. Considering Averil's presentation, and the fact that this element of the care plan was cover for therapy, not care coordination or risk monitoring, he thought either accepting or rejecting the NCEDS Consultant Clinical Psychologist's offer would have been reasonable decisions. As noted above the Eating Disorder Unit Psychologist committed to maintain some telephone contact instead.

D190. The First Psychologist Adviser said the NCEDS Consultant Clinical Psychologist discussed Averil's case with the NCEDS Care Coordinator between 2 and 15 October, passing on the information from the Eating Disorder Unit Psychologist and requesting for the NCEDS Care Coordinator also to obtain a handover from the Eating Disorder Unit Psychologist.

D191. The First Psychologist Adviser said the Eating Disorder Unit Psychologist had a telephone call with the NCEDS Care Coordinator on 15 October. The NCEDS Care Coordinator records that she was told Averil was below healthy weight but *'stable'*. It is not clear what this meant. The NCEDS Consultant Clinical Psychologist was aware as early as 21 September via email that Averil had lost weight, so perhaps it meant medically or psychologically stable. At any rate, four days later on 19 October the NCEDS Care Coordinator weighed Averil, so the overall trajectory since discharge was readily apparent. Handwritten notes presumably of the telephone call record the NCEDS Care Coordinator receiving information about the psychological formulation, eating patterns and a recommendation that she track progress.

D192. The First Psychologist Adviser said in combination with the ward S3 referral and documentation, and the Eating Disorder Unit Psychologist's letter in late September, the overall handover was comprehensive. The level and nature of the contact was appropriate for a patient like Averil. NCEDS were aware of the history, Averil's presentation and plan at the time of discharge and changes to her presentation by 19 October which did not indicate a necessity to change the plan by that point.

D193. In summary, the First Psychologist Adviser said the care co-ordination arrangements were individualised to facilitate Averil's wish not to make two transitions in quick succession. He said the actual care was consistent with established good practice, subject to the limitations imposed by the patient's wishes about where she wanted to be treated, facilitating starting university and the delay in allocation of a therapist at NCEDS. He said the Eating Disorder Unit Psychologist took responsibility for handing over medical monitoring, care planning and therapy, consistent with the discharge care plan, given the gap of time between discharge and GP transfer, in an appropriate manner. He said all the key functions of a care coordinator were discharged. The Eating Disorder Unit Psychologist performed consistent with HCPC standards (annex B, paragraph B18) for best interests of service users and communicating properly and effectively with other practitioners, as well as for effective communication of information, advice, instruction and professional opinion to colleagues and monitoring procedures to maintain safety. He said the Eating Disorder Unit Psychologist did so consistently with the ethical principles of informed consent and right to self-determination and decisions made a reasonable interpretation of client interests and potential harm from action or inaction.

D194. To put the individualisation into context, the First Psychologist Adviser said the NHS England Commissioning Board 2013/14 service specification for specialised eating disorder units requires units to *'Provide a personal service, sensitive to the physical, psychological and emotional needs of the patient and their family'*.

D195. The First Psychologist Adviser said to illustrate that, whilst it is usual to discharge immediately to the same community team a patient was admitted from, the arrangements made for Averil could be considered reasonable in exceptional circumstances and in keeping with established good practice. He said the same service specifications state: *'Some continued follow up and treatment in the outpatient setting can be provided to reduce risk of relapse and readmission, in the service user's best interest. This should be agreed with all services involved, through the process of CPA. In the vast majority of cases follow up will be provided by the relevant community eating disorder service and would only be agreed in exceptional cases where the community team was unable to meet the treatment needs of the patient'*.

Communication between NCEDS and primary care

D196. The First Psychologist Adviser said the NICE guidelines say under the heading *Primary-secondary care interface* [2.7.4, paragraph B9]:

> *'It is particularly important for effective management that communication is good and that areas of responsibility are clear. Sometimes, for example, a patient may be receiving psychological therapy from a secondary care service but*

responsibility for physical monitoring may remain with primary care.'

D197. And under physical health care it says [2.7.5, paragraph B9]:

> *'In any treatment plan, it must be clear who is taking responsibility for physical assessment and how any risk identified is to be managed. This often involves effective communication between primary and secondary care services.'*

D198. The NICE guidelines also say [4.2.1.4, paragraph B9]:

> *'Where management is shared between primary and secondary care, there should be clear agreement amongst individual health care professionals on the responsibility for monitoring patients with eating disorders. This agreement should be in writing (where appropriate using the care programme approach) and should be shared with the patient and, where appropriate, his or her family and carers.'*

D199. The First Psychologist Adviser said the Eating Disorder Unit Psychologist's communication of the physical monitoring aspects of the discharge care plan, according to the discharge CPA, to UEAMC was clear. The draft Part 2 Discharge Summary, including discharge plan, was copied to NCEDS with the referral letter dated 30 July 2012. The same was copied to UEAMC by the Eating Disorder Unit Psychologist on 27 September 2012. The Eating Disorder Unit Psychologist confirmed the medical monitoring arrangement in her letter to the NCEDS Consultant Clinical Psychologist dated 21 September 2012. The NCEDS Care Coordinator wrote a timely 'Start of Treatment' letter on 26 October, within one week of first contact, in which she maintained the importance of medical monitoring at the GP, clearly taking back into NCEDS the responsibility for weight monitoring. This is not recorded as 'cc' to UEAMC.

D200. Apart from that, the First Psychologist Adviser said he was not sure he would have expected any further contact between NCEDS and primary care, between the Eating Disorder Unit Psychologist's handover (27 September) and 7 December. The respective responsibilities were clear and up to that point there were not indicators for urgent or emergency GP actions or information beyond the existing documented plan as arranged by ward S3. He said each service has its own approach to review of monitoring undertaken within primary care. Sometimes investigations come to the service doctors, sometimes to other staff (including nurses, other professionals and support workers without core professions), who are able under guidance to identify anomalous results for further consideration by medical staff. At other times it is in keeping with established practice for outpatients for investigations to be checked in general practice and he said you would, for example, telephone to check they had taken place only if you had grounds to believe that a patient was not being honest when claiming they had had their checks and the risk was serious and imminent. He said these were not circumstances that one could have seen in Averil's case: she was not in that category; her reports and weight chart were broadly consistent; she had a history of engagement and compliance with monitoring and intervention; and her weight was going down and causing concern (that is, that had not been concealed).

D201. The First Psychologist Adviser said as of 23 November, a medical review within NCEDS was the obvious next step, which would have led in turn to any necessary contact – that is, whether to change to the medical monitoring plan or to alert the GP to any change to the care plan. Contact with primary care would have been indicated after Averil failed to attend the 7 December appointment to alert primary care to the non-attendance, but hospital admission superseded that occurring.

D202. In summary, the First Psychologist Adviser said responsibilities were handed over and documented by ward S3 and the Eating Disorder Unit Psychologist such that no additional interaction was necessarily indicated between NCEDS and UEAMC prior to Averil's hospitalisation. The NCEDS Care Coordinator acted consistently with HCPC standards [paragraph B18] for proper and effective communication, duty of care, and monitoring procedures to maintain safety.

The Second Psychologist Adviser

Discharge from ward S3 and transition to NCEDS

D203. The Second Psychologist Adviser told us that NICE guidelines were not specific regarding weight at discharge, but did advise that better outcomes are linked with greater BMI at discharge. She said that she was therefore basing her advice on established good practice within specialist eating disorder services.

D204. The Second Psychologist Adviser also told us the MARSIPAN guidelines suggested that those with a BMI of 15 to 17.5 are low risk. Medium risk was considered to be those with a BMI of 13 to 15. Outpatient services were generally considered appropriate for those of a BMI 14 and above, with some variation on a case-by-case basis depending on blood chemistry, rate of weight loss and mental well-being. Averil was discharged from inpatient services on 2 August 2012 with a BMI of 16.6. This was below her target weight, but she told us within a safe enough weight range to be able to receive treatment as an outpatient and take up her place at university within the following 6 weeks. This was what Averil wished and it was also documented by the Eating Disorder Unit Psychologist and the Eating Disorder Unit Lead Psychiatrist as a motivating factor in her recovery. Although this BMI was lower than the ideal planned for, the Second Psychologist Adviser said that it was part of established good practice and recovery to balance, on the one hand, a young person's wishes to go to university and the benefits to her recovery if she was able to focus on her goals, and on the other hand, the reality that while she was still underweight, this was not severe enough that she could be detained.

D205. The Second Psychologist Adviser said that some weight loss following discharge was common and often inevitable. This did not have to be catastrophic if weight can then be stabilised at the new lower weight while outpatient treatment begins. However, she said Averil was planning on moving away from home to university where the local services did not know her and she did not have any social support. She said this significantly increased her risks and once weight loss began, it would have been established good practice to have documented evidence that consideration was given as to whether Averil was well enough to go to university at that time. She said this would have been best placed within a CPA review [paragraphs B8 and B9] and included Averil's parents as well as Averil herself.

D206. The Second Psychologist Adviser said that Averil was entitled to follow-up within seven days of discharge as per national standards and she was seen by the Eating Disorder Unit Psychologist on 9 August, which was exactly a week after her discharge. Averil was offered a total of six contacts with the Eating Disorder Unit Psychologist between her discharge on 2 August, and her move to university on 23 September; Averil attended three of the six offered appointments face-to-face, she cancelled one and had two over the telephone after she left to go to university.

D207. The Second Psychologist Adviser also noted that Averil was not offered review by any other member of the multidisciplinary team. She explained that the NICE guidance [paragraph B9, 4.4.2.11] stated that *'following inpatient weight restoration people with anorexia nervosa should be offered outpatient psychological treatment that focuses both on eating behaviour and attitudes to weight and shape, and wider psychosocial issues with regular monitoring of both physical and psychological risk'*. She said the Eating Disorder Unit Psychologist was unable to see Averil between 9 and 30 August which was a three week gap with no specialist review or contact. The Second Psychologist Adviser added that she was unable to establish from the records the reasons for this gap other than that Averil was *'unavailable'*. She said in line with NICE guidance Averil should have had regular reviews with the specialist team that she remained under as part of the CPA process until registering with a new GP at university. If this could not be provided by the Eating Disorder Unit Psychologist, any other member of the team should have been able to offer regular review. During this period, Averil lost 2.4kg in weight.

NCEDS – the allocation of the NCEDS Care Coordinator

D208. The Second Psychologist Adviser noted that the NCEDS Care Coordinator was a newly appointed Band 7 counselling psychologist who had only her viva[91] to complete before she would be qualified. She said that this was a common practice in appointing to Band 7 psychology posts. The trainee at this point has passed all aspects of their three year training apart from the thesis, which is examined in a viva. It was usual to appoint at Band 6 until the viva had been successfully passed.

D209. The Second Psychologist Adviser told us that the British Psychological Society (BPS) advises on supervision that *'the amount and frequency is dependent on context, experience and work demands'* and that *'an absolute minimum will be one hour per month'*.

D210. The Second Psychologist Adviser noted that the NCEDS Care Coordinator received supervision from the NCEDS Consultant Clinical Psychologist on 24 October, 14 November, 21 November, 26 November, 5 December and 10 December. The NCEDS Consultant Clinical Psychologist was unavailable to meet the NCEDS Care Coordinator between 24 October and 14 November, and she therefore arranged for the NCEDS Care Coordinator to take any clinical queries to the team meeting and specialist colleagues on 29 and 30 October. The NCEDS Consultant Clinical Psychologist made the NCEDS Care Coordinator aware that she could be available on 1 November if the NCEDS Care Coordinator had any concerns. There

[91] Oral examination of the individual's thesis.

was then a gap until 14 November, but the reason for this and any contingency planning was unclear.

D211. Overall, the Second Psychologist Adviser told us that the NCEDS Care Coordinator received regular supervision and a good level of support from both the NCEDS Consultant Clinical Psychologist as well as her colleagues. She attended a training course for CBT and eating disorders on arriving at the service. With this level of support it was within established good practice that the NCEDS Care Coordinator was identified as the psychologist to be working with Averil.

D212. However, as someone only just qualified and possibly new to eating disorders, the Second Psychologist Adviser said that the NCEDS Care Coordinator could not be expected to know the inherent risks and would have needed this support from her supervision. Averil was described as *'strong willed'*, as *'finding it difficult to accept criticism or challenges'*, had a history of a very low BMI, was recently discharged from an admission and had already lost a significant amount of weight over a relatively short period of time. The supervision records and individual statements from both the NCEDS Care Coordinator and the NCEDS Consultant Clinical Psychologist identify that the focus of the therapeutic work was on engagement and collaboration in order that it could then be possible to begin to challenge Averil and for her to be able to tolerate the discomfort of this challenge within a supportive context. This is within an accepted and well established approach to therapy and good long term outcomes are influenced by first establishing strong therapeutic relationships. The NCEDS Care Coordinator appears to have worked hard to try to engage Averil within this framework.

D213. The Second Psychologist Adviser said records and statements also demonstrate that risk was considered, there was a clear rationale with regard to treatment approach and that the therapy provided was within an accepted and well documented CBT approach to low weight anorexia.

Care provided by NCEDS

D214. The Second Psychologist Adviser also told us that BPS *'Service Guidelines for people with eating disorders 2001'* says that outpatient treatment should be considered for patients who:

- are highly motivated;
- have good social support;
- are not losing weight rapidly;
- are metabolically stable; and
- whose weight is not below 70% average weight for height.

D215. The Second Psychologist Adviser said that there were no exact guidelines about when to admit someone suffering from anorexia and each decision is taken based on established good practice and in the round; for example, based on the individual's needs and best interests. At her first appointment with the NCEDS Care Coordinator, Averil's BMI had dropped to 14.4. Established good practice when there was continued and rapid weight loss, particularly in recent weeks from admission, would be regular and

transparent discussion with Averil and her family of the need to readmit Averil should she continue to lose weight, with clear conversations about the need to stabilise weight and a risk management plan in the event that rapid weight loss continued. The Second Psychologist Adviser said that it would have been prudent for there to have been early conversation with the inpatient provider and commissioners so that in the event of the need to admit quickly there would be no delay.

D216. After the first session with the NCEDS Care Coordinator, Averil gained 0.4kg in weight (BMI 14.4 to 14.56) and so will have appeared to clinicians that the weight loss was slowing and that the risks were reducing. Whether this was a true weight the Second Psychologist Adviser said, remained unknown. And given the dramatic weight loss by admission it remained possible that Averil was artificially increasing her weight for when she was weighed by the NCEDS Care Coordinator. If more experienced colleagues had worked alongside the NCEDS Care Coordinator at this time, and if they had regular sight of Averil, it might have been possible for this to have been picked up sooner.

D217. The Second Psychologist Adviser said to maintain engagement for therapy a decision has to be made that the person is safe enough that this can be placed as the priority for intervention. Difficult conversations, like readmission or the use of the Mental Health Act, are therefore best done by other members of the team to maintain this alliance, while still retaining the relationship with the therapist. The Second Psychologist Adviser said that in the absence of colleagues to help, this role fell to the NCEDS Care Coordinator and her supervisor the NCEDS Consultant Clinical Psychologist. She said the current guidance was that Averil should have had access to a full multidisciplinary team that was experienced in working with those suffering with anorexia and that was able to monitor her physical well-being, as well as her emotional needs. This should have taken place in collaboration with Averil's new GP and her family. As her weight began to deteriorate further there should have been regular multidisciplinary reviews as well as formal CPA review meetings with Averil and her family, and these should have been documented as part of the CPA process.

D218. The Second Psychologist Adviser said that given the risk history, risks during transition, weight loss and the personal style of Averil, the NCEDS Care Coordinator should not have been working in isolation with Averil, who was deteriorating, at risk and had complex needs. Although there was consideration of risk, recognition of the full risk picture would have been most thoroughly identified with full multidisciplinary involvement. She said that psychological therapy alone in this situation was not an adequate intervention. It would have been established good practice for this multidisciplinary approach to have included specialist dietetics who could have advised on nutritional intake (including suitable snacks if appropriate), the prescription of nutritional supplements if food was too difficult and the risks of refeeding syndrome, as well as the need for physical health monitoring.

D219. The Second Psychologist Adviser explained that specialist dietetic work could have increased Averil's knowledge and complemented the therapy therefore potentially increasing Averil's motivation regarding her own nutrition. As psychologists, neither the NCEDS Care Coordinator nor the NCEDS Consultant Clinical Psychologist would have had this specialist knowledge. Averil would have also benefitted from regular multidisciplinary reviews which involved medical or nursing staff.

D220. The Second Psychologist Adviser said that clear conversations with Averil about the risks she was facing and also the boundaries and limits of an outpatient approach could have motivated Averil, just as it had done previously when she was an inpatient and wanted to be able to be well enough to attend university. She said that she could find no documented evidence of these conversations with Averil.

D221. The Second Psychologist Adviser told us that it was a sensible decision for the NCEDS Care Coordinator to ask UEAMC not to weigh Averil, and it was established good practice in specialist eating disorder services. Weighing scales were not always accurate and different scales can show different weights for the same person. In keeping the conditions around weighing stable, the team could be more confident of a true weight and a more accurate picture. In addition, those with anorexia become very focused on repeated and frequent weighing which can cause huge distress if the scales show changes in weight. This is then counterproductive and hinders any treatment being offered.

Admission to NNUH

D222. The Second Psychologist Adviser told us that the role at this time was for the specialist multidisciplinary team at NCEDS to provide advice, consultation and support to the medical team. Averil was admitted to NNUH on Friday 7 December and by the time the specialist team were made aware of this and in contact with the medical team, it was already Friday afternoon. NCEDS was a '9 to 5 Monday to Friday' service and the staff would not have been available over the weekend. The Second Psychologist Adviser said that she could not find documentation that there was contingency plan in place for this eventuality.

D223. The Second Psychologist Adviser said that MARSIPAN guidelines were written to ensure the safe and effective management of really sick patients with anorexia nervosa. They were initially written in 2010 and were updated in October 2014. The guidelines state that '*when a patient is transferred from one service to another there should be a properly conducted and recorded meeting between representatives of the two services, usually also including the patient and their family, so that it is very clear what will happen during and after the transfer of care and who is responsible for what. Such meetings should be continued until transfer is satisfactorily achieved*'. This did not happen until 11 December.

NNUH

The Gastroenterology Adviser

What did happen?

D224. The Gastroenterology Adviser explained that Averil was admitted to NNUH on 7 December 2012 with '*abdominal discomfort, nausea and dehydration*' after having been found slumped in her halls of residence.

D225. He told us that her history of severe anorexia nervosa was identified as was her recent prolonged inpatient psychiatric care prior to going to university. Clinical assessment identified cachexia, hypothermia (temperature 34°C as recorded by the doctors) and a heart murmur but no significant abnormal abdominal findings (palpable stool in the sigmoid colon[92]). An electrocardiogram showed abnormalities consistent with severe anorexia nervosa[93]. An echocardiogram and an abdominal ultrasound were booked.

D226. The Gastroenterology Adviser noted that a nursing MUST (malnutrition universal screening tool) assessment recorded a BMI of 12. Averil was seen by the acute admitting team and subsequently a gastroenterology registrar who discussed her with the First Consultant. The Gastroenterology Adviser told us that a management plan was written but this did not include any specific nutritional input ('*patient told to keep food chart*'), reference to a psychiatric review or reference to specialist facilities.

D227. The Gastroenterology Adviser also explained that Averil was treated with intravenous fluids (Hartmann's solution[94] - electrolytes only - no nutrition) and subsequently glucose after severe hypoglycaemia (1.1mmol/L) was documented. She was also given injections of multivitamins. In the light of her history of taking therapeutic paracetamol and the raised liver enzymes, she was also treated with intravenous acetylcysteine (a drug given to reduce liver damage in paracetamol overdose).

D228. The Gastroenterology Adviser told us that having looked at the clinical notes and fluid charts, compliance with intravenous and oral regimes was patchy and there was evidence of food avoidance behaviour. He could not find any specific nursing records of Averil's food intake or dietetic input.

D229. He also told us that although there was a telephone call on 7 December with the consultant psychiatrist, there was no actual input [from NCEDS] until 10 December 2012.

D230. Over the weekend Averil was reviewed by the doctors (including consultant gastroenterology review) and her clinical notes record that she remained weak to the point that she had a significant fall. She also lost a further significant amount of weight and there were specific notes of hypoglycaemia and hypotension (low blood pressure).

D231. The Gastroenterology Adviser said that on 10 December 2012 Averil was seen by a specialty doctor from NCEDS and subsequently a dietitian. At the consultation with the specialty doctor it was agreed that Averil would be transferred to the specialist unit when she was medically fit. The following day psychiatric advice was that if she could not be transferred immediately she should have one-to-one nursing. He explained that the transfer was then agreed after consultant-to-consultant discussion.

[92] The S-shaped last part of the large intestine, leading into the rectum.
[93] These abnormalities included a borderline prolonged QT interval, t-wave inversion in the anteroseptal leads and a bradycardia (see MARSIPAN – risk assessment). Blood tests showed low platelets, a raised urea and creatinine, hypoglycaemia (low blood sugar), abnormal liver enzymes and a prolonged INR.
[94] A compound sodium lactate intravenous infusion solution used to replace fluid and salts.

What should have happened?

D232. The Gastroenterology Adviser told us that it was clear from the clinical notes that Averil was seriously ill and at risk of severe harm or death. Averil had severe anorexia as evidenced by cachexia, BMI 12 (from the MUST document completed by the nurse) hypothermia, hypotension, severe muscle weakness, blood tests showing hypoglycaemia AKI (acute kidney injury), dehydration, thrombocytopenia[95], abnormal liver enzymes, ECG showing a bradycardia[96] and other changes [see MARSIPAN guidelines, paragraphs B10 to B12]. She was at risk and in urgent need of refeeding.

D233. The Gastroenterology Adviser told us that the question was not whether Averil was assessed and treated well from the general medical point of view (the notes do indicate reasonable management of her immediate problems with consultant supervision), but whether the seriousness of her underlying condition was recognised by appropriate staff and appropriate action taken.

D234. He told us that the initial assessment of Averil was in line with established good practice, as was the review by the acute physician and the prompt transfer to the care of the gastroenterology team. She was seen by a gastroenterology registrar first at 6.15pm on the day of admission (a Friday) and discussed with a consultant gastroenterologist. However, the Gastroenterology Adviser told us that the First Consultant (and the Second Consultant that saw her) should have been aware of the MARSIPAN guidelines and recognised that she was at risk and therefore urgently needing feeding in a graded manner taking into account the risks of refeeding[97] and the questions of her acceptance of this (i.e. the psychiatric aspects).

D235. He said that therefore the First Consultant had two choices bearing in mind this was the Friday evening leading into the weekend. Firstly to admit Averil to a specialist eating disorders unit (SEDU)/associated unit [in accordance with NICE CG9 paragraph B9]. The most appropriate course of action would have been a direct consultant-to-consultant referral to SEDU at Cambridge (see MARSIPAN). This was not done.

D236. Secondly, he explained that the First Consultant should have ensured a monitored graded feeding regime was undertaken with psychiatric support. This was not done either. He told us that there was even a basic failing to ensure dietetic advice as required in all patients with a BMI of less than 18.5 [in accordance with NICE clinical guideline 32 paragraph B28].

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[95] A lower than normal number of platelet cells in the blood. Platelets play an important role in clotting and bleeding.

[96] A slow heart rate.

[97] In significantly malnourished patients, the initial stage of refeeding causes electrolyte and fluid shifts that may precipitate disabling or fatal medical complications, which can include cardiac complications, respiratory failure, severe muscle weakness and tetany, delirium, seizures, severe diarrhoea, liver dysfunction. In patients with gross malnutrition, the risk is reduced restoring weight with an amount of calories that is close to and above the resting energy expenditure, avoiding rapid increases in the daily caloric intake, and very closely monitoring the patient clinically and biochemically during the refeeding process. Complications are reduced by slowing the rate of nutritional support, watching for and correcting electrolyte abnormalities, especially phosphorous levels, and monitoring for and treating cardiovascular and pulmonary complications.

D237. The Gastroenterology Adviser said that there was no evidence of any attention to Averil's calorie intake and there was no evidence of any recognition of her food avoidance behaviour. Contrary to the Trust's letter of 14 February 2014, there is no evidence that the psychiatrist '*gave the team guidance regarding Averil's care on the ward*'.

D238. When Averil was seen by the specialty doctor from NCEDS on 10 December 2012 there was again no urgency of action and the notes did not provide any evidence of direct liaison between the psychiatric and medical teams. However, there is evidence of such direct liaison on 11 December 2012 after which she was transferred.

Impact

D239. The Gastroenterology Adviser said that these failings led to inadequate treatment of Averil's emaciated condition which was associated with her anorexia nervosa. This meant she was in a weaker state by the time she was transferred. However he said that it was not possible to link this directly to her subsequent death in Cambridge. What he could say was that there was a failure in an opportunity to treat Averil that may have reduced her chance of survival. We cannot say to what extent that would have made a difference to her treatment in Cambridge.

The First Nurse Adviser

Nutrition

What happened?

D240. The First Nurse Adviser told us that on admission Averil's past medical history and medical condition were identified. A MUST screening tool was used to calculate a nutritional score of 11. This score was identified as very high risk. However, there was no clear documented action plan to follow on from the risk assessment, apart from a dietitian referral.

D241. She also told us that in the full nursing assessment on 7 December 2012 the nutrition care domain [section of the form] was completed by identifying the diagnosis, but also documented that there were *'No issues identified'*. She said that this document should be completed 12 hourly and any changes and actions should be clearly identified. According to this document over the period from 7 to 10 December 2012 there did not appear to be any concerns about nutrition. A second domain on this document was mental state, which the First Nurse Adviser explained was directly correlated to nutrition in this circumstance. This was also completed as having *'No issues identified'* for the same period.

D242. The First Nurse Adviser said that there was no food chart or similar documentation to record and monitor the food intake during this period. There were occasional references made to Averil eating small amounts, but type and quantity were not specified. The documentation also says that food was offered, but again there was no reference to how receptive Averil was to the offer of food and in what quantity she ate it.

D243. The First Nurse Adviser told us that a fluid balance chart was completed during the period 7 to 10 December and was used to record the administration of intravenous fluids. There was an oral intake section to this chart, which only had three entries for this entire period, being sips of water and coffee.

D244. In summary, the First Nurse Adviser explained that the past medical history, the presenting complaint and the MUST risk assessment tool all enabled nurses to identify a high risk patient. However, apart from a dietitian referral there did not seem to be any further monitoring, action plan or escalation of concerns. Compliance and input were not clearly recorded and a consideration of enteral feeding[98] via nasogastric tube did not appear to have been considered by nursing staff.

What should have happened?

D245. The First Nurse Adviser said that once it had been established that Averil was a very high risk patient, a clear action plan with goals should have been identified in accordance with the NMC Code of Conduct [paragraph B27]. This should have been evaluated daily and if the goals were not met this should have been escalated. Goals may have included agreeing an achievable intake with Averil and recommendations from a dietitian. A food intake chart should have been completed after every meal time to include food type, quantity and compliance. Averil's behaviour before and after meal times should also have been documented. Compliance and concerns should be documented and escalated to the nurse in charge/ward sister and the medical team.

Impact

D246. The First Nurse Adviser said that there was no accurate record of Averil's nutritional intake, so escalation for consideration for further intervention was prolonged. She said that this may have contributed to her physical decline.

D247. However, there was no deprivation of liberty act[99] or Mental Health Act assessment completed at this stage and therefore implementing enteral feeding or changing her behaviour may not have been achievable prior to this.

Mobility

What happened?

D248. The First Nurse Adviser told us that on admission on 7 December 2012 an initial nurse assessment was carried out, which identified that Averil was at risk of falls. A further '*Daily Falls Risk Assessment*' was completed on 9 December which categorised Averil as a low risk of falls [score 5]. This was then rescored on 10 December to a score of 4, which was inaccurate as although it included hypoglycaemia it did not include her

[98] A way to provide food through a tube placed in the nose, the stomach, or the small intestine.
[99] A person's liberty can only be taken away from them in very specific situations. The *Mental Capacity Act 2005* calls this deprivation of liberty. It should only be used if it is the least restrictive way of keeping a person safe or making sure they have the right medical treatment.

hypotension. However, the First Nurse Adviser said that it would not have increased her score beyond the low risk category [low risk is a score between 3 and 8].

D249. The First Nurse Adviser said that although staff had documented that Averil was walking independently to the bathroom, there was no clear documentation about continual walking as a means to expend energy. There were two entries in the medical notes which had stated concerns around walking and bed moving and that Averil's mobility and strength were moving in a downward trend. However, the First Nurse Adviser said that there did not appear to be any correlation between this highlighted concern and the actions of nursing staff. There was no documentation to suggest that nurses had addressed this with Averil and implemented any agreed restriction to her mobilising.

D250. The First Nurse Adviser added that as Averil was not [detained] under the Mental Health Act restricting her mobility would not have been achievable without her agreement and therefore could not have been implemented by nursing staff alone.

What should have happened?

D251. The First Nurse Adviser told us that discussions should have been had with Averil about the effects of continual walking and pacing to expel energy and these should have been clearly documented. Averil's behaviour should have been escalated to the nurse in charge as a key indicator of decline in her mental and physical state in accordance with the NMC Code of Conduct [paragraph B27].

D252. She also told us that there should have been a discussion about whether a nurse ratio of one-to-one should have been implemented at this point to maintain Averil's safety and attempt to dissuade increased mobilisation and risk of falls.

D253. The First Nurse Adviser said that there should have been a further assessment by the psychiatric liaison team to establish whether a Mental Health Act assessment would be appropriate to implement restrictions to Averil's behaviour.

Impact

D254. The First Nurse Adviser told us that advice alone to Averil would probably not have impacted on her behaviour. Early escalation to the nurse in charge could have resulted in a one-to-one nurse and a Mental Health Act assessment, which together could have restricted some of her behaviour and reduced the risk of falling. Without this, prevention of continual walking and reducing the risk of her falling was very limited.

Assessment and planning care

What happened?

D255. The First Nurse Adviser said that all levels of trained nursing staff should have an understanding of the diagnosis of anorexia nervosa. She said that she would expect all nursing staff to have an understanding of some or all of the clinical symptoms of a deteriorating patient with this diagnosis and the required level of medical input and

monitoring. These would be: electrolyte imbalance; low BMI and malnourishment; hypoglycaemia; hypothermia; and cardiovascular instability.

D256. The First Nurse Adviser also explained that all nurses were expected to base their initial assessment on the ABCDE[100] approach and apply interventions accordingly. This along with medical notes and admission assessment tools - nutrition, falls, moving and handling and skin integrity - would provide the information needed to develop a plan of care.

D257. She further explained that not all junior nurses would understand the behavioural issues related to this condition – that is, pacing. But, although a junior nurse with little experience may not be expected to have knowledge of all of the above, an AMU has multiple resources to access information about a condition, signs and symptoms of a deterioration and implications for nursing care. Furthermore, a senior member of nursing staff would have been expected to have been able to identify deterioration in Averil and guide other nursing staff appropriately.

D258. In this case, the First Nurse Adviser explained, the initial patient care record was completed with details related to home circumstances, property and next of kin. A full nursing assessment was completed with specific care domains which related to activities of daily living. This assessment identified that Averil was anorexic, was known to an eating disorder clinic, was hypotensive and had mild pain. All other care domains identified no issues present.

D259. She said that Averil's initial observations were recorded which showed hypothermia and hypotension. No oxygen saturations were recorded as they were unreadable.

D260. A falls risk assessment was completed on 9 December which indicated a low falls risk and a MUST nutritional score was completed which indicated high risk. Although Averil's nutritional score indicated very high risk, no care plans were put in place to address this.

D261. Initial and daily assessments of mental state did not highlight any concerns and therefore there was no care plan.

D262. Finally, the First Nurse Adviser said that the multidisciplinary team notes, where nurses can write more freely to reflect events and actions, did not indicate any plans of care.

What should have happened?

D263. The First Nurse Adviser said that based on the initial assessment, clinical observations and medical history, a plan of care should have included:

[100] A = airway; B = breathing; C = circulation; D = disability (includes: blood glucose; neurological; nutrition); and E = exposure (full examination of the body).

- Hourly cardiovascular observations due to severe hypothermia, hypotension and hypoglycaemia, with clear parameters set and escalation values identified.
- Concerns about falls risk and level of mobility discussed with the patient and documented. Bed rest advised due to hypotension, hypoglycaemia and generalised weakness. However, this would be according to Averil's compliance.
- A food chart and dietitian advice implemented, and behaviour before and after meal times documented.
- A discussion with the psychiatric liaison team to identify deteriorating behaviour and the need for reassessment and escalation.
- A determination of whether Averil's level of care was achievable with the current staffing level and whether one-to-one nurse ratio should be considered.

Summary

D264. The First Nurse Adviser said that there was no accurate record of food intake and therefore there was no information to inform a decision about the need to escalate concerns about Averil.

D265. There was no discussion with the psychiatric liaison team, which would have given guidance on deteriorating behaviour and the need to escalate.

D266. Staff should have attempted to discourage Averil from walking and pacing.

Monitoring

What happened?

D267. The First Nurse Adviser said that there was no evidence that staff were monitoring what Averil ate. There were a couple of small references to Averil's intake, but with no accuracy or detail. A fluid balance chart was completed for intravenous therapy, but did not appear to have been completed for oral intake.

D268. Blood sugars were monitored accurately.

D269. The First Nurse Adviser said that the daily nursing assessments with the care domains for activities of daily living did not identify any concerns with deteriorating behaviour or mental health. Whilst there were some descriptive entries in the multidisciplinary notes with regard to thoughts and conversations with Averil, there was not an account of any changes to her condition. There was no documentation to suggest that the nursing staff had concerns about what Averil was eating or her behaviour and they did not seek advice from a senior nurse or psychiatric nurse.

D270. The First Nurse Adviser noted that vital signs were completed frequently, but inconsistently. There were periods of time with no record of oxygen saturations, and blood pressure readings at 81mmHg systolic [hypotension], which were not repeated for 4 to 5 hours. There was no clear reasoning for the frequency of observations.

What should have happened?

D271. The First Nurse Adviser told us that a food chart should have been accurately completed throughout the day to reflect Averil's nutritional intake. Behaviours before and after meal times should also have been noted. If there were any concerns, then these should have been escalated to the medical team and the nurse in charge.

D272. She also said that behaviour in general should have been documented, including time requested alone, pacing and walking. Again concerns or increased exercise should have been escalated and discussed with the medical team and psychiatric team.

D273. Finally, the First Nurse Adviser said that vital signs should have been measured more frequently. Oxygen saturations that were unobtainable due to hypothermia should have been taken again after warming Averil's hand.

Impact

D274. The First Nurse Adviser said that an early recognition of deteriorating behaviour and poor food intake could have resulted in earlier recognition of the need for nasogastric feeding and an assessment by a psychiatric liaison nurse/practitioner.

CUHT

The Second Nurse Adviser

D275. The Second Nurse Adviser told us that the nursing documentation was very sparse. She said that there were the first and second pages of a pro-forma admission booklet for nursing staff to complete. This had been signed by a registered nurse at 5am on 12 December, some fifteen hours after Averil's admission, although the booklet instructions state that it should be completed within twelve hours of admission, and some pages within six hours of admission. The remainder of the booklet was completed on the evening of 12 December after Averil had been transferred out of ward N2 [to the HDU].

D276. The Second Nurse Adviser explained that she would have expected in line with established good practice to see some assessment of Averil's needs, and from this assessment the nurse would determine the plan of care to meet those needs. Assessment, care planning and evaluation of care are the basis of individualised nursing care. The Royal Marsden Hospital Manual of clinical nursing procedures, 7th edition, 2008 [paragraph B33], is a manual of basic clinical procedures frequently used by Trusts to form their internal policies. The manual describes the principles of assessment, stating:

> *'1. Patient assessment is patient focused, being governed by the notion of an individual's actual, potential and perceived needs.*
> *2. It provides baseline information on which to plan the interventions and outcomes of care to be achieved.*
> *3. It facilitates evaluation of care given…influencing a patient's outcome…*
> *4. It is a dynamic process that starts when problems of symptoms develop, which continues throughout the care process, accommodating continual changes in the patient's condition and circumstances…'*

D277. The Second Nurse Adviser said that this would be compliant with *NMC Code: Standards of conduct, performance and ethics for nurses and midwives*, 2008 which states at 42, '*You must keep clear and accurate records of the discussions you have, the assessments you make, the treatment and medicines you give, and how effective these have been.'*

D278. She further explained that assessment and planning is integral to the continuity of care as it informs all nursing staff what care needs to be delivered. This is a dynamic process which should be re-evaluated regularly. Averil was admitted during the afternoon and some form of assessment should have been done and a plan of care documented.

D279. The Second Nurse Adviser noted that there was an admission checklist proforma completed by a nurse at 2.30pm. There was also an evaluation record written at 12.45am on 12 December (the signature is indecipherable); and there are two pages of a '*nursing round record sheet*', started at 4pm and the last entry is at 6am. Finally there was a physiological observation chart.

D280. All the other documentation within the nursing records bundle related to care given after Averil's transfer out of ward N2.

D281. There was also a Medicines Administration Record which showed that some medicines were given to Averil at around 10pm on 11 December. The adult diabetes record [has] only one recording of a blood sugar being recorded at 11.30pm on 11 December when it was recorded as being less than 0.6mmol/l which is very low[101].

D282. Finally the Second Nurse Adviser noted that there was a nursing entry written at 9am on 12 December, shortly after Averil was found unresponsive.

What happened?

D283. The Second Nurse Adviser explained that Averil was transferred to Addenbrooke's Hospital, ward N2, on 11 December 2012 arriving at approximately 2.30pm (as recorded on the pro-forma admission checklist).

D284. The Second Nurse Adviser said that the first set of observations recorded was at 3.30pm when Averil's temperature was around 34.5°C (the notation was not completely clear), blood pressure 95/55mmHg, respiratory rate 13 breaths per minute and pulse 55 beats per minute (bpm). The combined observations resulted in an early warning score (MEWS) of 4, and it is recorded on the chart that a doctor was told about this. No blood sugar level was recorded.

D285. The observations clearly indicated that Averil was unwell and needed prompt medical review, and the Second Nurse Adviser said that it did appear from the observation chart that this information was escalated to a doctor. There was a box questioning whether or not the abnormal findings have been escalated and this had been ticked.

[101] The Nurse Adviser here is referring to the two finger prick blood glucose tests done between 11.20pm and 11.30pm on 11 December 2012.

D286. The Second Nurse Adviser said that the observations should have been repeated within at least an hour to monitor Averil's ongoing condition closely. They were not repeated for three hours. At 6.30pm, when the Mews score was 4, there was a further note that the information was escalated.

D287. Nursing staff, having escalated the information about the abnormal physiological observations should have persisted in attempts to get medical staff to assess Averil. If this proved difficult, the Second Nurse Adviser said that the senior nurse on the ward would be expected to escalate this to more senior medical staff or to a senior nursing colleague and the more senior person would then ensure that Averil was seen promptly.

D288. Averil was seen by a psychiatrist at 7.30pm and no reference was made to the abnormal physiological observations. The psychiatrist has noted '*Nursing staff from ward S3 will deliver intensive nursing observations on N2 from* [8.50pm] *tonight'*.

D289. At 8pm she was reviewed by [the Consultant Gastroenterologist] who again does not refer to the observations. The [Consultant Gastroenterologist] has recorded '*watch BMs. If less than three give oral glucose'*.

D290. A dietitian reviewed Averil at 8.30pm. The Second Nurse Adviser noted that the diabetes record showed that a blood glucose reading at 11.30pm was less than 0.6mol/l. The records say that Averil was offered oral glucose, that she took a little and then refused, and that the doctor was told about this. The Second Nurse Adviser found no evidence of any previous or any further blood glucose readings [other than the subsequent laboratory test].

D291. Physiological observations were not recorded again until 1.10am on 12 December when they continued to score 4 and the Second Nurse Adviser said that there was no evidence that any action was taken regarding this.

D292. The next observations were taken at 6.30am, more than four hours later. At this point Averil's temperature had dropped to 32°C, her blood pressure was around 65/45mmHg and her pulse was 45bpm, resulting in her Mews score being 7. Even without Mews scoring, the Second Nurse Adviser said that a registered nurse should have recognised that Averil needed immediate medical intervention. There was no contemporaneous note in the nursing records that any action was taken at that time.

D293. However, she said that there was a record, written by the nurse who came on to day duty and took over from the night staff, which stated that she was informed that '*pt mewsing* [sic] *7 and awaiting night doctor to review patient'*, so there was some evidence that the doctor had been told about the abnormal observations.

D294. In addition, the Second Nurse Adviser noted that the file document '*Background to Averil's care*', reflected that the [Consultant Gastroenterologist] was interviewed during the Trust's investigation and he stated that he was contacted by the night staff.

D295. One hour and fifteen minutes (7.45am) after the 6.30am observations, the day nurse repeated them and they remained at 7. This nurse documented '*still mewsing 7. I informed the nurse in charge about the high Mews. Around* [8.45am] [the Consultant Gastroenterologist] *was on the ward and I informed him about pt's mews…'* There was no evidence that the nurse in charge escalated the observations, as it was not until the Consultant Gastroenterologist appeared onto the ward that he was aware of them.

D296. In conclusion, the Second Nurse Adviser said that Averil was unwell when she arrived to ward N2 and this was reflected in her abnormal observations. There was evidence from the charts that on that occasion and at the next set of observations, the abnormal findings were escalated. However, there was nothing documented to show that nurses persisted in their attempts to get a doctor to review Averil in a timely manner, or referred to senior staff for assistance in getting a doctor to attend.

D297. Averil's blood glucose was very abnormally low at 11.30pm and though this was discussed with the doctor, no further readings were done to ascertain her ongoing condition.

D298. The Second Nurse Adviser said the observations recorded at 6.30am should have resulted in the nurse asking a doctor to see Averil immediately. However, it was more than two hours before a doctor did see Averil. The nursing staff were responsible for recognising Averil's clinical condition and for escalating concerns and ensuring those were acted upon promptly and it would appear that a succession of nursing staff failed [to do this].

D299. The Second Nurse Adviser explained that after we asked the Trust for their policy on physiological observations and escalation of concerns, it gave us a procedure document entitled '*completing the adult generic observation chart*', dated January 2014. Although these events took place in 2012, the procedure for that time is likely to be very much the same as the one supplied[102].

D300. She told us that this document sets out the process for carrying out the observations and recording them. It included an algorithm informing staff of the action to be taken if there were concerns which indicated that a score of 4 or above must result in escalation and that observations must be repeated hourly. There was no information regarding expected time frames for response to the escalation[103]. However, the Second Nurse Adviser said that it was apparent that staff did not follow the Trust procedure.

Additional advice following CUHT's comments

D301. The Second Nurse Adviser told us that in her view the nursing issues had not been addressed in the complaints investigation and so there was no remedy in the action plan.

[102] Following the advice we obtained a copy of the policy in force in 2012 and in relation to the escalation of the MEWS score, the policy was the same.
[103] NICE guidance 50, Acutely ill patients in hospital: Recognition of and response to acute illness in adults in hospital, 2007 which states under *Graded response strategy,* that there should be *'immediate response'*.

D302. She noted that the consultant stated he was not told about Averil's admission until late evening, though the nursing physiological observation chart showed that a doctor was told about the raised MEWS at 3.30pm. The Second Nurse Adviser said that she had highlighted in her advice above that there were ongoing failures to monitor Averil adequately and to ensure escalation of those findings.

D303. She also noted that there were no statements from the nurse who escalated the 6.30am observations to the doctor, though the doctor says she had a conversation with a nurse who said that Averil's condition was no different from when she was previously seen.

D304. Finally, the Second Nurse Adviser said that there was also information that the day nurse repeated the observations at 7.45am and informed the nurse in charge of this, but still there was no medical intervention until about 8.45am.

The Gastroenterology Adviser

D305. The Gastroenterology Adviser explained that Averil was transferred from NNUH and was admitted at 2.40pm on 11 December 2012. The first evidence of any medical assessment was at 7.40pm when she saw a consultant psychiatrist. The first medical doctor she saw was at 8pm when she saw a consultant gastroenterologist[104]. He recommended blood tests but none appear to have been taken until after she had formal medical clerking by an on-call SHO at 10.20pm. The blood tests were taken from the femoral artery at 11.30pm.

D306. The Gastroenterology Adviser noted that the consultant psychiatrist who saw Averil wrote '*I will arrange a MHA assessment if she refuses treatment*'. The gastroenterologist who saw her concluded with a list of blood tests for tonight and '*tomorrow-ng tube and slow refeeding*' ... '*watch BM's -if BM<3 give oral glucose*'. The Gastroenterology Adviser noted that the gastroenterologist also stated that Averil was not for intravenous fluids or drugs and recommended a variety of supplements. The medical clerking at 10.20pm recorded no additional management changes. The written history included '*hypoglycaemic collapse 4/7 ago*.'

D307. The next record after the 11.30pm record of the femoral artery blood test was at '*1435*' which probably in fact meant 2.35am. This was written by the on-call SHO who clerked Averil. The Gastroenterology Adviser explained that the note recorded the returned blood results from the sample at 11.30pm and then '*Glucose added to bloods-unrecordable on finger prick and patient refusing glucogel*'. Then '*discussed with* [the consultant gastroenterologist] - *happy with current management. No need for glucogel if* [patient] *is stable/asymptomatic regardless of glucose level*'. There is then an arrow '*1.9*'. The Gastroenterology Adviser noted that it was stated in the serious incident report completed by the Trust that this was a laboratory result – this was confirmed in a sample

[104] Both the consultant psychiatrist and the consultant gastroenterologist saw Averil at the same time, but recorded their notes in Averil's records separately.

result timed at 11.42pm on 11 December 2012. No action in relation to this result was recorded[105].

D308. The Gastroenterology Adviser explained that there was no further medical record until 8am on 12 December when Averil was unresponsive and was given intravenous 10% dextrose (strong sugar solution). It was recorded in the serious incident report that the cardiac arrest team were called and resuscitation measures instituted although this was not clear from the contemporaneous clinical records (these state that no CPR was given)[106].

D309. The Gastroenterology Adviser said that the adult diabetic record for glucose monitoring, although difficult to interpret, appeared to have only one recording (at 11.30pm reading < 0.6) between Averil's admission and 8.50am on 12 December. This recording is at 11.30am on 11 December and is accompanied by a comment about refusal of dextrose and that the doctor was informed[107].

D310. The adult observation chart recorded a MEWS score of 4 from the first observation at 3.30pm on 11 December (in respect of pulse, blood pressure and temperature). The score rose to 7 at 6.30am on 12 December with significant hypotension (low blood pressure) and bradycardia (slow pulse) and was again 7 at 7.45am. There was no evidence that the initial MEWS led to any medical action. There was no evidence that when the MEWS rose to 7 that there was any medical action. The laboratory records showed results in relation to a sample timed at 11.42pm on 11 December including a glucose level of 1.9. The Gastroenterology Adviser could not see any evidence that the medical review led to any action in relation to this confirmed low blood glucose level (in relation to the written instruction to treat if less than 3).

D311. After the resuscitation with glucose and the intravenous fluids given when Averil saw the consultant after 8.00am on 12 December, she was transferred to the high dependency unit (HDU). Averil was subsequently diagnosed to have neurological damage. She continued to deteriorate and a decision was made to institute palliative care. Averil died on 15 December.

What should have happened?

D312. The Gastroenterology Adviser explained that Averil was recognised to be seriously ill with anorexia nervosa and documented to be at risk. She was transferred to Addenbrooke's for urgent refeeding, if necessary under section, in a unit close to the eating disorders unit. She was documented on the transfer note to have many of the 'at risk' problems associated with anorexia and treatment which included a note of intermittent 5% dextrose treatment. She arrived on the ward at Addenbrooke's in the early afternoon, but despite her history and a MEWS score of 4 soon after arrival, Averil

[105] The Gastroenterology Adviser here is commenting on the result which was available at 2.35am on 12 December. The reference to the sample timed at 11.42pm is in fact a reference to the actual time the blood sample taken from Averil was received by the laboratory, and not the time the blood tests were actually done.
[106] The notes do say that a nasopharyngeal airway was inserted.
[107] There were however two attempts to obtain Averil's blood glucose using a finger prick test – only one result was recorded as on both occasions, Averil's blood glucose was low (below 0.6mmols/l).

had no medical input until the evening, was not clerked until she was seen by the busy on-call SHO until 10.20pm, and had no blood tests until 11.30pm. The nursing observations (MEWS score 4) at 3.30pm did not result in medical review. The first actual documentation at all of her sugar was at 11.30pm on a finger prick sample. There was no action in relation to significant bradycardia and hypoglycaemia recorded 90 minutes before she was noted to be unresponsive.

D313. A MEWS score of 4 or above in the Trust's policy requires hourly observations and escalation to '*shift charge, critical outreach team and patient's medical team*'.

D314. The Gastroenterology Adviser said that the clinical situation on arrival required immediate medical assessment including blood tests to include a blood glucose, and then formulation of a robust monitoring and treatment plan communicated to the overnight medical and nursing team. There were no specific guidelines on this, but established good practice in any clinical unit should include plans for immediate action in patients at clinical risk.

D315. A decision was made at the delayed first clinical assessment not to pursue nasogastric feeding overnight. The Gastroenterology Adviser said that feeding a starved patient in this situation has the risk of the profound biochemical and physiological changes of refeeding and in Averil the logistic and psychiatric difficulties of inserting a nasogastric feeding tube overnight.

D316. The Gastroenterology Adviser further explained that in significantly malnourished patients, the initial stage of oral, enteral, or parenteral nutritional replenishment causes electrolyte and fluid shifts that may precipitate disabling or fatal medical complications. Simplistically when nutritional replenishment begins and patients are fed carbohydrates, biochemical changes occur which depletes the body's stores of phosphate. The lack of '*phosphorylated intermediates*' causes tissue hypoxia (low oxygen in the tissues) and myocardial dysfunction and respiratory failure due to an inability of the diaphragm to contract. The problem is compounded by kidney and other changes which lead to fluid overload. Medical complications that occur as a result of fluid and electrolyte shifts during nutritional rehabilitation of malnourished patients involve multiple organ systems. Most die from cardiac complications, but respiratory failure, severe muscle weakness and tetany, delirium, seizures, severe diarrhoea, liver dysfunction, etc. occur.

D317. In patients with gross malnutrition, the risk is reduced by restoring weight with an amount of calories that is close to and above the resting energy expenditure, avoiding rapid increases in the daily caloric intake, and very close monitoring of the patient clinically and biochemically during the refeeding process. Complications are reduced by slowing the rate of nutritional support, watching for and correcting electrolyte abnormalities, especially phosphorous levels, and monitoring for and treating cardiovascular and pulmonary complications. Such considerations would be weighed by consultants in relation to initiation of feeding at night[108].

[108] http://www.uptodate.com/contents/anorexia-nervosa-in-adults-and-adolescents-the-refeeding-syndrome?

D318. The Gastroenterology Adviser said that it was possible that prompt assessment with the availability of blood results, including glucose, may have led to a different decision in relation to nasogastric feeding. However an early assessment would certainly have emphasised the need for robust monitoring, including glucose monitoring, and allowed review of the blood tests, including blood glucose (including the fact that it was not initially done), by the responsible clinical team (rather than a busy on-call doctor).

D319. The Gastroenterology Adviser explained that when the fingerprick blood glucose was unrecordable and Averil refused treatment for this, urgent action was necessary. It was not reasonable to simply consider her apparent lucidity. An urgent laboratory blood sugar should have been taken and reviewed and appropriate action taken when it was significantly low (1.9). Hypoglycaemia results in brain damage and death and requires urgent treatment.

D320. The Gastroenterology Adviser said that the failure to act was a basic failing under GMC *Good Medical Practice*, which says doctors *'must provide a good standard of practice and care'* and must [paragraph B23]:

> *'a. adequately assess the patient's conditions, taking account of their history (including the symptoms and psychological, spiritual, social and cultural factors), their views and values; where necessary, examine the patient*
> *b. promptly provide or arrange suitable advice, investigations or treatment where necessary'* [109]

D321. When the laboratory blood test confirmed hypoglycaemia, treatment with glucose should again have been offered. If this was refused then an immediate capacity assessment should have been done. The consultant psychiatrist who had seen Averil earlier in the evening had written '*I have explained to her that her medical risk is our highest concern and that I would need to arrange assessment a MHA assessment if she refuses treatment*'.

D322. The Gastroenterology Adviser said that the SHO should have performed the capacity assessment (if necessary with senior advice). If the patient was judged not to have capacity she should have been treated in her best interests.

D323. If she was judged to have capacity then the SHO should have sought psychiatric advice urgently (directly or via the consultant). The consultant psychiatrist on-call would have noted the psychiatric opinion earlier and considered treatment under the Mental Health Act.

D324. When she became more hypotensive and bradycardic at 6.30am, urgent medical review was required. This would have led to escalation to senior medical advice and after assessment, resuscitation.

[109] In their advice the Gastroenterology Adviser quoted from *Good Medical Practice* 2013. *Good Medical Practice* 2006 (paragraphs B23 to B25) is actually relevant to this complaint. But in the context of the quote the Gastroenterology Adviser has used, *Good Medical Practice* 2006 and 2013 say essentially the same.

Impact

D325. The Gastroenterology Adviser said that the failures were failures of basic clinical care and monitoring. The failure to assess her in a timely manner denied her the opportunity of consideration of the optimal treatment for which she was referred in a specialist unit. The failures in assessments and overnight monitoring resulted in an unresponsive patient almost certainly due to untreated critical hypoglycaemia.

D326. The consequence was irreversible neurological damage and death.

The additional advice provided by our advisers in relation to the query raised by Mr Hart that it is common practice for community care eating disorder units to appoint trainees with no experience of ED's as the sole care coordinator for a high risk patient

The advice of the First Psychiatrist adviser

D327. The First Psychiatrist Adviser explained that her advice was based on her own personal experience, working closely with her service manager in an eating disorders service for 6 years. During that time they have had difficulty recruiting all grades of staff with experience in eating disorders. The last five posts advertised for eating disorder practitioners, attracted only three applicants, all of whom withdrew their applications before the interview.

D328. She told us that on the NHS Jobs site, there are currently 147 posts advertised for eating disorder staff, including eating disorder practitioners, clinical nurse specialists, nurse therapists, psychologists, CBT therapists, family therapists, occupational therapists and dietitians.

D329. Whilst some of these posts ask for previous experience in eating disorders, many mention *'support the development of specialist skills'*, *'further training provided'*, *'previous experience not essential as training will be prioritised'*, *'grow your expertise'*, *'develop clinical skills'*. She said that this would suggest that recruitment difficulties in this area were not unique to her Trust.

D330. She was unable to identify any helpful statistics or hard evidence suggesting a lack of suitably qualified professionals with experience of treating eating disorders.

D331. In her service, when a professional with no eating disorder experience is appointed, they shadow experienced therapists and co-work cases before taking on a care coordinator role.

The advice of the First Psychology Adviser

D332. The First Psychology Adviser said that evidence relevant to the questions about the availability and appointment of suitably experienced individuals to the role of care coordinators was anecdotal from his experience in services and contact with other services.

D333. The First Psychology Adviser explained that the psychologist seeing Averil at that time would not have been viewed as a trainee at that point, except technically, if he had assumed correctly that she had completed and passed all clinical aspects of her course and was only pending confirmation of her academic thesis via a viva examination. He told us that one of the services he had worked in has similarly recruited a newly qualified counselling psychologist on band 6 pending confirmation of their thesis result, at which point they moved up to band 7. This colleague was not viewed as being at a trainee level clinically in that interim period, but as newly qualified, although technically on a lower band pending the confirmation of the thesis result.

D334. The First Psychology Adviser also explained that most people who have not previously worked in a specialist eating disorder service will have had some experience of eating disorders if they have worked in other mental health services because of its prevalence and comorbidity. People with eating disorders are seen in community mental health teams, IAPT[110] and other psychological therapy services, acute and crisis services, personality disorder services etc.

D335. In terms of psychologists he explained that he could think of a few (at least three) instances of somebody without prior experience of working in a specialist eating disorder service being appointed at the band of the psychologist involved in Averil's care or above, across two services he had worked in, and a few more again when locum cover is included. Given the relatively small size of eating disorder psychology services and a tendency for a substantial proportion to stay in post for quite a while, this would represent a minority of posts but not an insignificant proportion. Conversations with colleagues in other services have not suggested that this is unusual.

D336. The First Psychology Adviser said that there had recently been several job adverts for posts in new or expanded child and adolescent services. He explained that in a recent conversation with a senior colleague in another trust they said they were open to recruiting suitable candidates without prior specialist eating disorder experience and offering appropriate training and induction. He had seen jobs advertised on NHS Jobs also recently stating that prior eating disorder experience was desirable but not essential. Furthermore, during a conversation at the BPS Faculty for Eating Disorders it was discussed that somebody moving into specialist eating disorders for the first time would need a defined induction, with training in relevant risk factors, and specific and frequent clinical supervision.

D337. The First Psychology Adviser said that given the pertinent role is that of a professional acting as the main or sole person that a patient with eating disorders is seeing face-to-face, there were many more instances in his experience of somebody moving into specialist eating disorders and having that role from other professions: medical doctors, dietitians, nurses and liaison support workers, occupational therapists. Of these he thought that the most likely to act as care coordinators or in that role would be doctors, liaison nurses or liaison support workers. Similar to the situation for psychologists described above these professionals were also likely to require specified induction, training and supervision arrangements.

[110] Improving Access to Psychological Therapies (IAPT) is part of a national programme to improve access to evidence-based psychological therapies for common mental health problems.

D338. He said that his experience had also been that somebody newly qualified or new to specialist eating disorders could be allocated patients suffering from anorexia nervosa including in Averil's situation. A community eating disorder service is likely to be holding a number of cases with indicators of a higher degree of acute risk than Averil had been showing, bearing in mind that the progression from her last community contact to the situation as it was when admitted to hospital was rare in his experience.

D339. He explained that for context, as a safety critical field, even when staff were experienced, rather than relying on individual judgment, safety needed to be built into the service assessing and managing risk via appropriate systems and protocols, such as:

- Review of symptoms and weight charts in clinical supervision;
- Review of higher risk patients at appropriate frequencies in multidisciplinary team meetings;
- Clear allocation of responsibilities for monitoring risk indicators between agencies and interpreting objective indicators according to clinical guidelines;
- Arranging for review by another professional in the multidisciplinary team or a joint meeting when needed.

D340. Also, he explained that when recruiting you would be looking for a range of indicators of knowledge, skills and attitudes pointing to safe and effective practice, of which prior eating disorder specialist experience would be one. Some managers might consider it safer to have the right person and give them the training and supervision they need.

D341. Regarding the availability of psychology staff, he told us that eating disorders can be seen as a 'niche' specialism and harder to recruit to sometimes compared to some other specialisms; again he said that this was a perception based on experience and contact with colleagues in other services. In services he had worked in they would have preferred to have taken a trainee clinical psychologist every year, but were not always allocated somebody from the courses because there were not always enough trainees interested in the field every year. He could think of two occasions when he had been told a qualified post had to be re-advertised. On the other hand, to his recollection the posts have not gone for long periods unfilled for that reason, and as above it has not been considered inappropriate for suitably trained and qualified professionals to be moving into the specialism with appropriate induction and supervision. If ever there has been a perception that staffing could be improved it has been related more to the overall level of service funding.

The advice of the Second Psychology Adviser

D342. The Second Psychology Adviser told us that as far as she was aware there was no specific evidence that related to care co-ordination and eating disorders except to say that those with an eating disorder are entitled to care co-ordination (NICE). Her evidence base was her own clinical and managerial experience working in the field.

D343. She told us that care co-ordination by its very nature is an activity that is undertaken by one individual and not shared. If the psychologist was the only clinician

involved with a client they are by this fact recorded as the care coordinator for that client. However, in complex cases, such as a low weight anorexic or someone with a recent history of very low body weight , it was her experience that this work is usually done within a multidisciplinary team of at least one or two other people and that care coordination is usually done by someone other than the person providing psychological therapy.

D344. She said that newly qualified staff of all professions are given care coordination roles, often this is nursing staff but this role is shared between team members. However, all staff have clinical and managerial supervision and as part of this any care coordination responsibilities are monitored.

D345. She also explained that newly qualified psychologists are not new to clinical work and have completed other clinical jobs prior to training for at least a year but often 2 or 3 years. They then train for 3 years which includes 3-4 days a week working in a variety of clinical settings, on rotations similar to medicine for 3 years. Care coordination is a role that is about bringing together all the professionals involved and regularly reviewing progress but does not assume the most expertise or an equivalence to the role of resident medical officer (RMO) in a medical context.

D346. She also said that based on her experience clinically and as a manager, she was aware of having regularly recruited to posts where there was little experience of eating disorders regardless of the length of qualification of the member of staff. This is beginning to change as services develop and grow but it is still a very specialised field with those new into post having to learn on the job. The level of service provided and the expertise of staff also varies on the geographical location of services and funding etc.